

Workforce Matters:

Putting people
affected by
dementia at the
heart of care



All-Party
Parliamentary Group
on Dementia

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Debbie Abrahams MP
Co-chair of the APPG
on Dementia

Foreword

In 2018, the All-Party Parliamentary Group (APPG) on Dementia committed to adopt a rights-based approach to achieving change for people with dementia.

All too often, conversations about the social care workforce are focused solely on the people providing social care, rather than on the people drawing upon it. People living with dementia should be able to live the lives they want to; this inquiry considers how the social care workforce can enable this to happen.

The All-Party Parliamentary Group (APPG) has engaged with a wide range of people affected by dementia during the inquiry to build a clear picture of what good (and poor) care looks like to them. We present our recommendations at a crucial time for social care, with the Government pressing ahead to deliver on commitments made in its adult social care white paper, 'People at the Heart of Care.' This presents the new Prime Minister with a huge opportunity to improve the lives of people affected by dementia.

During the inquiry, we have explored the specialist needs of people living with dementia who draw on care, what the barriers are to them accessing the kind of care they want, and the extent to which they can currently shape the care they receive.

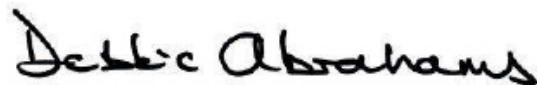
For the Government's vision for social care to be achieved, it must keep engaging people affected by dementia at every stage of its plans. Their message to us has been loud and clear: in order for people affected by dementia to live the lives they want to live, the social care workforce must be trained to understand dementia and deliver the personalised care people living with dementia want and need. They must have the time to get to know the person living with dementia, and be able to provide regular, consistent care so meaningful relationships can develop. Being able to provide care in a wide range of settings, including in the community, and a recognition of the role of family carers were also key themes throughout.

The report's overarching recommendation is for the Government to bring forward a comprehensive People Plan for social care,

developed alongside people affected by dementia. This is backed up with a number of more specific recommendations shaped by the change people affected by dementia want to see within the social care workforce to ensure they are empowered to live their lives with meaning, purpose, and connection.

We welcome the positive steps the Government has taken to begin the process of social care reform after decades of inaction. Now, we call on the Government to treat this report as a blueprint for reform of the social care workforce. We stand ready to discuss the recommendations herein and work to get them implemented so that every person living with dementia can draw on care that lets them live the lives they want to live.

Very sadly, before the publication of this report, the APPG's longstanding co-chair, Baroness Sally Greengross, passed away. Sally was a brilliant and tireless advocate for people living with dementia and their carers, and was instrumental in highlighting the issues affecting them in Parliament over many years. She played a vital role in conducting this inquiry, and so we dedicate this report to her memory – thank you for everything, Sally.



Debbie Abrahams MP
Co-chair of the APPG on Dementia

Executive summary

At its best, social care enables people with extra needs to live in the place they call home, with the people and things they love, doing the things that matter to them, in communities where people look out for one another.

This is the vision for social care put forward by Social Care Future¹, a group composed of people who draw on social care and those who support them. The All-Party Parliamentary Group on Dementia have sought to use this vision as the starting point of this inquiry.

Too often in debates about social care and its workforce, the focus has been on systems and paid staff. Both of these are crucial to enabling people who draw on social care to live well, but they should always be secondary to the wants and needs of those who draw on social care.

As one of the largest groups of people who draw on social care, our inquiry set out to identify what people affected by dementia want and need from the social care workforce in order to live the lives they want to. The inquiry received evidence via written submissions, four oral evidence sessions, and an online survey completed by nearly 2,000 people affected by dementia.

The Group heard that people affected by dementia want a workforce with knowledge and understanding of their specialist needs, who provide care that sees the whole person and focuses on what really matters to them. Family carers want the workforce to understand, value, and empathise with their own role in their loved ones' care.

People affected by dementia want a workforce with the time to understand the individual, with the time to deliver personalised care, and with consistency of staffing that allows a rich, supportive, and trusting relationship to develop. A workforce that can support people in places of their choosing, including with more choice of support that enables people to remain living in the community is needed.

Throughout the inquiry people affected by dementia shared their personal experiences of social care. For many people, the reality of care today does not match the standards of care that people with dementia need and deserve. Whilst the Group were inspired by some accounts of care that focused on

what mattered most to the individual and supported them to maintain their routines and live meaningful and connected lives, these experiences were not typical. The Group also heard some accounts of care failing to meet even basic personal care needs – let alone enabling them to live well – and experiences where people were treated with complete disregard of their individual, cultural and dementia-specific needs. This is unacceptable.

Every person with dementia deserves care that enables them to live well. In this report, the Group makes a set of recommendations on how to deliver this vision by building a care workforce with knowledge and skills in personalised dementia care, and who are enabled to deliver that truly personalised care by working practices, leadership and culture. These recommendations should be detailed in a comprehensive long-term People Plan for social care developed alongside people who draw on care.

The Group believes that this report presents vital new evidence from the biggest group of people who draw on social care, at the time in which the ambitions set out in the Government's adult social care white paper are beginning to be implemented.

About dementia



Dementia is caused by diseases of the brain



Common symptoms of dementia include memory problems, confusion, needing help with daily tasks, problems with language and understanding, and changes in behaviour



There are currently around 900,000 people living with dementia in the UK²



This figure is set to rise to 1.6 million by 2040³



Dementia is progressive and symptoms will get worse over time, meaning people will develop greater support needs



Many people with dementia need to draw on support from social care to help them live well



It is estimated that at least 70% of people living in care homes have dementia⁴ and 60% of people who draw on homecare have dementia⁵

Notes on language used in this report

This report uses the following terms for consistency and ease.

‘People with dementia’ — refers to people living with a diagnosis of dementia and drawing on social care.

‘People affected by dementia’ — refers to people with dementia and their carers.

‘Carers’ and ‘family carers’— in the text of the report , refer to unpaid carers. For many people these are a family member such as a partner or spouse, or a son or daughter, but they can also be a close friend. Where the term ‘carer’ is used in a quote from a person with dementia or a family carer, this refers to paid care staff.

‘Care staff’ and ‘the workforce’— refer to social care staff, including staff in residential care and homecare and other community-based settings.

We have used the term ‘personalised care’ throughout the report, except in citation of others’ work where they have used the term ‘person centred-care’. The two can be interchangeable.

A * indicates that the person’s name has been changed for anonymity.

Introduction

The Government's white paper on adult social care, '**People at the heart of care**'⁶, sets out a very welcome and much needed new vision for social care – one of personalised care, with genuine choice and control, enhancing quality of life and promoting independence. It presents an opportunity to deliver the high-quality, sustainable care and support that people affected by dementia need, transforming care from the current reality that falls far short of this vision.

As the Government begins to deliver on its commitments in the white paper, we must ensure those who draw on that care are considered and consulted in all aspects of delivery. In order for its vision to be realised, the Government must listen to and work with people who draw on care in the weeks and months to come. Otherwise, it won't deliver the change people affected by dementia really want to see.

In this inquiry the Group heard from the biggest group of people who draw on social care – people with dementia – about what being at the heart of care really means to them. Our inquiry focused on what people need from the care workforce because, at its core, care is about relationships between people. Care should not be transactional, about one person performing a task for another. It should be about connections where people are supported by others to live the life they want to live.

What does good care look like?

The Group heard some examples of good care:

'Two homecarers are excellent, they have developed very positive rapport with Mum and meet her needs very well. They take the time to talk with her and socialise, so visits are friendly rather than purely functional. They recognise her good and less good days. They have been a godsend and are so much appreciated.'

Lucy*, daughter of a person with dementia

'At the care home, my mother has had nothing but kindness and support from the staff. They are trained to support people with dementia and they treat her with humanity, understanding and kindness. They have made an effort to get to know her as a person and they try to provide support so that she can do the things she likes to do and is not bored.'

Cara*, daughter of a person with dementia

'The care company we used for homecare took full details of needs before commencing the contract. The information was updated and revised as the dementia got worse. The carers were well trained and happy to contact us if our relative was upset, anxious or refusing care. They would also spend time patiently trying to ascertain the cause of any upset and provide calming reassurance.'

Karen*, carer of a person with dementia

'Mum went in for respite care over a period of seven years. Staff continuity existed and they knew all about Mum's background and about her early life prior to dementia. They conversed with her about her life. They also encouraged her to try out classes they held, and took her to any musical event they had as they knew this bucked her up and made her smile.'

Gillian, daughter of a person with dementia

'Out of three homecarers, one is exceptional, the other two didn't fully understand dementia and would struggle to understand Mum's needs. The exceptional carer is able to understand Mum's world, to understand what stresses her. She has created an amazing bond with Mum. She is able to cope with Mum's speech which has been affected by dementia. She is patient and kind towards her at all times.'

Caroline, daughter of a person with dementia

This report sets out in detail what people affected by dementia told the APPG inquiry they need from good care, including exploring what personalised care means for people with dementia. Central to this is a workforce with the knowledge and skills to provide high-quality, personalised dementia care, that is skilled and enabled by working practices, leadership and a culture to deliver it.

What is personalised care?

Personalised care focuses on supporting people to achieve the outcomes that matter most to them, and gives people choice and control over their care.

Currently, people with dementia often experience care that is too focused on ‘personal care’, which supports them with basic needs of daily living such as washing and dressing. This is essential for daily functioning, but it doesn’t achieve the outcomes that matter most to them or help them to have a good quality of life, with meaning, purpose, and connection.

