

Advance care planning: concise evidence based guidelines



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The aim of this guideline is to inform health and social care professionals on how best to manage advance care planning in clinical practice.

Introduction

At the core of current health and social care are efforts to promote patient centred care, offer choice and the right to consent to or refuse treatment and care offered. This can be difficult to achieve when an individual has lost capacity – the ability to make one’s own, informed decision. Advance care planning (ACP) may help in such scenarios.

Advance care planning has been defined as a **process of discussion** between an individual, their care providers, and often those close to them, about future care¹. The discussion may lead to:

- **an advance statement** (a statement of wishes and preferences),
- **an advance decision to refuse treatment** (ADRT - a specific refusal of treatment(s) in a predefined potential future situation) or
- **the appointment of a personal welfare Lasting Power of Attorney (LPA)**

All or any of these can help inform care providers should the individual lose capacity. These terms supersede previous phrases such as ‘living wills’ and ‘advance directives’.

Advance decisions to refuse treatment only come into force if an individual loses capacity. The presence of an ACP or ADRT documents does not over-ride the decision of a competent individual.

Whilst ACP has been used for some time in North America, there has been relatively little experience in the use of ACP in the United Kingdom. However, with legislation in the form of the Mental Capacity Act², and NHS initiatives aimed at increasing uptake of ACP¹, it is likely that health and social care professionals will be faced more and more frequently with ACP scenarios.

Much of the evidence base for ACP comes from Canada and the United States (US); in interpreting the evidence we have been mindful of the differences between the two healthcare systems. In particular, US legislation requires that all individuals admitted to a care home are offered ACP.

In writing these guidelines, we have assumed that readers are familiar with making valid clinical decisions according to the Mental Capacity Act (figure 1). This guideline is primarily aimed at health and social care professionals in England and Wales, especially

those working with older people and patients with dementia, but will be relevant to any individual involved in ACP.

Methods

The guidelines have been developed in line with the AGREE criteria⁴; the methods are described in detail in appendix 1.

Each research paper identified was sent out to two reviewers for grading, using the appraisal tool developed for use in the NSF for Long Term Conditions⁵. Consensus on each recommendation was achieved through a series of stakeholder meetings. The guideline was formally externally reviewed by Professor Jane Seymour (Nottingham), Professor Peter Bartlett (Nottingham) and Professor Gideon Caplan (New South Wales, Australia). The grading system is shown in Table 1.

Table 1 Grading system used to indicate the level of evidence

Grade of evidence	Criteria
Research Grade A (RA):	<ul style="list-style-type: none"> • More than one study of high quality score ($\geq 7/10$) <i>and</i> • At least one of these has direct applicability
Research Grade B (RB):	<ul style="list-style-type: none"> • One high quality study <i>or</i> • More than one medium quality study (4-6/10) <i>and</i> • At least one of these has direct applicability <p><i>Or</i></p> <ul style="list-style-type: none"> • More than one study of high quality score ($\geq 7/10$) of indirect applicability
Research Grade C (RC):	<ul style="list-style-type: none"> • One medium quality study (4-6/10) <i>or</i> • Lower quality (2-3/10) studies <i>or</i> • Indirect studies only
Expert (E1/2)	<ul style="list-style-type: none"> • Guidelines can also or instead be graded as E1 or E2, reflecting expert evidence (E1 = user/carer derived evidence, E2 = expert body/professional evidence)

Background

Our review of the literature demonstrates that most of the general public (60-90%) are supportive of ACP⁶⁻¹¹, but only 8% of the public in England and Wales have completed an ACP document of any kind¹², compared to 10-20% of the public in the US, Canada, Australia, Germany and Japan¹³⁻¹⁶. Most health and social care professionals have a positive attitude towards ACP^{7 16-49}. However doctors, more than other professionals, have significant reservations about the applicability and validity of ACP documents⁵⁰⁻⁵².

The majority of individuals are happy to discuss ACP in primary and outpatient care settings, when their condition is stable⁵³⁻⁵⁸, in anticipation of future ill-health^{20 54-56 59 60}. Advance care planning discussions with patients with long term conditions^{47 58-60} or as part of a broad end of life care management programme⁶¹⁻⁶³ increase patient satisfaction. ACP discussions at entry into a care home may cause additional upset at a time of transition⁶⁴, but can be successful once the individual is more settled, given appropriate staff education and training^{21 65-69}. Whilst most professionals and patients (>80%) agree that ACP discussions should take place around the time of diagnosis of a life threatening illness^{54 70}, some patients with terminal disease⁷⁰ or serious illness requiring hospitalisation⁷¹ may not feel ready or able to do so.

