

Children and Young People with Cancer

A guide for parents



Children and Young People with Cancer: A Guide for Parents

This booklet has been written to help you and your family after your child has been diagnosed with cancer. It has been developed with the help of the staff in the Haematology/Oncology Unit of Children's Health Ireland at Crumlin. This is the national referral centre for all children with a cancer diagnosis in Ireland.

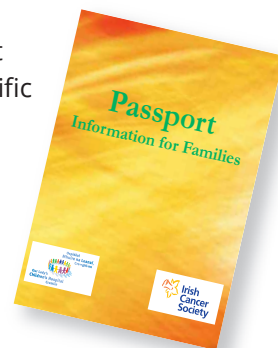
It is likely that you will have lots of questions and concerns both after the diagnosis has been confirmed and as your child goes through their treatment. Your child's consultant and the rest of the hospital team will be your main source of information and support.

However, we hope this booklet will help you too. It has information on:

- Common childhood cancers
- The hospital and who you will meet there
- Tests and treatments your child may need
- Support available after diagnosis
- The impact of a cancer diagnosis on your child and the rest of your family
- Support groups, helpful websites and booklets

You will also be given a copy of **Passport**, an information folder for you to use throughout treatment. It contains both general and specific information about your child's diagnosis and treatment. Together, these will be helpful resources for you and your family.

See page 20 for directions to Children's Health Ireland at Crumlin.





Contents

About childhood cancer	5
------------------------	---

Diagnosis and treatment	13
-------------------------	----

Parents coping with a child's cancer	33
--------------------------------------	----

Children coping with cancer	45
-----------------------------	----

Support resources	55
-------------------	----

Medical terms explained	79
-------------------------	----

Questions to ask your child's doctor or nurse	86
---	----

Reading this booklet



This booklet aims to help you throughout your child's cancer treatment. Remember, you don't need to know everything about childhood cancer straight away. You will probably find different sections useful at different times. If you don't understand something that has been written, discuss it with your child's doctor or nurse. It is often useful to write down questions as they arise, so you can remember to ask a hospital team member later.

Useful numbers

Children's Health Ireland at Crumlin	01 409 6100
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St John's Ward	01 4554 176
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	01 4096 654
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	01 4096 660
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Haematology/Oncology Day Unit (HODU)	
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Parents Accommodation Unit	
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Family doctor (GP)	
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Hospital records number	
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About childhood cancer

First reactions	7
-----------------	---

Why did my child get cancer?	7
------------------------------	---

Childhood cancers	7
-------------------	---

What is cancer?	8
-----------------	---

What are the most common types of childhood cancer?	9
---	---

Survival rates	11
----------------	----

Cancer Nurseline Freephone 1800 200 700

First reactions

Although many children with cancer can be cured, it is still devastating to hear that your child has cancer. Both you and your child will have many different feelings and emotions.

These may include fear, denial, sadness, guilt and anger. You may feel numb or like you've been physically hit. These are all normal reactions.

When a child is diagnosed with cancer, it has a big impact on all the family. Your child's routine is likely to change. They may have to stay in hospital for treatment and are likely to have regular hospital appointments. This can be overwhelming for you, your child and the rest of the family. But there are many healthcare professionals and support organisations that can help you through this difficult time.

Why did my child get cancer?

The causes of childhood cancer are still unknown but research is ongoing. It is important to remember that it's not your fault your child has cancer and it is not because of anything you've done or not done.

Most cancers are not caused by an inherited faulty gene and it is very rare for another child in a family to develop cancer. Siblings (brothers and sisters) usually do not need to be tested. Cancer is not infectious and cannot be passed on to anyone who comes into contact with your child.

Childhood cancers

Cancer in children and young people is rare. In Ireland, about 200 children under the age of 16 are diagnosed with cancer each year. In older teenagers, aged between 15 and 19, about 68 cases are diagnosed each year. See page 9 for more about individual cancers.

What is cancer?

Cancer is a disease of the body's cells, which are the building blocks of your body. Cancer can occur in different parts of the body. In fact, there are more than 200 different types of cancer, each with its own name and treatment. Cancer can occur in organs of the body such as the kidney or the brain. These are sometimes called solid tumours. Tumours can be either benign or malignant. Benign tumours do not spread to other parts of the body but can carry on growing and cause a problem by pressing on nearby organs.

A malignant tumour is when the cells break away and spread to nearby tissues. They may spread further to other organs in the body through the bloodstream or lymphatic system. When the cancer cells reach a new area, they may go on dividing and form a new tumour. This is known as a secondary cancer or a metastasis. Cancer can also occur in the blood cells in the bone marrow (leukaemia) or in the lymphatic system (lymphoma).



What are the most common types of childhood cancer?

There are many different types of childhood or paediatric cancers. The most common, which are grouped in this booklet according to the International Classification of Childhood Cancer (ICCC), is leukaemia, followed by brain tumours. Almost 3 in every 4 cancers in young children are leukaemia, lymphoma or tumours of the brain and nervous system.

Common types of childhood cancers include:

Leukaemia

Leukaemia is a cancer of the bone marrow. This is the spongy material in the centre of your bones where blood cells are made. With leukaemia, the body makes too many abnormal white blood cells.

Lymphoma

Lymphoma is cancer of the lymphatic system, which helps your body fight infection and disease. It can occur in any lymphatic tissue in the body. There are two main types: Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL).

Brain tumours and central nervous system tumours

There are many different forms of tumours found in the brain or in the central nervous system (CNS). Some are benign, while others are malignant. The most common types are astrocytoma, medulloblastoma and ependymoma.

Neuroblastoma

Neuroblastoma is a rare cancer that affects special nerve cells. These cells help develop the nervous system and other tissues.

Retinoblastoma

Retinoblastoma is a malignant tumour at the back of the eye. It develops in the cells of the retina, which is the part lining your eye that is sensitive to light.

Renal tumours

Renal tumours affect the kidneys. The most common type that affects children is called Wilms' tumour. It is also called a nephroblastoma.

Hepatic tumours

Hepatic tumours affect the liver. The most common types of malignant tumours in the liver are hepatoblastoma and hepatocellular carcinoma.

Sarcomas

Sarcomas are tumours that develop from tissue such as bone, muscle, fat or cartilage. They can occur in any part of the body and include soft tissue sarcomas, rhabdomyosarcoma and bone tumours (see below).

Malignant bone tumours

The most common malignant tumours in bones are Ewing sarcoma and osteosarcoma.

Gonadal and germ cell tumours

Germ cells are normally found in the embryo that develops into a baby in the womb. These cells in time mature into sperm or egg cells in the testicles or ovary. Some of the cells can remain in different parts of your child's body after birth and may develop into tumours. The tumours are known as germ cell tumours or embryonal tumours.

Other epithelial and melanomas

This category includes tumours in the roof of the mouth (nasopharyngeal carcinoma) and the skin (melanoma).

Langerhans cell histiocytosis (LCH)

Langerhans cells are a type of white blood cell that normally helps the body fight infection and are found in your skin and mucous membranes. In LCH, too many Langerhans cells are produced and build up in certain parts of the body where they can form tumours or damage organs.

Other and unspecified

This category includes very rare tumours that occur in children. They can be found in any part of the body. For example, cancer of the salivary gland, bowel, appendix, lung and bladder.

Survival rates

More children than ever are surviving cancer. There have been huge improvements in cancer treatment for children in the past 50 years. Some forms of cancers are now completely curable. Research is also continuing to improve treatments and reduce side-effects. Every child is different and your child's doctor will talk to you about their illness and the likely success of treatment.





Diagnosis and treatment

Diagnosis	15
Tests	15
Types of treatment	16
Side-effects of treatment	17
Complementary treatments	17
Children's Health Ireland (CHI), Crumlin	18
People you may meet	22
Life on the ward	27

Diagnosis

What does the word diagnosis mean?

Diagnosis means finding out what is wrong with your child, and if it is cancer, which type it is. Doctors will do this by assessing your child and their symptoms and by doing tests. When a child has symptoms that could be caused by cancer, usually they will be referred by their GP or local hospital to one of the following specialists:

A paediatric oncologist is a doctor who specialises in treating children with cancer.

A paediatric haematologist is a doctor who specialises in treating blood disorders in children.

A paediatric surgeon is a surgeon who performs surgery on children.

Tests

What tests might my child need?

Various tests will be done to give the doctors more information about your child's illness. Many of these tests will be carried out in Crumlin, but some may be carried out elsewhere.

Your doctors will tell you which tests your child needs, depending on their diagnosis. Possible tests include:

- Biopsy
- Blood tests
- Bone marrow tests (bone marrow aspirate)
- Lumbar puncture
- X-rays
- Ultrasound scan
- CT scan
- MRI scan
- Bone scan
- PET scan
- GFR test
- Audiogram
- Ophthalmology

See pages 79-85 for an explanation of these tests. They are also explained in more detail in *Passport*.

Types of treatment

The treatment offered to your child will depend on the type of cancer they have. There are a number of treatments available. The most common include:

Surgery

This aims to remove the tumour during an operation.

Chemotherapy

This uses anti-cancer drugs to destroy cancer cells.

Radiotherapy

This uses radiation to destroy cancer cells.

Stem cell and bone marrow transplants

These involve giving high doses of chemotherapy drugs to children and then helping them recover by giving an infusion of stem cells. The cells can come from the child themselves (autologous) or from a donor (allogeneic).

