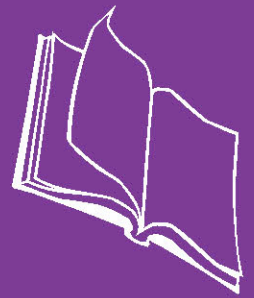


**The
Emily
Center**



Stem Cell Transplant Family Handbook

#778

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Introduction

When your child is diagnosed with a serious condition, you may feel out of control because you don't understand everything that is happening. However, once you learn about the illness and master home care skills, you will get your sense of control back. You may be feeling out of control and overwhelmed because you need to learn about stem cell transplant. This information may seem like too much to handle right now, but don't give up. Like other families, you will also be able to learn the skills needed so you can take your child home safely.

This booklet describes the journey you will take in caring for your child throughout the stem cell transplant process. Use it with your journey board. The purpose of the journey board is to list all of the things you will need to know about your child's illness and skills you'll need to know before you can take your child home safely. This booklet is an introduction to stem cell transplant. Your health care team will teach you the details. They will watch you practice and they will give time to teach back what you've learned.

Before we take the first step on the journey board, it is important to define some important terms:

- What is bone marrow?
- What does a transplant mean?
- Where do stem cells come from?

Bone Marrow is the spongy tissue inside of bones that looks like blood. It has many types of cells, including stem cells. The job of stem cells is to make and replace different cells in the body including:

- Red blood cells that fight infection
- Platelets that prevent bleeding
- White blood cells that fight infection

Stem Cell Transplant is a process that includes destroying the bone marrow and replacing it with new stem cells. Chemotherapy is used because it destroys the bone marrow that is the source of your child's illness. Radiation may also be used with chemotherapy. Then new bone marrow which has stem cells is given to make your child's body produce healthy blood cells.

Stem cells come from a few different sources. Different terms are used for stem cell transplants depending on where the stem cells come from. For example:

- Stem cells used for transplant from bone marrow are called a **bone marrow transplant**.
- Stem cells used for transplant from the body's blood stream are called a **peripheral blood stem cell transplant**.
- Stem cells used for transplant from a newborn's umbilical cord at birth are called a **cord blood transplant**.

Now that you have read this, tell your nurse or doctor what bone marrow is, what a transplant is, and where the stem cells come from.

To learn more, ask your nurse or doctor for these handouts:

- You're on the Healthcare Team, #167
- The Hematology/Oncology Health Care Team, #738

Now you are ready to take your first step on the journey board.

We can tell you how a transplant will help our child.

The Blood and Marrow Transplant Program together with Mayo Clinic is the only program of its kind in the Phoenix area. Using stem cell therapy, a specialized team of doctors, nurses, and other providers are able to replace unhealthy blood or marrow with healthy stem cells. The stem cells can then produce new and healthy blood cells.

Now that you have read this, tell your nurse or doctor how a transplant can help your child.

We can tell you what type of transplant our child is having.

There are three types of transplants:

- Autologous
- Allogeneic
- Syngeneic

Autologous: Your child is his or her own donor. Stem cells are collected from either the patient's bone marrow or from their blood using a machine made to collect these cells. This is called **apheresis**. After the stem cells are collected, they are frozen using special techniques to give back to the patient at a later date.

Allogeneic: Your child receives stem cells from a related family member or unrelated donor. Treatment for this type of transplant is high dose chemotherapy, with or without radiation, and powerful medicines which help your child's body accept the new cells.

Syngeneic: The donor is an identical twin to your child.

We can tell you how having a transplant will change the life of our child and family.

Patients who are involved in a support program during treatment cope better than those who have no access to support programs.

Our support programs are meant to meet the needs of each child and family. Our goal is to improve the quality of life for the people we care for. The support programs include:

- Activity programs, such as camps
- Counseling service
- Educational services
- Resource referrals
- Financial Counselors
- Supportive services, including support groups and parent to parent connections

Having a transplant will change the life of your child and family. During the transplant process, changes may be:

- Physical. Your child and family will not be able to do all of the activities they do now. Focus will need to be on eating right, exercise, and staying well.
- Emotional. Your child and each person in your family will respond to your child's illness in their own way.
- Spiritual. This illness may have a spiritual impact on your child and on those who love your child.
- Financial. This illness may cause you to worry about how treatment will be paid for.

Now that you have read this section, tell your nurse, social worker, or doctor how having a stem cell transplant will change the life of your child and family.

We can tell you how our donor will be determined.

If your child will not be able to be his or her own donor, another person will need to be chosen as your child's donor (**Allogeneic**). The best donor is a person whose tissue type matches as closely as possible to your child. The test to find the best match possible is a blood test called **HLA-typing** or **tissue typing**. The donor is usually a sibling, but a donor can also be found through the Bone Marrow Registry. The National Marrow Donor Program offers information on becoming an unrelated, volunteer bone marrow donor.

To find out what type of donor is best, your child needs to have several tests called a **Pre Transplant Work Up**. The results of these tests will give your doctor information that will be discussed with you. Then you and the team will decide which type of donor is best for your child.

The physician and stem cell transplant coordinator decide which tests your child needs. The following are common tests ordered for the **Pre Transplant Work Up**:

Complete Blood Count (CBC): to check the number of different kinds of blood cells in your child's body (white blood cells, hemoglobin, hematocrit, platelets).

Comprehensive Metabolic Panel (CMP): to check the level of salts and electrolytes in the blood and to look at organ functions.

Infectious Disease Testing: to check to see if your child has or has been exposed to certain viruses.

Scans: a bone scan, MRI, CT, and/or x-ray may be performed to check disease status.

Bone Marrow Aspiration and/or Biopsy: to check the condition of the bone marrow.

Dental Exam: to check the mouth, teeth, and for possible sites of infection.

Electrocardiogram (EKG) and/or Echocardiogram (Echo): to check the function of the heart.

Pulmonary Function Test (PFT): to check lung function.

Radiation Therapy Consult: to determine the dose of radiation treatment.

Social Work Evaluation: to look at and plan for ways to help the emotional status of your child and your family.

Neuropsychological Testing: to look at intellect, development, and your child's ability to solve problems.

Audiology exam: to check your child's hearing.

Gynecological/Reproductive Health Assessment: to check and talk about your child's future ability to have babies (fertility).

Basics about blood cells

Blood is a mixture of fluid (also called **plasma**) and many types of cells (**red blood cells, white blood cells, and platelets**). The liquid plasma is pale yellow, and the solid cells are red. All the cells in the blood are made in the bone marrow.

