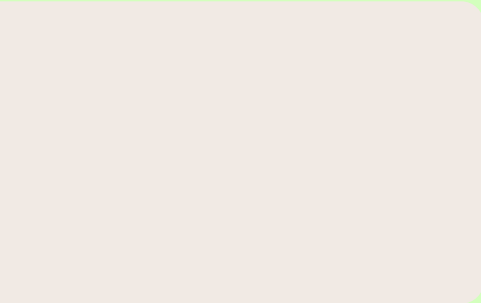


# End-of-life care: support for loved ones



At Anthony Nolan we take great care to provide up-to-date and accurate facts about stem cell transplants. We hope the information here will help you to look after yourself.

Each transplant centre will do things differently, so this booklet is just a general guide. It isn't intended to replace advice from your medical team.

Please speak to your medical team for more details about your own situation, as they will be able to give you personalised, specific advice.

### Ordering more copies

If you'd like to order more copies of this guide, or to request it in an alternative format, please get in touch with us at [patientinfo@anthonymolan.org](mailto:patientinfo@anthonymolan.org)

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If you have any questions or comments about this resource, or would like information on the evidence used to produce it, please email [patientinfo@anthonymolan.org](mailto:patientinfo@anthonymolan.org)

The information contained in this booklet is correct at the time of going to print (March 2026). We plan to review this publication within three years, by March 2029. For updates or the latest information, visit [anthonymolan.org](https://www.anthonynolan.org)

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## What's in this booklet?

This booklet is about preparing for the end of someone's life. It includes information on why this might be happening, planning ahead and what to expect, and how you can look after yourself and others. It also includes information and support for your loved one's stem cell donor.

There are spaces in this booklet for you to write down any thoughts, feelings, or questions you may have. Use these spaces however feels right for you.

You might not feel ready to read this information just yet, and that's OK. Please keep this booklet somewhere safe so you can pick it up at any time.

If you need to ask us any questions, or you would just like a chat, please get in touch with the Anthony Nolan Patient Services team at [patientinfo@anthonymolan.org](mailto:patientinfo@anthonymolan.org) or on **0303 303 0303**.

### We use the term 'loved one' in this booklet

This might not feel like the right term for the person who is nearing the end of their life. It might be your partner, child, parent, extended family member, friend or colleague. We're here to support you, whatever relationship you have with this person.



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## Why you have this booklet

You likely have this booklet as you have been told your loved one is nearing the end of their life. Whether you were given it by a healthcare professional or you ordered it yourself, we hope it helps a little during this tough time.

There are many reasons why your loved one is now having end-of-life care. It might have happened quickly, or might have been expected. In any case, it's complex and unique. You might have lots of questions and that's OK. We might have answered some of them in this booklet. If not, please do ask your loved one's medical team.

## Why did their stem cell transplant not work?

Your loved one's medical team will know more about why this might have happened, but here are a few common reasons:

### Graft failure

Graft failure is when the new immune system hasn't formed properly. Either:

- your loved one's immune cells attacked the donor's cells as they saw them as different
- the donor's cells didn't 'engraft' properly to form the new immune system.

### Relapse

Your loved one's condition might have returned (known as 'relapse') even if the stem cell transplant worked. Relapse is more likely in the first two years after transplant, but is possible even after five years.

### GvHD

Graft versus host disease (GvHD) is when the new immune system attacks other cells in the body as it sees them as different. GvHD is a common side effect if your loved one had a stem cell donor, but sometimes it can be fatal.

## Infection

The immune system is vulnerable to infection after a stem cell transplant. If your loved one picks up an infection, it's much harder for their immune system to fight it. If they pick up multiple infections, it can prevent their immune system from fully recovering.

There is only so much you can do to avoid an infection. It can happen even if you followed all the correct advice.

To die from post-transplant complications is often complex and not due to just one side effect or infection. Everyone's experience is different. Please do speak to your loved one's medical team if you have any questions or worries.

## Coping with this news

Having a stem cell transplant can come with so much hope. There's the high of finding a stem cell donor. You might have been on a long, emotional journey to get to the point of transplant. So it can feel devastating to know it didn't work.

This can be a distressing time. You might have been expecting this news, or it might be a shock. Whatever your situation, please take care. You are likely going to experience lots of different emotions, one after another or perhaps all at once.

### You might feel:

- Sad, hopeless or exhausted. It's OK to feel drained by this news.
- Worried about what might happen next. It might be challenging, but there are lots of people and services in place to support you.
- Angry, and want someone to blame. This is normal. It can feel so unfair and you might want more answers.
- Guilty, especially if you were their stem cell donor. This is a unique position to be in and we have more support for you in later in this booklet.



