

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

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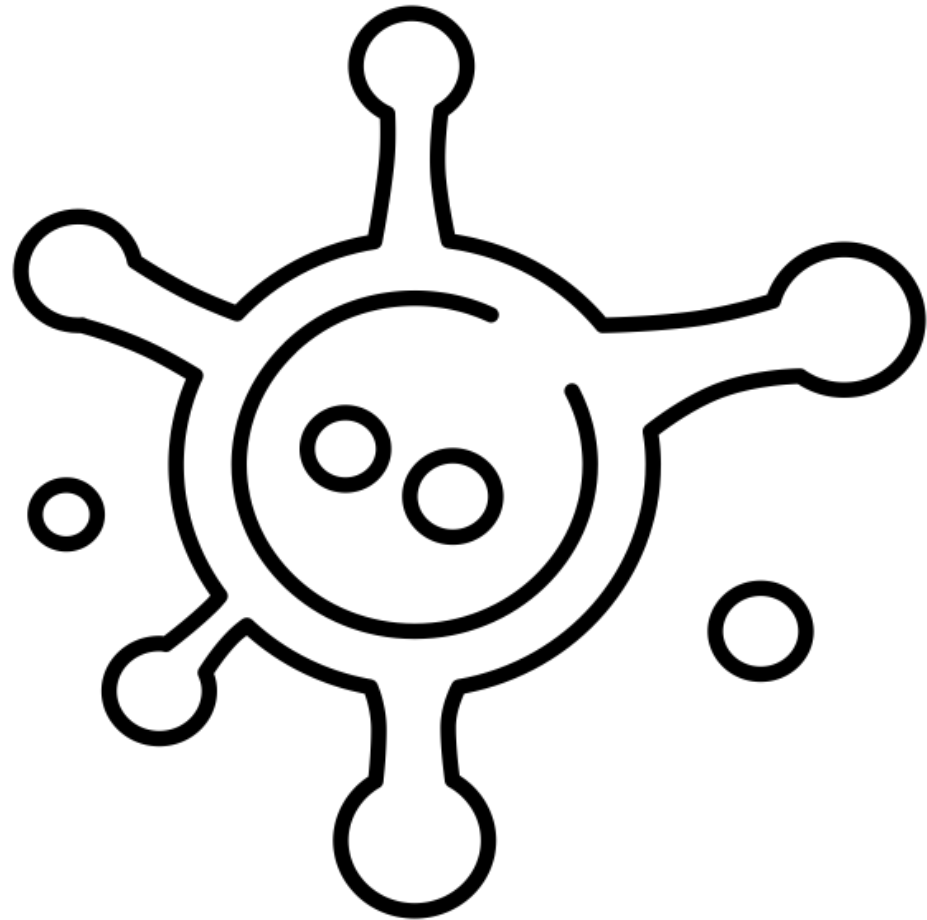
COVID-19 has had widespread effects on health and social care systems

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

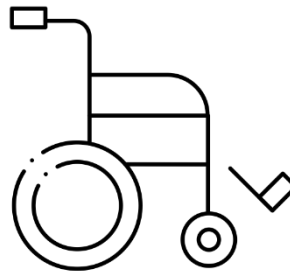
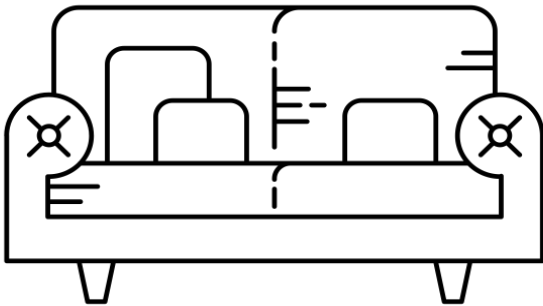


