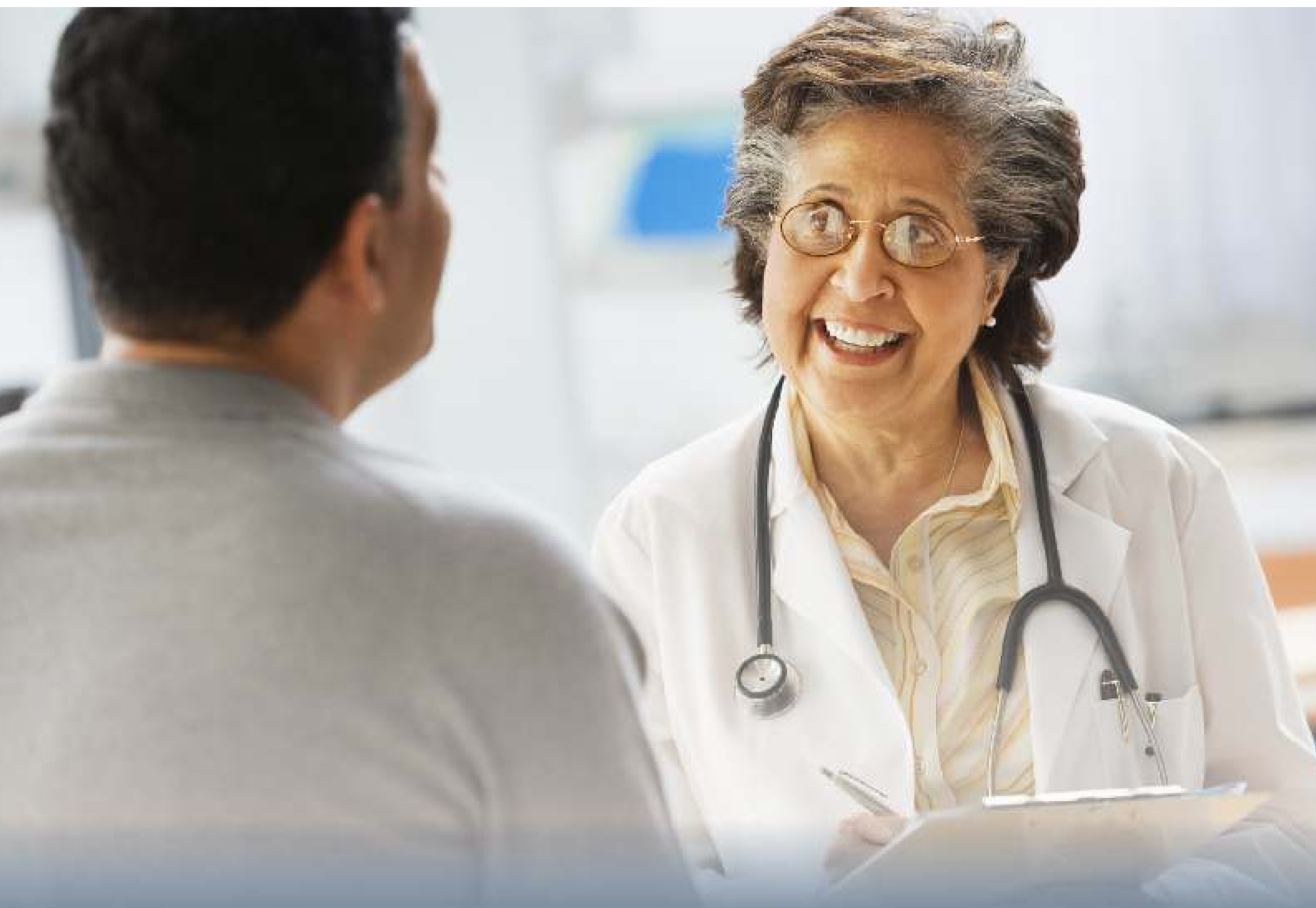
Compassion in dying



Advance Decision Toolkit

Guidance for Health Professionals

About Compassion in Dying

We are working to ensure that everyone can access the care and support that is right for them at the end of life. This means:

- Access to expert information about end-of-life options;
- Support to make informed choices;
- Care from the provider that the patient feels is the most appropriate.

Compassion in Dying is taking over the provision of Advance Decisions and the Advance Decision Toolkit from our partner organisation Dignity in Dying. Dignity in Dying have promoted the use of Advance Decisions (formerly called living wills) in the UK for over 20 years, as well as providing Advance Decisions and guidance on best practice to general practitioners, hospitals, care homes and solicitors.

