

Being cared for at home

Information for you and the people caring for you



Introduction

This booklet is for people living with a terminal illness, and their family and friends. Inside you'll find information about the care and support that's available for you.

If you have any questions about your care or individual circumstances, speak to your healthcare team.

You can find more information and support on our website at **mariecurie.org.uk/support** or contact the Marie Curie Support Line on **0800 090 2309***.



Throughout this booklet, you'll find images like this one. Next to each image, we've included a website address where you can find practical videos on caring for someone at home.

*Calls are free from landlines and mobiles.
Your calls may be recorded for training and monitoring purposes.

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Ben Gold/Marie Curie

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You may want to be at home as your health gets worse and towards the end of your life. Being close to the people you know, having privacy, and being in familiar surroundings can be important and comforting.

Wherever possible, your healthcare professionals will try to support your wish to be at home, and provide care to help you achieve this.

If you're in hospital or a hospice but would prefer to be at home, tell your healthcare professionals. They can talk with you about whether this is possible and the support you'll need.

What to expect from your care

You should receive care that is centred around what you need and what you want. We've outlined the care you might receive below. This can vary depending on your needs and the care available in your local area. Ask your healthcare team about what type of care you might need now and in the future, and what is available.

Medical and nursing care

Your healthcare professionals should check how you feel and respond to your needs. You might hear the terms 'palliative care', and, 'end of life care'.

Palliative care is care that helps people who have a terminal illness or complex health condition to have the best possible quality of life. It includes treatments for symptoms such as breathlessness, pain, feeling sick or anxiety. It also includes emotional support for you and the people close to you.

End of life care is an important part of palliative care. It's usually for people who are in the last year of their life.

Your GP or district nurse (see page 16) will coordinate your care at home and organise for other professionals to help. It's unlikely that healthcare professionals will be able to be with you all the time, so it's important to think about whether you're able and willing to stay at home.

Medical and nursing care is free in the UK.

Day-to-day personal care

You may need help with things like washing, dressing, eating and going to the toilet. Your friends and family may be able and willing to help with some of these things. Speak to your GP, district nurse or social services if you need more support. They'll be able to assess what help you need and talk to you about what's available.

They may be able to arrange for home care workers to visit your home and help with your personal care (see page 17). They'll usually visit for specific tasks, for example visiting in the morning to help you get up, go to the toilet and wash.

Personal care is sometimes free. Your local council or trust may pay for social care directly or they might give you money to pay for personal care.

But, you may have to pay for some or all of your social care yourself. This depends on the care you need and where you live. It's also usually 'means tested', which means it depends on how much income or savings you have. Social services can tell you more about this.

If you feel you need more care than you're getting, speak to your healthcare team or social services about the best option for you. They'll look at what care you might need. If you need

services that they can't provide, they may suggest that you contact a private company or agency. These companies can provide services from professional carers, which you pay for.

Planning your care

Your healthcare professionals will discuss your treatment, care and support with you. If you agree, they'll also discuss this with the people closest to you.

You may want to talk to them about where you'd like to be cared for if you become very ill and where you'd prefer to spend the last weeks or days of your life. For example, whether you'd prefer to stay at home if you are able to, and whether you'd prefer to be in a hospice, nursing home, or hospital if your needs can't be managed well at home.

If you haven't had any care at home yet, speak to your GP about your needs and what care is available.

Your care plan

Your healthcare professionals will put together a care plan that reflects your wishes and care needs. They will look at the care plan regularly with you and change it if needed. You can also ask them to change your plan.

The care plan tells your healthcare professionals about your care. This includes what treatment and care you've already had, what is planned and what your wishes are. The care plan may be written on paper or electronically. Either way, you can ask for a copy from your healthcare professionals.

Every healthcare professional should record the care they provide and any discussions you have about your wishes.

You may want to make decisions in advance about the type of care you would like in the future if you become unable to communicate your wishes. Read more about making decisions about your future care on page 25.

Giving your consent

Professionals involved with your care need to be sure that you consent (agree) to any treatment or procedure.

Before they start, they must explain what they will do, any risks involved and why they are doing it. It is your right to refuse any treatment or procedure offered.

Emotional support

Feelings you might have

It's natural to feel anxious or have a low mood when you're ill. These feelings may be worse towards the end of your life and may not be easy to recognise.

You might feel isolated or worry about being left alone, especially if you haven't been staying at home for a while.

You may have very changeable emotions. Your reactions towards the people caring for you or others who are trying to help may also keep changing.

You may experience:

- feeling hopeless or worthless
- apathy or loss of interest in your surroundings
- loss of appetite (this can also have physical causes)
- anger or irritability with other people, especially those caring for you

- unexpected or extended episodes of crying
- sleep problems (this can also have physical causes).

These can be symptoms of depression, so it's important to get some support to help you cope.

You might find it hard to admit to your feelings. Denial is common and is a way for people to cope with difficult feelings and emotions, particularly if they are approaching the end of their lives.

Coping with your feelings

You don't have to cope with your thoughts and feelings alone. There is support available and there are people who can help.

You can tell someone in your healthcare team about how you're feeling. They'll be able to tell you about what professional support is available, including counselling or support groups (see page 21).

You can also contact the Marie Curie Support Line on **0800 090 2309*** to talk to our trained staff about how you're feeling. They can provide a listening ear and tell you about how to get more support.

Your family and friends may be able to help you by talking and listening to you. Sometimes you may just want to sit in silence with someone for company.

You can visit mariecurie.org.uk/feelings for more information about expressing and coping with your feelings.

Your family and friends may also find themselves feeling angry or sad, or having some of the feelings and symptoms we've outlined above. Read more about how they might feel and what support is available on page 32.

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You may meet different health and social care professionals while you're being cared for at home.

It's sometimes hard to work out who to contact about what. You'll usually have a key point of contact – this might be your GP, district nurse, or social worker. It depends on your needs and what services are available in your area. Don't be afraid to ask for support – if the person you ask can't help, they'll tell you who can.

Tell your healthcare professionals if you'd like them to share information about your condition with your carer or a family member or friend. They'll only discuss your condition with you unless you tell them you want other people to know.



Layton Thompson/Marie

Your key contacts

You can fill this section in so that you know who the key people are for you to contact. Ask your doctor or nurse if you're not sure.

My GP

Name: _____

Address: _____

Telephone: _____

Notes: _____

My district nurse or community nursing team

Name: _____

Telephone: _____

Notes: _____

My pharmacist

Name: _____

Address: _____

Telephone: _____

Notes: _____

My social worker

Name: _____

Address: _____

Telephone: _____

Notes: _____

Who to contact in the evening, at night or at weekends

Name: _____

Telephone: _____

Notes: _____

GP and primary healthcare team

The primary healthcare team is a team of healthcare professionals, including your GP. They are usually based in a health centre or surgery.

If you need care at home, your GP will liaise with the district nurse, who is part of the healthcare team. The GP is in charge of your medical care which includes prescribing your medications.

Specialist palliative care team

Specialist palliative care teams are made up of different professionals who are experts in palliative and end of life care. They work with your GP and primary healthcare team. They can provide specialist advice and treatment.

District nurses

District nurses are part of the community nursing team and your primary healthcare team. They organise and coordinate home care and can arrange for you to access other professionals and services.

These services vary depending on where you live. They may include support from other community nurses, Marie Curie Nurses, specialist nurses, and social services.

The district nurse can also provide you with information about local services. This can vary but might include:

- support groups
- your local hospice
- complementary therapy practitioners

- interpreting services
- financial and benefits support.

Clinical nurse specialists

Clinical nurse specialists may be part of the specialist palliative care team. Some have a special focus on supporting people with a particular illness, such as cancer or heart disease.

They are highly trained in managing pain and other symptoms. They can also offer emotional support and practical advice to people and their families. They work with and advise the primary healthcare team.

Healthcare assistants and care workers

Healthcare assistants and care workers are trained to provide personal care and healthcare. They might come into your home to help you with specific tasks, such as washing and dressing. They are sometimes employed by your local council, or by a private agency or company.

Marie Curie Nurses and Healthcare Assistants

Marie Curie Nurses and Healthcare Assistants usually spend several hours at a time in your home. They provide nursing care and emotional support, often overnight. To find out if Marie Curie Nurses and Healthcare Assistants are available in your area, speak to your GP or district nurse.

Physiotherapists and occupational therapists

A physiotherapist or occupational therapist can help you to live independently for as long as possible. They often help with breathing problems or problems moving around. They can provide walking frames and other equipment that you may need.

Hospices

Hospices provide specialist care for people with serious illnesses, usually in the last years and months of their life. They also provide support to carers, families and children.

