



Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

Supporting brothers and sisters

A practical information guide for parents and other adults
who are caring for siblings of a child with cancer



www.cclg.org.uk



About this guide

Family, friends, neighbours, teachers and babysitters may all be involved in helping parents to look after brothers and sisters. This resource gives useful advice on how best to help brothers and sisters cope when their sibling has cancer.



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This edition was reviewed and edited by the Information Advisory Group, comprising multiprofessional experts in the field of children's cancer.

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When a child is diagnosed with cancer, it has an emotional effect on the whole family including brothers and sisters. Their world has turned upside down and they may not fully understand why this is happening. They will naturally have lots of questions and fears although they may not want to worry anyone at this anxious time.

An honest approach is nearly always best, but if you are not the parents, you should always check with them on what 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 advise.

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

Coping with changes at home

After diagnosis, families will likely face a lot of changes as the impact of having a close family member with cancer can alter normal routines. Parents may spend a lot of time at the hospital so siblings may need to be cared for by family members or friends. Daily life can become disruptive and unpredictable for the whole family including brothers and sisters.

Adapting to differences in their sibling

Brothers and sisters may worry because they can see that their sibling has lost their hair, has tubes attached, may have lost or gained weight, or is unable to join in with their usual games and playtime.

TIPS

It's good to try and prepare brothers and sisters before any changes take place. You can reassure them that hair will usually grow back, tubes don't usually hurt and explain what they are for, and what activities their sibling can still do such as playing a game in bed or watching a film. They need help to understand that the treatment is trying to make their brother or sister well again, even though it may make them more poorly to start with.

Missing their parents

When parents stay in hospital or are away from home more, brothers and sisters very often miss their parents. Even when parents are at home, many siblings notice that their parents are naturally preoccupied, tired and worried. They may worry that they are no longer important and will miss how life was before cancer.

TIPS

Brothers and sisters who are too young to talk and understand what is happening will appreciate extra attention, play and cuddles from trusted adults such as grandparents, family members and friends. This will help to make up for the contact they miss with parents who may have to spend a lot of time at the hospital.

If 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 to them.

Coping with difficult feelings

Having a sibling with cancer is tough to deal with and many children find it hard to cope with all of the changes in family life and routines. Brothers and sisters will likely feel a lot of the same emotions as parents which can seem overwhelming or wrong. However, all feelings are normal and there is no right or 'wrong' way to feel.

Feeling scared or anxious

Siblings of children with cancer can feel very scared and may have frightening fantasies about what is happening in the hospital and what will happen to their brother or sister.

TIPS

It is natural to want to protect children from the truth, however, their imagination can often be more frightening than what is actually happening in reality. It is often a good idea to be honest and open with them as much as possible by using simple explanations and basic facts to help make sense of what is happening. Children are often reassured by visiting their sibling in hospital as seeing where and how they are can take away some of their fear. While some siblings may want to see or help their brother or sister in hospital, others may prefer not to which is also fine.

Feeling left out or jealous

Brothers and sisters may feel jealous as their sibling seems to have more attention from everyone, more treats than they do, and don't get told off for behaving badly.

TIPS

Maintaining a normal level of discipline with all children in the family (including the child with cancer) will reassure all siblings that family life is still carrying on as normal. When discipline is hard, such as if the child with cancer is taking steroids as part of their cancer treatment, it can be helpful to explain to siblings how behaviour and discipline can change. Try to include brothers and sisters as much as possible, give treats to them too and spend time being with them.

Feeling guilty

Children can feel guilty that their sibling has cancer. They may feel that it is their fault if they wished something horrible happened to their brother or sister after arguing or fighting with them. They may feel guilty for being healthy and going to school as normal whereas their sibling can't.

TIPS

Brothers and sisters need to be reassured that nothing they or anyone else did caused their sibling's cancer and it certainly didn't happen because of any fall-out. Their sibling with cancer would want them to carry on as normal and might look forward to hearing about stories about school or friends from them.

Worrying about what might happen

Brothers and sisters may worry that their sibling might die. Depending on their age, they may have heard of cancer and know that people can die from it but will probably associate it with older adults. They may be too scared to admit it or they don't want to upset their parents by asking them about it.

TIPS

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. It is helpful to explain that while no one can be sure what will happen in each case, their sibling is having the best treatment available and doctors are doing all that they can. You may not know how to answer some questions, in which case, tell them that you need a bit of extra time to think about their question and, if you are not their parent, make sure that someone (a parent or a member of hospital staff) is aware so that their question can be answered as soon as possible.

