

# *5. Managing the common side effects of cancer treatment*

## **Effects on the blood**

The cells that make up the blood divide and grow very quickly. This means that they, like the cancer cells, are destroyed by the drugs and radiation. There are different side effects because there are different types of blood cells.

### **Low platelet count (thrombocytopenia)**

Major risk: Bleeding

Platelets are the blood cells that help the blood to clot. When their concentration in the blood falls below  $50 \times 10^9/L$ , the risk of uncontrolled bleeding increases. It is rare for a bleed to start without an injury, unless the platelet count is below  $20 \times 10^9/L$  (See Chapter 3 for information on blood counts).

Low platelet count is a risk of most chemotherapy and, sometimes, radiation therapy.

Caring for a child with low platelet count means:

1. Knowing what signs to watch for
2. Preventing bleeding
3. Managing bleeding early and in the right way
4. Getting professional help when appropriate

#### **1. Knowing what signs to watch for**

- Bleeding gums.
- Nosebleeds.
- Bruising.
- Dark, loose stools.
- Vomitus which has a bloody or "coffee grind" appearance.
- Red or brown urine.
- Red spots on the skin (called petechiae).
- Increased menstrual flow.
- Severe headache with or without vomiting.
- Changed level of consciousness.
- Bleeding that goes on too long after a cut, poke or scrape.

These symptoms may begin soon after chemotherapy starts but are usually at their worst 10-14 days later.

Normal range for platelets:  $180-440 \times 10^9/L$

## 2. Preventing bleeding

Ibuprofen and aspirin make it even harder for the blood to clot. Do not give your child any medications containing aspirin (listed on labels as acetylsalicylic acid). It is wise to check with your physician before giving your child any unprescribed drugs.

Use only an electric razor to prevent nicks while shaving.

There are large veins in the rectum (hemorrhoids). They can break when straining during bowel movements. Encourage your child to drink plenty of fluids and eat enough fibre. If necessary, use a stool softener recommended by your doctor.

Don't allow anyone to:

- take a rectal temperature,
- give a suppository or enema,
- do a rectal examination to your child,

unless the oncologist or oncology nurse tells you that there is no alternative.

Your child should not have an IM (intramuscular) injection while platelets are low. If it is unavoidable, press hard on the site for 5-10 minutes after the poke.

Tell health care professionals and your dentist if your child has low platelets. They can then adjust their care. Always check with the oncologist before having dental work done.

Avoid these when platelets are low:

- lifting heavy objects
- contact sports
- biking
- skateboarding
- and any other activities where there is a high risk of injury.

Protect younger active children against bumps and scrapes with a padded helmet and padded siderails on the bed.

A soft diet, soft toothbrush, "toothettes", or even sponges for cleaning the gums helps prevent scratches to the gums. Do not floss teeth.

Nosebleeds often start with nose picking, a hard blow or harsh sneeze. Dry mucous can scratch the lining of the nose and cause a nosebleed. You can prevent this by keeping the nostrils moist with a nasal ointment available at the pharmacy.

Keep all appointments for blood tests so that the platelet count can be monitored.

### 3. Managing bleeding early and in the right way

If there is a cut or breakdown of the skin, cover the wound with a clean bandage and press down on the area for 4 minutes. This gives the blood time to clot. (Don't lift the cloth and peek.)

Nosebleeds may start for no reason at all. If a nosebleed does start, squeeze above the nostrils. If the bleed does not stop or slow down in 10 minutes, try squeezing while someone holds an icepack on the back of the child's neck. If the bleeding still does not stop after another 5 minutes, call your doctor or the Oncology Clinic (if you are in Vancouver).

A platelet transfusion may be necessary if there is a bleed that cannot be stopped, or the platelet count falls below a safe level. See the section on Blood Transfusions in this chapter for more information.

### 4. Getting professional help when appropriate

**Inform your doctor or, if in Vancouver, the Oncology Clinic during the day if:**

- you see any of the signs listed under #1.
- any body fluid like urine, sputum coughed up, saliva, etc., looks as if it has some pink/red colour in it.
- you notice red or purple spots or large bruises on the skin or in the mouth.

**Call your local doctor or, in Vancouver, the clinic/oncologist on call immediately if:**

- you cannot stop the bleeding after two attempts to apply pressure.
- you notice blood in the vomit (may look like coffee grounds) or stools (may look like tar).

When you call, state your child's name, age, and diagnosis. Be ready with this information:

1. When did the bleeding start?
2. How long has it lasted?
3. How much blood has there been?
4. Is there bleeding anywhere else?
5. When were the last counts done? What were they?
6. When was the last chemo treatment - what drugs were given?
7. Is he getting radiation?
8. Has this happened before?
9. What did the doctor do then?

**Call the ambulance (911) to take your child to the Emergency Department if:**

- she loses consciousness or you are unable to wake him up.
- she is not breathing properly and is not able to get enough air, or stops breathing.

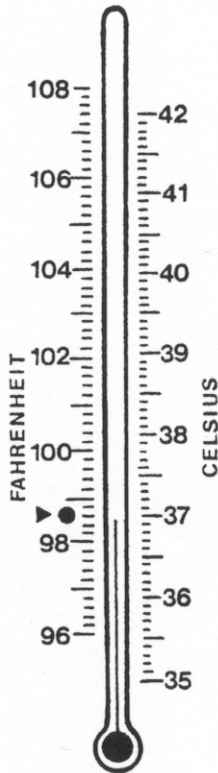
## Low white blood cell count (leukopenia)

### Major risk: Infection

White blood cells help the body fight infection. Chemotherapy and radiation destroys the white cells. Review the booklet *"The Immune System"* (in the Family Resource Library) for a more detailed explanation of the infection-fighting white cells. The chances of infection increase significantly when the ANC (see Chapter 3) is less than 1.0. Early action is important!

Caring for a child at risk for infection means:

1. Knowing what signs to watch for
2. Preventing infections
3. Managing infections early and in the right way
4. Getting professional help when appropriate
5. Respor



### 1. Knowing what signs to watch for

- Fever greater than 38.5 C.
- Shortness of breath.
- Irritability or listlessness.
- Chills.
- Warm forehead with a flushed or pale face.
- Vomiting/diarrhea.
- A sore and/or swelling which does not heal.
- Sores in the mouth or throat.
- Coughing, runny nose.
- Pain with a bowel movement.
- Change in level of consciousness.
- Need to pee often.
- Rashes.

These symptoms may begin soon after chemotherapy starts but are usually at their worst 10-14 days later.

Normal range for WBC: 6-18 x 10<sup>9</sup> per litre

## 2. Preventing infections

Infections are dangerous for children with cancer and you should do what is reasonable to protect against them.

Germs usually enter through the openings to the body - mouth, nose, breaks in the skin, urinary tract and rectum. Germs settle on the skin, stay on one's hands, and then get into an opening. The best way to prevent infection is to practice good hygiene.

- Wash hands often, brush teeth, and clean the skin, clothing and house.
- If parents are sick, but feel that they must be with their child, wash hands often and well. Think about whether you should wear a mask. Please stay away from others on the ward or in the clinic.
- Don't share glasses, spoons, towels, etc.
- Ask the teacher and school nurse to let you know when classmates have a contagious disease. If you wish, you can use the sample letter in the booklet *From Hospital to School: A Handbook for Parents* to ask cooperation from other parents in this matter. This booklet can be found in the school re-entry package, available from your primary clinic nurse.

## 3. Managing infections early and in the right way

Even with our best efforts, children with a low ANC often get sick. They are often infected by the bacteria always present in their bowels or mouth. The weak immune system can no longer keep the bacteria in check.

### Before your child comes home

- Purchase a centigrade thermometer with a digital read out to make things easier.
- Make sure you know how to take a temperature by mouth or underarm. Ask a nurse to show you the correct procedure if you are unsure. (Never take a rectal temperature as your child is more susceptible to infection and bleeding if the rectum is injured).
- Always clean the thermometer well after each use.
- Take your child's temperature whenever you think he is not feeling well. For example, if he is flushed and feels warm when you touch him.

### When your child has a fever

- Dress your child in light clothes and cover with a light blanket.
- Bathe the child in lukewarm water.
- Encourage plenty of fluids.
- Never use aspirin-containing medications. Give Tylenol or another medication, only on the advice of a doctor or nurse.

While it is important to monitor your child's temperature during treatment, it is not necessary to continue this for months and months. As soon as possible, try to phase out thermometers and rely on other cues like listlessness, a flushed appearance, and a forehead that is warm to the touch. This is just another aspect of normalizing where and when you can.

Fevers must always be treated with a course of drug therapy. Usually, it is necessary to use intravenous medications. In this event, your child will be admitted to a hospital. Be prepared for this.

## 4. Getting professional help when appropriate

**Inform your doctor or, if in Vancouver, the Oncology Clinic during the day if your child:**

- has a temperature of 38.5 C/101 F by mouth or 38 C/100 F underarm **and**
- has irritability or restlessness.
- has vomiting and/or diarrhea.
- has a sore throat that does not get better.
- has sores in the mouth or throat.
- has a cough.
- has a runny nose.
- is unable to drink fluids.

**Call your local doctor or, if in Vancouver, the clinic/oncologist on call immediately if your child:**

- has a temperature higher than 38.5 C/101 F by mouth or 38.0 C/100F under arm **and**
- has shortness of breath or rapid breathing.
- has chills.
- has pain anywhere.
- has a change in level of consciousness.
- has a rash.
- has decreased/no urine output for 6-8 hours.

**Call the ambulance (911) to take your child to the Emergency Department if:**

- she loses consciousness or you are unable to wake him up.
- she is not breathing properly and is not able to get enough air, or stops breathing.

When you call, state your child's name, age, and diagnosis. Be ready with this information:

1. What is your child's temperature?
2. When did your child last have chemotherapy? What drugs did your child receive?
3. When was your child last seen in clinic or in hospital?
4. What other symptoms does your child have?
5. Has your child had acetaminophen (Tylenol) today? If so, what time? What dose?
6. Do you know what your child's latest blood counts are? (ANC)
7. Is your child currently on G-CSF?
8. What type of line does your child have? (VAD, CVC, none)
9. How long will it take you to arrive at the Emergency Department?

*Note:* Please bring your discharge summary with you when you go to the Emergency Department. Ask the staff to follow the fever guidelines on the back.

Put EMLA on the VAD if your child has one.

If your child needs to be admitted with a communicable infection, he will be admitted to any unit of the hospital which has an isolation bed. He may be admitted to a local hospital if the staff at that hospital is able to give the needed care.

Infections can be alarming and frustrating setbacks. They are sometimes very serious indeed, but, new drugs and good care have made it easier to bring them under control.

## 5. Responding to special risks

### **Immunization is a risk for children with a low white cell count**

Cancer and its treatment is very hard on the immune system. We suggest you leave immunization for at least 6 months after the last treatment. Discuss timing with the oncologist.

- If a live vaccine (measles, rubella, mumps, oral polio) is given before the immune system has recovered, the vaccine could infect the child.
- If an inactive vaccine is given, the immune system, which has not fully recovered, will not respond.

Family members:

Siblings who are still in diapers should have the injectable polio vaccine rather than an oral vaccine. The child with cancer could be infected by a diaper. Siblings should be given all other immunizations on the regular schedule. It benefits the child to have the sibling protected from these diseases. An annual influenza shot may keep flu out of the household.

At school:

Tell the school nurse not to immunize your child through a school program. Explain the risks of contact with a live vaccine. Ask the nurse to teach classmates who receive a live polio vaccine good handwashing for a week or so following.

### **Chicken pox**

This common childhood viral infection can be a very serious problem for children whose immune system is not working well. It is a concern for:

- children having chemotherapy or those who have had chemotherapy in the last 6 months AND have not had chickenpox
- children on long term steroid therapy who have not had chickenpox
- children who are on immunosuppressive therapy (e.g., cyclosporine) after a bone marrow transplant
- children with a known immune deficiency disorder.

Children are usually tested to check their resistance (antibody levels) to the chickenpox virus at the time of diagnosis. Ask for the results of the test so that you know if your child is immune.

Chickenpox is highly contagious. The virus spreads into the air in the breath, sneeze or coughs of the sick person and is breathed in. Or, the virus sits on the skin and is transferred through touch. (Incubation period is 7 - 21 days). It is infectious from 24 - 48 hours before the blisters appear until the last blister has scabbed. The most contagious phase is while the blisters are forming.

Your child might have picked up the virus if he has been in the same room or house with a child with chickenpox for more than an hour (the virus can spread through the heating/air conditioning).

