

Supporting brothers and sisters of a child with cancer

A practical information guide



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Introduction

The development of new medical treatments has improved the life expectancy of children diagnosed with cancer. However, given the life-threatening nature of the illness and the need for lengthy and challenging treatments, childhood cancer continues to be a potentially traumatic experience, not only for the sick child but also for siblings and parents.

Throughout treatment and recovery, the family focus is on the sick child. Family members must adjust to significant changes in their routines while constantly having to deal with uncertainty regarding the health and wellbeing of the sick child.

During this difficult time, parents and siblings may experience a variety of emotions including shock, disbelief, fear, anxiety, hopelessness, sadness, anger and helplessness. These emotions are an understandable response to an extremely distressing situation.

Most children and families cope well and sometimes experience positive changes such as increased sensitivity to the needs of others, thoughtfulness, as well as gains in maturity, empathy and compassion. Others, however, experience emotional or psychological difficulties and may need extra support from professionals.

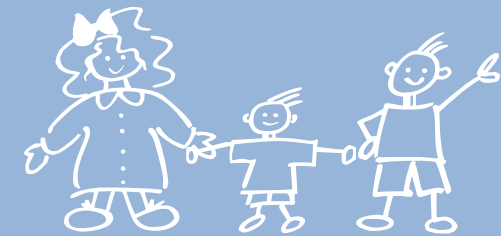
About this book

In this book, we explore how siblings might react to and cope with a brother or sister being diagnosed with cancer.

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

The book is based on the Children's Cancer and Leukaemia Group (CCLG) publication *Supporting brothers and sisters*, with input from CHI Crumlin.

Telling your family



Telling your family

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 difficult 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 feel unable to tell siblings what is happening, there may be staff at the hospital – such as your clinical nurse specialist, a medical social worker or a psychologist – who can give you advice. You can also call the Irish Cancer Society Support Line on 1800 200 700 and arrange to speak to our Children's Cancer Nurse.

Each brother and sister will react differently to the diagnosis and its consequences, but in the next few chapters we will look at some of the issues that commonly arise.



Coping 
with changes
at home

After diagnosis, families will likely face 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 disrupted and unpredictable for the whole family, including brothers and sisters.

Adapting to changes 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. Suggest 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 unwell to start with. Reassure them that they will not always be like this, and things will go back to normal in time.



Missing their parents

When parents stay in hospital or are away from home more, brothers and sisters very often miss them. Even when parents are at home, many siblings notice that they are preoccupied, tired and worried. The children 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 make them feel safe and 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, arrange for siblings 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 the children comfort and reassurance.



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 similar emotions to their parents. These emotions 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 frighten them more than what is happening in reality. Try to be honest and open with them, using simple explanations and basic facts to help make sense of what is happening. If it's possible, taking the children to visit their sibling in hospital can help to reassure them. Seeing where and how their sibling is can take away some of their fear. Some children may not want to see or help their brother or sister in hospital, which is also fine.



Feeling left out

Siblings are often the last ones to hear about their brother or sister's diagnosis. This can be difficult for them because they often feel worried about their mum and dad and their brother or sister. They may know very little about what is happening in their family and at times feel like they cannot ask questions.

Sometimes brothers and sisters may feel jealous as their sibling seems to be getting more attention from everyone, more treats, and doesn't get told off for behaving badly.



Tips

Try to create time for family chats and updates so that siblings feel included in the general conversation. Also, if you can, try to schedule one-to-one time with them.

As much as possible, maintain a normal level of discipline with all children in the family (including the child with cancer). This will reassure all siblings that family life is still carrying on as normal. Clear boundaries can help children and siblings to feel safe. However, if the child with cancer is taking steroids as part of their cancer treatment, their behaviour may change. They may become more emotional and angry. It can be helpful to explain to siblings how the medication changes behaviour and during this time some house rules may change. Reassure them that when the steroid treatment stops, things will go back to normal.

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 living 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 argument. Their sibling with cancer would want them to carry on as normal and might look forward to hearing their stories about school or friends.

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 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, reassure them their sibling is having the best treatment available and doctors are doing all they can. You may not know how to answer some questions, in which case, tell them you'll find out for them. Make sure you mention it to one of the hospital team (or parent if you are not the parent) so your child's questions can be answered as soon as possible.

Feeling angry

Brothers and sisters may feel angry about many different things: they have extra chores, family life has changed overnight and their sibling is enjoying extra attention. They might even feel angry towards their parents and 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. They may be 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 tummy 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 at night-time 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. This will also reassure them 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

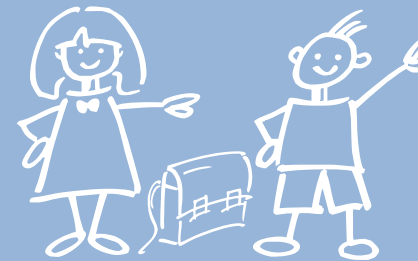
Brothers and sisters can feel lonely, as their sibling may no longer be able to play with or have fun with them while on treatment. Parents may be away at the hospital, and home might seem an empty place compared to before their sibling's diagnosis. Children might feel that they are on their own and 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. Try to keep some normality by arranging play dates with friends and continuing with sports and activities. Also, suggest activities for 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 they 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. School is often the place where siblings may show how they feel. 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 clinical nurse specialist from the hospital will 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, fearing they will catch 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 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 could suggest ways of relaxing instead such as drawing a picture, colouring in or reading a book to help calm their mind.

