



Caring for someone with an illness they will probably die from

Who can help?



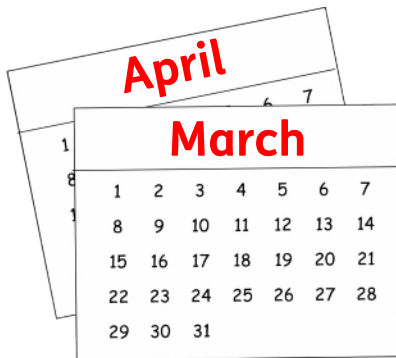
About this booklet



Sometimes people have an illness that cannot be cured and which they will probably die from.



This is often called a **terminal illness**.



Depending on the illness a person has, they might live for days, weeks, months or sometimes years.



Marie Curie is a charity. We have written this EasyRead booklet to tell you about the different people who can help if you are caring for someone with an illness they will probably die from.



You may want to read this booklet with someone you feel comfortable with. You can talk about what this booklet says together.



This booklet talks about:

- becoming a carer

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- doctors (GPs) and other health services

page 5



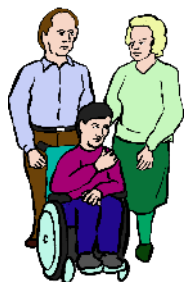
- palliative care teams

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- how Marie Curie can help **page 31**



- how you can help us **page 35**



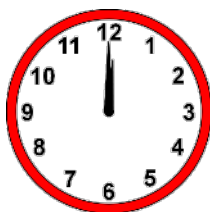
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Becoming a carer

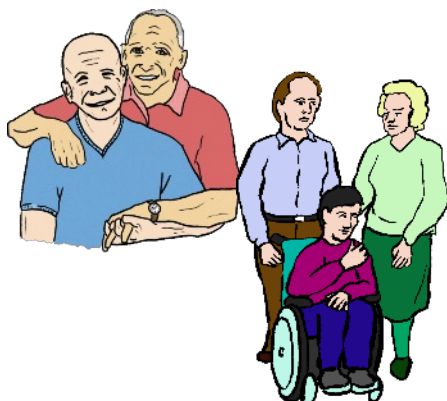


A **carer** is someone who looks after a friend or family member who cannot do everything they need for themselves.

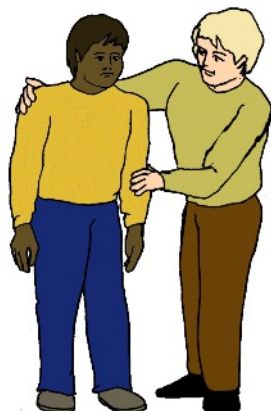
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You might care for someone all the time or for just a few hours a week.



You might not call yourself a carer. You might think of yourself as a wife, husband, partner, daughter, son or friend.



Caring can be difficult but there is a lot of support available for you and the person you look after.

Doctors (GPs) and other health services



The person you are caring for will be looked after by different people, like doctors, nurses and healthcare assistants. This section tells you about the ones you will probably meet.

The person's doctor



When someone is ill and living at home, their doctor (GP) will work with other people with special skills to help them get the best care.



Their doctor can:

- make sure they get the right medicines



- tell you about information, services and support that can help you and the person you are caring for



- tell you about **hospices**. A **hospice** is a place that cares for people who have an illness they will probably die from. They can support you too.



The doctor will also have a team they work with who they can ask to visit the person who is ill at home. This includes:



Practice nurses. They work at the doctors' surgery to help give medical care.



District nurses or community nurses.
They help care for the person at home.
This may include help with:



- washing



- eating and drinking



- changing bandages.



They can also get help for you and the person who is ill from other services like support groups.



Social workers usually work for the local council, health and social care trust, or a hospice. They can help the person get support which is not health care. This can help them live independently at home.



Occupational therapists look at daily tasks the person struggles to do, and helps to find easier ways to do them.