There is widespread support for a vision of personalised care across the sector. The vision is well-articulated by Social Care Future in their statement:

‘We all want to live in the place we call home with the people and things that we love, in communities where we look out for one another, doing things that matter to us’⁷.

Alzheimer’s Society have explored what personalised care means for people with dementia in two of their recent reports, *A Future for Personalised Care*, and *Stabilise, Energise, Realise*. The APPG on Dementia shares the view of sector leaders such as Alzheimer’s Society that personalised care is vital for people living with dementia.

While this report largely focuses on a vision of care that truly meets the needs of people living with dementia, the Group has also sought to reflect the balance of evidence received, recognising that there are lessons to be learned from examples of poor care. These lessons can help inform an understanding of what good care looks like and provide clarity on what people with dementia want and need from care.



What does poor care look like?

Some people shared experiences of very poor care with the Group. Poor care didn't only relate to care not being personalised; there were also examples of neglect and personal care needs not being appropriately met. This included:

- Someone refusing food, and staff responding by letting them go without food instead of trying to identify and understand the reasons for this. This resulted in weight loss and illness.
- **Someone being assessed** as incontinent and given continence pads because it was easier or less time consuming than helping them to go to the toilet, even though the person was able to do so.
- People being treated as objects and with a complete lack of empathy. This included situations where people with dementia were completely ignored and were spoken about instead of being spoken to.

'What struck me very much is the way that care staff viewed residents not as people, but as if they were things. They had lost sight of the human being.'

Gaye, carer and person living with dementia

'Homecarers coming in and doing the bare minimum, gone again in five minutes. Left her on the floor with a broken shoulder for 24 hours because she didn't open the door, they just went away and didn't report the lack of access to anyone. In the residential home, she was left on her own in her room for hours on end. She required feeding and took food easily, but they never gave her time and took the plate away with most of the food unfinished.'

Eva*, daughter of a person with dementia

'Mum loved to colour in colouring books and wear her favourite beads and have music playing in her room. The first few weeks I had to keep reminding them she enjoyed these things, it never was considered after that, they just treated her the same as everyone else... just left in a chair all day long sleeping the remainder of her life away. Dad was treated the same, he gave up with life long before he died.'

Julie, daughter of two parents with dementia

It was also striking the number of people who shared experiences of huge variation in the quality of care between different care workers and from different services.

'Staff shortages and resource issues meant Mum did not receive the care she deserved. Some staff were reluctant to engage in Mum's care plan and did the basics or the minimum possible. No interest in dementia or the person. It was a job for them and not a career. Some staff were amazing, trained in dementia and genuinely showed empathy, compassion and had the patience and interest in my mum. It gave her a better quality of life and she was happier and engaged. The extra mile some staff went was getting to know Mum and what made her happy, including music, talking, playing with teddies, and talking to her about her favourite things, including Elvis Presley.'

Edwina, daughter of a person with dementia

Currently, many people don't have choice over the service or provider. In situations where poor care was identified, some people described trying to change the care received by switching to self-funded care, through a complaints process, or with the support of an MP. However, these options aren't available to everyone, and changes often happen too slowly to actually benefit the person living with dementia. Trying to change service was often described as involving a great deal of stress, with people coming up against barriers that made the process very complicated and time consuming.

These experiences reflect the worst of care, and the urgent need to reform the social care system. Care Quality Commission (CQC) data from June 2022 showed one in five care homes registered in England with a dementia specialism were rated as inadequate or requiring improvement⁸. It is vital that regulators are effective in identifying services that are failing to ensure that they access the support they need to turn this around. Every person with dementia should be able to access good quality care.

The context of social care today

To understand why the quality of care can be poor for many people with dementia, it is important to look at the context of today's social care services. It is widely recognised that there is a crisis in social care funding. There isn't enough funding to pay for services that provide the quality of care that people deserve. The Group heard from a care home operator:

'Currently, we are having to provide the dementia care that fits into the limited funding we receive and the limited resources available to us – **dementia care decisions across the sector are made according to funds available, and not according to the needs of the service user.** There is a lot more that we can do (and a lot more that we really want to do) for people affected by dementia and their loved ones, but there will need to be significant changes in funding structures and policies to allow us, and so many organisations like us, to do this.'

Estimates of the need for additional funding for social care vary, but the Health and Social Care Committee have said an additional £7 bn per year was required by 2023/24 as a 'starting point', representing a 34% increase from the 2023/24 projected adult social care budget at the time of the report (October 2020)⁹.

The proposals in the Government's white paper set a good foundation for transforming care and building a care system that delivers high-quality personalised care for everyone. It sets us firmly in the direction of raising standards of care and spreading good practice, so long as the proposals are backed by the adequate funding required to deliver them. The coming months and years are vital for developing the proposals into plans and bringing the vision to life. The Group hopes that this report will be used as a vital tool to help this work take shape, and that it marks one step in the road of ensuring that people affected by dementia are truly at the heart of care.

Recommendations

Every person living with dementia who draws on care should be supported to do the things that matter most to them, so that they can live the lives they want to live.

The All-Party Parliamentary Group recommends that:

Government develop and publish a People Plan for social care that primarily considers the needs of people who draw on social care, including the workforce needed to deliver the Social Care Future vision of: **‘We all want to live in the place we call home with the people and things that we love, in communities where we look out for one another, doing things that matter to us’¹⁰.**

Government meaningfully engage with people affected by dementia, frontline care staff, leading dementia organisations, and the dementia research community to identify how knowledge and skills in dementia should be incorporated within the new Knowledge and Skills Framework. This should include a minimum mandatory level of training in dementia for all care staff, to tier 2 of the Dementia Training Standards Framework.

Government ensure the new Knowledge and Skills Framework provides ongoing learning opportunities to support development of dementia specialisms and progression into leadership roles. This will develop experts and leaders in dementia care, and ensure that all care staff are supported in accessing these opportunities.

Government conduct and publish an annual audit of knowledge and skills in care staff.

Government meaningfully engage with sector leaders to identify the size of the knowledge and skills gaps in dementia care in the current workforce, and set out a plan to deliver training to bridge these gaps, with funding for both training and back-fill of staff.

Government introduce clear standards for evidence-based training for the care workforce. This includes giving providers the information they need to identify training programmes with a sufficient evidence base in improving quality of care and outcomes in people with dementia. In addition, introduce oversight of training standards at a national level, and update NICE (National Institute for Health Care Excellence) guidelines on dementia care to support implementation.

Enabled by new standards on evidence-based training from Government, commissioners at a local level only commission services that demonstrate that their staff have received dementia training that is evidence-based to ensure the provision of high-quality care.

CQC ensure that personalised care is central to their new inspection framework for care services, with people affected by dementia meaningfully involved in the development of the new framework. An assessment of personalised care should be clearly communicated in inspection reports.

Government increase funding to local authorities to enable them to commission a wider range of services for people affected by dementia, allowing them choice and control over their care. This funding should be used to commission models of care beyond traditional care homes and homecare, such as Shared Lives schemes and Community Circles. This funding should also be used to invest in partnership working with community-based organisations with expertise in supporting people with dementia from ethnic minority communities, people with young onset dementia, and other specialist needs. The distribution of this funding should ensure that people living with dementia in all parts of the country have access to a choice of services that meets their needs.

Government ensure that the data collected and recorded within the forthcoming Adult Social Care Data Framework includes a breakdown by condition for dementia, and is made publicly available and easily accessible to people affected by dementia.

The Government's Dementia Moonshot funding includes investment specifically allocated to research in care, particularly relating to personalised care and improving quality of life. It should also include investment in translation and implementation of research that demonstrates improvements in outcomes, so that more practice in social care is evidence-based.

Government take immediate action to address the retention and recruitment crisis in social care, addressing the factors that underlie high levels of vacancies. This will help enable people living with dementia to receive dedicated one-on-one time with care staff, where staff can understand the person's individual needs and support them with personalised goals. With consistent carers, strong and trusting relationships can develop.



Chapter 1

What people affected by dementia want from good care: Staff with knowledge and understanding of dementia-specific needs

The inquiry survey asked whether people affected by dementia considered themselves or their loved ones to have specialist support needs, compared to people without dementia drawing on care. The overwhelming response was that people with dementia have significant specialist needs due to the unique nature of the condition and its symptoms.

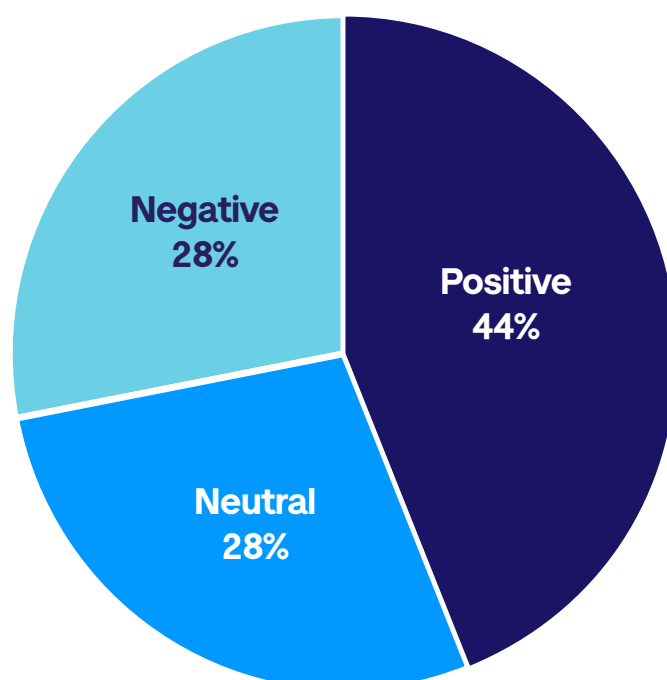
‘A diagnosis of dementia absolutely meant that my husband had specialist needs. In addition to physical care, he needed stimulation and engagement, patience and reassurance. He needed carers who understood something about this disease.’

