

A better death

How to plan the end of life you want



palliative,
neurological
and bereavement
support

The 'D' word

Death is a difficult subject. It's painful and sad to think about, and it can be even harder to talk about. But no matter how near or far it may seem, giving it some thought can be helpful and reassuring for you and your loved ones.

This guide covers some of the difficult questions you may have, things you might want to think about, how to plan for the kind of death you want, and ways to get the conversation going.

It's designed to be a starting point that can help you prepare for the end of life. You'll find some useful links to more detailed information on pages 12–14.

There when it matters

We are Sue Ryder. We support people through the most difficult times of their lives. Whether that's a terminal illness, the loss of a loved one or a neurological condition – we're there when it matters. Our doctors, nurses and carers give people the compassion and expert care they need to help them live the best life they possibly can.

“I realised it was important to have the difficult conversations with my own parents.”

Following the death of someone close to her, Karen began talking to her family about the end of their lives.

“I used to visit an older lady as a volunteer. She knew she was approaching the end of her life and knew it was important to say what she wanted to happen. One day she asked me to call the hospice that had cared for her husband and ask whether she could go there to die too. I made contact, but before she could go to the hospice she became very ill and died in hospital. Because her family lived overseas, she didn't want to worry her daughter by discussing her wishes with her, so she never knew about the hospice.

“That experience made me think about my own family and since then I've had lots of conversations about dying with my parents. They've told me they would like to stay at home if that's possible, but not if it's a burden to others. We've also discussed funerals and where they might want their ashes to be scattered. Mum has told me she feels less worried about the future now we've talked about those things.

“Sometimes I start the conversation by saying what I would want, and then it's easier for them to open up. Dad is harder to talk to than Mum. With him it's more about the practical things. Sometimes we even laugh about it – I've found it's whatever suits the person you're talking to.”

Why don't we talk about death?

Starting the conversation.

When we are well and busy getting on with our lives, there may seem little point in talking about death.

But if we avoid the subject until we or someone we care about is seriously ill, it can make things difficult. The person dying may be too unwell to express their wishes, and those close to them may be asked to make decisions for them, without being sure of what they would want. Talking about what we want can make things clearer for everyone.

“I don't want to upset my family”

Many people tell us they want to “be strong” for their loved ones or are afraid to talk openly about death. But families can be strong together. Talking about it can be difficult but can reduce our worries about the future.

“I don't know how to start the conversation”

Talking about practical options, such as letting people know where you'd like to be cared for at the end of your life, can lead into discussing other worries or concerns. If you're a friend or relative of someone who is dying, ask open questions like “Is there anything worrying you at the moment?”

“It’s impossible to be fully prepared for the death of someone who has been such a big part of your life. But we wanted to include Tia in the conversation, so nothing was a shock to her.”

Kerry Walters, who involved her daughter Tia, 7, in the decision to move her Grandad into Sue Ryder Thorpe Hall Hospice.

“Do we have to talk about it now?”

Many people wish they were better prepared for death when the time comes. Starting the discussion sooner allows everyone to feel open and able to talk about their worries, fears and wishes, and be part of the conversation while they’re still able.

“Is it alright to talk to children about dying?”

It’s normal to feel we should protect children from things that might upset them. But children are often stronger than we think. And the truth is usually less scary than what they imagine if we don’t involve them. So try and find the right moment to talk honestly and let them express their feelings in return.

“When shall I bring it up?”

It’s all about finding the right moment for you or your loved one. If it’s a planned conversation, think about what you want to say and where you want to talk. It’s normal for someone to want to shut the conversation down, so don’t be offended if they do, just think about how you might keep it going.

“What shall I say?”

Leading questions can help to get the ball rolling, starting with something like “Have you thought about...?”, allowing the other person to start talking. You can also try talking about what you want first, so they feel more comfortable sharing their wishes.

Choosing the right place

When life comes to its close, knowing where you would like to be is important. Lots of us hope we'll be surrounded by loved ones in the comfort of our home – and that's often exactly what happens. But the care available in a hospital, hospice or nursing home might make that the best place. And your family can still be with you towards the end.

Everyone's journey is different, and your care can be tailored to your unique needs. But it's important to let people know what you want as things change, so you have some control and people around you can plan to get it right for you.

Your wishes

By thinking about it now, you may decide where you would prefer to die. And by writing down your wishes, those caring for you will know what really matters to you. One way to do this is by preparing an Advance Care Plan.

