

the EXPERTS in CHILDHOOD CANCER

Coping with family life and cancer

Practical information for parents and families of children and young people with cancer to help balance everyday life during treatment



www.cclg.org.uk

About this guide

This booklet has been written by parents for parents, to share their experiences, tips and advice to help newlydiagnosed families cope better with the impact of cancer on their lives.



This edition was reviewed and edited by the CCLG Information Advisory Group, comprising parents, survivors and multiprofessional experts in the field of children's cancer. Originally written by Sharon Dempsey.

We are grateful to all those who have contributed to this publication. Any quotes in this publication are personal views and do not necessarily represent the views of CCLG. We make every effort to ensure that information provided is accurate and up to date at the time of printing. CCLG does not accept responsibility for information provided by third parties, including those referred to or signposted to in this publication. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

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Patient Information Forum

Contents

•	At diagnosis	4
•	Coping strategies	7
•	Tips and advice for hospital visits and stays	10
•	Asking for help and advice	12
•	Finding emotional support	13
•	Taking time out to recharge	15
•	Everyday life during treatment	17
•	Helping brothers and sisters	22
•	Dealing with emergencies	24
•	Sources of help and support	26

When you are told your child has cancer, it feels like the end of the world, or at least the end of normal life. One of the greatest challenges is balancing your child's needs and the demands of treatment while coping with everyday issues. Cancer is such a significant part of your family life that it can dominate at times. But it does not have to define your family. This booklet gives you tips to help you manage and still enjoy family life during this challenging time.

Sharon, mum of Owen who was diagnosed with a brain tumour

At diagnosis

When your child is diagnosed with cancer, it is devastating for the whole family. Families often feel that life will never be the same again. You will likely feel worried about what might happen to your child during treatment and beyond.

As time goes on, difficulties, limitations and challenges will unfold. You will find yourself embracing new vocabulary, meeting new people and facing issues that were unimaginable before. Whilst you are adapting to this new reality, everyday life continues. You may have work commitments, bills to pay and other children to care for. Birthdays, Christmas and holidays loom and these can all feel like an added burden to cope with.

How is family life affected?

When a child is diagnosed with cancer, families are forced to make huge adjustments which affect family life, for example:

- Changes to daily routines making way for time at hospital and community care visits as well as meeting the changing needs of your child in treatment.
- Changes to working patterns having to reduce hours or give up employment to work around treatment and care.
- Financial re-adjustments due to not being able to work the same hours as before diagnosis and new costs surrounding hospital visits and stays.
- Relationship stress caused by worry and tiredness, and sometimes each parent taking a different approach (it is quite common for one parent to want to talk or find out more information, while the other may not).
- Rivalry between siblings due to presents and extra attention being given to the sibling with cancer, and resentment over changes to home life.
- Childcare problems when siblings need to be cared for by others due to appointments and hospital stays.

Telling family and friends

When you have to share bad news with family or friends, for example, after diagnosis, take time to plan how and when you are going to do this. Their distress can sometimes be an additional burden, or you may feel guilty about upsetting someone you care about. If there are a lot of people to talk to, take your time and do it gradually. It might help to:

- Forewarn them and say you want to meet to talk about someone in the family who isn't well.
- Discuss your plans for letting others know by asking for help to share the news, or being clear that it is something you want to do personally.
- Prepare yourself for other people's shock. As a parent, you get used to living with the diagnosis so you forget others will feel the initial shock of the news when you tell them.
- Make sure you have someone close by to support you. Some family and friends may react in unexpected ways. If you are upset or worried by the reaction of a friend or family member, or how they respond to you or your child afterwards, talk it through with your specialist nurse or Young Lives vs Cancer social worker they can help you to understand their reaction.

You will be amazed, confused and dumbfounded by the reactions from some people when you tell them. Some will be supportive, some overwhelmed, some will immediately change the subject and then avoid you and some will expect you to support them!

A private Facebook group of close friends and family was useful to disseminate the latest news and saved a huge amount of time.

Be honest and say when you feel like you want to be alone.

What can help?