Lorelei, wife of a person with dementia

People living with dementia told the Group they need a care workforce with the knowledge, skills and understanding to meet dementia-specific needs.

However, a survey conducted for this inquiry found that less than half of people (44%) rated care staff’s understanding of dementia positively. 28% rated it neutrally, and 28% rated it negatively [See methodology, page 49, for full details].

How would you rate care staff's understanding of dementia?



There were three key specialist needs that stood out from the evidence.

Expressing themselves

The most common need people identified was related to communication.

People affected by dementia described how they needed care staff to know that the person was struggling with communication because of their dementia, and that just because they were struggling to express themselves, this didn't mean that they didn't have something to say. It is essential that people are understood and not dismissed as not having needs and wants. Care staff need to see the person first, not the dementia. Care staff need patience and understanding, to get to know the person and to learn how they can communicate effectively with them.

'It requires more time, more patience and thinking of creative ways to engage him.'

Ali, carer for a person with dementia

'Dementia workers need special skills/training to meet their needs. My husband cannot verbalise, for example. There has to be special attention to the person to understand them.'

Margaret*, carer for a person with dementia

'Many care home workers appear to have minimal training in communicating with people who have dementia. There needs to be far more training available in this area.'

Anne, carer for a person with dementia

Dementia has a profound effect on an individual's communication. The part of the brain that controls language can become damaged, and so people with dementia may experience difficulties in how they use words. They may struggle to find the right words or follow a conversation. Communication challenges increase as the condition progresses, and people with dementia can become frustrated, anxious, depressed, or withdrawn as they struggle with being able to express themselves. For people living with other conditions, where communication abilities are not impacted, they are usually able to say what they want help with, when they are in pain, or if something is wrong. It is a unique symptom of dementia that this core ability is impacted.

Communication forms a foundation for personalised care: for care to meet a person's needs, ambitions and desires, the person firstly needs to be able to express these, and have them be understood. It is vital that care staff receive training that enables them to understand the unique communication needs of people with dementia, and equips them with the skills to support effective communication.

Requiring appropriate support to respond to challenging behaviours

People affected by dementia also identified the need for the care workforce to know that people with dementia may be unable to communicate reasons for distress. People with dementia may struggle to communicate a response to environmental stimuli or an unmet need, which is causing them distress or pain. As a result, they may display behaviours such as agitation and aggression, both physical and verbal.

Some people shared examples of their experiences with the Group:

'Mum has challenging behaviour. Carers provided had no hands-on experience of providing care in this situation.'

Delia, daughter of a person with dementia

'Domiciliary care – not turning up, rushing for other appointments, leaving my mum to deal with challenging behaviour as they didn't know what to do.'

Emma, daughter of a person with dementia

‘Some staff took note of Dad’s history and things that would make him anxious or soothe him and took an interest in the reasons behind his behaviour. This made a massive difference.’

Denise*, daughter of a person with dementia

People with dementia need care staff to understand why these behaviours arise in people living with dementia, and how to respond appropriately by identifying the cause of distress rather than just the behaviour itself. This approach requires skill; it may not always be straightforward to identify the cause of the problem, and it often requires knowledge of the individual and thinking about the situation from their perspective. This approach also requires empathy, compassion and patience. Some people affected by dementia identified lack of time as a reason for care staff not responding appropriately – it is quicker to address the behaviour than to investigate the cause – but this can lead to the continuation of behaviour that challenges and further distress.

The Group heard from a member of a mental health crisis team who described the consequences they saw from care staff not being able to manage challenging behaviours due to poor training and inadequate staffing:

‘Many adults with behavioural and psychological symptoms of dementia who display behaviour that challenges end up referred to our team and, on a number of occasions, admitted to hospital. Furthermore, there have been instances where police have been called or the resident has been taken to A&E, which are also likely to be highly distressing for someone with dementia.’

The Group also heard examples of people living with dementia having care staff attempt quick fixes in response to their behaviour such as antipsychotic drugs, restraint, or keeping the person in their room. This can lead to a negative cycle whereby behaviour that challenges persists in the person living with dementia because inappropriate responses continue to be employed. Addressing the cause of this behaviour is key to preventing deterioration.

The Group received evidence of interventions that can help address this cycle. The ‘FITS’ (Focused Intervention Training and Support)¹¹ programme targets the inappropriate use of antipsychotics to manage behavioural problems in people with dementia in care homes. It has been shown to reduce the use of antipsychotics. The ‘WHELD’ (Improving the Wellbeing and Health for People Living with Dementia) programme, an evolution of the ‘FITS’ programme, also reduces use of antipsychotics, as well as delivering further positive outcomes including improving quality of life. The ‘WHELD’ programme is discussed in more detail later in this report.

The Group also received evidence of how music therapy can be used as an effective non-pharmacological intervention to help manage some behaviours including agitation and aggression. Care staff can learn about music therapy and how to apply this with support from professional music therapists or specially developed resources. For example, Nordoff Robbins, a charity providing music therapy services, training and research for people with life-limiting illness, disabilities or feelings of isolation, partnered with FutureLearn during the pandemic to provide an online course to help care staff feel more confident using aspects of music in their work.

Cognitively stimulating activities that benefit an individual’s health and wellbeing

Many people affected by dementia talked about the importance of activities that are cognitively stimulating – helping to preserve existing cognitive abilities and delay progression of decline – and bringing the individual joy in their daily life.

People affected by dementia shared experiences of not having enough mentally stimulating activity. They described being left alone for too much time without anything to engage them, or having little choice in activities, and only being able to participate in activities that weren’t meaningful or enjoyable to them.

‘No attempts at stimulation or real engagement related to interests.’

Rhys*, carer of a person with dementia

‘He was placed in a large lounge with the TV switched onto programmes that wouldn’t interest him and left there with 20 to 30 other elderly people. He just slept most of the time out of sheer boredom.’

Ben*, carer of a person with dementia

The importance of cognitively stimulating activities is universal, but they are especially vital for people with dementia due to some of their cognitive abilities being in decline. It is essential that everything possible is done to preserve these abilities in people living with dementia.

Many people noted how activities that have benefits for cognition and wellbeing in one person will not have these same benefits for someone else. For an activity to benefit someone cognitively they need to be engaged with the activity. Engagement is much more likely when an activity is interesting and meaningful on a personal level. For example, some people living with dementia may enjoy gardening, while others may find it boring. Where people are passive rather than engaged, they are unlikely to gain cognitive and wellbeing benefits. In fact, they may even experience a negative impact from feelings of not being understood, or not belonging.

Care staff need to understand the importance of identifying activities that are interesting and meaningful to the individual. They should get to know the individual and learn about the things they enjoy, and then support them in doing those things.

Not being able to participate in activities that are engaging can disproportionately impact people with young onset dementia. Activities or services are usually designed for older people with dementia, meaning they may not be accessible or interesting for people under 65.

‘People assume dementia is an illness which only affects elderly people. My mum was diagnosed at 64 and died aged 70. Music and other themed events aimed at 80- to 90-year-old residents had no relevance to her.’

Sofia*, daughter of a person with dementia

‘Organised music was only suitable for his parents’ generation. The TV was on constantly in the lounge with quiz shows and programmes he would never have watched. There was no option to opt out.’

Cerys*, carer for a person with dementia

The Group also received evidence on the importance of hearing for communication and engagement. Hearing problems can be a barrier to people with dementia being able to effectively communicate and fully engage with activities – and therefore missing out on potential health and wellbeing benefits. A number of people gave an example of care staff not helping people with dementia to put in their hearing aids, or hearing aids being lost and not replaced.

‘An ongoing issue is the failure of staff to aid my husband in inserting his hearing aids. This is an issue that creates another means by which he is then cut off from his surroundings.’

Ann, wife of a person with dementia

‘Hearing loss is often not understood, especially by new or inexperienced care staff. To be left without hearing aids means that she cannot respond to carers.’

Fatima*, daughter of a person with dementia

Hearing loss can have a considerable impact on social interaction and can affect overall wellbeing and quality of life¹². Hearing loss has also been found to amplify the effects of cognitive impairment¹³. It has been estimated that 75% of care home residents have some degree of hearing difficulty¹⁴.

Specialist needs of people with different types of dementia

Around 5% of people with a diagnosis of dementia are recorded as having Lewy body dementia, though it is likely the condition is under-diagnosed^{15 16}. People with Lewy body dementia often experience symptoms not commonly experienced by people with Alzheimer's disease, the most common form of dementia, including hallucinations, problems staying fully awake, difficulties with movement, and disturbed sleep.

Families of people living with a diagnosis of Lewy body dementia described the need for care staff to have an understanding of these symptoms and of how to support people. Some had experienced care staff not understanding the condition, or even not being aware of it at all.

