

Written evidence from Alzheimer's Society (HCS0008)

Submitted by Dr Alex Osborne, Public Affairs Officer of Alzheimer's Society

Evidence Summary – Key Points

- The central principle of social care should be a focus on what matters to people, including offering people choice and control in their care and supporting people to maintain their independence. While there is a lack of available data on quality-of-life measures for people with dementia drawing on care, there is evidence of a lack of high-quality care.
- Many people with dementia are not able to access the care they need. It is estimated that over 200,000 people with dementia have care needs yet receive no social care support. This means people are being left without the support they need to help them live a good life, as well as being left without support that can be vital in helping prevent their condition deteriorating – meaning they are only able to get support at a point of crisis.
- CQC's 2020 State of Care report found that "*despite years of the [Mental Capacity Act] legislation being in place, there is still huge variation in understanding and practice, and in the quality of training.*" Having a poor understanding of the legislation means that professionals could be using the Act inappropriately, resulting in people with dementia being deprived of their liberty unnecessarily and unlawfully, and in other cases without sufficient safeguards in place to protect them.
- In some cases, it's unclear if the Mental Health Act is being used to respond to people's behaviour, rather than to assess and treat them. People with dementia can find hospitals to be frightening places and this can exacerbate their condition, which then results in them being detained. It is vital for people to receive XXXersonalized care that considers their needs – this involves professionals looking at the underlying reason causing distressed behaviour and addressing it in different ways, rather than using the MHA to manage the situation.
- An Alzheimer's Society survey of 1,800 carers and people living with dementia showed that 41% of people who received a care and support package had had this reduced or stopped since lockdown began. A second Alzheimer's Society survey of over 1,000 carers during lockdown revealed that 45% felt that the level of care needed by the person they looked after was greater than they were able to provide. Family carers spent an additional 92 million hours providing care during the first lockdown, with 95% of carers we surveyed reporting these extra caring hours negatively impacted their own physical or mental health.
- During the pandemic the visiting restrictions in care homes meant many people with dementia went without face-to-face contact with loved ones for many months. The impact of this lack of meaningful contact has been linked to worsening of symptoms, deterioration in the condition, and possibly even deaths.

About Alzheimer's Society

Alzheimer's Society is the leading support services and research charity for the 850,000 people in the UK with dementia, as well as those who care for them. Working across England, Wales and Northern Ireland, Alzheimer's Society provides direct services and information to people affected by dementia, funds research and campaigns for change. The number of people with dementia is set to rise to over 1 million by 2025.

About dementia

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. Dementia is progressive, which means the symptoms gradually get worse over time, but how quickly this happens varies greatly from person to person.

People living with dementia have been worst hit by the COVID-19 pandemic. In the first wave, over a quarter of all COVID-19 deaths in England and Wales were people living with dementia¹ and the biggest increase in excess deaths was also in people with dementia.² For those who have survived the crisis, the impact of the 'lockdown' measures introduced to contain the virus have been severe and many people with dementia have seen their condition deteriorate at a faster rate over the course of the pandemic.³

1. What human rights issues need to be addressed in care settings in England, beyond the immediate concerns arising from the Covid-19 pandemic?

Quality care in social care

The Wellbeing Principle of the Care Act⁴ sets out the need for XXXpersonalized care. However, while this legislation sets a strong foundation for good quality care, all too often this simply isn't reflected in reality when people are drawing on care.

Currently, people's experience of social care is that it is often solely focused on receiving help with things that are essential to daily functioning, also described as 'personal care.' This includes tasks such as dressing and bathing. While essential, care that only focuses on tasks of daily functioning will not necessarily give people the quality of life that they have the right to lead.

¹ Office for National Statistics (2020). Available at: [Deaths involving COVID-19, England and Wales - Office for National Statistics \(ons.gov.uk\)](#) [Accessed 18 August 2021].

² Alzheimer's Society (2020). Worst hit: dementia during coronavirus. Available at: <https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>.

³ Alzheimer's Society (2021). Moving Forward Stronger: Addressing deterioration in people with long-term conditions during the pandemic. Available at: <https://www.alzheimers.org.uk/sites/default/files/2021-06/moving-forward-stronger.pdf>

⁴ Care Act (2014). <https://www.legislation.gov.uk/ukpga/2014/23/section/1/enacted>

By contrast, personalised care is care that upholds the right for people to be recognised for who they are, and for a diagnosis not to define or limit the life people lead, as demonstrated in the Dementia Statements.⁵ The Dementia Statements, originally developed in 2010 and revised in 2018 by people with dementia and their carers, set out the things people with dementia have said are essential to their quality of life, and are enshrined in the Equality Act, Mental Capacity legislation, health and care legislation and International Human Rights law.⁶

Our recent reports *A Future for Personalised Care*⁷ and *Stabilise, Energise, Realise*⁸ discuss the importance of personalised care for people with dementia. The central principle of social care should be a focus on what matters to people, including offering people choice and control in their care and supporting people to maintain their independence. It is also vital that supporting people to maintain relationships with loved ones, family members or people in the community, is central to care, and recognised for its role in health and wellbeing.

