

Dementia and Advanced Care Planning: whose responsibility is it?

“ Where say you have cancer or severe COPD or heart failure often patients will know themselves they are deteriorating because there is almost subjective evidence, but you don't have that in dementia you kind of lose that. ” - GP

“ If you talk about DNARs and stuff like that, they may forget they've had that discussion...it can be very scary and alarming for them what's this form in my house if they can't remember having that discussion. ” - GP

“ Palliative care is big part of our role and we should be in a good position to get involved and start ACP. ”
- District Nurse

Intro

Advanced Care Planning (ACP) is instrumental in ensuring a patient with dementia has the right end of life care and support in place. Yet, professionals are unclear as to who is best placed to undertake such a complex and sensitive process, meaning conversations around ACP are considered far too late or not at all.

Aim

To explore which professionals are best placed to take responsibility for ACP with patients with dementia.

Methodology

The study embraced a qualitative research method to explore how individual roles, working environments and personal beliefs relate to the reality of applying ACP in practice.

Data was collected via face-to-face semi-structured interviews with open ended questions. Participants included 11 healthcare professionals from the community setting.

Results/findings

- ACP with dementia patients was considered important but not routinely part of practice. Instead, reactive care planning in the more advanced and problematic stages of the illness tended to happen.
- National guidelines are difficult to achieve, given the diversity of professionals involved with dementia patients and the prolonged unpredictable trajectory.
- The Gold Standard Framework is not used as effectively as it could be.
- Barriers to ACP include lack of confidence, insufficient training, limited knowledge, inconsistent documentation and a pressured workload.
- Professionals are reluctant to embrace ACP for fear of causing distress, removing hope and feeling uncertain that wishes won't be able to be upheld.
- Whilst palliative care specialists and district nurses seem the most appropriate professionals in terms of time, focus, documentation and resources, they are unlikely to be involved in the care of the patient at the best time to facilitate effective ACP.
- A role that combines palliative care and dementia expertise could benefit patients, but this may be difficult to fund in the current economic climate.
- Admiral Nurses are unlikely to embrace all elements of ACP, with their main focus being on advance power of attorneys.
- There is a reluctance to talk about death and dying in society.

Conclusion

There is no conclusive answer that highlights one group of professionals as being best placed to exclusively take on this role. There is, however, a need to empower and encourage all professionals to engage in ACP with patients with dementia. This can be achieved by:

- Encouraging professionals, in particular GPs, to become more responsive to the concept of ACP.
- Utilising the Gold Standard Framework more appropriately to support patients with dementia.
- Better collaboration between dementia and palliative care specialists, to promote more effective multi-disciplinary working.
- Talking about death and dying more as a society, to help empower the general public.