



Children's
Cancer and
Leukaemia
Group

Grandparents

Information and support for grandparents of
children and young people with cancer



www.cclg.org.uk



Children's
Cancer and
Leukaemia
Group

Working together to
beat childhood cancer

This booklet was originally written by Sue Ablett and Katherine Green. This edition was reviewed and edited by the CCLG Publications Committee, comprising multiprofessional experts in the field of children's cancer.

The quotes in this booklet are from grandparents. They are personal views and do not necessarily represent the views of CCLG.

Thank you to all those who contributed to this booklet.

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.

Publication of this booklet was funded by CCLG.

© CCLG 2015

Published: October 2015

Next review due: October 2018

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



ChildrensCLG



CCLG_UK

Registered Charity number 286669



BMA Patient Information Awards

Highly commended 2005



The Information Standard



Certified
Member

Contents

Questions you may have

Are children's cancers the same as adult cancers?	5
Is it something we have done?	5
Someone else in the family had cancer. Is it in our genes?	5
Can cancer ever really be cured?	5
Why don't we hear of the successes?	6
Where can I find out more about my grandchild's cancer?	6

How you can help

If you are close at hand	9
If you live away	10
Supporting the parents	12
Supporting your grandchildren	12

Support for you

Why do I feel so helpless?	16
Make sure that you get what you need	16
Support from family and friends	19
Support from your grandchild's medical team	19
How talking can help	20
Support groups and counsellors	20

Sources of information and support 22





To be told that your grandchild has cancer comes as a terrible shock. Most grandparents worry not only about the ill child, but also about how their own son/daughter will cope. Most are also concerned about the effects it will have on any other children within the family and how, as grandparents, they themselves will cope.

Parents of the ill child usually have access to doctors and others who can answer their questions. It is not as easy for grandparents to get information first hand and this can lead to feelings of isolation. While the internet may provide useful information, not all of it is reliable. This booklet tries to answer some of the many questions grandparents have.

Questions you may have

Are children's cancers the same as adult cancers?

No. The most common cancers in adults, such as lung, breast and bowel cancers, are part of a group of cancers called carcinomas. These are all cancers of the lining of parts of the body and are caused, in part, by environmental/lifestyle factors. These cancers are almost never seen in children.

Many children's cancers come from cells left over from when the baby was still developing in the very earliest stages of pregnancy. These cancers are not seen in adults.

Some cancers found in children, such as leukaemias and brain tumours, are also seen in adults. However, even when the diagnosis is the same, the diseases often behave differently in people of different ages and children often respond better to treatment.

Is it something we have done?

No. As grandparents, you will of course have seen many changes over the years in the way children are brought up, their activities and diet, and may wonder if these changes have caused the cancer. There is absolutely no scientific evidence to support this.

Someone else in the family has had cancer. Is it in our genes?

Cancer is sadly a very common disease, particularly in older people. In many families where a child has been diagnosed with cancer, an adult member of the family will also have cancer - but there is no connection. Cancer is caused by changes in the genes that cause cells to divide abnormally. However, these gene changes will probably have only occurred in that individual and not because of an inherited faulty gene.

Very occasionally, childhood cancers do run in families. For example, when a child is diagnosed with a rare eye tumour, called retinoblastoma, the family will be advised about whether there is a need to monitor other family members for the condition.

Can cancer ever really be cured?

While you hope for the best outcome for your own grandchild you will still be very frightened. You may remember that it was not so long ago that cancer was a very scary word and a diagnosis was taken to mean that recovery was unlikely.

Today over 80% of childhood cancers are cured. Most children are not only cured of the disease, but go on to live full and active lives.

Sadly, there are still some children whose cancer cannot be cured. There may be treatment which will control or delay the progress of their cancer for some time.

For others it may only be possible to control symptoms (palliative care). This aims to keep the child well, active and pain free for as long as possible. In many cases the child can be cared for at home, if this is what the family and the child want and there are many forms of nursing care and support given by hospital staff, community nursing staff and others. Some children may be cared for at some stage in hospital or in a hospice.

Why don't we hear of the successes?