Advance care planning discussions can be successfully led by a competent case manager^{1 72-74}; in the US this is often a social worker or nurse. In the UK this could be a community matron or other specialist nurse, with the necessary expertise and knowledge base. Discussions can be conceived in various stages which are fluid and dynamic^{75 76} and should be a process rather than a single event^{59 77}. Patients can demonstrate any of the following responses to ACP:

- The patient has not and does not wish to consider ACP
- The patient does not wish to discuss specific aspects of future care, but may be willing to discuss other aspects
- The patient would like to make a verbal statement about their wishes
- The patient would like to document their wishes
- The patient would like to review their wishes

Patients can exhibit several of these responses at once, and may oscillate between responses. This is natural as illness changes their goals and focus and they adjust to changing circumstances. Any approach should be straightforward⁷⁸ and allow the patient to close the topic down at any time during the discussion⁷⁰ (see figure 2).

Drafting clinically relevant, valid and applicable ACP documents is difficult; only 10-62% of ACP documents relating to hospital treatment contain sufficient information to direct

care⁷⁹⁻⁸¹; physician agreement about the content of an ACP document varies from 75-88%⁸². Using ACP documents *without* prior discussion between the individual and their care provider to predict what that individual would have wanted is accurate 70-75% of the time⁸³⁻⁹⁰; however prior discussion increases proxy or physician surrogate decision accuracy^{85 88 89 91}, especially for decisions relating to coma or ventilation⁹². Multifaceted interventions involving case managers helping individuals draft ACP documents and collaboration between primary and secondary care can increase ACP documentation in medical records^{91 93 94} and reduce the number of treatment decisions *not* in agreement with the individual's wishes from 18% to 5%⁶⁸. Individuals prefer goal- or outcome-orientated statements rather than directives about specific treatments in specific circumstances^{87 95 96}, but health and social professionals find these more difficult to interpret⁸⁷; a combination of personal narrative and specific advance refusals may be the best option⁹⁷⁻⁹⁹.

Advance decision to refuse treatment

The Mental Capacity Act (MCA), section 25², sets out the requirements an ADRT must meet to be valid and applicable. Preferences are less likely to change if they have been discussed with a doctor¹⁰⁰. Even so, up to one-third of individuals will change their advance care plan over time (months-years), influenced by changes in diagnosis^{101 102}, hospitalisation, mood, health status, social circumstances and functional ability^{90 101-105}.

There is no good evidence that the completion of an ADRT leads to the denial of appropriate health care^{61 106-111} or increases mortality^{61 106 112-114}.

Implementation

Barriers to increased ACP uptake can be categorised according to client/individual factors (receptiveness and cognitive impairment); family factors (availability, unaware of need for ACP or difficult relationship with the patient); case-manager factors (previous experience/lack of knowledge, level of comfort with discussion, lack of training⁷⁴); service factors (lack of funding, lack of time⁷⁴), doctors' beliefs about appropriateness^{11 39 115-117} and system factors (lack of communication with providers, legislation, providers unaware of case manager)¹¹⁸.

Public awareness/education

Increased uptake of ACP is achieved through a combination of professionals initiating the discussions⁶⁸, combined with educational materials^{66 91 119 120}; and physician involvement^{21 65 66}, which can be prompted through routine reminders^{119 121 58 119 122}.

Training

Staff training should be based in the workplace repeated regularly and led by experts¹²³; peer mentoring is an effective educational intervention for selected patients¹²⁴. Staff need excellent communication skills and knowledge of the relevant disease process, prognosis and treatment options, in order to undertake useful ACP discussions. Staff should recognise and work within their own competencies, and ask for expert support when it is required.

System factors

In some countries (Denmark), doctors are obliged to consult a central register of ACP documents when making best interests decisions¹²⁵ and regionally funded voluntary register schemes operate in the US¹²⁶, which allow 24-hour, 7-day access to ACP documents. In England and Wales, details about LPAs and deputies should be available through the Office of the Public Guardian. Labelling of case notes regarding the presence/absence of ACP documents may only be accurate on 60-90% of occasions^{82 127}.

