

CHILDHOOD CANCER

# Diagnosis & treatment

A practical guide for parents and families

Edition 2

*Childhood cancer: Diagnosis & treatment*  
*A practical guide for parents and families*  
Edition 2

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This booklet is the first in a two-part childhood cancer series.  
The other booklet available in this series is:

*Childhood cancer: Coming off treatment & survivorship*  
*A practical guide for parents and families*

This series is available at [www.vics.org.au/pics](http://www.vics.org.au/pics)



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*Children with Cancer: A Guide for Parents*, National Cancer Institute

*Young People with Cancer: A Handbook for Parents*, National Cancer Institute

MacMillan Cancer Support [www.macmillan.org.uk](http://www.macmillan.org.uk)

Cancer Council Australia [www.cancer.org.au](http://www.cancer.org.au)

American Cancer Society [www.cancer.org](http://www.cancer.org)

## THE CHILDHOOD CANCER SERIES

**This two-part childhood cancer series aims to provide reliable information, suggestions and advice to parents and families of children and adolescents affected by childhood cancer.**

*Diagnosis & treatment* is the first booklet in this series. This booklet has been developed to provide you and your family with practical advice that may be useful during your child's cancer treatment. The booklet has five parts:

- **Part 1: Diagnosis**
- **Part 2: Treatment**
- **Part 3: Looking after your child during treatment**
- **Part 4: Looking after you and your family**
- **Part 5: A to Z of cancer diagnosis, treatment and the treating team**

(words appearing in **bold** throughout the booklet can be found in this section)

People have different levels of understanding of health- and medical-related terms. If you are finding information in this booklet difficult to understand you can talk to your child's treating team.

For families who speak a language other than English, the hospital can organise interpreters.

# Contents

Introduction .....	4
<b>Part 1: Diagnosis .....</b>	<b>5</b>
About childhood cancer .....	6
The diagnosis phase .....	7
Talking to your child about cancer .....	9
What questions might my child ask? .....	12
<b>Part 2: Treatment .....</b>	<b>14</b>
About treatment .....	15
Clinical trials .....	20
Fertility .....	24
Your child's treating team .....	24
<b>Part 3: Looking after your child during treatment. ....</b>	<b>28</b>
When to call the hospital. ....	29
Managing low blood counts. ....	30
Managing fever or infection .....	31
Managing medications .....	39
Managing procedures .....	43
Managing pain .....	45
Managing mouth and dental care. ....	47
Eating well during treatment .....	50
Managing nausea and vomiting. ....	52
Managing diarrhoea .....	53
Managing constipation .....	54
Managing dehydration. ....	54
Managing physical changes during treatment. ....	55
Managing fatigue during treatment .....	60
Helping your child remain physically active during treatment. ....	61
Helping your child remain engaged with school. ....	61
Managing sun and skin care .....	64
Late effects of treatment. ....	65
<b>Part 4: Looking after you and your family .....</b>	<b>66</b>
Your relationships .....	67
Your feelings and emotions. ....	73
Your work .....	75
Your social life .....	75
<b>Part 5: A to Z of cancer diagnosis, treatment and the treating team. ....</b>	<b>76</b>
Useful websites .....	88
Notes .....	89

## Introduction

**You have received this booklet because your child, or a child who you care for, has recently been diagnosed with cancer. The first thing doctors need to do is diagnose what type of cancer your child has and where the cancer is located (Part 1). Once doctors know what type of cancer your child has, a treatment plan will be decided and your child will begin treatment (Part 2).**

With a **diagnosis** of cancer, there are lots of things for you to think about. This booklet includes information to help you look after your child during treatment, including information on when to call the hospital, supporting your child through treatment and managing side effects of treatment (Part 3).

A diagnosis of childhood cancer in the family can be an overwhelming time and raises many questions. When a child is diagnosed with cancer, most families feel shock and disbelief. The treatment ahead may seem frightening. Many families talk about this experience as 'an emotional rollercoaster'. This booklet includes information to support you to look after yourself and your family (Part 4).

Finally, there is an A to Z explanation of diagnosis and treatment, medical terms and an explanation of the roles of staff who may be involved in your child's care (Part 5).

## PART 1: Diagnosis

**This section explains what cancer is, how cancer is diagnosed, the importance of cancer staging, some of the tests and procedures your child may need and how to talk to your child about cancer.**

# About childhood cancer

## WHAT IS CANCER?

To understand what cancer is, you need to understand how cells work. Cells are the basic building blocks that make up all of the tissues and organs in our body. Normally, cells in our body work in a controlled way; they divide and form new cells to replace the old or damaged cells. This is how our body grows, heals and repairs. When a person is suffering from cancer, cells start to multiply in an uncontrolled way.

An abnormal group of cells is called a **tumour**. A **primary tumour** is the first tumour that occurs in the body. When these cells spread to other parts of the body, this is called a **secondary tumour** or **metastasis**. Tumours can be **benign** (non-cancerous) or **malignant** (cancerous). The table below shows the differences between benign and malignant tumours.

BENIGN TUMOURS	MALIGNANT TUMOURS
Not cancer	Cancer
Often slow-growing	Often fast-growing
Can be removed and in most cases do not return	Have abnormal cells that divide without control
Do not spread to other parts of the body	Can invade and damage nearby tissues and organs
Not usually life-threatening	Can spread by entering the bloodstream or <b>lymphatic system</b>

## WHAT ARE CHILDHOOD CANCERS?

Cancer in children is different from cancer in adults. Cancer in children:

- is rare
- can develop suddenly without early symptoms
- usually occurs in different parts of the body compared with adult cancers
- responds better to treatment
- has a higher cure rate than adult cancers.

Childhood cancers are usually classified into **leukaemias**, **solid tumours** and **central nervous system tumours**. Your child's treating team will provide you with information specific to your child's cancer.

Over the past few decades, cure rates for childhood cancer have drastically improved. This is due to the availability of better diagnostic techniques and treatments, a strengthened **multidisciplinary** team approach, improvements in supportive care, and the outcomes from research and clinical trials.

## WHAT CAUSES CHILDHOOD CANCERS?

In most cases, we don't know why children get cancer, but researchers are working to find the causes. The causes of many adult cancers, such as smoking and other lifestyle factors, do not cause childhood cancer. Only a small number of cancers develop from a risk inherited from the child's parents. We do know that cancer is not **contagious**, and it is extremely rare for a second child in the same family to develop cancer. Sometimes two or three children at the same school or in the same town develop cancer, but no evidence has been discovered to suggest it is more than a coincidence, despite decades of paediatric cancer research.

Many parents are concerned about the cause of their child's cancer. Parents may feel responsible, even though they could not have prevented the cancer. These feelings may be upsetting. If you have thoughts or worries about what may have caused your child's cancer, please talk to your child's treating team.

# The diagnosis phase

## HOW IS CANCER DIAGNOSED?

Different tests or procedures are needed to find out if there are cancer cells present and to assess your child's general health. Depending on your child's symptoms, they may in some cases take weeks to complete. It is important for your child's treating team to get as much information about your child's cancer as possible so that the right treatment can be given. This booklet explains most of these tests and treatments.

## WHAT IS CANCER STAGING?

After your child's cancer is diagnosed, the cancer is staged. Cancer **staging** is the process used to work out how much cancer is in the body and where it is located. The cancer stage is important for planning treatment. Staging is also determined by other factors such as genetics, age and response to treatment. Different tests are used to determine how complex the cancer is based on the size and/or extent of the primary tumour and whether the cancer has spread in the body. If your child has leukaemia, the staging process is called '**risk stratification**'. If your child has a CNS tumour it may also be called '**grading**'.

### Important questions to ask your child's treating team about your child's DIAGNOSIS:

- What kind of cancer does my child have?
- What is the stage of the cancer?

## TESTS AND PROCEDURES DURING THE DIAGNOSIS PHASE

Tests and procedures help diagnose your child's cancer. Some of these tests and procedures may need to be done with sedation or **general anaesthesia**. Many of these tests may be done in the **medical imaging department**. Your child may have many of the tests listed here and some that are not listed. It is important to remember that not all children will have the same tests and some tests may be undertaken all the way through treatment. Your child's treating team will give you more information before your child has any of these tests or procedures.

Some of the tests and procedures used to make a diagnosis may include:

- **biopsy**
- **blood test**
- **BMA – bone marrow aspiration**
- **bone scan**
- **CT scan – computed tomography scan**
- **gallium scan**
- **LP – lumbar puncture**
- **MRI scan – magnetic resonance imaging**
- **PET scan – positron emission tomography**

- **ultrasound**
- **x-ray.**

### Important questions to ask about TESTS AND PROCEDURES during the diagnosis phase:

- Why is it being done?
- What will it feel like and will it be painful?
- What are the potential risks?
- How often will it be done?
- What can I do to help my child be as comfortable as possible during the test or procedure?
- When should I expect the results?
- Will any more tests or procedures be needed?

## Talking to your child about cancer

One of your first questions after your child has been diagnosed with cancer may be 'How do I tell my child about the cancer?' You may want to protect them, but children usually know when something is different in the family. Your child may not be feeling well, may be seeing doctors often, and may have already had some tests and procedures. They may also notice that you are upset and afraid. Every family is different and will handle a diagnosis of cancer in their own way. The following section provides general advice that may help you talk to your child about their cancer.

### WHY SHOULD I TELL MY CHILD?

Telling your child about his or her cancer is a personal matter, and family, cultural or religious beliefs may come into play. Telling children the truth about their cancer diagnosis and having an open discussion about what this means for them, shows the child that you respect their capacity to understand and to take in and think about this information. This type of communication builds trust between you, your child and your child's clinical team. It enables your child to begin to process what is happening to them. It is important to be as open and honest as you can. Children who are not told about their illness may imagine things that are not true. For example, a child may think they have cancer as a punishment. Telling children the truth about their illness may help them to adapt better emotionally and may

also help them to cooperate with treatment. Where possible use words that accurately reflect your child's illness. For example, using words such as 'cancer' or 'tumour' rather than avoiding these terms is likely to be most helpful to your child. Talking about cancer often helps families share their thoughts and feelings and may make dealing with the cancer a little easier.

### **WHEN SHOULD I TELL MY CHILD?**

You will be the best judge of your child's coping style and personal traits, so you are the best person to decide when they should be told they have cancer. Remember they are likely to know early on that something is wrong, so you may want to have a conversation soon after their diagnosis and before the treatment begins. It is sometimes a good idea to have a member of your child's treating team there when you have this talk – they will be able to answer any questions or concerns.

### **WHO SHOULD TELL MY CHILD?**

Some parents and family members find the idea of having this conversation difficult, but parents are typically the best people to do this. Thinking about what you are going to say and how you are going to explain the diagnosis beforehand will help you be more confident. It may be helpful to have another family member with you when you talk to your child. Your child's treating team is also available to help you have this conversation with your child.

### **WHO SHOULD BE THERE?**

Your child needs love and support when hearing about their diagnosis. Even if the doctor explains the illness, someone they trust should be there. Having the support of other family members at this time can be very helpful.

### **WHAT SHOULD MY CHILD BE TOLD?**

How much information and the best way to relate this information to your child depends on their age and what they are able to understand. Being gentle, truthful, and checking in with your child is important. This might mean pausing to see if your child wants to talk or asking them directly if they have any questions. The following section describes what most children are likely to understand at different ages. Please remember that this advice is very general, and each child is different.

### **Infants (0–2 years)**

Children this young do not understand cancer. They understand their sensory environment – what they can see, smell, hear, taste and touch. Their biggest concern is what is happening to them right now. They may become upset about being away from their parents. Beyond 12 months old, they think about how things feel and how to control things around them. Very young children may be afraid of medical tests and many cry or become distressed to express their feelings. At around 18 months, children generally develop more language and understand more about what is going on around them, so it is best to be honest. It is generally helpful to be truthful about visits to the hospital and explain procedures that may be uncomfortable or painful. You can tell your child that a procedure may hurt for a minute and that it's okay to cry or be upset. Being honest lets them know you understand and accept their feelings and helps them to trust you.

### **Preschool / early primary school**

Preschoolers are starting to seek independence and are developing many new skills especially with language, physical abilities and toilet training. They will be able to understand more information. It is important to keep providing simple explanations to your child and answer any questions they may have.

These approaches might help when talking with a child in this age group:

- Timing is everything. Many young children respond much better to conversations about procedures close to the event or the day before – this is something you will need to assess with your child.
- Explain that they have a sickness that needs special hospital treatment, and they will sometimes feel sick, and sometimes they will feel OK and be able to play.
- Explain that the treatment is needed so they can get better and play.
- Explain that the illness or treatment is not punishment for something they have said, done or thought.
- Be honest when you explain tests and treatments, and remind them that they are needed to help them get well.
- Use simple words or pictures to explain the illness.

### **Primary school**

Primary school-aged children have more sophisticated thinking and can, for example, understand that taking their medicine is important to help them get better. You can give more details when explaining cancer. For example, you could talk about how the body is made up of different types of cells, all with different jobs, and that the cancer cells get in the way of

the healthy cells doing their job. You can explain that treatment will help get rid of the cancer cells so the healthy cells can do their job properly. They may get confused about medical terms, so it is important to explain things as simply and clearly as possible.

### **Secondary school**

Young people are acquiring a much more complex and abstract view of the world. They may be concerned about how their cancer and treatment will affect their appearance, engagement in sport and social activities and relationships with friends/peers. Young people tend to think of illness in terms of specific symptoms, such as tiredness, and in terms of limits or changes in their everyday activity. Cancer can be explained in much more detail to older children. Be open to ongoing questions and discussion that your child may wish to have. Be prepared that you may not have all of the answers. Try to use words that are used in hospital (e.g. leukaemia, tumour, cancer, mass, growth) so they will not be surprised or worried when people use these words.

### **ADDITIONAL SUPPORT**

If your child has a developmental or learning difficulty it is important to talk with their treating team about additional support they may need. The team can work with you to decide the best way to communicate information to your child.

