

Being cared for at home

Information for you and the people caring for you



**Marie
Curie**

Care and support
through terminal illness

Disclaimer

Although every effort has been made to ensure accuracy, Marie Curie cannot accept any liability in relation to the information in this booklet or any advice that our Marie Curie Nurses or Healthcare Assistants provide in the home (other than for personal injury caused by our negligence). Readers are strongly advised to seek personalised advice from an appropriate professional.

Introduction

Whether you have a terminal illness or you are caring for a loved one, we hope this booklet will be useful to you.

Inside you'll find information about the practical and emotional aspects of care and the support that's available for you. We hope you find it helpful.

Throughout the booklet, you will find images like this:



By each image, we've included a website address where you can find films which focus on personal care and everyday living. They include practical demonstrations on caring for someone at home.

You can also find more information and advice for you, the person caring for you and your family on our website at mariecurie.org.uk/help

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Care in your home

If you have a terminal illness and want to be cared for at home, this booklet is for you.

Wherever possible, Marie Curie, the NHS and other care organisations will support your wish to be cared for at home, and provide services to help you achieve this.

If you're in hospital but would prefer to be at home, do tell your nurse or doctor so they can discuss the support and services you will need to make this happen.

Planning your care

The district nurse, specialist nurse or your doctor will discuss your care with you and the person caring for you. They will talk to you about different services and options that may be suitable for you.

You may want to talk to your nurse or doctor about where you'd like to be cared for if you become very ill and where you would prefer to spend the last weeks of your life.

For instance, do you hope to stay at home? Or would you prefer to go to a hospice or hospital?

Your care plan

The district nurse (or specialist nurse) will put together a care plan which reflects your wishes and care needs. The district nurse will review the care plan regularly with you and amend it if necessary.

The care plan tells all the healthcare professionals involved with your care, such as your GP, district nurse or specialist nurse, what treatment and care you have already had, what is planned and what your wishes are. The care plan may be kept in your home or may be online.

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

You may want to make decisions in advance about the type of care you would like if you are no longer able to communicate your wishes. If you have drawn up paperwork to reflect your wishes (for instance, an advance decision – often known as a living will), ask for a copy to be added to your care plan, and check that your care plan itself reflects your wishes.

The district nurse can help you decide what to include. They may have a standard form you can complete or use to help you. For more information see *Making decisions about your future care* on page 24 or visit mariecurie.org.uk/planningahead

If you don't have paperwork but would like your wishes to be recorded, you can ask the district nurse to add your wishes to the care plan.

Giving your consent

Professionals involved with your care need to be sure that you consent to the care they are suggesting before they begin any treatment or procedure.

Before they go ahead with it, they must explain what they will do, what the risks are (if any) and why they are doing it. It is your right to refuse any treatment or procedure offered.

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Who can help you at home

You may meet a number of different healthcare professionals while you're being cared for at home. We've introduced some of them in this section so you can have a clearer picture of who is involved in your care and how they can help you.

Please tell your doctor if you would like them to share information about your condition with your carer or a family member. Doctors will only discuss your condition with you unless you tell them you want other people to know.

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.

Your GP will liaise with the district nurse, who is part of the team, about your care if you are being cared for at home. 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 care. They work with your GP and primary healthcare team by providing specialist advice and treatment so you receive the care that you need in the place of your choice, such as your home or care home.

Palliative care is a type of care that helps you to have the best possible quality of life. It includes a variety of treatments for symptoms such as breathlessness, pain, depression or anxiety. It also includes support for your family members and friends who may have concerns about you and your illness. Palliative care can be given at the same time as other treatments you may be receiving.

You can read more about palliative care at mariecurie.org.uk/endoflifeexperiences

District nurses

District nurses are part of the primary healthcare team. They organise and coordinate home care and can arrange for you to get services if you are receiving care at home.

These services vary from area to area and may include support from Marie Curie Nurses, other specialist nurses, social services or prepared meals delivered to you.

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

- carers' groups
- your local hospice
- drop-in centres
- organisations offering grants
- complementary therapy practitioners
- interpreting services
- other relevant services and benefits

Clinical nurse specialists

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

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

Marie Curie Nurses and Healthcare Assistants

Marie Curie Nurses and Healthcare Assistants usually spend several hours at a time in a person's home. They provide hands-on nursing care and emotional support often overnight.

Physiotherapists and occupational therapists

A physiotherapist or occupational therapist can help you to live independently. They often help with breathing problems or mobility problems and they can provide walking frames and other equipment that you may need.

Hospices

Hospices provide specialist care for people with serious illnesses and support to their carers, families and children. Hospice services focus on relieving a person's symptoms and helping them remain independent for as long as possible.

Some hospices have specialist nurses who provide advice and support for people at home, while some may offer a 'hospice at home' service which provides nursing care and support in people's homes.

Some hospices offer short stays to people who are ill while the person caring for them takes a break. Hospices also care for people at the end of their lives, making them as comfortable as possible.

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. Visit mariecurie.org.uk/hospices or call the Marie Curie Support Line on **0800 090 2309***.

You can also find out where your nearest hospice is and other general hospice information by visiting hospiceuk.org or phoning **020 7520 8200**.

Social services

Social services can suggest services that would be helpful to you and the person caring for you. These might include assistance with shopping or deliveries of prepared meals. Services vary according to local authority.

Contact details of social services in your area can be found in your local phone directory (or on the internet) or you can contact your local council.

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

Support from people close to you

Your family and friends

Family and friends often want to help, but may feel awkward about bringing up the subject. They may find it useful if you make suggestions about ways they can help.

You could ask them to help with:

- cooking a meal
- companionship
- shopping
- visiting – to allow the person who cares for you to have some time for themselves

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



Having visitors in your home

Visitors can make you and the person caring for you feel better. However, sometimes you may be tired or the time of the visit may not be convenient.

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

- Mealtimes may be best avoided.
- Certain times may not be convenient – for instance, if your doctor is visiting.
- Visitors can be tiring when you are unwell – it is often recommended that visits are limited to half an hour, or to a couple of visitors at a time.

If a relative or friend seems reluctant to visit, do bear in mind some people may feel uncomfortable about visiting but would be very happy to provide practical help.

Visitors may well be afraid of seeing you. Some people may worry that they will become upset in front of you, or that they will say or do the wrong thing or upset you. The more explanations and openness you offer, the easier it will be for your visitors, and perhaps more satisfying for you.

Other support that's available

Support groups

There are support groups for people with serious illnesses or particular health conditions. Members usually include people who have personal experience of a similar situation.

To find a local support group:

- ask your district nurse or GP
- contact a Marie Curie Hospice if there is one near you (see pages 91 – 92 for details) or visit **mariecurie.org.uk/hospices**
- call the Marie Curie Support Line on **0800 090 2309***
- phone Macmillan Cancer Support on **0808 808 0000** or visit **macmillan.org.uk**

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 if a support group isn't convenient.

