

**MACMILLAN**  
CANCER SUPPORT

# A GUIDE FOR YOUNG PEOPLE LOOKING AFTER SOMEONE WITH CANCER





**I love helping dad,  
but sometimes it  
takes its toll and  
that's okay too –  
the better days  
are worth it.**

**Amy, aged 20, who  
cared for her dad Pete**

# About this booklet

**This booklet is about looking after someone with cancer. It is for young people under the age of 18. There is also some useful information for young adult carers.**

If you help look after someone with cancer, this can affect your life in many ways. It may be your mum or dad who has cancer, or your brother or sister. Perhaps you help care for a grandparent, uncle, aunt or friend.

You may feel shocked, angry or frightened about what is happening. You may be thinking, 'Why me?' or 'Why them?'

We hope this booklet helps you deal with some of the questions or feelings you may have. The booklet explains:

- what it means to be a young carer
- who can help support you and the person you are caring for
- how to look after yourself
- some of the practical, emotional and financial issues you may face and how to cope with them.

We have another booklet for adult carers called **Looking after someone with cancer** (see page 162).

## How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 5 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 166 to 179, there are details of other organisations that can help.

There is also space to write down questions and notes throughout the booklet.

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you with being a young carer.

## Using the glossary

You may hear a lot of medical terms when you are looking after someone with cancer. Some of these words can be confusing. We have explained them in the glossary on pages 151 to 157.

## Quotes

In this booklet, we have included quotes from young people who have looked after someone with cancer. These are from people who have chosen to share their story with us. This includes Amy, who is on the cover of this booklet. Amy helped care for her father Pete when he was diagnosed with prostate cancer. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

This information was originally developed with young carers at the South Tyneside Young Carers' Group, the Arden Cancer Network's Young People's Group, the Oxford City Young Carers' Forum, and the Spiral Children's Bereavement Service in Nottinghamshire. You will see quotes from them throughout this booklet. Some names have been changed.

## For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

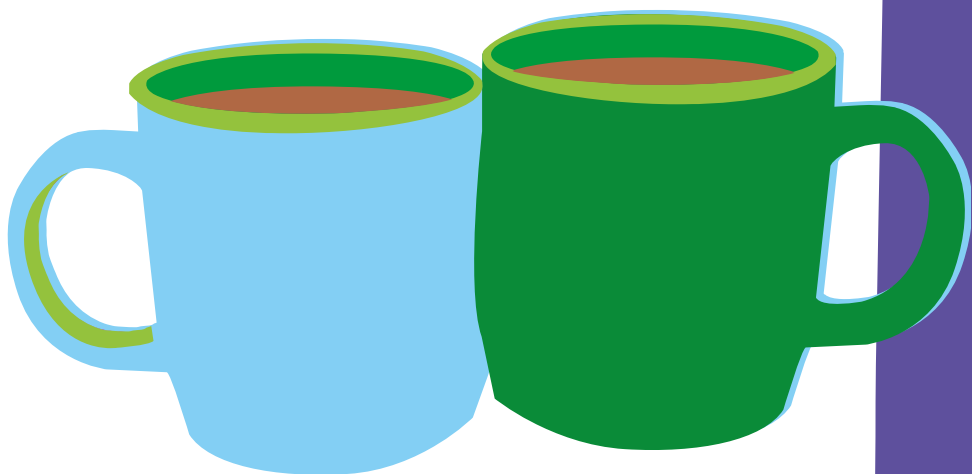
We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.





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# BEING A YOUNG CARER

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# Are you a young carer?

If you are under the age of 18 and spend time looking after someone who is ill, you are a young carer. Across the UK, about 1 in 5 children and young people are young carers.

You may not have realised that you are a young carer, or ever called yourself this before. But, as a young carer, you may do extra things to help your family. These may be things that your friends are not doing. For example, you might:

- clean or do other jobs around the house
- prepare meals
- wash the dishes
- do the food shopping
- go out with the person who is ill to help them with shopping or other tasks
- help look after your brothers or sisters.

You could be giving personal care to someone in your family who has cancer. For example, you might:

- help them get dressed
- give them their medicines
- change their bandages.

You may also give emotional support to the person who is ill. For example, you might:

- comfort them when they are upset
- listen when they need to talk.

When you are not with them, you may worry about how they are coping.

**Across the UK, about  
1 in 5 children and  
young people are  
young carers.**

# How being a young carer can affect you

Being a young carer can affect your life in many ways. You may have lots of different feelings and emotions (see pages 45 to 59).

It can be hard to concentrate at school or college, find time to study or keep in touch with friends (see pages 90 to 100 and pages 81 to 82). Sometimes you may have to cancel plans to look after the person who has cancer. It can even feel like being a carer has taken over your life.

You may also worry about what is happening at home. At times, you may feel angry with the person you look after. You might feel that you are not getting enough attention, but then feel guilty for thinking that way. These are all normal reactions.

It can feel challenging and like a big responsibility to be a young carer. But there can also be positive things about the experience. You may become closer to the person you look after, learn new skills and feel more grown-up.

**It was hard because I couldn't do some of the things I wanted to, because I had to help at home.**

**Bethan**

# Your rights and choices

If someone in your family has cancer, it is natural to want to try your best to help them. But your needs are also important. You should not do all the same things as an adult carer, or spend too much time caring for someone. This may affect your studies, emotions, leisure time or other parts of your life.

The person with cancer may be able to get to help from:

- their local council in England, Scotland and Wales (see page 176)
- or their Health and Social Care Trust in Northern Ireland (see page 177).

This means they should not have to rely on you to care for them.

As a young carer, you have the right to be supported and have the same chances as other people your age.

## Are you doing too much caring?

There are legal guidelines that say when you may be doing too much as a young carer. You should not have a caring role that:

- makes you feel worried, sad or lonely
- affects your health
- means that you cannot spend enough time with your friends
- stops you doing well in your studies
- stops you getting or keeping a job
- stops you achieving your goals for the future.

## Your right to a young carer's assessment

The law says that any young carer or their family can ask for a young carer's assessment. This is done in your home by a local social worker or young carer's worker. A young carer's assessment is a chat to find out what support you and your family may need or want.

To get an assessment, you or your family should contact your local council or Health and Social Care Trust (see pages 176 to 177). You can also speak to your GP, teacher, a youth worker or another professional working with your family. They can help you get a young carer's assessment.

Having an assessment is the best way to find out what support is available in your situation. It can help if you are struggling to look after the person with cancer, do your schoolwork or spend time with friends.

The assessment is not like an exam. It does not test how good you are at caring for the person with cancer. Instead, it looks at:

- how much care you give and whether you want to be a carer
- how your caring affects your studies, training, work or opportunities to relax
- how your caring role makes you feel about the future
- the needs of your whole family
- any support that could help you and your family.

You and your family should get a written copy of the assessment and be told what to do if you disagree with it.

If you live in Scotland, you have the right to ask your local council for a young carer statement. This starts with a conversation to find out about your caring role, what is important to you and what extra support you may need.

To find out more about having a young carer's assessment or statement, visit:

- **nhs.uk** and search for 'young carers rights', if you live in England or Wales
- **mygov.scot** and search for 'young carer support', if you live in Scotland
- **nidirect.gov.uk/young-carers** if you live in Northern Ireland.

**The young carers support service provided me with further help due to the information that came out of the assessment. It also meant my family got the support they needed.**

Carolina, aged 17




## Preparing for a young carer's assessment

Carers Trust has a guide to a young carer's assessment called **Know your rights: Support for young carers and young adult carers in England**. You can download a copy on the Carers Trust website (see page 167).

This guide gives practical tips on how you can prepare for a young carer's assessment. Before the assessment, you may find it helpful to think about these things.

### 5 practical tips

- 1.** Keep a diary of all the jobs you do around the house and how long each task takes.
- 2.** Make a list of any other ways that you support the person with cancer.
- 3.** Think about how being a young carer affects your health, feelings, relationships, studies, any paid job and future plans.
- 4.** Think about whether it is okay for you to continue being a young carer.
- 5.** Write down which services currently help you and the person with cancer, and any extra support you think you need.



**I pay bills, buy and cook food, wash clothes, and clean the house twice a day. I help my dad with medication and I help him get around.**

**Amy, aged 20**

## Becoming an adult

If you are approaching adulthood, you can get a different carer's assessment depending on where you live. This assessment is done before you reach the age of 18.

### England and Wales

If you live in England or Wales, the period when you approach becoming an adult may be called transition. You can ask for a transition assessment when you are ready to start thinking about your future. This is different from a young carer's assessment (see pages 12 to 13). It is a chance for you to talk about your future plans, such as going to university or getting a job. The assessment decides what support you and the person with cancer need after you are 18.

You can have a transition assessment at any age, but it should happen well before you become 18. It is important to allow enough time to discuss and decide what support should be ready when you are 18.

After the assessment, you should get a written report with information and advice to help you plan for your future.

All carers aged 18 or over have the right to an adult carer's assessment. This is explained in our booklet **Looking after someone with cancer** (see page 162).

## Scotland

If you live in Scotland, any young carer statement (see pages 12 to 13) continues to apply when you become 18, until you get an adult carer support plan. If you do not want to continue being a carer, you can choose not to have an adult carer support plan.

## Northern Ireland

If you live in Northern Ireland and are aged 16 or 17, you can ask for an adult carer's assessment instead of a young carer's assessment (see pages 12 to 13). But guidance suggests that this will only rarely be in your best interests. It may be better to have a young carer's assessment and wait until you are 18 to get an adult carer's assessment.

**If you are approaching adulthood, you can get a different carer's assessment depending on where you live.**

# Getting more support

As a young carer, you may feel overwhelmed by everything that is happening at home. Remember to look after yourself and ask for support if you need it.

We have details of lots of organisations that can help you (see pages 166 to 179) and more information about getting support (see pages 114 to 123).

## Talk to someone

You could talk to a family member, friend or teacher about anything that is worrying you. Talking about your situation at home may help you deal with problems and get support.

As a young carer, you may not want, or be able, to do the same things as an adult carer. If you do not feel comfortable with a task, let someone know. This could be things like taking the person you look after to the toilet or giving them their medication. Another family member or friend may be able to help with those things.

**Remember to look after yourself and ask for support if you need it.**

If there is nobody who can help, talk to a health or social care professional. They should be able to arrange for you to get some support. We have a list of health and social care professionals you may meet (see pages 27 to 32).

Local young carers' services can support you. They also run groups where you can meet other young carers. Find out more about young carers' services at **[childrenssociety.org.uk/youngcarer/young-carers-services](https://childrenssociety.org.uk/youngcarer/young-carers-services)**

There are some safe places online where you can chat with others going through a similar experience (see pages 122 to 123).

You can also chat with support workers. These people can give you information and advice. Someone from a young carers' service can also talk to your school and other organisations or professionals on your behalf. See pages 114 to 123 for more information on getting support.

For a confidential chat and emotional support, you can call our Support Line free on **0808 808 00 00** (open every day, 8am to 8pm).

## **Tell your school, college or work**

You may want to tell your school, college or manager at work that you are caring for someone with cancer. There may be times when you need extra help with your work or time off. If you are open about what is happening and the situation at home, your teachers or employer can support you.

We have more information about talking to your school and your work (see pages 90 to 111).

## Make time for yourself

It is important to look after your own mental and physical health, as well as the person you care for. If you do not look after yourself, you will not be able to help the person with cancer.

Try to set aside some regular time to do things you enjoy. This can help you relax and take your mind off the situation. We have more information about different activities you could do (see page 71).

Remember, you are still allowed to enjoy yourself and you do not need to feel guilty about this. Young carers' services can help you take a break from caring, make new friends and have some fun (see page 119).





# ABOUT CANCER

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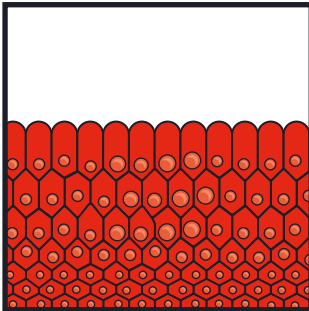
# What is cancer?

Cancer starts in our cells. Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal.

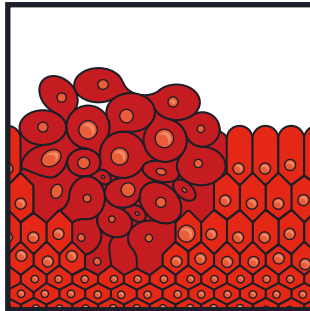
These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

Normal cells



Cells forming a tumour



A tumour can form in different parts of the body:

- It can form inside an organ. This is part of the body that has a special job, such as the liver or kidney.
- It can form inside a bone.
- It can form inside the lymphatic system. The lymphatic system is a network that helps defend your body from disease.

Cancer cells from a tumour can sometimes spread to other parts of the body. This is called secondary cancer.

Not all cancers form a tumour. Some types of cancer start from blood cells. Abnormal cells can build up in the blood, and sometimes the bone marrow. The bone marrow is where blood cells are made. These types of cancer are sometimes called blood cancers.

There are more than 200 different types of cancer. Each type has its own name and treatments. People with cancer need to have tests to find out exactly what type of cancer they have and whether it has spread. This helps the doctors plan the right treatment for each person.

We have more information about cancer types and treatment. You can order our booklets for free (see page 162).

## Worrying about getting cancer

Many people worry about getting cancer. If someone in your family has cancer, you may be worried that it will be passed on from one generation to another (inherited).

But most cancers are not caused by inherited cancer genes. Doctors think that only between 3 and 10 in every 100 cancers may be an inherited cancer.

Cancer is not contagious. This means it cannot be passed from one person to another.

**Most cancers  
are not caused  
by inherited  
cancer genes.**

# A to Z of professionals

When you look after someone with cancer, you will probably meet lots of different professionals. We have put together a list of people to make it clear who does what. These are people you may talk to in the hospital or at home. This list will help you understand their jobs and ask the right questions.

It can help to write down the names and details of the professionals you meet, in case you need to contact them.

## Benefits adviser

Benefits advisers are sometimes called welfare rights advisers. They help people get payments from the government. These payments are called benefits. Benefits advisers can also help you apply for grants from other organisations and charities.

## Clinical nurse specialist (CNS) or keyworker

A clinical nurse specialist gives information about a cancer type and support during treatment. They may also be your keyworker. A keyworker keeps in touch with you and the person you care for. They are your main point of contact and can help answer your questions.



## Community nurse

A community nurse supports people at home. They are also called district nurses. They can give the person you look after medication and provide other nursing care.