Immunotherapy

This uses specific drugs to help children's immune systems target particular cancer cells.

Targeted therapy

This uses drugs to target special proteins and genes in cancer cells.

Your child's doctor will explain to you which treatment, or combination of treatments, they consider suitable for your child. They will also respond to any worries or questions you might have. Before any treatment is given, consent and assent (agreement) will be sought from you and your child. Once a child reaches the age of 16, they can usually consent to their own treatment.

Side-effects of treatment

There are some side-effects to cancer treatment. These will depend on the type of treatment and how your child responds to it. The doctors and specialist nurses will give you specific advice about side-effects.

For example, hair loss is a possible side-effect of many chemotherapy drugs. If the hospital team expects this to happen to your child, they will advise you on ways to deal with it. Talk to them if you have any queries or concerns. Side-effects are also dealt with in *Passport*.

Complementary treatments

It is natural to want to try to help your child in any way you can. Complementary therapies can't treat or cure cancer, but can help to manage some side-effects of treatment and help your child to feel better in themselves. Some therapies are available in the unit, such as relaxation and gentle massage, and can be accessed after discussing them with your child's consultant.

What's the difference between complementary and alternative therapies?

Complementary therapies are used **together with** standard medical treatment. Alternative therapies are used **instead of** standard medical care. Modern medical treatments are very effective at curing cancer and keeping it under control. An unproven alternative could harm your child's health, or they might miss out on a treatment that could really help them. Talk to your child's consultant if you have any questions about treatment or alternative therapies.

Children's Health Ireland (CHI), Crumlin

Children's Health Ireland at Crumlin is the national referral centre in Ireland for children from birth to 16 years who have blood disorders and/or cancers. The hospital has a 19-bed inpatient unit called St John's Ward, which includes four transplant beds (Haematopoietic Stem Cell Transplant [HSCT]). As well as St John's Ward, there is the Haematology/Oncology Day Unit (HODU), which provides day care services.

The hospital has direct links with other hospitals to provide other specific services your child may need, such as:

- **Neurosurgical services** at Children's Health Ireland, Temple Street for younger children and at Beaumont Hospital for older children
- **Orthopaedic services** at Cappagh National Orthopaedic Hospital
- **Radiotherapy services** at St Luke's Radiation Oncology Network
- **Retinoblastoma services** at Children's Health Ireland, Temple Street

It also has links with hospitals around the country through its shared care programme. Shared care means some of your child's treatment can be given at a designated shared care centre in your local area. This can help you and your family spend as much time as possible close to home.

International links

World-class research is carried out at CHI, Crumlin. It teams up with the major international paediatric oncology groups, which helps us to stay up to date with the latest treatments. These are often available through clinical trials.

CHI, Crumlin is a member of the:

- International Society of Paediatric Oncology (SIOP) – based in Europe
- Children's Cancer and Leukaemia Group (CCLG) – based in the UK and Ireland (see page 19)
- Children's Oncology Group (COG) – international

Research and clinical trials

Cancer research trials and studies try to find new and better treatments for cancer. Because of clinical trials, the hospital is constantly improving and refining its treatments, and so the outcomes for children with cancer are getting much better.

Trials that are carried out on patients are known as clinical trials.

Children's Cancer and Leukaemia Group (CCLG)

CCLG is a network of 20 specialist centres for diagnosing and treating children's and teenage/young adult cancers throughout the UK and Ireland. CHI, Crumlin has one of the largest centres within the group. The group supports the 1,700 children who develop cancer each year in the UK and Ireland. See page 75 for more on CCLG.



Cancer Nurseline Freephone 1800 200 700

Getting to Children's Health Ireland at Crumlin



By car

From city centre

The hospital is about a 20- to 30-minute drive from Dublin City centre. Drive south onto Patrick Street and take a right onto Cork Street. Continue driving along Cork Street, onto Crumlin Road, and the hospital is at the end of Crumlin Road on the right. Sat. Nav. Co-ordinates: N 053.32633 degrees W 006.31757 degrees.

Via M50

Take Exit 9. Head to the city centre and follow the signs for R110/Long Mile Road. After passing Drimnagh Castle School, continue onto Drimnagh Road. After Ronald McDonald House, take the next left onto Cooley Road and you will come to Car Park Entrance 1 of the hospital.

By bus

Dublin Bus routes serving the hospital include:

No 18, 27, 56a, 77a, 122, 123, 150, 151. The buses operate from various points in the city centre and can change from time to time. For bus timetables and departure points, visit www.dublinbus.ie

By rail

Luas

The Red Line that services Tallaght and Connolly Station stops at Drimnagh, which is a 10- or 15-minute walk to the hospital. For further information, go to www.luas.ie

Dart

Coming from the southside of the city, take the Dart (Greystones/Bray to Malahide) to Pearse Station. As you exit the station, turn right and right again onto Pearse Street. Go to the nearby bus stop and take the No 56a or 77a, which will stop outside the hospital. Journey time is about 20–25 minutes, depending on traffic. For Dart timetables, visit www.irishrail.ie

Coming from the northside of the city, take the Dart (Malahide to Bray/Greystones) to Tara Street Station. As you exit the main entrance of the station, turn right onto George's Quay and you will find a nearby bus stop. Take the No 151, which will stop outside the hospital. Journey time is about 20–25 minutes, depending on traffic. For Dart timetables, visit www.irishrail.ie

Train

Most large towns and cities connect to Dublin city via Heuston Station. The hospital is about a 15-minute drive from the station. Or, you can take the Luas and get off at the stop for Drimnagh. The hospital is a 10- or 15-minute walk from there. For further information, visit www.irishrail.ie

People you may meet



At CHI, Crumlin, your child's consultant and a multidisciplinary (MDT) team of specialists will plan the treatment they feel is best for your child's condition. This team meets regularly and includes many of the professionals you and your child may meet during your child's treatment:

Paediatric oncologists and **haemato-oncologists** are doctors who treat children with cancer. They are specialists in planning and giving cancer treatments, such as chemotherapy, targeted therapy and immunotherapy. Haemato-oncologists specialise in blood disorders, including leukaemia and lymphoma. They are also involved in the haematology laboratory, where blood and bone marrow samples are analysed.

Radiation oncologists specialise in using radiotherapy to treat cancer.

Surgeons carry out operations. They may take a sample of the cells to be examined (biopsy) and/or remove a tumour. They also may put in central lines and implantable ports. Neurosurgeons are surgeons who perform surgery on the brain and spinal cord.

Paediatric anaesthetists are doctors who can put your child to sleep and monitor them throughout surgery.

Non-consultant hospital doctors are doctors on the team who work under the consultant as trainee specialists. For example, specialist registrars, registrars and senior house officers.

Ward nurses: The clinical nurse manager (CNM) is in charge of the ward. Staff nurses and student nurses work under the manager's direction. Nurses on the unit have specific training in working with children with cancer.

Advanced nurse practitioners (ANP) are nurses who have extensive knowledge and training and are skilled to a high level in the care of children with cancer.

Clinical nurse specialists (CNSp) are specially trained nurses that provide education and information to help you care for your child at home. They can also liaise with your primary healthcare team and shared care centre.

Transplant nurse specialists are specially trained nurses who can inform you and your family about bone marrow or stem cell treatments. They are involved in organising all tests needed before and after the transplant and can support you and your family throughout the process.

Healthcare assistants are trained to give children essential care and support with day-to-day living. They can also help nurses, doctors and other healthcare professionals.

Medical social workers can help you with any practical, emotional and financial problems you may have. They can meet you early on to discuss the diagnosis and how you are going to cope. They will give you information on what to tell your child, relatives or school. They can also advise you on how to talk to and involve your other children. Apart from providing counselling, they can also help with practical problems and give advice on entitlements and support services available to you.

Pharmacists are responsible for supplying medicines for use in the hospital and advising doctors, nurses and parents about all aspects of their use. They are based in the hospital pharmacy and may also visit the ward and Haematology/Oncology Day Unit.

Physiotherapists help to restore wellbeing to children and adolescents after injury, pain or disability. They can assess your child and develop individual treatments to promote, maintain and restore normal development, movement, balance and posture. This is done by taking account of your child's health status and their level of development.

Occupational therapists (OTs) provide rehabilitation and ways to help your child with their everyday activities. Their services are aimed at improving the loss of any functions and managing fatigue and energy loss. Therapies include helping your child if they're at risk of developmental delay because of long and frequent hospital stays.

Pathologists are doctors who analyse tissues samples (for example, biopsies) under the microscope to diagnose illness or see how an illness is responding to treatment.

Child psychologists can support your child, adolescent or family to adjust and cope with a cancer diagnosis and the impact of treatment. They can help your family address issues that may arise in relation to your child's behaviour, how they are coping emotionally and schooling concerns. These issues can happen at any stage of treatment, at the end of treatment or after it has finished.

Radiologists are doctors who interpret X-rays and scans to help diagnose the cancer and plan your child's treatment.

Radiographers take X-rays.

Radiation therapists deliver radiotherapy treatment.

Dietitians can help your child grow and develop as normal throughout their treatment. At times, some children may be unable to eat enough to either gain or maintain their weight. If that becomes an issue for your child, the dietitian can support you on how best to manage it.

