

# 4. About treatment

## Treatment options

Great advances have been made in the treatment of cancer. The greatest successes in treatment have been in childhood cancer.

The most common treatments for cancer are:

- **Surgery** - removing diseased cells. This is most successful when the cancer cells are massed within a clearly defined tumour.
- **Radiation** - using accelerated x-rays to shrink and damage those cancer cells that are located in a specific area in the body and that are sensitive to radiation.
- **Chemotherapy** - destroying cancer cells with powerful drugs when the cancer cells are sensitive to the drugs.

A treatment plan may include one or more of these methods.

For some types of cancer, other approaches might be used:

- Bone marrow or stem cell transplantation
- Immunotherapy - gears up the body's own immune system to fight the cancer. This treatment is used very rarely. Its effectiveness is still being evaluated.

The aim of cancer treatment is cure. Getting to the cure is a long journey which must be taken in stages.

The first stage in the journey is called **remission induction**. The goal is **remission**; ie. the symptoms are gone, and we can find no signs of cancer in the body. It may take more than one kind of treatment to achieve a remission. Remission may take weeks or, in a few cases, it may not be achieved at all.

The second stage of treatment is called **maintenance**. The goal is to destroy cancerous cells which may still be present in the body although they don't show up on tests. This stage may take a few months or a few years, depending on the type of cancer and the child's response to treatment. For some kinds of cancer, we may need to repeat a stage of the treatment.

If the cancer cells and, therefore, the symptoms, should return - **relapse** - the child will need to start over on the treatment journey.

If the child stays in remission for 5 years, we usually consider the cancer cured.

After the remission, your challenge is to help your child achieve a "psychological cure". A psychological cure is the point when the cancer is viewed as an event which no longer interferes with daily activities and is no longer blamed for all that goes wrong.

# Treatment decisions

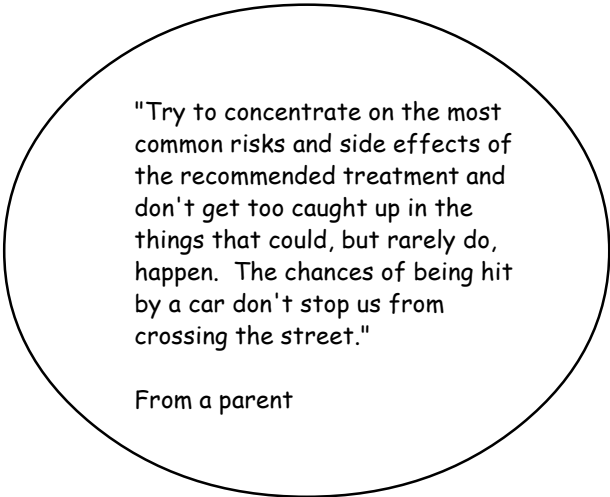
Over the years, several effective treatments for childhood cancer have been found. So, how does the team decide which treatments to use? The oncology team puts together a treatment plan (sometimes called a **protocol**) for your child based on the best information available. A protocol is like a treatment map. It provides the directions for the best possible route, starting from where the child is now, to the destination of a cure.

The oncologists use maps that have drawn on 40 years of clinical exploration made by pediatric oncology specialists throughout the world, who have shared their discoveries. This cooperation has allowed us to learn the best roads to take (not just the short cuts but also the least rocky paths). The oncologists at this hospital participate in an organization called the Children's Oncology Group (COG). This group is continuing the search for better ways to treat children with cancer. Through this organization, the oncologists also receive information about new treatment routes and improvements to established routes (protocols) as soon as they are known.

## Protocols provide guidelines

- How and when to test your child.
- What treatment approaches to use.
- The best doses and schedules.
- When and how to check the effects of therapy.
- How to modify the treatment if your child is not responding as expected.

The individual treatment plan (route) is decided by your child's oncologist. Thinking about this in terms of the map idea, the best medical information available, including the protocols (if available) from COG, provide the main direction. The individual treatment plan is the route mapped out for your child with side roads, short cuts, and rest stops. The route is based on your child's unique circumstances (see Chapter 3 under "About Diagnosis"). Even though your child may have the same kind of cancer as another, the treatment plans will probably not be identical. Treatment plans cannot usually be fixed at the beginning of the journey. Depending on what happens along the way, detours are often necessary. For some types of cancers there is no accepted general direction. Each step of the way is a new direction.



"Try to concentrate on the most common risks and side effects of the recommended treatment and don't get too caught up in the things that could, but rarely do, happen. The chances of being hit by a car don't stop us from crossing the street."

