

# 1. Dear reader,

Even though the chances of a successful outcome in the treatment of cancer are better than they have ever been, the diagnosis of childhood cancer is like a blow -- a blow beneath the belt -- or a blow to the head -- it leaves you stunned.

This handbook is here as one source of help, something which will be with you every step of the way. It contains a great deal of information about cancer, about the hospital, and about other issues that will become important as time passes. Use it as a reference manual. Take it a little at a time.

## How this handbook works:

The handbook is divided into sections, each dealing with a major topic.

It takes into account that you will want different information at different times; that you will sometimes not want to read a lot, but that, at other times, you will want as much detail as you can get. Use the "Quick Reference Guide" on page 1-3 to help you find what you need.

Many parents of children who have been through the oncology (cancer) unit have contributed wise advice and practical tips for the handbook. We have tried to include the wisdom of parents in each section on a separate sheet called *From Bitter & Sweet Experience*. We have also left space for you to add ideas and valuable tips as you gather them from conversations and sharing. Please leave these with us so that we can include them when we update the handbook.

No handbook can substitute for the support that comes from family or friends. We hope that they too will be with you every step of the way. Neither is the handbook meant to replace face-to-face talk with the staff.

*Editorial Note: We use "he" and "she" interchangeably in this handbook. "Parent" refers to the child's caregiver.*

"Dealing with this diagnosis is very difficult; you almost need someone with you every step of the way showing you the ropes. Even simple things become very difficult when your brain is set on stun!"

From a parent

This handbook has been produced by the Oncology/Hematology/BMT program and the Department of Patient/Family Education at British Columbia's Children's Hospital, Vancouver, Canada.



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## Ask questions and write things down

You probably have all sorts of questions already. As any parent who has been through this will tell you: *"Ask a lot of questions. If you don't fully understand the answer, ask the person to explain again until you do understand."*

You can ask anyone on the healthcare team a question. If they don't know the answer, they will refer you to the person who does. However, at this point in the history of medicine, there are some questions that have no answers.

At the back of this handbook are pages for you to:

- keep your own notes and reminders
- write down names of the people caring for your child
- record test results
- keep a log of the treatment your child receives.

*We can't stress enough how useful it will be for you to write things down.* You've probably already discovered that when you are under stress, it's hard to think as clearly, concentrate as easily or remember as well. When you write things down, it will help you understand and remember things, and it will be easier to share complete and accurate information with other family members.

Here are some ideas to help you.

- Write down questions as soon as you think of them
- Record the answers as soon as you get them
- Take notes of your conversation when you meet with the doctor or ask the nurse or someone else to do it
- Ask for the spelling of words with which you're not familiar

"No question is foolish.  
There is no such thing as  
too many questions.  
Responding to questions is  
an important part of the  
care".

From a parent

### **When you hear different things from the healthcare team.**

It is frustrating when people on the team give you conflicting information. Medicine is not like arithmetic. Two and two do not always add up to four. When people share their opinions with you, it shows that you are an accepted member of the team. You are hearing their thoughts and ideas before they have an agreed upon plan. Think about this as "rich" information rather than "confusing" information. Having various opinions helps you add your own observations to those of the professionals on the team.

When you read things that are different from what you have heard from the team, regard this as an opportunity to ask questions. Actually, it means you are learning more about diagnosis and treatment.

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Note: this handbook does not give information about specific types of cancer or drugs. Find this in the Family Resource Library

# About the hospital

## Staying with your child

- One parent may stay with the child overnight on a foldout or chairbed. Please do not push these beds into the hallways. The only other place where you may sleep in the hospital is in the 3B playroom. Please have your bedding and cot out of the way by 7:30 am, when the morning routines begin
- If you are using hospital bed linen, use the same linen for several days - we never have enough! Please label any linens you bring from home.
- There is a shower and toilet for parents and visitors in the Parent Lounge on 3B. Please do not use the toilet or shower in your child's room.
- Meals are provided for your child. You can buy your own meals and snacks from the cafeterias. See the section "A bite to eat" in the *"Family Issues"* Newsletter at the end of this chapter.
- If you plan to park on-site each day, it is cheaper and more convenient to buy a parking pass than to pay the regular daily rate. There are several different types of passes available:
  - 1 week
  - 2 week
  - 1 month
  - 30 hour pass for clinic visitsYou can buy the passes at Parking Booth #1 (the Oak Street exit). Monthly passes are sold at the cashier in the lobby.