Advance Decisions allow people to specify any medical treatment decisions they would like to be made on their behalf should they lose capacity. However, this toolkit will concentrate only on decisions to refuse life-sustaining treatment. In this document therefore the term Advance Decision will mean specifically an Advance Decision to refuse life-sustaining treatment.

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Executive Summary

What are Advance Decisions?

Advance Decisions are statements made by adults with capacity, in which they can make decisions about all treatment they may receive. They may be used to note down their wish to refuse (but not request) life-sustaining medical treatment at a point in the future, in case the individual loses the capacity to make such decisions. For example, a patient may use an Advance Decision to refuse mechanical ventilation in the event that he or she becomes permanently unconscious and unable to breathe. An Advance Decision to refuse life-sustaining treatment must be made in writing.

The Mental Capacity Act 2005 (MCA), which came into effect in 2007[1], puts advance decision-making on a statutory footing. It applies solely to England and Wales. It sets out the criteria that Advance Decisions must meet in order to be 'valid and applicable'. Provided that an Advance Decision meets these criteria, it is legally binding and must be complied with. The Mental Capacity Act 2005 refers to Advance Decisions. In some parts of the world such decisions may be known by another term: 'advance directives' or 'advance statements'. Living Will is also a common, informal term, and one that the public is likely to be familiar with. But we use the term: Advance Decision/s throughout this document.

The purpose and scope of this toolkit

While the MCA puts all Advance Decisions to refuse treatment on a legal footing, Advance Decisions that refuse life-sustaining treatment must meet additional requirements within the MCA, and raise particular issues for health professionals.

This toolkit is solely concerned with Advance Decisions relating to life-sustaining treatment; that is, where a patient with capacity has made a decision to refuse life-sustaining treatment at a point in future, and at a time when he or she may have lost capacity. The toolkit is not concerned with patients refusing any other type of treatment, whether contemporaneously or in advance. Nor does it refer to the withholding or withdrawing of treatment from patients whose wishes have not been set out in an Advance Decision.

The primary purpose of the toolkit is to improve the effectiveness of Advance Decision making and implementation. It identifies the potential difficulties health professionals may face when acting on Advance Decisions to refuse life-sustaining treatment, and also gives practical guidance on avoiding these difficulties. It gives a clear explanation of health professionals' obligations pursuant to the Mental Capacity Act. This toolkit should be read in conjunction with the Mental Capacity Act 2005 and its Code of Practice.

Who should use the toolkit?

The toolkit is designed for those who might be involved in implementing a patient's Advance Decision – typically doctors and nurses in the acute hospital setting. It may also be relevant to health professionals working in the community setting, and to general practitioners who may be approached by patients seeking advice on drafting an Advance Decision.

Part 1: The Principles and the law

1. Introduction

Background

1.1 Modern medical treatments such as mechanical ventilation and artificial nutrition and hydration offer considerable benefits to vast numbers of seriously ill patients. However, many patients are concerned that these treatments should not be used to prolong the dying process if their disease or condition cannot be reversed, or their quality of life improved.

1.2 Adults with capacity to understand the decision they are making have the legal right to refuse treatment. They may weigh up the benefits, burdens, risks and overall acceptability of any treatment,[2] but the right to refuse is enshrined in law, even if it results in his or her own death.[3]

My wife has been ill for many years and so we both made Advance Decisions. Following an operation she ended up on life support. Her Advance Decision was of considerable assistance when I was faced with discussing what my wife would want with her doctors.

Raymond (Husband).

1.3 Adults with capacity also have the legal right to refuse medical treatments in advance, via an Advance Decision, so that their wishes will be known if they lose the capacity to express them in the future. This right is now enshrined in the Mental Capacity Act 2005, which came fully into force in October 2007.

The benefits of Advance Decisions

1.4 Patients who make Advance Decisions to refuse treatment are often predominantly concerned with avoiding a lingering death. Some may have witnessed the slow deterioration of a relative, perhaps due to stroke or Alzheimer's disease, and wish to maintain as much autonomy and control as possible at the end of their own lives.

