

CONCISE GUIDANCE TO GOOD PRACTICE

A series of evidence-based guidelines for clinical management

NUMBER 12

Advance care planning

NATIONAL GUIDELINES

February 2009



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COUNCIL FOR
PALLIATIVE
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Concise Guidance to Good Practice series

The concise guidelines in this series are intended to inform those aspects of physicians' clinical practice which may be outside their own specialist area. In many instances, the guidance will also be useful for other clinicians including GPs, and other healthcare professionals.

The guidelines are designed to allow clinicians to make rapid, informed decisions based wherever possible on synthesis of the best available evidence and expert consensus gathered from practising clinicians and service users. A key feature of the series is to provide both recommendations for best practice, and where possible practical tools with which to implement it.

Series Editors:

Lynne Turner-Stokes FRCP and **Bernard Higgins** FRCP

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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. 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

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 care.¹ 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)
- 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 supercede 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 document does not override 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 Act,² and NHS initiatives aimed at increasing uptake of ACP,¹ 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 USA; 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 2005 (Fig 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 Appraisal of Guidelines Research and Evaluation (AGREE) criteria;⁴ 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 Conditions.⁵ The grading system is shown in Appendix 2. 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).

Background

Our review of the literature demonstrates that most of the general public (60–90%) is supportive of ACP,^{6–11} but only 8% of the public in England and Wales has completed an ACP document of any kind,¹² compared to 10–20% of the public in the US, Canada, Australia, Germany and Japan.^{13–16} 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 documents.^{50–52}

Figure 1. Making valid clinical decisions.

An advance refusal of treatment (ADRT) – see section 9.40 and 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 Fig 2)
- 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 act only 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 supercedes 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 interests 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 itself, 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
- need only be involved in specific decisions ('serious' medical treatments and admissions to hospitals or care homes)
- advise regarding best interests

NB 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: 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: www.publicguardian.gov.uk/docs/code-of-practice-041007.pdf
Office of Public Guardian: www.publicguardian.gov.uk

MCA = Mental Capacity Act 2005

The majority of individuals are happy to discuss ACP in primary and outpatient care settings when their condition is stable,^{53–58} 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 programme^{61–63} increase patient satisfaction. ACP discussions at entry into a care home may cause additional upset at a time of transition,⁶⁴ but can be successful once the individual is more settled, given appropriate staff education and training.^{21,65–69} While 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 Box 1).

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 care;^{79–81} 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 time;^{83–90} however, prior discussion increases proxy or physician surrogate decision accuracy,^{85,88,89,91} especially for decisions relating to coma or ventilation.⁹² 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 interpret;⁸⁷ a combination of personal narrative and specific advance refusals may be the best option.^{97–99}

Advance decisions to refuse treatment (ADRT)

The Mental Capacity Act (MCA), section 25,² sets out the requirements that ADRT must meet to be valid and applicable. Preferences are less likely to change if they have been discussed with a doctor.¹⁰⁰ 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 ADRT leads to the denial of appropriate healthcare^{61,106–111} or increases mortality.^{61,106,112–114}

Box 1. Tips for a successful ACP discussion.

- The individual needs to be ready for the discussion – it cannot be forced.
- Discussions usually need to take place on more than one occasion (over 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 (eg 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 empathy.¹³⁶
- A tool to introduce the concept and guide the discussion may help professionals to address ACP with people (see Box 2).
- Information should be given using words the person understands.
- Clarify any ambiguous terms used by your patient, for example: '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.
- The professional should summarise and check understanding with the patient.
- 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.

Box 2. Suggested content for an ACP document.

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 the individual wishes this), which should help direct care and a reference to any LPA.

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

ACP documents examined:

- Let Me Decide¹³⁸
- The Medical Directive¹³⁹
- Dignity in Dying (www.dignityindying.org.uk/livingwills/)
- Alzheimer's Society living will (www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=143)
- Hammersmith Expression of Healthcare Preferences¹³⁷
- Thinking Ahead – ACP planning discussion (www.goldstandardsframework.nhs.uk/advanced_care.php)
- Advanced Clinical management plan (Minnie Kidd House)
- Care Home Support Team – health care choices form
- Physician Orders for Life Sustaining Treatment (POLST) (www.ohsu.edu/polst)
- Lawpack Advance Medical Decision (www.lawpack.co.uk/Family/product859.asp)
- ADRT.nhs.uk (www.adrtnhs.co.uk/pages/links.htm)
- Preferred Priorities of Care (www.endoflifecareforadults.nhs.uk/eolc/ppc.htm)

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 discussions,⁶⁸ combined with educational materials^{66,91,119,120} and physician involvement,^{21,65,66} which can be prompted through routine reminders.^{58,119,121,122}

Training

Staff training should be based in the workplace, repeated regularly and led by experts;¹²³ peer mentoring is an effective educational intervention for selected patients.¹²⁴ 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 (eg Denmark), doctors are obliged to consult a central register of ACP documents when making best interests decisions,¹²⁵ while 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 healthcare costs,^{61,128} except when used systematically in the care home setting.⁶⁹ 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 hospitalised.^{130–133}

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Recommendation

Grade

A When and with whom should I be considering ACP discussions?

