



THE ROUGH GUIDE TO THE END OF LIFE



**Marie
Curie**

Contents



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FOREWORD

- INTRODUCTION
- ABOUT MARIE CURIE

1 PREPARING FOR THE END OF LIFE

- PLANNING AHEAD
- LET'S TALK ABOUT IT
- HOW WILL I REACT?

2 THE LEGALITIES

- MAKING A WILL
- POWER OF ATTORNEY
- SOCIAL MEDIA AND ONLINE ACCOUNTS

3 OTHER THINGS TO CONSIDER

- PLANNING A FUNERAL
- LEAVING BEHIND MEMORIES
- ORGAN DONATION
- PETS

4 CARE – WHAT, WHO, WHERE?

- WHAT IS PALLIATIVE CARE AND END OF LIFE CARE?
- MEET THE PALLIATIVE CARE TEAM
- WHERE'S BEST?

5 IMPORTANT DECISIONS

- ADVANCE CARE PLANS
- REFUSING TREATMENT

6 WHAT NOW?

- COPING WITH A DIAGNOSIS
- TALKING ABOUT IT
- WHAT WILL CHANGE?
- OFFERING SUPPORT

7 WHAT TO EXPECT AT THE END OF LIFE

- FINDING A PURPOSE
- UNDERSTANDING BEREAVEMENT AND GRIEF
- MEMORIES LIVE ON

Foreword

Like any journey, life eventually comes to an end – for all of us. It's something we know in our hearts, even though it can be hard to think and talk about. Some of us won't know it's coming. But most of us will. As a palliative care doctor, I know only too well that we all deal with the awareness of death differently. While some of us like to plan, others prefer to take each day as it comes.

Something I've seen time and time again is just what a difference it can make when people get the right support as they approach the end of their lives. The uncertainty can be what's truly scary. And when we have a chance to understand what may be down the road, to talk about our fears and discuss our questions with people who can help, the relief can be huge.

A good end of life experience means having the right care, support and systems in place, so you feel protected and safe, and your carers and loved ones understand what support is available. Where pain and other symptoms are managed, personal priorities are respected and you get to live well right up until you die. It will look different for everyone, as it depends on what matters most to you.

There's so much information out there on preparing for birth, but not very much to help us at this most profound point in our lives. That's why Marie Curie has supported Rough Guides to create *The Rough Guide to the End of Life*, a practical guidebook to help.

I work in the Marie Curie Hospice, Bradford, supporting people towards the end of their lives to live the best life they can right up until the very end, whatever their illness. I recently met a gentleman at our motor neurone disease (MND) clinic. As he was leaving, he turned and said: "This service is great. You don't feel like you're going down the road on your own".

When we can see the way ahead, we know what to pack to make it as comfortable as possible. My hope is that, like the care we provide at Marie Curie, this book will be with you to the end, helping you to prepare for whatever's around the corner. If you're familiar with what support is available long before you need it, it might just help make the news that there's no cure – if and when it comes – a little less frightening.

Dr Sarah Holmes
Chief Medical Officer, Marie Curie

Introduction

This publication was created by Rough Guides in partnership with Marie Curie, the UK's leading end of life charity. It is intended as a practical source of guidance and support for everyone, and as a go-to reference to help us all feel better prepared for the end of life.

There are countless manuals and guidebooks that prepare us for everything that life might throw at us, but there are hardly any that cover death. This is understandable. After all, thinking about our own or our loved ones' end of life can be uncomfortable and upsetting. However, current statistics show that someone dies every five minutes in the UK without receiving the care and support they need. Rough Guides and Marie Curie want to help change that by starting the conversation about death, with this publication aiming to shine a light on the help and support available to us all.

We hope that this guide will help readers to navigate a difficult journey more easily. It is designed to be read in bite-size chunks, with cross references to other relevant sections, if, and when, you want to know more, and features information about all the things you might want to think about when preparing for the end of life, as being prepared can make it much easier to cope. It also offers advice on what needs to be done or thought about, how to go about it and where to find support every step of the way.

We suggest you start with the sections you are most comfortable reading and remember – it doesn't have to be read from start to finish. As you read through, you will find links in bold font that will direct you to different sections of the guide where you may want to find out more, as well as to websites that will be a useful source of information.

It may also be reassuring to know that you are not alone and that there are many people throughout the UK who are affected in the same way every single day. We share some of their stories throughout this guide and we hope that their experiences will be a source of inspiration and comfort in times of need.

Whether you are family, a carer or a friend, consider reading this guide long before any difficult diagnosis. Familiarise yourself with the care and support that is available to you should it ever be needed – and tell others about it too. Together we can strive to ensure that everyone has the best possible quality of life at the end of life, leaving their loved ones to focus on and remember the happier moments in the future.

About Marie Curie



About Marie Curie

Founded in 1948, Marie Curie is a UK-based charity that offers a full range of support services for people diagnosed with a terminal illness and to their family, friends, carers, and other people close to them. Backed by an expert team of professionals, they offer support and care for anyone who is affected by illnesses such as Alzheimer's (and other forms of dementia), heart, liver, kidney or lung disease, motor neurone disease, and advanced cancer.

Marie Curie's expert care is driven by world-leading research and 75 years of experience. Thanks to donations, fundraising efforts, campaigning, and volunteer work, they are proud to fund more palliative care research and employ more palliative care nurses and healthcare professionals than any other charity in the UK. Marie Curie provides care at home and across their nine hospices located throughout the UK (see [map](#)), alongside practical and emotional support over the phone (0800 090 2309) and **online**.

A constant advocate for change and improved care services, Marie Curie is committed to ensuring the best end of life journey for all. Whatever the illness, and wherever you are, Marie Curie is with you to the end.



“I think this Rough Guide will be helpful for anyone going through bereavement.”

AJ Pritchard

One of the most significant deaths in TV presenter, dancer, and choreographer AJ Pritchard's life was his grandma, Angela, who died while he was filming *I'm a Celebrity, Get Me Out of Here* in 2020.

“She had dementia for quite a few years, but was still happy and bubbly and recognised our faces. The hardest thing was coming out of the TV show, and being told by the crew that she'd passed away.

On one side I was prepared – I knew when I went in that she'd had a fall and unfortunately broken her hip. But still, you can never really prepare yourself fully.

My parents came up and we sat there, and in the most healthy way just cried, laughed, were happy, sad – all the emotions that you have in 24 hours.

I think this Rough Guide will be helpful for anyone going through bereavement.

It's really important to have a concise point of reference. You want to know how others deal with things and whether a particular feeling is common, or, am I normal for thinking the way I am? So having small, valuable bits of information like this is really helpful.

It's important to talk about death. When my brother Curtis and I were younger, we were the only ones who attended the funeral of our classmate. The other children had nightmares about not understanding why she was there one day and wasn't the next. But because myself and Curtis talked about it with adults, we were able to process it differently. Even at that age, I think it made us value life a lot more.

Death is something we fear because it's not understood. If something is in the dark and you don't know what's there and you're afraid of it, shedding a little light on it and talking, it can help change that.”

1 Preparing for the end of life



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Being faced with the finality of the end of life is never easy, whether it concerns you or someone you care about. But being prepared can make it easier to cope. You may not feel like planning ahead, but doing so can help you to feel more in control when the time comes. What follows in the next chapters is some practical information about some of the things people need to think about, such as making a Will, care options, understanding feelings, planning and paying for a funeral, bereavement and grief. There is also a wealth of information on how and where to find support every step of the way.

Let's talk about it

Talking with family and friends is a good way to understand what is happening and to process feelings. In general, talking it over will help everyone to feel more in control. Some people will find it difficult to acknowledge or talk about the end of life: this is okay. Let them have the conversation in their own time.

Likewise, if you are supporting someone who is facing the end of life, it's good to let them know that you are there for them whenever they want to talk. For the person who is ill, it can offer them a sense of release or calm to have shared their news.

It's usually best to have difficult and emotional conversations face to face, so you can get a sense of how someone is feeling. Make sure that you choose a time when you will not be interrupted or distracted to broach the subject.



**Every 5 minutes,
6 people die in the UK**

Marie Curie calculation using figures for England and Wales: Deaths registered summary statistics, England and Wales - Office for National Statistics (ons.gov.uk); Scotland: List of Data Tables | National Records of Scotland (nscotland.gov.uk); Northern Ireland: Registrar General Annual Report | Northern Ireland Statistics and Research Agency (nirsra.gov.uk)

1 Preparing for the end of life

How will I react?

