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and a learning disability

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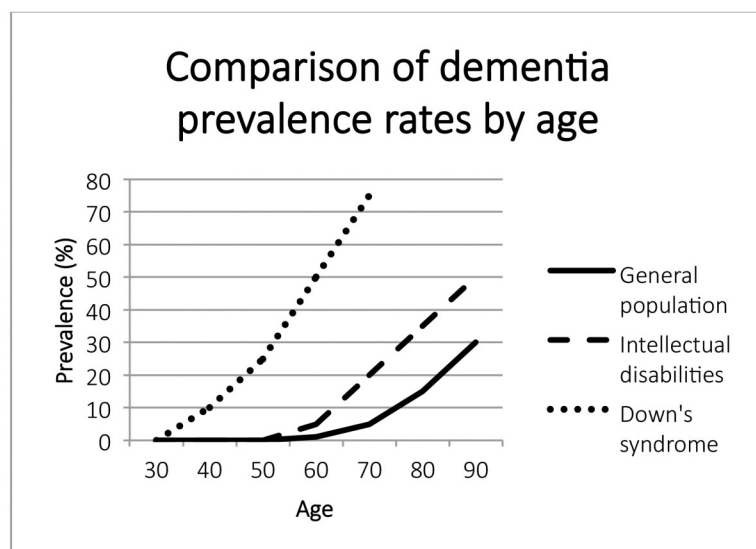
# Preparing to care: Training for carers of people with dementia and a learning disability

People with learning disabilities are at high risk of developing dementia, and they will face different and additional challenges. Care partners who know the person well play a vital role, and expert support for all involved is vital. Saff Davies and Teresa Atkinson describe the development of a specialised training package

It is reported that between 78-79% of adults with learning disabilities in the UK live in their own home or with their family (Nuffield Trust & The Health Foundation 2023). Gates (1997) defines a learning disability as ‘a term used to describe a group of people with significant developmental delay manifested as arrested or incomplete achievement of the ‘normal’ milestones of human development. These milestones relate to the intellectual, emotional, spiritual, physical, and social aspects of human development’. People with a learning disability are increasingly living longer with over one third now estimated to be over the age of 50 years old (Janicki & Dalton, 2000; McConkey *et al*, 2006).

According to the Alzheimer’s Society (2023) one fifth of people with a learning disability over the age of 65 will develop dementia, with greater risk associated with Down’s Syndrome where two thirds of people over the age of 60 may develop dementia, usually Alzheimer’s type. The graph below shows the prevalence of dementia in the general population compared to that of people with Down’s Syndrome. It demonstrates that people living with Down’s Syndrome can develop dementia at the age of 30 years old, increasing throughout the age span, compared to the general population who are at less risk of developing dementia until older age.

The presentation of dementia symptoms may be different in those with a profound learning disability and appear more subtly. There is greater reliance, therefore, on the expertise carers already have in understanding their loved



## Summary

The Alzheimer’s Society (2023) advises that people with learning disabilities, particularly those with Down’s syndrome, are at increased risk of developing dementia. If a person with a learning disability develops dementia, they will face different and additional challenges to people who do not have a learning disability. Many people, including family carers, are not aware of this risk and, in addition to the challenges of caring for an adult with a learning disability, are unprepared for the further complications that a diagnosis of dementia may bring. This article considers the needs of family carers and in particular, the development of a training package to provide support.

ones. Changes in mood and behaviours may become apparent, such as taking longer to perform tasks. There may also be changes in memory and language skills. Other neurological changes may take place, resulting, for example in the development of epilepsy. Where the learning disability is more profound, these changes may be masked and will rely more heavily on the skills of the carer. Co-morbid health related conditions add to the complexity of the picture. Additional health needs in this population include thyroid dysfunction and sight and hearing problems. This complex picture makes obtaining a diagnosis challenging, particularly due to the cognitive differences and difficulties already present. However, diagnosis is important to enable full support to be given to families who need to be able to access an appropriate dementia pathway. There is, however, a paucity of information and training available to support this complex dual diagnosis. The Prime Minister’s Challenge on Dementia (Department of Health 2012) strove to

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ensure that dementia awareness, understanding and expertise was a priority in society, yet people with learning disabilities and dementia are not explicitly mentioned in any government initiatives. The Foundation for People with Learning Disabilities (2018) suggest that ‘excellence in dementia care requires everyone involved to have an in-depth understanding of dementia’s impact on the individual’ (p.8).

### **Caring for a person with a dual diagnosis of learning disability and dementia**

The diagnosis of dementia comes as an added ‘layer’ on top of the diagnosis of learning disability. This picture is further complicated by the age of family carers who themselves may be classed as older adults at risk of developing age-related conditions or potential dementia themselves. Attention must therefore be directed to the support that families require to enable them to continue in their caring role, while considering how the additional diagnosis impacts on the already established long-term caring role.

