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CLINICAL REVIEW

An introduction to advance care planning in practice

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Advance care planning has been defined as a process of formal decision making that aims to help patients establish decisions about future care that take effect when they lose capacity.[1] It recently gained increased importance in the United Kingdom, after being recommended by the end of life care strategy.[2] The first national guidance for health and social care staff in the UK was produced in 2007 and revised in 2011.[3] Before this, terms and concepts used in the UK had included "living wills" and "advance directives," which have been replaced by terminology outlined in the national guidance and the Mental Capacity Act 2005.[4]

Advance care planning differs from general care planning in that it is usually used in the context of progressive illness and anticipated deterioration. This has implications for its acceptability to patients. It is a voluntary process and may result in a written record of a patient's wishes, which can be referred to by carers and health professionals in the future. If a patient loses capacity, health and social care professionals should make use of information gleaned from the advance care planning process to guide them in decision making when needed.

The Royal College of Physicians and other national organisations stress the need to avoid a document driven or "tick box" approach to this process,[5] and many authors advise focusing on communication rather than on specific interventions or outcomes.[6-8] The success of advance care planning should therefore not be defined on the basis of completed paperwork alone.[9]

This review aims to provide an overview of the potential benefits and risks of advance care planning, to summarise barriers to taking part in it, and to give practical guidance to health professionals on how to approach the process, with reference to the Mental Capacity Act 2005. Although this article is based on UK law and practice, we believe that the concepts and approaches discussed could be applied more widely. For example, both the Australian and American Medical Associations endorse similar concepts to those used in the UK.[10 11]

What are the benefits of advance care planning?

Theoretically, the process can facilitate patient autonomy so that patients' future wishes can be carried out once they can no longer decide for themselves,[1] but evidence regarding real benefit is mixed. A controlled trial of the impact of combining improved communication about resuscitation preferences with information on prognosis found no improvement in the quality of end of life care.[12] Other authors have suggested that the wider advance care planning process may also be ineffective in achieving positive outcomes.[13-16]

Conversely, some evidence, including that from a recent small systematic review in patients with dementia and cognitive impairment,[17] points to several possible benefits. These include less aggressive medical care and better quality of life near death, decreased rates of hospital admission, especially of care home residents, and increased rates of hospice admission,[18-20] with those having completed an advance care plan being more likely to receive care that is aligned with their wishes.[21 22] A UK retrospective study of 969 deceased hospice patients found that those who had completed such a plan (57%) spent less time in hospital in their last year of life. It also found that those who died outside of hospital had a lower mean hospital treatment cost than those who died in hospital.[23]

Advance care planning is also thought to help families prepare for the death of a loved one, to resolve family conflict, and to help with bereavement.[24 25] For example, a randomised controlled trial of facilitated advance care planning versus usual care in elderly patients in Australia showed that 86% of patients in the intervention arm had their end of life wishes known and respected compared with 30% in the control arm. The same study highlighted a greater level of satisfaction among patients and relatives in the intervention group. Family members of patients in the intervention group who died had lower levels of psychological morbidity.[25]

A systematic review published in 2008 examined evidence for improving palliative care at the end of life. It included 41 articles relating to advance care planning and found moderate evidence supporting multicomponent interventions to increase patient

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Summary points

- Advance care planning aims to help patients establish decisions about future care that take effect when they lose capacity
- Evidence for the benefit of advance care planning is mixed; more recent evidence suggests that it can facilitate the delivery of care more in keeping with patient wishes and increase patient and family satisfaction with care
- Advance care planning discussions should be centred around the beliefs, goals, and values of patients, rather than on specific outcomes or interventions
- A sound working knowledge of the Mental Capacity Act 2005 is important when facilitating advance care plan discussions

Sources and selection criteria

We searched Medline, Embase, and the *Cochrane Database of Systematic Reviews* using the search terms "advance care planning" and "advance directives", focusing on publications in the past five years, but including older papers that seemed relevant. Where possible we prioritised systematic reviews and controlled trials. We did not carry out a systematic review of the literature and studies are of variable quality, with many being small.

