‘I just want to be able to dance’

Promoting the wellbeing of people living with dementia through community development, social innovation, and personalised support

July 2025

making it real

Think Local Act Personal

DEMENTIA CHANGE ACTION NETWORK

Contents

1. Introduction

> ‘There is a person inside everyone with dementia, a person who remains an individual, capable of living fully and well for a long time, with a personality to which they can be kept connected if we go about it the right way, an innate dignity which can be cherished, and a life that can be affirmed and enhanced in all sorts of ways.’
>
> **Sally Magnusson**

1.1 About this report

This report explores what people living with dementia say helps them to maintain their wellbeing and how place-based community development and social innovation can grow and sustain the conditions, resources, and support that will allow more people to do so in future.

The report was written by Neil Crowther and Liz Leach on behalf of Think Local Act Personal and in partnership with Dementia Change Action Network.

For all of us, our health and wellbeing are shaped by how we are able to live our lives. As well as the foundations of shelter, warmth, and nutritious food, this includes being able to live in a place we call home, the quality of our relationships, how much we feel in control of our lives, being able to be and do the things that matter to us, maintaining a sense of purpose, feelings of worth, and experiencing love and joy in our lives. This does not change when we are living with dementia, but the world around us can too often conspire with the underlying conditions to undermine our ability to sustain all of these building blocks of our wellbeing. The consequences are felt in the diminished quality of life and pressures faced by people living with dementia and their families, in the premature, unwanted and avoidable use of acute public services, including hospital and residential care, and in our economy, particularly as people leave paid employment to offer unpaid care and support.

Yet as Geoff Mulgan recently argued: ‘Billions have been spent trying to find pharmaceutical cures for dementia with, still, very disappointing results. Far less has been spent on other solutions – from training up shopkeepers on how to spot and help people with dementia and mutual support clubs to dementia villages and imaginative uses of virtual reality…But I’m not sure it’s even recognised as a problem (and the dominance of biomedical means that even quite well-informed people are unaware that the sector has faced fifty years of declining productivity, with ever fewer useful drugs for each billion of spending..).’[1] Similarly, a recent report published by the Nuffield Trust notes how: ‘Public, political and media debate about dementia tends to focus on disease-modifying treatments and the search for a cure. While it is crucial that those

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[1] Mulgan, Geoff (2024) Why it’s smart policy and smart politics for the Labour government to engage with social innovation and experiment

developments are supported, too little attention has been paid in recent years by policymakers and government to how people with dementia, and their – unpaid – carers, should be supported to live well for as long as possible.'[2]

This report does not negate the value of continued medical research into viable ways to prevent or lessen the effects of dementia. However, its focus is on opportunities in community development, social innovation, and personalised support that hold the promise of improving the day-to-day experience and wellbeing of people living with dementia. Within the current horizon, such social change will continue to be necessary and urgent even as advances in medicine offer new drugs and treatments, all of which offer to slow or ameliorate, but not 'cure' dementia.

The report's findings and proposals are grounded in conversations with people who have dementia and family carers, leaders of voluntary and community groups, academics, and public sector professionals working with people with dementia about what matters most for maintaining wellbeing, what helps now and what people would value more of.

It finds that there are already many proven ways to grow the conditions, opportunities, connections, and support that permit people to live the best life possible when living with dementia, and many as yet unexplored new things to try. These also help to make supporting people we care about emotionally and practically easier when they are experiencing dementia.

However, it also finds that too often today these remain on the margins, or are only available in a handful of areas, while at a national level there has been a loss of focus and momentum from central government, NHS England, local government bodies, and national charities in support of their promotion and adoption. The last Dementia *Strategy Living Well with Dementia: A National Dementia Strategy* was launched in 2009 and covered the period 2009 – 2014.

With a shared mission to improve the lives and wellbeing of people living with dementia through place-based community development and personalised support, many more people could benefit from such social innovation in future. Moreover, these would assist in achieving key shifts underpinning the government's 10-year vision for health and care: from treatment to prevention, from hospital to community and towards a vision of 'neighbourhood care'.

It is hoped that this contribution can help to re-energise this discussion while offering practical, actionable ideas, drawing on the insights and ideas of people living with dementia and their families and those working alongside people to advance their opportunity to live as good a life as possible.

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[2] Oung, C et al (November 2024) What needs to improve for social care to better support people with dementia? Nuffield Trust

1.2 Summary of the report

The first part of the report summarises what people living with dementia who contributed to a series of conversations said mattered to their wellbeing, under the following headings:

- **Having a life beyond dementia**
- **Feeling recognised and having opportunities to be helpful**
- **Staying connected and not feeling alone**
- **Freedom from negative attitudes and life-limiting stigma**
- **Knowing where to find support and help with navigation**
- **Support and breaks for family carers**

The second part of the report recommends action, and includes promising practices and resources across the following areas:

- **Proactively confronting stigma and harmful stereotypes**
- **Co-producing broad, place-based strategies and plans engaging with and drawing on assets of the whole community**
- **Investing in early and ongoing support and navigation, from diagnosis until death (and beyond)**
- **Scaffolding mutual support**
- **Widening circles of support to stay connected and active and provide family carers with time out**
- **Increasing the supply of accessible housing and home adaptations**
- **Developing inclusive and accessible public spaces, transport, goods and services**
- **Harnessing technology**
- **Promoting innovation in community-based care and support, including support for family carers**

1.3 How this report was developed

This report is based upon a listening exercise involving people living with dementia and family carers that took place in London, the southeast of England, Yorkshire, and Lancashire between September and December 2024.

In total 67 people took part in the conversations which explored the following talking points:

- **When it comes to maintaining your wellbeing, please could you share what, for you, are the most important things and why?**
- **Since developing dementia, have you changed anything in your life to help maintain your wellbeing?**
- **Are there other things that you believe could help you to improve your wellbeing if they were available?**

These talking points framed focused conversation either one-to-one, in couples, or in groups. The majority of the groups exclusively involved people with dementia, but a number also included family carers. We spoke to one group exclusively made up of family carers (see below). The style of research adopted was based on Community Conversations, which are structured dialogues that bring together groups of people to discuss important topics that impact their community. These conversations aim to gather insights, share experiences, and identify common goals or solutions therefore moving away from a traditional question-and-answer interview approach. The summary of these conversations, contained in section 5 of this report, was shared with the groups for comment, as well as the full draft report.

Throughout the project, conversations were also held with paid professionals connected to the groups, including from the NHS, academic institutions, and local voluntary and community groups.

At the inception of the project a group of people active in dementia campaigning, social innovation, and care and support were invited to form an oversight group. They have actively provided their guidance and support throughout the project. The group included:

Ian McCreath, Director, Think Local Act Personal

Keith Day, Four Nations Dementia Working Group

Caroline Waugh, National Co-production Advisory Group

Dame Philippa Russell, Vice Chair, Carers UK

Rachael Litherland, Innovations in Dementia

Chloe Hawkins, Care Quality Commission

Jo Wallace, Care Quality Commission

Amanda Partington Todd, Care Quality Commission

Vanessa Pritchard-Wilkes, Housing 21

Claire Fry, NHS England

Paul Edwards, Dementia UK

Rachel Hoyles, Skills for Care

Ben Williams, Care City

This has been a small-scale qualitative listening exercise, conducted only in some parts of England and focused on people with dementia living in the community. The people who took part were already connected with and taking part in dementia groups and were often able to come through the support of a partner or family carer. There are clearly many people who do not or cannot take part in such groups. The report should be read with this in mind.

