

## Living with dementia during a pandemic

The COVID-19 pandemic is placing unprecedented pressure on health and social care systems as we respond to the threat of the virus. Along with many other vulnerable groups, people with dementia and their carers have seen a reduction in the services and support they normally receive.

Dr Stephanie Daley, Senior Lecturer in Older People's Mental Health and Education, Brighton and Sussex Medical School (BSMS) and Dr Naji Tabet, Dementia Theme Lead, [Academic Research Collaboration Kent, Surrey and Sussex \(ARC KSS\)](#) - together with colleagues at the Centre for Dementia Studies at BSMS and Sussex Partnership NHS Foundation Trust - are leading a study into the impact this pandemic is having on people living with dementia in Kent, Surrey and Sussex.

The research programme, funded by ARC KSS, aims to look at the quality of care and the impact social isolation has had on people with dementia, their family and carers, since the start of the pandemic.

**Dr Daley, explains:** "An estimated 850,000 people are living with dementia in the UK and the World Health Organisation recognises that they are at risk of being severely psychologically affected due to Coronavirus. Social distancing restrictions have left many people and their families without access to some of the support and services they need.

"This research will allow us to take a closer look at just how well people with dementia and their families and carers are coping during this pandemic and help identify any changes to services where needed."

Using an existing cohort of 359 family carers, Doctors Daley and Tabet, together with the team at BSMS, were able to start the research in early May, using a range of quantitative and qualitative methods.

- 1- Quantitative research - measuring quality of life and social functioning and comparing scores collected before with those during and after the COVID 19 social distancing period); and
- 2- Qualitative research - through semi structured in-depth qualitative telephone interviews to explore impacts in more detail during and after the social distancing restrictions.

The study was set up entirely remotely, using telephone to consent participants. As of 17 June 2020, 137 participants had agreed to take part in the telephone interviews. Repeat measures will be taken in the autumn.

**Dr Daley, adds:** "Participants have been very keen to take part, and have valued the opportunity to share their experiences. We have also set up a study specific lived experience advisory (LEAP) group to advise on study design, interview questions and analysis of data.

"We are planning to share the interim findings to service providers across the region in later in the year that will help inform the basis for further research in the area. The funding from KSS ARC has been crucial for allowing us to start this work at this time critical stage."

This research sits within the Time for Dementia study, which is looking at student and family outcomes from a wider dementia education programme for undergraduate healthcare students being delivered across all universities across Kent, Surrey and Sussex ([www.bsms.ac.uk/time4dementia](http://www.bsms.ac.uk/time4dementia)).

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