



Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

Supporting your grandchild and family

Practical information for grandparents of a child or young person diagnosed with cancer



www.cclg.org.uk



About this guide

This booklet is for grandparents of children and young people with cancer. Written by experts, it gives practical ideas on how to help your grandchild and family.



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Reviewed and edited by CCLG Information Advisory Group comprising parents, survivors and multiprofessional experts in the field of children's cancer.

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When a child is diagnosed with cancer, life is turned upside down for the whole family. Grandparents can help provide stability and comfort during this time of change and uncertainty.

Being told your grandchild has cancer comes as a terrible shock. Most grandparents worry not only about their poorly grandchild, but also about how their own child will cope.

Many are also concerned about the effects a cancer diagnosis will have on other children within the family, how they can support their family and how, as grandparents, they themselves will cope.

Your grandchild's parents will have direct access to a hospital team who can answer their questions. Sometimes, it is not as easy for grandparents to access information first hand, and this can lead to feelings of isolation and not knowing what is happening.

This guide answers some of the many questions grandparents might have during diagnosis and treatment.

“ It was really hard as a grandparent coping not only with my grandson's diagnosis but with my daughter's heartache. The help and support you can give has to be practical plus love, treats and cuddles (for all of them!) ”



Questions after diagnosis

Grandparents may have many questions when they hear the news that their grandchild has cancer. We have put together a comprehensive list of answers to help you understand more about childhood cancer and how it might affect your family.

What is childhood cancer?

Cancer develops when cells in the body start behaving abnormally by growing uncontrollably to form lumps of cells called 'tumours'. These can be non-cancerous (benign) or cancerous (malignant) where they grow and can spread into other areas of the body. Cancer can also develop in the blood stream (called leukaemia) and lymphatic system (called lymphoma).

About 1,645 children (aged 0-14) and 2,110 young people (aged 15-24) are diagnosed with cancer each year in the UK. Almost half of all childhood cancer occurs in children aged 0-4 years old. The most common types of childhood cancer are leukaemia, brain tumours and lymphomas.

Are children's cancers the same as adult cancers?

No. Common cancers in adults such as breast, prostate, lung and bowel cancers are partly caused by older age, environmental and lifestyle factors such as obesity, drinking too much alcohol and smoking. These cancers are very rarely seen in children.

Some cancers found in children are also seen in adults, such as leukaemia. However, even when the diagnosis is the same, the diseases often behave differently in people of different ages.

Is it something we have done?

No. The causes of childhood cancer are still mainly unknown. It is thought some childhood cancers could relate to problems when the baby was developing in the womb that were impossible to prevent or detect during pregnancy.

Over the years, there have been many changes in the way children are brought up, their activities and diet, and you may wonder if these changes have caused the cancer. There is no scientific evidence to support this.

Someone else in our family has had cancer.

Is it in our genes?

In some families where a child has been diagnosed with cancer, an adult member of the family may also currently have cancer but this is unlikely to be connected. Gene changes resulting in cancer cells will usually have only occurred in that individual and not because of an inherited faulty gene.

Very occasionally, childhood cancers do run in families. For example, an eye tumour called retinoblastoma is known to have genetic links and the family will be advised about whether there is a need to monitor other family members for the condition.

“When my granddaughter was diagnosed with leukaemia, the world felt like it had started spinning the wrong way. Waking up during the night is cold and miserable in the midst of this difficult time, and being at home while my daughter and granddaughter were in hospital offered endless helpless hours not knowing how best to help.”

What treatment will my grandchild have?

Treatment options usually include surgery, chemotherapy drugs and radiotherapy. Other types include immunotherapy and targeted therapy. These may be used individually or in various combinations. Treatment can last a number of weeks, months and even years. Your grandchild may also receive extra medication to help with side effects such as pain, feeling sick and being sick.

Many families say that living through a cancer diagnosis and treatment is like an emotional rollercoaster with ups and downs and unexpected hospital admissions. There will be times when your grandchild will feel poorly and tired, and other times when they can go to school and play with their friends.

Who will be looking after my grandchild?

There are 21 main treatment centres (hospitals) across the UK and Ireland that have specialist children's cancer units. Your grandchild will usually receive treatment at the one nearest to where they live. There is also a 'shared care' system where your grandchild may receive some of their treatment at their local hospital so that they do not need to travel long distances.