1.5 Health professionals' views on what their patients want do not always match the wishes of their patients. Research has found that active treatment is often provided during the final months of life even when the patient or family would have preferred comfort care only.[4] Some health professionals admit to providing more treatment to patients than they would want themselves.[5]

1.6 Advance Decisions to refuse treatment are legally binding under the Mental Capacity Act and must be followed even if others may not believe this to be the best course of action. While different views and feelings may be held by those close to the patient, clarity about the patient's wishes as set out in Advance Decisions is paramount.[6]

1.7 There is evidence that the vast majority of seriously ill patients are willing to discuss their care, but health professionals are sometimes reluctant to initiate these conversations.[7] The existence of an Advance Decision can form a useful starting point for these difficult discussions.

1.8 Advance Decisions have also been found to alleviate some of the anxiety family members experience when consulted by healthcare professionals on treatment decisions at the end of a loved one's life. This can lead to a more positive bereavement process.[8] Consultation with family members is given statutory force under the Mental Capacity Act. Additionally, if a Lasting Power of Attorney (LPA) has been drawn up under the provisions of the Mental Capacity Act by an individual, this will mean that for the first time, family members who are nominated under the LPA may make decisions, rather than the doctor.

Potential difficulties from past experience in implementing Advance Decisions

1.9 Unfortunately, Advance Decisions to refuse treatment in the past have not always operated as well as they could in practice, often due to one or more of the situations in Box 1 arising:

Box 1: Potential difficulties from past experience in implementing Advance Decisions

- **Health professionals may be unaware that an Advance Decision to refuse treatment has been written.** Patients may not be well enough to inform the health team that they have an Advance Decision to refuse treatment. At present there is no national registration system to help health professionals quickly establish whether an Advance Decision to refuse treatment has been made.
- **The Advance Decision may not follow the patient to other wards, departments or institutions.** Patients' care can be transferred many times during the last months, weeks and days of life – for example, between a geriatric ward, an emergency department and an intensive care unit. If communication between the various staff is not carefully co-ordinated, the existence of the Advance Decision may not emerge.
- **Relatives might object to the content of the Advance Decision to refuse treatment.** Faced with the imminent death of a loved one, relatives may urge health professionals to ignore an Advance Decision to refuse treatment and sustain the patient's life as long as possible. However, under the Mental Capacity Act, as indicated above, the Advance Decision to refuse treatment is legally binding.
- **There may be confusion about the legal status of Advance Decisions to refuse treatment.** Historically, research suggests that there has been confusion as to the legally binding nature of an Advance Decision to refuse treatment. Advance Decisions to refuse treatment under the Mental Capacity Act are legally binding and the Act gives much greater legal clarity to the issue. Health professionals have a legal obligation under the Mental Capacity Act to comply with valid and applicable Advance Decisions.[9]
- **An Advance Decision may be worded too ambiguously.** A patient may have little knowledge of end-of-life conditions and treatments, and write an Advance Decision that does not provide clinically useful instructions. For example, a patient might refuse all medical interventions in the event that his/her life becomes "intolerable". The health professional is then left to ponder whether the patient would consider the present situation intolerable or not. Under the MCA, ambiguous Advance Decisions may not be valid. It is therefore important that the individual specifies the treatment refused.
- **The Advance Decision may be worded too specifically.** Conversely, if an Advance Decision describes a condition or situation different to that which has arisen, it may be unclear whether the decision should still apply. For example, a patient may refuse artificial nutrition in the event that he/she becomes unable to swallow, but give no preference in the event that he/she becomes permanently unconscious. Family members may insist the patient would want the Advance Decision to apply, but the health professional will have no evidence to support this view.

Chapters 4 – 6 present solutions to the above challenges.

2. Advance Decisions and the law

The Mental Capacity Act 2005

2.1 Prior to the Mental Capacity Act, Advance Decisions were regulated under the common law.[10] The Act codifies the common law rules and puts Advance Decisions on a statutory footing, with some additional safeguards. Advance Decisions made prior to the Act coming into force may be valid if they do not refuse life-sustaining treatment. Advance Decisions made prior to the Act coming into force, which do refuse life-sustaining treatment are likely to require some amendment in line with the new safeguards, paying particular attention to point g) in Box 2. Box 2 gives a number of general requirements that Advance Decisions to refuse life-sustaining treatment must meet in order to be legally binding.

