Homecare Association

Homecare Association evidence for the APPG on Dementia

The All-Party Parliamentary Group on Dementia, co-chaired by Debbie Abrahams MP and Baroness Greengross, is undertaking an inquiry into the social care workforce, particularly how we can build a workforce that is able to meet the needs of people living with dementia and their loved ones. The inquiry's focus will be on how we can ensure that people with dementia can live the lives they wish lead, and this goal is not impeded on because the individual draws on social care.

The inquiry will consider what the more specialist needs are of those with dementia who draw on care, and how they can be met, how people's cultural and social needs are reflected in the care they receive, and what Government, providers and regulators can do to ensure that people with dementia receive personalised care.

The Group is accepting written evidence as a part of the inquiry and is particularly interested to hear thoughts on:

Understanding the issues

1. **What is some of the more specialist support people with dementia need compared to people without dementia receiving care? What projections are there for future demographic needs? (e.g any communities which may begin reaching older age).**

Adopting a person-centred approach in social care means that each individual's needs should be assessed, and a personalised care plan produced aimed at meeting those needs, in collaboration with the individual and their informal carers. To this extent, devising a care plan for someone with dementia is no different from doing this for anyone else.

Needs of a person with dementia are as varied as those who do not have dementia and it would be inappropriate to suggest a “one size fits all” approach to their support. Type and severity of dementia, age, physical function, mental capacity, pre-morbid personality and interests, healthcare needs, environment (e.g., noise, light, temperature), social circumstances and networks (e.g., lives alone or in a family/community), cultural background, presence and ability of family to provide support and a person’s wishes may all influence the nature of support required.

Outcomes for people with dementia at home related specifically to the progression of dementia as a disease, are affected principally by ability to meet: 1) physiological needs, e.g., behaviour issues, cognitive and functional impairments, and the frequency and duration of caregiving; and 2) psychological needs, e.g., anxiety, depression, and distress.

People with dementia typically gradually lose their ability to hold conversations and discuss events, information, or stimuli. This lack of communication may hinder them from being able to voice their psychological needs to the people supporting them. Therefore, caregivers of people with dementia may become primarily focused on addressing their physiological needs, such as their health, safety, shelter, and nourishment needs. In turn, this may leave the person with dementia with unmet psychological needs, resulting in agitated behaviours and poor psychological health outcomes, such as depression. Agitated behaviour among people with dementia is associated with multiple negative consequences. Similarly, it is possible to become unduly focused on agitated behaviour without realising it stems from an unmet physiological need. It is not unusual for agitated behaviour to cease as soon as a need is met.

Some people with dementia may find it difficult to adapt to new environments, visitors, or unfamiliar staff members, and new social networks may be very overwhelming and a source of stress.

The environment plays an important role in the way that an individual interacts with other people and understands their surroundings. Too often or too much stimulation can lead people with dementia to exhibit disruptive behaviours, including agitation. There is evidence that older adults in their own homes experience a higher quality of life and maintain more activities of daily living, including socialisation, than those in long-term care facilities, where they may face overwhelming stimulation from new environments and communal living.

Safety of people with dementia may be a challenge in a home environment if they are inclined to wander or be unaware of hazards, such as hot stoves and the need to switch off appliances. This can be extremely stressful for informal carers too. Technology solutions can assist with improving safety, provided there are surrounding support services, for example, to rescue someone who has wandered into potential danger or gone missing.

So, maintaining a calm and predictable home environment, with a stable homecare team, without multiple staff changes, is very important. It is also important to ensure adequate time is available for a care visit to understand and meet needs, which may be communicated non-verbally, and may be psychological and not just physiological. Providing adequate support for informal carers who are caring for a loved one with dementia is often overlooked, though this is vital to ensure that the domestic arrangements are sustainable.

Regrettably, the way that homecare is commissioned and purchased by local authorities does not always enable these conditions to be met. Typically, local authorities purchase care by the minute or hour, allocate inadequate time for visits, and focus purely on meeting physiological needs. This is particularly true for older people, for whom commissioned care is often much less generous than it is for under 65s. Furthermore, cut-backs have meant that respite care is often unavailable, which means informal carers are not supported to have a rest. Similarly, specialist services for day care for people have been cut and there are few that can cater for people with dementia.

People with early onset dementia often struggle to access care services that meet their needs as most services have been developed for older adults.

