



# Dementia and COVID-19: Social Contact

## June 2020

### Introduction

People living with dementia have been hardest hit by the COVID-19 pandemic. Dementia is the most common pre-existing condition found among deaths involving COVID-19, and there has been a huge surge in the number of deaths of people with dementia who do not have COVID-19<sup>1</sup>. Risks for people living with dementia are greater than ever and Alzheimer's Society won't stop until people living with dementia are better protected.

To date, government guidance during the COVID-19 pandemic has focused on social care systems and processes, rather than the people the systems are here to serve. It is vital we thoroughly examine why people living with dementia have been so disproportionately affected by this pandemic, and we should act urgently when we have evidence that harm is occurring. We know the damaging impact that the loss of social and family contact is having for people with dementia. Social stimulation and regular face to face contact with loved ones not only helps people living with dementia to feel secure and improve anxiety and mood, but also helps them to maintain basic cognition and communication skills and maintain independence.

Shielding and isolation were introduced to save lives, but we fear that for people living with dementia, they have contributed to an unprecedented surge in deaths over the last few months. It is essential for people living with dementia that as we emerge from the initial phase of coronavirus, we prioritise social contact alongside infection control to protect lives. Government must step in right now to prevent further tragedy.

We're calling on the Government to set up a **Dementia and Coronavirus Taskforce** which must work at pace to establish how best to keep people with dementia safe through any easing of the lockdown and in the event of a second spike. We need a high-level Taskforce led by a named official to undertake a rapid review of how people with dementia have been affected so far, and to then set out a coordinated approach across national and local Government. The work of the Dementia and Coronavirus Taskforce should also set a base for long term reform which delivers the high-quality care people with dementia need.

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<sup>1</sup> ONS (2020) Deaths involving COVID-19, England and Wales: deaths occurring in April 2020 [Online] Available at: [www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvingCOVID19englandandwales/deathsoccurringinapril2020](http://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvingCOVID19englandandwales/deathsoccurringinapril2020)

Alzheimer's Society (2020) Briefing: Data on dementia and COVID-19 [Online] Available at: [www.alzheimers.org.uk/sites/default/files/2020-05/Briefing\\_COVID-19\\_and\\_dementia\\_data\\_15052020.pdf](http://www.alzheimers.org.uk/sites/default/files/2020-05/Briefing_COVID-19_and_dementia_data_15052020.pdf)



This briefing sets out the evidence for action to support social contact for people living with dementia; the action that Alzheimer's Society has been taking so far; and what we need Government to do next.

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### **A world without dementia**

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A company limited by guarantee, registered in England and Wales (2115499) and the Isle of Man (5730F)  
Registered office: 43-44 Crutched Friars, London EC3N 2AE.

## The impact of COVID-19 on people with dementia in the UK

Although dementia wasn't initially thought to have been a high-risk condition, it's become clear that people with dementia have been the most severely affected by the coronavirus pandemic.

- A quarter of people who have died in the first two months of the pandemic in England and Wales had dementia (over 8,500 people in March and April).<sup>2</sup>
- Dementia is the most common pre-existing condition for coronavirus deaths<sup>3</sup>
- Aside from coronavirus, deaths from dementia are running 83% higher in England, and 54% higher in Wales, nearly 10,000 deaths in total in April.<sup>4</sup>

COVID-19 poses risks to the health and wellbeing of people with dementia needing social care, reduces the ability of families, friends and social care staff to provide support, and puts at risk the availability and quality of care due.<sup>5</sup>

**As well as the severe impact of COVID-19 itself, restrictions under lockdown have imposed a lack of social contact and interaction which are known to be contributing factor in the decline of people with dementia.**

- In a recent Alzheimer's Society survey<sup>6</sup>, 79% of care home managers told us that the health and wellbeing of their residents is deteriorating because of a lack of contact with loved ones.
- People calling our Dementia Connect support line are telling us how quickly their loved ones are 'going downhill', with examples including people losing key skills such as their ability to talk or feed themselves.
- People living with dementia have expressed<sup>7</sup> concerns to us that they feel like they are losing certain basic cognitive and communication skills during the period of imposed social distancing restrictions.