There is a lack of available data on quality-of-life measures for people with dementia drawing on care, but there is evidence of a lack of high-quality care. The Care Quality Commission (CQC) describe a lack of high quality, person-centred homecare and also a lack of suitable residential care provision for people with high support needs, including those with dementia.⁹

Providing high-quality care requires sufficient funding. Local authorities in England have faced cuts of 38% in real terms in grants from central government between 2009/10 and 2018/19¹⁰, significantly reducing their budgets. The King's Fund reports that 2019/20 spending on adult social care has finally returned to 2010/11 levels, but spending per person is still well below 2010/11 levels.¹¹

Access to social care

Many people with dementia are not able to access the care they need. It is estimated that over 200,000 people with dementia have care needs yet receive no social care support.¹² This means people are being left without the support they need to help them live a good life, as well as being

⁵ National Dementia Action Alliance, Dementia Statements, available at: www.nationaldementiaaction.org.uk/dementia-statements/

⁶ Dementia Action Alliance. Review of the Dementia Statements: Companion paper. 2017. https://www.dementiaaction.org.uk/assets/0003/3965/Companion_document_August_2017_branded_final.pdf

⁷ Alzheimer's Society (2021) A future for personalised care (2021). Available at: <https://www.alzheimers.org.uk/sites/default/files/2021-03/A%20Future%20for%20Personalised%20Care.pdf>

⁸ Alzheimer's Society (2021). Stabilise, energise, realise: a long term plan for social care. Available at: <https://www.alzheimers.org.uk/sites/default/files/2021-08/stabilise-energise-realise-report.pdf>

⁹ Care Quality Commission (CQC). The state of health care and adult social care in England 2019/20. 2020. https://www.cqc.org.uk/sites/default/files/20201016_stateofcare1920_fullreport.pdf

¹⁰ Institute for Government (IFS). Local government funding in England. 2020. <https://www.instituteforgovernment.org.uk/printpdf/9553>

¹¹ The Kings Fund. Available at: <https://www.kingsfund.org.uk/publications/social-care-360/expenditure>

¹² Alzheimer's Society. Available at: <https://www.alzheimers.org.uk/sites/default/files/2021-03/A%20Future%20for%20Personalised%20Care.pdf>

left without support that can be vital in helping prevent their condition deteriorating – meaning they are only able to get support at a point of crisis.

This also has an impact on unpaid carers. Carers may experience increased stress or exhaustion, which can also put their own health and wellbeing at risk. Our report *The Fog of Support* found that although the Care Act requires local authorities to identify and consider the needs of carers themselves, “there is still the chance of (1) not identifying carers due to them being in hidden populations; and (2) not identifying, assessing and supporting carers if they do not appear to be actively engaging with the local authority (which may be due to the complexity of their situation rather than not wanting or needing support).”¹³

Although not dementia-specific, ADASS have reported that almost 75,000 disabled and older people and carers are waiting for help with their care and support, as services struggle to cope with the high level of additional needs arising from the COVID-19 pandemic¹⁴. They also reported that in September¹⁵, there were up to 184,000 people waiting for reviews of existing care and support plans, which is up 15.6% from April-June.

In their 2018 annual report, the Local Government and Social Care Ombudsman has indicated that social care assessments are now among “the biggest areas of complaint”¹⁶. They found some councils at fault “for raising eligibility thresholds to qualify for services, particularly in adult social care, as a means to save money. Instead of starting by assessing needs, developing a care plan and then meeting eligible needs, councils have made resource-led decisions, sometimes missing out the care plan stage altogether.”¹⁷

Deprivation of Liberty Safeguards (DoLS)

Article 5 of the Human Rights Act guarantees the right to personal liberty and provides that no one should be deprived of their liberty unless it is prescribed in law.¹⁸ The DoLS were introduced into the Mental Capacity Act (MCA) to provide a legal process for authorising a deprivation of liberty for those who need to be in a care home or hospital for care or treatment but lack the mental capacity to consent to being there, for example because they have dementia. A lack of condition specific data makes it difficult to quantify the extent to which people with dementia are being impacted by the use of DoLS. However, we do know that 83% of people with a DoLS in England are over the age of 65 and the majority of DoLS applications are in care homes (residential and nursing).¹⁹ Given that aging is the biggest risk factor for dementia, and