'Some of the staff had not even heard of Lewy body dementia'

Caitlin*, carer for a person with dementia

'Dad is between care in hospital at the moment as his care home could not cope with his behaviour due to the hallucinations involved with Lewy body dementia.'

Elizabeth, daughter of a person with dementia

'My loved one has Lewy body dementia along with significant mobility problems. He cannot be left alone and care has to be provided by someone who knows how to manage delusions, hallucinations and irrational thoughts etc.'

Linda, carer for a person with dementia

This evidence demonstrates the importance of care staff having the knowledge and skills to support people with less common types of dementia. People with all sub-types of dementia need to be able to access high-quality care that meets their needs.



Where people described experiences of poor care, they often described staff having very little understanding and knowledge of dementia.

‘The carers in the main, although kind, do not actually appear to understand dementia at all. They lack significant training/education that would make a huge difference.’

Stella*, carer for a person with dementia

‘I feel that some of the carers in the home try their best but staffing levels and lack of specific training prevent the best care that these poor residents should expect.’

Maya*, carer for a person with dementia

‘It was supposedly a dementia specialist home, but very badly run, with staff with little to no understanding of dementia. There was no personal tailoring.’

Alexandra, carer for a person with dementia

‘I feel the staff are not given adequate or in-depth training to deal with the needs of a person with dementia.’

Michael, carer for a person with dementia

‘Carers should all have special training for dementia.’

Jean, carer for a person with dementia

‘On a number of occasions, my mother’s home carers left her without a meal or a drink, or did not ensure that she had a wash, clean clothing etc. This was usually because the carer did not understand her dementia and left her to do things for herself that she was unable to do.’

Siobhan*, daughter of a person with dementia

‘As wonderful and caring as the carer staff were, training is lamentable and entirely lacking’

Danielle*, daughter of a person with dementia

The Group also heard of the impact of this lack of knowledge and skills for family carers. It caused family carers concern about their loved one receiving poor care and, particularly with home care, resulted in having to increase their own caring responsibilities.

‘One or two carers understood dementia. Most of the others had no idea how to treat someone with dementia. It was the most stressful time in my life trying to manage the different carers.’

Rebecca*, carer for a person with dementia

‘The at-home carers were often not trained to understand dementia. They would accept what my mother told them and leave her, when the agency had been told that she was unable to do certain things for herself and needed help. Because of this, both her life and mine were made much more difficult and I often had to go to her home to complete jobs that the carers had not done.’

Any*, daughter of a person with dementia

Training can help care staff develop knowledge and skills in dementia care.

The Dementia Statements¹⁷, which were developed through extensive consultation with people with dementia, set out the key things that people with dementia have said are essential to their quality of life. One of the five statements says:

‘We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, **from trained people who understand us and how dementia affects us**. This must meet our needs, wherever we live.’

In the evidence, some people also described the difference that good training made to care.

‘The good care has come from dedicated, compassionate and caring people who have had dementia training.’

Kristina*, carer of a person with dementia

‘My husband is now in a specialist dementia care home, which is excellent. The staff have specialist training. I am very happy with his care, and feel that if this had been available at home, we could have managed at home longer than we did.’

Vanessa*, wife of a person with dementia

The importance of training in dementia is recognised in the NICE dementia guideline, which recommends that care and support providers should provide all staff with training in person-centred and outcome-focused care for people living with dementia. It also recommends that care providers should provide additional face-to-face training and mentoring to staff who deliver care and support to people living with dementia .

Statistics from Skills for Care show that only 44% of social care staff have a record of training in dementia¹⁹; however, it is important to note that this data doesn’t provide detail on the level of this training, and so is limited in what it tells us about the actual knowledge and skills in dementia care of the workforce.

A lack of dementia training was highlighted in evidence received from the Homecare Association:

‘Training in dementia care for homecare workers is not as routine or high quality as it needs to be’.

‘Levels of knowledge about dementia among staff tend to be low when they first join if they have no prior experience. Some providers offer excellent dementia training and others offer very little, so there is high variability in knowledge, skills and competence in this area.’

Dementia Training Standards Framework

There is a national framework for dementia training, designed to give staff the right skills and knowledge to deliver high-quality dementia care. This is the Dementia Training Standards Framework (DTSF)²⁰, commissioned by the Department of Health and Social Care and developed in collaboration by Skills for Health and Health Education England in partnership with Skills for Care. It is designed for staff in both care and health settings.

The framework has three tiers: all staff (tier 1), staff directly supporting people with dementia (tier 2), and staff in leadership roles (tier 3).

Tier 1 covers only a basic level of awareness of dementia.

Tier 2 includes:

- dementia identification and assessment
- person-centred dementia care
- communication
- health and wellbeing
- pharmacological interventions
- living well with dementia and promoting independence
- families and carers as partners in care
- equality diversity and inclusion
- law, ethics and safeguarding
- end of life
- research and evidence-based practice.

Tier 3 includes more advanced dementia knowledge and supports people to develop leadership in transforming dementia care.

There has also been research conducted into common features of effective dementia training. Leeds Beckett University carried out an international literature review of ‘What works’ in dementia education and training²¹. They identified features including:

- making training relevant to the role
- experience and practice of the learners
- presenting the experience of living with dementia (through direct involvement in training delivery or through video)
- skilled and experienced trainers
- interactive group face-to-face teaching methods (avoiding didactic teaching methods and avoiding self-directed learning alone)
- a supportive organisational context and learning culture.

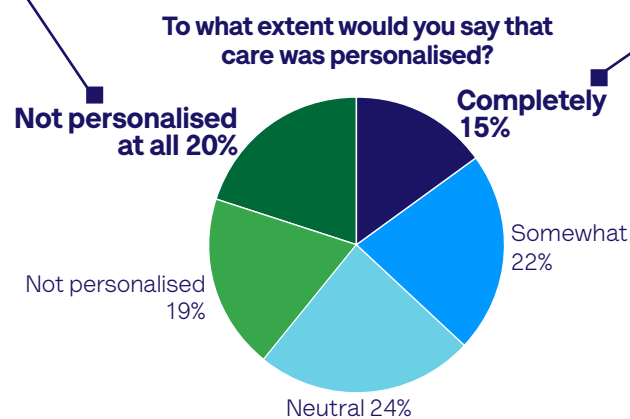
Guidance and resources on dementia training do exist; however, there are barriers in the social care system to this training being widely undertaken, which will be discussed more later.

Chapter 2

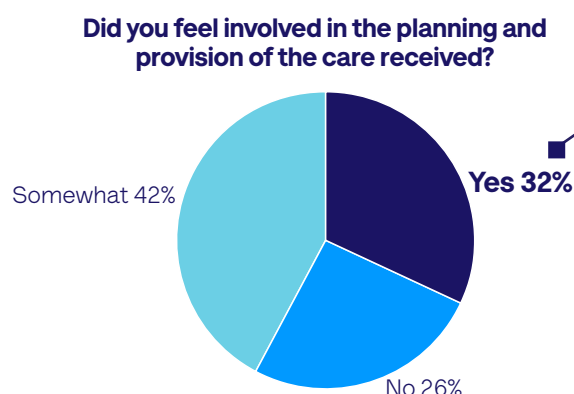
What people affected by dementia want from good care: Staff with the skills to provide personalised care

Two in five people said that care was not personalised

Less than two in five people responded positively that care was personalised



Only one third of people felt involved in the planning and provision of the care received



Source: Online survey conducted by Alzheimer's Society on behalf of the APPG for this inquiry. (See methodology, page 49, for full details).

Placing the individual at the centre of care

The Group heard overwhelmingly of the importance of staff really listening to the individual and getting to know them, to understand what matters most to them – and then providing care that supports these interests and goals. This ranges from understanding the things that give them a sense of meaning and joy – such as being in nature or listening to their favourite music – to preferences in daily routines, including the diet they follow and the clothes they wear. People with dementia need to be at the centre of their care in every way.

Everyone deserves to live their lives in the way they want to; for people with dementia, the symptoms of dementia can make it more difficult for them to do so without support. This is why a strong vision of personalised care, and conditions that enable this care are so vital for people with dementia.

Some people affected by dementia shared examples of individuals being supported by staff who did take the time to understand **‘the things that make them them’**, and provided truly personalised care.

‘The care home has always recognised how it benefits Mum to spend time with close family, and how by doing this it helps her to eat better, take her medication and interact with others. They recognised that my mum feels better about herself when her nails are painted and she is well dressed, and listening to her favourite music.’

Helen, daughter of a person with dementia

‘In the beginning, the care home took great care to make music a big part of my father’s day. This brings him great joy; he dances and feels uplifted.’

Silvia, daughter of a person with dementia

‘Good carers always used Mum’s name, gave her foods she liked, and kept to usual routines. They sat and chatted with her about day-to-day things’

Rose*, daughter of a person with dementia

‘Stimulation provided is related to my loved one’s interests; scrabble, walking, going out for coffee.’

Rhiannon*, carer of a person with dementia

‘He was allowed to spend time in the manager’s office, ‘helping’, as this was a familiar environment to him from his working life’

Helen, daughter of a person with dementia

‘Positioning of room in care home to enable direct garden access; important to Mum as she loves the outdoors and regularly sits outside.’

Matthew*, son of two parents with dementia

‘Rachel always had a love of horses. Two carers would take her out to see their horses. She loved that!’

