

When your Brother or Sister has cancer

Information for older children



This booklet was originally written by Katherine Green in association with the BCH Sibling Group and CCLG Publications Committee, comprising multiprofessional experts in the field of children's cancer.

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We are grateful to all those who helped to make this booklet. The quotes in this publication are from parents, patients and carers. They are personal views and do not necessarily represent the view of CCLG. CCLG makes every effort to ensure that information provided is accurate and up-to-date at 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 this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

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"It's really frightening having a sister who's got cancer and you always worry and sometimes you think it's your fault."

Introduction

You have been given this booklet because your brother or sister has been diagnosed with an illness called cancer. We hope you will find it helpful.

Inside you can read the thoughts and feelings of other brothers and sisters who we talked to. We want to say a big thank you to all the brothers and sisters who helped us to make this booklet.

If you've still got some questions when you've read this booklet, or would like someone to talk to about how you're feeling, your parents or teacher might be able to help. Or you might be able to talk to one of the nurses when you are visiting the hospital.



What is cancer?

The human body is made up of millions of tiny parts called cells. Cancer is the name given to all illnesses where one of these cells multiplies too quickly. Because far too many of this type of cell are made, this may mean other parts of the body do not work properly. There are two main sorts of cancer: leukaemia and tumours.

Leukaemia is a type of cancer where the white blood cells divide too quickly. All blood cells are made in the bone marrow, which is the soft part in the middle of our bones. In leukaemia, the bone marrow gets so clogged up with white blood cells that there's no room for healthy blood cells to grow. This is what makes people with leukaemia ill.

Tumours can grow in any part of the body, such as the bone and brain. The tumours grow where the cells are dividing too quickly. They can squash healthy parts of the body that are nearby and this is what makes people ill.

What causes cancer?

No-one knows why children get cancer, so it's definitely not your fault, or the fault of anyone in your family.

Facts

- You cannot catch cancer from someone else.
- The cancers children and teenagers get very rarely run in families.
- Even though cancer is caused by damaged genes, it is not usually a gene problem that runs in families.

To hear that your brother or sister has cancer is a big shock.

"When I first found out I didn't know what to feel."

"You feel so helpless because you can't do anything."

"When I found out that Michael had cancer I was thinking he can't die because that's not right. He's going to have medication and he's going to get better."

How is cancer treated?

There are three main types of treatment for cancer. Some people need just one or two of these, whereas others may need all three. The sort of treatment used depends on the type of cancer.

Treatment for leukaemia

The main type of treatment for leukaemia is nearly always chemotherapy. In the earlier part of treatment, this usually needs to be given in hospital. Later on treatment for leukaemia is chemotherapy tablets at home - they may need to take these for a few years.

For certain types of leukaemia, or if leukaemia comes back a second time, a stem cell transplant may be needed.

Radiotherapy is often given as preparation for a stem cell transplant or for people who have got leukaemia cells in the fluid in their head and spine.

Treatment for tumours

Sometimes it is possible to safely remove all or part of a tumour with surgery (an operation). This may be the only treatment needed. However, often an operation is just part of the treatment and other treatment is needed before and after.

Some cancer cells can be destroyed using a treatment called radiotherapy. This treatment is most effective if the cancer is in just one part of the body.

If the tumour is in several parts of the body, or if it cannot be completely removed by an operation or radiotherapy, then your brother or sister may need chemotherapy as well.

Chemotherapy

Chemotherapy is a treatment used to kill cancer cells. Sometimes people have chemotherapy by mouth as a tablet or medicine. Other chemotherapy has to be given into a muscle by injection or into the bloodstream through a drip. Some children have special tubes called central lines put in to help them to have their chemotherapy. Other children have hidden tubes called vascuports or portacaths.

Chemotherapy does not just kill cancer cells, but as a side-effect can also kill some healthy cells. This means that people receiving chemotherapy may have a lot of side effects.

Radiotherapy

Radiotherapy is also a treatment that kills cancer cells. Radiotherapy is given by a large machine. If your brother or sister has radiotherapy they will feel nothing while it is happening, but will need to be careful not to move so that the radiotherapy goes to the right part of the body. A mask might be used to help them keep still if the radiotherapy is needed in the head area.

