Coming Home

COMING HOME GUIDE

Caring for someone at the end of life: a family guide

For England, Wales, Scotland and Northern Ireland

Version 1.0 • October 2026. Next review: October 2027

About this guide

This guide is correct at October 2026, version 1.0. We've written it in good faith as general guidance to help carers and families. It isn't legal, financial or medical advice. Rules and rates change, so before you act, please make sure you have the latest version of this guide and look at the official sources: GOV.UK, Social Security Scotland, nidirect and your local council. To the extent the law allows, we can't accept liability for any errors or omissions, or for decisions made on the strength of this guide. In a medical emergency call 999. For urgent advice, contact NHS 111.

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How to use this guide

Version 1.0. October 2026. Next review: October 2027. Information read on 4 October 2026. We review this guide every year, and straight away if a service or rule it describes changes.

Who this guide is for: you, if you're caring for someone who is dying: your partner, a parent, a brother or sister, a grown-up child or a close friend. It covers England, Wales, Scotland and Northern Ireland.

How to use it: read only the part you need, when you need it. Sections 2 to 5 cover help, planning and money while the person is alive. Section 6 is about changes families often notice. Sections 7 to 9 cover what to do when someone dies and afterwards. Section 11 is about you, and grief. Every fact has a source and a date (see "Sources").

Guidance, not advice. This guide is about the carer's side of things. It can't tell you what's happening for the person you care for, how long they have, or what care or medicines they need. Only the nurses, the palliative care team and their GP can do that. If you have a question about their care, ask them.

If you're worried about their health, contact their GP or NHS 111. In an emergency call 999.

Write down the numbers the nurses or palliative care team give you, including any 24-hour or out-of-hours number, and keep them by the phone.

Palliative care or district nursing team:

_____

24-hour or out-of-hours number:

_____

GP surgery:

_____

Use them in the way the team has told you. In an emergency call 999.

For support at any point, call the Marie Curie Support Line on 0800 090 2309, 8am to 6pm Monday to Friday, and 10am to 4pm Saturday and Sunday (see "Who to call").

01

You're not on your own

Caring for someone who is dying is one of the hardest and most important things a person can do. You might feel dread, numbness, exhaustion, guilt, love, anger, relief and grief, sometimes all in the same hour. There's no right way to feel, and there's no right way to do this. You can't get it wrong.

You might be grieving already, before they have died. That's common too.

Marie Curie's Support Line offers information and emotional support for people living with a terminal illness and their family, friends and carers. It can talk with you in over 200 languages (Marie Curie, Support Line, read 4 Oct 2026).

What this guide does: it brings together what the NHS, the government and the end of life charities say about the help you can ask for, planning ahead, what to do when someone dies, money, and grief.

What it doesn't do: it doesn't say anything about the person's illness, their care or medicines, or how long they have. The nurses and palliative care team can talk with you about what to expect. Ask them.

02

Who can help

The NHS says end of life care is support for people who are in the last months or years of their life, and that the people providing care "should also support your family, carers or other people who are important to you" (NHS, What end of life care involves, read 4 Oct 2026).

Who's who

- **The GP.** The NHS says that if someone is being cared for at home or in a care home, their GP has overall responsibility for their care (NHS, What end of life care involves).
- **District and community nurses.** The NHS says community nurses usually visit at home (NHS, What end of life care involves).
- **The palliative care team.** Specialist nurses, doctors and therapists who help with comfort and support. The NHS says palliative care is available from when someone first learns they have a life-limiting (terminal) illness, so it isn't only for the last days (NHS, What end of life care involves).
- **Hospice teams.** Hospices offer care and support for the person and for the family. Ask the GP or nurses about your local hospice. Hospice UK's Hospice Care Finder shows adult and children's hospices near you (Hospice UK, Hospice Care Finder, read 4 Oct 2026).
- **Marie Curie.** Marie Curie offers hospice care at home (Marie Curie, Support Line). Ask the district nurse or GP whether it's available where you live.

