

What to expect at the end of someone's life

Information for family, friends and carers



Marie
Curie

Care and support
through terminal illness

This leaflet aims to help you and those around you prepare for the end of the life of a partner, relative or friend.

It includes information about making care arrangements, people who can help, and some of the changes that your partner, relative or friend may experience.

Knowing what to expect can help you prepare yourself for the last few weeks and days.

If you don't feel ready to read this information yet, you might decide to come back to it another time. You can also ask someone to look at it with you, like a nurse, so you have their support.

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What to expect

Everyone is different, so it's not easy to say exactly what will happen when the end of someone's life gets closer. But in the last weeks and days before death, it's common to experience certain changes in the body and mind. They are signs that life might be ending, which are part of a natural pattern.

Learning about these changes can make the future seem less frightening. It also helps with thinking ahead: what care will be needed, where is the best place to be, and how can family and friends be prepared?

This knowledge can be useful if you feel able to talk to your partner, relative or friend about their wishes. It can also help you to arrange their care so these wishes can be met.

When the nurses told us Dad was going to die soon, we were able to stay overnight and were there when he did die.

Lucy, family member

Standards of care

When someone is approaching the end of their life, they should receive a level of care that is compassionate and sensitive to their needs and wishes. Clear communication with them and those around them, including healthcare staff, is especially important. Their condition should be monitored and healthcare staff should respond if anything changes.

Each nation in the UK has set standards that healthcare professionals need to follow when caring for someone at the end of their life. You can read more about these on our website at mariecurie.org.uk/caresstandards or call the Marie Curie Support Line on **0800 090 2309***.

* Calls from landlines are free, but there may be a charge if you're calling from a mobile. Check with your mobile provider for details. Calls from any type of phone will be free from 1 July 2015.

Leaving hospital

There may come a time when your partner, relative or friend will not benefit from further treatment in hospital. If they're in hospital, deciding what to do next is a process called discharge planning. These decisions have to be guided by what the person really wants as they approach the end of their life, and their wishes must come first.

Making their wishes known

If your partner, relative or friend doesn't already have an advance care plan, now is a good time to make one. The plan can include what someone wants from their care at the end of their life, and what should happen if they become unable to make decisions. It can be written in a document that is sometimes called an advance statement or, in Scotland, an anticipatory care plan. You can ask the doctors and nurses for help with this.

Your own wishes, what you feel able to do, and practical limitations need to be considered, too. Remember that plans can always be changed, and this is OK. Things don't always work out as expected, and many people change their minds about what they want.

Choosing care

When choosing a place to be cared for after leaving hospital, there are three main options: home, hospice or nursing home.

Home

Care provided by your district nurse, along with other support services, can make it possible for your partner, relative or friend to be cared for at home. Marie Curie Nurses and Healthcare Assistants may be able to provide cover at night and this service is free of charge. See page 21 for more information.

If you have any questions or are worried about doing certain tasks, don't hesitate to ask the nurses before your partner, relative or friend comes home. You can also ask any of the nurses who visit your home later on. You might like to create a folder of nutrition and drinking charts, rotas for overnight nurses and contact numbers so you can quickly find the information you need.



For more help with care at home, have a look at the film guides for carers at mariecurie.org.uk/filmguides

Hospice

Hospice care is about comfort, peace and support for the patient and their family. Expert nursing and medical care is available around the clock, in a homely setting where visitors are warmly welcomed.

I want for nothing here (at the hospice). The staff give me all the medication I need and plenty of emotional support.

Sylvia, living with a terminal illness

Hospices are run by various charities, including Marie Curie. People don't have to stay in the hospice all the time, and it's not unusual to have short stays back at home.



We have more information to help people decide where to spend their last days at mariecurie.org.uk/planningahead

Nursing home

This is another option if it's too difficult or impossible to care for your partner, relative or friend at home, or if they don't want to be at home. If your relative or friend already lives in a nursing home, they may prefer to return there, where they feel settled and know the staff.



Layton Thompson/Marie Curie

If you and your partner, relative or friend are considering a hospice or a new nursing home, make a visit to see what it's like. The staff should be happy to answer any questions.