A blood test called a **complete blood count** can give your child's health care team much information. It may help them learn what illness your child has, or how sick your child is. We will draw your child's blood regularly during diagnosis and treatment to watch these changes. You will get a copy of the results of blood tests, and you can keep them in this notebook.

Here are the different types of blood cells, what they do, and what the numbers mean:

Platelets

What they do:

Platelets make the blood clot.

What the numbers mean:

The number of platelets in the blood is called the platelet count.

Normal platelet count: more than 150,000

Low platelet count: below 20,000

If the platelet count is too low, your child can bleed easier. Low platelets are also called **thrombocytopenia**.

You may see:

- easy bruising (bruises are bleeding under the skin)
- bleeding from the gums, nose, rectum, or in the stool or urine, or other parts of the body
- small red freckle-like marks (**petechiae** or small spots of bleeding under the skin)

If the platelet count is too low, your child's blood may not clot normally when bleeding starts.

If your child's platelet count is less than 50,000:

- your child should avoid contact sports or rough play of any kind.
- your child should not ride a bicycle, skateboard, in-line skate, or other activities where falling is a risk.
- tell your child to avoid straining when having a bowel movement.
- call your doctor if your child is constipated.
- your child should avoid flossing teeth.
- your child should avoid using razors.

What to do for bleeding:

Nose bleeds:

- Have your child sit up.
- Put firm pressure on the nose for 10 minutes with a cold washcloth.
- If the bleeding lasts longer than 10 minutes, call the doctor.

Call the doctor right away if your child has any of the following bleeding symptoms:

- blood in the urine or stool
- trouble seeing
- change in mental status
- seizure
- severe stomach pain
- severe headache

White Blood Cells or WBCs

What they do:

White blood cells kill germs and fight infection. There are many different kinds of white blood cells. Each fights a different type of infection. **Neutrophils** help the body fight bacteria. **Lymphocytes** help the body fight viruses.

What the numbers mean:

The number of white blood cells in the blood is called the **white blood cell count**, or **WBC**. To find out how well your child can fight an infection from bacteria, we calculate the **ANC** or **absolute neutrophil count**.

Normal ANC: over 1500

Low ANC: below 500

A low neutrophil count is also called **neutropenia**. A child with low neutrophils is called **neutropenic**.

If the white blood cell count is too low, children can not fight infection very well.

When your child's ANC is low, watch for signs of infection.

- fever higher than 101.5 F or 38.5 C
- chills, shaking, sweating
- sores or blisters on the skin or mouth
- loose stools, stomach pain
- cough
- headache
- sore throat
- earache
- pus or fluid from wound
- other signs of infection
- the child looks sick to you

If you think your child may have an infection, call your nurse or doctor right away.

Here are some ways to help prevent infection if your WBCs are low:

- Keep your child clean.
 - Your child should wash his or her hands after using the bathroom, before eating, and after playing outside.
 - Your child should have a bath or shower every day.
 - After using the toilet, your child should wipe from front to back.
 - Clean teeth and mouth with a soft toothbrush in the morning, after meals, and at bedtime. If your doctor has prescribed any medicines for mouth care, use them.
- Keep away from germs.
 - Your child should not go to places where there are crowds or large groups of people, like malls and movie theaters.
 - Your child should not be around anyone who has a cold, fever, cough, is ill, or has been with someone who is ill.

Red Blood Cells or RBCs

What they do

Red blood cells or RBCs carry oxygen from the lungs to all parts of the body. The part of the red blood cell that carries the oxygen is made of a protein called **hemoglobin**.

What the numbers mean

Hematocrit is a percentage that tells how much of the blood is made up of red blood cells. **Hemoglobin** tells us how much of the oxygen-carrying protein is in your child's blood.

Normal:

- hemoglobin 11 – 14
- hematocrit over 35%

Low, for many children:

- hemoglobin below 8
- hematocrit below 24%

If the hemoglobin or hematocrit counts are too low, less oxygen is carried to the body cells. A person with low red blood cell counts is said to have anemia.

A child with low hemoglobin or hematocrit may:

- be very tired
- have pale skin
- feel dizzy
- have a headache
- be irritable
- feel cold, and want to cover up
- feel out of breath with exercise

A child with these symptoms should play quietly and rest often. If you think your child may have a low hemoglobin or hematocrit, call your nurse or doctor.

Now that you have read this, tell your nurse or doctor about the process that helps decide how your child's donor will be determined.

We can tell you what type of central line our child has.

Your child may need to have a special IV put in. This IV is called a central line. It is a small tube (catheter) that is passed through a vein to end up in a large vein inside the chest or in the right atrium of the heart.

The central line is used for lab draws, transfusions, and for giving medications.

The Bone Marrow Transplant team will discuss with you which type of central line will be used for your child.

There are many types of central lines including:

- Apheresis catheter: Ash-Split
- Central line/Port: Hickman: Broviac, MedComp, Portacath
- PICC: Arrow, Groshong

Now that you have read this section, tell your nurse or doctor what type of central line your child will get.

We can demonstrate how to care for the central line.

You will learn how to care for your child's central line. It is very important to keep it very clean to stop infections from entering the body through the central line.

To learn more, ask your nurse or doctor for these handouts:

- How to Care for Your Child's Central Venous Catheter (CVC) #197
- Ask you nurse for the CVC care booklet.

We can tell you what things can be expected while in the hospital.

There is a unit in the hospital for stem cell transplant patients. Patient rooms in this unit are private rooms. The airflow system in each room pushes the flow of air out of the room when the door is opened. This is to help prevent infections carried in the air from getting into these rooms. There are also special air filters in each room called Hepa-filtration to clean the air that is already in the room.

Team rounds

Each morning your healthcare team will meet to talk about your child's health status, test results, and the plan of care for the day. Before rounds, members of the team will do a physical exam on your child, ask you and your child for input, and ask what questions you and your child have. This information will be discussed in team rounds. People at team rounds include:

- Doctors
- Nurses
- Pharmacists
- Nutritionists
- Pain Management Specialist
- Child Life Specialist
- Social Worker

Daily blood draws

Blood will be drawn every morning between 4:00am and 6:00am from your child's central line. Sometimes blood draws are more than once each day. The medical team checks the blood counts to see how your child is responding to the medical procedures and to see if blood transfusions are needed.