¹³ Alzheimer’s Society (2020). The fog of support. Available at: https://www.alzheimers.org.uk/sites/default/files/2020-09/as_new_the-fog-of-support_carers-report_final-compressed.pdf

¹⁴ ADASS (2021) *Spring Survey*, available at: www.adass.org.uk/adass-spring-survey-21

¹⁵ ADASS (2021), *Rapid Survey*, available at: <https://www.adass.org.uk/adass-new-rapid-survey-findings>

¹⁶ Local Government & Social Care Ombudsman. Annual reports. <https://www.lgo.org.uk/information-centre/about-us/our-performance/lgo-annual-reports>

¹⁷ Local Government & Social Care Ombudsman. Councils mustn’t throw out the rule book in the face of pressure. <https://www.lgo.org.uk/information-centre/news/2018/dec/councils-mustn-t-throw-out-the-rule-book-in-the-face-of-pressure-says-ombudsman>

¹⁸ <https://www.legislation.gov.uk/ukpga/1998/42/schedule/1>

the majority of care home residents are living with dementia, it is reasonable to assume that a significant number of people with dementia are cared for under a DoLS. We also know from older data collections, which were broken down by condition, that dementia accounted for over half of DoLS applications in 2015/16.²⁰

Since the DoLS were implemented in 2009, there have been consistent issues with how they are applied. The CQC's annual report (2010/11) on the state of health and care in England found that in the first year of monitoring DoLS, there were "*clear variations in organisations' understanding and practice of the Safeguards, and in staff training*".²¹ A decade later, CQC's 2020 State of Care report found that "*despite years of the legislation being in place, there is still huge variation in understanding and practice, and in the quality of training.*"²² Having a poor understanding of the legislation means that professionals could be using the Act inappropriately, resulting in people with dementia being deprived of their liberty unnecessarily and unlawfully, and in other cases without sufficient safeguards in place to protect them.

Following a Supreme Court ruling known as the 'Cheshire West' judgement in 2014, which effectively widened the definition of a 'deprivation of liberty',²³ providers have been unable to cope with the increased number of people who are subject to a deprivation of liberty. This has resulted in a significant backlog of applications waiting to be processed, with the latest data showing that there are nearly 120,000 outstanding applications, and over 46,000 of these have been outstanding for a year and over.²⁴ Again, this means that people with dementia are being deprived unlawfully and without the necessary legal system in place to protect them. The delay in processing an application also means that people may be unable to access the care they need. In some cases, by the time the application is processed, the person in question has died – this is a clear breach of the human rights to which people with dementia are entitled.

Through our Dementia Connect helpline and our Dementia Talking Point online community, people affected by dementia have told us that they encounter many issues with DoLS, including a lack of information about the process and their rights.²⁵ Another key problem is uncertainty around whether the DoLS or the Mental Health Act (MHA) should be used. The MCA Schedule 1A sets out a range of situations where a DoLS XXXauthorization is not available, and if the person needs to be deprived of their liberty, this must be under the MHA. Equally we have heard

¹⁹ NHS Digital (2021). Available at: [Latest statistics on use of Deprivation of Liberty Safeguards in England are published - NHS Digital](#)

²⁰ NHS Digital (2016). Available at: <https://files.digital.nhs.uk/publicationimport/pub21xxx/pub21814/dols-eng-1516-rep.pdf>

²¹ CQC (2011). The State of health care and adult social care in England. Available at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/247207/1487.pdf

²² CQC (2020). The State of health care and adult social care in England. Available at:

https://www.cqc.org.uk/sites/default/files/20201016_stateofcare1920_fullreport.pdf

²³ <https://www.cheshirewestandchester.gov.uk/your-council/policies-and-performance/deprivation-of-liberty-safeguards.aspx>

²⁴ NHS Digital (2021) Available at: [Mental Capacity Act 2005, Deprivation of Liberty Safeguards - 2020-21 - NHS Digital](#)

²⁵ Alzheimer's Society. <https://www.alzheimers.org.uk/get-support/your-support-services>

of people with dementia being detained under section 2 of the MHA but then remaining in hospital under a DoLS XXXauthorization. People with dementia receiving treatment in hospital are affected by this complex overlap between the two Acts, and the decision about which legal framework to use is left to professionals. The Department of Health and Social Care commissioned The King's Fund to conduct research to understand how professionals are making this decision. Their findings show that there is huge variation in professionals' understanding of both legislations, and worryingly, dementia was cited as the most common condition for which this interface applied, meaning that people with dementia are being disproportionately affected by this issue.²⁶ As a result, people with dementia could be cared for under the incorrect system and may not be receiving the rights that they are entitled to.

