

Flourishing through Music:
Understanding, Promoting and
Supporting Shared Musical Activity
within the Caring Relationships of
People with Dementia Living at
Home

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Flourishing through Music:
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Supporting Shared Musical Activity
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Abstract

Background: Changes that occur for a person as a consequence of dementia can be experienced as losses, both by people with the condition and those who care for them. People in these caring relationships can also discover different ways of being, and relating to each other as individuals, relationships and circumstances change. This opens up future possibilities for growth and development. Music and dementia research has been conducted predominantly within and, therefore, focused on issues of relevance within, institutional settings rather than peoples' own homes. Studies conducted within the home setting suggest that musical activity can be supportive of people with dementia and those that care for them; support that is greatly needed. In this study, I sought to understand musical activity in the home setting and caring relationships of people with dementia and how it can be promoted and supported, whereas the majority of previous studies have sought to establish the impact of musical interventions.

Method: I engaged in a process of 'gentle empiricism'; a method for the study of living processes that is attributed to Goethe. Gentle empiricism takes individual experience as a basis for coming to understanding and is a new approach to music and dementia research. My experience was the primary form of data for the study that was supplemented by documentation, video footage and other forms of media as 'secondary data'. To gain experience, I participated in musical activity within the homes of four people with dementia, each with a family member, during fieldwork sessions.

Understanding: This study offers a 'dynamic' perspective of personhood as human activity, dementia as disruption to this activity, and music as a medium offering coherence. The findings

- evidence the accessibility of shared musical experiencing and creating in the daily lives and caring relationships of people with dementia living at home;
- demonstrate a relevance for musical activity beyond health and well-being outcomes;

- and elucidate conditions, qualities and practical suggestions for promoting and supporting opportunities for musical activity in peoples' own homes.

Potential: The understanding from this study holds potential to contribute to the development of person-centred dementia care practice and music facilitation in the home setting. It also holds potential to promote and support the growth and flourishing of individuals with dementia living at home and those who care for them, their relationships and their musical activity. Gentle empiricism emerged as a pertinent approach for future music and dementia research and practice.

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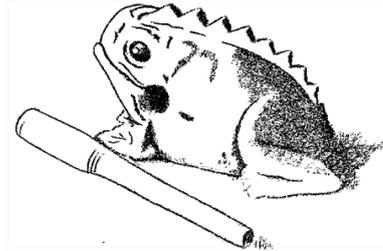
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Music Glossary



Frog-Shaped Guiro

Chanter

The pipe of a bagpipe with finger holes, on which the melody is played (Soanes and Stevenson, 2006, Chanter entry)

Bodhrán

A shallow one-sided Irish drum typically played using a short stick with knobbed ends (Soanes and Stevenson, 2006, Bodhrán entry).

Djembe

A kind of goblet-shaped hand drum originating in West Africa (Soanes and Stevenson, 2006, Djembe entry).

Entrainment

Biology: (of a rhythm or something which varies rhythmically) cause (another) gradually to fall into synchronism with it (Soanes and Stevenson, 2006).

Guiro

A musical instrument with a serrated surface which gives a rasping sound when scraped with a stick, originally made from a gourd and used in Latin American music (Soanes and Stevenson, 2006, Guiro entry).

Lyre

A stringed instrument like a small U-shaped harp with strings fixed to a crossbar, used especially in ancient Greece. Modern instruments of this type are found mainly in East Africa (Soanes and Stevenson, 2006, Lyre entry).

Melodeon

A small accordion of German origin, played especially by folk musicians (Soanes and Stevenson, 2006, Melodeon entry).

Ocean Drum

A frame drum having one or two heads filled with solid metal beads. When angled the beads roll around imitating the sound of the ocean surf (Strain, 2017, p. 131).

Rain Stick

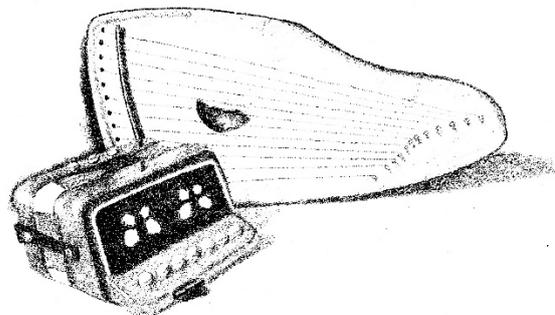
A ceremonial instrument originating in the Andes, consisting of a hollow branch sealed at both ends and containing small hard objects such as seeds or pebbles, which make a noise like falling rain when the branch is tilted (Soanes and Stevenson, 2006, Rain Stick entry).

Singing Bowl

A brass bowl that, when rubbed around the circumference with a leather mallet, produces a pitched, sustained tone (Strain, 2017, p. 167).

Sounding Bowl

A Sounding Bowl is a musical instrument made to create healing sounds. Unique in world history, its strings are contained within the resonant sound-space and made from one whole piece of locally grown hardwood (Kaye, 2015).



Lyre and Melodeon

Preface

The role and content of each chapter is summarised below to aid navigation and offer a sense of the whole thesis.

1. Introduction

An introduction to the research and thesis, and an invitation to the reader as an active participant in understanding.

2. Landscape

This chapter explores the landscape of music and dementia research, outlines the aims of the study, and introduces me as author and researcher.

3. Methodological Ground

A discussion of the study's philosophical roots that established the world view and approach to understanding that formed the ground from which the method grew.

4. Cultivating the Seed

This chapter explains the study design and my cultivation and development of the research method from 'seed'.

5. Growth and Flourishing

I give an account of my fieldwork experiences as a presentation of the study data that illustrates the growth and flourishing of musical activity and method in action.

6. Harvesting Findings

A comprehensive explanation of the findings harvested from the study data.

7. Gathering Indications

This chapter describes and discusses a systematic review of the literature as a means to gather indications to further inform the study.

8. Sharing Understanding

A discussion and contextualisation of the study findings and their potential to be shared within the music and dementia landscape.

9. Conclusion

This chapter draws together the essential elements of understanding as a stage in a continuing journey of research.

1 Introduction

1.1 Calling to the Reader

This study has grown and developed out of my own experience of knowing people and families affected by dementia through my work as a music facilitator. I observed that the music we shared so readily in community group settings did not translate so readily into the daily lives of people I worked with, many of whom lived at home. I recognised a potential to understand, promote and support such sharing. I explored relevant academic research and established that, beyond my own experience, there existed a broader need to understand, promote and support shared musical activity for people with dementia living at home and individuals that care for them in partnership. These partnerships are referred to as ‘caring pairs’ or ‘caring relationships’ from this point onwards for the sake of brevity.

In the context of dementia care, the term ‘home’ is ambiguous and requires a prefix to distinguish between peoples’ own homes and residential care homes. In attempting to navigate this semantic difficulty, I have chosen to use the term ‘living at home’, which consequently has necessitated using the term ‘person with dementia’ rather than the accepted term ‘person living with dementia’ for the sake of clarity. The latter term is therefore used occasionally to distinguish between people with a diagnosis of dementia and the broader group of people surrounding them, such as friends and family members who are also ‘living with dementia’.

Coming to understanding out of experience and responding to that understanding is not only the basis for undertaking this study but the essential gesture of my approach to the research. I chose to participate in the phenomena of musical activity with people in caring relationships as an experiential basis for coming to understand these phenomena and to inform how such musical activity might be promoted and

supported into the future. Embarking on this experiential path of research required me to develop my own inchoate capacities to be actively receptive of understanding rather than impose my own preconceptions. This development required a different view of the world and way of understanding, and the cultivation of empathy.

In keeping with the gesture of this research, I invite you, the reader, to accompany me on this journey in coming to understand this research as a participant. To this end, the thesis is presented in different forms of writing and visual media to offer opportunities for you to come to understanding from experience rather than abstract intellectual concepts. Beyond the current prose, other forms of writing include instructions for participatory exercises, illustrative descriptions of my experience and reflections, and examples of poetry written as part of the research process. One of the principle reasons for use of visual media is to offer the reader enjoyment in the activity of reading the thesis. The various forms of visual media, including representations of artworks, diagrams, photographs, notations of music and traced video stills, offer an experiential basis for understanding the concepts discussed.

Colour is used for differentiation and visual identification of text, such as foregrounding the voices of people in caring relationships in the Landscape chapter.

As a whole, the thesis is structured to reflect the organic, developmental process that it presents, with each chapter a different stage of development within the research process. I begin by mapping the landscape of music and dementia and trace my path through it. Within this landscape, I establish the methodological ground from which my method grew through participatory fieldwork. Harvesting the understanding developed through the study, and gathering indications from the research of others through systematic review, offers the seed of new knowledge to help cultivate new growth to flourish within the evolving landscape.

2 Landscape

Each person with dementia is travelling a journey deep into the core of their spirit, away from the complex cognitive outer layer that once defined them, through the jumble and tangle of emotions created through their life experiences, into the centre of their being, into what truly gives them meaning in life.

(Bryden, 2005, p. 11)

2.1 Introduction

Music and dementia are distinct, yet related phenomena. Both present cultural and social edifices of amassed concepts and practices that form the landscape for this study. This chapter maps their features, explores their common ground, and traces my path through the landscape.

2.2 Dementia

2.2.1 Understanding Dementia

‘Dementia’ is a broad term for symptoms of cognitive change that can develop from disease and damage to the brain (Theodoulou and Jaswal, 2020). The progression of dementia changes individuals’ capacity to engage in cognitive activity (Sandilyan and Dening, 2015), which can manifest as various signs and symptoms such as changes in speech (Taler and Phillips, 2008), memory (Camicioli, 2014), the ability to recognise objects and people (Mendez and Cummings, 2003) and to perform tasks (Camicioli, 2014).

The most common forms of dementia are Alzheimer’s, vascular and dementia with Lewy bodies (World Health Organization, 2020). However, the boundaries between

different forms of dementia, and also between dementia and other medical conditions, are not clear-cut, and ‘mixed’ or mistaken diagnoses are not uncommon (University of California San Francisco, 2020; World Health Organization, 2020). The incidence of dementia is increasing and is anticipated to reach 152 million people worldwide by 2050 (World Health Organization, 2020).

Figure 1: Action Potential (Dunn, 2017)



An animated microetching that simulates how a neuron receives and integrates incoming signals from connected neurons to trigger an action potential.

Neuroimaging has enabled visualisation of living human brain activity as fluctuating constellations within the dark stillness of the cranial cavity; depicting the constantly changing neural network in response to each new thought, emotion and action (Figure 1). ‘Seeing’ these tender root systems of neural activity has enabled great inroads into understanding the phenomena of the human brain, feeding the fire beneath the quest to understand consciousness (Damasio, 2010, p. vi; Cavanna *et al.*, 2013).

Materialist neuroscience draws no distinction between the brain and the self, ascribing the experience of consciousness to the activity of the brain and nervous system or dismissing it as an illusion (Beauregard and O’Leary, 2008; Damasio, 2010). In contrast to the materialist view, there are individuals working in the field of neuroscience that interpret scientific evidence in a different light, positing consciousness as an ‘irreducible quality’ that cannot be explained using a “...materialist frame of reference” (Beauregard and O’Leary, 2008, p. 277) that “...has its own dynamic, operating independently of the brain” (Bos, 2015, p. 125). Rather,

the brain is recognised as an organ that serves the consciousness (Chopra and Tanzi, 2012).

The materialist neuroscience view of the brain equates its degeneration during the dementia process to a gradual, irrevocable loss of consciousness and self. An alternative view of the dementia process is put forward by van Gerven and van Tellingen (2015) as “...stages of shifting I experience”, through which “...the ‘I’ itself lives on but the appearance of the ‘I’ is greatly altered” (Ibid., pp. 12-13), and “...the progress of dementia is...determined...mainly by the activity or inactivity of the I” (Ibid., p. 106). Sabat (2008, p. 82) asserts that individuals with dementia “...can retain aspects of selfhood, including worthy social personae, but the latter depends upon how they are treated by others”.

Although advances have been made into understanding the human brain, unexplained phenomena remain, such as the lack of correlation between awareness and the level of brain damage or deformity resulting from a variety of causes, including dementia, which have led to a recent resurgence in attention from research into ‘lucid’ or ‘paradoxical’ awareness (Chiriboga-Oleszczak, 2017; Eldadah, Fazio and McLinden, 2019; Mashour *et al.*, 2019). Such phenomena correspond with the concept of ‘I’ experience or awareness ‘shifting’ rather than irrevocably diminishing, which would mean that the ‘I’ may still be called upon throughout the dementia process if there exists a means of doing so.

2.2.2 Experiencing Dementia

From personal memoirs written by individuals with dementia, it appears that loss can also be a signature of the dementia experience:

“I feel again the sense of loss within myself, a complete detachment from my own mind” (Mitchell, 2018, p. 139).

“Use it or lose it’ is painfully true for us, and we risk losing everything by our learned helplessness. And then we face the toxic power of the ‘pointing-bone’ of diagnosis, when it seems as if our world has come to an end. We experience a defeat of spirit and of hope. We feel extreme fear of further loss, and dread what the future holds” (Bryden, 2015, p. 20).

“...the skills of daily living...If you lose these skills, then, as a person with dementia, you are up against your own limits every day. Limits that weren't there before. Thus dementia is constantly perceptible and reminding you of your own impairments” (Rohra, 2016, pp. 125-126).

“Dementia grief...can be extremely crippling; just as you get used to the loss of some function or capacity, it then gets worse, or you 'lose' some other function or capacity...the grief of my losses...sits inside my heart and does not go away. It doesn't heal either, because I know things will get worse not better” (Swaffer *et al.*, 2016, p. 118).

“Dear Alzheimer's...I know you encourage apathy, and then use this as a weapon to bring about decline...you are seeking to take...my identity, my personhood, my place in the world, my humanity...I do sense you stretching out your grasping hands to wrench them from me” (Oliver, 2019, pp. 87-88).

Although they speak of their continuing losses, the voices of people with dementia also speak of something else that endures. Their future potential:

“Dementia is not just decline and disintegration, and certainly not a long journey into oblivion. We are absolutely able to talk about our experience, and we also have something to say” (Rohra, 2016, p. 140).

“We can discover new talents, focusing on aspects of our lives such as relationships, emotions and spirituality, rather than being too focussed on changing our cognition. By assigning dementia a secondary place, we have more potential to enhance these other aspects of our humanity...It is through finding meaning in life, even with a diagnosis of dementia, that it is possible to create a new sense of purpose and meaning, and importantly to overcome the intense fear of loss and death...the sun will always keep rising, the sky will still be blue and our power to heal each other can still be fuelled by love” (Swaffer *et al.*, 2016, pp. 129-130).

“...you go through difficult times to enjoy a brighter future...These are difficult times, but I'm trying to restore my former drive in order to achieve a brighter future. Though what that future entails, I don't know” (Oliver, 2019, p. 108).

“By the very nature of my diagnosis, my book is about the loss of the old and the birth of the new me” (Mitchell, 2018, p. 314).

“Like a bud, my true self encapsulates all the potential of what it means to be me. This is a new way of living, maybe even the essence of living, and is the experience of dementia. I have found the answer to the question...Who will I be when I die? I'm becoming who I really am” (Bryden, 2015, p. 103).

In the following quote from Bryden's account of her dementia experience, it is clear that individuals' capacity to recognise, and actively seek to realise future potential themselves, changes:

"Many of us seek earnestly for this sense of the present time, the sense of 'now', of how to live each moment and treasure it as if it were the only experience to look at and to wonder at. But this is the experience of dementia, life in the present moment without a past or future" (2005, p. 11).

Narratives from family members affected by dementia illustrate that they can also experience loss. These losses can include the pain of no longer recognising the person they care for, of not being remembered and the loss of a pictured or planned future, as well as 'complicated emotions' such as guilt, anger, regret, grief and fulfilment:

"I hate this disease. I hate it with a boiling fury. It has robbed you of the ability to even imagine what you cannot remember. It has stolen your empathy (Magnusson, 2014, p. 271).

"...I lacked patience...I would shout sometimes at her when she'd done something wrong, something silly, or what seemed to be something silly...It's, it's a combination of frustration, anger and worry for them that causes you to" (Healthtalk.org, 2019, transcript 1).

"...that one thing might come out like a kiss or a name or a slight recognition, are the things that we've got to hang on to because eventually that will go as well. So I think, it's very difficult to think positively in a very, very, very negative situation" (Ibid., transcript 3).

"...I knew how frightened she had been of exactly this thing happening to her and it had happened and there was nothing that I could do about it, absolutely nothing. So the whole thing was a horror really...there were times when it was better not to be honest for the sake of her well being [sic], reassuring her rather than worrying her, which is not a comfortable situation to be in" (Ibid., transcript 5).

"...that's what we should have done, we should have had a bigger house with a place for her in it and nursing staff and I should have given up my job. I mean she actually said at one stage 'I know you'd have to give up your job, but I'll pay you'" (Ibid., transcript 6).

“...I look back and remember how he was, that was the man he used to be and that's the real man...and I started writing it down on the computer, my memories of his and my relationship. And I found that helped a lot. Because I was not just focusing on what he is now but what was and what could have been, and what should have been if everything had gone...normally” (Ibid., transcript 8).

“...it's fulfilling because she's my mum. I love her and it's like you're just returning the favour, so to speak...you still have these little moments that are just, like, fantastic...just the little cheeky things that she might say or do...on the graph it's generally down, but within that you have peaks and troughs” (AlzheimersResearch UK, 2015, 01:55).

Perspectives of people with dementia point to the importance of recognising and upholding who they have been, who they are in the present moment and who they are becoming by those that care for them. The accounts of family members affected by dementia indicate how challenging it can be to provide this care through the changes of dementia. Looking to the future is uncertain and painful and so can lead to a focus on the past and short-term thinking (Alzheimer's Research UK, 2015).

2.2.3 Recognising Potential

Kitwood introduced a social model of dementia that challenged the prevailing biomedical paradigm (Kitwood, 1997; Macdonald, Mears and Naderbagi, 2019). This new perspective placed the needs of the individual rather than their dementia at the heart of care. Kitwood's pioneering work (Kitwood, 1997) has since been taken forward and further developed (e.g. Innes, 2009; McCormack and McCance, 2010; Brooker and Latham, 2015; Kitwood and Brooker, 2019), contributing to a “...sea change in the recognition of the needs of people living with dementia” (Brooker and Latham, 2015, p. 22). However, it remains common for personhood to be undermined in dementia care; an aspect of care practice Kitwood termed ‘malignant social psychology’ in reference to “...episodes where people are intimidated, outpaced, not responded to, infantilised, labelled, disparaged, blamed, manipulated, invalidated, disempowered, overpowered, disrupted, objectified, stigmatised, ignored, banished and mocked” (Ibid., p. 19). Although they do not usually arise out of an intention to cause harm, such episodes can be profoundly detrimental to well-being. According to Kitwood, “the strong word malignant [*sic*] signifies something very

harmful, symptomatic of a care environment that is deeply damaging to personhood, possibly even undermining physical well-being” (1997, p. 46).

Person-centredness is yet to be firmly established in everyday dementia care practice, presenting a challenge that demands “...a global response in the same way as finding a cure for dementia” (Brooker and Latham, 2015, p. 24). Baldwin and Capstick tentatively posit that person-centred care could be advanced by “...reconfiguring the framing of dementia” using elements delinked from the ideas of “...neuropathology, decline, loss, disease and suffering” (2007, pp. 17-18), and by recognising the contribution of people living with dementia to the lives of others; not by denying tragedy but rather by including opportunity for growth. Macdonald challenges current practices of Kitwood’s person-centred care as “...not enough” and calls for a relational approach that “...goes further than person-centred care because it cannot be conceptualised outside of the relationship of connection formed between carer(s) and those cared for. A relational-care model requires that we conceptualise ourselves as relational beings” (2019, pp. 195-196). Dewing contends that such relational critiques are a consequence of the “popularization of Kitwoods’ [sic] work [which] is resulting in an oversimplification and side lining of his core ideas on moral concern for others as the basis of personhood” (2008, p. 11). Macdonald is joined by Mears and Naderbagi in seeking “...to move an understanding of dementia as a social experience to centre stage, to be given equal priority to biomedical concerns” (2019, p. 2) as a social imperative.

The perspectives of people with dementia paint a picture of continuing change, growth and development. From the accounts of family and professionals affected by and working with dementia, it is clear that the potential for individuals’ continuing development is increasingly facilitated and shaped through relationships with others. Caring partnerships and collectives hold the potential to co-create new future possibilities together, that promote each individual’s opportunity to live their future potential to the fullest, by looking to who they are becoming.

2.2.4 Living at Home

Living at home is more than a functional solution for the practicalities of day-to-day life and the housing of possessions, it is an activity of being human; “Dwelling, building a house and being at home are fundamental aspects of human existence. Being human *is* dwelling” (Dekkers, 2011, p. 291). People receiving care at home can feel at ease in daily habits and familiar sensations; surfaces, colours, creaks and smells, the sound of the letterbox, the shades cast by changing light through the day. The home can be the heart of life and embody identity. It is the beginning of journeys and a haven for safe returning from the world outside (Williams, 2004). Most older people would wish to remain in their own homes for as long as possible in the event of a dementia diagnosis, although this is not always possible, and many have their lives uprooted in moving to residential care, which can be disruptive for a person with dementia (Prince *et al.*, 2014; Department of Health, 2015).

Not only can delaying the need for institutional care have a positive impact on people with dementia and on those who care for them, it may help to reduce the economic burden on social care services (Dawson *et al.*, 2015; Elliott and Gardner, 2016). These benefits have prompted commitment from the UK government to support more people with dementia to remain in their own homes (Parliament, House of Commons, 2019). In order to achieve this, there is increasing need for supportive services and interventions (Dawson *et al.*, 2015; Elliott and Gardner, 2016). As the Prime Minister’s challenge on dementia 2020 states: “We want to see greater provision of innovative and high-quality dementia care at home, delivered in a way that is personalised and appropriate to the specific needs of the person with dementia, their family and carers” (Department of Health, 2015, p. 31).

People with dementia remaining at home also present challenges. The activities of daily living can become increasingly difficult for people with dementia (Carter, 2016) and families can require care and support from health and social care professionals in coping with the symptoms of dementia and the complexities of care in the home (Lethin *et al.*, 2016; Davies *et al.*, 2019). Professional care can be inadequate (Porteus, 2011; Carter, 2016) and “...hard to come by” (Carter, D. and Rigby, 2017, p. 7), with families often having to pay for it themselves.

Each family's experience of dementia is unique and can be both positive and negative (La Fontaine *et al.*, 2016). The physical and mental health of family carers can be put under immense strain by caring for a person with dementia (Alzheimer's Research UK, 2015). The challenges of caring for a family member with dementia can include changes in their behaviour and personality, social isolation and hidden financial costs beyond paying for care (Ibid.). Spousal caregivers of people with dementia can experience high levels of loneliness, depression and stress (La Fontaine *et al.*, 2016; Rio, 2018).

Dementia impacts on the individuals within families and upon family relationships (Alzheimer's Research UK, 2015; Benbow, Tsaroucha and Sharman, 2019), which can change in various ways, including the loss of companionship, mutual support and shared interests and can result in disconnectedness and conflict (La Fontaine *et al.*, 2016; Colquhoun, Moses and Offord, 2017). However, relationships can also be strengthened, and warmth, affection and love maintained through the shared experience of living with dementia (Alzheimer's Research UK, 2015; La Fontaine *et al.*, 2016; Elliott *et al.*, 2020). The well-being of individuals with dementia can be promoted by social relationships (Livingston *et al.*, 2008). For family carers of people with dementia, their relationships with those they care for are of primary importance for their own well-being (La Fontaine *et al.*, 2016); even more so than the severity of dementia symptoms and level of support needed (Riley, Evans and Oyebode, 2016). There is a clear need to support caring relationships in order to support the well-being of people with dementia living at home and those who care for them.

2.3 Music

Throughout history, music has been an integral part of human cultures that has shaped our physical, behavioural, emotional, social and spiritual evolution (Brown, Merker and Wallin, 2000) as well as our individual development. The enveloping rhythms of the womb are among our first sensory perceptions *in utero* (Neal and Lindeke, 2008), followed by the singsong vocalisations of infant-directed speech after birth (Parncutt, 2009). These experiences help to forge our earliest relationships and lay the foundation for development of language (Kitamura and Burnham, 1998;

Mithen, 2006; Parncutt, 2009) and musical identity through life (MacDonald, 2008). Our breath and heartbeat respond to music (Schneck, 2015), memories stir (Janata, Tomic and Rakowski, 2007; Tillmann, 2009) and emotions awaken (Pellitteri, 2009). Musicality is an inherent quality of being human (Pavlicevic, 1997; Perret, 2005; Malloch and Trevarthen, 2018).

Recognition of musicality as a universal human capacity has decreased in Western culture (Elliot and Silverman, 2012). The evolution of performance art has seen the development and refinement of musical skill, and an appreciation of aesthetic value that fosters:

...an 'us-them', listener-work separation that privileged an abstract and disembodied relationship with musical syntax, rather than a concrete, embodied, sensual, visceral, practical, 'moving', participatory relationship with musical-social sounds and group experiences of music-making (Ibid., p. 28).

This objectification of music has given rise to musical consumerism (Lines, 2015; Green and Mayes, 2017). Being 'musical' is widely considered to be a specialist area or natural talent, with those that 'have it' selling it to those that do not to enjoy (McPherson, Davidson and Faulkner, 2012).

Music makes the relationships between people and the world manifest to the senses, through the touch of instruments, the uniting of voices, the quality of expression. These musical relationships between people and 'things' are a dynamic process of continuous change that manifests as physical, physiological, emotional and cognitive movement (Schneck, 2015; Ansdell, 2016). Just as the practice of science has developed an 'objective' stance that divides people from things, so have we become divorced from our musicality:

Because music depends on active doing (music-making and partaking of any kind) music involves *embodied* knowledge and experience. In contrast to the dualistic separation of mind and body that grounds the aesthetic concept of disinterested contemplation, the praxial concept reunites the dualisms implicit in the 'fine art' concept of music (Elliot and Silverman, 2012, p. 30).

The prevailing materialistic understanding of sound as frequency (e.g. De Mayo, 2015) reduces music to vibration of the air. Whether these vibrations are produced through 'live' human activity or from a recording, the term 'music' is used interchangeably. And yet we do not mistake the 'frequency' of colour and shade we

perceive in a photograph of the performer, with the performer themselves. The photograph can only be viewed after the event; it is a visual artefact. In the same way, recordings of music are sonic artefacts. People manifest sonically just as they manifest visually. When a recording is played, it is a mechanical representation of the original event we hear in an encounter with the machine. The point of these observations is not to assert a binary distinction of music that bestows a secondary status upon recordings of music, as Sanden (2013, p. 20) observes:

Music is either live or mediated. It emanates from either a human or a machine. It is either a product of natural means or artificial means. According to conventional Western values, the former half of each of these particular binaries is usually favored, while the latter half, in these instances, is viewed as the degraded “other.”

There is undoubtedly a relationship between recordings and that which is recorded, as without music there would be no recordings of music. However, music is not mediated, does not emanate from a machine and is not the product of artificial means. The sounds that come from machines are recordings *of* music, not recorded music. These sounds are no more music than the photograph or video is the performer being photographed or filmed, but abstract mechanical illusions of music. Music is a living sonic manifestation, just as a performer is a living physical manifestation. This is an understanding of music that does not appear to be reflected in other literature, but that has developed through the course of this study. It is an understanding that foregrounds music as a living medium of our inherent musical potential as distinct from the performative and mechanised consumerist music culture that prevails.

Small (2012) coined the verb term ‘musicking’ as distinct from ‘music’ as a noun to denote the difference between ‘things’ that are referred to as music, such as sheet music and recordings, and music as an activity: “to music is to take part, in any capacity, in a musical performance, whether by performing, by listening, by rehearsing or practicing, by providing material for performance (what is called composing) or by dancing” (2012, p. 9). As will become apparent in subsequent chapters, this study includes other forms of activity together with musicking, such as sensory exploration and other art forms, and is concerned with other forms of response to music beyond dancing, such as laughter and speech, so the broad term

‘musical activity’ is used throughout as encompassing all these activities and responses. The term ‘music’ is used to refer to music as a living medium as it is created, perceived and experienced, and musical ‘things’ are referred to as the artefacts that they are, such as recordings and notation *of* music.

2.4 Music and Dementia

An understanding of music as a means to influence health and well-being has accompanied our musical evolution (McClellan, 2000) leading to the development of music therapy as a certified profession. The use of music in dementia care has received particular attention in recent times. The endurance of emotional memory through dementia means that a personal connection to music can also be sustained, and evidence is mounting to indicate that music can play a beneficial role in the lives of people living with dementia (All-Party Parliamentary Group on Arts Health and Well-being, 2017). There is also a growing awareness of the potential role that carers and professional caregivers play in developing arts activities in the care of people with dementia. According to Broome, Denning and Schneider, “activity coordinators play a crucial role in the success of arts interventions in care setting [sic] through their knowledge and support of residents” (2018, p. 1). Care staff can also play a pivotal role as evidenced by studies of singing as part of caregiving practice (Hammar *et al.*, 2011; Batt-Rawden and Stedje, 2020; Swall, Hammar and Craftman, 2020).

Anecdotally, listening to music has been reported to “...bring people back to themselves” for those with dementia (Baird and Thompson, 2018, p. 827) or “...restore them to themselves, and to others, at least for a while” (Sacks, 2008, p. 47). Drawing on his extensive experience as a neurologist, Sacks places emphasis on the ability of familiar music to enable access to memories of past experiences for people with dementia. He concludes that “...there is still a self to be called upon even if music, and only music, can do the calling”. Sacks’ observations echo findings from research that suggests familiar music that has a biographical significance can evoke memories of past experiences (Cuddy *et al.*, 2017; Baird *et al.*, 2018), representing “an island of preservation during the progression of Alzheimer’s disease” (Baird *et al.*, 2018, p. 693). However, it appears that this phenomenon differs between people

with different types of dementia (Baird *et al.*, 2020). Individualised selections of recordings of music are increasingly utilised in domiciliary, care home and clinical dementia settings, with research commonly attending to the impact of listening as a supportive intervention to achieve specific outcomes, such as reduced agitation and depression, and improved mood (Garrido *et al.*, 2017; Kwak, Anderson and O’Connell Valuch, 2018; Buller *et al.*, 2019; Gaviola *et al.*, 2020; Huber *et al.*, 2020). Research suggests that, for individuals with Alzheimer’s disease, “...regardless of the music intervention approach, individualized music regimens provided the best outcomes for the patient” (Leggieri *et al.*, 2019, p. 1).

Music listening, whether recordings or live, can promote shared interaction such as verbal reminiscence (Metcalf, 2020). Beyond listening to recordings, music-making is a potential means for individuals to act, express, interact and create, even when this is no longer as accessible through cognition for an individual with dementia (McDermott *et al.*, 2013), thus offering opportunity to relate and communicate (Ridder and Gummesen, 2015; Macgregor, 2016; Swall, Hammar and Craftman, 2020).

Music has potential to be a participatory and creative medium in the daily lives of people with dementia (Bellass *et al.*, 2019; Dassa, Rosenbach and Gilboa, 2020; Elliott *et al.*, 2020), and also a means “...to communicate and demonstrate their capacities” for those who are ‘postverbal’ (Quinn, Blandon and Batson, 2019, p. 1). Participation in arts, including music, reportedly “...enhances brain function, improving resilience to dementia” (All-Party Parliamentary Group on Arts Health and Well-being, 2017, p. 131). According to Baroness Greengross, chair of the All-Party Parliamentary Group on dementia, “It is vital for their well-being that when given a diagnosis that their brain is degenerating, they [people with dementia] should at the same time be directed to creative activity as cognitive rehabilitation” (Ibid., 2017, p. 130).

Developing a “...concrete, embodied, sensual, visceral, practical, ‘moving’, participatory relationship with musical-social sounds and group experiences of music-making” (Elliot and Silverman, 2012, p. 28) broadens the focus on music as an intervention for people with dementia that “...restore[s] them to themselves, and to others at least for a while” (Sacks, 2008, p. 47) to recognise developmental musical

relationships that draw on the past as a means to discover emerging future potential. Participatory, creative and relational musical activity is typically facilitated by trained music therapists or musicians, and the potential for people and families affected by dementia to explore their musicality for themselves as a means to create and connect is unclear. However, the potential for familiar music to ‘call to’ a person with dementia and provide a foundation for development of participatory, creative musical activity (Raglio *et al.*, 2014; Pavlicevic *et al.*, 2015), indicates that familiar music could provide an accessible starting point.

2.4.1 Music at Home

The majority of research studies in the field of music and dementia have been conducted within institutional settings. However, attention to music for people with dementia living at home does appear to be growing, as an international randomised controlled trial is currently being conducted at the time of writing this thesis (Baker *et al.*, 2019). Where the home has been the setting for research, the majority of studies have sought to understand the effects of music, finding that it can positively influence:

- Neuropsychiatric symptoms and behaviour (Lai and Lai, 2017; Carter, Wei and Li, 2019; Melhuish, Grady and Holland, 2019);
- Affective state (Baker, Grocke and Pachana, 2012; Särkämö *et al.*, 2014; Melhuish, Grady and Holland, 2019);
- Cognitive processes (Särkämö *et al.*, 2014; Li *et al.*, 2015; Satoh *et al.*, 2015);
- Quality of life and well-being (Hanser *et al.*, 2011; Särkämö *et al.*, 2014; Melhuish, Grady and Holland, 2019).

Observing the informal use of music in a caring relationship, Baird and Thompson (2019) found that musical activity can be used to support recognition. The caregiving experiences and well-being of family members have also been found to be positively influenced by music and music therapy (Baker, Grocke and Pachana, 2012; Särkämö *et al.*, 2014; Lewis *et al.*, 2015; Melhuish, Grady and Holland, 2019; Quinn-Lee and Mowry, 2019), providing a potential means of addressing the need for “...accessible, cost-effective strategies that support family caregivers in caring for their loved ones at

home, while maintaining their own health and well-being” (Elliott and Gardner, 2016, p. 2). Sharing music is a potential means for a carer to continue to experience reciprocity, communication, shared activity and positive emotion with the person they care for as their relationship changes (Dassa, Rosenbach and Gilboa, 2020; Elliott *et al.*, 2020; Garabedian and Kelly, 2020). Although existing research would appear to advocate the use of music in the homelives of people with dementia, few studies have sought to understand how people can be effectively supported to do this.

In practice, there are organisations working to promote music for people with dementia living at home. Playlist for Life (2019) offer training and national ‘Help Points’ to support people with dementia, at home and other settings, to create individual playlists. The BBC provide online music samples, memory radio and accompanying activity sheets on their Music Memories website (*BBC Music Memories*, 2020). Music for Dementia also provide a radio station (*MAD Radio*, 2020) as well as signposting and resources for musical activity (*Music for Dementia*, 2020) ([Appendix 11.1](#) contains a more comprehensive list of available resources). Independent groups and organisations such as the Alzheimer’s Society and Wigmore Hall offer community music sessions that provide opportunities for people to participate in singing, movement to music and creative music making. Beyond listening to recordings and online content, there appears to be little direct support and few resources that enable people and families affected by dementia to engage with and explore musical activities for themselves at home.

2.5 My Journey through the Landscape

From a young age I felt drawn to healing practices and enjoyed singing and learning to play musical instruments. These interests grew with me, becoming a deep-rooted calling to share music with others as a medium of change. My musical studies, performance and teaching gave way to facilitating music sessions as opportunities for health, well-being and social change. I experienced how transformative musical activity can be for people with dementia and their carers, and the potential for music to be shared within their caring relationships and homes. These experiences inspired

in me a wish to understand the relationships between music and people affected by dementia and how these relationships can be promoted and supported.

As a music facilitator, I have found outcome-directed uses of music and findings from research that claim to be generalisable can be restrictive of responding to individuals in the moment. I have also observed the limitations of measuring the cause and effect of musical interaction as a means to understand musical activity and demonstrate its 'value'. I recognised a fundamental necessity to move beyond a mechanistic view of music for health and well-being that I found echoed in the call for a more individualised approach to research (Greenhalgh, Howick and Maskrey, 2014) that shifts its focus from health versus illness outcomes towards more holistic concerns such as 'flourishing' (DeNora and Ansdell, 2014). A distinction between flourishing and well-being is also recognised by Titchen, Cardiff and Biong, who observe that:

Human flourishing focuses on maximising individuals' achievement of their potential for growth and development as they change the circumstances and relations of their lives. People are helped to flourish (i.e. grow, develop, thrive) during the change experience in addition to an intended outcome of well-being for the beneficiaries of the work (2017, p. 39).

In a musical context, Ansdell and DeNora speak of the relational nature of flourishing as:

...something that goes beyond individuals and discreet physical indicators to encompass the interconnections between people and their environments, understood as a reciprocal, ecological relation: in which both illness and health are reconfigured within a more spacious social and cultural landscape. Well-being involves our flourishing together, within our socio-cultural community (2012, p. 110).

This relational understanding transcends the dichotomy between both carer and cared-for and between performer and listener, or performer and work. When understood as a medium of interconnection between people and their environments, music is not a *cause* of change, but rather, participating in these relationships *is* change. Ansdell and DeNora conclude: "...when music flourishes, people flourish too" (2012, p. 111).

Such relationships exist beneath the surface of observable causality and understanding them requires a different way of seeing and thinking, for which DeNora and Ansdell suggest an approach called 'gentle empiricism' (Ansdell and

DeNora, 2012; DeNora and Ansdell, 2014). Gentle empiricism is a term coined by Johann Wolfgang von Goethe (1749-1832) to describe his approach to the study of phenomena. At various points in my life, I have encountered the work of Goethe as a writer and philosopher, which paved the way for my exploration of gentle empiricism as a potential means of observation for this study. In gentle empiricism, I discovered a complementary approach founded in a thorough, scientific methodology for studying the relationships between people and music on my continuing journey through the landscape of music and dementia.

2.6 Study Purpose

There is a need to increase the capacity to support people with dementia to live at home for as long as possible. Such an increase requires not just practical assistance, but support of caring relationships and recognition in the present of individuals' future potential, as well as their past. Familiar music can provide a means to 'call to' a person with dementia offering a foundation to explore relational musical activity. However, there is a lack of research into understanding musical activity in the caring relationships of people with dementia living at home, and how it can be promoted and supported. The aims for this study are:

- To seek understanding of musical activity in the caring relationships of people with dementia living at home;
- To seek understanding of how shared musical activity can be promoted and supported within the caring relationships of people with dementia living at home;
- Out of this understanding, to develop practical suggestions and ideas to inspire, promote and support the development of shared musical activity within the caring relationships of people with dementia living at home.

During the final year of this research, two studies have been published that each share one of these aims. Elliot *et al.* (2020) sought to understand the role and meaning of music for people with dementia who are living at home. Dassa, Rosenbach and Gilboa (2020) were concerned with promoting and supporting musical activity by

piloting a music therapy model. This model was intended to act as a basis for sustainable musical activity in daily life for people in caring relationships.

This study has potential to add to their findings in a unique way. Firstly, by seeking to understand musical activity in caring relationships through participation in them as phenomena, not specifically as having a role or meaning for individuals with dementia. Secondly, by coming to understand ways that such musical activity can be promoted and supported out of this understanding rather than through application of a therapeutic model. The philosophical and practical basis for developing this understanding are the subject of the following two chapters.

2.7 Summary

This chapter has mapped the landscape of music and dementia and identified the need for, and purpose of this study. The following chapter lays the methodological ground as a foundation for research.

3 Methodological Ground

...there is a kind of seeing that is also a kind of thinking...: the seeing of connections.

(Monk, 1991, p. 537)

3.1 Introduction

The following chapter lays the philosophical ground for this study. I explore the foundations of Goethe's method for studying the natural world, gentle empiricism, and shed light upon the world view, a path to understanding and methodological tenets implicit within it. Throughout the chapter, I offer the reader opportunities for experiential understanding by incorporating examples of images and poetry from my own activities in developing the research, and through participation in exercises and artistic examples.

3.2 Gentle Empiricism

The work of Goethe transcended the confines of contemporary disciplines and made original contributions to knowledge that now, some 200 years later, have come to be recognised as avant-garde. Although he is admired chiefly for his plays and poetry, his approach to science was his most radical and challenging work and the full potential and significance of his indications for future research are still being discovered (Seamon, 1998; Kaplan, 2002).

Goethe practiced a 'gentle' or 'delicate empiricism' (Goethe, 1988); seeking intimate knowledge of phenomena through participating in and interacting with his environment (Seamon, 1998; Wahl, 2005; Robbins, 2006). During Goethe's time, the thrust of western scientific endeavour continued along the course of a material science charted by Newton, seeking a universal causal order by breaking down

phenomena into constituent elements from an objective standpoint (Biener and Schliesser, 2014). Goethe on the other hand, sought universal understanding through individual experience and a science that could work in harmony *with* nature rather than *on* nature through manipulation and artificial syntheses (Bortoft, 1996; Brook, 1998).

An effective way to demonstrate the study of phenomena as they are experienced is through engaging in one of the colour experiments that Goethe conducted towards developing his *Theory of Colours* (Goethe, 1840; Schindler, 1970). You are invited to gaze at the yellow circle. After around 30-seconds, shift your gaze down to the white space beneath the yellow circle (see Figure 2 below).

Figure 2: Goethean Colour Experiment



Many people will experience a violet/purple after image.

Every colour has its complement that the eye sees and that we can experience through afterimages. However, afterimages are an individual experience not recognised by the Newtonian theory of colour, and were generally considered illusory during Goethe's time (Illetterati, 1993). The experiment with yellow is one of many conducted by Goethe studying afterimages (Schindler, 1970) that exemplify experience as being at the heart of his experiments.

Goethe's way of coming to know phenomena requires the individual to develop their capacity to perceive. The process of developing these capacities is recognised by contemporary practitioners of Goethean science as comprising distinct modes of perception (Irwin, 2007):

0. First impressions
1. Exact sense perception
2. Exact sensorial imagination
3. Inspiration: encountering the whole
4. Intuition: becoming one with the phenomenon

Development of each of the listed modes of perception provides a necessary foundation for development of the next. As an individual develops their own capacity to perceive in these modes, they cease to be experienced as distinct modes and become a seamless, flowing process of deepening perception (Brook, 1998). Goethean perception shines light on a relatively untrodden path to knowledge, cultivating the creation of understanding based on experience rather than understanding grasped through intellect (Bortoft, 1996).

The creative arts play an integral role in the development of the 'organs of perception' (Hoffmann, 1998, 2007; Kaplan, 2002) necessary for the deeper knowing that Goethean perception facilitates, that does not require reasoned understanding (Bortoft, 1996, 1998). The way the arts are used depends on how the individual chooses to express their insights and on the form of perceiving. For example, drawing lends itself to working with visual observation. The arts can be used as creative mediums for engagement, which are not dependent on prior experience or skill (Kaplan, 2002).

It is important to note that this is relatively uncharted territory and is not a finished, formulated ‘off the peg’ methodology. Many of the concepts presented here are not commonly shared and the language to express them is limited. Indeed, the methodology implicit in Goethe’s method, outlined below, cannot be adopted as given, for inherent in it is the principle that each individual must experience it and create it anew, in a living way for themselves; as *a* Goethean approach to studying phenomena, not *the* Goethean approach.

3.2.1 First Impressions

The impulse that draws any individual to study a phenomenon is the essential catalyst in a Goethean approach to perception (Bockemühl, 1985; Hoffmann, 1998).

Awareness of being ‘drawn to’ a phenomenon and one’s own thoughts and feelings in response to it, are cultivated in preparation to enable conscious distinction between individual subjectivity and universal subjectivity (Brook, 1998). To demonstrate this distinction experientially, you are invited to look at the following image (see Figure 3).

Figure 3: Visual Exercise (Bortoft, 1996, p. 50)



You may see a seemingly random collection of black, non-uniform, two-dimensional shapes within a circle, or you may see the black shapes grouped as a recognisable shape(s) or form(s). This image was created with the intention to portray a giraffe within an open texture to facilitate the observer in shifting between seeing a giraffe and not seeing a giraffe (to aid seeing the giraffe, see [Appendix 11.2](#), then return to the original image). The change that is occurring when shifting to seeing “giraffely” (Bortoft, 1996, p. 127) is the addition of the concept ‘giraffe’ to the sense perception,

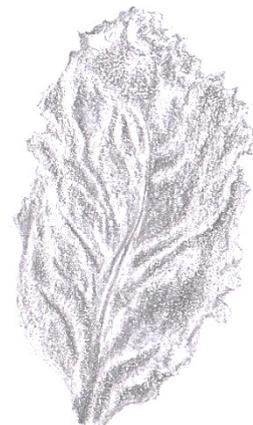
which also interestingly enables a three-dimensional experience of the image. The concept ‘giraffe’ and all the accompanying concepts and feelings that you associate with a giraffe are added through active participation in the act of seeing. That is not to say that seeing as a sense perception is a passive receiving of experience. Seeing requires active engagement of the senses rather than active thinking in adding intellectual concepts. This exercise, originated by Bortoft (1996), disrupts our everyday mode of seeing in which we habitually see the ‘things’ of the world, actively adding concepts without awareness or even the realisation that we are engaging in an active process.

3.2.2 1. Exact Sense Perception

Exact sense perception requires awareness of one’s own activity in order to develop the capacity to perceive independently of concepts and feelings *about* perceptions.

Perceiving ‘what is there’ provides a static, factual foundation for the activity to follow (Brook, 1998; Hoffmann, 1998; Brook *et al.*, 2017).

Increased awareness of sensory experience can be cultivated through various activities, for example drawing the object of study, or aspects of it in detail (Hoffmann, 1998; Kaplan, 2002), e.g. the leaf of a plant.



3.2.3 2. Exact Sensorial Imagination

The intention at this stage is to develop the imagination to perceive the temporal life of the phenomenon, becoming aware of change as movement over time. Taking the example of a plant, rather than identifying the parts that make up the whole plant in the frozen present, the imagination is active in picturing its development as an ongoing process (Hoffmann, 1998). The exact sense perception of the previous stage serves to bound the free flight of imagination from becoming fantasy and confine it to imaginative perception of what is possible for the phenomenon (Brook, 1998). An

established method of developing this imaginative faculty is through drawing. One exercise is to draw the phenomenon, or an aspect of it such as a leaf, at different stages of growth (Brook, 1998; Brook *et al.*, 2017).



Another leaf is then drawn from the imagination - one that could occur between two stages of the drawn process.

3.2.4 3. Inspiration: Encountering the Whole

The previous two stages, exact sense perception and exact sensorial imagination, are both participatory in nature, as interaction with the phenomenon through the senses and then through the imagination. The third stage is receptive, allowing inspiration to manifest (Brook, 1998; Brook *et al.*, 2017). Through inspiration, one can come to recognise the gesture or patterns that give rise to the formative process of the whole phenomenon perceived in the previous stage (Hoffmann, 1998); just as the relationships between the tones of music manifest as a musical form over time for the attending listener. Try listening attentively to the patterns, relationships and gestures of a piece of instrumental music, and notice how the form of the whole is only revealed to you in experience over time. The inspirations of this stage can be expressed through various art forms, for example gestural image or poetry (Brook, 1998; Hoffmann, 1998):

Opening, unfolding into the light
Unbinding release in spiralling flight
Thrusting forth to fall away
Life fades through gold to dark decay.



3.2.5 4. Intuition: Becoming One with the Phenomenon

The activity of the fourth stage adds content and meaning to the knowledge of a phenomenon's form developed through the preceding three stages of a Goethean approach to perception (Brook, 1998). The archetype or essential idea belonging to the phenomenon is united with its form through intuitive thinking (Brook, 1998; Hoffmann, 1998). At this fourth stage, it becomes possible to perceive "...in the inorganic realm, the appreciation of laws and, in the organic realm, the appreciation of type" (Brook, 1998, p. 57). In his study of plants, Goethe came to an understanding of metamorphosis:

...it came to me in a flash that in the organ of the plant which we are accustomed to call the leaf lies the true Proteus who can hide or reveal himself in all vegetal forms. From first to last, the plant is nothing but leaf, which is so inseparable from the future germ that one cannot think of one without the other (Goethe quoted in von Goethe and Miller, 2009, p. xvii).

3.2.6 Working with Gentle Empiricism

For me, learning to develop and work with gentle empiricism has been an experiential path to understanding through dedicated, conscious participation in life. The inexhaustible phenomena encountered daily have offered me opportunity for development of deepening 'modes of perception', and reciprocally, my view of the world has transformed. Continuing practice has run like a river through my life from the early beginnings of this study. The river has tracked a course through a rich and varied panorama of experiences from a diverse range of contexts and sources. Books and papers provided a foundation for my understanding and inspired me to explore a Goethean approach to research (e.g. Seamon and Zajonc, 1998; Robbins, 2006; Ansdell and Pavlicevic, 2010). Online video helped to bring characters and ideas to life by experiencing some of the human context beyond the words and meaning (e.g. Wise Cosmos, 2015; Robinson, 2016), not least because ideas can become dehumanised edifices, abstracted from mortal existence. 'Rehumanising' made these ideas attainable and helped me to see how I might work with them in the context of my life through less formal examples and anecdotes.

Early contact with others working with Goethe's indications, academic presentations, discussions and workshops along with conversations with family members, colleagues and friends have helped me to juxtapose, work through and consolidate ideas by their articulation. Attending workshops on Goethean observation (Brook *et al.*, 2017; Kennish, 2017; Evans, 2018) has enabled me to gain experience that I have continued to cultivate through observing plants and people in preparation for this study, and by engaging in the arts to practice observation exercises (Kaplan, 2002), observe phenomena and document insights (see examples of leaf drawings and poetry above). All of the experiences outlined above and the subsequent development of the fieldwork have been instrumental in my coming to recognise gentle empiricism, not only as a process for working *with* living, organic processes, but as a living, organic process that comes into being through the individuals that manifest it, each bringing a unique presentation into being.

There are individuals and organisations, past and present, who work consciously with Goethean science across disciplines, including philosophy (Bortoft, 2012), natural science (Brook, 1998; Seamon and Zajonc, 1998; Holdrege and Talbott, 2008; *The Nature Institute*, 2020) and social science (Kaplan, 2002; Scharmer, 2009; *The Proteus Initiative*, 2013; Robbins and Gordon, 2015). Goethe's approach informed the anatomical studies of Bolk that founded the continuing work of the Louis Bolk Institute towards developing sustainable agriculture, nutrition and health (*Louis Bolk Instituut*, 2010). The development of Steiner's philosophy was grounded in his study and practice of Goethe's approach to phenomena (Steiner, 1979a, 1979b). He went on to realise this philosophy through practical application in a range of fields including education, agriculture and medicine that are still being developed today. These examples do not constitute an exhaustive list, but are representative of the thriving, developing stream of work for which Goethe prepared the ground.

However, a Goethean approach to enquiry is also evident in the stream of phenomenology that has developed since Goethe's time, of which he is not recognised as a founder but only an influence (Robbins, 2006), and the writings of philosophers that preceded him, such as Plato and Aristotle (Bortoft, 2012). From my own experiences through this study and hearing the comments of colleagues describe how they have come to an understanding of a given topic or phenomenon, I

have discerned a fundamental process of ‘coming to know’ that is taken for granted, that we live within, and function out of, without explicitly acknowledging it. This process of understanding cannot be seen as one man’s idea. Goethe’s legacy was to see clearly the essential nature of understanding and give indications for others to work with and develop consciously.

3.3 Science of Wholeness

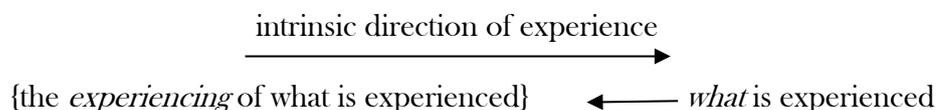
Natural science is the bedrock upon which western society is continuously building. It has yielded medical treatments and cures, informed the development of social science and given rise to the technology that dominates contemporary culture on a global level (Wertheim, 1997; Kaplan, 2002; Senge, 2009). More than just the study of the natural world, it has become our unconscious means of coming to know the world in our daily existence, which we tend to perceive in terms of familiar concepts (Bortoft, 1996; Kaplan, 2002). A Goethean approach to scientific investigation, frequently referred to as ‘Goethean science’ (e.g. Amrine, 1987; Hensel, 1998; Wahl, 2005), slows the process of adding concepts to experience, allowing perception and experience to reveal the concepts that are integral to phenomena rather than the habitual activity of conceptualising experience with immediacy. This process presents two ideas that challenge the ‘usual’ mode of perceiving: firstly, that thinking does not author meaningful concepts, that there exists a lawful relationship between perception and conception (Steiner, 1979a) and secondly, that phenomena manifest concepts; an idea that harks back to Aristotelian ‘hylomorphism’ (De Haan, 2018).

Although Goethe’s investigative process did require ongoing self-development, he did not turn the focus of his investigation to the experience of his own thinking activity (metacognition), which would be necessary for the explication of the philosophical basis for his methodology (Steiner, 1928). Ensuing proponents of Goethe’s work have since taken up the task of developing philosophy through a Goethean approach. Two of the most prominent figures to contribute to this stream of science are Steiner and Bortoft, both of whom recognised the significance of Goethe’s work and its unrealised potential, opening-up the field of study to include *thinking* (Steiner, 1979a, 1979b).

In his early philosophical writing, Steiner illuminates the monistic, self-sustaining world conception implicit in Goethe's work. Namely, that mind and matter are of one reality and that which we experience as the division between inner and outer worlds is an illusion brought about by sense perception (Steiner, 1979a). Meaning is not offered by sense perception, rather meaning is arrived at through thinking, just as the idea of a giraffe can be added to the monochrome image, so do we bring to pure sense perception concepts, or 'organising ideas' that enable us to make sense of the world.

That the content of thinking is not as a product of the brain but exists 'out there' as a 'hidden' aspect of the phenomenal world that we cannot perceive through the senses, but which we reunite with it to experience reality, is echoed more recently in the words of Bohm, "The source of intelligence is not necessarily in the brain. The ultimate source of intelligence is much more enfolded into the whole" (2003, p. 107). Materialist neuroscience accepts that the content of thinking originates in the brain, i.e. that matter thinks (Beauregard and O'Leary, 2008). However, according to Steiner, the physiological processes in the brain that we consider to be thinking, are rather the result or reflection of thinking activity that we participate in (Steiner, 1966, 1979a). Through intuitive thinking, we can receive content from the realm of thinking to form concepts and mental pictures. These concepts and mental pictures serve to inform individual actions and are worked with on a daily basis, forming the thinking, or cognitive perception used day-to-day (Steiner, 1966, 1979a; Bortoft, 1996).

According to Bortoft (2012), a 'dynamic' way of thinking underpinned the development of the European stream of philosophy that gave rise to the phenomenology movement through leading figures such as Husserl, Heidegger, Merleau-Ponty and Gadamer. Bortoft paints a picture of life coming into appearance as a stream of continuous activity moving intrinsically forwards into the present. The separate, independent entities we experience day-to-day lie 'downstream' of what is coming into appearance, but through dynamic thinking we can experience the unity that is manifesting in multiplicity by turning our attention 'upstream' into the activity of experiencing:



...Phenomenology is a shift of attention within experience, which draws attention back from *what* is experienced – i.e. where the focus of attention is on the *what* – into the *experiencing* of what is experienced: The { } is important. If we just say there is a shift of attention from *what* is experienced to the *experience*, we are in danger of unwittingly treating ‘experience’ as if it could be separated from what is experienced. But there can be no experience without something that is experienced. The shift of attention ‘back upstream’ is subtle, and not coarse as it would be if we made the mistake of trying to focus on ‘experience’ directly – this would mean trying to turn experience into *what* is experienced, which is the fallacy of introspection with which phenomenology has often been confused (Bortoft, 2012, p. 19, original emphasis).

Seeing the world dynamically reveals living systems of self-creating ‘wholes’ that are continually coming into being in a process of growth and change, with ‘parts’ of a whole being manifestations *of* the whole. Bortoft explains the protean activity of wholes coming into appearance in multiplicity, taking Peonies as an example:

There are...a thousand different varieties of Peony...what we see... extensively as many different plants is organically One plant which is intensively multiple – a ‘multiplicity in unity’ which is an expression of the dynamic unity of self-differencing. It is One plant be-ing itself differently and not just many different plants of a common kind...the unity is ‘hidden’ right in front of us as the diversity (2012, p. 79).

This world view forms the ontological basis of a ‘science of wholeness’ (Bortoft, 1996, 2012), which stands in contrast to the reductionist world view that observes a whole as the sum of its parts. Extending understanding and practice of Goethean science, this science of wholeness does not replace or undermine mainstream science, but complements it with deeper, more comprehensive understanding (Bortoft, 1996).

There are phenomenologists whose work clearly presents a dynamic view of the world. One such is Merleau-Ponty, who recognises the primacy of perception (Merleau-Ponty, 1964) and describes the body as lived rather than as a discreet object (Merleau-Ponty, 2002); reflecting Goethe’s understanding of the plant as living activity. The work of later phenomenologists, particularly Merleau-Ponty, further develops the dynamic way of seeing evident in Goethe’s work. Rather than being simply a choice of approach over other phenomenological approaches, gentle empiricism offers a clear path for individuals to develop their own capacities for dynamic seeing essential to phenomenological understanding.

Coming to know wholeness involves the researcher in “...going further into the parts rather than standing back from them” (Bortoft, 1998, p. 280), as is typically the approach of empirical research (Patten, 2017). Going ‘into’ the parts is an active and participatory process of developing the organs of perception necessary for other forms of knowing, as discussed above. This ‘going deeper into the parts’ activity is reflected in the phenomenological practice of thematic analysis through treatment of “...texts as sources of meaning at the level of the whole story; at the level of the separate paragraph; and at the level of the sentence, phrase, expression or single word” (van Manen, 2016, p. 320). Through phenomenological analysis, meanings are differentiated. However, there is a risk that meanings can become an abstract system of themes or structures applied to experience, rather than arising out of it (Bortoft, 2012; van Manen, 2016). When seen dynamically, “the act of distinction is simultaneously analytic and holistic”, a “unitary act of {differencing/relating} in which the types are seen as simultaneously different from and related to one another” (Bortoft, 2012, p. 20), i.e. one thing can only be distinguished from another to which it already belongs.

Within phenomenological enquiry, distinction is drawn between a focus on the lived experience of others, often concerned with pre-reflective or experiential narratives, and heuristic enquiry (Moustakas, 1990): the direct experience of the enquirer. This study is concerned with the living experience of other people and music through participation of the enquirer; a Goethean approach requiring the development of empathy for individuals as phenomena. Although similar in nature to ‘close observation’ (van Manen, 2016), the focus of enquiry is not on trying to understand and relate the experiences of the enquirer and others, but to come to understanding of phenomena in the act of appearing, in this case, people and music.

Participating in phenomena to gain direct experience as data opens up the pre-reflective experience by sharing in it as it happens, rather than working exclusively with documented accounts of experience. Through living, as distinguished from lived, experience, other appearances of phenomena are available to the senses in addition to words, that can bring insight, and which become especially important when words are not easily accessible for a person with dementia. The experience of a multiplicity of appearances and the insights these experiences provide can form the basis for what

Moustakas calls a ‘creative synthesis’ (Kenny, 2012) and Goethe ‘a theory’ (Goethe, 1840); becoming one with the phenomenon:

When consciousness is properly prepared, it becomes the medium in which the phenomenon itself comes into presence...Thus the phenomenologist of nature himself becomes the apparatus in which the phenomenon actualises as a higher stage of itself...For the intuitive knowledge of nature, when the phenomenon becomes its own theory, we have the ontological condition that the knower and the known constitute an indivisible whole (Bortoft, 1996, p. 109).

3.4 Creativity

Through a Goethean approach to phenomena, sense perception and experience is the basis to coming to an understanding of that which is perceived, and the meaning that belongs to it. Steiner’s development of Goethe’s approach seeks experience of meaning that is intuited from the wholeness of potential ideas (Steiner, 1979a).

Through this activity, we become creators, authors of original deeds in the world. Our creations then offer new sense perceptions and experience (Ibid.). Although the content of intuitive thinking is received (intuition), this content must be worked with through an individual’s capacity to form the thought content into concepts (inspiration); form mental pictures (imagination); and perform action out of free will (originating the perceptible) (Ibid.). By viewing Steiner’s approach to creative process alongside Goethe’s approach to coming to know, it is clear that the one is a reverse of the other (see Table 1):

Table 1: Comparison of Knowing and Creative Processes

Knowing	Creating
1. Exact sense perception	1. Intuition
2. Imagination	2. Inspiration
3. Inspiration	3. Imagination
4. Intuition	4. Creation (percept)

Working through a creative process of realising intuited ideas can be observed as working back through a Goethean process of coming to know the ideas that originated a percept. Through such creative activity the individual realises self in original deeds of free will (Steiner, 1979a) and we become creators of the world: “...we do not create meaning - we enable meaning to emerge, and the more that emerges, the more the world becomes” (Kaplan, 2002, p. 78).

Gray (Wise Cosmos, 2016) has developed an exercise in intuitive thinking from an example by Steiner (1966), included here as an aid to the reader. Through this exercise, it is possible to arrive at meaning that is not grounded in sense perception.

Intuitive Thinking Exercise

Recite the five words below inwardly to yourself with an easy rhythm

After about a minute, keep the rhythm of the words, but stop inwardly reciting one of the words but retain its meaning where it appeared in the pattern, i.e. drop the percept, but keep the concept. The meaning of the concept can only remain through intuiting it.

After about a minute, drop a second word, keeping the two spaces where the words are intuited.

Continue in this way, dropping a word with each minute that passes until you are reciting no words only intuiting the meaning. Continue to hold these five intuitive spaces and notice your experience; meaning of the concepts is coming to you inwardly, not through the sounding of the words but by actively keeping in touch with the meaning of them.

It is important to realise that the words are pointing to an experience, and that you are trying to ‘lift’ yourself to the experience free of perception, and it is crucial to keep you attention faithful to the words and not let it wander.

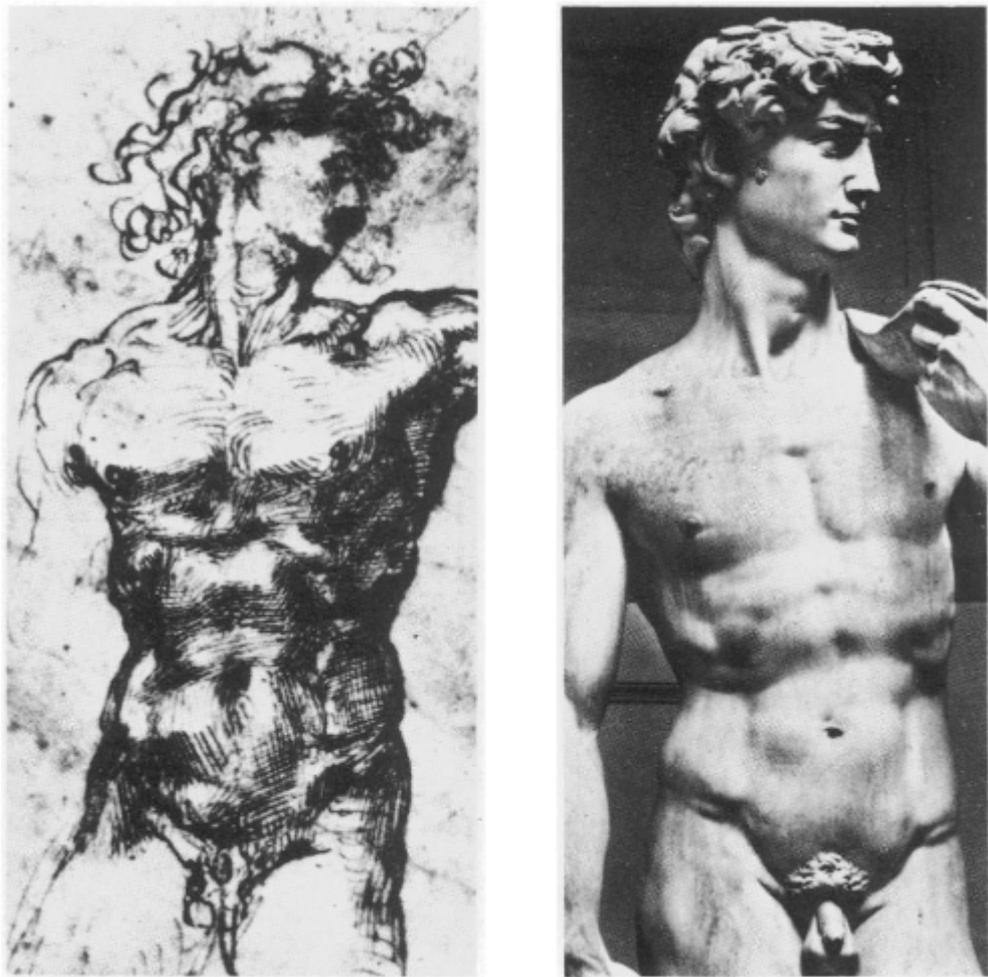
These are the five words:

Wisdom lives in the light

Gray (Wise Cosmos, 2015) also highlights an example of a creative process where intimate knowledge of a phenomenon empowers original action: the creation of Michelangelo’s renaissance sculpture *David*. Michelangelo was commissioned to work with a piece of poor-quality marble that had been partially worked and rejected

by two other sculptors and abandoned to the elements for over twenty years. Using his knowledge of marble and his craft, Michelangelo intuitively recognised the potential of the unique block of marble in the form of David and used his craft to reveal the form (Encyclopaedia Britannica, 2020). The accuracy of his vision is evident in the correspondence between his design sketch and the finished sculpture (see Figure 4).

Figure 4: Sketch and Statue of David by Michelangelo (Levine, 1984)



The idea of revisiting the stages of a Goethean process in retrograde in order to realise self through responsive, creative, original action, is explicitly reflected in the work of Brook, a contemporary practitioner of Goethean science, in her approach to agroecology. Brook's (1998) process of working with landscape adds an additional three stages to the first four indicated by Goethe. These additional stages echo

Steiner's development of Goethe's process (see Table 1 above), enabling Brook to act in service of the landscape in which she is working:

These three stages mirror the third, second and first as described above. For example, the sixth stage would mirror the second by trying out in imagination and with different models and plans, the various design options to see which could 'grow' in a particular place. In this situation the fourth stage is a switching point from what the place is saying to what can be developed there (1998, p. 57).

This mirrored Goethean process has shaped the design of the study overall and the method for the fieldwork, which will be discussed in the following chapter.

3.5 Summary

The ontological, epistemological and methodological perspective laid out in this chapter formed the ground that nurtured my method. The following chapter details the initial design and development of the method as it grew from seed within the landscape of music and dementia research through this study.

4 Cultivating the Seed

Every new object, clearly seen, opens up a new organ of perception in us.

(Goethe, 1988, p. 39)

4.1 Introduction

The methodological concepts discussed in the previous chapter formed the ground for cultivating the method for this research. The design of this study was intended to enable engagement in a Goethean approach to enquiry with enough flexibility to accommodate the ongoing development of my approach. This design was the seed from which fieldwork participation grew. In this chapter, the evolution of the study design and method is recounted.

4.2 Study Design

4.2.1 Method

A mirrored process of the stages of gentle empiricism as discussed in the previous chapter (see [Chapter 3](#)) shaped the design of the study (see Table 2 below). The potential to understand and support everyday musical activity for people that I worked with in community groups, and to extend this support out to those not able to access such groups, ‘called’ me to engage in this study. From being called to by my experiences of working with people and families affected by dementia and by the potential to work with gentle empiricism, I gained a first impression through immersing myself in relevant literature, workshops and videos and realised my intention for the study through its design. Fieldwork offered opportunities for participation in the phenomena of study (data collection): musical activity within the caring relationships of people with dementia living at home. Through the receptive

activity of working with my experiences (data analysis) I came to an understanding of these phenomena, which informed findings with the potential to promote musical activity by, and with, people with dementia living at home, and within caring relationships more broadly into the future.

Beyond establishing a need for this current research as a starting point, I approached literature inductively. Adding to my existing ‘store’ of concepts from the work of others could have offered me a broader conceptual palette to colour my experiences, potentially hindering exact sense perception (see [Chapter 3](#)). I decided that it would be more effective to give understanding space to emerge and develop as free from preconceptions as possible. This approach to literature is in keeping with the methodology for this study, i.e. taking experience as a basis for new understanding of phenomena, rather than existing knowledge as a basis for theory development and testing. Therefore, I conducted a systematic search and review of the literature (see [Chapter 7](#)) after I had worked with the data from my fieldwork sessions. This approach enabled me to supplement and contextualise my own findings.

Iterative development and refinement of written and experiential examples, coupled with picturing how the research could inform future practice and research, finally enabled me to produce this thesis.

Table 2: Study Phases as a Process of Gentle Empiricism

Gentle Empiricism	Phases of Study
0. First impressions	Study design
1. Exact sense perception	Fieldwork
2. Imagination	Working with the data
3. Inspiration	
4. Intuition	
5. Experimentation	Writing the thesis
6. Picturing	
7. Creating	

I have changed some of the gentle empiricism terms by differentiating each stage as unique for the sake of clarity and to avoid repetition. Point five, ‘Inspiration’, has

become ‘Experimentation’ and point six, ‘Imagination’, has become ‘Picturing’. These terms also reflect the more practical, manifesting nature of the activities in coming to realise action.

In detailing the method and subsequent accounts of the fieldwork and findings, I have sought transparency for the sake of “...trustworthiness, meaning, and implications of...[the] results for theory and practice” (Aguinis and Solarino, 2019, p. 1292). I have not sought replicability, as this is a process of coming to knowledge that can never be replicated, as each researcher must find their own unique path to understanding through development of their own organs of perception. However, other researchers taking their own path can come to and build upon the same understanding, as Goethe observed “The general and the particular coincide; the particular is the general made manifest under different conditions” (Goethe and Stoppe, 1998, p. 82).

4.2.2 Data

The primary data produced by this study was experiential, comprising my own sense perceptions, experiences and understandings of the phenomena of study, as well as my actions in response. For the purposes of this research, the phenomena of study comprised musical activity with four ‘pairs’ of participants (person with dementia and a carer; see [Participants and Setting](#)). Documentation, media and video footage were ‘secondary data’ that served to catalyse, verify, clarify and evidence my memory of events. Table 3 identifies the experiential time spent with each pair and the forms of secondary data that were later worked with (see below).

