

This leaflet has been created to help you have a conversation with a health or social care professional

When's the right time to
**think about it, talk about it
and write it down?**

Contents

- Making your end of life preferences and decisions.....2
- What you need to know about CPR.....3
- What if I don't want to (or can't) make a decision?4
- Communicating your choices.....5
- What happens if I get too ill to make decisions?5
- Making a message in a bottle6
- Useful resources7

For the purposes of this leaflet 'preferences' means what you would like to happen and 'decisions' means there may be legally-binding documentation in place relating to your treatment.

Making your end of life preferences and decisions

Most of us don't want to think about what happens in our last years of life. Talking to the people close to you and making plans can make it easier.

It's a good idea to write down your wishes when you're feeling well, fit and healthy, so that the people looking after you will know what to do for you when it matters most.

Talking to your healthcare team

Even healthcare professionals sometimes struggle to have difficult conversations about death and dying. Sometimes you just need to start the conversation. If you feel you're not being listened to or you're struggling to make your wishes known, contact your local Patient Advice and Liaison Service (PALS) for advice at www.pals.nhs.uk

What you need to know about CPR

You may be asked to consider cardiopulmonary resuscitation (CPR).

What is CPR?

Cardiopulmonary arrest is when your heart stops beating and your breathing stops. It is sometimes possible to restart your heart and breathing with a combination of emergency treatments called cardiopulmonary resuscitation (CPR). This might include:

- repeatedly pushing down firmly on your chest
- using electric shocks to try and restart your heart
- mouth-to-mouth breathing
- inflating your lungs using a mask over your nose and mouth or a tube inserted into your windpipe.

How could CPR help me and what are the risks?

Everyone is different. How well you recover from a cardiopulmonary arrest depends on what caused it. After CPR, a few people will make a full recovery, but if you have a long-term condition or terminal illness, it is much less likely to work.

Even if CPR does work, this is an invasive procedure and you may sustain an injury. You may also spend a lot of time in coronary care or intensive care, which can be upsetting for you and your relatives. Some people never return to the level of physical or mental health they enjoyed before. Some may have brain damage or go into a coma.

Who will decide whether I have CPR?

You can choose not to have CPR and allow natural death. If this is your decision you need an Advance Decision to Refuse Treatment (ADRT) in place (see page 5). Otherwise, your doctor or healthcare professional caring for you will make a clinical judgement about whether to attempt CPR based on how likely it is to succeed. Your health and social care team should offer you information about this, but they shouldn't make you talk about it if you don't want to.

Things to think about

If your health and social care teams are not sure whether CPR will work, this is when your preferences or decisions will be taken into consideration. It is important to consider:

- your long-term condition and whether your health has become significantly worse and may not improve
- how your condition may progress and how this might:
 - affect the way you live and need care
 - affect the way you think about your treatment
- your care needs, which define at which stage your care changes eg moves to hospital, hospice, care home or place of residence
- how successful CPR might be (your health team should advise you about this).

It is a good idea to talk to healthcare professionals who can help you make an informed decision. It's also important to talk to your family and your carers. Make sure they know about your preferences and decisions.

What if I don't want to (or can't) make a decision

You don't have to talk about CPR if you don't want to and you shouldn't feel rushed into making a decision.

If I haven't decided and my heart and breathing stop, what will happen?

If your heart and breathing stop your healthcare team will make a decision whether to attempt CPR. In an emergency situation, if there is no reason not to attempt CPR, attending paramedics or first aiders will attempt to restart your heart using all the appropriate methods.

In hospital, the clinical team in charge of your care will make a judgement and will perform CPR if they think it will be successful. Neither you nor your family can insist that CPR be tried.

Please note: You may need more time to consider your decisions. The professionals in charge of your care will always offer a second opinion and more information if this helps you. You also have the right to change your mind at any stage.

Can my family or friends decide for me?

If you are very ill you might not be able to make decisions about your treatment and care. At this stage your family and / or close friends may be asked if you have preferences or have made decisions about refusing or not wanting CPR as part of what's in your best interest. It is important to remember that they are not allowed to decide for you.

