A guide for young people caring for someone with cancer
Hello. And welcome to our handbook. We put it together along with Macmillan Cancer Support, to give help and advice 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, or an 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 that you can do to look after yourself while you are caring for someone with cancer.

We’ve split the guide into chapters, so you can dip in and out, or 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 which can help.

We hope that 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.

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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Let's talk about you: a guide for young people caring for someone with cancer

What is cancer?

About cancer

The A–Z of who does what
1. What is cancer?

**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 or anyone else’s.

**About cancer**

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells.

Cells get worn out and die, but new cells are being made all the time in your 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 a bone, or an organ, like the liver or kidney. It may also spread to other parts of the body, which is why it’s important to have treatment as soon as possible.

If the abnormal cells (the cells that are growing out of control) start in the blood, it can cause leukaemia. If they start in the lymphatic system, it can cause lymphoma. There are more than 200 different kinds of cancer, each with their own names and treatments.

People with cancer have to have tests, scans and investigations to find out exactly what type of cancer they have, and if it has spread in the body. This helps the doctors to plan the right treatment for each person. Some common treatments include surgery, chemotherapy and radiotherapy.

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

To make things even clearer, we’ve included a list of common medical words and phrases in chapter 12, which the doctors and nurses might use. We’ve marked them in italics throughout the handbook.

**Are you worried about getting cancer because your family member has it?**

Many people worry about getting cancer. Sometimes people think they might get cancer because there has been cancer in their family. People often worry that cancer can be inherited, or passed on from one generation to another. In fact, less than one in 10 cases of cancer (between 5 and 10%) has been shown to be due to a family history of the disease.
You may meet the following kinds of doctors during your time as a young carer:

- **Anaesthetist** They are trained to look after the person you care for when they’re having an operation. They’ll give them the right anaesthetic (see page 73) for the surgery.

- **Consultant** The senior doctor who is in charge of a person’s treatment. They will check the person’s progress and plan their treatment. They will be in charge of the person’s overall care (see also multidisciplinary team).

- **GP (general practitioner)** From 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** Doctors who specialise 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 and a clinical oncologist is trained to give both drugs and radiotherapy.

- **Pathologist** They test the blood to check that a person’s blood count is ok. They also look at biopsy samples under a microscope to look at the different cells.

- **Radiologist** Specially-trained to look at x-rays and scans.

- **Surgeon** 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.
The name given to the group or team of specialist healthcare professionals who will be looking after the person you care for. The consultant will be a member of an MDT and will discuss the person’s care with them to get their expert advice.

DOMESTIC
They will closely watch the progress of the person you care for and provide any extra support or information required.

MARIE CURIE NURSE
They are specially trained to provide care at home for people with cancer who are dying and want to stay at home.

MULTIDISCIPLINARY TEAM (OR MDT FOR SHORT)
Someone who can help the person you care for to carry out everyday tasks or find new things for them to do while they’re feeling unwell.

PHARMACIST
These nurses come to peoples’ homes and coordinate activities.

ONCOLOGY OUTREACH NURSE
They provide information about how to manage medicines. They also give out medicines that the doctors prescribe for the person you care for.

Usually they clean the wards and sometimes give out drinks and meals.

MACMILLAN OR SPECIALIST NURSE
The name given to the group or team of specialist healthcare professionals who will be looking after the person you care for. The consultant will be a member of an MDT and will discuss the person’s care with them to get their expert advice.

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

ONCOCLOGIST
If you’re finding it hard to cope, this is someone who can help you come to terms with the situation and help you work out ways to manage your feelings.

PHYSIOTHERAPIST
Someone who can help the person you care for with their physical mobility. What the physiotherapist does to help depends on what type of cancer the person you care for has and how it affects them.

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

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

RADIOGRAPHER
They carry out day-to-day care and provide ongoing treatment, such as giving injections, taking blood samples and blood count, and giving medication or chemotherapy.

You can get information about different types of cancer and their treatments from Macmillan. Call 0808 808 00 00 to speak to one of the cancer support specialists. They can recommend leaflets and send them through the post. Calls are free. Or you might like to read the information online at macmillan.org.uk/cancerinformation

And remember – all the information will arrive in plain packaging, so no one will know you have asked for it.