- Allow the illness to be part of family life accept that there will be changes and work around them so that life carries on as normally as possible.
- Don't be afraid to ask for support family and friends may be frightened to offer, for fear of treading on toes, or simply getting in the way. Share information and be open about what practical support you need. Often help with household chores, shopping, school pickups or just a friendly chat will make a big difference.
- Keep talking and listening to each other however hard it may be at times, communication can increase a sense of togetherness within the family.
- **Try and enjoy family life** celebrate birthdays, enjoy trips to the park, snuggle up at bedtime and read a story with the family. Children still need to feel loved and special.
- Know when to focus as a close family unit and when to open up your network to allow others to help and provide support.
- If you feel overwhelmed by the amount of information being given to you, keep it all in a safe place and refer to when needed or you feel ready. Don't be afraid to ask your child's health team to explain things again at anytime – they will be more than happy to help.

Take photos and keep a record of treatment – painful at the time but good for you and them to look back at and see the progress made. Take each hour and day as it comes and build from there.

Try not to search for information without checking it's a reliable source – use well-known trusted sites like NHS, CCLG, Cancer Research UK, Young Lives vs Cancer and Children with Cancer UK

Coping strategies

Every family's journey through their child's cancer treatment and care is different. Normal life is challenged and often disrupted as parents and carers find themselves managing the rollercoaster of their child's diagnosis and treatment.

The reality is that parents and carers take on a huge number of practical and emotional roles to support their child and the rest of the family through treatment, rarely stopping to notice their own needs. This can cause high anxiety/stress levels, poor sleep and other stress-related reactions.

You may find you take on lots of different roles in hospital and at home:



Coping with stress

Dealing with stress is about finding positive ways of managing. Discovering small ways to find some sense of enjoyment each day can make a positive difference to your mood and how you cope emotionally.

- **Getting outside and physical activity** can help ease stress. While this is not always possible, even a short walk around the hospital grounds can help.
- If you spend a lot of time at hospital, **try to take regular breaks.** Take things for you to do, such as reading, a craft or puzzles.
- Be organised at home and in hospital as much as possible.
- **Develop a routine for ordering and administering medicines**. Keeping a medicine diary may be a useful way of doing this.
- **Stay in touch with your own hobbies**, interests and friends away from hospital.
- Some hospitals offer **massages or other wellbeing services** for parents staying in hospital ask if they are available.
- **Practice mindfulness**. Focusing your attention on small details of the present, such as sights, sounds and smells around you helps to lower the stress levels by influencing our heart and breathing rates.
- Write down questions and worries, even if it's in the middle of the night, so that you can deal with them later.
- Consider limiting time on social media if this is making you anxious.

If anyone in your family is finding feelings overwhelming and struggling to cope, don't be afraid or embarrassed to visit your GP and tell them exactly how you feel. Your GP will be able to help you find professional help.

Useful websites offering practical advice on dealing with stress: www.nhs.uk/mental-health/self-help/guides-tools-and-activities www.mentalhealth.org.uk www.bemindful.co.uk

Connect with others

(a good support network can help you to see things differently)

Keep active

(helps clear your thoughts letting you deal with things more calmly)

Enjoy some 'me time' (taking care of yourself will help you to manage better)

WAYS TO HELP WITH STRESS

Take control of what you're able to

(it will help, however small)

Try to stay positive

(try writing down three things that you're thankful for each day)

Accept the things you can't change (working with the

(working with the limitations is less stressful than being frustrated by them) Avoid unhealthy habits or behaviours (relying on these things may cause long-term problems)

Tips and advice from other parents on hospital visits and stays

Ask a friend or neighbour to keep an eye on your house to collect post, feed pets, water plants and so on while in hospital.

56

Eat and drink properly while in hospital – if you become ill you may not be able to stay on the ward due to infection risk to the other children on the ward.

Try to get out in fresh air for even 10 minutes - let staff know how long you will be and how to contact you. 56

Use distractions for scans and procedures – we relied on our son's iPad when we went into hospital.

Label food in the communal fridge with a marker pen – label date brought in, who it belongs to and use-by date.

Chemotherapy can affect your child's smell and taste. For example, some children hate the smell of the alcohol wipes used to clean the ends of lines, try having a scarf or hanky smelling of a good smell to hold over their nose.



