

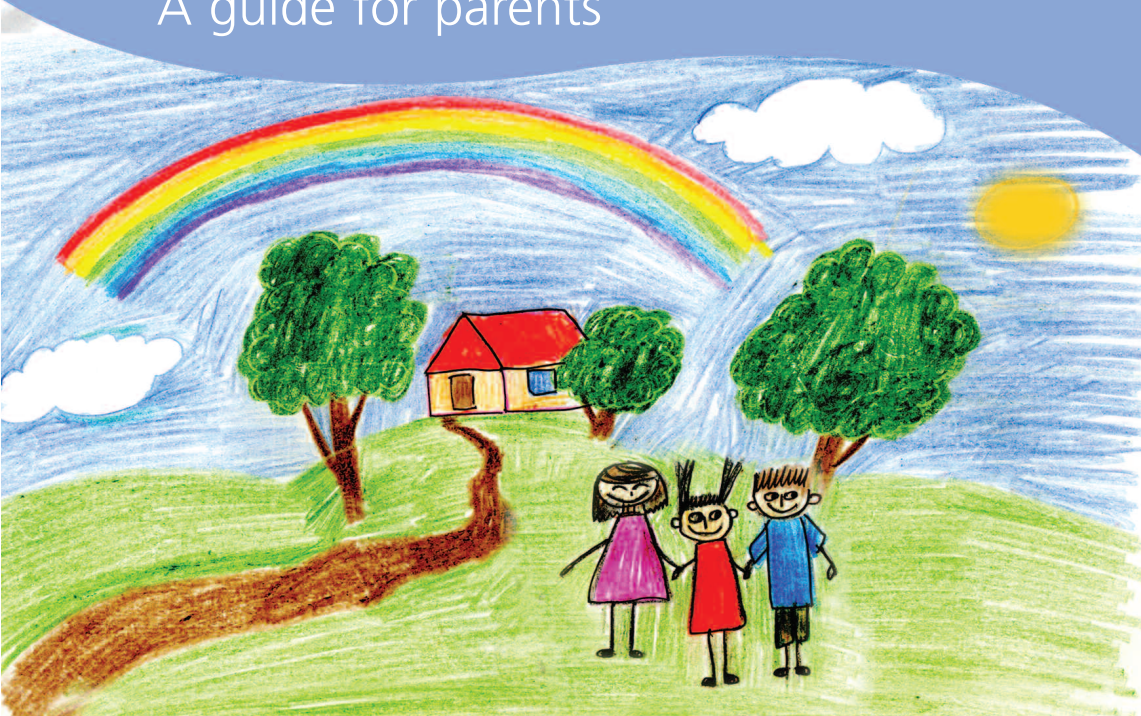
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## Children and young people with cancer : a guide for parents

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# 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 and support of the staff in the Haematology/Oncology Unit of Our Lady's Children's Hospital, Crumlin. This is the national referral centre for all children with a cancer diagnosis in Ireland. We hope that the booklet will help you to understand a little more about childhood cancer, its diagnosis and its treatment. Inside, you will find information about the unit, the people you will meet, and the support available as your child goes through treatment.

You can also make a note below of any contact numbers you may need. See page 14 for directions to Our Lady's Children's Hospital.



Our Lady's Children's Hospital Tel: 01 409 6100  
Crumlin, Dublin 9



St John's Ward Tel: 01 4554 176/4096 654/4096 660

Haematology/Oncology  
Day Unit (HODU) Tel:

Parents Accommodation Unit Tel:

Tel:

Tel:

Tel:

Tel:

If you like, you can also add:

Your name \_\_\_\_\_

Address \_\_\_\_\_

This booklet has been produced by the Irish Cancer Society and the Oncology/Haematology Unit of Our Lady's Children's Hospital, 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](http://www.cclg.org.uk). CCLG accepts no responsibility for the accuracy of this adaptation.

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- *Cancer Trends No. 23: Childhood Cancer*. National Cancer Registry Ireland, 2014.
- *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.

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## Introduction

This booklet has been written for parents, guardians and carers of children diagnosed with cancer. 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 the main source of information and support, but we hope this booklet will provide lots of useful information to help you support your child throughout their treatment and afterwards.

- **Part 1** gives an introduction to common childhood cancers, including types.
- **Part 2** gives an overview of what to expect in Our Lady's Children's Hospital, Crumlin and the range of different tests and treatments that your child may need.
- **Part 3** discusses how a cancer diagnosis can affect you as a parent or guardian and offers advice and support.
- **Part 4** discusses how a cancer diagnosis can impact on your child and the rest of your family.
- **Part 5** gives information on further sources of help and support. This includes various organisations, support groups, websites and booklets.

This booklet is aimed at parents of both children and young people, but it mainly refers to children's cancer within the text. If you find the booklet helpful, you could pass it on to your family and friends too. They might also like to receive information to help them support you at this time.

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.

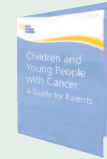


Cancer Nurseline Freephone 1800 200 700 – for sources of support



### Reading this booklet

Remember you do not need to know everything about childhood cancer straight away. First read a relevant item and then when you feel ready, read another section. If you do not 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.



### Sources of support

For advice on where to look for sources of support, you can also call the Cancer Nurseline Freephone 1800 200 700. It is open Monday to Thursday 9am–6pm and Friday 9am–5pm.



## About childhood cancers

### 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. When told the diagnosis, you may be numb or feel like you've been physically hit. Some of the feelings you have may include fear, denial, sadness, guilt and anger. These are all normal reactions. Do remember that it's not your fault your child has cancer and it is not because of anything you've done or not done.

When a child is diagnosed with cancer, it has a big impact on the entire family. Your child's routine is likely to change in some way. They may have to stay in hospital for treatment and are likely to have regular hospital appointments. This may feel 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.

### Childhood cancers

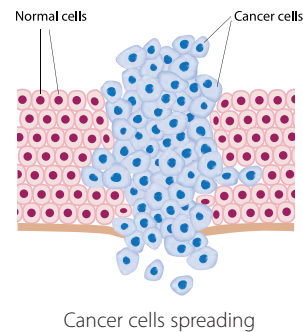
Cancer in children and young people is rare. In Ireland about 200 children under 16 years are diagnosed with cancer each year. In older teenagers, aged between 15 and 19 years, about 68 cases are diagnosed each year.

The childhood cancers discussed in this booklet are grouped according to the International Classification of Childhood Cancer (ICCC). This classification also includes benign tumours of the brain and central nervous system (CNS). See page 9 for more about individual cancers.

## What is cancer?

All cancers are 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 causes cancer?

The causes of childhood cancer are still unknown but research is ongoing. As a parent, it is natural you would worry that something you did or didn't do may have caused your child's cancer. Remember that you are not at fault, so do not feel guilty or blame yourself for your child's illness.

It is very rare for another child in a family to develop cancer, as most cancers are not caused by an inherited faulty gene, and so 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.

## What are the most common types of childhood cancer?

There are many different types of childhood or paediatric cancers. Those discussed in this booklet are grouped into the 12 categories of the International Classification of Childhood Cancer (ICCC).

