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MACMILLAN.  
CANCER SUPPORT

A guide for carers by carers

# A GUIDE FOR YOUNG PEOPLE LOOKING AFTER SOMEONE WITH CANCER





**'When I used to ask the nurses, they'd say that I was too young to understand. I don't think anyone should be too young to understand.'**

**Ryan, 13**

# Welcome

**Hello. Welcome to our information for young people under the age of 18 who are looking after someone with cancer.**

We have put it together with the help of young people who have been there themselves. They wanted to share their experiences with you, so you know that there are people you can turn to. And that there are things you can do to look after yourself. You will see quotes from them throughout this guide. Some are from Ryan, who is also on the cover.

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

We hope this guide helps you deal with some of the questions or feelings you may have. In it, we explain:

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

The guide is split into chapters. You can read it all in one go, or just read the parts that are helpful for your situation.

If there is something you would like to know more about, we have a list of organisations that can help on pages 111 to 116. And remember, there are lots of people you can talk to when the time is right for you.

This information was developed with young carers at the South Tyneside Young Carers' Group, the Arden Cancer Network's Young People's Group, the Oxford City Young Carers' Forum, and the Spiral Children's Bereavement Service in Nottinghamshire.

# Contents

About cancer	5
Being a young carer	11
Feelings	19
Relationships	35
School or college	41
Money and work	49
Getting help and support	55
Looking after yourself	65
Talking to professionals	73
Coping with death	81
Life after caring	93
Glossary	97
Further information	105





# ABOUT CANCER

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Finding out about cancer	6
What is cancer?	7
Are you worried about getting cancer?	9

# Finding out about cancer

If someone in your family has cancer, you might want to know more. If they give their permission, you could ask to speak with their doctors.

To make things clearer, we have included a list of common medical words and phrases that the doctors and nurses might use on pages 97 to 102.

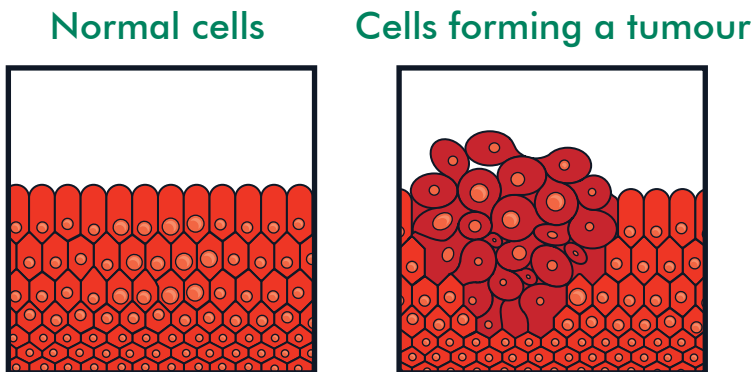


# What is cancer?

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

Healthy cells grow, divide and eventually get worn out and die. This cycle usually continues without any problems.

Cancer happens when something goes wrong with the cell and it grows and divides in an uncontrolled way. Cancer cells divide too much and don't die in the way normal cells do. These cells can form a lump called a tumour.



A tumour can form inside:

- an organ (part of the body that has a special job, such as the liver or kidney)
- a bone
- the lymphatic system (a network that helps defend your body from disease) – when a tumour forms here, it is called a lymphoma.

If the cancer affects the blood, the cancer cells do not form a tumour but affect the bone marrow (the spongy centre of the bones where blood cells are made). This type of cancer is called leukaemia.

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

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

# Are you worried about getting cancer?

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

But most cancers are not caused by inherited cancer genes. Doctors think that only 2 or 3 in every 100 cancers may be an inherited cancer.





# BEING A YOUNG CARER

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Are you a young carer?	12
How being a young carer can change things	13
Getting some support	14

# Are you a young carer?

If you are under the age of 18, and you spend time looking after someone who is ill, then you are a young carer.

As a young carer, you might do extra things to help your family – things that your friends might not be doing.

For example, you might:

- clean the house
- do the food shopping
- make cups of tea
- fetch things for the person with cancer, for example their slippers
- go out with the person who is ill, for example to help them with shopping
- do the laundry
- make dinner
- wash the dishes
- look after your brothers or sisters.

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

As well as helping with practical things, you might also care for them emotionally. You might comfort them when they are upset, or be there to listen when they need to talk. When you are not with them, you may worry about them.



# How being a young carer can change things

Being a young carer can affect your life in many ways. It can make you feel different, but that's okay. You may find that you can't concentrate at school or college, and that you don't have as much time to study. It might be hard to keep in touch with your friends. Or 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.

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

**Ellie**

You may also be worried about what is happening at home. You may feel angry with the person you are looking after. Or you may feel like you are not being given enough attention, and then feel guilty for feeling that way. But it is important to look after your own mental and physical health, as well as the person you are looking after.

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

# Getting some support

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

Here are some things that can help.

## Talk to someone

You could talk to a friend, a teacher or another family member. Or you may want to join a young carers' group. Young carers' projects can support you and give you time out from caring. They have groups where you can meet other young carers. You can chill out and no one will ask you why you are a young carer. Go to **[childrenssociety.org.uk/youngcarer/young-carers-services](https://childrenssociety.org.uk/youngcarer/young-carers-services)** to find one close to you.

You can also chat with other young carers and support workers online. They can give you information and advice. Young carers workers can also talk to professionals and your school on your behalf.

## Find a website or organisation that can help

We have details of lots of other organisations that can help you on pages 111 to 116.

## Let your school, college or work know

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

We have more information about talking to your school on page 43 and talking to your work on pages 52 to 53.

## Let people know what you are not comfortable with

As a young carer, you might not want to (or might not be able to) do the same things as adult carers. And that's okay.

If you don't feel comfortable doing something (for example, taking the person who has cancer to the toilet), you should tell someone. Another family member or friend might be able to help with those things. If there isn't anyone else who could help, or you don't feel like this is something you can talk about at home, you could try talking to a health or social care professional. They should be able to arrange for you to get some support. We have a list of health and social care professionals you might meet on pages 74 to 77. You can talk to any of them.

## Ask for a young carer's assessment

The law says that any young carer (or their family) can ask for a local social worker to visit them and do a young carer's assessment. The assessment is not a test. It is just a chat to find out what help you and your family might need or want. It may help you if you are struggling to get to school or to spend time with friends.

