



Supporting brothers and sisters of a child with cancer

A practical information guide



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About this book

In this book, we explore how brothers and sisters might react to a sibling 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.

This book is based on the Children's Cancer and Leukaemia Group (CCLG) publication ***Supporting brothers and sisters***, with input from the Psycho-Oncology Service at CHI Crumlin.

Introduction

There have been huge improvements in cancer treatments for children in the past 50 years. As a result, more children than ever are surviving cancer – over 8 in 10 children with cancer in Ireland will be cured. Research is also continuing to improve treatments and reduce side-effects.

However, dealing with childhood cancer can be a really challenging experience, not only for the sick child, but also for those around them, particularly their parents, brothers and sisters.

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

During this difficult time, parents, brothers and sisters 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 other, thoughtfulness, and gains in maturity, empathy and compassion. Others, however, experience emotional or psychological difficulties and may need extra support from professionals.





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 brothers and sisters what is happening, reach out to your medical and nursing team and they will be able to direct you towards staff in the hospital that can provide support and help you during this difficult time. Many hospitals have a medical social worker, a psychologist or a clinical nurse specialist 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 very 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

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After diagnosis, families will probably face many 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 brothers and sisters may need to be cared for by family members or friends. Daily life can become disruptive and unpredictable for the whole family.



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, has 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. This will help them stay connected and have fun. Brothers and sisters need help to understand that the treatment is trying to make their sibling well again, even though it may make them more unwell to start with. Reassure them that their sibling will not always be like this.

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, brothers and sisters may notice that they are preoccupied, tired and worried. Brothers and sisters may also 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, other 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 brothers and sisters to visit parents who 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 brothers and sisters that their parents love them and miss them will give the children comfort and reassurance. When possible, arrange video calls so brothers and sisters can see their parents and sibling. They may even get to meet some of the hospital staff this way.

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Having a sibling with cancer is tough to deal with. Many brothers and sisters find it hard to cope with all of the changes in family life and routines. They will likely feel a lot of the same emotions as 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

Brothers and sisters 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 sibling.

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 brothers and sisters 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 brothers and sisters may not want to see their sibling in hospital, which is also fine. In this case, try to help them find other ways to connect, such as through video calls.

Feeling left out

Brothers and sisters are often the last ones to hear about their sibling's diagnosis. This can be a very difficult time for them because they often feel worried about their mum and dad and their sibling with cancer. They may know very little about what is happening in their family and at times they feel like they cannot ask questions.



Sometimes brothers and sisters may feel jealous as their sibling seems to be getting more attention and treats from everyone. Their sibling may also not get told off for behaving badly.

Tips



Try to create time for family chats and updates so that brothers and sisters feel included in the general conversation. As much as possible, try to maintain a normal level of discipline with all children in the family (including the child with cancer). This will reassure everybody that family life is still carrying on as normal. Clear boundaries can help children to feel safe.

However, if the child with cancer is taking steroids as part of their cancer treatment, it can be helpful to explain to brothers and sisters how behaviour and discipline can change. The child with cancer may become more emotional and angry. It can be helpful to explain to brothers and sisters how the medication changes behaviour and as a result, some house rules may need to change for short periods of time. Reassure them that when the steroid treatment stops, things will go back to normal.

Feeling guilty

Brothers and sisters can feel guilty that their sibling has cancer. They may feel that it is their fault if they wished something horrible happened to their sibling after arguing or fighting with them. They may also feel guilty for being healthy and living normally when their sibling can't.



Tips



Reassure brothers and sisters that cancer is nobody's fault. They 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 they are worried, or they may not want to upset their parents by asking them about what might happen.



Tips



Brothers and sisters 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. This is a difficult thing for parents to hear because their first response is usually to promise that everything will be fine and back to normal. However, it is helpful to reassure them 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 they can.

You may not know how to answer some questions. If this happens, tell them you'll find out for them. Make sure you mention it to one of the hospital team (or the parent if you are not the parent) so the child's questions can be answered as soon as possible. Always keep communication open and encourage them to ask questions if they have any.

Feeling angry

Brothers and sisters may feel like family life has changed overnight. They may feel angry about some of these changes. For example, they may have extra chores or they may feel that their sibling is enjoying extra attention. They might even feel angry towards their sibling for being ill and causing these changes. 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 will 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 or have headaches and tummy aches 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 sibling. If they are focusing too much on their health, 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. Brothers and sisters 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. It is a good idea to explain to brothers and sisters 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.

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 they are 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.



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Behaviour

Many brothers and sisters keep their feelings bottled up at home to avoid worrying their parents. Often, the place where they 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 staff at school know what is happening at home so that appropriate support can be given. Most hospitals will have dedicated staff that can liaise with the school if needed. This could be a psychologist, medical social worker, teacher from the hospital or a clinical nurse specialist.