Check *"Family Issues"* for current rates.

## How to find places in the hospital

The information desk is in the main lobby. You can ask for information about where to find things.

### Tips for finding a room:

- the first number is the floor
- the next number is the room
- the letter represents unit or wing
- if the letter is before the number, the room is in the old Shaughnessy Building; eg. F416
- if the number is before the letter, the room is in BC's Children's Hospital building; eg. 3F12

## Where to find more information

The newsletter, *"Family Issues"*, has more information about the hospital and neighbourhood such as:

- visiting hours
- routines such as meal times or doctor's rounds
- services and facilities such as parent lounges
- parking and telephones, as well as maps of the hospital
- shopping, restaurants, parks and churches
- transportation
- accommodation for families from out of town
- other services.

## Hospital libraries

There are three libraries in the hospital:

The **Family Resource Library** is a Health Sciences Library for families. It contains written and audiovisual materials about health and disease related issues, in plain language.

Location: across from the elevators at the top of the main staircase on the 2nd floor (block 11) of the Ambulatory Care Building at BC Children's Hospital

Phone: 604-875-2345 ext 5102

Hours: Mon-Fri 10 am to 4 pm and some evenings and weekends

Books may be checked out for two weeks.

**Children's Library** has books for children.

Location: 3A/C Playroom on the 3rd floor

Hours: Open 24 hours every day

Books go out on an "honour" system

**Hamber Library** is a Health Sciences Library for professionals. It contains medical texts, health sciences journals and related materials. It is part of the UBC Library system.

Location: 2nd floor

Hours: Mon-Thurs: 8 am to 11 pm

Fri: 8 am to 5 pm

Sat: Noon to 5 pm

Sun: Noon to 10 pm

Families may read in the library but cannot check out books.

**The Children's Hospital (BCCH) Oncology website** can be accessed at:

[www.kidscancer.bc.ca](http://www.kidscancer.bc.ca)

# About the wards

About 150 children are diagnosed with cancer and cared for at BCCH each year. In most cases, when cancer is suspected or first diagnosed, the child is cared for on 3B - the Oncology/Hematology Unit of the hospital. Children with brain or spinal tumours are usually cared for on 3R - the Surgery Ward. A child with cancer may be cared for on another unit of the hospital. There may be no bed openings on 3B or 3R, or the child may need the facilities on a different unit. The staff on each ward will review their routines with you. Oncologists will care for your child on any unit in the hospital.

Oncology = cancer

Hematology = blood disorders

## The layout

### Rooms

#### Beds:

At Children's Hospital, the rooms have 1, or 2 beds. On 3B, there are 1 and 2 bed rooms. Several rooms are set aside for bone-marrow transplants. We do our best to consider your request for single rooms or roommates, but rooms are assigned according to availability and medical needs of the patient.

*Personal touch:* Personalize your child's bedside with familiar things from home, like special pillows, pictures, or quilts. Rooms are small, so please try and keep your area from becoming too cluttered. Please do not use tape on the walls as it peels the paint.

#### Telephones:

Each room has a telephone with its own local. Please ask for your telephone local at the nursing station and tell friends and family to call directly to your room. The telephone at the nursing station is very busy.

*Note:* If you need to make a long distance call, you can use a calling card, call collect, charge it to your home number, or use one of the pay phones in the lobby or Parent Lounge on 3B or 3M. You can buy a calling card from the gift shop.

#### Security:

It's sad, but things go missing. Don't bring precious things to the hospital. Keep your wallet safe.

#### Television:

All rooms on 3B are equipped with television sets. Most also have video machines and remote controls. Some portable video machines are available at the desk. Please treat this equipment with great care. It is very costly to repair.

## **Playroom**

Children being treated for cancer have a large playroom stocked with toys right beside 3B. This playroom is open only to the cancer patients and their families, so that the children are not exposed to infections from others.

The Child Life Specialist schedules activities for children in the playroom. She will let you know when special activities are scheduled. Children are welcome to use the playroom at other times but must be with an adult. Please help to keep the playroom tidy so that everyone can enjoy it.

## **Parent lounge**

For information about Parent Lounges, sleeping arrangements, TV, laundry, etc., see the "Family Issues" Newsletter at the end of this chapter.