Because I consulted the video footage as secondary data for the sections of footage relevant to my primary data, a full transcript of the video footage was deemed unnecessary. The length of video footage is not an accurate representation of time spent engaging in musical activity. For example, on several occasions the camera was left running while we left the room for a walk in the garden or refreshments.

Table 3: Study Data

Pair	Fieldwork Sessions	Contact Time hh:mm	Video Footage hh:mm:ss	Participant Music Log / Journal Entries	Reflection & Development Entries	Pieces of Multimedia (poetry etc)
1	12	41:30	22:36:31	9	14	25
2	1	02:45	00:59:35	0	2	2
3	11	33:15	19:26:30	8	13	13
4	11	27:15	20:09:27	1	13	11

I traced outline images without facial details of participants from video stills and transcribed quotes as needed to evidence my accounts for the reader. Quotes were transcribed with the omission of stutters and ellipses were used to indicate filler words, false starts and omitted sections of speech. Because most speech took place between me and carers, there are fewer quotes from participants with dementia. I have tried to capture their contributions in other ways such as description and traced image stills.

4.3 Fieldwork Design

4.3.1 Participants and Setting

In selecting participants for the study, I recruited people with dementia who were experiencing changes in verbal communication who might need, and offer, opportunity for the development of other forms of communication for connection, such as music (Quinn, Blandon and Batson, 2017; Strøm *et al.*, 2017). A familial carer complemented each person with dementia recruited to the study, constituting a ‘pair’. Although all pairs recruited to the study were familial, this was not a requirement. Unrelated companions and paid professionals were included in the carer criteria for inclusivity, so as not to exclude persons with dementia without a family carer. The focus of the study was limited to pairs of participants to facilitate in-depth and consistent contact experience through the fieldwork and promote sustainability beyond the study. Including three or more participants together would

also have changed the social dynamics from an individual caring relationship to a group setting. The fieldwork sessions took place in participants' own homes, providing a familiar, safe environment to facilitate navigation (Elliott and Gardner, 2016) and to participate in musical activity with people in the context with which this study is concerned. A maximum recruitment catchment radius of 30-miles from my home address limited travel time to and from participants' homes to within manageable parameters, in consideration of the combined workload of working with two pairs concurrently if the need arose.

During the recruitment process, it became apparent that, although volunteers with dementia were listed as having a formal dementia diagnosis, this was not always the case. Being registered as having a dementia diagnosis on the Join Dementia Research database was taken as indication that either a volunteer identified as having dementia or was believed to have dementia for inclusion in the study.

Table 4: Inclusion and Exclusion Criteria

	Inclusion	Exclusion
Participant with dementia	<p>Recorded as having a diagnosis of dementia by Join Dementia Research.</p> <p>Experiencing at least one of the following difficulties with verbal communication (Sandilyan and Dening, 2015, p. 43):</p> <ol style="list-style-type: none"> 1. Deterioration in the ability to understand spoken language. 2. Language has grammatical errors and poor structure. 3. Resorting to simple sentences. 4. Repetitive use of language. 5. Comprehension of language is impaired. <p>Living within a 30-mile radius of the researcher.</p> <p>Living at home and has at least one carer.</p> <p>Have some level of hearing</p>	<p>Does not have a personal consultee to provide their opinion in the event the person cannot provide informed consent.</p> <p>Has a co-existing severe and enduring mental illness.</p> <p>Does not have an awareness of his/her surroundings.</p> <p>Is profoundly deaf.</p> <p>Has a history of aggression/violence recorded by Join Dementia Research.</p>

	Speaks English as their first language.	
Participant carer	<p>Is a family member, an unrelated companion or a paid professional who regularly provides care for the participant with dementia.</p> <p>Is able to provide direct informed consent.</p> <p>Has some level of hearing.</p> <p>Speaks English as a first language.</p>	<p>Requires an interpreter.</p> <p>Is unable to provide direct informed consent.</p> <p>Is profoundly deaf.</p> <p>Has a history of aggression/violence recorded by Join Dementia Research.</p>

4.3.1.1 Join Dementia Research

Join Dementia Research (JDR) is an online gatekeeping service that enables volunteers with memory problems or dementia, carers of those with memory problems or dementia and healthy volunteers to register their interest in taking part in research. The purpose of JDR is to allow such volunteers to be identified by researchers as potentially eligible for their studies. Researchers can then contact volunteers to discuss potential inclusion.

I used the JDR database exclusively to recruit participants for this study. Using JDR enabled me to find participants locally who matched my inclusion and exclusion criteria and were interested in taking part in research. Seeking participants through a gatekeeper bypassed the need to recruit local people directly, which may have been experienced as coercive by people to whom I am familiar through my work with the local Alzheimer's Society branch.

4.3.1.2 Third Parties

Although the limitation to the number of participants and need for sessions to be uninterrupted were made clear in the study information provided and discussed in advance of the fieldwork, there were several times when sessions were interrupted by health professionals visiting with all pairs. These interruptions were unavoidable, and I was usually made aware of them before the start of the session. With Pair 3, carer visits became a regular, scheduled break during our sessions. I also received requests from participants for other family members or professional carers to join in with

sessions. Because the focus of the study and its approval was for two persons, I discussed my reasons for declining third-party requests with participants.

4.3.2 Pilot Design

A pilot of two fieldwork sessions informed the initial design and planning of the fieldwork cycles. The sessions were conducted with a pair already known to me. This was an informal arrangement and did not involve data collection for use in the study. The pilot gave me an opportunity for an initial experience of participating in the fieldwork sessions as a researcher and served to uncover and resolve many of the logistical issues involved in visiting people at home.

4.3.3 Questionnaire

During the pilot, it transpired that gathering biographical and musical preference information during fieldwork sessions was far more time consuming than anticipated, and primarily involved conversation, which was not an equally inclusive activity for this pair. As a result, I designed a 'Music and Life Story Questionnaire' to gather key information about the life and musical preferences of participants (see [Appendix 11.3](#)), reducing the need for verbal reminiscence to inform potential starting points for session content planning. The questions were developed out of existing research (Gerdner, 2013) and my own working experience. It was necessary to gather this information for each participant in a pair for sharing our own individual experiences and music as a means to explore and develop new musical and sensory experience. A separate version of the questionnaire was created for completion by family members to supplement the information gathered about the person with dementia (see [Appendix 11.4](#)). Images were incorporated into the questionnaire to assist individuals with dementia to answer the questions independently or together with a carer. In practice, the questionnaires proved a helpful starting and reference point for developing session content.

4.3.4 Recruitment

Participants were recruited as needed through JDR rather than from a pool, which would have meant long waiting times for volunteers. The flexibility of this approach also enabled me to recruit further participants as the need arose due to unforeseen circumstances. JDR volunteers that were matched to the study were contacted in order of closest distance first as needed and volunteers that expressed interest in the study were contacted on a first-come first-served basis. All contact with volunteers and participating pairs was made via their preferred method(s). Pair suitability beyond the JDR screening process was determined according to the inclusion and exclusion criteria and mutual agreement during first contact and/or at the initial meeting. During first contact with each pair, I arranged to visit them at home for the initial meeting, allowing at least a two-day window as a cool-off period. I made it clear that they were under no obligation to take part in the study and could cancel or rearrange the meeting without giving a reason by contacting me.

When recruiting for the next cycle, contacted volunteers were asked if they were happy to be put on a waiting list, with a maximum timeframe of 18 months.

Volunteers on the waiting list were then approached in order of closest distance. The time frame was longer than needed for completion of the anticipated three pair cycles of fieldwork sessions, to allow for unforeseen circumstances or an additional pair cycle. Volunteers who were happy to be put on a waiting list were informed that they may not be recruited and subsequently either participated in the study or were informed that they would not be recruited.

The following documents were provided for each potential participant pair in advance of the initial meeting, to give time for them to share the study information and for the ‘Music and Life Story Questionnaires’ to be completed.

- Participant information sheets (see [Appendices 11.5](#) and [11.6](#))
- Consultee information sheet (see [Appendix 11.7](#))
- A supplementary information sheet with simple, accessible text and images to aid understanding as needed for each person with dementia (see [Appendix 11.8](#))

- Inclusion and exclusion criteria checklist (see [Appendix 11.9](#))
- Two copies of a consent form (see [Appendices 11.10](#))
- Consultee declaration form (see [Appendix 11.11](#))
- Two each participant and family ‘Music and Life Story Questionnaires’ (see [Appendices 11.3](#) and [11.4](#))
- An accompanying letter (see [Appendix 11.12](#))

Consent forms, consultee information and consultee declaration forms were included as part of the information sheets to reduce the number of separate documents.

‘Music and Life Story Questionnaires’ were not fully completed in advance by most participants, so were completed together during the initial meeting. Only two were completed by other family members; one by Sue’s daughter (Pair 1) and one by Jerry and Lynda’s daughter (Pair 2).

During all recruitment contact with potential participants, I made every effort to ensure that no direct or indirect coercion took place. During first contact, I explicitly stated my role in the research and that participation in the study was voluntary, with no connection to the services provided by the Alzheimer’s Society, including JDR. All potential, foreseeable benefits and risks were made apparent to each pair as part of the recruitment protocol below:

- Provision of additional copies of documents as needed.
- Answering questions about communication for both individuals (see [Appendix 11.13](#)).
- Explanation of the study in detail and answering questions, with reference to participant information sheets and visual objects.
- Confirmation of suitability according to the inclusion and exclusion criteria.
- Opportunity to read through and discuss the information sheets and consent forms, and time to decide whether to participate.
- Confirmation that all parties, including myself, were happy to continue.
- Seeking consents and consultee declaration as appropriate.

- Arrangement of times and dates for the fieldwork sessions.

The anticipated sample size for recruitment was three to four pairs, with the possibility of recruiting further pairs as needed due to participant withdrawal or unforeseen circumstances. Four pairs were recruited to the study (see Table 5), including the pilot pair (Pair 1), who joined JDR so that they could volunteer for the study. Individuals with dementia are named first in each pair throughout the thesis and pseudonyms have been used to protect the identities of all participants.

Table 5: Participants

Pair	Names	Relationship
1	Sue and Ron	Spouses
2	Jerry and Lynda	Spouses
3	Dorothy and Chris	Mother and son
4	Jane and Kenneth	Spouses

4.3.5 Ethical Considerations

Engaging in fieldwork sessions that brought me into direct contact with people living with dementia and their carers, required formal ethical approval, which was sought and granted from the University of Worcester (UW) Research Ethics Committee. The ethical implications of the study were carefully considered in order to minimise risk to participants and to me.

Being a researcher with the Association for Dementia Studies, UW has given me access to expertise and resources to gain necessary experience and advice specific to lone working in people's own homes in a dementia context. This support, coupled with my freelance experience of singing facilitation with people with dementia in care homes, clinical and community settings, helped to minimise risk to participants and to myself as the lone researcher. In line with the UW's lone working guidance, a lone worker protocol was created to minimise my risk when visiting people's private homes, in addition to lone worker training provided independently by St John's Ambulance.

Consideration was given to the possibility that participants could become anxious, distressed, or aggressive in my presence, especially as music can evoke strong memories of past experiences, which are not always happy ones. Advice was sought from a local Early Intervention Dementia Service for contact details of other local services, such as Adult Social Care, for signposting pairs to a third party to discuss any issues, related or unrelated to participation in this study. I also designed a working protocol to follow in the event of participant upset.

My regular visits appeared to be welcome social contact for spousal Pairs 1 and 4, and the ending of fieldwork sessions was greeted with the expressed hope of continued contact in the future by the carers of both pairs. To ameliorate the impact that cessation of regular contact might have, I signposted Pairs 1, 3 and 4 to relevant community services that offered the potential to continue musical participation and social contact with others.

Musical activity with Jerry and Lynda (Pair 2), was shared during the last few weeks of Jerry's life, which is a privilege I am grateful to have been granted. Sadly, Jerry passed away after our first session. I contacted Lynda to offer my condolences and a final review session, but I received no further contact.

4.3.5.1 Ethical Challenges

Two challenging situations arose during the fieldwork sessions with Sue and Ron (Pair 1). Following one session, Ron left me alone in the house with Sue to attend a dental appointment, despite my reminding him that I required his presence at all times. Although Ron stated he would normally leave Sue alone to attend such appointments and I could leave if I wished, I did not feel comfortable being responsible for leaving Sue alone in the house. I decided to stay in the capacity of a friend until Ron's return and did not include our interaction during that time in my data. During the following session we discussed my role as researcher and that I could not be left alone with Sue.

On another occasion, Ron confided to me that he was struggling to cope with caring for Sue physically and emotionally, relaying incidents where their daily activities had caused them both injury and distress. I discussed this safeguarding issue immediately

after the session with my supervisory team and then with colleagues from the Association for Dementia Studies. Acting on this advice in consultation with Ron, I spoke to a local Alzheimer's Society Support Worker, who agreed to contact Ron to discuss their support needs. Before this could happen, Sue moved into residential care for health reasons.

4.3.5.2 Consent

Developing a consent process for participants living with dementia required particular attention, as capacity to consent to the research could not be assumed (Department of Health, 2005). For the purposes of this study, I adapted the consent process developed for use in the Person Interaction Environment Care Experience in Dementia (PIECE-dem) manual (Brooker *et al.*, 2011) for observing people with dementia living in care homes, taking into account the implications of the Mental Capacity Act to practice in England and Wales (Department of Health, 2005).

In seeking consent, I regarded and treated each individual, with and without dementia, as a capable person in meaningful and inclusive sharing of information (Dewing, 2002). Seeking consent has been a process rather than a one-off event (Dewing, 2008b; Alzheimer Europe, 2011), with individuals being given ongoing opportunities to decline consent at any time and withdraw from the study if they had so wished, taking into account that people can communicate their wishes through behaviour and body language as well as through verbal communication.

Gaining consent for the fieldwork sessions was a four-stage process (see [Appendix 11.14](#)), during which it was explained to all participants that they were free to withdraw from participation in the research at any point during the study. I worked with each carer to ensure that the pace and delivery of information was in accordance with individual needs. For people with dementia participating in the study, all written information was produced in line with The Dementia Engagement and Empowerment Project (DEEP) guidance (*Writing dementia-friendly information*, 2013) using larger font sizes and explaining information more slowly. Visual-tactile aids were used, including recorded media (LP, cassette tape, CD) and recording equipment (video camera and Dictaphone), which helped to describe the research when gaining consent and giving participants the opportunity to handle objects and

ask questions (Dewing, 2007). Consent to video record sessions for the purposes of transcription and analysis was requested in the initial written consent to participate in the research, and as a part of the ongoing process of consent. The consent and consultee declaration forms gave participants options to allow use of video/audio or not. Verbal consent was sought from participants before recording equipment was switched on at each session. Unfortunately, this meant that some of the spontaneous sung interactions that occurred at the start of several sessions were not captured.

As the sole researcher, I was the principal person involved in obtaining consent from all participants. Making a judgement on an individual's capacity to understand and retain information when experiencing communication changes was not a clear-cut process, especially when meeting the individual for the first time. With every pair, I experienced the inadequacies of a consent process that relied so heavily upon conceptual and semantic understanding. In assuming each individual's capacity to understand and retain predominantly abstract verbal information, I was also assuming that this was the most appropriate means to engender understanding. However, each individual's consent to participation was most clear to me through experiencing responses during participation in the sessions. Making the consent process participatory, e.g. participants playing simple instruments and viewing the footage of this activity, could potentially have promoted experiential understanding of what they were consenting to and provided context to information that could only be given verbally, such as data storage information. It may also have assisted me in assessing people's responses to participation to inform the consent giving and constituted a more enjoyable process, particularly when seeking ongoing consent with Jerry and Lynda (Pair 2). Being at the end of life, Jerry's condition appeared fragile. Focussing on and responding to questions appeared to require effort and seemed unnecessarily burdensome for him. I found myself heavily dependent upon Lynda to interpret his body language in response to activity rather than repeatedly asking Jerry if he was happy to try different activities.

The exploratory and experiential approach to the fieldwork sessions to participants was particularly challenging to explain. Not only did this approach appear unfamiliar to participants, it was unfamiliar to me. Trying to explain these unfamiliar concepts verbally did not appear to adequately convey the experiential nature of the fieldwork,

and I felt the need to demonstrate the approach rather than explain it, especially for the participants with dementia, all of whom appeared to find verbally communicated concepts challenging at times.

My observations of the consent process suggested a need for dementia researchers not only to recognise nonverbal ways of communicating consent but also nonverbal and nonconceptual ways of understanding and to assume individual capacity to understand experientially. This understanding would appear in keeping with Dewing's view that "...researchers need to assess the person's abilities and preferred ways of receiving information" (2008, p. 63). She goes on to give examples, including:

With some, it may be possible to judge consent based on a very slow gradually [sic] introduction of the research and consent is judged on how the person responds and what feelings they express. This in effect is what the process consent method advocates in all situations, however here it is drawn out to a pace that may better respond to remaining abilities (Ibid.).

Recognising other forms of understanding as well as other forms of communicating understanding would appear also to echo Cook's reflections on "...the incongruity of imposing such a cognitively driven and abstract conceptualisation of good practice on people with dementia", that of placing participant informed consent at the centre of ethical research practice, as "...going against all the principles of person-centred-care" (2003, pp. 28-29). I suggest that the potential for consent to be 'experientially informed' through participation offers future dementia research an ethical and person-centred approach to consent for individuals with a changing capacity for conceptual understanding.

4.3.5.3 Recorded Media and Recording Equipment

Being an active participant in the fieldwork sessions necessitated a means to document our activity as an aid to memory for later review when working with the data. Note taking during fieldwork sessions was not appropriate because of the potential to inhibit my participation and distract others. Because people with dementia who face problems communicating verbally often go beyond words to use other 'post-verbal' forms of communication (Quinn, Blandon and Batson, 2017), video recording offered a means to capture "...embodied practices and meanings"

(Keady *et al.*, 2017, p. 2) and “...the intricate interplay within couples” (Majlesi, Nilsson and Ekström, 2017, p. 56) that audio recording alone could not. Recording a visual presentation of events held potential to enhance understanding of verbal communication, capture events that real-time observation might miss and enable in-depth review (Antelius, Kiwi and Strandroos, 2017; Majlesi, Nilsson and Ekström, 2017).

The use of video footage for review enabled me to check back on and confirm my understanding and memory of events long passed when developing resources and working with the session data, which was particularly helpful for tasks such as checking vocal ranges of participants and tracing songs and memories that came up during sessions. Watching the video footage back was also a developmental activity for my practice as I became aware of areas that I needed to work on, such as talking less. Being in such an intimate environment, I was very aware of my observational activity and the importance of the relationships we were forging and the potential for these relationships to be negatively impacted by people feeling ‘observed’. Here the video footage was freeing, as I knew that I could review responses at a later time and did not need to watch people’s responses in an unnatural way, especially when we were physically inactive during collective music listening.

A tripod-mounted video camera was used to film fieldwork sessions with all pairs, and a Dictaphone was also used to capture audio in the event of video camera failure. Positioning the camera and providing appropriate lighting was difficult at times within the confines of people’s living space and the movement of people, and I inadvertently blocked the view of recording on several occasions. It was sometimes difficult to hear speech if the source of listening material, e.g. a laptop playing recordings of music, was too close to the video/audio recording equipment. For fieldwork sessions that were not captured on video due to equipment failure or my neglecting to start the equipment, field notes were made after leaving the setting to supplement the audio recording.

A protocol was in place that recording would cease in the event of a participant with dementia showing verbal or nonverbal signs of discomfort with being recorded. There were instances where individuals, usually carers, appeared more self-conscious when attention was drawn to the camera, such as during setup, checking the

equipment or upon mention of the video recording process. However overall, participants appeared to gradually lose awareness of being video recorded as sessions progressed. Such behaviour has been observed in other social studies (e.g. Latvala, Vuokila-Oikkonen and Janhonen, 2000; Rosenstein, 2002), although it is unclear whether people forget they are being filmed (Lomax and Casey, 1998; Hazel, 2015). One participant carer expressed reservation about singing on camera, so recording equipment was switched off during this activity. Over several sessions, the carer became more comfortable and we left recording equipment running.

4.3.5.4 Other Equipment

Much of the equipment used during fieldwork sessions differed for each pair, whose own equipment was also shared. [Appendix 11.15](#) lists the equipment used across all pairs excluding the resources created for each pair, which are listed separately. The use of certain items of equipment needed consideration. I found that I needed to be mindful about positioning the laptop that I used frequently for playback of recordings so that the screen was not openly visible, as I noticed it drew participants' attention during listening activities. With Dorothy and Chris (Pair 3), my equipment was an unfamiliar addition to Dorothy's environment that she commented on at times, and could be distracting, so I tried to keep it out of sight when not in use. With Jerry and Lynda (Pair 2), I became very conscious of the noise my equipment, especially musical instruments, could make when handling and moving, disturbing Jerry's quiet bedside environment. Had sessions continued, I would have tried to address the ways that I packed and laid out my equipment to minimise sudden environmental disturbance.

I tried to use objects that were not easily mistaken for something edible or threatening and ensured that they were not harmful as they were often explored with hands and mouths by participants with dementia. For example, when using flowers, I chose roses because they are edible, removing the thorns. When sharing musical instruments with mouthpieces, I tried to deal with this sensitively by consistently cleaning mouthpieces after use and sterilising harmonicas for use by a single participant for the duration of their sessions. When using balloons with Pair 1, I weighed up the risk of them bursting and causing a shock against the potential for

tactile fun and enjoyment. I sought consent before engaging with them and left them in a separate room until they were needed to minimise the risk. When playing recordings of music, I tried to fade tracks in and out, especially for excerpts, to avoid the potential for sudden onset, cessation or change to a different track in a playlist to detract from the listening experience.

For all pairs, seating was usually positioned so that all three of us could see each other's faces, but was adapted to participant preferences on the day, furniture constraints and the nature of specific activities, where sitting alongside was deemed preferable or more supportive. For Sue and Ron (Pair 1), it was particularly important for us to see each other's faces to support communication in consideration of Ron's hearing impairment. It was clear that Ron could not hear quieter speech and singing easily, and he needed to adjust his hearing aid when listening to recordings.

Many of the recordings, images and song lyrics utilised and shared during this study were sourced from the public domain. Materials that were subject to copyright were shared with co-researcher participants as working media of research as an exception to copyright (Intellectual Property Office, 2014), and were not made publicly available. I have not shared copyrighted material with people beyond the participants in the study or included such material in this thesis.

4.3.5.5 Data Security and Storage

All volunteer and participant confidential information, including contact details, names and addresses for the purposes of home visits, was stored in a folder on the UW OneDrive, which provided encrypted online data storage for individual users, and secure sharing of electronic data with other users within the institution. When paper-based information was required for travelling to participant residences, it was stored in a locked filing cabinet in my home, in the locked boot of my car during fieldwork sessions and subsequently destroyed after use. All data viewing and transcription was completed using an encrypted UW computer, to avoid the potential risks of working with sensitive data on a personal machine, such as access by other users. Care was taken to view footage and listen to audio in a private place. It was made clear to all participants that their responses would remain anonymous.

Pseudonyms have been used to refer to all participants and any individuals and place

names alluded to during the research in documentation. Care was taken to maintain the pseudonyms throughout working with the data and write-up of the research. Where necessary, I have slightly altered the details of particular biographical accounts in order to maintain anonymity. Some accounts of fieldwork activity are deliberately vague so as not to include identifiable information, such as a participant nickname that was associated with a song with lyrics containing that name, transcription of regional accents and words, and childhood regional music and memories that would locate participants geographically.

Video footage and audio recording digital data were transferred to primary and backup encrypted drives for storage immediately following my return from fieldwork sessions. All paper-based data (i.e. consultee declarations, consent forms, communication question sheets and music and life story questionnaires) were stored initially in a locked filing cabinet at my residence for which I was the sole key holder. Paper-based data originals were replaced with electronic copies on the encrypted primary and back-up hard drives upon completion of fieldwork sessions and destroyed at the end of the study.

Video footage, audio recordings, participant information, consultee declaration and consent forms, communication question sheets and music and life story questionnaires are subject to the terms of the **General Data Protection Regulation (GDPR)** (European Parliament, 2016) as they contain personal and identifiable data. All personal data will be held for a period of five years beyond completion of the study for my own further use, after which time it will be destroyed in line with the **GDPR Principle (e)** (Ibid.) that data will not be kept for longer than it is needed. It is reasoned that the data gathered should be used to its fullest potential in recognition of the time and expertise gifted to the advancement of knowledge by the research participants. This study has yielded a wealth of data in the form of video and audio recordings and observational data, potentially providing a valuable source of data for further research that could advance our knowledge about the role of music in the caring relationships of people with dementia living at home. When reaching a decision on use of data for secondary research, I will consider whether the secondary analysis violates the contract made between the participants and myself. In line with ethical recommendations, the secondary research question will not deviate far from

the original question, and relate to the topic of personally significant music for people living with dementia at home and their carers, as participants have been assured that data have been collected for this purpose. Data will be stored securely during this five-year period within the Association for Dementia Studies, UW.

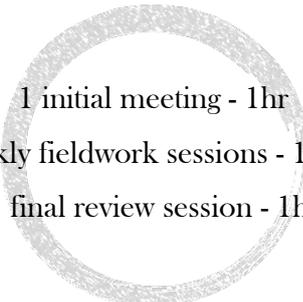
All anonymous/anonymised research data have been preserved in a non-proprietary digital format (all paper-based data have been digitised) and stored on two encrypted external hard drives (one as backup) in two separate locations within the Association for Dementia Studies, UW. Research data will be stored for a total period of 10 years by UW in adherence to their guidelines, which are compliant with good practice and guidance provided by the Digital Curation Centre (2019), the UK Data Service (2019) and the UK Data Archive (2019).

Participants were free to withdraw their session data within two weeks of a session. Beyond this timeframe, data were considered integrated into the study and could not be withdrawn. Participant data may be used for further studies during the five-year storage period unless the participant has previously withdrawn their data.

4.3.6 Structure

The 18-month timeframe for the fieldwork within this three-year study was the limiting factor to the number of pairs recruited. Working with as many pairs as possible was desirable, forming opportunities for me to gain as much experience as I could within the time, whilst allowing for the slow, in-depth work integral to the developing methodologic process being practiced. Further recruitment within a longer timeframe would have given opportunity to work with the experiences to greater depth, experience more presentations of the phenomena of study through working with additional participant pairs and potentially further develop my perceptive capacities.

The original study design required each of the participating pairs to engage in one fieldwork cycle, an approximate total of 14-hrs contact time over a period of six-months, comprising:



1 initial meeting - 1hr
12 weekly fieldwork sessions - 1hr each
1 final review session - 1hr

An initial meeting was held with each pair to discuss the study, answer questions, gain consents, surface intentions and hopes for the study and gather biographical and musical preference information at the start of their fieldwork session cycle. The number of fieldwork sessions was based on the median number of music-based therapeutic intervention sessions used with people who have dementia (van der Steen *et al.*, 2017) and was considered a maximum. I worked with four pairs in total. It was anticipated that pairs would participate in one fieldwork cycle consecutively. However, due to changing circumstances and time constraints, fieldwork cycles with Pairs 3 and 4 overlapped (see [Appendix 11.16](#) for fieldwork session schedule):



Fieldwork sessions with both Pairs 3 and 4 were disrupted by episodes of illness and hospitalisation. While Pair 1 participated in the full twelve sessions it was decided through ongoing consultation with Pairs 3 and 4 that eleven sessions were sufficient to complete the development of resources.

The fieldwork sessions were conducted weekly to limit disruption to participants' family routines and were scheduled to last for approximately 30-minutes. This is a frequency and duration that falls within the typical parameters for domiciliary-based music therapy interventions and music intervention sessions in elderly dementia nursing practice (Schmid and Ostermann, 2010; Li *et al.*, 2014). An additional 30-minutes per session was built-in to allow for set-up, pack-up, chat etc., resulting in a total of one hour planned contact time. This hour was anticipated as a mean figure to

allow for shorter sessions of little or no musical activity, or extended sessions according to the indications and wishes of each pair. In practice, actual contact time always extended beyond an hour, varying between 1 hr 15 mins – 3hr 45 mins. I found the regular contact over the period of several months necessary for the development of relationships that formed the basis of the fieldwork.

All sessions took place at mutually agreed times to fit in with each pairs' regular routines, and within the private residence of both parties, with the exceptional circumstances arising for Ron and Sue (Pair 1), with whom sessions were concluded in a residential care setting. Sue moved into residential care following our tenth session. After discussion with Ron, we decided that the continuity of regular sessions would be preferred for them both rather than stopping or phasing out contact. Verbal permission to conduct the fieldwork sessions in Sue's private room in the home was sought through discussion with the care home manager.

At the last fieldwork session with each pair that completed a cycle (Pairs 1, 3 and 4) I left a selection of resources tailored to each pair that I had developed in response to our session activity. These resources took longer to develop than anticipated, necessitating a gap of several weeks before their provision. The final review fieldwork sessions did not differ in duration or setting and took place two months following the end of the fieldwork sessions for each respective pair, to give opportunity for musical activity to develop without my presence.

From the carer responses to my visits from completing pairs, it was evident that Ron (Pair 1) and Kenneth (Pair 4) would have liked sessions to continue, whilst Chris (Pair 3) was happy with the short-term nature of the study because of the challenges of fitting sessions around fulltime work and weekly routines. Scheduling sessions with Dorothy and Chris necessitated compromise, as the only available time was at a weekend in the afternoon. Dorothy was usually sleepy, the pace of our sessions slow, and professional homecare visits disrupted most sessions. These factors led to the extension of our sessions on a regular basis in ongoing consultation with Dorothy and Chris. Although this extended contact time appeared to be amicable, Chris commented during our last fieldwork session that he had found the uncertainty of session duration and number of sessions difficult.

Flexibility was necessary with all pairs, as despite their intentions to keep sessions free of interruptions, holding sessions in family homes meant unavoidable delays and disruptions such as professional homecare visits, shopping deliveries and participants falling asleep. I tried various time saving strategies, such as playing recordings of music whilst setting up, but I came to the conclusion that adjusting to the slower pace of life, particularly of participants with dementia, was necessary for the fieldwork sessions, rather than expecting them to adjust to mine. However, I did find ways of working with some disruptions. For example, the regular session break with Dorothy and Chris (Pair 3) became an opportunity for identifying tunes likely to be familiar to them both from my sung examples for Chris while Dorothy spent time with the professional carers.

I experienced the span of each fieldwork cycle as a gradual harmonising between myself and the participants, which was echoed during each session. The shape of sessions accommodated this acclimatisation. The setting up and packing away that bookended our time together provided an opportunity for us to catch up, often over a cup of tea, with familiar music, recordings and activities preparing us for the less familiar and more active aspects of the session. After a break of several weeks between the end of sessions and the final review, it took some time to adjust to each other's company again with each pair. I found working simultaneously with Pairs 3 and 4 challenging and I did not always have enough time to engage in a process of reflection and development to sufficient depth between sessions. I felt this most keenly during the labour-intensive prototyping and developing of resources, when fortnightly sessions would have been more manageable for me with all pairs.

4.3.7 Evolving Method

Through my initial research in designing the study, I discovered Theory U; a framework for realising social change. Theory U differentiates between four levels of experience and participation (Scharmer and Kaeufer, 2015, p. 200):

1. Downloading
2. Seeing
3. Sensing
4. Presencing

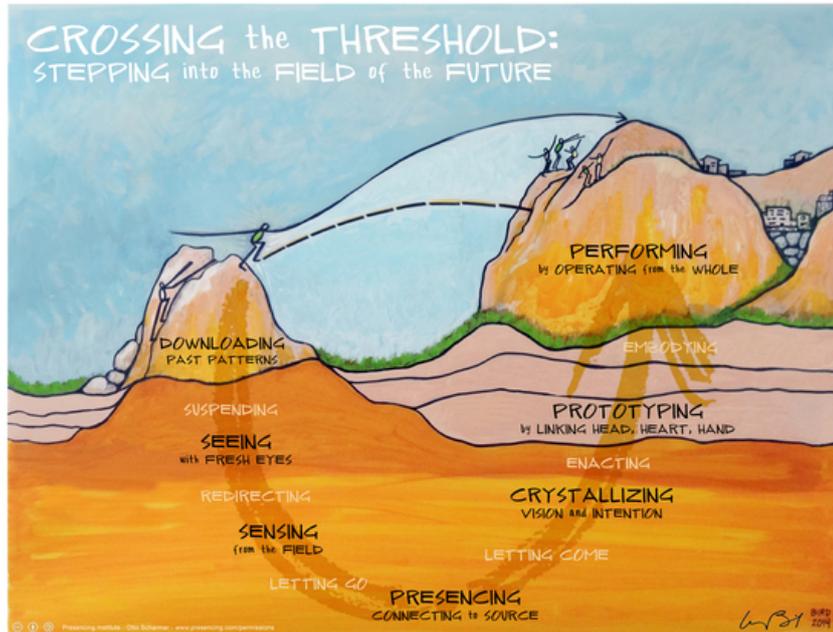
‘Downloading’ relates to habitual patterns of thinking and behaviour; the first impression before the shift into Exact Sense Perception; ‘Seeing’ what is ‘there’ in the present moment to establish concrete facts. ‘Sensing’ moves from diving into sensory experience through the Imagination to activating deep capacities of cognition. Attention is redirected to a receptive, inner ‘knowing of the heart’ or Inspiration and Intuition. A deepening awareness in the present that embraces not just the past and present, but incorporates the potential future by giving opportunity to release old patterns to let new patterns emerge. This threshold of Presencing acts as a turning point for transforming knowledge into action (Scharmer, 2009). Although much of the terminology is couched in global, business and institutional terms, in the underlying process I recognised the movement of gentle empiricism (see Table 6).

Table 6: Gentle Empiricism and Theory U

Gentle Empiricism	Theory U
Exact sense perception	Seeing
Imagination	Sensing
Inspiration	Presencing
Intuition	

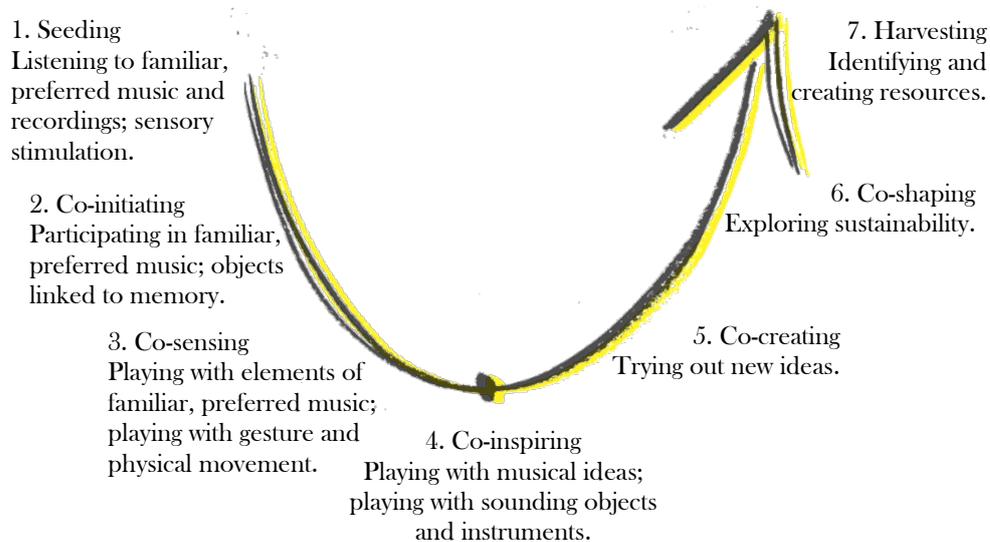
The seven-stage mirrored process represented by the U reflects Brook’s (1998) mirrored gentle empiricism informing action (see [Chapter 3](#); see Figure 5).

Figure 5: Crossing the Threshold (adapted from Scharmer and Kaeufer, 2015)



This Theory U framework provided a starting point for structuring and articulating a process of ‘coming to know’ informing action for this study (see Figure 6 below). Within this framework musical activity was intended to move from familiar music as a starting point for participation in musical activity in the present, into opportunities for musical creativity. These stages reflect the gesture of moving from the past into opportunities to realise future potential.

Figure 6: Musical Activity Framework (adapted from Scharmer and Kaeufer, 2015)



Accompanying sensory activities were intended to augment opportunities for participation beyond spoken interaction for all participants with the potential to be an accessible means of participation for individuals with dementia. For a person for whom cognitive awareness and verbal communication are less accessible because of changes experienced through the course of dementia, sensory stimulation and engagement such as music can offer alternative ways to develop communication and open doors to memory without relying solely on verbal cues and semantic understanding (Verbeek and van Campen, 2013; van Campen, 2014; Strøm *et al.*, 2017).

These starting points for stages of the process, music and other sensory activity formed a framework in preparation for each fieldwork cycle. Following each session's participation, my reflection and development of the next were designed as a gentle empiricism process that I outlined as a weekly working framework (see [Appendix 11.17](#)). Both these frameworks were intended as a departure point for exploration and development rather than fixed protocols.

During my fieldwork cycle with Sue and Ron (Pair 1), I experimented with a variety of ideas for involving them as co-researchers in a process of gentle empiricism. I attempted to facilitate reflection and sought direct input from Sue and Ron on ideas for the development of our activities and potential resources. I found this consultation was time consuming, leading to conversation that took us away from the starting point of our discussion and alienated Sue, who rarely joined in our conversations. Ron also made it clear on numerous occasions that he preferred to be directed by me during our sessions. It quickly became apparent that the most accessible means for them both to contribute was through their participation. I worked with the offerings that Ron made of his own volition, such as his *Rebel Song*, and the responses by them both to the things we tried to develop both session content and resources. This became the approach I subsequently took with all pairs. I gave each pair a notebook for jotting down thoughts, ideas and recording musical activity if they chose to, as an opportunity to contribute more cognitively to the research process. Only Kenneth (Pair 2) made a journal entry, recording their musical activity with a resource prototype during the Christmas break.

The musical activity framework (see Figure 6 above) designed in anticipation of the fieldwork cycles provided starting points for participating in music responsively according to the responses and preferences of individual participants. The material for activities was formed out of my own developing musical knowledge and ability, with the fieldwork generating ideas as it progressed, providing a greater breadth of possible starting points for engagement with subsequent pairs.

Structuring my gentle empiricism process was essential to its design, implementation and representation. However, developing my own capacities required coming to understanding of how to proceed through active participation rather than limiting my view by anticipating the essential elements of my evolving method. This paradox was an enduring tension through my study as I strove to hold a balance between working dynamically and formatively. I produced a large quantity of data (experiences, written reflections and video footage) during the early stages of the fieldwork with Pair 1. I tried to work with this data transparently and consistently according to the framework underpinning my approach, and at the same time, sought to develop my approach from the basis of my participation experience. It was a constant challenge, working with the uncertainty of a developing method and trying not to become too fixed in my thinking, planning and actions according to the designed framework. I came to a point where my gentle empiricism process became a protocol of activity and documenting. I tried to incorporate different methods and look at many different aspects of phenomena, which resulted in me not being able to work to any depth. This way of working was time consuming to the point that it was all I had time to do between weekly sessions and I yet still accrued a significant backlog of ideas and observations that I had not had the time to work with. I realised that I needed to free myself from the original frameworks that were inhibiting development of the project by distinguishing the essentials of a framework for a process to serve me, not vice versa.

I also came to recognise that intuition and inspiration arose through a letting go of activity, but that activities of perception and picturing were a necessary activity before letting go. In this way there was a consequence but also a rhythm and recapitulation of these activities, a breathing in and out of letting go and letting come. It became apparent to me that gentle empiricism was a naturally occurring process, as I

participated in sense perception, inner picturing and ideas in action on a daily basis. This was not new or unfamiliar activity, but an awareness gaining, clarifying, strengthening, deepening process of coming to develop and use these capacities consciously through repeated active participation and attention, both for the project and daily life. I recognised this living archetype in working patterns as the necessity to alternate focus with breaks in concentration, and physically inactive study with physical activity and vice versa, as well as in the need for balance between sleeping and waking. I recognised also that structured reflection and development, rather than simply journaling, offered a means to engage in this process with awareness, rigor, discipline and intention and was a way to work towards practical action within the constraints of time. Out of this developing understanding of the essentials of the gentle empiricism process, I created a simpler framework that continued to evolve through the fieldwork with subsequent pairs (see the last version in [Appendix 11.18](#)). This simple framework provided a rhythm and routine in developing the activities of gentle empiricism.

4.4 Fieldwork Journey

Engaging in gentle empiricism not only required me to study phenomena but to work on myself *through* the study of phenomena by developing my capacity for the different modes of perception and creation (see Table 7).

Table 7: Gentle Empiricism Modes of Perception and Creation

0. First impressions
1. Exact sense perception
 2. Imagination
 3. Inspiration
 4. Intuition
5. Experimentation
 6. Picturing
 7. Creating

Following on from my ‘calling’ to design the study, the following section describes my fieldwork journey of developing my capacities and the fieldwork activities.

4.4.1 Exact Sense Perception

Iterative fieldwork sessions provided opportunities to experience participation in different forms of musical activity with a range of people with dementia and people who care for them. Musical activity was not only a phenomenon of study, but, along with other forms of sensory media, acted as a means of participating ‘in people’.

Musical participation enabled the elicitation and experience of a wide a variety of responses and activity empathically, without relying solely on verbal communication and understanding. Changes to spoken communication were different for each of the individuals with dementia and I observed that musical and sensory activity such as singing, touch, taste, movement, smell and rhythm could be a more open channel of experiencing, participating and interacting than talking. While discussion did play a necessary and contributory part of sessions in conveying memories and practicalities, speech was not an equally accessible form of communication between us with each pair. When individuals with dementia did respond verbally to conversation or questions, it was not always evident whether they understood the content of the speech they were responding to. Despite efforts to make verbal communication inclusive by openly addressing both parties and keeping my speech slow and simple, most of the verbal conversation with each pair took place between myself and the carer. When it was necessary to offer explanations, I found that accompanying or replacing semantic speech with experiential examples could make them more accessible. For example, seeing, touching, feeling and hearing a musical instrument rather than trying to convey the idea of playing a musical instrument.

With each pair I became strongly aware of the need to try and balance the semantic with the sensory, as the latter appeared to be more accessible for the individuals with dementia much of the time. However, through introducing the sensory, I often found myself communicating in different ways with both participants of a pair individually, rather than together. Finding the forms of interaction that were mutually accessible and enjoyed by the pair and myself, was an essential basis and touchstone for balancing spoken and sensory participation during sessions. I also found that it was easier to pay attention to sensory activities when the expectation to speak was removed. Music and other sensory participation became media of expression and

relationship, giving indications for the development of session content and resources in ways expanded upon in the following chapters. While the 'Music and Life Story Questionnaire' provided a useful starting point for our activities, it was the participation itself that was most informative.

Participation in sensory and artistic media brought opportunities to gather experiential data that were far richer than answers to conceptual questions alone would have been and offered a means of contributing to the research for individuals who were unable to do so verbally or conceptually. Sensory forms of engagement have incorporated movement, exploring visual art and colour, taste, touch and smell, as a means to offer sensory experience and elicit response. Musical activities included listening to recordings and live music, playing instruments and singing. The specific forms that musical and other sensory activities took across the study are discussed in subsequent chapters. Sharing the media that participants offered such as home video footage, photos, music, writing, instruments and objects not only helped me to get to know them, but cemented our relationships as equal contributors to, and experiencers of, the fieldwork sessions.

Exact sense perception was a presencing activity that required actively sustaining awareness of my sense perception, not slipping into habitual thinking activity. When practising exact sense perception in anticipation of the fieldwork sessions with people, I made observations of plants as an accessible introduction and method for developing the different modes of perception (Brook, 1998; Kaplan, 2002; Brook *et al.*, 2017). When I progressed to studying human beings, I found that participation in their inner life required responsive encounters through sense perceptible means such as speech, gesture, movement, voice, touch and so on. My role in the sessions was not only as an observer of people's relationships to others and music. I was also *in* relationship to others and music and we were in relationship with each other *through* music. This became starkly apparent to me at times when I was not involved in interaction with people, such as during listening to recordings of music. I felt awkward and that my role had suddenly changed to one of spectator. I was also aware that individuals may have felt watched or scrutinised at such times, and so I tended to look away.

Music, and recordings of music, are intimate media to share, particularly when strong emotions are evoked or expressed. I shared exploration of simple world music instruments during the first session with each pair to gently introduce music in a sensory way as we became more comfortable in each other's company. Introducing music-making and listening informally as a part of other activities also helped to avoid some feelings of awkwardness and self-consciousness that appeared to be experienced when music or recordings were the sole focus, such as during shared listening or singing songs. An active focus related to the music or recording, such as looking at an image, could act as a bridge into such activities. As relationships progressed, sharing listening without another sensory focus appeared to become easier and more relaxed.

In working to develop my capacity to loosen my habitual addition of concepts to sense perception, I came to understand that this activity required an additional element because I was actively responding to individuals. I found I also needed to be aware of how my concepts manifested into action. It was not only necessary to let go of existing concepts in perception, but also existing concepts that informed action. I found that I needed to relinquish my preconceived ideas and make space for the new, otherwise I imposed my will on others by trying to make things 'work' or change. It became clear as the fieldwork progressed that the content of activities was secondary to how we shared them. My ability to be aware of my own activity and respond openly without imposing my will on others was crucial to the development of experience, participation and interaction. It was this current of relational warmth between us that carried our activity, and the activity in turn was the necessary meeting point and a medium of our interaction. I gradually became aware of the ways in which I did impose my will on others that I had not realised, and the difference between being open and responsive from being imposing or passive. I found that my strength of will was needed in consistently seeking to promote the future potential of music in the lives of participants through the development of session and resource ideas and materials.

4.4.2 Imagination

It took some time for me to fathom what imaginative activity involved. During the early stages of the fieldwork, I tried to recount every sensory detail of sessions in written narratives that were extremely long. I also watched the video footage after each session and found that this interfered with the ‘afterimage’ of memory. I realised that it was the process of creating memory pictures that was important for developing my imaginative capacity and that documentation needed to serve that process, not the other way around. I stopped working with the video footage and used it for reference if I needed to check a detail necessary to session development, such as the name of a song to learn.

Imaginative activity in the process of coming to understanding took the forms of remembering session events and imagining participants’ biographical development. Memory picturing of sessions immersed me in a slow replay of perceptions and experiences aided by the transcription of our participation in note form and the sketching of physical aspects such as faces and gestures. If circumstances prevented timely picturing and memories faded, I found it helpful to relive activities, such as listening to the recordings of music and looking at the images shared during the session.

I began systematically engaging in memory picturing each fieldwork session as it had evolved, following each session. Memory picturing became a staged process, first allowing the essential of a session as a whole to arise the same day and then ‘speak’ through receptive space the day following before picturing of the session in temporal detail, which I experienced as a ‘coalescence’ through memory. My imaginative activity was facilitated at times by the act of drawing aspects of participants such as faces, hands and posture. Music and poetry impressions helped to realise the mood and characteristics of individuals, situations and relationships. This was followed again by deliberate receptive space to provide opportunity for insights and ideas to arise that informed session and resource development. Although I have included examples of my figure and gesture sketching (see [Chapter 5](#)) I omitted those of faces for the sake of anonymity.

Imaginative pictures based on participants' biographical information, contextualised the sessions within the lives of each individual and offered a view from the past into the potential future. This broader view revealed different aspects of individuals and their relationships with each other and music and how these relationships might evolve. There came a point in the fieldwork where this picturing of individuals gave way to a review of session material, in a movement from coming to know, to developing creative action. This transition was not premeditated but occurred as a natural turning point in the mirrored gentle empiricism process. As each cycle of sessions progressed into the later stages, reflective picturing increasingly gave way to ideas of how to develop the sessions and resources.

Through the routine of regular practice, I noticed a maturation and strengthening in my capacity for picturing during the final stages of the fieldwork, at times finding it all consuming and blotting out my ability to visually perceive what my eyes were seeing. This may sound like a customary experience of imaginative activity in daily life, where memory and fantasy pictures freely emerge. However, I found that deliberate, generative picturing took effort, forming observable impressions from the immaterial.

4.4.3 Inspiration and Intuition

I found it necessary to discuss these two modes of perception together, as I experienced an integral relationship between them and their difference as less distinct than for other modes of perception. This may be because these capacities were still maturing for me. I anticipated the receptive space necessary for inspiration and intuition to arise to be synonymous with being present or in the moment, through a meditative practice such as mindfulness. What gradually became apparent to me through experience, was that being present is most akin to the starting point of enquiry, the active experience free from existing concepts. I grew to experience receptive space as a purposeful invitation that complemented each form of activity throughout this phase of the study. I discovered receptivity not as an absence of thought, but an attentive openness to 'receive' it in still awareness, without slipping into the habitual thought forms of unrestricted fantasy or concentrated logic in the language of existing concepts. Like the process of developing a photograph, pictures

would emerge, sometimes clearly defined, at other times impressions in colour, tone or word that I would transcribe. Often, I experienced an intuitive sense of significance about aspects of my experience that I would note down. After images, or impressions, (inspiration) would often precede knowing, or understanding (intuition). This emergent relationship is traced through the examples of understanding for each pair (see [Chapter 5](#)).

Impressions and understanding arising through receptivity were realised as gestural and colour mood sketching, musical improvisation and composition, poetry and descriptive writing as a process of crystallisation. Impressions and understanding could return many times and sometimes nothing at all would emerge. I found picturing to be the usual catalyst for receptivity, and at times I needed a recapitulation of picturing activity to frame or set the stage for it if my routine was disrupted. So many phenomena are observed and pictured, whether intentionally or not, in daily life that impressions and understanding pertaining to these phenomena also arose.

Between sessions, the impressions and understanding that emerged gave rise to indications and ideas for future action in responding to each pair through session development. The emergence of impressions, understanding, indications and ideas were not limited to times of deliberate receptivity, but often arose when I was active and not engaged in intentional thinking, especially when walking. Across the span of the fieldwork, I experienced recapitulations of inspiration and intuition about the relationships between people, music and the experience of dementia that transcended the individual participants and that grew gradually clearer and fuller over time. As sessions progressed, the emphasis of my development activities organically shifted from coming to know, to responding through developing and refining ideas for the creation of resources for the pair concerned. I experienced uncertainty during this turning point as impressions and understanding metamorphosed to become indications and ideas for potential avenues to investigate in developing resources for the future. Indications and ideas also came directly from participants. Our sensory exploration propagated ideas and responses that gave me indications and built on the foundation of the gathered musical and biographical history of individuals.

4.4.4 Experimentation

Ideas for the development of sessions and resources were tried-out in physical space and in real-time in the development of each fieldwork session and individualised resources. Possibilities for resources were also explored through experimentation collectively with participants during fieldwork sessions. Ideas were tried-out through session participation, with verbal and experiential responses giving indication of their viability and desirability, and I responsively changed, adapted and abandoned ideas as necessary.

In trying out session materials, experimentation with listening and music-making possibilities would frequently germinate new shoots of ideas for development in different directions, such as the potential for a familiar recording to offer opportunities for music-making. My preparatory ‘try outs’ ahead of a session usually served to consolidate and clarify potential activities and what would be needed for their fulfilment. I often tried ideas out with my family members to gain an experiential understanding and to get their feedback. When preparing activities previously engaged in, with, or across pairs, I often did not feel it necessary to try them out again.

I frequently ‘rehearsed’ my approach, as I found that the way in which I presented activities could be vitally important to how they were received. For example, a performative stance could engender a pressure to ‘get it right’. This was especially true in presenting the final resources, as I was keen not to demonstrate how they ‘should’ be used, leaving scope for free exploration by participants to make the resources their own, whilst giving sufficient direction to make sense of what I was presenting and some of the possibilities offered. I provided potential resources, including created prototypes for pairs to try out in their own time. The Christmas holidays presented a break from sessions for several weeks and a natural time to try out possible resources for Pairs 3 and 4. Verbal feedback from the carers on their shared use and ideas for resource development helped to form the final resources to leave with them. Table 8 gives examples of activities involved in trying out session materials and participant resources and the indications this activity offered for their development.

Table 8: Active Experimentation Activities and Indications for Development

Activities	Indications
Playing and singing through pieces / songs	Identification of suitable songs, keys, chords, strumming/plucking patterns, song length and lyrics.
Listening to different tracks / versions of the same track	Identification of recorded tracks to listen to and track list play order.
Trying singing and/or playing along to recordings	Identification of a need to edit certain tracks or to record tracks of myself singing and playing to tailor the number of verses, tempo and key.
Trying out seating positions with others	Identification of seating arrangements to encourage interaction and make it easier and safer to access equipment for different activities.
Trying music-making activities with others	<p>Identification of what elements of activity required explanation and modelling.</p> <p>Identification of issues with instrument combinations such as overpowering volume and incompatible key.</p> <p>Identification of appropriate approaches to take, such as:</p> <p>asking participants what the music evokes for them, rather than telling them what it is intended to evoke</p> <p>giving opportunity for individuals to participate spontaneously rather than putting them on the spot</p> <p>calling to their imagination and creativity by inviting them to contribute rather than asking them to do specific things.</p>
Trying different ways of playing the same instrument	Identification of accessible ways that playing instruments could be offered to specific individuals.
Trying out different ways of moving to music, alone and with others	<p>Identification of ways to vary movements to aid thinking on my feet when offering movement for others to mirror.</p> <p>Identifying track order for different movement activities such as bells/scarves and foot tappers.</p>
Trying out different media	Identification of the most suitable media to try, for example, block crayon and pastel as less messy than chalk and charcoal.

Trying out video recording for creating DVD resources	Identification of appropriate camera position, sound level, seating, equipment set up and spoken content.
Trying out looking at images and listening to music together	Identification of image and music groupings based on common characteristics, such as mood or theme.
Trying out sensory objects	Identification of ways to use objects, such as tying coloured scarves into bunches of similar colours to be more visually pleasing and easier to hold and control.
Trying out created resource lyrics and chord sheets	Identification of needed amendments to lyric formatting and content, keys for guitar accompaniment and number of songs.
Trying out printing and laminating process	Identification of formatting and image quality issues before creating large batches for resources.

4.4.5 Picturing

Systematic imaginative picturing offered a further stage of refinement and consolidation to the creative process. Picturing the development and application of potential session content and resources helped me see ideas through to practical fulfilment. Picturing the potential future events for each session often flagged up possible issues, prompting me to make changes and incorporate forgotten or new elements into my planning, such as the addition of chords to give a song more structure, or developing a question to ask. For the final resources, imaginative picturing of the resources in use by the participants guided their development.

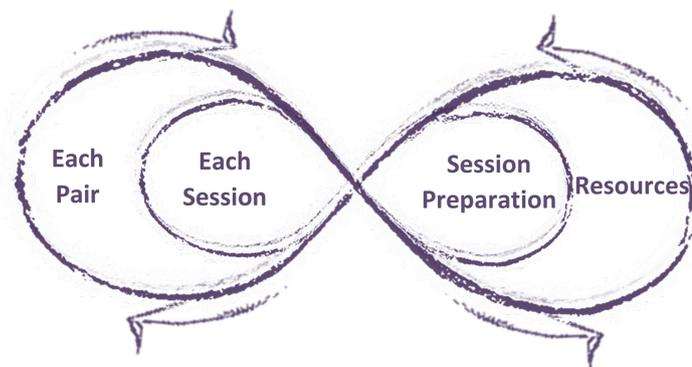
Through developing my capacity for imaginative picturing, I became increasingly aware of my own propensity to go too many steps ahead with an idea, rather than to encourage it to grow organically and see where it led. This awareness enabled me to work consciously with my tendency to ‘jump on’ ideas and try instead to promote participants’ contribution to developing ideas. My taking ownership of developing an idea and giving it to participants to try, rather than cultivating what was emerging

between us, even when not my idea of what it ‘should’ be, would often result in activity or resources that were not enjoyed or taken up by participants.

4.4.6 Creating

The development of each fieldwork session plan and materials facilitated the conditions for responsive activity during sessions, which also served as exact sense perception in a continuous flow of ongoing enquiry with each pair in developing resources (see Figure 7). Individualised resources for participants were developed as a potential means for participants’ continued music engagement beyond the study, constituting an encompassing form of responsive action across the course of fieldwork sessions. The activities and resources developed through this study are not intended for ‘off the peg’ use but as examples of individualised activities and resources developed responsively.

Figure 7: The Flow of Gentle Empiricism



4.4.6.1 Session Development

In anticipation of each fieldwork session, I prepared resources and a session plan of ideas for music and sensory activities, including my questions arising from the enquiry process, to serve as starting points for responsive participation. I tried to develop a variety of opportunities for musical and sensory exploration that offered each participant choices and a range of different things to try, rather than a fixed agenda; working within the bounds of what was possible and what was wanted. There were times when my session planning became a conceptual process to be adhered to or to

accomplish. Such inflexibility restricted my responsiveness and others' participation by seeking specific responses from individuals, rather than offering opportunities for them to respond freely. Identifying possibilities for simple activities provided starting points for participation that could be shared responsively. This approach enabled me to accompany the participants in their exploration rather than pulling them back to an agenda. Giving simple activities space and time to develop and be enjoyed to their fullest potential at that time offered the richest opportunities for exact sense perception.

As mentioned earlier, I facilitated opportunities for participants to contribute to the developing process through journaling and regularly encouraging input and feedback on session content and resource development. I also stayed attentive to responses and ideas to inform development of activities and resources as they occurred spontaneously during sessions, both verbally and non-verbally, such as through musical activity. Potential activities were usually discussed at the end of a session to inform planning and then again at the start of the next session to invite participants to be as involved as they would like in choosing and shaping our activities. In developing session activities and materials, I had several conversations with an art therapist family member of mine with experience of working with people with dementia about appropriate sensory and arts activities. I also drew on the work of other practitioners in the field of arts and dementia.

Although there were many common threads of sensory activity that ran through my sessions across the participating pairs, such as the natural world and singing, the content of such activities and the ways that we engaged in them were responsive to the individuals I was working with at the time. I found that when I tried 'superimposing' activities from one pair to another rather than developing activities responsively, which I did occasionally when I thought they might be enjoyed, they tended not to be so relevant or well received. However, I did observe a prevailing characteristic of sessions across all pairs in the waxing and waning of individuals' capacity for participation. Sharing musical opportunities to move between reflection and participation worked with this movement of energy and enjoyment.

4.4.6.2 Resource Development

Over the course of creating participant resources to leave with each pair at the end of the fieldwork sessions, it became clear that my primary purpose was not to provide opportunities for individuals to reproduce our session activities. Rather, I needed to recognise participants' unique potential to share musical activities without me and find ways to support and encourage this. Understanding was reinforced by the final review sessions with participants, which provided an opportunity to share experiences of continuing musical engagement, if any had occurred, and inform how this could be effectively supported going forwards. The activities that were most readily taken up by participants were those with which they were most comfortable and familiar rather than more novel activities introduced during sessions. The enjoyment of sharing these novel activities 'carried' them during the sessions, but without my facilitation, they did not translate so easily into participants' lives. Ron and Sue's (Pair 1) initial resources did not reflect this understanding, as I had tried to fulfil our collective potential through them, and I became frustrated when this did not prove possible.

When leaving resources with participants, I made it clear that there was no requirement or obligation to continue with musical engagement between the last fieldwork session and the final review session or to use the resources I left. The intention was to observe whether sustainable musical activity had been supported to grow within caring relationships rather than require musical activity for the purposes of the study. However, it is possible that participants felt a sense of obligation to use the resources I had provided. In addition to the developed resources, I offered each pair compiled video highlights from their sessions as a memento and asked carers to complete a Music Log (see [Appendix 11.19](#)). This simple form was designed for pairs to record their shared musical activity in the period between the last fieldwork session and the final review session eight weeks later.

During the final review sessions, I asked each pair to share their musical activities with me that they had engaged in since our last fieldwork session. This approach gave a retrospective emphasis, distinct from the exploratory, developmental activity of the fieldwork sessions. I also asked questions as they arose, along with those that I had prepared (see [Appendix 11.20](#)) to help me identify if and how musical activity had

continued and how it could be best supported. Many of the prepared questions were answered through participation and discussion, without being asked. Answers to direct questions and written feedback from the carer tended not to yield such comprehensive understanding for me as that arising from voluntary participation and the spontaneous verbal commentary that accompanied it. It was also a more inclusive means of eliciting responses from participants with dementia for each pair.

Participation also provided direct experience of how the resources were being used, helping to flag-up potential improvements and amendments. My understanding of how independent musical activity had developed for each pair was supplemented by carer written records in Music Logs. However, these completed logs contained little information that did not come up during review sessions. The continuing gentle empiricism process following each final review session informed the final refinement and changes to resources left with participants.

4.4.6.3 Creating Materials and Resources

Gathering and preparing materials for fieldwork sessions and resources was time consuming. I found it necessary to modify recordings of music to support individuals' participation, by changing the key for singing or playing to, repeating sections for thematic or rhythmic continuity, editing out long unfamiliar sections and reducing length. The following list gives an indication of activities involved in creating session materials and participant resources:

- Creating session plans
- Sourcing/creating chordal accompaniment for songs and melodies
- Transposing chords and melodies
- Sourcing/transcribing, editing and formatting song lyrics
- Handwriting chords on songbook lyric sheets
- Learning and practising songs, melodies and chords
- Creating 'playlists' of recordings for use in sessions

- Sourcing/purchasing appropriate or requested recordings and materials online
- Making/preparing materials and resources, e.g. wooden stands, foam Morris dancing sticks, preparing food
- Maintenance of equipment, e.g. sterilising harmonicas
- Sourcing and learning to use software to edit recordings, video footage and burn DVDs
- Editing, mixing, transposing and creating recordings
- Editing video footage
- Filming myself playing songs
- Transcription of melodies from recordings and video footage for reference when playing/singing
- Sourcing guidance and information on local services
- Collating spreadsheets for grouping lists of activities, recordings etc. for identifying known/appropriate materials with participants and the forming of resources
- Sourcing and formatting images from books/online
- Listening to indicated recordings of music
- Determining vocal range for the singing and recording of songs and accompaniment tracks
- Creating CDs, DVDs, case covers and track lists
- Editing, printing, laminating and numbering images
- Colour coding resources and creating indexes
- Sourcing stationary to create and present resources
- Printing and trimming paper materials
- Researching subjects to create resources for specific activities, e.g. birdsong

- Creating shared listening and participation suggestion sheets

4.5 Working with the Data

I worked with my experience of the fieldwork as data through a process of reflection and development as a continuation of the overarching gentle empiricism process of this study. I did not adopt the analytic convention of breaking data down into parts or reduction. In keeping with a dynamic approach as taken by Goethe to his *Metamorphosis of Plants* and *Theory of Colours* (Goethe, 1840, 2009; Bortoft, 2012), my fieldwork examples foreground experiences that present my understanding of the essential ‘protean becoming’ of the phenomena, rather than constituting a reductive single instance of a feature or pattern.

My approach to the data could not be summarised as a thematic analysis, which is a widely used approach to qualitative data analysis through grouping or ‘coding’ data. Thematic analysis groups data ‘artefacts’, commonly transcribed speech, according to conceived patterns or themes, and does not necessarily require the analyst to have experienced the speaker or even the speaking of the words (Braun and Clarke, 2006). I was not concerned with grouping the text and other media, but with identifying the relatedness and differences in the qualities of my own experiences that these media presented. The secondary data served as place markers for a process of going more deeply into the experiential data of the fieldwork, enabling me to group ‘experientially’ according to common and contrasting qualities in physical space. Conceptualisation of these groupings were formed and refined through the process of writing. I experienced this as a process of distillation; discovering a simplicity in the data that contrasted with the generated complexity of thematic analysis. Because the experiential data are unique to me as the researcher, the data cannot be accessed by others and therefore my process of working with the data is not replicable, but could be developed by others working with their own experiential data.

This way of working follows the “intrinsic direction of experience” (Bortoft, 2012, p. 19) (see [Chapter 3](#)), staying with the *experiencing* of perceiving, picturing, feeling and conceiving in response to and service of phenomena, rather than looking back ‘upstream’ at *what* was experienced as separate from the act of experiencing.

4.5.1 Imagination

I pictured my experiences by revisiting the reflection and development documentation systematically. I did this in retrograde from Pair 4 through to Pair 1, taking the most recent experiences first rather than leaving them to fade over time. This afforded me ‘fresher material’ with which to develop the newly unfolding process and effectiveness of my working. Picturing the fieldwork participation again was easier than it had been during the fieldwork, perhaps because I was ‘recapping’ inner pictures that were now familiar and/or because my capacity for picturing had matured. Articulating the essential of these imaginative pictures using expressive writing for the subsequent chapter, in which I present my fieldwork participation experiences, brought the qualities of perception and experience into focus as well as the physical events.

4.5.2 Inspiration and Intuition

I grouped my experiences of the fieldwork and the reflection and development process into areas of understanding, first for each pair, then across all pairs. Using the secondary data media as tangible ‘placeholders’ was necessary for keeping track of this process for clarity and consistency, ‘physically’ grouping text and images in various combinations. I did not seek to identify or refine conceptual themes, rather I grouped media together that distinguished difference and commonality across my perceptions, experiences, impressions and concepts. This task served as a process to facilitate the emergence of inspiration and understanding across pairs, rather than to create a product or synthesis.

4.6 Writing the Thesis

4.6.1 Experimentation

During the writing process, I actively experimented with ways of expressing and presenting my emergent understanding by trying out ideas in rough written notes and

drawn visual depictions. Feedback and discussion of my ideas and writing with my study supervisors, my family members and critical friends helped me to form and articulate ideas for the developing thesis, as did giving presentations on my research to different audiences.

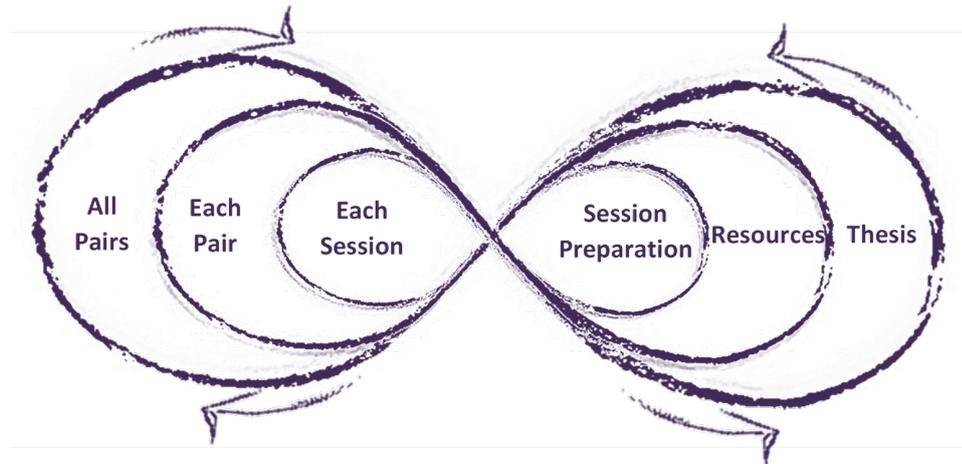
4.6.2 Picturing

Through the process of realising my understanding through writing and creating media, I engaged in active imaginative picturing of the relationships between the various areas of understanding that informed the final thesis to create a coherent narrative. Through a systematic review of the literature my understanding was augmented by the research of others (see [Chapter 7](#)). Contextualising the understanding arising from this study and from the literature within the broader landscape of research and practice was an imaginative process of picturing the future potential for this understanding to inform research and practice.

4.6.3 Creating

The final forming of each written chapter and multimedia illustrations in creating this thesis is an act of seeking to promote the phenomena of study in response to my own experience and understanding of them as an overarching form of gentle empiricism (see [Figure 8](#)). This is not a finite act, as the understanding this thesis presents is the new ground for cultivating my own future work and holds promise for informing the work of others in seeking to promote musical activity in the caring relationships of people with dementia.

Figure 8: Overarching Form of Gentle Empiricism



4.7 Indications for Dementia Research and Practice

Development of the research process outlined above offers indications for dementia researchers, people working in dementia care and support roles, and music/arts for dementia practitioners. Because these roles can overlap, as mine did in this study, the indications are not differentiated for people in specific roles.

4.7.1 Consent

- There is potential for dementia researchers to recognise nonverbal and nonconceptual ways of understanding and to assume individual capacity to understand experientially.

4.7.2 Video Recording Equipment

- Video footage is an enduring record that can offer a limited sense perceptible presentation of events for further observations and information gathering, as an aid to memory and material for self-observation in practice development.
- Video recording participatory activity allows for fieldwork observations to be made as a part of 'natural' interaction.

- Giving oneself a ‘reminder’ to start recording equipment could help avoid ‘missing data’.
- Positioning the camera in relation to sound, light and movement sources is an important consideration when filming fieldwork activity. Positioning and handling of equipment may also need consideration as it can cause a distraction or constitute an unfamiliar, uncertain or disruptive sensory addition to familiar surroundings for individuals with dementia.
- Participants can become more comfortable with their activity being filmed over time.
- Sharing equipment and activity with individuals with dementia can require consideration of the potential for harm or environmental change on an individual basis.
- Seating arrangements need to be considered in response to the changing support needs of individuals in the context of the activity.

4.7.3 Participant Contact

- Regular visits can be welcome social contact and consideration of ways to support participants to continue social contact is needed, for example by signposting to other services and social groups.
- Working with familiar people offers the advantage of existing knowledge, but research boundaries can become blurred. It could be helpful to:
 - Find a dementia care specialist(s) who is able to advise on any issues or queries arising during participant contact during planning.
 - Design a protocol for signposting if participants are in need of help but are resistant to it.
 - Consider carefully the boundaries that may be needed in the context of the contact for scenarios such as being asked to help with caregiving and the carer leaving or disclosing.

- Set clear boundaries around contact from the outset, make clear why they are necessary and be consistent.
- The potential for changing circumstances, such as frequent and extended periods of ill health and relocation to a different setting need to be accounted for in fieldwork planning.
- A consideration for the design of fieldwork sessions is the balance between responsiveness and structure. For example, time to develop personal relationships with participants, for acclimatisation in each session and the possible need to extend contact so as to pace activities responsively to each individual with dementia, balanced with providing clear boundaries and a manageable routine for everyone concerned.

