ADVANCE DECISIONS TO REFUSE TREATMENT

This is one of a series of resource materials for clinical ethics committees providing explanation and discussion of the sections of the Mental Capacity Act which are particularly relevant to their work.

What is an advance decision?
An advance decision enables a person to refuse particular types of treatment they would not want to have at a time in the future (when they no longer have capacity). Advance refusals (referred to previously in common law as ‘living wills’ or ‘advance directives’) have been recognised by the courts as being in some circumstances as effective as a contemporaneous refusal, i.e., they are legally binding. In building upon the common law the Act codifies and clarifies existing common law rules. It also introduces new conditions and safeguards.

The Mental Capacity Act (MCA) distinguishes between advance refusals to refuse life-sustaining treatment and other types of advance refusals (referred in this document as type 1 and 2 refusals respectively). In some cases too an attorney may have been given the authority to refuse treatment on the patient’s behalf.

NB. An advance decision to refuse treatment (if made in accordance with the Act) is not the same as an advance written statement setting out the person’s wishes and feelings which may be taken into account in assessing their best interests.

Step 1: preliminary questions
In cases where an advance decision may be relevant the following questions should first be asked:

  a) How old is the patient?
The Act’s provisions about advance refusals only apply to someone aged 18 and over. Advance refusals by young people under 18 are governed by the common law and statute law (e.g., Children Act 1989).

  b) Did the person have capacity when they made their advance decision?
An advance decision refusing treatment can only be legally binding if the person had capacity when they made it.

  c) Is the advance decision attempting to demand specific treatment (rather than refuse it)?
Only advance decisions to refuse treatment can be made. Nobody has the legal right to demand specific treatment (either at the time or in advance) that health professionals consider clinically unnecessary, futile or inappropriate. Any preferences or requests that are expressed, however, should be considered when deciding what is in a patient’s best interests unless they relate to procedures that are against the law.

  d) Does the advance decision cover basic care?
An advance decision cannot refuse actions that are needed to keep a person comfortable (sometimes called basic or essential care). Examples of basic care include warmth, shelter, actions to keep a person clean and the offer of food and water by mouth (Code.9.28). Section 5 of the Act allows healthcare professionals to carry out these actions (without consent) in the best interests of the patient without incurring legal liability.

e) Does the Mental Health Act (MHA) 1983 apply?
Where people are detained under the Mental Health Act 1983 (and can therefore be treated for their disorder without their consent under Part 4), they can be treated even though they have made an advance decision refusing the treatment in question (see resource materials on the relationship between the MCA and MHA).

Is the person asking for their life to be ended?
Nobody can receive procedures that are against the law (for example, help with committing suicide). The Act does not change any of the laws relating to murder, manslaughter or helping someone to commit suicide.

Once it has been established that the patient was 18 or over when the advance decision was made, had capacity to make it that the advance decision does not relate to basic care the following steps should be followed.

Step 1: Establish what type advance decision exists

There are two types of advance decisions refusing treatment. Type 1 covers advance decisions refusing all treatment and care (other than life-sustaining treatment). Type 2 covers life-sustaining treatment.

Type 1: Advance decisions refusing treatment (not life-sustaining)

Type 1 advance decisions cover the refusal of a wide range of treatment options, i.e. not just minor one such as routine interventions but also major surgery the refusal of which may have serious consequences. The definition of treatment includes treatment and the continuation of treatment. Thus an advance decision could state that the person wants treatment but only for a certain amount of time.

The Act does not impose any particular formalities about the format of this type of advance decision. This means that they can be made either verbally or in writing. But whatever format is adopted the responsibility for drawing attention to the existence of the advance refusal lies with the person making it.

The Code of Practice identifies various ways in which people making advance decisions can be sure their advance decision is drawn to the attention of health professionals (and others). In order to establish whether an advance decision exists see Box 1& 2.
Box 1  Establishing the existence of an advance decision

Verbal decisions (Type 1)

The person who made the advance decision could have alerted relatives/friends/healthcare professionals to its existence. Alternatively such people may simply be aware that one exists.

The Code of Practice (9.23) recommends that health professionals record (where possible) a verbal advance decision and that 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 (e.g. healthcare professional or family member), and
- whether they heard the decision, took part in it or are just aware that it exists

Box 2:  Establishing the existence of an advance decision

Written decisions (Type 1)

The Code of Practice (9.18-20) recommends that even though there is no set format for written advance decisions that do not refuse life-sustaining treatment they should nevertheless ideally include:

- full details of the person making it, including their date of birth, home address and any distinguishing features
- 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 person’s signature (or the signature of someone the person has asked to sign on their behalf)
- the date the document was written or reviewed
- the signature of the person witnessing the signature, if there is one

(Although witnessing the signature is not essential if the witness is a healthcare professional they may also be the person assessing capacity. If so a record of the assessment of incapacity should be made).