From a parent

## Clinical trials

Sometimes the medical information currently available suggests that a slightly different treatment may be more effective. The members of COG work together to discover whether the newer treatment direction is, in fact, better. Children are **randomly** assigned to either the standard or the newer treatment. The protocols are all recognized as effective treatments. We want to know if one is any better, faster, easier than another. Through clinical trials, we will learn this more quickly than we otherwise could. As soon as there is good scientific evidence to show the advantage of one protocol over another, all children are treated with the treatment plan established as better. With your consent, your child will be participating in a **clinical trial**.

Clinical trials have greatly improved the outlook for children with cancer. You can rest assured that the treatment decisions being made for your child are based on the best medical evidence available at this time. The treatment plan will be explained to you in some detail. **No treatment will be started without your consent.** If you do not want your child to participate in clinical trials, you are free to say so. If you are not part of a clinical trial, your child is treated with a standard protocol. It will seem confusing at first, but in time, your knowledge and experience will grow as will your ability to participate in the decisions made.

If you would like to read more about clinical trials, ask in the Family Resource Library.

## Informed consents

One of the really difficult times for parents is having to sign the "Informed Consent" documents. They indicate that you understand the treatment and its risks and benefits. Because these are legal documents, they spell out even the most unlikely risks. For people already overwhelmed with fears for their child, it is an awful task to have to consider the potential harm which the treatment itself may do. Keep in mind that while it is a hard road to travel, it is the best way we know to the destination.

For help with the consent discussions, see the "*Family Issues*" newsletter, after Chapter 1.

## Second opinions

Some parents wonder whether they should seek a second medical opinion. You might feel reassured to know that when your child is diagnosed and treated at this hospital, second and third opinions are actually built into the care. Each child is discussed at team meetings and opinions are shared. Your child benefits from the experience of all the oncologists working at the hospital. Oncologists here will also consult with leading experts when necessary. If you want another opinion from a pediatric oncologist, you will need to call or go out of B.C. to find it. If you have real concerns, your oncologist can refer you to another treatment centre. You should inquire whether your Medical Insurance Plan will cover this.

### Did you know:

- Children who participate in clinical trials have better outcomes.
- Clinical trials test not only outcomes, but balance outcomes with side effects.
- Clinical trials are not always available. They are started only when a new treatment looks promising.

# Surgery

Surgery is the oldest form of cancer treatment for solid tumours. It attempts to cure the disease by removing all the tumour and, if necessary, some of the surrounding tissue. The lymph channels and nodes in the area are sometimes removed because they are the route through which cancer cells travel. The surgeon tries to remove the whole tumour, in one piece, and to handle the cancerous tissue as little as possible. This helps prevent cells from shedding into the body during surgery. Blood and lymph vessels are tied off to prevent cancer cells from travelling along these routes.

The surgeon may place metal clips in the tissues to act as markers for future radiation treatments.

Surgery may be the only treatment necessary. However, it is usually part of a treatment plan that includes radiation and/or chemotherapy to kill any cancer cells remaining (microscopic disease).

Some surgery is done to control metastases, when there is a chance that this will give the child a normal period of life.

Palliative surgery is done to relieve distressing symptoms such as pain or internal bleeding. It is used when symptoms don't respond to other approaches.

## Preparing for surgery

Surgery makes most people anxious. If you feel that surgery is the best treatment for your child, then you can offer your child support with confidence and calm. If you are filled with doubts, it is harder to be a comfort.

You need to find out as much as you can about:

- the nature of the surgery
- the goal of the surgery and its benefits
- the possible risks
- the alternative treatments available and their risks and benefits
- what will be done to manage pain and discomfort
- what would happen if the surgery was not done
- how the child is prepared for surgery.

Ask questions until you understand and can sign the consent confidently.

## Preparing your child

### Emotionally

See the section "Helping Your Child Manage Tests and Procedures" in chapter 3 for some guidelines on preparing your child for the surgery. There are also some videotapes available to help with this. If your child is between 3 and 8 years of age, you could borrow the video called [All About Your Operation](#). If your child is 12 years or older, he could watch the video called [All Things Considered - Straight Talk About Surgery](#). All of these are available from the Family Resource Library.

### Physically

Different types of surgery require different types of preparation. All patients going for surgery are **NPO for a number of hours before the anesthetic**. The length of time depends on the age of the child and type of anesthetic. NPO means "nothing by mouth" or no food or drink - a rule that is very difficult for young children. NPO is important to prevent the child choking on stomach contents if he throws up after an anesthetic. If surgery is scheduled late in the day, be prepared with a lot of distractions.

