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Welcome

Welcome to the Blood and Marrow Transplant (BMT) Program at the Aflac Cancer and Blood Disorders Center of Children's Healthcare of Atlanta. We would like to help you as you begin to explore the process of having a transplant. Let us know if you have any questions or concerns at any time.

About the Aflac Cancer and Blood Disorders Center

- Is ranked as one of the leading childhood *cancer* and blood disorders programs in the country.
- Serves babies, children, teens and young adults with cancer and blood disorders.
- Has a team of childhood cancer and blood disorders specialists.
- Supports advanced medical care and research.
- Provides programs in cancer survival, neuro-oncology, sickle cell disease, leukemia and lymphoma, hemophilia, sarcoma and *blood and marrow transplants.*

The Aflac Cancer and Blood Disorders Center and its programs are located at:

- Children's Healthcare of Atlanta at Arthur M. Blank Hospital. This is where your child will receive their BMT transplant care.
- Children's Healthcare of Atlanta at Hughes Spalding

Our mission

To provide complete care to children and teens with cancer and blood disorders through:

- Caring for your child's physical and emotional needs.
- Teaching you what you need to know about cancer and BMT.
- Taking part in research to help find the best way to prevent and treat cancer.

We strive to do this by:

- Caring for your child's physical and emotional needs.
- Teaching children and families about cancer and blood disorders.
- Taking part in research to find the best way to help treat and cure these diseases with the fewest side effects.

About your BMT guide

This guide will help you and your family prepare for a blood and marrow transplant (BMT) and learn more about your child's illness and treatment. It will also introduce you to the members of the BMT team who will care for your child.

This guide was written for you, but your family will also be using it as they learn about your child's BMT. Words in *italics* are found in the glossary on page 104.

This guide should not replace any instruction from your child's healthcare team. It is not meant to be medical advice or a complete resource. Your child's BMT team is the best source of information about what is best for your child's BMT care.

To help you learn about your child's care more easily:

- Bring this guide with you to each BMT clinic visit.
- Write down any treatment changes or questions in the notes section.
- Plan to bring this guide to your hospital stay once your child's BMT is scheduled.

Our promise to you

At the Aflac Cancer and Blood Disorders Center, our priority is to provide you and your child with high-quality, family-centered care. Together, our team will support you throughout your treatment journey. At each hospital stay and clinic visit, we want you to have a nurturing, caring environment.

Our mission is to provide you and your family with the finest in cancer and blood disorders treatment. We are honored that you have placed your child in our care. We will work every day to help live up to that trust.

We want to hear from you

We work to improve our programs and renew our mission to provide the best care possible for your child. If you have concerns during your time at the Aflac Cancer and Blood Disorders Center, we want to hear from you. Please call 404-785-1200 with any questions or concerns during your time at the Aflac Cancer and Blood Disorders Center.

BMT Basics

When you first find out that your child needs a BMT, you may feel scared, confused, angry or shocked. These feelings are normal. We want to help you with your feelings and questions. You and your child have a long road ahead. We hope that the more you know about your child's treatment, the less stressful it can be for you and your child.

Your BMT consult

Your treating doctor will make a referral. The transplant coordinator will set up an appointment called a BMT consult. At your consult visit, you will meet with a BMT doctor, BMT coordinator and other members of the BMT team. They will talk with you about:

- Details of your child's disease.
- Why your child needs a BMT.
- Your child's transplant treatment options.
- Preparing for the BMT and your child's recovery.
- Possible risks and side effects of a BMT.
- Emotional and financial issues with a BMT.

This guide will help you learn about all of these items during the BMT process. You can find other information on the internet and other families. Information can help, but at times it is also confusing. Keep in mind that each child's care is different. Talk with your BMT team about what you have read or heard about BMT and how it may relate to your child.

Your child's BMT team

There are many people who will care for you and your child. These people make up your BMT team.

- **BMT Attending**: A doctor who oversees the care of your child before, during and after a transplant. You will meet your child's primary BMT doctor at the consult visit. There are several attending BMT doctors, and a different one can care for your child at any time.
- **BMT Fellow**: A doctor in training for childhood cancer and blood disorders. They help care for your child with the BMT Attending.
- **Advanced practice provider (APP)**: A pediatric nurse practitioner or physician assistant with advanced medical training who coordinates medical and nursing care for your child. They help care for your child with the BMT Attending.

- **BMT nurse**: Provides daily care for your child, such as giving medicine. A BMT nurse will help care for your child in the clinic after they go home from the hospital.
- **Transplant coordinator**: A nurse who helps you and your child's doctor arrange your child's transplant care. The coordinator is your main contact as you prepare for a BMT.
- **Financial coordinator**: Helps you learn about your insurance plan, helps you find financial aid for your child's care and helps you with insurance approval for the transplant.
- **Research staff member**: Coordinates treatment and testing of children enrolled in research studies. The research staff member also collects information on children enrolled in studies.
- **Psychiatrist**: A doctor who can help you and your child cope with your feelings and can prescribe medicines if needed. All BMT patients meet with a psychiatrist or psychologist at the start of the transplant and then as needed.
- **Psychologist**: A professional with training to help you and your child deal with the stress of a transplant. A neuropsychologist can also test your child's thinking abilities. All BMT patients meet with a psychiatrist or psychologist at the start of the transplant and then as needed.
- **Social worker**: Provides guidance and counseling to help you and your family. They can also help you with emotional support, financial concerns, travel, housing and follow-up care after going home from the hospital. All BMT patients meet with a social worker.
- **Chaplain**: Addresses your spiritual needs. The chaplain offers spiritual care, support and prayer based on your family's needs and faith.
- **Registered dietician**: A nutritionist who helps with your child's nutrition and diet needs. They will also teach you about safe and healthy food during the transplant process. All BMT patients meet with a nutritionist.
- **Pharmacist**: A professional with training to prepare medicines. The pharmacist helps the BMT team choose medicines and adjust doses for your child's special needs.
- **Case manager**: A nurse who works with your insurance company to help make sure that your child's hospital stay is covered. They also help arrange home healthcare and medicines when your child goes home from the hospital.
- **Patient teaching coordinator**: A nurse who will help prepare you to care for your child when you leave the hospital. They teach you things like how to care for your child's central venous access device (CVAD) or feeding tube and how to create a routine for medicines that your child will need.
- **Physical therapist**: Works with your child on exercises to keep up strength during the transplant. All BMT patients meet with a physical therapist at the beginning of the transplant and then as needed.
- **Speech therapist**: Works with your child if they have problems with speech, language or eating.
- **Occupational therapist**: Works with your child if they have problems with daily living activities.
- **Music therapist**: Uses music to help your child physically and emotionally. Music has been shown to help children gain strength, manage pain, meet developmental milestones and express their feelings.

- **Child life specialist**: Uses play to help your child feel comfortable in the hospital and learn about their transplant. The child life specialist will answer questions in a way that makes sense to your child.
- **Volunteers**: Trained hospital volunteers who help provide activities for your child.
- **School teacher**: A Georgia-certified teacher who will help your child keep up with school work while in the hospital. The hospital teachers work with any child in kindergarten through 12th grade. A teacher or volunteer will teach your child in their room and will also arrange home-bound teaching for children in public schools.

What is a BMT?

There are many different words that are used to describe a BMT. These include:

- Bone marrow transplant
- Stem cell transplant
- Blood stem cell transplant
- Peripheral blood stem cell transplant
- Hematopoietic stem cell transplant
- Cord blood transplant

These words mostly describe the same process and use the same kinds of cells - blood stem cells. The differences are where the blood stem cells come from and the exact treatment given. Ask your child's BMT doctor about the best words to use to talk about your child's type of transplant. Ask questions when you hear a new word.

BMT is not a surgery. It is a treatment that takes place for weeks and months. It helps restore blood stem cells that are damaged, missing or not working because of:

- *Chemotherapy* or *radiation* used to treat cancer
- Genetic disorders (passed from parent to child through the genes)
- Other diseases

Without healthy blood stem cells, the body cannot work as it should. The BMT process is explained in this guide. Your child will have treatment with chemotherapy and sometimes other medicines and radiation to get their body ready for the transplanted cells. This treatment is called the *preparative regimen* (see page 50).

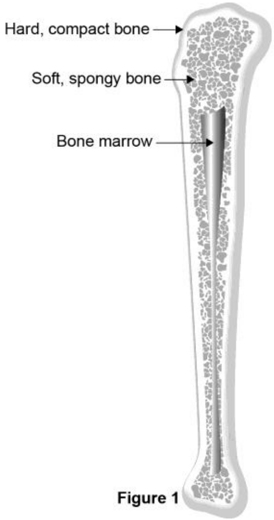


Figure 1

What is bone marrow?

Bone marrow is the soft, spongy tissue and liquid found inside bones. Marrow is where blood cells are made (figure 1).

What are blood stem cells?

Blood stem cells are the youngest type of blood cell found in bone marrow. Blood stem cells make more blood stem cells and other parts of the blood (figure 2):

- White blood cells that fight infection
- Red blood cells that deliver oxygen through the body
- *Platelets* that help clot blood and stop bleeding

Working together, these cells keep us alive and healthy. When the time is right, your child will get new blood stem cells through a central venous access device (CVAD). A CVAD is a soft, flexible tube that goes into a large vein in the body. It can be used to:

- Draw blood.
- Give fluids and medicine.
- Give blood stem cells. It is like getting a blood transfusion, but instead of getting red blood cells, your child will get healthy blood stem cells.

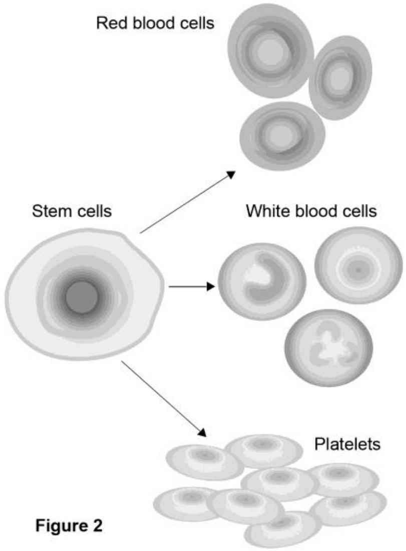


Figure 2

The cells travel to the bone marrow after they are in the blood. These new healthy blood stem cells will grow in your child's bone marrow over time. The blood stem cells will then support the body. The new blood stem cells are also known as the *graft*.

Why a BMT?

A BMT can treat many types of cancers and blood disorders. It may help if:

- Your child's bone marrow does not make healthy blood stem cells.
- Your child's *immune system* does not work well.
- Your child has a certain kind of cancer.
- Your child's bone marrow does not make enough blood stem cells.
- Your child's bone marrow does not make enough healthy red blood cells.

Blood cancers

Blood cancers, such as leukemia, cause the bone marrow to make unhealthy numbers of cells. These cells crowd out the healthy cells and cause them to not work well.

A BMT can help replace unhealthy blood stem cells in the bone marrow with healthy blood stem cells. The healthy blood stem cells help:

- Support the body and keep it healthy.
- Keep leukemia from coming back by using the immune system. This process is called a graft-versus-leukemia effect.

