Support for young people caring for someone with cancer

LET'S TALK ABOUT YOU

WE ARE MACMILLAN CANCER SUPPORT
Welcome

Hello. And welcome to our handbook. We’ve put it together, along with Macmillan Cancer Support, to give help and information to young people aged 12–18 who are caring for someone who has cancer.

Why? Because we’ve done it 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 lots of 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 huge list of websites and organisations in chapter 13 that can help.

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 Aphra, Sara, Eve, David and the Arden Cancer Network’s Young People’s Group; Jess; the young carers from the Oxford City Young Carers’ Forum; and the young people at Spiral Children’s Bereavement Service in Nottinghamshire.
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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.

About cancer

Every part of our body is made up of cells that fit together like building blocks. Cells of the same type group together to make different kinds of tissue, for example fat, muscle, bone, nerves and blood (a liquid tissue). Cancer is a disease of these cells.
Cells get worn out and die, but new cells are being made all the time in the body. A normal, healthy cell will split to create two new cells, and then carry on dividing in a controlled way. If this process gets out of control, the cells develop into a lump called a tumour. This can be in:

• an organ, such as the liver or kidney
• a bone
• the blood (which causes a type of cancer called leukaemia)
• the lymphatic system (which causes a type of cancer called lymphoma).

There are more than 200 different kinds of cancer, each with its own name and treatment. People with cancer have to have tests, scans and investigations 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. Some common cancer treatments include surgery, chemotherapy and radiotherapy.

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, in chapter 12 we’ve included a list of common medical words and phrases that the doctors and nurses might use.
Are you worried about getting cancer because your family member 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 (less than 5–10%) of cancer has been shown to be due to a family history of the disease.
The A–Z of who does what

As a young carer, you’re probably going to meet a lot of different people, both in and out of hospital. We’ve put together this list of some of the people you might meet and what they do.

Someone who can help you claim any benefits that you or other family members may be entitled to. Benefits are payments from the government to help people in need.

A nurse who cares for people at home and gives them any medication they need.

Someone you can talk to about your feelings and worries.

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

• **Anaesthetist**
  A doctor who’s trained to look after the person you care for when they’re having an operation. They’ll give them the right anaesthetic (see page 74) for the surgery.
• **Consultant**
The senior doctor who’s in charge of a patient’s treatment. They will check the patient’s progress, plan their treatment and be in charge of their overall care. (See also multidisciplinary team on page 11.)

• **GP (general practitioner)**
The doctor at your local doctors’ surgery. You may know this person already. They’ll look after the person you care for when they’re back at home. The consultant will keep the GP informed about treatment and progress.

• **Oncologist**
A doctor who specialises in looking after people with cancer. Most are either medical or clinical oncologists. A medical oncologist is trained in the use of drugs to treat cancer. A clinical oncologist is trained to give both drugs and radiotherapy (see page 77).

• **Pathologist**
A doctor who tests the blood to check that a person’s blood count is okay. They also look at biopsy samples under a microscope to check the different cells.

• **Radiologist**
A doctor who’s specially trained to look at x-rays and scans.

• **Surgeon**
A doctor who carries out operations, such as taking a biopsy of the tumour.

• **University medical students**
These are trainee 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.
**DOMESTIC** Someone who cleans the wards and sometimes gives out drinks and meals.

A nurse who will closely watch the progress of the person you care for and give them any extra support or information they need.

**MACMILLAN OR SPECIALIST NURSE**

A nurse who’s specially trained to care for people with cancer who are dying and want to stay at home.

**MARIE CURIE NURSE**

The name given to the group of healthcare specialists who will be looking after the person you care for. The consultant will be a member of the team. The consultant will discuss the person’s care with the team and get their expert advice.

**MULTIDISCIPLINARY TEAM (OR MDT FOR SHORT)**

Someone who can help the person you care for carry out everyday tasks or find new things for them to do while they’re feeling unwell.

**OCCUPATIONAL THERAPIST**

A nurse who comes to people’s homes and coordinates activities.