Try to keep your child away from places where you know there is chickenpox or a contact with chickenpox. The problem comes with how cautious you need to be. Be reasonable about reducing the risk but don't keep your child isolated or disrupt the family.

- Keep the child out of school only if chickenpox is going around in the class. Ask the teacher to tell you if any child gets chickenpox.
- Send a letter to parents of the classmates explaining the situation. Ask them to keep children with chickenpox home. (A sample letter is available in the school re-entry package available from the clinic nurse).

We think it is unreasonable to:

- remove a sibling who has had contact with chickenpox from home. (If the sibling gets chickenpox, phone the doctor to discuss the issue)
- keep a sibling out of school because chickenpox is going around
- take special precautions when the child has had chickenpox.

*If your child is in contact with chickenpox do not bring the child into the hospital unless asked to do so. Contact your doctor or the oncology clinic immediately (after-hours call oncologist on call). Your child may need an antibody called VZIG to prevent or reduce the impact of the chickenpox. The antibody should be given within 72 hours of the contact.*

*If your child shows signs of actual chickenpox, contact your doctor right away. The doctor may decide to treat with an intravenous drug (this will mean hospitalization).*

## Shingles

Shingles is caused by the same virus as chickenpox. It results when some of the virus "sleeps" in certain nerve cells. Later, it becomes active again in the skin linked to the nerves. That means that people in contact with shingles may develop chickenpox if they have not already had it. However, the virus is transmitted only through skin contact. It escapes from the infected person's body through the blisters on the skin. Therefore, contact the doctor if your child is at risk and has been in one of the following situations:

- in the same room for more than 15 minutes with someone who has shingles on an uncovered part of the body
- playing or working with the same toys or equipment as someone with shingles.

*Note:* Just being in the room with someone with shingles covered by clothing is highly unlikely to result in transmission of the virus unless they have been sharing objects.

### *At risk children*

- Those who have not had chickenpox.
- Those who have had a bone marrow transplant within the last 2 years. (Longer if on large doses of medications which weaken the immune system.)
- Those receiving intensive chemotherapy such as that given during induction and consolidation for ALL, throughout treatment for AML and Hodgkin's Disease.

If shingles develops, it is usually treated with intravenous antiviral medication, and must be given in hospital.

## Low hemoglobin (red blood cells) - anemia

### Major risk: Insufficient oxygen to the body

Anemia means there is not enough hemoglobin (Hgb) in the red blood cells or not enough red blood cells. Hemoglobin is what gives the blood its colour. It also carries the oxygen to all the tissues of the body. Oxygen provides some of the body's energy.

The red blood cells are constantly being renewed. The lifespan of a red cell is about four months. New cells are made in the bone marrow. Dead cells are removed by the liver and spleen. These events can cause the amount of hemoglobin to fall:

- the disease or chemotherapy/radiation reduces the bone marrow's ability to make healthy new cells;
- the treatment damages the new cells that are made;
- bleeding.

Caring for a child at risk for insufficient oxygen supply to the body/anemia means:

1. Knowing what signs to watch for
2. Preventing anemia
3. Treating anemia early and in the right way
4. Getting professional help when appropriate
5. Responding to special risks and problems

### 1. Knowing what signs to watch for

- No interest in anything.
- Fatigue and lack of energy.
- Weakness.
- Pale colouring especially noticeable around the lips and nailbeds.
- Dizziness/lightheadedness especially when shifting from lying to sitting or standing.
- When anemia is severe, there may be shortness of breath, headache and confusion.

These symptoms may begin soon after chemotherapy starts, but are usually at their worst several weeks later.

Normal range for hemoglobin: 107-131 x 10<sup>9</sup> per litre

### 2. Preventing anemia

Most of the anemia suffered by children with cancer is not caused by an iron deficiency or other inadequacy in the diet. It cannot be prevented or cured by giving your child vitamins or commercial iron supplements. However, children with cancer, like all children, will benefit from a well-balanced diet.

There is not much that can be done to prevent anemia, but there are ways of managing the major symptom - fatigue.

### 3. Managing anemia early and in the right way

Be alert for the symptoms of anemia and report them to your physician or clinic if they appear.

Keep all appointments for blood work so that anemia can be treated before it becomes serious.

If the Hgb falls very low, the physician may recommend a blood transfusion. It replaces the red blood cells while the child's own bone marrow is unable to do so. (See section on Blood Transfusion in this chapter).

### 4. Getting professional help when appropriate

**Inform your doctor or, if in Vancouver, the Oncology Clinic during the day if:**

- your child is more than usually fatigued.
- you see any of the signs listed in #1.

**Call your local doctor or, if in Vancouver, the clinic/oncologist on call immediately if your child:**

- is unusually sleepy and difficult to wake.
- is very dizzy and/or falls a lot.
- has skin that seems pale or bluish around the mouth and nails.
- seems breathless.

When you call, state your child's name, age, and diagnosis. Be ready with this information:

1. When was the last "incident"; e.g. dizzy spell that you are reporting?
2. How long did it last?
3. Have you noticed any other signs like being more tired, confused than usual?
4. When were the last counts done? What were they?
5. When was the last chemo treatment - what drugs were given?
6. Is your child getting radiation?
7. Has this happened before?
8. What did the doctor do then?

**Call the ambulance (911) to take your child to the Emergency Department if:**

- she loses consciousness or you are unable to wake her up.
- she is not breathing properly and is not able to get enough air, or stops breathing.

## 5. Responding to special risks and problems

### Fatigue

Children being treated for cancer feel tired and listless for many reasons. They feel sick and low. They may be anemic from the treatments. They may be depressed, anxious and scared. They may not be getting enough sleep.

Here are some ideas for managing fatigue.

- Plan the day so that visitors or outings happen when the child feels best and can get the most out of them.
- Build quiet, restful times into the day so that the time is not blank but does not require the child to act or respond. For example, have a time when you read another chapter in a book or listen to soothing lullabies.
- Keep outings or activities short or make sure there is a good place for a rest break. Sitting on a bench in a mall will not be a rest break. It is not just moving about that makes us tired. Things happening all around with noise and bright lights can be very tiring. Going to a playground in the park and then being able to move away from the play and lie on a blanket on the grass will work.
- Leave enough time for dressing and getting ready for going out so that there is no rush. Rushing will use too much energy. It is good to be able to rest after a bath, for example, before one has to dress.

- Do some things like shampoo or bathe in the evening so that bedtime happens soon after.
- Don't pack too much into a day. Suggest to your child that you choose the 3 most important things for the day and do those first so that if the energy runs out the rest of the things can be left.
- Plan some exercise for each day – even a short walk or some balls through a hoop. This can actually restore some energy.
- Keep a reasonable bedtime- enough sleep is essential. Keeping to regular bedtime and nap time routines make sleep easier.

Research shows that, along with anemia, lack of sleep and disrupted sleep are the most important causes of fatigue.

## Allergic reaction

An allergic reaction is the response of the immune system to something which it interprets as harmful to the body. Allergic reactions may occur when a drug or blood transfusion is given. They may occur immediately or after several hours. They may be mild or serious.

Caring for a child at risk for an allergic reaction means:

1. Knowing what signs to watch for
2. Preventing the reaction
3. Managing the reaction early and in the right way
4. Getting professional help when appropriate

### 1. Knowing what signs to watch for

- Rash such as hives.
- Itching.
- Difficulty breathing.
- Swelling in some part of the body.
- Fever and chills.

### 2. Preventing allergic reactions

We may not know when a child will have an allergic reaction. After the first allergic reaction, we can make some changes. For example, if we can avoid giving the drug, we will. If we know that your child reacts to a platelet transfusion, we will give an antihistamine, such as benadryl, or a steroid, such as hydrocortisone, before the transfusion.

### 3. Managing allergic reactions early and in the right way

Allergic reactions are usually treated with antihistamines and something to manage the symptom. So, if your child has difficulty breathing, he may receive oxygen until the reaction subsides. If the problem is a rash and itching, something can be offered to relieve the itch.

#### **4. Getting professional help when appropriate**

**Inform your doctor or, if in Vancouver, the Oncology Clinic during the day if your child has:**

- itching
- swelling in a part of the body other than the mouth and throat.

**Call your local doctor or, in Vancouver, the clinic/oncologist on call immediately if your child:**

- seems breathless
- has swelling around the mouth or throat
- has problems swallowing
- has hives or a rash
- has fever with chills.

When you call, state your child's name, age, and diagnosis. Be ready with this information.

1. When did you see the first signs of the reaction?
2. Have you noticed any other signs?
3. What drugs did he take today?
4. Did he have a blood transfusion today?
5. Has this happened before?
6. What did the doctor do then?

**Call the ambulance (911) to take your child to the Emergency Department if:**

- he loses consciousness or you are unable to wake him up.
- he is not breathing properly and is not able to get enough air, or stops breathing.
- he has swelling around the mouth or throat.

# Blood transfusion - a supportive therapy

(adapted from the C&W pamphlet)

## What is a transfusion?

A transfusion is a treatment that adds whole blood or parts of blood (called blood products) to your child's blood system. These products come from people who give blood (volunteer donors).

## What blood products are transfused?

### Whole blood

Whole blood, i.e. blood containing all its components, is only given to replace blood loss from massive bleeding (hemorrhage) or surgical procedures. This type of transfusion is seldom necessary for children.

In other situations, only the parts of the blood which the child needs are transfused. These may be:

### Packed red cells (Packed RBC, PRBC)

PRBC's are the most frequent types of transfusions. Given to correct anemia. One unit of PRBCs (250 cc or 1 cup) is given over approximately 2-4 hours. It takes longer for smaller children.

**Note on blood typing:** Red blood cells contain factors which are not the same in all people.

There are 4 different types of blood: A, B, AB, and O. Transfused blood must be matched to the child's type. Other factors, such as positive or negative Rh factor, also are important in the matching process. Inadequately matched red blood cells can cause a severe reaction.

Therefore, a crossmatch is done, before any transfusion, to be sure that your child receives blood matched to her system. The crossmatch is done with a sample drawn from your child. This sample can be used for 2 days. If another transfusion is required later, we must draw another blood sample.

### Frozen plasma (FP)

The liquid portion of blood, plasma, contains certain "factors" which help blood clot. We give FP when there has been major blood or fluid loss, or if the child needs clotting factors. It is transfused in an hour.

### Platelets

Platelets are given to prevent bleeding or decrease the risk of bleeding. Platelets are packaged in units. The child's size, platelet count and need determines the amount given. Transfusion of platelets usually takes 1-2 hours depending on how many units are ordered.

## Why is transfusion necessary?

A body must have the right amount of each blood part to be healthy. An injury, disease, surgery or cancer treatment can cause the loss of so much blood that the body cannot keep all its organs working. A transfusion puts back some of the blood or blood product it needs.

## Where does donor blood come from?

Canadian Blood Services collects and tests blood from volunteer donors. Blood donors are asked many questions about their lifestyle and medical history. Blood is not taken from anyone who may have an illness of any kind.

All blood is tested for several different infections. Blood that is infected is thrown away. **No more blood is collected from that donor.**

The blood, which the tests show to be disease free, is separated into parts called blood products. These are sent to the hospital laboratory where they are stored.

## Is transfusion safe?

No one can guarantee that any treatment is 100% safe. Every treatment has risks, some more than others. Blood products and transfusions are, however, safer today than they have been because the screening tests are improving all the time.

Going without a needed treatment also has risks.

**Your doctor will only advise you to have a transfusion if it is absolutely necessary.**

## What are the risks of transfusions?

### The risk of infection

Although the risk is very small, some diseases can still be passed on to your child by blood transfusion. This happens when the test does not "see" the infection. A donor may carry a virus and not feel sick at the time she gives blood.

The infections that cause the most concerns are Hepatitis B, Hepatitis C, Human T-Cell Lymphotropic Virus (HTLV), and Human Immunodeficiency Virus (HIV).

The risk\* of getting one of these infections after transfusion is:

Hepatitis B	1 per 63,000 - 200,000
Hepatitis C	1 per 250,000 - 500,000
HTLV	1 per 641,000
HIV (Aids virus)	1 per 913,000

\*This is the risk per unit of blood transfused.

*Note:* The more units of blood a person receives, the greater the risk. A transfusion of 10 units increases the risk 10 times.

Blood may also carry new and unknown viruses such as new types of Hepatitis and other agents for which we cannot test.

## Transfusion reactions

There may be other complications which are not life threatening. Your child may:

- feel hot or cold or develop a **fever**. This happens more often in those who have had many transfusions.
- have an **allergic reaction** and feel itchy or have hives or wheezing.
- have a serious reaction called a **hemolytic reaction**. Each transfusion your child has carries more risk of this type of reaction than the one before. This is because the blood your child receives never exactly matches his own. His body may produce antibodies that fight against the "foreign" blood. The more transfusions your child has, the more chance he has of developing antibodies that can destroy the red blood cells. But the risk remains small.

