The Children & Young People's Cancer Association

When your child's cancer comes back or does not respond to initial treatment

Information for parents and families of a child or young person with relapsed or refractory cancer

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The Children &
Young People's
Cancer Association

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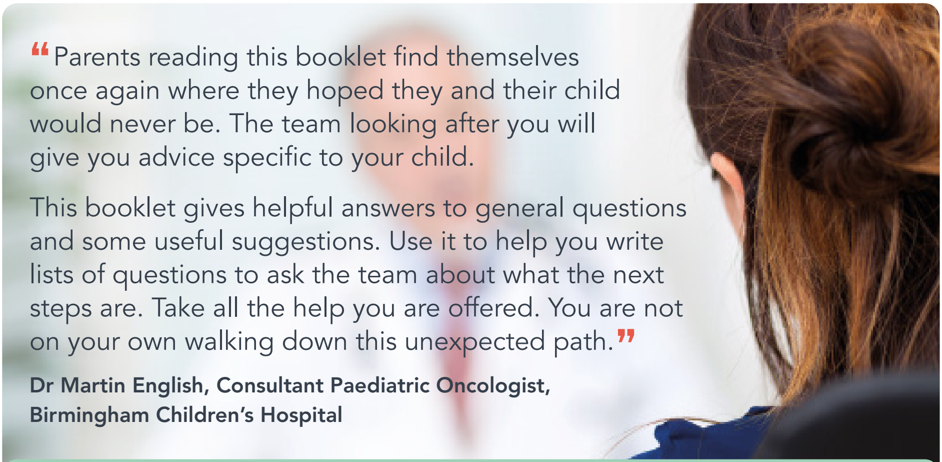
Contents

Being told your child's cancer has come back or hasn't gone away can come as a huge shock bringing back many emotions from your child's first diagnosis. This booklet acknowledges these feelings and gives information to help you cope with the experience once again.



> "Parents reading this booklet find themselves once again where they hoped they and their child would never be. The team looking after you will give you advice specific to your child.
>
> This booklet gives helpful answers to general questions and some useful suggestions. Use it to help you write lists of questions to ask the team about what the next steps are. Take all the help you are offered. You are not on your own walking down this unexpected path."
>
> **Dr Martin English, Consultant Paediatric Oncologist,**
> **Birmingham Children's Hospital**

What is relapsed cancer?

Cancer (including leukaemia) relapse or recurrence is defined as a return of cancer after your child's first treatment has finished, and after a period of time where the cancer has not been detected on tests or scans. The same cancer may come back where it first started or somewhere else in the body. The first signs of relapse can include your child starting to feel unwell, a new lump or swelling, a change seen in follow-up scans or abnormal results from routine blood tests.

What is refractory cancer?

Cancer that does not respond to standard first-line treatment is called 'refractory' cancer, meaning your child's cancer is still there and therefore is not in remission at this time.

Adjusting to the news

Many parents say finding out the cancer has come back or hasn't gone away can be more upsetting than the original diagnosis. You may have been told the chances of the cancer returning so perhaps, in the back of your mind, you always feared one day it might return. Or it may have happened completely out of the blue after a long period of time without cancer. Whatever your situation, it does not make the news any easier to deal with.

It is common to feel **scared** and **angry** that this has happened again and you may want to **deny** the cancer has returned as you try and adjust to the situation.

Parents can feel many intense emotions when finding out the cancer has come back or is still there. You may feel **shock**, **sadness**, **anger**, **fear**, **guilt**, **worry** and **anxiety** or even feel **numb**. You may find that within families you each cope differently with the news and this can lead to friction and anger.

Brothers and sisters may also feel these emotions and be confused about why this has happened again.

All of these feelings are completely normal and is your way of processing this new information. If you have dealt with these feelings in the past, you may feel more resilient in finding ways to cope with them now as well.

You may find your thoughts 'running ahead' of themselves, and you may find yourself worrying a lot about what might happen in the few days, weeks or months from now.

Other parents who have been in this situation have talked about the importance of **taking things one day at a time**, and trying to **keep their mind focused** on the 'here and now' aspects of what is going on around them.

However, you have something now that you didn't have before – **experience** and **knowledge**. You know a lot about what to expect, how to cope and what to hope for. This can make you feel stronger and more resilient, putting you in a better position to start again.

It is also worth remembering that treatments may have improved since your child first had cancer. New drugs or methods may help with treatment or in managing side effects.

Why has the cancer come back?

It is not always known why cancer comes back or doesn't go away.
It may be:

- Your child's first treatment **didn't fully remove or destroy cancer** cells which may have been too small to be seen in follow-up scans. This doesn't mean the treatment your child received was wrong. It means a small number of cancer cells survived the treatment. Over time, these cells have grown so that doctors can now detect them on scans and tests.
- It is possible your child has developed a **completely new cancer** that has nothing to do with their original cancer. This doesn't happen very often, and recurrences of the same cancer are more common.
- It may be that the **standard treatment did not work**, for example, if your child's cancer is resistant to a certain type of drug, and other options will need to be considered.

