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CARE



End of Life Care

ADVANCE DECISIONS TO REFUSE TREATMENT

A Guide for Health and Social Care Professionals



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Advance Decisions to Refuse Treatment

A Guide for Health and Social Care Professionals

Executive summary

The purpose of this guide is to help health and social care professionals understand and implement the new law relating to advance decisions to refuse treatment, as contained in the Mental Capacity Act 2005. The Mental Capacity Act (MCA) came into force in 2007 and it is supported by a Code of Practice. Everyone must comply with the requirements of the Act.

The legislative framework for advance decisions to refuse treatment is complex. This guide is intended to clarify the law for professionals and to offer additional practical information to enable them to support all people, whatever their age; race, faith, gender, sexual orientation, gender identity, disability or preferences that may choose to consider making an advance decision to refuse treatment.

This guide contains the text of chapter 9 of the Code of Practice (set out in blue text), which deals with advance decisions to refuse treatment, together with additional commentary (set out in black text). Cross reference will be made to other chapters of the Code of Practice. The guide also identifies additional links and resources, which it is hoped will prove helpful. It is always recommended that professionals seek appropriate help to resolve any questions they may have.

It may well be that social care professionals working with people living with life-threatening or long-term conditions, particularly where they are the key worker, find that they are being asked about advance decisions to refuse treatment. Whilst they will need to ensure that they signpost people to relevant healthcare professionals to ensure they receive proper medical advice about the implications, they should also understand that this may be an opportunity for them to open up wider discussions about the person's advance care planning. Should such discussions lead to refusal of life-sustaining treatment, health care professionals should ensure that the advice given reflects the requirements of the Act.

Advance decisions

This guide deals with advance decisions to refuse treatment at a future date. The Mental Capacity Act refers to these as "advance decisions." Advance decisions to refuse treatment that meet all the requirements of the Mental Capacity Act will be legally binding on health and social care professionals. This makes advance decisions to refuse treatment quite distinct from other aspects of advance care planning. The latter may include requests or other statements of wishes about future care and treatment. Such statements of values, wishes, priorities or preferences about what is to be done should the person lose capacity at some point in the future must be taken into account as part of an overall best interests judgement but are not legally binding.

The Act and Code of Practice clearly define that the responsibility for making an advance decision lies with the person making it. This guide states the legal requirements necessary for any advance decision to be valid and applicable and provides commentary to help with the sometimes difficult task of assessing whether or not an advance decision is binding.

It will often be helpful for the person to discuss their advance decision with a healthcare professional. If necessary this professional may give advice or support during this process about how to make the advance decision and ensure that health and social care professionals are aware of it. This may also be an opportunity to discuss the person's future care and treatment.

A Quick Summary of the Mental Capacity Act (2005) Code of Practice - Advance Decisions to Refuse Treatment

- An advance decision enables someone aged 18 and over, while still capable, to refuse specified medical treatment for a time in the future when they may lack the capacity to consent to or refuse that treatment.
- An advance decision to refuse treatment must be valid and applicable to current circumstances. If it is, it has the same effect as a decision that is made by a person with capacity: healthcare professionals must follow the decision.
- Healthcare professionals will be protected from liability if they:
 - stop or withhold treatment because they reasonably believe that an advance decision exists, and that it is valid and applicable
 - treat a person because, having taken all practical and appropriate steps to find out if the person has made an advance decision to refuse treatment, they do not know or are not satisfied that a valid and applicable advance decision exists.
- People can only make an advance decision under the Act if they are 18 or over and have the capacity to make the decision. They must say what treatment they want to refuse, and they can cancel their decision – or part of it – at any time.
- If the advance decision refuses life-sustaining treatment, it must:
 - be in writing (it can be written by someone else or recorded in healthcare notes)
 - be signed and witnessed, and
 - state clearly that the decision applies even if life is at risk.
- To establish whether an advance decision is valid and applicable, healthcare professionals must try to find out if the person:
 - has done anything that clearly goes against their advance decision
 - has withdrawn their decision
 - has subsequently conferred the power to make that decision on an attorney, or
 - would have changed their decision if they had known more about the current circumstances.
- Sometimes healthcare professionals will conclude that an advance decision does not exist, is not valid and/or applicable – but that it is an expression of the person's wishes. The healthcare professional must then consider what is set out in the advance decision as an expression of previous wishes when working out the person's best interests (see chapter 5 of the Code of Practice).
- Some healthcare professionals may disagree in principle with patients' decisions to refuse life-sustaining treatment. They do not have to act against their beliefs. But they must not simply abandon patients or act in a way that affects their care.
- Advance decisions to refuse treatment for mental disorder may not apply if the person who made the advance decision is or is liable to be detained under the Mental Health Act 1983.

Commentary

- The making of an advance decision is a voluntary process; people must not be coerced or pressurised into making an advance decision.
- Advance decisions to refuse treatment that comply with the requirements of the MCA have the same legal status as refusals of treatment made by people with capacity to make the decision at the time when it is needed. They must be respected in the same way that a refusal of treatment by a person with capacity would be.
- In cases when for reasons of conscience a doctor or health professional cannot comply with the terms of an advance decision, arrangements should be made for the management of the patient's care to be transferred to another professional.

An Advance Decisions check list

It may be helpful to use this check list to assess whether an advance decision to refuse treatment is legally binding.

If you conclude that an apparent advance decision is not legally binding, it should not be ignored. You should still take it into account as evidence of the person's wishes when assessing their best interests, if they are unable to make the decision for themselves. If you have any doubt about whether to answer yes or no to any of the questions below seek advice from your clinical lead. If necessary, seek legal advice.

Before using this check list, make sure that you have identified the treatment for which a decision is required.



**Always assume the person has capacity to consent to or refuse treatment.
You are required to maximise the person's capacity and facilitate communication.**

QUESTION	ANSWER YES/NO	
1.	Does the person have capacity to give consent to or refuse treatment him or herself, with appropriate support where necessary	<p>YES: The person has capacity to make the decision him or herself. The advance decision is not applicable. Ask what s/he wants to do</p> <p>NO: Continue with check list</p>
IS THE ADVANCE DECISION VALID?		
2.	Has the person withdrawn the advance decision? (This can be done verbally or in writing)	<p>YES: This is not a valid advance decision. Make sure that you have identified and recorded the evidence that the person withdrew the advance decision.</p> <p>NO: Continue with check list</p>
3.	Since making the advance decision, has the person created a lasting power of attorney (LPA) giving anybody else the authority to refuse or consent to the treatment in question?	<p>YES: This is not a valid advance decision. The donee(s) of the LPA must give consent to or refuse the treatment. The LPA decision must be in the person's best interests.</p> <p>NO: Continue with check list</p>
4.	Has the person done anything that is clearly inconsistent with the advance decision remaining his/her fixed decision?	<p>YES: This is not a valid advance decision. It is important to identify what the person has done, discuss this with anybody close to the person, explain why this is inconsistent with the advance decision remaining his/her fixed decision, and record your reasons.</p> <p>NO: The advance decision is valid. Continue with the checklist.</p>
IS THE ADVANCE DECISION APPLICABLE?		
5.	(a) Does the advance decision specify which treatment the person wishes to refuse?*	<p>YES: to both (a) and (b): Continue with the checklist</p> <p>NO: This is not an applicable advance decision</p>
	(b) Is the treatment in question that specified in the advance decision?	
6.	If the advance decision has specified circumstances in which it is to apply (see question 3 above), do all of those circumstances exist at the time that the decision whether to refuse treatment needs to be made? (N.B. It is possible for a person to decide that the advance decision should apply in all circumstances)	<p>YES: Continue with the checklist</p> <p>NO: This is not an applicable advance decision</p>
7.	Are there reasonable grounds for believing that circumstances exist which the person did not anticipate at the time of making the advance decision and which would have affected his/her decision had s/he anticipated them?	<p>YES: If such reasonable grounds exist, this will not be an applicable advance decision. It is important to identify the grounds, discuss this with anybody close to the person, and identify why they would have affected his/her decision had s/he anticipated them, and record your reasoning.</p> <p>NO: Continue with the checklist</p>

