



Older people's views on advance care planning

A survey in the east midlands found that only 5% of people aged 65 years or older had been offered an opportunity to talk about advance care planning by a health or social care professional, although around a third said they would be interested in discussing the topic.

Overview:

- A survey of people aged 65 years or older in the east midlands found that only 5% respondents said that they had been offered an opportunity to talk about advance care planning by a health or social care professional.
- Around a third of respondents said they would be interested in attending sessions on advance care planning or discussing the topic with their GP.
- Health and social care professionals should encourage people to make plans about their future care, even if only informally with their families.
- Informal conversations within families need to be supported by lasting powers of attorney to give them a legal basis.



Background: Advance care planning is a voluntary discussion about future care between an individual and their care providers ([End of Life Care Programme 2007](#)). The process aims to make clear a person's wishes and will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others.

Advance care planning should be documented, potentially as an advance statement of preferences, an advance decision to refuse treatments (ADRT) or both. Lasting powers of attorney or proxy decision-making are alternative forms of advance care planning.

A 2012 survey of adults in Britain found that only 5% of people had an advance care plan or 'living will', rising to 12% among people aged 75 years and older ([Shucksmith et al. 2013](#)).

Current advice: The [Gold Standards Framework](#) for end of life care encourages doctors, nurses and care assistants to talk to people about how and where they want to be cared for at the earliest and

most appropriate time. The process of advance care planning should help people approaching the end of their life to describe and clarify:

- What they want to happen
- What they don't want to happen
- Who will speak for them

All people should be given the chance to clarify their wishes, needs and preferences for the kind of care they would like to receive in advance statements of preferences.

The NICE guideline on [care of dying adults in the last days of life](#) recommends that if it is thought that a person may be entering the last days of life, information should be gathered and documented on the person's goals and wishes and the views of those important to the person about future care.

Health and social care professionals should explore with the dying person and those important to them whether the dying person has an advance statement or has stated preferences about their care in the last days of life (including any anticipatory prescribing decisions or an ADRT or details of any legal lasting power of attorney for health and welfare).

New evidence: [Musa et al. \(2015\)](#) conducted a survey of older people in England to assess their attitudes towards advance care planning.

A survey was developed with help from focus groups of older people and guidance from an expert advisory team. This survey was provided to 13 general practices in Leicestershire and Nottinghamshire, who posted the survey to 5375 people aged 65 or older who lived in the community.

A total of 1832 (34%) people returned the survey. The median age of respondents was 73 years, and just over half (59%) were women. Overall, 308 (17%) people had taken part in some type of formal advance care planning: 231 (13%) respondents had prepared an advance statement of preferences and 77 (4%) had made an ADRT.

Only 5% respondents said that they had been offered an opportunity to talk about advance care planning by a health or social care professional. A total of 12% of respondents said they had approached someone to talk about advance care planning. Of these people, less than a quarter (23%) had discussed their plans with a health or social care professional and the majority (73%) had discussions with friends or family. Most (85%) people said they would rather discuss decisions informally than write them down.

A third of respondents (33%) said they would be interested in attending sessions on advance care planning if they were available. A similar proportion (36%) said they would be interested in talking about advance care planning with their GP at an annual check-up.

Strengths of this study include the robust development of the survey items and the diverse socioeconomic status of the population. However, the response rate was low, and most respondents were white and of Christian faith, so the findings may not be generalisable to other populations.

Commentary by Dr Julian C Hughes, Consultant in Old Age Psychiatry and Honorary Professor of Philosophy of Ageing, Northumbria Healthcare NHS Foundation Trust:

"This research by Musa et al. (2015) helps to solidify the evidence that relatively few people actually engage in advance care planning, unless they have had a discussion with their GP. Lack of access to professionals, therefore, is a barrier to advance care planning, as is the feeling that advance care plans may not be followed in practice.

"The design of the survey used was robust, but the response rate was only 34%. Crucially, the authors did not report the characteristics of the non-responders. Intuitively, those who responded may have been more motivated and likely to participate in advance care planning. Hence, the study could be further evidence that the level of participation in advance care planning remains

very low: it is not yet the panacea some have hoped it would be.

“Some existing research has looked at advance care planning in people with cognitive impairment, where there is scanty evidence to support its effectiveness ([Robinson et al. 2012](#)). In dementia, there are professional barriers to the implementation of advance care planning ([Robinson et al. 2013](#)) and some specific concerns in this group; for example, about the timing.

“Nevertheless some barriers to advance care planning in people with dementia are the same as in people who do not have dementia; for example, a preference for informal discussions ([Dickinson et al. 2013](#)). Dickinson et al. (2013) suggested that health and social care professionals might help in informal planning. Repeated discussions over time are likely to be effective, even if brief, rather than passively giving people information sheets or attempting to give all the information in one meeting ([Tamayo-Velázquez et al. 2009](#)).

“This research by Musa et al. (2015) is a laudable attempt to explore public attitudes to advance care planning. The most interesting finding is the continuing preference for informal discussions within families. Perhaps, therefore, the focus of policy should be on encouraging the appointment of proxy decision-makers; for example, using lasting powers of attorney in England and Wales. As suggested in the Nuffield Council on Bioethics report, [Dementia: Ethical Issues](#), proxy decision-making may be a safer way than ADRTs to ensure the person's wishes, beliefs and values are honoured.”

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