Many healthcare professionals are involved in your grandchild's care through a multidisciplinary team (MDT) at your child's hospital. This team includes doctors, nurses, dietitians, play specialists and psychologists as well as other professional roles.

Will my grandchild be cured?

This is one of the most commonly asked questions but it is also the hardest one to answer. This is because there are so many factors to consider which are unique to your grandchild: how the cancer is behaving in your grandchild's body and how their body reacts to the cancer and its treatment.

It is tempting to search for survival rates, statistics, and whether children who had a similar diagnosis survived. But it is important to remember these are general statistics covering all patients – they do not tell you what will happen specifically to your grandchild.

Today, 84% of children with cancer are cured although survival rates vary greatly between cancer types. There is always ongoing research into finding better and kinder treatments.

What if I find something online that claims to cure my grandchild's cancer?

You may come across many things claiming to cure cancer in the media, ranging from diet supplements to experimental treatment overseas, but these can be misleading and inaccurate.

Sensationalist headlines can raise hopes about new cures and treatments but quite often the science behind the story is based on promising early trial results or results shown in the lab. In these cases, it is too early to know whether the treatment will work in clinical practice.

Friends may tell you of people they have known who have been cured of the disease. Similarly, some may come across less encouraging stories. Whatever you hear, it is important to remember that every cancer patient and every diagnosis is different which is why one single cure is unlikely.

Your grandchild's doctor is the only one who knows their individual condition and will certainly know about any real developments and discoveries in cancer medicine that could help your grandchild.

What happens when treatment finishes?


Ending treatment is something to look forward to with happiness and relief. But it can also bring mixed emotions while families try to readjust to normal life again while mentally processing the magnitude of what has happened.

It is very common to worry that your grandchild's cancer will come back. It is an anxious time but your grandchild will be regularly checked and monitored by the hospital so that any changes can be acted upon straightaway.

Having treatment as a child can sometimes cause long-term side effects (called late effects) later in life as adults. Late effects of childhood cancer can include issues with any organ or body system, such as heart, lungs, teeth, hormones, fertility and the psychological impact of having had cancer.

It is really important your grandchild continues to attend a long-term follow-up clinic at the hospital for check-ups. This makes sure your grandchild is fully supported throughout their life so any concerns are flagged up straightaway.

Grandparents can help to encourage their grandchild to lead a healthy lifestyle as they become older by not smoking, applying sunscreen, maintaining a healthy diet and staying physically active. This helps to reduce your grandchild's cancer risk.



Grandparents can help their grandchild feel secure and loved, no matter what the outcome of treatment might be.

What happens if treatment is unsuccessful?

If cancer does not respond to first treatment or your grandchild relapses sometime after finishing treatment, there may be other options available. Your grandchild may receive treatment as part of a clinical trial which may mean they will receive a new drug or treatment before it is available as standard. In many cases, cancer will respond to treatment again.

Sadly, there are some children whose cancer cannot be cured. At this point, the focus changes to palliative care and helping your grandchild to be as comfortable and pain-free as possible. In these cases, it is comforting to know that your grandchild and family will be fully supported with specialist help and care from the hospital, community and local hospice.



It is hard to deal with the fact your grandchild has cancer. Even the word itself is hard to cope with.



I feel so angry and hurt that the little boy I love so much is suffering so. I wonder, do other grandparents feel the same?



I wish someone would explain to me why this has happened to my innocent three-year-old grandchild.



The shock and numbness that my grandson had cancer with a poor prognosis was a nightmare one could not wake up from. There was no time to gather my thoughts or even take a step back to prepare myself.



Supporting your family

The amount of involvement you already have with your grandchild will differ from family to family. If you live close by, you may already be heavily involved in day-to-day life whereas other grandparents may be less involved due to a variety of circumstances, such as living further away or work commitments.

After a cancer diagnosis, most grandparents want to actively support their family and we have put together some practical suggestions on how you can help.

Your grandchild may have other grandparents besides yourself. It might be helpful to talk with everyone and decide how each of you can help and support the family.



If you live nearby

Grandparents who live near their family can give a huge amount of practical help that will be invaluable. Your son/daughter may be so absorbed by the needs of their poorly child that they are unable to tell you what they would find helpful.

