

The impact of the Covid 19 Pandemic on people with dementia and their carers (Findings from studies and key messages)

The COVID-19 pandemic and subsequent local, regional, and national lockdowns have led to significant disruption to health and social care services. For people with dementia and their family carers this is problematic. People with dementia rely upon timely and responsive services to live well. The abrupt closure and reduction of many health and community support services arising from the pandemic is of concern. Our two studies explored the impact of COVID-19 on the life quality of people with dementia and their carers. The purpose of this document is to share these findings and provide key messages for services and commissioners. The key messages have been developed in conjunction with people with dementia, their carers and researchers.

The Time for Dementia (TfD) study followed a group of 245 family carers during COVID lockdown who provided information on their quality of life and other factors affecting wellbeing before and during the pandemic. In-depth interviews about the impact of the pandemic on their quality of life were also undertaken with 16 carers.

The DETERMIND-C19 study compared information collected from 93 people newly diagnosed with dementia and 113 carers before the pandemic to that gathered during the pandemic. Changes in people's mental, physical and social well-being were explored as well as their use of services over this time period. In-depth interviews with 21 people with dementia and 42 carers were undertaken in order to better understand experiences and quality of life during the pandemic.

Our findings and key messages are as follows:

Impact on Quality of Life

- The impact of the pandemic was particularly challenging for carers of people with dementia.
- We found groups of carers who were more likely to be negatively affected, including: women, those living with the person with dementia; spouses; and those living in areas of higher deprivation.
- For many people with dementia and carers, the sudden loss of formal support services had a negative impact on their life quality.
- There were differences in how people adapted to the pandemic. Many found it difficult, but others were able to find positives in increased simplicity of life.
- The TfD study found that two components of carer quality of life, 'meeting personal needs' and 'feeling supported', decreased during the pandemic.

"That's why I found it so lonely, I'd been so used to going out." Person with dementia

"But you know, it's just um when, when will I be able to get a break, that's what I don't know."

Resident spousal carer

"He's got no anxiety so he doesn't worry about people not being around the house coz he doesn't remember."

Resident daughter carer

Key messages

- Identifying people with dementia and their carers who are more likely to be struggling is particularly important.
- Factors influencing an individual's quality of life are likely to have changed as a result of COVID, and services may need to adapt their support.
- Continuity of formal support is essential. Services need to find ways to provide targeted support to more vulnerable groups of carers. There should not be a one size fits all approach.

Hospitals and care homes

- Carers reported difficulties keeping in touch with people with dementia when they were in hospital or care homes.
- Importance of trust in care organisations was paramount to carer quality of life.

"And she's being looked after and it's the best place for her so therefore I suppose it, it, it does me help you know, it makes me feel better knowing that she's, she's okay you know... the homes very good, they put me straight onto X (person with dementia) and they let me know how she's getting on."

Care home spouse carer

"I asked, I asked every week, "can I see X (person with dementia), can I see X" "oh we don't know where the (I-Pad) tablet is, it must be in the manager's office". Hey ho they have lost it, it's now, I keep asking for this tablet and no one knows where it is"

Care home spouse carer

Key messages

- Services should recognise that with restricted visiting, the effect of hospitalisation or living apart is particularly distressing for carers and people with dementia.
- Hospital and care home staff should support active connection between people with dementia and their carers.
- Regular communication with carers will contribute to developing and maintaining a trusting relationship.

Support and connection with others

- Some carers, and particularly those living with the person with dementia, reported high levels of loneliness during the pandemic.
- Some people lost social support from families, friends, and neighbours during this time and this loss was widely felt. However, others had local family members, friends and neighbours who were able to provide them with support.
- In some communities, informal networks were established where volunteers were able to offer help and this was highly valued.
- The value of communication technology for keeping in touch with family members was clear. However, the use of this technology was not suitable for all and for some people it was no replacement for face to face contact.

"...I'm the only single person and they've all got other halves, and talk about their other halves, and I do feel a bit... I come off of there, to be honest with you, quite depressed, because they've all got someone on the line with them, and things like this, and they're going out with people, and got very close families." Person with dementia

"We seem to be coping with the help of the family, we wouldn't be able to do it by ourselves. They're very supportive, very supportive."

Person with dementia

"We've got friends and they would help out so the wife would come and uh look after X (person with dementia) and I go out with, with the husband. Um that stopped of course because um we can't even have someone come around to the house."

Resident spouse carer

Key messages

- The loss of informal social support on people with dementia and their carers was significant. Services need to encourage, support, and enable people with dementia and their carers to use informal networks, and find ways to ensure these remain sustainable.
- Services need to ensure that people with dementia remain connected, and provide support where needed to do this. This can include setting up or adapting communication technology for some people.

Understanding restrictions

- Both people with dementia and their carers reported difficulties in understanding the social distancing guidance and following it correctly.
- Mixed and unclear messages were unhelpful, especially for carers who often had to support the person with dementia to understand and follow the restrictions.

"And therefore she doesn't quite understand all of it. And uh just keeps repeating and repeating that you know 'Why can't we?'" Care home spouse carer

Key messages

- Dementia friendly summaries of complex guidance should be developed and shared by services.
- Services need to ensure that people with dementia and their carers can access information they need and that this is clear and simple.

Keeping active

- For some people with dementia and carers this period presented an opportunity to engage in new hobbies and activities that were beneficial for their mental, physical and social well-being.
- Others adapted their previous activities to overcome barriers imposed by the pandemic.
- Some people with dementia and their carers used natural environments to exercise, relax and gather their thoughts. This also provided a break for both the carer and the person with dementia.
- However, this was not possible for all, and reduced mobility for people with dementia during the pandemic period was a consequence of being less active.

"I remember doing woodwork at school, very vaguely, But I've done some research into doing basic woodwork, so that's what I'm going to do. Getting a hobby."

Person with dementia

"She's sitting down a lot more, not getting out and about and moving so, so she's got more aches and pains."

Non-resident daughter carer

Key messages

- Services should encourage and enable people with dementia and their carers to keep active, use their local environment, and get out into the fresh air. For some people, this could be a brief walk or even just sitting outside for a short period.
- To support mental, physical and social wellbeing services should work with people with dementia and their carers to identify new activities they could undertake or adapt existing ones.