uptake of advance directives; however, these studies seldom measured clinically important outcomes. The paper also concluded that recent research supports an approach to care planning that engages values, involves skilled facilitators, and focuses on key decision makers (for example, patients, care givers, and providers).[26]

Patients can find the process itself helpful, particularly when discussion focuses on their goals, values, and beliefs, rather than on particular treatments or interventions.[25-28]

Patients report several reasons for wishing to make advance decisions, including not wanting to be a burden on others and concern for self,[27 29] with underlying specific issues relating to their personal experiences and fears.[29 30]

What are the risks and barriers to advance care planning?

Some patients will not wish to engage in discussions about future care because this involves thinking about a deterioration in their condition.[6-32] There may also be cultural sensitivities to such conversations. Self identified barriers to the process in one qualitative study of older medical patients included perceiving advance care planning as irrelevant, having insufficient information to engage in the discussions, and the time constraints of health professionals.[33] A further challenge is that the process asks patients to predict their future experience of illness, which some may find difficult.[34 35] However, a person's willingness to engage in the conversation may change over time, so it may be appropriate to re-offer discussions at a later stage.

Equally, barriers may exist for professionals[31-37]; in particular, doctors may be unwilling to initiate such discussions, because this may "bring death into full view."[6] Some may fear that honesty about prognosis will cause patients undue distress or destroy their hope.[6 38] However, although caution in discussion is obviously needed, a longitudinal qualitative study found that patients have a variety of responses to, on the one hand, wanting support for hope and, on the other, wanting honest prognostic information; responses included being able to hope for things other than cure.[38] This accords with our experience—some degree of emotional upset may occur, but it is usually appropriate to the situation, and most patients who accept the offer of a discussion for advance care planning find such conversations empowering.

Some patients think that professionals should raise the matter,[39] so if we do not do this their needs may remain unmet. Being in a trusting relationship with patients,[24] or being able to develop such a relationship,[40] is helpful in this context.

How can we initiate discussions?

Advance care planning can apply to patients with a wide range of diagnoses, but particularly those with long term conditions or receiving end of life care.[5] It should be offered when the patient is still well enough to participate in the discussions and before any relevant loss of mental capacity.[5 41] This can mean that for certain conditions, such as dementia, discussions may have to be offered early in the course of disease. One UK systematic review found that a maximum of 36% of patients with cognitive impairment and dementia being admitted to a nursing home had capacity to participate in advance care planning.[17] However, data on the best timing of advance care planning discussions in patients with dementia are conflicting. One recent qualitative study suggested that patients with mild dementia find such discussions acceptable,[42] but another found that people with dementia had difficulty considering their future selves.[35]

More generally, some studies have identified particular triggers for initiating these conversations, such as recurrence of cancer.[6] The timing of conversations with patients with non-cancer conditions, such as chronic obstructive pulmonary disease, may also prove challenging. This disease is often not perceived to be terminal and therefore not relevant to the principles of advance care planning.[36] This reflects the nature of chronic conditions in which disease can be stable and well managed for many years, before moving on to the terminal phase. However, because sudden changes in condition can occur, the opportunity to take part in advance care planning could be missed if the subject is not broached early on.

Another crucial factor is the communication skills of health professionals. A number of authors recognise the potentially challenging, sensitive, and complex nature of conversations about advance care planning,[13 43] with others recommending that practitioners need specific training.[5-44] One component of such highly skilled communication is knowing when not to proceed with discussions—for example, when doing so might cause disproportionate levels of distress[5]—and how to "titrate" information over time.

Box 1 includes a list of suggested triggers for initiating or reviewing such discussions.

Practical approaches to communication

When preparing to offer discussions it may be useful to consider the following:

- Patients may need time to think and reflect, so the initial advance care planning process may extend over several conversations.[5 6] One study found that the process took a median of 60 minutes over one to three conversations[25]

Box 1 Triggers for initiating or reviewing advance care planning discussions

There is no agreed standard frequency with which to review these discussions, so the interval should be based on patients' wishes, taking into account their clinical condition.