We extend our thanks to all who have contributed insight, ideas, and intelligence to this study and to those who have commented on drafts of this report. In particular we extend our thanks to the welcome and contributions we received from members of the following groups who took part in the conversations:

Forget Me Nots, Canterbury* (people with dementia)

SUNshiners, Dover, Deal & Medway* (people with dementia)

Visible Voices, Hythe (people with dementia)

Pathfinders, Swale* (people with dementia)

Stevenage Dementia Involvement Group (family carers and people with dementia)

Young Onset Dementia Activists, part of South East London Mind, Bromley (people with dementia and family carers)

Memory Lane Support Centre, Barking and Dagenham (family carers)

Memory lane Café, Sowerby Bridge (people with dementia and family carers)

Memory Lane Café, Halifax (people with dementia and family carers)

The Beacon Project, Rossendale (people with dementia and family carers)

East Riders in Beverley* (people with dementia)

'Saints' in Market Weighton* (people with dementia)

*these groups are all part of the DEEP Network

We also extend our thanks to the following people for their help and support in organising these meetings:

Ben Williams, Care City; **Saira Addison**, South East London Mind; **Emily Dent** & **Andrew Reddicliffe**, Kent and Medway NHS and Social Care Partnership Trust; **Maxine Clubb**, Memory Lane Resource Centre; **Nicole Jones**, **Lindsey Parker** and **Michelle Bowen**, Stevenage Dementia Involvement Group; **Damian Murphy**, Innovations in Dementia; **Lisa Berret**, the Beacon Project; **June and Chris Harvey**, Memory Lane Café Halifax and Sowerby Bridge.

2. Background

2.1 The opportunity and the challenge

> ‘If you put support in early that works for that person, that ‘late stage’ is more than likely going to be offset for longer’
>
> **Person living with dementia**

The term ‘dementia’ describes a progressive degenerative condition which encompasses a collection of symptoms, including a decline in memory, cognition, and communication as well as changes in personality and behaviour. The most common cause of dementia is Alzheimer’s disease, but there are many other causes of dementia, all of which manifest in different ways.

It is estimated that around 676,000 people in England have dementia with or without a diagnosis.[3] In July 2024, there were around 490,000 people known to be living with a dementia diagnosis in England.[4] The majority of people first experience dementia in later life, often alongside other impairments or health conditions. However, the Alzheimer’s Society also estimates that 70,000 younger people are living with early-onset dementia, with or without a diagnosis, across the UK, of whom just over 15,000 in England have a formal diagnosis.[5] It is further estimated that in England around 540,000 friends and family offer unpaid care or support for someone with dementia, a number that is anticipated to rise considerably over the coming decades.[6] Many are the sole ongoing source of support for people living with dementia, with significant implications for their own health and wellbeing. Meanwhile, the Alzheimer’s Society reports that around 120,000 people with dementia in the UK live alone.[7]

The vision of the *World Health Organisation global action plan on the public health response to dementia* 2017-25 is ‘a world in which dementia is prevented and people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality.’[8] Over the past two decades this mission has been echoed in strategies and policy documents by the UK government, National Health Service, and local agencies.

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[3] Source: NHS England (accessed December 2 2024)

[4] NHS Digital (2024) Primary care dementia data, July 2024

[5] Alzheimer’s Society (no date) Young-onset dementia

[6] Source: NHS England (accessed December 2 2024)

[7] Alzheimer’s Society (2019)

[8] World Health Organisation (2017) Global action plan on the public health response to dementia 2017–2025

Both intrinsic and extrinsic factors shape how people individually experience dementia, its impact on their health and wellbeing, and its progress over time. In common with other people who experience a health condition or impairment, the disability people experience when living with dementia is a result of 'the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others'[9] (sometimes called 'the social model of disability'). As a result, how people experience dementia and the extent of its impact on their wellbeing is amenable to the influence of a wide range of external factors that can be attended to through public policy, social and institutional change, and through personalised support. This fact has given rise to a focus on social and system change to cultivate the conditions and supports that enabled more people to 'live well' with dementia.

The IDEAL study, the largest longitudinal study of 'living well' with dementia in Britain, explained that:

> 'The concept of living well is now frequently mentioned in policy documents and reports relating to dementia, and is used to convey the message that it is, or should be, possible to experience a subjective sense of 'comfort, function and contentment with life' while living with the condition. This reflects a move from a focus on symptoms and 'deficits' to a broader focus acknowledging personhood and the rights of people with dementia, enabling optimal functioning, and supporting participation and inclusion.'[10]

Despite this focus and the opportunity to improve the wellbeing of people living with dementia through means other than medicine, the World Health Organisation advises that: 'Long-term care pathways (from diagnosis until the end of life) for people with dementia are frequently fragmented if not entirely lacking. Lack of awareness and understanding of dementia is often to blame, resulting in stigmatization and barriers to diagnosis and care. People with dementia are frequently denied their human rights in both the community and care homes. In addition, people with dementia are not always involved in decision-making processes and their wishes and preferences for care are often not respected.'[11]

In England, it is estimated that around two thirds of people with dementia live in their own home in the community.[12] However, evidence suggests that the support, opportunities, and conditions for true social inclusion and a life well lived are not widely available. For example, a survey of 2,000 people living with dementia by the Alzheimer's Society on post-diagnosis support found around 60 per cent of people weren't receiving sufficient emotional and mental health support and 44 per cent said their support package did not allow them to remain independent.

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[9] United Nations Convention on the Rights of Persons with Disabilities (2006)

[10] Clare, L et al (2018) A Comprehensive Model of Factors Associated With Subjective Perceptions of 'Living Well' With Dementia Findings From the IDEAL Study

[11] World Health Organisation (2017) Global Action Plan on the Public Health Response to Dementia 2017-25 p3

[12] Source: Department for Health (2013) Dementia Care and Support

One in five (21 per cent) people did not receive peer support and and almost one in three (31 per cent) lacked the provision that helps maintain their social life, while 48 per cent weren't receiving support that treats them as an individual.[13] A London-focused study led by Care City found that: 'Londoners feel abandoned after they get a diagnosis for dementia, something that is for many extremely traumatic; Londoners living with dementia and their carers are facing a fragmented and hard to navigate healthcare system. What is available in one borough is not available in the next; and Carers don't know who to turn to for advice and are burnt out.'[14]

In its November 2024 report on improving adult social care to better support people with dementia, the Nuffield Trust notes how: 'Despite a policy focus on shifting care closer to home, as well as increasing numbers of people preferring care at home over residential care, there has been only patchy development of new or innovative services to meet changing needs, preferences and individual circumstances.'[15] Indeed, many people with dementia and family carers who contributed to the conversations summarised in this report did not make reference to support from health and social care when asked about their wellbeing, and when they did there was a low level of expectation regarding the support that could be provided.

National influencing opportunities are presented via the development of the NHS 10-year plan, plans for 'neighbourhood health' and the upcoming Casey Commission on adult social care, while at regional and local level, some combined authorities, Integrated Care Systems and local councils are developing or implementing place-based strategies and plans to improve the health and wellbeing of people living with dementia. The advocacy, activism, and involvement of local people living with dementia appears to be a decisive factor in the extent and success of such local strategies and plans.

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[13] Alzheimer's Society (2021) Left to Cope Alone – the unmet support needs after a dementia diagnosis

[14] Care City/London Dementia Clinical Network (2023) Living with Dementia in London 2023

[15] Nuffield Trust (November 2024) What needs to improve for social care to better support people with dementia?

2.2 Wellbeing and living with dementia: headline evidence from recent studies

A small number of recent studies have explored the questions of what matters and what helps in relation to maintaining wellbeing while living with dementia.

