

The care of all dying patients must improve to the level of the best



End of Life Care



Advance Care Planning: A Guide for Health and Social Care Staff



Advance care planning for adults affected by a life limiting condition

Foreword

Caring for people at the end of their lives is an important role for many health and social care professionals. One of the aspects of this role is to discuss with individuals their preferences regarding the type of care they would wish to receive and where they wish to be cared for in case they lose capacity or are unable to express a preference in the future. These discussions clearly need to be handled with skill and sensitivity. The outcomes of such discussions may then need to be documented, regularly reviewed and communicated to other relevant people, subject to the individual's agreement. This is the process of Advance Care Planning (ACP).

This document highlights the key issues and challenges of incorporating ACP into patient care. It contains useful information on the key principles of ACP and on the definitions of ACP and related terms. It also indicates how ACP links to the Mental Capacity Act (2005).

The document was initially developed as part of the three year (2004-2007) End of Life Care Programme hosted by the NHS. I believe it is directly relevant to the End of Life Care Strategy. I also believe that many health and social care professionals will find it useful in their clinical practice.

I would like to thank all those who have contributed to the development of this document and especially Claire Henry, National Programme Director, NHS End of Life Care Programme and Professor Jane Seymour, Sue Ryder Care Professor of Palliative and End of Life Studies at the University of Nottingham.



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For the purposes of this paper, the individuals referred to will be adults affected by a life limiting condition.

Advance care planning for adults affected by a life limiting condition

1. Introduction and aims

The area of advance care planning (ACP) is becoming increasingly important but can be confusing for health and social care professionals and the public. ACP has always been an intrinsic part of the NHS End of Life Care Programme (EoLC); the Preferred Priorities for Care (PPC) document is an example of this. Interest is growing, with more literature being published. The enactment of the Mental Capacity Act 2005 has highlighted the need for clarification and a national approach.

The first edition of the document was initially developed as part of the three year (2004-2007) End of Life Care Programme hosted by the NHS.

Following feedback and debate the National End of Life Care steering group met during 2006 and agreed that guidance relating to ACP was required for health and social care professionals which recognises their different contributions to an individual's care.

We were grateful for the opportunity to consult and discuss with key stakeholders and a wider reference group and address three objectives:

- 1 To clarify the definition of ACP and related terms
- 2 To provide practical guidance on core competences, education and training of different professional groups and related ethical and legal implications
- 3 To suggest next steps, to report on related work and suggest further work

The second edition of this document takes into account the implementation of the Mental Capacity Act 2005 which came into force in October 2007 along with the supporting Code of Practice. Chapter 9 of the Mental Capacity Act (MCA) 2005 Code of Practice refers specifically to Advance Decisions to Refuse Treatment and will be used as a guide to sections within this document that refer to advance decisions.

Advance care planning

ACP is a process of discussion between an individual and their care providers irrespective of discipline.

The difference between ACP and planning more generally is that the process of ACP is to make clear a person's wishes and will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others.

With the individual's agreement, discussions should be:

- documented
- regularly reviewed
- communicated to key persons involved in their care.
- If the individual wishes, their family and friends may be included.

Examples of what an ACP discussion might include are:

- the individual's concerns
- their important values or personal goals for care
- their understanding about their illness and prognosis, as well as particular preferences for types of care or treatment that may be beneficial in the future and the availability of these.

Statement of wishes and Preferences

This is a summary term embracing a range of written and/or recorded oral expressions, by which people can, if they wish, write down or tell people about their wishes or preferences in relation to future treatment and care, or explain their feelings, beliefs and values that govern how they make decisions. They may cover medical and non-medical matters. They are not legally binding but should be used when determining a person's best interests in the event they lose capacity to make those decisions.



Advance decision

An advance decision must relate to a refusal of specific medical treatment and can specify circumstances.

It will come into effect when the individual has lost capacity to give or refuse consent to treatment.

Careful assessment of the validity and applicability of an advance decision is essential before it is used in clinical practice. Valid advance decisions, which are refusals of treatment, are legally binding.

Lasting Power of Attorney

A Lasting Power of Attorney (LPA) is a statutory form of power of attorney created by the MCA (2005). Anyone who has the capacity to do so may choose a person (an 'attorney') to take decisions on their behalf if they subsequently lose capacity.

