

Worst hit: dementia during coronavirus



Acknowledgments

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This report was compiled based on evidence and publications from many sources. We commend the efforts of the many people and organisations that have gathered and published evidence, cited in the references section, on the impact of COVID-19 for people affected by dementia.

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Foreword

Over the past six months I have been so shocked and saddened to see people affected by dementia hit hardest by coronavirus. More than a quarter of those who died in England and Wales had dementia, which means it is the most common pre-existing condition for coronavirus deaths.

The biggest spike in excess deaths was also in people with dementia. Even without including deaths attributed to coronavirus, twice the number of people with dementia died at the pandemic's peak compared to what would normally be expected. Every one of those thousands of deaths leaves behind a grieving family – the loss of a partner, a parent, a grandparent, a friend. Despite the incredible efforts of care home staff, the sector was largely ignored during the first part of the crisis with devastating consequences. People with dementia have never been identified by government as an increased risk group.

Tragically, the effects of the pandemic go beyond this terrible death toll. I 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. And it is not just people with dementia who are affected. Our survey paints 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.

This report sets out the impact coronavirus has had on everyone affected by dementia. Knowing so many of the personal stories that lie behind these statistics makes it incredibly distressing to read, but we must not feel powerless in the face of these disastrous events.

I am proud that Alzheimer's Society adapted quickly to increase our support online and on the phone when we could no longer meet people face to face. We led the way in shining a light on the care home catastrophe and we made the voices of people affected by dementia heard. Backed by 11,000 supporters, we influenced local and national governments to increase protections for them.

But we cannot take on dementia alone. Coronavirus has laid bare the dire state of the social care system for all to see and no-one can be in any doubt of the urgent need for the Government to act in order to fix it.

Until then, people with dementia will continue to struggle to get the attention, funding and skilled support they need to live well and they will continue to be hardest hit in tragic circumstances.

We must prevent this from ever happening again and give people with dementia the dignified care they deserve. 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. Then and only then, will we finally see social care put on equal footing with the NHS, no longer the poor relation, neglected and forgotten.

Now is the time for action; now is the time to #FixDementiaCare.

Kate Lee

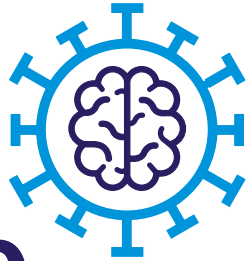
Chief Executive, Alzheimer's Society

Executive Summary

The coronavirus pandemic is having a devastating impact around the world. In the UK, people affected by dementia have been hardest hit and our fragmented social care system has been exposed for all to see.

Alzheimer's Society is the UK's leading dementia charity, and in this report we bring together evidence from a wide range of sources to shine a light on the impact of coronavirus disease 2019 (COVID-19) on people who have dementia and those who care for them.

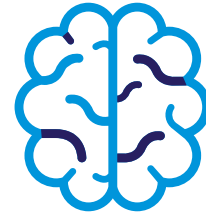
Over a quarter (27.5%) of people who died with COVID-19 from March to June had dementia.



13,840

deaths of people with dementia involving COVID-19 in England and Wales were recorded from March to June, making dementia the most common pre-existing condition in deaths involving COVID-19.¹ This is a hugely disproportionate impact on people with dementia who should have been protected.

The largest increase in excess non-COVID-19 deaths was in people with dementia.



5,049

excess deaths of people with dementia were recorded between 4 January and 10th July, in addition to deaths attributed directly to COVID-19.² In the peak weeks of the pandemic, double the number of people with dementia died compared to the five-year average.³

For people who survived the crisis, the effects of social isolation were severe.



46%

of people with dementia in our survey reported that lockdown had a negative impact on their mental health. In a wider group that included carers, 82% reported a deterioration in the symptoms of people with dementia.⁴

The crisis hit family carers and professional carers hard.



92million

extra hours have been spent by family and friends caring for loved ones with dementia.⁵ 95% of carers in our survey reported a negative impact on their mental or physical health.⁵ 268 social care workers died with COVID-19 between March and May, a statistically significantly higher rate of death compared to average for their age and sex.⁶

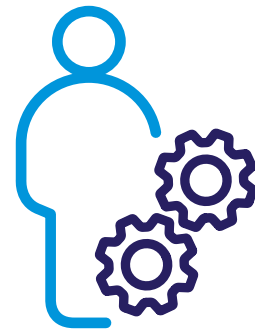
Regular health and social care services were put on hold, creating a backlog of people who have missed out on essential support.



75%

of care homes we surveyed in May said that GPs were reluctant to visit residents.⁹ The national dementia diagnosis rate has declined steadily since February 2020, dropping to 63.2% in July.⁷ This is substantially below the national target of 66.7%.⁸

Alzheimer's Society is here for everybody affected by dementia during this crisis. We worked in new ways to help people stay connected.



93%

of our service users felt that they were more able to manage following the support we provided over this period.

Recommendations

The devastating impact of COVID-19 on people affected by dementia cannot be undone. However, there is now a window of opportunity for action to mitigate against further effects of the virus and to help those who are recovering.

This pandemic has dreadfully exposed the dire state of social care and made the need for urgent reform indisputable. We welcome the Government's confirmation of a public inquiry so that lessons can be learnt, and the same mistakes not repeated. However, they must ensure that the needs and views of people affected by dementia, as those worst hit by the pandemic, are recognised as central to this process.

Mitigating against the effects of COVID-19 as we approach the winter

Reasonable worst-case scenario modelling suggests hospital deaths between September 2020 and June 2021 could be as high as 119,900, with even higher numbers if care homes are affected. However, this doesn't account for the action the Government could take to reduce the transmission rate.¹⁰ We must ensure that the safety and wellbeing of people with dementia are protected from a possible resurgence of coronavirus over the winter months.

- 1** The NHS and local authorities 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 with the NHS, 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** National UK governments 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.

Supporting people affected by dementia

People affected by dementia have experienced significant harm from the restrictions to social contact and reductions in services over this period. At all levels, decision makers must recognise that informal carers are an integral part of the care system, and the value that people with dementia receive from social contact and give these due priority.

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- 5** Recognising the key role that informal carers play in the lives of people living with dementia, national UK governments must take action to support people in this role by:
- a.** Allowing for at least one informal carer per care home resident to be designated a 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 local authority and health authority data on carer assessments and respite care.

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- 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.

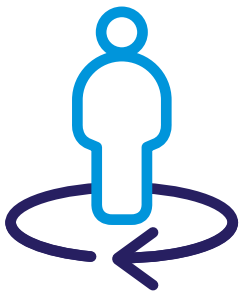
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- 7** National UK governments needs to set out a clear strategy to enable people affected by dementia to recover from the effects of the pandemic, including rehabilitation to counteract effects on cognitive or physical functioning, support for mental and physical health, and speech and language therapy.

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- 8** National UK health and social care departments 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.