LIFE SUSTAINING TREATMENT			
8.	Is the decision both valid and applicable according to the criteria set out above?		YES: Continue with the check list NO: This is not a binding advance decision to refuse the specified life sustaining treatment
9.	In your opinion is the treatment in question necessary to sustain the person's life?		YES: Continue with the checklist NO: This is a binding advance decision to refuse the specified non-life-sustaining treatment. It must be respected and followed.
10.	Does the advance decision contain a statement that it is to apply even if the person's life is at risk?		YES: Continue with the checklist NO: This is not a binding advance decision to refuse the specified life-sustaining treatment.
11.	Is the advance decision: <ul style="list-style-type: none"> • In writing AND • Signed by the person making it or by somebody else on his behalf and at his direction AND • Signed by a witness? 		YES TO ALL: This is a binding advance decision to refuse the specified life-sustaining treatment. It must be respected and followed. NO TO ANY: This is not a binding advance decision to refuse the specified life-sustaining treatment.

*NB It is possible to use layman's language to specify both treatment and circumstances



How can someone make an advance decision to refuse treatment?

What is an advance decision to refuse treatment?

9.1

It is a general principle of law and medical practice that people have a right to consent to or refuse treatment. The courts have recognised that adults have the right to say in advance that they want to refuse treatment if they lose capacity in the future – even if this results in their death. A valid and applicable advance decision to refuse treatment has the same force as a contemporaneous decision. This has been a fundamental principle of the common law for many years and it is now set out in the Act. Sections 24–26 of the Act set out when a person can make an advance decision to refuse treatment.

This applies if:

- the person is 18 or older, and
- they have the capacity to make an advance decision about treatment.

Information on advance decisions to refuse treatment made by young people (under the age of 18) will be available at www.dh.gov.uk/consent

9.2

Healthcare professionals must follow an advance decision if it is valid and applies to the particular circumstances. If they do not, they could face criminal prosecution (they could be charged for committing a crime) or civil liability (somebody could sue them).

9.3

Advance decisions can have serious consequences for the people who make them. They can also have an important impact on family and friends, and professionals involved in their care. Before healthcare professionals can apply an advance decision, there must be proof that the decision: - exists, is valid and is applicable to the current circumstances.

These tests are legal requirements under section 25(1). Paragraphs 9.38– 9.44 explain the standard of proof the Act requires.

Commentary

It is important to understand what is meant by applicable and current circumstances

- Applicable circumstances, is a reference to the circumstances in which the person who wrote the advance decision stated that the decision should apply.
- Current circumstances, means the present situation of the patient in which a treatment decision is necessary.
- In order to be applicable and therefore binding under the Act all circumstances specified in the advance decision must be present in the current situation.
- Health care professionals are required to assess any advance decision to decide whether it is both valid and applicable to the circumstances that exist at the time the treatment decision needs to be made.

What are the benefits of an advance decision to refuse treatment?

Some people may fear future illness and sometimes want to set out some principles to guide their future care. Benefits may be as follows:

- Providing the person with better control over their circumstances and so reducing the chance of potentially distressing situations.
- Advance decisions may be useful in some circumstances, for example when a person states that specified treatments should be withheld or withdrawn when a particular stage has been reached in the trajectory of a life-threatening condition.
- By enabling the person to refuse burdensome treatments and express a wish for a natural death.
- An advance decision can be made as part of an advance care planning process.

The MCA requires people to specify the treatment they wish to refuse and they may specify the circumstances, if any, in which that treatment is to be refused. It may be difficult to create a sufficiently specific advance decision to refuse treatment unless somebody already has a particular condition diagnosed. Once there is a diagnosis, it will be easier to anticipate specific events on the disease pathway which may give rise to a specific treatment decision.

It will be possible to refuse a specific treatment in all circumstances. For example, a person may have an allergy or religious objections to particular medications.



What are the risks of advance decisions to refuse treatment?

There are potential risks to be considered by those who sign an advance decision. It is recommended that those who decide to make an advance decision are advised by health and social care professionals of the benefits and the risks that may arise if they do so.

People who are healthy and do not have a life threatening diagnosis should exercise caution before making a decision that will bind future medical teams. It is not easy to anticipate or imagine when healthy how a person might respond to the reality of living with a life threatening condition.

Advance decisions that refuse treatment in a blanket approach applicable in all circumstances may inadvertently disadvantage a person. For example:

- An advance decision refusing treatment other than comfort measures after a stroke might prevent good treatment and rehabilitation opportunities, with the result that, rather than dying, the person is left with worsened long term disability.
- A patient with very severe unstable asthma might refuse mechanical ventilation but such refusal might result in survival with hypoxic brain damage rather than death.
- A person with dementia (lacking capacity to make decisions about medical treatment) can be physically reasonably well. This person could have a urinary tract infection which could be treated easily with a short course of antibiotics. If a refusal of antibiotics has been made this might prevent appropriate treatment and lead to distress.

These are all examples of cases where loss of capacity has arisen in the absence of a terminal illness with a short prognosis, and when there is a good level of activity and function despite lack of capacity. In such circumstances there is a risk that an advance decision intended to refuse burdensome treatment of irreversible symptoms might also prevent the same treatment being given to reverse treatable symptoms.

Taking the example of antibiotics which can be used to treat a urinary tract infection, this is a different clinical picture to the situation where the person with dementia is very ill and wishing that antibiotics not be given for a life threatening pneumonia. This risk can be dealt with by specifying whether antibiotics are to be refused in all circumstances, or whether they are to be refused for a chest infection which might be life threatening, but not a urinary tract infection which can be easily treated. This illustrates the need for great care to be taken in drafting an advance decision to avoid unintended adverse consequences.

Who can make an advance decision to refuse treatment?

9.4

It is up to individuals to decide whether they want to refuse treatment in advance. They are entitled to do so if they want, but there is no obligation to do so. Some people choose to make advance decisions while they are still healthy, even if there is no prospect of illness. This might be because they want to keep some control over what might happen to them in the future. Others may think of an advance decision as part of their preparations for growing older (similar to making a will). Or they might make an advance decision after they have been told they have a specific disease or condition.

Many people prefer not to make an advance decision, and instead leave healthcare professionals to make decisions in their best interests at the time a decision needs to be made. Another option is to make a Lasting Power of Attorney. This allows a trusted family member or friend to make personal welfare decisions, such as those around treatment, on someone's behalf, and in their best interests if they ever lose capacity to make those decisions themselves (see paragraph 9.33 below and chapter 7).

9.5

People can only make advance decisions to refuse treatment. Nobody has the legal right to demand specific treatment, either at the time or in advance. So no-one can insist (either at the time or in advance) on being given treatments that healthcare professionals consider to be clinically unnecessary, futile or inappropriate. But people can make a request or state their wishes and preferences in advance. Healthcare professionals should then consider the request when deciding what is in a patient's best interests (see chapter 5 of Code of Practice) if the patient lacks capacity.

9.6

Nobody can ask for and receive procedures that are against the law (for example, help with committing suicide). As section 62 sets out, the Act does not change any of the laws relating to murder, manslaughter or helping someone to commit suicide.