Solid tumor cancers

If your child has a tumor that is hard to treat, doctors sometimes use high doses of chemotherapy as part of treatment. The high-dose chemotherapy can damage healthy blood stem cells. Your child may need a BMT to help rescue their blood stem cells after chemotherapy. This process is called high dose chemotherapy with stem cell rescue.

Solid tumors that may need a BMT include neuroblastoma and certain brain tumors. These tumors are very aggressive cancers that do not respond as well to regular chemotherapy.

- High-dose chemotherapy or radiation is used to treat these cancers.
- High-dose treatment may increase the chance of a cure.

Diseases other than cancer

Diseases other than cancer may cause blood stem cells to not work as they should. These problems may affect the white blood cells, red blood cells or platelets. All bone marrow may need to be replaced with new blood stem cells to correct these problems. Some blood and genetic disorders that may need a BMT include:

- Hemoglobin disease, including sickle cell anemia and beta thalassemia major
- Aplastic anemia
- Immune deficiency syndromes, including SCID and Wiskott-Aldrich syndrome
- Fanconi anemia
- Paroxysmal nocturnal hemoglobinuria (PNH)
- Myelodysplastic syndrome
- Metabolic storage diseases

Types of BMT

There are 2 main types of BMT. The difference between them is based on who is donating the blood stem cells for transplant.

Autologous transplant - your child is the donor

The treatment needed to kill the cancer cells in your child's body can also destroy much of the bone marrow. Your child's own blood stem cells, which are collected before the chemotherapy or radiation begins, are then given back to them. The blood stem cells help the immune system and blood counts recover more quickly and safely than without the blood stem cells. We often call it a rescue.

- Depending on your child's needs, they may get 1 or more rescue transplants. These transplants are known as sequential or tandem transplants.
- Autologous transplants are mainly used for solid tumors, such as neuroblastoma and brain tumors.
- Sometimes autologous transplants are used as a treatment for cancers, such as certain types of leukemia.

Ask your BMT doctor about why an autologous BMT may or may not be right for your child.

Allogeneic transplant - someone other than your child is the donor

Finding a donor who is compatible with your child requires special testing of your child's blood. This special testing is called *human leukocyte antigen* (HLA) typing.

- Your child will have blood drawn to check their HLA type. The HLA type is different from a regular blood type test.
- Your whole family may get testing. This includes your child's brothers and sisters.
- Your child's doctor may do this test before the BMT consult.
- HLA testing results for your child and family members can take 2 or more weeks to come back.

An allogeneic transplant can be used to treat many types of diseases. This includes:

- Acute lymphoblastic leukemia
- Acute myeloid leukemia
- Non-Hodgkin's lymphoma
- Myelodysplastic syndrome
- Other disorders, such as bone marrow failure syndromes, sickle cell disease, immune deficiency syndromes and storage diseases

The BMT team will decide on the best donor for your child. The goal is to find the best matched donor possible for your child.

- The ideal donor is an HLA-matched sibling (brother or sister). Each full sibling has a 25 percent chance of being an HLA-match with your child.

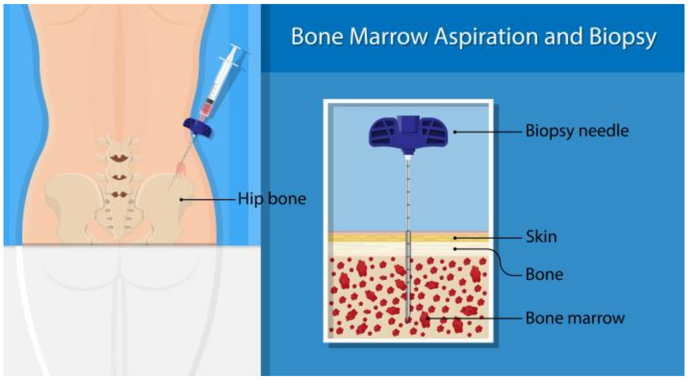
- If there is not a match within your family, a national or international search is done to find your child a donor.
  - Your BMT team will work with the National Marrow Donor Program (NMDP) or cord blood registries to do the search.
  - The search and donor evaluation process may take at least 2 months.
- If a matched donor is not found, your BMT doctor may consider using a partially matched donor. This donor could be from within your family, the NMDP or cord blood registries.

Where will the healthy blood stem cells come from?

There are 3 ways to collect a graft (healthy blood stem cells) for a transplant:

- From the bone marrow itself. This is called a bone marrow harvest.
- From the peripheral (circulating) blood. This is called a peripheral blood stem cell apheresis.
- From the umbilical cord at birth. This is called an umbilical cord blood collection.

Bone marrow collection



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- For a bone marrow collection, blood stem cells are most often collected (removed) from bone marrow in the hip bone (figure 3). We use the hip bone because it has a large amount of bone marrow and is easy to reach.
- The collection is done in the operating room (OR) while the donor is under general *anesthesia* (in a deep sleep and unable to feel pain).
- Once asleep, the donor is placed on their stomach.
- A large needle is placed into the hip bone. A small amount (about 1 to 2 teaspoons) of bone marrow is taken out with a syringe using sterile conditions.
- The needle is put back into the hip bone through the same skin hole many times. This allows the doctor to get enough cells for the transplant.
- The total amount of cells removed depends on the weight of your child and the weight of the donor.
- The bone marrow collection takes about 1 hour.
- The bone marrow from the donor is not permanently lost, and the donor's immune system will still be able to fight infection. The donor's bone marrow starts making new cells right away to replace the collected marrow.

After the collection is over, the donor will have 2 to 4 small skin holes on the back of their hip bones. Often there are no stitches. A large bandage is used to cover the holes for a day. The donor:

- May remove the bandage after 24 hours.
- Must keep the holes clean until they are healed all the way.
- Will likely be sent home the same day.
- May be given pain medicines by mouth (to swallow) for pain in the hip.
- May be asked to take iron supplements before and after the collection.

The risks of having a bone marrow collection are like having other minor surgery, such as getting your tonsils removed.

- There is a risk with general anesthesia, which the anesthesia doctor will explain.

The donor may:

- Have pain in the hips for a few days.
- Be tired for a few weeks because of anemia (low red blood cell count).
- Need a blood transfusion if a large amount of marrow is removed.

Peripheral blood stem cell collection

Blood moving through the bloodstream is called peripheral blood. Blood stem cells can be removed from the peripheral blood. This type of collection is called a peripheral blood stem cell apheresis.

- The donor may receive a medicine called a growth factor (GCSF or Plerixafor). This medicine helps the bone marrow make new blood stem cells quickly and pushes them into the bloodstream.
  - The donor may receive growth factor every day for 3 to 7 days.
  - The growth factor is given by a shot under the skin using a small needle.
  - The doctor will decide if the donor needs to receive the growth factor and for how many days.
- The blood stem cells are ready to be collected when there are enough blood stem cells in the donor’s bloodstream.
- The blood stem cells are collected through a large I.V. in the arm or CVAD into a machine called an apheresis machine. This machine collects blood stem cells and returns other important cells (red blood cells, white blood cells, platelets and plasma) back into the donor’s blood. The machine does not cause pain.

The collection takes 3 to 4 hours with the donor hooked to the machine.

- The collection may need to be repeated every day until enough blood stem cells are collected for the transplant.

- The blood stem cells are either frozen with a preservative and stored until the transplant or they are given to your child on the same day. Blood stem cells can be safely frozen and stored for at least 10 years.

The risks of having a peripheral blood stem cell collection include:

- Pain when the growth factor shots are given.
- Fever and bone pain from the growth factor medicine.
- Numbness and tingling of the lips and fingers. This is caused by low calcium levels. Your child may be given calcium supplements during the procedure to help with calcium levels.
- Low blood pressure or fever during the collection.
- Transfusions of blood or platelets are needed before or after the collection.
- The donor may not have enough blood stem cells to collect. This is rare.

Helpful tips for the collection day:

- Expect it to be a long day. It may last 4 to 8 hours. The day most often begins at 8 a.m. It is important to be on time.
- Bring activities, such as handheld video games, coloring or puzzle books, books to read or a music player with headphones.
- Pack a lunch or snacks for your child.

Umbilical cord blood collection

The placenta and umbilical cord of a newborn baby are rich sources of blood stem cells. The blood stem cells can be collected when a baby is born by:

- Cutting the umbilical cord.
- Removing the blood from the cord and placenta right away.

The blood stem cells are frozen with a preservative and stored until they are needed for transplant. The collection poses no risk to the mother or baby.

HLA typing

Why is HLA matching important?

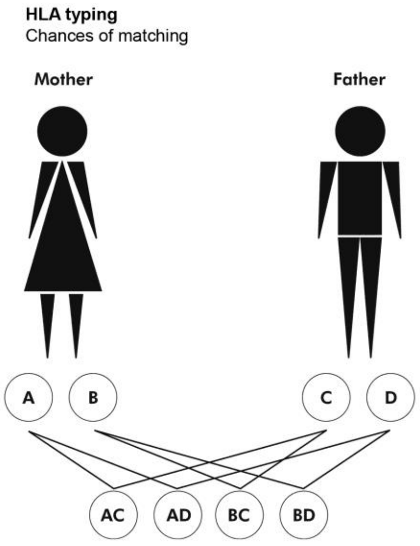

Figure 4

Human leukocyte antigens (HLA) are proteins found on cells in the body. Each person's HLA type is unique, like a fingerprint. The HLA system helps the body's immune system decide whether a cell belongs to the body (self) or if it is a cell from outside the body (non-self). When outside cells, such as germs, enter the body, they are seen as non-self. Our *immune system* then attacks and gets rid of these unwanted cells.

The HLA system also sees transplanted blood stem cells as non-self.

- If blood stem cells come from a brother or sister who is an HLA-identical match, they are more likely to be seen as self and be accepted.
- If blood stem cells come from a donor who is not HLA-identical, the cells may attack or be attacked because they are non-self. These donor cells can fight against your child's body, instead of working with it. If this fight happens, there can be problems and the BMT may not work.

How is HLA type determined?

The *genes* each parent passes onto their child determine HLA typing. We get half of our HLA genes from our mother and half from our father. Children with the same mother and father (full siblings) each have a 1 in 4 chance (or 25 percent) of being HLA-identical to each other (figure 4).

Your child's HLA typing can be compared to another person's HLA typing to see if they are a good match. If they are a good match, the other person could be a BMT donor.

Donor options

There are a number of ways to get allogeneic blood stem cells. No matter where the cells come from in the body or who donates them, your child is always given healthy blood stem cells.
For an allogeneic transplant, the donor may be related or unrelated.

Related (family member)

- **Matched, sibling donor**: Blood stem cells are collected from an HLA-identical brother or sister.
- **Partially matched, related donor**: Blood stem cells are collected from a family member who is at least a half match. This half match is also called a haplo donor. A child's mother or father is most often a half match. These donors can be compatible but not a perfect match.

Unrelated (not a family member)

- **Matched, unrelated donor**: Blood stem cells are collected from a person who is not related to the child. They have volunteered to be a donor and are an HLA match.
- **Partially matched, unrelated donor**: Blood stem cells are collected from a volunteer donor who is not a perfect HLA match but is compatible. A partially matched, unrelated donor may be an option when a better HLA match cannot be found.

The unrelated donor search process can take at least 2 months. This time depends on:

- How common your child's HLA type is in the national registries. HLA type often follows racial and ethnic lines.
- The donor's interest in donating.
- Physical problems that may prevent donation.
- Umbilical cord blood products that can be found more quickly.