Having a written care plan

England, Wales or Northern Ireland

Wherever they go after leaving hospital, your partner, relative or friend should be discharged with a written care plan. You may find that many different people become involved in your relative or friend's care, and it's vital that everyone knows what they want, and what has been agreed.

This is different to making an advance care plan (see page 6), which is something that your relative or friend decides with your input if you're the main person involved in their care.

When your partner, relative or friend is discharged, staff should give you a very clear idea about:

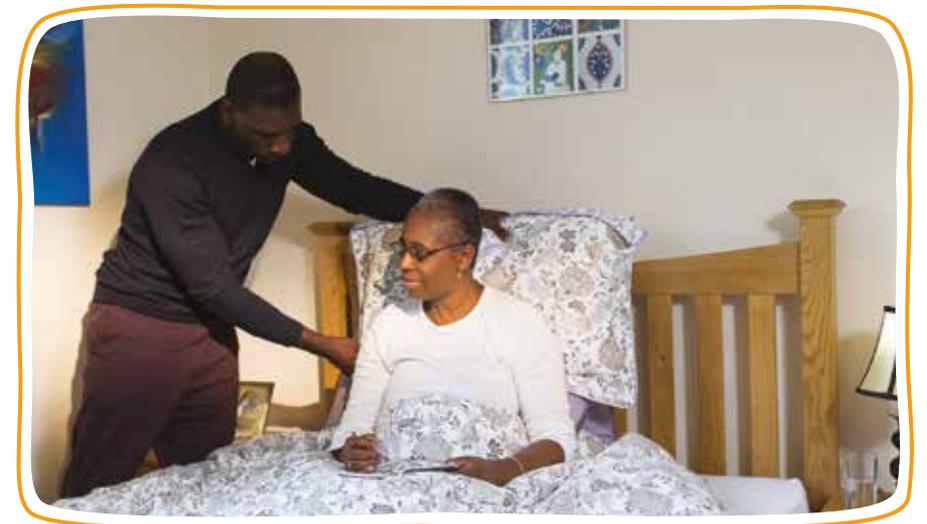
- their medical condition, and how it may change over time
- what care they will need
- who can help with problems, and how you can contact them

Scotland

Your partner, relative or friend will be discharged from hospital after their healthcare professionals have assessed the care they need. They'll be given a copy of their discharge document, which gives a summary of their hospital admission details. A visiting social care professional or district nurse will then create a care plan for your partner, relative or friend at their home, nursing home or hospice.

Help with care needs

With the right planning, your partner, friend or relative should be able to have all of their care needs met to a high standard. What matters most is having care and support from professionals with the right skills and experience.



Chris Renton/Marie Curie

Support from the hospital

The hospital's palliative care team can be extremely helpful, especially when your relative or friend is preparing to be discharged from hospital. These doctors, nurses and other professionals are experts in caring for people as they approach the end of their lives.

They can also give you lots of practical and emotional support. For example, they can explain what you might expect in the days or weeks ahead, and help you to put arrangements in place. If they're not already involved, ask for their assistance.

Once your relative or friend is discharged from hospital, their GP will take charge of their medical care. Even if they're managing well, it's a good idea for the GP to visit regularly. If your partner, relative or friend has returned home, their care may be shared by a team of healthcare professionals who will work together to meet all their needs. The team may include:

An occupational therapist

They can visit your home to determine what adaptations and equipment might be needed. Visit mariecurie.org.uk/adaptations for more information on different types of adaptations and equipment.

The district nurse

They can provide expert nursing care in your home.

Healthcare assistants or other paid carers

They can help with personal care, such as washing, dressing, and using the toilet.

Marie Curie Nurses or Healthcare Assistants

They can work closely with the district nurse. They may be able to come to your home and care for your partner, friend or relative.

A dietician

They can advise on dietary needs and ensure your friend or relative has the correct food if they have problems swallowing.

A social worker

You and your partner, friend or relative may need help from different services. Social workers can help you find your way around the health and social care system.

A palliative care nurse

They can visit regularly to advise the nursing team on managing pain, if there is any, and other symptoms. They can also help with practical problems, and listen if you're worried or upset.

