

# Managing family life and cancer

A practical guide for parents of a child with cancer



Originally written by Sharon Dempsey.  
This edition was reviewed and edited by the  
CCLG Publications Committee, comprising  
multiprofessional experts in the field of  
children's cancer.

CCLG makes every effort to ensure that information  
provided is accurate and up-to-date at the time of printing.  
We do not accept responsibility for information provided  
by third parties, including those referred to or signposted  
to in this publication. Information in the publication should  
be used to supplement appropriate professional or other  
advice specific to your circumstances. For information  
about the sources used to put this publication together,  
please contact us.

Publication of this booklet was funded by CCLG.

The quotes in this publication are personal views and  
do not necessarily represent the view of CCLG.

© CCLG 2016

Published: December 2016  
Next review due: December 2019

Children's Cancer and Leukaemia Group  
0116 252 5858  
info@cclg.org.uk  
www.cclg.org.uk

 ChildrensCLG

 CCLG\_UK

Registered Charity number 286669



This booklet has been written by a  
parent for parents. We thank all parents  
who have shared their experiences and  
passed on their tips and advice in this  
booklet to help newly-diagnosed  
families cope better with the impact  
of cancer on their lives.

# Contents

|  |    |
|--|----|
| Diagnosis                                      | 5  |
| • How is the family affected?                  | 5  |
| • How do we cope?                              | 5  |
| • Telling family and friends                   | 6  |
| Coping strategies                              | 7  |
| • Coping with stress                           | 8  |
| • Asking for help and advice                   | 11 |
| • While in hospital                            | 12 |
| • Finding emotional support                    | 14 |
| • Taking time out to recharge                  | 16 |
| Everyday life for<br>children during treatment | 17 |
| • Talking to each other                        | 18 |
| • Take on specific roles                       | 18 |
| • Keeping a normal routine                     | 19 |
| • The importance of play                       | 21 |
| • Going to school                              | 21 |
| • Helping siblings                             | 21 |
| • Eating                                       | 22 |
| • Sleeping                                     | 24 |
| • Dealing with emergencies                     | 25 |
| • Protecting your child from infections        | 25 |
| Sources of help and support                    | 26 |

Dear parents...

When you are told your child has cancer it feels like the end of the world, or at least the end of normal life. As a parent of a child diagnosed with cancer, I know first hand how difficult it is to try and look after your family with some sort of normality.

One of the greatest challenges of parenting a child with cancer is balancing your child's health needs and the demands of treatment while coping with everyday issues and still enjoying family activities. 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.

My son Owen was diagnosed at the age of two and his treatment included surgery, chemotherapy and radiotherapy. While devastated that Owen was so ill and had to endure such demanding treatment, we tried our best to ensure that he, and his sister Kate, still enjoyed life. Cancer became a part of our lives that limited us in many ways but we learned to live with it, while preventing the difficulties from affecting our family's quality of life as much as we possibly could.

On the ward we made many friends and we all shared information and tips on how to cope. I hope that this booklet helps you to manage, and still enjoy, family life during this challenging time. Cancer is one aspect of your child's life. It is not the whole of your child's life.

Sharon

(Mum of Owen who was diagnosed with a brain tumour aged two years old)



# Diagnosis

**When your child is diagnosed with cancer, it is devastating for the whole family. Families often feel as if everything in their lives is changing and life will never be the same again.**

You may feel anxious and worried about what might happen to your child through treatment and beyond. As time goes on, a new reality unfolds which includes difficulties, limitations and challenges. You will find yourself embracing new vocabulary, meeting new people and facing issues that were unimaginable before diagnosis. While the process of adapting to this new reality is going on, so too is everyday life. You may have work commitments, bills to pay and other children to care for. Children still have birthdays, Christmas still arrives 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. For example:

- ♦ **Daily changes to your home life routines** (hospital visits, hospital stays, visits from the shared care team, visits to your GP, hospital appointments)
- ♦ **Changes in work patterns**, with one parent often giving up their employment to care for the child, or single parent families finding that they can no longer manage to juggle work while caring for their child during treatment. These employment changes can impact on finances and career plans.
- ♦ **Financial re-adjustments** (this may be due to not being able to work the same hours as before diagnosis)
- ♦ **Relationship stress**, with both parents constantly tired and worried, and maybe each taking a different approach to the situation (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, extra care and attention being given to the sibling with cancer)
- ♦ **Childcare problems**, when staying at hospital or attending clinic appointments, where siblings need to be cared for by others
- ♦ **Knowing when to focus as a close family unit** and when to open up your network to allow others to help and provide support

## How can we cope?

- ♦ **Allow the illness** to be part of family life. Accept that there will be changes and adjustments and work around them so that life carries on as normal as possible.
- ♦ **Don't be frightened to ask for support.** Family and friends are often happy to be called on to help with household chores, school pickups or just a friendly chat. Don't be scared to ask for help and let people know that your need for help may continue for some time.
- ♦ **Let other family members and friends help you.** Often they will be frightened to offer, for fear of treading on toes, or simply getting in the way. Share information among family members and be open about what practical support you need.
- ♦ **If you feel overwhelmed** by the amount of information being given to you, keep the booklets in a safe place and refer to them when you need to, or feel ready.

Do not be afraid to ask your child's health team to explain things again at any time – they will be more than happy to help.

- ♦ **Keep talking and listening to each other.** However hard it may be at times, communication can increase a sense of togetherness and may help strengthen the family bond.
- ♦ **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.

## Telling family and friends

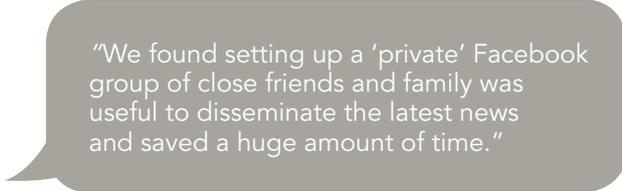
When you have to share bad news with family or friends, for example, after diagnosis, take time to plan how and when you are going to do this. Their distress and pain can sometimes be an additional burden, or you may find yourself feeling guilty that you upset someone you care about. If there are a lot 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
- ♦ You might want to discuss your plans for letting others know either asking for help to share the news, or being clear that it is something you want to do personally
- ♦ 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

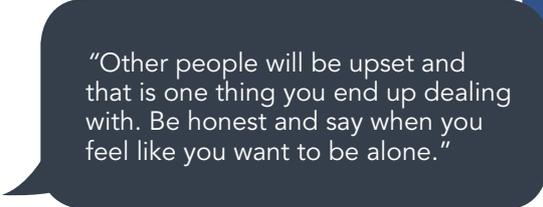
If you are upset or worried by the reaction of a friend or family member, or how they respond to you or your child afterwards, talk it through with your specialist nurse or CLIC Sargent social worker – they may help you to understand their reaction.



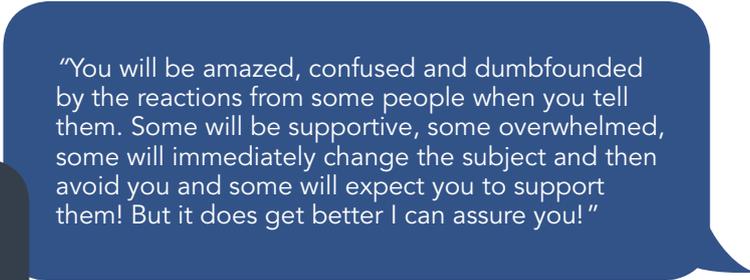
Some family and friends may react in unexpected ways, so make sure you have someone close by to support you.



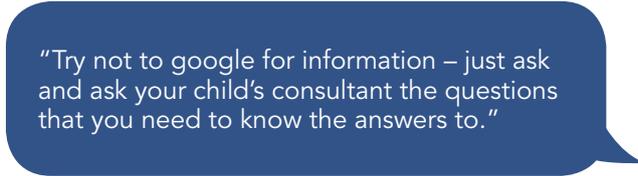
"We found setting up a 'private' Facebook group of close friends and family was useful to disseminate the latest news and saved a huge amount of time."