One of the biggest worries was Write down money. How were we going to questions you want afford to be off work with our child? to ask when they are We found out that our GP would whirring round your sign us off work. Knowing this at the head at 3am – great end of week one would have saved for de-stressing! us additional worry. Baby wipes are useful Carry a spare for freshening up. phone charger.

Put your child's name on a pile of about 4-6 bed pans when you arrive and keep by the bed. Saves writing in the middle of the night.

Ask for an explanation of the machine your child might be linked to – is bleeping normal? When should you alert a nurse? What signals an emergency? Should you touch the machine?

Buy a diary and keep a log of important information.

66

Flip flops or Croc-type shoes are great for the ward – comfortable, cool and quiet.

Be wary of food smells around other patients as it can make them feel sick.

99

Asking for help and advice Your child's health team

Over the course of your child's cancer journey, you will experience many things for the first time. Don't struggle alone. It is fine to ask questions and no question is silly. If you have any worries or questions, write them down and talk to a member of your child's team.

Research shows that you will only take in a small amount of what you have been told, so team members are always there to summarise and explain. At the beginning of any discussion, share what questions you want to ask or information you hope to gain.

Your GP

While your GP is not an expert in children's cancer, they can offer care and support throughout your child's diagnosis, treatment and beyond. They can give advice and information on what services may be available in your local area to help you to cope better as a family during this stressful time.

Questions to ask

- What benefits are available?
- How can I get a disabled car parking permit?
- Is there any help with travelling for treatment?
- What about school?
- Is there help with car parking at the hospital?
- What about carers leave?
- What shall I do about my job?

Finding emotional support

Other families in hospital

Chatting to other families can be great and the hospital ward is often the best place to make new friendships. You aren't alone, many parents have gone through, or are going through experiences very similar to yours. No one else will understand your situation better than another family in the same position.

Other families can be a huge source of useful information, particularly in the first few days and weeks after diagnosis. For example, they can:

- Show you where the toilets are, where to make a cup of tea, get a meal or where the nearest park is.
- Share advice on accessing help such as disability living allowance or grants and emotional support from charities and local organisations.
- Offer tips on how to keep your child occupied during appointments, what the ward is like or what support to ask for from social services.
- Introduce you to groups and charities that provide support and outings to give you the opportunity to meet up with people who have an understanding of what you are going through.
- Share advice on where to holiday or how to get suitable holiday insurance policies when travelling with a sick child.

While sharing experiences will be immensely important to many families, some people may only want to focus on their own family. Others may find the enormity of knowing about other families' problems too much to cope with. It is okay to just look after yourself and your child and not to take on someone else's problems. All families are different – there is no right or wrong way of coping.

Using social media

Facebook, blogs and other social media outlets offer an easy and instant way of communicating with others. Families can tap into a supportive network of fellow parents from around the world all facing a similar journey. Regardless of what country families live in, the feelings and human experiences of having a child with cancer can be the same. It is easy to be drawn to other cancer stories. It is important to be aware other people's posts may not be relevant to your child and may not be factually accurate.

Family and friends at home

Sharing information with family, friends, neighbours and work colleagues outside of the hospital environment can be a challenge. Remember it is up to you who you talk to and when – you need to feel comfortable.

Some families may feel isolated or alienated from their friends and neighbours. Your previous social network may seem irrelevant. However, your circle of friends may offer a welcome break, helping you to keep your sense of self and keep you connected to a world outside the hospital.

Friends and family may seem insensitive and not know how to approach you or what to say. Tell them what you need them to do: is it for them to listen? Or a hug? A shoulder to cry on? Or taking the dog for a walk? If someone offers help, say 'yes' as having support around you can make all the difference.

We were in hospital for a month and in isolation. I just wanted to talk to someone who understood. I eventually got told of a Facebook group for our ward and I found that a life saver.

After telling our family and close friends, I turned to Facebook to share this horrible news in one go (I couldn't face having the same text or conversation over and over).

Taking time out to recharge

Caring for a child undergoing treatment for cancer can be difficult and demanding over a long period of time. Taking time out to recharge and relax may help to prevent mental and physical exhaustion.

Relationships

Stress can cause a lot of strain to relationships and families. It is a good idea to make time for yourselves, especially if you are away from home a lot. Having a meal, a walk or cup of coffee together without distractions can help strengthen a partnership and allow time to reflect and talk.