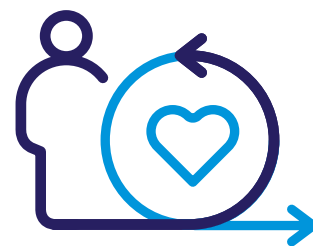
Changing the conversation on social care

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; it must be addressed within this parliamentary term. We know that it will be impossible to put in place an entirely new social care system overnight and, like the NHS over the last 72 years, its development will be iterative. However, we must put in place the necessary strong foundations now. The social care crisis is a dementia crisis – people with dementia are estimated to make up at least 70% of care home residents¹¹ and over 60% of home care recipients¹², so it is essential that their needs are a key consideration. Our Fix Dementia Care campaign has raised major social care issues across three areas – access, quality and cost. The social care crisis also has a huge impact on the NHS – in fact the successful implementation of the NHS Long Term Plan, as NHS leaders have stated, is reliant on a well-functioning social care system.

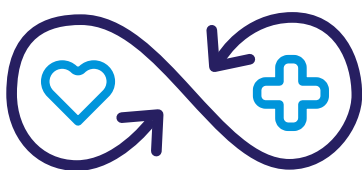
We are calling for care (including specialist dementia care) to be universal and free at the point of use. The additional costs of dementia-specific health and social care should not be funded by individuals but via a shared pooling of risk across society, just like education, the NHS, and other public services. Any proposal for long term reform needs to address these basic principles:



Care should be person-centred and include an element of choice.



Informal carers should be recognised as an integral part of the care ecosystem.



There must be greater integration between health and social care.

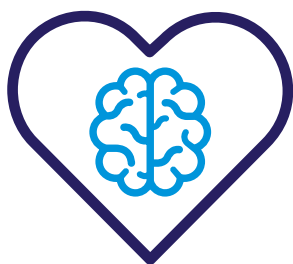


There must be a minimum set of national standards.

Introduction

There are currently around 850,000 people living with dementia in the UK.¹³ Dementia is a progressive condition which occurs when the brain is damaged by diseases (such as Alzheimer's disease) or a series of strokes. The symptoms of dementia can include memory loss and difficulties with thinking, problem-solving, language and physical function.

In the early stages of dementia, the symptoms can be quite subtle. People with dementia can and do live independent and active lives. As dementia progresses the symptoms can become very severe, and people with dementia may rely on others for much of their care; to get dressed, to eat and to look after their personal needs with dignity. It has been estimated that 86% of people with dementia in the UK are living with moderate or severe dementia.¹³



With no drugs to cure or slow down the condition, it's social care not the NHS that people with dementia depend on the most.

70% of care home residents are estimated to be living with dementia¹¹ and the UK Homecare Association has estimated that over 60% of people receiving home care have dementia.¹²



Dementia is a complex condition and people with dementia can have complex needs.

77% of people with dementia also have at least one other specific health condition; hypertension, diabetes and depression are fairly common.¹⁴



Managing these health needs often requires expert professional care, but the value of care that family members, friends and communities provide must never be underestimated.

It is thought that there are over 700,000 people in the UK acting as informal carers for people with dementia.¹⁵ The financial value of this care is estimated to be £13.9 billion each year¹³; the emotional and societal value is inestimable.

Alzheimer's Society's new report 'The Fog of Support' provides further detail on what is needed to better support informal carers of people with dementia, particularly around respite care and carers assessments.¹⁶

Before the COVID-19 pandemic, our Fix Dementia Care campaign had consistently drawn attention to how unfair and broken the current system is for people living with dementia. It is not right that people affected by dementia have to pay huge amounts of money for their care just because they developed dementia and not another health condition.¹⁷ This was recognised by the Government with the Prime Minister's commitment on his first day in office to 'fix the crisis in social care'.¹⁸

In this report we show how the COVID-19 crisis has exposed and deepened the fault lines in this fragmented system with disastrous consequences for people affected by dementia. Although we focus on the three nations in which Alzheimer's Society operates (England, Wales and Northern Ireland), many of the experiences described in this report will resonate beyond these borders. We must urge swift action to mitigate the continuing direct and indirect harm that COVID-19 brings. We must reform and better integrate our health and social care systems so that they provide quality care for people affected by dementia and are resilient against future catastrophic events.

A disproportionate death toll on people with dementia

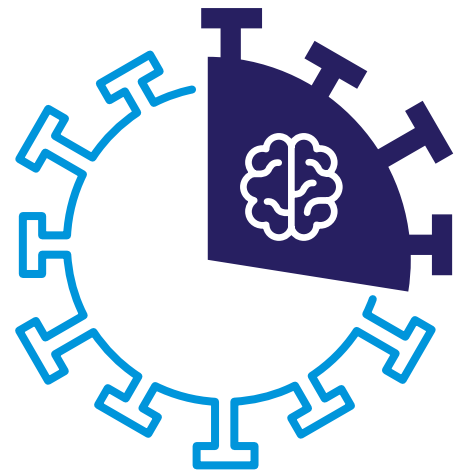
A high proportion people who died from COVID-19 had dementia

The most direct and devastating impact of COVID-19 on people affected by dementia is the high death rate. As the pandemic progressed from late March into April, the death toll across the UK began to unfold. Between 1 March and 30 June there were 50,335 deaths where COVID-19 was mentioned on the death certificate in England and Wales.¹

It became clear that people with dementia were the hardest hit as dementia was the single most common pre-existing condition in deaths involving COVID-19.¹ Data from the Office for National Statistics shows that 27.5% of people whose death certificate mentioned COVID-19 from March to June in England and Wales had dementia.¹ There were 13,840 deaths of people with dementia involving COVID-19 in these four months.¹ Through communication with the Northern Ireland Statistics and Research Agency we learned that 475 deaths in Northern Ireland mentioned COVID-19 on the death certificate in March and April 2020. Of these, 157 (33%) also mentioned dementia on the death certificate.

Despite the fact that males had a higher rate of COVID-19 deaths than females across all age groups,¹ there were more deaths of females (52%) than males (48%) with dementia involving COVID-19¹⁹ likely reflecting the greater prevalence of dementia among females than males.¹¹

There are also concerns over the higher proportion of deaths due to COVID-19 among Black and Asian people in adult social care. The majority of people who died in adult social care settings were white but the proportion of deaths due to confirmed or suspected COVID-19 was higher for Black (49%) and Asian (42%) people compared to White people (41%) and people from mixed or multiple ethnic groups (41%).²⁰ Unfortunately, data reporting the number of deaths of people with dementia from different ethnic groups is not currently available so we are unable to closely monitor for possible disparities. Public Health England has published a rapid review on the impact of COVID-19 on Black, Asian and minority ethnic groups, which has identified a need for comprehensive and quality ethnicity data collection in the NHS and social care.²¹



27.5%

of people who died with
COVID-19 from March to
June had dementia





Why were people with dementia hardest hit?