**ONCOLOGY OUTREACH NURSE**
Let's talk about you: support for young people caring for someone with cancer

**PHARMACIST** Someone who gives out medicines that doctors have prescribed. They can also give information and advice about storing and taking medicines.

**PHYSIOTHERAPIST** Someone who can help the person you care for with their ability to move around (their physical mobility).

**PSYCHOLOGIST** If you’re finding it hard to cope, this is someone who can help you come to terms with your situation and manage your feelings.

**RADIOGRAPHER** Someone who takes x-rays and does scans. They also give radiotherapy treatment, which is planned by the radiologist.

**SOCIAL WORKER** Someone who can help you and your family with financial, work or social issues.

**WARD NURSE** A nurse who will make sure the person you care for is looked after while they’re in hospital. They will give them any regular treatments they need. This could include taking blood samples and giving medications or chemotherapy (see page 75).
You can get information about different types of cancer and their treatments from Macmillan. Call 0808 808 00 00 to speak to one of their cancer support specialists. They can recommend leaflets and send them to you through the post. Calls are free. Or you might like to read the information online at macmillan.org.uk/cancerinformation

And remember – any information they send you will arrive in plain packaging, so no one will know you have asked for it.
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What is a young carer?

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Are you a young carer?

You may not think you are. But if you’re under 18 and you spend any of your 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:

• making dinner
• washing the dishes
• cleaning the house
• doing the food shopping
• washing clothes
• looking after brothers or sisters.

You may also be asked to do things for the person who has cancer, like helping them get dressed, giving them their medicines or changing their bandages.

You may comfort them when they’re upset, or be there to listen when they need to talk.
What does being a young carer mean?

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 could be hard to keep up with your friends. You may have to cancel plans 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’s happening at home. You may feel angry with the person you’re looking after. You may feel neglected, and then feel guilty for feeling that way.

Being a young carer is a big responsibility. And that can sometimes be really hard. But positive things can also come out of the experience. Things like becoming closer to the person you care for, learning new skills and feeling more mature.

‘At least when I got to uni I knew how to work a washing machine!’
Aphra, 18
Let's talk about you: support for young people caring for someone with cancer.
Looking after yourself

It’s very important to remember to look after yourself. You may feel like you have the weight of the world on your shoulders. But you should only ever take on as much as you can handle.

Here are some of the things that helped us:

• If you’re feeling stressed out, talk to someone. It could be a friend, a teacher or another family member. Or you may want to join a support group. Young carers’ projects (see page 45) 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 youngcarers.net 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.

• There are also lots of phone numbers and websites of other organisations that can help you in chapter 13 of this booklet.

• You may want to let your school or college know what’s going on. There may be times when you need extra help with your work, or when you need time off. Your teachers can only support you if they know what’s happening at home.

• Make time for yourself. Do something that takes your mind off the situation, like playing sport, spending time with friends, painting, or walking the dog. Remember, you’re still allowed to enjoy yourself and you don’t need to feel guilty for wanting your own life.

• As a young carer, if you don’t feel comfortable doing something (for example, helping someone go to the toilet), you can say no.
Let's talk about you: support for young people caring for someone with cancer.
## Feelings

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Coping with your feelings

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 he/she recover?’ and then, ‘Are they going to die?’ This uncertainty can make you feel all kinds of things.

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

You may feel angry with the world, or with the person who has cancer. You may feel guilty. You may be anxious or feel down. Whatever you’re feeling, it’s a natural part of the cancer experience.

Bottling it up

Try not to bottle up your feelings. 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
If you don’t feel comfortable talking to someone close, then maybe a young carers’ worker 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 even be the school nurse. You can also chat online with support workers or other young carers at youngcarers.net

There may be a local young carers’ support group you could join. Ask around at school or college. Or see chapter 13 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 plenty of trained specialists to hand. They can answer your questions about cancer, or just be there to listen to you if you feel like talking to someone about how you’re feeling.

You can find contact details for lots more helpful organisations at the back of this booklet.

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 that help is there when you feel ready for it.
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 whether it will be a good day or a bad day.

Because you’re going through such a confusing time, you may find that 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. But you don’t have to explain your situation to anyone if you don’t want to. It’s your business, and you should only talk to people about it if you trust them and feel comfortable with them.