Vital signs at least every four hours

Blood pressure, temperature, oxygen saturation, respirations, and pulse will be checked at least every four hours and sometimes more often.

Blood Products

If your child's platelet count or red blood cell count are too low, a blood transfusion through the central line may be needed. A nurse will monitor your child closely during a transfusion. The medical team will explain the transfusion information to you before any blood products are given. A hospital consent form needs to be signed before the first transfusion. The consent then remains in effect for the entire hospital stay. Medications such as Tylenol or Benadryl may be given before a transfusion.

Signs of a transfusion reaction are:

- hives
- rash
- itching
- fever
- chills
- changes in blood pressure
- trouble breathing

This is a list of some other things that our team will ask your child to do at least once each day while in the hospital:

- Bath/Shower
- Mouth care four times each day
- A breathing exercise called Incentive Spirometry
- Bed linen change
- Pajama or gown change
- Exercise with the Physical Therapy team
- Weight check on a scale
- Keep a record of everything your child drinks and when your child uses the restroom, have your nurse show you how the amount of urine is recorded. This is called I's and O's or Intake and Output.

Now that you have read this section, tell your nurse or doctor what tests, procedures, and daily care activities can be expected while in the hospital.

We can tell you about how long we will be in the hospital for the transplant and what can be brought to the hospital.

Your child will be in the hospital for 4 to 6 weeks after the bone marrow transplant. The goal is for the new stem cells to begin to grow healthy cells in the body. Another word for this is engraftment. Because bone marrow transplant is such a complex process, there can be complications that occur. Complications can sometimes make it necessary for your child to stay in the hospital longer than the normal 4-6 weeks.

Personal items can be brought to the hospital to help your child feel more comfortable. All items must be clean. Even new items should be washed before bringing them into the hospital room for your child.

Here is a list of some things you can bring to the hospital:

- New personal things such as nail file, comb, brush
- Clean toys and books
- Clean stuffed animals (some stuffed animals can be cleaned by placing them in the dryer for 15 minutes on high setting)

Each hospital room has a cabinet to store personal items. Please keep all of your things in the cabinet when not being used to keep the room clutter free. This

helps our cleaning staff to clean more thoroughly. It also makes it easier for the medical team to work with your child.

Now that you have read this, tell your nurse or doctor about how long your child will be in the hospital and what items can be brought to the hospital.

We can tell you how we can help care for our child while in the hospital and help decrease the risk of infections.

Mouth care:

Tooth brushing is done with an extra soft bristle 2 to 3 times per day. A disposable sponge-like toothbrush called a toothette can be used if the platelet count is less than 20 thousand or if the toothbrush hurts.

- Swish and spit normal saline every 1 to 2 hours 4 times a day. A new bottle of saline solution will be provided daily.
- If toothpaste is not used, swish and spit a liquid called Biotene 4 times per day.
- Until the day after transplant your child will be given Nystatin to swish and swallow 4 times a day.
- Your child should not use dental floss at any time during the stem cell transplant process because this may cause the gums to bleed.
- During the day mouth care is done every 2 to 4 hours while awake, especially after each meal and before bed.

Fingernails:

- Avoid clipping fingernails. Nail files can be used to care for fingernails.
- Your child will need to wash under nails daily.
- Artificial nails may not be worn.

Hair and Scalp:

- Use only electric clippers with a disposable clipper guide to remove hair.
- No razors should be used at any time.
- It is normal for children to lose hair on their head and other parts of the body. It may take a few months for hair to start growing back.
- Sometimes the hair returns with a different color, texture, or feeling.

Eye Care:

- Contact lenses are not to be worn at any time during the transplant process.

Acne:

- Some medicines given in the stem cell transplant process (such as steroids) may cause an increase in acne on the face, back and other areas of the skin.
- Keep all skin clean and dry.
- Your child should not pick at skin that is irritated.

Daily baths with linen changes:

- Bathe or shower daily. This helps reduce the amount of bacteria on the skin.
- Use antibacterial soap and rinse the skin well. Be sure not to miss cleaning areas of skin with creases or folds because bacteria can grow more easily there.
- Your child should put on clean clothes or a clean hospital gown after each bath or shower.
- Apply lotion to dry areas. Note that no lotion should be used within 24 hours of total body irradiation (TBI).

Information about visitors:

- Visiting hours are 8:00am-8:00pm in the hospital but they can be flexible.
- Due to limited space, only one caregiver is allowed to stay the night in the patient's hospital room. The hospital does not allow you to sleep in the hospital bed with your child. The child may not sleep in a sleeper chair with the caregiver. This is dangerous and can put your child at risk for injury.
- Children under the age of 12 often carry germs, so it is best if they don't visit. This is because children often carry illnesses that are harmful to stem cell transplant patients. During cold and flu season in the winter months, kids under the age of 12 are not allowed to visit your child in the hospital. In the winter months, a virus called Respiratory Syncytial Virus (RSV) is common. During RSV season, all hospital staff and visitors must wear a mask while in your child's hospital room.

Any visitor who has a fever, cold, or any kind of illness or has been with any other person who is ill should not come to the unit.

During the day there is no exact number of visitors a patient is allowed to have.

However, the more visitors a patient has, the higher the chance of becoming ill. For this reason, limiting the number of visitors is best.

Each time you come to visit a stem cell transplant patient:

- Check at the nurses' station before entering the room.

- Wash your hands and arms up to the elbows for 1 minute. Rescrub if you leave the unit when you return.
- Do not put your shoes on the hospital bed.
- Limit visitors if your child appears tired. Your child may not be feeling well enough to visit with people and may be too polite to ask a visitor to leave.
- Check with the nurse or dietitian before you bring foods for your child. Your child will be on a special diet for the stem cell transplant patient.
- No live flowers or plants are allowed in stem cell transplant hospital rooms.

Take care of yourself: You, the caregiver, need to remain clean and healthy. All caregivers need to take a bath or shower daily and wear clean clothes. Remember that good hand washing is the best way to stop the spread of infection to your child.

Now that you have read this, tell your nurse or doctor how you can help care for your child while in the hospital and ways to decrease the risk of infection.

We can tell you what differences will be in our child's care if our child goes to the PICU.