## Counsellor

A counsellor is someone that you or the person you look after can speak to about your feelings and worries. They are trained to listen to people talk about their problems. They can help you find ways to cope.



## Dietitian

A dietitian is someone who gives information and advice about food and food supplements.

## Doctors

A doctor is a trained medical expert. You may meet some of these doctors:

- Consultant – an expert doctor. They are in charge when the person you look after is treated in hospital. A consultant has a team of doctors working with them.
- GP (General Practitioner) – a local doctor who treats people for general medical conditions. You may know this person already. They can help when the person you look after is out of hospital. You can also talk to them about any problems you have.
- Haematologist – a doctor who diagnoses and treats blood disorders and cancers.
- Oncologist – a doctor who treats people who have cancer.
- Pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.
- Radiologist – a doctor who looks at scans and x-rays to diagnose problems.
- Surgeon – a doctor who does operations (surgery).
- Medical student – someone who is training to become a doctor. They may come around with the qualified doctors who are treating the person you look after in hospital. This helps them learn about what happens.
- Palliative care doctor – a doctor who helps with symptom control and end-of-life care, if needed.

## Healthcare assistant

A healthcare assistant supports the medical staff and patients in hospital. They work under the supervision of nurses or other health professionals.

Healthcare assistants help care for people who are unwell and give information to them and their families.

## Occupational therapist

An occupational therapist is someone who gives information, support and practical aids to help people with everyday tasks, such as washing and dressing.

## Palliative care nurse

A palliative care nurse helps with symptom control and end-of-life care. They also give emotional, social and spiritual support to people who are unwell and their families.

## Pharmacist

A pharmacist gives out medicine and can explain how to take it.

## Phlebotomist

A phlebotomist is someone trained to take blood samples.

## Physiotherapist

A physiotherapist can help the person you look after with walking or moving around, if they have problems with this.

## Psychologist

A psychologist can help you manage your feelings and behaviours, if you are finding it hard to cope. They can also help the person with cancer deal with their emotions.

## Radiographer

A radiographer plans and gives radiotherapy to destroy cancer cells. They also support people during radiotherapy treatment.

## Social worker

A social worker can help you and your family sort out practical and financial problems.

## Ward nurse

A ward nurse makes sure the person you look after is cared for in hospital. They give them any regular treatments that are needed.

## Youth support coordinator

A youth support coordinator can arrange activities and help young people stay active and social during and after treatment. They are funded by the Teenage Cancer Trust. You may meet them if you look after a brother, sister or young family member.

## Youth worker

A youth worker provides support and social activities for young people and helps them to achieve their goals. They can support young people living with cancer or young people looking after someone with cancer.

## Young carer worker

A young carer worker is specially trained to support young carers and their families. They may do different things in each area. Most will work with you and your family to make your caring role more manageable. In some areas, a young carer worker does the young carer's assessment to find out your needs (see pages 11 to 17).

# Talking to doctors and nurses

If you want to know about the health of the person you look after, doctors and nurses are the best people to ask. They are treating the person who has cancer and have all their medical notes. Doctors and nurses must have permission from that person to share any information about their health with you.

It can sometimes be hard approaching a doctor or nurse because they may seem very important and busy. But if they have permission from the person you look after, doctors and nurses will be happy to talk to you and help if they can. You may find it helpful to have a list of common medical words and phrases that the doctors and nurses may use. We have a glossary you may find helpful (see pages 151 to 157).

You may go to medical appointments with the person you care for.

**I used to take a pen and paper to the hospital. If the doctor was too busy to talk to me, I would write down my questions and ask an adult to pass them on.**

Fiona, aged 13



## 5 practical tips

1. Before the appointment, write down any questions that you and the person you look after want to ask the doctor or nurse.
2. It is a good idea to make notes during the appointment. These will help you and the person you look after remember what was said.
3. Ask the doctor or nurse to explain anything you do not understand.
4. If you feel shy or nervous, you can ask an adult to speak to the doctor or nurse for you.
5. Try to find out what will happen next.

Sometimes, you may meet support workers or healthcare assistants in the hospital. You can always ask them questions, too.

Here is a tool that may help you talk to doctors and nurses and get the most from appointments.

Appointment planner and record	
Time and date	
Location	
Questions that I and the person I look after want to ask the doctor or nurse	
Who was there?	
Summary of appointment (for example, what people said or did)	
What happens next?	



## Making sure you are included

You may be able to tell the doctors and nurses important things about the person you look after. For example, you may have noticed whether a new medicine they take is helping them or causing side effects.

Sometimes the doctors and nurses may talk directly to the adults and not to you. This may make you feel invisible. It can feel like your questions, thoughts and experiences do not matter.

If you find this happening to you, do not be afraid to say something about it. You could try talking to an adult who can support you and speak on your behalf. This could be an adult family member. They can then try to include you the next time you are with a health professional.

If you still do not feel properly involved in conversations with doctors and nurses, there are organisations that may be able to help. You can contact your local Healthwatch or Patient Advice and Liaison Service (see page 171). They may be able to support you, speak on your behalf or help make sure your voice is heard.

## Who else can give you information?

There are other people who can tell you more about different types of cancer and treatments. For example, you can speak to experienced cancer nurses on the Macmillan Support Line. They can talk to you about things like chemotherapy and what to expect. Call **0808 808 00 00** (every day, 8am to 8pm) if you would like to speak with someone.

**I had to learn how to change my dad's dressings. When she was showing us, the nurse talked to my mum – she didn't speak to me.**

Malik, aged 12

# Help with medicines

You may need to help the person you care for with their medicines. It is important to handle medicines safely. It is a good idea to make sure an adult knows you are helping with the person's medicines. This could be a health professional such as a pharmacist or GP, a family member or a friend.

The person you look after should take their medicines exactly as their cancer doctor or nurse has prescribed. You need to check:

- that the person's name and medicine are correct on the label
- that the expiry date on the medicine has not passed
- how often the medicine should be taken
- how to take the medicine (for example, with or after food).

You can get advice and information about medicines from a pharmacist in the hospital or a local pharmacy. This could be an independent pharmacy or part of a chain of stores, like Boots or Superdrug. A pharmacist may also be able to give the person you look after a pill organiser or a special calendar pack of tablets. These both show the day and time that the tablets should be taken.

Carers UK has an online and mobile app called **Jointly**. It is available for a small one-off payment. This app can keep track of the current and past medicines taken by the person you care for. You can also upload an image to recognise a medicine quickly. You should check with an adult before paying for the app.

If you prefer, you can use our planner to record which medicines need to be taken and when (see pages 40 to 41). You may want to make copies of the planner before filling it in. It was developed with help from Boots Macmillan Information Pharmacists. These pharmacists are available in some Boots stores and can help you with questions about medicines.

**My dad needs medication all of the time, including an oral morphine solution which he relies on – usually four times a day.**

Amy, aged 20

# MEDICATION PLANNER

This planner is to be completed together with the person you look after or another adult.

TIME	
Medication:	
How much to take (dosage):	
What it is for:	
Shape and colour:	Instructions:

TIME	
Medication:	
How much to take (dosage):	
What it is for:	
Shape and colour:	Instructions:

TIME	
Medication:	
How much to take (dosage):	
What it is for:	
Shape and colour:	Instructions:

TIME	
Medication:	
How much to take (dosage):	
What it is for:	
Shape and colour:	Instructions:

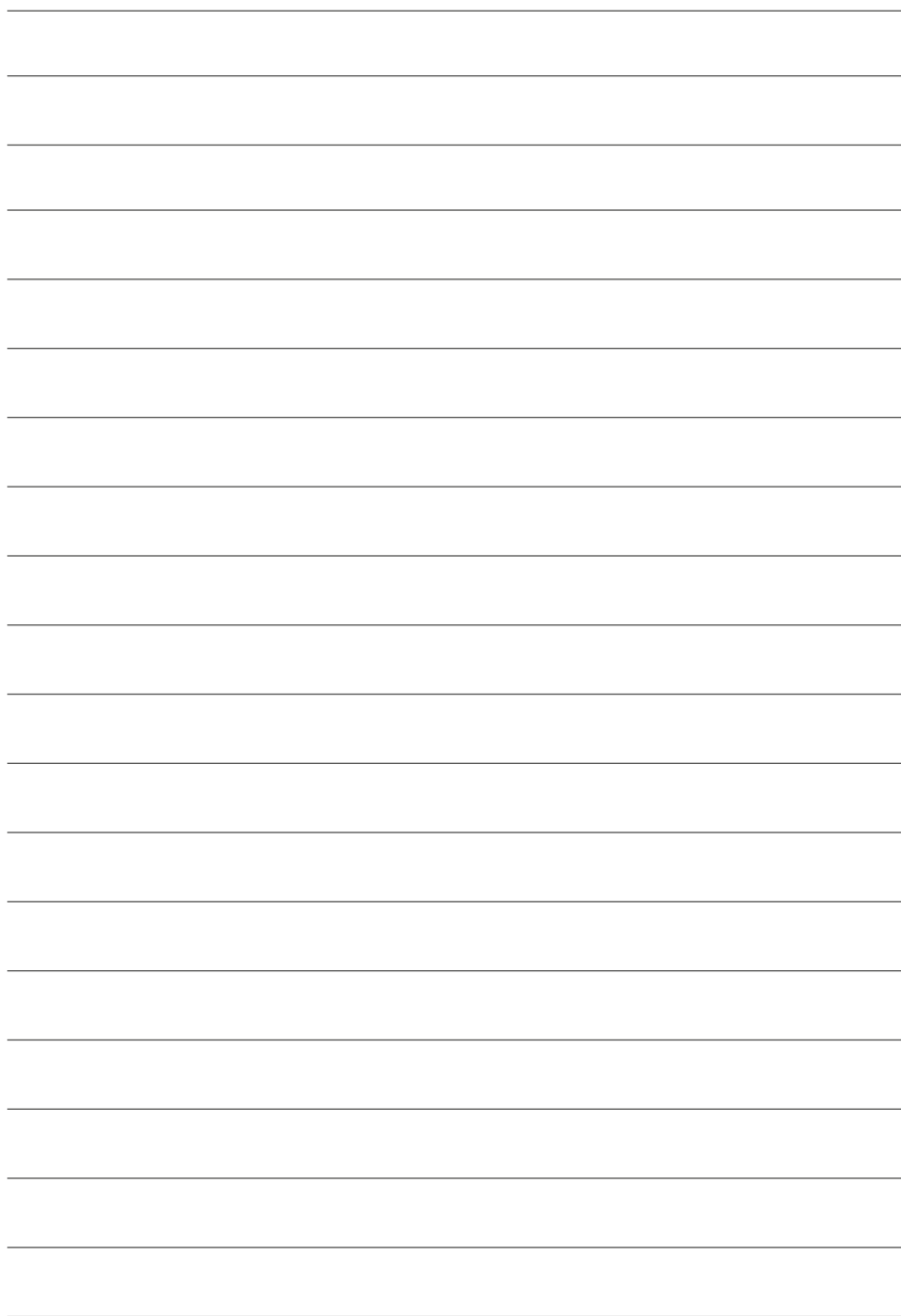
MON	TUE	WED	THU	FRI	SAT	SUN
				Reorder date:		

MON	TUE	WED	THU	FRI	SAT	SUN
				Reorder date:		

MON	TUE	WED	THU	FRI	SAT	SUN
				Reorder date:		

MON	TUE	WED	THU	FRI	SAT	SUN
				Reorder date:		









# YOUR FEELINGS

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# How cancer can affect your emotions

Finding out that someone close to you has cancer can cause many emotions. Common first reactions are 'What is going to happen? Will they recover?' and then, 'Are they going to die?'

It is common to have many different emotions. For example, you may feel:

- frightened about the future
- sad and upset that this is happening to someone you love
- exhausted or stressed because of the extra things you are doing
- angry with the world or the person who has cancer
- lonely or isolated
- guilty, even though what is happening is not your fault
- worried or sad.

These are just some examples of how you may feel, but everyone is different. Feelings like these are natural.

**I was crying every night because I didn't know what was going to happen or anything.**

**Jake, aged 13**

# Mood swings

Every day is different when you look after someone with cancer. You will have good days and bad days.

During this confusing time, you may have mood swings. This is when you feel happy one moment and then sad the next. One minute you could be laughing with your friends and the next you could burst into tears. Try not to worry too much about this. When you are dealing with difficult situations, it may take some time for your emotions to develop. You may have a delayed reaction.

It can be difficult for people to understand your mood swings if they do not know that you are affected by cancer. You do not have to explain your situation. But, if you feel comfortable with someone, it may help to share what is happening.

## Writing down your feelings

It can help to write down how you are feeling. You may like to use this table to write about your good and bad days. You could list things that made you feel happy or sad, and things that helped you feel better.

Try to think about things you can do to have more good days and write these down as well.

People affected by cancer designed this thinking tool. You can find more help using the tool, other tools and stories at **[thinkaboutyourlife.org](http://thinkaboutyourlife.org)** If you have any comments about the thinking tool, please **email [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)**



**Good days**



**Bad days**

**Next steps**

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# Telling people how you feel

Talking about your feelings can help you feel less stressed and more in control. You may feel comfortable with some parts of your role as a young carer, but uncomfortable about other parts. Remember that it is okay to share these feelings.

You may try not to get upset in front of the person who has cancer, in case you worry them. That is fine, but make sure you are not dealing with everything on your own. If possible, talk to someone else in the family or your friends about how you feel.

If you do not feel comfortable talking to family or friends, maybe a young carer worker or an adult at school or college could help. This does not have to be your form tutor or one of your teachers – it could be the school nurse or a teaching assistant. You can also chat online with support workers or other young carers at [riprap.org.uk](http://riprap.org.uk) or [kooth.com](http://kooth.com)

**I used to talk to my auntie. She was pleased, because she felt like she was supporting my mum by being there for me.**

**Jamie, aged 18**

There may be a local young carers' support group you could join see page 118. Your school or college may have details. We also have information about organisations that help support young carers.

You may find it useful to get help from a counsellor (see pages 54 to 55).

You can call our Support Line free on **0808 808 00 00** (every day, 8am to 8pm) and talk to a cancer support specialist. They can answer your questions about cancer, or just be there to listen if you feel like talking to someone.

It is often helpful to share your feelings, but do whatever is right for you. Remember that support is available whenever you are ready for it. If your emotions are becoming overwhelming or you feel depressed, it is important to talk to your GP (see pages 58 to 59).

**Remember that  
support is available  
whenever you are  
ready for it.**



# Coping with other people's feelings

It can be hard to cope with an adult getting upset or angry in front of you. You may not have dealt with this before. You may feel uncomfortable or helpless, or not know what to say.

