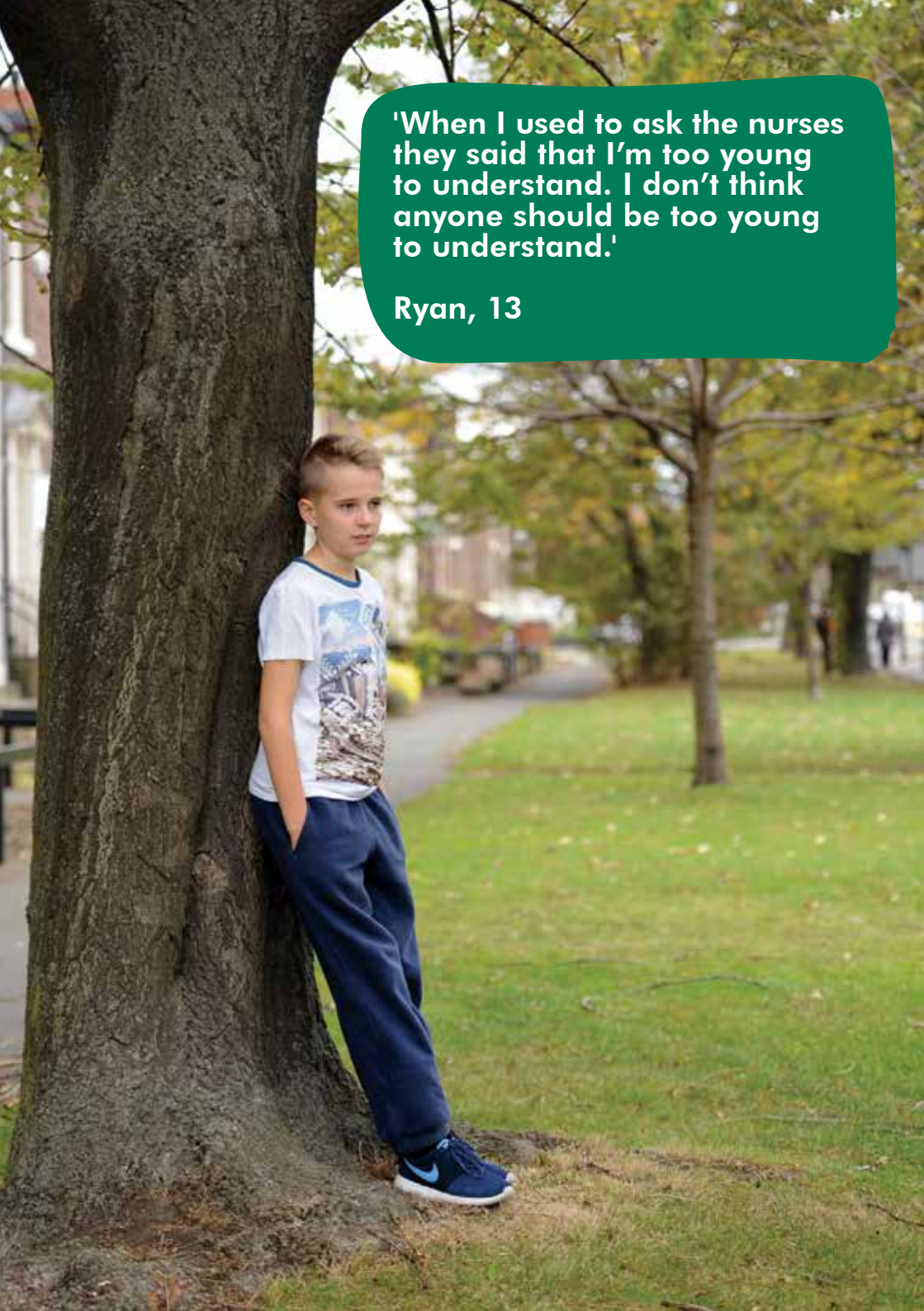


A GUIDE FOR YOUNG PEOPLE LOOKING AFTER SOMEONE WITH CANCER



A young boy with short brown hair is leaning against the thick, textured trunk of a large tree. He is wearing a white t-shirt with a colorful graphic of a cityscape, dark blue trousers, and blue and white sneakers. He is looking off to the side with a thoughtful expression. The background shows a grassy park area with other trees and a path in the distance.

'When I used to ask the nurses they said that I'm too young to understand. I don't think anyone should be too young to understand.'

Ryan, 13

Welcome

Hello. And welcome to our handbook. We've put it together, along with Macmillan Cancer Support, to help young people aged under 18 who are looking after someone with cancer.

Why? Because we've been there ourselves.

It may be your mum or dad who has cancer. Or your brother or sister. It could be a friend, grandparent, aunt or uncle.

You may be angry, shocked or frightened. You may be thinking, 'Why me?' or, 'Why them?'

We've been there. And we came through it. That's why we wanted to share our experiences with you, so you know that there are people you can turn to. And that there are things you can do to look after yourself.

We've split this guide into chapters, so you can dip in and out. Or you can read it all in one go if you like. If there's something you'd like to know more about, there's a list of websites and organisations that can help on pages 99–104.

We hope this handbook answers some of your questions. And remember, there are lots of people you can talk to when the time is right for you.

From the 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.

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ABOUT CANCER

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The big C word. Cancer. It's probably ruling your life right now. You may be blaming yourself.

'If only I'd spoken up about smoking.' 'If only I'd encouraged them to be healthier.' 'Maybe I could have stopped them getting cancer.'

That's what we thought too. But the fact is, anyone can get cancer. And it's not your fault.

If someone in your family is having treatment for cancer, you might want to know more. You could ask to speak with their doctors, as long as the person with cancer gives their permission.

To make things even clearer, check pages 84–91, where you'll find a list of some of the medical professionals you might meet, and a list of medical words the doctors and nurses might use.

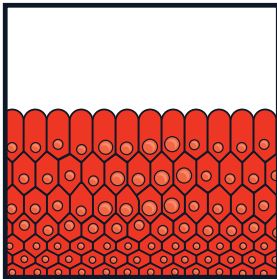
What is cancer?

Our bodies are made up of billions of tiny parts that fit together like building blocks. These parts are called cells.

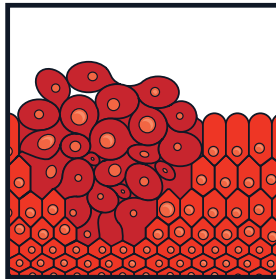
When cells are healthy they grow and divide. Eventually they get worn out and die. This is a normal process and it usually happens all the time without any problems.

Cancer occurs when this process gets out of control. Cancer cells divide too much and they don't die when they are supposed to. They form a lump called a tumour. The tumour can damage the healthy cells surrounding it, making the person ill.