Commentary

- The making of an advance decision is an entirely voluntary process. Nobody should be placed under any coercion or pressure to make an advance decision.
- If a person is considering making an advance decision it is clear that they are thinking about their future care and treatment. Professionals should consider how to respond to this sort of conversation and how to use the opportunity to engage the person in discussions not just about the advance decision, and what might be motivating the person to make one, but about other aspects of their future care and treatment.
- As professional health care providers we have a duty to maintain high standards of care and service delivery - this would apply to how we overcome language barriers and the use of interpreting and translation services. Non skilled members of family, relatives or others should not be used to overcome language barriers in our professional roles whether they be operational, administration or investigatory. The risk of misunderstanding of meaning or intent is very high and unsafe.
- Further guidance on initiating and responding to conversations about advance care planning can be found in *Advance Care Planning: A guide for Health and Social Care Staff* (2007) NHS End of Life Care Programme

- The advance decision cannot:
 - be used to refuse basic comfort and care
 - be used to demand specific forms of treatment.
- An advance decision only applies to refusals of treatment and not to other decisions for example about place of care.

Capacity to make an advance decision

9.7

For most people, there will be no doubt about their capacity to make an advance decision. Even those who lack capacity to make some decisions may have the capacity to make an advance decision. In some cases it may be helpful to get evidence of a person's capacity to make the advance decision (for example, if there is a possibility that the advance decision may be challenged in the future). It is also important to remember that capacity can change over time, and a person who lacks capacity to make a decision now might be able to make it in the future.

Chapter 3 of the Code of Practice explains how to assess a person's capacity to make a decision.

9.8

In line with principle 1 of the Act, that a person must be assumed to have capacity unless it is established that he lacks capacity, healthcare professionals should always start from the assumption that a person who has made an advance decision had capacity to make it, unless they are aware of reasonable grounds to doubt the person had the capacity to make the advance decision at the time they made it. If a healthcare professional is not satisfied that the person had capacity at the time they made the advance decision, or if there are doubts about its existence, validity or applicability, they can treat the person without fear of liability. It is good practice to record their decisions and the reasons for them. The Act does not require them to record their assessment of the person's capacity at the time the decision was made, but it would be good practice to do so.

9.9

Healthcare professionals may have particular concerns about the capacity of someone with a history of suicide attempts or suicidal thoughts who has made an advance decision. It is important to remember that making an advance decision which, if followed, may result in death does not necessarily mean a person is or feels suicidal. Nor does it necessarily mean the person lacks capacity to make the advance decision. If the person is clearly suicidal, this may raise questions about their capacity to make an advance decision at the time they made it.

Commentary

- If there are any grounds for reasonable doubt about any issue relating to an advance decision the professional may provide treatment to sustain life or prevent a serious deterioration to the person's condition while the issue is being resolved, if it is considered by the professional to be in the person's best interests to do so.
- The MCA contains a legal framework which must be followed when assessing capacity. This consists of a two-stage test as well as a prohibition against making superficial judgments about capacity.

- **The two stage test-**

- Diagnostic:** does the person have an impairment or disturbance of the mind or brain, which means that they are unable to make a decision for themselves?

- Functional:** the person is unable to make the decision for themselves if they cannot understand, retain use or weigh relevant information about the treatment, or if they are unable to communicate by any means.

Prohibition: capacity must not be assessed simply by reference to the person's age, appearance, any condition of his or any aspect of his behaviour which may lead others to make unjustified assumptions about his capacity.

Further guidance about assessing capacity can be found in *The Mental Capacity Act in Practice: Guidance for End of Life Care* (2008) National Council for Palliative Care

What should people include in an advance decision?

9.10

There are no particular formalities about the format of an advance decision. It can be written or verbal, unless it deals with life-sustaining treatment, in which case it must be written and specific rules apply (see paragraphs 9.24–9.28 below).

Commentary

- A verbal advance decision will not be binding for a refusal of life sustaining treatment.
- A clinician would have to give particular consideration to the impact of a verbal decision in the context of an expected death when there may be little time to write and witness a document when assessing best interests.

9.11

An advance decision to refuse treatment:

- must state precisely what treatment is to be refused – a statement giving a general desire not to be treated is not enough
- may set out the circumstances when the refusal should apply – it is helpful to include as much detail as possible
- will only apply at a time when the person lacks capacity to consent to or refuse the specific treatment. Specific rules apply to life-sustaining treatment.

9.12

People can use medical language or everyday language in their advance decision. But they must make clear what their wishes are and what treatment they would like to refuse.

9.13

An advance decision refusing all treatment in any situation (for example, where a person explains that their decision is based on their religion or personal beliefs) may be valid and applicable.

Commentary

- An advance decision cannot be made to refuse basic comfort and care.
- It is possible to make an advance decision to refuse a specified treatment in all circumstances, for example because of religious reasons or allergies. If that is what is intended, it would usually be advisable to state that explicitly.
- Many people will wish to refuse treatment only if particular circumstances exist, for example that they have reached a particular point on their disease trajectory. If that is the case they will need to specify the circumstances in which they wish to refuse the treatment in question (for example: *"I wish to refuse antibiotics in the event that I have a chest infection, but not if I have a urine infection"*).
- The MCA states that, where treatment is being refused in some circumstances but not others, all the circumstances identified must exist if the advance decision is to be applicable.
- That means that the more circumstances that are detailed in an advance decision the less likely it is to be applicable in the future.
- Advance decisions which lack detail may also prove to be inapplicable, as vague or general statements will not be adequate.

9.14

It is recommended that people who are thinking about making an advance decision get advice from:

- healthcare professionals (for example, their GP or the person most closely involved with current healthcare or treatment), or
- an organisation that can provide advice on specific conditions or situations (they might have their own format for recording an advance decision).

But it is up to the person whether they want to do this or not. Healthcare professionals should record details of any discussion on healthcare records.

9.15

Some people may also want to get legal advice. This will help them make sure that they express their decision clearly and accurately. It will also help to make sure that people understand their advance decision in the future.

Commentary

Legal advice may help to improve clarity but cannot be guaranteed to do so. It should be remembered that lawyers are not health care professionals and so may not be able to provide sufficient information about the benefits and burdens of different treatments or the circumstances in which decisions about them might arise.

9.16

It is a good idea to try to include possible future circumstances in the advance decision. For example, a woman may want to state in the advance decision whether or not it should still apply if she later becomes pregnant. If the document does not anticipate a change in circumstance, healthcare professionals may decide that it is not applicable if those particular circumstances arise.

9.17

If an advance decision is recorded on a patient's healthcare records, it is confidential. Some patients will tell others about their advance decision (for example, they might tell healthcare professionals, friends or family). Others will not. People who do not ask for their advance decision to be recorded on their healthcare record will need to think about where it should be kept and how they are going to let people know about their decision.

Written advance decisions

9.18

A written document can be evidence of an advance decision. It is helpful to tell others that the document exists and where it is. A person may want to carry it with them in case of emergency, or carry a card, bracelet or other indication that they have made an advance decision and explaining where it is kept.

9.19

There is no set form for written advance decisions, because contents will vary depending on a person's wishes and situation. But it is helpful to include the following information:

- full details of the person making the advance decision, including date of birth, home address and any distinguishing features (in case healthcare professionals need to identify an unconscious person, for example)
- the name and address of the person's GP and whether they have a copy of the document
- a statement that the document should be used if the person ever lacks capacity to make treatment decisions
- a clear statement of the decision, the treatment to be refused and the circumstances in which the decision will apply
- the date the document was written (or reviewed)
- the person's signature (or the signature of someone the person has asked to sign on their behalf and in their presence)
- the signature of the person witnessing the signature, if there is one (or a statement directing somebody to sign on the person's behalf).

Commentary

- A verbal advance decision cannot be used to refuse life sustaining treatment.
 - treatments must be specified rather than including vague statements, for example: *"I do not wish to be treated"*.
 - it would be good practice to record a note of any verbal decision to refuse treatment and ask the person to sign if they are able to do so.
- There is no set format for writing an advance decision. However, a pro forma example which contains the legal requirements can be found in the Appendices.