Sometimes circumstances dictate where someone dies, however the sooner your wishes are known, the more care can be shaped to meet your wishes. You can always change your mind and change what you have written down.

On page 10, you'll find information about making an Advance Care Plan.

Think about what you want to write down:

- Are your thoughts and wishes clear?
- Where will you keep them?
- Who will you tell?

The final days

Dying is completely unique to each person. People often worry about what might happen to them or someone they love when death is near, and ask us what to expect. It's helpful to be prepared for some of the changes that may happen as the moment gets closer. And it can also help when thinking about where you would like to be when you die, and the kind of care you would prefer.

Towards the end, there may be physical changes to appearance and breathing. It's normal to eat and drink less. And we usually spend more time sleeping as the body tries to save energy, until we are unconscious all the time. At this point, the body will begin to shut down, the heart eventually stops and we pass away. People often worry that they'll be in pain or distress when they die. For most people, these symptoms can be controlled.

It can be difficult to see these changes in someone you love, and you may find comfort in sharing your feelings with your loved ones and the health care team.

It is not always possible to:

- Know for sure that a person is in the last days of life.
- Predict exactly when a person will die.
- Know what changes the person you are caring for will experience.

You can prepare yourself, as much as possible by visiting these pages on our website [sueryder.org/near](https://www.sueryder.org/near)

About palliative care

Palliative care is about helping people to have the best quality of life possible, with specialist and compassionate care and support. People think that palliative care is only about helping people at the end of their lives, but it can help people earlier in their illnesses too. You can receive palliative care at home, in hospital or in a hospice.

Here are some things you might not know about hospices.

Hospices aren't just about looking after people with illnesses, they are about supporting the whole person and their family

There are consultants, doctors, nurses, nursing assistants and therapists to provide expert healthcare. People's physical, emotional, psychological and spiritual wellbeing is taken care of, with specialist teams looking after all aspects of the mind and body.

Hospices don't just offer end of life care

It's only part of the picture. Many patients living with potentially life-threatening illnesses receive care as an outpatient at a hospice, to stabilise ongoing complex symptoms and manage pain to make them more comfortable.

You can have hospice care in your own home

You may choose to have palliative care in your own home. In many cases, there will be nurses who can visit you at home to give you the care you need if you'd prefer to stay at home.

Specialist nurses, often called clinical nurse specialists, may visit you regularly and assess your needs as they change.

They can manage physical symptoms like pain, nausea or fatigue. And they will work closely with GPs, and other health and social care teams, to ensure care and support is coordinated.

Amanda Allsop didn't know where she wanted to spend her final days. She didn't like the idea of a hospice, but as it turned out – it was the perfect place for her and her family. Her daughter Sara explains.

“Even if the idea of going to a hospice completely terrified her and me, Mum knew that she needed specialist care and she felt neither home nor the hospital were the right place.

“It is incredible what images you can have in your head about a hospice until you actually see one. We were all dreading the idea of Mum coming to the hospice, but as soon as we walked through the doors of Sue Ryder Wheatfields Hospice, everything was better.

“There is this wonderful peaceful feeling embracing you. You almost feel like someone is hugging you.”



Advance Care Plan

There's a simple way you can prepare for the future now, with an Advance Care Plan. Even if you're quite well, there may be a time when life changes and it's comforting to know you've written your wishes down.

Your priorities

Advance Care Planning gives you the chance to write down your preferences for your future care.

Your wishes

Your statement of wishes and preferences is not legally binding but represents what you would like to happen. This should be taken into consideration by your family and healthcare professionals if you become too ill to make decisions yourself.

Your choice

It's up to you who you share your plan with, but it's helpful if your GP and other healthcare professionals are made aware of your wishes. You should keep a copy too, and give one to a trusted member of your family.

Find out more about writing an Advance Care Plan on our website
[sueryder.org/advance](https://www.sueryder.org/advance)

Questions to consider

When writing an Advance Care Plan, or preparing for a conversation with loved ones, these are some of the questions you may want to consider:

- Have you a preference about where you might like to be cared for?
- Will you register a lasting power of attorney so someone you trust can make important decisions for you, should you become too physically or mentally frail to do so?
- Who would you want informed if you became ill and needed treatment, and who would you not want informed?
- Who would you like with you, or to visit you, should you need care or treatment? Is there anyone you do not want involved?
- Who would you like to look after your dependants and pets should you be unable to do so because of illness? And who would you not want to have that responsibility?
- If you need care or treatment is it important that others are aware of any religious or cultural practices that need to be observed?
- If your condition worsens how much information would you like to receive about how serious your illness might be?

