

## **How do you measure the success of advance care planning and what should we now be focusing on?**

Advance care planning (ACP) in dementia has long been a hotly debated topic including what to do, how to do it and when (1). There has been much focus across research, policy and practice to increase the numbers of people living with dementia completing ACP as early as possible. Effectiveness of ACP in dementia has been mixed, with some evidence of association with reduction in hospitalisation and concordance between care received and prior wishes (2). The article from Bavelaar et al. highlights several other discursive points which are important to focus attention towards, including – the complexity of ACP, what is the role and importance of ACP; and how do you measure success. The challenge of measuring effectiveness has been something that researchers have struggled with whilst developing research projects around ACP and decisional support.

Thinking about ACP is often too simplistic, it should not be considered as a list of binary decisions about whether someone should go to hospital or not, a DNAR, or other types of advanced decisions to refuse treatment. Instead, ACP is a much more nuanced and intricate process of communication, where preferences and decisions change over time and need to be revisited. However, traditional outcome measurements in dementia ACP research have focussed on more system level outcomes such as hospitalisation, presence of advance decisions (i.e. DNAR), and place of death (2). Bavelaar et al's study reconceptualises ACP, with primary outcomes focussed on family centred measures such as decisional conflict and perceptions of care, moving the more traditional health care system outcomes to secondary. This is an important flip of focus on how the 'success' of ACP is conceptualised and is particularly relevant to those commissioning or governing health care services, or developing policy in this area.

We know that many people living with dementia reach the end of life without an ACP and do not always want to participate in discussions about their future, and this should be respected. We also know family carers often feel emotionally unprepared for end of life, they struggle with difficult decisions, feeling responsible and experience guilt (3, 4). Family carers are often less concerned with decisions such as DNAR and more about everyday support and wellbeing (5, 6). Bavelaar et al's study demonstrates the increasing momentum in research to consider decisional support for families in the later stages of dementia, and focussing on outcomes to demonstrate the support for them (7, 8). This research demonstrates early ACP is not always essential, but it is important to consider decisional support for family members when acting as proxy.

There needs to be a shift in attention from how we get everyone to do ACP as early as possible (i.e. around diagnosis), to consider how can discussions and decision making be supported in the later stages of dementia. However, we should not abandon the importance of early ACP altogether. This implementation study joins a growing body of resources which is supporting this shift, with resources to support families and professionals making decisions towards the end of life (6, 9-11). It is crucial that ACP and shared decision-making practice and research focusses on communication strategies and styles to ensure effective planning and decision making. It is

equally important to consider communication strategies and approaches to meaningfully engaging the person living with dementia too, even when they do not have capacity or may have limited communication abilities. This will ensure we empower people living with dementia and family carers right through to the end of life.

To get anything to change in practice and policy we need to ensure we consider implementation of planning and support (12). Dementia research has historically neglected implementation, however this is changing with the increasing presence of implementation science across the field of older adults and dementia care, and specifically within decisional support (13).

Van den Block (2019) states we need to consider the importance of how to do ACP, for example how to initiate conversations, how to deliver prognosis etc. with previous research focussed on 'the what', for example defining topics and themes of ACP conversations (1). Whilst many people would agree with this, we must not forget 'the what' that goes into ACP is not simply binary decisions, but instead as I state complex, nuanced and intricate discussions and decisions.

1. Van den Block L. Advancing research on advance care planning in dementia. *Palliative Medicine*. 2019;33(3):259-61.
2. Wendrich-van Dael A, Bunn F, Lynch J, Pivodic L, Van den Block L, Goodman C. Advance care planning for people living with dementia: An umbrella review of effectiveness and experiences. *International Journal of Nursing Studies*. 2020;107:103576.
3. Fisher E, Crawley S, Sampson EL, Cooper C, Jones R, Anantapong K, et al. Practical and emotional preparation for death: A mixed methods study investigating experiences of family carers of people with dementia. *Dementia*. 2022;21(3):934-56.
4. Lamahewa K, Mathew R, Iliffe S, Wilcock J, Manthorpe J, Sampson EL, et al. A qualitative study exploring the difficulties influencing decision making at the end of life for people with dementia. *Health Expectations*. 2018;21(1):118-27.
5. Davies N, De Souza T, Rait G, Meehan J, Sampson EL. Developing an applied model for making decisions towards the end of life about care for someone with dementia. *PLoS ONE*. 2021.
6. Davies N, Sampson EL, West E, De Souza T, Manthorpe J, Moore K, et al. A decision aid to support family carers of people living with dementia towards the end of life: Co-production process, outcome and reflections. *Health Expectations* 2021.
7. Davies N, Schiowitz B, Rait G, Vickerstaff V, Sampson EL. Decision aids to support decision making in dementia care: A systematic review. *International Psychogeriatrics*. 2019;31(10):1403-19.
8. Geddis-Regan A, Errington L, Abley C, Wassall R, Exley C, Thomson R. Enhancing shared and surrogate decision making for people living with dementia: A systematic review of the effectiveness of interventions. *Health Expectations*. 2020;n/a(n/a).
9. Davies N, Aker N, Vickerstaff V, Sampson EL, Rait G. A feasibility study of a decision aid to support family carers of people with severe dementia or those towards the end-of-life. *Palliative Medicine*. 2022:02692163221122379.
10. Davies N, Manthorpe J, Sampson EL, Lamahewa K, Wilcock J, Mathew R, et al. Guiding practitioners through end of life care for people with dementia: The use of heuristics. *PLOS ONE*. 2018;13(11):e0206422.

11. Anantapong K, Bruun A, Walford A, Smith CH, Manthorpe J, Sampson EL, et al. Co-design development of a decision guide on eating and drinking for people with severe dementia during acute hospital admissions. *Health Expectations*. 2022.
12. Dixon J, Karagiannidou M, Knapp M. The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their carers: a systematic review and critical discussion. *Journal of pain and symptom management*. 2018;55(1):132-50. e1.
13. Gillam J, Davies N, Aworinde J, Yorganci E, Anderson JE, Evans C. Implementation of eHealth to support assessment and decision-making for residents with dementia in long-term care: systematic review (Pre-print). *JMIR*. 2021;24(2):e29837.