



Children's
Cancer and
Leukaemia
Group

Helping brothers and sisters

A guide for parents and other adults supporting
siblings of children with cancer



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Working together to
beat childhood cancer

This booklet was originally written by Katherine Green. This edition was reviewed and edited by the CCLG Publications Committee, comprising multiprofessional experts in the field of children's cancer.

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ChildrensCLG



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This booklet is designed to help parents and the many other adults who come into contact with the brothers and sisters of children with cancer.

Family, friends, neighbours, teachers and babysitters may all be involved in helping parents to look after brothers and sisters, especially while parents are spending so much extra time with their ill child. We hope this booklet will provide some ideas on how best to help brothers and sisters cope when their sibling has cancer.

When a child is diagnosed with cancer it affects the whole family. Brothers and sisters naturally have concerns about

the changes that they see in family life and in their sibling. As well as their parents, other adults in their lives may have to deal with their questions and fears. An honest approach is nearly always best, but if you are not the parents, you should always check with them what it is ok to say. As parents, if you don't feel able to tell siblings what is happening, there may be staff at the hospital who can help.

Each brother and sister will react very differently to the diagnosis and its consequences but the following are some of the issues that may arise.



Coping with changes

Brothers and sisters may worry because they can see that their brother or sister has lost their hair, has tubes attached or is unable to join in the games that they usually play.

Suggestion

Try to warn brothers and sisters before changes with their sibling take place. Reassure brothers and sisters that the tubes don't usually hurt and explain what they are for. Tell them what activities the ill child can still do. They need help to understand that the treatment aims to make their brother or sister well again, even though it may make them more poorly to start with.

Fear

Brothers and sisters of children with cancer can be very scared and may have frightening fantasies about what is happening in the hospital.

Suggestion

Children's fantasies can often be more frightening than what is really happening to the ill child. Children are often reassured by visiting their sibling in hospital and by seeing where and how they are. Some brothers and sisters appreciate the chance to help care for the ill child, and may want to be present at hospital appointments. However, others prefer not to and should not be forced as this may frighten them.

Jealousy

Brothers and sisters may feel jealous as the ill child gets more attention and treats than they do, or because adults are less strict with the ill child.

Suggestion...

It is hard to tell an ill child off, but by trying to maintain a normal level of discipline with all children in the family you will reassure both them and brothers and sisters that family life is still as normal as possible.

When normal discipline is very hard, for example when the ill child is on steroids, it can be helpful to explain to brothers and sisters why behaviour and discipline has changed for a while.

Encourage visitors to bring something small for brothers and sisters as well if they have a gift for the ill child.

Guilt

Children can feel guilty about the illness. They may feel that it is their fault as they may have wished that something horrible would happen to their brother or sister or that fighting with them caused the cancer. They may feel guilty for being healthy.

Suggestion

Brothers and sisters need to be told that nothing they or anyone else did caused the cancer.



Concerns about what might happen

Brothers and sisters may worry about the possibility that their sibling might die. Depending on their age, they have usually heard of cancer and know that people can die from it.

They may not mention it because they are scared to admit it or because they can see their parents are suffering and they don't want to upset them.

Suggestion

Children may ask difficult questions about what will happen in the future. This may mean that they are worried that their sibling is not going to get better or worse still may die. It is helpful to explain that with cancer no one can be sure what will happen, but that the ill child is having the best treatment and that many children do get better.

You may feel unable to answer some questions, in which case, you should tell the child this and make sure that someone (a parent or a member of staff) is aware so that their question can be answered as soon as possible.

It can be hard to give extra support to other children when you are tired and worried about the child who is ill. Spending time with healthy brothers and sisters and making them feel that they are still special is important. Giving them your time and support can help them to understand and cope. If you feel you would like some help with meeting the special needs

of brothers and sisters, please ask a member of the hospital team as individual or group support may be available.

Anger

Brothers and sisters may feel angry about the unequal attention shown, and behave differently or become withdrawn. They may also feel angry that their sibling is ill.

Suggestion

Anger can often hide many other emotions. Brothers and sisters need to know its ok to feel angry. They may need the opportunity to talk about difficult things. Explain that sharing worries with other people makes things easier. Asking questions like "Do you think your brother is getting better?" may help children talk about difficult subjects.

Your patience may be needed, as children may not have the words to express thoughts and feelings that they have never dealt with before.



Problems at school

Concentrating on schoolwork may be difficult, due to the disruption to normal routine.

Problems at school may stem from other children teasing or bullying them or leaving them out as they might think that they can catch cancer.

Many brothers and sisters keep their feelings bottled up to avoid worrying their parents. Often, the place where siblings may show how they feel is at school.

Suggestion

Staff at school need to know what is happening at home so that appropriate support can be given at school. Nurses from the hospital will often be able to go to the child's school to help staff and pupils understand about the illness and treatment.

It may be useful to include brothers' and sisters' friends in discussions about what is happening so that they can help their friend cope.

Missing their parents

Brothers and sisters may miss their parents if they are staying in hospital with the ill child or are away from home more.

Suggestion

Brothers and sisters who are too young to talk and understand what is happening will appreciate extra attention, play and cuddles from

trusted adults. This will help to make up for the contact they miss with other members of the family who may have to spend a lot of time at the hospital.

If at all possible siblings should be taken to visit parents who might have to stay at the hospital for prolonged periods. If a parent can find even short periods of time that will be 'special time' with the brother or sister, this will help them feel important. Telling siblings that their parents love them and miss them will give comfort and reassurance.

Complaining about feeling ill

Brothers and sisters may complain of feeling ill. Sometimes this can become a real problem, making them anxious. They may panic even with a cold or become preoccupied with their own health or their body.

Suggestion

Brothers and sisters may need reassurance that it is a very rare disease and they will not catch cancer from their sibling. Older children may need to know that although cancer can be caused by problems in genes, except in a few rare eye and kidney tumours, childhood cancers are not inherited (they don't run in the family). All complaints of illness should be listened to so that the child is reassured that they are getting the same attention as their ill brother or sister. However, if a sibling is focusing too much on his or her health then some professional help, such as counselling, may be needed.



Children's Cancer and Leukaemia Group

Children's Cancer and Leukaemia Group is a leading children's cancer charity and the UK and Ireland's professional association for those involved in the treatment and care of children with cancer. Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Two out of ten children will not survive their disease.

We bring together childhood cancer professionals to ensure all children receive the best possible treatment and care. We fund and support research into childhood cancers, and we help young patients and their families with our expert, high quality and award-winning information resources.

If you have any comments on this booklet please contact us at the address below.

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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