Your knowledge of the family's usual activities will be your best guide as to what to offer, but here are some practical suggestions:

- Allowing parents to have a break by sitting with your grandchild at home or in hospital
- Giving lifts to and from the hospital
- Looking after your grandchild's siblings to help maintain stability and consistency
- Taking siblings to school and other activities
- Helping siblings with homework and play activities
- Taking care of the family's home and garden such as mowing the lawn or cleaning the bathroom
- Shopping and running errands
- Cooking family meals and stocking the freezer with family favourites
- Looking after pets
- Generally helping to ensure life continues as normally as possible for the whole family




If you live away

Grandparents who live away from their family, or are not able to offer practical help, may feel helpless and frustrated. However, there are still many ways in which grandparents can help. Here are some practical suggestions:

- Passing on messages and updating friends and family
- Providing a listening ear for the family by phone
- Sending cards, messages or little gifts to your family to let them know you are there for them and are thinking of them
- Sending children's activity bundles such as books, magazines, craft kits, films and games
- Offering financial or other practical support
- Sending practical items that might help in hospital or at home

“ I was able to share the burden of hospital stays meaning many nights living out of a suitcase so I could be on hand to look after either my grandson or his sister whenever it was needed. ”



I would go up to the hospital on the train armed with plated meals so that my daughter could eat something tasty, and would come home with bags of washing. Whilst at the hospital, I could give my daughter a break so she would be able to shower or eat or get some fresh air.

My daughter made a timetable each week to let my grandchildren know exactly who was where on each day and who was doing school pick-ups. Seeing it on a chart each week helped to give the children some normality in a very bad situation.

Supporting your child (and their partner)

Your son/daughter will be struggling with many difficult emotions when their child is diagnosed with cancer and will turn to others they trust for help and support.

For some, this means turning to their own parents. However, others will want to protect their parents and may find it easier to share their feelings with other friends or family members which may make grandparents feel left out. Many grandparents feel that they would rather know the full facts rather than be protected.

Your child may be happy for you to be involved in talking with your child's doctors and important decision-making or they may not. It's a good idea to talk honestly with your child (and their partner) about how you can be most helpful to them and to establish clear boundaries if needed.

If your child is a single parent or is now living with someone else, there may be extra challenges to cope with such as existing access arrangements or disagreements between the two separate parents or even within the new family.

The impact of cancer on estranged families can also be very hard as one or both of your grandchild's parent/s may deny access to grandparents. This is very upsetting but there are organisations who can help with mediation and access (see page 28).

Also, be mindful of your child's wishes around sharing information about their child and their cancer. This is particularly important on social media. Your child may want you to help to share news with the wider family and friends, or they may prefer to share things themselves. If you are sharing information it's important to make sure it is accurate and only done when your child is ready. Talk to your child to understand how they feel about you sharing and remember that they may feel differently at different stages, so it's worth checking in again as time goes on.


Listening and letting them talk

One of the most important ways in which you can help your child is by offering a listening ear and a shoulder to cry on. Although it will be painful to hear your child's distress and hard to know what to say, it may help your son or daughter to simply be able to put their worries into words. You don't need to have any answers; just listening to them can be invaluable. You can encourage them to make some time for themselves by taking them out somewhere or by babysitting for them.

Guiding them elsewhere

Sometimes, your son or daughter may not feel comfortable sharing their feelings with you or you may feel you are not the right person for them to share their worries with.

You can help by encouraging your child to seek help and support from other people such as other family members, close friends or a counsellor. You can suggest they talk to their child's hospital team about what support might be available or visit their GP who can signpost to local services.



“ We felt so helpless for our own daughter. She was supporting her daughter. We could do nothing, just be there and listen. ”

Supporting your grandchildren

How children cope

Children cope with difficult situations in many different ways. Normal family life as they know it has suddenly turned upside down and they will be trying to adjust to this huge change. Some children may want to talk to someone about what is happening and how they are feeling. Others may prefer to do fun activities or to see their friends as a way of distracting themselves. They need time to process the situation and their emotions so it is better to be led by them. The most important thing is to let your grandchildren know you are always there for them whether to talk, play with or for cuddles.

Children of different ages

Children of different ages will need different types of support depending on their age and level of understanding.