Health economics

Advance care planning does not reliably reduce health care costs^{61 128}, except when used systematically in the care home setting⁶⁹. Any cost reduction associated with ACP is probably related to avoiding 'terminal hospitalisation'¹²⁹, or because people with an ADRT are less likely to receive life-sustaining therapy when hospitalised¹³⁰⁻¹³³.

The recommendations

When and with whom should I be considering ACP discussions?

<ul style="list-style-type: none">• ACP should be offered during routine clinical practice, but never forced upon an individual	RB
<ul style="list-style-type: none">• Pre-existing ACPs should be acknowledged and reviewed if appropriate	E1/2
<ul style="list-style-type: none">• Professionals should initiate ACP discussions in patients with long term conditions or receiving end of life care, using their professional judgement to gauge the appropriate time. This will depend on prognosis and pattern of disease progression and on the patient's willingness to engage in the discussion (see figure 2)	RB
<ul style="list-style-type: none">• Ideally, ACP discussions should be initiated in primary care or in the outpatient setting, before individuals become acutely unwell.	RB
<ul style="list-style-type: none">• Professionals should avoid initiating discussions immediately after a move into a	RB

care home but should be undertaken once they are more settled	E1/2
<ul style="list-style-type: none"> ACP discussions should be initiated by an appropriately trained professional¹ who has rapport with the individual and, where necessary, supported by a professional with relevant specialist knowledge 	E1/2
<ul style="list-style-type: none"> The professional should have adequate knowledge about the disease, treatment and the particular individual to be able to give the patient all the information needed to express their preferences to make the plan. For example, it would be appropriate for a palliative care nurse or General Practitioner to initiate a general ACP discussion with a patient with cancer, but may not be appropriate for that them to offer specific advice about chances of survival with chemotherapy, unless they had specific training in that area. Instead, they may refer the patient to an oncologist to continue the more detailed discussion. 	E1/2
<ul style="list-style-type: none"> Individuals should be encouraged to choose who they would wish to be included in the discussion, such as next of kin or future proxy 	E1/2

The discussion

<ul style="list-style-type: none"> ACP discussions need to be skilfully led and should be a process not a single event or a tick box exercise 	RB
<ul style="list-style-type: none"> Professionals should ensure that individuals have every opportunity to participate in the discussion by treating reversible illness impacting on decision-making, such as delirium, sensory impairment, being pain-free, fed, not too tired etc. This may be better achieved when not an in-patient and also relieves any perception that the health service has provided 'undue influence' 	E1
<ul style="list-style-type: none"> ACP discussions should not be continued if they are causing excessive distress or anxiety to the patient 	E1/2
<ul style="list-style-type: none"> Professionals should take account of the following factors which influence attitudes to discussing ACP, and ensure that these factors do not act as artificial barriers: 	
<ul style="list-style-type: none"> <i>Older people may be concerned about the burden of their own illness on their family</i> 	E1&2
<ul style="list-style-type: none"> <i>The professional's own personal experience and beliefs. For example, if the professional has strong views on end of life care, influenced by their own religious beliefs, they should ensure that they do not impose their views on their patient. If there is a conflict of interest, a different professional</i> 	RC

¹ This does not need to be a health professional and could be, for example, a social worker or lawyer. But the professional does need to ensure that they are giving appropriate advice.

<i>opinion may be required.</i>	
<ul style="list-style-type: none"> • <i>The patient's gender, race, culture, sexual orientation, religion, beliefs and values</i> 	RB
<ul style="list-style-type: none"> • <i>The patient's concerns about euthanasia</i> 	RB
<ul style="list-style-type: none"> • Individuals should be encouraged to choose who they would wish to be included in the discussion, such as next of kin or future proxy 	E1/2

Figure 2 offers some suggestions as to how an ACP discussion should be led.

Will ACP work?

