

End of Life Care
Programme



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 key 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. These discussions clearly need to be handled with skill and sensitivity. The outcomes of such discussions 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 routine 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 has been developed as part of the three year (2004-2007) End of Life Care Programme currently running within the NHS. I believe it will also be directly relevant to the End of Life Care Strategy which is being developed by the Department of Health. 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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National Cancer Director

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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 Place of Care (PPC) document is an example of this. Interest is growing, with more literature being published. The forthcoming enactment of the MCA 2005 has highlighted the need for clarification and a national approach.

Through feedback and debate following the National EoLC steering group meeting on February 9th 2006 the steering group agreed that guidance relating to ACP was required for health and social care professionals which recognises their different contributions to an individuals care.

This paper is the result of consultation and discussion with key stakeholders and a wider reference group. It addresses 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

Claire Henry, National Programme Director, NHS EoLC Programme and Jane Seymour, Sue Ryder Care Professor of Palliative and End of Life Studies at the University of Nottingham, have led this work.

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

Advance care planning

ACP is a process of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included. With the individual's agreement, discussions should be:

- documented
- regularly reviewed
- communicated to key persons involved in their care.

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.

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.

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.



Advance decision

An advance decision must relate to a specific refusal of medical treatment and can specify circumstances. It will only come into effect when the individual has lost capacity to give or refuse consent.

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 new 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

ACP is a process of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included. With the individual's agreement, this discussion should be documented, regularly reviewed, and communicated to key persons involved in their care¹. An ACP discussion might include:

- the individual's concerns,
- their important values or personal goals for care,
- their understanding about their illness and prognosis,
- their preferences 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 should 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. ACP and the MCA

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 (section 3) or an advance decision (section 4) but 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 (section 5).

Providing that the advance decision which refused treatment is valid and applicable it is legally binding.

A statement of wishes and preferences is not legally binding. This must be taken into account when making a judgement on a person's best interests. Careful account needs to be taken of the applicability and validity of statements of wishes and preferences in making best interest decisions (section 4).

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.

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

2.4. Considering the use of ACP: timing and context

ACP may be instigated by either the individual or a care provider at the following key points in the individual's life in particular, although it may also be initiated at other times as well:

- Life changing event, eg the death of spouse or close friend or relative
- Following a new diagnosis of life limiting condition eg cancer or motor neurone disease where this is appropriate to the individual's condition and prognosis
- Assessment of the individual's need
- In conjunction with prognostic indicators–
www.goldstandardsframework.nhs.uk/non_cancer.php
- Multiple hospital admissions
- Admission to a care home

The following are examples of situations in which ACP may be appropriate²:

- 1) Mrs Adams - A 54 year old woman with cancer of the colon with liver secondaries and requiring a stent for jaundice who is feeling increasingly weak and tired.
- 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'.

² Prognostic Indicator Guidance Gold Standards Framework

3. Statement of wishes and preferences

Sometimes people will want to write down or tell others about their wishes and preferences about 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)
- 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. Such statements may also include requests and/or types of medical treatment they would or would not want to receive. Sometimes people may have views about treatments they do not wish to receive but do not want to formalise these views as an advance decision. A statement of wishes and preferences cannot be made in relation to any act which is illegal eg assisted suicide.

Health and social care professionals must consider statements of wishes and preferences carefully when assessing a person's best interest. However, they are not legally binding in the same way, as are advance decisions.

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 therefore include making reasonable efforts to find out what a person's wishes and preferences might be. This is likely to involve contacting the person's family or other care providers to ascertain whether any statements of wishes or preferences exists or for help in determining that persons wishes. This will not always be possible, eg if an individual is admitted as an emergency, is unconscious and requires rapid treatment.

4. Advance decision

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

An advance decision as defined in Section 24 of the MCA 2005 means a decision made by a person after he has reached 18 years of age and when he has capacity to do so, that if:-

- a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing healthcare for him, and
- b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.

A person may withdraw or alter an advance decision at any time when he has the capacity to do so.

