

MCA6 – Advance Decisions & Living Wills Guidance

Implementation of the Mental Capacity Act 2005

The Mental Capacity Act 2005 provides a legal framework to help empower people to make their own decisions and to make clear what actions carers and family can take. It puts the law on advance decisions (or living wills) on a clear statutory basis for the first time. The rules relate particularly to advance decisions to refuse treatment, including refusal of life-sustaining treatment.

The Act is fully in force, including the parts on advance decisions, from 1st October 2007. This guidance provides more details about advance decisions. It should be read in conjunction with the Essex Policy and associated guidance alongside the MCA Code of Practice.

The Code of Practice to the Mental Capacity Act gives guidance on how the legislation will work in everyday situations. Among other things, it explains how to assess whether someone lacks capacity to make a particular decision, and what it means to act in someone's best interests. Anyone dealing with an advance decision, in particular medical staff providing care to someone who has made an advance decision should have regard to the Code of Practice.

Further information about the Mental Capacity Act is available in a series of guidance booklets. This includes one for people who want to plan ahead themselves; one for family and unpaid carers; and one for people who work in health and social care.

Introduction

When a service user is ill, they can usually discuss their treatment options with their doctor and then jointly reach a decision about their future care.

However a service user may be admitted to hospital when unconscious or unable, on a temporary or permanent basis, to make their own decisions about their treatment or to communicate their wishes. This may happen, for example, if a service user has a car accident or a stroke or develops dementia. In such circumstances, the service user may lack the capacity to make informed decisions and/or to communicate their wishes. Professionals have a legal and ethical obligation to act in a service user's best interests. If a service user has made an advance decision to refuse treatment and that decision is valid and applicable to the circumstances, medical professionals providing a service user's care are bound to follow it.

The term 'living will' can be used to refer to either an advance decision or an advance statement. An advance decision is a decision to refuse treatment; an

advance statement is any other decision about how a service user would like to be treated. Only an advance decision is legally binding, but an advance statement should be taken into account when deciding what is in a service user's best interests.

Advance Directives can no longer be made. The Advance Decision Process set down in the Mental Capacity Act 2005 is to replace the ability under common law to make an Advance Directive as from 1st October 2007.

What is an advance statement?

This is a general statement about a service user's wishes and views. It allows a service user to state their preferences and indicate what treatment or care they would like to receive in the future, if they became unable to decide or communicate their wishes. An advance statement can include non medical things such as a service user's food beliefs or preferences or whether they prefer a bath to a shower.

An advance statement can reflect a service user's religious or other beliefs and any aspects of life that they particularly value. It can help those involved in a service user's care to know more about the service user's past expressed wishes and beliefs. An advance statement must be considered by professionals in determining best interests, but it is not legally binding.

Advance statements can provide professionals with information about who a service user would like to be consulted if they lose the capacity to make a decision themselves.

An advance statement can be included in a Lasting Power of Attorney (LPA), document. An LPA can be used if a service user wants to give someone else, or more than one person, the power to make decisions about their care and treatment - if they are not able to do so themselves. The service user's attorney(s) must take an advance statement into account when deciding what is in a service user's best interests. See below for more information about LPAs.

What is an advance decision to refuse treatment?

An advance decision to refuse treatment is the only type of living will that is legally binding.

An adult with mental capacity can refuse treatment for any reason, even if this might lead to their death. However no one is able to insist that a particular medical treatment is given, if it conflicts with what the medical professionals providing the treatment conclude is in the patient's best interests. This is why an advance decision can only be a refusal of treatment.

An advance decision to refuse treatment must indicate exactly what type of treatment a service user wishes to refuse and should give as much detail as necessary about the circumstances under which this refusal would apply. It is not necessary to use precise medical terms, as long as it is clear what treatment is to be

refused in what circumstances.

An advance decision can only be made by someone over age 18 who has the mental capacity to make the decision. This means they must be able to understand, weigh up and retain the relevant information in order to make the decision to refuse treatment; and they are then able to communicate that decision.