<ul style="list-style-type: none"> • Individuals preparing ACP documents should be advised that: <ul style="list-style-type: none"> a) completing an advance care plan alone does not guarantee that their wishes will be respected. However a valid and applicable ADRT must be followed. b) healthcare providers are not obliged to provide clinically inappropriate medical care c) ADRTs are not valid if an LPA covering the same treatment was appointed after the ADRT was made 	RB E2 E2
<ul style="list-style-type: none"> • Individuals appointing a LPA should be aware that there may be misinterpretation of the patient's wishes by a proxy, even following guided discussions 	RC
<ul style="list-style-type: none"> • Individuals should be strongly encouraged to discuss ACP with a health care professional 	RA
<ul style="list-style-type: none"> • While it is not a legal requirement, as a matter of practice it is particularly important that ADRTs concerning the refusal of life-sustaining therapy should be discussed with a doctor 	RB
<ul style="list-style-type: none"> • ACP documents should be reviewed periodically, and particularly if circumstances change, for example: <ul style="list-style-type: none"> ○ if the individual's health changes or there is a new diagnosis ○ if there is a change in the individual's functional abilities • An ACP document may be judged invalid if the individual behaves in a manner inconsistent with their original specifications; in such circumstances, the ACP document should be included in a broad reassessment of best interests.² 	RB RC E2

² Example in box: For example, what was once a clearly-expressed preference to be moved to a care home so as not to become a burden on the family could be overtaken by a poorly-expressed fear about losing control and a desire to cling to familiar surroundings. Care professionals must remain alert to behaviour which is inconsistent

<ul style="list-style-type: none"> Health care professionals should make reasonable efforts³ to seek out an advance care plan or ADRT and if one is found review the document with the individual [if they still have capacity] and ensure that it is placed in the medical record [if the patient consents] 	E2
<ul style="list-style-type: none"> Health care professionals should advise individuals to carry a card or equivalent, notifying others that they have completed an advance care plan, and how it can be accessed 	E1/2
<ul style="list-style-type: none"> Health and social care providers should ensure that advance care plans travel with patients and are respected across sectors, by ensuring that documentation is recognised/respected across sectors and included in transfer/hand-over procedures. 	RA

Individuals with progressive cognitive impairment

<ul style="list-style-type: none"> Individuals should be offered ACP discussions early in their disease process 	RC
<ul style="list-style-type: none"> HCPs should consider using clinical vignettes or examples as useful aids for ACP in individuals with moderate cognitive impairment 	RC
<ul style="list-style-type: none"> Once a patient has lost capacity to make decisions about their future care (see figure 1a), any care decisions not within the scope of a valid and applicable ADRT will need to be made in their best interests following the MCA framework. If an LPA with relevant authority has been appointed they make the decision on behalf of the patient; in these circumstances detailed discussion with the attorney is essential 	E1/2

Recommendations for training and implementation of ACP

<ul style="list-style-type: none"> Health and social care staff should be trained in ACP discussions, especially: <ul style="list-style-type: none"> Doctors Case managers, such as nursing staff, community matrons, social workers and other key workers 	E1/2 RA RC
<ul style="list-style-type: none"> Staff training should be workplace based, recurrent and led by experts and expert patients 	RC
<ul style="list-style-type: none"> Public awareness about ACP should be increased; this is the responsibility of individual practitioners through to government departments 	RC

with desires that were expressed before cognitive degeneration. Under such circumstances an ACP document may be regarded as invalid.

³ Reasonable efforts might include having discussions with relatives of the patient, looking in the patient's clinical notes held in the hospital or contacting the patient's GP (Mental Capacity Act, Code of Practice, section 9.49)

<ul style="list-style-type: none"> Public education must involve discussions with professionals as well the provision of educational material 	RA
<ul style="list-style-type: none"> Public education must not rely on handing out information leaflets alone 	RA
<ul style="list-style-type: none"> Peer education of patients should be included, using expert patients 	RC
<ul style="list-style-type: none"> Health and social care professionals should initiate ACP discussions with appropriate individuals and have access to information leaflets. But ACP is completely voluntary for the patient, who must be informed that they can decline or defer discussion 	RA
<ul style="list-style-type: none"> Physicians should be routinely reminded to offer ACP discussion at an appropriate time to their patients 	RA
<ul style="list-style-type: none"> ACP should be part of the Quality Outcomes Framework and considered in annual care reviews of patients with long term conditions 	E1/2
<ul style="list-style-type: none"> General practices should review how many people who have died in their practice were offered ACP, as part of an annual care reviews 	E1/2
<ul style="list-style-type: none"> Medical records should contain a specific section for advance statements, ADRTs and resuscitation decisions 	E1/2
<ul style="list-style-type: none"> People with ACP documents should be encouraged to ensure the ACP document is readily available at all times⁴ 	E1/2
<ul style="list-style-type: none"> A register should be created, which stores details about an individual's ACP document, and should be readily accessible with the individual's permission 	E1/2
<ul style="list-style-type: none"> Ultimately, ACP documents should be recorded on the electronic patient record [with the patient's consent (9.38 in the MCA Code of Practice)] 	E1/2

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Conflicts of interest

All authors and group members have declared that they have no actual or potential conflicts of interest

⁴ Methods include the 'message in the bottle scheme' in which a notice is placed at the front door and alerts the ambulance crew to the fact that an ACP document exists and its location. Other schemes include ensuring the ambulance service has copies of relevant ACPs, with the patient's consent.