We have more information about social workers on page 59. To find out more about having a young carer's assessment, visit [nhs.uk/conditions/social-care-and-support-guide/pages/young-carers-rights.aspx](https://nhs.uk/conditions/social-care-and-support-guide/pages/young-carers-rights.aspx) if you live in England, Scotland or Wales. If you live in Northern Ireland, visit [nidirect.gov.uk/young-carers](https://nidirect.gov.uk/young-carers)

The Carers Trust has also produced a guide to a young carer's assessment called **Know your rights: Support for young carers and young adult carers in England**. You can download a copy at [carers.org/know-your-rights-support-young-carers-and-young-adult-carers-england](https://carers.org/know-your-rights-support-young-carers-and-young-adult-carers-england)

You can also contact your local council to find out more, or speak to your GP, who can refer you for a young carer's assessment.

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

**Rayna, 17**

## Make time for yourself

Try to do things you enjoy. They can help you take your mind off the situation. We have more information about different things you could do on page 69.

Remember, you are still allowed to enjoy yourself and you don't need to feel guilty for having your own life. Young carers' services can provide opportunities for you to talk to other young carers and take a break from your caring responsibilities. You can search for a service near you at **[childrenssociety.org.uk/youngcarer/young-carers-services](https://childrenssociety.org.uk/youngcarer/young-carers-services)**





# FEELINGS

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How cancer can affect your emotions	20
Feeling up one minute and down the next (mood swings)	22
Letting people know how you feel	24
Coping with other people's feelings	26
Counselling (support if you would like to talk about your feelings)	28
Depression	32

# How cancer can affect your emotions

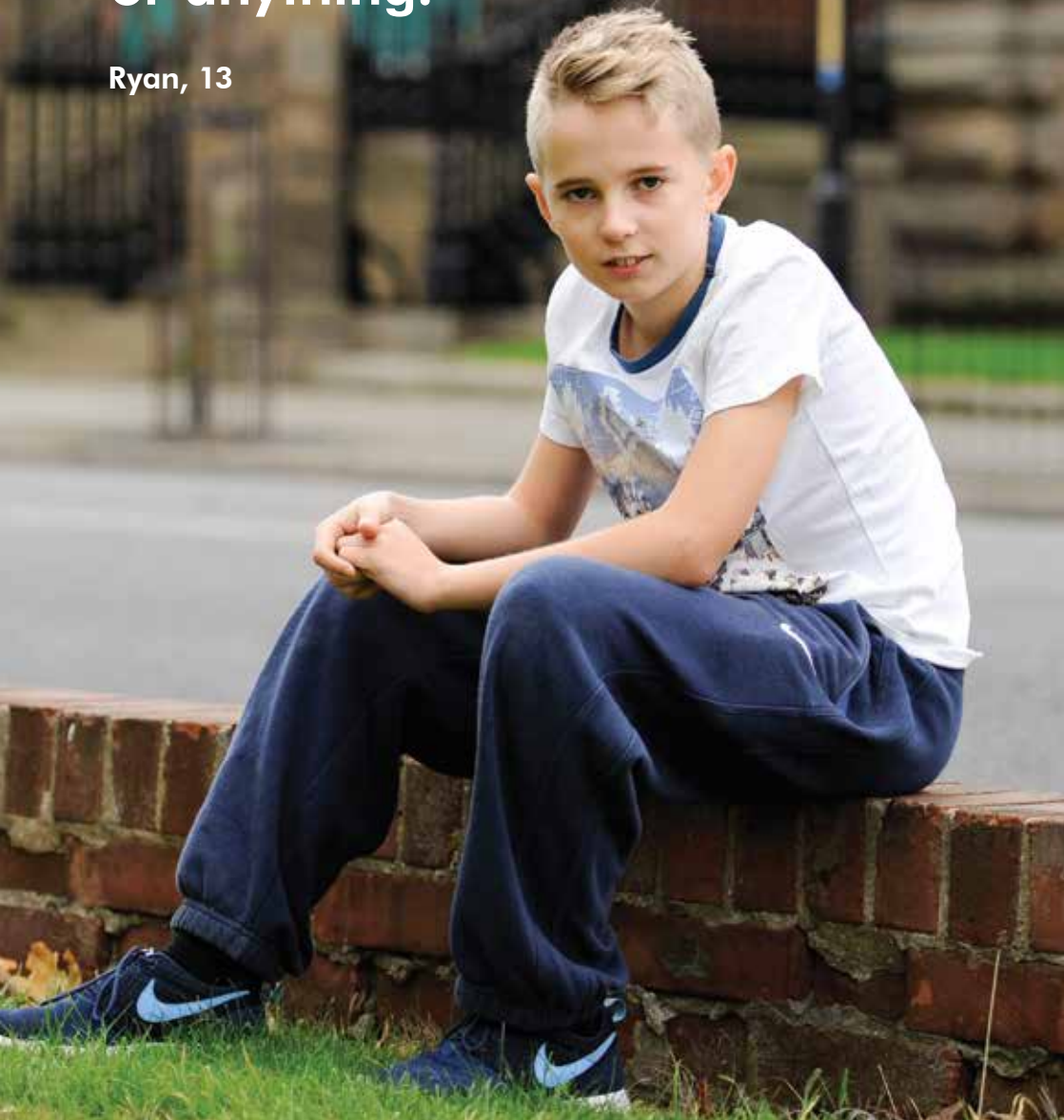
Finding out that someone close to you has cancer can cause many emotions. A lot of people say that their first reaction was: 'What's going to happen? Will they recover?' and then, 'Are they going to die?'. You may be dealing with all kinds of emotions. For example, you may feel:

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

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

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

**Ryan, 13**



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

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

Because you are going through such a confusing time, you may find you get mood swings. One minute you will 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 are affected by cancer. You don't have to explain your situation to anyone if you don't want to. But it is often helpful to share what you are going through. You should only talk to people about it if you trust and feel comfortable with them.

## Writing down your feelings

You might like to use the table on the opposite page to write about your good and bad days. You could list things that make you feel happy or sad, and things that helped you to feel better.

You can also think about things you can do to try and have more good days, and write these down too.

