

The impact of the COVID-19 Pandemic on people with dementia and their carers (Lay summary)

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 study compared information collected from 93 people with dementia and 113 carers before the pandemic to information 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.

These studies were undertaken in 2020. The key findings of both studies have been combined. The purpose of this document is to share these findings. The key messages have been developed in conjunction with people with dementia, their carers and researchers.



KEY FINDING 1

Mixed picture of impact on Quality of Life

- In both studies, at a group-level quality of life appeared to remain stable throughout the pandemic period.
- Being female, living with or being a spouse of the person with dementia or living in an area of higher deprivation negatively affected quality of life.
- The TfD study found that caring for someone with less advanced dementia had a negative effect on carer quality of life, whereas the DETERMIND study found that caring for someone with more advanced dementia had a negative effect on carer quality of life.
- Continuity of formal support was highly valued, and the loss of support had a strong impact for the groups of carers mentioned above.



KEY FINDING 2

Loss of informal social support

- Some people with dementia and their carers had local family members, friends and neighbours who were able to provide them with practical and emotional support.
- In some communities; informal networks were established where volunteers were able to offer help and this support was highly valued.
- Some people lost informal social support due to the impact of the pandemic and this loss was widely felt.



KEY FINDING 3

Variation of impact

- Some people with dementia and their carers found they were able to find positives during the pandemic, such as being able to stay in touch with family and friends.
- However, others found they were unable to do this and found the impact of Covid-19 more difficult.
- For some people with dementia and their carers, their activities were already limited by dementia and/or other long-term health conditions, therefore the pandemic and the restrictions had less impact on them.



KEY FINDING 4

Use of communication technology

- There was mixed evidence about the use of communication technology.
- The value of connection and keeping in touch with family members was clear.
- However, the use of communication technology is not suitable for all and for some people it was no replacement for face to face communication and contact.



KEY FINDING 5

Being in hospital or in a care home

- When people with dementia were taken into hospital or into care homes, carers discussed the difficulties they had keeping in touch with them.
- The importance of trust in care organisations was paramount to carer quality of life.



KEY FINDING 6

Engaging in new hobbies

- Some people with dementia and carers engaged in new hobbies and activities that were beneficial for their mental, physical and social well-being.
- Others also adapted their previous activities in order to overcome the barriers imposed by the pandemic.



KEY FINDING 7

Use of outdoor space

- 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 since the start of the pandemic was reported as a consequence of being less active.



KEY FINDING 8

Understanding restrictions

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



KEY FINDING 9

Change in factors influencing Quality of Life

- The TfD study noted a change in the factors influencing quality of life in the carers of people with dementia over the pandemic period.
- For example, prior to the pandemic 'worries about the future' were commonly observed, however this shifted to 'meeting personal needs' and 'feeling less supported'.