Normal cells



Cells forming a tumour



A tumour can form inside:

- an organ. This is part of the body that does a specific job, such as the liver or kidney
- a bone
- the blood. When a tumour forms here, this is a type of cancer called leukaemia
- the lymphatic system. This is a network that helps defend your body from disease. When a tumour forms here, the type of cancer is called lymphoma.

Cancer cells from the tumour may spread to other parts of the body after a while. That's why having treatment as soon as possible is important.

There are more than 200 different kinds 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 to find out whether it has spread in the body. This helps the doctors plan the right treatment for each person.

Are you worried about getting cancer because someone in your family has it?

Many people worry about getting cancer. Sometimes they worry because someone in their family has had cancer, and they think it will be passed on from one generation to another (inherited). In fact, fewer than 1 in 10 cases of cancer (less than 10%) have been shown to be due to a family history of the disease.



Fewer than 1 in 10 cases of cancer have been shown to be due to a family history of the disease.



BEING A YOUNG CARER

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Am I a young carer?

You may not think you are. But if you are under 18, and you spend time looking after someone who is ill, then you're a young carer.

As a young carer, you might do extra things to help your family – stuff that your friends won't necessarily be doing. Things like:

- cleaning the house
- doing the food shopping
- making cups of tea
- fetching things for the person with cancer, for example their slippers
- going out with the person who is ill, for example to help them with shopping
- doing the laundry
- making dinner
- washing the dishes
- looking after your brothers or sisters.

You may also be asked to do other things for the person who has cancer. You might help them get dressed, give them their medicines or change their bandages.

You may comfort them when they are upset, or be there to listen when they need to talk.

How being a young carer can change things

Being a young carer can affect your life in many ways. It can make you feel different, but that's okay. You may find that you can't concentrate at school or college, and that you don't have as much time to study. It might be hard to keep up with your friends. You may have to cancel plans because you need to look after the person who has cancer. Sometimes it can feel like being a carer has taken over your life.

You may also be worried about what is happening at home. You may feel angry with the person you're looking after. You may feel like you aren't being given enough attention, and then feel guilty for feeling that way.

Being a young carer can be really hard. It can feel like a big responsibility. But positive things can also come out of the experience. You may become closer to the person you care for, learn new skills and feel more grown-up.

'At least when I got to uni I knew how to work a washing machine!'

Aphra, 18

Looking after yourself

It's very important to remember to look after yourself. You may feel overwhelmed by everything that's happening. But you should only ever take on as much as you can handle.

Here are some of the things that helped us.

Talk to someone

You could talk to a friend, a teacher or another family member. Or you may want to join a support group. Young carers' projects (see page 50) can support you and give you time out from caring. The young carers' workers can also talk to professionals and your school on your behalf. They have groups where you can meet other young carers. You can chill out and no one will ask you why you're a young carer. Go to **babble.carers.org** to find one close to you. You can also chat with other young carers and with online support workers, who can give you information and advice.

Find a website or organisation that can help

There are details of lots of other organisations that can help you on pages 99–104.

Let your school, college or work know

You may want to let your school, college or workplace know what's going on. There may be times when you need extra help with your work, or when you need time off. Try and be honest about what is happening and the situation at home. That way, your teachers can support you.

Make time for yourself

Try to do things you enjoy. They can help you take your mind off the situation. See page 60 for some suggestions of things you could do.

Remember, you're still allowed to enjoy yourself and you don't need to feel guilty for wanting your own life.

Let people know what you're comfortable with

If you don't feel comfortable doing something as a young carer (for example, taking the person who has cancer to the toilet), you should tell someone. Another family member or friend might be able to help with those things. If there isn't anyone else around who could help, or you don't feel like this is something you can speak about at home, you could try talking to a health and social care professional. They should be able to arrange for you to get some support. See pages 84–86 for a list of health and social care professionals you might meet. You can talk to any of them.



FEELINGS

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Finding out that someone close to you has cancer can cause many emotions. A lot of people say that their first reaction was: 'What's going to happen? Will they recover?' and then, 'Are they going to die?' You may be dealing with all kinds of emotions.

We felt frightened about the future and upset that this was happening to someone we loved.

You may feel:

- sad, exhausted or stressed from the extra things you're doing
- angry with the world, or with the person who has cancer
- guilty, even though what's happening isn't your fault
- really worried or down.

These are just some examples of how you may be feeling, but everyone is different. Feelings like these are natural when someone close to you has cancer.

'No matter how bad the situation, remember there is always a light at the end of the tunnel. Tough times bring out the strongest people.'

Rima, 16

Feeling up one minute and down the next (mood swings)

Every day is different when you're caring for someone with cancer. You'll probably wake up wondering if it will be a good day or a bad day.

Because you're going through such a confusing time, you may find you get mood swings. One minute you'll be laughing with your friends, and the next you could burst into tears. This is perfectly normal. It can be hard to deal with every situation as it happens, and often your feelings hit you much later.

It can be difficult to explain your mood swings to people who don't know that you're affected by cancer. You don't have to explain your situation to anyone if you don't want to. It's often helpful to share what you're going through, but it's your business. You should only talk to people about it if you trust and feel comfortable with them.

Writing down your feelings

You may like to use the table on the next page to write about your good and bad days. This may help you decide on steps you can take to have more good days.

This table and the one on page 27 come from the website **thinkaboutyourlife.org**, which was created by people who have lived with cancer. The website has examples, stories and support to help you use the tool.



Good days

Bad days

Next steps

Letting people know how you feel

Try not to hide your feelings all the time. You might decide to try not to get upset in front of the person who has cancer in case you worry them, and that's fine. But make sure you're not dealing with it on your own. Talk to your friends, if you can. Or talk to someone else in the family. You may find that they want to share their feelings with you, too.

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

Sara, 18

You don't have to talk to someone if you're not comfortable speaking with them. If you don't feel comfortable talking to someone close, then maybe a young carer worker (see page 50) or an adult at school or college could help. It doesn't have to be your form tutor or even someone who takes you for lessons – it may be the school nurse or a teaching assistant. You can also chat online with support workers or other young carers at **babble.carers.org**

There may be a local young carers' support group you could join. Ask around at school or college. Or see the 'support for carers' section on pages 99–100 for some organisations that can help. It can be easier to make friends with other young carers when you all have something in common, like going to the same school.

There are also plenty of people you can phone. The Macmillan Support Line on **0808 808 00 00** is free and has trained specialists who can help. They can answer your questions about cancer, or just be there to listen if you feel like talking to someone about how you're feeling.

It's often helpful to share your feelings, but if you don't want to deal with how you're feeling right now, that's okay too. Do what works for you, and remember, help is there when you feel ready for it.

'As a young carer I feel both happy and sad.'

Maisie, 10

Coping with other people's feelings

It can be hard to see adults getting upset in front of you. You may not have had to deal with it before. You may feel weird or helpless, or you might not know what to say.