2. Advance care planning

2.1. Definition

Advance care planning (ACP) is a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. If the individual wishes, their family and friends may be included. It is recommended that with the individual's agreement this discussion is documented, regularly reviewed, and communicated to key persons involved in their care¹. An ACP discussion might include:

- the individual's concerns and wishes,
- their important values or personal goals for care,
- their understanding about their illness and prognosis,
- their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these.

2.2. Role of ACP in supportive care

If an individual wishes, ACP may be an integral part of the care and communication process and of their regular care plan review. The difference between ACP and care planning more generally is that the process of ACP will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others.

2.3. Documentation of ACP

There is no set format for making a record of advance care planning discussions, although having a person's wishes documented will prove helpful to those involved in their future care.

Professionals who support a person in advance care planning should try to avoid following a rigid prescriptive method of interview and recording of discussions, this can be achieved by using an open question style of dialogue.

2.4. ACP and the MCA

For individuals with capacity it is their current wishes about their care which needs to be considered. Under the MCA of 2005, individuals can continue to anticipate future decision making about their care or treatment should they lack capacity. In this context, the outcome of ACP may be the completion of a statement of wishes and preferences or if referring to refusal of specific treatment may lead onto an advance decision to refuse treatment (Chapter 9 MCA 2005 Code of Practice). This is not mandatory or automatic and will depend on the person's wishes. Alternatively, an individual may decide to appoint a person to represent them by choosing a person (an 'attorney') to take decisions on their behalf if they subsequently lose capacity (Chapter 5 MCA 2005 Code of Practice).

A statement of wishes and preferences is not legally binding. However, it does have legal standing and must be taken into account when making a judgement in a person's best interests. Careful account needs to be taken of the relevance of statements of wishes and preferences when making best interest decisions (Chapter 5 MCA 2005 Code of Practice).

If an advance decision to refuse treatment has been made it is a legally binding document if that advance decision can be shown to be valid and applicable to the current circumstances. If it relates to life sustaining treatment it must be a written document which is signed and witnessed.

¹ Guidance on communication is contained in the *Improving Supportive and Palliative Care Guidance NICE 2004*

In all cases, an individual's contemporaneous capacity must be assessed on a decision-by-decision basis. An individual may retain the ability to make a simple decision but not more complex decisions (Chapter 4 MCA 2005 Code of Practice).

2.5. Considering the use of ACP: timing and context

ACP may be instigated by either the individual or a care provider at any time not necessarily in the context of illness progression but may be at one of the following key points in the individual's life:

- Life changing event, e.g. the death of spouse or close friend or relative
- Following a new diagnosis of life limiting condition eg cancer or motor neurone disease
- Significant shift in treatment focus e.g. chronic renal failure where options for treatment require review
- Assessment of the individual's needs
- Multiple hospital admissions

Initiation of ACP discussion by a care provider requires careful consideration:

- ACP is voluntary and should not be initiated simply as part of routine record keeping or care
- The care provider may respond to 'cues' which indicate a desire to make specific wishes known e.g. worries about who will care for them
- ACP should not be initiated as a result of outside pressure e.g. family wishes or organisational pressures
- The care provider will require appropriate communication skills
- The care provider should have full knowledge of the person's medical condition, treatment options and social situation
- There may be someone more appropriate to carry out this discussion e.g. specialist nurse
- The time and setting should be appropriate for a private discussion

The following are examples of situations in which ACP may be appropriate:

- 1) Mrs Adams - A 54 year old woman with cancer of the colon with liver metastases. She develops jaundice which cannot be treated and is feeling increasingly weak and tired. This lady is now recognising she has a progressive disease and may wish to discuss her future care.
- 2) Mr Brown—A 76 year old man with heart failure with increasing breathlessness on walking who finds it difficult to leave his home, has had two hospital admissions in the last year and is worried about the prospect of any more emergencies and coping with the future.
- 3) Mrs Carter – An 81 year old lady with COPD, heart failure, osteoarthritis and increasing forgetfulness, who lives alone. She fractured her hip after a fall, eats a poor diet and finds mobility difficult. She wishes to stay at home but is increasingly unable to cope alone and appears to be 'skating on thin ice'.