Research has shown that risk of severe COVID-19 outcomes grows steeply with age.

94% of COVID-19 deaths in March to June were in people over the age of 60.¹⁹

94%



As the majority of people with dementia are over 65, their risk of severe COVID-19 is high, but the link between dementia and COVID-19 goes well beyond age.

There is emerging evidence to suggest that dementia itself may increase risk of severe symptoms of COVID-19 and death when age and other conditions are taken into account,^{22,23} but further research is needed to fully establish this. Other long-term health conditions such as diabetes and heart disease also raise the risk of severe COVID-19 illness and these are common comorbidities among people with dementia.¹⁴

Rapid research from the UK Dementia Research Institute (supported by Alzheimer's Society alongside the Medical Research Council and Alzheimer's Research UK) indicates that a fairly high proportion (18%) of nursing home residents who tested positive for COVID-19 were either asymptomatic or had only atypical symptoms (i.e. not fever or cough, but instead altered mental status or behaviour, anorexia, diarrhoea or vomiting)²⁴, which may have also contributed to the challenge of detecting and preventing spread of COVID-19 in this population. This is corroborated by research suggesting that being 'generally unwell' is an important sign to consider as part of COVID-19 diagnosis in care home residents.²⁵

Challenges presented by dementia itself may also have contributed to difficulties in stopping the spread of the virus. A person living with dementia who has memory problems or confusion may struggle with the guidance and rules to reduce the risk of being infected by coronavirus. Measures such as frequent handwashing and social distancing to reduce the risk of catching the virus may be hard for some people with dementia to follow.

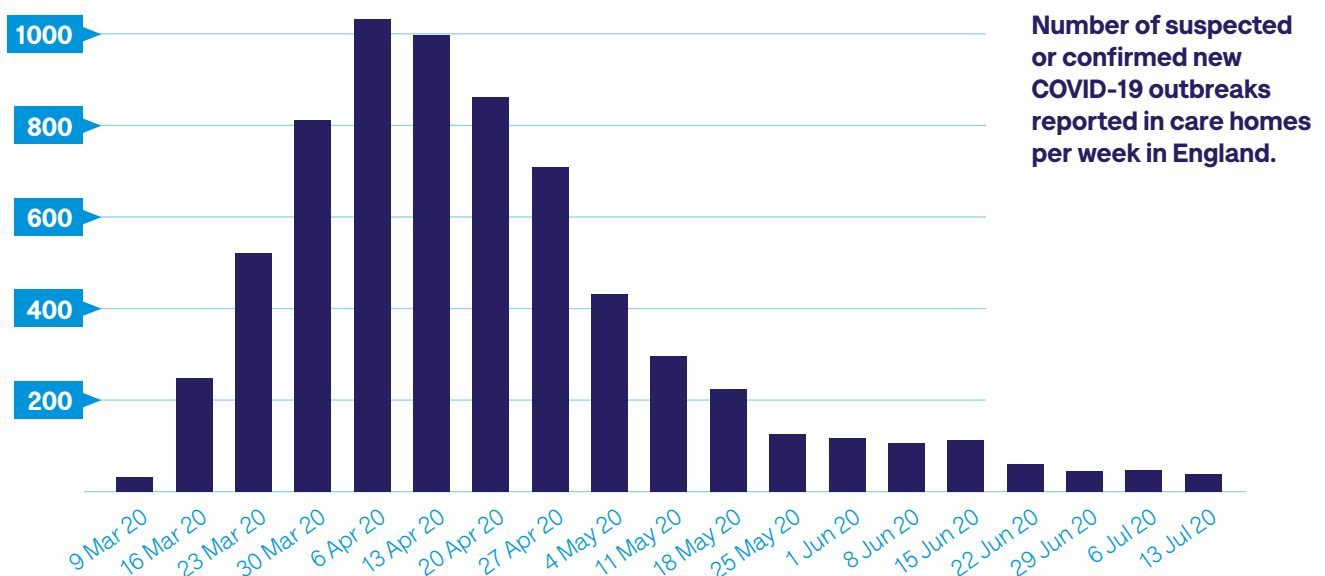
In addition, a significant proportion of people with dementia live in care homes¹¹ and as the next section of this report outlines, there were significant challenges in preventing the spread of COVID-19 in that setting.

Care homes were not sufficiently protected

It is estimated that 39% of people with dementia in the UK live in care homes and 70% of care home residents are living with dementia¹¹, so issues that affect care homes disproportionately affect people with dementia.

Although attempts were made to protect care home residents, the support for care homes fell short. Social care was not on an equal footing with the NHS and not prioritised for COVID-19 testing and personal protective equipment. Public Health England data shows there were four weeks in March to April where more than 800 new outbreaks in care homes were reported each week.²⁶ Between the start of March and end of April, deaths from any cause in care homes more than tripled.²⁷ Of all deaths registered as COVID-19 related in the UK, at least 21,775 (40%) were accounted for by care home residents.²⁸ In Northern Ireland, care home residents accounted for 51% of all COVID-19 related deaths, compared to 50% in Scotland, 39% in England and 34% in Wales.²⁸

Estimating the number of excess deaths is recognised as a way to compare the relative failure or success in handling the pandemic. Using this measure over the whole population, it is reported that England had a 38% increase in mortality compared with 29% in Scotland, 22% in Wales, and 20% in Northern Ireland.²⁸ However, the rate of excess deaths was markedly higher for care homes, with a 79% increase in mortality over the pandemic period in English care homes compared to 62% in Scotland, 66% in Wales, and 46% in Northern Ireland.²⁸ Although there has rightly been a focus on care homes, data from domiciliary care (only available in England) show that the overall proportional increase in deaths (but not total number of excess deaths) was even greater in domiciliary care than care homes.²⁹ Although the reasons for this are not clear and should be established, it is possible that this reflects delays in accessing health or care services or the overall reduction in hospital admissions during this time meaning that more deaths than usual occurred at home rather than in hospital.



There are a number of factors that may have contributed to the failure to keep care homes safe. A lack of testing for COVID-19 in care homes (and in hospitals prior to discharging patients to care homes) alongside a lack of personal protective equipment (PPE) were key issues. Difficulties with diagnosis and testing for COVID-19 (particularly given atypical symptoms mentioned above), and isolation for people with dementia are also noted in a recent commentary.³⁰ A report from the Older People's Commissioner for Wales developed similar conclusions, particularly highlighting delays in accessing PPE and testing.³¹

Regular testing for staff and residents was not announced until 3 July,³² and there have been significant delays in the rollout of this scheme.³³ By the start of June, only 40% of care homes had been able to access testing for asymptomatic residents, according to a survey of 77 care home managers and directors in England.³⁴ In September, we continue to hear evidence that the testing regime is not functioning properly. Care homes report tests not being collected to be couriered to laboratories and results taking too long to be returned.