The best thing we found was to just be there. Be there to listen if they need to talk. Be there with a cup of tea if they get upset. And it's important to be there for the good days, too.

Just as you need to take your mind off the situation, so does the person with cancer. Watch a DVD together. Play a board game (if they are up to it) or do a jigsaw. They will really appreciate just doing something normal and spending time with you.

If you have brothers or sisters, they'll also probably get upset. If you are older, part of your role as a young carer may be to look after your siblings. This might include talking to them and comforting them. It's not always easy to know what to say or do, but just doing your best to look after them is good enough.

Often families say that something like cancer brings them closer together. But if you aren't close to your brothers or sisters, it can sometimes make you feel alone. It can also be a lot of pressure and your family may get angry or fight more. Try not to let it get to you. If you feel like you need to talk to someone, you can always contact the Macmillan Support Line or the other useful organisations listed on pages 99–104.

Remember that everyone is different, and there is no right or wrong way to feel or behave.

'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.'

Michael, 16

Depression

It's not unusual for people to feel very low after being told they have cancer, and during or after treatment. Many people feel physically and emotionally exhausted from the treatment. This can make them feel low. However, for some people affected by cancer, their low mood may continue or get worse and they may need specialist help or treatment. Some people find that their mood is low most of the time for several weeks or more. This may mean that they have depression.

It's important to recognise that depression isn't anybody's fault. Depression is an illness that needs to be treated, just like cancer. If you're worried the person you are caring for may be depressed, try to talk to them about it. Or talk to another adult. It's important that the depression is diagnosed and treated.



If you want to know more about depression, you can call the Macmillan Support Line on 0808 808 00 00

Counselling (support if you'd like to talk about your feelings)

If you're struggling to cope or feel low, then it might be a good idea to see a counsellor. They are trained to help you understand your feelings so that you can cope better.

You can go to your GP and ask to be referred to a counsellor. There might also be a counsellor at your school or college.

If you do see a counsellor, you can decide how much you would like to share with them. Anything you tell them will be confidential.

You may feel embarrassed about needing to talk to someone when it seems as though other people don't need to.

But counsellors are there to help. You may find it helps to talk to somebody who isn't directly involved in your situation. If you're angry with someone or frustrated, you can talk about it to the counsellor without upsetting anyone.

If you decide that the counsellor is not the right person to help you, say so. Perhaps you could speak to someone different. Your GP, teacher, or whoever referred you to the counsellor, may be able to arrange for you to see a different counsellor. You shouldn't feel bad about asking for this, as it's important that you trust your counsellor and feel comfortable with them. Have a look at the organisations on pages 99–104 for more ideas about who to talk to.

Hopes and fears

You may like to use the tool on the opposite page to write down your hopes and fears. This might help you talk to other people about what is frightening you.

Even if you don't want to share it with other people, you may still find it useful to write down your hopes and fears. There's also space for you to think about the next steps you could take that may help with your concerns.



Did you find these tools useful? Let us know at cancerinformationteam@macmillan.org.uk

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

Jenna, 17



Hopes



Fears

Next steps



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Relationships play an important part in all our lives.

You may find that while you are looking after someone who has cancer, your relationships with friends and family will change. Try not to worry about this. All relationships change and develop over time. Think back to when you first started school. Who was your best friend? Is it still the same person? Some relationships drift away over time, while others grow stronger. You'll probably experience both.

'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.'

Laura, 14

'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.'

Sapna, 16

Friends

Talking to friends about cancer can be scary. We all reacted the same way at first. We hid away. We were in shock. We needed time to think things through. You might have done that, too.

When we did talk to our friends, we thought that they wouldn't understand what we were going through. But we were wrong.

If you decide to talk to your friends about your situation:

- you'll have someone to talk to when you're stressed without feeling guilty
- you won't have to make excuses if you cancel on them
- they'll know to back off if you're having a bad day
- you're less likely to bottle things up.

You may not want to tell all your friends straight away. But talking to one or two very close friends is a great place to start. You might have best friends who you feel you can turn to, or other friends who you feel would be the most supportive. Talking to supportive friends can help you to feel normal, which is really important.

Be prepared that your friends may react differently – no two people are the same. Some people will take it in their stride. Others may not know what to say to you. They may need time to take it in, just as you did.

Family

It's likely that the person you're helping to care for is your mum or dad, your brother or sister, or one of your grandparents – perhaps 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 work through it together. We found talking to each other and spending time together as a family helped.

Try to do all the normal things you did before. Don't feel bad if you have arguments with your family, including the person you're caring for. This is a normal part of family life.

It's also important not to do everything for the person you are caring for. They'll still want to be independent if they can.

Other members of your family may also want to help, so don't feel like you have to do everything yourself. There are lots of ways that they can lend a hand. Tidying the house or doing the shopping will give you a break, and help them feel that they are supporting you. Remember that you don't have to do anything you don't feel comfortable with. For example, the person you look after may need help getting to the toilet. If you feel uncomfortable about helping them, you should talk to them or another family member about it. You could talk to a health and social care professional instead if that's easier.

'No one mentioned it in the house at all. I think we didn't want to upset each other.'

Sasha, 12

Boyfriends and girlfriends

If you have a boyfriend or girlfriend, they may be someone else you can talk to about your situation. Spending time with them, for example going to the cinema or listening to music together, can also give you a break from being a young carer for a while. You could even ask them to help you with the extra stuff you have to do at home. They might help carry the shopping, mow the lawn, or take the dog for a walk. Don't be afraid to ask them for support.

Being in a relationship can be fun and exciting. But if things aren't going well, or if you split up, it can really hurt. This can be an added pressure if you're caring for someone who has cancer.

You may feel guilty for getting upset about your relationship. You may feel that you can't talk about it at home because it seems unimportant compared to what your family is going through. But what happens in your life is still important. You're allowed to have feelings about things other than cancer. Cancer may be a huge part of your life right now, but it's not your whole life. If you get upset about your relationship but don't want to talk with your family about it, find a close friend or professional to talk to.



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For some of us, going to school was a welcome relief. It meant that we could see our friends and forget about our problems for a few hours. For others, going to school meant that we were away from the person that we were caring for, and it made us worry.

Some of us got bullied at school, which was horrible. But all of us agree that if you tell your school that you're caring for someone with cancer it will be far easier to get support if you need it.

Some things you might be worried about include:

- getting to school on time
- finding it difficult to concentrate
- completing homework and keeping up with work
- finding it hard being away from the person you look after.

Telling your school about your worries or problems can help them support you. If you think it would help, you could always ask your school if you can contact the person you help look after during lunchtimes.

Homework

As a young carer, you may find that you don't have as much time to do your homework as you did before. After school, you may be cooking meals or doing housework or you may just not feel up to it. Try to take each day as it comes. If you're finding it hard to concentrate at home, is there another place that you can go to do your work? Maybe a relative or friend's house? Some schools have homework clubs, too.