NB.  1. A written document is very strong evidence of an advance decision.
    2. The person who makes the advance decision has the responsibility to tell others it exists and where it is
    3. In addition they may want to carry it with them or carry a card, bracelet or other indication.
Type 2: Advance decisions refusing life-sustaining treatment

Type 2 advance decisions cover life-sustaining treatment. Life-sustaining treatment is defined as treatment which ‘a health care professional who is providing care for the patient regards as necessary to sustain life’ (s.4(10)). As the Code of Practice explains whether a particular treatment will, or will not, be life-sustaining depends on the circumstances of each particular case. Thus, for example, whereas a refusal of artificial nutrition and hydration (ANH) is likely to result in a person’s death, antibiotics may (or may not) be life-sustaining (Code.9.25).

It is in relation to type 2 advance decisions that the Act makes the most significant changes to the common law - by imposing specific formalities and safeguards (see Box 3).

Box 3  Advance decisions refusing life-sustaining treatment (Type 2)

s.(26) (5)&(6) Code of Practice 9.24-28

To have legal effect the following criteria must be met:

a) the advance decision:
   • must be in writing (a record in medical notes is considered to be in writing). If the person is unable to write, someone else should write it down for them.
   • must include a clear, specific written statement from the person making the advance decision that the decision is to apply to the specific treatment even if life is at risk (‘life’ includes the life of an unborn child).
   • Must be witnessed.

NB. The ‘written statement’ can be made at a different time or in a separate document to the advance decision. If so, it too must be signed and witnessed.

b) the person making the advance decision must:
   • sign the advance decision. If the person is unable to sign it, they can direct someone else to sign it for them in their presence.

c) the witness must:
   • sign the advance decision (and the ‘written statement’ if it is in a separate document) in the presence of the person making it, or
   • if the person making the advance decision (and any separate ‘written statement’) is unable to sign the witness can witness them directing someone else to sign it on their behalf, and if so, then
   • sign to indicate that they have witnessed the nominated person signing the document in front of the person making the advance decision.

NB. The Code states that it is very important to discuss advance decisions to refuse life-sustaining treatment with a healthcare professional. But it is not compulsory (9.27)

Change: Under the common law there were no special legal formalities governing the format of an advance decision refusing life-sustaining treatment. The Act now requires these to be in writing, signed, witnessed and to include a specific statement that the advance decision is to apply even if life is at risk.
Step 2: Check whether the advance decision has been withdrawn or altered

Once it has been established that an advance decision exists it is necessary to check that it has not been altered or cancelled (in whole or part). The advance decision may have been made many years previously. Since then views and circumstances may have changed or new treatments may be available. A change in personal circumstances may also mean that an advance decision may not represent a person’s previous views. As the Code advises anyone who has made an advance decision should regularly review and update it, as necessary (9.29),

Section 24(3) allows people to withdraw or alter their advance decision at any time – provided, of course, they have capacity to do so. Both a withdrawal (which can be partial) and any alteration, can be verbal or in writing. The one exception is any change that includes the addition of a refusal of life-sustaining treatment (which must comply with the formalities outlined in Box 3.

The implications of these sections for the two types of advance decisions are outlined in Box 4

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<th>Box 4</th>
<th>Withdrawing/ altering advance decisions</th>
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| Type 1: advance decisions (not life-sustaining) | • can be cancelled or altered verbally or in writing (irrespective of the format of the original advance decision.  
• whatever the format adopted responsibility for bringing the change to the attention of health professionals lies with the person making the advance decision.  
• health professionals should record any changes of decision in the person’s healthcare notes. |

NB. If the alteration includes a refusal of life-sustaining treatment the formalities in Box 3 must be followed

Type 2: advance decisions refusing life-sustaining treatment |

• can be cancelled or altered either verbally or in writing  
• responsibility for alerting health professionals to the change lies with the person making it  
• health professionals should record any changes of decision in the person’s healthcare notes.

Step 3: Decide whether the advance decision is ‘valid’

This step is the first of two important safeguards introduced to ensure that the person who made the advance decision (either type 1 or 2) still intends to be bound it when they no longer have capacity. Questioning the validity of an advance decision is basically a way of establishing a) whether one still exists and/or b) whether it has been cancelled by the person’s subsequent actions or behaviour.
Determining the validity of an advance decision basically involves three crucial questions (set out in section 25(2)) of the Act:

1) Has the person withdrawn their advance decision when they had capacity to do so?
2) Has the advance decision been overridden by a Lasting Power of Attorney (LPA) appointed after the advance decision was originally made (giving the attorney authority to make the treatment decision in question)? (see Box 5)

Box 5 Decisions by LPAs (appointed after the advance decision was made)

1. An attorney has no power to refuse life-sustaining treatment unless the LPA document expressly authorises such a refusal.

2. In reaching any decision about refusing life-saving treatment the attorney must not be motivated in any way by the desire to bring about the person’s death (s.4(5).

3. If reaching any decision, i.e. whether to consent to or refuse treatment (life-saving or otherwise), the attorney must act in the best interests of the person (see resource materials on best interests).

Change: The Act has created a new statutory power to appoint an attorney to make end of life decisions. This proxy can refuse life-sustaining treatment if: a) the ‘personal welfare’ Lasting Power of Attorney gives the attorney to make such a decision and b) if the decision is in the person’s best interests..