How to make an advance decision to refuse treatment?

An advance decision does not have to be in writing, unless it is a decision to refuse life-sustaining treatment (see the next section below for the legal requirements for this type of decision). Verbal instructions can amount to a valid advance decision but there is more risk that a verbal refusal of treatment would not be carried out. The person providing treatment may not be aware of it, or there could be uncertainty about its validity or applicability.

For example, a statement made by a patient during a discussion with their doctor that they would not wish to have a particular type of treatment in certain circumstances in the future can be a valid advance decision without it being put in writing. It would however be best practice for the doctor to record the statement in the patient's medical records, but it can still be valid if this is not done. Even if a service user is putting their advance decision in writing themselves, it is a good idea for a service user to discuss their advance decision with their GP or a doctor involved in their care.

To avoid uncertainty over the validity of an advance decision it should always be put in writing, or written down for the service user. The following guidelines may be helpful:

- The advance decision should be put in writing
- It should include the service user's name, date of birth, address and details of their GP
- It should include a statement that the service user wishes the advance decision to apply if they lack the capacity to make a decision at a relevant time.
- It must specify precisely what kind of treatment is to be refused and in what circumstances, giving as much detail as possible.
- The document must be signed and dated by the service user.
- The service user's signature should be witnessed.
- A doctor or another relevant professional should sign a statement on the document stating that they have carried out an assessment of the service user and in their opinion; the service user has capacity to make the decisions recorded in the advance decision.

Whilst the above points are not legal requirements, they can help to avoid uncertainty over the validity and applicability of an advance decision and are good practice. There are legal requirements if a service user is making an advance

decision to refuse life-sustaining treatment. See below for details of these.

MCA7 provides a form for recording advance decisions. Advance decisions do not have to be recorded on MCA10 but it does provide a useful template.

How to make an advance decision to refuse life-sustaining treatment?

If a service user wants to make an advance decision to refuse life-sustaining treatment, it must meet certain requirements set out in the Mental Capacity Act. Life-sustaining treatment is defined in the Act as treatment that, in the view of the person providing health care to the person concerned, is necessary to sustain their life. This could include artificial nutrition and hydration to someone who cannot eat or drink by mouth.

The legal requirements for a valid advance decision to refuse life-sustaining treatment are as follows:

- The decision must be in writing. The service user can ask someone else to write it down if they can't do this for themselves.
- The document must be signed by the service user who can instruct someone to sign it on their behalf in their presence if they can't personally sign it themselves.
- The service user's signature (or the signature of the person signing on their behalf) must be witnessed. The witness must also sign the document in the service user's presence.
- The service user must include a written statement that the advance decision is to apply to the specific treatment even if the service user's life is at risk.

MCA7 provides a useful template for recording advance decisions; however advance decisions do not have to be recorded on this form to be valid.

Advance decisions made before 1st October 2007

The part of the Mental Capacity Act relating to advance decisions came into force on 1st October 2007. An advance decision made before that date can still be valid if it meets the requirements set out in the Act.

If you made an advance decision refusing life-sustaining treatment *before 1st October 2007*, you should review it to make sure it meets the requirements of the Act (see the previous section). It is likely that many such advance decisions will not meet those requirements; in particular, your decision must include a statement that it is to apply even if your life is at risk. **Service Users (with the capacity to do so) must remake Advance Decisions if their original decision does not meet the requirements of the Mental Capacity Act.**

There are transitional arrangements for people who made an advance decision to refuse life-sustaining treatment before 1st October 2007 but who have since lost the mental capacity to remake that decision. This is covered by Regulation 5 of the Regulations that can be found at www.opsi.gov.uk

A decision made before 1st October 2007 which does not meet the requirements (to be signed and witnessed and to include a statement that it will apply even if life is at risk) can still be valid and applicable if:

- It is in writing,
- The person providing the treatment has a reasonable belief that the advance decision was made before 1st October 2007, and
- The person providing the treatment has a reasonable belief that the person making the advance decision has lacked capacity to amend it since 1st October 2007.