Play specialists use play as a preparation and distraction while making your child's experience of hospital as normal as possible. Play is an essential part of every child's life and supports social, emotional, intellectual and physical development.

Schoolteachers: The Department of Education and Skills funds an education service in the hospital at both primary and secondary levels for children who are inpatients or repeat day patients. Your child may attend school in the ward classroom or teachers will go to your child's bedside. Teachers – with help from you, your child and the school – will design an education plan for your child to follow while in hospital.

Pastoral care team: The care and support of the whole person is important. As part of the hospital team, the chaplains (RC) or ministers of other faiths take particular care of the spiritual needs of your child and family. Chaplains are available 24 hours a day to listen, talk and/or pray with you. Ministers of other faiths can be contacted through the chaplains and are welcome at all times.

Palliative care team: This is a group of specially trained doctors, nurses and other professionals who help support you, your child and your family if your child is diagnosed with a life-limiting cancer. They focus on the quality of life for your child by providing practical support, such as pain and symptom management, and also emotional support. This emotional support is also available for you and your extended family.

A **complementary therapist** can provide therapies such as reflexology, relaxation, aromatherapy, Indian head massage, deep breathing and mindfulness for your child. They can help ease some of the stress and symptoms caused by a cancer diagnosis and its treatment.

Volunteers from Children in Hospital Ireland and Barretstown may also spend time playing with your child either in the playroom or individually. These volunteers are all carefully trained and vetted.

The **ward clerk** provides administrative and clerical support on the ward.

Community links: There are also healthcare professionals in the community that can be of help.

In your community

Family doctor (GP): Your GP will be contacted by the hospital so they are fully aware of the details of your child's case in the early stages of diagnosis and during treatment.

Public health nurse (PHN): Your clinical nurse specialist will make contact with the public health nurse and will explain how the PHN will support you at home.

Life on the ward

The ethos or code of the unit is one of holistic, family-centred care. It aims to promote an atmosphere of respect for all creeds and cultures. Safety is a priority and smoking and alcohol are not allowed within the hospital grounds.



Layout and facilities for parents

St John's Ward has 19 single rooms, each of which has sleep facilities for one parent. Eighteen of these rooms have ensembles. Lounge and kitchen areas are available for parents, as well as shower and toilet facilities. The unit has a playroom, schoolroom, teenagers' den, as well as a garden with an outdoor play area.

Children and their parents attend the Haematology/Oncology Day Unit (HODU) for day care services. When treatment is complete, outpatient follow-up visits take place on the third floor of the Medical Tower (HOOPS – Haematology/Oncology Outpatients Services), which is located off the main hospital corridor near the entrance to the canteen.

Ward routine

On your arrival, the ward staff will familiarise you with the ward and its routines. If you have any specific requests, feel free to discuss them with the staff.

Hospital facilities

There is a shop, canteen and two coffee shops in the hospital. You will find vending machines with sandwiches and snacks in common areas throughout the hospital, while a shop trolley comes to the ward on weekday mornings. There is a cash machine, a chapel and a postbox, which is located beside the main reception desk.

There are internet surfboxes with printers located on the ground floor. Free wifi is available in St John's Ward and in the Parents Accommodation Unit. A citizens information service, provided by the Citizens Information Board, is available outside the hospital canteen at specific times. There are limited car-parking facilities at the hospital, with hourly or daily rates.

Parent accommodation

You, or the second parent, have access to accommodation in the Parents Accommodation Unit. This is located on the second floor of the hospital and is reached by the stairwell near the canteen. The accommodation consists of single and double rooms, bathrooms and showers, sitting rooms and kitchens. It also has laundry facilities.

Also, the Ronald McDonald House can be found on the hospital campus. It is aimed at families who have to travel for 2 hours or more to get to the hospital. Your child should either be a patient on the ward or undergoing treatment as an outpatient for 5 days or more. The house has 20 ensuite bedrooms and meals are prepared for families most days. There are also full laundry facilities. It tends to get booked up very quickly and may have a waiting list. The staff will let you know how to book the various types of accommodation or recommend nearby hotels with reduced rates for families of sick children attending the hospital.

Looking after your child

As a parent, you are encouraged to stay with your child in hospital. You are essential to your child's wellbeing and will be given all the support you need to be involved in their care. Brothers and sisters over the age of 18 can stay overnight instead of a parent.



Having treatments

Most of your child's treatment will be given on St John's Ward or HODU as an infusion (drip) or injection through a Hickman line or portacath. It might also include medication taken by mouth. Some children may receive chemotherapy into a special reservoir under their scalp, or into their spinal fluid under anaesthetic in theatre.

It is better to be open with your child about a test or procedure that may hurt. For example: 'This will hurt, but only for a minute. Will I hold your hand until you feel better?' In this way, your child knows what to expect and is sure of your support. Your child might like to take part in the Beads of Courage programme. For every kind of test or treatment they have, they receive a coloured bead. They can collect these beads to keep track of their cancer journey and show just how brave they are.

Visits from family members

Visits from the wider family and school friends can be good for your child too. They can cheer up your child, especially if they're in hospital for long periods. Visiting times for relatives are between 8am and 9pm each day. But it's best to check with the staff if there are any restrictions. Remember, it can also be tiring for your child if there are too many visitors at once.

If your child is feeling unwell during or after chemotherapy, it may be best to have only one person with them at a time. Make sure your child gets all the rest they need. It may be better to encourage school friends and neighbours to visit when your child returns home and is in better form. All visitors should be well and have no signs of infection.

School and play

School is important for your child during treatment. As mentioned earlier, play is an essential part of every child's life and supports social, emotional, intellectual and physical development. See page 51 for more details about school and play.

Looking after yourself

Self-care

As parents, you may find it helpful to take turns being with your child in hospital. It is important to get home to other family members or just to take time for yourself. It can be a strain to be in the same surroundings all day, so you might find it helpful to leave the ward for at least one short break during the day. The nursing staff will understand this and encourage you to take regular breaks. A visit to the canteen or coffee shops is a good idea. You will meet other parents and get to know them. It will do you good to take a walk in the garden in the fresh air or to the nearby shops. A break from the ward and the hospital environment can often help to raise flagging spirits.

Complementary therapies

There are facilities for complementary therapies in the unit for both you and your child. These include relaxation, aromatherapy, reflexology and Indian head massage. They can help ease some of the stress and anxiety you may be experiencing.

Expressing your feelings and worries

Talk about your feelings or worries with the nurses or medical social worker. They are experienced in caring for children with cancer and are there to help and support you.





Parents coping with a child's cancer

Going home after diagnosis and starting treatment	35
How will my child's cancer affect me?	35
Feelings and emotions	36
Coping with the impact of the diagnosis	39
Practical support	41
Looking after yourself	43

Going home after diagnosis and starting treatment

This can be very daunting for you as a parent or guardian. Remember that the hospital team will be planning for you and your child to go home as soon as your child is well enough. They will organise some of the things you will need and services to link in with. For example, the pharmacist will talk to you before your child is discharged about giving medicines at home and provide information leaflets and charts, if needed. They will also contact your local pharmacy to advise them about any medicines needed. The hospital team will also help to prepare you for what to expect during your child's treatment.

Passport contains a lot of information and guidance and will be an important resource for you at home. It also has all the contact numbers you will need when you have questions or concerns. A plan will be made for when your child needs to attend the hospital and/or the local shared care hospital for check-ups or treatment.

How will my child's cancer affect me?

Having a child diagnosed with cancer will affect you and the people close to you. Understandably, you will feel worried and stressed as you come to terms with the diagnosis and what it means for your child. You will no doubt worry that your child will suffer and that your family life is going to be completely disrupted. Some parents may also feel that they will lose their child.

When first told the diagnosis, you may feel numb, confused, or unable to hear or remember information about your child's diagnosis or treatment. You may also feel overwhelmed by painful and powerful emotions. These reactions are normal – remember, the doctors and nurses are there to help you at this time. There are also other people and organisations that can offer support (see pages 70-74).

Who to tell and what to say

These questions worry all parents at first. A diagnosis of cancer comes as a shock. It is normal to find it difficult to talk about it to others. But each family will have their own way of dealing with the situation. Most parents find that it is best to tell close relatives and friends the truth. Their support will be invaluable and it will be a relief to talk to them. With acquaintances or colleagues, a short simple explanation is all that is needed.

Feelings and emotions

There is no right or wrong way to feel. You will probably find that your emotions go up and down a lot during the days and weeks following the diagnosis, and that your feelings change over time. You may not experience all the emotions we describe briefly here.



Shock

This is one of the most common feelings when first faced with a child's cancer diagnosis. Shock is a completely normal reaction that can, in the short term, cause a range of physical and emotional symptoms. These include lack of sleep, lack of appetite, nausea and anxiety.

Fear and denial

You may feel scared, anxious and panicky about what's going to happen and what the future holds. It can sometimes be hard to accept that children can experience serious illness.

Sadness

It is natural to feel sad or depressed at times. Every parent wants their child to be healthy, happy and carefree. Cancer and its treatment can have a big impact on you and your child's life. At times, you may have feelings of hopelessness. You may find it difficult to eat or sleep, or feel as though you have no energy for the things you need to do each day. Parents often say that they feel overwhelmed by the enormity of the situation. These painful and unpleasant feelings are sometimes unavoidable, and you may have them at various times during your child's illness. Remember, it is important to have support to help you through these times. It may help to talk to a medical social worker or specialist nurse or doctor. Call the Cancer Nurseline Freephone 1800 200 700 or visit your local cancer support centre to find out about parent peer-to-peer support.