Box 2: The Mental Capacity Act's general requirements for Advance Decisions to refuse life-sustaining treatment:

Advance Decisions to refuse life-sustaining treatment must:

a) Specify the treatment(s) that is to be refused, although this may be expressed in layman's terms;

b) Specify the circumstances in which the refusals of treatment are to apply;

b) Be made only by persons who are 18 years or older;

c) Be made only by persons who have capacity, as defined in the Act;

d) Be in writing;

e) Be signed by the patient (or, if the patient is unable to sign it, by another person in the patient's presence) in the presence of a witness;

f) Be signed by the witness, in the presence of the patient;

g) Be verified with a statement to the effect that the Advance Decision should apply even if life is at risk. This can be included in the document itself or can be a separate statement – in which case it must also be signed by the patient and a witness.

2.2 In order to be legally effective, an Advance Decision to refuse treatment will need to be both valid and applicable. Box 3 sets out circumstances that will make an Advance Decision to refuse treatment invalid and/or inapplicable under the Mental Capacity Act.

Box 3: Validity and applicability

An Advance Decision is invalid if:

a) The patient has withdrawn the Advance Decision at a time when he/she had capacity to do so (a patient with capacity can withdraw an Advance Decision at any time either in writing or verbally; no formal procedures are required); or

b) The patient has created a Lasting Power of Attorney after creating the Advance Decision, which gives the attorney the power to give or refuse consent to the life-sustaining treatment in question (see paragraphs 2.5 – 2.8 below); or

c) Since making the Advance Decision, the patient has acted in a way that is clearly inconsistent with the Advance Decision remaining his/her fixed decision. (See case study 1 below)

An Advance Decision is not applicable if:

d) At the material time, the patient still has the capacity to give or refuse consent to treatment; or

e) The treatment in question is not the treatment specified in the Advance Decision; or

f) If the circumstances are different from those that may have been set out in the Advance Decision; or

Note: Whilst an Advance Decision should set out the treatment being refused, an Advance Decision refusing all treatment in any situation, (for example, one that explains a person holds a particular religious or personal belief) may be valid and applicable.

g) There are reasonable grounds for believing that circumstances exist which the patient did not anticipate at the time of making the Advance Decision, and which would have affected his/her decision. (For example, if the refused treatment has developed significantly since the time the patient created the Advance Decision.)

CASE STUDY 1: Mr Smith creates an Advance Decision refusing mechanical ventilation in the event that he becomes unable to breathe. A year later, he is involved in a serious road accident and is paralysed from the neck down, but remains conscious and consents to artificial ventilation. Some weeks later, he loses consciousness and it is only then that his Advance Decision is discovered.

Given that Mr Smith had consented to treatment and remained on the ventilator for some time, the validity of his Advance Decision could be called into question. In this case it would be appropriate for the health professionals to supplement the information in his Advance Decision with a broader understanding derived from conversations with relatives or friends.

Limitations

2.3 Patients do not have a legal right to demand that any specific treatment be given, whether contemporaneously or via an Advance Decision.[11] Requests for treatment should be given serious consideration, but health professionals are under no obligation to provide treatments that they consider clinically unnecessary, futile or inappropriate.

2.4 Advance Decisions cannot be used to request unlawful procedures such as assistance in dying, or to refuse basic care such as warmth, shelter and hygiene measures.

Lasting Powers of Attorney and their relationship to Advance Decisions

2.5 Section 9 of the Mental Capacity Act creates a new legal tool called Lasting Powers of Attorney (LPA), to replace the current system of Enduring Powers of Attorney (EPA). It allows a person (described in the Act as a 'donor') to appoint another person (an 'attorney') to make decisions for them if they lose capacity to do so in the future. These can be financial decisions, or decisions about welfare and healthcare. This is a significant change from the EPA system, under which attorneys had no power to make welfare or healthcare decisions.

2.6 Donors may confer on their attorneys the power to give or refuse consent to life-sustaining treatment, provided that an express statement is included in the LPA document to that effect (and subject to conditions set out in the Act).

2.7 An attorney will not have the power to give consent to any treatment that is specifically refused in an Advance Decision to refuse treatment. However, if the donor has created a LPA after creating the Advance Decision to refuse treatment, and has given the attorney the specific power to give or refuse consent to the treatment in question, the LPA will take precedence, and the Advance Decision to refuse treatment becomes invalid.

2.8 Attorneys must be named individuals who are at least 18 years of age. The Act does not impose any further restrictions on who can be an attorney in relation to health or welfare decisions.[12]

Liability of Health Professionals

2.9 The Mental Capacity Act's Code of Practice states at 9.57, "Healthcare professionals must follow an Advance Decision if they are satisfied that it exists, is valid and is applicable to their circumstances. Failure to follow an Advance Decision in this situation could lead to a claim for damages for battery or a criminal charge of assault."

