

Keeping community groups and activities going

Sustainable Community Interventions for People Affected by **Dementia**:
Recommendations for Practice from the **SCI-Dem Project**



First published February 2021

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ISBN 978-0-903607-33-9

How to cite this booklet:

Morton, T., Brooker, D., Wong, G., Atkinson, T. & Evans, S.B. (2021) *Keeping community groups and activities going - Sustainable Community Interventions for people affected by Dementia: Recommendations for practice from the SCI-Dem Project*. University of Worcester ISBN 978-0-903607-33-9

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Introduction

Running a community-based group or activity for people affected by dementia can be challenging. Keeping a group or activity going long-term can be even more so – especially in a climate where community awareness and resources can vary dramatically from place to place; where funding is hard to come by and often short term; and where there is no standard model of formal support for such groups, applied consistently, across the country.

The SCI-Dem review has gathered together information from various sources about the common problems that face regularly-meeting groups and activities for people living with dementia (or people supporting someone who is). By doing so, we can share possible tips, strategies and good practices from this review that might help a community group or activity to keep going long-term, after getting established.

This booklet outlines recommendations, built upon the information we have found. This booklet aims to help those in practice (whether that's planning for a group or activity, managing one, running one day-to-day or supporting one through volunteering). There is a separate booklet of recommendations aimed at funders/commissioners and policy makers.

The information these recommendations are based upon was gathered and put together from dozens of sources of all types: research studies and papers, evaluation reports, magazine articles, info guides and how-to booklets, conference talks, even videos and artistic output from some groups. All examples given are fictional, but based upon what we found.

We hope that what we have found resonates with your group or activity and that you find something useful and informative in these pages, so that the important and much-needed work of such groups can be better helped to sustain long term.

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The key areas for keeping a group or activity going

As found in the SCI-Dem realist review





**Getting
Members**

- **Emphasise the social aspects of your intervention, including food and refreshments, for wide appeal**

While the activity itself will be an important draw for some, many will be more interested in the social side of things. The need for social connection is something most people share, regardless of their interests, and eating together can play a big role in this. A relaxed social feel can also make coming along less intimidating and more welcoming.

- **Ensure a warm, welcoming, non-stigmatising introduction, with strong staff interpersonal skills and an appealing venue**

People can be hesitant to join a new group or try a new activity because they are worried they will not cope, will be uncomfortable or embarrassed. They may have had a bad experience in the past. Empathetic staff with good interpersonal skills can help overcome this, especially with initial home visits or taster sessions to help build trust. An open, accessible venue with a homely atmosphere in everyday surroundings helps create a warm welcome.

- **Foster understanding and support from trusted friends, family and health professionals, as their encouragement can be key**

If friends or family recommend a group or activity, people may be more likely to give it a go. The same is true for known and trusted health professionals, for example someone's GP, dementia advisor, regular nurse or care worker. It is important to work with the people supporting those living with dementia, to ensure they are aware of your intervention and its benefits. Personal discussions with people in these groups will pay dividends in getting their support.

An example: Colin doesn't like going out to places he doesn't know. He worries about getting into a situation where he might struggle and be embarrassed in front of others. However, Silvia, a nurse he knows and trusts, kept talking about this social group she knows and how much people enjoy it, and he had to admit he wished he could experience something like it. Silvia spoke to the organisers and a man called Frank came to visit Colin in his own home a couple of times to chat. Frank was so easy to talk to that Colin soon felt comfortable with him and agreed to go along for just one group session as a taster – as long as Frank was there. Once there Colin found everything so relaxed, everyone so welcoming and the place so pleasant, comfortable and well laid out, that he has continued to go ever since.

- **Offer information and advice to connect with a broad range of people who may be in need**

When a group or activity can offer practical advice, information and links to services that can help people, then this alone will be a reason for people to come along – as they will be able to see it has something to offer them that will meet their most immediate and pressing needs.