## Other complications

A very rare condition called **Transfusion Associated Graft Versus Host Disease** can occur after large doses of cancer therapy or after a bone marrow transplant. This is a severe condition that can cause death. We prevent this problem by giving specially treated products.

**Please tell your nurse if you see any changes during or after your child's transfusion. You should let your doctor know if your child has had a reaction from a blood transfusion in the past. We can take steps to prevent this from happening again.**

## Can your child donate his own blood? (autologous blood donation)

Children who are being treated for cancer do not have blood healthy enough to donate.

## Can your friends or your family donate for your child?

Family members sometimes ask if they can donate blood. This is called a **Directed Donation**. Directed donations can only be given by parents for their child who has a high risk of needing a red cell transfusion.

In certain situations, Canadian Blood Services will collect blood from parents for their child. They will not collect blood from other family members or from friends. Our hospital is willing to transfuse this blood if it meets the Canadian Blood Services standards and tests for regular blood donors. The process for directed donation can take up to two weeks.

*Note:* Even if directed donor blood is collected, you may still need a blood product, which cannot come from the directed blood, eg. albumin. Children with cancer may need more blood than parents can donate.

There is evidence that a directed donation may be less safe.

- Directed donors, who are often first time blood donors, are more likely to carry viruses than regular, frequently tested, Canadian Blood Services donors. This is because frequent donors have been found to be virus free many times.
- Children who receive a transfusion from a family member have a much greater risk of developing Graft Versus Host Disease (GVHD) - *see earlier section*. To prevent this problem, the parent's blood must be specially treated.

## **Do you need to give consent before receiving blood and/or blood products?**

Your doctor will ask you to sign a consent form after you have discussed information about blood transfusion and you have had your questions answered.

If you refuse a transfusion of blood and/or blood products, you must sign a Refusal to Consent form.

## **What happens when your child needs a transfusion?**

We take a blood sample from your child and send it to the C&W Transfusion Medicine Laboratory. They test it and match it to donor blood to make sure that the blood your child receives is compatible. The donor blood is then labelled with your child's name.

The blood (or blood product) is given to your child through a needle into a vein, usually in his arm or a central line. During the transfusion, a nurse will take your child's temperature, blood pressure and pulse.

# Effects on the digestive tract

## Changes in appetite or weight

### Major risk: Weight loss/gain, dehydration and poor nutrition

Weight loss, rapid weight gain, and poor nutrition are, for the most part, caused by the side effects of cancer treatment:

- loss of appetite
- increased appetite
- changes in the way foods taste

As well, there are other effects on the digestive system that make it hard to manage weight and nutrition. We will all do the best we can to help the child maintain a reasonable weight and take in enough nutrients to give the body what it needs to build and restore tissues. Nourishment is important for all children's growth and development, and even more important at this time. But, getting healthy children to eat a healthy diet can be difficult. It is very difficult if the child feels sick, sad or depressed, has pain, and lacks the energy to eat.

Caring for a child at risk for weight loss, rapid weight gain, poor nutrition means:

1. Knowing what signs to watch for
2. Preventing weight loss/gain, dehydration, and poor nutrition
3. Managing weight loss/gain, dehydration and poor nutrition early and in the right way
4. Getting professional help when appropriate

### 1. Knowing what signs to watch for

- Child complains that the food tastes "funny". Some drugs make food taste "tinny" or bitter or bad. She may also be put off by some food smells.
- Child turns against food that was once a favourite. If the child feels nausea after eating, the food itself becomes connected to the feeling. Suddenly, the child is "off" the very food you counted on him eating.
- Child will eat only very salty snack foods. These mask the bad taste. (This is common while on steroids).
- Child finds it hard to chew and swallow. The mouth is dry or saliva thick. This is a side effect that can, in turn, cause mouth sores.
- Child finds eating tiring. Gives up after a mouthful or two.
- Child will eat only one or two foods.

## 2. Preventing weight loss/gain, dehydration and poor nutrition

You can't really prevent the changes in appetite or taste. You can reduce their impact on weight and nutrition by managing them early and in the right way. What you can prevent is turning food and eating into a battleground. **Remind yourself that a parent's job is to provide healthy food choices and encourage eating. It is not your responsibility to make your child eat.** If you take on that responsibility, you will only increase everyone's stress.

Eating becomes tense if you:

- blame your child or yourself
- bribe or threaten
- don't get help when you need it
- let your anxiety get the better of you
- forget the difference between "can't" and "won't"
- make eating a control issue (parent pushes; child pushes back).

### Manage the feelings around eating

It is difficult not to become upset and focused on your child's poor eating. This happens to parents even when their child is well. It can take on enormous importance when the child is ill and the parents feel that this is something they can and should control. Try not to allow your concern about nutrition to make mealtimes anxious and tense times for the family. Just as important as the food, is the pleasant family feeling that comes when everyone sits down together to an attractively served meal. Don't single your sick child out by placing demands about eating on him. Encourage good nutrition in some of the ways suggested here. Don't push too hard; sometimes your child simply can't choke the food down.

Some practical tips

- Offer your child reasonable alternatives: *"Would you like cereal with milk or toast?"*, rather than *"what would you like?"*
- Respond to "I don't want any - take it away" with something like, *"OK, maybe you'll feel like something later"*.
- When your child only wants chips, try offering a small quantity of chips mixed in with some dry cereal or nuts. Or create "chip time" - a specific time of day when it's OK to eat a small amount.
- When you've been worn down and give in, don't beat yourself up.

If your child is on a steroid such as Prednisone or Decadron, he may:

- want more "junk" food and be hungry all the time. Be sure to have healthy snacks, like peeled fruit and vegetables, ready.
- crave salty foods and drink a lot. This may cause high blood pressure. Provide alternatives to pickles, chips, pretzels, processed meats and other salty foods. Ask the dietitian for a list of low salt choices.

Hunger and weight gain will stop when the steroid is stopped.

### Keep mealtimes and snacks flexible

- Offer small meals often during the day. Be flexible. Take advantage of any time your child is willing to eat. If your child won't eat even a small meal, keep snacks at hand to nibble on all day. (Remember, a child who is nibbling all day is less likely to eat a meal.)
- Try a snack at bedtime.
- Make mealtimes fun:
  - ~ picnic lunches on a blanket in the yard or on the floor
  - ~ teddy bear's picnic with real food
  - ~ an "unbirthday" party
  - ~ mealtime jokes or games
  - ~ try to have the family eat together
  - ~ invite special guests
  - ~ establish fun rituals around meals; eg. pancakes on Sunday

### Make the food appealing.

Appetite is very much affected by how food looks:

- put small portions on the plate
- change the size of the plate - sometimes a small serving on a large plate makes the meal seem manageable
- put a centrepiece on the table or a flower on the tray
- use pretty dishes that add to the appeal of the food
- decorate the food with grated carrot, slices of mushrooms, shredded spinach or lettuce. Use your imagination!
- serve the meal in a box/basket.

### Experiment to find the foods that taste good now

#### • Start with adding mild flavours.

- ~ a dash of Worcestershire sauce
- ~ a sprinkling of parsley
- ~ a little minced green onion
- ~ a dash of nutmeg or cinnamon
- ~ basil or lemon juice
- ~ garlic.

Try one at a time so that you learn what your child likes and what puts him off.

*\*Some children will actually eat **more** spicy food such as tacos or spicy sauces. If your child happens to enjoy spicy food, and nausea is not a problem, there is no reason why she should not eat as much as desired.*

- Use more sugar and salt if these are OK for your child. They may take away the metallic taste.
- Plastic utensils may take away the metallic taste.
- Drinking with meals may help if food tastes bad - mint tea and ginger ale are especially good. (Remember, fluids cause fullness.)
- Some children find that red meat tastes funny. Chicken, eggs, cheese are just as good. Try marinating meat in different marinades.
- Food may taste better at room temperature or cold.
- Be aware that the texture of food is as important as taste.

### **Make every calorie count**

- Butter, mild cheese sauce, or gravy can be added to almost anything your child will eat to add flavour and calories.
- Cook cereals with milk or cream rather than water and add brown sugar or honey
- Use whole milk or cream.
- Choose high fat yogurt/cottage cheese.
- Make custards, puddings, ice-creams, milkshakes or malts made with added whipping cream, "Carnation Instant Breakfast"<sup>(R)</sup>, "Boost"<sup>(R)</sup>, "Ensure"<sup>(R)</sup> or "Pediasure"<sup>(R)</sup> if your doctor approves. (The dietitian can help you decide which of the supplements is most appropriate for your child.)
- Make Jello with cream cheese or sour cream into which you have blended fruits or vegetables.
- Use whole milk or cream rather than water for canned soup.
- Add extra cheese to pizza.
- Spread peanut butter on fruit slices, crackers or waffles.
- Spread butter thickly on sandwiches.
- Avoid all diet products.

### **Vary the diet**

- It is tempting to give your child the same thing again and again once you have found something that she will eat. However, this becomes boring and your child will soon refuse this dish too.
- Experiment with different combinations on the plate. A little food at a time is a good rule. You can always supplement with nutritious snacks between meals.

### **Offer food that is easy to swallow (if swallowing is hard)**

- Cool, creamy drinks or desserts can provide a lot of protein and calories in the diet in an easy to swallow form.
- Cook chicken or meat until it is tender, shred and blend it. You can then add it to a cream soup or stir it into rice or noodles.
- Baked/broiled/steamed fish flakes easily and makes a good chowder or casserole.
- Cottage cheese or yogurt is a good standby. You can stir some pureed fruit into it.
- Foods like eggs or cream soups are easy to swallow.

#### **Tip:**

Activity and fresh air before a meal make one hungry.

### 3. Managing weight loss and poor nutrition early and in the right way

Sometimes your child's best efforts to eat are not going to provide enough nourishment. If that happens, the next step is to feed the child by some means other than by mouth.

The easiest way to do this is by **tube feeding** and the simplest tube to put in is the NG (nasogastric) tube. This tube goes through the nose and throat into the stomach or small intestine. It is a soft, thin, flexible tube that is not uncomfortable once the child is used to it. The tube can stay in for months.

Depending on your child's needs, liquid nutrition is given through the tube all day and night, or at specific times during the day or night. The doctor and dietitian will work out the best schedule for your child.

You should still encourage your child to eat and drink what he is able. Mealtimes with the family are an important part of social life. Once they are taking enough by mouth, the tube is easily removed. For information about how to care for the tube and feed your child, check with the nurse or dietitian.

When the digestive tract cannot handle the tube feeds, it is possible to move to **TPN (total parenteral nutrition)**. Fluid containing vitamins, minerals, protein, fat, carbohydrates, and other nutrients is pumped at a controlled rate through a central line into a vein. If this is advised for your child, you will be given more information.

#### A note about unconventional nutritional therapies

Special diets that claim to "cure cancer" are promoted by honest, well-meaning friends, as well as by dishonest people. It is hard to resist stories of miracle cures which come from a variety of diets low in one thing or high in another. If there were a diet shown to be an effective treatment, your doctor would know of it and use it. However, to date, no diets, other than a healthy balanced one, have been shown to make a difference to the course of cancer. If you would like to try a homeopathic diet treatment with your child's conventional treatment, please inform your oncologist. Discuss the diet with the dietitian so that you can be sure that it provides what your child needs.

#### 4. Getting professional help when appropriate

**Inform your doctor or, if in Vancouver, the Oncology Clinic during the day if:**

- your child looks thinner or heavier.
- your child has had little to eat or drink in the past \_\_\_\_\_ days/ hours. Ask your doctor, nurse or dietitian to fill this in and to advise you on how much is too "little". If nausea/vomiting or mouth sores keep your child from eating and drinking, see the following sections for tips on managing this.

**Call your local doctor or, if in Vancouver, the clinic/oncologist on call immediately if your child is becoming dehydrated.**

The signs of dehydration are (please have your doctor or nurse fill in the blanks with you):

- not able to take in and/or hold down \_\_\_\_\_ mls of fluid within \_\_\_\_\_ hrs, either by mouth or tube feeding
- dry skin
- not urinating for \_\_\_\_\_ hours

When you call, state your child's name, age, and diagnosis. Be ready with this information.

1. When was the last time your child had anything to eat or drink?
2. What did he drink or eat?
3. How much did he have?
4. Has he been nauseated/vomited or had diarrhea?
5. How often?
6. When was the last chemotherapy or radiation therapy?
7. When was the last time your child urinated? Had a bowel movement?
8. Is your child losing or gaining a lot of weight?