Learning that someone close to you or that you care about has a terminal diagnosis can be difficult to hear and people will react differently. Your reaction can vary depending on your personal ways of coping, your support network, and what you understand about the diagnosis or illness. You may switch back and forth between these stages (see below) or feel a combination of a few of them at any one time. All of this is entirely normal.

- **Acceptance** – reaching a stage where you accept the diagnosis and prognosis can take some time. It may involve lots of conversations with family, friends and professionals. You may also feel many other emotions before you reach acceptance. People who accept their situation often feel a greater sense of calm and start to have more positive thoughts. Acceptance may also help you feel more in control of the situation.
- **Denial** – it may feel hard to come to terms with the diagnosis or prognosis, so pushing it away might feel easier. But this can take its toll emotionally. If you ignore the situation and your feelings, it can prevent you from getting the support you need.
- **Bargaining** – you may feel like saying “I’d do or give anything if this illness could be taken away”. If you are struggling to come to terms with the diagnosis, it might help to talk about it with someone. This could be with a health or social professional, or someone close to you.
- **Looking for meaning** – you may start to think about life and its purpose. As you reflect on things that are important to you, you may look to an existing or new spiritual belief, faith or philosophy that helps you cope with your emotions and any questions you have. Alternatively, you may start questioning any beliefs you held previously. Sometimes it helps to talk with a spiritual advisor, or community or faith leader, to help reconcile any worries or questions you may have.





“I learnt through speaking to Marie Curie the little mantra of ‘do whatever keeps you calm.’”

Jamie (on left)

Jamie received support from Marie Curie’s Support Line and Companions service.

“I called the Marie Curie support line on Christmas day last year. At that time, I was really struggling to spend any time with my dad at all. Dad was bed-ridden, so I was trying to figure out how I was going to sit in a room with him all day.

After we did presents together, I snuck back upstairs and poured my heart out for half an hour. I remember being called for lunch. It was like I was going to face the most intense challenge you could ever imagine – sitting with my dad while he’s very ill and knowing that it’s our last Christmas together.

When I went back downstairs, I ended up staying there for the entire day. It really helped to let it all out to Marie Curie, even just for that half an hour. I felt better able to face the rest of the day. After that, I had it in my back pocket – if I needed it, the Support Line was available to speak to.

I learnt through speaking to Marie Curie the little mantra of ‘do whatever keeps you calm’, so I got into this routine of playing computer games and listening to podcasts. It’s the same series mostly every day, which gives me a little bit of peace and humour.

I now speak to Michelle from Marie Curie’s Companions service. It helps to know there’s somebody who’s going to call you once a week and who cares. Our conversations aren’t too in depth about my dad. It tends to be a bit more light-hearted, like what am I watching on TV. Sometimes it’s important to have somebody you can speak to about the everyday things, instead of going over the same anxiety issues.”

2 The legalities



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It may feel overwhelming at first when you start to think about everything that needs to be done. One really important factor is dealing with the legalities. What follows is a step-by-step guide to making a Will and understanding Power of Attorney, as well as the implications of and what to do with online accounts.

Making a Will

It is a good idea to have a Will in place before you die. Many charities, including Marie Curie, offer Will-writing services and sometimes these are free. You may want to leave something to charity, but you shouldn't feel pressured to. If you have one, your trade union may also offer a free Will-writing service. To find out more about Marie Curie's Will-writing service, visit this [page](#).

SO YOU DON'T HAVE A WILL...

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 is called 'Intestacy' or the 'Rules of Intestacy'. The law protects spouses, civil partners and children but it doesn't protect unmarried partners or step-children. Anyone who inherits from you in this way will have to sort out your affairs when you die.



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2 The legalities

Ways to write a will

Ask a solicitor

A solicitor (sometimes called a lawyer) will make sure your Will contains the right information and is valid. Solicitors charge a fee to write or check a Will. Check the cost of their services before using one. It can help to use a solicitor if your affairs are complicated: for example, if you share a property with someone who isn't your spouse or civil partner, or have an ex-spouse or children from a previous relationship who may make a claim on your Will.

Write your own Will

You can write your own Will, but you must use legal wording to make it valid. You can ask a solicitor to help you write it or check it for you. The Will must be signed by two adults, known as **witnesses** and you must sign it in front of them. Important: your witnesses can't be beneficiaries of your Will (i.e. people you plan to leave things to), or their spouse or civil partner.

Use a Will-writing service

The cost of Will-writing services varies so ask for a quote from more than one party before you commit. It's important to make sure the company you use is either regulated by the Solicitors Regulation Authority or belongs to the Institute of Professional Will Writers or to the Society of Will Writers to ensure that your Will is legal and valid.

GIFTS IN YOUR WILL

Marie Curie knows the end is hard to talk about. Someone dies every 5 minutes in the UK without the end of life care they need. A gift in your Will to Marie Curie brings better end of life care to all. Get your free **Will Guide from Marie Curie**.



2 The legalities

Power of attorney

A Power of Attorney is a legal document that lets you choose a person (an attorney) to make decisions on your behalf regarding your health and social care, where you live, your finances and/or your property. You can choose more than one person and they must be 18 or older if you live in England, Northern Ireland or Wales, or over 16 if you live in Scotland. You can also appoint a firm to do this, such as a solicitor or an accountant – they will charge a fee.

There are three **Types of Power of Attorney**. You can also choose more than one type. You can download the forms **online**. In England, Scotland and Wales, you need to register the Power of Attorney before you use them. In Northern Ireland, you need to register the

Power of Attorney when someone loses capacity to make decisions. Across the UK, there is a fee to register them.

When you create your Power of Attorney, you must have **mental capacity**. Some people lose the ability to make certain decisions for themselves if they become more ill or if they have a condition that affects their memory or thinking; this is called lacking mental capacity. You are assumed to have mental capacity to make a decision unless a professional healthcare assessment states otherwise.

Note that you can cancel or change a lasting Power of Attorney at any time while you have mental capacity.



2 The legalities



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Types of power of attorney

Ordinary or general Power of Attorney

Ordinary or General Power of Attorney (called a General Power of Attorney in Scotland and Northern Ireland) is a way to transfer control of finances temporarily, but it stops working if you lose the capacity to make decisions, or either you or your attorney dies.

Financial Power of Attorney

A lasting Power of Attorney for property and financial affairs allows someone to make decisions about your money and property on your behalf. This is called a continuing Power of Attorney in Scotland and enduring Power of Attorney in Northern Ireland.

You can choose whether you want the person to be able to make decisions from when it's registered, while you still have capacity or only if you lose mental capacity (see **Power of Attorney** for more on this).

Lasting Power of Attorney

A lasting Power of Attorney for health and welfare decisions (called a welfare Power of Attorney in Scotland) gives someone else the right to make decisions on your behalf regarding medical treatment or moving into a care home. It also allows them to access your health records. It can be used in England, Wales, and Scotland. There's no equivalent in Northern Ireland – contact the Office of Care and Protection (OCP) for more information.

If there is an Advance Care Plan in place, this should be included here also. A lasting Power of Attorney ends automatically when you die. From that point onwards, your executors will look after everything.

WHAT HAPPENS IF THERE'S NOTHING IN PLACE?

A family member or friend can apply to be a deputy at the Court of Protection to be able to act on your behalf. In Northern Ireland, they can do this at the Office of Care and Protection and in Scotland at the Office of the Public Guardian. But be warned, this can be both a difficult and expensive process.

2 The legalities

Social media and online accounts

When someone dies, grieving people often have to decide what to do with their loved one's online accounts. In an ideal world, we'd all decide what to do with our online accounts long before we die. The sad reality is many people never consider the digital legacy they will leave behind. Even if you don't have Facebook, X (Twitter) or Instagram, don't imagine you have no digital legacy. Nearly everyone has digitally stored documents and online accounts, including gas and electricity, telephone, Wi-Fi and TV and music streaming service accounts.

Social media platforms have different options for what you can do. Look at the settings, options or terms of service for each account you have.



Companies have different rules about what happens to your account when you die and whether someone else can access them. If you need more help, you can contact **Digital Legacy Association** who can advise on what can be done with various accounts. You can also add preferences for your social media accounts to your Will (see **Ways to Write a Will**) or in a separate letter.

Online banking

Bank accounts are considered as part of your estate (money, possessions and property). This means they'll be managed by the people who handle your Will after you die, and it will be up to them to notify your bank. It's helpful to keep an updated list of your online bank accounts in a secure place alongside your Will. Do not give your login details to anyone before you check with your bank first.