Often, the best thing is just to be there for the person with cancer. Be there to listen if they need to talk or give them a hug or make a cup of tea if they get upset. It is also important to be there to share the happier times.

Sometimes the person you care for may want to take their mind off the situation, just as you do. If they feel well enough, you could watch a DVD together or play a game. They may appreciate just doing something normal and spending time with you.

**My older brother went out a lot. He withdrew from the family. It hurt at the time, but I understand now that it was his way of coping.**

**Samson , aged 16**

If you have brothers or sisters, they may also get upset. You may want to comfort them, especially if they are younger than you. It is not always easy to know what to say or do. But just trying your best to listen to how they feel can be a big help.

Families often say that something like cancer brings them closer together. But being a young carer can also sometimes make you feel alone. Having someone in the family with cancer can put a lot of pressure on everyone. This may mean that people get angry and upset more often, or argue with each other. If this happens, try not to let it affect you too much.

If you want to talk to someone about the situation at home, you can call our Support Line free on **0808 808 00 00** (every day, 8am to 8pm). We also have information about other useful organisations you can contact.

**I'm definitely closer to my dad and brother since my mum got cancer. We always try to be there for each other. I appreciate them so much more now.**

**Addy, aged 14**

# Counselling and talking therapies

Many young people get support by talking to close family members or friends. But you may find certain feelings hard to share with them. It can sometimes be useful to talk to a professional who has been trained to listen. They may be called a counsellor, therapist or psychologist. These professionals can help you explore your feelings and find ways to cope better.

There is no need to feel embarrassed about talking to someone. Counsellors are there to help.

## Talking therapies

Talking, counselling and support groups are called talking therapies. Talking about your thoughts and feelings can help you cope with stress, anxiety and difficult emotions.

There are many types of talking therapies and your GP can help you get the right support for your situation. They can refer you to a counsellor or you can refer yourself directly to a talking therapies service. There may be a counsellor at your school or college. Some young carers' services also offer counselling (see page 119).

If you have counselling, you usually meet someone face to face. But, if it is hard for you to leave the house, you could have phone or online counselling instead. You can have counselling by yourself or with your family.

You can decide how much you would like to share with the counsellor. Any information you give them is confidential. This means they will not tell anybody else. You may find it helpful to talk to somebody who is not directly involved in your situation. If you are angry with someone or frustrated, you can talk to the counsellor about this without upsetting anyone.

The counsellor can support you to explore your emotions and your relationship with the person you care for. They can help you find your own solutions to issues or make decisions about your life. If you do not feel comfortable talking to the counsellor you are given, you can ask to see someone else. There is no need to feel bad about this. It is important that you trust your counsellor and feel comfortable with them. If someone referred you, they may be able to arrange for you to see a different counsellor.

**You don't get time to think about what's going on, and don't realise that you're trying to run past it. It was much later that I suddenly started crying and didn't stop for a long time.**

Afiya, aged 17

## Hopes and fears

It may help you cope if you talk about what is frightening you, and things that you hope will happen. You can use this tool to write down your hopes and fears. This may be easier than saying them out loud and can help you to work out how you feel.

There is also space for you to think about what you could do next. These may be things that help you cope with your fears. For example:

- talking to the person you care for
- joining a support group
- chatting to other carers
- asking for extra help with everyday things.

You could share the feelings you have written down with others. Even if you prefer to keep things private, you may still find it useful to write down your hopes and fears. You may realise that there are some things you cannot change, because they are out of your control. Rather than focusing on these things, you can put your time and energy into helping yourself feel better.

People affected by cancer developed this thinking tool. You can find more help using the tool, other tools and stories at **[thinkaboutyourlife.org](http://thinkaboutyourlife.org)** If you have any comments about this thinking tool, please email **[cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)**



Hopes



Fears

**Next steps**

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# Depression

Caring for someone can be rewarding, but also demanding. There may be times when you feel sad. This could be when you are tired, cannot spend time with your friends, or the person you care for is unwell. These low moods may not last long. Most people find they have good and bad days.

But if your low moods continue for more than two weeks, this may be a sign you are depressed. Symptoms of depression can include:

- feeling sad, tearful or hopeless
- losing interest in things you used to enjoy, like your hobbies or social life
- trouble falling or staying asleep, or sleeping too much
- feeling tired all the time or having little energy
- poor appetite or eating too much
- finding it hard to motivate yourself, concentrate or make decisions.

**If your low moods continue for more than two weeks, this may be a sign you are depressed.**

If you think you may be depressed, it is important that you get some support. Remember that depression is not anybody's fault. There are many treatments that can help. Your GP, a health or social care worker, a young carers' service or a teacher at school can help you find the support you need.

To find out more about depression, call our Support Line free on **0808 808 00 00** (every day, 8am to 8pm). We also have information about looking after yourself and other organisations that can help support you (see pages 172 to 173).

## If you think the person you care for is depressed

You may be worried that the person you care for is depressed. Try talking to them about it and suggest they get support from a doctor or nurse. If you are not comfortable doing this, or it does not help, speak to another adult. Depression is an illness that needs to be treated. Most people with depression feel better with the right treatment and support.

**Being a young carer affected my sleep and mental health. This had a knock-on effect on my school, family and friendships. A young carers' service put me in contact with mental health services, which got me the help I needed.**

Carolina, aged 17







# LOOKING AFTER YOURSELF

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# Taking care of your health

It is important to look after your own health, even if you are busy caring for someone with cancer. Getting support from others and having regular breaks can help you stay well.

It is a good idea to tell your GP that you are a young carer. They can give you support and advice. Tell them if you have problems eating or sleeping, or if you are struggling with difficult feelings or finding it hard to cope. You can also speak to a school nurse about any health concerns.

You can also call our Support Line free on **0808 808 00 00** (every day, 8am to 8pm) for a confidential chat.

The Children's Society has a short video made by young carers. It talks about looking after your emotional well-being and mental health. Visit [childrenssociety.org.uk/youngcarer/advice-for-young-people/well-being-and-mental-health](https://childrenssociety.org.uk/youngcarer/advice-for-young-people/well-being-and-mental-health)

## It is important to look after your own health, even if you are busy.

# Healthy eating

As a young carer, you may sometimes feel too busy to eat. Or you may eat a lot as a way of coping. But it is important to have a healthy, balanced diet. This will give you the energy you need and help you feel your best.

Even if you are having a bad day, try to eat healthy food. It is also good to sit down and eat a cooked meal when you can. If you are tired, perhaps you could ask a family member or friend to make meals you can put in the freezer. Then you can easily heat up a meal when you need it.

To have a healthy, balanced diet, you should try to:

- eat at least 5 portions of fruit and vegetables a day
- eat plenty of starchy foods (carbohydrates) – these include potatoes, bread, rice and pasta
- have some milk and dairy foods (such as cheese and yoghurt) or dairy alternatives (such as soya drinks and yoghurts)
- eat some pulses (like beans, peas and lentils), fish, eggs, meat or other protein
- choose unsaturated oils and spreads, such as like vegetable, olive or sunflower oil and spreads, and eat them in small amounts
- eat foods that are high in fat, salt and sugar less often and in small amounts
- drink plenty of fluids (at least 6 to 8 glasses a day).

Here are some ways that you can find simple, healthy recipe ideas for you and your family:

- Visit the Change4Life website at [nhs.uk/change4life/recipes](https://www.nhs.uk/change4life/recipes) or download their free Smart Recipes app.
- Visit [nhs.uk/live-well/eat-well/20-tips-to-eat-well-for-less](https://www.nhs.uk/live-well/eat-well/20-tips-to-eat-well-for-less) to see 20 tips on how you can eat healthily and save money.

**Even if you are having a bad day, try to eat healthy food.**



# Keeping active

Keeping active is an important way to look after your health. This can strengthen your bones and muscles. It can also improve your energy, sleep and mood.

Here are some tips to keep active when you are a young carer:

- Try to do some exercise every day. This could be as simple as going for a walk. Physical activity can help you feel less tired and stressed.
- Download a free walking tracker app called Active 10 at **[nhs.uk/oneyou/active10](https://nhs.uk/oneyou/active10)**
- If you enjoy activities like sport, swimming, yoga or going to the gym, try to keep doing them. It may help to set aside a regular time in your diary.
- Try free online exercise videos from the NHS Fitness Studio. Visit **[nhs.uk/conditions/nhs-fitness-studio](https://nhs.uk/conditions/nhs-fitness-studio)**

For more tips on keeping active indoors or outdoors, visit **[sportengland.org](https://sportengland.org)**, **[sportscotland.org.uk](https://sportscotland.org.uk)**, **[sport.wales](https://sport.wales)** or **[sportni.net](https://sportni.net)**

# Sleeping

When you are caring for someone with cancer, you may struggle to get enough sleep. This could be for lots of reasons, but the main one for many young carers is worry.

It can be hard to stop worrying at night. When you go to bed, you may keep thinking about the person who is ill or what will happen in the future. This can keep you awake.

You may have people coming in and out of your home at different times. This can be a distraction if you are trying to sleep. You could also be kept awake if the person you care for is having a bad night.

There are some things you can do to try to get a good night's sleep.

## 5 practical tips

- 1.** Read a book or magazine or listen to an audio book before you go to bed. This can help focus your mind on something other than cancer.
- 2.** Don't look at your mobile phone, tablet, computer or TV for half an hour before bedtime. The screens on these devices give out a blue light that makes you more awake.
- 3.** Have a bath before bedtime. If you want to, you could add something like lavender oil or a bath soak to help you relax.
- 4.** Try simple breathing and relaxation exercises (see pages 70 to 72) or listen to soothing music.
- 5.** Write down your worries or make a to-do list for the next day. This can help calm your mind and stop you worrying at night.

# Relaxation

If you feel stressed or anxious, you often start to breathe quickly, and your muscles become tense. There are different techniques that can help relax your body and mind.

## Breathe slowly and deeply for 3 to 5 minutes

Take a deep breath through your nose, count to 5 and let your tummy expand like a balloon. Then breathe out through your mouth, count to 5 again and let your tummy deflate.

This breathing exercise should make you feel calmer within a few minutes. It is a good idea to practise every day.

## Relax your muscles

Think of each part of your body in turn, starting with your toes and then slowly moving upwards. Try to relax one muscle group at a time and release any tension, until your whole body feels calm and comfortable.

## Make time for yourself

It is important to take regular breaks from caring, accept or ask for help and do something that you enjoy. This could be:

- playing sport or doing other types of exercise
- meeting friends
- spending time with pets
- reading
- listening to music
- watching your favourite TV programme or a film
- doing something creative like arts and crafts, playing an instrument or baking.

You may feel guilty about going out or enjoying yourself when someone you love is ill. Talk to the person you are caring for about this. They will probably want you to make time for yourself and have some fun. Taking a short break from your routine can help you feel calmer and lift your mood.

## Focus on the present moment

When you are a young carer, it can be easy to rush through a busy day without stopping to notice much. If you try to be more aware of what is happening in the present moment, this can relax and calm your mind. This is sometimes called mindfulness.

Routine tasks, for example washing up, can be transformed into a mindful activity. Instead of focusing on stressful thoughts and worries, you can pay full attention to what is happening in each moment. You may notice the temperature of the water, the sound of the dripping tap and the smoothness of the plates.

There is a free website with guided mindfulness exercises for people affected by cancer (including carers) at [thisiskara.com](https://www.thisiskara.com)

**If you try to be more aware of what is happening in the present moment, this can relax and calm your mind.**





# Drink and drugs

Sometimes people use alcohol or drugs to escape their feelings when they are stressed or upset. But in the long term, this can make you feel worse and damage your health.

If you are thinking about drinking alcohol or taking drugs, talk to someone about how you feel. This could be anyone you trust, such as a family member, friend, GP, social worker or young carer worker. They can help you find other ways to cope and encourage you to make safe, healthy decisions.

If you already use drink or drugs to help you cope, it is important to get support quickly. You could try talking to family and friends. If you are not comfortable doing that, we have details of helplines and organisations you can contact (see pages 172 to 174). It is also a good idea to see your GP, who can refer you for counselling and professional support (see pages 54 to 55).

Other things that could help you cope are:

- physical activity, such as running or swimming
- talking to a friend
- changing your routine, so you are not thinking about alcohol or drugs at certain points of the day.

If your friends encourage you to drink a lot or take drugs, it may be better to spend time with other people.

You can watch videos of young people sharing their personal stories about alcohol and drugs at [healthtalk.org/drugs-and-alcohol](https://healthtalk.org/drugs-and-alcohol)

# Self-harm

Self-harm is when you deliberately hurt yourself. Anyone can self-harm, but it is often linked to difficult experiences such as extreme stress or being bullied.

People who care for someone with cancer may be at risk of self-harm. If you have any thoughts about self-harming or have started to hurt yourself, it is very important to get help quickly. Try to tell a family member, friend or young carer worker what is happening. We also have a list of organisations that can help.

It is also important to make an appointment with your GP. They can treat you if you are depressed and arrange for you to get the right support (see pages 58 to 59).

You can watch a video about why young people self-harm and find advice about getting support at [nhs.uk/conditions/self-harm](https://www.nhs.uk/conditions/self-harm)









# YOUR RELATIONSHIPS

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# How cancer may affect your relationships

Your relationships with people close to you are an important part of your life.

While you are caring for someone who has cancer, your relationships with friends and family may change. Try not to worry too much about this. All relationships change and develop over time. For example, you may now have a different best friend to when you first started school.

Some relationships do not last, while others grow stronger over time. You will probably experience both. But remember that help and support is always available.

**Some friends never knew. They couldn't support me because they didn't realise anything was wrong. Looking back, I should have talked to them more.**

Cameli, aged 16

# Friends

Talking to friends about cancer can be hard. When the person you look after is first diagnosed, you may be in shock. You may need some time to think about who to tell.

You may worry that your friends will not understand what you are going through. If you tell them, you may feel that things will not be normal between you.

But telling friends about your situation can be positive:

- You will have someone to talk to when you are stressed or upset.
- You will not have to make excuses if you cancel plans with them.
- They will understand if you are having a bad day and give you some space or more support.

You may want to start by telling one or two close friends that you are caring for someone with cancer. Be prepared for your friends to react differently. Some people will be calm and carry on as normal. Others may not know what to say or need time to think, just as you did.

Try to explain to your friends what it is like to be a young carer. This can help them understand your situation and how you feel.

You may see your friends less often because you are busy looking after the person with cancer. It is important to get support, so that you can spend time with your friends and do things you enjoy. Using social media is also a good way of keeping in touch with friends.