Triggers include:

- Patient initiates the conversation
- Diagnosis of a progressive life limiting illness
- The diagnosis of a condition with a predictable trajectory, which is likely to result in a loss of capacity, such as dementia or motor neurone disease
- A change or deterioration in condition
- Change in a patient's personal circumstances, such as moving into a care home or loss of a family member
- Routine clinical review of the patient, such as clinic appointments or home visits
- When the previously agreed review interval elapses

- Ensure that any outcomes of these discussions are appropriately shared among relevant teams and organisations,[26 45] and updated if decisions change
- Avoid giving the impression that it is possible to anticipate and plan for every eventuality[13]
- Do not assume that other health or social care professionals have offered opportunities for such discussions[36 37]
- Discussions that take place in the patient's wider family or social network may give rise to conflict, which is best dealt with early, to avoid conflict coming to light when the patient has lost capacity or died.[24]

Mahon suggests two questions that may be useful for initiating an advance care planning discussion that focuses on the patient's goals:

1) If you cannot, or choose not to, participate in healthcare decisions with whom should we speak?

2) If you cannot, or choose not to, participate in decision making what should we consider when making decisions about your care?[8]

For some patients answering question 1 may be as far as they wish to take such a discussion, and hopefully this question can be asked without causing patients undue anxiety. Box 2 outlines our communication suggestions.

How does advance care planning fit with the Mental Capacity Act 2005?

As well as knowing about a patient's disease and its likely consequences,[5] an adequate understanding of the law (including capacity assessment), the advance care planning process, and the related documentation is necessary.[9 48] However, two UK studies have shown that some professionals have a limited understanding of advance care planning,[44 49] with the authors of one suggesting that those with specialist skills in particular diseases may be better placed to undertake more complex aspects of the process.[44] This section serves as a brief introduction to some of the key legal problems.

The Mental Capacity Act 2005 legislates for England and Wales on the way in which decisions are made by, and on behalf of, people with impaired mental capacity.[4] It sets out five principles and a legal framework designed to protect patients with impaired capacity and their carers, who have to make decisions about their care and treatment. It is accompanied by the Mental Capacity Act 2005 code of practice, and practitioners have a legal duty to have regard to this.[50] Abiding by a person's wishes about a health related advance decision comes into effect only once the person has lost capacity to make that particular decision.

Mental capacity

People are assumed to have capacity unless it is established that they lack capacity despite all practicable steps taken to help them make the decision in question (see box 3 for the mental capacity assessment).

Best interests

Section 4 of the act deals with making decisions in accordance with the best interests of the person lacking capacity and specifies an initial checklist of common factors that must always be considered. It states that whoever determines what is in someone's best interests must consider, so far as is reasonably ascertainable, the person's past and present wishes and feelings, particularly any relevant written statement made when he or she had capacity,[4] thus giving "weight" to the advance care planning process.

What are the potential outcomes of an advance care planning discussion?

In addition to documents recording a person's preferred place of care or death, advance care planning has three main tools—advance statements, advance decisions to refuse treatment, and lasting powers of attorney.

Advance statements

These are statements about what the patient would or would not want to happen in the future, their goals of care, or their personal values; they are sometimes known as a statement of preferences and wishes. They can be about medical treatment ("I would wish to be ventilated if I stop breathing") or about social aspects of care ("I prefer coffee in the morning"). They are not legally binding but must be taken into account when best interest decisions are made about the person after capacity has been lost. They can be written by the patient or be verbal statements. It is useful to record verbal statements in the patient record, and it is important that they are accessible for those making decisions in the future.

Advance decision to refuse treatment

Valid and applicable advance decisions to refuse treatment (box 4) are legally binding statements (usually written documents) that allow patients to refuse specific medical treatments if they lose capacity in the future. Patients can refuse only medical and nursing treatments in advance and not basic care (such as the offer of food and drink by mouth and repositioning in bed).

