

## **Dementia UK evidence for APPG on Coronavirus**

### **Overview**

Dementia is an umbrella term used to describe a range of progressive neurological disorders, that include Alzheimer’s disease, vascular dementia and dementia with Lewy bodies. There is currently no cure for dementia and the majority of dementias cannot be prevented.

Dementia UK is a national charity that provides specialist dementia support for families through our Admiral Nurse services. Our Admiral Nurses are experienced, compassionate dementia specialists who offer the practical solutions and emotional support that help families face dementia with more confidence, dealing with the challenges of today and preparing for the future.

Throughout the pandemic our Helpline and local Admiral Nursing services have provided unrivalled support and advice to some of the most vulnerable people across the UK. Our Helpline nurses have taken thousands of calls from families affected by dementia with concerns related to the COVID-19 pandemic. Our local Admiral Nurse services have adapted their roles to work remotely so that families continue to receive their specialist support.

Below are some of the key issues and challenges facing **families affected by dementia** and **health and social care nursing professionals** during the pandemic, and it is predicted that there will be long-term effects for families and services after the pandemic is over.

### **1. Families affected by dementia**

#### **Diagnosis:**

There are delays in people being assessed by memory assessment services and therefore in receiving a diagnosis of dementia. This impacts on what services and support the person with the diagnosis and their family can access. It also affects the establishment of a personalised care and support plan, which should include an assessment of the person’s needs, provisions that need to be made, and support for the family carer/supporter. The impact is that the person with dementia and their family do not receive the practical or emotional information and support that they need to live with and die well with dementia. The health and wellbeing of families (as well as relationships between family members) can suffer and this can lead to additional pressures on primary and secondary care services (as families seek help and support elsewhere).

Timely referrals for a specialist assessment and access to diagnostic services need to remain in place during any future national or local lockdowns following NICE Guidance for Dementia 2018.

### **Managing complexity:**

Admiral Nurses have reported an increase in complex clinical cases, including a rise in safeguarding issues most commonly caused by a lack of groups, support and respite causing increasing distress in the family home. Family carers have reported that the person with dementia has presented with an increase in physical, emotional and behavioural symptoms due to the changes to their lives imposed by the COVID restrictions. The families have also seen a marked deterioration in cognitive functioning and everyday living skills in the person with dementia. Access to continence, speech and language, hearing and dental assessments has been very difficult, leading to poorer quality of life for people with dementia and their family carers.

Without access to the usual essential services, physically and emotionally exhausted family carers reach crisis point, leading to further pressures on primary and secondary care resources. Admiral Nurses report people with dementia falling between the gaps, because of the reduction in case management between health and social care. Admiral Nurses are trying to pull together support for families but this is very challenging due to very limited services available during the pandemic.

Person-centred and co-ordinated care and support needs to remain in place in a future outbreak to maintain the health and wellbeing of families affected by dementia as well as ensure the most effective use of emergency and critical services.

### **Community care:**

Admiral Nurses working in the community and on our Admiral Nurse Dementia Helpline continue to be in contact with family carers who have limited or no access to respite and other support services (e.g. memory cafes, peer support, day care services, drop ins etc.). During national lockdown many family carers caring for a relative at home were doing so 24/7 with no break or access to support or respite services – including help from other family members. This has had a huge impact on their physical health and emotional wellbeing. We have been contacted by exhausted carers at breaking point. They are very concerned that in future national or local lockdowns, they will find themselves in the same situation and they do not feel that they will be able to manage on their own again.

### **Care homes**

69% of people living in nursing and residential care homes have dementia<sup>1</sup>, and they have been disproportionately affected by the pandemic. Not only due to delay and confusion about testing and access to personal protective equipment (PPE), but also because people with dementia appear to be more at risk of contracting the virus; which has been all too evident in the numbers of deaths in care homes. As well as the biomedical risk of coronavirus, the shielding of care home residents through stringent visiting restrictions has led to residents having no or very limited access to family carers. Family carers are not just visitors; they provide an essential part of a person's care, particularly relevant for a person with dementia (e.g. emotional and spiritual care, help with communication, eating and drinking, mobility and day-to-day social interaction).