Regarding PPE, government policy prior to the adult social care action plan³⁵ (released 15 April) was that social care providers should procure their own PPE. This left care providers to fend for themselves against a background of the NHS's huge purchasing power, tightening domestic and worldwide demands for PPE.³⁴ Many struggled to purchase PPE and when it was available, it was often at inflated prices.

In the period from 6 April to 19 May, more than 80% of local resilience forums (multi-agency partnerships that exist to respond to emergencies) reported that PPE was having a high or significant disruptive impact in their area across health and social care services.³⁴ Although the situation later improved, this lack of PPE will have had dire consequences for people with dementia and those who care for them.

Between 17 March and 15 April, around 25,000 people were discharged from hospitals into care homes.³⁶ It is not known how many had COVID-19 at the point of discharge as testing of people being discharged was not required until 16 April.³⁷ 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'.³⁶ This may well have contributed to the number of care homes that experienced an outbreak.

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-19³⁸ but this is very difficult in practice. Restricting movement is a significant loss of autonomy, especially 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.³⁰

Staff factors including a lack of guidance for care homes about restricting staff movements between homes are thought to have played a part.³⁹ 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,⁴⁰ 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.³⁰

Finally, the level of support obtained from local authorities and Clinical Commissioning Groups (CCGs) varied dramatically across the country and many providers had still received no financial support by the start of June.³⁴ It is not only people with dementia who experienced the consequences of this failure to protect social care. Data from the ONS show that 268 social care workers died with COVID-19 between March and May, a statistically significantly higher rate of death compared to average for their age and sex.⁶

Alzheimer's Society's influence

At the beginning of pandemic, Alzheimer's Society took immediate and urgent action to draw attention to the unfolding crisis in care homes. We united with leading charities to call for a care home strategy.

Following this, we secured widespread media coverage and undertook intense private lobbying of parliamentarians, including meeting with the Minister of State for Care, leading to the announcement of the Coronavirus Adult Social Care Action Plan.

We continued to campaign to ensure people with dementia were represented in policy and planning, persistently calling for daily publication of care home death data through the media and through substantial private and public influencing activity. Alzheimer's Society supporters contacted their elected representatives to demand action.

Our activity influenced the Government in committing to:

- Publishing the number of care home deaths due to coronavirus daily
- Ensuring that anyone discharged from hospital into a care home was tested for the virus first
- Taking the lead on sourcing and providing PPE for care homes
- Prioritising care home and home care workers for testing in the same way that NHS staff are.

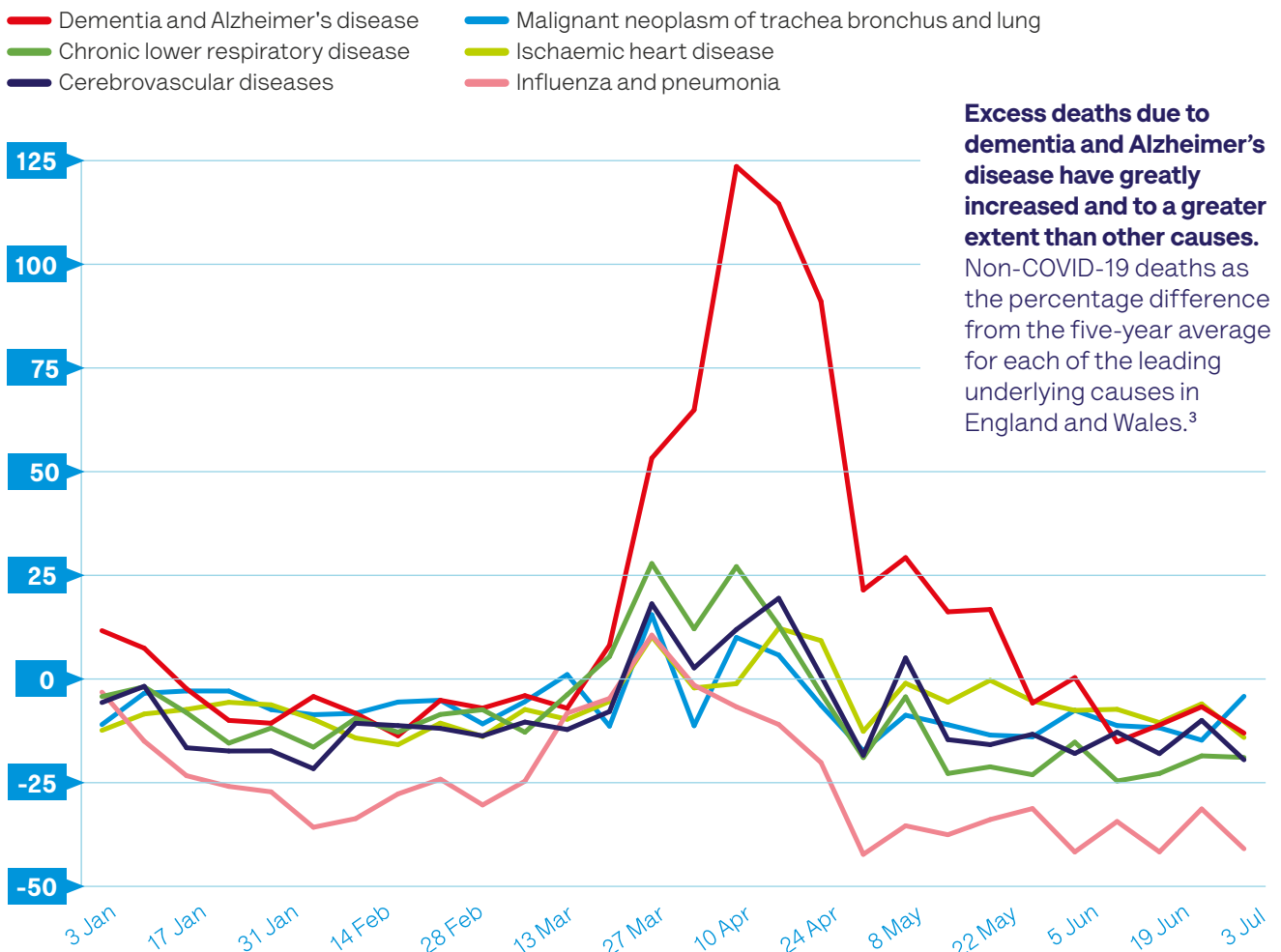
We have continued to work closely with charity and other partners to make the voices of people affected by dementia heard. United with John's Campaign, Innovations in Dementia, Dementia UK, TIDE (Together in Dementia Everyday), YoungDementiaUK and Alzheimer's Research UK we are speaking with #OneDementiaVoice to call on the Government to give family carers key worker status so that they can get back into care homes safely and provide the unique support only they can offer.