A paper for the IDEAL study, on developing supportive local communities reported that the key factors that influence the capabilities of people with dementia to 'live well' include:

- Overcoming feelings of isolation
- Levels of social engagement and connectedness with others and the environment
- Independence in daily activities and the ability to manage everyday life

To address these, four areas for action were identified:

- Improving awareness and understanding of dementia within the community
- Being able to secure support when you need it to live independently
- Support to engage with the community, including informal support from neighbours as well as accessible transport, built environment and signage
- Access to general social events and activities happening in their communities and support to find connection with others[16]

The living well with dementia toolkit that emerged from this IDEAL study identifies five keys to living well with dementia:

- Stay positive
- Stay safe and well
- Stay active
- Stay connected
- Keep a sense of purpose[17]

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[16] Quinn, C (2021) Developing supportive local communities: Perspectives from people with dementia and caregivers participating in the IDEAL programme

[17] IDEAL (2021) Living with Dementia Toolkit

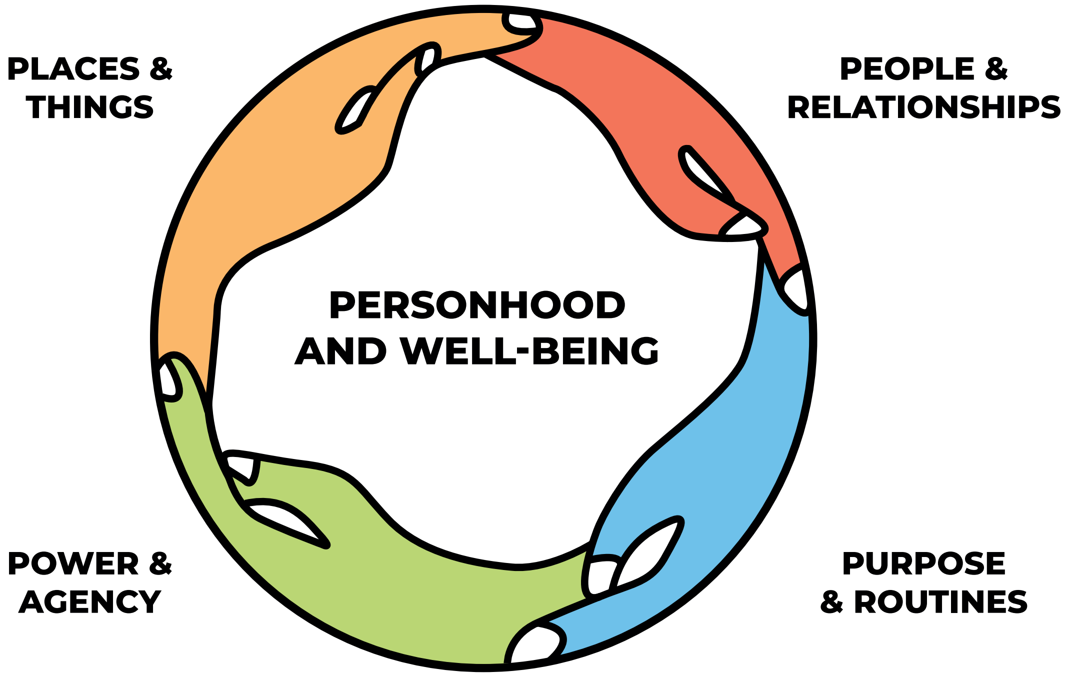
A 2017 report based on a collaboration between Age UK and Innovations in Dementia involved discussions about wellbeing with people living with dementia and their 'carers'. It identified three broad dimensions:

Personal wellbeing: in common with findings from the IDEAL study, the person's own feelings about themselves were regarded as fundamental to wellbeing. For example, having a good sense of oneself, being able to cope as an individual, and having a sense of acceptance and understanding of one's condition.

Positive relationships: including both maintaining the quality of existing relationships with spouses or children and establishing new connections and relationships to avert loneliness and isolation.

Active daily lives: including being able to carry on with 'day-to-day activities', including gardening, home maintenance and dealing with finances, as well as holidays and day trips, and leisure activities such as walking, keeping fit and learning new skills. Feeling part of groups, such as joining a choir or being involved in activism, were also identified.[18]

In a previous report for DCAN, Neil Crowther (2022) explored how developments in the literature and thinking around the wellbeing of people living with dementia and so-called 'dementia care' contrasted with developments in relation to person-centred care and disability rights more widely. Based on the analysis, the report proposed a framework for thinking about wellbeing and personalised care as it relates to people with dementia which focused on paying attention to growing, sustaining or repairing factors of a person's life that 'hold' and nourish personhood and wellbeing: important places and things, people and relationships, having purpose and routines, and maintaining a sense of power and agency.[19]



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[18] Jopling, K (2017) Promising Approaches to Living Well with Dementia

[19] Crowther, N (2022) Place, People, Purpose and Power - promoting the wellbeing of people living with dementia through personalised care and support (DCAN)

Proactive, preventive approaches that centre on supporting people with dementia to live in the place they call home, doing things that matter to them, hold the potential to save public money. For example, an evaluation of the NDIUS-family (New interventions for Independence in Dementia) pilot, which supported family carers to support people with dementia to set and pursue personalised goals concerning living independently at home indicated savings of almost £9,000 per person each year in NHS and social care costs.[20]

The next section builds on these findings, based on conversations with people living with dementia and family carers.

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20 Isaaq, A et al (2025) Cost-utility of a new psychosocial goal-setting and manualised support intervention for independence in dementia (NIDUS-Family) versus goal setting and routine care: an economic evaluation embedded within a randomised controlled trial. The Lancet

3. What matters and helps people to maintain wellbeing when living with dementia?

In this section we draw out key themes that have emerged from our conversations with people living with dementia and family carers, illustrated by quotations from contributors.

‘Dementia is not the end of my life’

Person living with dementia

3.1 Having a life beyond dementia

Contributors to the conversations expressed a strong desire to maintain their identity, to remain active, and to continue being and doing things that hold personal meaning for them. These include existing or new hobbies, work, and community involvement, as well as sharing their skills and talents. People wanted opportunities to live lives that are not solely defined by their dementia.

People talked about the importance of being able to look forward to seeing people and having fun, and to look ahead and plan things. One contributor commented that: ‘dementia is not the end of my life.’ Continuing, where possible, to enjoy the hobbies and activities that were important prior to dementia was important. One woman said she didn’t want to have a life defined by medical appointments, assessments and the mundanity of existence but to be able to continue on with what she enjoyed, saying: ‘I just want to be able to dance.’ However, she felt she would struggle to find and get somewhere to do so.

‘The opportunity to live a life and be involved in things that are not about dementia’

Person living with dementia

Equally important to people was the possibility of growth and personal development after a diagnosis of dementia. One contributor told us how: ‘So often a diagnosis of dementia is a real blow to confidence and might stop you in your tracks, I discovered that the tremor I was experiencing which has stopped me from painting was not in fact down to the dementia but because of another condition that has now been treated.’ As a result, the person rediscovered painting and started to do a lot more, with the renewed confidence that came from this spilling into other areas. Another explained how during the Covid-19 lockdowns, ‘a lot of people with dementia had to become self-reliant, as support was removed. But for some, it opened a new chapter with people connecting online and doing things they never imagined doing like writing a book.’

Generally, remaining active and having a daily sense of purpose was considered crucial to wellbeing. One person spoke about the need to ‘find things that keep me going including looking after a pet.’ Another talked about the choir they sang in, ‘because I have to think and keep my mind active.’

People said a reason they took part in the peer support groups was because it created structure and offered a reason to get up in the morning and leave the house. The various peer support groups that contributed to these conversations were also organising or taking part in a wide range of activities, including cricket, football, gardening, and museum visits. However, the views of some contributors were echoed in the comments of one person who said they wanted 'the opportunity to live a life and be involved in things that are not about dementia.'

