



When your Brother or Sister gets cancer





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"you'd expect you'd be really ill when you find out you've got cancer, but it's just such little things, you wouldn't expect it, would you?"

"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've probably been given this booklet because your brother or sister has got some sort of cancer. We hope you will find this booklet useful. It contains the thoughts and feelings of some brothers and sisters we met. 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 are feeling, please talk to one of the nurses at the hospital, or one of the Macmillan or outreach nurses or CLIC Sargent workers.



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 it is the white blood cells that 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** is the name given to the sorts of cancers that grow in lumps. Tumours can grow in any part of the body. If the cell that is dividing too quickly is in a bone then the tumour might be on the arm or leg. If the cell that is dividing too quickly is in the head then this will produce a brain tumour. Tumours can squash healthy parts of the body that are near to them and this is what makes people with tumours ill.

What causes cancer?

No-one knows why children in this country 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 nearly always gene damage done during the person's life, not a gene problem that runs in the family.

To hear that your brother or sister has cancer can be a big shock. Some young people told us how they had felt when they found out:

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

"Well at first I couldn't believe that she'd got cancer because she was so full of life"

"You feel so helpless 'cos you can't do anything"

"I feel like it's a punishment for something bad we've done"

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 your brother or sister may be given chemotherapy by injection into a muscle or vein or slowly into the bloodstream through a drip. This usually needs to be done 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 bone marrow transplant may be needed.

Radiotherapy is often given as preparation for a bone marrow 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 is sometimes 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. This chemotherapy is usually given by injection or drip into the bloodstream.

"When I found out that Michael had cancer I was just sitting in my bedroom and I was thinking - I can't just think that he's gonna die because that's just not right thinking that, so I was thinking what's good gonna happen to him, like he's just gonna have medication and he's gonna get better"

Chemotherapy

Chemotherapy is the name given to any chemical that can 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 often have a lot of side effects.

Radiotherapy

Radiotherapy is invisible treatment with rays that kill the 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.

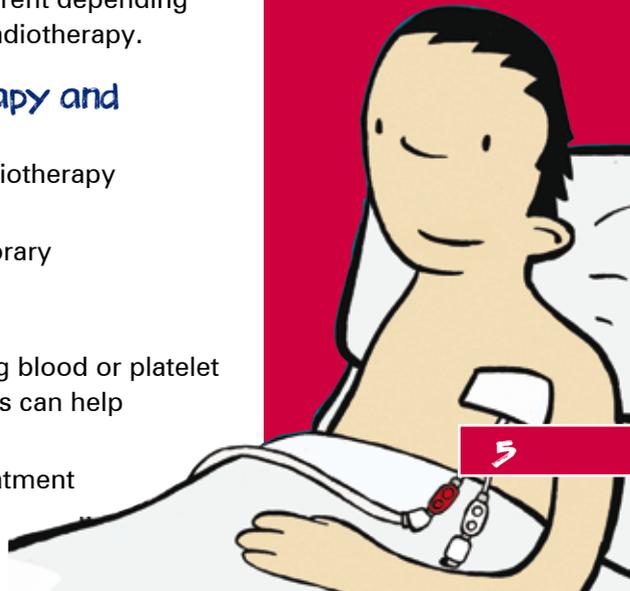
Unfortunately radiotherapy also kills some healthy cells as well as the cancer cells. This causes side effects. The side effects will be different depending on what part of the body gets the radiotherapy.

Side Effects of Chemotherapy and Radiotherapy

- Sore skin in the area of the radiotherapy
- Sickness and diarrhoea
- Baldness: this is usually temporary
- Tiredness
- Sore mouth
- Not enough blood cells. Having blood or platelet transfusions from blood donors can help
- Getting thinner or fatter
- Infection. This often needs treatment in hospital

"Some people go like
"He's fat" but it's
not his fault it's
down to the steroids"

"Leon had to have
radiotherapy and
everything, but he's
really well now but
he still has to go on
Tuesdays and he still
has to have loads
of medication even
though he's really
good in himself"



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

Bone Marrow Transplants

Sometimes when the cancer is in the blood, children need new bone marrow to help make healthy cells. The new bone marrow comes from a member of the family or someone else and is put into the child through a drip. It takes a while for the new bone marrow to start working. Before it does, the child will probably be pretty ill and need to be protected from infections by staying in a special hospital room. Brothers and sisters aren't allowed in the room for two weeks or more. If your brother or sister is going to have a bone marrow transplant, please ask for the special leaflet.

