



16th October 2020

Mr Colm Gildernew MLA
Chairperson
Committee for Health
Room 410, Parliament Buildings,
Stormont,
Belfast BT4 3XX

By E-mail: Committee.Health@niassembly.gov.uk

Dear Colm,

COVID-19 and Care Homes

Thank you for your letter of 23 September 2020 regarding the above, your ref: C221/20, inviting Alzheimer's Society to respond to the inquiry and seeking out views to develop recommendations to mitigate and manage a second surge of infections. As the UK's leading dementia charity, Alzheimer's Society welcome this engagement. We do everything we can to keep people with dementia connected to their lives and the people who matter who matter most.

Since the pandemic started, we have gathered evidence and published two reports – which have already been circulated to the Minister for Health and all MLAs - but I attach them here again for ease of reference and further reading:

“Worst Hit: dementia during coronavirus” available here
<https://www.alzheimers.org.uk/news/2020-09-29/exhausted-family-and-friends-spent-92-million-extra-hours-caring-loved-ones>

And “The Fog of Support” available here
https://www.alzheimers.org.uk/sites/default/files/2020-09/the-fog-of-support_national-recommendations-briefing_sept-2020.pdf

There are several factors that have contributed to the failure to keep Care Homes safe. We recognise your correspondence requested a structured format for responses. Please see our recommendations at the end and we are happy to respond per suggested heading with our evidence and experiences as follows:

Discharge from hospitals to Care Homes

A lack of testing for COVID-19 in hospitals prior to discharging patients to Care Homes was a key issue. We agree with the House of Commons Public Accounts Committee conclusion



that 'discharging patients from hospital into social care without first testing them for COVID-19 was an appalling error'.

Tragically, the effects of the pandemic go beyond this terrible death toll. We have heard from care professionals and people affected by dementia that isolation, depression, and not understanding why loved ones are no longer visiting could have contributed to a loss of skills, independence and, ultimately, premature deterioration in their dementia. This could include losing the ability to speak and communicate their symptoms, or even stopping eating and drinking, leading to a greater number of deaths among people with dementia. The cancellation of group activities and communal dining in Care Homes, to reduce the risk of coronavirus transmission, added to the isolation that people experienced.

Also, our recent surveys paint a distressing picture of the impact on those often overlooked – the army of unpaid carers, struggling to care round the clock for their loved ones, exhausted and 'burnt out' with nowhere else to turn.

Access to PPE

Regarding PPE, social care providers having to procure their own PPE left care providers to fend for themselves against a background of the NHS's huge purchasing power, tightening domestic and worldwide demands for PPE. Many struggled to purchase PPE and when it was available, it was often at inflated prices. Although the situation later improved, this lack of PPE will have had dire consequences for people with dementia and those who care for them.

Testing in Care Homes

Regular testing for staff and residents was not announced by the PHA until 3 August despite the NISRA figures continually showing that residents in Care Homes were making up around 40% of those dying with the virus. Care Homes report tests not being collected to be couriered to laboratories and results taking too long to be returned.

Funding and increased costs for Care Homes

See recommendation 3

Staffing issues & levels

When it comes to isolating people with dementia, guidance for Care Homes was to isolate people for 14 days if they came from hospital or had symptoms of COVID-19 but this is very difficult in practice. Restricting movement is a significant loss of autonomy, especially

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as people with dementia may not understand or remember the reasons for it, and it is difficult to provide appropriate supervision with available staffing levels when many residents are on their own.

Staff pay and conditions

Staff factors including a lack of guidance for Care Homes about restricting staff movements between homes are thought to have played a part in increasing infections rates. There is some evidence that more frequent use of agency staff is a common factor in Care Homes with higher infection levels, and that in Care Homes where staff receive sick pay there are lower levels of infection in residents, perhaps because staff without sick pay can't afford to stay away from work, even if they are unsure about their own health. Blanket testing for staff combined with robust contingency plans for backfilling staff who cannot work due to a positive test has been suggested as an important safeguard.

Visitors

Visits for people in Care Homes affected by dementia are critical. Family visitors play a huge role in the care of residents, providing love and company, helping with eating, keeping cognitive and communication skills sharp, grooming and recreation and advocacy and timely detection of changes in residents' health. Without visitors or excursions, residents will feel lonelier and more bored, and this may be expressed through agitated behaviour or social withdrawal. Also, the lack of physical activity may lead to loss of strength and the lack of cognitive stimulation may lead to greater cognitive decline.

Alzheimer's Society have seen and heard the devastating impact of social isolation for people with dementia. Without family and friends able to visit, people's symptoms have worsened much more quickly and connections to their loved ones, sadly even those who play a vital caring role, have been lost.

Regulation

COVID-19 has exposed how our fragmented social care system utterly fails to support people with dementia. The need for social care reform is clear and urgent. Our Fix Dementia Care campaign has raised major social care issues across three areas – access, quality and cost. Care should be universal and free at the point of use. The additional costs of dementia-specific health and social care should not be funded by individuals but via a shared pooling of risk across society, just like education, other health priorities and other public services. The legacy of the pandemic must be a universal social care system, free at the point of use, that provides every person with dementia with the quality care they need.