WARD NURSE
Someone who can help you and your family with financial, work or social issues.

Let’s talk about you: a guide for young people caring for someone with cancer
What is a young carer?

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2. What is a young carer?

Am I 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. These could include:

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

You might 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 are 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 ok. 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 is happening at home. You may feel angry with the person that 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.

‘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, too. You may feel that 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 like ours.

• Young carers projects can support you and give you time out from caring. The young carer 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.

• There are also lots of phone numbers at the back of this book of other organisations who can help you.

• 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 you need time off. Your teachers can only support you if they know what’s happening at home.

• If you don’t feel comfortable doing something – for example, helping someone go to the toilet, you can say no.

• 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.
Feelings

Coping with your feelings  

Bottling it up  

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

Coping with other people’s feelings  

Counselling (support if you’d like to talk about your feelings)
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Coping with your feelings

When you find out that someone close to you has cancer, you can experience a range of 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 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
Let’s talk about you: a guide for young people caring for someone with cancer

Feelings

If you don’t feel comfortable talking to someone close, then perhaps a young carer worker (see page 45) 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 or cook.

There may be a local young carers’ support group that 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, listen to you, or just be a shoulder to cry on.

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

If you don’t want to deal with how you’re feeling right now, that’s ok too. Do what works for you, and remember, 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 if it will be a good day or a bad day.

Because what you’re going through is 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. 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 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, helpless or not know what to say. Most of us do at some point.

The best thing we found for us 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 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.

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.

Everyone is different, and there is no ‘right’ or ‘wrong’ way to feel or behave.
Let's talk about you: a guide for young people caring for someone with cancer

Feelings

**Depression**
It’s possible that the person who has cancer may suffer from depression, either during their treatment or afterwards. It’s important to recognise that this 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 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, have a look at the glossary in chapter 12, or you can call the Macmillan Support Line on 0808 808 00 00.

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 is happening. It was much later on that I suddenly started crying and didn’t stop for a long time.’
Jenna, 17

**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. Or there might 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, 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.

‘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
I'm still me: a guide for young people living with cancer

Relationships

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4. Relationships

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 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. 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 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 know to back off if you’re having a bad day
• you’re less likely to bottle things up.

“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
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 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.

‘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

It’s likely that the person you’re helping to care for is your mum or dad, your brother or sister – someone who lives in your house, who you see every day.

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 want to help care for the person who has cancer, so don’t feel like you’ve got 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.
Boyfriends and girlfriends

Falling in love is part of human nature. So it’s still ok to have a boyfriend or girlfriend, even though you’re caring for someone who has cancer. They may be able to support you.

A girlfriend or boyfriend 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 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 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.
What about school?

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5. What about school?

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, and when, you need it.

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. For example, if you’re struggling at school or with homework, or you need time off, they will understand.

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?

Missing school

There may be times when you have to take time off school, like going to hospital appointments. If your school knows why you’re not there, you won’t get in trouble and they can help you catch up on the work you have missed. Perhaps the teacher could give you a handout after the lesson. Or the school could set up extra tuition, maybe at lunch time or after 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 worried that you might be falling behind, you can ask a young carer 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.
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Work and money

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6. Work and money

Telling your boss

If you’re working, even if it’s just part-time to fit in with school, 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.
• 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 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. Somewhere we didn’t have to think or talk about cancer.

Time off work

If you are 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 from the government website direct.gov.uk/en/caringforsomeone

Or 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.
Where can I go for help and support?

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7. Where can I go for help and support?

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.

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 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 book – 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.

Young carers projects

These projects are here to help you. They 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
• someone who will listen to you and who is on your side
• help, information and advice for the whole family.

Go to youngcarers.net to find a young carers project near you. Or to find your local Children’s Society branch visit childrenssociety.org.uk/kids_zone/about/how_we_do_it

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 are being protected and supported at home.
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 at 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, 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 which 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:

• you can be anonymous

• you can dip in and out when you want

• you don’t have to tell people anything you don’t want to

• you 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 this end of this booklet, we’ve listed lots of organisations and websites that can help – see chapter 13.
Let’s talk about you: a guide for young people caring for someone with cancer

Looking after yourself

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8. Looking after yourself

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.

