



Children's
Cancer and
Leukaemia
Group



Teenagers and
Young
Adults with
Cancer

When your brother or sister has cancer

An information guide for teenagers and young adults
whose sibling is diagnosed with cancer



This booklet is for you

Being told that your brother or sister has cancer can be overwhelming and you may be full of questions. It is a difficult time for everyone in your family as life is turned upside down almost overnight.

You will likely feel many different emotions as you try and come to terms with what your sibling's diagnosis means for you and your family.

You may feel worried or upset at this sudden change that you didn't want or ask for, and you may desperately want everything to go back to normal as it was before their diagnosis. Life can seem very unfair. These feelings are completely normal and you are not alone.

This guide covers how your brother or sister's diagnosis might affect you, your feelings and emotions, and how it is important to take care of yourself during this difficult time. It explains more about cancer, and what you can expect over the coming weeks and months.



This edition was revised and edited by the CCLG Information Team in conjunction with the CCLG Publications Committee, comprising multiprofessional experts in the field of children's cancer.

The quotes in this publication are from siblings of children and young people with cancer. They are personal views and do not necessarily represent the views of CCLG.

CCLG makes every effort to ensure that information provided is accurate and up-to-date at the time of printing. We do not accept responsibility for information provided by third parties, including those referred to or signposted to in this publication. Information in the publication should be used to supplement appropriate professional or other advice specific to your circumstances.

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Cancer: The facts

You may have heard the word 'cancer' but not know what it really means. You might think that it only affects older adults and not children. Knowing more about cancer can help you to understand better what your brother or sister has been diagnosed with.

FACTS

More than 8 out of 10 children now survive cancer

You cannot catch cancer from someone else

Scientists are discovering new treatments all the time

It isn't your fault and nothing you did has caused your brother or sister to have cancer

What is cancer?

Cancer is a name given to many types of diseases that all have the same thing in common: cells in the body start to grow, multiply and become out of control. These abnormal cells then attach to each other and form either a solid lump called a 'tumour', or start spreading around the body. Cancer can make someone feel poorly and tired. There are many types of cancer in children. The most common ones are leukaemia and brain tumours.

What causes cancer?

There is still a lot that we don't really know about what causes cancer in children but scientists are trying hard to find out. We do know that you cannot catch cancer from someone else and it is never because someone has done something wrong. We know that smoking cigarettes, drinking too much alcohol or being overweight can cause cancer in adults but these have not been shown to cause cancer in children and teenagers.



Cancer: The facts

How is cancer treated?

There are lots of different treatments for cancer. The treatment used depends on the type of cancer but the main ones are chemotherapy, radiotherapy and surgery.

Chemotherapy

Chemotherapy or 'chemo' is a drug treatment used to kill cancer cells. It is sometimes given through a plastic tube in your sibling's chest or arm called a central line so the drugs can go straight into the blood stream.

Radiotherapy

Radiotherapy uses x-rays that kill cancer cells. It is given by a large machine and your brother or sister will need to keep very still to make sure that the radiotherapy goes to the right part of their body.

Surgery

This is an operation to remove a tumour and your brother or sister will stay asleep throughout so they don't feel anything.

Common side effects of treatment that your sibling might have:

- Sore skin
- Feeling or being sick
- Losing hair, eyebrows and eyelashes
- Feeling very tired
- Being constipated or having runny poos
- Sore mouth
- Losing or putting on weight

These side effects usually go once treatment has finished.

Everyone reacts differently to treatment and some children may have more effects from treatment than others. It can seem that treatment is making your sibling more ill than actually having cancer is. Treatment can last from a few months to a number of years.



What happens when treatment finishes?

Your sibling will still need to go back to hospital for check-ups every few months to make sure that everything is still ok. Even though treatment has finished, your brother or sister will still feel both physical and emotional effects of having had cancer such as feeling down and tired. Readjusting to normal life again can take some time for the whole family.

What happens if treatment doesn't work?

It is possible for cancer to come back. This is called 'relapse' and happens when some cancer cells have still survived after the first treatment. While this comes as a huge shock, relapse is still often treatable and many young people now survive as we understand more about how it happens. Your brother or sister will need to go back to hospital for further treatment.