## **What questions might my child ask?**

Children are naturally curious and may have many questions about their cancer and cancer treatment. Your child is most likely to ask you questions about their illness. Children may begin to ask questions right after their diagnosis or may wait until later. Here are some common questions and some ideas to help you answer them.

### **WHY ME?**

A child, like an adult, will wonder 'Why did I get cancer?' They may feel it is their fault, that somehow they caused the illness. Make it clear that not even doctors know exactly what causes childhood cancer. Neither you nor your child has done anything to cause the cancer. Make sure they understand that cancer is not contagious and that they did not 'catch' it and cannot give it to someone else. If you have other children it is also important to have similar conversations with them.

### **WILL I GET BETTER? WILL I DIE?**

Children may know about family members or friends who have died from cancer. Because of this, children may be afraid to ask if they will get better because they fear the answer will be 'no'. You might want to tell your child that cancer is a serious disease, but that treatment, such as medicine, radiation or an operation, has helped to get rid of cancer in other children, and the doctors and nurses are doing their best to cure the cancer. You may also want to explain how cancer and treatment in children is different from adults. Knowing that caring people, such as family, doctors, nurses and therapists, surround your child and your family may also help them feel more secure.

### **WHAT WILL HAPPEN TO ME?**

When your child is first diagnosed with cancer, many new and often frightening things will happen. While visiting the doctor, hospital or clinic, they may see or play with other children with cancer who may not be feeling well or have lost their hair because of cancer. They may wonder 'Will this happen to me?' However, they may be too frightened to ask questions. It is important to help them talk about any concerns they may have. Explain ahead of time about the cancer, treatment and possible side effects. Discuss what the doctors will do to help if these side effects occur. You can also explain that there are many different types of cancer and that even when two children have the same cancer, what happens to one child will not always happen to the other.

Children should be told about any changes in their treatment schedule or in the type of treatment they receive. This information helps them prepare for visits to the doctor or hospital. You may want to help them keep a calendar that shows the days for doctor visits, treatments or tests. Don't tell younger children about upcoming treatments too far ahead of time if it makes them nervous or anxious.

### **WHY DO I HAVE TO TAKE MEDICINE WHEN I FEEL OKAY?**

With cancer, your child may feel fine most of the time but need to take a lot of medicine. Children do not understand why they have to take medicine when they feel well. You may need to remind them of the reason for taking the medicine in the first place.



## PART 2: Treatment

This section provides information on treatment including the treatment plan and consent, common tests and procedures, types of treatments, clinical trials and the treating team who may look after your child.

### About treatment

After your child's cancer has been diagnosed, their treating team will discuss treatment options with you, and a treatment plan will be agreed. There are three main types of treatment for cancer:

- **chemotherapy** (medication therapy)
- **radiation therapy**
- **surgery.**

Your child may receive one or more of these treatments at different times throughout their care. For a small number of children, a **bone marrow transplant** may be needed as part of treatment. Please remember that not all children will require all types of treatment.

The treatment given to kill the cancer cells also kills some normal healthy cells. When normal cells are damaged or killed, there are side effects. However, normal cells repair themselves quicker than cancer cells, and the side effects are nearly always temporary. The normal cells most often affected by treatment are those that grow fastest. These are in the **bone marrow**, the digestive system, hair, skin and the reproductive system.

### THE TREATMENT PLAN

Treatment will depend on your child's general health, age, type, the stage of the cancer they have (or risk stratification) and their initial response to treatment. Based on this information, doctors will prepare a **treatment plan** for your child that outlines the type of treatment, how often they will receive treatment and how long it will last. The schedule for each treatment, test and procedure will usually be detailed in the plan, often called a **roadmap**. Many parents find it helpful to refer to the roadmap during treatment to know when the next scheduled treatment is and which tests are planned. Each child will receive their own plan, as children may receive different or varied treatments even if they have the same type of cancer. The treatment plan and roadmap may seem complicated at first; however, your child's treating team will explain each step to you.

## INFORMED CONSENT

After your child's doctor discusses the treatment plan with you, you will be asked to give your permission to start treatment. This is called giving **informed consent**. It is important that you understand your child's treatment plan, the risks and benefits of the treatment and what other treatments may be available. When you give informed consent, you are saying that you understand what your child's treating team has explained to you and you agree to start the treatment. Remember that the team will continue to explain all aspects of care to you and that you can always ask questions before any treatment if you are unsure.

If your child is old enough to understand, he or she may be asked to '**assent**' or agree to the treatment plan as well. If your child is a minor (a child under 18 years old), their treating team will help to explain the treatment plan in words that he or she can understand.

Informed consent is a process that continues throughout your child's treatment. When you visit the hospital for appointments and treatment, your child's treating team will discuss the plan of care with you. This is your chance to ask questions to ensure you understand and agree with the plan for treatment.

## TESTS AND PROCEDURES DURING TREATMENT

Tests and procedures occur throughout treatment. Depending on your child's age and ability to stay still, some of these tests and procedures may be done under sedation or general anaesthesia. It is important to remember that not all children will have the same tests and procedures. Your child's treating team will give you more information before your child undertakes any of these tests or procedures. You should also ask your doctor whether any tests and procedures can be done closer to home, especially if you live a long way from the cancer centre.

In addition to the tests and procedures during diagnosis, other tests and procedures during treatment may include:

- **audiogram**
- **central line** insertion (such as an implanted port (Totally Implanted Venous Access Device) or Hickman's line (Tunnelled Cuffed Centrally Inserted Central Catheter (TC-CICC)))
- **ECG – electrocardiogram**
- **echo – echocardiogram**
- **GFR – glomerular filtration rate**

- **Insuflon** insertion
- **intramuscular injections**
- **nasogastric (NG) tube** insertion
- **percutaneous endoscopic gastrostomy (PEG)** insertion
- **pulmonary (lung) function test**.

Adjusting to these new procedures and tests can be upsetting for your child, especially at the start of treatment. Specially trained staff are available to help develop a procedural plan for your child and provide you with information on how best to support them.

## CHEMOTHERAPY

Chemotherapy is the use of medicines to treat cancer. Chemotherapy (also called **cytotoxic** medicines) circulates throughout the body to damage or destroy cancer cells. Because chemotherapy usually works via the bloodstream, it may also affect some normal cells. It is important to understand that the effect on normal cells is usually temporary and that the cells will usually recover after treatment. Your child's treating team will order regular blood tests to find out if your child needs treatment for a low **blood count** and when it is safe to give the next dose of chemotherapy.

There are many different combinations of chemotherapy drugs. Chemotherapy may be used alone or in combination with radiation therapy or surgery.

Chemotherapy can be given in different ways and will depend on your child's type of cancer and which chemotherapy is given:

- orally (by swallowing medications or via a **nasogastric tube**)
- intravenous injection (a needle into a vein or a **central line**)
- intramuscular injection (a needle into the muscle)
- intrathecal injection (a needle into **cerebrospinal fluid** usually in the spine).

Your child's treating team will give you more information on the specific chemotherapy your child needs, how it will be given and any potential side effects.

### Tips for parents: PRECAUTIONS HANDLING BODY WASTE FOLLOWING CHEMOTHERAPY

After receiving chemotherapy, small amounts of the drug leave the body in body fluids, including blood, urine, faeces, sweat, saliva and vomit. Body fluids that might be contaminated by chemotherapy should be handled with good hygiene practices. Some tips on handling body fluids after chemotherapy are listed below:

- Urine, faeces and vomit can be disposed of in the toilet by flushing with the lid down to avoid splashes.
- Wash your hands thoroughly after handling your child's body fluids.
- All caregivers should wear gloves when handling body fluids and waste, including faeces and vomit.
- Soiled disposable nappies should be double-bagged and disposed of immediately in the kerbside bin.
- Other soiled items such as cloth nappies, soiled linen and clothing should be washed separately from your normal washing.

## IMMUNOTHERAPY

Immunotherapy is treatment that uses the child's immune system to fight cancer. This involves stimulating the immune system or using medicines to boost the body's immune system to work harder and smarter to fight the cancer. Your child's treating team will discuss whether immunotherapy is part of your child's treatment plan.

## RADIATION THERAPY

Radiation therapy (also called radiotherapy) uses high-energy x-rays to damage or destroy cancer cells so these cells can no longer divide. It is painless, usually takes only a few minutes and is often given daily on weekdays for a period up to seven weeks. Radiation therapy is used alone or in combination with chemotherapy or surgery. The radiation oncologist will see your child at least once a week during treatment. In most centres around the world, radiation therapy is given at a different hospital to your child's hospital.

## SURGERY

Many children with cancer will have some type of surgery during their treatment. Surgery may be used to biopsy a suspicious mass or lump at diagnosis, stage a disease, insert a central line and/or remove or reduce a tumour. The type and extent of surgery required will be explained by the surgical team. See the A to Z guide (page 76) at the end of this booklet for explanations of types of surgery.

### Tips for parents: PREPARING YOUR CHILD FOR SURGERY

The following are some tips on helping your child prepare for surgery:

- Learn as much as you can about your child's operation so you can give them the right answers to their questions.
- Give honest answers to their questions, which are appropriate for their level of understanding.
- If possible, ask to visit the areas where your child will wait before the surgery and where they will recover so they are familiar with the environment and staff.
- Talk to your child about any worries they may have about the surgery.
- Depending on the age of your child, it may help if they are part of the consent process with the surgeon.

## BONE MARROW TRANSPLANT

Some cancers need very high doses of chemotherapy and/or radiation therapy to destroy the cancer cells. These high doses may also permanently destroy the normal **stem cells** in the **bone marrow**. A bone marrow transplant may be required to replace the damaged cells with healthy bone marrow stem cells.

If your child does not have any cancer cells in their bone marrow, they may be able to donate their own stem cells for transplant. This is called an **autologous transplant**. If their bone marrow has cancer cells, healthy stem cells are donated by another person. This is called an **allogeneic transplant**.

### Important questions to ask about **CANCER TREATMENT**:

- What are the treatment choices?
- Which treatment do you recommend and why?
- What is the goal of this treatment?
- Have you treated other children with this type of cancer?  
How many?
- What are the chances that the treatment will work?
- How will the treatment be given?
- How long will the treatment take?
- What will be the treatment schedule?
- Will the treatment disrupt my child's school schedule?
- How long will my child be in hospital?
- Can my child have some or all of the treatment at a hospital near home?
- Can any treatment be done at home? Will we need any special equipment?
- Does the hospital have a place where I can stay overnight during my child's treatment?
- What are the next steps if my child does not respond to this treatment?
- What are the side effects we should expect?
- Are there any long-term consequences of this treatment?

## Clinical trials

This section about **clinical trials** has been developed by the Australian and New Zealand Children's Haematology/Oncology Group and has been included in this booklet with their permission. Choosing to participate in a clinical trial is an important decision. The information on the following pages may help you in making this decision. For more information about clinical trials, speak with your child's treating team.

### WHAT IS A CLINICAL TRIAL?

A clinical trial is a medical research study that searches for a better or improved way to treat a particular disease. Clinical trials can be designed to study how to prevent or treat cancer, or how to improve a person's comfort or quality of life. In a clinical trial, participants are followed closely over time to see which treatments offer the best chance of cure with the fewest side effects. New clinical trials are planned based on the results of past clinical trials and what is known about the disease and cancer treatments.

### WHY ARE CLINICAL TRIALS NEEDED?

Clinical trials are necessary to show that the new treatment given is safe and works well in treating the disease. Clinical trials help to establish if the treatment being studied will work, what (if any) are the side effects and what the correct dose should be. Clinical trials are usually the fastest and most efficient way to improve treatment for children with cancer. Without clinical trials, cancer-directed medicines cannot be approved for use in Australia.

### HOW ARE CLINICAL TRIALS APPROVED?

Clinical trials need to be approved by independent ethics committees. These ethics committees operate according to guidelines issued by the National Health and Medical Research Council and ensure clinical trials conform to the Declaration of Helsinki and to international good clinical practice guidelines.

### WHO RUNS A CLINICAL TRIAL?

Most clinical trials are led by a doctor. The clinical trial team includes doctors, nurses, **clinical research associates**, pharmacists and other healthcare professionals. The clinical trial team is responsible for checking the health of the participants at the beginning of the trial, monitoring them during the trial and observing them for a period after the trial.

### WHAT ARE THE BENEFITS OF PARTICIPATING IN A CLINICAL TRIAL?

There are a number of possible advantages of participating in clinical trials. These can include:

- receiving the most up-to-date treatment including access to new medicines and therapies that may not otherwise be readily available
- findings from clinical trials add to knowledge and progress in cancer treatment.

Participation in clinical trials may have downsides, which may include the following:

- New medicines and procedures may have side effects or risks unknown to the doctors.
- The trial medicine may not work for your child.
- Your child may be placed in the group that receives the trial treatment or the current standard treatment (see 'What is randomisation?' below).
- Your child may need to visit the doctor or hospital more often and/or stay there for longer.
- You may not be able to have treatment close to home if you are from a regional area.

### WHAT IS RANDOMISATION?

The clinical trial offered to your child may compare two or more treatment arms (plans). One treatment plan is the 'standard' or current best known treatment, and the other is the new treatment that the doctors think will work even better. To learn if one treatment is better, each participant in the clinical trial is randomly assigned by a computer to one of the treatment arms. Randomisation is a process like flipping a coin that ensures each participant has a fair and equal chance of being assigned to any of the treatment arms.

### HOW CAN MY CHILD PARTICIPATE IN A CLINICAL TRIAL?

After your child's doctor reviews the treatment plan with you, you will be asked to give your permission or consent to start treatment as part of a clinical trial. You will be asked to sign a form that describes the treatment plan for your child. This form lists the risks and benefits of the treatment. When you sign the form you are saying that you understand what the doctor has explained to you and agree for your child to start the treatment. You don't have to participate in a clinical trial, and you can withdraw your child from a trial at any time.

