



Family life and Cancer

A guide for parents of a younger child with cancer



Written by Sharon Dempsey in conjunction with the CCLG Publications Committee, comprising multiprofessional experts in the field of children's cancer.

We are grateful to those families who contributed quotes for this booklet, or have otherwise shared their experiences in order to help other families.

Publication of this booklet was made possible by a donation from the Chelsea FC Foundation.

Designed and published by CCLG June 2012.
Review date June 2014.

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INTRODUCTION

One of the greatest challenges of parenting a child with cancer is balancing your child's health needs and the demands of treatment with normal family life.

Cancer is a significant part of your family life and can at times dominate. It does not have to define your family. The challenge is how to cope with the day-to-day issues and still enjoy normal family activities.

When you are told that 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 a brain tumour I know first hand how difficult it is to try and provide your family with some sort of normality. Our son Owen was diagnosed at the age of two. His treatment included neurosurgery, 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 encroaching on Owen's and his sister'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 Dempsey

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

Liz, mother of David, diagnosed with bone cancer

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“Accept help, realising that at this time you cannot re-pay that help and that it is not expected. People do understand.”

Ginny, mother of Alex, diagnosed with leukaemia





DIAGNOSIS

A child's diagnosis of cancer is devastating for the whole family.

At the time of diagnosis, families often feel as if everything in their lives is changing. A new reality unfolds, which includes difficulties, limitations and challenges. You find yourself embracing new vocabulary, meeting new people, and facing issues that were unimaginable before diagnosis. While the process of adapting is going on, so too is everyday life. You may have work commitments, bills to pay, other children to care for. Children still have birthdays, Christmas still arrives and holidays loom.

How do we cope?

- Incorporate the illness into family life. Accept that there will be changes and adjustments and work around them to achieve a new normality.
- Don't be frightened to ask for support. Family and friends are often happy to be called on. Explain that you may need them to help with household chores, school pick ups or just a friendly chat. Let people know that your need for help may continue for some considerable time.
- Allow extended family members to help. Often they will be frightened to offer, for fear of treading on toes, or simply getting in the way.
- 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.

"Friends at church cooked lots of home-made meals that were frozen and we could microwave as and when necessary, while Katie was on treatment."

Fiona, mother of Katie, diagnosed with Wilms tumour

HOW IS THE FAMILY AFFECTED?

When a child is diagnosed with cancer families are forced to make huge adjustments ranging from:

- Daily changes to your home life routines, (hospital visits, hospital stays, visit 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.
- Financial re-adjustments (this may be due to one parent not being able to work the same hours as before diagnosis).
- Marital stress, with both parents constantly tired and worried, and maybe taking a different approach to the situation. (It is not uncommon for one parent to want to talk or find out more information, and the other not.)
- Sibling rivalry (due to presents, extra care and attention being given to the sibling with cancer).
- Childcare problems when siblings need to be cared for by others when staying at hospital or attending clinic appointments.
- Knowing when to focus as a close family unit and when to open up your network to allow others to help and provide support.

“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. People need to be aware that that happens.”

Paul, father of Edward, diagnosed with neuroblastoma





Normal family routines change to incorporate treatment, hospital appointments and hospital stays.

- Share information among family members and be open about your need for practical support.
- As a family discuss ways in which to support and help each other.
- Keep talking and listening to each other. However hard it may be at times, ongoing family communication will increase a sense of togetherness and help strengthen the family bond.
- Strive to enjoy family life – celebrate birthdays, enjoy Christmas and other holidays, try to plan trips away.

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 that you want to do personally. Some family and friends may react in unexpected ways, so make sure you have someone close by to support you. If you are troubled 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, CLIC Sargent social worker or psychologist – they may help you to understand the reaction.

“Normal everyday life and celebrations can seem like an added burden. Organisation and planning can help ease the pressure of dealing with family celebrations. Though often you will feel as if you are just making do, this is fine. Don't put added pressure on yourself to try to make everything perfect.”

Sharon, mother of Owen, diagnosed with a brain tumour

COPING STRATEGIES

Coping with stress

Regular outings 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 and if possible try to limit the amount of time spent in hospital.
- Develop a routine for ordering medicines and administering them. This will help to minimise the impact of the treatment on family life.