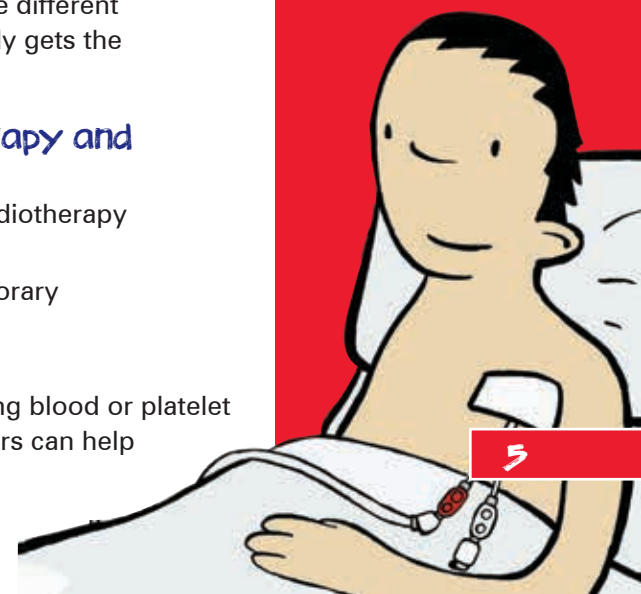
Like chemotherapy, radiotherapy also kills some healthy cells as well as the cancer cells. This causes side effects. The side effects will be different depending on what part of the body gets the radiotherapy.

Side effects of chemotherapy and radiotherapy

- Sore skin in the area of the radiotherapy
- Sickness and diarrhoea
- Hair loss: this is usually temporary
- Tiredness
- Sore mouth
- Not enough blood cells. Having blood or platelet transfusions from blood donors can help
- Losing or putting on weight
- Infection risk.

"Some people think he's fat, but it's not his fault, it's the steroids."

"Leon had to have radiotherapy but he's really well now. He still has to have loads of medication though he's really good in himself."



"All of a sudden the treatment seemed to make her more ill than the cancer."

Surgery

Your brother or sister may need an operation to remove one or more lumps. They will be given an anaesthetic to ensure that they stay fast asleep so don't feel anything. When they wake up medicines will be given to stop them feeling pain. Sometimes during an operation tubes are used and these may stay in for a few days after the surgery. After the operation your brother or sister may feel sleepy for a day or more.

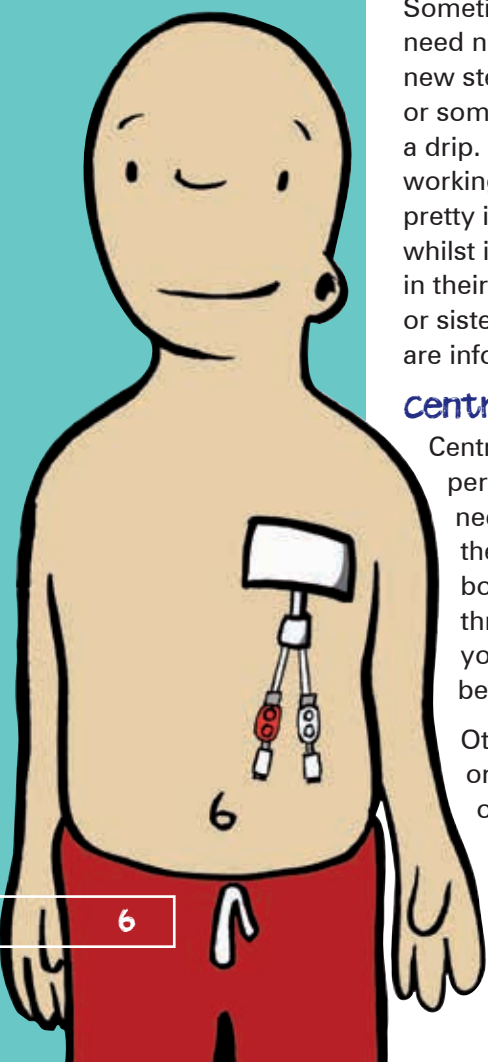
Stem cell transplants

Sometimes when the cancer is in the blood, children need new stem cells to help make healthy cells. The new stem cells come from a member of the family or someone else and are put into the child through a drip. It takes a while for the new stem cells to start working. Before they do, the child will probably be pretty ill and need to be protected from infections whilst in hospital. Brothers and sisters aren't allowed in their room for two weeks or more. If your brother or sister is going to have a stem cell transplant, there are information booklets you can obtain from CCLG.

Central lines

Central lines are plastic tubes that are put into a person to help them have chemotherapy. This needs a small operation. One end of the tube is in the blood stream and the other end is outside the body. The end of the tube may divide into two or three separate tubes. If your brother or sister is younger he/she may call the central line "Wiggly" because it looks a bit like a wiggly worm.

Other people choose to have a vascuport or portacath. These are also put in with an operation and go into the blood stream but there is no part outside the body. If your brother or sister has one of these, a needle will be put into it when it is used.



Who can you talk to?

Brothers and sisters have told us how tough it can be being in a family with a sick child. All these different feelings are completely normal.

"People, don't understand and they don't think it's affecting you, it affects the whole family."

"It affects your life as well, the way you act, different moods."