It is important to know that if you decide not to participate in a clinical trial then the best-known established treatment will be given. Also, a decision not to participate will not affect the treating team's attitude towards you or your child.

### WHAT HAPPENS IF SIDE EFFECTS OCCUR FROM TAKING A MEDICINE IN A CLINICAL TRIAL?

In some clinical trials, the treatment may already have been extensively tested for acceptable side effects. However, there might be additional side

effects, especially with new medicines. It is not possible to predict in advance if any side effects will occur, but, if they do, your child will receive appropriate care to manage these side effects.

### WHAT HAPPENS WITH THE RESULTS FROM CLINICAL TRIALS?

The results of clinical trials are made available to the healthcare team so they can be used to improve future treatment for other children. Records are reviewed during the trial, and if important information is discovered, it will be reviewed. Results from clinical trials are published as group data. Individual details about your child are always kept confidential.

#### Important questions when considering participating in a CLINICAL TRIAL:

- What are all the treatment choices for my child?
- What is the current standard treatment for the type of cancer my child has?
- What is the purpose of the clinical trial you are suggesting?
- Why is this treatment expected to be effective? Has it been tested before?
- How many children are currently taking part in this clinical trial?
- What kind of tests and procedures are involved and how often will they be needed?
- How do the possible risks, side effects and benefits of the trial compare with the standard treatment offered?
- What will my child have to do as a part of this clinical trial that is different from the standard treatment?
- Are there any extra costs to me or my family in being involved in a clinical trial?
- If my child takes part in this clinical trial, will it affect the choice of future treatments?
- For what reasons would the clinical trial be stopped?
- Will I have access to the results of the clinical trial when it is completed?

## Fertility

Some cancer treatments can affect future fertility of children and adolescents with cancer. However, it is important to remember that most treatments do not cause infertility. Whether or not this is likely to be an issue for your child depends on many factors including:

- age at treatment
- gender
- type and location of cancer
- type and dose of treatment received.

Before beginning treatment it is important to discuss with your consultant oncologist any fertility implications related to your child's treatment. Procedures such as sperm collection for older boys and egg collection for adolescent girls are part of standard treatment for some cancers. Other options for younger boys and girls, such as storing testicular or ovarian tissue for use in the future, can be discussed with a fertility specialist. Depending on the urgency of beginning your child's treatment, it may be recommended not to delay starting treatment to enable fertility preservation procedures to take place. Where appropriate, you will be referred to a fertility specialist for further discussion about these options.

## Your child's treating team

Your child's treatment will be managed by a multidisciplinary treating team consisting of medical, nursing and allied health professionals. The professionals involved in your child's care will depend on the type of cancer and any individual needs they may have during treatment. Your child will be discussed in multidisciplinary meetings, where the whole team will come together to talk about the diagnosis and treatment plan. Your child's treating team will include some of the following health professionals:

- medical
  - **consultant oncologist**
  - **radiation oncologist**
  - other medical specialists – for example, specialists in radiology, surgery and pathology (the specialists involved in your child's care will depend on the type of cancer your child has and their treatment plan)
  - other medical staff including **fellows, registrars** and **residents** (much of your child's day-to-day care will be delivered by fellows and registrars, directed by your oncologist)
- nursing
  - **nurse unit manager (NUM)**
  - **associate nurse unit manager (AUM/ANUM)**
  - clinical **nurse consultant** / clinical nurse coordinator (CNC)
  - bedside **nursing staff**, on wards and in outpatient areas
- allied health
  - **art therapist**
  - **audiologist**
  - **dietitian**
  - **mental health clinician**
  - **music therapist**
  - **neuropsychologist**
  - **occupational therapist**
  - **oncology pharmacist**
  - **orthotist**
  - **child life therapist**
  - **physiotherapist**
  - **procedural pain clinician**
  - **prosthetist**
  - **psychologist**
  - **social worker**
  - **speech pathologist**

- support staff
  - **administrative staff**
  - **blood collector (pathology)**
  - **chaplain**
  - **clinical research associate**
  - **patient services assistant (PSA)**
  - **teaching and education support officer**
  - **ward clerk**
  - **volunteers.**

## COMMUNICATING WITH YOUR CHILD'S TREATING TEAM

It is important that you and your child have a trusting and open relationship with your child's treating team. The people in the treating team need to know if you are having difficulty interacting with them. Let them know what you need, how much information you and your child want, and what fears and worries you may have.

Below are some suggestions to help you communicate with your child's treating team during, between and after hospital visits.

### Before and between hospital visits

- Prepare for each visit by making notes to help you remember important information you want to discuss with your child's treating team. Use your phone, computer or a notebook to keep information organised and in one place.
- Write down questions and concerns as they arise. Make a note of any changes you notice in your child.
- Bring your questions and notes with you and put the most important questions first on your list.

### During a hospital visit

- Include your child in the conversation by encouraging them to talk and ask questions.
- If you or your child do not understand something, speak up and ask for it to be explained until you understand.
- Take notes or ask for information in writing during the visit so you can remember important information.
- Tell your child's treating team about any medical or emotional changes you notice in your child.

- Make sure you know who you should contact if your child becomes unwell and when you should make contact, including after hours and weekends. Your child's treating team will provide their contact details.
- If you have more questions that can't be answered in your appointment, ask to schedule another appointment or follow-up phone call or email.

### In between hospital visits

- Call your child's treating team about any problems, concerns or changes you notice between appointments.
- Track your child's test results, medicines and treatments.

## PART 3: Looking after your child during treatment

This section will support you in looking after your child during treatment. It includes information on when to call the hospital, supporting your child through their treatment and managing some of the effects of treatment.

### When to call the hospital

If you are concerned that your child is unwell, please call the hospital immediately. In an emergency, call triple zero (000). Some examples of when you should call the hospital are listed below.

TIP: seek out and ensure you have the appropriate numbers in your phone contacts for when to call the hospital.



Any time you are worried about your child



Your child's temperature is 38°C or higher



You notice a rash, spots or chickenpox on your child's skin



Your child is unusually tired



Your child is vomiting excessively



Your child reports severe or persistent pain



Your child refuses to drink



Your child missed a dose of medication

You know your child best. If you are concerned or worried, or if something doesn't feel quite right, speak to your child's treating team.



## Managing low blood counts

Sometimes your child's **blood counts** may drop as a side effect of chemotherapy. Below is some practical advice regarding low blood counts including how to spot the signs of a low blood count.

### LOW RED BLOOD CELL COUNT

**Red blood cells** contain **haemoglobin**, which is responsible for carrying oxygen to the body's organs and tissues. The haemoglobin level indicates the number of red blood cells in the blood. **Anaemia** occurs when the level of haemoglobin in the blood is low. If your child's haemoglobin level drops too low, a **blood transfusion** may be required.

#### Tips for parents: ANAEMIA

Signs that your child may have anaemia include:

- pale skin
- lack of energy
- increasingly tired
- shortness of breath
- racing heart
- headache
- dizziness
- irritability
- nausea.

### LOW WHITE BLOOD CELL COUNT

**White blood cells** fight infection. **Neutrophils** are very important white blood cells because they fight bacterial infections. When the neutrophil count is low, this is called **neutropenia**. Your child is at risk of getting a serious bacterial infection if their neutrophil level is low. If your child has a fever of 38°C or higher you must call the hospital **immediately** for medical attention.

### LOW PLATELET COUNT

**Platelets** are needed for the blood to clot. When the platelet count is low (**thrombocytopenia**), a person is more likely to bleed. If your child's platelet count drops below a certain level it is possible they may need a platelet

transfusion to increase the number of platelets in the blood. Sometimes the platelets will recover by themselves.

#### Tips for parents: THROMBOCYTOPENIA

Signs that your child may have thrombocytopenia include:

- bruising that appears spontaneously and is larger or more frequent than usual
- small, red pinpoint spots on the skin called **petechiae**
- blood in the urine, stool or vomit
- bleeding from the gums (especially after brushing teeth), nose or central line site.

If your child develops any signs of bleeding, contact their treating team. The team may recommend your child has a blood test to check their blood count.

When your child has thrombocytopenia:

- Stay away from contact sports or rough play that could cause physical injury.
- Use a soft bristle toothbrush when cleaning teeth (anything harder may cause irritation and bleeding). Do not let your child use dental floss.
- Do not take rectal temperatures or use rectal suppositories. Anything pushed into the rectum could tear the lining and cause bleeding.
- If your child is constipated, ask their treating team for a stool softener. Hard bowel movements can cause rectal bleeding.

Your child's doctor will tell you when your child's blood counts are okay for him or her to return to school. It may be recommended to stay away from school if their neutrophil count is very low.

## Managing fever or infection

### FEVER

A fever is a temperature higher than 38°C. It may be a sign of a serious infection. If your child has a fever, contact the hospital immediately.

If chemotherapy is a part of your child's treatment, you may be given a risk alert card to carry with you at all times. On the front of the card are instructions for you if your child becomes unwell or has a temperature of 38°C or higher. On the back of the card are instructions for the medical staff at the emergency department about how to treat your child. If you are bringing your child to hospital because they are unwell or have a fever, it is very important that you show this card to each doctor and nurse you meet in the emergency department so they know what to do and the importance of starting treatment immediately.

### Taking your child's temperature

You do not need to take your child's temperature every day. You should take their temperature if they feel warm to touch or do not look or feel well. Take their temperature by mouth, in the ear (using an ear thermometer) or under the arm. For children under 12 months old, taking their temperature in the ear is not recommended. Do not take a rectal temperature because this could cause bleeding or infection. Make sure you have a thermometer at home that works and that you know how to use correctly.

### FEBRILE NEUTROPENIA

Febrile neutropenia is a condition that can occur in children with cancer. It refers to the onset of a high temperature (38 or above) in the setting of low neutrophil count, a type of white blood cell important for fighting infections. If your child develops a fever while they are on treatment for cancer you should attend your closest hospital for a medical review. If your child is unwell or if they have febrile neutropenia, it is likely they will have some blood tests taken and be admitted to hospital for observation and antibiotics through the vein (usually through their central line). This is because a serious infection, such as a blood stream infection (also known as septicemia) can develop during periods of neutropenia or cancer treatment.

Children usually stay in hospital for between 3 and 5 days for treatment of febrile neutropenia. Depending on the results of your child's blood tests and what stage they are at in their chemotherapy cycles, they may be able to have some, or all, of this antibiotics treatment at home. This can be given through the central line by a hospital-in-the-home (HITH) nurse or with oral antibiotics. Your child's treating team will assess if your child is suitable for this type of treatment.

### INFECTION

Children who are receiving chemotherapy have lower immunity and are at more risk of infections. Sometimes infection can occur without a fever. If your child has chills or does not look well, even if there is no fever, contact their treating team immediately.

#### Tips for parents: SIGNS OF INFECTION

Some signs and symptoms of infection may include (but are not limited to):

- fever
- flushed appearance, sweating, shivering
- skin rash or red spots
- vomiting, diarrhoea
- coughing, sneezing, runny nose, shortness of breath, chest tightness
- redness, swelling or pain around the central line
- redness, swelling or pain in the throat, eyes, ears, skin, joints or abdomen
- headaches, blurred vision or difficulties with sight
- foul-smelling, discoloured urine or frequent, urgent or stinging urination.

#### IMPORTANT

Remember, it is important to contact your child's treating team immediately if your child has a fever or signs of infection. If your child's temperature is 38°C or higher call your hospital and get medical attention as soon as possible.

Some of the reasons why infections can occur during treatment are listed below.

#### Physical barriers

Physical barriers to infection include the skin and **mucous membranes**. Mucous membranes are found in the lining of the mouth and gut. Chemotherapy can cause thinning of the mucous membranes, which can result in mouth ulcers that may become infected. Likewise, infection can occur when the skin is broken from cuts and grazes.

### Neutrophils

Neutrophils are a type of white blood cell that fight **bacteria**. The neutrophil count in the blood will increase and decrease while your child is receiving chemotherapy. When the neutrophil count is low, there is a greater risk of your child getting a **bacterial infection** and they are considered neutropenic.

### Immune system

The immune system is the main defence mechanism of the body against viral infections. Your child's immune system will be weaker while they receive chemotherapy and for around six to 12 months after treatment is finished.

### Antibodies

Antibodies are the body's long-range defence mechanism against infection. After some infections or routine immunisations, the body makes antibodies to prevent getting the infection again. Chemotherapy can affect the production of antibodies. This means that children who are receiving chemotherapy may get chickenpox even if they have already had chickenpox or the chickenpox vaccine before their cancer diagnosis.

## PREVENTING INFECTION

Many infections in children who are receiving chemotherapy cannot be prevented; however, below are some suggestions about how to help your child avoid getting an infection.

### Going out

Although your child will have a reduced immunity during their treatment it is not practical or necessary to keep them apart from other children. In general, they are able to go to school, parties, shopping centres and cinemas, and to catch public transport. A sensible approach is to avoid large crowds where social distancing is not possible, avoid visiting family or friends who are unwell, and ensure their school has a plan in place to advise you if there are children who have chickenpox, measles or mumps. Your healthcare team can provide further guidance for the needs of your child.

### General hygiene

Good personal hygiene is important for preventing infection. Ensure your child and all family members bath or shower daily and wash their hands with soap before eating and after using the toilet. In the home, weekly cleaning and vacuuming is adequate. There is no need to disinfect your home.

### Foot care

Ensure your child wears shoes or has their feet covered, especially when they are outside. If they get any cuts, grazes or splinters, clean the area immediately and apply an antiseptic solution.

### Food

Ensure food is stored and refrigerated properly (e.g. eggs should be kept in the fridge). Ensure all food is well cooked, particularly meat and chicken. You should avoid feeding your child food that has been sitting in a warm environment (see page 51 for more information about good food hygiene).