If you're worried that you might be falling behind, you can ask a young carer worker (see page 50 to find one) or a family member to talk to your school about your homework. It may be possible for the school to look at the amount of work that they give you, to make it easier to handle.

Teachers

You'll probably have a few favourite teachers. And you may have a few that you really don't like. You may not want to tell your teachers that you're helping to care for someone, but if they know, they may be able to help you. If you prefer, tell other members of staff at the school who you trust.

Missing school

Finding the time to balance caring and going to school can be hard. Sometimes you may feel like you need to take a day off to look after the person you look after. Or you may struggle to get into school on time. If these things happen, speak to a teacher or someone who works at your school. They should be able to arrange support for you or the person you care for, so that you don't need to miss school. If you don't feel comfortable talking to the school yourself, you can ask a family member or young carer worker to do this for you.



Bullying

Bullies pick on people who are different to them. If you're a young carer, you may find that you are the target of bullying.

If you're being bullied because of your situation at home, it's important not to blame yourself. Talk to someone about it. Tell your school. Perhaps they could arrange to teach a lesson about cancer. It may help your classmates and teachers understand more about your situation.

You could tell your teacher about the website **kidscape.org.uk/beingme** where they can download a young carers' teaching resource, created by Kidscape and Carers Trust.

'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.'

Ryan, 13



MONEY AND WORK

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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. And 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 – things like travelling to hospital. These changes to the family can affect you if you're a young carer. But there is help available if you or your family are having money problems because of cancer.



Benefits and financial help

The government makes payments to people in need. These are called benefits. If the person you care for is getting certain benefits, and you're over 16, you may be able to get a benefit called Carer's Allowance. This is paid to people who look after someone for 35 hours a week or more.

To find out more about Carer's Allowance and other benefits:

- call Macmillan on **0808 808 00 00**
- find out if you can speak with a social worker about getting a carer's assessment – where they chat with you about financial and practical help you might need (see page 51)
- find out more about benefits online at **gov.uk** (if you live in England, Scotland or Wales) or **nidirect.gov.uk** (if you live in Northern Ireland).

The person with cancer could also call Macmillan to find out more about Macmillan Grants. These are one-off payments to cover a wide range of practical needs. They are for the person who has cancer. They can include things such as heating bills, extra clothing, or a much needed break. The person with cancer has to apply for them through a health or social care worker.

If you work

If you're working, even if it's just part-time, you may decide to tell your boss or someone else at work that you're helping to care for someone with cancer.

Here are some reasons why you may want to tell them:

- If you get upset at work, they will be better able to support you.
- They will understand if you have to miss work.
- They may be able to give you time off, or arrange for you to work flexible hours.
- If you work shifts, they could arrange your shifts to fit around your chores at home.
- Depending on what job you do, you may be able to do some work at home.

You may be worried about telling your boss, in case they think you can't do your job properly. You may think that you'll lose your job if you tell your boss that you are a carer. In the UK, if you're the main carer for someone who has cancer, it's against the law for anyone to treat you badly at work because of your circumstances.

Of course, you may choose not to tell anyone at work that you are a young carer. Some of us didn't, because we wanted to go to work and just be normal. We found that having a part-time job was a good chance to get out of the house and do something for ourselves. We wanted to have somewhere we didn't have to think or talk about cancer.

Time off work

If you're the main carer for someone who has cancer, you could be entitled to paid or unpaid leave from work to look after them. You can find out more at **[macmillan.org.uk/legalrights](https://www.macmillan.org.uk/legalrights)**

You can also call the Macmillan Support Line on **0808 808 00 00** to speak to a cancer support specialist. They'll be able to talk you through what time off you're entitled to at work.





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When we were helping to care for someone with cancer, we weren't too sure how to get information about cancer, or about being a young carer. We went on the internet and searched for things, but we often ended up on random websites that gave us no information.

That's why at college a few of us started our own support groups. We wanted a way to share information, and to help each other cope with the different feelings we were having.

'No matter how bad a time you are having, never give up.'

Liam, 14

Support groups

Support groups are a really good way to relax and chill out. They give you a chance to meet up with other young people like you – people who understand you and will be there for you on the bad days as well as the good ones.

Your school or college may already have a support group. Or your local council might have set one up. Ask around, or look online to see if there's one in your area. There are some website addresses that can help you do this at the back of this booklet – see pages 99–104. Support groups aren't scary – they're fun. Most of the time we sit around chatting and being ridiculous. Sometimes we talk about cancer, but not always.

If there isn't a support group that you can go to locally, you can set one up. And now support groups like ours are being set up right across the country.

Macmillan can help you start your own support group, with advice, training and grants. There is more information and a search tool to find local support groups at **macmillan.org.uk/supportgroups**

You could also encourage your school to set up a support group. Your teachers can get help doing this from the Carers Trust website – **professionals.carers.org/young-carers**

Young carers' projects

These projects are run by young carer workers and offer:

- a chance for you to have a break and do something fun
- opportunities to talk to other young carers
- the chance to speak with someone who will listen to you and who is on your side
- help, information and advice for your whole family.

Go to **[youngcarer.com/young-carers-services](https://www.youngcarer.com/young-carers-services)** to find a young carers' project near you.

Social workers

A social worker is someone who helps people sort out their practical and financial problems. Not everyone has access to a social worker, but your family might have been given one. This might be to help you all cope with caring for someone who has cancer. Social workers are a really good source of information. If you have any questions or worries, you can talk to them.

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

Young carers' assessment

You may be able to have an assessment with a local social worker. From April 2015, the law in England is changing so that all young carers are entitled to this assessment.

This isn't a test – it's just a chat to find out what kind of extra support you may need. It could be useful, for example, if you're struggling to find time to go to school or meet up with your friends. The laws that say you can get this assessment are called the Care Act 2014 and the Children and Families Act 2014.

If you live in England, Scotland or Wales, visit **nhs.uk** and search for 'young carers' for more information about assessments. Or if you live in Northern Ireland, you can visit **nidirect.gov.uk/young-carers**

Charities

There are lots of charities in the UK that can help you, whatever your situation.

Cancer charities that can help include:

- Macmillan Cancer Support offers practical, emotional and financial help for anyone affected by cancer.
- Cancer Research UK is trying to find the causes of cancer. It can give you lots of information about different types of cancer.
- Marie Curie Cancer Care gives free nursing care to people with cancer at home.

There are also charities for particular types of cancer.

There are charities just for young people, like the Children's Society.

Charities like the Carers Trust and Carers UK are there for anyone who looks after an ill person.

All of these charities can give you information. They can also help you get the support you need.

See pages 99–104 for the contact details for these charities.