In the past people felt there was a stigma attached to having cancer. This meant that it was often only after a death, that the name of the illness would be known, so when a cancer was treated successfully, no-one knew about it.

Now that your grandchild has been diagnosed with a cancer it may be that friends will tell you of people they have known who have been cured of the disease. Similarly, some may have less encouraging stories.

Whatever you hear it is important to remember that every cancer patient and every diagnosis is different and that progress is continually being made in developing effective treatments.

Where can I find out more about my grandchild's cancer?

With your son/daughter's permission, you may be able to ask the medical team at your grandchild's hospital to help with this. Each child or young person's family will have a social worker or nurse specialist key worker assigned to them who may be able to assist you.

The Children's Cancer and Leukaemia Group website (www.cclg.org.uk) has comprehensive, reliable information about childhood cancers. You can also download or order our range of publications written by experts about childhood cancers.

“

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

”

“

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

”



“

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

”

How you can help

Many grandparents play crucial roles in the lives of their grandchildren even before there is illness in the family. Others may have much less involvement due to practical issues such as living away, work commitments or other pressures on time.

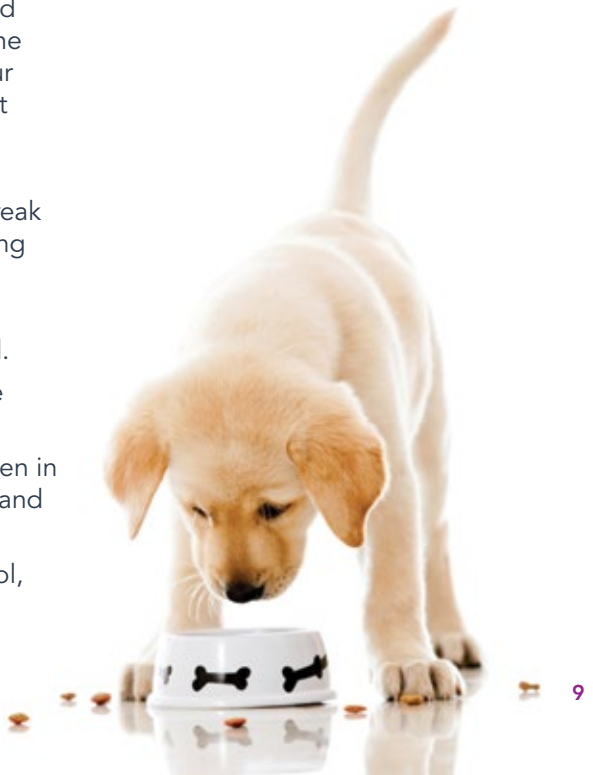
If you are close at hand

Once the illness is discovered, most grandparents are eager to help. Clearly for those who live close to the ill child, there is no shortage of practical help that can be given. Your son/daughter may be so absorbed by the needs of the ill child that they are unable to tell you what they would find helpful. Your knowledge of the family's usual activities will be your best guide as to what to offer, but here are some suggestions.

- Enabling parents to have a break from hospital routines by sitting with the ill child.
- Provide reassurance and a comforting ear for the ill child.
- Providing lifts to and from the hospital.
- Looking after any other children in the family, providing stability and consistency.
- Taking other children to school, clubs, football, shopping etc.

- Helping with school work, if appropriate.
- Lawn mowing and collecting post.
- Shopping and running errands.
- Providing meals and stocking the freezer with family favourites.
- Looking after the house and pets.
- Generally helping to ensure life continues as normally as possible.

You may also be able to do some of the suggestions we have given for grandparents who live further away.



If you live away

It can be very frustrating for those grandparents who live away, or perhaps for other reasons, cannot offer practical help. There are, however, still many ways in which grandparents in this position can help. Here are some ideas:

- Providing an 'answerphone' service to deal with the many enquiries and pass on updates to friends and family.
- Act as an intermediary between the parents and ill child and the wider extended family, providing updates on progress.
- Being a listening ear for your son/daughter, the ill child or other children in the family.
- Sending cards/letters/e-mails/text messages to your son/daughter, the ill child and any their brothers and sisters to let them know you are thinking about them.
- Sending activities suitable for the ill child (e.g. comic books/magazines, craft kits, DVDs and games).
- Ensuring that well children in the family still feel cared for by phoning just to see how they are, or sending them cards/gifts.
- Sending practical items to your son/daughter (e.g. phone cards for use with hospital payphones, mobile phone top up cards).
- Supporting, or even organising, local fundraising activities perhaps for a chosen cancer charity.
- Becoming a blood donor or, if you are unable to donate due to age (over 65 years) or health problems, encouraging others to do so.