These kinds of emotional and behavioural responses to having a brother or sister who is unwell are very normal and understandable. There is no right or wrong way to react. It is important to remember that the clinical team caring for your child with cancer can make a referral to the hospital psychology service if you feel that you or one of your children may benefit from some professional support and advice.



How parents can help

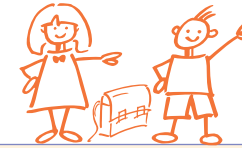
Some children and young people who have a brother or sister with cancer suggested ways in which families and friends can help. These include:

- ✓ **Tell brothers and sisters at home what is going on in the hospital and encourage them to ask questions about the treatment.** The staff at the hospital can give you booklets that explain your child's illness and treatment. These can be useful for siblings as well as the sick child.
- ✓ **Tell the children that their brother or sister with cancer is getting really good care from the doctors and nurses** and that they are doing their very best to help them feel better.
- ✓ **Help children to talk about their feelings and stress that cancer is nobody's fault.** Younger children may need reminding that cancer is not contagious and cannot spread like a cough or cold.
- ✓ **Remind siblings that it is helpful to talk about and share their worries with someone.** This might be a parent, grandparent, neighbour or friend.
- ✓ **Talk to someone at school – a teacher or principal – to let them know what is going on and that things are difficult.** That way they will understand if the children are finding it hard to concentrate on schoolwork. They can be there if your children want to talk about their worries.
- ✓ **Let your children and young people know that it is ok to keep having fun** and doing normal things like swimming, football or just hanging out with friends.
- ✓ **Praise your children for the good things they do at home and at school.**

How others can help

It is hard to give extra support to siblings when you are tired, stressed and worried about your sick child. Accept help from others so that you have more time to spend with siblings.

There are some practical things other people – such as grandparents, aunts and uncles, family friends and neighbours – can do to help siblings cope with their brother or sister's diagnosis.



Practical ideas on helping siblings



Ask them for their help so that they feel they are contributing



Make sure they have regular mealtimes and eat well



Give them lots of cuddles!



Take them to their usual activities and clubs



Establish a regular bedtime routine for them so they sleep well



Acknowledge their feelings and worries



Help them with homework or revision so they don't fall behind at school



Read stories with them, play games or watch TV to help distract them



Ask them about their day and listen to their stories to help them feel important and special



Encourage them to spend time with their friends with playdates and sleepovers



Take them out into the fresh air so they can run off some energy and muscle tension

The Irish Cancer Society provides information and support to families affected by a child or adolescent cancer diagnosis.

To find out how we can help:

- **Contact a Children's Cancer Nurse through the Support Line Freephone 1800 200 700**
- **Email supportline@irishcancer.ie**

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. Contact your social worker or your clinical nurse specialist for more advice on who to talk to or what services are available. You can also access psychology services in the community through your child's GP.

You can call our Support Line on 1800 200 700 to talk to a nurse about community-based therapeutic services for children affected by cancer. These services are available online or face to face in cancer support centres across the country.

And finally...

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



Help and support

Our services for children and families

The Irish Cancer Society Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital.

Peer-to-peer support

All of our trained parent peer-to-peer volunteers have children who have been treated for cancer in the past. They can give you emotional and practical support. For a referral, contact the Irish Cancer Society Support Line on Freephone 1800 200 700.

Website

See www.cancer.ie/cancer-information/cancer-children-teenagers for information on children's cancers, how to cope and a list of helpful services, including an interactive map.

Community-based cancer support centres

The Irish Cancer Society works with community-based cancer support centres across the country. The centres can support adults affected by a child's cancer diagnosis and some have services for children with cancer or children affected by a family member's cancer. Call our Support Line on 1800 200 700 or visit a Daffodil Centre and our nurses will tell you what's available in your area and can refer you to a centre. They can also organise free counselling for you, your child or others affected by your child's cancer. The Society partners with organisations to fund the cost of counselling and creative therapies for children.

Support Line Freephone 1800 200 700

Our cancer nurses can help you if you need information and advice on coping with a child's cancer, looking after yourself and practical support. Contact us and ask to speak with our children's cancer nurse or be referred to one of our trained parent volunteers.

The Support Line is open Monday to Friday, 9am to 5pm. Or email us on supportline@irishcancer.ie or visit our online community at www.cancer.ie

For the deaf community, our Support Line is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie





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

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Publication of the original booklet was funded by CCLG.

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