3 Other things to consider



© Philip Hardman/Marie Curie

Planning a funeral

Some people only start thinking about their funeral when they're diagnosed with a terminal illness or nearing the end of their life. But you can start thinking about it at any time. A funeral director can advise you and help you to plan. Things to consider include whether you would like to be buried or cremated, specific clothing, flowers, and music you would like or any final words you might like to be read out at the service. Once you've decided what you want, it's helpful to let the people closest to you know your wishes.

“Dad wanted to plan everything. He knew exactly how he wanted his funeral, he knew what music he wanted, all his assets sorting out, he wanted to give everything away before he died. He got a lot of comfort from having control over those final choices.”
Isabelle, whose dad was cared for in a Marie Curie hospice

PAYING FOR A FUNERAL

You can put plans in place to pay for your funeral in advance. This can help your family and friends to make arrangements as they may not have immediate access to any money you have left. Consider a pre-paid funeral plan, taking out insurance or leave money in your estate to cover these costs. People receiving certain benefits can apply for a Funeral Expenses Payment (known as a Funeral Support Payment in Scotland) from the government at www.gov.uk.



**Every 5 minutes
someone in the UK
dies without the care
and support they need**

3 Other things to consider

Leaving behind memories

It can help those left behind to have things to remember a loved one by.

Some ways this can be done include:

- creating a memory box filled with photos, letters and mementos special to you
- creating video or voice messages
- writing cards for special birthdays
- writing out family recipes
- writing letters for future big events such as weddings, going to university, getting a first job, and dealing with heartbreak
- leaving gifts to mark special occasions
- making photo albums or scrapbooks
- making drawings or recording a song
- using a platform such as **MyWishes** to leave digital messages for people
- recording an interview with an organisation such as **Stories for Life** featuring your life story

“Wayne arranged his own funeral, wrote his eulogy and a beautiful reading for me. He knew I’d be bereft and did everything he could to comfort me even after he’d gone. After his death I found a little note he’d written for me in my bag.” Tracey, whose husband Wayne died from heart failure



3 Other things to consider

Organ donation

Donating your organs, tissue, or body after you die is a personal choice. You can donate organs such as your kidney, heart, liver, small bowel, pancreas, or lungs. You can also donate your skin, bone, tendons, part of your eyes (corneas), or heart valves. You can choose to donate all of your healthy organs and tissue or just some of them. Your doctor can advise you if your condition prevents you from becoming a donor.

SAVE A LIFE

In the UK, you are automatically considered for organ and tissue donation if you're over 18 when you die. An organ or tissue donation can improve someone's health or even save their life. If you prefer to opt out, you must register this decision **online** or by telephone in the country in which you are resident (T 03001 23 23 23).

Pets

As your condition worsens, you may need help minding your pets. Ask friends and family if they can help. For dog owners, you can find a dog walker locally or through the **UK Dog Walker Directory** and **Borrow My Doggy**. **The Cinnamon Trust** can help with many pets, including cats and dogs.

VISITORS ALLOWED

Did you know that if you need to go into a hospice, your pets may be allowed to be brought in to visit you there? Check with your local hospice for their policy on pets.

Organisations that can help with pets

Many of the following organisations listed below can help with rehoming pets. Some charities may be able to offer financial support to help care for pets, too.

- **Blue Cross**
- **Battersea Dogs & Cats Home**
- **The Cinnamon Trust**
- **Cats Protection**
- **PDSA**
- **RSPCA**
- **SSPCA**
- **The Dogs Trust**

WANT TO KNOW MORE?

Marie Curie has free information and **support** about dying, death and bereavement, available online, in print, and over the phone. From first questions after a terminal diagnosis or information about accessing services, to experiences shared by carers, guidance on planning for death, and support for grief.

"Everything on the Marie Curie website was in one place with support on finances, funerals, Wills and all the practical information you need when you are in that situation. It removed the worry and gave me all the information to protect my family's future. I arranged a Will through the site and logged all my social media log-on details." Simon, living with kidney cancer

4 Care – what, who, where?



© Philip Hardman/Marie Curie

Palliative care

Anyone living with a terminal illness will be offered physical, emotional, psychological and practical support, including symptom management. This type of care is called palliative care. Palliative care aims to make a person feel supported and comfortable. It can be offered at any point following a terminal diagnosis.

“He was getting support from the palliative care team for eight years – not needing them all the time, but dipping in for pain relief and talks and things.” Mair, whose husband died in 2023

IS PALLIATIVE CARE THE SAME AS END OF LIFE CARE?

No. Although it can include end of life care, palliative care is much broader. Having palliative care doesn't necessarily mean that someone is likely to die soon – some people have palliative care for years.

What is end of life care?

End of life care is treatment, care and support for people who are thought to be in the last year of life. End of life care aims to help a person to live as comfortably as possible in the time they have left. The timeframe can be difficult to predict, so some people might only receive end of life care in their last weeks or days, while others may have end of life care for longer. It can be given in a variety of places, including at home, a hospital, a care home or nursing home or a hospice. Your GP is the best first point of contact.



© Philip Hardman/Marie Curie

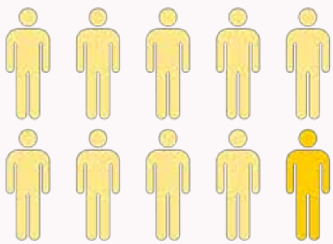
4 Care – what, who, where?

Meet the palliative care team

After being diagnosed with a terminal illness, a number of health and social care professionals will get involved to offer care and support. This is the palliative care team. The professionals involved will depend on the care and support needed. They are usually community-based and work outside of a hospital or hospice. Ideally, they should be involved as early as possible following a diagnosis. When specialist palliative care professionals are needed, they will be referred by a GP or district nurse.

GPs

If the person who is ill lives at home or in a care home, their GP will be the main point of contact. A GP will prescribe medication, help to manage symptoms, discuss wishes and needs and offer information about the illness. They can also advise on the available support services and will work alongside the district nurse and the palliative care team to provide the right care. They can also advise on local hospices.



**9 in 10 people
dying in the UK today
would benefit from
palliative care**

Estimates of Population-level Palliative Care Needs in the UK Pre-Pandemic and During the Pandemic.
Fanton, Wynne & Finucane, 2023 (awaiting publication)

District nurse

A district nurse can help if someone cannot leave their house for appointments or treatment, and requires care at home. They may be involved with organising care at home, providing medical care, such as managing symptoms or changing dressings, and ordering equipment, such as a commode or adjustable bed. They can also arrange for other people to get involved, such as a physiotherapist, a Marie Curie nurse or a care worker. For more on Marie Curie's nursing services, see **box**.



© Philip Hardman/Marie Curie

Pharmacists

Pharmacists can support patients by dispensing medication and working alongside the palliative care team. Some pharmacies have palliative care pharmacists who can offer more specialised support, such as advising on the management of any symptoms and suggesting local palliative care services.

4 Care – what, who, where?

Marie Curie Nurses

Marie Curie nurses or healthcare assistants can help when the person who is ill is still living at home. They can advise on the medication that has been prescribed and assess the person's needs. They can also help create a care plan. To get care or support from a Marie Curie nurse, you will need to go through the district nurse or GP. This service is not currently available in every area of the UK.



Marie Curie is the UK's largest charitable funder of palliative care research

UKHealth Research Analysis 2018 - HRCS

Healthcare assistants

Healthcare assistants are trained professionals who can help with washing and dressing, staying mobile and taking medication. Marie Curie has trained healthcare assistants in some areas of the UK. If you think you would benefit from one, you can contact the district nurse or your GP.

MARIE CURIE'S HOSPICE AT HOME SERVICE

Marie Curie can help people get the care they need at home. Their nurses, healthcare assistants and specialists provide medical help and emotional support in the comfort of the patient's own home. They also support family, friends and caregivers by providing practical information, offering reassurance and letting them take a break.

"Marie Curie gave us peace of mind. Just having that person there who you trusted implicitly – and they were caring about me as well as about Neil. I could see that he had trust in them as well, which meant everything to me. There really are no words to describe the calm, peace, love and care that pervaded our home while they were there." Georgina, who cared for her husband Neil



4 Care – what, who, where?

Social workers

Social workers offer non-medical support, such as arranging meals to be delivered or help in getting the home adapted to the patient's needs. If the person who is ill wishes to remain at home, they, a member of the palliative care team, or a family member or friend, can request a social worker to assess their needs. Equally, all **carers** are entitled to a carer's assessment to help identify the support needed.

Doctors or consultants

A doctor or consultant is usually the professional who manages the terminal illness and condition, including any tests or medical treatment.