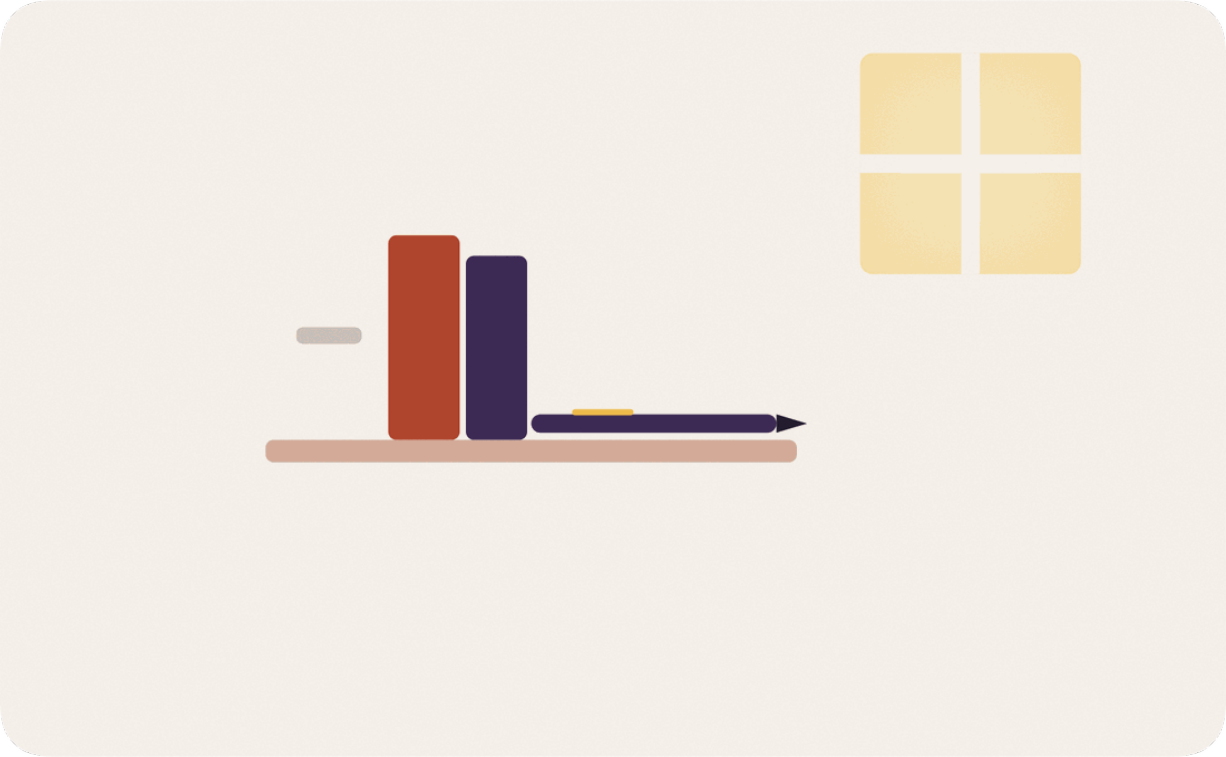
- **Social care.** The council's adult social services (the Health and Social Care Trust in Northern Ireland) can arrange help with personal care at home.
- **The out-of-hours GP service.** Through NHS 111 when the surgery is closed.

The NHS also names chaplains "of all faiths or none" among the people who may be involved (NHS, What end of life care involves). Many hospices have them too.

Where care can happen

The NHS says end of life care can happen at home, in a care home, in a hospice or in hospital, depending on the person's needs and preferences, and that people have the right to say where they'd like to be cared for and where they want to die (NHS, What end of life care involves).

Wishes can change, and that's fine. The team can talk through what's possible.



03

Planning ahead and wishes

This section is gentle on purpose. You don't have to read it now. If the person wants to, it can help to talk while they can say what matters to them, so their wishes are known and followed.

Power of attorney

A power of attorney lets someone they trust make decisions for them if they can't. Our power of attorney guide explains the rules in each nation (Coming Home, Power of attorney).

Recording wishes about future care

England and Wales.

- An **advance statement** sets down someone's preferences, wishes, beliefs and values about their future care, such as where they'd like to be cared for, or how they want their religious or spiritual beliefs reflected. The NHS says it isn't legally binding, but anyone making decisions about their care must take it into account (NHS, Advance statement, reviewed 19 Sep 2023).
- An **advance decision to refuse treatment** (ADRT) is a decision someone makes now to refuse a specific kind of medical care in the future, if they can't make or communicate the decision themselves. The NHS says an advance decision is legally binding as long as it meets certain criteria (NHS, Advance statement). If it covers life-sustaining treatment, it must be written down,

signed and witnessed (NHS, Advance decision (living will), reviewed 19 Sep 2023). The NHS suggests talking it through with a doctor or nurse who knows them first.

Scotland: this is called future care planning. People can ask their doctor, nurse or care team about making a future care plan, which can be added to their health record and updated at any time (NHS inform, Future care planning, read 4 Oct 2026).

Northern Ireland: the Department of Health's policy on advance care planning is called "For Now and For the Future" (Department of Health (NI), Advance Care Planning policy, read 4 Oct 2026). Ask the GP, the nurses or the Health and Social Care Trust how to record wishes.

Plans for an emergency

ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment. It's a form that records a person's wishes and the recommendations made with them about care in a future emergency, when they may not be able to say what they want. The Resuscitation Council UK says ReSPECT isn't legally binding, and is used in many parts of England and Scotland, with Northern Ireland adopting it across the country in 2026. Wales doesn't use ReSPECT, and keeps its own All Wales DNACPR policy (Resuscitation Council UK, Where in the UK has adopted the ReSPECT process?, read 4 Oct 2026).