A chaplain or other spiritual adviser

They can offer spiritual support to you and your partner, relative or friend, if you want them to. It doesn't matter what your beliefs are, or whether you have any religious beliefs at all. They can also support you before and after someone has died. See page 19 for more information about spiritual support.

Managing care at home

If care at home is a possibility, you'll need to get a realistic view of what to expect, and make plans. Here are some questions to think about.

Do they want to be cared for at home?

If your partner, relative or friend is unable to communicate their wishes, do they have an advance care plan or have they made other plans for how they want to be cared for? As someone who knows the person well, it may fall to you to speak on their behalf.

How does the rest of the family feel?

It's hard to accept that someone you care about is dying. Is everyone ready for the experience of seeing this through at home? It might also change your relationship with the person. For a while, it might mean there's less time for other people in the family, who also need attention and support.

If children or teenagers are involved, they'll need extra help to understand what's happening and to cope. On the other hand, the family may really welcome the chance to have the person they care about at home, so they can help with care and spend as much time together as possible.

As a family we want Mum to be cared for at home as it's what she wants too, but there have been tough times. We were really struggling on our own but now we have help we know we are doing the right thing.

Patrick, family member



We have more information about supporting children on our website at mariecurie.org.uk or call **0800 090 2309***.

What will your role be?

You might want to take on a lot of the care yourself – or you might not. Caring for a person who is terminally ill can be very rewarding, and bring you closer together. But it's also an around-the-clock job that can put a lot of demands on your wellbeing.

It may change your relationship with the person. You might feel you're not able to care for them at home. This could make you feel guilty, or as if you've let them down.

Remember that you can get help at home with carrying out personal care tasks. Call the Marie Curie Support Line on **0800 090 2309*** or visit mariecurie.org.uk for more information. You can also find details of some useful organisations on pages 21-22.

What help will you need?

In addition to specialist nursing care, as they grow weaker the person will need a lot of help with washing, eating and using the toilet. They may need incontinence care if they lose control of their bladder and bowels. If you're busy with caring, you may need extra help with housework, shopping, laundry and cooking.

Some people don't like to accept help from trained carers, but it can be very difficult to do it all on your own. And these helpers often become a good support system for you.

Do try to take care of yourself. One way of doing this is by arranging respite care, which means having someone to stay with your partner, friend or relative sometimes so you can have regular breaks and a good night's sleep.



We have more information for carers, including sources of support, on our website at mariecurie.org.uk

Planning for emergencies

It's especially distressing when emergencies happen at night and over the weekend. Check with your doctor about who to call at these times, so your partner, relative or friend gets prompt and appropriate care if they need it. You might also be given a 'Just in Case' box by your healthcare team. These contain emergency medical supplies like painkillers, along with instructions on how to use them.

What's practical?

You might need to adapt your home and find room for a lot of equipment such as a hospital bed, a hoist and a commode. You'll need to be able to get to both sides of the bed, so it can't be against a wall. Do you have enough room, and can you manage the physical work?

You might find our film guides for carers helpful. These can be found on the Marie Curie website at mariecurie.org.uk/filmguides. They cover some typical tasks you'll need to carry out if you're caring for someone at home. You might also want to know more about getting specialist equipment and adaptations. Ask an occupational therapist or Marie Curie Nurse about this, or see our information online.

Try to talk to someone

Wherever your friend or relative is staying, you'll need someone to talk to about it. Friends and family might be the natural place to turn, but sometimes someone who's not so close can really understand what you're going through. Nurses and trained carers are very good at this. You can also call the Marie Curie Support Line on **0800 090 2309*** for information and support.

Coping with changes

While you're looking after someone who's dying, you're very close to everything they experience, and there can be distressing moments. It's less difficult to cope if you know what physical and mental changes to expect as the end of life comes nearer. It might also help to know how other people have managed in a similar situation.

In the last days and weeks, a person's condition can change rapidly. Here are some of the changes that can often happen.



