

Caring for someone at home



Providing personal care and
managing symptoms: a guide
for carers, family and friends

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

Introduction

The information in this leaflet is aimed at carers, family members and friends. But it may also be useful for someone with a terminal illness, to help explain the type of care they might receive.

If you're not sure how to help with the things we talk about in this leaflet, or you're not comfortable helping with them, that's OK. You could talk to the GP or district nurse about what support is available.

Some of the symptoms we talk about are more common towards the end of life. If you do not feel ready to read about that, you might prefer not to read those bits for now. You may choose to only read about the symptoms or personal care topics that are relevant for you and the person you care for.



Philip Hardman/Marie Curie

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What is personal care?

We use the words ‘personal care’ to describe anything to do with personal hygiene, such as washing, dressing, and going to the toilet. These may be some of the everyday tasks you are doing to support your family member or friend. You might hear these tasks called ‘activities of daily living’ (ADLs) by healthcare professionals.

In this booklet, we also cover things like walking, eating or drinking, and taking medication. People might use the words ‘social care’ to describe these things.



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Caring for someone at home

When giving personal care, try to follow their usual daily routine and do things how they usually do them. For example, continuing to use their usual brand of shampoo.

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 stay independent.



Find out more about all of the topics we cover in this booklet by visiting [**mariecurie.org.uk/support**](https://mariecurie.org.uk/support), calling the free Marie Curie Support Line on **0800 090 2309*** for tips, or speaking to the healthcare assistant, GP or district nurse.

Getting support as a carer

Caring for and supporting someone can take a lot of time and energy, and it's OK to ask for extra support. Some health and social care professionals can visit your family member or friend at home to help with different tasks.

You may also be able to get financial support or benefits, as well as emotional support for yourself.



You can order our free booklet **Being cared for at home** at [**mariecurie.org.uk/publications**](https://mariecurie.org.uk/publications) or by calling our Support Line on **0800 090 2309***.

Helping someone move

You should seek advice from a relevant healthcare professional before trying to move someone. This could be an occupational therapist, physiotherapist or district nurse.

They can review the situation and provide appropriate support to make sure your needs, and the needs of the person you are caring for, are met safely. This may involve:

- further assessment of the patient
- equipment provision
- education for you and the person you're caring for on how to move someone safely.

It's important to remember that:

- you must look after your own health, and not move or handle someone else unless you are fit and well and have been advised by healthcare professionals
- you should only help someone get out of bed, stand up, or walk if they are unable to do it on their own
- you should not support all or even most of the weight of another person – you could injure yourself or hurt them.

Getting support with moving someone

You may not feel confident or comfortable moving someone on your own, even after speaking with a district nurse or other healthcare professional. Instead, you could ask them about trained professionals who can support you. For example, if someone is not able to move by themselves or needs equipment, an occupational therapist or physiotherapist may be able to help.



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Helping someone wash

It's important that someone with a terminal illness washes regularly for comfort and morale, and to prevent infection. If you're helping someone wash, try to:

- let them do whatever they can themselves – for example, washing their own face
- be gentle when washing and drying to prevent damaging 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 (face, arms, back, chest and tummy), then wash their feet and legs, and finally wash the area between their legs and their bottom
- change the water in the bowl when needed
- only expose the body parts of the body that are being washed at the time, to help keep them warm and maintain their dignity
- dry them gently and thoroughly, making sure you dry all their skin folds.



Find out more about washing at mariecurie.org.uk/washing

Looking after someone's appearance

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. If they cannot manage on their own, you can offer to help.

Mouth care

Many people who are unwell can have problems with their mouths, including a dry mouth and lips, ulcers and infection.

Keeping their mouth clean

Keeping someone's mouth clean can help reduce the risk of these problems. You could help by suggesting or using:

- a soft toothbrush, such as a baby toothbrush, if the person's mouth is sore
- a small amount of toothpaste
- warm water or slightly salty water (one teaspoon of salt in one pint of water) to rinse their mouth – if they prefer to use a mouthwash they've bought, check with the healthcare team that it's one that will not irritate their mouth.

Dentures should be rinsed thoroughly after meals, and cleaned and soaked overnight.

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 or pain medicines, 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 help a dry mouth by:

- eating or sucking on ice cubes or ice chips
- drinking cold, unsweetened drinks
- chewing gum to stimulate saliva production, if their mouth is still able to make saliva
- rinsing the mouth with water or a mouthwash after brushing, if the toothpaste makes their mouth feel dry
- applying a saliva substitute before eating or having conversation – the effects last about 10 to 15 minutes, and it may be uncomfortable if you use too much of it or use it too often.



Find out more about mouth care at [**mariecurie.org.uk/mouth-care**](https://mariecurie.org.uk/mouth-care)

Pressure ulcers

If someone stays in bed or a chair for long periods, they might become sore and numb in the areas on their body that carry most of their weight. If this 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.