It is best, but not a requirement, if the specific circumstances in which patients wish to refuse treatments are made clear, because this information will be used by clinicians in the future

Box 2 Communication tips

Initiating the conversation

Start with general open questions, then be guided by the patient's cues and responses to know whether to explore further

Examples:

- How have you been coping with your illness recently?
- Do you like to think about or plan for the future?
- When you think of the future, what do you hope for?[46]
- When you think about the future, what worries you the most?[46]
- Have you given any thought to what kinds of treatment you would want (and not want) if you became unable to speak for yourself?[47]
- What do you consider your quality of life to be like now?[47]

During the conversation

Use language that patients can understand and any other communication aids you might need

Give patients enough information to make informed choices without overloading them

Clarify any ambiguous statements that patients make—for example:

- Patient: "I don't want heroics"
- Professional: "What do you mean by heroics?"

Ending the conversation

Summarise what has been discussed to check mutual understanding, or ask the patient to do so

Screen for any other problems—for example: "Is there anything else you would like to discuss?"

Arrange another time to continue, complete, or review the discussion if necessary—for example, if the patient would like help completing an advance decision to refuse treatment

Document the contents of the discussion in the patient record

Share the contents (with the patient's permission) with anyone else who needs to know, such as family, carers, the community team, and the general practitioner or specialists

Box 3 Assessing mental capacity

Mental capacity is decision specific and time specific—it is specific to the decision in question and may be of time limited relevance.

The test for mental capacity has two parts:

- The diagnostic test. This is positive if the person has "an impairment of, or disturbance in the functioning of, the mind or brain" (Mental Capacity Act 2005 section 2). Otherwise, by definition, the person has capacity
- The functional test (Mental Capacity Act 2005 section 3) applies only if the diagnostic test is positive. People who can understand, retain, and use or weigh information relating to a decision, as well as be able to communicate their decision, have not lost capacity, even if the diagnostic test is positive. Loss of one or more of these four elements confirms loss of capacity for the specific decision

Mental capacity for a particular decision may fluctuate over time and may need to be reviewed frequently. For example, a patient may be temporarily incapacitated by an episode of sepsis, or through the use of alcohol.

Box 4 Determining whether an advance decision to refuse treatment is valid and applicable

Such decisions come into effect only if the person has lost mental capacity to make the decision in question. The person must have had relevant capacity at the time the advance decision was made and it must be about the decision in question.

Validity

For such a decision to be valid, it should not have been withdrawn by the person, and the person should not have later behaved in a way that is inconsistent with it. In addition, if the person has subsequently made a lasting power of attorney regarding the same decision the advance decision is rendered invalid.

Applicability

For the refusal to be applicable it must be about the treatment currently in question and relate to the circumstances in which the patient now finds himself or herself, if these have also been specified. For example, a person specifically refusing antibiotics for treatment of a chest infection might receive antibiotics for a urinary tract infection if clinically appropriate. However, if the advance decision covers all antibiotics under the specified circumstances then health professionals would be bound not to administer them.

An advance decision may not be applicable if circumstances have changed (for example, an unanticipated advance in medical treatment) and there are reasonable grounds to believe that these changes would have affected the advance decision if the person had known about them when making the decision.

Life sustaining treatment

When the treatment to be refused is potentially life sustaining, such as cardiopulmonary resuscitation, as well as being valid and applicable, the decision must be written, signed by the patient in the presence of a signed witness, and must state that it applies even if life is at risk.

to determine if the refusal is applicable. The wording of these statements can be difficult, because potential future situations must be anticipated and described unambiguously. If more than one circumstance is specified for a given refusal of treatment, all have to be present at the same time for the advance decision to apply. Verbal wishes to refuse treatments that do not sustain life can be recorded in the patient's notes.