DNACPR stands for do not attempt cardiopulmonary resuscitation. It's a decision, made with the person where possible, that CPR shouldn't be attempted if their heart or breathing stop. Ask the GP or the nurses to explain any form the person has, and what it means for you.

Keep the papers where they can be found. Tell the people who need to know where the advance statement, the ADRT, any ReSPECT or DNACPR form, and the power of attorney are kept. The NHS suggests keeping an advance statement somewhere safe and telling people where it is (NHS, Advance statement).

Wills

If the person wants to make or update a will, GOV.UK (Making a will), mygov.scot (Create a will) and nidirect (Making a will) explain how. A solicitor can help.

04

Care at home and NHS-funded care

Help at home

Ask the district nurse or GP about equipment and help at home. An occupational therapist can advise on equipment that makes moving and personal care easier and more comfortable. The council (the Health and Social Care Trust in Northern Ireland) can do a needs assessment and arrange carers to come in. Our guide to coming home from hospital covers this in more detail (Coming Home, Coming home from hospital).

NHS continuing healthcare

NHS continuing healthcare is care arranged and funded by the NHS for some adults with long-term complex health needs (NHS, NHS continuing healthcare, reviewed 11 Apr 2024).

The fast-track pathway (England). The NHS says someone who is nearing the end of their life, and whose health is changing quickly, should be considered for the NHS continuing healthcare fast-track pathway, so that care and support can be put in place as soon as possible, usually within 48 hours (NHS, NHS continuing healthcare). The form professionals use is called the Fast Track Pathway Tool (GOV.UK, NHS continuing healthcare fast track pathway tool, read 4 Oct 2026).

Wales: this is called Continuing NHS Healthcare. The Welsh Government says that if someone's condition is changing quickly and their need for care is increasing, possibly because they may be nearing the end of their life, staff should ask for a fast track assessment, which should be completed within 2 working days (Welsh Government, Continuing NHS Healthcare: how it is organised if you are eligible, updated 21 Sep 2026).

Scotland: NHS continuing healthcare was replaced in 2015 by Hospital Based Complex Clinical Care, which is hospital based care for people whose care needs can only be met in hospital (Care Information Scotland, read 4 Oct 2026). Ask the nurses or GP what help applies at home.

Northern Ireland: ask the nurses, the GP or the Health and Social Care Trust about help with complex care needs.

If you think the fast-track pathway might apply, ask the district nurse, the palliative care team or the GP. Our MND guide uses the same wording (Coming Home, MND).

05

The special rules for end of life

Some benefits can be paid more quickly, and at a higher rate, under what GOV.UK calls the special rules for end of life. This is how GOV.UK defines who is eligible. It's a benefit rule, not a statement about the person you care for. GOV.UK says someone is eligible if both of these apply:

- they have an illness that gets worse over time
- their doctor or medical professional has said they might have 12 months or less to live

GOV.UK says that if a medical professional hasn't talked to them about this, they can still ask whether the professional will support a claim under the special rules. The doctor or medical professional fills in a form called SR1 (GOV.UK, Get benefits if you're nearing the end of life, read 4 Oct 2026). The same special rules apply to PIP in Northern Ireland (nidirect, Personal Independence Payment, read 4 Oct 2026). Our Attendance Allowance and PIP guides explain how to claim (Coming Home, Attendance Allowance; Coming Home, PIP).

Scotland has different rules. Social Security Scotland says a registered doctor or nurse confirms the illness on a form called BASRiS, and that, unlike the UK system, it doesn't need someone to have a fixed life expectancy to apply under its fast-track process (Social Security Scotland, Special Rules for Terminal Illness, read 4 Oct 2026).

Ask the GP, the nurses or the palliative care team whether they'd support a claim. It's a form, and it can be a hard conversation, but it can make a real difference to money.

06

Changes families often notice

You don't have to read this section. Some families find it helps to know; others would rather not. Both are fine.

NHS inform says: "Everyone is different so it's hard to say exactly what will happen when someone is dying. But, there are some changes that often happen and things can be done to help." (NHS inform, What happens when someone is dying, updated 31 Jul 2026)

These are changes that often happen, in no particular order. They aren't a timetable, and they don't tell you how long someone has. For each one, tell the nurses or palliative care team. They can help with comfort.

Sleeping more. NHS inform says: "They are likely to spend more time sleeping, and will often be drowsy even when they're awake." It also says: "Even when the person is, or appears to be, sleeping or resting, they may still be able to hear you. If you want to, keep talking to them." (NHS inform, What happens when someone is dying)

Eating and drinking less. The NHS says: "Not wanting to eat is common in people who are dying." It says families may find this upsetting, but they don't need to make the person eat (NHS, Changes in the last hours and days of life, reviewed 26 Oct 2023). Ask the nurses how to keep their mouth and lips comfortable.