## Changes in the lining of the mouth and throat

### Major risk: Mouth/throat sores

Radiation to the head and neck area as well as some chemotherapeutic drugs may cause sores in the mouth or throat. This is because the tissues that line the mouth and the whole digestive tract are made up of the type of cells which divide and renew themselves quickly. These tissues are damaged by the same things that damage the cancer cells. (See section on "Chemotherapy" in Chapter 4 of this handbook).

Caring for a child at risk for mouth and throat sores means:

1. Knowing what signs to watch for
2. Preventing mouth sores
3. Managing mouth sores early and in the right way
4. Getting professional help when appropriate.

### 1. Knowing what signs to watch for

- The child refuses food and drink.
- Pain in the jaw or face when opening the mouth.
- Difficulty swallowing (the child may feel as if there is a lump in the throat) - this is because of swelling of the throat.
- Red, raw patches, sores, white spots or swelling inside the mouth.
- Complains that some foods burn.
- Bleeding from lips, gums or inside mouth.
- More or less, or thicker, saliva than usual.

These are usually at their worst 5-7 days after chemotherapy starts.

Mouth sores usually clear up when the neutrophil count rises, usually 1-2 weeks after the treatment has stopped.

### 2. Preventing mouth sores

#### Keep the mouth clean

- Brush teeth with soft toothbrush after every meal and before bedtime.
- Rinse with a mouthwash made from 1/4 teaspoon baking soda mixed into 1 cup of tap water about every 4 hours while awake (do not use commercial mouthwashes - they may irritate).
- Do not floss if ANC is less than 1.0 or platelet count is less than 50.
- Use Nystatin (a medicine that treats fungus infections) as prescribed by the doctor. Have your child swish it around his mouth and swallow. Use a swab for young children.

#### Keep lips moist

Use a lip balm. Apply it with your finger to avoid re-infections.

*Note:* Mouth sores may develop even with good mouthcare. But, a clean mouth reduces the risk of germs entering the bloodstream.

### 3. Managing mouth sores early and in the right way

#### Keep the mouth clean

- Clean the mouth and teeth gently every 2-3 hours during waking hours and before bedtime with a very soft toothbrush, Q-tips, or toothettes.
- Rinse the mouth with the homemade mouthwash or Chlorhexidine (your doctor will order this).
- Use Nystatin (a medicine that treats fungus infections) as prescribed by the doctor. Have your child swish it around his mouth and swallow. Use a swab for young children.

#### Avoid things that irritate the tissues

- Serve food and drinks cool or lukewarm. Hot food can burn. This refers to food that is hot in temperature as well as spicy hot.
- Avoid food that is acidic, such as citrus fruits and juices, tomato based sauces, and carbonated drinks like pop.
- Avoid irritating products like tobacco and alcohol.
- Avoid rough and hard to chew foods.

#### Manage the pain

- Apply an oral anesthetic, such as Viscous Xylocaine, Seattle mouth wash or Diclon spray, about 10 minutes before mealtimes or mouthcare. Paint the mouth with the anesthetic using a cotton swab or have the child "swish and spit". The anesthetic numbs the mouth, but makes it harder to control the food or saliva in the mouth. The anesthetic also affects the reflex that stops food going down the wrong way. Watch carefully to make sure your child doesn't choke.
- Sucking a hard candy or popsicle may be soothing. (Some children find that the cold aggravates the sore and hard candy scratches the mouth, so this does not work for everyone.)
- Give pain medication as prescribed by the doctor. Sometimes this means an admission for IV pain medication. See the section on Pain for more information about pain management.

#### Maintain the best nutrition possible

See the previous section on diet and nutrition.

#### Tip:

Offer bland, soft foods like hamburger mixed with bread crumbs and gravy before cooking, puddings, yogurt, creamy noodle dishes, ice cream and mild, soft cheeses.

#### **4. Getting professional help when appropriate**

**Inform your doctor or, if in Vancouver, the Oncology Clinic during the day if:**

- you can see any signs that mouth sores are developing.

**Call your local doctor or, if in Vancouver, the clinic/oncologist on call immediately if:**

- swallowing is so painful that your child cannot eat, drink or take medications.
- he has a fever of 38.5 orally or 38.0 under the arm or higher.
- he has bleeding.

When you call, state your child's name, age, and diagnosis. Be ready with this information.

1. When did the problem start?
2. Are there white patches in the mouth?
3. How much has your child had to eat/drink today?
4. Can you actually see sores?
5. What medicine is she taking for the mouth/throat? How often?
6. When was the last chemotherapy or radiation therapy? What drugs were given?

## Changes in the stomach

Major risks: Nausea/vomiting resulting in dehydration, electrolyte imbalance, poor nutrition

Nausea and vomiting is a complex side effect. It has both mind and body aspects. The radiation and drugs act on the cells in the digestive tract and also on the place in the brain that makes us feel nausea. As well, the nausea can become a "conditioned response" to the treatment. This means that the brain "learns" to connect the nausea to the treatment. Anything, even a thought that suggests the treatment, such as the sight of the treatment room, signals the brain to send the nausea messages.

Vomiting and nausea may not happen at all. But it is a common side effect of many chemotherapy drugs and radiation to the abdomen or brain. It may last for hours, days or, in a few cases, for weeks.

Caring for a child at risk for nausea/vomiting means:

1. Knowing what signs to watch for
2. Preventing nausea/vomiting
3. Managing nausea/vomiting early and in the right way
4. Getting professional help when appropriate

### 1. Knowing what signs to watch for

Review the side effects of all your child's drugs and treatments. Not all chemotherapy drugs cause nausea. Drugs such as some antibiotics may also cause nausea.

Nausea can start immediately or be delayed for up to 12 hours depending on the drug. Nausea sometimes occurs even before the chemotherapy. This is called "anticipatory" nausea/vomiting.

The most common time for nausea and vomiting is 2-6 hours after treatment. The pattern can be different for your child. When the vomiting has stopped it does not mean that the nausea has gone away. Vomiting stops within 48 hours for most children and nausea lasts about 72 hours.

Not all children are able to tell you about their nausea. They will give other signs such as: gagging, refusing fluids or foods, restless, irritable behaviour, more saliva or drooling than usual.

## 2. Preventing nausea and vomiting

If you know that nausea is a side effect of your child's treatment, it is worth taking steps to prevent it. This way you avoid the brain learning to connect treatment with nausea. Preventing the nausea is much better than managing the symptoms after they occur.

- Medicines to prevent and manage nausea are called "anti-emetics". For more information about anti-emetics, see chapter 6-7. Your doctor will prescribe these. Make sure you give them at the right times and in the right dose. This keeps enough anti-emetics in the blood at all times to help them work effectively. If you have any questions, check with the nurse.
- Some of the same relaxation and imaging techniques that are useful for pain management may be successful at preventing and controlling nausea. Practice these techniques before the first chemotherapy or radiation therapy, if possible. Use them during the treatment. Try different techniques. Preventing the anxiety that many children feel often helps prevent the nausea.
- "Sea-bands" are acupuncture devices worn on the wrist. They have a small button that puts pressure on a particular point on the wrist. This helps prevent nausea in some people. You can buy them in health food or drug stores.

## 3. Managing nausea and vomiting early and in the right way

### Plan snacks carefully

- Dry toast or crackers help some people.
- Offer small nutritious "mini-meals" or snacks many times during the day rather than the conventional 3 large meals a day.
- Cooking odours and food with a strong smell can bring on nausea. Try to keep your child away from kitchen smells. In hospital, remove the lid from the food tray before you bring the tray to the child. This allows the smell to escape with the steam. At home, try eating meals out of doors in warm weather. Hot food has more smell than food served cold or at room temperature.
- Encourage your child to sip as much as possible throughout the day. Clear soups, sports drinks, eg Gatorade, flat pop, tea, jello, sherbet, and non-citrus fruit juice are best after a bout of vomiting. Citrus fruit juices and milk drinks may upset the stomach. Sucking ice or popsicles will help get fluid into your child.
- Avoid fried, fatty, or spicy foods. When nauseous, many children find bland foods, like cereal, pretzels, toast, pasta, mashed potatoes and vegetables (green peas, beans or carrots), and easily digestible meat like chicken, more acceptable.
- After eating, have your child sit upright in a comfortable, relaxed position. He should not lie flat for at least 2 hours.
- Nausea may be better if the stomach is neither too full or empty.

- Allow your child time to recover after vomiting before trying another snack. Make sure she brushes her teeth, rinses her mouth and regains calm before you offer more food.
- Don't push your child to eat. Parents often try to tempt the child with a favourite food. The problem is that this food will not taste good during a bout of nausea. The end result may be that the child is turned off this food even when the nausea passes.
- Offer sour candies or chewing gum. These help cover up bad taste.
- Some people find it helpful to have something in the stomach just before treatment. Others do best on an empty stomach. Experiment to see what works best for your child.
- Dairy products may increase nausea.
- See previous section on "Changes in Appetite" for more ideas.

### **Provide comfort**

- After vomiting, rinse the mouth with club soda, mouth wash, or salt water (1 tsp of salt in a litre of water).
- Make sure your child is in loose, comfortable clothing.
- Once you learn the times when you can expect a bout of nausea, you can encourage your child to take a nap and try to sleep it through.
- Use relaxation and distraction at the first sign of nausea.
- Get as much fresh air as possible - open windows, sit out doors.
- Encourage deep breaths.

### **Give medications**

Your doctor can prescribe medications to relieve some of the feelings of nausea and control vomiting. Experiment with the timing of this medication. It may be most effective given before the treatment or half an hour before a meal or at some other time. Ask the nurse or pharmacist for some advice about this.

For more information on anti-emetics, their side effects, and how to give them to your child, see the section on Going Home, Chapter 6.

### **Keep track**

If your child is receiving treatment on an outpatient basis, keep a record of the course of this side effect. Note in the pages provided at the end of this section:

- when the nausea occurs
- when the vomiting happens, how long it lasts, and what it looks like (dark brown, bloody, undigested food, etc.)
- what helps the child recover
- what food and drink the child is able to keep down
- the amount of fluids taken in.

Make sure you share this information with the clinic staff.

#### 4. Getting professional help when appropriate

**Inform your doctor or, if in Vancouver, the Oncology Clinic during the day if:**

- the nausea/vomiting goes on for longer than \_\_\_\_\_ days
- you need support from a doctor or nurse.

**Call your local doctor or, if in Vancouver, the clinic/oncologist on call immediately if your child:**

- has blood or stuff that looks like coffee grounds in the vomit.
- vomits more than \_\_\_\_\_ mls in \_\_\_\_\_ hours.
- has projectile vomit - vomit shoots out of the mouth.
- vomits up the medicine for more than one dose.
- has bad pain in the stomach while vomiting.
- is unable to eat and keep down \_\_\_\_\_ mls of fluid or has other signs of dehydration (see notes in previous section about dehydration).

When you call, state your child's name, age, and diagnosis. Be ready with this information.

1. When did the nausea start?
2. How long does it last?
3. What have you done to manage the nausea?
4. What anti-emetic is he getting? How much?
5. When was the last dose of anti-emetic given?
6. How much/how many times has he vomited in the last \_\_\_\_\_ hours?
7. What does it look like?
8. How much has he had to eat or drink in the last \_\_\_\_\_ hours?
9. When was the last chemotherapy/radiation therapy treatment?
10. What chemotherapy did he receive?
11. Is he having diarrhea? How much?
12. Is he having pain? Where? How often?

## Changes in the bowels

Major risks:

Diarrhea, resulting in dehydration (loss of fluid from body tissues), and electrolyte imbalance (loss of essential minerals and salts).

Constipation, resulting in pain, bloating, vomiting, bowel obstruction, hemorrhoids or fissures (tears).

*Note:* Diarrhea and constipation can damage the sensitive lining of the bowel and around the anus. When blood counts are low, there is a greater risk for infection and bleeding in the damaged areas. See the sections on low white blood cells and low platelets for more information.

## Diarrhea

Infections, abdominal radiation, some chemotherapy drugs, and some antibiotics can cause loose and frequent stools. This happens because damage to the cells in the bowel makes the bowel "irritable".

Caring for a child at risk for diarrhea means:

1. Knowing what signs to watch for
2. Preventing diarrhea
3. Managing diarrhea early and in the right way
4. Getting professional help when appropriate

### 1. Knowing what signs to watch for

- Loose, watery stools
- Frequent and urgent bowel movements
- Cramping pain in the abdomen

### 2. Preventing diarrhea

You can't really prevent diarrhea. You can prevent the dehydration and loss of salts and minerals that may result by managing diarrhea in the right way.

