



The Experiences of Carers of People Living with Dementia during the Covid-19 Pandemic

Together in Dementia Everyday (Tide) is a UK-wide charity that focuses on supporting carers of people living with dementia to recognise their own value and use their lived experience to influence positive change in policy, research and practice. In the UK, the contribution of the 700,000 unpaid carers of people living with dementia to the care economy is estimated to be at least £13.9bnⁱ and makes up 40% of the dementia workforceⁱⁱ.

Despite the fact that unpaid carers provide the majority of care and support to people living with dementia, the policy focus on carers has diminished and many carers have felt that their own needs, as well as those of the person they care for, are often ignored by government and decision-makers. Dementia has been largely excluded as a disease or 'underlying condition', communication and information has been lacking, services and support have disappeared, and coverage and attention on these issues has been slight. The effects of the crisis on carers themselves in terms of the additional practical demands, effects on physical and emotional health and wellbeing, the lack of support available, and the isolation and loss felt by many have been sadly neglected.

Practical Issues

Although not evident in the response of decision-makers, people living with dementia have been particularly vulnerable during the Covid-19 pandemic, causing additional stress to carers and an increase in the hours spent caring due to reduced support, withdrawal of services, lack of respite, self-isolation and shielding. Many carers have

expressed concern about deterioration in the symptoms of the person they care for due to lack of social interaction and cognitive stimulation and this has, in turn, led to increased complexity of care. Some of the other practical issues mentioned have been the difficulties in working out what is an acceptable level of risk e.g. whether to go out for a walk or not; how to get food & medication if you, as the carer, have been told by your GP not to go out; difficulty sourcing their own PPE and having to pay inflated prices; supermarket opening times not reflecting the needs of carers or difficulty in obtaining a supermarket delivery slot; and worries about finances.

‘Total inability to get supermarket deliveries’

‘I’ve been unable to attend to my Mother’s personal care needs (as care calls ceased several weeks ago), unable to assist my Father to care for her. (I was) unable to offer the emotional support my Father needs or respite for him. My Mother has lost all motivation or direction since the day centre was the focal point of her week prior to this. She has rapidly declined.’

‘I was in the process of emptying Mum’s house to get it on the market to pay for her care. I can’t do anything now & house sales have stopped. Mum’s money in the bank is starting to run out, so I am worried about how to pay her bills.’

Services for People Living with Dementia

The lack of services and support for the person they are caring for has been the main source of concern to carers. They are talking about the fact that there is “no support” available, that it is unclear when services will re-open & what they will look like when they do. They are worried about whether the person they care for will still be eligible for support, including concerns about the potential impact of the Coronavirus Act on health & social care services available. Carers are also talking about:

- Not hearing from adult services
- Hospitals discharging back into a residential home even though nursing care was required

- The difficulty of getting food to loved ones when Extra Care Housing cancelled lunches
- Withdrawal of services, lack of support services still running, & cases being closed or put on hold.

‘We lost access to dementia day care & family support due to lock down restrictions’

‘I had a phone call from the social worker saying my Mum’s case was being closed. I had such a struggle to get an appointed social worker. (I) couldn’t believe, especially in these circumstances, that support has been withdrawn.’

‘When the need for support arose, it very quickly became apparent that there was NO emergency care or support available & we were left to fend for ourselves.’

‘The support systems that were in place are no longer available - for obvious reasons, but it’s no less stressful’.

Visiting Care Homes & Hospitals

Many carers have told us about their distress due to not being able to visit their loved ones in residential and care homes. The physical and mental health of many residents, particularly those with dementia, has deteriorated during Covid-19 and this has not been helped by the ban on visitors. The various care home providers have interpreted guidance differently, leaving carers confused and frustrated, particularly when some care homes went out of their way to arrange garden visits and some offered only technology, whether that was appropriate for the resident or not.

‘I can’t visit my husband in his care home...can’t talk to him as he can no longer converse. He wouldn’t use Skype as it would confuse him.’

‘I can’t visit my mum in the care home. I can see her through the lounge window but not being able to physically be in the same room & hold her hand is hard to deal with emotionally for me. Especially as there is no time limit on how long this situation will last.’

‘Not being able to visit my Mum in her care home - the way she was going, she might not know who I am when I eventually get to see her.’

‘We all rejoiced at the prospect of socially distant visits in the gardens with families & friends (obviously only one household a day) but yet no-one anywhere has thought about when & how we can make it possible for those in care homes to see their families. Where are their human rights?’