If an initial search shows there may be a match, the BMT team requests a formal search.

- The formal search includes further typing of the volunteer donor or umbilical cord blood unit.
- This further typing makes sure the donor is truly HLA-compatible.

A person must learn about the donation process before making a final decision to donate. They will also be tested for any health problems that could prevent the donation. Once a donor is medically cleared for donation, your child may begin the transplant process.

The National Marrow Donor Program (NMDP) helps locate blood stem cell donors for patients who do not have a donor in their family. The NMDP manages the world's largest registry of volunteer blood stem cell donors and cord blood units. Visit marrow.org for more information.

Note: For patients who receive an unrelated donor's marrow or stem cells, there are rules about contacting the donor. The BMT team will talk about these rules with you and your child during the transplant process.

Preparing a family member to donate

To make sure the donor is healthy enough to move forward, a pre-harvest evaluation is done and most often includes:

- Blood tests to check blood counts and chemistries.
- A physical exam by a *pediatrician* or *internist* to look for any signs of illness.
- A health history with questions about any recent surgery or illness.
- A standard donor questionnaire that asks about risk factors for certain infections. Since the questionnaire is often used for adults, you may find some of the questions strange for a young child. However, they all need to be answered.

Notes

Notes

Preparing for the BMT Journey

Preparing for a BMT is a busy time. Your child will be at or near the hospital for a long time. You may be away from home for many months. Getting ready is even more important if you live outside of the Atlanta area.

You and your child will take a tour of the BMT unit during the period before the transplant. The tour may help you and your child feel more at ease when you check into the hospital for your child's transplant. This section will help you with the many things you need to think about as you prepare for your child's BMT journey.

Choosing your child's primary caregiver

You will need to choose a primary caregiver for your child to care for them during the BMT process. This will include a long hospital stay and frequent clinic visits after discharge. It is best if this person is a parent, but it can also be another family member or friend. The caregiver is an important member of the transplant team. Your child needs a strong and able caregiver for a safe transplant process.

The caregiver must be someone who can:

- Be with your child every day.
- Be reached by cell phone at all times.
- Provide care. This includes:
    - Doing mouth care, bathing your child, changing diapers or helping your child to the toilet.
    - Doing central venous access device (CVAD) care (see page 41).
    - Giving medicine by mouth (to swallow) and by CVAD.
    - Watching for changes in your child and telling the transplant team right away.
- Provide personal and emotional support. This includes:
    - Talking with other family members and friends.
    - Giving updates on your child.
    - Letting the transplant team know when you need help.
    - Asking questions when something is not clear.
- Make sure your child:
    - Keeps all visits.
    - Has transportation going to and from the hospital and clinic.
    - Has a clean home or place to stay away from home.
    - Has safe and healthy food.

Your child’s transplant timeline

Your child’s transplant days are referred to by numbers. Numbering the days helps the BMT team share information with each other about your child’s status. It helps them to know what to expect at a given time.

- The day of your child’s transplant (infusion) is Day 0.
- When talking about the 7th day before the transplant, it is called Day -7.
- One hundred days after transplant is called Day +100.

The timeline of each child’s BMT process varies. It is affected by:

- The type of transplant your child gets.
- Your child’s illness.
- Donor availability.
- Your child’s response to pre-BMT treatment.

Some children may meet with the BMT team but then need several months of treatment before the transplant. Other children may be newly diagnosed but then begin the transplant process right away. Your child’s doctor will talk with you about the expected length of treatment before transplant.

The month before transplant: pre-BMT period

You will need to help get your child ready for their BMT. Getting ready involves helping your child through many tests and exams. The goals of the pre-BMT period are to:

- Check your child’s overall organ functions and general health.
- Check the status of your child’s underlying disease.
- Get insurance approval.
- Prepare for the transplant admission.

We will:

- Give you a detailed, pre-BMT evaluation schedule with date, time, place and other important information.
- Schedule meetings with you and your child’s BMT doctor. They will talk with you about the treatment plan and results of your child’s tests. You will have a chance to meet other important BMT team members.

Organ function and health screening

During your child’s first visit before the transplant, we will check your child and get their health history. We will do tests that will tell us about your child’s heart, lungs, liver and kidneys. We need to know they are working well before we start treatment. These tests also give us a baseline of health to compare to when watching for problems after the transplant.

Some tests may include:

- **Echocardiogram (echo)**: Checks the heart's shape, size and ability to pump. It is an ultrasound of the chest and is not painful.
- **Pulmonary function test (PFT)**: Checks how well your child's lungs work to move air. Your child will blow into a machine to look at how the lungs work.
- **Glomerular filtration rate (GFR)**: Checks how well your child's kidneys are working. It is most often done by drawing blood several times during the day after the injection of a special medicine.
- **Computed tomography (CT) scan**: Checks to see if there is any infection that may need to be treated before BMT.
- **Audiogram**: Checks your child's hearing. Some medicines can damage your child's hearing.
- **Other consults**: Your child may need to see other doctors or specialists, such as the radiation oncologist if radiation is planned.

Blood tests

Your child will have blood tests at different times. They may include:

- **HLA typing**: This test is often done before your child comes for the first visit to see if anyone in your family can donate matched blood stem cells for your child (see page 14).
- **Complete blood count (CBC)**: Checks your child's white blood cell, red blood cell and platelet counts.
- **Chemistry panel**: Checks how well your child's kidneys and liver work and the level of salt in the blood.
- **Infectious disease markers**: Checks for certain *antibodies*. These antibodies will show if your child has been exposed to certain viruses, such as *hepatitis*.

Physical exam

Before your child's BMT, they will have a physical exam. The exam will take place in the Aflac Cancer and Blood Disorders Center clinic at Children's Healthcare of Atlanta at Arthur M. Blank Hospital. The time needed for the exam depends on your child's illness. If the donor is a family member, that person will also need a physical exam in the clinic before the transplant.

Dental exam

Make sure your child gets a dental exam before treatment starts. If your child needs dental work, it should be done well before the BMT. It may not be safe for your child to have dental work in the months after the transplant. This is because the mouth is normally full of germs. During the transplant, these germs can get into the bloodstream and cause your child to get very ill.

If you do not have a family dentist, let your BMT coordinator know. We can refer you to one.

Disease work-up

We may need to do more tests before your child is admitted to the hospital. This depends on your child's disease and treatment plan. Some tests may include:

- Bone marrow aspiration and biopsy
- X-rays or imaging scans
- Eye exams
- Psychological tests

Central venous access device (CVAD)

There will be many times when your child needs blood drawn or medicine given during the BMT process. Your child will have a central venous access device (CVAD) placed before or on the day of admission to the hospital for BMT. The CVAD is a soft, flexible tube that is put in the chest and into a large vein above the heart. The CVAD is used for:

- Chemotherapy
- Infusion of blood stem cells
- Nutrition
- Fluids or blood products
- Antibiotics and other medicines
- Blood samples for tests

Your child will need a CVAD even if they already have a port-a-cath. The CVAD may be removed when your child does not need frequent blood draws, medicines or transfusions. Most often, the CVAD can be removed several months after the transplant. This decision will be made by your BMT team based on your child's progress after transplant.

Informed consent conferences

We want to make sure that you and your family understand the transplant process. We also want you to have the chance to ask questions.

- We will set up 2 meetings with members of your child's BMT team for you and your family.
- Your child should also come if they are old enough. We will talk with your child in a way they can understand.
- These meetings are called *informed consent* conferences. Informed consent means your child's doctor will tell you important facts before you give your permission, or consent, for your child to have a BMT.

During the first meeting, the BMT team will discuss:

- Your child's BMT treatment plan.
- The reason for your child's treatment and BMT.
- Possible benefits, risks or problems.
- Possible side effects from medicines.
- The expected length of time needed for your child's treatment.
- Whether or not your child can take part in a research study for their treatment.
    - If so, you should understand which parts of your child's treatment are research and which parts are standard care (see page 86).
    - The BMT team will also discuss supportive treatment research studies and non-treatment research options that are available.

At the end of the meeting, you will be given informed consent papers to take home and read when you have more time. Feel free to make notes and write down questions on these forms. Take time to discuss the information with your family and your child. Do not sign the forms until you come back and have a chance to ask more questions of the BMT team.

During the second meeting, the BMT team will again review as needed:

- Your child's BMT treatment plan.
- Possible risks or problems.
- Research studies in which your child can take part.

We will also answer your questions and give you any other information that you need. At the end of the meeting, we will review the informed consent forms with you. Before signing any forms and starting treatment, make sure:

- You understand the information and your child's treatment plan and options.
- All of your questions are answered.

The BMT team wants you and your child to read and ask questions about the treatment plan and consent forms before signing them. When you sign the consent form, it means you have agreed your child should have a BMT. Make sure you understand all that has been explained to you about the BMT. If your child is young, you may want to bring another adult to play or sit with your child while you meet with the BMT team.

Before the transplant

- Write down your questions and concerns. Bring them to your child's clinic visits. Use the Notes sections in this guide. Bring the guide with you every time you come to the hospital or clinic.
- Ask a family member or friend to come with you to meetings with your child's doctor and BMT team members.
- Tour the hospital floor and patient rooms before your child is admitted. This tour may help you and your child feel less afraid and more at ease.
- Arrange childcare for your other children.
- Get a flu shot. Parents and siblings of a transplant patient should get a flu shot during the flu season.
- Be open and honest about your feelings and needs with family and friends. This will help them know how to help you. Have answers ready to share when they ask, "How can I help?"

Ideas for how others can help

- Donate blood or platelets in honor of your child. Your child may need many units of blood and platelets. Family and friends can help keep up the supply, even though the donated blood or platelets would not go directly to your child. They do not have to have the same blood type as your child.
- Take care of housework, or help with childcare, family meals and errands.
- Visit or stay with your child for part of a day or overnight if you need a break. Make sure the visitor is not sick (see page 35).
- Prepare activities to keep your child busy during the hospital stay. Ask for hard-surface, easy-to-clean items. Avoid stuffed animals and cloth items.
- Take your other children for a special outing or activity.
- Talk with your BMT team about any pets you have. There may be special guidelines.

For older children and teens

- If your child is male and has been through puberty:
    - He may want to think about sperm banking. Talk with the transplant coordinator for more information (see page 81).
- If your child is female:
    - She may want to meet with a fertility specialist to talk about options. Your transplant coordinator can help you arrange a consult with a fertility specialist.
    - If she has started her menstrual periods, tell the doctor. She may need to take medicines to prevent periods.

- If your child is 18 years of age or older, they may want to prepare an Advance Directive. The BMT social worker will talk about this with you and your child.

The chart below lists some items that patients are not allowed to have when getting a transplant. These items can have germs and increase the risk for infections.

Items NOT allowed	When it is NOT allowed	Follow these directions
Artificial (fake) nails	Before, during and after transplant	• Remove artificial nails. • Keep natural nails trimmed short.
New tattoos and body piercings	During and after transplant	• Remove all piercing jewelry before admission.
Teeth braces	During transplant	• Remove braces before admission.
Contacts	During transplant	• Remove contacts. • Use eyeglasses.

