

## 5.2 ACP in Patients with Dementia

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### Understanding advance care planning for people living with dementia: a review of reviews

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**Background:** Worldwide, every three seconds someone develops dementia. Dementia is a terminal condition. Therefore, communication about future care preferences (advance care planning, ACP) is important for people with dementia (PwD) and their network. This review of reviews aims to synthesize the evidence on ACP for PwD and their carers.

**Methods:** PubMed, CINAHL Plus, SCOPUS, SocialCareOnline and Cochrane Library, were systematically searched for systematic reviews in July 2018. After tabulation of primary research, PubMed, CINAHL Plus and SCOPUS were searched for additional recent primary research articles in September. Methodological quality was assessed using AMSTAR-2 and the Joanna Briggs Institute instruments. Overarching themes were identified.

**Results:** 19 reviews and 10 primary research articles met the inclusion criteria. Methodological quality was variable. Preliminary analysis suggests that ACP interventions led to increased ACP documentation, an increase in PwD dying in their preferred place and a decrease in hospitalisations. Qualitative data showed that the ACP process can be experienced as stressful, but is also perceived as relevant by PwD and carers. Lack of knowledge about ACP and dementia were barriers to ACP use for all parties involved. Facilitators for ACP were; education to improve healthcare professionals' communication skills and legal and ethical knowledge; education for PwD and carers about the ACP process, the differences between palliative and terminal care and the dementia disease trajectory.

**Conclusion:** ACP interventions have shown to be effective on health utilization outcomes, however education for all parties involved is key to optimize the ACP process for PwD and their carers.

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### Use of Advance care directives for individuals with dementia living in residential accommodation: A descriptive survey

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**Background:** End-of-life decision-making for individuals with dementia needs to be addressed because as dementia progresses, their capacity to make decisions about their health care, living arrangements and end-of-life care changes. Advance care directives (ACDs) provide an opportunity for individuals with dementia to communicate their wishes, about these important issues.

**Aim:** The aim of this study was to understand how Australian registered nurses (RNs) use ACDs for individuals with dementia living in residential aged accommodation.

**Methods:** Two hundred and thirty eight RNs working in Australian residential aged care accommodation were recruited via social media, professional organisations and organisations providing residential accommodation. Respondents completed an online survey delivered via Survey Monkey.

**Findings:** 59.7% of respondents reported commencing discussions around ACDs within the first month of individuals living with a dementia relocating to residential accommodation. However, 42.4% never or rarely completed ACDs. Only 59.3% stated that ACDs for individuals with dementia were always or often regularly reviewed. 53.8% identified that ACDs were always adhered to when an individual's circumstances changed. 62.6% felt that understanding amongst families about ACDs was sometimes, or often, a barrier to using ACDs.

**Conclusion:** The implementation of ACDs in Australian residential accommodation for those living with dementia remains sub-optimal. The study has demonstrated that ACD documentation and policies describing how they should be used exist; but gaps remain around the practical implementation of ACDs. Strategies to promote communication and collaboration between residential facilities, general practitioners and carers/families could also assist in providing cohesive, high quality care.

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### Trials and tribulations of implementing ACP in dementia care

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**Background:** Although loss of decision-making capacity forms part of the expected trajectory of dementia progression, advance care planning (ACP) is not routine in dementia care.

**Methods:** Dementia-specific ACP intervention piloted with 20-30 patient-relative dyads in the context of a university memory clinic in French-speaking Switzerland. Recruiting patients with early dementia and preserved decisional capacity and piloting this intervention unveiled unforeseen obstacles. We want to present these obstacles and discuss potential strategies in order to advance ACP research internationally.

**Results:** Concern that ACP may cause distress to patients and their families was evidenced by the fact that the research ethics committee required formal consent of the patients' primary care physicians as well as an emergency response plan to address distress emerging during ACP. Care professionals in the memory clinic showed substantial gatekeeping, based on a reluctance to inform patients and families about the dementia course and complications and on skepticism about the ethical justification of ACP. The distinction between ACP and traditional advance directives is also unclear to many health professionals who therefore do not see the benefit of ACP. Despite these barriers, people with dementia and their relatives report relief after ACP conversations they had and were satisfied with the tool.

**Conclusion:** Paternalism and misconceptions among healthcare providers have the power to impede research and implementation of ACP. There is an urgent need to increase healthcare providers' awareness and knowledge of ACP in French-speaking Switzerland. Working with patient advocacy groups offers opportunities to promote ACP in dementia care.

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### **Advance care planning by proxy for elderly people without decision-making capacity**

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**Background:** Advance care planning (ACP) as commonly understood requires decision-making capacity (DMC). When people lose DMC proxies are called upon to make surrogate decisions. *ACP by proxy* is an extension of classic ACP that specifically promotes patient autonomy in this context. Little research focuses on how ACP by proxy is best conducted, and most ACP research in nursing homes has excluded residents without DMC. Our project aims to identify current proxy planning practices, difficulties and needs, and to explore how ACP by proxy can be implemented in nursing homes in Switzerland.

**Methods:** We present the results of five focus groups; one with physicians of nursing home residents and four with health professionals involved in planning processes in nursing homes in French-speaking Switzerland. Focus groups were audio-recorded and transcribed verbatim. Themes important to the concepts of 'current practice', 'difficulties' and 'future needs' were identified through thematic analysis.

**Results:** Current practices: communication between health professionals, residents, and family, use of advance directives for documentation and as conversation starters, and a variety of systems for recording information. Difficulties: 'timing' of communication with families, interpersonal conflicts, roles of family members, hesitancy talking about end of life care and transfer of information. Future needs: documentation, conversation guides and decision aids specifically adapted for ACP by proxy.

**Conclusions:** The identification of specific needs for ACP by proxy can inform the adaptation of existent tools to facilitate ACP by proxy in nursing homes and therefore promote care in accordance with the presumed wishes of residents without DMC.