You may make new friends with other young people in a similar situation. You can do this by joining a support group, a young carers' project or an online forum (see pages 114 to 123).



# Family

The person that you are caring for may be your mum or dad, brother or sister, or one of your grandparents. They could be someone who lives in your house or who you see often.

It will take time for you all to come to terms with the cancer. The most important thing is to try to find ways of coping together. Talking to each other and spending time together can help. For example, the person you care for may be too unwell to go to the cinema. But you could buy some popcorn and watch a film together at home instead.

Having someone in the family with cancer can cause lots of different emotions (see pages 45 to 59). People may get angry and upset more often, or argue with each other more.

Do not feel bad if you have arguments with your family, including the person you care for. If the problem continues, you may want to consider counselling on your own or with your family (see pages 54 to 55). This can help you understand your emotions and work with family members to resolve the issues.

## Talking to each other and spending time together can help.

It is important not to do everything for the person you look after. This could affect your relationship because it may feel like your roles have been reversed. Most people will still want to be as independent as they can.



## Getting help from family members

There are lots of ways that other family members can help, such as tidying the house or doing the shopping. This will give you a break and make them feel that they are supporting you. Do not feel like you need to do everything yourself.

It is important to tell someone if you feel uncomfortable about a caring task. Another family member may be able to help instead. You could talk to a health or social care professional about how you feel if that is easier. See pages 18 to 20 for more information on getting support.

Sometimes it is useful to write down who is helping, when they are coming and what they are doing. This can help make the best use of everyone's time.

Carers UK has an online and mobile app called **Jointly**. It is available for a small one-off payment. You can use this app to share caring tasks with others, organise who is doing what and store useful contacts. You should check with an adult before paying for the app. You can find contact details for Carers UK on page 167.

If you prefer, you can use our weekly family rota (see opposite). We have included examples of details you can add to the rota. You and your family can make your own version of this table. You can also make copies of the rota and use it for different weeks.

## Weekly family rota

Day of the week	Activity	Contact details
<b>Monday</b>	8am: Saffiyah taking your younger brother and sister to school	Saffiyah's phone number:
<b>Tuesday</b>	1pm: Pat driving the person with cancer to hospital day unit for chemotherapy	Pat's phone number: Phone number for hospital day unit:
<b>Wednesday</b>	8am: Saffiyah taking your younger brother and sister to school	
<b>Thursday</b>	3pm: Stu calling physiotherapist to ask about exercises	Stu's phone number: Physiotherapist's phone number:
<b>Friday</b>	5pm: Keisha cooking dinner	Keisha's phone number:
<b>Saturday</b>	10am: Pat doing the ironing	
<b>Sunday</b>	4pm: Liz visiting	Liz's phone number:

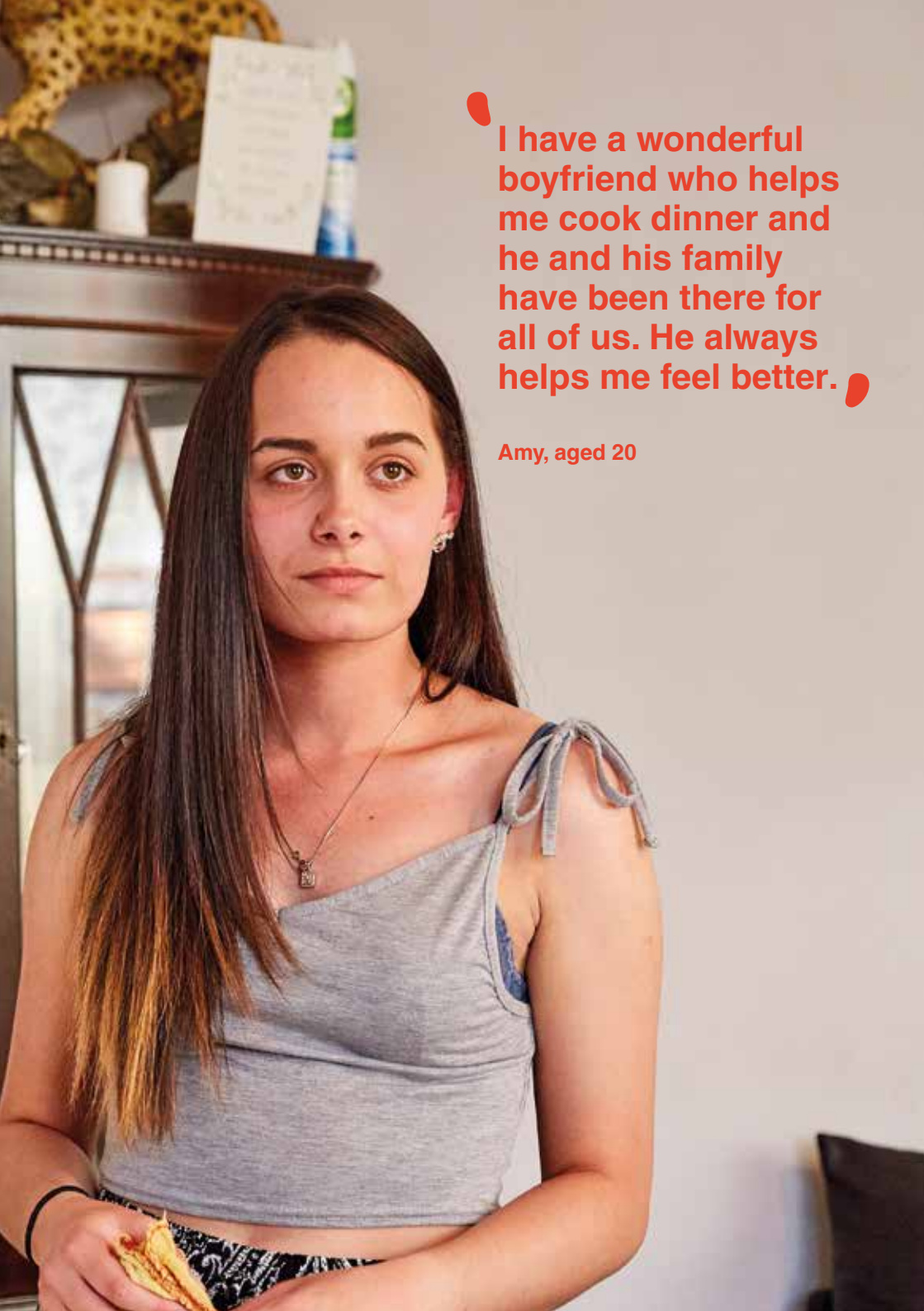
# Boyfriends and girlfriends

If you have a boyfriend or girlfriend, you might also feel able to talk to them about your situation. Spending time with them can also give you a break.

Your boyfriend or girlfriend might be willing to help you with the extra jobs you do at home. For example, they may agree to carry the shopping, mow the lawn or take the dog for a walk. Do not be afraid to ask them for support. But remember that these things are not their responsibility, so you should check that they are happy to help.

Being in a relationship can be fun and exciting. But you may have less spare time as a young carer and may often be thinking about the person you look after. This can affect your relationship. If things are not going well or your relationship ends, you may feel very sad. This can cause more stress in addition to your caring responsibilities.

You may feel guilty for getting upset about your relationship. Perhaps you feel that you cannot talk about this issue at home because it seems unimportant compared to the cancer. But what happens in the rest of your life still matters. Remember, you can always talk to a close friend or professional about how you feel (see pages 54 to 55).



I have a wonderful boyfriend who helps me cook dinner and he and his family have been there for all of us. He always helps me feel better.

Amy, aged 20





# SCHOOL OR COLLEGE

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## At school or college

As a young carer, you may find going to school or college a welcome relief. It means that you can see friends and forget about your problems for a few hours. Or you may find that it can be worrying.


Some of the things you may be worried about are:

- getting to school on time
- finding it difficult to concentrate
- completing homework
- managing your studies as well as your caring responsibilities
- being away from the person you care for.

There is no right or wrong way to feel. Not everyone has the same experience. But telling your school that you are a young carer makes it much easier to get support. There will be someone at school who can make sure you do not have to go through everything alone. You can ask your teacher if there is a young carers' lead in your school to help support you.

## Not everyone has the same experience.



A photograph of a man and a woman looking at a smartphone together. The man, on the left, is bald and wearing a green t-shirt. The woman, on the right, has long dark hair and is wearing a white t-shirt. They are both looking down at the phone held by the woman. The background shows a doorway with a patterned curtain.

It was my choice to become dad's carer. I left college when dad was diagnosed and I've never regretted it. Maybe in the future I can pick up where I left off.

Amy, aged 20

# Talking to your teachers

You may not want to tell your teachers that you are caring for someone with cancer. But if they know what is happening, they may be able to help you. They are likely to be more understanding if you are late for school or struggle to keep up with homework.

If you find it hard to talk about your home life, here are some tips that may help.

## 5 practical tips

- 1.** It is a good idea to tell at least one person at school that you are a young carer. You could approach a teacher or member of staff that you like and trust.
- 2.** You could say something like: 'Please can I speak with you in private after class? I would like to talk to you about what is happening at home and how this may affect my schoolwork.'
- 3.** You could show your teacher a list or diary of all the jobs you do around the house.
- 4.** If you do not feel comfortable talking to your teacher, ask a family member to contact them for you. Perhaps they could write a letter to the school.
- 5.** Young carers' services can also speak to your school for you. The Children's Society can help you find a service near you (see page 168).

# How your school can support you

Teachers are there to help you reach your full potential, whatever challenges you face. If you tell them about your situation at home, they may be able to:

- let you phone the person you are caring for during breaks or lunchtimes
- help you with homework or deadlines if you are struggling (see page 97)
- organise help for your family to travel to parents' evenings if it is hard for them to leave the house
- arrange for you to talk about how you feel with a school counsellor (see pages 54 to 55 for more information about counselling).

In England and Wales, there is a free programme called Young Carers in Schools. It is run jointly by Carers Trust and The Children's Society. This programme can help your school put the right support in place for you and other young carers. See pages 167 and 168 for their contact details.

There is lots of information available for schools on supporting young carers.

## England

If you live in England, your school can visit the Carers Trust website at **carers.org** and search for 'young carers in schools' for more information.

## Wales

If you live in Wales, your school can visit the Carers Trust website at **carers.org** and search for 'young carers in schools' for more information.

## Scotland

If you live in Scotland, your school can visit **carers.org/resources/all-resources** On this page, they can search by clicking on 'I work in: Schools' and 'Location: Scotland' in the right-hand menu. They will then find information for different areas in Scotland.

## Northern Ireland

If you live in Northern Ireland, your school can download the Education Authority's **Supporting Young Carers in School** booklet. Visit **eani.org.uk** and search the booklet title.

# Managing homework

As a young carer, you may not have as much time to do your homework as others in your class. After school, you may be cooking meals or doing housework, or you may not feel able to study. Try to take one day at a time.

If you find it hard to concentrate at home, think about whether there is another place that you can do your homework. This could be at the house of another family member or friend, or at a school or homework club. Some young carers' projects (see page 119) also run homework clubs.

If you are worried about not getting your homework done, you can ask a young carer worker or family member to talk to your school. The school may be able to give you a bit less homework, or more time to do it.

These websites may help you with your homework, coursework or revision for exams:

- BBC Bitesize – offers free videos, step-by-step guides, activities and quizzes to support your learning and exam preparation. Also available as an app.  
Visit **[bbc.co.uk/bitesize](https://www.bbc.co.uk/bitesize)**
- Grid Club – has a news section and a library. It offers help with homework, puzzles and quizzes.  
Visit **[gridclub.com](https://www.gridclub.com)**
- Homework Elephant – has over 5,000 resources to help you with your homework projects.  
Visit **[homeworkelephant.co.uk](https://www.homeworkelephant.co.uk)**

# Missing school

Balancing caring and going to school can be hard. Sometimes you may feel that you need to take a day off to look after the person with cancer. There may be days when you struggle to get to school on time. If this happens, speak to a teacher or someone who works at your school as soon as you can. They may be able to help you get more support at home, so you can concentrate on your studies.

A GP, nurse, social worker or young carer worker can also help you get support for yourself and your family (see pages 11 to 19).



# If you are being bullied

Bullies often pick on people who are different to them. If you are a young carer, you may find that you are the target of bullying. The bullies probably do not understand what your life is like outside of school.

Bullying can include being:

- called unkind names
- deliberately left out of activities or friendship groups
- threatened
- hit, kicked or punched.

If you are being bullied because of your situation at home, it is natural to feel upset and scared. But do not blame yourself. Bullying is unacceptable and should not be allowed to continue. There are ways to deal with the problem.

It is important to tell an adult what is happening. Try talking to a teacher or school counsellor. Perhaps your school could arrange to teach a lesson or hold an assembly about cancer. This may help your classmates and teachers understand more about your situation.

## It is important to tell an adult what is happening.



Young carers' services can offer support (see pages 119). You may be able to talk to other young carers who have been bullied.

We also have contact details for different organisations that can help (see pages 166 to 179). For example, you can call Childline free on **0800 1111** to have a confidential chat with a trained counsellor. They may be able to help you deal with the bullying.

You could tell your teachers about the website **kidscape.org.uk/resources** Here they can download a free bullying awareness classroom resource, created by Kidscape and Carers Trust. This shows students the challenges that young carers face.

**The teacher spoke about cancer in assembly, which made a difference. Now my brother is treated like a king and has made lots of friends.**

**Jake, aged 13**





# MONEY AND WORK

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# Cancer and money issues

When someone has an illness like cancer, it can affect how much money everyone in the family has. The person who is ill may have to stop working for a while. Other people in the family may also have to stop working, or work less, so that they can be carers.

There can also be extra costs, such as travelling to hospital or higher heating bills. These changes to the family can affect you if you are a young carer. But help is available if you or your family are having money problems because of cancer.



# Benefits and financial help

The government makes payments to people who need financial help. These are called benefits. Some benefits are just for carers and some are for people with a disability. This includes cancer. Other benefits help people if they have a low income.

As a young carer, you may be able to get some benefits yourself. The person with cancer may be entitled to different benefits. This could make things easier for you and your family.

## Carer's Allowance

Carer's Allowance is a benefit to help people who look after someone with a lot of care needs. You may be able to get this if you look after someone for 35 hours a week or more. To get Carer's Allowance, you must be aged 16 or over and not be in full-time education. The person who you care for must also get a certain disability benefit.

Before you apply for Carer's Allowance, it is a good idea to get some advice. Carer's Allowance can affect other benefit payments that you and the person with cancer get.

If you live in Scotland, you may get two extra payments a year called Carer's Allowance Supplement.