Counselling

If you have concerns or questions about living with cancer, Macmillan Cancer Support can provide you with emotional and practical help. Phone **0808 808 0000** or visit **macmillan.org.uk**

The British Association for Counselling and Psychotherapy can provide information on counsellors, including those with specialist training in helping people with terminal illnesses. Phone **01455 883 300** or visit **bacp.co.uk**

Spiritual support

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

If you are in contact with a Marie Curie Hospice (see pages 91 – 92 for details) or another local hospice, the hospice chaplain (or someone in an equivalent role) can offer advice and recommend a local person for you to contact.

Complementary therapies

Complementary therapies – sometimes called alternative therapies – are often used alongside conventional healthcare. Complementary therapies include relaxation, massage, aromatherapy and reflexology.

You can find out more about these and other complementary therapies at **mariecurie.org.uk/complementarytherapies**

If you wish to try a complementary therapy, we recommend discussing it with your nurse or doctor. They will be able to tell you if there are any medical reasons why it's not a good idea to use a particular treatment. They may also be able to tell you about local complementary therapy practitioners or you can contact the Institute for Complementary and Natural Medicine on **020 7922 7980** or visit **icnm.org.uk**

Emotional support for you

Coping with your feelings

It's natural for a person to feel anxious or depressed when they are ill. These feelings may be worse towards the end of someone's life and may not be easy to recognise.

People who are ill can feel isolated or fear abandonment, especially if they are cared for away from home for a time. You may be worried that you will be left alone, and need reassurance.

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 some or all of the following (or those around you may notice them):

- 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)

Some people might not admit to their feelings. Denial is a common and often a necessary stage in the emotions people experience, particularly if they are approaching the end of their lives.

You may want to seek help from your doctor, nurse or a support group, especially if feelings like that continue or become worse.

Your family and friends may be able to help you by talking and listening to you.

It might help to consider the following points together:

- It is important for others to feel comfortable listening to and talking about what you are saying.
- Are others prepared to discuss your concerns if you wish?
- Will others be honest with you?
- Your feelings may change from day to day, or even hour to hour.
- Sometimes you may just want to sit in silence with someone for company.

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

Emotional support for the person caring for you

Your family, friends and especially those caring for you may also find themselves feeling sad or depressed, or showing some of the signs outlined in the previous section.

If they are finding things difficult, you could encourage them to seek help or support for themselves, just as they would for you.

Encourage them to seek help from their doctor or a support group, especially if these feelings continue or get worse.

The person who cares for you can also talk to your Marie Curie Nurse or Healthcare Assistant about their feelings and emotional needs. Our nurse or healthcare assistant is there for the people close to you as well as for you.



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Planning for the future

Making decisions about your future care

A time may come when you cannot make decisions or express your wishes about your care and treatment. You may want to ensure that the people who will be caring for you know how you want to be cared for.

Advance care planning is about discussing and writing down the care you would prefer. To find out more, visit mariecurie.org.uk/planningahead or visit nhs.uk and type the words *planning ahead for future care* in the search box.

You may want to give someone Power of Attorney – this means you can choose someone to make decisions on your behalf if you become unable to do so in the future. In each UK nation the legal names for this and the paperwork required are different.

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

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

If your doctor doesn't know what your wishes are, they may consult your next of kin. Life partners might not be considered next of kin unless you are married or in a civil partnership. Your doctor is obliged to use his or her medical judgment and act in your best interests, whoever they talk to.

Making decisions in advance

You can decide what treatments you would want to refuse in specific circumstances. However, you cannot insist on receiving specific treatment (for instance, you cannot insist that a doctor resuscitate you if it is 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 terminally ill and expected to die within a few days, you do not want to be treated with antibiotics if you get an infection. However, you cannot rule out all medical treatment for any condition that might arise.

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 doctor and nurse and give them a copy of any formal paperwork, or tell them you have recorded your wishes in this way. Ask them to put a copy in your medical records and nursing care plan.

If you update your wishes in writing, ask the person who is caring for you to make sure everyone who needs it 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.

In England and Wales

You can use an advance decision to refuse treatment to state your wishes about refusing certain forms of medical treatment in certain situations.

An advance decision to refuse treatment does not have to be in writing unless it includes your wishes relating to refusing treatment that could keep you alive.

An advance decision to refuse treatment is legally binding if you follow some specific requirements.

An advance decision to refuse treatment does not override measures to make you more comfortable like warmth, shelter and basic care (such as hygiene and offers of food and water by mouth).

You can use a Preferred Priorities of Care document to state your wishes about any other aspects of your care and treatment. This will reflect your beliefs and values so people know what is important to you. It is not legally binding, but should be taken into account by your doctor and family.

For more information see:

- The Planning ahead section on our website at **mariecurie.org.uk/planningahead**
- The NHS website **nhs.uk** and type the words *planning ahead for future care* in the search box.
- Age UK's (previously called Age Concern) information sheet on Advance Decisions, Advance Statements and Living Wills. Phone **0800 169 6565** (free call) or visit **ageuk.org.uk** and type the words *living wills* in the search box.
- The NHS website, Advance Decisions To Refuse Treatment. Visit **www.adrt.nhs.uk** and select *public and patients* in the menu bar.
- The Natural Death Centre sells a sample advance healthcare directive, and their publication *The Natural Death Handbook* includes information about issues you may want to cover in such paperwork. Phone **01962 712 690** or visit **naturaldeath.org.uk**

If you drew up paperwork before October 2007, you are strongly advised to review it because the Mental Capacity Act is now in force and may affect it.

Nominating someone to make decisions on your behalf

You can choose a person to make decisions on your behalf if you set up a Lasting Power of Attorney to cover healthcare or financial matters.

Information about Lasting Powers of Attorney is available on our website at **mariecurie.org.uk/attorney** and in the leaflet *Making decisions ... about your health, welfare or finances* from the Office of the Public Guardian. Phone **0300 456 0300** for a copy, or visit **gov.uk/opg**

In Scotland

An Advance Directive sets out your wishes regarding your future care and treatment. It is not legally binding but your wishes would be taken into account by your family and doctors if you became unable to communicate.

Nominating someone to make decisions on your behalf

You can choose a person to make decisions on your behalf if you are unable to do so in the future by setting up a:

- Welfare Power of Attorney (for health and welfare decisions)
- Continuing Power of Attorney (for financial decisions)

The Office of the Public Guardian (Scotland) provides guidelines and sample power of attorney paperwork. Phone **01324 678 300** to request a copy or visit **www.publicguardian-scotland.gov.uk** and select *power of attorney* in the menu bar.

In Northern Ireland

There is currently no legislation covering advance decisions, advance statements or living wills in Northern Ireland.

However, your doctor is obliged to act in your best interests when planning your care and treatment. If you set up an Enduring Power of Attorney to cover your financial affairs it will not cover welfare or healthcare issues.