Take some time to write down your thoughts, feelings, and questions you might have. It can feel better to have them on the page and not heavy in your head.



If you have questions, you could take this booklet to your loved one's medical team. You could go through the booklet and your questions together.

## What to expect next

What happens next in your loved one's care will depend on their individual situation. There can be a lot to understand, process, and plan. You might have questions or worries.

This might be a good section to read through with family or friends, or your loved one's medical team. They might be able to support you, especially with practical things.

Your loved one will likely receive palliative or supportive care. Below, we've explained a little bit about what this is. It might help to manage your expectations.

### Palliative and supportive care

Palliative and supportive care gives support to people who have a terminal illness. It can be given at any time, not just when someone is nearing the end of their life.

This type of care aims to make you feel as comfortable and supported as possible. Your loved one's healthcare team will:

- manage any pain and symptoms in the best way for your loved one
- help you and your loved one to plan for the future, using their advance care plan if they have one
- offer any emotional, psychological, or spiritual support.

Your loved one can have palliative and supportive care at home, in hospital, or in a hospice. It might depend on where you live, what support services are available, and what your situation is.

Palliative and supportive end-of-life care ultimately aims to give your loved one a good quality of life in the time they have left. Advance care planning can help with this. You can read more about advance care planning on **page 10**.

Marie Curie has information on what you can generally expect when your loved one is in the final days or weeks of their life. Visit [mariecurie.org.uk/end-of-life](https://mariecurie.org.uk/end-of-life) or scan this QR code:



## Your loved one's wishes

Does your loved one have an advance care plan? This might have been created before or during their treatment and can help with their end-of-life care, needs and wishes.

If they do have an advance care plan, now is the time to read through it with your loved one and medical team.

If they don't have an advance care plan, here are some things that are usually included. It might help to talk each of these things through with your loved one and their healthcare team:

- Where would your loved one like to be cared for in their last few days or weeks, if it's possible to choose?
- How would they like any pain or other symptoms to be managed? Is there anything in particular that would bring them comfort?
- Who would they prefer to carry out their personal care, like washing and dressing?
- Who would they like to be surrounded by in their last few days?
- Do they have any favourite music you can play? Or favourite films or TV shows?
- Do you know where their important documents are, like their passport, driving licence, or important bits of paperwork, like their Will?
- Similarly, do you know their passwords to important accounts or social media?
- How would they like their social media accounts to be used after they die?
- Would they like to plan their own funeral?

Thinking about these things can feel overwhelming. Marie Curie has some resources you might find helpful. Visit [mariecurie.org.uk/planning-ahead](https://mariecurie.org.uk/planning-ahead) or scan this QR code:



Use this space to write down any thoughts you, your family or loved one have on planning ahead. You could also use it to write a to-do list or note down any questions you have.

## Looking after yourself

Your priority right now is your loved one. You want to make sure they're as comfortable as they can be and that their wishes are being met. You will likely want to spend as much time with them as possible. This is completely understandable.

You might also have other dependants or responsibilities. You might have children, grandchildren, or other family members to care for. You might have a job, hobbies, or any other commitments that need your time and attention.

Please take a moment. **You must look after yourself.**

You will be able to support others best if you are looking after yourself, or allowing yourself to be looked after by others. Lean on people around you, if you can.

Family and friends might not know how best to help. They might even think giving you space is best, when it's not. So try to be specific when asking for the things you need. Below is just a small list of things that might help:

- Ask family or friends to do the school run or take your children for a sleepover, or take the dog for a walk.
- Accept offers of meals, taking a load of laundry, or doing a food shop.
- Ask a trusted person to speak to any relevant workplaces, schools or universities about your situation.
- Have a good cry with someone close to you, if that's what you need.



If other responsibilities are taken care of, this can give you time to look after yourself with the basics:

- Take a shower.
- Get some sleep.
- Drink plenty of water.
- Try to eat as well as you can.
- Have some time to yourself, if your situation allows it.



Take some time to write a list of things others could help with, or simply use this space to journal more thoughts:

## Supporting your loved one

Supporting your loved one through this time is going to feel hard. It's OK if you feel worried or overwhelmed. You want to get it right and feel in control, and that's understandable.

Firstly, remember to refer to their advance care plan, if they have one. This will hopefully help with any decision-making. If they don't have an advance care plan, speak to their medical team to ask what would be included.

