

Written evidence submitted by Professor Linda Clare (ScD), on behalf of the IDEAL Programme, University of Exeter

Summation

Families living with dementia have been disproportionately affected by the COVID-19 pandemic, though much of this remains hidden from view. It is incumbent on us to recognise these challenges, and financially plan the route to recovery from COVID-19 for this distinct group of the population through resourcing the relevant services, support and third-sector organisations.

These plans need to consider the interconnecting costs which dementia creates, and be proactive in their consideration of how the situation is unfolding: the pandemic might be unpredictable, but the likely detrimental outcomes for people with dementia and their carers if nothing is done are not.

This submission addresses the overarching theme of how to combat the inequalities that have been exacerbated due to the pandemic, and the focus on disability, gender, and race. We will address:

- The hidden costs of dementia care, foregrounding the complex interdependencies of the condition
- The cognitive declines people with dementia have experienced due to lockdown which may necessitate increased care or service use as they try to regain function
- The specificity of minority ethnic groups' experiences of the pandemic with dementia, which highlights the need for community and third sector organisations being appropriately resourced

Solution

- **Allocation of funding for social care must be a strategic priority** if we aren't to exacerbate the inequalities for people with dementia and carers further, as emphasised in Alzheimer's Society's discussion paper [A Future for Personalised Care](#) (published earlier this year).
- **Plans to and funds for the restoration, continuation and expansion of services for people with dementia and carers**, from those which were halted due to the pandemic, to those like regular telephone/online 'check-ins' which were introduced and found to be beneficial. Many of these services are run by third sector organisations, where small amounts of funding would be of great benefit to people affected by dementia.
- **Promote links between primary care and ethnic minority community leaders** to identify novel ways to engage with people from minority groups

The research team

Linda Clare, Professor of Clinical Psychology of Ageing and Dementia, directs the [Centre for Research in Ageing and Cognitive Health \(REACH\)](#) at the University of Exeter, and is chief investigator for the IDEAL cohort study of people with dementia and carers, an Alzheimer's Society Centre of Excellence. [IDEAL](#) – Improving the experience of Dementia by Enhancing Active Life – studies how to live well with dementia over time, from two perspectives: people with dementia, and carers. With over 250 peer-reviewed articles to her name, Professor Clare is a recognised expert in the field of living with dementia or other age-related neurodegenerative conditions. This submission, co-ordinated by Dr Catherine Charlwood, is based on the work of the entire IDEAL team.

The IDEAL team comprises 10 Universities, 2 partner organisations (Alzheimer's Society and Innovations in Dementia), 30 researchers and a wider network of advisers (including people with dementia and carers), affiliates and artists. IDEAL has been collecting evidence since 2014, so is in a unique position to evaluate the impact of the COVID-19 pandemic on people with dementia and their carers.

Context: The case for the cost

The economic burden of COVID-19 on people affected by dementia is difficult to assess, and thus too often ignored, because:

- **Its roots are in historic underfunding of services:** for instance, someone may have relied on an unpaid family carer pre-pandemic (which wouldn't have been recorded) and needed increased care during the pandemic.
- **There are many indirect costs:** for instance, if someone's abilities decline, they may require increased care services. The long-term economic impact of COVID-19 on individuals affected by dementia, and the local councils and the NHS who provide services to support them, is likely to be much higher than realised.
- **One cost can lead to another**, since dementia often co-occurs in combination with other conditions (almost [three-quarters of the IDEAL cohort had more than one co-morbidity](#), for instance). Furthermore, our evidence shows that [the domains of living well are interlinked](#): for instance, feeling more isolated through declines in communication abilities could lead to depressive symptoms and a different kind of service usage.

Therefore, we present evidence here which gestures towards current and future financial uncertainties, knowing that often this burden is shouldered silently by families affected by dementia. We encourage the Committee to explore the complex costs for this unique group.

The IDEAL programme conducted two studies specific to COVID-19:

- The [IDEAL COVID-19 Dementia Initiative \(IDEAL-CDI\)](#) funded by NIHR, which collected evidence May-June 2020
- The [INCLUDE project](#), a rapid-response project funded by ESRC, which collected evidence September 2020-April 2021

Our submission relates to the evidence we gathered through these studies in the wider context of related recent publications and reports.