Hospice care focuses on managing symptoms, improving quality of life, and helping you remain independent for as long as possible.

You might stay in a hospice to get your symptoms under control and give people close to you a break from caring. Or you might visit the hospice for appointments and support. Some hospices offer a 'hospice at home' service which provides nursing care and support in your home.

Hospices also care for people staying in the hospice at the end of their lives, making them as comfortable as possible. If you choose to die in a hospice, you'll usually move there in the last few weeks of your life.

Ask your GP or district nurse if there is a Marie Curie Hospice or other hospice near you, and whether they think a referral would help. For more information about Marie Curie Hospices, visit mariecurie.org.uk/hospices or call the free Marie Curie Support Line on **0800 090 2309***.

You can also find out where your nearest hospice is from Hospice UK at hospiceuk.org or by calling **020 7520 8200**.

Social services

Social services can organise services that would be helpful to you and the people caring for you, for example help with shopping and deliveries of prepared meals. You can also contact social services if you need support from care workers or are thinking of moving to a care home or nursing home. They can assess your needs and explore your options with you. Services vary across the UK – talk to your social services about what's available in your area.

You can find contact details of your local social services in your phone directory, on the internet, or by contacting your local council or trust.

Support from people close to you

Your family and friends

You may have one or two people who are supporting you on a regular basis – this might be a partner, family member or friend. They might help you with things like cooking your food, picking up your medicines, or helping around the house.

Other family and friends often want to help, but may feel awkward about offering support. They may find it useful if you make suggestions about ways they can help. Some people find it beneficial to have a list of things that others can help with. Then, if a friend or family member asks if there's anything they

can do, you could choose something from the list and ask them to help.

You could ask them to help with:

- cooking a meal
- keeping you company
- shopping
- looking after a pet.

If they're able to spend some time with you, this may allow any other people caring for you to have a break.

They can also visit mariecurie.org.uk/family-friends for more ways to help.

Having visitors in your home

Visitors can make you and others looking after you feel better. However, sometimes you may be tired or the time of the visit may not be convenient.

You or the people caring for you may find it useful to mention some of the following things to potential visitors:

- Certain times may not be convenient, for example mealtimes or when a healthcare professional is visiting.
- Having visitors can be tiring when you are unwell – it may help to limit visits to half an hour, or to a couple of visitors at a time.
- They could check with you that you're ready for visitors before they come over, and try not to be upset if you aren't feeling up to it.

If a relative or friend seems reluctant to visit, it may be because they feel uncomfortable or are worried about visiting.

They could be worried that they'll become upset in front of you, or that they will say or do the wrong thing or upset you.

It might help to talk to them about what to expect and how you're feeling. You could also suggest practical things that they can do to help.

Other support that's available

Support groups

There are support groups for people with terminal illnesses or particular health conditions. Members usually include people who have personal experience of a similar situation. At the support group, people may talk about the challenges they have and how they cope with things.

To find a local support group, ask your district nurse or GP or call the free Marie Curie Support Line on **0800 090 2309***.

If you don't want to go to a support group or aren't able to, online communities like the Marie Curie Community at community.mariecurie.org.uk can be a good place to share your experiences and speak to people in a similar situation.

Counselling

A trained counsellor or psychologist can help you understand and work through your feelings. Counselling is sometimes free at hospices, hospitals or GP surgeries. If this is something you want to try, ask a member of your healthcare team. They can let you know what's available locally and can help you decide which treatment is best for you.

You may also want to contact a private counsellor – someone that you pay directly. To find a counsellor near you, contact the British Association for Counselling and Psychotherapy at **bacp.co.uk** or call **01455 883300**.

Spiritual support

Some people find that they start questioning the meaning of their life or worry about things from their past. You may wish to contact a local religious leader or spiritual adviser for support. They're usually happy to help, even if you haven't been actively involved with a religious group.

If you are in contact with a Marie Curie Hospice or another local hospice, the hospice chaplain or spiritual coordinator can offer advice and recommend a local person for you to contact.

Complementary therapies

Complementary therapies are often used alongside your usual treatment and care. They could help you feel more relaxed or better able to cope with your illness or treatment.

Complementary therapies include relaxation, massage, aromatherapy and reflexology.

If you want to try a complementary therapy, discuss it with your healthcare team first. They'll be able to tell you whether it's safe for you to have a therapy or if there are any medical reasons why it's not a good idea. They may also be able to tell you about local complementary therapy practitioners – these services are sometimes free through a hospice. You can also contact the Complementary and Natural Healthcare Council on **020 3668 0406** or visit **cnhc.org.uk**

It's important to check that your complementary therapist is qualified. Make sure they're aware of your illness and any treatments you've had or are having.

Find out more about complementary therapies at **mariecurie.org.uk/complementarytherapies**



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Making decisions about your future care

A time may come when you can't make decisions or communicate your wishes about your care and treatment. You may want to make sure that your healthcare professionals and family or friends know how you want to be cared for.

Advance care planning

Advance care planning is about discussing and planning the care you would prefer and anything that is important to you. You might do this with your healthcare professionals, as well as your friends and family.

If you record your wishes in writing you should ask for a copy to be added to your medical records and care plan. Even if you don't have anything in writing, you can ask for your wishes to be added to your records.

If you change your mind, you can ask for your medical records and care plan to be updated.

In England, you may be able to have your wishes added to your 'Summary Care Record'. This means that health and social care professionals in different settings can see what care you'd prefer if they're caring for you.

If you're unable to communicate your wishes, your doctor will speak to anyone who is named in your health or welfare Power of Attorney (see page 27). If there's no Power of Attorney, they may ask your close family and friends what you might have wanted.

Your doctor has to use their medical judgment and act in your best interests, whoever they talk to.

To find out more, visit mariecurie.org.uk/planningahead or speak to your healthcare professionals.

Power of Attorney

You may want to set up a Power of Attorney to choose someone to make decisions on your behalf.

In England, Wales and Scotland, you can choose someone to make decisions about your healthcare and other aspects of your welfare. They will make decisions on your behalf if you become unable to do so in the future. This is called a Lasting Power of Attorney for health and care decisions in England and Wales, and a Welfare Power of Attorney in Scotland. There is currently no equivalent to a health and Welfare Power of Attorney in Northern Ireland.

Across the UK, you can choose someone to make decisions about your financial affairs and property. This is called a Lasting Power of Attorney for property and financial affairs in England and Wales, a Continuing Power of Attorney in Scotland, and an enduring Power of Attorney in Northern Ireland. You can choose whether you want the person to make decisions immediately or only if you become unable to do so in the future.

We have more information about the different types of Power of Attorney and how to set one up at mariecurie.org.uk/attorney

Deciding not to have treatments

You can decide what treatments you would want to refuse in specific circumstances in the future. This is sometimes called an Advance Decision to Refuse Treatment (ADRT), a Living Will or, in Scotland, an Advance Directive. You can't insist on receiving

specific treatment (for example, you can't insist that a doctor resuscitate you, as it might be against their medical judgment).

You will have to state what treatments you wish to refuse and in which circumstances your refusal of treatment will apply.

For instance, you might state that if you are expected to die within a few days, you do not want to be treated with antibiotics if you get an infection. But you can't say that you don't want any medical treatment.

You don't need to use medical terms. Your GP or another healthcare professional can advise you about what to include and what may be relevant in your situation.

Do tell your healthcare team that you've recorded your wishes. Give them a copy of any paperwork and ask them to put a copy in your medical records and care plan.

You can make changes to your wishes if you change your mind. If you update your wishes in writing, make sure everyone gets a new copy.

It's a good idea to review your paperwork on a regular basis, even if there are no changes to your health, just to make sure it still reflects your wishes.

Discussing your choices with your family may make it easier for them to understand and accept your decisions.

Funeral planning

Thinking about and planning your funeral can feel very difficult. Some people want to be involved in planning their own funeral. Others don't feel comfortable doing this – and that's OK too.

If you feel able to think about this now, it may help your family after you've died. When people have just been bereaved, they may not have the time or ability to explore all available options. If you discuss your wishes for your funeral with your family or friends, they'll be clearer about what you want and may feel more prepared.

Things to consider include, who you'd like to be invited, what music or readings to have, whether to be buried or cremated, and where to be buried or have your ashes scattered.

If your partner or family don't wish to discuss your funeral, you could write down your wishes so they have something to help them make decisions in the future.

Paying for a funeral in advance

If you want to pay for your funeral in advance, you can arrange this by taking out a pre-paid funeral plan or taking out funeral insurance. You can also set up a savings account with money for your funeral and tell your solicitor and close family or friends.

Marie Curie's booklet, *When someone dies*, gives an overview of funeral planning and lists useful sources of information. To order a free copy, visit **mariecurie.org.uk/publications** or phone **0800 090 2309***.