'Life goes on and we've got a right to live that life'

Person living with dementia

Despite the above, it appeared that few people had heard of a local 'social prescribing' service and those that were aware shared that 'social prescribing' seemed relatively unexplored when it comes to supporting people to live with dementia, apart from 'music for the mind.'

A few contributors spoke about the importance of their faith, or that of the person they supported. A family carer told of how faith stayed with one person with dementia after all other interests appeared to have subsided. Places of faith also served as an important point of connection between people with dementia, their partners, and communities that could offer support and sanctuary.

While the importance of remaining active and pursuing new interests was emphasised, some contributors expressed wariness that the language of 'living well with dementia' could serve as a double-edged sword. Some people commented that it can become an expectation whereby when you're not feeling yourself to be living well you can feel like you're failing, or worry that is how others perceive you. It was suggested that the focus needs to be on support to live each day as well as possible, but without pressure.

3.2 Feeling recognised and having opportunities to be helpful

Building on the previous section, contributors agreed that central to their wellbeing was feeling that they are doing something useful, and that their contributions are recognised and valued within their family and wider community. People explained how they wanted to continue to celebrate life's achievements, past and present.

'It helps to feel helpful – doing something useful when I can'

Person living with dementia

One contributor explained how it was important to her to be close to and feel involved in her family's life. She had moved into a specially built annex to her daughter's home, maintaining her independence with support from her family. She joined the family for meals made by them, as this was something she struggled with. However, to reciprocate she does all the family's ironing, which she enjoys.

The desire for reciprocity extends beyond family. One man who attended a peer support group had just come back from setting up a tree display in the local Minster. He had worked with a team of people to achieve this and the project would raise funds for a local charity.

People expressed a desire for opportunities to share their gifts and talents with others. One contributor at a group conversation spoke of her experience of feeling infantilised when joining an arts group for people with dementia that had offered only 'painting by numbers.' The woman, who was herself an artist, said she felt overlooked and undermined. The group then discussed how the event organisers might have explored the gifts and talents of those attending and invited people who could lead some sessions.

'We should not be made to feel useless'

Person living with dementia

One of the peer support groups had become involved in accessibility audits of major tourist attractions, including the Tower of London, recognised by these organisations as expert advisers.[21] One contributor talked of how busy he now found himself going out to speak to different organisations to change attitudes to people with dementia.

For those of working age, being able to stay in work has been important. One contributor explained how her colleagues had set up a circle of support to enable him to carry on working. This circle of support would only step in to actively support him as he needed.

Finally, some contributors said that they desired more opportunities to have time with others without their family carer present. They explained that this provided opportunities for their qualities and strengths to be recognised that might otherwise be submerged in the dynamic of 'carer' and 'cared for.' We also heard how the opportunity to have time apart could help to reduce the pressure of the caring relationship for both the person living with dementia and their family carer.

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[21] See: ENLIVEN – Living Well With Dementia Conference

3.3 Staying connected and not feeling alone

Contributors to the conversations were unanimous in the importance they attached to staying connected. This included staying living in the place people called home, maintaining existing friendships, developing new social networks, and actively striving to avoid feelings of loneliness. Social groups, courses, and activities offer opportunities for companionship and a sense of belonging. Peer support is highly valued, where individuals can share experiences and offer mutual encouragement.

'Keep talking to people'
Person living with dementia

One woman, living with dementia, said simply that it was important to her wellbeing to 'keep talking to people.' Another explained how: 'With dementia you lose friends because you can't get out and about or use the telephone.'

People spoke of their desire to stay close to family as well as having the opportunity to spend time with people of different age groups. To those ends, one group who took part in the conversations organised for the children from the local school to come and play games with its members and to help run the session, serving drinks and food.

The ability to stay connected relates to the opportunity to remain living in a familiar place. The wife of a man with dementia explained how: 'We were going to move home, but my husband changed his mind and said, 'I don't want to move because I know where everything is and everybody here knows me."

'I know everybody. I know where I am, if I want to go anywhere'
Person living with dementia

A number of things were highlighted during the conversation as important to being able to stay living in the place people call home and to remain connected. These included: living somewhere with good access to local services and facilities; access to easy adaptions to be able to continue living at home such as handrails and kitchen equipment; reliable, accessible and affordable transport, and in particular the avoidance of continual changes to timetables; more and safer pedestrian crossings; and having places to go walking that are free from trip hazards.

Part of the value people attached to peer support groups was as a 'safe space' in which acceptance was guaranteed. As well as companionship and solidarity, people said they could feel more at ease in such environments. One contributor told how 'because we've got dementia we can take the piss out of ourselves – people outside (from a person attending a group in the deep network) would find that inappropriate.' Such groups also were a source of local intelligence, tips, and solutions. They also left people feeling 'part of a team.' One contributor explained how such groups had left her and her husband who has dementia 'feeling wrapped by' circles of support including offers of lifts from other members of groups to be able to attend and get home. In some instances, people had first met at a community group focused on supporting people with dementia, which over time stopped suiting them, for example because it had become too big for the space in which it was held or too noisy. However, people had then self-organised smaller groups to meet to do things together that they enjoyed.

A number of contributors talked about their faith community as a source of emotional and practical support. For example, one woman told how a person from church was helping her by doing work around the home while keeping her husband, who has dementia, company. A wife supporting her husband with dementia felt that the church had offered a 'safe space' saying: 'I know I can relax and he is safe and people are looking out for him.'

People had maintained or found valued connections online. For example, the wife of one man with dementia, who was largely 'non-verbal' having previously been a college lecturer, explained how he remained a keen photographer and that he shared his photographs via an online community as a way to stay connected.

Some contributors commented on how community-based social care failed to address loneliness and disconnection. One contributor said that 'some people only see homecare workers, and homecare workers don't have time to talk and form relationships – loneliness is a big issue.'

> 'Because we've got dementia we can take the piss out of ourselves – people outside (the dementia voices group) would find that inappropriate'
> **Person living with dementia**

3.4 Freedom from negative attitudes and life-limiting stigma

Contributors felt that their lives were constrained by the impact of stigma and negative attitudes. Some reported feeling frightened of ridicule and wanting to hide their diagnosis. Others agreed that there is a need to challenge the perception that dementia is 'all downhill' and acknowledge the potential for personal growth and development after diagnosis. It was deemed important to increase understanding of the different stages of dementia and highlight that many people can continue to live good lives after a diagnosis of dementia.

Contributors talked about how they experienced a change in how people with whom they had enjoyed long-standing relationships related to them, and about losing friendships and contacts after developing dementia.

> 'Everyone with a diagnosis of dementia should get an Oscar – you put on such a persona it's just exhausting'
> **Person living with dementia**

One contributor spoke movingly of how she felt compelled to mask her dementia when out in public. She explained: 'When I go around a shop and I need something, I have to ask the person who's taken me – I feel too ashamed to ask the shop workers. When I go out, I try to act as normal as possible and keep my mouth shut. I'm frightened of ridicule.'

Others spoke of how they felt people did not believe that they had a dementia diagnosis because they did not conform to stereotypes about people with dementia. For example, one contributor reported how, following a talk they had just given, an audience member said to them 'you look normal.' Another felt that they were 'punished' for being seen to live well, with people not believing they could actually have dementia.

There was a sense among the groups that there was a growing message that: 'You don't understand dementia unless it is at a late stage.' People felt that it was crucial to bring into view the different types and stages of dementia to confront this.

'I'm still me'
Person living with dementia

Contributors talked about a complex relationship between attitudes to dementia and ageism. Because dementia is associated with ageing and frailty, there is a perception that people with dementia are too old to partake in certain activities regardless of their actual age, hence younger people with dementia can sometimes feel unserved by groups targeting people with dementia.

