

Patient information factsheet

Making your advance care plan: BMT and cellular therapy

This booklet is about how to make an advance care plan. An advance care plan is a record of your thoughts and wishes about your medical treatment and care in the future.

We hope this booklet will help to answer some of the questions you may have about making your advance care plan.

Why do I need to make an advance care plan?

Planning ahead is something that many people do, whether or not they have any specific medical conditions.

We want to provide the best possible care for people having bone marrow transplants and other cellular therapies such as CAR-T. An advance care plan helps us to do this. The course of this treatment can be unpredictable, so we feel it is important to know what your wishes would be in the event of a significant decline in your health.

Making your advanced care plan gives you an opportunity to express and discuss your concerns, wishes and requests for your future care with your health care team, and your family and friends.

We know that the future may be a difficult topic to talk about. Having these discussions and writing an advance care plan ensures that both your family and your medical team know your preferences in the event of you becoming ill or reaching the end of your life. Even if you're not approaching the end of your life, it can still be helpful to plan ahead.

As with any type of plan, your views and wishes may change over time. Please be aware that you can review your plan with your medical team at any stage and update it according to your health needs and wishes.

Planning ahead

What is an advance care plan?

An advance care plan is a record of your thoughts and wishes about your medical treatment and care in the future.

Making an advance care plan involves making decisions about your future care with your health and social care professionals. If your illness progresses in the future and you are unable to make decisions or tell us your thoughts (known as 'losing capacity'), your health care team will use your plan as a guide to your wishes for your care.

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Writing your plan down on paper or as a digital document can make it easier for people to understand and follow your wishes in the future. However, you do not have to write your wishes down if you don't want to.

An advance care plan is not a legal document.

What does an advance care plan include?

An advance care plan can include anything about your future care.

For example, an advance care plan might include the answers to these questions:

- How would you like to be looked after if your health gets worse in the future?
- Where would you like to be looked after in the future or in your final days?
- Are there any spiritual or religious beliefs you would like to be considered in your care?
- Who would you like to spend time with?
- Who should your doctors or nurses talk to about your wishes if you become unable to make decisions?
- Do you want to appoint someone to make decisions on your behalf if you're unable to make them (known as lasting power of attorney)?
- How you would like practical matters dealt with, such as the care of a pet, if your health gets worse in the future?
- Have you made any funeral plans or decisions about what you wish to happen to your body after you die? (Many of us do not have any plans for what we want to happen after we die, whenever that may be, but planning these things can help the people around you.)

How do I make an advance care plan?

Start by talking about your wishes with your healthcare team, and your family and friends. We can set up a meeting to discuss your plan with you, your team, and any friends or family members you would like to be present.

Your healthcare team may have an advance care planning form to help you think about different topics to discuss. You can use the form to write down your thoughts and wishes. You can also use this booklet as a guide to the care and support that is available to you and the choices you have about your care.

Telling people about your advance care plan

Ask your doctor or clinical nurse specialist about how to make sure that other health and social care professionals know about your advance care plan.

They may be able to create an electronic record of your plan that could be accessed by hospital staff or out-of-hours doctors. In England this is called a summary care record. These services can vary depending on where you live.

Will my advance care plan be followed?

Making an advance care plan makes it more likely that your wishes will be understood and followed.

However, this is not legally binding and there could be circumstances when the doctors or nurses don't follow the wishes you've recorded. In this situation, they would always consider your best interests in their decision.

Refusing treatment

You're entitled to say whether there are particular treatments that you don't want to have. This is called an advance decision to refuse treatment (ADRT). It's sometimes called an 'advance decision' or 'living will'.

An advance decision to refuse treatment will only be used if you lose the ability to make your own decisions about your treatment (see 'mental capacity' on page 5). It is important to remember that you can change your mind about anything in your advance care plan at any time, including ADRT.

How do I make an advance decision to refuse treatment (ADRT)?

It's helpful to discuss your options with a doctor or nurse who knows your medical history and health conditions. You can ask them what treatments you're likely to need and what it might mean if you choose not to have them.