You can also visit **mariecurie.org.uk/funeral** for more information.



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Dealing with change as a carer

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When someone close to you has a terminal illness and needs extra care and support, it can change your life in a lot of ways.

You may find that your time and energy is taken up with supporting your friend or family member. You might be helping with things like dressing, preparing food, taking medicines and contacting health and social care professionals. You might experience changes in your family roles and relationships. And you may have to deal with changes to your work and finances.

Your feelings may change from day to day, hour to hour and even minute to minute. It's normal to feel denial, anger, fear, loneliness, sadness, guilt, or low in mood.

You may sometimes feel disbelief that the person you're caring for has a terminal illness, and find this difficult to accept.

These feelings are normal and there is support available to help you cope with them.

Coping with your feelings

Supporting and caring for someone with a terminal illness may be too much for you to handle by yourself.

Talking to others about your feelings can help you to deal with your emotions and the impact the person's illness is having on your life. You may find it easier to talk to a close friend rather than someone in the family.

Support is available – you may find it helpful to speak to a friend, therapist, counsellor or someone at a support group.

You can also contact the Marie Curie Support Line for free emotional support on **0800 090 2309***.

Visit mariecurie.org.uk/being-there for more information on supporting someone with a terminal illness.

Taking time out

Providing care for someone who is ill can place physical and emotional demands on you. It's important that you take time out for yourself. You could spend time with your friends, do some gentle exercise or have some time alone.

You might be able to organise for someone to look after the person who is ill while you take a break – this is called respite care. It might be a friend or family member, a healthcare professional or a volunteer. Speak to your health or social care professionals about what support is available.

Remember that you're human and you can only provide the support you're able to. Try to get the most out of your day and, if you have any spare time to yourself, think about what you would like to do. You might want to relax by reading a book or listening to music.

If you work, you may choose to continue with this if it's possible. Some people find that it's a good distraction and can provide a sense of continuity.

Looking after your health

You might find that looking after your friend or family member makes you feel tired or exhausted. Rest is very important, and short naps can help revive your energy levels. Doing some physical activity can also help you feel more energetic.

You may become more likely to have physical and mental health problems. Make time to see your own GP if you feel unwell. And try to eat a healthy and balanced diet to give you the energy you need.

Coping with the feelings of the person you care for

The person you are caring for is likely to have good and bad days. They may have physical health problems, and they might be finding it difficult to cope with their diagnosis or prognosis. They may also try to hide their feelings from you or behave in a way that you don't expect.

Sometimes they might act as if nothing is bothering them. They might not want to upset you by talking about their illness. At other times they might blame you for their illness or become angry at you.

These changes can be very distressing for you and may affect your relationship with the person you're caring for. If you're struggling to cope, it's important that you talk to someone about it . You could speak to a good friend, support group, your own doctor, or the healthcare professionals caring for the person who is ill.

You can find more information on looking after yourself at **mariecurie.org.uk/carers**. You might also want to share your feelings with people in a similar situation through the Marie Curie Online Community at **community.mariecurie.org.uk**

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Before you help someone change
position or move

These pages provide general information about moving and handling someone. They won't be suitable for every person in every situation, so it's important that you get advice on your individual circumstances.

If the person you're caring for needs support moving or carrying out activities, talk to their district nurse or other healthcare professionals. They'll be able to give you advice about your individual circumstances and may provide training if you need it.

You must ensure you look after your own health and not move and handle the person you are caring for unless you are fit and well and have been advised by healthcare professionals.

Marie Curie, its employees and its agents shall not be liable whether in tort or any other form of legal liability for any loss, damage or injury (other than personal injury caused by our negligence) caused by following the guidelines contained in this booklet.

Helping someone move

If you're looking after someone at home, this section will help explain some ways you can help them move around.

It's important for you to encourage the person you're caring for to do as much as they are able and willing to do themselves for as long as possible. This helps to keep up their morale and helps them stay independent.

If you're not confident or comfortable helping the person move, talk to their GP or district nurse about what support is available. They'll be able to show you how to do things or tell you about who else can help.

Before they move

Before you help the person move, think about these things:

- Clear the floor of shoes, rugs, electronic cords or wires, or other items that you might trip over or that could get in the way.
- If you are helping the person to a chair or commode, position it near the bed.
- Explain exactly what you plan to do so that the person understands and can work with you.
- Be as gentle as possible when helping the person move.
- Take it step by step, don't rush.

General safety

These tips can help to reduce the risk of injury:

- Make a good stable base with your feet, one foot slightly in front of the other, hip width apart.
- Bend your knees, and use your legs to power the move.
- Keep your back in a comfortable upright position.
- Keep your head up.
- Use any equipment that you've been taught how to use.
- If in doubt about helping the person move, ask for advice.

Ask a healthcare professional to show you the movements before carrying them out yourself.

You should only help someone get out of bed, stand up, or walk if they are able to do it on their own. You shouldn't bear all or even most of the weight of another person. You could injure yourself or hurt them. Instead, speak to their healthcare professionals about what to do.

You should only help them move around if they can understand what you're doing and follow your instructions.

Moving someone in bed

You may want to change the person's position in bed for comfort or to wash them. The following moves will allow you to guide them into the right position and move them without needing to lift them.

Before you start, move the bedclothes and extra pillows out of the way. If there's a backrest and it's raised, make the bed flat. Make sure the person isn't at the edge of the bed.

Step 1

Cross one leg over the other leg towards you.



Step 2

Move their arm over their chest towards you.



Step 3

With one hand on their hips and the other behind their shoulders, roll them towards you onto their side. Make sure that the person is not on the edge of the bed.



Watch this manoeuvre in action at mariecurie.org.uk/movinginbed

Helping someone to stand

This section explains how you might help someone stand.

You should only try to help someone move if they are able to stand by themselves, and you're providing minimal assistance. If this is not possible, it may not be safe to help the person to stand.

It can help to make sure they have chairs or beds that are a stable and a good height for them to get out of.

Before you start, clear the floor of things like clothes, shoes, bags, and electronic wires or cords. You should both wear shoes or slippers in case the floor is slippery.

Step 1

With the person you're helping already on their side, ask them to drop the lower part of their legs over the side of the bed.



Step 2

Have them gently push themselves into a sitting position.



Step 3

Ask them to move to the edge of the bed or chair and place their hands on the bed.



Step 4

Sit alongside them and place your hand around their waist. If they are in a chair, stand alongside them and bend your knees, keeping your back straight.

**Step 5**

Both of you should place one foot slightly in front of the other. On the command 'ready, steady, stand', they should stand by pushing both hands down on the bed.

**Step 6**

Use small steps and a walking aid if needed.

If they need to hold your hand for support, don't interlock your fingers or thumb with theirs.

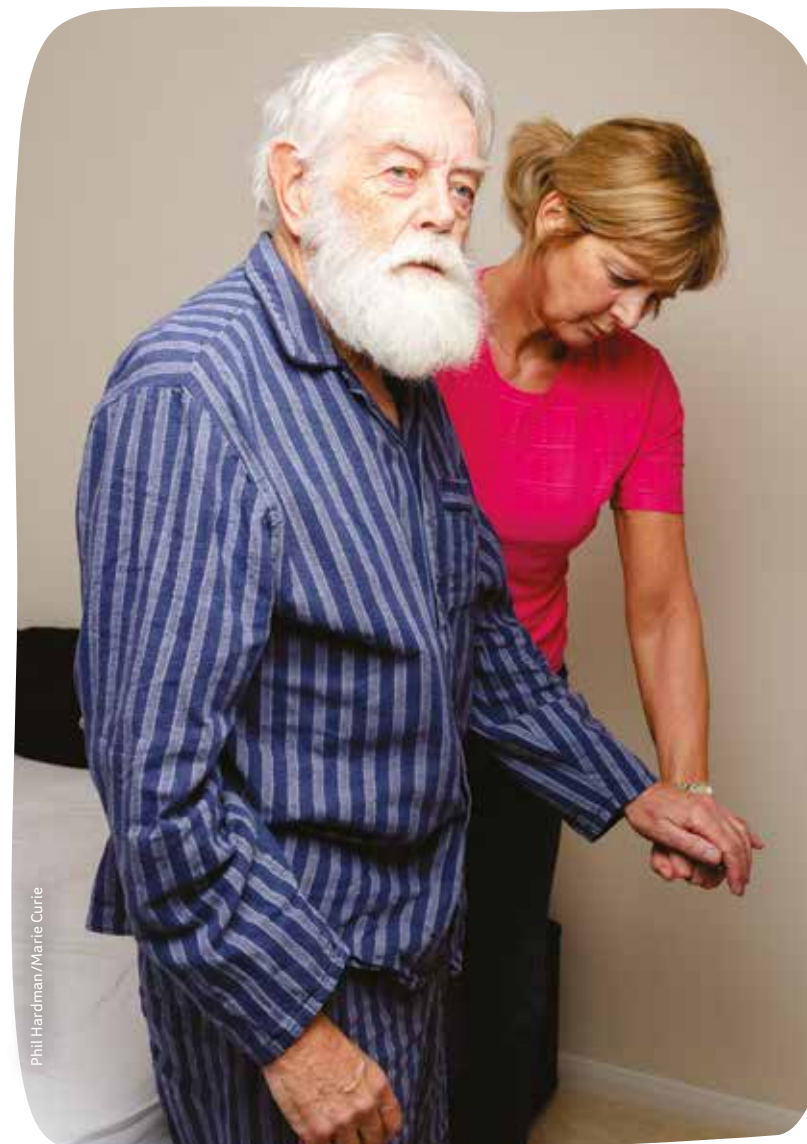
This could make it more likely you'll both fall if one of you falls over.