All parents feel the need to spend time doing things outside of the family routine at times. Taking time away from your sick child is not always possible or you may not want to, but if you can spend a couple of hours a week doing something you enjoy, you can return recharged and able to cope better. You shouldn't feel guilty about needing or wanting a break. Sometimes a short respite break can make all the difference.

> Make time for your partner as this experience can either bring you closer or drive you apart.

As a family

Sometimes you may not want to think beyond treatment, medication and hospital appointments. However, focusing solely on the illness is not good for your child or your family. Your child is still the same person they were before their diagnosis: first and foremost still a child.

They still need to experience family outings, picnics, trips to the beach, holidays and birthday parties. It may take extra planning and a lot of energy but it will be worth it. The demands of planning trips and days out can seem overwhelming especially if your child is undergoing treatment, but making an effort to engage in activities can benefit the whole family.

Activities

There are charities that provide entertainment and activities for families of children with cancer. Many families feel safer attending an event that has been planned by an organisation that understands their child's needs and saves them from planning and organising. It is also an opportunity to meet other families who can relate to your circumstances. There may be limits on whether your child can participate in some activities if there is a particular risk of infection or your child has a low immune system. Please check with your child's health team first for further information.

Holiday breaks

Some charities specialise in providing short breaks for families of children with cancer and their siblings. This can give the whole family the chance of time away together, away from the hospital routine, but with support (including medical) at hand if needed. Your child's team will be able to give you information on what is available.

Getting professional help

Professional help offers time with a member of your child's team who has expertise in how we think, feel and behave when facing a situation such as this. It can sometimes help to talk to someone else outside your circle of friends and family. Talking therapies and counselling can help you to talk through your emotions in a safe and honest way, helping you to cope better. Your GP will be able to refer you or you can search for a qualified counsellor yourself (you may need to pay for this).

Useful websites to visit for emotional support: www.maggies.org www.itsgoodtotalk.org.uk www.relate.org.uk www.samaritans.org

Everyday life during treatment

Depending on their age, the child with cancer may have a greater understanding than you think about their illness. Siblings too can pick up on things, both spoken and unspoken.

Talk to each other

Talk about how the illness or condition affects the whole family; how can you lessen the impact and help each other? Discuss how you can all work together to support each other. At the same time, however, you need to be clear how much information you want to give, and when. Try to:

- Talk to each other and try to identify particular concerns.
- Look out for signs of anyone becoming withdrawn or being over anxious, or siblings feeling resentful.
- Be sensitive to changes in behaviour of siblings which may reflect fears and worries.

Take on specific roles

Within families, there are always things that some people are better at than others. Take advantage of this when dividing up the key tasks. For instance, one parent may feel more competent dealing with the practical day-to-day concerns such as keeping the house running with washing and cleaning while the other parent attends hospital appointments and deals with medicines.

Try and talk to your child and make everything as normal as you can for them. Make sure your other children understand and explain to them the changes happening in the house. Plan little treats for your child, small and inexpensive ...try to surprise them!

Keeping a normal routine

It is helpful for families to keep to a routine as much as possible while allowing for flexibility during times of stress or demands of treatment. Routine helps everyone to have a sense of stability and security. Children often feel a loss of control in their lives because of their condition but a good routine at home helps them to feel secure. As far as possible try to:

- Plan for hospital stays and procedures.
- Be organised at home.
- Keep school routines.
- Keep regular mealtimes and bedtimes.

Children respond well to consistency and like to know rules and boundaries. Sometimes sick children need to have more freedom within the family. Understanding the boundaries imposed by the family is part of learning to work as a team and to be thoughtful and aware of other people.

They may not always be able to do chores, complete homework or be responsible for younger siblings. It is important they are encouraged to develop and to contribute to the family according to their age and abilities. A child's self-worth can be improved if they feel of value to the family's daily tasks. Over-dependence on parents and siblings to carry out tasks will limit their ability to cope and to develop.

Children who do not have a good understanding of their health problems and treatment may take risks and be overly independent. They need to have some understanding of their condition, in age-appropriate terms. Their health needs may be different, complex and demanding but ultimately they need their mum and dad to parent them as a child first and foremost, not as a sick child.