- ACP should be offered during routine clinical practice, but never forced upon an individual. **RB**
- Pre-existing ACPs should be acknowledged and reviewed if appropriate. **E1/2**
- Professionals should initiate ACP discussions with 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 Box 1). **RB**
- Ideally, ACP discussions should be initiated in primary care or in the outpatient setting, before individuals become acutely unwell. **RB**
- Professionals should avoid initiating discussions immediately after a move into a care home; discussions should be undertaken once individuals are more settled. **RB**
- ACP discussions should be initiated by an appropriately trained professional* who has rapport with the individual and, where necessary, supported by a professional with relevant specialist knowledge. **E1/2**
- 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 GP to initiate a general ACP discussion with a patient with cancer, but may not be appropriate for 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**
- 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**

B The discussion

- ACP discussions need to be skilfully led and should be a process, not a single event or a tick box exercise. **RB**
- Professionals should ensure that individuals have every opportunity to participate in the discussion by treating reversible illness impacting on decision-making, such as delirium or sensory impairment, and ensuring that the patient is pain-free, fed, not too tired etc. This may be better achieved when the individual is not an inpatient, and also relieves any perception that the health service has provided 'undue influence'. **E1**
- ACP discussions should not be continued if they are causing the patient excessive distress or anxiety. **E1/2**
- 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:
 - Older people may be concerned about the burden of their own illness on their family. **E1&2**
 - 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 opinion may be required. **RC**
 - the patient's gender, race, culture, sexual orientation, religion, beliefs and values **RB**
 - the patient's concerns about euthanasia. **RB**
- 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**

Box 1 offers some suggestions as to how an ACP discussion should be led.

Continued overleaf

* 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.

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Recommendation

Grade

C Will ACP work?

- Individuals preparing ACP documents should be advised that:
 - completing an advance care plan alone does not guarantee that their wishes will be respected. However, a valid and applicable ADRT must be followed. **RB**
 - healthcare providers are not obliged to provide medical care that is clinically inappropriate. **E2**
 - ADRTs are not valid if an LPA covering the same treatment was appointed after the ADRT was made. **E2**
- Individuals appointing an LPA should be aware that there may be misinterpretation of the patient's wishes by a proxy, even following guided discussions. **RC**
- Individuals should be strongly encouraged to discuss ACP with a healthcare professional. **RA**
- 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**
- ACP documents should be reviewed periodically, and particularly if circumstances change, for example:
 - if the individual's health changes or there is a new diagnosis **RB**
 - if there is a change in the individual's functional abilities. **RC**
- 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.* **E2**
- Healthcare professionals should make reasonable efforts† 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**
- Healthcare 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**
- 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**

D Individuals with progressive cognitive impairment

- Individuals should be offered ACP discussions early in their disease process. **RC**
- Healthcare professionals should consider using clinical vignettes or examples as useful aids for ACP in individuals with moderate cognitive impairment. **RC**
- Once a patient has lost capacity to make decisions about their future care (see Fig 2), 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**

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

† 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).