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



Good days



Bad days

Things I can do:

## Letting people know how you feel

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

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

**Sara, 18**

You don't have to talk to anyone who you are not comfortable speaking with. If you don't feel comfortable talking to someone close to you, then maybe a young carer 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 be the school nurse or a teaching assistant. You can also chat online with support workers or other young carers at **[riprap.org.uk](http://riprap.org.uk)** or **[kooth.com](http://kooth.com)**



There may be a local young carers' support group you could join. Ask around at school or college. We have more information about organisations that can help on pages 111 to 116. 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. You could call the Macmillan Support Line for free on **0808 808 00 00** and talk to a cancer support specialist. They can answer your questions about cancer, or just be there to listen if you feel like talking to someone. It is often helpful to share your feelings, but if you don't want to deal with how you are feeling right now, that's okay too. Do what works for you, and remember that help is there when you feel ready for it.

## Coping with other people's feelings

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

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

Sometimes they may want to take their mind off the situation, just as you do. You could watch a film together or play a board game (if they are up to it). They will really appreciate just doing something normal and spending time with you.

If you have brothers or sisters, they might get upset too. If you are older, one of your responsibilities as a young carer may be to look after your siblings. This might include talking to them and comforting them. It is not always easy to know what to say or do. But just doing your best to look after them is good enough.

**'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**

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

If you feel like you need to talk to someone, you can always contact the Macmillan Support Line on **0808 808 00 00**. We also have information about other useful organisations on pages 111 to 116.

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

'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**

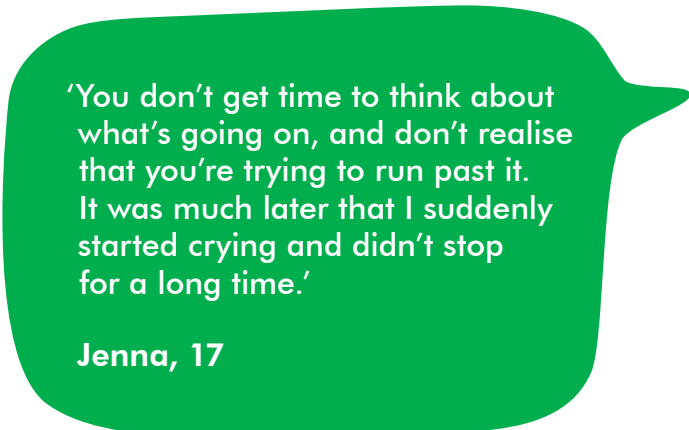
# Counselling (support if you would like to talk about your feelings)

If you are 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 may feel embarrassed about needing to talk to someone when it seems as though other people don't need to. But counsellors are there to help.

You can go to your GP and ask to be referred to a counsellor. There might also be a counsellor at your school or college. If you do see a counsellor, you can decide how much you would like to share with them. Anything you tell them will be confidential, so they won't tell anybody else.

You may find it helps to talk to somebody who is not directly involved in your situation. If you are angry with someone or frustrated, you can talk to the counsellor about it without upsetting anyone.



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

**Jenna, 17**

If you decide that the counsellor you are given is not the right person to help you, tell someone. It is important that you trust your counsellor and feel comfortable with them. You shouldn't feel bad about asking to see someone else if it doesn't feel right. The person who referred you to the counsellor may be able to arrange for you to see a different counsellor. We also have more information about different people you can talk to on pages 55 to 63.

## Hopes and fears

It might help you cope if you talk about what is frightening you, and things that you hope will happen. If you are finding it difficult to talk about these things, the table on the opposite page might help. You could use it to write down your hopes and fears. Putting them down on paper might be easier than saying them out loud at first. Or it might just help you to work out how you feel.

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

**Siana, 14**

Even if you don't want to share it with other people, you may still find it useful to write down your hopes and fears.

There is also space for you to think about what you could do next to help with your fears. This could be talking to the person you look after, joining a support group, chatting to other carers or just asking for some extra help with day-to-day things.

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





Hopes



Fears

Things I can do:

# Depression

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

It is important to recognise that depression is not anybody's fault. Depression is an illness that needs to be treated, just like cancer. If you are worried the person you are looking after may be depressed, try talking to them about it. If you are not comfortable doing this, or if it doesn't help, talk to another adult. It is important that the depression is diagnosed and treated.

Young carers can also have feelings of depression. If you think you might be feeling depressed, it's important that you get some support. You could talk to a health or social care worker, a young carers' service, your GP or a teacher at school. They will be able to help you find the support you need.

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

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

**Rayna, 17**

**'Sometimes I would have to walk my little sister to school, or ask the next door neighbour to walk her to school.'**

**Ryan, 13**



# RELATIONSHIPS

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How cancer might affect your relationships	36
Friends	37
Family	38
Boyfriends and girlfriends	39

# How cancer might affect your relationships

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

While you are looking after someone who has cancer, your relationships with friends and family may change. Try not to worry about this. All relationships change and develop over time. For example, your best friend now may not be the person they were when you first started school. Some relationships disappear over time, while others grow stronger. You will probably experience both. But remember there are people who will always be there for you.

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

**Sapna, 16**

# Friends

Talking to friends about cancer can be difficult, and you might be scared about telling them.

When the person you look after is first diagnosed, you may be in shock. You might want to hide away. Or you might just need time to think things through, and that's okay.

You might be worried that your friends won't understand what you are going through. Or you may feel that if you tell them, things won't be normal between you.

But there are lots of positive things about deciding to talk to your friends about your situation:

- You will have someone to talk to when you are stressed or upset.
- You won't have to make excuses if you cancel plans with them.
- They will understand if you are having a bad day, and will give you some space or more support.
- You are less likely to bottle things up.

You may not want to tell all your friends straight away. But talking to one or two very close friends is a great place to start. You might have best friends who you feel you can turn to, or other friends who you feel would be the most supportive. Be prepared for your friends reacting differently – no two people are the same. Some people will be calm and simply carry on as normal. Others may not know what to say to you, and some might be upset. They may need time to take it in, just as you did.

# Family

It is likely that the person you are looking after is your mum or dad, your brother or sister, or one of your grandparents. It could be someone who lives in your house, or who you see often.

It will take time for you all to come to terms with the cancer. The most important thing is to try to work through it together. Talking to each other and spending time together as a family can help. Doing as many as possible of the normal things you did before the cancer can also help.

Having someone in the family with cancer can cause lots of different emotions. People might get angry and upset more often, or argue with each other more. Don't feel bad if you have arguments with your family, including the person you are looking after.