See paragraphs 9.24–9.28 below if the advance decision deals with life-sustaining treatment.

9.20

Witnessing the person's signature is not essential, except in cases where the person is making an advance decision to refuse life-sustaining treatment. But if there is a witness, they are witnessing the signature and the fact that it confirms the wishes set out in the advance decision. It may be helpful to give a description of the relationship between the witness and person making the advance decision. The role of the witness is to witness the person's signature, it is not to certify that the person has the capacity to make the advance decision – even if the witness is a healthcare professional or knows the person.

9.21

It is possible that a professional acting as a witness will also be the person who assesses the person's capacity. If so, the professional should also make a record of the assessment, because acting as a witness does not prove that there has been an assessment.

Commentary

In practice, professionals may have to witness advance decisions to refuse treatment. If they have doubts about the person's capacity to make an advance decision to refuse treatment the professional should refuse to witness it until the person's mental capacity has been assessed. If they do not have the skills to assess capacity themselves, they should seek advice.

Verbal advance decisions

9.22

There is no set format for verbal advance decisions. This is because they will vary depending on a person's wishes and situation. Healthcare professionals will need to consider whether a verbal advance decision exists and whether it is valid and applicable (see paragraphs 9.38–9.44).

9.23

Where possible, healthcare professionals should record a verbal advance decision to refuse treatment in a person's healthcare record. This will produce a written record that could prevent confusion about the decision in the future. The record should include:

- a note that the decision should apply if the person lacks capacity to make treatment decisions in the future
- a clear note of the decision, the treatment to be refused and the circumstances in which the decision will apply
- details of someone who was present when the oral advance decision was recorded and the role in which they were present (for example, healthcare professional or family member), and
- whether they heard the decision, took part in it or are just aware that it exists.

What rules apply to advance decisions to refuse life-sustaining treatment?

9.24

The Act imposes particular legal requirements and safeguards on the making of advance decisions to refuse life-sustaining treatment. Advance decisions to refuse life-sustaining treatment must meet specific requirements:

- They must be put in writing. If the person is unable to write, someone else should write it down for them. For example, a family member can write down the decision on their behalf, or a healthcare professional can record it in the person's healthcare notes.
- The person must sign the advance decision. If they are unable to sign, they can direct someone to sign on their behalf in their presence.
- The person making the decision must sign in the presence of a witness to the signature. The witness must then sign the document in the presence of the person making the advance decision. If the person making the advance decision is unable to sign, the witness can witness them directing someone else to sign on their behalf. The witness must then sign to indicate that they have witnessed the nominated person signing the document in front of the person making the advance decision.
- The advance decision must include a clear, specific written statement from the person making the advance decision that the advance decision is to apply to the specific treatment even if life is at risk.
- If this statement is made at a different time or in a separate document to the advance decision, the person making the advance decision (or someone they have directed to sign) must sign it in the presence of a witness, who must also sign it.

Commentary

A checklist - advance decision refusing life sustaining treatment must:

- be in writing
- be signed by the patient and a witness
- include the statement that the treatment is refused 'even if my life is at risk'
- cannot override comfort measures such as warmth, shelter and basic care (hygiene and offers of food and water by mouth).

and should as good practice

- be retained by the patient with, (if the patient agrees) a copy in all patient Records'

Although analgesia is not perceived as a treatment it is still an artificial intervention which can be refused as part of an advance decision. Most people would not wish to refuse analgesia as a comfort measure.

Cardiopulmonary Resuscitation (CPR) and Do Not Attempt Resuscitation (DNAR)

The impact of the MCA provisions for advance decisions to refuse treatment is complex. If a healthcare team considers that CPR has no realistic prospect of success then they may decide it is not to be attempted or offered. In these circumstances this decision is made by the healthcare team and is not an advance decision to refuse treatment made by the patient.

In 2007 the British Medical Association, the Royal College of Nursing and the Resuscitation Council have published a joint statement on decisions relating to cardiopulmonary resuscitation which considers these issues in more detail. Professionals should refer to that statement. Further commentary is also contained in the National Council for Palliative Care's publication: *The Mental Capacity Act in Practice: Guidance for End of Life Care* (2008)

9.25

Section 4(10) states that life-sustaining treatment is treatment which a healthcare professional who is providing care to the person regards as necessary to sustain life. This decision will not just depend on the type of treatment. It will also depend on the circumstances in which the healthcare professional is giving it. For example, in some situations antibiotics may be life-sustaining, but in others they can be used to treat conditions that do not threaten life.

9.26

Artificial nutrition and hydration (ANH) has been recognised as a form of medical treatment. ANH involves using tubes to provide nutrition and fluids to someone who cannot take them by mouth. It bypasses the natural mechanisms that control hunger and thirst and requires clinical monitoring. An advance decision can refuse ANH. Refusing ANH in an advance decision is likely to result in the person's death, if the advance decision is followed.

Commentary

- Artificial nutrition and hydration (ANH) includes subcutaneous and intravenous fluids, parenteral nutrition, feeding and hydration via nasogastric and PEG tubes. Death will occur if patients do not receive nutrition and hydration but many will die anyway even if these are provided.
- The cause of death will normally be the patient's underlying illness, except in circumstances where death would not otherwise occur without the withholding of artificial ANH.
- Further guidance on ANH can be found in the National Council for Palliative Care's publication: *Artificial Nutrition and Hydration - Guidance in End of Life Care for Adults* (2007)

9.27

It is very important to discuss advance decisions to refuse life-sustaining treatment with a healthcare professional, but it is not compulsory. A healthcare professional should be able to explain:

- what types of treatment may be life-sustaining treatment, and in what circumstances the implications and consequences of refusing such treatment (see also paragraph 9.14).

Commentary

The following have been identified as core competencies for health and social care professionals participating in any advance care planning discussions. *Advance Care Planning: A Guide for Health and Social Care Staff* (2007) NHS End of Life Care Programme

- Awareness of the context in which an advance care plan may be appropriate.
- Awareness of advance care planning.
- Awareness of advance decision to refuse treatment and relevant guidance documentation.
- Knowledge of communication skills.
- Knowledge of informed consent and the ability to give sufficient information.
- Knowledge of legal and ethical issues – codes of practice, MCA.
- Knowledge of relationship building skills.
- Knowledge of local resources which are available.

9.28

An advance decision cannot refuse actions that are needed to keep a person (sometimes called basic or essential care). Examples include warmth, shelter, actions to keep a person clean and the offer of food and water by mouth. Section 5 of the Act allows healthcare professionals to carry out these actions in the best interests of a person who lacks capacity to consent (see chapter 6). An advance decision can refuse artificial nutrition and hydration.

Commentary

It could be considered that drug measures to ensure comfort do constitute basic care but some may see these as treatments which have both benefits and possible harmful effects. In very specific circumstances it might be possible to refuse drug measures for comfort, but those writing such an advance decision will need to be very clearly aware that doing so may leave them with enhanced suffering at the time they are dying. In such circumstances the validity and applicability of the advance decision would require stringent scrutiny.

Deciding whether a treatment is “life sustaining” depends on the circumstances of intervention. The MCA states that “life sustaining treatment” is any treatment that health professionals treating the person consider necessary to sustain life. For example, antibiotics can be life sustaining in treatable pneumonia or can be a comfort measure for terminally ill patients with purulent sputum.

When should someone review or update an advance decision?