## Carer Premium

If you are entitled to Carer's Allowance, you may be able to get extra money added to certain other means-tested benefits. This is called Carer Premium.

## Young Carer Grant (Scotland)

This is a yearly payment for young carers aged 16 to 18 in Scotland, who are not entitled to Carer's Allowance. You must spend an average of 16 hours a week caring for someone who gets a certain disability benefit. Visit [mygov.scot/young-carer-grant](https://mygov.scot/young-carer-grant)

## Young Carers Package of Opportunities (Scotland)

If you are a young carer aged 11 to 18 in Scotland, you can get a package of non-cash benefits. These include:

- cinema tickets
- 50% off meals out
- discounted study guides
- first-aid training.

To sign up for the package, you need a Young Scot National Entitlement Card. Visit [young.scot/get-informed/national/young-carers-package](https://young.scot/get-informed/national/young-carers-package)

## Finding out about benefits and financial help

Here are some ways that you can find out more about Carer's Allowance and other benefits:

- Call our Support Line free on **0808 808 00 00**.
- Order our free booklet **Help with the cost of cancer** (see page 162).
- Have a young carer's assessment to find out what financial and practical help is available in your situation (see pages 11 to 17).
- Encourage the person with cancer to get their own needs assessment from your local council or Health and Social Care Trust. This could help your family get extra support and benefits. There is more information in our booklet **Looking after someone with cancer** (see page 162).
- Visit **gov.uk** (if you live in England, Scotland or Wales) or **nidirect.gov.uk** (if you live in Northern Ireland).

You or the person with cancer may be able to get help from a charitable fund. For more information, contact the charity Turn2Us (see page 177).

The person with cancer can also apply for a Macmillan Grant through a health or social care professional (see page 165). Macmillan Grants are small, one-off payments to help with the extra costs that living with cancer can bring. They can be used to help with things like energy bills, furniture or the cost of travel to and from hospital. Macmillan Grants are available to people with cancer whose income and savings are below a certain level.



## If you work

If you have a job, it can be hard to balance working and caring. But work can be a chance to socialise, improve your confidence and reduce money worries.

You may be thinking about whether to tell your employer that you look after someone with cancer. As a young carer, you have important rights that protect you at work.

Carers Trust has produced a free guide called **Getting into work: A guide for young adult carers in England** (see page 167). It includes advice on how to find a job, speak to your employer about being a carer and manage at work.

## As a young carer, you have important rights that protect you at work.

### Looking for a new job

As a young carer, you are probably learning lots of practical, organisational and communication skills. These skills are likely to be valuable to employers when you apply for a new job. You could highlight this experience on your CV and application forms.

At an interview, you could give examples of skills that you have used in your caring role. For example, you may be asked to describe a situation where you have managed your time well. There is also likely to be a chance for you to ask questions. It is a good idea to find out if, for example, the employer offers flexible (different) working arrangements (see page 111).

You can get help looking for a new job from your local Jobcentre Plus (in England, Scotland and Wales) or Social Security or Jobs and Benefits office (in Northern Ireland).

## Talking to your manager

If you are working, even if just part-time, it is your choice whether to tell your manager that you are caring for someone with cancer.

You may choose not to tell anyone at work that you are a young carer. For some people, having a part-time job is a good chance to get out of the house and do something for themselves. It means having a place where you do not have to think or talk about cancer.

But if you tell your manager about your situation, they may be able to give you more support. Your manager is likely to be more understanding if you need to miss work or are late. They may be able to give you time off or arrange a more flexible work pattern.

On the next page there are practical tips for talking to your manager about being a young carer.

## 6 practical tips

- 1.** Try to arrange a meeting with your manager. You could say something like: 'Please can we arrange a time to have a private conversation? I would like to talk to you about my caring responsibilities at home.'
- 2.** It is useful to make a list of the main things to talk about and questions to ask at the meeting. To get help with this, call our Work Support Service free on **0808 808 00 00**.
- 3.** If you feel nervous, take someone with you to the meeting for support. It is best to meet in a quiet place where you will not be interrupted. You can remind your manager to keep everything you tell them confidential.
- 4.** At the meeting, it is a good idea to make notes and keep a record of them. You can explain briefly that you look after a family member and what you do to help. You do not have to say that the person has cancer, but you can if you feel comfortable.
- 5.** Try to explain how being a young carer may affect your work. For example, you may sometimes have to take time off at short notice. You and your manager can then talk about possible solutions, such as working at home sometimes.
- 6.** Ask your manager what leave (time off) you can take and what other support is available in your situation. Suggest having regular catch-up meetings. You can then review how any changes are working and whether you are getting enough support.

## Your rights at work

You have rights at work that may make it easier to keep working while you are a young carer. If you have any questions about your rights, call our work support team free on **0808 808 00 00**.

### Protection from discrimination

You may be worried that you will lose your job if you tell your manager that you are a young carer. But it is against the law for your employer to treat you unfairly because you look after someone who has cancer. That would be discrimination. If you think you are experiencing discrimination, you can contact Citizens Advice for help (see page 175).

### Right to ask for flexible working

If you have worked for your employer for at least 26 weeks, you can ask them for a more flexible work pattern. This could mean having different start or finish times, working from home sometimes or doing fewer hours. Your employer can refuse your request if it is not in the best interests of the business.

If you want to ask for flexible working, there is a procedure that you and your employer must follow. It may be possible to agree a temporary or small change informally.

### Time off in an emergency

Employees can take reasonable time off to deal with an emergency involving someone they care for. This time off is usually unpaid, but you can check your employment contract or company policy.

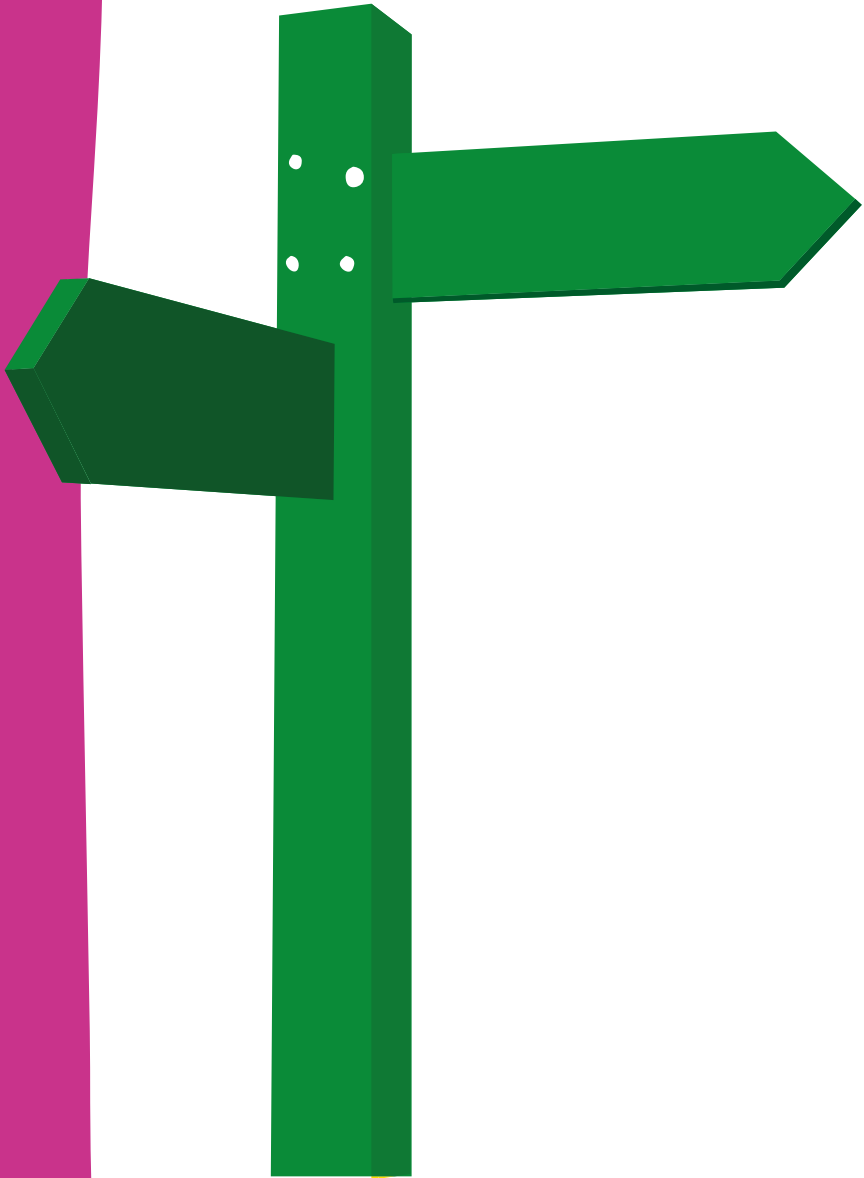
We have more information in our leaflet **Questions for carers to ask about work and cancer** (see page 162).





# GETTING HELP AND SUPPORT

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## Where can you get help and support?

When you are caring for someone with cancer, you may not be sure how to get the information you need. This could be information about the illness or about being a young carer. If you search the internet, you may sometimes find unhelpful websites that do not give accurate or reliable information.

You can call our Support Line free on **0808 808 00 00** (open every day, 8am to 8pm). Our experienced cancer nurses can answer your questions, give you guidance and help you find support in your local area.

Many professionals and organisations help young carers, including social workers, hospices and charities. The Children's Society has lots of advice and resources for young carers (see page 168). If you live in Scotland, you can find information about caring for someone on the Young Scot website (see page 169).

## You can call our Support Line free on 0808 808 00 00.

You may want to join a local support group, young carers' project or an online forum. This is a good way to share information with other young people in a similar situation. You may be able to help each other cope with the different feelings you have.



## Support groups

Joining a support group is a great way to relax and meet other young carers. You can make friends with people who understand what you are going through. They will support you on good and bad days.

Many young carers find that support groups are fun. Meetings sometimes include activities, a social event or a talk from a guest speaker. You can share as little or much as you like with others. You may want to talk about cancer, but you will probably chat about all sorts of things.

Your school or college may already have a support group. You can also ask your GP, or look online to see if there is one in your area. There is a search tool to find local support groups at [macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)

## Joining a support group is a great way to relax and meet other young carers.

If there is no support group that you can go to locally, you can set one up. Macmillan can help you start your own support group. We can give you advice, training and possibly funding. You could also encourage your school to set up a support group. Your teachers can find information about this on the Carers Trust website (see page 167).

# Young carers' projects

Young carer workers run projects that can support you and your family. These projects can give you the chance to:

- have a break and do something fun
- talk to other young carers
- talk to someone who will listen to you and your concerns
- get help, information and advice for your whole family.

Visit [youngcarer.com/young-carers-services](http://youngcarer.com/young-carers-services) to find a project near you.

## Social workers

A social worker helps individuals and their families sort out practical and financial problems. Any young carer or their family can ask a local social worker to visit them and do a young carer's assessment (see pages 11 to 17). Sometimes a young carer worker does the assessment instead.

If a social worker is asked to visit your family, they can help you all cope with looking after someone who has cancer. They can give you information, advice and support. You can talk to them if you have any questions or worries.

Your social worker is there to make sure that, as a young person, you are being protected and supported at home.

# Voluntary organisations and charities

There are lots of charities across the UK that can support young carers and their families.

Here are some health charities that can help:

- Macmillan Cancer Support offers practical, emotional and financial help for anyone affected by cancer, including young people and carers (see pages 163 to 165).
- Cancer Research UK is trying to find the causes of cancer and possible cures. It can give you information about different types of cancer (see page 170).
- Marie Curie gives free home nursing care to people at the end of their life (see page 178).

There are also charities for specific types of cancer.

Some charities, like the Children's Society, are there to protect children and young people. Other charities can support you and your whole family, including Action for Children, Barnardo's and Family Action.

Charities like Carers Trust and Carers UK support anyone who looks after a person who is ill or disabled.

See pages 166 to 169 for details of these charities.

# Hospices

Hospices support people with an incurable illness and their family members, close friends or carers. The care and support from a hospice are always free.

You may think that hospices only look after people at the very end of their life. But if people are diagnosed with an incurable illness, they can use hospice care at any stage of their condition. They often get care in their own home or by visiting the hospice as a day patient. Sometimes people stay in a hospice for a short time to give their carers a break.

A hospice provides a wide range of services and can support your whole family. The person with cancer may be offered:

- help to manage symptoms like pain
- relaxation therapies
- emotional, spiritual or practical support.

## People can use hospice care at any stage of their condition.

You may be able to join a support group or counselling sessions for carers at the hospice.

Your local hospice can explain what services are available. To find a local hospice, ask a GP or district nurse, or visit the Hospice UK website (see page 177).

## Online forums

Online forums can be a good way to get support and talk to people who are in a similar situation. But it is important to stay safe on the internet.

Here are some tips to make sure you are safe online:

- Tell a responsible adult which forum you use and who you talk to online.
- Tell someone if you feel unsure or uneasy about anything.
- Do not use your real name – make up a nickname instead.
- Do not share personal information, such as which school you go to or where you live.
- It is not a good idea to meet someone you have only chatted to online – they may not be who they say they are.
- You can leave a forum or take a break whenever you want to.

For more information about staying safe online, speak to your school or visit **[saferinternet.org.uk](https://www.saferinternet.org.uk)**

Joining an online forum can put you in contact with other young people and carers. You can use a forum whenever you like, make new online friends and share tips to help each other. It is useful to read the advice on the forum about how to protect your privacy.