- Learn what medications, treatments and conditions might cause diarrhea.
- Consult with the dietitian about what foods to avoid if diarrhea is an expected side effect.

*Note:* Some tube feeding formulas may cause diarrhea. Consult with the dietitian if your child has a problem. She may suggest a change in the feeding plan.

### 3. Managing diarrhea early and in the right way

Your main goal is to replace lost fluids, salt and minerals without irritating the bowel further.

#### Day 1

Don't give any formula, milk, or solid food unless your doctor advises otherwise. (Continue to breastfeed a baby).

Offer small amounts of any of the following clear fluids frequently:

- If your child is under 2 years: Pedialyte<sup>(R)</sup>/Lytren<sup>(R)</sup>/Gastrolyte<sup>(R)</sup> (buy these at the pharmacy)
- If your child is older than 2 years: same as above or Gatorade<sup>(R)</sup> or apple juice diluted as follows - 1 part juice to 3 parts water.

#### Tips:

- Wash the anus gently with mild soap and water after every stool.
- Check the area for signs of infection - redness, swelling, pain - often.
- Use a mild lotion/cream/petroleum jelly to protect the skin. Note areas of skin breakdown.

#### Day 2

If the diarrhea is decreasing, offer small amounts of soft foods such as apple sauce, mashed banana, rice cereal, crackers, arrowroot biscuits. You can begin to offer a baby his regular formula but start with half the usual strength diluted with water.

Continue to encourage as much drink as possible.

#### Day 3

If the diarrhea continues to decrease, start full strength formula or, for older children, gradually return to a normal diet including a little milk and milk products.

*Note:* Do not give antidiarrheal drugs such as Kaopectate<sup>(R)</sup>, Kaocon<sup>(R)</sup>, Lomotil<sup>(R)</sup>, Imodium<sup>(R)</sup>, Diban<sup>(R)</sup>, Donnagel<sup>(R)</sup>, Mitrolan<sup>(R)</sup>, Pomalin<sup>(R)</sup>. These medications can cause problems in children under the age of 3 years. Older children are given these medications only with the advice of a physician. It is advisable not to give any nonprescription medications without checking with your doctor.

#### Tips:

- Do not give plain water as it does not contain enough minerals.
- Do not give grape, prune or full strength apple juice as this increases the diarrhea.
- Do not add sugar or salt to the fluids you give your child.
- Give small amounts at a time so as not to overburden the bowel.
- Potassium is vital to the body and is lost in loose stools. Peaches, apricots, bananas and potatoes are good food sources. Offer these.

#### 4. Getting professional help when appropriate

**Inform your doctor or, if in Vancouver, the Oncology Clinic during the day if:**

- your child's diarrhea is not decreasing after 24 hours on clear fluids (if your child has renal problems or is on the chemotherapy drug Cisplatin<sup>(R)</sup>, call the doctor if diarrhea continues for more than 6 hours.).
- your child has a stomach ache for more than 2 hours.
- your child is very irritable and very drowsy.
- your child's lips, tongue or mouth lining is very dry.
- the diarrhea does not clear up completely in 5 days.

**Call your local doctor or, if in Vancouver, the clinic/oncologist on call immediately if your child:**

- has bloody stools.
- is vomiting, has diarrhea and is not taking fluids.
- does not urinate or have a wet diaper in 8 hours.
- is so drowsy that she does not respond to you.

When you call, state your child's name, age, and diagnosis. Be ready with this information.

1. When did the diarrhea start?
2. How many stools has she had since it started? Within the past 12 hours? How much stool?
3. What does the stool look like? e.g. dark, blood, watery
4. Is she having stomach cramps or pain?
5. Is she vomiting or having nausea?
6. Is there fever? Signs of infection?
7. How much has she had to eat/drink? Is she on tube feedings?
8. What medications is she taking?
9. Has she had chemotherapy or radiation therapy? When?

## Constipation

Some drugs affect the movements which push the stool through the bowel.

Caring for a child at risk for constipation means:

1. Knowing what signs to watch for
2. Preventing constipation
3. Managing constipation early and in the right way
4. Getting professional help when appropriate

### **1. Knowing what signs to watch for**

- change in normal bowel patterns
- bloated (distended) abdomen
- stomach ache
- change in eating habits and appetite
- hard stools
- stool or blood smears on underwear or sheets
- stomach cramps after eating.

Constipation may take a week or longer after treatment to become a problem.

### **2. Preventing constipation**

You can't always prevent constipation but you may be able to decrease its effects.

- Make sure your child is taking plenty of fluids.
- Keep your child as active as possible. Lack of exercise contributes to constipation.
- Establish a daily toilet routine and encourage your child to stick with this - same time each day.
- Learn what medications, treatments and conditions might cause constipation. Consult with the dietitian about what foods to avoid, or those that might help, if constipation is an expected side effect.

### **3. Managing constipation early and in the right way**

#### **Encourage fluids**

Fluids help relieve constipation - prune juice, water, apple and grape juice are all good. Offer fluids every 30 minutes. Popsicles and ice-chips are a good way to get fluids into your child.

#### **Encourage regular high fibre meals and snacks**

Unless your child is eating very little or a bowel obstruction is suspected, try gradually increasing the fibre content in the diet. You can do this by offering fresh or dried fruits, nuts, fresh vegetables and whole grain products, even popcorn. Bran is particularly good and is found in muffins, cereals and breads. You can also add a tablespoon or so to meat loaf.

Caution: Children under 4 years may choke on raw vegetables, popcorn, and nuts.

#### **Use laxatives only with the advice of your doctor**

Do not use laxatives, enemas or suppositories unless you have discussed this with your doctor. If your child develops diarrhea, stop the medication until the stools are solid again. If the diarrhea does not stop, inform your doctor.

**If your child is troubled with constipation while on tube feedings, consult the dietitian.**

#### **Tips to encourage drinking.**

- Buy many coloured straws - change the straw often.
- Use a straw with a crazy shape.
- Offer the drinks in different size glasses
  - ~ a small amount in a giant mug looks very small
  - ~ a very small glass seems manageable
- Have a drinking competition.
- Carry a water bottle with you.

#### **4. Getting professional help when appropriate**

**Inform your doctor or, if in Vancouver, the Oncology Clinic during the day if:**

- your child has not had a stool in \_\_\_\_\_ days.
- stools are hard and painful to pass.

**Call your local doctor or, if in Vancouver, the clinic/oncologist on call immediately if:**

- has severe stomach cramps.
- has bleeding around the anus or the outside of the stool.

When you call, state your child's name, age, and diagnosis. Be ready with this information.

1. What is your child's normal bowel pattern?
2. When was her last bowel movement?
3. What did it look like? eg. dark, bloody, hard?
4. Is she vomiting? Having nausea?
5. Does she have stomach cramps or pain?
6. What medications is she taking?
7. What has she had to eat/drink in the past 24 hours?
8. When was the last chemotherapy/ radiation therapy?

# Handle food safely

Cancer treatment lowers the body's resistance to disease. The way you handle food can do much to reduce the risk of illness from the bacteria and germs in food.

## Keep hands and nails clean

Handwashing is probably the single most important thing you can do.

- Wash with lots of soap and warm water often, but particularly before food preparation, or eating, after touching pets, sneezing, using the washroom, or changing diapers. If you are handling raw meat or fish, wash your hands again before moving on to the rest of the food preparation.
- Use a soft nailbrush to clean under nails where germs can collect.
- Remove rings before you wash your hands.
- Don't let your child accept unwrapped food from the hands of someone else.

## Buy food carefully

- Check the expiry date on foods. Don't serve anything out of date.
- Put meat and fish purchases into plastic bags so they do not leak onto other foods.
- Ground meats are more likely to contain lots of bacteria. Whenever possible, try to buy these somewhere that grinds the meat on the premises. The fresher the better.
- If you are not going right home from the grocery store, take a cooler in which to keep your meats, milk and eggs.
- Use only pasteurized milk and cheese. Farm milk is often unpasteurized.

## Store foods properly

- Keep meat and fish in containers so that they do not drip onto other food.
- Thaw frozen meat in the fridge or microwave rather than on the counter.
- Don't give your child the egg if the shell has had a crack.
- Keep food refrigerated. Discard open food after 2 days.
- Don't leave warm foods on the stove for longer than two hours. Refrigerate as soon as you can.

## Cook food all the way through

## Keep everything clean as you prepare food

- Anything that touches the food should be clean (hands, towels, utensils, cutting boards). Wash counters and utensils with an antibacterial dishwashing liquid.
- Use a different cutting board for meat, fish and poultry. Do not use a wood board.
- Wash a knife that has cut meat or fish before using on other food.
- Wash dishtowels and kitchen brushes and sponges daily. Use a little bleach in the water.
- Use a dishwasher rather than handwash if possible.
- Cook meat and fish all the way through (red meat is well done at 160°F).
- Cook stuffing separate rather than inside the bird's cavity. The juices from the poultry seep into the stuffing. The stuffing may not be sufficiently cooked to kill the bacteria.
- Never give your child food made with undercooked or raw egg, such as homemade mayonnaise, or unbaked cookie dough.
- Wash very well any fruits or vegetables that will be eaten raw. Discard the outer leaves of leafy vegetables.

### Tip:

Keep a solution of 2 tsps bleach in a litre of water in a spray bottle. Use this on boards that have had meat on them. Rinse thoroughly.

# Effects on hair and skin

## Hair loss

### Major risk: Baldness

Cancer treatments work because they damage fast growing body cells. Unfortunately, hair follicles are this kind of cell. Most hair loss is temporary. The hair begins to grow back even while therapy continues sometimes, and certainly by about 3 months after treatment ends. The hair which grows back may be of a different texture and/or colour.

Radiation for brain tumours or a very few types of chemotherapy cause permanent loss.

Caring for a child at risk for hair loss means:

1. Knowing what signs to watch for
2. Preventing hair loss
3. Managing hair loss early and in the right way
4. Getting professional help when appropriate

### 1. Knowing what signs to watch for

About 1-2 weeks after starting therapy, hair may start to come out in chunks or fall out when brushing or washing. Eyebrows, eye lashes and body hair may also fall out several weeks later.

### 2. Preventing hair loss:

You can't prevent hair loss. You can, however, take steps to lessen the emotional impact. Teens, in particular, often find this hard because body image and self esteem is so important at their stage of development. There are no easy solutions.

## Prepare your child for hair loss

- Don't make light of your child's distress. Accept and agree that the hair loss is as hard as anything else.
- Understand that your reaction and your child's is not silly. Hair loss often represents other losses. The feeling is a kind of grief.
- Don't assume she feels the same as you do about hair loss. Don't rush to buy wigs, hats, scarves, etc., without discussing how she would like to deal with it.
- Start to wear scarves tied in interesting styles yourself.
- Offer some gifts that decorate or comfort the body, e.g. funky hat, new lipstick/nail polish, body lotion, fun T-shirt.
- Your social worker can give you a list of places where you can buy wigs if your child would like to try this. Wearing a wig does not stop or slow the hair returning. You can buy wigs attached to hats. They look and feel good.
- Solutions like perming or colouring thinning hair can damage the hair and make it fall out more quickly; on the other hand, this is a good time for purple hair!
- Put up posters of glamorous people with bald heads.
- Your attitude to hair loss can foster courage or self pity. Respect your child's inner strength. Call on him to value his own character strengths. One way to do this is to open a discussion about why the "body beautiful" is so important.

Your social worker can give you more ideas about how to cope with hair loss.

### **3. Managing hair loss early and in the right way**

Losing hair can be messy and uncomfortable, especially when sleeping. Wearing a soft cloth cap can catch the hairs as they fall out.

If your child has long hair, cutting it into a shorter style often makes the transition to baldness less startling.

Some children want to get rid of their hair all at once by cutting or shaving it off.

### **4. Getting professional help when appropriate**

Hair loss is not a condition that is harmful to physical health. But, if your child becomes distressed and does not respond to the suggestions outlined here, discuss his concerns with your social worker.

## Skin changes

### Major risk: Skin breakdown

The radiation that passes through the skin damages some of the skin cells in the treatment area. Some drugs also affect the skin, especially chemotherapy and some antibiotics.

Caring for a child at risk for skin changes means:

1. Knowing what signs to watch for
2. Preventing skin breakdown
3. Managing skin breakdown early and in the right way
4. Getting professional help when appropriate

### 1. Knowing what signs to watch for

*Note:* Some of these apply only with radiation; others, e.g. acne, only with some chemotherapy drugs; and some apply to both.