Further information is available in the leaflet *Enduring Power of Attorney*, produced by the Northern Ireland Courts and Tribunals Service. Phone **028 9032 8594** for a copy, or visit **courtsni.gov.uk**

Funeral planning

Some people want to be involved in the planning of their own funeral. Others feel it is inappropriate to plan or even discuss a funeral while they are alive.

If you feel able to think about this now it may help your family when the time comes.

When people have just been bereaved, they may not have the time to, or be able to, explore all available options. If you discuss your wishes for your funeral while you are alive, your partner or family will be clear about what you want and will feel more prepared.

You can make decisions without the time pressures and there will be time to make any special arrangements you would like.

It may feel uncomfortable at first, but people often take comfort from making firm decisions. Things to consider include what music to have, whether to be buried or cremated, and where to be buried or have their ashes scattered.

If your partner or family do not wish to discuss the subject, you could write down your wishes so they have something to help them make decisions later.

Marie Curie's booklet *When someone dies* gives an overview of funeral planning and lists useful sources of information. Visit **mariecurie.org.uk/publications** to download or phone **0800 090 2309*** for a copy.

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



Information for the people caring for you

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Dealing with change

Having a terminal illness changes a person's life and the lives of those closest to them.

Feelings can change from day to day, hour to hour and even minute to minute. People may experience changes in family roles and relationships. They may have to deal with the prospect of giving up work and changes to their financial independence.

It is common for people to feel denial, anger, fear, depression and even guilt. At times they may be angry, afraid or worried, and at other times feel sad, guilty or lonely. All these feelings are normal.

At other times, people may not really believe the person they are caring for has a terminal illness.

Coping with your feelings

Supporting and caring for someone with a terminal illness may be too much for you to handle by yourself. Try to talk to people about your feelings and how you are coping or visit mariecurie.org.uk/being-there for more information on supporting someone with a terminal illness.

Talking to others about your feelings can help you to deal with your emotions and the impact the illness is having on your life. You may find it easier to talk to a close friend rather than someone in the family if that will help – you can be yourself and talk more openly about what you're thinking and feeling.

Help is available, so do let someone know if your feelings are stopping you from doing the things you want to do. You may find it helpful speaking to a friend, counsellor or someone at a support group.

Taking time out

Providing care for someone who is ill can place great physical and emotional demands on you. It is important that you take time out to recharge – by spending time with your friends, taking some gentle exercise or having some time alone if you feel tired or overwhelmed.

Remember that you are human and you can only provide what you can. 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. Our booklet, *Being there for someone with a terminal illness*, can help you with this.

You may choose to continue working if this is possible. Some people find that it's a good distraction and can provide a sense of continuity.

Tiredness and exhaustion

Rest is very important, and short naps can help revive your energy levels. Some people find relaxing to music particularly helpful.

You may become prone to, or be at greater risk of, infections, so try to make sure you are getting enough vitamins. Try to eat five portions of fruit and vegetables each day or consider taking vitamin supplements.

Consider having the flu jab – it's free for carers so ask your GP about it. Remember not to neglect your own health – if you feel unwell, see your GP as soon as possible.

Coping with the feelings of others

Just as you have strong feelings and may struggle at times to cope with your own emotions, other people around you will have similar feelings and emotions and they may look to you to support them as well.

The person you are caring for is very likely to have good and bad days. They may also try to hide their feelings from you or behave in a way that you do not expect.

You may find they change from not wanting to upset you by talking about their illness to blaming you for their illness. At other times they may act as if nothing is bothering them.

This can be very distressing for you and may affect your relationship with the person you're caring for. If you are struggling to cope with varying emotions, it's important that you talk to someone about it – a good friend, support group, your own doctor, or the nurse or doctor caring for the person who is ill.

Healthcare professionals can help you, so don't hesitate to talk to them about how you are feeling.

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

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Practical information on caring for someone

Moving and handling

If you're looking after someone at home, this section will help explain some ways you can help them move around. It should also help the person you're caring for to understand what you are doing, and why.

Mobility

It's important for you to encourage the person you're caring for to be as independent as they can for as long as possible. This helps to keep up their morale and helps with physical comfort.

Before you help the person move, please note the following points:

- Clear the floor of shoes, rugs or other items on which you might trip or which might prevent you getting into the correct position.
- If you are helping the person to a chair or commode, remember to position it near to the bed.
- Explain exactly what you plan to do so that the person understands and can cooperate with you.
- Remember to be as gentle as possible when moving the person.
- Take it step by step.

Important disclaimer

While every care has been taken to give clear and accurate guidance regarding moving and handling someone who is being cared for at home, these guidelines are for information purposes only. The guidelines show how someone who has received adequate and proper training, and is proficient in moving and handling someone who is being cared for at home, may carry out the relevant operations.

The guidelines should not be regarded as a substitute for training. The guidelines may not be suitable for every situation, or for everyone who is being cared for at home or who is caring for someone at home. We therefore recommend that if you are not fully trained, you should seek advice from your district nurse before undertaking any operation involving the moving and handling of someone who is being cared for at home.

All moving and handling operations carry an element of risk. In addition, moving and handling tasks are complex and require each situation to be assessed upon its own merits.

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 or any advice that our Marie Curie Nurses or Healthcare Assistants provide in the home.

Safer handling

Before helping someone to move, please read the following tips. These should reduce the risk of injury.

- Make a good stable base with your feet, one foot in front of the other, hip width apart.
- Bend your knees, and use your legs to power the manoeuvre.
- Keep your back in a comfortable upright position.
- Keep your head up when carrying out a manoeuvre to promote good posture.
- Use any equipment that you have been given, provided you have been told, and understand, how to use it.
- If in doubt about moving the person, ask for advice from the district nurse, or the Marie Curie Nurse or Healthcare Assistant.

Safety

The following pictures and guidance are designed to help you to roll someone in bed, or move them from bed to a chair at home.

Ask the district nurse, or the Marie Curie Nurse or Healthcare Assistant, to demonstrate the movements before carrying them out yourself.

Due to the risk of injury, either to yourself or to the person you're helping, you should only attempt to help someone get out of bed and stand up if they are able to stand on their own. You must not bear all or even most of the weight of another person.

These techniques should only be carried out with someone who is able to help you with the movement and who can follow instructions.

Moving someone in bed

If you 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 allow you to move them without needing to lift them:



Step 1

Remove the bedclothes and all but one pillow. 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 at the start or finish of the move.)



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

Helping someone stand and walk

You should only attempt to help someone move from the bed to a chair if they are able to stand by themselves.

Before you can help the person sit in a chair or commode, you need to get them to sit on the side of the bed. They should need very little help. You should clear the floor of any obstructions before you start and wear light footwear 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, one foot in front of the other.



Step 2

Have them gently push themselves into a sitting position. Now you need to help them stand.