Although the Government is reforming the current system through the Mental Capacity (Amendment) Act, which will see the DoLS replaced with the Liberty Protection Safeguards (LPS), there has been a significant delay in implementation which is causing uncertainty. The CQC's Covid Insight report found that as providers' concentrate their efforts on preparing for LPS, focus on the DoLS has waned, increasing the risk of people being deprived without the proper XXXersonalizedXXX.²⁷

Mental Health Act

Dementia falls within the definition of 'mental disorder' used within the MHA, and therefore in certain cases, people with dementia are detained, assessed, and receive treatment under the MHA. Due to a lack of condition-specific data and variation in data collection across mental health trusts, it is unclear to what extent people with dementia are being impacted by the use of the MHA. It is however clear from recent data that although generally detention rates decrease with age, rates rise again for people over the age of 65.²⁸ Therefore, it is reasonable to assume that a significant number of people with dementia are coming into contact with the MHA. Furthermore, data obtained from 76 hospitals and local authorities (under the Freedom of Information Act) found that nearly 3,000 people with dementia were detained under the MHA in 2018/19. Between 2014-2019, just over 25,000 people with dementia were detained under the MHA.²⁹

The instances where the MHA is used for people with dementia often involve cases of aggression, where there is a concern for the person or other people's safety and other techniques

²⁶ The King's Fund (2021). Understanding clinical decision-making at the interface of the Mental Health Act (1983) and the Mental Capacity Act (2005). Available at: <https://www.york.ac.uk/media/healthsciences/images/research/prepare/reportsandtheircoverimages/Understanding%20the%20MHA%20&%20MCA%20interface.pdf>

²⁷ [The impact of COVID-19 on the use of Deprivation of Liberty Safeguards | Care Quality Commission \(cqc.org.uk\)](https://www.cqc.org.uk)

²⁸ NHS Digital (2019-20), *Mental Health Act Statistics Annual Figures*. Available at: [Mental Health Act Statistics, Annual Figures 2019-20 - NHS Digital](#)

²⁹ The Telegraph (2020), *More than 25,000 dementia patients sectioned in past five years amid warnings they are being locked up to 'control' their behaviour*. Available at: <https://www.telegraph.co.uk/news/2020/02/07/25000-dementia-patients-sectioned-past-five-years-amid-warnings/>

to calm the person have not helped. Other cases from our experience involve serious self-neglect for example, where the person is in danger and all other attempts to help have failed. As people with dementia may experience behavioural symptoms, knowing how to respond to these is vital to ensure they get the care they need, whilst XXXersonalize that the MHA should only be used as a last resort. However, it is unclear in some cases whether the MHA is being used to respond to people's behaviour, rather than to assess and treat them. For example, a person with dementia who is in hospital for other reasons (such as for a physical condition) and becomes distressed due to being in hospital can experience behavioural symptoms. People with dementia can find hospitals to be frightening places and this can exacerbate their condition,³⁰ which then results in them being detained. It is vital for people to receive XXXersonalized care that considers their needs – this involves professionals looking at the underlying reason causing distressed behaviour and addressing it in different ways, rather than using the MHA to manage the situation. Therefore, it is important that staff are trained in dementia, so that they are able to effectively respond to distressed behaviour.

We also know that a lack of mental health services in the community is contributing to the number of people with dementia being detained under the Act.³¹ Carers have shared examples with us, where their loved ones have started displaying distressed behavior, but they have been unable to access support from services within the community, particularly at the weekends, and so they have had no choice but to present to A&E departments. The MHA should never be used as a fall back for good person-centered care in the community but only as an absolute last resort.