- **Ensure people can get there easily, safely, reliably and cheaply**

One of the things that stops people attending a group or activity is when they find it difficult to get to. If there is no affordable transport, or the venue is too far away, people will not be able to come. Equally, if transport isn't appropriate, reliable and respectful of people with dementia, they will not want to use it. Forging links with community and public transport/taxi firms can help, but this remains a major problem for rural areas in particular.

- **Provide meaningful activities that have resonance with people's interests and experience, personal history and culture**

Providing meaningful activities that allow people to continue engaging with their interests will motivate people to come along. If groups make an effort to recognise people's history and culture, people will feel more comfortable, respected and valued when they attend and less likely to worry about discrimination and stigma.

- **Be sensitive to differences in abilities, ages and stages and aim to empower members rather than avoid challenges for them**

If those with different abilities feel "lumped in together", this can put people off attending. People may feel a group is not "for them" as it is more focussed on others with different needs. Risk-averse activities may feel too easy or restricting to some. Different roles and activities for members, sensitive to ability, can help people feel there is an appropriate place for them. Focussing on what people can do rather than what they can't can encourage people to try new things – and to attend.

An example: Jabbar, who is 67 and physically fit, tried going to a community exercise group when he was first diagnosed but found it far too easy as it seemed to be aimed only at the oldest members, in their late 80s to 90s. The group also did reminiscence sessions but they were always about the era of Jabbar's parents' youth, not his own, and about growing up in England when he grew up in Pakistan and Scotland. Now he has joined a walking and lunch group where people of various ages and abilities can set their own pace – and it has other members from a South Asian background, who bring more cultural diversity to both the food and conversation topics, making him feel a little better understood.

- **Stay in constant contact with potential referrers and keep them involved**

How people get "referred" to your group is vital for keeping numbers up. Health and social care professionals, community organisations and other groups who might refer people need to understand who you are, what you do and for whom. Building a relationship with potential referrers through personal and ongoing contact will help this.

- **Your "public relations" strategy should focus on who the intervention is for and what people can expect, and use existing networks to spread your message**

Clarity also matters when advertising your group or activity – people need to understand who it is for and what to expect if they attend. Publicity materials need to be appropriate in tone, avoiding stigmatising language, and presented to people at an appropriate place and time when they may find it most helpful. Existing groups, organisations and venues can help spread the word and reach the right people, as can health and social care professionals working together.

- **Consider simple and easy self referral**

Waiting lists, red-tape and issues with GP diagnosis can all prevent people from being referred. If your group accepts self-referral, you may get a wider range of potential members and avoid excluding people who might benefit. Sign-up needs to be straight-forward, simple, clear and concise.



**Keeping
Members**

- **Keep activities relaxed, loose and focussed on the social, and encourage friendships and peer support**

People are more likely to keep coming if they forge friendships in the group and feel at home. If they can't relax and enjoy things, because of a fast pace or too many rules and expectations, they may stop coming. More social time means more opportunities for members to give you feedback on what they want and need, and engage in peer support. It also fosters group cohesion and ownership.

An example: *Heather and Harriet became firm friends at the village hall drop-in centre. Though there are lots of activities to do, they mainly like to chat or sit in companionable silence together. However, staff started focussing more on the activities, prompting everyone to always take part in group games and exercise. Formal seating plans were introduced that meant Heather and Harriet were often not together. Harriet left, saying she only went to chat and relax. Heather said she liked the activities, but also left shortly after. "It's not the same without Harriet," she said, "if only they'd allowed us time to do our own thing together".*

- **Encourage normalised activities and social integration outside of the group to empower members and reduce stigma**

Inviting guests in or taking trips out can help members feel more socially connected and reduce stigma. Engaging in normal, mainstream activities helps, as do links to public amenities in the community. Projects in which members can do something to help others in the community can also help people feel useful, valued and empowered.

