



When your child's cancer comes back

...or if it does not respond to treatment

Contents



When cancer comes back	3
What is relapsed cancer?	4
What is refractory cancer?	4
Adjusting to the news	4
Why has the cancer come back?	7
Where can cancer return?	8
Treatment options	9
What are the treatment choices?	10
Taking part in a clinical trial	11
Getting a second opinion	13
Searching for alternative treatments	14
Coping with cancer again	15
Talking to your child and their siblings	16
Coping with an uncertain future	18
Coping strategies	20
Staying hopeful	23
Jane's story	24
Help and support	25
Irish Cancer Society services	26
Questions to ask your child's doctor	28
Your notes	29

About this book

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 this situation.

'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



When cancer comes back



What is relapsed cancer?

Cancer (including leukaemia) relapse or recurrence is defined as a return of cancer. This can occur during or after a period where the cancer has not been detected or has been "stable" 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 adequately to standard first-line treatment is called 'refractory' cancer. This means your child's cancer is still there and therefore is not in remission.

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 this might happen. 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. See page 15 for some practical ways to help you and your family adjust at this time.

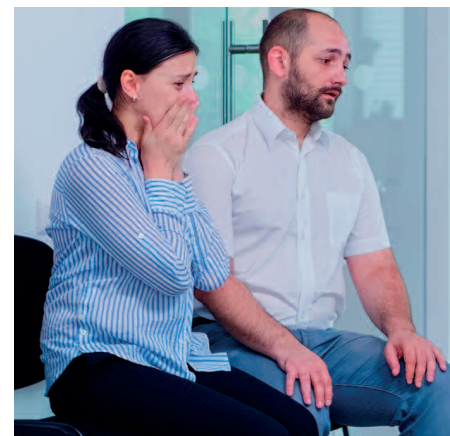


Quotes from parents

'How can this be happening to us again?'

'I'm so angry and upset.'

'Haven't we been through enough?'



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 to 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 are 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 be frightening but it can also 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.

Talk to your medical social worker and nurse specialist about your fears and concerns. They are there to support you and your family.

Support for you

If you are feeling anxious or overwhelmed at this time and would like to speak to a nurse outside of the hospital environment, call the Irish Cancer Society Support Line on 1800 200 700 and ask them to arrange for you to speak to their Children's Cancer Nurse. It can help to chat things over or to ask them for support and advice.

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 the 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 or locally advanced:** This means the cancer is in the same place as the original cancer or is very close to it.
- **Metastatic:** In these cases, the cancer has spread (metastasised) to lymph nodes or to organs or tissues far from the place of the original cancer.



Treatment options



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. These or similar treatments 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.

Don't be afraid to ask questions and 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!

It is a good idea to write down any concerns or queries you may have, so you don't forget anything. See page 28 for some question ideas. There is also some space for you to take notes or compile your own questions.

Taking part in a clinical trial

Clinical trials help us to find better ways of treating different kinds of cancer. Clinical trials allow us to test new treatments and ways of controlling symptoms, or to investigate new ways of preventing or diagnosing cancer.



Generally, in paediatrics, clinical trials aim to identify better treatments for cancer, or to find treatments which are effective but cause fewer side-effects.

Taking part in a clinical trial is completely optional, and your child will be expertly cared for, regardless of whether they are included in a clinical trial or not. Each study has rules about who can take part based on certain criteria. There are not always clinical trials "open" for recruitment, at any given time.

Your doctor will tell you if there is a clinical trial that your child may be eligible for. Or you can ask the healthcare team about clinical trials. Clinical trials in Ireland are listed on www.clinicaltrials.ie.

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.



Getting a second opinion

Some families are interested in exploring the possibility of a second opinion.

It is reassuring to know your child's options will be discussed at the national multidisciplinary team (MDT) meeting. This means a group of expert health professionals will agree on recommendations for treatment following detailed discussion of your child's case. Your child's main oncologist or haematologist is usually the person who will explain these treatment recommendations to you.

If you are interested in having a second opinion, please let your oncologist or haematologist know. Sometimes they may be able to advise you where to go for the second opinion. There may be a possibility to seek a second opinion from a different consultant in the same department.

Your consultant may ask colleagues abroad for their opinion in some cases. They may also approach international specific tumour-type advisory groups. They should, of course, ask your permission to do this, and at no cost to you.

Sometimes, families want to seek independent second opinions, which is completely acceptable. It is likely you will need a summary of your child's case and copies of scans. You may find some hospitals abroad have charges for opinions and for treatment.

It is really important to let your child's oncologist or haematologist know if you are seeking a second opinion so that they can be sure all relevant information is given to the doctor providing this opinion.

It is best not to be tempted to seek multiple opinions as this can lead to conflicting views and confusion.

Searching for alternative treatments

It is natural to want to try and help your child in any way you can. 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 Ireland 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 too early to know if the treatment 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 are considering 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.

Coping with cancer again



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 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 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. They sense that something is going on, but they aren't sure what it is.

It is important not to overburden 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 on to the next.