Eating disorders
Sometimes food becomes a problem when it’s used to help you to 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.

‘My room became a sanctuary – somewhere relaxing just for me.’
Sara, 18

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 bath soak that can help you to 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.
Looking after yourself

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 that 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 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 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.

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 that you’re drinking too much, or you’re 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 in the back of this book in chapter 13.

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 chill out, for example go 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 10 teenagers self-harm. 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 to 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 carer worker if you’re worried that you may have depression.
Talking to doctors and nurses

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9. Talking to doctors and nurses

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 book 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 me and you.

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.

‘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

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 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 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 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. If you’d like to speak to a nurse, call 0808 808 00 00.
Coping with death

Facing reality
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10. Coping with death

When someone you love dies 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 is a normal reaction.

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 choose to stay in denial. If that happens, try to accept it.

‘My mum drank because she couldn’t cope with the fact that she was going to die.’
Rhiannon, 16

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 one of the nurses if 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 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 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 ok too.
Let’s talk about you: a guide for young people caring for someone with cancer

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 will 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, 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 that 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 is responsible for planning the funeral that you’d like to do this.

You could also help to 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.

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, like ours, or a trusted friend. Maybe you could talk to a young carer 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 ok. 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.

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 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.

‘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

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11. Life after cancer

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. 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.

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.

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

‘My mum’s treatment was a success, but she became very depressed. There was always a fear that the cancer could return.’

Aisha, 14
Glossary
12. Glossary

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 which puts people to sleep while they have an operation or procedure done.

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

**Benign**
Describes a tumour or growth that isn’t cancer.

**Biopsy**
This involves removing a small part of the tumour by either using a special needle (a needle biopsy) or by having a small operation. The sample of the tumour is then sent to the laboratory and looked at under a microscope to see what type of tumour it is.

**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 skin of the chest into a vein near the heart for chemotherapy. One end stays outside the body.

**Chemotherapy**
A treatment using anti-cancer drugs to destroy cancer cells.

**Consent**
Agreement to treatment.

**Cytology**
The microscopic study of individual body cells – very important in making a diagnosis.
Let’s talk about you: a guide for young people caring for someone with cancer

Diagnosis The identification of a patient’s illness or disease – usually based on symptoms and doing tests.

Depression It’s not unusual to feel very low after being told you 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 sadness gives way to a situation where their mood is low most of the time for several weeks or more, and they are depressed.

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

Glossary

Diagnosis The identification of a patient’s illness or disease – usually based on symptoms and doing tests.

Depression It’s not unusual to feel very low after being told you 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 sadness gives way to a situation where their mood is low most of the time for several weeks or more, and they are depressed.

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

Intravenous An injection into a vein (in the arm or another part of the body).

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 which may or may not be cancer.

Lymphoma A cancer of the lymphatic system.

Malignant Describes a growth or tumour which is cancerous and can grow and spread to other 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 treatment of cancer.

Paediatric The medical care of children.

Palliative care This is treatment that is given to help improve a person’s 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 your chest.

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

Prosthesis An artificial replacement for part of the body, eg a leg or arm.

Radiotherapy A cancer treatment involving high energy x-rays.

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

Secondary cancer A cancer which has spread to another point in the body.

Steroids A type of drug that can help treat cancer.

Surgery An operation.

Terminal This is when someone enters the last few months or weeks of life because the cancer cannot be cured.

Tumour A growth or lump which may, or may not be cancer.
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13. Further information

We all experience cancer in different ways. It’s a difficult time, but help and support is always available. Either face-to-face, over the phone, or online.

Here you’ll find a list of organisations, helplines and websites for you to call upon. Even if you don’t feel the need to do so right away, it’s good to know that help is out there.