At difficult times like this it is very important to have people you can turn to, talk to, cry with, or just be with. We asked a group of brothers and sisters who they could go to with their problems.

"I talk to my nan a lot about things and how I feel about Marcus having cancer. I can talk to the nurses too."

"I've got two friends I can talk to, and others I just call up and go out with to take my mind off it all."

Many brothers and sisters feel that they shouldn't tell their parents how they feel.

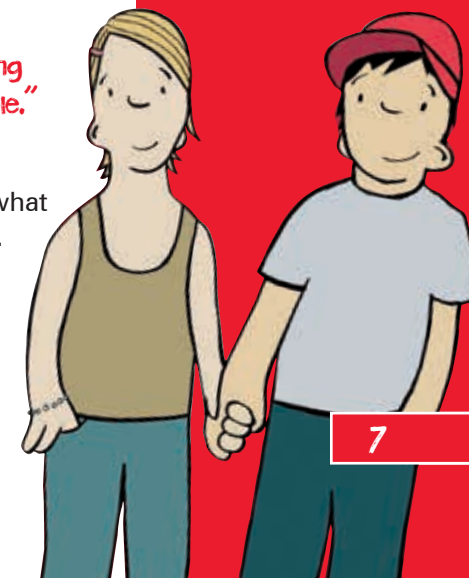
"They've got enough to cope with without handling our problems as well."

"They've got so much to do with our brother being sick, they're all over the place and really irritable."

Some young people find that not everyone is helpful. It may be that they don't understand what is happening and what you are going through. This can be hard.

Sometimes it can feel hard to do things you would normally do and enjoy yourself, because your brother or sister can't join in. It is really important that you do still have fun sometimes.

"Sometimes people don't understand and don't know what to say. This can make it feel as if they aren't helping."



"I used to be able to talk to my Mum and Dad, I don't so much now because my mum is always with Sofia and she hasn't got time. And, as for my Dad, we're just far apart."

"You feel so helpless because you can't do anything."

Facts

1. Lots of young people have difficulty coping with having a sick brother or sister. You may feel some of the following:

- Find it hard to sleep
- Can't concentrate at school
- Don't feel like eating
- Feel quiet and shy
- Feel very frightened
- Are jealous of your sick brother or sister.

It is quite normal to feel these things some of the time.

2. You may feel as though you feel ill too. This is usually because of all the extra worry and stress you are going through.
3. You may feel angry, sometimes with your parents and sometimes with your sick brother or sister.
4. You may feel that having a sick brother or sister has helped your family in some way, maybe bringing the family closer together or making family members appreciate each other more.

When things go badly

Despite the best available treatment, some cancers come back. Often different sorts of treatment can work well and can make the cancer go away again. In a few people the cancer cannot be cured. When this happens everyone is very sad and frightened. The treatment is still important to try and keep a person well and healthy for a long time.

If things go badly it will be particularly important for you to find an adult to talk to. Why not ask a teacher, someone in your family or from the hospital, or someone else you know? The more you tell people about how you feel the more they will understand.

How to cope with School

This can be a really difficult time and some young people find it hard to cope with school. It can be really hard to concentrate if you are worrying about what is happening at home or at the hospital.

"When you're in your bedroom and you've got homework to do, it's really hard when your brother is in hospital, and you know something is wrong, you just can't think about what you're doing, you're just thinking about what's going to happen to your brother."

Sometimes young people find that their brother or sister with cancer gets teased or bullied. This may be because they look different (they may have lost their hair, for instance) or it may be because of fear about what cancer is. You may also find that you get teased because of your brother or sister.

You will probably think that this is very unfair because you know what your brother or sister has been through. You might also feel angry and want to say something back. That doesn't usually help. It would be much better to talk to your parents or one of your teachers. You need to remember that you aren't on your own.

"If your sick brother or sister goes to the same school as you then the teachers will probably already know what is happening. If you are at another school, it might make things easier for you if you or another member of your family, a friend or a nurse told a teacher you get on well with, about your brother or sister, you could choose whether or not that teacher should tell your other teachers. It can make school much easier if there is someone around who understands what you are going through."



"I find it difficult because Mohammed gets a lot of attention, Mum is always with him and there's never any time for me."

your feelings

Having a brother or sister with cancer is a really difficult time for everyone in the family. Everyone will be worried and they may show it in different ways. You may feel left out as your parents spend more time with their sick child, and maybe you have to spend more time with other members of the family, such as grandparents.

Sick children often get extra presents or treats and attention. This is really hard on other young people in the family. You might feel jealous. You probably understand why it's happening but it would be nice if people gave you treats as well.

There are lots of other feelings that you might experience. It isn't unusual to feel guilty because you are well and your brother or sister is not. You will probably also feel scared about what is happening and whether your brother or sister will be OK. All these feelings are quite natural. Talk to your parents, or someone else in the family or, perhaps a teacher, that you can trust and feel comfortable with.