Changes in breathing. NHS inform says: "The person's breathing may become shallower. It can get faster or slower and there may be longer pauses between breaths." Breathing can also sound noisy or rattling. NHS inform says: "This may be upsetting to hear, but it doesn't usually cause any distress to the dying person." (NHS inform, What happens when someone is dying)

Restlessness or confusion. NHS inform says: "It's quite common for people to be restless at times in their last few days." It also says: "Sometimes people can appear confused and they may not recognise familiar faces." Hospice UK says this is not a sign that they feel differently about you (Hospice UK, What to expect when someone is in the last few days of life, read 4 Oct 2026).

Cold hands and feet. NHS inform says: "Their hands, feet, ears and nose may feel cold to the touch." It suggests: "It may be comforting to put gloves or socks on the person to keep them warm. You can also make sure they're covered with a blanket or duvet." (NHS inform, What happens when someone is dying)

What you can do

- Be there. Sitting quietly with them is enough.
- Talk to them, even if they don't answer.
- Hold their hand, read to them, or play music they love. Hospice UK and NHS inform both suggest these.
- Keep things calm, with familiar photos or favourite things nearby.
- Take breaks. Let others sit with them while you eat, sleep or step outside. If you aren't in the room when they die, that isn't a failure, and it doesn't mean you let them down.

If you're worried about their health, contact their GP or NHS 111. In an emergency call 999.

07

When someone dies

There's no rush. NHS inform says it's important that you don't feel rushed to "get on with things", and that you may like to spend some time with the person who has died, on your own or with other people close to you (NHS inform, What to do when someone dies in Scotland, updated 31 Jul 2026).

If they die at home and the death was expected

When someone's death has been expected, the nurses or palliative care team will usually have told you who to call when it happens. Ask them now if they haven't, and write it in the box at the front of this guide.

What the NHS says (Scotland). NHS inform says: "If the person died at home, contact your GP practice (if it's open) or phone 111 to contact NHS 24. A doctor or nurse will come to the house to confirm that the person has died." (NHS inform, What to do when someone dies in Scotland)

What nidirect says (Northern Ireland). nidirect says that if the death was expected, you "should immediately call the deceased's family doctor" during surgery hours, and that outside surgery hours "the on call doctor should be told." It also says: "In cases of expected death a medical certificate will be given by the doctor stating cause of death." (nidirect, When someone dies at home, read 4 Oct 2026)

England and Wales. Call the number the nurses or palliative care team gave you. If you don't have one, call the GP surgery, or NHS 111 when it's closed, and say that the death was expected. Someone will come to confirm that the person has died.

If you're not sure whether they have died, or the death was unexpected, call 999. nidirect says: "You should dial 999 if someone dies unexpectedly. The operator will tell you what to do to see if the person can be resuscitated." (nidirect, When someone dies at home)

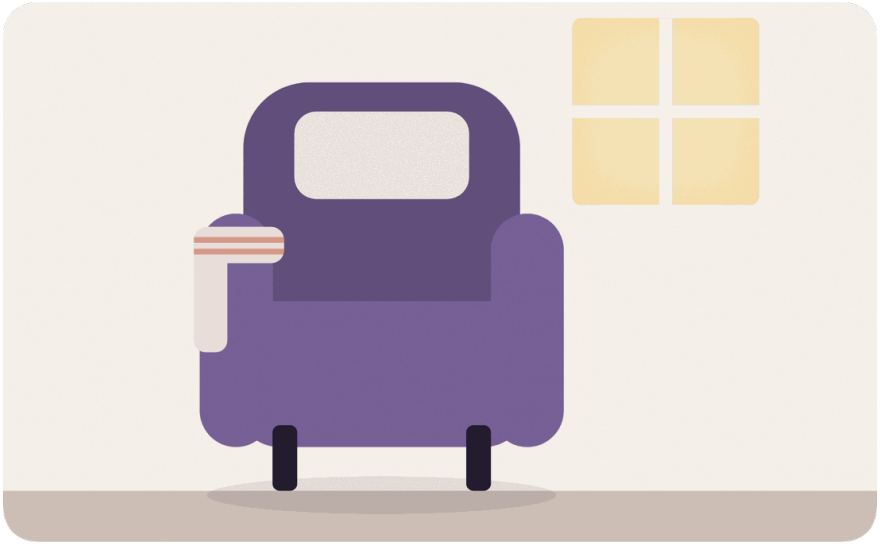
If you're alone when they die, NHS inform suggests asking someone to come and be with you, such as a friend, a relative or someone from your faith or belief community (NHS inform, What to do when someone dies in Scotland).

If they die in a hospital, hospice or care home

The staff will help and support you, and explain what happens next (NHS inform, What to do when someone dies in Scotland).