People affected by dementia are facing a number of issues when they encounter the MHA. People find the process of being detained frightening and confusing, and they are not always meaningfully involved in their care and treatment or provided with information. A lack of information and support has a significant impact on wellbeing and exacerbates an already difficult situation. Not being provided with information also means that people are unclear about their rights and how they can challenge decisions. We also know that mental health wards are not always appropriate or therapeutic. The independent Review of the MHA found that “*people are often placed in some of the worst estate that the NHS has, just when they need the best*”.³² Carers have shared examples of their loved ones with dementia being placed in wards where there were no activities, lots of noise and other distressed patients, who were sometimes violent. When someone is detained under the MHA, they should be placed in a setting close to their community, and local support networks. However, the CQC reported that “*patients continue to be hospitalised out-of-area, sometimes over a hundred miles from home, usually because there are no beds in the local hospital. Worryingly, this is frequently being accepted without challenge.*”³³

³⁰ Alzheimer's Society (2016), *Fix Dementia Care: Hospitals*. Available at: [fix_dementia_care_-_hospitals.pdf \(alzheimers.org.uk\)](#)

³¹ Alzheimer's Society (2016). Available at: [Fix Dementia Care: NHS and care homes \(alzheimers.org.uk\)](#)

³² Modernising the Mental Health Act, Increasing Choice, Reducing Compulsion, Final Report of the Independent Review of the Mental Health Act 1983 (2018). Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/778897/Modernising_the_Mental_Health_Act_-_increasing_choice_reducing_compulsion.pdf

Being detained can be an extremely difficult experience for someone with dementia, and carers and family members can provide much needed comfort and reassurance, which can help the person with dementia to recover more quickly. Therefore, regular contact is important, but being placed in settings that are far away makes visiting very difficult.

2. How effective are providers at respecting the human rights of people under their care?

We know that providers want to do their best to protect the rights of people in their care, but they are finding this increasingly difficult to do because of the significant funding cuts that local authorities have experienced. The Local Government Association estimated that by 2020, local authorities faced a reduction to core funding from the Government of nearly £16 billion over the preceding decade.³⁴ Local authorities have had to respond to this by streamlining their services, and despite their efforts to continue to deliver quality services, residents are feeling the consequences of these significant cuts.

3. How effective are regulators in protecting residents from human rights breaches and in supporting patients and residents who make complaints about their care provider?

We have heard from carers who are hesitant about making complaints to providers due to fear that this could further impact on the care that their loved ones with dementia receive. This is particularly concerning given the number of reports we often see in the media of residents and patients being mistreated. It is important that measures are in place to identify safeguarding issues early on and that people are supported to make complaints and reassured that doing so will not have a negative impact on care, however we know this is not always happening.

Alzheimer's Society recently worked with Tide ('Together in dementia everyday') to respond to an inquiry from the Equality and Human Rights Commission into challenging decisions about adult social care. Tide undertook a short survey of carers of people living with dementia (short, to meet the timescale of the inquiry), receiving 27 responses. The survey found that three quarters of people who responded said nobody from the council told them that they had the right to challenge any decisions that were made about their support; and over half of those that responded said that they felt that it was difficult to challenge a decision, followed by several people saying that it took a bit of effort and an equal number saying that they found it so difficult that they gave up.³⁵

4. What lessons need to be learned from the pandemic to prevent breaches of human rights legislation in future?

³³ Care Quality Commission (2019), State of Care, Monitoring the Mental Health Act in 2018/19. Available at: [Monitoring the Mental Health Act in 2018/19 \(cqc.org.uk\)](https://www.cqc.org.uk/publications/state-of-care)

³⁴ Local Government Association (2018). [5.40_01_Finance_publication_WEB_0.pdf \(local.gov.uk\)](#)

³⁵ Alzheimer's Society and Tide (2021), *Submission to EHRC Inquiry into challenging decisions about adult social care*, available online at <https://www.tide.uk.net/tide-members-respond-to-inquiry-into-challenging-decisions-about-adult-social-care/>.

Do Not Attempt CPR (DNACPR) orders

During the first wave of the pandemic, we heard a number of concerns from people affected by dementia in relation to DNACPR orders. People told us they received letters from their GP surgery asking them to consider completing a DNACPR form, and in other cases, people in hospital for minor conditions were being asked about their feelings about DNACPR.³⁶ This is reflected in the review conducted by the CQC (2021) into how DNACPR decisions were made during the pandemic. Their research found that professionals felt conversations were often taking place at a much faster pace during the pandemic, and carers often felt these conversations came ‘out of the blue’. Some people had even been discharged from hospital with a DNACPR order of which they or their families were unaware. Some families stated that they had been pressured into agreeing to these decisions. There was also blanket application of DNACPRs orders applied to groups of people.³⁷ This is simply unacceptable and breaches people’s right to life. Conversations about DNACPR must be approached sensitively and should be part of wider discussions around advance care planning, instead of being sprung on people - particularly during a pandemic.