4.7.4 Research Participation

- Musical, sensory and artistic activity can be an open channel of experiencing, participating and interacting when verbal communication and understanding is challenging. This channel can be a means for experiential communication and understanding as collaborative research that is not dependent upon contributing verbally or cognitively.
- Participation in sensory and artistic activity is a rich form of research data beyond verbal and conceptual data that can be particularly appropriate in dementia research.
- Sharing musical and sensory activity can be a means of participating empathically in people as phenomena in order to develop relationships and understanding of individuals, both experientially and conceptually.
- When sharing musical and sensory activity as a means of coming to know and understand people, the ways that activity is shared stand in relief to the activities that are shared. The end ‘product’ is a presentation of the relationships and experiences forming through the act of its creation. Facilitating activity in this way can require:

- promoting activity in consideration of individual and collective potential.
 - not restricting or directing activity by imposing one's own ideas of how it 'should be' or trying to force a particular outcome.
 - awareness of one's own motivation.
 - facilitation of activity as exploration and discovery rather than achievement or failure.
 - supporting individuals to find their own shared relationship with music rather than re-enact a set of activities.
- Artistic activity can be a means of engaging in a process of reflection and development in research.
 - Experimentation and imaginative picturing can serve to consolidate and refine ideas.
 - Participatory activity as demonstration can be an effective and accessible complement to verbal questioning.

4.7.5 Facilitating Musical, Artistic and Sensory Activity

- Gathering and preparing materials for musical, sensory and artistic activities and for creating and curating individualised resources can be time-consuming and labour intensive.
- Recordings of music can require modification to support individual participation.
- Introducing musical activity informally as a part of other more familiar sensory activities, such as looking at a picture, can be a helpful introduction when sharing musical activity is unfamiliar.
- Developing activity responsively can be received more positively than 'superimposing' preformed activities.

- Sharing musical opportunities to move between reflection and participation can be supportive of individuals' fluctuating energy and enjoyment.
- Shared musical activity can be threefold; past present and future. Participation and exploration in the present can grow out of individuals' biographical relationship with music in light of their potential for future development.
- My understanding of the essential elements for session planning through development of the fieldwork offer the following considerations:
 - the importance for musical opportunities to move between reflection and participation.
 - accompanying planned discussion with relevant sensory opportunities for understanding and communication.
 - enjoying a few activities responsively, giving them space and time to develop and be enjoyed to their fullest at that particular moment.
 - planning a range of simple options rather than a conceptually complex or rigidly structured plan with many elements.

4.7.6 Gentle Empiricism

- Structure is necessary for establishing rhythm and rigor of gentle empiricism practice. However, structure can become a template to be fulfilled rather than a means of orienting activity.
- Gentle empiricism can be a means of working dynamically at all stages of research including data collection and analysis and across a study as a whole.
- Experiential data offers an empirical basis for qualitative understanding of phenomena. Working with this data through a process of gentle empiricism can be a means of staying with the inherent flow of experience in coming to understanding, rather than applying understanding abstractly.
- The 'writing up' of research can be a process of working with data that serves to realise emergent understanding through the mirrored creative modes of gentle empiricism.

4.8 Summary

This chapter has traced the emerging method and study design as they have evolved throughout the study. The following chapter introduces the participants and tells the story of our participation in a living process of musical activity as I experienced it.

5 Growth and Flourishing

Life becomes ideas and the ideas return to life.

(Merleau-Ponty, 1968, p. 119)

5.1 Introduction

The following chapter gives a detailed account of my fieldwork participation experiences that were the primary data for the study. This account is supported by illustrative evidence of the secondary data as quotes and traced video stills, along with media from my reflection and development process. This chapter presents the ‘essential’ of my experience that I realised through ‘working with the data’ and offers impressions of the participants and our activities for the reader. It traces how both gentle empiricism and our musical activity integrally grew, flourished and yielded resources for future sharing with each pair. Within the account of each pair’s fieldwork cycle, the modes of gentle empiricism are grouped under headings that reflect the movement of coming to understanding from the basis of experience, into realising creation through the development of creative action (see Table 9). I recount the process in this simplified form for the sake of coherence and to aid understanding.

Table 9: Modes of Enquiry and Chapter Headings

Gentle Empiricism	Heading
First impressions	Background
Exact sense perception	Experiencing
Imagination	Understanding
Inspiration	
Intuition	
Experimentation	Creating
Picturing	
Creating	

A brief 'background' introduces each pair with an overview of their biographical relationship to music and recordings, and reasons for being 'called to' participate in the study, to provide context as it did for me in developing the fieldwork.

To invite the reader's active participation in experiential understanding, I have created a 'collage' for each pair, weaving together various media in the following forms:

Background: an anonymised traced video still of each pair as a visual introduction.

Experience: descriptive impressions and images to aid inner picturing for the reader.

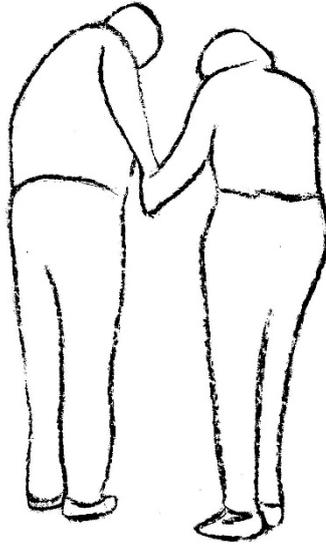
Understanding: word impressions, scores of music and colour impressions accompany descriptions of the gentle empiricism process of picturing, inspiration and intuition that gave rise to them. I have only included those most pertinent to aiding understanding for the reader from the body of artistic impressions I produced.

Creation: photographic examples offer a more comprehensive picture of the resources created than words alone.

To further encourage experiential understanding, you are invited to try musical activities described in this chapter and those in [Appendix 11.22.3](#) that are based on the fieldwork activities.

For each of the pairs that participated in a review session, I have provided an account of the 'essential' of the event and how it further informed my understanding and action. I have used language that I hope does not in any way undermine the individuality of the people I have worked with and the relationships that we developed during the study, often necessitating careful consideration and additional description to avoid obscurity. Visual examples have been traced from video stills, omitting identifiable features. Fieldwork video and audio recordings are referenced for each pair by session number, recording number and time elapsed, e.g. Session 1, Video 1, 1 hr 25 minutes (S1, V1, 01:25:00). A full list of music, recordings and activities itemised by session is provided in [Appendix 11.21](#).

5.2 Sue and Ron



5.2.1 Background

At the time of our sessions, I had known Sue and Ron for several years. As a result of our existing contact, Sue and Ron volunteered to take part in the pilot for this study and subsequently, the study itself.

Music was a constant in Sue's early life, as her mother played piano and church organ and sang. Hymns of worship and Sunday school sat alongside traditional and music hall songs in her repertoire. Sue enjoyed singing herself, if more informally round the house, during her work milking cows and sharing songs with her brother. Evenings out with family and friends at the local village hall for whist and dancing were accompanied by a band playing lively traditional country music tunes, and Sue's enjoyment of dancing grew to encompass dancehall and ballroom. According to Ron, cheerful music could always cheer Sue up, and at the time of our sessions, songs from musicals and Classic FM radio constituted Sue's regular listening, along with hits from the 40s - 50s and pub singalong songs enjoyed with her daughter.

For Ron, music has been one of life's mainstays. In his youth, Ron enjoyed popular bands and wartime singers. Maturity broadened and varied his taste to include classical, big band and swing and introduced a depth to his appreciation; "Music has the ability to change my mood. For example, Bruch's First Violin Concerto can bring me almost to tears" (from Ron's Music and Life Story Questionnaire). His eclectic

taste informed the accumulation of an extensive collection of recordings on LP, CD, DVD and cassette, a collection of printed lyrics, music books and musical instruments, including recorder, keyboard, guitar, bongos, harmonica and glockenspiel. The only instrument Ron played with any regularity was the keyboard “...I must get back at it. I used to do it a lot; not with any great skill. I’d come down in the morning early...and sit at the keyboard, playing away quite happily on my own” (S2, V3, 01:52).

Their continuing shared enjoyment of recordings and radio listening began when they met, later in life. They shared many hours getting to know each other in the company of favourite artists. Ron created a narrated mixtape of tracks they shared during their courtship and went on to share over the years. Although they had not shared their earlier lives, they had both enjoyed wireless programmes, such as *Two-Way Family Favourites*, ballroom dancing and singing around the house independently. Sue’s spontaneous singing in the home continued through her life, as a means of enjoying some of her favourite songs, especially Country music, and an enduring form of interaction with Ron, that had become invariably initiated by him; “...I might start singing and then Sue will join in when she feels like it...I’m only singing for myself actually, not for Sue; then I suddenly see her lips start moving” (S6, V1, 02:48).

When we discussed our hopes for the study, Ron was optimistic that it might benefit Sue and others in a similar position, provide welcome social contact for them both and bring the satisfaction of knowing that they were supporting my studies. However, Ron also expressed doubt over whether Sue would participate in session activity and whether they would be able to participate for a full cycle of sessions.

5.2.2 Experiencing

Ron’s careful consideration and planning between sessions regularly greeted my arrival with the room set up in anticipation of our activities, a new selection of biscuits or cake and items of interest waiting for our attention, such as LPs, DVDs and photos. His generosity and kindness extended to preparing lunch that we enjoyed after sessions and that often served as a time to reflect on the preceding session and talk about ideas for the future. Ron was an amiable host, offering regular invitations to make myself at home and keen to accommodate my ideas, and it took some time for

me to attune to his subtleties of manner to give indication of his underlying feelings. A hint of stiffness or formality indicated to me that he was not entirely in agreement with an activity or idea.

Conversation with Ron played a significant part in our sessions, accompanying our activities and personal memories, photos and poetry that Ron shared. Our sessions came at a challenging, transitional time for them both and conversation appeared to be a welcome form of human connection for Ron that he was no longer able to share with Sue in the way they used to. Ron spoke of Sue 'fading', observing that he was increasingly aware of her disabilities and was trying to find ways to help her to express meaning by rehearsing her words before speaking, answering questions with a 'yes' or 'no' and verbalising the theme of her thoughts. Ron found it necessary to adjust his hearing aids during our sessions and occasionally appeared to miss quiet speech and singing, so I suggested he sit opposite Sue so that he could see her face, rather than alongside her.

It was unclear how the world appeared visually to Sue as a result of macular degeneration. Her relationship to the environment concentrated primarily in activity through her hands and feet. We often found the certainty of each other's presence through the touch of our hands, Sue's usually cool, strong and dry to the touch. When seated, Sue's hands were often restless. She would persistently rub, pull or fiddle with irregularities, contrasts or textures of clothing and materials discovered by her seeking fingertips; sometimes with her hands themselves. At times her hands and feet would move in repetitive rapidity with unfocussed forcefulness, at others her heels would lift in suspension from the floor. These forms of movement were characterised by tension and rigidity.

Sue usually moved little with her upper body, although, infrequently she still performed spontaneous acts of daily living with natural ease such as retrieving her hanky to blow her nose and taking a sip of coffee. She invariably leaned back when seated, legs often crossed, her shoulders drawn over in a manner that Ron referred to as "sombre" (S1, V1, 00:10). This gesture of contraction typified her posture. It occasionally became evident in her hands and developed into a tendency to sink into a semi-recumbent position to one side during our later sessions.

Holding and grasping were a signature of Sue's contact with the world through touch. Ron reported on Sue's ability to undo knotted material and tendency to clutch her

bath towel. Sue's strength of presence waxed and waned during our sessions. Sometimes she was alert and assertive in speech. More often, she was distant, speaking and engaging little. Sue's usual quietness lent the spontaneous moments of her presence in humour more emphasis, making them all the more amusing. Ron's prompting and reminders to do things could be met with an expressive look that said 'unimpressed' more clearly than words, and I often shared laughter with her at irreverent comments and regional phrases that came up in conversation.

Although Sue engaged in spontaneous music-making several times, both leading and responding creatively, from Ron's perspective the sessions were not really 'working', and they were not getting any benefit from them. I endeavoured to frame our shared participation as exploration to help me understand their relationships to music, rather than to have a specific effect, and he did not see his role in the sessions as significant, making comments such as "I'm the makeweight" (S1, V1, 24:52) and referring to the sessions as 'training'. I attempted to provide regular opportunities for direct input on ideas for session content for both Sue and Ron, but these were not forthcoming, Ron observed "It's difficult for me to say 'let's try this' because, unless I've actually done it, I don't know what it is that we might be trying, do I?" (S2, V2, 33:24) and frequently referred to me as being 'in charge'.

At the start of our first session, Ron announced that, to get over the embarrassment of singing in front of each other, he was going to start us off by singing his *Rebel Song* that he learned during wartime. He sang briefly, reminiscing about the origins of the song. This was to prove the first of many offerings from Ron, who went on to introduce many songs to the sessions and my repertoire, singing from songbooks, sharing songs from memory and providing me with copies of printed lyrics. Sue also sang spontaneously, not only along to recordings and the singing of others, but once singing a tune as she entered the room, assisted by Ron, who informed me this was a common occurrence.

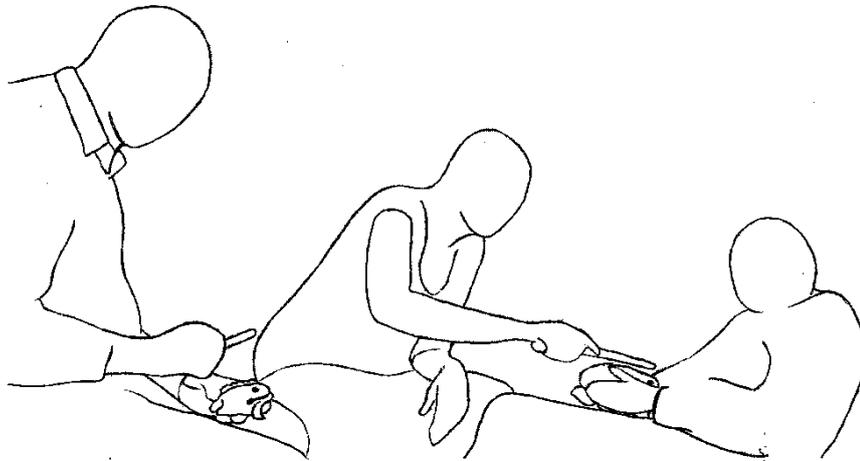
We experimented with supporting our singing with guitar playing and with recordings. Acoustic guitar accompaniment seemed superfluous, given Sue and Ron's existing propensity to sing, and though the recorded tracks were greeted with our singing, their purpose in providing a supportive structure for deliberately sharing singing did not appear necessary to Ron. However, he did demonstrate appreciation for the support of printed lyrics on several occasions, even when just listening to a song.

Ron's love of words was manifest in his extensive written compositions, and he gave us several readings of his poetry and lent me a comprehensive selection of his works, including short stories, to read at my leisure. Inspired by Ron's past enthusiasm for creative writing, I challenged him to write new lyrics for an existing melody. This task sparked Ron's imagination, and when I returned the following session, Ron sang two verses of new words to the hymn tune *Abide with Me* (Lyte and Monk, 1847/1861).

We continued to explore singing beyond the bounds of existing songs by experimenting with the relationship between our voices in 'call and response'. I initiated with simple vowel sounds sung to single pitches, patting my legs to give my vocal offering supportive rhythmic structure. Ron appeared keen to oblige and echoed my sounds, frequently prompting Sue to do likewise. Sue eventually joined in and our interactions became a playful interplay of tone, sound and laughter as we made associations between the sounds and animals and Sue's regional dialect. I introduced sounds sung to melodic phrases from existing songs with a repetitive structure. Ron continued to echo and prompt, and Sue's uncertainty manifested as an "Oh, dear!" (S3, V1, 29:34) sung to my last sounding pitch, that I echoed, and we relaxed into a comfortable rendition of *O! Dear, What can the Matter Be?* (Unknown composer, c. 1775/1935), Ron moving his legs to the beat.

As well as singing, our playing of musical instruments also began during our first session through exploring the timbre and tone of simple instruments as sounding objects. Sue pulled a face and laughed at the sound of the frog-shaped guiros (see [Music Glossary](#)) and I held one steady for her to explore with a stick. For a short time, our divergent striking and rasping came together in a regular rhythm, Sue moving her guiro up and down rhythmically to strike against my stick in response to Ron's regular rhythm (see Figure 9).

Figure 9: Playing Frog-Shaped Guiros



The sound of the rain stick (see [Music Glossary](#)) was greeted with a breathy, chirruping whistling from Sue that sounded like a birdsong, which Ron assured me had become a common articulation from Sue.

The mysteries of the singing bowls' (see [Music Glossary](#)) resonant tones emitted by circling contact with a stick, akin to sounding a wineglass held a fascination for Ron, who delighted in new experiences. I left the singing bowls, rain sticks and ocean drum with them for them to explore further for a few weeks at Ron's request.

Our adventures in music making with instruments continued by experimenting with comb and paper, a cause of amusement for Sue, who laughed at the buzzing tone Ron created, and responded to my rendition of *Oh, Susannah* (Foster, 1848) with "Oh dear, I'm running!" (S4, V1, 14:48). More laughter ensued from us all as I joined in Ron's brisk reprise of *Oh, Susannah* (Ibid.) for its finale. Sue explored the comb and paper with her fingertips, and while I encouraged her to touch her lips to the paper while blowing, Ron playfully sang *Softly, Softly* (Roberts, Dudan and Paul, 1942/1955) through his comb with words; a song whose lyrics talk about the gentle touching of lips. Sue tried blowing hers a little and laughed, saying "I don't think so!" (S4, V1, 15:43), and we joined in with Ron's singing instead. Sue continued to sing along through a comb and paper rendering of *Oh My Darling, Clementine* (Montrose, or Bradford and Thompson, 1884/1863) played by Ron and I, adopting the consonant 'D' in place of some of the lyrics. This song too brought humour with its ending, shared as laughter between Sue and Ron, after which Sue held the tip of her thumb to her mouth for a while.

While we got the harmonicas out, Ron proclaiming his inability to play the instrument, Sue made several comments that appeared to sympathise with the tone of conversation, including “I don’t want it filling up” and “It’s terrible” (S4, V1, 19:15; 19:31). Ron began to play a repeated ascending phrase on his own harmonica, to which Sue responded with a descending vocal phrase to the sound ‘dee’, that developed into a sung exchange between Sue and I, while Ron continued to improvise.

In response to my playful encouragement, Sue tentatively put a harmonica to her lips, discovering single notes and chords with gentle breaths, and we all shared in exchanges and playing together. I gently supported Sue to reposition her harmonica so that she could explore its full range, having become ‘stuck’ in the higher register. A visible vitality came over Sue, her facial expression ‘expanded’, she became visibly more upright in posture and a rhythmic pulse came into her breathing with which she sounded the harmonica on both the exhale and inhale, her breath deepening.

I clapped along encouragingly, and Ron ceased blowing his harmonica. Sue’s whole body became more tense, supporting and moving with her playing that culminated with a vibrato created by Sue moving the harmonica rapidly from side-to-side. I cheered and clapped, Ron said, “You enjoyed that didn’t you?” (S4, V1, 26:33) and Sue’s legs resumed their customary rapid motion. Later, Sue began to play the harmonica of her own volition, sounding rhythmic high notes, then again in joining Ron’s playing, culminating on this occasion with a recognisable rendition of the first few phrases of *Oh My Darling, Clementine* (Montrose, or Bradford and Thompson, 1884/1863) and during a subsequent session, *The Blue Danube* (Strauss II, 1866), playing rhythmically to my singing.

Our instrumental exploration included a brief foray on guitar, an instrument that Ron owned. Ron experimented with plucking and strumming, expressing that he was “no good” (S8, V1, 29:39) on the guitar. Ron’s electric keyboard, on the other hand, offered greater scope. Over many years of his adult life, Ron sat patiently at his keyboard, working out tunes to songs by ear and from books. In anticipation of exploring the keyboard as a part of our sessions, Ron revisited his keyboard, informing me “...I was terribly, terribly disappointed...all the hard work I’d put in to working out some of the tunes and getting them; gone...and I can’t see very well, so I can’t see the music” (S3, V1, 12:09). Ron shared his keyboard playing with Sue and I

during several sessions. On the first occasion, we all sat at the keyboard in the dining room, and Ron played the hymn melody *Abide with Me* (Lyte and Monk, 1847/1861). Sue spontaneously joined in with wordless singing after the first few notes sounded. I joined her singing, adding the words where I knew them, which seemed to support Sue in finding the words also. Ron said that he could not play and sing at the same time and was very aware of playing notes that did not belong to the tune, and frequently ran his fingers up the keys in a glissando when this happened, interrupting the flow of the music. One afternoon, Sue and I continued to enjoy the keyboard together in Ron's absence. Sue did not respond to my invitations and encouragement to play, but she readily joined in singing familiar songs with me while I provided chordal accompaniment.

Sue's relationship to music could be immediately apparent in her response, and could also be slow and subtle, observable in slight physical movement, a quiet stillness, responsive changes in her breathing or eventually joining in singing a final chorus. Recordings of music often brought opportunities for Sue to move and sing, especially in the participatory company of others. During a recording of *Land of Hope and Glory* (Benson and Elgar, 1901/1996), Sue's rhythmic, subtle foot movements, a deceptively complex lifting of opposing heel and toes simultaneously, suddenly blossomed to become full-limbed expressions of the pulse, her held hand leading mine, our voices rising to join the rousing chorus in unison. A recording of another song familiar to Sue, *You are My Sunshine* (Davis and Mitchell, 1939/1940), provoked her immediate, sustained laughter, that spread to both Ron and I, with Ron exclaiming, "I don't know why you're laughing, you know this song well" (S1, V2, 10:09). Sue then promptly began to slap her legs rhythmically with her hand in time with the changing lyrics, moving between syllabic thigh slaps with both hands together whilst mouthing the words during sung sections, and alternate hand slaps on quaver beats during an instrumental section, ultimately joining in with a chorus in full song and rhythmic limb movement. Ron and I joined in with Sue's singing, and I tried to mirror her actions in support.

Leading into this listening, we explored experiences common to them both, even though not shared in the past, such as farming life. We created and listened to recordings of various animal sounds and looked at farming images, bringing the outdoors in with a backdrop of birdsong recordings for our talking about farming

memories such as the named pigs kept by Sue’s family and the tractor she drove. Sue suddenly spoke quite animatedly but struggling to find the words and making a regular, rhythmic sound in demonstration and indicating movement through space with her arm “...I was on that thing...then it starts to come out d-d-d-d-d...” (S2, V1, 30:32). I lay a sheepskin across Sue and Ron’s legs for them to touch and we all took it in turns to play a cowbell, Ron remarking that it sounded like the ‘mind the doors’ sound trains used to make when about to depart. Ron and I then played coconut shells to sound like horses’ hooves, eliciting “It’s ever so nice to see them...” (S2, V2, 00:02) from Sue, who trailed off, then continued with humorous indignation, pulling at the sheepskin, “Not this; this is nothing!” (S2, V2, 20:00). Ron continued to play with the coconut shells for several minutes, refining his horse-hoof sound, while Sue’s leg began moving up and down rapidly, until I offered her a coconut shell. I asked Sue questions about the horse on the farm where she grew up and she answered lucidly, before stamping her feet along with our coconut playing (see Figure 10).

Figure 10: Sharing Sensory Activities Associated with Farming Life



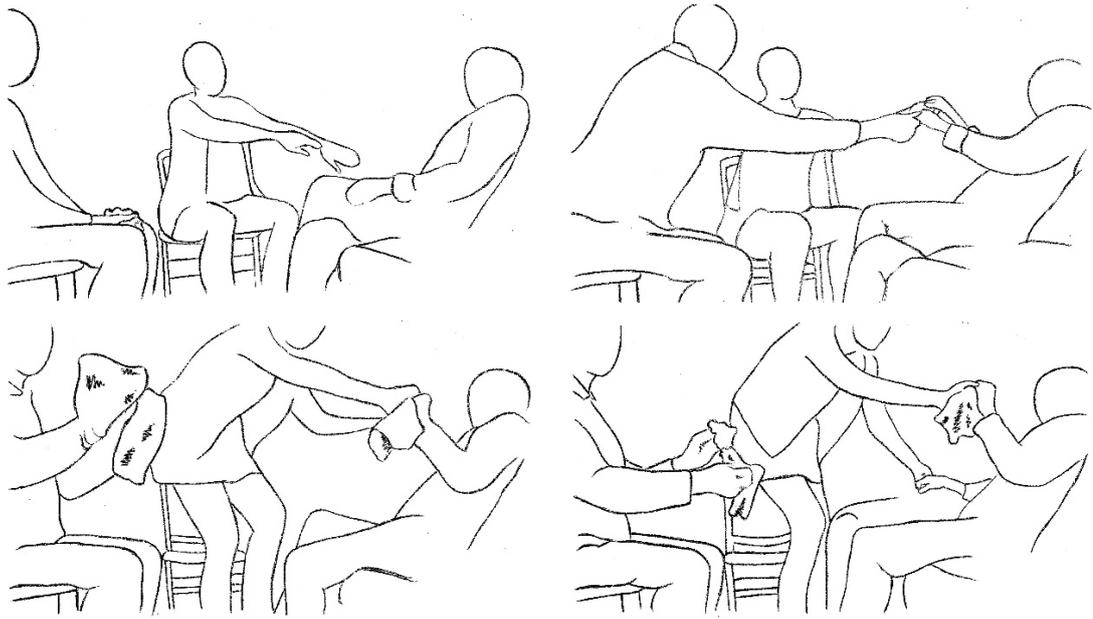
We experimented with creating rhythms on several more occasions. Our improvised rhythmic exchanges were usually short lived and lacked the energy and enthusiasm of many other musical activities we shared. Clapping along to a recording of *The Blue Danube* (Strauss II, 1866), on the other hand, was met with energetic participation and enjoyment, yet rhythmic engagement did not appear to come as easily to Sue’s limbs as through her breath on the harmonica. Sue joined in with our clapping until the rhythmic emphasis of the music changed; a decreasing hiatus between her claps and the rhythms of the melody.

For Sue, rising from seated to standing and walking were often difficult experiences and challenging for Ron to support. Tense and uncertain, Sue often resisted the help Ron sought to give with each step, making for slow progress. I suggested playing music that might hold a ‘physical memory’ of standing for Sue, such as a hymn. This suggestion sparked a memory for Ron, who spoke about an experience of physical memory in his working life. The next time we needed to move, I played a recording of one of Sue’s favourite hymns and sat down next to her. I asked if she would like to stand for the hymn, giving verbal encouragement and we rose together. Supported either side by Ron and I, Sue moved willingly across the room, chivvying us with a “Come on!” (S0, V1, 16:05).

As Sue enjoyed dancing to traditional music in her youth, I played a recording of a well-known example of a country dancing tune on another occasion when Sue and Ron were facing the challenge of walking across the room. Ron led Sue with both hands, tense and resistant. Within the first few seconds of the recording, Sue began to move with ease and rhythm to the music, Ron observing with a smile “Enjoying that, aren’t you love?” (S1, V3, 02:26).

We continued to explore music and movement in a variety of ways. We danced across the room, in our seats, and sang familiar tunes with a regular pulse to support walking together with Sue. Recordings of country dancing music became a regular feature of our sessions, inviting our movement while seated. Sue responding with delight to one track in particular, exclaiming “Oh, I like that...Oh, it’s lovely” (S3, V1, 44:15). On one occasion, I introduced small coloured scarves. Ron playfully took one in each hand and waved them along to the recording, but Sue did not appear to take to them, so I offered her my hands instead. Sue began to lead my arms in rhythmic movements to the recording. She varied these movements at times and, at one point, crossed our arms over. We shared in interplay of Sue leading and me supporting when her movements faltered, and I suggestively initiating new movements when opportunities arose. Ron joined us in handheld movement briefly and then independently with scarves. Sue gradually became freer and more vigorous and playful in her movements, eventually uncrossing her legs and moving them in time with the music (see Figure 11).

Figure 11: Sharing Seated Country Dancing



Ron pointed out that dancing was not something he and Sue had shared, asserting that their ‘body rhythms’ differed. I invited Ron to share in arm movement with me, demonstrating resistance, leading, supporting and inertia in my arm movements so that Ron could experience how these felt. He began to move responsively with Sue, both smiling and sharing rhythmic arm movement. We tried out makeshift ‘tappers’ for our shoes that I made using metal bottle tops and elastic bands, putting wooden boards down under our feet for ‘tap dancing’. Ron tapped out intricate rhythms, leading us into tapping along to recordings of familiar jazz. Sue made occasional small rhythmic movements with her feet after being prompted by Ron to uncross her legs and to try tapping.

We continued to explore the potential for recordings to support our interaction in movement with colourful balloons accompanying a recording of light-hearted contemporary instrumental music, assumed to be unfamiliar to both Sue and Ron. I introduced Sue to a green balloon that she held for the duration of the track, enthusing with a smile “Look at it it’s so nice. Oh, that’s lovely” (S3, V1, 54:26). Ron demonstrated making balloons stick to his hand and Sue deliberately made her balloon squeak by rubbing it with her hand. I mirrored Ron’s activity and Sue mimicked my balloon squeaks with her whistled birdsong. Sue used both her balloon and her free hand to interact with the other balloons that Ron and I playfully batted about with arms and legs. Sue’s movement gradually expanded through space, reaching out to meet me with her balloon. Finding its knot with her fingertips, she

held it, batting her balloon against mine, rhythmically in time to the music, increasing in vigour to bat other balloons and leaning forward in her seat, batting into space to seek them out. This was one of the few times I observed Sue sitting forward spontaneously (see Figure 12).

Figure 12: Sharing Playful Movement with Balloons to a Recording



When the track ended, Sue gently reclined, her green balloon held in front of her by the knot, arm extended, whistling her chirruping birdsong that she and I extended in imitative exchange.

As it was unclear how much of her environment Sue could perceive visually, I suggested sharing colour to see if this could be an enjoyable sensory experience for her. I brought vibrantly coloured cloths in red and yellow, holding them up before Sue to fill her field of vision. Sue gave no observable indication that she could see the cloths. In the company of each coloured cloth, we shared other sensory experiences that might evoke imaginative experience of the colour, for if Sue could not perceive colours visually, then opportunities to experience them in other ways would have potentially greater significance. For each of the colours red and yellow we sang songs and listened to recordings that either had an association with the colour or evoked something of a colour mood, such as strident, fiery music for red. We also held, smelled and tasted foods of that colour, including a lemon for yellow. We shared the scent of a red rose that Sue held to her open mouth, breathing it in and tasting some of the petals, exploring the stem and leaves with her fingertips

During one of our later sessions, I introduced the idea of reducing our use of speech, that invariably did not invite Sue's participation, to promote a 'sensory space' exploring bringing the garden indoors. Sue had been an avid gardener in years gone by. Their garden, Sue's pride and joy, was now maintained by Ron, who commented on Sue's lack of interest in it. I asked Ron to sit next to Sue to promote sharing and offering produce from my own garden. We enjoyed the smell and taste of berries and the smell and touch of edible herbs and flowers, while I kept my speech minimal. We sang familiar songs about plants with lyric sheets, including *The Sprig of Thyme* (Habergham, 1689), a favourite of Sue's that accompanied the sensory experience of thyme from my garden. Ron led us in singing *Lavender's Blue* (Traditional), Sue's singing slightly delayed but falling more readily in time towards the end of the lines, full with vibrato.

Ron's speech diminished as we went on to explore bird calls with plush-toy sounding birds along to a recording of songbirds, the playful touch of feathers in our hands to the jaunty strains of Brahms' *Hungarian Dance No. 7* (Brahms, 1879/1984), and singing songs about birds. Ron inadvertently initiated interaction with Sue by playing a bird call, to which Sue responded with her familiar chirruping birdsong, something Ron could not normally reciprocate, being unable to whistle.

Ron was often joking and playful, yet at times his joviality belied a heavy resignation to the difficulties of life. Over the course of our sessions, Sue and Ron experienced increasing difficulties with activities of daily living, such as eating, dressing, bathing, standing and walking. Ron related events occurring between sessions, including falls. Ron said he felt 'fraught' at one point and that he doubted his capacity to provide care for Sue much longer. He began to look at the possibilities of home adaptations and additional or residential care. The idea of ceasing to provide care for Sue was upsetting for Ron, as he had vowed to care for Sue 'until the end'. Being witness to such struggles, I asked if Ron felt he needed additional support and put him in contact with a Dementia Support Worker at the local Alzheimer's Society branch. Change was precipitated when Sue became poorly, necessitating a stay in a local care home, which became a permanent move.

Ron and I discussed the options for our remaining contact time, and he was positive that the continuity of weekly sessions was preferred to their phase out or abrupt cessation, so our final two were held in Sue's room at the care home, with the

agreement of a care home manager. During these sessions we explored how musical activity could be a part of life for Sue in her new setting and the potential for her and Ron to continue sharing musical activity together.

We shared simple, gentle activities during our remaining sessions, trying out ideas in the forming of resources to leave them with, whilst being mindful of the physical and emotional trauma of Sue's recent health incident and the unsettling upheaval of the move for them both. Singing with lyric sheets had become a staple of our sessions that Ron invariably said he enjoyed the most and this continued with our familiar songs and hymns that we had not yet shared together. We experimented with recordings of piano accompaniment to our hymn singing as a familiar link to Sue's early experiences of hearing her mother's piano playing in the home. Ron and I sang the words he had written to the hymn tune *Abide with Me* (Lyte and Monk, 1847/1861). Sue did not join in, but appeared to be actively listening, her mouth moving a little with our singing. I then introduced new words that I had written for the song *Daisy Bell* (Dacre, 1892) about Sue's childhood on the farm, starting us all off singing with the verse we knew well, then I continued into the new. Although Ron stopped singing to listen to the unfamiliar verse, Sue continued to sing the new words with me, hanging back slightly on each word until she could echo it and I slowed my singing in support.

I took a prototype resource of garden-themed activities to our penultimate session and we tried out one of them before I left it with them to try. The activity involved Ron and I giving Sue a hand massage with lavender scented cream, during which we all shared laughter, and went on to sing *Lavender's Blue* (Traditional) all together, Sue initiating arm movements to the beat.

5.2.3 Understanding

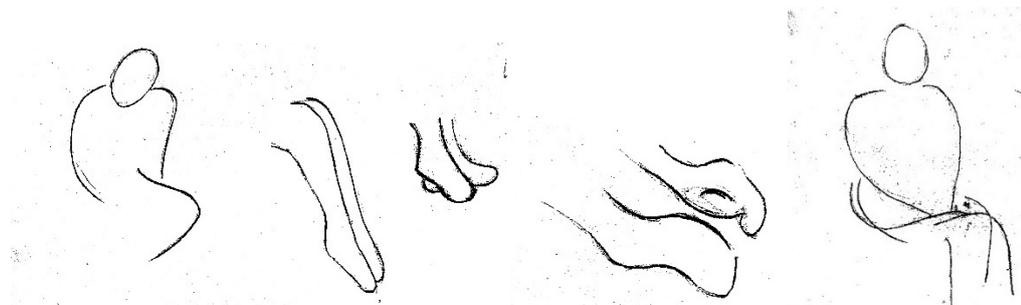
An enduring impression that accompanied my sessions with Sue and Ron was the movement between contraction and expansion, expressed in the following sketch impressions, and the expansive movement of the accompanying score of a musical impression (see Figure 13).

Figure 13: Sketch and Music Impressions



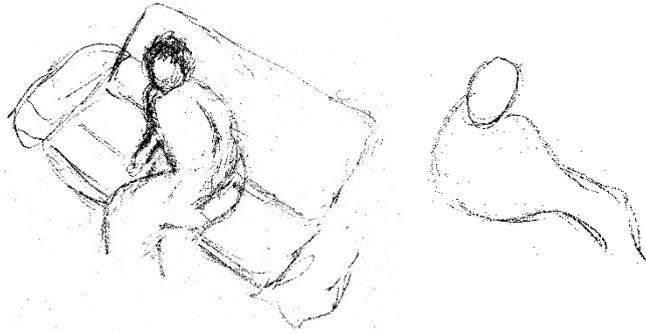
Physical contraction was a characteristic of Sue’s posture and the tension in much of her movement, and Ron’s postural gesture also often carried the signature of contraction in polite reserve. These characteristics stood out during memory picturing and were captured in memory sketches (see Figure 14).

Figure 14: Memory Sketches



In contrast, the contractedness of Sue’s seated posture, could also result from a lack of physical tension, as depicted in the following memory sketch and video observation sketch (see Figure 15).

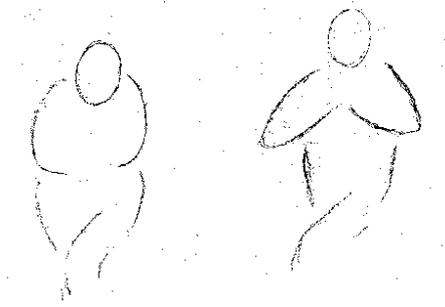
Figure 15: Memory and Video Observation Sketches



Repeatedly across the span of our sessions I experienced the introduction of movement in relationship to music and recordings, and contraction becoming more open and freer in various ways. Examples include the immediate transformation of Sue's resistant, arrhythmic walking into the rhythmic ease of dancing movement to a recording of country dance music; the complexity of her subtle foot movements becoming flowing song and limbic movement to *Land of Hope and Glory* (Benson and Elgar, 1901/1996); and our interactive movement with balloons to an unfamiliar recording. These are just a few of the moments where Sue's experience of recordings manifested through flowing physical movement, balancing the rigidity of contraction and the flaccidity of expansion. This active relationship to music and recordings often blossomed for Sue through responsive interaction with others in the sharing of experience. Equally, Sue's relationship with others and the world often blossomed through the experience of music and recordings.

Movement to music also occurred in other ways for Sue. Singing and harmonica playing engendering deeper, more expansive breathing. Sue expressed emotional warmth and laughter in appreciation of music and recordings, and memory through the singing of familiar songs. When playing the harmonica, a rhythmic coherence in breath, body and the experience of her own creation occurred, along with a visible postural expansion. This event stood out as significant during memory picturing, capturing Sue's postural change (see Figure 16).

Figure 16: Memory Sketch



These various forms of movement were evident for us all, but most pronounced in Sue, who was sedentary for much of the time and whose interaction with others was limited. Offering opportunities for movement for Sue held a particular poignancy given her love for the physical freedom of open country spaces, bike riding and dancing in her youth. A vitality was often quick to manifest in her relationship to music and recordings, inspiring the following sketch and word impressions (see Figure 17), as well as an improvisatory folk composition in honour of Sue that I recorded and included in their resources.

Figure 17: Sketch and Word Impressions



Your music calls to mine
Waking my roots
Rising up, living in rhythm
Musical flow to my fingers and toes
Feel my soul
Hear my rhyme
Infinite space every moment in time

Through the opportunity to work closely with Sue and Ron I grew to appreciate what a challenging transition moving from the ‘getting things done’ of fulltime caregiving into responsive sensory exploration can be when providing fulltime care for a loved one. This transition required an emotional receptivity at a time of emotional and physical exhaustion, and broadening a lifetime’s view of music as entertainment to

encompass music as a means of relating. While both Sue and Ron enjoyed our sessions and the company of my visits, the sensory interaction I experienced with Sue during our sessions seldom seemed to translate into a means of interaction for Sue and Ron. I often experienced a lack of coherence between the three of us as a struggle to hold the balance between verbal conversation with Ron and sensory interaction with Sue. Providing Sue with opportunities to move and relate, both with and through music could be easily afforded on a practical level by providing a supportive sensory environment. A lively tune, a willing hand inviting rhythm and an openness to follow and support Sue, for example, were usually met with her enthusiastic participation. Musical resources already existed in plentiful supply in their home. Collections of instruments, recordings and lyrics were supplemented by the experiences of shared singing and music-making as part of a community group. However, the sensory interaction that often came easily between Sue and I, did not appear to translate into Sue and Ron's interactions with each other. Ron invariably prompted Sue's participation or became absorbed in his own activity while Sue and I interacted.

Ron's comments about being a 'makeweight' and a 'stooge' in our sessions, led me to understand that he took part in activities because I was asking him to, and that he did not recognise his role or relevance within the study or the potential for our activities to be a means of sharing with Sue rather than a task to be done correctly or incorrectly. However, there were times when we were all united in sensory interaction and shared enjoyment, reflected in various receptive impressions. The following examples illustrate our coming together in enjoyment depicted in words, and the coming together of independent elements in harmonious movement as colour impressions (see Figure 18).

Figure 18: Word and Colour Impressions

Closed buds softening, releasing, warmed by the sun

Of simple songs, laughter and fun

Bringing warmth and life, our colours run





A potential for supporting the continued growth of musical interaction that had flourished in our sessions appeared to lie in offering resources for activities that held a relevance and appeal to Ron, as well as to Sue. The shared enjoyment of recordings and singing stood out as a thread of connection and a means for consistency even through the disruption of Sue's move into residential care. At this time, the familiarity of their shared routines and constant company had suddenly changed and I was left with an impression of disorientation and their need to find connection with each other, that I expressed through the following word impression (see Figure 19).

Figure 19: Word Impression

The rhythm of your step
The notes of your voice
The light from the window casting familiar shadows
Holding and constant
Now the shadows shift and change
Giving way to wary quiet and uncertainty

The rhythm of your daily needs
The notes of your voice
The light you cast from your familiar smile
Holding and constant
Now your light is distant
I search for new ways to reach you



5.2.4 Creating

Sue's occasional sleepiness necessitated the development of a range of possibilities for each session, to help me tailor our activities responsively to both Sue and Ron's

mood and energy levels. I found this a fruitful approach, allowing me to offer options for participation. It also allowed for the freedom of exploration that I was keen for our activities to promote, away from predetermined outcomes or responses that would limit possibilities and could have led to direction-giving rather than responding, and participation being framed as ‘right or wrong’.

An avenue with seeming promise during our sessions was Ron’s keyboard playing. This was a practice he was keen to resume and that appeared to offer an enjoyable means of sharing music with Sue. We explored a variety of possibilities for supporting this development, and I created chord sheets for simple songs familiar to them both, with a view to creating a resource to support their continued singing together supported by Ron’s playing. In responding to Sue’s propensity for rhythmic movement, I drew on resources demonstrated by Diane Amans, practitioner in community dance, in her use of balloons, feathers, coloured scarves and foot tappers. I tried out these ideas with recordings and sung music favoured by Sue and Ron, incorporating recordings and music of the types played for the dancing they had enjoyed separately in the past, for us to go on and explore during our sessions.

Sue’s love of gardening inspired a prototype to try out in development of the final resources to leave with them. Sensory activities associated with gardening offered a potential means to encourage playful sharing of music. The prototype included a selection of activities on a garden theme outlined in an activity booklet with accompanying lyrics folder and CD of music recordings (see Figure 20), planned as a part of the final resources. A thyme plant, lavender hand cream and seed packets were also provided for the suggested multisensory activities. When we met again the following week for our final session, Ron returned the resource, saying that he would not use it, but kept the lyric stand and lavender cream that he used sometimes for Sue’s arms.

Figure 20: Garden Resource



I developed a comprehensive selection of sensory activities for Sue and Ron to explore as a final resource. This development was informed by my understanding of Sue's relationship with music as offering opportunities for different forms of movement, in body, breath, emotion and memory, and the potential for other forms of sensory engagement to enhance these forms of movement and offer opportunities for interaction with Sue.

The design of resources changed significantly from my original plans when Sue moved from her family home into residential care. The change in circumstances meant the opportunities to share musical activity were dramatically reduced. At this time, I also began to realise the importance of offering resources that appealed to Ron as well as to Sue. This emergent understanding appeared to be confirmed by Ron's lack of engagement with the prototype resource I had offered. In response to this understanding, the idea arose to 'call to' Ron's imagination and enthusiasm for listening to recordings of music, singing and creative writing in simple ways to intentionally share musical activity with Sue within the confines and challenges of her new setting. I decided to give Ron more writing 'challenges', creating a folder for him to add to that incorporated the lyrics he and I had both written during our time together, and provided a list of suggestions that included setting his poetry to music using his keyboard and personalising the lyrics of songs. Included in a reference folder were simple guidance on sharing music specific to Sue and information from Playlist for Life (2019) on creating and using playlists for the MP3 player and USB sticks. I also provided him a list of the original sensory resources that were available

for him to try on request and a USB stick of video footage highlights from our sessions.

I incorporated favoured recordings and songs enjoyed by them both from across our sessions, compiling lyrics for shared enjoyment of singing and recordings of music for listening with Sue. I arranged the lyrics in a folder, introduced by a page of guidance on sharing musical activity with Sue for reference by family and care staff, encouraging musical interaction in singing, listening and moving, and emphasising the need for a steady pace to help Sue find the words when singing together. I cut the length of many song lyrics down to a simple structure, keeping the most well-known sections, as Sue invariably sang from memory and it was unclear whether she could read lyrics. For very short songs, I indicated for the singer to repeat.

Both the lyric folder and recordings I grouped as either 'Uplifting' or 'Relaxing' to enable responsive use in a simple way, with the potential to support daily routines and changes in Sue's mood and energy. For the recordings of hymns, I chose piano renditions, potentially familiar from Sue's childhood, lowering the pitch to promote comfortable participation in singing from Sue. I also lowered the pitch of *The Blue Danube* (Strauss II, 1866) and edited the structure to enable consistent rhythmic participation, such as clapping, and playing along on a standard harmonica in C. Having previously observed Sue's difficulty in holding maracas vertically and her propensity to reach out with her hand, palm down, I included D-bells that could be held horizontally and that I had observed Sue play several times with enthusiasm. I also included coconut shells that Ron had enjoyed.

Sue's move to the care home also meant that they no longer had shared access to equipment and instruments such as Ron's keyboard and their stereo. The only device available for playing recordings in Sue's room was through her talking radio via USB stick. Ron was reluctant to bring in another form of sound system that Sue could not operate herself. I put all the recordings onto two separate USB sticks for playing through the talking radio, accompanied by a small folder containing colour coded track lists and instructions for using the sticks with the talking radio, to encourage its use by other family members and care staff. Ron also asked me to transfer their courtship mixtape and a personalised CD for Sue to listen to in this way.

The communal lounge, where Sue was seated for much of each day, did not lend itself to comfortable participation between Sue and Ron. I transferred the 'Uplifting'

and 'Relaxing' recordings onto an MP3 player with headphones and a splitter for shared listening in the communal lounge. I also spoke to the care home manager, highlighting the resources that were available for Sue in her room and encouraging their use by care staff. Unfortunately, I omitted to take a photograph of the final resources to include in the thesis before giving them to Sue and Ron.

5.2.5 Review Session

On my return to the care home eight weeks later Ron had the customary selection of items ready for our attention, including redundant equipment and paperwork from the study and information and photographs to share. He led Sue and I in singing many familiar songs to demonstrate their musical sharing since our last meeting. Ron sang from a selection of lyrics that I had printed for use during one of our sessions that he had kept. Ron commented, "This is a pleasure to have Sue singing; I haven't had it for a while. I've had to sing for both of us" (S13, V1, 13:01). Sue spoke more than was usual for our sessions and reached out with her hand often, Ron commenting "She's always feeling for things" (S13, V1, 01:14:22). At one point, Sue and I conversed in birdsong.

We moved to singing a few songs from the folder of lyrics I left for Sue's room. During our singing, Sue drew my arm towards her, saying "Who is it?" (S13, V1, 36:57), to which I replied, "It's Ruby". "Come on, love" she said, as she drew my other hand to her, moving them both in rhythm to Ron's continued singing, and we re-joined him with our voices.

The familiarity of Sue's enveloping rhythm met my offered hand that sought to reciprocate her reaching one, moving to our rousing rendition of *Daisy Bell* (Dacre, 1892). Ron struggled to fit the words that I had written for the second verse. When we had finished singing, I asked the prepared questions (see [Appendix 11.20](#)) that I felt had not been covered by our participation. Ron made it clear, as he had done on several previous occasions, that our sessions had not met his expectations:

One of the comments I should make about the course, I made when you first started it, which is, that you'd left it too late. Our age and physical capabilities; we're past it...had you done it two years ago, it would have been better...I wouldn't say that we got an enormous lot of benefit from this; I enjoyed it and I miss it, but nothing much changed (S13, V1, 28:07)

Despite his reservations, Ron asserted that there was nothing he would have changed about the project, and when I asked what they had enjoyed most, he responded:

Ron: You! ...I suppose you could say that that's the opposite of what I said about 'you should start earlier'. You've come in at a time when I've been very glad of your company, because we don't see many people.

Ruby: ...do you think the music added something?

Ron: There needs to be a point in it really...if you'd come for the cup of tea and biscuits and the pleasure of my company...it wouldn't last as long, would it?

Upon enquiry about their use of each resource, Ron indicated that they had tried the MP3 player but could not get on with it, further indicating that he would not want to share recordings of music with Sue in the communal lounge. He had written several more verses to the hymn tune *Abide with Me* (Lyte and Monk, 1847/1861), and shared them with Sue. The reference folder, containing guidance from Playlist for Life (2019) and a list of sensory resources available for them to borrow from me had not been used. Ron said that they had played with the coconut shells and the D-bells a little, but "We don't really need an attachment to our singing. If we're singing, we're singing" (S13, V1, 01:13:11). He also indicated that he had bought Sue a harmonica, but "...she couldn't get on with it. Neither did I" (S13, V1, 56:54).

The USB sticks containing recordings of music and the lyrics folder had been shared in their entirety, and Ron asserted that he intended to continue sharing music with Sue in these ways, concluding "I tend to just pick things up and use them" (S13, V1, 01:04:15). Ron also informed me of an error in the track listing I had made for their mixtape USB stick. I left all the resources with them in case Ron or anyone caring for Sue wished to use them in the future and asked if there was anything I could change or add to them, to which Ron responded, "No, we're past it. I know it sounds terrible to say, but it's true. It's a downhill slope that we're on at the moment" (S13, V1, 01:15:38).

When asked if he thought that sharing music together was important, Ron answered, "It's very pleasurable, and I'm sure it's important to the point of the fact that music is part of our nature isn't it?" (S13, V1, 01:16:32). From Ron's responses, it was clear that his enjoyment of the music and activities they shared was important, and informed his choices of songs to sing with Sue (S13, V1, 01:17:20):

Ruby: ...so, if it's a song you like, you'll sing that one?

Ron: No, I ask Sue... "Shall we sing this one?" And if she says "No", we don't. If she says "Yes" we do and if she doesn't answer, we do [laughs]. I've always made the decisions. Sue not only accepts that, she wants that most of the time...I do it for her. She knows that and she's quite happy with it, aren't you love?

Ron did not believe that the project had supported them in sharing music in any way at all (S13, V1, 01:26:17):

Ron: ... I've wasted so much money on music, I don't need supporting...Sue's got the right point, she says "you're never, ever going to listen to all those". She's right, I won't. I just like having them.

Ruby: ...I just wondered if there's anything that we've done together that has given you...different ideas or helped you to see it in a different way, maybe?

Ron: ...I don't honestly think so. I've enjoyed what we've done, I've enjoyed doing things with you.

The completed feedback sheet that I received from Ron contained little information about their shared activities since our sessions that did not come up during our review session. However, backdated entries for music Ron remembered sharing with Sue before her move into residential care indicated they had tried singing together at the keyboard, something I had not been aware of. Ron's written comment on the activity was "Not very successful".

Ron was not aware of family members or care staff using the resources beyond one occasion he had heard of, when some of Sue's recordings of music were played for her and the other residents. I spoke to one of the care home managers, who reported that the USB stick recordings were played regularly for Sue during caregiving routines such as washing and dressing, as she could be agitated at these times, with caregivers sometimes singing along if they knew the song, and Sue laughing. Recordings were also played at the end of the day. I left the MP3 player and headphones with them to offer to Sue in the communal lounge, guiding a volunteer carer through the process of operation.

The impression I left our final session with was one of disconnection between Sue and Ron that manifested as the following word impression (see Figure 21).

Figure 21: Word Impression

*I have not gone away my love
Though I no longer appear the same.*

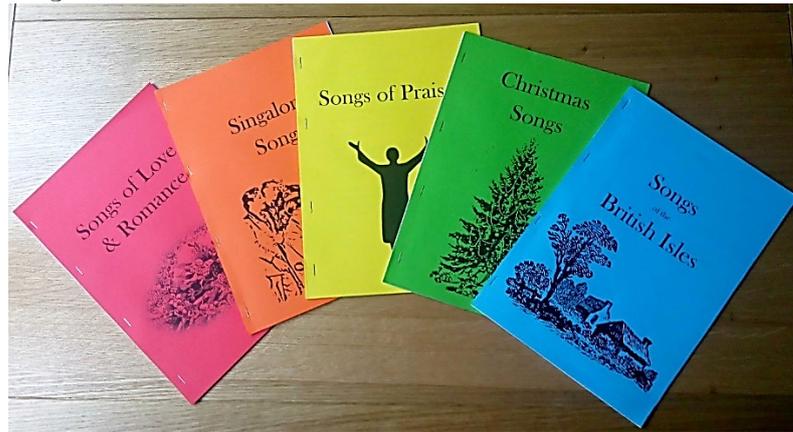
*Hold me close as you knew me,
But look for me with unfamiliar eyes;
Call to me with a favourite song;
Receive me with an open heart.
Here I am.
Take my hands,
And let the music move us closer*



Biographical picturing highlighted again my experience of Sue's strong relationship to touch that was still evident. I understood that reciprocal touch offered Sue the opportunity to engage in rhythm, movement and encounters with other people, and that music seemed to support this relationship to touch. I was also left with a strong sense of purpose in wanting to continue to work with Sue and Ron, to support music as a means for them to relate to one another and seek ways for Sue to continue to experience opportunities for musical movement into the future. As the resources I had offered to promote these forms of sharing had not been taken up, and our session contact was now at an end, I decided to write a letter to Sue and Ron highlighting some of the ways we had shared music during our sessions, the interaction and pleasure these activities had held for us all and the importance of touch for Sue. I repeated the offer of sensory resources to support these kinds of activity if they were wanted.

I recognised that the future potential for musical sharing between Sue and Ron most likely extended from their existing foundation of singing and listening together. To support their continued singing, I created a collection of songbooks (see Figure 22) containing lyrics to songs that were not included in the original resources, and that I knew or anticipated would be familiar to them, to augment their sung repertoire. I also indicated that websites could be used for sourcing further song lyrics in the future and sent Ron links to these in an email.

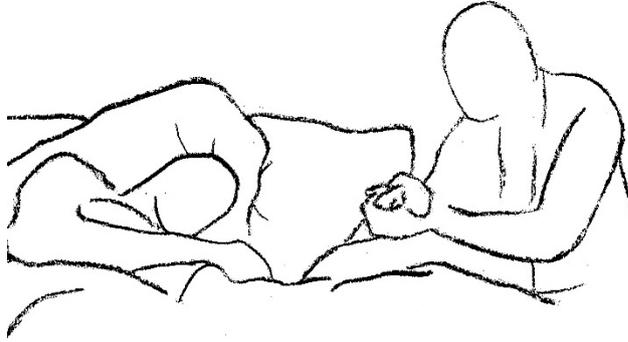
Figure 22: Songbook Resource



Their large collection of recordings of music offered a means for Ron to share something he enjoyed with Sue and to experience not just memories of the familiar, but also adventures into the unknown, as Ron had indicated they had not listened to it all before. Within the accompanying letter, I proposed that Ron could take a CD and tape player in to Sue, suggesting different themes or artists, such as ‘songs about flowers’ or ‘Ruby Murray’ to give structure to their ongoing sharing.

In response to indications from the session, I amended the personalised lyrics I had written for *Daisy Bell* (Dacre, 1892) to make them easier to sing, changed the lyrics to another song to match those familiar to Ron and corrected the track list for their courtship mixtape. I also created a DVD of the session highlights that Ron requested as a format that he could share with Sue and other family members, and a USB stick containing a recording of *Sue’s Joy* (my composition inspired by our sessions).

5.3 Jerry and Lynda



5.3.1 Background

Jerry and Lynda shared a Celtic heritage, Scottish and Irish respectively, and a lifetime of companionship and music since the early flush of young love in their teenage years. Traditional Irish singalongs with Jerry's family cultivated in him a love of rebel songs and welcomed Lynda into the aural tradition, instilling in her the words to time-honoured classics. From singing in a Roman Catholic church choir as a boy, Jerry's singing continued to accompany his favourite listening to recordings of Irish folk, American Country and Rock and Blues in the house and car, sharing his love of bands and artists such as *Red Hot Chili Peppers*, *Nirvana* and Eric Clapton with his children.

Lynda and their daughter provided me with comprehensive information on Jerry's biography, and I quickly compiled long lists of bands, artists tracks and songs that illustrated the significance that music had played in his life. His appreciation of the guitar cultivated in Jerry admiration for skilled playing, and a particular fondness for Django Reinhardt. Having tried to learn guitar, he satisfied his appetite for participation in rock music by developing his own unique style in vocally mimicking recordings of guitar solos, and dancing to his favourite music. Although Jerry could no longer participate in these ways and spoke very few words, he still shared enjoyment of listening to recordings of music and watching TV concerts together with Lynda when we met.

5.3.2 Experiencing

My visits to Jerry and Lynda came at the close of Jerry's life. Following our initial meeting, we shared one session before Jerry's death, and I was deeply honoured to be invited to share in this precious time. I felt that I was walking into a space in time, where the linear progression of life had enfolded to hold Jerry and his family during his final days; a pause on the inbreath of life. Embraced within the courageous positivity of his close, loving family circle, who actively attended to his needs and comfort, Jerry frequently moved between awareness and disengagement, often sleeping.

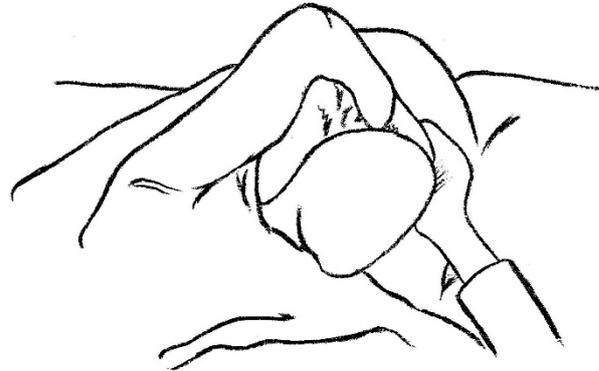
At our initial meeting I was struck by my first encounter with Jerry. His presence belied his physical frailty, and shone through his sure, steady gaze that greeted me more surely than words. Lynda, quick in understanding and speech was alert and attentive to the subtle changes in Jerry and his environment. Although our limited time together meant that we did not verbally establish Lynda's hopes for the study, her purpose in caring for Jerry was evident through her selfless actions and words. She clearly upheld and respected Jerry's personhood and sought to bring him joy and find connection.

Following our discussion of the study and gaining consent, we decided to listen to a few recorded tracks in recognition that the time we had together in the coming weeks was uncertain. Lynda sang along intermittently while making gentle rhythmic hand movements to a familiar recording of Josef Locke. Towards the end of the track Jerry subtly mouthed the words. Frank Zappa received no response from anyone, whereas a recording of Jimi Hendrix received a thumbs up from Jerry when Lynda asked if he had enjoyed it. A favourite track of Jerry's recorded by Leonard Cohen concluded our listening, interwoven with Lynda's occasional singing and Jerry's breathing falling in restful harmony with the regularity of the rhythm.

Jerry's presence appeared to have waned when I returned for our first and only session, making little eye contact. He moved fitfully between sleep and physical restlessness, frequently moving his hands to the top of his head (see Figure 23), while Lynda bravely brushed aside her weariness with a cheerful smile. In the quiet environment the hum of the electric bed, noises in the house and the sounds emitted

from unpacking and moving musical instruments sounded conspicuously loud and intrusive.

Figure 23: Jerry Moving His Hands to His Head



We began by experiencing the tone of two singing bowls, one higher, one lower. Jerry physically turned away when I played the higher bowl, shaking his head when asked if he liked the sound, that evoked church bells for Lynda. Jerry was supported by Lynda in shared playing of the larger, lower bowl, pointing out that in rhythmically striking it several times, Jerry was being “co-operative” (S1, V1, 15:29) rather than enjoying the experience. The ocean drum (see [Music Glossary](#)) invited Lynda’s experimentation, finding her way through enjoyment of the sound into subtle motion to elicit the sound of “waves coming into the shore” (S1, V1, 13:40). Lynda’s participation continued, singing intermittently to another recording of Josef Locke while Jerry appeared to doze, remarking “That’s bringing back memories of his mother for *me*” (S1, V1, 19:13).

To my unfamiliar senses, Jerry appeared to continue sleeping through a recording of another Irish singer, Mary O’Hara. However, Lynda encouraged me to continue playing recordings, as she saw a response in Jerry: “I didn’t recognise it [the song], but I thought I saw a flicker there” (S1, V1, 28:44). I found myself heavily reliant upon Lynda’s sensitivity to subtle changes and reactions in Jerry to gauge how to respond to him. At times, this reliance engendered a fundamental shift away from the ‘doing with’ of sharing, exploring and enjoying music to a ‘doing to’ of looking for the effect music was having on Jerry.

We continued our listening with recordings of hymns traditionally arranged for choir and organ. I chose a rendition of a Catholic hymn that featured boys’ voices, potentially a familiar arrangement for Jerry from his time as a choir boy. Despite

Jerry being a “lapsed Catholic” (S1, V1, 37:04), the hymn did not appear to evoke unpleasant memories, as Lynda observed “He’s very relaxed, isn’t he? Very relaxed...” (S1, V1, 32:31) and “If you put something on that he hated, you would know I think” (S1, V1, 33:18). Restlessness slowly disturbed Jerry’s relaxation as movement increased in his limbs that was at odds with a slow Irish air, recorded by a favoured band, the Chieftains. This activity gave the impression that the recording was a peripheral experience for Jerry compared to the dominating experience of his physical condition and restlessness.

An Irish rebel song that Lynda identified as a favourite of Jerry’s, introduced our singing with lyrics. Lynda and I serenaded Jerry; whose movement gradually stilled. Following both this song and my rendition of a traditional Irish lullaby, Jerry gave a slight nod in affirmation of his enjoyment when Lynda asked. During our singing, Jerry finally managing to reach and take Lynda’s lyrics sheets to hold and look at, illuminating the unrecognised purpose of a repeated reaching arm movement. Lynda expressed the opinion that Jerry had enjoyed the singing most of all, asking “Did you enjoy the singing?” (S1, V1, 54:21), to which Jerry nodded.

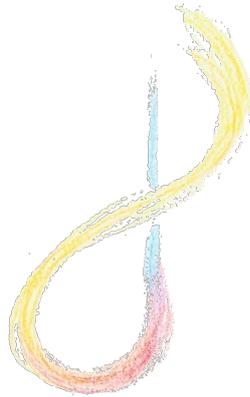
As I packed away, Lynda encouraged Jerry to try the ocean drum once more and spontaneously sang, trying to remember Irish songs that she and Jerry knew for singing in future sessions. I hummed a song from the session gently as I continued to pack up. Lynda gradually joined me, and we found our way naturally back into singing together.

5.3.3 Understanding

The germinal impressions that arose from our brief time together, recognised Jerry as tired, fragile and needing to be held in the love that encircled him, yet exerting an effort of will to be present with his family and to cooperate, maintaining a strength of presence.

The family’s surrounding warmth meeting Jerry’s resilience can also be seen reflected in the colour impression resulting from our initial meeting (see Figure 24).

Figure 24: Colour Impression



Lynda's unwavering focus on being there for Jerry resulted in my having a much sketchier picture of her relationship with music and her hopes for the project. My impression of her unstinting efforts to let Jerry know of her presence, and to comfort, reassure and connect with him inspired the following words during my session picturing (see Figure 25).

Figure 25: Word Impression

Nested in sweeping waves of long grass

I know you are near

I walk the paths that belong to you



From this impression, understanding formed of the potential for musical activity to support Jerry in moving from presence and restlessness into finding rest, and as a medium for Jerry and Lynda to find connection with each other.

5.3.4 Creating

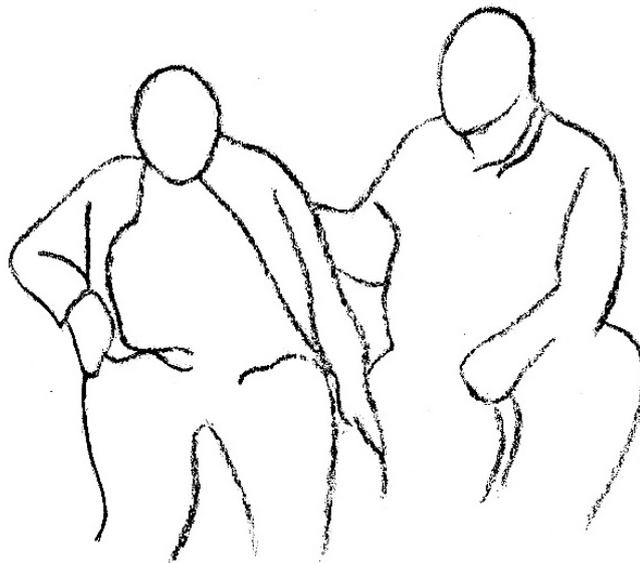
To explore the possibility of finding connection through music for Jerry and Lynda during our first session, I offered song lyrics that were possibly familiar to them both, and the singing bowls and ocean drum as instruments that would be potentially easy to sound and share. Both these forms of music-making create simple sound-spaces that are potentially more restful than complex recordings of music, especially genres such as rock, with the possibility to support Jerry in finding rest.

When choosing recordings of music to listen to, I took gentle, familiar music, free from a strong pulse, as a starting point to gradually lead into exploration of the less familiar. I deemed the latter half of the playlist inappropriate to play during the session, as it contained more rhythmic and complex recordings that I felt might be unsettling for Jerry in his restlessness.

In anticipation of a second session, I planned to explore Jerry and Lynda's relationship to the Celtic through opportunities for creation and connection in rhythm, singing and other sensory activity. I hoped to include exploration of vision and touch in response to Jerry's desire to hold the lyric sheets and his past enjoyment of gardening, the theatre and cinema.

I invited Lynda to participate in a review session, to share our thoughts on our activity. I received no further contact from Lynda following the session and the offer of a review session after eight weeks was not taken up.

5.4 Dorothy and Chris



5.4.1 Background

For Dorothy, Chris' mother, music had been a modest companion, playing a supporting role to other leading pursuits of life. During her formative years, singing in church, school and gatherings around a neighbour's piano and later, occasional

concerts, dancing with friends and ballroom lessons. At the time we met, Dorothy enjoyed dancing vicariously through TV's *Strictly Come Dancing*, along with televised musicals, *Last Night at the Proms* and recordings of music from the war years featured in programmes. Within the family home, musical instruments and recordings were heard over the years, with Chris learning the guitar in his youth and his brother learning the harmonica. A collection of LPs served as reminders of enjoyed listening from the past, but no longer played and lying dormant. At the prospect of exploring musical activity during weekly sessions, Dorothy responded, "I don't mind it, yeah, but I don't know about a long slide of it, if you know what I mean" (S1, V1, 28:28).

For Chris, music had played a supportive role; "...music has made my life a hell of a lot more bearable and helped me cope with a lot more things and brought a lot of joy to my life" (S1, V1, 29:02), giving rise to his hopes that it might become supportive for Dorothy through participating in our sessions, as a medium for sharing and as a tool for daily life, that eventually might offer support for other people in similar situations. Specifically, Chris expressed a hope for tools and things to do together that 'work' in the way the company of Dorothy's canine soft-toy companions did, which were no longer toys in this context.

Chris' love of rock-music endured over the decades and he still enjoyed attending concerts and listening to recordings within the privacy of his own space. Sharing music beyond their joint appreciation of TV programmes featuring recordings and singing competitions, our sessions explored a new relationship with music for both Dorothy and Chris.

5.4.2 Experiencing

Our sessions introduced the unfamiliar and, at times, the uncomfortable, to a relationship, roles and patterns of behaviour forged over their lifetimes, yet Dorothy and Chris both greeted my endeavours graciously and willingly. My visits usually found them both amiable and relaxed, winding down after a family outing and warming to my company over a cup of tea. Chris, attuned to the comfort of others, attended with kind consideration to our practical needs, and reassured Dorothy when the interplay of objects, light, shade and colour conjured seated strangers or objects in

our midst. Vibrant colours and contrasts often drew Dorothy's attention: cars parked on the road outside, coloured light from my equipment, a red maraca. Flowering plants on the windowsill sparked ruminations about the process of digging them up and their variations in colour.

Exploration of simple musical instruments eased us amiably into sharing sound during our first session. Chris tried different ways of interacting with his frog-shaped guiro, embracing sound experimentation and encouraging Dorothy to join him. Dorothy, attentive to the subtleties of slow experience and the uniqueness of her delicate sound amidst ours, discovered her own approach to playing the singing bowl. Her drawing of the ringing stick lightly across the rim to create an ethereal chime contrasted with Chris' more conventional techniques of striking and resonating. Dorothy's gentle touch elicited the ocean drum's voice in circular strokes of its skin, with a tidal authenticity often disjointed in first encounters with this instrument.

Family LPs gave us a starting point for familiar listening, from The Military Band of the Royal Scots Dragoon Guards and Glenn Miller, to The Kinks and Simon and Garfunkel. Sharing album covers enhanced Chris' childhood memories of hearing them played. At first, Dorothy appeared to have no observable relationship to recordings of music beyond the occasional comment or facial expression. However, over time I came to notice that an alert attentiveness, her head indistinctly animated, often accompanied Dorothy's perceptive awareness, and infrequently occurred during listening to music. Our sensory adventures in recordings, touch and image could summon memories into lucid presence through Dorothy's clear depiction of remembered people and places. Dorothy's pronounced breath as a verbal preface and her slowness of speech and physical movement, all bore witness to the effort and intention demanded by activity. This intensity of presence receded into vagueness and uncertainty, often through the fog of tiredness and fatigue, accompanied by the impalpable trawling of memory for an elusive word or name that at other times tripped off the tongue.

Time took on a fluidity in Dorothy's company; a stream that pooled generously during physical movement and amply accommodated a lengthy pause. Meandering leisurely downstream, past and present converged in eddy and play, and the tide marks of memory provided bearings in the current beyond the usual demarcations of hours and minutes. Shared objects were often held in equilibrium above the cool

depths of memory, a sleepy backwater beyond the flow of the present, only to be caught in the pull of the moment by a nudge of encouragement to become sensible of the weight in her hands.