Searching Google

There is lots of information about cancer online and finding out more information is a good thing. However, there is also misleading information and scare stories that are not true. Personal posts on forums or social media only relate to one individual's cancer experience which may not happen to your brother or sister. It is best to look at reliable sites (see page 18) and to find out more from your parents.

Our online information hub has reliable and trustworthy information in one searchable place.

www.cclg.org.uk/infohub



Coping with changes

After diagnosis, you and your family will likely face a lot of changes as the impact of having a close family member with cancer can affect normal routines. Life can become unpredictable, so it helps to stay open-minded and flexible as much as possible. Here, we talk about some of the main changes that can happen.

At home

Home life can change significantly for everyone in the family. Your parents might spend lots of time with your sibling, staying with them in hospital or not going to work so that they can care for them at home. It is likely that your brother or sister will need to stay in hospital for periods of time and might involve long trips for treatment at specialist hospitals or overnight stays for your parents and sibling. Extra costs can also add up meaning there is less money available for other things.

Others such as grandparents, older siblings or friends of your parents may become more involved in your life, by cooking meals or taking you to school or sports clubs. This can be a huge help not only for you but also your parents, particularly if your parents do not live together.

Stress levels will be high as you are all trying to cope with your own feelings and worries. Your parents might expect you to help out more at home with extra chores and responsibilities. This can be frustrating and annoying, particularly

when your friends don't have to do the same. Talking to your parents, friends and family members can help as they may not realise how you feel.

Doing active things can help you feel more in control of what is happening as well as helping you to feel that you are doing your bit at home.

Here are some suggestions on what you can do:

- Keep your bedroom and other rooms tidy
- Take the dog for a walk
- Pick up your younger siblings from school
- Buy essentials like bread or milk
- Vacuum the floors
- Cook a quick and easy meal
- Keep up to date with homework
- Tell your parents if school things need signing or paying for



Missing your parents

Having a brother or sister with cancer can be lonely and you might worry that your parents have just simply forgotten about you. Don't worry, they haven't, but they will have a lot on their mind and may not always say or do the right things. Your parents will be dealing with their own emotions like you, as well as trying to keep on top of everyday house chores like cleaning, cooking and shopping. They will probably seem tired, stressed and preoccupied but this is because their attention is on caring for your sibling and trying to understand the unfamiliar world of hospitals and cancer. It isn't because you have done anything wrong.

Sometimes, you might have to take the first step to talk with them about how you feel. You shouldn't feel guilty or that you are adding more stress onto them, being honest is usually the best way. Your parents will be able to reassure you that they still love you even if they seem to be busy with other things.



Helping your brother or sister

You may want to help your brother or sister but not know how. It is hard to imagine what they might be thinking and feeling but it will be very similar to you. They will wish this wasn't happening to them and may dislike all the extra attention. Ask them if there is anything they need or how you can help them.

Here are some simple suggestions:

- Watch a film, TV or play video games with them
- Tell them about what everyone has been up to
- Wash your hands to avoid spreading colds or bugs
- Visit them in hospital
- Distract them with games or activities
- Act the same with them as before their diagnosis - even if you did fight with each other!
- Listen to them and ask them how they feel
- Just be with them so they know they are not alone

At school, college or university

It is really hard to concentrate at school when you are worrying about what is happening at home or hospital. You might feel more tired as you are doing extra at home, and you might have less time to do homework. Or you might lose interest as you have more important things on your mind.

Being at school can help distract you from your worries even if sometimes you want to be left alone. These reactions are normal but try not to bottle up how you feel and remember that you are not on your own. Talk to your teachers so that they know how you are feeling and can therefore help and support you. You can choose who needs to know so not all teachers or pupils have to be told anything at all.

If you are at college or university, talk to your student wellbeing service who will help work out a plan to help you cope with your studies while you are supporting your sibling and family. Most universities will offer counselling or support that is open to all students.

Bullying

Occasionally, your brother or sister might be teased or bullied because of their cancer. This may be because they look different or it may be because the bullies don't understand about cancer. You may also be teased because of your brother or sister.

This will feel very unfair because you know what your sibling and family are going through at the moment. You might be angry and want to say something back. This is understandable but doesn't usually help. It is much better to talk to your parents or a teacher about what is happening so that any issues can be sorted.