“

I couldn't easily get to the hospital to visit - I wore the carpet out waiting for the phone calls.

”



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

Supporting the parents

Your son/daughter (in-law) will be dealing with many difficult emotions when their child is diagnosed with cancer. They will need to find people they trust to share these feelings and worries with. For some, turning to a parent is an automatic response. However, an equal number will feel they want to protect their parents from their worries and may find it easier to share their feelings with other friends or family members. As a grandparent, either situation can be difficult.

Listening and letting them talk

Although it will inevitably be painful for you to hear your child's distress and hard to know how to deal with their fears and sadness, many grandparents feel that they would rather know than be protected. It may help your son or daughter to simply be able to put their worries into words. You don't need to have answers, but a listening ear can be very supportive. If your son or daughter (in law) know you understand something of what they are feeling, they may feel less alone with their worries.

Guiding them elsewhere

You may find that you are not the right person for your son or daughter (in law) to share their worries with. In this situation you can help by encouraging them to have time with other people that they are close to. You can also help by encouraging

their children to share their thoughts and fears with members of staff caring for the ill child. Most treatment centres have links with CLIC Sargent Social Workers, community nurses, Macmillan or other outreach nurses and psychologists, any of whom may be able to help.

Some parents do not feel that sharing their feelings is helpful. This should be respected as some people find that, at times, this is the easiest way of coping. If you find yourself in this situation, just show that you are ready to listen if your son/daughter does want to talk.

Supporting your grandchildren

How children cope

Children, like adults, vary in their ways of coping in difficult situations. Some children will find it helpful to talk about what is happening. Others would rather be distracted with fun activities, have cuddles or see their friends. Whatever their preference it is important to be led by them. A child who says "I don't think I'm getting better" should be encouraged to talk about why they think this. Children who change the subject when their illness is mentioned are telling you that they don't want to talk at the moment. It is important that all children have someone to turn to for information and support, but they should choose who to turn to, and when they are ready to do so.

Children of different ages

Children of different ages need different things. For babies, physical affection from a calm, trusted adult is important. Toddlers and young children cannot put their fears into words. However, an adult who knows them well may be able to guess what is worrying them and give reassurance. As children become old enough to talk about their illness, it is important to try to find out from them what they understand about the illness and what their worries are. If children do not have the information they need they will often rely on their imagination to fill in the gaps. Their fantasies are often worse than what is really happening.

Children need to know that cancer is nobody's fault, that it was not caused by bad thoughts or bad behaviour, and that it cannot be caught from somebody else. Older children may need to know that cancer rarely runs in families. Storybooks for younger children can be a safe way to talk about difficult subjects. Older children might value more factual information in the many booklets or websites available. (See page 22). Remember, whatever the child needs to know, simple honest answers are nearly always best.

Discipline

Following the diagnosis, parents and grandparents often feel they want to give the ill child gifts and special treatment. Naturally some

treats and special consideration can give an ill child the boost they need. However, children are also reassured by normality. Most children will be used to adults treating them and their brothers and sisters the same. Gifts for the ill child with something small for brothers and sisters will be better for everyone.

Some treatments, for example, steroids, can have a marked effect on the ill child's mood and behaviour. It can be hard to maintain normal discipline for an ill child, striking the right balance between showing understanding and setting some limits.

At the same time it can be very difficult for brothers and sisters if they see the ill child being treated differently.

Maintaining the family's usual rules can be very reassuring to the ill child. Being told off can convey the message that "You're poorly now but you're going to get better and so we still expect you to be good." Where family rules on behaviour have to be changed, it is helpful for brothers and sisters to know why the rules have changed and that the change is only for a while. It's important too that grandparents and parents all follow the same rules on discipline, otherwise problems can occur.