It is important to understand there is nothing you could have done to stop this from happening.

Where can cancer return?

The different types of recurrence are:

- **Local:** This means the cancer is in the same place as the original cancer or is very close to it.
- **Regional:** This is when tumours grow in lymph nodes or tissues near the place of the original cancer.
- **Distant:** In these cases, the cancer has spread (**metastasised**) to organs or tissues far from the place of the original cancer.

What are the treatment choices?

There are many treatment choices for relapsed or refractory cancer. Treatment will depend partly on the type of cancer and treatment your child had before, where the cancer has recurred and your child's current health. Treatments can aim:

- to get rid of the cancer completely
- to control the cancer and stop it growing or spreading any more

The treatment plan which your child will receive also depends on how soon the cancer has returned since your child's first treatment. **If relapse occurs after a long time**, the same drugs might still be effective and the same or similar treatment may be given to achieve remission again. **If relapse happens after a shorter time or if the cancer never fully went away**, then a different combination of drugs or more aggressive treatment may be needed.

Your doctor may also suggest a 'watch and wait' approach for your child. This means actively monitoring the cancer rather than treating it immediately if it is not causing problems for your child.

Questions to ask your child's doctor:

Why has the cancer come back?

What treatment options are available?

What are the chances of it being successful?

Will the side effects be the same?

Will the treatment aim to get rid of the cancer or to control it?

Are there any clinical trials my child can take part in?

Who do I contact if I have any questions or concerns?

Don't worry about asking the same questions again. The most important thing is that you have all the answers and information you need. If you don't understand something, say so and ask the doctor or nurse to go through it again with you – they will be more than happy to explain things more!

Taking part in a clinical trial

Your child may be eligible to join a clinical trial which tries to find better ways of treating cancer. Each study has rules about who can take part based on certain criteria.

There are different phases of clinical trials:

- **Phase I trials** test what dose of the new treatment is safe and how it should be given. This is the first time the treatment has been tested outside of the laboratory and only small numbers of children will participate for whom there are no standard treatment options available.
- **Phase II trials** discover how cancer responds to a new drug or treatment.
- **Phase III trials** compare current cancer treatment with a new treatment that researchers believe might be better. This phase recruits the largest number of patients to give the most accurate results.

Early phase I/II clinical trials can be an important treatment option for children whose cancer has relapsed or is refractory. Taking part may mean your child receives a new drug or treatment before it is available as standard treatment. Your child's doctor will discuss with you if there are any open clinical trials suitable for your child to join.

Our booklet 'Taking part in clinical trials' is available free of charge from your child's hospital

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

Getting a second opinion

It is understandable for parents to want to make sure they are doing everything they possibly can for their child and that you may look into getting a second opinion.

However, it is reassuring to know your child's options will be discussed at the **multidisciplinary team (MDT) meeting** in the main hospital where your child was treated. In most cases, there will be other consultants on the team and you could ask to see one of them as well.

Your consultant may ask the MDT in another main hospital, or sometimes ask colleagues abroad, for their opinion in some cases. They may also approach national MDTs and specific tumour-type advisory groups. They should, of course, ask your permission to do this, and at no cost to you.

If you would like your child's case discussed at another hospital, you should ask your consultant to refer you for a second opinion to another principal treatment centre. Most consultants in other hospitals will want to review your child's scans and sometimes the biopsies themselves in their own MDT meeting before seeing you for a second opinion. These would be referrals within the NHS and should not incur any charges for you.

Sometimes, families want to seek **second opinions from teams in other countries**. It is more likely your consultant will ask you to make those contacts yourself, but you can ask for a summary of your child's case and ask for copies of scans. The hospital may charge you for the cost of scans copied for yourself. You may find some hospitals abroad make charges for opinions and for treatment.

Searching for alternative treatments

It is natural to want to try and help your child in any way you can and your immediate response to hearing the news about your child's condition might be to search online for any new cures or treatments, either in this country or overseas. Well-meaning friends may tag you into social media posts about a wonder drug, a new therapy overseas or a supplement claiming to 'cure' cancer.

Media reports can be about genuine developments in cancer research by reputable scientists and your child's doctor will almost certainly know about them. Many news reports are on promising early trial results or are based on results shown in the lab where it is far too early to know whether the treatment actually works in humans.

However, some reports, adverts and online chatroom conversations about 'cure' treatments can be misleading and give false claims for success. They are sold with promises and cancer-free patient stories in the hope that families will want to know more, but such treatments will usually be very expensive with no scientific evidence for their use. Sadly, such claims can create false hope costing parents' time, money, stress and energy.

