

Grandparents



**A guide for grandparents of children
and young people with cancer**



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We are grateful to all those grandparents who helped to make this booklet. All quotes used are from actual grandparents.

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CONTENTS

Introduction	4
<u>EARLY QUESTIONS</u>	5
Are children's cancers the same as adults?	5
Is it something we've done?	5
Someone else in the family has cancer. Is it in our genes?	6
Can cancer ever really be cured?	6
Why don't we hear of the successes?	7
Why do I feel so helpless?	8
<u>HOW YOU CAN HELP</u>	9
If you are close at hand	9
If you live away	10
Supporting your son/daughter (in-law)	12
Supporting your grandchildren	13
<u>SUPPORT FOR YOU</u>	18
Make sure that you get what you need	18
Support from family and friends	19
How talking can help	20
Support groups and counsellors	21
Useful contacts	22
Useful books/booklets	22

INTRODUCTION

To be told that your grandchild has cancer comes as a terrible shock. Most grandparents worry not only about the sick 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 of course, how, as grandparents, they themselves will cope.

Parents of the sick 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. This booklet tries to answer some of the many questions grandparents may have.

EARLY QUESTIONS

ARE CHILDREN'S CANCERS THE SAME AS ADULTS'?

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.

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

IS IT SOMETHING WE'VE 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.

“ There was just so much to take in – words were used that we couldn't understand, had never even heard of. ”



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 most families where a child has been diagnosed with cancer there will be at least one other family member who has had cancer. Nearly all of these cancers will have occurred by chance. Cancer does originate in the genes, in that 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.

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.

“ After the diagnosis of my grandson’s cancer I felt very helpless and also very angry.”

CAN CANCER EVER REALLY BE CURED?

Yes. Nowadays three quarters of childhood cancers are cured. Most grandparents find this hard to believe. And, while accepting that cure is a reasonable goal, it is still a very worrying time. For the older generation there are very good reasons for this. Even as recently as the 1960s it was very unusual for cancer to be treated successfully unless it could be fully removed by a surgeon. Today, with better treatment, most children are not only cured of the disease, but go on to live full and active lives.

Sadly, though, there are still some children whose cancer cannot be cured. For these children treatment can often keep the cancer under control for some time. For others it may only be possible to control symptoms. Every effort is made to keep the child well and active for as long as possible. The child can be cared for at home, if that is what the family wants, with support being given by the hospital team and others.

WHY DON'T WE HEAR OF THE SUCCESSSES?

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.

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

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.

“ It has been a very hard and painful time since my granddaughter was diagnosed, but she is the one who has kept me going.”



WHY DO I FEEL SO HELPLESS?

Most grandparents accept that they could not have prevented the cancer but many still feel helpless, or even guilty, when it is diagnosed. Why is that? As a parent, and later as a grandparent, most see protecting their offspring as their most important role. It is possible to protect against most threats to a child. However when a serious illness like cancer occurs, which families can do nothing to prevent, the same feelings of guilt or helplessness occur. As no-one can say why this has happened to your grandchild, many people find that their minds turn to all sorts of possible causes. For some grandparents their faith can be a great comfort, while for others it may be seriously challenged.

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

Some grandparents feel that if anyone in the family had to have a cancer, it should have been them.

Cancer seems a

particularly cruel disease when it threatens a young innocent life.

Some grandparents wish they could swap places with the sick child rather than allow them to go through long treatments. 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 live life to the full more. For young children very little may be remembered about the treatment.

“ 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? ”

“ I thought that my world had come to an end. I couldn't accept why it had happened to my grand-daughter.”



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 problems such as living away, other pressures on time, or their own health problems.

“ We were needed to look after the family pets, and granny did a fantastic line in creamy rice puddings. ”

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 sick child, there is no shortage of practical help that can be given. Your son/daughter may be so absorbed by the needs of the sick 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.

- Sitting with the sick child in hospital
- Lifts to and from the hospital
- Looking after any other children in the family



- Taking other children to school, clubs, football, shopping etc.
- Lawn mowing and collecting post
- Shopping and running errands
- Providing meals and stocking freezer with family favourites
- Looking after house and pets
- Generally helping to ensure life continues as normally as possible.

You may also be able to do some of the things we have listed for grandparents who live away.

“ I found that as time went on and I read more and my daughter explained what was happening, I felt more confident in handling my grand-daughter and helping out. ”

IF YOU LIVE AWAY


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

- Providing “answerphone” service to deal with the many enquiries and pass on updates to friends and family

- Being a listening ear for your son/daughter, the sick child or other children in the family
- Sending cards/letters/e-mails/text messages to your son/daughter, the sick child and any other children to let them know you are thinking about them
- Sending activities suitable for the sick child (e.g. comic books/magazines, craft kits, videos)
- 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, reading matter)
- 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 60 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 phone calls. ”

“ I found it all very stressful, especially the travelling. ”

A photograph of a woman and a man sitting at a table, looking at each other. The woman is on the left, wearing a white top, and the man is on the right, wearing a purple shirt. They appear to be in a conversation. The background is bright and out of focus.

“ It was a very difficult period initially as we lived away from the family. Our desperation eased as we were given more information. ”



SUPPORTING YOUR SON/DAUGHTER (IN-LAW)

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.

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

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/daughter (in-law) to simply be able to put their worries into

“ One thing is very important. Help the family when they request it. Don't force attention on them. They are very traumatised. Help by looking after siblings, but tread very carefully. This is a dreadful time and everyone is very brittle.”

words. You don't need to have answers, but a listening ear can be very supportive. If your son/daughter (in law) know you understand something of what they are feeling, they may feel less alone with their worries.