A disproportionate rise in excess deaths

Alongside COVID-19 related deaths, the largest increase in excess non-COVID-19 deaths was in people who have dementia. Between 4 January and 10 July, there were 5,049 excess deaths of people with dementia compared to the expected level (based on a five-year average).² These deaths are in addition to the deaths directly attributed to COVID-19.

Analysis of excess deaths shows that even excluding deaths identified as involving COVID-19, in the peak weeks of the crisis double the number of people with dementia died compared to the five-year average.³ Towards the end of June and the start of July the number of dementia-related deaths fell slightly below the five-year average perhaps reflecting that some deaths that would have happened at this time occurred earlier in the year instead.³

The reasons for a disproportionately high level of excess deaths among people with dementia need to be established urgently. Although we do not yet have a definite answer, it is possible that a number of these are deaths due to COVID-19 where the symptoms were not recognised.



The ONS points out that the absence of large rises in deaths attributed to dementia that mention conditions that could exhibit similar symptoms to COVID-19, suggests that if COVID-19 is involved in this increase in excess deaths the usual symptoms of COVID-19 were not apparent.⁴¹ This could be due to atypical symptoms in this group or difficulty distinguishing symptoms in people with communication difficulties due to dementia. The exclusion of family carers from care settings may have contributed to some of those atypical and subtle symptoms being missed.

We have also 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.

Another possible explanation is that when health service resources were tightly stretched, people with dementia were not prioritised for treatment and care. Reports of Do Not Attempt Cardiopulmonary Resuscitation orders inappropriately added to the files of people living in care homes lend support to this possibility.⁴²

Furthermore, healthcare professionals were often only providing telecare rather than in-person consultations. Given that diagnosis of health problems in people with dementia can be particularly complex, it is possible that more remote working by GPs and primary care teams made it harder for people with dementia to get help when they needed it.

Losing a loved one during the COVID-19 pandemic

Sam Evans describes her mum Dotty, 90, as ‘the best mum in the world. If I become half the mum that my mum was, I will have done a fantastic job.’

Dotty lived with Alzheimer’s disease in a care home in Portsmouth and Sam would visit several times a week. Before lockdown, Dotty was able to walk and try to communicate.

With lockdown in place Sam says the care home staff were very good at facilitating FaceTime calls with her mum. But only a month into lockdown the care home rang to say Dotty wasn’t well. Sam knew that hospitals were very upsetting for her mum and that having a doctor come out was the only option. The doctor prescribed Dotty with antibiotics but unfortunately Dotty’s condition worsened and just a day later the care home called and said that Sam should come and say her goodbyes.

Sam was shocked. She found it hard to understand how her mum, who was walking a month beforehand, could have gone downhill so quickly.

Sam went to see her mum, and dressed in PPE, told her how much she was loved. She could only hold her hand. She didn’t get to hug her mum. She didn’t get to kiss her goodbye.

‘I really wish I had that chance to say goodbye to my mum properly. I feel I was cheated. I feel she was cheated. No one wants to leave this earth that way’.

Dotty died on 13 April. Her death was attributed to COVID-19 on the death certificate.

Although care home staff were brilliant, Sam felt they were abandoned by the government in those first crucial weeks. She doesn’t believe professional carers, or the people they were responsible for were considered properly. ‘I’m angry at the government. Carers and care homes were just left to fend for themselves.’



A surge in loneliness and isolation

The restrictions on social contact put in place to slow the spread of COVID-19 had an impact across the population, but were particularly detrimental for people with dementia

Social contact is very important for people with dementia.^{43,44} Survey data from Alzheimer's Society and early academic research suggests that not only did many people with dementia experience a negative impact on their mental health, but also that a significant number of people with dementia have experienced a marked decline in their cognitive abilities and physical wellbeing as a consequence of reduced social contact.

Although the Government eventually issued guidance allowing care homes to safely reopen to visitors⁴⁵, accountability has been left to local decision-makers, which means many continued to struggle to get the access they need. Family carers are an integral part of the care system, they provide companionship, they help with practical elements of care and they support communication. This role shouldn't be underestimated. When family carers can't be part of care, the wellbeing of people with dementia can seriously decline.

Loneliness and isolation increased

In March 2020, the government recommended that people aged over 70 years should be particularly stringent in following social distancing measures as they were classified as clinically vulnerable.⁴⁶

People with dementia and people over 70 were not given advice to stay at home for 12 weeks (shielding) as they were not identified as clinically extremely vulnerable, but there has been significant confusion on this point.⁴⁷ Health is a devolved matter but differences in guidance between England, Wales and Northern Ireland were initially minor.⁴⁸

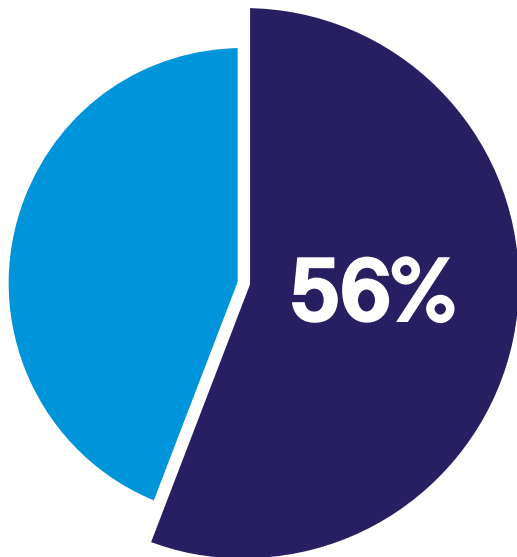
For many people with dementia living at home, social distancing guidelines for friends and family combined with the reduction or cancellation of home care services meant they were left without vital social interaction and support.

Similarly, people with dementia living in care homes and assisted living communities were unable to see family and friends, or even their informal carers and healthcare professionals due to no visitor policies. The ONS Vivaldi study carried out in England between 26 May and 20 June estimated that 97% of care homes had been closed to visitors.⁴⁰ Although comparable studies are not available, Alzheimer's Society has heard similar experiences across England, Wales and Northern Ireland and this has been reflected in the media.^{49,50,51} 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.