- Artificial nails are not allowed for BMT patients before or after transplant. Your child should not get artificial nails before admission to the hospital.
- If your child has a piercing, remove the jewelry before their transplant admission.

Talking with your child about a transplant

Explaining a BMT to your child can be overwhelming. Child life specialists can help talk with you or your child. Some ideas for talking about a BMT with your child include:

- Talk slowly. Allow time for your child to understand.
- Give them a chance to ask questions.
- Give your child hope that will help carry them through the times ahead.
- Tell the truth so your child can continue to trust you.
- Give age-appropriate information.
- Realize your child does not need to know everything you do.

Think about your child’s age and developmental stage when talking with them about their BMT.

Babies (birth to 12 months)

- Look to their parents to meet their needs.
- Rely on adults for food, comfort, play and care.
- Learn about the world around them through their senses, such as smelling and tasting.
- Trust people and things that are familiar.
- May fear being separated from you.
- May fear strangers.
- Respond to the new people and environment around them.

Some issues and fears	How you can support your baby
• Separation from familiar people	• Be with your baby as much as possible. • Leave a shirt with your smell on it if you need to leave. • Rock or hold them. • Keep familiar blankets and toys nearby.
• Fear of strangers	• Have the same people care for your baby when possible. • Limit the number of people and voices in the room.
• Development	• Allow your baby to explore toys with their hands and mouth. Be sure toys are clean and there are no small pieces that they could choke on. • Use gentle touch and massage to comfort them. • Talk to them and play games, such as peek-a-boo, like you would at home.
• Sense of safety	• Keep your baby’s crib a safe space - ask if the staff can use the treatment room for painful procedures; this is not always possible. • Wake your baby before a painful procedure. • Try to keep normal feeding, bathing and bedtime routines as much as possible.

Toddlers (13 months to 3 years)

- Start to do more on their own. Your toddler's favorite words may be "me do" or "no."
- Do some things by themselves. Allow them to do this because it gives them a sense of control.
- Use actions to show you how they feel because they do not have the words to describe their feelings.
- Have a hard time understanding how the inside of their bodies work.
- Think they make things happen. They may create ideas about how they got sick and what happens to them.

Some issues and fears	How you can support your toddler
• Fear of separation • Fear of strangers	• Be with your child as much as possible. • Have the same people care for your child when possible. • Provide security objects, such as a blanket or stuffed animal. • When leaving, tell them where you are going and when you will be back. • Leave something of yours, such as a picture or shirt, for them to keep until you return.
• Loss of control	• Allow your child to make choices when you can (like choosing apple or orange juice). • Do not offer a choice when there is not one ("Are you ready for your medicine?" is not a choice). • Give them a job to do, such as holding a bandage or Band-Aid. • Allow them to play and be in control of the game or activity.
• Loss of normal routine	• Try to keep normal eating, sleeping and bathing routines as much as possible. • Let them play with their favorite toys.
• Behavior changes	• Give them safe ways, such as painting and building blocks, to express anger and other feelings. • Tell them it is OK to feel mad or sad. • Spend time with them, and reassure them. • Set limits and give discipline when needed. Your child needs limits to feel safe. • Praise them whenever possible.
• Fear of treatment (like medicine, vital signs and tests)	• Ensure them that they did nothing wrong. • Keep security objects nearby (like a blanket, pacifier or stuffed animal). • Use simple words, pictures or books to tell what will happen. • Tell them what will happen just before the treatment.

Preschoolers (4 years to 5 years)

- Take pride in being able to do things for themselves: “I can do it.”
- Know more words to tell you what or how they feel. They still use actions to tell you things.
- May see the hospital, treatment and pain as punishment for “being bad.”
- Get confused by adult words and make up reasons for the things that happen.
- May fear being separated from you.
- May fear a new environment.
- May fear needles.
- May act younger than normal.

Some issues and fears	How you can support your preschooler
• Magical thinking (make up reasons for what happens) • Medical words they may not understand (like thinking a CT scan has to do with a cat) • Fear of harm to their bodies • Fear of the unknown	• Use simple words, pictures or books to tell them what will happen. • Tell your child what will happen a little before the treatment. • Let your child play with doctor kits and safe medical supplies, such as a blood pressure cuff.
• Loss of control	• Allow your child to make choices when you can (like choosing apple or orange juice). • Do not offer a choice when there is not one (“Are you ready for your medicine?” is not a choice). • Give them a job to do, such as holding a bandage or Band-Aid.
• Loss of normal routine • Behavior changes	• Praise your child for doing things for themself (like dressing, brushing teeth and feeding). • Give them time to get used to new changes. • Use play to help your child show their feelings.

School-age children (6 years to 12 years)

- Take pride in doing most things by themselves.
- Enjoy school because it helps them learn and get good at new things.
- Think friends are important.
- Think about cause and effect. They have a better sense of time.
- Learn more words to describe their bodies, thoughts and feelings
- Understand more of how their bodies work. They may still have a hard time understanding medical words.
- May fear loss of control.
- May worry about pain.

Some issues and fears	How you can support your school-age child
• Loss of control	• Allow your child to make choices when you can (like choosing apple or orange juice). • Do not offer a choice when there is not one (“Are you ready for your medicine?” is not a choice). • Give your child a job to do, such as holding a bandage or Band-Aid. • Let them practice things that are new or scary. • Let them go to school or do schoolwork. • Provide games, play and activities.
• Being away from friends and school	• Have your child write letters or call friends. • Let friends visit when they feel well enough (see page 30).
• Fear of harm to their bodies • Fear of the unknown	• Use simple words, pictures or books to tell them what will happen. • Tell them what will happen a few days before the treatment, if possible. • Let your child play with safe medical supplies, such as a blood pressure cuff).

Teens (13 years to 18 years)

- See themselves as individuals in the world. They want to be independent.
- Worry about how others see them. Illness and treatment cause teens to be different when they are trying so hard to be the same.
- Understand cause and effect but also see things from many points of view

Some issues and fears	How you can support your teen
• Loss of control • Loss of independence	• Allow your teen to make choices when you can. • Let your teen be active in social and school activities. • Involve them in the treatment plan. Include them when talking to the care team about the plan of care. • Have them do their own self-care as much as possible (like washing and going to the bathroom).
• Body image • Self-esteem	• Give your teen chances to talk about physical and emotional changes. • Tell them it is OK to have many different feelings about illness and treatment. • Point out things they do well. • Allow your teen to do things that make them feel good about themself.
• Loss of privacy	• Respect that they may need to do some things by themself (like going to the bathroom and making phone calls). • Knock before entering your teen's room. • Offer them private time.
• Separation from peers	• Encourage time with friends. • Allow friends to visit and call.
• Concern for the future	• Answer questions openly and honestly. • Help your teen plan for the future. • Encourage them to keep doing normal things, such as going to school.
• Behavior changes	• Give your teen safe ways to express their feelings, especially anger. They may do this through physical activity, talking or writing. • Assure them that their feelings are normal (like guilt, fear and sadness).

During the hospital stay

There are a few things that can help you with the transplant hospital stay:

- Try to keep your child's schedule the same each day.
- Write down your questions. Notes can help you remember to ask the doctor or nurse about any concerns you may have.
- Keep a diary. A diary can help you work through your feelings and remember what happens day-to-day.
- Ask select family and friends to visit the hospital and give you support. They may be able to stay with your child when you need a break.
    - Ask visitors to call before coming to the hospital to make sure it is a good time to visit.
    - When visitors call before they come to visit, make sure they are not sick (see page 35).
- Keep in touch with your other children at home through phone calls, e-mails, Web chats and visits.
- Know that your child may act younger than their age. They may be more demanding, irritable, withdrawn or unfriendly.
- Try to keep a positive attitude. Take everything 1 day at a time.
- Maintain your own health. Get enough sleep, eat well, take breaks to exercise and do something for yourself.

Coping with the transplant process

Hospitals can be tough places for children and their families. It is normal to be scared and worried. Knowing the facts and what to expect is important; so is being able to express your fears, uncertainties and feelings. The medical team and family support teams are here for your child and family. The following may help to make your child's hospital stay less stressful:

- **Ask**: Encourage your family and your child to ask questions when you need more information. Talk with the care team at any time to answer your questions. If you need an interpreter, we can provide one for you.
- **Be honest**: Let your child know you may not have the answer to every question but that you can ask the care team to try to find the answer.
- **Listen and talk**: Listen to your child. Give them permission to ask questions, cry and talk about feelings. Let your child know it is OK to be afraid and say that something hurts.
    - Share your feelings, too.
    - Keep your child and family up to date about what is happening. They may feel less scared knowing what to expect. Prepare them for any changes before a visit. Ask the care team if you need help.
- **Comfort**: Being sick can be scary for a child, especially when they cannot be held or comforted like normal. Check with the nurse to find out what you can do to comfort your child. Remember that you, your other children and family members may need comforting also.

- **Maintain**: Keep as normal a routine as possible.
  - Bring in your child's favorite toy, game, picture or book.
  - Leave a shirt or other personal items with your child when out of their room. It tells your child you are not far away.
  - Tell them when and why you leave the room or hospital. Telling the truth helps them learn to trust you.
  - Other thoughts to share with your child and family include:
    - Being in the hospital is not a punishment.
    - No one is to blame.
    - Hospitals help people get well.
    - Post a daily schedule in your child's room.

Learning about finances

The BMT team wants to help you learn about insurance and finances for your child's BMT. Finances are a big concern to our families. BMT can be costly. We hope to decrease the stress around finances by giving you information and support. Our financial counselor is here to help with any questions or concerns. Let the BMT team know if you need help at any time.

The transplant financial counselor can help you learn about:

- Your insurance coverage.
- Billing issues.
- Information on fundraising and other options to help lower your out-of-pocket expenses (amount of money you have to pay).

Your social worker may also know of financial resources that can help you. Talk with the social worker about any financial concerns or other issues when you meet with them before a transplant.

For billing questions, call the Patient Accounts department for Children's Healthcare of Atlanta at
Arthur M. Blank Hospital at 404-785-5589.

How your social worker can help

Your social worker will discuss many topics with you before your child's admission for transplant. This can help make the transplant process go more smoothly for you and your family. Some topics may include:

- Documents that you need to provide.
- Financial issues and resources.
- Your family's personal needs.

Your social worker may know of resources that can help you. Talk with your social worker about any concerns you have. The following information outlines areas in which your social worker can help.

Before admission

- **Advance Directives:** By law, we need to ask anyone 18 years of age and older if they have an Advance Directive. If not, we will ask if they would like more information.
  - An Advance Directive is a legal way to make a decision about future medical care. This allows them to record their choices about medical treatment. This will also state who they want to make medical choices for them if they are too sick to do it on their own.
  - **Your child's social worker can provide Advance Directive forms. Complete them before admission.**
  - There are several types of Advance Directives.
    - Living wills
    - Durable power of attorney for healthcare
    - The Five Wishes document
- **Consent for alternative caregiver**: This is a medical consent, or permission, form that you may want to fill out and sign. It allows other family members or friends to care for, discharge or sign consents for certain procedures for your child if you are not able to.
- **Leave of absence**: If you need a leave of absence from your job to care for your child, you will need to obtain and fill out the proper forms for your employer. Contact your human resources department for more information.
- **Family Medical Leave Act (FMLA)**: Also ask if you are able to use the Family Medical Leave Act. It allows up to 12 weeks per year to care for a sick family member. While this is not paid leave, it can help protect your job.