"Other people will be upset and that is one thing you end up dealing with. Be honest and say when you feel like you want to be alone."



"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! But it does get better I can assure you!"



"Try not to google for information – just ask and ask your child's consultant the questions that you need to know the answers to."



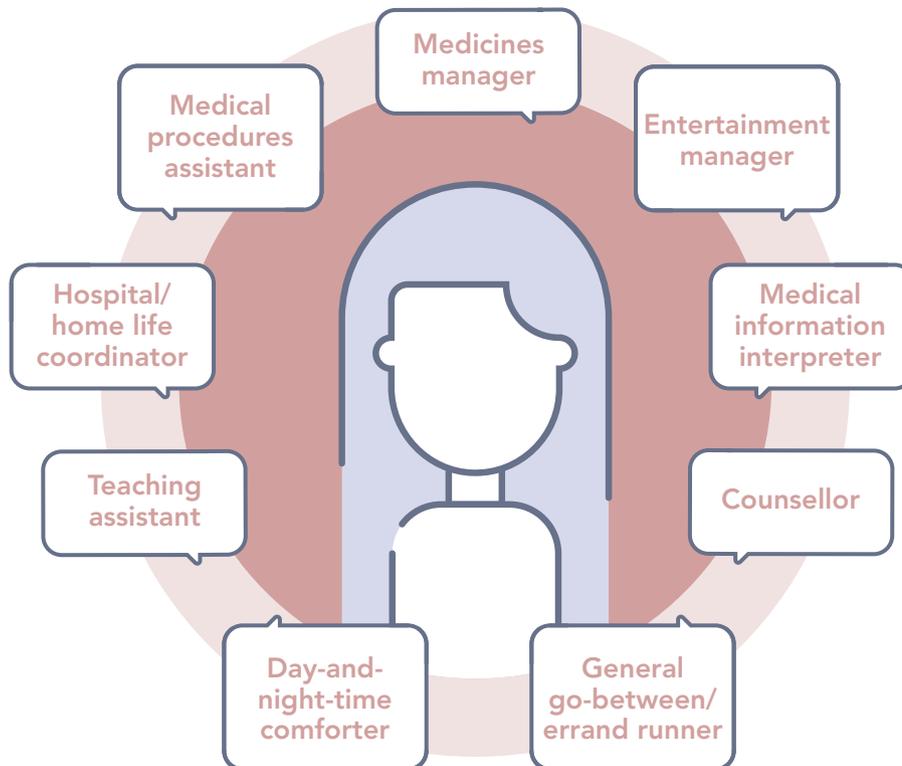
"After telling our family and close friends, I turned to Facebook to share this horrible news in one go (I couldn't face having the same text or conversation over and over)."

# 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 a variety of different roles in hospital and at home:



## Coping with stress

Coping with stress is about finding positive ways of coping and there are many support systems in place to help you. Discovering small ways to find some sense of enjoyment each day can make a real positive difference to mood and emotional coping.

Getting out of the house and physical activity can help ease stress. If you spend a lot of time at hospital, try to take breaks, read a book or a magazine. While this is not always possible even a short walk around the hospital grounds can help.

- ♦ Be organised at home and in hospital as much as possible
- ♦ Develop a routine for ordering and administering medicines which will help lessen the impact of treatment on family life
- ♦ Stay in touch with your own hobbies, interests and friends away from hospital
- ♦ Some hospitals offer massages or other services for parents staying in hospital - use them if they are available

The NHS Moodzone website offers practical help and advice on dealing with stress, anxiety and depression, featuring expert help and audio guides. [www.nhs.uk/conditions/stress-anxiety-depression/pages/low-mood-stress-anxiety.aspx](http://www.nhs.uk/conditions/stress-anxiety-depression/pages/low-mood-stress-anxiety.aspx)

Other useful websites to visit: [www.bemindful.co.uk](http://www.bemindful.co.uk), [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)



Mindfulness approaches can help you to slow down and bring your attention to the smallest of details 'in the moment' such as the sights, sounds and smells around us. This can lower the stress levels in our bodies by influencing our heart and breathing rates. You can do this wherever you find yourself such as on the ward or sitting in a clinic waiting room.