If you do find an alternative treatment, please talk it through with your child's doctor. Don't worry that they will be offended by your questions. They will take you seriously and give you honest, balanced advice based on your child's individual diagnosis.

Talking to your child and their siblings

What to say to your child will depend on a range of different factors, such as their age, diagnosis, previous treatment, and their own unique personality.

Seek advice from your child's medical team about how to explain things to your child. This will be a two-way discussion as you know your child best, and the team has lots of experience in talking to other children about relapse, or when initial treatment hasn't worked.

It is best to be honest and open with your child about what is happening as covering things up generally makes children more anxious, as they know something is going on, but they aren't sure what it is.

It is important not to over burden younger children with lots of information they may not be able to cope with. It is best to give information at your child's pace, as they may need time to process one piece of information before moving onto the next.

Encourage them to ask questions and don't worry if you need to say that you do not know the answer but you can find out. Some children have lots of questions and others don't although this does not mean they do not want to know what is happening.

Allow your child to talk about how they are feeling and if they have any particular worries. Your child's hospital team will be able to help with talking to your child and siblings.

Keep the routine going for siblings as much as possible as this helps them to feel secure.

Watch for any behavioural changes in your child or their siblings which show they might be worried or upset.

Coping with an uncertain future

Feelings at this time can be overwhelming and parents may feel they are struggling to find strength, again, to cope with what will happen next.

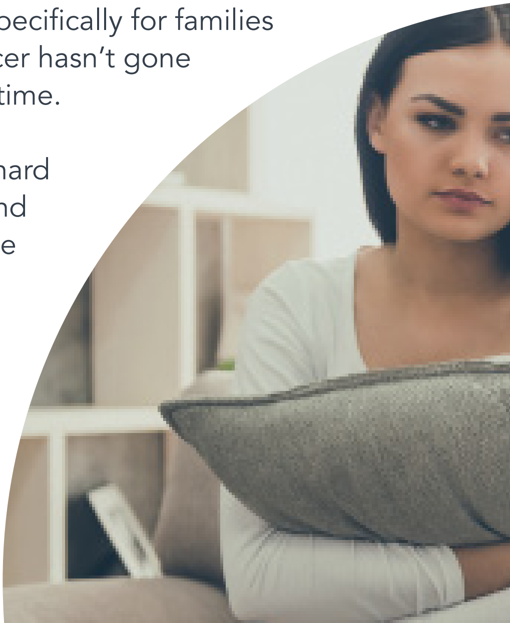
Use the same support network from before that will hopefully still be there for you such as family members, neighbours and friends.

Talk about how you feel whether to other family members, your partner or friends. If feelings are bottled up, this can lead to frustration and anger that can be directed at others or loved ones.

You may have become friends with other parents you met while in hospital the first time around and those from online cancer communities such as social media groups. These can be an invaluable source of support. However, it is worth remembering that their child may be at a different point in their cancer journey which can also affect your emotions and perceptions. For example, you may feel angry that your child has relapsed and theirs hasn't and then feel guilty for feeling this way. This is normal and understandable.

There may be **online support groups** specifically for families whose child has relapsed or whose cancer hasn't gone away that may be helpful to you at this time.

If you have difficult thoughts that are hard to control, talk them through with a friend or try writing them down. If they become overwhelming or unhelpful, take ten minutes of your day to think about them and work through them to help move onto more helpful and positive thoughts.



If you are struggling with your feelings and you are finding it hard to get through everyday activities, there are many people who can help and support you and your family. These can include:

- your GP
- your child's keyworker
- support centres based at your child's hospital such as Maggie's Centres
- local hospices with emotional support centres for anyone affected by a serious health condition
- counselling, therapy and psychological services either via your child's hospital team, your GP or paid for privately

You may also be able to access free complementary therapies such as massage, aromatherapy and reflexology to help you to unwind, relax and enjoy some peace and quiet. You can also pay for these privately too.

> The important message is to not struggle alone and to ask for help – there is support available even if it is someone to sit and listen to you talk through how you feel.

Some coping strategies

This is an anxious and upsetting time and, unfortunately, there are no quick fixes to make you feel better.

Some parents may feel uncomfortable or guilty about spending time on themselves but it is extremely important that you look after yourself too. Caring for a sick child is difficult and demanding, and parents need to take a break from their child's cancer for a little while to recharge and avoid feeling overwhelmed.

Here are some things you can do to help take back some control:

'Me time'

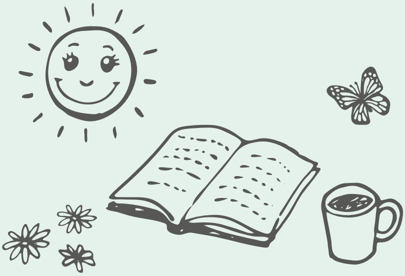
Take time out away from the situation such as enjoying a long hot bath or watching a film.