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

Other members of your family may also want to help, so don't feel like you have to do everything yourself. There are lots of ways that they can help out, such as tidying the house or doing the shopping. This will give you a break, and help them feel that they are supporting you.

It is also important to remember that you don't have to do anything you are not comfortable with. For example, the person you look after may need help getting to the toilet. If you feel uncomfortable about helping them, you should talk to them or another family member about it. You could also talk to a health or social care professional instead if that is easier.



# Boyfriends and girlfriends

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

Being in a relationship can be fun and exciting. But if things are not going well, or if you split up, it can really hurt. This can cause more stress on top of looking after 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 the cancer. But what happens in the rest of your life is still important. Cancer may be a huge part of your life right now, but it's not your whole life. Remember you can always talk to a close friend or professional about how you are feeling.



# SCHOOL OR COLLEGE

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What about school?	42
Talking to your teachers	43
Keeping up with homework	44
Missing school	46
If you are being bullied	47

# What about school?

For some young carers, going to school or college is a welcome relief. It means that you can see friends and forget about your problems for a few hours. For others, going to school means being away from the person that you are looking after, and this can make you worry.

Not everyone will have the same experience. But telling your school that you are looking after someone with cancer will make it far easier to get support if you need it.

Young carers' services can also speak to your school for you. There will be someone at school who can make sure you don't have to go through this alone, and some schools have extra help for young carers.

Some things you might be worried about are:

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

Telling your school about your worries or problems can help them support you. For example, you could ask if you can contact the person you look after during lunchtimes.

# Talking to your teachers

You may not want to tell your teachers that you are looking after someone with cancer. But if they know, they may be able to help you. There might be a few teachers who you really like and trust, so you could start by talking to them. Or you could tell other members of staff at the school who you trust.



# Keeping up with 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 are finding it hard to concentrate at home, think about whether there is another place that you can go to do your homework. This could be a relative or friend's house, or a school or homework club.

If you are worried that you might be falling behind, you can ask a young carer worker or a family member to talk to your school about your homework. It may be possible for the school to give you a bit less homework, to make things easier.





## Missing school

Balancing 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 with cancer. Or you may struggle to get to school on time. If these things happen, speak to a teacher or someone who works at your school. They may be able to help you get support for yourself and your family. 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.



# If you are being bullied

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

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

Young carers' services can also offer support, and we have contact details for organisations who can help on pages 111 to 116. You may be able to talk to other young carers who have experienced bullying.

You could tell your teachers about the website **[kidscape.org.uk/beingme](https://kidscape.org.uk/beingme)** Here, they can download an anti-bullying resource for teachers, created by Kidscape and Carers Trust.

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

**Ryan, 13**



# MONEY AND WORK

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Cancer and money issues	50
Benefits and financial help	51
If you work	52

## Cancer and money issues

When someone has an illness like cancer, it can affect how much money everyone in the family has. The person who is ill may have to stop working for a while. Other people in the family may also have to stop working, or work less, so that they can be carers. There can also be extra costs from things like travelling to hospital. These changes to the family can affect you if you are a young carer. But there is help available if you or your family are having money problems because of cancer.

# Benefits and financial help

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

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

- Call Macmillan on **0808 808 00 00** or visit **macmillan.org.uk/benefits**
- Find out if you can speak with a social worker about getting a young carer's assessment to find out what financial and practical help you might need. We have more information about having a young carer's assessment (see page 16).
- Visit **gov.uk** (if you live in England, Scotland or Wales) or **nidirect.gov.uk** (if you live in Northern Ireland).

The person with cancer could also call Macmillan on **0808 808 00 00** to find out more about Macmillan Grants. These are one-off payments to cover a wide range of practical needs. They are for the person who has cancer. They can include things such as heating bills, extra clothing, or a much-needed break. The person with cancer has to apply for them through a health or social care worker.

Your school or college, or a young carers' service, may also be able to help.

## If you work

If you are working, even if it is just part-time, you might decide to tell your manager or someone else at work that you are looking after someone with cancer.

Here are some reasons why you may want to tell someone at work about your situation:

- If you get upset at work, they will be able to support you better.
- They will understand if you have to miss work or are late.
- They may be able to give you time off, or arrange for you to work flexible hours.
- If you work shifts, they could arrange your shifts to fit around your responsibilities 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 work, in case they think you can't do your job properly. You may think that you will lose your job if you tell your boss that you are a young carer. In the UK, if you are the main carer for someone who has cancer, it is 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. You might want to go to work and just be normal. For some people, having a part-time job is a good chance to get out of the house and do something for themselves. It means having a place where you don't have to think or talk about cancer.

Carers Trust has produced a free guide called **Getting into work: A guide for young adult carers in England**. It includes advice on how to deal with problems finding and staying in employment, how to find a job, how to apply for jobs, and how to speak to your employer about being a carer. You can read the guide at [carers.org/article/getting-work-guide-young-adult-carers](https://carers.org/article/getting-work-guide-young-adult-carers)

## Time off work

If you are the main carer for someone who has cancer, you could get paid or unpaid leave from work to look after them. You can find out more at [macmillan.org.uk/information-and-support/organising/work-and-cancer/if-youre-a-carer](https://macmillan.org.uk/information-and-support/organising/work-and-cancer/if-youre-a-carer)

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





# GETTING HELP AND SUPPORT

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Where can you go for help and support?	56
Support groups	57
Young carers' projects	58
Social workers	59
Voluntary organisations and charities	61
Online forums	62

# Where can you go for help and support?

When you are looking after someone with cancer, you might not be sure how to get information about cancer, or about being a young carer. When you search the internet, you can often end up on unhelpful websites that give you no information.

This is why some young carers start up their own support groups, often through school or college, or a young carers' service. It's a good way to share information, and to help each other cope with the different feelings you are having. There is always someone to talk to, including other young people who are going through something similar to you and who will understand.

# Support groups

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

Your school or college may already have a support group. Or your local council might have set one up. Ask around, or look online to see if there is one in your area. We have information about websites that can help you do this on pages 111 to 116. You might be nervous at first, but support groups aren't scary – lots of young carers find that they are good fun. You might want to talk about cancer, but you will probably end up chatting about all sorts of things.

If there isn't a support group that you can go to locally, you can set one up. Macmillan can help you start your own support group, with advice, training and funding. There is more information and a search tool to find local support groups at **[macmillan.org.uk/supportgroups](https://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](https://professionals.carers.org/young-carers)**

## Young carers' projects

These projects are run by young carer workers. They can offer:

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

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

# Social workers

A social worker is someone who helps people sort out their practical and financial problems. Not everyone has a social worker, but your family might have been given one. This might be to help you all cope with looking after someone who has cancer. Social workers can give you lots 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.