Babies need physical affection and care from adults who they love and trust. Toddlers and young children may not be able to put their fears into words but they can be encouraged to talk about how they feel and you can give them reassurance. Older children and teenagers may have lots of complicated feelings so it is important to find out what they already know about cancer and what they are worried about in a sensitive and tactful way.

Family members may wish to protect children from the realities of the situation and be frightened of telling them the truth about what is happening. But this can be more damaging to children as they will then rely on their imagination to fill in the gaps. Children can often understand more than adults think so explaining cancer in simple and honest terms helps limit any confusion. It can be helpful for children to know that having cancer is nobody's fault, it isn't caused by bad thoughts or bad behaviour, and it cannot be 'caught' from somebody else.

How much information you give to your grandchild depends on their age, understanding and what the child's parents are happy for them to know. CCLG have a range of publications including storybooks available online or at treatment centres for younger children which can be a safe way to talk about difficult subjects.

It is important to be consistent in how you speak with your grandchild. It may be helpful to speak to the child's parents to make sure you are using the same language and sharing the same information. This will help your grandchild to feel secure and avoid any confusion.

Discipline

After diagnosis, parents and grandparents can sometimes start treating the child with cancer differently by buying gifts or giving special attention. This is natural and can help their grandchild to take their mind off things. However, treating them the same as before helps to give them a sense of normality when other aspects of life seem out of control.

Cancer treatment is hard for a child to cope with and it can affect your grandchild's mood and behaviour. While it can be hard to maintain normal discipline for the child, it can still be done while striking a balance between understanding and setting firm boundaries.

It can also be difficult for brothers and sisters to see their sibling treated differently or even 'getting away' with what they see as bad behaviour. If this is the case, it can be helpful to explain why family rules have changed and that the change is only for a while.

Your grandchild with cancer

A diagnosis of cancer is likely to turn your grandchild's world upside down. You will probably have been a welcome part of your grandchild's life before diagnosis so your presence will be a huge comfort to them now. You can help them in many different ways:

- Visiting and sitting with them in hospital
- Playing fun games with them, reading a book or watching TV or a film
- Giving lots of cuddles and love
- Listening to them and reassuring them
- Carrying on with normal family routines to help give normality
- Helping them to feel less scared by answering difficult questions with 'What makes you think that?' or 'Have you been worrying about this?' – children's fears can be different to adult ones.
- Phoning, messaging or video calling them regularly

During high-dose chemotherapy, all I could do was hold him and comfort him for hours on end when he was so poorly. I knew I could give him exactly what he wanted – just to be held and cuddled.

I try hard not to smother my poorly grandchild, yet give her love and attention, but you have to realise that the well grandchildren need the attention too. It's easy for them to become jealous of the ill child.

Brothers and sisters

The effect of a cancer diagnosis on brothers and sisters can be enormous. They can feel left out, as much of the attention is on their sibling, and resentful that the whole family's life now revolves around them.

Parents are busy and stressed so it is easy to see why some brothers and sisters can feel they are no longer important or that they are not loved as much. They may keep these strong feelings to themselves as they don't wish to cause additional upset. However, these feelings can show up in other ways such as a change in behaviour at school.

Grandparents can be particularly valuable to brothers and sisters by reassuring them they are still loved and cared for and giving them undivided attention and time. Important ways you can help could be with homework or activities and making life seem more 'normal' by doing school runs and drop-offs to clubs or parties.

As with your grandchild, it is important to be consistent with the language you use and the information you share with their siblings. Using the same terminology and talking in the same way as the child's parents will avoid confusion, build trust and help them to feel secure.



Supporting yourself

Learning that your grandchild has cancer is a huge shock. You may feel overwhelmed by the enormity of the situation as you worry about both your child and grandchild. Many grandparents experience emotions such as:

- Grief for the loss of normal life and the devastating impact of cancer on all members of your family
- Anger at the lack of control
- Frustration at why this has happened
- Sadness at what is happening
- Anxiety, which may make eating and sleeping difficult
- Fear at what the future holds
- Denial that any of this is actually happening to your family

Feeling helpless

As parents and grandparents, you are used to protecting your family and keeping them safe. When a child is diagnosed with cancer, you may feel guilt or helplessness because you feel that you were unable to prevent it. Many struggle to make sense of what is happening to their family.