If you find that you or any of your family's feelings are overwhelming and are finding it difficult to cope, then it is a good idea to visit your GP and tell them exactly how you feel. Your GP will then be able to tell you what professional help is available to you.

## Stressbusters

**Be active** (helps clear your thoughts and lessens physical symptoms)

**Take control** (being passive is a major cause of stress)

**Connect with people** (helps you to relax and see things differently)

**'Me time'** (make time for socialising, relaxing and exercise)

**Avoid unhealthy habits** (smoking, alcohol, caffeine)

**Try to be positive** (be thankful for the small things)

**Accept the things you can't change** (concentrate on the things you do have control over)

*Source: NHS Moodzone*

"I appreciated a nurse friend taking me out for lunch. She knew not knowing what is happening to your little one in the operating theatre is one of the worst times."

"Take each hour and day as it comes and build from there."

"Most days will have their good times, even the darkest days. They are difficult to find sometimes and may only be tiny, but try to find them for your child's sake and your own."

"Write down questions you want to ask when they are whirring round your head at 3am – great for de-stressing!"

"A sense of humour helps. If you haven't already got a dark sense of humour, you may well find you develop one!"

"Buy a diary and keep a log of important information."

"Take photos and make a scrapbook of treatment – painful at the time but good for you and them to look back at and see the progress made."

## 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. Communicating with the range of health professionals you will meet will provide you with many answers and much practical advice.

It is fine to ask questions and no question is silly. 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 keyworker and/or the CLIC Sargent social worker will be able to answer questions on all aspects of life that might affect you and your family.

If you have any worries or questions, write them down and talk to a member of your child's team.

### Your GP

While your GP is not an expert in children's cancer services, they will know you and your family and 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 helping you to cope better as a family during this stressful time.

"One of the biggest worries was money. How were we going to afford to be off work with our child? We found out that our GP would sign us off work. Knowing this at the end of week one would have saved us additional worry."

Questions to ask:

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

## While in hospital



“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?”

“Baby wipes are useful for freshening up.”

“Check hospital’s infection control guidelines to find out about washing items brought from home.”

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

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

"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."

"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."

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

"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."

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

"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."

"Find out where the toilets and shower are - check if you can leave your child if you go to the toilet."

"Important to try and get enough rest when you are in hospital to be able to look after your child."

"Make sure you have loose change for vending machines, small purchases and car park."

## Finding emotional support

### Other families in hospital

Chatting to other families of a child with cancer can be great and the hospital ward is often the best place to make new friendships. Parents can find support in working together and sharing information. 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 where to holiday or how to get suitable holiday insurance policies when travelling with a sick child
- **Advice on accessing financial help** in the form of a disability living allowance that could help pay for a new car
- **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

Support groups and organised outings by groups supporting your child's condition also offer the opportunity to meet up with people who have an understanding of the stress and strains.

You aren't alone, many parents have gone through, or are going through experiences very similar to yours.

While sharing experiences will be immensely important to many families, there may be some who are not able to become involved with others on the hospital unit as they can only focus on what is happening within their own family.

Others may find the enormity of being given information about other families' problems too much to cope with. It is ok 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.



"Every child and family are different and other parents you may come across will be at different stages and diagnoses. Remember, it's you and your child that is important, so find out what is relevant to you."

"Make friends with other parents. My 'hospital' family has been my lifeline as only they truly understand what I am going through."

"Make as many friends on the ward as possible."

"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."

"Spending so much time in hospital can be a lonely and isolating time. When the visitors had gone home and I was alone, I'd get very down and my mind would go into overdrive. Facebook was a lifeline; I knew if I posted on a support group I'd get supportive responses from people who knew exactly how I was feeling."

## Using Facebook and 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 the same 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

You may find 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 when sharing information.

Some families can experience social isolation and feel alienated from their friends and neighbours. Your previous social network may seem irrelevant to your new lifestyle, which can be dictated by treatment regimes. 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. For example, enjoying a coffee with a friend.

Friends and family may seem insensitive as they will 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 you help, say 'yes' as having support around you can make all the difference.