Hidden costs of care

“Life is dripping away”
– participant missing cancelled clubs and social groups in lockdown

Alzheimer’s Society’s [Worst Hit: dementia during coronavirus](#) report (2020) reveals the extent to which people with dementia and their carers have suffered disproportionately during the COVID-19 pandemic. Results from an Alzheimer’s Society survey revealed that 92 million extra hours have been spent by family and friends caring for loved ones with dementia.

While carers have taken on more caring hours, they have also lost many of their previous outlets for respite, due to the pandemic: not only the lack of availability of respite care services like a short-stay in a care home for the person with dementia, but also the closure of day centres and groups for people with dementia – which provide a less easily recognised respite. IDEAL-CDI recommends

- Needs assessment in regard to respite
- Novel forms of respite care that incorporate social distancing

This fits with [Alzheimer’s Society’s fifth recommendation \(5b\)](#) to mitigate against the effects of COVID-19 to ensure “the delivery of carers’ assessments and provision of short breaks for carers”. Indeed, the fraught situation for carers is explained in the Alzheimer’s Society’s [‘The Fog of Support: An inquiry into the provision of respite care and carers assessments for people affected by dementia’](#).

INCLUDE heard from carers whose employment status had changed because of the pandemic – going part-time, retiring early, or resigning. The shift to working from home was another point of contention: while some carers have found it better to be around the person with dementia to support them, others told us that the most difficult aspect of the coronavirus outbreak was “Working from home and caring for [their loved one]”.

From IDEAL’s broader research programme, we know that [how well the carer is coping affects not just them](#), but also the person with dementia. IDEAL has been identifying the different areas (or domains) which co-ordinate to create the feeling of ‘living well’ for a given individual. We’ve found that the psychological domain – a

person's psychological characteristics and psychological health – [is the strongest predictor of the ability to live well](#), so this overburdening of carers during the pandemic could lead to other difficulties. Health and social care services are yet to realise the extent of carer fatigue, even burn-out, from the pandemic, and the funding needs to be in place for the provision of this support.

Postponed or cancelled health appointments also form a hidden cost, as delays could turn easily resolved problems into larger health concerns. As IDEAL-CDI reports, "Interruption of planned health services affects both carers and people living with dementia", noting further that some impacts "have yet to be fully felt".

As mentioned above, people with dementia are likely to have other medical conditions as well. IDEAL-CDI evidences a range of conditions where investigations or treatment were halted: heart condition, daily visits by District Nurses to manage diabetes, physiotherapy/reablement following a fractured hip, and more.

An INCLUDE participant's carer similarly observed:

"He is having investigations done for possible bowel cancer. The whole process has been quite drawn out, he has been waiting for appointments and scans."

While delays in health investigation or treatment are not confined to people with dementia, there are particular knock-on effects for this group, and for their carers. We have focused primarily on hidden costs, as these are the ones which are rarely addressed, but there have understandably been direct cost implications from COVID-19 for people with dementia and carers, too.

One participant in INCLUDE highlighted how COVID19 had markedly changed her social care needs, and the difficulties of co-ordinating a change in payments to reimburse her assistant:

"One of the biggest impacts has been managing the direct payment hours she gets from social services as everything has taken longer (e.g. daily tasks - personal assistant (PA) goes to get daily shopping items on the way to work which pre-COVID would only take 15 minutes out of the day but now can take a major chunk out of the hours), so that has been really difficult and social services are not taking that into account."

Decline and restoration

"[Lockdown] enabled dementia to get bigger hold of me than it would have done before"
– INCLUDE participant

Early analyses of the INCLUDE data reveal a steeper than usual trajectory of decline in cognitive and functional ability, and hence ability to manage self-care and everyday activities, resulting from the conditions experienced during periods of restriction due to the pandemic. Compared with our pre-pandemic benchmark data, there are significant differences for people with dementia's self-perceptions of:

- Memory being very poor
- Difficulties with self-care
- Feeling they are not the same person
- Feeling lonely

Loneliness is a particular concern, given that our pre-pandemic research found that approximately [one-third of our participants experienced loneliness and that social isolation is a key predictor of loneliness](#). Our previous results have been borne out by the pandemic, where lockdown has upped everyone's levels of social isolation, further affecting this already at-risk group. Loneliness is linked not only to depression, but many negative health outcomes, so this increase gives cause for concern.

