

# Caring for someone at home



**Marie  
Curie**

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 to skip 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 loved one.

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 loved one 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 bear 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.



Find out more about washing at [mariecurie.org.uk/washing](https://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, as long as it's rinsed out properly to prevent a dry mouth
- 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.

### 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 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
- 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/mouthcare](https://mariecurie.org.uk/mouthcare)



Layfon Thompson/Marie Curie

# 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 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.



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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 should not be forced.

It can help to talk to the healthcare professionals, especially about difficulty swallowing or nausea. 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](https://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.



## Bladder and bowel care

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

- 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 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/bladderandbowel](https://mariecurie.org.uk/bladderandbowel)

## 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.

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

- stroking 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.



Watch our short film on making someone comfortable in bed at [mariecurie.org.uk/comfortable](https://mariecurie.org.uk/comfortable)



Philip Hardman/Marie Curie

# 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, it 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](http://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](https://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, 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.

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.





Philip Hardman/Marie Curie



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



Read more about the final hours of life at [mariecurie.org.uk/final-moments](https://mariecurie.org.uk/final-moments)

## 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

Limbs, 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.

## 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 will not 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 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](https://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](https://mariecurie.org.uk/support). Open between 8am to 6pm from Monday to Friday, and 11am to 5pm on Saturday.

## 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](https://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](https://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](https://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](https://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](https://mariecurie.org.uk/nurses)

## Looking for more information?

If you found this booklet useful, we have free information available online at [mariecurie.org.uk/support](https://mariecurie.org.uk/support) or to order at [mariecurie.org.uk/publications](https://mariecurie.org.uk/publications)

# Useful organisations

## Hospices and care centres

### Hospice UK

**020 7520 8200**

[hospiceuk.org](http://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](http://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](http://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](mailto: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](mailto: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](https://mariecurie.org.uk/support)

We also have an Online Community where you can share thoughts, feelings and experiences at [community.mariecurie.org.uk](https://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](https://mariecurie.org.uk/donate)

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