Day-to-day in the hospital

- **Cultural issues and interpreter needs**: We have Spanish interpreters in the hospital. If needed, we can provide you with an interpreter for another language. If you have other needs based on your culture or religion, let the BMT team know before admission so they can make plans to help you.
- **Meals**: There is a kitchen in the family room that you can use to make meals. Most expenses during a hospital stay are spent on food. Buying drinks, snacks and food to prepare yourself will help you save money. If food expenses are a concern for you, talk with your social worker. Room service is available from 7 a.m. to 8 p.m. for patient meal trays. Parent trays are available for purchase.
- **Parking fees and transportation**: Parking at Arthur M. Blank Hospital is free. If you do not have transportation, talk with your social worker about resources to help with this need.

- **Phone service**: You must have reliable phone service before, during and after your child's transplant.
  - If you do not have a cell phone, be sure to have voicemail on your home phone. The care team must be able to reach you with important instructions about your child's care.
  - Tell the care team if your number changes or if you are having other communication problems.
- **Internet service**: The hospital has wireless Internet service (Wi-Fi). You may bring your personal computer or check out a computer through the hospital's family library.

For you and your child

- **Stress relief**: Being in the hospital is stressful. Often parents feel they do not get enough sleep, which can affect your ability to think clearly. It is important to take care of yourself so you can care for your child.
  - Bring items that can help you relax, such as books, crafts or music.
  - Limit the amount of TV you watch. It is helpful to have some quiet time to wind down at night.
  - Take a walk in the garden or go to chapel services.
  - Choose a friend or family member to pass along information about how you and your child are doing. This person can keep you from having to repeat the same things over and over to people who care about you. You can also use CarePages to provide updates.
- **Wish organizations**: There are several organizations that fulfill wishes for children with life-threatening diseases. Your social worker can give you more information. Keep in mind that your child cannot travel right after the transplant. Talk with your child's BMT doctor about the best timing for any wish trips.
- **CarePages**: This is a secure and private website you can create to update family and friends about your child's progress. It is also a way for them to share messages of support and offer help in a way that is not intrusive.
  - The service is free through choa.org.
  - You can use your CarePages before, during and after your hospital stay.
  - Once you register, you can invite your family and friends to visit the site for news and updates.
- **Managing your household**: You may be away from home for many months. Even though your focus will be on your child going through BMT, the rest of your life still goes on.
  - Make a list of who will manage things at home in your absence. This may include paying bills, feeding pets, picking up mail, and taking care of your house and yard.
  - Have a family member or friend stay in your home to care for your other children if needed. They can help your children keep a normal routine.

Leaving the hospital

- **Medicine**: Sometimes insurance companies or Medicaid will not cover certain medicine. Your social worker may know about resources to help you with these costs. Many drug companies may provide medicines to patients in need. Talk with your social worker about your medicine or home care needs.

- **Lodging**: Before the transplant admission, you and your child may need to make several trips to the hospital for tests and meetings.
    - If you must travel a long way:
        - You may be able to stay at Ronald McDonald House.
        - Your social worker can give you a list of hotels that provide a discount for hospital families.
    - After leaving the hospital, you may have to stay close to the hospital because of your child's condition. Your social worker can help you plan for how to cover the cost.
    - Insurance or organizations that provide financial assistance or lodging can help cover costs. You can use funds that have been raised in your community for your lodging. If you have no other resources, your social worker will find out if you can get help through a transitional housing fund.

Family support team

You may have many questions about how to help your child and family. The family support team is a group of experts who have special training to help answer your questions and offer emotional support. This team includes social workers, child life specialists, school teachers, chaplains and psychologists (see page 5).

Notes

During the Hospital Stay

Helpful hints and guidelines

There are many things that everyone can do to help protect your child from infections. Listed below are some important guidelines for you and your child to follow. Knowing these guidelines will help protect your child when it is time to go to the hospital.

Preventing infection

Your child's immune system is weak during and after BMT. It is easy for your child to get an infection through:

- Air.
- Food.
- Being around someone who is sick.
- Touching a surface, such as a doorknob or counter, that a sick person touched.

Your child can even get an infection from their own body since it is normal for germs to live on the skin and in the body. Most of the guidelines listed here can help protect your child from infection.

Visitor guidelines

- No visitors, including siblings, under 12 years old may visit your child in the hospital.
- Talk with your child life specialist for ideas about ways to keep brothers and sisters in touch.
- Your child should not have any sick visitors while in the hospital. Ask visitors to call you before they come so you can ask about recent symptoms or exposure to illness. All visitors will be screened for these before entering the unit:
    - Runny nose, cough or sore throat
    - Diarrhea
    - Vomiting (throwing up)
    - Eye drainage or pink eye
    - Fever
    - Rash
    - Chickenpox or *exposure* to chickenpox
    - Tuberculosis (TB) or exposure to TB
    - Any infection that can be passed to others

    If a visitor has any of these symptoms or exposures, they will be asked to leave the unit right away. If they have questions about these or any other symptoms, ask a nurse before they enter your child's room.

- All visitors must wash their hands before going into your child's room.
- All family members and visitors should get the flu shot before visiting your child.

- **Do not visit other patient rooms or patients in the playroom.** Other patients, both inpatient and outpatient, and their families cannot visit your child. Parents are welcome to visit with other parents in the family room or cafeteria.
- Media staff (such as TV or radio staff) are **not** allowed in your child's room or on the BMT unit, unless approved and escorted by Children's staff.

Hand hygiene guidelines

- Hand hygiene is the best way to help prevent the spread of germs.
- Everyone must wash their hands before entering your child's room.
- Wash your hands after you:
  - Go to the bathroom.
  - Handle uncooked food.
  - Touch garbage or anything that may have germs.
  - Blow your nose, cough or sneeze.
- You must also wash your hands after you care for your child. Wash them after you:
  - Change a dressing.
  - Change a diaper or help your child go to the bathroom.
  - Put cream on wounds or diaper area.
  - Wipe their nose.
- There are 2 good ways to clean your hands:
  - Soap and water (sinks are throughout the BMT unit and in your room)
    - Wet your hands.
    - Put soap on them.
    - Rub your hands together for at least 20 seconds.
    - Rinse them with water.
    - Dry hands with a paper towel. You can use the paper towel to turn off the water or open the door. This helps to keep germs off your hands.
  - Alcohol-based gel or foam (found inside and outside your child's room)
    - Put a small amount on your hands.
    - Rub your hands together. Be sure to rub both the fronts and backs of your hands.
    - Let your hands dry on their own.

Items in your child's room

- These items are **not** allowed:
  - Fresh flowers

  - Silk or artificial flowers
  - Live animals
  - Toys that hold water, such as fish tanks, rubber ducks or desktop fountains
- **Linens:** If you choose to bring linens from home for your child's bed, you will need to wash them every day during the hospital stay. Hospital linens can be used until items from home are clean.
- **Electrical items:** The engineering department needs to check any item that will be plugged into an outlet in the hospital.
- **Toys:** Use disinfectant wipes to clean toys, games, puzzles and dolls after each use.
  - If your child has brought a favorite stuffed animal, wash it 1 time each week. Bring only 1 stuffed animal.
    - Try to avoid bringing soft items like stuffed animals because they collect dust easily and can increase the risk of infection.
    - **Let your family and friends know that your child cannot have stuffed animals during their transplant.**
  - **Do not use toys from non-BMT playrooms for your child.** They are not clean for use with BMT patients.
  - Your child may use toys in the BMT playroom. Use disinfectant wipes to clean the toys when your child is finished.
- Clean all items before bringing them into the hospital.
- Latex balloons are **not** allowed into the hospital because of the danger of latex allergy.

Your child's room

- Do not leave food or drinks sitting around in your child's room for more than 1 hour. Germs may grow in the food and cause your child to get sick.
- Keep your child's room and counters free of clutter to help our environmental services (EVS) staff to better clean. Use the cabinets in the room to store your personal things.
- Keep the door to your child's room shut. There is a special filter in your child's room that helps clean the air of germs. This filter only works when the door is shut. If the door is left open, you will hear a soft alarm.
- Only parents can use your child's bathroom. Visitors should use the family room bathrooms.
- You may **not** nail anything to the wall. This includes pictures, posters and shelves.

When your child leaves their room

- Your child may not go into the family room.
- Your child should only leave the unit for tests or procedures.
- When your child leaves their room, they should wear a mask at all times. Your child's nurse can get you several masks to keep in your room.

- Your child may go to the BMT playroom.
  - Only 1 BMT patient is allowed in the playroom at a time.
  - Your child does not need to wear their mask inside the BMT playroom. The air is filtered to help clean the air of germs.
- Unless your child is a baby, they will need to walk laps during their transplant stay. Laps provide much-needed exercise.
  - Your child may walk around the nurses' station (with a mask on), but they cannot leave the unit.
  - They should not touch the counters, walls or other surfaces while walking laps.
- Your child should not sit at the nurses' station. This can put your child at risk for infection passed from another person or from contact with dirty surfaces.

In the hospital: what to expect

Your child is most often admitted to the hospital about 7 to 10 days before their transplant. You will receive a calendar on admission. **Most children spend 1 or more months in the hospital, but every child is different.** Your child's length of stay in the hospital will depend on the type of transplant and how quickly your child recovers. Ask your child's doctor to help you plan for how long your child may be in the hospital.

This section of the handbook will help you know what to expect each day during your child's hospital stay.

BMT rounds

Each day, your child's BMT team comes together to discuss the plan of care for your child. You will have the chance to make suggestions and ask questions. This meeting includes:

- Your child's nurse for the day
- BMT doctor
- Advanced practice provider
- Pharmacist
- Nutritionist
- Case manager
- Family support team members, such as a social worker psychologist or child life specialist

The team:

- Checks your child's blood tests and their intake and output.
- Talks about how your child is responding to treatment.
- Examines your child and talks with you about the plan of care.

Always check with your child's nurse before leaving the unit to make sure you know when the team may round on your child.

It is helpful to write down your questions before rounds so you will remember what to ask. It may also be helpful to get up and dress before the team comes so that you are ready to talk with them when they arrive.

We know that you and your child may be tired and not wish to be disturbed early in the morning. It is important that decisions are made early in the day so your child's needs are met as soon as possible.

- You can expect to see your child's BMT team every day between 9 a.m. and 12 p.m. (noon).
- The team may come back to see your child in the afternoon or evening if they need to make more plans or to answer any questions.

Weight

Keeping track of your child's weight is important. Tracking weight helps the BMT team keep a close watch on your child's body fluid balance.

- Fluids can sometimes build up in your child's body during and after transplant. Many problems can happen if your child's body is holding too much fluid.
- A care team member will weigh your child 2 times each day. They will do this around 8 a.m. and 8 p.m. It is important that we weigh your child every day at the same time and on the same scale.
- Your child needs to take off their shoes, and sometimes their clothes or diaper, before we weigh them.

Hygiene

Your child's immune system will be weak during and after transplant. They will have more of a chance of getting sick. Our skin normally has many germs on it. It is important to keep your child's skin as clean as possible.

