

Caring for someone with an illness they will probably die from Looking after yourself



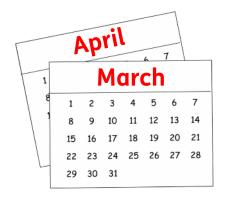
About this booklet



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



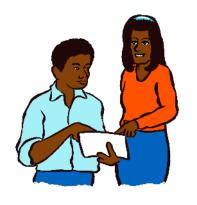
This is often called a terminal illness.



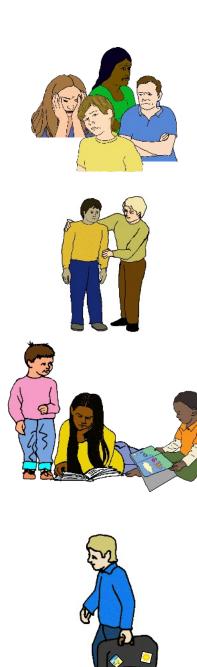
Depending on the illness you have, you might live for days, weeks, months or sometimes years.



Marie Curie is a charity. We have written this EasyRead booklet to help you think about looking after yourself 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:

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Your feelings



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





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 son, daughter, wife, husband, partner or friend.



Being a carer can be stressful. It can be difficult to find time to do things you like, such as meeting up with friends or going out. This can make you feel very alone.



But it is important to look after yourself and get support if you need it.



Feeling angry or guilty

It is normal to feel angry sometimes about what is happening and the way things have changed.



It is also normal to feel guilty or sad.



Many people feel this way.



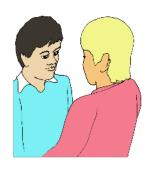
Hiding your feelings can make you feel worse. This could also make it harder for you to care for the person who is ill.



Things can sometimes feel too big to think about or deal with.



It might help if you talk to friends or family about it.



Or you might want to talk to someone who is going through the same thing.



Carers UK and Carers Trust are charities that can help you speak to other people who are carers too.



Their webistes are: www.carers.org and www.carersuk.org
These websites are not EasyRead.



You might feel more comfortable talking about your feelings with someone who isn't a family member or friend.



Marie Curie may be able to help. Call our Support Line for free on **0800 090 2309**.



If your feelings become a big problem for you, you can talk to your doctor (GP).



They may be able to help you talk to a **counsellor**.



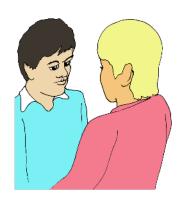
Counsellors are specially trained to help you talk about your feelings.

Other people's feelings



The person you are caring for

The person you are caring for will probably have lots of strong feelings. They will have good days and bad days.



Sometimes they might not want to talk about their illness. At other times they might want to talk about it a lot which could upset you.



They might act differently to how they normally are.



Try to get the person to do as much as they can for themselves and make as many choices as possible, if that's what they want.



We have more information for people who are ill about coping with their feelings in our EasyRead booklet: Living with an illness you will probably die from – your feelings



Friends and other people in your family

Friends or family members might want to talk to you about the person you are caring for. They might want to:



find out how they're doing



ask questions about their illness



• share their feelings.



Your friends or people from your family might feel frightened, upset or angry. It can be difficult if they do not understand how ill the person is.



You might find it helpful to ask one or two family members or friends to tell everyone else about what is happening, so you don't have to. This can make things easier for you.



Remember that you are not responsible for other people's feelings and that they need to look after themselves.



You could tell them to call the Marie Curie Support Line or visit our website to get more support.



You can call the Marie Curie Support Line for free on **0800 090 2309**. You can find more information on our website: www.mariecurie.org.uk/support

Talking to children



It is best to tell children what is happening as soon as possible.



Sad news is better coming from someone the child knows. Choose a time and place where you both feel relaxed and comfortable.



Involve the person who is ill if they want to be there.



You could tell the child that the person is very ill. Sadly they won't get better from their illness and they're likely to die.



If the child is older, you may be able to tell them more about the illness. Younger children won't understand as much.



The child might ask lots of questions. If you don't know the answers, it's OK to tell them you don't know.



If you're not sure what to say, you can ask a nurse or doctor for help. You can also ask them to be there when you talk to the child.



You could also tell the child's teacher. This may help them support the child at school.



If you are taking a child to hospital to see the person who is ill, it's good to tell the child what they will look like and what to expect.



If the child does not want to visit, they could draw a picture or make a card for the person who is ill.

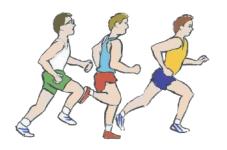
Taking a break



Being a carer can make you very tired and upset so it is important to look after yourself by:



eating healthy



 getting some exercise so you feel more happy and healthy



getting enough sleep.