Clinical nurse specialists (CNS)

A terminally ill person may have a Clinical Nurse Specialist (CNS), who will be their main point of contact regarding their care. The patient will usually meet them after their diagnosis. The CNS will make sure that everyone has the information they need about the diagnosis, and they can guide everyone involved through any complex information or questions. They also offer practical and emotional support and can put you in touch with other services, such as palliative care services, that may be helpful.

Occupational therapists

Occupational therapists focus on your ability to do everyday tasks. They will do an assessment of the current situation, including whether the patient's home needs any adaptations and if any equipment, such as a wheelchair, would be helpful – and can arrange for this to be put in place. A GP or the district nurse can do a referral, as can your local council or Health and Social Care Trust.

Physiotherapists

A physiotherapist aims to help with any movement or mobility problems following a patient's diagnosis. These may be caused by the terminal illness or any symptoms the person is having. A physiotherapist can teach the patient some gentle exercises to manage or ease mobility issues. A GP or the district nurse can do a referral.



Certain groups face significant barriers in accessing palliative care

including people from minoritised ethnic groups, LGBTQ+ communities, travellers, and those living in poverty, poor housing, alone, in prison, with dementia or a learning disability

Tobin J, Rogers A, Winterburn I, et al. (2021) Hospice care access inequalities: a systematic review and narrative synthesis. *BMJ Supportive & Palliative Care* Published Online First: 19 February 2021. doi: 10.1136/bmjspcare-2020-002719; Calanzani N, Koffman J, Higginson IJ. (2013) Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK: Demographic profile and the current state of palliative and end of life care provision. London: Marie Curie

4 Care – what, who, where?

Where's best?

Care at home

Many people prefer to be cared for at home. This may be because they want to be surrounded by their loved ones or be in familiar surroundings. If they need care from health and social care professionals, it's important to think about how this will work in the home. Your GP can advise what care and support is available in your area. Your GP will involve a district or community nurse who will organise and coordinate care at home.

The GP or district nurse may also contact your local social services if you need help with things like getting dressed, washing and eating. Social services can also help with adaptations or equipment for your home, which make it easier to perform day-to-day tasks.

If a family member or friend is the carer, they should consider whether they're able to provide the level of care that is required. A carer's assessment (called an Adult Carer Support Plan in Scotland) will assess their needs as a carer and look at what support they might require.



Half a million people in the UK are caring for someone with a terminal illness

Grande, G., Stajduhar, K., Acun, S., Toye, C., Funk, L., Addington-Hall, J., Todd, C. (2009). Supporting lay carers in end of life care: current gaps and future

MARIE CURIE COMPANIONS

Companion volunteers focus on what's important to the person who is ill and those close to them. It might be accompanying them to appointments, being there to listen to how they are feeling without judgement, or stepping in so family or carers can take a break. Companions provide the **emotional and practical support** required – at home, in hospital or over the phone.

"Marietta started coming to visit my dad, which was brilliant. She would get him up and take him out, because dad can't go out on his own. She keeps his spirits up and is part of the team that keeps him going. We really wouldn't have managed so well without all the support we've had from Marietta and Marie Curie." Mandy, whose dad got support from Marietta, a Companion Volunteer



4 Care – what, who, where?

Care in a hospice

Hospices provide free palliative and end of life care. The aim of palliative and end of life care is to improve a person's quality of life. You may think that people only go to a hospice to die, but this isn't necessarily true. Hospices can provide care for anyone with a terminal illness, sometimes from the time they receive a terminal diagnosis. Hospices are run by a team of professionals, which can include nurses, specialist nurses and doctors, physiotherapists, occupational therapists, complementary therapists, social workers and a chaplaincy/spiritual care service. Some hospices also offer day patient care, and others can offer care services in the home.

MARIE CURIE HOSPICES

Hospices help people with any illness they're likely to die from, and the people close to them can receive the support they need.

From medical and physical support to psychological and emotional care, whatever the illness, and at whatever stage of the journey, Marie Curie Hospices can help a person to live the best life possible, right to the end.

Marie Curie Hospices have an entire team of professionals on hand, including specialist nurses and doctors, physiotherapists, occupational therapists, complementary therapists, and social workers. **Find out more about Marie Curie hospices here.**



Map showing locations of Marie Curie's UK-wide hospices

4 Care – what, who, where?

Hospital care

If a person becomes unwell or needs tests or treatment, they may have to go into hospital. Some people are referred to a hospital by their doctor or nurse. Others are admitted to hospital in an emergency. Decisions about their care might be made by staff in Accident and Emergency (A&E) when they first arrive in the hospital. They may then be transferred to another unit. Some hospitals have specialised Palliative Care Units, sometimes called Supportive Care departments. The staff can provide emotional support and information to family and loved ones.

PRIVACY AND DIGNITY

A calm and private environment might be comforting and help a person to cope with any physical symptoms, thoughts and feelings they are experiencing and allow them the privacy to speak openly with friends and family. Dignity can mean different things to different people. It might be maintaining one's independence for as long as possible, or it might mean being cared for by people who treat them with respect and kindness. It's important to think about what this would be like in different settings.

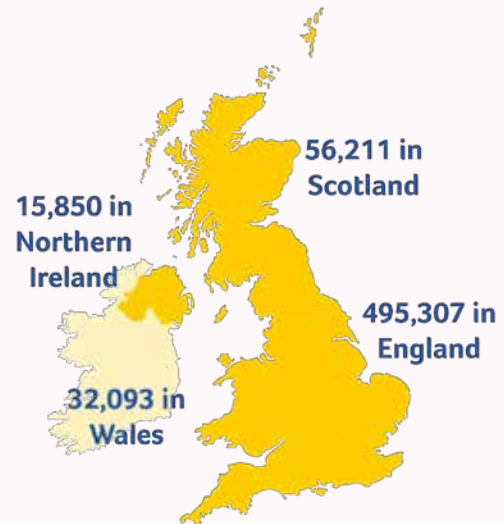


4 Care – what, who, where?

Residential care homes and nursing homes

A care home or nursing home might be the right choice if a person can no longer manage in their own home. In a care home, staff are on duty day and night. The staff are professional carers, but they're not nurses. They provide help with washing, dressing and meals. Residential care homes usually offer long-stay care, but they may also offer short-stay or respite care to support family and carers. A nursing home is similar to a residential care home, but there are trained nurses on duty.

Number of deaths that would benefit from palliative care by nation:



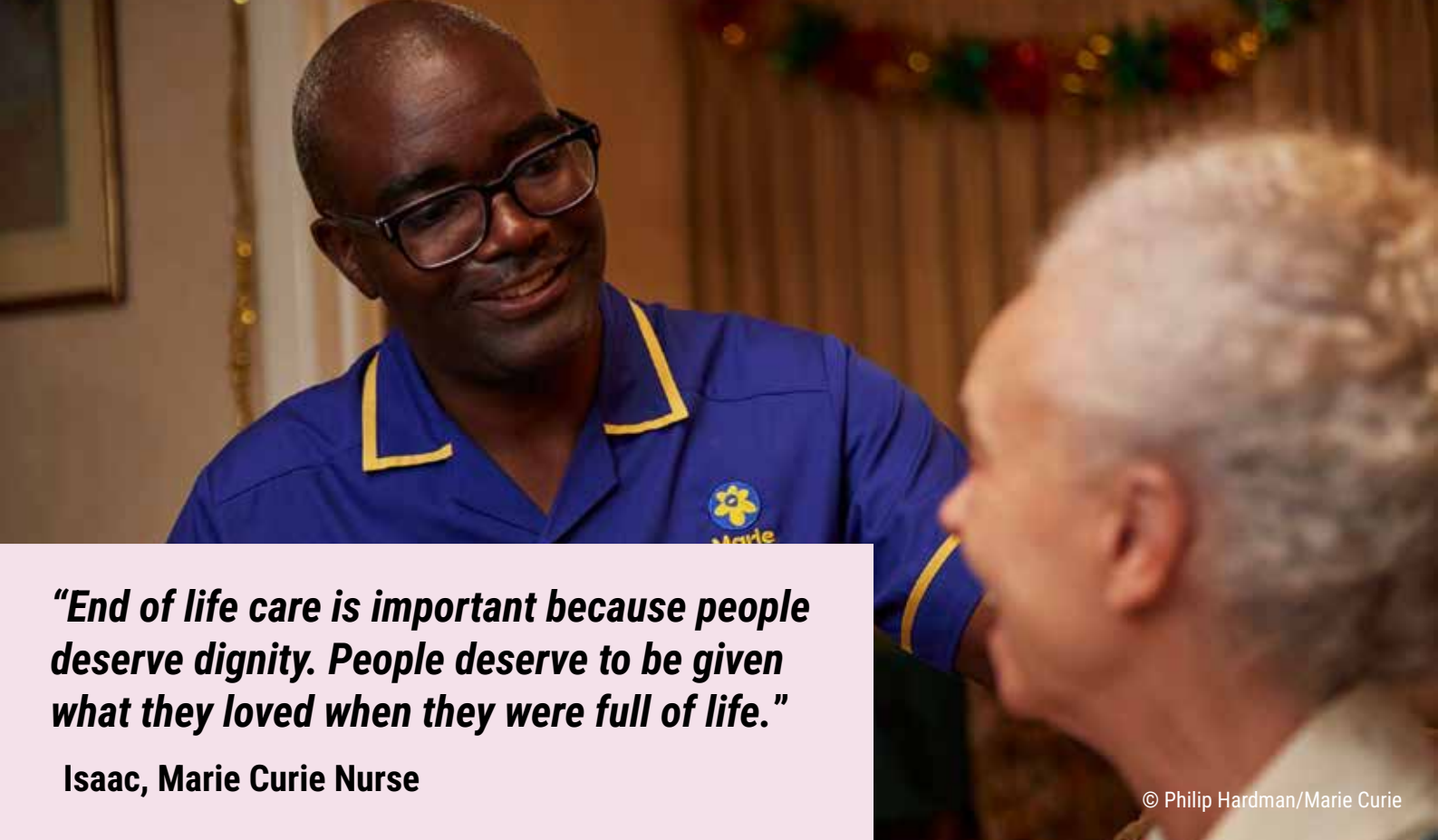
Note: includes those that do receive palliative care (not a figure for unmet need).