The law says that any young carer or their family can ask for a local social worker to visit them and do a young carer's assessment. We have more information on page 16.



# Voluntary organisations and charities

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

These are some cancer charities that can help:

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

There are also charities for particular types of cancer.

There are charities just for young people, like the Children's Society. And there are charities that support you and your family, such as Family Action.

Charities like Carers Trust and Carers UK are there for anyone who looks after someone who is ill or disabled.

We have contact details for all these organisations on pages 111 to 116. They can give you information and help you get the support you need.

## Online forums

Many young people communicate online, and this can be a good way to talk to people who are in a similar situation to you. But it is important to always stay safe and use secure online forums.

Here are some things you should do to make sure you are safe:

- Tell a responsible adult which forums you use and who you talk to.
- Tell someone if you are feeling unsure or uneasy about anything.
- Don't use your real name – make up a nickname instead.
- Don't give out personal information, for example which school you go to or where you live.
- Remember that it is not a good idea to meet someone that you have met in a forum – they may not be who they say they are.
- Remember that, even though it's great to offer support to others as well as get support yourself, you can leave a forum or take a break whenever you need to.

Your school should be able to give you more information about staying safe online.

Joining an online forum can put you in touch with lots of people who are in the same situation as you. Some examples are:

- **[riprap.org.uk](http://riprap.org.uk)**
- **[kooth.com](http://kooth.com)**
- **[carersuk.org/forum](http://carersuk.org/forum)**



The best things about forums are that you:

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

We have a list of organisations that can help on pages 111 to 116.



# LOOKING AFTER YOURSELF

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Eating – food and your feelings	66
Sleeping	67
Making time for you	69
Drink and drugs	70
Self-harm	71

## Eating – food and your feelings

Yes, we know it's obvious, but you must remember to eat. And eat healthily. It's normal to not feel like eating when you feel worried. And it's also normal to eat 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 look after someone who is living with cancer.

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

If the person you look after or other family members have had to stop working, you may be worried about paying the bills, including buying food. We have more information about financial support and help with money worries on pages 50 to 51.

# Sleeping

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

It can be hard to switch your brain off at night. Your head hits the pillow and your mind goes into overdrive. You may be thinking about the person who is ill or 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 are caring for is having a bad night, which then keeps you awake.

Here are some things you can do to try to get a good night's sleep:

- Read a book or magazine before you go to sleep. This will focus your mind on something other than cancer.
- Take a break from your phone, laptop or TV for half an hour before bedtime to help you to wind down and relax.
- Have a bath. If you like, you could add something like lavender oil or a bath soak that can help you to relax.
- Listen to relaxing music.
- Write a diary, or a to-do list for the next day. If you put all your thoughts down on paper, they won't be quite so busy in your head.

If lack of sleep is affecting your physical or mental health, speak to a teacher or nurse at school, or your GP, who may be able to help.

It is important to look after your emotional wellbeing. If you are feeling stressed or anxious, there are lots of tools and resources available to help you to relax and clear your mind. Speak to your school, GP or young carers' service for more information.

Writing down any thoughts and questions you have might help too.

# Making time for you

It's easy to feel guilty or selfish about going out and having fun. You may worry that if you go out with your friends, something might happen to the person you look after. You might feel guilty for having a good time when someone so close to you is ill.

It is important that you make time for yourself to do the things that you like doing. These might be things like:

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

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

# Drink and drugs

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

If you are thinking about drinking alcohol or taking drugs, talk to someone about how you are feeling. This could be anyone you trust, such as a friend or family member, GP, social worker or young carer worker. Talking to someone might help with how you are feeling. They may be able to suggest different practical ways of coping, and help you get the right information and advice about drugs and alcohol and how to stay safe.

If you think that you are drinking too much alcohol, or if you are taking drugs to help you cope with what is happening in your life, you should try to get help as soon as possible. Try talking to friends and family. If you don't feel comfortable doing that, there are lots of helplines and groups you could go to for support. We have contact details for organisations that can help on page 114.

You may want to go to your GP, who can refer you for counselling and support.

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



# Self-harm

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

If you are looking after someone with cancer, you may be at risk of self-harming. If you have had thoughts about self-harming, or if you have started to hurt yourself, it is really important that you get help. Tell a family member or friend. Or we have a list of organisations on pages 111 to 116 that can help. You should also make an appointment with your GP or talk to a young carer worker if you are worried about how you feel, or whether you may have depression. There is more information about depression on pages 32 to 33.



**‘When I used to ask the nurses, they’d say that I was too young to understand. I don’t think anyone should be too young to understand.’**

**Ryan, 13**

# TALKING TO PROFESSIONALS

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The A to Z of who does what	74
Asking questions	78
Making sure you are included	79

# The A to Z of who does what

When you are looking after someone with cancer, you will probably meet a lot of different health and social care professionals. This could be in the hospital, or at home.

We have put together a list of people you might talk to. This will help you to understand their jobs and ask them the right questions.

## Benefits adviser

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

## Clinical nurse specialist (CNS) or keyworker

A clinical nurse specialist is a nurse who specialises in a particular illness. They may also be your keyworker. A keyworker is someone who will keep in touch with you and the person you care for, and provide any extra support or information you need.

## Community nurse

A nurse who cares for people at home. They can give the person you look after any medication they need, and provide other nursing care. They are also called district nurses.

## Counsellor

Someone you or the person you look after can talk to about feelings and worries.

## Dietitian

Someone who can help with eating and nutrition.

## Doctors

You may meet some of the following doctors:

- **Consultant** – an expert doctor. They are in charge when the person you look after is given treatment in hospital. They have a team of doctors working with them.
- **GP** – a local doctor. You may know this person already. They can help when the person you look after is out of hospital. You can also talk to them about any problems you have.
- **Haematologist** – a doctor who specialises in blood problems.
- **Oncologist** – a doctor who is an expert in cancer.
- **Pathologist** – a doctor who studies cells and looks at biopsies.
- **Radiologist** – a doctor who is trained to look at x-rays and scans.
- **Surgeon** – a doctor who does operations.
- **Medical student** – someone who is training to become a doctor. They may come round with the qualified doctors who are treating the person you look after, so that they can learn about what happens.
- **Palliative care doctor** – a doctor who specialises in helping people cope with the symptoms of cancer.

