



ADVANCE DECISIONS TO REFUSE TREATMENT

A Guide

Background

The Mental Capacity Act (2005) makes new rules which must be followed when making advance decisions to refuse treatment. This booklet gives you guidance on how to make an advance decision within those rules. You are strongly advised to seek advice from a healthcare professional before making an advance decision to refuse treatment.



Advance Decisions to Refuse Treatment

Making choices about medical treatment

You may at some point in your life decide that you wish to make some very specific choices about your future health care, should a time come when you lose the capacity to make decisions for yourself.

Expressing wishes and preferences about your future care can be done by a process of advance care planning discussions with your care providers (eg nurse, doctor, care home manager, social worker).

If during the discussion you decide to make a very specific choice that you do not wish to receive a particular medical treatment in the future, this must be done through making an advance decision to refuse treatment.

What is an advance decision to refuse treatment?

An advance decision to refuse treatment (previously known as a living will or advance directive) is a decision you can make to refuse a specific medical treatment in whatever circumstances you specify. This can include the choice to refuse treatment even if doing so might put your life at risk. The advance decision to refuse treatment will not be used if you are able to make your own choices at the time that the treatment is needed and offered.

Why make an advance decision to refuse treatment?

Many people fear losing control or being unable to tell health care professionals what they want for themselves. An advance decision to refuse treatment can inform the professionals of your choice. It will only be used if you lose the ability to make decisions or to communicate your views about your treatment, for example in the case of being unconscious or incapacitated.



Thinking about making an advance decision

The benefits and implications of making an advance decision to refuse treatment

An advance decision to refuse treatment can give you better control over what happens in the future if there is a particular treatment that you do not wish to have. It can be part of letting people know what is important to you about your future care and treatment. It can help discussions between healthcare professionals and your relatives, partners or carers during a period of illness if, for any reason, you can no longer communicate or express yourself.

It is important that before making an advance decision to refuse treatment, you discuss it with your doctor. Your doctor will explain all of the facts involved in the refusal of treatment including the possibility of any future discomfort or of putting your life at risk.

Advance decisions to refuse treatment apply only in the circumstances that you specify, so think carefully about the circumstances that are important to you.

What an advance decision to refuse treatment cannot do

An advance decision to refuse treatment cannot be used to refuse the basic nursing care required to keep a person comfortable eg warmth and hygiene. Nor can an advance decision be used to request any specific form of treatment; it applies only to refusals. An advance decision to refuse treatment is not a last will and testament.

Making an advance decision

How can I make an advance decision to refuse treatment?

You do not need to use a special form to make an advance decision. However it might be sensible to do so, as your advance decision must meet with all the rules of the Mental Capacity Act if it is to be legally binding. You can if you wish make a verbal advance decision. If you do make a verbal advance decision, it would be sensible to ask somebody to write it down for you so that there is an accurate record of what you want.

If you wish to refuse treatment that is potentially life-sustaining, for example ventilation, special rules apply. Your advance decision must be in writing, signed and witnessed.

Where can I get hold of an advance decision to refuse treatment form?

Ask a health or social care professional. The doctors or nurses involved in your care may have a sample form which they can help you complete. An example form can also be downloaded at www.adrtnhs.co.uk. It is not essential that you use a particular form, you can write your own decision or make a verbal one (if not about life-sustaining treatment).

An advance decision to refuse treatment can be legally binding.

This is a way of expressing a decision not to have a specific treatment in the future and can be legally binding if all the specific circumstances that you have identified have been met. It can be difficult to imagine these future circumstances, so you should discuss this with your doctor to make sure you understand what making an advance decision will mean to your future care.

Who do I tell about my advance decision to refuse treatment?

If you have made an advance decision to refuse treatment you must be sure that the people involved in your care know this. Ask your nurse or doctor to help you do this. This will help to avoid difficult situations during a time when for reasons of ill health you cannot make your wishes known.

It is possible to have a copy of your advance decision stored in your medical records but you would need to be sure this is updated if you change your mind.

What information to include in an advance decision to refuse treatment.

Although there is no set format for an advance decision, it must specify the particular treatment that you want to refuse and the circumstances in which this is to apply. If you do not specify a particular treatment then the advance decision will not be binding.

It will be helpful to include the following:-

- your name, date of birth, address
- name, address and phone number of your GP
- a statement that the document should be used if you ever lack the capacity to make decisions and it is relevant to the situation
- the date written
- your signature
- the signature of the person witnessing your signature
- if the decision is to apply even if it places your life at risk, then you must make a clear written record that states 'the decision is applicable even if my life is at risk'

Can you change your mind?

Yes, you can change your mind at any time, whilst you have capacity to do so. If you change your mind then simply inform all your health and social care professionals straightaway. It is important that you inform all of the people who have a copy of the previous advance decision to refuse treatment to make sure that they know that you have withdrawn it.

Important safeguards

- An advance decision can only be made by someone over 18 years of age
- Discuss your decision with carers, family, partner, health or social care professionals
- Distribute copies to people who need to know
- Keep your own copy somewhere handy
- Let doctors, nurses or ambulance crews know you have an advance decision eg a card in your wallet
- Review the decision as necessary, because circumstances can change
- If a decision is changed inform all of the people who may have copies of your original decision
- If you specify that an advance decision to refuse treatment is only to apply in certain circumstances, all the circumstances that you specify must be present if the advance decision is to be binding.

Further Information

Making an advance decision to refuse treatment can be challenging. Some further helpful information may be found on the following websites. You may be able to get help to access these through your GP or healthcare worker, your library or at a hospital information centre.

Office of Public Guardian

The Office of Public Guardian is there to protect people who lack capacity from abuse. The website contains links to the text of the Mental Capacity Act and to the accompanying Code of Practice, which provides guidance and information about how the Mental Capacity Act works.

www.publicguardian.gov.uk

Tel. 0845 3302900

Making Decisions – a guide

Information booklets about the Mental Capacity Act

www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet01.pdf

Tel. 02380 878038

Further guidance can be found in:

The Mental Capacity Act in Practice:

Guidance for End of Life Care (2008)

Good Decision Making – the Mental Capacity Act and End of Life Care (2009)

The National Council for Palliative Care

www.ncpc.org.uk

Preferred Priorities for Care

A document which could be used to help write down preferences and wishes for the future.

www.endoflifecareforadults.nhs.uk/eolc/files/F2110-Preferred_Priorities_for_Care_V2_Dec2007.pdf

Advance Decisions to Refuse Treatment website

(patient section)

www.adrtnhs.co.uk

Age Concern

www.ageconcern.org.uk/AgeConcern/is5.asp

Alzheimer's Society

www.alzheimers.org.uk/factsheet/463

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