Irish Cancer Society

When your child's cancer comes back

or does not respond to initial treatment

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Contents

About this book

Being told that 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 cancer recurrence?

Cancer (including leukaemia) recurrence is defined as a return of cancer. This can occur during or after your child's first treatment plan has finished. It can occur 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 recurrence 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.

Your child may also develop a different type of cancer. This is referred to as a second primary cancer rather than cancer recurrence.

What is refractory cancer?

Cancer that does not respond adequately to standard first-line treatment, or is resistant to treatment, is called refractory cancer. Your child's cancer may not respond at the beginning of treatment or this may happen during treatment. This means your child's cancer is still there (not in remission).

Adjusting to the news

Many parents say finding out that 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. 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. See page 23 for some practical ways to help you and your family adjust at this time.

"How can this be happening to us again?"

"Haven't we been through enough?"

"I'm so angry and upset."

Quotes from parents

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

The affected child and their parents can feel many intense emotions when finding out the cancer has come back or is still there. They may feel shock, sadness, anger, fear, guilt, worry and anxiety. They may even feel numb.

Brothers and sisters may also feel these emotions and be confused about why this has happened again. You may find that within families, each person copes differently with the news and this can lead to friction and anger.

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 yourself thinking a lot about what is to come and worrying about what might happen in the 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, despite the challenges, 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 and research is continuing to further improve treatments and reduce side-effects.

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 to speak to our Children's Cancer Nurse. It can help to chat things over or to ask for support and advice.

Why has the cancer come back?

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

- 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 is known as a second primary cancer and it doesn't happen very often. 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 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:** This means the cancer has spread (metastasised) to lymph nodes or to organs or tissues far from the place of the original cancer.

Treatment and options

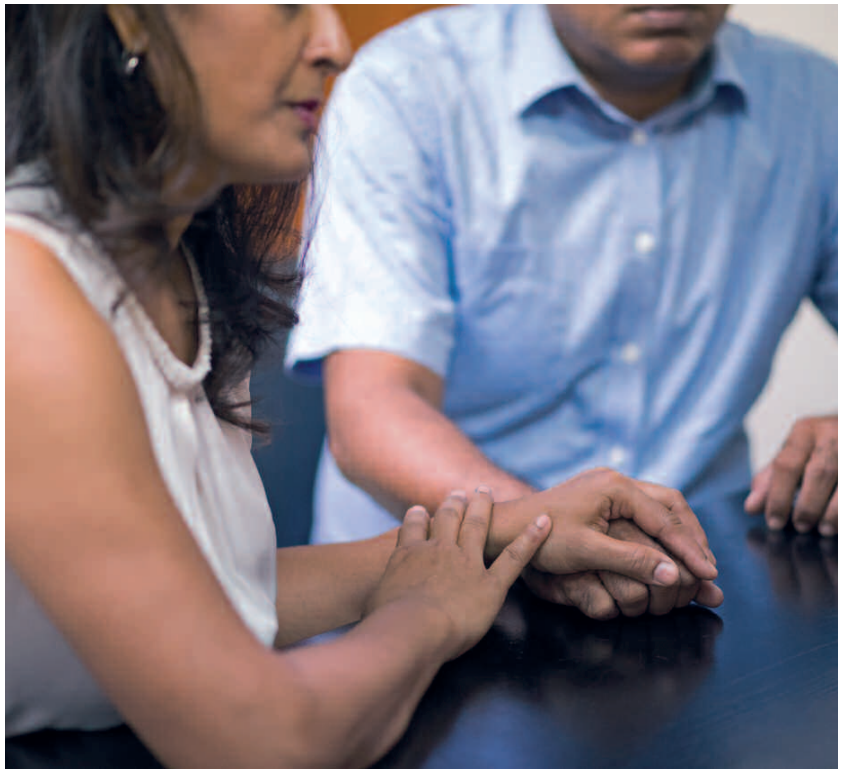
What are the treatment choices?

There are many treatment choices for cancer that has recurred and for 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

Your child's treatment plan also depends on how soon the cancer has returned since your child's first treatment. If recurrence occurs after a long time, the same drugs might still be effective. These or similar treatments may be given to achieve remission again.
If recurrence 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 information you need. If you don’t understand something, 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 46 for some question ideas. There is also some space for you to take notes or write your own questions (see page 47).

Taking part in a clinical trial

Clinical trials help us to find better ways of treating the 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 that are effective but cause fewer side-effects.

Taking part in a clinical trial is completely optional. Be assured that 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 recurred 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 getting a second opinion.

