The aim of developing this Information Book has been to provide reliable information to parents and families of children affected by childhood cancers. A diagnosis of childhood cancer in the family is an overwhelming time and raises may questions. This book has been compiled with comprehensive information about childhood cancers, tests and available treatments, caring for your child and your family during this period and the staff, services and facilities available at the primary cancer treatment centres and regional hospitals.

You are encouraged to review this book and seek information, however it is advisable to always discuss and seek answers from your child’s treating team who will be able to provide you with supplementary information customised to your child’s illness and your family needs.

It is hoped the book will be a resourceful guide to provide preliminary information and support to you and your family during your child’s cancer journey.
The Information Book has been developed by the Paediatric Integrated Cancer Service (PICS) for parents and families of a child with cancer. PICS is primarily a partnership between The Royal Children’s Hospital, Monash Children’s at Southern Health and The Peter MacCallum Cancer Centre. PICS is committed to strengthen the quality, consistency and integration of cancer care throughout Victoria. More information about PICS can be obtained by accessing the PICS website on www.pics.org.au

The Information Book is a revised version of A Guide For Parents Of Children With Cancer (2000). The Guide was written and produced by the nursing team at the Children’s Cancer Centre at the RCH and has been revised in 2006 and again in 2011 by the PICS.

PICS would like to acknowledge the staff of the Children’s Cancer Centres at both the RCH and Monash Children’s and the paediatric services at the Peter Mac and the regional centres for their clinical advice and review. The Victorian Children’s Cancer Parent and Family Advisory Group has again provided valuable insight and counsel to this edition which we are thankful for.

We are grateful to the KOALA Foundation and the Children’s Cancer Centre Foundation for funding the costs of printing The Information Book.

Produced by the Educational Resource Centre
The Royal Children’s Hospital, Melbourne
50 Flemington Road
Parkville 3052

Supported by

KOALA Foundation

Children’s Cancer Centre Foundation
Supporting research and clinical care for children with cancer and their families

Monash Children’s Hospital

Peter Mac

The Royal Children’s Hospital Melbourne

Developed by the Paediatric Integrated Cancer Service for use by the Children’s Cancer Centres at The Royal Children’s Hospital, Monash Medical Centre (MMC) at Southern Health and The Peter MacCallum Cancer Centre. July 2012

Updated July 2012
The Information Book has the following sections:

**Quick Help**  
*Quick Help – The Royal Children’s Hospital*  
*Hot numbers – The Royal Children’s Hospital*  
How to contact the CCC at The Royal Children’s Hospital

*Quick Help – Monash Children’s*  
*Hot numbers – Monash Children’s*  
How to contact the CCC at Monash Children’s

*Hot numbers – Peter Mac*

**Section 1**  
**Your Child** is about your child’s diagnosis and what will happen next

**Section 2**  
**Your Child’s Hospital** is about the ward, outpatients, the emergency department, hospital and local facilities

**Section 3**  
**Cancer** is about childhood cancers, tests and procedures, treatment and side effects, clinical trials and what happens after treatment

**Section 4**  
**Caring for your child and family** is about helping your child cope with illness and procedures, nutrition, school and relationships

**Section 5**  
**Your child’s treating team** is about all the different people who work in the hospital as a team to care for your child

**Section 6**  
**Support and Assistance** contains information about financial support and social support groups, charities and philanthropic organisations

**Section 7**  
**Information Resources** is a guide to some online resources and safety tips when using social media

**Section 8**  
**Frequently Asked Questions** is a compilation of common questions asked by families

**Section 9**  
**Glossary** of abbreviations and terms used in the hospitals
Contents

The Royal Children's Hospital
Quick Help
Hot numbers
How to contact the CCC

Monash Children's
Quick Help
Hot numbers
How to contact the CCC

Peter Mac
Hot numbers

1 Your child
1.1 Your child’s details
1.2 Your child's diagnosis
1.3 What happens next?
1.5 Your child's team
1.5 Children’s Cancer Centres

2 Your child's hospital
2.1:1 The Royal Children’s Hospital (RCH)
2.1.2 The ward
2.1.2 How the ward works
2.1.2 Staff
2.1.3 Emergency department
2.1.2 Day Cancer (Outpatients)
2.1.5 Coming to the hospital: what to bring
2.1.6 At the hospital
2.1.12 Discharge planning
2.2.1 Monash Children’s
2.2.2 The ward
2.2.2 How the ward works
2.2.2 Staff
2.2.3 Emergency department
2.2.3 Children’s Cancer Centre (Outpatients)
2.2.4 Coming to the hospital: what to bring
2.2.5 At the hospital
2.2.10 Discharge planning

2.3.1 Peter MacCallum Cancer Centre (Peter Mac)
2.3.2 The ward
2.3.2 How the ward works
2.3.2 Staff
2.3.3 Outpatients
2.3.5 Coming to the hospital: what to bring
2.3.6 At the hospital

2.4.1 Your child’s regional hospital
2.4.2 Map of regional zones

3 Cancer
3.1 What are childhood cancers?
3.4 Tests and procedures to diagnose cancer
3.8 Cancer treatments
3.12 Medication and sharps returns and disposals
3.16 Side effects
3.25 Clinical trials
3.29 Off treatment and Long Term Follow-up (LTF)

4 Caring for your child and family
4.1 If your child is sick
4.3 Infection
4.5 Immunisation
4.6 Helping your child cope with illness
4.8 Helping your child cope with tests and medical procedures
4.11 Eating well
4.16 Oral and dental care
4.18 School support
4.26 Exercise and activity during treatment
4.26 Pets, Sunsmart, wigs, holidays
4.28 Taking care of your relationships

5 Your child's treating team
5.1 Doctors
5.2 Nursing staff
5.3 Allied Health
5.6 Support staff
5.7 Communication with your child's team

6 Support and assistance
6.1 Welfare services and entitlements
6.2 Other assistance
6.3 Hospital-based information groups
6.5 Support groups
6.6 RCH support groups
6.9 Monash Children's support groups

7 Information resources
7.1 Seeking information
7.4 How to safely use social media

8 Frequently Asked Questions

9 Glossary
9.1 What does that word mean?
9.7 What does that abbreviation mean?
Quick Help – RCH

If you are concerned about any of the following call the Nurse Coordinator Hot Line (Monday to Friday 9.00am – 4.30pm) or the ward and ask to speak to the nurse in charge.

After hours please call the ward and ask to speak with the nurse in charge.

- Any time your child does not feel well or look right
- Any time you are worried about your child
- If temperature is 38°C or above
- Infection – redness, tenderness anywhere on the body
- Contact with Chicken Pox, Measles or Mumps
- Bleeding – nose bleed for more than five minutes, bleeding gums, bruising or petechiae (tiny red or purple flat spots on the skin)
- Excessive tiredness, paleness, shortness of breath
- Dehydration – decreased urine, dry mouth, no tears when crying
- Pain – severe or persistent
- Refusing to drink
- Not swallowing saliva
- Missed a dose of medication (call Pharmacy)
- Vomiting less than half an hour after medication (call Pharmacy)

Nurse Coordinator Hot Line 9345 5677
Kookaburra Ward Nurses Station (all hours) 9345 5645
Emergency Department (triage desk) 9345 6139
RCH Switchboard 9345 5522
Cancer Pharmacy 9345 6290
# Hot numbers – RCH

## Children’s Cancer Centre at The Royal Children’s Hospital

These numbers may help you. Keep them where it suits you – in this book, on your fridge or in your diary. Please ask your nurse coordinator for extra copies if required.

<table>
<thead>
<tr>
<th><strong>Emergency numbers</strong></th>
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<tbody>
<tr>
<td>Registrar or Fellow (ask switch to page)</td>
<td>9345 5522</td>
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<td>Emergency Department triage desk</td>
<td>9345 6139</td>
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<td><strong>RCH Switchboard</strong></td>
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<td>RCH Switchboard</td>
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<td><strong>Clinical numbers</strong></td>
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<td>Cancer Pharmacy</td>
<td>9345 6290</td>
<td></td>
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<tr>
<td>Day Cancer</td>
<td>9345 5603</td>
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<td>RCH Inpatient wards via switchboard</td>
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<td></td>
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<td>RCH Outpatient appointments</td>
<td>9345 5605</td>
<td></td>
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<tr>
<td><strong>Nursing</strong></td>
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<tr>
<td>Nurse coordinator’s hot-line (Mon – Fri 9:00 am – 4:30 pm)</td>
<td>9345 5677</td>
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<tr>
<td>Kookaburra ward nurses station (all hours)</td>
<td>9345 5645</td>
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<tr>
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<td>9345 5649</td>
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<tr>
<td>Day Cancer nurse unit manager</td>
<td>9345 9444</td>
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<tr>
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<td>Psychosocial Services appointments and referrals</td>
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<tr>
<td>Interpreter Services</td>
<td>9345 5998</td>
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<tr>
<td><strong>Administration</strong></td>
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<tr>
<td>CCC community liaison manager</td>
<td>9345 4855</td>
<td></td>
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<tr>
<td>CCC administration and management</td>
<td>9345 5656</td>
<td></td>
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<tr>
<td>CCC billing enquiries</td>
<td>9345 5605</td>
<td></td>
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</tbody>
</table>
CCC fax 9345 6524
RCH Consumer liaison officer 9345 5676

**Other telephone numbers**
Ronald McDonald House
Parent accommodation 9345 5359
Office 9345 6300
Parents’ kitchen 9345 6319
Family Resource and Respite Centre 9345 4662 or 9345 4660

**Street address**
Children’s Cancer Centre
Level 2
The Royal Children’s Hospital
50 Flemington Road
Parkville Victoria 3052
Melway Reference Map 43 3E

**Public transport**
Tram Numbers 55 from William Street
59 from Elizabeth Street
How to contact the CCC at The Royal Children's Hospital

You need to contact the CCC at The Royal Children's Hospital

**Urgent concerns**
- eg. your child is unwell, has a temperature >38°C

**Monday-Friday 9am-4.30pm**
- Ring the CNC* Hotline
  - 03 9345 5677
- Call your CNC* directly or page via the hospital switchboard
  - 03 9345 5522

**Weekends and after business hours OR if unable to contact via CNC* phones**
- Call the ward and ask to speak to the nurse in charge
  - 03 9345 5645

**Non-urgent concerns**
- Call your CNC* directly. Mon-Fri calls will be returned by the end of the day (please note Working days for each CNC*)

**Medication Enquiries**
- Call the Cancer Pharmacy
  - 9am-5.30pm
  - Mon-Fri
  - 03 9345 6290

**Appointment Enquiries**
- Call the CCC Outpatients Clerks
  - 9am-5pm
  - Mon-Fri
  - 03 9345 5605

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* CNC: Clinical Nurse Coordinator
Quick Help – Monash Children’s

Call your hospital if you are concerned about any of the following:

- Any time your child does not feel well or look right
- Any time you are worried about your child.
- If temperature is 38°C or above, during business hours call the CCC and seek advice. After hours, call the switch and ask them to page the paediatric registrar.
- Infection – redness, tenderness anywhere on the body
- Contact with chicken pox measles, or mumps
- Bleeding – nose bleed for more than five minutes, bleeding gums, bruising or petechiae (tiny red or purple flat spots on the skin)
- Excessive tiredness, paleness, shortness of breath
- Dehydration – decreased urine, dry mouth, no tears when crying
- Pain – severe or persistent
- Refusing to drink
- Not swallowing saliva
- Missed a dose of medication
- Vomiting less than half an hour after medication

CCC Reception (business hours)  9594 7660
Nurse coordinator (business hours)  9594 7657
Paediatric registrar via switch (after hours)  9594 6666
Hot numbers – Monash Children’s

Children’s Cancer Centre at Monash Children’s

These numbers may help you. Keep them where it suits you – in this book, on your fridge or in your diary. Please ask your nurse coordinator for extra copies if required.

**Emergency numbers**
- Paediatric registrar or oncology fellow (ask switch to page) 9594 6666
- Nurse coordinator 9594 7657
- MMC Emergency desk 9594 2149
- MMC Switchboard 9594 6666

**Clinical numbers**
- Children’s Cancer Centre – Day Oncology Unit 9594 7660
- Inpatient 41N Ward nurses station 9594 4160
- Inpatient 42N Ward nurses station 9594 4260

**Administration**
- CCC Administration and management 9594 7660
- CCC Patient Accounts 9594 7660
- MMC consumer liaison officer 9594 2702
- CCC fax number 9594 6292

**Medical Appointments**
- Outpatient appointment bookings 9594 7660

**Pharmacy and pathology**
- MMC pharmacy (phone switchboard and page paediatric oncology pharmacist) 9594 6666 Pager #4223
- Paediatric oncology pharmacist 9594 7662
- Outpatient pathology blood tests 9594 7660
Ronald McDonald House – Monash Medical Centre
Ronald McDonald House accommodation  9594 3588

Social work and interpreters
Social work (via CCC reception)  9594 7660
Interpreters service  9594 2374

Street address
Children’s Cancer Centre
Level 2, Monash Medical Centre
246 Clayton Road
Clayton VIC 3168
Melway Reference Map 79 1D

Public transport
Pakenham train line to Clayton Station

Postal address
Locked Bag 29
Clayton South VIC 3169
How to contact the CCC at Monash Children's

You need to contact the CCC at Monash Children's

- All calls URGENT AND NON-URGENT
  - Monday-Friday 8.30am-5.00pm
    - Call the CNC* Hotline 03 9594 7657
  - Weekends and after business hours call the switchboard 03 9594 6666 and ask to have the Paediatric Registrar paged

- Medication Enquiries
  - Call the Oncology Pharmacist 9am-5.30pm Mon-Fri in the CCC 03 9594 7662

- Appointment Enquiries
  - Call the CCC 9am-5pm 03 9594 7660
Hot numbers – Peter Mac

These numbers may help you. Keep them where it suits you – in this book, on your fridge or in your diary. Please ask your nurse coordinator for extra copies if required.

**Emergency numbers**
- Paediatric nurse coordinator (direct line) 9656 1756
- Paediatric nurse coordinator (page through switchboard) 9656 1111
- Monday – Wednesday pager #7405
- Wednesday – Friday pager #1335

**Switchboard**
- Peter Mac switchboard 9656 1111

**Clinical numbers**
- Ward 9 nurses station 9656 1099

**Administration**
- Admissions office (reception) 9656 1335
- Complaints officer 9656 1870
- Paediatric and adolescent administration and management 9656 1756

**Medical Appointments**
- Outpatient appointment bookings 9656 1313

**Pharmacy and Pathology**
- Pharmacy 9656 1018
- Outpatient pathology blood tests 9656 1694

**Cancer Imaging**
- PET scan 9656 1833
- Diagnostic imaging reception 9656 1026

**Radiotherapy and Nuclear Medicine**
- Radiotherapy planning reception 9656 1389
- Radiotherapy treatment reception 9656 1349
- Nuclear medicine 9656 1231
Social Work
Social Work Department

Street address
Peter MacCallum Cancer Centre
St Andrews Place, East Melbourne VIC 3002
Melway Reference 2G and 2A

Public transport
Parliament Station/Tram numbers 12, 109, 48, 75.
1 Your child

Your child’s details

These are the details we have from your child’s hospital records. If we need to contact you, these are the details we will use. Please tell us if they change or need updating.

YOUR CHILD’S NAME:

UNIT RECORD NUMBER:

UR (RCH):          (MMC):           (Peter Mac):

MEDICARE NUMBER:

CONCESSION CARD NUMBER:

HOME ADDRESS:

HOME TELEPHONE:

PARENT / CARER:

MOTHER’S NAME:

Mobile:   Work telephone:

FATHER’S NAME:

Mobile:   Work telephone:

YOUR CHILD’S CONSULTANT ONCOLOGIST:

OTHER MEDICAL:

COMFORT FIRST:

DIETITIAN:

NURSE COORDINATOR:

SOCIAL WORKER:

(Affix label here)
YOUR CHILD’S DIAGNOSIS:

Your child has been diagnosed with a type of cancer called:

This is a cancer of the:

For children from regional areas

REGIONAL CENTRE:

ADDRESS:

UNIT RECORD NUMBER:

Children’s Ward phone:

Nurse Unit Manager phone:

GP phone:

Address:

Paediatrician phone:

Address:

OTHER IMPORTANT CONTACTS:

Your child’s diagnosis

The hospital where the diagnosis of cancer is made, and the treatment plan decided for your child, is referred to as the Primary Treatment Centre (PTC). There are two children’s cancer primary treatment centres in Melbourne; one at The Royal Children’s Hospital and the other at Monash Medical Centre, Clayton. One of these two cancer treatment centres will be your child’s PTC.

When a child is diagnosed with cancer, most families feel shock and disbelief. The treatment ahead and the decisions you will make, may seem very frightening. Many people talk about this experience as “an emotional rollercoaster”. Your child may also have many different feelings about his or her illness and treatment. The other families and the staff at your child’s cancer treatment centre will have a good idea of how you and your family are feeling and they will help you along the way. Our best care will be available to your child, to you and your family.

The diagnosis of cancer means your child will have visits to hospital both as an inpatient and outpatient and as part of the cancer treatment may have chemotherapy and radiotherapy.
What happens next?

It varies from child to child, but this is what happens for most children. First, a child sees a general practitioner or comes to a hospital emergency department in Melbourne or in regional Victoria. Then the child comes to one of the two cancer primary treatment centres in Melbourne and is allocated to an oncology consultant. This is a paediatric doctor (children’s doctor) who specialises in the treatment and management of cancer. This consultant organises tests to identify the sort of cancer and where it is. There are blood tests, X-rays and different kinds of radiology. The consultant might talk with other specialists as needed. Then the consultant talks to the parents about the diagnosis and together they work out the plan for the child’s treatment.

1. **Child is unwell**
2. **Child sees a General Practitioner (GP)**
3. **Child comes to a hospital emergency department**
4. **Child is referred to a children’s cancer primary treatment centre either at The Royal Children’s Hospital (RCH) or Monash Medical Centre (MMC)**
5. **Child is seen by an oncology consultant (a children’s doctor who specialises in the treatment and management of cancer)**
6. **Oncology consultant orders blood tests, X-rays and other radiology and consults with other specialists in a multidisciplinary meeting**
7. **Oncology consultant and parents together work out a treatment plan for the child**
8. **If the child needs chemotherapy, he/she is treated at their children’s cancer treatment centre either as an inpatient or as an outpatient**
9. **If the child needs radiotherapy, he/she receives it at the Peter MacCallum Cancer Centre**
Your child’s treatment plan or protocol is a ‘recipe’ of treatment and includes the doses and the timing of drugs and other treatments. A protocol is often divided into blocks, phases or cycles. **On Treatment** is while your child is being treated with chemotherapy or radiotherapy – sometimes called the active phase of treatment. **Off Treatment** is after treatment stops and your child is getting over the effects. 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.

The roadmap is the shorter version of a protocol or treatment plan. A copy of your child’s roadmap is included in your child’s medical history for reference by the team. Copies of the roadmap are also given to your child’s general practitioner and/or paediatrician. You and your family are also given a copy of your child’s roadmap. If things change during your child’s treatment, your child’s protocol and roadmap will be updated.

Your child goes home as soon as possible. Treatment continues over different periods of time, sometimes as an outpatient, sometimes in hospital. Your child can go back to crèche, school or kindergarten and usually manages normal routines during treatment.
Your child’s team

A multidisciplinary team consisting of medical, nursing, social work, dietetics and psycho-social professionals will work together to care for your child and your family. The medical staff range from junior doctors known as registrars and residents to more senior doctors training in oncology called Fellows. The consultants are the oncology specialists who make the diagnosis of cancer and work out a treatment plan for your child. There may be other health professionals that specialise in various medical fields involved in your child’s care depending on the type of cancer and associated individual needs. Nurses will work with you and your child on the ward, in outpatients, during all procedures and will help coordinate the overall treatment.

As your child’s illness can be a very stressful time for your family, a social worker is available to provide you with practical and emotional support throughout your child’s treatment. Additionally, there are allied health and psycho-oncology professionals including play, music and art specialists, psychologists, family therapists and psychiatrists who can also help you deal with the emotional impact of your child’s illness. Education Advisors will help to keep your child connected to school.

There’s more detail about the people and what they do in Section 5, YOUR CHILD’S TREATING TEAM.

Children’s Cancer Centres

There are children’s cancer primary treatment centres at The Royal Children’s Hospital, and at Monash Medical Centre, Clayton. All children’s radiotherapy is managed at the Peter MacCallum Cancer Centre (Peter Mac).

The Paediatric Integrated Cancer Service (PICS) was formed as a partnership with The Royal Children’s Hospital, Southern Health and the Peter MacCallum Cancer Centre in 2004. The PICS aims to ensure consistency of care and improved quality of services for children and adolescents diagnosed and being treated for cancer throughout Victoria. The PICS promotes the development of a cohesive, integrated, coordinated, multidisciplinary approach to the provision of paediatric cancer services. The Regional Outreach and Shared Care Program (ROSCP) is an initiative of the PICS that facilitates shared care between the primary treating hospital and regional centres, where it is appropriate to do so.

If you are a family from regional Victoria, discuss with your doctor and treating team if it is appropriate that you access services closer to home, at some stage of your treatment.
2.1 Your child’s hospital

The Royal Children’s Hospital

The centre where your child is diagnosed and the treatment plan decided, is called the Primary Treatment Centre (PTC).

There are two children’s cancer primary treatment centres in Melbourne; one at The Royal Children’s Hospital (RCH) in Parkville and the other is located at the Monash Medical Centre, Clayton.

This section is about the RCH and includes information regarding the Kookaburra Cancer Care Ward, Day Cancer centre and the cancer care team. The cancer service at the RCH is known as the Children’s Cancer Centre (CCC). This section also provides information on things to bring to the hospital when your child is admitted, services and facilities available at the hospital during your stay.
The ward – Kookaburra Ward

Location: Level 2, North building via Green lifts

Kookaburra Cancer Ward is the inpatient ward for children with cancer. It has 22 single rooms and two shared rooms, making a total of 26 beds. The structure of the RCH inpatient wards is based on a flexible arrangement so that if the Kookaburra ward is full, your child may be admitted to another ward. If this happens, please know that the nurses in other wards are caring and competent and are supported by staff from your child’s team.

There is a separate Bone Marrow Transplant (BMT) unit in the ward. This unit has eight single rooms and is for children having bone marrow transplants. It has different isolation rules from the rest of the ward. If your child is in this unit, you will be fully informed of these rules.

How the ward works

The ward is like a household. There are routines and specific ways of doing things. The mornings are often busy with organising and doing treatments and procedures. The afternoons are quieter and can be a good time for your child to rest. Even though there are some routines that cannot be changed, please discuss your child’s care and routines with your child’s nurse. We try to be as flexible as possible.

The ward cares for children at different stages of their treatment. Some children are relatively well, others may be very sick. The ward staff manage things so that every child gets the best possible treatment.

The ward is a shared space. Your child’s visitors may affect other children. The smell of visitor’s food might upset a child who is feeling sick. Please be considerate of others.

Staff

The Nurse Unit Manager (NUM) is the overall leader on the ward and is usually there during business hours. The NUM makes sure that the ward runs smoothly and that your child is cared for properly. If you have any concerns please talk to the NUM.

The Associate Unit Managers (AUM) run the ward in shifts working with bedside nurses, 24 hours, seven days a week. They are also the people to talk to if you have any concerns or questions.
A consultant oncologist attends the ward each day. The consultant meets with the fellows and registrars and they discuss all the children on the ward. The consultant may not need to see every child each day. It is important for you to know that the junior doctors and nursing staff communicate closely and frequently with the consultant medical staff.

### Emergency department

**Location:** Lower Ground via Yellow lifts

When children come to the Emergency Department, the ‘triage’ nurse briefly sees each child and decides the order of priority for medical assessment. This triage is necessary so that the sickest children get prompt and necessary medical treatment. This can mean that other children wait longer for their medical assessment. In general, children with cancer are given some priority but on occasions you may have a considerable wait, depending on how ill your child is and how many other children require urgent care.

### Day Cancer

*formerly the Day Oncology Unit*

**Location:** Level 2, West building, Reception E via Green or Yellow lifts

After your child is discharged from the hospital – no longer an inpatient – your child will be seen regularly as an outpatient by your child’s consultant oncologist or fellow in the Outpatient Clinic.

Before your child goes home, your child’s nurse coordinator/ward nurse will usually introduce you and your child to the outpatient department and to the nurses in Day Cancer.

**At Day Cancer**

On arrival for your child’s appointment go to the reception desk and let the desk staff know you have arrived. The outpatient desk staff will then prepare your child’s history and tell your doctor that you have arrived.

Usually, the doctor’s appointment and your child’s treatment are on the same day – but not always. If your child is to have treatment after the doctor’s appointment, your child’s height and weight will be measured when you register with the outpatient staff. This will usually happen before every outpatient appointment as your child’s treatment doses are calculated on weight and height and these can vary between appointments. While you are waiting for your doctor to call you, it is a good opportunity to have Angel® or EMLA® (local anaesthetic) cream applied, if required. This cream takes 40 to 60 minutes to work so it is important to have this done in time.
**Waiting**

Sometimes there can be a wait. If there is a long wait to see the doctor, ask the desk staff if a pager is available. You can carry the pager with you in the hospital and be paged when the doctor is able to see your child. There are a number of activities to join in while waiting or while your child is having treatment. These include art, music, Nintendo®, TV, videos, books and toys. Tea and coffee facilities are available in the kitchen in the shared Parent Lounge on Level 2 near the entry of the Kookaburra ward.

**Treatment at Day Cancer**

After you have seen your child’s doctor and are waiting for treatment, it is a good idea to go to the outpatient desk to see the patient accounts officer, where you will be bulk billed for your child’s’ outpatient treatment and appointment. If your child is to have treatment you will have a booking time with Day Cancer. Before going into Day Cancer, take your child’s history to the Cancer Pharmacy. Pharmacy will then process the medication required for treatment.

Day Cancer has booked times for all treatments such as chemotherapy, blood products, central line care or the administration of other medications.