### Pets

Pets can be an important part of your child's life. It is safe for your child to play with their pets, and there is no need to remove pets from the family home. If you have pets at home, you can help prevent infection by ensuring your child:

- washes their hands after contact with animals
- does not kiss animals or let animals lick them
- avoids being scratched or bitten by animals
- does not clean the animal's environment (e.g. litter trays, bird cages or fish tanks)
- avoids wild animals and birds.

Ensure your pets:

- are immunised and wormed appropriately
- have no ticks or fleas
- do not sleep on your child's bed.

### Flowers, plants and soil

Water and soil from flowers and plants can hide **bacteria** and other bugs that can be harmful when your child has low immunity. Your child should avoid contact with water and soil from plants (especially potting mix and compost) and ensure their hands are washed when dirtied. This is very important when they are neutropenic because their risk of serious infection is increased.

It may be safe for your child to play in a sandpit (ideally when they are not neutropenic). If you do use a sandpit make sure it is covered when not in use to avoid contamination by birds and animals, and ensure your child washes their hands after playing. You can also discuss this with your child's treating team.

#### **Tips for parents: PREVENTING INFECTION WHEN YOUR CHILD IS NEUTROPENIC**

- Ensure family and visitors (in the hospital and at home) wash their hands before visiting your child. Good handwashing is essential to reducing the risk of infection.
- Avoiding contact with people who are sick.
- Avoiding sharing crockery, cutlery and drinks.
- Do not take rectal temperatures or use rectal suppositories because these can accidentally tear the lining of your child's bottom, potentially allowing bacteria to enter their bloodstream.
- Check inside your child's mouth daily and contact the hospital if mouth sores develop.

#### **CHICKENPOX AND OTHER CHILDHOOD DISEASES**

Chickenpox, measles and mumps are common childhood illnesses. Even if your child has previously been exposed to, or vaccinated against, these illnesses they can catch them again because chemotherapy drugs reduce their immunity and the ability to fight infection. The best protection is not being exposed to these infectious diseases. This means asking the parents of children who play with your child to tell you if their child is infectious or if they have any concerns at all that their child may be unwell. If you, your child or other family members have been exposed to any of these illnesses, please call your child's treating team immediately. For some infections, your child might need urgent treatment.

##### **Signs of chickenpox**

- Slight fever, headache, decreased appetite
- Pink spots of different sizes – very itchy
- Spots first appear on the body, then on the face
- Spots change to small fluid filled blisters
- Blisters then burst to form scabs

Chickenpox spreads through direct contact with someone who has it – playing, kissing or sharing cups, towels or bedding. Chickenpox is contagious (catchable) from one to two days before the pink spots appear until after the last blisters become scabs. If your child has contact with someone with chickenpox, or you think they might have chickenpox, contact their treating team immediately – they may need medication to reduce the severity of the infection.

##### **Signs of measles**

- Sneezing, watery red eyes (similar to signs of a head cold)
- Hoarse voice or harsh irritating cough
- Hot skin
- A strange feeling in the tongue with a strawberry-like appearance
- A red blotchy rash appearing a few days after flu-like symptoms – a rash may be subtle or even absent in children with low immunity

Measles spread like chickenpox (see above). It is contagious from about one day before the first signs until several days after the rash appears. If your child has contact with someone with measles, or you think they might have measles, contact their treating team immediately.

##### **Signs of mumps**

- Painful swelling of the saliva glands near the jaw (called the 'parotid glands')
- Fever
- Headache
- Loss of appetite

The mumps virus is usually spread through contact with tiny, airborne droplets of saliva when people laugh, sneeze or kiss. It can also be spread by contact with saliva from shared drinks, tissues, etc. It is contagious from two to three days before the first signs until six days after they disappear. If your child has contact with someone with mumps, or you think your child might have mumps, contact their treating team immediately.

## IMMUNISATIONS

During treatment your child should not have immunisations (also called 'vaccinations') without consulting their treating team. There are some immunisations that are safe and recommended for your child during treatment such as the influenza ('flu') vaccine.

Some immunisations have a small amount of virus that has been altered to make it safe to be given to people. These are called 'live' vaccines and include the chicken pox (varicella) vaccine and the MMR (measles-mumps-rubella) vaccine. They don't normally cause disease because the healthy immune system clears the infection, but children with cancer have a weaker immune system and are less able to do this, therefore they should not be given these vaccines during treatment. This is why it is important to consult your child's treating team before your child receives any vaccinations.

Your child's treating team will make sure you know what immunisations are necessary for your child. Your child will need 'catch-up' immunisations about six to 12 months after finishing treatment. You can download a copy of your child's immunisation history via Medicare Online for all immunisations given after 1st January 1996.

An important way to protect children with cancer is to ensure all household and close family contacts are up to date with their immunisations. Adult family members are able to download their own immunisation history documents from Medicare Online. If their record is incomplete they can visit a GP to request antibody testing to confirm whether they are immune.

A schedule of immunisations recommended for all Victorians can be found at <https://www2.health.vic.gov.au/public-health/immunisation/immunisation-schedule-vaccine-eligibility-criteria/immunisation-schedule-victoria>. It is safe for all other children in the family to follow the normal immunisation program recommended for their age (including the live vaccines). It is also recommended that all household and close family contacts have the yearly flu vaccine. Vaccination against COVID-19 is also recommended for all household and close family contacts. Refer to PICS website for further information.

## Managing medications

It is important that you tell your child's treating team about all your child's medications including those:

- prescribed by the hospital(s)
- prescribed by another doctor (such as your child's paediatrician or general practitioner)
- prescribed by a complementary or alternative medicine practitioner
- bought at a pharmacy or supermarket
- bought from a health food shop.

### TAKING ORAL MEDICATIONS

It is a good idea for you to help give your child their medications while they are in hospital. It may make medicine-taking easier if your child needs to continue treatment at home.

#### Tips for parents: GIVING MEDICATION

- Small rewards are more helpful than threats. Use an incentive if needed.
- Re-direct your child's attention by playing a game.
- It might be easier to give liquid medication with a syringe instead of a spoon.
- If your child misses a dose of medication, only swallows a part-dose, or vomits soon after, you need to tell their treating team.
- Some medications must be taken at specific times. Make sure you know when your child's medication needs to be taken and always check the expiry dates.
- Explore other ways for taking medication (i.e. tablets or liquids). Often a child who struggles with tablets does not experience difficulty with liquids or vice versa.

If you are giving your child oral chemotherapy it is important that it is handled and administered very carefully. You can refer back to the treatment section of this booklet for more information.

#### **Tips for parents: GIVING ORAL CHEMOTHERAPY AT HOME**

- Use gloves when handling chemotherapy tablets, especially if you are pregnant or breastfeeding.
- Wash your hands thoroughly after giving your child oral chemotherapy.
- Never crush chemotherapy tablets. Some medications may be dissolved in water. Discuss how to do this with your pharmacist.

Some children have difficulty swallowing oral medication such as tablets and capsules. If your child is having ongoing difficulty swallowing, please speak to their treating team.

#### **Tips for parents: HELPING YOUR CHILD SWALLOW TABLETS**

- Add crushed tablets to a teaspoon of jam, apple sauce or juice. Some tablets cannot be crushed, so check with your child's pharmacist first.
- Avoid hiding tablets in foods that your child likes. You don't want to put them off their favourite foods.
- Break large tablets into halves or quarters.
- Have your child put the tablet on the back of their tongue, take a big mouthful of water, tip their head back and swallow.
- Some tablets can be put inside a gel cap for children who can swallow capsules.
- Have your child take a mouthful of water first to wet their mouth when taking capsules.
- Tablet crushers, tablet cutters and gel caps are available from most pharmacies.
- Teaching children over 4 years how to swallow tablets and capsules is a useful resource available from The Royal Children's Hospital at [http://www.rch.org.au/pharmacy/medicines-information/Teaching\\_children\\_how\\_to\\_swallow\\_tablets\\_and\\_capsules/](http://www.rch.org.au/pharmacy/medicines-information/Teaching_children_how_to_swallow_tablets_and_capsules/)

#### **IMPORTANT**

Contact your child's treating team if your child vomits immediately after taking oral medication. In most cases, the dose will be repeated, especially if vomiting occurs within 15 minutes or you can see the tablets in the vomit.

Also contact your child's treating team if your child misses a dose of medication. If you are having difficulty remembering to give your child their medication on time, please speak with their treating team. Medication smartphone apps, calendars or pillboxes may help you to give your child their medication on time.

#### **DISPOSING OF MEDICATION**

Any unused or unwanted medications should be returned to a pharmacy where they can be disposed of appropriately. This includes any tablets, capsules, mixtures, creams, inhalers or patches.

Syringes with needles should be returned to a pharmacy in a sharps container. This is the safest way to dispose of syringes with needles for both you and the pharmacy staff. Syringes with needles that are not returned in a sharps container will not be accepted by the pharmacy. Empty sharps containers are often supplied by the hospital (during business hours) or can be purchased from some community pharmacies.

Medication packaging, empty blister packs, containers, gloves, medicine cups and syringes (without needles) are safe to dispose of in your home rubbish bins.

## COMPLEMENTARY AND ALTERNATIVE MEDICINE

Some vitamins, herbs and natural products may interfere with the effectiveness of your child's chemotherapy. If you would like to give your child vitamins, herbs or natural products please speak to their treating team first.

Complementary and alternative medicines are also known as 'traditional medicines' or 'natural remedies'. They may include:

- vitamins, minerals, herbs and tonics
- aromatherapy, homeopathy or naturopathy
- Chinese or Ayurvedic medicine
- massage, magnet therapy or crystals
- mind-body therapies such as hypnosis, meditation, guided imagery or biofeedback
- lifestyle changes such as relaxation, stretching and exercise.

Complementary medicine means that it is used along with standard medical treatment. Alternative medicine means that it is used instead of standard medical treatment. Your child's treating team may be able to help you find more information about any complementary or alternative medicines you may be interested in giving your child. It is very important that you speak with your child's treating team before using any complementary or alternative medicines because they can sometimes interact or interfere with standard medical treatment.

A useful complementary and alternative medicines resource is available from Cancer Council Australia at [www.cancer.org.au/about-cancer/treatment/complementary-therapies-and-cancer.html](http://www.cancer.org.au/about-cancer/treatment/complementary-therapies-and-cancer.html)

## Managing tests and procedures

Some tests and procedures may be uncomfortable, distressing or painful for your child. Your child's treating team can provide personalised information and practical suggestions to help you and your child cope while they are undergoing medical procedures. Some methods of promoting effective coping may include education, preparation, procedural play, helpful thinking, distraction, imagery and deep-breathing or relaxation exercises. Hospitals have different programs to support children during medical procedures. Some general suggestions to help your child cope during medical procedures are described below.

### BEFORE THE PROCEDURE

- Speak with your child's treating team so you have a good understanding of what the medical procedure involves and why it is being performed.
- Prepare your child by giving simple and accurate information. Use language they understand and answer their questions honestly. The amount of information you give them will depend on their age and level of development and how you think they will cope with the procedure.
- Listen to your child's concerns about the procedure – they may be different from your concerns.
- For young or anxious children, it may help to speak to them shortly before the procedure to avoid overwhelming them with information. This should be long enough to process the information but short enough to not increase their anxiety.
- Speak with them about coping techniques they can use to help manage any worry or concerns about the procedure, and practice some of these coping techniques with them.
- Where possible, give them a choice such as choosing which finger to use for a finger-prick.



## DURING THE PROCEDURE

- A calm atmosphere in the treating room is reassuring for your child and can reduce anxiety.
- Explain in a clear, simple manner why they are having the procedure.
- Provide basic, sensory information about the procedure – what will they feel, what will they see, what will they hear.
- Maintain physical contact such as patting, rubbing or stroking their hand.
- Suggest they focus on other things rather than on the procedure. The team will be able to support you with some strategies. Use age-appropriate coping techniques such as:
  - blowing a party-blower, looking at a pop-up book, counting objects around the room, telling a favourite story
  - watching their favourite shows on your tablet or smartphone
  - asking them to imagine a favourite place or activity, and help them to describe the sights, smells, sounds and tastes as if they were actually happening
  - asking them to use coping statements such as 'I need to relax now', 'Soon it will be finished' and 'It is helping me get better'.
  - using a buzzy or visual schedule

## AFTER THE PROCEDURE

- Be positive. Noticing small achievements such as sitting still or settling quickly can build your child's coping response.
- Small rewards can be helpful, but avoid bargaining or excessive rewards.
- If they cry or are distressed, comfort them by letting them know that it is okay to feel upset.
- Speak with them about the coping techniques you have tried and what they found helpful.
- Persist with using coping techniques even if they seem to be ineffective at first.

If you are concerned about your child's level of distress after procedures, or your own, speak with their treating team for guidance.

## Managing pain

Your child may experience pain for reasons that include:

- the cancer itself
- side effects from cancer treatments
- tests, procedures and treatments.

We know that children can experience pain during cancer treatment, and it is important that their pain is treated and managed appropriately. It is important that you tell your child's treating team if your child experiences pain or you think they are in pain. The treating team will work to find out what is causing their pain and identify ways to manage this pain.

Children of different ages understand and respond to pain differently. To understand if your child is experiencing pain it may be helpful to use a pain rating scale. Your child's treating team may be able to provide you with an appropriate scale. Some pain rating scales for children use faces to understand how the pain makes the child feel, while other scales use numbers. Your child can choose a face or number to communicate if they are in pain and how much pain they are experiencing. The Wong-Baker FACES® Pain Rating Scale is a useful scale developed for children three years and older. You can get individual access to this scale, for personal use only, by visiting <http://wongbakerfaces.org/licensing-dashboard/personal-use>

Your child may be given medicine to assist in pain relief. The type and amount of pain medicine and how it is given will depend on the type of pain, their weight and whether or not they can swallow medicine.