Children who have had radiation or chemotherapy may need a transfusion of platelets, to help the clotting and healing of the wound, or a transfusion of red blood cells. An intravenous (IV) line is started to provide food, fluid and medication. These are just some of the ways that help the child recover from surgery.

Find out what your child needs before surgery so that you can participate in the preparation when possible.

## Recovery after surgery

Most children recover in the **PACU** (post anesthetic care unit) where they are cared for and watched closely for several hours. When the child is awake and stable, she is moved back to a ward, or, for some types of surgery, to the **ICU** (intensive care unit). Ask ahead of time where your child will go after surgery. The "high tech" environment of the ICU can be a frightening place for parents and children. You might want to ask to see it before your child's surgery.

Ask about:

- any tubes, monitors, breathing support systems that might be used
- when your child will start to eat
- special precautions that may be needed during the recovery period.

Learn about:

- any coughing or deep breathing exercises that assist in recovery
- when and how your child should sit up and begin moving around.

These exercises make a real difference to recovery after surgery. They also help prevent complications like pneumonia, blood clots, and weak muscles. Your child may not want to do these exercises, but find creative, fun ways to support her through them. The physiotherapists and nurses will guide you.

When your child wakes, try to be there beside her. Talk with her and touch her. She will know you are there even though she seems to be sleeping.

All things considered, most children, even those with cancer, recover quickly from surgery.

# Chemotherapy

Chemo (chemical) therapy (treatment) is the term used to describe the treatment of cancer with drugs. There are many different drugs available. Different cancers respond to different drug combinations. Chemotherapy is a major weapon in the fight against the cancer cell. It can do what surgery and radiation cannot - seek, find and destroy the cancer cells that are moving in the blood and lymph vessels. Because even a single cancer cell can cause a new tumour, chemotherapy is often given even when tests show no cancer cells are present.

In most types of cancer, chemotherapy is the main form of treatment. Chemotherapy works by interfering with the cell's growth or division at one or more stages during its life cycle, causing it to die. Chemotherapy drugs are most attracted to, and effective on, rapidly dividing cells, such as cancer cells. Unfortunately, drugs that are strong enough to destroy cancer cells can also destroy normal cells that divide rapidly. Cells of this kind are hair roots and lining of the mouth and stomach. This is why many of the chemotherapy drugs also produce unwanted effects which are termed **side effects**.

Most normal cells can repair themselves. Cancer cells are defective and cannot repair themselves. For this reason, chemotherapy treatments are given in **cycles** or **courses** - the time between each cycle allows the normal tissues to recover.

The most significant advance in chemotherapy has been treatment with a combination of drugs which act in different ways to destroy cells. This is like attacking with ground, air and sea forces at the same time - you certainly increase your chances of success. **Combination chemotherapy**, as this is called, has another advantage. It makes it more difficult for the cancer cells to develop a resistance to a drug.

## Chemotherapy drugs

The oncologist of the 21st century has a huge arsenal of drugs available to destroy cancer cells. The choice of drugs, the schedule, dose and course, is directed by the type of cancer cells. How the chemotherapy affects the child's body is checked with regular blood tests, physical examinations and other tests. This is necessary because some drugs are **toxic**. They damage organs such as bone marrow and heart. Organs which are particularly vulnerable are the liver and kidneys. They filter and remove chemicals from the body. Tests are done before each course of treatment. If the body has not recovered well enough, a longer recovery period and/or an adjustment in the doses is needed.

Chemotherapy treatments differ not only in drug type and dose, but also in the number of courses. One child may receive only a single course of chemotherapy; while another may need many courses, spreading over years, rather than months. Many factors are taken into account and each child's response is different. Don't expect that your child's chemotherapy schedule will be like that of another with the same type of cancer. **Treatment routes are planned for the particular situation of each child. They are not "off the shelf" maps.**

Before any chemotherapy is given, the nurse/doctor will say out loud the child's name, the drug, the dose, the method. This is a safety measure. If this doesn't happen, please remind us.

## Helping your child with chemotherapy

Chemotherapy can be given in different ways.

### By needles

**Intramuscular injection** - "IM" - which means into the muscles

**Subcutaneous injection** - "SC" - which means under the skin

**Intravenous injection** - "IV" - which means into a vein

**Intrathecal injection** - "IT" - which means into the fluid around the spinal cord

Some drugs can be given in more than one way, depending on their chemical makeup. Most anticancer drugs must be given intravenously; however, they can be given "IV push", i.e. rapidly over a few minutes, or mixed with intravenous fluid and "dripped" (infused) over a longer period of time.

Needles are painful and happen often during treatment. There are 2 videotapes which may be helpful - [No Fears No Tears](#) and [Playing the Hurt Away](#). These are both available in the Family Resource Library.

