Advance Decisions

This month’s paper will look at advance decisions, which you’ve also probably seen referred to as advance directives or living wills. We will aim to examine what they do, why a person might want one, and the requirements for an advance decision to be valid.

WHAT IS AN ADVANCE DECISION?

An advance decision is a decision made by a person refusing consent to the giving or continuing of certain medical treatment. This statement is made whilst they have capacity, in anticipation of a time in the future when they no longer have capacity.

Advance decisions are also commonly referred to as an advance decision to refuse treatment, a living will or an advance directive.

Advance decisions were given a statutory recognition by s24-26 Mental Capacity Act 2005 (MCA), which came into effect from 1 October 2007. Before this point the courts had recognised advance decisions under common law and an advance decision made before this date would be valid if it complies with the rules under the Mental Capacity Act 2005.

If a healthcare professional is aware of that the advance decision exists, the advance decision is valid, and it applies in the current circumstances, they are bound to follow it even if they do not believe it is in the maker’s best interests. If a healthcare professional does not follow the advance decision in these circumstance, they could face a civil action or even a criminal prosecution.

WHY MAKE AN ADVANCE DECISION?

Advance decisions are commonly made by people diagnosed with a terminal or degenerative illness, or those with religious, spiritual or personal beliefs that are relevant to their medical treatment to refuse certain types of medical treatment. If that person later loses capacity, without the use of an advance decision to refuse medical treatment, healthcare professionals would act in what they believe is in the person’s best interests. This may not be what the person would have wanted.

Without using an advance decision, if a person has lost capacity it will be up to healthcare professionals to make decisions in what they believe is the person’s best interests. Alternatively, a person may have made a Health and Welfare Lasting Power of Attorney (LPA), in such case the attorneys would make these decisions based on what they believe is in the donor’s best interests. A person making an advance decision can refuse treatment even if it may not be seen in their best interests to do so.
**REQUIREMENTS**

An advance decision is valid as long as it is made by a person over 18 who has capacity at the time that it is made (S24(1) MCA). If the decision-maker’s capacity is in doubt the drafter ought to obtain a written assessment of their capacity from a medical professional.

There is no statutory requirement that an advance decision is made in writing unless it contains a refusal of life-sustaining treatment. The following conditions contained in S25(5) and (6) apply:

- It is made in writing
- It is signed by the person making the advance decision or by another person on their behalf and in the maker’s presence
- The signing is witnessed by one person who also signs
- A clear and specific statement to say that the advance decision applies even if their life is at stake (a verification statement) is included.

The verification statement can be made at a different time or in a separate document. If so, it must also be signed and witnessed.

There has been one instance of an oral advance decision containing a refusal of life-sustaining treatment being upheld in *Newcastle upon Tyne Hospitals Foundation Trust v LM* [2014] EWHC 454 (COP) concerning a Jehovah’s Witness refusing blood transfusions. However, it is a case that is limited in its effect. The case was urgent, the proposed treatment may not have prolonged life and the judge made it clear that ignoring the advance decision would have produced the same result as it was in the patient’s best interests to not treat them due to their long-standing beliefs.

Whilst there is no requirement for an advance decision not refusing life-sustaining treatment to be made in writing, it is highly advisable to do so. An oral advance decision may not be followed due to lack of evidence regarding its existence or validity.

**WHAT TO INCLUDE**

1. **What can’t be included in an advance decision?**

A person cannot require that a *particular* treatment is provided. The legal effect of an advance decision is limited to a refusal of consent to treatment. Any statements requesting that a particular treatment is used could however be written as a non-binding wish. It is acceptable for the advance decision to include preferences as to particular treatments, and a medical professional may take their preference into account when deciding on a particular treatment.

Illegal acts, such as euthanasia, cannot be requested in an advance decision.

An advance decision cannot refuse basic care. These are actions needed to keep them comfortable, such as food and water by mouth, basic hygiene and providing warmth. Such acts are not seen as medical treatment and therefore cannot be refused. Artificial nutrition and hydration however can be refused, as this is considered medical treatment.
An advance decision refusing treatment for mental disorder can be overruled if that person’s treatment is regulated under the Mental Health Act 1983.

2. What can be included in an advance decision?

There is no set form for written advance decisions, as contents will vary from person to person. The Code of Practice for the Mental Capacity Act 2005 at paragraph 9.19 advices that the following be included in a written advance decision:

- Full details of the person making the advance decision, including date of birth, address and distinguishing features (in case an unconscious person needs to be identified).
- Names and address of the maker’s GP and whether they have a copy
- 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 maker’s signature and the witness’ signature.

Layman’s terms rather than medical terms can be used as long as it is clear what the maker’s wishes are (S24 (2) MCA).

It is advisable to consider future circumstances. For example, a woman may wish to state whether her wishes may change if she is pregnant at the time, alternatively a person’s decision may or may not change if certain treatments are available in the future. Where changes in circumstances are not accounted for, healthcare professionals may decide that the advance decision is not applicable in those particular circumstances.

A refusal of all treatment in any situation, for example based on religious beliefs, may be valid and applicable.

It is advisable for a person to discuss their wishes with a healthcare professional who knows their medical history.

**Applicability**

Healthcare professionals are bound to follow an advance decision if they are satisfied that it exists, is valid and is applicable in the current situation. Not doing so could lead to civil or criminal proceedings against them.