"If I needed help, I'd ask on my Facebook page so I'd not be asking anyone specific. but someone would usually reply as people want to help."

"Friends cooked homemade meals that were frozen and we could microwave as and when necessary."

"My elderly aunt helped more than she knew, just by being there and listening while I talked."

"It's good to talk but some people really lift your spirits and others drag you down, and you don't know which ones are which when you start talking."

"Take help from those who offer – let people cook and leave meals for you. You will be amazed at who steps up and you will be upset and disappointed by those who don't!"

"The thing that helped us more than anything was not kind words, but a heartfelt hug!"

## Taking time out to recharge

Caring for a sick child undergoing treatment for cancer can be difficult and demanding over a long period of time. Parents may need to distract themselves to help prevent mental and physical exhaustion by taking time out to recharge and relax.

### Relationships

Stress can cause a huge amount of strain and tension within relationships and families. It is a good idea to make time for yourselves either with your partner, a friend or family member, especially if you are spending a lot of time away from home such as at work or in hospital. Finding the time for a meal, walk or cup of coffee together can help to strengthen a sense of partnership without distractions and is a time to reflect and talk.

From time to time all parents feel the need to spend time doing things outside of the family routine. 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 a hobby or sport you enjoy, you can return home recharged and better able to cope. You shouldn't feel guilty about needing or wanting a break. Sometimes a short respite break can make all the difference returning with new energy to cope better with ongoing caring demands.

“Make time for your partner as this will either bring you closer or drive you apart.”

### As a family

Sometimes you will feel that you want to focus on your child alone. You may not want to have 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 some charities that provide entertainment and family activities for children with cancer. It is often easier to attend an event that has been planned by an organisation that understands your child's needs. It is also an opportunity for families to meet other families living with the same condition. They can offer emotional support and a network of friends who can relate to your circumstances and have shared experiences. Many families feel safe attending events organised or hosted by organisations connected to their hospital or local charity because of their awareness and support. This also saves the need to use up energy in planning and organising.

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 information on what is available.

## Getting professional help

Professional help offers time with a member of your child's team who has specialist 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).

[www.itsgoodtotalk.org.uk](http://www.itsgoodtotalk.org.uk)  
[www.relate.org.uk](http://www.relate.org.uk)  
[www.samaritans.org](http://www.samaritans.org)

# Everyday life for children 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.

- Talk to each other and try to identify particular concerns. Look out for any signs of anyone becoming withdrawn or being over anxious, or siblings feeling resentful.
- Changes in behaviour of siblings may reflect fears, which may or may not be accurate.

“Try and talk to your child and make everything as normal 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!”

“I was positive and cheerful in front of my son and upset later. This was hard but helped how he dealt with it.”

## 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, cleaning and so on, while the other parent attends hospital appointments and deals with medicines.





Routine helps everyone to have a sense of stability and security.

## 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 plan for hospital stays and procedures
- ♦ being organised at home will help lessen the stress when staying in hospital
- ♦ school is an important part of normal routine for children

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 heightened if they feel of value to the family's daily tasks. Over-dependence on parents and siblings to carry out tasks for the sick child will inhibit their ability to cope and to develop.

It is all too easy 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, this is to deny the child the right to be treated as a regular member of the family.

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.

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.

"Siblings can have conflicting feelings, at times resenting the extra attention given to the ill child and at others feeling responsible and worried."



## The importance of play

Play is a huge part of a child's life. Through play they explore their environment while learning 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 ascertain 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 schoolwork. 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 siblings

Siblings can experience fear and worry. Their 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. 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, though sometimes there may be a family house at the hospital where parents and siblings can stay. 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 hospital stays.

Some siblings find their role in the family structure changes.

## How you can help ease tensions and worries

- To support well siblings, try to be open and honest. If they understand why family life is disrupted they will be more likely to accept the situation.
- Encourage siblings to ask questions and feel secure in voicing their worries. Give them honest, but appropriate, answers.
- Often siblings experience a sense of guilt that they are well and active. Siblings can have conflicting feelings, at times resenting the extra attention given to the ill child and at others feeling responsible and worried. Good ongoing communication can help ease these emotions.