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 not know what to say. Most of us felt like this at some point.

The best thing we found we could do 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’re 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 get upset. If you are older, part of your role as a young carer may be to look after your siblings. This could include talking to them and comforting them.

‘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

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. Cancer can also cause a lot of pressure, and your family may get angry or fight more. Try not to let it get to you. 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

If you feel like you need to talk to someone, you can always contact the Macmillan Support Line or the other useful organisations listed in chapter 13 of this booklet.

**Depression**

It’s not unusual for someone 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, and 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 that the person you’re 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)

‘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

If you’re struggling to cope or are feeling low, then it might be a good idea to see a counsellor. They’re 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. Or there might be a counsellor at your school or college. If you do see a counsellor, you can decide how much you’d like to share with them, and 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 just people, and they’re 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. Have a look at the organisations in chapter 13 for ideas on who to talk to.
Let's talk about you: support for young people caring for someone with cancer
# Relationships

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Relationships play an important part in all our lives. Think back to when you first started school. Who was your best friend? Is it still the same person today?

You may find that while you’re 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. Some drift away, while others grow stronger. You’ll probably experience both.

**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 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. Your best friends should accept you no matter what. And they will help you 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.

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

Sapna, 16
Family

‘No one mentioned it in the house at all. I think we didn’t want to upset each other.’
Sasha, 12

It’s likely that the person you’re helping care for is your mum or dad, your brother or sister, or one of your grandparents – 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’re 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 they can lend a hand. If they tidy the house or do the shopping, it will give you a break and help them feel that they’re supporting you.
Boyfriends and girlfriends

If you have a boyfriend or girlfriend, they may be someone 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 little while. You could even ask them to help you with the extra stuff you have to do at home. They might help you 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 cool and something just for you. But it can also be painful. 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 with what your family’s 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.
Let's talk about support for young people caring for someone with cancer.
What about school?

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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 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 and when you need it.

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? Perhaps a relative or friend’s house?

If you’re worried that you might be falling behind, you can ask a young carers’ worker (see page 45 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 care for someone, but if they know, they may be able to help you. For example, if you’re struggling at school or with homework, or you need time off, they’ll understand.

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 care for. Or you may struggle to get into school on time. If these things happen often, 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 carers’ 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’re the target of bullying.

If you’re being bullied because of your situation at home, it’s important that you don’t 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.
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## Work and money

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Telling your boss

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 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.

• 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 get the sack if you tell your boss that you’re 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 work to be somewhere where 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 about your rights at macmillan.org.uk/legalrights

You could 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.

Benefits

If you’re over 16 and a young carer, you may be entitled to certain benefits, including Carer’s Allowance or Carer’s Credit.

If you’d like to know more about these and other benefits, you can call Macmillan’s cancer support specialists on 0808 808 00 00 and they will be happy to help. Or you can call the free Benefits Enquiry Line (BEL) on 0800 882 200 or textphone 0800 243 355.
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**Where can you go for help and support?**

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When we were helping 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.

Support groups

These 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 who 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 whether there’s one in your area. There are some website addresses that can help you do this at the back of this booklet – see chapter 13. 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. That’s what we did. 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’s more information about this, 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 here to help you. They are run by young carers’ 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’ll listen to you and who is on your side
- help, information and advice for your whole family.

Go to youngcarer.com/young-carers-services to find a young carers’ project near you. Or to find your local Children’s Society branch, visit childrenssociety.org.uk/in-your-area
Social workers

Your family might have been given a social worker, 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’re being protected and supported at home.

You may be able to have an assessment with your social worker. 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 law that says you can get this assessment is called the Children Act 1989. Visit youngcarers.net for more information about assessments.

Charities

There are lots of cancer charities in the UK, and they can all give you information and support. Here are some of the main ones you may want to get in touch with:

- **Macmillan Cancer Support** offers practical, emotional and financial help for anyone affected by cancer.

- **Cancer Research UK** funds important research into the causes of cancer, and can give you lots of information about different types of cancer.