The most common way of giving chemotherapy is through an **intravenous**. Starting IVs in the small veins of children is not an easy task. If staff are unable to succeed on their first attempt, pressure builds. The child and parents are unhappy, and the staff know that. Try as they might, they cannot avoid hurting the child. Play your part on the team. Work with the nurse to maintain as much calm as possible. The nurse is doing precise work under stress. Support the child and the nurse by breathing easily and saying encouraging things. If it is not going well, suggest that everyone take a break to regain some calm. Be sure this doesn't come out sounding like blame or threat.

Ask the nurse about EMLA. EMLA cream numbs the skin so needles aren't quite so bad.

### Central venous catheters (CVC) and vascular access devices (VAD)

#### Long term access to veins

Your doctor may recommend a **central venous catheter (CVC)** or **vascular access device (VAD)**. Plastic tubes are surgically set into a vein and left in place for weeks and months. These make it easier to give drugs and collect blood samples. Needles go into these lines rather than into the child's veins. If the doctor suggests this option, **ask for the pamphlets or booklet describing these in more detail**. You will also be shown how to care for the lines at home.

## **By mouth (oral/PO) - tablets, pills, capsules and liquid**

Some children find it difficult to take the drugs by mouth. This can become a battleground between child and parent. There are some tips from other parents in the "From Bitter and Sweet Experience" sections. Here are some other ideas.

### **Tips to help your child take medicine**

1. Treat taking medicine as part of the normal daily routine. Being positive, firm, and consistent will help him understand the importance of it.
2. Do not try to force it down. You will have more success if he takes it willingly. Offer a choice that allows some control, such as kind of juice with which to swallow the pill.
3. Have your child suck on ice chips or popsicles just before giving the medicine. This numbs his mouth and taste buds. This will help to hide the bad taste of the medicine.
4. Some children will place the tip of an oral syringe into their mouth. You then gently help the child depress the plunger, swallowing a little at a time.
5. Some of the oral meds have an awful taste, even if they are swallowed quickly. Many of us have found that they go down a lot easier if they are crushed and then put in gelatin capsules. These capsules are available at pharmacies for a small fee and come in several sizes.
6. Use M&M's to practise swallowing pills. The "baby size" ones can be used to get him started. Make a game of it.

*Caution: Use this with older children.*

These suggestions are adapted from the Pediatric Oncology Resource Centre website:

<http://www.acor.org/ped-onc/treatment/Pills/pills.html>

### Crush and mix

The basic strategy is to get the tablets, crush them, and place them in a small amount of food that your child likes (applesauce, juice, etc).

**Beware: Your child may grow to dislike the food and drink you use for medications.**

Be prepared to try a different mixture if suddenly your child refuses to eat the latest successful concoction.

Use only a small amount of food or drink because your child must eat or drink every bit of the food or drink.

*Note: Check with your pharmacist or doctor about crushing pills. Not all of them can be crushed. Be aware of safe handling guidelines in Chapter 6, page 6-6.*

- Ice cream and chocolate
  - Crush the pill and put it in vanilla ice cream.
  - Try sprinkling it on ice cream and covering it with chocolate syrup.
  - Crush it and mix it with chocolate syrup. We found that it disguised the taste better than anything else.
- Candy and sugar
  - Melt down fruit chewies in the microwave just enough to soften and place the crumbled pill in it and make it into a little ball of candy.
  - Wrap the pill in a fruit rollup.
  - First crush the pill, then take 1/2 teaspoon of powdered sugar, about two match heads of your child's favourite powdered drink, and a little bit of hot water, and down it goes.
  - Crush the pills and mix them in jelly.
- Fruits and juices
  - Crush the pill and mix it in a small amount of a sweet fruit juice or punch - the sweeter the better to mask the taste.
  - Use a fruit, like berries, cherries or grapes. Put the pill in the fruit after removing the pit.
  - Use syrup that is used to mix lattes and Italian ices.
  - Jello jigglers. Make a pan of them, slice a small square, then make a small slit and stuff the pill inside. The jello will slide down, the pill will stay inside.
  - Drop the pill into a syringe (without a needle), then pour juice or syrup in and let the pill dissolve. Younger children can take medications this way.

# Radiation therapy

Radiotherapy aims speeded up high energy X-rays at cancer cells. The rays damage cells and stop them from dividing. High energy X-rays are either naturally emitted from Cobalt sources, or made using machines called **linear accelerators**.

Radiotherapy treatments are carefully planned. The aim is to give the cancer cells a high dose of radiation while protecting the normal tissue.

Each treatment takes about 15 minutes.