Discharge of patients with COVID-19 to care homes

During the COVID-19 pandemic, between 17th March and 15th April 2020, around 25,000 people were discharged from hospitals into care homes³⁸. It is not known how many of these people had COVID-19 at the point of discharge, as testing of people being discharged was not required until 16th April³⁹. The House of Commons Public Accounts Committee concluded that ‘discharging patients from hospital into social care without first testing them for COVID-19 was an appalling error’⁴⁰. This may well have placed residents and staff within the care homes at greater risk of COVID-19, and may have contributed to the number of care homes that experienced an outbreak.

Access to care

Comprehensive data on how care provision was impacted during the pandemic is limited as local authorities only record data about people for whom they contribute towards the cost of care, whilst many people fund their own care without local authority support. An Alzheimer’s Society survey of 1,800 carers and people living with dementia showed that 41% of people who received

³⁶ BBC (2021). Available at: <https://www.bbc.co.uk/news/uk-wales-52117814>

³⁷ [20210318_dnacpr_printer-version.pdf \(cqc.org.uk\)](https://www.cqc.org.uk/publications/20210318-dnacpr-printer-version.pdf)

³⁸ House of Commons Public Accounts Committee. Readyng the NHS and social care for the COVID-19 peak. [Online] 2020. <https://publications.parliament.uk/pa/cm5801/cmselect/cmpublic/405/405.pdf>

³⁹ NHS England and NHS Improvement. Letter: New requirement to test patients being discharged from hospital to a care home. [Online] 2020. <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0324-Newrequirement-to-test-patients-being-discharged-from-hospital-to-a-care-home.pdf>

⁴⁰ House of Commons Public Accounts Committee. Readyng the NHS and social care for the COVID-19 peak. [Online] 2020. <https://publications.parliament.uk/pa/cm5801/cmselect/cmpublic/405/405.pdf>

a care and support package had had this reduced or stopped since lockdown began⁴¹. A second Alzheimer's Society survey of over 1,000 carers during lockdown revealed that 45% felt that the level of care needed by the person they looked after was greater than they were able to provide⁴². Family carers spent an additional 92 million hours providing care during the first lockdown⁴³, with 95% of carers we surveyed reporting these extra caring hours negatively impacted their own physical or mental health⁴⁴. Although not specific to dementia care, research carried out by the Universities of Birmingham and Sheffield in partnership with Carers UK showed that 50% of carers needing formal services in April could not get them⁴⁵. The proposals in the Health & Care Bill to require information from all CQC regulated providers of adult social care and to cover those who access care privately, are welcome – such standards should be co-designed with providers to ensure they are not too onerous and people who draw on services to ensure they collect data on what matters most to people drawing on support, and have regard to the conditions people may be living with to enable us to understand the experiences of people affected by dementia drawing on care support.

The Coronavirus Act introduced in March allowed councils to adopt easements to their duties under the Care Act, designed to temporarily relax certain responsibilities during this period of significant pressure. These easements included reducing obligations to carry out assessments of people's needs, to undertake financial assessments for care needs, to prepare or review care and support plans, or to undertake assessments of the needs of informal carers⁴⁶. This raised concerns that, if these easements were applied, people with dementia might experience reduced support, with potential for irreversible deterioration to their condition if their needs were not met. While few councils did apply the easements, this is nonetheless an important issue. Alzheimer's Society has published recommendations for how to adopt Care Act easements appropriately in the future if they are required in exceptional circumstances.⁴⁷

Visiting restrictions in care homes

⁴¹ Alzheimer's Society. Alzheimer's Society online survey: The impact of COVID-19 on People Affected by Dementia. [Online] 2020. <https://www.alzheimers.org.uk/news/2020-07-30/lockdown-isolation-causes-shocking-levels-declinepeople-dementia-who-are-rapidly>

⁴² Alzheimer's Society. Survey: Caring for a person living with dementia during the COVID-19 pandemic. [Online] 2020. <https://www.alzheimers.org.uk/COVID-19-report-news>

⁴³ Ibid

⁴⁴ Ibid

⁴⁵ Carers UK. Caring and COVID-19, Loneliness and use of services. [Online] 2020. <https://www.carersuk.org/news-and-campaigns/press-releases/covid-19-leaves-unpaid-carers-withoutphysical-and-mental-health-treatment>

⁴⁶ 7. Department of Health & Social Care. Care Act easements: guidance for local authorities. [Online] 2020. <https://www.gov.uk/government/publications/coronavirus-covid-19-changes-to-the-care-act-2014/careact-easements-guidance-for-local-authorities>