Patients who have severe complications during the stem cell transplant process, may need to go to the Pediatric Intensive Care Unit (PICU). If your child is in the PICU, the staff there will give you all of the information you will need to know. Some information you should know includes:

- PICU nurses receive training to care for BMT patients.
- PICU rooms are private rooms with a couch for parents. There is a family center near the PICU with bathroom facilities, showers and family gathering areas.
- Parents are invited to be a part of morning rounds with Physicians, Nurses, Pharmacy and Nutrition.
- The PICU is a restricted unit with access given by armband for parents and up to 4 family members. Other visitors may be escorted by a banded family member.
- Patients are monitored very closely in the PICU with vital signs every hour and assessments every 2 hours or as needed.
- The PICU at Phoenix Children's Hospital prides itself in caring for not only our patients but our families. We strive to provide the best care available and also to provide a healing, supportive environment during a very stressful time.

- Patients heal faster when they are allowed to have time to rest. Between the hours of 1:30-3:30 PM and 1:30-3:30 AM lights will be dimmed, and we will try to keep the noise level down.
 - Hospital staff will not be doing tests or disturbing children during this time. This is of course depends on how stable your child is. Sometimes we cannot allow a child to be left alone for 2 hours because they are so ill.
 - The staff will ask you to also rest during this time. TVs will be turned off. Please ask visitors to not visit during this time, and we ask you not to talk on the phone loudly. It is “nap time” and our patients need their rest.
 - If you have any questions or concerns ask your nurse or you can ask to speak a Supervisor.
- Now that you have read this, tell your nurse or doctor what some of the differences will be in your child’s care if your child needs to go to the PICU.

We can tell you some key points about our child’s meal plan and why good nutrition is important.

Good nutrition for your child is very important during the transplant process. A goal of the BMT team is to help your child receive the right foods needed to grow, develop, and heal. A registered dietitian is part of the BMT team and will meet with you and your child during the transplant process.

This section has information about food safety and healthy eating. More information is available from the nutritionist who helps with a variety of problems such as:

- Poor appetite
- Nausea and vomiting
- Diarrhea
- Constipation
- Tooth decay
- Problems with taste
- Dry mouth
- Thick saliva
- Inflammation of mouth and esophagus (mucositis)

Tell the doctor and nutritionist if any of the above symptoms are a problem.

Food Safety Guidelines

Safe Food Handling

- Wash hands before, during, and after you touch food. Use soap and hot water and wash for 20 seconds. Sing the “Happy Birthday” song twice while you wash your hands.
- Buy and use a food thermometer:
Safe food temperatures are:
 - Hot foods above 140° F
 - Cold foods below 40° F
- Cook meat until well done and check final temperature with a food thermometer:
 - Red meat above 165° F
 - Poultry above 180° F
- Thaw all meats in the refrigerator away from fresh fruits, vegetables, and other prepared foods:
 - Place meat on a dish to avoid bacteria spreading to other foods.
 - If meat is thawed in microwave, cook food immediately.
- Do not thaw foods at room temperature.

More food safety tips

- Never leave food out for longer than 2 hours total.
- Wash the tops of canned foods before opening. Clean can opener before and after use.
- While making food, do not taste the food from the utensils used for stirring.
- Cook eggs until yolk and white are firm.
- Do not eat foods that contain raw eggs (Example: cookie dough).
- Do not taste or eat foods that smell or look strange.

Microwave Cooking

- Microwaves cook unevenly and can leave bacteria in foods. Rotate foods in microwave if there is no turntable in the appliance.
- To reheat leftovers: Use a loose fitting lid or vented dish and stir several times while reheating. Reheat to minimum of 165°F, cover, and let sit for 2 minutes.
- Do not cover container with plastic wrap. Use wax paper or paper towel.

- Use glass or ceramic containers in the microwave. Heat can drive plastic into the food.

Grocery Shopping

- Buy only fresh products. Check the “sell by” and “use by” dates.
- Check the seal on all packages. Do not buy opened packages. Do not buy dented, swollen, or rusted canned items.
- Produce should look and smell fresh, without bruises.
- Do not buy any foods with mold present, including berries and cheese.
- Avoid deli foods including prepared salads, meats, and cheeses.
- Avoid un-refrigerated cream and custard type desserts and pastries.
- Do not eat from self serve or bulk containers.
- Avoid ice-cream and yogurt from soft-serve machines.
- Do not taste free samples.
- Do not eat cracked or un-refrigerated eggs.
- Pick up frozen items last at the store.
- Put groceries away right away after returning from store.

Dining Out

- Eat early to avoid crowds.
- Ask that food be prepared fresh in fast food restaurants.
- Only drink pasteurized fruit and vegetable juices.
- Eating uncooked fresh fruits and vegetables in a restaurant is not recommended because it is hard to know if the food has been prepared safely.
- Avoid public self serve condiment dispensers. Ask for individual packets.
- High risk food locations should be avoided: Salad bars, delis, potlucks, and sidewalk vendors.
- Look at how clean a restaurant is before you eat there.

Kitchen Sanitation

- Use separate cutting boards for cooked and raw foods.
- Wash cutting boards after each use with hot, soapy water or in dishwasher.
- Sanitize cutting boards weekly using a dilute bleach solution (one part bleach to ten parts water) and allow to air dry.
- Keep appliances free from crumbs: toaster, microwave, blender, and can opener.
- Wash blender blades and can opener after each use.
- Keep counter tops free of crumbs.

Sink Area Sanitation

- Provide soap for hand washing.
- Use paper towels to dry hands.
- Replace dish towels and cloths daily. Wash in hot water with bleach.
- Replace sponges weekly.
- Do not store food supplies under sink.
- Do not store chemicals near foods.

Refrigerator/ Freezer

- Keep refrigerator clean.
- Maintain refrigerator temperature between 35°F to 40°F.
- Maintain freezer temperature below 5°F.
- Cool hot foods uncovered in shallow containers in the refrigerator until cool.
- Once cooled, cover foods. Store all foods covered in refrigerator.
- Throw away or freeze all food from refrigerator within 3 days.
- Throw away:
 - Eggs with cracked shells
 - Expired foods
 - Moldy foods. Throw away whole container, not just mold.
 - Freezer burned foods

Cupboards/ Pantry

- Keep cupboards clean.
- Rotate food items so old foods are eaten first.
- Do not use foods past the date they expire.
- Do not eat any home canned foods with bulging lids or bad odor.
- Home canned foods must be eaten within one year from canning.