3) Has the person done anything clearly inconsistent with the advance decision suggesting they have changed their mind? (Box 6)

Box 6 ‘Clearly inconsistent’

With no guidance in the Act as to what amounts to actions or behaviour that are ‘inconsistent with the advance refusal’ it seems that:

- a person could invalidate their advance decision indirectly by subsequent actions/behaviour
- explicit actions, such as renouncing the religious beliefs on which their advance decision was based, constitute stronger evidence of behaviour inconsistent with the advance refusal.
- the person’s ‘inconsistent’ behaviour could have occurred when they no longer had capacity.
If the answer to any of the above three questions is: Yes, the advance decision is not valid. This means health professionals are not legally obliged to follow it. Nevertheless it would need to be seriously considered as part of the process of determining the person’s best interests- assuming, of course, that it is a true expression of the person’s wishes. Once a decision has been made that the advance decision is not valid then health professionals must act according to the person’s best interests (see File 2).

If there is any doubt about the validity of an advance decision step 5 should be followed next.

If the answer to all of the above 3 questions is: No, then step 4 must be followed.

**Step 4: Decide whether the advance decision is ‘applicable’**

The second safeguard governing advance decisions to refuse treatment requires health professionals to decide whether the advance decision is applicable to the treatment in question. This safeguard is necessary because even though an advance decision does exist and is valid, it may not necessarily actually apply to the current circumstances.

S.25 (3) - (6) deals with applicability and again basically requires health professionals to ask a series of questions:

1) **does the person have the capacity to accept or refuse treatment at the relevant time?**
   
   NB. If the person now has capacity they can refuse treatment there and then, i.e. any advance decision lapses if the person regains capacity, to come into effect again if capacity is again lost.

2) **is the proposed treatment different from the treatment specified in the advance decision?**
   
   NB. A decision may be regarded as specifying a treatment or circumstances even though it is expressed in everyday language rather than medical terminology

3) **are the circumstances in which the person finds himself different from those set out in the advance decision?**

4) **are there reasonable grounds for believing that that there has been an unanticipated change of circumstance which casts doubt on whether the advance decision now truly reflects the person’s wishes?**

5) **if the advance decision applies to life-sustaining treatment does it fail to comply with the requirements set out in Box 3?**

Because the answers to these 5 questions may be difficult the Code provides guidance on the factors healthcare professionals should consider, Box 7)
If the answers to any of the above 5 question’s is: Yes, the advance decision is not applicable. This means that health professionals are not legally obliged to follow it. It would, however, need to be seriously considered as part of the process of determining the person’s best interests. Once a decision has been made that the advance decision is not applicable health professionals must make a decision based on the person best interests.

If there is any doubt about the applicability of the advance decision step 5 should be taken.

If the answer to all of the above questions is: No, the advance decision is applicable; (go to step 6).

**Step 5: Postpone making a decision**

Because it may sometimes be very difficult to determine whether or not an advance decision refusing treatment exists, that the person had capacity when they made it and it is both valid and applicable, it may be wise to postpone making a decision until any uncertainties are resolved or a declaration from the court is obtained (see File 7). According to the Code of Practice (9.60) the following situations might be enough in themselves to raise concerns:

- a disagreement between relatives and healthcare professionals about whether verbal comments were really an advance decision
- evidence about the person’s state of mind raising questions about their capacity at the time they made the decision
- evidence of important changes in the person’s behaviour before they lost capacity that might suggest a change of mind

**NB. The Act makes it clear that if there is doubt or dispute about whether a particular refusal exists, is valid or applicable, treatment that is necessary -to prevent the death of the person concerned, or a serious deterioration in their condition – can be provided until the matter is resolved.**
Step 6: Ensure that legal protection is available

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. This means that if healthcare professionals are satisfied that an advance decision to refuse treatment exists, is valid and applicable, they must follow it (i.e. not provide the treatment refused in the advance decision). Failure to do so could result in legal action – a civil claim for damages or a criminal charge of assault.

Alternatively legal action could follow if health professionals do not provide treatment believing (wrongly) that an advance decision refusing the treatment exists.

So health professionals may either:

1) **give treatment that has been refused in an advance decision**
   Section 26(2) makes it clear that a treatment-provider can safely treat (i.e. without fear of liability) if he is not satisfied that a valid and applicable advance decision exists, **Or**

2) **withdraw or withhold treatment thinking (wrongly) that there is an advance decision?**
   Section 26(3) makes it clear that a treatment-provider may safely withdraw or withhold treatment as long as he reasonably believes that an advance decision exists which is valid and applicable (Box 8)

*Change: Sections 26 (2) and (3) clarify the rules about legal liability. Previously it was assumed that under common law a defence of ‘reasonable mistake’ would have protected healthcare professionals from liability.*

Step 7: Make a final decision

At this final stage there are two options, either to:

a) **Follow** the advance decision- by withdrawing/ withholding treatment specified, or

b) **Reject** the advance decision and provide treatment (that must be in the person’s best interests).