Step 3

Sit alongside them and hold one hand (so that their palm rests on your fist) while placing the other around their waist. Do not interlock your fingers or thumb with theirs – this can be dangerous. Both of you should place one foot slightly in front of the other.



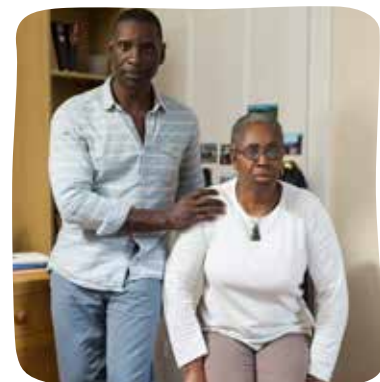
Step 4

On the command 'ready, steady, stand' – help them to stand. They can help by pushing against the bed with their other hand.



Step 5

Using small steps, gently help them to the chair. If the chair has arms, the person should feel for one with their free hand. Once they feel the chair against the back of their legs they can lower themselves into position.



This manoeuvre is only appropriate if the person giving the care is providing minimal assistance, and the person who needs to stand is doing most of the work. If this is not possible, it may not be safe to help the person to stand.



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

Personal care

Equipment to help you and the person you're caring for

There are various pieces of equipment that may be helpful to the person you are caring for at home. People often need a pressure-relieving mattress or a commode.

The person's physiotherapist, occupational therapist, district nurse or GP should be able to advise what equipment is available and how to use it. The NHS provides some equipment and will advise how to obtain things that it does not 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 **0844 871 1111** or visit **redcross.org.uk**

An audio or video baby monitor can allow you to stay aware of how the person is while you get on with activities elsewhere in the house.

A wireless doorbell will enable the person you're caring for to contact you even if they're out of earshot (try a high street catalogue retailer or DIY store).

Some other items you may find useful include drinking straws, non-spill beakers, a urine bottle and a bedpan (available from some chemists, or search online for companies specialising in home mobility aids).

For more information on adaptations and care needs, visit **mariecurie.org.uk/careneeds**, or call the 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.

- It is important to 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.
- Soap must be rinsed off completely and the person's skin should be dried gently but thoroughly to prevent their skin from becoming itchy.
- The water in the bowl should be changed several times during the wash.
- Only those parts of the person's body that are being washed at the time need to be exposed. This helps to keep them warm and maintains their dignity.
- The person you are caring for may be able to wash their own face. A mild cream cleanser may be better than soap for this.
- Talcum powder may be used in small quantities if their skin is not too dry. Excess powder must be brushed away.
- Moisturising creams may be applied gently to dry areas such as the person's elbows, heels and soles of the feet.

If they don't feel like a full wash, a good occasional alternative may be to use wet wipes and dry shampoo.



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 have a positive effect on how they feel. For instance, it can be helpful for them to put on fresh clothes, have a shave, put on make-up or wear jewellery. If they can't manage on their own, do offer to help.

Hair washing can be managed, even if the person is bedbound. It can have a positive effect on how they feel. You can use:

- dry shampoo powders
- a special bowl with splash attachment – this may be available from the district nurse
- a plastic sheet, towels and an ordinary bowl in the most comfortable position for the person
- a no-rinse, waterless hair-washing cap which lets the person have a shampoo without water (ask their district nurse, try a chemist or buy online)

Helping with mouth care

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

- a dry mouth and lips
- ulcers
- infection
- bleeding gums
- too much saliva
- an altered sense of taste

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

A soft toothbrush (such as a baby toothbrush) is best if the person's mouth is sore. Toothbrushes should be changed every three months or more often if needed. Do use toothpaste – a small amount – but be aware that it can have a drying effect if the person doesn't rinse their mouth.

They can rinse their mouth with saline solution (one teaspoon of salt in one pint of water) or a mouth rinse from the chemist. Do not use a sodium bicarbonate rinse, which can cause problems with the person's mouth, teeth and general health if they are very ill. If the person cannot rinse their mouth, talk to their nurse for advice.

False teeth should be cleaned as usual using soap and water, and soaked overnight if required. If the person has lost weight, their false teeth may not fit and can cause mouth ulcers. If necessary, please talk to a dentist.

If the person has mouth pain, do tell their GP, who may be able to prescribe medication to help relieve it.

Thrush is a common mouth infection in people who are ill. It causes a very sore mouth and tongue, and can be recognised by white patches on the tongue, gums and inside the cheek. Report it to the person's nurse or doctor as it can be treated easily.

You can relieve a dry mouth with ice cubes or ice chips, frozen fruit, lemonade or tonic water. Tinned, unsweetened pineapple can cleanse and help to relieve a dry mouth.

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. But the effects only last 10 to 15 minutes and it may cause discomfort if too much is used or it is used too often.

Unflavoured lip salve can help to prevent dry lips. Flavoured lip salves are not recommended since many people end up licking them off. Many people use products such as Vaseline for lip care. Please be aware that 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 preparing healthy meals and snacks and helping someone to relax. Visit mariecurie.org.uk/filmguides

Pressure area care

If the person you're looking after is confined to bed or sits in a chair for long periods, they can become sore and numb at the points on their body that carry most of their weight, particularly the bony points.

If pressure is not relieved frequently, the skin may break down and a pressure ulcer (bed sore) may develop. This is uncomfortable and often painful. People who are immobile and thin are most at risk.

The best way to prevent these sores 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.

When you are washing the person, it's a good idea to look for signs of redness, discolouration or changes in the 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 redness, discolouration or changes in the appearance of the person's skin, tell their district nurse. 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 on our website. Visit mariecurie.org.uk/bedsores

Healthy meals and snacks

It's important that the person you're caring for has a healthy diet – they particularly need to get enough protein (meat, fish, eggs, milk, pulses etc).

However, they may have a small appetite or none at all, or their tastes and preferences may change rapidly.

You may find the following suggestions helpful:

- It's easier to eat if the person is sitting upright in a chair.
- Encourage them to get out of bed for meals if they're able to.
- It helps if the food looks attractive – and small portions may be more appealing.
- Nourishing drinks and food supplements are useful, as well as meals or as an alternative.
- It may be easier for the person to manage soft or liquid foods such as soup, ice cream, jelly, milk puddings or milk jellies.
- You can use high calorie fruit juice drinks to make jelly, using the juice instead of water.
- Ask the person's nurse or doctor for advice if nausea is preventing them from eating.
- Serve the food cold if cooking smells make the person feel unwell.
- Sucking boiled sweets or ice cubes can soothe a dry mouth and relieve nausea or sickness.
- Fizzy drinks that have gone flat – lemonade, cola or ginger beer – can help relieve nausea. Ginger beer may be too spicy for some people.

- If the person has a coated tongue, you can relieve it with unsweetened pineapple chunks or juice if their mouth is not sore.
- Rinsing the mouth after meals will keep it clean and comfortable.