- **Be person-centred: Give members input into planning and decision-making, and respect their individual needs and autonomy**

People are more likely to keep coming if they feel things are tailored towards their needs, and they are respected, valued and understood. Regular meetings to "tune" activities to the wants and needs of members can help this, as can input from family and friends. Involving members in decision-making when planning will give them a sense of ownership. Doing the same in carrying out day-to-day activities will help them feel their voice is heard and freedom of choice respected.

An example: *The Friends Together group was set up by Winifred, who is living with dementia, and her husband Winston. The membership is made up of people with dementia and also the family and friends that support them. Winston and Winifred stick by policy of "nothing about us without us": At their meetings they ask all members for feedback on how things should be done, plus they invite everyone to special planning meetings twice a year to decide on their own activities in the coming months. When a new member joins they talk to them about their interests and see if they can use those interests in their sessions. This means what the group does often changes slightly with the group's membership, and it keeps things fresh.*

- **Talk to family or care partners about what arrangements and support they need in place**

Difficulties for family or friend care partners, such as work commitments or problems finding transport, can be a deciding factor in whether someone can come along or not. Talking to family and friends about what they need can help solve problems you may not have known about otherwise.

- **Be sensitive to differences in abilities, ages and stages and have strategies to differentiate and manage activities so needs don't clash**

If a group does not cater equally both for newer members and older members whose condition has progressed, this can discourage one or the other from continuing to attend. Assessing individual needs and planning strategies to meet them with different roles and activities can help. A clear target criteria for membership is helpful. Links with other groups and services that people can progress to when no longer meeting that target criteria are also good to have.

- **Ensure your venue is comfortable, stable and familiar, with adequate facilities and multiple spaces for use**

This will help people feel relaxed, secure and at home. Being able to move around, with a choice of spaces, activities and companions within the venue, helps keep things interesting and comfortable for members. Environmental factors such as noise, lighting and layout also matter. The happier people are in their environment, the more likely they are to want to return there.

- **Stability and reliability matters to members, so aim for structure and minimise disruption**

If sessions are regular, routine and structured then people will feel comfortable and secure. If the venue and timings remain the same, it's easier for sessions to become part of people's routine. Continuity of staff helps this, while not having enough staff can lead to disruption. Having a tried and tested model to base your group or activity on also helps with structure. However new ideas and variety are also important to avoid things becoming stale or boring for attendees.

An example: *Woldbridge Crafters Club, an arts and crafts group aimed at older adults including those living with dementia, had been running two years when they lost the use of their usual community hall meeting place. At the same time the group's main facilitator, Sue, had to leave as funding for her role ran out. This led to nine months with different facilitators stepping in to keep the group going, often at different venues on different days of the week. By the end of this period the group had dwindled from 30 regular attendees to just seven. Member Steve stopped going as he said he couldn't keep track of when and where he was supposed to be, and couldn't always get there in any case. Another ex-member, Manuella, said: "The magic has gone – it was such a lovely place to go before and Sue ran it so well".*



**Getting
Staff &
Volunteers**

- **Network proactively: Engage in outreach activities to boost visibility and awareness; approach other groups and organisations for help**

Taking part in outreach activities will raise the profile of your group with people in the community, and help reach potential staff and volunteers. Links with like-minded groups, local authorities, third-sector and community organisations are good to forge as they may be able to help with both finding and training staff and volunteers.

- **Get to know potential stakeholder groups in the local population that may provide a reliable volunteer base, and consider how to reach out to them**

Many groups have been successfully run with social care students as volunteers, thanks to partnerships with local colleges or universities. In rural areas this may not be an option, however. Be prepared it may take time and personal contacts to recruit volunteers. Retirees can have the time and experience to make good volunteers; friends and family of current or previous group members can make highly motivated volunteers who truly understand the value of what you do.