Instead, make a fist with your hand and ask them to rest their palm on your fist.



If they aren't able to move by themselves or need equipment, they might be able to get support from an occupational therapist or physiotherapist (see page 18).

Watch this manoeuvre in action at mariecurie.org.uk/standandwalk



Phil Hardman/Marie Curie

Personal care

Your friend or family member may need help with things like washing, brushing their teeth and going to the toilet. Always let them do as much as they are able and willing to do themselves. Try to follow their usual daily routine and do things how they usually do them – for example you could use the brand of shampoo they normally use.

If you're not sure how to help with these things or you're not comfortable helping with them, talk to their GP or district nurse about what support is available. They'll be able to show you how to do things or tell you about who else can help.

Getting equipment

There's different equipment that may be helpful for the person you are caring for. People often need things like a pressure-relieving mattress or a commode.

The person's healthcare professionals should be able to assess the person's needs and advise what equipment is available and how to use it. The NHS provides some equipment and healthcare professionals can tell you how to get things that it doesn't provide.

The British Red Cross offers some equipment on short-term loan. If the person's healthcare professional has not requested a loan on their behalf, you can approach them directly. Phone **0344 871 1111** or visit **redcross.org.uk**

An audio or video monitor, like the ones people use to watch or listen to babies, can help you check the person is OK. Or you could give them a hand bell to ring so they can get your attention if they need you.

Some other items you may find useful include drinking straws, non-spill beakers, a urine bottle and a bedpan. These can be bought from some pharmacies and online companies.

For more information on adaptations and care needs, visit **mariecurie.org.uk/careneeds**, or call the free Marie Curie Support Line on **0800 090 2309***.

Helping someone wash

It's important that the person you're looking after has a wash regularly for their comfort and morale, and to prevent infection.

These are some helpful points about helping someone wash:

- Let the person do whatever they are able to do themselves, for example washing their own face.
- Be very gentle to prevent damage to the skin.
- Use two separate flannels, one for the face and top half of the body and one for the bottom half.
- Start at the top of the body, washing their face, arms, back, chest, and tummy. Next, wash their feet and legs. Finally, wash the area between their legs and their bottom.
- Rinse off soap completely to stop their skin feeling itchy.
- Dry their skin gently but thoroughly.
- During the wash, change the water in the bowl when needed.
- Only expose the parts of the person's body that are being washed at the time – you can cover the rest of their body with a towel. This helps to keep them warm and maintains their dignity.

- You can use talcum powder in small quantities if their skin is not too dry and if they don't have pressure ulcers. Brush away any excess powder.
- You can apply moisturising creams gently to dry areas, such as the person's elbows, heels and soles of the feet.

If the person you are caring for doesn't feel like a full wash, you could occasionally use wet wipes and dry shampoo instead.

When you're washing the person, it's a good time to check the person's skin for any problems. For example, pressure ulcers (see page 49) can cause changes to their skin colour. If you notice any changes, don't rub the skin. Tell their healthcare professionals as soon as possible.

Watch our short film on helping someone to wash at mariecurie.org.uk/washing



The person's appearance

Paying attention to the person's appearance can often have a positive effect on how they feel. Some people feel better if they put on fresh clothes, have a shave, put on make-up or wear jewellery. Ask the person you're caring for if they would like to do any of these things and, if they can't manage on their own, you can offer to help.

You can help someone wash their hair, even if they're not able to leave their bed. You can use:

- dry shampoo powders to keep their hair looking clean
- a special bowl with splash attachment – the district nurse may be able to order this

- a plastic sheet, towels and an ordinary bowl in the most comfortable position for the person (if you can move the mattress down the bed safely, you may be able to fit the bowl in the gap that's created)
- a no-rinse, waterless hair-washing cap which lets the person have a shampoo without water (ask their district nurse, try a pharmacy or buy online).

Helping with mouth care

Many people who are unwell can have problems with their mouths. Some of the most common are:

- a dry mouth and lips
- ulcers
- infection
- bleeding gums
- too much saliva
- change in their sense of taste.

Keeping their mouth clean

The person you're caring for will be more at risk of mouth problems if they're struggling to keep their mouth clean. Offer to help if they are finding it hard to manage themselves.

It's important to think about what the person you're caring for prefers for their mouth care and do things they are comfortable with.

A soft toothbrush (such as a baby toothbrush) is best if the person's mouth is sore. You can use a small amount of toothpaste, but be aware that it might make their mouth dry if they don't rinse their mouth.

The person might feel comfortable rinsing their mouth with warm water or slightly salty water (one teaspoon of salt in one pint of water). They might want to use a mouth rinse from the pharmacy. Some mouth washes, including a sodium bicarbonate rinse, might irritate the person's mouth.

False teeth should be cleaned how the person usually cleans them. They might use soap and water or toothpaste, and may soak them overnight. If the person has lost weight, their false teeth may not fit and can cause mouth ulcers. If this happens, please talk to a dentist.

Helping with a sore mouth

If the person has mouth pain, tell their GP. They may be able to prescribe medication, such as artificial saliva, to help relieve it.

Some people who are ill get an infection called thrush in their mouth. It causes a very sore mouth and tongue, and can be recognised by white patches on the tongue, gums and inside the cheek. Tell the person's healthcare professionals as it can be treated easily.

Helping with a dry mouth

You can relieve a dry mouth with ice cubes or ice chips, lemonade or tonic water.

Chewing gum may stimulate saliva production if the person's mouth is still able to produce saliva. A saliva substitute applied before they eat or have a conversation can be helpful. The effects only last 10 to 15 minutes and it may cause discomfort if too much is used or it's used too often.

Unflavoured lip salve can help to prevent dry lips. If the person is receiving oxygen therapy, they must not use oil-based products such as Vaseline because there is a risk of fire.



Watch our short film on mouth care at mariecurie.org.uk/mouthcare

We have more film guides on our website, including tips for helping someone go to the toilet. Visit mariecurie.org.uk/carers

Pressure area care

The person you're looking after may stay in bed or a chair for long periods. They might become sore and numb at the areas on their body that carry most of their weight, particularly the bony points.

If pressure is not relieved frequently, the skin can break down and a pressure ulcer (bed sore) may develop. This can be uncomfortable and often painful. People who don't move or change position often are most at risk.

The best way to prevent pressure ulcers is for the person to change position regularly, whether in bed or on a chair. The district nurse can advise you about how often this should be.

The healthcare team might suggest things to help prevent or relieve pressure ulcers, including special mattresses or cushions.

When you are washing the person, look for signs of redness, or changes in the colour or appearance of their skin.

In particular, check:

- the back of the head and ears
- shoulder blades and elbows
- the base of the spine, hips and buttocks
- ankles, heels and between the knees.

If you notice any redness, discolouration or changes in the appearance of the person's skin, tell their district nurse. Do not rub the area.

They will take action to try to stop it getting worse and advise you on what you should do.

We have more information about pressure ulcers at mariecurie.org.uk/bedsores

Eating and drinking

It's important that the person you're caring for has a healthy and balanced diet if possible. They particularly need to get enough protein – for example meat, fish, eggs, milk, and pulses.

They may have a small appetite or none at all, or their tastes and preferences may change quickly.

Ask the person's healthcare professionals for advice if they are eating less or not eating, or if symptoms such as feeling sick are stopping them eating.

Tips to help someone with a loss of appetite or problems eating include:

- Choose foods that the person enjoys eating.
- Offer snacks regularly – sometimes little and often is preferable.
- Choose high calorie options so that they get more calories.
- Try to get them out of bed or sitting upright in a chair.
- Choose attractive looking food.
- Small portions may be more appealing than big ones.