- Your child will need a bath with chlorhexidine gluconate soap (such as Hibiclens) every day. This helps prevent infection.
- You will be given a special cleanser or soap for bathing your child each day.
- You may be asked to bathe your child more than 1 time each day.
- Your child's skin may get red and irritated from chemotherapy, soap or other skin care products. You will be given other types of skin care products if irritation happens.
- Keep your child's skin moist using lotions that the BMT team gives you. Moisture helps keep germs from getting into the bloodstream through the skin.
- Do not bring soap or skin care products from home. Many products, such as soaps, perfumes or deodorants, have alcohol or other ingredients in them that can irritate your child's skin.

Mouth care

Good mouth care is important. The mouth is normally full of germs. During transplant, these germs can get into the bloodstream and cause your child to get very sick. To help prevent infection:

- Keep your child's mouth clean. Have your child do mouth care at least 3 times each day.
- Mouth care includes brushing the teeth with a soft toothbrush.
- After brushing, your child will rinse with a special mouthwash that the BMT team gives you. Do not use mouthwashes that have alcohol in them.
- Other rinses may be used to help reduce pain from mouth sores.
- It is important to keep your child's mouth and lips moisturized to prevent drying and cracking. The BMT team will provide you with a special lip moisturizer.
- The BMT team will give you mouth care supplies for your child.

Fluid intake and output

BMT patients can have many problems with body fluids. It is important to see how much fluid your child is taking in and how much fluid is coming out. The nurses will record the intake and output every shift. They will let the doctors know if the fluids are not balanced. To help keep track of your child's intake and output:

- Let the nurse know anytime your child has something to eat or drink and how much it was.
- Save all urine, vomit and stool for the nurse to see and measure.
  - Let the nurse know when your child uses a urinal, bedpan or toilet. Do not flush anything until the nurse can record the amount and do any needed tests.
  - Older children are often embarrassed by this request. Help your child understand why it must be done.
- When you change your child's diaper, do not throw it away. We will weigh it to see how much urine or stool it has in it.

Exercise

Your child's illness and the BMT process can make your child weak. During and after the BMT, exercise is needed to help them gain strength. Have your child spend as much time as possible out of bed.

- Each day, your child should walk 10 laps around the nurses' station.
  - Walking laps is an important part of exercise during BMT. It helps strengthen the lungs, bones and muscles. It also helps improve mood.
  - Movement helps circulation and improves control of bodily fluids.
- Your child can use the BMT unit and BMT playroom for exercise.
- They must wear a mask at all times when leaving the room
- Your child cannot go to the clinic or leave the BMT unit.

- Your child **cannot** go to the:
    - Regular playroom
    - Teen room
    - Family room
    - Cafeteria
    - Garden
    - Chapel
    - Gift shop
    - Bingo

Rehabilitation (rehab) therapy

A physical and/or occupational therapist may work with your child.

- Physical therapy (PT) helps maintain your child's muscle mass and build endurance. Even when your child is not feeling well, make sure they get out of bed to exercise.
- Occupational therapy (OT) can help your child regain skills for daily activities, such as eating, dressing, playing and going to school.
- If your child is a baby or young child, the physical and occupational therapists will help them reach normal developmental milestones.

Incentive spirometer

Your child is at high risk for pneumonia because they are not able to fight infections after the transplant. They are also not using their lungs as well as they were before they became ill.

Each day, your child will use an incentive spirometer for breathing exercises to help prevent problems.

- An incentive spirometer is a handheld device that your child breathes into to exercise their lungs.
- Using it many times a day may help your child avoid pneumonia while they are in the hospital.
- Smaller children can use pinwheels, bubbles, blow pens and other toys for this exercise.
- Your child's nurse or respiratory therapist will show you how to use this device.

Central venous access device (CVAD)

Your child's CVAD needs care so that the tubes do not get infected or blocked.

- The nurses will flush your child's CVAD with heparin at least 3 times each week.
- The dressing that covers the CVAD is changed 1 time each week or more often if it gets wet, dirty, loose (the edges are coming up or the dressing is not sticking to the skin) or falls off.
- When the dressing is changed, the skin around the CVAD site is checked for redness, swelling, tenderness, pain or drainage. Tell the nurse or doctor **right away** if you see any of these or if your child complains of tenderness at the site.
- You will be taught how to take care of the CVAD before you go home. Several months after the transplant, the CVAD may be removed when your child no longer needs frequent blood draws, medicines or transfusions.

Child life specialists

Child life specialists are available Monday through Friday. They use play and other tools to help your child learn about and cope with their treatment and hospital stay. Child life specialists can:

- Make a list of jobs for your child to do each day. Jobs may include a bath, mouth care, walking laps or an exam by a doctor or nurse.
- Help motivate your child to do their daily routine. Programs like a sticker chart or "BMT bucks" can be used.
- Review the policies with you for using the BMT playroom and keeping toys clean.
- Help your child learn about and cope with any procedures they have.
- Help your child express their feelings through play, art, music and other interests.

Nutrition for your child in the hospital

Good nutrition can help your child recover from their transplant. Your child may need extra care to help them get good nutrition. The nutritionist will meet with you on day 1 of admission or the day after to discuss the nutrition process during the BMT stay.

- Most children lose their appetite and find it hard to eat during the BMT.
- The nutritionist may order nutritional supplements, such as Boost Kids Essentials, Ensure, Ensure Clear or Boost, to give them more nutrition.
- Most children need added nutrition from feedings through a nasogastric (NG) tube or a CVAD.
    - An NG tube is a soft, flexible tube that goes from the nose into the stomach. Feedings given through an NG tube are called enteral feedings.
    - The nutrition given through the CVAD is called total parenteral nutrition (TPN) or hyperalimentation (hyperal).
    - NG tube feedings or TPN will give your child protein, calories, vitamins and minerals that their body needs.
    - The BMT team will decide which way is best for your child. They will also decide how much your child needs.
    - Your child can still eat. Try not to worry if they do not feel like eating.

When children first start to eat again after transplant, it is common for food to taste differently. Favorite foods may no longer taste good. Taste will change over time. Offer a variety of foods.

What happens if my child is ready to go home but still cannot eat?

Your child may not want much because of a poor appetite, different tastes or problems with their stomach and intestines. If they do not already have one, an NG tube can be placed.

- The tube feeding formula has protein, calories, vitamins and minerals.
- A nurse will teach you how to use the NG tube at home.
- Your child may not be able to tolerate fluid going into their stomach without getting sick. If this happens, your child can get TPN or I.V. fluids through their CVAD at home.

What if my child does not feel like eating?

Your child’s appetite will return to normal after BMT, but it may take some time. There are some things you can do to help.

- Limit drinks between meals. Sugary drinks, such as juice, sodas or fruity drinks, can decrease appetite if taken before a meal.
- Give your child water if they are thirsty. It will help with their thirst, but not fill them up.
- Plan family meals. Children often eat better when they are eating in a group. Family meals also allow parents to show good eating habits.
- Turn off the TV and radio during meals. These can be distracting.
- Keep food portions kid-sized. Do not put too much on your child’s plate. A toddler-sized serving is 1 tablespoon for each year of the child’s age. For example: give 3 tablespoons of potatoes for a 3 year old. If your toddler asks for more, give it to them.
- Keep meal times happy. Discuss only pleasant topics.
- Offer foods that have lots of calories and protein. The nutritionist can suggest foods.
- Sometimes your child may need more help with getting their appetite back. They may need medicine to help stimulate their appetite. The care team will discuss options with you if needed.

What foods should my child eat to get good nutrition?

There are many nutritious foods. Ask for the “Food Safety for BMT Patients” teaching sheet for ideas about safe, nutritious foods to offer your child. Other hints include:

- Offer new food at the start of a meal.
- Do not complain if your child refuses to try new food at first. It may take several times before your child is willing to try a new food.
- We all have favorite foods. Allow your child to help plan meals with you.
- Limit food choices to what you are willing to buy and prepare.
- Set limits at home. You are responsible for where, when and what your child eats. Your child is responsible for how much of a meal or snack that they eat.
- Never use food as a reward.

Food safety for BMT patients

Good eating habits can help your child recover after a BMT. You must also follow food safety rules closely to help protect your child from infection. After the transplant, your child will be more sensitive to germs, molds and fungus found in some food.

There are ways your child can eat healthy and avoid infection during and after BMT. This plan is called Food Safety for BMT Patients.

Why does my child need to follow the food safety diet?

Children who have BMTs are more likely to get serious infections from germs that do not make others sick. Food can carry germs and molds that may make your child sick.

Foods need to be prepared and stored safely to keep germs and molds from growing on them. There are also foods that your child should not eat because they may be unsafe.

How long does my child need to follow the food safety diet?

The care team will tell you when your child can come off the food safety diet. Your child may need to follow it forever, but talk with the care team about what is best for your child.

- **If your child has an autologous transplant:** They will follow the food safety diet in the hospital. After going home, it is best if they follow the food safety diet forever.
- **If your child has an allogeneic transplant:** They will follow the food safety diet in the hospital and until they can stop immunosuppressive medicines, such as tacrolimus and cyclosporine.

Food group	Foods NOT allowed
Fish, meat and poultry and substitutes	• Raw or undercooked meat, fish, poultry substitutes • Undercooked eggs • Cold smoked or pickled fish (smoked salmon, smoked oysters, lox) • Raw fish (sushi and sashimi) • Meats from deli counters, salad bars and buffets • Uncooked hotdogs or lunch meats
Milk and milk products	• Milk products made from unpasteurized or raw milk • Aged and soft cheeses (blue, brie, Roquefort, Camembert, Stilton, farmer's cheese, soft cold Mexican cheese, feta) • Cheeses or dairy products from deli counters, salad bars and buffets • Homemade eggnog

Food group	Foods NOT allowed
Fruits	• Unwashed produce or produce in bad condition (moldy, bruised, cuts, brown, mushy) • Unpasteurized fruit juice • Fresh fruit from restaurants, salad bars and buffets
Vegetables	• Unwashed produce or produce in bad condition (wilted, moldy, mushy, brown spots, cuts/bruised) • Raw/uncooked mushrooms and sprouts • Items from deli counters, salad bars and buffets • Garnishes (such as lemon slices, parsley or lettuce) used for decoration at restaurants • Homemade Kimchi • Salsas stored in refrigerated case at grocery store
Nuts and seeds	• Nuts or seeds in the shell • Unroasted raw nuts and seeds
Breads, cereals and grains	• Bread items with mold that you can see • Raw grain products, such as uncooked flour or uncooked oats
Drinks	• Well water, unless tested and approved by the care team • Soda fountain drinks • Ice from public ice machines • Sweet tea made with warm or cold water, mate tea • Unpasteurized milk, fruit and vegetable juices • Kombucha
Desserts	• Cream-filled pastries not kept in the refrigerator • Soft serve ice cream, frozen yogurt, milkshakes made with soft serve • Icees, slushies, snow cones • Homemade ice cream or ice cream with raw egg
Other foods	• Any foods from salad bars, buffets and deli counters (such as coleslaw, potato salads, fruit salads or vegetable dishes) • Foods from food trucks, street vendors or sidewalk vendors, ice cream trucks • Raw or unpasteurized honey, honey in honeycomb

Food group	Foods NOT allowed
Other foods (continued)	• Fresh and dried herbs and spices added after cooking • Homemade jams, jellies, mayonnaise or home canned foods • All Miso products • Herbal and other supplements unless approved by the care team • Uncooked bakers or brewer's yeast

Can my child go out to eat or have takeout food on the food safety diet?