***An example:** Walking football sessions for those affected by dementia had proved a success in town of Dunsbury, thanks to a partnership between a leading dementia charity and Dunsbury College. The college let the charity use their sports facilities, and student volunteers helped run sessions. With both sports science and health and social care students to draw on, they always had plenty of volunteers. Charity worker Bobby wanted to try the same kind of thing in Church Aldercott, a village 30 miles to the south with a large older population; in Church Aldercott there was a village sports pitch, but no college and no students. There were, however, many fit and healthy retirees, some with a keen interest in sport. It took time, community contacts and hard work to locate and recruit some of these people, but eventually Bobby had enough volunteers to make his football club possible.*

- **Not all personnel need expertise, but ensure facilitators have good interpersonal and leadership skills, and your volunteer workforce is reliable**

Personnel do not need professional training if there are no specialist elements or members with high care needs. However, good leadership, communication and interpersonal skills from a facilitator will engage and inspire other staff and volunteers. Those in funded roles should devote time to building a volunteer base as reliable volunteers with consistent skills will help a group or activity sustain.



**Keeping
Staff &
Volunteers**

- **Foster flexibility, collaboration and communication skills in personnel to create a healthy and effective working environment**

A healthy and effective working environment is one where personnel feel capable and invested in their work. By sharing knowledge, experience, innovation, resources and effective working practices with others, everyone works more effectively. If personnel are given the right guidance and are open to new ways of working, they will be more likely to successfully collaborate with others.

- **Plan strategies to maintain the satisfaction and enjoyment of staff and volunteers, and to avoid burnout**

Running a group can be stressful and demanding. Staff can experience burnout or lose enthusiasm if things are too challenging. Planning strategies for adequate recruitment, training, and support of personnel can help avoid this. A culture of community, camaraderie and helping people can also make things more rewarding and enjoyable. Volunteers will feel more satisfied if they can do something that suits their abilities and interests, and if their skills and development are valued.

- **If possible, have financial support in place for staff roles and volunteers activities, so they will feel secure and valued**

Limited and inconsistent funding can make it hard to retain paid staff because they may not feel they have job security. If unpaid volunteers are treated as a replacement, remaining staff may feel their roles are undermined and un-valued. If volunteers are treated as “coming for free”, they may feel their time and expertise is taken for granted. Though difficult to find, some form of financial support, both for staff roles and volunteer activities, is necessary to retain personnel.

An example: *Dunsbury Friendship Club involves lots of organisations working together: Club facilitators, club volunteers, local GPs, dementia advisers, charity workers, council workers, social care workers, community group representatives and so on. At first these did not always work together well; they tended not to mix and viewed each other with caution, thinking each did not understand the other’s role. However, decision makers with each group met and agreed they would lead by example, working closely together and sharing the same information with everyone on a regular basis – as well as providing training on good communication and collaboration practice for all staff and volunteers. As a result, all those involved with the club feel included, respected and informed, understanding who does what and why. This has in turn encouraged a culture of sharing and camaraderie, which makes for a more rewarding and enjoyable experience for staff, volunteers and members alike.*



**Getting
Support of
Other
Organisations**

- **Focus on raising awareness and communicating value both to professionals and the community, involving them where possible**

If there is higher public awareness of people living with dementia in general, you are more likely to get support from other organisations and services because they will recognise the importance of groups like yours. Having strong evidence of the benefits of your activities helps. Following an evidence-based model, or engaging with research and evaluation, will boost this. Involving key people from other organisations will also help them understand the value of what you do.

- **Approach and ask other community organisations if they can help with venue, resources, training, volunteers or contacts**

Communities have a range of organisations operating in them, whether that's local authority or third sector bodies, faith groups, businesses or educational establishments. Some or all of these may be willing to offer some kind of support if asked. Being flexible in terms of how and where a group runs can help in being able to adapt to the resources and opportunities available.

- **Use your physical location (venue or neighbourhood) as an opportunity to build links with others sharing that space**

Local organisations and services are already invested in the same community, so it is often easier to build a network with them than with national organisations. Being based at a visible location such as a civic centre, public venue or local club helps others know who you are and that you are there. Public venues or local clubs will also have an existing network of users and contacts that your group may benefit from working with.