- |    |  |
|----|--|
| 1  | Leukaemia                              |
| 2  | Lymphoma                               |
| 3  | Brain and central nervous system (CNS) |
| 4  | Neuroblastoma                          |
| 5  | Retinoblastoma                         |
| 6  | Renal tumours                          |
| 7  | Hepatic tumours                        |
| 8  | Malignant bone tumours                 |
| 9  | Sarcomas                               |
| 10 | Gonadal and germ cell tumours          |
| 11 | Other epithelial and melanomas         |
| 12 | Other and unspecified                  |

The most common childhood cancer is leukaemia, followed by brain tumours. Almost 3 in every 4 cancers in young children are either leukaemia, lymphoma or tumours of the brain and nervous system.

**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 nerves 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.

**Sarcoma:** 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):** LCH occurs when the body accumulates too many immature Langerhans cells. They belong to the larger family of cells known as histiocytes, which are part of your immune system. 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 before 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. To compare the results of treatments, doctors often use five- or 10-year survival rates. Every child is different and your child's doctor will discuss their illness and the likely success of treatment with you.

>>> The doctors and specialist nurses will give you specific information about the type of cancer your child has.





## Diagnosis and treatment

### Diagnosis and tests

#### 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, they will be referred by their GP or local hospital to usually one of the following specialists:

- **A paediatric oncologist:** this is a paediatrician who specialises in treating children with cancer.
- **A paediatric haematologist:** this is a paediatrician who specialises in treating blood disorders in children.
- **A paediatric surgeon:** this is a surgeon who performs surgery on children.

#### Our Lady's Children's Hospital, Crumlin (OLCHC)

Our Lady's Children's Hospital, 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 (Haemopoietic 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 with Temple Street Children's University Hospital for younger children and with Beaumont Hospital for older children
- Orthopaedic services with Cappagh National Orthopaedic Hospital
- Radiotherapy services with St Luke's Radiation Oncology Network
- Retinoblastoma services with Temple Street Children's University Hospital

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

### International links

World-class research is carried out at Our Lady's Children's Hospital. It teams up with the major international paediatric oncology groups. This makes it possible for the most modern treatment to be available, often through clinical trials. The hospital is a member of the following groups:

- International Society of Paediatric Oncology (SIOP) – based in Europe
- Children's Cancer and Leukaemia Group (CCLG) – based in the UK and Ireland
- Children's Oncology Group (COG) – based in North America, but also internationally

### Children's Cancer and Leukaemia Group (CCLG)

CCLG is a network of 20 specialist centres, known as principal treatment centres, for diagnosing and treating children's and teenage/young adult cancers throughout the UK and Ireland. Our Lady's Children's Hospital is a member of the CCLG group and 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.

## Getting to Our Lady's Children's Hospital in Crumlin

### By car

**From city centre:** The hospital is about 20-30 minutes' 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.s 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](http://www.dublinbus.ie)

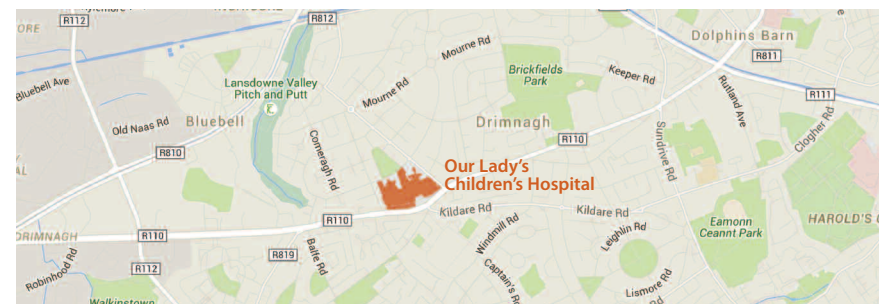
### By rail

**LUAS:** The Red Line that services Tallaght and Connolly Station has two stops within walking distance of the hospital. The Drimnagh stop is 10-15 minutes' walk to the hospital. For further information, go to [www.luas.ie](http://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](http://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 bus, which will stop outside the hospital. Journey time is about 20-25 minutes, depending on traffic. For DART timetables, visit [www.irishrail.ie](http://www.irishrail.ie)

**Train:** Heuston Station is about 15 minutes' taxi drive away from the hospital. It services visitors or patients from many destinations, including Cork, Tralee, Limerick, Waterford, Galway, Westport and Ballina, and many towns en route. You can take the LUAS outside Heuston Station and get off at the stop for Drimnagh. The hospital is 10-15 minutes' walk from there. For further information, visit [www.irishrail.ie](http://www.irishrail.ie)



## What tests might my child need?

Various tests will be done to diagnose your child's illness. Many of these tests will be carried out in Crumlin, but some may be carried out elsewhere. Do remember that tests are individual to each child. Some of the following tests may be needed:



- 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 63–67 for an explanation of these tests. They are also explained in more detail in *Passport*.

>>> Tests are individual to each child.

## Research and clinical trials

Cancer research trials and studies try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. 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. Our Lady's Children's Hospital collaborates with international trial organisations, as previously mentioned.



>>> You may find the following CCLG booklets helpful: *A Guide to Clinical Trials and Donating Your Child's Tissue for Research*. Also visit the website: [www.clinicaltrials.ie](http://www.clinicaltrials.ie)

## Types of treatment

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

- **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 system target particular cancer cells.
- **Targeted therapy:** This uses special drugs to target special proteins and genes in cancer cells.



Giving stem 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 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 this is an expected side-effect for your child, the hospital team will advise you on ways to deal with it. Do talk to them if you have any queries or concerns. Side-effects are also dealt with in *Passport*.

>>> Side-effects are dealt with in *Passport*.

### Complementary treatments

It is natural to want to try and help your child in any way you can. Complementary therapies can help to manage some side-effects of treatment and improve a sense of well-being. 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.

### Alternative treatments

Alternative treatments are unproven therapies that aim to treat cancer and are not part of standard treatment. There is often no scientific evidence for their use. Some alternative medicines can interact or interfere with conventional treatment. Do speak to your child's doctor if you want to explore alternative therapies.

## People you may meet

In Our Lady's Children's Hospital, 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 MDT meets regularly and includes many professionals you and your child may encounter during your child's treatment. The team may include some of the following:

**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** are doctors who 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** are doctors who specialise in using radiotherapy to treat cancer.

**Surgeons** carry out operations. They may take a sample of the cells to examine it (biopsy) and/or remove the whole tumour. They also can 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 (NCHDs):** You may meet a range of 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.

An **advanced nurse practitioner** (ANP) is a nurse who has extensive knowledge and training in children's cancers. Their expert knowledge and skills in patient assessment allow for extended nursing practice.

**Clinical nurse specialists** (CNS) 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 health care team and shared care centre.

A **transplant nurse specialist** is a specially trained nurse 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 essential care and support to children 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 with you early on to discuss the diagnosis and how you are going to cope. They will provide you with information specifically for parents and children, such as what to tell your child, relatives or school. You can also draw on their advice 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 HODU.

**Physiotherapists** help to restore well-being 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 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 being affected by 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, emotional coping and schooling. These issues can be at any stage of the cancer treatment, including the end of treatment and afterwards.

**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 and if unwell will be visited at their bedside by teachers. Helped by you, your child, the base school and the medical team, teachers will design an individual 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, pray and share burdens. 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 the organisation Children in Hospital Ireland 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.