Objects such as wartime medals, a Player's Navy Cut cigarette packet and silver sixpences, accompanied by recordings from Glenn Miller, George Formby and other wartime artists, provided a rich environment for exploring earlier memories for Dorothy, who remarked: "It is nice to hear all that though, isn't it?" (S2, V1, 29:24). Chris prompted his mum with questions and snapshots of family history gleaned over the years, with Dorothy becoming more clearly articulate in her recounts of the past as we three freely conversed.

Memories of Scotland and the seaside shared by Dorothy and Chris gave scope for reminiscence with images, shells and recordings. Laughter erupted to recordings of amusing songs and comical noises from our experimentation with a bagpipe practice chanter (see Music Glossary) added to the humour, with Chris' tones becoming varied, and Dorothy's rapid and rhythmic. Playfulness initiated rhythm with coconut shells, with Chris taking the lead and me following. An ocean drum emulated the sound of the sea, and a recording of the ocean provided a backdrop for my singing of a traditional Scottish sea song, to which Dorothy and Chris quietly listened.

The experience of diverse artistic images and recordings of classical music on the theme of 'water' formed a tributary of our seaside memories, and provided opportunities for Dorothy and Chris to profess both appreciation and dislike for aspects of images and recordings, as well as further instrumental exploration.

Amplifying Dorothy's ocean drum articulation with a flat brush, we experimented with creating sounds suggestive of water, the fitful interplay between Dorothy's ocean tide and Chris' maraca ballasted by my undulating chordal plucking on the lyre (see Music Glossary).

We shared images and recordings from musical films familiar to Dorothy and Chris, including *The King and I*, *Meet Me in St. Louis* and *Wizard of Oz*, with a recording of a song from *Brigadoon* finding particular favour with Dorothy as "nice music" (S3, A1, 53:47). Images from the film *The Third Man* and its soundtrack feature instrument, the zither, introduced play on similar instruments, with Dorothy and Chris exploring an open chord together on the lyre while I kept a regular plucked chord on the guitar, lulling Dorothy to sleep.

Our musical explorations awakened memories as our sessions progressed. For Dorothy, seemingly asleep, memories of her brother were stirred upon hearing sung fragments of songs from her youth. Chris rediscovered treasures lost to adult life in the songs recalled from his own childhood and memories of Dorothy singing to him. Such experiences nurtured Chris' inspiration and enthusiasm for our endeavours, prompting him to share family photos, a Swiss cowbell from his Dad's travels, a calling bell kept in the house and ideas for avenues to explore, such as recordings of spoken guided imagery with music, and birdsong with images.

Exploring elements of the natural world enriched many of our sessions, with both Dorothy and Chris having a fondness for nature. Dorothy's affinity to flowers and love of gardening led us to share flowers on several occasions. She gave the blooms her close attention, holding and moving them to look at their various aspects and remarking on difference and uniqueness. We appreciated the 'elegance' and smell of a single red rose to the melancholy romance of strings that introduced Dorothy's 'nice music'.

In response to Chris' ideas for guided imagery, we explored a combination of sounds, recordings of music, narration, singing and images in different forms. We enjoyed soundscape recordings that evoked nostalgic scenes such as the clinking of bottles and distant whistling of milk being delivered and a peal of church bells introducing songs of worship. Echoing the owls heard from their home at night, we played an owl pipe. Chris emulated a hooting call, Dorothy blew a strong, staccato rhythm, and I cupped my hands to blow a tonal hoot. A duck whistle introduced humour with Chris' spirited duck impression, followed by Dorothy sounding a long initial quack that hatched a brood of smaller quacks of greater and lesser degree, leaving us all laughing. Songs about birds afforded opportunities for listening to recordings and singing accompanied by my guitar. I invited participation from Dorothy and Chris with printed lyrics to sing along to. My singing lulled Dorothy to sleep and Chris commented: "It was lovely that was, it was beautiful...it's so...relaxing as well to listen to someone sing...such a gentle song" (S5, V1, 32:26).

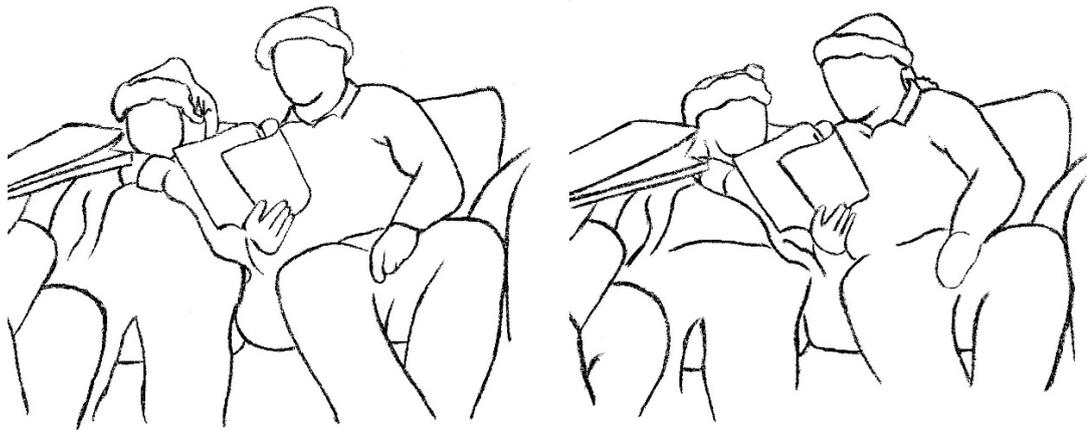
During our early sessions, I sang songs with guitar accompaniment likely to be familiar to both Dorothy and Chris, joined in with snatches of recordings that we listened to and spontaneously sang songs that came up in conversation. This offered experience of live music as well as recordings, and as a means of gradually

introducing singing, in response to initial indications from them both that this was an area they would like to explore. As singing together did not develop organically, I spoke about singing as a means of interacting and expressing and highlighted its potential beyond musicianship. Our fourth session welcomed singing as a deliberate activity, initially off camera, as both Dorothy and Chris appeared apprehensive. Dorothy commented laughingly, “Well, I wouldn’t want to make anybody...awkward” (S4, V1, 16:47). After singing familiar songs together, Chris later reflected, “It’s great to hear you singing Mum, it’s fanta[stic]...I can’t remember a time when I’ve head you sing actually...unexpected really” (S4, V1, 45:11). By the end of our sessions, Chris indicated that he had enjoyed singing the most of all our activities.

Finding a comfortable range for songs to suit both Dorothy and Chris was challenging, and recordings did not always lend themselves to our singing along with for this reason, especially church hymns. We also found that the structure of some recordings of songs featured long instrumental breaks and sections with unfamiliar melodies or words, disrupting participation. We experimented with easing ourselves into singing, by humming, then la’ing the tune before adding words. Chris observed this to be an effective lead into singing. Despite challenges, self-consciousness was quickly shed as confidence grew and we came to sing together regularly. Sometimes we sang to guitar accompaniment or recordings, at other times a cappella. Chris borrowed an acoustic guitar from me to explore the possibility of revisiting chords from the past to bolster their singing.

Dorothy did not always join in with Chris and I, but the songs that she did sing were usually those instilled across a lifetime, and were equally familiar to Chris. When asked if she had enjoyed the experience after we sang *Loch Lomond* (Unknown composer, c. 1841), Dorothy responded assuredly “Yes, I did...It isn’t always that you get a song that you...really like” (S5, V2, 17:44). As the nights drew in, Dorothy’s singing became a welcome Christmas gift as our unaccompanied rendering of *White Christmas* (Berlin, 1942) brought a moment of connection between Dorothy and Chris, who, looking up from their songbook, turned to each other in song (see Figure 26).

Figure 26: Dorothy and Chris Turned to Each Other, Singing



As well as an accompaniment to sensory activities and singing, recordings of music also invited our rhythmic participation and movement at various times. Sustained, coherent or enjoyable activity did not always accompany lively tracks, with excursions on percussion instruments or harmonicas often fizzling out or not getting off the starting blocks. However, on one occasion, we quickly drowned out a recording of djembe (see [Music Glossary](#)) drumming. Dorothy and I struck a shared bodhrán (see [Music Glossary](#)) with maracas in responsive interplay, and Dorothy led with changing regular rhythms. Chris, engrossed in the groove between his bongos and the drum track, gradually became aware of our rhythms and regulated his playing responsively, long after the recording had finished. Another occasion saw us moving with coloured scarves and bells to a recording of country dance music, Dorothy's arm constant in gentle vertical motion, while Chris found his initial vigour unsustainable. I offered my hands and we all moved our arms together to the music until our aching arms failed us (see Figure 27).

Figure 27: Sharing Seated Dance



5.4.3 Understanding

Through my memory picturing of sessions, I came to recognise and appreciate Chris' enduring kindness and patience that bridged the time shift between the pace of life in the world outside and that within their home, and that bolstered our musical endeavours. There were occasions when Chris participated in activities that were uncomfortable for him. He braved this discomfort to support opportunities for Dorothy's participation in musical activity that he hoped might promote recall, engagement and memory.

My biographical picturing drew my attention to both Dorothy and Chris' relationship to music, highlighting Chris' inclination to light up at the mention or hearing of music and recordings he knew or liked. Dorothy's expressed preference for flowing, gentle musical qualities stood in contrast to her participation along to recordings that were often lively.

Combining recordings of music with other sensory activity such as movement, objects and images provided a focus that grounded activity in the present moment and often engendered a presence and clarity in Dorothy's demeanour and speech. I recognised the significance of Dorothy's relationship with the world through touch and sight, which is acknowledged in the following receptive word impressions (see Figure 28).

Figure 28: Word Impressions

Strong, sure hands
A lifetime of running through soil
Lifting vegetable from the earth
Stripping leaves and cupping fruit
Soothing skin, smoothing fur

The eye leads the hand in gentle caress
A tender attention to form, expressed
In colour and shade

❧

❧

Hearing music without such a focus appeared to enhance the passive fluidity of Dorothy's relationship to time and memory, creating a timeless space within which her awareness of the present approached and receded. I captured this impression of Dorothy in words following our first meeting (see Figure 29).

Figure 29: Word Impression

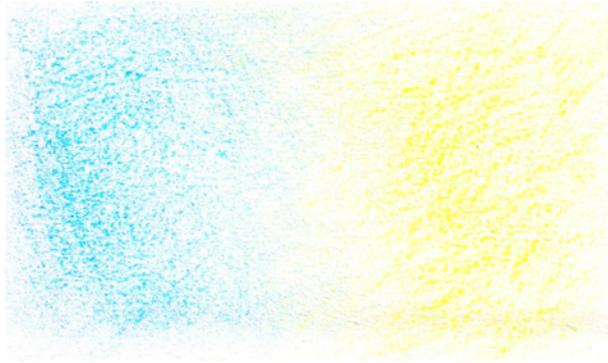
Drifting easy on the tide.
Golden sun tipped crests dance the blue depths.
Memories surge and recede
Free of time, flowing with mine
Pooling clear on the shore.

❧

Introducing sensory change, such as clipped rhythms and increased tempo of a song or a visual or tactile stimulus, could interrupt this flow of memory and engender Dorothy's presence and participation.

In the company of Dorothy and Chris I experienced an amiable willingness to participate and to oblige me as their guest, coupled with a cardinal appreciation for peace and comfort. This was an impression reflected in an early colour impression, where the warmth of willingness meets the coolness of the unchanging (see Figure 30).

Figure 30: Colour Impression



Sustaining familiar, comfortable patterns of activity and interaction through the changes that life had brought, appeared not to offer the means to connect and share life in the ways they once did for Dorothy and Chris. I came to recognise the potential to venture beyond the stasis of long-established patterns of relationship by meeting willingness, uncertainty and self-consciousness with clear and certain starting points that held the possibility of enjoyment. At times, these activities fell flat. At others, they sparked the fire to explore new, harmonious experiences and ways to relate to each other and our environment. I expressed this observation in the form of a word impression (see Figure 31).

Figure 31: Word Impression

Melodies' gentle breeze
Awakens emotion
Stirs flurries of remembrance
Kindles embers of enthusiasm



Chris responded to our activities with imagination and enthusiasm, seeing the potential for musical engagement and offering up ideas to try. Exploring our ideas not only led to new experiences and created opportunities for the unexpected, but also new ways to share the familiar and a contentment in serenity that can follow activity, distinct from the equilibrium of disengagement. I observed a new openness and energy in Chris over the course of our sessions as he became reconciled to the need for a relaxed pace and change to their routines in response to the changes that Dorothy was experiencing. This accompanied an increased willingness to share and participate in exploring sensory activity for Chris. My emerging impression of this development of movement from equilibrium is expressed in the following musical

impression, in which the stasis of hesitancy is animated in decisive melodic ascent that leads into new tonality (see Figure 32)

Figure 32: Musical Impression



Singing familiar songs together emerged as one of the most significant ways that musical creation flourished through the cycle of our sessions. The singing of Chris and I could sustain Dorothy in intermittent participation or carry her away on the tide of sleep, with both Dorothy and Chris displaying appreciative warmth for the other's singing and enjoyment in participation. Over time we all appeared to become more comfortable, both with ourselves and each other through singing. We moved from accompanied singing to unaccompanied and Dorothy came to participate more in her own time, with less prompting from Chris. For my part, the development of our musical relationship engendered experiences that I expressed as essential words:

warmth, harmony, affection, rapport, trust, privilege

Towards the end of our cycle of sessions, I experienced a readiness for their conclusion to make way for the next stage of exploration, for which I was no longer needed. This impression was echoed by Chris in our ongoing discussions and by the following receptive word impression of Dorothy and Chris venturing into the unknown (see Figure 33).

Figure 33: Word Impression

*Cast the boat off from the shore
We'll bob along together
You can steer, I'll take my turn
And find us shelter in bad weather
We'll be guided by the stars
To distant unfamiliar lands
Where I can lead and take your hand
To find our way together*

**∞*

5.4.4 Creating

In developing session content for Dorothy and Chris, I followed up on indications arising directly from their individual backgrounds and our experiences together, and my understanding and ideas arising in response. Dorothy's gentle, sweeping touch on the ocean drum suggested the use of brush on drum skins and the strum of an open lyre chord. Her strong, sure breath producing rhythmic tone with the practice chanter, supported by Chris, illuminated the prospect of blown instruments, leading to our trying harmonica and bird whistles. Many avenues of exploration were not fruitful but served to delimit the bounds of what enjoyable shared activity could be for them at that time and refine resources accordingly. These included experimenting with colour to recordings of music using wax crayons, leaves and textured image rubbing plates; exploring textiles in light of Dorothy's past enjoyment of sewing and knitting; and Chris revisiting his past guitar playing.

In developing resources to leave with Dorothy and Chris, I offered recordings, objects and ideas that reflected my understanding of the importance of familiar music and recordings for Chris and the role that they could play for Dorothy in eliciting memory and promoting participation. I was also keen to involve Dorothy and Chris, as much as was possible and desirable for them, in the development and production of the resources, which I did through continuous consultation and observation, working with all verbal and experiential feedback from our session exploration and offering frequent opportunities for involvement and the contribution of ideas.

Because Dorothy and Chris' time together was limited during the week as was Chris' time for relaxation, it was clear to me that resources needed to be easily initiated, carried and enjoyed by Chris. In designing resources, I tried to offer clear definite starting points to give tangible support to activities with suggestions for further exploration. I was careful to keep suggestions free from specific outcomes to offer opportunities and space to allow for and encourage responsiveness, spontaneity, imagination and creativity. In shaping the resources, I tried to balance offering a breadth of possibilities with keeping them simple and appealing to use. I pared them down to what I hoped would be enough to sustain activity over time and to provide a basis with the potential to inform and stimulate Chris' imagination and creativity in developing new avenues for exploration, which I felt could be stifled if I provided too

much. I hoped that engaging with these resources would convey the potential I had felt unable to convey verbally, that of musical participation offering opportunities for being present, for memories and starting points for new journeys to explore their own ways forwards.

Many of the recordings, songs, images and activities included in the resources were developed and incorporated in response to Chris' ideas and contributions during our sessions. Chris also voluntarily contributed to the practical resources for exploring music beyond our sessions by purchasing a boombox and streaming subscription for listening to recordings of music in their shared living space downstairs.

I developed a range of options for Dorothy and Chris to try during our first tentative steps into singing together during our sessions. I prepared lyric sheets and chords for my guitar accompaniment of shortened well-known songs to choose from. I sourced contextually authentic-sounding recordings of common hymns and hymn accompaniment that Dorothy was likely to have heard in her youth, for singing along to with lyrics.

Because of their difference in age, much of the music that we explored was not familiar to them both, and it became apparent that I would need to compile a list of music that they both enjoyed and knew well for them to sing together, which I often worked on with Chris during times that Dorothy fell asleep or was busy with visiting caregivers. These lists eventually became songbooks of lyrics, grouped as Traditional, Popular and Praise (see Figure 34), that held the potential to support and broaden their singing together by offering the security of a visual focus and an aid to memory.

We experimented using commercial recordings and instrumental tracks as a backing for singing. I decreased the level of support over our sessions, to see what was most comfortable and preferred. I found that many existing commercial recordings were more suitable than others for singing along to as an activity for various reasons:

- the obscurity of lyrics and/or melody of verses to songs with well-known choruses;
- the version of the song or artist being unfamiliar;
- the pitch range being too high or low;
- the tempo being too fast to keep up with;

- the number or complexity of words and combinations difficult to manage;
- the complexity of the orchestration, e.g. clear melody line.

For these reasons, I decided that recordings of songs tailored to Dorothy and Chris would be the most supportive option, given Chris' indications that recorded accompaniment for singing would be helpful. I created a DVD to accompany each songbook (see Figure 34), featuring footage of me singing each song to offer my visual presence, with the loan of a DVD player to watch them. I extracted the audio from the footage to create CDs (see Figure 34) providing corresponding track numbers on the lyric sheets for ease of navigation. I tried to infuse energy into my renditions of the songs to encourage Dorothy's presence for participation and sang through the first section of each song to 'la' before introducing the lyrics to help ease the transition into singing. I listened back to our recordings of session singing to establish a comfortable pitch range for them both. The overlap between their ranges for shared singing was limited, necessitating the transposition of many songs and careful consideration of key for songs with a broad range.

Figure 34: Songbook Resource



Chris' suggestion for guided imagery recordings evolved through trying out prototypes, including a narrated village journey and a scripted story with songs to sing, before arriving at sound and music 'soundscapes'. These recordings emulated sound environments such as the chatter, laughter and play-songs of a schoolyard. The intellectual verbal concepts of a recorded narrative were abandoned in favour of evocative sounds with accompanying images, sensory objects and colourful, tactile instruments, included in the resources to leave (see Figure 35 below).

Some of the scenes were related to specific memories, such as the duck pond, piano singalong and church, features of Dorothy's childhood. Other scenes were more universally reminiscent, such as of the seaside and milk delivery. Each soundscape was intended to be played on a loop whilst sharing the corresponding image and sensory object or instrument (see Table 10).

Table 10: Soundscape Scenes, Sensory Objects and Instruments

Soundscape and image		Object or instrument
Milk Delivery	-	Whistling
School Yard	-	Singing
Circus	-	Slide whistle
Duckpond	-	Duck whistles
Farm	-	Cow bell & sheepskin
Seaside	-	Ocean drum
Church	-	Singing
Piano Singalong	-	Singing
Woodland	-	Owl shaped hooter

On the reverse of each image, sensory suggestions were provided to prompt the sharing of objects and instruments and to offer ideas for other ways to explore the senses, music and recordings, including details of thematically related tracks to listen to through the streaming music service. These suggestions were intended to promote exploratory experience, participation and playful interaction through the familiar, free of a predetermined outcome.

Images formed a basis for several musical resources to potentially complement and enrich Dorothy's prolonged enjoyment of colour and visual detail and provide opportunities to share in these experiences with Chris. In selecting images, I was

guided by the type of content preferred by both Dorothy and Chris, who shared images from magazines with me. I in turn brought images to them accompanied by recordings of music, including copies of fine art, posters, photographs and drawings. All these image types ultimately featured in the resource packs, with jigsaw scenes being most prominent as their detailed composition offered a wealth of material for Dorothy and Chris to share. Memories evoked during our sessions also provided inspiration for images such as seeing hot air balloons take off, as did preference for certain features such as animals and flowers. Aversion to features, including views from a height and dramatic scenes with the potential to cause consternation, also informed image selection.

Marrying images with recordings of music provided opportunity to create sensory environments to promote activity and relaxation in response to Chris' suggestion of morning and evening listening. For the 'Relaxing' resource, pastoral scenes of the British countryside and homely images lent themselves to being accompanied by recordings of music with pastoral associations and slow, sleepy songs. In contrast, cheery busy scenes of daily life, a working harbour and bustling village street, were coupled with animated recordings to form the 'Waking' resource.

Complementing Dorothy's enjoyment of visual colour, recordings of music provided opportunities to experience a palette of mood and emotion with vibrant images, constituting the 'Colour' resource. Images of activity and participation such as dancing and sports enhanced lively rhythmic recordings with the potential to engage in rhythm and movement with the coloured scarves, flags, D-bells and banana shaker included in the 'Active' resource (see Figure 35).

Figure 35: Scarves, Flags, Objects and Instruments



When selecting songs and recordings for the resources, I drew upon the those enjoyed by Dorothy and Chris that came to light during our sessions, such as Dorothy’s ‘lovely’ sweeping, dreamy, romantic strings, musicals, wartime hits, ‘crooners’ and Simon and Garfunkel and pieces featured in Last Night of the Proms. To aid selection, I brought possible recordings to sessions for feedback and to observe responses. The recordings for the various resources were presented as CDs, which could be used independently and accompany other activities of daily life, and be shared with visiting care givers and other family members (see Figure 36).

Figure 36: Image-Based Resource CDs



In response to Dorothy’s fluid relationship with time and memory and our shared enjoyment of reminiscing with music, recordings and objects on various themes such as wartime, images with the potential to foster sharing of specific memories that had arisen during our sessions formed the basis for a ‘Memory’ resource. Lyrics to songs well known by them both and with a thematic relationship to the images were integrated to promote more spontaneous, unaccompanied singing than that offered by the songbook resource. I incorporated poetry and recording suggestions for the streaming service to extend the activity into exploring other memories and new experiences.

Dorothy’s love of gardening, once a daily part of her life, inspired a ‘Garden’ resource, which, like the ‘Memory’ resource, integrated nature-inspired poems and well-known songs for singing with garden images through the seasons. The resource included a ‘Sensory Ideas’ sheet, featuring suggested further listening on the theme and indoor sensory gardening activities, such as sharing the feel, smell and taste of unprepared fruit and vegetables.

In organising the resources for practical use, I colour coded groups of A4 laminated image and text sheets and corresponding CDs, and compiled all grouped sheets within a folder divided by coloured clips, with a colour key index and CD track lists (see Figure 35).

Figure 37: Image Folder



I included a wooden stand for displaying sheets to enable hands to be free for activity and created a 'flip board' to hold individual packs or selections of images and text sheets, for ease of viewing and sharing (see Figure 38).

Figure 38: Image 'Flip Board' on Wooden Stand



We explored the possibility of making resources available for Dorothy to use when on her own and the potential for visiting care givers to share them. With this in mind, I designed the resources so that Chris could leave them out during the day if desired, with the possibility of creating a sensory tray or table of objects, instruments and selected images on the 'flip board', displayed on the stand, that could be accompanied by a CD.

5.4.5 Review Session

Upon meeting after a break of twelve weeks, Dorothy appeared initially wary of my presence, with a defensive tone I had come to recognise from professional carergiver visits during our sessions. Both Dorothy and Chris appeared rested and quickly warmed to me again in their familiar relaxed, friendly manner, reinforcing my previous impressions of their calm, quiet, gentle placidity.

Chris guided us through activities they had shared, briefly playing several of the instruments and commenting that Dorothy had shown no interest in the scarves when they tried them and he had not felt inclined to use the flags or instruments much; “I find the musical instruments less useful really, ‘cause ...unless you’ve got a certain skill, you can’t really create anything that you’re going to want to listen to for a long time” (S12, V1, 53:18). Chris indicated that the recordings of music complemented sharing the images; “I think it adds a lot, yes...a bit of...atmosphere, the music itself provokes memories...To be honest, if you sit Mum down, she’ll probably go to sleep eventually anyway... it just seems like a nicer way, providing a nice atmosphere” (S12, V1, 26:55).

He played the ‘Relaxing’ resource CD, selecting several images enjoyed from various resource packs that were united in their detailed, colourful depiction of homely scenes and nature, and shared one with Dorothy (S12, V1, 11:34):

Dorothy: Isn’t that nice

Chris: There is always an immediate reaction with some of these scenes, with the colours and everything

Chris had completed log entries for eight occasions of musical activity they had shared during our break, each indicating that images with CD listening had been shared in varying combinations, and occasionally with instruments, scarves and flags. Only in one instance were images omitted. Not only did the images and recordings provide material for shared time together, but also took on a purpose in their lives. According to Chris (S12, V1, 06:10):

...sometimes...I’ve stopped everything and done it ‘cause I thought it would perhaps ease Mum’s anxiety...get her focussed and it has really. And I think it’s worth the time to sit down and do it rather than Mum...doing what she usually does and perhaps getting more anxious as time goes on...

Singing had not formed a part of their activity during the break, and Chris indicated that this was something he would still like to try, but felt uncertain about doing it without my presence, and requested that we sing together during the session. I held a songbook for Dorothy and Chris to see and we sang a selection of songs without accompaniment that Dorothy had responded to or sung during our sessions. Dorothy did not sing but looked at Chris and me several times, appearing to feel awkward at my singing and eye contact, so I tended to look away.

I asked several questions at the end of the session that I felt had not been covered by our interaction, and while Chris responded Dorothy dozed. I reminded Chris of his original hopes and expectations for the study and asked whether he felt they had been met. He responded:

Chris: I wasn't sure... what was going to come out of it, but certainly what you've given us has proved to be very useful and ...good for me...maybe more than Mum really, 'cause it helps me kind of focus and stop, and look at things and perhaps maybe get on more of a wavelength with where Mum is at... So it helps me focus on the important things really... I think stuff like this ... can ... build up the good memories of who she is now, so I can look back on this and, maybe when she isn't so well, she can't really interact with things, I can remember things like this. So it gives a bit more quality time really, it's something to do and that, 'cause it's hard to know what to do really. I mean, ...me and my brother thought it would be great to like to take her out to certain places. It is good, but when we bring her back she tends to be exhausted for the day after and...then she's like anxious and...so it's hard to know how to balance that, and having things that are quite simple to use are very useful.

Ruby: Would you say that the study supported you in sharing music together?

Chris: Yes, and find things in common really... songs that I'd forgotten I knew and I'd forgotten about when Mum used to sing to me, we used to sing together; that had all completely gone. And lots of memories came back around that, like singing with other children, Grandfather's Clock, things like that. Things came into my head that I hadn't thought about for years, which is good...really good. And it's good to find the songs that Mum knew that I hadn't heard, and I didn't know she knew them.

Ruby: ...do you think you'll use...and share music going forwards?

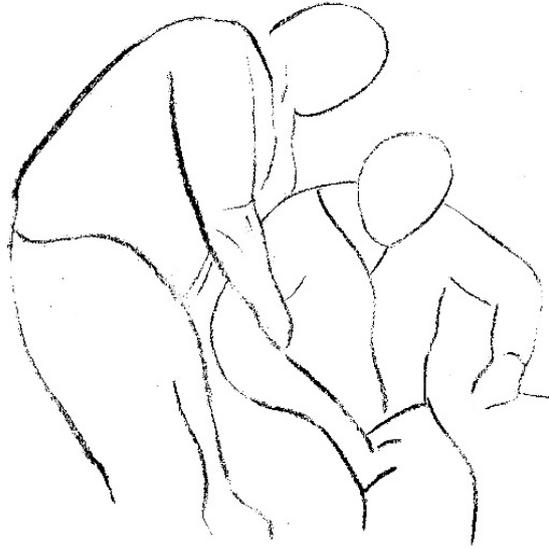
Chris: yes, definitely. I mean, I've got these resources now. We've also actually got you know the garden...we could use music for that as well I think.

Ruby: Is there any other feedback on the project?

Chris: ...I think it's been great having you come here really and certainly it's probably helped bring us kind of closer together as well...getting a chance to spend that time together and listen to things and talk about things. 'Cause we wouldn't have had that otherwise, 'cause there wouldn't have been someone to kind of facilitate that, so that's been great that has...it's brought me closer to Mum I'd say, a lot closer...(S12, V1, 50:41).

Upon reflection after the session, I recognised the signature of relating and expressing through memory that had underscored much of our session activity, as the comfortable, safe ground supporting their continued sharing, and the need for more support in exploring less familiar, participatory activities such as playing instruments and singing. Arising from this understanding, I saw the potential for some guided exploration. This might offer Chris an experiential foundation in initiating exploration to gain confidence in moving beyond memory into sharing movement, participation and creativity. I was also conscious of a lack of clarity in the subtle differentiation of resources, that could engender uncertainty as a basis for exploration. Playing with ideas concluded in the creation of a booklet as a unifying point of reference to clarify differences between resources, highlight some of the possibilities and offer support and guidance for exploration and participation. Within the booklet I included information on both local community music and home supported activities, following discussion with Chris, who indicated this information would be welcome.

5.5 Jane and Kenneth



5.5.1 Background

As a mutual friend to both Jane and Kenneth, music was present at our sessions from the first by introducing Jane in a song that rose in an arm-guided descent of free-flowing motion from the burden of her right-side. Out of a shared history of singing with church congregations and classrooms of children, music greeted Jane with a familiar recording as she woke each morning and accompanied her regularly to a local community singing group. Kenneth spoke of a close companionship with music that grew over a lifetime, through developing his skill as a performer, reminiscing with beloved recordings of folk tracks on solitary drives and sharing the confidence of clandestine guitar practise.

From dancing together at discotheques in their courting days, to village green Morris dances, their shared history with music generously embraced historical and cultural diversity, including the triumphant refrain of a Baroque orchestra, the tender strains of an Irish ballad, the American Deep South's soulful tones and the vibrant colours of hot jazz. With maturity, the shared role of music in their lives together had changed, with favourite classical recordings accompanying car journeys and occasional singing including renditions of *Happy Birthday to You* (Hill and Hill, 1893) rehearsed and performed as a means for Jane to articulate family names.

Although Jane and Kenneth both found a tireless companion in music, it was apparent that this was a friend rarely invited to share time with them both. Their hopes for the study were to find things to do together and stimulation for Jane beyond the enjoyment of TV viewing.

5.5.2 Experiencing

Our first venture into the musical unknown together surprised, delighted and intrigued with sounds made by simple instruments from far flung countries, by now trusted allies in enticing the cautious into sensory exploration over the course of the study. The frog-shaped guiros' resonant rasp spoke to Kenneth of Mediterranean nights serenaded by insects. Jane carefully traced their shape with a tine and lent them her own vocal expression.

Vocalising sounds came more easily for Jane than making sounds through use of her hands or the forming of speech. She often voiced a world of meaning through the colours of a single word that punctuated our activity: 'Oh, *lovely*', a welcoming, warm embrace; a cursory, descending 'lovely', acknowledging yet dismissive, moving us on; a curtly clipped 'lov-ely' rising with a finality that drew to a close. Augmented by gesture and facial expression, the meaning Jane was trying to convey would often dissipate like smoke from the initial fire of her intention. Kenneth appeared initially most at home on the safe ground of semantic communication and understanding. However, over time, Kenneth's patient warmth slowly thawed the constraints of thought's wary caution, becoming a warm, trusting current through which we shared his excitement at musical discoveries, memories, joys and sorrows.

Several instruments that were not congenial to being played with ease or enjoyment paid us fleeting visits. The exploration of light and dark's stark contrasts often had a more accessible appeal for Jane than the confounding causal mechanism of plucking lyre strings, pressing keyboard keys, striking glockenspiel bars and the rhythmic bellowing of a melodeon (see [Music Glossary](#)). Jane's sensitivity to sound environments appeared cleaved by the brash sound of the drum.

Although Jane responded to encouragement and practical support, neither eased nor promoted her physical activity as did spatial interaction. The challenges of manipulating and using instruments and objects were transformed into effortless,

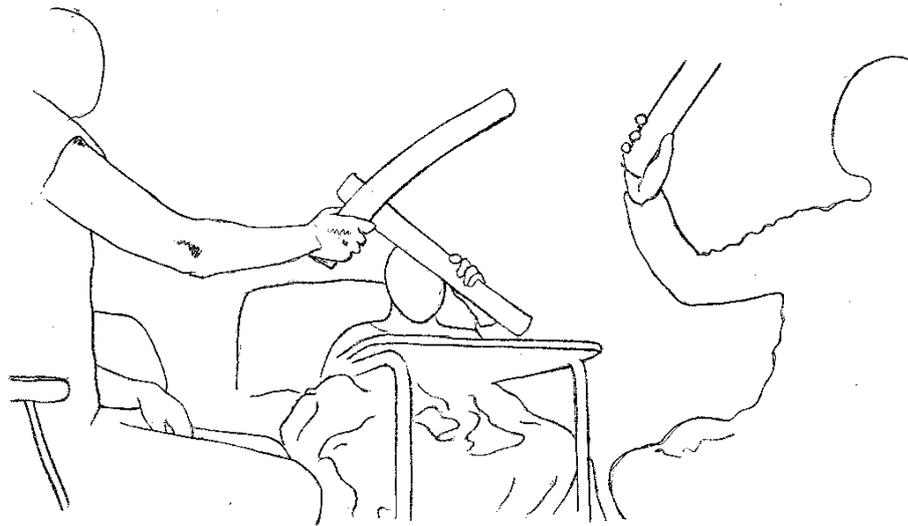
graceful gesture in space, the holding and kissing of hands and mutual mirroring and playful interaction of our arms.

Harmonicas had a greater presence as an old friend for Kenneth and a new acquaintance for Jane. They presented a challenge in aligning breath and tone, but with a little practical support yielded pleasing harmonies for all that we set to an animated, train-chugging blues recording, carrying us along at a rolling pace. An ocean drum conjured reminiscent pictures of coastal memories at Kenneth's subtle tilt, spontaneously complimenting Jane's impromptu sung reprise of *Skye Boat Song* (Macleod and Boulton, 1884) as I eased into enriching harmony on guitar. There were times when music-making seemed to flow like this, as if it were a passing stream that we joined. Then there were other occasions where our musical endeavours remained disjointed, unable to form a coherence between us.

Of all instruments, the guitar held sway. Played by both Kenneth and me, it provided an inconspicuous support to many a song and melody. We formed a merry band, with Kenneth and I alternating guitar, penny whistles and harmonica and Jane moving between tambourine, shakers and movement with scarves. Our activity inspired Kenneth to purchase a new tin whistle and guitar. Jane appeared somewhat reticent during live music-making and singing as a group of three, often taking turns to participate, and once assertively shushing Kenneth's participation while she and I sang.

Rhythmic movement flowed naturally in the musical company of Jane and Kenneth, often elicited by lively folk and Morris dance music and recordings, which we shared on several occasions with waving scarves, a caucus of percussive noise-makers and the click of bottle tops strapped to the soles of our shoes. Home video footage depicted summer days shared in country villages, with Kenneth 'sticking' in formation, observed by Jane from the cool of a shady tree. Donning leg bells and a straw boater, Kenneth provided a lively footwork demonstration, and striking soft sticks, we re-enacted a seated formation. Amusement became apprehension for Jane amidst the flailing and striking (see Figure 39).

Figure 39: Seated Morris Dancing



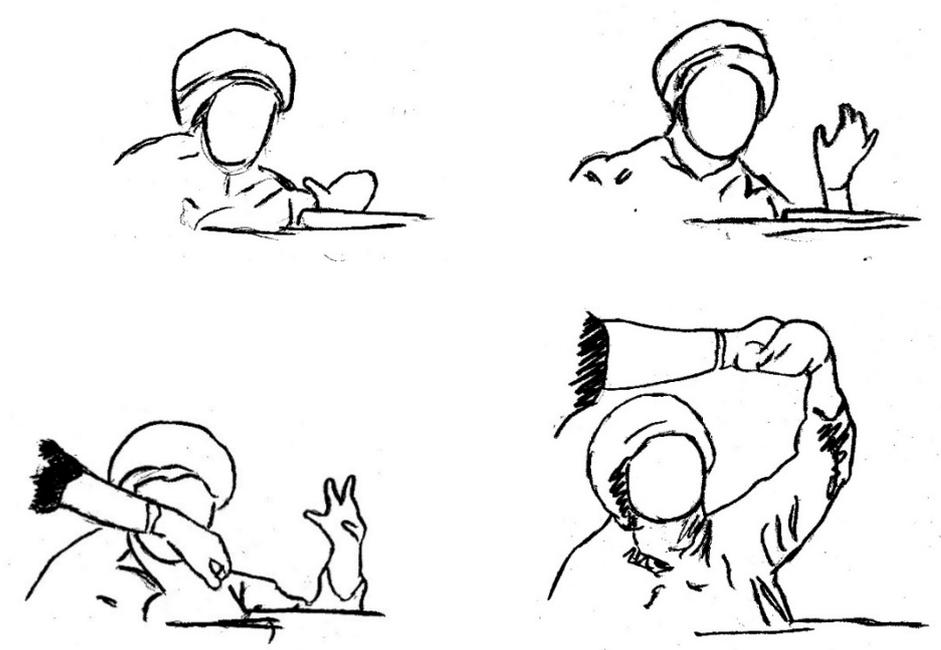
Although recordings of folk music became a stalwart of our sessions, we shared a breadth of listening from across ages and traditions, both secular and sacred, encompassing church hymns, rock and roll, gospel, jazz, classical and pop genres. The favoured and familiar of these recordings formed a weft in the fabric of life for Jane and Kenneth; a comfortable garb for them both that was readily shaken off by Jane in anticipation of new musical adventures.

Harmonising experiences of movement and singing often accompanied our listening, usually between Jane and me. Sometimes these were joyful and exuberant, at other times reflective and soulful, with a familiar awkwardness joining us for recordings that did not invite our interaction. Jane would lead and follow in equal measure with a propensity for engaging in short intense bursts, her freedom and confidence growing with a spontaneity that the planned synchronisation of an intended musical performance or activity constrained. However, the occasional moment of uncertainty pointed to a sudden dawning of self-consciousness whispering, ‘Am I doing this right?’.

From the richness of swung measures, jaunty syncopation, strident regularity and capering jigs afforded by our listening, it became apparent that Jane’s movement flourished within recordings of music not restricted by a finite beat. This rhythmic ‘spaciousness’ offered Jane the freedom to move her arm expressively around a beat that would often abandon her in an out-of-kilter fashion when she tried to reconcile with it. An image sequence drawn from session video footage captures moments of

Jane's metamorphosis from constrained beat tapping to flowing, gestural expression through interactive play to a recording (see Figure 40).

Figure 40: Jane's Movement



On one occasion, Jane's exploratory playing on a tambourine, in playful interaction with my sounding guitar, was interrupted by Kenneth demonstrating how to play the beat. This disruption appeared to be an unwelcome one for Jane.

Our adventures took us to shores familiar and new as we indulged in the music, sights and tastes of other cultures, mingling Jane's love of food, hats and art with their shared enjoyment of travel and world music. Our sensory excursions moved Kenneth to relate tales of cultural encounters and holidays abroad, such as a visit to the Uffizi gallery in Florence where Jane disappeared for hours, lost to the magic of the Renaissance. These stories added colour and contour to the picture I was forming of their artistic natures. Kenneth, skilled on a range of instruments, revealed a depth of enthusiasm and sensitivity that waxed and waned from vital animation to pensive melancholy. These contrasts were reflected in the ardent passion and surrender to tender, emotive depths of the Spanish guitar recordings he loved. Jane, with a history of artistic study and a sensitive appreciation of beauty, colour and design that she continued to express through paint impressions, inspired the sharing of artworks and images accompanied by recordings with a kinship to their subject, qualities or era.

We dabbled with paints, pastels and crayons, buoyed by classical strains that promoted an observable rhythmic emphasis in our application of colour. Jane was drawn to the vibrancy of warmer colours and repeated motifs, needing practical support and guidance, and Kenneth moved from concrete depiction to freer exploration of blues, greens and yellows. During our play with colour, Kenneth serenaded us with some blues guitar at my request, which drew Jane into complete absorption, with rhythmic movement imperceptibly intensifying in her left hand and knee, eyes closed.

Nature tagged along on many of our ventures, having a longstanding relationship with each of us. Birds made frequent appearances, observed from the comfort of our chairs visiting the garden's amply stocked bird table and as a theme of songs that we sang. We created bird song with a variety of whistles and sounding plush toy birds, who Jane playfully gave voice to with chirruping vocalisations and a spontaneously sung greeting of *Hello, Hello! Who's Your Lady Friend?* (Fragson, David and Lee, 1913). We held, smelled and shared roses in musical space, Jane breathing in her rose, eyes closed in surrender to the experience. Beyond the roses, smell came to form a part of our collective vocabulary. Jane regularly offered me a spray of her perfume and, on one occasion, we shared homely smells including vanilla essence and carbolic soap that brought opportunities for associations in song.

As the year waned and Christmas came on in the cycle of seasons, we celebrated with German spice biscuits and recordings of Christmas carols, music boxes and singing. Carols appeared a favourite for Jane at any time of year, an enthusiasm that overflowed in spontaneous rendition of a long-forgotten gem at the mere hint of the word 'Christmas'.

Jane and Kenneth's memory for songs enabled us to sing many together and introduced much new material to our sessions. Jane invariably sang to 'la', but occasionally liked to refer to the lyric sheets often used by Kenneth, who during one session shared several from his compiled folder of favourite song sheets with guitar chords. Along with the spirituals and folk songs it contained, the humour of comedy songs brought welcome waves of energy and warmth for Jane and Kenneth, at a low ebb following a virus.

Jane's development of singing 'la' in place of words due to the confines of restricted speech, opened-up a freedom to move easily between instrumental music and songs,

and to enjoy harmonic exploration with familiar and unfamiliar recordings of music. On one occasion, we listened to a recorded track of African lyre and voice, its repetitive form and undulating, contrapuntal harmonies providing an enveloping cocoon of sound into which Jane quickly settled in harmonic vocal relationship. Eyes closed, graceful arm gestures reflecting the shape of her vocalisations, she eventually emerged from the sea of harmonies having exhausted the possibilities of the song's enduring rhythmic tide for the day.

We delved further into the unfamiliar, sharing call and response style songs that lend themselves to learning through doing. Singing the gradually lengthening repeated verses of one of these songs gave way to laughter, peaking with Jane's spontaneous suggestion of an additional word to the song where I had left a gap.

During our seventh session, Kenneth confessed a newfound passion for a song from a dramatization of *My Uncle Silas* (Saville and Clegg, 2012) that he and Jane had been watching. The song was a romantic exchange between a man and woman, alternating in freely rhythmic expression. Singing this song became a significant feature of our final sessions together. Together we played our part, Jane and I singing the woman's verse and Kenneth the man's in a rendition that reached out to their wider family through Kenneth's video recording of our singing.

We experimented collectively with our voices, tentatively trying humming, vowel sounds and melodic improvisation. These were unfamiliar waters for Jane and Kenneth to share, as Kenneth habitually found comfortable expression in the forming of recognised songs and melodies. Our singing sometimes diverged into harmony, with Jane gliding into a descending soprano cadence in the conclusion of *Happy Birthday to You* (Hill and Hill, 1893) while revealing her playful humour using received pronunciation of the lyrics, and holding a line of the round *Frère Jacques* (Unknown composer, 17th century) in complementary agreement with mine. This accomplishment by Jane was one of several acclaimed by Kenneth.

Jane's melodic freedom of voice brought us into relationship with each other in a way that words could not. Jane's restricted speech led us to discover this means of relating, that was not a substitute for it or alternative to it, but a different way of relating. An intimate immediacy and intensity of unity that transcended reason and concepts. Not an experience of communication, but of communion with Jane that had a significance no less profound than speech. This singing would often occur

during our first minutes together, left alone while Kenneth made us tea. Often, I would hum or la a simple tune, familiar or improvised, sometimes just mention the words ‘music’ or ‘singing’, and melodic play ensued.

Singing and perfume were not the only ways that Jane reached out to me beyond words, offering me her glasses and her watch, demonstrating the ring of her call-bell, holding my hand in movement and tenderness. During our final session, Jane held my hand for several minutes, massaging it with a firm, rhythmic touch. This was a profound experience of connection that stayed with me long after our sessions ceased.

5.5.3 Understanding

My biographical picturing revealed a contrasting nature between the evolving role of music in the lives of Jane and Kenneth. From a foundation of relating to music and people through dancing, sharing in collective hymnal worship and uniting classes of children through song, music remained a means of coming into harmonious relationship with others and the world for Jane. This enduring role of music had grown to become a tangible, accessible medium Jane could take hold of through memory, emotion, perception and physicality, offering opportunities to join in and initiate freely. Such participation could be disrupted during our sessions when musical orchestration and planning introduced a cognitive element. Music transcended the challenge of grasping conceptual meaning and taking hold of physical objects coherently, emerging like water to buoy the burden of heavy, disjointed movement in unhindered expressive flow of voice and arm gesture. This was an impression that emerged for me as the movement of colour (see Figure 41). Through musical activity, I also experienced Jane’s capacity for expressive change, wonder, curiosity, playfulness and creativity that I articulated as a word impression (see Figure 41).

Figure 41: Colour and Word Impressions



*Dancing through shadows,
Light catching glimpses of the past
Flickering, weaving, resting in awe-
filled joy*

A dance for joining



Folk dancing brought more than social interaction and enjoyment for Kenneth over the years, it also gave opportunity for the honing of skill and performance, alongside that of singing and playing musical instruments alone and with others. His development of vocal and instrumental proficiency engendered an appreciation for skilled musicianship and ease with playing recognised musical pieces as part of a collective. His strong sense of belonging to the familiar in music underpinned a refined sensitivity to the qualities of performance and musical moods. His favoured music and recordings softened the reticence of his kindly reserve through physical and emotional movement, having the contrasting capacity to kindle enthusiasm and offer a holding space for the vulnerability of melancholy. This juxtaposition of emotion is reflected in the following musical depiction of my impression of Kenneth (see Figure 42).

Figure 42: Musical Impression



The experience of the familiar promoting movement contrasted with the impression I gained through picturing of past abilities, experience and understanding restricting action. In painting and the singing of songs she knew, Jane would often falter, uncertainty curtailing activity. In music making, Kenneth acknowledged and

promoted pleasing and accurate renditions of songs, pieces and skills, encouraging and supporting Jane to adhere to rhythmic and melodic structures.

Unfamiliar activities could also be both restricting and freeing. The improvised singing of vowel sounds lacked the grounding of melodic and rhythmic organisation. This lack of form limited activity through uncertainty in the unfamiliar use of voice; an instrument with a range of defined, familiar uses over a lifetime. Playing the world music instruments, on the other hand, had no musical parameters beyond the exploration of timbre, pitch and rhythm, on instruments free from past associations and preconceptions.

Through picturing the essential of my experiences with both Jane and Kenneth, further contrasting relationships with freedom and restriction became evident, not only between them, but for each of them individually. While Jane was grounded in rhythmic routines such as her regular morning's listening, enjoying her daily TV programmes and frequent applications of scent, she would comfortably move into spontaneous musical expression and exploration in response to her environment. Kenneth was enigmatic, accommodating and impulsively exuberant, having a strong allegiance to his time-tested musical favourites, the rock of structured music-making and the cool of calm consideration. These differences were at times reconciled through the harmony of musical experience and music-making. At other times, dissonance occurred between the spontaneous and the constrained, our interactions lacking coherence and introducing a sense of estrangement and uncertainty that I expressed as a word impression (see Figure 43). At such times, I would find myself interacting with each of them differently, perhaps mirroring Jane's movements whilst conversing with Kenneth.

Figure 43: Word Impression

*What is the purpose of these things that we do?
They seem to bring us closer
You to me, me to you
The music runs like a stream through our play,
Yet the road that leads us back there often seems far away*



At times I experienced this sense of estrangement coupled with an underlying sadness, articulated in the minor mood of a musical impression (see Figure 44). My

biographical picturing rendered an impression of Jane and Kenneth working hard for long hours throughout their lives, now estranged from a present situation so different from the retirement they had hoped to share.

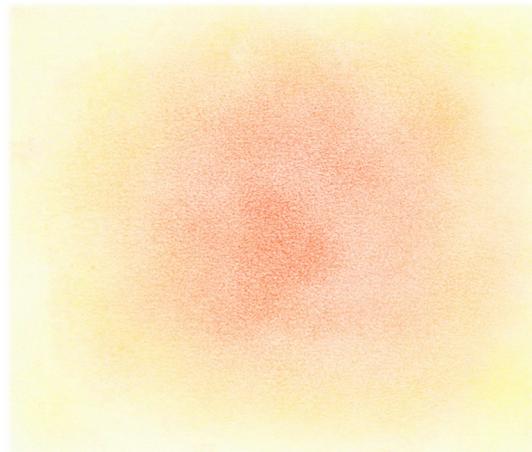
Figure 44: Musical Impression



In response to my growing recognition of restriction and freedom within our interactions, I often felt compelled to explain aspects of my approach and emerging understanding. I felt that doing so might help us to foster a culture of exploration, where the conventions of performance held less sway over music as a means to express and share. However, I came to comprehend that I was attempting to change the situation by imposing my view, when really, I was there to learn from and respond to the phenomena I met. I realised that the activities engaged in and resources we ultimately developed must embrace both Jane and Kenneth's existing values and preferences to be relevant and enjoyable, with the potential to invite shared exploration and evolve with them into the future.

Emerging from the impressions that I gained of Jane and Kenneth and their relationship with music came an understanding of the need to explore the common ground of warmth, reflected in the colour impression below (see Figure 45).

Figure 45: Colour Impression



The common ground where Kenneth's enthusiasm and Jane's spontaneity met, stirring movement between the familiar and the new, the constrained and the formless, to promote the growth of musical companionship. These insights culminated in the following word impression (see Figure 46).

Figure 46: Word Impression

*We still sit as we used to sit
In familiar comfort, in loving ease
But between our chairs a mist has crept
That shrouds your eyes as if you slept
That I cannot appease by wishing or fighting it*

*Yet we still sit as we used to
At times I'll take your hand
In the way you used to take mine
And I close my eyes and remember 'our time'
My eyes become shrouded too and everything feels fine
Feels as it used to*

*But these are memories, they come and go
And stay the same, a safety net
That catches me in dark hours of fret and dread and fear and sorrow
As comforting as they can be, they are not you
As you are, changing before my open eyes
Into someone unfamiliar
Yet to hear your voice, your laugh, your sigh
When I don't understand
It really is as if you slept and one day
You will wake and take my hand
As you used to*

*Yet I am discovering moments
When the mist falls away
Like clear space among the clouds on a mountain top
I know we must come down again
But in those moments, life feels raw
Your eyes shine and we seem even more alive
Than we used to*

And I am beginning to understand, that to get there

I need to move my chair, to take your hand

In unfamiliar ways



5.5.4 Creating

Initial and ongoing discussions around musical and biographical history often formed an integral part of our sessions and offered a wealth of material to explore: a broad range of styles, songs and melodies, for recorded listening and participation, the potential to play instruments in various combinations, the singing of children's songs and spirituals and the love of dance, travel, art and nature. Jane and Kenneth's direct contributions also helped to shape the sessions and resources. Kenneth would often comment on which aspects of our sessions both he and Jane enjoyed or disliked, sharing his instruments and ideas for others to try, along with relevant objects, song lyrics and chords as they came up. Jane's spontaneous singing introduced a breadth of songs, some of which were unfamiliar to Kenneth. At times, Kenneth would identify songs Jane had been singing between our sessions, which we would then incorporate.

Sensory responses gave practical indications for potential avenues to explore. During our adventure in birdsong, Jane blew into a birdsong whistle and subsequently tried to elicit sound from the plush birds in the same manner, which required squeezing to sound. Jane's actions highlighted the potential to explore instruments requiring sustained breath such as the harmonica, and a need for me to be aware of the differences between, and combinations of, actions involved in sensory participation. Jane's attraction to visual contrasts, patterns and William Morris prints gave indication to explore contrast with textiles and development of textile leaves and flowers for free arrangement in design against a pale felt background (see Figure 48, [1] below).

In Jane's capacity to form words to the *Happy Birthday to You* (Hill and Hill, 1893) song and experience coordinated movement with music, I saw an opportunity to work developmentally with speech and motion. We ventured in this direction briefly in a variety of ways, such as introducing simple speech sounds to songs. However, it

soon became apparent to me that this was an avenue requiring intensive effort, perseverance and conceptual instruction, with the focus on outcomes for Jane working contrary to the expansive nature of free exploration their sharing offered.

Understanding of the possible basis for promoting musical companionship between Jane and Kenneth led to the sharing of music and recordings, and development of resources offering reflective and rousing opportunities to initiate, freely express, and share through singing, playing and moving. The songs enjoyed by them both during our time together, with the addition of others likely to be known and enjoyed, offered a broad collection of material with the potential to encourage and support singing into the future as songbooks (see Figure 48, [2] below), acting on Kenneth's indication that lyrics with chords for accompanied singing would be helpful for them. Included in the repertoire were comedy songs to promote warmth and humour; rounds to give opportunity for harmony singing; and popular, musical, music hall, traditional and childhood songs to enjoy memory. These songs were accompanied with indications for movement, playfulness and fun in their sharing. Hymns and spirituals brought space to explore the poignant depths and soaring exultant heights of emotion these songs can inspire, avoiding those with sombre associations of enforced churchgoing for Kenneth. Within the finished songbooks, an introductory message to the songbooks invited participation by other family members and carers and DVDs and CDs of me singing the songs brought opportunities for accompaniment and my continued 'presence'.

The *My Uncle Silas* (Saville and Clegg, 2012) song held a special place in the repertoire. Unknown to us all when our sessions began, it became familiar through shared appreciation and singing, and appeared to appeal to both Jane and Kenneth in its reflective tenderness. Requiring no instrumental support, the song allowed for the freely rhythmic, expressive exchange of voices, inviting Kenneth's enthusiasm to sing it and Jane's spontaneous turn taking in response, rendering an organic, shared performance. Kenneth showed appreciation for Jane's ability to learn, remember and sing with beauty and sensitivity when we sang this song together.

To promote more informal singing together, development of a well-known song title 'lucky dip' for 'la-ing' together (see Figure 47, [1] below), offered material to kindle Jane's spontaneous associations between words and music. A small, lidded box

formed an accessible receptacle for the pieces of folded coloured paper, that might be added to and shared by others.

I experimented with recordings and playing guitar chordal sequences and textures as a supportive basis to promote vocal and instrumental improvisation, transposing several recordings to playable keys on Kenneth's existing instruments. A CD of tailored folk tunes, some commercial and some performed by me, gave opportunities for movement and participation on a range of instruments. Edited commercial tracks with a relatively static and predictable or repetitive structure, along with a recording of a melody improvised by Jane sung by me with supporting chords (*Jane's Song*), formed an environment for instrumental and vocal improvisation and harmonisation (see Figure 47, [2] below).

I created a DVD of the tracks I recorded myself to accompany the CD and *Making Music* booklet. The booklet contained ideas for a variety of activities to encourage musical exploration, guitar chords for playing the folk tunes and *Jane's Song*, guidance on sharing music safely and links to online musical resources. A selection of coloured scarves for movement, percussion instruments (small tambourine, foot tambourine, mini D-shaped tambourine with ribbons, wrist bells, maracas and banana shaker) and an accessible harmonica, for sharing with and without the DVD or CD, completed the *Making Music* resource.

Figure 47: La That Tune [1] and Making Music [2] Resources



Figure 48: Felt [1], Songbooks [2] and Art & Travel [3] Resources



Art and travel provided themes for listening to recordings accompanied by sensory interaction. Opportunities to share these themes included collections of laminated images with CDs of commercial recordings of music by era, laminated images of favourite countries with CD recordings of traditional music from those countries, food suggestions and objects (Spanish fan and castanets) (see Figure 48, [3] above).

5.5.5 Review Session

When we met for our final review session, the reticence between us born of time apart quickly fell away, and we were soon sharing in the activities that Jane and Kenneth had been enjoying. I experienced a greater ease between the two of them in sharing music together as we spontaneously sang and revisited carols from the songbooks (see Figure 48, [2] above) with Kenneth on guitar, working up to a spontaneous, rousing acapella rendition of *My Old Man's a Dustman* (Donegan, Buchanan and Thorn, 1960), invigorated by percussion playing.

Jane and Kenneth appeared to have embraced using many of the resources I had left with them, moving from trying them out into making them their own. According to Kenneth "...it became spontaneous, it could be any time of the day, it might be a short time... she [professional carer] would put various things on and do things" (S12, V1, 04:50). Listening to the commercial music CDs had become a part of daily routines, especially for Jane:

Kenneth: The one that has definitely stuck...as a requirement, is...Jane...is happy to play CDs and she used to have television on, which is a big advantage, I think.

Jane: Yeah

Kenneth: ...so she's watching a morning programme... and then after that, she loves to have a CD on, and she'll ask for that if I forget about it. And that has become a habitual and an enjoyable part of life

Ruby:...is it enjoyable for you as well?

Kenneth: Well, it depends what the music is, but... yes. We have got other classical music as well... I could just, you know, lie back and listen to those, very much, which I hadn't before

Ruby: ...so that's a change?

Kenneth: Oh yes, that's a change of life if you like

We watched one of the songbook DVDs together, as these were among the most enjoyed materials, often requested and sung along to by Jane (S12, V1, 05:42):

Kenneth: Jane loved the songs you sang on the DVD, she kept on watching those, didn't you?

Jane: Yeah, lovely

Kenneth: with Ruby actually playing and you could see her

Jane: [nodding] yeah (S12, V1, 20:38)

The Morris tunes on the *Making Music* resource CD (see Figure 47, [2] above) had provided material for movement with scarves, and playing along with guitar and percussion, but time restrictions had prevented them from trying the activity suggestions in the accompanying booklet, which were kept for future use. Most of the instruments were enjoyed, particularly the banana shaker and maracas that also accompanied singing. According to Kenneth "when Jane uses... [them] it has to be on a rhythmic song like [starts singing and playing] *My Old Man's a Dustman*...that's a perfect song, and I found a few others as well, and when I do those...it's very uplifting" (S12, V1, 44:30). The tambourine featured as a mutual medium for participation between Jane and Kenneth, with Brenda (regular professional carer) joining in on occasion.

Kenneth did not feel that sharing the food with the music of other countries (see Figure 48, [3] above) was something they would take forward beyond listening to the CDs: "We did, for example try Greek music with hummus and olives, which we

greatly enjoyed, but I, personally, it didn't sort of take me back to Greece. I like the food, I like the music, but maybe it wasn't recent enough for us" (S12, V1, 09:11). The art images and accompanying music CDs were also enjoyed separately rather than in combination. Kenneth remarked "...we looked at these [art images] and they were very nice...the sort of thing we wouldn't look at all that often. But they're just nice, a bit like the Uffizi you know, after a couple of hours, you want to go and have a coffee" (S12, V1, 17:20).

Although I observed Jane's keen engagement with the felt resource (see Figure 48, [1] above) before our break, Kenneth indicated that this had not been an accessible activity for Jane, and so I took it away. The *La That Tune* lucky dip (see Figure 47, [1] above) had yet to be tried. We revisited its possibilities and Kenneth asserted that he would like to try sharing it with Jane. Jane and Kenneth's enjoyment of the resources and intention to continue sharing music and further exploration of untried material, gave no indications to me for revisions or additions to the resources. However, I provided further copies of the session highlights DVD for family members at Kenneth's request.

5.6 Summary

The growth and flourishing of the experiential, participatory activity of the fieldwork depicted in this chapter supplies a presentation of the data for this study. The next chapter yields the fruits of understanding harvested through working with this data.

6 Harvesting Findings

How words are understood is not told by words alone.

(Wittgenstein, 1970, p. 26e)

6.1 Introduction

Working through a process of gentle empiricism with the phenomena of people in caring relationships and music has revealed to me new understanding of them and the relationships between them. This chapter presents the harvest of my understanding evidenced by examples from fieldwork activity as a starting point for further development by myself and others, and as a basis for exploring and sharing music by, and with, people in caring relationships.

Exploring the phenomenon of music experientially during the fieldwork, beyond the concepts of performance and skill, revealed music as an activity of being human. Through musical activity it was possible for individuals to perceive, experience, be and fulfil their potential and relate to one another. For individuals with dementia this developmental activity stood in contrast to the prevailing view of the condition as one of decline and loss, and a common focus of music interventions on preserving the past rather than looking to the future. Sharing musical activity with participants in this study illuminated an essential difference between experiential and conceptual activity that is fundamental to understanding the relationships between people with dementia, those that care for them, and music.

During the fieldwork, I sought to encourage the development of musical activity that could potentially promote 'coherence' in a process of dynamic, responsive growth. 'Disruption' and 'coherence' in individuals' responses to, and participation in, musical activity guided my own responses in the development of sessions and resources. The understanding arising from this developmental activity offers indications for growing musical activity within caring relationships beyond this study.

6.2 Musical Experiencing

6.2.1 Sensing, Experiencing and Conceiving

Engaging in exact sense perception as a mode of gentle empiricism (see [Chapter 3](#)) required me to develop awareness of my own activity of ‘adding’ concepts to my sense perception and responses to sense perception. Through engaging in exact sense perception of music, I became aware of my perception as an active process; a weaving together of a musical ‘event’ where each note and sound was perceived in the context of a greater ‘whole’, a past and potential future, not in isolation. This insight indicates that perception of music is an active participation in the musical event by uniting linearly perceived musical elements over time, just as understanding is an active process (Bortoft, 1996; Brentano, 2014).

I also became aware of a distinction between the sensory perception of music and my experiences of music in response. It became apparent that the characteristics and qualities of music shared during the study could promote a range of physiological and emotional experiences, such as the restfulness of slow tempos and the melancholy of minor keys. These musical qualities came into expression through activity in response to the sense perception of music as an environment and could manifest through physical activity such as speech, laughter, movement and changes in breathing. Beyond subconscious entrainment (see [Music Glossary](#)), the choice to respond to the qualities inherent in musical environments and enjoyment, dislike and memories that they evoke can be seen as an activity of the individual. Differences between an individual’s response to the same music over time and between individuals to the same music, as I observed during this study, point to experiences of music as an active encounter between each individual and the actively perceived qualities of the musical environment, not merely a passive receiving of experience. These observations indicate that we can experience ourselves in response to music.

Learning to navigate my own modes of perception developed my capacity to differentiate between my sense perception of music and other sensory media, my physiological response, emotional response, memory and imaginative ‘pictures’ and conceptual responses. Developing my capacity to differentiate between my own activities enabled me to recognise these differences in the responses of others and

vice versa. I have distinguished between these forms of perceptible individual activity in the fieldwork examples in subsequent sections.

Through working from an understanding of humans and other living beings as activities rather than objects through gentle empiricism (see [Chapter 3](#)), I realised that perceiving and experiencing can be seen as activities of coming into being. A living process of reciprocal relationship in continuous flow between individuals and the world.

Through my exact sense perception as an element of gentle empiricism, purposefully disrupting the habitual flow of adding concepts to my perceptions and experiences (see [Chapter 3](#)), I came to recognise experiential activity as distinct from conceptual activity of being. I realised that concepts become abstracted from the perceptions and experiences that give rise to them and manifest as activity such as speech and intentional acts.

Throughout this chapter, I draw distinctions between experiential and conceptual forms of being and further distinguish between the physical, emotional and memory aspects of individuals' appearances as they manifested these forms of being. These distinctions became apparent to me through observing coherence and disruption in the perceptible activity of participants, and also observing my own forms of activity.

6.2.2 Disruption

Through working deliberately with conceptual disruption in my own gentle empiricism process, I came to recognise that both experiential and conceptual activity were disrupted for study participants with dementia in different ways. Over the course of fieldwork sessions, I observed in each participant with dementia, disruption both as an absence of activity, resulting in less opportunity for sense perception and experiential activity, and 'overactivity' such as unregulated movement, restlessness and agitation. In the examples throughout this chapter, colours are used consistently to differentiate between participating pairs to aid continuity for the reader.

Macular degeneration appeared to disrupt Sue's activities of being, who showed no signs of being able to visually perceive her surroundings. Sue moved restlessly at times, her postural restriction and stillness contrasted by rapid limbic movements.

Jerry moved restlessly at times, shifting between inactivity, making limbic gestures and turning in the bed.

Dorothy moved very little while seated, and her movements and speech were slow. The flow of Dorothy's relationship with the sensory present also appeared disrupted, as the content of her speech indicated that her orientation to time and context fluctuated. She appeared unable to unite concepts with aspects of her environment at times, seeming uncertain about what objects were or misidentifying them.

Jane's physical restrictions inhibited the appearance of experiential and conceptual forms of activity; for example, the movement to music and recordings that flowed through her left arm was not possible with other limbs and she often needed assistance with intentional physical activity such as walking.

I observed apparent disruption to the flow of conceptual activity of all participants with dementia. The forms of disruptions I observed were difficulties in verbally articulating concepts and uniting concepts with sense perceptions. Despite these difficulties, they all communicated and participated in sensory relationships with the world and others. Instances of this observed activity and disruption are elaborated in the following individual examples.

Sue's speech was often stilted as she tried to form words, and at times she would make sounds in communication with others. The content of her speech was often vague, leaving me uncertain of her meaning or if she understood others' meaning, but she freely conversed in whistled birdsong. She would often reach with her hands, engaging with her environment and others through touch and movement.

Jerry communicated positive and negative responses when prompted through hand and head movements, repeatedly reaching for Lynda's held papers.

Dorothy often searched for words, and those she used did not always appear to articulate the intended concepts. Her response to her canine soft toys was one of caring and companionship but she demonstrated no recognition of the concept that they were toys rather than living creatures. She often engaged in the familiar activities of sorting through cupboards and moving objects in her environment, but these activities had no discernible purpose.

Jane's physical gestures and accompanying vocal sounds were often expressive and assertive but could quickly wane, leaving her seemingly uncertain as to what she was trying to convey. Jane shared sensory media with me such as the smell of her perfume and demonstrated her understanding through her physical activity at times, including pointing at relevant objects.

In Sue, Dorothy and Jane, I observed a surety and rhythm in direct contact with 'things' that was often undermined in 'secondary' action, i.e. using an object to 'cause'

something to happen. There was an apparent difference between ‘direct’ touch as a sensory relationship and the ‘causal’ touch of ideas in action. Although all three women still engaged in some familiar activities of daily living such as eating, drinking and nose blowing, there were times when disruption to the flow of conceptual activity was evident.

For Sue, holding and playing instruments usually required support.

Dorothy’s tender, attentive touch in eliciting sound from instruments, moving and handling objects and flowers did not require the prompting and support from Chris that shaking, striking and blowing instruments often did.

Jane’s direct touch of my hand and tracing of the frog-shaped guiro with a tine as an extension of her hand, appeared to flow naturally with a regularity and firmness of intention, whereas holding instruments and art materials such as paint brushes in a way that they could be used for a purpose often posed a challenge, despite the familiarity of holding art materials over the course of her life.

6.2.3 Coherence

Participation in the sensory perception of various media, including music, appeared to promote coherence in the flow of experiential and conceptual activity for individuals with dementia participating in the study in different ways, as illustrated in the examples that follow.

6.2.3.1 Sensory Perception

The ‘presence’ I discovered in practicing exact sense perception through deliberately disrupting my own conceptual activity in response to sense perception, I also observed in appearance of the participants with dementia in response to musical and other sensory environments:

Sue’s usual quiet inactivity was contrasted by alert, assertive activity, often in response to sensory environments, and her intermittent, unregulated leg movement could be interrupted in response to changes in the sensory environment.

Jerry was strongly ‘present’ through his direct eye contact in response to the sensory presence of others; a presence that had waned for our second and final encounter.

In response to sensory environments such as music and plants, Dorothy often spoke of their qualities as she perceived and experienced them in the present, in contrast to much of her speech that was about the past.

Jane could become immersed in perception of sensory environments; denying her visual perception with closed eyes to focus on smelling a flower, listening to music and tasting food.

6.2.3.2 Physical

Sue demonstrated a spatial relationship to music in her freedom of bodily movement that contrasted with her physical difficulties often apparent during intentional activities such as walking and playing instruments. Music with a strong beat appeared to provide a welcome emphasis that supported Sue in moving her feet in deceptively complex combinations to Elgar's *Pomp and Circumstance* (Benson and Elgar, 1901) and stamping her feet to Ron's regular beat with coconut shells. I also observed entrainment between Sue's breathing and the tempo of musical environments at different times.

Jerry's restless physical activity relaxed within the musical environments of a Catholic hymn and an Irish rebel song, and I also observed entrainment between his breathing and the tempo of musical environments at different times.

Jane demonstrated a spatial relationship to music in her freedom of bodily movement that contrasted with the difficulties she often experienced with intentional activities. However, a strong beat posed a challenge for Jane to adhere to compared to music with a more implied beat, that supported her propensity for continuous rhythmic movement; continuity of motion that also expressed itself in the rhythmic touch of her hand holding mine. Music with a strong beat appeared to promote physical emphasis that disrupted this continuous motion for Jane.

6.2.3.3 Memory

Although Sue did not verbally articulate memories as a conceptual narrative in my presence, she actualised embodied memory through the patterned arm and leg movements of country dancing to music of that style. She also expressed memory through gesture, verbal sounds and phrases in response to sensory sounds and objects reminiscent of farming life leading to a coherent and lucid verbal response to a conceptual question about her childhood family farm.

Jerry formed the words with his mouth to a song familiar from his early home life but formed no other words in my presence.

Where the content of Dorothy's speech was often vague and thematic, she verbalised spontaneously clear, specific memories in response to music on several occasions; memories that were sometimes unfamiliar to Chris.

6.2.3.4 Emotion

Sue was far more emotionally expressive in response to hearing music than at other times in my company, spontaneously laughing and appearing joyfully moved in response to music through physical movement, gesture and expressive verbalisations. Although shared laughter formed a regular part of our interactions, I did not hear Sue clearly communicate emotion through words, facial expressions and body language as she did in response to music and recordings. Her enjoyment in moving to music and recordings was tangibly observable in the vitality of her smiling, clapping and lively movement that contrasted her normal activity and posture.

Jerry's dislike of hearing the singing bowl's high pitch was evident from his physical movement, as he turned away and shook his head. Although only perceptible to me through his nodding and 'thumbs up' in response to Lynda's questions, his enjoyment of specific recordings and singing was evident to Lynda.