The funeral director

When you're ready, you can contact a funeral director of your choice. They can collect the person and help with the funeral arrangements. You don't have to choose straight away. It's fine to ask for prices and to ask for what matters to you and to the person who died, including any faith or cultural customs. A faith leader, celebrant or hospice chaplain can also help.



08

Practical things after a death

You don't have to do everything at once. These are the main steps, with the official time limits. They're about paperwork, not about how you feel.

Registering the death

England and Wales. GOV.UK says the doctor confirms the death and contacts the medical examiner, who looks at the cause of death. The medical examiner's office will then contact you to explain the cause of death and answer questions, if you want to talk to them. You must wait for the office to confirm you can register the death, then register it within 5 days of getting that confirmation, including weekends and bank holidays. You'll be given a certificate for burial or cremation, often called "the green form", to give to the funeral director (GOV.UK, What to do after someone dies: register the death, read 4 Oct 2026).

Scotland. NHS inform says a death must be registered within 8 days, at any registration office in Scotland, and that you need to contact the registrar's office first. A doctor completes the Medical Certificate of Cause of Death and usually sends it straight to the registrar (NHS inform, What to do when someone dies in Scotland).

Northern Ireland. nidirect says a death should be registered within 5 days. The doctor or hospital sends the Medical Certificate of Cause of Death to the registrar, who usually contacts you, and registration can often be done by phone. There's no fee to register a death, only for copies of the certificate (nidirect, Registering a death with the district registrar, read 4 Oct 2026).

Telling the government: Tell Us Once

GOV.UK says Tell Us Once lets you report a death to most government organisations in one go, if the person was living in England, Scotland or Wales. The registrar will explain it when you register the death, and either complete it with you or give you a unique reference number. You must use the service within 28 days of getting the number (GOV.UK, Tell Us Once, read 4 Oct 2026). NHS inform says Tell Us Once is available in some parts of Scotland, and the registrar will tell you (NHS inform, What to do when someone dies in Scotland).

Northern Ireland doesn't have Tell Us Once. The Department for Communities' Bereavement Service is the single point of contact for reporting a death for benefits (see "Who to call").

Help with funeral costs

- **England and Wales: Funeral Expenses Payment.** GOV.UK says you may get help if you or your partner get Universal Credit, income-related Employment and Support Allowance, Pension Credit or Housing Benefit, and you meet the rules on your relationship with the person who died. It usually won't cover all the costs (GOV.UK, Funeral Expenses Payment, read 4 Oct 2026).
- **Scotland: Funeral Support Payment.** It helps pay for funeral costs if you live in Scotland, and usually won't cover the full cost (mygov.scot, Funeral Support Payment, updated 1 Apr 2022).
- **Northern Ireland: Funeral Expenses Payment.** nidirect says it's for people on certain benefits, and you must apply within six months of the funeral (nidirect, Funeral Expenses Payments, read 4 Oct 2026).

Wills and the estate

The estate is the money, property and belongings of the person who died. GOV.UK explains probate and dealing with the estate in England and Wales (GOV.UK, What to do after someone dies). mygov.scot (What to do when someone dies) and nidirect (Probate) explain what happens in Scotland and Northern Ireland. A solicitor can help.

09

Money for you after a death

Bereavement Support Payment

This is for people whose partner has died. GOV.UK says you may be able to get it if you were married, in a civil partnership, or living together as if you were married, and you were under State Pension age when your partner died. There are also rules about your partner's National Insurance contributions (GOV.UK, Bereavement Support Payment, read 4 Oct 2026).

The most you can get at the higher rate:

- a one-off payment of £3,500
- 18 monthly payments of £350

The most you can get at the lower rate:

- a one-off payment of £2,500
- 18 monthly payments of £100

GOV.UK says you must claim within 3 months of your partner's death to get the one-off payment and all 18 monthly payments, and that after 21 months you usually can't get any payments (GOV.UK, Bereavement Support Payment: what you can get, read 4 Oct 2026). You can claim online, by phone through the Bereavement Service, or by post (GOV.UK, Bereavement Support Payment: how to claim, read 4 Oct 2026).

Northern Ireland has the same payment with its own rules on claiming. nidirect says you must claim within 12 months to get the first payment, and within three months to be eligible for up to 18 monthly payments (nidirect, Bereavement Support Payment, read 4 Oct 2026).

Carer's Allowance after a death

Carer's Allowance can carry on for up to 8 weeks after the person you care for dies, as long as you still meet the other rules (DWP, Decision makers' guide, volume 10, chapter 60 (Carer's Allowance), read 4 Oct 2026). GOV.UK says you can't use the online Carer's Allowance change service to report the death of the person you care for, and should use Tell Us Once instead (GOV.UK, Carer's Allowance: report changes, read 4 Oct 2026).