**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 discuss their role with you.

## 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 neither smoking nor alcohol is 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 ensuite facilities. A parents lounge and kitchen facilities are available as well as shower and toilet facilities. The unit also 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:** A shop, canteen and two coffee shops are located in the hospital. Vending machines with sandwiches and snacks are found throughout the hospital in common areas, while a shop trolley comes to the ward on weekday mornings. An ATM machine, a chapel and a postbox beside the main reception desk are also available. There are internet surfboxes with printers located on the ground floor should you need them. Free wifi is available to you and your child in St John's Ward and in the Parents Accommodation Unit. A Citizens Advice Bureau, provided by the Citizens Information Board, can be found 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 has 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/showers, sitting rooms and kitchens. It also has laundry facilities. Family accommodation is available in two Home from Home houses located near the hospital.

Also, the Ronald McDonald House can be found on the hospital campus. It is aimed at families who have to travel a journey of 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 seen as essential to your child's well-being and will be given all the support you need to participate in their care. An older sibling, if staying overnight instead of a parent, must be 18 years or over.

**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 schoolfriends can be good for your child too. They can boost your child's morale, especially when in hospital for prolonged periods. Visiting times for relatives are between 8am and 9pm each day. But do 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 at a time to sit with him or her. Do make sure your child gets all the rest they need. It may be better to encourage schoolfriends and neighbours to visit your child when they return home and are 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 38 for more details about school and play.

>>> All visitors should be well and have no signs of infection.

### Looking after yourself

**Self-care:** As parents, you may find it helpful to take turns being with your child in hospital. Getting home to other family members or just taking time for yourself is important. Being in the same surroundings all day can be a strain, 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. A walk in the garden in the fresh air will also do you good or a walk 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:** Do 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

This can be very daunting for you as a parent or guardian. Do remember that the hospital team will be planning for you and your child to go home as soon as they are 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 52–59).

### 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

Some feelings and emotions you may have are described briefly below. Your feelings are likely to change over time and you may not experience all the emotions described 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.

**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 failed to do that caused the cancer, or that 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.

**Getting support:** 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. There are many people who can help you deal with these difficult

feelings and emotions. You might want to talk to someone close to you, such as your partner or other 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, specialist nurses and doctors, can listen and talk to you too.

## Coping with the impact of the diagnosis

No two families are the same. The size of the family, age of children, financial circumstances, etc. can all vary greatly. Each parent or couple must work out their own solution to suit their own needs. Here are some general guidelines that hopefully may help you.

- **Work together and share the burden:** As 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 both fully understand what the diagnosis and treatment mean. With this in mind, try to attend important discussions with your child's consultant together. You will be in a state of shock at first and may feel confused by all the new information you receive. You may also feel angry, frustrated and hard done by. These are all very common reactions to a cancer diagnosis. All parents feel them.
- **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 straightaway.
- **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:** Make a conscious decision to take a mental step back from your sick child when their need of you has lessened. Take opportunities to spend time by yourself, with your partner and with your other children. Get a babysitter occasionally so that you can each pursue your own interests, or go out for a relaxing few hours together. Your sick child will enjoy the company of someone outside the family.
- **Ask for help if you need it:** Coping with having a child with cancer may bring a couple together. Sometimes, though, the new crisis puts 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 that can offer you, as parents and guardians, extra support. In parent groups you can meet other parents with similar fears and worries. See pages 52–59 for details of useful organisations.

>>> Staff will do their best to answer questions honestly but remember not all questions can be answered straightaway.

See page 33 for more about looking after yourself.

## Practical supports

Practical supports are also available from the following.

**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 unexpected 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. Do ask for help from family, friends and neighbours in coping with your new routine. They may be happy to prepare a meal, do a school run, or help with laundry, as they wish to help in a practical way.

The medical social worker will be able to give you advice about benefits to which you may be entitled and other financial support, such as grants. See page 49 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 in this case. There may be less support readily available to give you emotional support or to help you with the practical aspects. You may also have difficulties juggling work commitments and caring for your sick child. 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, neighbours, clergy 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. Asking for and accepting help will be beneficial to you and to your family.

>>> CCLG has a leaflet entitled *How Can the Internet Help Us?* It gives tips on finding reliable and user-friendly information about cancer care and treatment on the internet.

### 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 remember 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, CCLG, Macmillan Cancer Support, or Cancer Research UK. See page 57 for a list of useful websites.

## Looking after yourself

Do take care of your own needs. Even though your focus and priorities can change over time, your own health and well-being is important too. For example, eating and sleeping well, exercising if possible, dealing with any health problems and taking regular breaks will help you cope and care for your child.

Different people have different ways of coping with stress and what helps one can irritate another. If you can, try to talk to your partner as openly as possible, and be as supportive and patient as you can.

**Keeping healthy:** Relaxation will help to preserve your own physical health and mental well-being. Remember it is important that you both stay well during your child's illness. Have the usual check-ups and consult your family doctor if you feel at all run down. If either of you should become mentally or physically exhausted, there will be even greater stress on your partner and the rest of the family.

**Socialising:** When feeling unhappy, you might avoid seeing friends and taking part in social activities. This is very understandable. But it can help to keep up with your usual interests as much as possible and if your energy allows. 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 hasty 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.

>>> You may find the following CCLG booklets helpful: *Family Life and Cancer* and *Grandparents*.



## Children coping with cancer

### 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 and having side-effects of treatment to cope with. 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 page 60 for more details.

*It was a rollercoaster ride going at full steam but we got by taking it one day, even one hour, at a time. We drew on whatever strengths we could find on the day.*

*Ken, father of Mark, 8 years*

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

### 1 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 to ensure 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 quite young children can understand about 'good cells' and 'bad cells' in their body. They can understand that the treatment will kill the 'bad cells' and prevent 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. Do let your child know that nothing they or anyone else said, did or thought caused their cancer to develop.

### 2 My child is too young to understand why he needs treatment. He does not want to come to the hospital. I find it hard to handle the situation.

This is a very understandable problem. A small child will naturally object to having a treatment he finds both 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.

### 3 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 to include well brothers and sisters when bestowing gifts and attention.

### 4 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 of 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 while supported behind the scenes by health professionals. This is called therapeutic recreation. All of its programmes are free of charge. Do ask your child's specialist nurse or medical social worker for more details.

### 5 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](http://www.canteen.ie) or see page 54 for more details.

>>> Schoolfriends 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 daily 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. It is even possible for children to 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 returning 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.

**Keeping teachers informed:** Do 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. At any stage of treatment, your child should be involved in letting the teacher know what information they would like shared with their classmates.

>>> 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 61 for more details.

**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 attendance 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 or all of the same feelings and emotions that you have. If you need to spend a good deal of time in the hospital with your child, your other children may need to be cared for by family members or friends. They may experience a lot of time away from you and 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 siblings keep their feelings bottled up inside to avoid worrying their parents. Often the place where siblings may show how they feel is 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

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

They may in fact experience a range of emotions. Help them to realise that these are all normal and that they have your loving support. Do watch out for changes in their behaviour, as feelings may not be openly spoken about. Encourage them to express these new feelings, making an opportunity for them to do so while you both share, for example, a household chore or a walk.

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 things to eat – you can 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 new 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.

>>> 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 ensure your child does not have any long-term problems after their cancer treatment. This will be discussed with you at the time.

>>> Talk to staff about when to expect your child to be feeling fully fit and well, after treatment ends.

