

Thinking about care if you are seriously ill – a patient’s guide

A guide for patients across the UK (except Scotland)

About this leaflet

COVID-19 means that during this period, many people will become unwell. Some people may need to go to hospital and receive intensive medical treatment to try to keep them alive. Even with the best possible treatment, sadly, there are some people who will not survive.

The current situation with COVID-19 might have made you think about what you want to happen to you in the event that you become seriously unwell, or how you would like to be cared for at the end of your life.

Thinking about this now, and sharing your wishes with those close to you and other people involved in looking after you, means that if you do become very ill and are no longer able to make decisions for yourself, the doctors and other healthcare professionals looking after you will know what you would like to happen.

This leaflet is for anyone who might want to think about how they would like to be treated and cared for in the future – including in the event of getting COVID-19. It explains what advance care planning is, and covers different types of advance care planning, such as:

- do not attempt cardiopulmonary resuscitation (DNACPR) decisions;
- advance decisions to refuse treatments (ADRTs);
- lasting power of attorney (LPA); and
- writing down or recording what you would like to happen.

You might want to take your time to think about your wishes and to speak to those close to you or a trusted person about it – and that’s OK. You can come back to this leaflet and find the information you need when you feel ready.

This leaflet should not replace discussions with those close to you and other people involved in looking after you, and you should make sure that you speak to them as well as using the information in this leaflet. We have also included a list of useful resources in the body of this leaflet in case you would like further information or support.

Thinking about care you would like when seriously ill

Advance care planning (often called ACP) is a way of thinking about and recording what you want to happen to you if you become so unwell that you are not able to make decisions about your medical care or treatment for yourself at the end of life. It is a way of letting the care team involved in looking after you, and those close to you, know your views and what you would like to happen.

It is not a new idea that has started with COVID-19 and you may have already started to think about some of these issues.



Why should I be thinking about this now?

Thinking about this now means that if you do become unwell, the healthcare team looking after you will be able to make decisions on the basis of what you have told them, rather than having to make a decision based on what they think you might want to happen.

An advance care plan is helpful for the medical team managing your care, but it is entirely up to you whether you want to make one. If you do want to do so, it is important to remember that there is no pressure on you to make any particular decision – it is your plan and it should be made in a way that reflects your individual wishes.

How do I make an advance care plan?

Your doctor or nurse might have already spoken to you to suggest making an advance care plan. You can start to think about advance care planning at any time, however, and you do not need to wait for someone to ask you.

You might want to talk about your wishes and thoughts with your doctor or another healthcare professional. This can help you to understand the different medical options that might be available to you. They might be able to suggest the best way of writing down your wishes, for example, by giving you a form or template to use.

You might also want to talk to those close to you, or a trusted person, about your advance care plan to make them aware of your wishes. This will help to make sure that the people around you know what you would like to happen.

You can then write down your wishes in a document and tell people where they can find it. This will make it much easier for people to know your wishes and for them to be followed in future. Some people call this an “advance statement” or an “anticipatory care plan”.

What sort of things should it include?

Advance care planning can include anything that is important to you in relation to your future care – from very serious decisions to more day-to-day things. For example:

- where you would like to be cared for – at home, in a hospice, or in a hospital;
- the types of treatment you would, or would not, like to receive – for example, whether you would want to be put on a ventilator if you are no longer able to breathe on your own;
- any religious or spiritual beliefs that you would like to be respected;
- whether you would like to appoint someone to make decisions on your behalf if you are no longer able to (a lasting power of attorney, which we talk more about below); and
- the names of any people you would like the doctors to involve in discussions about your care and treatment.

It is also a way of making doctors and other members of the healthcare team aware of who you are as a person: your likes and dislikes, what is important to you, and your wishes and feelings about different things.

Part of this will involve thinking about what is most important to you. You might want to go to hospital and receive all possible treatment to help you get better. Or, it might be more important for you to be able to stay at home and be kept comfortable and pain-free, even if this risks that you might not live as long.

As part of this, you should think about whether you have any wishes that are different depending on whether they relate to COVID-19 or not. For example: you might not want to go to hospital or be put on a ventilator if you are sick with COVID-19, but would still go to hospital and receive treatment for any other illnesses you might have or if you had an accident.

An advance care plan is not set in stone, and you can make changes to it if your circumstances or your views change over time. It is important that you tell the healthcare team looking after you and those close to you about any changes you have made or wish to make.

Find out more:

[Understanding treatments and outcomes in hospital and critical care](#). This website, produced by the Royal College of Physicians and its patient partners, explains more about what happens in hospitals and critical care units and the types of treatment you might receive.

Compassion in Dying is a national charity which supports people to plan for their treatment and care in case a time comes when they cannot make decisions. You can make an Advance Decision or Advance Statement using their online tool at www.MyDecisions.org.uk or go to www.compassionindying.org.uk where they have produced a special resource on making decisions about treatment for COVID-19.

[Marie Curie UK](#) has some helpful guidance about advance care planning.

NHS England has a [short guide and template](#) for advance care planning which you might find helpful to use.

NHS Wales has a dedicated Advance & Future Care Plans [webpage](#) which includes a set of forms for patients and for healthcare professionals, including Advance Decision and Advance Statement forms.

Dying Matters in Wales have created a [website](#) with explanatory videos for patients, carers and health and social care professionals.

Age UK is a charity dedicated to helping people make the most of later life. On their [website](#) they have a range of resources on planning for the end of life.

Will my family be able to make decisions for me?

No. A lot of people assume that family members or “next of kin” will be able to make decisions on their behalf, but this is not true.