To address this issue, tide has joined with other dementia organisations as the ‘One Dementia Voice’ campaign to call on UK government to grant designated family carers the same status as a ‘key worker’; as an essential member of the care and support network:

‘They not only provide practical services that contribute directly to the family member’s wellbeing, but also act as their advocates, voice & memory, keeping them connected to the world’

The full statement can be read here: <https://www.tide.uk.net/letter-to-the-government-about-care-homes/>

One carer, who was eventually allowed to stay with their parent in hospital, described a particularly distressing experience (amongst a catalogue of incidents) where a doctor had given them a very graphic description of resuscitation when recommending a Do-Not-Resuscitate (DNR) Order:

‘They said ‘Do you know what it takes to resuscitate a person? You won’t be allowed in the room. There will be a gang of people jumping up & down on their chest, so hard that you’ll be able to hear the ribs crack &, when struck by the paddles, they’ll fly up into the air & crash back down’.

The Impact of Caring for People Living with Dementia during the Pandemic



Carers of people living with dementia have, along with the people they care for, found themselves ever more isolated and at much greater risk of negative impacts on their health and wellbeing. Many are still restricted to their homes and are likely to stay there long after other people have emerged from lockdown. Some carer support services have been able to put virtual support services in place, but not all of them, and whilst it is true that some carers have been able to access more flexible online activities than would usually be the case, many carers are unable to access virtual support at all. Many carers have described feelings of grief & loss and, where there has been bereavement, an impact on the ability to provide end of life care. The fact that communal rituals have largely not taken place, and that grief has not been shared has only compounded the experience.

'I am finding it depressing as I am having to deal with my bereavement & isolation, & I fear for my mental health at times'

Carers talked about the effects of caring 24/7 with limited support as: causing stress, lack of sleep, lack of respite, isolation and loneliness, anxiety and worry; and the struggle of having to manage mental health for both themselves and their loved one.

‘I was struggling before the lockdown, but at least I could get away for a couple of hours from caring... That lifeline has been taken away’

‘I can feel that I am slowly getting to the end of my tether & finding it hard to stay patient’

‘I’m struggling some days as it can be relentless & I worry constantly’

‘Self-isolation & social distancing is nothing new to the caring role. I have been feeling totally isolated for over 10 years now &, if I thought that it was bad before, since the lockdown it has escalated beyond belief.’

‘For that matter when will I be able to resume my own life? We are told we are all in this together but why so little acknowledgement of the role of unpaid carers? ... How will I get respite for mum (& me) at a care home when they have suffered such heavy losses & they might be hesitant to open their doors to short term residents?’

‘The ongoing demands of caring for someone with dementia & other health needs which can be individually demanding, taken together becomes a real juggling act. The unpredictability of dementia, the life-threatening crises it can throw up, can - does - take its toll on us physically, mentally, spiritually.’

‘No-one Is Talking about Unpaid Carers’

This year, during Carers’ Week in June, many carers of people living with dementia expressed anger. They felt there had been a loss of identity for carers during the pandemic as the media started referring to all health & social care workers as ‘carers’; and that ironically, during a week with the theme of ‘Make Caring Visible’, they had never felt less visible.

‘I care for my husband at home & I have many friends, colleagues, fellow travellers, who care for someone in another setting. We all face

challenges daily, during this era of Covid-19; very little of which is being aired in public. Talk of ‘heroes’ is the dominant narrative. Probably because it is easier, ‘better’, to keep things positive. No-one is talking about unpaid carers because no-one knows what to say.’

Whilst it has always been the case that carers of people living with dementia experience higher levels of stress, depression, anxiety, poorer physical and mental health, and financial and social disadvantages, the Covid-19 pandemic has placed an almost intolerable level of stress on carers and exacerbated the many existing issues in health and social care services for both carers and those living with dementia. It is clear that the voice of carers needs to be listened to urgently by government and decision-makers and that access to physical and mental health services, social services, respite and crisis support for carers must become a priority. The focus for tide going forward is to continue sharing the voices and experiences of carers strategically and to raise awareness of the issues across the UK. Our hope is that carers will become a priority focus for the UK and devolved governments and that there will be a greater degree of investment in carers who, apart from being valuable in their own right, are also one of the most valuable unpaid assets in terms of the economy.

Tide - Together in Dementia Everyday

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www.tide.uk.net

ⁱ Alzheimer’s Society (2019) Dementia Update 2014 (2019 Update)

ⁱⁱ Wittenberg, R et al (2019) Projections of Older People with Dementia & Costs of Dementia Care in the UK 2019 – 2040, Care Policy & Evaluation Centre, London School of Economics & Political Science (CPEC Working Paper 5)