#### Tips for parents: PAIN MEDICINES

- Discuss with your child's treating team what is best for them.
- Paracetamol (Panadol) may be used for mild pain, but check your child's temperature before giving paracetamol, and remember paracetamol may mask a fever so consider other signs of infection.
- For moderate to severe pain, your child may need stronger pain medicines such as opioids.
- Do not give your child any medicines that contain aspirin or ibuprofen (e.g. Nurofen) because these medicines can increase bleeding problems and irritate the stomach lining.
- Check with your child's treating team or pharmacist before giving any over-the-counter medicines for the first time.

#### HELPING YOUR CHILD BE MORE COMFORTABLE

As a parent, you know your child best and how to make them more comfortable. Some ways you can help your child when they are in pain is to use distraction and visual imagery. Distraction is a way to help your child think or focus on something fun or relaxing such as watching a movie or listening to music. Taking deep breaths helps the body to relax and may also serve as a distraction. Visual imagery is when a person pictures themselves in a safe, relaxing or fun place. Using any of these methods may help your child to feel more relaxed and have less pain. Please remember to tell your child's treating team if you think your child has pain and what has helped to ease the pain in the past.

## Managing mouth and dental care

### MOUTH CARE

During treatment, some children get a sore mouth and may develop mouth ulcers. The most effective way to maintain good oral hygiene is by brushing teeth after meals and before bed using a soft toothbrush. When your child is an inpatient in hospital, their mouth should be inspected at least once a day.

### SORE MOUTH

Your child's treating team can provide you with more information and instructions on how manage mouth pain. If your child refuses to drink fluids or is unable to swallow saliva, please contact their treating team as soon as possible.

### Mucositis

The cells that line the inside of the mouth normally reproduce rapidly to repair any damage caused by normal wear and tear. Chemotherapy and, sometimes, radiotherapy may temporarily stop this repair, and the mouth and gastrointestinal lining can break down and become inflamed. This is known as **mucositis**. Mouth ulcers are sores that form on the inside of the mouth or lips, making it difficult to eat, talk and swallow. It is important to keep your child's mouth and teeth as clean as possible. They will feel more comfortable and it can help prevent an infection from developing in their mouth.

You can help by checking your child's mouth regularly and tell their treating team if any of the following occur:

- red, white or pale areas
- ulcers
- a white coating on the tongue
- bleeding gums
- swallowing problems
- difficulty eating or drinking.

The hospital staff will let you know if your child requires any oral hygiene care other than normal brushing of their teeth.

#### **Tips for parents: GENERAL MOUTH CARE**

- Have your child brush their teeth with a soft toothbrush after each meal and before bed.
- Encourage them to rinse their mouth with water after brushing.
- Do not use mouthwashes that contain alcohol.
- If dry mouth is a problem for your child, have them suck on hard sugar-free lollies or ice cubes.
- Remember mouth ulcers are a side effect of treatment and are not always preventable.

#### **Tips for parents: MOUTH ULCERS AND EATING WITH A SORE MOUTH**

Ask your child's treating team for medicines for mouth ulcers. Hints for eating with a sore mouth:

- Encourage your child to drink plenty of fluids, and use a straw.
- Encourage them to rinse out their mouth with water or a recommended mouthwash several times a day.
- Apply a barrier cream or balm to their lips, including before eating.
- Offer them cool rather than hot drinks.
- Offer them cool or room-temperature foods.
- Cut food into small pieces or puree foods in a blender.
- Avoid foods with sharp or rough edges such as chips, toast or tacos, as well as dry or course foods.
- Avoid spicy foods or foods with a high acid content such as tomatoes, orange juice or pickles.
- Feed them soft or pureed foods such as:
  - mashed vegetables with sauces
  - minced beef with gravy
  - breakfast cereals with plenty of milk
  - scrambled eggs
  - soups
  - ice-cream and jelly
  - soft puddings, custards and mousse
  - milkshakes and fruit smoothies
  - yoghurt.

#### **DENTAL CARE**

Your child should go to the dentist as usual during treatment. However, it is important that your dentist knows they are having treatment for cancer. Antibiotics may be required prior to certain dental procedures. If your child requires dental procedures during treatment, please contact their treating team to determine if their blood counts are at safe levels for dental work.

## Eating well during treatment

Every child reacts differently to treatment. You may notice that your child has:

- a smaller appetite that leads to an initial weight loss (they will usually regain this weight once they are feeling better)
- a bigger appetite due to some medicines such as **steroids**
- changes in their eating habits, food choices or desire for food
- changes in the taste of some foods
- increased nausea and vomiting
- increased diarrhoea or constipation
- abdominal pain.

Good nutrition will help your child:

- grow and develop normally
- fight infection
- tolerate chemotherapy
- feel better
- have more energy.

Your child's body needs a balanced diet that consists of a variety of foods from the major food groups. These foods include:

- carbohydrates such as bread, cereal, pasta, rice and noodles
- fruits and vegetables
- meat or meat alternatives such as beef, chicken, fish, eggs and legumes
- dairy such as milk, cheese and yoghurt
- fats such as butter, margarine, oil and cream.

You can get more information about eating well from your child's treating team.

## GOOD FOOD HYGIENE

Your child's ability to fight infection is reduced during cancer treatment. Sometimes **bacteria** can grow in food and cause gastroenteritis. Gastroenteritis causes nausea, vomiting and diarrhoea. Some suggestions for preventing bacteria growing in food are:

- Wash your hands thoroughly before preparing any food.
- Wash all fruits and vegetables before eating.
- Store raw and cooked foods in different sections of the fridge.
- Keep raw meat away from other foods.
- Use a separate chopping board for raw meats.
- Defrost, cook and reheat foods thoroughly, particularly meat.
- Never use unpasteurised dairy products.
- Do not keep hot foods at room temperature.
- Check the 'use by' and 'best before' dates.

## EATING WHEN YOUR CHILD IS NEUTROPENIC

If your child is neutropenic (has a low **neutrophil** count in the blood) they should avoid having foods that have a higher risk of bacterial contamination such as:

- take-away foods, particularly if you do not know how long ago they were cooked or are not kept very hot
- paté and soft cheeses such as blue vein, camembert, brie and ricotta
- fresh fruits that are very difficult to wash such as berries
- soft-serve ice-cream
- purchased pre-prepared salads such as coleslaw and potato salad
- uncooked or fermented deli meats such as salami
- uncooked herbs or herbal supplements
- reheated food.

#### Tips for parents: HELPING YOUR CHILD TO EAT WHEN THEY FEEL UNWELL

- Provide familiar foods that you know they like.
- Feed them small serves of food more regularly.
- Feed them cold foods that don't smell.
- Serve food in a well-ventilated room to eliminate food odours.
- Do not force them to eat, but encourage and praise them when they do eat.
- Offer them fluids to sip regularly.
- Offer them a variety of foods.
- Keep nutritious snacks in your bag for quick access when you are not at home.
- Keep small portions of their favourite foods in the freezer for quick access.
- Avoid them filling up on low-nutrient foods such as cordials or lollies.
- Sit and eat with them when they are eating.
- Try to stick to your usual food routines, but be flexible because they may not always eat the same way depending on their appetite.
- Make sure they eat regularly even if they feel unwell.

## Managing nausea and vomiting

Chemotherapy and radiation can result in varying levels of nausea and vomiting. Depending on the chemotherapy, nausea and vomiting may occur at the time of treatment, or even up to a few days after. There are anti-nausea medicines that can help decrease nausea and vomiting that can be given before the treatment starts. They may also need more than one type of anti-nausea medication to control their symptoms.

#### Tips for parents: NAUSEA AND VOMITING

- Offer smaller serves of food more frequently.
- Offer bland dry foods such as toast or dry biscuits.
- Sometimes cold foods with no smell are better tolerated.
- Feed them in a room that is free of cooking smells or strong odours.
- Avoid giving them sweet, greasy or spicy foods, or foods that have strong smells.
- Encourage them to sip cool liquids.
- Rinse their mouth after vomiting.
- Make sure you follow any medication plans from your child's treating team.
- Talk to your child's treating team about other strategies if nausea and vomiting is impacting on your child's wellbeing.

## Managing diarrhoea

Infection, some **antibiotics**, chemotherapy and radiation therapy can cause diarrhoea. If your child has had diarrhoea, their treating team may want to know about the colour, consistency and frequency of bowel movements each day. A stool sample may also be needed for laboratory testing. Some children may require an admission to hospital. If your child has diarrhoea and experiences any of the following, call the hospital:

- severe diarrhoea or more than three loose stools per day
- diarrhoea that persists for longer than two days
- blistered, broken down skin or bleeding around the anus (bottom).

#### Tips for parents: MANAGING DIARRHOEA

- Offer small amounts of food more often instead of large meals.
- Encourage fluid at least every 30 minutes.
- If your child has **nasogastric tube** feeding, you may need to talk to your dietitian about reducing the rate of feeding.

## Managing constipation

Some chemotherapy or pain medicines can cause constipation. Your child's treating team may recommend a fibre supplement or a medicine to soften the stool. If your child has constipation and experiences any of the following, contact the team:

- no bowel motion for more than two days, beyond normal bowel movement
- pain or bleeding after a bowel motion.

### Tips for parents: CONSTIPATION

- Encourage your child to drink water regularly throughout the day.
- Encourage them to be physically active (such as walking) to stimulate bowel function.
- Give them foods that are high in fibre (such as wholegrain breads and cereals, brown rice, dried fruits and raw fresh vegetables). Introduce a high-fibre diet slowly over time.
- They should not have enemas or suppositories without discussing this with their treating team first.

## Managing dehydration

Fever, vomiting and diarrhoea can cause dehydration, especially if your child cannot drink enough to replace the fluid that is lost. Signs that they may be dehydrated include:

- dry skin or mouth
- reduced urine output
- no tears when crying
- small amounts of dark-coloured urine.

If they have signs of dehydration or you are concerned about their fluid intake, get medical attention as soon as possible.

## Managing physical changes during treatment

### WEIGHT LOSS

Your child may lose weight during treatment, even while eating a well-balanced diet. The dietitian will monitor weight and nutritional status, and provide nutritional support when necessary. If your child cannot eat enough to maintain a healthy weight, they may need to receive nutrition through a **nasogastric tube**. Formula can be given via the tube that goes into the stomach through the nose. If they cannot take food into their stomach or via the nasogastric tube, another formula called **total parenteral nutrition (TPN)** can be given through a needle into their central line.

### Tips for parents: WEIGHT LOSS

- Keep healthy foods that they like to eat on hand.
- Give small snacks or meals frequently throughout the day.
- Feed them foods with high calories (such as ice-cream in a milkshake or peanut butter on toast).
- Avoid giving lots of fluids during meals because this will make them feel full more quickly.
- Take advantage of the times when they want to eat.

Most children on treatment will have a poor appetite at some stage, or they may have problems with slow growth or weight loss. A diet high in energy (kilojoules) may be necessary. Generally there are two ways to increase the energy in your child's diet:

- eat foods with a higher energy content
- eat more food.

### Tips for parents: High-energy eating – FOODS WITH HIGHER ENERGY CONTENT

You can increase the energy content of food your child eats in the following ways:

- Margarine – melt over vegetables, rice and pasta. Spread thickly on bread and toast. Spread on sweet and savoury biscuits.
- Oil – fry foods where possible and stir-fry vegetables. Try fried rice. Use oil to baste with if grilling food and use oil-based salad dressing.
- Mayonnaise – use on salad sandwiches, mix with tuna or egg to use on dry biscuits or in sandwiches. Use as a salad dressing or serve with fishcakes or fish fingers. Do not use raw egg products when your child is neutropenic.
- Cheese – add grated cheese to soups, pasta, casseroles, mashed potato, egg dishes, tinned spaghetti or baked beans or melted on vegetables.  
Use cream cheese in dips or spread on biscuits and bread.
- Cream – add to milk, breakfast cereals, desserts, custard, yoghurt, sauces and soups.
- Milk – make soups and puddings with milk instead of water. Add extra milk powder (full cream) to milk to use for drinks and cooking.
- Sauces – use gravies and sauces where possible on vegetables and meat dishes. Add sweet sauces and toppings to ice-cream and other desserts.

### WEIGHT GAIN

Your child may need to take a steroid medicine as a part of their treatment. The side effects of steroid medicines include an increased appetite, excessive weight gain (particularly in the face and abdomen) and fluid retention. The weight gain caused by steroid medicines is temporary, and your child's weight will usually return to normal after the steroids are stopped.

### Tips for parents: USEFUL STRATEGIES TO HELP MINIMISE WEIGHT GAIN WHILE ON STEROIDS

#### DO

- Ensure your child eats three moderate-sized meals plus two to three snacks per day. Ensuring that your child eats regularly means they are less likely to get to the point where hunger is overwhelming making it difficult to control eating.
- Remember, it is difficult for your child to make good food choices while taking steroids, therefore it is important that healthy foods are the most accessible options. Try to have your kitchen well stocked with healthy meals and snack options.
- Discourage your child from frequently eating small meals throughout the day because this is likely to lead to weight gain. Instead, be firm about sticking to set meal and snack times.
- Grill, bake, BBQ, steam and roast rather than frying, and avoid adding fats and oil to cooking.
- When going out pack healthy snacks.
- Try to distract your child from food with other activities such as playing games, reading and outdoor activities if they are well enough.
- Encourage your child to wait for 20 minutes after eating before eating more.
- Have a designated eating area in your home such as the dining room or kitchen table and encourage your child to eat all meals and snacks there when at home.
- Ensure your child drinks plenty of fluids, preferably water or low-fat milk.

### Tips for parents: USEFUL STRATEGIES TO HELP MINIMISE WEIGHT GAIN WHILE ON STEROIDS

#### DON'T

- Have high-fat, high-sugar 'junk' foods in your home because these are likely to be very tempting to a child on steroids and will contribute to weight gain, especially when eaten in excess.
- Allow your child to drink juice, soft drink or cordial because these contain large amounts of sugar, which will contribute to weight gain.
- Allow your child to eat in front of the TV.
- Buy take-away food, which is often high in calories.

