

The Coronavirus Actⁱ introduced the Care Act easements in England. These easements allow local authorities to temporarily relax certain responsibilities in order to prioritise care during periods of significant pressure. Alzheimer's Society recognises that the measures are temporary and should only be used in exceptional circumstances. This briefing sets out recommendations for local government on how to appropriately adopt Care Act easements on behalf of people affected by dementia.

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1. Overview: Why people with dementia need additional consideration

Those most at risk must receive the most protection. Dementia is the second highest pre-existing health condition for people dying of COVID-19 in England and Walesⁱⁱ. The easements guidance includes that local authorities may wish to RAG-rate or determine high, moderate and low risk for the care packages they provide.

Many people with dementia will have underlying health conditions which put them at greater risk of contracting COVID-19. Dementia is a progressive condition, meaning people's needs get worse over time. Nearly 60% of people living with dementia in 2020 have severe dementiaⁱⁱⁱ, including at least 100,000 people with severe dementia who live in the community, often only with support from unpaid carers.^{iv} We know that people with dementia are often more at risk of dying from respiratory diseases such as pneumonia.^v Furthermore, data from Public Health England suggests 77% of people living with dementia also have one or more other health conditions, with 22% having three or more and 8% having four or more.^{vi}

We are greatly concerned that by adopting the easements and not meeting the needs of people with dementia will lead to an irreversible deterioration in their condition. Not meeting the activity needs of people with dementia is also associated with the progressive worsening of cognitive and functional deterioration, resulting in the loss of levels of autonomy and the capability to satisfy their own needs.^{vii} Additionally, easements guidance notes that need levels may fluctuate, which is particularly true of people with dementia as capacity and ability to perform basic activities of daily living can fluctuate greatly over a short period of time or decline rapidly if needs aren't met.

Alzheimer's Society recommends:

- **Councils should take into account the progressive needs of dementia and take mitigating steps to prevent the dementia from progressing more rapidly than it might otherwise under the easements.**

2. Key areas

Having listened to people affected by dementia, social care professionals and care homes, Alzheimer's Society has identified the following key areas for local authorities to consider when planning to adopt Care Act easements:

a) **Democracy and oversight:**

In line with government guidance, the easements should only be adopted when the workforce is 'significantly depleted' or when demand on social care has increased to a point where it is not possible to meet the needs of people

with urgent or acute needs. Any change resulting from such a decision should be proportionate to the circumstances in the relevant local authority.

The decision to activate the easements should be taken democratically, in agreement with the Director of Adult Social Services (DASS) and in conjunction with, or on, the recommendation of the Principal Social Worker (PSW). The DASS and the PSW must ensure their lead member has been involved and briefed as part of this decision-making process. The Health and Wellbeing Board should be kept informed, and the decision should be fully informed by discussion with the Local NHS CCG leadership.

In addition, to ensure adequate oversight, Alzheimer's Society recommends that:

- **Lead Members for Adult Services consult with the opposition lead member(s) and chair of the appropriate Overview and Scrutiny Committee ahead of any decision to adopt easements.**

b) Adopting and communicating easements

Local authorities are expected to continue to do everything they can to continue to meet their duties under the Care Act. The easements should only be used in exceptional circumstances on an area-by-area basis and should be applied gradually.

Local authorities are also expected to observe the [Ethical Framework for Adult Social Care](#). This provides a structure for local authorities to measure their decisions against and reinforces that the needs and wellbeing of individuals should be central to decision-making.

Local authorities should have a record of the decision with the evidence that was taken into account. This decision should be communicated to all providers, people living with dementia and carers.

Alzheimer's Society recommends that:

- **A record of the decision to adopt easements, the reasons for doing so, and how often easements will be reviewed should be made available publicly.**
- **Information provided to people affected by dementia is inclusive, accessible and presented in a dementia-friendly format. We know that people living with dementia can face communication challenges and often need family members or loved ones to advocate for their rights.**

c) Assessments and meeting support needs

From Stage 3 of the easements, although local authorities will not have to carry out detailed assessments of people's care and support needs in compliance with pre-amendment Care Act requirements, they will still be expected to respond as soon as possible to requests for care, and support and consider the needs and wishes of people needing care, their family and carers. Importantly, 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 (ECHR). These include the right to life under Article 2 of the ECHR, the right to freedom from inhumane and degrading treatment under Article 3, and the right to private and family life under Article 8.