3. Statement of wishes, preferences, beliefs and values

Sometimes people will want to write down or tell others their wishes and preferences for future treatment and care, or explain their feelings or values that govern how they make decisions. Statements of wishes and preferences or documented conversations the person has had with their family or other carers may be recorded in the person's notes. A statement of wishes and preferences can be of various types, for example:

- A requesting statement reflecting an individual's aspirations and preferences. This can help health and social care professionals identify how the person would like to be treated without binding them to that course of action if it conflicts with professional judgment (see section 3.1 ACP)
- A statement of the general beliefs and aspects of life which an individual values. This might provide a biographical portrait of the individual that subsequently aids deciding his/her best interests.

Statements of wishes and preferences can include personal preferences, such as where one would wish to live, having a shower rather than a bath, or wanting to sleep with the light on. Sometimes people may wish to express their values e.g. that the welfare of their spouse or children is taken into account when decisions are made about their place of care. Sometimes people may have views about treatments they do not wish to receive but do not want to formalise these views as a specific advance decision to refuse treatment. These views should be considered when acting in a person's best interests but will not be legally binding. A statement of wishes and preferences cannot be made in relation to any act which is illegal e.g. assisted suicide.

3.1. Professional responsibilities in relation to statements of wishes and preferences

Under the MCA, anybody making a decision about the care or treatment of an individual, who has been assessed as lacking the capacity to make that decision for himself, will be required to take any statement of wishes and preferences into account when assessing that person's best interests.

Part of assessing best interests should include making reasonable efforts to find out what a person's wishes, preferences, values and beliefs might be. This is likely to involve contacting the person's family or other care providers. They may be able to advise whether any statements of wishes or preferences exists or for help in determining that person's wishes. This will not always be possible, e.g. if an individual is admitted as an emergency, is unconscious and requires rapid treatment.

3.2 Acting in a person's 'best interests'

A person assessing an individual's best interests must:-

- Not make any judgement using the professional's view of the individual's quality of life
- Consider all relevant circumstances and options without discrimination
- Not be motivated by a desire to bring about an individual's death
- Consult with family partner or representative as to whether the individual previously had expressed any opinions or wishes about their future care e.g. ACP
- Consult with the clinical team caring for the individual
- Consider any beliefs or values likely to influence the individual if they had capacity
- Consider any other factors the individual would consider if they were able to do so
- Consider the individual's feelings

4. Advance decision to refuse treatment

During the course of ACP discussions it may become apparent that the person wishes to make an advance decision to refuse treatment. The making of an advance decision should be made under the guidance of someone who understands the complexities of the process.

The professional involved in the discussion should be willing and able to discuss what is involved in the making of an advance decision or be able to give direction as to the appropriate action to be taken (refer to the MCA 2005 Code of Practice Chapter 9).

The MCA 2005 provides the statutory framework to enable adults with capacity to document clear instructions about refusal of specific medical procedures should they lack capacity in the future.

An advance decision to refuse treatment

- Can be made by someone over the age of 18 who has mental capacity
- Is a decision relating to refusal of specific treatment and may be in specific circumstances
- Can be written or verbal
- If an advance decision includes refusal of life sustaining treatment, it must be in writing, signed and witnessed and include the statement 'even if life is at risk'
- Will only come into effect if the individual loses capacity
- Only comes into effect if the treatment and circumstances are those specifically identified in the advance decision
- Is legally binding if valid and applicable to the circumstances.

5. Lasting Power of Attorney (LPA)

Part of ACP may be making the professional aware of the existence of a Lasting Power of Attorney (LPA). A LPA is a statutory form of power of attorney created by the MCA. Anyone who has the capacity to do so may choose a person (an 'attorney') to take decisions on their behalf if they subsequently lose capacity. The LPA replaces the Enduring Power of Attorney (EPA) the Enduring Powers of Attorney Act 1985. Unlike the EPA, this can extend to include personal welfare matters as well as property and affairs.

www.dca.gov.uk/menincap/faq.htm

Under the MCA 2005, the holder or holders of a personal welfare LPA may be appointed by the individual to make all or specific health and welfare decisions on their behalf, should they lose capacity, as if he/they were the person receiving care. In particular, the individual must specify whether the appointed holder of the LPA has the authority to make decisions on life sustaining treatment. Any decisions taken by the appointed person must be made in the individual's best interests. Part 1, Section 4, MCA gives a checklist to define 'best interests'.

www.opsi.gov.uk/acts/acts2005/20050009.htm

5.1. Personal welfare decisions

Example²

Caroline has dementia and lives at home with the support of carers from a domiciliary care agency. Over the last two days, she has become very confused and unable to make decisions about the care she receives. The care worker has suggested that the GP be called. Caroline is adamant that she does not require the GP. It is clear that Caroline is unwell and the care worker, having consulted the family, assesses that Caroline lacks the capacity to make the decision about whether or not to call the doctor. So the care worker calls the GP and records her actions in the care plan.