Bringing your plans together

In addition to your Advance Care Plan, there are more ways you can ensure your wishes and intentions are noted and followed.

Wills and probate

Having a Will is the only way to ensure that your money and possessions are shared between the people and causes you care about in the way you want. You can find information about making a Will on our website sue Ryder.org/will

As a member of the National Free Wills network, Sue Ryder is able to offer the opportunity to make a simple Will with a qualified solicitor, free of charge with no obligation to include a gift to Sue Ryder.

Leaving a gift in your Will

You might feel inspired to remember a charity in your Will to ensure a cause you care about can continue to make a difference in the future. You can find out more about gifts in Wills by visiting sue Ryder.org/gift

Donor registration

If you'd like to donate your organs and tissue after death, you can register your details now at the NHS Organ donation website organdonation.nhs.uk



Power of attorney

If you're worried about what happens if you become too unwell to make decisions about your health and care, you can give someone you trust lasting power of attorney. You can find information about power of attorney and how to set one up on our website sueryder.org/power

Funeral planning

Find out how you can plan ahead for your funeral sueryder.org/planning

Managing your digital self

Whether it's your social media identity, or your online banking passwords, it's important to think about what you want to happen about the information you have online. You can find out more about how to manage this at digitallegacyassociation.org/resources-2

“Like most people, we made a Will when we had our first child. The solicitor asked us who we would want to become our son’s guardian if we were both to die. It’s not something we’d ever thought about.”

Ben Russell

Other useful links

Sue Ryder

If you would like to find out more our palliative, neurological and bereavement support, visit [sueryder.org](https://www.sueryder.org)

Our care

Find your nearest Sue Ryder hospice, palliative care hub or neurological centre at [sueryder.org/local](https://www.sueryder.org/local)

What to do if someone has died

Although this is likely to be a very emotional time, there are still some formal things that need to happen. Our website has information on what needs to be done after a loved one dies [sueryder.org/after](https://www.sueryder.org/after)

Coping with grief

Grief is a normal yet often overwhelming feeling and it is important to know that there is no “standard” way of experiencing loss and no “right” way to grieve. Our website has information on coping with death [sueryder.org/coping](https://www.sueryder.org/coping)

The Sue Ryder Online Community

You are not alone. If someone you love is dying or has died, our online community is a place to share experiences, get things off your chest, ask questions and chat to people who understand. Visit us at [sueryder.org/onlinecommunity](https://www.sueryder.org/onlinecommunity) We also provide Online Bereavement Support where you can talk to a trained bereavement counsellor via video chat from your home.

A supportive community

In the midst of grief, Wynne Barrett found the support she was looking for from the Sue Ryder online community. Thankfully, she found kindness in the form of new friends, who understood exactly what she was going through.

“The first few weeks you are just ‘gutted’ basically, the physical and emotional pain you are experiencing is just overwhelming. I started using the Sue Ryder online support, I wanted to talk and explain things to a neutral audience.

“It’s not just the emotional support but also the very practical advice like ‘what should I do with the ashes?’ that really helps coming from people who have been there who can share this experience with you. I found sharing with other people helps to reduce the grief.”



“On my Mum and Dad’s 39th wedding anniversary, staff helped her come home for a few hours to celebrate with us. That was the last time she got to come home, but we cherish that day and are so thankful to Wheatfields, the nurses and the doctors who made it happen, and allowed us to have one last day in our home as a family.”

India Haresign

For more information about Sue Ryder

call: **0808 164 4572**

email: supportercare@sueryder.org

visit: sueryder.org



[/SueRyderNational](https://www.facebook.com/SueRyderNational)



[@sue_ryder](https://twitter.com/sue_ryder)

This document is available in alternative formats on request.

The information contained within this leaflet is derived from our extensive experience of providing care.

To share your feedback on this leaflet, please contact healthandsocialcare@sueryder.org



Sue Ryder is a charity registered in England and Wales (1052076) and Scotland (SC039578).
Ref No. 06765 ©Sue Ryder, January 2019.
This product will be reviewed in January 2022.



**palliative,
neurological
and bereavement
support**