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Legend

Figure 1 Making valid clinical decisions

Figure 2 Top tips for a successful ACP discussion

Figure 3 Suggested content for an ACP document

Appendix 1: Guideline Development Process

Figure 1a

Making best interests decisions in serious medical conditions in patients over 18 years

Adapted from Regnard C. From: Regnard, Dean & Hockley; *A Guide to Symptom Relief in Palliative Care 6th ed.*, Oxford: Radcliffe Publishing

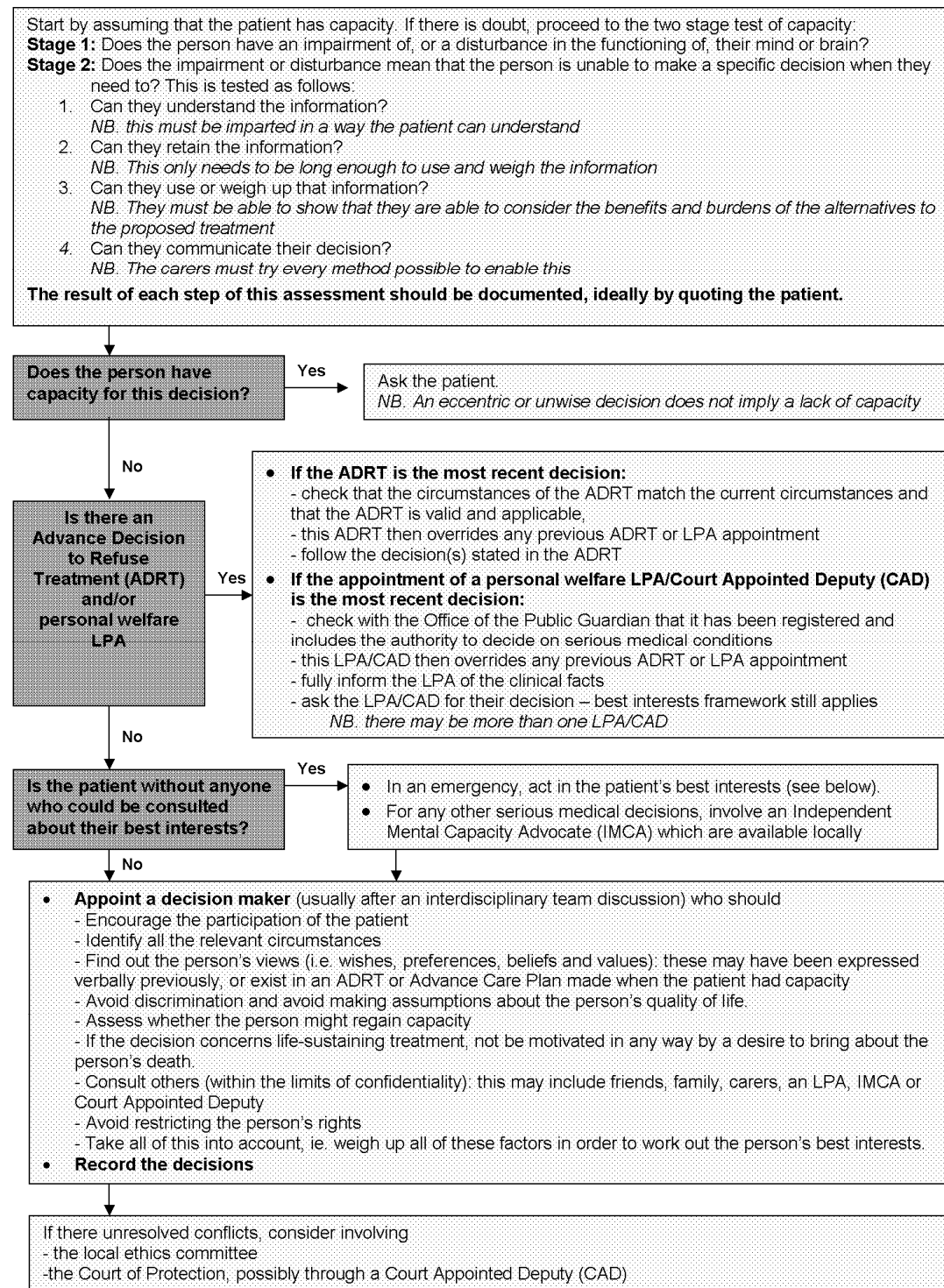


Figure 1b

An Advance Refusal of Treatment (ADRT) – see section 9.40 & 9.41 of the MCA Code of Practice

- Can only be made by a patient while they still have capacity, but only becomes active when they lose capacity
- Only applies to a refusal of medical treatment
- Is invalid if any of the following apply:
 - the person withdrew the decision while they still had capacity to do so
 - after making the advance decision, the person made a Lasting Power of Attorney (LPA) giving an attorney authority to make treatment decisions that are the same as those covered by the advance decision
 - the person has done something that clearly goes against the advance decision which suggests that they have changed their mind
- Is only applicable if it applies to the situation in question and in the current circumstances. An ADRT is not applicable if any of the following apply:
 - the proposed treatment is not the treatment specified in the advance decision
 - the circumstances are different from those that may have been set out in the advance decision
 - there are reasonable grounds for believing that there have been changes in circumstance, which would have affected the decision if the person had known about them at the time they made the advance decision.
 - the ADRT must be in writing if it is for the refusal of life-sustaining treatment, but not for non-life threatening conditions; however a signed and witnessed document will avoid confusion
- *If an advance decision is not valid or applicable to current circumstances*, the healthcare professionals must consider the ADRT as part of their assessment of the person's best interests if they have reasonable grounds to think it is a true expression of the person's wishes, *and* they must not assume that because an advance decision is either invalid or not applicable, they should always provide the specified treatment (including life-sustaining treatment) – they must base this decision on what is in the person's best interests.

Capacity see section 4 of the MCA Code of Practice

- Is assumed to be present in all cases
- Can be tested using the two stage test (see overleaf)