You'll need to state the specific treatments you wish to refuse and in what circumstances your refusal will apply. You can choose to refuse treatment that could potentially keep you alive (known as 'life-sustaining treatment' or 'life-prolonging treatment'), such as a mechanical ventilator to help you breathe. You can't refuse care to make you comfortable or request help to end your life.

If you decide to make an advance decision to refuse treatment (ADRT), you must make sure the decision is:

- written down
- signed by you
- signed by a witness (if you want to refuse life-sustaining treatment)

Your healthcare professional may have a form or template you can use. Some organisations, such as Macmillan Cancer Support, also have forms you can download or order.

You need to share your advance decision to refuse treatment with your health and social care professionals so that they know what treatments you don't want to receive. It can also help to share this with your family and friends.

Will my ADRT be followed?

Your doctor or nurse must follow your advance decision to refuse treatment as long as it is valid and applies to your situation at the time.

In England and Wales, an advance decision to refuse treatment is legally binding under the Mental Capacity Act 2005.

Where could I be cared for?

It can be helpful to think about where you may want to be cared for now, in the future and in your final days if that situation arises. Think about how comfortable you would feel in different places and whether you would be able to get the medical and personal care you might need.

Talk to your medical team about the care you may need and what support is available in your area, as this information may influence your decision.

Care at home

Many people prefer to be cared for at home because they can be surrounded by home comforts, such as loved ones, pets, their own room and the food they wish to eat. However, it is important to consider what care and support your family and friends are able and willing to provide.

You will be able to get extra support through your GP which may include palliative care visits and district nurses who may coordinate your care at home.

Care homes

You may choose to be cared for in residential care, for either the short or long term. In a care home, staff will look after you day and night. They can give personal care, such as help with getting washed or dressed and providing meals.

A nursing home is similar to a care home but has trained nurses on duty. If your health needs require nursing care on a frequent basis, this type of home may be suitable for you.

Paying for care

Medical care is usually free, including care in hospices. You may have to pay or contribute towards the costs of your personal or social care, including getting care at home or staying in a care home or nursing home. This depends on where you live, your savings and your income. Ask your doctor, nurse or social care services what care is available.

Outpatient care

We may be able to support your medical needs while you are feeling well through the outpatient setting. This means you would live at home and come into hospital during the day for blood tests and blood product support if necessary.

This may be a short-term solution to keep you well for as long as possible, but it is not an appropriate setting for end-of-life care if that situation arises.

Legal advice

Setting up a power of attorney

If you have a terminal illness, organising and making decisions about financial matters and your healthcare can be hard, especially when you have so much to deal with. You can set up a power of attorney to let someone help make decisions for you. This can be particularly helpful if you're worried about your ability to manage your affairs in the future. While you have capacity, you are entitled to continue to make your own decisions.

There are different types of power of attorney. You can choose to set up more than one type if you want.

1. Ordinary power of attorney

You might set up an ordinary power of attorney because you feel that you don't want to make decisions about your finances yourself. It lets you transfer control of your financial affairs temporarily to the person you choose. It can cover all your financial affairs or just some aspects of them. The power automatically stops if you lose the ability to make decisions for yourself (lose mental capacity).

How to set up an ordinary power of attorney

If you want to set up an ordinary power of attorney, you should contact a solicitor or other legal expert, for example at a citizens advice bureau, to help. The wording needs to be very precise so it's clear what authority you're giving to your attorney. There are organisations that can help you find legal advice in your area.

2. Lasting power of attorney for financial affairs

This allows someone to make decisions about your financial affairs and property for you. For example, this may include managing a bank account or selling your home. You must have mental capacity when you create the power of attorney, and you need to register it with the Office of the Public Guardian.

3. Lasting power of attorney for health and care decisions

This gives someone else the right to make decisions about your healthcare and other aspects of your welfare. For example, this could include medical care or moving into a care home. It also allows them to access your health records. It can be used in England, Wales and Scotland.