- **Marie Curie Cancer Care** provides free nursing care to people with cancer in their own home.
There are also charities for particular types of cancer, for example breast cancer or leukaemia, and charities just for young people, like the Children’s Society. All of these charities will be able to help you understand more about cancer, its treatment and side effects. They can also put you in touch with other people who are going through the same experience. See chapter 13 for more organisations that can help.

**Online forums**

Joining an online forum can put you in touch with loads of people who are in the same situation as you. 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
- can make new online friends.

There are plenty of forums for carers and for people affected by cancer. You can choose whatever best suits your situation. Just remember when you’re 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 up with someone you’ve talked to 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 chapter 13.
Let's talk about you: support for young people caring for someone with cancer
# Looking after yourself

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Eating – food and 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.

Eating disorders

Sometimes food becomes a problem when it’s used to help you cope with painful situations or feelings, or to relieve stress. If this is how you deal with emotions and feelings, and you’re unhappy about it, then you should try to talk to someone you trust.

Sleeping

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

Sara, 18

When we were helping 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’s ill. Thinking 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’d suggest 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 bath soak, which can help you relax.

• Light some candles.

• Have a warm drink.

• Listen to a relaxation tape or CD.

• Write a diary – if you get all your thoughts out on paper, they won’t be quite so busy in your head.
Making time for you

It’s easy to feel guilty or selfish about going out and enjoying yourself. We all did. We worried that if we went out to see our friends then something might happen to the person 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 you should be doing. This might include catching up with friends, going shopping, playing sports, doing some art, or going to the cinema. Things like these are an important part of life.

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

Drugs and alcohol

Lots of young people experiment with drugs and alcohol. But if you’re stressed or upset, you may be using drugs or alcohol to block out your feelings.

If you think you’re drinking too much, or if you’re taking drugs to help you cope with what’s 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 in the back of this
booklet in chapter 13. You may also want to go to your GP, who can offer counselling and support.

‘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

Perhaps there are other things you could do to help you chill out, for example going swimming or for a walk. Change your routine so that you’re not thinking about drugs or alcohol at certain points of the day. And if your friends are drinking heavily or taking drugs, it could be time to rethink who you hang out with.

Self-harm

One in ten teenagers self-harms. Self-harm is when you deliberately hurt yourself. Self-harm is linked with depression, and it usually affects girls more than boys.

If you’re helping care for someone with cancer, you may be at risk of self-harming. If you’ve had thoughts about self-harming, or if you’ve started to hurt yourself, you must get help. Tell a relative or friend. Or call one of the helpline numbers listed in chapter 13. You should also make an appointment with your GP or talk to your young carers’ worker if you’re worried that you may have depression.
Let's talk about you:
support for young people caring for someone with cancer
Talking to doctors and nurses

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When you’re affected by cancer, you’ll probably meet a lot of doctors and nurses. This could be in the hospital, or at home.

In chapter 1 we introduced you to 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. But doctors and nurses are people, just like you are.

‘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
We found it useful to write down any questions we wanted to ask in a notebook, 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.

**Feeling invisible**

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 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.
Let's talk about you: support for young people caring for someone with cancer.
Talking to doctors and nurses

That way, they can try to include you next time the doctor or nurse comes around.

‘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 you information?

There are other people who can tell you a bit more about cancer and its 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. If you’d like to speak to a nurse, call 0808 808 00 00.
Let's talk about you: support for young people caring for someone with cancer.
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 if 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 it’s 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 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 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. It’s a good idea 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 nurses who provide pain relief for the person who’s ill, and who help the person and their family cope with their feelings.

Some hospices will let you stay overnight from time to time. If you’d like to do this, ask one of the nurses whether this is possible.

At this stage, you’ll have some very difficult decisions to make, and talking to the nurses and doctors can help you with this. 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 make sense of what’s 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 carers’ worker could speak to 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 that people know that and that 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. You won’t know how you’ll feel until this happens. Some people say they feel relieved that the pain and suffering is now over.

**The funeral**

Your family will usually start planning the funeral within a couple of days. You may have a funeral director, or a vicar or other 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 you had.