Scotland: Social Security Scotland's guidance says Carer Support Payment carries on for 12 weeks after the person you care for dies, as long as you still meet the other rules (Social Security Scotland, Carer Support Payment decision making guide, read 4 Oct 2026).

Northern Ireland: report the death to the Bereavement Service, and ask the Carer's Allowance Unit how long your payment carries on (see "Who to call").

When caring ends, your own money can change in other ways too. Our Carer's Allowance and Money and help guides explain more (Coming Home, Carer's Allowance; Coming Home, Money and help), and the Benefits finder asks 8 quick questions (Coming Home, Benefits finder).

10

Work

Time off in an emergency. GOV.UK says employees can take a reasonable amount of time off to deal with an emergency involving a dependant, such as a partner, parent or someone who depends on them for care. Employers don't have to pay for it. If you aren't given time off for dependants, your employer may allow compassionate leave, which can be paid or unpaid (GOV.UK, Time off for family and dependants, read 4 Oct 2026).

Carer's leave (England, Scotland and Wales). GOV.UK says employees can take up to one week of unpaid carer's leave every 12 months to give or arrange care for someone with a long-term care need, from their first day in a job (GOV.UK, Unpaid carer's leave, read 4 Oct 2026). Our cancer guide explains the details (Coming Home, Cancer).

Northern Ireland has different rules. nidirect explains time off and flexible working for carers (nidirect, Caring for someone while working, read 4 Oct 2026). Advice NI can help (see "Who to call").

It can help to tell your manager or HR team what's happening, and to ask whether your workplace has a policy on compassionate or bereavement leave.

11

Looking after yourself, and grief

Caring for someone who is dying can take everything you have. Looking after yourself isn't selfish. It helps you keep going, and it helps them too.

While you're caring:

- Tell your GP you're a carer.
- Ask the council for a carer's assessment (the Health and Social Care Trust in Northern Ireland), or for an Adult Carer Support Plan in Scotland (mygov.scot, Help if you're a carer, updated 12 Sep 2025).
- Let people help, and tell them what would help most, even small things.
- Rest when you can. Eat something. Step outside.
- Call the Marie Curie Support Line, Carers UK, or your local carers' centre.

Grief

Grief can start before someone dies, and it can feel like many things at once. NHS inform says grief may include feeling sad, anxious or worried, lonely, numb or empty, overwhelmed, exhausted, shocked or relieved, and that many people have feelings that change over time (NHS inform, What to do when someone dies in Scotland). Feeling relieved doesn't mean you loved them any less.

There's no timetable and no set of stages you have to go through. Sue Ryder says everyone's grief is different (Sue Ryder, Grief support, read 4 Oct 2026).

Support with grief

- **Cruse Bereavement Support** has a helpline run by trained bereavement volunteers, who offer emotional support to anyone in the UK affected by grief. It's free to call (Cruse, Helpline, read 4 Oct 2026).
- **Cruse Scotland** is a separate charity with its own helpline for anyone in Scotland, also free to call (Cruse Scotland, Free Bereavement Helpline, read 4 Oct 2026).
- **Sue Ryder** has online grief support and information on the practical things after a death (Sue Ryder, Grief support).
- **Marie Curie's Support Line** can help with bereavement as well as caring (Marie Curie, Support Line).
- **The hospice.** If the person was cared for by a hospice, ask about its bereavement support.
- **Your GP.** The NHS says to see a GP if you're struggling to cope, or have had a low mood for more than 2 weeks (NHS, Grief after bereavement or loss, read 4 Oct 2026).

Children and young people grieve too. Cruse's helpline volunteers can talk with you about how to talk to children or young people about death (Cruse, Helpline).

If you're struggling and need to talk to someone, Cruse suggests calling Samaritans on 116 123 (Cruse, Helpline).

If you're worried about your own health, contact your GP or NHS 111. In an emergency call 999.

12

Across the four nations

England: NHS end of life care pages, advance statements and the ADRT, ReSPECT in many areas, NHS continuing healthcare fast track, registration within 5 days after the medical examiner's office confirms, Tell Us Once, and Funeral Expenses Payment.

Wales: NHS 111 Wales for health information, advance statements and the ADRT, the All Wales DNACPR policy, Continuing NHS Healthcare fast track, registration within 5 days, Tell Us Once, and Funeral Expenses Payment.

Scotland: NHS inform for health information, future care planning, ReSPECT in many health boards, Social Security Scotland's special rules (BASRiS), registration within 8 days, Tell Us Once in some areas, Funeral Support Payment, Carer Support Payment, and Cruse Scotland.

Northern Ireland: nidirect for health and practical information, advance care planning ("For Now and For the Future"), ReSPECT being adopted across Northern Ireland in 2026, registration within 5 days with no fee, the Bereavement Service instead of Tell Us Once, Funeral Expenses Payment, and Advice NI.