## **Nourishment station**

The nourishment station on the unit has juices and snacks which you can give to your child at any time. This food is for patients only. You can store food, which you bring for your child from home, in the fridge at this station. Please mark it clearly with your child's name and the date. Unlabelled food will be discarded. Labels are available on the counter or from the ward clerk. You are free to use the microwave, kettle, paper/plastic utensils, but please clean up when you are through.

## **Nursing station**

This is the central work area for all staff. The desk is staffed by the nursing unit clerk who can assist you. Space is limited and the nursing station is busy. Please don't come behind the desk.

## **Parent boards**

Notices about meetings, groups, or anything else of interest to parents, are posted on boards around the ward.

## **Routines**

### **Nurses' shift change**

7 am and 7 pm. See "Family Issues" at the end of this chapter.

### **Ward rounds**

Ward rounds take place daily. Doctors are unable to stop and answer questions or discuss concerns until rounds are over. We suggest that you ask the unit clerk or nurse to let the doctor know if you would like to see him briefly, or set up an appointment for you if you want to have a longer discussion with him.

### **Blood sample draws (blood work)**

These are done in the early morning and at other times as needed. Blood samples are drawn by the laboratory technologist. If the child has a central venous line, blood samples are drawn by a nurse certified in this technique.

### **Vital signs**

This term refers to the check made by the nurse of your child's:

- temperature
- pulse
- breaths per minute (respiratory rate)
- blood pressure

Vital signs are checked about every 4 hours, unless otherwise indicated by your child's medical condition.

### **Menus**

Meal selections are brought to the bedside daily.

*Note:* If your child has a special diet requirement, ask the unit clerk to contact the dietician or food supervisor.

# About the people taking care of your child

Every parent wants the best for his or her child. When that child is seriously ill, the parent wants to know that the care and treatment offered is the most promising available. Be assured that your child is being cared for by a team of dedicated health professionals. They will leave no stone unturned to help children with cancer regain health and wellbeing. They are specialists in:

- the care of children,
- their particular field such as medicine, nursing or nutrition,
- the treatment of cancer, and often in subspecialties within the field.

When these people combine their special expertise to form the Oncology/Hematology Team, they represent a wealth of knowledge and skill.

The Oncology/Hematology Team consults with other health professionals in the hospital whenever necessary, and are in contact with experts and researchers in other treatment centres around the world. If there are treatments that have been successful with your child's type of cancer, the doctor here will know of them.

## Tip:

Nurses coordinate the day to day care for your child. If you are not sure who to speak to about any issue, ask your nurse.

Many different health care professionals will treat your child. Meeting so many people in a short time can be confusing. As you meet each new person, we suggest you:

- Introduce yourself by the name you wish to be called (otherwise you may be called "Mom" or "Dad").
- Ask the health professional to give you his professional title and explain what he will do with, and for, your child.

## Parents as partners

Always remember that you are an essential person on your child's healthcare team. The touch of your hand, the sound of your voice and the familiar ways you comfort, are important to healing. There is much about your child that only you know. Each day, talk to your nurse about how you will share the care.

We believe the best healthcare happens when healthcare professionals and parents work together as equal partners. This way of working together may require some new skills:

- Building trust and respect
- Sharing information
- Negotiating conflict
- Making decisions together
- Managing emotions.

A skill-building video and manual called, [Partners: Becoming a partner on your child's healthcare team](#) is available in the Family Resource Library.

## Members of the team

### Nurses

**Staff nurses** in the oncology program have had special training to meet the needs of children with cancer.

The nurses welcome your help with the care that a parent can do better than any professional - feeding, bathing, soothing or other activities of this kind. Please share your understanding of your child's needs with the nurses.

*Note:* When there are student nurses on the unit, they are supervised by a clinical instructor and the staff nurses.

If you are concerned about any aspect of the nursing care your child is receiving, please speak to the Clinical Nurse Coordinator. Don't bottle things up inside you that can be dealt with.

**Clinical nurse coordinators** act as leaders for the nursing teams.

Phone numbers: \_\_\_\_\_

### Doctors

BC's Children's Hospital is a teaching hospital for the medical school of the University of British Columbia.

The pediatric oncology specialists make the major decisions about your child's medical treatment. Doctors in specialty training care for your child on a daily basis under their guidance.

The **attending oncologist/oncologist** is the hematology/oncology specialist (also called a consultant) who is on call for the oncology (cancer) service at the time your child is admitted. There are 11 oncology/hematology consultants on staff. They work as a team. Your oncologist makes the diagnosis and plans the treatment for your child. The other oncologists on the service know about all patients. They will add their experience to your child's treatment plans.