Peter, carer of a person with dementia

In an oral evidence session, the Group heard from Trevor about the experience of his wife, Yvonne, who had a diagnosis of young onset dementia, moving into residential care. On a visit to the home Yvonne spotted that there wasn’t a bird feeder in the garden, and she loved birds. On the day she moved in, a care worker took her to a store to choose a bird feeder for the home. Trevor said: ‘The entire journey of person-centric care started at that moment. Once Yvonne was living in the home, the staff helped her in the garden to fill the bird feeder. They also supported her with her other interests, including baking, and they treated her differently to other residents, recognising that she was around ten years younger.’ Trevor referred to the care home as ‘a home from home environment’.

In contrast, the Group heard examples of the impact when people with dementia did not receive personalised care; where they weren't supported to do the things that they love, and where personal preferences in daily routines weren't adhered to. There were some examples of good intentions – with a personalised care plan being drawn up – but then not followed or even read.

'No thought at all given to Mum's background, hobbies or things that made her relax and smile'

Kym*, daughter of a person with dementia

'Care plan not being followed. Mum regularly doesn't have her glasses or hearing aid on and more recently now doesn't have her false teeth in. These are during planned visits, so I'm not sure what is going on when I'm not visiting. My mother dislikes dairy apart from cheese. She was given custard, milk and cream regularly despite me telling them her preferences.'

Catrin, daughter of a person with dementia

'They ask a few questions over the phone but no background on my dad. I sent in pictures, records and tapes, as he is calm with music, but I never see them put it on.'

Grant*, son of a person with dementia

People affected by dementia described observing the support they received as too often task-oriented and rushed, rather than being based around an individual's needs. They experienced staff lacking the time to work one-on-one with people to understand their needs and engage in tailored activities. These issues are explored more later.

The Group also heard examples of care with a lack of focus on the wishes of the person with dementia once they were deemed to lack mental capacity. There is legislation through the Mental Capacity Act (MCA) which provides guidance on this and aims to protect people who lack capacity to make decisions. However, the Group heard from people who reported care staff lacking knowledge of the MCA. This has also been found by the CQC, who have reported **"despite years of the [MCA] legislation being in place, there is still huge variation in understanding and practice, and in the quality of training"**²². It is important that people with dementia are supported by care staff with knowledge of how best to support people with dementia who lack capacity.

The Group also heard of the need for a personalised approach to someone's care to start before a person with dementia engages directly with a service. People and their families, with local authorities if applicable, need to be able to make a decision about which service best meets the individual's support needs, being able to choose a service from a range of options. In evidence submissions received by the Group, people described a lack of choice of services to meet their needs, with limited options for care. Many said they were faced with a one-size-fits-all system. People should be able to choose from care homes and homecare services tailored to meeting specific needs, but should also be able to choose other services too. Much of the evidence received in this inquiry related to homecare and care homes, but in an oral evidence session the Group heard of different models of care centred on a personalised approach and based in the community, such as 'Shared Lives'²³ schemes and 'Community Circles'²⁴. Commissioners of social care services need to have an understanding of personalised care and the importance of offering a choice of services. They must also have an understanding of the needs of people with dementia within their own community – in addition to sufficient funding that allows them to make commissioning decisions based on those needs.

It was also highlighted in the written evidence that volunteers in care homes can play an important role in supporting people with dementia, through one-to-one befriending. It's important to note that the need for training extends to volunteers too, so they can understand dementia and develop skills in supporting people with dementia.

Placing the individual at the centre of care: Community Circles

Community Circles places the person at the centre of their lives and their care. It starts with what matters most to the individual, by recognising that the person drawing on care is the expert in their own lives. It also draws on the principle of relationships being key to wellbeing, and takes an asset-based approach. This means building and strengthening an individual's existing connections with the people in their lives, and seeing everyone as a potential source of support. This can include connections with family members, friends, neighbours, and wider members of the community. It builds on the idea that some people may be more willing to accept help from trusted people already in their lives, who know what's important to them. This model takes an expansive, community-based vision of care – that care should be everyone's business.

The 'Circle' starts with identifying people who could potentially help an individual and bringing them together. The Circle discuss the goals of the person, and challenges they may be experiencing, to collectively and creatively develop ideas and practical solutions to help them continue to do the things that are important to them, such as maintaining hobbies, interests, and social relationships.

In an oral evidence session, the Group heard from Kath about the impact a Circle had for her husband, Dave. Kath found that, before setting up the Circle, people often didn't know what help was appropriate to offer or how to offer it sensitively. Dave's Circle was a network of neighbours and friends, each taking small actions to look out for Dave's welfare such as talking to him when he had wandered out of the house and taking turns to check on him when out on a group visit to the pub. In her blog, Kath said 'Sharing our challenges and having this group of people backing us really felt like a weight being lifted.' Kath also described how, after her husband passed away, the Circle continued to benefit her, supporting her to live her own life, including helping her through a patch of ill health. Benefits of the Circle can extend further too, to everyone involved, through a greater sense of community and connection which can be good for general wellbeing.

Placing the individual at the centre of care: Shared Lives

'Shared Lives' recognises the importance of strong and sustained relationships, and involves people sharing their lives and their homes. Through Shared Lives Schemes, someone drawing on social care support is matched with a Shared Lives carer, who has been assessed and approved to open up their home to someone else. The match is based on shared interests and lifestyles, and arrangements can be long term or short term, for example to give a family carer a break. Shared Lives Schemes are CQC registered.

The Group heard an example of someone who had benefited from the scheme:

'My dad was his usual self on his return and slotted straight back in as though he hadn't even been away. Whilst this may not seem like much, when he went to a care home during my operation and hospital stay, he came back quiet, withdrawn, unable to do things like his much-loved wordsearch, and seemed what I can only describe as depressed (hard to tell as he can't tell you). It took us over three weeks to get him into some kind of former self, however some things were lost forever.'

Lynne, daughter of a person with dementia

Alternative community-based models of care

There are other alternative models of care in the community.

- Retirement villages provide a place to live independently with the option to arrange care where needed.
- Sheltered housing includes support from a warden, with 24-hour emergency support available and communal areas.
- Assisted living is an option which offers more tailored 24-hour support.

More research is needed into the benefits of these models. A National Institute for Health and Care Research (NIHR) rapid review of literature on supported housing found that evidence on outcomes in these care settings was limited²⁵. We know that a range of care options is valuable to people with dementia, to offer greater choice and to meet different needs, but currently in many areas of the country choice of services is limited. A greater strength of evidence demonstrating the benefits of these services may help increase commissioning of them, making them available to more people. There also needs to be the funding available to enable commissioners greater flexibility in commissioning decisions, as well as awareness raising so that people affected by dementia know about the services that do exist.

Evidence-based practice in improving person-centred care

There are examples of programmes that are evidence-based in improving person-centred care for people with dementia.

In an oral evidence session, the Group heard about the 'WHELD' programme.

The WHELD programme²⁶ provides training to staff in care homes and has been found to deliver significant benefits across a range of outcomes including:

- quality of life
- reduction in agitation
- reduction in neuropsychiatric symptoms such as depression
- fewer emergency hospital admissions and fewer GP visits.

The first WHELD programme was delivered face-to-face, but the researchers have now built on this to create a digital version of the programme, with online learning supported by virtual coaching. It was developed through consultation with stakeholders including people with dementia, family carers, and staff working in social care. The programme involves around 20 hours of training over 12 weeks, and additional virtual coaching. The coaching uses a champion model of training 2–4 coaches in each care home who then support staff to follow the programme, which also helps to embed the skills within the home. The researchers are now working on a project exploring enablers and barriers to implementing the training in the real world.

In the oral evidence session, the Group heard how important it is for training to be evidence-based to ensure it actually delivers impact and improves outcomes, rather than just ticking a box. They described how it is important for both the content and method of delivery to be evidence-based. For example, excellent training content delivered solely through e-learning may not be effective; the WHELD researchers found that virtual coaching was needed alongside e-learning. The researchers also found that care staff preferred shorter sessions rather than one longer session. Due to lower levels of literacy in some care staff, video content was better than relying on text. It is vital that where money and time is invested in training it is invested in effective training.

Further, following training, there needs to be the conditions that enable implementation of learnings in daily practice. WHELD researchers found that attitudes of staff and delivering learnings in daily practice were two elements that corresponded strongly with better outcomes.

The Group also heard about a research project developing an evidence-based training programme for homecare staff: 'NIDUS' (New Interventions for Independence in Dementia). The training includes peer support and group learning, which the researchers found to be important and valued by homecare staff. This research is ongoing and the researchers hope that in the future this programme can be adopted in everyday practice to improve care for people with dementia drawing on support at home.

Addressing the barriers to implementing evidence-based practice

WHELD informed the Group how currently very little training in social care is evidence-based. In an audit of nearly 200 training programmes, WHELD researchers found that only four had an evidence base, and these were used in very few care homes. They also described how some training wrongly claims to be evidence-based, risking confusion about the quality of training and outcomes it can deliver.

Where there is evidence of programmes that are effective in improving quality care, it's important that these are implemented at scale so that everyone living with dementia can benefit. The Group heard that key barriers to implementation of evidence-based programmes are a lack of oversight of training, a lack of access to reliable and trusted information on which programmes deliver improved outcomes, and a lack of funding. There needs to be national oversight to encourage and support providers to purchase evidence-based training, and commissioners to commission services that can demonstrate evidence-based practice. Services and commissioners need to be able to access reliable and trusted information on which programmes are truly evidence-based, to support them in decision making about which programmes to purchase.