The GP visits Caroline and diagnoses a urinary tract infection. He requests a urine sample for analysis and commences treatment with antibiotics. Within three days, Caroline has regained her capacity, for this decision.

5.2. Healthcare decisions

Example²

Mrs Jones has never trusted doctors and prefers to rely on alternative therapies and remedies. Having seen her father suffer for many years after invasive treatment for cancer, she is clear that she would wish to refuse such treatment for herself, even with the knowledge that she would die without it. When she is diagnosed with bowel cancer, Mrs Jones discusses this issue with her husband. Mrs Jones trusts her husband more than anyone else and knows he will respect her wishes about the forms of treatment she would or would not accept. She therefore asks him to act as her attorney to make welfare and healthcare decisions on her behalf, should she lack the capacity to make her own decisions at any time in the future. Mrs Jones makes a general welfare personal LPA appointing her husband to make all her welfare decisions and includes a specific statement authorising him to refuse life-sustaining treatment on her behalf. He will then be able to make decisions about treatment in her best interests, taking into account what he knows about his wife's feelings as part of making the best interests determination.

A LPA must be in a prescribed form and be registered with the Office of the Public Guardian.

The Office of Public Guardian supports and promotes decision making for those who wish to plan for the future. The website provides information

- on making personal arrangements
- what to do if there are concerns about someone else making decisions
- information for those allowed to make decisions for others e.g. LPA

www.publicguardian.gov.uk/index.htm

² MCA 2005 Code of Practice

² Frequently Asked Questions MCA 2005 Department for Constitutional Affairs

6. Key principles of Advance Care Planning Process

- The process is voluntary. No pressure should be brought to bear by the professional, the family or any organisation on the individual concerned to take part in ACP
- ACP must be a patient centred dialogue over a period of time
- The process of ACP is a reflection of society's desire to respect personal autonomy. The content of any discussion should be determined by the individual concerned. The individual may not wish to confront future issues; this should be respected
- All health and social care staff should be open to any discussion which may be instigated by an individual and know how to respond to their questions
- Health and social care staff should instigate ACP only if in the context of a professional judgement that leads them to believe it is likely to benefit the care of the individual. The discussion should be introduced sensitively
- Staff will require the appropriate training to enable them to communicate effectively and to understand the legal and ethical issues involved
- Staff need to be aware when they have reached the limits of their knowledge and competence and know when and from whom to seek advice
- Discussion should focus on the views of the individual, although they may wish to invite their carer or another close family member or friend to participate. Some families may have discussed their issues and would welcome an approach to share this discussion
- Confidentiality should be respected in line with current good practice and professional guidance
- Health and social care staff should be aware of and give a realistic account of the support, services and choices available in the particular circumstances. This should entail referral to an appropriate colleague or agency when necessary
- The professional must have adequate knowledge of the benefits, harms and risks associated with treatment to enable the individual to make an informed decision
- Choice in terms of place of care will influence treatment options, as certain treatments may not be available at home or in a care home, e.g. chemotherapy or intravenous therapy. Individuals may need to be admitted to hospital for symptom management, or may need to be admitted to a hospice or hospital, because support is not available at home
- ACP requires that the individual has the capacity to understand, discuss options available and agree to what is then planned. Agreement should be documented www.opsi.gov.uk/acts/acts2005/20050009.htm
- Should an individual wish to make a decision to refuse treatment (advance decision) they should be guided by a professional with appropriate knowledge and this should be documented according to the requirements of the MCA 2005 www.opsi.gov.uk/acts/acts2005/20050009.htm