Layton Thompson/Marie Curie

Eating less and losing a lot of weight

It's very hard to see someone you care for become thin and frail, but they may not feel hungry. Their body is slowing down and eating too much might make them feel worse. Whether extra nutrition is needed or not is a decision for the person's doctor, who will take their wishes into account.

If you find this situation difficult, it might help to focus on other ways to make it easier for the person and show how much you care for them. For example, giving them a gentle hand massage is very soothing.

Drinking less

Again, the body's needs are changing and insisting the person has more drinks than they need could cause them discomfort. It may also become harder to swallow. They might prefer to suck on a bit of ice or an ice lolly. You could try freezing some of their favourite drinks in an ice cube tray, so that they can still enjoy the flavour. As with nutrition, whether extra fluids are needed is a decision for the doctor, who will take the person's wishes into account.

Sleeping a lot

Near the end, the person might sleep longer, and more often. When they're awake, they might seem distant and drowsy. But they can still hear what's going on, so it can be a comfort to talk gently to them. If the house is too silent, try playing some quiet music or radio programmes that the person likes.

Confusion

Some people become agitated, restless and anxious. They might say things that don't make sense, or see things that you don't. If the person is distressed, sedative medication might be recommended.

You can help by talking calmly to them and trying to understand what they're thinking about. Sometimes it works to try to distract them, for example by playing some music that you know they'll like. Just holding their hand can help them feel safer and reassured.

Stories from experience

You can hear how other people managed by visiting [healthtalk.org](https://www.healthtalk.org) which has several articles and videos made by people who've cared for someone at the end of their life.

Final moments of life

It may be reassuring to know that for most people with a terminal illness, the final moments are peaceful.

Loss of consciousness

Most people lose consciousness near the end of their life. But there may still be some awareness of other people in the room, and hearing what's being said. This can be a good time to say some last words and hold the person's hand.

Skin changes

The skin can change colour and limbs, hands and feet may feel colder, because the blood circulation is slowing down.

Breathing changes

Breathing may become loud and noisy if a lot of mucous has built up in the lungs and airways. It's not a medical term but some people call this the death rattle. You may find some of the breathing

patterns alarming or distressing but they generally don't cause any discomfort.

As the moment of death comes nearer, breathing usually slows down and becomes irregular. It might stop and then start again or there might be long pauses between breaths. This can happen quickly, or it can take a long time before breathing finally stops.



There's more information about changes in breathing patterns at the end of life, including a film guide for carers at mariecurie.org.uk/breathingchanges

Moment of death

It's not always clear when the exact moment of death occurs. When a person dies, those around them may notice that their face suddenly relaxes and looks peaceful. On the rare occasion this is not the case, it's unlikely that the person will have been aware of what's happened.

A doctor or other healthcare professional will announce the death if breathing, the heart and circulation have stopped. They may also check the eyes and body for other signs.

There are many different beliefs about what happens after death, but those nearby may sense that consciousness has left. There is more information about the final moments of life on our website at mariecurie.org.uk

When someone you love has a terminal illness, you're scared and don't know what will happen. Our nurses explained the signs to look out for, like changes in my mum's breathing. They gave us that bit of medical reassurance.

Caroline, family member

Bereavement support

This can be a very upsetting time for family and friends, so emotional and spiritual care for you and those around you is important too. Your nursing team, including your Marie Curie Nurse if you have one, can help. They can also arrange further bereavement support, so that family and friends don't have to cope with their feelings alone. We have a booklet about practical and emotional support during a bereavement. Call **0800 090 2309*** to order a copy for free.

We've also listed some organisations that offer free bereavement support on pages 21-22, or call the Marie Curie Support Line on **0800 090 2309*** to find support near you.

End of life experiences

Some people who've been close to someone near the end of their life talk about more than the physical closing down of the body's systems. People nearing the end of their life may want to resolve matters from their past, or they may experience visions or dreams. For more information about these experiences, visit mariecurie.org.uk/endoflifeexperiences

Spiritual support

If you would like more support at this time, you may want to speak to a spiritual adviser or faith leader. Most faith leaders will have been through this experience with many others and they're happy to help people of any or no religious faith.