9.29

Anyone who has made an advance decision is advised to regularly review and update it as necessary. Decisions made a long time in advance are not automatically invalid or inapplicable, but they may raise doubts when deciding whether they are valid and applicable. A written decision that is regularly reviewed is more likely to be valid and applicable to current circumstances – particularly for progressive illnesses. This is because it is more likely to have taken on board changes that have occurred in a person’s life since they made their decision.

9.30

Views and circumstances may change over time. A new stage in a person's illness, the development of new treatments or a major change in personal circumstances may be appropriate times to review and update an advance decision.

Commentary

- Review of an advance decision can be done at any time by the person whilst they have mental capacity.
- Review can be done in any form, by amendment, or addition both verbally or in writing.
- If an advance decision is cancelled all copies should be destroyed or clearly marked cancelled.
- If a review is verbal it should be recorded in the person's patient notes.
- If following a review someone wishes to include the addition of a decision to refuse life sustaining treatment it must be in writing, signed and witnessed.
- It would be good practice to review any advance decision as part of an overall view of the person's advance care planning, if they are agreeable.

How can someone withdraw an advance decision?

9.31

Section 24(3) allows people to cancel or alter an advance decision at any time while they still have capacity to do so. There are no formal processes to follow. People can cancel their decision verbally or in writing, and they can destroy any original written document. Where possible, the person who made the advance decision should tell everyone who knew about their advance decision that it has been cancelled. They can do this at any time. For example, they can do this on their way to the operating theatre or immediately before being given an anaesthetic. Healthcare professionals should record a verbal cancellation in healthcare records, so that there is a written record for future reference.

How can someone make changes to an advance decision?

9.32

People can make changes to an advance decision verbally or in writing (section 24(3)) whether or not the advance decision was made in writing. It is good practice for healthcare professionals to record a change of decision in the person's healthcare notes. However, if the person wants to change an advance decision to include a refusal of life-sustaining treatment, they must follow the procedures described in paragraphs 9.24–9.28.

How do advance decisions relate to other rules about decision-making?

9.33

A valid and applicable advance decision to refuse treatment is as effective as a refusal made when a person has capacity. Therefore, an advance decision overrules:

- the decision of any personal welfare Lasting Power of Attorney (LPA) made before the advance decision was made. So an attorney cannot give consent to treatment that has been refused in an advance decision made after the LPA was signed
- the decision of any court-appointed deputy (so a deputy cannot give consent to treatment that has been refused in an advance decision which is valid and applicable)
- the provisions of section 5 of the Act, which would otherwise allow healthcare professionals to give treatment that they believe is in a person's best interests.

9.34

An LPA made after an advance decision will make the advance decision invalid, if the LPA gives the attorney the authority to make decisions about the same treatment (see paragraph 9.40).

9.35

The Court of Protection may make declarations as to the existence, validity and applicability of an advance decision, but it has no power to overrule a valid and applicable advance decision to refuse treatment.

9.36

Where an advance decision is being followed, the best interest principle (see chapter 5 of the Code of Practice) does not apply. This is because an advance decision reflects the decision of an adult with capacity who has made the decision for themselves. Healthcare professionals must follow a valid and applicable advance decision, even if they think it goes against a person's best interests.

Commentary

- A valid and applicable advance decision that complies with all the requirements of the MCA is legally binding. The patient has refused the treatment. That must be respected, as if the patient had capacity to do so. Professionals cannot make the decision to treat them in their best interests in these circumstances.
- With regard to an advance decision to refuse treatment and a Lasting Power of Attorney the most recent order takes precedence as long as it specifically concerns the same treatment.

Advance decisions regarding treatment for mental disorder

9.37

Advance decisions can refuse any kind of treatment, whether for a physical or mental disorder. But generally an advance decision to refuse treatment for mental disorder can be overruled if the person is detained in hospital under the Mental Health Act 1983, when treatment could be given compulsorily under Part 4 of that Act. Advance decisions to refuse treatment for other illnesses or conditions are not affected by the fact that the person is detained in hospital under the Mental Health Act. For further information see chapter 13.

How can somebody decide on the existence, validity and applicability of advance decisions?

Deciding whether an advance decision exists

9.38

It is the responsibility of the person making the advance decision to make sure their decision will be drawn to the attention of healthcare professionals when it is needed. Some people will want their decision to be recorded on their healthcare records. Those who do not will need to find other ways of alerting people that they have made an advance decision and where to find any written document and supporting evidence. Some people carry a card or wear a bracelet. It is also useful to share this information with family and friends, who may alert healthcare professionals to the existence of an advance decision, but it is not compulsory. Providing their GP with a copy of the written document will allow them to record the decision in the person's healthcare records.

9.39

It is important to be able to establish that the person making the advance decision was 18 or over when they made their decision and that they had the capacity to make that decision when they made it, in line with the two-stage test for capacity set out in chapter 3 of the Code of Practice. But as explained in paragraphs 9.7–9.9 above, healthcare professionals should always start from the assumption that the person had the capacity to make the advance decision.

Deciding whether an advance decision is valid

9.40

An existing advance decision must still be valid at the time it needs to be put into effect. Healthcare professionals must consider the factors in section 25 of the Act before concluding that an advance decision is valid. Events that would make an advance decision invalid include those where:

- the person withdrew the decision while they still had capacity to do so
- after making the advance decision, the person made a Lasting Power of Attorney (LPA) giving an attorney authority to make treatment decisions that are the same as those covered by the advance decision (see also paragraph 9.33)
- the person has done something that clearly goes against the advance decision which suggests that they have changed their mind.

Deciding whether an advance decision is applicable

9.41

To be applicable, an advance decision must apply to the situation in question and in the current circumstances. Healthcare professionals must first determine if the person still has capacity to accept or refuse treatment at the relevant time (section 25(3)). If the person has capacity, they can refuse treatment there and then, or they can change their decision and accept treatment. The advance decision is not applicable in such situations.

9.42

The advance decision must also apply to the proposed treatment. It is not applicable to the treatment in question if (section 25(4)):

- the proposed treatment is not the treatment specified in the advance decision
- the circumstances are different from those that may have been set out in the advance decision, or
- there are reasonable grounds for believing that there have been changes in circumstance, which would have affected the decision if the person had known about them at the time they made the advance decision.

9.43

So when deciding whether an advance decision applies to the proposed treatment, healthcare professionals must consider:

- how long ago the advance decision was made, and
- whether there have been changes in the patient's personal life (for example, the person is pregnant, and this was not anticipated when they made the advance decision) that might affect the validity/applicability of the advance decision, and
- whether there have been developments in medical treatment that the person did not foresee (for example, new medications, treatment or therapies).

Commentary

An advance decision to refuse treatment is not applicable if:

- the patient still has the capacity to make a decision about treatment
- the treatment refused is not specified
- any circumstances specified in the advance decision are absent
- the present circumstances were not anticipated by the patient when they made the decision and would have affected the patient's decision if they had known about them when they made the advance decision.

Health care professionals should assess whether an advance decision is valid and applicable and record their determination. The fact that an advance decision contains a statement that it is intended to be binding does not mean that it is binding. It must be assessed in the circumstances existing at the time the decision about treatment needs to be made.

9.44

For an advance decision to apply to life-sustaining treatment, it must meet the requirements set out in paragraphs 9.24–9.28.

What should healthcare professionals do if an advance decision is not valid or applicable?

9.45

If an advance decision is not valid or applicable to current circumstances:

- healthcare professionals must consider the advance decision as part of their assessment of the person's best interests (see chapter 5 of Code of Practice) if they have reasonable grounds to think it is a true expression of the person's wishes, and
- the professionals must not assume that because an advance decision is either invalid or not applicable, they should always provide the specified treatment (including life-sustaining treatment) – they must base this decision on what is in the person's best interests.

What happens to decisions made before the Act comes into force?