- Rash.
- Gradual reddening of the skin in the treatment area.
- Hair loss on the skin.
- Little to no perspiration.
- Dryness, flaking and peeling.
- Sensitivity to sunlight.
- Itching.
- Acne.
- Pain and oozing or peeling blisters (this is very rare).
- Darkening of skin.

## 2. Preventing skin breakdown

### Clean the skin in the area, *gently*

- Don't use soap unless really necessary and then select a mild soap such as Ivory<sup>(R)</sup>, Neutrogena<sup>(R)</sup>, Baby soap, Dove<sup>(R)</sup> or Alpha Keri<sup>(R)</sup>. Rinse all soap from the skin.
- Use lukewarm water.
- Gently pat dry with a soft towel.

### Don't put medication, deodorant, perfume, cosmetics, or powders on the skin in affected areas

Some brands of cosmetics and toiletries are safe. Please check with the nurse or doctor in the Radiation Therapy Department/Clinic if your child is getting radiation therapy.

### Use a moisturizer on dry or flaking skin

Use the moisturizer often each day. We recommend:

- Cream/lotion containing Vitamin A & D or E
- Baby oil/cream/lotion
- Aquaphor lotion<sup>(R)</sup>
- Aloe vera<sup>(R)</sup> gel
- Sween<sup>(R)</sup> cream/pericare cream
- Hollister<sup>(R)</sup> skin conditioning cream.

*Note:* Don't use a cream lotion just before a radiation treatment.

If the skin is very itchy, ask the nurse for suggestions to control the itchiness. There are creams or sprays to reduce the itch.

### Relieve itching

- Keep nails short and clean.
- Bathe with cool water.
- Use oatmeal soap or one with oil.
- Add baking soda or Alpha Keri<sup>(R)</sup> oil to bathwater.
- Put cool (not icy) damp soft cloth over itchy areas.

### Be extra careful with the skin

- Do not rub, scratch or massage the skin in the affected area.
- Avoid wearing scratchy clothes like rough wool.
- Wash clothing that is worn against the skin, bath towels and bed sheets in specially mild detergents. Rinse very well. A double rinse in the washing machine helps get all detergent out.
- Wear loose clothing. Avoid tight, elastic or snug collars, cuffs, etc.
- Wear warm clothing outside to prevent irritation from the cold. Never put ice on the affected area.
- Direct cold, like ice packs, or heat, such as hot water bottles, heating pads, sun lamps or hot water, can damage the skin.
- Do not shave hair in the affected area.
- Do not use sticky bandages or tape on the skin. If your child needs a dressing, ask the nurse or doctor how to apply one without damaging the skin.

### Avoid direct sunlight

The skin in a radiation treatment area remains sensitive to direct sunlight **always**. Some chemo drugs make the skin more sensitive to sun. In general, the sun's rays increase cancer risk. Make sure your child is never exposed to the sun for long periods. Wear sunglasses and a hat. Keep skin covered with clothing or protect with a sunscreen with a SPF #15 or higher.

### 3. Managing skin breakdown early and in the right way

Any opening in the skin provides an opportunity for germs to infect the body. That is why prevention and, if necessary, early treatment is important.

- Check the skin for any signs of breakdown every day (see the section above, "Knowing what signs to watch for"). Teens can do this on their own. You can check young children at bathtime or when dressing her.
- Review the prevention strategies.
- You need professional help to decide on the best way to manage skin problems. Don't apply creams, lotions, medications or cover the skin with dressings, unless advised to do so by the doctor or nurse.
- Treat acne by keeping the skin clean and dry. Ask the doctor if there are special medications to treat acne safely.

### 4. Getting professional help when appropriate

**Inform your doctor or, if in Vancouver, the Oncology Clinic during the day if:**

You see any of the signs of skin breakdown listed #1.

When you call, state your child's name, age, and diagnosis. Be ready with this information.

1. What is the problem, where is the skin problem, and when did it start?
2. How long has your child had the problem?
3. What have you done to prevent or relieve it?
4. What medications is she taking?
5. Has she had radiation therapy? Chemotherapy? When? What drugs did she have?
6. Does she have a fever?
7. Do you see any bleeding, pus, or oozing?
8. Is there any pain? Itching?

#### Extravasation

One special type of skin breakdown is called **extravasation**. When some chemotherapy drugs are given into veins, they may leak around the needle. The drug seeps into and burns the surrounding tissues. Very severe burns can cause permanent damage. The damage must be repaired with skin grafts.

Watch for and report swelling, pain or redness around the needle site. If any of these appear after leaving the hospital, call your doctor immediately.

# Effects on the nervous system

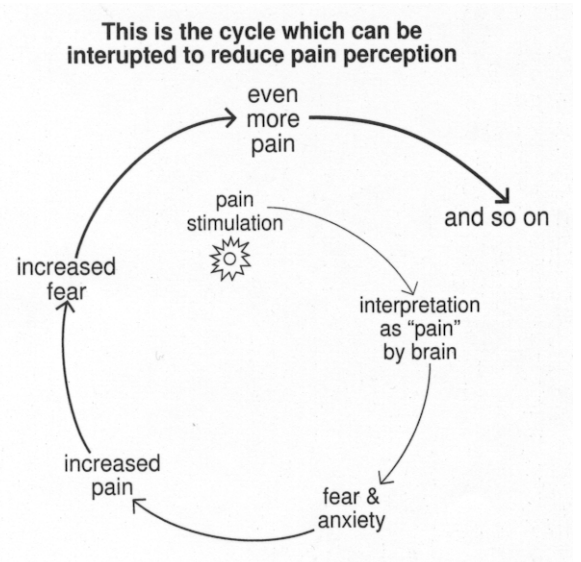
## Pain

Cancer cells don't, themselves, cause pain. Pain isn't always part of cancer or its treatment.

In children with cancer, pain can be from:

- The disease. Some tumours cause pressure when they expand in the body. Some press on nerves. Some cause damage to organs.
- The treatment. Side effects like mouth sores, sore muscles from vomiting, and the pain from surgery are sometimes part of treatment-related pain.
- Tests and procedures. Bone marrow aspirations, lumbar punctures, even finger pricks can be painful.

Almost every part of the body has nerve fibres which carry sensations to the spinal cord and from there to the brain. The brain interprets these signals as "pain", "cold", "prickly", etc. We experience pain only when the brain calls a sensation "pain". Often, it takes a while **after** you have injured yourself to feel the pain. Although the nerve signals reach the brain almost instantly, it takes time for the brain to decide that this is pain! Understanding that pain is always "all in the mind" is important. It helps us understand that pain is real, whether we can find a physical cause or not. We can change pain by interfering with the way the brain interprets sensation:



Caring for a child in pain means:

1. Knowing what signs to watch for
2. Preventing pain
3. Managing pain early and in the right way
4. Getting professional help when appropriate

## 1. Knowing what signs to watch for

There are individual differences in the way pain is experienced and expressed by children. Most of the time, a child's pain is obvious, especially when the cause is obvious. But, sometimes, neither the cause nor the pain is obvious. For example, a child with leukemia may be pain free for many months then become irritable, tired, and withdrawn. This mood change may signal pain but it could also signal quite a few other things.

As a parent, you will be familiar with many of your child's pain signals. You will also know whether your child is mild or intense in the way she expresses pain. For example, some children raise the roof whether their pain is mild or intense. Other children can be very stoic, even in the face of great pain.

Some helpful ways to figure out if your child is in pain:

- more irritable and restless, shifting position often
- tense, stiff and unwilling to be touched or to move
- unwilling to play or be social
- sleep more or sleep less
- more needy/clingy or more withdrawn
- crying, moaning or complaining, or not crying at all
- clutching a part of the body
- rocking.

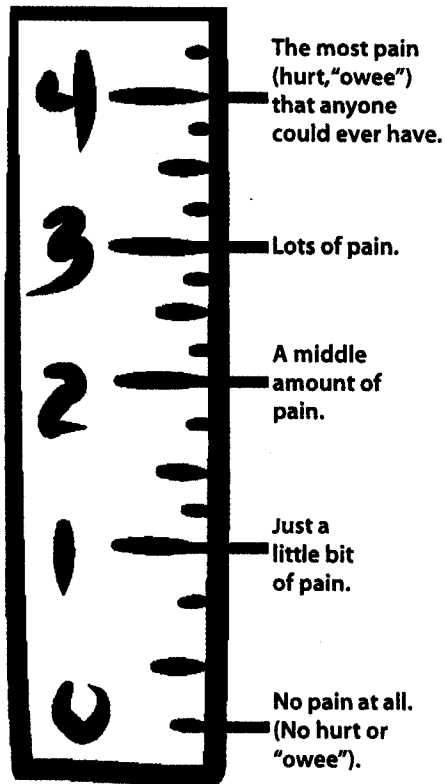
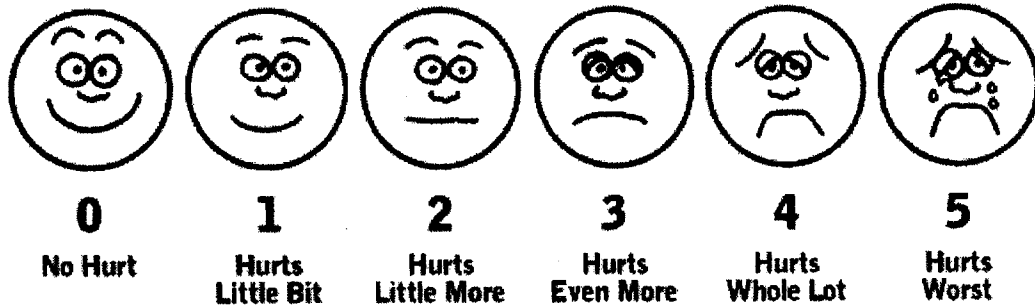
These signs are very general - they could be related to almost anything, from anxiety to getting up on the wrong side of the bed. If you see any of these or other signs, check with your child. Use your child's pain words.

*"Are you hurting or are you feeling sick?" or  
"Do you have an owie?" or  
"Do you feel sore or grumpy today?"*

Try to relate it to something that the child can describe.

*"Is this a screaming pain or a quiet pain?" or  
"Is it sharp like a knife or dull like a pinch?"  
"Is it creeping and crawling all over or is it  
staying in one place?"  
"Where is it? Can you show me on your body?  
Or on your teddy?"  
"Can you tell me how strong the pain is? If '1' is  
the easiest pain, and '5' [or 10] is the worse  
pain you can think of, what number is this  
pain?"*

Here are some examples of tools you can use to help measure pain. Check in one of the books about pain management in the Family Resource Library for more ideas.



## 2. Preventing the pain

Sometimes there is nothing you can do to prevent pain, for example, after an operation or during a painful procedure. You can, however, head off some of the factors that are often a part of the pain or make the pain worse.

### Reduce the fear and anxiety

Fear and anxiety take many forms. All make pain worse.

- Fear of the unknown - "what is causing the pain; what will they do because of the pain". Be careful of statements like "this pain is very strange" or "I don't know what we can do to make it better".
- Fear of the pain itself - "will the pain come again, get worse, never go away".
- Fear of losing control - "I can't handle this". Reassure your child that he will have support.
- Other people's fear - "I must be in danger if Mummy is so upset".

### Take the pain seriously and be sympathetic

Suggestions that the pain isn't real or serious makes pain worse. It is as if the brain offers more evidence of pain when we don't take pain seriously. But, it is a fine balance between offering sympathy and sharing the child's anxiety.

### Keep your child relaxed and comfortable

- Things like being tense, tired, thirsty, or spoken to crossly, make things worse.
- Make sure your child has enough sleep and rest periods.
- Offer drinks frequently.
- Learn and practice simple relaxation techniques like music, breathing exercises. (There are resources in the Family Resource Library.) See also ideas in "From bitter and sweet" at the end of this section.

### Keep your child distracted

Pain sensations that have no competition in the mind will be felt more intensely. Being left with no distraction from the pain, will make the pain sharp and clear. Many people do not understand this. They think the child is using the pain as an attention getter: "He's fine while someone is keeping him amused, but as soon as I try to leave him, he starts to cry about the pain - putting it on a bit thick!"

### Learn how to use a calm voice and manner to reassure

- Someone in pain panics easily. Your job as a parent is to help your child maintain calm. Your own calm can be transferred to your child.
- Control your voice. Speak in a slow, low voice.
- Slow and deepen your breathing.
- Relax your own body.
- Slow down your movements.
- Be aware of how your body shows tension and how it shows that you are calm.