How to prevent pressure ulcers

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.



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How to check for pressure ulcers

When you are washing the person, look for changes in the colour or appearance of their skin. People with lighter skin tones may have red patches. People with darker skin tones may have patches that are blue or purple, or another colour that's different to the surrounding area – normally darker. 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 discolouration, or changes in the appearance of the person's skin, tell their district nurse. Do not rub the area.

Eating and drinking

It's important that someone with a terminal illness has a healthy and balanced diet if possible.

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.



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Tips to help with loss of appetite or problems eating

- Choose foods that the person enjoys eating.
- Offer snacks regularly – sometimes eating 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 – if you can, ask a health or social care professional for help with this.
- Small portions may be more appealing than big ones.
- Try soft or liquid foods such as soup, ice cream or jelly.

Eating and drinking less towards the end of life

Some people do not want, or are not able, to eat or drink towards the end of their life. Although this can be hard to accept, it is normal and they should not be pressured.

It can help to talk to the healthcare professionals, especially about difficulty swallowing or nausea (feeling sick). They can look at whether extra nutrition or fluids are needed. There are advantages and disadvantages of giving these, which they can talk to you about.



Find out more about eating and drinking at mariecurie.org.uk/eating-drinking

Bladder and bowel care

People may experience some bladder and bowel problems because of their illness, or as a side effect of medication or treatment.

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 the healthcare professional what might help. They may suggest:

- using a portable toilet (commode) if someone is mobile
- using pads and wipes if someone is less mobile
- having a catheter, which is a small tube that drains urine from the bladder into a bag.

Constipation

If the person you're looking after is eating and drinking less, they may become constipated. This means they may find it hard to poo, or poo less than usual.

Constipation can be caused by different things, including not moving around. It can also be caused by some pain relief medicines.

There are things that can help to prevent constipation, including:

- drinking more fluids, particularly water
- keeping active or moving around.

Eating fibre and fruit can help with constipation. But if the person has a low appetite, it's important to have food and drink that they are able to eat and enjoy.

If they're bedbound, privacy while they go to the toilet is important. Ask the healthcare professionals for advice if you are concerned or if the person is in discomfort. They might suggest laxatives, which are medicines to help them poo.

Bladder and bowel problems towards the end of life

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.



Find out more about bladder and bowel problems at mariecurie.org.uk/bowel-problems

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), medicines, or a combination of these. Ask the person's doctor or nurse for advice if poor sleep is affecting them.

There are ways to help someone relax and help them sleep, including:

- having a daily routine – for example, opening the curtains in the morning and changing into daytime clothes
- soothing them or giving them a gentle massage – you should only touch them gently, especially if the person is frail
- making 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, someone's room can feel a bit like a hospital. It may help to:

- use photos, cards and art to make their surroundings seem more personal and less clinical
- play their favourite music.



Find out more about making someone comfortable in bed at mariecurie.org.uk/comfortable



Managing pain

Pain is common in people who have a terminal illness, but not everyone has pain. If someone is in pain, it is important that you tell their healthcare team. As well as physical factors, things that can influence pain include:

- lack of sleep or tiredness
- emotions such as worry, anger and fear
- spiritual concerns.

Ways to help manage pain

With the right treatment and support, pain can usually be managed:

- **Pain relief medicines.** Speak to the healthcare team about what painkillers could be prescribed and how they should be given. If someone has problems swallowing medication or their medicines are not working, they can be given using a syringe driver. This is a small battery-powered pump that delivers medication through a very thin, soft plastic tube placed just under the skin. Watch our short film on syringe drivers at mariecurie.org.uk/syringedrivers
- **Making the person more comfortable.** This could include changing positions, putting cushions or pillows around them for support, or moving from the bed to a chair if possible (or the other way around). You could also use hot and cold packs to ease pain or adjust body temperature. Hot and cold packs should be covered, not placed directly against the skin, and not used if the area has reduced sensation – for example, if someone has a swollen limb.

Managing pain

- **Physiotherapy.** A physiotherapist can teach you some gentle exercises to manage or ease mobility issues.
- **Complementary therapies.** This could include massage, aromatherapy and reflexology. Speak to the healthcare team before arranging any complementary therapies.
- **Helping the person feel supported.** People often feel less pain when they feel relaxed and supported. You can do this by spending time with them, talking about any concerns (or arranging emotional support, such as a counsellor), and helping them relax.



Find out more about managing pain by visiting mariecurie.org.uk/managing-pain

Feeling and being sick

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

Agitation and confusion

Towards the end of life, changes in someone's condition 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 you or other people around them to see. You can offer reassurance by:

- holding their hand and being close to them
- being in a calm and quiet environment
- speaking to the healthcare professionals to find out about any medicines to help treat underlying causes, or to help them feel calm and relaxed.