If you want to get involved with the funeral, make sure you tell your family. It may be that you’d like to read a poem, do a
special reading, or simply talk about the person. Tell the person who’s responsible for planning the funeral that you’d like to do this.

You could also help choose the music. Or perhaps there’s a special wish that the person had that they 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.

Before the person we were caring for died, some of us had nurses coming around 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 someone at a cancer support group, or a trusted friend. Maybe you could talk
to a young carers’ worker or a counsellor. Just make sure you don’t bottle your feelings up.

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 come to an agreement about when would be a good time.

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

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. 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’ll 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’s 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.

‘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

Don’t be afraid to talk about the person you’ve lost – you might want to tell little stories or talk 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.
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Life after cancer

Moving on 71
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 was immediate and final. Others had less certainty. But for all of us, our lives had changed forever.

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.

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.

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 did 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 the 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 doing all the things you want to do.

Let yourself be young. Let yourself be happy. And make the most of all the wonderful opportunities that you have.
Let's talk about you: support for young people caring for someone with cancer
Doctors often use unfamiliar and strange words that you may not understand. Here are some of the most common ones explained (in alphabetical order):

**Anaesthetic (general)**
A drug that puts people to sleep while they have an operation or procedure.

**Anaesthetic (local)**
A drug, cream or injection to make part of the body temporarily numb.

**Benign**
This means non-cancerous. Benign tumours usually grow slowly and don’t spread.

**Biopsy**
This is when a doctor takes a small sample of tissue from the body to be examined under a microscope, to see whether or not the cells are cancerous.

**Blood count**
This is a blood test to measure the number of platelets, red blood cells and white blood cells in the blood. Platelets help the blood clot if you have a cut or become bruised. Red blood cells carry oxygen around the body. White blood cells help defend your body against illness.

**Cell division**
The process by which cells divide in two – doubling their number each time. This is how living things develop and grow.
**Central line**
A thin, flexible tube inserted through the vein near the heart for chemotherapy. One end stays outside the body.

**Chemotherapy**
The use of anti-cancer drugs to destroy cancer cells.

**Consent**
Agreement to treatment.

**Cytology**
The microscopic study of individual body cells. This is very important in making a diagnosis.

**Diagnosis**
When the doctors know the kind of disease the patient has.

**Infertility**
When someone can’t get pregnant or make someone pregnant.

**Intravenous (IV)**
This means that a drug or fluid is given into a vein.

**Hickman line**
A thin tube inserted through the skin of the chest into a vein near the heart for chemotherapy. One end stays outside the body.

**Lesion**
Damage or change to body tissue that may or may not be cancer.
Let’s talk about you: support for young people caring for someone with cancer

**Lymphatic system**
Part of the immune system – the body’s natural defence against infection and disease. The lymphatic system is made up of organs such as bone marrow, the thymus, the spleen and lymph nodes.

**Lymphoma**
The name given to cancers that develop in the lymphatic system.

**Malignant**
This means cancerous. Malignant tumours have the ability to spread to different parts of the body.

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

**Oncology**
The study and practice of treating cancer.

**Paediatrics**
The medical care of children.

**Palliative care**
Treatment that’s given to help improve quality of life but not to cure the cancer. Palliative treatment aims to meet the physical, spiritual, psychological and social needs of a person with cancer.

**Portacath**
A thin, flexible tube put into a vein. It has an opening (port) just under the skin of the chest.
Primary cancer
A cancer that starts in a single area of the body (site). Most cancers, other than leukaemias and lymphomas, are primary cancers. See also secondary cancer.

Prognosis
The way a disease is likely to affect someone in the future.

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

Radiotherapy
The use of high-energy x-rays to destroy cancer cells.

Scan
A computer-generated image of the inside of the body.

Secondary cancer
A cancer that has spread to another part of the body.

Steroids
A type of drug that can help treat cancer.

Surgery
An operation.

Terminal
This is when no more treatment can be given to control the cancer, and the end of life is near.

Tumour
A growth or lump that may or may not be cancer.
Let's talk about you: support for young people caring for someone with cancer.
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Let’s talk about you: support for young people caring for someone with cancer

How Macmillan can help you

Cancer is the toughest fight most of us will ever face. But you don’t have to go through it alone. The Macmillan team is with you every step of the way.