Bullying

Issues at school may also happen if other children tease or bully them, or leave them out, fearing they will catch cancer themselves. Brothers and sisters may feel angry at this unfairness and protective of their sibling with cancer.

Schools should have a strict anti-bullying policy that is enforced. Brothers and sisters should be encouraged to talk openly and honestly with a trusted adult, such as a teacher or family member, to make sure any issues are dealt with quickly.

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One way of coping with challenging events in our lives is by talking about them. It can help brothers and sisters 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 reassure them that what they are feeling is OK. They 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 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. You could suggest ways of relaxing instead, such as drawing a picture, colouring or reading a book to help calm their mind.



It is normal and understandable for children to have emotional or behavioural responses to a sibling who is unwell – there is no right or wrong way to react. However, if you are concerned about your child, it is important to reach out to your medical team and ask for a referral to a member of the psycho-oncology team, such as a psychologist or medical social worker. You can also contact your GP or call the Irish Cancer Society Support Line on 1800 200 700 and ask to speak to our Children's Cancer Nurse.

How parents can help

Some children and young people who have a sibling 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 brothers and sisters as well as the sick child.
- ✓ Tell brothers and sisters that their sibling with cancer is getting really good care from the doctors and nurses, who are doing their very best to help them feel better.
- ✓ Help brothers and sisters to talk about their feelings and explain that cancer is nobody's fault. Younger brothers and sisters may need reminding that cancer is not contagious and cannot spread like a cough or cold.
- ✓ Remind brothers and sisters that it is helpful to talk about and share their worries with someone. This might be with a parent, grandparent, other relative or friend.
- ✓ Encourage brothers and sisters to talk to someone at school – a teacher, guidance counsellor or principal – to let them know what is going on and that things are difficult. That way they will understand if brothers and sisters are finding it hard to concentrate on schoolwork and they can be there if your child wants to talk about their worries.
- ✓ Let brothers and sisters know that it is OK to keep having fun and doing normal things like playing sport or just hanging out with friends.
- ✓ Praise brothers and sisters for the good things they do at home and at school.

How others can help

When you are tired, stressed and worried about your sick child, it is hard to give extra support to brothers and sisters. Accept help from others so that you have more time to spend with them.

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



Practical ideas to help brothers and sisters

- **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 as much as possible**
- **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**
- **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 our Children's Cancer Nurse through the Support Line on Freephone 1800 200 700**
- **Email supportline@irishcancer.ie**



Need further help?

It is normal to have bad days, but if you think that a brother or sister is experiencing stronger feelings, is 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 psychologist or child psychotherapist. These professionals are trained to listen, help children talk through how they feel and find ways to cope better with difficult feelings.

Families who are treated in one of the main hospitals often have a dedicated social worker and/or clinical nurse specialist. It is important to reach out to them and ask for more advice about who to talk to and what services are available. Your GP may also be able to direct you to psychology services.

Families whose child is attending the National Children's Cancer Service at CHI Crumlin for treatment can ask their medical team to refer them to the National Paediatric Psycho-Oncology (NPPO) service. The NPPO's main function is to assess and meet the psychological and psychosocial needs of every family with a diagnosis of childhood cancer. The NPPO service involves many professionals who work together to support families, including psychologists, medical social workers, play therapists, music therapists and occupational therapists.

You can also call our Support Line on 1800 200 700 to talk to a cancer 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 always recommend that you talk to your child's hospital team, as they will have experience of supporting brothers and sisters.

Support Line Freephone 1800 200 700

Irish Cancer Society Services

Our services for children and families

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The Irish Cancer Society provides a range of support services for people with cancer and their families, at home and in hospital. Our services for children and families include:

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses or ask to be put in touch with our Children's Cancer Nurse for confidential advice, support and information. Our Support Line is open Monday to Friday, 9am–5pm. You can also email us any time on supportline@irishcancer.ie



In-hospital support

Our Children's Cancer Nurse is in Children's Health Ireland (CHI) at Crumlin one day a week to provide free and confidential advice, support and information to anyone affected by a child's cancer. She will be around the playrooms, wards and clinic areas. See the in-hospital posters for times and days.

Parent Peer Support

Speak to a parent of a child who has gone through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone whose child is going through or finished their treatment. This service is also available to other adult family members, like grandparents, aunts and uncles. Call our Support Line on 1800 200 700 for more information.



Child and adolescent counselling and psychological support services

We work with cancer support centres across the country to help provide services and support for children and adolescents with a cancer diagnosis. Many centres offer counselling services, creative therapies and practical support for those affected and their families. We also offer telephone and video-call counselling. If you or your child needs psychological support, we can refer you to an appropriate service. For more information on any of these supports, call our Support Line on Freephone 1800 200 700.