- **While your child is in the hospital:** Your child cannot eat:
  - Restaurant food.
  - Takeout or fast food.
  - Food that you buy in the hospital cafeteria.
  - Food from outside organizations like CURE.
  - Food and drinks from places like coffee shops.
- **After discharge**: Your child can eat restaurant food and takeout or fast food, but you must:
  - Check the Health Department Food Inspection rating (score), also known as the food score. **The score must be 90 or greater** (95 or greater is preferred). You can check the score at http://ga.healthinspections.us/stateofgeorgia.
  - Know what foods are not allowed for your child, so you know not to order those foods (see list on pages 43 to 44 or see the "Food Safety for BMT Patients" teaching sheet).
  - Ask for fully cooked food, including eggs and meats. Send the food back if it is undercooked.
  - Ask that foods be made fresh. Do not eat food that is sitting out or under a heating lamp.
  - Ask that they do not use garnishes like lemon slices, parsley or lettuce used for decoration. Your child can have lettuce, onions, tomato or pickles on foods they order, such as hamburgers or sandwiches.
  - Ask for single serving condiment packets.
  - Order bottled drinks. Avoid soda fountain drinks and ice machines.
  - If staying at Ronald McDonald House (RMH) after discharge:
    - Your child may eat foods prepared by RMH chef. Follow the same rules listed in this guide.
    - Your child should not eat foods brought into RMH or cooked by volunteer groups or organizations.

Can I bring food from home?

Yes, but you must follow food safety rules.

- Make sure food is made and brought to the hospital on the same day.
- Keep food in a cooler with ice during transport. Reheat foods to the correct temperature.
- You can also make your child commercially packaged frozen foods.
- **Eat leftovers within 24 hours of being cooked.**

Are there other foods my child should avoid?

Some children have trouble during or after BMT with foods that used to be favorites. Dairy products, fatty foods, spicy foods and others may cause upset stomach or diarrhea (loose stools) until your child's body recovers all the way.

- Your child should return to these foods slowly and at their own pace.
- Avoid certain food if it causes a problem. Then, try it again in a few days or weeks.

Other things to know about food safety

Why do I need to practice food safety?

Food poisoning is most often from improper food handling. Food safety is very important for everyone, especially BMT patients.

- Your child's immune system is not normal yet. This makes it easier to catch infections and to get sicker from them.
- Food may carry germs and molds that can make your child sick. Foods need to be prepared and stored safely to keep germs and molds from growing on them.
- When foods carrying germs cause infection, it is called foodborne illness.

What guidelines should I follow when shopping for food?

- Be aware of food recalls. Learn more at fda.gov/safety/recalls.
- Do not buy products past the "expiration," "sell by" or "best used by" date.
- Do not buy canned items that have dents or damage.
- Shop for foods in this order:
    - Shelf stable/dry goods
    - Refrigerated products
    - Frozen foods
- Buy cold foods that feel cold and frozen foods that feel hard.
- Keep raw meat, seafood and eggs separate from other foods in your cart and bags.

What are the guidelines when I put food away?

- Take food home as soon as you are done shopping.
- Put away refrigerated and frozen foods quickly.
- Check the temperature of your freezer and refrigerator.
  - The freezer should be 0 °F (degrees Fahrenheit) or below.
  - The refrigerator should be 40 °F or below.
- Keep dry foods away from heat, moisture and chemicals.
- Seal packages closed. Keep foods in containers with lids.
- Do not leave food out for more than 1 hour.
- Put cooked foods in the refrigerator or freezer as soon as you are done eating.
- How long foods are considered safe in the refrigerator:
  - Eggs: 7 to 14 days
  - Milk: 5 days from opening
  - Lunch meat or deli meat: 3 to 5 days
  - Raw meats: 1 to 2 days
  - Raw fish and seafood: 1 to 2 days
  - Raw fruits and vegetables: 7 days
  - Leftovers: 24 hours
- Download the FoodKeeper App on your personal device or go to foodsafety.gov for more information on food storage times.
- **When in doubt, throw it out.**

What are the guidelines when I prepare food?

- **Wash hands often. Clean them with soap and warm water for at least 20 seconds.**
  - Wash them before, during and after each step of making food.
  - Make sure your child washes their hands before they eat.
  - Use paper towels to dry your hands.
- **Clean areas where you prepare and serve food.**
  - Clean countertops before and after you prepare food.
  - Wash cutting boards with soap and hot water or in the dishwasher before you prepare food on them.
  - Use only clean and washed cookware, serving dishes, plates, bowls, cups and utensils.
  - Dish towels and sponges can grow germs. Clean and change them out often.
  - Wipe down the top of canned foods before you open them.

- **Keep raw meats, seafood and ready-to-eat foods separate.**
  - Use different cutting boards for raw meats, seafood, and cooked or fresh foods like fruits and vegetables.
  - Separate raw meat, seafood and eggs from other foods in your refrigerator.
  - Never put ready-to-eat foods on a plate that had raw meat or eggs on it.
- **Check foods before cooking and eating them.**
  - Check all fruits and vegetables carefully. Do not eat or serve them if they are bruised or mushy, have torn or cut skin, or are wilted or brown.
  - Check foods for mold. Throw away the entire package of food if there is mold. This includes bread, pastries, cheese, yogurt, fruits, vegetables and jellies.
  - Do not use eggs that are cracked or kept out of the refrigerator.
  - Throw away dented or damaged cans of food.
  - Do not eat foods past their expiration dates.
- **Wash fresh fruits and vegetables well.**
  - Clean fruits and vegetables with cold running water. You can use a produce brush that is clean. Then, use a paper towel to dry the fruits and vegetables.
  - Do not use soap or other chemical cleaners to wash fruits and vegetables. If you would like, you can:
    - Cover produce in water. Add ¼ cup vinegar and 1 tablespoon baking soda to the water.
    - Let produce soak in the mixture for 10 to 15 minutes.
    - Then, drain and rinse well.
    - Dry them with a paper towel.
- **Thaw food safely.**
  - Never thaw food on the kitchen counter or at room temperature.
  - Thaw food in a refrigerator on a dish to catch any drips, in the microwave, or in a water-tight plastic bag under cold water.
- **Cook foods to safe temperatures.**
  - Cook food to the correct temperature to help kill germs. Buy a food thermometer to check the temperature.
    - Hot foods, meats and reheated foods should be 165 °F (degrees Fahrenheit) or hotter.
    - Poultry (chicken, turkey, duck and quail) should be 180 °F or hotter.
  - Do not taste and stir foods with the same spoon.

Where can I find more information about food safety?

Please ask your child’s nutritionist or other care team member if you have questions about food safety for your child. You can also read more about food safety at these websites:

- foodsafety.gov/keep/charts/storagetimes.html - food storage chart from the U.S. Department of Agriculture
- eatright.org/food/home-food-safety - food safety tips from the American Dietetic Association

Preparative regimen

The treatment plan or *preparative regimen* that your child receives before their transplant is based on their disease and their condition. Your child's doctor will tell you what to expect for your child. Your child will be admitted about 7 to 10 days before the transplant to receive *chemotherapy* with or without *radiation* therapy.

Chemotherapy

Chemotherapy is given before transplant to help prepare your child's body for their new, healthy blood stem cells.

- Chemotherapy kills cancer cells if your child has cancer.
- Chemotherapy also destroys your child's bone marrow cells so they will not fight off or reject the new healthy blood stem cells after transplant. Chemotherapy is needed, even if your child does not have cancer.
- Chemotherapy may be given by mouth to swallow or through the CVAD. Your child's dose is based on their weight and size.

The most common side effects of chemotherapy are nausea and vomiting (throwing up). Your child will get medicine before and after chemotherapy to help with nausea and vomiting. Other side effects include:

- Low blood counts
- Loss of hair
- Mouth sores
- Poor appetite
- Diarrhea

The BMT doctor will give you more information about the side effects of your child's chemotherapy once they decide your child's BMT plan.

Radiation therapy

Your child may need radiation therapy before their BMT to help kill cancer cells or to help prepare the body to accept the new blood stem cells. For BMT, radiation is given to the entire body. This treatment is called total body irradiation (TBI).

- TBI is given 1 or 2 times each day for several days.
- Treatments most often take 10 to 15 minutes each.
- You and your child will travel to the Emory Clinic in the Winship Cancer Institute building for each treatment.
- For this therapy, strong X-rays are aimed at your child's body while they lie on a table. The X-rays are like the ones used to see a broken bone, but they are much stronger.
- The radiation helps destroy any cancer cells that are left. It also weakens your child's immune system. This gets your child's body ready to accept the new blood stem cells.

- If your child is very young, they may need to be sedated for each radiation treatment. This is to make sure they stay still.

The radiation oncologist is the doctor who will set up a plan for how the TBI will be given. The doctor will use ink marks on your child's skin to know where to set the X-rays. This planning process is called simulation. Do not wash any ink marks left on your child's body until the radiation therapy is finished.

During radiation therapy

- Heavy, lead pads may be put over parts of your child's body. These pads help protect sensitive organs.
- Your child may also be given medicine to help them relax. Young children may need *anesthesia* to put them to sleep. This is because your child must stay in one position without moving.
- The X-ray machine makes a soft, clicking sound and does not hurt. Some children say their skin feels warm and tingly afterward.
- Your child can talk to you through a speaker system.

After radiation therapy

- Your child's skin may get red like a sunburn. It may be sensitive to some soaps, deodorants and perfumes.
- Use only mild cleansers that your BMT team gives you to wash your child's skin. This could include Aveeno or Cetaphil.
- Use hypoallergenic lotions that the BMT team gives you to help keep your child's skin from getting too dry. With time, the skin most often returns to normal.

Radiation may also cause nausea and diarrhea. Your child will get medicine to help prevent nausea.
Your child may also have pain and swelling along the jaw. This is from inflammation of the parotid gland. The parotid gland makes saliva (spit), so your child may also have a dry mouth. The pain most often goes away in a few days and can be treated with pain medicine.

Your child's BMT: Day 0

The day of your child's transplant is Day 0.

A BMT is not surgery. It takes place in your child's hospital room. The transplant can take 5 minutes to a few hours. Many children find that the transplant infusion is a lot easier than they expected. Your child may get Benadryl, Tylenol, Zofran or other medicines to help prevent reactions during the BMT infusion.

Your child gets the new blood stem cells through the CVAD.

- **If the blood stem cells are donated from a matched-sibling marrow donor or unrelated marrow donor:** the blood stem cells are donated right before the transplant (on Day 0). The cells are placed in a sterile bag, just like a blood transfusion, and given over a few hours.
- **If the blood stem cells are from your child, a cord blood donor or a peripheral blood stem cell pheresis:** they may have been frozen. The cells will need to be thawed and then given using a syringe. The infusion most often takes less than 10 to 20 minutes.

Your child can talk to family members, watch TV, read, listen to music or just rest during their BMT infusion. We ask that you limit the number of family members in the room on the day of transplant to no more than 2 people.