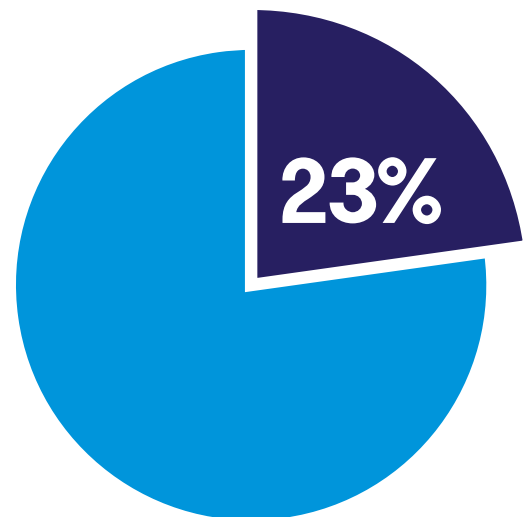


The importance of visits for people affected by dementia is reflected in a commentary from Associate Professor Lee-Fay Low as part of the International Long-Term Care Policy Networks' resources in response to COVID-19.⁵² This highlights the role that family visitors play the care of residents in care homes, providing love and company, helping with eating, keeping cognitive and communication skills sharp, grooming and recreation and also advocacy and timely detection of changes in residents' health. The commentary also suggests that without visitors or excursions, residents will feel more lonely and 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.⁵²

Emerging findings from the Alzheimer's Society supported Improving the Experience of Dementia and Enhancing Active Life (IDEAL) COVID-19 Dementia Initiative based in the UK suggest that during the period of lockdown, people affected by dementia living in the community were experiencing an increased sense of loneliness and/or of being socially isolated (findings awaiting publication).



56% of people with dementia living alone felt more lonely over lockdown



23% of people with dementia living with others felt more lonely over lockdown

A survey conducted by Alzheimer's Society which included 134 people who have dementia tells a similar story. Our survey revealed that a significant proportion of people who have dementia felt lonelier during the lockdown period. This was particularly true for people with dementia living on their own (56% felt lonelier over the lockdown period), but also true for people with dementia who live with others (23% felt lonelier over this period).⁴

Textual analysis of Alzheimer's Society's records used to support more than 2,000 people affected by dementia revealed marked trends in negative experiences over the lockdown period that support these survey findings. There was a doubling in the percentage of conversations that mentioned isolation (3% to 6%) and depression (9% to 18%) as we went into lockdown; these peaked in April and gradually declined as restrictions were eased.

Health and cognitive function deteriorated

Alzheimer's Society's survey on the effects of lockdown for people with dementia shows that the impact extends far beyond loneliness and social isolation. 45% of respondents said that lockdown has had a negative impact on their mental health, and 82% of respondents reported a deterioration in the symptoms of people with dementia.⁴



of people living with dementia said lockdown has had a 'negative impact' on their mental health



of people affected by dementia have reported an increase in dementia symptoms during lockdown

The most common symptoms that people living with dementia reported having increased since lockdown began were difficulty concentrating (48%), memory loss (47%), and agitation or restlessness (45%). The most common symptoms that carers reported in their loved ones with dementia – that increased since lockdown began - were memory loss (54%), difficulty concentrating (47%), agitation/restlessness (49%) and stress or depression (46%).⁴

Further to this, 79% of 128 care home managers reported that lack of social contact was causing a deterioration in the health and wellbeing of their residents with dementia, in an Alzheimer's Society survey published in June.⁵³ Care home staff reported that residents felt 'isolated... and suffering depression', that 'those in the end stages of dementia are declining at a faster rate than normal' and that 'residents living with dementia particularly are losing weight because they are constantly in their rooms and not eating and drinking as before'.



of care home managers reported lack of social contact was causing deterioration in health and wellbeing of their residents with dementia

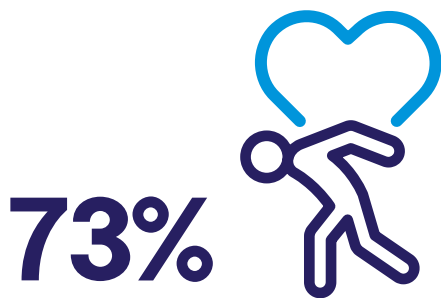
This survey data provides a strong indication of the experiences of people with dementia, and is corroborated by two research studies. An Italian study involving 139 people with dementia found that in the first month of lockdown, 31% of respondents reported worsening of memory and orientation abilities and 54% worsening or onset of agitation, apathy and depression.⁵⁴ A study conducted in Spain compared neuropsychiatric symptoms of 40 people with dementia before and after five weeks within lockdown. The study showed significant worsening of apathy and anxiety scores for people with dementia over the lockdown period in Spain.⁵⁵

An additional possible effect of increased isolation is highlighted in guidance on safeguarding during COVID-19 from the Social Care Institute for Excellence. Both in care homes and in the community there are increased concerns that people may be vulnerable to abuse or neglect and that the likelihood it will be reported and dealt with may be reduced.⁵⁶ Although we are not aware that evidence has been collected on this issue, it should be considered in future efforts to understand the impact of the pandemic on people affected by dementia.

Paid and unpaid carers were affected

It is not just people who have a diagnosis of dementia that experience the effects of loneliness and isolation; family members, friends and professionals who care for people with dementia have also been affected.

In a recent Alzheimer's Society survey of over 1,000 carers of people with dementia, we found that:⁵



of carers reported that their caring responsibilities have increased during lockdown.



reported their caring responsibilities had increased because of worsening dementia symptoms of the person they care for.



The percentage of people spending 100 hours or more a week looking after or helping the person they care for increased from 40% before 23rd March to 50% after 23rd March.



According to this survey, on average informal carers spent 9.8 more hours a week than normal in their caring role during the pandemic. Based on the number of informal carers in the UK, we estimate that family and friends spent an extra 92 million hours caring for loved ones with dementia in the 20 weeks between the start of lockdown on 23 March and the start of our survey.⁵

95% of carers reported that the increased caring responsibilities had an impact on their mental or physical health; 69% reported that they feel constantly exhausted, 64% feel anxious, 50% have developed problems sleeping and 49% feel depressed.⁵ 14% reported that they had not had time to see a GP about a health problem and 13% said they'd had an injury from caring.⁵ It is clear that more must be done to support people in this incredibly tough situation.

A large research study supported by Alzheimer's Society before COVID-19 showed that loneliness is one of the psychological factors significantly linked with the ability of caregivers of people with dementia to live well.⁵⁷ This makes the social isolation that COVID-19 brought for carers of people with dementia all the more concerning.

Although we do not have data specifically for professional carers of people with dementia, some existing evidence points to the impact on the health and wellbeing of professional carers. In April, the Institute for Public Policy Research found that 71% of surveyed healthcare workers said their mental health had deteriorated since the COVID-19 crisis began.⁵⁸

Living with dementia and losing skills during lockdown

John O'Doherty was diagnosed with vascular dementia in 2016. A husband and father of four sons, prior to lockdown John led a busy and social life in his local community in Manchester. Both John and his wife were considered high risk and therefore had to shield for 12 weeks, unable to leave the house.

Sadly, since going into lockdown and shielding John has noticed a fast deterioration of his dementia symptoms.

'Prior to my shielding I was relatively busy attending meetings, writing, and doing public speaking. I was even working with the Halle orchestra.

Now I do virtually nothing, I am stagnating, hoping tomorrow will be different but deep down knowing it will simply be more of the same. I have tried different things to occupy myself. Watching television didn't work. After watching 10 minutes of a film or a programme, my concentration and poor memory meant I had completely forgotten the plot.