## Occupational therapist

Someone who can help the person you look after to do everyday tasks if they are unwell or unable to do things themselves.

## Pharmacist

Someone who gives out medicines that have been prescribed, and gives advice about medicines.

## Phlebotomist

Someone who takes blood samples.

## Physiotherapist

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

## Psychologist

Someone who can help you manage your feelings, if you are finding it hard to cope. They can also help the person you look after.

## Radiographer

Someone who takes x-rays and scans. They also give radiotherapy treatment, which is planned by an oncologist.

## Social worker

Someone who can help you and your family with money or work issues or other problems.

## Ward nurse

A nurse who makes sure the person you look after is cared for in hospital. They will give them any regular treatments they need.

## Youth support coordinator

Someone who can arrange activities and help young people stay active and social during and after treatment. They are funded by the Teenage Cancer Trust (see page 116 for contact details). You may meet them if you look after a brother, sister or young family member.

## Youth worker

Someone who works with young people to help them stay active and social, and to reach any goals they would like to achieve. They can support young people living with cancer, or young people looking after someone with cancer.

## Young carer worker

A young carer worker is specially trained to support young carers and their families.

# Asking questions

If you want to know about the health of the person you are looking after, doctors and nurses are the best people to ask. They are treating the person who has cancer, so they have all their medical notes.

It can sometimes be difficult approaching a doctor or a nurse, because they might seem very important and busy. But if they have permission from the person you are looking after, doctors and nurses will be happy to talk to you and help if they can.

You might find it useful to write down any questions you want to ask so you have them ready for when you speak to the doctor or nurse.

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

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

**Cerys, 13**



# Making sure you are included

You may know important things about the person you look after, which would be useful to share with the doctors and nurses. Sometimes the doctors and nurses might talk directly to the adults, and not to you, which might make you feel invisible. It can feel like your questions, thoughts and experiences don't matter.

If you find this happening to you, don't be afraid to speak up about it. Or talk to an adult who can support you and speak on your behalf. You might be able to explain to an older family member that you are feeling left out. That way, they can try to include you next time you are with a health professional.

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

**Abdul, 12**

## Who else can give me information?

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



# COPING WITH DEATH

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Accepting what is going to happen	82
Before someone dies	83
When someone dies	85
The funeral	86
What happens now?	87
Feeling sad because someone has died (grief)	88

# Accepting what is going to happen

If someone you love is going to die of cancer, it feels like the end of your world.

Some of the young carers who helped develop this information have been through it. They 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.

If the person you are caring for has been told that they are going to die, it can be hard for them 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.

However, it is also important to ask any questions you might have about what is going to happen, so that you know what to expect. You might also want to say things to the person who is dying, such as telling them you love them, or talking about a special time you had with them.

You might be feeling angry, and that's okay too.

# Before someone dies

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

Young carers' services, or other organisations that support young carers, can help you and your family put together a plan of what to do in an emergency. This might be if the dying person's health suddenly gets worse or they die at home.

If they get very ill, or if your family decides that they cannot cope or need a break, the person may go into a hospice. A hospice is a place where people with serious illnesses go for specialist care and support. They have special nurses who provide palliative care (special care towards the end of life), including pain relief for the person who is ill, and support for the person and their family to cope with their feelings.

Hospices are designed to be nice places, and friends and family members are welcome.

Some hospices will let you stay overnight from time to time. If you would like to do this, ask a family member or one of the nurses if this is possible. You can also speak to hospice or hospital staff about things you can do for your loved one, if you would still like to be involved in their care.

Talking to the nurses and doctors can help a lot at this stage. Palliative care nurses will understand what you are going through, and they can help you to make sense of what is happening.

People may think that, because you are young, they need to protect you when someone is dying. If that happens, it can feel really frustrating. You might feel as if you are not being allowed to make decisions for yourself. A young carer worker could speak to your family, or the hospice or hospital staff for you.

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

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

We have more information about what will happen in the last few weeks, days, and at the end of life in our booklet **End of life: a guide**. You can order a copy from **be.macmillan.org.uk** or by calling **0808 808 00 00**.

# When someone dies

If you have 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.

You might not be able to tell the exact moment when the person dies, but there are some physical changes that you may notice. Their body may relax completely and they may look very peaceful. You won't know how you will feel until this happens. Some people say they feel relieved that the person is at peace. Remember that there are people around to support you. It's important to keep talking and not bottle your feelings up.

# The funeral

Your family will usually start planning the funeral quite quickly. A funeral director or a religious leader may come to your home. They will probably want to talk to you about the person, and hear about your memories. You don't have to talk to them, but you may find that this helps you feel better.

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

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

If you don't want to go to the funeral, or you are 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 is 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.

You might have had nurses coming around to help out, or other family members coming to visit. So it can feel very quiet for a while until you get used 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. It might be difficult for you to talk about the person who has died, too. But it is important to find someone who you can talk to. It could be a cancer support group, or a trusted friend. Maybe you could talk to a young carer worker or a counsellor. Just make sure you don't keep your feelings to yourself.

You may also need to sort through the belongings of the person who has died. This can be very upsetting, and feel very final. You might not want to do this for a while, and that's okay. Talk to the rest of your family, and try to agree with them when would be a good time. If there is anything you would like to keep, such as a watch, a ring, or photographs, make sure you tell someone.

# Feeling sad because someone has died (grief)

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

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

You may have lots of different emotions, which may come and go in waves. Many people describe feeling shocked and numb in the days and weeks immediately after the death of someone they love.

You may feel very angry. Try not to worry about it, because it is a normal feeling to have.

You may feel guilty. You might think that if you had said or done something differently, the person might not have died. If you are feeling like this, you might find it helpful to talk to a doctor or nurse who was caring for your relative or friend. You could also talk to your GP.

The person you were looking after may have been very ill for a long time, or had symptoms that were difficult to control. You might feel relieved that they are not suffering any more, and there is no need to feel guilty about this.

You may feel lonely, or have a feeling of intense longing to see, speak to or hold the person who has died. If you had a difficult relationship with the person who has died, you may not feel any of the emotions we have described here.

Try not to worry about how often you cry. And don't worry if you can't cry. It doesn't mean you don't feel the loss. Just do what feels right for you.