1 in 14 over-65s have dementia

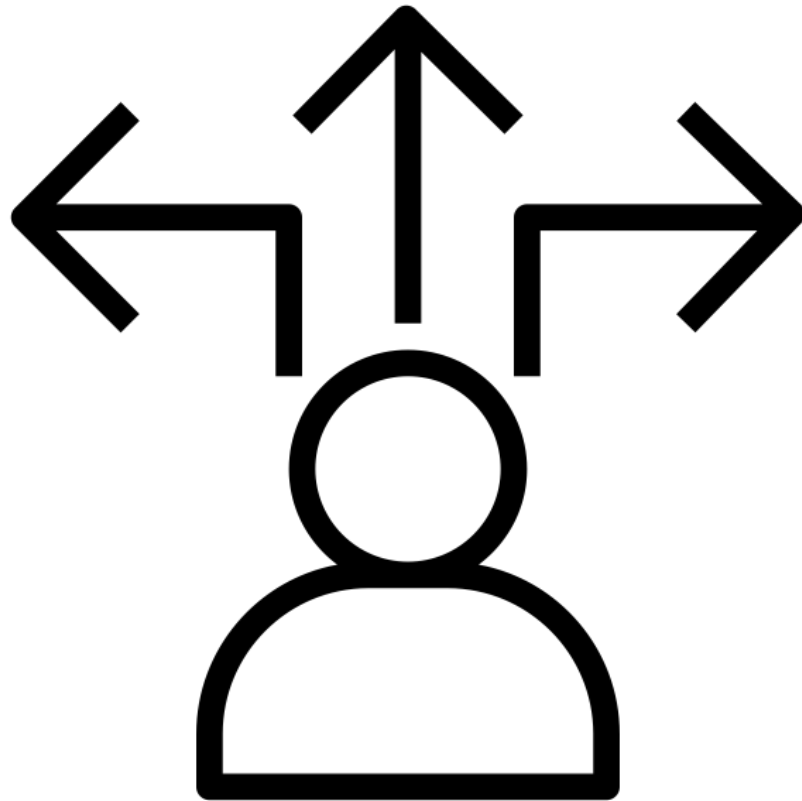
Over 850,000 in the UK

48.4% of carers have long-standing illness or disability

36% of carers spend over 100 hours a week caring



dementiastatistics.org



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

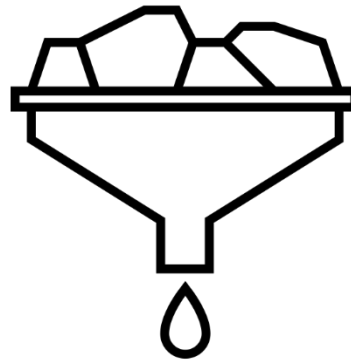
Issues of trust, agency and confusion were key in these conversations

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 focussed on decisions surrounding place of care and place of death



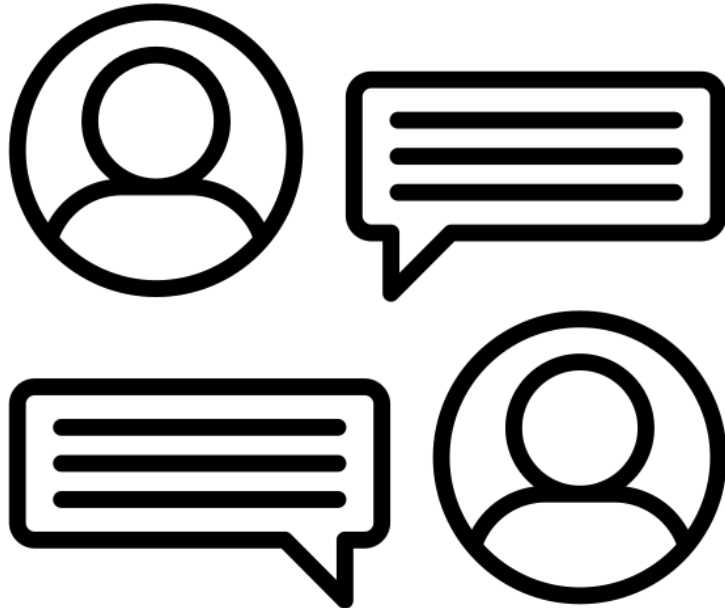
Preparedness and a sense of control

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



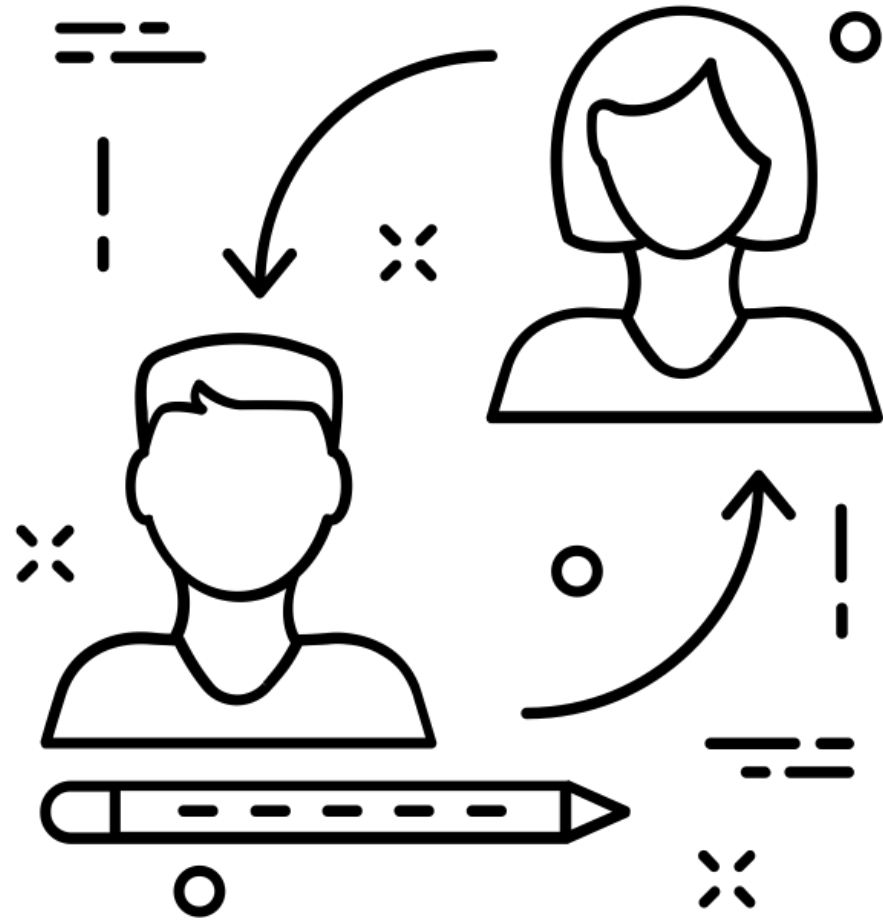
This included uncertainty around visiting at home or in a care home