The normal requirements regarding validity and applicability (see below) must also be met.

Deciding if an advance decision is valid and applicable

A service user should take steps to make sure that the people providing their treatment will be aware of any advance decision at the relevant time. This could mean discussing it with their GP, or other treating doctors, while they still have capacity to do so, and making sure that a copy of their decision is kept in their medical notes.

Professionals should routinely question on assessment whether a service user has an advance decision and request a copy for the service user's records. Professionals should seek to ascertain if a service user has advised their family and friends are aware of the decision. Professionals, who are aware of a service user's advance decision, must consider whether the advance decision is valid and applicable to the particular circumstances.

In determining if an advance decision is valid, professionals should try to find out:

- If the service user has withdrawn the decision since they made it, at a time when they had the mental capacity to do so, and
- If the service user has done anything which is inconsistent with the decision and suggests that it no longer represents their wishes, and
- If the service user has since made a Lasting Power of Attorney, giving someone else the authority to make the decision consenting to or refusing the particular treatment.

When deciding whether an advance decision is applicable to the particular circumstances, a professional must:

- Assess whether the service user still has the mental capacity to make a particular decision about their treatment at the time it has to be made. (Professionals must start from the assumption that the service user has capacity and the advance decision will only be relevant if there is evidence that this is not the case),
- Check that the treatment and circumstances are the same as those referred to in the decision, and
- Consider whether there are any new developments that the service user didn't anticipate at the time they made their decision, which could have affected their decision; for example new developments in medical treatment, or changes in the service user's personal circumstances.

Professionals providing medical treatment are protected from liability for not providing treatment if they reasonably believe there is a valid and applicable advance decision.

Professionals can provide treatment if they are in doubt over the existence, validity or applicability of an advance decision, and they are again protected from liability.

MCA10 provides a useful checklist for professionals who are considering if an advance decision is valid.

Why make an advance decision?

A service user may wish to make an advance decision if they have strong feelings about a particular situation that could arise in the future. This might relate to having a limb amputated following an accident or having a blood transfusion.

More commonly, a service user may have been told that they have a terminal illness or form of dementia. A service user may wish to prepare an advance decision indicating the type of treatment they would not want to receive in the future. Making an advance decision may give a service user peace of mind in knowing that their wishes should not be ignored if they are unable to take part in a decision making process at a relevant time.

Service users do not have to make an advance decision. A service user may decide to leave decisions as to what is in their best interests to the healthcare professionals providing their treatment. In determining best interests, professionals must take into account any evidence of a service user's past wishes, beliefs and values; and should consult with a service user's friends, family and carers. Professionals may decide that what is in a service user's best interests is not the same as what the service user would have decided themselves.

Lasting Powers of Attorney

The Service User may have created a Lasting Power of Attorney (Personal Welfare). This allows a service user to choose who should make decisions about their treatment if they lose capacity. In the personal welfare LPA document there is a section where a service user can specify if they want their attorney(s) to have the

power to make decisions about life-sustaining treatment.

MCA12 provides a useful checklist for determining if an LPA-PW is valid.

What an advance decision cannot be used for?

An advance decision cannot be used to:

- Ask for anything that is illegal such as euthanasia or for help to commit suicide;
- Demand care a healthcare team considers inappropriate;
- Refuse the offer of food and drink by mouth;
- Refuse the use of measures solely designed to maintain comfort such as providing appropriate pain relief, warmth or shelter;

Refuse basic nursing care that is essential to keep a service user comfortable such as washing, bathing and mouth care.

Who to consult about an advance decision?

It is not necessary for service user's who wish to make an advance decision to involve a solicitor, although a service user may wish a solicitor to confirm that their views are clearly presented in the document.

Service user's should be encouraged and supported to discuss their intentions with a medical professional such as their GP and their family and friends.