Contributors commented that it can feel easier to come to events where others have dementia, and where dementia is known and already accepted than general community events and gatherings. However, one contributor who was already part of a brass band told how he had explained his dementia and its impact to members and had found them to be really supportive. The wife of another man with dementia explained how her husband lost friends as his dementia progressed, but that they had joined the Irish Society for exercise classes and socials and developed a new network of friends who had become a source of much needed practical and emotional support. These stories suggest potential to learn from other anti-stigma campaigns that have centred on encouraging openness and conversations about dementia.

3.5 Knowing where to find support and help with navigation

'You can't hide from it. But you can prepare for it'
Family carer

Both people with dementia and family carers who contributed to the conversations conveyed the stress, anxiety, and exhaustion caused by not knowing what support and opportunities were available and at having to navigate complex, disconnected, and sometimes unreliable systems. As well as hoping such systems could be better integrated and connected, people expressed the desire to have a consistent and ongoing point of contact who will be alongside you and help to navigate and coordinate support. People also emphasised the importance of looking ahead – and support to do so – in order to know what to anticipate and to prepare for the future.

A number of contributors spoke about having felt at sea after diagnosis, whether having dementia themselves or supporting someone with dementia. One person talked of his and his wife's poor experience of the memory clinic, summarising what was said to them as: 'You have dementia – now go away and live your life. You can get a blue badge and a council tax discount.'

People had found it challenging to understand what could be helpful or to find out what resources, support, and opportunities were available locally. This was sometimes even after engaging with key professionals. For example, one person had received an assessment within their home from an occupational therapist but the couple had not been made aware of the availability of a Disabled Facilities Grant to install a downstairs shower room.

'I wanted to be there (for my mum). I was an anchor for her when everything else was so confusing'
Family carer

People talked about the importance of needing strong support and advocacy in order to access services, benefits, and entitlements, including referral to the memory clinic by GPs. Concern was expressed about the situation of people who do not have strong partners or family to support them. One contributor said he felt there needed to be an 'independent, disinterested person – not NHS or social services – to act as an ongoing source of advice and support.'

Peer support groups partially addressed this challenge in some places. Some groups had formalised such support, piloting a 'buddying scheme' whereby someone newly diagnosed with dementia is matched with someone living with dementia, and offering practical and emotional support.

People also placed value on the knowledge and navigation that some professionals were able to offer, including Admiral nurses – where they exist – and also 'dementia coordinators' (also called 'dementia navigators,' 'dementia advisers,' and 'link workers' in other areas where similar roles exist). These roles work alongside people and families from diagnosis to death, offering emotional and practical support. However, there is very much a 'postcode lottery' concerning access to such support, with limited coverage across much of the country.

3.6 Support and breaks for family carers

Given the connected lives of people with dementia and their partners and family carers, many of the issues outlined above concern the wellbeing of both parties. However, it was also clear from the conversations that family carers experience specific challenges to their health and wellbeing, particularly as the impact of dementia becomes more significant on the person they support.

'Work was my respite'
Family carer

Family carers placed particular emphasis on their desire to have 'time out' not just periodically, but during each day, without which the emotional and physical pressure can become a serious threat to their health and wellbeing. However, people reported either that there was no support to these ends, or that what was offered either didn't work for the person they supported, or didn't give them sufficient confidence. Some said that they were terrified of being ill and what this would mean for the person they supported.

As with people with dementia, peer support was considered invaluable among those family carers who belonged to or attended groups. The ability to meet people who were supporting people who were ‘further along’ with their dementia was considered particularly valuable. Some family carers valued contributing to and drawing on the support of such groups after the person they had supported had died.

3.7 In summary

In summary, people living with dementia emphasised the importance of maintaining their identity, social connections, and independence, while also having access to practical support to address day-to-day as well as more complex issues. To those ends, people with dementia felt it crucial that negative perceptions about dementia are challenged. Both they and family supporting them want to be able to gain support from people that are knowledgeable, understanding, and independent of statutory provision. For family carers, time out from caring on an ongoing basis was crucial, both to be able to support the person they care about sustainably, and in maintaining their own identity, connections. and independence.

> ‘It all builds up’
> **Family carer**

4. What are the implications and opportunities for policy-makers and practitioners?

It is clear from the conversations that there are countless opportunities to improve people's experiences of living with dementia, and in turn supporting the people with whom they share their lives, including those acting as a family carer. Broadly, this demands that:

The focus of policy and practice is on supporting people to sustain their wellbeing: supporting people with dementia to live in the place they call home, to establish or maintain valued relationships, and to be and do the things that matter to them, contributing to their families and communities.

People are reached further upstream: reaching and supporting people – whether with dementia or supporting someone with dementia – to maintain their health and wellbeing before they might require or be deemed eligible for adult social care, as forms of early action and prevention, delaying, or averting the need for more costly health or social care.

Action starts far beyond the NHS and adult social care: focusing on the broader building blocks of health and wellbeing and drawing on the strengths, assets, creativity, and talents of people, families, communities, local businesses, designers, technologists, and others to create the conditions for people to live as well as possible with dementia, and when supporting people with dementia.

Things are done with people, not to people: recognising people with dementia and their families as agents of change in their own lives and communities, scaffolding people's ability to pursue their own wellbeing in a manner that works for them and to engage in mutual support and co-production.

Below we set out a number of thematic areas for action, and include examples of promising practice, useful resources, and tools related to each. These have been brought to our attention by people living with dementia, voluntary and community groups, public sector professionals, and through desk research. Crucially, it is only through acting across and stitching together these initiatives, approaches and social conditions in local places that more people living with dementia will be better positioned to maintain the cornerstones of their health and wellbeing.

Collectively, these offer a vehicle for achieving key shifts set out by the government in relation to both the NHS 10-year plan and adult social care: from hospital to community and from treatment to prevention. They are equally an opportunity to harness the potential offered by Integrated Care Systems, new powers devolved to local regions and places, and the promise of neighbourhood care.

4.1 Proactively confronting stigma and harmful stereotypes

It was clear from the conversations that many of the people living with dementia who contributed felt themselves to encounter life-limiting stigma and harmful stereotypes, some of which they had struggled not to internalise.

Contributors to the conversation recognised the diversity of how people experience dementia at different stages and the complexity of offering a single account of living with dementia. However, it was felt that public communications about dementia from leading charities now focused only on the 'late stages' and portrayed the experience of living with dementia as one defined solely by the underlying condition. This left little scope to imagine people living with dementia as active agents in their own lives or as people with gifts and talents to contribute to their families and communities. Moreover, such narratives say nothing about the social conditions or supports that could offer the potential for people to live a good quality of life and maintain their health and wellbeing despite living with dementia.

In contrast, in 2024 the Scottish Government launched a major campaign to challenge stigma concerning living with dementia. The campaign 'Rethink Dementia' is focused on the attitudes and behaviours of the family and friends of people with a diagnosis of dementia. Launching the campaign, the Scottish Cabinet Secretary for Health and Social Care, Neil Gray, said:

'One of the key elements in the Rethink Dementia campaign is asking us to think differently about a dementia diagnosis. There are many practical steps we can take to help the people closest to us to lead fulfilling lives and stay well for longer.'

More information: https://www.gov.scot/news/new-rethink-dementia-campaign/

The influence of people living with dementia themselves has been key to the Scottish Government's decision to run this campaign.

Another initiative focused on shifting perceptions about living with dementia, led by people with dementia, is Dementia Diaries. Initially supported by Comic Relief and latterly by the National Lottery Community Fund (NLCF), Dementia Diaries is a UK-wide project that brings together people's diverse experiences of living with dementia as a series of audio diaries, with the aim of promoting dialogue and changing attitudes.

More information: https://dementiadiaries.org/

Recommendation:

The government and other funders in England should continue to support both communications campaigns and initiatives to amplify the voice of people living with dementia to shift narratives and confront the stigma about living with dementia.

