

Written evidence submitted by Alzheimer's Society (DEL0115)

About Alzheimer's Society

Alzheimer's Society is the UK's leading support services and research charity for people with dementia and those who care for them. It works across England, Wales and Northern Ireland. The Society provides information and support to people with all forms of dementia and those who care for them through its publications, dementia helplines and local services. It runs quality care services, funds research, advises professionals and campaigns for improved health and social care and greater public awareness and understanding of dementia.

There are currently 850,000 people with dementia in the UK, with this number set to rise to over 1 million by 2025.

Immediate concerns

Dementia is the second most frequent pre-existing health condition for people dying of coronavirus.¹ Research shows 70% of older care home residents have dementia.² Throughout the pandemic our Dementia Connect support line has been inundated with thousands of calls, 80% of which are from people affected by dementia concerned about coronavirus issue which demonstrates that people affected by dementia are extremely worried during this period

Care Act easements

Alzheimer's Society recognises that the measures contained within the Coronavirus Act 2020 are temporary measures and should only be used in exceptional circumstances. However, before the pandemic, social care was already facing significant challenges in its ability to support people affected by dementia.

To prevent this pandemic being exacerbated, those most at risk must receive most protection.

Care Act easements suggests local authorities may need to RAG-rate or determine High, Moderate and Low risk for the care packages provided. Dementia is a progressive condition, meaning people's needs get worse over time. Nearly 60% of people with dementia in 2020 have severe dementia³, including at least 100,000 people who live in the community, often only with informal care.⁴ We know people with dementia are at heightened risk of dying from respiratory diseases such as pneumonia as a result of potentially having a weaker defence mechanism for overcoming infection⁵

PHE data shows 77% of people with dementia have one or more other health conditions, with 22% having three or more and 8% having four or more additional⁶. These underlying health conditions may put them at greater risk of COVID-19. Due to progressive nature of dementia, the needs of those living with the condition may fluctuate regularly or decline rapidly. This could be particularly exacerbated when social contact is inhibited due to self-isolation or other restrictions on visits. Research shows that if people with dementia's need for engaging activities is not met, it is associated with progressive cognitive and functional deterioration, which can result in them losing their autonomy and ability to take care of themselves.⁷ We are greatly concerned that the application of easements will result in people with dementia's needs not being met, subsequently leading to an irreversible deterioration in their condition.

Rights

Under the easements, local authorities do not have to carry out assessments of care and support needs in compliance with pre-amendment Care Act requirements, they are still expected to respond as soon as possible to

¹www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvingcovid19englandandwales/deathsoccurringinmarch2020#pre-existing-conditions-of-people-who-died-with-covid-19

² Wittenberg, R et al. (2019) 'The Costs of Dementia in England'. International Journal of Geriatric Psychiatry. [Online] Available at <https://onlinelibrary.wiley.com/doi/epdf/10.1002/gps.5113>

³ <https://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-scale-impact-numbers>

⁴ <https://onlinelibrary.wiley.com/doi/full/10.1002/gps.5113>

⁵ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6417730/>

⁶ Public Health England (2019). Dementia: comorbidities in patients - data briefing. [Online] Available at <https://www.gov.uk/government/publications/dementia-comorbidities-in-patients/dementia-comorbidities-in-patients-data-briefing>. Last accessed 22/04/2020.

⁷ Passos et al, (2012) 'The Needs of Older People with Mental Health problems: A Particular Focus on Dementia Patients and their Carers', *International Journal of Alzheimer's Disease*, vol 2012. <https://doi.org/10.1155/2012/638267>

requests for care and support, and consider the needs and wishes of people needing care and their family and carers. Local authorities are still required to meet needs where failure to do so would breach an individual's human rights under the European Convention on Human Rights. These include the right to life under Article 2, the right to freedom from inhumane and degrading treatment under Article 3 and the right to private and family life under Article 8. However, courts have traditionally held that ill-treatment must reach such a level of severity that few cases have found a breach of human rights to have occurred. To establish that someone's rights are not being breached, an assessment must take place of how to maintain their safety. Furthermore, duties in the Care Act in relation to safeguarding and promoting wellbeing remain. Local authorities must ensure there is a clear and transparent pathway for people being supported, carers, and providers to quickly raise concerns should they believe either the decision or the care package is in breach of the ECHR. It is important assessments take into consideration that people with dementia are likely to have additional needs than during 'normal' times, including support with accessing food and medication.