Estimates of Population-level Palliative Care Needs in the UK: Pre-Pandemic and During the Pandemic.
Fantoni, Wynne & Finucane, 2023 (awaiting publication)



PAYING FOR RESIDENTIAL CARE HOMES AND NURSING HOMES

In some cases, your local council will cover some or all of a person's residential care home or nursing home costs. This will vary depending on their healthcare needs, where they live and how much money they have. Most people will be expected to pay something towards their residential care. Your local social services team can assess this. If the person who is ill lives in England and Wales and has a complex healthcare need, they may be eligible for free care under the NHS continuing healthcare scheme, which can include paying for care home fees.



“End of life care is important because people deserve dignity. People deserve to be given what they loved when they were full of life.”

Isaac, Marie Curie Nurse

© Philip Hardman/Marie Curie

Isaac is a Marie Curie Nurse, getting to the people who need him as quickly as possible to provide urgent hospice care at home.

“We are dealing with various scenarios every shift. We mostly attend to pain, which is the most common symptom at the end of life. We are called to go and check on patients, assess and see what medication to give. We set up syringe drivers, which have been prescribed by the doctor, and continue to monitor them.

We do personal care, and we give reassurance because it is a difficult time, especially for the families, who often need somebody just to talk to. They need someone to reassure them and support them, not only at the point where the patient is at the end, but even after that.

End of life care is important because people deserve dignity. People deserve to be given what they loved when they were full of life.

They wanted to lead their life independently, in a certain way, and therefore we should respect that and give them the opportunity to choose how they live, even at the end of their lives.

I feel a lot of fulfilment in my work. I feel content when someone says ‘thank you’. It brings a lot of joy to me to know that I have impacted someone’s life who was at a very vulnerable stage, who needed care and who needed to be given dignity.

There is a perspective that Marie Curie is just for cancer, but no, we offer a lot more than that. We care for young people, old people, cancer patients, patients with other terminal conditions. We help with the wellbeing of the family, not only the patient.”

5 Important decisions



Advance care planning

Advance care planning (called **anticipatory care planning** in Scotland) is the process of making decisions about what kind of care a terminally ill person would like to have in the future. All plans are individual. However, they are not legally binding. Doctors or nurses can discuss what sort of care might be best now and in the future. Remember, a plan can be changed at any time and should be reviewed regularly to ensure it still meets that person's wishes.

What is in an advance care plan?

An **advance care plan** usually includes things such as how and where a person would like to be looked after, any spiritual or religious beliefs, who they want to spend time with, who their doctors or nurses should talk to if they don't have the mental capacity to make decisions or the name of their lasting Power of Attorney, how they would like practical matters dealt with, such as the care of a pet and what they would like to happen to their body after they die.

Having conversations with the healthcare team and loved ones will help to create a plan that is right. An advance care plan can include an advance decision to refuse treatment.

PAIN MANAGEMENT

For many people, being free from pain and discomfort is an important factor when deciding where to be cared for. Sometimes pain and discomfort can be managed well at home or in a care home, with support from family, friends, and health and social care professionals. Some people might need specialist care in a hospice or hospital to manage their pain effectively. You can talk to your GP about what options there are for you and the best way to manage any pain.

5 Important decisions

Advance decision to refuse treatment

An **advance decision to refuse treatment (ADRT)** is a written decision by someone to refuse a specific type of medical treatment. It's sometimes called an "advance decision" or "living will". In Scotland, it's called an **advance directive**. An ADRT can be part of your advance care plan, but you need to write it in a certain way, and it will need to be signed by the person who is ill, as well as a witness. It will only come into effect if a person loses the ability to make decisions about their own treatment. See more on **Mental Capacity**.

In England and Wales, an ADRT is legally binding under the Mental Capacity Act 2005. In Scotland and Northern Ireland, there isn't an act of law, but it's likely to be considered legally binding by a court. In an ADRT, a person cannot refuse care to make them comfortable, such as keeping them warm, clean and safe, and giving them food and water by mouth.

Note that an ADTR cannot request help to end a person's life. It's important to share an ADRT, if there is one in place, with the healthcare team involved.

Do not attempt cardiopulmonary resuscitation (DNACPR) decisions

Cardiopulmonary resuscitation (CPR) is a treatment that aims to start breathing and blood flow in people who have stopped breathing, or whose heart has stopped beating. Some people decide that they don't want to have CPR. CPR isn't always beneficial for everyone and can cause serious complications in some instances. A doctor or healthcare team member can explain what these might include. If a person decides that they do not want to have CPR, it is called a **do not attempt cardiopulmonary resuscitation (DNACPR) decision** or **DNACPR order**. If there is no DNACPR decision in place and CPR is a realistic treatment option, the healthcare team will make a decision about what's in the best interests of the patient.



5 Important decisions

Planning for emergencies

Everyone can plan ahead for what they'd like to happen in a medical emergency, for example, if they become suddenly unwell with an infection or suffer a stroke. One way to do this is by using the **ReSPECT** (Recommended Summary Plan for Emergency Care and Treatment) process, which is being introduced across the UK. A plan may include things such as a DNACPR decision, and whether they want to go to hospital for treatment.



MARIE CURIE'S URGENT HOSPICE CARE AT HOME SERVICE

In some parts of the UK, Marie Curie's Urgent Hospice Care at Home service helps prevent unnecessary hospital admission, allowing people to spend their final weeks at home. Nurses can come to your home or give support over the phone if you need urgent care in the night or at the weekend. They can help to manage your symptoms and give you emotional support. **Find out how you can get support.**

Lacking mental capacity

Some people lack mental capacity – this means that they are not able to make decisions for themselves. This could be because they're not conscious or they have a condition that affects their memory or thinking. It might be temporary or long-term. The healthcare team will try to follow any wishes while they are still able to communicate or that they have discussed or recorded in the past. Note that family or friends won't be asked to make decisions about someone's care unless they're legally appointed to do so, and they have been named an attorney in a lasting Power of Attorney. If there is an ADRT, the healthcare professional will check that it's valid and relates to the present situation. If it is, they will follow the ADRT.



“My progress has only been possible because of all the support around me, and especially the Marie Curie Hospice.”

Kerry

Kerry is living with terminal bowel cancer and has had support from a Marie Curie Hospice.

“Back in 2021, I was feeling very poorly and tired, which is unlike me. I was diagnosed with a rare form of bowel cancer in early 2022.

I had a bad reaction to one of my targeted therapy sessions. I was in very bad pain, so they kept me in hospital for a bit. I was introduced to the palliative care team there – they were fantastic and talked about the possibility of being transferred to a Marie Curie Hospice if there were any beds available. Luckily, a couple of days later, I was able to move there.

With the support of Marie Curie, we sat my children down and explained about the Hospice, how it was a much more comfortable place than hospital, and that mummy wasn't leaving the Hospice – that I would die at the Hospice, which was such a tricky conversation to have with them.