Surgery

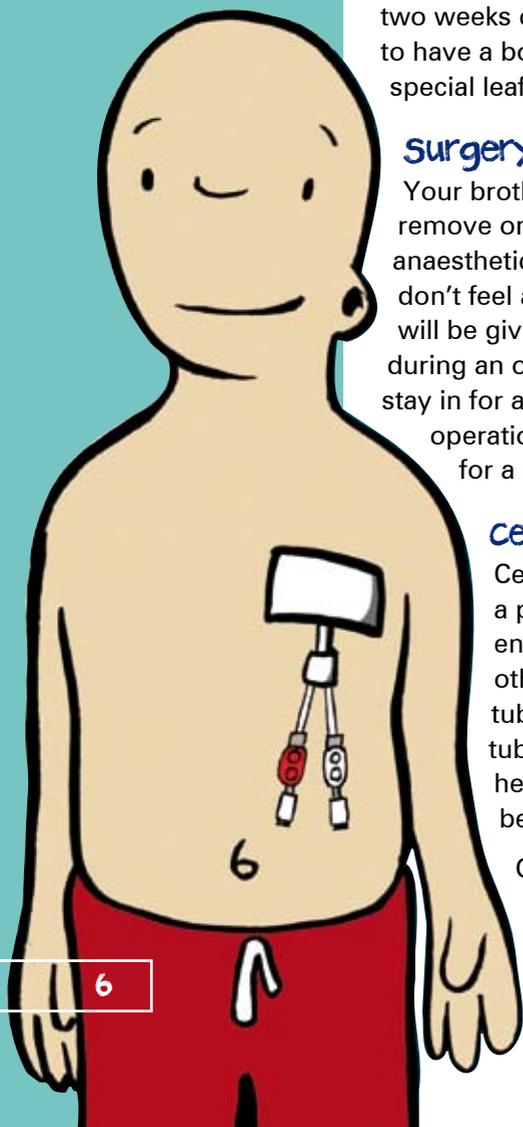
Your brother or sister may need an operation to remove one or more lumps. They will be given an anaesthetic to ensure that they stay fast asleep so don't feel anything. When they wake up medicines will be given to stop them feeling pain. Sometimes during an operation tubes are used and these may stay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

Central Lines

Central lines are plastic tubes that are put into a person. 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.

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Who Cares About you

Brothers and sisters have told us how tough it can be being in a family with a sick child;

"People, they don't understand and they don't think how it's affecting you, it seems selfish, but it's not just the person with cancer, it's affecting the whole family"

"I've got 2 friends who I can speak to really about my sister and stuff and I've got other friends who I can call up and go out with just to take my mind off it really"

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

All these different feelings are completely normal.

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.

"Then there's my Nan, I speak to about a lot of things, like how I feel about Marcus having cancer...then I got nurses, I can speak to nurses"

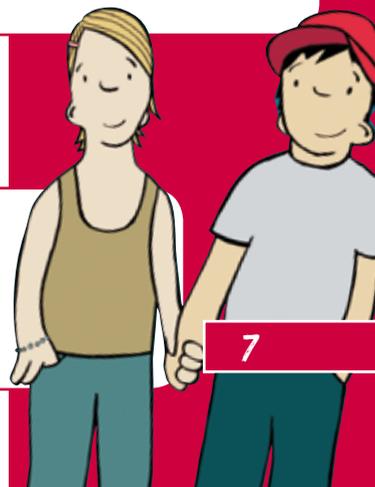
"I've got my Mum and Dad and my brothers and my grandparents, they're like really close, but I find it easier to talk to my friends, with like my problems, it's like, less embarrassing, and my closest friend is probably Dave, 'cos he really kind of understands like"

Many brothers and sisters feel that they shouldn't tell their parents how they feel - some told us why

Some young people find that not everyone is helpful.