When carers were asked, there were significant differences in how they felt the person with dementia was doing with regards self-care, in particular. As an illustrative example, one carer participant in INCLUDE noted that "She has to really help with showering now, getting him into the shower, reminding him to put shower gel on etc. She also has to lay his clothes out – he can dress himself but it varies, sometimes he will put underwear over his trousers." A decline in self-care reduces the person with dementia's independence, and the consequent increased dependence on their carer can be upsetting as well as markedly broadening the scope of their caring role.

While we were heartened to find that self-reported pain or feelings of depression had decreased during lockdown for people with dementia, the increased loneliness could have knock-on effects of social withdrawal and further loss of communicative skills. As [Professor Alistair Burns](#), Co-I on the INCLUDE project and NHS England Lead for Dementia notes, "Dementia, par excellence, is a condition where connection is key" though admits the effects of prolonged isolation through lockdown are "probably less easy to measure" than, for instance, increased medication. In his memory clinics Professor Burns is seeing "people who over the last year have really felt a deterioration in memory, often in language, because of the loss of social connectedness".

Through INCLUDE's telephone interviews, we've heard people's fears – either for themselves, or for the person they care for – that they won't come out of lockdown with the same abilities. Much of this, though, is hard to see because it begins with a loss of confidence:

- "Confidence was an issue, didn't want to go out again – agoraphobic, anxiety so tried deep breathing exercises with Psychologist"

- “Confidence affected, the less you do the less you want to do. Was a long 3 months”
- “Confidence - it has made her worry more about when we come out of the virus, when we come out she won't know if she can do the things she could do before”

Practice is key to maintaining skills, but many opportunities to practice were removed by lockdown. Some lost ground might potentially be recoverable, but this would require appropriate support for reablement, such as that offered by the [GREAT programme](#). Otherwise, more rapid and extensive decline is likely to result in increased needs for care and higher demands on family carers, and ultimately the NHS – with all the associated financial burden. As an output of the [GREAT into Practice project](#), e-learning resources for NHS and social care staff will soon be made available on the NHS e-learning hub. Parallel self-help resources co-developed with a group of people with dementia are also soon to be available through Alzheimer’s Society. Now is a good time to financially underpin reablement offers, as they stand to help many people regain skills lost during the pandemic.

People with dementia and carers want to be able to ‘build back better’ for themselves, but they can only do so if the services which support them are properly resourced, back up and running, or still exist at all. We urge the Committee to consider allocating funding to dementia services now to save greater costs – financial, physical and psychological – in the future.

Ethnic minority experiences of dementia during COVID-19

- “So there’s lots of appointments I should go to but I’ve just been too scared to go there because I don’t trust the process.”
- Black British Caribbean person living with dementia, IDEAL-CDI

Study 3 of the [IDEAL-CDI](#) focused specifically on BAME participants, to further explore the specific nature of their experiences of the pandemic. Mistrust was a feature of these interviews “that was not readily apparent in Study 1 and 2”, with a predominantly white sample. As IDEAL-CDI reports: “This included mistrust of news and official advice about coronavirus”. Compared with IDEAL-CDI’s other studies, there was also much more involvement among ethnic minority participants with community groups and faith communities for information and support.

This could be an indication to offer culturally relevant support ([Department of Health and Social Care, 2016](#)) to mitigate fears and stigma by investing in local third sector services who are more easily able to build trust with an ethnically diverse community ([Public Health England, 2020](#)). Drawing on the expertise and knowledge of these community and faith groups will provide the much-needed perspectives of people on the ground to ensure that future resources are better co-ordinated and will achieve greater engagement, trust and ultimately outcomes for ethnic minority people..

The importance of speaking to people in their own language led IDEAL to have our [dementia coronavirus leaflets](#) translated into Arabic, Bengali, Chinese, Gujarati, Kurdish, Punjabi, Portuguese, Polish, and Somali, but we know that information has most impact when it comes from sources the person already knows. The importance of organisations like [Meri Yaadain CiC](#) cannot be overstated: they've made [COVID19 information videos](#) in English, Urdu, Bangla and Gujarati for people with dementia to ensure that rules about social distancing and information about vaccine roll-out reaches people in a way which they understand. Funnelling funding towards such community groups would help redress the particular inequalities felt by ethnic minority people with dementia.

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