7. Principles of record making in Advance Care Planning

- Healthcare professionals cannot make a record of the discussion without the permission of the individual
- The individual concerned must check and agree the content of the record
- Information cannot be shared with anyone, unless the individual concerned has agreed to disclosure. Where the individual refuses to share information with certain individuals the options should be explained to them and the consequences made clear
- Any record should be subject to review and if necessary, revision and it should be clear when this is planned. Review may be instigated by the individual or care provider, can be part of regular review or may be triggered by a change in circumstances
- A clear record of who has copies of the document will help facilitate future updating and review
- Copies in notes should be updated when an individual makes any changes
- Where an advance decision is recorded, it should follow guidance available in the Code of Practice for the MCA <http://www.dca.gov.uk/menincap/legis.htm#codeofpractice> and be recorded on a separate document to that used for ACP
- The professional making the record of an advance decision must be competent to complete the process
- Where this is part of a professional's role, competence based training needs to be available and accessed
- If the individual agrees for their record to be shared, it should be ensured that systems are in place to enable sharing between health and social care professionals involved in the care of the individual, including out of hours providers and ambulance services
- For an individual who has lost capacity disclosure of a statement will be based on best interests
- There should be locally agreed policies about where the document is kept. For example, it may be decided that a copy should be given to the individual and a copy placed in the notes