Appointments can be booked by your treating team; alternatively you can make an appointment for procedures such as central line care by phoning Day Cancer yourself at the number listed on the Hot Numbers page in the front of this book.

Day Cancer is open between 8.00 am – 7:00 pm Monday to Friday and Saturday from 8.00 am – 4:00 pm. Saturday appointments can be on the Kookaburra ward, you will be notified if this is so scheduled.

**Transfer to ward**

Children have a variety of treatments in Day Cancer. These vary from a quick push of chemotherapy to an all day infusion of chemotherapy/fluids or blood products. Sometimes children will need to be transferred from Day Cancer to a ward to finish off treatment at the end of the day. Outpatient treatment may also include lumbar punctures or other procedures.
Coming to hospital: what to bring...

Your child might need to be admitted several times to hospital for treatment. Here’s a list of things you and your child might need:

For your child
• Day clothes
• Pyjamas
• Favourite toys and security items – dummies, teddy, blanket. Please select toys carefully as space is limited
• Toiletries – soap, tooth brush, toothpaste
• Nappies and wipes, if needed
• Headphones

For yourself if staying overnight
• Clothes
• Sleeping bag
• Pillow
• Towel
• Toiletries
• Headphones
• Spare change for the telephone
• Food and drink*

*There are facilities to store a small amount of food and drink in the parent fridge. Please ensure all personal food and drink are clearly labelled. Please read the RCH ‘Food From Home’ policy further on in this section for more information.
## At the hospital

The following table summarises some of the services and facilities at The Royal Children’s Hospital.

<table>
<thead>
<tr>
<th>Services</th>
<th>For the child</th>
<th>For the parent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Accommodation</strong></td>
<td><strong>Kookaburra ward</strong>&lt;br&gt;Level 2, West building&lt;br&gt;22 single and 2 shared rooms; total 26 beds&lt;br&gt;8 separate rooms in Bone Marrow Transplant (BMT) Unit</td>
<td><strong>Ronald McDonald House</strong>&lt;br&gt;28 Gatehouse Street&lt;br&gt;Parkville&lt;br&gt;<strong>Contact the ward staff for details of cost and facilities</strong></td>
</tr>
<tr>
<td><strong>Meals</strong></td>
<td>Menu monitors collect order&lt;br&gt;Separate snacks menu also available</td>
<td>Tea / coffee and breakfast provided in the Parent Lounge (no meals)&lt;br&gt;Range of food outlets on Ground floor&lt;br&gt;Vending machines on Levels 1-5</td>
</tr>
<tr>
<td><strong>Shower and toilets</strong></td>
<td>Baths can happen at any time during the day, discuss with your nurse</td>
<td>Single rooms have an ensuite that parents can use&lt;br&gt;If your child is sharing a room, please use the bathrooms in the Parent Lounge on Level 2&lt;br&gt;Parents of BMT patients cannot use the ensuite in the child’s room, use bathrooms in Parents Lounge on Level 2</td>
</tr>
<tr>
<td>Services</td>
<td></td>
<td></td>
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<tr>
<td>---------------</td>
<td>-----------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Laundry</td>
<td>Please ask for directions to the laundry and obtain a swipe card from the ward clerk in the Kookaburra ward</td>
<td></td>
</tr>
<tr>
<td>Baby change</td>
<td>Baby change facilities are available in the Kookaburra ward</td>
<td></td>
</tr>
<tr>
<td>Parking</td>
<td>Discounted rate card is available from your social worker</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Show this card at the security desk on Lower Ground floor before collecting your car</td>
<td></td>
</tr>
<tr>
<td>Public transport</td>
<td>Tram 59 from Elizabeth street to RCH</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tram 55 from William Street to RCH</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stop 19 directly outside RCH on Flemington Road</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tram/train tickets can be purchased at the retail pharmacy on Ground floor</td>
<td></td>
</tr>
<tr>
<td>Telephones</td>
<td>Public telephones are located in Main Street and Emergency</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mobile phones can be used in the ward</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Obtain the child's room phone number from the ward clerk</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No incoming calls to child's room after 8:30 pm or before 7:30 am</td>
<td></td>
</tr>
<tr>
<td>Visitors</td>
<td>Visiting hours end at 7:30 pm</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Visitors with coughs or colds or who have been in recent contact with anyone with an infectious disease should not visit the child</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not more than two visitors allowed near the child’s bedside at one time</td>
<td></td>
</tr>
<tr>
<td>ATM</td>
<td>Westpac and ANZ ATMs are on the Ground floor, Main Street</td>
<td></td>
</tr>
<tr>
<td>Television</td>
<td>Private televisions, videos and other electrical appliances cannot be brought into wards. See ward clerk to discuss further</td>
<td></td>
</tr>
<tr>
<td>Pathology</td>
<td>RCH outpatient pathology</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ground floor</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Open from 8:00 am</td>
<td></td>
</tr>
<tr>
<td>Pharmacy</td>
<td>Cancer pharmacy prepares and dispenses all cancer drugs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Level 2, West building, behind Reception E</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Open 8:30 am – 5:30 pm Monday to Friday</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Private retail pharmacy is on Ground floor Main Street,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Open 8:30 am – 6:00 pm weekdays</td>
<td></td>
</tr>
<tr>
<td></td>
<td>9:00 am – 3:00 pm Saturday</td>
<td></td>
</tr>
<tr>
<td>Services</td>
<td>Others</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>--------</td>
<td></td>
</tr>
<tr>
<td><strong>Family Resource and Respite Centre</strong></td>
<td>Ground floor, North building</td>
<td></td>
</tr>
<tr>
<td>A non-clinical place with a wide range of facilities for family and care-givers including internet access, a quiet room, resource information, tea and coffee supplies.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Education Institute</strong></td>
<td>RCH Education Institute works in collaboration with young people, families, schools and health professionals to ensure that children continue to engage with learning and remain connected to their school community while receiving treatment for cancer at the RCH.</td>
<td></td>
</tr>
<tr>
<td><strong>Going Nuts With Macadamia</strong></td>
<td>An in-house, hospital television show, broadcast live from the Educational Resource Centre on Thursday mornings on the hospital TV channel. Filming on the wards is on Wednesdays and children and adults are invited to participate. Nursing staff will let you know if filming is going to take place in the ward.</td>
<td></td>
</tr>
<tr>
<td><strong>Starlight Express Room</strong></td>
<td>Art and craft activities, Nintendo®, computer games, movies, in-house television for any child at RCH – patient or visitor. Activities are supervised by Captain Starlight and volunteers. Ask ward staff about weekly activities schedule and opening times. Unfortunately, children with intravenous fluids running are unable to attend the Starlight Express Room.</td>
<td></td>
</tr>
<tr>
<td>Shopping</td>
<td>North Melbourne shopping centre is 15 minutes walk from the hospital via Errol Street</td>
<td></td>
</tr>
<tr>
<td>IGA supermarket on the corner of Flemington Rd and Villiers Street is a five minute walk from RCH</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Queen Victoria Market is open Tuesday and Thursday morning, all day Friday, Saturday morning, and all day Sunday for food and clothing (number 55 and 59 trams run to and from the hospital to the market)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Meals
We recognise that feeding children admitted to the Kookaburra ward is challenging, which is why we provide additional services such as the ‘High Energy Menu’.

Children admitted to the Kookaburra ward will also have access to a ‘Snacks Menu’ to maximise oral intake when appetite may be low. On admission you will be provided with a snacks menu so you can select mid-meal snacks for your child during their stay.

A menu monitor will collect your child’s menu daily. Please write clearly any extra items your child would like in the space provided. Nutritional supplements such as Sustagen may be recommended. If your child requires special diet or supplements, please contact the Dietitian or ask your nurse coordinator to make contact.

Generally there are set meal times for breakfast, lunch and dinner – please ask your nurse for details. If the food does not suit your child, you may bring food from home. Please read the ‘Guidelines for food brought from home’ below. Please ask for a referral to the dietitian if you have any comments or concerns. We welcome any feedback.

Guidelines for food brought into the hospital from home
Often children admitted to the Kookaburra ward have a lower immune system than normal healthy children. Some food items that are normally served to children at home may be unsuitable for patients during their stay at the RCH. This applies especially to foods that are considered high risk. High-risk foods include meals that contain meat, poultry, seafood, dairy, and eggs. The main kitchen and all of the food handling staff employed at the RCH adhere to strict food handling guidelines, as detailed in the Food Safety Program. Check with your child’s nurse before giving your child food from home to ensure that it will not interfere with your child’s medical treatment.

The RCH ‘Food from Home’ policy
It is preferred that meals from home or outside suppliers (take away) are not consumed during your child’s admission. Preparing, cooking, transporting and then reheating food from home can cause harmful bacteria to grow in food, which can make you child unwell. It is very important that if you wish to bring food from home or outside suppliers that you adhere to the guidelines on the following page:
• Meals prepared at home must be immediately refrigerated and transported with an icepack or in an insulated food carry bag. Food transported at room temperature is more likely to allow bacteria to grow and make your child unwell.

• If you bring food from home or an outside supplier it must be eaten immediately after its arrival. A microwave is available in the ward kitchen so that you can reheat meals. Make sure the meal is heated through evenly.

• Only packaged/portioned/sealed items such as yoghurts, drinks, custards, ice cream etc. with attached name and date may be stored in the ward fridge. Home cooked meals must not be stored in the fridge, but should be consumed immediately. Check with your child’s nurse before giving food from home to your child. This is to ensure that it will not interfere with your child’s medical treatment.

• If your child does not finish the meal it must be thrown out. Do not store partially eaten meals or leftovers in the ward fridge. Staff will discard food found in the ward fridge which does not meet the guidelines.

• Ward staff are not able to prepare food that is brought from home.

• Non-perishable items such as lollies, chocolate bars, muesli bars and chips can be brought in from home. These items must be individually wrapped or packaged and can be stored at your child’s bedside.

• To comply with safe food hygiene practices, all families are requested not to share food brought from home or outside with other patients and families in the ward.

**Being with your child**

Parents are welcome in the ward at all times. As a parent, your role in caring for your child during the time in hospital is very important. Your presence allows you to comfort your child and makes your child feel more safe and secure. You are an essential member of the team in providing practical and emotional support. This includes:

• Continuing your normal parenting role

• Engaging your child in play and distraction activities. There are many things that you and your child can do in the ward. Ask the staff about DVDs, Gameboys, interactive games, laptop computer, music therapy and art therapy
• Supporting your child during treatment procedures – see Section 4, CARING FOR YOUR CHILD AND FAMILY, Helping your child cope with tests and medical procedures

• Telling the staff what food and drink your child has had, and how many toilet visits and/or nappy changes

• Talking with staff about any concerns you have about your child or your child’s care

• Letting your child be as active as he/she wants to be

• Negotiating who does what and when

It can be emotionally demanding to spend long periods of time supporting your child. The staff understand that it is important for parents and carers to take breaks from the ward and from the hospital. The nursing staff will make sure your child is well cared for while you are taking a break.

Helping your child cope with being in hospital
Different children cope differently with being in hospital, with medical procedures and treatment. Here are some suggestions to help your child cope with being in hospital. Please talk to people on your child’s team for more help.

For younger children
Babies and toddlers will feel most secure with their main caregivers. They may fear strangers and separation from their parents. Toddlers will find ways to try and assert their independence. Some ideas to help your younger child cope are:

• Bring favourite items from home – toys, security blanket, stuffed animals, books, music

• Soothe or relax your child with music, singing, rocking/cuddling, reading favourite stories

• Offer your child real choices where possible – Do you want to walk to the treatment room or let me carry you?

• Encourage your child to play with real or pretend medical equipment, dolls, puppets, art supplies, to help your child express feelings and to work through experiences

• Read books to your child that relate to his or her concerns or experiences

• Reassure your child that he or she has not done anything wrong and is not being punished
• Encourage your child to participate in his or her care as much as possible – for example, letting your child take medication

• Set limits and boundaries for your child to enhance his or her sense of security

• Encourage members of the team to talk to your child before approaching him or her.

School-age children and adolescents
School age children have an increasing ability to solve problems, and prefer to be in control of situations. They tend to worry, and may fear bodily harm or loss of function. Some may still fear separation. Adolescents are able to think about the future. They value independence, privacy and interactions with peers.

Some ideas to help your older child cope are:

• Allow your child to participate in his or her care whenever possible

• Allow your child to direct familiar procedures when appropriate – for example, announcing the next step in a dressing change

• Use humour as a distraction technique

• Read books with your child that are about his / her feelings and experiences

• Keep your child informed about what’s going on at home with brothers, sisters, friends and pets

• Bring familiar items from home such as books, games, school work, photos of friends and pets

• Respect your child’s need for privacy by allowing him / her time alone

• Encourage your child to express feelings in whatever way feels comfortable – speaking, music, art, writing

• Encourage your child to participate in group activities with other children of the same age – art or music groups, recreational activities with support groups.

Discharge planning
Planning for discharge starts from admission! Parents will be provided with education by the ward or nurse coordinators either individually or as groups. The nursing staff together with the medical staff will arrange appropriate appointments, blood tests and treatments prior to your child going home.
...and going home: what to take

There is a lot to remember before your child is discharged from hospital. The nurses on the ward, your child’s nurse coordinator and doctors will organise most things for you. Here is a checklist. Feel free to copy it and use it to make sure you have everything done when it is time to go home.

<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A</strong> Apointments</td>
<td></td>
</tr>
<tr>
<td>-</td>
<td>Do you have a follow-up appointment?</td>
</tr>
<tr>
<td>-</td>
<td>Do you know the arrangements for your child’s next admission?</td>
</tr>
<tr>
<td>-</td>
<td>Do you have a ‘road map’?</td>
</tr>
<tr>
<td><strong>B</strong> Blood Card</td>
<td></td>
</tr>
<tr>
<td>-</td>
<td>Do you have your blood card?</td>
</tr>
<tr>
<td>-</td>
<td>Where will you have your next blood test taken?</td>
</tr>
<tr>
<td>-</td>
<td>Do you know what day and time to have them taken?</td>
</tr>
<tr>
<td>-</td>
<td>Do you have a request slip for your next test?</td>
</tr>
<tr>
<td><strong>C</strong> Chemotherapy Plan</td>
<td></td>
</tr>
<tr>
<td>-</td>
<td>Do you know where and when your next treatment will be?</td>
</tr>
<tr>
<td>-</td>
<td>Will it be given in Day Cancer or will you be staying overnight?</td>
</tr>
<tr>
<td>-</td>
<td>How many days?</td>
</tr>
<tr>
<td><strong>D</strong> ‘Drugs’ or medicines</td>
<td></td>
</tr>
<tr>
<td>-</td>
<td>Do you need to collect medications from pharmacy before you go home?</td>
</tr>
<tr>
<td>-</td>
<td>Are you running low on any of your medications?</td>
</tr>
<tr>
<td>-</td>
<td>Do you have any questions about any of your medications?</td>
</tr>
<tr>
<td><strong>E</strong> Emergency letter and everything else</td>
<td></td>
</tr>
<tr>
<td>-</td>
<td>Have you got a CCC emergency letter?</td>
</tr>
<tr>
<td>-</td>
<td>When and where will your child next have their Hickman line/port flushed and what arrangements have been made?</td>
</tr>
<tr>
<td>-</td>
<td>Is your child having medications via an insulfon and what arrangements have been made?</td>
</tr>
<tr>
<td>-</td>
<td>Do you need any equipment at home ie nasogastric supplies, tapes, insufsons?</td>
</tr>
</tbody>
</table>

If you are not sure about your ABCDEs please speak to your CCC nurse coordinator or the nurse in charge of the shift
Quick Help

If you are concerned about your child at any time please ring the Nurse Coordinator Hot Line (Monday – Friday 9.00am – 4.30pm) or ring the ward and ask for the nurse in charge – see the Hot Numbers page in the front of this book. If the AUM thinks your child should come to the Emergency Department, the ward will coordinate this. If you are from regional Victoria and it is appropriate to do so, the AUM will help organise for you to be seen at your local hospital. It is a good idea to bring with you a small bag of essentials in case your child needs to be admitted. Refer to Section 4, CARING FOR YOUR CHILD AND FAMILY, If your child is sick, which talks about the times when you might need to make unplanned visits to the hospital. Also see the Quick Help guide in the front of this book.

Note: The Royal Children’s Hospital – Your Guide for patients, families and visitors is a booklet which has details about the hospital facilities such as accommodation, the Family Resource and Respite Centre, the chemist, gift shop, money and valuables, banks and transport. Please ask your nurse coordinator for a copy.
2.2 Your child’s hospital

Monash Children’s at the Monash Medical Centre

The centre where your child is diagnosed and the treatment plan decided, is called the Primary Treatment Centre (PTC).

There are two children’s cancer primary treatment centres in Melbourne; one at The Royal Children’s Hospital in Parkville and the other is located at the Monash Medical Centre, Clayton.

This section is about the Monash Children’s and includes information regarding the two paediatric wards, 41 North and 42 North, and the day treatment centre, known as the Children’s Cancer Centre (CCC). This section also provides information on things to bring to the hospital when your child is admitted and services and facilities available at the hospital during your stay.
The ward

Location: Level 4, Main building
Monash Children’s has two wards for children – 41 North and 42 North. 41 North is a 26 bed medical ward for children between 0–12 years. 42 North is a 26 bed ward for adolescents and children, with surgical, related illnesses. Both wards have shared and single rooms.

The Monash Children’s oncology service is known as the Children’s Cancer Centre (CCC). It is located on Level 2 near the main entrance and is a day centre. Most of your child’s outpatient care will be provided within the CCC.

How the ward works

The ward is like a household; there are routines and specific ways of doing things. The mornings are often busy with organising and doing treatments and procedures. The afternoons are quieter and can be a good time for your child to rest. Even though there are some routines that cannot be changed, please discuss your child’s care and routines with your child’s nurse. We try to be as flexible as possible.

The ward cares for children with a variety of illnesses. The ward staff manage things so that every child gets the best possible treatment taking into account the individual needs of the child.

Staff

The Nurse Unit Manager (NUM) is the overall leader on the ward and is usually there only during business hours. The NUM makes sure that the ward runs smoothly and that your child is cared for properly. If you have any concerns please talk to the NUM.

The Associate Unit Managers (AUM) run the ward in shifts, 24 hours, seven days a week. They are also the people to talk to if you have any concerns or questions.

A consultant medical staff member (consultant doctor) attends the ward. The consultant meets with the fellows and registrars and they discuss all the children on the ward. The consultant may not need to see every child each day, but it is important for you to know that the junior doctors and nursing staff communicate closely and frequently with the consultant medical staff.
Emergency department

Location: Level 2, Main building
When people come to the Emergency Department, the ‘triage’ nurse briefly sees each patient and decides the order of priority for medical assessment. This triage is necessary so that the sickest patients get prompt and necessary medical treatment. In general, children with cancer are given some priority but on occasions you may have a wait, depending on how ill your child is and how many other people require urgent care.

The Children’s Cancer Centre

Location: Level 2, Main building
After your child is discharged from the hospital – no longer an inpatient – your child will be seen regularly as an outpatient. Your child’s hospital doctor will see your child in the Children’s Cancer Centre.

Before seeing the doctor as an outpatient, your child will almost always require a blood test. The finger-prick blood test may be done by the District Nurse at home, at the pathology centre/hospital or at MMC just past the CCC main entrance. If the blood test is done at MMC, your child needs to be there at least one hour before the outpatient appointment time. This is to ensure that the blood test results are ready in time for your appointment. This blood test is done in the outpatient pathology department on the 2nd level, open from 8:30 am – 5:00 pm, Monday to Friday.

On arrival for your child’s appointment, please go to the reception desk at the CCC and let staff know you have arrived. They will take your Medicare details and will then prepare your child’s history and notify the doctor that you have arrived. Your child’s height and weight will be measured when you arrive in the CCC. This will usually happen before every outpatient appointment as your child’s treatment doses are calculated on weight and height and these can vary between appointments.

While you are waiting for your doctor to call you, it is a good opportunity to speak to the nursing staff who can apply Angel® or EMLA® (local anaesthetic) cream, if required. This cream takes about 40 to 60 minutes to work so it is important to have this done in time. Nursing care required outside clinic appointment times can also be better coordinated if the nursing staff in the CCC know when you are coming. This can be done by phoning your nurse coordinator using the number listed on the Hot Numbers page in the front of this book. The CCC is open between 9:00 am and 5:30 pm Monday to Friday.
Children have a variety of treatments in the CCC. These vary from a quick push of chemotherapy to an all day infusion of chemotherapy / fluids or blood products. Sometimes children will need to be transferred from the CCC to the ward to finish off treatment at the end of the day.

Children with cancer who are treated at Monash Children’s may access the CCC directly during business hours if the child is febrile and neutropaenic. Outside of these hours children should access the emergency department. If you are coming in to the CCC and your child is unwell you must always call first.

The CCC is usually a busy place, with lots of children, siblings and families. There are a number of activities to join in while waiting or while your child is having treatment. These include art, music, Nintendo®, TV, videos, books and toys. Tea and coffee facilities are available in the kitchen in the outpatient area. You will also find a family resource board in the kitchen. During fine weather the playground is open for children and siblings attending the CCC. Parents are reminded to supervise their children in the playground.

**Coming to hospital: what to bring...**

Your child might need to be admitted several times to hospital for treatment.

Here’s a list of things you and your child might need:

**For your child**
- Day clothes
- Pyjamas
- Favourite toys and security items – dummies, teddy, blanket. Please select toys carefully as space is limited
- Older children and adolescents: activities they enjoy: iPods, books, drawing etc
- Toiletries – soap, tooth brush, toothpaste
- Nappies and wipes, if needed
- Headphones

**For yourself (parent) if staying overnight**
- Clothes
- Sleeping bag (optional, linen is provided)
- Pillow
- Towel
- Toiletries
- Spare change for the telephone
- Food and drink*  
  *There are facilities to store a small amount of food and drink in the parent fridge. Please ensure all personal food and drink are clearly labelled.
At the hospital

The following table summarises some of the services and facilities at Monash Children’s.

<table>
<thead>
<tr>
<th>Services</th>
<th>For the child</th>
<th>For the parent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Accommodation</strong></td>
<td>Two paediatric wards 41 and 42 North 26 bed capacity each Both shared and single rooms</td>
<td>One parent can stay overnight Sofa bed and linen provided Ronald McDonald House (Monash) may provide accommodation for a small cost. See nurse coordinator for details</td>
</tr>
<tr>
<td><strong>Meals</strong></td>
<td>Set meal times Basic provisions in ward kitchen Can bring home cooked meals but talk to nurse coordinator about hospital safety requirements for storing food from home</td>
<td>Meals provided only to breastfeeding mothers Can order food to child’s room for a fee, see nurse for details Cafe on Level 2 near front entrance. Open 6:00 am – 8:00 pm</td>
</tr>
<tr>
<td><strong>Shower and toilets</strong></td>
<td>Baths can happen at any time during the day, discuss with nurse coordinator</td>
<td>Single rooms have an ensuite that parents can use If your child is sharing a room, please use bathrooms in Parents lounge on Level 4, Ronald McDonald Family room</td>
</tr>
<tr>
<td>Services</td>
<td>Details</td>
<td></td>
</tr>
<tr>
<td>------------------</td>
<td>-------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Laundry</td>
<td>Available in the Ronald McDonald Family room on Level 4</td>
<td></td>
</tr>
<tr>
<td>Baby change</td>
<td>Babies’ bathroom at the back of 41 and 42 North</td>
<td></td>
</tr>
<tr>
<td>Parking</td>
<td>Discounted rate card is available for parents of children having chemotherapy, see CCC reception staff</td>
<td></td>
</tr>
<tr>
<td>Public transport</td>
<td>Rail: Pakenham line to Clayton Station. Monash Medical Centre is 500m north along Clayton Road</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bus Lines 631, 703, 733 stop outside Monash Medical Centre in Clayton Road</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Melway References; Map 79 C1; Map 84A</td>
<td></td>
</tr>
<tr>
<td>Telephones</td>
<td>Mobile phones can be used in the ward</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Obtain child’s bedside phone number from nursing staff</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No incoming calls to child’s room after 8:30 pm or before 7:30 am</td>
<td></td>
</tr>
<tr>
<td></td>
<td>To make outgoing calls you can have your child’s telephone connected for a small daily fee</td>
<td></td>
</tr>
<tr>
<td>Visitors</td>
<td>Visiting hours end at 8:00 pm</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Visitors with coughs or colds or who have been in recent contact with anyone with an infectious disease should not visit the child</td>
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<tr>
<td></td>
<td>Not more than 2 visitors allowed near the child’s bedside at a time</td>
<td></td>
</tr>
<tr>
<td>ATM</td>
<td>Located at the hospital front entry</td>
<td></td>
</tr>
<tr>
<td>Television</td>
<td>Private televisions, videos and other electrical appliances cannot be brought into wards</td>
<td></td>
</tr>
<tr>
<td></td>
<td>A television service (including Foxtel) can be connected</td>
<td></td>
</tr>
<tr>
<td></td>
<td>NOTE: CanTeen cards are no longer available</td>
<td></td>
</tr>
<tr>
<td>Pathology</td>
<td>Outpatient Pathology Department</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Level 2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Open 8:30 am – 5:00 pm Monday to Friday</td>
<td></td>
</tr>
<tr>
<td>Pharmacy</td>
<td>Cancer pharmacy prepares and dispenses all cancer drugs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Located opposite CCC</td>
<td></td>
</tr>
<tr>
<td></td>
<td>If there are any concerns about child’s drugs, speak to the pharmacist in the CCC</td>
<td></td>
</tr>
<tr>
<td><strong>Services</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Others</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| **The Ronald McDonald Family Room**  
Located on Level 4, the room is looked after by volunteers.  
The room is usually open from 7.30am in the morning to around 9pm at night, 7 days per week  
The room is available for families and carers who have a child admitted to the hospital. Facilities in the centre include a kitchen, dining area, laundry, and bathroom facilities, lounge, TV and a quiet area with reclining chairs for parents needing a rest |
| **Parents room**  
Located on both the paediatric wards  
Facilities to make tea and coffee, fridge, microwave, sandwich maker and toaster  
Also has a shower and toilet, contact ward clerk for a towel |
| **Postage**  
Stamps can be bought at the gift shop in the entrance foyer  
9:00 am – 4:45 pm Monday to Friday  
10:00 am to 3:00 pm weekends  
A mail box is located near the main lift on level 2  
Incoming mail should be addressed c/o Ward 41 North or 42 North, Monash Medical Centre, 246 Clayton Road, Clayton 3168 |
| **Starlight Express Room**  
Level 4, 42 North  
10:00 am to 4:00 pm Monday to Friday  
Art and craft activities, Nintendo®, computer games, movies, in-house television for any child at MMC – patient or visitor. Activities are supervised by Captain Starlight and volunteers. Unfortunately, children with intravenous fluids running are unable to attend the Starlight Express Room |
| **Shopping**  
The Clayton Shopping Centre is approximately 800m south along Clayton Road and has a variety of shops |
Being with your child
Parents are welcome in the ward at all times. As a parent, your role in caring for your child during the time in hospital is very important. Your presence allows you to comfort your child and make your child feel more safe and secure. You are an essential member of your child’s team in providing practical and emotional support. This includes:

• Engaging your child in play and distraction activities
• Supporting your child during treatment procedures – see Section 4, CARING FOR YOUR CHILD AND FAMILY, Helping your child cope with medical tests and procedures
• Telling the staff what food and drink your child had, and number of toilet visits and/or nappy changes
• Talking with staff about any concerns you have about your child or their care
• Letting your child be as active as he/she wants to be
• Negotiating who does what and when.