If you are satisfied that the advance decision to refuse treatment is valid and applicable then you will have to abide by it (best interests do not apply). The only circumstance in which an advance decision is not binding is when the person is detained under the Mental Health Act 1983.[51] Such patients can be treated for their mental disorder without their consent, even if they have a valid and applicable advance decision to refuse the treatment

in question (electroconvulsive therapy is an exception to this rule).

Lasting power of attorney

These are legal documents that replace the previous enduring power of attorney. They allow patients (donors) to nominate someone (attorney) to whom they want to give decision making powers (if they lose capacity in the future). There are two types of lasting power of attorney: "property and financial affairs" and "health and welfare." Once made, these documents must be registered with the Office of the Public Guardian (for a fee) before coming into effect. It is possible to nominate more than one person as an attorney, or nominate different people for different decisions.

A health and welfare lasting power of attorney comes into effect only when the donor loses the capacity to make the decisions that are covered by the document. If there are worries that an attorney is not making decisions in the best interests of the donor, the decision should be challenged. It can then be adjudicated on by the Court of Protection (which might appoint a court appointed deputy, usually someone close to the patient, who would be able to take best interests decisions for the patient).

What are electronic palliative care coordination systems?

Appropriate dissemination of advance care planning decisions is a challenge; other than for lasting powers of attorney, the UK has no central register of advance care plans. Electronic palliative care coordination systems are designed to improve communication and facilitate health professionals' access to this information. Electronic registers, or urgent care records, such as Coordinate my Care in London (www.coordinatemycare.co.uk/index.html), hold immediately accessible information about patients' advance care plans and other information, such as treatment escalation plans, and are available to a wide range of relevant professionals. In some areas, this has led to an increase in patients dying in their preferred place of care.[52]

When should advance care planning decisions be reviewed? (see box 1)

Although no specific evidence or recommendations are available on when to review these decisions, on the basis of personal experience, several factors may be relevant and should prompt review. For example, if the personal circumstances of patients change, such as place of residence or perception of quality of life, they may wish to reconsider their decisions. New therapeutic options may become available or, as the condition progresses, the patient's values and goals may change, and this may affect earlier decisions. Advance care planning must be reconsidered regularly, either to confirm or amend the content, while the person has mental capacity to do so. This will allow the document to reflect the patient's current wishes and increase the likelihood that it will be judged as valid and applicable at the relevant time.