**Interruptions to usual health services could also be a contributory factor in the high number of deaths among people living with dementia:**

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<sup>2</sup><https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvingCOVID19englandandwales/deathsoccurringinapril2020>

<sup>3</sup><https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvingCOVID19englandandwales/deathsoccurringinapril2020>

<sup>4</sup> [https://www.alzheimers.org.uk/sites/default/files/2020-05/Briefing\\_COVID-19\\_and\\_dementia\\_data\\_15052020.pdf](https://www.alzheimers.org.uk/sites/default/files/2020-05/Briefing_COVID-19_and_dementia_data_15052020.pdf)

<sup>5</sup> Comas-Herrera, Adelina, Fernández, José-Luis, Hancock, Ruth, Hatton, Chris, Knapp, Martin, McDaid, David, Malley, Juliette, Wistow, Gerald and Wittenberg, Raphael (2020) COVID-19: implications for the support of people with social care needs in England. Journal of Aging and Social Policy. ISSN 0895-9420 (In Press)

<sup>6</sup> Alzheimer's Society survey of 100 care homes April 2020

<sup>7</sup> AS webinar with Three Nations Dementia Working Group April 2020

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- Care Act Easements adopted by local authorities have meant that there will be delays in preparing or reviewing care support plans, detailed assessments of support needs aren't taking place and financial assessments are delayed.
- Three quarters of care homes in our survey reported that GPs have been reluctant to visit residents
- There has also been a slight decrease in dementia diagnosis rates over April 2020 which means people are living without a formal diagnosis of dementia, unable to access the vital support and advice services they need<sup>8</sup>.
- Academic research is already underway into how disruptions to care provision has impacted on people. The International Long-Term Care Policy Networks (LTC)<sup>9</sup> is documenting the impact of COVID-19 on people who rely on long-term care (including unpaid care) and those who provide it

Given this early evidence, we also need to urgently address whether the increase in deaths from dementia are resulting from cognitive impairment due to isolation and from reduction in essential care as numbers of care workers reduce, and family carers cannot visit. A better understanding of how social isolation is contributing to the increase of dementia deaths and the role for family contact in saving lives is needed.

We're calling for rapid research to be undertaken, either through newly commissioned work or existing research projects that assess the links between COVID-19 and dementia, and the impact of reduction in social contact which can inform and direct the work of the Dementia and Coronavirus Taskforce.

## The importance of social contact for people living with dementia

As the pandemic continues, we are hearing more and more stories from families and care staff that social distancing is causing people to lose recognition of loved ones, or to deteriorate more rapidly.

Social contact and interaction with others is a vital element of care for people living with dementia, whether they live in care homes or in the community<sup>10</sup>. Some of the symptoms associated with dementia include difficulties with concentrating, feeling confused and memory loss, which in turn can result in people feeling distressed. Being surrounded by loved ones can help people to feel calm when they are experiencing certain symptoms of dementia.

### **Tony and Pauline**

*Tony used to visit Pauline almost every day, but he hasn't been allowed to be with her since the beginning of the coronavirus lockdown in March, this year. The care home hasn't allowed access to anyone except*

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<sup>8</sup> RCPsych/MSNAP: Effect of COVID-19 on Memory Services: MSNAP Survey results. Data collection open from 4th – 11th May 2020. Responses from 93 UK memory clinics

<sup>9</sup> <https://ltcCOVID.org/>

<sup>10</sup> Social Networks and Loneliness in people with Alzheimer's dementia, Balouch et al, International Journal of Geriatric Psychiatry 2019 <https://onlinelibrary.wiley.com/doi/abs/10.1002/gps.5065>

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healthcare professionals. Pauline had a stroke four years ago and Tony is the only person Pauline really responds to. Tony told us:

*'I am really worried about Pauline. I worry that she will feel alone. She won't understand what is going on. I know she is not eating as well as she normally does.'*

*Tony has managed to place some video calls to Pauline with help from care home staff and Pauline responded to his voice and gave him a signal to say she could hear him. But he says those reactions are only occasional and are becoming fewer as the weeks under lockdown pass by.*

Regular social contact with loved ones not only helps people living with dementia to feel secure, but also helps them to maintain skills and independence, including basic cognition such as recognising family members, and communication skills like remembering words and following a conversation.