Evidence highlighting the challenges faced by carers of adults with learning disabilities comes almost entirely from small qualitative studies, which is congruent with the demographic and the often-complex role. Although evidence from these smaller localised studies is not necessarily representative of all parent carer views, there are common themes that offer useful insight and learning about outcomes for other similar family contexts. Howson & McKay (2020) suggest that the challenges facing older carers are usually socio-structural rather than related to the care recipient’s needs. Studies such as Deville *et al* (2019) highlight that despite loneliness and isolation often increasing with age, older carers feel their own needs are ignored by professionals, and sustaining relationships with them continues to be increasingly challenging with reduced health and social care resources. It is not surprising then that Cairns *et al* (2013) concluded that older carers found the role had a negative impact on both their emotional and their physical wellbeing, and that poor mental health increases their vulnerability further still, reducing quality of life. Although the latter study is unusually large for this field, with 100 participants, smaller localised studies draw out very similar themes and each of these studies highlights carers’ awareness of their own frailty, concluding they would benefit from person centred and carer specific support.

Howson and McKay (2020) reported that there is often an assumption among families who support an adult child with a dual diagnosis, that a sibling will take over when the parent who is caring dies or is not able to continue. This lack of preparation or contingency planning, and having to make decisions about somebody’s care needs quickly, is not a situation unique to parent carers of people with learning disabilities who develop dementia, but if it is accepted that socio-structures are the root cause of challenges to older carers, then it is important to address the issue of future planning and what role support services should play in this. The literature shows overwhelmingly that carers of people with dementia, particularly older carers, and those who care for people with learning disabilities, worry about future planning in some capacity

## **Key points**

- families who are ageing together and are caring for adults with learning disabilities and dementia need access to health professionals who are knowledgeable in both diagnoses
- training packages should be made available to family carers as well as paid care staff
- family carers of people with Down's syndrome need information early about risks of their loved one developing dementia
- if family carers of people with LD and dementia are informed, it can help with feel less isolated and reduce risks of carer burnout
- professionals working in LD and dementia require better training about family carers' needs and how to support them.

(Greenwood, Pound & Brearley 2019; Mahon *et al* 2019). Forrester-Jones (2021) concludes that more exploration around the views of the care recipient is needed to best support future planning needs with their carers, but in the meantime, we can look at the existing health and social care frameworks and also consider whether parent carers’ perspectives of their identity plays a role in when they feel able or ready to ‘let go’ of having a major responsibility for looking after their child.

Whilst there are positive aspects to the caring role, such as purposefulness, family connectivity and sense of belonging (Howson & McKay 2022), which must be celebrated, this positivity does not occur in the absence of distress. Beighton & Wills (2019) note that where the care recipient displays behavioural challenges or has more severe medical issues, a positive outlook is harder to sustain for parent carers with increased demands placed on their caring role.

There is also compelling evidence showing older carers, particularly parents of lifelong disabled people, experience multiple losses over their child’s lifetime and that experiences of loss only accumulate over time. Howson & McKay (2020) mention sleep, career, identity, and friendships among other losses.

### **The need for training in dual diagnosis: learning disabilities & dementia**

The Care Act (2014) promotes a strength-based assessment process that takes account of co-support between parent and child (Department of Health and Social Care 2016). The National Institute for Health and Care Excellence’s ‘Care and Support of People Growing Older with Learning Disabilities’ (2018) guideline recommends skills training is needed for both parties but integral to longevity is specific support from a professional with clinical knowledge of both learning disabilities *and* dementia. This specialist support for parent carers is appropriate given the *complexities* of the care recipient’s needs.

Reliable access to expertise, early information about dementia, and help with future planning are some of the professional led outcomes related to this carer group. ▷

What is Dementia?	Communication and Behaviour	Health	Living Well with Dementia	End of Life Care Planning
<p>A simple definition to aid understanding</p> <p>Explanation of why people with Down Syndrome are at greater risk</p> <p>Opportunity for carer to raise any particular issues or concerns that can be addressed on the programme</p> <p>Basic outline of early, middle and late stages</p> <p>Explore with the carer at which stage their loved one may be, to enable a better understanding of the disease trajectory</p>	<p>'Life Story' work/ This is Me booklet</p> <p>Look at meaningful activities for each stage of dementia, identify some activities at each stage for their loved one, match to their likes/ dislikes</p> <p>Reasons for presenting with behaviours of concern or distress behaviours, and how to respond</p> <p>Where to seek further support if behaviour presents risk</p>	<p>Provide basic information on medication/ advise on relevant care pathway</p> <p>Ensure these discussions are within the frames of the Mental Capacity Act and involve the person with dementia</p> <p>Explain other common health issues that people with Down Syndrome may experience with ageing e.g. hearing loss, cataracts</p> <p>Explore relevant symptoms that may require further intervention e.g. new or worsening epilepsy</p>	<p>Eating, drinking and nutritional information and skills, to minimise risk of choking, malnutrition and dehydration</p> <p>Importance of keeping active, link to meaningful activities and exercise</p> <p>Signposting to assistive technology, aids and adaptations to promote and maintain independence</p>	<p>Discussion around dementia as a terminal illness</p> <p>Explanation of advanced care planning</p> <p>Information about Respect forms and how to complete</p> <p>Where to access emotional support for carer but also resources in accessible formats for person with learning disability and dementia</p>