Online forums

Joining an online forum can put you in touch with loads of people who are in the same situation as you. Some examples are **[babble.carers.org](https://www.babble.carers.org)** and, if you're aged 16 or above, **[matter.carers.org](https://www.matter.carers.org)** The best things about forums are that you:

- can be anonymous
- can dip in and out when you want
- don't have to tell people anything you don't want to
- don't have to use them at set times
- can make new online friends.

There are plenty of forums for carers, for people affected by cancer – whatever best suits your situation, really. Just remember when you are using forums that you must stay safe:

- Avoid using your real name – make up a nickname instead.
- Avoid giving out personal information, for example which school you go to or where you live.
- It isn't a good idea to meet someone that you have met in a forum – they may not be who they say they are.

At the end of this booklet, we've listed lots of organisations and websites that can help – see pages 99–104.



LOOKING AFTER YOURSELF

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Eating – food and your feelings

Yes, we know it's obvious, but you must remember to eat. And eat healthily. Some of us didn't feel like eating because we were so worried, we felt sick. And some of us ate a lot as a way of coping.

Being a young carer can be very hard, both physically and mentally. You may be having a bad day, or be too busy to bother about food. But your body needs food for energy. And you need energy to care for someone who is living with cancer.

If you feel like you're having any problems with eating or your diet, you should talk about it with someone you trust.



Sleeping

When we were helping to care for someone with cancer, we could have done with a lot more sleep. This was for lots of reasons, but the main one, and the one we all shared, was worry.

It can be hard to switch your brain off at night. Your head hits the pillow and your mind goes into overdrive. Thinking about the person who is ill. About what will happen in the future. And all that worrying keeps you awake.

You may also find that there are people coming in and out of your home at different times, and that can be a distraction if you are trying to get to sleep. Or it could be that the person you're caring for is having a bad night, which then keeps you awake.

Here are some things we did to try to get a good night's sleep:

- Read a book. It will focus your mind on something other than cancer before you go to sleep.
- Have a bath. If you like, you could add something like lavender oil or a bath soak that can help you to relax.
- Light some candles.
- Have a warm drink.
- Listen to relaxing music.
- Write a diary. If you get all your thoughts out on paper, they won't be quite so busy in your head.

'My room became a sanctuary – somewhere relaxing just for me.'

Sara, 18



Making time for you

It's easy to feel guilty or selfish about going out and having fun. We all did. We worried that, if we went out to see our friends, something might happen to the person that we were caring for. And we felt guilty for having a good time when someone so close to us was ill.

It's important, for your own sake, that you make time for yourself to do the things that you like doing. Things like:

- playing sport
- spending time with friends
- watching your favourite TV programme or film
- painting or drawing
- playing an instrument or singing
- listening to music
- walking the dog.

If you're worried or feel guilty about going out, talk to the person who you are caring for. Let them know how you feel. It's likely that they will want you to go and have fun. They will want to see you happy, because they love you.

Drink and drugs

Sometimes people use drugs or alcohol to block out their feelings when they're stressed or upset.

If you think that you're drinking too much, or if you are taking drugs to help you cope with what is happening in your life, you should try to get help as soon as possible. Try talking to friends and family. Or if you don't feel comfortable doing that, there are lots of helplines and groups you could go to for support. Their phone numbers are on pages 99–104.

You may want to go to your GP, who can offer counselling and support.

Perhaps there are other things you could do to help you relax. For example going swimming, or going for a walk. Change your routine so that you're not thinking about alcohol or drugs at certain points of the day. And if your friends are encouraging you to drink lots or take drugs, it could be time to rethink who you hang out with.

'I started doing solvents. From 11 until I was 14 I was looking after my mum and didn't quite realise how much it was affecting me, because I just put it to the back of my head.'

Frankie, 19



TALKING TO DOCTORS AND NURSES

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When you're looking after someone with cancer, you'll probably meet a lot of doctors and nurses. This could be in the hospital, or at home.

If you turn to pages 84–86, you'll find a list of pretty much everyone we could think of. You could take this booklet with you when you go to the hospital, so you can refer to it each time you meet someone new. It will help you understand their job and ask them the right questions.



Asking questions

If you want to know about the health of the person you're caring for, doctors and nurses are the best people to ask. They are treating the person who has cancer, so they have all their medical notes. If they have permission from the person you're caring for, it's very likely they'll be happy to talk to you.

It can sometimes be difficult approaching a doctor or a nurse, because they might seem very important and busy. But doctors and nurses will usually be happy to talk with you and help if they can.

We found it useful to write down any questions we wanted to ask so we had them all ready to ask when we spoke to the doctor or nurse.

If you feel shy or nervous, you can ask an adult to speak to the doctor or nurse for you. Sometimes you may meet support workers or health assistants in the hospital, and you can always ask them too.

'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.'

Cerys, 13

Making sure you're included

Some of us found that the doctors and nurses talked directly to the adults, not to us.

This was really annoying, as it made us feel like our questions, thoughts and experiences didn't matter. Here we were, helping to care for someone with cancer, and we felt invisible.

If you find this happening to you, speak up about it. Talk to an older family member, so that they know you're feeling left out. That way, they can try to include you next time you are with a health professional.

'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.'


Abdul, 12

Who else can give me information?

There are other people who can tell you a bit more about different kinds of cancer and their treatments. For example, the Macmillan Support Line has qualified cancer nurses on the end of the phone. They can talk you through things like chemotherapy, and let you know what to expect. Call **0808 808 00 00** if you'd like to speak to a nurse.

'I wanted to be told more and not be cut out.'

Jak, 12



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.'

Siana, 14

COPING WITH DEATH

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Not everyone who has cancer dies from their illness. Many people make a full recovery. But if someone you love does die of cancer, it feels like the end of your world. And it will take a long time for life to feel in any way 'normal' again.

Before you read this chapter, we just want you to know one thing. It may be the worst time in your life right now, but it won't last forever. You will get through this.



Facing reality

Those of us who cared for someone with terminal cancer found it easier when everyone was honest. Being honest – about everything – can make it less frightening for everybody.

However, if the person you're caring for has been told that they are going to die, it can be hard to accept. This is called denial, and is a normal reaction.

'My mum drank because she couldn't cope with the fact that she was going to die.'

Rhiannon, 16

If the person with cancer or another family member is in denial, it can be very hard to communicate with them. There are certain things that they may not talk about. While it may be upsetting for you, denial is a strong coping tool and needs to be respected. Some people will eventually accept their situation, but some choose to stay in denial. If that happens, try to accept it.

Before they die, the person you're caring for will get very ill. Try to be prepared for this, as it will be upsetting. This is a good time to ask lots of questions, so that you know what to expect.

If they get very ill, or if your family decides that they can't cope or need a break, the person may go into a hospice. A hospice is a bit like a hospital. They have special palliative care nurses who provide pain relief for the person who is ill, and help the person and their family cope with their feelings.