4.2 Co-producing broad, place-based strategies and plans engaging with and drawing on assets of the whole community

Many of the things that people living with dementia and family carers identified as important to maintaining wellbeing did not concern the health or social care 'system' but involved the action or contribution of diverse actors across the places in which they lived. To these ends, a number of areas have, or are co-producing place-based (rather than service-focused) strategies and plans, centred on promoting the health, wellbeing, and inclusion of people living with dementia. These plans and strategies employ a strengths and asset-based approach, embracing and encouraging the mutually supporting contributions of local councils, the NHS, other public bodies, business, local communities, and people and families living with dementia.

For example, in Greater Manchester, the Live Well Dementia Plan is a community-oriented approach to support people with dementia to live well in their communities and homes. It was co-designed with Dementia United and many organisations, including the NHS, and individuals with lived experience. The plan centres on four areas of development:

- **Dementia Hubs:** These hubs act as a 'front door' to dementia support. They offer a welcoming, community-based space where individuals can connect with others, access information, and receive support from a multidisciplinary team.
- **Dementia Navigators:** These individuals provide personalised support to people with dementia and family carers. They help navigate the support system, connect with services, and develop care plans tailored to their needs and aspirations.
- **Dementia Networks:** These networks connect organisations that provide dementia support. They work together to share best practices, resources, and skills, and to identify and address gaps in support.
- **Dementia Friendly Communities:** These communities are equipped with the knowledge and resources to support people with dementia. Training and awareness building are provided to local organisations and individuals to create inclusive and supportive environments.

More information: https://gmpcca.wordpress.com/wp-content/uploads/2024/11/live-well-dementia-2024-for-upload.pdf

Sheffield Council and the Sheffield Place Integrated Care Board shared its city-wide plans in 2024, the vision of which is 'to make sure people with dementia are supported to live life to their full potential.' The plan says that: 'Our priority is for our organisations to work together to make sure people with dementia in Sheffield are supported to live life to their full potential. People with lived experience of dementia will be key partners in this work.' The plan includes 9 commitments:

- Sheffield will become a Dementia friendly city.
- More will be done to prevent, reduce, and delay the risk of developing dementia.
- Improved access to dementia diagnosis at the earliest possible stage for the people of Sheffield.
- Support will be personalised, local, and accessible, to help people with dementia to remain independent for as long as possible.
- High quality support to families and carers of people living with dementia in Sheffield will be provided.
- People living with dementia and their carers will receive care and support that recognises and works with them as individuals.
- Families and staff will be supported to plan ahead to reduce the likelihood of dementia-related crisis.
- Improved care for people with dementia attending hospital.
- Personalised, good quality palliative and end-of-life care when needed.

More information: https://democracy.sheffield.gov.uk/documents/s71523/Approval%20of%20Citywide%20Dementia%20Strategy%20Oct%2024.pdf

In 2015, the Local Government Association published guidelines on the development of what are known as 'dementia friendly communities', taking a whole place approach.

More information: https://www.local.gov.uk/sites/default/files/documents/dementia-friendly-communi-8f1.pdf

Recommendation:
Other areas should adopt place-based approaches to supporting people with dementia to live as well as possible, co-producing local plans with people living with dementia and drawing on all of the cross-sector contributions, creativity, and assets of the local community.

4.3 Investing in early and ongoing support and navigation, from diagnosis until death (and beyond)

Contributors, including both people with dementia and family carers, consistently called for a single point of ongoing support to navigate the frequently complex systems of health, social care, and wider services and entitlements.

To these ends, a number of areas of the country have instituted a much-valued dementia keyworker/coordinator role, this includes Sheffield and Barnsley, Oxfordshire, Kent Medway, Greater Manchester, West London, Dorset and Shropshire.

For example, in Oxfordshire, Age UK has been commissioned to run a network of dementia advisors, who offer personalised guidance, information, and emotional assistance. Their primary role is to help people navigate the complex journey of dementia by offering practical advice and connecting them with local resources and services.

The advisors act as a consistent point of contact, ensuring that people living with dementia and family carers receive ongoing support. They help create individualised action plans that consider the person's stage of dementia, preferences, and specific needs – working closely with local health services, social care providers, and community organisations to ensure comprehensive and coordinated support. They also organise and facilitate support groups, workshops, and educational programs to help build a network of care and reduce the sense of isolation often experienced by both people living with dementia and family carers. Additionally, they assist people and families in understanding the condition and how best to manage its impact, providing reassurance and empowering them to make informed decisions.

More information: https://www.dementiaoxfordshire.org.uk/dementia-support/dementia-advisers/

In West Sussex, Sage House acts as a 'dementia hub' bringing local dementia support services under one roof. It's Wayfinding Service connects people with dementia and family carers with professional one-to-one support and advice on an ongoing basis. The hub also offers activities, a café, respite and personal care, as well as supporting the wider community to become more dementia-inclusive.

More information: https://www.dementiasupport.org.uk/sage-house

Recommendation:

Other ICB areas should invest in equivalent advice, navigation, and coordination roles and 'hubs', supporting people with dementia and their families from first contact with memory clinics through to end-of-life and beyond.

4.4 Scaffolding mutual support

Among those contributing to this exercise, peer support was considered invaluable, offering emotional and practical support, connection, and purpose– whether among people living with dementia, family carers, or in some cases both at the same time. Such support, while best shaped and directed by contributors, requires 'scaffolding,' including spaces or platforms to meet, organisation and support for people to participate, where required, including during meetings, or in relation to transport.

For example, DEEP (Dementia Engagement and Empowerment Project) is a UK-wide network of involvement groups of people with dementia. The groups work together to raise awareness, influence policy, and challenge others' views about dementia. The groups are:

Independent: The network belongs to the groups themselves, not to any particular dementia service or organisation.

Diverse: Groups are strongly rooted in their local communities, including some in care homes.

Rights-based: Groups encourage each other to identify and speak out about issues that are important to them.

Some participants have said that DEEP groups are life-changing, and that they provide a sense of hope, friendship, and peer support. Dementia Voices also offers resources to help run DEEP groups, including reports, templates, logos, and checklists. Dementia Voices is hosted by the national community interest company, Innovations in Dementia.

More information: https://www.dementiavoices.org.uk/

Meeting Centres are community-based clubs designed to support both people with dementia (referred to as 'members') and their family carers. Originating in The Netherlands, they operate on the principle of inclusivity and shared experience, fostering a sense of 'we are in this together'. They aim to create a welcoming and supportive environment where people with dementia and their carers can connect, participate in meaningful activities, and receive the help they need to live well with dementia.

Through regular club meetings, usually several times a week for at least five hours, at a fixed time and location, they offer ongoing, reliable support. The small group size, typically around 15 members per day, allows for personalised attention with programmes tailored to the interests and abilities of the members, utilising their talents and incorporating their feedback. Meeting centres are committed to monitoring their impact and contributing to the evidence base for this model of support. They collect data on member attendance and wellbeing and participate in research and evaluation activities. The centres rely on a dedicated team of staff and volunteers who understand the ethos and are known and valued by members. They receive training and supervision to effectively deliver the programme.

The centres actively promote practical, emotional, and social adjustments to living with dementia. This includes providing advice and guidance on coping with symptoms, promoting a positive self-image, and fostering social connections. To those ends, the centres are deeply embedded within their communities. They involve a variety of community stakeholders in their planning and delivery, ensuring that the programme is relevant and accessible. They actively engage with local organisations and services to raise awareness and promote dementia friendly practices.

More information: https://www.meetingcentres.scot/

Recommendation:
Local statutory agencies and partners should make available funding and resources in kind, including meeting spaces, administrative support, coordination and help with travel, to scaffold such groups and to enable such mutual support, under the direction of participants and contributors.