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1 Hayhoe B, Howe A. Advance care planning under the Mental Capacity Act 2005 in primary care. *Br J Gen Pract* 2011;61:e537-41.
2 Department of Health. End of life care strategy: promoting high quality care for adults at the end of their life. 2008. https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life.
3 NHS National End of Life Care Programme. Capacity, care planning and advance care planning in life limiting illness. A guide for health and social care staff. Department of Health, 2011. www.endoflifecare.nhs.uk/assets/downloads/ACP_booklet_2011_Final_1.pdf.
4 National Archives. The Mental Capacity Act 2005. www.legislation.gov.uk/ukpga/2005/9/contents.
5 Royal College of Physicians. Advance care planning. Concise Guidance to Good Practice series. No 12. 2009. www.rcplondon.ac.uk/sites/default/files/concise-advance-care-planning-2009.pdf.
6 Barnes K, Jones L, Tookman A, King M. Acceptability of an advance care planning interview schedule: a focus group study. *Palliat Med* 2007;21:23-8.
7 Billings JA. The need for safeguards in advance care planning. *J Gen Intern Med* 2012;27:595-600.
8 Mahon MM. An advance directive in two questions. *J Pain Symptom Manage* 2011;41:801-7.
9 Fried TR, O'Leary JR. Using the experiences of bereaved caregivers to inform patient- and caregiver-centered advance care planning. *J Gen Intern Med* 2008;23:1602-7.
10 Australian Medical Association. The role of the medical practitioner in advance care planning. 2006. https://ama.com.au/position-statement/role-medical-practitioner-advance-care-planning-2006.
11 American Medical Association. Opinion 2.191—advance care planning. 2011. www.ama-assn.org//ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2191.page.
12 The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA* 1995;274:1591-8.
13 Perkins HS. Controlling death: the false promise of advance directives. *Ann Intern Med* 2007;147:51-7.
14 Tonelli MR. Pulling the plug on living wills. A critical analysis of advance directives. *Chest* 1996;110:816-22.
15 Schneiderman LJ, Kronick R, Kaplan RM, Anderson JP, Langer RD. Effects of offering advance directives on medical treatments and costs. *Ann Intern Med* 1992;117:599-606.
16 Goodman MD, Tarnoff M, Slotman GJ. Effect of advance directives on the management of elderly critically ill patients. *Crit Care Med* 1998;26:701-4.
17 Robinson L, Dickinson C, Rousseau N, Beyer F, Clark A, Hughes J, et al. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age Ageing* 2012;41:263-9.
18 Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300:1665-73.
19 O'Malley AJ, Caudry DJ, Grabowski DC. Predictors of nursing home residents' time to hospitalisation. *Health Serv Res* 2011;46:82-104.
20 Molloy DW, Guyatt GH, Russo R, Goeree R, O'Brien BJ, Bédard M, et al. Systematic implementation of an advance directive program in nursing homes: a randomized controlled trial. *JAMA* 2000;283:1437-44.
21 Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* 2010;362:1211-8.
22 Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol* 2010;28:1203-8.
23 Abel J, Pring A, Rich A, Malik T, Verne J. The impact of advance care planning of place of death, a hospice retrospective cohort study. *BMJ Support Palliat Care* 2013;3:168-73.
24 Rhee JJ, Zwar NA, Kemp LA. Advance care planning and interpersonal relationships: a two-way street. *Fam Pract* 2013;30:219-26.
25 Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010;340:c1345.
26 Lorenz KA, Lynn J, Dy SM, Shugarman LR, Wilkinson A, Mularski RA, et al. Evidence for improving palliative care at the end of life: a systematic review. *Ann Intern Med* 2008;148:147-59.
27 Pautex S, Hermann FR, Zulian GB. Role of advance directives in palliative care units: a prospective study. *Palliat Med* 2008;22:835-41.
28 Kaldjian LC, Curtis AE, Shinkunas LA, Cannon KT. Goals of care toward the end of life: a structured literature review. *Am J Hosp Palliat Care* 2008-2009;25:501-11.
29 Levi BH, Dellasega C, Whitehead M, Green MJ. What influences individuals to engage in advance care planning? *Am J Hosp Palliat Care* 2010;27:306-12.
30 Piers RD, van Eechoud IJ, Van Camp S, Grypdonck M, Deveugele M, Verbeke N, et al. Advance care planning in terminally ill and frail older persons. *Patient Educ Couns* 2013;90:323-9.
31 Rhee JJ, Zwar NA, Kemp LA. Uptake and implementation of advance care planning in Australia: findings of key informant interviews. *Aust Health Rev* 2012;36:98-104.
32 Knauft E, Nielsen EL, Engelberg RA, Patrick DL, Curtis JR. Barriers and facilitators to end-of-life care communication for patients with COPD. *Chest* 2005;127:2188-96.
33 Schickedanz AD, Schillinger D, Landefeld CS, Knight SJ, Williams BA, Sudore RL. A clinical framework for improving the advance care planning process: start with patients' self-identified barriers. *J Am Geriatr Soc* 2009;57:31-9.
34 Halpern S. Shaping end-of-life care: behavioral economics and advance directives. *Semin Respir Crit Care Med* 2012;33:393-400.
35 Dening KH, Jones L. Sampson EL. Preferences for end-of-life care: a nominal group study of people with dementia and their family carers. *Palliat Med* 2013;27:409-17.