2.10 However, it adds that health professionals with genuine doubts about the existence, validity or applicability of an Advance Decision can provide treatment without incurring liability. In such situations, health professionals should make clear notes explaining why they have not followed the Advance Decision.

Conscientious objection

2.11 Health professionals with a conscientious objection to limiting treatment in line with a patient's Advance Decision do not have to act contrary to their beliefs. However, health professionals must not simply abandon their patients and have a duty to find another doctor who will comply with the wishes of the patient.[13]

2.12 Paragraph 9.62 of the Code of Practice advises that health professionals with a conscientious objection should make their views clear when the matter of the Advance Decision is initially raised. Patients with capacity should immediately be given the option of having their care transferred to another health professional, where this is feasible. If the patient lacks capacity, the health professional should make arrangements for their care to be transferred.

2.13 If transferral of the patient's care cannot be agreed, the Court of Protection has the power to direct that a different health professional takes responsibility for the patient (see Sections 45 to 56 of the Act and Chapter 6 below for more on the Court of Protection and its role).

3. Definitions and related guidance

3.1 The General Medical Council and the British Medical Association (amongst others) have produced a wealth of guidance to help health professionals make difficult end-of-life treatment decisions.[14] Below is a summary of the guidance most relevant to Advance Decisions to refuse treatment. This is by no means comprehensive; health professionals should refer to the full guidance to ensure they act within the law and in accordance with best practice.

Life-prolonging or life-sustaining treatments

3.2 The British Medical Association defines life-prolonging treatments as "all treatment which has the potential to postpone the patient's death and includes cardiopulmonary resuscitation, artificial ventilation, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection and artificial nutrition and hydration."[15] The MCA defines life-sustaining treatment for the purposes of Advance Decision as that which "in the view of a person providing health care for the person concerned, is necessary to sustain life." This is the definition that will determine whether or not an Advance Decision has to meet the requirements that relate to life-sustaining treatment. In the context of Advance Decisions, life-sustaining treatments usually refers to a distinct group of therapies whose purpose is to maintain or replace a vital bodily function, and without which death would most likely occur as a result of organ or system failure.

Artificial nutrition and hydration (ANH)

3.3 'ANH' refers to a group of medical techniques used to administer nutrition or hydration to patients who are unable to swallow. Options include percutaneous endoscopic

gastronomy (PEG), subcutaneous hydration, nasogastric tubes or intravenous cannula.

3.4 ANH is distinguished from oral nutrition and hydration (ONH), which is swallowed in the usual process. ANH is classified in common law as medical treatment, because it involves specialised knowledge and input from health professionals.[16] In contrast, ONH is considered part of 'basic care' rather than medical treatment.

3.5 Whilst patients have a legal right to refuse medical treatment in an Advance Decision, they do not have a right to refuse basic care. Thus ANH can be refused in an Advance Decision, but ONH cannot.

Identifying capacity

3.6 The Mental Capacity Act stipulates at Section 2 (1) that, for the purposes of the Act, "A person lacks capacity in relation to a matter if at the material times he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain."

3.7 A person must always be assumed to have capacity unless the opposite is established.[17] The Act therefore requires that the inability to make a decision be caused by an impairment or disturbance in the mind or brain. If no impairment or disturbance can be diagnosed, the person cannot be said to lack capacity. Section 2(3) makes clear that a lack of capacity cannot be established merely by reference to a person's age or appearance, or from unjustified assumptions based on the person's condition or behaviour. Nor can a person be said to lack capacity merely because he/she makes an unwise decision (Section 1 (4)).

3.8 Section 3 (1) sets out a functional test for determining the person's ability to make a decision for him/herself (see box 4).

Box 4: A person is unable to make a decision if he/she is unable to:

a) understand the information relevant to the decision;

b) retain that information;

c) use or weigh that information as part of the process of making the decision; or

d) communicate the decision (whether by talking, using sign language or any other means).

3.9 A lack of decision-making capacity in one area of life does not automatically indicate a lack of capacity to make a decision on a different issue – each decision must be considered separately.