Sharing information and finding support

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. Talking to other families experiencing similar difficulties can be a lifeline and help to resolve difficulties. For instance, a child living with physical disabilities can find transport to be problematic. Through talking with other families solutions can be shared. For example, advice on obtaining a suitable holiday insurance policy when travelling with a sick child can be helpful. One family may have experienced adapting their car to accommodate their child, have advice about obtaining a blue badge, or have accessed government help in the form of financial aid to help pay for a new car. You can share advice on where to holiday, where to eat out, how best to keep your child occupied during appointments, or how to negotiate support from social services. Sharing information is also a good form of support. Parents can find support in working together. No one else will understand your situation better than another family in the same position.

"When Katie had her surgery, I appreciated a nurse friend taking us out for lunch. She knew that not knowing what is happening to your little one in the operating theatre is one of the worst times."

Fiona, mother of Katie



While for many, sharing experiences will be immensely important, there may be some families who are not able to become involved with others on the 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. All families are different – there is no right or wrong.

Some families living with chronic illness can experience social isolation, feeling alienated from their friends and neighbours. Your previous social network may seem irrelevant to your new lifestyle that can be dictated by treatment regimes.

You may create new friendships with other families living with cancer and the hospital ward is often the best place to form them. Your child may be nursed in a side room. This can be isolating but does have benefits of being quieter and easier for visiting. Support groups and outings organised 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 that are very similar to yours.

However, you may find sharing information with family, friends, neighbours and work colleagues can be a challenge.

“We found the best way to manage the amount of medicine we were giving was to be very organised. We created our own charts in Microsoft Word that told us what time to give medicine and what days of the week to give medicine.”

Neil, father of Anne, diagnosed with leukaemia

Taking time to recharge

In the short-term, caring for a sick child is difficult and demanding but when care is long-term it is necessary for parents to create diversions for themselves to prevent mental and physical exhaustion. Some parents need respite breaks more than others. For some, short breaks make the difference between coping and not coping. They return with new energy and ready to face the ongoing demands of caring for their child. Parents need to make time for themselves as a couple, especially if they are spending a lot of time taking on different roles in the family. Finding the time for a meal, a walk or a cup of coffee together helps bolster the sense of partnership. A family walk in the fresh air is good for everyone. It is time together without distractions – time to reflect or talk. Its an antidote to days or weeks in a stuffy hospital and can often help everyone sleep better.

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 desirable but if you can spend a couple of hours a week engaging in a hobby or sport you can return home recharged and better able to cope. You shouldn't feel guilty about needing or wanting a break.


- Encourage individual family members to engage in activities outside of the family.

There are some charities that specialise in providing short breaks for families of children with cancer. 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. See page 22.

“Have a ‘telephone tree’ so that when you come out of hospital, or have test results, you telephone (or text) just one person, who then passes the message on to the next person and so on. This not only saves money, but also time in repeating the same news to a lot of different people. Social networking is another good way to get the message out.”

Rachael, mother of Connor, diagnosed with leukaemia





Family fun time

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 deserve 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.

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. Such an event also provides an opportunity for families to meet other families living with the same condition. They can provide 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 expend energy in planning and organising.

When a child is at particular risk of infection or has a low immune system creating fun outings can be difficult. They may not be able to socialise with other children for fear of infection and visits to the park or the local swimming pool may prove too risky.

It might be a good idea to avoid trips or days out when your child is on dexamethasone.

“Horses were a vital part of Jenny’s recovery. Getting out of the hospital into a muddy field was a vital part of my ‘recovery’ too!”

Julie, mother of Jenny, diagnosed with leukaemia

“When Owen was receiving chemotherapy he was often immune suppressed. I contacted the local leisure centre and asked to book the bouncy castle for him and his sister to play on. The manager of the leisure centre offered us use of the bouncy castle before or after parties, free of charge.

Owen and Kate could enjoy a half hour of play outside the home without risk of Owen coming into direct contact with other children, who may have had colds, coughs or chickenpox and other childhood illnesses.”

Sharon, mother of Owen





EVERYDAY LIFE FOR CHILDREN

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 therapist 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.

Education

There will be times when your child is off school so misses out on peer group interaction. Or your child may not be willing to interact with peers, either because of their illness or perhaps change in appearance. The team treating your child will be able to advise.

"I would put on a nurse's apron and hat and a humorous 'nurse voice' when I had to perform any sort of procedure for Verity. Once we were finished, I took it off very quickly so that I could revert to being mum. It seemed to work!"

Deborah, mother of Verity, diagnosed with leukaemia

Communication

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 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.
- Discuss any concerns you have about the child with cancer or their siblings with the school.

Division of responsibilities

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, while the other parent attends hospital appointments and deals with medication.