Some hospices will let you stay overnight from time to time. If you would like to do this, ask a family member or one of the nurses if this is possible.

Talking to the nurses and doctors can help a lot at this stage. Nurses who provide palliative care (special care at the end of life) to people with cancer will know what you are going through, and they can help you to make sense of what is happening.

People may think that, because you're young, they need to protect you when someone dies. In our experience, that is the worst thing to do. Some of us felt our family took away our choices. We weren't allowed to make decisions for ourselves, and that was really frustrating. If this happens, a young carer worker could speak to your family, or the hospice or hospital staff for you.

Be honest with your family about what you want. If you want to be there at the end, make sure people know that and they respect your right to do so.

If you'd rather not be there, that's okay too.

When it happens

If you've decided that you want to be there at the end, knowing what to expect can help to prepare you.

When someone is dying, they can often still hear you, even if they can't respond, so keep talking to them.

The moment of death is not always recognisable, but there are some physical changes or actions that you may notice. Their body may relax completely and they may look very peaceful. You won't know how you will feel until this happens. Some people say they feel relieved that the person is at peace.

The funeral

Your family will usually start planning the funeral quite quickly. You may have a funeral director or a religious leader come to your home. They'll want to talk to you about the person, and share your memories. You may find that this helps you feel better, because you're talking about the good times that you had.

If you want to get involved with the funeral, make sure you tell your family. The way the funeral happens will depend on your family's culture and beliefs. Depending on the type of funeral, and your family's wishes, it may be possible for you to read a poem, do a special reading, or simply talk about the person. Tell the person who is responsible for planning the funeral that you'd like to do this, to find out what's possible.

If there will be music played at the funeral, maybe you could help to choose it. Or perhaps there's a special wish that the person told you about – make sure you let someone know.

If you don't want to go to the funeral, or you're not allowed to go, there may be other ways that you can say goodbye. Perhaps plant a flower, or a tree. You could tie a message to a balloon and let it go. If there's a special place the two of you used to go, perhaps you could visit and say a few words.

What happens now?

When it's all over, life at home can feel really flat. This is especially true if the person who has died was being cared for at home.

Some of us had nurses coming round to help out, or other family members coming to visit. So it felt very quiet for a while until we adjusted to the new situation.

Give yourself plenty of time and space, and don't put too much pressure on yourself.

You may worry that you can't talk about the person who has died to your family, in case it upsets them. Make sure that you do find someone who you can talk to. It could be a cancer support group, or a trusted friend. Maybe you could talk to a young carer worker or a counsellor. Just make sure you don't keep your feelings to yourself.

You may also need to sort through the belongings of the person who has died. This can be very upsetting, and feel very final.

You might not want to do this for a while. That's okay. Make sure you talk to the rest of your family, and try to agree with them when would be a good time.

If there is anything you'd like to keep, such as a watch, a ring, or photographs, then speak up.

Feeling sad because someone has died (grief)

The most important thing to remember about grief is that it affects everyone in different ways.

Some people cry a lot. Other people keep themselves busy. Some people feel angry. Try to understand that everyone will cope in their own way.

Your grief is unique to you. It may come and go in waves. You will have good days, and bad days.

Some of us found it helpful to get back to our usual routine quite quickly. But a few of us took a long time before we were ready to face the world again.

Try to make sure that you don't cut yourself off from life. It can be harder to adjust if you've been out of school or college, and away from your friends, for a long time.

If you feel that you want to stay connected to the person who has died, there are lots of ways you can do this. Write them a letter (it might sound silly, but it works). Or perhaps you could put together a memory box. Maybe there's a favourite photo that you could put in a frame.

Don't be afraid to talk about the person you have lost, whether it's little stories or talking about their cancer. And don't worry if you go over and over the same stories – it's good to remember.

Eventually, your grief will lift. You'll have fewer bad days. And you'll start to feel like a normal person again.

There are charities who can help if you're coping with grief. Turn to pages 99–104 for details of some organisations you can contact.

'Having a memory box helped me to cope better after losing my dad. At first when I opened it, it made me sad. Now as time has gone by, I can smile when I open my memory box.'

Siana, 14

'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.'

Jamal, 15



LIFE AFTER CANCER

Moving on

81

When you've been a young carer, it's very strange when it comes to an end. For some of us, our situation meant that the end of caring was immediate and final. Some of us had less certainty. But for all of us, our lives had changed forever.

When you stop being somebody's carer, you might find that you have a lot of time on your hands. It may make you feel quite down. Or you may get ill, because stress catches up with you. Give yourself some time to recover. You've been through a lot.

It may be that the person you've been caring for has got better, and they don't need as much support any more. It can be tempting to try to keep on caring for them in the same way. But you should give yourself a break – you deserve it. And after all, they will probably tell you if they ever need some more help.

You might want to fill your time with a new hobby. Many of us became volunteers, so that we could put our skills and experiences as carers to good use. We found that we were stronger people. We were able to do things that other people couldn't do. We were emotionally more mature.

And soon, our lives started to get back to normal. We saw our friends more. We took up new activities. We sat exams. We made decisions about our future.

Moving on

There will come a time when you consider moving away from home. You may go to college or university, or get a job away from home. And that's fine.

You may feel guilty about leaving home. You may worry about cancer returning, or be sad because you're leaving someone who has lost a loved one. This is how we felt, too.

But you have your whole life ahead of you, and your experience with cancer shouldn't stop you from doing all the things you want to do.

If you're looking for a job, thinking about moving out from home, or trying to plan your future studies or career, **thesite.org** is a great source of information. It's a website just for young people.

Let yourself be young. Let yourself be happy. And make the most of all the wonderful opportunities that you have.



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The A–Z of who does what

You will probably meet lots of different professionals while looking after someone. This list tells you about some of the people you might meet and what they do.

Benefits adviser

Benefits advisers can help people get payments from the government if they need it. These payments are called benefits. Benefits advisers are also sometimes called welfare rights advisers.

Clinical nurse specialist/keyworker

A clinical nurse specialist (CNS) is a nurse who specialises in a particular illness. They may also be the keyworker for the person with cancer. A keyworker is a particular nurse who keeps in touch with the person, and provides any extra support or information they need.

Community nurse

A community nurse cares for people at home. They give people any medication they need. They are also called district nurses.

Counsellor

A counsellor is someone you can talk to about your feelings and worries.

Doctors

You may meet the following kinds of doctors during your time as a young carer:

- A **consultant** is a very senior doctor. They are in charge when someone is given treatment in hospital.
- A **GP** is a local doctor. You may know this person already. They can help the person you look after when they are out of hospital.
- A **haematologist** is a doctor who tests the blood and treats leukaemias and lymphomas.
- An **oncologist** is a doctor who is an expert in cancer. They are trained to treat people with cancer.
- A **pathologist** is a doctor who looks at samples of cells under a microscope to find out if someone has cancer.
- A **radiologist** is a doctor who is specially trained to look at x-rays and scans. This helps them find out what is happening in the person's body.
- A **surgeon** is a doctor who carries out operations.
- **University medical students** are people who are training to become doctors. They may come round with the qualified doctors who are treating the person you care for, so that they can learn about what happens.