Guilt

It is very common for a parent to feel guilty if their child has cancer. Some people wonder if it was something they did or didn't do that caused the cancer, or if it's a punishment for something they did in the past. Sometimes parents blame themselves for not noticing their child's symptoms quickly or feel they did not do enough. Always remember that you are not responsible for causing your child's cancer.

Anger

It is also normal to feel angry at times. You may feel angry that your child has to endure tests and treatments and that results are not available immediately. Coping with the unfamiliar world of hospitals, doctors and nurses may also be difficult. Some people may even find that they are angry with their child, as it's their illness that is causing so many problems for the family. This can be distressing but it is also normal.

Parents can feel angry at each other, especially if they have different ways of coping with their child's illness. For example, one parent might want to talk about it a lot, while the other might just want to get on with normal life as much as possible. You may also feel angry with family or friends who make thoughtless remarks or are too busy to give you support. Or you might feel frustrated with people who avoid you because they don't know what to say.

Stress

It is natural too to feel stressed as you deal with the pressure that the diagnosis and treatment can cause. Trying to balance looking after your sick child and the needs of their siblings at home can be difficult. The hospital team looking after your child will guide you towards whatever supports are in your area. Sharing your worries can be helpful.

Finding support

Family and friends

Grandparents, aunts, uncles or other close family relatives often have reactions similar to those of parents and may struggle to deal with some of the same emotions. They usually need to be given a reasonable amount of accurate information about what is happening. They may appreciate being asked to give help and support.

Emotional support

There are many people who can help you deal with any difficult feelings and emotions. You might want to talk to someone close to you, such as your partner, or a friend or family member. However, some people find it easier to talk to someone they don't know so well, such as a healthcare professional or perhaps a colleague at work. The staff at the hospital, including medical social workers and specialist nurses and doctors, can listen and talk to you too. The team may direct you to counselling services, complementary therapies and parent peer to peer support at your local cancer support centre. See www.cancer.ie/support.

Coping with the impact of the diagnosis

No two families are the same. The size of the family, age of children, financial circumstances, and so on, can vary greatly. Each parent or couple must work out a solution to suit their own needs. Some general guidelines that might help include:

- **Work together and share the burden**

If you are part of a couple you will need to share the new burden together, not just on a practical level but on an emotional level too. You need one another and your child needs you both. If you can both be involved in accompanying your sick child to the hospital or in caring for the other children and your home, so much the better. This may not always be possible, of course, but do try to share the demands of the new situation.

- **Two heads are better than one**

It is important that you fully understand what the diagnosis and treatment mean. You will be in a state of shock at first and may feel confused by all the new information you receive so you may find it hard to take it all in. If you are attending important meetings with your child's consultant, try to have your partner, a friend or family member with you.

- **Ask questions – don't be afraid**

When you have recovered from the shock of the diagnosis, you will have many questions. Many parents find it useful to write out a list of their questions at home to bring with them to the hospital. Don't be afraid to ask questions about any aspect of the diagnosis and its effect on your family. Staff will do their best to answer them honestly but, remember, not all questions can be answered straight away.

- **Family and friends can help**

Try not to make your sick child the centre of your world. You will lose out if you cut yourselves off from family and friends. Stick to the normal routine and family activities as far as you can to keep the whole family feeling secure. Accept any offers of help with household tasks or to look after your other children, so that both you and your partner can go to the hospital.

- **Relax – take a break**

Take a mental step back from your sick child when they need you less. Take opportunities to spend time by yourself, with your partner, family or friends and with your other children. Get a babysitter occasionally so that you can pursue your own interests, or go out for a relaxing few hours. Your sick child will enjoy the company of someone outside the family.

- **Ask for help if you need it**

Sometimes, coping with a child with cancer can put a strain on a relationship. If you feel this is happening, ask for help. The medical social worker is there to help you during this difficult time.

- **Seek support from parents groups**

There are various groups where you can meet other people with similar fears and worries, share information and advice, and support each other. Call the Irish Cancer Society Cancer Nurseline on Freephone 1800 200 700 or email cancernurseline@irishcancer.ie to find out about parent peer-to-peer support.

Practical support

GP and public health nurse

Your specialist nurse will contact your GP, local hospital and public health nurse and tell them about your child's diagnosis and treatment plan. These local support services are important, as some of your child's care might take place closer to home.

Travel costs and practical help

Looking after a sick child can cause extra expenses and difficulties. Often parents living outside the Dublin area face the added difficulties of travel and having to organise the care of their families for longer periods while away. For some, there is the added problem of living in an isolated area. Ask for help from family, friends and neighbours in coping with your new routine. They may like to help in a practical way. For example, prepare a meal, do a school run, or help with laundry. The medical social worker will advise you about benefits to which you may be entitled and other financial support, such as grants. See page 57 for more about financial matters.



Advice for one-parent families

Being a lone parent of a child with a life-threatening illness can be especially difficult. You may have less emotional or practical support if you are a lone parent. You may also have difficulties juggling work commitments and caring for your sick child. Asking for and accepting help will help you and your family.

Try to find people to talk with and to help with your family's day-to-day needs. The medical social worker can be a great support at this time. Your family, friends, neighbours, or religious leader may be able to help too.

Employers may find or arrange special ways for you to do your job and still be with your child. Try to be as clear and specific as possible about what your needs are and what is most important to you. Your other children need time with you too, but you should look after your own needs as well.

Seeking information

You may want to find out as much as possible about the cancer and its treatment. There is a great deal of information on the internet but not all of it is reliable. Talk to the doctors and nurses about where to look. The best advice is to use a website by a recognised organisation such as the Irish Cancer Society or the Children's Cancer and Leukaemia Group (CCLG). You can also talk to an Irish Cancer Society cancer nurse. Call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Some UK websites such as Macmillan Cancer Support, or Cancer Research UK have good information, but remember that treatments and supports may not be the same in the UK. See pages 70–75 for a list of support organisations and websites.

Looking after yourself

Remember to take care of your own needs. Your health and wellbeing are important at this stressful time. For example, eating and sleeping well, exercising, dealing with any health problems and taking regular breaks will help you cope and care for your child.

Everyone has different ways of coping with stress and what helps one can irritate another. Talking to a friend or loved one can be very helpful. Try to be as supportive and patient as you can with others who are affected by your child's diagnosis.

Keeping healthy

Relaxation will help to preserve your own physical health and mental wellbeing. Remember, it is important for parents to take care of themselves during their child's illness so you can cope at this difficult time. Have the usual check-ups and let your family doctor know if you feel run down or you're finding it hard to cope emotionally.

Socialising

At this time, you might avoid seeing friends and taking part in social activities. This is very understandable. However, it can help to keep up with your usual interests as much as possible. Having a break and being distracted from the cancer and its treatment will do everyone good. Some of your friends may not know what to say, so it may be up to you to bring up the subject of your child's illness. Others may surprise you with their sympathy and understanding.

Returning to work

It is sometimes very difficult for families to know how to manage work and how and when to return to work. Don't rush into any decisions but tell your employers about your situation and see what flexible working arrangements they can offer you. If you feel unable to work, then it might be a good idea to make an appointment to see your GP.



Children coping with cancer

Your child's feelings	47
Talking to your child	47
Dealing with school	51
Effects on brothers and sisters	52
After treatment and follow-up	54

Your child's feelings

When a child is diagnosed with cancer, it obviously has a big effect on them. They may be very frightened along with feeling unwell, while having to cope with the side-effects of treatment. Being away from home, family and friends can also be difficult for a child to cope with. Understandably, this can have an effect on their behaviour.

Keeping normal discipline during this time is reassuring for your child and can help them feel more secure. Treatment may cause changes in their appearance, such as weight loss or gain, or hair loss. These changes can affect their confidence, especially for older children and teenagers.

Talking to your child

One of the hardest parts of caring for a child with cancer is knowing what to say and how much information to give them. Answering questions honestly is best. Some children may not ask questions, but this does not mean they do not want to know what is happening.

They may be frightened and uncertain of many things. Some children may even wonder if they have done something wrong and if it is the reason they have cancer. You can ask the doctors, nurses and medical social workers for guidance on how to talk to your child. There are also booklets available from CCLG and CLIC Sargent that can help you explain the illness and treatment. See pages 76–77 for more details.



Here are some questions that parents commonly ask after a cancer diagnosis:

Should I tell my child that they have cancer?

Yes, if your child is old enough to understand. It is better to be truthful with them so they trust you and the hospital team. If you explain the basic facts of the disease, your child will realise that the treatment is needed. Even children who are quite young can understand about 'good cells' and 'bad cells' in their body. They can understand that the treatment will kill the 'bad cells' and stop them from becoming very ill.

Your medical social worker can provide you with children's books about cancer and its treatment. These can help your child to understand their illness at their own level. Tell your child that nothing they or anyone else said, did or thought caused their cancer.

My child is too young to understand why he needs treatment. He does not want to come to the hospital. How can I handle the situation?