*Note:* Consultants from other medical specialities such as surgery, radiology, or neurology may be called in to see your child.

A **fellow** is a pediatrician who is training to be an oncologist.

The **resident** is a fully licensed physician who has at least one-four years of medical experience and is specialising in pediatrics. Residents spend 2-3 months on the unit and then move to a different unit in the hospital. The resident may do the first examination and medical history on your child.

**Clinical assistants** are qualified physicians who assist in the same way as the residents. They are part of the permanent staff of the oncology service.

*Note:* When there are **medical student interns (MSI's)** on the ward, they may examine your child but make no treatment decisions. These students, who are in their final year of medical school, are supervised by qualified physicians.

Your attending physician is:

\_\_\_\_\_  
Phone number: \_\_\_\_\_

Fellow:

\_\_\_\_\_  
Resident:

\_\_\_\_\_  
Clinical assistant:

## Chaplain

The hospital chaplains are specially trained and experienced in supporting children and teens and their families during times of stress. Spiritual care, provided by hospital chaplains, is available to help you explore questions, offer comfort and compassion, listen, help with ethical dilemmas, and offer spiritual support and prayer if you wish.

The chaplain is:

Office: 3F45

Phone number: (604) 875-2345 local 2753

## Child life specialist

Child life specialists provide activities and projects to make life in the hospital easier. They offer emotional support and a chance to express feelings through play.

The child life specialists are:

Phone number: \_\_\_\_\_

## Dietitian

A dietitian offers guidance around nourishment. Cancer and its treatment will often alter your child's appetite and ability to tolerate food.

The dietitian is:

Phone number: \_\_\_\_\_

## Occupational therapists

Occupational therapists plan activities to help children meet the learning challenges of normal growth and development.

The occupational therapist is:

Phone number: \_\_\_\_\_

## Patient/parent advocate

The patient/parent advocate links parents to other parents so that they can share their strengths and hard-earned experiences. He listens like a friend when you need one.

The patient/parent advocate is:

Phone number: \_\_\_\_\_

## Pharmacist

The pharmacist's main job is to give information about drugs to staff. She can also answer your questions and concerns about your child's medications.

The pharmacists are:

Phone number: \_\_\_\_\_

## Physiotherapists

Physiotherapists help children whose disease affects their bones, joints and muscles maintain strength, endurance, balance coordination and normal movement. They also use special techniques to assist with breathing.

The physiotherapist is:

\_\_\_\_\_

Phone number: \_\_\_\_\_

## Psychologist

A psychologist is available to help you and your child cope with, understand, and manage the emotions, thoughts, and behaviours that can come with serious illness. She can teach strategies for managing pain, stress, and anxiety. If your child has completed a treatment which may affect his learning, the psychologist or neuropsychologist can test your child's learning skills.

Your psychologist is:

\_\_\_\_\_

Phone number: \_\_\_\_\_

## School teachers

School teachers help children keep up with their school work.

The school teacher guiding your child is:

\_\_\_\_\_

Phone number: \_\_\_\_\_

## Social worker

Social workers help children and families cope with emotional and practical concerns through individual, family and group counselling and support. They also provide information about financial and community resources. Social workers can guide you through the health care system and help you advocate for your child and family.

Your social worker is:

\_\_\_\_\_

Phone number: \_\_\_\_\_

## Lab technicians

Lab technicians (phlebotomists) are the people who are trained to draw blood for blood tests.

## Porter aides

Porter aides transport children around the hospital.

## Unit clerk

The unit clerk does the clerical work on the unit and in the clinic. The unit clerk is at the Nursing Station and can take messages for the team and help you find the people you need to see.

The unit clerks are:

\_\_\_\_\_

\_\_\_\_\_

Phone number: \_\_\_\_\_

## Volunteers

Volunteers support families and children in many ways. All volunteers have been screened and understand the need for confidentiality. The Red Cross Family Support Volunteer program has coffee evenings, visiting, and offer parents small comforts like a break or a cup of coffee.