9.46

Advance decisions made before the Act comes into force may still be valid and applicable. Healthcare professionals should apply the rules in the Act to advance decisions made before the Act comes into force, subject to the transitional protections that will apply to advance decisions that refuse life-sustaining treatment. Further guidance is available at www.dh.gov.uk/consent.

Commentary

People with advance decisions or similar documents that pre-date the MCA should be advised to review them to ensure they meet the requirements of the MCA.

What implications do advance decisions have for healthcare professionals?

What are healthcare professionals' responsibilities?

9.47

Healthcare professionals should be aware that:

- a patient they propose to treat may have refused treatment in advance, and
- valid and applicable advance decisions to refuse treatment have the same legal status as decisions made by people with capacity at the time of treatment.

9.48

Where appropriate, when discussing treatment options with people who have capacity, healthcare professionals should ask if there are any specific types of treatment they do not wish to receive if they ever lack capacity to consent in the future.

Commentary

For a professional to discuss all the relevant treatment options with a patient will require consideration of appropriately allocated time. It will require the expertise to be able to inform the patient about the benefits, burdens and consequences. It will require good communication skills and avoidance of complex jargon. Health professionals should also take account of the differing needs and beliefs that exist.

- When considering making an advance decision a person should be advised to try to decide the nature of the outcome they seek and should then be advised as to what the steps might be to achieve that outcome
- In practice it is likely to be easier to create an advance decision to refuse specific treatment once there is a well established diagnosis
- Discussions should form part of overall and continuing advance care planning.
- All professionals should be open to any discussion instigated by a patient but should be able to recognise if they have reached the limit of their own knowledge and competence, and seek advice where necessary
- Before offering advice, the professional should be fully aware of the person's medical condition, prognosis and treatment options plus the legislative framework for making an advance decision.

9.49

If somebody tells a healthcare professional that an advance decision exists for a patient who now lacks capacity to consent, they should make reasonable efforts to find out what the decision is. Reasonable efforts might include having discussions with relatives of the patient, looking in the patient's clinical notes held in the hospital or contacting the patient's GP.

9.50

Once they know a verbal or written advance decision exists, healthcare professionals must determine whether:

- it is valid (see paragraph 9.40), and
- it is applicable to the proposed treatment (see paragraphs 9.41–9.44).

9.51

When establishing whether an advance decision applies to current circumstances, healthcare professionals should take special care if the decision does not seem to have been reviewed or updated for some time. If the person's current circumstances are significantly different from those when the decision was made, the advance decision may not be applicable. People close to the person concerned, or anyone named in the advance decision, may be able to help explain the person's prior wishes.

9.52

If healthcare professionals are satisfied that an advance decision to refuse treatment exists, is valid and is applicable, they must follow it and not provide the treatment refused in the advance decision.

9.53

If healthcare professionals are not satisfied that an advance decision exists that is both valid and applicable, they can treat the person without fear of liability. But treatment must be in the person's best interests (see chapter 5). They should make clear notes explaining why they have not followed an advance decision which they consider to be invalid or not applicable.

9.54

Sometimes professionals can give or continue treatment while they resolve doubts over an advance decision. It may be useful to get information from someone who can provide information about the person's capacity when they made the advance decision. The Court of Protection can settle disagreements about the existence, validity or applicability of an advance decision. Section 26 of the Act allows healthcare professionals to give necessary treatment, including life-sustaining treatment, to stop a person's condition getting seriously worse while the court decides.

Commentary

- There is no set recommendation for the frequency of review of an advance decision. For a healthcare professional the key issue is whether the patient's circumstances have changed since the decision was made.
- Some people may wish to identify a review date. If so, it would be good practice to make a note of the review date.

Do advance decisions apply in emergencies?

9.55

A healthcare professional must provide treatment in the patient's best interests, unless they are satisfied that there is an advance decision that is:

- valid, and
- applicable in the circumstances.

9.56

Healthcare professionals should not delay emergency treatment to look for an advance decision if there is no clear indication that one exists. But if it is clear that a person has made an advance decision that is likely to be relevant, healthcare professionals should assess its validity and applicability as soon as possible. Sometimes the urgency of treatment decisions will make this difficult.

Commentary

- If a valid advance decision comes to light and is applicable in the current situation then the treatment which was initially provided in an emergency will have to be withdrawn.
- A treatment refused in an apparent advance decision can only be given in two circumstances, if:-
 - the advance decision is not valid or applicable or does not comply with the Act's requirements relating to life sustaining treatment
 - there is doubt whether the advance decision is valid or applicable and the issue is still being resolved.

When can healthcare professionals be found liable?

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.

9.58

But they are protected from liability if they are not:-

- aware of an advance decision, or
- satisfied that an advance decision exists, is valid and is applicable to the particular treatment and the current circumstances (section 26(2)).

If healthcare professionals have genuine doubts, and are therefore not 'satisfied', about the existence, validity or applicability of the advance decision, treatment can be provided without incurring liability.

9.59

Healthcare professionals will be protected from liability for failing to provide treatment if they 'reasonably believe' that a valid and applicable advance decision to refuse that treatment exists. But they must be able to demonstrate that their belief was reasonable (section 26(3)) and point to reasonable grounds showing why they believe this. Healthcare professionals can only base their decision on the evidence that is available at the time they need consider an advance decision.

9.60

Some situations might be enough in themselves to raise concern about the existence, validity or applicability of an advance decision to refuse treatment. These could include situations such as:

- a disagreement between relatives and healthcare professionals about whether verbal comments were really an advance decision
- evidence about the person's state of mind raises questions about their capacity at the time they made the decision (see paragraphs 9.7–9.9)
- evidence of important changes in the person's behaviour before they lost capacity that might suggest a change of mind.

In cases where serious doubt remains and cannot be resolved in any other way, it will be possible to seek a declaration from the court.

Commentary

Professionals are protected from liability if:

- they withhold the specified treatment on the reasonable belief that an advance decision is valid and applicable
- they provide any treatment because of genuine doubts about the existence, applicability or validity of an advance decision to refuse treatment
- they can point to reasonable grounds why they held these beliefs or doubts.

What if a healthcare professional has a conscientious objection to stopping or providing life-sustaining treatment?

9.61

Some healthcare professionals may disagree in principle with patients' rights to refuse life-sustaining treatment. The Act does not change the current legal situation. They do not have to do something that goes against their beliefs, but they must not simply abandon patients or cause their care to suffer.

9.62

Healthcare professionals should make their views clear to the patient and the healthcare team as soon as someone raises the subject of withholding, stopping or providing life-sustaining treatment. Patients who still have capacity should then have the option of transferring their care to another healthcare professional, if it is possible to do this without affecting their care.

9.63

In cases where the patient now lacks capacity but has made a valid and applicable advance decision to refuse treatment which a doctor or health professional cannot, for reasons of conscience, comply with, arrangements should be made for the management of the patient's care to be transferred to another healthcare professional. Where a transfer cannot be agreed, the Court of Protection can direct those responsible for the person's healthcare (for example, a Trust, doctor or other health professional) to make arrangements to take over responsibility for the person's healthcare (section 17(1)(e))

What happens if there is a disagreement about an advance decision?

9.64

It is ultimately the responsibility of the healthcare professional who is in charge of the person's care when the treatment is required to decide whether there is an advance decision which is valid and applicable in the circumstances. In the event of disagreement about an advance decision between healthcare professionals, or between healthcare professionals and family members or others close to the person, the senior clinician must consider all the available evidence. This is likely to be a hospital consultant or the GP where the person is being treated in the community.

9.65

The senior clinician may need to consult with relevant colleagues and others who are close to or familiar with the patient. All staff involved in the person's care should be given the opportunity to express their views. If the person is in hospital, their GP may also have relevant information.