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<sup>1</sup> Prince, M et al (2014) Dementia UK: Update Second Edition report produced by King's College London and the London School of Economics for the Alzheimer's Society, accessed from <https://www.dementiastatistics.org/statistics/care-services/>

Since the early stages of the outbreak, Dementia UK has urgently called for improved access to PPE and regular testing for care home residents, staff – and family carers so they can visit residents. We remain concerned that these fundamental measures are still not consistently in place, even after assurances from the government. This is crucial for the safety of residents and staff and to ensure that family visits can safely resume now and in the future.

### **Family visits in hospital and hospice settings**

The negative impact of social distancing requirements and restricted visiting is not only seen in care homes. In the hospital and hospice setting, people with dementia are admitted without their family carer to help them communicate (e.g. provide a medical history, convey their questions or concerns or understand information), or support them at a time when they maybe disoriented due to unfamiliar routines, delirium or illness. The routine wearing of face masks by healthcare professionals further complicates communication because it muffles the voice and hides the mouth. This makes communication even more challenging for a person with dementia without their family carer to advocate on their behalf. Flexible and clear guidance for family visits and access to PPE and testing needs to be in place for all care settings.

### **Family support bubbles**

Admiral Nurses on the Dementia UK Admiral Nurse Dementia Helpline are receiving a high number of calls from family carers who are worried that they will lose their support bubbles if lockdown measures are re-introduced. Family carers have also expressed concern about the lack of clarity about government guidance or acknowledgement of the support needs of family carers and people living with dementia at home.

Dementia UK strongly supports the need for family carers to continue to have access to support bubbles during future lockdowns.

### **Loneliness and isolation**

During the height of the outbreak, in addition to the general social distancing requirements, many families affected by dementia were advised, or chose, to shield. This has had a negative impact. Restricted or no peer, family or service support leads to a significant increase in family carers feeling lonely or isolated. This is particularly relevant as family carers of people with dementia already suffer from social isolation. Furthermore, carers express a loss of self, outside of their caring role, as well as a loss of social connection and freedom of movement. This can have a negative impact on the emotional and physical health and wellbeing of both the carer and person with dementia.

There has been an increase in virtual support but we have found that this is not always appropriate for people living with dementia. For example, digital exclusion is a reality for many people<sup>2</sup> in terms of not only access to, confidence and competence with technology, but also in terms of if people with dementia find that type of communication possible. There have been great examples of individuals and communities galvanising to support more vulnerable people living within the

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<sup>2</sup> Cambridge Centre for Housing and Planning Research (CCHPR), University of Cambridge:  
<https://www.cam.ac.uk/stories/digitaldivide>

community during the pandemic. We need to ensure mechanisms remain in place to check in on and maintain connections with people who are older and more vulnerable – even when the pandemic subsides.

### **End of life care, grief, loss and bereavement**

The coronavirus outbreak has had an unprecedented impact upon people – not only in terms of the volume of deaths (in a short period of time), but also because people have often died without the presence of family members to accompany them during the dying period or help convey or advocate their advance care planning wishes and decisions. People living with dementia are already at risk of not receiving the relevant care at the end of life, and the outbreak has exacerbated their vulnerability (e.g. not being able to convey their wishes or for their advocate to do so for them). In addition, there is increasing evidence, that those who have been bereaved during the pandemic are at risk of complicated, disenfranchised grief, because of the impact of social distancing, visiting restrictions and isolated deaths.

### **Supporting people as restrictions ease**

Many carers have contacted us because they are unclear about the changes in government guidance and how it relates to their family situation, e.g. shielding coming to an end and exemptions on face masks. Many families remain concerned about contracting the virus and passing it on to the person they're caring for. This is making them cautious and worried about going out in public.

Dementia UK feels strongly that messaging about changes to guidance and how it affects vulnerable people should be made clearer and more widely published.

### **Financial support for unpaid carers**

There are estimated to be 670,000 acting as primary unpaid carers for people with dementia<sup>3</sup>. Many unpaid carer are facing financial hardship. This has been exacerbated by the pandemic with carers reporting that that they feel they have no choice but to give up work or reduce their hours to provide more care. They are experiencing a sharp reduction in income while still having to pay the rising costs for care such as higher utility bills, paying for additional care and adaptive equipment.