Respecting patients' views and beliefs

3.10 Health professionals have a duty to recognise and respect their patients' individual values and beliefs,[18] and must never put pressure on a patient to accept treatment contrary to his/her wishes. Health professionals must acknowledge that competent patients have an absolute legal right to refuse treatment, "notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent."[19]

> ***"Advance Decisions are a powerful tool to ensure that patient's wishes are respected when they have impaired mental capacity and their wishes are at risk of being overridden."***
>
> **Professor Raymond Tallis, Emeritus Professor of Geriatric Medicine**

4. Procedural policy on Advance Decisions

4.1 The following procedures are recommended for inclusion in hospital Advance Decision policies.

Establishing that an Advance Decision exists

4.2 One member of staff on each ward/department should be responsible for determining whether an Advance Decision to refuse treatment has been made, as part of routine practice. It is for the individual PCT or hospital to appoint the appropriate member of staff.

4.3 If the patient cannot speak for him/herself, but there is reason to believe the patient has an Advance Decision, staff should make reasonable efforts to obtain a copy by:

- Contacting any person nominated by the patient;
- Contacting the patient's GP;
- Checking for a MedicAlert emblem (bracelet or necklet)

MedicAlert is an international charity specialising in the transfer of medical data to health professionals in emergency situations. Patients can register their Advance Decisions with MedicAlert, and will wear an emblem which states 'has Advance Decision' and provides MedicAlert's 24-hour telephone number. MedicAlert will fax a copy of the Advance Decision to the health professional on request.

Recording and communicating the existence of the Advance Decision

4.4 The Advance Decision should be placed in a prominent position in the patient's healthcare record and the health professional with overall responsibility for the patient's care should ensure that all members of the multi-disciplinary team are informed of the Advance Decision. The same person should ensure that staff in different departments, wards or institutions are informed of the Advance Decision, if the patient's care is transferred.

Compliance with the Mental Capacity Act

4.5 The health professional with overall responsibility for the patient's care may wish to check that the Advance Decision meets the requirements of the Mental Capacity Act (see Part One: Boxes 2 and 3). However, this is not a requirement of the Act and it would be hard for a doctor to be sure that an Advance Decision meets the requirements of the MCA when the person still has capacity and the situation is yet to arise when it will be required.

See Chapter 5 part B for further information on Advance Decisions belonging to patients who lack capacity.

5. Caring for patients with Advance Decisions

Part A: Patients with capacity

5.1 Good communication between health professionals and patients is very important in end-of-life decision making. If the patient still has capacity, the Advance Decision to refuse treatment should be understood as an aid to, rather than a substitute for, open dialogue.[20]

A discussion between the patient and health professional regarding the content of an Advance Decision to refuse treatment can:

- Assist the patient's understanding of his/her diagnosis and prognosis, the available treatment options, and the implications of accepting or refusing these options;
- Clarify exactly what the patient's wishes are;
- Enable the health professional to elicit and understand the patient's wider goals of care, which may clarify the way to proceed in grey areas.

Such discussions will need to be on going to reflect changes in the patient's condition and preferences.

5.2 The goal of any conversation should always be to clarify the patient's position on any treatment as well as on which life-sustaining treatments he/she wishes to refuse (or consent to), and in which circumstances. Health professionals should conduct any such conversations with reference to the guidance set out in Chapter 3.

5.3 Patients are not legally required to discuss their decisions, nor accept an offer of advice from a health professional. That an Advance Decision has not been discussed with a health professional does not render it invalid.

5.4 A person's needs and preferences can often change over time. What someone states while relatively well, may change radically as their condition, the support they receive and personal circumstances change. Healthcare professionals will be involved in assessing the needs of the patient, and agreeing a care plan. The care plan could also include reviewing an Advance Decision to refuse treatment in the light of changes.

5.5 The details and outcomes of any such conversation should be recorded in the patient's medical notes. Any amendments to the Advance Decision that follow as a result of a discussion must be properly recorded in accordance with the criteria set out in the Mental Capacity Act. If the patient has lodged a copy of the Advance Decision with his/her GP, solicitor or other, that person may need to be contacted to ensure consistency.

Assisting the patient's understanding

5.6 Research suggests that patients with Advance Decisions to refuse treatment do not always understand the life-sustaining treatments mentioned in them, which can lead to confusion for health professionals attempting to implement the Advance Decision to refuse treatment.[21] If a patient is willing and able to discuss the content of an Advance Decision to refuse treatment, health professionals should ensure this occurs before an emergency situation arises.