Abuse and reporting

People with dementia can be vulnerable to financial, physical, sexual and emotional abuse. Symptoms of dementia can affect communication, memory and reasoning skills which can make it difficult for them to understand or explain what has been happening. This risk can be reduced through provision of ongoing support. This is important as the Care Quality Commission has suspended inspections and the Local Government and Social Care Ombudsman has suspended casework regarding local authorities or providers.

As of Thursday, 7 May we know that 7 local authorities adopted easements (an 8th had adopted easements for approximately one week before reverting). We have received some worrying evidence that some local authorities are adopting a form of "Care Act Lite", without formally adopting the easements.

With even more local authorities likely to adopt easements, we have the following concerns and recommendations:

- The adoption of Care Act easements should happen through consultation with local partners, and the Health and Wellbeing Board must be informed to ensure decisions are taken in a democratic way and that there is sufficient oversight. Local authorities should publicise their decision to adopt easements, as well as information on how the decision was made and how often it will be reviewed.
- When prioritising need, councils should take into account the specific needs of people with dementia and the likelihood that dementia as a condition leaves them at heightened risk.
- Local authorities should commit to urgent reviews of emergency arrangements in cases where a carer is no longer able to provide care.
- Needs assessments should be carried out where possible and records kept.
- Safeguarding, complaints and escalation procedures must be maintained during the crisis, and people affected by dementia must have a clear and accessible route to access them.
- Light touch financial assessments must be done in a way that is accessible to people affected by dementia and offer a realistic understanding of how much they should be saving to pay for care.

Impact of isolation on people affected by dementia and access to care homes

Research funded by Alzheimer's Society - Improving the Experience of Dementia and Enhancing Active Life (IDEAL) programme found that a third of people with dementia and two thirds of carers experience loneliness.⁸ The study found that people with dementia experiencing social isolation and depression, and those living alone, were more likely to report feeling lonely. It is concerning that so many people affected by dementia felt lonely before the pandemic, and it is likely that people will feel even more cut off during the course of the pandemic. As a result of the social distancing measures, face to face services have closed, meaning that people are not able to attend days centres, social gatherings and support services.

Nearly 60% of people living with dementia in 2020 have severe dementia, including at least 100,000 people with severe dementia who live in the community⁹, often only with support from unpaid carers. Social contact is important for people with dementia who live in the community as well as those who live in care homes, as interaction with

⁸ <https://onlinelibrary.wiley.com/doi/full/10.1002/gps.5305>

⁹ <https://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-scale-impact-numbers>

loved ones can help to reassure someone when they are feeling anxious. Some of the symptoms associated with dementia include difficulties with concentrating, feeling confused and memory loss, this in turn can result in people feeling distressed. Being surrounded by loved ones can help people to feel calm when they are experiencing certain symptoms of dementia.

Care homes across the country have adopted government guidance to restrict visits to residents except for the most essential purposes, including medical treatment. Some have also implemented 'cocooning' - placing residents in preventative isolation. For many residents, family and friends can play a significant role in care, whether it's through interpreting needs to staff to providing personal care. People with dementia can lose skills without usage including basic cognition, such as recognising family members, and communication skills such as remembering words and how to form sentences.