Maintaining routines

It is helpful for the family to keep to a routine while allowing for flexibility during times of crisis or treatment. Routine enables 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.
- Be informed of risks and how to respond to emergency situations.
- Have an overnight bag packed for emergencies.
- Being organised at home will help lessen the stress when staying in hospital.
- School is an important part of normal routine for children. Discuss with the school any specific arrangements for your child to attend. The medical team will advise what is practical and will also liaise with the school.

Children respond well to consistency. They like to know the 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 that they are encouraged to develop their abilities 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.

“We always had a small ‘bag of tricks’ ready for episodes of febrile neutropaenia, with favourite DVDs and pyjamas (and a few bits of essential clothing for mum), so if you have to dash off in the middle of the night with a fever, you don’t have to worry about packing.”

Danielle, mother of Gregory, diagnosed with leukaemia

It is all too easy to want to over-compensate for your child's health problems. Many parents find that 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.

“Anne was just over three when diagnosed with leukaemia. It was very tempting to spoil her but we didn't and we think that helped her and us get through the tough times. She knew that when she had to have medicine, no matter whether it was painful or tasted horrible, she had to have it, and it was “non-negotiable” and not worth kicking up a fuss. Of course we often treated her to something nice afterwards as I know how horrible some of the medicine was.”

Neil, father of Anne





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 chronically-ill 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. They should provide them with 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 the chronically-ill child receives and at others feeling responsible and worried. Good ongoing communication can help ease these emotions.
- The siblings need to feel that they are important and that their needs are not being overlooked. Perhaps there is a family member, friend or teacher who they trust and respect and 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. Parents should highlight the disruption to family life which the well sibling experiences along with the emotional stresses.

“At the age of 14, I moved into a caring role for my dad and brother ... It put me off ironing for life!... It isn't the typical role of a 14 year old and I did sometimes feel resentful...”

Abi, sister of cancer survivor, Katherine

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. Children can also experience nausea and vomiting as a result of chemotherapy and radiotherapy.

Try to avoid 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. Maximise their good eating days.

Children requiring steroid treatment like Dexamethasone will experience hunger and it can be difficult to help them feel full up.

Your ward will have access to a dietician. If you require advice on any food related issues ask for a referral.

“To cope with the overeating on steroids, give the food but in smaller portions. They will still ask for more, but it will help to prevent some of the weight gain.”

Rachael, mother of Connor





Sleeping

Sleep can be affected in numerous ways when a child has cancer. Children can experience sleep disturbance for many reasons: 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. Try and establish a regular night-time routine.

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 not always quiet. Nurses continue the business of monitoring 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 find that their need to be vigilant, listening out for a sick child during the night can prevent them from achieving deep sleep.

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.

“Sleep was such a difficult issue for us. Owen often woke several times throughout the night. It was so draining. Even now, seven years later, I still suffer from insomnia.”

Sharon, mother of Owen

WHERE TO TURN FOR HELP

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

There are a number of organisations that provide telephone help lines to support families. These are manned by trained and experienced staff, usually nurses. Contact details can be obtained from the following websites:

- www.clicsargent.org.uk
- www.macmillan.org.uk
- www.gapsline.org.uk
- www.cancerhelp.cancerresearch.org.uk

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.

A number of charities and organisations offer holiday breaks to children with cancer, their siblings and sometimes the whole family. Other organisations grant wishes to seriously-ill children. Your local treatment centre will have contact details.

Finally, CCLG produces a very comprehensive range of booklets and leaflets, which are an invaluable source of information and support to families. The topics covered include: siblings, grandparents, bone marrow transplant, radiotherapy, helping your child to eat, children with cancer and pets, and sport and exercise for children with cancer. All booklets are available free of charge (see inside cover for contact details) or can be downloaded from the CCLG website (www.cclg.org.uk).

In addition to these booklets, CCLG also produces *Contact*, a free quarterly magazine, which includes both informative articles as well as personal stories. *Contact* is widely available in treatment centres. If you prefer to receive an individual copy, just contact us and you will be added to the mailing list.





Useful contacts

Name:

Telephone:

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Other notes:

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“A friend gave me a small notebook to keep all essential phone numbers and so on in. This was really helpful.”

Danielle, mother of Gregory

“We’re not used to asking people to do things.
A lot of friends ask what they can do to
help but we can barely think about what
we need without having to think about
what they could do for us. The best people
are those who just get on and do something.”

Paul, father of Edward



The CCLG supports the 1,700 children who develop cancer each year in Britain and Ireland. As an association for healthcare professionals involved in their care, it works to benefit children through development of the highest standards of care. CCLG is a major provider of accredited information for patients and families.

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Registered Charity No: 286669

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