

GLOUCESTERSHIRE MULTI AGENCY MENTAL CAPACITY ACT POLICY

APPENDIX 7

Gloucestershire Mental Capacity Act Governance Group (MCAGG)

Advance Decisions Guidance

Implementation of the Mental Capacity Act (MCA) 2005

The MCA 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*' as previously known) 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.

This guidance provides more details about Advance Decisions. It should be read in conjunction with the Gloucestershire Multi-Agency Policy, Procedure and 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 MCA Code of Practice.

Introduction

When a person is ill, they can usually discuss their treatment options with their doctor and then jointly reach a decision about their future care. However, a person 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 person has a car accident or a stroke or develops dementia. In such circumstances, the person 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 person's best interests. If a person has made an Advance Decision to refuse treatment and that decision is valid and applicable to the circumstances, medical professionals providing a person's care are bound to follow it.

The term '*living will*' used to 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 person 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 person's best interests.

What is an advance statement?

This is a general statement about a person'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 person's beliefs or food preferences or whether they prefer a bath to a shower. An advance statement can reflect a person'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 persons 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 person 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 person's attorney(s) must take an advance statement into account when deciding what is in a person'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 person 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 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

person is putting their Advance Decision in writing themselves, it is a good idea for a person to discuss their Advance Decision with their GP or a doctor involved in their care. It is the person's responsibility to ensure healthcare professionals are made aware of the existence of an Advance Decisions/s.

To avoid uncertainty over the validity of an Advance Decision it should always be put in writing, or written down for the person. The following guidelines may be helpful:

- The Advance Decision should be put in writing
- It should confirm that the person is writing it of their own free will
- It should include the person's name, date of birth, address and details of their GP
- It should include a statement that the person wishes the Advance Decision to apply if they lack the capacity to make a decision at a relevant time e.g. assisted ventilation, anti-biotics for a particular infection, surgery
- 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 person
- The person's signature should be witnessed including at review
- It should include the address and contact telephone numbers of each of the witnesses and people the Advance Decisions has been discussed with for ease of reference in an emergency situation
- A doctor or another relevant professional should sign a statement on the document stating that they have carried out an assessment of the person and in their opinion, the person has capacity to make the decisions recorded in the Advance Decision
- It should indicate whether the person has given permission for the Advance Decisions to be discussed with relatives and/or carers.

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 person is making an Advance Decision to refuse life-sustaining treatment. See below for details of these.

How to make an Advance Decision to refuse life-sustaining treatment?

If a person 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 person can ask someone else to write it down if they can't do this for themselves.
- The document must be signed by the person who can instruct someone to sign it on their behalf in their presence if they can't personally sign it themselves.

- The person's signature (or the signature of the person signing on their behalf) must be witnessed. The witness must also sign the document in the person's presence.
- The person must include a written statement that the Advance Decision is to apply to the specific treatment even if the person's life is at risk.

Deciding if an Advance Decision is valid and applicable

A person 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 check on assessment whether a person has an Advance Decision and request a copy for the person's records. Professionals should seek to ascertain if a person has advised their family and friends are aware of the decision. Professionals, who are aware of a person'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 person has withdrawn the decision since they made it, at a time when they had the mental capacity to do so,
- If the person has done anything which is inconsistent with the decision and suggests that it no longer represents their wishes,
- If the person 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 person 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 person 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
- Consider whether there are any new developments that the person 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 person'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.

Why make an Advance Decision?

A person 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 person may have been told that they have a terminal illness or form of dementia. A person 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 person 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. Persons do not have to make an Advance Decision. A person 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 person's past wishes, beliefs and values, and should consult with a person's friends, family and carers. Professionals may decide that what is in a person's best interests is not the same as what the person would have decided themselves.

Lasting Powers of Attorney

The Person may have created a Lasting Power of Attorney (Personal Welfare). This allows a person 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 person can specify if they want their attorney(s) to have the power to make decisions about life-sustaining treatment.

What an Advance Decision cannot be used for?

- An Advance Decision cannot be used to:
- Ask for an assisted death;
- Refuse food and drink by mouth or basic care that attends to your comfort, and/or personal hygiene. This is because these things are a basic human right that no one can decline in advance;
- Nominate someone else to decide about treatment on your behalf. Nominating another person to make decisions about your health and care is done by making a Lasting Power of Attorney;
- Demand certain treatments. This is because doctors don't have to give you treatment just because you ask for it. Doctors decide whether treatment is medically appropriate and then you decide if you want that treatment.

Who to consult about an Advance Decision?

It is not necessary for person's who wish to make an Advance Decision to involve a solicitor; although a person may wish a solicitor to confirm that their views are clearly presented in the document. Person'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 person has a terminal illness, they may wish to speak to the doctor

involved in their care. Professionals should be aware that person'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 person's wishes are expressed clearly; they can also verify that a person 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 person has not changed their mind since their Advance Decision was made. If new or improved medical treatments are now available, or a person's personal circumstances have changed, its validity may be questioned if the Advance Directive was signed many years ago.

Professionals undertaking routine care reviews of persons should discuss any known Advance Decisions with a person (whilst they still have capacity) to be sure it continues to reflect their views and record this discussion in the person's case notes and electronic record. Where a person has capacity, they should be encouraged to sign and date the Advance Decision to indicate that they have reviewed it. Any changes made by a person to an Advance Decision should be shared with all professionals who hold copies of the Advance Decision.

A person 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. If the amendments in the review are substantial, the person should consider drafting a new Advance Decision to avoid confusion. 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 person 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 person 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 brought 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 person does not have the capacity to make a decision.

An Advance Decision is NOT valid if a Personal Welfare LPA was created after the Advance Decision, which gave the Attorney authority to give or refuse consent to treatment to which the Advance Decision relates (9.34 MCA CoP). In this situation the Attorney takes precedence and their authority must be sought to proceed with the treatment.

In terms of LPAs made before the Advance Decision para 9.30 of the MCA CoP states that an Advance Decision overrules the decision of any Personal Welfare 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.

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 and Guidance.

Gloucestershire Website – www.gloucestershire.gov.uk/mca

Office of Public Guardian –

<https://www.gov.uk/government/organisations/office-of-the-public-guardian>

The OPG publishes the Mental Capacity Act 2005 Code of Practice and a range of information leaflets.

Where can I download an Advance Decision form?

<https://www.alzheimers.org.uk/get-support/legal-financial/how-make-advance-decision>

<https://www.nhs.uk/conditions/end-of-life-care/?tabname=planning-ahead>