Pharmacist

A pharmacist gives out medicines that doctors have prescribed. They can also give advice about medicines.

Physiotherapist

A physiotherapist can help people to walk or move around, if they have been having problems with this.

Psychologist

A psychologist is someone who can help you manage your feelings, if you are finding it hard to cope.

Radiographer

A radiographer takes x-rays and does scans. They also give radiotherapy treatment, which is planned by the radiologist.

Social worker

A social worker is someone who can help you and your family with money, work or other problems.

Ward nurse

A ward nurse makes sure the person you care for is looked after while they're in hospital. The ward nurse will give them any regular treatments they need.

Medical terms

Doctors often use words that non-medical people find hard to understand. Here are some of the most common ones. Lots of these words are quite confusing even for adults – so don't worry if you find them tough to understand.

Anaesthetic

An anaesthetic helps make people more comfortable. It can be a general anaesthetic, which puts the person to sleep for a while. Or it can be a local anaesthetic, where the person stays awake but part of their body becomes numb for a while.

Benign

Benign means not cancerous. Benign tumours usually grow slowly. They don't usually spread.

Biopsy

A biopsy is where a doctor takes a small sample from the body. The sample is then checked under a microscope. This is done to see if the cells are cancerous.

Blood count

A blood count is a type of blood test. It measures different types of cells in the blood. There are platelets, which help the blood clot if you have a cut or become bruised. Then there are red blood cells, which carry oxygen around the body. And white blood cells help defend your body against illness.

Cell division

Cell division is where cells divide in two – doubling their number each time. This is how living things develop and grow.

Central line

A central line is a thin, flexible tube used to give chemotherapy treatment. One end is in a large vein near the heart, and the other end stays outside the body. Central lines are sometimes called by their brand names (for example Hickman® Line or Groshong® Line).

Chemotherapy

Chemotherapy is a type of cancer treatment. It uses drugs to destroy cancer cells.

Consent

When someone consents to treatment, it means they agree to it.

Cytology

Cytology is where individual body cells are examined in very close detail. This is very important in making a diagnosis.

Diagnosis

A diagnosis is a description of what disease someone has. When someone is diagnosed, it means the doctors tell them what disease or condition they have.

Infertility

When someone is infertile, it means they can't get pregnant or make someone pregnant.

Intravenous (IV)

When a drug or fluid is given intravenously, it means it is given into a vein.

Lesion

A lesion is where body tissue has been damaged or changed, and it may or may not be cancer.

Lymphatic system

The lymphatic system is part of the body that defends against infection and disease.

Lymphoma

Lymphoma is the name given to cancers that happen in the lymphatic system.

Malignant

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

Metastasis

Metastasis is where the cancer has spread from one part of the body to another. Cancer that has spread is sometimes called metastatic disease.

Oncology

Oncology is the study and practice of treating cancer.

Paediatrics

Paediatrics is the medical care of children.

Palliative care

Palliative care is treatment that helps to reduce pain. It aims to meet the physical, spiritual, psychological and social needs of a person with cancer.

PICC line

A portacath is a thin and flexible tube. It is put into a vein to give chemotherapy or other treatments.

Primary cancer

A primary cancer is one that starts in a single area of the body. Most cancers, other than leukaemias and lymphomas, are primary cancers. See also **secondary cancer**.

Prognosis

A prognosis is a prediction of how someone's disease is likely to affect them in the future.

Prosthesis

A prosthesis is a specially made replacement for a part of the body that has been removed – for example, an artificial leg or breast.

Radiotherapy

Radiotherapy is a type of cancer treatment. It uses high-energy x-rays to destroy cancer cells.

Scan

A scan is a computer-generated image of the inside of the body.

Secondary cancer

A secondary cancer is one that has spread to another part of the body.

Steroids

Steroids are a type of drug that can help treat cancer.

Surgery

Surgery means an operation.

Terminal

When a cancer is terminal, it means no more treatment can be given to cure the cancer.

Tumour

A tumour is a growth or lump. It may be benign (not cancer) or malignant (cancer).



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Information from Macmillan

Macmillan provides expert, up-to-date information about cancer. And all of it is free for everyone.

Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call **0808 808 00 00**.

Macmillan has booklets on different cancer types, treatments and side effects. It also has information about work, financial issues, diet, life after cancer and information for carers, family and friends.

All the information is also available online at **macmillan.org.uk/cancerinformation**. There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

Macmillan also provides information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- Easy Read booklets
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**. If you'd like information in a different format, email **cancerinformationteam@macmillan.org.uk** or call **0808 808 00 00**.

Help improve Macmillan's information

Macmillan knows that the people who use its information are the real experts. If you've been affected by cancer, you can help Macmillan improve its information.

Macmillan gives you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk** You can get involved from home whenever you like, and you don't need any special skills – just an interest in Macmillan's cancer information.



Other ways Macmillan can help you

Macmillan knows how a cancer diagnosis can affect everything, and they are here to support you. No one should face cancer alone.

Talk to Macmillan

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

The free, confidential phone line is open Monday–Friday, 9am–8pm. Macmillan’s cancer support specialists can:

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

Call **0808 808 00 00** or email Macmillan via the website, **macmillan.org.uk/talktous**

Information centres

Macmillan’s 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’d 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** or call **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's why Macmillan helps to bring people together in their communities and online.

Support groups

Macmillan 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 them or by visiting [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)

Online community

Thousands of people use Macmillan's 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

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

'Everyone is so supportive on the online community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

Help with money worries

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

Financial advice

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

Help accessing benefits

Macmillan's 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 **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. They can also tell you about benefits advisers in your area.

Visit **macmillan.org.uk/financialsupport** to find out more about how Macmillan can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, you can find support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**



Macmillan's My Organiser app

This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

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

Support for carers

Carers Direct

Tel 0300 123 1053

(Mon–Fri, 9am–8pm,
Sat–Sun, 11am–4pm)

**www.nhs.uk/
carersdirect/young/pages/
youngcarershome.aspx**

Offers free and confidential
information for carers.

Gives information about
how to access financial help,
getting a break from caring,
going to work and much more.
Its website includes a section for
young carers with information
and videos.

Carers Trust (Princess Royal Trust for Carers in Scotland)

32–36 Loman Street,
London SE1 0EH

Tel (England)
0844 800 4361

Tel (Scotland)
0300 123 2008

Tel (Wales)
0292 009 0087

Email info@carers.org
www.carers.org and
www.youngcarers.net

Provides support, information,
advice and services for people
caring at home for a family
member or friend. You can
find details for UK offices
and search for local support
on the website.