How to set up a lasting power of attorney

Letting someone else control your financial and legal affairs is an important decision, so you may want to get advice from a solicitor.

Here are some steps you can follow:

1. Fill in the forms and guidance from the government.
2. Register your power of attorney.
3. Let any relevant organisations or people know that you've set up a power of attorney.
4. Keep your power of attorney up to date.

Choosing your attorney

Choose someone you trust completely and who understands you well. They'll have a duty to act in your best interests. Your attorney needs to be aged 18 or older. They need to have the ability to make their own decisions (mental capacity).

Many people choose a family member or friend to be their attorney. You can also appoint a firm – for example, a solicitor or an accountant – as your attorney, but they will charge a fee.

Mental capacity

Mental capacity is your ability to understand and make a decision. If you lack mental capacity, this means that you're unable to understand and make a particular decision at the time it needs to be made.

You and the people close to you may find you need to prepare for this possibility and put plans in place. People who may lack capacity include those with dementia, or memory or thinking problems, or people who are being given sedation medicines.

Laws about mental capacity

There are laws to protect and empower people aged 16 or over who may lack the mental capacity to make their own decisions. In England, the law is called the Mental Capacity Act 2005.

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Mental capacity can vary from day to day, and issue to issue. It can also vary according to the type and importance of the decision being taken. For example, you might be able to decide where you want to live, but not be able to decide what to do about your will.

All practical steps to help you make a decision must have been taken without success, before someone else can make a decision on your behalf. An advocate can only take decisions on your behalf if you've been assessed as lacking capacity. Even then, someone can only make those decisions that you can't make for yourself.

If you're not able to make a decision, the person making the decision should take into account what you would want and what is best for you as an individual. They should involve you as much as possible when decisions are being made.

Who makes the decision?

The person who makes the decision on your behalf is called the 'decision-maker'.

This could be:

- a family member or carer for day-to-day things, such as what to wear
- a health or social care professional or someone legally appointed to make decisions about treatment, care and accommodation
- someone legally appointed to make decisions about finances and property

Making decisions

If it's decided that you lack mental capacity, any lasting power of attorney will be put into effect.

If there's no power of attorney, a family member, carer or professional can apply to the court of protection for a decision to be made on a particular matter. If there's a continuing need to make decisions on your behalf, they can ask the court of protection to appoint them as your deputy.

If there's no one suitable or willing to act as a power of attorney or deputy and decisions need to be made about your health or social care, an independent mental capacity advocate (IMCA) may be appointed to support and represent you. The court of protection can also appoint a professional deputy.

Wills

Making a will is something that many of us put off. Making a will lets you decide what happens to your money, property and possessions when you die. These things are sometimes called your 'estate'. You can also use a will to decide who should look after any children under 18.

You might want to make a will so that you can make these decisions yourself and to help your loved ones feel less worried about the future.

If you haven't made a will or your will is invalid, your money, property and possessions will be shared out according to the law. This can leave a very complicated and stressful situation for loved ones to sort out, having to guess what your wishes might have been.

How to make a will

Here are some steps you can take:

1. Calculate the value of any money, property and possessions (your 'estate').
2. Decide who you want to benefit from your will (the 'beneficiaries').
3. Decide what you want each beneficiary to receive.
4. Decide who you want to sort out your will (the 'executors'). It could be your family, friends, or a professional, like a solicitor (lawyer) or an accountant.
5. Write your will. It's helpful to use a solicitor, especially if your affairs aren't straightforward.
6. Give a copy of your will to your executors along with a list of your money, property and possessions.
7. Review your will. Make sure you review and update your will every five years and whenever your circumstances change.

Many charities offer a will-writing service and sometimes these are free. It's important to make sure your will is legally valid.

Online accounts

Protecting or sharing your online accounts

Most people have lots of social media and online accounts, sometimes called digital assets. It can be helpful to think about what you want to happen to these accounts if you were to die. You can put plans in place to make things easier for your family members and friends to carry out your wishes.

