

ESSENCE SUMMARY 10

Advance care planning: economic evidence

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BACKGROUND

Around 2 million people in England and Wales may lack the capacity to make certain decisions for themselves at some point in their life because of illness, injury or disability. Most of us will lose our capacity to make or communicate decisions at some point towards the end of life. The National Institute of Health and Care Excellence (NICE) recommends advance care planning for the future

care and support needs of individuals at risk of either losing capacity or who have fluctuating capacity. The Mental Capacity Act of 2005 legally supports advance care planning as an important end of life intervention. Despite these trends and policy movements, many localities in England have as low as 4% of the general population with advanced care plans completed.

KEY POINTS

- Advance care planning is an important end of life care intervention that helps people at risk of losing their mental capacity or their ability to communicate plan for their future care and support needs, including medical treatment.
- It helps people get the treatment they want during the final stage of their life and increases their chance to die in their preferred place of death. It benefits the mental health of the person caring for them.
- Advance care planning is likely to be cost-effective. This is due to improvements in carer's quality of life, reductions in the use of aggressive life-sustaining treatment and more people dying at their place of residence rather than in hospitals.
- Future research needs to address gaps in implementation knowledge of advance care planning.
- Implementing advance care planning effectively is challenging and requires substantial organisation and system-wide changes.

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CONTEXT

In England, advance care planning is legally supported by the Mental Capacity Act of 2005 (1) and recommended in guidance by the National Institute of Health and Care Excellence* (NICE) (2). Offering advance care planning to people can be an important part of high-quality end of life care (3–5). The intervention aims to involve people in decisions about their treatment and care when they reach end of life, including their preferred place of death. In practice, there are many implementation challenges that prevent people from being offered advance care planning. Additionally, uptake of advance care planning is in

many areas as low as 4% of the general population (6). Economic evidence on whether advance care planning is good value for money (particularly from a government perspective) might help decision-makers when planning investments in this area.

This case summary presents such evidence. It includes evidence from literature reviews and an economic modelling study (7) carried out for the NICE guideline (2) on this topic, which informed their recommendations supporting the roll-out of the intervention.

WHAT IS ADVANCE CARE PLANNING?

Advance care planning involves ‘discussing and recording patient preferences concerning goals of care for patients who may lose capacity or communication ability in the future’ (8, 9).

The main goal of advance care planning is to clarify peoples’ wishes, needs and preferences towards end of life, in particular regarding treatment and place of death.

According to NICE, advance care planning should be a voluntary process and include the person’s family and friends according to their wishes (2). Furthermore, if the person agrees, discussions should be documented, regularly reviewed and communicated to key persons involved in the person’s care.

The process may lead to:

- Advance decision to refuse treatment and a do not attempt cardiopulmonary resuscitation decision;
- The appointment of a lasting power of attorney, who can make decisions if the person loses their capacity;
- Advance statements for particular preferences of treatment and support - different from advance decisions those are NOT legally binding.

According to NICE, there are two kinds of advance care planning: general and targeted (2). In contrast to general advanced care planning, targeted advance care planning concerns specific populations. As such, it should be provided with a comprehensive understanding of the relevant condition (2).

* www.nice.org.uk

IS ADVANCE CARE PLANNING EFFECTIVE?

Since advance care planning is a complex intervention, its effectiveness depends on many contextual factors and person's characteristics. These include the availability of care services and support available in the community, people's understanding, attitudes and behaviours and service response to advance statements (10).

If carried out in the way recommended by NICE, advance care planning can increase compliance with a person's wishes in regards to treatment and care, and also place of care (2). For example, people with advance care planning are less likely to receive cardio-pulmonary resuscitation

inappropriately. They are also less likely to use life-prolonging treatment such as chemotherapy, assisted ventilation, or dialysis (11-14).

Additionally, people with advanced care planning are more likely to die in their preferred place of death, typically their usual place of residence (8, 10, 15, 16, 17). Advance care planning can also have a positive impact on people dying, such as an improved experience of death (as reported by carers) and better symptom control. In addition, carers of people dying with advance care planning report greater satisfaction with services and improved mental health (17, 8).

WHAT DO PEOPLE SAY ABOUT ADVANCE CARE PLANNING?

Advance care planning can be a very challenging process for people. Nevertheless, most people say they want the opportunity to discuss their preferences for treatment and care as they reach the end of life (18–20). Furthermore, many service users and family carers experience advance care planning as a relevant and useful experience that increases their feeling of autonomy and control over their own life and death (18, 19, 21).