- Nourishing drinks and food supplements may be useful if they're needed – they can be used as well as or instead of meals.
- Try soft or liquid foods such as soup, ice cream or jelly.
- You can use high calorie fruit juice drinks to make jelly, using the juice instead of water.
- Serve cold food if cooking smells make the person feel unwell.
- Giving them boiled sweets or ice cubes can soothe a dry mouth.
- Fizzy drinks can help relieve nausea.
- Rinsing the mouth after meals can keep it clean and comfortable.

If the person isn't able to eat or drink

Some people don't want to eat or drink or aren't able to towards the end of their life. This is normal and they shouldn't be forced. Talk to their healthcare professionals – they can look at whether extra nutrition or fluids are needed, for example by giving fluids through a syringe driver. There are advantages and disadvantages of giving these, which they can talk to you about.

Bladder and bowel care

Incontinence

Near the end of life, some people lose control of their bladder or bowels as their muscles relax – this is called incontinence. There are ways to make sure comfort and dignity are maintained as much as possible.

Ask their healthcare professional what they would suggest to help with this. If someone is mobile, they may be able to use a commode (portable toilet). If they're less mobile, they might use pads and wipes. Some people use a catheter, which is a small tube that drains urine from the bladder into a bag. It can help to talk to the doctor, nurse, and the person you are caring for about what is needed and who should provide this care.

Constipation

If the person you're looking after is eating and drinking less, they're likely to empty their bladder and open their bowels less.

They may also find they become constipated (opening their bowels less than usual or finding it hard to open their bowels). Constipation can be caused by different things, including not moving around and some pain-relieving medicines.

There are things they can do to prevent constipation. These include:

- eating more fruit, especially prunes and rhubarb
- eating more fibre
- drinking more fluids (particularly water)
- doing exercise or moving around.

If they're bedbound, privacy while they go to the toilet is important.

Ask their healthcare professionals for advice if you are concerned or if the person is in discomfort. They might suggest laxatives (medicines to help them empty their bowels).

Sleep problems or restlessness

Some people have problems sleeping or feel restless. This can be caused by physical factors (such as pain), non-physical factors (such as anxiety) or a combination of both. You could ask the person's doctor or nurse for advice if you're not sure.

Finding ways of helping the person to relax can sometimes relieve pain and help them sleep. Stroking them or giving them a gentle massage can be a useful way of doing this. You should only touch them gently, especially if the person is frail. Try to make their room comfortable and relaxing – you could ask them whether they're too hot or cold, or whether any noise is affecting their sleep.

Making someone comfortable in bed

If special equipment and medical supplies have been brought in, the person's room can feel a bit like a hospital. Photos, cards and art can make their surroundings seem more personal and less clinical.

Playing their favourite music can also be very soothing and relaxing for them.



Watch our short film on making someone comfortable in bed at mariecurie.org.uk/comfortable

Dealing with pain

Pain is common in people who have a terminal illness, but not everyone has pain. If the person is experiencing pain, it is important that you tell their healthcare team.

Many factors influence pain, including lack of sleep, tiredness, worry, anger and fear. Spiritual and emotional concerns, such as wondering why this is happening, can also influence pain. With the right treatment and support, pain can usually be managed.

Pain relief medicines

Some people feel that they should wait until the pain is really bad before taking any painkillers. But it's much better to take painkillers as prescribed and on time, even if they are not experiencing pain at the time. This helps to keep the pain controlled between doses.

If the person is in pain between doses, you should tell a member of their healthcare team, who can review their medication.

If they're unable to swallow their medication or it isn't being absorbed properly, the doctor can prescribe medication that can be given using a syringe driver. This is a small battery-powered pump that delivers medication from a syringe through a very thin, soft plastic tube placed just under the skin.

Watch our short film on syringe drivers at mariecurie.org.uk/syringedrivers



The person you're caring for may be prescribed anti-inflammatory or anti-depressant medication as well because painkillers sometimes work better when combined with them.

All medicines have the potential to cause some side effects. Side effects of some strong painkillers include:

- drowsiness, which will generally wear off after a few days
- nausea, which usually settles down after a few days – the GP is likely to prescribe medication to help
- constipation – the doctor may prescribe a laxative or stool softener.

If you're worried about side effects, speak to the person's healthcare team.



Watch our short film on helping someone take their medication at mariecurie.org.uk/takingmedication

Other pain relief techniques

Other ways of relieving pain include:

- changing their position so they're more comfortable
- putting cushions or pillows around them for support and comfort
- moving from the bed to a chair if possible, or the other way around

- hot and cold packs, covered and not placed directly against the skin
- physiotherapy
- complementary therapies such as massage, aromatherapy and reflexology.

We know that people feel less pain when they feel relaxed and supported. You can support someone who is in pain by spending time with them and helping them relax.

The person you are caring for may find it helpful to talk about their concerns. If they find it hard to talk about these things with their family or friends, they could talk to their nurse or consider contacting a support group, counsellor or spiritual adviser.

For more information about managing pain, visit mariecurie.org.uk/pain

Watch our film guide on helping someone to relax at mariecurie.org.uk/relaxing



Philip Hardman/Marie Curie

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How Marie Curie can help

Marie Curie Nurses and Healthcare Assistants

If the person you're caring for has been referred to Marie Curie's nursing team, visits from our nurses or healthcare assistants can give you a break from your caring role.

The person you're caring for will most likely have a key worker looking after their care needs (usually their district nurse). Our nurses and healthcare assistants will work closely with them to make sure that you and the person you're caring for get the best quality care and support.

Our nurses or healthcare assistants can also talk to you about the care outlined in the care plan for the person you are looking after. This will give you the opportunity to discuss their care needs at the outset, and to make sure that the care we provide meets both of your needs.

Marie Curie Hospices

Hospices provide expert care for people with a terminal illness and free support for carers and family members. Many hospices offer respite care, allowing the person who is ill to stay at the hospice for a short period while the people caring for them take a break.

Hospices also offer day services, which focus on relieving a person's symptoms and helping them remain independent for as long as possible. Some hospices have specialist nurses who can provide advice or support for people at home.

If you live near one of our Marie Curie Hospices, you may find that it can help you. Each of our hospices has a team of highly experienced staff including doctors, nurses, social workers, physiotherapists, counsellors and complementary therapists. They provide specialist care and support tailored to the needs of the person with a terminal illness and those caring for them.

If the person you are caring for has been referred to a Marie Curie Hospice, you may be able to access:

- emotional support from counselling sessions or carers' groups
- a range of therapies from trained complementary therapists
- spiritual and religious support
- specialist support for children and young people in the family
- bereavement support.

There are Marie Curie Hospices in Belfast, Bradford, Cardiff and the Vale (Penarth), Edinburgh, Glasgow, Hampstead (London), Liverpool, Newcastle and the West Midlands (Solihull). Speak to your GP or a district nurse if you would like to get help from a local hospice, and they can make a referral for you.

If you don't live near a Marie Curie Hospice, you may still have a hospice near you where you can get this type of care and support. Hospice UK has a database of hospices across the UK at hospiceuk.org or your GP can help you find your nearest one.

Marie Curie Helper Service

In some areas, we provide Marie Curie Helper volunteers – they're specially trained volunteers who visit people in their homes to give companionship and support for a few hours each week. To find out if this service is available in your local area, visit mariecurie.org.uk/helper

Information and support from Marie Curie

For practical information or emotional support, contact the free Marie Curie Support Line on **0800 090 2309*** (8am – 6pm Monday to Friday, 11am – 5pm Saturday). You also contact us on web chat at **mariecurie.org.uk/support**

Visit **mariecurie.org.uk/support** for clear, practical information on caring for someone and lots of resources on planning ahead and financial matters.

Many people feel alone when looking after someone at the end of life and can find support by talking to others in a similar situation. Visit our online community at **community.mariecurie.org.uk**

What other support is available for you?

As well as the support that Marie Curie may be able to offer you, you may also need some help with practical things like household tasks, the personal care of the person you are looking after, or money. You may also need emotional support.

There are many organisations providing a range of services to help you. But even if you have support from various professionals and organisations, you should not hesitate to ask for help from friends and family as they may want to help you too.

How to get support

The first step in getting more help is to speak to your GP or the district nurse. They can be a valuable source of support – you can tell them that you are a carer so that they understand the needs you might have.

They can also refer you to other services that can help you, such as those provided by your local hospice.

District nurses

District nurses, who are part of the primary healthcare team, arrange care in people's homes. They can arrange services such as nursing and social care for the person you are caring for. And there may be ways they can support you, including arranging respite care for the person you care for so that you can have a break from caring. They might also be able to provide information about local services such as carers' groups, hospices, organisations offering financial grants, complementary therapists, interpreting services and other services and benefits.