Safe Preparation of Fresh Fruits & Vegetables

- Wash hands thoroughly before handling any food.
- Rinse fruits and vegetables well under running, cold water just before you eat it.
- Use a clean vegetable scrubber to remove dirt from skin of fruits and vegetables with a thick rind or skin (for example: melons, potatoes).
- Do not use commercial rinses, soaps, detergents, or chlorine bleach solutions on fruits and vegetables. They will absorb these products.
- Wash the outside of all fruits and vegetables, even if you are going to peel them. The bacteria from the outside can get into the inside when you cut or peel them.

- Wash all pre-packaged produce and other pre-cut produce. Even if the label states it is pre-washed. Check the dates on the package.
- Raw vegetable sprouts should not be eaten because bacteria can often be found on them.
- You still have to wash organic produce. Organic fruits and vegetables can have the same amount (or more) bacteria on them than non-organic fruits and vegetables.

Safe Storage of Fresh Fruits & Vegetables

- Refrigerate fruits and vegetables. Bacteria grows slower in a clean refrigerator with a temperature of 35-40°F.
- Throw away fruits and vegetables that have been stored too long or are slimy or moldy.

Eating Fresh Fruits and Vegetables at a Restaurant

It is hard to know if the restaurant has prepared fresh fruits and vegetables correctly, so it is best that your child not eat fresh fruits and vegetables at a restaurant or salad bar.

Guidelines for Outside Food brought from Home, Fast Food, or Restaurants

The menu at Phoenix Children's Hospital is designed for the special diet your child needs and has a variety of children's favorite foods. The food at the hospital is bought, stored and made in a way that meets all state health regulations as well as the individual needs of stem cell transplant patients.

The hospital has "room service" as an option. This is a safe way of providing food to your child.

There are guidelines for bringing outside food into the hospital:

- Fast food must be ordered fresh.
- Do not buy the items that are sitting under the heating lights.
- Fresh fast food items must be brought immediately to the hospital.
- Inform the nurse of any food brought in from the outside.
- Use the microwave to reheat food.

Here are some tips:

- Food must follow the patient's medical diet order and the immunosuppressed diet.
- Home prepared foods to be served hot need to be frozen in individual serving sizes at home and brought into the hospital frozen.

- Transport cold foods in a cooler with ice, especially during the summer months.
- Food can be reheated in the microwave. Clean the microwave before and after use.
- Label refrigerated food with your child's name and the date. Unlabeled food and food that is older than 48 hours is thrown away by hospital staff.
- Throw away leftovers (or take home). Do not place back in the refrigerator.
- Food for the family should not be stored in the patient's room.
- Throw away disposable utensils after one use.
- Throw away any drink after 4 hours. Try to buy drinks in single serving sizes. Large size bottles may be labeled and stored in refrigerator.

Non-Perishable Foods

- Non-perishable foods like cookies, crackers, and chips must be brought into the hospital unopened.
- Non-perishable foods for the patient are stored in the patient's cupboard. Label and date these foods.
- Bring small packages to avoid large quantities of food in rooms.

Water Safety Guidelines

Tap Water

Water from your home faucet is safe if your water is from a city water supply or a municipal well that serves a large city.

Well Water

Well water from private or small community wells is not safe for immunosuppressed people to drink. Boiled water or bottled water should be used instead.

To learn more, ask your nurse or doctor for these handouts:

- BMT food record
- Progression 1 low microbial
- Progression 2 low microbial

Now that you have read this, tell your nurse or doctor some key points about your child's meal plan and why good nutrition is important.

We can tell you the importance of skin and mouth care.

Breakdown of the skin and mouth tissue is common during the BMT process. The plan of care to protect the skin and mouth from harm includes:

- Daily shower or bath
- Good hand washing
- Care of the diaper area and bottom
- Use of lotions and barrier creams
- Regular mouth care as discussed previously

Some of the causes of skin breakdown are:

- chemotherapy
- total body irradiation (TBI)
- post-transplant complications (infections and graft versus host disease (GVHD))
- not moving the body enough
- poor oxygen flow to the skin
- medications
- infections
- low blood counts

Your child's skin can be affected especially when Total Body Irradiation (TBI) is part of the medical plan. The effects usually go away after TBI is stopped.

Signs of skin changes with TBI include:

- skin redness that looks like a sunburn
- skin appears brown (called hyperpigmentation) at TBI site
- skin dryness at TBI site. These effects are similar to sunburn, and usually resolve after administration

Things your child can do to help prevent skin changes during TBI include:

- Avoid topical creams, ointments, and powder.
- Use mild soap on skin surface that got radiation.
- Do not place adhesive strips or medical tape on skin that got TBI.
- Use paper tape, gauze dressings, burn netting or other products that won't bother the skin.
- Remove jewelry (including body piercing).
- Avoid scratching.
- Avoid elastic waistbands or clothes that are tight.

- Allow radiation field marks on skin to wear off; do not scrub them.
- If necessary apply lotions approved by the TBI staff between treatments.
- Remove lotions, diaper creams, and deodorants before each TBI treatment.
- Bathe using cool or warm water and pat the skin dry after.
- Avoid the sun. Apply sun block with an SPF of 30 or more.
- Do not use harsh skin cleansers, lotions, creams and antiperspirants, especially with alcohol or fragrance (such as baby wipes).
- Apply lotion while skin is still damp.
- Wear hats and long sleeve cotton clothing when outside.
- Your child's skin may be permanently affected due to TBI. If skin does not return to normal after treatments stop, there can be an increased risk in the future for skin cancer.

Now that you have read this, tell your nurse or doctor some keys points about the importance of skin and mouth care.

We can tell you some common infections and how they are treated or prevented.

3 types of common infections are:

- Bacterial
- Viral
- Fungal

Ways to prevent spread of infection:

- **Good handwashing is the best way to prevent the spread of infection.**
- Low bacteria diet
- Making sure area around your child is kept clean
- Avoid being around others who are sick
- Your child's doctor may order medicine to help prevent certain illnesses

To learn more, ask your nurse or doctor for this handout:

Good Handwashing, #100

Now that you have read this, tell your nurse or doctor how you can prevent infections.

We can tell you some common side effects of radiation and how they are treated or prevented.

Total body irradiation (TBI) is a procedure using radiation to get your child's body ready for bone marrow transplant. TBI is given to the whole body. The goal of TBI is to prevent rejection of the donor's bone marrow or blood stem cells after they have been given to your child.