Encourage them to ask questions and don't worry if you need to say you don't know the answer but you will 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 your child and their siblings as much as possible as this helps them to feel secure. If your child is feeling well, and the hospital team have said it's okay, going to school and seeing friends can give your child a sense of familiarity, which can be reassuring.

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

Contact our Support Line 1800 200 700 for a free copy of the booklet *Supporting brothers and sisters of a child with cancer*. This is a practical information guide for parents and other adults who are caring for siblings of a child with cancer. You can also download it from our website www.cancer.ie



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 or from online communities the first time around. 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.

If you have difficult thoughts that are hard to control, talk them through with a friend or try writing them down. Take 10 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 clinical nurse specialist**
- **Your child's medical social worker**
- **Irish Cancer Society Support Line 1800 200 700** (ask to talk to our Children's Cancer Nurse)
- **Community-based cancer support centres.** As a parent of a child with cancer, you can avail of a variety of services including complementary therapies or peer support (see page 27)
- **Counselling, therapy and psychological services,** either via your child's hospital team, your GP or sometimes through the Irish Cancer Society

 *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.*

The Irish Cancer Society provides information and support to families affected by a child or adolescent cancer diagnosis.

- **Contact our Children's Cancer Nurse through the Support Line Freephone 1800 200 700**
- **Email supportline@irishcancer.ie**

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:

Take breaks

Take time out away from the situation – have a long hot bath, watch a film or simply relax and focus on a little “me time”.



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.

Eat well

Although sometimes difficult, taking time to eat and have a balanced diet will help you get the nutrients you need to remain healthy and stay well.



Sleep

Getting enough sleep is important to allow your body and mind to recharge. Try to have a good bedtime routine. Avoiding caffeine and removing computers and smart phones from the bedroom may improve your sleep.

Limit unhealthy habits

It can be tempting to use alcohol, smoking or caffeine 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.

Stay 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.

Try relaxation techniques

This can be a very stressful time. Take a little time each day to do something that will help you to relax and unwind – listen to music, go for a walk or a run, or simply have a chat with friends. Learn about breathing techniques and mindfulness – which can also help to reduce stress and anxiety.

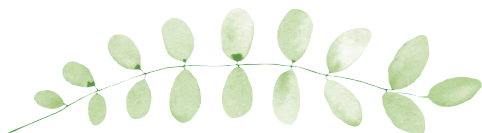
Don't be afraid to ask for help

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. 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.

The Irish Cancer Society funds one-to-one counselling through many local cancer support centres. Go to www.cancer.ie and search 'Find Support' to find your local cancer support centre. You can also talk to a cancer nurse on our Support Line 1800 200 700.



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 family and 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 control it for some time, allowing a child to live longer. Hopes can differ from expectations. Talking openly about both with your child's hospital team can help 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.

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



Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- Support Line
- Daffodil Centres
- Survivor Support
- Support in your area
- Night nursing
- Website information

Support Line Freephone 1800 200 700

Our cancer nurses can help you if you need information and advice on coping with a child's cancer, looking after yourself and practical support. Contact us and ask to speak with our Children's Cancer Nurse or to be referred to one of our trained parent volunteers.

The Support Line is open Monday to Friday, 9am to 5pm. Or email us on supportline@irishcancer.ie or visit our online community at www.cancer.ie

For the deaf community, our Support Line is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie



Parent Peer Support

All of our trained Parent Peer Support volunteers have children who have been treated for cancer in the past. They can give you emotional and practical support. For a referral, contact the Irish Cancer Society Support Line on Freephone 1800 200 700.



Website

See www.cancer.ie/children for information on children's cancers, how to cope and a list of helpful services, including an interactive map.

Community-based cancer support centres

The Irish Cancer Society works with community-based cancer support centres across the country. The centres can support adults affected by a child's cancer diagnosis and some have services for children with cancer or children affected by a family member's cancer.

Call our Support Line on 1800 200 700 or visit a Daffodil Centre and our nurses will tell you what's available in your area and can refer you to a centre. They can also organise free counselling for you, your child or others affected by your child's cancer. The Society partners with organisations to fund the cost of counselling.

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?

Your notes

Your notes

Your notes



Adapted by the Irish Cancer Society (2022) with permission from the publication *When your child's cancer comes back*, produced by Children's Cancer and Leukaemia Group (CCLG) – the UK's leading provider of accredited cancer information for children and young adults, and their families www.cclg.org.uk. CCLG accepts no responsibility for the accuracy of this adaptation.

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CCLG makes every effort to ensure that information provided is accurate and up-to-date at 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 this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

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Irish Cancer Society

CONTENT ADVISERS

Dr Sarah Curry, Consultant Paediatric Oncologist

Stephanie O'Brien, Senior Medical Social Worker

Elaine Smyth, Children's Cancer Coordinator, Irish Cancer Society

The Irish Cancer Society is a registered charity, number CHY5863.

Irish Cancer Society

43/45 Northumberland Road, Dublin, D04 VX65

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Support Line Freephone 1800 200 700

Email: supportline@irishcancer.ie

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