Social services

If you need services such as prepared meals delivered to your home or help with shopping, the district nurse can contact social services on your behalf. Or you can contact them directly through your local council or, in Northern Ireland, your Health and Social Care Trust.

Social services will look at what you, and the person you are caring for, need and suggest services to help you. This is sometimes called a needs assessment, carer's assessment, adult

carer support plan or young carers statement (see below). The support they offer depends on what's available in your local area.

Carers' support groups

Support groups enable people who are going through difficult situations to meet others in a similar position. In support groups, people support one another and share personal experiences.

There may be different groups to choose from – they often support people with specific needs or illnesses, as well as the people caring for them. Some groups will even visit your home if you are finding it difficult to leave the house.

To find a support group near you, contact your local council, ask your GP or district nurse, or call the free Marie Curie Support Line on **0800 090 2309***.

Carers' organisations

There are a number of organisations that can help people who are caring for someone at home. They include:

- Carers UK – provides information and support to people caring for relatives and friends. Visit **carersuk.org**
- Carers Trust – has a network of carers' centres across the UK. Visit **carers.org**

Carer's assessment

Having a carer's assessment is an opportunity to discuss what support or services you need with the local social services. If possible, both you and the person you are caring for should be assessed so that you can get the right amount of support.

If there is more than one person providing regular care to the person, you can both have an assessment.

To get an assessment, contact your local social services department. They may be based in your local council or, if you live in Northern Ireland, your Health and Social Care Trust.

The assessment will involve a discussion with a trained person who works with social services. They will look at how caring affects your life, including your physical, mental and emotional needs. They'll discuss whether you are able and willing to carry on caring.

Following the assessment, you may be able to get help and support. This may include aids and equipment, financial support, or help to take short breaks from your caring responsibilities (sometimes called respite breaks).

An assessment may also make you or the person you are caring for eligible for direct payments. That means you could be given money to buy services or new equipment, or employ somebody to provide assistance such as help around the house.

You can visit **mariecurie.org.uk/carers-assessments** on our website to find out more.

In Scotland, you can get an adult carer support plan or young carers statement. As part of this, you will have an assessment to look at your needs – this is a similar process to a carer's assessment.

Counselling

If you are in contact with a Marie Curie Hospice or another local hospice, ask if they have a counsellor or social worker who can help you or the person you are caring for.

You can also ask for counselling through your GP or the district nurse.

The British Association for Counselling and Psychotherapy can provide information on counsellors, including those with specialist training in helping people who are dealing with a particular illness such as cancer. Visit **bacp.co.uk**

Spiritual support

You may wish to contact a local religious leader or spiritual adviser for support. They're usually happy to help, even if you aren't actively involved with a religious group.

If you're in contact with a local hospice, the chaplain or spiritual coordinator can offer advice and recommend a local person to contact.

Holidays and travel insurance

If you are planning to go on holiday with the person you care for, it's a good idea to talk through any holiday plans with their healthcare professionals. They can help you to think through some of the things you may need to plan in advance, such as managing symptoms and medication.

You could arrange medical travel insurance for the person you care for. This may cover the financial costs if the person you care for needs medical treatment, has to cancel their holiday, has to come home, or dies while abroad.

You may want to get travel insurance for yourself. You can do this even if you're not going on holiday with the person you care for – for example, in case you need to cancel or rearrange your holiday to look after them.

People with terminal illnesses and their friends and family may find it difficult to get medical insurance to go abroad, or have to pay more for insurance.

It's important that you tell the insurance company about any medical conditions you or the person you are caring for has. Most companies will require a medical certificate. It will probably take longer than usual to arrange cover, so do contact them as early as you can.

The insurer may ask the person you are caring for to take a medical summary of their condition with them. This may need to be translated into the language of the country you're visiting.

Blue Badge parking scheme

This scheme provides a range of parking benefits for people with a disability. It's run by local councils or, if you live in Northern Ireland, the Blue Badge Unit.

If the person you are caring for doesn't drive, they can nominate you as their driver. Then you can use their Blue Badge when driving them.

Benefits and finances

The financial impact of a terminal illness can be an added burden – both to the person who is ill and to the people caring for them. There are different grants and benefits that may be available, which we've listed on the following pages.

You can get more information on the benefits and entitlements that might be available to you on the Marie Curie website. Visit **mariecurie.org.uk/benefits** for more details or call our free Support Line on **0800 090 2309***.

Grants

Your district nurse should be able to give you information about any local financial grants that are available.

Visit mariecurie.org.uk/grants for more information.

Changes to benefits in Scotland

In 2022, benefits in Scotland may change, including which benefits are available and how you apply for them. Visit mygov.scot for the latest benefits information.

Attendance Allowance and Personal Independence Payment

Attendance Allowance and Personal Independence Payment (PIP) are benefits to help with the extra costs caused by long-term health problems or disabilities.

The person you are caring for may be able to claim Attendance Allowance if they are State pension age or over and a resident of the UK.

If they are aged 16 or over, and haven't yet reached State pension age, they may be able to claim Personal Independence Payment.

These aren't 'means-tested', so the person you are caring for can get them regardless of how many savings or how much income they have.

As the person you are looking after is terminally ill, they may be able to get these benefits more quickly and easily than someone who isn't terminally ill.

Speak to a benefits adviser for the most up-to-date information. You can find one at citizensadvice.org.uk

Carer's Credit

If you can't work or don't earn enough to pay national insurance contributions because of your caring role, you may be eligible for Carer's Credit. This will help protect your state pension.

You can get Carer's Credit if the person you care for receives one of the qualifying disability benefits.

Carer's Allowance

You may be able to claim Carer's Allowance if you:

- are aged 16 or over
- look after someone who gets a qualifying disability benefit
- look after the person for at least 35 hours a week
- are not in full-time education
- satisfy UK presence and residence conditions.

You may not be able to claim it if you earn more than a certain amount. Carer's Allowance is taxable if you have another income.

In Scotland, you may also be able to get Carer's Allowance Supplement.

Income Support

If you are claiming Income Support and are also entitled to Carer's Allowance, you may be able to get extra Income Support.

Housing Benefit and Council Tax

You may be able to get help with paying your rent or Council Tax if you are on a low income and you are caring for someone.

Planning ahead for the future

People who are terminally ill may want to consider what their options are – particularly around how and where they would like to be cared for and where they would prefer to die.

If the person you're caring for has specific wishes or preferences, it's a good idea for them to discuss these with you or another family member. You can also talk about different options with their health and social care professionals.

You may find it difficult to have these conversations at first. By talking and putting wishes in writing, you will know what the person wants if they become unable to tell you.

It might help to write down specific needs or requests they have so that people have a clear understanding of what the person wants.

Find out more about advance care planning and Power of Attorney on pages 26 to 27.

Writing a Will

Making a Will lets someone decide who their estate (eg money, possessions and property) should go to after they die.

If someone doesn't write a Will, their estate will be divided up according to the law. It could mean that more of their estate than necessary may be liable for inheritance tax.

To learn more about making a Will, visit mariecurie.org.uk/wills

Planning ahead for the funeral

Some people want to make decisions about their own funeral. Not everyone will want to do this – and that's OK too.

You may feel that it is inappropriate to plan or even discuss a funeral while the person you're caring for is still alive. However, when the time comes to make decisions, you and any family members may find it helpful to know what the person wanted.

You may feel uncomfortable discussing it at first but people often become more comfortable with the subject as time goes on. The person you're caring for may take comfort from deciding matters such as what music to have, whether they wish to be buried or cremated, and where they would like to be buried or have their ashes scattered.

You can find more information from the National Association of Funeral Directors (see page 93) or by visiting the Marie Curie website at mariecurie.org.uk/funeral

Writing down funeral wishes

If the person you are caring for doesn't want to discuss the subject, they might prefer to write their wishes down so you have something to help you later.

Dying Matters and the National Association of Funeral Directors, have produced a useful booklet, *My funeral wishes*, for recording what people would like to happen after their death. Visit dyingmatters.org/page/my-funeral-wishes

You can also find lots of useful information in Marie Curie's booklet, *When someone dies*. To order a free copy, visit mariecurie.org.uk/publications or phone **0800 090 2309***.

Collecting key documents

You could suggest that the person you’re caring for gathers key documents such as birth certificates, passports, insurance policies, Wills, and organ donor cards. They could also make a list of any banks they have accounts with.

If they have been looking after things like bills or utility accounts, it might be helpful for them to make a list of companies they have accounts with.

It can be helpful if these documents are kept together in a safe place and you know where to find them.

