Advance Decision to Refuse Treatment

This information is an extract from the booklet Your life and your choices: plan ahead (England and Wales). You may find the full booklet helpful. We can send you a free copy – see page 8.

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What is an Advance Decision to Refuse Treatment (ADRT)?

An Advance Decision to Refuse Treatment (ADRT) is a written statement of your wishes to refuse a particular treatment in a specific situation. It is a way of making sure that everyone knows what treatment you don’t want to have if you’re unable to make your own decisions in the future.

For example, you may decide that:

• If your illness couldn’t be cured and you became very unwell after all possible treatment, you wouldn’t want to be kept alive by being fed or given fluids through a feeding tube or drip.

• If you are being fed or given fluids through a feeding tube or drip, you do not want this to continue if your condition were to get worse and it isn’t improving your quality of life.

• You do not want to be given antibiotics for an infection if you’re only expected to live for a few days.

See page 5 for an example of how some of this information could be written in an ADRT document.
An ADRT can’t include a request to have treatment or to have your life ended. You can request, but not insist on, treatment in your wishes for your care. We have more information about your wishes for your care in our booklet *Your life and your choices: plan ahead (England and Wales)*.

It’s important to be as clear as possible about:

- the circumstances when you’d like your ADRT to apply
- what type of treatment you would want to refuse.

This is to make it clear to anyone reading the document what your wishes are. It will also help them decide whether your ADRT meets all the legal requirements of the Mental Capacity Act 2005. This Act came into force in 2007 and applies to people aged 16 and over in England and Wales. It aims to protect people who can’t make a decision for themselves. There is more more information about this in *Your life and your choices: plan ahead (England and Wales)*. If your ADRT does meet the requirements of the Act, it is legally binding. This means it must be respected by your doctors and those involved in your care.

If you make an Advance Decision to refuse a specific treatment, you will still be given the best possible care. You will have support, comfort and medicines to control your symptoms.

‘I feel strongly that I don’t want to be kept alive artificially. I’m now 85, I’ve had a very good time and I don’t want to be a burden in a sort of inanimate way. And so I would rather just die cleanly as it were. We’ve arranged this with our solicitor and I’m very happy with those arrangements.’

Percy
Who can make an ADRT and who should be involved?

You can only make an ADRT if you are aged 18 or over, and are able to understand what it is and what it means for you (have mental capacity). A person will lack capacity if they cannot do one of the following:

• understand the information about the decision

• retain that information

• use or weigh up that information as part of the process of making the decision

• communicate their decision (by talking, using sign language or any other means).

Before making an ADRT, it’s important to discuss the decisions you’d like to make with one of your healthcare professionals. This may be your GP, or a doctor or nurse specialist looking after you at the hospital. They will be able to tell you what the likely effects of stopping a treatment are and will make sure your ADRT meets legal requirements.

What should be included in an ADRT?

Although most Advance Decisions to Refuse Treatment can be made verbally (spoken), it’s better to write it down. This helps avoid confusion later on.

There are certain situations where the law says that an ADRT must be in writing. For example, an ADRT that refuses treatment to keep you alive (life-sustaining treatment), such as resuscitation or being put on a ventilator (breathing machine), must be:

• written down

• signed by you or someone else with you at the time

• witnessed.

It must say exactly what treatment you want to refuse and in which situation. For example, you may want to refuse a treatment in a particular situation but not in another. It must also contain a statement such as, ‘I refuse this treatment even if my life is at risk as a result’ to make it legal.
There’s nothing in law that says what must be included in an ADRT if it doesn’t relate to life-sustaining treatment. However, it’s advisable to include the following:

- Your name, date of birth, address and any obvious distinguishing features. This is in case you’re unconscious or unable to communicate, and healthcare professionals need to identify you.

- The name, address and phone number of your GP, and whether they have a copy of your ADRT document.

- A statement that the document should be used if you ever don’t have the capacity to make decisions.

- A statement of which treatment(s) is to be refused and the circumstances when your decision would apply.

- The date your ADRT was created.

- Your signature and a dated signature of at least one witness (if it’s a written statement).

- If it’s an ADRT that will keep you alive, it must also include the statement, ‘I refuse this treatment even if my life is at risk as a result’.

Sometimes, a person may wish to refuse a specific treatment in all circumstances, rather than identifying a specific circumstance. For example, you may want to refuse a specific medication in all circumstances if you have an allergy or a religious objection to it.

If you want to make a statement about refusing a treatment in all circumstances, you should talk this through with a healthcare professional first. They will make sure that your ADRT will be clear to any health professional who may need to use it in the future.

**Writing an ADRT**

You can write your own ADRT, but you may find it easier to use one that has a set format. There are various organisations that have created forms for people to use. Hospitals and hospices often have written information and forms that people can use to prepare their own ADRT.