Things to help you cope

1. Try to tell someone what's worrying you.

"I talk mostly to my best friend Shelly. I can talk about anything with her, I can talk about my sister being ill."

2. Find out about the facts.

(See page 12 for some more information.)

"It's easier now because I know what's going on. At first I'd never even heard the word cancer."

3. Find some way to deal with your feelings.

Talking to somebody really helps. If you can't or don't want to do that, maybe you could write down your thoughts and worries. You could write it all as a letter to someone, even if you don't want to send it. If you feel angry, try and control your anger.

"When I heard my brother relapsed, I was so angry. When I get angry I have to take it out on something, like throw something or kick a ball."

4. Find a way of doing something positive.

Some young people find it easier to carry on as normal. That's fine.

You might find you're asked to do extra things to help, and you might feel a bit cross about that. Just remember that it is a way you can help your sick brother or sister, or your mum and dad.

You might like to help raise money for the hospital or a charity. Ask a teacher or another adult to help you. Maybe your friends would like to help too.

Some young people decide they are going to be blood donors when they are old enough. Or maybe you could ask adults you know to give blood or become a bone marrow donor.

"Mum always says to me, could you just do me a favour and clean the living room or take the dog for a walk or something. I moan sometimes because I don't want to do it. But when Matthew's in hospital, I do things. I just think anything to help."

Coping with questions

You might find that people are always asking you questions about how your brother or sister is, or even how your mum and dad are. It can be quite hard to always be answering questions. They might not think to ask about how you are doing. Think about how you want to respond to questions.

"I just say as little as possible. If you act as if you don't know, then they don't ask you any more questions."

"It's really hard when my friends come round. They see Grace and I have to explain to them what's wrong with her. I find that really hard."

Useful facts

- Nowadays over 8 out of 10 children are cured of their cancer.
- It's much easier to cure cancer in children and young people than in adults.
- A lot of work is going on to find new cures for cancer and to improve the different kinds of treatment.
- There are a large number of adults who are survivors of childhood cancer.

Want to know more?

Children's Cancer and Leukaemia Group

An organisation for professionals treating children with cancer. Provides a range of award-winning information for patients and families affected by childhood cancer.

Website: www.cclg.org.uk

Email: info@cclg.org.uk

Tel: 0116 249 4460

Siblinks

An organisation that provides information and support for brothers and sisters aged 13-25 years who have a sibling or other relative with cancer.

Website: www.siblinks.org

Teenage Cancer Trust

Deals with all issues of teenagers and young adults with cancer.

Website: www.teenagecancertrust.org

Tel: 020 7612 0370

CLIC Sargent

An organisation that provides information and support for all family members.

Website: www.clicsargent.org.uk

Helpline: 0300 330 0803

Macmillan Cancer Support

Information and support for all affected by cancer.

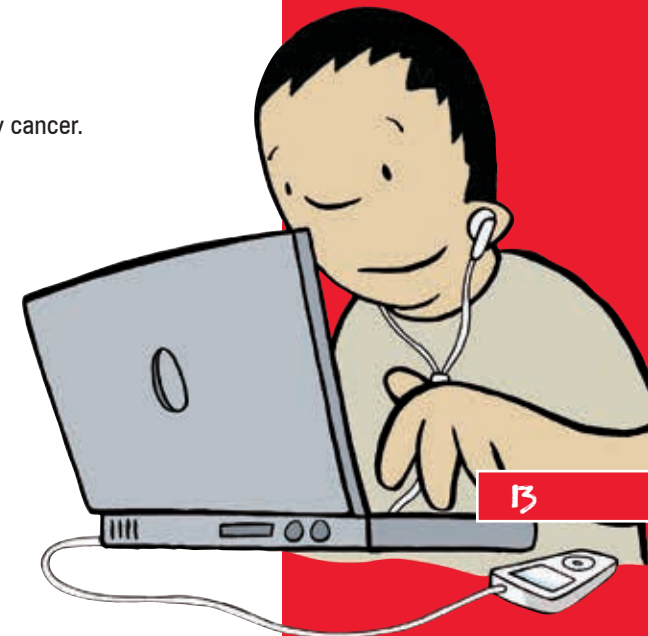
Website: www.macmillan.org.uk

Helpline: 0808 808 0000

Jimmyteens.tv

Online film project for teenagers and young adults who have been affected by cancer.

Website: www.jimmyteens.tv





The CCLG supports the 1,700 children who develop cancer each year in Britain and Ireland. As an association for healthcare professionals involved in their care, it works to benefit children through development of the highest standards of care. CCLG is a major provider of accredited information for patients and families.

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