Sometimes, you may wish that you had been diagnosed with cancer instead of your grandchild who has their whole life ahead of them. You might wish that you could change places with them rather than see them suffer and go through long treatment. These are very common feelings but it is important to remember that grandparents can still feel helpful and needed in lots of valuable ways.

Taking care of your own needs

Many grandparents put their own 'normal' lives on hold as they help and support their family through diagnosis and treatment. Unfortunately, this means that grandparents can neglect to take care of themselves as they feel their own needs are less important than the needs of the rest of the family. Making sure that you are well-supported in your own life will help you support your child and grandchild.

Life after diagnosis can become very busy and grandparents can find that days are suddenly filled with other responsibilities. Not all grandparents are retired or have a lot of spare time available and may even have health concerns themselves. This can result in grandparents feeling worn out with juggling everything. It is really important that you look after yourself too by taking breaks, getting plenty of rest and not neglecting your own doctor's appointments and medications.

It is helpful to let people around you know about the situation such as friends and your employer. It might be a good idea to take time to look at how much you are trying to do and see if there is anything that can be put on hold. Sometimes you may need to say no and not feel bad about it.

Most employers will be understanding when they are told of the circumstances and they may be willing to look at reduced or flexible working hours and special leave for dependents.

But it can be hard to completely relax. Even when there is time to rest, you may find that you can't stop yourself from worrying about everything and getting to sleep can be a challenge. If this happens, writing a list of your worries can help you to gain some perspective.



It was the unknown.
We felt so isolated. People just
didn't know what to say to us.



My grandson having his first bloods done was my
first time of feeling helpless and in a situation that I had
no prior experience of, or ability to reassure myself and the
rest of the family. I longed to be able to do something to
help him and to feel I was contributing to the fight.



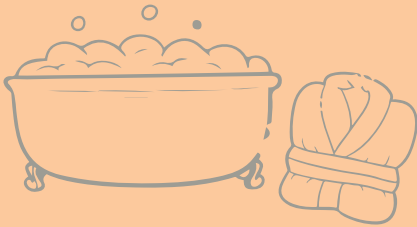
Try these tips to help you find time to still enjoy your own interests. Even on a small scale, this will help you to recharge and relax.

read a good book
or join a book club

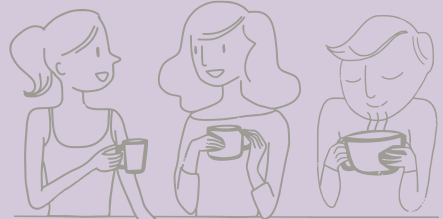


draw or
paint

relax in the bath

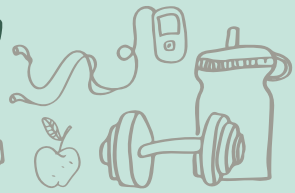


watch your
favourite film



meet with friends

go for a walk or get out in
the garden



go to a gym class

Finding support from others

Some grandparents will have friends and relatives around them who are keen to offer practical help. Most people will be happy to help if you ask them directly.

There may also be friends who are unable to give you the emotional support you need. They may not know the right thing to say and so say something insensitive or maybe even avoid you. This can be upsetting and disappointing but those friends may still be able to offer help by acting as a diversion from the difficulties of your grandchild's diagnosis by talking about other things.

Some people believe that they should be strong, and contain their emotions at times of crisis. It has been shown that talking about your worries can help. No-one can change the situation, but there can be comfort in knowing that someone else understands something of how you feel. Talking to others helps to make your own thoughts clearer, stops problems whizzing around in your head and becoming bigger.

You may feel able to share your thoughts and concerns with those closest to you. Others find it easier to talk to someone outside the immediate family who is not directly affected by the illness. It may help to talk to a number of different people to gain a wider range of perspectives.

Asking about your grandchild's cancer and treatment

Some grandparents find it difficult to talk to their son/daughter about their grandchild's cancer and treatment. Depending on existing relationships before diagnosis, they can feel left out or may not want to create more worry by asking questions. Grandparents sometimes have to rely on second-hand information or by searching online.

Your son/daughter may not be aware of how you feel so it might be a good idea to explain to them and ask how best you can get the information you need without being a burden to them. It is understandable that you want to know more about the care and treatment that your grandchild will receive.

With your son/daughter's permission, you may be able to ask the medical team at your grandchild's hospital for more information. Each patient will have a key worker or nurse specialist assigned to them who will be able to help you with information.