Siblings need to feel they are important and their needs are not being overlooked. Perhaps there is a family member, friend or teacher who they trust and respect who can provide them with support.

- Many siblings worry about their brother or sister. They become anxious and underlying concerns can manifest into behavioural problems outside of the home. It is important to inform the sibling's school about the difficulties of living with chronic illness. Be aware that sometimes siblings can hide feelings from their parents to avoid further upset to the family.
- The team of professionals supporting your family may be able to offer advice, guidance or even work directly with siblings to help with support and answer their questions.
- 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.

All CCLG booklets and leaflets can be downloaded or ordered from our website.



## 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 their good eating days.

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."

Our CCLG booklet  
**'Helping your child to eat'**  
is available free of charge from  
children's cancer hospitals.

All CCLG booklets and leaflets can  
also be downloaded or ordered  
from our website  
[www.cclg.org.uk](http://www.cclg.org.uk)



## 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.

While sleep disruption is physically and mentally draining for you and your child, it can be difficult to impose a routine when treatment, hospital stays and periods of illness regularly cause ongoing disruption.

It can be difficult to establish a good bedtime routine if the 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 the child's sleep pattern.

Parents can find that their need to be vigilant by listening out for a sick child during the night can prevent them from achieving deep sleep themselves.



"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 beeping in the night."

## How can I help my child sleep better?

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

## 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 straightaway for assessment even in the middle of the night so it's best to prepare things as much as possible beforehand.

"Unexpected admissions do happen – usually in the middle of the night. Each time you get home from a hospital stay repack your bag so that it's ready."

"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."

"Make sure you have small change with you – it's always handy for a vending machine or shop."

"I always tried to stay calm for my child to make sure she was never frightened."

## Protecting your child from infections

Good hand hygiene is the best way of preventing the spread of germs and bacteria. The regular washing of 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. Avoid anyone who is obviously unwell such as coughing or sneezing.

"Place a hand sanitiser at the front and back door."

"Make sure people understand your child is immunosuppressed and can't be exposed to anyone who is unwell."

"No shoes in the house."



# Sources of help and support

## Your child's health team

Within the hospital, there will be a team of people who can provide advice and support. These will include your child's doctor, specialist nurse or key worker, psychologist, social worker, play specialist, dietitian, as well as family support workers.

## Charities and organisations

### Children's Cancer and Leukemia Group (CCLG)

[www.cclg.org.uk](http://www.cclg.org.uk)

Supports young patients and their families with expert, high-quality and award-winning information resources including Contact magazine, a free quarterly magazine featuring informative articles and personal stories.

### CLIC Sargent

[www.clicsargent.org.uk](http://www.clicsargent.org.uk)  
Helpline: 0300 330 0803

### Macmillan Cancer Support

[www.macmillan.org.uk](http://www.macmillan.org.uk)  
Helpline: 0808 808 0000

## Holiday breaks

A number of charities and organisations offer holiday breaks to children with cancer, their siblings and sometimes the whole family including:

[www.barretstown.org](http://www.barretstown.org)  
[www.otw.org.uk](http://www.otw.org.uk)  
[www.ellenmacarthurcancertrust.org](http://www.ellenmacarthurcancertrust.org)  
[www.youthcancertrust.org](http://www.youthcancertrust.org)  
[www.donnasdreamhouse.co.uk](http://www.donnasdreamhouse.co.uk)  
[www.kidscancercharity.org](http://www.kidscancercharity.org)

## Special treats for your child

### Kids & Teens Star Awards (Cancer Research UK)

Each child nominated receives a trophy, t-shirt, certificate and £50 TK Maxx voucher. Their siblings will get a special certificate too.

