

Background: There are a range of symptoms and challenges at the end of life which someone with dementia and their family may face. Despite attempts to increase advance care planning, many people with dementia reach the end of life without a plan. This means decisions are often left to family caregivers. Aim: The aims of this study were 1) Explore what significant decisions family caregivers need to make when caring for someone with dementia at the end of life; 2) Understand how family caregivers make these decisions. This will inform the development of a decision aid to support family caregivers at the end of life. Methods: Semi-structured interviews were conducted with family caregivers (n=16) of someone with dementia at the end of life. Participants were recruited through general practice, memory services and an online research register. Interviews were analysed using thematic analysis. Results: Six main decisions were discussed by caregivers: 1) the best place of care and when was the right time to move; 2) managing agitation; 3) managing nutrition and hydration; 4) how to ensure the person is washed and bathed; 5) how do I know if something is wrong; 6) when to stop treatment or interventions. These decisions were broken down into a series of stages, with considerations at each stage. Each decision will be presented as a diagram. Caregivers discussed balancing the impact on their life with the effect on the person with dementia. Caregivers were often managing difficult family dynamics with conflicting views, or a lack of input from some members which impacted their decision making processes. Conclusion: The findings from this study are informing the development of a decision aid to support family caregivers of people with dementia at the end of life. Caregivers often make a series of decisions which they are unaware of. This study has highlighted the unconscious decision processes and considerations caregivers make when making these decisions.