4.5 Widening circles of support to stay connected and active and provide family carers with time out

Participants told of their desire for a 'life beyond dementia' in which they can maintain relationships, be and do the things they already value and enjoy, or find new interests, activities and opportunities. This relies on the accessibility, inclusivity, and welcoming and supportive attitudes of the wider community, as outlined in 4.1 above and 4.6 below. For some people with dementia, some additional support may permit them to participate in their communities and do the things that matter to them, without which people can become isolated and inactive. This also offers the opportunity for time apart from family carers, offering both parties valued time out.

Shared Lives is a model of support where people are matched with a Shared Lives carer who offers them support to participate in their community from the foundation of the Shared Lives carers home and family. This can take the form of 'day opportunities' or short breaks, offering people with dementia support to maintain connections with their communities and continue pursuing interests they enjoyed before their diagnosis, or those that they have developed latterly. This ongoing engagement is crucial in combating the isolating effects of dementia and preserving a sense of identity. It also provides family carers with a break, confident in the knowledge that the person they care about is both safe and doing things they enjoy doing. The careful matching between individuals and Shared Lives carers ensures compatibility and minimises emotional disruption that can be caused by frequent changes in care arrangements. This consistency also promotes a sense of stability and security, which can be particularly beneficial for individuals with dementia who may experience anxiety or confusion with unfamiliar situations.

Anecdotal evidence from the Shared Lives Scheme in Moray, Scotland, found that family carers attributed the approach to giving them the space and energy to continue supporting their loved one, delaying or averting admission to residential care.

With support from the Accelerating Reform Fund, areas in England are, at the time of writing, exploring expanding their Shared Lives offer to reach people with dementia and family carers.[22]

More information: https://sharedlivesplus.org.uk/wp-content/uploads/2019/04/Shared_Lives_Moray_final_2019-ilovepdf-compressed.pdf

Community Circles facilitators help to develop a circle of support around an individual – bringing people together around a person to share ideas about making a positive change in their lives. This change can be anything – from getting out and about more, to starting a new hobby, restarting an old one or creating opportunities to spend more time with friends or family. They also support people to connect through shared interests and creating opportunities where friendships can flourish. In an example of how Circles supported a man living with dementia and his family, involving family, friends and neighbours, his wife noted: 'The practical solutions people came up with and committed to meant that Dave could continue to enjoy the hobbies, interests, and connections he was involved in, giving me the space and opportunity to do likewise. Sharing our challenges and having this group of people backing us really felt like a weight being lifted.' Their son noted how, 'the role of the Circles facilitator is crucial in creating a space to bring people together, where challenges can be raised, ideas offered, and plans made.'

More information: https://www.community-circles.co.uk

Social prescribing could and should play a critical role in supporting people living with dementia to remain connected and active. However, beyond awareness of valued initiatives concerning 'music for dementia,' we heard little evidence of it fulfilling that potential during the course of this exercise. To those ends, the SPLENDID project, funded by NIHR and led by the University of East Anglia will explore the benefits of a 'social prescribing pathway for people living with dementia.'

More information: https://arc-eoe.nihr.ac.uk/news-blogs/blogs/improving-social-prescribing-people-living-dementia-and-their-carers

Recommendation:

Local councils and Integrated Care Boards should co-invest in developing, expanding or adapting, and evaluating the social and economic value of these and similar approaches and initiatives to support people living with dementia to remain connected and active, doing the things that matter to their health and wellbeing, as models of early action and prevention.

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[22] See: Shared Lives and Homeshare in England receive their biggest government funding boost yet

4.6 Increasing the supply of accessible housing and home adaptations

Contributors talked of the importance of remaining living in their present home, or to find a suitable alternative when their current home is no longer suitable or meeting their needs, and the challenges of doing so. However, people felt largely on their own and without support to navigate the housing options available to them, to make their existing home more suitable, or to find more suitable accommodation elsewhere.

A lack of housing advice for older people prohibits forward planning and the potential to avert or avoid unnecessary and unwanted moves into residential care. Giving people more awareness of their housing options would enable informed decision making about the different housing settings available and what they can offer.

To these ends, Alzheimer's Society published a Dementia Friendly Housing Guide in 2020 which was an outcome of the Prime Minister's *Challenge on Dementia*.

In its 2021 inquiry report *Housing for people with dementia: are we ready?* the All-Party Parliamentary Group on Dementia recommended that: 'Providers of housing for older people, in the private and social sectors, should consider the design and adaptability of their homes to meet the needs of those living with dementia. This should cover both 'hard design' – wider doorways, accessible kitchens and bathrooms that enable independence – and 'soft design' – covering the auditory impact of surfaces, the use of tactile and visual cues as reminders, signposting, labelling.'[23] Since the report, the Dementia Housing Working Group[24] has produced a Dementia Friendly Homes Design Guide.

More information: https://www.housinglin.org.uk/_assets/Resources/Housing/OtherOrganisation/Dementia-design-guide-LOWRES.pdf

The Older Person's Housing Taskforce, supported by the UK Government, issued its final report and recommendations in November 2024, *Our Future Homes: housing that promotes wellbeing and community for an ageing population*. It encourages 'local planners to engage with dementia charities/organisations to ensure local design codes are dementia-inclusive.'

More information: https://www.gov.uk/government/publications/the-older-peoples-housing-taskforce-report/our-future-homes-housing-that-promotes-wellbeing-and-community-for-an-ageing-population

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[23] APPG Dementia (2022) Housing for people with dementia – are we ready?

[24] The Housing Learning and Improvement Network Dementia and Housing Working Group

Regarding the adaptation of existing housing, it is not clear that people living with dementia are being routinely referred to occupational therapy teams for advice and support with equipment and adaptations to live safely and well in the place they call home, despite strong evidence concerning the benefits occupational therapy can bring and its role in accessing financial support and valuable resources.[25] Indeed, the All Party Parliamentary Committee on Dementia reported that: 'Access to home improvement agencies or occupational therapists (for people with dementia) can be variable across the country.'[26] This is a potential missed opportunity given that the Department for Health and Social Care announced in early 2025 that an additional £85 million would be made available for distribution via Disabled Facilities Grants.

Recommendation:

Principles for inclusive and accessible housing design, including with reference to dementia friendly design, should be further embedded in national planning guidance and codes to ensure that the future supply of housing reflects the changing needs of our population.

Moving forward, an increase in provision of advice and guidance services on housing for people living with dementia to assess their choices would address the issues and concerns highlighted in this report.

People living with dementia should be routinely offered periodic proactive assessments for potential home adaptations by occupational therapists.

4.7 Developing inclusive and accessible public spaces, transport, goods, and services

The desire people expressed during the conversations to remain connected, active, and able to contribute to their communities is mediated by the accessibility and availability of public spaces – indoors and outdoors, transport, and wider goods and services. Action across these areas implicates a wide range of public and private actors, professional fields, legislation and regulation.

There are, at present, no official national standards or guidelines related to accessible and inclusive design and living with dementia. However, various organisations have developed and shared useful guidance.

Regarding the wider built environment and transport, the place-based guidance on dementia friendly communities shared by the Local Government Association in 2015 (mentioned in 4.1 above) contains guidance and links to further advice concerning the design and organisation of housing, the built environment, and transport.

More information: https://www.local.gov.uk/sites/default/files/documents/dementia-friendly-communi-8f1.pdf

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[25] Bennett, S et al (2019) Occupational therapy for people with dementia and their family carers provided at home: a systematic review and meta-analysis

[26] APPG Dementia (2022) Housing for people with dementia – are we ready?

In 2022, the University of Stirling shared the *Environments for Ageing and Dementia Design Assessment Tool* (EADDAT) designed to 'support families, businesses and professionals to make homes, premises and public places more accessible to an ageing population and those living with dementia.' The tool has been piloted by Kirklees Council and Transport for London.