You can formally appoint someone to speak for you – called a lasting power of attorney (health and welfare) or LPA. You have to go through a particular legal process to do this, and we explain a bit more about this in the section below.

If you have not made an LPA, then your family will be consulted, if they can be contacted in time, but they cannot make the decision on your behalf. This is why it is helpful to have discussed and recorded your own wishes, so that these can be taken into consideration when a decision is made.

How can I appoint someone to make a decision on my behalf?

In England and Wales, you can choose to appoint someone close to you to be a health and welfare attorney, with the power to make decisions about your care and treatment on your behalf. In England and Wales, this is referred to as a lasting power of attorney, or an LPA.

It is important to note that there are two possible kinds of power of attorney:

- one who can deal with decisions about health and welfare (called a health and welfare attorney in England and Wales); and
- one who covers decisions about money and property (called a property and financial affairs attorney in England and Wales).

Only an attorney with health and welfare powers can make a decision about your care and treatment.

In Northern Ireland, there is no way to give another person the legal power to make decisions about your medical treatment or care.

In the event that you lose capacity and are unable to make decisions about your treatment or care, the person you have appointed to be an attorney can make decisions on your behalf, as long as they are making those decisions on the basis of your best interests. If you would like your attorney to be able to consent to or refuse life-sustaining treatment on your behalf, you must give them this power when you make the LPA.

There is a particular process you need to go through in order for an LPA to be valid, including registering it with the Office of the Public Guardian, so it is important that you seek advice on how to do this.

Find out more:

In England and Wales, you can find out more information about LPAs at the [website of the Office of the Public Guardian](#), which is the government body that registers LPAs.

Can I refuse certain types of treatment?

If you have a clear opinion about treatment that you do not want to receive, you can record these in a more formal document.

If you are in England and Wales, you can record your wishes in a legal document called an advance decision to refuse treatment (often called an ADRT or a Living Will). In Northern Ireland, it is called an Advance Decision.

If certain conditions are met, these documents will be legally binding, which means that healthcare teams must follow what you have said. There are some templates available online which can help you write one.

Find out more:

In England, you can find out more about advance decisions on an NHS England [webpage](#).

In Wales, you can find a Decision to Refuse Treatment document and guidance notes on the NHS Wales Advance & Future Care Plans [webpage](#).

Compassion in Dying have a [factsheet](#) on end-of-life decision-making in Northern Ireland.

Can I ask for certain types of treatment?

If you would like to receive certain types of treatment, or if you would like to receive all possible medical treatment, then you can include this in your advance care planning.

However, the doctor is not bound by your wishes to give you treatment that they do not think will benefit you or that is not available.

It does mean that the healthcare team will know what sort of treatment you would like to receive, and they will take your wishes into account as part of their decision.

What is a “do not attempt cardiopulmonary resuscitation” (DNACPR) decision?

As part of talking to you about advance care planning, the people involved in looking after you might want to talk to you about what you want to happen if your heart and breathing stop. They want to make sure that you know what is involved and that you have had the opportunity to think about your wishes.

When someone’s heart stops working unexpectedly, cardiopulmonary resuscitation (CPR) can help restart the heart and restore them to a quality of life that they value.

However, CPR is not always beneficial for everyone. Unlike what you might see on television, it is a vigorous and difficult procedure. It is often not successful in restarting the heart and breathing. In many cases it is followed by prolonged treatment in an intensive care unit (ICU), often including artificial ventilation.

For some people, particularly those who have serious underlying health conditions, it is even less likely to work.

Even if the heart is restarted, many people can be left with serious injuries or other complications which means they do not regain a quality of life that they would like. For people who are approaching the end of life, it can deprive them of the chance to die “peacefully” and can be traumatic for them and for their loved ones.

For this reason, after discussion, sometimes a decision will be recorded in advance to not attempt CPR. This decision is then documented in something called a DNACPR or a “do not attempt resuscitation” DNAR.

Some doctors and healthcare professionals like to call this “allow natural death” or “natural anticipated and accepted death” to indicate that in some cases, a decision not to attempt CPR will simply allow death to happen naturally. You may hear these phrases used in conversation.

A DNACPR decision only applies to CPR and does not affect any other treatment that you would normally receive or be considered for.

How are DNACPR decisions made?

Every decision will be made after a careful assessment of each individual’s illness and all that is known about them. Decisions about CPR are never made on grounds of age or disability alone.

A DNACPR decision may be made:

- by you, if you decide that you would like to refuse CPR;
- as a shared decision between you and your doctor, because you both agree that the likelihood of CPR being successful and benefitting you is extremely small compared to the risks of receiving it; or
- by your doctor because they do not believe that CPR has a realistic chance of being successful. If your doctor makes this decision, they should still discuss this with you.

If you cannot be involved because you are not able to make decisions for yourself, the healthcare team looking after you will consult your relatives and others close to you about your wishes.

If your doctor or other healthcare professional tells you that they do not think that attempting CPR will be successful, this does not mean that they think you are not worth saving. It only means that they think that attempting CPR will not work for you. In these circumstances you will, of course, continue to receive appropriate care and treatment for other medical problems that may arise, or to manage any pain or other symptoms.

Find out more:

The Resuscitation Council (UK) is an organisation that promotes resuscitation guidelines and contributes to saving lives through education, training, research and collaboration. It has produced a range of resources about CPR, including about CPR for people with COVID-19, which you can find on their [website](#).

The [Talk CPR website](#) and videos, created by NHS Wales, have been co-produced by patients and carers and have useful pointers to why someone may ask their healthcare team to fill in a DNACPR form for them.