### Adjusting to life after treatment

Finishing treatment is a long-awaited day for you and your child. Yet despite all the relief, for many parents it is also a time of high anxiety. 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 relapse 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.



## Support resources

### 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. Details of the following are given here:

- 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 that rates and charges can change every year with future Budgets.

#### Hospital cover

At present, everyone, including children, is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €75 a night charge up to a limit of €750 in 1 year. These charges do not apply to medical card holders. Higher rates can apply for semi-private 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

Since July 2015, 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 drugs and medicines, inpatient

public hospital services as well as outpatient services and medical appliances. You may have to pay a prescription charge, currently €2.50 per item up to a limit of €25 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](http://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. To qualify for it may depend on a means test this time. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office or from their website: [www.hse.ie](http://www.hse.ie)

If your means are above but close to the guidelines, you should apply for a card anyway as 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. But it 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 under 6s

Since July 2015, GP care is free for children under 6 years of age. Your child is entitled to free GP visits, assessments at the age of two and five, and asthma care. The assessments are preventive checks that include charting their age, weight and height and taking suitable action. 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 this new scheme. Otherwise, you must register online for the scheme at [www.hse.ie](http://www.hse.ie) If you have any queries beforehand, LoCall 1890 252 919. To register online, you will need your personal public service (PPS) number, the PPS number of your child, and your choice of participating GP. Remember your child must be registered with a GP who has signed up to the scheme.

If you prefer to register using a paper application form, you can download the form from [www.hse.ie](http://www.hse.ie), have it signed by the GP, and post it to: GP Visit Card – Under 6s, PO Box 12629, Dublin 11.

### GP visit card for children aged 6 and over

Once your child has reached the age of 6, you can reapply for another GP visit card. This card similarly covers visits to your GP only and you will have to pay for drugs, hospital charges and medical appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at your child's hospital or your HSE office to see if you and your child are eligible.

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



### 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 drugs, 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 drugs and medicines for the treatment of your child's condition. They will receive these medicines free of charge through your community pharmacist. Other drugs and medicines not related to your child's condition must be paid for by yourself. The scheme does not cover the cost of staying in hospital either.

To apply, fill in an application form from your family doctor (GP) or your local health centre.

### Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €144 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. In Ireland, this is available through the VHI, Laya Healthcare, AVIVA Health, GloHealth, and other schemes. They provide cover for day care or inpatient treatment and hospital outpatient treatment. Before attending hospital, do 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 get done 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 on these is available in a booklet called *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*. For a free copy, contact the Cancer Nurseline Freephone 1800 200 700 or visit a Daffodil Centre. You can also download it from [www.cancer.ie](http://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](http://www.welfare.ie) or [www.citizensinformation.ie](http://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. If you have any problems getting medicines, do let them know.

### Travel to hospital

You can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your medical social worker at the hospital. Limited help may also be available from your local higher executive officer (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. These medical expenses include phone costs, overnight accommodation, and hygiene products all directly connected to your

child's treatment. Remember to keep all receipts from doctors, pharmacies, hospitals, travel, accommodation, etc.

To apply, register on the Revenue website [www.revenue.ie](http://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 direct you and help with suitable applications. Every situation is different and 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 (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check eligibility is to contact:

- The higher executive officer (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

Oisín House, 212–213 Pearse Street, Dublin 2

Tel: 1890 662 244

Leaflet line: 1890 202 325

Email: [info@welfare.ie](mailto:info@welfare.ie)

Website: [www.welfare.ie](http://www.welfare.ie)

If you have queries about health and social services, contact the HSE office in your area. **HSE infoline:** 1850 24 1850 **Email:** [info@hse.ie](mailto:info@hse.ie)

**Website:** [www.hse.ie](http://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](mailto:information@citizensinformation.ie)

Website: [www.citizensinformation.ie](http://www.citizensinformation.ie)



### If you have financial worries...



A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, like 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.

There is help available if you find it hard to cope with all these expenses. Contact the medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your child's illness. See page 50 for more details. You can also call the Cancer Nurseline Freehone 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on 0761 07 2000 or visit [www.mabs.ie](http://www.mabs.ie). This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 52 for contact details.



## 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 Freephone 1800 200 700
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support
- Night nursing
- Publications and website information

**Our 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 Thursday 9am to 6pm and Friday 9am to 5pm. You can also email us on [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie) or visit our online community at [www.cancer.ie](http://www.cancer.ie)

**Our 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 affected by cancer.

**Our Survivor Support.** In the case of adults, speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

**Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling.

**Patient travel and financial support.** We provide practical and financial support for patients in need, who are undergoing cancer treatments. There are three services available 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.

- Through our **Financial Support** programme, limited financial support is available to patients identified as being in need, who are undergoing cancer treatments nationally. This includes children. A total of three applications can be assessed over the course of a 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. The medical social worker in your child's hospital will apply on behalf of your family, if eligible.
- **Irish Cancer Society Volunteer Driver Service** is mainly for adult patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments. This service is currently not available to child patients and their parents.

To access any of these services, please contact your hospital healthcare professional.

**Irish Cancer Society Night Nursing.** We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. This includes children, if a nurse is available. 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.

**Our 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](http://www.cancer.ie) or call the Cancer Nurseline for a free copy of our publications.



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

## Useful organisations and websites

### Irish Cancer Society

43/45 Northumberland Road  
Dublin 4  
Tel: 01 231 0500  
Cancer Nurseline Freephone: 1800 200 700  
Email: [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)  
Website: [www.cancer.ie](http://www.cancer.ie)

### Children's Cancer and Leukaemia Group (CCLG)

University of Leicester  
Clinical Sciences Building  
Leicester Royal Infirmary  
Leicester LE2 7LX  
United Kingdom  
Tel: 0044 116 252 5858  
Email: [info@cclg.org.uk](mailto:info@cclg.org.uk)  
Website: [www.cclg.org.uk](http://www.cclg.org.uk)

### 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.

Childhood Cancer Foundation  
7 Keypoint  
Rosemount Business Park  
Ballycoolin  
Dublin 11  
Email: [info@childhoodcancer.ie](mailto:info@childhoodcancer.ie)  
Website: [www.childhoodcancer.ie](http://www.childhoodcancer.ie)

### Citizens Information

Tel: 0761 07 4000  
Email: [information@citizensinformation.ie](mailto:information@citizensinformation.ie)  
Website: [www.citizensinformation.ie](http://www.citizensinformation.ie)

### CLIMB®

CLIMB® is a programme developed in the US by the Children's Treehouse Foundation and stands for Children's Lives Include Moments of Bravery. It is a six-session programme aimed at children between the ages of 5 and 12 coping with the cancer diagnosis of a significant person in their lives. It helps normalise their feelings of sadness, anxiety, fear and anger, while improving communication between them

and their parents. The programme is available in eight centres in Ireland.  
Website: [www.childrenstreehousefdn.org](http://www.childrenstreehousefdn.org)

### Money Advice and Budgeting Service (MABS)

Commercial House  
Westend Commercial Village  
Blanchardstown  
Dublin 15  
Tel: 01 812 9350  
Helpline: 0761 07 2000  
Email: [helpline@mabs.ie](mailto:helpline@mabs.ie)  
Website: [www.mabs.ie](http://www.mabs.ie)

### Irish Oncology and Haematology Social Workers Group

Website: [socialworkandcancer.com](http://socialworkandcancer.com)

### Roches Hair Solutions

A dedicated wig and hair loss centre that offers advice and a range of services for adults and children.