Total body irradiation:

- destroys your child's bone marrow which allows for space for the donor's cells to live
- kills any other cancer cells that are still in your child's body
- lowers your child's immune system response to help prevent rejection

Not all children get Total Body Irradiation (TBI) as part of the stem cell transplant process. If TBI is to be started, you and your child will have an appointment with a doctor who is a Radiation Oncologist to talk about the treatment plan. If TBI is to be started, your child's body will be measured to decide the right amount of radiation to be given.

At your meeting with the Radiation Oncologist, the doctor will:

- Ask about any radiation therapy that your child has had in the past
- Talk about common side effects of TBI
- Answer questions
- Obtain your consent for the treatment

If the Radiation Oncologist determines that TBI should be given, a TBI schedule is planned for your child. TBI is given during the first few days after admission to the hospital for stem cell transplant. Sometimes TBI may be started as an out-patient. TBI takes place in the Radiation Department of Good Samaritan Hospital. Your child will be transported from the hospital by ambulance. A nurse may go in the ambulance with your child two to three times a day on the days of TBI treatment.

Getting TBI is not painful or uncomfortable. TBI may be scary or cause anxiety for some children. For this reason, medication may be given to make your child sleep during TBI to help your child hold still.

The following are common short term side effects of TBI:

- Nausea and vomiting
- Rash or redness of skin, much like a sunburn

- Being tired
- Low blood counts
- Swelling of the mouth or esophagus called Mucositis
- Hair loss
- Diarrhea
- Possible sterility

Now that you have read this, tell your nurse or doctor some common side effects of TBI and how they can be treated or prevented.

We can tell you some of the immediate (within 3 months) side effects from having a transplant.

The day of the Stem Cell Transplant is considered Day 0.

The day after Day 0 is Day +1 and the days after are +2, +3, and so on.

Day 0 often represents a special milestone in the treatment plan for patients.

On day 0:

- The stem cells are delivered to the your child's nurse and infused through your child's central line.
- These stem cells then travel into the bone marrow, where they mature, grow, and begin to make new blood cells.
- The infusion of cells takes place in the your child's hospital room.
- Before the infusion your child will receive medicine to help prevent a reaction to the cells and additives.
- Patients who receive an autologous stem cell transplant have the stem cells preserved (until use) with a chemical called DMSO. A common side effect of DMSO is a garlic or fish-like smell. This can last for up to 2 to 3 days after the stem cell infusion and may make your child feel sick to the stomach. Your child can chew gum or suck on hard candy (as appropriate for age) while the cells infuse to decrease this smell. DMSO is released from the body through the lungs with breathing.
- During the days to weeks after the stem cell infusion, but before the cells have matured, blood counts are very low because of the chemotherapy and radiation treatments received before the transplant.

Possible side effects of BMT:

- nausea and vomiting
- mouth sores
- pain

- fevers and infection
- bleeding
- diarrhea
- skin changes
- liver and kidney problems

The medical team monitors and treats complications: Your child will likely have fevers and will then receive IV antibiotics (through the central line) to fight infections. To speed the return of white blood cells, which then helps many of the side effects listed above, your child may receive a drug called G-CSF, also called Neupogen.

Now that you have read this, tell your nurse or doctor some of the immediate side effects to expect from having a transplant.

We can tell you what Graft Versus Host Disease (GVHD) is.

A Graft Versus Host Disease (GVHD) is a possible complication for the child who receives stem cells from a allogeneic transplant. The donor's cells are called a **graft** and your child's body is the **host**.

GVHD occurs when the graft cells of the donor attack the weak or immunosuppressed cells of the host. The result is damage to the host tissues or organs.

- GVHD is not common with a self (**autologous**) or twin (**syngeneic**) bone marrow transplant.
- GVHD is not common before engraftment.
- GVHD happens when the donor's healthy T cells attack the child's weak cells. T cells are part of the immune system that fight diseases. The T cell directs the immune system to attack other cells that have become damaged or infected.
Sometimes T cells are described as Homeland Security for the body.
- The organs most commonly affected by GVHD are the skin, GI tract and liver. A single organ or a combination of organs may be involved.

Now that you have read this, tell your nurse or doctor what GVHD is.

We can tell you what is done to prevent rejection and ease Graft versus Host Disease (GVHD) flare-ups.

Ways that the BMT team will work to prevent GVHD in your child include:

- Use of medicines that deplete donor T-cells
- Use of medicines that block donor T-cell activation

If your child develops GVHD, medicines are used to:

- Help control the body's immune response. These medicines are called Corticosteroids.
- Control T cell growth and activity
- Help prevent GVHD

It is important for you to assess your child for the following symptoms of GVHD and report any of these to the BMT team right away. Symptoms include:

- Infection:
 - redness —swelling —drainage —fever —diarrhea —chills
- Electrolyte abnormalities:
 - muscle cramping —stomach cramping
 - changes in potassium or magnesium levels
- Malnutrition:
 - vomiting —poor intake —weight loss —diarrhea
- Skin changes on body including hands, soles, behind ears:
 - rash —itching —peeling or flaking skin —blistering
 - redness that looks like a sunburn

Now that you have read this, tell your nurse or doctor what is done to prevent rejection of the stem cell transplant and ways to ease GVHD flare-ups.

We can tell you what Veno-Occlusive Disease (VOD) is.

The most common complication after bone marrow transplant is called **Veno-Occlusive Disease**. This is when the liver becomes swollen which causes tiny veins in the liver to become blocked or destroyed. It is usually caused from high-dose chemotherapy and radiation. VOD usually occurs 1 to 3 weeks after bone marrow transplant. This time frame is also called Day +7 to Day +21 after bone marrow transplant.

It is important for you to watch your child for the following symptoms of VOD and report any of these to the BMT team right away. Symptoms include:

- Pain near the liver found on the right upper area of the belly
- Weight gain
- Swelling
- Skin color changes to yellowish tone called **jaundice**

Now that you have read this, tell your nurse or doctor what VOD is.

We can tell you what chemotherapy meds our child will be receiving.

The BMT team will tell you the names of the chemotherapy medications that will be given to your child. Using the handouts in the next section, you will learn about chemotherapy, the side effects of chemotherapy, and how to treat the side effects.

Once you have learned about chemotherapy, you can teach back this information to your nurse or doctor.

We can tell you why chemotherapy is being given and what side effects can occur.