### 3. Managing pain early and in the right way

It is important to manage pain. The idea that pain does no harm - it just tells us that something is wrong - is incorrect. There is clear evidence that pain slows healing and stresses the body. Pain causes muscle tension and disturbs sleep. A tired body is less able to handle the stresses of cancer treatment. There are ways to manage pain. These include **medications** and **mind-body strategies**. The care team will work with you to find the best combination for your child. This is called **the pain management plan**. At the end of this section, you will find a chart to help you keep track of the plan and how it is working. This is very useful if the plan needs to be changed.

#### Medications

Pain medications are often very effective ways to control pain. To get the best from them you need to use them correctly.

- Give enough - the right dose. **Less medication is not better**. In order for any medicine to work, there must be enough to create the desired effect. The effect we want is to keep the child pain free without making her too drowsy to enjoy company and play.

*Question:*

*What if the medicine is not controlling the pain? Can I give more?*

*Answer:*

*Don't change the dose without advice from a health professional who knows your child and the medicine.*

- Give it regularly - pain medications work best when there is a constant amount in the blood at all times. If you leave it too long before giving the next dose, the pain "breaks through". This means you need to give more medication to get the pain back under control.

*Question:*

*What if the pain comes back and it is not yet time for the next dose?*

*Answer:*

*If it is less than an hour to the next dose, give the dose and schedule the next doses from the time you give this one. If it is more than an hour to the next dose, call your doctor or nurse for advice. If this happens all the time, talk to the doctor about changing the schedule or dose.*

*Question:*

*What if I forget a dose?*

*Answer:*

*Give it as soon as you remember and schedule the next doses from the new time. **Never** double the dose to catch up.*

*Question:*

*What if the pain wakes my child during the night?*

*Answer:*

*Ask for an answer to this question when the pain plan is being discussed. In general, if this happens, the pain control plan will need to be reviewed. Right then, if it is less than an hour to the next dose, give the dose and schedule the next doses from the time you give this one.*

- Give the medication at the first sign of pain - pain builds. Catch it early. The less pain, the less medication needed to control it. The higher it builds, the more it will take to get on top of it.
- Give it in the right way. Some medications lose their "oomph" if crushed or diluted; others release slowly over time and should not be crushed or diluted. In our efforts to get the medicine down, we sometimes forget basics like this. If you are finding it hard to give the medicine in the right way, talk to the doctor or nurse. Medicine is available in a variety of forms; e.g. a skin patch or suppository may be easier than a pill.
- Give the right medication. Pain medications are very "clever" these days. They act as "specialists". One type may work better for one type of pain, while another "specializes" in a different type of pain. Some medicines are useful for mild pain and others for intense pain. Sometimes pain control needs a combination of different types. The aim of a pain plan is to find the right combination and dose and schedule for your child. This may require some trial and error. Also, what is best for this month may not work so well when the condition changes. The pain control plan is flexible.

*Question:*

*What happens when my child reaches the maximum dose of the strongest medicine?*

*Answer:*

*Some pain medications have no maximum dose. The dose that is a dangerous starting dose may be perfectly safe if the child reaches it after slow increases. The body can adapt to very high doses if the increase is gradual. (This does not apply to Tylenol.)*

## Some examples of pain medications

Drug	Forms	Possible side effects
<p><b>Acetaminophen</b> (Tylenol<sup>(R)</sup>) Used mostly for mild pain and in combination with stronger drugs.</p>	Pills, liquid, suppository	Masks fever High doses can damage the liver
<p><b>Non steroidal anti-inflammatory</b> Ibuprofen (Advil<sup>(R)</sup>, Motrin<sup>(R)</sup>) Naproxen (Naprosyn<sup>(R)</sup>) Used to decrease pain caused by inflammation, bone pain, and in combination with stronger drugs.</p>	Pills, liquid, suppository	Blood clots less well Stomach irritation High doses over a long period can damage the kidneys
<p><b>Mild opioids</b> Codeine Used for all types of pain not well controlled by acetaminophen or non steroidal anti-inflammatory</p> <p><b>Strong opioids</b> Morphine Hydromorphone (Dilaudad<sup>(R)</sup>) Fentanyl Used for moderate to severe pain not well controlled by any of the above.</p>	<p>Pills, liquid, suppository, injection into the muscle</p> <p>Pills, capsules, liquid, suppository, IV, injection into the muscle or tissue under the skin</p> <p>Skin patch (Fentanyl)</p>	Constipation Drowsiness Nausea/vomiting Itching Slower breathing Confusion Problem urinating
<p><b>Other types</b> <b>Anti-depressants or anti-convulsants</b> are known to be effective for controlling nerve pain</p>	Pills, suppository, IV	Drowsiness Nausea/vomiting
<p><b>Topical (on the skin)</b> EMLA cream<sup>(R)</sup></p>	Cream	Loss of sensation White patch or redness of skin Allergic reactions

Pain medication takes time to work:

By mouth: about 20 - 30 minutes

By IV: about 5 - 10 minutes

## Mind-body strategies

Help your child manage pain. Use mind-body strategies to interrupt or distract the mind from its pain sensation. This breaks the cycle of distress - tension - pain. Try:

- even, deep breathing which blows air - and hurt - out slowly
- relaxation exercises
- distraction (play, blowing bubbles, music, storybooks)
- providing competing sensations (back or feet rubs, warmth, ice/heat, massage, patting)
- using fantasy and create images in the mind which help tune out the pain.

Psychologists on the team may be able to offer more suggestions on how to manage pain. Ask your doctor for a referral.

If your child must have several long, painful treatments, or the pain is constant, you can help your child learn how to use stories, fantasy, "imagining", or self-hypnosis to take the mind away from the pain. One such technique is described in Chapter 2. There are many variations on these pain management strategies. It is important to find one that "fits" your child's needs and personal style. Moreover, these techniques need to be planned, learned and practised. Learn more about them by watching the video *No Fears, No Tears*, or reading the book, *A Child in Pain*, by Dr. Leora Kuttner. An audiotope from the "Touch the sky" package might be a useful tool as well as other tapes in the Family Resource Library.

Here are some ideas for helping your child:

### Newborn to 1 year

#### **What you can do for your child:**

Rapid rocking or patting works because the body sensations compete against the pain.

#### **What you can help your child do for herself:**

Sucking is the baby's way of creating a competing sensation.

### 1 - 5 years

#### **What you can do for your child:**

Physical sensations like stroking, massaging, rocking, as well as comfort measures, like changes of position, fluffing pillows, warm pads or cold compresses, work well. These measures work for only short periods. The key is to do these things often. They are not only ways of showing your care, but also do relieve the hurt for short periods.

#### **What you can help your child do for herself:**

Bubble blowing, pop-up books, and other distraction play.

## 6 - 11 years

### **What you can do for your child:**

Physical sensations like stroking, massaging, rocking, as well as comfort measures, like changes of position, fluffing pillows, warm pads or cold compresses, work well. These measures work for only short periods. The key is to do these things often. They are not only ways of showing your care, but also do relieve the hurt for short periods.

### **What you can help your child do for herself:**

Bubble blowing, pop-up books, and other distraction play. School-age children can learn simple relaxation like trying to be "as floppy as a Raggedy Ann doll", or "as limp as a cooked spaghetti", or breathing in and blowing out slowly. Plan these and practice them at times when the child is pain free.

## Adolescents 11 years and up

### **What you can do for your child:**

Physical sensations like massaging, as well as comfort measures, like changes of positions, fluffing pillows, applying warm pads or cold compresses, work because the body sensations created compete against the pain. These measures work for only short periods. The key is to do these things often. They are not only ways of showing your care and concern, but also do relieve the hurt for short periods.

### **What you can help your child do for him/herself:**

Progressive relaxation or breathing in and blowing out slowly can be helpful for reducing stress and breaking in to the vicious pain cycle. A videotape called *The Relaxation Tape* teaches and guides through 4 different relaxation techniques. Distraction techniques are useful for short term pain. Music on a personal stereo is an effective distractor for this age group. An audiotape as well as a videotape to help someone into a state of relaxation is available in the Family Resource Library.

#### **4. Getting professional help when appropriate**

Pain is often worse during the night. One is reluctant to call and awaken people during the night. Therefore, we encourage you to call sooner rather than later about pain. However, if your child is having pain, do not hesitate to call.

##### **Inform your doctor or, if in Vancouver, the Oncology Clinic during the day if:**

- your child continues to be uncomfortable and cranky.
- your child cannot eat, sleep or carry on with daily activities due to the pain.
- your child is afraid to move because he is afraid of the pain.
- you feel that the pain could be better controlled.
- side effects of the pain medicine are becoming a problem.

##### **Call your local doctor or, if in Vancouver, the clinic/oncologist on call immediately if:**

- there is sudden, severe pain anywhere in the body.
- your child has been crying for a long time and is inconsolable.
- you have been following the pain management plan and all your efforts to relieve pain are not working.

When you call, state your child's name, age, and diagnosis. Be ready with this information.

1. How long has your child had the pain?
2. Where is the pain?
3. Can your child describe the pain, e.g.: burning, tingling, sharp, stabbing, etc?
4. Has he ever had this pain before? When?
5. What is your pain plan? What have you tried and how has it worked?
6. When and what was the last medication you gave?
7. Does he have any side effects from the medication?

## My child's pain management plan

- **My child's pain signals:**

Cries:

Behaviours:

Body language:

Words:

- **Where the pain is:**

- **How intense the pain is:**

Tools your child uses to measure the pain:

How often I should measure the pain:

- **What makes the pain worse:**

- **What makes the pain better:**

- **What I can do when my child is in pain:**

Mind-body strategies:

Medications - how and when to give them:

Medication	Dose	How often	How fast it works

- **Who I can call when I need help managing my child's pain:**

# Changes in hormone chemistry

## Major risk: Mood and behaviour changes

There are many obvious reasons why children who are ill with cancer may have less self-control and be more irritable, angry and depressed. But the moodiness that comes from the steroids (eg. Prednisone) is different in its feel and impact.

Steroids have an affect on the body's hormones and are likely to cause mood and behaviour problems over which the child has little or no control. The experience is disturbing for the child and everyone who cares about her. Parents often describe children on prednisone as being "out of control".

Fortunately, children regain their self-control very soon after coming off the drug.

Caring for a child with mood and behaviour changes means:

1. Knowing what signs to watch for
2. Preventing mood and behaviour changes
3. Managing mood and behaviour changes early and in the right way
4. Getting professional help when appropriate

### 1. Knowing what signs to watch for

- Changes in the child's usual way of coping.
- Extremely irritable one minute and calm the next.
- Mood and behaviour changes suddenly for no reason.
- Extreme reactions to people and situations that would normally not cause stress or distress.
- Cannot be consoled or comforted.
- Becomes unreasonable.

### 2. Preventing mood and behaviour changes

We can't prevent these changes, but we can be prepared to manage them.

### 3. Managing mood and behaviour changes early and in the right way

#### Manage your responses

Managing mood and behaviour changes is really managing your own response. How you respond can make things better or worse. Nothing you do will change the fact that the child's hormones are controlling mood and behaviour. When you say "my child is not herself", recognize that this really is the case. This is the time when you put in place your "don't panic" strategies. If you cannot remain calm and steady, you cannot expect this from a child.

Act rather than react.

- Instead of **arguing** (the child is beyond reason), state the limits as a fact.
- Instead of **yelling** (this increases the emotions), force your voice lower or stay silent.
- Instead of **pleading** (too much power may scare the child), take the whine out of your voice, say what you expect and offer a reward.
- Instead of **demanding an end to the behaviour** (this increases anger and frustration), take the anger out of your voice, say what you expect and use one of the strategies below.
- Instead of **giving in** (this removes all boundaries and limits), take the helplessness out of your voice. This is scary for your child. Confidently maintain your normal limits.
- Instead of **lecturing** (falls on deaf ears), just act.
- Instead of **punishing** (sets you up as the enemy rather than the support), kindly but firmly take over control as explained on the next page.
- Instead of **shaming** (lowers self-esteem), be on your child's side. Explain how you will help your child maintain self-respect through this bad experience.

#### Tip:

At the moment when you feel ready to fall into the "reaction", imagine you are talking to your employer or a new friend.

## Manage your child's responses

The less self-control your child has, the more you have to take over providing control. Here are some examples.

- If your child is thrashing and hitting out at others, gently but firmly hold him and say, *"It's okay. I'm going to help you remember not to hit."*
- If your child is screaming, sometimes it is best to find a quiet place where you and your child can be alone. Stay calm and still; say nothing. If the screaming doesn't stop, tell the child, *"Your screaming is hurting my ears. I'm going to go out of here for a little while"*. Younger children may only respond to gentle holding, rocking or patting.
- If your child is rude and abusive, let him know that this behaviour is not acceptable. You can help him say it differently: *"That came out wrong. It's not OK to say that. I'll help you say it right"*.
- Limit choices. Children can feel overwhelmed at the best of times with too many choices. Keep the choices simple and clear.