They are however not liable for not following the advance decision if they are not aware of the advance decision or not reasonably satisfied that it exists, is valid and is applicable to the particular treatment or situation based on the information available to them at the time.

1. Deciding whether it exists

It is the maker’s responsibility to make others aware of their advance decision. A person making an advance decision should be advised to:
• Make relatives and close friends aware
• Ask for a copy to be placed with their GP, hospital records and Summary Care Record
• Carry a copy on their person e.g. in their wallet, or a carry a card or bracelet on their person detailing the location of the advance decision

7.1.1. Case of Brenda Grant

Brenda Grant made an advance decision stating if she was no longer of sound mind for suffered from a list of certain illnesses, she should not be given food artificially and symptoms should be controlled by pain relief even if it may shorten her life.

Her hospital however misplaced her advance decision and was artificially fed for 22 months in a nursing home after suffering a stroke leaving her unable to walk, talk or swallow.

Mrs Grant did not tell her children about her advance decision; her GP alerted her children to the advance decision shortly before she was re-admitted to hospital.

The hospital admitted liability and settled out of court.

Brenda Grant’s case highlights the need for advising a maker of an advance decision to inform both family and medical professionals of the existence of an advance decision.

2. Deciding whether it is valid

It would need to be proven that the maker was over 18 at the time of making the advance decision and that they had capacity at that time.

S25(2) MCA covers situations where an advance decision would no longer be valid, these are where the maker:

• Has withdrawn the advance decision whilst the maker had capacity to do so
• Has created an LPA after the advance decision was created giving the attorneys authority to make the same decisions
• Has done anything else clearly inconsistent with the advance decision remaining in force

3. Deciding whether it is applicable

To be applicable, it must apply to the situation in question and circumstances at that time.

If the maker still has capacity, they can refuse treatment themselves there and then. An advance decision is therefore not applicable in those situations (25(3) MCA)

The treatment proposed must also be covered by the advance decision. If the treatment is not specified in the advance decision, the circumstances are different from those set out or there are reasonable grounds for believing that there have been changes in circumstance that would have affected the decision if the maker had known about them at the time, the advance decision will not be seen as applicable (25(4) MCA).

Healthcare professionals will therefore need to consider how long ago the advance decision was made, whether there have been any changes in the maker’s personal life that might affect the validity or
whether there have been developments in medical treatment that the maker did not foresee (e.g. new medicines, treatment or therapies).

7.4. What if it is found to not be valid or applicable?

If an advance decision is found to not be valid or applicable in the circumstances, healthcare professionals would then need to base their decisions on the person’s treatment on what is in that person’s best interest. They must however still consider the advance decision however when deciding what is in the person’s best interest as long as they still believe that the advance decision is a true expression of the person’s wishes.

DEALING WITH DISAGREEMENTS

In the event of disagreements between healthcare professionals, family members or others, the senior clinician (likely a hospital consultant or a GP) in charge of the maker’s care must consider all evidence available. They may need to consult with colleagues and others who are close to the maker.

The point of consulting should not be to attempt to overrule the advance decision, only to seek evidence regarding the validity and applicability. Where the senior clinician believes that the advance decision is both valid and applicable, it would be complied with.

The Court of Protection can also make a decision on the existence, validity or applicability of an advance decision (S26(4) MCA), but they cannot overturn it. Whilst the court is making their decision, healthcare professionals can still provide life-sustaining treatment or act to prevent a serious deterioration in the maker’s condition (S26(5) MCA).

REVIEWING OR REVOIKING

An advance decision may be revoked or amended at any time whilst the maker has capacity. There is no formal procedure to follow to revoke an advance decision. It can be verbally, in writing or by destroying the document. Where the advance decision is revoked, the maker should inform anyone who knew about it or held a copy that they have revoked it. A written revocation is advisable to provide evidence for future reference.

It is advisable that advance decisions are regularly reviewed and updated if necessary, as an advance decision made some time ago may raise doubts as to whether the decision is still applicable. A regularly viewed document will give a healthcare professional confidence that the maker’s views have not changed.

Even if the contents of the document are not changed, the maker could sign and date the document to indicate that it has been reviewed, or alternatively sign a new copy of the same document. A copy of the new document should be sent to any person who has a copy of the old document.
RELATIONSHIP WITH LPAS

The exact relationship between an advance decision and a health and welfare LPA depends on which document was created first.

If an advance decision is created after a health and welfare LPA, attorneys cannot consent to any treatment refused in the advance directive.

If a health and welfare LPA is created after an advance decision, the creation of the LPA will make the advance decision invalid if the LPA gives the attorneys the authority to make decisions about the same treatment. For example, if an advance decision includes provisions about refusing life sustaining treatment, giving the attorneys authority to make decisions regarding life sustaining treatment would make that advance decision provision invalid.

If the advance decision should be taken into account, the Office of the Public Guardian (OPG) advise in their LP12 guide that reference to the advance decision should be made in the instructions in section 7 of the LPA. A copy of the advance decision should also be included when the LPA is sent to the OPG for registration.

Important Reminder:

These notes are produced solely for the benefit of SWW members when completing the June CPD test to gain 1 hour of structured CPD towards their annual quota. The notes do not represent legal advice and no reliance can be made on the content of the notes in any or individual specific client circumstances. Having read the notes members should cement their understanding by considering further reading around the subject – cases details can be found by searching the case references using BAILII or GOOGLE.