At work

If you are over 18 years old, you may be in full-time employment. It is your choice whether you tell your manager or work colleagues about your sibling's cancer. If you do tell them, you will likely find that they are supportive and understanding, especially if you need to take time off or are having a stressful day. Some employers can offer access to benefit schemes which include counselling or emotional support – it is worth taking whatever is available to help get through this difficult time.

Being asked questions

Other people might always ask you questions about how your brother or sister is doing, or how your parents are. It is hard to always be answering questions, or you can feel resentful if people don't think to ask about how you are doing. Sometimes, you want to tell people about what's going on and other times you might find it easier to say nothing. If you don't want to talk about anything, you can say "thanks for asking, but can we talk another time?". Preparing some general answers to common questions can help with this.

Your friends

Good friends can make all the difference to how you feel by being there for you and keeping life as normal as possible. But it can be hard for them to know what to say to you. They might be afraid of upsetting you so avoid you or say insensitive things. Or they might just carry on as though nothing has happened.

This can seem selfish, but it is likely that your friends are finding it difficult to relate to your situation as it hasn't happened to them before.

You might need to take the first step and let your friends know that it's fine for them to ask questions about your brother or sister, or to ask you how you are doing. Try explaining that you have a lot to deal with at the moment but that you would still like to spend time with them as normal. This can help keep you busy and take your mind off from what's happening at home.



Your feelings

Having a sibling with cancer is tough to deal with and you may find it hard to cope with all of the changes in family life and routines. You will likely feel a lot of emotions that can seem overwhelming.

It is important to take care of yourself and paying attention to how you feel is an important part of this. All of these feelings are normal in these circumstances and there is no 'right' or 'wrong' way to feel.

Feeling numb

It is common to feel nothing and 'in shock' as you absorb the unexpected news of a diagnosis. You might worry there is something wrong but feeling numb is completely normal and is your body's way of processing the news.

Feeling stressed

Stress can affect how your body feels, thinks and behaves. You might find it hard to sleep or eat properly, have headaches and stomach ache or other aches and pains from tension. Or you might feel distracted or irritable as your mind is taken up with worries. It is important to recognise these signs and to look at ways of helping yourself feel better (see pages 14-15).

Feeling guilty

You may feel guilty for lots of reasons: being healthy when they are ill, for doing or saying something wrong, not being able to do anything to help them, or that you aren't able to give as much time to other things in your life like friends can.

Feeling angry

You might feel angry that someone you care about has cancer and that this is happening to you, and having an impact on your life. You might feel anger towards your parents, and even your sibling for being ill. This can be confusing but is perfectly natural. Sometimes, feeling angry covers up how you really feel deep down like feeling frightened.

Feeling sad

It is common to feel sad for many different reasons. You might feel sad for them and wish that it hadn't happened. You may feel sad for missing the life you all had before cancer happened. It can take time to come to terms with this, and it is important to allow yourself to accept these changes.

Feeling lonely

You might feel like you are on your own, and that other people don't understand what you're going through. Others may have no idea on how this is affecting you and friends might not understand.

Feeling left out or jealous

You might feel jealous if it seems that your parents' attention is always focused on your brother or sister, who might get extra treats and not be told off for things. You might feel jealous of friends who are carrying on as normal without anything to worry about.

Feeling embarrassed

You might feel awkward and embarrassed that your sibling has cancer. They may look different because they have lost their hair and you don't want other people to stare at you. Or you might feel embarrassed that you don't know how to answer people's questions. This is perfectly natural and will get easier with time.

Worrying about your own health

Illnesses like colds and viruses are really common but you might worry if it could also be cancer. Maybe you are looking for cancer symptoms and worrying about your own health but you don't want to bother your parents. You cannot catch cancer and it is highly unlikely that you do have cancer. But it is useful for all of us to know the common signs and symptoms to look out for. If you find that you are thinking about it too much then you might need some extra help to put things into perspective again (see page 15).

Feeling scared or anxious

Worrying about the future and what might happen can make you feel scared and anxious. It helps to take each day as it comes and not to think too far ahead.

No one would ever choose to experience cancer but some young people say that they found it helped them to feel closer and more connected to their family, by spending more time together and supporting each other. You might even have a better relationship with your brother or sister which is a positive change even if you do still argue with them!

Looking after yourself

It is important to look after yourself too as staying fit and healthy can help you to keep strong for your sibling and family. It is completely fine to still have fun and laughter with your friends and to go out as usual.