Recordings and play with sound prompted Dorothy's laughter and humorous facial expressions and expressive verbalisations of appreciation and dislike that did not require her to remember concepts to explain or understand. According to feedback from Chris on the resources I left with them, Dorothy's feelings of anxiety could ameliorate in response to listening to recordings of music whilst looking at images.

Jane's depth of emotional experience in response to hearing music and recordings was evident in her absorption and movement. She became a part of her musical environment, sometimes closing her eyes, moving gently, at other times erupting in joyful animation of physical movement, facial expressions and expressive verbalisations and vocalisations.

6.2.4 Indications from Understanding

Recognising sensory exploration, including music, as coherent activity for individuals whose activities of being were disrupted indicates a potential for sensory activity as a medium of coherence for other people with dementia beyond this study. Regarding sense perception and experience as activities of being contrasts with existing understanding of music listening as a passive receiving of musical experience (Yinger, 2018). The music 'calls to' the individual to take up the invitation out of their own activity. By acknowledging the individual's activity in musical encounters, music can be considered an invitation to the individual to participate, rather than as a means for cause and effect. This distinction points towards musical exploration beyond predefined interventions.

6.2.5 Promoting Musical Experiencing

I often found participation in the phenomenon of each individual with dementia with awareness of my own conceptual activity (exact sense perception) easier than during participation with carers. Changes to the conceptual activity of individuals with dementia meant that concepts were a less dominant part of our interactions. For the participants with dementia, the flow of experiential activity also appeared disrupted in different ways, such as by changes in vision or heightened sensitivity to sound.

Recognising disruption and coherence of the experiential activity of individuals with dementia gave indications for the development of participatory activity and resources:

6.2.5.1 Sensory Perception

Sue's strong sensory relationships including touch with hands and feet, and hearing, particularly listening to rhythmic music and recordings, indicated trying tactile objects, instruments, foot tappers and handheld rhythmic movement. Because of the disruption to Sue's vision, I shared other forms of sensory 'colour' through music, taste and smell. Although sometimes immediate, the gradual development of her activity at times indicated a need to allow time for Sue's response to sensory activity to unfold.

Jerry's heightened sensitivity to the intense high pitch of the singing bowl gave indication for avoidance.

Dorothy's slow, attentive response to colours, contrasts and recordings of emotive music gave indication to try sharing complementary images and recordings as a sensory space.

Jane's sensitivity to the sensory intrusion of the drum gave indication for avoidance; her attraction to visual contrasts and patterns indicated that she might enjoy activities and resources that incorporated these elements. Jane's absorption in singular sense perceptions indicated activities with a single or dominant sensory focus, such as listening.

6.2.5.2 Physical

Sue's freedom of bodily movement in response to music and recordings, particularly those with a strong beat, gave indication to explore movement and walking in musical environments and to provide recordings to promote movement as a resource. Sue's response in standing and moving through space more easily to music and recordings as a sensory environment gave indication of the potential for musical environments to be supportive of the daily activities of standing and walking.

Jerry's relaxation from restless movement in response to specific tracks gave indication to further explore music and recordings with similar characteristics to promote his relaxation.

Jane's freedom of bodily movement in response to music and recordings, especially those with an implied beat that supported her propensity for continuous rhythmic movement, gave indication to explore movement to such musical environments and to provide recordings to support it as a resource.

6.2.5.3 Memory

Sue embodied memory through the patterned arm and leg movements of country dancing to recordings of music in that style. She also expressed memory through gesture, verbal sounds and phrases in response to sensory sounds and objects. These forms of memory appearances gave indication to provide resources for their continued promotion.

Jerry's mouthing of the words to a song familiar from his early home life gave indication to explore further recordings from his childhood and adolescence.

Dorothy's verbalised memories in response to music and recordings gave indication to try reminiscence-based musical activity.

6.2.5.4 Emotion

Sue's joyful responses to particular recordings gave indication to include these tracks in activities and resources to give opportunity for continued emotional coherence.

Jerry's indications of enjoyment and displeasure in response to musical experiences informed choices of further musical activity to explore during sessions.

Chris' observation that Dorothy's feelings of anxiety could ameliorate in response to listening to recordings of music whilst looking at images indicated to him to utilise this resource to promote relaxation for Dorothy.

Jane's dynamic emotional responses to music gave indication for music that might evoke a range of emotion to include in sessions and resources that could continue to offer opportunities for coherent emotional expression.

6.2.5.5 Memory and Emotion

There were times in the fieldwork when music and recordings appeared to be enjoyed by participants because they were familiar, and times when they appeared to become familiar because they were enjoyed. Because of the apparent interrelatedness between familiarity and preference, I discuss these aspects of participants'

relationship to music together rather than separately as aspects of memory and emotion.

Active perception and experience of music was often responded to with varying degrees of appreciation or dislike by participants in the study. Pieces and recordings of music that were enjoyed were usually, but not always, familiar to individuals and most often promoted activities of being, such as movement. Although not all participants verbalised their preferences, enjoyment and dislike were often evident in their activity such as Jerry's 'thumbs up', or lack of response. There were instances where verbal remarks were the only indication of enjoyment, such as Dorothy's "nice music" (S3, A1, 53:47). Familiar and enjoyed pieces, and recordings, promoted expression most often. Pieces and recordings that were not particularly enjoyed or were disliked sometimes brought opportunities for conversation and humour in response, indicating that musical material does not always need to be 'liked' to offer opportunities for coherent activity.

6.2.6 Indications from Promoting

Recognising disruption and coherence in individuals' activities of being can give indications for musical activity with the potential to promote coherence, for example

- recognising the disruption to Sue's physical activities of standing and walking indicated the possibility to try these activities with music and recordings;
- and recognising the coherence of Dorothy's vision indicated combining visual media and music.

Recognising how musical qualities can promote coherent activity for individuals can provide indications for appropriate music and recordings to further promote coherence. For example, creating beat and rhythm interrupted motion for Jane. However, flowing rhythmic movement was still accessible, and the musical qualities that promoted her fluid movement were suggestive of other music to try.

Musical perception can support activity in fulfilment of a purpose, e.g. standing and walking to go somewhere, in instances when trying to communicate concepts about the purpose of such activities are apparently unsupportive. Identifying opportunities specific to an individual, such as the physical memory of standing to a hymn can give indications for supportive sensory environments in daily life.

Combining sensory media, such as recordings of music and images, can provide a rich sensory environment that offers individuals a range of possibilities for experiential activity. Perception of multiple sensory media may not be accessible for an individual simultaneously.

Pieces and recordings of music that are familiar and enjoyed can be a foundation for promoting coherent experiential and conceptual activity. Exploration of unfamiliar and/or pieces and recordings that are not enjoyed to varying degrees can open up the possibility of a greater range of experience and response, although it is important to differentiate between pieces and recordings that are disliked and those that an individual finds distressing.

Responses can be immediate or develop gradually for the same individual, so extending opportunities for an individual to respond are important.

6.3 Musical Being and Becoming

6.3.1 Musical Being

Coming into being is a continuous flow of living activity. Across the course of this study, I have also come to understand music as a living process. Music is constantly changing and developing. The live playing of a song, piece or composition, brings into being a new and unique presentation of it. It retains a unique identity, yet becomes more than it was, with each rendition a part through which the whole manifests (Bortoft, 2012). As discussed earlier (see [Chapter 2](#)), recordings of music are static *representations*, as a photograph is a *representation* of a place or an event in time.

When people make music, they come into being through the music as more than they were. They change and develop in various ways. Through the participation of individuals with dementia and those that care for them, I came to recognise music-making as more than a musical activity that focusses on how music is played and why. I understood music to be a medium for expression of the person, i.e. a medium of being. The examples that follow illustrate how music was a medium of being for the participants with dementia in differentiated ways.

6.3.1.1 Musical Physicality

A coherent flow in vocalisation was apparent in the act of singing that was usually disrupted in speech.

Sue experienced a challenge with speech at times, often struggling with words that did not appear to articulate the meaning she was trying to convey. Although the challenge of forming words was still often present during Sue's singing, the communal singing of words in familiar songs provided a sensory environment for Sue to join in with and echo words with a slight delay when they did not come easily, or they were new to her. Occasionally, Sue sang freely without words.

For Jane, voice was a medium of expression that came readily; giving voice to a frog-shaped guiro came more easily than eliciting sound with her hands, and she would often sing spontaneous melodies, both familiar and improvised to 'la'. The physical shaping of speech sounds was challenging for Jane. Occasionally a few words would come naturally, but usually the forming of speech required a conscious effort. Through regular practise with Kenneth, singing *Happy Birthday to You* (Hill and Hill, 1893) had become a supportive means for Jane to physically remember the forming of words and names.

I observed an ease and coherence in the flow of breath of participants with dementia when playing wind instruments and singing that contrasted with the disruption apparent in other aspects of their physical activity:

Although the holding and positioning of a harmonica could require support for Sue, she freely created tone. Sue used vibrato to colour her singing at times.

Dorothy's rapid, rhythmic and strong breath that sounded instruments stood in contrast to her slow gentle, touch and movement.

Jane freely created tone on a harmonica, despite needing assistance with holding and positioning the instrument at times. Jane used vocal colouring techniques to change the character of her singing in humour on one occasion.

Participating in music-making also appeared to promote rhythmic coherence in physical movement for individuals with dementia whose physical movement was disrupted:

Sue's complex clapping and leg slapping to *You Are My Sunshine* (Davis and Mitchell, 1939) was spontaneous, rhythmic, strong and sure, where her physical movement was often restricted and unregulated and followed much prompting from Ron.

Jane sang folk melodies to 'la' whilst sounding the beat with her alternating feet using 'tappers', and on another occasion, played a maraca to the beat while singing *My Old Man's a Dustman* (Donegan, Buchanan and Thorn, 1960). Singing melodies herself appeared to support Jane more in moving to and playing a 'beat' than music environments alone.

6.3.1.2 Musical Memory

For Sue, Dorothy and Jane, music-making appeared to be a means of actualising memory activity when memories were no longer articulated verbally:

Sue clapped along to the familiar rhythms of *The Blue Danube's* (Strauss II, 1866) melody. She also sang many familiar songs and articulated recognisable renditions of two familiar melodies on the harmonica. Sue did not verbally recount memories with conceptual coherence during our sessions.

For Dorothy, joining in with singing became a means to articulate memory that did not require her to search for the concepts and words that so often escaped her when articulating memories.

For Jane, singing familiar melodies was a means to articulate memory when she could no longer do so verbally, both through joining in, and spontaneously initiating.

6.3.1.3 Musical Emotion

Music-making and responsive physical movement to musical experience appeared to manifest emotional change without the need for verbal articulation. These observations were made of both carers and individuals with dementia, however they appeared most pertinent for Sue, Dorothy and Jane in the following ways given the changes in their speech:

The vitality of Sue's enjoyment and enthusiasm was often embodied in her lively singing and harmonica playing. Her singing could also be a means of expressing more contemplative emotions, particularly through sombre songs such as traditional ballads and church hymns that Sue often coloured with a rich vibrato. Singing and playing the harmonica were a means for Sue to articulate emotion experientially without the need for conceptual activity.

Dorothy expressed affection for Chris through her singing, which was particularly evident in her eye contact with him during *White Christmas* (Berlin, 1942). Manifesting her affection in this way bypassed the need for concepts around Chris' relationship to her that could become confused, such as referring to him as her husband.

The emotion evident in Jane's body language and movement in response to music and recordings was also made manifest through her singing, which could be joyful and lively, and reflective and expressive in equal measure.

6.3.2 Musical Becoming

While existing experiences and concepts about music were important starting points for our musical activity, they can be seen as the ground from which new activity grew and returned as it became familiar. Through strengthening my capacity to distinguish between presence in sensory perception and my responding activity, I experienced the stilling of conceptual ‘chatter’ as a relief from constantly trying to ‘get somewhere’ on the treadmill of purposeful activity where there is always something to be done. A move from productivity into process. However, in witnessing the conceptual disruption that dementia brought to individuals within the study, I realised this conceptual activity enabled me to act in fulfilment of my own needs and future potential for growth and development. From direct observation of participants in the study, it became apparent that such conceptual disruption can mean that individuals increasingly do not conceive of their own needs and future potential, and the activities required to fulfil them. Instead they become dependent upon people to support their fulfilment. It also became apparent that as conceptual activity increasingly becomes disrupted through the changes that dementia brings, a person’s needs may be more easily identified than their potential for continuing growth and development.

There were moments of individuals’ musical activity during the fieldwork that stood out from the activity of being as activity of becoming. Through the experiential flow of manifesting new musical experiences and intuitive, spontaneous musical ideas, individuals were becoming more than they were in new ways, beyond the established patterns of the past. They were realising their future potential through the creative activity of making music more than it was, indicating that we can experience fulfilment of our own future potential through music.

The following examples from the fieldwork illustrates the activity of musical becoming that I observed in individuals with dementia.

Sue improvised on the harmonica, transforming the exploration of musical elements into a coherent ‘musical event’; an all-consuming and coherent physical and emotional investment in the creative act of manifesting an intuitive musical ‘idea’. Later, Sue spontaneously played the harmonica again, this time her experimentation giving rise to the melody *Oh, My Darling Clementine* (Montrose, or Bradford and Thompson, 1884). Although a familiar tune, the act of producing it through the harmonica is likely to have been a new experiential activity for Sue arising out of her own creativity in the present, as, reportedly, she did not play the harmonica in the past. Sue also contributed her own creative activity to musical environments; through adding variations in rhythmic ‘body percussion’ to a recording of the familiar song *You Are My Sunshine* (Davis and Mitchell, 1939) and whistling birdsong to the sound of the rain stick.

Learning to sing the *My Uncle Silas* (Saville and Clegg, 2012) song was a new experiential activity for Jane, who also manifested intuitive musical ideas. On one occasion, she spontaneously sang an improvised melody and, on another, sang improvised harmonies to an (assumed to be) unfamiliar recording.

6.3.3 Indications from Understanding

Understanding music to be a medium of being and becoming indicates that music-making can be a coherent flow of physical activity, of actualised memory and emotion, and realisation of future potential. Musical activity can be seen as offering an alternative means for coherence for individuals whose activity is disrupted, such as actualising memory and emotion for Jane who rarely did so verbally. It is apparent from the fieldwork examples that playing musical instruments as a ‘causal’ activity can be challenging for individuals, but that making music with the breath through singing and playing wind instruments can be a medium of expression and memory free from the challenge of forming words, and of physical movement free of the challenge of limbic movement.

6.3.4 Promoting Musical Being and Becoming

Participant responses informed my development of activities and resources to promote active musical being and becoming in a variety of ways, as illustrated by the following examples.

6.3.4.1 Physicality

Recognising disruption and coherence in individuals' physical musical activities gave indications for musical activity with the potential to promote coherence:

In singing, Sue's delayed echo of words, occasional spontaneous use of word sounds in place of words and the challenge of words that changed quickly, indicated the need for a responsive slowing of pace in singing with her, reducing the quantity of lyrics in songs, and to try offering opportunities for wordless singing. Sue's echoing also brought opportunity to share singing new words to songs. Her rhythmic foot and leg movements in response to music with a regular pulse gave indication to try sounding rhythms with our feet using foot 'tappers' and for singing familiar tunes with a regular pulse to promote walking. Sue's propensity to reach out with her hand, palm down gave indication to try instruments that could be held and sounded in this manner. Sometimes Sue's responses and participation took time to manifest and I learned to prolong the opportunities for activity to give her chance to respond and participate.

Dorothy would invariably only join in singing with words and sometimes speak words rather than singing them, indicating the importance of familiar lyrics for Dorothy. Her uncertainty in singing was contrasted by her strong, sure breath in playing instruments, indicating that creating tone with breath was more comfortable with instruments than voice for Dorothy and held potential for musical exploration. Dorothy's gentle, sweeping touch in eliciting sound from instruments gave indication to explore ways to amplify these musical contributions with brushes and the possibility of sounding an open string instrument such as a lyre.

Forming words to songs was a challenge for Jane, giving indication to try wordless singing together and the use of simpler vowel and consonant sounds to promote inclusive activity with Jane. We discovered that words sung by others did not appear to impede Jane singing freely to 'la'. We explored actively encouraging Jane's participation in singing word sounds, but it became clear this was a formative activity in conceptual fulfilment of speech development, distinct from singing as an experiential activity. The freedom of Jane's wordless singing with both instrumental / vocal music and recordings alike suggested exploring instrumental recordings and music-making as an environment to promote her participation. The challenge of playing along to the strong beat of a recording for Jane gave indication to try an embodied beat through physical movement while singing familiar melodies together.

6.3.4.2 Memory and Emotion

Music that was familiar and enjoyed by individuals appeared to be the most comfortable and accessible material for participation in music-making. Familiarity and enjoyment were also important to the forms that music-making took in sessions, informing development of resources.

With Sue, our improvised rhythmic exchanges were usually short lived and lacked the energy and enthusiasm of many other musical activities we shared. Clapping along to a recording of Strauss' *Blue Danube Waltz* (Strauss II, 1866) on the other hand, was met with energetic participation and enjoyment, giving indication for a potential resource activity to promote musical being.

Jane's freedom to enjoy sung harmonic exploration with familiar and unfamiliar recordings of music indicated harmonious soundscapes with the potential to give Jane opportunity for vocal improvisation.

The following examples illustrate that there were occasions when opportunities for music-making were not comfortable or not taken up. However, they also demonstrate that there were times when unfamiliar musical activities were enjoyed and times when they afforded opportunities for participating in familiar ways, indicating the potential to explore unfamiliar music and forms of musical expression further.

I offered Sue opportunity to explore the keyboard and comb and paper, both of which were unfamiliar for her to play, and she responded to both through the familiar activity of singing; as she did to a familiar song, rather than play along with the offered percussion. Sue freely explored the harmonica and frog-shaped guiro that were relatively unfamiliar instruments for her to play.

For Dorothy, singing was not a familiar activity in her current daily life, yet she appeared to enjoy singing with Chris, despite her articulated discomfort "Well, I wouldn't want to make anybody...awkward" (S4, V1, 16:47).

Music-making that manifested memory and emotional change also gave indications for the development of session content and resources, especially when memories and emotions were no longer articulated verbally:

Sue's clapped, sung and harmonica renditions of remembered melodies gave indication to provide environmental opportunities to join in with and initiate familiar tunes. The enjoyment and enthusiasm embodied in Sue's singing and harmonica playing, as well as her more contemplative singing, indicated the inclusion of songs in a range of moods along with opportunities for harmonica playing in sessions and resources.

I took Dorothy's articulation of memory through participation in singing familiar songs as an indication to support its continuation during the sessions, and into the future, with resources to join in with. The affection that Dorothy expressed for Chris through her singing, gave indication for specific songs to include in their resources.

Jane's articulation of memory through singing familiar melodies when she could no longer do so verbally, gave strong indication to develop ways to support this activity into the future. Jane's emotional expression through singing gave indication for the inclusion of songs and recordings in a range of moods for sessions and resources that could offer opportunities for Jane to manifest emotion through singing.

6.3.4.3 Potential

The organic development of musical being and spontaneous acts of musical becoming that our activity gave rise to, prompted me to produce resource suggestions for multisensory exploration for all pairs. The suggestions offered starting points for responsive interaction, weaving together complementary sensory and music-making media, familiar and new, with the potential to provide multiple opportunities for sense perception, experiencing and musical being and becoming to grow, as did the following simple starting points during the fieldwork sessions:

Simply listening to a familiar recording with Sue promoted sustained laughter that evolved into spontaneous complex rhythmic body percussion and singing. Sue's rendering of a familiar melody and improvisation on the harmonica developed out of sensory exploration, requiring only the opportunity to play and a little practical support.

Exploring bird song with a variety of whistles and sounding plush toy birds afforded Jane opportunity to 'give voice' to the birds and spontaneously introduce a familiar song that was new to our sessions. Musical environments, recorded and live, offered Jane opportunities to improvise melodies and harmonies through vocal exploration.

6.3.5 Indications from Promoting

Indications for promoting coherence through musical activity can be garnered by observing disruption and coherence in an individual's musical activity, for example

- the disruption to both Sue and Jane's singing of words indicated to try wordless singing;
- and the coherence of Sue's renditions of remembered melodies indicated playing and singing known music and recordings of familiar tunes to join in with.

Musical characteristics can be both supportive and restrictive, depending on the individual. For example, words were a bridge into singing for Dorothy but a challenge for Sue and Jane.

Participation in familiar and enjoyed music can offer indications for the selection of musical suggestions, lyrics and recordings to include in activities and resources, and indication for musical characteristics to promote further musical exploration.

Forms of music-making that are familiar and enjoyable can be an important starting point for musical activity that can lead onto exploration of unfamiliar music and forms of musical expression that can become enjoyed and familiar over time.

Planned starting points that weave together complementary sensory and music-making media, both familiar and new, can offer multiple opportunities for musical sense perception, experiencing, being and becoming to grow.

Musical environments, recorded, live and the presence and sounding of musical instruments, can offer opportunities to promote musical being and becoming.

6.4 Musical Relating

Although the focus of understanding thus far has been on participants with dementia, music can also be observed as an activity of perceiving, experiencing, being and becoming for participant carers also. These activities do not stand out as so remarkable where there is little or no disruption to the 'usual' ways of being for an individual. However, disruption to experiential and conceptual flow for individuals with dementia participating in this study could also be seen to disrupt the flow of reciprocity in their caring relationships. The familiar ways of relating to one another had become increasingly disrupted within all the caring relationships between participating pairs:

Sue and Ron no longer shared eye contact, Sue's cooking, or conversations that had been a mainstay of their relationship. Most of Sue's activity in fulfilment of ideas was initiated and accompanied by verbalised conceptual meaning as prompting from Ron; concepts that appeared to convey little to Sue of what was happening and what was required of her, evidenced by her resistance, confusion and uncertainty in response. Sue still participated in relational activity through sense perceptible means, including facial expressions, laughter, touch, movement and the expression of verbal communication more than its conceptual meaning, although she did speak lucidly at times.

Conceptual meaning as a means to relate between Jerry and Lynda was chiefly restricted to questions from Lynda and physical indication of a positive or negative response from Jerry. Experientially, they related through reciprocal touch and eye contact, Jerry reaching out to Lynda and holding her hands, conveying a striking presence in connection through his direct eye contact that I experienced during our initial session. Lynda appeared attuned to Jerry's experiential activities of being and relating, recognising them and responding to them.

Verbal communication of conceptual meaning appeared to be Dorothy's primary means of relating to others, although at times the concepts could loosen and become confused, vague or thematic, having an experiential tenor such as appreciation or dislike. The roles in her relationship with Chris had changed in response to the disruption to Dorothy's activity, with Chris tending to the practical tasks of daily life that Dorothy used to do such as cooking. Sharing their environment and food were experiences they both continued to enjoy together, offering opportunity to converse. Trips out shopping and to places of interest were becoming less possible and Chris spoke of wanting opportunities for reciprocity.

Communication of conceptual meaning appeared still to be a principle means of relating between Jane and Kenneth, although the flow of activity had become disrupted. Jane seemingly tried to convey conceptual meaning physically through gesture, vocal sound and direction of gaze, to which Kenneth would respond with verbal guesses as to her meaning. This process could be frustrating for them both and it was apparent at times that the meaning Jane was trying to convey dissipated before it could be understood. From my own relationship with Jane, I found that she often related to me in experiential ways through her touch, offers of objects and sharing sensory perception such as the smell of her perfume.

In the examples above, it is apparent that the distinctions between experiential and conceptual meaning differ from the widely used binary distinction between verbal and nonverbal communication. Jerry and Jane appeared to communicate conceptual meaning nonverbally using body language. Sue and Dorothy appeared to communicate experiential meaning using words. Whereas verbal communication can manifest concepts *about* experience, I found that the apparent meaning conveyed in Sue and Dorothy's examples could be less readily understood as conceptual meaning of the words. I found their words more readily conveyed their emotion and memory pictures through the 'theme' of words, and the nonverbal ways in which they were expressed.

Understanding of these distinctions by the carers seemed equally important for communication to become a reciprocal channel of relationship. For example, the qualities with which the words were spoken, and the tenor of the words used by Sue and Dorothy often appeared to be 'masked' by the conceptual understanding of words for Ron and Chris, resulting in literal correction rather than reciprocity. Recognising the experiential meaning conveyed in both verbal and nonverbal communication could potentially have promoted mutual reciprocity between these participants in the study.

For all the participants caring for a person with dementia, conceptual communication was the readiest means of relating. I frequently experienced the difference between

relating conceptually with them and experientially with individuals with dementia through sensory participation. Trying to do both simultaneously could be challenging, and often resulted in my focusing on one form of communication or the other, which could be alienating to the other person. There were also times when music became a relational medium, a coherent reciprocal flow of experiential activity where this flow was usually disrupted. Experiencing one another as music was a means for relational being and becoming through reciprocally promoting, realising and recognising our individual and shared future flourishing. In this way it is possible to regard music as a medium of warmth and caring between people; a form of empathic activity with the potential to promote being and becoming of self and other. The following examples illustrate times during the fieldwork sessions when musical experiencing and music-making promoted relational activity and became relational activity.

6.4.1 Music Promoting Relating

Music and recordings provided an environment that promoted relational flow between individuals participating in the study. Our individual activities of 'being' in response to the active perception of music and recordings during fieldwork sessions such as touch, movement, talking and laughter often became reciprocal activity:

Between Ron, Sue and I, a recording of music supported our playful interaction with balloons; Sue sitting forward and reaching out to make physical connections with her balloon, using it rhythmically with the music. Sue's reaching into space and receptivity to offered hands that led to her leading and following in rhythmic arm movements to the recording with Ron. The emotion that Sue manifested as laughter to a recording of *You Are my Sunshine* (Davis and Mitchell, 1939) became a shared emotion between us, with Ron and I joining in Sue's laughter.

I shared hand-held arm movement to lively recordings of music with Dorothy and Chris on one occasion. Shared listening to recordings was a mutually relational means to verbally share our stories with both Dorothy and Chris; an activity that was not mutually accessible for the other pairs. Both Dorothy and Chris shared verbalised memories evoked by listening to recordings of music and Chris became aware of stories and tracks from Dorothy's life he had been previously unaware of, and memories for music they had shared from his childhood, long forgotten.

I shared and mirrored rhythmic arm movements with Jane to our playing and singing, and to recordings, of various styles. Jane, Kenneth and I also struck foam Morris 'sticks' to recordings of Morris dancing music together.

Combining opportunity for other sensory activity with musical environments appeared to be a supportive means to promote experiential reciprocity:

Ron's speech decreased during several activities, including our balloon play and exploration of bird calls and feathers with recordings of songbirds and music.

For Chris, sharing images accompanied by recordings of music provided an experiential foundation for the conceptual reciprocity of conversation with Dorothy that was usually unsustainable when abstracted from her experience. This enabled Chris to get on a more experiential 'wavelength' with Dorothy; as he observed "...it helps me kind of focus and stop, and look at things and perhaps maybe get on more of a wavelength with where Mum is at..." (S12, V1, 50:41).

6.4.2 Music as Relating

As discussed earlier, I came to recognise perception of music as an active weaving together of a 'musical space in time'. Through the activity of collective music-making during the fieldwork, I also came to recognise musical creation as such. There were several times during the fieldwork where our playing and singing came together in musical coherence. These musical events were not necessarily structured 'pieces' but existed 'in the moment', revealing both the familiar and unknown future in real-time through collective creation.

During the fieldwork sessions, musical being and becoming became a means for experiential reciprocity within the caring relationships of participants and between them and me, through which individuals supported, promoted and recognised the musical being and becoming of others. The flow of experiential relating also often promoted other reciprocal activity such as touch, movement, talking and laughter.

The sensory exploration of musical instruments brought all participants into physical relationship with others by sharing the practicalities of creating musical elements such as timbre and tone and the collaborative playing of instruments. Collaborative exploration of musical sound was a means of 'doing with', as distinct from the 'doing for' of many caregiving interactions within the relationships of the study participants:

When exploring the frog-shaped guiros, Sue found her own way of sounding the guiro by raising it to meet my stick rhythmically.

Lynda held the singing bowl for Jerry to strike and shared movement of the ocean drum with him.

Dorothy and I struck a shared bodhrán (see [Music Glossary](#)) with maracas in responsive interplay.

Jane and Kenneth shared rhythmic playing of a tambourine.

Exploring and playing instruments and singing often introduced fun and playfulness to our interactions as opportunities for experiential reciprocity of emotion, including:

Shared laughter between Sue and Ron at the conclusion of singing *Oh, my Darling Clementine* (Montrose, or Bradford and Thompson, 1884), and between Sue and I over her response to our explorations with comb and paper.

My singing with Lynda was a means to reach out to Jerry through the senses; both Jerry and Lynda indicated that he enjoyed our singing during our brief contact.

I shared laughter with Dorothy and Chris over the comical sounds that we took turns to play on the practice chanter and duck whistle. On one occasion, singing with Dorothy and Chris brought a moment of closeness between them through singing and eye contact that was moving to witness.

Jane became introspectively immersed in her experiential response to Kenneth's blues guitar playing. I shared laughter with Jane and Kenneth while we sang humorous songs.

Shared memory for familiar songs and melodies realised through our collective singing and playing brought opportunities for experiential reciprocity that did not depend on conceptual understanding, or even words in many instances:

Singing with Sue and Ron and playing instruments with Jane and Kenneth, both spontaneously and with lyric/chord sheets, was a frequent and comfortable activity that gave opportunity for the free flow of voice and tone where conversation was restricted, supporting each other's activity of being.

Singing familiar songs from the past was also a means for discovery and new activity in the present.

Through singing, Chris witnessed Dorothy's capacity to be and relate in new and forgotten ways beyond the habitual patterns of their daily lives; through listening, he discovered musical pieces and recordings from Dorothy's past that were new to him.

Jane and Kenneth discovered uplifting shared participation in playing and singing rediscovered songs they both knew such as *My Old Man's a Dustman* (Donegan, Buchanan and Thorn, 1960). For Jane, singing familiar songs was also a means of conceptual reciprocity, participating in conversations about music through music-making rather than speech, such as singing carols when Christmas was spoken of; conceptual activity that Kenneth acknowledged with incredulity.

Familiar melodies were both a means of reciprocity through the unity of unison melodies and also through the 'difference' of harmony, instrumentation and counterpoint:

Sue played a chordal rendition of *Blue Danube Waltz* (Strauss II, 1866) on the harmonica along with my singing the melody.

Dorothy played the drum with maracas in rhythmic interplay with me.

Jane held harmonic lines of familiar songs, independently singing *Frère Jacques* (Traditional) and a harmony line on *Happy Birthday to You* (Hill and Hill, 1893), and sometimes took turns in music-making.

Participation in familiar music often developed through experiential reciprocal exchange, without conceptual planning or agreement, for example:

Sue led me in rhythmic arm movement and song in response to my sensory presence and a musical environment.

Lynda joined my hummed melody that opened out into song through experiential agreement.

Kenneth and I spontaneously responded to Jane's sung reprise of *Speed Bonny Boat* (Macleod and Boulton, 1884) with supportive harmony and percussion.

Musical reciprocity sometimes grew out of sensory exploration and play, realising new musical experience and activity by responding to one another in the present:

Exploring single notes and chords on the harmonicas became exchanges of harmonica and voice with Sue and Ron, and an 'accidental' exchange developed through exploration of bird calling.

Chris and I shared a playful interaction on coconut shells.

Jane sang exchanges with me, usually during our time alone, that I would sometimes invite by starting to sing.

When new songs and improvisational activities were initiated as deliberate acts rather than arising from sensory exploration or 'invitation', they were often accompanied by a tangible uncertainty. Sometimes these activities 'fizzled out', other times they brought opportunity for reciprocity and new experience and activity:

Sue exclaimed uncertainly "Oh dear!" (S3, V1, 29:34) during playful interplay of words, sounds and melodic phrases with Ron and me, and "I don't think so!" (S4, V1, 15:43) in response to the comb and paper, finding firm ground in singing familiar songs in both instances.

Fitful improvisation on combinations of percussion, lyre and guitar with Dorothy and Chris on one occasion became a coherent, rhythmic 'event' beyond the support of a recorded track; Chris regulating his playing responsively to the interplay between Dorothy and me.

Jane, Kenneth and I took ownership of the new *My Uncle Silas* (Saville and Clegg, 2012) song as it became a familiar part of our shared repertoire. Hesitancy in echoing the new call and response songs relaxed into a coherent musical exchange and brought opportunity for Jane's conceptual contribution of a new word to a song. Uncertainty for Jane in creating sound with the harmonica became animated chordal improvisation to a recorded track with Kenneth and me.

There were also examples of how new musical activity was enjoyed and could also become familiar and enduring. Activity that was mutually enjoyed and familiar to the carer was that most readily continued without my presence:

Sharing exploration of movement and instruments had been enjoyable activity for Sue and Ron with my support but had not continued without it. Singing familiar songs had previously been a spontaneous activity that appeared to become more frequently an intentional, shared activity outside our sessions.

Singing and listening to recordings with Dorothy and Chris had become enjoyed, familiar activities with my support. The less familiar activity of singing had not continued without me, whereas listening did.

Jane enjoyed music that was new to her and the new *My Uncle Silas* (Saville and Clegg, 2012) song became a familiar favourite for both Jane and Kenneth. Sharing listening to recordings and music-making together became enjoyed, familiar activity that endured for them beyond our sessions.

There were activities that were tentative and hesitant in their unfamiliarity, including Dorothy and Chris' singing together, that may have had the potential to become familiar and enjoyable activities over time, in the same way that activities that were comfortable in their familiarity had become so, such as spontaneous singing round the house for Sue and Ron.

As well as inspiring experiential ideas in the moment of reciprocity, our musical and sensory activity also inspired new ideas and actions to further promote musical and sensory reciprocity:

Ron wrote several verses to a familiar tune in his own time and shared their existing instruments, recordings of music, objects and song lyrics during our sessions spontaneously. Ron also introduced the *Rebel song* from his childhood that was new to me.

Chris shared ideas for potential activities and resources and also shared their existing instruments, recordings of music and objects during our sessions spontaneously.

Jane introduced songs through her spontaneous singing. Kenneth purchased a new tin whistle and guitar and shared their existing instruments, recordings of music, objects, song lyrics, and chords during our sessions. Kenneth also introduced the *My Uncle Silas* (Saville and Clegg, 2012) song, new to us all.

At a time when their familiar ways of contributing to the lives of others through intentional activity were disrupted for the participants with dementia, music-making, especially singing, became a means of enriching the experiences of others within their caring relationships. This activity was recognised by carers verbally:

Ron commented “This is a pleasure to have Sue singing” (S13, V1, 13:01).

Chris said to Dorothy “That was brilliant. Well done, well done, fantastic. And you sang the whole thing...That was wonderful that was, that was great to hear you do that [sing]” (S9, V2, 10:01).

When talking of the recording we made of *My Uncle Silas* (Saville and Clegg, 2012) song the previous week, Kenneth commented on the verse sung by Jane and me “I’ve sent off that song to ...our sons and other people. That second verse...sounds really like a duet. It fitted in very well. Not necessarily words but in tune with... what you were singing” (S10, V1, 03:20).

6.4.3 Indications from Understanding

It is evident from the fieldwork examples above that experiencing and making music together can promote relating in mutually accessible ways where familiar relational activity has become disrupted through the changes dementia can bring. Musical activity can also be a means to move beyond conceptual activity for caregivers to a common ground of experiential relating where individuals can meet beyond the roles of caregiver and cared for. Not only can music-making afford opportunity to mutually enrich each other’s experience through reciprocal experiential and conceptual activity, it can also be a means of relational autonomy by ‘holding one’s own’ in musical harmony and difference, and realising shared future potential. This understanding indicates a potential for musical activity to play a supportive role in caring relationships for people with dementia living at home, and potentially in other settings.

The fieldwork examples above indicate that musical relating is a developmental, generative activity. Familiar music can provide material to unite people in planned and spontaneous ways. Recordings and exploration of both the familiar and the unfamiliar in music-making can be a foundation for moving into, and returning from, new shared musical experiences and activities that require varying degrees of ‘living with uncertainty’. Sharing music and other sensory activity can inspire new ideas, enthusiasm and actions to further promote reciprocity.

Music is an accessible medium that can be shared without the need for developing musical 'skills'. Through experience over time, music can develop into a mutually enjoyable, shared medium within caring relationships that can continue to grow as the unfamiliar becomes familiar through experiential exploration. My role in introducing and promoting opportunities for enduring activity indicated the need for initial support for the new to become familiar and sustainable, and individuals to develop confidence in, and ownership of, their musical activity.

Differentiating between conceptual and experiential meaning offers a more nuanced understanding of verbal and nonverbal communication. Recognising these distinctions could be a helpful contribution to understanding that supports caregiver communication for individuals with dementia.

6.4.4 Promoting Musical Relating

Media and activities that were enjoyed were the foundations for coherent relational musical activity with each pair. This starting point afforded opportunities for realising shared future potential as we ventured into the spontaneous, the unfamiliar and the uncertain, that in some instances became familiar and enjoyable ground from which to venture even further afield. Exploring this common ground with each pair gave indications for developing session activities and resources which could promote coherent reciprocal activity:

Sue and Ron's shared enjoyment of singing where conversation was restricted indicated exploration of singing in different ways during our sessions and the provision of songbook resources to support singing into the future. The fun we all shared during musical activities such as playful interaction with balloons and comb and paper gave indication to provide resources for the continuation of such activities.

Jerry and Lynda's enjoyment of singing gave indication to explore this further, had we continued with our sessions.

Dorothy and Chris' shared enjoyment of images and recordings of music gave rise to their inclusion in resources for continued sharing. The closeness and enjoyment they shared through singing inspired the creation of songbooks with recordings to sing with, and suggestions to cultivate singing as a more comfortable activity. The fun we shared creating comical sounds indicated the inclusion of sound makers, and the pair's tentative movement, the inclusion of recordings for its promotion in their resources.

Jane and Kenneth's shared enjoyment of music-making and singing where conversation was restricted occasioned recordings, chords, lyrics and instruments for the playing of tunes and singing of songs explored during our sessions, including the humorous songs that evoked our laughter. Their enjoyed listening to recordings of classical and world music inspired a collection of recorded material for sharing, accompanying images from an art gallery they enjoyed visiting in the past, and foods and sensory objects from favourite countries. Jane's enjoyment of spontaneous movement to music and recordings with me, and Kenneth's love of Morris dancing gave indication to encourage shared movement between them during our sessions and to provide suggestions for its continuation within their resources.

Activities that were particularly enjoyed by either individual in participating pairs were shared in sessions and included in resources as they offered the possibility that this enthusiasm could be shared within their caring relationship and so promote a coherent flow of relational activity:

Sue's enthusiasm for movement to music and recordings with me gave indication to encourage shared movement with Ron during our sessions and to provide suggestions for its promotion within their resources. Ron's love of creative writing and singing inspired me to encourage Ron to unite them by writing lyrics to sing to and with Sue. Ron's enthusiasm for new experiences led me to suggest exploration of new listening material to share with Sue after her move into care.

I developed the ideas for potential activities and resources shared by Chris and included suggestions for existing instruments, recordings of music and objects that he shared spontaneously during our sessions. For Chris, forgotten memories of enjoying music with Dorothy in his childhood brought new, enjoyed songs to our sessions.

Jane's enjoyment of movement to music with me gave indication to encourage shared movement between Jane and Kenneth during our sessions and to provide suggestions for its promotion and coloured scarves within their resources.

Kenneth's enthusiasm for instrumental musicianship was encouraged through music-making during our sessions and promoted in the resources. Jane's readiness to contribute to sung exchanges inspired the *'La' that Tune Resource* (see [Chapter 5](#)), that offered Jane the opportunity to initiate and participate in singing familiar songs and the possibility of taking turns with Kenneth. I included songs that they each contributed to the sessions in their songbook resource.

The organic development of musical reciprocity out of sensory exploration and play with instruments and voice and through the 'difference' of harmony, instrumentation and counterpoint indicated the inclusion of resources to support such sensory exploration:

Coconut shells and D-bells with recordings and songs to play along with were provided for Sue and Ron. An accessible harmonica for Sue, as a complement to the one owned by Ron, and bird whistler for expressive exploration and exchanges with Sue were offered but not taken up.

Resources for Dorothy and Chris included a selection of simple percussion and whistles for participation in recorded soundscapes.

For Jane and Kenneth, an accessible harmonica and a range of simple percussion were provided for continuing their music-making together, along with recordings, chords and song lyrics to play along with. Recordings of rounds and soundscapes were designed to support them in creating harmony and vocal exploration mutually.

The potential for reciprocity and new activity to arise from new songs and improvisation, and for the unfamiliar to become familiar and enjoyable over time informed my development of resources. Opportunities for these activities were explored during our sessions and included within resources in various ways with the possibility to promote shared future potential:

Suggestions for ways to continue with the playful exploration of voice and sounds that we enjoyed during our sessions and for sharing new lyrics to songs were offered to Sue and Ron.

I provided suggestions for shared listening to recordings that were likely to be unfamiliar to Chris and familiar to Dorothy, so together they might continue to explore music from Dorothy's past that was new to Chris.

In the resources for Jane and Kenneth, I included recordings and lyrics for the new songs we explored together during our sessions and others that shared characteristics with familiar, enjoyed songs. Recorded tracks with suggestions for music-making activities were designed to offer opportunities for familiar and improvisatory exchanges between them.

6.4.5 Indications from Promoting

Sharing musical activities that are mutually or individually enjoyed by people in caring relationships can offer indications for promoting coherence and creating opportunities for spontaneous and new activity.

6.5 Conceptual Activity

When the flow of conceptual activity, manifesting concepts in thought and action, is disrupted, it is apparent that it can still be possible for individuals to come into being

and relationship with others, and realise future potential, through music as experiential activity. However, it is also clear that conceptual activity is often necessary to provide opportunities and support for this experiential activity. The following examples highlight how conceptual activity both inhibited and promoted our musical activities during the fieldwork sessions. Indications for sharing music within the caring relationships of people with dementia beyond the study are discussed.

6.5.1 Practical Support

Understanding of the need for physical assistance and conceptual explanations were necessary at times for supporting each other's musical activities, especially when the practicalities of an activity were proving to be a barrier to participation:

I supported Sue to reposition her harmonica so that she could explore its full range, and a guiro for exploration with a tine.

Lynda held the singing bowl for Jerry to strike.

Chris helped Dorothy to position the practice chanter and explained that she needed to blow into it, which she then did, with gusto.

There were also instances of explanation and physical support that served to illustrate the limitations conceptual activity imposed on musical activity. In playing unfamiliar instruments for the first time, individuals were free of the host of existing concepts that accompany familiar objects and activities and could find their own ways into playing through exploration. Where conceptual activity was disrupted for participants with dementia, I observed this exploratory, sensory approach to playing culturally familiar instruments such as tambourines and drums and how this activity could be interrupted and 'corrected' by those caring for them according to their concepts of how it 'should' be done:

After sounding the rain stick himself, Ron gave verbal instructions to Sue on the required technique. Sue whistled like a bird and moved with the rain stick but did not produce the anticipated rain sound. Ron responded by physically supporting Sue to create the sound of rain rather than responding to Sue's sensory invitation.

Kenneth interrupted Jane's exploratory playing on a tambourine in playful interaction with my sounding guitar, demonstrating how to play a beat. Jane appeared indignant.

Conceptual verbal explanations could also be limited in supporting musical activity and require sensory demonstration, not only because of the disruption of conceptual

activity for individuals with dementia, but also because music-making is a sensory activity. For this reason, I often accompanied or replaced verbal explanations with sensory examples, such as playing instruments in different ways to demonstrate some possibilities for participation.

My use of thematic associations between activities were, in some cases, conceptual, such as the link between sensory objects including carbolic soap and songs about washing. While these connections did not usually appear to be familiar associations for individuals I was working with, they did facilitate continuity between different sensory activities such as smell, touch and song. For Jane, connecting sensory associations with concepts appeared to come more readily rather than vice versa, such as spontaneously singing a lively traditional dancing tune upon mention of the words ‘Morris dancing’, or carols for ‘Christmas’.

6.5.2 Familiarity

Musical concepts around genre, style and artist also helped to identify potential music and recordings to share with all participating pairs. When trying new activities, existing concepts could offer context to promote understanding:

Ron’s own past physical memory event gave him a conceptual point of reference for my suggestion to try standing to hymn music with Sue.

Chris’ existing thoughts about music as a supportive medium in his own life appeared foundational to his understanding of the potential for music to be supportive for Dorothy, despite her comments about music holding little interest for her. Chris’ perspective supported our music-making, as he was prepared to participate in the unfamiliar and uncomfortable in exploring what might be supportive for Dorothy.

In contrast, there were also times when individuals’ existing concepts appeared to limit their recognition of musical future potential. The activities of musical being, becoming and reciprocity that emerged through sensory exploration often went unrecognised or not responded to, meaning so too were the opportunities to promote them, effectively limiting individual and collective future potential.

Ron’s existing idea of the benefit music could offer Sue and his concepts about the future appeared to overshadow their activities. For Ron, Sue’s spontaneous harmonica improvisation appeared to be an enjoyable experience, but for him, our efforts were too late, and there was no future potential for growth and development, only decline.

Jane apparently had existing ideas about singing and music-making together with Kenneth that were evident from her hesitancy and turn taking during our collective music-making and singing as a group, and her shushing of Kenneth's participation on one occasion. Kenneth often appeared reticent to join in spontaneous experiential musical relating with Jane and me, compared to 'orchestrated' music making of familiar instrumental pieces and songs.

6.5.3 Encouragement

From unrecorded carer comments at our initial meetings, it was apparent that existing concepts about the potential for musical activity to be supportive for those they cared for appeared to be a motivating factor for their participation in the study:

Ron seemed optimistic that Sue might find participating in the study beneficial.

Chris hoped for tools and things to do together that 'work' in the way the company of Dorothy's canine companions did.

Kenneth hoped that the study could be stimulation for Jane beyond watching TV.

Verbalised concepts were a means of expressing appreciation for each other's music-making during the fieldwork sessions, encouraging further activity, as discussed above. There were also times when verbal encouragement appeared to be experienced as coercive:

Jerry 'cooperated' in playing the singing bowl.

On several occasions Dorothy sang after being prompted by Chris and appeared uncomfortable. Once, when not prompted, she joined in of her own accord eventually.

My role as facilitator appeared to be conceived of as necessary for the development of musical activity from the comments made by carers:

Ron observed "It's difficult for me to say, 'let's try this' because, unless I've actually done it, I don't know what it is that we might be trying, do I?" (S2, V2, 33:24) and made several references to having done their 'homework' and to me being 'in charge'.

Chris commented "...I think it's been great having you come here really and certainly it's probably helped bring us kind of closer together as well...getting a chance to spend that time together and listen to things and talk about things. 'Cause we wouldn't have had that otherwise, 'cause there wouldn't have been someone to kind of facilitate that, so that's been great that has...it's brought me closer to Mum I'd say, a lot closer...(S12, V1, 50:48)

The increase in musical activity, throughout and following our sessions, indicated that my participation and facilitation had been promoting and supportive. However, it was apparent from all completing pairs that the activities we had enjoyed together in coming to know each other and develop resources were not necessarily the same activities enjoyed within their caring relationships. For example, country dancing for Sue and Ron, instrumental exploration for Chris and Dorothy, and combining recordings with flavours of other countries for Jane and Kenneth.

6.5.4 Ability

Meeting the challenge of conceived musical mastery promoted music-making for carers Ron, Chris and Kenneth, who all showed enthusiasm for the challenge of creating sound and music with instruments. However, this enthusiasm did lead, at times, to absorption in independent activity and missed opportunities for reciprocity. There were also instances that served to illustrate that concepts around musical ability could restrict musical activity. Uncertainty and doubt in one's own musical abilities were apparent in many of the participant actions and comments:

Ron commented about being 'no good' on the guitar, needing practise on the harmonica and losing his learned tunes on the keyboard. His awareness of 'mistakes' stopped the flow of his playing.

Chris spoke about the skill needed to play musical instruments "...unless you've got a certain skill, you can't really create anything that you're going to want to listen to for a long time" (S12, V1, 53:18).

The free flow of Jane's spontaneous singing could be interrupted with a frown or expression of puzzlement, as if unsure she was getting it 'right'.

For several individuals, singing was apparently an activity associated with ability, quality and the emotional responses that the idea of it evoked for individuals:

Ron referred to his "...embarrassment of singing to [me]" (S1, V1, 21:43) in our first session.

Both Dorothy and Chris made remarks about their feelings of awkwardness at the conceptual prospect of singing.

Kenneth indicated off camera that he only sang with Jane when she could 'put up with his voice' [paraphrased].

Over the course of the fieldwork, our musical activity called to the imagination and enthusiasm of some of the participant carers, who developed new concepts and creative ideas about the future potential for music in their lives:

Ron wrote new song lyrics to share with Sue.

Chris shared new ideas for musical activity, recognised listening to recordings as a means to get on Dorothy's 'wavelength' and used them as an environment to promote relaxation for Dorothy when she felt anxious.

Kenneth saw their ongoing musical activity as a "...change of life" (S12, V1, 22:01).

6.5.5 Indications

The examples above elucidate understanding that conceptual activity can both promote and inhibit musical experiencing, being, becoming and relating for individuals with dementia whose conceptual activity is disrupted. This understanding suggests the potential for development of conceptual indications to support carers, and individuals with dementia whose disruption to conceptual activity is minimal, in promoting mutual exploration of music as shared experiential activity. Given that concept-based experience can help to promote understanding, an experiential foundation for exploring these new concepts is likely to be more supportive than abstract concepts.

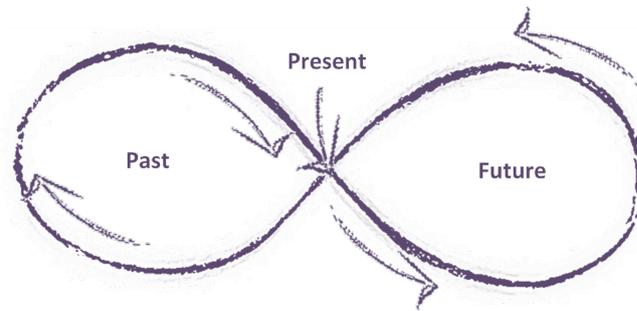
It is apparent that an understanding that music could be beneficial for their loved ones can be a motivating factor for carer participation in musical activity. Facilitation can be necessary to promote and support sensory, artistic and musical activity but enjoyment by people in caring relationships does not necessarily equate to activity that will be enjoyed independently.

6.6 Past, Present and Future

It has become apparent to me through the progression of this study that the flow of life in the present draws from both the past and the future. I realised that activity of the past, the memories held in our bodies, the concepts we have formed, our memory pictures of past events and the emotions evoked by our memories are essential for our ability to engage in the activities of daily life, which would be extremely limited if we started each day with a blank slate. It also became apparent to

me the extent that day-to-day activities are also dependent upon our ideas for the future. The deeds we perform are in light of a future outcome, whether this is conceived or not. From breathing, to climbing a mountain, the past is the ground out of which the future flows into the present (see Figure 49). The ways we cultivated this ground during the study brought the opportunities to realise flourishing that otherwise would not have occurred.

Figure 49: Living Activity



Through becoming a part of participants' lives, I came to understand that sharing familiar activity afforded by the enduring capacities of an individual in enjoyed ways can become treasured activity in the present through the changes dementia brings to individuals and their relationships. I also observed that in holding on to the unchanging solely in the context of what has changed, the possibilities in the present appear to shrink as an individual is decreasingly able to engage in the activities of life as they used to. This observation was reflected in the threads of contraction, restriction and stasis that emerged through understanding during the fieldwork (see [Chapter 5](#)). Exploring what endured for each individual in the present as the fertile ground for new experiences, activity and ideas introduced expansive developmental movement to the contracted and staid through acting in light of future potential, rather than in the shadow of past abilities. Thus, musical activity can be a means to develop movement in restrictive conditions of change.

Through sharing the 'enduring', musical activity promoted continuity as well as promoting the new activities of change discussed above. This was especially true for Sue and Ron. Their shared enjoyment of recordings of music and radio listening that began when they met, and singing familiar songs together with lyric sheets that had become familiar activity across our sessions, remained coherent activity of shared experiencing and relating through the profound disruption of Sue moving into

residential care. This contrasting role of music indicates that musical activity can also be a means to sustain continuity in disruptive conditions of change.

6.7 Summary

The harvest of understanding cultivated by entering more deeply into my experiences of the fieldwork through gentle empiricism indicates a potential for music to play a supportive and developmental role in caring relationships in the following ways:

- Experiencing music and recordings can promote a coherent flow of experiential, conceptual and relational activity where the flow of these activities is disrupted for individuals with dementia and their caring relationships.
- Music-making can promote and be a coherent flow of experiential, conceptual and relational activity where the flow of these activities is disrupted for individuals with dementia and their caring relationships.
- Musical activity can be both a means to develop movement in restrictive conditions of change and to sustain continuity in disruptive conditions of change.
- As experiential activity, music-making offers a greater range of possibilities for being and relating beyond conceptual activity and a means to realise creative future potential, both individual and collective.
- Musical activity can be enjoyable for carers too and offer opportunities for mutual experiential relating where individuals can meet beyond the roles of caregiver and cared for.

In this way, music can become a medium for contact, connection and communication that looks to the future as well as the past with enjoyment and enthusiasm through the changes that life brings, and a continuing means for individuals to flourish in fulfilment of their future potential. This understanding of the ways that music can play a supportive and developmental role in caring relationships can be a catalyst for promoting shared musical exploration for people in caring relationships beyond this study. The indications arising from this understanding and the ways in which the phenomena were promoted during fieldwork are further

informed by indications gathered from the research of others through a systematic review of the literature in the following chapter. Collectively, these three sets of indications (see Chapter 4, Chapter 6 and Chapter 7) form the findings of this study.

7 Gathering Indications

...we neither discover an objective reality nor invent a subjective reality, but that there is a process of responsive evocation, the world 'calling forth' something in me that in turn 'calls forth' something in the world.

(McGilchrist, 2019, p. 133)

7.1 Introduction

From the kernel of my own gentle empiricism process, the indications harvested in the previous chapter are augmented by indications gathered from academic literature. In order to comprehensively and robustly source relevant literature, I have conducted a systematic search and review to arrive at the final selection of articles. The purpose and aims of the final articles are various and are largely concerned with utilising music towards achieving health and well-being outcomes. As this study is concerned with phenomenological understanding and responsive development rather than achieving a quantifiable outcome, it was the story of *how* music was shared and developed within caring relationships that bore relevance. In most cases, this story was a thread in the backdrop of an article's journey to achieving these various aims, and my task was to tease out these threads and bring them to the fore. The relatedness and differences apparent within the stories of musical development gave rise to understanding that is presented as a creative synthesis.

7.2 Approach

In order to gain as comprehensive a view as possible of others' research and experience of the phenomena of study with transparency and rigour, I have engaged in a systematic search process to identify relevant literature for review. Although I have not limited my field of search to qualitative literature, the nature of my inquiry is such that most literature of relevance is qualitative.

Qualitative evidence synthesis is becoming increasingly accepted as a valid means to inform policy and practice (Dalton *et al.*, 2017; France *et al.*, 2019). Of the various approaches to reviewing and synthesising qualitative literature, meta-ethnography is thoroughly established in health-related research and recognised for its methodological rigour (Campbell *et al.*, 2011; France *et al.*, 2019; eMERGe Project, 2020). The methods of conducting a meta-ethnographic synthesis are consistent with the dynamic approach I have taken to this study; in that they offer a comprehensive range of activities for ‘going deeply’ into the concepts presented in literature.

Although I have synthesised literature using methods that are common to meta-ethnography, the understanding that underpinned this activity at methodological, epistemological and ontological levels differed from that outlined by originators Noblit and Hare (1988). I have treated each article as presenting the phenomena of study in different ways; a multiplicity in unity of music within the homes and caring relationships of people with dementia. I have not reduced or created my own interpretations of authors’ original meanings, as in Noblit and Hare’s approach, because a ‘dynamic’ understanding of a text does not find meaning as intended by the author, “...a repetition of something past” (Gadamer, 2004, p. 394), or in interpretive, “...subjective variations imposed on the text” (Bortoft, 2012, p. 119). Rather, meaning is a “...manifestation of the possibility of the work which is in accordance with...[the] specific situation, and is not a preformed possibility which is already there in the text” (Ibid., p. 120). In response to a process of going more deeply into the concepts, or parts, meaning appeared through my activity of understanding with no divide between understanding and meaning. This has resulted in a synthesis that is subtly but significantly different from one that I would have produced using traditional methods.

Where a traditional meta-ethnographic synthesis is concerned with “...reduction of the data (Noblit and Hare, 1988, p. 33) and then “...making a whole into something more than the parts alone imply” (Ibid., 1988, p. 28), my dynamic concern has been what was essential to all presentations of the phenomena of study in the literature. Ultimately, these processes work in opposite directions. Creating interpretations at increasing levels of removal from original meaning constitutes a process of abstraction, in contrast to seeking the essence of meaning that becomes itself more fully through each unique manifestation.

7.3 Methods

I have engaged in a seven-stage process based on the methods for meta-ethnographic synthesis as laid out by Noblit and Hare (1988), with reference to a worked example (Britten *et al.*, 2002) to help me navigate the process in practice:

1. Getting started
2. Deciding what is relevant to the initial interest
3. Reading the literature
4. Determining how the literature are related
5. Translating the literature into one another
6. Synthesising translations
7. Expressing the synthesis

These seven-stages did not constitute a linear progression, rather a range of activities that were gradually introduced and that overlapped with each other in various configurations as part of a creative process. The movement from coming to understand how the literature are related through active participation in reading and writing to development of a synthesis out of this understanding, reflects the gesture of gentle empiricism (see [Chapter 3](#)).

7.3.1 Getting Started

The interests that motivated me to conduct a literature review arose through development of the current study as a wish to strengthen my findings by situating them within a broader context.

7.3.2 Deciding What is Relevant to the Initial Interest

7.3.2.1 Search Strategy

Major and Savin-Baden's (2010) question development framework provided a means to form a question from the essential elements of the current enquiry as a foundation for the search strategy:

Person: Person with dementia and carer

Environment: Living at home (person with dementia)

Intervention: Shared musical activity

Comparison: Evident concepts

Outcome: Indications for promoting and supporting music

Points for ‘comparison’ could not be usefully anticipated but emerged through the reading experience as the act of differencing/relating. Determining the ‘outcome’ element has been a developmental activity throughout the screening process, ultimately producing the following question for the literature review:

What are the indications for promoting and supporting shared musical activity in the caring relationships of people with dementia at home?

Databases appropriate for a literature search in the cross-disciplinary field of arts and health were identified through consultation with my supervisory and institute librarian teams, as: Academic Search Complete, PsycINFO, MEDLINE, CINAHL, PubMed, Scopus, Proquest Central and Web of Science. Newspaper and magazine articles were filtered from Proquest Central results due to their high number of returns.

The final search term string served to limit returns by participants, setting and exposure of interest. The search strategy was developed using various iterations in refinement of the final search string for all databases within the title, abstract and keywords search fields:

musi* OR piano OR keyboard OR percussion or drum* OR cello OR bassoon OR viola OR harp OR trombone OR bass OR flute OR guitar OR oboe AND dementia OR alzheimer* AND home OR "in home" OR community OR "ageing in place" OR house

Search results could not be effectively limited using search terms, as studies with a focus on people living at home frequently included terms related to institutional care or community settings for music activities in either abstract or keywords. The term ‘group’ was not used as an exclusion criterion within the search string as the term was used in articles to refer to participant sample groups as well as collective gathering for an intervention.

Database searches were conducted in April 2019 and updated in October 2019. I ran a final search of the same terms on 17th October 2020 prior to submission of this

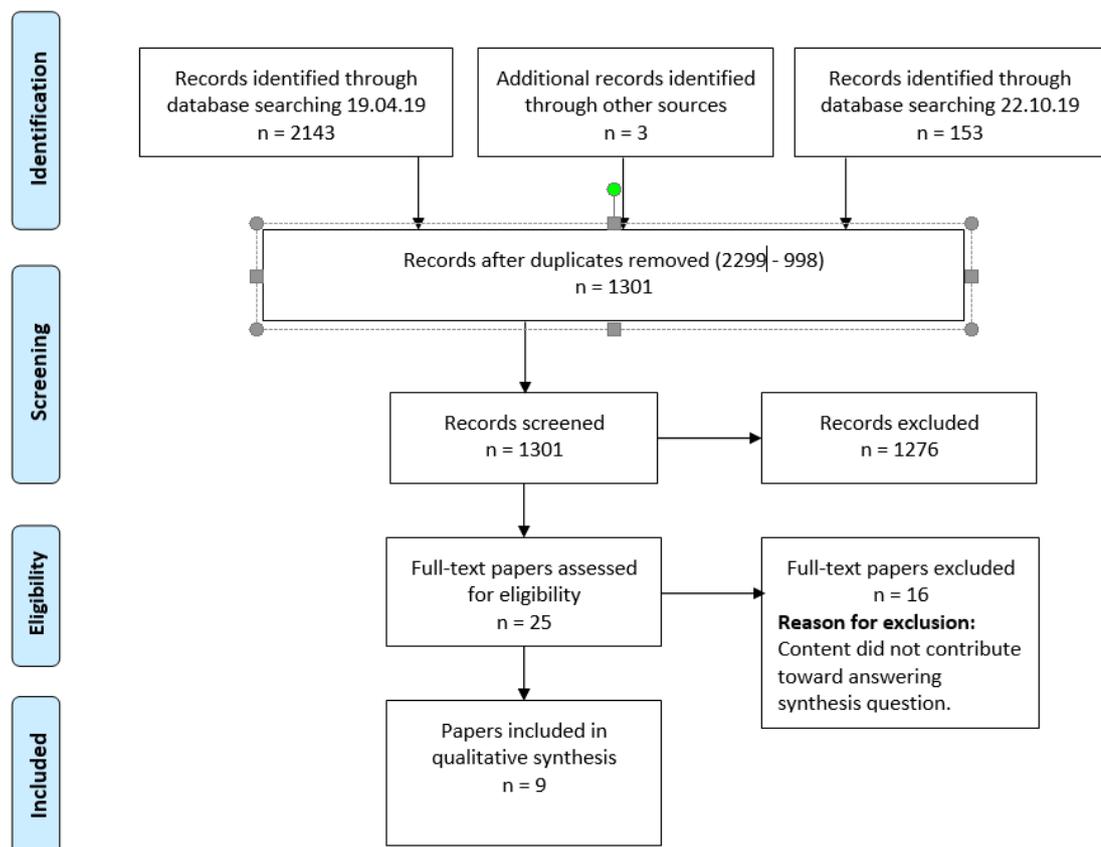
thesis using the same databases. However, PsycInfo was unavailable to me on the date of the search update, so a search of this database was not run until 28th October 2020. Returns from this final search were subject to the same process of screening as previous searches and the same process of review. Three new articles were identified that could have been included in the synthesis (Baird and Thompson, 2019; Dassa, Rosenbach and Gilboa, 2020; Elliott *et al.*, 2020) and an overview of their contribution to the findings from this review is included in the discussion of the synthesis.

7.3.2.2 Literature Screening

All search returns were collated, and duplicates were removed. The remaining articles were screened by (i) title, abstract and keyword searches (ii) presentation and quality of the content and (iii) whether the content contributed toward answering the synthesis question. Figure 50 summarises the retrieval and inclusion processes.

Figure 50: Flow Diagram of Literature Retrieval and Inclusion Process

Adapted from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement (Moher *et al.*, 2009).



7.3.2.3 Literature Eligibility

Screening was conducted according to inclusion and exclusion criteria. Articles were included that (i) were empirical studies or empirical articles; (ii) were published in the English language; (iii) were concerned with shared musical activity between human subjects, both those who a) had a diagnosis of dementia or were believed to have dementia, and b) were caring for a person with dementia; (iv) contained sufficient text concerned with music sharing between subjects not exceeding one person with dementia and three other people within the private residence of the person with dementia; (v) were concerned with music as the primary exposure of interest. Articles were excluded if they were case reports, reviews, editorials, letters, book chapters or news articles.

The final literature selection were all journal articles with one exception, which was a master's thesis (Macgregor, 2016). For the sake of brevity, I refer to all final literature selections collectively as articles. As a significantly more substantive body of text than the other articles, the thesis offered a greater breadth and depth of material for review, which is reflected in the material included in the synthesis. One of the journal articles is in fact a literature review (Pickles and Jones, 2006) containing a relevant case history describing independent musical activity within a caring relationship. Only the case history is included in the review process and synthesis.

7.3.2.4 Critical Appraisal

All the final articles have been included because they describe promoting and supporting shared musical activity in the caring relationships of people with dementia at home. These accounts of musical activity are but one element of either narrative articles concerned with discussing other topics, such as spirituality, or study articles concerned with using music to achieve outcomes, such as improved sleep. This synthesis is concerned with identifying indications from the accounts of musical activity, not with the validity and reliability of arguments or outcomes, which would necessitate a critical appraisal of the articles for the purposes of inclusion. Therefore, I have not conducted a critical appraisal in selecting the final articles.

7.3.3 Reading the Literature

Reading the literature was an iterative process of deepening engagement. This process started with the scoping of titles and abstracts during searches and culminated in the close, repeated re-reading of the relevant concepts presented by the final group of articles. The information essential to contextualise the concepts that informed the synthesis are recorded in a table of attributes (see Table 11 below). Subsequent article references are identified by their tabulated number in square brackets [#].

7.3.4 Determining how the Literature are Related

I engaged in a process of grouping, as explicated in an example by Britten *et al.* (2002), using tables. I began by grouping the concepts relevant to addressing the research question for each article through a process of differencing/relating in the context of the synthesis question. The use of written words in tables served as ‘markers’ to aid my process of conceptual activity in coming to understanding, rather than a task to be fulfilled. I gradually identified a unifying or essential concept that appeared to underpin each of the differentiated groups of related concepts across all articles through experimentation, creating a table that summarised each article’s content related to these concepts. These concepts did not form neatly as a result of making tables, rather my understanding of the concepts developed through the process and I then needed to revisit the material to understand and explicate the basis for these concepts within the text.

7.3.5 Translating the Literature into One Another

The development of understanding the relationships between articles resulted in identification of ‘essential’ concepts that encompassed those of the individual articles. This activity differed from Noblit and Hare’s (1988, p. 28) translation that “...involves treating the accounts as analogies: One program is like another except...”. This was not a reductive or deductive result of grouping, rather reading, writing and grouping served as going deeper into the parts of the written concepts, with impressions and understanding arising in response to this process.

Table 11: Article Attributes

#	Author(s), date and country	Type of article/ study	Aim of inquiry	Participant population	Musical activity / intervention	Frequency / duration of musical activity	Musical activity provider	Training/ resources	Anticipated impact of musical activity
1	Baker, Grocke and Pachana (2012), Australia	Mixed Methods Study	To discover the value of intervention in affecting the quality of the spousal relationship, satisfaction with caregiving and caregiver well-being.	Five couples; one partner with dementia.	Singing, movement-to-music; memory recall after music; relaxed listening to recordings of music.	Three sessions per week over six consecutive weeks.	Spousal caregiver	A home-based music therapy training session.	To prolong fulfilling relationships in couples where one person has dementia, to stimulate meaningful interaction between the spouses.
2	Collins and Bowland (2012), USA	Opinion piece	To seek alternatives to medication that would help the care recipient and family/caregivers to cope with stressors related to illness and caregiving, and as a spiritual practice.	Family and elderly mother with Alzheimer's disease.	Singing and listening to recordings of music.	As part of day-to-day practices	Family and caregivers	Gospel lyrics on CDs, cassette tapes and radio.	To help the care recipient and caregivers to cope with stressors related to illness and caregiving; specifically, during meals to help improve appetite, before bedtime to help sleep, and during the daytime to sooth.
3	Hanser <i>et al.</i> (2011), USA	Mixed methods exploratory, feasibility study	To test the efficacy and impact of the music program, specifically: (a) Will individuals with dementia who participate improve their relaxation, comfort and happiness? and (b) Will	14 family caregivers living with individuals with dementia.	Listening to recordings of music with a choice of eight methods for musical activity encompassing discussion,	Three days per week, with a target goal of eight to 20 total sessions; at least three baseline and three music sessions.	Family caregivers	An initial two-hour training session with a music therapist. CDs of recorded stress reduction instructions by the first author followed by chosen music. CD players for	To reduce distress and enhance satisfaction with caregiving for caregivers, to improve mood and psychological state of care recipients and to contribute to the

5	Kulibert <i>et al.</i> (2019), USA	Mixed methods study	To understand how personalised music delivered via iPod Shuffles affects persons with dementia, their care partners, and their interactions with one another by assessing if quality of life, music experience, caregiving distress, or memory and behaviour problems differed after using the Music & Memory program.	10 women and 14 men with dementia, with 22 spousal care partners and two daughters who cared for parents with dementia.	Listening to recordings of music.	At participants' discretion.	Caregivers and care receivers	Each dyad received an iPod Shuffle, headphones, a small speaker, a charger, equipment instructions, an activity sheet for enjoying the music using the speaker (e.g. singing along, tapping, dancing, talking about associations with the music). Researchers gave instructions and examples to participants in their homes.	To reduce care recipient behaviours that challenge caregivers, for caregivers to gain in positive feelings about their roles, and to reduce caregiver distress generated by caregiving responsibilities.
6	Lai and Lai, (2017), China	Case study	To describe the effects of the music-with-movement intervention on anxiety and sleep.	A woman with dementia and her husband.	Music-with-movement intervention including Tai Chi, playing hand drums and rhythmic activities. Full description not given.	30-minutes at least three times per week for eight-weeks.	Husband caregiver	Weekly two-hour training sessions for five weeks given by a registered music therapist and/ or trained research staff at a day care center. Home visits provided remedial instructions and/or further training if needed.	Improved sleep quality and depressive symptoms in the care recipient.
7	Macgregor (2016), USA	Collective case study	To examine the impact that an individualized, home-based music therapy program had on the emotional connection and	Four familial caregiving dyads; one partner with dementia.	Listening to recordings of music, movement to music, active music, active	The researcher conducted two weekly demonstrations followed by two weekly observations	Caregivers	A therapist participant demonstrated the interventions during week one and two and supportive	The use of familiar music as a basis for eliciting reciprocal interaction within the context of the caregiving dyad.