The volunteers are:

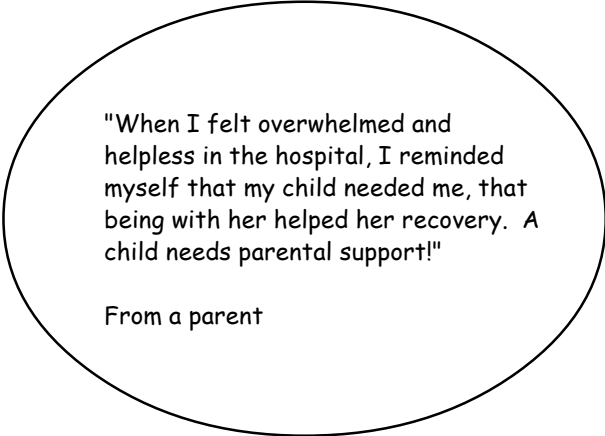
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Phone number: \_\_\_\_\_

## Other professionals

Other professionals are called in if their expertise is needed in your child's treatment.



"When I felt overwhelmed and helpless in the hospital, I reminded myself that my child needed me, that being with her helped her recovery. A child needs parental support!"

From a parent

## Questions

Your questions will be answered best if you take them to the team member who is a specialist in the area of concern.

- **Finances:** Check with the social worker on your team.
- **Nutrition:** Ask the unit clerk to call the dietitian.
- **Medication information:** If your nurse is unable to help you, ask to speak to the pharmacist attached to your service or the physician.
- **Spiritual Care:** Call the chaplain at local 2753.
- **Breastfeeding (Women's Hospital):** Call the lactation specialist at local 3539.
- **Play and Recreation:** Talk to the child life specialist.
- **Schoolwork:** Talk to the teachers at local 7656.
- **Parking:** Talk to the social worker or call Employee Services/Security at local 3192.
- **Accommodation:** Talk to the social worker.
- **Babysitting siblings:** There are no facilities for brothers and sisters. A hospital ward or clinic is a very difficult place for siblings. Keep visits short. We suggest that you do your best to make other arrangements rather than expecting siblings to spend hours here. Suggest to friends, who ask how they can help, that they care for your other children.
- **Interpreters:** Ask the nurse, social worker or call Cross Cultural Programs at local 2553.

- **Emotional support for me and my family:** Most health care professionals believe that part of their role is providing support for you and your family. Feel free to call on any member of the health care team with whom you feel comfortable. Some emotions or family situations are very complex. They need time and the help of a specialist such as your social worker or a psychologist. Child life specialists help your child through tough times. A great deal of strength comes from sharing joys and sorrows with others. Look to support groups, volunteers and other parents.

## What to do when there is disagreement or conflict

Work through the section on conflict in the program Partners to prepare to negotiate rather than argue.

*First try to talk with the person(s) directly involved:*

- Make an appointment and tell her what it's about.
- If you want help sorting out your thoughts, you can try the Parent Line 875-3500 or your social worker.

*If this fails or it is too hard for you:*

- For doctor related problems, call the Medical Director of your unit/clinic:  
Dr. Paul Rogers  
(604) 875-2322
- Any other issues, call the Patient Services Manager of your unit/clinic:  
Ms. Patti Byron, RN, BSN  
(604) 875-2345, local 7624

If you reach a brick wall, and the issue relates to *what is in the child's best interest, this becomes an ethical dilemma*. You can seek help from the hospital Ethics Committee. To find out how to contact the chair of this committee, ask anyone on the child's health care team.

If the issue is more about *hospital policies, procedures, behaviour toward you*, contact the Vice President of Child Health at local 6001.

If the issue is more doctor related, contact the Vice President of Medical Services and Quality Promotion at local 3795.

# From Bitter & Sweet Experience

Sometimes, all these "team members" all at once, in the beginning, are overwhelming. Give yourself time to sort out who they are and how to use them. Sometimes you feel there is too much, too fast...and you can't absorb it all...and you should be...and if you don't, you'll miss something somewhere. Whew!! That's exactly what it's like.

If you travel frequently on the ferry for treatments at the hospital, ask your social worker about the Travel Assistance Program for help with ferry fees. She can also help you get a letter for preferred loading.

**A walk to a neighbourhood restaurant on Oak Street was a change from the hospital food and surroundings - friendly and reasonable. I went often with friends to get a sense of balance again.**

Keep all receipts related to the hospital organized - cafeteria, groceries, cabs, ferries, gas, taxis, parking, etc. These may be useful when claiming a medical deduction on your income tax or if you are receiving assistance from an agency.

Bring some tea or coffee and a mug from home to make life at the hospital a little easier.

The pancake breakfast at the Shaughnessy Cafeteria is one of the best buys in town.

Write other tips here:

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