- Depends on the decision being made, eg. a patient may have capacity for simpler decisions, but not complex issues.
- Can change with time and needs to be monitored

Communication see section 3 of the MCA Code of Practice

- Carers have to take all practicable steps to help a patient understand the information and communicate their decision
- Professionals should take all practicable steps to include the patient in the decision

Liability

The MCA does not have any impact on a professional's liability should something go wrong, but a professional will not be liable for an adverse treatment effect if:

- Reasonable steps were taken to establish capacity
- There was a reasonable belief that the patient lacked capacity
- The decision was made in the patient's best interests
- The treatment was one to which the patient would have given consent if they had capacity

Personal Welfare Lasting Power of Attorney (LPA) see section 7 of the MCA Code of Practice

- Must be made while the patient has capacity, but an LPA can only act when the patient lacks capacity to make the required decision
- Must act according to the principles of best interests
- Only extends to life-sustaining treatment if that was expressly contained in the original application
- Only supersedes an advance decision if the LPA was appointed after the advance decisions and the conditions of the LPA cover the same treatment as in the ADRT

NB. Holders of LPA for Property and Affairs have no authority to make health and welfare decisions, but should be consulted as part of the best interest determination

Court Appointed Welfare Deputies (CADs) see section 8 of the MCA Code of Practice

- May be appointed by the Court of Protection; the Court makes single decisions themselves but deputies may be appointed where a series of decisions are required
- Are helpful when a patient's best interests require a deputy consulting with everyone
- Can make decisions on the patient's behalf, but cannot refuse or consent to life-sustaining treatments.
- Are subject to the principles of best interests (see above)

Independent Mental Capacity Advocates (IMCAs) see section 10 of the MCA Code of Practice

- Are part of a new public consultation service for individuals with no other representative
- They need only be involved in specific decisions ('serious' medical treatments and admissions to hospitals or care homes)
- Advise regarding best interests
- in emergencies it is not necessary to delay the necessary decisions and treatment by waiting for an IMCA's views

The court of protection can advise on and resolve difficult problems: <http://www.publicguardian.gov.uk/about/>