I used to be an avid reader and whilst I had not read for a while, I thought that I would try to read a magazine. Even this simple process was ineffective. By the time I had reached the third paragraph I had forgotten the first two. The fact is I can no longer read a leaflet – never mind a magazine or a book.'

'Whilst shielding will protect me from Covid-19, it won't shield me from my dementia.'

'Every aspect of my life has been turned upside down. Prior to the lockdown I maintained a large degree of independence, I made decisions alone and could function effectively. Now that independence is waning. I feel vulnerable, depressed and have lost my self-worth.

Living with a diagnosis of dementia means that you wish to retain as much independence and control of your life as you possibly can. That independence and control has been lost due to my lockdown. I am also fiercely proud and dislike having to ask people to do things that ordinarily I would do myself. This control has been totally lost.'



Our Emergency Coronavirus Appeal

During the coronavirus pandemic thousands of people have turned to us for support. But our ability to fundraise has been hit and we have lost tens of millions in income.

We are asking anyone who shares our passion to make a difference for people with dementia to support our Emergency Appeal so we can continue to fund services for isolated and vulnerable people during this crisis and beyond.

alzheimers.org.uk/coronavirus-appeal

Health and social care at breaking point

During the pandemic, resources for health and social care were rerouted towards acute settings, with a focus on increasing the number of intensive care beds available, including efforts such as the NHS Nightingale hospitals. While the NHS Nightingale hospitals were thankfully under-used, social care settings took significant strain with little extra capacity provided.

The guidance on social distancing, self-isolation and shielding has meant that many services have not been able to operate as normal. This resulted in a reduction in the health and social care services people affected by dementia would normally receive, leaving people without vital support. A lack of data and focus on social care, combined with challenges in coordination between health and social care has made monitoring the impact harder and deepened existing cracks in the system.

Changes in healthcare provision

Since February 2020, there has been a steady decline in dementia diagnosis rates in England, dropping from 67.6% in February 2020 to 63.2% in July⁷ which is below the national target of 66.7%.⁸

This means that more people are now unable to access the benefits that a diagnosis can bring. Without diagnosis and post-diagnostic care, people affected by dementia miss out on essential care and treatment, and the period of fear and uncertainty of unexplained symptoms is prolonged.⁵⁹

People affected by dementia also experienced reduced access to primary care. Alzheimer's Society's survey of care home managers in May revealed that 75% of respondents (79/105) said that GPs were reluctant to visit residents and 52% (54/104) had to verify causes of death in the homes as GPs were not visiting.⁹

In our survey of informal carers supporting people affected by dementia in the community, 90% (of 795 respondents to this question) stated that the person they care for had experienced interruptions to their regular health or social care.⁵ The services most frequently mentioned were GPs, dentists, memory clinics and chiropodists. Respondents to our survey felt that these interruptions had consequences, with 83% indicating that the health of the person with dementia had declined during the pandemic, and 84% of those stating that the changes in level of care had some impact or a big impact on this decline.⁵

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. A survey conducted by The Queen's Nursing Institute of their care home nurse network found that 10% of respondents (16/163) had negative experiences around DNACPR, for example blanket DNACPR instructions from the GP or CCG with no discussion with the resident, family or care home.⁴² A letter was sent in April from the Chief Nursing Officer and National Medical Director for NHS England underlining that DNACPR orders should only ever be made on an individual basis and in consultation with the individual or their family.⁶⁰ It is crucial that people who have had these orders inappropriately applied to their records can have them expunged.

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.⁶¹ 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.

Reductions in social care services

In addition to the complex medical needs that people with dementia have, many people with dementia need non-medical support due to the symptoms they experience. This can include support at home with dressing or bathing, social activities, day care or respite care⁶², which are essential to support people to live as well as possible with dementia.

Many people rely on privately funded care (an estimated four in ten pay for their own care entirely)⁶³ but local authorities only record data about the people whose care they contribute towards. For this reason, comprehensive data on how care provision has been impacted by COVID-19 is limited.⁶⁴ 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.⁴ Most respondents (57%) stated they did not receive these services in the first place, although the survey did not indicate whether those respondents needed such services and we know many struggle with access to basic care. Combined with distancing and shielding guidelines, this means that many people affected by dementia have been struggling to cope in isolation, with even less support than usual to deal with the sometimes severe and complex care needs that dementia can bring.

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.⁵ A smaller survey from The Beeston Studio, an arts-led day centre for people with dementia, showed that 28% of the 75 respondents felt their caring situation had not been tolerable and 47% did not receive the support they needed to provide good care.⁶⁵

In line with our survey, 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 in need of formal services in April could not get them.⁶⁶

The Coronavirus Act introduced in March allowed councils to adopt easements to their duties under the Care Act. The purpose of this was to temporarily relax certain responsibilities in order to prioritise care 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 carers.⁶⁷ This raised concerns that people with dementia may experience reduced support with potential for irreversible deterioration to their condition if their needs were not met. Alzheimer's Society published recommendations for how to adopt Care Act easements appropriately if they are required in exceptional circumstances.⁶⁸

A lack of focus on social care and coordination with healthcare

In its report on readying the NHS and adult social care in England for COVID-19, the National Audit Office highlighted a number of issues that affected the government's response, and therefore reduced the support available to people affected by dementia.⁶⁴

The report recognises that the relationship between adult social care and the NHS has been problematic for decades, and a lack of meaningful integration going into the pandemic made responding to the crisis more difficult. A report from the Welsh Parliament Health, Social Care and Sport Committee on health, social care and COVID-19 in Wales drew some similar conclusions, citing a 'pressing need for better integration of the two services'.⁶⁹ In the Institute for Government's red-amber-green fitness ratings of preparedness and resilience at the start of COVID-19, adult social care is the only public service to be red in all categories.⁷⁰

The National Audit Office report notes that the £3.2 billion funding for local authorities to help them respond to COVID-19 pressures was targeted at those providing adult social care, but the funding was not ringfenced.⁶⁴ There have been concerns in the sector that this funding has been used to fund councils' wider COVID-19 response activities and not used as extensively as it might to mitigate the impact on care providers.

Attempts were made to collect daily data from care providers, but were hampered by the fact that no such process existed prior to the outbreak, despite the National Audit Office previously raising gaps in adult social care data as an issue.⁶⁴ This was echoed in a report from the Public Accounts Committee, which reflected that the Department of Health and Social Care had much better and more timely information for the NHS than for social care.³⁶ The case for a minimum dataset for care homes is further described in a recent editorial in *The BMJ*.⁷¹

The National Audit Office report also notes that between mid-March to mid-May, various pieces of guidance were issued to the adult social care sector with numerous updates, but provider organisations raised concerns that the number of updates made guidance hard to follow, and some issues regarding testing, PPE and the workforce were unaddressed.⁶⁴

The Public Accounts Committee report states that guidance was changed 40 times without consulting service providers, leading to confusion on the ground.³⁶ The adult social care action plan was not published until 15 April. This will have contributed to the difficulties care providers experienced.