8	Melhuish, Grady and Holland (2019), UK	Evaluated project report	To evaluate the effectiveness of providing music therapy to support couples at home and to explore a good model for delivery through co-production with relevant organisations.	Seven people with dementia each with a family carer.	Music therapy singing, improvisation and listening to recordings of music.	12 weekly sessions lasting up to one hour, 30 minutes.	Music therapists	Instruments varied but included laptop snare, maracas, tambourines, metallophone, desk bells, guitar (used by the therapist to support singing) and an iPad (for listening to preferred music). Music therapists aimed to develop carers' own skills and provide	To make a positive difference to care and well-being, to optimise the effects of the therapy by encouraging the use of music to support daily care, and to develop a robust delivery model through forging new working relationships with local organisations.	observation session during week three and four.	
			reciprocal interactions between four familial caregiving dyads. Also, to answer 1. What are the dynamics inherent in the music therapy process that facilitate persons with dementia? 2. How does the use of familiar music elicit emotional reciprocity and meaningful communication between a person with dementia and their familial caregiver? 3. How do shared musical experiences support the personhood of an individual with dementia?.	music making and singing.	of caregiver conducted sessions. Caregivers were required to conduct additional sessions at least at least twice per week. The total suggested time per week for caregiver participant input ranged between one hour, 45 minutes - two hours, 45 minutes. Care recipients were required to participate three times per week for twenty minutes duration, over a period of four weeks.						

9	Pickles and Jones (2006), UK	A case history within a literature review article	No reported inquiry.	A man with dementia and his wife.	Piano playing, listening to live music, listening to recordings of music.	As a part of daily life.	Person with dementia and spousal caregiver	resources to use music to support daily care including individualised CDs, playlists and songbooks to be used outside session times.	None explicitly reported, but to continue an established musical relationship and to influence mood were inferred.
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7.3.6 Synthesising Translations

I engaged in a formative process of grouping and writing in order to present how the articles demonstrate the concepts and themes outlined above. Again, this differs from Noblit and Hare's (1988) approach of creating a whole that is more than the sum of its parts. Rather, I have sought to express the wholeness of the phenomena in a unifying form, bringing together parts, or articles, that each presence the whole.

7.3.7 Expressing the Synthesis

The decision to express the synthesis below in the written word was a considered one. As it is necessary to understand the concepts arising from this review in detail to understand their relationship to the study and to inform subsequent discussion within the written thesis. For this reason, the synthesis is presented below in the written word for an academic audience. However, the text holds the potential to form a basis from which to develop presentations of the indications for other relevant audiences in various media in the future, such as people with dementia and families affected by dementia, arts practitioners and dementia care and support workers.

7.4 Synthesis

Of the nine final articles included in this review, none explicitly sought to identify ways that shared musical activity could be promoted and supported in caring relationships, which was the aim of this study. However, seven articles [1, 3, 4, 5, 6, 7, 8] reported on the use of designed music interventions, the ways this musical activity was supported and promoted, and how musical activity flourished, or not, in response to interventions. Two articles [2, 9] offered accounts of how musical activity developed independently in caring relationships over time. In reviewing these accounts, I have recognised the conditions in which shared musical activity appeared to flourish and the qualities of approach by those seeking to cultivate musical activity within caring relationships. This approach resembles that of a gardener who recognises the conditions in which particular plants can flourish and the qualities of

their approach that contribute to developing these conditions. Although I have distinguished between them, these conditions and qualities appear interrelated, influencing one another in various ways.

7.4.1 Conditions

Within the content of the final articles, three conditions appeared to promote and support music sharing in caring relationships: resources, community and empowerment.

7.4.1.1 Resources

Resources were a necessary element in every article. These resources included recordings of music, equipment for playing recordings, recordings of instructions, song lists, songbooks and musical instruments, along with practical instructions for use (see Table 11 above for a full list of resources listed in articles).

7.4.1.2 Community

A community of people surrounding caring pairs such as music therapists and musicians played a role in introducing and/or supporting shared musical activity. In the seven articles that reported on use of an intervention [1, 3, 4, 5, 6, 7, 8], practical demonstration or training was provided with the aim of enabling independent musical activity. The forms this demonstration and training took encompassed one or two introductory sessions with a music therapist [1, 3, 7], regular music therapy sessions [4, 8], researcher instruction on using music listening equipment [5] and five weekly training sessions with a music therapist [6]. The remaining two articles [2, 9] reported on family development of musical activity. The approach reported in five of the nine articles [1, 3, 4, 6, 7] explicitly required carers to deliver a musical intervention, with all nine articles including accounts of musical activity that was dependent upon carers. From the examples of changes reported by carers and article authors, it was clear that, for some caring pairs, the introduced musical interventions and accompanying

resources rekindled a relationship to music and recordings or introduced new musical activities:

[Carer:] ...we...came to enjoy spending this time together. It was nice to sit and listen to the music together and just enjoy it (Baker, Grocke and Pachana, 2012, p. 13) [1].

[Carer:] I appreciate having a reason to turn to music at that time of day...This study was a trigger to get us back into music (Hanser *et al.*, 2011, p. 19) [3].

[Author:] ...an obvious change was seen after the intervention. The patient changed from being uninterested in singing to exhibiting clear enjoyment of the MWM [music-with-movement] activity and making MWM her daily routine (Lai and Lai, 2017, pp. 2-3) [6].

[Author:] In several instances a renewed interest in long-forgotten favorites was activated as a result of having being [*sic*] given 'license to explore' memories and events from the past through the music that was chosen (Macgregor, 2016, p. 86) [7].

[Author:] Julia embraced this approach and sang with Andrew at times when I was not present...Leonard shared some favourite songs on DVD; he seemed delighted to be able to sing these himself for the first time (Melhuish, Grady and Holland, 2019, pp. 21-22) [8].

Although Macgregor sought to promote musical independence for caring pairs, she also advised caution, endorsing music therapists "...to support and facilitate any emotional disturbances brought about by the act of listening to music" (2016, p. 92) [7].

Three articles [2, 3, 8] described development of a wider community of support, with music sharing in the home growing to include friends, family and care professionals as music became a greater part of caring pairs' lives. One article [2] suggested the potential for "...social workers, nurses, chaplains and other professional caregivers...[to] encourage families to use music" (Collins and Bowland, 2012, pp. 244-245) [2].

Both articles that reported working exclusively with caring pairs where the person with dementia was experiencing BPSD indicated that these symptoms could be an issue for people in the community offering support:

...the additional burden of a weekly scheduled appointment for caregivers, even when provided within the home, should be considered. This may

explain the unexpected decrease in caregiver-rated self-efficacy (Holden *et al.*, 2019, p. 282) [4].

Not all referrals could be progressed despite their suitability for the project. Two people declined to take part, despite both carers wanting the intervention to go ahead, due to strong resistance on the part of the person with dementia who appeared to feel threatened by unfamiliar visitors in their home...The carer of a third client cancelled the assessment visit as she was struggling with his behavioural challenges (Melhuish, Grady and Holland, 2019, p. 24) [8].

7.4.1.3 Empowerment

The third condition apparent within eight of the nine articles [1, 2, 3, 5, 6, 7, 8, 9] was that of empowerment. I have recognised empowerment as the development of confidence in, and ownership of, musical activity. Musical empowerment of people with dementia and carers was apparent in accounts in the following ways: taking the lead in musical activities, using and sharing music in new and independent ways and engaging in musical activity beyond that required by the providers of an intervention. From the accounts of several articles, it appears that empowerment to develop musical activity independently could be an important element for music sharing to flourish in caring relationships. Accounts of carers and authors from articles that reported on the introduction of an intervention and accompanying resources, indicated that musical empowerment developed for some individuals through this process as evidenced by the following examples:

Taking the lead in musical activities:

[Author:] ... Iris' [carer] diary entries revealed increases in the number of times Bill initiated musical interactions. Before implementing the program, Iris was the sole initiator of all interactions (Baker, Grocke and Pachana, 2012, p. 14) [1].

[Author:] The patient would also remind her husband that 'It is time to listen to songs' (referring to the MWM intervention) (Lai and Lai, 2017, p. 3) [6].

[Author:] ...for the most part respondents either requested, or sought out additional music themselves through various means (Macgregor, 2016, p. 86) [7].

[Carer:] You suddenly realise there's something you can do (Melhuish, Grady and Holland, 2019, p. 20) [8].

[Author:] Andrew would initiate a strong, lively pulse that we would play and sing to... Julia...sang with Andrew at times when I was not present (Ibid., p.21) [8].

Using and sharing music in new and independent ways:

[Carer:] We didn't use the words at all after a couple of times... We didn't use [instruments]. They didn't add anything (Hanser *et al.*, 2011, p. 20) [3].

[Author:] By having their loved ones occupied with the personalized music, care partners could accomplish various tasks in the home that had become difficult. Sometimes, keeping the individual occupied helped the care partner 'not go bonkers'... Care partners also described the ... use of the music to focus attention when engaged in other activities like walking, doing projects, and working on jigsaw puzzles...Care partners appreciated being able to anticipate the potential for behaviors that challenged them and preemptively give their loved ones the iPod Shuffles (Kulibert *et al.*, 2019, pp. 6-11) [5].

[Author:] Del was very encouraging re his instrumental playing and D more confident - he's trying new things...Emilio found his voice and was no longer shy about singing to Maria in my company...What was also clear was that the caregivers had, for the most part, reclaimed their music. They were not just using it as a means to connect with their loved ones, but were coming around to viewing its use as a viable tool to help them explore their own feelings and/or simply as a means of relaxation and/or reminiscence...David and Delia already had a lot in common when it came to their choice of music, and together they became very adept at incorporating this "joy" back into their daily routine (Macgregor, 2016, pp. 69-81) [7].

Engaging in musical activity beyond that required by the providers of an intervention:

[Carer:] There will be music therapy in our house from now on (Hanser *et al.*, 2011, p. 18) [3].

[Author:] In order to complete the protocol, dyads needed to participate in at least three baseline and three music sessions... Caregivers determined the number of sessions they would conduct, based on a target goal of eight to twenty total sessions...the number of music sessions [conducted] ranged from 3 to 10 (Ibid., pp. 9-14) [3].

[Author:] The intervention requires the primary caregiver to facilitate the delivery of a 30-min MWM at home for at least three times per week...MWM intervention became part of the patient's daily routine. The patient's husband conducted the protocol with the patient 7 days a week (Lai and Lai, 2017, pp. 2-3) [6].

Authors of the two articles that reported on the development of music sharing by families without the intervention of an external agent [2, 9] both indicated that empowerment to develop musical activity arose through exploration and experimentation that built on the person with dementia's existing relationship with music:

Following a series of different relaxation approaches, he [the author's father] discovered that my mother relaxed and demonstrated greater calm when he played vinyl records of old gospel hymns... During the daytime my family identified a local radio station that played easy-listening music that proved soothing (Collins and Bowland, 2012, pp. 239-240) [2].

I use music of all kinds: art music from mediaeval to modern, musicals, jazz, older pop music, radio signature tunes from the past and children's songs such as he might have known in his childhood (Pickles and Jones, 2006, p. 88) [9].

7.4.2 Qualities

The examples above illustrate the three conditions of resources, community and empowerment as a common thread within the identified articles in response to which music sharing appeared to flourish. However, resources and interventions provided by people from the community were not always enjoyed, and it seemed that not all caring relationships became empowered to share musical activity independently. Two distinct qualities of approach appeared to be important for developing these conditions; the qualities of being purposive and responsive.

7.4.2.1 Purposive

In different ways across the range of article reports, conceiving of music as having a purpose appeared to be a motivating factor for engaging in musical activity, both by people in the community and by caring pairs, particularly carers. Provided interventions and resources were designed and implemented with a range of intended outcomes in mind. These included shared outcomes, such as meaningful interaction [1], contribution to quality of life [3], a sense of collaboration [4], emotional reciprocity, [7] meaningful communication [7] and the support of care and well-being [8]. Individual outcomes for people with dementia included improved mood [3],

improved psychological state [3], the redirection of bothersome behaviours [4], reduced BPSD [4], enhanced cognitive function [4], reduced behaviours that challenge carers [5], reduced anxiety [6] and improved sleep [6]. There were also individual outcomes for carers, such as enhanced satisfaction with caregiving [3], reduced distress [3, 5] and gains in positive feelings about their roles [5]. The purposive use of music reported in the two accounts of independently developed musical activity families [2, 9] echoed several of these outcomes, including; communication [9], to help carers manage stress related to providing care [2], to improve appetite [2] and aid sleep [2].

Engaging in provided interventions also appeared to engender understanding of musical activity as purposeful for caring pairs:

[Carer:] ...the music...definitely helped me relax. I think just being able to stop and sit was great and this project helped me do it (Baker, Grocke and Pachana, 2012, p. 12) [1].

[Carer:] This experience helped me to realise the importance of music (Hanser *et al.*, 2011, p. 18) [3].

[Author:] In this study, all caregiver respondents expressed a willingness to persevere with applying music interventions and strategies because, they said, it seemed to have the effect of helping them just as much as it did the care recipient - if not more (Macgregor, 2016, p. 90) [7].

[Carer:] Yes, I will keep trying because it helps me too maybe he can join in more if I keep playing the music with him (Ibid., p. 73) [7].

[Author:] All carers reported positive benefits for their relatives, including improved well-being and mood, engagement, language functioning, challenging behaviours and sleep (Melhuish, Grady and Holland, 2019, p. 20) [8].

Lai and Lai came to view the carer's understanding of their music intervention's purpose as essential for its future use and that "...more intense training will be needed if a caregiver-delivered intervention is to be successful" (2017, p. 2) [6].

Although musical activities were shared, it is evident that carers conceived of musical activities as achieving individual outcomes for those they cared for in the following examples:

[Carer:] Well, if he was in a bad mood, or if he was quiet, and we would listen to music, [then] after music he was a lot better. Sometimes I think [music]

helped brighten his mood or changed him and helped him feel a bit better. And I think it was the music because we did nothing else out of the ordinary that I think could have had that effect (Baker, Grocke and Pachana, 2012, p. 13) [1].

[Carer:] The music improved the tension factor...The music was evocative for memories (Ibid., p. 19) [3].

[Carer:] When I feel his frustration at not being able to talk, we use this and can just see him relax.” (Kulibert *et al.*, 2019, p. 6) [5].

[Carer:] For me some days to not go bonkers, I just do that” (gives father the iPod) (Ibid., p. 8) [5].

[Author:] The patient’s husband was...more relaxed about the patient’s performance. He later told the interviewer that he understood that the purpose of MWM was for her to enjoy the experience, rather than the accuracy of completing each tasks [sic]. Therefore, he allowed her to express herself and move along with the music (Lai and Lai, 2017, p. 3) [6].

[Author:] She [carer] thinks the instrument playing is really making a difference to his movements and communication (Macgregor, 2016, p. 77) [7].

Understanding musical activity as a one-way provision may well have been promoted by the design of interventions. Three articles reported that music selections were made in consideration of the person with dementia only, not both individuals in caring pairs [4, 5, 6] and five articles were unclear on this point [1, 2, 3, 8, 9]. Only Macgregor (2016) [7] explicitly reported making mutual musical selections. Observations by Kulibert *et al.* indicated that providing music as a one-way activity added to the ‘burden’ of caregiving, inhibiting music sharing rather than promoting it for some caring pairs:

For some participant pairs, the M&M program added stress to their lives because of the equipment and feeling like it was one more caregiving responsibility added to an already lengthy list...Some care partners and participants enjoyed listening to the music together as it played on the speakers, while others exclusively used the headphones or did not listen together through the speakers (2019, p. 11) [5].

As a result of their study, Kulibert *et al.* reflected on “...the importance of seeing a program like M&M used at home not only in terms of individual outcomes for the persons with dementia and the care partners, but also in terms of outcomes related to couplehood or the parent/adult child relation” (Ibid.) [5].

Understanding music as having a mutual purpose to promote relationship and/or as a means to relate, seemingly did develop for some caring pairs through experience of musical activity:

[Author:] Three caregivers...spoke of a strengthened reciprocity in their relationship (Baker, Grocke and Pachana, 2012, p. 14) [1].

[Carer:] The caregiving would stop, the playing begin, and the drudgery would disappear (Hanser *et al.*, 2011, p. 19) [3].

[Author:] The patient's husband commented that overall, he believed that the intervention...provides an opportunity for the caregiver and the PWeD [People With early Dementia] to connect with each other (Lai and Lai, 2017, p. 3) [6].

[Carer:] We've now got a friend who comes in once a week; singing has given meaning to his visits (Melhuish, Grady and Holland, 2019, p. 21) [8].

[Author:] ...Malcolm... continued to improvise on the piano...With his own speech becoming gobbledegook, these pieces were a strong clue for me about how Malcolm was feeling (Pickles and Jones, 2006, p. 88) [9].

Such examples are particularly evident in Macgregor's study, who sought to facilitate relational activity using music that held meaning for both individuals in caring pairs.

Such activity promoted carer understanding of music as a relational medium:

[Carer:] ...interacting with the music is helping us get back a little of how we used to be . . . more spontaneous (Macgregor, 2016, p. 62) [7].

[Author:] Maria spoke her first words for months...as a direct response to Emilio "dancing" around the front room with her in her wheelchair to a recording of Frank Sinatra singing 'Day by Day.' That small, but significant response from Maria proved to be the motivation Emilio needed to persevere with trying to engage with her more through the medium of music (Ibid., p. 87) [7].

[Author:] ...when she was engaged in musical interaction with David (her care recipient), Delia commented that she felt she had suddenly become "less like a teacher waiting for a verbal response I know I'm not necessarily going to get" and more like "a player on a level playing field who is more aware of where the goal posts are' (Ibid., p. 84) [7].

What is also apparent from these examples is carer understanding of music, and recording of music, as media that are engaged with and responded to out of individuals' own activity. This is a subtle but empowered difference from the passive stance of regarding music and recordings as being the active elements in causing

outcomes. However, it is also clear from earlier examples that carers observed individual outcomes for those they cared for, and for themselves, as a consequence of this reciprocal, two-way activity; outcomes such as movement, communication, help and relaxation.

Macgregor sought to engender carer understanding of nonverbal communication through musical activity. This approach "...proved a revelatory experience for all caregiver respondents because experiencing the process seemed to help them to understand the significance of non-verbal communication" (2016, p. 83) [7].

Macgregor also observed this approach as promoting carer empowerment; "Active participation in shared music making interactions seemed to provide stimulation and rekindle in them [carers] a sense of connection - to the extent that they partook enthusiastically with the material at their disposal" (2016, p. 87) [7]. This new relationship to music appeared to be empowering of musical activity for individuals with dementia also, as Macgregor found that musical activity was a more accessible means for them to relate to their care partners than verbal communication "...the autonomy and relational capacity of each care recipient respondent were able to be supported to a much greater level when using music, as opposed to simply trying to communicate through verbal means" (Ibid., p. 84) [7].

Macgregor (2016, p. 89) [7] highlighted that learning to share music in this way can require support from the community by "engaging the services of a trained clinician, for example in a consultative capacity, may assist caregivers in gaining the confidence they need to support themselves through explorative means of communicating through what is typically an unfamiliar mode of interaction". She speculated that her "...validation of gesture, vocalization and facial affect during our shared sessions led them to re-evaluate the importance of non-verbal communication" (Ibid., p. 72) [7]. It is also possible that asking caregivers to record observations of the responses they observed in journal logs, and providing guiding questions to assist with this task, was developmental for carer understanding of this approach. She also asserts that support from a music therapist can be needed due to the "...potentially volatile nature of emotional response in the care recipient" (Ibid., p. 92) [7] and the intense level of participation called for by carers.

7.4.2.2 Responsive

The quality of being responsive is taken here to mean that of acting in response to changing people and situations, in contrast to applying static ideas. This is not meant to imply an absence of forethought or intentional activity, rather, that they serve to cultivate encounters ‘in the moment’, not limit them. Across the selection of articles, the quality of being responsive is evident in the ways that musical activity was shared and, in the design, and purpose of interventions and resources. In articles that reported on the development of interventions that were less responsive in design and use, challenges in promoting musical activity were encountered.

It was apparent from accounts in all but one article [4] that familiar and/or preferred music and/or recordings were included as a basis for musical activities such as listening and were identified responsively through consultation and/or as part of the process of engaging in musical activity. Macgregor highlighted that, in her study, “...music choices played an important, perhaps pivotal role in participants' resolve to persevere with the study” (2016, p. 53) [7], asserting that she initially made assumptions about what music would be enjoyed by participants “...but quickly learned that it would be better to let the respondents make their own music choices, and to build up the repertoire of each dyad based on their own initial selections” (Ibid.) [7]. The one article that did not report responsive sourcing of music was the study by Holden *et al.*, that offered participants “...a choice of three recordings along a weekly theme...to increase the likelihood that PWD [people with dementia] were familiar with the music being presented” (2019, pp. 273-274) [4].

Along with three other articles [3, 5, 6], Holden *et al.*, reported challenges for caring pairs in engaging with music interventions. Although the authors demonstrated a concern with promoting responsive interaction, stating that carer attendance was also intended “...to improve positive social and emotional interactions within the session between the people with dementia and caregivers” (2019, p. 273) [4], the design of their intervention appeared to be less responsive. For the study, a neurologic music therapy (NMT) protocol was designed “... to ensure standardized and consistent protocol implementation” (Ibid., p. 271) [4] in treatment sessions for persons with dementia. Carers were required to be present “...in order to provide the caregiver

their own education regarding NMT techniques”. Three pairs withdrew due to the “...distress with sessions” (Ibid., p. 279) [4] of people with dementia and one pair withdrew due to difficulty finding time to schedule sessions. Authors concluded that they had introduced their intervention too late in the course of dementia, recognising that “...in-home NMT can be stressful and difficult to maintain for people with dementia, particularly when BPSD [Behavioural and Psychological Symptoms of Dementia] are more prominent” (Ibid., p. 281) [4]. They suggested that existing familiarity with the intervention could be helpful, as caring pairs “...would already be familiar with the techniques of NMT, continue the methods they have learned independently, and be able to call upon these tools in times of need as the disease progresses” (Ibid., p. 282) [4].

In the study conducted by Hanser *et al.* (2011) [3], caring pairs were asked to listen to an individualized CD together on three days each week, applying their choice of activities from a predefined selection. The protocol was widely appreciated by carers, who conducted more than the required number of three music sessions and reported increases in household music-making and other family members joining care partners in music-making or listening. However, leading music sessions posed a challenge for some carers. Three pairs withdrew due to the burden of care and two others withdrew due to problems with the care recipient's participation. The protocol and resources featured elements and restrictions that were not welcome for some: “Four caregivers had an aversion to the verbal instructions and imagery, while two caregivers were opposed to playing instruments along with the musical selections” (Ibid., p. 21) [3]. The authors recognised the need for more responsive support, suggesting that:

Had these sessions been facilitated by a qualified music therapist, it is likely that the attention to individual needs and preferences, and flexibility in structure, would have resulted in greater satisfaction and improvement... the presence of a qualified music therapist could have helped the caregiver manage some of the behavioral symptoms that characterize dementia (Ibid., p. 21) [3].

Kulibert *et al.* (2019) [5] introduced caring pairs to the Music and Memory Program, providing iPod shuffles loaded with personalised playlists of recordings. Although participants exercised autonomy and choice in when and how music was played and the intervention was found to be enjoyable and beneficial, it also posed challenges

and limitations. The iPod was difficult for participants to use and was viewed as “...yet another task added to so many other daily activities” (Ibid., p. 7) [5] by some carers that added stress to their lives, with the study’s high attrition rate attributed to a need for more carer support. For a number of participants, selections of recordings were too limited or not enjoyed, and in one case a person with dementia became upset in response to the lyrics on the recording of a song. Carers conceived of offering the personalised playlists to their care partners as a low priority. As a result of the study, the authors recognised the need for more responsive intervention design and utilisation of playlists, highlighting “...the importance of acknowledging individual differences and following up to ensure a good fit between the person and the music” (Ibid., p. 9) [5].

The study conducted by Lai and Lai (2017) [6] trained a spousal carer to share an MWM intervention with his wife at home. The intervention was a predesigned protocol with the potential to be individualised. Although the article did not give details of the activities involved in the MWM protocol, it was clear from accounts of the process that the intervention was intended to be used responsively: “Mr L...focused on the patient’s ability to accurately follow the activity protocol, which was not the spirit of the intervention...the patient’s husband...lacked the flexibility to adapt the intervention to the needs of the patient” (Lai and Lai, 2017, p. 2) [6].

As the intervention became more accepted, the couple appeared empowered to take on the intervention, engaging with it beyond the required three times per week. However, this level of activity reduced again and a lack of responsiveness in the protocol design was apparent as the carer still found aspects of delivering the protocol challenging at the end of the eight-week intervention period, reporting:

...that they had decreased their MWM intervention to just once a week for 15 min...the intervention had become less interesting after it had been repeated for 6-7 weeks, and...the last few activities of the protocol (i.e. Tai Chi, playing with hand drums, and rhythmic activities) were very difficult. He would try a few times, but the patient would still be unable to perform these tasks well (Ibid., pp. 2-3) [6].

The challenges reported in these four examples appeared to arise from resources and training being imposed upon caring pairs. The interventions appeared structured, limited and geared towards performing an activity or following a protocol rather than

being developed in response to both individuals' needs and preferences and encouraging carer empowerment to share musical activity in response to changing needs and encounters. Despite the challenges and limitations apparent in these four articles, accounts from carers in two of them [3, 5] reported responsive musical activity shared by caring pairs:

The music was wonderful. He wouldn't follow instructions but would enjoy the music by listening or dancing. We were out in the kitchen dancing again! (Hanser *et al.*, 2011, p. 18) [3].

We're now putting music into our days. (CR) [care recipient] sits with me on the piano bench and sings while I play...We did not follow or use instructions (Ibid., p. 19) [3].

When I feel his frustration at not being able to talk, we use this and can just see him relax. (Kulibert *et al.*, 2019, p. 6) [5].

The remaining three articles reported on more responsively developed interventions and resources that appeared to be well received and did not report the same setbacks, even when the challenges of BPSD and the burden of care were reported [7, 8], and promoted responsive musical activity.

Baker, Grocke and Pachana (2012) [1], designed an active music intervention and trained spousal carers to:

...successfully adapt and implement the intervention at home without need of supervision...[and] to use music effectively and strategically to facilitate interaction...Outcomes demonstrated the caregivers' had abilities to provide the intervention, were empowered to deliver the intervention, and found great value in their couple relationship engagements with the intervention (Ibid., pp. 8-20) [1].

Taking the triple role of observer/participant, clinician and researcher, Macgregor formed "...a supportive, consultative and collaborative relationship with the caregiver respondents" (2016, p. 89) [7], observing two weekly caregiver implemented sessions following the initial training. A self-selected time schedule for musical activity involved participants in decision making, which was welcomed. Responding to a difference in the levels of support needed between participants in her study, Macgregor met with one caring pair needing assistance with the therapeutic process more frequently than the others. For another caring pair, Macgregor observed that her support helped

cultivate a new shared relationship to music with potential for future independent development:

E [carer] developing his own music protocol now...Feeling that I've done my job and glad that I've been able to fulfil my intentions of being supportive. E will definitely discover different ways of using the music. Very hopeful for him AND he's loving it. Very animated; M seems to be affected by his enthusiasm (2016, p. 77) [7].

The study had a zero-attrition rate, with all carers continuing "...with the program even amid personal difficulties such as health issues" (Ibid., p. 78) [7].

Not only was Macgregor's approach responsive, but it was intended to promote empowered, responsive development of musical activity by participants, who learned to conduct sessions independently and "...to take a more considered view of the care recipient's responses...as well as an interest/enthusiasm in their role" (Ibid., pp. 77-78) [7].

As part of an evaluation project conducted by Melhuish, Grady and Holland, music therapists providing regular therapy sessions sought "...to empower carers at home on a daily basis by helping them learn how to support their partner both within and outside the sessions" (2019, p. 23) [8] using music and recordings. Therapists took a responsive approach to achieving this, adopting "...various methods of skill-sharing...appropriate to each case and each occasion." (Ibid., p. 22) [8]. Carers and the individuals they cared for came to engage with and through music spontaneously in sessions and in daily life, even beyond the end of the project, with two couples continuing domiciliary music therapy sessions at their request. In response to this developing musical activity "personalised resources such as songbooks and playlists were created as required" (Ibid., p. 23) [8].

This project formed a part of Mindsong's ongoing work as a "...collaboration between the disciplines of music, music therapy and medicine" (Ibid., p. 16) [8]. In recognition of individuals' changing needs for support over time, "...a Mindsong ecology is beginning to take shape in response to need, allowing people to connect in different ways to different parts of its service" (Ibid., p. 24) [8]. This meant they were able to offer caring pairs a range of supported opportunities at the end of their project, such as singing groups and events.

Accounts from each of these three articles described music and recordings being used responsively by caring pairs through engagement in the musical interventions:

[Carer:] ...when things were a bit dicey, I just turned on the music (Baker, Grocke and Pachana, 2012, p. 13) [1].

[Author:] The music utilized during each intervention was at the discretion of the caregiver or the care recipient - depending on their levels of engagement at the time (Macgregor, 2016, pp. 53-70) [7].

[Author:] Julia was fully involved in every session, singing with me and initiating songs when Andrew made eye contact with her...Their daughter texted me to describe how her mother's anxiety about food preparation 'was soon diffused with song!' (Melhuish, Grady and Holland, 2019, pp. 21-22) [8].

It is apparent from the first example where the carer responded purposively to things getting 'dicey' by playing music that the qualities of responsiveness and purposiveness are not exclusive. For the two articles that did not report on an intervention provided by an external agent [2, 9], musical activity developed in response to individual need, with carers and other family members taking the responses to, and participation in, musical activity by the person with dementia as suggestions for development of further activity and resources. In the account of Mrs James' relationship to music through the course of dementia by her daughter, she describes how her family revisited various musical activities familiar to Mrs James (Collins and Bowland, 2012) [2]. Through exploration, new musical practices arose, such as listening to favourite music to support eating, sleeping and a spiritual connection. In turn, these activities became familiar:

Our family decided to experiment with gospel songs and religious hymns to relieve stress because my mother was especially responsive to this form of music. I copied black gospel lyrics onto CDs and cassette tapes for my mother and her caregivers. The plan included playing music during meals to help improve her appetite. The caregivers also played her favorite songs or artists before bedtime to help her sleep. She became reliant on this practice and would sometimes ask for this music...music became a source of transcendence and of remembering a connection with a loving God who desires our well-being (Collins and Bowland, 2012, pp. 239-240) [2].

Pickles and Jones reported Barbara's story of her husband, and the changes dementia brought to his lifelong and professional relationship to music. She described his relationship to music as changing, but also a constant through this journey:

...Malcolm eventually gave up reading music altogether and also became unable to write down his own compositions in conventional notation. But...he was still able to improvise fluently...He eventually stopped playing altogether...He no longer recognizes me as his wife...but, amazingly, he recognizes pieces of music which mean a lot to him and a tear will trickle down his face (2006, pp. 88-89) [9].

She also described how this existing relationship to music provided a foundation for new, responsive development through playing recordings of music and utilising resources in response to need:

...listening to music still wholly engaged his attention. I often used recorded music instead of drugs to change his mood—whether to stimulate or to calm him down—particularly useful in his aggressive phase. It was fortunate that Malcolm's tastes were so eclectic – there was always something to fit the bill...I found using a Sony Walkman, where the earpieces blocked out extraneous environmental noise, better for him than listening to music from loudspeakers in the room (Ibid., p. 88) [9].

7.5 Discussion

Three conditions are evident within the literature that appear to promote and support shared musical activity for caring pairs; resources, community and empowerment. Also apparent are two qualities of approach that contribute to developing these conditions; purposiveness and responsiveness. The following ways in which the literature demonstrates these conditions and qualities offer indications for consideration by caring pairs and those that support them in seeking to cultivate musical activity. These indications complement and augment those from my fieldwork.

Resources appear to be a common necessity promoting and supporting the development of shared musical activity. Resources can be designed, curated, created and utilised for and with caring pairs by professionals, family and friends, forming a local community of creative support. They can also arise out of independent activity

by caring pairs. The reviewed examples of musical activity appear to suggest familiar preferred music and recordings chosen by caring pairs as a basis for development of musical activities specific to each caring relationship. It is evident that enjoyment of the same intervention differed between individuals and could change over time, as did the need for support from their communities. It is also apparent that caring pair's enjoyment of musical activities and resources was an essential part of their acceptance and participation, as it was for participants in this study. Caring pairs choosing their own music and recordings that are familiar and preferred seems to be an important element of empowering musical activity and a basis for development of familiar and new musical activity, both independently and with support from communities.

It is evident that community can introduce, facilitate and foster shared musical activity both familiar and new for caring pairs, as my participation did through this study's fieldwork, but that this activity can also arise through independent exploration and experimentation. Support from communities can take the form of ongoing facilitation and of training and demonstration of musical activity to promote independent use. Conversely, it seems that music sharing can grow to include a wider community of creative support including friends, family and care professional as musical activity develops for caring pairs.

Even though it appears that support from music therapists can be necessary for caring pairs experiencing **BPSD** and for understanding and sharing music and recordings safely and purposefully, there seems to be potential for people in various community roles such as professional caregivers to not only share in musical activity, but also to promote it to caring pairs through encouragement and signposting. It is also apparent that some caring pairs experiencing **BPSD** need forms of support from communities that do not involve home visits. Although introducing new musical activity to pairs experiencing **BPSD** was considered to be 'too late' for an **NMT** intervention, the introduction of more responsive musical activity appeared well received. However, given the developmental nature of musical activity, as is evident from the literature and this study's findings, it is reasonable to speculate that introducing musical activity soon after diagnosis of dementia could give musical activity a greater opportunity to grow and flourish for caring pairs.

There is a clear need to promote and support musical activity for caring pairs at home, both with and without home visits by people from the community offering support. Not everyone is comfortable inviting strangers into their home and people with dementia can respond to home visits with anxiety. Offering support in community settings such as activity groups is one approach; however, it is reasonable to assume that some people will be unable to attend such settings. None of the articles in this review report on external support without demonstration or training in the home or community. There appears to be potential for future research into support for caring pairs without such visits to better understand how musical activity can be promoted and supported within communities.

It is apparent that there is not one 'right' way to cultivate musical activity and that promoting and supporting musical activity means different things for different people, or even the same people, at different times. Caring pairs can be empowered to promote and support musical activity for themselves, but this can require support from communities to catalyse and, in some cases, sustain. Some caring pairs appear to welcome more structured interventions that are an imposition for others. Understanding and engaging in purposeful use of musical activity can require differing levels of support and time for individuals.

The dynamic nature of promoting and supporting caring pair musical activity suggests a potential for continuously available, responsive support from communities to catalyse and inform ongoing development and of empowered musical activity when it is needed. In this way, communities could promote and support musical activity to grow and flourish through the changing needs and experiences of caring pairs. There appears to be a potential for community 'ecologies' of support such as that in development by Mindsong (Melhuish, Grady and Holland, 2019) to evolve in response to need and provide opportunities for caring pairs to explore and learn about different ways of sharing musical activity for themselves. For participants in this study, continued facilitation may have supported the further development of relational musical activity into daily life for Sue and Ron, and the continuation of shared singing for Dorothy and Chris.

Motivation to share musical exploration in new and independent ways, and empowerment to take the lead, appear to be important elements for continued

development of resources and musical activity through change for caring pairs. It seems that empowerment can develop through community supported and independent musical activity. Seeking to promote such empowerment “...is an innovative approach and the potential for development within music therapy and dementia care is increasingly being recognised” (Melhuish, Grady and Holland, 2019, p. 23) [8], and as such would appear to be an avenue for further research and practice development.

Music and recordings can be shared for a range of purposes, including the intention to achieve health, well-being and relational outcomes. Understanding musical activity as purposive can be a motivating factor for engaging in it and can influence the ways in which it is promoted and supported. It is clear that carers play a central role in facilitating shared musical activity in caring relationships, but that shared musical activity is not always for a mutual purpose. Carer understanding of purpose can be necessary for sharing musical activity purposefully and can be inspired and empowered by purposive support from communities.

Carers can conceive of musical activity as achieving individual outcomes for those they care for and for themselves that can manifest as a one-way activity of provision, adding to the ‘burden’ of caregiving for some and inhibiting sharing rather than promoting it. Understanding and sharing music as a relational medium gives musical activity a mutual purpose and appears to be empowering for caring pairs to share music in this way. This understanding echoes my fieldwork findings that shared musical activity can offer caring pairs opportunities for relating in a mutually accessible, experiential way beyond the roles of caregiver and cared for; an activity that requires carers to participate in the space, time and communication of person with dementia rather than requiring the person with dementia to orient to the carers time, space and habitual forms of communication.

Relational musical activity is reported to be an unfamiliar concept and practice for many caring pairs, requiring intentional support from communities to develop. However, it would seem it can develop spontaneously for some caring pairs through participating in shared musical activity. External support that seeks to engender understanding of nonverbal communication can promote carer understanding of musical activity as a stimulation of, and a mutually accessible medium for, relating.

Facilitated participation in relational musical activity and encouraging and validating carer observation of responses by the person they care for may be instrumental for cultivating such understanding.

It is apparent that purposive use of music and recordings as caregiving tools in pursuit of individual outcomes can promote musical activity for caring pairs but also can be experienced as an additional caregiving task that inhibits the growth and sustainability of shared musical activity. Sharing music as a relational medium appears to offer a mutual purpose that can promote shared musical activity and that may provide a foundation for seeking individual outcomes for both parties in caring pairs responsively. Individuals' relationship to music can be a generative foundation for shared musical activity. However, including music and recordings preferred by both members of caring pairs and developing musical activity and resources in response to the individual preferences, needs and capabilities of both parties may be more likely to promote and support relational musical activity.

It would seem that musical activity can promote relationships not only between people, but between people and experience by facilitating a continuity of musical and spiritual experience through the changes of dementia. This observation reflects elements of my earlier findings that music experiencing, and music-making, can be a coherent activity through change and can introduce the movement of change through the restrictions that dementia can bring. This recognition of the dynamic nature of musical activity highlights a potential to develop musical activities and resources for independent use that can 'grow with' and be adaptable for individuals as they and their circumstances change over time. For example, as a pair gains confidence to sing a cappella.

Given the wide range of purposes that shared musical activity can have, it would appear important to consider these possibilities when promoting and supporting musical activity, especially sharing music as a relational medium that holds potential to be a mutually purposive foundation for responsive development, continuity and change. My fieldwork findings add to this a purpose for musical activity as an opportunity to fulfil individual and collective potential for caring pairs, and the wider community of creative support that share music with them.

Interventions and resources provided by communities that are developed responsively and seek to promote responsiveness and empowerment can be promoting in these ways. Most articles reported selecting preferred music and recordings as a basis for pre-designed musical activity and resources. However, where musical activities and resources were developed responsively, they were more well received than those pre-designed, as in the current study (see [Chapter 4](#)).

Interventions and resources that are less responsively designed and engaged with can be less well received. Such interventions and resources may also ‘impose’ challenges upon caring pairs and the development of musical activity, including distress for the person with dementia, increased caregiving ‘burden’ and related stress. Responsive musical activity can also develop independently for caring pairs and be inspired by interventions and resources.

7.5.1 Search Update Articles

Of the three additional studies identified by the final search update, one introduced music therapy to caring relationships (Dassa, Rosenbach and Gilboa, 2020) with a view to promoting sustainable musical activity in their daily lives, while the other two sought to understand existing informal musical activity without taking a therapeutic perspective (Baird and Thompson, 2019; Elliott *et al.*, 2020). All the articles include accounts of resources, community and empowerment as conditions that were promoting and supportive of musical activity in caring relationships in ways already described. Where they are apparent, the qualities of responsiveness and purposiveness appear to have been promoting of these conditions. As well as reinforcing the understanding from the synthesis, these three studies add to it in the following ways.

For one caring pair in Baird and Thompson’s study, a suggestion by a gerontologist “...to sing a familiar and significant song to her” (2019, p. 458) prompted the spouse to try singing as a means for his wife to recognise him, as she experienced misidentification delusion. The gerontologist’s advice promoted new, purposive musical activity, confirming my earlier observation of the potential for people in various community roles to promote musical activity to caring pairs through

encouragement and signposting. The potential that I observed for support from the wider community to respond to the changing needs of people in caring relationships is further validated by the differing support needs of the two participating pairs in Dassa, Rosenbach and Gilboa's study, with one pair requiring ongoing support beyond the study period due to "...the deteriorating health of the spouse with dementia" (2020, p. 7).

The caring pairs in two of the studies (Baird and Thompson, 2019; Elliott *et al.*, 2020) already shared musical activity, including music-making, in familiar and, in some cases, new ways in daily life. Empowerment to share this activity appears to have grown through their developing relationships with music across their lives. Dassa, Rosenbach and Gilboa (2020) also reinforce the familiar and preferred as a basis for musical activity by empowering participants 'natural forces'.

The study by Baird and Thompson also evidences the new becoming the familiar over time. Through the new activity of singing a familiar song to his wife with dementia, a husband observed: "everything changed. It worked quickly. She came back. She stopped sending me away, and became my shadow" (Baird and Thompson, 2019, p. 458). The authors speculate that the participant's love of singing and frequent singing activity prior to her dementia diagnosis may have played a role in the 'sparing' of this ability as her dementia progressed, as well as her responsiveness to singing as a means to recognise her husband. If this proved to be the case, it could point to the potential for developing regular and enjoyed musical activity earlier in life as a familiar basis to support its continuation and development through dementia.

Musical activity was shared for both individual and relational purposes in all three studies, including enjoyment, and this purposiveness appeared to promote musical activity. However, it is evident that existing relationships to musical activity became disrupted through the changes of dementia for pairs in Elliot *et al.*'s (2020) study, just as Malcolm's relationship with music changed, as described by Barbara above (Pickles and Jones, 2006) [9]. Elliot *et al.* made it evident that an existing relationship to music could simultaneously promote and inhibit musical activity:

The connection to music fueled the want, and arguably need, of both the participant and partner to hold on to this piece of their life that still felt

“normal” amidst so much change...Participants began to forget, or had already forgotten, how to play their instrument, practice choral singing, read music, and/or use devices for listening to music...Partners also felt the struggle of dementia, which required constantly finding new ways to integrate music into their lives; they...wanted to keep things consistent for themselves and their loved one but were struggling to do so (2020, p. 9).

The challenge that such changing relationships can present suggests that support to continue musical activity in new, accessible ways could be needed by some people.

Dassa, Rosenbach and Gilboa (2020) report their music therapy program as promising as a model for promoting sustainable musical activity in the daily lives of people in caring relationships. This was achieved by drawing on the ‘natural forces’ of each pair, such as their propensity to sing songs, “...which can empower each of the spouses individually, as well as together as a couple” (Dassa, Rosenbach and Gilboa, 2020, p. 1) and by providing a ‘strong foundation’ of 12 weekly music therapy sessions with content developed in the ‘here-and-now’. The sessions were accompanied by the ‘ongoing support’ of regular phone counselling for each care partner, tools to use themselves, and a follow up session. These findings echo my own discussed above; namely that facilitation and resources from the wider community, in this case music therapy, that are developed responsively can promote and support musical activity in caring relationships.

7.6 Indications

The review of the literature above offers the following indications for people seeking to promote and support musical activity to grow and flourish in caring relationships:

- Musical activities and resources that are developed in response to individual preference, need and capability can be more promoting and supportive than those that are not.
- Musical activity can be shared for a range of purposes, that include the intention to achieve health, well-being and relational outcomes, facilitating a continuity of musical and spiritual experience through the changes of dementia, to promote musical empowerment and to fulfil individual and collective potential.

- Empowerment to develop musical activity independently can develop through exploration and experimentation.
- Conceiving of a purpose for musical activity can influence the ways in which it is promoted and supported and the ways in which it develops.
- Carer understanding of purpose can be motivating and necessary for sharing music purposefully.
- Musical activity that is understood to be for the person with dementia only can inhibit sharing of musical activity.
- Understanding and sharing music as a relational medium can promote empowered mutually purposive musical activity.
- Sharing music and recordings as relational media can provide a foundation for seeking individual outcomes for both parties in caring pairs responsively.
- Relational musical activity can require intentional support from communities to develop.
- Developing musical activity and resources in response to the individual preferences, needs and capabilities of both parties may be more likely to promote and support relational musical activity.
- Support from communities can take the form of ongoing facilitation, training and demonstration of musical activity to promote independent and purposive use.
- Support from communities can promote carer understanding of purpose; purposive, responsive and shared musical activity; and musical empowerment.
- Community support from music therapists can be necessary for caring pairs experiencing BPSD and for understanding and sharing musical activity safely and purposefully.
- A community ‘ecology’ of responsive support provision options could promote and support dynamic, empowered musical activity through the changes of dementia.

- A community of creative support including friends, family and care professionals can grow through empowered musical activity.
- The development of regular enjoyed musical activity by individuals in caring relationships can empower shared musical activity and its responsive further development through dementia and may be supportive of the capacity for participating in musical activity for the person with dementia.
- Relationships to musical activity can become disrupted by the changes of dementia, which may necessitate support to continue musical activity in new, accessible ways.

Accounts from Macgregor (2016) [7] and Melhuish, Grady and Holland (2019) [8] also offer specific recommendations for music therapists in promoting responsive, empowered musical activity with caring pairs that could also have broader relevance for others promoting and supporting musical activity in caring relationships:

- Demonstrating musical activity without being specific so that pairs/ carers can be free to make music choices based on moods/ levels of cooperation, or choices expressed by the person they care for.
- Encouraging carers' ideas for alternatives to suit their own needs.
- Encouraging and modelling for carers ways of relating with the person they care for that are less self-conscious.
- Cultivating confidence to keep a steady beat on accessible instruments.
- Encouraging spontaneity regardless of musical ability.
- Designing interventions and resources that are accessible for a person who may not have a sophisticated musical skill set. For example, using recordings of music.
- Clearly labelling resources can make them easier to recognise and allow caring pairs to be more proactive in making choices and taking the lead in musical activity.

The extant need to promote and support musical activity for caring pairs and lack of research into how to do so means that the indications can only be considered a

starting point for further research and practice to build on the findings from this study. The indications above and the literature accounts are suggestive of the need for further research and development in the following areas:

- Resources and support from communities that do not require home or community visits.
- The promotion of musical activity by people in community roles through encouragement and signposting.
- Introducing musical activity early in the course of dementia to promote sustainable musical activity.
- The emerging music therapy ‘indirect’ approach that seeks to promote musical empowerment in caring relationships.
- Approaches to cultivating caring pair understanding and participation in relational musical activity, including facilitated participation and encouraging and validating carer observation of responses.
- Promoting and supporting musical activity in caring relationships.

I have transformed the understanding and indications from this and preceding chapters, and the ways of working that gave rise to them, to create a synthesis of creative possibilities for promoting and supporting musical activity within caring relationships (see [Appendix 11.22](#)).

7.7 Summary

By reviewing the literature in this chapter, I have gathered indications to potentially promote and support musical activity to grow and flourish in caring relationships beyond this study. The contribution of the indications gathered above, together with the other findings harvested through this study, to the landscape of music and dementia is the subject of the following chapter.

8 Sharing Understanding

...do not seek anything behind the phenomena; they are themselves the teaching.

(Goethe quoted in Steiner, 1950, p. 252; Steiner's emphasis)

8.1 Introduction

The preceding chapter presented the understanding that grew through shared musical activity with participants and its promoted continuation towards fulfilling the original aims of this research. This understanding informed development of practical suggestions and ideas for ways musical activity can be promoted and supported in caring relationships. My development of gentle empiricism in coming to this understanding also offered indications with the potential to contribute to music and dementia research (see [Chapter 4](#)). This chapter continues to map my journey through the landscape of music and dementia on a path illuminated by dynamic understanding. Through discussion of the relationships and differences between the understanding that grew through this study and the landscape within which it is situated, I sift the seed of original contribution from the harvest of this research. I go on to explore the potential and limitations for sharing this seed to help shape the landscape and promote shared musical activity for more people in caring relationships into the future.

8.2 Dementia

8.2.1 Personhood

This study is the first to take a dynamic view of music and dementia with people living at home. Consequently, the understanding and ways to support and promote

musical activity presented in this thesis constitute new knowledge in the field of music and dementia research.

Participating in this research has introduced me to what has become an ongoing development of my capacity for ‘living thinking’ (Holdrege, 2013), or, as Bortoft (2012) terms it, for ‘seeing dynamically’ (see [Chapter 3](#)). Over the course of this study, I have begun to recognise the interrelated wholeness of existence. As Holdrege observes:

...there is an integrity to each of the myriad different species of organisms on the planet—each forms and reforms itself in constant interaction with other organisms and influences in the environment. But every “itself” is itself by virtue of others. “Otherness” and “separateness” are, therefore, a matter of degree. Neither can be conceived of as being absolute...We can consider the earth as one large and unitary sphere of living existence that differentiates into myriad kinds of activities and presences that remain related to one another. How they relate and interact is continually changing and evolving. Yet there is always connectedness or interweaving relatedness (2020, p. 6).

In seeing people dynamically, I have come to recognise each person as a unique part of the whole human race. Every one of us is a protean manifestation of an essential ‘human’ idea, simultaneously related and unique. We can only be differentiated because we are integral to one another; an authentic whole that appears through each one of us as individuals.

The concept of human Proteanism has deep philosophical and theological roots (Saracino, 2003) that appear to have put forward more recent shoots in the fields of psychology (Lifton, 1999) and anthropology (Pandian and Parman, 2004). Seeing ourselves dynamically as protean beings means recognising that each of us is constantly becoming ourselves differently in order to remain ourselves. We are each in a process of constant change, and yet we do not become ‘other’. We remain the same unique person but differently, with or without dementia. Personhood is simultaneously our relatedness, or humanity, and our difference, or individuality. Such an understanding echoes Dewing’s (2008, p. 6) suggestion that “...personhood evolves and comes into an ever increasing presence over time”. Such a dynamic perspective of personhood as activity rather than status offers a clear viewpoint out of which dementia care could be developed that recognises each individual in their continuing development, and responds to the call to recognise the relationships at the centre of care (Macdonald, Mears and Naderbagi, 2019). This dynamic perspective

appears close in nature to Kontos' 'embodied selfhood'. However, a fundamental difference is evident in her recognition of the body as "...a fundamental source of selfhood" (Kontos, 2014, p. 114), rather than as the activity of selfhood, or individuality coming into appearance.

8.2.2 Experiential and Conceptual Activity

In speaking of Goethe's work on plant morphology, Bortoft (2012) draws on the thinking of other Goethean scientists, Steiner (1968) and Holdrege (1996), in summarising the relationship between plants and their environment; "The living organism configures itself actively, instead of being conditioned passively, in response to the environment...the specific form which an individual plant takes is neither determined by the environment nor predetermined by the organism itself" (Bortoft, 2012, p. 78). Translating this understanding into a human context introduces sentience and cognitive activity beyond the physical morphosis we share with the plant. This activity enables us to shape our environment intentionally (Holdrege, 2020) and to choose how we respond to it (Frankl, 1985). A dynamic perspective casts a new light on each of us as perpetual reciprocal activity that is no more a product of our environment than the result of a predetermined idea.

Just as Holdrege (2020) views the world as a unitary interrelationship of different activity, so too can each organism that forms a part of this activity be viewed in this way. As living activity that is constantly coming into being, each person can be seen to manifest through a harmonious symphony of activity. We perceive our sensory relationships, experience their qualities and understand the concepts belonging to them (Bortoft, 1996, 2012). In these ways, we can be seen as actively receptive. We also respond to that which we receive through activity such as consciousness, thinking and feeling (Wittgenstein, 1970; Bortoft, 2012), that manifest in physical appearance as changing organic activity. Thanks to the advances of material science, we are becoming more capable of observing such activity through developments in physiological monitoring equipment and imaging. Such technologies make it possible to observe representations of appearances that are not usually sense perceptible. In observing these physical appearances, behaviours, expressions, physical changes and actions tend to become objectified, either dualistically as expressions or consequences of the mind 'behind' appearance, or as a consequence of the circumstances imposed

by the 'external' world. For example, the idea that crying is an 'outer' expression of an 'inner' emotion, or that an event can cause a person to cry. Seen dynamically, a person's crying is emotion appearing in response to the event. Dynamic seeing offers a means to "...walk the tightrope between dualism, on the one hand, and reductionist behaviourism on the other" (Bortoft, 2012, p. 174). It does so by recognising our physicality as an activity of incarnating subjectivity, rather than as an object housing it (Merleau-Ponty, 2002).

As cognition changes through dementia (Sandilyan and Dening, 2015), so too can an individual's potential to change their own environment purposefully (Harciarek, Sitek and Barczak, 2017) and to be active through conceptual understanding (Snowden, 2010) and verbalisation (Taler and Phillips, 2008). Seen dynamically, these changes foreground other forms of activity that are also appearances of the person. In other words, the tone of voice, touch of the hand, fall and rise of the breath, laughter, gesture, cries and smiles are just as much a person as their spoken words and intentional action. No part of them ceases to exist; they continue to come into appearance in ways that are still accessible. The fieldwork from this study demonstrated that by recognising the forms of activity that are still accessible to a person, and those that are disrupted, it is possible to create environments that offer opportunities for an individual to respond, act and create in new ways. These are opportunities for the person to come into appearance differently in order to remain themselves.

Through our evolution, cognitive forms of activity have been bestowed with a superior status over other forms; "...a cultural belief that persons need to have cognition to be considered and accommodated as persons" (Dewing, 2008, p. 5). The usual distinction between verbal and nonverbal activity and communication reflect this. That which is other than verbal is referred to as what it is not, nonverbal, rather than the form that appearance takes such as gesture, tone and movement. Myriad forms of appearance are subsumed by a single term with secondary status.

In both the physical appearances of participants and my own activity, I observed:

- a distinction between experiential and conceptual activity;
- a distinction between sensory, emotional and memory forms of experiential activity;

- understanding and expression of concepts, including concepts about experiential activity;
- individual activity in relationship with the activity of environments and others.

All these observations are made in acknowledgment of their nascence and potential for further differentiation and development. Differentiating between forms of activity as principally experiential and conceptual, recognises that which is coming into appearance in different ways, whether verbally or otherwise, and offers a more nuanced understanding of appearance. For example, Jane's singing of Christmas carols in response to conversation about Christmas could be seen as vocally conceptual, whereas her improvisatory harmonies sung to a recording of African music could be seen as vocally experiential and not requiring conceptual understanding or semantic expression.

From participation in the fieldwork for this study, I found that differentiating between experiential and conceptual appearances of those whose activity was disrupted by dementia required "taking appearances seriously" (Bortoft, 2012, p. 176). I found it equally important to pay attention to the ways a person *was* appearing, as well as recognising the ways they were not. An account from neuropsychologist Sabat of conducting a language function test with a man with dementia demonstrates how knowledge of the individual and their lives made it possible for him to recognise conceptual activity:

In 20 minutes, he was able to say only five coherent words through the muscular rigidity that had grown ever more severe...Uttered with what seemed to have been herculean effort, the five words were "Welder" and "She's knocking herself out," and they had nothing whatsoever to do with the test items. In fact, however, the man had worked as a welder in a shipyard for decades, and he was living at home with his wife who truly was "knocking herself out" in the process of caring for him. He was telling me something significant about himself and about his wife and their situation at home (2001, p. 339).

It is easy to see how this conceptual activity could be dismissed as a symptom of dementia, as on the surface the concepts appeared to have no relevance to the situation. Equally, it would have been easy to miss Sue's experiential activity that appeared as verbal sounds, phrases and gesture in response to sensory sounds and objects reminiscent of farming life that harkened back to her childhood; "...I was on that thing...then it starts to come out d-d-d-d-d..." (S2, V1, 30:32). It is apparent

from the fieldwork for this study that recognising and responding to conceptual and experiential activity can provide reciprocal environments that offer opportunities for an individual to respond, act and create in ways that are accessible as activity changes. It was also apparent that understanding and responding to a person conceptually whose own conceptual activity is disrupted can inhibit experiential activity, whereas joining in with experiential activity can be promoting.

Drawing a distinction between experiential and conceptual activity is strikingly akin to observations made by Kontos (2014) differentiating between cognitive and embodied consciousness in the context of dementia. An understanding of experiential activity can also be recognised in dementia care approaches such as validation (Feil and de Klerk-Rubin, 2012) and intensive and adaptive interaction (Ellis, Astell and Scott, 2017) that involve mirroring and physical forms of communication. However, such approaches are based upon interpreting and reacting to behaviour as representing an ‘inner’ dualistic reality. From a dynamic perspective, experiential activity can be seen as embodying this ‘mode’ of being rather than applying specific techniques of interaction to encounters. Each person with dementia offers me opportunities for learning ways of being myself differently and being in relationship differently. By sharing in these ways of being I can also promote their activity; not as caregiver and care receiver, or practitioner and client, but through mutual human relationship. Understanding experiential activity in this way could inform the further development of interaction in daily life with people with dementia.

8.3 Music and Dementia

8.3.1 Personhood

Through taking a dynamic view of music, I have come to recognise that people appear musically just as music appears through people’s activity. Music is not separate from the act of singing or playing just as the voice is not separate from the speaker:

The living voice is certainly the fulfilment of our corporeality and living nature in their totality. We become aware of this if we consider modern reproduction technology where a fixed “voice” is transformed back into a voice by a mechanical means. Actually that means that the “voice” does not really speak now. It is rather only a type of audible writing. Even the elevated

meaning that reproduction technology has for today's musical culture does not change anything concerning the fact that it demands leaps over abysses (Gadamer, 2000, p. 34).

Recordings of music are unchanging, re-playable environments. In this study I observed them to manifest musical qualities that offered opportunities for individuals to respond alone or in reciprocal activity with others, such as conversation, laughter, gesture and so on. Along with the live music we encounter, these musical artefacts have become a part of our culture (Dyson, 2009) and individual biographies (Bergh and DeNora, 2009). They have also become associated with memories and emotions (Garrido and Davidson, 2019). When played, these recordings create personally significant sensory environments that offer opportunity for people to actively respond.

Through the fieldwork for this study I observed disruption to the physical, experiential and conceptual activity of participants with dementia. Examples include Jerry and Jane's limited speech and movement, and Dorothy's temporal disorientation and difficulty in recognising objects. I also observed coherent activity, such as Sue's touch, Dorothy's vision and memory, and Jane's concepts (see [Chapter 6](#)). Musical and other sensory environments promoted individual's coherent activity at times and in ways that were otherwise disrupted, such as flowing, rhythmic movement to music for Sue. Music and recordings, in particular those that were familiar and preferred, provided the conditions for activities of being and relating, as they appeared to call to individuals to be more active in their relationship with their environment and with others. This finding echoes common anecdotal accounts that, for those with dementia, musical environments can "...bring people back to themselves" (Baird and Thompson, 2018, p. 827). When personhood is understood as both individual and relational activity, the examples above demonstrate music as promoting personhood.

An understanding of musical environments, both recorded and live, as presenting conditions for individual activity in response, introduces a 'reciprocal' perspective into the debate between 'cognitivist' (emotion recognised in music) and 'emotivist' (music causing emotion) perspectives (Kivy, 1991; Juslin and Sloboda, 2011). In light of the understanding from this study, the 'cognitivist' view can be seen as the conceptual understanding of emotion in music, and the 'emotivist' view as emotional activity in response to music. In both instances, individuals encounter a musical environment to which they can respond and contribute.

Recordings have limitations as reciprocal environments, as they cannot in turn respond to the responder, and so can only *promote* relational activity between people. In order to promote relatedness as well as individuality, the reciprocal activity of others is necessary. The development of relatedness through reciprocal interaction as a part of musical environments for people with dementia was demonstrated by a recent study that observed the development of a greater range of relational activity in “...a multisensory communicative environment” (Clare *et al.*, 2020, p. 1115) than in a music recording environment, for the same group of people. The term ‘multisensory’ in the context of Clare *et al.*’s study referred to “...visual, auditory, physical, and tactile components. The instruments could be seen, heard and touched; everyone was seated in a way that allowed them to see, hear and potentially physically interact [with] each other” (2020, p. 1121).

In this study, the term ‘multisensory’ has referred to the introduction of opportunities for other sensory perception and experience, such as tasting, smelling and touching. This approach opened up different kinds of possibilities for responding to individuals to and through music, such as sharing tastes, smells and music from other countries. Creating multisensory environments for people who cannot seek out sensory activity for themselves is the basis upon which Snoezelen, a multisensory based intervention including music, was developed and has been adapted for use in dementia care settings (Chung *et al.*, 2002). It appears less common for musical interventions to include the other senses in this way, although combining different music with other artforms appears to be a growing area of practice (Richards, 2020). Given the observations from this study indicate that sharing musical activity as a part of multisensory environments can offer a greater range of musical possibilities and opportunities for individual and relational activity, this could indicate a path for future research and practice development.

Through taking a dynamic path of participation in the fieldwork, I came to understand my music-making, and that of the participants, as an activity of being and relating alongside other forms such as speech, movement and gesture that can manifest in response to it. Making music through playing simple instruments and embodied music-making such as humming, singing and rhythmic clapping and patting were accessible, coherent forms of activity where other forms were disrupted such as speech and physical movement. These simple forms of music-making were also a

medium, not dependent upon conceptual activity, through which participants with dementia perceived and experienced others. As a medium of being, we simultaneously encountered music, and others as music, in reciprocal relationship. This dynamic perspective offers a complementary understanding of music-making as not only a human activity, but an activity of being human; understanding that is self-referential rather than conceptual (Hertz, 2010).

However, understanding music as a medium of expressing and relating is not new. What *is* new is understanding musical activity as a way people can come into appearance – as a medium of personhood. In other studies that discuss the relationship between personhood and music, personhood seems to be considered as something separate from the musical activity that comes about as a result of it rather than as an activity in response to and through it. Musical relating is seen as a means “...to be respected as a person capable of connection and meaningful interaction with others” (Macgregor, 2016, p. 93), with personhood ‘enhanced’ (Johnston and Narayanasamy, 2016) or ‘maintained’ (Otera *et al.*, 2020) by it. Elliott *et al.* observed music to be a ‘catalyst’ for different forms of connection “...(a) self-connection within the individual with dementia, (b) connection to their partner, and (c) connection with the music” (2020, p. 6) rather than music as a medium of self and relating to others.

This study offers a unique understanding of music and personhood. From this understanding it is apparent that providing opportunities for responding to, and *through* music in simple ways, can promote the activity of personhood.

8.3.2 Flourishing

As discussed at the start of this thesis, individuals with dementia can experience loss as their activity changes but can also recognise their own potential for new and developing experiences, understandings and relationships; to flourish (see [Chapter 2](#)). As McCormack and Titchen observe:

Human flourishing...[is] experienced when people achieve beneficial, positive growth that pushes their boundaries in a range of directions – for example, emotional, social, artistic, metaphysical directions. And that it could be experienced in diverse ways, such as deep fulfilment, radiance, being our real selves and through deep connection with nature, beauty and people...

Juxtapositions are important for flourishing because if you stay in the safe zone, the comfort zone, you don't flourish, you exist (2014, p. 17).

A dynamic view of personhood recognises each person as a process of becoming in reciprocal relationship with their environment, including the activity of others. As such, our potential to grow and develop is not determined by environmental conditions but promoted by them. For individuals with dementia whose potential to shape their own environments with intention changes, the possibility to recognise and create opportunities for flourishing increasingly sits with those around them. During this study, I recognised such growth and flourishing in participants in response to opportunities we shaped together. Dorothy and Chris' singing, Sue spontaneously playing the harmonica and Ron singing his Rebel song, Jane's vocal improvisation and Kenneth's blues guitar playing, all illustrated music-making to be a means of realising creative potential for people in caring relationships. In recognising the potential of people living with dementia to be creative, to grow and flourish, this study contributes to the reframing of dementia using elements antithetical to the ideas of "...neuropathology, decline, loss, disease and suffering", as proposed by Baldwin and Capstick (2007, p. 18). In doing so, this study sits alongside that of Elliott *et al.* whose "evidence for connection to self, partner, and the music challenges the idea that with a diagnosis of dementia there is only loss" (2020, p. 9).

Understanding the potential for reciprocal musical activity beyond recorded environments to promote personhood and flourishing has implications for the use of music across dementia settings. Listening to individualised, preferred recordings of music is increasingly recognised as a means to achieve caregiving outcomes such as decreased agitation as an alternative to pharmacological interventions provided for people with dementia. Such provision can constitute a one-way intervention rather than a shared activity (Gaviola *et al.*, 2020), "...potentially losing the opportunity to connect" (Elliott *et al.*, 2020, p. 11). Utilising recordings of music as a medicalised intervention to effect specific change places the symptoms of dementia at the centre of care. Sharing recordings of music as a foundation for reciprocal activity between people and environments offers a different approach; one that places the potential to promote the individual and their relationships at the centre of care. These observations are not meant to denounce the use of music as an alternative to pharmacological interventions; quite the contrary. Instead, my intention is to demonstrate how the developing of musical relationships as an element of person-

centred care might open up a landscape of possibilities for shared activity that supports individual needs.

My findings show that simple, ‘everyday’ forms of musical expression and interaction can be mutually accessible for people with dementia and those that care for them, echoing recent studies (Baird and Thompson, 2019; Dassa, Rosenbach and Gilboa, 2020; Elliott *et al.*, 2020). Such forms of musical activity can be unfamiliar and require facilitation and time to become familiar. It is also evident that ‘everyday’ music-making can be a medium of being, becoming and relating for people with dementia that is not dependent upon conceptual understanding and communication. Recognising this provides a purpose for promoting and supporting musical opportunities beyond caregiving outcomes and adds to emergent research that indicates participatory, creative musical activity can be a part of daily life for people with dementia (Hanser *et al.*, 2011; Macgregor, 2016; Bellass *et al.*, 2019; Melhuish, Grady and Holland, 2019; Swall, Hammar and Craftman, 2020). Beyond people’s own homes, this understanding can be seen to have relevance across dementia care settings.

8.4 Music and Caring Relationships

The findings from this study demonstrate that, with varying levels of support, people in caring relationships can develop relational musical activity for themselves at home and explore their own musicality to create and connect in unfamiliar ways. These findings also show that musical activity can be mutually enjoyable and accessible, whilst being a medium for coherent relational activity when the usual ways of relating in caring relationships are disrupted. These findings add to existing evidence that advocate music as supportive for caring relationships (Baker, Grocke and Pachana, 2012; Macgregor, 2016; Allan, 2018; Baird and Thompson, 2019; Dassa, Rosenbach and Gilboa, 2020; Elliott *et al.*, 2020). Given the importance of relationships to the well-being of people with dementia and those that care for them (La Fontaine *et al.*, 2016; Riley, Evans and Oyebode, 2016), shared musical activity at home could also promote well-being through supporting caring relationships.

This study demonstrates the foundational status of familiar, enjoyable musical activity as both a means of continuity through the changes of dementia and a starting point

from which to explore new sensations, experiences, understanding and ways of relating. In time, these could become familiar, enjoyed starting points for further activity within caring relationships at home. Sharing music as a developmental, generative activity in this way recognises both an individual and collective past, and future potential in the present. This is one of a small number of studies (Macgregor, 2016; Melhuish, Grady and Holland, 2019; Dassa, Rosenbach and Gilboa, 2020) that demonstrate the potential of a developmental approach to sharing familiar, enjoyed music in this setting and the only one that does not involve a music therapist seeking therapeutic outcomes.

Research has sought to understand how music can help people with dementia living at home and those that care for them by demonstrating the impact of pre-designed music interventions and music therapy practices. Although several studies (Hanser *et al.*, 2011; Macgregor, 2016; Lai and Lai, 2017; Holden *et al.*, 2019; Kulibert *et al.*, 2019; Melhuish, Grady and Holland, 2019; Dassa, Rosenbach and Gilboa, 2020; Monroe *et al.*, 2020) have sought to introduce independent musical activity into the daily lives of people with dementia and their carers, this study is the first seeking to understand *how* such musical activity can be promoted and supported beyond music therapy interventions and what music can ‘do’. Findings from the systematic literature review conducted alongside this research show that music interventions that are not responsively designed, and are understood to be solely for the person with dementia, can constitute a one-way task of provision. This can add to the challenges of providing care and inhibit shared musical activity.

The potential for individual and relational coherence through shared musical activity demonstrated by the findings from this study, indicates the purposive development of mutual relationships with music. This purpose is distinct from seeking health and well-being outcomes. However, such mutual relationships could provide a foundation of musical activity out of which other purposes could grow that are specific to the individuals in caring relationships, such as singing supporting the recognition of a loved one as observed by Baird and Thompson (2019). This is an area requiring future research and development.

8.4.1 Conditions and Qualities

It is apparent from my fieldwork findings and literature review that interrelated conditions and qualities of approach can cultivate exploration and development of a mutual relationship with music for people in caring relationships. These conditions are resources, community and empowerment, and the qualities are responsiveness, and purposiveness.

A responsive approach to developing musical activity in caring relationships, both by carers and community facilitators, holds potential to inform and promote musical empowerment, relational music activity and development of musical activity that is in harmony with individuals. During the fieldwork sessions, recognising disruption and coherence in experiential and conceptual activity, both individual and relational, provided me with indications for responding in different ways. I responded by offering reciprocal environments as opportunities to promote coherence that I observed in an individual's usual activity. Examples included my responses to Dorothy's strong relationship to visual colour, contrast and design and enjoyment of emotive musical qualities by sharing complementary pictures and recordings. I responded to coherent activity that was usually disrupted, such as physical movement for Jane, by playing recordings of music free of a strong pulse and joining her in her flowing movement. I responded to the potential for experiential relational activity between Sue and Ron, by sharing uplifting music and balloon play, as their usual conceptual relational activity, conversation, was disrupted. I also responded to the relationships between individuals and the qualities of music that could be supportive or restrictive, for example sharing a slower pace of singing or wordless singing with Sue when words proved difficult.

Responding to coherence in this way can support people's existing capabilities through musical activity. Recognising and promoting a person's abilities is an important aspect of dementia care that is not always recognised (Sabat, 2019). It is one that Higgs and Gilleard (2016) place at the centre of care rather than personhood. A view of personhood as activity, both individual and relational, means that recognising and responding to a person's capabilities, or coherent activity, is at the same time recognising and responding to their personhood as it appears to, and through, music; resolving this apparent dichotomy.