**Macmillan Cancer Support**

89 Albert Embankment, London SE1 7UQ

General enquiries 020 7840 7840

**Questions about living with cancer?**

Call the Macmillan Support Line free on 0808 808 00 00, (Mon–Fri, 9am–8pm)

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

Non English speaker? Interpreters available.

Alternatively, visit macmillan.org.uk

Macmillan Cancer Support improves the lives of people affected by cancer. They provide practical, medical, emotional and financial help, and they have a wide range of services and activities that might be of help and interest.

**Clear, reliable information**

They provide expert, up-to-date information about cancer – the different types, tests and treatments, and living with the condition.

They can help you by phone, email, via our website and publications, or in person. And the information is free to all – people with cancer, families and friends, as well as professionals.

Just call and speak to one of the cancer support specialists. Or visit one of the information and support centres – based in hospitals, libraries and mobile centres – and speak with someone face-to-face.

**Someone to talk to**

When you or someone close to you has cancer, it can be difficult sometimes to talk about how you’re feeling. You can call the cancer support specialists to talk about how you feel and what’s worrying you. Alternatively, they can help you find support in your local area, so you can speak face-to-face with people who understand what you’re going through.

**Teen Info on Cancer**

www.click4tic.org.uk

TIC (Teen Info on Cancer) is Macmillan’s community information site for young people affected by cancer. Here you can make friends, blog your journey and share advice about your experiences. The site also has a huge amount of information on cancer, its treatment and how to cope with what’s happening. TIC has groups on Facebook and Bebo, and you can follow TIC on Twitter too.
Let’s talk about you: a guide for young people caring for someone with cancer

Other useful organisations

Support for carers

Carers Direct
PO Box 4338, Manchester M61 0BY
Helpline 0808 802 0202
(Mon–Fri, 8am–9pm, weekends, 11am–4pm)
Email from the website www.nhs.uk/carersdirect
Offers information, advice and support for carers.

Carers UK
20 Great Dover Street, London SE1 4LX
Tel 020 7378 4999
Carers line 0808 808 7777
(Wed and Thurs, 10am–12pm and 2–4pm)
Email info@carersuk.org
www.carersuk.org
Offers information and support to carers. Can put people in contact with support groups for carers in their area. Has national offices for Scotland, Wales and Northern Ireland:

Carers Scotland
The Cottage, 21 Pearce Street,
Glasgow G51 3UT
Tel 0141 445 3070
Email info@carerscotland.org
www.carerscotland.org

Carers Wales
River House, Ynsbridge Court,
Gwaedol-y-Garth,
Cardiff CF15 9SS
Tel 029 2081 1370
Email info@carerswales.org
www.carerswales.org

Carers Northern Ireland
58 Howard Street,
Belfast BT1 6PJ
Tel 028 9043 9843
Email info@carersni.org
www.carersni.org

Crossroads Care
10 Regent Place, Rugby,
Warwickshire CV21 2PN
Tel 0845 450 0350
Fax 01788 565498
Email from the website www.crossroads.org.uk
Services are provided through a network of local independent charities across England and Wales, each offering Crossroads’ core service where a trained carer support worker comes into the home to take over the caring responsibilities.

Crossroads Care Scotland
24 George Square,
Glasgow G2 1EG
Carers Information and Support Line 0141 353 6504
Email info@crossroads-scotland.co.uk
www.crossroads-scotland.co.uk
A charity providing short breaks for carers in their own homes. Has services throughout Scotland, which provide practical support for carers of all ages.

Crossroads Care (Northern Ireland)
7 Regent Street,
Newtownards, Co Down,
Northern Ireland BT23 4AB
Tel 028 9181 4455
Email mail@crossroadscare.co.uk
www.crossroadscare.co.uk
A Northern Ireland-based charity which gives carers a much-needed break, offering peace of mind that their loved one is well taken care of by a Crossroads care attendant.

Oxford Young Carers Project
174a Cowley Road, Oxford OX4 1UE
Tel 01865 205192
(ask to speak to somebody from the Young Carers project team)
Email youngcarers@carerscentre.co.uk
www.cooolyoungcarerscare.com
A project offering support to children and young people aged 5–21 who emotionally or physically care for someone who has a disability, long-term illness, mental health problem, or addiction to drugs or alcohol.