It can be emotionally demanding to spend long periods of time supporting your child. The staff understand that it is important for parents to take breaks from the ward and from the hospital. The nursing staff will make sure your child is well cared for while you are taking a break.

Helping your child cope with being in hospital
Different children cope differently with being in hospital, with medical procedures and treatment. Here are some suggestions to help your child cope with being in hospital. Please talk to people on your child’s team for more help.

For younger children
Babies and toddlers will feel most secure with their main caregivers. They may fear strangers and separation from their parents. Toddlers will find ways to try and assert their independence. Some ideas to help your younger child cope are:

• Bring favourite items from home – toys, security blanket, stuffed animals, books, music
• Soothe or relax your child with music, singing, rocking/cuddling, reading favourite stories
• Offer your child real choices where possible – “Do you want to walk to the treatment room or let me carry you?”
• Encourage your child to play with real or pretend medical equipment, dolls, puppets, art supplies, to help your child express feelings and to work through experiences
• Read books to your child that relate to his or her concerns or experiences
• Reassure your child that he or she has not done anything wrong and is not being punished
• Encourage your child to participate in his or her care as much as possible – for example, letting your child take medication
• Set limits and boundaries for your child to enhance his or her sense of security
• Encourage members of the team to talk to your child before approaching him or her.

School-age children and adolescents
School age children have an increasing ability to solve problems, and prefer to be in control of situations. They tend to worry, and may fear bodily harm or loss of function. Some may still fear separation. Adolescents are able to think about the future. They value independence, privacy and interactions with peers.

Some ideas to help your older child cope are:
• Allow your child to participate in his or her care whenever possible
• Allow your child to direct familiar procedures when appropriate – for example, announcing the next step in a dressing change
• Use humour as a distraction technique
• Read books with your child that are about his / her feelings and experiences
• Keep your child informed about what’s going on at home with brothers, sisters, friends and pets
• Bring familiar items from home such as books, games, school work, photos of friends and pets
• Respect your child’s need for privacy by allowing him / her time alone
• Encourage your child to express feelings in whatever way feels comfortable – speaking, music, art, writing
• Encourage your child to participate in group activities with other children of the same age – art or music groups, recreational activities with support groups.
Discharge planning
Planning for discharge starts from admission! Your nurse coordinator, together with the rest of your health care team, will provide you and your family with information and education needed to prepare you for going home. The nursing staff together with the medical staff will arrange appropriate appointments, blood tests and treatments prior to your child going home.
...and going home: what to take

There’s a lot to remember before your child is discharged from hospital. The nurses on the ward, your child’s nurse coordinator and doctors will organise most things for you. Here’s a checklist. Feel free to copy it and use it to make sure you have everything done when it is time to go home.

<table>
<thead>
<tr>
<th>A Appointments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have a follow-up appointment?</td>
</tr>
<tr>
<td>Do you know the arrangements for your child’s next admission?</td>
</tr>
<tr>
<td>Do you have a ‘road map’?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B Blood Card</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have your blood card?</td>
</tr>
<tr>
<td>Where will you have your next blood test taken?</td>
</tr>
<tr>
<td>Do you know what day and time to have them taken?</td>
</tr>
<tr>
<td>Do you have a request slip for your next test?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>C Chemotherapy Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you know where and when your next treatment will be?</td>
</tr>
<tr>
<td>Will it be given in the CCC or will you be staying overnight?</td>
</tr>
<tr>
<td>How many days?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>D ‘Drugs’ or medicines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you need to collect medications from pharmacy before you go home?</td>
</tr>
<tr>
<td>Are you running low on any of your medications?</td>
</tr>
<tr>
<td>Do you have any questions about any of your medications?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>E Emergency letter and everything else</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you got a CCC emergency letter?</td>
</tr>
<tr>
<td>When and where will your child next have their Hickman line/port flushed and what arrangements have been made?</td>
</tr>
<tr>
<td>Is your child having medications via an insulfon and what arrangements have been made?</td>
</tr>
<tr>
<td>Do you need any equipment at home ie nasogastric supplies, tapes, insulfons?</td>
</tr>
</tbody>
</table>

If you are not sure about your ABCDEs please speak to your CCC nurse coordinator or the nurse in charge of the shift
Quick Help

If you are concerned about your child at any time please ring the Monash Children’s CCC during hours or the Paediatric Registrar after hours – see the Hot Numbers page in the front of this book. A senior nurse or doctor will let you know if your child needs to come into the Emergency Department and will coordinate this admission. It is a good idea to bring with you a small bag of essentials in case your child needs to be admitted. Refer to Section 4, CARING FOR YOUR CHILD AND FAMILY, *If your child is sick*, which talks about the times when you might need to make unplanned visits to the hospital. Also see the Quick Help guide in the front of this book.
2.3 Your child’s hospital

Peter MacCallum Cancer Centre

Peter Mac in East Melbourne is the only hospital in Victoria that provides a specialised radiation therapy service for children and adolescents. Your child will need to go to Peter Mac if he/she requires radiotherapy as part of the cancer treatment.

This section is about Peter Mac and contains information regarding the ward, outpatients and the cancer care team. It also provides information on things to bring to the hospital when your child is admitted here and services and facilities available at the hospital during your stay.

Peter Mac is located at St Andrew’s Place, corner Lansdowne Street, East Melbourne. Melway Reference MAP 2G: A2.
The ward

Location: 9th Floor, Tower Block via lifts at the end of red carpet tiles on Ground floor

Ward 9 at Peter Mac is where your child stays if he/she is having total body irradiation (TBI). Ward 9 is on the 9th floor of the Tower Block. You get to ward 9 via the lifts at the end of the red carpet tiles on the ground floor. Your child will have his/her own single room. Your child will be admitted on the afternoon of the day before starting TBI and will be transferred back to your hospital after the final TBI treatment.

How the ward works

The Nurse Unit Manager (NUM) is the overall leader on the ward and is usually there during business hours. The NUM makes sure that the ward runs smoothly and that your child is cared for properly. If you have any concerns please talk to the unit manager.

The Associate Unit Managers (AUM) runs the ward in shifts, 24 hours, seven days a week. They are also the people to talk to if you have any concerns or questions.

The consultant radiation oncologist meets with the registrars and they discuss all the children on the ward. The consultant or registrar will see your child each day with the Peter Mac nurse coordinator. The medical and nursing staff communicate closely to support and care for your child.

Staff

The paediatric service at Peter Mac includes medical staff, nursing staff, radiation therapists, social work, pastoral care and music therapy. The Peter Mac team works closely with the team at your child’s referring hospital (The Royal Children’s Hospital, Monash Children’s and other private hospitals). The telephone numbers of your child’s Peter Mac team are listed on the Hot Numbers page in the front of this book.

The consultant radiation oncologist is a specialist in the delivery of radiation treatment to children and adolescents with cancer.

A senior radiation oncology registrar is present at Wednesday clinics. If your child is admitted to Peter Mac for Total Body Irradiation (TBI), the registrar will review your child each day while he/she is an inpatient at Peter Mac.
The clinical nurse coordinator (CNC) helps provide coordinated care for your child and family throughout the radiation treatment. With the medical team, the CNC gives information about radiation treatment and about the short-term and long-term side effects of this. The CNC communicates frequently with your child’s treating team at your child’s referring hospital.

Radiation therapists plan and give the radiation treatment. The planning staff make moulds, supports or masks, take x-rays and scans and make measurements of the treatment position. The therapists use computer systems to work out the best treatment plan for your child and make sure that everything is positioned correctly at each radiotherapy session. Your child might find the first visit scary, but the radiation therapists work hard to make your child feel comfortable.

The social worker contacts all children and their families, and provides additional support throughout the treatment.

A pastoral care worker is available to provide spiritual, religious or emotional support to you, your child and family.

The music therapist provides group and individual sessions to children and their siblings throughout the treatment. The music therapist is available at Wednesday morning clinics, and at other times (throughout treatment) as necessary.

See Section 5, YOUR CHILD’S TREATING TEAM for more information.

Outpatients

First appointment at Peter Mac
The Peter Mac team will have information about your child’s referral – letters from your child’s doctor, scans and reports – before your child’s first appointment. Your child’s first appointment and radiation planning is at the Paediatric Clinic which runs every Wednesday morning. The clinic appointment may be followed by a radiation planning appointment.

You will be advised of the details of your child’s appointment before coming to Peter Mac. If your child is an inpatient at The Royal Children’s Hospital or Monash Children’s, the ward nursing staff will arrange transport to Peter Mac.

On your first visit to Peter Mac, your child will need to go to the admissions/patient registration desk on the ground floor, 20 minutes before the appointment time. This is to register your child as an outpatient at Peter Mac. Then your child will attend the appointment in clinic D on the Ground floor.
If you and your child have not met the nurse coordinator or the rest of the Peter Mac team, this is the first thing that happens. They will give you written and verbal information about your child's treatment.

Next, you will meet the paediatric radiation oncology registrar who will do a complete physical assessment of your child and record your child’s health history.

You will also meet your child’s consultant (radiation oncologist) who will explain the radiation therapy, possible side effects and answer your questions.

During your clinic appointment you will need to sign a consent form for your child’s radiation therapy. The radiation oncologist will go through this with you.

If your child is having radiation planning after the clinic appointment, you and your child will meet the treatment planner who will coordinate your child’s treatment. You and your child may also be able to visit the treatment delivery room and meet members of staff who will care for your child throughout the entire treatment. Your child may have a visit to the mould room and may have a simulator test as a part of the planning process. There are different methods of making masks and the method that is most appropriate will be discussed during your initial clinic appointment at Peter Mac. The mask can either be made directly on your child or on a life-size model of your child. These models are made either by making a plaster mould or by taking a 3D photograph.

**Radiotherapy planning**
Planning for radiotherapy is done on the Upper Ground Level of the Smorgon Family Building. Use the silver lifts at the main entrance to take you to Upper Ground (UG).

**Radiotherapy treatment**
Radiotherapy treatment is done on Lower Level 2 of the Smorgon Family Building. Use the silver lifts at the main entrance to take you to Lower Level 2 (LL2).
Coming to hospital: what to bring...

Your child might need to be admitted to hospital for treatment. Here’s a list of things you and your child might need:

For your child

- Day clothes
- Pyjamas
- Favourite toys and security items – dummies, teddy, blanket. Please select toys carefully as space is limited
- Toiletries – soap, tooth brush, toothpaste
- Nappies and wipes, if needed
- Headphones

For yourself if staying overnight

- Clothes
- Sleeping bag (optional, linen is provided
- Pillow
- Towel
- Toiletries
- Spare change for the telephone
- Food and drink*

*There are facilities to store a small amount of food and drink in the parent fridge. Please ensure all personal food and drink are clearly labelled.
At the hospital
The following table summarises some of the services and facilities at Peter Mac.

<table>
<thead>
<tr>
<th>Services</th>
<th>For the child</th>
<th>For the parent</th>
</tr>
</thead>
</table>
| Accommodation     | Ward 9, 9th Floor  
Child will be admitted on the day of the treatment                                                                                      | Apartments available for minimal fee depending upon availability to families living more than 100 km from Peter Mac  
Contact the Peter Mac social worker for details of cost and facilities                                                                                                      |
| Meals             | Set meal times  
Basic provisions in ward kitchen  
Can bring home cooked meals but talk to nurse coordinator about hospital safety requirements for storing food from home | Café Macchiato by Zouki on ground floor outside main entrance next to ambulance parking area. Open 7 days from 6.30 am to 6.00 pm  
Vending machines are on the ground floor, main building, near outpatient clinic entrance                                                                                 |
| Shower and toilets| Baths can happen at any time during the day, discuss with nurse coordinator                                                                                     | Ask ward staff for directions to toilets and showers                                                                                                                                                           |

<table>
<thead>
<tr>
<th>Services</th>
<th></th>
<th></th>
</tr>
</thead>
</table>
| Parking           | Discount car park is available. Please show a referral or appointment letter to the car park attendant when entering or exiting the car park  
Wilson’s car park is also available on St Andrew’s Place, commercial charges apply; check price before entering |                                                                                                                                                                                                               |
| Public transport  | Parliament train station is nearby  
Trams 48, 75, 112 and 109 stop near the hospital                                                                                                                                                               |
| Telephones        | Public phones are on the ground floor, main building, near cashier’s office  
Family and friends can phone ward 9 directly on 9656 1099 and will then be transferred to your child’s room number |                                                                                                                                                                                                               |
<table>
<thead>
<tr>
<th>Services</th>
<th>Description</th>
</tr>
</thead>
</table>
| Visitors         | Visiting hours end at 8:00 pm  
Visitors with coughs or colds or who have been in recent contact with anyone with an infectious disease should not visit the child  
Not more than 2 visitors allowed near the child’s bedside at a time  
Please limit the number of visitors during rest period between 12:30 pm and 2:00 pm |
| ATM              | Commonwealth Bank ATM outside the hospital in Lansdowne Street               |
| Television       | Private televisions, videos and other electrical appliances cannot be brought into wards |
| Pharmacy         | Upper Ground level, Smorgon Family Building  
Open 8:30 am – 5:00 pm Monday to Friday  
10:00 am – 12:00 pm Saturdays |
| Patient Info and Support Centre | Located at the entrance |
| Nancie Kinsella Library | Level 4, Tower Block  
A range of books for parents to borrow. It is also a quiet place to visit if your child is an inpatient at Peter Mac. Children's literature range is limited, however some children’s books and activity books are in the clinic area on the ground floor |
| Auxiliary Gift Shop | Ground floor  
Open 9:00 am – 4:30 pm Monday to Friday  
Offers a range of gifts, knitted toys and clothing |
### Services

<table>
<thead>
<tr>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activity cupboard</strong> – games, colouring books, pencils, textas</td>
</tr>
<tr>
<td>Outpatients clinic, Ground floor, Main building</td>
</tr>
<tr>
<td>Small amount available on the ward</td>
</tr>
<tr>
<td><strong>Music related activities</strong></td>
</tr>
<tr>
<td>Outpatients clinic</td>
</tr>
<tr>
<td><strong>Starlight multipurpose game machine</strong> – games, DVDs</td>
</tr>
<tr>
<td>Radiation Therapy (L2)</td>
</tr>
<tr>
<td>Also available for use if an inpatient</td>
</tr>
<tr>
<td><strong>Television/video/DVD video</strong></td>
</tr>
<tr>
<td>Radiation therapy (L2)</td>
</tr>
<tr>
<td>Outpatients clinic</td>
</tr>
<tr>
<td>Ward 9</td>
</tr>
<tr>
<td><strong>Toys (no electrical goods)</strong></td>
</tr>
<tr>
<td>Radiation therapy (L2)</td>
</tr>
<tr>
<td>Play room on Upper Ground</td>
</tr>
<tr>
<td>Outpatients clinic</td>
</tr>
</tbody>
</table>

### Being with your child

Parents are welcome in the ward at all times. As a parent, your role in caring for your child during the time in hospital is very important. Your presence allows you to comfort your child and make your child feel more safe and secure. You are an essential member of your child’s team in providing practical and emotional support. This includes:

- Engaging your child in play and distraction activities
- Supporting your child during treatment procedures – see Section 4.8, CARING FOR YOUR CHILD AND FAMILY, *Helping your child cope with tests and medical procedures*
- Telling the staff what food and drink your child had, and how many toilet visits and/or nappy changes
- Talking with staff about any concerns you have about your child or their care
- Letting your child be as active as he/she wants to be
- Negotiating who does what and when.
It can be emotionally demanding to spend long periods of time supporting your child. Discuss with the nursing team about taking a break when your child is inpatient at Peter Mac for treatment.

**Helping your child cope with being in hospital**

Different children cope differently with being in hospital, with medical procedures and treatment. Here are some suggestions to help your child cope with being in hospital. Please talk to people on your child’s team for more help.

**For younger children**

Babies and toddlers will feel most secure with their main caregivers. They may fear strangers and separation from their parents. Toddlers will find ways to try and assert their independence. Some ideas to help your younger child cope are:

- Bring favourite items from home – toys, security blanket, stuffed animals, books, music
- Soothe or relax your child with music, singing, rocking/cuddling, reading favourite stories
- Offer your child real choices where possible – “Do you want to walk to the treatment room or let me carry you?”
- Encourage your child to play with real or pretend medical equipment, dolls, puppets, art supplies, to help your child express feelings and to work through experiences
- Read books to your child that relate to his or her concerns or experiences
- Reassure your child that he or she has not done anything wrong and is not being punished
- Encourage your child to participate in his or her care as much as possible – for example, letting your child take medication
- Set limits and boundaries for your child to enhance his or her sense of security
- Encourage members of the team to talk to your child before approaching him or her
**School-age children and adolescents**

School age children have an increasing ability to solve problems, and prefer to be in control of situations. They tend to worry, and may fear bodily harm or loss of function. Some may still fear separation. Adolescents are able to think about the future. They value independence, privacy and interactions with peers.

Some ideas to help your older child cope are:

- Allow your child to participate in his or her care whenever possible
- Allow your child to direct familiar procedures when appropriate – for example, announcing the next step in a dressing change
- Use humour as a distraction technique
- Read books with your child that are about his / her feelings and experiences
- Keep your child informed about what’s going on at home with brothers, sisters, friends and pets
- Bring familiar items from home such as books, games, school work, photos of friends and pets
- Respect your child’s need for privacy by allowing him / her time alone
- Encourage your child to express feelings in whatever way feels comfortable – speaking, music, art, writing
- Encourage your child to participate in group activities with other children of the same age – art or music groups, recreational activities with support groups.
2.4 Your child’s regional hospital

Historically, children and adolescents with cancer have had the majority of their treatment managed by their Primary Treatment Centre (PTC) at the RCH or Monash Children’s at Monash Medical Centre. The philosophy underpinning the Regional Outreach and Shared Care Program (ROSCP) is to permit, for agreed stages in the cancer treatment journey, aspects of treatment and supportive care which can be safely provided as close to home as possible. Usually, shared care is only offered and available after the first stages of treatment and the treatment plan is always organised and coordinated by the Children’s Cancer Centre doctors and nurses at the RCH or Monash Children’s. The regional program provides opportunities for shared care and provides agreed levels of training and for medical, nursing, allied health and supportive services in the regional centres.

At the time of writing this Information book, the ROSCP has formalised arrangements with seven regional centres across Victoria.

If you are a regional family or have close family living in regional Victoria, discuss with your doctor and the treating team if it is appropriate for you to access services closer to home at some stage of your child’s treatment.

Depending on which region you are from, your nurse coordinator will provide detailed information on the regional hospital in your area.

The regional partners across Victoria are:

- Albury Wodonga Health, Albury
- Ballarat Health Service, Ballarat
- Barwon Health, Geelong
- Bendigo Health Care Group, Bendigo
- Goulburn Valley Health, Shepparton
- Peninsula Health, Frankston
- South West Healthcare, Warrnambool

For more information about the regional program visit [http://www.pics.org.au/RegionalOutreachSharedCareProgramROSCP](http://www.pics.org.au/RegionalOutreachSharedCareProgramROSCP)

See map overleaf.
3 Cancer

What are childhood cancers?

Normally cells in our body work in a controlled way; they divide and form new cells to replace the old cells. When a person is suffering from cancer, body cells start to multiply in an uncontrolled manner. They damage the part of the body where they first start (primary tumour) and can spread to other parts of the body (secondary tumour or metastasis).

Children's cancers are rare. Only one in every 600 children under the age of 15 years develops cancer. In Victoria there are between 180 and 200 children diagnosed with cancer each year. The percentages of the various types of cancers diagnosed are shown in the following chart.

Children’s cancers are different to adult cancers. Things that cause adult cancers such as smoking and chemicals, do not cause children’s cancers. Children’s cancers occur in different parts of the body than adult cancers. They look different under the microscope and respond differently to treatment. Cure rates for children’s cancers are higher than those for adults.

In most cases, we don’t know why children get cancer. But research is going on to find the causes. We know it’s very rare for another child in a family to develop cancer. Sometimes two or three children at the same school or town develop cancer, but as far as we know this is a coincidence.
Over the past fifteen years, the cure rates and remission rates have improved. This is due to availability of better treatments, a strengthened multidisciplinary team approach, and availability of more information from research and clinical trials. Inpatient stays are shorter and many procedures and treatments are now done as day procedures and don’t require overnight admission.

The following flowchart lists the common childhood cancers and tests and treatments available to diagnose and treat childhood cancers.

**Solid tumours**
some common types are:
- Wilm’s tumour
- Bone tumours
- Lymphomas
- Neuroblastoma

**Leukaemias**
- Acute Lymphoblastic Leukaemia – ALL *(most common type in children)*
- Other leukaemias
- Acute myeloid leukaemia – AML
- Juvenile CMML
- CML

**Central Nervous System tumours**
- Medulloblastoma
- Ependymoma
- Other brain and spinal cord tumours

**Tests and investigations to diagnose childhood cancers**
(not all tests are done for each patient)
- Blood tests
- X-rays
- Scans
- Bone marrow tests
- Lumbar punctures

**Treatments available to treat childhood cancers**
(not all treatments are done for each patient; it will depend on the type and spread of the child’s cancer)
- Chemotherapy (drug therapy)
- Radiation therapy
- Surgery
Childhood cancers are commonly classified into solid tumours, leukaemias and tumors of the central nervous system.

In order to ascertain if any cancer cells are present, the consultant oncologist will usually order some tests to make an accurate diagnosis and assess the child’s general health. The tests will also enable the specialist to know where the cancer started and whether it has spread to other parts of the body, which is called staging.

Please remember that not all children have all the tests or procedures. The consultant oncologist will decide what tests are relevant, based on each individual case.

Doing the tests may delay the start of treatment for a few days, but it is important to get all the information together so that the right treatment is given. Descriptions of many tests and procedures are in Section 3.4, CANCER, Tests and procedures to diagnose cancer.

Some of the tests are repeated during treatment to monitor progress and check for any side effects. Some tests and procedures are painful. Pain management techniques and medications are routinely used to reduce the possible pain and to help your child during a painful procedure. Please ask any of the people in your child’s treating team about pain management. For more details see Section 4.8, CARING FOR YOUR CHILD AND FAMILY, Helping your child cope with tests and medical procedures.

Once it is established exactly what type of cancer your child has, your consultant oncologist will give you detailed information about it and the specific treatment. A written plan, called a roadmap, will show when your child will receive treatment. You can have a copy of this. If you have any questions, ask your consultant oncologist, one of the oncology ward doctors or your clinical nurse coordinator.

Treatment depends on the particular type of cancer and how much it has spread. There are three main types of treatment: chemotherapy (drug therapy), radiation therapy, and surgery. Not all children will require all these three types of treatments, your consultant will discuss the treatment needed to treat your child’s cancer.

These treatments are described in more detail further on in this section.
Tests and procedures to diagnose cancer

Tests
Here are brief descriptions of some of the tests that might be done during diagnosis and treatment. A child does not have every one of these tests.

Audiology
Some drugs can affect hearing. Baseline hearing tests (audiology) and regular testing during treatment are done with children receiving these drugs.

Biopsy
If it is suspected that a tumour is malignant (cancerous), the surgeon may first remove a part of it, either by inserting a small needle through the skin (needle biopsy) or by doing a small operation (open biopsy). A CT guided biopsy may also be done by a radiologist. The whole tumour may be removed at the initial surgical procedure. This specimen is then examined by a specialist doctor – a histopathologist – who can tell whether or not it is malignant and exactly what type of tumour it is. It usually takes a few days to get the results. Sometimes specialised tests such as chromosome analysis or special staining tests to look more closely at the tumour tissue may be required to help with the diagnosis. The type of biopsy done depends on the individual child’s specific clinical circumstances.

Blood tests
Blood tests are done at the time of diagnosis, during treatment and occasionally after treatment, to monitor the effects of treatment. The blood cells are counted in the haematology department. The blood count is one of several different ways to monitor the effects of treatment. Your child’s doctor can tell you what your child’s blood counts are, what this means and what they are expected to be. Microbiologists may check the blood to see whether there is infection. This is called a blood culture. The chemistry laboratory measures certain salts and chemicals in the blood sample. This gives information about kidney and liver function. Blood samples may also be obtained to cross-match blood in case a transfusion is needed. A short video, ‘Blood counts explained’ is on the PICS website.

Bone marrow aspirate
The bone marrow is like a factory where the blood cells in the body are produced. In children, bone marrow is in the long bones, ribs, pelvis and hips. To see whether the cancer has affected the bone marrow it is necessary to obtain a sample. This is done by placing a fine needle into the bone in the
Hip and taking out a small amount of the marrow which is then examined in the laboratory. Occasionally a core of marrow (trephine biopsy) is required to examine the marrow in more detail. Bone marrow aspirate is generally performed under a general anaesthetic.