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

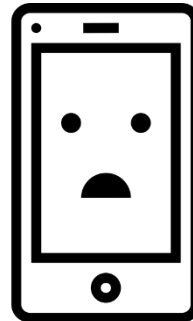


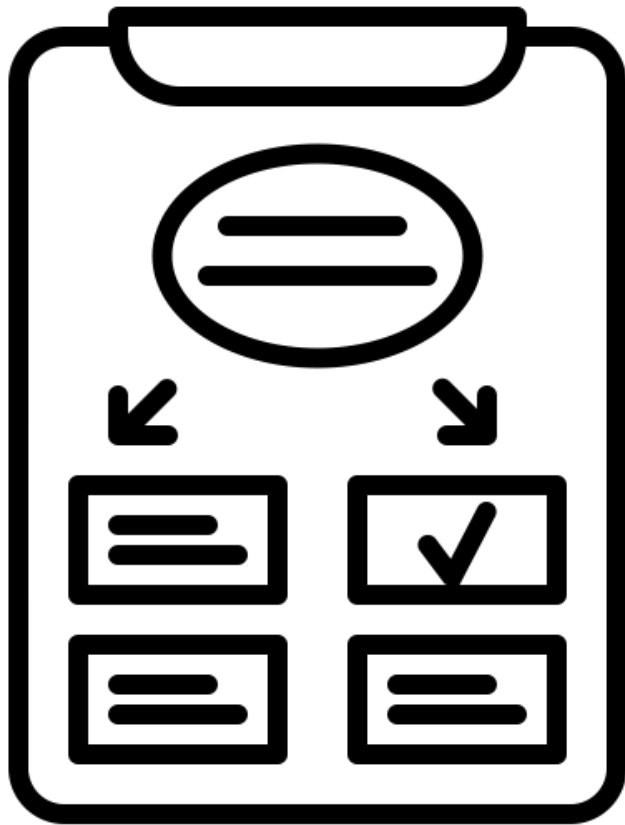
The decision-aid covered care planning, caregiver support systems,
access to information
and contingency considerations

“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



Supporting you to make decisions while caring for someone living with dementia during Coronavirus (COVID19) and beyond

Name of person completing this document:

Relationship to the person living with dementia:

Name of person living with dementia:

Use this section to keep important phone numbers for example, care home, GP, pharmacy, district nurse, home care agency

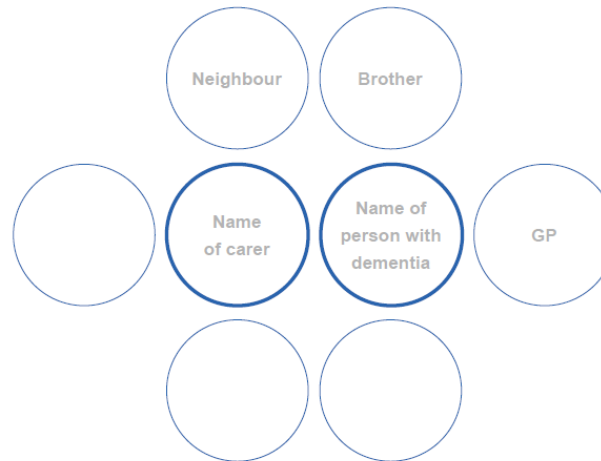
Name	Name of key contact	Number



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.



If you can fill no or few circles, speak with your GP about how to access more support. Contact details for services are on page 17.

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 friend/relative is able to stay where they feel familiar/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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