Further information
Further information

The Princess Royal Trust for Carers
Unit 14, Bourne Court, Southend Road, Woodford Green, Essex IG8 8HD
Tel 0844 800 4361
Email info@carers.org
www.carers.org and www.youngcarers.org

The largest provider of carers’ support services in the UK. Through its network of 144 independently managed carers’ centres, 85 young carers’ services and interactive websites, the trust provides information, advice and support services to over 400,000 carers, including around 25,000 young carers.

Siblinks
1 Betjemin Close, Coulsdon CR5 2YA
Tel 01737 555411 or 07713 082797 (evenings)
Email ben.johnson@siblinks.org
www.siblinks.org

Provides support for young people who have, or have had, a family member affected by cancer, mainly siblings.

They can also provide support to young people who know a non-family member affected by cancer. They also provide days out.

Young Carers Initiative at the Children’s Society
This initiative provides information for young carers and those who support them across the UK. You can find information of local young carers and projects in your area via the website.
www.youngcarer.com

Young Carers at The Princess Royal Trust for Carers
A website for young carers which is very young-person friendly and interactive. Offers support, information and a place to share your experiences.
www.youngcarers.net

Money
Benefit Enquiry Line
2nd Floor, Red Rose House, Lancaster Road, Preston, Lancashire PR1 1HB
Tel 0800 882 200
Textphone 0800 243 355
Email BEL-Customer-Services@dwp.gsi.gov.uk
www.direct.gov.uk/en/DI1/Directories/DG_1001165

Provides advice about benefits and can help you to complete some disability-related claim packs.

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

A network of professionals and organisations working with bereaved children and young people.

ChildLine
Weston House, 42 Curtain Road, London EC2A 3NH
Freephone helpline
0800 11 11
(Seven days a week, 24 hours)
Textphone 0800 400 222
Email info@childline.org.uk
www.childline.org.uk

Helpline for children and young people in danger or distress. Telephone counselling for any child with any problem, including bullying. Provides support and advice and refers children in danger to appropriate helping agencies. Also has a text message board and an online community.

Freepost address for children at Childline, Freepost NATN1111, London E1 6BR.

Also runs The Line for children living away from home:
Tel 0800 884 444
(Mon–Fri, 3.30–9.30pm, Sat and Sun, 2–8pm).
Let’s talk about you: a guide for young people caring for someone with cancer

The Children’s Society
Edward Rudolf House, Margery Street, London WC1X 0JL
Tel 0845 300 1128
Email supportercare@childrenssociety.org.uk
www.childrenssociety.org.uk
A leading national charity that makes childhood better for all children in the UK.

Citizens Advice Bureau
Find contact details for your local office in the phone book or at citizensadvice.org.uk
Find advice for the UK online, in a range of languages, at adviceguide.org.uk
Citizens Advice Bureaus provide free, confidential, independent advice on a variety of issues including financial, legal, housing and employment.

Citizens Advice Scotland
www.cas.org.uk

Connexions Direct
Freephone 0808 001 3219
(7 days a week, 8am–2am)
www.connexions-direct.com
This organisation is for young people aged 13–19, and gives advice about health, housing, relationships and careers.

Cruse Bereavement Care
PO Box 800, Richmond, Surrey TW9 1RG
Helpline 0844 477 9400
(Mon–Fri, 9.30am–5pm)
Helpline email helpline@cruse.org.uk
Young person’s freephone helpline 0808 808 1677
Young person’s helpline email info@rd4u.org.uk
www.crusebereavementcare.org.uk
Provides bereavement counselling, information and support to anyone who has been bereaved. You can also download booklets and leaflets about coping with the loss of a loved one from the website.

DIAL UK
St Catherine’s, Tickhill Road, Balby, Doncaster DN4 8QN
Tel 01302 310123
Fax 01302 310404
Email informationenquiries@dialuk.org.uk
www.dialuk.info
A national organisation with a network of around 120 local Disability Information and Advice Line services (DIALs) run by and for disabled people. These services are based throughout the UK and provide information and advice to disabled people and others on all aspects of living with a disability. You can search for your local DIAL on the website.