13

How Coming Home can help

Coming Home: Family Care is an iPhone app for families looking after someone. It's coming soon. It helps you organise. It isn't medical advice.

The care circle brings the family, friends and neighbours who help into one place, with shared notes, tasks and a calendar. It means you aren't the only one passing on news, and people can see who's sitting with them, who's doing the shopping, and when you need a rest.

The family care diary helps you note questions and changes as they come up, so you have them ready for the nurses or the GP.

The document vault, stored in the UK, keeps the advance statement, any ReSPECT or DNACPR form, the power of attorney and other important papers in one place, so the right people can find them.

To hear when Coming Home is ready, join the waitlist:
www.cominghomecare.app/?ref=guide-end-of-life

Built by people who have run home care.

14

Who to call

This guide is guidance, not advice. For support and advice:

Write down the numbers the nurses or palliative care team give you, including any 24-hour or out-of-hours number, and keep them by the phone.

Palliative care or district nursing team:

_____

24-hour or out-of-hours number:

_____

GP surgery:

_____

Use them in the way the team has told you. In an emergency call 999.

- **Marie Curie Support Line:** 0800 090 2309, 8am to 6pm Monday to Friday, and 10am to 4pm Saturday and Sunday. Free from landlines and mobiles (Marie Curie, Support Line)
- **Hospice UK Hospice Care Finder:** find adult and children's hospices near you (Hospice UK, Hospice Care Finder)
- **Sue Ryder:** online grief support (Sue Ryder, Grief support)

- **Cruse Bereavement Support helpline:** 0808 808 1677. Monday, Wednesday, Thursday and Friday 9.30am to 5pm; Tuesday 1pm to 8pm; closed at weekends (Cruse, Helpline)
- **Cruse Scotland helpline:** 0808 802 6161. Monday to Friday 9am to 5pm, and until 8pm on Monday and Thursday (Cruse Scotland, Free Bereavement Helpline)
- **Bereavement Service (DWP), England, Scotland and Wales:** 0800 151 2012, Welsh language 0800 731 0453, Monday to Friday 8am to 6pm (GOV.UK, Bereavement Support Payment: how to claim)
- **Bereavement Service (Department for Communities), Northern Ireland:** 0800 085 2463, Monday to Friday 9am to 5pm (Department for Communities, Bereavement Service, read 4 Oct 2026)
- **Carers UK Helpline:** 0808 808 7777, Monday to Friday 9am to 6pm (Carers UK, Helpline and other support, read 3 Oct 2026)
- **Age UK Advice Line:** 0800 678 1602, 8am to 7pm, every day of the year (Age UK Advice Line, read 3 Oct 2026)
- **Advice NI:** 0800 915 4604 (Advice NI, Contact, read 3 Oct 2026)
- **Samaritans:** 116 123 (Cruse, Helpline)
- **The GP, the district nurses or the palliative care team,** on the numbers they've given you

If you're worried about their health, contact their GP or NHS 111. In an emergency call 999.

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Sources

All read on 4 October 2026 unless another date is given. Dates in brackets are the page's own published, updated or reviewed date.

NHS

- NHS, What end of life care involves: www.nhs.uk/tests-and-treatments/end-of-life-care/what-it-involves-and-when-it-starts/
- NHS, Changes in the last hours and days of life (reviewed 26 Oct 2023): www.nhs.uk/tests-and-treatments/end-of-life-care/your-wellbeing/changes-in-the-last-hours-and-days/
- NHS, Advance statement (reviewed 19 Sep 2023): www.nhs.uk/tests-and-treatments/end-of-life-care/planning-ahead/advance-statement/
- NHS, Advance decision (living will) (reviewed 19 Sep 2023): www.nhs.uk/tests-and-treatments/end-of-life-care/planning-ahead/advance-decision-to-refuse-treatment/
- NHS, NHS continuing healthcare (reviewed 11 Apr 2024): www.nhs.uk/social-care-and-support/money-work-and-benefits/nhs-continuing-healthcare/
- NHS, Grief after bereavement or loss: www.nhs.uk/mental-health/feelings-symptoms-behaviours/feelings-and-symptoms/grief-bereavement-loss/
- NHS inform, What happens when someone is dying (updated 31 Jul 2026): www.nhsinform.scot/care-support-and-rights/palliative-care/dying-death-and-grief/what-happens-when-someone-is-dying/
- NHS inform, What to do when someone dies in Scotland (updated 31 Jul 2026): www.nhsinform.scot/care-support-and-rights/palliative-care/dying-death-and-grief/what-to-do-when-someone-dies-in-scotland/
- NHS inform, Future care planning: www.nhsinform.scot/care-support-and-rights/decisions-about-care/future-care-planning/