Roches Hair Solutions  
153 Kimmage Road Lower  
Dublin 6W  
Tel: 01 492 6829  
Email: [info@roches.ie](mailto:info@roches.ie)  
Website: [www.roches.ie](http://www.roches.ie)

## Help and support in Republic of Ireland

### Aoibheann's Pink Tie

A registered charity that provides practical assistance and support for families in need who have a child with cancer. They take referrals through St John's Ward at Our Lady's Children's Hospital, Crumlin.

Aoibheann's Pink Tie  
Unit 22, Docklands Innovation Centre  
128-130 East Wall Road  
Dublin 3  
Tel: 01 240 1332 / 086 353 3897  
Email: [lindaconnell@aoibheannspinktie.ie](mailto:lindaconnell@aoibheannspinktie.ie)  
Website: [www.aoibheannspinktie.ie](http://www.aoibheannspinktie.ie)

### ARC Cancer Support Centre

Two centres that offer a range of support, counselling and therapy services to adults diagnosed with cancer, to their families, to parents of children with cancer and to friends and carers. This includes the CLIMB® programme. Offsite support for children can be arranged.

### ARC Cancer Support Centre

ARC House  
65 Eccles Street  
Dublin 7  
Tel: 01 830 7333  
Email: [info@arccancersupport.ie](mailto:info@arccancersupport.ie)  
Website: [www.arccancersupport.ie](http://www.arccancersupport.ie)

### ARC Cancer Support Centre

ARC House  
559 South Circular Road  
Dublin 8  
Tel: 01 707 8880  
Email: [info@arccancersupport.ie](mailto:info@arccancersupport.ie)  
Website: [www.arccancersupport.ie](http://www.arccancersupport.ie)

### Arklow Cancer Support Group

A cancer support centre that offers emotional support and practical help to people with cancer and their families and friends. Children are referred offsite and funded by the group.

Arklow Cancer Support Group  
25 Kings Hill  
Arklow  
Co Wicklow  
Tel: 040 223 590 / 085 110 0066  
Email: [info@arklowcancersupport.com](mailto:info@arklowcancersupport.com)  
Website: [www.arklowcancersupport.com](http://www.arklowcancersupport.com)

### Athenry Cancer Care Centre

A holistic cancer support service for people on a cancer journey. Counselling, complementary therapies and financial aid are available to children and parents.

Tel: 091 844 319 / 087 412 8080  
Email: [athenrycancer@care@gmail.com](mailto:athenrycancer@care@gmail.com)  
Website: [www.athenrycancer@care.com](http://www.athenrycancer@care.com)

### Balbriggan Cancer Support Group

A cancer support centre that offers professional services to parents and teenagers onsite. Children under 12 are referred offsite for services.

Tel: 01 841 0116 / 087 353 2872

### Barretstown

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

Barretstown  
Ballymore Eustace  
Kildare  
Tel: 045 864 115  
Email: [info@barretstown.org](mailto:info@barretstown.org)  
Website: [www.barretstown.org](http://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.

The Bubblegum Club  
16 Mellifont Avenue  
Dún Laoghaire  
Co Dublin  
Tel: 01 236 0456 / 086 262 8888  
Email: [info@bubblegumclub.ie](mailto:info@bubblegumclub.ie)  
Website: [www.bubblegumclub.ie](http://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.

BUMBLEance  
The Saoirse Foundation  
Castledrum  
Castlemaine  
Co Kerry  
Website: [www.bumbleance.com](http://www.bumbleance.com)

**Cancer Care West: The West of Ireland Cancer Care Charity**

A centre that provides support to cancer patients and their families from all over the west of Ireland. This includes counselling for children or siblings affected by cancer.

Cancer Care West  
72 Seamus Quirke Road  
Galway  
Tel: 091 540 040  
Email: info@cancercarewest.ie  
Website: www.cancercarewest.ie

**Cancer Support Sanctuary LARCC**

A centre that offers various services such as children's play therapy, which is facilitated by a fully qualified children's play therapist. This includes the CLIMB® programme.

Cancer Support Sanctuary LARCC  
Coole Road  
Multyfarnham  
Mullingar  
Co Westmeath  
Tel: 044 937 1971  
CallSave: 1850 719 719  
Email: info@larcc.ie  
Website: www.larcc.ie

**CanTeen Ireland**

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

CanTeen Ireland  
Carmichael Centre  
North Brunswick Street  
Dublin 7  
Tel: 01 872 2012  
Email: info@canteen.ie  
Website: www.canteen.ie

**CARE Cancer Support Centre**

A centre that provides emotional support and practical help to those who have or have had cancer and their carers. Services include emotional support, information, counselling, support groups, complementary therapies, yoga, tai chi and art classes. All services are free of charge.

CARE Cancer Support Centre  
14 Wellington Street  
Clonmel  
Co Tipperary  
Tel: 052 618 2667  
Email: caresupport@eircom.net  
Website: www.cancercare.ie

**Children in Hospital Ireland (formerly Yoobyoo)**

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.

Children in Hospital Ireland  
Suite 415  
1-3 Burton Hall Road  
Sandyford  
Dublin 18  
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.

Children's Leukaemia Association  
9 Dyke Parade  
Cork  
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.

Cliona's Foundation  
Unit B3, Eastway Business Park  
Ballysimon Road  
Limerick  
Tel: 061 400 640  
Email: info@clionasfoundation.com  
Website: clionasfoundation.com

**Cork ARC Cancer Support House**

A holistic centre that provides emotional support and practical help to those with cancer and their families. This includes the CLIMB® programme. Open to adults diagnosed with cancer, parents of children with cancer, and adult family members and friends.

Cork ARC Cancer Support House  
Cliffdale  
5 O'Donovan Rossa Road  
Cork  
Tel: 021 427 6688  
Email: info@corkcancersupport.ie  
Website: www.corkcancersupport.ie

**Cuan Cancer Social and Wellness Group**

A group that provides services to parents and family members affected by cancer. This includes the CLIMB® programme.

Cuan Cancer Social and Wellness Group  
2nd Floor, Cootehill Credit Union  
Market Street  
Cootehill  
Co Cavan  
Tel: 086 455 6632  
Email: kermullen@gmail.com

**Cuisle Cancer Support Centre**

A centre that offers various services such as play therapy for children with cancer and for children whose parents have cancer. This includes the CLIMB® programme.

Cuisle Cancer Support Centre  
Block Road  
Portlaoise  
Co. Laois  
Tel: 057 868 1492  
Email: cuislecentre@eircom.net  
Website: www.cuislecentre.com

**Dóchas: Offaly Cancer Support Group**

A support group that provides a holistic cancer support service to adults affected by cancer throughout the Midlands. It offers a range of supports and services, from Reiki and reflexology to creative writing and art classes.

Dóchas: Offaly Cancer Support Group  
Teach Dóchas

Offaly Street  
Tullamore  
Co Offaly  
Tel: 057 932 8268  
Email: info@dochasoffaly.ie  
Website: www.dochasoffaly.ie

**East Galway & Midlands Cancer Support**

A centre that offers a wide range of programmes and services to anyone affected by cancer. It includes play and art therapies for children.