5.7 The health professional's role is to provide factual, accessible information with which the patient can assess the benefits and burdens of life-sustaining treatments, within the context of his/her own condition. Health professionals should provide simple and honest information on the patient's diagnosis and prognosis; the likely illness trajectory; an explanation of the common forms of life-sustaining treatments; the benefits and burdens of such treatments for the particular patient; and the implications of refusing these treatments.

Clarifying exactly what the patient's wishes are

5.8 Ambiguities in the wording of an Advance Decision to refuse treatment can not only lead to a lack of clarity about exactly what the patient wants, and under what circumstances, but also can render the Advance Decision to refuse treatment invalid.[22]

5.9 Pro-forma Advance Decisions often simply decline "life-sustaining treatments" in general, in the event of serious illness or permanent loss of cognitive function. Health professionals should encourage the patient to consider life-sustaining treatments individually since there may be different benefits and burdens attached to each treatment.

5.10 Words such as 'severe', 'serious', and 'grave' can be particularly difficult to interpret.[23] Health professionals should try to establish what situation the patient envisages when he/she considers these words. For example, a patient might refuse life-sustaining treatments in the event that he/she develops 'severe brain disease'. Different patients will have different ideas on what constitutes 'severe'.

5.11 Patients may also use the word 'terminal' very loosely. Health professionals should try to establish what stage the patient would consider the 'terminal' stage in a chronic progressive illness. Would the patient want the Advance Decision to refuse treatment to apply even if he/she had a prognosis of six months to live? Or 12 months?

5.12 Health professionals might sensitively pose a number of hypothetical questions to avoid misunderstandings at a later date. While it may be difficult to answer these questions, and patients' wishes may have changed over time, these questions are included as a guide. For example, did the patient intend to refuse Cardiopulmonary Resuscitation (CPR) altogether, or were there certain circumstances in which he/she would accept it? What if the doctor felt that there was a 50% probability that the patient could regain normal cognitive function? Or if there was a 10% probability? Would the patient be willing to receive mechanical ventilation for a trial period of a week? Would the patient find a nasogastric tube more acceptable than a gastric PEG?

Understanding the patient's wider goals of care

5.13 Advance Decisions can never account for every eventuality. The clinical scenario a patient finds him/herself in may be entirely different from the one envisaged in the Advance Decision. It is the case that valid Advance Decisions are legally binding, it is nevertheless the case that health professionals can, and do, get involved in discussions about a patient's general values and attitudes towards health, quality of life and end-of-life care. This can be helpful for doctor and patient. A broad conversation of this nature may also be appropriate for patients who are unable or unwilling to participate in the more detailed type of discussion outlined above.

5.14 A discussion of the patient's values need not necessarily lead to clinical instructions being recorded; instead it is an opportunity for the health professional to engage with the patient's goals, hopes and fears, and understand the patient as a person. A conversation in non-medical language may help a patient communicate his/her general treatment preferences, which may indicate the appropriate course of clinical action at a later stage.[24] Uncomplicated, sensitive questions such, as 'what for you makes life enjoyable?' may be all that is needed to begin the discussion.

Part B: Patients without capacity

5.15 Patients who have already lost capacity will not be able to clarify any ambiguities in their Advance Decisions to refuse treatment. Health professionals must therefore take a different approach. The first step will be to establish that the Advance Decision to refuse treatment meets the Mental Capacity Act's general requirements, as set out in Box 2 on page 8 and its specific criteria for validity and applicability, as set out in Box 3 on page 9. Health professionals may provide or continue treatment until they are completely satisfied that an Advance Decision to refuse treatment meets all of the Act's requirements, provided that the treatment is in the patient's best interests. See Chapter 6 on 'resolving disputes' for further information.

5.16 Box 5 sets out how the patient's next of kin, partner or significant other may be able to provide valuable information as to the patient's thinking when he/she made the Advance Decision.

Box 5. Relatives or friends of patients without capacity may be able to provide information on:

- When the Advance Decision to refuse treatment was drafted and how regularly it has been updated;
- The situation envisaged by the patient when he/she drafted the Advance Decision to refuse treatment;
- The patient's illness trajectory and his/her views at each stage;
- The patient's attitudes towards and understanding of his/her condition;
- The patient's awareness of and attitudes towards the available medical treatments; and factors that may have shaped those attitudes.

5.17 The patient's GP and healthcare record may also provide evidence that can be used to determine the validity and applicability of an Advance Decision.