The Macmillan Online Community is a free online place for people affected by cancer to chat about everyday issues. The site is intended for people aged 16 and above. If you are in this age group, you can blog about your experiences, ask questions or read other people's posts. Visit **macmillan.org.uk/community**

Online forums for young people and carers include:

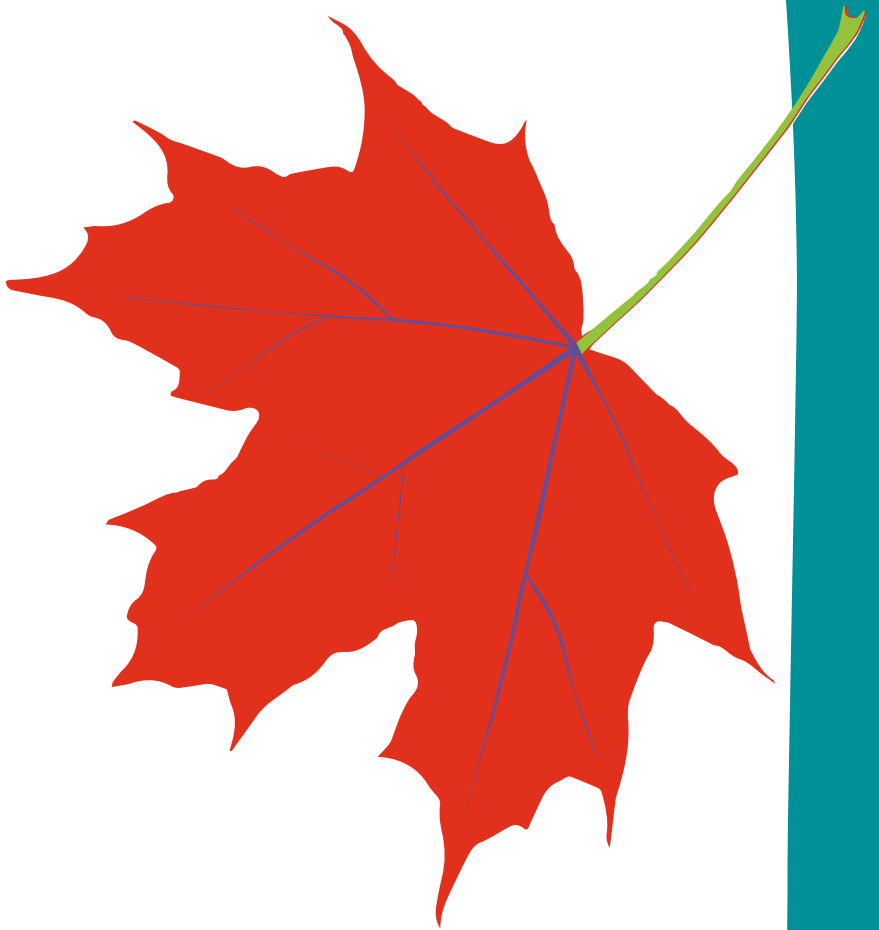
- **riprap.org.uk**
- **kooth.com**
- **carersuk.org/forum**
- **community.themix.org.uk**
- **yacbook.co.uk**

See pages 167 to 172 for more details about these forums.









# IF THE PERSON YOU CARE FOR DIES

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# Accepting what is going to happen

Many people with cancer get better and recover from treatment. But sadly, some people do not. If someone you love is going to die of cancer, it can feel like the end of your world.

Some of the young carers who helped develop this information have been through the experience. They want you to know one thing: it may be the worst time in your life right now, but this will not last forever. You will get through it and there is lots of help available.

If the person you care for is told that they will die, it can be hard for both of you to accept. This is called denial. It is a natural reaction. If the person with cancer is in denial, they may not want to talk about some things. While this may be upsetting for you, denial is a strong coping tool and needs to be respected. Some people eventually accept their situation, but others stay in denial.

It is still important to ask any questions you may have about what is going to happen. You need to know what to expect, so you can try to prepare yourself. You could talk to close family members, a doctor or a nurse (see pages 33 to 37).

You may want to say things to the person who is dying. The time that you have together is special, and you are likely to cherish it in future. You could tell the person you love them or talk about favourite memories you have shared. Maybe you could ask them to tell you about their hopes and dreams for your future.

This is a difficult and emotional time. If you need extra support, you can call our Support Line free on **0808 808 00 00** (open every day, 8am to 8pm).

**It is still important  
to ask any questions  
you may have  
about what is  
going to happen.**

## Before someone dies

Before they die, the person you look after may get very ill. Try to be prepared for this, as it will be upsetting.

Young carers' services, or other organisations that support young carers, can help you and your family make an emergency plan. This can cover what to do if the dying person's health suddenly gets worse or they die at home. If you are by yourself when that happens, call their GP or the NHS helpline **111**. A doctor will then come to your home to help you.

## Hospices

If the person you look after becomes very ill, they may go into a hospice. This may also happen if you or your family decides that they cannot cope or need a break.

A hospice is a place where people with serious illnesses get free specialist care and support. They have nurses who provide palliative care. This is special care towards the end of life. It includes pain relief for the person who is ill and emotional support for them and their family.

Hospices are designed to be friendly, comfortable places, where family and friends are welcome. Some hospices will let you stay overnight from time to time. You can speak to the nurses about things you can still do to help your loved one.

## Talking about your needs

Talking to nurses and doctors can help a lot at this stage. Palliative care nurses can help you make sense of what is happening.

People may think that, because you are young, they need to protect you when someone is dying. This can be frustrating. If you want to be told more information, a young carer worker could explain this to your family or the healthcare staff.

## Palliative care nurses can help you make sense of what is happening.

It is important to be open with your family about what you want. If you would like to be there at the end, make sure people know this and respect your wishes. But if you would rather not be there, that is okay too.

We have more information about what happens in the last few weeks, days, and at the end of life in our booklet **A guide for the end of life** (see page 162).



# When someone dies

If you have decided that you want to be there at the end, knowing what to expect can help you prepare. This will be an emotional experience. But remember you are doing something special by being there to comfort and reassure the person you love.

When someone is dying, they can often still hear you even if they cannot respond. So, keep talking to them.

You may not be able to tell the exact moment when the person dies, but you may notice some physical changes. Their body may relax completely, and they may look peaceful. You cannot be sure how you will feel until this happens. Some people say they feel relieved that the person is at peace and their illness is over.

Losing someone you love is very hard. But remember that there are people around to support you. It is important to express how you are feeling.

# The funeral

Your family will usually start planning the funeral quite quickly. This can be a chance to say goodbye to the person who has died, celebrate their life or share memories with others.

A funeral director or religious leader may come to your home. They may want to speak with you about the person who has died and hear about your memories.

If you want to get involved with the funeral, make sure you tell your family. What happens at the funeral depends on your family's culture and beliefs. Depending on the type of funeral and your family's wishes, you may be able to:

- read a poem
- do a special reading
- choose a piece of music
- simply talk about the person who has died and your memories of them.

Tell the person planning the funeral if you want to do any of these things and find out what is possible.

If you do not want to go to the funeral, or you are not allowed to go, there are other ways that you can say goodbye. Here are some ideas:

- Plant a flower or tree, or light a candle, in memory of the person who has died.
- Tie a message to a balloon and let it go.
- Visit a place with a special meaning or memories and perhaps say a few words. This could be a place where the two of you used to go, or just somewhere peaceful.

# After someone has died

After someone has died, life at home can feel flat or empty. If the person was cared for at home, nurses and family members may have visited regularly. It can feel quiet and lonely for a while, until you get used to the new situation. Give yourself plenty of time and space. Do not put too much pressure on yourself.

You may worry that you cannot talk about the person who has died to your family, in case it upsets them. But your family will probably understand how you feel at this time. You could comfort each other and share memories.

If you need to sort out the belongings of the person who has died, this can be upsetting. It may feel very final. You may prefer not to do this task for a while. Talk to the rest of your family and try to agree when would be a good time. Make sure you tell someone if there is anything you want to keep. This could be something like a watch, a ring or photos.

Someone close to you dying when you are young can make you feel alone. You may find that none of your friends or classmates have gone through a similar experience. They may not know how to react or what to say. Try to explain to your friends gently that they can support you just by being there and listening. You could encourage them to watch the **How to help a grieving friend** video from the charity Winston's Wish (see page 179).

If it is hard for you to talk to your family or friends, you could contact a cancer support group, young carer worker or counsellor. Just make sure you do not keep your feelings to yourself.

# Grief

Grief is a word for some of the feelings you may have after someone close to you has died. The thoughts and feelings you have will change. Sometimes they may be very strong. They might stop you doing things. At other times, they may be in the background and you can still do your daily activities.

You may have lots of different emotions. They are unlikely to stay the same. It can feel like they come and go in waves.

If you had a difficult relationship with the person who has died, your feelings may be complicated.

## Common feelings

### Shock and numbness

Many people describe feeling shocked and numb in the days and weeks after someone they love has died. You may find it hard to believe what has happened. It can feel like you expect the person to walk through the door at any moment.

### Anger

You may feel angry and think that your loss is unfair. This is a natural reaction.

### Guilt

You may think that you could have done more to help or behaved differently. Perhaps you could talk to a doctor or nurse who looked after the person who has died. You could also talk to your GP. They can reassure you that there is nothing that you could have done to prevent the death. It is not your fault that the person with cancer died.

## Relief

The person you looked after may have been ill for a long time or had symptoms that were difficult to control. You may feel relieved that they are not suffering any more. You should not feel guilty about this.

## Loneliness

You may feel lonely, even when surrounded by family and friends. This is understandable, as the person who has died was a big part of your life. It will take time to get used to them not being around.

## Longing

You may have a powerful longing to see, speak to or hold the person who has died or dream about them. Some people find looking at photos or thinking about good memories helpful. Others find they need to be distracted by other things.

## Fear

You may worry about the future and how you and your family will cope. This is natural. When you feel ready, you could talk to your family about how you feel. It may be possible to make some plans together to help you feel more secure.

## Sadness

The sadness you feel after someone close to you dies can be overwhelming. Some people describe it like a physical pain in the chest.

Try not to worry how often you cry. Crying is a healthy way to release strong emotions. If you cannot cry, you may be expressing your grief in a different way. Just do whatever feels right for you.





## Physical impact of grief

Grief can also have effects on your body. You may:

- have a poor appetite (do not feel like eating much)
- be irritable or easily annoyed
- find it hard to sleep
- find it hard to concentrate at school or work.

Some people become depressed and stop looking after themselves properly. If this happens, it is important to see your GP and get extra support (see pages 58 to 59).

Your grief is unique to you. You will have good days and bad days. Try to take one day at a time.

**I used to talk to my mum after she died. It helped me. I still talk to her now. I know she can hear me.**

Farouk, aged 15

## Coping with grief

After someone you loved has died, it can feel like nothing is the same any more. But you may find it helpful to get back to your usual routine quite quickly. Try to make sure that you do not isolate yourself. It can be harder to adjust if you have not been to school or college, or seen your friends, for a long time.

There are some things that may help when you are grieving.

### 5 practical tips

- 1.** Look after yourself. Grieving can be a very tiring process. It is important to take care of your health. Try to eat healthily, make time to relax and do regular exercise. These things can help improve your mood (see pages 62 to 75).
- 2.** Do things you enjoy. It is a good idea to keep your mind busy and distract yourself from sadness. Try to make time for your hobbies. You could spend time with friends or pets, go for a walk or read a book. Try not to feel guilty if you have some fun. This does not mean you have forgotten the person who has died.
- 3.** Stay connected to the person who has died. There are lots of ways to do this. You could write them a letter, put a favourite photo in a frame or visit a place that has nice memories. Do not be afraid to talk about the person or share stories about them.
- 4.** Make a memory box. This is a container that holds special things to remind you of the person who has died. You could put in photos, some of their favourite music or letters or cards from them. These things can help remind you of happy times you spent together and give you comfort.
- 5.** Ask for support. It is important to find someone to talk to about your grief. This could be a family member, close friend, teacher, your GP or anyone else you trust.



There are charities that can help if you are coping with grief (see pages 178 to 179). You could call the Cruse Bereavement young people's helpline free on **0808 808 1677**.

Child Bereavement UK runs support groups and has an app for people aged 11 to 25. This includes stories from bereaved young people and short films they have made. The charity has also made a game called **Apart of me – A quest into loss and love**, which you can download on your phone. It is designed to help you cope with the death of a loved one.

You will always feel love and sadness for the person who has died. Eventually, you will have fewer bad days and can start to look to the future. This does not mean you are forgetting your loved one.

**I was always really worried about my dad and I didn't know what I could do. I couldn't make him be able to do the things that he wanted to.**

Jordyn, aged 14



# LIFE AFTER CARING

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# When you stop being a young carer

When you stop being someone's carer, it can be a big change. You probably need time to adjust. The person you looked after may have got better and no longer need the same help, or they may have sadly died. Emotionally, these are very different situations. But, whatever your situation, it is important to bring some routine back into your life and be kind to yourself.

## Coping with your emotions

Being a young carer is demanding and can cause many emotions (see pages 45 to 59). When you were caring for the person with cancer, you may have been too busy to deal with all these different feelings. Now, you may have more time to think and reflect. You may start to feel emotions you did not have time to recognise before.

**It's important to know that you're not horrible if you go out and have a good time or keep doing normal things after they've died.**

Jordyn, aged 14

After being a carer, you need time to recover. Try to focus on doing things you enjoy and that help you relax. You may have been putting someone else's health first for a long time and it is important to look after yourself (see pages 62 to 75).

To talk with someone about how you feel, call our Support Line free on **0808 808 00 00** (every day, 8am to 8pm). You may also find it helpful to get support from other people who used to be young carers. For example, you could join a support group or an online forum (see page 118).

If the person you looked after has died, you may be coping with difficult emotions (see pages 127 to 140). It can sometimes take a long time to accept what has happened. Lots of support is available and your GP can help if a low mood or anxiety are affecting your daily life (see pages 45 to 59). Eventually, you will start to feel less sad and more hopeful about the future.

## Filling your time

A typical day as a young carer may have involved lots of different tasks. When you stop looking after someone, it can leave a gap in your life. You may feel you have lost your purpose and might not be sure how to fill your time at first.

It is a good idea to get back into a routine slowly. You may want to start spending more time with your friends or focus on your school or college work.

When you feel ready, you may enjoy trying a new hobby or learning some new skills. Carers UK have designed an e-learning programme called **Learning for Living**. This can help you recognise the skills that you have gained from caring and what you can do to make the most of them. Visit [learning4living.org](http://learning4living.org)

Some young carers put their skills to good use by becoming volunteers. Your caring experience may have made you more emotionally mature than other people your age. Volunteering can be a great way to make a difference, have fun and meet new people. You can find volunteering opportunities across the UK at [do-it.org](http://do-it.org)

You can also volunteer for Macmillan. Visit [volunteering.macmillan.org.uk](http://volunteering.macmillan.org.uk)



## Focusing on your future

There may come a time when you consider moving away from home, or want to make decisions about your future. You may want to go to college or university, get a job or travel to new places.

If your loved one has long-term care needs, social care services may be able to help support them. Your local council or Health and Social Care Trust can assess what support you and the person with cancer need after you are 18 (see pages 16 to 17). It is important that you have a chance to focus on your future goals.

If you plan to move away from home, you may feel guilty about leaving. You may be worried about the cancer coming back or leaving people behind who have also lost a loved one. These feelings are natural, but you have your whole life ahead of you. Your experience with cancer should not stop you from doing all the things you want to.

**It is important that you have a chance to focus on your future goals.**



If you are looking for a job, contact your local Jobcentre Plus (in England, Scotland and Wales) or Social Security or Jobs and Benefits office (in Northern Ireland) – see page 176. They can help you search and apply for jobs, prepare for interviews and claim benefits like Jobseeker's Allowance or Universal Credit.