East Galway & Midlands Cancer Support  
Bracknagh  
Ballinasloe  
Co Galway  
Tel: 090 964 2088 / 087 984 0304  
Email: info@egmcancersupport.com  
Website: www.egmcancersupport.com

**Éist: Carlow Cancer Support Group**

A centre of reflection, retreat and recovery. It offers psychological, emotional and practical support to those with cancer and their families and carers. Services for children and teens are provided, which includes the CLIMB® programme. Services for parents include professional counselling and complementary therapies.

Éist: Carlow Cancer Support Group  
Waterfront, Mill Lane  
Carlow  
Tel: 059 913 9684  
Email: info@eistcarlowcancersupport.ie  
Website: www.eistcarlowcancersupport.ie

**Gary Kelly Cancer Support Centre**

A centre that offers a supportive environment for people affected by cancer. It provides counselling, education, information and support, and holistic and complementary therapies to cancer patients and their families. Services for children and teenagers are delivered offsite.

Gary Kelly Cancer Support Centre  
George's Street  
Drogheda  
Co Louth  
Tel: 041 9805 100 / 086 8172473  
Email: info@gkcancersupport.com  
Website: www.gkcancersupport.com

**Greystones Cancer Support Group**

A group that offers practical help to families with a child diagnosed with cancer. It includes meal provision, transport, house cleaning and funding for respite trips. Counselling is available to parents.

Greystones Cancer Support Group  
La Touche Place  
Greystones  
Co Wicklow  
Tel: 01 287 1601  
Email: info@greystonescancersupport.com  
Website: www.greystonescancersupport.com

**Hand in Hand**

A national support service that provides practical support for families of children with cancer. This includes the CLIMB® programme.

Hand in Hand  
Oranmore Business Park  
Oranmore  
Co Galway  
Tel: 091 799 759  
Mobile: 087 660 0103  
Email: info@handinhand.ie  
Website: www.handinhand.ie

**Hope Cancer Support Centre**

A centre that provides emotional support to people affected by cancer, including carers. Free services for children are offsite. Counselling and complementary therapies are available for parents.

Hope Cancer Support Centre  
22 Weafer Street  
Enniscorthy  
Co Wexford  
Tel: 053 923 8555  
Email: info@hopesupportcentre.ie  
Website: www.hopesupportcentre.ie

**Julie Wren Trust**

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

**Julie Wren Trust**

c/o Our Lady's Children's Hospital  
Crumlin  
Dublin 12  
Tel: 01 409 6300 / 087 968 7469  
Email: juliewrentrust@gmail.com  
Website: www.cmrf.org

**Make-A-Wish Ireland**

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

Make-A-Wish Ireland  
2 Leopardstown Business Centre  
Ballyogan Avenue  
Leopardstown  
Dublin 18  
Tel: 01 205 2007  
Email: info@makeawish.ie  
Website: www.makeawish.ie

**Mayo Cancer Support Association**

A centre that provides professional counselling onsite to those diagnosed with cancer of all ages. The CLIMB® programme is available for children. Complementary therapies, life coaching and stress management are also available to adults.

Mayo Cancer Support Association  
Rock Rose House, 32 St Patrick's Avenue  
Castlebar  
Co Mayo  
Tel: 094 903 8407  
Email: info@mayocancer.ie  
Website: www.mayocancer.ie

**Purple House Cancer Support**

A centre with outreach that provides a range of support services for children and young adults, including counselling, arts and crafts, and social outings. Parents can also avail of some services.

Purple House Cancer Support  
36 Main Street  
Bray  
Co Wicklow  
Tel: 01 286 6966  
Website: www.braycancersupport.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 Our Lady's Children's Hospital, Crumlin.

The Ronald McDonald House  
Our Lady's Children's Hospital  
Crumlin  
Dublin 12  
Tel: 01 456 0435  
Email: ronaldhouse@rmhc.ie  
Website: www.rmhc.ie

**The Solas Centre**

A centre that offers people with cancer and their families support, counselling, holistic therapies and healing workshops in a caring and tranquil environment. The centre also offers services for children and young adults.

The Solas Centre  
44 Wine Street  
Sligo  
Tel: 071 917 0399  
Email: scsc@eircom.net  
Website: www.sligocancersupportcentre.ie

**South Eastern Cancer Foundation: The Solas Centre**

A centre that offers support services to cancer patients, their families and their carers. The centre offers art psychotherapy for children and one-to-one support.

South Eastern Cancer Foundation:  
The Solas Centre  
Williamstown  
Co Waterford  
Tel: 051 304 604  
Email: info@solascentre.ie  
Website: www.solascentre.ie

**Tuam Cancer Care Centre**

A centre that provides many services to parents and family members affected by cancer. This includes the CLIMB® programme.

**Tuam Cancer Care Centre**

Cricket Court  
Dunmore Road  
Tuam  
Co Galway  
Tel: 093 28522  
Email: support@tuamcancercare.ie  
Website: www.tuamcancercare.ie

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

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

**Beads of Courage**

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

**Children's Treehouse Foundation**

www.childrenstreehousefdn.org

**CLIC Sargent for Children with Cancer**

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

**Headstrong**

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

www.headstrong.ie  
www.jigsaw.ie

**healthtalkonline.org  
youthhealthtalk.org**

Websites that contain information about cancer, and have video and audioclips of people talking about their experiences.  
youthhealthtalk.org [for young people]  
healthtalkonline.org

**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 well-being 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](http://www.teenagecancertrust.org)

**TYAC (Teenagers and Young Adults with Cancer)**

Information and support for teenagers and young adults with cancer.  
[www.tyac.org.uk](http://www.tyac.org.uk)

**2bMe**

For teenagers dealing with social and physical issues of being treated for cancer.  
<http://lookgoodfeelbetter.org/2bMe/2bMe.html>

**Useful contacts outside Republic of Ireland****Action Cancer**

Action Cancer House  
 1 Marlborough Park  
 Belfast BT9 6XS  
 Tel: 028 9080 3344  
 Email: [info@actioncancer.org](mailto:info@actioncancer.org)  
 Website: [www.actioncancer.org](http://www.actioncancer.org)

**The Brain Tumour Charity**

Hartshead House  
 61-65 Victoria Road  
 Farnborough GU14 7PA  
 Tel: 0044 808 800 0004  
 Email: [support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org)  
 Website: [www.thebraintumourcharity.org](http://www.thebraintumourcharity.org)

**Cancer Focus Northern Ireland**

40-44 Eglantine Avenue  
 Belfast BT9 6DX  
 Tel: 048 9066 3281  
 Email: [hello@cancerfocusni.org](mailto:hello@cancerfocusni.org)  
 Website: [www.cancerfocusni.org](http://www.cancerfocusni.org)

**Cancer Research UK**

Tel: 0044 20 7242 0200  
 Website: [www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)

**Children's Cancer and Leukaemia Group (CCLG)**

3rd Floor, Hearts of Oak House  
 9 Princess Road West  
 Leicester LE1 6TH  
 United Kingdom  
 Tel: 0044 116 249 4460  
 Email: [info@cclg.org.uk](mailto:info@cclg.org.uk)  
 Website: [www.cclg.org.uk](http://www.cclg.org.uk)

**CLIC Sargent: Caring for Children with Cancer**

Horatio House  
 77-85 Fulham Palace Road  
 London W6 8JA  
 Helpline: 0044 300 330 0803  
 Email: [info@clicsargent.org.uk](mailto:info@clicsargent.org.uk)  
 Website: [www.clicsargent.org.uk](http://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 Northern Ireland Cancer Fund for Children (NICFC). Open to children and their families from Republic of Ireland.