An example: *Woldbridge Crafter's Club has got back on its feet with the help of the local community. After agreeing use of a room in Woldbridge Library with the council, new facilitator Sergei approached businesses and a church group in the same neighbourhood. A supermarket has agreed to include the group its ongoing fundraising work; an art shop has agreed to provide materials; and the church group has begun a drive to find furniture and has even offered alternative rooms if the library falls through in the future. The council has also agreed volunteers can join already-running social care training that it provides.*

- **Seek out like-minded groups to band together with and share knowledge, resources, contacts and strategy**

If a group is small it can be more difficult to network with larger organisations. If links are forged with a wider (e.g. regional or national) network of similar interventions, groups can support each other by sharing resources, knowledge, contacts and strategy. Similarly, if a small group is struggling, merging with other local groups means resources, personnel, knowledge and ideas can be pooled.

- **To avoid conflict with other organisations, minimise overlap, involve them or offer them something of benefit**

Other local organisations might see you as competition, so not offer support. There are some things you can do to avoid this. Minimise overlap with what others are doing (and *when* they are doing it) and offer to act as a link or gateway to other services. If you share your knowledge and resources, others are more likely to view you positively. Inviting other organisations and health care professionals to meetings, and asking for input, will help you learn more about each other and invest in each other's success.



**Keeping
Support of
Other
Organisations**

- **Maintain constant contact and information sharing with the organisations, services and referrers you work with, with a dedicated person responsible if possible**

If regular contact is not maintained, communication and admin problems can arise, and the interest and enthusiasm of others can dwindle. Having someone whose responsibility it is to keep up regular communication can help. It's also good to foster relationships with key people in partner organisations who can champion your cause. Staff turnover – both in your group and the organisations that support you – can be a challenge for this.

An example: Dunsbury Friendship Club involves lots of organisations working together: Club facilitators, club volunteers, local GPs, dementia advisers, charity workers, council workers, social care workers, community group representatives and so on. In order to keep everyone in the loop – and the club at the forefront of everyone's minds – volunteer Sheila, a local writer, and Geoff, a trustee governor of the club, work together to produce a quarterly newsletter covering the events, successes and challenges of the past three months for the club. It is produced in both digital and printed formats and sent out to list of collaborators and stakeholders that is kept up to date by Sheila – as well as potential referrers and funders.

- **Seek authoritative external advice on overcoming differences in culture with other organisations, and up-skilling staff for collaboration**

Differences in culture between organisations can be a problem, as people will not be working with the same focus and goals. If staff have negative or competitive attitudes to other organisations, they may resist sharing information, learning and resources. Those running a group can lead by example in how they collaborate with others but having independent advice – for example from local authorities or large third sector organisations – is a good idea.

- **Take time to formally plan how collaboration will work, involving collaborators in that planning**

Organisations you work with can be brought together in a formal steering group, to focus on your shared agenda and how your work can complement each other. Having a written “collaboration protocol” outlining goals, expectations and what each party will do is useful. Regularly logging and reviewing discussions with collaborators is good practice, to air and resolve issues. Partnerships should work together from planning to practice so each feels equally invested and involved.

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**Getting
Funding
& Income**

- **Ensure communication is clear about what the intervention does and its value**

Don't assume it's obvious who your group is for and what it does – if funders do not fully understand your group's purpose or value they will be less likely to fund it. Explain how you meet the needs of people in the community and use standard, recognised materials (e.g. from the Alzheimer's Society) to gather evidence of your value where possible. Keeping potential funders alert to your work can help when asking for funding in the future – e.g. by including them in newsletter or leaflet mail outs.

- **Build “social capital” and forge partnerships with other community organisations to help with costs and boost the case for viability and value for money**

Funders look for value for money. If something is perceived as more expensive than other alternatives this can put funders off. If you have support from other organisations, it can help keep costs low through the sharing of resources. It can also help you appear more legitimate, viable and valuable to existing services, which funders like. If your group can generate some income through offering services to others also, this will help your case for the same reasons.