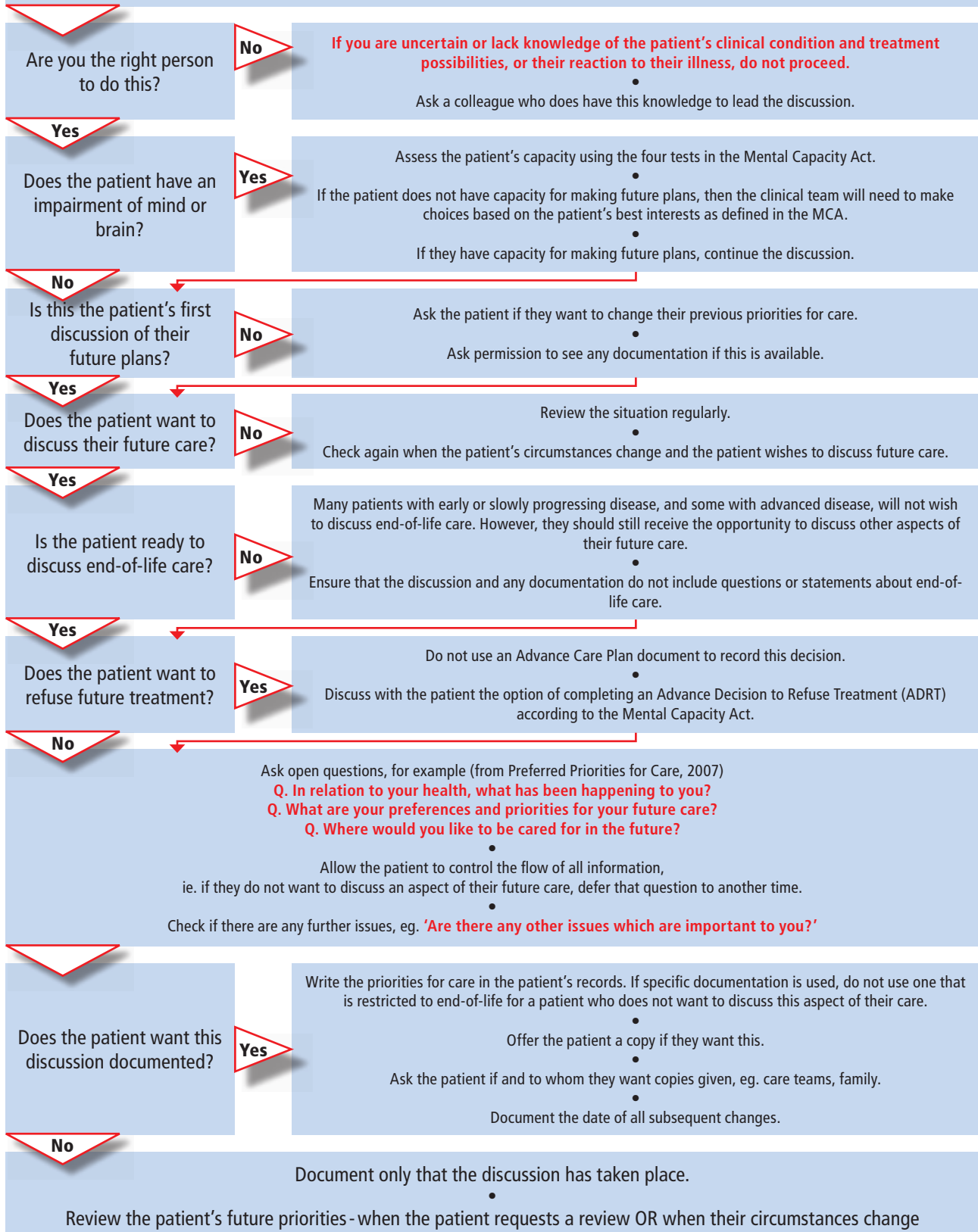
Examples

Local ambulance policies - London Ambulance Service, Yorkshire Ambulance Service have communication systems in place to inform ambulance crews of patient choices, Shropshire PCT provide information for individuals and suggest that the individual carry a card informing people of an advance decision, East Midland Ambulance Service have commenced a registration system for End of Life decisions to avoid situations when resuscitation efforts were commenced that were either inappropriate or against the wishes of the patient.

Discussing future care with patients

© v11. Regnard C, Randall F. 2008 (from A Guide to Symptom Relief in Palliative Care, 6th ed. Oxford: Radcliffe Press)

Enabling patients to express their wishes regarding future plans is an important part of effective communication. It is a process of discussion between an individual and their care providers irrespective of discipline, and the purpose is **to convey** the patient's **wishes so that they can be taken into account at a future time when the patient has lost capacity** (www.endoflifecareforadults.nhs.uk/eolc/acp.htm).



8. Core competences for health and social care professionals

The key issues to be addressed are:

- awareness of the context in which ACP may be appropriate (section 2)
- awareness of ACP
- awareness of advance decision to refuse treatment and relevant guidance about documentation
- communication skills
- informed consent and the ability to give sufficient information
- legal and ethical issues – codes of practice, MCA
- technical skills and knowledge
- relationship building
- knowledge of local resources

It is important that professionals recognise their own levels of skill and limitations. Protocols need to be agreed to support the ACP process. Consideration should be given to delivery of education and training and the different providers need to ensure consistency. It needs to be linked with existing frameworks e.g. NHD Knowledge and Skills Framework (KSF).

Some examples of these are listed:

Examples of existing competences:

Skills for Health and skills for care have a framework of competences and National Vocational Qualifications (NVQ) assessed against the National Occupational Standards (NOS)

Social care staff, level 2–4 contain core units of communication, and principles of care
www.skillsforcare.org.uk

Health and social care, level 3 HSC385 Support individuals through the process of dying
www.skillsforhealth.org.uk

9. Conclusion and next steps

There are now opportunities to address the fundamental issues of planning for future care and to engage and integrate with agencies working on similar issues. This will involve learning from the experience in other countries and taking account of other initiatives.

This is a complex area in which there is a need not only for guidance and information for health and social care staff, but also for individuals, families, care providers and the public. There is a specific need to involve users in the production of such information.

The Preferred Place of Care (PPC) document has been reviewed to take account of this guidance and changes brought about by the MCA 2005 and has now been launched as Preferred Priorities for Care - 2008.

Further work needs to be undertaken on the education, training and core competences for health and social care staff.

Further research on ACP is necessary, both to evaluate the effect the ACP process itself may have on individuals, and to evaluate any interventions in care or treatment that may result from ACP. Any existing evidence from research on ACP must also be reviewed.

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Please note some of these individuals may have changed roles

NB. All information correct at time of print

Glossary

Advance Care Planning	ACP
Advance Decisions to Refuse Treatment.....	ADRT
Chronic Obstructive Pulmonary Disease	COPD
Department of Health	DH
End of Life Care Programme.....	EoLC
General Practitioner	GP
Gold Standards Framework.....	GSF
Knowledge and skills framework	KSF
Lasting Power of Attorney.....	LPA
Liverpool Care Pathway.....	LCP
Mental Capacity Act.....	MCA
National Council for Palliative Care	NCPC
National Health Service.....	NHS
National Occupational Standards	NOS
National vocational qualifications	NVQ
Out of Hours	OOH
Preferred Priorities for Care.....	PPC
Strategic Health Authority.....	SHA

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Prognostic Indicator Guidance Gold Standards Framework - 2006

Background material

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www.respectingpatientchoices.org.au

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Advance Decisions Policy South Downs NHS Trust – 2005

Mid Trent Guidance on Advance Decisions to Refuse Treatment

Advance Decisions to Refuse Treatment training www.adrtnhs.co.uk

The Mental Capacity Act in Practice-Guidance for End of Life Care

www.ncpc.org.uk/publications



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