⁴⁷ Alzheimer's Society. Alzheimer's Society makes recommendations for local authorities adopting Care Act easements. [Online] 2020. <https://www.alzheimers.org.uk/news/2020-05-07/alzheimers-society-recommendations-localauthorities-care-act-easements>

During the pandemic the visiting restrictions in care homes meant many people with dementia went without face-to-face contact with loved ones for many months. The impact of this lack of meaningful contact has been linked to worsening of symptoms, deterioration in the condition, and possibly even deaths. Our own inquiry found that 79% of 128 care home managers surveyed reported a lack of social contact was causing deterioration in the health and wellbeing of their residents with dementia⁴⁸. Whilst basic care needs were being met, many people were being left without what matters most to so many of us – seeing people they love. In commentary from the International Long-Term Care Policy Network’s resources in response to COVID-19, Associate Professor Lee-Fay Low explains the role that family visitors play in providing love and company, helping with eating, keeping cognitive and communication skills sharp, grooming and recreation, advocacy and timely detection of changes in health.⁴⁹ Without visits, residents are more likely to become lonely or bored, which may be expressed through increased agitation or social withdrawal. Lack of physical activity may lead to loss of strength, and reduced cognitive stimulation may lead to greater cognitive decline.

In our report, *Worst Hit: dementia during coronavirus*, we called for informal carers to be recognised as an integral part of the care system. We must learn the lessons from the pandemic on just how vital meaningful contact with loved ones is to the health and wellbeing of people with dementia and how they must be maintained, even in exceptional circumstances.

Rise in antipsychotic prescribing

Rates of antipsychotic prescribing for people with dementia increased over the pandemic.⁵⁰ Pre-pandemic, the percentage of people living with dementia prescribed an antipsychotic drug was around 9.4%. However, this has increased and has remained steady at around 10% since December 2020. Care homes and clinicians reported to us that many residents experienced increased agitation and distress over the course of the pandemic, possibly due to a lack of in-person contact with loved ones, infection protocols such as mask-wearing and reduced social contact, as well as a lack of access to non-pharmacological interventions designed to mitigate agitation and distress. We understand that community nursing teams were unable to access care homes during the pandemic, and therefore were unable to undertake appropriate assessments for agitation and distress as well as provide non-pharmacological interventions to reduce these symptoms. Without adequate access to assessment and non-pharmacological treatment, we believe that, in some instances, antipsychotic prescriptions had been delivered, which may have contributed to a rise of these prescriptions over the pandemic.

Care home residents’ access to healthcare

⁴⁸ Alzheimer’s Society. Thousands of people with dementia dying or deteriorating – not just from coronavirus as isolation takes its toll. 2020. <https://www.alzheimers.org.uk/news/2020-06-05/thousands-people-dementia-dying-or-deteriorating-not-just-coronavirus-isolation>

⁴⁹ Low, L-F. Easing lockdowns in care homes during COVID-19: risks and risk reduction. [Online] LTCcovid, 2020. <https://ltccovid.org/2020/05/13/easing-lockdowns-in-care-homes-during-covid-19-risks-and-riskreduction/>

⁵⁰ NHS Digital (2021). Recorded dementia diagnosis. Available at <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses> [Accessed 25 August 2021].

70% of care home residents are living with dementia.⁵¹ During the pandemic, people in care homes struggled to access healthcare – 75% of the care homes we surveyed in May 2020 said that GPs were reluctant to visit residents.⁵² Being unable to access healthcare early on means that the person's condition is likely to deteriorate further, and they are more likely to present to acute services when they reach crisis point. The British Geriatrics Society has been campaigning to improve residents' access to healthcare and are calling on the NHS to work with care homes to roll out and fund programmes to enable enhanced healthcare services to be provided in all care homes⁵³ – Alzheimer's Society is supportive of this call.

Visiting restrictions in hospitals

Over half of people with a diagnosis of dementia in 2018/19 were admitted to hospital, and it is estimated that around 25% of hospital beds are occupied by people living with dementia.⁵⁴ Given that people will generally be admitted to hospital during a crisis, visits are extremely important for people with dementia. Carers not only provide reassurance, but they also play a significant caring role in hospitals, including helping with washing and feeding, and communicating care needs to staff. This is even more important during the COVID-19 pandemic when hospital resources and staff remain overstretched. However, from March 2020 all visits to hospitals were suspended with very few exceptions. A report by the Royal College of Psychiatrists (2020) examining the impact of COVID-19 on dementia care in hospitals, found that a lack of visits had a significant impact on people with dementia. People with dementia did not understand or remember why carers were not visiting and felt abandoned. Hospital leads felt that a lack of social contact with carers resulted in isolation, loneliness and a lack of stimulation in people with dementia.⁵⁵ Carers told us that after a stay in hospital, people with dementia experienced a significant decline in their cognitive and social abilities. People were unable to recognise carers and it took a long time to re-establish their relationships.