This is a very understandable problem. A small child will naturally object to having a treatment that they find needless and unpleasant. Loving firmness is the best approach here. Your child must have the treatment, so avoid getting involved in long arguments. Instead, be firm, very encouraging and loving.

Bring all the moral support you can to the hospital in the form of a favourite teddy, soother, prized blanket or other possession. Talk to the play specialist for more ideas and support.

I feel so sorry for my child. Should I let them have what they want? I want them to be happy.

The best gift you can give a seriously ill child is a normal, predictable environment and a loving family. In general, children feel more secure when the normal home rules continue to apply. Many parents find it helpful to ask family, friends and neighbours not to give too many gifts to their child and not to forget brothers and sisters when they're giving gifts and attention.

I am afraid to let my child go out to play. Suppose they get hurt?

If your child has been given permission from the hospital to mix with other children, then encourage them to do so. They need the company of children their own age. Your child will benefit from the give-and-take of social contact and the feeling that they are like other children. Play can greatly boost a sick child's morale and self-esteem.

You might like to sign them up for a residential camp, such as Barretstown. This is a specially designed camp for children with serious illnesses and their families, based in Ballymore Eustace in County Kildare. It offers a range of adventurous and challenging activities, supported behind the scenes by health professionals. This is called therapeutic recreation. All of its programmes are free of charge. Ask your child's specialist nurse or medical social worker for more details.

My teenage daughter undergoing treatment thinks her friends are avoiding her. Is there any particular support for teenagers?

Teenagers diagnosed with cancer face particular difficulties and stresses. They are longing to be independent and make their own way in the world, but at the same time become more dependent due to their illness. Cancer can affect friendships too. Some relationships may grow stronger, while others may fade. It often helps to understand how friends feel and for your child to learn how to tell them how she feels.



CanTeen is a nationwide teenage cancer support group set up in 1990. It aims to provide support, enjoyment, information and encouragement for teenagers who have or have had cancer. It also welcomes brothers, sisters and friends. CanTeen organises meetings, fun activities and weekends away. It provides an opportunity for teenagers to share their feelings and experiences in a supportive environment. Visit the website www.canteen.ie or see page 71 for more details.

School friends may find the CCLG leaflet *I Have a Friend Who Has Cancer* useful.

Dealing with school

Children with cancer often have gaps in their education. This can be due to prolonged periods spent in hospital, the side-effects of treatment, or generally not feeling well enough to take part fully in school life. The teaching staff at the hospital will contact your child's teachers to make sure they can continue their schooling whenever they feel well enough. Children can even take exams in hospital, if needed.

As your child's health improves and when treatment allows, going back to school is a very good idea. For many children, school is a refuge from the world of hospitals and tests – a place for fun, friends and learning. Going back to school can be a sign that life is returning to normal. But some children, especially teenagers, may have some worries about going back to school. This may be because of temporary or permanent changes in their appearance. Or they may worry that they will have missed a lot of schoolwork, or that being away will have affected their relationships with their friends.

Schoolteachers may find the CLIC Sargent information pack for schools called ***Cancer and School Life*** useful. There is also a DVD called ***Back to School***. CCLG has a helpful book called ***Welcome Back! A Guide for Teachers Helping Children and Young People Returning to School after a Diagnosis of Cancer***.

See page 76 for more details.

Barretstown also runs an outreach School Education Programme.



Keeping teachers informed

Let the school know how your child is doing. As soon as your child is diagnosed, contact the school principal to tell them what is happening. It can help to let the school know about the plans for treatment. Your child should be involved, at any stage of treatment, in letting the teacher know what information they would like shared with their classmates.

Preschool children

Many children diagnosed with cancer are very young and have not yet started school. It may be useful for you to talk to your specialist nurse or medical social worker about playschool and discuss any specific queries you might have.

Effects on brothers and sisters

The brothers and sisters of a child with cancer might have many similar feelings and emotions to you. If you have to spend a lot of time in the hospital with your child, your other children may need to be cared for by family members or friends. They may have to spend a lot of time away from you or find their daily routine keeps changing. As well as worrying about their brother or sister's health, they may also resent all the attention they are getting. This can make them feel very left out and angry. They may even worry that they are also going to get ill.

The needs of siblings can sometimes be overlooked, particularly in the early months when you may spend most of your time caring for your sick child in hospital or at home. Many will keep their feelings bottled up to avoid worrying their parents. Often, however, they may show how they feel when at school. They may:

- Withdraw and become very quiet
- Become disruptive in the classroom
- Cry easily
- Become frustrated and have outbursts of anger

- Fall behind in classwork
- Get lower marks than usual
- Start missing school
- Become rebellious towards teachers
- Have arguments and fights with friends and other children in their class

It will help to let your children's principal(s) know that their brother or sister has been diagnosed with cancer. Remember, you can ask for the school's help and support for your children. The teachers will understand that feelings may be expressed through behaviour at school, once they are aware of the stresses facing your family.

Helping brothers and sisters

The whole family will be more likely to understand and deal with the new situation if you create an open atmosphere. Depending on their ages, the children will understand to varying degrees what is going on. Giving them small amounts of information at the beginning is useful. You can then add to it as you feel they are ready for more.

They may experience a range of emotions. Help them to realise that these are all normal and that they have your loving support.

Watch out for changes in their behaviour, as they may not openly speak about their feelings. Encourage them to express these new feelings. Doing a household chore together or going for a walk can create an opportunity for them to talk to you.

Try to give each of your children some individual attention, listen to them and reassure them of your love, even though it must seem that their sick sibling is taking up all your energy. Even 10 minutes at the end of a day can make a big difference. If your child with cancer is having some special attention – for example, having their favourite food – do the same for the other children in the family so they don't feel left out.

Include siblings in the housework and shopping where possible and think up ways of making things easier or more cheerful for everyone.

They will rise to the challenge when they feel a part of the situation.

If a sibling is obviously having difficulty dealing with the situation, talk about it with staff at the hospital, such as the specialist nurses or the medical social worker. The CCLG has a range of information for brothers and sisters of children with cancer, including a leaflet for parents called *Helping Brothers and Sisters*.

After treatment and follow-up

It is important for you and your child to attend outpatient clinics when their treatment is over. This is called follow-up. The doctors will want to check that everything is well and that your child does not have any long-term problems after their cancer treatment. This will be discussed with you at the time.

Adjusting to life after treatment

Finishing treatment is a long-awaited day for you and your child, but it can still be an anxious time. It is often only at this stage and in the quietness of your home that the full enormity of what has happened really hits you. Fears that your child's cancer might return are very common. You may also find yourself missing all the support from the staff on the ward and the contact with the other parents. Just remember that this is all normal. It takes time to feel and trust that all is well again.

The CCLG booklet *My Child Has Finished Treatment* helps answer some of the questions and concerns that arise when a child finishes their cancer treatment. CCLG also has a booklet for older children and teenagers: *I have finished my treatment—What happens next?*



Support resources

Health cover and financial matters	57
Irish Cancer Society services	65
Local cancer support services	69
Useful organisations and websites	70
Helpful books	76

Health cover and financial matters

One of the first worries many parents have is how to pay for all the extra costs their child's cancer diagnosis brings. Health cover falls into two groups – cover for medical card holders and cover for all other groups. We will break this section up under the following headings:

- Hospital cover
- Outpatient cover
- Medical card
- GP visit card
- Long-Term Illness Scheme
- Drug Payments Scheme (DPS)
- Private healthcare cover
- Benefits and allowances

At the end of this section, there are also some useful telephone numbers and addresses for further help. Remember, rates and charges can change each year in the Budget. The figures we quote are correct at the time of going to print (December 2019).



Hospital cover

Everyone, including children, is entitled to hospital inpatient services in a public ward in all public hospitals. There is an €80 a night charge up to a limit of €800 in 1 year. These charges do not apply to medical card holders. Higher rates can apply for semiprivate or private care.

Outpatient cover

If you bring your child to the outpatients or emergency department of a public hospital, without being referred by a GP, you may be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the emergency department first.

Medical card

Children under 18 diagnosed with cancer are entitled to a medical card for 5 years following diagnosis. Any child under the age of 18 who had a diagnosis in the previous 5 years is also entitled to a medical card for 5 years. A medical card usually allows your child to have free GP services, prescribed medicines, inpatient public hospital services as well as outpatient services and medical appliances. You may have to pay a prescription charge, currently €2 per item (due to change to €1.50 from July 2020) up to a limit of €20 (€15 in 2020) per family per month.

To apply for a medical card on behalf of your child, download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 1890 252 919.

If, after the 5 years, your child still has considerable health expenses, you can apply for another medical card. You may be means-tested to qualify for a second card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office or from its website: www.hse.ie.

If your means are above but close to the guidelines, you should apply for a card anyway. A card may be granted in some situations – for example, if you have a large amount of medical costs. This is known as a discretionary medical card, and will depend on your financial circumstances and how long your child's treatment is expected to last. The burden of their illnesses will also be taken into account and the card will be reviewed periodically. If your child has a terminal illness, they will receive a permanent medical card that will not be reviewed.



GP visit card for children

GP care is free for children under 6 – which is due to change to under 8 in September 2020. Your child is entitled to free GP visits, assessments at the age of 2 and 5, and asthma care. The visits also include home visits and out-of-hours, urgent GP care. The card does not cover the cost of medications prescribed by the GP, hospital charges or medical appliances.