Additional educational resources

Resources for patients

National End of Life Care Programme (www.endoflifecare.nhs.uk/search-resources/resources-search/publications/planning-for-your-future-care.aspx)—Outlines the different options available to people when planning for their end of life care and comes in a range of languages

Aging with Dignity (www.agingwithdignity.org/forms/5wishes.pdf)—US based website that aims to help people take control of how they are treated if they are seriously ill

Regents of the University of California (www.prepareforyourcare.org)—Aims to help patients make medical decisions for themselves and get the right medical care

Resources for professionals

Thomas K, Lobo B, eds. Advance care planning in end of life care. Oxford University Press, 2011

National End of Life Care Programme. Capacity, care planning and advance care planning in life limiting illness. A guide for health and social care staff. 2011. www.endoflifecare.nhs.uk/assets/downloads/ACP_booklet_2011_Final_1.pdf

Office of the Public Guardian. A guide for people working in health and social care. OPG603. 2009. www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/opg-603-0409.pdf

Macmillan Cancer Support/NHS. Tips for advance care planning for GPs. 2012. www.endoflifecare.nhs.uk/search-resources/resources-search/publications/acp-tips-for-gps.aspx

36 Gott M, Gardiner C, Small N, Payne S, Seamark D, Barnes S, et al. Barriers to advance care planning in chronic obstructive pulmonary disease. *Palliat Med* 2009;23:642-8.
37 Spence A, Hasson F, Waldron M, Kernohan WG, McLaughlin D, Watson B, et al. Professionals delivering palliative care to people with COPD: qualitative study. *Palliat Med* 2009;23:126-31.
38 Curtis JR, Engelberg R, Young JP, Vig LK, Reinke LF, Wenrich MD, et al. An approach to understanding the interaction of hope and desire for explicit prognostic information among individuals with severe chronic obstructive pulmonary disease or advanced cancer. *J Palliat Med* 2008;11:610-20.
39 Barnes KA, Barlow CA, Harrington J, Ornadel K, Tookman A, King M, et al. Advance care planning discussions in advanced cancer: analysis of dialogues between patients and care planning mediators. *Palliat Support Care* 2011;9:73-9.
40 Prendergast TJ. Advance care planning: pitfalls, progress, promise. Crit Care Med 2001;29:N34-9.
41 National Institute for Health and Care Excellence. Dementia: supporting people with dementia and their carers in health and social care. CG42. 2006. http://guidance.nice.org.uk/CG42.
42 Poppe M, Burleigh S, Banerjee S. Qualitative evaluation of advanced care planning in early dementia (ACP-ED). *PLoS One* 2013;8:e60412.
43 Callaghan D. Once again, reality: now where do we go? *Hastings Cent Rep* 995;25:S33-6.
44 Robinson L, Dickinson C, Bamford C, Clark A, Hughes J, Exley C. A qualitative study: professionals' experiences of advance care planning in dementia and palliative care, "a good idea in theory but . . ." *Palliat Med* 2013;27:401-8.
45 Randall F. Advance care planning: ethical and clinical implications for hospital medicine. *Br J Hosp Med* 2011;72:437-40.
46 Pantilat S, Steimle A. Palliative care for patients with heart failure. *JAMA* 2004;291:2476-83.
47 Quill T. Initiating end-of-life discussions with seriously ill patients—addressing the elephant in the room. *JAMA* 2000;284:2503-7.
48 Boddy J, Chenoweth L, McLennan V, Daly M. It's just too hard! Australian health care practitioner perspectives on barriers to advance care planning. *Aust J Prim Health* 2013;19:38-45.
49 Boyd K, Mason B, Kendall M, Barclay S, Chinn D, Thomas K, et al. Advance care planning for cancer patients in primary care: a feasibility study. *Br J Gen Pract* 2010;60:e449-58.
50 Department for Constitutional Affairs. Mental Capacity Act 2005. Code of practice. 2007. www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/mca-code-practice-0509.pdf.
51 National Archives. The Mental Health Act 1983. www.legislation.gov.uk/ukpga/1983/20/contents.
52 Smith CF, Riley J. Coordinate My Care: a clinical service for end-of-life care underpinned by an IT solution [electronic response to: There IT goes again. Cross M]. www.bmj.com/rapid-response/2011/11/03/coordinate-my-care-clinical-service-end-life-care-underpinned-it-solution.

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