“

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

”

The ill child

For the ill child the diagnosis of cancer is likely to turn their world upside down. Grandparents are often a welcome part of life before the illness and the ill child may get a lot of comfort from familiar games and activities with a grandparent.

Ill children usually know more about their illness than adults think they do. Family members often fear what children might want to know, but children who ask questions are also likely to be able to cope with the answers. It can be helpful to try to get a better idea of what the child is asking before trying to answer a difficult question. "What makes you think that?" or "Have you been worrying about this?" can be good ways to find out more. Children's fears are likely to be very different from those of adults.

For many children the words leukaemia or cancer may mean nothing. An open approach encourages the child to also be open with their thoughts and fears. This gives adults the chance to correct misunderstandings. It is always best to check with the child's parents about what information they want the child to have before answering difficult questions.

Well brothers and sisters

Well brothers and sisters often have fewer people with time to support them than the ill child. The changes they experience as a result of their brother's or sister's illness may be enormous. They can often feel very left out. The whole family's life tends to revolve around the ill child.

It is easy to see why some brothers and sisters feel that they are no longer important or that they are not loved as much as the ill child. Grandparents can be particularly valuable in showing love, giving time and practical help and generally making things seem more "normal".

If possible, brothers and sisters should always be given choices about whether they attend the hospital or are involved in the ill child's care. It is always best to try to warn them about changes they might see in the ill child. Tubes and other changes are often less frightening if children know the reasons for them.

For more information on helping brothers or sisters ask at your treatment centre for the series of booklets aimed at brothers and sisters and those caring for them. CCLG and CLIC Sargent produce a range of information booklets that you might find helpful.

Support for you

Why do I feel so helpless?

As parents and grandparents we see protecting our offspring as our most important task. We feel we should protect our children and our families and keep them safe. So, when something like cancer strikes our grandchild we feel guilt or helplessness because we were unable to prevent it. No-one seems able to explain why it has happened so we seek explanations wherever we can. Some may find comfort through their faith, while some find their beliefs seriously challenged. Many struggle to make sense of what is happening to their family.

You may feel that if anyone in the family had to have cancer it should have been you because you have had the chance to live your life while your grandchild's young life is threatened. You may wish that you could change places with the ill child rather than see them suffer and go through long treatment. It is worth remembering though that cancers in the young are much more curable than those which occur in older people and that children are physically better able to cope with treatment than adults. Children often cope well with the disease. Older children will sometimes say that having had the illness, they learn to appreciate their health and try to live life to the full. Young children may remember very little about their treatment.

Make sure that you get what you need

Many grandparents feel that their own needs should come second to those of the rest of the family, but support for you will give you more strength to cope. This, in turn, will help others.

If you live close to the family, life after diagnosis may become very busy. Some grandparents find that their hours are suddenly filled by helping with other grandchildren or with trips back and forth to the hospital. Yet all the other routine demands on grandparents' time and energy continue. You may still be working or have an active social life with a lot of commitments. Finding opportunities to get enough rest may be difficult. Take time to look at just how much you are trying to do. Maybe something will have to be put on hold. Sometimes you will need to say no and not feel bad about it. For grandparents who work this can be difficult although most employers, other organisations and friends will be understanding when they are told of the circumstances.

Of course even when there is time to rest, managing to relax and sleep can still be a challenge. Many grandparents find that when they do eventually lie down in bed they can't stop themselves worrying about everything that is happening to their family.

If this happens, try writing a list of your worries, even if you can't add solutions at that point.



“

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

”



It can be hard to completely relax, but many people can find places or activities that make them feel more at peace. Whether it's the bath or the tv, listening to music or seeing friends, do take time to find strength from the things you enjoy.

Grandparents may have health problems themselves. It is easy for these to be neglected and for you to become run down. It is important to keep taking medication and to keep any doctor's appointments.