Watch our short film guide about preparing healthy meals and snacks at mariecurie.org.uk/healthyeating

Bladder and bowel care

If the person you're looking after is eating and drinking less and less, they're likely to have less need to empty their bladder and open their bowels. They may also find they become constipated more easily.

A number of drugs used for pain control are known to cause constipation so the person may need to be prescribed medication to counteract this side effect.

There are things they can do to prevent constipation. These include eating more fruit, especially prunes, rhubarb and bananas. Eating more fibre and drinking more fluids (particularly water) can also be of benefit.

Exercise and moving around can also help. If they're bedbound, privacy while they go to the toilet is important.

Do ask their nurse or doctor for advice if you are concerned or if the person is in discomfort. The Marie Curie website has more information on bladder and bowel care at mariecurie.org.uk/bladderandbowel

Dealing with pain

If the person is experiencing pain, it is important that you discuss it with their nurse or doctor.

People with a terminal illness often expect to have pain, but nowadays most people do have their pain managed successfully.

Some people feel they should wait until the pain is really bad before taking any painkillers. It is better for the person to take painkillers as prescribed and on time even if they are not experiencing pain at the time. This helps to keep the pain at bay between doses.

If the person is in pain before their next dose, you should tell their nurse or doctor.

If they are unable to swallow their medication, 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 soft plastic tube placed just under the skin.



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

Painkillers sometimes work better when combined with other drugs such as anti-inflammatory drugs or anti-depressants.

It is important to read the label as some strong painkillers may cause side effects. These can 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. See page 48 for tips on how to deal with nausea.
- Constipation – the doctor may prescribe a laxative or stool softener. See the bladder and bowel care section on page 49 for more advice.



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

Other ways of relieving pain include:

- changing their position so they're more comfortable
- hot and cold packs
- physiotherapy
- complementary therapies such as massage, aromatherapy and reflexology.

Music can be very soothing and relaxation techniques like massage or visualisation exercises can be helpful.

You could also ask the person's nurse or doctor for advice, or try your local library for information on relaxation. Our website has more relaxation suggestions. Visit mariecurie.org.uk/relaxing

Many factors influence pain. They might include lack of sleep, fatigue, worry, anxiety, anger and fear, as well as spiritual concerns (such as wondering why this is happening).

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

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

See page 18 to find out who else can help you.



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

Sleep problems or restlessness

Sleep problems or restlessness may be due to physical causes, non-physical factors (such as anxiety) or a combination of both. You could ask the person's doctor or nurse for advice.

Stroking or massage can be a useful way of helping the person to relax, and can sometimes relieve pain and help them sleep. You should only touch them gently, especially if the person is frail.

Making someone comfortable in bed

If special equipment and medical supplies have been brought in, it is very easy for the person's room to start to feel like a hospital. Photos, cards and art can make their surroundings seem 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



Information for the people caring for you

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Support for carers

If you are caring for someone with a terminal illness at home, it's important that you look after your own health and get enough rest.

While it can be difficult to ask for help, or find the time to look for someone to help you, there are many things that organisations like Marie Curie can do to support you and your family.

You could also ask for help from friends and relatives, as well as healthcare professionals such as your GP.

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). We will work closely with them to make sure that you and the person you are 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 terminal illnesses 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 person caring for them takes 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. And 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, 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 get:

- emotional support from counselling sessions or carers' groups
- a range of therapies from trained complementary therapists
- welfare or benefits advice
- 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). Please

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.

Marie Curie Helper volunteers

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

If you'd like someone to talk to about any questions you might have, either for yourself or the person you're looking after, you can contact the Marie Curie Support Line on **0800 090 2309*** (9am – 5pm, Monday to Friday) to speak to a trained adviser.

You can also visit mariecurie.org.uk/help where you'll find clear, practical information on caring for someone and lots of resources on planning ahead and financial matters. And to share your experiences and find support by talking to people in a similar situation, visit community.mariecurie.org.uk

Hear from other carers on HealthTalkOnline

Marie Curie awarded funding to a research project by the Health Experiences Research Group at the University of Oxford. The project's aim is to improve the understanding of carers' experiences of providing care at home.

People from across the UK were interviewed about their experiences of caring for someone with a terminal illness in the context of their family, work and social lives. To listen to the interviews, visit mariecurie.org.uk/healthtalkonline

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 with 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 relatives 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. They can be a valuable source of support and they need to know that you are a carer with your own health needs as a result of your caring role.

They can also refer you to other services that can help you, such as those provided by your local hospice. Visit hospiceuk.org to find a hospice in your local area.

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 you and the person you are caring for. They can also provide information about local services such as carers' groups, hospices, organisations offering grants, complementary therapists, interpreting services and other services and benefits.

If you are in contact with a Marie Curie Hospice or another local hospice, ask if they have a social worker who can advise you on local support for carers.

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.

Social services will look at what you, and the person you are caring for, need and suggest services to help you. Services will vary according to the local authority you live in.

Carers' support groups

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

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

To find a support group near you:

- contact your local council or ask your GP or the district nurse
- call the Marie Curie Support Line on **0800 090 2309*** for information on support groups and other helpful organisations
- phone Macmillan Cancer Support on **0808 808 0000** to find support groups that are available for people with cancer and their carers

Carers' organisations

A number of organisations 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 **Carers.org**
- Carers Trust – has a network of Carers' Centres across the UK. Visit **Carers.org**

Carer's assessment

It is important for you to have a carer's assessment so you can get the support you need. You can get one from the local council (for the area where the person you are caring for lives). 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 in your household, you can both have an assessment. You can contact your local council through its website or by contacting the adult social services team.

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

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 may also be able to get a Community Care Grant. To qualify, you need to already be getting certain benefits and need financial help to ease exceptional pressure on your family.

You can visit **mariecurie.org.uk/carer-assessments** on our website to find out more about getting an assessment.

Blue Badge parking scheme

This scheme provides a range of parking benefits for people with a disability. It's run by local councils.

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.

Help with money

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.

The Marie Curie website has lots of information about benefits, entitlements and financial matters. Visit **mariecurie.org.uk/finance** to find out more.

There are many other organisations that can help too:

- Adviceguide is the Citizens Advice Bureau website. You can find information and factsheets about financial, legal and other issues including benefits for people who are ill or disabled. There are separate sections for England, Wales, Scotland and Northern Ireland. Visit **adviceguide.org.uk**
- Age UK has an online benefits calculator as well as downloadable information sheets on financial and other issues. Visit **ageuk.org.uk**
- Carers UK's website has a section on financial help which provides links to other websites with information on the

main benefits for carers and the people they look after.