Get in touch

Macmillan Cancer Support
89 Albert Embankment,
London SE1 7UQ
Questions about cancer?
Call free on 0808 808 00 00
(Mon–Fri, 9am–8pm)
www.macmillan.org.uk
Hard of hearing?
Use textphone
0808 808 0121 or Text Relay.
Non-English speaker?
Interpreters are available.

Macmillan Support Line
The free, confidential phone line is open Monday–Friday, 9am–8pm. Macmillan’s cancer support specialists provide clinical, financial, emotional and practical information and support to anyone affected by cancer. Call 0808 808 00 00 or email via the website, macmillan.org.uk/talktous

Information centres
Macmillan’s information and support centres are based in hospitals, libraries and mobile centres, and offer you the opportunity to speak with someone face-to-face. Find your nearest one at macmillan.org.uk/informationcentres

Clear, reliable information about cancer

Macmillan can help you by phone, email, via its website and publications or in person. And its information is free to everyone affected by cancer.
Publications
Macmillan provides expert, up-to-date information about different types of cancer, tests and treatments, and information about living with and after cancer. It can send you free information in a variety of formats, including booklets, leaflets, fact sheets and audio CDs. Macmillan can also provide its information in Braille and large print.

You can find all its information, along with several videos, online at macmillan.org.uk/cancerinformation

Review Macmillan’s information
Did you find this guide helpful? Macmillan would be interested to know so that it can improve the next edition. You could even get involved by becoming an information reviewer, or by sharing your story or photos if you’d like. Email cancerinformation team@macmillan.org.uk

Need out-of-hours support?
You can find a lot of information on Macmillan’s website, macmillan.org.uk
For medical attention out of hours, please contact your GP for their out-of-hours service.

Someone to talk to
When you or someone you know has cancer, it can be difficult to talk about how you’re feeling. You can call Macmillan’s cancer support specialists to talk about how you feel and what’s worrying you.

Macmillan can also help you find support in your local area, so you can speak face-to-face with people who understand what you’re going through.
Professional help

Macmillan’s nurses, doctors and other healthcare and social care professionals offer expert treatment and care. They help individuals and families deal with cancer from diagnosis onwards, until they no longer need this help.

You can ask your GP, hospital consultant, district nurse or hospital ward sister if there are any Macmillan professionals available in your area, or call Macmillan on 0808 808 00 00.

Support for each other

No one knows more about the impact cancer has on a person’s life than those who have been affected by it themselves. That’s why Macmillan helps to bring people with cancer and carers together in their communities and online.

Support groups
You can find out about support groups in your area by calling Macmillan or by visiting macmillan.org.uk/selfhelpandsupport

Online community
If you’re 16 or over, you can also share your experiences, ask questions, get and give support to others in Macmillan’s online community at macmillan.org.uk/community
Financial and work-related support

Having cancer can bring extra costs.

If you’ve been affected in this way, Macmillan can help. Call the Macmillan Support Line, and a cancer support specialist will tell you about the benefits and other financial help you may be entitled to.

If you work, they can also give you information about your rights at work as an employee, and help you find further support.

Macmillan Grants

Money worries are the last thing a person needs when they have cancer. A Macmillan Grant is a one-off payment for people with cancer, to cover a variety of practical needs including heating bills, extra clothing, or a much-needed break.

Find out more about the financial and work-related support Macmillan can offer at macmillan.org.uk/financialsupport

Learning about cancer

You may find it useful to learn more about cancer and how to manage the impact it can have on your life.

You can do this online on Macmillan’s Learn Zone – macmillan.org.uk/learnzone – which offers a variety of e-learning courses and workshops. There’s also a section dedicated to supporting people with cancer – ideal for people who want to learn more about what their relative or friend is going through.
Other useful organisations

Support for carers

Carers Direct
Tel 0808 802 0202
(Mon–Fri, 9am–8pm,
Sat–Sun, 11am–4pm)
www.nhs.uk/carersdirect/
young/pages/young
carershome.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 0844 800 4361
Email info@carers.org
www.carers.org
www.youngcarers.net
Supports carers of any age,
including young carers.
Helps young carers through
specialised services across
the UK and its website
youngcarers.net which
provides information,
advice, email support,
supervised message boards
and chat sessions.