### **Kathy and Mavis**

*Mavis lives with dementia in a care home. Her daughter Kathy told us:*

*'My absolute main concern is that bit by bit, Mum is forgetting who I am. It's heart-breaking. When we were able to meet up, I could nudge the needle on the broken record and stop it getting stuck. For the hours we were together she knew (roughly) who I was. But using virtual means, that's impossible.'*

### **Trevor and Yvonne**

*Yvonne lives with dementia in a care home. Her husband Trevor told us:*

*'Coronavirus and lockdown changed Yvonne's care home overnight. The familiar faces of family and friends are gone, and carers are behind masks and can't touch or comfort the residents. Yvonne has lost her sparkle, she's in a world she doesn't understand. The staff at the care home are doing an amazing job looking after the residents, but we've only got video calls to keep in touch, and Yvonne doesn't always understand them. If lockdown continues, I'm really fearful my wife won't be able to recognise me at the end of all this.'*

The implementation of personalised care planning with daily social interaction has been shown to improve quality of life and reduce agitation in people with dementia through the Wellbeing and Health for People with Dementia programme<sup>11</sup>. The lack of contact and communication with carers and family members under the conditions of lockdown is impacting on the quality of person-centred care planning and individual needs are being lost or ignored.

**We know what good care looks like, and have evidenced based solutions – these have not changed, however the context and the ability to implement them has, and we now need to look urgently at how to enable the provision of and access to high quality, effective care for people with dementia during the COVID-19 restrictions, a vital element of which is social contact.**

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<sup>11</sup> <https://www.oxfordhealth.nhs.uk/research/making-a-difference/improving-wellbeing-and-health-for-people-with-dementia-wheld/>

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Social contact and stimulation are just as important for people living with dementia in their own homes as they are for people living in care homes. The issues to address may be different in different care settings. Given the major impact of COVID-19 has been on care homes, we have set out some recommendations below to kick-start social and family contact for people living with dementia in residential care, and on ensuring that home care can still be delivered safely to support people living with dementia at home.

We know that social isolation will also continue for longer and impact significantly on people with dementia living at home and their family carers who are also not receiving the same level of support as before. Alzheimer's Society is committed to supporting everyone affected by dementia. In a letter we jointly signed with other charities on 29<sup>th</sup> May, we called on the Government to create a cross Government advisory panel with a named lead minister to develop a detailed strategy to protect the quality of life of people who will need to continue to self-isolate due to the risk COVID -19 will continue to pose for them. This strategy must address how social contact is encouraged and maintained among vulnerable people, including those with dementia being cared for in the community over the next 6-12 months as we emerge from lockdown. In addition, we will drive our calls for a Dementia and Coronavirus Task Force to address and provide solutions for the range of challenges and risks that COVID-19 has presented to people affected by dementia.

## Maintaining social contact in care homes

### The role of family and friends in dementia care within Care Homes

While the majority of the care needs for someone with dementia are met by staff in the care home, the role of family and friends often extends beyond visiting. Depending on the individual circumstances, type of dementia and severity, it can range from social stimulation through to carrying out regular personal caring tasks and activities that supplement the provided care and could therefore be designated as integral to that person's wellbeing. Suddenly or abruptly stopping family visits could lead to isolation, confusion, disorientation, exacerbation of behavioural symptoms and deterioration in the person with dementia, and may also place extra requirements on care home staff.