**Table 1: Content of Training Package**

▷ However, the literature available offers recourse to additional interventions. All parent carers of adults with learning disabilities in Howson & McKay's (2020) paper report positive accounts of sharing their experiences with other carers of learning-disabled adults. While there are several national support networks for carers of people with dementia, and for carers of adults with learning disabilities several different charitable organisations relating to specific diagnoses, in practice local support networks for parent carers of people with both diagnoses are very much in their infancy and in most areas non-existent. This is concerning given the issues of isolation, negative impacts on carers' mental health and difficulty in accessing formal support.

Mahon *et al* (2019) discuss the need for professionals to have better access to training specifically about carers' needs, along with a greater understanding of mutual caring relationships, to best support these families. The evidence base does not offer sufficient indication of what might best support the positive outcomes for parent carers of adults with learning disabilities and dementia, other than continual review and consistency in personnel. McAuliffe, O'Connor and Meagher (2014) explored the experiences of parent carers of adults with schizophrenia and concluded that a family-centred approach is required to deal with the uniqueness of individual parents' circumstances, and assessment and care planning should take into account the family as a unit. This is a useful perspective, particularly if

the parent carer also develops dementia, as a whole family approach could be beneficial, drawing on other close sources of support who know both individuals well. Finally, Jacobs *et al* (2023) examined couples with learning disabilities where one partner develops dementia, and offer a relational perspective providing professionals with the information to support the wellbeing of both partners. This offers an alternative way of meeting parent carer needs of adults with learning disabilities who develop dementia, keeping both parties' wellbeing as the main focus, with attention given to the *parenting* aspect of this relationship whilst adapting to another feature of their carer identity.

While training packages are available to support carers of people with dementia, evidence suggests that those caring for people with a dual diagnosis of dementia and a learning disability require specific information to understand the changes they are more likely to see and generally have little support or guidance. Bressan, Visintini and Palese (2020) emphasise the need for families to be trained and educated to support the changes encountered with dementia. Dennehy *et al* (2022) found that carers of people with learning disabilities and dementia may not have access to specific education or training in the provision of appropriate care for individuals with both diagnoses. Without awareness of the issues that could affect their loved ones, carers cannot effectively manage the changes and advocate appropriately when they require professional help. It is important that families caring for people with

learning disabilities and dementia are as prepared and confident as they can be, so that they themselves can be prepared and in turn help their loved one to understand what is happening to them and feel safe.

### The training package

The training package was developed as part of the Postgraduate Certificate in Person-centred Dementia Studies (Atkinson, 2023) and could be transferable across a range of family contexts to support carers in the complex dual diagnosis situation. It has already been trialled and successfully delivered in several formal care settings where family members have been invited to also attend, with excellent feedback. It aims to prepare and equip family carers of people with learning disabilities and dementia to understand and manage the changes their loved ones will experience. It provides informative and experiential training, delivered in a chosen setting, by a trusted and trained health care professional, aiming to achieve sustained and improved caring roles and relationships; empower carers and promote partnership working to support effective care planning; increase understanding of dementia; reduce risk of carer burnout; and reduce health inequalities for people with learning disabilities. The training aims to maintain and improve the quality of life and promote the wellbeing of both the family carer, and the person with dementia and learning disabilities. The content of the training package can be tailored to the needs of the individuals it serves to inform, with suggested content to be covered for each session (see Table 1 on previous page, p.....). This allows for a two-way learning process with the health care professional learning more about the carers needs to ensure each family setting is supported in the most effective way. The specific content is described in the table.

### Conclusion

We are well informed from the literature that carers learn best in an environment where they support each other. Having a training package available which can support those in potentially stressful situations caring for people with a dual diagnosis of a learning disability and dementia is crucial to avoid the burn-out that carers experience. Caring for the carers is vital to support the wellbeing of people living with dementia and a learning disability. This training package could provide that vital support, to ensure our carers are informed, prepared and supported.

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