9.66

The point of such discussions should not be to try to overrule the person'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 person's healthcare records. Where the senior clinician has a reasonable belief that an advance decision to refuse medical treatment is both valid and applicable, the person's advance decision should be complied with.

Commentary

- In cases of disagreement the aim is to inform the process by consideration of all available evidence (this may mean calling on second opinions, discussions with families etc.)
- In general cases of disagreement can be resolved by either informal or formal procedures, however serious disagreement may only be resolved by application to the Court of Protection.

When can somebody apply to the Court of Protection?

9.67

The Court of Protection can make a decision where there is genuine doubt or disagreement about an advance decision's existence, validity or applicability. But the court does not have the power to overturn a valid and applicable advance decision.

9.68

The court has a range of powers (sections 16–17) to resolve disputes concerning the personal care and medical treatment of a person who lacks capacity (see chapter 8). It can decide whether:

- a person has capacity to accept or refuse treatment at the time it is proposed
- an advance decision to refuse treatment is valid
- an advance decision is applicable to the proposed treatment in the current circumstances.

9.69

While the court decides, healthcare professionals can provide life-sustaining treatment or treatment to stop a serious deterioration in their condition. The court has emergency procedures which operate 24 hours a day to deal with urgent cases quickly. See chapter 8 for guidance on applying to the court.



Example Proforma – (see appendix 1.)

The Act and Code of Practice clearly defines that the responsibility for making an advance decision belongs to the person (the maker). This guide states the legal requirements necessary for any advance decision to be valid and applicable and gives commentary to help explain this sometimes difficult decision. It is often helpful for the person to discuss their advance decision with a healthcare professional. If necessary this professional may give advice or support during this process to make and disseminate the advance decision.

People may find the use of patient information and example forms to be very helpful in formulating an advance decision. This guide includes an example proforma. People and professionals might use this example or develop it to meet their own individual or local needs. There are other examples to be found but care is required to ensure that they comply with the legal requirements.

Appendix 1.

My Advance Decision to Refuse Treatment

My Name	Any distinguishing features in the event of unconsciousness
Address	Date of Birth
	Telephone Number

What is this document is for?

This advance decision to refuse treatment has been written by me to specify in advance which treatments I don't want in the future. These are my decisions about my healthcare, in the event that I have lost mental capacity and can not consent to or refuse treatment. This advance decision replaces any previous advance decision I have made.

Advice to the reader

I have written this document to identify my advance decision. I would expect any health care professionals reading this document in the event I have lost capacity to check that my advance decision is valid and applicable, in the circumstances that exist at the time.

Please Check

Please do not assume I have lost capacity before any actions are taken. I might need help and time to communicate.

If I have lost capacity please check the validity and applicability of this advance decision.

This advance decision becomes legally binding and must be followed if professionals are satisfied it is valid and applicable. Please help to share this information with people who are involved in my treatment and care and need to know about this.

Please also check if I have made any other statements about my preferences or decisions that might be relevant to my advance decision.

This advance decision does not refuse the offer and or provision of basic care, support and comfort.

My Name	
---------	--

My advance decision to refuse treatment

I wish to refuse the following specific treatments:	In these circumstances:

(Note to the person making this statement: If you wish to refuse a treatment that is or may be life-sustaining, you must state in the box above that you are refusing that treatment even if your life is at risk as a result. An advance decision refusing life-sustaining treatment must be signed and witnessed).

My Signature (or nominated person)	Date of Signature
Witness	Witness Signature
Name	Telephone
Address	Date
Person to be contacted to discuss my wishes:	
Name	Relationship
Address	Telephone

I have discussed this with (e.g. name of Healthcare Professional)	
Profession / Job Title Contact Details	Date
I give permission for this document to be discussed with my relatives / carers	
YES	NO <i>(please circle one)</i>
My General Practitioner is: (Name)	
Address	
Telephone	
Optional Review Comment	Date / Time
Maker's Signature	Witness Signature

The following list identifies which people have a copy and have been told about this Advance Decision to Refuse Treatment (and their contact details)

Name	Relationships	Telephone Number

Further Information (Optional)

I have written the following information that is important to me. It describes my hopes, fears and expectations of life and any potential health and social care problems. It does not directly affect my advance decision to refuse treatment but the reader might find it useful.

Appendix 2.

The process for making best interest decisions in serious medical conditions in patients over 18 years

V16 © 2008. Regnard C. From: Regnard, Dean & Hockley; A guide to Symptom Relief in Palliative Care 6th ed, Oxford: Radcliffe Publishing

Start by assuming that the patient has capacity. If there is doubt, proceed to the two stage test of capacity:

Stage 1: Does the person have an impairment of, or a disturbance in the functioning of, their mind or brain?

Stage 2: Does the impairment or disturbance mean that the person is unable to make a specific decision when they need to? Their capacity for this decision can be assessed by four functional tests:

1. **Can they understand the information?** *NB. this must be imparted in a way the patient can understand*
2. **Can they retain the information?** *NB. This only needs to be long enough to use and weigh the information*
3. **Can they use or weigh up that information?** *NB. They must be able to show that they are able to consider the benefits and burdens of the alternatives to the proposed treatment*
4. **Can they communicate their decision?** *NB. The carers must try every method possible to enable this*

The result of each step of this assessment should be documented, ideally by quoting the patient.

Does the patient have the capacity to make this decision for themselves?

YES



Ask the patient.
NB. An eccentric or unwise decision does not imply a lack of capacity

NO

Is there an Advance Decision to Refuse Treatment (ADRT) and/or a Personal Welfare Lasting Power of Attorney (PW-LPA)?

YES



- **If the ADRT is the most recent decision:**
 - check that the circumstances of the ADRT match the current circumstances and that the ADRT is valid and applicable,
 - this ADRT then overrides any previous ADRT or LPA appointment
 - follow the decision(s) stated in the ADRT
 - **If the appointment of a PW-LPA is the most recent decision:**
 - check with the Office of the Public Guardian that it has been registered and includes the authority to decide on serious medical conditions
 - this PW-LPA then overrides any previous ADRT or LPA appointment
 - fully inform the PW-LPA of the clinical facts
 - ask the PW-LPA for their decision
- NB. there may be more than one LPA*

NO

Is the patient without anyone who could be consulted about their best interests?

YES



- In an emergency, act in the patient's best interests (see below).
- For any other serious medical decisions, involve an Independent Mental Capacity Advocate (IMCA) which are available locally

NO

- **Appoint a decision maker** (usually after an interdisciplinary team discussion) who should
 - Encourage the participation of the patient
 - Identify all the relevant circumstances
 - Find out the person's views (ie. wishes, preferences, beliefs and values): these may have been expressed verbally previously, or exist in an ADRT or Advance Care Plan made when the patient had capacity
 - Avoid discrimination and avoid making assumptions about the person's quality of life.
 - Assess whether the person might regain capacity
 - If the decision concerns life-sustaining treatment, not be motivated in any way by a desire to bring about the person's death.
 - Consult others (within the limits of confidentiality): this may include an LPA, IMCA or Court Appointed Deputy
 - Avoid restricting the person's rights
 - Take all of this into account, ie. weigh up all of these factors in order to work out the person's best interests.
- **Record the decisions**
- **Agree review dates and review regularly.**

If there unresolved conflicts, consider involving

- the local ethics committee
- the Court of Protection, possibly through a Court Appointed Deputy (CAD)

The process for making clinical decisions in serious medical conditions

An Advance Refusal of Treatment (ADRT) – see section 9.40 & 9.41 of the MCA Code of Practice

- Can be made only by a patient while they still have capacity, but becomes active only when they lose capacity
- Applies only to a refusal of treatment
- Is invalid if any of the following apply:
 - the person withdrew the decision while they still had capacity to do so
 - after making the advance decision, the person made a Lasting Power of Attorney (LPA) giving an attorney authority to make treatment decisions that are the same as those covered by the advance decision
 - the person has done something that clearly goes against the advance decision which suggests that they have changed their mind
- Is only applicable if it applies to the situation in question and in the current circumstances. An ADRT is not applicable if any of the following apply:
 - the proposed treatment is not the treatment specified in the advance decision
 - the circumstances are different from those that may have been set out in the advance decision
 - there are reasonable grounds for believing that there have been changes in circumstance, which would have affected the decision if the person had known about them at the time they made the advance decision.