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

"They've got so much to do with the ill child, they're like all over the place and really irritable"



Sometimes it can be hard to believe that if it was you who

"...my friends-they were just like horrible to me. They were just backing away saying oh no I'm going to catch something if I go near her, so I was just so angry it's not his fault, he couldn't help it if he's got cancer and anyway you can't catch cancer. They were still like it until I told them what it was and they calmed down and said "I'm sorry"

"Sometimes people don't understand and don't know what to say. This can make it feel like they are not helping."

were ill you would get the same special treatment from everyone as your sick brother or sister is, but it is true.

Sometimes it can feel hard to do stuff and enjoy yourself because your brother or sister can't join in, but it's really important that you have some fun times.

"I used to be able to talk to my Mum and Dad quite a lot, but not so much now I don't: My mum 'cos she's always with Sofia and she hasn't got time, and my Dad, we're just far apart"

"If I get a cold like, I just go to school, I don't tell my Mum, 'cos she's got to worry about my brother as well"

FACTS

1. Lots of young people have difficulty coping with having a sick brother or sister:

- Some find it hard to sleep
- Some can't concentrate at school
- Some don't feel like eating
- Some feel quiet and shy
- Some feel very frightened
- Some are jealous of their sick brother or sister

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

2. Some brothers and sisters can begin to feel ill themselves. This is usually because of all the extra worry and stress.
3. Some young people feel very angry. Sometimes they feel angry with their parents, and some feel angry with their sick brother or sister.
4. A few young people feel that having a sick brother or sister has helped their 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 is so aggressive that it 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.

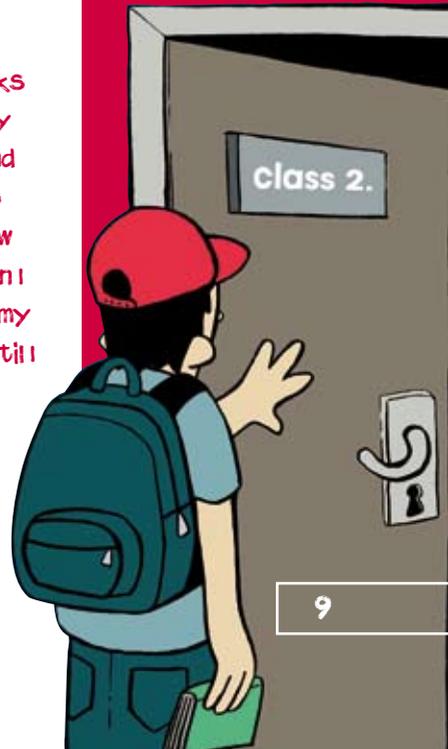
How to Cope with School

Some young people find school really hard to cope with at a time like this. It can be really hard to concentrate if you are worrying about what is happening at home or at the hospital.

"When I'm in school my Mum phones the school and asks if I can go back to my aunty's after school. This day when she phoned she didn't tell the secretary why and they come up and they say Amy you've got to go to your Aunty's. I couldn't stop crying 'cos I didn't know what's happened to Jonathan. That was the point when I thought he was going to die everyday. I couldn't get my mind off him and I was unhappy for about 3 months until I knew he was going to be ok"

"When you've got to do your homework in your bedroom, and you know something's wrong with your brother, he's in hospital or something's happened, you're trying to do your homework, you just can't think about it, you're just thinking about what's gonna happen to your brother"

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



"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."

"What gets me, is why they have to pick on people who have got leukaemia"

A lot of young people find that their brother or sister with cancer gets teased or bullied because they look different. This can make you feel very angry. It can also be very difficult if you get teased because of your brother or sister. Try thinking of some things you could say if you get teased. How about:

"I wouldn't expect you to understand how ill my brother is or what he's going through to try and get better" or **"Only cowards pick on people who are ill."**

It can be really hard not to hit out, but if you can just say something calmly and walk away, you won't get into trouble and probably make them think about how cruel they've been.

Feeling Left out

Sick children often get extra presents treats and attention. This is really hard on other young people in the family.

"If he's in hospital and he's not really ill like my Nan gives him a fiver and my Mum and Dad give him coins, he always gets loads of stuff, he always gets loads of money"

"If Michael wants something he always gets it and me and Craig (my brother) we think, yes, he should get most of what he wants, but then we think, but why can't we have some stuff?"