Resources

Any professional making decisions on behalf of a person without capacity is required by law to have regard to the Mental Capacity Act Code of Practice: <http://www.publicguardian.gov.uk/docs/code-of-practice-041007.pdf>
Office of Public Guardian: www.publicguardian.gov.uk

Figure 2

- The individual needs to be ready for the discussion – it cannot be forced
- Discussions usually need to take place on more than one occasion (days, weeks, months) and should not be completed on a single visit in most circumstances.
- Discussions take time and effort and cannot be completed as a simple checklist exercise.
- Discussions should take place in comfortable unhurried surroundings; time is a key factor.
- It is important that capacity is maximised by ensuring the treatment of any transient condition affecting communication and optimising sensory function (e.g. by obtaining the patient's hearing aid).
- A step-by-step approach should be used.
- Discussions should be characterised by truthfulness; respect; time; compassion and empathy¹³⁶.
- A tool to introduce the concept and guide the discussion may help professionals to address ACP with people (Figure 3).
- Information should be given using words the person understands.
- Clarify any ambiguous terms used by your patient, such as 'could you explain what you mean by not wanting any heroics?' Checking and reflecting in this way is a key part of effective communication.
- Individuals should be given sufficient information about their possible options and under what circumstances their plan would be activated. They need to understand what the consequences of their decision would be.
- The professional should look out for cues that the individual wishes to end the discussion.
- Summarise and check understanding.
- The discussion should be documented if the patient so wishes.
- Not all people will be able to document their wishes, but may well be able to nominate their preferred decision maker, and discuss their long term values as these come to mind more readily than anticipating abstract situations.
- Audio-visual recordings might be helpful in providing the individual a record of the discussion.
- Plan for a review.

Figure 3

A document is not a requirement of ACP, unless the patient specifically wishes to record an ADRT refusing life-sustaining treatment. However, we reviewed a variety of ACP documents (see below); none is ideal. In practice a combination of documents are likely to be required:

- an administrative section with relevant contact numbers
- a tool to help people express their preferences, such as the Hammersmith Expression of Healthcare Preferences¹³⁷
- an MCA compliant ADRT (if individual wishes this), which should help direct care and a reference to any LPA

Accompanying notes should be clear, concise and unambiguous. It should be however emphasised that ACP is more about discussion and communication than the forms, though documentation is important, especially for ADRTs.

ACP documents examined

- Let me decide¹³⁸
- Emanuel-the Medical directive¹³⁹
- Dignity in dying (<http://www.dignityindying.org.uk/livingwills/>)
- Alzheimer' society living will
(http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=143)
- Hammersmith Expression of Healthcare Preferences¹³⁷
- Thinking Ahead – ACP planning discussion
(http://www.goldstandardsframework.nhs.uk/advanced_care.php)
- Advanced Clinical management plan (Minnie Kidd House)
- Care Home Support Team -health care choices form
- POLST (<http://www.ohsu.edu/polst/edmat.shtml>)
- Lawpack Advance Decision
(http://www.lawpack.co.uk/advance_medical%20decision.asp)
- ADRT.nhs.uk (<http://www.adrtnhs.co.uk/pages/links.htm>)
- Preferred Priorities of Care
(<http://www.endoflifecareforadults.nhs.uk/eolc/eolc/current/G522.htm>)

Appendix 1

These guidelines have been developed in accordance with the principles laid down by the AGREE collaboration (Appraisal of Guidelines for Research and Evaluation).

Scope and purpose

The scope	
Overall objectives of the guidelines	The objective of the Guideline Development Group was to inform health and social care professionals on how best to manage ACP in clinical practice.
The patient group covered	The guidelines focus on adults, with particular emphasis on older people. Relevant evidence from all countries will be considered, but the guidelines will reflect the legal situation in England and Wales. ADRTs relating to psychiatric treatment would be excluded, as would any papers concerning minors (<18 years old).
Target audience	All clinicians, including general physicians, GPs and other health and social care professionals

Clinical areas/questions covered

Attitudes

- 1 Is the general public in favour of ACP?
- 2 What are the attitudes of health care professionals towards ACP?

Barriers

- 3 How often do individuals change their minds about ACP?
- 4 Does ACP increase mortality?
- 5 Does ACP deny access to appropriate health care?
- 6 How can uptake of ACP be improved?