Feeling angry

Brothers and sisters may feel angry about many different things: someone they care about has cancer, how family life has changed overnight, they have extra chores to do at home and their sibling is enjoying extra attention. They might even feel angry towards their parents and even their sibling for being ill and causing this 'upheaval'. This can negatively affect behaviour both at home and school.

TIPS

Anger can often hide many other emotions such as feeling frightened. It is ok for brothers and sisters to feel angry but they may need help in processing these feelings to limit the impact on others. Explain that sharing worries with other people makes things easier. Giving them the opportunity to talk about how they feel by asking questions like "Do you think your brother is getting better?" may help children talk about difficult subjects. Your patience and compassion may be needed as children may not have the words to express thoughts and feelings that they have never dealt with before.



Complaining about feeling ill

Brothers and sisters may complain of feeling ill and worry that they also have a serious illness like cancer. This can make them more anxious and preoccupied with their body and health causing them to panic even with a common cold or virus. It might also be a subconscious way of making sure they receive the same level of attention as their sibling.

Feeling stressed can also affect how a child feels, thinks and behaves. Children might find it hard to sleep, have headaches and stomach ache as a result of anxiety and tension.

TIPS

Reassure brothers and sisters that cancer is not common in children and they will not catch cancer from their sibling. Simple things like a fluffy hot water bottle to cuddle can help relieve muscle tension or a soft light before bedtime can help children feel calmer and more relaxed.

Any complaints of illness should be listened to in case a visit to the GP is needed and the sibling is reassured that they are getting the same attention as their brother or sister. If a sibling is focusing too much on his or her health, then professional support such as counselling may be useful.

Feeling lonely

Brothers and sisters can feel lonely as their sibling may no longer be able to play with or have fun with them while on treatment. Parents may be away at the hospital, and home might seem an empty place compared to before their sibling's diagnosis. Children might feel that they are on their own and that nobody understands what they are going through.

TIPS

This is a difficult time for the whole family, and it is a good idea to explain how the routine of cancer treatment will affect home life temporarily so they can be prepared. Also, suggest enjoyable activities they can do to help distract them when they are on their own such as reading, writing in a diary or journal (this is a good way of processing worries too), drawing and mindfulness colouring. If your child is a teenager, it is important for them to still go out and spend time with their friends to keep that social connection going. Finally, reassure them that you are always there for them at any time.

Coping at school or college

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. They may:

- withdraw or become very quiet
- become disruptive in class
- cry easily
- become frustrated and have outbursts of anger
- fall behind with class work
- get lower marks than usual
- start missing school
- become rebellious with teachers

Concentrating on schoolwork can be difficult because of changing routines, taking on extra responsibilities at home, and lack of sleep. Homework can be easily forgotten, and they may feel very tired.

It is important that the staff at school know what is happening at home so that appropriate support can be given at school. Any behavioural problems will be dealt with firmly but with sensitivity and understanding. The nurse specialist or keyworker from the hospital would be happy to liaise with the school if needed.

Bullying

Issues at school may also happen from other children teasing or bullying them or leaving them out from fear of catching cancer themselves. They may feel angry at this unfairness and protective of their brother or sister. Schools should have a strict anti-bullying policy that is enforced so siblings should be encouraged to talk as openly and honestly to make sure any issues are dealt with quickly.