Guiding them Elsewhere

Some grandparents find that they are not the right people for their son/daughter (in law) to share their worries with. This can be hard, but, in this situation grandparents can help by encouraging their son/daughter to have time with other people that they are close to. Grandparents can also help by encouraging their children to share their thoughts and fears with members of staff caring for the sick 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.

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.

“ She never wanted her granny to know how ill she was. Even at the age of 12 she wanted control over who was told what. She always wanted granny to just be granny – normal like things were before she was ill. ”

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.

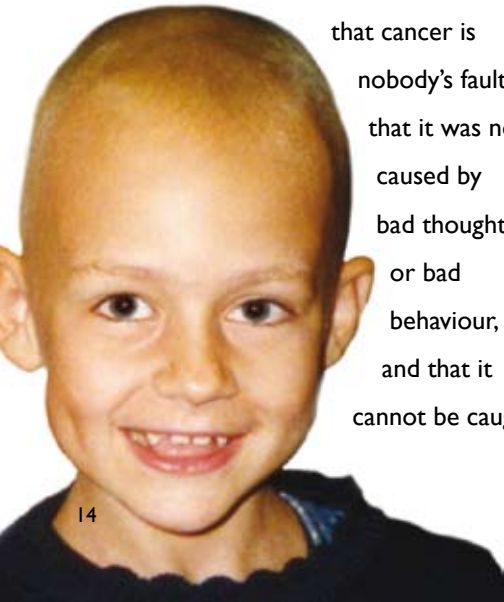
Children need to know that cancer is nobody's fault, that it was not caused by bad thoughts or bad behaviour, and that it cannot be caught

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 sick child gifts and special treatment. Naturally some treats and special consideration can give a sick 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 sick 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 sick child's mood and behaviour. It can be hard to maintain normal discipline for a sick 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 sick child being treated differently. Maintaining the family's usual rules can be very reassuring to the sick 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.

The Sick Child

For the sick 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 sick child may get a lot of comfort from familiar games and activities with a grandparent. Sick 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 sick child. The changes they experience as a result of their brother’s or sisters’s illness may be enormous. They can often feel very left out. The whole family’s life tends to revolve around the sick 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 sick 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 sick child’s care. It is always best to try to warn them about changes they might see in the sick child. Tubes and other changes are often less frightening if children know the reasons for them.

For more information on helping brothers and sisters ask at your treatment centre for the series of booklets aimed at brothers and sisters and those caring for them.

“ 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 sick child.”

SUPPORT FOR YOU

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.

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 doctors appointments.

If you live close to the family, life after diagnosis may become very busy. Some grandparents find that their hours are suddenly filled with 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. 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. Don't feel you can't sometimes say 'no'. 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.

“ I was emotionally drained trying to cope with a stressful full-time job, and watching my lovely grand-daughter deal very bravely with the ravaging effects of chemotherapy.”

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 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 golf course, Beethoven or bingo, do take time to find strength from the things you enjoy.

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

SUPPORT FROM FAMILY AND FRIENDS

You may find that you have friends or relatives around you that 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 access to 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 even harder for grandfathers to find the support they need. Men, particularly older men, have often grown up with the belief that they should be strong, and contain their emotions at times of crisis. It has been shown that talking about your worries can help.

“ I was in such a state of shock when I first heard of my grand-daughter’s illness. I couldn’t ask my daughter or son-in-law. Once the initial period passed they did keep me fully informed and that helped.”

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.

“ We take their (grandparents) support so much for granted and many operate under the ‘stiff upper lip’ syndrome left over from the war: I bet we’ve got them all wrong. ”

SUPPORT GROUPS AND COUNSELLORS

Some grandparents may find support groups helpful. A few 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 CancerBACUP or Macmillan Cancer Relief (contact details on page 22). 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 sick grandchild, the rest of the family, and for you.

“ I don’t feel anyone has the right answers. We all cope in such different ways. ”



USEFUL CONTACTS

CancerBACUP

A national cancer charity providing information and resources for anyone affected by cancer.

Tel: 0800 800 1234

www.cancerbacup.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: 020 7009 8820

www.cancerresearch.uk.org

CLIC Sargent

An organisation providing information and support for all family members affected by childhood cancer.

Tel: 0845 301 0031

www.clic.org.uk

Grandparents Association (formerly Federation) Help, support and a point of contact for grandparents particularly those who are bringing up their grandchildren or are estranged from them.

Tel: 01279 428040

www.grandparents-association.co.uk

Grandparents Plus

Promotes the role of grandparents at all levels, particularly in circumstances of family breakdown, single parenthood or other difficult conditions.

Tel: 020 8981 8001

www.grandparentsplus.org.uk

Macmillan Cancer Relief

UK charity offering support to people with cancer by providing expert care and practical support.

Tel: 0808 808 2020

www.macmillan.org.uk

Teenage Cancer Trust

Deals with all issues of teenagers with cancer.

Tel: 020 7387 1000

www.teencancer.org

UKCCSG

An organisation for professionals treating children with cancer. Provides a range of information for patients and families affected by childhood cancer.

Tel: 0116 249 4460

www.ukccsg.org.uk

USEFUL BOOKS/BOOKLETS

- A Parent's Guide to Children's Cancers by the UKCCSG and CancerBACUP

More UKCCSG Siblings Project Group publications:

- Brothers & Sisters - A guide for parents of children and young people with cancer
- How to Help Brothers and Sisters (for adults)
- My Brother has Cancer (for children aged 3-9)
- When your Brother or Sister gets Cancer (for young people aged 9-18)

Go to www.ukccsg.org.uk to download, or order a booklet, or contact the UKCCSG at the address on the back cover.

Multiple copies of all UKCCSG Siblings Group booklets are available from CLIC Sargent - see above.





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