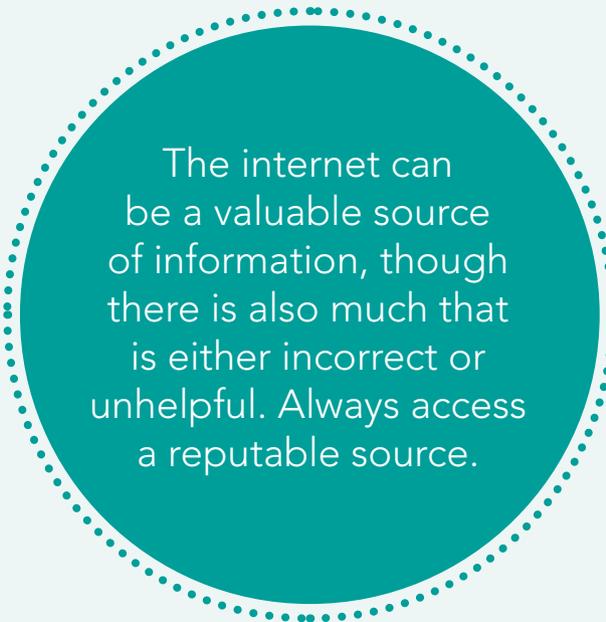
### Tom's Gift

#### (The Tom Grahame Trust and Macmillan Cancer Support)

Tom's Gift is a special present sent to children aged 0 to 16 who require treatment for cancer. It includes a mystery item and a £30 Debenhams gift voucher for them to spend in-store or online on anything they will find fun and enjoyable.

### Make a Wish

The charity grants wishes to enrich the lives of children and young people fighting life-threatening conditions.



The internet can be a valuable source of information, though there is also much that is either incorrect or unhelpful. Always access a reputable source.

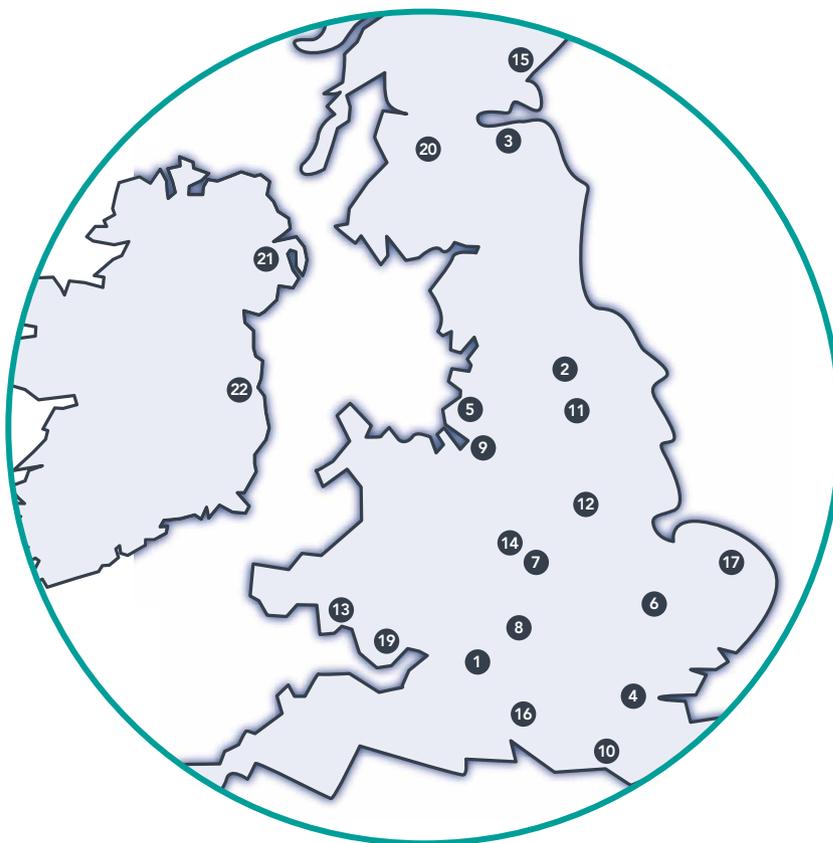
## Local charities supporting families across the UK and Ireland

There is a range of organisations helping and supporting local children with cancer and their families. Find the nearest one to you on the following map or by contacting CCPA.



The CCPA is a national parent-run organisation with the common aim of working together to support children and young adults with cancer and their families.