Chemotherapy is medicine used to kill cancer cells. The BMT team will explain:

- what chemotherapy will be used for your child
- side effects to expect during chemotherapy treatment
- how chemotherapy affects different types of cells in your child's body

To learn more, ask your nurse or doctor for these handouts:

- About Chemotherapy, #734
- Side effects of Chemotherapy and how we treat them, #735
- About Blood Cells, #736

Now that you have read this, you can tell your nurse or doctor why chemotherapy is being given and what side effects can occur.

We can tell you what other medicines our child will be receiving.

In addition to chemotherapy, your child will receive other medications during the stem cell transplant process. These medications help decrease the side effects. The medications include:

Antibiotics to treat bacterial infections. Antibiotics can prevent a bacterial infection, or treat a known infection.

Antifungals treat fungal infections. Antifungals can prevent a fungal infection, or treat a known infection. Antifungals are used as part of your child's daily mouth care to prevent a fungal infection that looks like a white coating in the mouth and esophagus called thrush.

Antivirals treat viral infections. Antivirals can prevent a viral infection, or treat a known infection. Acyclovir and Gancyclovir are examples of antiviral medications. Medicines called Immunoglobulins (IVIG) may be used to help boost your child's ability to fight viral infections. Patients take antiviral medications if they or their donor have been exposed to certain viruses.

Immunosuppressant medications weaken your child's immune system to prevent or treat stem cell rejection or Graft-vs-Host Disease (GVHD). Patients receiving an allogeneic stem cell transplant will receive immunosuppressant medications. Because chemotherapy and immunosuppressant are given during stem cell transplant, severe bone marrow suppression occurs. To help decrease the severity, your child may be given medications to help the bone marrow to make infection fighting cells called white blood cells. A common medication given in the vein or as a shot to help your child's body make white blood cells is called GCSF (or Neupogen).

Antiemetics fight nausea and vomiting.

Analgesics help control pain. Your child may have some pain during the stem cell transplant process. The pain is usually from sores in the mouth (mucositis), stomach, or from bottom discomfort. A common way to give analgesics during the stem cell transplant process is with a Patient Controlled Analgesia (PCA) machine. This machine allows a specific amount of medicine to go through the IV at a constant rate, but also allows your child to push a button which gives extra pain medication if needed. The PCA only gives a safe amount of medication. Morphine is the most common pain medication used.

Most of the medications discussed above are given through the patient's Central Venous Catheter (CVC), although some are given by mouth. When your child goes home, most of the medications are given by mouth. However, it may be necessary to receive IV medications at home or return to the clinic to receive them.

To learn more, ask your nurse or doctor for these handouts:

- About taking Medicine, #24
- Medicines to take, #337

Now you are ready to tell your nurse or doctor the information you've learned about different types of medicines your child will be taking.

We can tell you why these medicines are being given and what side effects can occur.

Your medical team will explain what medicines your child will get, what side effects he or she may get from the medicine, and what the treatment will be. After you have learned about your child's medicines, you should be able to answer the following questions:

- What is the name of the medicine?
- What are the common side effects?
- How is the medication given ? (for example: by mouth, rectum, central line)
- How often is the medication given?
- What do I do if a dose is missed?
- Where should the medicine be stored?
- When should I call the doctor?
- When should I stop taking the medicine?
- Can I refill this medicine? How many times?

Now you are ready to tell your nurse or doctor the information that you've learned about your child's medicine.

We can tell you what things can be done to help our child's pain.

There are both medical and non-medical ways to help control your child's pain.

Two medical ways to help control pain are:

- **Analgesics:** Your child may have some pain during the stem cell transplant process usually from sores in the mouth (mucositis), stomach or bottom. Morphine is the most common pain medication used, but examples of other pain medications are Dilaudid and Fentanyl. Common oral pain medications are Tylenol and Oxycodone.

- **PCA machine:** A common way to give analgesics during the stem cell transplant process is with a Patient Controlled Analgesia (PCA) machine. This machine allows a specific amount of medicine to go through the IV at a constant rate, but also may allow the patient to push a button which gives extra medication if needed. The PCA only gives a safe amount of medication.

Some non-medical ways to help control your child's pain include:

- Music
- Reading
- Play
- Videos/Video Games

Now that you have read this, tell your nurse or doctor some medical and non-medical things that can be done to help your child's pain.

We can tell you what medications our child will be discharged on and where we will fill the prescriptions.

- Medicines to Take, #337
- About taking medicines, #24
- Always Have Medicine, #909

Prescriptions will need to be filled at a pharmacy in network with your health care insurance. The BMT team can help you know where to go to fill your child's prescriptions.

Now you are ready to tell your nurse or doctor what medications your child will take at home and where you can go to fill the prescriptions.

We can tell you how to prepare our home and what protective measures we need to follow.

You will need to get your house ready for when your child is ready to go home. The goal is to limit the risk of infection.

You will need to clean your home before your child goes home from the hospital:

- Vacuum all carpets. Wash small area rugs in the washing machine.
- If indoor pets are present – clean carpets.
- Clean drapes and blinds.
- Sweep and mop all floors.
- Dust all surfaces such as furniture, window sills, computer, television, and gaming equipment.
- Clean the toilet, bathtub, shower and sink with Lysol, or a cleaning product like that.

Once home, cleaning should be done while your child is in another room. Your child should not enter a room that has just been dusted for at least 30 minutes to give the air a chance to settle. Some other tips include:

- Pets such as birds, turtles, snakes, iguanas, and rodents should not come in contact with your child.
- Child should not come in contact with pet litter and aquariums.
- Flowers and plants may remain in the home, but your child should not be in contact with them. Flowers and plants should not be in rooms where your child spends a lot of time. Patients should not work directly with plants or soil.
- If other family members share the bathroom, clean the shower or tub with Lysol or similar product, after each use.
- Keep utensils for food preparation very clean. Wash dishes with dish soap and hot water.
- Regularly replace filters in heating and air conditioning equipment. If a furnace or air conditioner is used, change the filter frequently for the first year. If a swamp cooler is used, change the pads monthly for the first year when the cooler is in use.

Preventing infection is the goal. Some other ways to decrease the chance of infection include:

- Limit your child from being in large groups of people. Don't take your child to stores, movie theaters, malls, school, church.
- Avoid construction areas and musty places.