Here are some suggestions on what you can do to keep healthy

- Eat well
- Keep active to help you feel less tense and anxious
- Get plenty of sleep
- Stick to your normal routines and interests
- Don't drink too much alcohol, smoke or take drugs as a way of coping

Talk about how you feel

One of the ways in which we cope with challenging events in our lives is by talking about them. It can help to talk about how you feel with someone you trust so that negative thoughts don't build up in your head. Talking to others can put things into perspective and reassure you that what you are feeling is ok helping you to feel less anxious and stressed.

You might not want to talk to your parents about how you feel but they love you and will want to help you feel better. The important thing is to keep talking to someone who will listen.

Writing down your thoughts and feelings in a notebook or blog can also help break them down so they become more manageable and less scary. See page 19 for some activities to help.

Who can you talk to?

- Your parents
- Other family members like grandparents, aunts and uncles
- Your boyfriend/girlfriend
- Friends
- Teacher or other club leader (like football, scouts, dance)
- Others who are in the same situation as you (like a friend from the ward)
- Helplines
- Online support
- Local support groups or charity organisations



Sometimes, it is all too much and you may not want to share how you feel with anyone else. This is ok and you can just take yourself off somewhere for a while or plug in your headphones.

Knowing when to ask for extra help

It is normal to have bad days but if you find that your feelings are becoming stronger, you feel more anxious or are struggling to cope with each day then it might help to talk to someone who can support you better, such as a counsellor or psychologist. They are trained to listen and help people talk through their problems, and find ways of coping with them.

The important thing is to not struggle on your own. Talk to someone about how you feel and you can also make an appointment to see your GP, with or without your parents, and they can talk things through with you and refer you to see a counsellor if needed.

And finally...

The important thing to remember is that you are not on your own. We hope this booklet reassures you that other brothers and sisters have gone through similar experiences, and however you feel is ok. There is help available to you and we hope this booklet gives you useful advice on where to go for support.



Helpful organisations

Cancer Research UK

www.cancerresearchuk.org

Accurate and reliable information about cancer

ChildLine

www.childline.org.uk

Call FREE on 0800 1111

Free, private and confidential service for anyone under 19 years old (phone and online) where you can talk about anything that is worrying you

NHS Every Mind Matters

www.nhs.org

Online practical help and support for mental health

NHS MoodZone

www.nhs.org

Online practical help on coping with stress and anxiety

Samaritans

www.samaritans.org

Call FREE on 116 123

Free and confidential 24hr emotional support (phone and online)

Teenage Cancer Trust

www.teenagecancertrust.org

Information, care and support for teenagers and young adults with cancer

Young Minds

www.youngminds.org.uk

Help and advice for mental wellbeing in young people



Notes

A little moment for yourself

Use these mindfulness activities to help you to set small daily goals and feel calmer when things may seem overwhelming.

Sometimes when we feel stressed or worried, it can help to write down some things you feel thankful for or how you are feeling today...

At the beginning of the day:

What would you **love** to do today... 

One thing you **need** to do today...

At the end of the day:

 What **inspired** you today?

What are you  **proud** of today

Activity/feelings notes:

Glasses of water: 

Your **mood** today: 

Special **treat** or **reward**:

Use this space to write down or draw the things that **went well** today and what you **enjoyed**...



Teenagers and Young Adults with Cancer

Having cancer is hard at any age, but for a teenager or young adult it's unthinkable.

'Normal life' suddenly stops and young people find themselves thrown into a scary unknown world of hospitals and cancer treatment. This has a devastating impact at a time when they are already coping with changes in how they think and feel as adolescents.

Teenagers and Young Adults with Cancer (TYAC) recognises that teenagers and young adults


(ages 13-24) have different and specific needs. This is why we work tirelessly to make sure that every teenager and young adult with cancer is treated and cared for in a sensitive and age-appropriate way with the right to fast diagnosis and best treatment, no matter where they live.


TYAC is the UK's professional association for those involved in the treatment, care and support of teenagers and young adults with cancer. By providing information on best practice and new developments, training

and support to our members, and through funding and supporting research into teenage and young adult cancer, we aim to improve the quality of life and likelihood of survival for young people with cancer. TYAC is part of Children's Cancer and Leukaemia Group (CCLG).

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Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.


If you have any comments on this booklet, please contact us. CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.

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