Visit [carersuk.org/financial-support](https://www.carersuk.org/financial-support)

- The Department for Works and Pensions (formerly Department of Social Security) provides information for people who are disabled or ill and their carers. Visit [gov.uk/browse/benefits/disability](https://www.gov.uk/browse/benefits/disability) or [nidirect.gov.uk](https://www.nidirect.gov.uk) if you live in Northern Ireland.
- Macmillan Cancer Support's website provides information on help that is available and the Macmillan Benefits Helpline. Visit [macmillan.org.uk](https://www.macmillan.org.uk)

Grants

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

CLIC Sargent may be able to provide grants to help families who have a child with cancer with immediate financial needs. Visit [clicsargent.org.uk/content/financial-support](https://www.clicsargent.org.uk/content/financial-support)

Macmillan Cancer Support awards one-off grants for practical needs. Applications are made on behalf of the person you are caring for by their healthcare or social work professionals. For information about who can apply and what grants are for, as well as how the application process works, visit [macmillan.org.uk/grants](https://www.macmillan.org.uk/grants)

Turn2us has an online search facility for finding grants (by occupation, illness, location) in the UK. Visit [turn2us.org.uk](https://www.turn2us.org.uk)

Visit Marie Curie's grants page at [mariecurie.org.uk/grants](https://www.mariecurie.org.uk/grants) for more information.

Holidays and travel insurance

People with terminal illnesses may find it difficult to get medical insurance to go abroad. Some insurance companies offer cover but they may impose age restrictions or geographical limitations. Most will generally require a medical certificate. It will probably take longer than usual to arrange cover, so do bear this in mind.

The insurer may ask the person you are caring for to take with them a medical summary of their condition. This may need to be translated into the appropriate language (depending on the country being visited).

Attendance Allowance, Disability Living Allowance and Personal Independence Payment

The person you are caring for may be able to claim Attendance Allowance if they are aged 65 or over and a resident of the UK.

If they are under the age of 65, they may be able to claim Personal Independence Payment or Disability Living Allowance in Northern Ireland. Please speak to a benefits adviser for the most up to date information. You can find one at [citizensadvice.org.uk](https://www.citizensadvice.org.uk)

As the person you are looking after is terminally ill, they will be able to get these benefits more quickly and easily.

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 someone for at least 35 hours a week
- are not in full-time education
- satisfy UK presence and residence conditions

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

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.

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 Support Line on **0800 090 2309***.

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.

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. Phone: **01455 883 300**.

If you have concerns or questions about living with cancer, Macmillan Cancer Support can offer you and the person you are caring for emotional and practical help. They can also put you in touch with other sources of support. Phone: **0808 808 0000**.

Spiritual support

You may wish to contact a local minister or religious leader for spiritual support. They're usually happy to help, even if you were not previously actively involved with your local place of worship.

If you're in contact with a Marie Curie Hospice or another local hospice, the chaplain or someone in an equivalent role can offer advice and recommend a local person to contact.

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.

If the person you're caring for wants advice on deciding what care they want and making their wishes known, you'll find this section helpful.

If the person you are caring for has specific wishes or preferences, it's a good idea for them to discuss these wishes with you or another family member.

You may find it difficult to have these conversations at first but, by talking and putting wishes in writing, you and your family will know what to do if the person you're caring for becomes unable to tell you.

Specific needs or requests should be written down so people have a clear understanding of the type of care and treatments which the person prefers. One way of doing this is known as advance care planning.

Advance care planning

Advance care planning – sometimes also referred to as a living will, advance decision, advance directive or advance statement – is about thinking ahead.

It helps people express their views, preferences and wishes about the care they would like to receive. For more information, visit our website mariecurie.org.uk/planningahead or the NHS page at nhs.uk/Planners/end-of-life-care

Power of Attorney

The person you are caring for may also want to consider arranging a Power of Attorney. This allows people to choose someone to make decisions on their behalf if they become unable to do so in the future.

In each UK country, the legal name for each of these terms is different, as is the paperwork. See page 24 for more details.

If the person you're caring for writes down their wishes, or simply tells you their preferences, these should be added to their medical records or care plan.

If their wishes are not known, their doctor may consult a next-of-kin. Life partners might not be considered next of kin if they are not married or in a civil partnership.

Whoever they talk to, doctors have to use their medical judgement and act in the best interests of their patient.

You can find more information on setting up a Power of Attorney on the Marie Curie website at mariecurie.org.uk/attorney

Writing a Will for peace of mind

It's a good idea to encourage the person you are caring for to make a Will. It is simple and inexpensive to have one drafted by a properly qualified professional.

Making a Will ensures that someone's wishes are followed after their death. If they've written a Will, their estate will go to the family, friends and organisations it was intended for.

If they don't write a Will, 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 on our website.

Planning ahead for the funeral

Some people take comfort in being involved in all aspects of their life. This can mean being actively involved in the planning of their own funeral. This is a very personal issue and not something everyone will feel comfortable doing.

For people who do feel comfortable with it, planning their own funeral or discussing what they would like means that everyone knows what their wishes are.

You may feel that it is inappropriate to plan or even discuss a funeral while the person you are caring for is still alive. However, when the time comes to make decisions, you and any family members may well find it very helpful to have discussed the subject in advance.

You may feel awkward or uncomfortable discussing it at first but people often become more comfortable with the subject as time goes on. They 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 the Natural Death Centre or by visiting the Marie Curie website at mariecurie.org.uk/funeral

Writing down 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 and your family members 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*. Visit mariecurie.org.uk/publications to download, or phone **0800 090 2309*** for a copy.

Practical considerations

It may also be an idea to suggest that the person you are caring for start gathering key documents such as birth certificates, passports, insurance policies and wills, and organ donor cards.

It can be really helpful if these documents are kept together in a safe place and you or another family member knows where to find them.



Information for the people caring for you

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

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 reassure you, and the person you are caring for, that many of these changes are natural and normal at the end of life.

You may find it helpful to read this section and discuss it with the person you are 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, do ask one of the healthcare professionals looking after you.

Alternatively, you may wish to skip this section for now and read it at a later date.

Changes you may expect

As the person you're caring for becomes more frail, they will need more support from you.

It's not easy for someone to give up their independence, so it's important for you to recognise that they will still have preferences about how they are cared for. They may still want to make decisions about their care, even what may seem like small decisions to others.

There will be many changes to life when the person becomes very ill, but this doesn't mean they can't enjoy those aspects of 'normal' life which are still possible. If they enjoy an alcoholic drink there is no reason why they shouldn't still be able to do so – check with your nurse or doctor.

If they want children or pets to be around, there's no need to exclude them from the person's room (though you may also want to schedule quiet times for them to rest).

If they like to show physical affection to family and friends through touching or hugging, there is no reason not to continue as long as it's not physically uncomfortable for them.

Food and drink

The person you're looking after may stop eating and may want only sips of liquid. This can be hard to accept, because it is 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 and they may appreciate some

help. If you are helping them to eat, giving them a few moments to rest after they have finished each mouthful can be helpful.

If they start to find it difficult to swallow, or are having problems with nausea, tell their nurse or doctor.

Loss of appetite, nausea or difficulty in swallowing may affect the person's ability to take medication. Their nurse or doctor will be able to advise you about other ways of giving them their medication. It's common for people to have a syringe driver, which gives a carefully measured dose of drugs over 24 hours directly under their skin, or a patch which is placed on the skin.