### HAIR LOSS (ALOPECIA)

Some types of chemotherapy and radiation therapy may cause **alopecia**, which is hair loss or thinning of the hair. The amount and timing of hair loss will depend on the treatment your child receives. Hair loss can range from very little thinning to complete baldness. Some children may also lose their body hair, eyebrows and eyelashes. Nothing can be done to prevent hair from falling out. Some children and parents prefer to cut the hair as short as possible when it starts to fall out. Many children wear hats or bright scarves, and some wear a wig until their hair grows back. Your child will decide what feels right. Ensure they wear sun protection (a hat) when outside.

Hair lost through chemotherapy will nearly always grow back when treatment becomes milder or finishes. Hair may grow back slightly different in colour or texture (curlier, thicker or thinner) than before the cancer treatment. In some cases, the hair may not grow back in the spot where radiation was given.

### SKIN CHANGES

Some children develop rashes, acne, hives or changes in skin colour because of chemotherapy. You can reassure your child that their skin should return to normal after chemotherapy has finished.

If they have had radiation therapy, it may cause reddening of the skin, rashes, dry skin or itchiness at the site of radiation. Some treatments make the skin more sensitive to sunlight, and extra sun precautions are necessary. During such treatments it is important to avoid excessive exposure to the sunlight and use a high-SPF sunscreen. Your child's treating team will tell you how to care for your child's skin during treatment.

### HEARING LOSS

Some chemotherapy medicines and **antibiotics** may cause a degree of permanent hearing loss. If these medicines are a part of your child's treatment, regular **audiograms** will be organised to monitor their hearing.

### PERIPHERAL NEUROPATHY

Some chemotherapy medicines (especially vincristine) can cause temporary damage to the nerves in the hands and feet. This results in numbness, weakness or a tingling sensation called **peripheral neuropathy**. Peripheral neuropathy can lead to reduced coordination, clumsiness and 'drop foot' (where you can't lift the front part of your foot). While symptoms will nearly always disappear once the treatment is finished, peripheral neuropathy can be distressing and can lead to lasting problems if not managed by a healthcare professional. To avoid lasting problems and to make sure your child can safely walk and keep physically active, some children may temporarily require splints (orthoses) in conjunction with physiotherapy. A physiotherapist can develop an exercise program to increase strength and balance.

#### Tips for parents: PERIPHERAL NEUROPATHY

- Report any numbness, weakness or tingling to your child's treating team.
- If your child has pain associated with peripheral neuropathy, their oncologist can prescribe a pain relief medicine.
- Your child may be unsteady when walking, so keep them in a safe environment.
- For younger children, look for changes in function such as difficulty doing up buttons or climbing stairs.
- Follow the strategies given to you by the physiotherapist.
- Reassure your child that the sensation will in most cases go away.

## Managing fatigue during treatment

Many children with cancer get tired during and after treatment. There are several factors that can contribute to fatigue including:

- the cancer treatment itself
- low **haemoglobin**
- poor nutrition
- fever
- pain
- worry
- changes to sleep patterns or getting less sleep
- overexertion.

Fatigue may be **acute** (short-term) or **chronic** (long-term). In the short term, fatigue may be tiredness that is relieved by rest. In the long term, fatigue may be a feeling of exhaustion along with other symptoms such as lack of energy, dizziness, weakness and difficulty concentrating.

### Tips for parents: FATIGUE

- Plan rest periods when your child is tired.
- Ensure they take frequent naps.
- Encourage eight hours' sleep each night.
- Avoid having too many visitors at once.
- Ensure they are physically active for a period each day.
- Avoid caffeine-based drinks such as cola.
- Continue normal activities as much as possible.
- Plan outings during times when they have more energy.
- Ensure a healthy diet and adequate fluid intake.
- Ask the physiotherapist to develop an exercise program to increase strength and endurance.
- When they return to school, plan for half days first and gradually increase their attendance over time.

## Helping your child remain physically active during treatment

Your child may be less active than normal during treatment. However, it is important that they remain as physically active as possible. Long periods of inactivity can lead to tiring more easily, decreased muscle strength and a decline in daily activities.

Encourage your child to be active every day and to participate in family activities whenever possible and appropriate. They should participate in outdoor activities, such as walking and bike riding, at an intensity that is comfortable and enjoyable. You can adjust the amount of time they spend doing physical activities depending on how they are feeling. Remember that even small amounts of physical activity are beneficial. If your child is having particular issues with keeping physically active, speak with their treating team. A physiotherapist may be recommended to provide specific exercises and ideas to help keep your child physically active.

## Helping your child remain engaged with school

It is important your child keeps in contact with their school, engages in learning and interacts with their peers during treatment. While general health and treatment for cancer will be a priority, education and socialisation are also important to their wellbeing.

### COMMUNICATION AND INFORMATION SHARING

You need to decide how much information you and your child would like to share with their school, classmates and wider community about their diagnosis and treatment. You may also like to discuss who will be responsible for sharing information, who you would like to receive the information, and how and when information will be shared. Whatever you decide, maintaining communication with the school about how your child is coping academically, socially, physically and emotionally during treatment is important. You can also discuss with the school the best method of communication and how schoolwork will be exchanged.



## KEEPING UP WITH SCHOOLWORK

If your child is unable to attend school for long periods during treatment, there are several ways that you can help them to remain connected with school and their friends. An important first step is to discuss with your child's treating team, including the education support person, about developing a school-based health support plan that outlines how your child's diagnosis will impact on their ability to attend school and complete the school curriculum. A health support plan should be reviewed annually or whenever there is a significant change in their condition or treatment. An individual learning plan (ILP) may also be appropriate to address your child's learning needs. An ILP should be developed in consultation with your child's school and treating team to set achievable goals for your child and implement helpful strategies to support them during treatment and as they transition back to full-time schooling.

## KEEPING UP WITH SCHOOL FRIENDS

It is important your child maintains a connection and social presence in the classroom during their absence from school. Some ways to help them keep in contact with their peers include:

- maintaining regular communication via email, text message, phone calls, video calls and social media
- ensuring they are included in class events such as footy tipping, cards, photos and posters
- for younger children, placing a teddy bear on their classroom chair
- hanging a communication bag on the chair for exchanging messages
- ensuring they are still invited to school events and remembered at appropriate times during the day.

## RETURNING TO SCHOOL

It is normal for you to be concerned about your child returning to school. You may feel it is not safe for them to return to school while they are receiving treatment. You may also worry that it will be overwhelming, that they might catch an infection, become overly tired or be teased for being different. However, it is important for your child to return to school as soon as they can after diagnosis and when they can during treatment. Most children see school as more than just a place for learning – it is also a place for socialising with peers and friends.

Your child's treating team will be able to help you plan their return to school during treatment. Once you have a likely date, you may like to meet with your child's teacher(s) and principal to discuss the next steps. Some topics you may like to discuss with the school include:

- their treatment plan and changes to their routine during treatment
- medicines they will need to take and how to give them
- special devices they need and how to use them
- what kinds of problems to look out for and report to you
- who to call with questions and emergency contact information.

## SUPPORT SERVICES AT SCHOOL

Most schools have support services available to help your child attend school as much as possible during treatment for cancer. If you feel they would benefit from additional support contact the school principal, teacher or welfare officer.

### Tips for parents: HELPING YOUR CHILD KEEP UP AT SCHOOL

- Working with your child's school and teachers throughout your child's cancer treatment is important.
- Relevant information about your child's condition should be shared with school staff when necessary.
- Maintain regular communication with the school about how your child is coping at school and home.
- Look for opportunities for your child to participate in school activities that will help them maintain a connection with their peers and wider school community.
- Ensure appropriate modifications are made to allow your child access to the school environment and curriculum.
- Explore possible sources of additional support for your child when they return to school.

## Managing sun and skin care

Protection from the sun is essential because cancer treatments can make the skin more sensitive and more easily sunburnt. To prevent sunburn, your child should wear protective clothing such as a wide-brimmed or legionnaire's hat (one with flaps of material that protect the neck) and long-sleeved clothing. They should have factor 30+ sunscreen applied to exposed skin 30 minutes before going outdoors and reapplied every two hours or after playing in water. When applying sunscreen, pay special attention to the:

- back of the hands
- tops of the feet
- back of the neck
- ears
- scalp.

If your child has hair loss as a side effect of chemotherapy, remember that hair normally protects some areas of skin. Sunscreen should be applied where they have lost hair.

If your child is receiving radiation therapy, do not apply sunscreen to the skin in the area where the radiation is being delivered. Sunscreen may have certain properties that cause the skin to burn during radiation therapy. Talk to the radiation therapy nurse about skin care following radiation therapy. Remember that sun exposure can happen all year and not just during summer. Limiting the time your child spends in the direct sun is the best way to prevent skin damage.

## Late effects of treatment

Cancer treatment can cause side effects that happen years after treatment has ended. The risk of your child developing late effects depends on the type and amount of treatment they receive. Your child needs regular follow-up care by a cancer specialist while they are a child and adolescent, and they will need continuing follow-up care throughout adulthood. This care will include regular tests to look and screen for late effects. It is important to remember that not all children will develop late effects. When they finish treatment you will receive information about long-term follow-up and referral to a long-term follow-up service.

### **Important questions to ask your child's treating team about LATE EFFECTS OF TREATMENT:**

- What late effects could my child experience after treatment is finished?
- How long will these late effects last?
- How will my child's treating team work to reduce these late effects?
- What can I do to help my child feel better?
- Will my child's fertility be affected? What are the options to preserve my child's fertility?

## PART 4: Looking after you and your family

A diagnosis of childhood cancer in the family is an overwhelming time. This chapter provides advice to support you in looking after yourself as well as looking after your relationships with family.

### Your relationships

As a parent of a child with cancer, your relationships with other people, such as your family, friends and work colleagues, may be affected. For some, support may come from family members, whereas others may rely on friends and other social networks. Family structures vary (e.g. single-parent, two parents, same-sex parents, blended families, living with extended family). Below is some advice on how to look after your relationships during your child's treatment. It is important to note that not all of this information is relevant to all families. Please speak to your child's treating team if you or your family is experiencing difficulties so they can help link you with support options. You may also find it helpful to seek support from your local community and networks.

#### YOUR PARTNER

Your child's treatment may be an emotionally stressful time for you and your partner. It is important that both of you have a thorough understanding of your child's disease and treatment. People have different ways of coping with stress, and sometimes these differences can cause conflict in a relationship. You might disagree over important issues or feel more tension in your conversations. You may see less of each other when your child is in hospital. It is important that you find time to spend together and that you talk about each other's thoughts, feelings and experience. Speak to your child's treating team if you and your partner need support during this time.

#### Respecting coping styles

Each person reacts differently to stress. Some parents may cope by withdrawing, whereas others will need to share their thoughts and feelings. At other times, you may find yourself becoming upset or angry. Some parents will want to be optimistic, whereas others may feel they are carrying the worry. For some parents, gathering as much information as possible is important, but this is not the case for everyone. It is important to understand your partner's coping style and respect the way each of you are coping with your child's illness, especially if you are coping differently.

#### Maintaining communication

Communicating about feelings, fears and information is important. By sharing your feelings and information you can stay connected and will be better able to make decisions together. It is important to understand people have different communication styles, and finding ways to share information that suits both you and your partner is important.

## Accepting changing roles

The usual roles and responsibilities you and your partner share may change during your child's treatment. These changes in roles can cause stress. It is important to remember that temporary role changes may be necessary to better support your child and family during treatment.

### Tips for parents: WORKING TOGETHER

- Recognise that you must continue to share in caring for your other children.
- Share your own feelings of anger, sadness, sorrow and hope with each other.
- Accept help from family, friends and neighbours to reduce your stress.

## WHEN FAMILIES ARE SEPARATED

It is important, where possible, for your child to have the support of both parents during treatment. If you and your child's other parent are not in a relationship together this can be difficult. This may be particularly stressful if you have had limited contact prior to your child getting sick. You may have to face issues or people that you haven't had to deal with for a long time. If you are having difficulty managing the care of your child in cooperation with their other parent, please talk to your child's treating team.

### Tips for parents: SEPARATED OR DIVORCED PARENTS

- If both parents feel comfortable, meet with your child's treating team together to avoid any confusion about your child's care.
- Share notes if one parent is not present for a meeting with the treating team.
- Ask for two copies of all information so both parents can have the same information.
- Place a copy of any court orders related to custody or visitation rights in your child's medical record.
- Talk with your child's treating team if you are having difficulty communicating with your child's other parent.

## YOUR CHILD WHO HAS CANCER

During treatment, it is likely both you and your child will experience a range of intense and complex emotions. This can sometimes lead to differences in behaviour and in the way you and your child interact. Often your relationship can become closer as you face difficult times together. At times your child will feel upset, sad or fearful and may become withdrawn. Your child may focus anger towards you because they feel secure with you in your relationship and need a safe target to express their feelings. Your child may alternate between being angry with you and being dependent on you. Your child may also want to protect you and may not want to tell you how they are feeling. It can be challenging to create times with your child that are not focused on being sick or in hospital.

Open communication and discussion about your thoughts, feelings and experiences can show your child that it is normal to have a range of emotions. This can encourage your child to ask for support when needed. Sometimes professional assistance can be helpful to facilitate open communication and discussion with your child. If you would like more information about what help may be available, please speak to your child's treating team.

## YOUR OTHER CHILDREN

Siblings of a child with cancer may feel sadness about their sibling's health, worried about their own health, jealous or angry of the attention their sibling is receiving, lonely when you are spending time away from them and guilty that their sibling is ill. Some siblings are able to cope with the extra challenges that illness brings to a family, but others find it difficult to cope. It is important to encourage your other children to communicate with you and to express their emotions openly. The needs of your other children can sometimes be overlooked, particularly in the early months of treatment when you may spend most of your time caring for your ill child in hospital or at home. They may often be cared for by family or friends, have a lot of time away from you and find their daily routine keeps changing. They may keep their feelings to themselves to avoid worrying you.