It is reassuring to know that if your child is under the age of 16 and is still attending CHI Crumlin for care, their options will be discussed at the national multidisciplinary team (MDT) meeting. This means that you get the consensus treatment recommendation from multiple expert health professionals following detailed discussion of your child's case. Your child's primary oncologist or haematologist is usually the person that will explain these treatment recommendations to you.

If you are interested in getting a second opinion for your child's case, please let your child's oncologist/haematologist know. Sometimes they may be able to advise you where to go for the second opinion. It may be possible 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 there should be 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 communicated 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 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 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 and energy.

If you are considering 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. They may be some years older than at the time of the original diagnosis, so the amount and type of information they can understand may be different.

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 that 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. You can seek advice from your child's medical team – they 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 your child's hospital team has said it's OK, going to school and seeing friends can provide a reassuring sense of familiarity.

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

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

Siblings

This can be a really difficult time for siblings. They may face lots of different issues such as:

- **Worrying about their brother or sister** with cancer
- **Missing their parents** who might have to spend a lot of time in hospital
- **Feeling left out** if they are not being told what is happening
- **Having to take on extra chores** at home
- **Worrying about falling behind in school**
- **Feeling angry** that this has happened again

Contact our Support Line on Freephone 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 the 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. Parents may feel they are struggling to find the 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 loved ones or others.

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 may affect your emotions and perceptions. For example, you may feel angry that your child's cancer has recurred 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. You can ask to speak to our Children's Cancer Nurse or ask about parent peer support (see page 40)
- Community-based cancer support centres. As a parent of a child with cancer, you can avail of a variety of services, such as support groups and complementary therapies
- Counselling, therapy and psychological services via your child's hospital team or your GP. The Irish Cancer Society also funds professional one-to-one counselling for those affected by a cancer diagnosis, including family members. This can be remote (by telephone or video call) or in person. Call our Support Line on 1800 200 700 for more information

Do not struggle alone. Ask for help if you need it. There is support available.

Support Line Freephone 1800 200 700

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 on 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. 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 yourself:

Take breaks

Take time out away from the situation. You could take a long hot bath, watch a film or simply relax and enjoy some "me time".

Keep active

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

Eat well

Although sometimes difficult, taking time to eat a well-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. Avoid stimulants like caffeine and alcohol in the evening. Try not to use electronic devices for an hour before bedtime.

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 can be difficult, but it is worth being aware of the things that you can feel grateful for. Try writing down 3 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 5 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.

Prioritise tasks

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.

You can also speak to a cancer nurse on our Support Line. Or you can visit a local cancer support centre, which provide services such as support groups and complementary therapies. Call our Support Line on 1800 200 700 to speak to a cancer nurse or to find your nearest cancer support centre, or visit **www.cancer.ie/local-support**

Email: supportline@irishcancer.ie

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, such as:

- 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 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.

There have been huge improvements in cancer treatments for children in the last few decades and research is continuing to improve treatments and reduce side-effects. Be assured, your child will receive the best current treatments and care available.

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

It is important to remember that every child is different and will respond to treatment in different ways. 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. While 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 that 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.

Support Line Freephone 1800 200 700

Help and support

Irish Cancer Society services

The Irish Cancer Society provides a range of support services for people with cancer and their families, at home and in hospital. Our services for children and families include:

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses or ask to be put in touch with our Children's Cancer Nurse for confidential advice, support and information. Our Support Line is open Monday to Friday, 9am-5pm. You can also email us anytime on supportline@irishcancer.ie

In-hospital support

Our Children's Cancer Nurse is in Children's Health Ireland (CHI) at Crumlin one day a week to provide free and confidential advice, support and information to anyone affected by a child's cancer. She will be around the playrooms, wards and clinic areas. See the in-hospital posters for times and days.

Parent Peer Support

Speak to a parent of a child who has gone through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone whose child is going through or finished their treatment. This service is also available to other adult family members, such as grandparents, aunts and uncles. To be referred to a Parent Peer Support volunteer, call our Support Line on 1800 200 700.

Child and adolescent counselling and psychological support services

We work with cancer support centres across the country to help provide services and support for children and adolescents with a cancer diagnosis. Many centres offer counselling services, creative therapies and practical support for those affected and their families. We also offer telephone and video-call counselling. If you or your child needs psychological support, we can refer you to an appropriate service. For more information on any of these supports, call our Support Line on 1800 200 700.

Creative arts therapy

Creative arts therapy includes art therapy, dance-movement therapy, drama therapy and music therapy. Creative arts therapy is the purposeful and planned use of creative processes with a qualified therapist to support child development, emotional expression, social interaction, physical improvements and cognitive goals.