There will come a time when they don't want or need food and drink. This is not a rejection of care – simply a natural step as their illness progresses.

Withdrawal

The person you're caring for may start withdrawing from what's happening around them. They're likely to get weaker and weaker, day by day, as their illness progresses. They may prefer to stay in bed and rest.

They will spend more time sleeping, be harder to rouse and often be drowsy when awake.

This apparent lack of interest in their surroundings is part of a natural process. It does not mean that they are rejecting or losing interest in the people around them.

You may find it rewarding if some of the time you spend with the person is when they are least drowsy and most conscious. Being together at any time can be a great comfort to both of you.

Even if the person is drowsy or asleep, they may still hear what's going on and can take comfort from hearing the usual sounds of life around them, or hearing someone talking to them. Do encourage their friends and family to continue to live as usual around them, even if they are asleep.

If the person is awake, they may be too weak to talk but still want others to talk to them or just sit quietly with them. Being cared for in this way can help them to feel comforted and loved.

Towards the end, they may lapse into unconsciousness and you may not be able to rouse them at all. How long they remain in this state varies for each person. However some people will die without lapsing into unconsciousness.

Making sure the person is comfortable in bed

Sometimes it is hard to balance the person you're caring for's comfort with the need to move them to prevent pressure sores.

If they have been given a special pressure-relieving mattress, it may not be necessary to continue to move them in the last few hours of life.

If they become uncomfortable from being in one position, you may be able to ease this by gently moving and massaging their arms and legs.

Changes in breathing

People who suffer from breathlessness are often concerned that they will die fighting for their breath. Towards the end of someone's life, as the body becomes less active, the demand for oxygen is actually reduced to a minimum.

This may be comforting if the person has had breathing problems, as people often notice that when someone is dying their breathing is easier than it has been for a long time.

Breathing difficulties can be made worse by feelings of anxiety. Knowing someone is close at hand can be reassuring and can help the person to remain calm.

Occasionally, in the last hours of life, breathing can become noisy. This is due to a build up of mucus in the back of the throat, which the person is no longer able to cough up or swallow. Medication and changing their position may help to reduce this.

If the person is breathing through their mouth, their lips and mouth will become dry. Moistening their mouth with a damp sponge and applying lip salve will give comfort. Sometimes it can be refreshing to have very small chips of ice melt in their mouth and on their lips.

When death is very close (within minutes or hours), the person's breathing pattern may change again, with breaths becoming more shallow and irregular. At this stage, they will probably not be aware of this.

Sometimes there are long pauses between breaths, or the abdominal muscles (stomach) will take over the work – the abdomen rises and falls instead of the chest. Gradually there will be longer pauses between each breath until the last one is taken.



You may want to watch our short film on changes in breathing at the end of a person's life at mariecurie.org.uk/breathingchanges

Other physical and psychological changes

As the person drinks less there will be a decrease in the amount of urine they produce. It may also be darker in colour and more concentrated.

As their muscles get weaker they may lose control over their bladder. Their nurse will give advice on how to manage this, and provide pads and incontinence sheets.

The person may become restless and agitated or confused and may pull at the bedclothes. Sometimes if someone just sits with them, holding their hand and speaking gently, it can have a calming effect.

However, you should check whether they are too hot or too cold, whether the lights are too bright, or whether there is too much noise. Soft music may have a calming effect.

If they continue to be restless and agitated, you should tell their nurse or doctor. The nurse or doctor will decide how best to help them and adjust their care plan as necessary, which may include changing their medication.

The person may become confused about where they are or what time it is, and may not recognise people around them. Reminders from the people around them as to what day it is, what time it is, and who is in the room can be comforting.

They may see or hear people and things which are not really there. This may not necessarily be frightening for them and sometimes may even be comforting. However, if hallucinations increase in severity or seem to be distressing for the person, you should tell their nurse or doctor. It may be necessary to review their medication and consider a different dose or drug.

Their hearing and vision may deteriorate, but people should assume that they can hear, since hearing is believed to be the last of the senses to diminish. Telling the person what is happening around them, and continuing to talk to them, can be a comfort.

Towards the end, their arms and legs may become cool to the touch and bluish, and the underside of their body may become much darker as a result of blood circulation slowing down. Fevers are also common.

On the other hand, the skin can become pale, moist and slightly cool.

Most people do not wake up, but die peacefully, comfortably and quietly.

If you would like more information on the changes that might happen closer to death, you can visit mariecurie.org.uk/preparing

What happens after someone dies?

It can be a bewildering time immediately after a death. This section explains some of the practical issues that need to be dealt with when someone has died.

When someone dies, their family and friends may be in shock or very upset. When you are able to do so, you need to ring the person's nurse or GP who will tell them what happens next. The doctor will need to know what time the person died. During the night you may have to contact the out-of-hours service.

Please visit mariecurie.org.uk/bereavement for more information and support or see our booklet *When someone dies* for more information about what happens after death. You can visit mariecurie.org.uk/publications to download, or phone **0800 090 2309*** for a copy.

Customs or preferences at time of death

If a Marie Curie Nurse or another 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.

Last offices or laying out the body

Last offices and laying out the body mean different things to different people. Here we refer to care of the person after they have died – this may include washing the person's body, dressing them in clean clothes and arranging their hair or putting on their wig.

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 carry out this care or you may prefer not to be in the room. There is no right or wrong decision – do whatever you feel comfortable with.

If you are 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. The surgery, or someone from their deputising service, will arrange for a GP or healthcare professional to visit to verify the death and advise you.

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. This paperwork will allow you to register the death, obtain the death certificate and arrange the funeral.

This paperwork 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.

Please visit mariecurie.org.uk/practical-legal 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 are using a funeral director, you can contact them once you are ready. You do not have to rush. The funeral director will generally come 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.

Funeral directors usually take the body away promptly, but in most cases they don't have to do so. If you are using a funeral director and want to keep the body at home for a few hours, discuss this with them and they will advise you.

- 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 a funeral and dealing with the estate. Visit mariecurie.org.uk/publications to download, or phone **0800 090 2309*** for a copy. You can also go online to mariecurie.org.uk/funeralplanning

If the person you cared for died in a Marie Curie Hospice, other local 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 team) should be able to advise you about contacting a funeral director, or what to do next if you do not 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.

Your immune system could be low and you may become more prone to infections.

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

You may also find it easier to talk to someone outside your family and friends – such as a counsellor. This can enable you to open up honestly and share your fears, emotions and memories.

Further help

You can find further information and support from the following organisations.

For a longer list, please refer to our booklet, *When someone dies*. Visit mariecurie.org.uk/publications to download, or phone **0800 090 2309*** for a copy. You might also want to read our information about coping with grief at mariecurie.org.uk/bereavement

Bereavement Advice Centre

A national organisation offering advice on all aspects of bereavement, from registering the death and finding a funeral director to probate, tax and benefit queries.