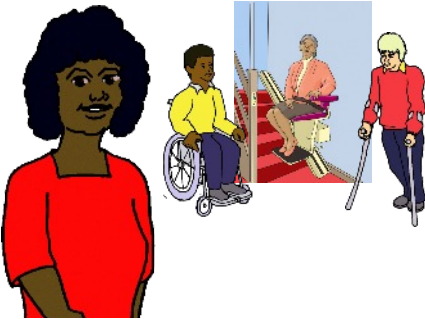
You or the person you are caring for can ask your local council or trust to send a social worker or occupational therapist to visit you.



They will do an **assessment**.



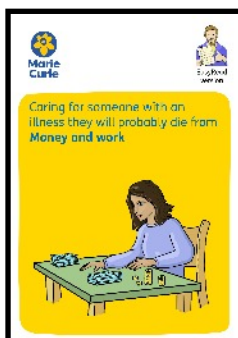
This means looking at the things the person who is ill needs help with. These things might include moving around the house and help with getting dressed.



The occupational therapist can also help with getting equipment or changes to the home to make life easier.



A social worker can look at the things you might need, like taking a break from caring.



To find out more about how social workers and your local council or trust can help, read our booklet: **Caring for someone with an illness they will probably die from – money and work.**

Palliative care teams



Palliative care is for people who have an illness that they will probably die from.



Palliative care also gives support to the family and friends of the person who is ill.



The palliative care team can help the person who is ill. They can help them cope with any pain they have.



The palliative care team can also help them if they are feeling worried or sad.



The palliative care team will include doctors, nurses, and any other health experts who are looking after the person who is ill.



They can care for them at home, in hospital, in a hospice or in a care home.



The team will also help you and the other friends and family of the person who is ill. If you are feeling worried, they can give you support.



You and the person you care for can find out about choosing where they can have care on our website:
www.mariecurie.org.uk/support

End of life care



The person you are caring for might need more support near the end of their life.



End of life care is an important part of palliative care.



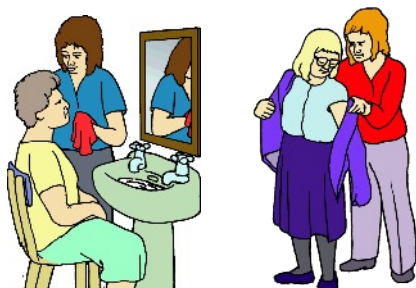
It also helps them have as much control as possible over how and where they are cared for. The team will support them for as long as they need it.

Day-to-day caring



When someone you care for is very ill, you might do lots of things to help them like:

- help them take their medicine



- help them get washed and dressed



- get their food and drink ready.



If you can, you might like to spend some time doing things you have always done together. This might be things like:

- going for a walk



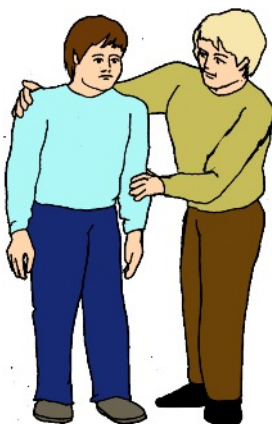
- watching a film



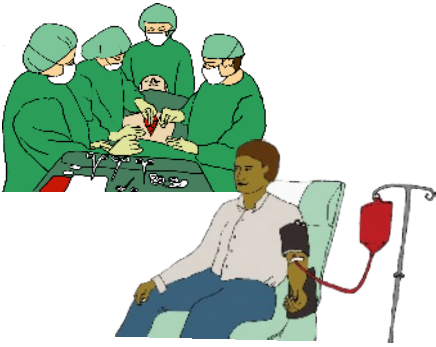
- visiting a place that is special to you both.



Try to understand what is important to the person and help them to do these things, if they are well enough. Ask them what they'd like to do.



You might not know what to say sometimes. That's OK. Just being there can be comforting.



Helping the person cope with pain

Some people have pain because of their illness, treatment or an operation.



Different people can help with pain, such as:

- doctors



- nurses



- **physiotherapists** (people who help with illness, injuries or moving around, using things like massage or exercise)



- **pharmacists** (people who know about medicines).



They will look at the best way to manage the pain.



Everyone's experience of pain is different. With the right treatment and support, pain can usually be managed.



The person you are caring for might not be able to tell you they are in pain.