Keep active

This won't make stress disappear but can help to reduce emotional intensity and clear your thoughts. A brisk walk outside, running, gym, swimming or classes such as yoga can all help.

Limit unhealthy habits

It can be easy to take comfort from or rely on alcohol, smoking, caffeine or food as a way of coping. However, these habits won't solve any problems and may even create new ones in the long run, particularly in terms of your own health.

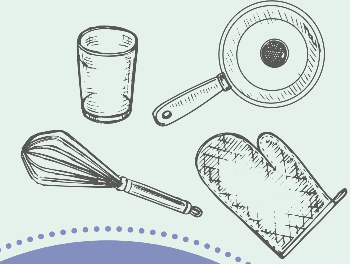


Accept the things you cannot change

Changing a difficult situation isn't always possible. Try to concentrate on the things you can control such as cooking your child's favourite meal for them.

Staying positive

This, of course, can be difficult but it is worth being aware of the things that you can feel grateful for. Try writing down three things that went well at the end of every day such as finishing a book, tidying the 'bits and bobs' drawer or even just sitting down for five minutes with a coffee.



Don't be afraid to ask for help

Life can suddenly become busy again when treatment starts so concentrate on tasks that will make a real difference to you. For example, cleaning the house can be left another week if needed. Accepting offers of help from others can also relieve pressure.

Talk to others

Good support networks and spending time with friends can help you to relax, sort through feelings and put things into perspective.

[Adapted from NHS Choices Stressbusters:
www.nhs.uk/Conditions/stress-anxiety-depression/Pages/reduce-stress.aspx]

Staying hopeful

All parents hope that the cancer will respond to treatment again and their child will live for as long as possible. This will happen for many but hopes and expectations may change over time and can widen to cover many different things for your child:

- improving their quality of life and wellbeing
- reducing any suffering they might be experiencing
- living a normal life as much as possible enjoying time with friends
- making sure they feel loved and special

Parents should be clear about the goal of any treatment. For example, a child’s cancer may not be cured but things can be done to keep it from growing and so allowing a child to live longer. Hopes can differ from expectations and talking openly about both with your child’s hospital team can help both parents and doctors to focus on plans of care for your child.

Medical science advances every day with new cancer treatments, and knowledge is improving all the time so your child will always receive the best current treatments and care available.

Staying hopeful is one thing that can help parents come through the cancer journey again. Parents can hope for their child to feel secure and loved, no matter what the outcome of treatment might be.

It is important to remember that every child is different and will respond to treatment in different ways. Even doctors can only tell you information based on what has been seen before in similar cases.

Your child is an individual, not a statistic.

Jane's story

“Hearing the news Alice's cancer was back was devastating and in many ways worse than the initial diagnosis. We had just started to relax a little and enjoy normal life so to hear she had relapsed broke our hearts.

We knew so much more this time and this knowledge can be a double-edged sword. Whilst we understood the treatment process better, we also knew what she had to face and that treatment would be more aggressive, which was terrifying.

Alice with her family

In time, I found a Facebook group just for relapsed Wilms' parents. I think the important thing that other parents in the group gave me was hope Alice would come through this, and from that the strength to face the battle all over again.”

Jane, mum to 5-year-old Alice who had relapsed Wilms' tumour. Alice is now in remission.

Help and support

Young Lives vs Cancer
0300 330 0803
Support and advice for anyone affected by childhood cancer

Macmillan Support Line
0808 808 00 00
Support and advice for anyone affected by cancer

NHS Mindfulness
www.nhs.uk/conditions/stress-anxiety-depression/pages/mindfulness.aspx

NHS MoodZone
www.nhs.uk/Conditions/stress-anxiety-depression/Pages/low-mood-stress-anxiety.aspx

Maggies
www.maggiescentres.org
Offering free practical, emotional and social support to people with cancer and their families and friends.

Samaritans
www.samaritans.org/how-we-can-help-you

Carers UK
www.carersuk.org
Expert advice, information and support for anyone caring for others.

Itsgoodtotalk.org
Counselling and psychotherapy advice and help in finding a local therapist.

Online communities are also a good source of support for parents via social media such as Facebook.

Our booklet 'Complementary and natural therapies for your child' is available free of charge from your child's hospital

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

Your notes

CCLG The Children &
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Cancer Association

We are CCLG: The Children & Young People’s Cancer Association, a charity dedicated to creating a brighter future for children and young people with cancer. Powered by expertise, we unite the children and young people’s cancer community, driving collective action and progress.

We fund and lead pioneering research, provide trusted information and guidance for children and young people with cancer and their families, and bring together professionals to improve treatment, care, and outcomes.

Our expert information helps children and young people, their families and everyone supporting them, to navigate the challenges of cancer and its impact, offering reassurance and clarity when it’s needed most.

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