If your child has a medical card or a GP visit card, they will automatically be registered for the GP scheme. Otherwise, you must register online for the scheme at www.hse.ie or by post.

Long-Term Illness Scheme

There is a list of medical conditions that qualify for the Long-Term Illness Scheme. Acute leukaemia is one of these conditions. It is important to note that cancer in general is not covered by the scheme. Under this scheme, run by the HSE, your child can get free medicines, and medical and surgical appliances for the treatment of their condition.

The scheme does not depend on your income or other circumstances and is separate from the medical card scheme and the GP visit card scheme. If your child qualifies, you will get a long-term illness book. This book lists the medicines for the treatment of your child's condition. They will receive these medicines free of charge through your local pharmacist. You must pay for other medicines not related to your child's condition. The scheme does not cover the cost of staying in hospital. To apply, fill in an application form from your family doctor (GP) or your local health centre and send completed applications to PCRS-PO Box 12962, Dublin 11.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €124 (€114 from September 2020 under Budget commitments) each month to cover the cost of prescribed drugs, medicines and appliances. To apply, contact your local HSE office or local pharmacy.

Private healthcare cover

Private health insurance pays for private care in hospital or from various specialists in hospitals or in their practices. There are a number of private health insurers in Ireland. They provide cover for day care or inpatient treatment and hospital outpatient treatment. Before attending hospital, check the level of cover provided by your insurer, both for inpatient and outpatient services. If you have private insurance, your child's tests might not be carried out as quickly as you would like. This is because your health insurer has to approve some tests in advance. For example, PET scans. Sometimes it might take 24-48 hours to get approval from your health insurer.

Benefits and allowances

You, or a family member, may qualify for a number of benefits and allowances – for example, the Domiciliary Care Allowance. The medical social worker will let you know what you are entitled to. More information is available in the booklet *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*, which you can get through the Cancer Nurseline Freephone 1800 200 700 or at a Daffodil Centre. Or, you can download it from www.cancer.ie



Application forms for the benefits are available from social welfare offices or Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or LoCall 1890 927 770. You can also download the forms from websites such as www.welfare.ie or www.citizensinformation.ie

Domiciliary Care Allowance

This is a monthly payment to the carer of a child under 16 with a serious illness or disability. The illness or disability must be such that your child needs care and attention and/or supervision over and above that given to another child of the same age. To apply, fill in an application form from your local social welfare office or Citizens Information Centre.

Local pharmacy

Your specialist nurse or the ward pharmacist will link directly with your local pharmacist where needed. You can let them know if you have any problems getting medicines.

Travel to hospital

If it is costing you a lot to travel to and from the hospital, discuss it with your medical social worker at the hospital. Limited help may also be available from your local Department of Employment Affairs and Social Protection representative (formerly community welfare officer). Some local communities might also provide volunteer transport services.

Tax relief for medical expenses

If you pay medical expenses that are not covered by the State or by private health insurance, you can claim tax relief on some of those expenses. Medical expenses are allowed for mileage to and from the hospital. Phone costs, overnight accommodation, and hygiene products all directly connected to your child's treatment are also included. Remember to keep all receipts from doctors, pharmacies, hospitals, travel, accommodation, etc. To apply, register on the Revenue website www.revenue.ie or complete Form Med 1 and return it to your local Revenue office.

Further information

For advice about health cover and benefits, talk to the medical social worker. They can give you advice and help you to apply for benefits. Every situation is different. The help that is available can depend on your income, your child's illness, their age, and the distance you have to travel. There are many other benefits and entitlements that may be relevant to you and your child. Always have your PPS number to hand when you are enquiring about entitlements and benefits. The most direct way to check eligibility is to contact:

- The Department of Employment Affairs and Social Protection representative (formerly the community welfare officer) in your local social welfare office
- The medical social worker in your child's hospital

For social welfare queries, contact:

Department of Social Protection – Information Service

Tel: 1890 662 244

Leaflet line: 1890 202 325

Email: info@welfare.ie

Website: www.welfare.ie

If you have queries about health and social services, contact the HSE office in your area or use HSE Live: Callsave 1850 24 1850, email: hselive@hse.ie or visit the website: www.hse.ie

Information is also available from your local Citizens Information Centre. A list of these centres is available from:

Citizens Information

Tel: 0761 07 4000

Email: information@citizensinformation.ie

Website: www.citizensinformation.ie

Cancer Nurseline Freephone 1800 200 700

If you have money problems

A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, such as medication, travel, food, heating, laundry, clothing and childcare costs. If you have had to take time off work to care for your child, this may cause even more stress and affect your income.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs and other expenses in certain cases. See page 67 for more details of our Travel2Care fund and Children's Fund programme.

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

You can also call our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

More information

Go to www.cancer.ie/publications and check out *Managing the Financial Impact of Cancer*. This explains:

- Medical costs and help available
- Benefits and allowances that you or your family may qualify for
- Travel services
- Ways to cope with the cost of cancer

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:

- Cancer Nurseline
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support services
- Night nursing
- Publications and website information

Cancer Nurseline Freephone 1800 200 700

Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. In relation to children with cancer, the nurse can offer advice about supports that are available. The Cancer Nurseline is open Monday to Friday, 9am to 5pm. Or email us on cancernurseline@irishcancer.ie or visit our online community at www.cancer.ie



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

Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- End-of-life services
- Local cancer support groups and centres

You can email daffodilcentreinfo@irishcancer.ie or visit www.cancer.ie to find your local Daffodil Centre.

Survivor Support

We have trained parent peer supporters available to provide emotional and practical support to you while your child is going through or has finished treatment.

Patient travel and financial support services

We provide practical and financial support for patients in need, who are undergoing cancer treatments. There are two services available to children through the Society:

- **Travel2Care** is a fund, made available by the National Cancer Control Programme (NCCP), for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence. The medical social worker in your child's hospital will apply on behalf of your family, if eligible.
- Our **Children's Fund** is a special fund to help families in financial hardship when their child is faced with a cancer diagnosis. The fund is for families who cannot meet a specific financial burden only because of their child's cancer diagnosis or treatment. This includes children who are having active treatment or receiving palliative care.

You can make three applications over the course of your child's treatment, with a 12-month interval between each application. The most that can be paid out is €1000 for the first application and €500 each for a second and third application. There is no automatic entitlement and each application is assessed on a case-by-case basis. As with the Travel2Care, the medical social worker in your child's hospital will apply on your behalf.

If you would like more information on any of our services, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Irish Cancer Society Night Nursing



We provide end-of-life care for cancer patients, including children in most areas, in their own home. We offer up to 10 nights of care for each patient. Check with your palliative care team if this service is available in your area. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.

Publications and website information

We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our **website** www.cancer.ie or call our Cancer Nurseline for free copies of our publications.

Local cancer support services

The Irish Cancer Society works with cancer support groups and centres across the country to ensure people affected by cancer have access to confidential support, including professional counselling. This includes parents of children diagnosed with cancer.

As a parent of a child with cancer you may like to avail of a variety of services including complementary therapies or peer support at your local cancer support centre.

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at www.cancer.ie/support/support-in-your-area/directory



Useful organisations and websites

Irish Cancer Society

Tel: 01 231 0500
Cancer Nurseline Freephone:
1800 200 700
Email:
cancernurseline@irishcancer.ie
Website: www.cancer.ie

Childhood Cancer Foundation

Ireland's national independent body for childhood cancer. It raises awareness about childhood cancer, advocates for improved services and funds vital supports for affected families.

Email: info@childhoodcancer.ie
Website: www.childhoodcancer.ie

Citizens Information

Statutory body provides comprehensive information on public services and on the entitlements of citizens in Ireland.

Tel: 0761 07 4000
Email:
information@citizensinformation.ie
Website:
www.citizensinformation.ie

Money Advice and Budgeting Service (MABS)

This is a free and confidential service for people who are having problems with money management and debt.

Helpline: 0761 07 2000
Email: helpline@mabs.ie
Website: www.mabs.ie

The Little Princess Trust

A charity which funds real hair wigs for children.

Website: www.littleprincesses.org.uk

Help and support in Republic of Ireland

Go to www.cancer.ie/support/support-in-your-area/directory for the most up-to-date information on support in your community for parents and families.

Aoibheann's Pink Tie

A registered charity that provides practical assistance and support for families in need who have a child with cancer. It takes referrals through St John's Ward at Children's Health Ireland at Crumlin.

Tel: 01 240 1332
Email:
lindaconnell@aoibheannspinktie.ie
Website: www.aoibheannspinktie.ie

Barretstown

A specially designed camp for children with serious illnesses and their families.

Tel: 045 864 115
Email: info@barretstown.org
Website: www.barretstown.org

Bubblegum Club

A club that provides outings for children who have a life-threatening or long-term illness, or are disadvantaged in some other way.

Tel: 01 236 0456/086 262 8888
Email: info@bubblegumclub.ie
Website: www.bubblegumclub.ie

BUMBLEance

A nationwide professional medical transport service for long-term sick and seriously disabled children. It transports children in a fun environment from home to their treatment centres.

Tel: 083 00 44 444
Email: info@BUMBLEance.com
Website: www.bumbleance.com

CanTeen Ireland

A nationwide support group for young people who have or had cancer, and also for their siblings and friends.