We have included an ADRT document that has been adapted from the National End of Life Care Programme in *Your life and your choices: plan ahead (England and Wales)*.
Remember to review your ADRT regularly so you can be sure it’s up to date and reflects your current wishes.

**ADRT and Lasting Power of Attorney**

An ADRT may become invalid if:

- you have made a Lasting Power of Attorney after making an ADRT and
- you have given your attorney the authority to accept or refuse treatment on your behalf.

You should let all the relevant people know if you’re in this position. It’s important to keep written records of when you made decisions and what they were. Make sure that everyone who may need to make decisions for you in the future knows where to find all your documents.

Here is an example of some of the information included on an ADRT document.

**My Advance Decision to Refuse Treatment**

<table>
<thead>
<tr>
<th>I wish to refuse the following specific treatments</th>
<th>In these circumstances</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>If you wish to refuse a treatment that is or may be life-sustaining, you must state in the box: ‘I am refusing this treatment even if my life is at risk as a result.’</em></td>
<td></td>
</tr>
<tr>
<td>Cardiopulmonary resuscitation – I refuse cardiopulmonary resuscitation if my heart and lungs stop functioning, even if my life is at risk as a result.</td>
<td>If I have terminal cancer and my heart and lungs stop functioning in a way that allows me to breathe spontaneously.</td>
</tr>
<tr>
<td>Artificial feeding or hydration – I refuse artificial feeding or hydration even if my life is at risk as a result.</td>
<td>If I have terminal cancer, become unconscious and am unable to swallow fluids or food unaided.</td>
</tr>
</tbody>
</table>
Advance Decision to Refuse Treatment

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

You may hear doctors or nurses talk about a DNACPR request. These may also be referred to as DNARs. A DNACPR is a written statement to not give cardiopulmonary resuscitation (CPR) if someone has a cardiac arrest.

A cardiac arrest is when the heart stops beating. If the breathing stops, it is called a respiratory arrest. They commonly happen together, which is known as a cardiopulmonary arrest. Cardiopulmonary resuscitation (CPR) is a way of trying to restart the heart and breathing when they have stopped.

You may have already made a decision about not wanting to be resuscitated in a specific situation and included this in your ADRT (see pages 3–4). However, if you haven’t made a decision about CPR and you want to, you should discuss this with your medical team or specialist nurse. You may also want to talk this through with your family, a close friend or a spiritual carer such as a chaplain. Your medical team will be able to tell you how successful CPR is likely to be in different situations. They will take into account any other health problems you have.

A senior healthcare professional may sometimes ask if you want CPR to be attempted if you were to have a cardiac arrest. This may happen if the doctor believes that you might have a cardiac arrest and resuscitation could be successful. For example, you may have a cancer that can’t be cured but you are expected to live with the condition for a long time, sometimes years. In this situation, the doctor will make sure that you have all the information you need to make an informed decision. They will tell you what is likely to happen if you have CPR, how this might extend your life and what your quality of life might be.
If, after discussion with your medical team, you make the decision not to have CPR attempted, this is written as a DNACPR or not for CPR (NFCPR) order. After meeting with you, a senior doctor or nurse who has responsibility for your care will make, write and sign the DNACPR. This might be a hospital consultant, a palliative care doctor, a specialist or consultant nurse, or your GP. The decision will be clearly written in your medical and nursing notes.

If you’re at home, you’ll be asked to keep a written record of your DNACPR where it can easily be found. This is so emergency services, such as out-of-hours ambulance services and doctors, will know your wishes.

Your decision about CPR won’t affect any other care or treatment you have. You can change your mind at any time about whether CPR should be attempted. If you do change your mind, it’s important to discuss this with a member of your healthcare team. They will discuss their views on your changed decision with you. If they agree with your changed decision, they will make sure this is recorded in your medical notes. Remember to also tell your family or the person looking after you as this will help to avoid any confusion.

If your doctor feels that CPR is unlikely to be successful and doesn’t believe it should be attempted, but you don’t agree, you can ask for a second medical opinion from another senior doctor. They should also let your family know what they recommend, unless you have asked them not to.

Your healthcare team will take your wishes about CPR into account. However, you cannot insist a doctor attempts CPR if, in their clinical judgement, they think it’s not appropriate.

We have more information about cardiopulmonary resuscitation for people with cancer – call our support line on 0808 808 00 00 to order this.
More information and support

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don’t have to go through it alone. The Macmillan team is with you every step of the way.

To order a copy of Your life and your choices: plan ahead (England and Wales) or any other cancer information, visit be.macmillan.org.uk or call 0808 808 00 00.

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