The benefits of regular input from and collaboration with family or loved ones is shown through the work of the Wellbeing and Health for people with Dementia (WHELD)<sup>12</sup> programme. This research found that increasing social interaction improves the wellbeing of people living with dementia in care homes, based on a programme of daily interaction from trained staff in conjunction with personalised care planning. The study found that 10 minutes of social interaction a day helps to improve wellbeing, and continued to be demonstrated in terms of positive outcomes for several months post study, in care homes which had previously only been providing an average of 2 minutes of social interaction per day.

This has also been demonstrated in acute care through John's Campaign, originally set up to challenge the practice of restrictive visiting times within hospital settings and the negative impact on outcomes of people with dementia. John's Campaign applies to all hospital settings but is rapidly gaining traction and

<sup>12</sup> <https://www.oxfordhealth.nhs.uk/research/making-a-difference/improving-wellbeing-and-health-for-people-with-dementia-wheld/>

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sign up within the care home sector. In April 2020 John's Campaign successfully lobbied to get a reversal on similar levels of restriction that the NHS were proposing be put in place around COVID-19 for visiting patients in hospital. We know some people's care plan reference the need for social contact/interaction, and it is important that in moving out of lockdown measures that these care plans are followed in a way that protects people living with dementia from infection.

In addition to the inherent value of social interaction and the additional care provided by loved ones, family members are often more attuned to changes in mood and wellbeing of someone living with dementia and are often the first to spot when something isn't right. This can be vital to ensuring that quick action is taken to provide medical help or adjustments made to their care to prevent a more rapid decline in health. Research is currently being undertaken as to how COVID-19 symptoms present in older people, and for people with dementia this could include finding it more difficult to express how they are feeling.<sup>13</sup> Family members and loved ones may be a vital link in preventing the further spread of COVID - 19 in the care setting, through prompting a quick response and testing for someone living with dementia.

### **Protective measures for people with dementia in care homes**

Care homes are a high-risk area for COVID-19 to staff, residents and visitors. Some care homes chose to close their doors to visitors prior to the issuing of guidance in March that then required them to do so. Since then families have not been able to visit their loved ones, check on their care or provide care that they might usually.

Care homes are people's homes and people should have the right to see their loved ones, in the same way that they would do if they were living at home. Due to the Government's aim to free up hospital beds by moving people out of hospital as soon as they are medically fit, more people may have been discharged and moved to care homes during the pandemic. This is a huge change even under normal circumstances, especially for people with dementia who may find it difficult to adjust to a change in their environment.

Some care homes have enabled friends and family members to stay in touch with their loved ones through video or phone calls. For some this has worked well as a short term measure, but relying on digital and telephone support is not the answer for everyone. For many people the technology is not accessible or user friendly, in particular for some people with dementia, and long-term is not a substitute for visiting and being able to care for loved ones. A digital visit only allows for certain interactions to take place, family members can't be involved or check on the care the person living with dementia is provided with, for example.

### **Infection control, access to testing and equipment**

The implementation of robust infection prevention and control practices, and the availability of Personal Protective Equipment (PPE) unlocks much of the ability for social contact/caring to be enabled.

Our central call remains that care homes need to be provided with PPE and testing to ensure the safety of their staff and residents. Secure supplies of PPE and a comprehensive testing regime in care homes must

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<sup>13</sup> <https://www.imperial.ac.uk/news/197773/urgent-need-coronavirus-testing-care-homes/>  
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be in place to enable family carers and loved ones to be able to visit people with dementia if they want or are able to.

We need to recognise that not all carers or loved ones may be in a position to visit and provide care to people with dementia – they may not want to bring in any germs or catch the virus themselves, or it might be because they are elderly and frail and therefore at higher risk - but key here is that people should have the right to visit their loved ones or people they care for in residential homes if they want, and to do so safely without risk of infection

### **Guidance to date**

During the pandemic, care home staff have come under increased pressure and in some cases had to continue working with reduced numbers, and so may not have the time to engage with residents beyond providing for physical care needs. The environment of care homes has changed dramatically, with staff wearing personal protective equipment, many residents being isolated to their rooms, and the number of deaths within care homes increasing substantially<sup>14</sup>. Despite care home staff doing incredible work with the resources they have, this is undoubtedly creating an incredibly stressful environment for anyone living with dementia in a care home, making it even more important that people are able to engage with loved ones.