Marie Curie put these activities in place to make memories. One of them was painting each other's hands with our favourite colours and putting our handprints onto pillowcases. So they will all have a pillowcase with my handprint when I'm no longer around.

My progress has only been possible because of all the support around me, and especially the Marie Curie Hospice. They're asking all the time, 'How are you feeling?' or 'Is there anything you want to talk about?' I've never felt that I've had to hold back. I've laughed freely with them, and I've cried freely, and I've asked all sorts of questions – they're just there for you.”

6 What now?



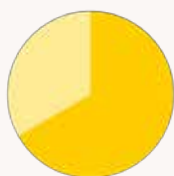
© Philip Hardman/Marie Curie

Living with someone or being close to someone who has been diagnosed with a terminal illness is likely to make the future seem uncertain.

Emotions may change quickly, and at some points, you may experience several feelings at once.

However hard it might be, try not to push these emotions aside. See **Box** opposite for more information on how you might feel.

“It’s like being in the middle of a maelstrom, in the middle of a whirlwind – you don’t see the storm because you’re in the middle. I’m just perhaps at the beginning of being able to see the storm, to analyse, assess and feel emotionally what I’ve gone through.” Barry, whose wife Fiona got support from a Marie Curie Hospice



Two thirds of people over 65 will be living with multiple health conditions by 2035

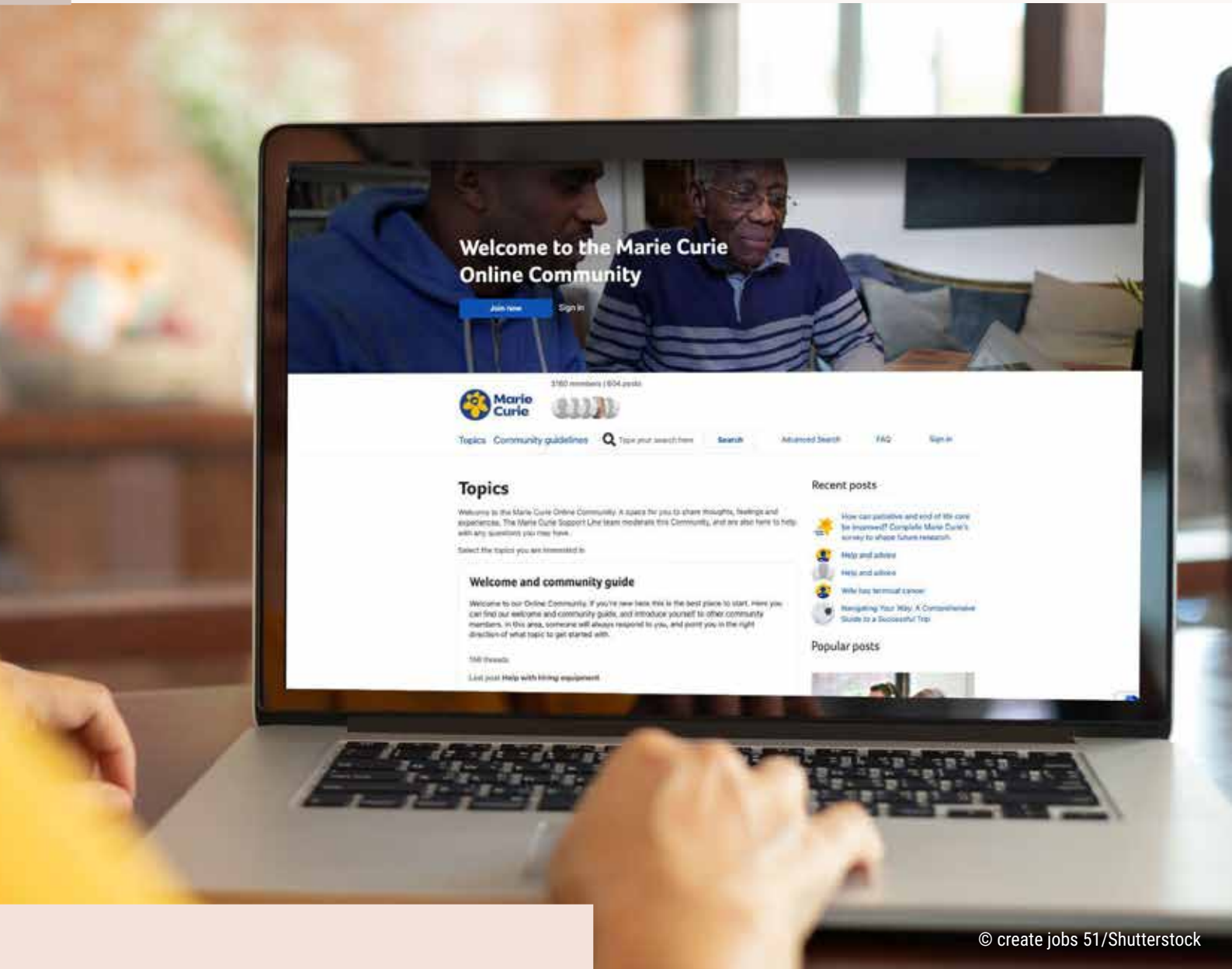
National Institute for Health and Care Research, Multi-morbidity predicted to increase in the UK over the next 20 years

HOW MIGHT I FEEL?

There is no right or wrong way to feel, and everyone reacts differently. You may feel all or some of these emotions at different stages and even go back and forth on some of them before reaching another stage. This is entirely normal.

- Fear – it’s common to feel scared after learning of a terminal diagnosis, either because of a specific fear you have, or simply the unknown.
- Anger or resentment – you may think, ‘Why them?’, ‘Why this illness?’ and feel anger towards the impact it’s having on your life and plans.
- Guilt or regret – perhaps you haven’t had the chance to do something together, or wish you could have done some things differently.
- Sadness or depression – you may begin to feel very low and, if it persists or begins to affect everyday life, it’s important to get professional support.
- Loneliness – you may feel isolated and alone.
- Frustration – you may feel annoyed or frustrated that this is happening.

6 What now?



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MARIE CURIE'S ONLINE COMMUNITY

This **online space** is a platform on which you to share your thoughts, feelings, and experiences with others from the comfort of your own home. It's for anyone affected by terminal illness, including people who are bereaved. It's free and available 24 hours a day. You can share your own experience, give and get support, make connections and share information.

"I think for me, this whole social media thing started because I just wanted to express myself without having to directly talk to anyone. I wanted people to know exactly what was going on. My first video was literally just venting, and then it turned into creating inspiring and entertaining content." Will, living with a terminal illness

6 What now?

Talking to children

Telling a child that someone close to them has a terminal illness and is going to die isn't easy. You may still be processing the news yourself. It can be very difficult to know what to say or how to begin the conversation. Being too optimistic can give children false hope. Ask them what they know already, or whether they've noticed anything different about the person who is unwell. Try to use clear and simple language and give information in small chunks. You may be surprised at how a child or young person reacts to hearing about someone dying. They might seem less affected or upset than you expected, or they might ask questions which you find difficult to answer. It's okay if you don't know the answer – some children just want to know that they are being listened to. Some children might not have any questions at all at first.

CHILDREN'S Q&A

Are they going to die?

Yes, they are going to die. I know it might not feel nice if you're not sure about what's going to happen. I feel that way sometimes, too. What I do know for sure is that I love you very much. Is there anything you want to ask me about?

When will they die?

This is a difficult question to answer. We don't know exactly when they will die, but it could be in a few days/weeks/months.

Can I catch it?

No, you can't catch their illness.

Will they be cured?

The doctors have tried really hard, but there is nothing that anyone can do to cure their illness. But they may give the person some treatment which will help them feel comfortable.

Will they look different?

They might look a bit different, and they might not be able to do as many things as they used to, like play football with you or cook dinner. But they are still the same person on the inside, and they still love you very much.

They will always be your [mum, dad, grandma, for example].

Why do people die?

Some people die because they are very old, or have an illness or an accident which the doctors can't make better.

Does dying hurt?

Having an illness might hurt, but the doctors might give the person medicines to help them with their pain. They can't feel pain after they have died.

Is it like being asleep?

No, it is not like being asleep. When people are asleep, they wake up, but death lasts forever.

Why can't we stop people dying?

There are some illnesses we can fix and some we can't. Some people die because they are very old, and their body has worn out.

When will I/you die?

I don't know the answer to that. Probably not for a long time yet.

6 What now?



MARIE CURIE'S COMPANIONS SERVICE

If you, or someone close to you, is terminally ill, you might be finding it harder than ever to get the support you need right now, and you might be feeling lonely.