It is understandable to want to over-compensate for your child's health problems. Many parents find they want to give their child lots of treats to make up for everything they have to endure. However, it is worth thinking about how this affects the child's need to be treated as a regular member of the family.

Sleeping

Sleep can be affected in many ways when a child has cancer. This may be because of their illness, chronic pain, side effects of medication, symptoms or repeated hospital stays. Sometimes certain drugs, like dexamethasone, can impact on the child's sleep pattern. If your child has trouble sleeping then the whole family is often affected.

It can be difficult to establish a good bedtime routine if your child is spending a lot of time in hospital. Hospitals at night time are rarely quiet. Nurses continue to monitor your child, lights are dimmed but still on, the whirr of the IV pumps and other hospital equipment and the need to wake a child to give them medication all affect sleep patterns. Parents can find that their need to listen out for a sick child during the night can prevent them from achieving deep sleep themselves.

Sleep disruption is physically and mentally draining for you and your child so it is important to encourage good routines where possible.

How can I help my child sleep better at home?

- Establish a good bedtime routine: supper, bathing, story, bed.
- Introduce a star chart to reward good behaviour at bedtime.
- If you experience a bad night, try to find time for you and your child to rest during the day.

We found out that, had she taken all of her steroids by lunchtime, then she would have slept a lot better, so it is worth checking this with your child's doctor. The best thing for my son was bringing in his pillow and bedding from home so he had his normal sleep surroundings. It took him a week to get used to the machines bleeping in the night.

Eating

Eating can be a huge problem for children with cancer. It can be difficult to maintain a normal healthy diet as treatment can affect how foods taste and some foods that were favourites may no longer taste nice. Children can also feel or be sick as a result of chemotherapy and radiotherapy.

Try to avoid family mealtimes becoming stressed. If your child doesn't want to eat with the family, allow them to have smaller meals or frequent snacks throughout the day. It is a good idea to take advantage of when they do want to eat.

At some point during treatment, your child may need a feeding tube. While some parents may dread this, many are reassured that food is actually reaching their tummy.

The important thing is to keep your child's calorie intake up as much as possible. A dietitian will be part of your child's hospital team and will be on hand to offer help and advice. Children having steroid treatment such as dexamethasone will feel extremely hungry and it can be difficult to help them to feel full up.

Midnight mushy peas sandwiches, 22 boiled eggs with toast soldiers, endless bowls of pasta and hot dog sausages became the norm for us while our son was on dexamethasone. Ice lollies can be more palatable during chemo.

To cope with the overeating on steroids, give the food but in smaller portions to help prevent some of the weight gain.

Playing

Play is a huge part of a child's life. Through play they explore their environment and learn skills necessary for all stages of life. Play enables a child to express emotions and feelings and can be a useful strategy to help them come to terms with illness and express their concerns.

Young children do not have the vocabulary to explain how they feel but, through play, parents and play therapists can find out how they are coping. Children can explore confusing situations through play. They relate events in their life to play activities and can gain power and control through exploring issues in this way. Parents can help the child bring their experiences to their play time by play acting hospital situations.

Speak to your hospital play specialist for ideas. Some hospital play therapists can fit out a soft-bodied doll with a central line, which the child can then learn to 'flush'. Teddy can be given sticking plasters, or be fitted with a radiotherapy mask. Clearly use of dolls may not be appropriate for all children. Some may require a more 'grown-up' approach.

Going to school

There will be times when your child is off school during treatment and so can miss out on playing with their friends or keeping up with their school work. Or your child may not be willing to socialise with their friends, either because of their illness or perhaps changes in their appearance.

School is an important part of normal routine for children. It helps them to feel 'normal' and can reduce the isolation and loneliness which many children with cancer face. Children are encouraged to attend school as much as possible. Your child's health team will advise on what is practical and will liaise with your child's school. They can talk about the impact of diagnosis on siblings and their education. You can also discuss any concerns with your child's school.

Most children's hospitals have schools that can support children while they are in hospital and the teachers will liaise with you directly if this is required.