What to expect when the person is approaching the end of their life

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The following information explains what may happen in the last few days and hours of someone's life. Some of the things that happen at this time may seem strange or frightening, especially if you are not expecting them.

We hope this information will help you understand what is happening and prepare you.

You may find it helpful to read this section and discuss it with the person you're looking after.

If you would like support as you read this section, or if you would like to discuss any of the issues in more detail, ask one of their healthcare professionals.

If you don't feel ready to read this section, you can always come back to it at a later time.

Supporting the person and their wishes

The person you're caring for may need more support from you at this time. It may not be easy for them to ask for or accept support. They'll still have preferences about how they live their life and how they're cared for. Try to support them to make decisions about their care as much as they are able to, even for things they may seem like small decisions to others.

They can enjoy aspects of 'normal life' that are still possible. Unless there's a specific reason not to, they can still enjoy things like having an alcoholic drink, seeing children and pets, and being physically affectionate with friends and family. Check with their healthcare team if you're not sure.

Changes you may expect in the last weeks and days

Everyone is different, so it's not possible to say exactly what will happen when someone approaches the end of their life. But, in the last weeks and days before death, it's common to experience certain changes.

Feeling weak and tired

Some people need to spend more time in a chair or in bed as everyday activities become too tiring. Needing to sleep more than usual is normal. They may still be able to hear others talking gently to them or feel them holding their hand.

Eating and drinking less

The person you're looking after may stop eating and may only want sips of liquid. This can be hard to accept, because it's a physical sign that they are not going to get better.

As they become weaker, the effort of eating and drinking may be too much for them. You can support the person to eat and drink if they want to and are able to.

If they start to find it difficult to swallow, or are having problems with nausea, tell a member of their healthcare team.

Some people don't want to eat or drink or aren't able to at the end of their life. This is normal and they shouldn't be forced. Their healthcare professionals can look at whether extra nutrition or fluids are needed, and talk about the advantages and disadvantages of giving these.

Problems taking medicines

Having a sore or dry mouth, feeling nauseous or having difficulty swallowing may affect the person's ability to take medication. Their healthcare professionals will be able to advise you about other ways of giving them their medication. Some people have a syringe driver if they can't swallow or absorb their medicines. This is a pump that gives a carefully measured dose of drugs over 24 hours directly under their skin.

Bladder and bowel problems

Near the end of life, some people lose control of their bladder or bowels as their muscles relax. There are ways to make sure comfort and dignity are maintained as much as possible. It can help to talk to them and their healthcare professionals about what is needed and who can provide this care.

Breathlessness

Some people become breathless. Their healthcare professionals may give them medicine or advise taking practical steps, like having a fan in the room or opening a window.

Pain

Some people experience pain but not everyone does. Tell a member of their healthcare team about any pain the person you are caring for has. With the right treatment and support, pain can usually be managed.

Feeling and being sick

If the person feels sick, their healthcare professionals can look at what is causing this and what can help. They might suggest changing their medicines, trying different foods, or doing activities that are distracting or relaxing.

Agitation and confusion

Changes in the person's body can also affect their brain, their behaviour and how they understand the world around them. They might seem confused, feel restless or agitated, or become delirious.

If this happens, it may be very upsetting for people around them to see. Offering reassurance, holding their hand and being close by might help them. Being in a calm and quiet environment can also help.

Their healthcare professionals might suggest using medicines to help treat underlying causes or to help them feel calm and relaxed.

On the other hand, some people appear calm and detached from what's going on around them.

Final hours of life

It may be reassuring to know that for many people with a terminal illness, their needs are met in the last couple of days and the final moments are peaceful.

Loss of consciousness

Many people lose consciousness near the end of life. But they may still have some awareness of other people in the room. They may be able to hear what's being said or feel you holding their hand.

Changes to skin

The skin might look slightly blue or become mottled (have different coloured blotches or patches). Limbs, hands and feet may feel colder. This is because the blood circulation around the body is slowing down.

Noisy breathing

Breathing may become loud and noisy if mucus has built up in the throat. Some people call this type of breathing the death rattle because it can happen in the last days or hours of life.

It can be upsetting or frightening for people around them to hear the noisy breathing. But it's unlikely to be painful or distressing for the person who's dying. Often they will be unconscious or won't be aware of it.

Shallow or irregular breathing

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 or stops between breaths. This can last for a short time or long time before breathing finally stops.

Moment of death

It's not always clear the exact moment when someone dies. When a person dies, those around them may notice that their face suddenly relaxes and looks peaceful.

If the death isn't completely peaceful, it's unlikely that they will have been aware of it. If people around them find the death distressing, it might help to speak to a bereavement counsellor afterwards.

A doctor or other healthcare professional will confirm the death if the breathing, the heart and circulation have stopped. They may also check the person's pupils and body for other signs.

What happens when someone dies?

It can be a confusing time immediately after a death – family and friends may be in shock or very upset.

Here are some practical things that usually need to happen. They are explained in more detail on the following pages. They don't always happen in the same order.

1. Anyone who is present needs to tell the person's nurse or GP.
2. Everyone should respect any wishes the person had about how their body should be cared for.
3. A healthcare professional needs to verify the death, to confirm that the person has died (known as 'formal verification of death').
4. Friends and family should call the funeral director, if they are using one.

5. A healthcare professional needs to certify the death by completing a 'medical certificate of cause of death' (this is different from a death certificate).
6. Friends and family need to take the 'medical certificate of cause of death' to the local registrar to register the death, the registrar will issue the 'death certificate' and 'certificate for burial or cremation'.

Customs or preferences at time of death

If a healthcare professional is present, they will check the care plan to see if there are any religious or other customs or preferences that need to be observed directly before or after death.

Please tell them if there is anything they should or should not do. They will respect your wishes and those of the person who has died.

Care after death

This may include washing the person's body, dressing them in clean clothes and arranging their hair or putting on their wig. This is sometimes called 'last offices' or 'laying out the body', although these mean different things to different people.

If a Marie Curie Nurse or another healthcare professional is present, you can ask them to help you with this, or ask them to do it for you. You may wish to be present while they do this or you may prefer not to be in the room. There's no right or wrong decision – do whatever you feel comfortable with.

If you're alone when the person dies, you may find it comforting to carry out these tasks. On the other hand,

you might find it distressing, or prefer to leave it to others. Again, do whatever you feel comfortable with.

For religious or personal reasons, you may not want a healthcare professional to lay out the body. This should be in the care plan but do let them know your wishes.

Do leave any equipment (such as a syringe driver) in place until a healthcare professional has properly recorded that the person has died (this is known as formal verification of death).

Verifying and certifying the death

Even if it's clear that the person has died, at some point an appropriate healthcare professional will need to verify the death. This involves making checks to be sure that the person has died. It is best not to move the body from the home before this has taken place.

If there are no Marie Curie nursing staff or other healthcare professionals present at the death, you will need to call the GP's surgery within two or three hours of the person dying. The surgery or out-of-hours service will arrange for a GP or healthcare professional to visit to verify the death. They may not come to your home immediately if they are seeing other patients.

A registered medical practitioner (usually a GP) will also need to certify the death. If the death was expected and they are sure it resulted from natural causes, they do this by completing a form called a medical certificate of cause of death.

They will also give you a formal notice that the medical certificate has been signed and tell you how to register the death. This paperwork will allow you to register the death,

obtain the death certificate and arrange the funeral.

The medical certificate of cause of death is not a death certificate (although some people may call it that). The death certificate is issued by the registrar later.

- Sometimes a GP will verify and certify the death at the same time.
- Sometimes another healthcare professional will verify the death in the person's home while a GP certifies the death later (for instance, at the person's home the next day or at a funeral director's premises).

The GP who certifies an expected death should be the person's regular doctor who treated them during their illness and who visited them during the two weeks before their death.

If no GP meets these conditions, the GP of the person who has died will need to report the death to the coroner (procurator fiscal in Scotland). This is usually a formality, and may simply lead to discussions between the GP and coroner.

A death may be reported to the coroner for other reasons – for instance, if the person died of an occupational disease or if the GP has any questions about the death. Try not to worry if the death is reported. If you have concerns, contact the coroner's office to find out what will happen next.

Visit mariecurie.org.uk/bereavement for more information on practical and legal matters after someone dies.

What happens next?

After the death has been formally verified, the next stage depends on whether you have decided to use a funeral director or are handling the arrangements yourself.

If you're using a funeral director, you can contact them once you are ready, you do not have to rush. Most funeral directors are open 24 hours a day, seven days a week. The funeral director will generally come to collect the body within an hour of being contacted. If this is too soon, discuss with them what time you want them to come. For instance, you may want a little more time to sit with the body, or wait for family or friends to arrive, or simply to collect yourself.