Creative arts therapy is available to all children, adolescents and young people (0-24 years) during or after their treatment. Creative arts therapy is also available to the siblings of cancer patients. Sessions can take place:

- In-person or online
- One-to-one or in a group
- In your home or nearby

If you're interested in availing of creative arts therapy support sessions, please email creativeartstherapy@irishcancer.ie and one of our team will be in touch.

Transport Service

We provide transport for patients in need who are in cancer treatment.

- We have expanded our Transport Service to bring children and young adults (CAYA) travelling from Kildare, Meath, Dublin and Wicklow to CHI at Crumlin for treatment.
- Travel2Care is a fund for patients who are having difficulty getting to and from their diagnostic test appointments or cancer treatments. Patients can apply for the fund if they are travelling over 50 kilometres one way to a designated cancer centre. Travel2Care is made available by the National Cancer Control Programme (NCCP).

To access any of these supports, please contact your hospital healthcare professional, our Children's Cancer Nurse in CHI at Crumlin or call our Support Line on 1800 200 700.

Publications and website information

We provide information on a range of topics around children's cancer, including treatments, side-effects and how to cope emotionally. Visit our website **www.cancer.ie** to read, share or download information or call our Support Line on 1800 200 700 to order free copies of our publications.

Fertility preservation

Sometimes, children's cancer treatment can affect their future fertility. The Childhood Cancer Fertility Project is a partnership between the Irish Cancer Society and Merrion Fertility Clinic, which offers free fertility preservation and other services to young people with a cancer diagnosis. For more information, speak to your child's medical team or contact our Support Line on 1800 200 700.

Email: supportline@irishcancer.ie

Barretstown camps

Every year the Irish Cancer Society teams up with Barretstown to run a variety of camps specifically designed for children and adolescents living with cancer. These camps allow children, adolescents and their families to come together to enjoy new adventures, create magical moments, make new friends and find support. There are fun surprises around every corner and there is no cost involved.

Child and family camps

Enjoy a weekend away for all the family that is full of activities, adventure, creative play and relaxing family time together. This camp is for children up to 17 years of age and their family members. For more information call our Support Line on 1800 200 700 or visit **www.barretstown.org**

Night Nursing

We provide end-of-life care for children, adolescents and young adults with cancer in their own homes. Our service allows children and young people to remain at home for the last days of their lives, surrounded by their families and loved ones. This is a unique service in Ireland, providing night-time palliative nursing care to cancer patients, mostly between 11pm and 7am.

To access this service please contact the healthcare professional looking after your loved one. For more information visit **www.cancer.ie/our-services/night-nursing**

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, many of which are free. These include counselling, support groups and complementary therapies. You can call our Support Line on 1800 200 700 to find your nearest cancer support centre.
Or visit **www.cancer.ie/local-support**

To find out more about the Irish Cancer Society's services and programmes:

- Visit us at **www.cancer.ie**
- Call our Support Line on Freephone 1800 200 700
- Email us at supportline@irishcancer.ie
- Contact your nearest Daffodil Centre
- Follow us on:
  - Facebook/IrishCancerSociety
  - X @IrishCancerSoc
  - Instagram @irishcancersociety
  - Linkedin @irish-cancer-society

There are other charities and national organisations that may also be able to help. A full list of these is available on the HSE's website, **www.hse.ie**. Search 'CAYA Cancer Support Directory: national organisations/charities'.

Questions to ask your child's doctor

Why has the cancer come back?

What treatment options are available?

What are the chances of treatment being successful?

Will the side-effects be the same as last time?

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

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

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

Your notes

Your notes

Your notes

Your notes

Adapted by the Irish Cancer Society (2025) with permission from the publication ***When your child's cancer comes back or does not respond to initial treatment,*** produced by CCLG: The Children & Young People's Cancer Association, a UK charity which funds pioneering research, provides trusted information and guidance for young cancer patients and their families, and brings together healthcare professionals to improve treatment, care and outcomes **www.cclg.org.uk**. CCLG accepts no responsibility for the accuracy of this adaptation.

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Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team! Visit **www.cancer.ie** if you want to get involved.

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Peer Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Did you like this booklet?

We would love to hear your comments or suggestions. Please email reviewers@irishcancer.ie

Irish Cancer Society

Our cancer nurses are here for you:

- Support Line Freephone **1800 200 700**
- Email **supportline@irishcancer.ie**
- Contact your nearest Daffodil Centre

Irish Cancer Society

www.cancer.ie