- **Learn how to effectively plan and network to find funding, through knowledge-sharing with like-minded groups and seeking external advice**

Up-to-date knowledge of funding processes and a realistic strategy to attract donations and grants is key. Having a business case ready will help you respond quickly when a window of opportunity opens with a funder. Seeking external help on business planning and networking is a good idea. Third sector organisations or local authorities might be able to help with this. Sharing successful ideas with like-minded groups will help to find innovative funding solutions.

An example: Mai, a trustee of Dunsbury Friendship Club, signed up to a scheme put on by a local social enterprise group to give small, non-profit and volunteer-run groups the tips and tools to improve their ability to network and manage their money. Mai learnt what the club needed to do to write a good business plan and make bids for external funding. She also built up some local community contacts and was able to forge better links with the local NHS trust, boosting referrals. Now when the club makes a bid, funders can see their investment will benefit local health services also. Mai also reaches out to other small groups to pass on what she has learnt, in turn raising more awareness of the work of Dunsbury Friendship club.

- **Initiatives in rural areas should make clear the particular challenges that they face when seeking funding**

Groups in rural areas tend to be smaller in scale due to population and geography. This means they may struggle to produce statistics that rely on larger numbers, such as demonstrating demand, effectiveness and savings to health and social care services. With fewer staff, they may also find it challenging both to gather evidence and continually apply for funding. Funders are not always aware of these issues, so it may help to explain your position (if this applies) when making a bid.

- **Find out what the national priorities are for dementia, and see if you can tailor your activities to fit; if not, lobby to change the national agenda**

If a group's goals are aligned with those of the national authorities, it is more likely to get funding and support. Groups should emphasise how they fit with the national agenda when seeking funding. This is not always possible as local needs do not always align with national policy, and medical needs and costs tend to be prioritised over social and emotional needs. If groups, members and their families speak out about their needs, this may shift the national agenda in their favour, however.



**Keeping
Funding
& Income**

- **Keep in touch with previous, current and potential funders on an ongoing basis, as this will help when applying in the future**

If funders are kept informed and alert to your continuing work, they are more likely to fund again in the future. This is especially true if demand is clear that and people's needs are being met. Without this contact your group or activity could be forgotten or overlooked. A short, punchy newsletter is a good way to do this. Keeping in touch with funders also helps you stay alert to fresh opportunities.

- **Pay attention to how money can be put to use most efficiently and effectively for the benefit of all by co-operating and sharing with other organisations**

If groups and organisations communicate and work together, existing funds are less likely to be lost on inefficiencies and duplication of services. Working together may help keep costs low through the sharing of resources such as venue, personnel, equipment or training.

- **Plan a long-term strategy to build a portfolio of multiple income streams, that are flexible in what they contribute to paying for**

Don't put all your eggs in one basket. If you have more than one funding or income stream then if one stops, others will still be available. However, make sure money coming in is flexible in what you can use it for, so that you can move things around if a funding stream stops. Identify what income is paying for what in your budget and prioritise your most important, core activity. Planning ahead to spread existing funds and allot spending carefully and realistically is also important.

- **Ensure someone has the time and expertise to continually seek and apply for funding**

Long-term funding for community groups and activities is hard to come by in the current climate. This means groups have to continually seek and apply for fresh funding, particularly challenging for small-scale initiatives with fewer personnel and more limited time and resources. If possible, groups should have someone dedicated to systematically seeking and applying for new income streams on an ongoing basis, to maximise chances of keeping enough coming in to meet costs.

- **Emphasise deep learning and experience as an asset when calling for longer term funding**

When external funding is always short-term and focussed upon new projects, "quick win" projects can be encouraged over support for existing and experienced groups. This means and deep learning on what works to meet people's needs can be lost as a result. If groups, members and their families speak out about the need for stable, reliable and experienced community-based services this may help change things so that funders and authorities value this more, with better financial support.