A withdrawal (including a partial withdrawal) of any advance decision need not be in writing although it is best practice to record any such withdrawal; nor does any alteration unless it relates to life sustaining treatment.

4.1. Validity and applicability of advance decisions

In order for advance decisions to apply they must be valid and applicable. The following factors are important to consider:

- A valid and applicable advance decision has the same force as a contemporaneous refusal of treatment
- An advance decision must relate to a specific treatment
- An advance decision can be expressed in lay terms but it must be clear
- An advance decision only ever comes into effect when a patient has lost capacity to make that decision for themselves. The MCA says that advance decisions may specify the circumstances for which they are refusing treatment – eg If I cannot swallow
- If a professional has reasonable grounds for believing that there have been changes in circumstances not anticipated by the person when they made the advance decision and which would have affected the advance decision had s/he anticipated them at the time then the professional will need to consider if the advance decision is still valid
- An advance decision which refuses all treatment or particular types of treatment in all circumstances because of an explained religious or philosophical position may be valid and applicable.

It is made clear in the MCA that an advance decision will have no application to any treatment, which a doctor considers necessary to sustain life, unless strict formalities have been complied with. These formalities are that the decision must specify the treatment, be in writing, signed and witnessed. This can mean recorded in the person's notes and signed by the person or by someone else at the person's direction. In addition, there must be an express statement that the decision stands, even if life is at risk (Summary of Section 25, MCA 2005 DH).

An advance decision is not valid:

- If it has been withdrawn by the individual while they had the capacity to do so. Withdrawals do not have to be in writing.
- If the person has overridden it by making a later LPA that relates to the treatment specified in the advance decision.
- If the individual has done anything which is clearly inconsistent with the advance decision. It is important to check for actions that clearly indicate a person has changed their mind, although it will not be possible to scrutinise every action since the advance decision was made.

Example³

A young man, whose friend died after prolonged hospital treatment, made a signed and witnessed treatment specific advance decision and statement refusing any treatment to keep him alive by artificial means if he was injured in this way. A few years later, he is seriously injured in a road traffic accident and is paralysed from the neck down and is only able to breathe with artificial ventilation. Initially he remains conscious and is able to consent to treatment on being taken to hospital. He participates actively in a rehabilitation programme. Some months later, he loses consciousness. It is at this point that his written advance decision is located, though he has not mentioned it during his treatment. His previous consent to treatment and involvement in rehabilitation is clearly inconsistent with his actions prior to his lack of capacity. Anyone assessing the advance decision would need to make careful consideration of the considerable doubt this inconsistency puts on its validity.

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

Where a person has made an advance decision to refuse treatment and that advance decision is assessed as not valid and/or applicable, there may be reasonable grounds for believing that it is a legitimate expression of the person's wishes. In such circumstances, it must then be taken into account as part of any 'best interests' determination.

The absence of a valid and applicable advance decision to refuse treatment should not automatically lead to the presumption that treatment (including life-sustaining treatment) must always be provided. Any such decision must be based upon an overall assessment of the individual's best interests.

³ MCA 2005 Draft Code of Practice

4.2. The broader context of advance decisions

All adults with capacity have an established legal right in common law ahead of the implementation of the MCA (2005) to refuse medical procedures in advance. An unambiguous and informed advance refusal is as valid as a contemporaneous decision. Health and social care professionals are bound to comply when the refusal specifically addresses the situation which has arisen.

Refusal is a serious matter, ideally to be considered in discussion with health and social care professionals. An individual may also want to seek advice from a patient support group or other organisation that can provide information based on experience of specific conditions or situations. This is voluntary. (MCA 2005 draft Code of Practice, Chapter 8.

Further guidance is contained in the MCA 2005 Draft Code of Practice

www.dca.gov.uk/menincap/mcbdraftcode.pdf

The MCA states, that in cases where there is serious doubt, these should be referred to the Court of Protection. Furthermore, the current position on issues of conscience remain unchanged under the Act. Health or social care professionals who disagree in principle with an individual's decisions to refuse life-sustaining treatment are entitled to have their personal beliefs respected and will not be pressurised to act contrary to those beliefs.