Family Action
501–505 Kingsland Road, London E8 4AU
Tel 020 7254 6251
www.family-action.org.uk
Provides practical, emotional and financial support to children and families.

Get Connected
Tel 0808 808 4994
(7 days a week, 1–11pm)
Email help@getconnected.org.uk
www.getconnected.org.uk
Helpline for young people under 25-years-old. The service can direct callers to relevant sources of help such as hostels, counselling and where to get food. The helpline is staffed by 60 volunteers; two thirds are under 30-years-old. Has live web chat from 7pm–10pm.

Samaritans
Chris, PO Box 9090, Stirling FK8 2SA
Tel 0845 790 9090
Email jo@samaritans.org
www.samaritans.org.uk
Provides confidential non-judgemental emotional support, 24-hours a day, for people who are experiencing feelings of distress or despair, including those which could lead to suicide. Service provided by phone, email or letter.

Young Minds
48–50 St John Street, London EC1M 4DG
Childline 0800 11 11
www.youngminds.org.uk
A youth organisation for people with depression and self-harm issues.
National Self Harm Network
PO Box 7264, Nottingham NG1 6WJ
Support helpline
0800 622 6000 (7pm–11pm)
Email info@nshn.co.uk
www.nshn.co.uk
A charity giving support and distraction, enabling people to seek alternatives to self-harm.

Online support

Cruse for Young People aged 12–18
The website has been developed by young people and contains personal experiences, a chat room and other activities. It aims to support people after the death of someone close to them.
www.rd4u.org.uk

KidsKonnected
US website with a chatroom for kids who have a parent with cancer. It can be accessed by children in the UK and provides a support and information service for children and young people.
Email info@kidskonnected.org
www.kidskonnected.org

Riprap
This is a site especially for 12–16 year olds who have a parent with cancer. In riprap, you can learn more about cancer and its treatment, and through individual stories you can see how this may affect you and your family. You can also make contact and share your experiences with other teenagers, find out about how others deal with their situation, and you can say what’s on your mind. You can also ‘ask a question’, ‘ask for advice’, or send an email which will be answered by experienced professionals working in this field.
www.riprap.org.uk

Supporting Bereaved Young People
This website has guides and information to support bereaved young people.
www.hospicenet.org/html/child.html

Youth Access
Can provide the addresses and telephone numbers of local services that provide counselling, advice, information and befriending for children and adolescents.
Email admin@youthaccess.org.uk
www.youthaccess.org.uk

Further resources

Useful websites
A lot of information about cancer is available on the internet. Some websites are excellent; others have incorrect or out-of-date information. The sites listed here are considered by nurses and doctors to contain accurate information and are regularly updated.

www.macmillan.org.uk
(Macmillan Cancer Support)
Find out more about living with the practical, emotional and financial effects of cancer. The website contains expert, accurate up-to-date information on cancer and its treatments, including:
• their 100+ booklets and 300+ fact sheets
• how Macmillan can help, the services offered and where to get support
• how to contact the 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.
Let’s talk about you: a guide for young people caring for someone with cancer

Further information

www.cancer.gov  
(National Cancer Institute – National Institute of Health – USA)  
Gives a wide range of information on cancer and treatments.

www.cancer.org  
(American Cancer Society)  
Nationwide community-based voluntary health organisation dedicated to eliminating cancer as a major health problem. It aims to do this through research, education, support and service.

www.cancerhelp.org.uk  
(Cancer Research UK)  
Contains patient information on all types of cancer and has a clinical trials database.

www.healthtalkonline.org  
www.youthhealthtalk.org  
(site for teens and young adults)  
Both websites contain information about some cancers and have video and audio clips of people talking about their experiences of cancer and its treatments.

www.nhs.uk (NHS Choices)  
NHS Choices is the online ‘front door’ to the NHS. It is the country’s biggest health website and gives all the information you need to make choices about your health.

www.nhsdirect.nhs.uk  
(NHS Direct Online)  
NHS health information site for England – covers all aspects of health, illness and treatments.

www.nhsdirect.wales.nhs.uk  
(NHS Direct Wales)

www.nhs24.com  
(NHS 24 in Scotland)

www.patient.co.uk  
(Patient UK)  
This website provides people in the UK with good-quality information about health and disease.