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

"Yes it was really hard being sent away to Gran's 'cos, they call it pillar to post, and it was like Gran's everyday or it was home or it was hospital"

Coping with Questions

You might find that people are always asking you questions about how your brother or sister is, or ask about your Mum and Dad. People might not think to ask about how it is for you. We asked some young people how they coped with this.

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

"Like when my friends come round and they see Grace and I have to explain to them what's wrong with her and it's really hard"

How to cope with the worry

1. Try to tell someone what's worrying you

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

2. Find out about the facts

"It's easier now 'cos I know what's going on. At first I'd never heard the word before"



"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"

"Mum always says to me, could you just do me a favour and clean the living room or take the dog to the vets or something. I moan sometimes and say "oh Mum I don't want to", but when Matthew's in hospital I say "OK Mum I'll do it", you think yeah, anything to help"

3. Find some way to let your feelings out

"I take my anger out on my sport like in rugby if I'm feeling really angry I really hit them hard"

"When I found my brother had relapsed, then I had all fears and anger in me and I just walked upstairs and I just didn't know what to do because all this fear was inside me and I just broke my lamp, I just had to do it, just to get all the fear out of me and the anger"

These young people found it hard to control their anger. It's best if you can find things that don't matter to take it out on like a pillow or your bed.

Other people find it helpful to write down their thoughts and worries. You could write it all as a letter to someone, even if you don't want to send it.

4. Find a way of doing something positive.

Some young people decide that they are going to be blood donors when they are older. Maybe you could ask adults you know to give blood or become a bone marrow donor. (You can just give them the number of the Blood Transfusion Service 0845 7711 711). It helps some young people to find ways to help their sick brother or sister, or their Mum or Dad. Other young people find it easier to carry on as normal and feel cross that they're asked to do extra things.

You might like to help raise money for the hospital or a charity. Try asking a teacher or another adult to help you.

FACTS

- Nowadays three quarters of children are cured of their cancer
- It's much easier to get rid of children's cancers than adult's cancers
- Billions of pounds are spent every year to find new cures for cancer, so there are better treatments all the time.

Want to know more?

Children's Cancer and Leukaemia Group

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

Website: www.childcancer.org.uk

Email: info@cclg.org.uk

Tel: 0116 2494460

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 with cancer.

Website: www.teenagecancertrust.org

Email: tct@teenagecancertrust.org

Tel: 020 7612 0370

CLIC Sargent

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

Website: www.clicsargent.org.uk

Email: helpline@clicsargent.org.uk

Child Cancer Helpline: 0800 197 0068

Macmillan Cancer Support

Information and support for all affected by cancer. Operates a Youthline for young people aged 12-21 who have questions about cancer or just need to talk.

Website: www.macmillan.org.uk

Macmillan YouthLine:

Freephone 0808 808 0800

Email: youthline@macmillan.org.uk

Macmillan CancerLine:

Freephone 0808 808 2020

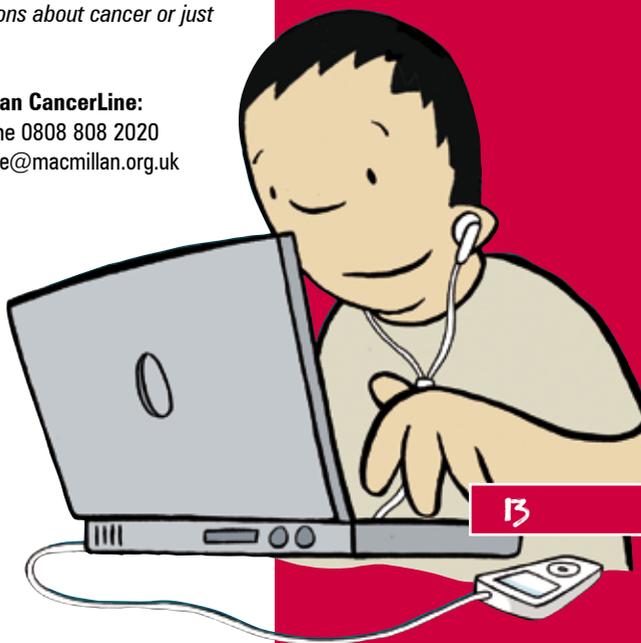
Email: cancerline@macmillan.org.uk

Click4Tic

Information for teenagers affected by cancer and for family members.

Website: www.click4tic.org.uk

Tel: 0808 800 1234





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