5. Lasting Power of Attorney

A LPA is a new 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 will replace the Enduring Power of Attorney (EPA) currently provided for by the Enduring Powers of Attorney Act 1985. Unlike the EPA, this can extend to 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 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

Example³

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 mental capacity, and can therefore make decisions herself.

5.2. Healthcare decisions

Example⁴

'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 Public Guardian which will be established by the Department of Constitutional Affairs after the Act is implemented.

³ MCA 2005 Draft Code of Practice

⁴ 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 on the individual concerned to take part in ACP
- The process of ACP is a reflection of society's desire to respect its individuals autonomy, therefore the content of any discussion should be determined by the individual concerned, for example an individual may not wish to confront future issues, and this should be respected
- All health and social care professionals should be open to any discussion which may be instigated by an individual and know how to respond to an individual's questions. They will require the appropriate training to enable them to communicate effectively and to understand the legal and ethical issues involved
- A professional should instigate the discussion only if s/he has made a professional judgement that the ACP process is likely to benefit the care of the individual. The discussion should be introduced sensitively
- 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 are likely to have discussed preferences and would welcome an approach to share this discussion.
- Confidentiality should be respected in line with current good practice and professional guidance
- 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) this should be documented according to the requirements of the MCA 2005.
www.opsi.gov.uk/acts/acts2005/20050009.htm
- Health and social care professionals 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. An explanation of the treatment and care options, by a competent person, can assist an individual in making an informed choice. Choice in terms of place of care will influence treatment options, as certain treatments will not be available at home or in a care home, eg 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
- Professionals need to be aware when they have reached the limits of their knowledge and competence and know when to seek advice

7. Principles of record making (where record signifies any type of statement/advance decision)

- The individual concerned must agree the content of the record
- In order for information to be shared with anyone, the individual concerned must agree 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 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.
- Where an advance decision is recorded, it should be documented that the individual concerned has the capacity to make the decision. Some guidance in the draft Code of Practice for MCA
www.dca.gov.uk/consult/codepractise/draftcode0506a.pdf
- The professional making the record must be competent to complete the process. Where treatment is being discussed the professional must have adequate knowledge of the benefits, harms and risks associated with that treatment to enable the individual to make an informed decision
- Where this is part of a professional's role, competence based training needs to be available and accessed
- 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:

Examples

Local ambulance policies - London Ambulance Service, Tees East and North Yorkshire Ambulance Service have communication systems in place to inform ambulance crews, Shropshire PCT provide information for individual and suggest that the individual carry a card informing people of an advance decision

Out of hours – Practices in Southport and Formby use 'Info fax' to transfer information about palliative patients to the GP on call centre (a Gold Standards Framework on-call centre)