If a service user has a terminal illness, they may wish to speak to the doctor involved in their care. Professionals should be aware that service user's who wish to make an advance decision will need to understand the consequences of refusing or opting for a particular treatment and to be able to discuss specific decisions that may relate to the likely course of their illness. Advance Decisions must be specific. Medical professionals can be very helpful in ensuring that a service user's wishes are expressed clearly; they can also verify that a service user was competent at the time they prepared and signed the Advance Decision.

Reviewing an Advance Decision

It is important for the people providing treatment to feel confident that a service user has not changed their mind since their advance decision was made. If new or improved medical treatments are now available, or a service user's personal circumstances have changed, its validity may be questioned if the Advance Directive was signed many years ago.

Professionals undertaking routine care management reviews of service users should discuss any known advance decisions with a service user (whilst they still have capacity) to be sure it continues to reflect their views and record this discussion in the service user's case notes and electronic record. Where a service user has capacity, they should be encouraged to sign and date the advance directive to indicate that they have reviewed it. Any changes made by a service user to an

advance directive should be shared with all professionals who hold copies of the advance directive.

A service user can change their advance decision at any time whilst they still have capacity to do so. This can either be verbally or in writing (unless it is a decision to refuse *life-sustaining* treatment), but to avoid uncertainty it is advisable to record the changes in writing if possible. Any changes to an advance decision to refuse life-sustaining treatment must be in writing and follow the legal requirements mentioned above.

How to cancel an advance decision?

A service user can cancel an advance decision at any time while they still have capacity to do so. The cancellation does not have to be in writing; a verbal statement cancelling the decision should be respected. To avoid the risk that the relevant people do not know a service user has cancelled their decision, it is advisable to put the cancellation in writing, if possible, and to inform everyone who was aware of the decision's existence. The original document should be destroyed or marked that it has been withdrawn.

What is the relationship between advance decisions and Lasting Powers of Attorney (Personal Welfare)?

The Mental Capacity Act brings in a new system of Lasting Powers of Attorney (replacing Enduring Powers of Attorney). Lasting Power of Attorney (LPA - PW) gives one or more people the power to make decisions about their personal welfare, including medical treatment, where a service user does not have the capacity to make a decision.

An advance decision refusing treatment becomes invalid if a service user later creates an LPA-PW giving someone else the power to refuse medical treatment on their behalf, when the service user no longer has capacity.

If an advance decision is made *after* creating an LPA-PW, this overrules the LPA. The LPA-PW (attorney) cannot make a decision about treatment that the advance decision refuses, as long as the advance decision was made after the LPA - PW.

What happens if there are disagreements about an advance decision?

It is the senior healthcare professional who is responsible for making the decision as to whether there is a valid applicable advance decision. If there is a dispute over this, an application can be made to the Court of Protection.

The Court of Protection can make a declaration on:

- Whether the person has mental capacity to make the decision themselves at the time it must be made (in which case, the advance decision does not come into play)

- Whether the advance decision is valid
- Whether the advance decision is applicable to the particular treatment and circumstances.

The Court of Protection cannot overturn a valid and applicable advance decision; so it cannot order that treatment should be provided if this has been refused in a valid advance decision.

Further information/Guidance

- **Ministry of Justice** – www.justice.gov.uk – A series of information booklets on the Act is available to download on this website.
- **Office of Public Guardian** – www.publicguardian.gov.uk – The OPG publishes the Mental Capacity Act 2005 Code of Practice and a range of information leaflets.
- **Direct Gov** – www.direct.gov.uk – General Guidance and links
- **ADRT** – www.adrtnhs.co.uk – Specific guidance on advance decision to refuse treatment
- **Department of Health** - www.dh.gov.uk

Where can I download an Advance Decision form?

- **Alzheimer Society** - www.alzheimers.org.uk/advanceddecisionform
- **SEPT** - www.southessex-trust.nhs.uk/Form
- **Mind** - www.mind.org.uk/Form