Tel: 01 872 2012
Email: info@canteen.ie
Website: www.canteen.ie

Children in Hospital Ireland

An organisation that works directly with children in hospitals to help them cope with illness and being in hospital. It also provides ongoing support to their families.

Tel: 01 290 3510
LoCall 1890 25 26 82
Email: info@childreninhospital.ie
Website: www.childreninhospital.ie

Children's Leukaemia Association

An association that supports and assists families of children with leukaemia in the Munster region.

Tel: 021 494 9801
Email: info@cla.ie
Website: www.cla.ie

Cliona's Foundation

A registered charity that provides financial help for hidden costs in caring for critically ill children in Ireland.

Tel: 061-331333/1800 90 10 90
Email: info@clionasfoundation.ie
Website: clionasfoundation.ie

Hand in Hand

A national support service that provides practical support for families of children with cancer.

Tel: 091 880 360/087 660 0103
Email: info@handinhand.ie
Website: www.handinhand.ie

Julie Wren Trust

A trust that provides complementary therapies for children with cancer at Children's Health Ireland at Crumlin. It also provides funding for palliative care for children at home or in hospital.

Tel: 01 409 6300/087 968 7469
Email: juliewrentrust@gmail.com
Website: www.juliewren.ie

Make-A-Wish Ireland

This organisation grants the wishes of children aged between 3 and 17 living with life-threatening medical conditions to bring hope, strength and joy. It is an affiliate of the International Make-A-Wish family.

Tel: 01 205 2007
Email: info@makeawish.ie
Website: www.makeawish.ie

Ronald McDonald House

An international charity that provides accommodation in a caring and supportive environment for families whose children are seriously ill in hospital or undergoing treatment at Children's Health Ireland at Crumlin.

Tel: 01 456 0435
Email: ronaldhouse@rmhc.ie
Website: www.rmhc.ie

Useful websites**Alex's Lemonade Stand Foundation**

US children's charity that provides useful resources.
www.alexslimonade.org

Beads of Courage

Provides arts-in-medicine supportive care programmes for children coping with serious illness, their families and carers.
www.beadsofcourage.org

Children's Oncology Group (COG)

Based in the US, the world's largest organisation for childhood and adolescent cancer research.
www.childrensoncologygroup.org

Jigsaw (formerly Headstrong)

An Irish charity that focuses on youth mental health. Its programme gives young people somewhere to turn to and someone to talk to when in need.

www.jigsaw.ie

**healthtalkonline.org
youthhealthtalk.org**

Websites that contain information about cancer, and have video and audioclips of people talking about their experiences.

Medikidz

Medical information for kids and teens with clear explanations of different conditions, including leukaemia.

www.medikidz.com

Reachout.com

For children and teenagers coping with stress, anxiety, bullying, suicide, depression, and other mental health and wellbeing issues.

http://ie.reachout.com

SteppingUP.ie

Irish website with information and support for young people with long-term illnesses moving from child to adult health services.

http://steppingup.ie

Stupid Cancer

Global support community for young adults with cancer.

http://stupidcancer.org

Teenage Cancer Trust UK

Cancer information and support forum for teenagers with cancer.

www.teenagecancertrust.org

TYAC (Teenagers and Young Adults with Cancer)

Information and support for teenagers and young adults with cancer.

www.tyac.org.uk

Useful contacts outside Republic of Ireland**The Brain Tumour Charity**

UK charity dedicated to funding research and raising awareness of brain tumours.

Tel: 0044 808 800 0004

Email: support@thebraintumourcharity.org

Website:

www.thebraintumourcharity.org

Cancer Focus Northern Ireland

Supports local cancer patients, their families and carers.

Tel: 048 9066 3281

Email: hello@cancerfocusni.org

Website: www.cancerfocusni.org

Cancer Research UK

Tel: 0044 20 7242 0200

Email:

supporter.services@cancer.org.uk

Website: www.cancerhelp.org.uk

Children's Cancer and Leukaemia Group (CCLG)

For more information, see page 75.

Tel: 0044 333 050 7654

Email: info@cclg.org.uk

Website: www.cclg.org.uk

CLIC Sargent: Caring for Children with Cancer

UK children's charity that publishes a wide range of books, including storybooks.

Helpline: 0044 300 330 0803

Email: info@clicsargent.org.uk

Website: www.clicsargent.org.uk

Daisy Lodge

A purpose-built therapeutic centre for children aged 0–24 diagnosed with cancer and their families. Based in Newcastle, Co Down, it is operated by the Cancer Fund for Children. Open to children and their families from the Republic of Ireland.

Tel: 048 4372 4212

Email: daisylodge@nicfc.com

Website: cancerfundforchildren.com

Bloodwise (formerly Leukaemia & Lymphoma Research)

Blood cancer research charity in the UK.

Tel: 0044 20 7504 2200

Email:

info@beatingbloodcancers.org.uk

Website: www.beatbloodcancers.org

Lymphoma Association (UK)

A UK charity that provides in-depth information on lymphoma.

Helpline: 0044 808 808 5555

Email: information@lymphomas.org.uk
Website: www.lymphomas.org.uk

Macmillan Cancer Support (UK)

A UK charity that provides specialist healthcare, information and financial support to people affected by cancer.

Tel: 0044 20 7840 7840

Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre

Provides high-quality information and support to people affected by cancer.

Tel: 048 9069 9202

Email: cancerinfo@belfasttrust.hscni.net

National Cancer Institute (US)

Co-ordinates the national cancer programme in the US.

Website: www.nci.nih.gov

Neuroblastoma UK (formerly Neuroblastoma Society)

A small UK charity dedicated to finding a cure for neuroblastoma.

Tel: 0044 20 3096 7890

Email: hello@neuroblastoma.org.uk
Website: <https://www.neuroblastoma.org.uk>

Cancer Fund for Children

Provides practical, emotional and financial support to local children with cancer and their families in Northern Ireland.

Tel: 048 9080 5599

Email: info@cancerfundforchildren.com
Website: www.cancerfundforchildren.com

Sarcoma UK

UK charity that funds vital research and offers support for anyone affected by sarcoma.

Tel: 0044 808 801 0401

Email: supportline@sarcoma.org.uk
Website: www.sarcoma.org.uk

Children's Cancer and Leukaemia Group

CCLG is a leading children's cancer charity and the UK and Ireland's professional association for those involved in the treatment and care of children with cancer.

CCLG brings together childhood cancer professionals to ensure all children receive the best possible treatment and care. They fund and support research into childhood cancers, and help young patients and their families with their high-quality information resources.

Publications

CCLG produces an extensive range of accredited information resources for families. See the website www.cclg.org.uk for a full list or to download publications. Its *Contact* magazine is a free quarterly magazine featuring information articles and personal stories.

Principal treatment centres

CCLG's principal treatment centres work together to make sure families across the UK and Ireland have access to the best possible treatment and care.



Helpful books

There are a number of useful publications available from various organisations. These are aimed at parents, guardians, carers, family members, friends and schools.

CCLG

The CCLG has a wide range of booklets and factsheets on, for example, types of children's cancers, diagnosis, treatments and managing symptoms and advice for family members. All CCLG publications are free to patients and their families. Examples include:

Diagnosis

Children and Young People with Cancer: A Parent's Guide (2017)

Managing family life and cancer (Dec 2016)

Taking part in clinical trials (2017)

School

I have a friend who has cancer (2017)

Welcome back (2018)

Everyday life

Anna loses her hair (Oct 2018)

Helping brothers and sisters (2016)

After treatment finishes

Aftercure: A guide for teenage and young adult survivors of childhood cancer (2017)

I have finished my treatment...what happens next? (Aug 2014)

Go to www.cclg.org.uk/publications to see their current publications. For copies, call 0044 116249 4460 or email: info@cclg.org.uk or download from the website.

CLIC Sargent

CLIC Sargent is a UK cancer charity for children and young people and their families. It also publishes a wide range of books and online information for children, parents and families. Visit www.clicsargent.org.uk for a full list of publications. Examples include:

For parents and guardians

What now? A practical guide for parents and carers

How can I help? – a leaflet for friends and family

For teenagers and young adults

Cancer and treatment - factsheet

Boredom busters when you're staying in hospital

For children

Joe has leukaemia (March 2017)

Lucy has a tumour (Sept 2017)

Tom has lymphoma (Nov 2018)

For schools and teachers

Cancer and school life

Chemotherapy, cakes and cancer

Winston's Wish

Winston's Wish is the leading childhood bereavement charity in the UK. It offers practical support and guidance to bereaved children, their families and professionals. Visit www.winstonswish.org.uk

Books from Royal Marsden Hospital

Pupils with cancer: A guide for teachers (2008)

Booklets and information from Children's Health Ireland at Crumlin

Chemotherapy: What is it? A colouring book for children who are receiving chemotherapy

Passport: Information for parents



Booklets from the Irish Cancer Society

Precious Times: A handbook on palliative care for parents of children with cancer (2019)

Helping Hand: A guide for parents of children with a brain tumour

Managing the financial impact of cancer: a guide for patients and their families (2019)



Medical terms explained

Doctors may use words that you don't understand. Here are some of the most common ones.

If you don't understand the words a doctor or nurse uses at any time, don't feel embarrassed to ask them to explain them to you.

