

Background: Many people with dementia do not have an advance care plan, decisions regarding their care and treatment are often left to their families. There is limited work exploring the views of people with dementia about end of life and what factors they would like their family to consider when making decisions. Aim: The aim of this study was to explore with people with mild dementia the factors they would like family caregivers to consider when making decisions on their behalf at the end of life. Methods: Ten semi-structured interviews were conducted with people with mild dementia in England. Participants were recruited through general practices, memory services and an online research register. Interviews were analysed using thematic analysis. Results: Most participants had not discussed end of life or advanced dementia with either professionals or their family. Many felt these discussions were not needed or only needed to be discussed once, however the experience of the interview often changed this view with participants acknowledging a need for such discussions. The key considerations participants wanted their family to consider when making decisions about their health and care on their behalf included: the level of awareness they have, for example are they still aware who their family are and where they are living; the need to minimise the distress on the family; include them as an individual with dementia in the decisions if possible; consult with professionals to reduce the emotional strain on family caregivers. Conclusions: Despite participants not considering discussions about end of life, they were keen to take part in this study. It is important to talk to people with dementia about end of life, highlighting the role and the decisions family caregivers have to make at the end of life may be a way to encourage discussions. These findings are contributing to the development of a decision aid to support family caregivers.