You might need to ask someone to sit with the person you care for so you can take a break and do these things.



If you think caring is making you unwell, it is important to talk to someone about it. You could speak to your doctor (GP) or call our Support Line on **0800 090 2309**.

Complementary and creative therapies

Complementary therapies and creative therapies are treatments that may help you to relax or sleep better. They include things like:



massage



yoga



art therapy.



Sometimes these therapies are free and sometimes you have to pay for them.



Your local hospice or support group might offer some therapies for free or for cheaper.



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



The Complementary and Natural
Healthcare Council has a list of therapists
you pay for on their website:
www.cnhc.org.uk
This website is not EasyRead.



You may have to pay for these therapists. Always ask how much it will cost before you see a complementary therapist.

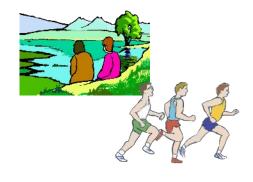
Taking time out



It is important to take some time to have a rest. If you cannot leave the person you are caring for, you can get **respite care** to give you a break.



Respite care means someone else cares for the person who is ill so you can:



 have a short break to do a hobby or exercise or meet friends



get some sleep



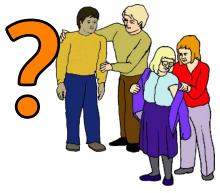
go on holiday.



Sometimes your family and friends can help.



If not, your local council can do an **assessment** to see what support you need. If you live in Northern Ireland, your local health and social care trust will do an assessment.



This means looking at the things both you and the person you care for need help with. Your local council or trust will then decide if you can get support.



If the council or trust gives you respite care you might have to pay for it.



Charities like **Carers UK**, **Carers Trust** or your local carers group can tell you more about respite care. Their websites are: www.carersuk.org and www.carers.org
These websites are not EasyRead.

Getting ready for the end of the person's life



It can take time for the person you are caring for to understand and believe that they have an illness that they will probably die from.



For some people, when they do understand that they have an illness they will probably die from, they feel more comforted and in control.



This can help you plan together. It can also help you and the person you care for to prepare for their death.



The most important thing is for the person to have the care they choose, if it is possible. This could be in their home, a hospital, a care home, or a hospice.



You might find it helpful to talk to someone during this time.



You may like to talk to family members or friends.



You might want to talk to a religious leader about your beliefs and faith. They can also talk to the person who is dying.



They will talk to you even if you do not have religious beliefs. They can support you before and after the person you care for has died.



Your hospital or hospice can tell you how to contact a religious leader.



You could also talk to a counsellor who can help you if you are feeling sad, worried or finding it hard to face up to things.



They can talk to you about your feelings.



You can also contact the Marie Curie Support Line on **0800 090 2309**.

After the person has died



Your feelings

Your life will change when you stop caring for the person. There will be lots of things you will not do anymore.



These changes can be hard. You might feel sad. You might feel that you do not have anything important to do now.



Some people feel relieved when caring stops. Caring for someone is difficult, so don't feel guilty if this is how you feel.



You might also feel proud that you were able to help someone who is special to you at the end of their life.



All these feelings are normal so try not to be too hard on yourself. If you are finding it difficult, you could speak to your doctor (GP).



You could also call the Marie Curie Support Line on **0800 090 2309**.



Changes in your life

While you were busy caring you might not have spent much time with your friends.



You may have spent a lot of time with doctors and nurses and might miss them now.



You might want to carry on seeing the doctors and nurses that helped look after your friend or family member.



You could do this by going back to the hospital or hospice as a volunteer. But it may be better to wait for a while, as it could upset you.



You could also volunteer with Marie Curie.



If you want to know how to get involved you can ring us on **0800 090 2309**.



You might want to start doing things you did before you were a carer. Or you might want to try something new.



This can be good for you. But don't rush into things if you do not feel ready. Take your time.



Volunteering is a good way to meet new people. There is information about volunteering on our website: www.mariecurie.org.uk/get-involved and on the Do-it website: www.doit.life/volunteer
These websites are not EasyRead.



Support

You may be very sad and upset that the person you cared for has died.



It might help to talk to family, friends, or a counsellor about your feelings.



If you don't want to talk to someone face to face, there are telephone helplines you can call:



Cruse Bereavement Care 0808 808 1677 Cruse Bereavement Care Scotland 0845 600 2227



Marie Curie Support Line 0800 090 2309



Bereavement Advice Centre **0800 634 9494**



If you have one, your Marie Curie Nurse can tell you about support to help you cope with your feelings. They can also tell you about services that can help. Your doctor (GP) can also tell you about support.

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 that they will probably die from.

Who can help?



Money and work



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



We also have 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



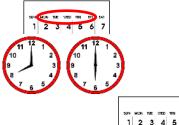
Your feelings



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.

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