[www.ccpa.org.uk](http://www.ccpa.org.uk)



1. CALM (Children's Cancer and Leukaemia Movement) - Swindon  
[www.calmcharity.org](http://www.calmcharity.org)
2. Candlelighters - Leeds  
[www.candlelighters.org.uk](http://www.candlelighters.org.uk)
3. CCLASP (Children with Cancer and Leukaemia, Advice and Support for Parents) - Edinburgh  
[www.cclasp.co.uk](http://www.cclasp.co.uk)
4. CCUPA (Childhood Cancer Unit Parents Association) - Royal Marsden  
[www.royalmarsden.nhs.uk/your-care/children-and-young-people/our-partners](http://www.royalmarsden.nhs.uk/your-care/children-and-young-people/our-partners)
5. CHICS (Children's Cancer Support Group) - Liverpool  
[www.chicsonline.org](http://www.chicsonline.org)
6. COPARS (Childhood Cancer Organisation for Parents and Relatives Support) - Cambridge  
[www.copars.org](http://www.copars.org)
7. CROCCS (Carers and Relatives of Children with Cancer Support) - Coventry  
[www.bethanyswish.co.uk/croccs-carers-and-relatives-of-children-with-cancer-support.aspx](http://www.bethanyswish.co.uk/croccs-carers-and-relatives-of-children-with-cancer-support.aspx)
8. Friends of O.S.C.A.R. - Oxford  
[www.friendsofoscar.org.uk](http://www.friendsofoscar.org.uk)
9. The Joshua Tree - Cheshire  
[www.thejoshuatree.org.uk](http://www.thejoshuatree.org.uk)
10. LEUCAN - West Sussex [www.leucan.org.uk](http://www.leucan.org.uk)
11. PACT (The Parents Association of Children with Tumours and Leukaemia) - Sheffield  
[www.pactfriends.co.uk](http://www.pactfriends.co.uk)
12. PASIC (Formerly, The Parents' Association for Seriously Ill Children) - Nottingham  
[www.pasic.org.uk](http://www.pasic.org.uk)
13. Kids Cancer Charity - Swansea  
[www.kidscancercharity.org](http://www.kidscancercharity.org)
14. SPOCC (The Society of Parents of Children with Cancer) - Birmingham [www.spocc.org.uk](http://www.spocc.org.uk)
15. TCCL (Tayside Children with Cancer and Leukaemia) - Dundee [www.tccl.org.uk](http://www.tccl.org.uk)
16. The Joe Glover Trust - Winchester  
[www.thejoeglovertrust.org](http://www.thejoeglovertrust.org)
17. Wiggly - Norfolk  
[www.wigglysupportgroup.co.uk](http://www.wigglysupportgroup.co.uk)
18. The ARCHIE Foundation - Aberdeen  
[www.archiefoundation.org.uk](http://www.archiefoundation.org.uk)
19. LATCH (Welsh Children's Cancer Charity) - Cardiff  
[www.latchwales.org](http://www.latchwales.org)
20. Glasgow Children's Hospital Charity - Glasgow  
[www.glasgowchildrenshospitalcharity.org](http://www.glasgowchildrenshospitalcharity.org)
21. Cancer Fund for Children - Belfast  
[www.cancerfundforchildren.com](http://www.cancerfundforchildren.com)
22. Irish Cancer Society - Dublin [www.cancer.ie](http://www.cancer.ie)



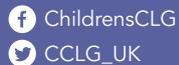
Children's  
Cancer and  
Leukaemia  
Group

Children's Cancer and Leukaemia Group is a leading children's cancer charity and the UK and Ireland's professional association for those involved in the treatment and care of children with cancer. Each week in the UK and Ireland, more than 30 children are diagnosed. Two out of ten children will not survive their disease.

We bring together childhood cancer professionals to ensure all children receive the best possible treatment and care. We fund and support research into childhood cancers, and we help young patients and their families with our expert, high quality and award-winning information resources.

Children's Cancer and Leukaemia Group  
University of Leicester  
Clinical Sciences Building  
Leicester Royal Infirmary  
Leicester LE2 7LX

0116 252 5858  
info@cclg.org.uk  
www.cclg.org.uk



Registered charity number 286669

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