Public Health England published COVID-19 [guidance on residential care provision](#) in March 2020, but following the more stringent lockdown measures imposed on 23 March 2020 where everyone was advised that they must stay at home, one of the four reasons given for people being able to leave home was for 'any medical need, or to provide care or to help a vulnerable person'

Further guidance on [admission and care of people in care homes](#) outlines considerations for visitors and non-essential staff:

- Family and friends should be advised not to visit care homes, except next of kin in exceptional situations such as end of life. Follow the social distancing guidance.
- Alternatives to in-person visiting should be explored, including the use of telephones or video, or the use of plastic or glass barriers between residents and visitors.

The DHSC's Social Care Action Plan published on 16 April states that in response to a COVID-19 outbreak in a care home:

- "An appropriate response to PPE, staffing, and controlling visitors will be agreed."
- "Alternatives to in-person visiting should be explored, including the use of telephones or video, or the use of plastic or glass barriers between residents and visitors."
- "Whilst we have recommended care homes limit unnecessary visits, we are clear that visits at the end of life are important both for the individual and their loved ones and should continue. We will

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<sup>14</sup> ONS (2020) Deaths registered weekly in England and Wales, provisional: week ending 22 May 2020 [Online] Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredweeklyinenglandandwalesprovisional/latest> , date accessed 02/06/2020.





continue to work with the sector to develop and share best practice on how to enable visits at the end of life in a safe and compassionate way”

The immediate shock of the pandemic is now passing, but we will need to find ways to live with infection control measures for many months to come. This guidance is no longer sufficient and we want the Government to urgently review it to enable the ongoing support of family members in care homes.

## **Connected Issues**

### *Mental Capacity*

A considerable number of people living with dementia in care homes lack mental capacity. For the period 2018/19 216,005 people in England were provided with care under the Deprivation of Liberty Safeguards (DoLS) in care home and hospital settings<sup>15</sup>. Data from 2016 shows that over half of those with a DoLS application in England had dementia recorded as their primary condition<sup>16</sup>. For people with dementia who lack mental capacity to make decisions, it is important to be able to maintain contact with loved ones who often provide support to people to help make decisions, and help people with dementia to understand information that is being provided to them about their care. When someone is suspected of lacking capacity to make decisions, as part of the DoLS process people who know the person well should be consulted, including family and Lasting Power of Attorneys. Some helpful [guidance](#)<sup>17</sup> has been produced relating specifically to these issues.

### *Access to specialist services*

In addition to regular interaction with carers, family and loved ones, there is also evidence that demonstrates the impact of various interventions or approaches to help people with dementia improve their memory and thinking skills to enable them to cope better with memory loss, such as cognitive stimulation therapy<sup>18</sup>.

Specialised services provided to people living with dementia, such as physiotherapy, speech and language therapy, occupational therapy, podiatry/chiropractic have a positive impact on health and well-being and on slowing cognitive decline. These services need to be restarted as soon as possible alongside the focus on maintaining social contact for people living with dementia.

Specialised services also include mental health services. 1 in 5 (20%) of wider population have depression at some point in their life, whilst the incidence of depression is significantly higher (possibly 30%) in vascular dementia and in Alzheimer's disease<sup>19</sup> (though this will vary with dementia type, stage and setting). Where people living with dementia are more likely to have depression than the general

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<sup>15</sup> [NHS Digital](#)

<sup>16</sup> [NHS Digital](#)

<sup>17</sup> <https://1f2ca7mxjow42e65q49871m1-wpengine.netdna-ssl.com/wp-content/uploads/2020/05/Mental-Capacity-Guidance-Note-COVID-19-testing-and-capacity-4-May.pdf>

<sup>18</sup> Cognitive Stimulation Therapy (CST): summary of evidence on cost-effectiveness - Adelina Comas-Herrera and Martin Knapp PSSRU, London School of Economics and Political Science May 2016

<sup>19</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4674029/>

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population, the impact of distancing and restrictive measures could increase this, so it is important that people are also able to access mental health services and support.