There are different ways of finding out if someone is in pain. For example, you could use picture cards. You can also look for other signs that they are in pain.



These may include:

- frowning



- changes in breathing



- changes in mood (they might be more angry)

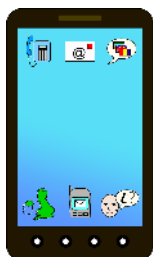


- changes in their behaviour, like not eating food or not being able to sit still.



You can find out about pain and medicines on our website:

www.mariecurie.org.uk/support

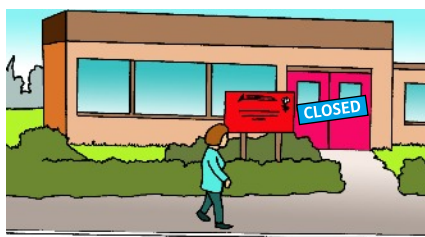


Or you can call our Support Line on **0800 090 2309**.

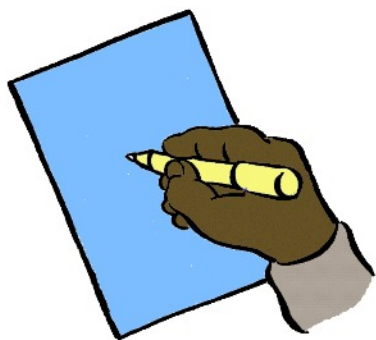
If the person needs more care



Sometimes the person needs more care than you can give them. They might be upset or in a lot of pain. If you are worried or need help, it is important to talk to a doctor or nurse about this.



If this happens when the doctors' surgery or health services are closed you can use the **out-of-hours** service.



If you ring the person's doctors' surgery, there will be a message telling you who to contact. It is useful to have a pen and paper to write down the number.



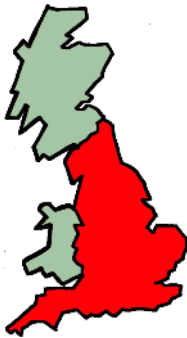
They will ask you some questions to help decide the best thing to do for the person you care for.



If you do not know the telephone number for the person's doctor (GP), you can call one of these organisations:



NHS 24 (if you live in Scotland)
Phone: 111



NHS 111 (if you live in England)
Phone: 111



NHS Direct (if you live in Wales)
Phone: 0845 46 47
Or 111



There are different phone numbers for the out-of-hours service in Northern Ireland for each area. You can ask the doctor (GP) or nurse which number is the right one for the person you care for.



If it is an emergency, ring **999**.



Sometimes, the person may have to go to hospital after they have contacted the out-of-hours service.



Managing symptoms at home

You might be able to get a box of medicines to keep at home. These medicines can help the person if they are feeling unwell or in pain. Sometimes this is called a 'Just in Case' box. You can ask the doctor (GP) or nurse about this.



Marie Curie Nurses might be able to care for the person at night to give you a chance to get some sleep.



The nurse or doctor (GP) can help arrange this for you.



Helping the person get the care they want

It is important for everyone to understand where the person would like to live and what type of care they want.



An **advance care plan** is a good way to make sure their choices are written down. You can ask the doctor (GP) or nurse about making an advance care plan.

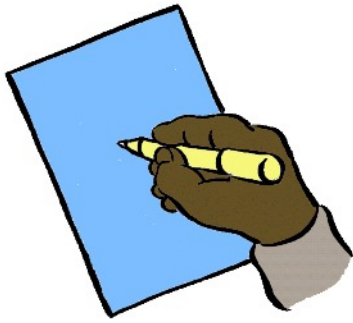


But sometimes things change. For example, you may not be able to care for someone at home anymore because they need more help than you can give.

Having an emergency plan



An emergency plan tells other people what to do if you are ill or something happens which means you cannot care for the person.



Your emergency plan should have:

- the name, address and telephone number of the person you care for



- name, address and telephone number of the people who can help in an emergency. This might be a family member or friend – just make sure they know about the plan



- a list of the medicines the person you care for needs, and the things you help them with



- information about how to find important things in the person's home.