More information: https://www.stir.ac.uk/news/2022/september-2022-news/pioneering-tool-to-support-design-of-dementia-friendly-spaces/

In 2018, Innovations in Dementia worked with Professor Mary Marshall and a number of Dementia Voices groups to co- produce audit checklists for both inside and outside public spaces.

More information: http://www.innovationsindementia.org.uk/what-we-do/accessibility/

Outside of the UK, the Canadian organisation Happy Cities has developed guidelines on dementia-inclusive planning and design as well as a free online training course.

More information: https://happycities.com/projects/dementia-inclusive-planning-and-design-guidelines

Opening up the economy to the spending power of people living with dementia is a major opportunity which the International Longevity Centre estimates could boost the UK economy by around £948 million if effort was made to make 'spending environments' on and offline more inclusive to those living with dementia and other cognitive impairments.

More information: https://www.housinglin.org.uk/Topics/type/Retail-therapy-Dementia-and-spending/

Recommendation:
National regulations and guidelines concerning accessibility, inclusive design, and reasonable adjustments in the context of the built environment, transport, and access to goods and services should reference dementia-inclusive design and signpost available guidance.

4.8 Harnessing technologies

Technology didn't emerge in the conversations as a major factor influencing or helping people to maintain their wellbeing, save for frustrations some felt with the shift to digital and automation across many fields of life.

People told how online conferencing platforms had enabled connection between hitherto disconnected people living with dementia and exposed people to new ways of thinking and opportunities. This was particularly valuable during the Covid-19 lockdowns.

Some people had drawn on commercially available technologies, such as voice assistants, to assist in support with day-to-day routines, setting reminders and answering questions, though others said they had given similar technologies a try and found them too challenging to use, confirming research into their value.[27]

One group had been working with Care City in the co-production and development of a wayfinding device called 'Dorothy' which used Artificial Intelligence to support people to navigate physical spaces.

More information: https://www.carecity.org/projects/supporting-independence-for-people-living-with-dementia/

It is welcome that UK Research and Innovation, in partnership with the National Institute for Health and Care Research, is making available funding for the 'development of research and communities focused on the use and development of tools and technologies to enable people to live independently with dementia.'

More information: https://www.ukri.org/opportunity/technologies-to-enable-independence-for-people-living-with-dementia/

Recommendation:
It is recommended that investment is made in the continued development of new technologies to support people living with dementia and those who offer care and support to them. People with direct experience of living with dementia should be meaningfully involved in developing tech-based solutions, from identifying areas of life where tech could help, to identifying the technical approaches that could help, and testing the tech during the development stages.

4.9 Promoting innovation in community-based care and support, including support for family carers

As noted in Section 2.1, there has been limited innovation in relation to more formal care and support for people living with dementia. With respect to community-based care, people are often only offered or able to access time and task, life and limb homecare. Unless highly personalised, relational and flexible, this can be poorly suited to people living with dementia due to its often transactional nature, short 'visits' and changing roster of care workers. As a result, many people with dementia may be avoidably or prematurely being admitted to costly residential care. Meanwhile, alternatives to residential care, where a person's existing home is no longer suitable and they require ongoing support, are in their infancy.

Approaches that merit further exploration with respect to supporting people living with dementia in the community are the broader use of direct payments and individual service funds to facilitate choice and control over support, 'Small Supports' and wellbeing teams.

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[27] See for example: Salai, Ana-Maria et al (2022) Views and experiences on the use of voice assistants by family and professionals supporting people with cognitive impairments

The difference that **individualised funding** has made for people living with dementia and their carers has been documented in various pieces of 'grey literature.'

In her book *Where Memories Go – how dementia changes everything*, Sally Magnusson shares a detailed insight into her family's response to their mother's diagnosis of dementia and how the family respected their mother's wish to continue to live at home, a wish held by the whole family, by accessing direct payments to employ a team of people to support her.[28]

In a 2016 blog post shared by Think Local Act Personal on Personal Budgets and Dementia Support, George McNamara, then Head of Policy at Alzheimer's Society, is quoted as saying:

'People with dementia and their families tell us of the very real impact personal budgets have had on their lives – from the 85-year-old woman who returned home after being left alone in her care home room each day with no way of communicating, to the husband and wife who are now able to go dancing in Blackpool dancehall each week.'[29]

However, among people with dementia eligible for publicly funded social care, take up of direct payments or individual service funds remains very low compared to other groups, with most care and support arranged directly by local councils.

Small Supports organisations start with the person's aspirations about where they want to live and the life they want to have, on which conversations about support are built. Paid supporters are then recruited around the individual, rather than working across people and services. They are not, however, substitutes for friends, peers, or neighbours. People choose where they live and with whom, if anyone at all. They are the tenant or owner of their own home or live with family. Access to support is not contingent on where the person lives. Funding is designed and used around the individual in a sustainable way. Small Supports organisations anticipate change and challenges and stay with people rather than withdrawing support. The organisations stay relatively small in order to know each person they support well. To date Small Supports organisations have largely supported people with learning disabilities and/or autism, including people who have or might otherwise face admission to specialist hospitals.

The National Development Team for Inclusion, which supports the development of Small Supports, has recently begun work to explore the efficacy of the approach for people living with dementia.

More information: https://www.ndti.org.uk/projects/what-are-small-supports

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28 Magnusson, S, (2014) Where Memories Go – how dementia changes everything. Two Roads

29 TLAP (2016) Local Authorities urged to make personal budgets dementia friendly

Wellbeing Teams are self-managed teams designed to provide personalised care and support to people in their homes or communities. They focus on promoting overall wellbeing, autonomy, and dignity for those they serve. Inspired by the principles of self-management and organisations like Buurtzorg, Wellbeing Teams aim to shift the traditional model of hierarchical care delivery toward one that empowers teams to make decisions collaboratively and prioritise the needs of the people they support. Wellbeing Teams have been particularly noted for their innovative approach in the UK, championing a model that emphasises quality of life, partnership, and meaningful relationships in care and support.

More information: https://www.humanlearning.systems/uploads/Wellbeing%20Teams.pdf

Regarding **alternative models of housing with support**, the Commission on the Role of Housing in the Future of Care and Support, supported by the Social Care Institute for Excellence, made extensive recommendations and highlighted promising practices.[30]

Recommendation:
It is recommended that the UK government and partners mount a dedicated programme to stimulate, incubate, evaluate and promote alternative, sustainable models of personalised, community-based care and support for people living with dementia and their families adopting 'home first' principles and allied to a goal of reducing the proportion of people with dementia admitted to residential care homes.

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[30] Commission on the role of housing in the future of care and support (2021) A place we can call home: A vision and a roadmap for providing more options for housing with care and support for older people

5. Conclusion

People's experience of living with dementia is – like living with any other health condition or impairment – shaped not just by the disease and its impact on functioning, but by the way our societies are organised. Just like other disabled people, people with dementia encounter disabling barriers which hinder their full participation in society on an equal basis with others and which in turn deplete their health and wellbeing. The removal of these barriers is a legal obligation, arising from the UK being party to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and from domestic law such as the Equality Act 2010, the Human Rights Act 1998 and the Care Act 2014. Doing so requires social action and innovation across a range of fields to, in the words of Professor Gerard Quinn, one of the authors of the CRPD, 'nourish personhood and create the conditions for human flourishing.' This report sets out a range of areas where social and system change holds the prospect of creating those conditions, based on what matters most to the wellbeing of people living with dementia. Think Local Act Personal hope that it might inspire a new era of social action and innovation so that those of us living with dementia, and those with whom we share our lives, have the opportunity to live each day as best we can.

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