In an oral evidence session, Professor Clive Ballard, the lead researcher from WHELD, and Jenny Paton, Director of Strategy, Impact and Policy at Skills for Care, discussed how the sector needs more guidance on what levels of evidence base they should be looking for in training, and how to know if training is sufficiently evidence based in delivering outcomes. Finally, services need sufficient funding to purchase evidence-based high-quality training; where funding is severely limited they may be left with no choice but to purchase training that is cheaper, even if it lacks evidence in improving outcomes. The NIDUS research project found that financial pressures, as well as time, meant training was very hard to fit around current homecare practices²⁷.

Chapter 3

What people affected by dementia want from good care: Staff with skills to provide culturally appropriate care

The definition of personalised care means that it should encompass all aspects of an individual's identity, including their cultural identity. The Group heard very strongly in the evidence though how care that recognises an individual's cultural identity is an important factor in its own right. The Group also heard how currently many people are experiencing care that fails to adequately recognise and respond to their cultural needs.

The Group heard a woman describe her experience of trying to find appropriate care for her husband, who first experienced symptoms of early onset dementia when he was 50 years old.

'From a cultural perspective he is in places where staff do not understand Muslims, their beliefs or their culture. Even the basics such as celebrating Eid, places that are important to him ie Mecca, listening to Quran or Nasheed (Islamic a cappella songs).

He is now regressing to his native tongue, and this is not understood by staff. A document produced by ourselves which has common phrases in different languages, is not used or referred to and therefore when he is saying 'yes' in Gujrati this is interpreted as 'go away'. This is especially frustrating when we have given them the information to help him, and it remains unused. His speech is limited and he cannot communicate his needs.

If you do not understand someone's culture or religion, how can you possibly understand the type of care they require? The idea of having a care plan is that the uniqueness of the individual and their particular likes and dislikes are clear. Unfortunately, if you do not have the staff with the time, skills, or consistency to provide the care for each person then the person's individual identity gets lost and the care plan is effectively useless. The person with dementia quickly loses their skills when they are not being encouraged by the staff. Activities in care homes are for groups rather than individuals. Singing 1950s songs is not age appropriate, it is also not something that he would choose to do or would want to do. Listening to the Quran would be his choice.'

People from ethnic minority communities described the need for a workforce who understand the role of cultural identity and its impact on daily life. People with dementia need staff who seek to understand what cultural practices are important and how they can work with an individual to maintain them.

There will be cultural practices that people have adhered to their entire lives that are important to who they are as a person, such as the clothes people wear or the food they eat. For people with dementia, the condition can impact their sense of self, and so these practices become even more vital in helping preserve their sense of identity. Additionally, familiarity can provide a source of reassurance and comfort. When cultural practices that are important to a person are disrupted, this can have a detrimental effect. For example, where someone is given food that isn't consistent with their cultural diet, they may refuse food. If the carer doesn't understand the reason for this, the individual may then lose weight, with a resulting impact on their health. Where certain cultural practices aren't recognised, well-intentioned care can be interpreted as demeaning or insulting.

Where people aren't able to maintain their cultural identity, they can experience distress, and due to the dementia this may be expressed through challenging behaviour such as agitation or aggression. As discussed in the previous chapter, if care staff don't have the knowledge and skills to identify the cause of the behaviour and address it, it can result in care staff responding with inappropriate use of medication, restraint, or neglect.

The care workforce must also be aware that some people may have experienced discrimination or hostility towards their community (based on their ethnicity, sexuality, etc) in the past. Such memories may be foregrounded by dementia, and can be triggered by certain stimuli. These memories can lead to difficult emotions, which may then be expressed in challenging behaviour. People with dementia need care staff to take the time to understand these issues, identify an appropriate response, and reassure the individual. There are resources available that can help, which have been developed by the communities themselves. These include specially developed guides building on people's experiences, such as Age UK's 'Safe to be me' guide²⁸ for health and social care workers supporting LGBT+ people.

The first chapter discussed the importance of activities being tailored to personal interests, which benefits mental stimulation and overall wellbeing. This issue is likely to disproportionately impact people from ethnic minority communities, who may be less likely to engage with activities designed for people of a different culture.

People affected by dementia also need a workforce that understands unconscious bias and prejudice. Unconscious bias can influence attitudes and behaviours of care staff towards the people they are caring for, and can result in people receiving a lower standard of care. Because people are not consciously aware of this bias, it is vital that staff receive education and training that helps them to understand this issue and how it may be affecting them, as well as what they can do about it.

People with dementia will sometimes need support from care staff who can speak their first language, especially if they have reverted to their first language due to dementia. Care staff who can speak the same language are more able to communicate effectively, and can therefore have a big impact on their ability to live well.

The Group heard a strong message on the need for information about culturally appropriate services to be communicated to these communities. The view that services don't meet the needs of people from ethnic minority communities can contribute to people not seeking help until too late – due to a belief that the help isn't there. It is also vital that commissioners and services don't act on the misconception that some communities 'look after their own' – people from all communities may need support from social care, and should be able to draw on this, rather than be expected to rely on unpaid family carers.

Care staff should also have awareness of the stigma around dementia that can exist in some communities²⁹. In some communities there isn't a direct translation of the term dementia³⁰ and some communities will attribute the symptoms of dementia to something else, due to stigma and denial, or a lack of awareness.

It is vital that today's workforce are equipped with the knowledge and skills they need to support people with dementia from minority ethnic groups. It is also important to recognise that the number of people from ethnic minority communities with dementia is increasing, and at a faster rate than for the white British community: in 2013 the APPG on Dementia reported there were an estimated 25,000 people living with dementia in the England and Wales from an ethnic minority background, and that this figure was expected to double to nearly 50,000 by 2026, and to rise to over 172,000 by 2051³¹.

This is an increase of a much faster rate in comparison to the white British population, due to a combination of factors. There was an increase in people from ethnic minority communities moving to the UK in the 1950s and 1970s, who are now reaching an age at which they are at greater risk of developing dementia³². People from some ethnic minority communities, including African-Caribbean communities, may also be at increased risk of developing dementia in comparison to the White British population³³; and in particular at greater risk of developing vascular dementia, due to greater prevalence of vascular risk factors^{34 35}.

Improving culturally appropriate care

Training that gives care staff an understanding of the experiences of people from ethnic minority communities drawing on care can be particularly useful. The Group heard how training for the care workforce can draw on the expertise of organisations that specialise in supporting people from minority communities.

Some examples of specialist organisations are Meri Yaadain, Touchstone Support, Chinese Wellbeing, and Irish in Britain. Many have successful partnerships locally where they are providing expertise and support to social care providers, as well as providing support to people affected by dementia directly.

The Group heard that specialist services can be particularly important for communities in which there are high levels of stigma. People can feel more comfortable talking about dementia with people from their own community, who they know will understand their culture, whilst they can't be confident of this in other services.

The Group also heard that some specialist organisations have produced excellent resources which are available online, including through webinars and videos. There is also a resource available from the CQC to support culturally appropriate care, with guidance for providers and examples of good practice³⁶.

Training is needed at all levels to embed a culture that recognises the importance of culturally appropriate care and facilitates its delivery. A workforce must be representative of the community it serves at all levels, from frontline roles to service management, to commissioning and other decision-making roles. This diversity is essential in developing services that meet the needs of people with dementia from minority ethnic communities.

Using music to provide culturally appropriate care

The Group heard that music can be a good way for care staff to help people from a different culture feel a sense of familiarity and comfort, and of being understood. This can be particularly useful for people who may have reverted to their first language. The Group heard a case study from the Cambridge Institute for Music Therapy (CIMTR) at Anglia Ruskin University, in partnership with MHA care homes, of a woman born in Hong Kong, living in a care home in the UK.

“K’ was born on a small fishing island of Hong Kong. She came to the UK with her husband 50 years ago and worked for many years in a family Asian takeaway store. K doesn’t speak or understand English anymore due to the cognitive impairment caused by dementia. She only says a few words in Cantonese and regularly sings a specific type of song which we managed to identify as a variation of the Cantonese folk songs called the fishermen ballads . As a person of a different cultural background living in a British care home, K can experience a lack of opportunities for communication, engagement, and social interaction. This can raise the issue of isolation and increase possibilities of social and cultural exclusion. During music therapy sessions Cantonese words, Cantonese Christian hymns and well-known songs from K’s era were used to create a sense of familiarity and comfort and to increase a sense of identity and feeling understood. This also helped to foster interaction, communication, and a sense of togetherness. The specific material was provided by K’s relatives and other music therapy professionals working with a similar population in Hong Kong.’



Chapter 4

What people affected by dementia want from good care: Staff that involve family members as partners in care

A strong theme from the evidence received was that family carers need to be involved in their loved one's care. This needs to start with care planning and be maintained throughout provision of care, with involvement in decisions about care as needs change, and with regular ongoing communication with care staff.

Family carers need the care workforce to treat them as a partner in care planning. The NICE dementia guideline recommends that care and support plans should be agreed and reviewed with the involvement of their family members or carers, though the Group heard some family members describe having little or no involvement.

Some family members shared experiences of their input being completely disregarded.

'Care home did not think I had anything to offer in the care of my husband. We were married for 54 years. I don't think they thought of asking me and although I made suggestions to care staff, it was not welcome.'

Elizabeth*, wife of a person with dementia

Others, however, shared positive experiences of being involved in their loved one's care. One man described that care staff saw him 'as a member of their team', and he saw the care staff as 'my extended carers'.