The economic impact of the pandemic is still unfolding. Many carers still in employment are worried about losing their jobs. We strongly recommend that the government's furlough scheme be extended to offer a level of reassurance during these uncertain times.

Carer's Allowance remains at £67.25 per week and it is completely ineffective at preventing financial hardship. We urgently want to see a rise in Carer's Allowance to better reflect the financial implications of caring. We also want to see the earning limit for claiming Carer's Allowance to be raised to ensure those juggling work and care on low pay can receive support.

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<sup>3</sup> Alzheimer's Society (2014), Dementia UK: 2014 edition, Alzheimer's Society, Carer Information and Support Programme

## **2. Health and social care nursing professionals**

### **Admiral Nurses (specialist dementia nurses)**

The pandemic has highlighted the clinical vulnerability of people with dementia and the emotional and physical toll this is having on family carers. It stresses the need for families to have access to the specialist advice and support throughout the dementia pathway. Providing families with the right information and support will also take pressure off primary and secondary services who may need to focus resources on a future COVID-19 outbreak. However, greater access to dementia specialists such as Admiral Nurses will need government funding – particularly to ensure that specific regions or harder to reach communities have access to this specialist support.

Our local Admiral Nurse services were able to adapt to provide support remotely to families during lockdown, largely through phone contacts. When clinically necessary the Admiral Nurses are starting to meet with families following the latest Government guidance. Admiral Nurse caseloads continue to increase and our Helpline has been exceptionally busy with a 40% increase in calls over the last few months.

However, Admiral Nurses face challenges in the support they can offer to families due to the limited services they are able to refer people onto. This is having an emotional toll on our Admiral Nurses as they are increasingly seeing more and more people in crisis. As a charity, we have put mechanisms in place to support Admiral Nurses who may be feeling overwhelmed, but wider dementia support services need to be re-established in communities as a priority. Our concern is that funding for support services may be taken away. These services are vital, not only for families, but also for clinicians such as Admiral Nurses who have been trying to arrange support for families in very challenging situations.

### **Person-centred care**

Person-centred care is at the heart of all good quality nursing, across all care settings. However, COVID-19 restrictions has meant care pathways have become more process-led, rather than person-centred. Nurses are seeing this with the 'blanket' approach to Do Not Resuscitate orders (DNR) and there are rising numbers of people with dementia in acute settings who are without family carer visits due to restrictions imposed by the ward. We would like to see a return to more individualised care, which will lead to better outcomes for patients, their families and the nursing staff supporting them.

### **Limited learning and development opportunities within nursing**

Social distancing restrictions have meant nursing staff across all care settings have had limited access to practical, face-to-face learning opportunities, e.g., learning particular end of life care techniques. This lack of clinical skills training is impacting on staff competencies and resilience. Where it is clinically safe, we would like to see a return to more practice-based learning and skills training.

### **Social care nursing**

More widely, the pandemic has stressed the nursing workforce crisis – particularly within social care. The Queen's Nursing Institute (QNI) has recently published (24<sup>th</sup> August 2020) a new report on COVID-19's effect on care home

nursing staff<sup>4</sup>. This highlights a workforce that is stretched too thin and are held lower in esteem, in a very challenging environment. Nursing staff are anxious, stressed and demoralised. Better support and guidance for nursing professionals needs to be in place ahead of any future lockdowns to ensure their health and wellbeing is safeguarded.

**Health and social care reform is urgently needed**

COVID-19 has exacerbated the above issues and challenges facing both families affected by dementia and nursing professionals. It has highlighted that the social care system is broken. No quick fix will work, it urgently needs complete restructuring and this cannot be delayed any longer.

We call on the government to honour their commitment to finding a long term, fair and sustainable solution to social care that protects and cares for people now, and into the future and connects the system up so that people with dementia and their families do not fall through the cracks

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<sup>4</sup> Queen's Nursing Institute (QNI), (2020), The Experience of Care home Staff During COVID-19: <https://www.qni.org.uk/news-and-events/news/major-new-survey-of-care-home-leaders-confirms-severe-impact-of-covid-19/>