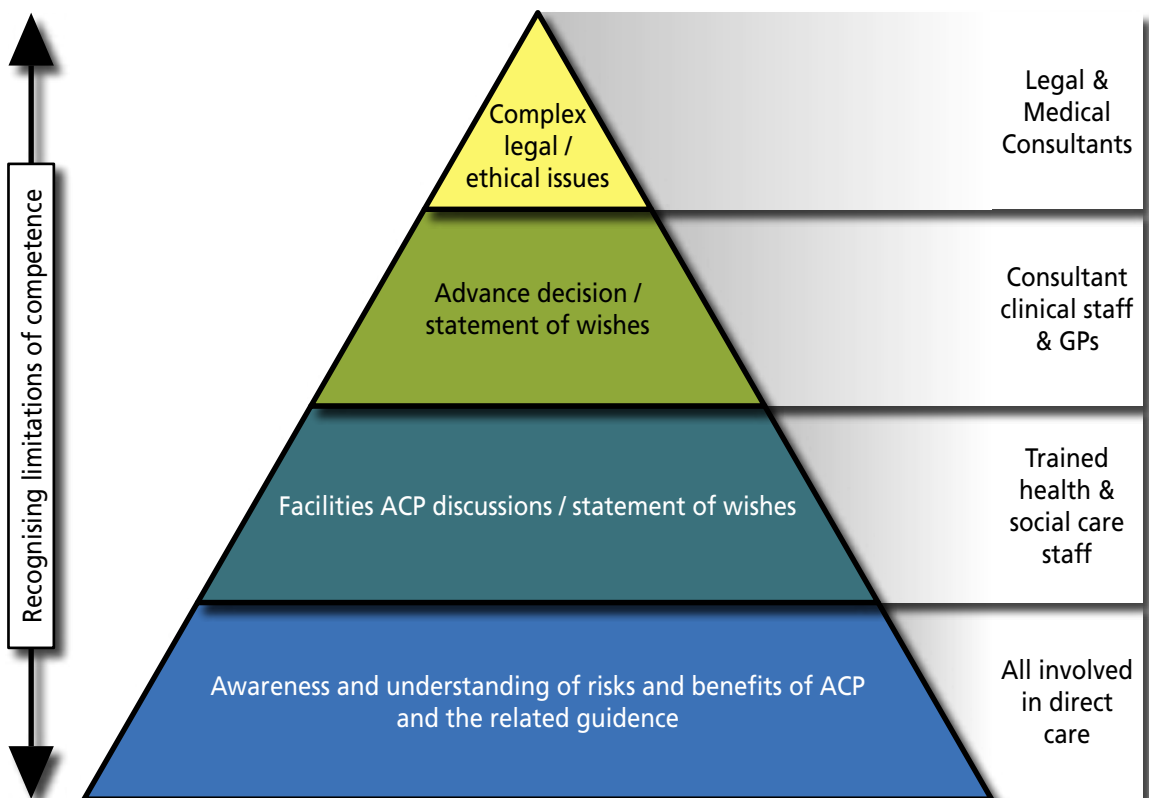
- The record must specify which treatment or care option is the subject of the statement or advance decision and the circumstances in which it is intended to apply. For example, a person with motor neurone disease may wish to refuse resuscitation when their disease progresses to a certain stage; however, this request will not apply if they are involved in an accident.
- 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

8. Core competences for health and social care professionals

The key issues to be addressed are:

- awareness of the context in which an ACP may be appropriate (section 2)
- awareness of ACP
- 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

Different levels of skills are required for different levels of practice as shown in the following diagram.



It is important that people recognise their skills and limitations including how to identify complex needs even if they are unable to address them themselves. Protocols need to be agreed to support the ACP process. Consideration needs to be given to delivery of education and training and the different providers need to ensure consistency. It needs to be linked with existing frameworks eg NHS Knowledge and Skills Framework (KSF). Some examples of these are listed overleaf:

Examples of existing competences:

Skills for Health and Social 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 NOS 2004 www.skillsforhealth.org.uk

Professional bodies and Royal Colleges

Locally developed short courses. eg North East England SHA, 1 day communication courses, Lancashire and South Cumbria Enhanced Communications Training

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 going on within the NHS EoLC Programme and in a number of academic centres.

This is a complex area in which there is a need not only for guidance and information for health and social care professionals, but also for individual's, families, care providers and the public, including the involvement of carers in ACP eg for individuals with Alzheimer's, learning disabilities etc. There is a specific need to involve users in the production of any such information.

The Preferred Place of Care (PPC) document will be reviewed to take account of this guidance and changes brought about by the MCA 2005.

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

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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NB. All information correct at time of print.

Glossary

Advance Care Plan	ACP
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 Place of Care	PPC
Strategic Health Authority.....	SHA

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Background material

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www.respectingpatientchoices.org.au

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The Glossary Report 2006 Health Canada

Let's Talk – This is my voice a workbook for Advance Care Planning, Fraser Health

www.fraserhealth.ca

Living with Dying –Hospice Foundation of America

Advance Decisions Policy South Downs NHS Trust - 2005



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