Official

- GOV.UK, NHS continuing healthcare fast track pathway tool: www.gov.uk/government/publications/nhs-continuing-healthcare-fast-track-pathway-tool
- Welsh Government, Continuing NHS Healthcare: how it is organised if you are eligible (updated 21 Sep 2026): www.gov.wales/continuing-nhs-healthcare-how-it-organised-if-you-are-eligible-html
- Care Information Scotland, hospital based care for complex needs: www.careinfoscotland.scot/topics/how-to-get-social-care-support/hospital-based-complex-clinical-care/
- Department of Health (NI), Advance Care Planning policy: www.health-ni.gov.uk/publications/advance-care-planning-now-and-future
- GOV.UK, Get benefits if you're nearing the end of life: www.gov.uk/benefits-end-of-life
- nidirect, Personal Independence Payment: www.nidirect.gov.uk/articles/personal-independence-payment-pip
- Social Security Scotland, Special Rules for Terminal Illness: www.socialsecurity.gov.scot/special-rules-for-terminal-illness
- GOV.UK, What to do after someone dies: register the death: www.gov.uk/after-a-death
- GOV.UK, Tell Us Once: www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once
- nidirect, When someone dies at home: www.nidirect.gov.uk/articles/when-someone-dies-home
- nidirect, Registering a death with the district registrar: www.nidirect.gov.uk/articles/registering-death
- GOV.UK, Funeral Expenses Payment: www.gov.uk/funeral-payments
- mygov.scot, Funeral Support Payment (updated 1 Apr 2022): www.mygov.scot/funeral-support-payment
- nidirect, Funeral Expenses Payments: www.nidirect.gov.uk/articles/funeral-payments
- GOV.UK, Making a will: www.gov.uk/make-will
- mygov.scot, Create a will: www.mygov.scot/create-will
- nidirect, Making a will: www.nidirect.gov.uk/articles/making-will
- mygov.scot, What to do when someone dies: www.mygov.scot/when-someone-dies
- nidirect, Probate: www.nidirect.gov.uk/articles/probate
- GOV.UK, Bereavement Support Payment: www.gov.uk/bereavement-support-payment
- GOV.UK, Bereavement Support Payment, what you can get: www.gov.uk/bereavement-support-payment/what-youll-get
- GOV.UK, Bereavement Support Payment, how to claim: www.gov.uk/bereavement-support-payment/how-to-claim
- nidirect, Bereavement Support Payment: www.nidirect.gov.uk/articles/bereavement-support-payment

- Department for Communities, Bereavement Service: www.communities-ni.gov.uk/contacts/bereavement-service
- DWP, Decision makers' guide, volume 10 (chapter 60, Carer's Allowance): www.gov.uk/government/publications/decision-makers-guide-vol-10-benefits-for-incapacity-disability-maternity-and-bereavement-staff-guide
- GOV.UK, Carer's Allowance: report changes: www.gov.uk/carers-allowance-report-change
- Social Security Scotland, Carer Support Payment after the death of the cared for person: www.socialsecurity.gov.scot/publications/2017/07/carer-support-payment-decision-making-guide/pages/death-of-an-individual/payment-of-carer-support-payment-after-the-death-of-the-cared-for-person
- GOV.UK, Time off for family and dependants: www.gov.uk/time-off-for-dependants
- GOV.UK, Unpaid carer's leave: www.gov.uk/carers-leave
- nidirect, Caring for someone while working: www.nidirect.gov.uk/articles/caring-someone-while-working
- mygov.scot, Help if you're a carer (updated 12 Sep 2025): www.mygov.scot/help-for-carer

Charities

- Marie Curie, Support Line: www.mariecurie.org.uk/services/support-line
- Hospice UK, Hospice Care Finder: www.hospiceuk.org/hospice-care-finder
- Hospice UK, What to expect when someone is in the last few days of life: www.hospiceuk.org/information-and-support/death-and-dying-what-expect/last-few-days
- Resuscitation Council UK, Where in the UK has adopted the ReSPECT process?: www.resus.org.uk/respect/respect-patients-and-carers/respect-adoption-uk
- Cruse Bereavement Support, Helpline: www.cruse.org.uk/get-support/helpline/
- Cruse Scotland, Free Bereavement Helpline: www.crusescotland.org.uk/get-support/free-bereavement-helpline/
- Sue Ryder, Grief support: www.sueryder.org/grief-support/
- Carers UK, Helpline and other support (read 3 Oct 2026): www.carersuk.org/help-and-advice/helpline-and-other-support/
- Age UK Advice Line (read 3 Oct 2026): www.ageuk.org.uk/services/age-uk-advice-line/
- Advice NI, Contact (read 3 Oct 2026): www.adviceni.net/contact

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Changelog

Version	Date	What changed	Why
1.0	October 2026	First published	Information read on 4 October 2026

The next review is due in October 2027, or straight away if a service or rule changes. The latest version is always at www.cominghomecare.app/guides/end-of-life

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