The skills that you have learnt as a young carer will be valuable to a future employer. These may include being able to:

- communicate well
- organise your time
- deal with challenging situations
- cope under pressure.

The National Careers Service has a skills health check involving quizzes and activities. This online tool can help you identify your skills and which jobs might suit you. Visit **[nationalcareers.service.gov.uk/skills-assessment](https://nationalcareers.service.gov.uk/skills-assessment)**

The Mix is a website and support service for young people under the age of 25. It can help if you are looking for a job, thinking about moving out or planning future studies or your career. Visit **[themix.org.uk](https://themix.org.uk)**

You have been through a lot as a young carer and learnt many things along the way. Now it is time to let yourself be young and make the most of the opportunities you have.





# GLOSSARY

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# Medical terms

## Anaesthetic

An anaesthetic is a drug that makes people more comfortable. It tops them feeling pain during a medical procedure. A **general** anaesthetic puts a person to sleep for a while. A **local** anaesthetic numbs a part of the body, so the person cannot feel anything.

## Benign

Benign means not cancerous. Benign tumours usually grow slowly. They do not spread to other parts of the body.

## Biopsy

A biopsy is when a doctor takes a small sample of tissue from the body and looks at it under a microscope. This is to see if the cells are cancerous or not.

## Blood count

A blood count is a blood test. It measures the levels of different blood cells in the blood. The three main types of blood cells are:

- red blood cells, which carry oxygen
- white blood cells, which fight and prevent infection
- platelets, which help the blood to clot.

This is also called a full blood count.

## Central line

A central line is a long, thin, hollow tube. The line is put into a vein in a person's chest. It is used to give chemotherapy treatment and other medicines. A Hickman<sup>®</sup> line is a type of central line.

## Chemotherapy

Chemotherapy is a cancer treatment. It uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Chemotherapy can be given alone or with other treatments.

## Consent

When someone consents to treatment, it means that they agree to have it. The doctor usually asks them to sign a form to confirm this.

## Diagnosis

A diagnosis is a description of the illness a person has.

## Fertility

Fertility is the ability to get pregnant or make someone pregnant.

## Hormonal therapies

Hormones are substances produced naturally in the body. They act as chemical messengers and affect the growth and activity of cells. Hormonal therapies change the hormones in the body. This can stop or slow down the growth of some types of cancer.

## Intravenous (IV)

This means being given into a vein. A person may have fluids or drugs given into a vein.

## Lymphatic system

The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels, which connect to groups of lymph nodes throughout the body. These nodes trap or destroy anything harmful that the body does not need.

## Malignant

Malignant means cancerous. Malignant tumours may spread to different parts of the body.

## Metastasis

A metastasis is a cancer that has spread from where it started to another part of the body. Cancer that has spread is sometimes called secondary cancer.

## Oncology

Oncology is the medical specialty that deals with cancer. A doctor who specialises in cancer is called an oncologist.

## Paediatrics

Paediatrics is the medical specialty that deals with children. A doctor who specialises in treating children is called a paediatrician.

## Palliative care

Palliative care is treatment to help improve someone's quality of life when the cancer cannot be cured. It can also help them manage symptoms, such as pain. Palliative treatment aims to meet the physical, spiritual, psychological and social needs of a person with cancer.

## PICC line

A PICC line is a long, thin and flexible tube. It is put into a vein to give chemotherapy or other treatments. The tube usually stays in place until treatment finishes.

## Portacath

This is a long, thin tube. It is put in under the skin to give chemotherapy and other drugs. The tube is connected to a small box under the skin.



## Primary cancer

Primary cancer means where the cancer started. The cancer type is usually named after the part of the body where it first started to grow. For example, a cancer that starts in the lung is called a primary lung cancer.

## Prognosis

A prognosis is the likely outcome of a disease. The prognosis gives an idea of how long a person may live.

## Prosthesis

A prosthesis is an artificial body part. It can be used if that part of the body has been removed. This helps with mobility (moving around) and appearance.

## Radiotherapy

Radiotherapy is a cancer treatment. It uses high-energy rays to destroy cancer cells in the area where the radiotherapy is given.

## Surgery

Surgery is a cancer treatment. It involves an operation to remove all or part of the cancer from the body.

## Targeted therapy

Targeted therapy is a cancer treatment. It interferes with the cell processes that cause the cancer to grow. Targeted therapy is sometimes called biological therapy.

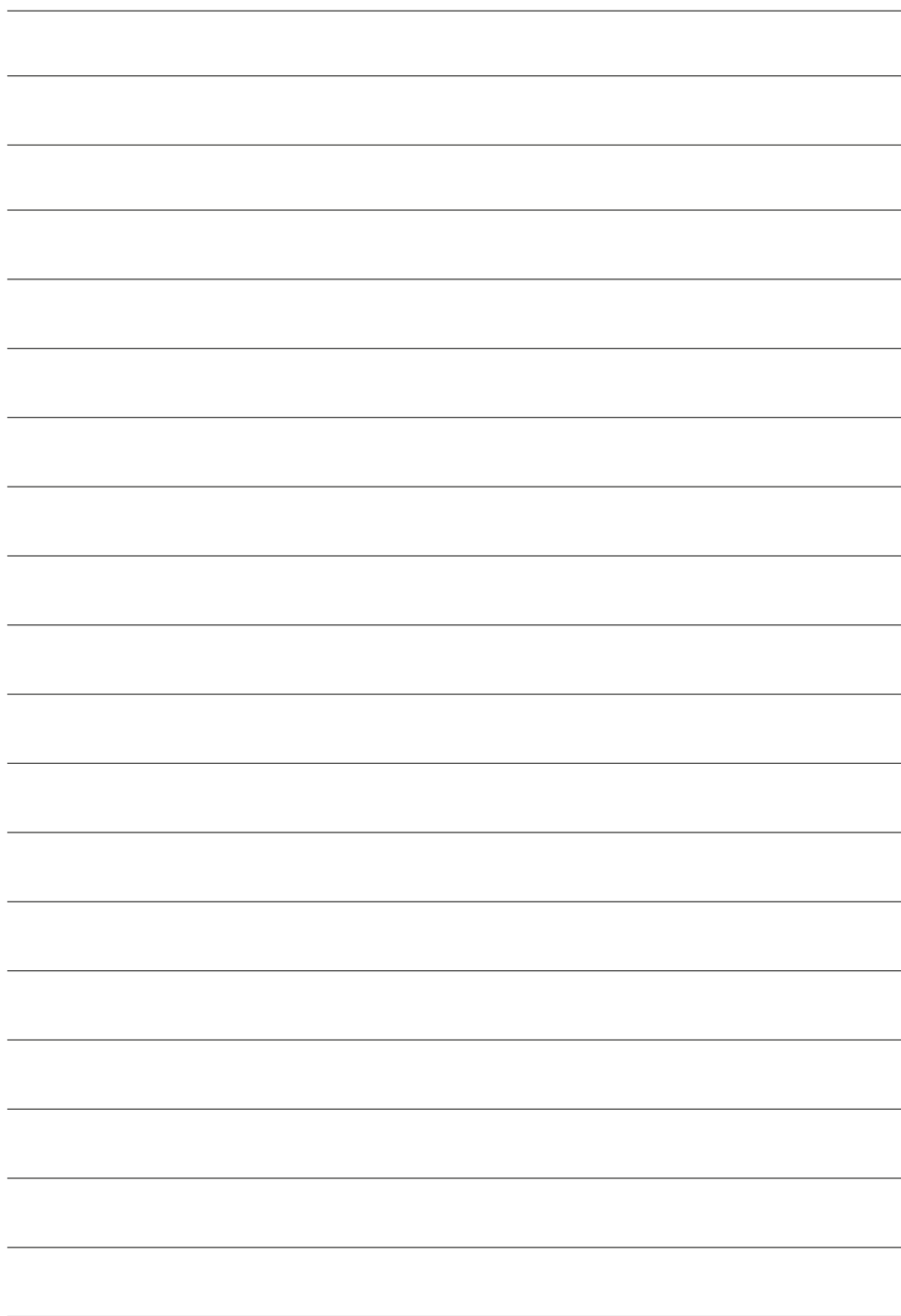
## Terminal

Terminal cancer is the term used to describe a cancer that cannot be cured or controlled with treatment. It may mean that someone should prepare for the end of life.

## Tumour

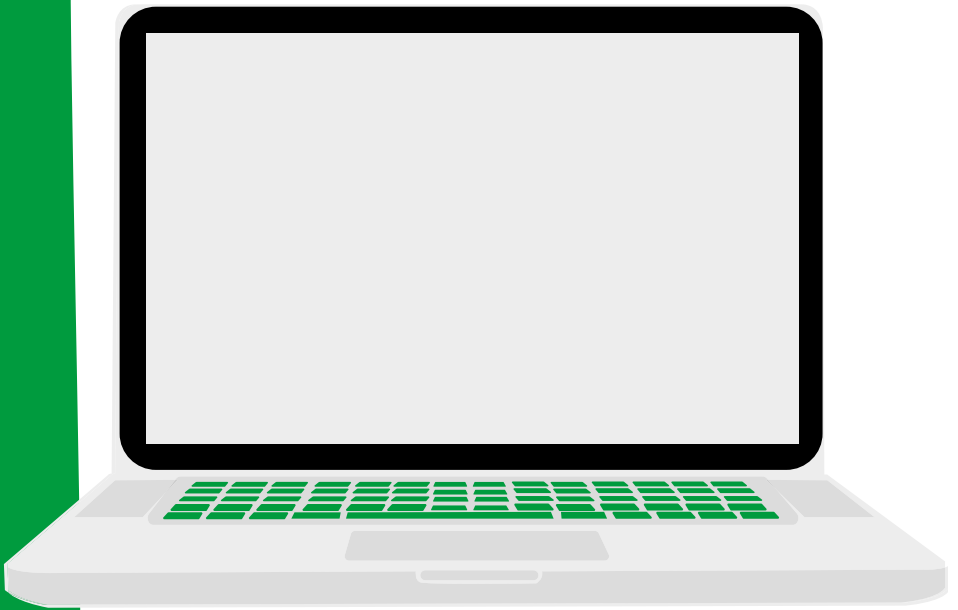
A tumour is a growth or lump in the body. It is made up of a group of cells that are growing in an abnormal way. Tumours may be benign (not cancer) or malignant (cancer).





# FURTHER INFORMATION

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# About our information

We provide expert, up-to-date information about cancer.  
And all our information is free for everyone.

## Order what you need

You may want to order more booklets or leaflets like this one.  
Visit [be.macmillan.org.uk](http://be.macmillan.org.uk) or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

## Online information

All our information is also available online at [macmillan.org.uk/information-and-support](http://macmillan.org.uk/information-and-support) You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

## Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at [macmillan.org.uk/otherformats](http://macmillan.org.uk/otherformats)

If you would like us to produce information in a different format for you, email us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk) or call us on **0808 808 00 00**.

# Other ways we can help you

**At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.**

## Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

### Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](https://macmillan.org.uk/talktous)**

### Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **[macmillan.org.uk/informationcentres](https://macmillan.org.uk/informationcentres)** or call us on **0808 808 00 00**.



## Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help to bring people together in their communities and online.

### Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)

### Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

## The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

## Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help.

## Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

## Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

## Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **[macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport)** to find out more about how we can help you with your finances.

## Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **[macmillan.org.uk/work](https://www.macmillan.org.uk/work)**

## Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

# Other useful organisations

There are lots of other organisations that can give you information or support.

## Support for young carers

### Action for Children

Tel **0300 123 2112** (Mon to Fri, 9am to 5pm)

Email [ask.us@actionforchildren.org.uk](mailto:ask.us@actionforchildren.org.uk)

[www.actionforchildren.org.uk](http://www.actionforchildren.org.uk)

Offers practical and emotional support to young carers across the UK. Works with whole families and schools to ensure that the right support is in place. Provides regular breaks, access to fun activities and opportunities to meet other young carers.

### Barnardo's

Tel **020 8550 8822**

[www.barnardos.org.uk](http://www.barnardos.org.uk)

Organises outings, activities and counselling sessions for young carers across the UK. Helps the family get support from social services, talks to schools and runs drop-in centres, where young carers can take a break.

### Carers Direct Helpline

Tel **0300 123 1053**

(Mon to Fri, 9am to 8pm, and Sat and Sun, 11am to 4pm)

Email enquiry service [carersdirectenquiry.serco.com/newcarersemail](http://carersdirectenquiry.serco.com/newcarersemail)

Offers confidential advice and support for carers. Gives free information about how to get financial help, taking a break from caring, going to work and much more.

### **Carers Trust**

Tel **0300 772 9600**

Email **info@carers.org**

**www.carers.org**

Supports carers of any age and helps young carers through specialised services across the UK. You can find details of UK offices and search for local support on the website.

### **Carers UK**

**www.carersuk.org**

Offers information and support to carers across the UK, including young carers. Has an online forum and lets you search for local support on the website.

### **England, Scotland and Wales**

Tel **0808 808 7777** (Mon to Fri, 9am to 6pm)

Email **advice@carersuk.org**

### **Northern Ireland**

Tel **028 9043 9843**

Email **advice@carersni.org**

### **Crossroads Care NI (Northern Ireland)**

Tel **028 9180 0661**

Email **ycarer@crossroadscare.co.uk**

**www.crossroadscare.co.uk/young-carers**

Offers support services to young carers and their families in Northern Ireland. Organises outings for young carers to meet others in similar situations and workshops to equip them with different skills.

### **Crossroads Caring Scotland**

Tel **0141 226 3793**

Email **info@crossroads-scotland.co.uk**

**www.crossroads-scotland.co.uk**

Supports vulnerable people and their carers. Has services throughout Scotland that provide care in the home and practical support for carers of all ages.

### **The Children's Society**

Tel **020 7841 4400**

**www.childrenssociety.org.uk**

Runs local services to help vulnerable children and young people in England and Wales, including young carers. You can search for local young carers' projects across the UK and find information for young carers on the website.

### **The Children's Society Include Programme**

Tel **01962 711 511** (Mon to Fri, 9am to 5pm)

**www.childrenssociety.org.uk/information/young-people/  
young-carers**

This programme specifically supports young carers and their families. You can search for local young carers' projects across the UK and find information for young carers on the website.

### **YACbook**

Tel **0800 181 4118**

Email **Info@carersupportwiltshire.co.uk**

**yacbook.co.uk**

An online community and resource centre for young adult carers aged 18 to 25. You can get advice, information and support, read regular blogs and find out about events in your area. There is also a forum where you can talk to other young adult carers.