Carers UK
20 Great Dover Street,
London SE1 4LX
Tel (England, Scotland
and Wales) 0808 808 7777
Tel (Northern Ireland)
028 9043 9843
(Wed–Thu, 10am–12pm
and 2–4pm)
Email
adviceline@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. To contact The Children’s Society, you can call 020 7841 4400 or visit childrenssociety.org.uk

Crossroads Caring for Carers (Northern Ireland)
7 Regent Street, Newtownards, Northern Ireland BT23 4AB
Tel 028 9181 4455
www.crossroadscare.co.uk
A charity offering respite for carers by providing them with a much-needed break.

Crossroads Caring Scotland
24 George Square,
Glasgow G2 1EG
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

Benefit Enquiry Line
(England, Scotland, Wales)
Warbreck House, Warbreck Hill Road, Blackpool FY2 0YE
Tel 0800 882 200
(Mon–Fri, 8.30am–6.30pm)
Email BEL-Customer-Services@dwp.gsi.gov.uk
www.gov.uk/benefit-enquiry-line
Provides advice and information for disabled people and carers on the range of benefits available.

NI Direct
(Northern Ireland)
Tel 0800 220 674
www.nidirect.gov.uk/money-tax-and-benefits
Citizens Advice
Provides free, confidential, independent advice on a variety of issues including financial, legal, housing and employment. Find contact details for your local office in the phone book or at citizensadvice.org.uk
Find advice for the UK online, in a variety of languages, at adviceguide.org.uk

Citizens Advice Scotland
www.cas.org.uk

Get Connected
Tel 0808 808 4994
(daily, 1–11pm)
Free text service 80849
(Mon–Fri, 7–11pm)
Email through the website 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 (NSHN)
PO Box 7264,
Nottingham NG1 6WJ
Tel 0800 622 6000
(Thu–Sat, 7–11pm,
Sun, 6.10–10.30pm)
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.

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.
Further information

Samaritans
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, for people who are experiencing feelings of distress or despair.

YoungMinds
Suite 11, Baden Place, Crosby Row, London SE1 1YW
Parents’ helpline 0808 802 5544 (Mon–Fri, 9.30am–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
This national network supports children and young people who’ve had someone close to them die. It has an online directory where you can find local services.

RD4U
Tel 0808 808 1677 (Mon–Fri, 9.30am–5pm)
Email info@rd4u.org.uk
www.rd4u.org.uk
Designed for young people by young people, RD4U is part of Cruse Bereavement Care. It supports young people after the death of someone close.
Let’s talk about you: support for young people caring for someone with cancer

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

Support if you have a disability

DIAL UK
Tel 01302 310 123
Email response@scope.org.uk
www.dialuk.info
An independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

Support for families

Family Action
501–505 Kingsland Road, London E8 4AU
Tel 020 7254 6251
Grants service
020 7254 6251
(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.
Other useful organisations
Let’s talk about you: support for young people caring for someone with cancer

Further resources

Online support

A lot of information about cancer is available on the internet. Some websites are excellent; others have misleading or out-of-date information.

The sites listed here are considered by nurses and doctors to contain accurate information and are regularly updated.

Macmillan Cancer Support
www.macmillan.org.uk
Find out more about living with the practical, emotional and financial effects of cancer. Macmillan’s website contains expert, accurate, up-to-date information about cancer and its treatments, including:

• all the information from their 150+ booklets and 360+ fact sheets

• videos featuring real-life stories from people affected by cancer and information from medical professionals

• how Macmillan can help, the services they offer and where to get support

• how to contact their cancer support specialists, including an email form to send your questions

• local support groups search, links to other cancer organisations and a directory of information materials

• a huge online community of people affected by cancer sharing their experiences, advice and support

• a section written specially for carers at macmillan.org.uk/carers
The Northern Ireland Regional Young Carers Service
www.youngcarersni.com
An interactive website that allows you to sign up for activities, information and help and support services in your region of Northern Ireland.