Siblings who may be struggling to deal with a cancer diagnosis may show how they feel by:

- withdrawing and becoming very quiet
- crying easily
- becoming clingy
- seeking constant reassurance
- reverting to behaviours consistent with a younger child (e.g. bedwetting, sucking their thumb, using a 'baby' voice)
- finding it difficult to sleep
- becoming frustrated and having outbursts of anger
- becoming rebellious
- falling behind in classwork or getting lower marks than usual
- starting to miss school
- becoming disruptive in the classroom
- having arguments with friends and other children in their class.

Letting the school and teachers know what is going on at home can be helpful for siblings and for the family.

The demands of caring for your child during treatment as well as trying to maintain normality for your other children can be physically and emotionally exhausting. Also, it is common for parents to feel:

- guilty about not spending enough time with their other children
- like they are not across everything that's happening
- confused by their responses or reactions.

It is important to communicate that you are there for your other children and that you understand it can be difficult to be the brother or sister of a child with cancer. Your other children may benefit from participating in activities offered by the hospitals or cancer support groups specifically for siblings. These may include family camps, patient and sibling camps, fundraisers and other child-friendly activities. If you would like more information about support or activities for your other children, please speak to your child's treating team.

#### **Tips for parents: SUPPORTING YOUR OTHER CHILDREN**

- If possible have a regular special time with each of your other children where they can discuss anything that might be on their mind.
- Make sure your other children have time for normal activities, and reassure them that it is okay to play and feel happy.
- Try to make sure your other children have access to age-appropriate and child-friendly information about their sibling's cancer.
- Include other children in the treatment plan wherever possible and appropriate – often the unknown is more frightening than the known.
- Ensure your other children understand that it is not their fault that their sibling has cancer. It is important they understand that the cancer is not related to anything they did or did not do.
- Ask if your other children can spend some time with their sibling while they are in hospital. They may also be able to suggest ideas for entertaining your sick child during treatment.
- If possible ensure your other children have a trusted adult friend outside of the immediate family who they can talk to about their worries.
- Remind your family and friends to ask about and visit your other children regularly.
- Ask for extra support for your other children at school such as for a class teacher to check on them each day.

#### **FAMILY AND FRIENDS**

Family and friends are often not sure how they can help during your child's treatment. Sometimes their attempts at helping may be misplaced but almost always their intentions are good. Sometimes you may feel overwhelmed by phone calls, visitors and advice. It may feel like you are supporting others when it is you and your child who need the support. It is not uncommon to feel disappointed by people you thought would be more supportive and surprised by others who you did not think would be so helpful.

It is important to remember that your family and friends will experience a variety of different emotions and will respond in different ways. Some will maintain little contact, usually because they don't know what to do or say. It does not mean that they do not care or are not thinking of you or your child.

It can be helpful to have a list of things prepared, such as errands or practical tasks, for when family and friends ask how they can help. Sometimes it is enough to just say 'knowing you are there is helpful'. During times of greater stress, it is helpful to ask a few trusted people to pass on information about how things are going to the rest of your family and friends. Some parents choose to send a group email or blog for friends and family who want to know how you and your child are going. This will not only minimise the number of people you need to talk to but also help others to understand your situation and support you and your family.

## GRANDPARENTS

Your parents can play an important role in helping you care for your child. At times of increased stress, you may need more help from your family, and your parents may be the major source of support. However, sometimes your parents' support may feel like interference. It is important to let your parents know what is helpful and to keep them informed of important information so they can understand your decisions. Grandparents will be distressed for you as their child and also for their grandchild. Sometimes the thoughts and feelings you both are experiencing, as well as your existing relationship, can make communication with your parents difficult. If you are experiencing difficulty in managing your relationship with your parents, please speak with your child's treating team.

## YOUR WORK COLLEAGUES

Sometimes continuing to work can be a helpful distraction from the stress of your child's treatment. Some parents view their work as a time when they feel more in control. Being at work puts them in a world away from hospital visits. It is important to tell people at work only as much as you want to tell them. Be clear about how much you want to discuss your child's illness. Some days you may only need to say 'we are fine, thanks' to your work colleagues. Other days you may want to go into more detail with particular colleagues. Most people will understand this.

## OTHER PARENTS OF A CHILD WITH CANCER

The parents you meet in hospital will have a unique perspective on your experience because they too have a child with cancer. It is common for parents to form close bonds with each other. Often parents gain a great deal of support by sharing each other's experiences. Even when children have different types of cancer and treatment, your feelings, thoughts and experiences are often similar to those of other parents.

Getting to know other children with cancer and their parents means that you may benefit from their wisdom and knowledge. You may also share their pain and triumphs. However, there may be times when you do not feel like hearing about the experience of others and that's okay. It is also important to remember that each child/family's treatment is unique to them, so it is important to be mindful of taking in information from other families that may not be relevant to your child's illness. If you would like more information about meeting other parents of a child with cancer, please speak with your child's treating team.

## Your feelings and emotions

As the parent of a child with cancer you will understandably feel worry and stress as you come to terms with what it means for your child to go through treatment. There is no right or wrong way to feel, and your emotions are likely to change over time. Some feelings and emotions you may experience are described below.

### SHOCK

Shock is one of the most common feelings experienced by parents when they are first confronted with their child's cancer diagnosis. This is a completely normal reaction that can, in the short term, cause a range of physical and emotional symptoms such as a difficulty sleeping, lack of appetite, nausea and anxiety.

### FEAR

You may feel scared, anxious and panicky about what the future holds. Sometimes the fear of the unknown may be overwhelming. This may be your child's first time in hospital. Dealing with the stress of your child adapting to a new and sometimes frightening environment can be stressful. Talking about these fears and stresses can be helpful.

## ANGER

It is normal to feel angry at times. You may feel angry with the hospital staff for putting your child through tests and treatment or for not finding an answer to what is happening to your child. You may feel angry that you have to cope with such uncertainty and the unfamiliar environment of hospitals. Some parents even feel angry with their child because their illness has turned your family life upside down. This can be distressing but is also normal.

## GUILT

It is very common for parents to feel guilty. You may wonder if it was something you did or didn't do that caused your child's cancer. Some parents blame themselves for not noticing their child's symptoms quickly enough. Many parents will have strong feelings of guilt, but it is important to remember that you are not responsible for your child's cancer.

## SADNESS

It is normal to feel sad or depressed at times. Feeling sad is a common reaction because every parent wants their child to be healthy and happy. Your child's cancer treatment can be demanding and cause changes in your family life. You may experience crying spells, decreased or increased appetite, decreased energy, lack of concentration and even physical symptoms such as headaches or tightness in your chest.

## COPING WITH YOUR FEELINGS AND EMOTIONS

There are many people who can help you deal with these difficult feelings and emotions. You may want to talk to someone close to you such as your partner or another family member or friend. Talking with your child's treating team or another parent of a child with cancer may also be helpful. Some people find it easier to talk to someone they don't know so well. Individual or family counselling may also allow you to express your feelings.

## Your work

It is sometimes very difficult for families to manage their work commitments and to know when to return to work. It is important that you don't rush into any hasty decisions about your job. Instead speak with your employers about your situation and what flexible working arrangements they may be able to offer you. If you feel you are unable to work, are having difficulty arranging time away from work or your employer needs documentation about your child's condition, please speak to your child's treating team.

## Your social life

It is understandable that when you are feeling unhappy you may want to avoid seeing friends. You may also find it difficult to find time to take part in social activities. Try to maintain social connections and normal activities as much as possible and when your energy allows. You can keep connected with friends via a private blog, email or Facebook group.

## PART 5: A to Z of cancer diagnosis, treatment and the treating team

<b>Acute</b>	Severe and occurring suddenly.
<b>Acute lymphoblastic leukaemia (ALL)</b>	A cancer of the blood and bone marrow that affects immature white blood cells called lymphoblasts.
<b>Acute myeloid leukaemia (AML)</b>	A cancer of the blood and bone marrow that affects immature white blood cells called myeloblasts.
<b>Administrative staff</b>	Staff who support medical, nursing and allied health staff to help them run services efficiently.
<b>Allogenic transplant</b>	A type of bone marrow transplant using stem cells donated from another person.
<b>Alopecia</b>	Loss of body hair.
<b>Amputation</b>	Surgical removal of all or part of a limb. For some children with solid tumours, such as osteosarcoma, amputation surgery of the affected limb may be required. Advances in childhood cancer treatments mean that amputation surgery is needed less often.
<b>Anaemia</b>	A deficiency in the number or quality of red blood cells.
<b>Antibiotics</b>	A medicine used to treat infection.
<b>Art therapist</b>	Art therapists use a variety of art media to help express feelings, thoughts, fears and experiences. These may be about their illness, treatment and being in hospital.
<b>Assent</b>	A child's agreement to medical procedures in circumstances where he or she is not legally authorised to give consent.
<b>Associate nurse unit manager (ANUM)</b>	ANUMs are experienced nurses responsible for running the ward or day cancer centre during each shift.
<b>Astrocytoma</b>	A cancer that develops from the star-shaped cells called astrocytes that form the supportive tissue of the brain.
<b>Audiogram</b>	A hearing test performed by an audiologist. Some drugs can affect hearing. Baseline hearing tests and regular tests during treatment are done with children who receive these drugs to monitor any changes to hearing.
<b>Audiologist</b>	Audiologists check a person's hearing. This is important because some antibiotics and chemotherapy can affect hearing.



<b>Autologous transplant</b>	A type of bone marrow transplant using a person's own stem cells.
<b>Bacteria</b>	Living one-celled organisms that are only visible through a microscope (while most bacteria are harmless, it can cause disease if the body's resistance is lowered).
<b>Bacterial infection</b>	An infection caused by bacteria.
<b>Benign tumour (buh·nain tyoo.muh)</b>	A non-cancerous mass of cells (tumour) that do not spread to other parts of the body.
<b>Biopsy</b>	The removal of a small piece of tissue most often done to examine tissue for disease. The surgeon may remove a part of the tumour tissue, either by inserting a small needle through the skin (needle biopsy) or by doing a small operation (open biopsy). The biopsied tissue is then examined to determine whether it is malignant and exactly what type of tumour it is.
<b>Blood count</b>	A laboratory test to count the number of white blood cells, red blood cells and platelets in a sample of blood. Blood counts are one of several different ways to monitor the effects of treatment. There are three different types of blood cells: red, white and platelets. The blood count for each child depends on their age, type of cancer and the type of treatment.
<b>Blood collector (pathology)</b>	Blood collectors take finger-prick samples and take blood samples needed to establish blood counts.
<b>Blood tests</b>	An examination of a sample of blood, taken to identify the presence of an infection, disease or medical condition.
<b>Blood transfusion</b>	The transfer of blood or blood components to the patient.
<b>Bone marrow</b>	The sponge-like material in the centre of bones that is responsible for manufacturing blood cells.
<b>Bone marrow aspiration (BMA)</b>	A sample of bone marrow removed for examination by inserting a special needle usually into the hip bone under anaesthetic. This is done to see whether the cancer has affected the bone marrow.
<b>Bone marrow transplant (BMT)</b>	A procedure to replace damaged or destroyed bone marrow with healthy bone marrow stem cells.

<b>Bone scan</b>	An imaging test used to see if there is any cancer present in the bone(s). An injection of radioactive material (isotope) is given first and then a scan performed a couple of hours later. Where there is increased cell activity the isotope will accumulate and become visible on the scan, which determines the location and severity of bone diseases or infection.
<b>Central line</b>	A long, thin, flexible tube inserted into a large vein used to give medicines, fluids, nutrients or blood products over a long period of time (several months or years). There are different types of central lines – for example, ports, PICCS and Hickman's.
<b>Central nervous system (CNS) tumour</b>	A tumour that develops in the brain or spinal cord.
<b>Cerebrospinal fluid (CSF)</b>	A colourless fluid that surrounds the brain and spinal cord.
<b>Chaplain</b>	Chaplains provide spiritual, emotional and religious support. You don't need to belong to a religious group or church to ask for a chaplain's help.
<b>Chemotherapy</b>	The use of drugs to treat cancer. Chemotherapy drugs (also called cytotoxic medicines) circulate throughout the body to damage or destroy cancer cells.
<b>Child life therapist</b>	Child life therapists (formerly called 'play therapists') use play to reduce anxiety about an unfamiliar place and to help children understand medical procedures. Play therapy can be at the bedside or in a playroom.
<b>Chronic</b>	Persisting for a long time or constantly recurring.
<b>Clinical nurse consultant/coordinator</b>	A clinical nurse consultant/coordinator coordinates a child's care and ensures the treatment plan is followed. The nurse consultant coordinates appointments and is the link between you and your child's treating team.
<b>Clinical research associate (CRA)</b>	Clinical research associates are also known as data managers or clinical trial coordinators. They make sure that research and clinical trials are approved by the ethics committees and that the child's treatment plan follows the approved research procedures and clinical trial. They also liaise with trial sponsors and collect and manage research data.

<b>Clinical trial</b>	A research study that evaluates the effects of different treatments on health outcomes
<b>Computed tomography (CT) scan</b>	A type of scan that uses x-rays to create a cross-sectional image of all or part of the body. A needle may be required to inject contrast to get a better picture of the tumour and its relationship to other structures. A CT scan usually takes less than five minutes. A sedative or general anaesthetic may be needed to ensure the child stays still during the scan.
<b>Consultant oncologist</b>	A specialist in treating and managing childhood cancers. Consultant oncologists order tests, make the diagnosis of cancer and develop a treatment plan for your child. They will oversee your child's care throughout treatment.
<b>Contagious</b>	A disease spread from one person to another, typically by direct contact.
<b>Cytotoxic</b>	Any agent or process that kills or is toxic to living cells.
<b>Debulking</b>	Surgical removal of part of a tumour. Debulking the tumour may be recommended to reduce the size of a tumour before chemotherapy or radiation therapy begins.
<b>Diagnosis</b>	Identifying the nature of an illness or disease by examining the symptoms.
<b>Dietitian</b>	Dietitians monitor growth and nutritional needs and provide special diets and suggestions for ways to help maintain a child's weight during and after treatment.
<b>Echocardiogram (echo)</b>	An ultrasound test used to assess heart function. Some chemotherapy drugs have the potential to affect heart function. Heart function is monitored at regular intervals when these drugs are used, and will be done at diagnosis to obtain baseline heart function before treatment begins.
<b>Electrocardiogram (ECG)</b>	A test that records the rate, rhythm and electrical activity of the heart.
<b>Enucleation</b>	Surgical removal of the eye. For children with retinoblastoma, removal of the affected eye may be required. Advances in childhood cancer treatments mean that enucleation surgery is needed less often.
<b>Ependymoma</b>	A type of brain tumour.