People with a learning difficulty, such as Down syndrome, are now living longer and developing dementias. Generally, they receive more bespoke supported living services, so it is easier to adapt these to meet changing needs over time. That said, some people with learning difficulties may also access day care services, which may not be able to cater for people with dementia. More specialist day care services for people with dementia are needed, though day care services in general have been harder to deliver during the COVID-19 pandemic.

Projections of prevalence of dementia and need can be found on the Dementia Statistics Hub.

An estimated 60% of people receiving homecare services are living with dementia.

In England and Wales, the number of people living with dementia who need palliative care will almost quadruple by 2040.

2. What are the barriers (within the workforce) currently which limit people drawing on care being able to live the lives they wish? How are people with dementia involved in decisions on the kind of support they receive?

The answer to this question depends on whether people are state-funded or self-funded and whether they are under 65 or over 65.

People who pay for their own care and their families typically have greater choice and control in the care they receive than those who are funded by the state. Care plans are drawn up in collaboration with the person receiving care and their families.

Those who are state-funded have to accept what they are prescribed by a social worker and homecare providers have to deliver what is on the purchase order. In theory, the assessments by social workers should account for people's wishes but the reality is that people only receive the care that councils can afford. Due to budget cuts over the last decade, the number of people receiving homecare has declined and the number of people relying on informal carers has increased.

People under 65 who have received care and support throughout their lives are probably in a better position, as the amount spent per person is typically 2x higher than for older people and is more individualised.

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 careworkers are expected to provide care for people with dementia in 30 minute visits, without flexibility to adjust timings according to fluctuating needs.

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

Social and cultural identities

3. How does someone's culture or social identity impact on the type of care they wish to receive? How is provision of care and support adapted for people's language, cultural and other needs?

As stated at the outset, people's needs and wishes vary and the principle is that care assessment and planning is person-led.

The process of creating a care plan will, if done properly, explore all aspects of a person's needs and wants and identify how best these can be met. It may not always be possible to meet a person's preferences, for example, if they speak an unusual language and live in a place with no other speakers of that language, it may not be possible to find a care worker who speaks that language. In this case, providers may try to find other ways to enable the person to connect to others who speak the language, e.g., online.

Normally, every effort is made to ensure that a person's cultural background is respected and care workers are matched with care recipients. For example, if a person wants a vegan diet, this will be supported. Culturally appropriate care is something the Care Quality Commission considers in their inspections.

4. What is some of the best practice in the UK being carried out at the moment as it relates to delivering against people's social and cultural needs? What is the impact on the individual of not providing for people's cultural and social needs?

There are many examples of best practice, including:

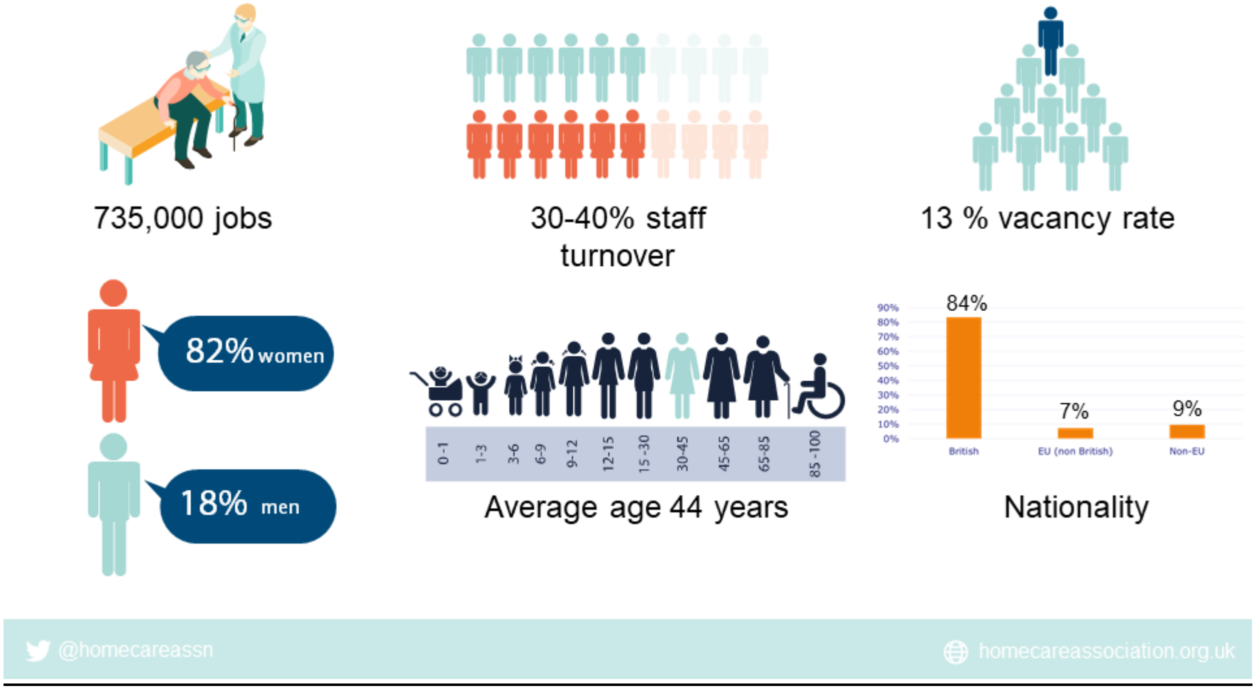
- Many places of worship are streaming prayers, services and other events because of the pandemic and people are being supported to join in with services or activities in churches, gurdwaras, mosques and temples.
- Someone who follows a vegan diet is involved with preparing their meals so they can see how their food is prepared. Careworkers will also check that their medicines do not contain gelatin.
- Some people want to fast during Ramadan, so the timing of their medication may be changed after discussion with their GP.
- If a person living with dementia decides to eat something not normally allowed under their faith, providers may use the principles of the Mental Capacity Act to help them determine whether the person lacks capacity or has just changed their mind.
- Some people were concerned about accepting COVID-19 vaccines in case they contained animal products, or any ingredients precluded by their religious beliefs. Help was sought from local religious leaders or community pharmacists from the same cultural background to provide trusted information and advice.
- COVID-19 vaccination was difficult for some people with dementia, as though they were not technically housebound, the act of going to a vaccination centre was very stressful for them. Some providers persuaded local GPs to administer vaccines in people's own homes.
- Some people from different cultural backgrounds are supported to wear clothes from their own backgrounds, e.g., saris for Indian women, if they wish.
- Some people living with dementia revisit memories that are specific to their culture. It might be something that makes them upset, for example, memories

of a war. Providers try to find family or friends to help them understand the background if the person themselves is unable to explain.
- End of life care requires awareness of different traditions, for example, burials normally happen very quickly in Jewish and Islamic faiths. Providers ensure their staff are aware of this.
- Some providers provide training in cultural competence. They also try to match careworkers with people receiving support.
- Equality, diversity and inclusion issues need to be addressed. For example, sometimes careworkers may experience discrimination by a person receiving care on the basis of a protected characteristic, e.g., race, gender, sexual orientation. A person may say, for example, that they don't want a "foreign careworker". If the person has full mental capacity, racism is not tolerated and many councils will inform people receiving care that if they decline a careworker without a valid reason, they will have to fund their own care. If a person lacks capacity, for example, as a result of dementia, a different conversation is needed and a mutually beneficial solution will be sought.

The workforce

5 What is the profile of staff in the care sector? Generally, what qualifications do they have and what drives them to work in the sector? What level of understanding of care staff have of dementia? What knowledge and other training gaps do care staff feel exist for the workforce?

The graphic below is a summary of key features of the homecare workforce.



Over two thirds (69%) of care workers that started in the sector after January 2015 have engaged with the Care Certificate.

Just under half of the direct care-providing workforce (43%) held a qualification at Level 2 or higher in 2020/21.

Care staff typically remain in the workforce because they want to make a positive difference to the lives of others and enjoy doing so. Over time, social relationships form between care recipients and care givers, which are mutually beneficial.

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.

The Homecare Association offers training on dementia care to our members.

Care workers need to understand the different types of dementia and the way this disease may manifest and develop. They need to know how best to understand and meet a person’s physiological and psychological needs, especially if verbal communication is not possible. They need to know how best to support people with memory loss and deal with the ethical dilemmas that arise, for example, whether to enter the person’s reality or to refute their perception of reality, which may result in an intense emotional reaction. They need to understand how to support a person who is experiencing agitation. They need to understand the Mental Capacity Act and its implications, including how best to ensure safety whilst being mindful of deprivation of liberty safeguards.

