



# 4 WRITING AN ADVANCE DECISION

You may have heard of an advance decision (or the older term, living will). Such a document can allow you to legally refuse certain treatments. This is a formal procedure which is likely to be relevant to only a few people. However, for some people, it is very important to have a legal document which specifically allows them to refuse treatment in certain situations, as this would not be acceptable to them.

An advance decision has to be very specific in order to be useful. For example: patients who have motor neuron disease can anticipate that swallowing will become a problem as part of the progression of the disease and for some patients the insertion of a feeding tube might be completely unacceptable. This could be formally documented as an advance decision.

You **cannot** make an advance decision to ask for medical treatment, or to have life ended. You can only say what types of treatment you would refuse. The Mental Capacity Act (2005) addresses issues that can affect anyone unable to make some or all of their own decisions and gives them increased legal rights. This has given advance decisions a legal status.

There is no specific format to follow to make an advance decision. It can be verbal or written. However, if you wish to include situations in which you would **refuse life-sustaining treatment**, the advance decision must be in writing (it can be written on the patient's behalf), and must be signed by the decision maker in the presence of a witness, who must also sign the document. It must also be verified by a specific statement within the document that states the advance decision is to apply to the specified treatment, even if life is at risk.

If this is something you wish to consider then you should discuss it with the most appropriate healthcare professional (i.e. the professional who knows you and your condition well and can spend time with you assisting this process). It may be that expressing your wishes to your family and healthcare professionals is sufficient.

If you decide after your discussion that you do want to proceed with an advance decision document then we would recommend that you discuss this with at least one of the doctors who are looking after you; this may be your General Practitioner, your palliative care (Hospice) consultant, medical consultant etc. It may also be appropriate for you to ask a solicitor to be involved.



## AT THE TIME YOU MAKE AN ADVANCE DECISION YOU MUST BE

- Aged 18 or over
- Mentally competent and not suffering from any kind of mental distress at the time it is drawn up
- Must not have been influenced or harassed by anyone else
- Must appear to be fully informed about the treatment options and their implication when the statement was written
- Must not have modified the advance decision verbally or in writing since it was signed and dated

In considering making an advance decision there are some treatments you may wish to consider whether (if offered) you would find acceptable

### RESUSCITATION

Cardio-pulmonary resuscitation (CPR) is just one of a range of active interventions which you may wish to consider.

In patients who are generally weak, who are gradually deteriorating and in whom there are a number of medical problems, then the chance of resuscitation being successful is extremely low (less than 1%). Given the low chance of success in these situations then doctors will sometimes decide that offering resuscitation is inappropriate as it would be extremely unlikely to lead to a return to a reasonable quality of life. It may also be felt that discussing this, when it is not likely to be successful, may simply add to distress.

Where there is a possibility that resuscitation may be successful then it will be discussed with you. If this has not been discussed with you and you would like to do so, then ask any specialist nurse or doctor involved in your care, including your own GP.

### OTHER ACTIVE INTERVENTIONS

For patients with neurological conditions e.g. MND then it may be appropriate to consider whether tube feeding (via a PEG), or any form of ventilatory support would be acceptable. These decisions are not straightforward and should be fully discussed with your family and medical team. Information is available from the MND association ([www.MNDassociation.org](http://www.MNDassociation.org)) where there are useful fact sheets on swallowing and breathing difficulties, which may be experienced in motor neuron disease patients and the pros and cons of the different approaches.

Other treatments relevant to your condition (e.g. cancers or advanced stages of heart or lung conditions) which you may wish to consider include the use of intravenous antibiotics, stent insertion, nasogastric feeding. Some of these treatments may be offered to help control distressing symptoms and not simply 'to prolong life'. If not giving any of these treatments might threaten life, then you need to have made it clear that you would not want the specified treatments even though life is at risk.

It is important you are as specific as you can be about the situations in which you would be refusing treatment. Where doubts exist for the doctor as to whether the particular situation was the one that was anticipated - then the advance decision would not be considered applicable.

There is an advance decision document attached if this is something you feel is appropriate for you. As mentioned, please complete it alongside discussions with any specialist Nurse or Doctor involved in your care, as well as your GP. The advance decision needs to be specific to you and your health problems.



# ADVANCE DECISION DOCUMENT

You will need at least 4 copies of this completed form

One for you to keep

One for your GP to keep with your records

One to be kept with someone who you wish to be consulted about your treatment should this ever be necessary. (e.g. next of kin, solicitor)

Others for healthcare professionals involved in your care such as hospice staff / MacMillan nurse specialists or nursing / care home managers and the local acute hospital.