Some people become very depressed and stop looking after themselves properly. If this happens, you may need extra support. We have lots of information about what to do if you think you are depressed on pages 32 to 33.

Your grief is unique to you. You will have good days and bad days.

## Coping with grief

You might find it helpful to get back to your usual routine quite quickly. Or it might take a long time before you feel ready to face the world again.

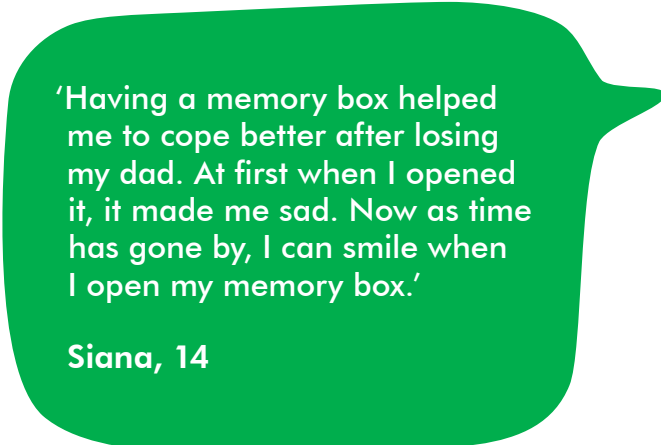
Try to make sure that you don't cut yourself off from life. It can be harder to adjust if you have not been to school or college, or seen your friends, for a long time.

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 maybe there is 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**

You could also think about making a memory box. A memory box is a container that holds special things to remind you of the person who has died. You could put in photos, some of their favourite music or letters or cards from them. These things can help remind you of happy times you spent together and offer you some comfort. You might find making the box very emotional, but it might also be nice to think about your memories.



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

**Siana, 14**

Don't be afraid to talk about the person that has died, 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 will have fewer bad days. And you will start to feel like a normal person again.

There are charities who can help if you are coping with grief. We have information about organisations you can contact on page 115.



# LIFE AFTER CARING

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When you stop being a young carer

94

# When you stop being a young carer

When you have been a young carer, it is very strange when it comes to an end. 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 have been through a lot. If you need someone to talk to, there are lots of organisations that can help. You can find details on pages 111 to 116.

It may be that the person you have been looking after has got better, and they don't need as much support any more. It can be tempting to try to keep 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.

If the person you have been looking after has died, you might be coping with difficult emotions, and trying to come to terms with what has happened. Make sure you give yourself time to grieve. Eventually, you will start to feel less sad and you can start to move on.

You might want to fill your time with a new hobby. For example, some young carers become volunteers, so that they can put their skills and experiences as carers to good use. You might feel stronger. You might feel more emotionally mature. You can do things that other people might not be able to.

And soon, life will start to get back to normal. Seeing friends. Starting new activities. You might have exams to take or want to make some decisions about your future.



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

**Siana, 14**

## Moving on

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

You may feel guilty about leaving. This might be because you are worried the cancer will come back. Or you are sad about leaving people behind who have also lost a loved one. These feelings are normal.

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

If your loved one has long-term care needs, young carers' services and social care services can help support them, and you can focus on your future.

If you are looking for a job, thinking about moving out, or trying to plan your future studies or career, **[themix.org.uk](https://themix.org.uk)** is a great source of information. It is a website just for young people.

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



# GLOSSARY

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Medical terms

98

# Medical terms

## Anaesthetic

An anaesthetic helps make people more comfortable during a medical procedure. A general anaesthetic puts a person to sleep for a while. A local anaesthetic will numb a part of the body so the person cannot feel anything.

## Benign

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

## Biopsy

A biopsy is a small sample of cells taken from the body. Doctors look at the sample to see if there are cancer cells there.

## Blood count

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

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

## Central line

A central line is a long, thin, flexible tube. It is inserted into a vein in a person's chest to give chemotherapy and other drugs. A Hickman line is a type of central line.

## Chemotherapy

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

## Consent

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

## Diagnosis

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

## Fertility

Fertility is the ability to have children.

## Intravenous (IV)

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

## Lymphatic system

The lymphatic system helps to protect us from infection and disease. It is made up of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body.

## Malignant

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

## Metastasis

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

## Oncology

Oncology is the medical specialty that deals with cancer.

## Paediatrics

Paediatrics is the medical specialty that deals with children.

## Palliative care

Palliative care is treatment to help manage symptoms (for example, pain) when the cancer cannot be cured.

## **PICC line**

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

## **Portacath**

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

## **Primary cancer**

A primary cancer is where a cancer starts.

## **Prognosis**

A prognosis is what is likely to happen with someone's disease in the future.

## **Prosthesis**

A prosthesis is an artificial body part. It can be used if that part of the body has been removed.

## **Radiotherapy**

Radiotherapy uses high-energy x-rays to destroy cancer cells.

## **Surgery**

Surgery is an operation, often to remove something (such as cancer) from the body.

## **Terminal**

Terminal is when no more treatment can be given to control the cancer. It can mean the end of life is near.

## **Tumour**

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







# FURTHER INFORMATION

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About our information	106
Other ways we can help you	108
Other useful organisations	111
Your notes and questions	117

# About our information

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

## Order what you need

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

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

## Online information

All of our information is also available at **macmillan.org.uk/information-and-support**

There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

## Other formats

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

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

Find out more at **macmillan.org.uk/otherformats**

If you'd like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

## Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

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

If you'd like to hear more about becoming a reviewer, email **[reviewing@macmillan.org.uk](mailto:reviewing@macmillan.org.uk)**. You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



# Other ways we can help you

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

## Talk to us

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

### Macmillan Support Line

Our free, confidential phone line is open Monday to Friday, 9am to 8pm. Our cancer support specialists can:

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

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

## Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

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

## Talk to others

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

### Support groups

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

## Online Community

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

## The Macmillan healthcare team

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

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

Mal

## Help with money worries

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

### Financial guidance

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

### Help accessing benefits

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

### Macmillan Grants

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

Call us on **0808 808 00 00**

to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit **[macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport)** to find out more about how we can help you with your finances.

## Help with work and cancer

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

### My Organiser app

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



# Other useful organisations

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

## Support for young carers

### Action for Children

**Tel** 0300 123 2112

**Email** ask.us@

actionforchildren.org.uk

**www.actionforchildren.org.uk**

Offers practical and emotional support to help give young carers a break to learn and have fun.