5.18 The details and outcomes of any relevant conversations should be recorded in the patient's medical notes and where relevant, communicated to the patient's GP.

6. Resolving disputes

6.1 There is potential for disagreement on the validity and applicability of an Advance Decision to refuse treatment. Members of a multi-disciplinary team may interpret the patient's wishes, or the severity of his/her condition, in different ways. The family may not share the patient's attitudes towards end-of-life care and may urge health professionals to override the Advance Decision to refuse treatment.

The Mental Capacity Act Code of Practice guidance (paraphrased):

6.2 Ultimately it is for the health professional with overall responsibility for the patient's care when the treatment is required (likely to be a hospital consultant) to decide whether there is a valid and applicable Advance Decision. In the event of a disagreement, either between health professionals or between health professionals and family members (or others close to the patient), the senior health professional must consider all the available evidence. He or she may need to consult with relevant colleagues and others who are close to or familiar with the patient. All staff involved in the patient's care should be given the opportunity to express their views. The patient's GP may also have relevant information.

6.3 The point of such discussions should not be to try to overrule the patient's Advance Decision but rather to seek evidence concerning its validity and to confirm its scope and its applicability to the current circumstances. Details of these discussions should be recorded in the patient's records.

The Court of Protection

6.4 As a last resort, where there continues to be genuine doubt or disagreement about the existence, validity or applicability of an Advance Decision to refuse treatment, a declaration can be sought from the Court of Protection.

6.5 The Court does not have the power to overturn a valid and applicable Advance Decision. It does have the power to make declarations as to:

- Whether a person does or does not have capacity to consent to or refuse treatment at the time the treatment is proposed;
- Whether an Advance Decision is valid;
- Whether an Advance Decision is applicable to the proposed treatment in the circumstances that have arisen.

6.6 Information on when and how an application to the Court of Protection should be made will be available from the Office of the Public Guardian. See also Chapter 8 of the Mental Capacity Act Code of Practice.

References

1 The Act was implemented in two stages. In October 2007, the clauses related to Advance Decisions and Lasting Powers of Attorney came into effect, and the new Court of Protection, Public Guardian and the Office of the Public Guardian became operational for England and Wales. The independent mental capacity advocates (IMCA) and some directly related elements of the legislation, the code of practice to provide guidance, and the criminal offence of ill treatment and willful neglect came into place in April 2007.

2 General Medical Council, Withholding and withdrawing life-prolonging treatments: Good practice in decision making, London: 2002. Please note that the General Council will be replacing this guidance document with new guidance on end-of-life decision making, which is due to be published in Spring 2010.

3 Airdale NHS Trust v Bland [1993] 1 All ER 821 at page 860 per Lord Keith and page 866 per Lord Goff. Also Re MB [1997] 2 FCR 541 and Re JT (Adult: Refusal of Medical Treatment) [1998] 1 FLR 48 and Re AK (medical Treatment: Consent) [2001] 1 FLR 129. Confirmed as an absolute right in St George's Healthcare National Health Service Trust v S (No 2): R v Louize Collins & Ors, Ex Parte S (No 2) [1998] 3 WLR 936.

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11 Burke v General Medical Council [2005] EWCA 1003 (Civ).

12 There are, however, certain restrictions on who can be an attorney in relation to financial and property affairs for example, a bankrupt individual would not be permitted. See Chapter 8 of the Mental Capacity Act Code of Practice for detailed information on Lasting Powers of Attorney.

13 Re Ms B v a NHS Hospital Trust [2002] EWHC 429 (Fam).

14 See for example General Medical Council, Withholding and withdrawing life-prolonging treatments: Good practice in decision making (London:2002). Please note that the General Council will be replacing this guidance document with new guidance on end-of-life decision making, which is due to be published in Spring 2010; British Medical Association, Advance statements about medical treatment (BMJ Publishing, London:1995); British Medical Association, Withholding and Withdrawing Life-Prolonging Medical Treatment: Guidance for decision making 2nd edition (London:2001), also see 3rd edition, 2007 Hammicks/BMA.

15 BMA 2001, ibid, Page 7. The Mental Capacity Act defines life-sustaining treatments at section 4 (10) as "treatment which in the view of the person providing health care for the person concerned is necessary to sustain life."

16 Airdale NHS Trust v Bland [1993] 1 All ER 821.

17 Confirmed in Section 1(2) of the Mental Capacity Act 2005.

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Notes

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