Despite the positive views and experiences of carers and service users, practitioners feel more ambivalent about providing advance care planning. Many reasons for this include lack of time, knowledge and skills; not feeling responsible; attitudes and emotions such as fears of talking about dying (18, 21, 22). Practitioners are also more sceptical about positive outcomes for people because they are unable to guarantee that expressed wishes and preferences can be followed (23).

IS ADVANCE CARE PLANNING COST-EFFECTIVE?

One systematic review by Dixon et al. (2015) identified 18 studies predominantly from the US (24). Among these studies, there were indications of cost savings with advance care planning, which primarily referred to reductions in hospital use. The savings (reported in US dollars) ranged from \$64,827 for the terminal hospital stay to \$56,700 for total healthcare costs over the past 6 months for people living with dementia. There were also \$1,041 savings in hospital costs over the last week of life for people with cancer.

An economic study from England found that individuals in a hospice setting who used advance care planning spent considerably less time (about eight days) in the hospital in their last year of life (15). The study also showed that the mean cost of hospital treatment during the last year of life for those who died in hospital were higher than those dying outside of hospital (£11,299 vs £7,730). This finding also indicated potential cost savings linked to advance care planning.

Additional economic modelling was carried out for the NICE guideline (7). Findings showed that advance care planning was likely to be cost-effective. Total costs to the NHS and social care were £3,748 for those in the advance care planning group and £3,072 in the standard care group. On average, the advanced care planning group had more quality-adjusted life years compared to the standard care group (0.82 vs 0.79). Outcomes were measured in terms of quality-adjusted life years gained from the perspective of the person caring for the person dying. Costs of delivering the intervention ranged between £214 and £1,874, with average costs amounting to £821. Overall, the study indicated

that probabilities that advance care planning was cost-effective compared to standard care ranged between 55% and 80%. The mean incremental cost-effectiveness ratio of advance care planning was £22,533 per quality adjusted life year, just above the lower threshold that NICE uses when making its recommendations. Sensitivity analyses examined the effect of decreasing the average duration of advance care planning discussions. If the discussions were reduced to 2 hours instead of 4 hours, the incremental cost-effectiveness ratio decreased to under £9,000 per quality-adjusted life year. As such, the probabilities that advance care planning would be cost-effective increased to just under 100%.

WHAT IS THE QUALITY OF EVIDENCE ON ADVANCE CARE PLANNING?

So far, there has been no study that evaluated the cost-effectiveness of advance care planning using primary data. The only cost-effectiveness evidence is from the modelling study presented here (7). However, modelling studies have their own limitations. In particular, this modelling study only includes outcomes to carers and not the person dying. Furthermore, effects on those were derived from one small randomised controlled trial in Australia. Sensitivity analysis was carried out to understand the impact of different assumptions regarding this outcome on the findings. Nonetheless, findings need to be interpreted with a level of caution.

Another issue with the evidence is that most of the economic evidence presented in the systematic review by Dixon et al. (2015 (24)) referred to cost savings studies from the US. This makes it challenging to apply to England since spending on end of life is generally considerably lower in the US. However, studies found that the potential cost reductions linked to advance care planning are stronger in higher spending areas (25). This could suggest that effects in England are even stronger compared to the US since spending is higher. Overall, economic studies identified in the review had a limited cost

perspective. This means that they tended to include only hospital costs rather than costs in the community or costs incurred by people participating in advance care planning.

How is advance care planning implemented?

NICE recommends offering advance care planning to everyone at risk of losing capacity (e.g. through progressive illness), and those who have fluctuating capacity (e.g. through mental illness) (2). It also recommends providing information on advance care planning so that individuals can make informed decisions as to whether they want to participate in it (2). Additionally, they provide details about how this should be done and by whom (2).

NICE also sets out a number of recommendations to commissioners and provider organisations to ensure that advance care planning is implemented at an organisational level (2). For example, they recommend the development of standard protocols and plans for joint working and sharing of information on advance care plans between practitioners, people and families. They also recommend training on advance care planning, while emphasising that protocols and plans reflect the optional nature of advance care planning.

OTHER INFORMATION

Reference to main study referred in summary: Bauer A and Knapp M (2018) Decision making and mental capacity, Appendix C3: Economic report. National Institute for Health and Care Excellence.