National guidance was revised on 8 April 2020, meaning visits continued to be suspended except in circumstances where not being present would cause distress to a person with dementia, or where someone was nearing end of life.⁵⁶ This was a positive step, but there were still issues. Carers told us that their loved ones with dementia were unable to communicate to hospital staff that they were feeling distressed (i.e they became withdrawn), and this was not picked up by staff or considered to be distressed behaviour. Some hospital staff were also waiting until patients

⁵¹ Wittenberg, R et al (2018). *The Costs of Dementia in England*, International Journal of Geriatric Psychiatry, <https://onlinelibrary.wiley.com/doi/full/10.1002/gps.5113>

⁵² <https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>

⁵³ [Ambitions for change: Improving healthcare in care homes | British Geriatrics Society \(bgs.org.uk\)](https://www.bgs.org.uk/ambitions-for-change-improving-healthcare-in-care-homes)

⁵⁴ Dementia Statistics Hub. Available at <https://www.dementiastatistics.org/statistics/hospitals/>

⁵⁵ National Audit of Dementia, Royal College of Psychiatrists (2020). Impact of the COVID-19 pandemic on hospital care for people with dementia: Feedback from carers/families and hospital leads. https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/round-5/impact-of-covid-19-on-dementia-care-report.pdf?sfvrsn=35546bbc_8

⁵⁶ HSJ (2020). 'Trusts told not to ban visits. <https://www.hsj.co.uk/coronavirus/trusts-told-not-to-ban-all-hospital-visits/7027383.article>

demonstrated signs of distress before allowing visits, rather than taking a preventative approach, which was not helpful. For example, a carer told us that she was not allowed to visit her husband with dementia for the first five days that he was in hospital, until one evening she got a call from a nurse who said “*Can you speak to David? He is very distressed, and we don’t know what to do*”. The carer was then able to visit regularly, however by this point her husband’s dementia had deteriorated.

In the absence of a preventative approach, people with dementia might start to display behaviour that challenges. This could result in them unnecessarily being referred to a psychiatric hospital, as well as the use of antipsychotic drugs. We heard from one carer that over a period of two weeks, her husband was placed in five different wards, then sent to a care home to recover, but then moved back to hospital – she was unable to visit for the majority of this time. As a result of displaying behaviour that challenges, it was decided that he should be moved to a psychiatric hospital. The carer felt that the number of times her husband was moved and the restrictions on visits resulted in him becoming agitated. Within this context it is even more important that carers can visit, and this should be a preventative measure to help the person feel calm in hospital. We also heard from carers that they were not allowed to enter wards for visits due to the risk of spreading COVID-19, and that visits took place in corridors instead, which was entirely inappropriate.

A survey by CQC (2020) looking at people’s experiences in hospital during the pandemic, found that people with dementia had by far the lowest rate of feeling able to keep in touch with their families during their stay – 23% said they ‘never’ spoke with friends or family while in hospital.⁵⁷ While communication through technology was encouraged by the government, not all hospital patients had been provided with an iPad. One person with dementia informed us that they had to wait nine weeks for a skype call with her daughter, due to having to wait for an iPad to be donated to the hospital. The iPad was shared amongst patients, and patients were unable to provide their own technology as it needed to be PAT tested. Not everyone with dementia finds video calls helpful but for those who do, technology should be made available and staff should be on hand to support people to use technology.

Revised NHS England guidance, published on 13 October 2020, confirmed that “*visiting is allowed in inpatient settings, in a very careful and Covid-secure way.*”⁵⁸ Under the guidance, organisations could “*exercise discretion where Covid rates are higher*”. However, no further information was provided on how high the infection rate would need to be to stop visits. Allowing individual hospitals to use their own discretion without clear guidance resulted in unnecessary regional variance.

⁵⁷ Care Quality Commission, (2020). Inpatient experience during the COVID-19 pandemic. Available from: https://www.cqc.org.uk/sites/default/files/20201118_COVID-IP-survey_report.pdf

⁵⁸ NHS England (2020). Visiting healthcare inpatient settings during the COVID-19 pandemic: principles, Available at: https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0751-visiting-healthcare-inpatient-settings-principles-131020_.pdf

29/10/2021