Family carers taking the strain

Karen Preston's mum, Joyce, is 87 and has dementia. Back in March Joyce lived on her own, with the support of care staff visiting four times a day. They would assist with medication, personal care and meal preparation, but due to the pandemic, this vital care was withdrawn.

'Mum was visited by a district nurse to care for her leg ulcer and the nurse noticed her temperature was higher than normal. That was reported to the care providers who then withdrew their support as they didn't have the appropriate PPE.'

Karen rang her mum's GP and social services for support. They promised to see what help could be provided and advised to isolate for 7 days. After just four hours had passed, Joyce needed care.

Karen is in her 60s and has asthma so hesitated before visiting.

'I knew that if mum had coronavirus and I caught it, it could be fatal. I was planning to isolate and keep shielded from the virus myself. But at that point no-one else was going to look after mum. Not the NHS. Not the carers.'

Karen stayed with her mum five hours a day for two days, covering food, medication and leaving a sandwich for an evening meal. On the third day social services offered two weeks of respite for Joyce in a care home.

But knowing there were new cases of coronavirus in care homes, Karen didn't feel she could take the chance.

At this point Karen brought her mum to live with her and her husband in lockdown. 'Mum was angry, frustrated and tearful but at least she was safe. Her temperature was back to normal the day after her care was withdrawn.' As far as we know Joyce didn't have coronavirus.

Karen, helped by her husband, had to take on the physically arduous job of looking after her mum who has mobility issues. With no support available for Joyce to go home there was no choice.

'After 12 weeks we were exhausted. Mum was eventually able to go home with her care package back, but she's not as independent now as she once was.' Joyce is now deemed to be unable to live on her own and is waiting for a place in a care home.



Help us to support and campaign

Alzheimer's Society alone cannot solve the crisis in health and social care, but with your support we can unite to hold the government to account and provide vital support and advice that helps people to live as well as possible with dementia.

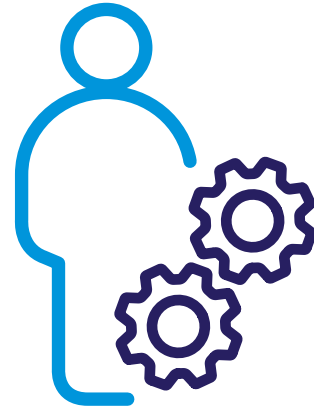
Please support our work and unite with us against dementia.

Alzheimer's Society COVID-19 response

Dementia Connect, Alzheimer's Society core support service, has been there for anyone needing support during the coronavirus pandemic. It offers personalised support to anyone with dementia, their carers, families and friends and it connects people to a whole range of dementia support, by phone, online and face-to-face (when safe to do so). It's free and puts them in touch with our Dementia Advisers who offer the support they need, from local help to telephone and online advice.



Our support services have been accessed over 2 million times between 23 March – 31 August and have helped a huge number of people with concerns during the pandemic.



People who are affected by dementia can find it difficult to manage and cope, but **93% of our service users now feel more able to manage after the support they received from us.***



We know how hard and tough dementia can be, but **95% of our service users feel as though the support we have given them has improved their life in some way.***



Our staff know how to support people affected by dementia and **98% of service users felt that we understood their needs.***

*average 608 responses between 1 April – 28 August

How we adapted our services

As face-to-face services have been suspended due to COVID-19 the Society had to adapt how we supported service users. Our Dementia Advisers now make Welfare Calls to our service users at regular intervals to check in and see how they are and to offer ongoing support, so they always have the right support in place. These calls also help to reduce loneliness and manage the potential worsening of dementia symptoms

Our dementia advisers have seen a noticeable uplift on requests for advice for care home visits, home support, how to manage mental health and safeguarding issues.

Some of our services have gone virtual, like Singing for the Brain, where service users can still join their regular groups by Zoom, which helps to reduce isolation, keep a sense of routine and have some fun. A Singing for the Brain national singalong took place during lockdown, where thousands joined in with special guest Vicky McClure to sing some classic hits.

To help people get the information and support they need, regular support emails are being sent to offer COVID-19 specific advice and tips. Our website, blog and social media channels have also been providing COVID-19 specific support content, with our support webpages accessed over 1.4 million times from 23 March – 31 August. Talking Point, our online community saw a huge uplift in engagement with 2,500 new users joining the community since 23 March.

As the scale of COVID-19 began to unfold we needed to innovate to help people stay connected, reduce their sense of isolation and improve their mental wellbeing. To do this we created our Companion Calls service, where a Society volunteer calls a service user for a regular chat to see how they are doing and talk about day-to-day things. This has proved very successful with over 24,000 companion calls carried out so far by 1,400 volunteers.



133,000

welfare calls have taken place since 23 March 2020 and we are continuing this service for as long as necessary.

Methodology

Alzheimer's Society strives to adopt an evidence informed decision-making approach and acknowledges the value that combining different sources of evidence can provide, including the direct voices of people affected by dementia, survey data, academic studies, policy reports and national statistics.

This report considers the best available published research and policy evidence on the impact of the coronavirus pandemic on people affected by dementia during the period March to August 2020, focusing on the three nations in which Alzheimer's Society operates (England, Wales and Northern Ireland). It aims to triangulate data from academic as well as non-academic sources such as market research surveys, expert opinion and anecdotal evidence from Alzheimer's Society's online community Talking Point as well as the Dementia Connect support line.

To collate published research, we searched the MEDLINE database using the search terms 'dementia', 'Alzheimer's', 'COVID-19', 'coronavirus' and 'pandemic' during the period 23 March 2020 to 28 August 2020. We also used data from the International Long Term Care Policy Network's LTCcovid website, which has provided immensely valuable summaries of the impact of COVID-19 on people in long term care.⁷² Other sources of information include those from journals with opinion pieces such as The BMJ, the Social Care Institute for Excellence website, data from the Office of National Statistics and data from NHS England. We also approached researcher contacts on social media to scour any evidence that we may have missed including unpublished research. It is important to note that some research included in this report was not peer reviewed at the time of publication owing to the necessity for academics to produce information at speed during the pandemic. As such, it is important to continue to review the published evidence included in this report. However, the research community should be especially commended for their efforts to generate knowledge in such an agile way.

Data from four Alzheimer's Society surveys was included:

- 1) Survey of care home managers on infection control (published May 2020),⁹
- 2) Survey of care home managers on social contact (published June 2020),⁵³
- 3) The impact of COVID-19 on people affected by dementia (published July 2020)⁴ and
- 4) Care during the pandemic (2020)⁵.

This report was written by colleagues in the Alzheimer's Society's Research and Influencing directorate. The report has been reviewed by academic experts as well as internal experts in the fields of research and policy.

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