<b>Ewing's sarcoma</b>	A cancer that develops in the bones or occasionally in the brain or soft tissue.
<b>Fellow</b>	Oncology fellows are doctors training to specialise in cancer and blood disorders, who also supervise registrars.
<b>Gallium scan</b>	A test to look for swelling (inflammation), infection or cancer in the body using a radioactive material called gallium. Before the scan, an injection of gallium is given. Gallium gathers at the sites of infection or malignancy. The first scan is usually done 48 hours after the injection and a second scan is done a week later.
<b>General anaesthesia (a.nuhs.thee.zee.uh)</b>	A medically induced state of unconsciousness or sleep.
<b>Glomerular filtration rate (GFR)</b>	A laboratory test used to check how well the kidneys are working from multiple samples of blood taken on the same day. Some drugs have the potential to affect kidney function. Children having these drugs have their kidney function monitored regularly during treatment.
<b>Haemoglobin</b>	The protein responsible for carrying oxygen in the blood to tissues and organs in the body.
<b>Hereditary</b>	Passed on from a parent to child.
<b>Informed consent</b>	A formal agreement that is signed by a parent or guardian that gives permission for a medical procedure or treatment after being told about the risks and benefits.
<b>Insufion</b>	When a drug needs to be injected several times, a small device called an Insufion can be inserted under the skin and can stay there for up to seven days. It can be inserted into the skin of the abdomen, thigh or upper arm. The Insufion allows drugs to be administered without the need for repeated injections. With the Insufion in place a child can continue with activities of normal daily living, including bathing. At home the Insufion site should be checked regularly for signs of swelling, redness or discharge.
<b>Intramuscular injection</b>	An injection into muscle
<b>Leukaemia</b>	Cancer of the blood cells.

<b>Lumbar puncture (LP)</b>	A test that involves inserting a needle into the lower spine to collect a small sample of cerebrospinal fluid (CSF) for examination. With some cancers, such as leukaemia or lymphoma, malignant cells can pass into the brain and CSF fluid around the brain. To find out whether this has occurred an LP is performed.
<b>Lymphatic system (lim.fat.ick)</b>	A network of vessels through which fluid drains from the tissues into the blood.
<b>Lymphoma</b>	A cancer of the lymphatic system that starts in white blood cells called lymphocytes. It may be either Hodgkin's or non-Hodgkin's lymphoma.
<b>Magnetic resonance imaging (MRI) scan</b>	An imaging test that uses powerful magnets and radio waves to create pictures of the body. An MRI can give an accurate picture of a tumour and the surrounding structures. Sometimes a special fluid called contrast is injected into the blood to get a better picture of the tumour and its relationship to other structures.
<b>Malignant tumour (muh.lig.nuhnt tyoo.muh)</b>	A cancerous mass of cells (tumour) that grow out of control and can spread to other parts of the body.
<b>Medulloblastoma</b>	A type of brain tumour.
<b>Medical imaging department</b>	The department where tests such as CT, x-ray, ultrasound and MRI are done. Medical imaging may also be called radiology.
<b>Mental health clinician</b>	Mental health clinicians include psychologists, family therapists, psychiatrists and psychotherapists. A mental health clinician can assess and treat the emotional and behavioural issues affecting children with cancer and their families. These may include anxiety about medical procedures and hospital admissions, changes in children's behaviour and mood, difficulties with siblings and family relationships.
<b>Metastasis (muh·ta·stuh·suhs)</b>	The spread of cancer from the place where it first occurred as a primary tumour to distant locations in the body.
<b>Mucositis</b>	The inflammation and ulceration of the mucous membrane.
<b>Mucous membrane</b>	A thin, wet layer of skin that is inside some parts of the body such as the mouth and digestive tract.

<b>Multidisciplinary</b>	A multidisciplinary team includes medical, nursing, allied health and support care professionals, who work together to plan and deliver treatment.
<b>Music therapist</b>	Music therapists use music to give the child a way to express their feelings. This can help relaxation and pain control, focus on healthy parts of the body and lets the child make choices and have a sense of control.
<b>Nasogastric (NG) tube</b>	A thin, flexible tube passed through the nose and into the stomach to administer food and medicine when a child cannot take food or drink by mouth. This tube is used to give liquids including nutrition and medicine.
<b>Neuroblastoma</b>	A cancer that develops from immature nerve cells most commonly occurring in the adrenal glands.
<b>Neuropsychologist</b>	Neuropsychologists investigate the relationship between the brain and behaviour. They look at different aspects of thinking, learning and problem solving. Neuropsychological assessments allows progress to be monitored and, if there are problems, the neuropsychologist can recommend suitable ways to manage them.
<b>Neutropenia</b>	A lower than normal number of neutrophils in the blood.
<b>Neutrophils</b>	A type of white blood cell that helps fight infection.
<b>Nurse unit manager (NUM)</b>	The NUM has overall responsibility for nursing care in the ward or outpatient/day cancer centre.
<b>Nursing staff</b>	Nursing staff provide day-to-day nursing care, including giving chemotherapy, both in the ward and in the outpatient/day oncology area.
<b>Occupational therapist</b>	Occupational therapists help when a child has difficulty with daily tasks such as play, self-care or school activities. Occupational therapists assess and treat these difficulties with a focus on decreasing the impact of disability and improving the quality of life.

<b>Oncology pharmacist</b>	Oncology pharmacists prepare and dispense the drugs used to treat cancer and check that the prescription is correct. Oncology pharmacists work closely with the medical and nursing staff and can tell you and the team about chemotherapy and its side effects.
<b>Orthotist</b>	Orthotists design and make supportive braces (orthoses) to improve comfort, maintain alignment or assist with mobility.
<b>Osteosarcoma</b>	A cancer of the bone that develops from immature bone cells.
<b>Percutaneous endoscopic gastrostomy (PEG)</b>	A gastrostomy is a feeding tube placed through a hole made directly the abdominal wall into the stomach.
<b>Patient services assistant (PSA)</b>	PSAs help in the cleaning and maintenance of the ward and in some hospitals assist the health team with daily ward help, like delivering food and messages.
<b>Peripheral neuropathy</b>	Damage to the nerves that causes numbness, tingling and weakness in the hands and feet.
<b>Petechiae</b>	Small red spots (bruises) on the skin that may indicate a low platelet count.
<b>Platelet</b>	A type of blood cell that helps to clot blood to stop bleeding.
<b>Physiotherapist</b>	Physiotherapists work with children to improve muscle strength, flexibility, balance and coordination through exercises, games and activities. Education plays a key role in assisting families in maximising their child's physical activity. A physiotherapist may also be involved if a child develops respiratory complications during their treatment.
<b>Positron emission tomography (PET) scan</b>	A type of imaging test that shows the size, shape and scan position of tissues and organs in the body and how well they are working. A small amount of radioactive chemical is injected or breathed in. PET scans can help identify tumours.
<b>Primary tumour</b>	The first tumour that occurs in the body when cancer cells begin to divide.
<b>Procedural pain clinician</b>	Procedural pain clinicians specialise in child development and focus on providing support during procedures to children and families throughout their cancer treatment.

<b>Prosthetist</b>	Prosthetists design, make and fit artificial limbs (prostheses) where an amputation has been necessary. A prosthesis may also be a replacement for another part of the body that may have been removed, such as an eye or limb.
<b>Psychologist</b>	A psychologist can assess and treat the emotional and behavioural issues affecting children with cancer and their families.
<b>Pulmonary function tests</b>	A group of tests that measure how well the lungs take in and release air and how well they move gases such as oxygen from the atmosphere into the body's circulation.
<b>Radiation oncologist</b>	A medical specialist who has specific training in managing patients requiring radiation therapy as part of treatment.
<b>Radiation therapy</b>	Radiation therapy (also called radiotherapy) is the use of high-energy x-rays to damage or destroy cancer cells so these cells can no longer divide.
<b>Red blood cell</b>	Blood cells that carry oxygen around the bloodstream.
<b>Registrar</b>	Doctors doing specialist training.
<b>Resection (of a primary tumour)</b>	The surgical removal of all or most of the primary tumour, which may happen before or after chemotherapy. In some cases, complete removal of the tumour may be the only treatment needed. Sometimes, due to the size of the tumour or its location, the entire tumour cannot be removed. In this case, chemotherapy or radiation therapy may be given before the surgery to shrink the tumour so it is easier to remove.
<b>Resident</b>	Residents (also called 'resident medical officers' or 'RMOs') are qualified doctors who are getting experience in a hospital as part of their graduate medical training.
<b>Retinoblastoma</b>	A rare tumour that develops from the immature cells of the retina or light-detecting tissue in the eye.
<b>Rhabdomyosarcoma</b>	A cancer that develops from cells that normally develop into skeletal muscles.
<b>Risk stratification</b>	The process by which the healthcare team use information to establish the risk of relapse, and tailor therapy to reduce this risk.

<b>Roadmap</b>	A plan for treating cancer that details required tests and procedures. This is the shorter version of a protocol or treatment plan.
<b>Secondary tumour</b>	Cancer cells that have spread to another part of the body.
<b>Second-look procedure</b>	Some children with solid tumours and brain tumours may have a 'second look' procedure three to six months after the initial surgery. Treatment (chemotherapy and/or radiation therapy) may have shrunk the tumour, and the tumour may now be easier to remove surgically. Second-look procedures may also be performed to check the area where the tumour was located to make sure it hasn't come back or to take a sample of the surrounding tissue for testing.
<b>Social worker</b>	Social workers provide emotional and practical support and counselling and can link children and families with other resources and services.
<b>Solid tumour</b>	A type of childhood cancer that forms an abnormal mass of tissue that usually does not contain cysts or liquid areas.
<b>Speech pathologist</b>	Speech pathologists assess and treat speech, language and eating abilities. Speech pathologists can work with the child and family to set realistic communication goals. If there are chewing and swallowing difficulties, a speech pathologist can suggest suitable foods and feeding positions.
<b>Staging</b>	The process of determining how much cancer is in the body and where it is located.
<b>Stem cell</b>	A cell from which a variety of other cells in the body develop.
<b>Steroid</b>	A medicine used to relieve swelling and inflammation.
<b>Teaching and education support officer</b>	Different hospitals have varying resources available to support children to remain connected to school and to support learning while in hospital.
<b>Thrombocytopenia</b>	A lower than normal number of platelets in the blood.
<b>Total parenteral nutrition (TPN)</b>	A method of getting nutrition into the body through the veins used when a child cannot receive food or fluids by mouth.

<b>Treatment plan</b>	A treatment plan or protocol is a 'recipe' for treatment and includes the doses and the timing of drugs and other treatments. The treatment plan also lists many of the tests necessary before and during treatment, the criteria before starting each phase or block of treatment and other relevant information. The protocol may be from a clinical trial if your child is enrolled in one, or from an established treatment plan.
<b>Tumour (tyoo.muh)</b>	An abnormal mass of tissue that may be cancerous or non-cancerous.
<b>Ultrasound</b>	An imaging test that uses sound waves to create a picture of the organs. Ultrasound waves are sound waves that the human ear cannot hear. A special machine directs waves at a certain part of the body. Differences in how the sound waves are reflected helps form an image, which includes normal structures in the body, blood flow and abnormal growths.
<b>Volunteer</b>	Volunteers help with things such as sitting with your child if you need a break. They are often on the ward and can be a great help to you and your child.
<b>Ward clerk</b>	Ward clerks do many things in the ward – making appointments, answering telephones, filing and keeping medical records.
<b>White blood cell</b>	Blood cells that are involved in protecting the body from infection.
<b>Wilms' tumour</b>	A tumour of the kidney (also known as nephroblastoma) that typically occurs in children.
<b>X-ray</b>	An imaging test that sends individual particles through the body to create a picture of structures in the body. Because tumour tissue looks different from ordinary bone or normal tissue, an x-ray can show whether there is a tumour and can also look for signs of infection if your child is unwell.

## Useful websites

(in alphabetical order)

**Australian and New Zealand Children's Haematology/Oncology Group**

<https://anzchog.org/>

**Cancer Australia – Children's cancer**

<https://childrenscancer.canceraustralia.gov.au>

**Cancer Council Victoria – Children, teens and young adults**

<https://www.cancervic.org.au/cancer-information/children-teens-and-young-adults>

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

[www.cclg.org.uk](http://www.cclg.org.uk)

## Children's Oncology Group (USA)

[www.childrensoncologygroup.org](http://www.childrensoncologygroup.org)

**Monash Children's Hospital – Cancer**

[www.monashchildrenshospital.org/cancer/](http://www.monashchildrenshospital.org/cancer/)

**National Cancer Institute**

<https://www.cancer.gov/types/childhood-cancers>

## Paediatric Integrated Cancer Service (PICS)

[www.vics.org.au/pics](http://www.vics.org.au/pics)

**Peter MacCallum Cancer Centre**

<https://www.petermac.org/cancer/paediatric>

**The Royal Children's Hospital Children's Cancer Centre**

[www.rch.org.au/ccc](http://www.rch.org.au/ccc)

## Notes

### **Paediatric Integrated Cancer Service**

Administrative Host:

The Royal Children's Hospital

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