If an advance decision is not valid or applicable to current circumstances, the healthcare professionals must consider the ADRT as part of their assessment of the person's best interests if they have reasonable grounds to think it is a true expression of the person's wishes, and they must not assume that because an advance decision is either invalid or not applicable, they should always provide the specified treatment (including life-sustaining treatment) – they must base this decision on what is in the person's best interests.

Capacity

- Is assumed to be present, unless the two stage test shows otherwise
- Is assessed by applying the two stage test (see algorithm)
- The ability to make a decision is assessed by four functional tests (see algorithm)
- Depends on the decision being made, eg. a patient may have capacity for simpler decisions, but not complex issues.
- Can change with time and needs to be monitored

Communication

- Carers have to take all practicable steps to help a patient understand the information and communicate their decision
- Professionals should take all practicable steps to include the patient in the decision

Liability

The MCA does not have any impact on a professional's liability should something go wrong, but a professional will not be liable for an adverse treatment effect if:

- Reasonable steps were taken to establish capacity
- There was a reasonable belief that the patient lacked capacity
- The decision was made in the patient's best interests
- The treatment was one to which the patient would have given consent if they had capacity

Personal Welfare Lasting Power of Attorney (LPA)

- Replaces the previous Enduring Power of Attorney
- Must be chosen while the patient has capacity, but can only act when the patient lacks capacity to make the required decision
- Must act according to the principles of best interests (see algorithm)
- Can be extended to life-sustaining treatment decisions (Personal Welfare LPA including health), but this must be expressly contained in the original application
- Only supersedes an advance decision if the LPA was appointed after the advance decisions, and if the conditions of the LPA cover the same treatment as in the ADRT

NB. Holders of LPA for Property and Affairs have no authority to make health and welfare decisions

Court Appointed Welfare Deputies (CADs)

- May be appointed by the Court of Protection, where a regular decision making power is necessary.
- Are helpful when a patient's best interests require a deputy consulting with everyone
- Can make decisions on the patient's behalf, but cannot refuse or consent to life-sustaining treatments.
- Is subject to the principles of best interests (see algorithm)

Independent Mental Capacity Advocates (IMCAs)

- Are part of a new statutory consultation service
- Must be involved in specific circumstances when a patient without capacity has no relative or partner who can be consulted
- Are advocates for the patient and not decision makers, so they cannot refuse or consent to life sustaining treatments.
- Can be bypassed if an urgent clinical decision is needed

Resources

- Any professional making decisions on behalf of a person without capacity is required by law to have regard to the Mental Capacity Act Code of Practice:
www.publicguardian.gov.uk/docs/code-of-practice-041007.pdf
- Office of Public Guardian:
www.publicguardian.gov.uk
- Court of Protection:
www.publicguardian.gov.uk/about/court-of-protection.htm
- IMCA service:
www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet06.pdf
- ADRT training programme:
www.adrtnhs.co.uk

Appendix 3.

Useful Information and contacts

Websites

Advance decision to refuse treatment training

www.adrtnhs.co.uk

British Medical Association

www.bma.org.uk

Court of Protection

www.publicguardian.co.uk/about/court-of-protection.htm

Department of Health

www.dh.gov.uk

End of Life Care /Advance Care Planning

www.endoflifecare.nhs.uk

Help the Hospice e learning site

www.helpthehospice.org.uk/elearning/mca.presentations.htm

Mental Health Foundation

www.mentalhealth.org.uk

Ministry of Justice Mental Capacity Act site

www.dca.gov.uk/legal-policy/mental-capacity/publications.htm

Ministry of Justice

www.dca.gov.uk

The National Council for Palliative Care

www.ncpc.org.uk

Office of the Public Guardians

www.publicguardian.gov.uk

Decisions relating to cardiopulmonary resuscitation

(October 2007) British Medical Association, the Royal College of Nursing and the Resuscitation Council:

[http://www.bma.org.uk/ap.nsf/AttachmentsByTitle/PDFCPRDecisions07/\\$FILE/DecisionRelatingResusReport.pdf](http://www.bma.org.uk/ap.nsf/AttachmentsByTitle/PDFCPRDecisions07/$FILE/DecisionRelatingResusReport.pdf)

End of Life Care Programme Tools

Gold Standards Framework

www.goldstandardsframework.nhs.uk

Preferred Priorities for Care

www.endoflifecareforadults.nhs.uk

Liverpool Care Pathway

www.mcpcil.org.uk

Publications

Artificial Nutrition and Hydration- Guidance in End of Life Care Adults

www.ncpc.org.uk/publications

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

www.ncpc.org.uk/publications

Appendix 4.

Section 24-26 of the Mental Capacity Act

Advance decisions to refuse treatment

24 Advance decisions to refuse treatment: general

- (1) "Advance decision" means a decision made by a person ("P"), after he has reached 18 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 health care 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.
- (2) For the purposes of subsection (1)(a), a decision may be regarded as specifying a treatment or circumstances even though expressed in layman's terms.
- (3) P may withdraw or alter an advance decision at any time when he has capacity to do so.
- (4) A withdrawal (including a partial withdrawal) need not be in writing.
- (5) An alteration of an advance decision need not be in writing (unless section 25(5) applies in relation to the decision resulting from the alteration).

25 Validity and applicability of advance decisions

- (1) An advance decision does not affect the liability which a person may incur for carrying out or continuing a treatment in relation to P unless the decision is at the material time—
 - (a) valid, and
 - (b) applicable to the treatment.
- (2) An advance decision is not valid if P—
 - (a) has withdrawn the decision at a time when he had capacity to do so,
 - (b) has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or
 - (c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision.
- (3) An advance decision is not applicable to the treatment in question if at the material time P has capacity to give or refuse consent to it.
- (4) An advance decision is not applicable to the treatment in question if—
 - (a) that treatment is not the treatment specified in the advance decision,
 - (b) any circumstances specified in the advance decision are absent, or
 - (c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.
- (5) An advance decision is not applicable to life-sustaining treatment unless—
 - (a) the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk, and
 - (b) the decision and statement comply with subsection (6).

- (6) A decision or statement complies with this subsection only if—
 - (a) it is in writing,
 - (b) it is signed by P or by another person in P's presence and by P's direction,
 - (c) the signature is made or acknowledged by P in the presence of a witness, and
 - (d) the witness signs it, or acknowledges his signature, in P's presence.
- (7) The existence of any lasting power of attorney other than one of a description mentioned in subsection (2)(b) does not prevent the advance decision from being regarded as valid and applicable.

26 Effect of advance decisions

- (1) If P has made an advance decision which is—
 - (a) valid, and
 - (b) applicable to a treatment,
the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued.
- (2) A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment.
- (3) A person does not incur liability for the consequences of withholding or withdrawing a treatment from P if, at the time, he reasonably believes that an advance decision exists which is valid and applicable to the treatment.
- (4) The court may make a declaration as to whether an advance decision—
 - (a) exists;
 - (b) is valid;
 - (c) is applicable to a treatment.
- (5) Nothing in an apparent advance decision stops a person—
 - (a) providing life-sustaining treatment, or
 - (b) doing any act he reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as respects any relevant issue is sought from the court.

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