Rapid development of a COVID-19 specific decision-aid for people with dementia and their families

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COVID-19 has had widespread effects on health and social care systems

Rapid-response approach to care planning and decision-making is increasingly necessary

Systems are responding to changing triage and infection control needs

COVID-19 has disproportionately affected older adults, including those with dementia

Carers are having to make multiple difficult care decisions
1 in 14 over-65s have dementia

Over 850,000 in the UK

48.4% of carers have long-standing illness or disability

36% of carers spend over 100 hours a week caring
We developed a decision aid to help carers of persons with dementia.

We wanted to support carers to make difficult decisions in uncertain circumstances.

Decisional burden can affect caregiver grief after bereavement (Yamamoto et al 2017).

Decision aids can help to increase knowledge and reduce conflict (Cardona-Morell et al 2017).

We gathered data from a combination of interviews, rapid review and online forum analysis.
Interviews were with support line staff and concerned conversations with people who were seeking support.

Issues of trust, agency and confusion were key in these conversations.

Rapidly changing government guidance was confusing when making decisions around visiting and allowing external carers access.

Community support was unclear, confusingly presented and often unregulated.
Rapid review of current evidence on making decisions with older people at the end of life focused on decisions surrounding place of care and place of death

- Preparedness and a sense of control

- Continual consideration of decisions over time, as illnesses progress and priorities and capacities change

- Appropriate multidisciplinary professional involvement

- Appropriateness of available information in terms of cultural, language and access needs
Online forum data showed that many people felt guilty and anxious about many issues. This included uncertainty around visiting at home or in a care home. Carers were also upset at the possibility or reality of not being able to be with the person at the end of their life. Decisions around admission to hospital or care homes were also fraught.
Interview, review and forum data were presented to two co-design groups of people living with dementia, current and former carers and experts in dementia, general practice and social care.

We collected individual in-depth comments from additional experts in the field to finalise the tool.
The decision-aid covered care planning, caregiver support systems, access to information and contingency considerations

“It is safe for her carers to still come?”

“I’m scared that going into hospital would just make him worse”

“Will she still remember me if I don’t visit for all of this time?”
Creating a novel decision-making tool for persons with dementia and their families within the context of COVID-19 was feasible using a combination of sources of evidence.

Upon publication, the tool was adopted by NHS England and other leading healthcare organisations.
Access the decision aid here:

ucl.ac.uk/psychiatry/decision-guide

Who is supporting you?

We all need support from people to maintain our physical and mental wellbeing. If you are caring for someone you may benefit from extra practical, emotional and moral support from others. Draw your support network below by writing the names of people who support you in the circles. For example, spouse or partner, daughter, son, sister, GP, home care worker, neighbour, friend, social worker or volunteers.

Place yourself and the person with dementia in the centre two circles. Not everyone in your network will provide direct care, but they may support you in other ways. Add and delete circles as needed.

Wishes and preferences

This section is to help you consider your own wishes and preferences and the person with dementia's wishes and preferences about their care and treatment if they have suspected or confirmed to have coronavirus. This is important if they do not already have an advance care plan.

What is important to you?

For example:
- My relative is able to stay where they feel familiar and comfortable.
- Being able to be with them if they are seriously unwell or at the end of life.
- Knowing they are getting the care they need

How might coronavirus affect their wishes and preferences?

What is important to the person living with dementia?

For example, staying in their own home or a particular care home, being pain free and comfortable, having family and loved ones around, seeing and talking to their pet...
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