Marie Curie's **free Companions service** is here for you. It's a telephone service that provides free ongoing emotional support over the phone with the same person each week, no matter where you live in the UK or whether you've accessed support from Marie Curie before.

You'll be matched with a trained volunteer for a weekly call, on the same day and time, to talk over the phone for around 30 to 40 minutes for up to 12 weeks.

"It's a comfort to me knowing that my wife is getting support. It really has changed her perception of things." Andy, living with terminal cancer

6 What now?

How life might change

Changes to relationships, intimacy and sex are common issues that arise when faced with terminal illness. Sexuality and intimacy mean different things to different people, and a person's feelings and attitude are likely to evolve throughout their life. This is especially true in times of illness and when relationship dynamics change. Sexuality and intimacy are not just about having sex, though. It can foster a feeling of togetherness, of closeness and of being accepted by another person for who you are, as well as offering a sense of reassurance and a distraction and relief from illness. Other benefits of sex and intimacy can include a reduction in stress, anxiety and depression.

Illness can affect how someone feels about themselves and their body image. It might also affect intimate relationships and sexual desire. There's no right or wrong way to be – it's different for everyone. For many people, intimate relationships and sex are important aspects of their life, so when this changes, it can affect their wellbeing, relationship and overall quality of life. Taking on the role of caregiver can also affect how you feel about intimacy and sex, and it might also affect the dynamic of your relationship. Make sure to talk to your partner about your feelings so you can better understand what you both want. You can also reach out to a professional to talk. To read more about this, visit the **Marie Curie web pages on intimacy**.

"We were together for 38 years, but our relationship was totally different. There was no intimacy since she was diagnosed. So, caring for Jacky did have an impact on me. But we did get to spend some quality time. You know, I could have a giggle with her."
Shelley, whose partner Jacky had dementia and Parkinson's disease

Supporting someone at the end of life

The idea of an illness that cannot be cured and is likely to lead to someone's death can feel extremely scary. It can be hard to know what to say, either because you just are not sure or for fear of saying the wrong thing. Try to be led by the person living with a terminal illness, and don't avoid the topic. Be honest, try to avoid giving advice or comparing experiences and most importantly, keep sharing things about your life.

You can support someone at the end of their life in many ways, depending on their wants and needs and what you are able to give. You can offer emotional support by talking to them and spending time with them or practical support offering to help with grocery shopping and chores, or a combination of both.

6 What now?

Coping with feelings

Everyone's experience of caring for someone is different and can involve dealing with a mix of feelings. At times, it can be difficult and upsetting. Other times, it may feel rewarding and bring you closer. There's no right or wrong way to feel and this might change daily. Some common emotions include anxiety, stress, sadness, depression, helplessness, grief, fatigue, loneliness, guilt, shame, frustration, resentment and anger.

When you are caring for someone at the end of life, it may feel as if there aren't enough hours in the day. But making a little time each day for some normality can help. Remember to continue doing little things that you enjoy throughout the day and keep in touch with your friends. You may also find it cathartic to speak with others who are going through something similar. Online forums and virtual chats can be a good way to connect with others.



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At times, the strain of caring for someone at the end of life can develop into depression. Common symptoms of depression, such as feeling tired, forgetful and having a loss of appetite can be caused by the extra demands of caring for someone in these circumstances. If you feel like this may be the case for you or someone close to you, reach out for help. See **Box** below.

GETTING HELP

Talking to someone outside of your inner circle can be a great source of relief and support.

Carer's UK provide an online forum to chat with people who are going through similar experiences. **Sue Ryder** also offers a support service. For those dealing with loved ones who suffer from Alzheimer's and other forms of dementia, the Alzheimer's Society runs an inclusive **Café** which provides a social outing for people living with dementia and their carers, and a supportive environment in which to talk.

For younger carers aged 25 and under, **The Mix** is an online forum where you can chat about how you are feeling and find the support you need. See also **Getting Support**.



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7 What to expect at the end of life



© Philip Hardman/Marie Curie

What you can do to help

As people approach the end of their life, they are likely to experience many different feelings and emotions. Some of these feelings can be comforting, while others can be difficult or upsetting for everyone involved. They may wish to reflect on their values and beliefs and question the meaning of their life. Some people may want to share their thoughts with friends and family, while others may not. They may want to talk about their life or reflect on things alone.

If you are a friend, family member, or in the person's support network, there are things you can do to help. You can consider helping the person to do activities to revisit their past. This could involve seeing old friends, visiting places (when possible) that are important to them or going through old photographs, memories or letters. Ask them questions and engage with their stories and simply let them talk and reminisce if they wish to.

Many people will also feel anxious at some point when they're approaching the end of life. They might feel worried about the possibility of dying. Listen to any worries or concerns with compassion and understanding. If you feel they would benefit from support from health and social care professionals who can look at any underlying problems and talk about different things that may help, do not hesitate to reach out to Marie Curie's **support network**.

TALK IT OUT

Marie Curie's **free Support line** can offer you the support you need to help you when dealing with the end of life. Trained staff, including nurses, can offer practical information and talk you through the different stages and will be able help you understand what to expect. They are also trained to offer emotional support and can offer you advice on different coping mechanisms.



© Philip Hardman/Marie Curie

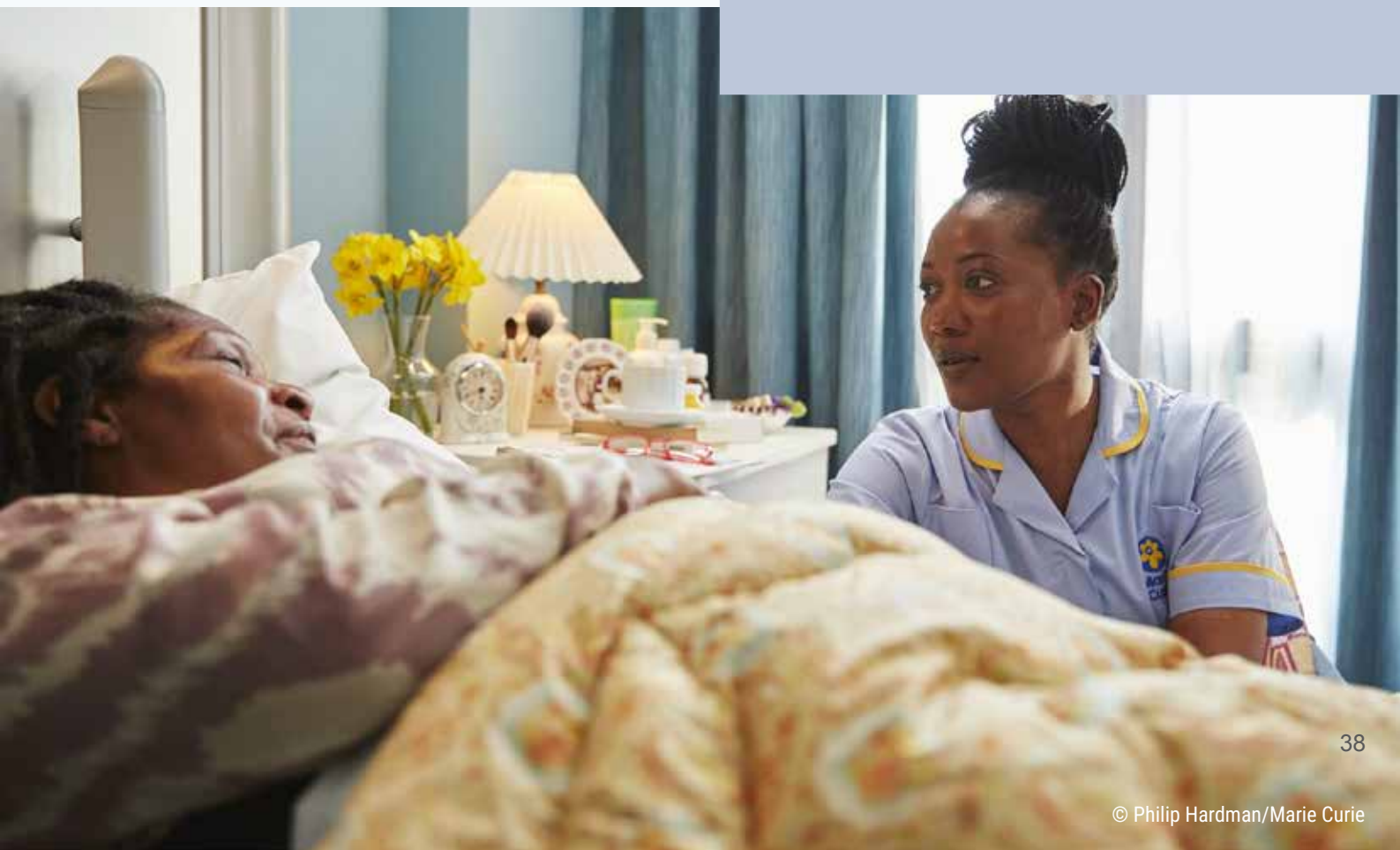
7 What to expect at the end of life

Finding a purpose

If someone is finding it hard to see purpose or meaning in their life, this can be quite painful. This is sometimes called emotional or spiritual pain. It can also make physical pain and symptoms worse. They may ask questions like, "Why is this happening to me?" which can feel impossible to find an answer to. Talking about feelings openly with someone you trust can help a person explore their feelings and make sense of them. Give them space to talk about how they feel without judgement. Beliefs and religion can be a great source of strength and support during this time, and many people may find it helpful to seek guidance and support from a counsellor or chaplain, even if they're not particularly religious.