You could think about your accounts for:

- music and other media subscriptions (Netflix, Spotify, newspaper subscriptions)
- social media (Facebook, Twitter, Pinterest, Instagram)
- professional sites (LinkedIn, Google Apps)
- email (Gmail, Hotmail)
- cloud storage services (Dropbox, Apple iCloud)
- smartphone or tablet apps
- online accounts for utility or mobile network providers

If you're not sure how to manage your online accounts, you might like to ask a family member or friend to help you.

Deciding what to do with each account

Companies have different rules about what happens to your account if you die and whether someone else can have access. It's a good idea to look at your options for each account and decide what you want to do with it.

You might be able to:

- memorialise a social media account, so that your timeline and pictures can be seen by friends, but no one can make changes to it
- download your data (photos, videos, and messages) and keep them in a secure place
- deactivate an account so that it isn't publicly available, but the information is stored with the company in case someone needs to access it in the future
- delete an account so that it isn't publicly available, and all the information is deleted
- assign someone you trust to have access to some or parts of your account if you die

Putting plans in place for your accounts

You could decide what you want to do with each account and, if you can, put these plans in place with the company. You can also write down your wishes.

You could write down your account details and passwords and leave these with someone you trust. Check with each account before giving someone else your password, as it may not be possible for someone else to legally access your account, according to the terms and conditions of the company.

Online banking

Bank accounts are counted as part of your estate (your money, possessions and property). This means that your bank accounts will be managed by the executors of your will. You don't need to change your online banking. If you die, your family, friends or executors of your will need to tell your bank. You may wish to keep an updated list of your online bank accounts in a secure place with your will so that your executors know which banks to contact.

Check with your bank before giving someone else the log in details for your online banking. If you give someone else the details and the account is accessed without your permission, the bank may refuse to compensate you for any damage.

Funeral

Planning your own funeral

It may be that you have never thought about what you would like to happen at your funeral before. Many of us will make funeral plans at some point, but some of us are prompted to do so by a major life event, such as a serious illness.

Some people want to make decisions about what they would like to happen if they die, and other people don't. You could tell your friends and family about what you want for your funeral. It might help to write your wishes down.

You could also put plans in place for your funeral by organising it yourself or speaking to a funeral director.

You could consider questions such as:

- Do you want to be buried or cremated? If so, where?
- If you are cremated, would you like your ashes to be kept or scattered?
- Where would you like the funeral to be held?
- Who would you like to be invited?
- Are there any music, poems, prayers or readings you want included?
- Do you want a memorial service, wake or gathering – and, if so, where?

Paying for your funeral

Paying funeral costs in advance is becoming more popular. If you haven't already, you might like to consider paying for your funeral in advance with a pre-paid funeral plan or insurance, or by leaving money in your estate to cover the funeral costs if you die. Your friends and family might not have immediate access to your money. Your bank or building society may release funds to pay for the funeral, so check with them about how to do this.

Pets

Rehoming your pet

You may be worried about who will look after your pet if your condition gets worse or if you die. It may be helpful to plan for your pet's future. This can be useful for family and friends if they need to find a new home for your pet.

You might have a friend or relative who would like to look after your pet. You could ask them if they could help, either on a short-term or long-term basis.

There are organisations that can rehome pets with loving and responsible new owners. Some organisations have schemes where you can register your pet in advance to be looked after if you die.

Information about your pet

It can help to gather information about your pet and keep it in a safe place so that you, or a friend or family member, have everything to hand if it's needed.

This could include:

- what food your pet eats
- how much food they need and how often
- what activities they like and don't like doing
- your pet's vet records and dates of any operations or vaccinations
- details of any pet insurance

If you rehome your pet you may want to make sure that they have familiar things around them, as it could help them feel more comfortable in their new home.

Useful links

This is a list of links or contacts you may find helpful:

www.macmillan.org.uk/cancer-information-and-support/treatment/if-you-have-an-advanced-cancer/advance-care-planning

www.gov.uk/power-of-attorney

www.england.nhs.uk/publication/universal-principles-for-advance-care-planning/

www.goldstandardsframework.org.uk/advance-care-planning

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For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**

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