People with dementia are more likely to have depression than the general population (23%¹⁰ against 19%¹¹) and lack of contact has the potential to deepen that depression. Social contact has been proven to be of benefit to people with dementia helping to raise self-esteem, helping someone from feeling anxious or depressed. The Wellbeing and Health for people with Dementia¹² programme found increasing social interaction for just ten minutes improves the wellbeing of people with dementia in care homes, yet many care homes provided just two minutes.

During the pandemic, care home staff are under pressure and may have less time to engage residents. NHS England guidance¹³ has been issued to hospitals allowing visitors where not being present would cause the person living with dementia to be distressed. Alzheimer's Society recommends similar guidance is published for care homes. Care homes should also be supported with technology so that people with dementia are able to stay connected with loved ones.

End of life

Much focus has been on the number of people dying with COVID-19, but there is a notable absence of discussion of quality end of life care, particularly in care homes.

Care homes are used to providing palliative care, however in normal times such care is provided alongside geriatricians, district nurses or GPs. With many clinicians redeployed to other services, or unable to provide visits, the provision of palliative care has often been led by non-clinical care staff. This limits the scope of end of life care, potentially leading to a more traumatic experience for the person who is dying, as well as for the staff providing care. Alzheimer's Society recommends:

- Care homes must be provided with adequate clinical support to ensure end of life needs and wishes are fully met.

Changes to the Mental Health Act (1983) (MHA)

Alzheimer's Society has been at the forefront of campaigning to ensure humane treatment of people with dementia. We are glad that over the last few years, use of anti-psychotics to manage behavioural symptoms of dementia has declined dramatically¹⁴ - it is important that during this pandemic, we maintain vigilance.

Dementia falls within the definition of 'mental disorder' used within the MHA, therefore people with dementia can be treated under the Act. Over 25,000 people with dementia have been detained under the MHA within the previous 5 years. The Coronavirus Act creates the ability for changes to be made to the MHA so functions relating to detention can be carried out with less oversight. Currently two doctors must agree to detention, this is an important safeguard for people affected by dementia and protects against incorrect decisions being made. The Act reduces that to one doctor. There must be no further weakening of the safeguards within the MHA.

¹⁰ J Browne et al (2017) Association of comorbidity and health service usage among patients with dementia; <https://research-information.bristol.ac.uk/files/120965391/e012546.full.pdf>

¹¹ Evans, J., Macrory, I., & Randall, C. (2016). Measuring national wellbeing: Life in the UK, 2016. ONS. Retrieved from <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/measuringnationalwellbeing/2016#how-good-is-our-health>.

¹² Alzheimer's Society (2018) Ten minutes of social interaction improves wellbeing in dementia care [ONLINE] www.alzheimers.org.uk/news/2018-07-30/ten-minutes-social-interaction-improves-wellbeing-dementia-care

¹³ https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0030_Visitor-Guidance_8-April-2020.pdf

¹⁴ <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses>

Longer-term concerns

Access to diagnosis

Ensuring access to a dementia diagnosis must be central when considering how we can provide healthcare over the next six months. Diagnosis opens the door to emotional, practical, legal and financial advice, support services, and pharmacological and non-pharmacological interventions.

It is critical that future government and NHS messaging encourages people to contact their GP if they are worried about their memory or other potential dementia symptoms. In the medium term, we are concerned that people might avoid accessing services due to fear of contracting COVID-19 or being a burden on the NHS. This is compounded by the fact people over 70, a population at higher risk of dementia, are being deterred from face-to-face assessments due to social distancing measures. We are concerned that GPs moving to online or telephone consultations not only risks acting as a deterrent, but also prevents initial assessment of dementia, as it requires a physical assessment¹⁵. Anecdotal evidence from the East of England highlights that referrals from primary care are down by about half. It will be important to assess primary care referral data to pinpoint barriers in a new virtual diagnostic pathway and ensure primary care can evolve to enable access to a diagnosis at a memory clinic.