Comprehensive and reliable information about childhood cancer is also available from a variety of charities and organisations.



It was very much a team effort and one where we all had a role to play - each one of us supporting the other.



Being needed and getting involved has helped me cope.



Finding emotional help and support

Many grandparents feel that they need to put a brave face on their feelings to protect their family despite feeling upset, sad, distressed and worried themselves. This is completely normal and is why grandparents need support too.

Some people find that crying can bring a sense of emotional release helping them to feel stronger and think more clearly. Being able to let go and allow your emotions to come out can help enormously. It is important for your own wellbeing that you find a way to cope with your feelings that works for you.

Sometimes, it can all get too much and every day can feel like a struggle. Help and support is available and can be accessed in many different ways:

- Your grandchild's hospital team
- Local cancer charities may have support specifically for grandparents
- Local support groups for carers or via your local hospice
- Online communities and forums where you can chat online and share experiences
- Visit your GP and tell them how you feel – your GP will be able to help you find professional support

Remember: You are not alone. There are other grandparents who have been or are going through a similar situation and feel the same worries and anxieties that you do. It is important that you seek support for yourself so that you can continue to be there for your grandchild and family.

Useful organisations for help and support

Medical terms explained

www.cclg.org.uk/about-childhood-cancer/medical-terms-explained

Provides simple explanations of medical terms you may come across.

Social media groups

Social channels such as Facebook may have online community groups for grandparents.

Online community forums

www.gransnet.com

Kinship

0300 123 7015 | www.kinship.org.uk

Promotes the role of grandparents and the wider family in children's lives - especially when they take on the caring role in difficult family circumstances.

Family Lives

0808 800 2222 | www.familylives.org.uk

Supporting families to deal with changes that are a constant part of family life.

Grandparents Apart UK

0141 882 5658 | www.grandparentsapart.co.uk

Offers comfort and helps families to build bridges, prevent further alienation and will act as go-between (mediation) with anyone who is willing to repair family relationships.

Charities and organisations

Children's Cancer and Leukaemia Group (CCLG)

www.cclg.org.uk

Supports families with expert, award-winning free information resources to order or download including Contact magazine, a free quarterly magazine featuring informative articles and personal stories.

Young Lives vs Cancer

0300 330 0803 | www.younglivesvscancer.org.uk

Provides practical support and advice for children and young people affected by cancer and their families.

Macmillan Cancer Support

0808 808 0000 | www.macmillan.org.uk

Offers help and support to people affected by cancer and their families.

Teenage Cancer Trust

www.teenagecancertrust.org

Provides practical and emotional support for every young person affected by cancer.

Local charities

There is a range of local charities helping and supporting children with cancer and their families. Your hospital team or Young Lives vs. Cancer social worker will be able to advise on what is available in your area.

Emotional support organisations

Maggies

0300 123 1801 | www.maggies.org

Maggie's centres offer free, comprehensive support for anyone affected by cancer.

Samaritans

116 123 | www.samaritans.org

Offers a safe place for you to talk any time you like, in your own way about whatever's getting to you.

Carers UK

www.carersuk.org

Advice and support for anyone caring for others.

Marie Curie

0800 090 2309 | www.mariecurie.org.uk

Care and support through terminal illness.

NHS Every Mind Matters

www.nhs.uk/every-mind-matters

www.nhs.uk/mental-health/self-help/guides-tools-and-activities

Tips and advice on managing stress, anxiety and unhelpful thoughts.

Be Mindful

www.bemindfulonline.com

Mindfulness digital program to help people enjoy better mental health.



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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. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

We want to make sure that our information resources are relevant and useful. It would help us if you could tell us what you think about this booklet by scanning this code to complete a short survey or contact us at publications@cclg.org.uk.



CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.

Publication of this booklet was funded by CCLG. If you would like to help, text '**CCLG**' to **70085** to donate **£3**. You may be charged for one text message at your network's standard or charity rate. CCLG (registered charity numbers 1182637 and SC049948) will receive 100% of your donation.

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 [ChildrensCLG](https://www.facebook.com/ChildrensCLG)   [CCLG_UK](https://www.instagram.com/CCLG_UK)

Registered charity in England and Wales (1182637)
and Scotland (SC049948).