Involving family carers in care planning and decisions about care is an extension of personalised care. An evidence review found that a formal mechanism that legitimises and invites family involvement leads to greater personalisation of care³⁷. In addition to the person with dementia, family carers can be a vital resource to draw on for information about the person, what's important to them, and their personal history. When the family carer has themselves been caring for the person with dementia, they may have a wealth of knowledge about what works and doesn't work with their care. The exchange of this information can be hugely valuable for care staff starting to take on the caring role for an individual, and not doing so is a huge missed opportunity.

An approach similar to that of life story work in adoption could be taken – involving a wide range of people in the person's life, and providing a really rich account of who the person is and their personal history. Community Circles is a great example of drawing on the knowledge of not only the primary family carer, but the whole support network of an individual – extending to wider family, friends, neighbours, and others in the community. The support network help develop a personalised support plan, as well as helping provide support themselves.

Family carers also want regular ongoing communication with care staff, to receive updates on their loved one's care, and to share information and advice that can support care as different scenarios arise and needs change. The Group heard from some family carers who reported good communication with care staff, with regular meetings or calls. The Group also heard from people who reported poor communication from care staff, being excluded from conversations and struggling to receive updates on an ongoing basis. Some examples were from during the pandemic, when there were additional pressures on services but also increasing need for this communication due to restrictions on care home visits. However, there were also examples of longer-term issues with communication.

'The communication and attitude of care staff is terrible. Either we don't get any communication, or we get conflicting information when asked about our loved one's care. Very defensive. I now feel intimidated by staff if I phone to check on them, and I am suffering from mental health problems myself as I don't feel I can protect them.'

Hannah*, carer of a person with dementia

'In general communications were sadly lacking between the home and the family. We still don't feel included – imagine our concern when told that the home had Covid one week but then didn't hear anything further except, 'You'll be told if it's your relative who has Covid!'. Almost without exception the weekly Zoom meetings didn't happen unless we rang after waiting for 5 or 10 minutes, leaving us with less time to speak to Mum. Staff also didn't seem to realise that they couldn't just leave Mum with the laptop to talk to us as she needed encouragement to engage with us on the screen, it being bewildering to her and somewhat out of her experience or comprehension, unless someone had the time to be with her. That interaction with us all made a huge difference to the call.'

Teresa*, daughter of a person with dementia

After a person with dementia first moves into a care home, their family carer may be adjusting to a big change. Before the move, they may have spent many hours of their day caring for their loved one, and knew everything about their health and wellbeing. It is a big change to then entrust the care of their loved one to a care home, not knowing how their loved one is doing each day. It is important that care staff recognise that this experience can be a difficult adjustment, and that they are sensitive to this when communicating with family carers. They should aim to provide regular updates, as well as reassurance, particularly during this period of transition.

Caring for someone with dementia can be different to caring for people with other conditions. The primary unpaid caregiver to a person with dementia is most commonly a partner or spouse and it is important to remember that they are that – a partner in a loving relationship. Their role does not change from ‘partner’ to ‘carer’ overnight when a person is diagnosed with dementia. The role change to ‘carer’ occurs over time, as the condition progresses, and caring responsibilities increase. The emotional impact of this change should not be underestimated. There is also an emotional impact from seeing the person they love change, in communication and behaviour. There can be a huge physical toll of caring for long hours, which can have an impact on health and wellbeing too. Navigating the system to find the right support for their loved one can also cause a great deal of stress.

When care staff and family carers understand each other’s experiences and perspectives, it can aid effective communication. The Group received evidence from researchers from the ‘NIDUS’ project who found homecare staff felt family carers did not understand the pressures of their role, whilst some family carers felt that homecare staff didn’t care. The researchers developed two training programmes, one for homecare staff and one for family carers, that would help change this³⁸. The programmes aim to support joined up care between homecare staff and family carers, resulting in improving personalised care for the person with dementia.

It is important also that family carers themselves are supported in their own needs. In an oral evidence session the Group heard from Paul Edwards, Director of Clinical Services at Dementia UK, about Admiral Nurses and the role they can play: ‘Their key focus really is on maintaining family relationships and keeping families together by providing support to the whole family, because we recognise that it’s not just the person that lives with dementia, it’s very often the family that lives with it too. And all of those changes and adaptations and all of the emotional difficulties, practical difficulties and clinical difficulties, Admiral Nurses are there to try and support families through those times.’ The health and wellbeing of family carers also has an impact on their ability to care for the person with dementia at home for as long as they would like to.



Chapter 5

What people affected by dementia want from good care: A workforce enabled to deliver personalised care

Time to care

In the written evidence, lack of time of care staff was identified as a barrier that prevents people with dementia from living their lives how they want to. Where people affected by dementia weren't experiencing personalised care, they often described care staff not having the time to provide this care.

People described needing staff to have the time to get to know the person with dementia.

'Time is needed to be spent with the person and their family/friends who know what they love /hate and what works/doesn't.'

Emma, carer for a person with dementia

'The management had no interest in her care. The carers did their best but didn't have time to tailor her care to suit her needs.'

Elizabeth, daughter of a person with dementia

People described staff lacking the time for one-on-one care.

'There is not enough time to spend with individual people. My mother loves to go outside but no one takes her, she loves to paint or draw, but can only do it if someone shows her.'

Valeria*, carer for a person with dementia

'He rarely had companionship from the carers. They kept him clean and fed but didn't spend time with him, talking to him or watching telly with him. Unless they were doing personal care or feeding him, I think he spent a lot of time on his own as he was bed bound. I don't think they had time to spend with him.'

Sam*, carer for a person with dementia

It was clear that family members recognised that staff didn't have the time, rather than just not taking the time. This wasn't a case of staff **choosing** not to take the time, but staff **not being able** to take the time.

'It was understaffed so even though the carers did their best, they didn't have time to care for her properly.'

Elizabeth, daughter of a person with dementia

'Some members of staff were excellent but often overworked, so had no time to deal with an individual's issues.'

Sienna*, daughter of a person with dementia

‘The care home staff were excellent. The at-home carers less so because of time constraints. I was paying for 30 minutes but their client list meant they were keen to leave after 10.’

Maxine, daughter of a person with dementia

Many people with dementia are experiencing care that is often task oriented instead of being focused on outcomes. There is a focus on meeting personal care needs, with social or emotional wellbeing often side-lined. This is the result of a system where care homes are struggling with staffing numbers; where homecare is commissioned and purchased based on tasks and time. This has resulted in a focus on meeting needs of personal care, rather than extending to supporting people with the things that matter most to them in a truly personalised way.

The Group heard from the Homecare Association:

‘Regrettably, the way that homecare is commissioned and purchased by local authorities does not always enable these conditions [specialist needs of people with dementia] to be met. Typically, local authorities purchase care by the minute or hour, allocate inadequate time for visits, and focus purely on physiological needs.’

‘Demand for homecare is exceeding supply. Inadequate workforce capacity means there are not enough staff available to provide the more intensive support required for people with dementia, or indeed, any care at all. Many care workers are expected to provide care for people with dementia in 30 minute visits, without flexibility to adjust timings according to fluctuating needs.’

Developing a strong and trusting relationship

The Group heard many people describe the importance of a strong, trusting relationship to develop between the person with dementia and care staff. The Group also heard of the difficulties in adapting when the carer changes to someone new and unfamiliar.

Where care involves personal care, this often deals with intimate needs, such as bathing, dressing and toileting. Many of us may struggle with suddenly having a stranger help with these tasks. It is not surprising that it is important for many people to build a relationship and trust with the person that provides this help, and that there may be resistance or lack of cooperation if the person that helps with these intimate tasks suddenly changes.

One person spoke of trying to get around this challenge by employing someone who had been cleaning the house to care for her husband for a period before starting more formal care; they were both familiar with her, and he liked her, and he didn’t want help from someone he didn’t know. The knowledge and understanding required for personalised care is developed through spending time with the individual. When a carer changes, this relationship is lost and the process must start again. Shared Lives is a good example of care that is based on a strong, sustained relationship – between the person with dementia and the person who has opened up their home to them.

The Group heard many examples of people drawing on homecare experiencing inconsistency of care staff.

‘We rarely got the same carer twice.’

Joan, wife of a person with dementia

‘At home, care had a rotating group of carers, so they formed transient relationships at best.’

Neil, carer for a person with dementia

‘They had to change carers a few times which upset and confused my mum. She was happy whilst she had the same carer for quite a while.’

Layla*, daughter of a person with dementia

‘When continuity of the same carers is available my father is happier and more settled.’

Jennifer, daughter of a person with dementia

The Group also heard from people who described care staff being switched as a result of complaints.

‘My mother and a caregiver worked extremely well together, understood and engaged in conversation, then she suddenly stopped coming. I happened to see her and was told they had moved her to another person due to complaints from family regarding other carers. She admitted when any problem arose from complaints, they always moved her to care for them.’

Linda Anne, daughter of two parents with dementia

The care sector is facing significant challenges with staff retention and recruitment. The number of staff vacancies stands at over 100,000³⁹ and a survey of Homecare Association members in November 2021 found that 85% said recruitment was the hardest it has ever been⁴⁰. This issue has been worse at particular times over the course of the pandemic when high numbers of care staff have been off work sick, either with Covid or isolating after being identified as a close contact of someone with Covid. However, the issue existed prior to the pandemic, and is set to get worse in the future – Skills for Care forecasts show that to meet demand from population growth in over 65s between 2020 and 2035, 490,000 more staff would be needed, an increase of 29%⁴¹.