**Bone scan**
A bone scan is done in the nuclear medicine department to get an image of a bone or bones, to see if there is any cancer present. The scan itself is not painful, however an injection of radioactive material (an 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.

**CT scan**
Computerised Axial Tomography – also called a CAT scan – takes many pictures of soft tissue inside the body, from different directions. A computer integrates the pictures to show any tumours. Scanning is painless but a needle is sometimes required to inject contrast. A CT scan usually takes less than five minutes. A sedative or a general anaesthetic may be needed to ensure that the child stays still for this time.

**CVAD**
Central Venous Access Device. See Port, Hickman, Insuflon or Portacath.

**Echocardiogram**
An ultrasound test is 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.

**Electrocardiogram (ECG)**
This records the rate, rhythm and electrical activity of the heart.

**Gallium scan**
Gallium scans are done in the nuclear medicine department. Before the scan, an injection of Gallium is given. Gallium gathers at 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.

**Glomerular Filtration Rate (GFR)**
Some drugs have the potential to affect kidney function. Children having these drugs have their kidney function monitored regularly during treatment. Glomerular Filtration Rate (GFR) is a very specialised nuclear medicine test of kidney function. Two blood samples are taken on the day to measure kidney function.
**Lumbar puncture**

With some cancers, such as leukaemia or lymphoma, malignant cells can pass into the brain and cerebrospinal fluid surrounding the brain. To find out whether this has occurred, a few drops of the fluid are removed by inserting a fine needle between two vertebral bones in the spine.

**Magnetic Resonance Imaging (MRI) scan**

Magnetic waves are passed through the body and produce different images depending on the type of cell they pass through. They are harmless. The MRI can give an accurate picture of a tumour and the surrounding structures. Sometimes in CT, MRI and X-ray a special fluid called ‘contrast’ is injected into the blood to get a better picture of the tumour and its relationship to other structures.

The MRI machine is noisy and may be scary because the child has to lie in a tunnel. Different hospitals may use different ways to help children learn about the MRI scan procedure and prepare them to stay calm and still during the scan. Please speak to your child’s treating team about the facilities available at your child’s treating hospital. A ‘mock MRI’ is available (at RCH only) to let the child experience what having an MRI is like. Although having the MRI is painless, a general anaesthetic may be required to keep the child still.

**PET scan**

PET Scan – Positron Emission Tomography – gives a picture of how a part of the body is working. A small amount of radioactive chemical is injected or breathed in. The PET scan shows where this chemical goes. PET Scans can help identify malignant and benign tumours.

**Ultrasound scan**

Ultrasound waves are sound waves that the human ear cannot hear. A special machine directs the waves at a certain part of the body. Differences in how the sound waves are reflected helps form an image. This is interpreted to distinguish a healthy part from a tumour.

**X-Ray**

An x-ray can show whether there is tumour in the chest, abdomen or bones because tumour tissue looks different from ordinary bone or normal tissue. X-rays can also be taken to look for signs of infection if your child is unwell.
Procedures

Procedures are done by nurses and doctors as part of a child’s treatment – like putting in an IV or a nasogastric tube or accessing a port. A child does not have every one of these procedures. Some procedures are done with sedation or general anaesthesia. Some of the devices used during procedures are:

Central lines
These are tubes put into a large central vein to give fluids and chemotherapy. Blood samples can sometimes be taken from them. They are semi-permanent and can stay in place for several months or years and are put in under general anaesthetic. There are different types – Port-a-caths, PICCs, Hickmans. Your nurse will give you more information if your child needs a central line.

Insufions
Several drugs may be given under the skin by subcutaneous injection. When a drug needs to be injected several times, we use a small device called an Insufion. This reduces the pain and worry of daily injections. The Insufion is 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. Either you, your child, or your nurse can administer the injections using the Insufion.

With the Insufion in place your child can continue with activities of normal daily living, including bathing and swimming. At home the Insufion site should be checked regularly for signs of swelling, redness, and/or discharge. If you notice any of these signs, or should the Insufion accidentally be removed please contact your hospital team.

Nasogastric tube
A nasogastric tube goes from the nose into the stomach. It is used to give liquids including nutrition and medicine. If your child needs a nasogastric tube, the nurses will give you more details. There is more information about nasogastric feeding in SECTION 8, Frequently asked questions.
Cancer treatments

Once it is established what type of cancer your child is diagnosed with, the consultant oncologist will decide the type of treatment that is required. There are three main types of treatments: chemotherapy (drug therapy), radiation therapy, and surgery. Not all children will require all these; your consultant will discuss the treatment needed to treat your child’s cancer.

Chemotherapy

Chemotherapy is treatment with drugs. Chemotherapy is used alone or combined with surgery and/or radiotherapy. Chemotherapy drugs (also called cytotoxic drugs) injure or kill body cells. Chemotherapy attacks cancer cells but will also affect some normal cells and this causes side effects. These side effects are usually temporary.

Different drugs have different side effects and children can react differently to the same chemotherapy drug.

Chemotherapy can be given in many ways. In children, it is usually given by tablets or by injection into the blood, tissue or spinal fluid. Chemotherapy can be given over different periods of time, in hospital or at home as an outpatient. How chemotherapy is given depends on the drug and the type of cancer.

Precautions with chemotherapy

After receiving chemotherapy, small amounts of drugs are sometimes excreted in your child’s body fluids including blood, urine, faeces or vomit. The amount will vary greatly depending on the drug given.

- Urine, faeces and vomit can be disposed of in the toilet. Double flush with the lid down to avoid splashing
- Soiled disposable nappies should be placed in a plastic bag and disposed of in the normal way
- Other soiled items such as cloth nappies, linen and clothing can be washed with lots of detergent and water
- Good general hygiene is recommended after handling urine, faeces and vomit. **Washing hands is the single most important measure**
- Pregnant and/or breastfeeding women should wear gloves when handling waste.
Sometimes chemotherapy can be given at home. Oral chemotherapy is often given at home. If this is an option, the nursing staff or pharmacist will teach you all about this.

Radiotherapy

Radiotherapy is the use of high energy radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply. Radiotherapy is used alone, or with chemotherapy and/or surgery.

Children have their radiotherapy treatment at the Peter MacCallum Cancer Centre (Peter Mac). Radiotherapy is painless and usually takes a few minutes each time. Radiotherapy is usually given each day, over 4 – 6 weeks. Before radiotherapy begins, the radiotherapy scientist/technician does ‘planning’ – working out the exact position in which to place your child. This allows the radiotherapy to be given at the right place each time.

If radiotherapy is part of your child’s treatment, the radiotherapy healthcare team at Peter Mac will arrange your child’s appointments and give you information about the treatment, possible side effects and how to manage them.

Radiotherapy is a very effective treatment for cancer but it can damage some healthy cells close to the area being treated. This can cause short term and long term side effects. The side effects will depend on how much radiation is used and the part of the body that is being treated. Not all children will have all of the possible side effects. Your radiation oncologist and healthcare team will ensure your child is followed up to identify and manage, if necessary, any side effects from radiotherapy.

The radiation oncologist or registrar will see your child at least once a week while your child is having radiotherapy. You can ask any questions and discuss your child’s treatment and side effects.
Surgery
Many children with cancer will have surgery during their treatment. Surgery is used to biopsy a suspicious mass or lump at diagnosis, stage a disease, insert a central line, remove and/or debulk (reduce the size of) a tumour. Surgery may be an important part of the treatment for children with solid tumours or brain tumours. The general surgeon, orthopaedic surgeon or neurosurgeon will be part of a team of people involved in your child’s care.

Resection of a primary tumour
The surgical removal of the primary tumour may happen before or after chemotherapy. In a few cases complete resection (removal) of the tumour may be the only treatment needed, however most children will require additional chemotherapy and/or radiotherapy. Resection of a primary tumour involves major surgery being performed under a general anaesthetic. The exact nature of the surgery will be explained by the surgical team.

Debulking a tumour
Sometimes a tumour is too large to be removed safely. Debulking the mass (removing as much as possible without removing it entirely) can be beneficial as it may make the child more comfortable, particularly if the mass is large. Chemotherapy and radiotherapy may then be more effective on a smaller tumour.

Second look procedures
Some children with solid tumours and brain tumours may have a ‘second look’ procedure, 3 – 6 months after the initial debulking. Treatment – radiotherapy and/or chemotherapy, may have shrunk the tumour and it may now be easier to remove surgically. Alternatively, the surgeon may check the area for recurrence and may biopsy the surrounding tissue.

Amputation and enucleation
For some children with retinoblastoma and sarcoma, surgery includes the removal of all or a portion of a body part. Advances in childhood cancer treatment mean that amputation or removal of the cancer mass are needed less often. Surgery for bone tumours can often be complex, involving bone grafts and limb salvage. For accurate, individual information it is best to talk with your child’s orthopaedic surgeon or ophthalmologist.
Oral medications

It is a good idea for you to help to give your child’s medicines in hospital. It may make medicine-taking easier if your child needs to continue treatment at home. Many children don’t like taking any sort of medicine.

Hints to help your child take medicine:

• Rewards are more helpful than threats. Use an incentive like a Star Chart
• Re-direct your child’s attention by playing a game
• It might be easier to give medicines with a syringe instead of a spoon. Your nurse will show you how to do this
• You might need to hold your child firmly. Your nurse will help show you the best way if needed
• If the medication is missed out, you need to tell your child’s team
• Some medicines/tablets must be taken at specific times. Make sure you know when your child’s medicine should be taken and always check the expiry dates.

Before giving any medication that has not been ordered by your child’s consultant oncologist, check with your child’s team whether it is okay to give the medication.

Never give aspirin or drugs that contain aspirin.

Taking tablets
Some children have trouble swallowing tablets. If you are having problems with your child taking tablets ask your nurse coordinator or pharmacist for the written information about taking tablets.
Hints to help your child take tablets:

- Crush tablets and add to a teaspoon of jam, ice-cream or juice, but take care not to put your child off something he/she likes. A tablet crusher can be obtained.
  
  NOTE: Some tablets shouldn’t be crushed. Check with the pharmacy first.

- Break large tablets into halves or quarters. Tablet cutters can be purchased from a pharmacy.

- Try this: Put the tablet on the back of the tongue, take a big mouthful of water, tip head back and swallow.

- Tablets that taste horrible can be put inside a gelatine capsule – available from the pharmacy.

- When taking capsules, take a mouthful of water first to wet the mouth.

Vomiting tablets

- If vomiting happens after taking tablets, talk to the oncology pharmacist, nurse coordinator or the ward. The pharmacist can tell you what to do and can supply replacement tablets or capsules if necessary.

- If vomiting always happens with tablet taking, tell your consultant oncologist.

Medication and sharps return and disposal

The reason to destroy unwanted medicines and equipment

Unwanted medicines stored in the home can be a source of poisoning. Medicine and equipment can also contaminate the environment and harm others when discarded via routine rubbish collections or flushed down the toilet.

Other equipment such as gloves, plastic medicine cups, syringes (but not with needles), empty medicine containers and empty blister packs can be disposed of in normal rubbish. This also applies to the equipment used with cytotoxic or cancer medication and drugs.
### How to return unwanted medicines

Any unused medication such as tablets, capsules, mixtures, creams, inhalers or patches should be returned to a pharmacy for appropriate disposal. Syringes with needles should be returned to a pharmacy in a sharps container. This is the only safe way to bring them back, both for you and for the staff.

<table>
<thead>
<tr>
<th>Medication</th>
<th>Tablets, capsules, mixtures, creams, inhalers or patches</th>
<th>Return to any pharmacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equipment</td>
<td>Gloves, plastic medicine cups, syringes, empty medicine containers and empty blister packs</td>
<td>Rinse containers and put in the normal household rubbish bin</td>
</tr>
<tr>
<td>Sharps</td>
<td>Needles with a purple sticker</td>
<td>Put in a purple sharps container</td>
</tr>
<tr>
<td></td>
<td>Other needles and syringes with needles</td>
<td>Put in a yellow sharps container</td>
</tr>
</tbody>
</table>

### Where to purchase sharps containers

There are two kinds of sharps containers
- purple for cytotoxic needles and sharps
- yellow for other needles and sharps.

**The Royal Children’s’ Hospital:** Sharps containers can be obtained from the Cancer Pharmacy during business hours.

**Monash Children’s at Monash Medical Centre:** Sharps containers can be obtained from the Children’s Cancer Centre during business hours.

Some community pharmacies also sell yellow sharps containers in various sizes.

Returned syringes that are not in an appropriate sharps container will not be accepted for destruction.
Complementary medicine and alternative medicine

The Children’s Cancer Centres use standard medical treatment (conventional treatment) that has scientific evidence to show that it works. The centres also use some complementary treatments and know about the use of alternative medicine in the treatment of children who have cancer.

Complementary medicine and alternative medicine use treatments and therapies that are different from standard medical treatment or conventional treatment. Complementary medicine means that it is used along with standard medical treatment. Alternative medicine means it is used instead of standard medical treatment.

Choosing a therapy involves different belief systems. A medical belief system uses scientific evidence such as that gained from clinical trials. Psychological and life style belief systems use evidence from people’s experience, beliefs and attitudes. Sometimes the different belief systems agree, sometimes they don’t. Some families and patients integrate what they find useful from complementary medicine with conventional medicine. Some don’t tell their child’s doctor about other therapies because they fear the doctor will not support what they are doing. Other people find it hard to watch their child experiencing the side effects of conventional treatment, and look for something else.

Complementary medicines are sometimes called ‘natural remedies’ and include: high dose vitamins, minerals, herbal therapies, tonics, aromatherapy, and homeopathic medicines. They are also sometimes known as ‘traditional’ or ‘alternative’ medicines.

It is not a good practice to use complementary medicine or alternative medicine without first talking with your child’s oncology consultant. This is because some chemotherapy and herbal medicines interact and can affect how well the chemotherapy works. Your child’s doctor needs to know if your child is having complementary or alternative medicine. If you need more information about conventional treatment and other therapies, the children’s cancer centres can help you find it.
Complementary/alternative medicine also includes:

- Treatments that are well established in other countries, such as traditional Chinese medicine in China and Ayurvedic medicine in India
- Treatments, such as magnet therapy, crystals
- Mind-body medicine – therapies and techniques that use the mind to help heal the body – hypnosis, meditation, guided imagery and biofeedback
- Lifestyle changes such as nutrition, social support, relaxation, stretching and exercise, to balance the body and calm the mind
- Older therapies such as massage, osteopathy, naturopathy, herbal medicine and homeopathy.

Please tell the doctors and nurses about all of your child’s medicines, including:

- medicines prescribed by the hospital
- medicines prescribed by another doctor (maybe your GP)
- medicines you bought at the chemist or the supermarket
- medicines bought from a health food shop
- complementary medicines (‘natural’ remedies).
Side effects and what to do

Treatment kills cancer cells, but it also kills some normal, healthy cells. When normal cells are damaged or killed there are side effects. However, normal cells repair themselves better than cancer cells, and the side effects are nearly always temporary. The normal cells that are most often affected by treatment are those that grow fastest. They are in bone marrow (where blood cells are produced), the digestive system (mouth, stomach, bowels or intestines, rectum), hair and skin and the reproductive system.

This section describes the possible side effects of treatment and includes hints to manage them. It’s a long list but each child won’t have every possible side-effect. Many children will have only a few side effects. Most side effects are short-term. Side effects can be managed in hospital and at home. The pharmacy provides information sheets on individual chemotherapy drugs and their side effects.

Bone marrow side effects – low blood counts

Blood counts are used to monitor treatment. These are counts of different types of blood cells. The blood count for each child depends on age, type of cancer and the type of treatment. Your child’s doctor will tell you what your child’s blood counts are and what this means. See Section 3.4, CANCER, Tests and procedures to diagnose cancer for more details about blood tests.

Low red blood cell count

Red blood cells (RBC) contain haemoglobin. The haemoglobin level in the blood indicates the number of red blood cells in the blood. When the haemoglobin level is low, a person is said to have anaemia. The signs of anaemia include:

- Paleness
- Lack of energy
- Increased tiredness
- Shortness of breath
- Racing heart
- Headache
- Dizziness
- Feeling cold
- Irritability.
If a child’s haemoglobin drops below a certain level, a blood transfusion may be given.

**Neutrophil count**

Neutrophils are important white blood cells (WBC) that fight bacterial infections. When the neutrophil count is low, there is a greater risk of getting a bacterial infection and your child is considered neutropaenic.

**Hints for when a child is neutropaenic (has a low neutrophil count). These reduce the risk of your child getting an infection:**

- If your child’s temperature is 38°C or higher, call the hospital and seek medical attention as soon as possible
- Family and visitors (at home and in the hospital) should wash their hands before visiting your child. Good hand washing is essential
- Avoid large crowds – shopping centres, supermarkets and cinemas at busy times
- Limit the number of people visiting your child (at home and in hospital). Sick people should not be in contact with your child
- If a member of the family is sick, ensure strict handwashing. Do not share crockery or cutlery
- Do not take rectal temperatures or use rectal suppositories. These can accidentally tear the lining of your child’s rectum, potentially allowing bacteria to enter your child’s bloodstream
- Check inside your child’s mouth daily. Call the hospital if mouth sores develop
- No dental work should be performed unless previously discussed with your child’s doctor
- Your child’s doctor will tell you when your child’s blood counts are okay for him/her to return to school. It may be recommended to stay away from school when the neutrophil count is low.
Platelet count

Platelets are needed for the blood to clot. When the platelet count is low (thrombocytopaenia), 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 it is appropriate to let the platelets recover by themselves unless your child is actually bleeding.

Signs of thrombocytopaenia include:

- Increased bruising
- A persistent nose bleed that doesn’t stop with pressure
- Gums that bleed easily
- Bleeding from small cuts and scrapes that is hard to stop
- If your child develops any signs of bleeding contact your child’s treating team who may recommend your child has a blood count
- Red freckles that suddenly appear (tiny bruises called petechiae).

Hints for when your child is thrombocytopaenic (has a low platelet count)

- 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 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 the doctor for stool softeners, (eg. Coloxyl® or liquid paraffin) as hard bowel movements can cause rectal bleeding.
Digestive system side effects

**Mouth ulcers**
The cells that line the inside of the mouth normally reproduce rapidly to repair any damage caused by the teeth and normal wear and tear. Treatment temporarily stops this repair, and the mouth lining can break down. This results in mouth ulcers. Section 4.16, CARING FOR YOUR CHILD AND FAMILY, *Oral and dental care* has suggestions for managing mouth ulcers.

**Diarrhoea**
Some chemotherapy drugs, antibiotics and radiotherapy to the abdomen can cause diarrhoea. If your child has diarrhoea, the doctor will need to know about the colour, consistency and number of bowel actions each day. A sample of the diarrhoea may be needed for laboratory testing.

Severe diarrhoea can cause dehydration. Make sure your child is drinking fluids often. If concerned about your child’s fluid intake, contact the doctor or the hospital as soon as possible.

**Constipation**
Medications for pain relief and some chemotherapy drugs can cause constipation.

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**Hints for preventing or managing constipation**
A stool softener such as Coloxyl® or liquid paraffin may be ordered to prevent constipation. If your child continues to be constipated after two days, please contact the ward. Please remember, no enemas or rectal suppositories should be given unless ordered by someone in your child’s team.

**Nausea and vomiting**
A child may have nausea and/or vomiting after chemotherapy and/or radiotherapy. This is caused by irritation of the stomach lining or from stimulation of the nausea and vomiting centres in the brain. Nausea and vomiting can occur within minutes of receiving chemotherapy, or after several hours or days.
A number of medicines called ‘antiemetics’ (anti-vomiting) are used to prevent nausea and vomiting. Ondansetron (Zofran®) is one of the most effective medicines used. It can be given orally (syrup, wafers or tablets) or intravenously, and has few side effects. If your child is receiving chemotherapy, Ondansetron may be ordered as part of your child’s treatment. It may be given regularly throughout your child’s hospital stay, and if required, can be continued at home. If your child continues to have difficulty with nausea and vomiting, changes or additions to your child’s antiemetic treatment may be made.

**Hints to help control nausea and vomiting:**
- Avoid fried, spicy and rich foods
- Offer bland, dry foods such as toast and dry biscuits
- Rinse your child’s mouth well after vomiting, because stomach acid left in contact with the teeth and mouth lining will cause tooth decay and irritate an already tender mouth
- Serve smaller portions
- Roughly estimate and record how much fluid your child is consuming, and how much he/she vomits. Monitor for the signs and symptoms of dehydration, which include a reduction in the amount of urine passed, a dry mouth or persistent vomiting
- Encourage the use of regular anti-emetics at home.

**Hair and skin side effects**
Some treatments can cause changes to the body – hair loss, skin changes, weight gain or loss.

**Hair loss (Alopecia)**
Hair lost as a result of chemotherapy will always grow back. The amount and timing of hair loss will depend upon the treatment. Hair loss usually begins two to three weeks after starting chemotherapy. Some children may lose their hair overnight, while others lose it over days or weeks. Hair loss can range from very little to severe thinning, to complete baldness. Hair loss may also include body hair, eyebrows, and eyelashes. When hair grows back it may be different.

Hair loss or thinning can be permanent in areas of the scalp for children having radiotherapy to the brain, and in some intensive chemotherapy treatments.
Hair loss can be a traumatic part of treatment, especially for adolescents. It is recommended that your child use some kind of headwear, as a lot of heat is lost through the scalp and the skin is especially sensitive to the sun. Some children choose to wear a cap, scarf, or bandana. Please speak to a member of your child’s team about the options.

**Skin changes**
Children often develop rashes, acne, hives, or changes in skin colour as a result of chemotherapy. Reassure your child that skin changes should return to normal after chemotherapy has stopped.

If your child has radiotherapy, it may cause reddening of the skin and/or skin rashes, dry skin, itchiness at the place that had radiation. Your radiotherapy nurse will tell you how to care for your child’s skin during radiotherapy.

**Body changes**

**Excessive weight gain**
Your child may have to take a steroid drug (e.g. Prednisolone, Dexamethasone) as part of treatment. There may be side effects to steroids but these usually disappear some time after the steroids are stopped. These side effects can be an increased appetite, excessive weight gain (particularly in the face and abdomen), and fluid retention.

**Hints for managing weight gain:**
- The weight gain caused by steroids is temporary. Your child’s weight will return to normal after the steroids are discontinued.
- Encourage a healthy diet.
- Make sure your child has healthy snacks.

**Excessive weight loss**
Your child may lose weight during treatment, even while eating a well-balanced diet. The dietician will monitor your child’s weight and nutritional status closely, and provide nutritional support when necessary. Because weight loss needs to be avoided, many children have a nasogastric tube for a while during treatment to give them nutritional supplements.

If your child needs a nasogastric tube, you will be taught how to manage the tube and feeding through the tube at home. Section 8, FREQUENTLY ASKED QUESTIONS has more information about nasogastric tube feeding.
Hints for managing weight loss:
• Offer small meals frequently throughout the day
• Offer drinks with extra calories
• Offer foods with high calories
• Roughly estimate and record how much fluid your child is consuming, and how much he/she vomits. Monitor for the signs and symptoms of dehydration, which include a reduction in the amount of urine passed, a dry mouth or persistent vomiting

Section 4.11, CARING FOR YOUR CHILD AND FAMILY, Eating well has more hints.

Reproductive system side effects

Impaired fertility
Some anti-cancer therapies can affect the reproductive health and future fertility of children and teenagers who are treated for cancer. Whether or not this is likely to be an issue for your child depends on many things, including the age of your child at time of treatment, whether your child is male or female, the type of cancer they have, and the types and doses of anti-cancer treatments they receive.

Prior to the start of treatment it is important to discuss with your child’s consultant oncologist whether exploring possible fertility preservation procedures is a priority or an option for your child. Depending on the urgency of beginning your child’s treatment it may be recommended by doctors that treatment not be delayed to enable these activities to take place. Where appropriate your child’s oncologist will provide a referral to another specialist for further discussion regarding these options.

Strategies for managing impaired fertility:
• Adolescent boys can be offered the option of sperm banking
• Adolescent girls can be offered the option of having wedges of their ovaries removed and stored. This requires a surgical procedure
• Many children are too young to consider storage of sperm or ovaries.

If you have any questions, please speak to your consultant oncologist.
Radiotherapy side effects
As well as the immediate side effects, radiotherapy to the brain can also have long term effects. These can be learning difficulties and growth changes such as short stature, late or early onset of puberty. The side effects depend on the area of the brain being treated. Not all children will have these side effects. The side effects of radiotherapy are manageable. The radiotherapy team will give you more information about side effects and how to manage them.

Other side effects

**Hearing loss**
Several chemotherapy drugs and some antibiotics may cause a permanent hearing loss. If your child is having one of these drugs, regular hearing tests (audiograms) will be organised to monitor hearing. Your child may need to have their chemotherapy dose reduced if there is a significant hearing loss.

**Peripheral neuropathy**
Some chemotherapy drugs (especially Vincristine) can cause damage to the ends of the nerves in the hands and the feet, causing numbness, weakness or a tingling sensation (peripheral neuropathy). This can lead to reduced coordination, clumsiness and ‘drop foot’. While symptoms will eventually disappear once the treatment is stopped, peripheral neuropathy can be distressing. For more information, talk to your consultant oncologist.

<table>
<thead>
<tr>
<th>Hints for managing peripheral neuropathy:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Report any numbness, tingling or weakness to your child’s team. Rapid identification and treatment can reduce the severity of the symptoms</td>
</tr>
<tr>
<td>• Reassure your child the sensation will eventually go away</td>
</tr>
<tr>
<td>• If your child has pain associated with peripheral neuropathy, your child’s doctor will prescribe medicine to relieve the pain</td>
</tr>
<tr>
<td>• Your child may be unsteady when walking: keep him/her in a safe environment.</td>
</tr>
</tbody>
</table>

**Pain and fever**
Your child may have some pain or discomfort as a side effect of treatment. If pain relief is required, discuss this with your child’s team.