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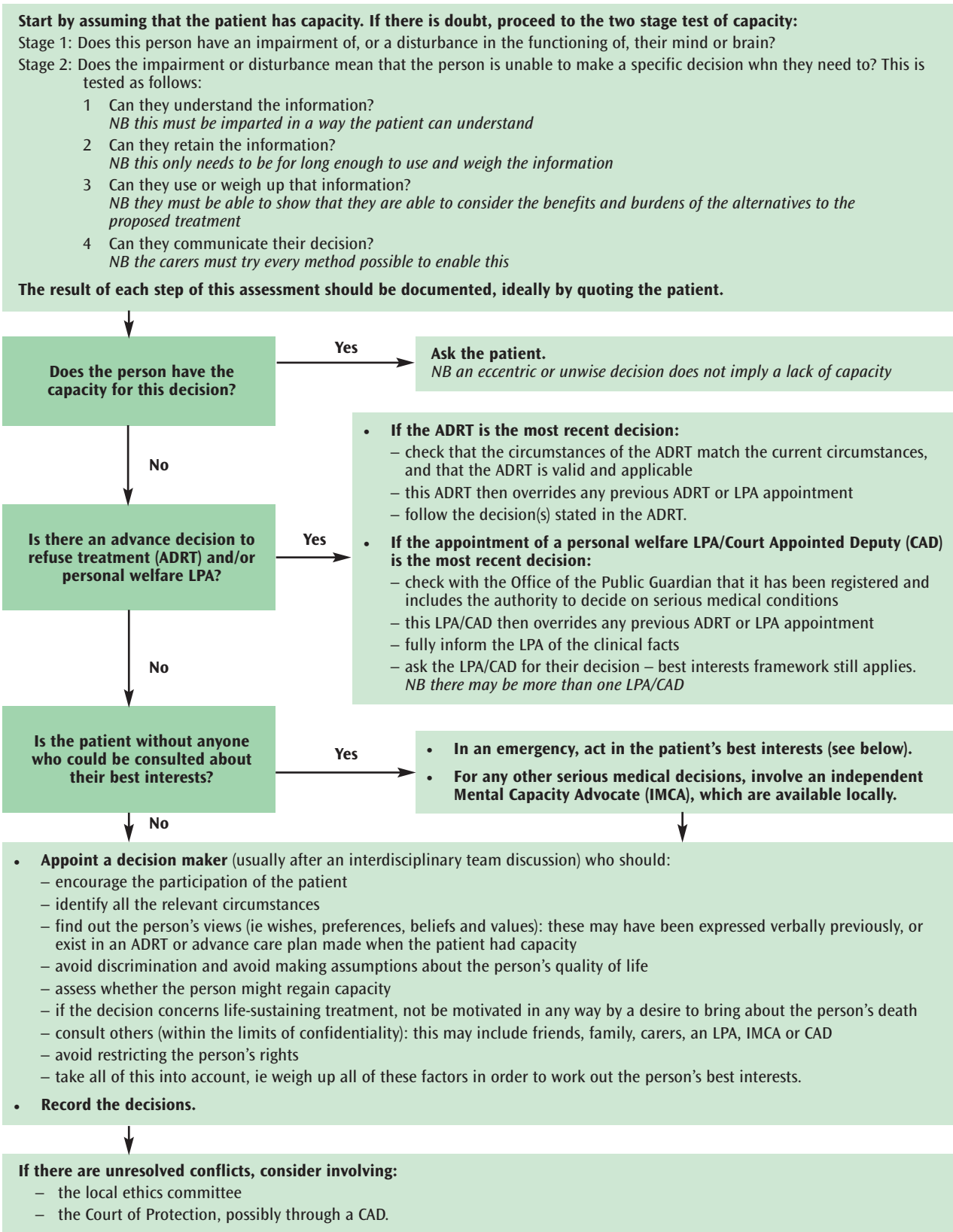
E Recommendations for training and implementation of ACP

- Health and social care staff should be trained in ACP discussions, especially:
 - doctors E1/2
 - case managers, such as nursing staff, community matrons, social workers and other key workers. RA
- Staff training should be workplace-based, recurrent and led by experts and expert patients. RC
- Public awareness about ACP should be increased; this is the responsibility of individual practitioners through to government departments. RC
- Public education must involve discussions with professionals as well the provision of educational material. RA
- Public education must not rely on handing out information leaflets alone. RA
- Peer education of patients should be included, using expert patients. RC
- 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
- Physicians should be routinely reminded to offer ACP discussion at an appropriate time to their patients. RA
- ACP should be part of the Quality Outcomes Framework and considered in annual care reviews of patients with long-term conditions. E1/2
- General practices should review how many people who have died in their practice were offered ACP, as part of annual care reviews. E1/2
- Medical records should contain a specific section for advance statements, ADRTs and resuscitation decisions. E1/2
- People with ACP documents should be encouraged to ensure the ACP document is readily available at all times.* E1/2
- 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
- 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

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

Figure 2. Making best interest decisions in serious medical conditions in patients over 18 years.

Adapted from Regnard, © Regnard, Dean and Hockley, *A Guide to Symptom Relief in Palliative Care* 6e. Oxford: Radcliffe Publishing; 2009. Reproduced with the permission of the copyright holder.



CAD = Court Appointed Deputy; LPA = Lasting Power of Attorney

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Appendix 1. Guideline development process

Scope and purpose

Overall objective 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	<p>Attitudes</p> <p>1 Is the general public in favour of ACP? 2 What are the attitudes of healthcare professionals towards ACP?</p> <p>Barriers</p> <p>3 How often do individuals change their minds about ACP? 4 Does ACP increase mortality? 5 Does ACP deny access to appropriate healthcare? 6 How can uptake of ACP be improved?</p> <p>Communication</p> <p>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 healthcare records and are available to healthcare practitioners seeing the patient for the first time?</p> <p>Content</p> <p>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?</p> <p>Demand</p> <p>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?</p> <p>Healthcare proxies</p> <p>20 Do LPAs influence care? 21 What is the concordance between surrogates and patients? 22 How accurate are substitute judgements in ACP?</p> <p>Outcomes</p> <p>23 Can ACP improve healthcare choices? 24 Does ACP affect satisfaction with healthcare? 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?</p>

Continued overleaf

Role of healthcare professionals

28 Which healthcare professionals should be involved in ACP?

Training

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

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

Dementia

31 What is known about ACP in people with dementia?

Stakeholder involvement

The Guideline Development Group	<p>The guideline committee was made up of various stakeholders, including strong lay representation, general practice and other clinicians. 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.</p> <p>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 (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>
Scoping exercise	<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).</p> <p>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 Conditions.⁵</p>
Link between evidence and recommendations	<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. Evidence-based summary statements were derived from the literature and used to develop the guidelines at a series of consensus meetings.</p>
Piloting and peer review	<p>The Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians reviewed the methodology and reviewed the final guidance prior to publication. 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>

Appendix 2. 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)