Ask your hospital or local hospice to put you in touch with someone nearby. Most hospitals and hospices offer religious, spiritual and pastoral care, with representatives from different faiths.

It's difficult to think about this now, but faith leaders may also help your partner, relative or friend have a calmer death and create a sense of deep respect when the time comes. They can also support you before and after the person you care about has died.

Caring for someone near the end of their life is hard, and having this kind of support can help you stay strong, so you can be there for the person you care about.

How we can help

We help everyone affected by a terminal illness get the information and support they need, whether you have an illness yourself or you're a family member or friend.

Marie Curie Support Line

0800 090 2309*

Ask questions and find support. Open 9am to 5pm Monday to Friday. (Your call may be recorded for training and monitoring purposes.)

*Calls from landlines are free, but there may be a charge if you're calling from a mobile. Check with your mobile provider for details.

Calls from any type of phone will be free from 1 July 2015.

Marie Curie Community

community.mariecurie.org.uk

For anyone affected by terminal illness to share experiences and support each other. Available 24 hours a day.

More information and further support

We also have an extensive range of information materials available to view online or in print. Visit **mariecurie.org.uk/help** where you can also find film guides, information about our services, and links to further support.

Marie Curie Nurses

Marie Curie Nurses work night and day, in people's homes across the UK, providing hands-on care and vital emotional support. If you're living with a terminal illness, they can help you stay surrounded by the people you care about most, in the place where you're most comfortable.

mariecurie.org.uk/nurses

Marie Curie Hospices

Our hospices offer the reassurance of specialist care and support, in a friendly, welcoming environment, for people living with a terminal illness and their loved ones – whether you're staying in the hospice, or just coming in for the day.

mariecurie.org.uk/hospices

Marie Curie Helper

We know the little things can make a big difference when you're living with a terminal illness. That's where our trained Helper volunteers come in. They can visit you regularly to have a chat to over a cup of tea, help you get to an appointment or just listen when you need a friendly ear.

mariecurie.org.uk/helper

Useful organisations

Bereavement Advice Centre

0800 634 9494

bereavementadvice.org

Offers a free helpline for people who are bereaved and for professionals. It also has information on its website about practical matters and coping with grief.

Carers UK

0808 808 7777 (England, Wales and Scotland)

028 9043 9843 (Northern Ireland)

carersuk.org

Provides expert advice, information and support to carers. There are links to its national services from the website homepage.

Cruse Bereavement Care (England, Wales and Northern Ireland)

0844 477 9400

cruse.org.uk

Provides bereavement support, either face-to-face or over the phone, from trained volunteers around the UK.

Cruse Bereavement Care Scotland

0845 600 2227

crusescotland.org.uk

Provides bereavement support, either face-to-face or over the phone, from trained volunteers in Scotland.

Winston's Wish

08452 03 04 05

winstonswish.org.uk

A child bereavement charity which offers specialist practical support and guidance to bereaved children, their families and professionals.

Did you find this information useful?

If you have any feedback about the information in this leaflet, please email us at **review@mariecurie.org.uk** or call the Marie Curie Support Line on **0800 090 2309***.

Further information

This leaflet was produced by Marie Curie's Information and Support team. It has been reviewed by health and social care professionals and people affected by terminal illness.

If you'd like the list of sources used to create this information, please email **review@mariecurie.org.uk** or call the Marie Curie Support Line on **0800 090 2309***.

Notice

The information in this publication is provided for the benefit and personal use of people with a terminal illness, their families and carers.

This information is provided as general guidance for information purposes only. It should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified medical practitioner. For legal, financial or other matters covered by this information, you should also consider seeking specific professional advice about your personal circumstances.

While we try to ensure that this information is accurate, we do not accept any liability arising from its use. Please refer to our website for our full terms and conditions.

Marie Curie – what we're here for

We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

Marie Curie Support Line
0800 090 2309*

Ask questions and find support. Open 9am to 5pm Monday to Friday. (Your call may be recorded for training and monitoring purposes.)
mariecurie.org.uk/help

You can also visit **community.mariecurie.org.uk** to share experiences and find support by talking to people in a similar situation.

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