Your child should not have any medication containing Aspirin or Ibuprofen (Nurofen) because these drugs can increase bleeding problems and irritate the lining of the stomach.
Other drugs containing Aspirin or Ibuprofen should not be used throughout treatment without first talking to your child’s oncologist. All over-the-counter medications should be checked by the doctor before being given for the first time. If the doctor is not available, contact the oncology pharmacy for further advice. Paracetamol (Panadol®) may be used for mild pain, provided that your child’s temperature is normal. Paracetamol should not be given continually because it will mask a true temperature.

**Fatigue and sleepiness**

Fatigue is a common side effect of treatment. Fatigue may be acute (short lasting) or chronic (lasting some time). In the short term it may be tiredness relieved by rest. In the long term it may be a feeling of exhaustion accompanied by other symptoms such as lack of energy, dizziness, weakness and/or trouble concentrating.

Fatigue may continue for some time after treatment is finished. Sleepiness can be a side effect of radiotherapy to the brain. It’s called somnolence syndrome and can last for many weeks. If your child is having radiotherapy as part of his/her treatment, the radiotherapy healthcare team will discuss this with you.

**Hints for managing fatigue:**
- Plan appropriate rest periods during energy lows
- On return to school, plan for half days, then full days
- Avoid having too many visitors at once
- Ensure your child is active to maintain fitness and well being
- Continue normal activities as much as possible
- Plan outings when your child has more energy
- Ensure your child’s food and fluid intake is maintained
Clinical trials

The information below has been developed by the Australian and New Zealand Children’s Haematology Oncology Group (ANZCHOG) and has been included in this Information Book with their permission. For more information regarding clinical trials, please see your consultant oncologist.

Choosing to participate in a clinical trial is an important personal decision. This information may help you in making that decision for you or your child.

What is a clinical trial?
A clinical trial is a medical research study that searches for a better 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 results of past trials and what is known about the disease and cancer treatments.

Why are clinical trials needed?
Clinical trials are necessary to show that the treatment is safe and works well in treating cancer. Clinical trials help establish if the treatment being studied will work, what, if any, are the side effects and what the correct dose should be. This helps doctors to decide if the treatment is more effective and/or safer than existing medicines or treatments. Clinical trials are usually the fastest and most efficient way to improve the care of children and adolescents with cancer. Without clinical trials, medicines cannot be approved for use in Australia and New Zealand.

How are clinical trials approved?
Before clinical trials can go ahead they need to be approved by independent ethics committees. These ethics committees operate in accordance with the guidelines issued by the National Health and Medical Research Council (NHMRC) and ensure that clinical trials conform to the Declaration of Helsinki and to international Good Clinical Practice (GCP) guidelines.

Who runs a clinical trial?
Each clinical trial is led by a doctor. The clinical trial team includes doctors and nurses as well as pharmacists and other health care 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 staying in touch with them for a period of time after the clinical trial has been completed.
What are the benefits from participation 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 interventions not otherwise available
- Close monitoring of any treatment related side effects
- Findings from clinical trials add to knowledge and progress in the treatment of cancer

Participation in clinical trials is not, however, without its downsides, which may include:

- New drugs and procedures may have side effects or risks unknown to the doctors
- The trial medicine may not work for you or your child
- You or your child may be placed in the control or reference group and may receive the standard treatment, and not the trial treatment
- You or your child may need to visit the hospital or doctors’ room more frequently and/or stay there longer.

Randomisation
The clinical trial offered to you or your child may compare two or more treatment arms (plans). The treatment arms come from other studies that have shown that both treatments are effective, but doctors do not know if one treatment may be better in some way. One treatment plan is thought to be the ‘standard’ or the current best known treatment, and the other is the new treatment doctors think will work well. To learn if one treatment is better, each participant is assigned randomly to one of the treatment arms by a computer. Randomisation is a process like flipping a coin that assures each participant has a fair and equal chance of being assigned to any of the treatment arms.

How can I or my child participate in a clinical trial?
After your or your child’s doctor reviews the treatment plan with you, you will be asked to give your permission to start treatment. You will be asked to sign a form that describes the plan. This form lists the risks and benefits of the treatment and what other treatments may be available. When you sign the form, you are saying that you understand what the doctor has explained to you and you agree for you or your child to start the treatment.
Participation in a clinical trial is voluntary. It is important to know that if you decide that you or your child will not participate then the best known and established treatment will be given. You can withdraw yourself or your child from a trial at any time, without any effect on the ongoing medical care.

**What happens if side effects occur from taking a medicine in a clinical trial?**

By the time a medicine reaches the clinical trial stage it has already been extensively tested for likely side effects. However, especially with new medicines, there might be additional side effects. It is not possible to predict in advance if any side effects will occur but, if they do, appropriate care will be provided to you or your child.

**What happens with the results from clinical trials?**

The results of clinical trials are made available to doctors so that they can be used to improve future treatment for other children and adolescents. The results are also published in medical journals and other relevant publications, and are available on the internet.

In addition, study doctors will be notified of the results of the study as they are made available. Records are reviewed during the trial and if important information is discovered, it will be reviewed. All details about your or your child’s treatment are kept confidential even when the results of the study are published. Results of the treatment will be analysed, but confidentiality is assured.

**What else do I need to know about clinical trials?**

Questions you can ask include:

- What is the purpose of the study?
- What are the treatment choices for me or my child?
- Why is this treatment expected to be effective? Has it been tested before?
- What kind of tests and procedures are involved?
- How do the possible risks, side effects and benefits of the study compare with the standard treatment offered?
- What will I or my child have to do as a part of this clinical trial that is different from standard treatment?
- How long will the trial last?
- Will it be necessary to be hospitalised?
• What will happen if I or my child suffers a serious side effect as a result of the trial?

• Will I or my child have access to the treatment after the trial is over?”

Whatever your decision, your child will still get the best known and established treatment.

A decision not to participate in a study will not affect the Children’s Cancer Centre team’s attitude towards you or your child.
Off treatment and Long Term Follow-up (LTF)

Once your child has finished their cancer treatment, they will move into the surveillance or ‘off-treatment’ phase of care.

Everyone looks forward to the end of cancer care and life ‘getting back to normal’. Sometimes this means going back to how things were before, and sometimes this means adapting to a ‘new kind of normal’.

The LTF team will help children, young people and families to navigate life after cancer, and will empower survivors and families to take charge of their future health care.

When cancer treatment is finished, you will continue to see your child’s oncologist on a regular basis for tests, investigations and clinic appointments. The number and frequency of tests and follow-up appointments will vary depending on your child’s diagnosis and the type of treatment they have received.

These appointments will gradually become less frequent as the immediate effects of the cancer therapy disappear and the chance of recurrence becomes less likely. The change from ‘off-treatment’ to ‘long term follow-up’ is a gradual process and the timing depends on the type of cancer your child had and what treatment they have received.

Once you have been referred to the LTF program, the LTF team is available to answer questions or provide direction with regard to services and information about the LTF program. If you are an off-treatment patient, there is a ‘Coming Off Treatment’ book available. Ask your consultant oncologist or nurse coordinator for a copy of the book.

In the initial ‘off-treatment’ phase, regular investigations and appointments aim to:

- Make sure the disease remains under control (doesn’t increase or come back)
- Manage any ongoing issues resulting from either the disease or its treatment.

Your child’s consultant oncologist will refer you to the long term follow-up program after an appropriate length of time in the surveillance/off-treatment phase. This is generally around two years from your child’s last treatment.
What is LTF?
Long term follow-up is the continuation of your child’s health care beyond the active treatment for childhood cancer. The aim of this care is:

- to assess the impact of cancer and treatment on your child’s physical, social, emotional and psychological well-being
- to enhance your child’s quality of life by managing current and ongoing health issues, and to minimise the risk of future health complications
- to support your child, and your family, in their return to school, community and lifestyle
- to provide information to you about the potential delayed effects of the disease and treatment
- to provide you with a patient passport, including health information, a summary of your child’s treatment and a ‘road map’ of planned future investigations
- to gather information about your child’s health and well-being after treatment, which may influence cancer care for other children and young people in the future.

Who is eligible for LTF?
Every child or young person who has lived through cancer and is more than two years off treatment is eligible. Knowing about the actual and potential effects of their experience means that individuals can make informed health care choices.

Do I have to come to hospital?
LTF care can be provided in a variety of locations, depending on your child’s diagnosis and the intensity of the treatment received. Some children or young people will need to attend specialised clinics in the Children’s Cancer Centres, at either The Royal Children’s Hospital or Monash Medical Centre, while others will be able to have investigations and follow-up care provided within outreach clinics, at other hospitals, or by GP’s or paediatricians in their own community.

What are the benefits of LTF?
The LTF program focuses on:

- health promotion and awareness
- early detection and intervention of cancer-related or other health and wellbeing issues
• the provision of accurate and relevant education and information
• empowering young people and families to take charge of their health care in a supportive environment.

During this time we are also preparing you and your child for transition into a suitable adult health care setting at the appropriate time. Your local doctor (GP) will be kept informed about your child’s medical management.

The program also aims to ensure:
• Each survivor has the knowledge and confidence to manage their own healthcare requirements – improving their future health possibilities
• Early identification of complications and intervention to reduce their impact
• Increased access to information and resources for health professionals – to raise awareness and increase confidence to manage individual healthcare requirements related to previous treatment of childhood cancer
• Links and referrals to other community service providers (specialist health care, education, financial, support services, peer group networks)
• Collection of treatment-related health information which will not only benefit current survivors, but may also reduce the occurrence of long-term, treatment-related health effects for children diagnosed with cancer in the future.

**Who is in the LTF team?**
The LTF team is made up of a variety of medical, nursing and allied health professionals including people with expertise in social, financial, educational and other information areas.

The team may look different depending on your child’s needs – you and your child will only see the professionals who will benefit you.

**How can I find out more?**
Your doctor, social worker or nurse coordinator will be able to give you more information about the program and put you in contact with the LTF team if you need more information. You can also email the LTF team directly on: ltf.program@rch.org.au
4 Caring for your child and family

Living with a child with cancer needs teamwork from your family, relatives and friends. This section has suggestions on what to do when your child is sick, immunisations, how to help your child during tests and medical procedures, during treatment and at home. Also included are notes about exercise and activity, tips for eating well, oral hygiene, school, dental care and pets.

If your child is sick

If your child is sick you may need to go to your local doctor or to the Emergency Department at your child’s hospital. The Quick Help guides in the front of this book will help you decide what to do. It is sometimes useful to give copies of the Quick Help guides for other people who look after your child. There are different Quick Help guides for RCH and MMC. The following guidelines may also help you to decide what to do:

• While it is important to let your nurse coordinator know of any symptoms your child might have such as: coughs, colds, earaches, sore throats and mild tummy upsets (with some vomiting or diarrhoea) most general childhood illnesses can be dealt with by your local doctor

• If your child has completed a course of intensive chemotherapy within the past 7–14 days and now has a temperature of 38 degrees or higher, ring your hospital. Follow the Quick Help guide in the front of this book

• If your child has a temperature of 38°C or higher ring your hospital. Follow the Quick Help guide in the front of this book

• If your doctor has started treatment for an infection and your child still has a fever of more than 38°C for 24 hours, he/she needs to be reassessed promptly and seen in Emergency

• If your child is receiving intensive treatment, re-admission with fever is likely, so you will be given an alert card and sometimes a letter to present to the Emergency Department indicating that admission without waiting for blood results is appropriate
• If you live in the country your consultant will have discussed with you the procedure to follow if your child is ill. Usually you will need to contact your child’s treatment centre in Melbourne on the numbers provided in the *Quick Help* guide in the front of this book. They will be able to give you appropriate advice and will usually contact the regional health service to let them know you are on your way to that hospital. Your nurse coordinator will provide you with the appropriate information on how to access your local hospital.

• During treatment, your child is more susceptible to infection. If he/she has the signs and symptoms of infection, listed under Infection (below), you should contact your hospital and follow the *Quick Help* guide in the front of this book.

If you are unsure about whether your child needs to see a doctor, follow the *Quick Help* guide in the front of this book for what to do next. If you phone the ward, use the *Hot Numbers* page in the front of this book. The ward will ask you:

• Whether your child has a temperature and if so, what is it?
• What his/her diagnosis is
• What stage of treatment he/she is at
• When treatment was last given.

DO NOT bring your child directly to the ward. **All admissions must be arranged via the Emergency Department.** If your child is very ill he/she will be attended to promptly. You might worry that your child may catch an infection in the Emergency Department. In fact, most infections in children with low blood counts occur from germs within the patient’s own body and are not caught from others. Your child’s temperature should be taken orally (under the tongue with the mouth firmly closed for three minutes) or axillary (left firmly under the arm for three minutes). An ear thermometer may be useful for small children. **A child on cancer therapy should never have their temperature taken rectally (via the bottom) because of the risk of bleeding or infection.**
Infection

Sometimes your child is well enough to go home but the white cell count may be low. This means your child has a greater chance of getting an infection.

Care should be taken in crowded public places – pools and spas should be avoided at all times. Remember, most infections in children with low blood counts occur from germs within the patient’s own body and are not caught from others. If you aren’t sure what to do, speak with the nurse coordinator or the ward.

If you notice any of the following symptoms, contact the ward or nurse coordinator immediately.

**Signs and symptoms of infection**

If you think your child might have an infection, follow the *Quick Help* guide in the front of this book.

- **Temperature**
  - Take the temperature if your child looks unwell or feels unwell.
  - 38°C or above – contact the ward immediately
- **Flushed appearance, complains of being hot and/or cold, sweating, shivering**
- **Coughing, sneezing, runny nose, shortness of breath, tightness over the chest**
- **Redness, swelling and/or pain in the throat, eyes, ears, skin, joints, abdomen**
- **Blurring vision, headaches and difficulties with sight**
- **Smelly, discoloured urine, needing to do wee often and urgently, stinging**
- **Redness, swelling and/or discomfort at the site of a central line or insufion/port-a-cath**
- **Pain or stinging when doing poo**
- **Constipation for more than 48 hours**
- **Diarrhoea**
- **Any skin rash or red spots**
- **Vomiting**
Chickenpox, Measles and Mumps

These are common childhood illnesses that your child can catch again because chemotherapy drugs reduce your child’s immunity and ability to fight off infection and will do so for at least six months after the completion of chemotherapy. The best protection is not being exposed to these diseases. This means asking the parents of children who play with your child to tell you if their child currently has chickenpox or measles. This includes friends at school and kindergarten. A letter to the school is available, if needed.

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 blisters. Blisters burst and form scabs.

Chickenpox is spread by direct contact with someone who has it – playing, kissing, sharing cups, towels, bedding. It is contagious (catchable) from one day before the pink spots appear until six days after the last blisters become scabs.

If your child has contact with chickenpox, or you think your child might have chickenpox, phone the ward or your nurse coordinator immediately.

ZIG – a temporary immunisation – can sometimes be given if your child has had contact, but not if your child has chickenpox. It is only effective if given within 72 hours of contact with chicken pox. It does not prevent getting the chicken pox in 100% of cases.

Signs of Measles

- Sneezing, watery red eyes, similar to signs of a head cold
- Hoarse voice or harsh irritating cough
- Hot skin
- Complaint of a strange feeling in the tongue with a strawberry like appearance
- Red blotchy rash appears four days after flu-like symptoms.

Measles spreads like chickenpox (see above). It is contagious (catchable) from one day before the first signs until four days after the rash appears. If your child has contact with someone with measles, ring the ward or your nurse coordinator immediately.
**Signs of Mumps**

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

The mumps virus is usually spread by contact with tiny, airborne droplets of saliva when people laugh, sneeze or kiss. It can also be spread by contact with saliva from shared drinking vessels, tissues. It is contagious from two to three days before the first signs until six days after they disappear. There is an incubation period – while the disease develops – of 12 to 25 days after contact.

Phone the ward or your nurse coordinator if you think your child has mumps or has been in contact with someone who has mumps.

**Immunisation**

During treatment and for a while after, your child should not have immunisations without your consultant oncologist’s approval. Certain immunisations should not be given to other children in the family. The only exception is tetanus immunisation. Contact the ward or your nurse coordinator if your child has a wound that needs a tetanus shot – rusty iron cut, animal bite, dirty puncture wound. Also, the child with cancer and his/her immediate family must take the annual flu vaccine in between treatment cycles. Your consultant oncologist will tell you when it is okay to have immunisations. The nurse coordinator can give you a letter for exemption from school immunisations.
Helping your child cope with illness

Coping with cancer and treatment can be difficult at times for children and their parents/carers. Children may show they are not coping through changes in their behaviour and/or emotional state. Here are some tips on how to recognise these signs and some strategies that may help.

**Signs of behavioural or emotional distress**

- Your child’s behaviour is different to what it was like before his/her illness.
- Sometimes this may be more oppositional and argumentative behaviour towards you and other people.
- Your child may be more clingy and show some separation anxiety from you or others.
- Your child may act more like a younger child. For very young children this may be regression in behaviours such as toileting, sleeping, eating.
- Older children may swing between being dependent and independent. You may find it hard at times to know what your child needs or wants.
- Your child may become withdrawn from friends and/or family members and seem less confident.
- Your child may be more tearful than before or show other signs of sadness such as thinking in a more negative way or having trouble sleeping.
- Your child may worry more about things than before.

**How you can help your child during treatment**

Most children who have cancer will make good psychological adjustment in the long-term. Remember this when you are feeling worried about your child and how he/she is coping.

It helps if you can respond to your child’s emotional and/or behavioural changes in a calm and reassuring way. One of the most important things is to make sure you are well supported and can find ways to care for yourself as this will help you to help your child. Some suggestions are as follows:

- Try to keep your child’s environment as consistent as possible, despite the hospital visits. Maintaining routines – baths, bedtime, sleeping and eating – is very important especially for younger children. For older children, keep consistent limits and expectations. Treat your child as normal.
- Stick to your family rules and expectations about behaviour. Children feel more secure knowing what they can and can’t do.
- If your child is experiencing separation anxiety, make sure your child has familiar toys or special things to help them feel more secure.

- If your child is finding it hard when you need to leave, even for brief times, try giving something belonging to you – keys, your cardigan. This helps your child to feel confident you are coming back.

- Think of creative ways your child can release strong feelings – banging pots, punching a pillow or punching bag, making lots of noise.

- If your child is showing negative behaviour, a reward system can help encourage more positive behaviours. Be clear with your child about the behaviour you would like to see and then give rewards when this has been achieved. With a younger child, a chart showing progress is a good idea. Remember, everyone loves to get praise.

- Children do not always have the words to express how they feel. Sometimes you may need to guess what your child may be thinking and feeling. It is important to raise these issues at a time when you can give your full attention to your child and when you are both relaxed. Before a medical procedure is probably not the best time. If you see that your child is more sad than usual, you may start a conversation by saying that if you were in the situation you would feel sad sometimes. Then ask your child if he/she has felt sad.

- As much as possible, encourage your child’s contact with his/her friends. This is very important for all children and especially, adolescents. The social contact not only can help your child feel better but will also help with his/her return to school and other normal activities.

- Relaxation exercises are a great way for getting rid of stress and tension. Take note of how your child likes to relax. Make sure that your child has an opportunity each day to do something that he/she finds relaxing. Often it is great to do these things with your child. Try resting comfortably with your child while thinking about a happy past experience, making up a story or imagining you are in a special place together.

Try not to give-up if some of these ideas don’t seem to work at first – it may take a little time. Remember that no strategy will suit every child. Talk with your child about what he/she finds helpful, then build on that.

If you are concerned by your child’s level of behavioural or emotional distress, talk to your doctor/nurse or social worker about a referral to the psychosocial team for further help.
Helping your child cope with tests and medical procedures

Procedural Support Services
Support and assistance is available to children diagnosed with cancer and their families in coping with medical procedures at the children’s cancer treatment centres at RCH, Monash Children’s and Peter Mac. Play therapists, occupational therapists, music therapists and procedural pain clinicians who specialise in child development work with children and families to help build upon their existing strengths and coping strategies. In addition, nurses and support staff are trained and are familiar with the coping strategies that can be used to support children who are undergoing medical procedures. Clinicians can provide information and practical suggestions to aid families in their adjustment to hospital. Support is tailored for each individual child, and effective coping may be promoted with a number of techniques, some of which include: education, preparation, procedural play, helpful thinking, distraction, imagery, and deep-breathing/relaxation exercises.

Different health services have different programs and procedures for supporting children throughout medical procedures. Some health services follow formalised programs such as the Comfort First program at the RCH CCC. Following an initial assessment, and where appropriate, the child’s procedural preferences can be documented on a treatment plan known as a Comfort Plan. The Comfort Plan document provides written details of the child’s preferred procedural coping strategies (eg. how the child likes to be prepared for procedures, positioning options, distraction and imagery techniques, helpful thoughts). It is designed as a communication tool for staff and to ensure that the preferences of the child and family are acknowledged. Where available, procedural support clinicians are available to provide information, guidance, and emotional and procedural support to children and their families throughout their treatment journey.

Your child will have some tests and medical procedures before, during and after treatment. These are described in the Section 3.4, CANCER, Tests and procedures to diagnose cancer. It can help your child if you can be there during tests and medical procedures. If you can’t be there, think about having another person who your child is comfortable with.
Before the procedure

- Talk with the nursing and/or medical staff to get a good understanding of what the procedure involves and why it is being done.

- Prepare your child by giving simple, accurate information in a calm, non-emotional way. Use language your child can understand. Answer any of your child’s questions.

- Listen to your child’s concerns about the procedure – your child’s worries may be different from your concerns.

- How much information you give depends on your child’s age and how your child will cope. For a young child or for an anxious child, talk about the procedure only a day or two beforehand – rather than risk overwhelming them.

- Talk to your child about coping techniques eg. distraction, breathing he/she can use to help manage any worry or discomfort about the procedure. Practise these techniques together. Talk to your child about when and how to use these techniques.

- Where possible, give your child a choice. For example, your child can choose which finger for a finger-prick, or choose a position such as lying down, sitting in your lap – check first with the nurse/doctor if this is possible. However, it is not helpful to offer your child a choice such as when to start a procedure.

During the procedure

Avoid giving your child long explanations about the procedure while it is happening. Stay calm during the procedure; this will let you support your child as best as you can. Useful techniques include:

- **Maintain physical contact**: patting, rubbing and stroking can be very soothing.

- **Distraction/imagery**: encourage your child to focus on other things – rather than on the procedure. Distraction may be blowing a windmill or party-blower, looking at a pop-out book or favourite book, counting objects around the room, telling a favourite story, recalling a happy event, watching a video or TV. Imagery involves imagining events – particularly sights, smells, sounds and tastes – as if the events were actually happening. Ask you child to choose a favourite place or activity and focus on helping your child imagine that experience using all the senses.
• **Breathing/relaxation**: Telling your child to “Blow away the worry” can be very helpful before and during a procedure. Practise this with your child. It may help to imagine blowing out candles on a cake, or letting air out of a tyre. This can be combined with encouraging your child to relax. For younger children you can suggest they “Go all floppy”. Older children can be taught to breathe in comfortable feelings and breathe out tension, and to notice changes in their muscles and whole body.

• **Coping statements**: It may help for your child to use some coping statements before, during and after the procedure. These statements can help your child to use their coping techniques and to praise themselves – “I need to relax now. Soon it will be finished. It is helping me get better”.

What you say to your child during a procedure and how you say it can influence your child’s coping. Generally, it is not helpful to talk about the procedure while it is happening. Talk about something else – a recalled event – or coach your child to use a coping technique. Avoid statements such as “It’ll be all right”, “I’m sorry to have to do this”, “I know it’s hard” or “Stop being a baby”.

**After the procedure**

• Praise your child and mention any attempt at using a coping technique. Rewards can be very helpful but avoid bargaining with your child during a procedure – “I’ll buy you a Play Station”

• If your child cries or is distressed because of pain, let your child know that it is okay to feel upset

• Persist with coping techniques even if they do not seem to be effective at first. Talk with your child and build on the parts that he/she found helpful

• Provide opportunities to explore your child’s feelings more generally about their illness and treatment. Talking with your child and helping your child with any other worries is important

• If you are concerned about your own or your child’s level of distress or persistent distress associated with procedures, talk to your Comfort First clinician, procedural pain play therapist or another member of your treating team for further help.
Eating well

You may find that your child eats a little less than usual at the beginning of treatment and during chemotherapy sessions. Although there may be a small weight loss at this time, your child will regain it once they are feeling better.

Try not to bribe your child with sweets and food treats as you may find they will only eat or demand these foods later and want less of their usual ‘healthy’ foods. Try reward charts or sticker charts to encourage your child to eat the right foods.

It is best to offer familiar foods you know your child likes, but are the same as what the rest of the family is eating.

Although your child may seem more ‘fussy’ at times, continue to offer a variety of foods, even if they are sometimes refused. Try to stick with your usual routines, but be flexible, as your child may not always eat the same way depending on their appetite. Mealtimes may take a little longer at times, but try not to let them last longer than 30 – 40 minutes.

While there are no special foods that must be eaten or avoided, some of the side-effects of chemotherapy may alter eating habits. See your dietitian for advice and written information on how to deal with the most common side effects experienced by children. Your child might eat a little less than usual during treatment. There are many reasons for this.

This information gives some ideas on how to maximise energy and nutrients in your child’s diet. Not everybody reacts exactly the same way to treatment so it is important to be aware of good nutrition to help your child cope with any nutrition related problems that might occur.

Regardless of any eating difficulties or effects of treatment, good nutrition is important for the whole family.
Offer a balanced diet
Good nutrition will help your child to:

• Maintain adequate growth
• Help the body fight infections
• Tolerate chemotherapy
• Feel better and have more energy

A balanced diet is one that contains a variety of foods from the major food groups. These include:

• Breads and cereals including rice, pasta and breakfast cereals
• Fruits including fresh, tinned and dried
• Vegetables including fresh, dried, frozen and tinned
• Meat and meat alternatives such as beef, chicken, fish, eggs and legumes
• Dairy foods including milk, cheese and yoghurt
• Fats including butter, margarine, oil and cream.

Even if your child feels unwell, it is important that your child doesn’t go too long without eating.