In radiation therapy, the total dose is divided into multiple fractions (**fractionation**). These fractional doses are usually delivered 5 times a week for as many weeks as it takes to give the total dose. This is different for each child.

Children do not have to be in hospital for radiotherapy. They are often feeling well and can spend the remainder of the day at home resting or playing. Some children may even want to go back to school.

Radiation services are scarce. Appointments are scheduled to allow as many treatments as possible in a day. Many people wait many weeks for an appointment. When you are late, don't come, and fail to cancel, you put your child and others at risk.

There are often some side effects from radiation. These are similar to those from chemotherapy. The type of side effects depends on the part of the body being treated. Your doctor will talk with you about what you can expect. Refer to the chapter on side effects (Chapter 5) for more information. Radiotherapy treatments, themselves, are never painful.

## The procedure

Radiation requires sophisticated machinery and specially trained oncologists and technologists. BCCH has no radiotherapy services. If your child is referred for Radiation Therapy, a radiation oncologist from the B.C. Cancer Agency will see your child at Children's Hospital - on the ward or in the clinic. She will discuss how the radiation will fit into your child's treatment, and when it will be done. All radiation treatments are done at the BC Cancer Agency.

## The first visit

The child is usually taken to the **mould room**.

The radiation beams must hit the mass of cancer cells and avoid, as far as possible, normal tissue. Bearing this in mind, you will understand that it is extremely important for the child to be in exactly the same position for each treatment and to lie still. Sometimes it is necessary to use medicines to sedate or quiet the child.

A technician settles the child on a table in the best position for radiation. She then makes a plaster mould of the section of the body needing treatment. Before each treatment, the child is placed in this mould.

*Note:* Sometimes the child's skin is covered with lotion or plastic wrap before the plaster is applied. Tell your child about this. Some children find this upsetting.

The first visit may take an hour or so.

## The second visit

The child goes to a **simulator room**.

Before any treatment can begin, the treatment area, called **the field**, is mapped and the dose calculated. The child lies on the table in the mould. A machine called a **simulator** is rotated until exactly the right angles for treatment are found. X-rays and CT scans are sometimes used in the mapping. The treatment field is outlined on your child's skin with a coloured marking pen. **DO NOT wash off the marks until the treatment is completed. If they disappear, the simulation process may have to be repeated.** Sometimes a tiny dot is "tattooed" at the very centre of the field. This is a permanent marker and serves as a guide if radiation is necessary in the future.

The second visit may take about 20-30 minutes.

## Treatments

Treatments take only 15 or 20 minutes. The child is carefully positioned on the table using the mould. Sometimes protective shields are placed over body parts close to the treatment area. Safety belts are used to keep the child secure as the table is quite high off the ground. When the child is ready, you must leave the room. Your child will be alone in the room during the actual treatment, which may be only a minute or two.

You will be able to watch your child on the TV monitor or through the window and speak with him on an intercom. He must remain still. If he is not able to do this, he may need a sedative. Most children over 2 years of age are able to manage once they realize that it doesn't hurt and is soon over.

## Helping your child with radiation therapy

Your child will manage better if you have prepared him. It is uncomfortable to have to lie on a table in the mould room and have part of your body (for brain or neck tumours, your face) wrapped with wet plaster bandages. Some children get very upset.


- You can avoid some of this distress by explaining what is going to happen. For example:

*"They're going to make some specially shaped shields for your body like the kind of shields that hockey players wear - they will do that by..."*

Then tell your child it will take about as long as this \_\_\_\_\_ (demonstrate about 15-20 minutes). Explain that you are going to be beside him, that it won't hurt, but it will be uncomfortable lying still on the table and it might be BORING. So, to make the time go quickly and not be boring, you are going to plan some things to do like, storytelling - use your voice or a tape; music; use your imagination.

- You can expand this idea by playing out radiation treatment with a teddy/doll. Make a mask from paper mache and plastic wrap. Play the treatment out many times. Move from this to practising lying still. You can play "Simon says, lie very still" as the starting point.

- Guided imagery is a good strategy to use while the mould is being made. It is also useful for treatments when the child is on his own, and you have only voice contact with him. Guided imagery or "making a dream" is explained in Chapter 2.
- For the mould making, you could also take a puppet, pop-up book or some other distracting toy.
- Ask the child life specialist on the team to help you plan an age appropriate distraction or relaxation technique.
- Make sure you include your child in the planning and build some anticipation. Practising relaxation or distraction allows the child to feel some control in the situation. You can coach the child in the strategy through the intercom.
- "Rocketing Through Radiotherapy" is a video that describes the experience of radiation therapy from the child's point of view. It is available in the Family Resource Library.