Support from family and friends

You may find that you have friends or relatives around you who are keen to support you or offer practical help. The offers they make are likely to be very sincere. It may well make them feel better too if they can do something to help. If people are not offering the help you need, most will be happy if you ask them directly. Perhaps the hardest thing for grandparents to find is people to give them emotional support. Some are lucky enough to have good friends who will share their worries during the bad times.

However, most people also come across friends and relatives who cannot or will not share their sadness and anxiety. This can be disappointing, but these friends may still be able to support you in other ways either with practical help or as a diversion from the difficulties the illness has brought. It is perhaps harder for grandfathers to find the support they need. Some people believe that they should be strong, and contain their emotions at times of crisis. It has been shown that talking about your worries can help.

Support from your grandchild's medical team

The team at your grandchild's Principal Treatment Centre are there for all of the family, including grandparents. It may be worthwhile contacting the team to discuss your support needs.



How talking can help

No-one can change the situation, but there can be comfort in knowing that someone else understands something of how you feel. Talking also helps to make your own thoughts clearer. Problems that go round and round in your head often seem to get bigger and bigger. Putting them into words can stop this happening. If you feel able to share your thoughts and concerns with those closest to you then that is great. Others find it easier to talk to someone outside the immediate family who is not directly affected by the illness. It may help to talk to a number of different people.

Many grandparents feel that they must put a brave face on their feelings a lot of the time to protect their child, grandchild or others from seeing the extent of their distress. It is important, however, to find time to let go and allow your emotions to come out. Crying can bring a sense of release and sometimes helps people to feel stronger and think more clearly afterwards.

Support groups and counsellors

Some grandparents may find support groups helpful. Some childhood cancer treatment centres run groups specifically for grandparents. Where these are not available more general cancer or carer support groups may be useful.

Details of these are available from organisations such as Macmillan Cancer Support, including online support networks such as the ones operated by Macmillan. The online communities have many different categories such as emotional issues, like caring for someone with cancer, and users can chat online about their feelings and share their experiences with others.

Participating in such communities will help to remove feelings of isolation. Some people prefer support on a one-to-one basis, such as counselling. The organisations listed will also be able to guide you to what is available in your area. Your GP may also be able to provide support and advice if you are finding it hard to cope.

Remember that you're not alone. Many grandparents have exactly the same feelings and anxieties that you do. However much you have in common with other grandparents, people still react and cope in different ways. What's important is what is right for your ill grandchild, the rest of the family, and for you.

“

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

”



“Being needed and getting involved has helped me cope.”

Sources of information and support

Children's Cancer and Leukaemia Group

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. Provides a range of information for patients and families affected by childhood cancer.

Tel: 0116 252 5858

www.cclg.org.uk

CLIC Sargent

CLIC Sargent is the UK's leading cancer charity for children and young people, and their families, providing clinical, practical and emotional support to help them cope with cancer and get the most out of life.

Tel: 0300 330 0803

www.clicsargent.org.uk

Macmillan Cancer Support

A national cancer charity offering support to people with cancer and their families by providing information and practical support.

Tel: 0808 808 0000

www.macmillan.org.uk

Cancer Research UK

National charity devoted to the causes, treatment and prevention of cancer. Provides a range of information for anyone affected by cancer.

Tel: 0808 800 4040

www.cancerresearchuk.org

Teenage Cancer Trust

Deals with all issues of teenagers with cancer.

Tel: 020 7612 0370

www.teenagecancertrust.org

The Brain Tumour Charity

A national charity providing support and information for all those affected by brain tumours.

Tel: 0808 800 0004

www.thebraintumourcharity.org

Grandparents Association

Help, support and a point of contact for grandparents particularly those who are bringing up their grandchildren or are estranged from them.

Tel: 0845 434 9585

www.grandparents-association.org.uk

Grandparents Plus

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

Tel: 0300 123 7015

www.grandparentsplus.org.uk

Maggies Cancer Care UK

Maggie's Cancer Caring Centres offer free, comprehensive support for anyone affected by cancer.

Tel: 0300 123 1801

www.maggiescentres.org

“

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

”





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 with cancer. 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.

If you have any comments on this booklet please contact us at the address below

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

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

 ChildrensCLG

 CCLG_UK

Registered Charity number 286669