Hints for eating when your child feels unwell:

• Offer small serves of food more frequently – perhaps five to six times a day – to avoid getting too full or too empty
• Offer cold foods that have little smell
• Don’t force your child but encourage and praise your child when he/she eats
• Eat meals in a well ventilated room to clear the smell of foods away
• Sit with your child while eating – eat something too
• Snacks of salty dry biscuits and fizzy drinks may be better tolerated
• Fluids are important, so offer these regularly to sip
• Offer a variety of foods
• Keep portions of favourite foods in the freezer for quick access
• Keep nutritious snacks handy so your child can get to them
• Try not to fill up on low nutrient foods such as cordials, soft drinks and lollies as there will be less room for other healthier foods
Enjoy a variety of foods every day

Vegetables, legumes

Fruit

Bread, cereals, rice, pasta, noodles

Milk, yoghurt, cheese

Lean meat, fish, poultry, eggs, nuts, legumes

Drink plenty of water

Choose these sometimes or in small amounts

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Hints to increase the nutrition level of the food your child eats:

- **Milk:** Use full fat varieties in milk shakes, on cereals, in puddings, to make up soups, mash into potato. Make white sauce or cheese sauce for pasta and vegetables
- **Yoghurt:** Use as an in-between meal snack. Add to milk drinks or to fruits and desserts
- **Cheese:** Grate cheese into soups, mashed vegetables, sauces and omelettes, sprinkle over vegetables, mix into tinned soups, baked beans or spaghetti
- **Offer cheese on toast, or cheese and dry biscuits for a snack**
- **Meat, chicken and fish:** All meats are suitable. Leave the fat on meat, and serve with a sauce or gravy. Add some oil to the cooking for extra energy
- **Oils, margarine, butter, cream and mayonnaise** increase the energy content of foods. Melt over vegetables and spread more thickly on toast, bread and dry biscuits. Add cream to desserts, sauces and breakfast cereals
- **Supplements:** Foods such as Sustagen® and Polyjoule® are often used for children who have poor intake and appetite

**What if my child loses weight?**
Children with cancer have increased calorie and protein needs. If your child loses weight and eats poorly, you should speak to your doctor, dietitian or nurse for further advice. Your dietitian can provide information about ‘high energy eating’.

**Good food hygiene**
During treatment, your child’s ability to fight infections is reduced. Sometimes, bacteria can grow in food, and cause gastroenteritis, which then causes nausea, vomiting and diarrhoea. Here are some things you can do to stop bacteria growing in your child’s food. These guidelines are particularly important when your child’s blood count is low:

- Wash your hands before preparing any food
- Fruits and vegetables should always be washed before eating
- Store raw and cooked foods in different sections of the fridge
- Keep raw meats away from all other foods
- Use a separate chopping board for raw meats
- Defrost and cook foods thoroughly, particularly meats
- Never use unpasteurised dairy products
- Do not keep hot foods at room temperature. Keep hot foods hot in the oven, and cold foods cold in the fridge
- Check ‘use by’ and ‘sell by’ dates of foods.

**Eating during low blood counts**
If your child’s blood count is very low, avoid some foods that have a higher risk of bacterial contamination:

- Take-away foods, particularly if unsure of how long they have been cooked, or if not kept very hot
- Pâté and soft cheeses such as blue vein, ricotta, camembert, brie
- Fresh fruits that are very difficult to wash such as berries
- Soft serve ice-cream
- Bought pre-prepared salads such as coleslaw and potato salad
- Uncooked/fermented deli meats such as salami and mettwurst
- Uncooked herbs or herbal supplements
- Reheated food.

**Alternative or fad diets**
Many diets and dietary supplements are promoted as a treatment for cancer. These may not have the essential nutrients for normal growth and good health and may be expensive, hard to follow and impractical. Some may even be dangerous. It is essential to discuss any changes to diet, or plans to take a food, vitamin or mineral supplement with your child’s consultant oncologist. If you would like some more detailed information ask your doctor, dietitian or nurse for a copy of *Understanding Complementary Therapies – A guide for people with cancer, their families and friends* (Cancer Council, 2008).
Other eating problems
If your child experiences any of the following symptoms, his/her eating may be affected, but usually for a short period of time only.

- Sore mouth or mouth ulcers please refer to Section 4.16, CARING FOR YOUR CHILD AND FAMILY, Oral and dental care.

- Nausea and vomiting. It is very difficult to eat when nauseous. No special diet will treat or solve this problem, but it is important that your child does not go for too long without eating. Never force your child to eat. You can make up for lost energy when your child feels better. Medication is often prescribed for severe nausea. Please refer to Section 3.19, CANCER, Digestive system side effects.

Other resources available from your dietitian and on the PICS website: www.pics.org.au

- Breastfeeding during your baby’s treatment
- Fussy eating
- High energy eating
- High energy eating for infants on treatment
- Dealing with increased appetite on steroids
- Home enteral feeding (tube feeding). A video for ‘tube feeding’ is available on the PICS website under ‘Information DVDs for families’
- Food guidelines during bone marrow transplantation (not available online)
- Food guidelines for home after bone marrow transplantation (not available online).
Oral and dental care

Mouth care

During treatment, some children get a sore mouth and may develop mouth ulcers. The most effective way to prevent mouth ulcers is to maintain good oral hygiene. This is best achieved by brushing the teeth and also the gums, tongue, inside the cheeks, and roof of the mouth 2–3 times a day, with a soft toothbrush.

While in hospital, your child’s mouth should be inspected at least once a day, and advice will be given if oral hygiene other than tooth brushing is required. When your child is ready to go home, tooth brushing will usually be the appropriate care, and the best way to prevent oral problems. Infants’ and toddlers’ teeth should be cleaned with a soft cloth wrapped around the finger.

Check your child’s mouth regularly and tell your child’s team if any of these occur:
- red or white or pale areas
- ulcers
- white-coated tongue
- bleeding gums
- swallowing problems
- difficulty eating or drinking.

A sore mouth

If your child’s mouth is bleeding or too sore to brush, a mouthwash can be used. The type of mouthwash will depend upon the presence of mouth ulcers. If no ulcers are present, a saline mouthwash is used, and if indicated, Nystatin liquid may be ordered. Nystatin is used to prevent oral thrush – a mouth infection. Nystatin must be swished and swallowed. No food or fluid should be taken for 20 minutes after using Nystatin.

If ulcers are present, Chlorhexidine mouthwash is used three times a day. Chlorhexidine is swished for one minute and then spat out. Swabs may be used if your child is too young to swish. No food or drink should be taken for 20 minutes following the Chlorhexidine, then use Nystatin as above. Chlorhexidine does not prevent mouth ulcers. It should only be used if your child has mouth ulcers to reduce the amount of bacteria in the mouth.

If your child refuses to drink fluids, or is unable to swallow saliva, please contact your nurse coordinator as soon as possible.
Eating well with a sore mouth
Some children have a sore mouth or mouth ulcers as a side effect of treatment. For them, eating can be uncomfortable or painful. The following hints may help to maintain their food intake:

Hints for eating with a sore mouth:

- Make sure you tell your child’s doctor
- Lip balm on the lips often helps
- Try soft foods with sauces and gravies – minced beef and gravy with mashed vegetables, scrambled eggs, soups, ice cream, jelly, custards
- Breakfast cereals with lots of milk
- Soft desserts such as milky puddings, custards and mousse
- Milkshakes/fruit smoothies, to help wash foods down
- Cut food into small pieces or puree food in a blender
- Avoid foods with sharp or rough edges, such as chips, toast and tacos
- Avoid foods with high acid content – tomatoes, orange juice and pickles – which will irritate mouth ulcers and cause pain
- Provide cool drinks rather than hot ones
- Keep up fluids to keep the mouth moist.

Section 3.16, CANCER, Side effects has hints for managing eating if your child has some of the side effects of treatment such as diarrhoea or constipation.

Dental care
Your child should go to the dentist as usual, but your dentist needs to know that your child is having treatment for cancer. If dental procedures are needed, your child’s consultant oncologist should be contacted to check if your child’s blood counts are at safe levels for dental work.
How schools can support young people receiving treatment for cancer

Schools play a vital role in supporting students with a chronic illness by assisting them to maintain links with their classroom and with their school community. It is important to keep your child in contact with their school, engaged in learning and in contact with their peers whilst they undergo treatment for cancer. While we understand that your child’s health is a priority, we would encourage you to also consider the importance of education as part of the journey towards better health. We encourage you to work very closely with your child’s school. A sample letter which you may like to send to your child’s school principal can be requested from your nurse coordinator or a member of the education team.

Listed below are key areas that you and the school will need to discuss and plan for. The best way to do this is to ask for a meeting with key staff at your child’s school (ie. Principal/assistant principal, student welfare/wellbeing coordinator, classroom/homeroom teacher, year level coordinator) as this may provide an open line of communication between the student/family and the school.

**Sharing information**

Decide how much information about your child’s condition needs to be shared with school staff, classmates and the wider school community. Discuss who will be responsible for the giving of information, to whom, in what way and when.

**Developing a student health support plan/individual learning plan**

Discuss with your child’s treating team/social worker/education support person at your treatment centre about developing a school-based health support plan which outlines how your child’s condition will impact on their ability to attend school and access the school curriculum. It should also include emergency contact details, the process to follow in case of emergency and information about how chicken pox, measles and shingles could impact on your child. A sample letter that your child’s school may wish to use is also available from your nurse coordinator.
It is recommended that an Individual Learning Plan (ILP) be developed to address the specific needs of the student. This is to be shared with the parents, school teacher(s) and your treating centre’s teacher(s). During the student’s lengthy admissions, day treatments, appointments, recovery at home and gradual return to school, an ILP is critical in ensuring their educational needs are met (a copy of this can be forwarded to the teachers on your ward to assist in supporting learning).

The health support plan should be made available to all relevant staff (including casual replacement teachers and other staff who have occasional care of your child). The health support plan should be reviewed annually or whenever there is any significant change to your child's condition or treatment.

**Maintaining communication**

If your child is going to be absent from school for prolonged periods, there are several measures that can be taken to lessen the educational and social impact of these absences. Maintaining regular communication with the school about how your child is coping at home and school (academically, socially, physically and emotionally) is of key importance.

Work with the school to organise:

- The best method of contact between home and school (ie. phone calls, email, communication book)
- How school work will be exchanged.

Many children keep in touch with school and friends via the internet. Ask the hospital staff about how this can best be done during your stay.

If you have access to a laptop computer (from home or school) it would be useful to bring it to the hospital for your child to use. You can then contact the hospital teaching service for assistance in connecting to the internet while in the hospital.

In addition, maintaining the classroom connection and student’s presence in the classroom is important for children who will have frequent absences from school.
Suggestions to maintain links include:

- Contact via email from peers and teachers, text messages, phone calls, Skype, MSN, Facebook
- Inclusion in class events eg. footy tipping, jokes, stories, cards, letters, posters, DVDs, music, photos
- Place a teddy bear in the absent student’s chair
- Hang a communication bag on the absent student’s chair
- During morning roll call, mention the absent student’s name and perhaps take a moment to reflect about the student.

Different hospitals have varying resources available to support children in hospital to remain connected to school and to support learning whilst in the hospital. The cancer centre staff will link you into the teaching service available at the hospital.

**Making modifications/reasonable adjustments**
Discuss with the school whether your child’s condition will require:

- Adaptations to the physical environment to allow full access to school facilities and activities
- Modifications to uniform, the curriculum, work requirements, timetable or subject choices
- An application for VCE Special Provision or a modification to the VCAL learning program on behalf of your child.

**Support Services offered by schools**
There is a variety of support services available to assist schools in effectively supporting students with cancer.

The principal or welfare coordinator of your child’s school is the best person to ask about accessing these support services.

**School Support Services Officers**
School support services officers include guidance officers, curriculum consultants, visiting teachers, speech pathologists, occupational therapists, psychologists, social workers and integration aides.
Visiting Teacher Service
In Victoria, the Department of Education and Early Childhood Development (DEECD) and the Catholic Education Office (CEO) provide a Visiting Teacher service. If your child attends an Independent school, please contact your child’s principal to discuss additional support.

Your child’s school is responsible for applying to the Visiting Teacher service.

Student welfare coordinators/primary welfare officers/pastoral care coordinators
All school systems have dedicated staff members who work to support schools to strengthen a whole school approach to the wellbeing of students.

Program for Students with Disabilities
The Program for Students with Disabilities supports the education of students with disabilities and additional learning needs in Victorian government schools by providing schools with additional resources.

Your child’s school is responsible for applying for the Program for Students with Disabilities if your child is deemed eligible under one of the following seven categories:

- Physical disability
- Visual impairment
- Severe behaviour disorder
- Hearing impairment
- Intellectual disability
- Autism spectrum disorder
- Severe language disorder and critical educational needs.

There are similar programs within the Catholic system and the independent schools system. In the Catholic education system, the program is called the Disability Funding: Literacy, Numeracy and Special Learning Needs (LNSLN) and in the independent sector it is called Education Funding: Students with Disabilities and Special Needs. Contact your school for more information.

Professional development opportunities for school staff
Visit the following sites and/or ask your child’s school to visit the following sites to download a copy of each of the following publications ‘When a student has cancer’ and ‘Cancer in the school community. A guide for staff members’

Other educational support available for young people receiving treatment for cancer

There are a range of programs, scholarships and funding opportunities from community support groups to assist with educational needs.

The Ronald McDonald Learning Program provides assessment and specialist individual education programs to students who are recovering from a serious illness. To find out more about the program, call 1300 307 642 or visit www.rmhc.org.au

McDonald’s Camp Quality Puppet Program is an educational program for primary schools. Life-sized puppets deliver a fun and positive message about supporting children living with cancer and other serious illness.

If the child is feeling well enough and the family agree it is appropriate, the child can be present during the puppet show. Schools are wonderful at seizing moments to promote inclusivity and making a child feel extra special during such times. The puppets often visit the RCH so patients are familiar with them. To find out more or to make a booking, call 02 9876 0500 or visit www.campquality.org.au/index.cfm

Red Kite can provide special interest and educational tutoring grants to help children and young people adjust and catch-up with their studies. They also offer a variety of scholarships for young people aged 15-24 years. To find out more about their services, visit www.redkite.org.au or email scholarships@redkite.org.au

Challenge offers the Christopher Wise Scholarship which provides financial support towards any primary/secondary/tertiary educational or training costs for young people who have been diagnosed with cancer or another life threatening blood disorder. The Scholarship is awarded annually, to Challenge members who are aged between 5 and 18-years-old. For further information regarding the Christopher Wise Scholarship or to have an application sent to you, please contact Challenge on 03 9329 8474 or visit www.challenge.org.au

The Learning Difficulties Centre at The Royal Children’s Hospital offers assessment and education services for students. To find out more about their services and fee structure, call 03 9345 5881 or visit www.rch.org.au/learndiff

The Specific Learning Difficulties Association is able to provide professional assessment, educational assistance and information services for students with specific learning difficulties. To find out more about their services and fee structure, 03 9489 4344 or visit www.speldvic.org.au
Cancer Council Tasmania offers post-secondary education and training scholarships for young people between 16-25 years who have been affected by cancer directly or through an immediate family member (sibling, parent, guardian, spouse or child). For more information and application form contact 03 6233 2030 or email seizetheday@cancertas.org.au

Transition back to school
With approval and encouragement from his/her consultant oncologist, a student can make a gradual return to school when they are feeling ready. The initial return to school may be brief as fatigue and reduced levels of concentration are ongoing issues during and post chemotherapy and/or radiotherapy treatment. This may make the reintegration back into school routines a very daunting process for both the child and the parents. It is important to provide support to the parents through this transition process to alleviate their anxiety about the child restarting school.

It is therefore helpful to encourage students and their families to choose times and classes that will provide a positive experience for them (eg. favourite subjects, specialist classes) and ensure support structures are organised in advance for the student.

Scheduling the school return or visit with recess/play or lunchtime provides an opportunity for the student to reconnect with his/her peers. The school may need to provide a quiet space where the child/young person can meet with small groups of peers during these class breaks. Create a quiet classroom space for the student to take time out or to rest, eg. a beanbag in the reading area, a headset with meditation or relaxing music. The school sickbay is not an ideal resting space, as chemotherapy suppresses immunity and the student may be more susceptible to everyday germs and viruses. Upon returning to school, there may be fluctuating periods of wellness and illness and morning medical/personal routines may take some time. Shorter school days and flexible schedules will assist in accommodating the student’s needs.

School photos
Being a valued member of the school community despite their absence is important for children managing a chronic illness. In the student’s absence it is possible to contact the photo company and enquire how the family can supply a photo to be superimposed on the class group photo.
**Things to remember**

- A consistent and ongoing, whole-school approach to supporting a child with cancer is important
- Relevant information about your child’s condition should be shared with appropriate school staff
- Maintain regular communication with the school regarding how your child is coping at school and home
- Look for opportunities for your child to participate in activities with the school which will help them to maintain a social connection with their peers and the school community
- Ensure appropriate modifications are made to allow your child access to the school environment and curriculum
- Explore possible sources of additional support.

**Other resources that may be useful**

**SuperClubsPLUS**

SuperClubsPLUS is a safe social learning network where children experience first-hand how to keep themselves safe online.

The SuperClubsPLUS community provides young children with an environment where they meet friends, and create their own personalised content, web pages and clubs. All activity on the site is mediated by highly trained and qualified staff. Visit www.scplus.com

**Cancer Council Victoria**

**When a Student has cancer**

*Cancer in the School Community: A guide for staff, parents, students and family members* is a resource to assist schools in supporting students, parents and colleagues with cancer. Visit www.cancervic.org.au/about-cancer/cancer-and-children/for-schools

**Canteen**

CanTeen is an Australian support organisation for young people living with cancer. The touchstone of CanTeen is the belief that young people, through meeting and talking with one another, are better able to cope with the uncertainties of a cancer diagnosis, and that no young person should go through cancer alone. Visit www.canteen.org.au
Livewire
Livewire provides supportive, safe and secure online communities for families affected by a serious illness, chronic health condition or disability. Livewire allows members to connect with others going through similar experiences, gain support, share stories and access relevant content. Visit www.livewire.org.au
Exercise and activity during treatment

Your child might be less active while having treatment – usually for a good reason. Your child may not be able to exercise at a particular time, for example with a high fever or low blood count. But prolonged inactivity can lead to tiring more easily, decreased muscle strength, and a decrease in daily activities. When appropriate, your child should be encouraged to walk every day and participate as much as possible in family activities. Include your child in activities as part of the normal routine. Outdoor activities such as walking or bike-riding can have positive effects during treatment, but they should be enjoyable and not work-outs. The duration of an activity can be altered depending on how your child is feeling. Even small amounts of exercise will help. A physiotherapy assessment may be required if your child has particular problems with mobility. However for most children, keeping active is all that is needed. “Don’t push it and don’t let the child push it”.

Pets

You don’t have to get rid of your pets – they are an important part of your child’s family, however;

- Wash hands after handling or patting the pet
- Wash hands before meals
- Your child should not clean out the pet’s places including litter trays, fish tanks and bird cages
- Most pets are suitable according to the age of the child, although some playful pups (and other pets) can scratch or bite. If the child is bitten or scratched, then the wound should be washed well with cool running water, cleaned with an antibacterial agent and covered if necessary with clean gauze. Ring the Cancer Centre for further advice
- Maintain pet immunisation and regular worm medication, as per animal schedule
- Ensure pets have no ticks or fleas, keeping their coat healthy with regular brushing and cleaning
- Pets should not be allowed to hunt or feed from rubbish bins, but maintained on a commercial diet for their species. Other foods such as eggs, poultry or meat products should be adequately cooked and water should only be taken from sources that are fit for human consumption
- It is not ideal to allow pets to sleep on your child’s bed
- Children on chemotherapy treatment should avoid animals and wild birds.
Horses: regular contact is not recommended, particularly grooming and mucking out stables

Birds: can carry disease. Don’t keep caged birds inside. Don’t let your child clean out the cage

Farm animals: limited contact allowed, taking care of good hygiene especially footwear

New pets: Check with your consultant oncologist for the right time to get a new family pet.

Sun Smart
Protection from the sun is essential for children having chemotherapy or radiotherapy. Chemotherapy and radiotherapy make the skin more sensitive to the sun – the skin burns more easily. Outside, all children having treatment must dress in light-coloured, long-sleeved clothing, and wear a wide-brim or legionnaire’s hat. When applying factor 30+ sunscreen, pay special attention to the backs of the hands, tops of the feet, back of the neck, ears, and scalp.

If your child is having radiotherapy, do not put sunscreen on the skin where the radiotherapy is done. The sunscreen may have certain properties which may cause the skin to burn when it gets radiation during radiotherapy.

A variety of Sun Smart products are carried by most chemists and The Cancer Council Victoria shops.

Remember
- Healthy, intact skin protects your child against infection
- Hair normally protects the back of the neck, ears and shoulders.
  There is less protection when there is hair loss.

Wigs
Generally, wigs aren’t needed. Hair loss only lasts a short time and wigs can be uncomfortable. If your child wishes to wear a wig, speak with your child’s social worker, nurse coordinator or consultant oncologist before you buy one.

Holidays
It is also important that when you do go on holiday there is a plan in place should your child become unwell or require assistance. Please speak to your nurse coordinator before planning a holiday so they can advise you of shared care partners and what you should do if your child becomes unwell.
Taking care of your relationships

Having a child with cancer can affect your relationships with other people – partner, ex-partner, other children, parents, friends and workmates.

With your partner
The demands of your child’s treatment and of running a family home when you are often elsewhere, means that you might see less of each other, at a time when each other’s support is important. As well, both of you may be emotionally stressed. It’s normal to have different ways of coping with stress, but these differences may add to the problems. You might disagree more over important issues or feel more tension in your relationship. This is a common experience for parents of a sick child, but it is painful and can be distressing. It is important that you find time to talk about each other’s thoughts, feelings and experience. If the tension between you and your partner is a problem, please talk to your child’s doctor, social worker or mental health practitioner. Further help is available.

With your ex-partner or your child’s other parent
It is important for your child’s other parent to be involved in your child’s care. But this can cause extra stress. You may suddenly have to relate to your child’s other parent, when you no longer have friendly contact with him/her. You may have to face issues or people that you chose not to deal with in the past. Sometimes the feelings you had when your relationship ended may be felt again. If you are not currently in a relationship, it might be hard to see other parents getting support from their partners while you are facing things alone. Interacting with your ex-partner is a difficult task. If you are having difficulty managing the care of your child in co-operation with your ex-partner, please speak to your child’s doctor, social worker or mental health clinician. Further help is available.

With your other children
It is common for parents to feel guilty about their other children while they are caring for their sick child. The demands of caring for your sick child, as well as trying to maintain normality for your other children, can be exhausting. Sometimes, you can feel out-of-touch with your other children and may be confused by their responses or reactions. With these complex and varied emotions being felt on both sides and being expressed in behaviour, it is important to encourage open communication and expression of emotions.
Brothers and sisters of a child who has cancer are likely to find it a difficult time. Some siblings are able to cope with the extra challenges that the illness brings to the family and learn something positive from the experience. But others find it very difficult to cope. They may feel anger, fear, jealousy or sadness which may result in acting-out behaviour, withdrawal, anxiety about their own health, and difficulty at school both academically and socially. They may even feel guilty that their sibling is sick.

Strategies that may help you support the siblings of your sick child include:

• It is a good idea to have a trusted relative or friend who comes specifically to see the other children regularly

• Remind family and friends to ask about and visit the other children

• Ensure that the kinder/school is aware of their brother/sister’s sickness

• Request a buddy system to support the well child. For example, a class teacher might check on the child each day. The teachers may make sure that the child knows who to talk to at school if he/she is feeling upset

• Ensure that the well children have contact with a trusted adult friend outside the immediate family who they can talk to about their worries. Often children do not want to add to your stress by admitting that they are worried or upset as well

• Ensure that the siblings are included in the treatment plan where possible and appropriate. Often the unknown is more scary than the known. It may be possible for siblings to spend some time with their brother or sister while they are in hospital and they may be able to come up with ideas for entertainment

• Ensure that the siblings are able to access age-appropriate child-friendly information about their brother/sister’s cancer. If you are unsure what information is available, talk to your nurse coordinator or social worker. They will be able to discuss relevant resources with you

• If possible ensure that you have a regular special time with each sibling where they can discuss anything that might be on their mind. This time does not need to be long. Just be clear that you are there for the sibling and understand that it can be difficult to be a brother/sister of a child with cancer

• Where possible ensure that siblings have time for normal activities. Reassure them that it is okay to play and feel happy
• Some siblings benefit from cancer support groups. These may include: CanTeen (12 years and up), Camp Quality, Challenge, Very Special Kids. Section 6.5, SUPPORT AND ASSISTANCE, Support groups has details. These groups provide a range of supports for both patients and siblings including family camps, patient/sibling camps, fundraisers, and other child friendly opportunities.

• Siblings can participate in sibling groups held at the Children’s Cancer Centre, RCH and Monash Children’s. Please talk to your child’s social worker for more information. See For brothers and sisters further on in this section for more information for siblings.

**With your child who has cancer**

After your child is diagnosed with cancer, you and your child will experience a range of intense and complex emotions. This can sometimes lead to differences in behaviour and differences in the way that you see one another. Often the relationship can become closer as you face difficult times together. Sometimes your child will feel upset, sad or fearful and become withdrawn or angry. Your child might focus anger on you because he/she feels secure in this relationship and needs a safe target to express his/her feelings. Your child may alternate between being angry with you and being very clingy and dependent.

Sometimes, it may feel like you are parenting a different child every day and a different child from the one before cancer. Your child may also want to protect you and may not want to tell you how he/she is feeling or thinking. It can be a challenge to create times with your child which are not focussed on being sick or being in hospital.

Your feelings, thoughts and behaviour will also influence your child and this can alter your relationship. It is important to discuss and acknowledge these changes. They can be positive.