Helpful books

Hello, and how are you?  
Macmillan Cancer Support, 2009, Free  
This guide for adult carers of people with cancer could be useful for any adults who are helping to care for the person you support. It’s also written by carers, for carers, and covers everything from emotional issues to legal matters. They can order it by calling 0808 808 00 00 or through be.macmillan.org.uk

Out of the blue. Making memories last when someone has died  
Winston’s Wish, £7.99  
This book has been written and designed for teenagers to support them through their bereavement. Narrated throughout by teenagers, the book talks openly about the real feelings they may struggle with when someone important in their life dies. The activities in the book allow those feelings to be worked through and safely explored.

The Secret C  
Julie A. Stokes & illustrated by Peter Bailey, 2000  
Winston’s Wish  
This book attempts to answer some of the questions and worries you may have about cancer, especially when it involves someone in the family. This book will help adults and children to talk about the difficult issues and feelings involved when someone is seriously ill and briefly talks about the possibility of death.

The selfish pig’s guide to caring  
Marriott H. Polperro  
Heritage Press, 2003  
Has a chapter for young carers.
Straight Talk about Death for Teenagers: How to Cope with Losing Someone You Love
Earl A. Grollman, 1999
Sagebrush Ed Resources
This book was written after the author spoke to thousands of teenagers and found they often felt forgotten after someone has died. Written in short, clear sentences that are easy to read, it covers feelings, different types of death and the future. This book gives the reader many options of what can happen, how they may feel, giving advice and reassuring readers that grief is normal.

Taking care of ourselves. The young carers recipe book
The Children's Society
Available to download from youngcarer.com/pdfs/YCIRecipe%20Book.pdf

What’s up with Bridget’s mum? Medikidz explain breast cancer
Medikidz, 2009
£6.99
A comic book based on Bridget, an A-grade student and star of the school soccer team but her mum just doesn’t seem to care. She just stays in bed all day, ignoring her daughter. All of Bridget’s successes seem empty without mum’s support. You can order this comic and others from the range for free at be.macmillan.org.uk

Young Carers
Help the Hospices, 2008
This is a section of the Help for Hospice’s Carers Pack. It’s designed to give support and information to young people who provide practical and/or emotional support to someone with a life-limiting or terminal illness (including cancer). It’s free and can also be downloaded from the Help the Hospice website at helpth hospices.org.uk/hweb/get_Document.aspx?id=3910

Young carers poetry book
The Children’s Society, 2005
Available to download at youngcarer.com/pdfs/Poetry%20Book%202005.pdf

When your brother or sister gets cancer
Children’s Cancer and Leukaemia Group, March 2009, Free
Free from Children’s Cancer and Leukaemia Group or CLIC Sargent
This illustrated booklet is for 9–16 year olds who have a sibling with cancer. It describes what cancer is and how it’s treated. Young people describe their experiences, how they felt and how they coped. Available on the Children’s Cancer and Leukaemia Group website at cclg.org.uk/families/publications/pdfs/CCLG_WhenYourBrotherSisterGetsCancer.pdf
Versions in Bengali, Gujarati and Punjabi are available on the CLIC Sargent website at clicsargent.org.uk
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We feature real life stories in all our articles. Some photographs are of models.

Thanks
This booklet has been written and edited by Macmillan Cancer Support’s editorial team and the Arden Cancer Network’s Young People’s Group. It has been approved by Charlotte Argyle, Carers Support Manager, and our medical editor, Dr Terry Priestman, Consultant Clinical Oncologist.

With thanks to: Jess; the Oxford City Young Carers Project Forum; Spiral Children’s Bereavement Service in Nottinghamshire; and the people affected by cancer who reviewed this edition.
Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care.

One in three of us will get cancer. Two million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

General enquiries 020 7840 7840
Questions about living with cancer? Call the Macmillan Support Line 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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Next planned review in 2012