Helping brothers and sisters

Siblings can experience fear and worry, and often a sense of guilt that they are well and active. They can have conflicting feelings, at times resenting the extra attention given to the ill child and at others feeling responsible and worried.

Many siblings worry about their brother or sister. They become anxious and underlying concerns can manifest into behavioural problems. They may have issues which might only surface a long time after the immediate period of crisis.

The well siblings also experience disruptive changes to their home life; parents often spend time with the sick child in hospital, meaning that siblings may need to stay with other relatives. Sometimes there may be a family house at the hospital where parents and siblings can stay.

Some siblings find their role in the family structure changes. The family can experience financial difficulties, holidays can be disrupted or cancelled, eating out can be more difficult, special diets are adopted – all of which impact on the well siblings. Younger siblings can experience difficulty in being separated from their parents during hospitals stays.

Siblings' needs are often over-shadowed by the greater demands of their sick brother or sister. Often the sick child receives more attention than the well siblings. While this is unavoidable, it can cause resentment and jealousy. Often, however, the well sibling may try and cover up their feelings or worries so as to avoid further burdening their parents.

Siblings need to feel they are important and their needs are not being overlooked.

How you can help:

- Try to be open and honest if they understand why family life is disrupted they will be more likely to accept the situation.
- Encourage them to ask questions and feel secure in voicing their worries.
- Find time to share activities with siblings such as a trip to the swings or enjoying a hot chocolate, as it is the little moments that help.
- Ask for help from the team of professionals supporting your family they may be able to offer advice, guidance or even work directly with siblings to help with support and answer their questions.
- Inform the sibling's school about the situation.
- Be aware that sometimes siblings can hide feelings from their parents to avoid further upset to the family – there may be a family member, friend or teacher who they trust and respect who can provide them with support.



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Dealing with emergencies

Your child's hospital team will tell you what to do if your child has a temperature or is unwell. It may mean going to hospital straight away for assessment, even in the middle of the night, so it's best to prepare things as much as possible beforehand. Make sure you have your hospital/shared care unit and community nursing team phone numbers saved on your phone and available at home. Keep a digital thermometer handy.

Include things for yourself in the bag such as phone charger, toiletries, books, hairbrush, pen, child's favourite toy/games.

Plan who'll be able to take care of other children, pets etc. if you need to go into hospital.

Protecting your child from infections

The best way to prevent germs and bacteria from spreading is having good hand hygiene. Regularly washing hands with soap and water, particularly after going to the toilet, changing a nappy or before eating and drinking, can help reduce the risk of infection. Alcohol gel is a good way of quickly disinfecting hands that are already clean. Antibacterial hand gel is useful to keep with you at all times, and to have available for visitors to your home.

As your child's treatment may suppress their immune system it is important to inform your team if your child comes into contact with anyone who has chicken pox, measles or shingles. It is a good idea to avoid contact with people who are showing signs of being unwell, such as coughing or sneezing. Follow the advice of your team for socialising and taking part in activities as this will depend on your child's personal circumstances.

Sources of help and support

The internet can be a valuable source of information, but it is important to be aware that there is much that is either incorrect or unhelpful. Always use well-known, reputable sites. Check when information was published and where a site is based as information from other countries may not always be relevant. Don't worry that your child's doctor will be offended if you turn up with a list of questions about things you have found out online. They will take you seriously and give you honest, balanced advice based on your child's individual situation.

Your child's health team

Your child's health team can provide advice and support. They know your child's individual condition in detail, so it is always best to discuss worries, concerns and questions with them. Your team will include your child's doctor, specialist nurse or key worker, psychologist, social worker, play specialist, dietitian, as well as family support workers and community nursing teams.

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

www.younglivesvscancer.org.uk

Helpline: 0300 330 0803

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

Macmillan Cancer Support

www.macmillan.org.uk Helpline: 0808 808 0000 Offers help and support to people affected by cancer and their families.

Teenagers and Young Adults with Cancer

www.tyac.org.uk Provides expert information resources for patients 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.

Notes

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Children's Cancer and Leukaemia Group the EXPERTS in CHILDHOOD CANCER

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.

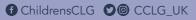
We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website. If you have any comments on this booklet, please contact us at publications@cclg.org.uk.

Our work is funded by donations. 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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