"I read her a story through the intercom. We agreed that she would hold teddy and herself still. If either moved, the story would stop until both were still again"

From a parent

# Bone marrow and stem cell transplantation

Transplants of this kind have moved from being last chance attempts, to a standard treatment option for many types of cancer.

## Stem cells

Stem cells are the "seeds" out of which all mature blood cells develop. They are produced and grow in the bone marrow. Stem cells are found in:

- bone marrow (bone marrow transplant)
- the bloodstream, after chemotherapy (peripheral blood stem cell [PBSC] transplant)
- umbilical cord blood of a newborn (cord blood transplant).

## Stem cell transplants

Stem cell transplants are used in two ways:

- to "rescue" the child after very high doses of chemotherapy and/or radiation therapy have destroyed the blood cells.
- to replace "sick" cells with healthy ones. In this case, the transplant actually is part of the treatment along with the chemotherapy and radiation.

Some of the treatment protocols include stem cell transplants. Research has indicated that stem cell transplants have a better outcome than other treatment choices in some types of childhood cancer:

- children with certain types of leukemia
- children with solid tumours who need very high doses of chemotherapy and radiation
- children with some types of immune system and biochemical diseases

## The procedure

**Bone marrow transplant:** your child will be in a special isolation room on the oncology ward (3B) until his counts recover enough for discharge.

**PBSC and cord blood transplants:** your child may not need a special isolation room and will recover in a single bed room on 3B.

## The team

The people who have been caring for your child will continue to do so. They will arrange a meeting to give you information about the procedure. This is a good time for you to ask any questions and voice any concerns about the transplant. Come prepared with your questions. It is a good idea to take notes, or ask someone to take the notes for you.

## The kind of transplant

Any of the 3 kinds of transplants can be used. Based on research and the physician's judgement, he will decide which type of transplant is best for your child. Another factor is finding stem cells matched to your child's cells.

## The donor

This could be the child's own cells (from his bone marrow or bloodstream) or those of a family member (most likely a sibling) or those from a matched stranger off the donor list. Tissue typing, to find a match, is done with a blood test.

## The timing

In some cases, this is set out in the protocol. The timing must always take into account the child's physical ability to recover.

## The "harvest"

Stem cells are collected from:

- The **bone marrow** - while the donor is under general anesthesia in the operating room. Many bone marrow samples are collected (see Chapter 3, describing bone marrow aspiration).
- The **bloodstream**. This procedure is done in your child's room or the clinic. Your child will have a stronger central line put in. The line is connected to a machine that collects blood cells. In order to collect enough cells, many samples may be necessary. The pamphlet "*Peripheral Blood Stem Cell Collection Using an Apheresis Machine*" (PE223) describes this in detail. Find it in the Family Resource Library. A blood test shows the right time to harvest stem cells.
- The **umbilical cord** in the delivery room. The oncologist will contact your doctor to set it up. There is no danger to you or to your baby. The samples are filtered and put into a bag used for blood transfusions.

## The preparation of the stem cells

In some cases, the stem cells are specially treated and frozen. In other cases, the bag of cells comes right from the donor to your child.

## The preparation of your child

For about 10 days before transplant, your child will get high doses of chemotherapy and, in some cases, total body irradiation. This destroys as many cancer cells as possible, reduces the immune system's reaction, and makes room in the bone marrow space for the new stem cells to grow. The type of preparation depends on the type of cancer and transplant.

## The infusion of the stem cells

The stem cells are infused through the central line. The nurse will take vital signs and watch your child closely. A doctor will be on the ward.

## Recovery after the transplant

All transplants have side effects. Most of these are the same as the side effects of chemotherapy and radiation therapy. Because blood counts usually are low for a long time, your child may feel sicker for longer. Other complications, such as veno-occlusive disease (VOD) and graft-versus-host disease (GVHD), are possible in bone marrow transplantation. You can find information about them in the Family Resource Library.

## Discharge

Your child will be discharged when:

- the ANC is at least 0.5 (see chapter 3)
- he is able to take enough food to maintain or increase his weight
- he does not have a fever or other signs and symptoms of infection
- he is strong enough to do some things for himself.

He will have to stay in the Vancouver area for about 100 days from the day of the transplant. He will be seen a few times a week in the Oncology clinic. He will probably need blood and platelet transfusions and other medications to support his immune system.

Go to the Family Resource Library for more information about stem cell transplants. Check with your doctor and nurses about specific information for your child.