You might feel like you have to be strong for your loved one. You might not want them to see you upset or anxious. All people and situations are different, but it's OK to feel and show emotion. By looking after yourself, you are looking after them.



## Supporting others

There might be lots of different people who have a relationship with your loved one. It can be hard to know how to manage these relationships and look after everyone. In reality, you can't be there for everyone, but the below might help:

### Supporting children

Children are affected by change in different ways, just like adults. It's tricky to know the best way to support them, especially when you are also finding things difficult.

Don't be afraid to show them your emotions but do explain why you're feeling them, so they know your feelings aren't caused by them. Understanding it's OK to show emotion will encourage them to do the same.

Children might have lots of questions. You might not know how to answer these questions, or how much to share. Marie Curie offers information on how to support children through the end of someone's life and through their grief.

Visit [mariecurie.org.uk/supporting-children](https://mariecurie.org.uk/supporting-children) or scan this QR code to find this information and support:



## Supporting extended family members

Every family is different. You might have a large family or a small one. You might be close with your family or not at all. All families come with unique needs.

Grandparents might be looking after their grandchildren more than usual, long-distance cousins might feel out of the loop, or step-family might be struggling with where they fit in this situation.

Here are some ideas that could help you manage your family needs:

- Ask a trusted family member or friend to pass messages on to your wider family and friends network.
- Set up a WhatsApp group for updates, or ask someone else to do this for you. You can have a setting which only allows you, or whoever you ask to create the group, to add messages. This can help if group chats feel overwhelming.
- Chat with some family members and ask them to help in specific ways, or to support each other while you're looking after your loved one.
- Set your boundaries. You're likely to have some tricky conversations that are highly emotional. People will hopefully understand this is a tough time for you all.
- Similarly, even people with the best intentions can sometimes say the 'wrong' thing. Or they might not say anything at all. Try to be prepared for this.
- Signpost them to charities like Anthony Nolan, Marie Curie or Macmillan. We've shared a list on [page 29–31](#). We're here to support you all.



## What about their stem cell donor?

There can be so many unique and complicated feelings if your loved one had a stem cell donor, especially if they were related.

### Related stem cell donor

If you donated your stem cells to your sibling, parent, or child, the feelings you might experience if they die can be overwhelming. There are extra, deeper feelings of responsibility, awareness, and attachment.

**Please remember: it is not your fault. You did something incredible by donating your stem cells. That will never change.**

You're in a unique situation. Your experiences may be different to those around you, and this can feel isolating. Make sure you share how you're feeling and ask for support. You're allowed to feel however you're feeling, and to put yourself first. Find a trusted family member or friend, or trained professional to talk to.

We offer the same advice if your child or partner was your loved one's stem cell donor. It can be especially hard to support a child through this unique situation and their complex feelings. If they think it's their fault, please remind them this is absolutely not the case.

### Unrelated stem cell donor

If your loved one had an unrelated stem cell donor, you might be wondering about them. You might already have a relationship with them, or if not, you might wonder if they'll find out what has happened.

If you are not in touch with their donor, it is up to you whether you want to contact them. Here are some things to consider:

- Give yourself time before deciding to make contact. Emotions are high and feelings can change, so it's good to be sure this is definitely what you'd like to do.
- Your contact might be the first time the donor learns of what's happened so it could be a shock to them. They too might feel a sadness and a loss.
- Some donors choose to not know what happens after they have made the donation, and this is their choice. There is no guarantee they will accept your contact or respond.
- Once contact has been made, the donor might hope to stay in touch. Think about your expectations and what your boundaries are.
- For some international donors, there might be some restrictions on contact. Our Donor Follow Up team will be able to advise on this.

If you'd like to speak to someone about contacting your loved one's donor, please email [donor@anthohnolan.org](mailto:donor@anthohnolan.org)



## After your loved one's death

The death of your loved one can feel shocking and devastating, no matter the circumstances. **Please remember, we're here for you.**

There can be lots to sort out after someone dies. It can feel mentally and physically exhausting, especially when you're grieving. Think about asking family and friends to help with:

- sharing the news with others
- funeral arrangements
- cancelling any bills or appointments
- tidying and cleaning your home
- cooking you some meals
- getting you out of the house for a walk and talk.

Please visit our webpage on bereavement after stem cell transplant for more information and support:  
[anthohnolan.org/bereavement](https://anthohnolan.org/bereavement)  
or scan this QR code:



It can feel overwhelming to think about your loved one dying and life afterwards. **Please take some time to look after yourself, and let people look after you too.**

### It's important to talk

Bereavement counselling can be offered through your GP, local hospice, charities or private practices. Your loved one's medical team might also be able to refer you.

