Impact of COVID-19 on people with dementia and carers

Dr Clarissa Giebel
University of Liverpool / NIHR ARC NWC
• 850,000 people living with dementia in the UK
• Unpaid carers contribute over £13 billion in care each year
UK Public health restrictions

• Nationwide lockdown 23rd March
• Shielding for vulnerable people and those aged 70+ prior to 23/03
UK-wide COVID-19 Dementia study

50 qualitative baseline interviews
(42 carers & 8 people with dementia)

April 2020

20 follow-up interviews
(16 carers & 4 people with dementia)

24th June – 10th July

Giebel et al. (2020) Aging & Mental Health, in press

The voices of persons with dementia and their carers during the COVID-19 pandemic
Faster deterioration

“I think that the longer this goes on the more he won’t be able to go back to the things that he was doing. He would go into the village himself and go to get a few bits of shopping sometimes or he would walk up to church. That’s another thing because church has stopped, he used to go up to church and he’d go and see my mum’s grave and all of that’s stopped as well.”

Female carer (Daughter)

“Five weeks ago my Dad was a totally different person than he is now and he won't come back from this.”

Female carer (Daughter)
Uncertainty

“I’m just hoping all these services eventually do come back and they come back sooner rather than later because my Dad hasn’t been out, he hasn’t been to the shops he hasn’t been obviously walking and him and my Mum loved to go for coffees we used to go to the garden centre if it was nice and he really likes that because he really loves being round people. “

Female carer (Daughter)
Adapting to the new normal

“[PLWD] can’t engage in video conferencing or anything like that, he doesn’t partly because of the vision issues of PCA he doesn’t really see the screen or anything like that and he doesn’t now give you eye contact when he’s talking to you.”

Female Carer (Spouse)
Decision making for receiving paid home care

Giebel et al. (2020) BMC Geriatrics, in press

The voices of persons with dementia and their carers during the COVID-19 pandemic
The voices of persons with dementia and their carers during the COVID-19 pandemic
Inability to cope without paid carers

“I couldn't cope on my own and I'm just grateful to them [paid carers], that they still come... I don't know what I would do if they didn’t”

Female carer (daughter)
Worry about financial support

“I am fearful and I know this has happened to a family friend of ours who’s already been told by their social worker that because they’ve managed without the [paid] care they’re not likely to get it back after the coronavirus and I’m quite fearful that will be the case for us because I’m not able to do this fulltime”

Female carer (daughter)
The voices of persons with dementia and their carers during the COVID-19 pandemic

Survey snapshot

**T1**
660 older adults, carers, people with dementia
17th April – 15th May

**T2**
481 older adults, carers, people with dementia
26th May – 29th June

**T3**
411 older adults, carers, people with dementia
7th July – 10th August
THANK YOU!

To all participants
To carers and person with dementia joining our research team
To the many organisations who are part of our team:

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