### Barnardos

**Tel** 0208 550 8822

**www.barnardos.org.uk**

Supports young carers and their families across the UK. Provides advice and emotional support through counselling and drop-in sessions, and works with schools so that teachers can better support students.

### Carers Direct Helpline

**Tel** 0300 123 1053

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

Offers free and confidential information for carers. Gives information about how to get financial help, getting a break from caring, going to work and much more. A webchat service is also available (Mon to Fri, 9am to 8pm, Sat and Sun, 11am to 4pm).

### Carers Trust

**Tel** 0300 772 9600

(Mon to Fri, 9am to 5pm)

**Email** info@carers.org

**www.carers.org**

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

## **Carers UK**

### **Helpline**

**(England, Scotland, Wales)**

0808 808 7777

(Mon to Wed, 10am to 4pm)

**Helpline (Northern Ireland)**

028 9043 9843

**Email [advice@carersuk.org](mailto:advice@carersuk.org)**

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

Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.

## **Crossroads Caring for Carers (Northern Ireland)**

**Tel 028 9180 0661**

**Email [ycarer@](mailto:ycarer@crossroadscare.co.uk)**

[crossroadscare.co.uk](http://crossroadscare.co.uk)

**[www.crossroadscare.co.uk/young-carers](http://www.crossroadscare.co.uk/young-carers)**

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

## **Crossroads Caring Scotland**

**Tel 0141 226 3793**

**[www.crossroads-scotland.co.uk](http://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.

## **The Children's Society**

**Tel 020 7841 4400**

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

Runs local services to help vulnerable children and young people in England, including young carers. From the website, you can search for local young carers' projects across the UK, and also access information for young carers.

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

**Tel 01962 711511**

**[www.childrenssociety.org.uk/youngcarer/home](http://www.childrenssociety.org.uk/youngcarer/home)**

This programme specifically 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.

## **General cancer support organisations**

### **Cancer Research UK**

**Helpline** 0808 800 4040

(Mon to Fri, 9am to 5pm)

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

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

### **Marie Curie**

**Helpline** 0800 090 2309

(Mon to Fri, 8am to 6pm,  
Sat, 11am to 5pm)

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

Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

## **Help with money or work**

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

**Tel** 0345 608 4321

(Mon to Thu, 8.30am to 5pm,  
Fri, 8.30am to 4.30pm)

**[www.gov.uk/carers-allowance-unit](http://www.gov.uk/carers-allowance-unit)**

Provides information and advice about benefits for carers.

## **Citizens Advice**

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

### **England**

**Helpline** 03444 111 444

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

### **Wales**

**Helpline** 03444 77 2020

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

### **Scotland**

**Helpline** 0808 800 9060

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

### **Northern Ireland**

**Helpline** 0800 028 1181

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

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

**Tel** 0300 123 3356

(Mon to Fri, 9am to 5pm)

#### **Email**

dcs.incomingpostteamdhc2

@nissa.gsi.gov.uk

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

Provides information and advice about benefits for carers.

### **Getting help with your feelings**

#### **Childline**

**Tel** 0800 1111

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

Children and young people can contact Childline if they feel worried, scared, stressed or 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.

#### **The Mix**

**Tel** 0808 808 4994

(Daily, 11am to 11pm)

**[www.themix.org.uk](http://www.themix.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 and scheduled group chats. You can get in contact by phone, email and web chat.

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

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

An online support forum for people affected by self-harm.

#### **Samaritans**

**Tel** 116 123

**Email** [jo@samaritans.org](mailto:jo@samaritans.org)

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

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

## Support after the death of a loved one

### Childhood Bereavement Network

**Tel** 020 7843 6309

(Tue to Thu)

**Email** [cbn@ncb.org.uk](mailto:cbn@ncb.org.uk)

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

This national network supports children and young people who have had someone close to them die. It has an online directory where you can find local services.

### Hope Again

**Tel** 0808 808 1677

(Mon to Fri, 9.30am to 5pm)

**Email** [hopeagain@cruse.org.uk](mailto:hopeagain@cruse.org.uk)

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

Hope Again is Cruse Bereavement Care's website for young people. Cruse is a national charity that provides support, advice and information to children, young people and adults when someone close to them dies.

### Winston's Wish

**Helpline** 08088 020 021

(Mon to Fri, 9am to 5pm)

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

**[www.winstonswish.org.uk](http://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

### Scope

**Helpline** 0808 800 3333

(Mon to Fri, 9am to 5pm)

**Email** [helpline@scope.org.uk](mailto:helpline@scope.org.uk)

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

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

## Support for young people and families

### Family Action

**Tel** 020 7254 6251

**Email** info@

family-action.org.uk

Or to contact the grants service:

**Tel** 020 7254 6251

(Wed to Thu, 2pm to 4pm)

**Email** grants.enquiry@

family-action.org.uk

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

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

### 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.

### Teenage Cancer Trust

**Tel** 0207 612 0370

(Mon to Fri, 9am to 5.30pm)

**Email** hello@

teenagecancertrust.org

**www.teenagecancertrust.org**

A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

### Youth Access

**Tel** 020 8772 9900

**Email** admin@

youthaccess.org.uk

**www.youthaccess.org.uk**

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



You can search for more organisations on our website at **macmillan.org.uk/organisations** or call us on **0808 808 00 00**.

# YOUR NOTES AND QUESTIONS

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

## Disclaimer

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

## Thanks

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

With thanks to: Charlotte Argyle, Macmillan Carers Support Programme Manager; Laura Bennett, Lead – adult policy, public affairs and development (England), Carers Trust; Karen Aylward, Macmillan Counselling Services Lead, East Sussex Healthcare NHS Trust; Helen Sanderson, Thinkaboutyourlife.org; Belinda Tweed, Macmillan Family Support Worker, Family Action; and Rayna, the young carer who helped us update this edition.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

## Sources

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



# Can you do something to help?

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

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



## **Share your cancer experience**

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

## **Campaign for change**

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

## **Help someone in your community**

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

## **Raise money**

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

## **Give money**

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

**Call us to find out more**

**0300 1000 200**

**[macmillan.org.uk/getinvolved](http://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

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Valid from

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Expiry date

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Issue no

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Security number

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

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

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

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



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

This guide is about looking after someone who has cancer. It is for young people under the age of 18. We have put it together with the help of other young carers.

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

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

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

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

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