Riprap
www.riprap.org.uk
A site for teenagers who have a parent with cancer. You can connect with other teenagers and find out about how they deal with their situations. You can also send an email which will be answered by specialists.

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.
Helpful books

Hello, and how are you?
Macmillan Cancer Support, 2012, free
This is a guide for adult carers of people with cancer. It could be useful for any adults who are helping support the person you care for. It’s written by carers, for carers. They can order it by calling 0808 808 00 00 or visiting be.macmillan.org.uk

Out of the blue: making memories last when someone has died
Winston’s Wish, 2006, £8.99 (plus P&P)
This book aims to help you if someone close to you has died. It’s narrated by teenagers. It talks about what you might be feeling, and includes activities.

Stories about surviving cancer
Franklin Watts, 2010, £12.99
This book has stories about young people who faced cancer, as either a patient or a family member of someone with cancer, and who all came out the other side. It also includes basic information about cancer.

Straight talk about death for teenagers: how to cope with losing someone you love
Grollman EA, Beacon Press, 1999, £15.50
This book was written after the author spoke to thousands of teenagers and found they often felt forgotten after someone has died. It talks about how you may feel, gives advice and reassures you that grief is normal.

Taking care of ourselves: the young carers’ recipe book
The Children’s Society, 2005, free

The secret C
Stokes J, Winston’s Wish, 2000, £5.95 (plus P&P)
This book tries to answer some of the questions and worries you may have about someone
in your family having cancer. It can help you (and any adults close to you) talk about any difficult feelings you may have.

**The selfish pig’s guide to caring: how to cope with the emotional and practical aspects of caring for someone**
Has a chapter for young carers.

**What’s up with Bridget’s mom? Medikidz explain breast cancer**
Chilman-Blair K, Medikidz, 2009, £6.99
A comic book based on Bridget, who’s an A-grade student and star of the school soccer team, and her relationship with her mum. You can also order this comic and others from the range for free at [be.macmillan.org.uk](http://be.macmillan.org.uk)

**When your brother or sister gets cancer**
Children’s Cancer and Leukaemia Group, 2009, free
This booklet is for 9- to 16-year-olds who have a brother or sister with cancer. It describes what cancer is and how it’s treated. Young people describe their experiences, how they felt and how they coped. It’s available to download from [cclg.org.uk/products_files/CCLG-WhenYourBrotherSisterGetsCancer.pdf](http://cclg.org.uk/products_files/CCLG-WhenYourBrotherSisterGetsCancer.pdf)

**Young carers**
Help the Hospices, 2008, free
This is a section of the Help for Hospices Carers’ Pack. It’s designed to help you if you care for someone with a serious illness. It’s free and can be downloaded from [helptehospices.org.uk/hweb/get_Document.aspx?id=3910](http://helptehospices.org.uk/hweb/get_Document.aspx?id=3910)

**Young carers’ poetry book**
The Children’s Society, 2005, free
Let's talk about you: support for young people caring for someone with cancer.
Your notes and questions
You could use these pages to write down any questions you want to ask, and then to write down the answers you receive.
Let’s talk about you: support for young people caring for someone with cancer
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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Some carer quotes sourced from Youthhealthtalk – www.youthhealthtalk.org
Let’s talk about you: support for young people caring for someone with cancer

Sources


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.

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
Please fill in your personal details

Mr/Mrs/Miss/Other
Name
Surname
Address
Postcode
Phone
Email

Please accept my gift of £

(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature
Date / /

Don’t 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 taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that 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’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
Cancer is the toughest fight most of us will ever face. If you or a loved one has been diagnosed, you need a team of people in your corner, supporting you every step of the way. That’s who we are.

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 supporting you online, any time. The fundraisers who make it all possible.

You don’t have to face cancer alone.
We can give you the strength to get through it.
We are Macmillan Cancer Support.

Questions about living with cancer?
Call free on 0808 808 00 00 (Mon–Fri, 9am–8pm)
Alternatively, visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.

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This organisation has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org

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