An example: When Bobby set up Church Aldercott Walking Football Club, he bagged funding from the council to employ coach and co-facilitator Imiah. Bobby and Imiah worked hard to build up links in the community and get to know the local people and their needs. Finding ways to reach potential members and volunteers took months of careful work. After six months they realised the village would be better served with a club offering a range of sporting activities and altered plans accordingly. After one year they finally felt they had a thriving club that people valued... but then Imiah's funding (which was for new projects only) ran out and he had to take a job elsewhere. They hadn't had time to find longer term funding and Bobby couldn't continue running the club alone, so it folded. A year later another charity worker arrived in Church Aldercott and started again, unaware of Bobby and Imiah's work.

An overview of all the factors contributing to sustainability



Acknowledgements



This research was funded by **Alzheimer's Society UK**

www.alzheimers.org.uk

Original project bid: Brooker D. & Evans, S. B. (2018-2020). *SCI-Dem Realist evaluation of sustainable community based support for people and families affected by dementia. Alzheimer's Society Grant 402 (AS-PG-17b-023)*

Completion of the SCI-Dem review was made possible with the invaluable feedback, guidance and expertise of a range of stakeholders, to which we give our thanks. They included:

Alzheimer's Society research monitors Sue Comely, Maggie Ewer and Mair Graham; Philly Hare, Rachael Litherland, Damian Murphy and Rachel Niblock of DEEP/Innovations in Dementia, and all who attended the national meeting of DEEP groups at Woodbrooke, Birmingham, July 2019; Teresa 'Dory' Davies, James McKillop and Dreane Williams of DEEP; Judith Baron and the Face It Together DEEP group; Jill Turley and the Buddies DEEP group; the Friends for Life DEEP group; Kim Badcock of Kim's Cafe (Denmead, Havant and Waterlooville, Hampshire); Jo Barrow and the Forget Me Not Lunch and Friendship Club (Bicester, Oxfordshire); Elizabeth Bartlett of Laverstock Memory Support Group (Wiltshire); Shirley Bradley of Friends of the Elderly (Worcester); David Budd of Our Connected Neighbourhoods (Stirling); Di Burbidge of Liverpool DAA Diversity Sub-Group and Chinese Wellbeing (Liverpool); Kishwar Butt of the South Asian Ladies' Milaap Group (Wolverhampton); Michelle Candlish of Ceartas Advocacy (Kirkintilloch, East Dunbartonshire); Annette Darby of Brierly Hill Health and Social Care Centre (West Midlands); Sue Denman of Solva Care (Haverfordwest); Gerry Fouracres of Scrubditch Farm (Cirencester); Graham Galloway of Kirrie Connections (Kirkriemuir, Angus); Reinhard Guss; Deborah Harrold of Agewell CIC (Oldbury, West Midlands); June Hennell; Jacoba Huizenga of Health and Social Care in Communities, Utrecht (Netherlands); Lynden Jackson of the Debenham Project (Suffolk); Ghazal Mazloumi of Trent Dementia Services Development Centre; Cheryl Poole of Leominster Meeting Centre; Anita Tomaszewski and Jennifer Williams of Me, Myself and I (Briton Ferry, Neath Port Talbot); Dame Louise Robinson; Droitwich Meeting Centre; Leominster Meeting Centre; the members of the UKMCSP National Reference Group; and Jennifer Bray, Shirley Evans, Nicola Jacobson-Wright, Chris Russell and Mike Watts of the Association for Dementia Studies, University of Worcester.

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**Association for
Dementia Studies**

The Association for Dementia Studies – Changing Hearts and Minds in Dementia Care

Led by Professor Dawn Brooker, the Association for Dementia Studies is a multi-professional University research and education centre. We make a cutting-edge contribution to developing evidence-based practical ways of working with people living with dementia, their families, friends and carers that enable them to live well.

If you think that we can help please feel free to contact us.

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ISBN 978-0-903607-33-9