Listening to them

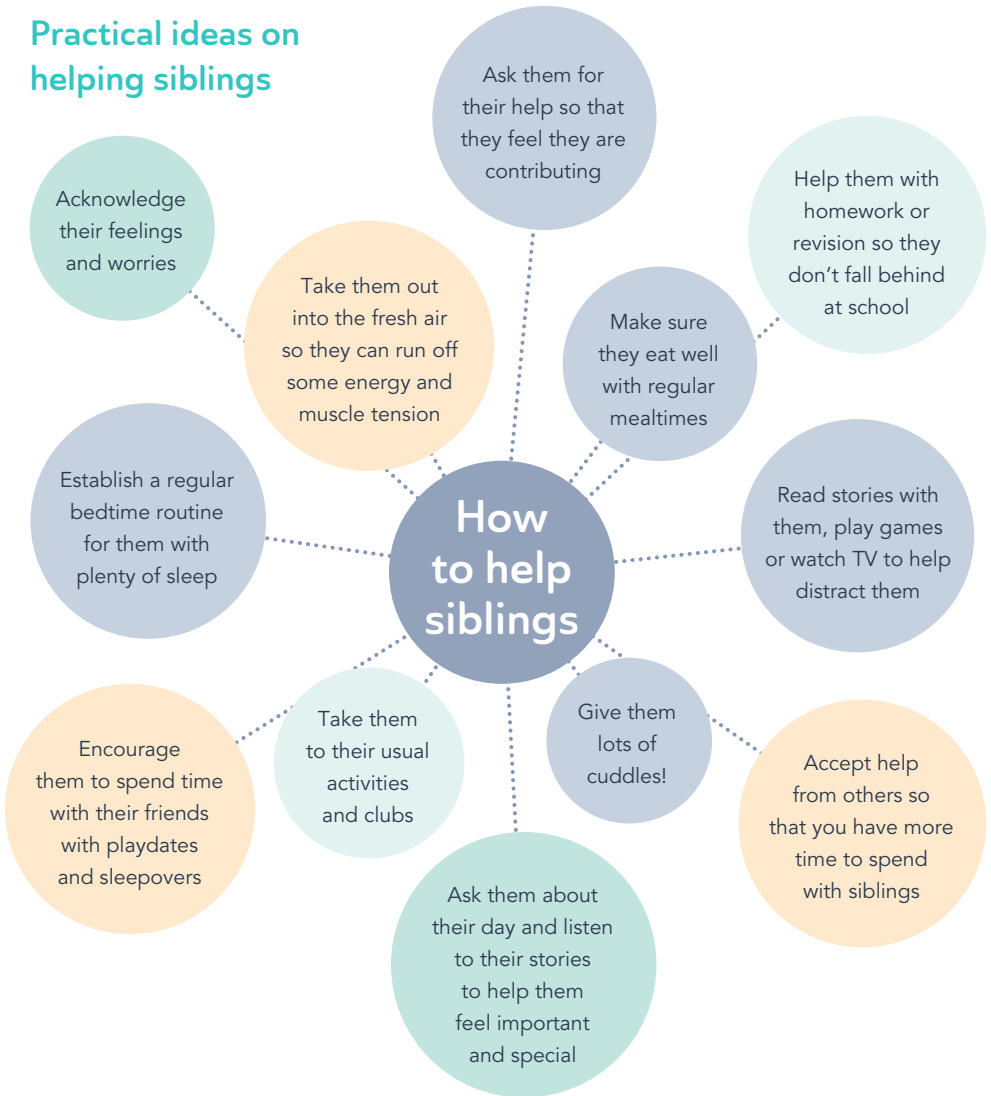
One way of coping with challenging events in our lives is by talking about them. It can help for siblings to talk to someone they trust about how they feel so that negative thoughts don't build up in their head. Talking to others can help put things into perspective and reassures them that what they are feeling is ok. Children can talk to their parents, other family members, friends, teachers or even a helpline.

Sometimes, it is all too much and they may not want to talk to anyone about it. This is ok too and you should let them take their own time to process how they are feeling without any pressure. Writing thoughts down in a notebook can help break them down so they become more manageable and less scary.

Young children can find it hard to express how they feel or to find the right words so you can suggest ways of relaxing instead such as drawing a picture or colouring in or reading a book to help calm their mind.



Practical ideas on helping siblings



It is hard to give extra support to siblings when parents are tired, stressed and worried about their child with cancer. However, this is a practical way for others such as grandparents, aunts and uncles, family friends and neighbours to help by giving siblings time and support to help them understand and cope with their brother or sister's diagnosis.

Need further help?

It is normal to have bad days but if you think that a sibling is experiencing stronger feelings, feeling more anxious or is struggling to cope with each day, then it might help for them to talk to someone who can support them better such as a professional counsellor or psychologist. They are trained to listen and help children talk through how they feel, and find ways of better coping with difficult feelings. You can access these services via the child's GP or your local Children and Adolescent Mental Health Services (CAMHS).

And finally...

We hope this resource offers practical suggestions and tips on how to support brothers and sisters affected by childhood cancer. If you have any specific questions, we recommend that you talk to your child's hospital team as they will have previous experience of supporting siblings, or GP as they will be able to offer local help and advice.

Helpful organisations

NHS Every Mind Matters

Online practical help and support for mental health
www.nhs.org

NHS MoodZone

www.nhs.org

Young Minds

Help and advice for mental wellbeing in young people
www.youngminds.org.uk

CCLG resources for supporting siblings

Download or order free of charge from our website at www.cclg.org.uk/publications



'My brother or sister has cancer' booklet and animation for younger children.

Watch online at cclg.uk/my-brother-or-sister-has-cancer



'When your brother or sister has cancer' booklet for teenagers.





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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.




Our work is funded by donations. If you would like to help, text '**CCLG**' to **70300** to donate **£3**. This costs £3 plus a standard rate message.



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