If you need some support with practical matters, the following organisations and resources might be helpful:

### Tell Us Once

[GOV.UK/tell-us-once](https://gov.uk/tell-us-once)

Tell Us Once is a UK government service which lets you report a death to most government services at just one time. Tell Us Once will then notify organisations like HMRC, DVLA, and the passport office, among others.

### Marie Curie

[mariecurie.org.uk/information/grief](https://mariecurie.org.uk/information/grief)

Marie Curie has a checklist of practical steps to take when someone dies, and offers simple information and advice on how to go about them.

### Citizens Advice

[citizensadvice.org.uk/family/death-and-wills](https://citizensadvice.org.uk/family/death-and-wills)

Citizens Advice has a similar section on their website which can help you with your loved one's finances, Will, and funeral plans.

We've listed more helpful organisations in the next section of this booklet.



You might have lots of questions, thoughts and feelings. Please use this space however you need to. Write a to-do list, use it as a journal, or write down any questions you might have.

## Need to talk?

Anthony Nolan's Patient Services team is here for you.

Call us on **0303 303 0303** or email [patientinfo@anthohnolan.org](mailto:patientinfo@anthohnolan.org), Monday to Friday, 9am to 5pm.

Find support from other patients and their families by joining our Patients and Families Forum at [anthohnolan.org/forum](https://anthohnolan.org/forum)

You can find lots more information and support at [anthohnolan.org/patients](https://anthohnolan.org/patients)

## Further information and support

There are lots of organisations that are here to help during this time. We have shared a few below:

### British Association for Counselling and Psychotherapy

[bacp.co.uk](https://bacp.co.uk)  
**01455 883300**

The British Association for Counselling and Psychotherapy has a therapist directory. You can find the right accredited therapist for you and your situation.

### Bereavement Advice Centre

[bereavementadvice.org](https://bereavementadvice.org)

Bereavement Advice Centre supports and advises people on what practical tasks they need to do after someone dies.

### Citizens Advice

[citizensadvice.org.uk/family/death-and-wills](https://citizensadvice.org.uk/family/death-and-wills)

Citizens Advice can offer practical help on what to do after someone dies, including dealing with your loved one's finances, their Will, and funeral plans.

### Cruse Bereavement Support

[cruse.org.uk](https://www.cruse.org.uk)  
0808 808 1677

Cruse is a charity offering bereavement information and support. They have a helpline and local support groups.

### GOV.UK

[gov.uk/after-a-death](https://www.gov.uk/after-a-death)

The UK government website has a section about what to do after someone dies. It includes a helpful step-by-step guide.

### Hospice UK

[hospiceuk.org](https://www.hospiceuk.org)

Hospice UK is a charity supporting people who are nearing the end of their life and need hospice care. They have lots of information on advance care planning, end-of-life care, and bereavement support.

### Marie Curie

[mariecurie.org.uk](https://www.mariecurie.org.uk)  
0800 090 2309

Marie Curie is a charity supporting people who have an illness they're likely to die from, and those close to them. They offer information and support online and over the phone, for the time before and after death.

### Macmillan

[macmillan.org.uk](https://www.macmillan.org.uk)  
0808 808 00 00

Macmillan support those affected by cancer. They offer information and support for end-of-life care and bereavement.

### Tell Us Once

[gov.uk/tell-us-once](https://www.gov.uk/tell-us-once)

Tell Us Once is a UK government service which lets you report a death to most government services at just one time. Tell Us Once will then notify organisations like HMRC, DVLA, and the passport office, among others.

### The Good Grief Trust

[thegoodgrieftrust.org](https://www.thegoodgrieftrust.org)

The Good Grief Trust is a charity run by the bereaved, for the bereaved. They can help you find the support you need as quickly as possible.

### Together For Short Lives

[togetherforshortlives.org.uk](https://www.togetherforshortlives.org.uk)  
0808 8088 100

Together For Short Lives is a charity making sure children and families can access high quality palliative care. They have a helpline and offer financial grants.



**For further patient information:**

[anthohnolan.org/patientinfo](https://anthohnolan.org/patientinfo)  
[facebook.com/anthohnolanpatients](https://facebook.com/anthohnolanpatients)  
[patientinfo@anthohnolan.org](mailto:patientinfo@anthohnolan.org)  
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