*Some questions you may want to ask the healthcare professionals:*

1. What happens if we don't do anything to treat?
2. What makes you recommend this treatment rather than \_\_\_\_\_ or other options?
3. How long can I take to make the decision? Do I have to decide right now?
4. How many children with this condition have you treated? Does the success rate here match that of other places?
5. How will you include me in treatment decisions?
6. What is the best outcome from this treatment?
7. What is the worst that might happen?
8. In your experience what should we realistically hope for?
9. What should I expect once my child starts the treatment?
10. What are side effects and their treatment?
11. What are the signs that things are getting better or worse?
12. Are there risks associated with this treatment other than the side effects?
13. Are there any cautions we need to keep in mind while my child is on this treatment?

# Alternative and complementary therapies

The words "alternative medicine" mean many different things to people. There is no simple definition that we can agree on. Much of what comes to us as "alternative medicine" comes from healing traditions other than those used in the West. The healing tradition of this hospital is grounded in scientific evidence based on practice. Healing approaches that come from other traditions are called alternative, complementary, holistic, integrative. From now on, we will use the term "alternative" to refer to healing practices that are not part of evidence-based health care.

Evidence-based healthcare uses treatments that have been proven to be effective. The proof relies on scientific testing. This means that a group of people given the treatment has done significantly better than a group without this treatment. The benefit has been shown often enough to predict that those on the treatment have a better chance than those without. Treatments tested in this way let us know the good and the bad effects on the child's body. Because we know this, we can evaluate the risks and benefits. This is the difference between a "claim" and a "proof".

We can think of alternative therapy as falling into 2 groups:

- Therapy which hopes to remedy a problem in the body by using herbs, plant, or animal extracts (eg. shark cartilage, herbal teas) to act on the body tissues and body chemistry.
- Therapy that hopes to improve the state of mind through relaxation, therapeutic touch, imagery, etc. and, in this way, help the body and spirit heal. This is often called "complementary" care. The focus of complementary care is to provide more holistic treatment.

## Making treatment choices for your child

You will be faced with many treatment decisions along the way. The scientific protocols give the treatment choices offered here. However, the final responsibility for the choice of treatments is yours and your child's. This is as true for our recommendations as for other treatments you may consider. The starting point for your decision should be a clear understanding of what you are looking for. This may change as your child's condition changes.

Are you looking for:

- a cure
- longer survival
- improved quality of life
- more control over your child's health
- better control of side effects and symptom management, eg. nausea, vomiting, pain
- easier treatment
- everything possible.

The answer to these questions will guide your choices.

As a parent making decisions on behalf of your child, you have the responsibility to make sure your choices are "informed" - based on the best information available. Some families want to keep the responsibility for choice and others find this too hard. They prefer to hand over the decisions to the team. Do what feels right for you.

## **Some suggested questions before consenting to treatment of any sort**

### **How will this treatment/remedy help to make my child healthier?**

What is the goal of this treatment? Is the claim to make the child feel better, is it a cure, or both? If it is cure, is it permanent? On what basis is this claim for cure made? What is the evidence that this works for children? What is the chance of it working? (In other words, what can you really expect?)

### **Can this treatment be used safely alongside what is already being done for my child?**

Anyone offering any type of treatment to your child must know what else he is getting. Treatments interact with one another. A specific treatment, which is safe in itself, may not be safe when it is given with another therapy. It may alter how well the treatment works. Always be open with the doctors and practitioners of alternative therapies about **ALL** the tonics, supplements, therapies and drugs your child is taking. How the treatment is given can also affect its safety. Cancer and its treatment disturbs the way the body works normally. Anyone who does not understand how the organ systems respond to cancer treatments may prescribe a therapy that has unexpected results. Be aware that the fact that there is no information about harm does not mean that there IS no harm. For example, even something that seems as if it could only do good, eg. massage to achieve relaxation, might have the effect of increasing the flow of blood to a tumour and helping it to grow.

### **How does this treatment work?**

How exactly does it work in the body? How does it work against the disease/condition for which it is being offered? How do you know that this is the case? How many people have you treated and what sort of records do you keep on how they are doing? If they are better, do you know what is happening to them one month, one year, or five years down the road? How do you know that the treatment that you are offering made the difference for the person rather than something else? Has the treatment been used in children? What are the side effects?

### **What group outside of the people offering the treatment has checked on this drug or therapy?**

Be aware that if there are no checks, it is rather like buying street drugs. You have to rely on the person's word that:

- the treatment is what is claimed
- it is pure
- the dose in which it is packed is correct and accurate
- it will do what the person says

Anything that has not been approved by the regulatory bodies of the Canadian government may contain ingredients that neither you or anyone else knows anything about. The words "natural" or "chemical" are not guides to safety. Nature can harm as easily as the laboratory. "Secret" equals unchecked and unknown. In what other circumstances would you give your child a spoonful of something without knowing the ingredients? How can you choose if you don't know what you are choosing?