NICFC Daisy Lodge  
 124A Bryansford Road  
 Newcastle  
 Co Down  
 Tel: 028 4372 4212  
 Email: [daisylodge@nicfc.com](mailto:daisylodge@nicfc.com)  
 Website: [cancerfundforchildren.com](http://cancerfundforchildren.com)

**Leukaemia & Lymphoma Research**

39-40 Eagle Street  
 London WC1R 4TH  
 Tel: 0044 20 7405 0101  
 Email: [info@beatingbloodcancers.org.uk](mailto:info@beatingbloodcancers.org.uk)  
 Website: [www.beatbloodcancers.org](http://www.beatbloodcancers.org)

**Lymphoma Association (UK)**

PO Box 386  
 Aylesbury HP20 2GA  
 Helpline: 0044 0808 808 5555  
 Email: [information@lymphomas.org.uk](mailto:information@lymphomas.org.uk)  
 Website: [www.lymphomas.org.uk](http://www.lymphomas.org.uk)

**Macmillan Cancer Support (UK)**

Tel: 0044 20 7840 7840  
 Email: [cancerline@macmillan.org.uk](mailto:cancerline@macmillan.org.uk)  
 Website: [www.macmillan.org.uk](http://www.macmillan.org.uk)

**Macmillan Support & Information Centre**

Belfast City Hospital Trust  
 77-81 Lisburn Road  
 Belfast BT9 7AB  
 Tel: 028 9069 9202  
 Email: [cancerinfo@belfasttrust.hscni.net](mailto:cancerinfo@belfasttrust.hscni.net)

**National Cancer Institute (US)**

Website: [www.nci.nih.gov](http://www.nci.nih.gov)

**Neuroblastoma Society**

Helpline: 0044 20 8940 4353  
 Email: [info@neuroblastoma.co.uk](mailto:info@neuroblastoma.co.uk)  
 Website: [www.nsoc.co.uk](http://www.nsoc.co.uk)

**Northern Ireland Cancer Fund for Children**

Curlew Pavilion  
 Portside Business Park  
 Airport Road West  
 Belfast BT3 9ED  
 Tel: 028 9080 5599  
 Email: [info@cancerfundforchildren.com](mailto:info@cancerfundforchildren.com)  
 Website: [www.cancerfundforchildren.com](http://www.cancerfundforchildren.com)

**Sarcoma UK**

49-51 East Road  
 London N1 6AH  
 Tel: 0044 20 7250 8271  
 Email: [info@sarcoma.org.uk](mailto:info@sarcoma.org.uk)  
 Website: [www.sarcoma.org.uk](http://www.sarcoma.org.uk)

**About the Children's Cancer and Leukaemia Group (CCLG)**

The CLLG 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. Each week in the UK and Ireland, more than 30 children are diagnosed. Two out of 10 children will not survive their disease.

The CLLG 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 expert, high-quality and award-winning information resources.

**Publications**

CCLG produces an extensive range of accredited award-winning information resources for families (see [www.cclg.org.uk](http://www.cclg.org.uk) for a full list or to download publications) including *Contact* magazine – a free quarterly magazine featuring both information articles and personal stories.

**Principal Treatment Centres**

Its members who work in the network of principal treatment centres 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:** All CCLG publications are free to patients and their families. They provide many booklets and factsheets ranging from different types of children's cancers, treatments and managing symptoms to follow-up and advice for family members. For copies, call 0044 116 249 4460 or email: [info@cclg.org.uk](mailto:info@cclg.org.uk) or download from their website at [www.cclg.org.uk](http://www.cclg.org.uk)

**CLIC Sargent:** CLIC Sargent is the UK's leading cancer charity for children and young people and their families. They publish a wide range of books and online information for children, parents and families. Visit [www.clicsargent.org.uk](http://www.clicsargent.org.uk)

**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](http://www.winstonswish.org.uk)

### Books and leaflets from CCLG

- Aftercure: a guide for teenage and young adult survivors of cancer (2014)
- A guide to clinical trials: for parents and young people (2012)
- All you need to know about research: for teens and young adults who are undergoing treatment for cancer (2013)
- Autologous haematopoietic peripheral blood stem cell (PBSC) harvesting and transplantation: for young people and their families (2014)
- Brain and spinal tumours in children and young people: a parent's guide (2008)
- Children and young people with cancer: a parent's guide (2014)
- Donating your child's tissue for research (2013)
- Donating your stem cells to your brother or sister (2010)
- End of treatment: what happens next?: a guide for parents (2007)

- Family life and cancer: a guide for parents of a younger child with cancer (2012)
- Grandparents: a guide for grandparents of children and young people with cancer (2013)
- Guide to radiotherapy (2015) [for teens]
- Helping brothers and sisters (2013)
- Helping your child to eat: a practical guide for parents, carers and children coping with cancer (2010)
- How can the internet help us? (2014)
- I have a friend who has cancer (2014)
- My child has finished treatment (2014)
- Sport and exercise for children and young people with cancer: a parent's guide (2011)
- Welcome back!: a guide for teachers helping children and young people returning to school after a diagnosis of cancer (2015)
- When your brother or sister has cancer (2014)

### Storybooks from CCLG

- Ben's stem cell transplant (2015)
- Jess's bone marrow donation (2014)
- My brother or sister has cancer (2013)
- Ruby's stem cell journey (2014)
- Sam and Lucy visit the dentist (2013)
- Will and Sophie have radiotherapy (2013)

### Booklets, leaflets and DVDs from CLIC Sargent

- A long way from home: the impact of travel on children and young people with cancer (2010)
- Back to school DVD (2014)
- Cancer and school life (2014)
- Chemotherapy, cakes and cancer (2013) [for teenagers]
- What now?: a guide for parents and carers (2012)

### Storybooks from CLIC Sargent

- Joe has leukaemia (2012)
- Lucy has a tumour (2012)
- Mary has a brain tumour (2012)
- Tom has lymphoma (2013)

### Books from Royal Marsden Hospital

- Pupils with cancer: A guide for teachers (2008)

### Booklets and information from Our Lady's Children's Hospital, Crumlin

- Chemotherapy: what is it? A colouring book for children who are receiving chemotherapy
- Passport: information for parents
- Helping hand: a guide for parents of children with a brain tumour

### Booklets from Irish Cancer Society

- Managing the financial impact of cancer: a guide for patients and their families (2014)



## Medical terms explained

Doctors may use unfamiliar words that you don't understand. Here are some of the most common ones explained in alphabetical order. 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.