If the person becomes suddenly confused, they may have delirium. Speak to their doctor or nurse as soon as possible for advice.

Not everyone will seem confused or agitated. Some people appear calm and detached from what's going on around them.

Feeling weak and tired

Towards the end of life, 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.

Feeling breathless

Towards the end of life, 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.





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Changes in the final hours of life

This section has information about changes you may see in the last hours of someone's life. If you are not ready to read this yet, you can come back to it or speak with the healthcare team when it's time.

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.

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 days and hours before death, it's common to experience certain changes.



Read more about the final hours of life at mariecurie.org.uk/final-moments

Loss of consciousness

People sleep more and need to rest as their body slows down. In the last few days of life, they might sleep for longer periods and seem less aware of what's going on around them. They may still have some awareness of what is happening in the room. They may be able to hear what's being said or feel someone holding their hand.

Changes to skin

The person's arms, legs, hands and feet may feel colder. This is because the blood circulation around the body is slowing down.

Lighter skin tones may look slightly blue or mottled (have different coloured blotches or patches). On darker skin tones, blue can be hard to see. Instead, you might see their lips, nose, cheeks, ears, tongue, or the inside of their mouth looking slightly blue. Mottling is also harder to see on darker skin tones – it might look darker than normal, purple or brown in colour.

Noisy breathing

Breathing may become loud and noisy if secretions (saliva or mucus) have built up in the throat or chest. 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 this is normal and is not usually uncomfortable or painful for them. Speak to their doctor, nurse or care home staff if you are worried.

Shallow or irregular breathing

In the last days of life, 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 is not completely peaceful, it's unlikely that the person will have been aware of it.

If you, or anyone else 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 eyes and body for other signs.

We have information about practical things to do after someone dies, as well as services to support you with grief. You may want to order our free booklets

When someone dies or **Coping with grief** at mariecurie.org.uk/publications or by calling our free Support Line on **0800 090 2309*** – they can also tell you more about our bereavement support service.



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How Marie Curie can help

Marie Curie is here for anyone with an illness they're likely to die from, and those close to them. Whatever the illness, wherever you are, we're with you to the end.

Marie Curie Support Line

0800 090 2309*

Our free Support Line is for anyone with an illness they're likely to die from and those close to them. Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Our Support Line is available in over 200 languages, or via webchat at mariecurie.org.uk/support-line

Marie Curie Companions

Companion volunteers focus on what's important to you and those close to you. It might be accompanying you to appointments, being there to listen to how you're feeling without judgment, or stepping in so family or carers can take a break. Companions provide the emotional and practical support you want – at home, in hospital or over the phone.

mariecurie.org.uk/companions

Marie Curie Telephone Bereavement Service

Get ongoing bereavement support over the phone from the same volunteer. You can access up to six sessions of 45 minutes. We can help if your bereavement was expected, happened recently or was some time ago.

mariecurie.org.uk/bereavement

* Your call may be recorded for training and monitoring purposes.

Marie Curie Online Community

Our Online Community is a space for you to share thoughts, feelings and experiences. It's moderated by the Marie Curie Support Line team, who can also help answer your questions.

community.mariecurie.org.uk

Marie Curie Hospice care where it's needed

Our hospices

Our hospices help people with any illness they're likely to die from, and the people close to them, receive the support they need. From medical and physical support to psychological and emotional care, whatever your illness, at whatever stage of the journey, we help you to live the best life possible, right to the end.

mariecurie.org.uk/hospices

Hospice care at home

Our nurses, healthcare assistants and other healthcare professionals bring the clinical, practical and emotional help you need to you, in the comfort of your own home. And we offer support to the people close to you too – from reassurance and practical information to letting them take a break.

mariecurie.org.uk/nurses

Looking for more information?

If you found this booklet useful, we have free information online at mariecurie.org.uk/information or to order at mariecurie.org.uk/publications

Useful organisations

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

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](https://www.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](https://www.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.

About this information

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

If you'd like the list of sources used to create this information, please email review@mariecurie.org.uk or call the free 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.

Did you find this information useful?

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

Your notes

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Marie Curie

Marie Curie is the UK's leading end of life charity. Whatever the illness, wherever you are, we're with you to the end.



0800 090 2309*

Marie Curie provides free support over the phone in over 200 languages, and via webchat, to anyone with an illness they're likely to die from and those close to them.

Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Visit mariecurie.org.uk/support

We also have an Online Community where you can share thoughts, feelings and experiences at community.mariecurie.org.uk

We can't do it without you

Our free information and support services are entirely funded by your generous donations. Thanks to you, we can continue to offer people what they need, when they need it.

To donate, visit mariecurie.org.uk/donate

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