Careworkers receive training in numerous areas, including but not limited to:

- Health and safety
- Moving and handling
- Fire safety
- First aid
- Assessment and care planning
- Infection control
- Wound care
- Medicines management
- Safeguarding
- End-of-life care
- Pain management
- Disease specific training, e.g., diabetes
- Nutrition and hydration
- Food hygiene
- Data protection
- Record keeping
- Equality, diversity and inclusion

Government proposals

6. What opportunities does the Government’s £500m investment in the workforce from the Health and Care Levy provide, and how can this be used to ensure that those drawing on care are able to draw the care they wish to receive? How much do the Government’s proposals for social care workforce reform reflect the needs of those who draw on care?

The £500m investment in the workforce is welcome and amounts to £111 per employee per year for 3 years. The policies to be delivered with this funding are:

- A Knowledge and Skills Framework (KSF), career pathways and linked investment in learning and development to support progression for care workers and registered managers.

- Funding for Care Certificates, alongside significant work to create a delivery standard recognised across the sector. This will improve portability, so that care workers do not need to repeat the Care Certifcate when moving roles.
- Continuous Professional Development (CPD) budgets for registered nurses, nursing associates, occupational therapists, and other allied health professionals.
- Investment in social worker training routes.
- Initiatives to provide wellbeing and mental health support and to improve access to occupational health.
- A new digital hub for the workforce to access support, information and advice, and a portable record of learning and development
- New policies to identify and support best recruitment practices locally.
- Exploration of new national and local policies to ensure consistent implementation of the above, as well as higher standards of employment and care provided.

The social care reform proposals for workforce do not address careworkers' pay, terms and conditions.

The proposals may reflect the needs of those who draw on care if the latter are analysed and used to shape the development of the Knowledge and Skills Framework. At this stage, plans for the Knowledge and Skills Framework appear embryonic and it is unclear how the needs of people receiving care will be considered.

The role of regulators

7. What role do statutory authorities have a role in ensuring that personalised care is provide and how is this measured? How do regulators measure whether the provision of personalised care for people with dementia?

In England, the Care Quality Commission has a clear framework for inspection with five standards – safe, effective, caring, responsive and well-led – with a range of Key Lines of Enquiry (KLOEs) for each standard. Demonstrating a person-led focus on improving outcomes for people receiving services is necessary to be rated outstanding.

CQC's proposed new strategy for regulation is risk-based and data-driven. Evidence collected will include people's experience; observations of care; feedback from staff and leaders; feedback from partners; processes; and outcomes. It is unclear how this approach will ensure effective care for people with dementia, particularly as there will be fewer comprehensive inspections and regulators are now focusing on risk rather than on best practice. Gaining feedback from people receiving services is more challenging for those with cognitive impairment and inspectors have to rely more on observations of care and feedback from others.

Commissioning authorities also have responsibility for monitoring quality of care. This does not include comprehensive inspection and tends to depend on asking providers to complete contract monitoring forms.

The way that homecare is typically commissioned and purchased by public sector organisations mitigates against high standards of dementia care at home. In particular, homecare is usually purchased on a time and task basis rather than focusing on outcomes.

Research and technology

8. How do providers and regulators involve people affected by dementia and evidenced research in developing training pathways and role requirements? What support/training is available for staff to be able to use this technology to provide better care to people with dementia?

Involvement of people affected by dementia and evidenced research in developing training pathways and role requirements is, in our view, patchy. Research evidence on care for people at home with dementia is not robust. Conducting research on care for people with dementia at home is challenging. Grant awarding bodies, such as NIHR, have demonstrated an intrinsic bias against homecare. Feedback on academic grant applications has included views such as “there is no point in funding homecare research because staff turnover is so high”. The latter is not universally true, though homecare providers have become increasingly stretched due to workforce shortages, especially in the state-funded part of the sector. It is easier to find homecare agencies willing and able to participate in research in the private-pay part of the sector, which tends to raise questions from grant-awarding panels about ability to extend findings to the wider sector.

In general, we consider training on dementia in homecare to be inadequate, particularly as it is estimated that 60% of people receiving homecare are living with dementia. There are no national training standards for any aspect of homecare delivery. The Homecare Association provides “train the trainer” courses on dementia care.

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30 April 2022