While findings from this study suggest that having preconceived ideas about music and an individual can inhibit shared musical activity, conceiving of a purpose can be a motivating factor for participation that can influence its development. It is evident from MacGregor's (2016) study that for carers to share in 'nonverbal' relational activity to and through music can require conceptual and experiential understanding of this purpose in sharing music, as it is typically unfamiliar. The understanding developed through this study offers a purpose beyond caregiving outcomes and music as a pastime or product to 'consume'; that of developing a relationship with music in daily life as a potential means of being, becoming and relating for both individuals in caring relationships through the changes that dementia brings. Developing understanding and sharing of music in this way would conceivably require community facilitation and resources to introduce, promote and support it in caring relationships. Promoting musical empowerment of people in caring relationships at home is gaining traction as an 'indirect' approach of music therapy (McDermott *et al.*, 2018; Melhuish, Grady and Holland, 2019) that aims to "...support carers to develop skills to manage...challenges and improve their quality of life... challenges such as maintaining their relationships, communications, and activities of daily living of people with dementia" (McDermott *et al.*, 2018, p. 262). The understanding from this study points to the potential for empowerment of people's inherent musicality, to share experiencing and creating music as an everyday way of being oneself in relationship with others; as "...a concrete, embodied, sensual, visceral, practical, 'moving', participatory relationship with musical-social sounds (Elliot and Silverman, 2012, p. 28).

From this perspective, music is not an activity people do as a means to an end, nor an end in itself, but an activity that people *are*. I do not talk to my family, hug them, laugh with them as an activity to enjoy together or as a means by which to promote our relationships. These activities are each of us, and our relationships, manifesting. Making music is another form *of* activity, one which can still be accessible through dementia as other activities change. Promoting and supporting such activity may very well require the development of new understanding and the opportunity to acclimatise to the unfamiliar, but working with these activities in a therapeutic way lies downstream of this relationship to music.

The literature indicates that many people in caring relationships require facilitation and/or resources, whether to introduce, or support, musical activity. It is also evident that understanding, confidence, ownership and continuing development of familiar and new musical activity can require facilitation. For these reasons, there appears to be potential to develop further resources and community provision beyond that currently available to people in caring relationships. For such resources and facilitation to be responsive, they need to offer person and relationship centred opportunities for people to explore and discover musical activity for themselves in an ongoing way rather than prescribing what music could or should be for them.

When developing mutual musical relationships, establishing support for people in caring relationships early on would give more time for the unfamiliar to become familiar, forming a strong foundation to support them through the changes to come and offering a greater breadth of opportunity for musical activity. This observation is echoed more broadly by Schneider: “In anticipation of cognitive and functional decline, it would be advisable to explore a range of expressive modalities through the arts, knowing that these activities may well extend one’s capacity to communicate despite dementia” (2018, p. 1151).

To meet the need for differing and changing levels of support, a range of provision would be needed for initial, ongoing and specialist resources and facilitation as they are required in order to reach people not able to participate in group or community settings. As mentioned previously, a developing ecology of support at a local level, such as that provided by Mindsong (Melhuish, Grady and Holland, 2019) in response to need, could provide a basis of musical activity within local communities (see [Chapter 7](#)). Such provision could include training for caregivers, informal and professional, and people in community roles such as doctors and social workers. The focus of this provision might not only be to encourage and signpost musical activity, but also to develop responsive and musical ways of relating to people with dementia, as practiced by some music therapists and advocated in music therapy research (Beer, 2017; McDermott *et al.*, 2018).

There are existing resources and facilitation available to people in caring relationships to share in musical activity in the home (see [Appendix 11.1](#)), many of which are currently online. There appears to have been a recent increase in online provision in response to the 2020 Covid-19 pandemic as many providers have switched to virtual

platforms in order to reach people and families affected by dementia who are isolated at home. Given that many people aged 75-years and over use the internet infrequently or not at all (Office for National Statistics, 2019) and 76% aged 65-years and over have limited or no basic digital skills (Lloyds Bank, 2018) it seems that offline and non-technology based resources and facilitation is an area still in need of development. It is the domain of future researchers to determine if online virtual provision could be a viable alternative to the potential for ‘real life’ facilitation to promote and support musical activity in caring relationships at home.

A foundation for promoting individualised and relational musical activity more readily, both in the home and other settings, could be developed further by increased availability of a wider range of resources and facilitation. Specifically, these could include facilitated opportunities to develop empowerment to explore inherent musicality over time purposefully and responsively, and to create recordings to promote and support participation, making use of simple musical structures and alternative keys to sing or play along to. The current UK copyright law (*Copyright, Designs and Patents Act 1988*) makes it difficult to share recordings of music as a resource. The increasing evidence of the benefits that access to recordings of music can offer people living with dementia constitutes an argument to make such music freely available for this purpose. Much culturally traditional and religious music is in the public domain, along with music that is newly created, thus offering the possibility for recordings of this music to be freely shared. Recordings might be created through community projects in which people and families affected by dementia could participate. The development of local projects in response to local people could afford the means to share and participate in a collective musical heritage and musical opportunities by creating recordings for participation; seed to be shared for others to cultivate musical activity.

It does appear that musical accessibility is a concern being taken forward in different ways. Examples include the development of dementia specific devices such as the Musical Memory Box (Kleinberger *et al.*, 2019) and technological interfaces such as touchscreen apps (Tyack and Camic, 2017; Cunningham *et al.*, 2019). However, there appears to be less impetus in developing technologies that promote living, responsive music-making without machine sounds as an intermediary, such as

sounding bowls (see [Music Glossary](#)) (Kaye, 2020). This is an area of potential development that stands out in the context of the findings from this study.

8.4.2 Recognising Potential

The possibility of sharing new and developing experiences within caring relationships diminishes as shared habitual activity and ways of interacting can become less accessible for individuals with dementia (La Fontaine *et al.*, 2016; Colquhoun, Moses and Offord, 2017; Benbow, Tsaroucha and Sharman, 2019). Moments of clarity or recognition, as the person appears to orient in space and time, however fleetingly, can be seen to offer glimpses of the person ‘as they were’ to be treasured (Whinder, 2012; Dementia UK, 2020). Seeing the person only in the context of their past recognises the person they were as their potential; a potential that is seldom and decreasingly fulfilled, and their change a painful process of continuous loss. Of the participants in this study, this appeared true for Sue and Ron in particular. It was apparent that Ron’s view of Sue as he had known her in the past obscured the view of who she was still becoming. Through the challenging and transitional time of Sue’s move to care, music remained a way of being together as they had in the past that they could still share. However, this too was diminishing. The need for continuing external facilitation to recognise and support Sue’s newfound flourishing was evident from the development of musical activity through our sessions. As an outsider who had not known Sue before her dementia diagnosis, I was able to see her with fresh eyes; to meet Sue in the present for the first time and recognise her potential to create and relate through music.

Considering the continuing growth of each person with dementia, as well as their past, opens up future possibilities for individuals and their relationships. Music as an experiential form of activity, “...not the function of a cognitive form of consciousness...a bodily form” (Kontos, 2014, p. 114), is potentially accessible to both individuals in caring relationships to be mutually shared as a person’s cognitive capacities change. Such sharing can require a carer to disrupt their own conceptual activity in order to participate experientially in recognition of the other person’s potential to *be* differently; or as Chris put it, to “...get on more of a wavelength with where mum is at...” (S12, V1, 50:44). As an individual’s need for support with daily activities increases through the course of dementia (La Fontaine *et al.*, 2016; Connors

et al., 2020), the onus falls on the carer to provide opportunities for musical activity in daily life. Because musical activity can be a one-way 'burdensome' act of caregiving, as the findings from this study indicate, it appears crucial for carers to act out of understanding that shared musical activity can offer a new creative life that could be mutually fulfilling. Aldridge observes of musical relationships "...the person with whom I am is also the source of my potential and possibility" (p. 20). It is apparent from the fieldwork and literature review for this study that facilitators seeking to promote musical activity in caring relationships can augment this collective potential or impose limitations upon it.

The observations above are in no way intended to diminish the losses experienced by individuals with dementia and those who care for them as earlier identified (see [Chapter 2](#)). Rather, they are intended to offer an expanded view of caring relationships that have the potential to endure, grow and flourish through dementia differently.

8.5 Research

8.5.1 Music and Dementia Research

There appears to be an increasing awareness of a need to bridge the gap between social science research and practice, not only to learn from phenomena directly, but to produce research that has relevance to the practice it informs (Levin and Greenwood, 2013; Bradbury, 2015). This awareness is reflected in the field of dementia research that is seeing a rise in the number of studies involving people living with dementia (Join Dementia Research, 2019; Wang *et al.*, 2019) and a call for "...a more active role in research exploring musical experiences and...a heightened emphasis is placed upon participatory approaches to knowledge generation" (Dowlen *et al.*, 2018, p. 197). The collaborative participation of people and families affected by dementia through this study contributes to increasing this body of research and responds to the need for participatory approaches to understanding in the field of music and dementia specifically.

In taking a developmental method that evolved in response to the individuals participating in the research, this study echoes the approach recently advanced by

Webb *et al.* who state: “People with dementia require researchers in the field to be creative in their methods, reflexive in their approach, and person-centred in their goals” (2020, p. 1). When gaining consent, I felt constrained by a predefined process that was dependent upon conceptual activity and I saw the potential for dementia research to recognise experiential activity along with conceptual activity in developing responsive consent processes, as well as participatory methods (see [Chapter 4](#)). My concerns reflect those expressed by Gray *et al.*: “There may be an ethical imperative to find modes of enquiry which empower the communication capabilities of people living with dementia and to explore ethical processes that more fully allow their informed involvement” (2017, p. 780). Webb *et al.* endorse data collection in dementia research through observation of ‘normal’ interactions “...where other forms of qualitative methods that rely on memory, recall, and a level of verbal fluency may not be fitted to their competencies” (2020, p. 7). The spectrum of ways interaction can take place is broadened by findings from this study that indicate arts-based activity, including music, can still be accessible to individuals with dementia when more conceptual forms of interaction typical of qualitative research, such as verbal interviews and questionnaires, are less so. These findings add to other studies utilising the arts as methods in dementia research (Hara, 2011; Kindell and Wilkinson, 2017; Wood, 2020).

Research into music and dementia takes a predominantly medicalised view of music as an alternative to pharmacological interventions for neuropsychiatric symptoms of dementia, which could be a consequence of the prevailing biomedical perspective (Dowson, McDermott and Schneider, 2019). This view applies existing conceptual frameworks for influencing health and well-being to understanding the relationship between people with dementia and music. However, it is also apparent that there is a growing concern with understanding individual differences in the relationship between music and people with dementia and their changing experiences of music (e.g. Unadkat, Camic and Vella-Burrows, 2017; Dowlen *et al.*, 2018; Garrido *et al.*, 2018; Ekra and Dale, 2020). Yet, even these studies appear to fall into the Cartesian divide that separates people from music by observing or measuring the impact that music, whether a living process or a recording of it, has upon people and their relationships. Such a view objectifies music as a commodity that exists ‘outside’ of people and acts upon them, with dementia symptoms defined as something separate to the individual to be treated and underpins musical practice by musicians, therapists

and caregivers of people with dementia. A dynamic perspective frames this pervasive approach as “...an intellectual framework imposed on the phenomenon by the mind” (Bortoft, 1996, p. 109) in contrast to each person as a phenomenon that appears through and in response to music as “...the teaching” (Goethe quoted in Steiner, 1950, p. 252). Within this intellectual framework we look to abstract, generalised data to inform our musical activity. We give away our capacity for developing intuitive relationships, to respond to individuals in the present in recognition of who they have been and who they are becoming, to standardised ways of sharing and working with people and music.

To find research that does not have an overriding concern with what music can ‘do’ requires opening up the field of view beyond that of music and dementia to therapeutic music more broadly. Ansdell and Pavlicevic assert that “contemporary pressures on music therapists to provide evidence for the efficacy of music therapy increase the risk of producing research that negates the phenomenon at the very heart of music therapy work” (2010, p. 131). Through taking a gentle empiricism approach (see [Chapter 3](#)), DeNora and Ansdell (2014) loosened the confines of the prevailing medicalised framework to understand how music helps beyond health and well-being outcomes; articulating a concern with flourishing and the myriad opportunities that musical activity can offer. They also demonstrate an understanding of the encounters between people and music as affording opportunities for reciprocal activity:

It is music plus people plus practices plus other resources that can make a change for the better. In a sense then, music can do nothing and everything. Its potential to promote flourishing, even in extremis, is simply waiting to be tapped...music is *not* like a pill or a medical procedure...it does not, in it-self, ‘make anything happen’ (DeNora and Ansdell, 2014, pp. 3-9).

As became apparent through this research, phenomena reveal themselves in different ways, and not all these ways are quantifiable or sense perceptible. Other ways of revealing are no less valid than the quantifiable and sense perceptible, as Dreyfus observes in his comments on Heidegger’s *Being and Time* “...different understandings of being reveal different sorts of entities, and since no one way of revealing is exclusively true, accepting one does not commit us to rejecting the others” (1991, p. 263). As discussed above, applying a medicalised framework to the landscape of music and dementia has its limitations, but it is apparent that, until we

can open up research approaches to understanding phenomena on their own terms, that which is quantifiable will continue to dominate the research agenda.

8.5.2 An Emerging Paradigm

From my experience of working with gentle empiricism in this study, it is clear to me that a rhythmic ‘breathing’ occurs between activity and receptivity. There is a ‘conversation’ taking place, where the enquirer is active and then receptive to emerging ‘afterimages’, leading to concepts, and so discerning the ‘hidden’ dynamics of the phenomenon (Bortoft, 2012). The enquirer creates the conditions for becoming one with the phenomenon through developing a reciprocal relationship with it. This process is not driven by the ‘subjective’ emotion that is experienced and acknowledged in being ‘called to’ but requires the cultivation of a universal empathy that supersedes likes and dislikes; a ‘universal’ love for phenomena, whether elements, plants, animals or individuals, that motivates the sustained striving necessary for this unitary activity. The enquirer can then respond through action that is in harmony with the phenomenon, or empathic action. Gentle empiricism offers a means for empathic enquiry as a reciprocal development of enquirer and phenomenon. Through the enquirer’s new activity, ‘organs of perception’ develop, more of the phenomenon is revealed to understanding, and empathic action promotes opportunity to support the phenomenon’s potential for growth. This is a mutually developmental process of research.

Through my own development of gentle empiricism, I have demonstrated that taking a dynamic approach is a means to cultivate understanding and action that is in harmony with, and promoting of, individuals and their relationships. This is an approach to research that is ‘ethically responsive’ according to Robbins (2006). The gentle empiricism method that evolved through this study is a protean manifestation; simultaneously unique and related to the phenomenon that is the appearance of Goethean science through practice. Such a method cannot be adopted on a theoretical basis but must be practiced out of a different way of seeing and knowing the world as it comes into appearance through activity, rather than imposing an intellectual framework on the research by replicating an existing method.

Recognising responses to musical environments as an individual's activity of being, and music as a medium of being, requires a shift in the ontological perspective prevailing in music and health research. The current study contributes to the growing body of research working with gentle empiricism as a developmental method of understanding that is evident not only in the field of music and health research (Ansdell and Pavlicevic, 2010; DeNora, 2012, 2013; DeNora and Ansdell, 2014, 2017; Pavlicevic *et al.*, 2015), but across disciplines, including natural science (Brook, 1998; Seamon and Zajonc, 1998; Holdrege and Talbott, 2008; *The Nature Institute*, 2020) and social science (Kaplan, 2002; Scharmer, 2009; *The Proteus Initiative*, 2013; Robbins and Gordon, 2015). The practice of gentle empiricism is incompatible with the binary ontological positions of realism and idealism and the 'continuum' of possibilities (Pope and Mays, 2020) between these Cartesian polarities. Goethe's way of science introduced "...a fundamentally new ontology of nature"; a twofold ontology where subject and object appear together as one that cannot be understood until we "...take this step for ourselves" (Bortoft, 1996, p. 320). This twofold ontology that Bortoft recognised as implicit in the work of Goethe was also described by Steiner:

The single human individual is not actually cut off from the universe. He is a part of it, and between this part and the totality of the cosmos there exists a real connection which is broken only for our perception...intuitive thinking...destroys the illusion due to perceiving (1979, pp. 211-212).

The unified appearance of subject and object creates an "...ontological condition that the knower and the known constitute an indivisible whole" (Bortoft, 1996, p. 109), uniting ontology and epistemology. Through the activity of understanding, the phenomenon and the knower come into appearance together and the phenomenon is itself "...the teaching" (Goethe quoted in Steiner, 1950, p. 252) that the researcher must unite through understanding. Coming to intuitive knowledge requires participation in the individual, protean appearances of a phenomenon, or plunging "...into the sheer phenomenality of the phenomenon" (Bortoft, 2012, p. 54) by developing organs of perception. Thus, the researcher becomes the tool of research (Bortoft, 1996) and methodology also becomes integral to the ontological-epistemological whole. This constitutes a fundamentally different approach to research that constructs abstract theories about the many appearances. As Goethe

observed: “What is general? The individual case. What is specific? Millions of cases” (1998, p. 57).

From discussing above, it is apparent that the dynamic approach taken for this study is more than a perspective. The ontological, epistemological, methodological and ethical elements discussed above constitute the four first principles of a paradigm (Denzin and Lincoln, 2012); one that is slowly emerging in research through the growing number of people turning to Goethean science as a path to understanding. As a contribution to this incipient paradigm, I recognise the naivety of the current study as an early shoot in its potential to grow across all fields of research. Within the landscape of music and dementia this paradigm holds promise as a person-centred approach to research through participating in relationships with individuals as their own teaching.

8.6 Limitations and Learning

A limitation I encountered when beginning this study was the lack of existing academic literature and research to consult on taking a Goethean approach to researching with people as phenomena. However, as the nature of this methodology is dynamic, the research of others before me provided a starting point for developing my own enquiry. Therefore, the emergence of this approach is only a limitation on the initial methodological design. The understanding offered by this study grew out of the development of musical activity with, and by, participants and the maturation of my own inchoate ‘organs of perception’. If we were to conduct another study together, our previous encounters would provide an evolved starting point for a potentially broader range of activity and more comprehensive understanding. As such, our activity and my capacities can be seen as both limiting and cultivating.

A broad limitation of this study is that the participants, including myself, were all culturally situated in the UK. This condition is likely to have contributed to shaping individual relationships to music. Therefore, there is potential for future research to explore shared musical activity in caring relationships at home in a diversity of cultures.

As this study progressed, an unavoidable limitation arose in the form of Sue’s move into residential care, which meant changing the resources that were developing for

this new setting rather than that intended for the study, her home. However, this situation did offer up an interesting insight into the accessibility of musical activity and opportunities for sharing music as more restricted in the care setting for Sue and Ron. Changing circumstances and illness caused delays to the fieldwork sessions along with other aspects of daily living that appear inevitable when working with people over several months. Although flexibility had been built into the study design, the fieldwork still took longer than anticipated. Preparing for significant life changes and allowing plenty of extra time stand out as areas of learning from this study for planning participatory fieldwork over prolonged periods with people in caring relationships living at home.

One thing I would have done differently in the writing of this thesis would have been to include video timing references for all forms of activity that I observed, not only verbal quotes. Initially, I gave video references to verbal quotes out of adherence to academic convention. I realised later that in doing so I was unintentionally giving verbal forms of activity a greater emphasis, and ultimately a higher status than the other forms of activity I observed, which goes against the grain of this thesis.

The understanding from this study has the potential to inform the responsive development of enjoyable experiential and conceptual exploration of shared musical activity by, and with, individuals in caring relationships through practice and further research. However, the understanding is new in several areas and requires a new way of seeing and understanding the world that can only be achieved through experiencing, not abstract intellectual concepts alone. This level of participation from the reader has implications for the ease with which the findings from this study can be taken up by people in caring relationships, practitioners and researchers. As this research is dependent upon the understanding and activity of others to take forward, the participatory nature of understanding the findings may limit the contribution this study can make to the landscape of music and dementia practice and research.

Understanding that experiential activity underpins conceptual activity and that it can be mutually accessible for people with, and without, dementia, indicates a need to develop an experiential basis for working with the findings from this study. It is clear from the fieldwork that this would require transforming these dry concepts into living activity that speaks to the enjoyment and enthusiasm of both people in caring relationships. Therefore, it is necessary to make the concepts from this research as

accessible as possible for facilitators, resource creators and researchers to work with if the findings from this study are to be taken forward. The suggestions and ideas for promoting and supporting musical activity produced during this study (see [Appendix 11.22](#)) are a first step in this direction. However, further working examples as an experiential basis for understanding such as practical workshops and videos could contribute to the accessibility of the research findings.

8.7 Summary

In this chapter I have discussed the dynamic understanding harvested and gathered over the course of this study within the context of the music and dementia landscape and its potential. The following final chapter recaps the essential aspects of understanding from this study and of the possibilities for its continued development and fulfilment through action into the future.

9 Conclusion

9.1 A Continuing Journey

By reading this account of my living research process, you have accompanied me on my path to understanding through the landscape of music and dementia. Through our dynamic understanding of it, the landscape has become more than it was before, and a view of future possibilities for a continuing journey in shaping the landscape is revealed. Much of this understanding has implications beyond the horizon of the current landscape as a part of the broader meeting ground of music and health disciplines within which it is situated, and the developing stream of Goethean science that now runs through many established areas of research.

A dynamic perspective of personhood as individual and relational activity recognises each one of us as simultaneously unique and related, regardless of whether a person has dementia or not. This perspective appears in harmony with that articulated by Dewing:

Maybe it is time we stopped searching for some special definition of personhood for human beings living with dementia and, in the desire to achieve unity and inclusion, instead perhaps look, alongside persons living with dementia, to more general considerations of personhood that capture our shared humanity, whatever way is our individual or collective being in the world (2019, p. 23).

As protean manifestations of human beings, the personhood of each individual is not separate from that of another, but a unique manifestation of our humanity. By promoting the personhood of another, we promote our shared humanity, as Sabat observes: "...might it be the case that when we find and support the humanity of the person diagnosed, we find and support our own as well?" (2019, p. 171).

From a dynamic perspective, people with dementia do not need a special definition of personhood, but rather the understanding that the activity of personhood can be disrupted by dementia in different ways. The activity of personhood can be promoted

by recognising and responding to disruption and coherence and observing the manifold forms activity takes beyond verbalised concepts. In doing so, we also manifest our individuality by drawing on our unique experiences and understanding. We respond to individuals as an individual.

Music is commonly regarded as external soundwaves (e.g. De Mayo, 2015) that impact on us physiologically, emotionally and cognitively (von Georgi, Gobel and Gebhardt, 2009; Theorell, 2014; Särkämö, 2020). This study offers a dynamic perspective of music as a living manifestation coming into appearance, with which we are integrally related, and in response to which we can manifest, musically or otherwise. We can create recordings of music, but these recordings are representations, not the music itself. Music manifests through our activity, just as we can manifest through music as an activity of being and relating alongside speech, movement, gesture and so on, i.e. our activity of personhood. Seen from this perspective, offering musical opportunities for responding to, and *through*, music can promote the activity of personhood.

Gentle empiricism offers a means to participate in understanding *through* practice that does not require ‘translation’ *into* practice, in contrast to other forms of research that are more removed from the phenomena of study. It is a dynamic approach to developing understanding and action that is in harmony with, and promoting of, individuals and their relationships beyond the limitations of a medicalised research framework. Taking this approach requires each individual researcher to develop their own capacities. These are human capacities of coming to understanding and action in all areas of life that can be seen reflected in common skills that are valued and utilised as an implicit part of research. Consider skills such as empirical observation, memory, imagination, creativity and practical application. By explicitly acknowledging these capacities, or organs of perception and creation, and working to develop them, researchers can become more aware of their own appearances and those of others and so increase heuristic transparency and rigor in research. Whether researcher, practitioner, carer, or friend, the basic principles of gentle empiricism:

- calling to the person;
- sharing activity;
- attentive observation;

- working with experience;
- staying receptive, not imposing;
- recognising possibilities;
- and responding out of understanding and empathy,

are a means of exploring together, and of relating to, promoting and supporting others and oneself simultaneously through a practice of shared humanity.

This research makes a unique contribution to the stream of Goethean science by studying the phenomena of music and dementia. As a consequence of this study, gentle empiricism has emerged as a pertinent approach to research in this field. The participatory, experiential approach offers an individually responsive form of research that recognises all forms of appearance rather than being limited to specifics such as spoken language. In this way, developing a gentle empiricism approach to research involving participation in sensory and arts activity, can be seen as inclusive of forms of appearance that are coherent and accessible for each individual with dementia.

Distinguishing between individuals' sensory, experiential and cognitive activity without hierarchy has implications for person-centred dementia care and research, as well as supporting and promoting musical activity for people in caring relationships.

Recognising disruption and coherence in these forms of individual and relational activity can inform the development of opportunities for coherent musical activity and so promote personhood. This understanding points to a potential for musical activity to become an integral element of person-centred dementia care.

Nurturing a responsive, relational, developmental and exploratory approach to sharing musical activity offers a foundation for working with music and people in other ways, such as towards health and well-being outcomes and creative projects. Sharing such musical activity can also be a means of looking to the future and discovering other ways of being and relating through the challenges that dementia can bring for people in caring relationships. Musical activity can be a medium for recognising and upholding who each person has been, who they are in the present moment, and who they are becoming, independently and in relationships with one another. As a person's cognitive capacities change, the experiential, sensory nature of

music can come to the fore as a medium for growth and flourishing through co-creating new future possibilities together.

The original understanding of ways to promote and support musical activity for people in caring relationships presented here illustrate that enjoyment and familiarity form a foundation of continuity, warmth and interchange. From this foundation, musical activity, people and relationships can grow and flourish intrinsically. The findings from this study present a case for responsively designing and sharing musical activity and resources by people in caring relationships and others in the wider community that support them, with the purpose of empowering musical being, becoming and relating. To this end, ongoing localised community facilitation and resources could be developed that promote and support an exploratory, developmental, relational approach to sharing familiar and unfamiliar musical activity and that respond to changing needs.

This thesis is not a product separate from the activity of understanding. Through the writing and reading of it understanding comes into appearance. Neither is this thesis an endpoint; rather it marks a stage in the continuing development of the music and dementia landscape and dynamic paradigm of research that can be further developed by myself and others into the future. Conducting this study has been a reciprocally developmental activity. By evolving this research, all participants have not only realised new understanding with the potential to contribute to change in the field of music and dementia, but we have also changed our own lives.

The understanding arising from this study is dependent upon being taken forwards by others in order to realise its future potential. This dependence necessitates the production of materials for dissemination that are accessible to people in caring relationships, care professionals, music facilitators and academics. Understanding is also dependent upon readers of this thesis and disseminated materials to embrace a dynamic approach to seeing and sharing music. Given these conditions, this study can inform future research and practice to promote and support musical activity in caring relationships:

- as an integral part of daily life at home and potentially in other settings;
- in a diversity of cultures;
- in support of activities of daily life;

- as a part of multisensory environments;
- and through development of living, responsive music technologies.

Throughout this study, I have sought understanding of musical activity in caring relationships and how shared musical activity can be promoted and supported, including practical suggestions and ideas. The understanding this study affords to those living and working within the landscape of music and dementia illustrates a relevance and potential for shared musical activity in the daily lives and caring relationships of people with dementia, beyond achieving health and well-being outcomes. The indications and suggestions provided offer a starting point for promoting and supporting such musical activity to grow and to flourish.

10 References

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11 Appendices

11.1 List of Available Resources for People in Caring Relationships at Home

This is a list of resources that I am aware of and is not exhaustive. Not all resources are specifically or solely for people with dementia, but offer accessible material for use by or with them. Some are free, others are not. I have not tried them all and so cannot endorse their use. All the links on this page were accessed 31st October 2020 and descriptions copied or summarised from provider's descriptions.

11.1.1 Websites

Age of Creativity

Lists dementia friendly creative opportunities for older people online, including musical activities.

festival.ageofcreativity.co.uk/events

Alzheimer's Society Online Shop

The Alzheimer's society sell a range of equipment for sharing musical activity at home, including devices for playing recorded media, CDs and songbooks.

shop.alzheimers.org.uk

BBC Music Memories

Use music to help people reconnect with their most powerful memories.

musicmemories.bbcrewind.co.uk

Blue Skies Singing Group

Videos for singing along to.

youtube.com/channel/UCOSFVS9P_KtG1oXxN6QBCew

Deepness Dementia Radio

Relaxed, soothing music during the night and discussion on living well with dementia, with segments such as storytelling and “Dementia Island Disks”.

deepnessdementiamedia.com/deepness-dementia-radio

Folk Cloud

Listen to original folk and traditional music from around the world.

folkcloud.com

Golden Carers

Themed playlists of music recordings on YouTube.

youtube.com/c/goldencarers/playlists

Leaf Creative Arts

Videos of people’s stories and creative activities to try, including music.

leafcreativearts.wordpress.com

Luminate @ home

A series of creative activity films to enjoy at home, including music.

vimeo.com/luminatescotland

Music for Dementia 2020

Online advice, resources and a UK map of dementia-friendly musical activities and services.

musicfordementia2020.com

M4D Radio

A group of 5 themed radio stations available 24 hours a day, 365 days a year playing music that evokes memories. Choose your era.

m4dradio.com

Playlist for Life

Online resources and guidance for creating and using personal playlists of music recordings.

playlistforlife.org.uk

Radiooooo

Enjoy sharing and discovering recordings from around the world through the musical time machine.

radiooooo.com

Room 217

Products (Canada: CD, DVDs, books, cards), education (webinars, training), research on using music in care.

room217.ca/dementia

Sing 4 Health and Happiness

Join in with pre-recorded video singing sessions.

youtube.com/channel/UCH48cq8uSN83qSzSX9wWpvA

Sound Recordings

Material from Alan Lomax's independent archive.

research.culturalequity.org/home-audio.jsp

78 RPMs and Cylinder Recordings

Listen to recordings from the early 20th century.

archive.org/details/78rpm

11.1.2 Technology and Equipment

Memory Tracks

A smartphone app that connects daily events to the person's choice of reminiscence music.

memorytracks.co.uk

Music Memory Box

A box to fill together with meaningful objects, music and photographs.

musicmemorybox.com

Sound Travels

A website selling a wide range of instruments from around the world, including for therapeutic purposes.

soundtravels.co.uk

Soundtrack to My Life – Fink Cards

48 Questions to help people with dementia choose music to help: stimulate senses; connect with a particular time or place; release strong emotions; calm, soothe and comfort.

joco.gb.net/shop/life-story/soundtrack-to-my-life-fink-cards

11.1.3 Books

Connecting Through Music with People with Dementia

A book by Robin Rio giving practical advice on sharing music.

Creativity and Communication in Persons with Dementia: A Practical Guide

A book by John Killick and Claire Craig that explores the arts and dementia, including music, with ideas for participating.

Soundtrack to My Life

A book by John Osborne designed to help people to draw together those pieces of music that are most significant to them. These become a compilation that can travel with them on their dementia journey.

The Creative Arts in Dementia Care: Practical Person-Centred Approaches and Ideas

A book by Jill Hayes with Sarah Povey that discusses creative practices in dementia care including singing describing their therapeutic benefits and giving examples of how they can be used.

11.2 Seeing 'Giraffely'



(Bortoft, 1996, p. 50; edited)

11.3 Music and Life Story Questionnaire



Music & Life Story Questionnaire

Please answer these questions about your life and the music you enjoy

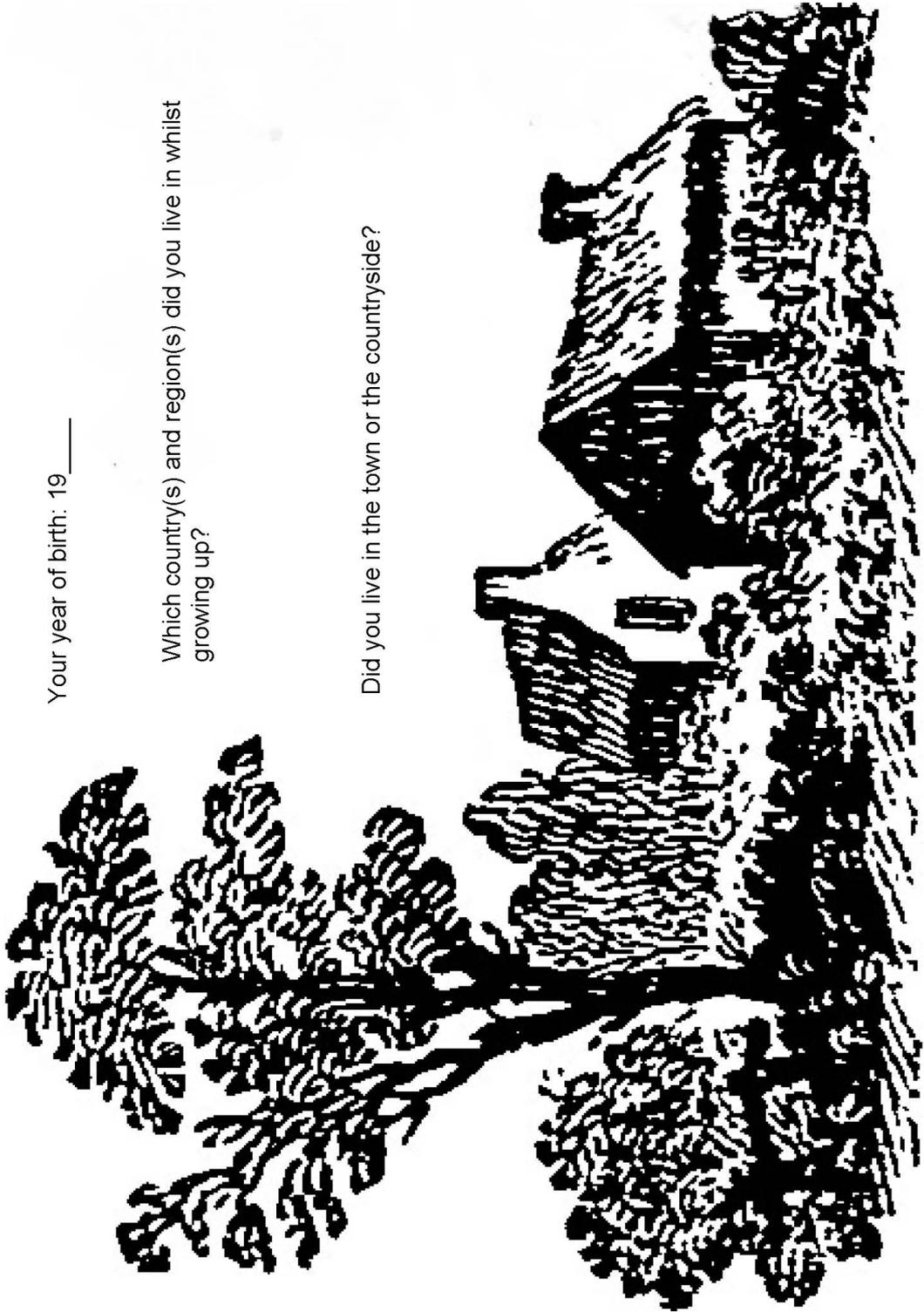


Version 1.0 12/02/18

Your year of birth: 19 ____

Which country(s) and region(s) did you live in whilst growing up?

Did you live in the town or the countryside?



What jobs have you had?

What hobbies have been important to you?



Can you tell me about any music you heard at home when you were young – music your parents enjoyed playing, singing or listening to?

Can you tell me about any music you listened to as a teenager?



Do you/did you enjoy singing?

If yes, where do you/did you sing? (e.g. around-the house, choirs, church)

What types of music do you/did you enjoy singing? (E.g. hymns, classical, folk)

How important has music been to you?

1. Very Important _____
2. Moderately Important _____
3. Slightly Important _____
4. Not Important _____
5. Unsure _____



Do you/did you play a musical instrument?

If yes, what instrument(s)?

The following is a list of different types of music. What are your three (3) most favourite types of music?

___ 1. Rock and Roll

___ 2. Musicals

___ 3. Big Band/Swing

___ 4. Classical

___ 5. Spiritual/Religious

___ 6. Country and Western

___ 7. Folk

___ 8. Blues

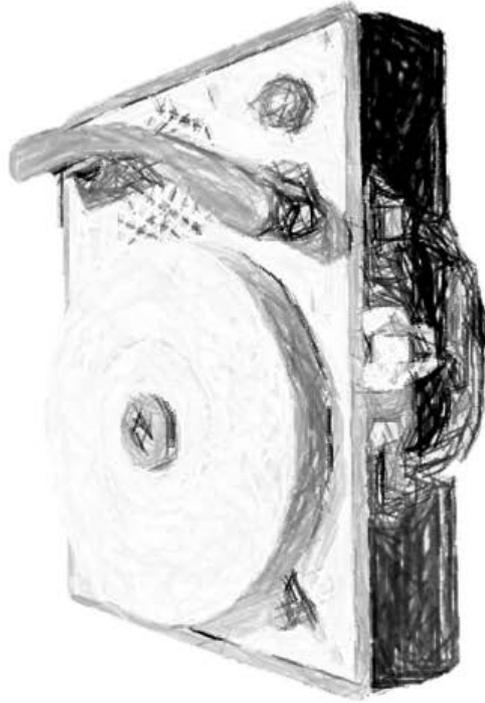
___ 9. Jazz

___ 10. Pop

___ 11. Easy Listening

___ 12. Cultural or Ethnic Specific (Czech polkas, Indian, Spanish, Scottish, Irish)

___ 13. Other: _____

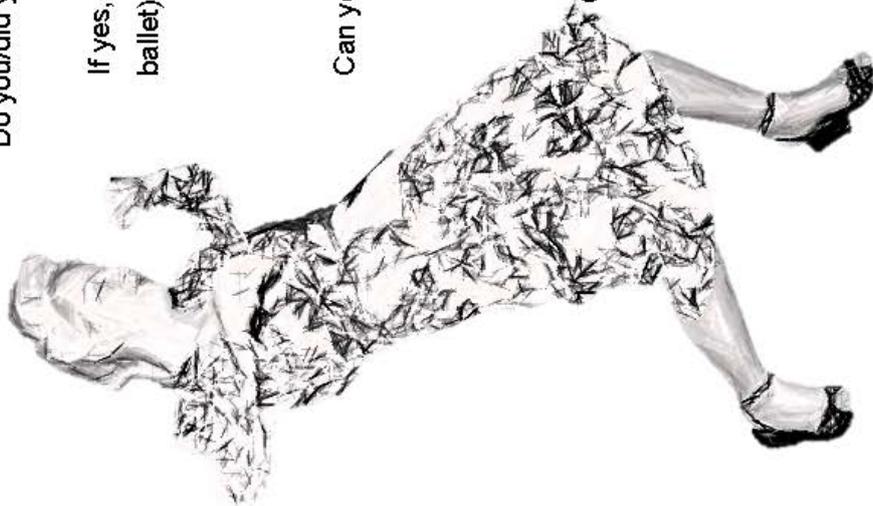


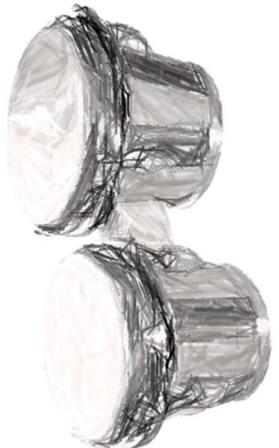
Do you/did you enjoy dancing?

If yes, what types of dancing? (E.g. country dancing, ballroom, tap, modern, ballet)

Can you name some of your favourite songs or pieces of music?

Can you name some of your favourite albums or cassettes?





What music listening, playing or singing do you currently enjoy?

Did you/do you share any music listening, playing or singing together with the person you are participating in this study with?
If yes, can you tell me about it?



Please use this space to tell me anything else you think is important about you and/or the music that is important to you.

Thank you

11.4 Music and Life Story Questionnaire: Family Member



Music & Life Story Questionnaire for Family Members

Please answer the questions based on your knowledge of your family member's life and their music preferences

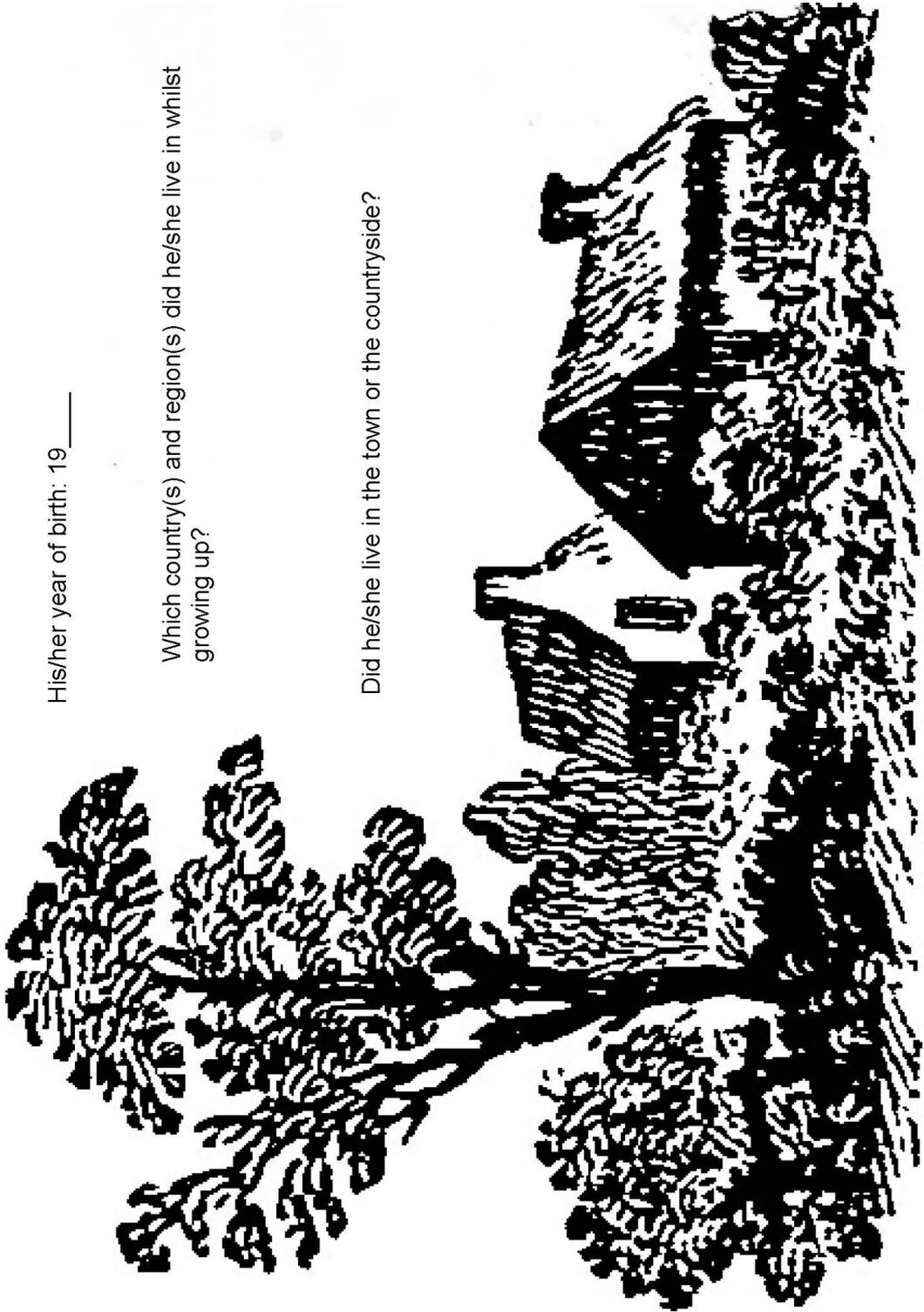


Version 1.0 12/02/18

His/her year of birth: 19 _____

Which country(s) and region(s) did he/she live in whilst growing up?

Did he/she live in the town or the countryside?



What jobs did s/he have?

What hobbies have been important to him/her?



Can you tell me about any music your family member heard in his/her home when growing up – music his/her parents enjoyed listening to?

Can you tell me about any music your family member listened to as a teenager?



Does/did s/he enjoy singing?

If yes, where does/did s/he sing? (e.g. around-the house, choirs, church)

What types of music does/did s/he enjoy singing? (E.g. hymns, classical, folk)

How important has music been to him/her?

1. Very Important _____
2. Moderately Important _____
3. Slightly Important _____
4. Not Important _____
5. Unsure _____



Does/did s/he play a musical instrument?

If yes, what instrument(s)?

The following is a list of different types of music. What are your family member's three (3) most favourite types of music?

___ 1. Rock and Roll

___ 2. Musicals

___ 3. Big Band/Swing

___ 4. Classical

___ 5. Spiritual/Religious

___ 6. Country and Western

___ 7. Folk

___ 8. Blues

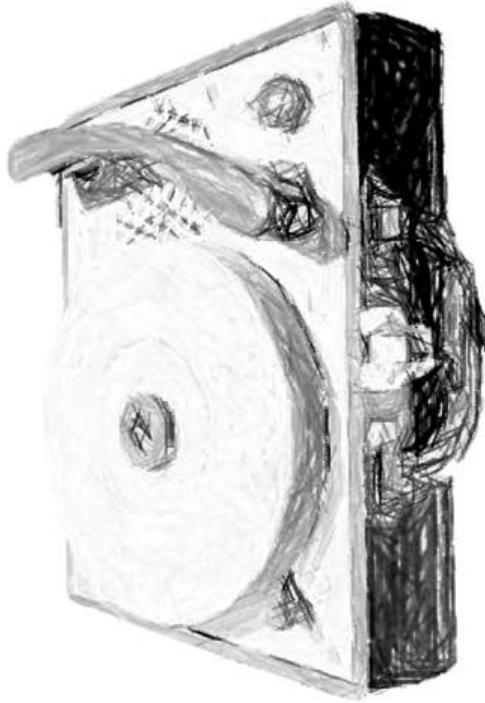
___ 9. Jazz

___ 10. Pop

___ 11. Easy Listening

___ 12. Cultural or Ethnic Specific (Czech polkas, Indian, Spanish, Scottish, Irish)

___ 13. Other: _____

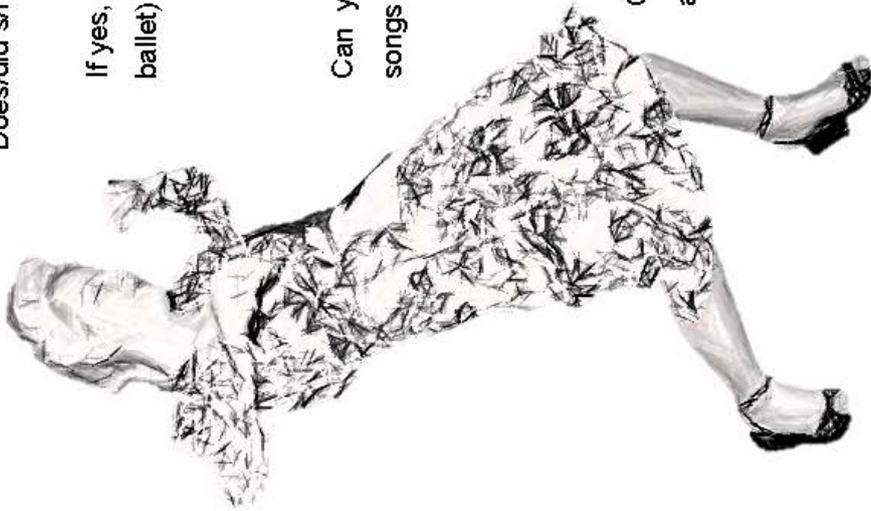


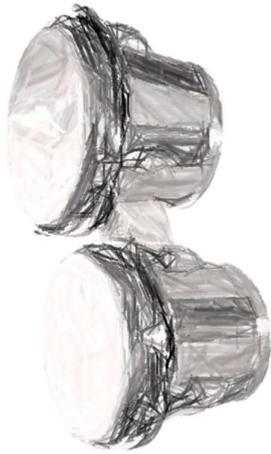
Does/did s/he enjoy dancing?

If yes, what types of dancing? (country dancing, ballroom, tap, modern, ballet)

Can you tell me the titles some of your family member's favourite songs or pieces of music?

Can you tell me the titles some of your family member's favourite albums or cassettes?





Can you tell me about any music listening, playing or singing that s/he currently engages in?

Did you/do you share any music listening, playing or singing together with your family member? If yes, can you tell me about it?



Please use this space to tell me anything else you think is important about your family member and/or the music that is important to him/her.

Thank you

11.5 Participant Information Sheet for a Person with Dementia

Version 1.1

08/11/2017

INVITATION TO PARTICIPATE IN A STUDY

Detailed information participant 1

Study: Exploring and developing 'Personally Significant Music' as creative process within the caring relationships of individuals with dementia living at home



Who I am

My name is Ruby Swift. I am a PhD researcher based at the Association for Dementia Studies at the University of Worcester. My PhD is focused on exploring personally meaningful music and active music making with people with dementia living at home and those who care for them. I explain more about this on the next page.

My PhD is part of a larger programme of work exploring the value of arts based activities for people with dementia, and I am one of six PhD students based at the TAnDem (The Arts and Dementia) Doctoral Training Centre. The Doctoral Training Centre is funded through the Alzheimer's Society and represents a partnership between the Association for Dementia Studies at the University of Worcester, and the Centre for Dementia at the University of Nottingham.

Why I am contacting you

I am looking for pairs of participants (a person with dementia and a person who cares for them) to take part in my PhD study.

What is the study about?

Music that has a strong link to past experiences can offer a means of connecting with an individual with dementia when other means of connection/communication have diminished. For individuals with dementia living at home, musical engagement typically takes the form of listening to recorded tracks, and other forms of engagement with music tend to be overlooked. Responsive, creative musical engagement, such as singing, can have significance in the present moment to a person with dementia and can foster connections. Through this research, I am seeking to develop methods and resources that will enable people with dementia living at home and the people who care for them to explore and develop musical engagement together.

Taking part in the study

Both you and the person who cares for you will be invited to take part in:

- 1 initial meeting (approx. 1 hr)
- Up to 12 weekly music sessions (approx. 1 hr each)
- 1 final meeting (approx. 1 hr)

Initial meeting

This meeting will provide an opportunity to:

- discuss the study in more detail
- address any questions/concerns
- sign the consent forms if you feel comfortable doing so
- provide the opportunity to discuss arising questions

- share our intentions for this project
- share music that is personally meaningful and familiar

Weekly music sessions

These sessions will be opportunities for us to explore familiar and unfamiliar music and sensory stimulation, which can offer alternative ways to develop communication and open doors to the memory without relying solely on verbal communication. The types of activities that we might engage in include:

- Listening to music
- Handling tasting/smelling objects
- Playing musical instruments
- Arts and crafts
- Humming / singing
- Conversational interviews to share experiences
- Movement

These sessions will take place in your own home at mutually agreed times that fit in with your regular routines and when we are unlikely to be interrupted by household noise, visitors etc. We will need a quiet, smoke-free space that we can use for each session. Each music session will last for approximately 60 minutes (30 minutes for music and 30 minutes for set-up, pack-up, and discussion).

Final meeting

This meeting will take place about 8 weeks after the music sessions have ended and will provide an opportunity to:

- Share music, methods and tools explored and developed through the research
- Share our experiences of continuing to explore and develop musical engagement

It is important to note that music sessions will be video and audio recorded.

What are the possible benefits of taking part

Taking part in this study will give you the opportunity to explore music as creative process, which includes not only listening, but also experiencing, creating, expression, communication and movement. Enjoying and sharing music together could have a positive impact on both your lives. Your input would be highly valued and could potentially contribute to providing methods and resources for others in your situation to enjoy and share music together at home.

What are the possible disadvantages of taking part?

It is possible that you and/or the person who cares for you may feel uncomfortable about my presence or the activities we are sharing, and music can evoke strong emotions. If you or the person who cares for you becomes uncomfortable or distressed, I will discontinue the session and arrange to come back another time.

How will the data I collect be used?

The information I gather during this study will be published in my PhD thesis. I also intend to publish my findings in journals and other publications, and plan to present my findings at conferences and workshops for academics, artists, therapists and care professionals.

Your research data could potentially provide a valuable resource for future research beyond the life of this project. With your consent, your research data will be stored securely for a further 5 years, and may be used by me in future studies that relate to the topic of personally significant music as an intervention for people living with dementia at home and their carers. At the end of 5 years, all stored data that could identify you or the person who cares for you will be destroyed; all other

data will belong to the University of Worcester and will be stored anonymously by them for 10 years.

You do not have to take part in this research. If you do decide to take part, you may withdraw at any time without giving a reason. If either you, or your carer, decide to withdraw, the sessions will cease.

Will this data be confidential?

When I present my findings at conferences/ workshops, in my thesis or in any publications, details will be changed so that you will not be identifiable. All measures will be taken to protect your identities. The content of all sessions will be kept confidential and any quotes anonymised so that no participants are identifiable.

In the unlikely event that I hear or see something that makes me think somebody could be hurt or in danger, I will follow Adult Protection procedures that could involve reporting to the Safeguarding Adults team of the Social Care Department. Any disclosures of a criminal nature will be reported to the appropriate authorities.

Consenting to participate in this study

It is important for you to understand the reasons for this study, and why I am asking you to take part. Please take time to read the enclosed information sheets carefully. I will ask you to sign a consent to participate form at the initial meeting. You can change your mind regarding whether you wish to take part in this study at any point. You do not have to give a reason.

I will be re-seeking your consent continuously throughout this study, meaning that I will ask your permission at the start of each music session as well as whenever an activity changes. I plan to video and audio record our sessions as this will allow me to reflect on our sessions in more detail and remember everything that took place. If you object to this, please let me know and we can discuss other options.

If you are not able to provide informed consent, i.e. not able to understand or retain information about the research long enough to consider whether or not you should take part, I will ask the person who cares for you to act as your 'personal consultee'. Acting as a 'personal consultee' would mean giving advice at the initial meeting, and ongoing, about whether you should take part in this study. Their agreement to the participation does not constitute consent on your behalf; I will always approach you to gain your consent before including you. The person who cares for you will only be asked to act as a 'personal consultee' if you are unable to give informed consent to participate in study and they will be required to be present at all times during the consent process and music sessions.

How do I make a decision?

When deciding if you would like to join this study, please consider the different aspects of the study listed in '[Taking part in the study](#)' on p.2.

You will not be asked to take part in anything that you do not want to do or do not feel comfortable with.

What happens next?

If you have no objection to taking part in the study, I will ask you to read and sign the enclosed consent form. You will be provided with a copy of this for your personal records. I will understand fully if you decide not to be included in this study.

How do I contact you?

Ruby Swift:

Tel: Email: r.swift@worc.ac.uk

Help and Support

If you need help and support, you can contact your local [INSERT TITLE] **Dementia Advice service**

Phone: [INSERT NUMBER]

Alternatively, you can get help and advice from the **Alzheimer's Society helpline:**

Phone: 0300 222 1122 (Mon-Fri, 9am-5pm. Weekends, 10am-4pm)

If you would like to speak to a third party from the University of Worcester about your participation in this research project, please contact:

Phone: Email:

If you need to emotional support at any time of the day or night, you can contact the **Samaritans** confidentially

Phone: 116 123 (free 24-hour helpline)

Thank you for taking the time to consider my study

11.6 Participant Information Sheet for Carer

Version 1.2

08/11/2017

INVITATION TO PARTICIPATE IN A STUDY

Detailed information participant 2

Study: Exploring and developing 'Personally Significant Music' as creative process within the caring relationships of individuals with dementia living at home



Who I am

My name is Ruby Swift. I am a PhD researcher based at the Association for Dementia Studies at the University of Worcester. My PhD is focused on exploring personally meaningful music and active music making with people with dementia living at home and those who care for them. I explain more about this on the next page.

My PhD is part of a larger programme of work exploring the value of arts based activities for people with dementia, and I am one of six PhD students based at the TAnDem (The Arts and Dementia) Doctoral Training Centre. The Doctoral Training Centre is funded through the Alzheimer's Society and represents a partnership between the Association for Dementia Studies at the University of Worcester, and the Centre for Dementia at the University of Nottingham.

Why I am contacting you

I am looking for pairs of participants (a person with dementia and a person who cares for them) to take part in my PhD study.

What is the study about?

Music that has a strong link to past experiences can offer a means of connecting with an individual with dementia when other means of connection/communication have diminished. For individuals with dementia living at home, musical engagement typically takes the form of listening to recorded tracks, and other forms of engagement with music tend to be overlooked. Responsive, creative musical engagement, such as singing, can have significance in the present moment to a person with dementia and can foster connections. Through this research, I am seeking to develop methods and resources that will enable people with dementia living at home and the people who care for them to explore and develop musical engagement together.

Taking part in the study

Both you and the person you care for will be invited to take part in:

- 1 initial meeting (approx. 1 hr)
- Up to 12 weekly music sessions (approx. 1 hr each)
- 1 final meeting (approx. 1 hr)

Initial meeting

This meeting will provide an opportunity to:

- discuss the study in more detail
- address any questions/concerns
- sign the consent forms if you feel comfortable doing so
- provide the opportunity to discuss arising questions
- share our intentions for this project

- share music that is personally meaningful and familiar

Weekly music sessions

These sessions will be opportunities for us to explore familiar and unfamiliar music and sensory stimulation, which can offer alternative ways to develop communication and open doors to the memory without relying solely on verbal communication. The types of activities that we might engage in include:

- Listening to music
- Playing musical instruments
- Humming / singing
- Movement
- Handling tasting/smelling objects
- Arts and crafts
- Conversational interviews to share experiences

These sessions will take place in the home of the person you care for (this may be your home also) at mutually agreed times that fit in with your regular routines and when we are unlikely to be interrupted by household noise, visitors etc. We will need a quiet, smoke-free space that we can use for each session. Each music session will last for approximately 60 minutes (30 minutes for music and 30 minutes for set-up, pack-up, and discussion).

Final meeting

This meeting will take place about 8 weeks after the music sessions have ended and will provide an opportunity to:

- Share music, methods and tools explored and developed through the research
- Share our experiences of continuing to explore and develop musical engagement

It is important to note that music sessions and the final session will be video and audio recorded.

What are the possible benefits of taking part

Taking part in this study will give you the opportunity to explore music as creative process, which includes not only listening, but also experiencing, creating, expression, communication and movement. Enjoying and sharing music together could have a positive impact on both your lives. Your input would be highly valued and could potentially contribute to providing methods and resources for others in your situation to enjoy and share music together at home.

What are the possible disadvantages of taking part?

It is possible that you and/or the person you care for may feel uncomfortable about my presence or the activities we are sharing, and music can evoke strong emotions. If you or the person you care becomes uncomfortable or distressed, I will discontinue the session and arrange to come back another time.

How will the data I collect be used?

The information I gather during this study will be published in my PhD thesis. I also intend to publish my findings in journals and other publications, and plan to present my findings at conferences and workshops for academics, artists, therapists and care professionals.

Your research data could potentially provide a valuable resource for future research beyond the life of this project. With your consent, your research data will be stored securely for a further 5 years, and may be used by me in future studies that relate to the topic of personally significant music as an intervention for people living with dementia at home and their carers. At the end of 5 years, all stored data that could identify you or the person you care for will be destroyed; all other data

will belong to the University of Worcester and will be stored anonymously by them for 10 years.

You do not have to take part in this research. If you do decide to take part, you may withdraw at any time without giving a reason. If either you, or the person you care for, decide to withdraw, the sessions will cease.

Will this data be confidential?

When I present my findings at conferences/ workshops, in my thesis or in any publications, details will be changed so that you and the person you care for will not be identifiable. All measures will be taken to protect your identities. The content of all sessions will be kept confidential and any quotes anonymised so that no participants are identifiable.

In the unlikely event that I hear or see something that makes me think somebody could be hurt or in danger, I will follow Adult Protection procedures that could involve reporting to the Safeguarding Adults team of the Social Care Department. Any disclosures of a criminal nature will be reported to the appropriate authorities.

Consenting to participate in this study

It is important for you to understand the reasons for this study, and why I am asking you to take part. Please take time to read the enclosed information sheets carefully. I will ask you to sign a consent to participate form at the initial meeting. You can change your mind regarding whether you wish to take part in this study at any point. You do not have to give a reason.

If the person you care for is not able to provide informed consent, I will ask you to act as a 'personal consultee' on their behalf.

I plan to video and audio record our sessions as this will allow me to reflect on our sessions in more detail and remember everything that took place. If you object to this, please let me know and we can discuss other options.

How do I make a decision?

When deciding if you would like to join this study, please consider the different aspects of the study listed in 'Taking part in the study' on p.2.

You will be not be asked to take part in anything that you do not want to do or do not feel comfortable with.

What happens next?

If you are happy to take part in the study, I will ask you to read and sign the enclosed consent form. You will be provided with a copy of the consent forms for your personal records. I will understand fully if you do not think it is appropriate for you to be included in this study.

How do I contact you?

Ruby Swift:

Tel:

Email: r.swift@worc.ac.uk

Help and Support

If you need help and support, you can contact your local [INSERT TITLE] **Dementia Advice service**

Phone: [INSERT NUMBER]

Alternatively, you can get help and advice from the **Alzheimer's Society helpline:**

Phone: 0300 222 1122 (Mon-Fri, 9am-5pm. Weekends, 10am-4pm)

If you would like to speak to a third party from the University of Worcester about your participation in this research project, please contact:

Phone:

Email:

If you need to emotional support at any time of the day or night, you can contact the **Samaritans** confidentially

Phone: 116 123 (free 24-hour helpline)

Thank you for taking the time to consider my study

11.7 Consultee Information Sheet



Personal Consultee Information Sheet

Consent

If the person you care for is unable to provide informed consent, i.e. is not able to understand or retain information about the research long enough to consider whether or not s/he should take part, I will ask you to act as her/his 'personal consultee'. Acting as a 'personal consultee' would mean giving advice at the initial meeting, and ongoing, about whether the person you care for should take part in this study. Your agreement to the participation does not constitute consent on the behalf of the person you care for; I will always approach him/her to gain their consent before including them. You will only be asked to act as a 'personal consultee' if the person you care for is unable to give informed consent to participate in the study.

I will be re-seeking consent continuously throughout this study, meaning that I will ask permission from the person you care for at the start of each music session as well as whenever an activity changes. I will require your presence at all times during the consent process and music sessions. I plan to video and audio record our sessions as this will allow me to reflect on our sessions in more detail and remember everything that took place. If you object to this, or if you think the person you care for would object to this, please let me know and we can discuss other options.

It is important for you to understand the reasons for this study, and why I am asking the person you care for to take part. Please take time to read the enclosed information sheets carefully. If the person you care for shows any sign of annoyance or if s/he appears uncomfortable, s/he will not be included in the study. You can change your opinion regarding whether the

person you care for wishes to take part in this study at any point. You do not have to give a reason.

How do I make a decision?

When deciding if the person you care for should join this study, consider whether or not s/he would want to be involved. Please consider what you know of their wishes and feelings, and also consider their interests. Please let me know about any advance decisions s/he may have made about participating in research as these should take precedence. It is possible that the person you care for would consent to some aspects of the study and not to others. Please consider the different aspects of the study detailed on p.2 of Participant Information Sheets A and B.

The person you care for will not be asked to take part in anything that they do not want to do or do not feel comfortable with.

What happens next?

If the person you care for is unable to provide informed consent, and you decide they would have no objection to taking part in the study, I will ask you to read and sign the enclosed consultee declaration form. You will be provided with a copy of the consent forms for your personal records. I will understand fully if you do not think it is appropriate for the person you care for to be included in this study.

Professional Consultees

If you are a paid carer, you will only be permitted to act as a 'professional consultee' and participate in the study in the event that a 'personal consultee' cannot be identified who is willing to act as consultee and participate in the study.

11.8 Supplementary Information Sheet

Version 1.1

13/10/17



INVITATION TO PARTICIPATE IN A STUDY

I would like to invite you to take part in my research project. Before you decide whether to take part, it is important that you take time to read this leaflet carefully and ask me if you have any questions.



WHO AM I?

My name is Ruby Swift. I am a PhD student at the University of Worcester.



WHAT IS THIS ABOUT?

I would like to explore music with you for my PhD research project.



WHY HAVE YOU BEEN INVITED?

You have been invited to take part in the study because you experience memory problems and may like to explore ways that music might be enjoyed within your life.



WHAT WILL YOU DO?

You will be invited to listen to music, and perhaps create music with your _____ and me.



DO YOU HAVE TO TAKE PART?

No, you do not have to take part. If you decide not to take part it will not affect your care in any way.



WHAT WILL HAPPEN TO THE RESULTS OF THIS RESEARCH STUDY?

The findings of this study will be included in my PhD thesis, and may also be presented in other publications and at conferences and workshops.



WHAT WILL HAPPEN IF YOU DECIDE TO TAKE PART?

You will be invited to listen to music, and perhaps create music with your _____ and me. I will video record and sound record our sessions together to help me remember what we did and then write about it.



WHAT HAPPENS NEXT?

I will spend some time talking with you more about the research. I will ask you if you would like to be involved.

THANK YOU

Ruby Swift

Telephone:

E-mail: r.swift@worc.ac.uk

11.9 Inclusion and Exclusion Criteria Checklist

Checklist

Participant 1



- Has a diagnosis of dementia
- Experiencing at least one of the following difficulties with verbal communication:
 - Deterioration in the ability to understand spoken language
 - Language has grammatical errors and poor structure
 - Resorting to simple sentences
 - Repetitive use of language
 - Comprehension of language is impaired
- Living within a 30-mile radius of Kidderminster Hospital
- Living at home and has at least one carer
- Has some level of hearing
- Speaks English as a first language



- Does not have a personal consultee to provide their opinion in the event the person cannot provide informed consent
- Co-existing severe and enduring mental illness
- Does not have an awareness of his/her surroundings
- Is profoundly deaf
- Has a history of aggression and/or violence

Participant 2



- Is a family member, an unrelated companion or a paid professional who regularly provides care for the participant with dementia
- Is able to provide direct informed consent
- Has some level of hearing
- Speaks English as a first language



- Requires an interpreter
- Is unable to provide direct informed consent
- Is profoundly deaf
- Has a history of aggression and/or violence

11.10 Consent Form

Version 1.2
08/11/2017



Participant Consent Form

Title of project: Exploring and developing 'Personally Significant Music' as creative process within the caring relationships of individuals with dementia living at home

Participant Identification Number for this study:

Name of Researcher: Ruby Swift

Please initial

I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

I confirm that I have had sufficient time to consider whether I want to take part in this study.

I understand that I do not have to take part in this research and I can change my mind at any time. I understand that I may withdraw my individual session data within 2 weeks of each session by contacting the researcher.

I agree to the research sessions being video recorded.

I agree to the research sessions being audio recorded.

I agree to my research data including anonymised quotations being used in publications or reports.

I agree to take part in the study.

I know who to contact if I have any concerns about this research.



I agree to my research data being used beyond the life of the project for up to 5 years for further research by Ruby Swift. I understand that I may withdraw my data from storage for further use during the 5 years, but not from a future study once the data has been integrated into that study.

I understand and agree to the terms of use of the data from this study.

Name of participant _____

(Name of witness _____)

Date _____ Signature _____

Name of person taking consent _____

Date _____ Signature _____

11.11 Consultee Declaration Form

Version 1.2
08/11/2017



Consultee Declaration Form

Title of project: Exploring and developing ‘Personally Significant Music’ as creative process within the caring relationships of individuals with dementia living at home

Participant Identification Number for this study:

Name of Researcher: Ruby Swift

Please initial

I [name of consultee] have been consulted about [name of potential participant] participation in this research project. I confirm that I have read the information sheet and have had the opportunity to ask questions about the study and understand what is involved.

In my opinion, s/he would have no objection to taking part in the above study.

I understand that I can request s/he and/or his/her individual session data is withdrawn from the study within 2 weeks of each session, without giving any reason and without his/her legal rights being affected.

In my opinion s/he would have no objection to taking part in the proposed music sessions and community sessions.

In my opinion s/he would have no objection to being video recorded during music sessions and community sessions.

In my opinion s/he would have no objection to being audio recorded during music sessions and community sessions.

I agree to the research data including anonymised quotations being used in publications or reports.

I understand that the data gathered during the study will be used in publications and presented at conferences and workshops, but that all steps will be taken to protect the identity of the person I care for.



I agree to the research data being used beyond the life of the project for up to 5 years for further research by Ruby Swift. I understand that I may withdraw the research data from storage for further use during the 5 years, but not from a future study, once the data has been integrated into that study.

I understand and agree to the terms of use of the data from this study. In my opinion, s/he would have no objection to the terms of use of the data from this study.

Name of consultee: _____

Date: _____ Signature: _____

Name of participant:

Relationship to consultee:

Name of researcher: _____

Date: _____ Signature: _____

11.12 Accompanying Letter

Version 1.1

21/02/18

Ruby Swift
Association for Dementia Studies WB 139
University of Worcester
Henwick Grove
Worcester
WR2 6AJ

Tel:
r.swift@worc.ac.uk

21st February 2018

Dear Volunteers,

Thank you for expressing interest in my study. Please find enclosed the following documents:

- 1 Participant Information Sheet A: detailed information for the person with dementia
- 1 Participant Information Sheet B: detailed information for the supporting person
- 1 Participant Information Sheet C: supplementary information
- 2 Music and Life Story Questionnaires (1 each)
- 1 Music and Life Story Questionnaire for Family Members

Participant Information Sheets

Please take time to read the enclosed information sheets carefully to help you decide if wish to go ahead and participate in the study. I will answer any questions at the initial meeting and ask you both to give your consent.

There is a separate **Participant Information Sheet** for each of you (A and B) and a supplementary **Participant Information Sheet** (C) with images to use, if helpful.



Questionnaires

If you happy to, please complete one **Music and Life Story Questionnaire** each with details about your own life and music. You can complete them individually, together or on behalf on each other as necessary.

If one of you is unable to answer some or all of the questions due to memory problems, please pass on the **Music and Life Story Questionnaire for Family Members** to a family member who may have helpful memories.

Completing the questionnaires will provide me with helpful information about you both, and the music that is important to you, so that I can prepare our sessions. If you would like help completing the questionnaires, we can work on them together when we meet. If you choose not to complete the questionnaires or particular questions that is fine, but this will mean spending music session time talking with you both to find out the information that I need. I will collect completed questionnaires at the initial meeting.

I look forward to meeting you both.