In order to establish that someone's human rights are not being breached, an assessment of their needs to keep them safe will need to take place. This should include an assessment of physical and mental health needs, the type of care and support that is required, and the consequences if support is not provided. Local authorities must ensure there is a clear and transparent pathway for people with care and support needs, 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 that an assessment of needs takes into consideration that people affected by dementia are likely to have additional needs than during 'normal' times, including support with accessing food and medication. People living with dementia can be more vulnerable to abuse, including financial, physical, sexual and emotional abuse. Symptoms

of dementia can affect communication, memory and reasoning skills, which can make it difficult for people to understand or explain to others what has been happening to them. People living with dementia can experience abuse in a variety of settings, including in the community and in care homes. The risk of abuse amongst people living with dementia can be reduced through the provision of ongoing adequate support.

It is important that a 'needs and care assessment' is carried out and a record of this is made. In line with the guidance, complaints and escalation procedures remain the same as under the Care Act and local authorities must provide a clear mechanism for raising concerns should they believe that either the decision or the care package is in breach of their rights. All assessments that are not completed in detail should be followed up and completed in full once the easements are lifted, and people affected by dementia should be kept informed at all stages.

Alzheimer's Society recommends that:

- **Needs assessments are carried out, where possible, and a record is made.**
- **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.**
- **Councils must ensure this clear and transparent pathway for escalating concerns is accessible to people living with dementia.**

Following implementation of Stage 3, the duties on local authorities to meet eligible care and support needs, or the support needs of a carer, are replaced with a power to meet only some needs. Local authorities will still be expected to take all reasonable steps to continue to meet needs as they are now. In the event they are unable to do so, the powers will enable local authorities to prioritise the most pressing needs, for example enhanced support for people who are ill or self-isolating, and to temporarily delay or reduce other care provision. There are 700,000 primary carers for people living with dementia and 1.8 million family, friends and neighbours who provide some support to people with dementia in England.

Alzheimer's Society recommends that:

- **Local authorities commit to urgent reviews of emergency arrangements in cases where a carer is no longer able to provide care.**
- **Local authorities proactively review emergency arrangements in advance of adopting the Care Act easements**

d) Care and support plans

Dementia is a progressive condition, meaning that health and care needs will get worse over time. The risk of delayed care planning means that any increased need cannot be documented and therefore support cannot be put in place to mitigate needs. Under the easements, local authorities will not have to prepare or review care and support plans in line with the pre-amendment Care Act provisions.

They will, however, still be expected to carry out proportionate, person-centred care planning. This helps to ensure that people living with dementia are able to take part in activities they enjoy, which can be an effective way of managing behavioural symptoms of dementia. In line with [NICE](#) guidelines, the key to achieving good person-centred care for people affected by dementia is to look at the person's perspective, and ensure they are at the heart of care planning. This guidance also notes the importance of understanding the needs of the carer and supporting them. Carers who are well supported will be able to provide better care.

Alzheimer's Society recommends that:

- **Any change to someone's care and support plan must happen through involvement with the individual and their carer. This includes ensuring information is communicated clearly to people affected by dementia so they know what to expect.**

e) Financial assessments

From Stage 3 of the easements, local authorities will not have to carry out financial assessments in compliance with pre-amendment Care Act requirements. They will, however, have powers to charge people retrospectively for the care and support they receive during this period, but not if the care package was put into place to prevent the individual being hospitalised. As we know that in 2016/17 alone there were 70,000 avoidable admissions for people over 65 with dementia in England^{vii}, largely due to insufficient access to appropriate social care, many packages may avoid this type of hospitalisation and thus should be covered by NHS England following the suspension of NHS Continuing Healthcare decision-making.

Paying for care retrospectively will be a source of concern for people affected by dementia who may feel anxious if they do not have a clear indication of how much they will be charged at a later date. To reassure people, local authorities should undertake a light-touch financial assessment to provide an indication of any potential future financial obligations.

Alzheimer's Society recommends that:

- **Light touch financial assessments must be done in a way that is accessible to people affected by dementia and offers a realistic understanding of how much they should be saving to pay for care.**
- **Family and carers should be consulted and kept informed. This is particularly important for people who lack capacity to seek involvement from carers.**
- **People affected by dementia should also be signposted to sources to independent financial information.**

ⁱ <http://www.legislation.gov.uk/ukpga/2020/7/contents/enacted>

ⁱⁱ ONS

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

^{iv} <https://onlinelibrary.wiley.com/doi/full/10.1002/gps.5113>

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

^{vi} 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.

^{vii} 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>

^{viii} Alzheimer's Society FOI Requests of 86 NHS Trusts in 2018, <https://www.alzheimers.org.uk/sites/default/files/2019-05/Dementia%20Fund%20Report.pdf>