Creative arts therapy

Creative arts therapy includes art therapy, dance-movement therapy, drama therapy and music therapy. Creative arts therapy is the purposeful and planned use of creative processes with a qualified therapist to support child development, emotional expression, social interaction, physical improvements and cognitive goals.



Creative arts therapy is available to all children, adolescents and young people (0-24 years) during or after their treatment. Creative arts therapy is also available to the siblings of cancer patients.

Sessions can take place:

- In-person or online
- One-to-one or in a group
- In your home or nearby

If you're interested in availing of creative arts therapy support sessions, please email creativeartstherapy@irishcancer.ie and one of our team will be in touch.

Transport Service

We provide transport for patients in need who are in cancer treatment.

- We have expanded our Transport Service to bring children and young adults (CAYA) travelling from Kildare, Meath, Dublin and Wicklow to CHI at Crumlin for treatment.
- Travel2Care is a fund for patients who are having difficulty getting to and from their diagnostic test appointments or cancer treatments. Patients can apply for the fund if they are travelling over 50 kilometres one way to a designated cancer centre. Travel2Care is made available by the National Cancer Control Programme.

To access any of these supports, please contact your hospital healthcare professional, our Children's Cancer Nurse in CHI at Crumlin or call our Support Line on Freephone 1800 200 700.



Children's Fund

Through our Children's Fund, a once-off grant payment of €3,000 is available to the families of children undergoing cancer treatment nationwide.

To qualify for this fund, there are some criteria the applicant must meet:

- The fund is for patients under the age of 18 years.
- The child must live permanently in Ireland.
- The child has been diagnosed with cancer and is currently receiving treatment.

For more information on the Children's Fund, call our Support Line on 1800 200 700.



Publications and website information

If your child has been diagnosed with cancer or you are worried about children's cancer, we have information and support to help. Visit our website www.cancer.ie to read, share or download information, or call our Support Line on 1800 200 700 for free copies of our publications.

Fertility preservation

Sometimes, children's cancer treatment can affect their future fertility. The Childhood Cancer Fertility Project is a partnership between the Irish Cancer Society and Merrion Fertility Clinic, which offers free fertility preservation and other services to young people with a cancer diagnosis. For more information, speak to your child's medical team or contact our Support Line on 1800 200 700.

Barretstown Camps

Every year the Irish Cancer Society teams up with Barretstown to run a variety of camps specifically designed for children and adolescents living with cancer. These camps allow children, adolescents and their families to come together to enjoy new adventures, create magical moments, make new friends and find support. There are fun surprises around every corner and it's all for free.



Child and family camps

Enjoy a weekend away for all the family full of activities, adventure, creative play and relaxing family time together. This camp is for children up to 17 years of age and their family members.

For more information, call our Support Line on 1800 200 700 or visit www.barretstown.org

Life coaching for 18-24-year-olds

The Irish Cancer Society offers a targeted coaching programme for young adults (18-24 years) who have or had cancer. We provide a dedicated programme of 6 one-to-one coaching sessions with an accredited coach. Topics covered include moving forward from diagnosis and treatment, setting new goals and building up your confidence. For more information, call our Support Line on 1800 200 700.

Night Nursing

We provide end-of-life care for children, adolescents and young adults with cancer in their own homes. Our service allows children and young people to remain at home for the last days of their lives, surrounded by their families and loved ones. This is a unique service in Ireland, providing night-time palliative nursing care to cancer patients, mostly between 11pm and 7am.

For more information, please contact the healthcare professional looking after your loved one.

Support Line Freephone 1800 200 700

To find out more about the Irish Cancer Society's services and programmes:

- Visit us at www.cancer.ie
- Call our Support Line at Freephone 1800 200 700
- Email us at supportline@irishcancer.ie
- Contact your nearest Daffodil Centre
- Follow us on:
 - Facebook/IrishCancerSociety
 - X @IrishCancerSoc
 - Instagram @irishcancersociety
 - LinkedIn @irish-cancer-society

There are other charities and national organisations that may also be able to help. A full list of these is available on the HSE's website, www.hse.ie. Search 'CAYA Cancer Support Directory: national organisations/charities'.



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- *National Model of Care for Psycho-Oncology Services for Children, Adolescents and Young Adults with Cancer and their families in Ireland*. H Greally, C Besani and D Love. National Cancer Control Programme (2023).

Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team! Visit www.cancer.ie if you want to get involved.

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Peer Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Did you like this booklet?

We would love to hear your comments or suggestions. Please email reviewers@irishcancer.ie



Our cancer nurses are here for you:

- Support Line Freephone **1800 200 700**
- Email **supportline@irishcancer.ie**
- Contact your nearest Daffodil Centre