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Medical care within Care Homes

There have also been concerns around end of life care, particularly reports of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders being added to files of people living in Care Homes en masse, without consultation with their families.

Antipsychotic medication is sometimes used to treat behavioural and psychological symptoms in people with dementia. Prescription of antipsychotic medication for people with dementia is closely monitored as it can cause serious side effects, especially when used for longer than 12 weeks. Data from NHS Digital reveal that the percentage of people with dementia in England prescribed antipsychotics has risen from a stable 9.4-9.5% in the 8 months prior to March, to 10% in the six weeks leading up to 30 April.

Although it is not possible to say with certainty whether this increase in prescriptions is appropriate or not, this should be investigated as a possible effect of lockdown in Care Homes and the trend should be monitored, allowing for intervention to reverse this trend if required.

Preparedness within the HSC and in Care Homes: pre-COVID baselines and future requirements

Prior to the pandemic there was 22,000 people living in Northern Ireland with dementia and the Westminster All-Party Parliamentary Group on dementia “Hidden No More – Dementia and Disability” 2019 report outlined how people living with dementia feel they are treated differently to people with other health conditions or disabilities due to the progressive but ‘hidden’ nature of dementia, the individuality of dementia and its symptoms, and the stigma surrounding the condition. The social care crisis is a dementia crisis as 70% of Care Home residents are living with dementia, so issues that affect Care Homes disproportionately affect people with dementia.

The Department’s Surge Planning Strategic Framework has to show how people living with dementia have been accommodated for and the wider Reform of Adult Social Care is important as we need to end the unfair daily injustice people with dementia and their families face in accessing and paying for the good quality care to which they are entitled which should be free at the point of need. We need a frank public discussion about the value of social care to society – not only to those who use it.

Conclusion and Recommendations

The devastating impact of COVID-19 on people affected by dementia cannot be undone. Although attempts were made to protect Care Home residents, the support for Care Homes fell seriously short. Despite the incredible efforts of Care Home staff, the sector was largely ignored during the first part of the crisis with devastating consequences. However, there is now a short window of opportunity for action to mitigate against further effects of the virus and to help those who are recovering.

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Our recommendations to government are:

1. The Department of Health must set out how they will involve social care providers and Care Homes in winter pressure planning to ensure that social care is placed on an equal footing within the health care system and that their situation is understood, accounted for and supported. This must include the provision of regular and timely testing and PPE.
2. National UK governments must guarantee that where care was stopped due to coronavirus precautions (particularly domiciliary care), it will be reinstated when deemed safe, without the need for unnecessary further formal assessment
3. The UK Government must ensure that the Infection Control Fund remains in place until at least April 2021 and care providers should be able to use that fund flexibly, including for infection control, technology and supporting visits.
4. Government should commit to ensuring that any communications to, or requirements of, people affected by dementia (both in the community and in Care Homes) are clear, consistent and straightforward to understand. Any guidelines should reflect the daily lived experience and particular needs of people affected by dementia.
5. Recognising the key role that informal carers play in the lives of people living with dementia, the Department of Health must take action to support people in this role by:
 - a. Allowing for at least one informal carer per Care Home resident to be a designated key worker, with access to training, COVID-19 testing/ vaccinations and PPE.
 - b. Ensuring the delivery of carers' assessments and provision of short breaks for carers.
 - c. Collecting data on carer assessments and respite care.
6. Where Care Homes are unable to facilitate visits from loved ones, they must be required to notify national care inspectorates (CQC/CSSIW/RQIA) and seek to put in place suitable alternative arrangements to maintain appropriate contact between loved ones and Care Home residents who have dementia.
7. National UK governments needs to set out a clear strategy to enable people affected by dementia to recover from the effects of the pandemic, including rehabilitation to counteract effects on cognitive or physical functioning, support for mental and physical health, and speech and language therapy.

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8. The Department of Health must develop and implement a clear recovery plan to ensure that all elements of memory assessment services can re-open and urgently catch up on waiting lists so the freefall in dementia diagnosis rates does not continue.

People with dementia have never been identified by government as an increased risk group from the virus. Worrying and separate from coronavirus, the largest increase in excess non-COVID-19 deaths was in people with dementia. Every one of those deaths also leaves behind a grieving family – the loss of a partner, a parent, a grandparent, a friend. For people who survived the crisis, the effects of social isolation were severe. Regular health and social care services were put on hold, creating a backlog of people who have missed out on essential support. This pandemic has dreadfully exposed the dire state of social care and made the need for urgent reform indisputable.

We in Alzheimer's Society hope that both you as Chair and the wider Health Committee find this submission to be of assistance in your inquiry and Bernadine McCrory, NI Country Director, would be happy to brief you and the Committee in person if you wish.

Yours sincerely

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