Even if one of your family or friends has been given a **Lasting Power of Attorney** (see page 6), they cannot insist on CPR being used. This is a decision made by the clinical team in the absence of any other legally binding decision. If there are particular people who you do (or do not) want to be consulted, let your care team know.



Communicating your choices

If I don't want CPR, how do I make my decisions known?

Once a decision has been made not to attempt CPR a form will be put in your medical records. This is called a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form.

A DNACPR form is usually only added to your records:

- if your healthcare team believe CPR will not be successful. They will tell you if that is the case.
- if you and your healthcare team have discussed CPR and it is unclear whether the outcome would be successful and you decide you do not want CPR. You will need to make an ADRT.

Be assured, if you are not going to receive CPR, you will continue to have all other treatments and care for your condition. A DNACPR form only applies to CPR itself.

Will the decisions be recognised wherever I am?

You should keep the original signed and dated DNACPR form with you and make sure your family and everyone in your healthcare team knows about it. This is in case, for example, an ambulance is called and the ambulance crew ask if you have a DNACPR form.

What happens if I get too ill to make decisions at all?

It's a good idea to plan for what will happen if you're too ill to make decisions about your own treatment. That way, you can still have a say in what happens.

Think about questions like:

- Are there any particular treatments you don't want?
- Is there a point in your illness when you would not want to be treated or receive CPR?

What is an Advance Decision to Refuse Treatment?

If you want to make a legally-binding decision to refuse medical treatment you can make an **Advance Decision to Refuse Treatment (ADRT)**. This is a document which allows you to set out exactly which treatments you don't want to have and in which circumstances. You may need advice to help you come to your decision (see back page).

If you have made an **ADRT**, this does not mean you won't be treated with care, compassion and dignity or be given appropriate symptom and pain relief.

Making a Lasting Power of Attorney

You can also make a **Lasting Power of Attorney** in which you name someone to make decisions for you when you're not able to. It is a legal document confirming that the person you name is authorised to make decisions about your health. It is important to be aware that giving someone a **Lasting Power of Attorney** can take up to 20 weeks.

Making sure everyone knows

If you have made a firm decision and you created an ADRT and / or a DNACPR to reflect this, you must make sure your healthcare team (for example, your GP, nurse / matron, palliative care teams) all know about it and have noted it in your records.

You should also tell people close to you, so they can tell the healthcare team if they're asked. If your health gets much worse, your family should know what to do in various different circumstances – for example, when they should phone 999 and when it is appropriate to call other healthcare professionals you see regularly.

Making a Message in a Bottle

A Message in a Bottle is an easy way to keep your personal and medical details on a standard form and in a common location – your fridge. Anyone can have one and there are no costs involved.

It means that if emergency services are called to your home, they can quickly find your medical details and choices.

Your local Lions Club International volunteer organisation runs a Message in a Bottle scheme and provides free bottles with blank forms to complete. Or you can create your own simply by keeping important information in a clearly labelled container in the fridge. Bear in mind that there's some specific information which needs to be included. You can find forms to download and print on www.adrt.nhs.uk

You also need to sign and date the information and remember to put a sticker inside your front door underneath the lock so emergency services know about your Message in a Bottle.



Useful resources

There are a number of resources to help you make informed preferences and decisions. Some of these are listed below. It's a good idea to check these out and make sure you understand the decisions open to you.

Planning for your Future Care outlines many of the issues you need to consider when you're thinking about your care choices.

www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare

Information about lasting power of attorney

www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/index.htm

Lions International Message in a Bottle tells you more about the Message in a Bottle scheme.

www.lions.org.uk/health/miab/index.php

Advance Decisions to Refuse Treatment explains more about refusing treatment. It also provides links to forms you can use.

www.adrt.nhs.uk

For more information on end of life care, visit

www.nhs.uk/planners/end-of-life-care

Your GP's name:

.....

Your GP's telephone number:

.....

Remember, you can always speak with your GP or other health and social care professional if you have any questions or concerns.

Campaign developed by East Midlands Strategic Health Authority
With thanks to South Central Strategic Health Authority