It is possible to arrange all or part of a funeral yourself. If you choose not to use a funeral director, *The Natural Death Handbook*, as well as other publications and internet sites, can provide further advice and information. For a copy of the handbook, visit naturaldeath.org.uk or phone **01962 712 690**.

Marie Curie's booklet, *When someone dies*, has more information on other practicalities including registering a death, arranging and paying for a funeral and dealing with the estate. To order a free copy, visit mariecurie.org.uk/publications or phone **0800 090 2309***.

You can also find this information online at mariecurie.org.uk/funeralplanning

If the person died in a hospice or hospital

Hospices and hospitals have their own local arrangements for verification and certification of death and they will issue the medical certificate confirming cause of death. They will also provide information about how to register the death.

A member of staff (for instance, the family support or social worker) should be able to advise you about contacting a funeral director, or what to do next if you don't plan to use a funeral director.

Your reaction to loss

Grief is a normal reaction to loss for both adults and children. It is a natural process that can take place after any kind of loss, especially the loss of someone to whom you were very close.

Grief is an individual experience which affects people in different ways – emotionally, physically, socially, and in many practical areas of life.

Your relationship with the person you've lost was unique. In the same way, you will grieve in a way that is unique to you. There is no right or wrong way to grieve.

The range of emotions felt following bereavement can differ vastly. Some of the more common feelings are: guilt, anger, relief, despair, apathy and loneliness. Some people feel too numb to experience any emotion for a while.

You may notice changes in your sleeping patterns and appetite. You may feel panicky and restless, or you may feel exhausted, especially if you had been providing care for the person before they died.

Getting support

This can be a very distressing time for you and other family and friends, and getting the right emotional and spiritual support is important.

It can often help to talk to people about your loss – a friend or neighbour, or your GP or another healthcare professional.

The healthcare professionals of the person you were caring for, including any Marie Curie staff, can help.

Your healthcare professionals can also arrange bereavement support from a professional.

This could be a bereavement support worker, a counsellor or a therapist. They can give you space to think about how you feel and help you make sense of your thoughts, feelings and emotions.

It can also help to connect with other people who have had similar experiences, through a support group or online community.

There are organisations that can offer you emotional support and practical information. See page 93 for more information. Or call the Marie Curie Support Line on **0800 090 2309***.

Our booklet, *When someone dies*, provides practical information on organising a funeral and registering a death, as well as information about dealing with grief and getting support. You can order one for free at mariecurie.org.uk/publications or by calling our Support Line on **0800 090 2309***.

Useful contacts

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Marie Curie can help

We help everyone affected by a terminal illness get the care and support they need, including people who have been bereaved.

Marie Curie Support Line

0800 090 2309*

Ask questions and find support. Speak to a trained member of staff or a nurse for free confidential information on all aspects of terminal illness. Open 8am to 6pm Monday to Friday and 11am to 5pm Saturday. Your call may be recorded for training and monitoring purposes.

Marie Curie Online Chat

You can talk to our trained staff and get information and support via our online chat service.

mariecurie.org.uk/support

Marie Curie Community

Share experiences and find support by talking to people in a similar situation.

community.mariecurie.org.uk

Marie Curie Information

We have a range of free information available to view online or as printed booklets.

mariecurie.org.uk/support

*Calls are free from landlines and mobiles.
Your calls may be recorded for training and monitoring purposes.

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. Our hospices also support people who have been bereaved, and some offer support for children.

mariecurie.org.uk/hospices

Marie Curie Nursing Services

Marie Curie Nurses and Healthcare Assistants work 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 Helper Volunteers

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 over a cup of tea, help you get to an appointment or just listen when you need a friendly ear.

mariecurie.org.uk/helper

Other organisations

Support organisations

Alzheimer's Society

0300 222 11 22

alzheimers.org.uk

Provides information and support for people affected by dementia.

British Association for Counselling and Psychotherapy (BACP)

01455 883 300

bacp.co.uk

BACP provides information about choosing a counsellor and details of counsellors near you.

British Red Cross

0344 871 1111

redcross.org.uk

The British Red Cross loans equipment, such as wheelchairs and commodes. They also support people who are leaving hospital and moving home.

Complementary & Natural Healthcare Council

020 3668 0406

cnhc.org.uk

The Complementary & Natural Healthcare Council has a database where you can find a registered complementary therapist near you.

Macmillan Cancer Support

0808 808 00 00

macmillan.org.uk

Macmillan Cancer Support provides practical, medical and financial support for people affected by cancer.

Samaritans

116 123

samaritans.org

Samaritans provides confidential, emotional support 24 hours a day, for people who are experiencing feelings of distress or despair.

NHS services

England

111
nhs.uk

Wales

0845 46 47 or 111
nhsdirect.wales.nhs.uk

Scotland

111
nhsinform.scot

Northern Ireland

hscni.net

Hospices and care centres

Hospice UK

020 7520 8200
hospiceuk.org

Hospice UK provides general information on hospice care in the UK and overseas, and information to help you find your nearest local hospice.

Sue Ryder

0808 164 4572
sueryder.org

Sue Ryder runs hospices and care centres in the UK for people with many different disabilities and diseases. Services include long-term care, respite care, symptom control, rehabilitation, day care and home care.

Support for carers

Carers UK

0808 808 7777 (England, Scotland and Wales)
028 9043 9843 (Northern Ireland)
carersuk.org

Carers UK provides information and support to people caring for relatives and friends, including advice and leaflets on rights and entitlements.

Carers Trust

0300 772 9600
carers.org

Carers Trust offers information, advice and support for carers, including care in the home by support workers who help carers to have a break.

GOV.UK

gov.uk

GOV.UK provides information for people caring for someone at home. You can find information about subjects such as support services, useful organisations, how to get someone's needs assessed and looking after yourself.

You can also find an overview of the benefits you may be able to get when caring for someone.

Carers Direct helpline

0300 123 1053
nhs.uk/carersdirect

Carers Direct provides information, advice and support for carers, including services in people's local area.

Help with money

Age UK

0800 678 1602

ageuk.org.uk

Age UK provides information and advice on a range of financial matters, including expert support with claiming benefits.

Citizens Advice

03444 111 444 (England)

03444 77 20 20 (Wales)

0808 800 9060 (Scotland)

0800 028 1881 (Northern Ireland)

citizensadvice.org.uk

Citizens Advice provides support with claiming benefits, including on the phone and in local branches.

GOV.UK

gov.uk

GOV.UK provides information about the benefits you may be able to get if you're living with a terminal illness or caring for someone.

Macmillan Cancer Support

0808 808 00 00

macmillan.org.uk

Macmillan Cancer Support provides support on managing finances to people affected by cancer.

Turn2us

turn2us.org.uk

Turn2us provides online financial support and information, including a benefits calculator and a grant search.

Funeral planning

National Association of Funeral Directors

0121 711 1343

nafd.org.uk

The National Association of Funeral Directors provides information about organising a funeral and a database where you can search for funeral directors near you.

Natural Death Centre

01962 712 690

naturaldeath.org.uk

The Natural Death Centre provides information on organising a funeral, including how to organise a funeral or burial without using a funeral director.

Bereavement support

Bereavement Advice Centre

0800 634 9494

bereavementadvice.org

The Bereavement Advice Centre offers advice on all aspects of bereavement, including registering a death and getting financial support.

Child Bereavement UK

0800 02 888 40

childbereavementuk.org

Child Bereavement UK supports children and families when a child is dying or has died, or when a child is facing bereavement.

Cruse Bereavement Care

0808 808 1677

cruse.org.uk

hopeagain.org.uk (support for young people)

Cruse Bereavement Care helps people who have been bereaved, including counselling, social contact and advice on practical matters.

Cruse Bereavement Care Scotland

0845 600 2227

crusescotland.org.uk

Cruse Bereavement Care Scotland provides help to people who have been bereaved in Scotland, including support on the phone and in person.

Notes

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Notes

This image shows a full page of blank, lined paper. It features approximately 20 evenly spaced horizontal blue lines across its entire width. The background is a solid off-white color, and there are no margins, text, or other markings present.

About this information

This booklet 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 would like to provide feedback about this booklet or would 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. In respect of 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 – who 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 from trained staff and nurses.

Open 8am to 6pm Monday to Friday,

11am to 5pm Saturday.

mariecurie.org.uk/support

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

We can't do it without you

Our Information and Support service is entirely funded by your generous donations, so the work we do would not be possible without your help. Thanks to you, we can continue to offer people the free information and support they need, when they need it.

mariecurie.org.uk/donate

*Calls are free from landlines and mobiles.

Your call may be recorded for training and monitoring purposes.