Carers UK

**Tel (England, Scotland,
Wales)** 0808 808 7777

Tel (Northern Ireland)
028 9043 9843

(Wed–Thu, 10am–12pm
and 2–4pm)

Email

advice@carersuk.org
www.carersuk.org

Offers information and
support to carers across
the UK. Can put people in
contact with support groups
for carers in their area.

The Children's Society's Include Programme

Ground Floor,
Unit 4,
Wessex Business Park,
Wessex Way SO21 1WP
Tel 01962 711511

www.youngcarer.com

This programme supports young carers and their families. From the website you can search for local young carers' projects in the UK, and also access information for young carers.

Crossroads Caring for Carers (Northern Ireland)

7 Regent Street,
Newtownards,
Northern Ireland BT23 4AB
Tel 028 9181 4455

Email

mail@crossroadscare.co.uk
www.crossroadscare.co.uk

A charity offering respite for carers by providing them with a much-needed break.

Crossroads Caring Scotland

Tel 0141 226 3793

www.crossroads-scotland.co.uk

A charity providing short breaks for carers within their own homes. Has services throughout Scotland that provide practical support for carers of all ages.

Help with money or work

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

Palatine House,
Lancaster Road,
Preston,
Lancashire PR1 1HB

Tel 0345 608 4321

(Mon–Thu, 8.30am–5pm,
Fri, 8.30am–4pm)

www.gov.uk/

carers-allowance-unit

Provides information and advice about benefits for carers.

Disability and Carers Service (Northern Ireland)

www.nidirect.gov.uk/disability-and-carers-service

Provides information and advice about benefits for carers.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of these websites:

England and Wales

www.citizensadvice.org.uk

Scotland

www.cas.org.uk

Northern Ireland

www.citizensadvice.co.uk

You can also find advice online in a range of languages at **adviceguide.org.uk**

Getting help with your feelings

Childline

Tel 0800 1111

www.childline.org.uk

Children and young people can contact Childline if they feel worried, scared, stressed or just want to talk to someone about any problem. It offers information and support through its helpline and website. On the website you can write emails, post on message boards and have a 1-2-1 chat with a counsellor.

Get Connected

Tel 0808 808 4994

(daily, 1–11pm)

Free text service 80849

www.getconnected.org.uk

A UK-wide helpline for young people under 25 who have a problem but don't know where to turn. Also provides an online directory of help. You can get in contact by phone, email, text and web chat.

National Self Harm Network

PO Box 7264,
Nottingham NG1 6WJ
Email info@nshn.co.uk
www.nshn.co.uk

A charity offering support, advice and advocacy services to people affected by self harm directly or in a care role. Has an online support forum.

Samaritans

Freepost RSRB-KKBY-CYJK,
Chris, PO Box 9090,
Stirling FK8 2SA
Tel 08457 90 90 90
Email jo@samaritans.org
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

Suite 11,
Baden Place,
Crosby Row,
London SE1 1YW

Parents' helpline

0808 802 5544
(Mon–Fri, 9.30pm–4pm)
www.youngminds.org.uk

A charity offering information to young people and children about mental health and emotional well-being. Also provides support and advice for any adult worried about the emotional problems, behaviour or mental health of a child or young person.

Support after the death of someone close

Childhood

Bereavement Network

8 Wakley Street,
London EC1V 7QE
Tel 020 7843 6309
Email cbn@ncb.org.uk
www.childhoodbereavementnetwork.org.uk

A national federation of organisations and individuals working with bereaved children and young people. Has an online directory where you can find local services.

Hope Again

Tel 0808 808 1677
(Mon–Fri, 9.30am–5pm)
Email hopeagain@cruse.org.uk
www.hopeagain.org.uk

Hope Again is the youth website of Cruse Bereavement Care. It supports young people after the death of someone close.

Winston's Wish

3rd Floor, Cheltenham House,
Clarence Street,
Cheltenham GL50 3JR
Tel 08452 03 04 05

Email

info@winstonswish.org.uk
www.winstonswish.org.uk

Helps bereaved children and young people re-adjust to life after the death of a parent or sibling.

Support if you have a disability

Scope

6 Market Road,
London N7 9PW
Tel 0808 800 3333
(Mon–Fri, 9am–5pm)
Email helpline@scope.org.uk
www.scope.org.uk

Offers confidential advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

Support for young people and families

Family Action

501–505 Kingsland Road,
London E8 4AU

Tel 020 7254 6251

(Grants service:

Tue–Thu, 2–4pm)

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.

Riprap

Maggie's, The Stables,
Western General Hospital,
Crewe Road,
Edinburgh EH4 2XU

www.riprap.org.uk

Developed especially for teenagers who have a parent with cancer.

Siblinks

www.siblinks.org

An online forum and information resource for young people aged 13–25 who have or have had a family member affected by cancer.

Youth Access

www.youthaccess.org.uk

Youth Access is the national membership organisation for young people's information, advice, counselling and support services (YIACS). Find your local Youth Access service via the website.

Youth Health Talk

www.youthhealthtalk.org

A collection of interviews with young people about their experiences of health issues or illness. You can watch videos, listen to the audio or read the interviews.



You can search for more helpful organisations at **macmillan.org.uk/organisations**, or call **0808 808 00 00**.

YOUR NOTES AND QUESTIONS

A series of horizontal green lines for writing notes and questions. The lines are evenly spaced and extend across the width of the page, providing a structured area for text entry.

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 photographs are of models.

Thanks

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With thanks to: Karen Aylward, Macmillan Counselling Services Lead, East Sussex Healthcare NHS Trust; June Hindmarsh, CAST Macmillan Young Carers School Co-ordinator, South Tyneside Young Carers Group; Daniel Phelps, Development Manager (Young Carers and Adult Carers), Carers Trust; Helen Sanderson, Thinkaboutyourlife.org; and all the young carers who helped us update this edition.

Sources

We've listed a sample of the sources used in the publication below. If you'd like further information, please contact us at bookletfeedback@macmillan.org.uk

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Gates MF, Lacky NR. Youngsters Caring for Adults with Cancer. *Journal of Nursing Scholarship*. 1998. 30 (1): 11–15.

The Princess Royal Trust for Carers, The Children's Society. *Supporting Young Carers: A Resource for Schools*. Carers Trust, London. 2010.

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're 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're there 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.



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

Please fill in your personal details

Mr/Mrs/Miss/Other

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Surname

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Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)

I enclose a cheque / postal order /
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Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

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Date / /

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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.

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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'd rather donate online go to macmillan.org.uk/donate

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

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way,
call Macmillan on 0808 808 00 00
(Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone
0808 808 0121, or Text Relay.

Non-English speaker? Interpreters available.
Braille and large print versions on request.

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