Analysis from Skills for Care has shown a relationship between staffing issues and quality of care: establishments with the lowest CQC scores had more issues retaining staff (an average turnover rate of 33.7%), compared to those with the highest scores (which had an average turnover of 29.2%). Additionally, establishments with lower vacancy rates, on average, received better CQC scores: those receiving high CQC scores had an average vacancy rate of 5.0% compared to a rate of 6.1% for those with lower scores. Care homes with more staff in post per bed, on average, also received better CQC scores than those with lower staffing ratios⁴². It is vital that staffing issues are addressed to enable continuity of care for people with dementia to support the development of strong and trusting relationships.

The importance of leadership in embedding practices

Some people affected by dementia described seeing the culture of care coming from the ‘top’ of the care home.

‘It seemed that the culture in the home coming right from the top down was such that facilitated this, and there was no empathy, there was no sympathy.’

Gaye, carer and person living with dementia

‘What we know about good care is that good care is often led. If you’ve got a care home with the right culture, the right leadership and the right support around care teams, then that makes a massive difference.’

Paul Edwards – Director of Clinical Services, Admiral Nurses

There is evidence from CQC of a strong relationship between quality care and good leadership: over 90% of services rated good or outstanding for being well-led by the CQC were also rated good or outstanding overall⁴³.

An evidence review from the University of Leeds has also highlighted the importance of leadership in high-quality care⁴⁴. The review explored the relationships between the care home workforce and quality of care. It found that the quality of care is impacted by how leaders use available resources and how they promote a culture in which high-quality relationships between individuals and carers can flourish. A clear, managerially endorsed philosophy that puts residents at the centre of care, combined with a core number of consistent staff – with regular contact with residents and relatives, and time spent understanding and responding to individual preferences – was important. It was found to promote meaningful reciprocal staff-resident relationships, and led to more individual needs being met. They identified other important factors including promoting team relationships, with staff drawing on each other’s knowledge and skills; staff being treated as expert partners in care; and recognition and reward of staff.

Delivery of high-quality personalised care doesn’t start with frontline care staff; a culture of delivering personalised care needs to start from and be embedded by leadership. It is vital therefore that leaders and managers in care have an in-depth knowledge and understanding of the importance of personalised care too.

Valuing the care workforce

Where people affected by dementia described accounts of good care, their appreciation for carer staff was clear. Many people also specifically stated that they wanted the care workforce to be better valued by society, and to have working conditions that reflect that value. There was recognition that currently this isn’t the case.

‘We expect carers to give the love and care at a level we would ourselves and yet they are some of the lowest paid and least appreciated workforce.’

Leah*, carer for a person with dementia

‘Carers are doing their best in a bad situation. Care is underfunded and undervalued.’

Maria*, person living with dementia, receiving care in a care home

[Discussing barriers to good care] ‘The poor pay, the lack of career structure etc, and culture.’

Gaye, carer and person living with dementia

‘Care in any setting needs to be seen as a profession with clear career progression and decent levels of pay. My dad is in a care home and they have lost a really good carer to be a takeaway delivery driver as it was a higher rate of pay.’

Naomi*, carer of a person with dementia

Skills for Care analysis shows that employers with favourable workforce metrics, such as high levels of learning and development, on average had better outcomes of lower staff turnover and/or high CQC ratings⁴⁵. Their analysis has also shown that higher care worker pay was associated with higher CQC scores. Care workers at the lowest scoring establishments had a median hourly rate of £8.86 compared to £9.20 with the highest score.

In March 2022, sector leaders, including the Association of Directors of Adult Social Services (ADASS), the Local Government Association (LGA), and the Social Care Institute for Excellence (SCIE), came together to call on Government to deliver a long-term care workforce strategy to address these issues. They warned that failing to address these issues would make it difficult to make meaningful progress towards the goal of best supporting people to live the lives they want to lead⁴⁶.

To support people with dementia to live their lives well, the care workforce need to be supported themselves, in their career and overall wellbeing. This will enable them to be their best selves in their role of supporting people with dementia.



Conclusion

In this inquiry the Group has heard what people affected by dementia need from the care workforce to enable them to live their lives well. The Group has also heard how for many people, the reality of care today does not match the standards of care that people with dementia need and deserve. Examples of very good care, however, show the impact of care done well – people with dementia living meaningful and connected lives.

Delivering the recommendations set out in this report would deliver benefits extending beyond people affected by dementia. It would also change the lives of 1.5 million people working in care. The calls of the workforce themselves are well-recognised and it is striking that this mirrors much of what people drawing on care want too.

We need to empower our workforce with the knowledge and skills to truly understand and connect with the people with dementia they care for, so that they can identify the things that are most important to the individual and support them in living fully. This is an opportunity to transform jobs in care, to make care the fulfilling and rewarding career we know it can be. Care should be a career that brings high job satisfaction, where every day people know they have helped people to live well. Sadly for many care staff, they feel stressed and physically and emotionally drained from the hard work, lack of support, and working in conditions that do not enable them to care in the way they want to. There are jobs in care located in every part of the country. By introducing a career structure with an aligned framework for learning, development and pay, there is an untapped potential to ensure care work improves wellbeing, supports progress in the workplace, and raises earning potential in all areas of the country. The Group believes these aims are best achieved through a People Plan for social care.

By expanding the concept of care to offer more services that take an asset-based approach in the community, and by providing greater resources for under-utilised local community organisations, there is also the potential to harness the power of social capital. This can develop and strengthen community cohesion, cooperation, belonging and trust.

The Government has the opportunity now to deliver on the vision of care set out in the social care white paper to unlock far-reaching benefits for everyone.

As we look to the next steps in the road to delivering on reform, the Group hopes that this report is one exercise of many that listens to people affected by dementia and places their needs at the centre of care. Government needs to see people affected by dementia as partners in every step of design and implementation of reform.

Methodology and acknowledgements

In January 2022, the APPG on Dementia launched its inquiry into what people affected by dementia want and need from the social care workforce. The inquiry included:

- A call for written evidence from people affected by dementia and organisations with expertise and experience in dementia care.
- Four oral evidence sessions, with a total of 11 witnesses.
- An online survey for people affected by dementia with experience of drawing on social care, which was completed by 1,914 people, throughout January and February 2022.

The Officers of the APPG on Dementia would like to thank everyone who responded to the online survey and shared their experiences and views. The APPG would also like to thank the following respondents for evidence to the inquiry:

Oral evidence:

Trevor Salomon, carer

Gaye Pain, carer who also lives with dementia

Paul Edwards, Director of Clinical Services at Dementia UK

Mohammed Akhlak Rauf MBE, Founder and Director of Meri Yaadain CiC

Barbara Gray, former family carer and community worker

Morcea Walker, community leader and former carer

Professor Clive Ballard, Pro-Vice Chancellor and Executive Dean of The University of Exeter College of Medicine and Health

Jenny Paton, Director of Strategy, Impact and Policy at Skills for Care

Cath Barton, Development and Operations Lead at Community Circles

Kath Crowther, carer

Claire Morphet, Family Based Support Manager at Shared Lives

Written evidence:

Cambridge Institute for Music Therapy Research (CIMTR) at Anglia Ruskin University

Care Home Volunteers

Central and Cecil Housing Trust

Claudia Cooper, Professor of Psychiatry of Older Age at University College London

Debora Price, Professor of Social Gerontology at the University of Manchester

Dementia Research Centre, University College London

Dementia UK

Dr Clarissa Giebel, Senior Research Fellow at the University of Liverpool

Essity

Homecare Association

Irish in Britain

Joseph Sawyer, Academic Clinical Fellow at University College London

Justine Schneider, Professor of Mental Health and Social Care at the University of Nottingham

Katherine Hay, Consultant Old Age / General Adult Psychiatrist

Manchester Centre for Audiology and Deafness, University of Manchester

Meri Yaadain CiC

MHA (Methodist Homes)

NIHR Manchester Biomedical Research Centre, Manchester Centre for Audiology and Deafness, University of Manchester

Nordoff Robbins

Race Equality Foundation

Skills for Care

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Dementia Research and Innovation Centre

The Lewy Body Society

Together in Dementia Everyday (tide)

Tony Severwright, carer

Understanding Dementia

Vegetarian for Life

Young Dementia Network

The inquiry also took evidence from a number of people affected by dementia and academics who wished to remain anonymous.

Thank you also to Jordan Clark, Tom Redfearn, Jo Baxter, Alex Morden Osborne and all at Alzheimer's Society for their help in managing this inquiry and drafting this report.

If you would like to find out more about this report or inquiry, please contact appgondementia@alzheimers.org.uk

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Recordings of the four oral evidence sessions held for the inquiry are available online at <https://www.alzheimers.org.uk/about-us/policy-and-influencing/all-party-parliamentary-group-dementia>

The All-Party Parliamentary Group (APPG) on Dementia is a group of cross-party parliamentarians with an interest in dementia. It was created to build support for dementia as a publicly stated health and social care priority, in order to meet one of the greatest challenges presented by our ageing population.

The APPG prides itself on remaining at the forefront of debates on the future of dementia care and services. Over the past ten years we have run parliamentary inquiries into key issues affecting people with dementia, their families and carers.

September 2022

**Alzheimer's Society provide the
secretariat for the APPG on Dementia.**

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