Research focus

Advance care planning for people with dementia

Advance care planning (ACP) provides a framework for discussing and documenting care preferences in preparation for situations in which a person loses the cognitive capacity to make decisions. It can be particularly valuable in assisting people in the early stages of living with a dementia, supported by their families, to document their preferences for care at the later stages of their illness. While the potential benefits of ACP are widely acknowledged, there remain gaps in the research evidence on ACP and challenges in implementing ACP in practice. The three recently-published studies described below address these issues.

Advance care planning for nursing home residents with dementia: policy vs. practice

Despite the potential benefits of ACP for nursing home residents with dementia, the authors of this study highlight that hardly any research has focused on the involvement of residents/families in ACP and that ACP is rarely realised for these people. Their research aimed to evaluate the ACP policy for people with dementia in nursing homes and to gain insight into the involvement of residents with dementia and their families in ACP.

In this observational cross-sectional study of 20 nursing homes in Belgium, an audit assessed the views of the nursing homes’ staff on the ACP policy. In addition, individual conversations were analysed with ‘ACP criteria’ (realisation of ACP) and the ‘OPTION’ instrument (involvement of residents/families). The findings identified that the nursing homes generally met three quarters of the pre-defined criteria for ACP policy.

ACP was explained and substantively discussed in almost half of the conversations but, generally, healthcare professionals only managed to involve residents/families on a baseline skill level. There were no statistically significant correlations between policy and practice. The authors conclude that the evaluations of the policy are promising, but the actual practice of implementing ACP needs improvement. They recommend further assessment of policy and practice of ACP is required to improve consistency in practice. In addition, integration between gerontology and palliative care and synthesising the existing evidence will allow for further understanding of the key issues, potentially resulting in improved implementation in practice.


Uptake of a newly implemented advance care planning program in a dementia diagnostic service

Through a three-stage project in a specialist memory clinic in Australia, researchers introduced ACP to clients with mild cognitive impairment or recently diagnosed dementia and their families. Clients and carers were initially posted a survey assessing completed documentation for future care, understanding of the principles of ACP and willingness to receive further information. Those wanting more information were invited to a seminar introducing the ACP programme and service. Participants wanting to complete ACP documentation could make an appointment with the ACP clinicians.

The researchers found that, despite initial interest, ACP completion was low. They suggest this was possibly because clients and carers felt their current planning was sufficient or possibly because they were still contemplating plans and thus unready to document them. The short timeframe of study was deemed a likely reason for the low follow up in that participants did not have time to understand the principles and practical aspects of ACP to complete the documentation. The authors recommend introducing ACP to people over time to allow for full explanation, full consideration and ongoing discussion.


Research focus was compiled by Hazel Heath, independent nurse consultant.