Open communication and discussion about feelings, thoughts and experience should be encouraged as this will give your child the message that it’s okay and normal to have a range of emotions. This will also allow your child to ask for support when needed. Sometimes, professional assistance can be helpful. Please discuss this with your child’s social worker or doctor. See also, Section 4.8, CARING FOR YOUR CHILD AND FAMILY, Helping your child cope with tests and medical procedures.
**With your family and friends**

Friends and family are often not sure how they can help you. Sometimes their attempts at helping may be misplaced but almost always their intention is to be helpful. Sometimes you can feel overwhelmed by phone calls, visitors and advice. It may feel like you are supporting others when you and your child 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. Those who maintain little contact usually do this 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 for when your family and friends ask how they can help – errands, practical tasks – or just say “Knowing you are there is helpful”. During times of greater stress, it is helpful to ask a couple of your friends or family to pass on information about how things are going with you, to the rest of your friends and family. 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.

Some parents set up a group email or blog for people who want to know how things are going.

**With your parents**

See also *Grandparents*, further on in this section. Grandparents can play an important part in helping you care for your child. At a time of increased stress, you may need more help from your family and friends and sometimes your parents will be the major source of support. At times, what is meant as support can feel like interference. It is important to let your parents know what is helpful and to keep them informed of important information so that they can understand and support your decisions. Grandparents will be distressed for you as their child, and also for their grandchild. Sometimes, the thoughts and feelings you and they are experiencing, as well as your existing relationship, can make communication difficult. If this is the situation, please talk with your child’s social worker, doctor or nurse coordinator.
**With your workmates**

Sometimes, continuing work can be helpful as a useful distraction from the stress of having a child with cancer. Some parents see it as a time when they feel more in control. Being at work puts them in a world away from hospital trips and hospital stays. At work, it is important to tell people only as much as you want to tell them. Be clear about how much you want to discuss your child’s illness. Some days, at work, and with family and friends, you may only need to say “We are fine”. Other days you may want to go into more detail with certain colleagues. Most people will understand this and respect your right to protect yourself.

Most employers are very understanding of the demands of having a child with cancer and are willing to allow parents to take leave – paid and sometimes unpaid. If you are having difficulty arranging time away from work, or if your employer needs documentation about your child’s condition, please speak to your child’s social worker.

**With other parents**

The other parents who you meet in the hospital will have a unique perspective on your experience as they also have a child with cancer. It is common for parents to form close bonds with each other and gain a great deal of support from sharing each other’s experience. Even when children have different conditions, the feelings, thoughts and experiences are often similar.

Getting to know other parents and children means that you may benefit from their wisdom and knowledge. You may also share their pain and their triumphs. At times, you may not feel like hearing the experience of others. At other times, this may be a helpful thing to do.

The Cancer Centres offer different ways to help parents access and meet each other – support groups, parent/family information days, referral to the Parents Connect Cancer program through the Cancer Council of Victoria. Please discuss this with your social worker.

**Grandparents**

Grandparents are concerned about their grandchild and also concerned for their own son/daughter and for their other grandchildren. Sometimes this ‘double hurt’ is not fully appreciated by other people. Grandparents’ roles in the family may change and this can be a joy and a challenge. They might be more involved in their adult child’s life than they have been for years. They might want to be more helpful but not know how to help their child, their grandchild and the family.
Grandparents can give practical support – taking their child and grandchild to and from hospital, looking after other children. Their emotional support is also important – sitting with their child or grandchild in hospital, listening to them, and sharing their emotions about what is happening, giving time to brothers and sisters who may be feeling left out.

Grandparents may need to consider looking after themselves. Informal support from friends and family and formal support services may help them manage the shock of a diagnosis of cancer and the implications of treatment for their grandchild and family. Other people who may help are your child’s social worker or mental health clinician or community counsellors.

**For brothers and sisters**

It’s not easy having a brother or sister who has cancer. You might feel lots of different things. Your friend’s lives are not as complicated as yours. You might feel empty or lost, or even jealous. You didn’t expect your brother or sister to get cancer. You aren’t in control and don’t know what’s going to happen. You might feel happy that you aren’t sick. You might feel bad because you feel jealous or happy. Your feelings might go up and down – and you might be surprised by them. What you are feeling isn’t wrong, but your feelings can affect other people.

Most other people won’t know how you are feeling. They think they understand but they won’t. It’s not happening to them. Don’t expect your friends to be able to read your mind. Tell them how you feel and how you want them to act.

They may be too scared to ask questions. Don’t let people down-play your feelings. What you are going through is difficult and sometimes it’s good to hear someone else say this. You might be hard on your friends because their problems aren’t as big as yours – but that’s not how they might see it.

It is important for you to be able to talk to someone who understands you, and who can help you when things are hard. People who might support you include friends, parents, other relatives, teachers, school counsellors and hospital social workers.

You can help your brother or sister. He/she will need your company, love and support. Some things you can do are:

- Visit your brother or sister in hospital
- Stay with your brother or sister while your parents have a break
- Do things together – games, puzzles, listening to music, reading aloud, writing and drawing
- Phone calls
- Send letters and cards.
5 Your child’s treating team

Your child’s treating team will have medical, nursing, allied health, support people – and more. The people and services will vary from hospital to hospital.

Doctors
There is a team of specialists who specialise in a particular stream of medicine with many years of training and experience that provide cancer care for your child.

Primary Consultant Oncologist
The primary consultant oncologist is a doctor who specialises in the management and treatment of cancer.

Your child’s primary consultant oncologist is the doctor who will order tests and make the diagnosis of cancer and develop a treatment plan for your child. They will oversee your child’s care throughout the duration of treatment.

When your child is an inpatient at the Children’s Cancer Centres at the RCH or Monash Children’s, there will be an oncology consultant on ward duty every day who may not be your child’s primary oncology consultant. If you have any concerns regarding your child’s condition and treatment while an inpatient, please do not hesitate to discuss it with the oncology consultant on ward duty.

Once your child is discharged from the hospital, all your outpatient visits are booked with an oncology consultant or doctor in the outpatient clinic.

Other specialists
As well as the oncology consultants, there are other specialists involved in caring for your child who specialise in radiation therapy, surgery, fertility, nerves, bones and cells. The specialists involved in the treatment plan for your child will depend on the type of cancer your child has. Referrals to and discussions with other medical specialists will be decided by your primary oncology consultant when designing the treatment plan for your child.
**Other Medical Staff**
Clinical fellows are doctors training to specialise in cancer and blood disorders and supervise registrars, who are doctors doing specialist training, working towards being a consultant. Residents (resident medical officers or RMO’s) are qualified doctors who are getting more experience in the hospital.

In the ward, day to day medical care is provided by the paediatric registrar and residents. The registrar and residents make a daily ward round to check all children and are available to answer questions about the day-to-day management for your child.

**Nursing staff**

**Nurse unit manager (NUM)**
The nurse unit manager has overall responsibility for your child’s nursing care in the ward. The nurse unit manager is sometimes called the unit manager or charge nurse.

**Associate Unit Managers (AUM)**
Associate Unit Managers are experienced nurses responsible for running the ward during each shift. There is always an associate unit manager on duty in your child’s ward.

**Nurse coordinator**
A nurse coordinator co-ordinates your child’s care in the hospital and at home. The nurse coordinator is also the link between you and your child and the staff.

**Nursing staff**
The nursing staff provide day to day nursing care for your child both in the ward and in the day treatment centres.

Some nursing care can be provided at home by a number of different services such as Royal District Nursing Service (RDNS). This can reduce the number of hospital visits. The nurses at your treating hospital or primary treating centre can arrange this for you.
Allied Health

**Art therapist**
The art therapist uses a variety of art media to help your child express feelings, thoughts, fears and experiences. These may be about your child’s illness, treatment and being in hospital.

**Audiologist**
The audiologist checks your child’s hearing. This is important because some antibiotics and chemotherapy can affect your child’s hearing.

**Chaplain**
The chaplain provides care for your child, your family and for you. The chaplain listens to your concerns and provides spiritual, emotional, religious or simply human support. You don’t need to belong to a religious group or church to ask for a chaplain’s help.

**Comfort First clinicians**
A team who specialise in child development and focus on providing procedural support to children and families throughout their cancer treatment.

**Comfort Plan**
A document which is completed in collaboration with the child, family and Comfort First clinician, which specifies the child’s procedural preferences (eg. how the child prefers to be prepared for procedures, positioning options, distraction and imagery techniques, helpful thoughts).

**Dietitian**
The dietitian monitors your child’s nutritional needs and provides special diets and suggestions for ways to help maintain your child’s weight during and after treatment.

**Teaching and education support officers**
Different hospitals have varying resources available to support children in hospital to remain connected to school and to support learning while in the hospital. The ward or day oncology outpatient staff will link you into the teaching service at the hospital.
**Mental health clinician**
Mental health clinicians include psychologists, family therapists, psychiatrists and psychotherapists. The 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. While you may feel you do not require this assistance initially, if, at any point later in treatment or even after treatment finishes, you feel it would be helpful, please speak to your nurse coordinator who can arrange for an appointment.

**Music therapist**
The music therapist uses music to give your child a way to express their feelings. This can help relaxation and pain control, focus on healthy parts of the body and let your child make choices and control things.

**Neuropsychologist**
Neuropsychologists investigate the relationship between the brain and behaviour. They look at different aspects of thinking and problem-solving. Neuropsychological assessment allows your child’s progress to be monitored, and if there are problems, the neuropsychologist can recommend suitable ways to manage them.

**Occupational therapist**
The occupational therapist helps when your child has difficulty with daily tasks such as play, self-care or school activities. The occupational therapist assesses and treats these difficulties with a focus on decreasing the impact of disability and improving the quality of life.

**Oncology pharmacist**
The oncology pharmacist prepares and dispenses the drugs used to treat cancer and checks that the prescription is correct. The oncology pharmacist works closely with the medical and nursing staff and can tell you and the team about chemotherapy and its side effects.

**Orthotist**
The orthotist designs and makes supportive braces to improve your child’s comfort, maintain alignment or assist with mobility.
**Play therapist**
The play therapist uses play to reduce your child’s anxiety about an unfamiliar place and to help your child understand the medical procedures. Play therapy can be at your child’s bedside or in the playroom.

**Physiotherapist**
A physiotherapist works with children and adolescents 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.

**Prosthetist**
The prosthetist designs, makes and fits an artificial limb (prosthesis) where an amputation has been necessary. A prosthesis may also be a replacement for another part of the body which may have been removed, such as an eye or breast.

**Social worker**
The social worker provides emotional and practical support and counselling for your child, you and your family and links you with other resources and services. Your family might need extra help because of the stresses relating to having a child with cancer. All families at the two Children’s Cancer Centres are referred to a social worker. While you may feel you do not require this assistance initially, if, at any point later in treatment or even after treatment finishes, you feel it would be helpful, please speak to your nurse coordinator who can arrange for an appointment.

**Speech pathologist**
The speech pathologist assesses and treats speech, language and eating abilities. The speech pathologist can work with your child and family to set realistic communication goals. If there are chewing and swallowing difficulties, the speech pathologist can suggest suitable foods and feeding positions.
Support Staff

**Administrative staff**
The administrative staff at the children’s cancer treatment centres, and the paediatric services at Peter Mac and the regional centres support the medical and nursing staff to help them run the services efficiently.

**Blood collectors**
Blood collectors take finger prick samples of your child’s blood for a blood test. When your child is an outpatient, blood collectors in the pathology department take a finger prick blood sample before a clinic appointment.

**Clinical research associates, data managers and clinical trial coordinators**
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 treatment plan follows the approved research procedures. They also liaise with trial sponsors and collect and manage research data.

**Patient services assistants (PSA)**
PSA 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.

**Volunteers**
Volunteers help with things such as sitting with your child if you need a break and assisting the play therapist. They are often on the ward and can be a great help to you and your child.

**Ward clerks**
Ward clerks do many things in the ward – making appointments, answering telephones, filing and keeping the medical records.
Communication with your child’s team

Your child’s team will help you in caring for your child. This is a partnership. Forming partnerships between the family and the team is a joint responsibility. It is important that you and your child have a trusting and open relationship with the team. Sometimes, tension and misunderstanding can occur. Sometimes you might be angry towards staff who you believe are not being helpful. The people on your child’s team need to know if you are having difficulty interacting with them. Telling the team this will not have a bad effect on the care your child receives.

Strategies to improve communication and build trust

• Ask questions and keep asking until you understand the answer
• Be aware that there may not always be definite answers and you may not always get the answer that you want (no matter how many times or how many people you ask)
• If appropriate, write questions in advance so that you won’t forget. This lets you stay focused and you can feel more confident
• It’s okay to interrupt to ask technical things that you don’t understand
• When appropriate, encourage other family members to be involved and ask questions or talk to the doctor but only in your presence or with your permission
• Don’t expect the team to always be able to anticipate your needs
• Let the team know what you need, how much information you and your child want, what fears or worries you may have. The team will try to help once they are aware of your needs.

If you are having problems with a particular team member, and if it is possible to do so, speak to them directly about the problem. Often this will resolve the matter. Alternatively, you can speak to someone else on the team who can help to resolve the matter. The hospital also has a consumer liaison officer who you can contact if other approaches have not worked.
Welfare services and entitlements

Centrelink/Income support

Centrelink provides two payments for carers: Carer Allowance and Carer Payment. You could be eligible for one or both payments and we encourage families to contact Centrelink for more information.

Claiming

To apply you must call Centrelink on 13 2717. Centrelink will ask you a set of questions which will determine which forms need to be completed. The forms will then be mailed to you to complete.

Care Adjustment Payment

You may be eligible for this one-off payment if your child is 6 years or under at diagnosis and;

- You are eligible for the carer allowance, and
- You have applied for the carer payment and been rejected, and
- You are not receiving an income support payment from Centrelink, and
- You are an Australian permanent resident.

Claim forms for Carer Adjustment Payment only are available online at www.centrelink.gov.au

The Royal Children’s Hospital Family Resource and Respite Centre has a phone available for you to call Centrelink. Also, a Centrelink officer visits the RCH once a week and is based in the Family Resource and Respite Centre. He/she will sight your identification and accept your completed forms. For an appointment, please call the Family Resource and Respite Centre at RCH on the number provided on the Hot Numbers page in the front of this book.
Other assistance

Ambulance transport and Air Ambulance
This is sometimes available on a doctor’s recommendation. Ambulance transport is expensive, and you are strongly urged to join the ambulance fund if not already a member. For people with a current Health Care Card in their name, travel in an ambulance is free. Please confirm requirements with your social worker.

Financial assistance
Financial stress due to increased expenses and/or decreased income is not uncommon. If the costs related to your child’s illness and regular treatment create significant financial difficulties, the social work team can help you access relief through special grants from various sources. The financial impact may be minimised if dealt with early. Please discuss any concerns with your social worker.

Financial counsellor
Hospital Based Financial Counselling Service is available to assist all families with a child who is a patient at the children’s cancer treatment centres at the RCH or Monash Medical Centre. Speaking with the financial counsellor early in your child’s illness may assist you to put financial plans in place to avoid financial stress later on. The counsellor can help you negotiate your current financial commitments such as mortgages, debt repayment and access to utility bill relief and other assistance where eligible. You may see the financial counsellor at any point in your child’s illness, and as many times as needed.

At the RCH, this service is a partnership between the RCH social work department, Kildonan Uniting Care, Red Kite and Origin Energy. The financial counsellor is on site at the RCH two days a week and is available at Kildonan every Monday. There is a brochure available that explains the service. Please ask your treating team for this brochure or speak with RCH social work department on the number provided on the Hot Numbers page in the front of this book.

At the Monash Medical Centre, the financial counsellor is available by appointment; please contact the social work department on the number provided on the Hot Numbers page in the front of this book, to arrange a meeting or a phone consultation.
Transport
Some families may experience difficulties with transport getting to and from their treating hospital appointments. Red Cross Transport and/or the Leukaemia Foundation may be able to assist.

If you are having, or anticipate having difficulty attending hospital, please discuss this with your child’s social worker.

The Victorian Patient Transport Assistance Scheme (VPTAS)
VPTAS is available to regional families living 100 km or more away from the hospital. Each state has an Isolated Patient Travel Assistance Scheme (IPTAS). These schemes provide a travel subsidy and cover nearly all accommodation costs at Ronald McDonald House (or other hospital parent accommodation). Claim forms are available at Ronald McDonald House, on the wards or from your social worker. Additional forms can be obtained from your local VPTAS (or IPTAS), Department of Health, Victoria on (03) 5333 6040.

Angel Flight
Angel Flight is a charitable organisation that can provide air transport for children and families living in rural communities who are experiencing financial hardship and need transport for hospital treatment. This is not a form of ambulance transport and no medical equipment is on board. It is provided free of charge. Angel flights can be organised by your social worker.

Hospital based information and support groups

Look Good Feel Better
This group is for teenagers with cancer and is run in conjunction with the Cancer Council of Victoria. The group focuses on self-esteem and self image and is a fun way for teenagers to get together to experiment with cosmetics and accessories and talk about things that are important to them. See your child’s social worker for more details.

Victorian Children’s Cancer Parent and Family Advisory Group
The Victorian Children’s Cancer Parent and Family Advisory Group has the overall goal of providing better outcomes for children and families attending the Children’s Cancer Centres (CCCs) at The Royal Children’s Hospital, Monash Medical Centre and/or Peter Mac. The group meets regularly and seeks input from CCC families and responds to comments and suggestions from families and staff.
It is the primary source for consumer feedback to the hospital and identifies priorities for issues and suggests solutions.

The Parent and Family Advisory Group includes parents from both the CCC at the RCH and Monash Medical Centre and some of these parents have had experience at Peter Mac. If you wish to make a suggestion for improving something, or would like to be involved in the Parent and Family Advisory Group, please contact the CCC Community Liaison Manager. See the Hot Numbers page in the front of this book.

**Sibling groups**

Sibling groups are for primary and secondary age siblings and are held at RCH and Monash Children’s at Monash Medical Centre during the year. Siblings have an opportunity to meet together, to talk to a member of the medical team, meet with a nurse, have a behind-the-scenes tour of the CCC and through fun activities, to explore the experience of being the sibling of a child with cancer. The day is facilitated by the social work team with assistance from other members of the health care team. See your child’s social worker for details and dates of the groups.

**Other Groups**

Other groups such as parent support and information groups, adolescent groups etc. run at both RCH and Monash Children’s at Monash Medical Centre depending on the needs at the time. Please speak to your social worker about other groups which may be available.

**Community Liaison Manager**

The community liaison manager at the RCH CCC is the person who acts as a communication link between patients and the health service regarding services that may include organising fund-raising, looking after visitors and supporting the Parent and Family Advisory group. If you, your friends or family would like further information about working with, or donating or raising funds, please contact the community liaison manager at the RCH, listed on the Hot Numbers page in the front of this book, or contact the Foundation at the particular hospital of interest.

At Monash Medical Centre or Peter Mac, please talk to your social work department listed on the Hot Numbers pages in the front of this book.
Support groups and charities

The PICS does not specifically endorse, denounce or reject any charity, support group or philanthropic organisation. PICS is appreciative of all the assistance and support that is made available through the charities and support groups to families of children suffering with cancer. The information below has been developed to aid families of children with cancer to make their own informed decisions when seeking help from any support group and charity.

There are many national, state and local charities, support groups and philanthropies that work together with the children’s cancer treatment centres at RCH, Monash Medical Centre, Peter Mac and with regional centres across Victoria to offer assistance with finances, transport, accommodation, family situations, education and dealing with the diagnosis of cancer. The individual health services can recommend charities and support groups to their patients after assessing the needs of the families and the services offered by the group.

We recommend speaking to your child’s social worker at your child’s hospital regarding accessing community based services.

If you contact a charity, we advise you to ask your own questions, particularly about the privacy of the information you give them. You may wish to ask questions such as:

- “Will my information ever be passed on to anyone else?”
- “Will my ‘story’ be used for publicity or any other purpose without my consent?”
- “How will you gain my consent for my information to be used?”
- “If I consent for my ‘story’ to be used in publicity, will this be forever or for a specific time period?”
- “Are you putting me on any sort of mailing list?”
- “How do I get off a mailing list when I no longer want to receive communications?”
- “Are you planning to contact me in any other way because I have asked for help?”

For more information, please ring the social work department at RCH, Monash Medical Centre or Peter Mac on the numbers listed on the Hot Numbers pages in the front of this book.
Childhood Cancer Support Groups

Listed in this section are the childhood support groups who work with the Children’s Cancer Centre at The Royal Children’s Hospital.

When agreeing to work with external organisations, The Royal Children's Hospital, Children’s Cancer Centre, in keeping with RCH processes, asks organisations about important information aimed at protecting you as well as our hospital. The types of things we ask about are:

- Is there transparency around the dispersal of the funds raised?
- What policies and practices do they have to respect patient and family privacy and confidentiality?
- Do they provide support without ongoing obligations or requirements of families to participate in the organisation or activities associated with fund raising?
- Do they appropriately use the RCH logo and branding in their communications with the public, donors and families?
<table>
<thead>
<tr>
<th><strong>Services for children</strong></th>
<th><strong>Contact details</strong></th>
</tr>
</thead>
</table>
| **Camp Quality**         | Support organisation for 0–13 year olds  
                        | Recreational support  
                        | Kids and family camps  
                        | Family fun days, siblings days  
                        | Financial support  
                        | Holiday accommodation  
                        | Education and puppets program  
|                          | www.campquality.com.au  
                        | vic@campquality.org.au  
                        | Phone 9329 6566  
| **Cancer Council**       | Generic cancer educational material  
                        | Free work shops  
                        | Family Connect  
                        | Phone support and support services Helpline  
                        | Financial support  
                        | Find a support group  
|                          | www.cancervic.org.au  
                        | Phone 13 1120  
| **CanTeen**              | Support organisation for 12–24 year olds living with cancer  
                        | Support to patients, siblings, offspring  
                        | Peer support camps and recreational days  
                        | Online and printed educational and support resources  
|                          | www.canteen.org.au  
                        | vicadmin@canteen.org.au  
                        | Phone 9329 5288  
| **Challenge**            | Camps  
                        | Family activity days and playgroup  
                        | Parent support  
                        | Hospital support  
                        | Educational and musical scholarships  
                        | Holiday accommodation  
                        | Financial support  
                        | Challenge Family Centre — massage, art and music therapy, counselling, information seminars, childhood cancer library  
|                          | www.challenge.org.au  
                        | mail@challenge.org.au  
                        | Phone 9329 8474  
| **Children's Cancer Centre Foundation** | Philanthropic group funding clinical care, basic laboratory and translational research, and hospital-based activities for cancer patients at RCH and MMC  
|                          | www.cccf.org.au  
                        | info@cccf.org.au  
                        | Phone 9635 6605  
| **CIKA — Auxiliary of the RCH** | Fundraise for solid tumour research  
|                          | president@cika.org.au  
                        | Phone 9345 4855  
| **KOALA Kids**           | Philanthropic group, part of the Children's Cancer Centre Foundation, funding hospital-based activities and providing the small things that make a difference to the lives of cancer patients and their families  
|                          | www.cccf.org.au  
                        | koalakids@cccf.org.au  
                        | Phone 9635 6605  

Support and assistance | Sec.6.7
Updated July 2012
<table>
<thead>
<tr>
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<th>Contact details</th>
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</thead>
<tbody>
<tr>
<td><strong>LARCH — Auxiliary of the RCH</strong></td>
<td>Fundraise to support research</td>
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<tr>
<td><strong>Leukaemia Foundation</strong></td>
<td>Generic education programs</td>
</tr>
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<td></td>
<td>Transport assistance</td>
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<td></td>
<td>Some accommodation</td>
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<td>Some practical support</td>
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<tr>
<td><strong>Make A Wish</strong></td>
<td>Wish granting for children from 3–17 years</td>
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<td></td>
<td>old Toy hampers for children under 3 years</td>
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<tr>
<td><strong>MyRoom</strong></td>
<td>Philanthropic group funding research, social work and clinical programs</td>
</tr>
<tr>
<td><strong>Redkite</strong></td>
<td>Financial assistance and counselling</td>
</tr>
<tr>
<td></td>
<td>Support a social worker position</td>
</tr>
<tr>
<td></td>
<td>Book club</td>
</tr>
<tr>
<td></td>
<td>Telephone and email support</td>
</tr>
<tr>
<td></td>
<td>Telegroups</td>
</tr>
<tr>
<td></td>
<td>Education grants</td>
</tr>
<tr>
<td><strong>Ronald McDonald House</strong></td>
<td>Accommodation</td>
</tr>
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<td></td>
<td>Education scholarships</td>
</tr>
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<td></td>
<td>Ronald McDonald learning program</td>
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<td></td>
<td>Family holiday accommodation</td>
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<tr>
<td></td>
<td>Family retreats</td>
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<tr>
<td><strong>Starlight</strong></td>
<td>Wish granting up to the age of 18</td>
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<tr>
<td></td>
<td>Starlight Express Room at the RCH</td>
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<tr>
<td></td>
<td>Teenage programs</td>
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<tr>
<td></td>
<td>Livewire</td>
</tr>
<tr>
<td><strong>Strike a Chord</strong></td>
<td>Music for Life grants</td>
</tr>
<tr>
<td><strong>Very Special Kids</strong></td>
<td>Respite care</td>
</tr>
<tr>
<td></td>
<td>Family activity days</td>
</tr>
<tr>
<td></td>
<td>Sibling support</td>
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<td></td>
<td>Counselling and emotional support</td>
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<tr>
<td><strong>WACK (Wimmera against Cancer in Kids)</strong></td>
<td>Food and petrol vouchers for families from the Wimmera District</td>
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Childhood Cancer Support Groups

Listed in this section are the childhood support groups who work with the Children’s Cancer Centre at Monash Children’s at Southern Health, Clayton.