- Avoid dusty or windy conditions, or wear a mask in these conditions.
- Avoid people who are ill.
- Take a bath or shower every day. Use antibacterial soap and put on clean clothes after bathing.
- Wear cotton underwear.
- When using the restroom, your child should wipe from front to back.
- Mouth care four times a day. Rinse mouth following all meals, snacks, and before bed.
- Wash hands after playing outside, using the bathroom and before eating.
- Clean the bathtub, shower, toilet, sink and floor every other day with Lysol, or similar cleaning product.
- When in public restrooms, do not sit on toilet seat, use a paper cover, and wash hands well before leaving the restroom. Do not touch door handles with bare hands.
- If washing clothes at a laundromat, spray the inside of the washer with Lysol before starting the laundry.
- Your child should not get immunizations or vaccinations until ordered by the stem cell transplant Doctor. If other children in the house need to be immunized, discuss this with the stem cell transplant Doctor or Coordinator.
- All of your child's make-up should be new. Discard old make-up. Makeup should not be shared with anyone else.
- Your child should not wear artificial nails.

To learn more, ask for nurse or doctor for this handout:

How to Avoid Infections If You Are At Risk, #61

Now that you've read this, tell your nurse or doctor how to avoid infections if you are at home.

We can tell you what activities our child can participate in.

Physical activity is a very important part of recovery. The goal of physical activity is to help children keep their strength so they can return to their favorite activities as soon as possible. Your child may find that energy levels are not the same as before the bone marrow transplant. Your child should maintain an activity level that is comfortable. Strength will slowly return. Simple exercise such as daily walks and gentle play are a good way to start physical activity again. Your child should balance activities to avoid getting too tired. Avoid walking outside on windy or dusty days. If this cannot be avoided, your child will need to wear a mask.

Don't allow your child to do activities with a high risk of injury such as:

- roller blading
- bicycling
- climbing trees
- jumping on trampolines

Now that you've read this, tell your nurse or doctor what activities are safe for your child to participate in.

We can tell you what home care company we will be using.

The bone marrow transplant team will arrange for an outside company to deliver all of the supplies needed to take care of your child at home. All of the supplies you will need at home will be ordered by your Doctor. The team will tell you the name of the home care company and how to contact them. The company is chosen based on the type of Insurance you have. The company can be contacted 24 hours daily for problems with home equipment or supplies. You can also call the bone marrow transplant team if you are having difficulty with home equipment or supplies after your child goes home from the hospital.

Now you are ready to teach back the information about which home care company you will be getting supplies from.

We can tell you when to call the doctor/nurse.

Even with perfect care, it is possible for your child to get an infection. Once home, you will need to watch for the signs of infection.

Call the doctor immediately if any of these common signs of infection occur:

- Fever
- Shaking, chills, sweating
- Loose Stools
- Vomiting
- Cough
- Drainage from a sore
- Ear aches
- Stomach pain
- Tiredness

- Headache
- Vaginal discharge/odor
- New skin rash
- Pain when urinating
- Bottom sores or abscess
- Redness or drainage at the central line site
- Bleeding

More information about fevers:

- Call the doctor right away if the your child's temperature is greater than 38.3 degrees Celsius which is the same as 101 degrees Fahrenheit.
- If your child's temperature is greater than 38 degrees Celsius or 100.4 degrees Fahrenheit for four hours or more, call the doctor. Your Doctor may ask you to give Tylenol for fever. Do not give Tylenol unless instructed by the doctor or nurse.
- Never give Aspirin, Aspirin-containing medications, or Ibuprofen for fevers. Blood may not clot normally when taking these medications.
- If a fever develops, your child will need to be examined by a doctor. A complete blood count (CBC) and blood cultures will need to be drawn. A CBC determines the Absolute Neutrophil Count (ANC). The ANC is a measure of your child's immune status. Blood cultures show if there is bacteria in the blood.
- If your child has an abnormally low level of neutrophils in the blood and develops a fever, IV antibiotics will be ordered by your doctor. To give the antibiotics, this usually means an admission to the hospital.
- Fever in a stem cell transplant patient can be life-threatening (even with a good ANC) and is taken very seriously.

Now that you've read this, tell your nurse or doctor when you will need to call the doctor or nurse from home.

We can tell you how often we will need to come to the clinic after discharge.

Your child may need to come to the clinic for an appointment with the bone marrow transplant team 2 to 5 times per week for the first year after discharge from the hospital.

You may bring siblings to the clinic visits, when RSV restrictions are not in place.

Bring the following to your clinic appointment:

- your immunosuppressant medications (FK506 or CsA).
- any other medications due at the time of the clinic appointment. This is because blood will be drawn at the clinic visit and the medication will need to be given after the blood is drawn. The clinic does not have these medications available.
- home feeding supplies including your child's feeding pump, IV pump, and IV fluids.

To learn more, ask your nurse or doctor for this handout:

About the Hematology/Oncology Clinic at Phoenix Children's Hospital, #739

After you have read this, tell your nurse or doctor how often your child will need to come to the clinic after discharge and what items you will need to bring to the appointment.

My child can go home when:

- Engraftment is present without active infection.
- Our home is clean.
- We have completed a 24 to 48 hour process of providing all care and treatments for our child in the hospital called "nesting."
- We have demonstrated how to do central line care.
- We have all medications for home and have given them to our child.
- We have changed our meal planning to include the special diet my child will need.
- We have met with the Home Care company and received all of our supplies.
- We have made our follow-up appointment and we have transportation to get to the clinic visits.

To learn more, ask your nurse or doctor for this handout:

Are you ready to leave the hospital? #1017

Disclaimer

The information provided at this site is intended to be general information, and is provided for educational purposes only. It is not intended to take the place of examination, treatment, or consultation with a physician. Phoenix Children's Hospital urges you to contact your physician with any questions you may have about a medical condition.

Tuesday, May 3, 2011 • DRAFT to family review
#778 • Written by Jamie Barker, MS, RN

Development of this handbook has been supported by funding from the Caitlin Robb Foundation.



Name of Health Care Provider: _____ Number: 778

For office use: Date returned: _____ db nb

Family Review of Handout

Health care providers: Please teach families with this handout.

Families: Please let us know what you think of this handout.

Would you say this handout is hard to read? Yes No

easy to read? Yes No

Please circle the parts of the handout that were hard to understand.

Would you say this handout is interesting to read? Yes No

Why or why not?

Would you do anything differently after reading
this handout? Yes No

If yes, what?

After reading this handout, do you have any
questions about the subject? Yes No

If yes, what?

Is there anything you don't like about the drawings?

Yes No

If yes, what?

What changes would you make in this handout to make it better or easier to understand?

Please return your review of this handout to your nurse or doctor or send it to the address below.

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Thank you for helping us!