REFERENCES

1. Social Care Institute for Excellence (2016) Mental Health Capacity Act 2005 at a glance. Social Care Institute for Excellence.
2. National Institute for Health and Care Excellence (2018) Decision-making and mental capacity. NICE Guideline [NG108].
3. Carr D and Luth EA (2017). Advance Care Planning: Contemporary Issues and Future Directions. *Innovation in Aging*, 1(1).
4. Department of Health, L. (2015). End of life care strategy: promoting high quality care for adults at the end of their life. London: Department of Health and Social Care.
5. Mullick A, Martin J, Sallnow L (2013) An introduction to advance care planning in practice, *BMJ*; 347: f6064doi: 10.1136/bmj.f606.
6. Kitzinger J and Kitzinger CK (2016) Increasing understanding and uptake of advance 27 decisions in Wales. Public Policy Institute for Wales.
7. Bauer A and Knapp M (2018) Decision making and mental capacity, Appendix C3: Economic report. National Institute for Health and Care Excellence.
8. Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A (2014) The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med*. 28:1000–1025.
9. Seymour J, Almack K, Kennedy S (2010) Implementing advance care planning: a 10 qualitative study of community nurses' views and experiences. *BMC Palliat Care*. 9: 4.
10. Dixon J, King D, Knapp M (2016) Advance care planning in England: Is there an association 27 with place of death? Secondary analysis of data from the National Survey of Bereaved 28 People. *BMJ Supportive & Palliative Care* Published Online First: 0:1–10.
11. Zhang B, Wright AA, Huskamp HA, et al (2009) Health care costs in the last week of life: 22 associations with end-of-life conversations. *Arch Intern Med*. 169:480–488.
12. Wright AA, Zhang B, Ray A, et al (2008) Associations between end of life discussions, 18 patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 300:1665–1673.
13. Kirchhoff KT, Hammes BJ, Kehl KA et al. (2012) Impact of a Disease-Specific Advance Care Planning Intervention on End-of-life Care, *J Am Geriatr Soc* 60(5), 946–950.
14. NCEPOD (2012), Time to intervene? A review of patients who underwent cardiopulmonary resuscitation as a result of an in-hospital cardiorespiratory arrest. A report by the National Confidential Enquiry into Patient Outcome and Death (2012).
15. Abel J, Pring A, Rich A, Malik T, Verne J (2013) The impact of advance care planning of place of death, a hospice retrospective cohort study. *BMJ Supportive & Palliative Care* 3: 168–173.
16. Detering KM, Hancock AD, Reade MC, & Silvester W (2010). The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 340. doi:10.1136/bmj.c1345.

17. Hughes P, Bath P, Ahmed N, et al. (2009) What progress has been made towards implementing national guidance on end of life care? A national survey of UK general practices. *Palliative Medicine*, 24, 68–78.
18. Ashton S, Roe B, Jack B, et al (2014) End of life care: The experiences of advance care planning amongst family caregivers of people with advanced dementia – a qualitative study. *Dementia*. 15: 958–975.
19. Poppe M, Burleigh S, Banerjee S (2013) Qualitative Evaluation of Advance care planning in Early Dementia (ADVANCE CARE PLANNING-ED). *PLoS ONE* 8: e60412.
20. Sharp T, Moran E, Kuhn I, & Barclay S (2013) Do the elderly have a voice? Advance care planning discussions with frail and older individuals: a systematic literature review and narrative synthesis. *C. Br J Gen Pract*, 63(615):e657–68.
21. Bisson J, Hampton V, Rosser A et al (2009) Developing a care pathway for advance decisions and powers of attorney: qualitative study. *British Journal of Psychiatry*. 194: 55–6.
22. Wilson E, Seymour J, Perkins P (2010) Working with the Mental Capacity Act: findings from specialist palliative and neurological care settings. *Palliative Medicine*. 24: 396–402.
23. Robinson L, Dickinson C, Bamford C, et al (2013) A qualitative study: professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but ...' *Palliative Medicine* 25: 401–408.
24. Dixon J, Matosevic T, King D, et al (2015) The economic case for advance care planning: a systematic review. *Palliat Med*. 29:869–884.
25. Nicholas LH, Bynumm JP, Iwashynam TJ, et al (2014) Advance directives and nursing home 13 stays associated with less aggressive end of life care for patients with severe dementia. *14 Health Aff*. 33:667–674.

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