However, we also have concerns about memory clinic services, as we know that many are no longer operating due to not being considered essential. We have received examples of this happening across the country, with staff redeployed to support the response to COVID-19 in acute care. This means a large cohort of people will not be able to benefit from an early, timely, or accurate diagnosis. Data must be collected on the number of memory clinic closures, why there were closed, and how they are operating so that we can understand the scale of the problem now and understand demand and capacity when services resume.

There are already long waiting times for a diagnosis in some localities, with data showing waiting times from referral to diagnosis varying from three to 34 weeks in 2019¹⁶. Some memory clinics are beginning to consider resuming services, with others beginning to deliver virtual assessments. It is crucial when services are redesigning ways of working that there are mechanisms set up centrally to enable sharing best practice, as well as combatting issues around technology access. While it is understandable services need to evolve during the pandemic, there are elements of virtual assessments that are concerning should they become the norm, including the delivery of a life-changing diagnosis which should be done face-to-face.

We are also concerned about making a diagnosis of unspecified dementia in the absence of scans. It is recommended in national guidance to diagnose a dementia subtype. While the majority of people with dementia develop Alzheimer's disease, there are over 100 different subtypes that fall under the umbrella of dementia and can have very different symptoms. This can have implications on future medication, care plans, interventions and opportunities to engage in research, which can all impact on a person's ability to live well. It is imperative that provisional diagnoses of unspecified dementia are recalled as soon as possible for necessary testing and subtype diagnosis. We are concerned that given there will be long waiting times at memory clinics due to COVID-19, diagnosing a subtype might be deprioritised. We also need to ensure that people in the very early stages who it might have been difficult to diagnose virtually, are also not deprioritised when services resume.

Diagnosis rates will be a key metric. While a reduction is expected with service closures, we should strive to ensure variation is not exacerbated by memory services in only some localities adapting to the current situation and others remaining closed. It is also important to highlight the merging of Clinical Commissioning Groups from April 1, which will affect regional diagnosis rates, meaning it will be harder to analyse the impact of COVID-19 on diagnosis rates at a local level.

Access to support and services

¹⁵ National Institute for Health and Care Excellence. (2018). Dementia Assessment and Diagnosis. Available: <https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#diagnosis>

¹⁶ London Dementia Clinical Network (2020). The 2019 national memory service audit. [Online] Available at <https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2020/04/The-2019-national-memory-service-audit.pdf>

The Care Act easements will significantly impact on people affected by dementia. It is imperative they are utilised for the shortest time possible to reduce potential long-term impact of unmet need. All assessments that are not completed in detail must be followed up and completed in full once the easements are lifted. However, we are concerned about the heightened demand facing local authorities, and how the backlog of assessments will be handled to ensure detailed assessments can take place promptly and support needs are met.

We are also concerned about continued and ongoing isolation leading directly to an increase in dementia symptoms. People with dementia told us they fear deterioration in their cognitive and functional ability, independence and wellbeing given the current restrictions. Heightened access to community support and services must be prioritised for people with dementia and carers.

Carers of people with dementia will be impacted by easements in the long-term. Statistics show two thirds of people with dementia live at home with most being supported by unpaid carers¹⁷, yet, respite provision – or short breaks - for carers has been substantially restricted during the period of the pandemic. Research indicates 40% of carers of people with dementia have clinically significant depression or anxiety. This has been shown to be unrelated to the severity of dementia¹⁸, which suggests if carers have the right support with their mental health, it could improve their wellbeing and enable them to better cope with caring responsibilities as the condition progresses. We know a carer's psychological health can also predict a breakdown in care and therefore the need for the person with dementia to move into residential care¹⁹.

End of life and staff attrition

Care home staff are managing unprecedented levels of deaths. This is against a backdrop of trying to support residents who are not having loved ones visit and becoming distressed with changing routines. Given the significant emotional pressures facing care home staff, it is vital they are supported to continue, both now and in the future. This will potentially exacerbate pre-existing high turnover rates among the social care workforce – 29.6%²⁰ in care homes and 31.5%²¹ in nursing homes in 2018/19.