**How much training have you had in the treatment of my child's disease/condition?**

Do you know and respect the person's training in the treatment they are offering and their understanding of childhood cancer?

**What costs are involved in this treatment?**

There are some people who are prepared to make money off the fears of others. The more frightened and desperate one gets, the more likely we are to grasp at anything that promises hope. Be aware that not everyone offering treatment will put your child's best interests above his own.

Be sure you know everything that will be charged. You should be considering travel, places to stay, food and the cost of the alternative therapy itself. Most alternative therapies are not covered by health insurance. If you must leave the country, find out first if your health insurance will cover any needed health care if your child becomes sicker; find out what happens if he needs to stay in a hospital or receive emergency care outside of BC. Call Medical Services Plan out of country/out of province division. Ask your social worker for the phone number. Be aware that the cost also involves leaving the support of family and friends at home.

**We would like to maintain an open discussion about the use of alternative therapies**

The health care team understands that you want your child to have every chance possible. We respect your choices and decisions. We welcome the chance to help you sort through the many options and considerations involved in treating a child with cancer. If you are considering an option other than what we offer, please discuss it with us. We will give you what information we have about it, tell you if there are any risks involved, and put you in a better position to make an informed decision on behalf of your child. However, we may not have studies on how the alternative medicines affect chemotherapy. The best we can offer is an educated guess.

# Relapse

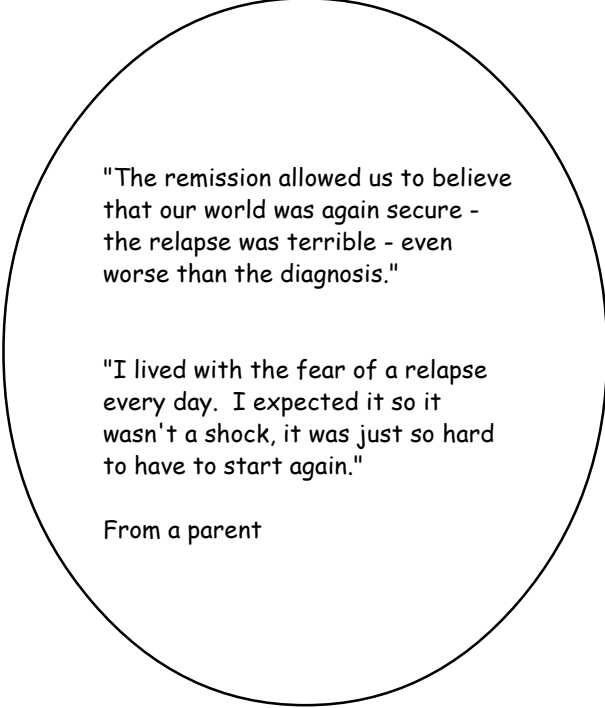
Relapse is a return of the cancer cells. It may happen while the child is still receiving treatment or after the treatment is over. The longer the remission holds, the less chance of a relapse.

If the child relapses during treatment, it suggests that the protocol is ineffective. The usual decision is to change the treatment. If the child relapses after remission, it suggests that the treatment killed most of the cancer cells, but that a few escaped. In either case, the oncologist will review all treatment options with you.

The positive side of beginning treatment again is that the child is usually in much better health after the remission than he was at the time of diagnosis. The negative side is that the treatment is often longer and more intense. It is harder to achieve the second remission.

The fear of relapse can become overwhelming. Some people find themselves reacting to each cold or sign of fatigue as a symptom of relapse. In fact, most relapses are picked up through testing before the symptoms become obvious. The relapse statistics for each type and stage of cancer is different.

Clearly there is no solution to the problem of living with uncertainty. Many parents say that living with cancer has taught them to take each day one at a time and appreciate what was good about it. You will have learned how to maintain hope in the face of serious illness and will find that strength again should it be necessary.



"The remission allowed us to believe that our world was again secure - the relapse was terrible - even worse than the diagnosis."

"I lived with the fear of a relapse every day. I expected it so it wasn't a shock, it was just so hard to have to start again."

From a parent

# From bitter & sweet experience

*Create your own scrap book with pictures - give your child a disposable camera to take pictures of people and places.*

*Note:* Ask the child life specialist for help with this.

To help through the numerous treatments, purchase or create a project that requires pieces that can be added each day; for example, a doll house - furniture; Barbie and outfits to change; lego or duplo blocks; a card collection; a series of story books, such as "Thomas the Tank". Offer a new piece after each treatment.

Write other tips here:

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