If you do not have anyone who can help if you have an emergency, you can ask the local council for help, or the local health and social care trust if you live in Northern Ireland.



They will do an **assessment**.



This means looking at the support that you and the person you care for needs.



Some parts of the UK have an emergency carer card with a number you can telephone 24 hours a day if you have an emergency.



Your local carers organisation can tell you about this or you can telephone the **Carers Direct helpline** on **0300 123 1053**.



If you live in Northern Ireland, you can find out more about emergency care through your local health and social care trust.



Personal health information

You might need to look at health information for the person you are caring for to check their treatment or find out about their care.



For example, they might have had a scan or a blood test and you might want to know the results.



You should email or write to the person's doctor (GP), the hospital where they were treated, or any other service that has the information you want.



You won't usually be charged for this by the doctor (GP) or hospital.



You will also need permission from the person you are caring for before you can look at their health information.



This means the person you are caring for must write down that they agree you can look at their information. You should also send a copy of this to the organisation you are contacting.



If the person you are caring for is too ill to agree, their doctors will decide if you can see their health information.



If the person you care for cannot make decisions for themselves, you can ask a court to say you can make decisions for them.



If the court agrees, you are also allowed to look at the person's health information.

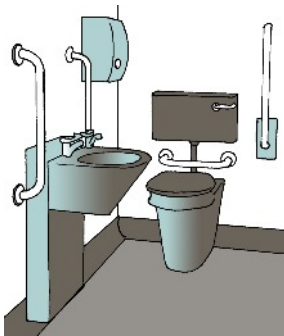


You should always think about what is best for the person you are caring for and for other people in the family.

Equipment and changes to the home

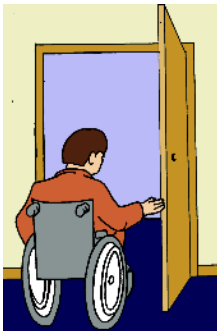


You might need to make changes to your home or the home of the person you are caring for to make life easier for both of you.



Changes could be things like:

- getting a toilet on the ground floor



- making doors wider so a wheelchair can go through.



The person you are caring for might need equipment like a wheelchair, crutches or a different bed.



It is important to ask for help before you buy anything. An **occupational therapist** can help.



Occupational therapists are trained to help people do everyday things like cooking or looking after themselves.



They will meet you and the person you care for. They will find out what things are difficult for you, like opening cupboards or getting out of bed, and help you get what you need.



The doctor (GP) for the person you care for can help you find an occupational therapist.



If you or the person you care for rents the house or flat you must ask the landlord before you make any changes.



Paying for equipment or changes

You can sometimes get free equipment from your council or borrow it from the NHS.



If you live in Northern Ireland, you may be able to get equipment from your health and social care trust.



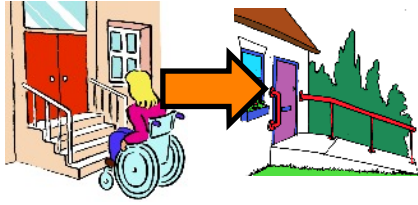
You can also buy equipment yourself.



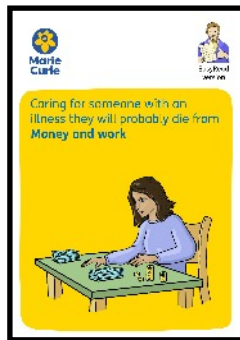
It is good to try equipment out to make sure it is right for the person you are caring for before buying it.



If an occupational therapist says you need equipment or changes to the home, your local council or trust might pay towards it.



They can also help you organise the changes.



You can find out more about getting help with paying for things in our booklet:
Caring for someone with an illness they will probably die from – money and work.

How Marie Curie can help



There are lots of different ways we can answer questions or support you and the person you are caring for.

We have more booklets about caring for someone with an illness they will probably die from.



Looking after yourself



Money and work



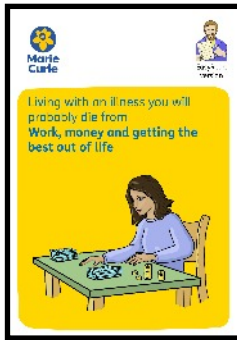
We also have a booklet on feelings you might have when someone dies

We also have other booklets about living with an illness you will probably die from.