## Supporting the delivery of Home Care Services

There are approximately 80,000-100,000 people living with dementia in England who receive domiciliary (home) care<sup>20</sup>. Home care often prevents unnecessary admission to care homes and hospitals as it enables to people to stay living well and independently at home. Many people living with dementia want to continue living at home and being cared for at home for as long as possible. Remaining in a familiar setting, and maintaining close contact with family members has been shown to slow the progression of dementia and help people to maintain levels of wellbeing and independence.<sup>21</sup> Informal carers provide vital social contact and support to the person living with dementia, but informal carers themselves need social contact, and support from formal home care services to be able to continue caring.

Alzheimer's Society has received anecdotal evidence that some recipients of home care are cancelling calls due to a fear of infection. In other examples, some homecare providers have disputed the need for the use of PPE while others are unable to source sufficient supplies. The UK Home Care Association (UKHCA), the representative body for home care providers in the UK, says some smaller providers are facing additional monthly costs for face masks of £13,000.<sup>22</sup> They will also have less purchasing power than the larger providers as they won't be able to bulk buy.

We need to ensure that family carers, or people living on their own, get the levels of care and support they need. To support this, we are calling for

- Government to ensure that domiciliary care providers are able to access sufficient PPE through the national procurement scheme at a reasonable rate.
- If any of the 700,000 people who act as primary carers are taken ill with COVID-19 and are unable to care for their loved one with dementia at short notice for a period of at least two weeks they should be prioritised for domiciliary care.
- Homecare workers should be tested for COVID-19 on a weekly basis, with those receiving care being tested at least monthly.
- All new recipients of domiciliary care should be tested for COVID-19

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<sup>20</sup> Estimated from

<sup>21</sup> Social Networks and Loneliness in people with Alzheimer's dementia, Balouch et al, International Journal of Geriatric Psychiatry 2019 <https://onlinelibrary.wiley.com/doi/abs/10.1002/gps.5065>

<sup>22</sup> <https://www.homecare.co.uk/news/article.cfm/id/1625441/home-care-chief-centre-stage-government-fight-COVID-19>

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## What Alzheimer's Society is doing

Alzheimer's Society has been responding to the issues raised by the pandemic that affect people living with dementia. Our Dementia Connect support line is being flooded with thousands of calls, with people desperately worried about their loved ones in care homes, hospitals and the community.

**As we move away from the immediate crisis caused by the pandemic, we want to look specifically at how to provide high quality, effective care for people with dementia during the ongoing COVID-19 restrictions and longer term. Alzheimer's Society is bringing leading experts in infection control together with colleagues in the care sector in a roundtable discussion to start examining this issue, and to feed into a Government taskforce.**

## Recommendations to Government

**We are calling on the Government to lead a task force with Local Authorities and expert groups to address how they will support people with dementia as the country emerges from the lockdown over the next 6-12mths, with social contact at the heart of the solution.**

### The taskforce should:

- investigate how social isolation is contributing to the increase of dementia deaths and the role for family contact in saving lives
- promote rapid research, either through newly commissioned work or existing research projects that assess the links between COVID-19 and dementia, and the impact of reduction in social contact

While a Taskforce is being established, the following commitments must be made urgently

### For Care Homes -

- PPE, testing and staffing supply issues must be addressed so that family/loved ones can come and visit and provide care if they want to or are able to
- Family carers of people should be considered first for antibodies testing when it becomes available to ensure that there is minimised risk in enabling them to continue caring
- Government must issue renewed guidance setting out how care homes can work with family carers to support people with dementia in this new phase of lockdown
- Care homes should actively be assessing those residents who receive family carer input and work with the carer(s) to discuss what's needed and how they can support the person living with dementia
- For those assisting in the provision of care, visits should be enabled under circumstances where the care/support is deemed integral to the person with dementia's wellbeing or ongoing daily care

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### **For Home Care -**

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