Please also ask the healthcare team to fax a copy to the Ambulance Service and 'out-of-hours' medical service so that they can update their alert system, particularly relating to any refusal of resuscitation.

All forms should be signed by at least one person, who is not a close relative or expecting to benefit from your will. (e.g. GP, or hospice/ hospital doctor). You might also wish to consult with your solicitor.

Remember to review this document at regular intervals to ensure it still represents your wishes. Signing and dating at the bottom when you do this will indicate how recently you have thought about it. If you change your mind about anything you have written, tell your GP, hospice or MacMillan nurse, next of kin or appointed representative and amend the document accordingly.

## PROXY /NEXT OF KIN

Who else would you like to be involved if it ever becomes too difficult to make decisions? Do they have Lasting Power of Attorney (LPA) to make decisions on your behalf relating to treatment?

Contact 1 ..... Relationship to you .....

Telephone ..... Do they have Lasting Power of Attorney Yes / No

Contact 2 ..... Relationship to you .....

Telephone ..... Do they have Lasting Power of Attorney Yes / No

To my family, my doctor and all other persons concerned this directive is made by me:

Full name .....

Of (address) .....

I am writing this at a time when I am able to think things through clearly and I have carefully considered my situation. I am aware that I have been diagnosed as suffering from:

- Advanced and widespread cancer
- Advanced degenerative disease of the nervous system (e.g. motor neuron disease)
- Advanced and irreversible organ failure (e.g. severe heart failure, renal failure, dementia, COPD) or other progressive chronic condition. Please state diagnosis:



I declare that if I become unable to participate effectively in decisions about my medical care, then and in those circumstances, my directions are as follows:  
(only sign the sections you feel are applicable).

1. I am not to be subjected to any medical intervention or treatment aimed solely at prolonging my life.

Signature .....

2. Any distressing symptoms (including those caused by lack of food or fluids) are to be fully controlled by appropriate analgesic, sedative or other treatment, even though that treatment may shorten my life.

Signature .....

3. This advance decision applies to the specific treatments stated below, even if my life is at risk.

Signature .....

(continue in box below/on a separate sheet if necessary)

Treatment to be refused (e.g. resuscitation, stoma formation, surgery, IV antibiotics)	Details of situation you have anticipated in which the refusal would be valid (FOR EXAMPLE 1. for resuscitation - details might be: in the event of cardiac arrest I would not want resuscitation either at home or in an ambulance or in hospital. e.g. 2. refusal of PEG- details if unable to swallow. e.g. 3. use of antibiotics in the situation of developing a chest infection. e.g. 4. re-insertion of a stent- if it blocks. e.g. 5 placing of a nasogastric tube if the bowel is blocked, etc)

I consent to anything proposed to be done or omitted in compliance with the directions expressed above and absolve my medical attendants from any civil liability arising out of such acts or omissions.

I reserve the right to revoke this advance decision at any time, but unless I do so it should be taken to represent my continuing directions

My General Practitioner is:

Name of GP .....

Address .....

Telephone .....

Before signing this I have talked it over with my :

GP Dr .....

Hospice or MacMillan Nurse .....

Hospice Consultant/ Hospital Doctor Dr .....

Solicitor .....

(it is recommended that you discuss this with at least one of the above professionals. If you are in hospital or hospice then the consultant caring for you should be aware of and clear about the scope of this advance decision).

I have attached a sheet with further wishes about my treatment. Yes/No

**Are you happy for the information in this document to be shared with other relevant healthcare professionals?** Yes/No

Signed ..... Date .....

Witnesses:

We testify that the person making this advance decision signed it in our presence, and made it clear to us that he/she understood what it meant. We do not know of any pressure being brought on him/ her to make such an advance decision and we believe it was made by his/ her own wish. So far as we are aware we do not stand to gain from his/ her death.

(Only one witness is legally required).

Witnessed by:

**Witness 1** (Ideally GP, or Hospice Doctor, Hospital doctor)

**Witness 1** (not close family, or persons expecting to benefit from your will)

Signature .....

Signature .....

Date .....

Date .....

Name .....

Name .....

Address .....

Address .....

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Reviews This directive was reviewed and confirmed by me on:

Date ..... Signed .....

Date ..... Signed .....