Best wishes,

11.13 Communication Questions

Version 1.0

08/11/2017

Document P: Communication Questions

How can I tell if you are happy and content?
How can I tell if you are uncomfortable with what is happening to you?
How can I tell if you are experiencing pain?
Is your behaviour affected by medication? If so, how?
Please provide any other relevant information to help me communicate with you

Please continue on a separate sheet if necessary

11.14 Consent Process

Stage 1: The first stage of the consent process will be for me to meet with each dyad. The dyad will be asked to complete a Communication Questions sheet, which will be used to inform the best way to approach communication with each individual with dementia during the consent process and interpret appearance and behaviour effectively. I will approach this openly with each dyad and complete it together with them, omitting if unnecessary. This understanding will help to inform the decision making.

Stage 2: The next stage is gaining formal written consent to take part. The inclusion criteria for this study specifically seeks potential participants who have experienced decline in their capacity for verbal communication, which increases the likelihood that there will be participants that may be unable to provide fully informed consent. The capacity to consent is defined in the Mental Capacity Act as a process that requires individual assessment of capacity for each decision to be made, and so will not exclude any potential participant from the consent process altogether. In accordance with the key principles of the Mental Capacity Act, capacity will be assumed for all individuals unless proved otherwise, and individuals will be given all appropriate help to make a decision before it is concluded that they cannot decide for themselves. It will not be assumed that a participant cannot give consent; capacity to consent will be assessed as information is given to them.

Seeking consent will be accompanied by the carer, for if the person with dementia cannot give consent, a decision will need to be made regarding their participation. This decision will involve talking to the person and assessing their reaction to an explanation of the research or to my presence. By having another person, unconnected to me, present it ensures that the needs of the research do not override the interests of the potential participant.

When seeking consent, I will have a conversation with the dyad. This will take place at a time when the individual with dementia is most likely to be able to concentrate. The dyad will be provided with detailed information leaflets and a supplementary information leaflet about the research to support this discussion. I will check with the dyad that it is okay to spend some time with them talking about the planned research and, if this seems acceptable to both individuals, move on to discuss the research process. I will be mindful to pitch the explanation at a level likely to maximise the

person's chances of understanding. I will use phrases such as 'I want to listen to music with you and play music. I would also like to talk to you about music'. I will use the supplementary information sheet with simple, accessible text and images as an aid to understanding as necessary.

During this conversation I will provide plenty of time for the person with dementia to respond and will be attentive to their body language and facial expressions. I will also make sure to ask each person with dementia explicitly if they would like to take part. If a person with dementia shows any signs that they are not comfortable with my presence or with the discussion, then this will be accepted as a possible refusal of consent and the person will be withdrawn as a potential participant.

After the discussion based on looking at the information sheets, the individual will be given as much time as they require to ask questions and reach a decision. I will then ask if they would like to take part in the study. If the person seems able to understand, retain the information and make an informed decision, they will be asked to initial and sign the consent form or communicate their decision by talking, using sign language or any other means. If the individual is unable to provide initials or a signature, I will ask their carer to witness their consent to participate. As the study calls for individuals living with dementia who experience difficulties with verbal communication, extra care will be taken in providing support and opportunity for individuals to communicate their understanding and assent or dissent to participation in non-verbal ways such as physical / muscle movements or using a computer keyboard.

If the individual appears to lack the capacity to give consent, and shows no sign of apprehension about the research, the decision for inclusion in the study will be based on the advice of the personal/professional consultee. If the person with dementia does not appear to be expressing unwillingness or anxiety about the idea of participating, or with my presence, then the carer needs to confirm this assessment and provide any further information on whether they feel this is something the potential participant would be happy with based on their knowledge of the person. In the event that both the carer and I agree that a person appears to be showing assent thus far, this should be recorded and signed on the consultee declaration form.

Stage 3: is an ongoing consideration of the person's willingness to continue their involvement and recognition that capacity to consent may fluctuate for some individuals in the study. Each time a period of research contact is undertaken involving the person with dementia, I will reintroduce myself to the participant and remind them of what I am doing. I need to be satisfied that they are happy to be still included before beginning any research activity and whenever a new activity is introduced. If they do not appear happy or willing at the prospect, no research activity will occur that day and I will leave. In these situations, I will arrange an alternative time/date to return.

Stage 4: Throughout the research process, I will assess continually that engagement in the research is not causing distress to the participant. Should the carer or I feel that engaging in the research is causing them distress, anxiety or affecting the quality of their care/experiences, I will stop research activities immediately and arrange an alternative time to return or withdraw the participant from the research altogether if deemed to be in the person's best interest by their carer or me.

It will be made clear to all participants as part of the initial and ongoing consent processes that they are free to withdraw from participation in the research at any point and free to withdraw their data from a session within 2 weeks of that session.

11.15 The Equipment Used Across All Pairs

This is a list of equipment used for fieldwork sessions across all pairs. It does not include participants' own equipment, or the final resources left with participants.

Musical instruments

Acoustic guitar x 2, tuner and capo	Harmonica in C x 3
Bat tambourine x 2	Jaw harp
Bell	Kazoo
Bodhran	Lyre
Bongos	Maracas x 2
Coconut shells	Ocean drum
Comb and greaseproof paper squares x 3	Padded beater
Cowbell	Practice chanter
Cymbal chimes	Shaky eggs x 6
D-bells	Shaky eggs on sticks x 6
Didgeridoo	Singing bowls of different pitch x 2
Djembe	Small accordion x 2 (keyboard and button)
Electric keyboard	Small rain sticks x 2
Foot 'tappers' and boards	Tambourine x 3 (skin, ring and 'D')
Frog shaped guiros of different sizes x 4	Tin whistle (B-flat, C, D)
Glockenspiel	Triangle
Gong	

Music equipment

Auxiliary cable and spare	Laptop (for music, images and video playback) and charger
Book stand	Music tins
CDs and DVDs	Portable LP player
DVD player and scart cable	Sheet music
Guitar chords	Song lyrics
Large computer speakers (compact and large)	

Other arts / sensory materials

Balloons	Old British sixpences
Bamboo table mats	Owl whistle
Bird whistler	Poetry
Feather boa	Prepared food (e.g. washed berries)
Feathers	Roses
Felt Christmas tree with felt decorations	Rubber ball
Fir cones	Scented objects / ingredients (e.g. vanilla extract, carbolic soap)
Folded paper fan	Seed packets
Fresh herbs (lavender, mint, thyme, basil, rosemary, sage, lemon balm)	Sewing basket with contents (e.g. sample textiles, button card, ribbon)
Hat selection (e.g. beret, fez, ARP helmet)	Sheepskin
Images (prints, posters and in books)	Small bucket and spade
Large conch shell (listening)	Themed image and text A6 laminated cards
Large pieces of coloured material	WWII memorabilia (e.g. medals, reproduction ration book)
Large shells	
Leaves	

Other arts / sensory equipment

A4 paper	Pastels (chalk and oil)
Blu tac	Rubbing plates
Masking tape	Voile scarves (various colours)
Paint brushes	Water colour paint (liquid)
Paint pots	Watercolour paper
Painting boards	Watercolour pencils
Painting paper	Wax block colour crayons
Painting sponge	Wax stick colour crayons
Painting water jar	

Other equipment

Baskets	Lone worker buddy contact details
Bottle of drinking water	Notepad and pen
Boxes	SD card
Butler's tray	Spare batteries
Charged mobile phone	Spare video camera with two charged battery packs
Dictaphone	Tissues
Emergency/crisis contacts list	Video camera tripod
Extension cable	Video camera with two charged battery packs
Foldable table	
ID card (first visit)	Wet wipes

11.16 Fieldwork Session Schedule

Pair	Session no.	Date	Times	Duration of visit (h:mm)	Duration of video (h:mm:ss)
1 (pilot)	1	18/01/18	11:00 - 14:30	3:30	NA
1 (pilot)	2	01/02/18	11:00 - 13:30	2:30	NA
1	0	04/05/18	11:00 - 13:45	2:45	NA
1	1	11/05/18	10:30 - 13:45	3:15	1:34:18
1	2	18/05/18	10:30 - 12:00	1:30	1:14:18
1	3	25/05/18	10:30 - 12:45	2:15	1:40:55
1	4	01/06/18	10:30 - 13:00	2:30	2:04:33
1	5	08/06/18	10:30 - 13:30	3:00	1:55:20
1	6	15/06/18	10:30 - 13:45	3:15	2:24:13
1	7	22/06/18	10:30 - 14:15	3:45	2:10:09
1	8	29/06/18	10:30 - 14:00	3:30	2:23:18
1	9	13/07/18	10:30 - 14:15	3:45	2:25:30
1	10	20/07/18	10:30 - 13:15	2:45	0:54:23
1	11	27/07/18	10:30 - 13:45	3:15	0:55:13
1	12	03/08/18	10:30 - 14:00	3:30	1:21:22
2	0	23/08/18	11:15 - 12:45	1:30	NA
2	1	28/08/18	11:00 - 12:15	1:15	0:59:35
3	0	29/09/18	15:00 - 17:30	2:30	NA
1	8 wk. review	09/10/18	14:00 - 16:30	2:30	1:32:59
3	1	13/10/18	15:00 - 17:15	2:15	1:53:19
3	2	20/10/18	15:00 - 17:15	2:15	1:54:02
3	3	27/10/18	15:00 - 17:00	2:00	NA
4	0	12/11/18	16:00 - 17:45	1:45	NA
3	4	17/11/18	15:00 - 17:00	2:00	1:25:15
4	1	19/11/18	13:00 - 14:30	1:30	1:09:49
3	5	24/11/18	15:00 - 17:30	2:30	1:13:25
4	2	26/11/18	13:00 - 14:45	1:45	1:26:39
3	6	01/12/18	15:00 - 17:15	2:15	1:32:20
4	3	03/12/18	13:00 - 14:30	1:30	1:04:33
3	7	08/12/18	15:30 - 18:15	2:45	2:00:37
4	4	10/12/18	13:00 - 14:45	1:45	1:12:49
4	5	20/12/18	12:00 - 13:45	1:45	1:12:08
3	8	05/01/19	15:00 - 18:00	3:00	1:52:58
4	6	08/01/19	12:00 - 14:45	2:45	1:49:17
3	9	12/01/19	15:30 - 18:45	3:15	2:04:26
4	7	14/01/19	12:00 - 14:30	2:30	2:18:04
4	8	22/01/19	12:00 - 14:00	2:00	1:36:43
3	10	26/01/19	15:00 - 18:15	3:15	2:44:33
4	9	28/01/19	12:00 - 14:45	2:45	2:29:28
4	10	13/02/19	12:00 - 14:30	2:30	1:59:19
3	11	16/02/19	15:00 - 17:00	2:00	1:17:25
4	11	05/03/19	12:00 - 14:15	2:15	1:51:52
3	8 wk. review	11/05/19	15:00 - 18:15	3:15	1:28:10
4	8 wk. review	20/05/19	13:00 - 15:30	2:30	1:58:46

11.17 Fieldwork Weekly Working Framework

0. First Impression
<p>Express my first impression</p> <p>Highlight what 'called to' me as important</p>
1. Exact Sense Perception
<p>Identify my sensory perceptions</p> <p>Document music activity and sensory perceptions</p> <p>Document information that may inform starting points, e.g. spoken biographical information and responses to sensory stimulation</p>
2. Exact Sensorial Imagination
<p>Picture session as process</p> <p>Picture session as process in context of previous sessions and Musical Activity Framework</p> <p>Picture session process in context of biographies</p>
3. Inspiration
<p>Walk in nature (inner and outer space)</p> <p>Document ideas</p>
4. Intuition
<p>Be present</p> <p>Document insights</p>
5. Developing ideas
<p>Try out ideas in physical space</p>
6. Shaping ideas
<p>Picture ideas as session process</p> <p>Plan next session</p>
7. Creating
<p>Create and curate resources as starting points for next session</p>

11.18 Evolved Fieldwork Weekly Working Framework

Reflection

Day 1 (day of session): Post Session Reflective Picturing

Activity 1: 30mins reflective picturing of the essential of session encounter, not process/detail; immerse self in experience of meeting

Document:
(e.g. keywords, gesture etc)

Day 2: Intentional Space and Memory Reflection

Activity 1: 15 mins space (presence, e.g. Mindfulness) for emerging after image

Document:
(e.g. keywords, gesture etc)

Activity 2: 1hr reflection on session process

Summary of events:

First Impression & Setting, document and describe:

Sensory engagement:	
Activity	Engagement
E.g. singing Que Sera Sera with lyrics	E.g. we all sang Que Sera Sera and clapped on the choruses.
Other indications:	
Information (biographical, musical)	
Ideas & contributions	
Participant comments	
Indications for resources	
Notes on Process	
Other	

Activity 3: 30 min biographical picturing of sessions in context of biography (early sessions) or review of all session material to inform development of resources

Document: (e.g. keywords, gesture etc)

Development

Day 3: Intentional Space

Activity 1: 15 mins space (presence, e.g. Mindfulness) for developing ideas and insights

Activity / resource chosen	Rationale (note differences in motivation)

Activity 2: 30 mins trying out ideas

Note changes:

Activity 3: 10 mins imaginative picturing of ideas as a session process

Note changes:

Activity 4: 1 hr 45 mins creating resources & session plan

Resources created:

Notes

N.B. Timings are indications based on experience to date. The number of days activity spread across varied according to workload and circumstances, and the alignment of other sessions running at the same time

11.19 Music Log

Version 1.3

22/07/18

Music Log

When possible, please keep a record of musical activities you share together using this form

Date	Musical activity shared Example: sang <i>Abide with Me</i> together; listened to <i>Rosemarie</i>)

Continue on separate sheet if necessary

11.20 Prepared Questions

Following the review session with Pair 1, the questions were refined for Pairs 3 and 4.

11.20.1 Questions for Pair 1

- What resources have you used? Will you continue to use them?
- Have other people used the resources?
- Which tracks/songs have you listened to/sung? Any not included in the resources?
- Is there anything that could be helpfully changed or added to the resources?
- Do you think sharing music is important? Why?
- What guides your choice of music/activity?
- Is it important for you to enjoy music/activity?
- Is it necessary for me to be present for certain activities? Which ones?
- What do you think might help other people in a similar situation to explore music?
- Has the project supported you both to share music?
- What have you enjoyed most about project?
- Is there anything you would have changed about the project?
- Do you have any other feedback on the project?

11.20.2 Questions for Pairs 3 and 4

- Did participation in the study meet your hopes and expectations to [recap hopes and expectations expressed during early contact]?
- Has the project supported you both, and perhaps others, to share music?
- Do you share the resources at a particular time or for a particular purpose?
- Do you hope to share music into the future?
- Do you have any other feedback on the project?

11.21 Session Activities and Included Music/Recordings

The following list gives a broad overview of musical activities that occurred during fieldwork sessions with all pairs. Activities are inclusive of both pair participants and me, unless otherwise stated.

11.21.1 Pair 1

11.21.1.1 First Meeting

Discussing study information

Signing consent forms

Discussing shared intentions and hopes for the study

Listening, moving and singing to recordings of music, Sue and Ruby

- Pomp and Circumstance by Elgar
- Hungarian Dance No. 5 by Brahms
- Housewives' Choice Theme

Standing to a recording of music

- All Things Bright and Beautiful by St. Michael's Singers

11.21.1.2 Session 1

Exploring sound and rhythm on instruments

- Frog guiros
- Rain sticks
- Ocean drum
- Triangle
- Singing bowls

Listening to recordings of music

- You Are My Sunshine by Jimmie Davis

- A-Tisket, A-Tasket by Ella Fitzgerald
- Skye Boat Song by Paul Robeson
- Two Lovely Black Eyes by Stanley Holloway
- New Rag by Scott Joplin
- Swing Low by Etta James
- L'Accordéoniste by Édith Piaf
- Requiem: Lacrimosa by Mozart
- Zadok the Priest by Handel

Walking to a recording of music

- Soldier's Joy

Listening and singing to Ron playing the keyboard

- Abide with Me
- Somewhere Over the Rainbow
- Unknown melody
- Keyboard pre-set: seaside music

Singing, Sue and Ruby

- Bunch of Thyme
- Roses are Red My Love
- Daisy Bell
- Build me up Buttercup
- Lavender's Blue

Ron demonstrating keyboard functions

11.21.1.3 Session 2

Spontaneous singing, Sue

Making birdsong to a recording of birdsong

- Voice/whistling
- Owl caller

Sharing a farming theme

- Farming images
- Sheepskin
- Playing a cowbell
- Playing coconut shells

Listening to recordings

- Peg O My Heart by Leslie Hutchinson
- Pathé theme with Pathé logo image
- Anything Goes (Wurlitzer organ rendition)
- Red Sails in the Sunset by Bing Crosby
- Red Sails in the Sunset by Guy Lombardo
- Red Sails in the Sunset by Jack Jackson

Playing percussion Sue/Ruby on maraca, Ron on tambourine

- Rhythmic play
- To a recording of Rosemarie by Slim Whitman
- To a recording of Jewish Klezmer music
- Djembe Drums of Ghana by African Drums

Singing to a recording of piano accompaniment

- The Lord's My Shepherd

11.21.1.4 Session 3

Sharing Ron and Sue's photos

Vocal play

- Echoing sounds and pitches
- Echoing melodic phrases
- Singing Dear, Dear, What Can the Matter Be?

Movement to recordings

- Perhaps by Doris Day with a feather boa
- Dashing White Sergeant by The English Country Dance Band

- Soldier's Joy by The English Country Dance Band, with coloured handkerchiefs

Playing with balloons to a recording

- Air a Danser by Penguin Café Orchestra

Listening to recordings, Sue and Ruby

- John the Farmer by Chris Bartram
- Jolly Sixpence by Chris Bartram
- Loch Lomond by Paul Robeson
- Bunch of Thyme by Foster and Alan
- Rosemarie by Slim Whitman

11.21.1.5 Session 4

Playing comb and paper

- Improvisation
- Oh, Susannah!
- Softly, Softly
- Oh, My Darling Clementine

Playing harmonicas

- Improvisation
- Oh, My Darling Clementine

Singing echo songs

- Welcome to My World, Ruby on guitar
- Ooh a Lay Lay

Singing

- I See the Moon

Playing percussion

- Bongos, Sue, Ron and Ruby; Sue used a beater
- Maraca, Sue and Ruby

- Bat tambourine, Ruby

Standing and walking to a recording

- Blue Danube

Singing, Ron playing keyboard melody with pre-set track

- When the Saints

Playing keyboard and singing, Sue and Ruby

- Melodies and scales
- You Are My Sunshine
- Loch Lomond
- Daisy Bell
- Blue Danube
- Blow the Wind Southerly

11.21.1.6 Session 5

Listening to a recording

- Always by Deanna Durbin

Ron reading a poem he had written

Sharing a seaside theme

- Basket lined with a blue cloth
- Conch shell
- A small bucket and spade
- Ocean drum
- Folded paper fan
- Singing songs about the sea
 - o Blow the Wind Southerly
 - o Skye Boat song
 - o I Do Like to Be Beside the Seaside
 - o My Bonnie Lies Over the Ocean
 - o Donkey Riding

○ Drunken Sailor

Walking with a recording

- 2/4 Marches by Jimmy Shand

Exploring harmony on the keyboard, Ron and Ruby

Singing, Ruby playing the keyboard

- You Are My Sunshine

Singing, Ron playing the keyboard with pre-set

- I Can't Help Falling in Love with You

Playing bird song maker and harmonica, Ruby and Sue

Listening to recordings of regional folk tunes, Sue and Ruby

Singing with walking, Sue and Ruby

- When the Saints Come Marching In

Listening to Ron's recorder learner CD

11.21.1.7 Session 6

Playing Didgeridoo

Playing singing bowls and singing

Movement with foot tappers to recordings

- Steppin' Out with My Baby by Fred Astaire
- Charleston by Sam Levine
- Square Dance: Chicken Reel / Joys of Quebec / Arkansas Traveller by John Carmichael and His Scottish Dance Band

Singing snatches of Al Jolson songs

Playing percussion instruments

- Bat tambourines, Sue and Ron.
- Maraca, Ruby

Playing drum in response to Sue's leg movement, Ruby

Listening to recordings from 1949, Sue and Ruby

- The Heart of Loch Lomond by Anne Shelton
- It's Magic by Doris Day
- Put 'em in a Box by Doris Day
- Far Away Places by Bing Crosby
- 12th Street Rag by Pee Wee Hunt
- Forever and Ever by Russ Morgan
- Lavender Blue by Joe Loss
- 'A' You're Adorable by Jo Stafford
- To Whit Too Woo by Dorothy Squires

Listening to a farmyard soundscape, Sue and Ruby

11.21.1.8 Session 7

Sharing a garden theme

- Strawberries and raspberries
- Lemon balm, mint, lavender and thyme sprigs
- Roses
- Singing
 - o Lavender's Blue
 - o Bunch of Thyme
 - o My Love is Like a Red, Red Rose.
 - o Down by the Sally Gardens
 - o Lily of Laguna
 - o The Honeysuckle and the Bee
- Listening to recordings
 - o The Last Rose of Summer by Joan Hammond
 - o The Garden Where the Praties Grow by Josef Locke
 - o English Country Garden by The Band of the Blues and the Royals
- Singing
 - o Bye Bye Blackbird,

- Plush birds with birdsong,
- Making bird songs and playing bird callers
- Recorded birdsong
- Singing
 - Morning has Broken

Playing instruments

- Harmonicas, Sue and Ruby
- Bongos and Kazoo, Ron
- Comb and paper, Ruby

Singing and walking

- Blue Danube
- Soldier's Joy
- Little Red Monkey

11.21.1.9 Session 8

Sharing Ron and Sue's photos

Playing guitars

- Ron plucking and strumming
- Sue and Ruby with a padded beater

Playing melodies on keyboard and exploring pre-set functions, Ron and Ruby

- Don't Cry for Me Argentina
- Wooden Heart
- Abide with Me
- Tea for Two

Listening to recordings, Sue and Ruby

- Three Yorkshire Men Went Hunting by Chris Bartram
- Hop Hop Hop by the Oldham Tinkers
- Jollity Farm by The Bonzo Dog Band
- Farm animal sounds: hens, dog, pigs, cows, horses

11.21.1.10 Session 9

Singing, Ron

- My Grandfather's Clock

Sharing the colour red

- Red Cloth
- Red rose
- Singing fragments of songs
 - o Roses are Red Dilly Dilly
 - o Roses are Red My Love
 - o Little Red Monkey
- Singing
 - o Red Sails in the Sunset
- Listening to a recording
 - o Mars by Holst

Sharing the colour yellow

- Yellow cloth
- Yellow rose
- Lemon
- Singing
 - o You Are My Sunshine
- Listening to a recording
 - o Yellow Rose of Texas

Sharing a tree theme

- Fir cones
- Oak twig
- Dry leaves
- Singing, Ruby playing guitar
 - o Underneath the Spreading Chestnut Tree
 - o Ash Grove
 - o The Green Grass Grew All Around
- Singing to a recording
 - o Hearts of Oak by Jerry Bryant and Starboard Mess

Playing a keyboard melody, Ron and Ruby

- Forgotten Dreams

Singing personalised songs, Sue and Ruby

- Keel Row
- O'Leary / Belfast City
- Old Macdonald

11.21.1.11 Session 10

Singing newly composed words to a familiar tune, Ron

- Abide with Me

Movement with foot tappers to recordings of country dance music by The English Country Dance Band

- Galopede Polka
- Soldier's Joy
- Dashing White Sargent
- Sir Roger de Coverley

Singing to recorded accompaniment

- When You're Smiling

Singing music hall and sing-along songs, including

- Henry the VIII, I am
- My Old Man's a Dustman
- Yours
- Burlington Bertie of Bow

Clapping to recordings of music

- Blue Danube by the Manhattan Pop Orchestra
- You are my Sunshine by Jimmie Davis

11.21.1.12 Session 11

Listening and singing to Sue and Ron's mixtape recordings

- You'll Never Know by Dick Haynes
- Slowly with Feeling by Ruby Murray
- It's Impossible by Perry Como

Tasting and smelling a fresh orange as a specific memory

Singing

- Westering Home
- Danny Boy

Singing hymns to recordings of piano accompaniment

- What a Friend We Have in Jesus
- Holy Holy Holy

Singing

- Que Sera Sera

Singing with lavender hand massage

- Lavender's Blue

Singing new words to familiar tunes

- Ron's words to the tune of Abide with Me
- Ruby's words to Daisy Bell

Listening to recordings of traditional Irish instrumental music whilst packing away

11.21.1.13 Session 12

Singing songs with a childhood connection for Sue or Ron to recordings

- Run rabbit
- Teddy bears picnic
- Red monkey
- Grandfather's clock

Singing and playing banana shaker, coconut shells and hand bells to a recording

- I've Got a Lovely Bunch of Coconuts by Billy Cotton

Listening to a recording with a rubber ball

- One, Two, Three O'Leary by the Andrews Sisters

Singing ball game and playground songs and rhymes with a rubber ball

- One, Two, Three O'Leary
- Plainsie, Clapsie
- My Mother Said

- A Sailor Went to Sea, Sea, Sea
- Eeny Meeny Miny Mo
- One Potato, Two Potato
- Dip, Dip, Dip

Playing harmonica to a recording, Sue and Ruby

- Blue Danube by Manhattan Pops Orchestra

Singing

- When You're Smiling

11.21.1.14 Review Session

Sharing Ron's information and photographs

Singing

- Teddy Bears Picnic
- Grandfather's Clock
- Little Red Monkey
- Jolly Sixpence
- Lavender's Blue
- Dear, Dear, What Can the Matter Be?
- Lily of Laguna
- Lily Marlene
- She's a Lassie from Lancashire
- Daisy Bell
- Down at the Old Bull and Bush
- Run Rabbit, Run
- When You're Smiling
- My Love is Like a Red, Red Rose
- All Things Bright and Beautiful

Birdsong sounds, Sue and Ruby

Singing

- I See the Moon

Discussion of prepared questions

11.21.2 Pair 2

11.21.2.1 First Meeting

Discussing study information

Signing consent forms

Listening to recordings of music

- Hear My Song Violetta by Josef Locke
- Willie the Pimp by Frank Zappa
- All Along the Watchtower by Jimi Hendrix
- Hallelujah by Leonard Cohen

11.21.2.2 Session 1

Exploring instruments

- Singing bowls
- Ocean drum

Discussing biographical and musical history to complete questionnaire together

Listened to recordings of music

- I'll Take You Home Kathleen by Josef Locke
- The Castle of Dromore by Mary O'Hara
- Immaculate Mary by The Choirs of the Diocese of Leeds
- The Lord's My Shepherd by the Scottish Festival Singers
- Mná Na hÉireann by The Chieftains

Singing

- Black Velvet Band
- Dirty Old Town
- Ruby singing
- Einini
- Star of County Down
- Parting Glass

Playing the ocean drum

Spontaneous singing

- Black Velvet Band

11.21.3 Pair 3

11.21.3.1 First Meeting

Discussing study information

Signing consent forms

Discussing biographical and musical history to complete questionnaire together

Looking at LP images of film stars from the 1950s

11.21.3.2 Session 1

Completing musical history questionnaire

Discussing shared intentions and hopes for the study

Exploring instruments

- Frog guiros
- Rain sticks
- Ocean drum
- Triangle
- Singing bowls

Listening to LPs and playlist songs while looking at LP album covers

- Bridge Over Troubled Water by Simon and Garfunkel
- Lola by the Kinks
- All Things Bright and Beautiful
- Blow Wind Southerly
- Two lovely black eyes

Ruby singing traditional songs with guitar

- Loch Lomond
- Dear, Dear, What Can the Matter Be?
- Early One Morning
- Drunken Sailor

11.21.3.3 Session 2

Wartime recordings, objects and images

- In the Mood by Glen Miller
- Moonlight serenade by Glen Miller
- Tuxedo junction by Glen Miller
- Dad's Army theme
- Run Rabbit Run by Flanagan and Allan
- Bless 'em All by George Formby
- We'll Meet Again by Vera Lynn

Ruby singing

- Jolly Sixpence

Ruby singing with guitar

- Mull of Kintyre

Scottish recordings, objects and images

- Mull of Kintyre
- My Love is Like a Red Red Rose [with a fresh rose]
- A Wee Deoch an' Doris by Harry Lauder
- Roamin' in the Gloamin' by Harry Lauder
- Auld Lang Syne by The Glasgow Phoenix Choir
- Donald Where's Your Trousers by Andy Stewart
- Marie's Wedding by The High Kings
- Playing bagpipe practise chanter

Seaside objects and images

- Playing ocean drum, Dorothy and Chris
- Playing coconut shells

Ruby singing with guitar to recording of the ocean

- Skye Boat Song

Listening to seaside recordings

- Laughing Policeman by Charles Penrose
- Beside the Seaside by Jim Boyes

Recordings of wireless music

- I've Got a Lovely Bunch of Coconuts by Billy Cotton
- Workers' Playtime theme tune

11.21.3.4 Session 3

Sharing a cinema theme

- Popcorn and jelly babies
- Looking at photo of local Danilo cinema
- Watching 'Gongman' video
- Playing a gong

Playing comb and paper

Listening to recordings and image of Doris Day

- Comb and Paper Polka
- Whip Crack Away

Playing harmonicas unaccompanied and to a recording

- Popping the Harmonica by Lonnie Glosson

Image from The Third Man film and a Zither (stringed instrument)

Playing instruments

- Lyre, Dorothy and Chris
- Guitar, Ruby

Break

Image of Brigadoon movie posters with recordings of songs from the film

- Heather on the Hill
- Almost Like Being in Love

Playing meditation bells and a handbell

Image of musical movie posters with recordings of songs from the films

- Getting to Know from King and I
- Trolley Song from Meet Me in St. Louis
- Somewhere Over the Rainbow from Wizard of Oz

Image of Pathé logo and recording of the theme

11.21.3.5 Session 4

Singing, Ruby guitar accompaniment

- All Things Bright and Beautiful
- You Are My Sunshine
- Morning has Broken

Listening to sections water-themed recordings and looking at water-themed images

- Une Barque sur l'Océan by Maurice Ravel
- Fingal's Cave by Felix Mendelssohn
- Aquarium by Camille Saint-Saens
- Sea Fever by John Ireland
- Jardins sous La Pluie by Claude Debussy
- Spiegel im Spiegel, for Cello and Piano by Arvo Pärt
- Peter Grimes: The Storm by Benjamin Britten
- Etude de Concert: Au Matin by Marcel Tournier
- Die Forelle by Franz Schubert
- Hebridean Symphony: Tranquillo, molto sostenuto by Granville Bantock
- Hebridean Symphony: Con moto by Granville Bantock
- Hebridean Symphony: Animando by Granville Bantock

Exploring water theme with instruments

- Ocean drum and brush, Dorothy
- Bongos, Chris
- Ruby, lyre

Playing percussion to a recording of Djembe Drums of Ghana by African Drums

- Bodhrán, maracas and shaky eggs on sticks, Dorothy and Ruby
- Bongos, Chris

Singing songs

- Kumbaya
- You are My Sunshine

Professional carer visit

11.21.3.6 Session 5

Sharing plush birds with bird calls

Making bird song with sound makers

Listening to recordings of birdsong with bird images

Listening to recordings of songs about birds

- Hey' Little Hen by Ambrose and His Orchestra

- Chickery Chick by The Three Stooges

Ruby singing with guitar, songs about birds

- The Nightingale
- Bye Bye Blackbird

Recordings of songs about trees and creating leaf rubbings

- The Trees They Grow High by Martin Carthy
- Autumn Leaves by Nat King Cole
- The Ash Grove by Diane Schneider
- Heart of Oak by Jerry Bryant & Starboard Mess
- Tie a Yellow Ribbon 'Round the Ole Oak Tree by Frank Sinatra
- Home Boys Home by The Dubliners
- Underneath the Spreading Chestnut Tree by Ivor Kurchin & His Band
- Don't Sit Under the Apple Tree by The Andrews Sisters

Professional carer visit

Ruby tuning guitar to leave with Chris

More leaf rubbing

Shopping delivery

Ruby singing

- The Sun has Got His Hat On
- My Grandfather's Clock

Singing, Ruby guitar

- Drunken Sailor
- Bring Me Sunshine
- You Are My Sunshine
- Loch Lomond

Chris playing guitar

11.21.3.7 Session 6

Movement to a recording of music with shaky eggs / shaky eggs on sticks

- Scherzo and Trio by Penguin Café Orchestra

Singing to recordings of music

- All Things Bright and Beautiful
- Jerusalem

Discussion, Chris and Ruby; Dorothy snoozing

Professional carer visit

Playing shaky eggs / shaky eggs on sticks and drums to recordings of music

- Djembe Drums of Ghana by African Drums
- Cecelia by Simon and Garfunkel

Singing to commercial recordings of music

- The Sun has got His Hat by Harry Hall
- My Grandfather's Clock by Johnny Cash
- Mull of Kintyre by Wings

11.21.3.8 Session 7

Playing a cowbell

Sharing Christmas music tins with gingerbread and mince pies

DVD player setup

Listening to a compilation of choral and lyre traditional carols with wax winter scene rubbing

Professional carer visit for Dorothy; identifying familiar songs from my sung examples, Chris and Ruby

Listening to recordings of Phil Spector Christmas songs whilst decorated felt Christmas tree

Singing Christmas carols, Ruby guitar

- Jingle Bells, Dorothy D-bells
- When the Red Red Robin
- White Christmas (unaccompanied)
- We Wish You a Merry Christmas (unaccompanied)

Identifying familiar songs from my sung examples

11.21.3.9 Session 8

Recordings of world music with tastes and smells

- Zorba the Greek by Mikis Theodorakis with olives
- La Vie en Rose by Edith Piaff with roule on bread
- Grenadina by Cascabel de Jerez with an orange
- Fishermans Song at Dusk by Ziang Sihua with fortune cookies
- New York New York by Frank Sinatra and Jailhouse Rock by Elvis with Twinkies

Listening to a recorded soundscape

Sharing a sensory story with song singing, images, smell and touch

- Are you going to Scarborough Fair? with fresh basil
- Lavender's Blue
- Ring-a-ring o' roses
- Daisy Bell

Themed images, singing and listening to recordings

- All Things Bright and Beautiful
- Drunken Sailor
- Pack Up Your Troubles in Your Kit Bag
- It's a Long Way to Tipperary
- Side by Side
- Bing Crosby (recording)
- Nimrod by Elgar (recording)

Exploring sensory table ideas

Sharing and discussing possible objects

Identifying familiar songs for singing from my sung examples

Professional carer visit for Dorothy; identifying familiar songs from my sung examples, Chris and Ruby

Listening to recordings of music on Chris' phone

- Battle Hymn of the Republic
- How Much that Doggy in Window

11.21.3.10 Session 9

Listening to sections of recordings

- Peer Gynt by Grieg
- Lara's Theme by André Rieu
- Golden Slumbers by The Cambridge Singers
- Anything You Can Do by The Andrews Sisters
- Meet Me in St. Louis by Judy Garland
- Blow the Wind Southerly by Kathleen Ferrier
- Golden Tango by Victor Sylvester
- Take the A-train by Gino Marinello
- St. Bernard Waltz by Victor Sylvester
- Too-ra-loo-ra-loo-ra by Bing Crosby
- Agnus Dei by Barber
- Deer Hunter theme
- Flower Duet from Lakme by Leo Delibes
- Cello Suite No.1 by Bach
- Coral Wonder by Fenton
- Pavane by Faure
- Nessun Dorma by Puccini
- Gymnopodie No.1 by Satie
- Pennies from Heaven by Bing Crosby

- Alexander's Ragtime Band by Bing Crosby
- My Love is Like a Red Rose by Kenneth McKellar
- The Heather on the Hill by Gene Kelly

Professional carer visit

Sharing images, Dorothy and Ruby

- Singing unaccompanied
- You Are My Sunshine

Movement to recordings of music with coloured scarves and D-bells to

- Country dance music
- Foot tappers to recordings of music
- Country dance music
- Steppin' Out with My Baby by Fred Astaire

Clapping to singing and a recording

- Singing If You're happy and know it
- Recording of the Blue Danube

Sharing farming images and soundscape

11.21.3.11 Session 10

Listening to recordings of sounds

- Church bells
- Milk delivery
- Owls
- Schoolyard
- Ducks on a river
- Steam train
- Singalong song

Playing instruments and sound makers

- Banana shaker
- Owl hooter

- Duck quacker
- Cow moo
- Cockerel crow
- Ocean drum
- Coconut shells

Listening to farm soundscapes and image

Sharing fresh roses

Looking at family photos

Listening to morning/uplifting recordings and looked at image examples

- “Pastorale” Symphony No. 6 by Beethoven
- Morning has Broken by Art Garfunkel
- Good Morning by Debbie Reynolds
- Singing in the Rain by Gene Kelly

Listening to evening/relaxing recordings and looked at example images

- Nimrod by Elgar

Listening to moving mood recordings and looked at example images

- Land of Hope and Glory by Elgar
- Bridge Over Troubled Water by Simon And Garfunkel
- Mull of Kintyre by Wings
- La Carnival Des Animaux Camille Sains-Saens
- Scotland The Brave by The Scottish Bagpipes Highland Pipes
- Fantasia on A Theme by Thomas Tallis By Vaughan Williams
- Carmen Overture by Bizet
- Une Barque sur l’Océan by Ravel
- Somewhere Over the Rainbow by Judy Garland
- Jerusalem by Parry
- Genevieve Love Theme and Blues by Larry Adler

Professional carer visit for Dorothy; identifying familiar songs from my sung examples, Chris and Ruby

Listening to lively mood recordings and looked at example images

- In the Mood by Glenn Miller
- Soldiers Joy by The English Country Dance Band
- The Third Man Theme by Anton Karas
- Keep the Customer Satisfied by Simon And Garfunkel
- The Golden Tango by Victor Silvester
- Swedish Rhapsody by Mantovani
- British Grenadiers by The Albion Morris Men
- 2/ 4 Marches by Jimmy Shand
- Charleston By Sam Levine
- Chattanooga Choo Choo By Glenn Miller
- Can-Can from Orpheus In the Underworld by Offenbach
- Overture from William Tell by Rossini
- The Laughing Policeman by Charles Penrose
- The Sun Has Got Its Hat On by Henry Hall
- Cumberland Gap By Lonnie Donegan
- Fantasia on British Sea Songs: Sailor's Hornpipe by Sir Henry Wood

Continued listening to moving recordings and sharing fresh roses

Listening to recordings of songs from musicals

- I'm Gonna Wash That Man Right Outa My Hair by Kelli O'Hara
- Some Enchanted Evening by Kelli O'Hara
- Happy Talk by Loretta Ables
- Wooden Heart by Elvis Presley
- With A Song in My Heart by Doris Day
- Moon River by Henry Mancini
- Moon River by Audrey Hepburn
- Make 'em Laugh Donald O'Connor
- The Trolley Song by Judy Garland
- Somewhere Over the Rainbow by Judy Garland
- We're Off to See the Wizard by Judy Garland
- Getting to Know You by Deborah Kerr

- Get Me to The Church on Time by Stanley Holloway
- Wouldn't It Be Lovely by Julie Andrews
- Oh, What A Beautiful Morning by Gordon Macrae
- West Side Story by Leonard Bernstein (several songs)

11.21.3.12 Session 11

Sharing possible images for resources

Sharing possible instruments and objects

- Slide whistle
- Banana shaker
- Sheepskin

Sharing soundscape recording

Singing with songbooks

- Drunken Sailor
- How Much is That Doggy in The Window
- You Are My Sunshine

11.21.3.13 Review Session

Sharing fresh flowers, Dorothy and Ruby

Chris demonstrating playing instruments

- Banana shaker
- Duck whistle
- Owl hooter

Sharing images and listening to Relaxing CD

Sharing material flower

Discussion of musical activity and resources

Singing with songbooks

- Jeepers Creepers

- The Sun Has Got His Hat On
- You Are My Sunshine
- Loch Lomond

Discussing prepared questions

A Walk in the Garden

11.21.4 Pair 4

11.21.4.1 First Meeting

Discussing study information

Signing of consent forms

Discussing biographical and musical history to complete questionnaire together

Jane singing and moving

11.21.4.2 Session 1

Discussing shared intentions and hopes for the study

Exploring sound and rhythm on instruments

- Frog guiros
- Rain sticks
- Ocean drum
- Triangle
- Singing bowls

Listening to recordings of music

- All People That on Earth Do Dwell by Norwich Cathedral Choir
- Coolie's reel by The Dubliners
- Wooden Heart by Elvis Presley
- Swing Down Sweet Chariot by Elvis Presley
- Down to the River to Pray by Alison Krauss

- West End Blues by Louis Armstrong and His Hot Five
- Minor swing by Django Reinhardt and Stéphane Grappelli
- Surfin' USA by The Beach Boys
- Sevillana by Cascabel de Jerez
- Kothbiro by Ayub Ogada

11.21.4.3 Session 2

Listening to recordings of music

- Spem in Alium by Thomas Tallis
- Zadok the Priest by George Handel
- Requiem: Lacrimosa by Wolfgang Mozart
- Carnival of the Animals: Aquarium by Camille Saint-Saens
- Spiegel im Spiegel, for Cello and Piano by Arvo Part

Listening to recordings of music and playing shakers

- Giles Farnaby's Dream by Penguin Café Orchestra

Singing traditional songs, Ruby on guitar

- Loch Lomond
- Skye Boat Song (Kenneth & Jane playing ocean drum)
- Early One Morning
- The Ash Grove
- The Nightingale
- Bye Bye Blackbird

Making bird song with plush sounding birds and bird song makers

Jane singing

- Hello, Hello Who's Your Lady Friend

Leaf rubbings in colour to recordings of music

- (Recording playlist as for Pair 3, Session 5 above)

Carol singing

- God Rest Ye Merry Gentlemen

11.21.4.4 Session 3

Vocal play, Jane and Ruby

Morris dancing with foam sticks to recordings of music

- British Grenadiers by The Albion Morris Men

Watching video footage of Kenneth Morris dancing, Jane & Ruby moving with foam sticks, hankies and bells

Sharing world music recordings and food

- Zorba the Greek by Mikis Theodorakis with baklava and olives
- La Vie en Rose by Edith Piaff with grapes and bread with roule
- Granadina by Cascabel de Jerez with Navel orange
- Fishermans Song at Dusk by Xiang Sihua with lychees and fortune cookies

11.21.4.5 Session 4

Sharing Christmas music recordings and food

- Winter [album] by Steeleye Span with German Lebkuchen

Sharing Christmas music tins

Singing Christmas carols, Ruby on guitar

- God Rest You Merry Gentlemen
- Angels from the Realms of Glory
- White Christmas
- O Little Town of Bethlehem (unaccompanied)
- We Wish You A Merry (unaccompanied)

Playing lyre

Playing the Irish Washerwoman on instruments together

- Jane tambourine

- Kenneth guitar
- Ruby tin whistle

11.21.4.6 Session 5

Carol singing, Jane and Ruby

- The First Tree in the Greenwood

Jane demonstrating bell ringing

Sharing images of New York with pretzels, Hershey's chocolate, cowboy hat and recordings of USA music

- Jailhouse Rock by Elvis Presley
- I Am a Man of Constant Sorrow by The Soggy Bottom Boys
- Bright Morning Stars by The Wailin' Jennys
- I Wanna Be Loved by You by Marilyn Monroe
- The Star-Spangled Banner by MGM Studio Orchestra
- Don't Think Twice It's Alright by Bob Dylan
- The Star-Spangled Banner - On the Town Orchestra

Sharing the smell of fresh basil

Playing baby accordion

Singing girl guide and traditional songs together

- Happy Birthday to You
- Black Socks (round)
- Coming Round the Mountain
- A Ram Sam Sam (round)
- My Bonnie Lies Over the Ocean
- The Meatball Song
- BINGO
- Frere Jaques (round)
- Kookaburra (round)
- Head, Shoulders, Knees and Toes
- John Brown's Baby

- If You're Happy and You Know It
- Home on the Range

11.21.4.7 Session 6

Vocal play, Jane and Ruby

Sharing perfume, Jane and Ruby

Discussing resources left over Christmas break

Playing harmonicas with and without a recording

- Found Harmonium by Penguin Café Orchestra

Singing songs from memory, Jane and Ruby

- The Holly and the Ivy
- All People That on Earth Do Dwell
- He Who Would Valiant Be
- Those in Peril on the Sea
- Holy Holy Holy
- Jesus Bids Us Shine

Singing song extracts from Kenneth's lyric/chord folder

- You Raise Me Up
- Samuel Pepys Diary
- The Old Rugged Cross

Singing familiar tunes to vowel sounds

- Blue Danube
- [song unknown to me]

Singing a new song

- The Green Grass Grew All Around

Listening and moving to recordings of music

- Gay Gordons by Jimmy Shand
- Killiekrankie by The Corries

- Boogie Wonderland by Earth Wind and Fire
- It's Raining Men by the Weather Girls

Playing harmonicas with and without a recording

- Popping the Harmonica by Lonnie Glosson

11.21.4.8 Session 7

Vocal play, Jane and Ruby

Sharing smells and singing songs about the home/cooking:

- If I Knew You Were Coming I'd've Baked a cake
- Shortenin' bread
- I'm Gonna Wash that Man Right Out of My Hair
- Fairy liquid Advert Theme
- Dashing Away with the Smoothing Iron
- Scarborough fair
- Bunch of thyme
- Will Ye Go Lassie Go

A song by The Corries sung spontaneously by Jane

Listening to a recording

- The Town I loved So Well by The Dubliners

Singing

- The Green the Green Grass Grew All Around
- Ooh a Lay Lay
- Vowel sounds

Movement with scarves, bells, tambourines, maracas, Morris dancing leg bells and foot tappers with singing and recordings

- Recording: British Grenadiers by the Albion Morris Men
- Singing: If You're Happy and Know It
- Singing: folk tunes
- Recording: That'll be the Day by Buddy Holly

- Recording: 2/4 Marches by Jimmy Shand
- Recording: Soldiers Joy by The English Country Dance Band

Playing Belfast City, British Grenadier, Mhari's Wedding and improvisation on instruments together

- Jane harmonica, tambourine
- Kenneth harmonica, tin whistle
- Ruby guitar, voice

Singing playground and Scottish songs Jane and Ruby

- A Sailor Went to Sea Sea Sea
- The Big Ships Sails on the Ally Ally O
- Will Ye No Come Back Again?
- Loch Lomond

11.21.4.9 Session 8

Vocal play and songs, Jane and Ruby

- Bunch of Thyme
- Blue Danube

Sharing perfume, Jane and Ruby

Handling fresh roses while listening to a recording of music

- Air á Danser by Penguin Café Orchestra

Painting and pastels while listening to a CD of classical music chosen by Kenneth and guitar playing by Kenneth

Listening to recordings by The Corries, Jane and Ruby:

- Killiecrankie
- Flower of Scotland

Singing

- My Uncle Silas song
- Will Ye No Come Back Again

11.21.4.10 Session 9

Vocal play, Jane and Ruby

Shared scent of dried rose petals from previous session

Playing British Grenadier

- Jane harmonica and percussion
- Kenneth harmonica, percussion and guitar
- Ruby harmonica, percussion and guitar

Spontaneous singing, Jane and Ruby

- O Come All Ye faithful

Impressionist images with recordings of music

- Claire de Lune by Claude Debussy
- Gymnopédie No.1 by Erik Satie
- Bolero by Maurice Ravel
- Prelude a l'Après-Midi d'un Faun by Claude Debussy

Water images with recordings of music

- (Recording playlist as for Pair 3, Session 4 above)

French images with recordings of music:

- Bistro Fada by Stephane Wrembel
- Indifference by Café Accordion Orchestra
- Boum! By Charles Trenet
- Minor Swing by Django Reinhardt
- Jean de Florette by Jean-Claude Petit
- La Mer by Charles Trenet
- L'Accordéonist by Édith Piaf
- West End Blues by Louis Armstrong and His Hot Five
- The Old Quarter by Frank Barcellini
- Le Parc de Plaisir by Francois Parisi
- Le Grand Café by Charles Trenet

- Parlez-Moi D'amour by Dana Boulé
- Can-Can from "Orpheus in the Underworld" by Jacques Offenbach

'Magic places' images with recordings of music:

- Mashua by Alpamayo
- Morfa'r Frenhine by Celtic Harp Soundscapes
- Sevillana by Cascabel de Jerez
- Lima Morena by Los Colchakis
- Granadina by Cascabel de Jerez

Sharing perfume, Jane and Ruby

Singing

- My Uncle Silas song

11.21.4.11 Session 10

Vocal play, Jane and Ruby

Humming and singing

- Humming single pitches and improvised melodies
- Moving pitch to vowel sounds

Singing, Ruby guitar

- Repeated motifs and improvisation
- Jane's song

Interactive play on melodeon, Jane and Ruby

Singing, Ruby accordion

- Oom Pah Pah from Oliver

Free play on instruments

- Glockenspiel
- Keyboard

Looking at William Morris images

Carol singing, Jane and Ruby

- Joseph Dearest, Joseph Mine

Discussing and singing snatches of familiar songs

- Oom Pah Pah from Oliver
- Food Glorious Food from Oliver
- She'll be Coming Round the Mountain
- On Top of Old Smoky

11.21.4.12 Session 11

Vocal play, Jane and Ruby

Sharing and trying resources

11.21.4.13 Review Session

Singing, Jane and Ruby (off camera)

- Blue Danube

Rhythmic hand touch, Jane and Ruby (off camera)

Vocal play, Jane and Ruby (off camera)

Singing, Kenneth playing guitar

- carols with songbooks
 - o Angels from the Realms of Glory
 - o Silent Night
- Singing spontaneously, Jane and Ruby
- Familiar melody

Singing, Jane and Kenneth playing shakers, Ruby clapping

- My Old Man's a Dustman

Singing

- Fragments of familiar melodies
- Fragments of melodies from the 'La that Tune' resource

Video watching

Songbook 2 DVD

Discussing prepared questions

11.22 Synthesis of Creative Possibilities

11.22.1 Introduction

The understanding, indications and ideas that have arisen through this study have informed the following creative possibilities for musical activity. These possibilities are intended to stimulate and support peoples' own imagination and creativity to develop musical activity responsively within caring relationships in their own way. They have been written with the caring family relationships of people with dementia living at home in mind but could also be used in other forms of caring relationship, personal or professional, or situated in other settings. They may also have relevance for the caring relationships of individuals with other cognitive conditions.

11.22.2 Suggestions and Ideas for Sharing Musical Activity

The ideas of 'skill' or 'talent' can get in the way of experiencing and participating in music as a part of daily life. The following considerations are based in the understanding that we are all musical beings. This is not a prescriptive method for planning musical activity or an intervention. They are intended as a companion in growing musical activity. Making a start by sharing music in a mutually comfortable and enjoyable way is the experience from which further activity can grow. These considerations may help to stimulate, promote and support ongoing development of opportunities for musical activity.

As musical activity develops, it can open up opportunities for sensory experience, for feeling emotions, for picturing memories and for sharing these actively through physical and vocal expressions such as laughter, movement, gesture and facial expression. Simple forms of music-making such as singing, sounding rhythm and playing instruments can also offer these opportunities. Musical activity can be a chance for new experiences, new memories, creativity and a means to fulfil potential. In this way, music can present opportunities for forms of activity that have reduced through the course of dementia.

You might feel that you need support to develop musical activity in your caring relationship, in which case you could consider a form of community provision, such as facilitated activity workshops, regular music groups, or music therapy. If you care for a person experiencing behavioural and psychological symptoms of dementia, such as anxiety or depression, you may require specialist, individualised support from a music therapist.

11.22.2.1 Approach

Both people in a caring relationship are central to this approach. Musical activity is a mutual activity to share in equal partnership rather than an intervention only for the person with dementia. This approach to sharing music is concerned with moving from music as a product such as a recording, a familiar melody or a composed piece of music, into a process of exploring music as a sensory activity. It is also concerned with the unique experiences that arise for each individual in response to such musical activity. This requires us to let go of the typical ways that music is thought about. We need to move beyond our own preconceptions of what music is and what we appreciate or dislike, music consumers and experienced musicians alike, and be present in the unfolding of musical experience and activity with the other person. Consider:

- deliberately reducing verbal concepts and unnecessary words in speech, using them supportively and responsively. Try accompanying or replacing verbal explanations with experiential demonstrations of your meaning where possible.
- whether the activities you are sharing are being experienced as a requirement to be fulfilled or ‘co-operated’ with by the other person. Do they want to share musical activity in this time and place? As well as asking them, it is important to consider what their activity, or lack of it, indicates about their experience during sharing. It might be that just a few minutes of activity is enough.

- whether your practical support and encouragement for an individual supports them in finding their own way in musical activity, rather than imposing existing concepts or coercing.
- remaining open to where an activity can go, responding to what comes from the other person rather than directing towards a preconceived activity or outcome. Try approaching familiar activities as one would the unfamiliar. Experiment and play.
- not making assumptions based on what you think the other person is capable of or has liked up until now. Offer opportunities and choice and take the lead from the other person. Share activities that are mutually accessible.
- thinking through possibilities to avoid problems arising, e.g. if sharing flowers, use edible ones without thorns for freedom in sensory exploration.
- musical exploration as an adventure together rather than as providing activity for the other person that they can contribute to equally when you follow each other's lead.
- allowing plenty of time for the other person to respond to opportunities of their wish to and recognising it as their choice if they do not. This may mean going outside your own 'comfort zone' in sustaining opportunities. A simple musical offering is a way of reaching out to the other person and can be enough.
- sharing musical opportunities that move between reflection and participation. This can support fluctuating energy and enjoyment.

11.22.2.2 Starting Out

Share simple musical and sensory experiences and activities that are familiar and enjoyable for you both, as a basis for further sensory exploration. These could be media and experiences you have in common but have not necessarily shared in the past. You might try:

- Listening to music from your lives, past and present; music that you and the other person know and enjoy.
- Sharing sensory activities that you both enjoy. For example, looking at images or enjoying particular tastes.
- Sharing musical activities that you both enjoy. For example, singing around the house, dancing, playing an instrument, or sharing music as a spiritual experience.

11.22.2.3 Responding to the Other Person

Observing the other person's activities of daily life and their responses to, and participation in, musical and sensory activity, can inform further exploration. If the person has enjoyed music in the past, consider how this activity has changed (if it has), and possible ways musical activity could be accessible going forwards.

11.22.2.3.1 Sensory

Identify the other person's prevalent sensory activities, for example, restless 'fiddling' with clothing or visual absorption with contrasts. Identify how their senses have changed, if they have. Consider:

- what music and sensory media could be shared that might afford opportunities for familiar and enjoyed sensory activity for the other person. For example, tactile objects if they have a strong relationship to touch.
- how the individual's sensory activities might promote creating musical sound. For example, a tendency to stroke could promote sounding skin instruments such as drums and ocean drums, perhaps with a textured material or flat brush. A sure use of breath could indicate play with a harmonica or kazoo. This could give indications for activities to try, resources to create and support to offer.
- how experiencing could be enriched for individuals in light of sensory disruption. For example, offering an experience of 'colour' through taste, smell and music.

11.22.2.3.2 Expressive

Identify how their physical, emotional, memory and conceptual activities (e.g. rhythmic movement, verbally expressed memories), have changed in their daily life (if they have) and which are now prevalent. Consider:

- how experiencing music and sensory media might afford opportunities for these familiar and enjoyed activities, such as rhythmic music for movement or familiar media for sharing memories.
- how music and other sensory media could be shared to support activities of daily living, such as animation, relaxation or a particular ‘mood’ that could be supportive of particular activities or times of day.
- indications for avoidance for the individual, such as music that evokes painful memories and genres or features of music that are disliked such ‘jazz’, a particular instrument or high pitch. For further guidance on sharing music safely, please see guidance from Playlist for Life (playlistforlife.org.uk*).

11.22.2.3.3 Creative

Identify enjoyed and accessible music-making activities. For example, humming, singing or playing simple instruments. Consider:

- how music-making could be shared to support activities of daily living, such as rhythmic singing whilst walking.
- how musical characteristics are supportive and restrictive of music-making for the individual. For example, singing the words of songs. Content can be adapted to be more supportive and promoting of participation. For example, reducing the lyrics or singing speech sounds or singing more slowly with an individual.
- how music-making might afford opportunities to participate in physical, emotional, memory and conceptual activities. An example could be singing familiar songs to move to, or as a memory, especially where these activities are disrupted for an individual in their daily life.

11.22.2.3.4 Relating

Identify how ways of relating to the others (e.g. conversation) are, or have become, disrupted. Consider:

- how music and other sensory media could offer opportunities for relating. Think about sharing mutual experiencing and expression through touch, movement, emotion, memories, concepts and music-making.

11.22.2.4 Exploring and Developing

Once you are comfortable sharing simple familiar activity together, you could share this activity with friends, family and care professionals. You might also try something new. Sharing new activity can feel uncomfortable. As long as no one is upset and distressed by it, try to stay with the activity and return to it more than once. You might find you both enjoy it more over time (or not). The following indications may help you to develop your own ideas for activities to try.

11.22.2.4.1 Sensory Activities

- Try exploring sensory media that hold memories for the other person or you both. Consider the different senses and what might stir memory from different times and places of life.
- Try exploring sensory media that are unfamiliar to one or both of you.
- Try exploring media that ‘speak’ to the different senses: sight, smell, taste, sound, touch. It is important to consider allergies and whether it is necessary for all media to be edible and risk-free for the other person. Consider the different ways these senses can be stimulated and different media you might try. For examples, see Table A.
- Combinations of sensory media may not be accessible for the other person simultaneously.
- As well as exploring sensory media, you could try sensory based activities, for example: Making and kneading dough, painting colours, collage or scenes

using paper, textiles, or natural materials, coloured wax crayon leaf rubbing and hand or face massage.

- Try exploring the various sensory possibilities of different media. For example, a lemon is a tactile, visual medium that can be smelled and tasted. Many objects can also be sounded.

Table A: Examples of Sensory Stimulation and Media

Sense	Stimulation	Media
Sight:	contrasts and colours, individually and combined	objects, images, photos, coloured material and textiles, video, blowing bubbles. The BBC <i>Remarc</i> website hosts images, video and audio from the past (remarc.bbcrewind.co.uk).
Smell:	medicinal, cosmetic, culinary, natural, chemical	prepared food, cooking ingredients, fruit and vegetables, scent, soap, cosmetics, wool, leather, earth, flowers, herbs, grass cuttings, hay, beeswax, wood, medicinal, cleaning products.
Taste:	salty, sweet, savoury, bitter, sour, spicy	prepared food, cooking ingredients, fruit and vegetables, edible flowers, herbs, beverages.
Sound:	resonant and dull, loud and quiet, harsh and gentle	shaken packets, pots, tins and jars of seed, pulses and grain; struck tins and tubs; splashing and swirling water; different kinds of paper; rustling dry leaves; rasping fir cones on bark; tin foil; hollow objects; blown bottles; music boxes; recorded sounds, e.g. the wind.
Touch:	warmth and cold, soft and hard, textured and smooth, hands, feet and skin	shells, bark, moss, grass, earth, wood, metal, wicker, textiles and materials, paper, clay, pottery, glass, wool, fur, leather, leaves, fir cones, felt, seaweed, water, hot water bottle, skin cream or oil, sand, stones and crystals, balloons.

11.22.2.4.2 Recordings of Music

- Try exploring unfamiliar recordings in mutually enjoyed genres and styles to extend material for sharing in various ways.
- Try exploring recordings in unfamiliar genres, styles and cultures to extend material for sharing in various ways.

- Try listening to recordings with a range of characteristics, for example: lively, slow, humorous, emotionally stirring, or emotionally rousing.
- As well as listening to recordings, try activities such as reminiscence and movement along with them
- Consider sharing different recordings at different times of day or to match the mood of the other person, for example slow recordings of music before bed.
- Try exploring new ways of sharing enjoyed responses to recordings and sensory experiencing. For example, if moving to rhythmic movement is enjoyed, try different ways of moving and different styles of music recordings for moving to, such as flowing, expressive movement.
- Try exploring unfamiliar responses to music. Consider responses such as movement, emotion, humour, talking, singing, making sounds and relaxation. Think about what musical characteristics could promote these.

11.22.2.4.3 Music-Making

- Try exploring new ways of sharing enjoyed music-making. For example, if singing familiar songs is enjoyed, you could try a new song, new words to a song, or exchanging simple, improvised sung phrases.
- Try venturing into unfamiliar forms of music-making. You could try the following with, or without, recordings of music:
 - Explore beat and rhythms with body percussion (clapping, thigh patting etc) or simple percussion instruments.
 - Sing familiar songs. Incorporate playing familiar and new music on instruments if this is familiar activity for either or both of you.
 - Explore singing/playing melodies and harmonies. Familiar music can be a sure starting ground and place to return to from exploring the new.
 - Sound and explore simple instruments (see Instruments). Try experimenting with various instrument combinations.

- Consider promoting musical participation by offering instruments, recordings of music and your own live participation, singly or in combination. Try thinking of as invitations to an individual to freely participate in creating sound and music.
- Try responding to the other person in different ways, for example:
 - Mirroring
 - Echoing
 - Doing something different but complementary
 - Modelling activity as an invitation for the other person to respond.
- A spirit of adventure, exploration and fun is key. Let go of whether it sounds right or wrong. Whether you and your creations sound beautiful or unusual, they are all opportunities to share in new musical discovery. The more you explore and share, the freer and more confident your music will become.
- Consider how unfamiliar activity might be supported for you both. Exploring unfamiliar musical activities can feel uncertain and uncomfortable but where there is potential for enjoyment, stick with it. Over time it can become familiar and enjoyable activity.
 - Singing: try ‘easing’ into singing by humming, then la’ing a tune, then add words if appropriate. A visual focus, such as lyrics sheets or a sensory object, can be helpful if there is ‘where to look’ awkwardness.
 - Rhythm: try ‘easing’ into creating rhythm with playful tapping, patting and clapping.
 - Instruments: try experimenting different ways to make sounds and what different sounds can be made with an instrument. Explore playful interactions with these sounds rather than trying to create a recognisable or familiar melody or musical structure.

11.22.2.4.4 Multisensory Environments

Try bringing together complementary sensory and musical media and activities, both familiar and new. A variety of sensory media offers a greater range of opportunities for experiencing, participation and interaction to grow organically. Consider:

- playing recordings of music or singing to provide an enhancing environment to shared sensory activities.
- exploring different ways of combining media. These could include:
 - Natural, social and cultural themes, such as the seaside or harvest festivals.
 - Temporal associations such as era or life stage.
 - Qualities, such as mood.
 - Specific memory associations for the individual.
- experiential relationships between sensory media for the other person, for example the smell of a lemon might have been regularly experienced during cake baking along with singing favourite songs whilst baking. The smell of lemon, the taste of cake and singing these songs could be offered together.
- conceptual associations between media, such as a lemon and the song *Oranges and Lemons*. Smelling and tasting a lemon or an orange could be combined with singing the song. Consider whether the conceptual associations between music and other sensory media are appropriate for the individual. Associations, both experiential and conceptual, may be used to offer a range of experiences and promote activity without the unifying theme needing to be conceptually understood.
- the various opportunities for exploring sounds, singing and music-making that could accompany, and be accompanied by, sensory media (for some ideas, see [Activity Examples](#)).
- what media and activities you and the other person enjoy independently and imagine how they could be shared in ways that are mutually enjoyed. For example, if they enjoy travel, try sharing images of another country(s) with

traditional music from there. If you enjoy writing, try composing new words to a familiar melody to share.

11.22.2.5 Resources

The following ideas for finding and creating resources offer a basis for developing your own ideas for personalised resources to support and promote opportunities for shared musical activity and exploration. Creating and preparing materials and resources can be time consuming.

11.22.2.5.1 Choosing Music

When looking for music that is familiar to you, try humming or singing those that you know to the other person, as song/piece titles may not be remembered. The BBC offer a free online service for playing short clips of tracks called *Music Memories* to help people identify familiar recordings (musicmemories.bbcrewind.co.uk*). They also provide online radio programmes of recordings and radio content by decade with accompanying activities called *Memory Radio* (bbc.co.uk/programmes/p07mvnd1*). Compilation CDs and online music service 'playlists' by decade, genre etc could also be helpful.

When looking for music that is new to you, you might consider recordings in familiar styles or by familiar artists. Or you could try something completely different. You might try listening to different radio stations, your local library, or online services for inspiration.

You might consider making lists of recordings, pieces and songs, perhaps with specific activities or mood in mind such as 'relaxing', 'singing along to', 'the sea', 'dancing' etc. This could be a written list for music-making or reference to tracks from your own recording collection, a created digital playlist, or through an online streaming service. For further information on finding and playing music recordings, see Playlist for Life (playlistforlife.org.uk*).

Not all recordings will be appropriate for singing, playing, or moving to, e.g. they may be too high or low, too fast or slow, too 'wordy' etc. You may need to try different versions of a track, or even different tracks to support your needs. If you have access

and know how to use editing software for music recordings, it can be possible to edit tracks for your own use, e.g. change the key for singing.

11.22.2.5.2 Song Lyrics

If you feel written song lyrics may support your shared singing, there are a number of places to source them:

- Write down what you know/hear from memory.
- Purchase song books or borrow them from a library.
- Search online. There are many websites offering free song lyrics to print.
- You might consider organising your song lyrics in a folder or book. Consider grouping lyrics by specific activities or mood.

Consider whether simplifying the song lyrics could be supportive. Repeating a small, familiar section of a song can be more manageable than multiple verses. Sometimes just a chorus is enough.

Consider whether the presentation of the lyrics is accessible. Using a larger font and increasing the space between lines can make them easier to read. Some people find a different colour of paper helpful. See the DEEP guidance for advice on formatting (dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf*).

Sometimes lyrics sheets can get in the way of interaction. Consider trying singing without them when singing becomes more comfortable.

11.22.2.5.3 Instruments

Consider exploring what sensory media is accessible and enjoyed before investing in musical instruments. For example, certain shakers need to be held and moved in particular ways to make them sound that may not be accessible for an individual. You could try experimenting with shaking, striking, patting, tilting, scraping and brushing sounding objects you have readily available as part of sensory exploration to give indication of instruments that may be accessible and enjoyed. Household objects may

be enough, or you may wish to go on to purchase simple instruments. The following list is not exhaustive, but offers a basis to work from:

- Blowing: kazoo, harmonica, slide whistle
- Shaking: shaky eggs on sticks (without sticks, these can be a choking hazard), maracas, seed pods, shakers, tambourines, sleigh/D-bells
- Striking (with beater/stick): triangle, tambourine, claves, glockenspiel, drum, cow bell
- Tapping: drum, tambourine with skin
- Tilting: ocean drum, rain stick
- Scraping: guiros
- Brushing: drum, ocean drum, tambourine with skin

Accessible instruments are also available that can be worn, such as shakers on hands, wrists, legs and feet. Consider whether the angle a particular instrument needs to be played at is accessible. For example, some shakers, like maracas, are held vertically, whereas others, like D-bells, can be held horizontally. Some instruments require use of two hands/support.

To make tappers for sounding with feet and for seated tap dancing, sew a button onto a loop of elastic to go over each shoed foot. Place chopping boards under feet.

11.22.2.5.4 Sensory and Artistic Media

Most of the sensory media suggested in Table A above are commonly found in households or are cheaply and readily purchasable. Images can be sourced from magazines, books and online. Second-hand shops can be a good source and there are companies that sell dementia specific image books. Many online images are either paid for or subject to copyright. However, there are websites that include some public domain and free to use images, such as Wikimedia Commons (commons.wikimedia.org*). Laminating images can help them to last longer.

Consider using matt laminating pouches to minimise reflective glare. When sharing images, a bookstand can be helpful to leave hands free for other activity.

For exploring craft and arts-based activities indicated above (see [Sensory Activities](#)), some recommended basic materials include:

- **Dough:** find a basic bread dough recipe from a recipe book or online. The ingredients are usually flour, salt, yeast and sugar. You will need a large bowl to make it in, boards to knead it on and a damp cloth for cleaning hands. If you want to go on and bake it to eat, you will need a bread tin.
- **Painting:** water based, nontoxic paints in a few simple colours, heavy paper, brushes, sponge, a painting board and an apron.
- **Paper collage/scenes:** a selection of coloured and patterned paper, card and magazine cuttings, nontoxic glue, plain paper or card and a craft board or tray.
- **Textile collage/scenes:** a selection of material/scraps in a variety of colours. Felt is recommended.
- **Natural material collage/scenes:** shells, moss, fir cones, stones, twigs, leaves, flowers and a tray.
- **Coloured wax crayon leaf rubbing:** large flat leaves, wax crayons (block crayons are most effective but can be a choking hazard), stick tac, nontoxic glue and a board or tray.
- **Hand or face massage:** simply scented skin cream, such as lavender (relaxing).

11.22.2.5.5 Resources in the Home

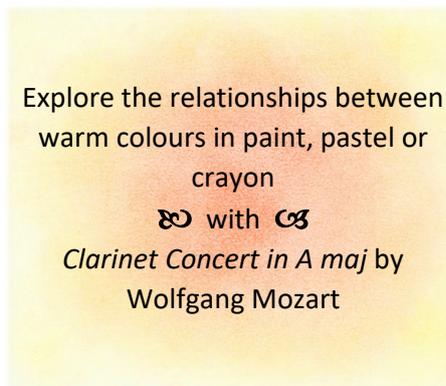
Consider how resources for musical activity could be incorporated into the home environment in an accessible way that encourages independent exploration. For example, it may be possible to have resources such as instruments or lyric books within easy reach or to create an accessible 'sensory table'. Clearly labelling resources can aid recognition and initiating activity and promote choice. There are dementia-friendly music players on the market to make playing recordings of music easier.

*All web links were accurate at the time of writing, 8th November 2020.

11.22.3 Activity Examples



Rub coloured crayon
 or chalk on paper
 covering secured,
 clean leaves
 with with
*The Trees They Do
 Grow High* by Martin
 Carthy



Explore the relationships between
 warm colours in paint, pastel or
 crayon
 with
Clarinet Concert in A maj by
 Wolfgang Mozart



Enjoy paintings by Claude
 Monet
 with
Clair de Lune by Claude
 Debussy



Explore harmonies and contrasts
 to
Kothbiro by Ayub Ogada



Explore movement with 1 or 2
 hankie-size pieces of material
 to
British Grenadiers by The Albion
 Morris Men



Enjoy salty olives or sticky baklava
 with
Zorba's Dance by Mikis Theodorakis



Smell and handle cut
 roses; thorns removed
 with
Air à Danser by
 Penguin Café
 Orchestra



Experience the smell of
 vanilla essence
 and sing
*If I Knew You Were Comin'
 I'd've Baked a Cake* by
 Eileen Barton