COVID-19 has highlighted the importance of advance care planning (ACP) to improve better planning and provision of care for people who may be nearing the end of life²². Given dementia is a progressive condition that affects mental capacity, it is imperative early and ongoing conversations are undertaken before a lack of capacity prevents a person from documenting what care they would like at end of life. However, we know that these conversations are not happening in a routine way, if at all, for people with dementia. This is either because there are mixed views on when is the right time or who should do it, and whether staff are trained or feel comfortable. We know people who have no contact with healthcare services after a diagnosis – who have effectively 'fallen off' the pathway – struggle to access opportunities to engage in advance care planning until a crisis, such as a hospital or care home admission, when it is potentially too late. One research study involving 85 people with advanced dementia across London, revealed fewer than 40% had an ACP²³. It is important these conversations become embedded within the dementia pathway after COVID-19 to ensure that a person's wishes are met at the end of life. It has also highlighted the importance of this being a person-centred process, exemplified by bad practice surrounding blanket approaches to Do Not Attempt Resuscitation forms and unscheduled calls from GPs.

Moving forwards, there must be a more prominent role for ACP within post-diagnostic support, with clear levels of responsibility outlined at a local level. Implementation of technological solutions such as sharable care plans amongst the patient and health and care professionals involved in their care would create opportunities to discuss

¹⁷ Carers Trust. (2020). Key facts about carers and the people they care for. Available: <https://carers.org/key-facts-about-carers-and-people-they-care>.

¹⁸ Livingston, G. et al. (2013) [Clinical effectiveness of a manual based coping strategy programme \(START, STRategies for RelaTives\) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial](#)

¹⁹ Livingston, G., et al. (2020). Clinical effectiveness of the START (STRategies for RelaTives) psychological intervention for family carers and the effects on the cost of care for people with dementia: 6-year follow-up of a randomised controlled trial. *British Journal of Psychiatry*, 216(1), 35–42. <https://doi.org/10.1192/bjp.2019.160>

²⁰ Skills for Care. (2019). Workforce Intelligence Summary: Care only homes in the adult social care sector. Available: <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/Summary-of-care-only-home-services-2019.pdf>

²¹ Skills for Care. (2019). Workforce Intelligence Summary: Care homes with nursing in the adult social care sector. Available: <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/Summary-of-care-home-services-with-nursing-2019.pdf> Care homes with nursing in the adult social care sector

²² Gold Standards Framework. (2020). Advance Care Planning. Available: <https://www.goldstandardsframework.org.uk/advance-care-planning>

²³ Sampson, E. L., et al. (2018). Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. *Palliative Medicine*, 32(3), 668–681

ACP and improve patient outcomes. One example of this is Coordinate My Care (CMC). Research shows that 83.7% of dementia patients with a CMC record died in their preferred place of death, and just 12% died in hospital²⁴ in 2019.

Technological advances

Some steps that have been taken to facilitate prompt response to the COVID-19 crisis could be maintained after the situation changes. Improvements in hospital discharge planning through use of the Capacity Tracker, access to telemedicine, and increased use of digital tools for staff such as NHSMail and Microsoft Teams should result in more adaptable services. We know at present that approximately half of all delayed discharge days are due to delays in arranging care in the community or at a care home which has a huge impact on people with dementia – the Capacity Tracker could make substantial inroads in reducing this number. Rolling out the Enhanced Health in Care Home programme with its dementia component, with appropriate support for primary care services, could lead to better outcomes and more personalised care for people living with dementia in residential care. As the crisis de-escalates, NHS England and the Government should look to improve and increase their use if the evidence supports their effectiveness.

April 2020

²⁴ Wiggins, N., et al. (2019). Understanding the factors associated with patients with dementia achieving their preferred place of death: a retrospective cohort study. *Age and Ageing*, 48, 433-439