Phone: **0800 634 9494**
bereavementadvice.org

Cruse Bereavement Care

A national charity that provides help to people who have been bereaved. Cruse offers services such as counselling, social contact and advice on practical matters.

Helpline: **0844 477 9400**

cruse.org.uk

Young persons' helpline: **0808 808 1677**

hopeagain.org.uk

Cruse Bereavement Care Scotland

Phone: **0845 600 2227**

crusescotland.org.uk

Samaritans

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

Phone: **08457 909 090**

samaritans.org

Childhood Bereavement Network

A national organisation with the aim of improving the quality and range of bereavement support for children, young people, their families and other caregivers. Offers information about support services.

Phone: **020 7843 6309**

childhoodbereavementnetwork.org.uk

Age UK

Age UK's advice line can help with advice on benefits and entitlements.

Helpline: **0800 169 6565**

ageuk.org.uk

Useful contacts

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Organisations that can help

Further information and links to useful websites for many of the categories on the following pages can be found on Marie Curie's website: mariecurie.org.uk/help

Charities

Marie Curie

Freephone: **0800 090 2309***
mariecurie.org.uk

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.

Our nurses work night and day, in people's homes across the UK, providing hands-on care and vital emotional support. Our hospices offer specialist round-the-clock care.

And we support people throughout their illness by giving practical information, support from trained volunteers and being there when someone wants to talk.

Macmillan Cancer Support

Freephone: **0808 808 0000**
macmillan.org.uk

Macmillan Cancer Support provides information on sources of support or living with cancer. Contact them for information on:

- cancer types, treatments or what to expect
- support centres and support groups
- travel and travel insurance

Cancer Research UK

Freephone: **0808 800 4040**

cancerresearchuk.org

Online forum: cancerchat.org.uk

Cancer Research UK provides free, comprehensive information for anyone affected by cancer.

You can use the online forum to join other people affected by cancer or to share information and experiences.

Hospices and care centres

Many people visit hospices for a few hours each week to help them relieve their symptoms through medical and nursing care, physiotherapy and occupational therapy. They also attend the hospice for emotional or spiritual support.

Some hospices offer complementary therapies which may help improve a person's sense of wellbeing and their quality of life. In addition, some hospices provide services in the community and care at home.

Your district nurse or GP can provide you with information on hospices or care centres near you. They can also refer you to these services.

Marie Curie Hospices

Freephone: **0800 090 2309***
mariecurie.org.uk/hospices

Marie Curie is the UK's largest independent hospice provider, caring for more than 8,900 people each year.

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

There are Marie Curie Hospices in Belfast, Bradford, Cardiff and the Vale (Penarth), Edinburgh, Glasgow, Hampstead (London), Liverpool, Newcastle and the West Midlands (Solihull).

Hospice UK

Phone: **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

Phone: **0845 050 1953**

sueryder.org

Sue Ryder runs 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.

Carers' organisations and information

Your district nurse should be able to provide information about local carers' organisations.

Carers UK

CarersLine: **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

Phone: **0844 800 4361**

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 all of the benefits you may be able to get when caring for someone at **gov.uk/browse/benefits/families**

Carers Direct

Phone: **0300 123 1053**

nhs.uk/CarersDirect

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

Macmillan Cancer Support

Freephone: **0808 808 0000**

macmillan.org.uk

Macmillan provides practical, medical and financial support for people with cancer and their carers.

The Motability Scheme

Phone: **0300 456 4566**

motability.co.uk

This scheme helps disabled people to buy or lease a car at an affordable price. If you care for a disabled person who doesn't drive, they can still apply to buy or lease a car through this scheme.

Natural Death Centre

Phone: **01962 712 690**

naturaldeath.org.uk

The centre publishes *The Natural Death Handbook* which includes information on caring for someone at home.

Support groups

Your district nurse should be able to provide information about local support groups – for you and the person who is caring for you.

See also Macmillan Cancer Support on page 93.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Phone: **01455 883 300**

bacp.co.uk

BACP provides a factsheet about choosing a counsellor and details of local counsellors. It includes people who may be able to provide free or low-cost counselling or offer concessionary rates.

Equipment

Your physiotherapist, occupational therapist, district nurse or GP should be able to advise you on how to obtain and use equipment. Alternatively, they may refer you to the British Red Cross. Find out more about getting help with care needs at **mariecurie.org.uk/careneeds**

British Red Cross

Phone: **0844 871 1111**

redcross.org.uk

Services include loans of medical equipment, transport and home care.

Complementary therapies

Your district nurse may be able to provide you with information about local practitioners of complementary therapies.

You can read more about complementary therapies at

mariecurie.org.uk/complementarytherapies

Institute for Complementary and Natural Medicine

Phone: **020 7922 7980**

icnm.org.uk

The institute can supply names of local practitioners of complementary medicine.

Financial assistance

Your district nurse or local Citizens Advice Bureau should be able to provide you with information about benefits that you may be entitled to claim for yourself or the person caring for you. Visit **mariecurie.org.uk/finance** for more information on financial matters.

Gov.uk

gov.uk

Gov.uk provides information on money, tax and benefits.

Age UK

Phone: **0800 169 6565**

ageuk.org.uk

Age UK provides information and advice on a range of financial matters. Some of these may be relevant to people with a terminal illness.

Grants

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

Marie Curie has more on grants at **mariecurie.org.uk/grants**

Macmillan Cancer Support awards one-off grants for a wide range of practical needs. Applications are made on your behalf by healthcare or social care professionals. See page 93 for contact details.

Information about the NHS and local NHS services

England

Phone: **111**

nhs.uk

Wales

Phone: **0845 46 47**

www.nhsdirect.wales.nhs.uk

Scotland

Phone: **111**

www.nhs24.com

Northern Ireland

Health and Social Care in Northern Ireland

www.hscni.net

Other useful information

Marie Curie publications and resources

On our website, you can find our booklet, *When someone dies*, which includes information on supporting children going through the loss of someone close.

You can also find short films focusing on personal care and everyday living and other resources.

For information and support for you and the person caring for you, visit: mariecurie.org.uk/help

Phone: **0800 090 2309***

Other publications

What can I do to help?

Deborah Hutton's experience of cancer prompted her to write this book for the family and friends of people who have cancer. It gives advice on how to communicate sensitively and how to help in practical and supportive ways.

Short Books Ltd, 2010

Dying to know: bringing death to life

Combining compelling images with striking insights, this book of ideas and reflections cuts through taboos and places death firmly in the cycle of life. From eco-friendly funerals and online headstones to how to tell the kids – it covers it all.

Hardie Grant Books London, 2007

Notes

Marie Curie – what we're here for

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

Marie Curie Support Line

0800 090 2309*

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

mariecurie.org.uk/help

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

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



**Care and support
through terminal illness**