## Young Scot

Tel **0808 801 0338** (Mon to Fri, 10am and 5pm)

Email **info@young.scot**

**young.scot/campaigns/national/young-carers**

Find out how to apply for benefits for young carers if you live in Scotland. You can watch videos about other young carers' experiences and get lots of information on caring for someone.

## Support for young people and families

### Family Action

Family Line (for adult family members) **0808 802 6666**

(Mon to Fri, 9am to 9pm)

Text **07537 404 282**

Email **familyline@family-action.org.uk**

**www.family-action.org.uk**

Offers support services for children and families, including support projects for young carers. Provides grants for people and families in need.

### Kidscape

Parent Advice Line (WhatsApp) **07496 682785** (Mon to Tue, 9.30am to 2.30pm)

Email **info@kidscape.org.uk**

**www.kidscape.org.uk**

Provides children, families and schools with advice, training and practical tools to prevent bullying and protect young lives.

## General cancer support organisations

### Cancer Research UK

Tel **0808 800 4040** (Mon to Fri, 9am to 5pm)

Email enquiry service [www.cancerresearchuk.org/about-us/contact-us/talk-to-our-nurses](http://www.cancerresearchuk.org/about-us/contact-us/talk-to-our-nurses)

[www.cancerresearchuk.org](http://www.cancerresearchuk.org)

A UK-wide organisation that has information on different types of cancer. It is trying to find the causes of cancer and possible cures. Also offers a live chat service, which has the same opening hours as the helpline.

### Riprap

[www.riprap.org.uk](http://www.riprap.org.uk)

A site for teenagers who have a parent with cancer. Has an online forum, where you can connect with other teenagers going through similar experiences. You can also send an email, which a cancer support specialist will answer.

## Counselling

### British Association for Counselling and Psychotherapy (BACP)

Tel **01455 883 300**

Email [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

[www.bacp.co.uk](http://www.bacp.co.uk)

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their 'How to find a therapist' page.

## Youth Access

Tel **020 8772 9900**

Email **admin@youthaccess.org.uk**

**www.youthaccess.org.uk**

A UK-wide organisation providing counselling and information for young people. Find your local service by visiting **youthaccess.org.uk/find-your-local-service**

## General health support organisations

### Healthwatch

Tel **03000 683 000** (Mon to Fri, 8:30am to 5:30pm)

Email **enquiries@healthwatch.co.uk**

**www.healthwatch.co.uk**

Independent champion for people who use health and social care services. Find your local Healthwatch on the website. Also has advice and information.

### Patient Advice and Liaison Service (PALS)

**www.nhs.uk/service-search/other-services**

Offers confidential advice, support and information on health-related matters. They are a point of contact for patients, their families and their carers. You can find officers from PALS in your local hospital. They can help you or your family resolve any concerns or problems when using the NHS.



## Getting help with your feelings

### Childline

Tel **0800 1111**

**[www.childline.org.uk](http://www.childline.org.uk)**

Children and young people can contact Childline if they feel worried, scared, stressed or upset. A trained counsellor can listen and support you with any problem that you want to talk about. On the website, you can write emails, post on message boards and have a 1-2-1 online chat with a counsellor.

### Kooth

**[www.kooth.com](http://www.kooth.com)**

A free, safe and anonymous place for young people to find online mental health support and counselling.

### Mind

Infoline **0300 123 3393** (Mon to Fri, 9am to 6pm)

Text **86463**

Email **[info@mind.org.uk](mailto:info@mind.org.uk)**

**[www.mind.org.uk](http://www.mind.org.uk)**

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

### The Mix

Helpline **0808 808 4994** (Daily, 3pm to 12am)

**[www.themix.org.uk](http://www.themix.org.uk)**

A UK-wide support service for young people under the age of 25. Can help you with any challenge that you are facing, including mental health, relationship, work and study or money issues. Provides counselling services, discussion boards and scheduled group chats. You can get in contact by phone, email or live web chat.

### **National Self Harm Network Forum**

**[www.nshn.co.uk](http://www.nshn.co.uk)**

An online forum to support people who self-harm and their family or carers.

### **Samaritans**

Tel **116 123** (24 hours a day, 7 days a week)

Email **jo@samaritans.org** (24 hours a day, 7 days a week)

**[www.samaritans.org](http://www.samaritans.org)**

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

### **YoungMinds**

Parents Helpline **0808 802 5544** (Mon to Fri, 9.30am to 4pm)

**[www.youngminds.org.uk](http://www.youngminds.org.uk)**

Provides information, advice and support for young people affected by mental health issues and their parents.

## **Support with drink and drugs issues**

### **Drinkaware**

Tel **0300 123 1110** (Mon to Fri, 9am to 2pm, and Sat and Sun, 11am to 4pm)

Email enquiry service **[www.drinkaware.co.uk/advice/support-services/chat-with-an-advisor](http://www.drinkaware.co.uk/advice/support-services/chat-with-an-advisor)**

**[www.drinkaware.co.uk](http://www.drinkaware.co.uk)**

An independent charity working to reduce alcohol misuse and harm in the UK. Aims to help people make better choices about drinking. Runs a confidential helpline and online chat service. There is a section on the website with advice, tips and facts for parents of underage drinkers.

### **Talk to Frank**

Tel **0300 123 6600** (24 hours a day, 7 days a week)

Text 82111

Email **frank@talktofrank.com**

**www.talktofrank.com**

Provides confidential advice and information about drugs to young people and their parents. The website has tips on how to deal with peer pressure.

## **LGBT-specific support**

### **LGBT Foundation**

Tel **0345 330 3030** (Mon to Fri, 9am to 9pm,  
and Sat to Sun, 10am to 6pm)

Email **info@lgbt.foundation**

**www.lgbt.foundation**

Provides a range of services to the lesbian, gay, bisexual and transgender (LGBT) community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

## **Help with money or work**

### **Advice NI**

Helpline **0800 915 4604**

Provides advice on a variety of issues including financial, legal, housing and employment issues.

### **Carer's Allowance Unit (England, Scotland, Wales)**

Tel **0800 731 0297** (Mon to Fri, 8am to 6pm)

Textphone **0800 731 0317**

**www.gov.uk/carers-allowance-unit**

Gives information on the benefit Carer's Allowance and how to apply for it.

## **Citizens Advice**

Provides advice on a variety of issues, including financial, legal, housing and employment problems. Use their online webchat or find details for your local office in the phone book or by contacting:

### **England**

Helpline **0800 144 8848**

**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

### **Scotland**

Helpline **0800 028 1456**

**[www.cas.org.uk](http://www.cas.org.uk)**

### **Wales**

Helpline **0800 702 2020**

**[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)**

## **Disability and Carers Service (Northern Ireland)**

Tel **0800 587 0912** (Mon to Fri, 10am to 4pm)

Textphone **0800 012 1574**

Email **[dcs.incomingpostteamdhc2@nissa.gsi.gov.uk](mailto:dcs.incomingpostteamdhc2@nissa.gsi.gov.uk)**

**[www.nidirect.gov.uk/contacts/disability-and-carers-service](http://www.nidirect.gov.uk/contacts/disability-and-carers-service)**

Provides information and advice about benefits for carers in Northern Ireland.

### **Jobcentre Plus (England, Scotland and Wales)**

Tel **0800 055 6688** (Mon to Fri, 8am to 6pm)

Textphone **0800 023 4888**

Welsh language **0800 012 1888**

**[www.gov.uk/contact-jobcentre-plus](http://www.gov.uk/contact-jobcentre-plus)**

Gives information about finding and contacting your local Jobcentre Plus. They can help you find a job and apply for the benefit Jobseeker's Allowance. You can also use their online 'Find a job' service.

### **Jobs and Benefits offices (Northern Ireland)**

**[www.nidirect.gov.uk/contacts/jobs-benefits-offices](http://www.nidirect.gov.uk/contacts/jobs-benefits-offices)**

Lists the contact details of local Jobs and Benefits offices in Northern Ireland. They can help you find a job and apply for the benefit Jobseeker's Allowance.

### **Local councils (England, Scotland and Wales)**

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim education benefits, and for help from social services (the Social Work department in Scotland).

#### **England**

[www.gov.uk/find-local-council](http://www.gov.uk/find-local-council)

#### **Scotland**

[www.cosla.gov.uk/councils](http://www.cosla.gov.uk/councils)

#### **Wales**

[www.wlga.wales/welsh-local-authority-links](http://www.wlga.wales/welsh-local-authority-links)

### **Macmillan Benefits Advice Service (Northern Ireland)**

Tel **0300 1233 233**

Email **[info@macmillanbenefitsservice.co.uk](mailto:info@macmillanbenefitsservice.co.uk)**

Provides benefits information and support in Northern Ireland.

## NiDirect

**[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

Has information about benefits and public services in Northern Ireland. Find contact details for Health and Social Care Trusts at **[www.nidirect.gov.uk/contacts/health-and-social-care-trusts](http://www.nidirect.gov.uk/contacts/health-and-social-care-trusts)**

## Turn2us

Tel **0808 802 2000** (Mon to Fri, 9am to 5pm)

**[www.turn2us.org.uk](http://www.turn2us.org.uk)**

Runs a free confidential helpline, which provides help with benefits, debt, housing and legal issues. Has an online tool to search for grants that you or your family may be able to get. Also offers some grants themselves to people in financial hardship.

## Support if you have a disability

### Disability Rights UK

Tel **0330 995 0400**

Email **[enquiries@disabilityrightsuk.org](mailto:enquiries@disabilityrightsuk.org)**

**[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)**

Provides information on welfare benefits and disability rights in the UK. Has several helplines for specific support, including advice for disabled students.

## Advanced cancer and end-of-life care

### Hospice UK

Tel **020 7520 8200**

**[www.hospiceuk.org](http://www.hospiceuk.org)**

Promotes hospice care and provides information about living with advanced illness for individuals and their families. Also provides free booklets and a directory of hospice services in the UK.

### **Marie Curie**

Tel **0808 090 2309** (Mon to Fri, 8am to 6pm,  
and Sat 11am to 5pm)

**[www.mariecurie.org.uk](http://www.mariecurie.org.uk)**

Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices. The charity offers information and support for people living with a terminal illness and their families. Also runs an online chat service, which is available during the Support Line opening hours.

## **Support after the death of a loved one**

### **Child Bereavement UK**

Helpline **0800 02 888 40** (Mon to Fri, 9am to 5pm)

Email **[support@childbereavementuk.org](mailto:support@childbereavementuk.org)**

**[www.childbereavementuk.org](http://www.childbereavementuk.org)**

Supports children and young people up to the age of 25 who have lost someone close to them. Provides confidential support through a helpline and live chat on the website (available during the helpline opening hours). Runs support groups and has developed a special app and game to help you cope with the death of a loved one.

### **Grief Encounter**

Helpline **0808 802 0111** (Mon to Fri, 9am to 9pm)

Email **[griefftalk@griefencounter.org.uk](mailto:griefftalk@griefencounter.org.uk)**

**[www.griefencounter.org.uk](http://www.griefencounter.org.uk)**

Offers a service called 'griefftalk'. Children and young people who have lost a parent, brother or sister can call, email or have an instant chat with a trained counsellor. Runs a support programme for bereaved families, produces grief relief kits including memory making materials and provides e-counselling.

### Hope Again

Tel **0808 808 1677** (Mon to Fri, 9.30am to 5pm)

Email **hopeagain@cruse.org.uk**

**www.hopeagain.org.uk**

Designed for young people by young people, Hope Again is the youth website of Cruse Bereavement Care. It supports young people across the UK after the death of someone close. You can find information about coping with grief, learn from other people's experiences and send a private message to a trained young supporter.

### Winston's Wish

Tel **0808 802 0021** (Mon to Fri, 9am to 5pm)

Email **ask@winstonswish.org**

**www.winstonswish.org.uk**

Helps children and young people throughout the UK re-adjust to life after the death of a parent, brother or sister.





## Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date, but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

## Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It is based on content originally produced with support from the Arden Cancer Network's Young People's Group; the Oxford City Young Carers' Project Forum; the Spiral Children's Bereavement Service in Nottinghamshire and the South Tyneside Young Carers' Group. The booklet has been approved by our Chief Medical Editor, Prof Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Sarah Gregory, Macmillan Senior Policy Adviser (Social Care and Carers); Helen Hall, Young Carers Practitioner, Family Action; Marie Shotbolt, Young Carers Coordinator, New Forest Young Carers Service; Helen Sanderson, Thinkaboutyourlife.org; and Rachel Smith, Young Carers Project Manager, The Bridge Young Carers Service (County Durham), Family Action.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories. This includes Amy, who is on the front cover. She helped look after her father Pete when he was diagnosed with prostate cancer. Sadly, Pete died in 2019. We'd like to thank his daughter for allowing us to continue sharing his story, so others can benefit from Macmillan's support.

We welcome feedback on our information. If you have any, please contact **[cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)**

## Sources

Below is a sample of the sources used in our information for young carers.

If you would like more information about the sources we use, please contact us at **[cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)**

Carers Trust. [www.carers.org](http://www.carers.org) (accessed April 2020).

Carers UK. [www.carersuk.org](http://www.carersuk.org) (accessed April 2020).

The Children's Society. [www.childrenssociety.org.uk](http://www.childrenssociety.org.uk) (accessed April 2020).

Mind. [www.mind.org.uk](http://www.mind.org.uk) (accessed April 2020).

NHS. Being a young carer: your rights. Available from [www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/being-a-young-carer-your-rights](http://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/being-a-young-carer-your-rights) (accessed April 2020).

# Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

## 5 ways you can help someone with cancer

### **Share your cancer experience**

Support people living with cancer by telling your story, online, in the media or face to face.

### **Campaign for change**

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

### **Help someone in your community**

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

### **Raise money**

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

### **Give money**

Big or small, every penny helps. To make a one-off donation see over.

**Call us to find out more 0300 1000 200**  
**[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)**

## Please fill in your personal details

Mr/Mrs/Miss/Other

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Surname

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Postcode

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Email

Please accept my gift of £  
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I enclose a cheque / postal order /  
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OR debit my:  
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Card / Switch / Maestro

Card number

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Expiry date

Issue no

Security number

Signature

Date / /

## Do not let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box.

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online  
go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)



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Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

**This guide is about looking after someone who has cancer. It is for young people under the age of 18. There is also some useful information for young adult carers.**

**The guide explains what it means to be a young carer and how to get support. It also has tips to help you look after yourself and cope with practical, emotional and financial issues.**

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

**MACMILLAN  
CANCER SUPPORT**

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Patient Information Forum