Communication

- 7 When should ACP discussion take place?
- 8 Where should ACP discussion take place?
- 9 What are the best methods for communicating about ACPs with individuals?
- 10 What is the optimal method for communicating about ACP within families?
- 11 What are the optimal methods for ensuring that ACPs are available at the point of care, especially in emergency settings?
- 12 What are the optimal methods to ensure ACP documents are noted in health care records and are available to healthcare practitioners seeing the patient for the first time?

Content

13 Should people preparing ACP documents use values statements or be more specific in their guidance?

14 Do patients change their healthcare decision in a given situation?

15 How often should advance care planning decisions/statements be reviewed?

16 How recent does an ACP document need to be in order to remain valid?

Demand

17 How many individuals have completed advance care plans in England and Wales? How does this compare internationally?

18 Who is using ACP?

19 Who does not use ACP and why not?

Health care proxies

20 Do LPAs influence care?

21 What is the concordance between surrogates and patients?

22 How accurate are substitute judgements in ACP?

Outcomes

23 Can ACP improve health care choice concordance?

24 Does ACP affect satisfaction with health care?

25 Can ACP improve the quality of end of life care?

26 What are the costs of an ACP programme?

27 What additional benefits do ACP discussions offer apart from directing care?

Role of health care professionals

28 Which health care professionals should be involved in ACP?

Training

29 What are the training needs of health care professionals, including care home sector staff?

30 What are the optimal methods for delivering ACP training and awareness to health care professionals?

Dementia

31 What is known about ACP in people with dementia?

Stakeholder involvement

The Guideline Development Group (GDG)	<p>The guideline committee was made up of various stakeholders, including strong lay representation, general practice and other clinicians.</p> <p>Organisations represented on guideline committee included the British Geriatrics Society, the Faculty of Old Age Psychiatry, Royal College of Psychiatrists, the Royal College of General Practitioners, the National Council for Palliative Care and the Royal College of Nursing. Additional input was given by palliative care physicians. Users were represented through the involvement of Alzheimer's Society, Age Concern, Help the Aged and the patient representative panel of the Royal College of Physicians.</p>
Funding	<p>These guidelines were commissioned by the Clinical Practice and Evaluation Committee of the British Geriatrics Society. Funding was obtained from the British Geriatrics Society.</p>
Conflicts of Interest	<p>No external funding has been sought or obtained. All authors and group members have declared that they have no actual or potential conflicts of interest</p>

Rigour of Development

Evidence gathering	<p>The following databases were searched: OVID MEDLINE(R) (1966+), EMBASE (1980+), PsychINFO (1967+), BNI (1985+), HMIC (July 2006), CINAHL (1982+), AMED (1985+)</p> <p>The systematic review consisted of two phases. The first phase (scoping exercise) identified evidence from sources least susceptible to bias. A comprehensive search strategy was used to identify all eligible randomised controlled trials, previous systematic reviews, and existing evidence-based guidelines. The second phase searched for evidence from studies more prone to bias (cohort studies, case-control studies and where relevant, surveys).</p> <p>Where evidence was lacking for a specific question, additional sources were examined including case reports, literature reviews, and evidence from expert opinion or consensus. Special attention was given to non-research publications, such as government reports, including the Mental Capacity Act and the accompanying Code of Practice.</p>
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	<p>Scoping exercise</p> <p>Grading of evidence during the scoping exercise followed the principles used by the Scottish Intercollegiate Guideline Network [SIGN] and the National Institute of Clinical Excellence [NICE]. The reviewers felt that the SIGN appraisal tool did not lend itself well to the papers being examined, and following external consultation the guideline development committee agreed to change to using the appraisal tool developed for use in the NSF for Long Term Conditions¹⁴⁰.</p>
<p>Links between evidence and recommendations</p>	<p>A set of key questions to help guide the literature search were identified by the guideline development group and these were incorporated into the search criteria along with the generic search terms.</p> <p>Evidence based summary statements were derived from the literature and used to develop the guidelines at a series of consensus meetings.</p>
<p>Piloting and peer review</p>	<p>The Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians reviewed the methodology and reviewed the final guidance prior to publication.</p> <p>All stakeholder organisations were asked to ratify and co-badge the final guidelines.</p> <p>Formal external reviews were obtained from Professor Jane Seymour (Nottingham), Professor Peter Bartlett (Nottingham) and Professor Gideon Caplan (New South Wales, Australia).</p>

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