Please remember to ask your own questions when you give any personal information to a charity. Please refer to Section 6.5, Support groups and charities for examples of such questions.
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Recreational support  
Kids and family camps  
Family fun days, siblings days  
Financial support  
Holiday accommodation  
Education and puppets program |
| **Cancer Council**   | www.cancervic.org.au  
Phone 13 1120 |
| Generic cancer educational material  
Free work shops  
Family Connect  
Phone support and support services Helpline  
Financial support  
Find a support group |
| **CanTeen**          | www.canteen.org.au  
vicadmin@canteen.org.au  
Phone 9329 5288 |
| Support organisation for 12–24 year olds living with cancer  
Support to patients, siblings, offspring  
Peer support camps and recreational days  
Online and printed educational and support resources |
| **Challenge**        | www.challenge.org.au  
mail@challenge.org.au  
Phone 9329 8474 |
| Camps  
Family activity days and playgroup  
Parent support  
Hospital support  
Educational and musical scholarships  
Holiday accommodation  
Financial support  
Challenge Family Centre – massage, art and music therapy, counselling, information seminars, childhood cancer library |
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info@cccf.org.au  
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koalakids@cccf.org.au  
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| Philanthropic group, part of the Children’s Cancer Centre Foundation, funding hospital-based activities and providing the small things that make a difference to the lives of cancer patients and their families. |
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<tr>
<td>Toy hampers for children under 3 years</td>
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<tr>
<td><strong>MyRoom</strong></td>
<td><a href="http://www.myroom.com.au">www.myroom.com.au</a></td>
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<tr>
<td>Philanthropic group funding research, social work and</td>
<td>Phone 9345 4855</td>
</tr>
<tr>
<td>clinical programs</td>
<td></td>
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<tr>
<td><strong>Redkite</strong></td>
<td><a href="mailto:support@redkite.org.au">support@redkite.org.au</a></td>
</tr>
<tr>
<td>Financial assistance and counselling</td>
<td><a href="http://www.redkite.org.au">www.redkite.org.au</a></td>
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<tr>
<td>Support a social worker position</td>
<td>Phone 1300 722 644</td>
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<tr>
<td>Book club</td>
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<tr>
<td>Telephone and email support</td>
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<td>Telegroups</td>
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<tr>
<td>Education grants</td>
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<tr>
<td><strong>Ronald McDonald House</strong></td>
<td><a href="http://www.rmdh.org.au">www.rmdh.org.au</a></td>
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<tr>
<td>Accommodation</td>
<td>Phone 9594 3588</td>
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<tr>
<td>Education scholarships</td>
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<tr>
<td>Ronald McDonald learning program</td>
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<td>Family holiday accommodation</td>
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<td>Family retreats</td>
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<tr>
<td><strong>Starlight</strong></td>
<td><a href="http://www.starlight.com.au">www.starlight.com.au</a></td>
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<tr>
<td>Wish granting up to the age of 18</td>
<td>Phone 1300 727 827</td>
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<tr>
<td>Starlight Express Room at the RCH</td>
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<tr>
<td>Teenage programs</td>
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<tr>
<td>Livewire</td>
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<tr>
<td><strong>Strike a Chord</strong></td>
<td><a href="http://www.strikeachordforchildren.org">www.strikeachordforchildren.org</a></td>
</tr>
<tr>
<td>Music for Life grants</td>
<td>Phone (08) 9227 7930</td>
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<tr>
<td><strong>Very Special Kids</strong></td>
<td><a href="mailto:mail@vsk.org.au">mail@vsk.org.au</a></td>
</tr>
<tr>
<td>Respite care</td>
<td><a href="http://www.vsk.org.au">www.vsk.org.au</a></td>
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<tr>
<td>Family activity days</td>
<td>Phone 9804 6222</td>
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<tr>
<td>Sibling support</td>
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<tr>
<td>Counselling and emotional support</td>
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</tbody>
</table>

There are also other groups that can provide assistance as their funds allow, that are not listed here. Please speak with your social worker for further details.
7 Information resources

Seeking Information

Websites, the internet and emails can give accurate and up to date information about cancer. But the information can also be confusing, misleading, and sometimes wrong! If you are considering seeking further information about your child’s cancer, it is important to understand that information from CCC staff or material provided to you by the CCC is carefully considered, checked to be accurate, tailored to individual circumstances, with support immediately on hand. By comparison, internet material (even from reputable sources) is not carefully relayed, may relate to circumstances that do not apply to your child, is not necessarily accurate and without support on hand, you may find this unexpectedly emotionally challenging. If you choose to seek information via this source, and have any questions or are anxious about information you have located, please discuss this with your child’s team.

We have listed some things to look for when you are using a website for information. You can use these to check on other information sources – books, pamphlets, meetings, casual advice. If you have any questions about information please discuss these with your child’s team.

OncoLink FAQ: Evaluating cancer web sites

This is adapted from a webpage that is no longer available on line, based on an editorial by the directors of OncoLink, a comprehensive website related to cancer diagnosis and treatment. OncoLink Editor-in-Chief, Joel W Goldwein, MD, Associate Professor, Radiation Oncology. Last revision date – 9th December, 1998.

The things to look for (not in order of importance) are:

1. **Accuracy of information** – avoid sites where information is not referenced, or where authors and dates of content are not stated

2. **Availability of editorial staff** – a web resource should list their editorial staff, the credentials of the people behind the resource. An address and email contact should also be provided
3. **Qualifications of editorial staff** – many resources are run by people who are not qualified to provide medical advice. There is nothing wrong with this, provided that it is clearly stated. However we feel that the best information, in general, is provided by health care professionals who are health care providers themselves. Much of what physicians, nurses and other professionals do involves interacting with patients and providing information in the clearest, most appropriate manner.

4. **Freshness of content** – sites with regularly updated content are likely to be ones which are best managed. Beware of sites where nothing changes!

5. **Disclosure of conflicts of interest** – conflicts of interest should either be obvious or clearly disclosed.

6. **Price of information** – So far, very few medical web resources are charging for information. While this may change in the future, we believe that open access to information with minimal fees should be the rule. If you are being charged for the information, make sure it is not information others are providing for free.

7. **Confidentiality** – most medical web resources will not respond to direct medical inquiries by users. This is, in part, due to concerns over patient confidentiality, accuracy of information either sent from or to the patient. It is important to make sure sites which require registration are not releasing contact data without permission.

8. **Reputation** – Resources run by reputable institutions are more likely to provide timely, accurate, and unbiased information.

9. **Look and feel** – Resources must be attractive and able to provide the best possible information to users. Content rich in graphics is attractive, but if it is poorly organised, or if it takes a long time to download, it may not be serving its primary purpose.

10. **Navigation and searching** – make sure the site is well organised, easy to navigate and has a good search engine.

The domain name can give you an idea of the type of website. Sites that have addresses with .org .edu or .gov are often better than commercial sites that have .com in the address.

Some web sites that families find useful are:

**www.rch.org.au/ccc**

The web site for the RCH Children’s Cancer Centre.
www.curesearch.org
The combined website for the National Childhood Cancer Foundation and Children’s Oncology Group in North America. The Children’s Cancer Centre is a member of this group.

www.cancerbacup.org.uk
The United Kingdom’s national cancer information service.

www.cancersourcekids.com
A good site for children with links to information for parents.

More credible information resources

Kids Health Info
(formerly the Resource Centre for Child Health and Safety)
Kids Health Info at The Royal Children’s Hospital is a parent resource centre open to the public. Located on the Ground Floor, the centre has a wide selection of books for adults, children and sibling about health-related issues, as well as medical texts and home safety products.

www.rch.org.au/chas
Telephone 9345 6429 Email chas.bookshop@rch.org.au

Paediatric Integrated Cancer Service (PICS)
PICS supports the health services to provide consistent information to children and adolescents diagnosed and being treated for cancer throughout Victoria. The PICS has worked with the health services and the Children’s Cancer Centres Parent Advisory Group to develop information for families. There are many information resources on the PICS website that may be of interest to you including:

- Medications
- Nutritional care
- Types of cancer
- Treatments
- Living with cancer
- Emotional care
- Hospital services
- Support services
- Information resources
- Useful website links
• Information translated in languages other than English including Arabic, Chinese (simple and traditional), Dari, Khmer, Sinhalese, Turkish and Vietnamese translations
• Links to peer reviewed external information in languages other than English.

Information for families can be accessed via the PICS website www.pics.org.au under the Consumer, Carers and Families link http://www.pics.org.au/ConsumersCarersAndFamilies

**How can you carefully use social media websites such as Facebook, Twitter, blogs, YouTube and emails to share and discuss your child's cancer information?**

Social media is a common way of sharing information with family and friends and reaching out to the wider social community to seek and share advice and support. Responsible use of social media by parents, and more so, teenagers, is critical to safeguard your family’s privacy regarding personal information and information about your child’s cancer diagnosis and treatment. There are potential risks and dangers that may not be apparent at present but may prove harmful later on in your child’s life as they grow up.

Following are some tips to responsibly use social media that have been compiled from Microsoft’s safe blogging guidelines, RCH social media policy and some other reputable websites. These tips are just a starting point and not a comprehensive collection; you are encouraged to include and set your own boundaries for yourself, your child, family and friends. The suggestions are in no way intended to discourage the use of social media to connect with others, they are purely meant to guide you to safely navigate through these websites while protecting your child’s information and respecting the privacy of your child’s treating hospital.

• Never post any personal information about your child’s cancer diagnosis and treatment, hospital UR number, your last name, contact information, home address, phone numbers, school’s name, email address, last names of friends or relatives, instant messaging names, age, or birth date

• Never mention names of any other hospital patients or post photos of those patients

• Parents, families and friends are also asked NOT to record any information including names or photographs on social websites of the staff at the hospitals who are/have cared for your child. Staff caring for your child are performing the job they have been employed to do – and they should not form part part of your social networking circle
• Use blogging provider sites with clearly stated terms of use, and make sure the site can protect the actual blogs, not just the user accounts, with password protection.

• Keep blogs positive and don’t use them for slander, defamation, harassment or to attack others.

• Assume what you publish on the web is permanent. Anyone on the internet can easily print out a blog or save it to a computer. If you are sharing private information about your child’s treatment and experiences, remember that when the child grows up, they may not want their own information out in the public domain for everyone to see, including future employers, insurance agencies, etc.

For more information and advice please contact your nurse coordinator or social worker.
8 Frequently asked questions

During your child’s treatment there will be many questions. All questions regarding your child’s illness and treatment are significant; please do not hesitate to discuss any such questions with your child’s treating team.

**Animals**

**Can we keep our household pets?**
Yes. Pets are an important part of any family. There is no need to get rid of your family pets. Please see more information in Section 4.26, CARING FOR YOUR CHILD AND FAMILY, Pets.

**Can our child be in contact with farm animals?**
Farm animals can be a source of fungal infections and direct contact should be avoided.

**Blood donation**

**Can family members donate blood?**
Family members can always donate blood to the general pool of blood donations available for anyone in need. Under certain circumstances it is possible to donate blood for the use of a specific person. But it is not usually possible to donate blood specifically for your child because your child may need blood or platelets urgently.

**Contact – people and places**

**Can we take our child out in public?**
Yes. It is important to maintain as normal a family life as possible, however crowds should be avoided if your child’s blood count is low.

**Should relatives and friends kiss and hug our child?**
Yes. Maintaining affection is important. However, your child should not be kissed by anyone with a cold sore, cold or flu.

**When our child is neutropaenic and in hospital is it safe to be around other children and their families?**
Yes. But other people with coughs and colds should avoid your child. The best way to protect your child is to ensure everybody visiting your child washes his or her hands.
Is it safe for our child to go to the beach, pool, spa, sauna, river, creek or dam?
If your child is having radiotherapy and you notice any skin changes (eg. peeling or blistering), you should not go to the beach, pool, spa, sauna, river, creek or dam.

Beach – Yes. But not if your child is neutropaenic or has a Hickman® in place. Be careful in the sun as sunscreen should not be applied to radiotherapy areas.

Spa / sauna – No

River, creek or dam – No

Pools – Yes, if the pool is well maintained and your child is not neutropaenic. No, if your child is neutropaenic or has a Hickman® in place.

Can our child still go to school even though he / she is receiving treatment?
Yes. It is very important for your child and your family to maintain as normal a routine as possible. Please see Section 3, Living with cancer, How schools can support young people receiving treatment for cancer.

Is it safe for our child to continue with sport and leisure activities?
Yes in general. If your child’s platelet count is low, avoid contact-sports and activities where there is increased risk of injury. Discuss individual cases with your consultant.

Diet
Do I need to alter our child’s diet?
As a general rule, no. Milk must be pasteurised (not straight from the cow). Under-cooked meats should be avoided. If you have any questions regarding your child’s food, the dietitian is the best person to talk to.

Can our child take multivitamins and other herbal medicines?
Multivitamins are not usually necessary. The dietitian will discuss your child’s nutritional needs with you. Some herbal medicines can be potentially dangerous. You should talk to your child’s consultant before giving your child any of these. Anti-oxidants should not be given during radiotherapy.

Can our child drink tank water?
Tank water should be boiled before drinking.
What is a high-energy drink for when our child is not wanting to eat much?

**Sustagen milkshake**
- 250 mls of full cream milk
- 2 tablespoons of Sustagen® powder
- 2 scoops of ice-cream
- Flavouring eg. chocolate topping

**Fortified milk**
- 600mls full cream milk
- 2 tablespoons dried milk powder
- (3 tablespoons Polyjoule® optional) as topping

**House cleaning**
Is it necessary to spring clean the house?
No. Maintaining a clean environment is important. Going to extremes is not necessary.

Do we need to take up the carpets?
No. This can be potentially dangerous as it can stir up dust mites, bugs etc.

**Infection**
What should we do if one of our immediate family has a cold?
Wash hands frequently and discard used tissues. You do not need to isolate your child. You do not have to isolate the person who has the cold.

What happens if our child comes into contact with someone who has, or has been in contact with someone who has chicken pox, measles, mumps etc?
If your child has had direct contact with someone with an infectious illness (such as chicken pox, measles, mumps) you will need to contact the hospital as soon as possible. Your child may need to have an injection to provide temporary immunity.

If your child has not had direct contact (eg. someone in the school has chicken pox but your child does not play with them) you do not need to do anything.

Should our child and the family have the flu vaccination every year?
In general yes. However you should discuss this with your child’s consultant.

**Mouth care**
Should our child be using mouthwashes at home?
Not as a routine. Tooth brushing and maintaining good oral hygiene are important. Please see Section 4.16, CARING FOR YOUR CHILD AND FAMILY, Oral and dental care.
**Nasogastric feeding**
What is a nasogastric tube and why might my child need one?
A nasogastric tube is a thin, clear or yellow plastic tube. It is threaded into a nostril, down the back of the throat, down the oesophagus and into the stomach. Your child might need a nasogastric tube inserted if unable to eat and drink enough to maintain weight or to grow. Nutritional supplements can be given through the nasogastric tube. Occasionally a nasogastric tube may be inserted to give medications if they can’t be swallowed.

**Temperature**
How often should I take our child’s temperature?
There is no need to take your child’s temperature regularly. You should only take your child’s temperature if he or she appears unwell.

What temperature is too high?
If your child’s temperature is 38°C or above you should call the hospital. Follow the *Quick Help* guide in the front of this book.

Should I buy an electronic thermometer?
No. It is an unnecessary expense. Effective digital thermometers are available from pharmacies for $15 – 20.

How do I take my child’s temperature?
Orally: under the tongue with the mouth closed for three minutes.
Axillary: firmly held in place in the armpit for three minutes.
NEVER rectally.
What does that word mean?

**ACUTE** – occurs suddenly, lasts a short time.

**AFEBRILE** – the absence of a fever.

**ALL** – Acute Lymphoblastic Leukaemia is the most common form of childhood leukaemia.

**ALOPECIA** – loss of body hair.

**ANAEMIA** – a lower than normal number of circulating mature red blood cells.

**ANOREXIA** – loss of appetite.

**ANTIBIOTIC** – drug used in the treatment of bacterial infection.

**ANTIBODY** – a protein produced by the body to fight against bacteria and viruses.

**ANTIEMETIC** – a drug to reduce vomiting.

**ANTIGEN** – a foreign substance that stimulates production of antibodies.

**ARTERY** – blood vessel that carries blood from the heart to the tissues and organs.

**AUDIOGRAM** – hearing test. The audiologist is the person who does this.

**BACTERIA** – living one-celled organisms that are only visible through a microscope. While most bacteria are harmless, they can cause disease if the body’s resistance is lowered.

**BENIGN** – not malignant or not cancerous.

**BIOPSY** – a small piece of tissue is removed from the body to make a diagnosis. The tissue is removed by a needle or it is cut away.

**BLAST** – an immature blood cell.
**BLOOD CULTURE** – blood is taken and incubated in a special culture medium for 24–72 hours. If there is an infection in the blood, germs will grow in the culture and the sensitivities of the germs to different antibiotics can be determined.

**BLOOD TYPE** – red blood cells contain certain factors that are not the same for all people. The three main types are A, B, and O. These types are important when cross-matching blood that has been taken from one person to give to another.

**BOLUS** – intravenous drug administered over a short period of time.

**BONE MARROW** – spongy tissue in the cavities of large bones, where blood cells are produced.

**BONE MARROW ASPIRATE** – a sample of bone marrow is taken from the bone in the hip and is examined under the microscope.

**BUTTERFLY** – a small needle, with butterfly shaped plastic wings, used for taking blood or administering bolus intravenous drugs.

**CANCER** – an uncontrolled growth of abnormal cells.

**CAT SCAN** – See CT Scan.

**CELL** – the smallest living unit of the body.

**CENTRAL VENOUS ACCESS DEVICE (CVAD)** – a small flexible plastic tube inserted into a large vein through which drugs and fluids can be given and blood specimens taken painlessly.

**CHEMOTHERAPY** – drugs that destroy cancer cells. The drugs may also affect normal cells.

**CHRONIC** – lasting a long time.

**CLINICAL TRIAL** – a research study about treatment (protocol). See Section 4, CANCER, Clinical Trials for details.

**CROSS MATCH** – ensuring blood to be transfused is compatible with the patient’s blood.

**CT SCAN** – an x-ray scan that gives a three dimensional view of a part of the body. Also called a CAT Scan.

**CVAD** – Central Venous Access Device

**DRIP** – see intravenous.
**DRUG LEVELS** – drug levels in the blood can vary between patients, even when the same dose is given. It is necessary to measure the blood level of some drugs to ensure an effective dose is given. Some antibiotics need to be monitored in this way.

**ECHOCARDIOGRAPH (ECHO)** – an ultrasound of the heart which is used to give information about the pumping efficiency of the heart.

**ELECTROCARDIOGRAPH (ECG)** – records the rate, rhythm, and electrical activity of the heart.

**ELECTROLYTES** – minerals and salts that are required to provide the proper environment for the cells of the body. May be measured through a blood test.

**EMLA and ‘Angel’** – two different local anaesthetic creams used to numb the skin for procedures. They need to be applied about 40 – 60 minutes before the procedure.

**FEBRILE** – the presence of fever.

**FEVER** – when the body temperature rises above 38°C.

**FINGER PRICK** – the process of obtaining a sample of blood via a needle prick to the finger.

**FULL BLOOD EXAMINATION (FBE)** – examines the blood and counts the number of red blood cells, white blood cells (total number and different types), and platelets circulating in the blood – also called a complete blood count (CBC).

**GLOMERULAR FILTRATION RATE (GFR)** – a test to measure the function of the kidneys.

**HAEMOGLOBIN (Hb)** – the part of red blood cells that carries oxygen to the tissues.

**HICKMAN CATHETER** – a central line with one, two, or three barrels which can remain in place for months to years.

**IMMUNE SYSTEM** – the body’s defence network against infection and foreign particles.

**IMMUNOSUPPRESSED** – when a person’s immune system is functioning at a lower than normal level.

**INFECTION** – an invasion of body tissues by disease causing germs.
INFUSION – fluids and/or drugs that are administered intravenously over a period of time.

INSUFLON – a small tube inserted under the skin. It is used to administer drugs and can stay in place for about a week. It is an alternative to having many injections.

INTRAVENOUS (IV) – method to administer fluids and medications through a small plastic tube inserted into a blood vessel (vein).

IV PUMP – an electronic pump used to deliver intravenous fluids and medications.

LEUKAEMIA – a cancer of blood cells usually originating in bone marrow. There are several types of leukaemia. About 35% of childhood cancers are leukaemias.

LIVER FUNCTION TEST (LFT) – measure a variety of substances to show normal or abnormal liver function.

LUMBAR PUNCTURE – the procedure of inserting a fine needle into a space of the spinal column to obtain a sample of fluid and/or give medications.

LYMPH SYSTEM – a network of glands and vessels that carries lymph—a fluid that makes and stores infection fighting cells.

LYMPHOCYTE – a type of white blood cell that helps protect the body against foreign substances by producing antibodies and regulating the immune system response.

LYMPHOMA – a cancer of the lymphocytes, a type of white cell in the body.

MAGNETIC RESONANCE IMAGING (MRI) – a diagnostic test using a magnetic field to take pictures of parts of the body.

MALIGNANT – able to invade and destroy surrounding tissue.

METASTASIS – the spread of cancer cells to other parts of the body.

MYELOSUPPRESSION – a reduction in the number of circulating blood cells as a result of the toxic effects of chemotherapy on the bone marrow.

NEUTROPAENIA – a reduction in the normal number of neutrophils.

NEUTROPHIL – a type of white blood cell that is the body’s first line of defence against bacterial infection.

ONCOLOGY – the study of cancer.
OSTEOSARCOMA – a cancer of the bone.

ORGANISM – living thing.

PALLIATIVE CARE – treatment that relieves the symptoms but is not expected to cure the disease. The main purpose is to improve the child’s quality of life.

PET Scan – a scan that uses radioactive chemicals to show how a part of the body is working. Used to identify malignant and benign tumours.

PETECHIAE – small red spots (bruises) on the skin that usually indicate a low platelet count.

PERIPHERAL LINE – an intravenous line inserted into a vein in the hand, arm, or foot.

PLATELET – a cell in the blood that helps form clots and stop bleeding.

PRE-HYDRATION – intravenous fluids necessary before certain chemotherapy.

POST HYDRATION – intravenous fluids necessary after certain chemotherapy.

PORT – a central line surgically inserted under the skin, usually the chest wall. It provides quick and easy access to the blood and can be left in place for years.

PROTOCOL – a plan of tests and treatments.

PUSH – the manual administration of an intravenous medication over a short period of time.

RADIOTHERAPY – the use of x-rays or radiation from radioactive substances in the treatment of disease.

RED BLOOD CELL (RBC) – blood cells that pick up oxygen from the lungs and transport it to tissues throughout the body.

RELAPSE – the return of a disease after a period of remission.

REMISSION – complete or partial disappearance of a disease. A period during which signs of a disease remain under control.

RETINOBLASTOMA – cancer of the eye (retina).

SARCOMA – cancer of supportive or connective tissue – muscle, bone, cartilage, fatty tissue.

SOMNOLENCE SYNDROME – Sleepiness as a side effect of radiotherapy.
STAGING – assessing the spread of cancer through the body to decide the best treatment.

SHINGLES – a localised form of chicken pox where the virus in the nerve cells is re-activated.

STEM CELL – the most primitive blood cell from which all blood cells arise.

THROMBOCYTOPENIA – a reduction in the number of circulating platelets.

TOTAL BODY IRRADIATION (TBI) – is a form of radiotherapy used primarily as part of the preparative regimen for haematopoietic stem cell (or bone marrow) transplantation. As the name implies, TBI involves irradiation of the entire body.

ULTRASOUND – the use of very high frequency, inaudible (not able to be heard) sound waves that are transmitted into the body to create a picture of the underlying structures. It is a painless procedure.

VEIN – blood vessel that carries blood from the tissues and organs back to the heart.

VARICELLA-ZOSTER – a virus that causes chicken pox and shingles.

VIRUS – tiny organism, smaller than bacteria, that can produce disease.

WHITE BLOOD CELL (WBC) – blood cells with the chief function of protecting the body against foreign substances. WBC are divided into groups with different functions.

WILMS TUMOUR – cancer of the kidney that occurs in children.

X-RAY – radiation that goes through body tissues and is used to get a picture of what is inside.
### What does that abbreviation mean?

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ALL</td>
<td>Acute Lymphoblastic Leukaemia.</td>
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<td>AML</td>
<td>Acute Myeloid Leukaemia</td>
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<tr>
<td>APML</td>
<td>Acute Promyelocytic Leukaemia</td>
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<tr>
<td>BMT</td>
<td>Bone Marrow Transplant</td>
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<tr>
<td>CBC</td>
<td>Complete Blood Count – a count of red and white blood cells and platelets</td>
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<tr>
<td>CNC</td>
<td>Clinical Nurse Coordinator</td>
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<tr>
<td>CNS</td>
<td>Central Nervous System – the brain and spinal cord</td>
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<tr>
<td>CVC</td>
<td>Central Venous Catheter</td>
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<tr>
<td>CVAD</td>
<td>Central Venous Access Device</td>
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<tr>
<td>ECG</td>
<td>Electrocardiograph</td>
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<tr>
<td>GCSF</td>
<td>Granulocyte Colony Stimulating Factor – a drug that stimulates the bone marrow to increase neutrophil production</td>
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<tr>
<td>Hb</td>
<td>Haemoglobin</td>
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<tr>
<td>Dx</td>
<td>Diagnosis. ‘x’ is often used for the rest of the word after the first letter in capitals</td>
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<tr>
<td>IM</td>
<td>Intramuscular – injection in the muscle</td>
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<tr>
<td>IT</td>
<td>Intrathecal – injection in the spinal fluid</td>
</tr>
<tr>
<td>IV</td>
<td>Intravenous – injection in a vein</td>
</tr>
<tr>
<td>NPO</td>
<td>Nothing by mouth (Latin)</td>
</tr>
<tr>
<td>LP</td>
<td>Lumbar Puncture</td>
</tr>
<tr>
<td>PO</td>
<td>By mouth (Latin) – medication can be taken by mouth</td>
</tr>
<tr>
<td>SC</td>
<td>Subcutaneous – under skin</td>
</tr>
<tr>
<td>Rx</td>
<td>Prescription</td>
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<tr>
<td>TBI</td>
<td>Total Body Irradiation</td>
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<tr>
<td>Tx</td>
<td>Treatment</td>
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<tr>
<td>X</td>
<td>‘x’ is often used for the rest of the word after the first letter in capitals eg. diagnosis – Dx, Treatment – Tx</td>
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