<b>Acute</b>	Occurring suddenly over a short period of time.
<b>Alopecia</b>	Hair loss.
<b>Anaemia</b>	A reduced number of red blood cells.
<b>Anaesthetic</b>	Drugs that put your child to sleep (general anaesthetic) or that numb a part of their body (local anaesthetic).
<b>Antibodies</b>	Proteins created by the immune system when exposed to foreign proteins such as viruses and bacteria.
<b>Audiogram</b>	A hearing test. Your child wears headphones and responds to various volumes and tones. The test is not painful.
<b>Benign</b>	A tumour or growth that is not cancerous but may still cause problems.
<b>Biopsy</b>	A small sample of tissue taken from the body to make a diagnosis.
<b>Blood count</b>	A blood test to check the number of different cells in the blood. Sometimes it is called a full blood count or FBC.
<b>Bone marrow</b>	The spongy material in the centre of large bones in the body, which makes blood cells.
<b>Bone marrow aspirate/biopsy</b>	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.
<b>Bone scan</b>	A test that can show if cancer is present in bones using a radioactive dye.
<b>Cannula</b>	A short plastic tube put into a vein to deliver medication, fluids or a transfusion.
<b>Cardio-</b>	To do with the heart.

<b>Catheter</b>	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, i.e. Hickman line.
<b>Cerebrospinal fluid (CSF)</b>	Fluid made in the brain that surrounds the brain and spinal cord.
<b>Chemotherapy</b>	Drug treatment that kills cancer cells.
<b>Chromosome</b>	Structure in the nucleus of the cell that contains the genetic make-up of the cell.
<b>Chronic</b>	A condition that lasts for a long time.
<b>CNS</b>	Central nervous system. It refers to the brain and spinal cord.
<b>Congenital</b>	Any condition existing at birth.
<b>CT scan</b>	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.
<b>Cyto-</b>	To do with cells.
<b>Cytogenetics</b>	The study of chromosomes in cells.
<b>Dysfunctional</b>	Something not working properly.
<b>ECG</b>	Electrocardiogram. This tests the electrical activity of the heart muscle. Electrical sensors are placed on your child's chest for the test.
<b>ECHO</b>	Echocardiogram. This is an ultrasound scan of the heart. It checks how well the heart is working.
<b>EEG</b>	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.
<b>Electrolytes</b>	The minerals and salts in the body. For example, sodium, potassium and calcium.
<b>Endocrine</b>	To do with hormones.
<b>Excision</b>	Cutting out.
<b>GCSF</b>	A growth factor called granulocyte colony-stimulating factor. This protein boosts the bone marrow making white blood cells, usually neutrophils.
<b>Genetic</b>	A condition caused by abnormal genes (may be inherited).

<b>GFR</b>	Glomerular filtration rate is a test that shows how well the kidneys are working.
<b>Haematology</b>	The study of blood and blood disorders.
<b>Haemoglobin</b>	The substance in red blood cells that carries oxygen around the body.
<b>Histopathology</b>	The study of body tissues.
<b>Hormone</b>	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.
<b>Immune system</b>	The body's defence against infection, disease and foreign substances.
<b>Immunology</b>	The study of the body's immune system, which fights infection.
<b>Immunophenotyping</b>	A test to identify particular proteins in the cells to help find out which type of cell has become cancerous.
<b>Immunosuppressive</b>	Lowering the body's ability to fight infection.
<b>Intramuscular (IM)</b>	Into a muscle.
<b>Intrathecal (IT)</b>	Into the spine, usually by lumbar puncture. See also lumbar puncture.
<b>Intravenous (IV)</b>	Into a vein.
<b>Lumbar puncture (LP)</b>	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.
<b>Lymph</b>	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.
<b>Lymphatic system</b>	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.
<b>Lymph nodes</b>	Small bean-shaped structures found along vessels in the lymphatic system. They become enlarged due to infection or cancer.

<b>Lymphocyte</b>	A type of white blood cell that fights infection.	<b>PRN</b>	Medicines to take when required.
<b>Malignant</b>	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.	<b>Prognosis</b>	The expected outcome of a disease and its treatment.
<b>Metastases</b>	Tumours that have spread from the first (primary) tumour into another part of the body. Also known as secondary tumours.	<b>Prosthesis</b>	An artificial replacement of something – for example, a bone.
<b>MIBG scan</b>	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.	<b>Pulmonary</b>	To do with the lungs.
<b>Microbiology</b>	The study of germs.	<b>Pulmonary</b>	Tests that measure how well the lungs take in and
<b>MRI scan</b>	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.	<b>function tests</b>	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.
<b>Nausea</b>	Feeling sick.	<b>Radiotherapy</b>	The use of high-energy X-rays to destroy cancer cells.
<b>Neuro-</b>	To do with the nerves or the nervous system.	<b>Red blood cell</b>	Blood cells that carry oxygen around the body. The part that contains iron called haemoglobin gives blood its red colour.
<b>Neutropenia or neutropenic</b>	Low levels of neutrophils.	<b>Refractory</b>	Resistant to treatment.
<b>Neutrophils</b>	White blood cells that fight infection.	<b>Relapse</b>	The return of a disease after previous treatment.
<b>Oedema</b>	Swelling caused by fluid.	<b>Remission</b>	There is no evidence of the disease being present, using the available tests.
<b>Oncology</b>	The study and treatment of cancer.	<b>Renal</b>	To do with the kidneys.
<b>Ophthalmology</b>	The study of the eyes.	<b>Sarcoma</b>	A tumour that forms in bone, muscles, fat or cartilage cells.
<b>Oral</b>	To do with the mouth.	<b>Stem cell</b>	Early, immature blood cell from which other blood cells are made.
<b>Osteo-</b>	To do with bones.	<b>Subcutaneous (SC)</b>	Under the skin.
<b>Paediatric</b>	To do with children.	<b>Therapy</b>	Treatment.
<b>Palliative</b>	Relief of a symptom (for example, pain) rather than cure of the disease.	<b>Thrombocytopenia</b>	Low levels of platelets in the blood leading to bruising and bleeding.
<b>PET scan</b>	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. After the injection, your child rests for an hour to allow the substance to spread through the body.	<b>TPN</b>	Total parenteral nutrition. Giving nutrients into a vein when a child is unable to take food in the normal way.
<b>Platelet</b>	A type of blood cell that helps the blood to clot.	<b>Ultrasound</b>	A test that uses sound waves to examine the tissues inside the body.
		<b>White blood cells</b>	Blood cells that defend the body against infection.

## 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-effect?
- 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?

## Your own questions

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Answer \_\_\_\_\_

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2 \_\_\_\_\_

Answer \_\_\_\_\_

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Answer \_\_\_\_\_

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4 \_\_\_\_\_

Answer \_\_\_\_\_

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5 \_\_\_\_\_

Answer \_\_\_\_\_

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6 \_\_\_\_\_

Answer \_\_\_\_\_

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## Notes

Large light green area for taking notes.



## Acknowledgements

We would like to extend a special word of thanks to the following for their invaluable contributions to this booklet:

Gráinne Dowdall, Child Health Information Centre Coordinator

Maura Toner, Parent and volunteer member of Childhood Cancer Foundation

Áine Richards, Parent and volunteer member of Childhood Cancer Foundation

## Would you like more information?

We hope this booklet has been of help to you. After reading it or at any time in the future, if you feel you would like more information or someone to talk to, please call the Cancer Nurseline Freephone 1800 200 700.

### Would you like to be a patient reviewer?



If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.

If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at **reviewers@irishcancer.ie**

If you would prefer to phone or write to us, see contact details below.

## Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, research and education. This includes patient information booklets. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us at CallSave 1850 60 60 60 or email: **fundraising@irishcancer.ie**

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Friday 9am to 5pm

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