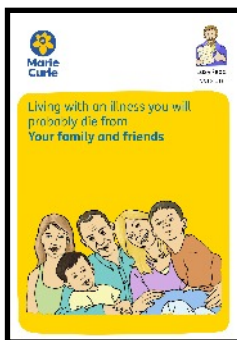
Who can help?



Work, money and getting the best out of life



Your family and friends

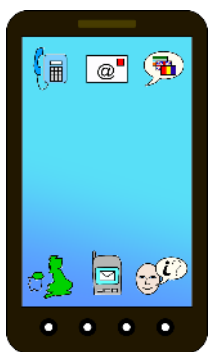


Your feelings

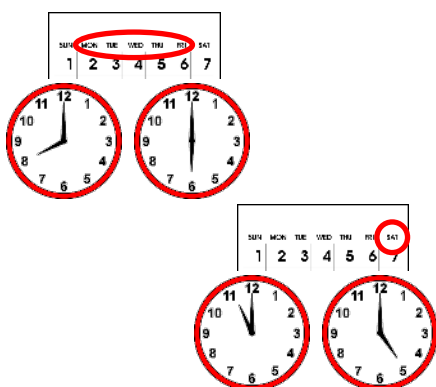


How to keep comfortable, healthy and happy





You, the person you are caring for or your family and friends can phone us to talk about what is happening and how you are feeling. You can call our Support Line on **0800 090 2309**.



It is open 8am – 6pm Monday to Friday and 11am – 5pm on Saturdays.

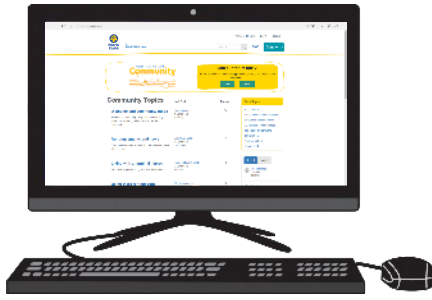


There is also information on our website: **www.mariecurie.org.uk/support**



The information on our website is not EasyRead but if you call us we can explain things to you.

Marie Curie Community



Share ideas or talk to other people who are caring for someone with an illness that cannot be cured:

www.community.mariecurie.org.uk
24 hours a day

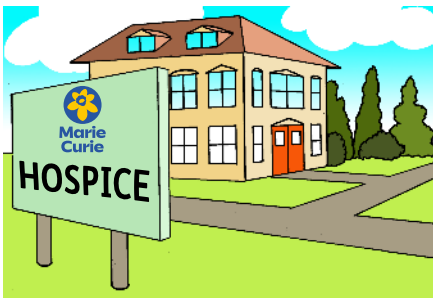
Marie Curie Nurses



Some people want to stay in their own home when they are dying. Sometimes, a Marie Curie Nurse can help give care at home:

www.mariecurie.org.uk/nurses

Marie Curie Hospices



A hospice is a place that cares for people who have an illness they will probably die from and can support you too:

www.mariecurie.org.uk/help

Marie Curie Companion



Our trained volunteers may be able to visit the person for a chat or take them to appointments:

www.mariecurie.org.uk/helper

How you can help us



Please tell us what you think about this booklet.



It will help us to write better information for people who are caring for someone with an illness they will probably die from.



You can email us at:
review@mariecurie.org.uk



or call our Support Line on
0800 090 2309.

How this booklet was made



This is an EasyRead booklet about caring for someone with an illness they will probably die from.

It was written by the charity Marie Curie.

This booklet uses words and pictures to make the information easy to understand.



It meets the European EasyRead Standard.



The **Your Voice Counts** - making EasyRead information.



Artwork includes material from the Inspired EasyRead Collection and cannot be used anywhere else without written permission from Inspired Services.

www.inspired.pics



How you use this booklet is up to you, not Marie Curie.



You should still get information from your doctor (GP), nurses, or other professionals.



It can help to speak to your doctor or other professionals before you decide about things like your health, care and finances.

Marie Curie – why we're here

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.