## Protect your child from situations in which you know he becomes overwhelmed

- These may be supermarkets, malls, play groups. Try to avoid these until your child is off steroids. This is a good chance for others to help you out by minding your child while you go shopping.
- There may be times when you cannot avoid these situations, such as visiting the clinic or doctor.
- Here is a 6 step plan that both you and your child can follow.
  1. Before you set off, remind your child that this kind of outing is sometimes hard for both of you.
  2. Explain why it is important for him to behave well.
  3. State what "good behaviour" looks like in this situation.
  4. Provide some coping tools.
  5. Offer a reward for managing well.
  6. Say how you will act if things don't go well.

Here is how this might play out for a visit to the clinic:

*"The last few times we have gone to the clinic, it has been really hard. Let's make a plan together to help both of us feel proud, not bad, at the end. It is important for you not to yell, swear or hit because it upsets many, many people; it makes everything take longer. Why don't we take your Game Boy (anything else?) and pack a nice snack so that you aren't bored or hungry. When we come home, we'll both feel so much happier. We can rent a movie and have some popcorn. If you start to yell or hit, I will sit with you in a treatment room until you are calm. That means I will not feel like renting a movie or making popcorn. I will be too tired"*.

### Don't use shame or guilt

- Make it clear to your child that you understand that it is hard for him to control behaviours. Be matter of fact about the fact that you are helping with control. During this tough time, you are going to help him to control himself. Don't blame the child for behaviour that is out of his control.

#### **Tip**

Inform the team of the control strategies that work best for your child.

## 4. Getting professional help when appropriate

The strategies we have suggested may not work as you would like them to. Your child may continue to be "out of control". Even so, we suggest that these are the best ways to manage over this "Prednisone period". The social worker that is working with you and your family is a good resource to help you and your child through this rough time. Other resource people on the team who can help you are: the nurses, the child life specialist, the chaplain, and the psychologist.

# Late effects of cancer treatment

By "late effects" we mean the permanent damage done by the cancer and/or its treatment. We are unable to predict who will develop late effects. We do know that these are important factors:

- where the tumour is and how far it has spread
- the kind of therapy and how much is required
- the child's age and stage of development at the time of diagnosis and treatment (some organs develop more rapidly at stages; eg. puberty, and are more sensitive at this stage.)
- a genetic tendency makes the risks greater for some.

Being put between a rock and a hard place - choosing to offer aggressive treatment knowing that it may cause further damage - is a tough place to be.

Late effects only occur in survivors.

- Remember, though, **serious** late effects occur in a small number of survivors. These effects are NOT inevitable.
- We can now identify what parts of the body are most sensitive and take steps to limit the damage.

Late effects is one of the reasons why it is so important to keep all of your follow-up visits.

## Organ: Heart

### Most likely cause

**Chemotherapy:** doxorubicin, epirubicin, daunorubicin, idarubicin and mitoxantrone, particularly doses over 400 mg/m<sup>2</sup>; risk is increased when combined with cyclophosphamide or chest radiation therapy.

**Radiation therapy:** chest (above a certain dose at a young age).

### Late effect

- cardiomyopathy (damage to the heart muscle) leading to congestive heart failure
- inflammation of the heart muscle or membranes
- heart valve disease
- atherosclerosis.

### What can be done

#### During active therapy:

- the oncologist may decide to limit doses of mentioned chemotherapy
- regular echocardiograms during treatment
- lowered doses of radiation therapy.

#### After active therapy:

- monitor heart function with EKG's, echocardiograms, and chest x-rays every 2-5 years and when pregnant
- watch for symptoms: breathlessness, fatigue, odd heart beats, enlarged liver
- take prescribed heart medications.

## Organ: Lungs

### Most likely cause

**Chemotherapy:** bleomycin, nitrosurea, high dose methotrexate, busulfan

**Radiation therapy:** chest

### Late effect

- scarring
- breathing difficulties
- inflammation
- in young children, underdeveloped lungs.

### What can be done

#### During active therapy:

- dose reduction of mentioned chemotherapy
- watch lung function.

#### After active therapy:

- close monitoring of lung function
- discourage smoking
- encourage exercise.

## Organ: Reproductive-sexual

### Most likely cause

**Chemotherapy:** cyclophosphamide, procarbazine, nitrogen mustard, carmustine, lomustine

**Radiation therapy:** craniospinal, ovaries, testes, pelvis

**Surgery:** bladder, prostate, uterus, ovaries, testicles

### Late effect

Girls:

- infertility (not sexual dysfunction)
- early menopause
- delayed or arrested puberty.

Boys:

- sexual dysfunction after prostate or pelvic lymph node surgery
- infertility (not sexual dysfunction)
- low testosterone production
- low sperm count
- delayed or arrested puberty.

### What can be done

#### During active therapy:

- sperm banking (only after puberty).

#### After active therapy:

- hormone replacement therapy.

## Organ: Bones and muscles

### Most likely cause

**Chemotherapy:** prednisone

**Radiation therapy:** depends on area treated - high doses to children under age 6 years or during growth spurts, such as puberty, increase the risk of severe effects.

**Surgery:** amputation; limb salvage

### Late effect

- reduced or uneven bone growth
- scoliosis (spine curves)
- short stature
- uneven limbs
- back pain
- weak bones leading to fractures
- phantom limb pain
- avascular necrosis
- muscle wasting or scarring
- osteoarthritis.

### What can be done

#### During active therapy:

- calcium and vitamin D supplements as recommended by your doctor
- weight bearing exercises as recommended by your doctor/physiotherapist
- evaluation and treatment by a physiotherapist
- monitor growth.

#### After active therapy:

- calcium and vitamin D supplements as recommended by your doctor
- weight bearing exercises as recommended by your doctor/physiotherapist
- evaluation and treatment by a physiotherapist
- monitor growth
- growth hormone therapy.

## Organ: Skin and hair

### Most likely cause

**Chemotherapy:** bleomycin, adriamycin, VP-16, ifosphamide, daunorubicin, idarubicin, prednisone, busulfar

**Radiation therapy:** depends on the area and dose of radiation.

**Surgery:** e.g. removal of tumors, biopsies, insertion of central venous lines.

### Late effect

- darkening in creases and folds of skin and around nail beds
- scarring (from surgery)
- permanent hair loss (high doses of radiation to the head, occasionally busulfar, ifosphamide, VP-16)
- moles
- stretch marks
- thinning of skin
- spidery capillaries
- skin ulcers
- loss of elasticity
- early aging of the skin.

### What can be done

#### During active therapy:

- protect skin from the sun
- use sunscreen of at least SPF 30
- inspect moles regularly for changes in shape, color, size
- report new moles to your doctor.

#### After active therapy:

- protect skin from the sun
- use sunscreen of at least SPF 30
- inspect moles regularly for changes in shape, color, size
- report new moles to your doctor.

## Organ: Kidneys/bladder

### Most likely cause

**Chemotherapy:** ifosphamide, methotrexate, cyclophosphamide, carboplatin, cisplatin, particularly when used together

**Radiation therapy:** to the pelvis.

### Late effect

- high blood pressure
- permanent kidney damage and failure
- loss of electrolytes (salts and minerals)
- bladder irritation
- scarring of bladder and kidney
- increased risk of urinary tract infections.

### What can be done

#### During active therapy:

- use of a protectant drug like Mesna (cyclophosphamide and ifosphamide only)
- hydration with fluids by IV and/or by mouth
- supplement electrolytes
- limit doses if tests (such as creatinine clearance test) show kidneys are not working well)
- avoid antibiotics that may damage the kidneys; eg. tobramycin or gentamycin.

#### After active therapy:

- supplement electrolytes if necessary
- regular checks of blood pressure and kidney function
- medication to regulate blood pressure
- exercise daily
- reduce salt intake if recommended
- maintain normal weight
- dialysis
- kidney transplant.

## Organ: Liver

### Most likely cause

**Chemotherapy:** methotrexate, 6-MP, 6-TG, BCNU, actinomycin.

**Radiation therapy:** to the abdomen.

### Late effect

- scarring
- hepatitis.

### What can be done

#### During active therapy:

- avoid alcohol intake
- use over the counter medications with caution
- do not use dietary or herbal supplements without checking with your doctor
- monitor with liver function blood tests.

#### After active therapy:

- restrict alcohol intake
- use over the counter medications with caution
- do not use dietary or herbal supplements without checking with your doctor
- monitor with liver function blood tests.

## Organ: Stomach and bowels

### Most likely cause

**Chemotherapy:** no known drugs affect stomach and bowels

**Radiation therapy:** high doses of radiation to the abdomen and pelvis.

**Graft versus host disease**

**Surgery:** abdominal

### Late effect

- malabsorption resulting in nutrition problems
  - starts during treatment and persists
- chronic bleeding of the bowels
- constipation or diarrhea may be ongoing problems after treatment for cancer
- bowel obstruction/scar tissue.

### What can be done

#### During active therapy:

- watch stomach and bowel function.

#### After active therapy:

- watch stomach and bowel function for ongoing problems, further tests may be required, such as endoscopic examination
- watch for weight loss.

## Organ: Eyes

### Most likely cause

**Chemotherapy:** long term use of steroids

**Radiation therapy:** high doses to head and neck.

### Late effect

- cataracts
- retinopathy
- keratoconjunctivitis.

### What can be done

#### During active therapy:

- protect eyes with sunglasses (good quality that block UV rays) and hat
- artificial tears and ointments
- treat infections immediately.

#### After active therapy:

- protect eyes with sunglasses and hat
- artificial tears and ointments
- treat infections immediately
- regular checks with an ophthalmologist.

## Organ: Ears

### Most likely cause

**Chemotherapy:** cisplatin, carboplatin

**Other drugs:** some antibiotics (gentamycin, tobramycin, amikacin) may cause hearing loss

**Radiation therapy:** high doses to the head.

### Late effect

- ringing in the ears
- sensation of drifting in space
- vertigo
- hearing loss: partial or total. High frequencies most affected.

### What can be done

#### During active therapy:

- regular hearing testing.

#### After active therapy:

- hearing testing, especially if your child withdraws socially and shows language delay
- hearing aids, lip reading, signing
- treat ear infections immediately.

## Organ: Endocrine

### Most likely cause

**Chemotherapy:** no known effects from chemotherapy

**Radiation therapy:** to the head, neck, pelvis.

### Late effect

- decreased growth and development
- weight gain or loss
- early or late puberty
- hypo or hyper thyroidism
- adrenal insufficiency (following high doses of radiation to the brain)
- infertility.

### What can be done

#### During active therapy:

- watch growth and development
- watch diet and nutrition.

#### After active therapy:

- watch growth and development
- growth hormone, testosterone, estrogen, and thyroid hormone replacement
- tests of thyroid and adrenal function
- watch diet and nutrition.

## Organ: Brain and nervous system

### Most likely cause

**Chemotherapy:** high dose IV methotrexate and methotrexate into the spinal fluid.

**Radiation Therapy:** to the head

\*related to the dose and age at the time of treatment, particularly children under 2 years.

### Late effect

- memory and learning problems
- calcifications leading to seizure disorders, nerve and motor problems
- problems with balance and coordination
- stroke-like symptoms leading to weakness and speech difficulties (rare).

### What can be done

#### During active therapy:

- delay the use of radiation therapy to the brain in very young children when possible
- reduce the dose of radiation in very young children when possible
- watch for signs of delay in development and learning difficulties
- evaluate seizure disorders and treat with medication.

#### After active therapy:

- watch for signs of brain damage
- watch for developmental delays and plan appropriate interventions with health care professionals
- work with school personnel to assess and intervene at the first sign of learning difficulties
- evaluate seizure disorders and treat with medication.

## Organ: Teeth

### Most likely cause

**Chemotherapy:** gum and tooth decay (resulting from neutropenia).

**Radiation Therapy:** to teeth and salivary glands.

### Late effect

- abnormal tooth enamel and root development
- dry mouth
- increased risk of cavities and gum disease.

### What can be done

#### During active therapy:

- good dental and mouth hygiene
- drink fluids
- artificial saliva.

#### After active therapy:

- good dental and mouth hygiene
- drink fluids
- artificial saliva
- regular visits to a dentist who is aware of the child's history.

## **Secondary malignancies**

Children who survive cancer are at risk for developing another type of childhood or adult cancer. Chemotherapy and radiation therapy, while curing cancer, also damage the cells.

### **What can be done**

- learn all you can about new developments
- attend all follow-up appointments for early detection and treatment
- healthy lifestyle choices.