FINDING PEACE

Some people find that near the end of their life, they spend more time reflecting on life, its purpose and meaning. This sometimes means they experience a deep peace and acceptance of what's to come. This may be a gradual process, or it might happen more suddenly. Resolving unfinished matters from the past, particularly with family members, can feel cathartic or liberating, so it is important for those concerned to be open to this. If the other party involved has already passed away or is unwilling or unable to meet, it can still provide relief to write down or verbalise feelings and thoughts about it.



7 What to expect at the end of life

Visions or dreams

Some people who are dying experience visions or dreams, or give accounts of being visited by relatives, friends, religious figures, and people who have died. They may say these visitors have come to collect them or help them let go of life. Some people talk about moving in and out of reality or describe experiences of what seems to be another world. Others talk about starting on a journey. These experiences can have significant meaning for dying people and may provide comfort.

Nobody knows what causes these visions or dreams. They may be related to heightened emotions, or spiritual or religious beliefs. If someone seems upset, distressed or confused, speak to the doctor or nurse to see if they can do anything to help.



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This is because sometimes these symptoms can be caused by underlying problems such as pain, an infection or side effects of medicines. The doctor or nurse can try to improve comfort and manage any underlying problems.

There's no right or wrong way to say goodbye. Saying goodbye is personal to everyone and may be complicated by complex or estranged relationships. If you need support, don't hesitate to reach out to Marie Curie's Support Line. See **Box** below for more information and for how to contact them.

MARIE CURIE'S SUPPORT LINE

Marie Curie's free Support Line is there for you with the support you need, when you need it. Trained staff, including nurses and specialist Energy Support Officers, offer practical or clinical information and emotional support if you're living with or caring for someone who has a terminal illness or has experienced a bereavement.

If you speak a language other than English, the Support Line is available in over 200 languages. Get in touch and we can request an interpreter who can join the call and translate live. Call **0800 090 2309**.

"I only made the one call – it was just so lovely to talk to somebody who just listened to me, and listened to my concerns without hearing those words 'you'll be fine, don't worry about it'. She was lovely, she just listened to me and helped me learn." Sue, after her call with the Marie Curie Support Line



“They just listened and allowed me to kind of express how I was. No judgement, no agenda. I think that allowed me to drop my guard.”

Jonathan

© Philip Hardman/Marie Curie

Jonathan had bereavement support from Marie Curie following his nan’s death from dementia.

“My nan was like a second mum, like a best friend. When you’re a carer, that’s your job. It may not be your main job, but it is a role that causes you the most stress and gives you the most reward too – you’re taking care of another human being. My nan transitioned in December 2020, five years after being diagnosed with dementia.

Grief is personal and unique. I always assumed no one would have time to listen to what I was really going through. I voiced my concerns to my friends. But, still, I felt like I didn’t want to just go to my friends to speak on this topic.

My mother-in-law led me to Marie Curie bereavement support. At first, I thought they only dealt with people that were going through cancer. I contacted Marie Curie after my nan’s funeral. I thought it was necessary to talk to someone outside of my family, to bring a new perspective.

The first call came, and I would talk and explain exactly how I was feeling. They just listened and allowed me to kind of express how I was. No judgement, no agenda. I think that allowed me to drop my guard.

I had six sessions, and it was good to share my experience. I didn’t know what the person I spoke to went through, but it was just good to share what happened with someone other than family.

It gave me more of an outlet. I consider myself to be very in tune with myself, but to open up about what I was going through while taking care of my nan was something new to me. It felt good.”

7 What to expect at the end of life

Understanding bereavement and grief

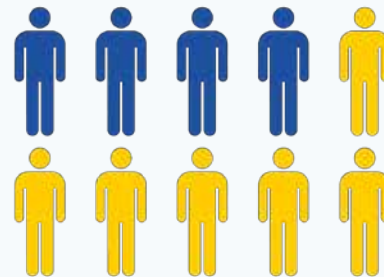
Most of us think of grief as something which happens after a death. In fact, grief can start a long time before someone dies, but this is often not acknowledged, talked about or even understood.

It's completely normal to begin grieving before death, if you become aware that the person is going to die soon. When a loved one receives a terminal diagnosis, grief can begin right there and then. All the feelings and thoughts experienced at this time can be just as intense and difficult as those after death. We often don't know exactly when someone will die, as this is hard to predict. Everyone's last weeks and days are as unique as they are.

You also cannot tell in advance how you will feel when someone dies. Common emotions include sadness, anger, despair, and frustration,

hopefulness, desperation, anxiety, panic, insecurity, guilt, shame, love, isolation, depression and even resentment.

Remember that all of these feelings are entirely natural and normal emotions to have. There's no right or wrong way to grieve, and it feels different for everyone. Each time that we grieve during our lifetime will feel different too.



Over 40% of UK adults couldn't get the expert bereavement support they wanted

UK Bereavement Commission Summary Report, 2022

"When you are told you might lose somebody in six months, you automatically go into a form of grief. Alan, too, struggled with his sadness. He and I couldn't stop crying most days for a long time. We didn't fully understand what was happening to us until we got some bereavement support and were told by the psychologist, 'You're suffering from anticipatory grief'." Hazel, whose husband Alan died from motor neurone disease

7 What to expect at the end of life

How long will it last?

Most people say that over time, their grief becomes less intense, and they adapt to living a life without the person physically in it. But that does not mean that their grief ends or it goes away completely. Some people find that their feelings of grief don't ease, and they find it difficult to manage normal daily activities. Some people feel comfortable speaking with their family and friends about their feelings and needs but not everyone.

If you are finding it hard to cope with any of your feelings or emotions at any stage, you should speak to your GP. You can also speak to the palliative care team involved, as they are trained to offer emotional and spiritual support for people who are dying and for those close to them. Chaplains, spiritual coordinators and other faith leaders can offer support, whether or not you're religious. Hospices also sometimes offer support services, such as group sessions, for family and close friends. There may also be local services, including support groups, for people going through a similar experience.

You can get advice from health and social care professionals. They may be able to give you tips on having conversations, and may also be able to speak to your family and friends. You can also call the Samaritans on **T 116 123** - they are available 24 hours a day, every day, or you can get in touch with Marie Curie's Bereavement support service.



MARIE CURIE'S TELEPHONE BEREAVEMENT SUPPORT SERVICE

Marie Curie's **free bereavement service** is for people who might want to have ongoing support, from the same bereavement volunteer, over the phone. You'll be matched with a specially trained volunteer who'll give you regular bereavement support. They'll provide a safe space where you can talk openly about your grief. You can access up to six telephone sessions of 45 minutes.

"Speaking to a stranger helped me. Sometimes I like to be alone, but most of the time, I like some support. Ben told me that's okay. I can open up without upsetting people." Simeon had bereavement support calls from Marie Curie after his dad died

7 What to expect at the end of life

Memories live on

When someone you love dies, it can feel as if part of your life has stopped. And you may be worried that you will forget what they look like or the sound of their voice. It can help with grief to understand that while the person has died, the relationship you had with them has not.

You can keep someone's memory alive in many ways, by looking at photos of them and by doing activities or going to places that remind you of them. Consider writing down your memories of them, talking about them with friends and family or marking their life by doing something special in their memory. In some instances, they may also have already thought about this and have left a legacy for you to remember them by (see **Leaving behind memories**). In time, your focus will change from grief and sadness to remembering moments and events that make your heart smile.

Whatever the illness, wherever you are, Marie Curie is with you to the end. Shared in this guide, may you find solace and inspiration in the stories of hope, courage, love and loss that are shared, and through them find the strength and determination to appreciate every moment that life has to give. Cherish every day until the end.



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