Acute	Occurring suddenly over a short period of time.
Alopecia	Hair loss.
Anaemia	A reduced number of red blood cells.
Anaesthetic	Drugs that put your child to sleep (general anaesthetic) or that numb a part of their body (local anaesthetic).
Antibodies	Proteins created by the immune system when exposed to foreign proteins such as viruses and bacteria.
Audiogram	A hearing test. Your child wears headphones and responds to various volumes and tones. The test is not painful.
Benign	A tumour or growth that is not cancerous but may still cause problems.
Biopsy	A small sample of tissue taken from the body to make a diagnosis.
Blood tests	Doctors often examine blood samples to help them to diagnose your child's illness. Blood tests may be done when your child is diagnosed, during treatment, and afterwards at follow-up appointments.
Blood count	A blood test to check the number of different cells in the blood. Sometimes it is called a full blood count or FBC.

Bone marrow	The spongy material in the centre of large bones in the body, which makes blood cells.
Bone marrow aspirate/biopsy	A test that takes samples of bone and bone marrow and examines them under a microscope. If bone is taken, it is called a trephine biopsy, whereas if bone marrow is taken it is called an aspirate. The test is usually done in theatre.
Bone scan	A test that can show if cancer is present in bones using a radioactive dye.
Cannula	A short plastic tube put into a vein to deliver medication, fluids or a transfusion.
Cardio-Catheter	To do with the heart. A thin, flexible tube used to give fluid into the body or to drain fluid from the body. For example, a urinary catheter or a central line, ie Hickman line.
Cerebrospinal fluid (CSF)	Fluid made in the brain that surrounds the brain and spinal cord.
Chemotherapy	Drug treatment that kills cancer cells.
Chromosome	Structure in the nucleus of the cell that contains the genetic make-up of the cell.
Chronic	A condition that lasts for a long time.
CNS	Central nervous system. It refers to the brain and spinal cord.
Congenital	Any condition existing at birth.

CT scan	A computerised axial tomography scan. It is a series of detailed pictures of areas inside the body taken from different angles. The pictures are created by a computer linked to an X-ray machine. Sometimes a dye called contrast may need to be given before the scan to get a better picture.
Cyto-Cytogenetics	To do with cells. The study of chromosomes in cells.
Dysfunctional	Something not working properly.
ECG	Electrocardiogram. This tests the electrical activity of the heart muscle. Electrical sensors are placed on your child's chest for the test.
ECHO	Echocardiogram. This is an ultrasound scan of the heart. It checks how well the heart is working.
EEG	Electroencephalogram. This tests the electrical activity of the brain. It is not painful but will involve electrical sensors being attached to your child's head.
Electrolytes	The minerals and salts in the body. For example, sodium, potassium and calcium.
Endocrine	To do with hormones.
Excision	Cutting out.
GCSF	A growth factor called granulocyte colony-stimulating factor. This protein boosts the bone marrow making white blood cells, usually neutrophils.
Genetic	A condition caused by abnormal genes (may be inherited).
GFR	Glomerular filtration rate is a test that shows how well the kidneys are working.

Haematology	The study of blood and blood disorders.
Haemoglobin	The substance in red blood cells that carries oxygen around the body.
Histopathology	The study of body tissues.
Hormone	A substance made by a gland and carried in the bloodstream to parts of the body where it has a specific effect on the way the body works.
Immune system	The body's defence against infection, disease and foreign substances.
Immunology	The study of the body's immune system, which fights infection.
Immunophenotyping	A test to identify particular proteins in the cells to help find out which type of cell has become cancerous.
Immunosuppressive	Lowering the body's ability to fight infection.
Intramuscular (IM)	Into a muscle.
Intrathecal (IT)	Into the spine, usually by lumbar puncture. See also lumbar puncture.
Intravenous (IV)	Into a vein.
Lumbar puncture (LP)	This test can be done to diagnose, prevent or treat disease. The fluid that surrounds the brain and spinal cord is called cerebrospinal fluid (CSF). During the test, some CSF is removed by putting a needle into the lower back and the fluid is then examined in the laboratory.
Lymph	A clear fluid that is part of the body's defence against infection. It is carried around the body in a network of lymphatic vessels.

Lymphatic system	Part of the circulatory system. It consists of a network of vessels that carry a clear fluid called lymph in the direction of the heart. Excess fluid (lymph) in the tissues is drained by the lymphatic system into the bloodstream. It also defends the immune system.
Lymph nodes	Small bean-shaped structures found along vessels in the lymphatic system. They become enlarged due to infection or cancer.
Lymphocyte	A type of white blood cell that fights infection.
Malignant	A tumour or growth that is cancerous. If a tumour is malignant it grows without control and can travel to other parts of the body.
Metastases	Tumours that have spread from the first (primary) tumour into another part of the body. Also known as secondary tumours.
MIBG scan	Metaiodobenzylguanidine scan. It is usually done in children who have a diagnosis of neuroblastoma. It involves a radioactive substance being injected into the bloodstream and the scan being taken the next day. This will show up any areas of tumour in the body.
Microbiology	The study of germs.
MRI scan	Magnetic resonance imaging scan. This uses radio waves and a powerful magnet linked to a computer to take detailed pictures of areas inside the body. These pictures can show the difference between normal and diseased tissue.
Nausea	Feeling sick.
Neuro-	To do with the nerves or the nervous system.
Neutropenia or neutropenic	Low levels of neutrophils.

Neutrophils	White blood cells that fight infection.
Oedema	Swelling caused by fluid.
Oncology	The study and treatment of cancer.
Ophthalmology	The study of the eyes.
Oral	To do with the mouth.
Osteo-	To do with bones.
Paediatric	To do with children.
Palliative	Relief of a symptom (for example, pain) rather than cure of the disease.
PET scan	Positron emission tomography. This scan is normally done in children who have Hodgkin lymphoma. A very small amount of a radioactive substance is injected into the bloodstream, which can show up cancer cells on a scan.
Platelet	A type of blood cell that helps the blood to clot.
PRN	Medicines to take when required.
Prognosis	The expected outcome of a disease and its treatment.
Prosthesis	An artificial replacement of something – for example, a bone.
Pulmonary	To do with the lungs.
Pulmonary function tests	Tests that measure how well the lungs take in and breathe out air, and also how well they move oxygen into the bloodstream. Your child breathes through a mouthpiece connected to a special machine called a spirometer.
Radiotherapy	The use of high-energy X-rays to destroy cancer cells.

Red blood cell	Blood cells that carry oxygen around the body. The part that contains iron called haemoglobin gives blood its red colour.
Refractory	Resistant to treatment.
Relapse	The return of a disease after previous treatment.
Remission	There is no evidence of the disease being present, using the available tests.
Renal	To do with the kidneys.
Sarcoma	A tumour that forms in bone, muscles, fat or cartilage cells.
Stem cell	Early, immature blood cell from which other blood cells are made.
Subcutaneous (SC)	Under the skin.
Therapy	Treatment.
Thrombocytopaenia	Low levels of platelets in the blood leading to bruising and bleeding.
TPN	Total parenteral nutrition. Giving nutrients into a vein when a child is unable to take food in the normal way.
Ultrasound	A test that uses sound waves to examine the tissues inside the body.
White blood cells	Blood cells that defend the body against infection.
X-ray	An image that helps a doctor see the inside of the body.

Questions to ask your child's doctor or nurse

Here is a list of questions that you might like to ask your child's doctor or nurse. There is also some space for you to write down your own questions if you wish. Never be shy about asking questions. It is always better to ask than to worry.

What type of cancer does my child have? Where is it?

What tests and investigations does my child need?

What stage is the cancer at? What does this mean?

What treatment choices are there?

Does my child need more than one type of treatment?

Is this the best treatment for my child? Why do you think so?

How long will treatment last?

Will my child be cured and recover?

What are the chances of the treatment working?

How and when will we know if the treatment has been a success?

What side-effects can my child expect in the short term?

Are there any long-term side-effects?

Will treatment affect my child's fertility in the long run?

How can we help our child before and during treatment?

Does my child need to eat special foods?

Can accommodation be arranged for us while our child is in hospital?

Should we tell our child that he/she has cancer?

What happens if the cancer comes back?

What happens if my child cannot be cured?

Are there any counselling or support services for parents?

Acknowledgments

This booklet has been produced by the Irish Cancer Society and the Oncology/Haematology Unit of Children's Health Ireland at Crumlin. Our aim is to help improve communication, information and support for parents of children with cancer throughout diagnosis and treatment. We would like to thank all the parents and the haematology/oncology team whose support and advice made this publication possible.

Parts of the booklet have been adapted with permission from the publication *Children and Young People with Cancer: A Parent's Guide*, 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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The following sources were used in the publication of this booklet:

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- *Cancer Trends No. 4: Cancer in Adolescents and Young Adults*. National Cancer Registry Ireland, 2010.
- *Cancer in Ireland 1994–2012*. National Cancer Registry Ireland, 2012.
- *Children and Young People with Cancer: A Parent's Guide*. Children's Cancer and Leukaemia Group (CCLG), 2014.
- *Children with Cancer: A Guide for Parents by Parents*. Cancer Plus and Irish Cancer Society, c.2001.

Published in Ireland by the Irish Cancer Society.

© Irish Cancer Society, 2016, 2019

Next revision: 2022

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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!

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 Survivor 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

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

We would love to hear your comments or suggestions.

Please email reviewers@irishcancer.ie

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