

Advance care planning: concise evidence-based guidelines

Simon Conroy, Premila Fade, Aileen Fraser and Rebekah Schiff on behalf of the
Guideline Development Group*

Simon Conroy

MB ChB MRCP,
Senior Lecturer/
Geriatrician,
Leicester Royal
Infirmary

Premila Fade

BSc MB BS MA FRCP,
Consultant
Geriatrician, British
Geriatrics Society

Aileen Fraser

RGN NPD
MSc(Nursing),
Consultant Nurse,
British Geriatrics
Society

Rebekah Schiff

MB BS MRCP,
Consultant
Geriatrician, British
Geriatrics Society
Concise Guidance
to Good Practice
Series Editors:
Lynne Turner-
Stokes FRCP and
Bernard Higgins
FRCP

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Introduction

At the core of current health and social care are efforts to promote patient-centred care, offer choice and offer 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 care. 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.

In writing these guidelines, we have assumed that readers are familiar with making valid clinical decisions according to the Mental Capacity Act (MCA) 2005.

Methods

This concise guidance is extracted from *Advance care planning: concise evidence based guidelines*. Details of the development process are given in the full guidelines along with the list of references. Each research paper identified was graded using the appraisal tool developed for use in the National Service Framework for Long Term Conditions.

Background

The majority of individuals are happy to discuss ACP in primary and outpatient care settings, when their condition is stable, in anticipation of future ill-health. Advance care planning discussions with patients with long-term conditions or as part of a broad end-of-life care management programme increase patient satisfaction. Advance care planning discussions at entry into a care home may cause additional upset at a time of transition, but can be successful once the individual is more settled, given appropriate staff education and training. While most professionals and patients (>80%) agree that ACP discussions should take place around the time of diagnosis of a life threatening illness, some patients with terminal disease or serious illness requiring hospitalisation may not feel ready or able to do so.

Advance care planning discussions can be successfully led by a competent case manager; this could be a community matron or other specialist nurse, with the necessary expertise and knowledge base. Discussions should be a process rather than a single event.

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. Multifaceted interventions involving case managers helping individuals draft ACP documents and collaboration between primary and secondary care can increase ACP documentation in medical records and reduce the number of treatment decisions not in agreement with the individual's wishes from 18% to 5%. Section 25 of the MCA 2005, 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 doctor. Even so, up to one-third of individuals will change their ACP over time (months or years), influenced by changes in diagnosis, hospitalisation, mood, health status, social circumstances and functional ability.

Implementation

Barriers to increased ACP uptake can be categorised according to client/individual factors (receptiveness

*This guidance was prepared on behalf of the multidisciplinary Guideline Development Group (GDG) convened by the British Geriatrics Society and the Royal College of Physicians with representation from the Royal College of General Practitioners, National Council for Palliative Care, Royal College of Nursing, Age Concern, Alzheimer's Society, Help the Aged, Faculty of Old Age Psychiatry (Royal College of Psychiatrists and British Society of Rehabilitation Medicine)

The guidelines

Recommendation	Grade
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 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	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 but should be undertaken once they are more settled	RB E1/2
• 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 general practitioner 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 have 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
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, sensory impairment, being pain free, fed, not too tired etc. This may be better achieved when 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 excessive distress or anxiety to the patient	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
Will ACP work?	
• Individuals preparing ACP documents should be advised that:	
(a) completing an ACP alone does not guarantee that their wishes will be respected. However a valid and applicable ADRT must be followed	RB
(b) healthcare providers are not obliged to provide clinically inappropriate medical care	E2
(c) ADRTs are not valid if an LPA covering the same treatment was appointed after the ADRT was made	E2
• 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
<i>continued</i>	

The guidelines – continued

Recommendation	Grade
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Will ACP work? – continued

- | | |
|---|------|
| ● 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 ACP 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 ACP, and how it can be accessed | E1/2 |
| ● Health and social care providers should ensure that ACPs travel with patients and are respected across sectors, by ensuring that documentation is recognised/respected across sectors and included in transfer/handover procedures | RA |

Individuals with progressive cognitive impairment

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|---|------|
| ● 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, 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 2005 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

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|--|------|
| ● Health and social care staff should be trained in ACP discussions, especially: | E1/2 |
| – doctors | RA |
| – case managers, such as nursing staff, community matrons, social workers and other key workers | RC |
| ● 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 as 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 an annual care reviews | E1/2 |

continued

The guidelines – continued

Recommendation	Grade
Recommendations for training and implementation of ACP – continued	
• 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

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 training); service factors (lack of funding, lack of time), doctors' beliefs about appropriateness and system factors (lack of communication with providers, legislation, providers unaware of case manager).

Public awareness/education

Increased uptake of ACP is achieved through a combination of professionals initiating the discussions, combined with educational materials; and physician involvement, which can be prompted through routine reminders.

Training

Staff training should be based in the workplace repeated regularly and led by experts; peer mentoring is an effective educational intervention for selected patients. 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 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.

Health economics

Advance care planning does not reliably reduce healthcare costs, except when used systematically in the care home setting. Any cost reduction associated with ACP is probably related to

avoiding 'terminal hospitalisation', or because people with an ADRT are less likely to receive life-sustaining therapy when hospitalised.

Members of the Guideline Development Group

Dr Simon Conroy, British Geriatrics Society and development lead; Mrs Jane Buswell, Consultant Nurse, British Geriatrics Society; Mr Simon Chapman, National Council for Palliative Care; Dr Judi Edmans, University of Nottingham; Dr Premila Fade, British Geriatrics Society; Mrs Aileen Fraser, Consultant Nurse, British Geriatrics Society; Dr Ann Homer, Royal College of General Practitioners; Mrs Margaret Hughes, lay representative; Dr Debra King, British Geriatrics Society; Mr Roy Latham, lay representative; Dr Jane Liddle, British Geriatrics Society; Ms Rebecca Neno, Royal College of Nursing; Dr Rebekah Schiff, British Geriatrics Society; Mrs Pauline Thompson, Age Concern; Professor Lynne Turner-Stokes, Royal College of Physicians; Dr Jonathan Waite, Faculty of Old Age Psychiatry, Royal College of Psychiatrists; Ms Sara Wilcox, Alzheimer's Society; Ms Katharine Young (technical support), Royal College of Physicians.

New Title

The full version of the guidelines including methods, additional tables and references can be purchased at www.rcplondon.ac.uk/pubs/brochure.aspx?e=267