How your child's body responds on Day 0

Problems during the infusion are not common. Still, they may sometimes happen. The nurse will check your child's vital signs often. Your child will be watched closely during the transplant for these possible side effects:

- Nausea and vomiting
- Allergic reaction (shortness of breath, itching or chills)
- Hemolytic reaction (fever, back pain or red urine)
- Changes in heart rate or blood pressure

The BMT infusion is like getting a blood transfusion. Instead of blood, your child will be getting blood stem cells.

If your child is getting blood stem cells that were frozen before the transplant, your child may have a cream corn or garlic odor (smell) for several hours after the transplant. This odor is due to a chemical (DMSO) that is added to the blood during the freezing process.

DMSO may cause:

- Red blood cells to break apart during thawing and infusing. The blood from those cells may make your child's urine look pink or red. This is normal. The pink or red color will fade over 1 to 2 days.
- Nausea and an unpleasant taste. It may be helpful to give your child gum or hard candy if they are old enough.
- Headaches, blood pressure and heart rhythm changes, and allergic reactions. Your child's nurse will watch closely for these side effects.

Waiting for engraftment

A successful transplant means the new healthy blood stem cells have found their way through the bloodstream and into the bone marrow, and have started to grow. When the cells grow, it is called *engraftment*.

- Engraftment time is different for each child.
- Engraftment most often happens about 10 to 28 days after the BMT (Day +10 to Day +28).

There are 3 kinds of blood cells. Each comes in at different times after the BMT.

- White blood cells (fight infection): These come in first (Day +10 to Day +28).
- Red blood cells (carry oxygen): These take longer. Your child may still need blood transfusions for several weeks or months.
- Platelets (stop bleeding): These come in last. They may take up to several months to start growing.

Recovery and possible problems

Recovery starts in the hospital. Each child is different, and the length of your child's hospital stay is hard to predict.

- Autologous transplant patients often stay in the hospital until about Day +14 to Day +21.
- Allogeneic transplant patients often stay in the hospital until at least Day +21 to Day +35.

During your child's hospital stay, the nurses and doctors will pay special attention to signs of problems that happen after a transplant. Listed in this guide are some common problems that come with a BMT after the preparative regimen is started.

Anemia (low hemoglobin or red blood cell count)

The *hemoglobin* level will fall a few days afterward. Hemoglobin is the protein in red blood cells that carries oxygen through the body. A low hemoglobin level is called anemia.

- Your child may feel tired, have headaches and look pale.
- If your child's hemoglobin level drops too low, they will be given a blood transfusion.

Thrombocytopenia (low platelet count)

The platelet count will fall about a week afterward. Platelets help to stop bleeding. A low platelet count is called thrombocytopenia. Normal platelet count is greater than 150,000. If your child's platelet count is too low:

- They will have a platelet transfusion.
- They will not be able to take any aspirin or ibuprofen (Motrin, Advil or less costly brands) because these medicines can cause bleeding.
- They should avoid having tests or treatments that may cause bleeding, such as rectal temperatures or suppositories.

- They may have certain symptoms. Tell the nurses **right away** if you see any of these:
    - Bruises
    - *Petechiae* (pinpoint, flat, round, red spots under the skin caused by bleeding into the skin)
    - Nose bleeds
    - Blood in the urine
    - Bleeding at the CVAD site
    - Severe (very bad) headaches
- If your child is female and has been through puberty, they may have vaginal bleeding

Neutropenia (low white blood cell count)

The white blood cell count will fall a few days afterward. White blood cells fight infection. A type of white blood cell that helps do this is called a *neutrophil*.

- When the neutrophil count is less than 500, it is called *neutropenia*.
- The neutrophil count will stay at zero until engraftment.
- During this time, your child is at a very high risk for infection. Your child should avoid having rectal temperatures or suppositories for this reason.

Fever and infection

Signs of infection include:

- Fever
- Irritability
- Tiredness
- Cough
- Pain when urinating
- Redness or tenderness anywhere on the body

Fevers can be caused by:

- Bacterial infections - such as those caused by staph or strep germs.
- Fungal infections - such as those caused by yeast or molds.
- Viral infections - such as flu, herpes or cytomegalovirus (CMV).

If your child has a fever:

- Blood tests called cultures will be taken from the CVAD. Blood cultures test to see if there are germs growing in the bloodstream that are causing fever and infection. Your child may also have other tests.
- They will get *antibiotics* until the white blood cell count recovers. Your child may also get other medicines if they keep having fevers.

Mucositis (mouth sores)

5 to 10 days after the preparative regimen starts, the inside of your child's mouth, gums, throat, stomach and intestines may get sore and red, and have ulcers (open sores). This problem is called *mucositis*.

- Mucositis happens because the fast growing cells in the mouth, stomach and intestines are injured by high doses of chemotherapy or radiation therapy.
- It is often so painful that pain medicine is given.
- Your child will likely not be able to eat or drink for several days or weeks. Extra nutrition will be given (see page 42).
- The mouth sores start to heal when the white blood cell count increases.

Diarrhea (frequent, liquid stool)

Your child may have diarrhea from chemotherapy or radiation therapy. The cells that line the *gastrointestinal* (GI) tract are affected by chemotherapy and radiation therapy. This causes an increase in the movement of water and stool through the intestines.

- If your child has moderate to severe mucositis (mouth sores), diarrhea may also happen. It can get worse during the second week after the transplant.
- Your child's rectal area may get red, tender and infected.
- Keep your child's rectal area as clean as possible.
- Save all stools for the nurse to see and measure.

Alopecia (hair loss)

Alopecia means hair loss. Most children who have chemotherapy or radiation therapy lose some or all of their hair. Hair loss happens because the chemotherapy drugs cannot tell the difference between unhealthy and healthy cells, such as hair cells.

- Hair most often begins to fall out in the week after the *preparative regimen* ends.
- Your child may be bothered by itching from the hair falling out and by hairs in the bed.
- Talk with your child and your child life specialist about shaving your child's head. Shaving may give your child a sense of control by removing the hair when they choose to. The child life specialist can also give you other ideas to help cope with hair loss.
- Hair most often grows back to the original color and texture. Some children will have a different color or texture of hair when it grows back.

Fluid retention

Your child may urinate less often and gain fluid weight in the weeks after the transplant. This fluid retention happens because their body holds onto fluid instead of getting rid of it through the kidneys.

- The extra fluid leaks out of the blood vessels and into the tissues.
- If too much fluid is in the body and leaks into the tissues, it may leak into the lungs and cause pulmonary edema. Pulmonary edema is when the lungs fill with fluid, making it hard for your child to breathe.

Every day, the BMT team will look closely at how much urine is made, how much fluid is taken in and how much your child weighs. Medicines called diuretics, such as Lasix, may be given to help your child urinate more. Be sure to save all urine, stool and vomit for the nurse to see and measure.

Weight loss

It is common for your child to lose interest in food the week before and several weeks after the transplant.

- Your child may not want to eat during the preparative regimen because the chemotherapy and radiation therapy may cause nausea and vomiting.
- Painful mucositis may also make it hard for your child to eat or drink for a few weeks after the transplant.
- Many children have a low appetite from 2 to 3 weeks to several months after the transplant.
- Extra nutrition will be given (see page 42). A nutritionist will check your child’s food intake, weight and lab values each day and adjust their intake for their needs. Ask to talk with the nutritionist if you are concerned about your child’s eating.

Veno-occlusive disease of the liver

For several weeks, your child may have fluid retention, belly pain, an enlarged liver and jaundice (yellowing of the eyes and skin). This problem is called veno-occlusive disease (VOD). VOD happens when the very tiny veins in the liver are damaged by chemotherapy and radiation.

- VOD causes the veins to get inflamed, narrowed and blocked. It may lead to decreased blood flow through the liver with swelling, belly pain and fluid buildup.
- VOD most often goes away. Sometimes, it does not get better and can be life-threatening.
- The BMT team will watch your child closely for signs of VOD.
- Controlling fluid buildup is important to help prevent and treat VOD.
    - Your child may get *diuretics* to urinate out extra fluid buildup. They may also get medicines for pain.
    - Exercise and breathing exercises can help control fluid retention.

Hemorrhagic cystitis (irritation to the bladder)

Cyclophosphamide and melphalan are chemotherapy medicines that your child may receive. These medicines, as well as radiation or viral infection, may cause hemorrhagic cystitis (irritation to the bladder).

- Hemorrhagic cystitis causes bleeding and blood clots in the bladder.
    - Your child may have pain as these clots pass through the bladder and the urethra.
    - The nurse will check for blood in your child's urine often.

- Hemorrhagic cystitis can often be prevented by flushing the kidneys and bladder with I.V. fluids and by urinating often.
    - Your child will get fluids through the CVAD several hours before and after getting cyclophosphamide or melphalan.
    - Your child will be asked to urinate often. Emptying the bladder will help prevent these medicines from staying in the bladder and causing irritation.
        - If your child is in diapers: Change their diapers often.
        - If your child is not urinating: We may give them more fluid through the CVAD. We may also give them a medicine called Lasix to help them urinate.
- The nurse will give your child a medicine called mesna to help prevent hemorrhagic cystitis.

Relapse

Relapse means that your child's original disease has returned. Even though the BMT team hopes the transplant will cure your child's disease, it is still possible for relapse to happen after transplant. Relapse is life-threatening. The doctor will talk with you and your child about treatment options if your child's disease comes back.

Graft-versus-host disease (GVHD)

GVHD can only happen in children who receive an allogeneic transplant. Around 10 to 21 days after the transplant, you can expect to see signs of *engraftment*. After the new cells start to grow and become active, GVHD may be seen.

- GVHD happens when the donor cells (the graft) see your child's body (the host) as foreign or different. When this happens, the donor cells see your child's body as a threat and try to fight it.
- Medicines are used to help prevent GVHD. Some common ones include methotrexate, cyclosporine, tacrolimus, Cellcept and prednisone.
- The most important thing your child can do to prevent GVHD is to take all medicines on time every day.

Acute GVHD

Acute GVHD happens in:

- About 25 percent of patients who have a matched sibling transplant. Acute GVHD is most often mild to moderate in children who have had this type of BMT.
- Up to 60 percent of patients who have a mismatched or unrelated transplant.

The symptoms often go away over time with treatment. If GVHD is severe, it may be life-threatening and is much harder to treat.

The parts of the body that may be affected by GVHD include the skin, intestinal tract (gut) and liver. GVHD may be mild to severe in each area.

Symptoms	Mild GVHD	Severe GVHD
• Skin rash	• Red spots on the skin • Sunburn-like rash	• Red spots all over the body • Severe rash with blistering of the skin
• Diarrhea	• Small amounts of loose stool	• Severe diarrhea with cramps • Bloody stools
• Nausea or vomiting	• Queasiness • Poor appetite	• Frequent vomiting • Severe weight loss
• Abnormal liver tests	• Mild changes on liver function test (blood test)	• Severe jaundice (yellowing of the eyes and skin)

Diagnosis of acute GVHD

There is no blood test that can diagnose GVHD. Doctors may diagnose acute GVHD by:

- Looking at your child’s signs and symptoms.
- Checking measurements like amounts of diarrhea each day.
- Doing other tests to rule out problems like infection and to confirm GVHD.

The most common test is a *biopsy*. A biopsy means taking a piece of tissue from the body and checking it under a microscope in the lab.

- **Skin**: A dermatologist (skin doctor) is often asked to check your child’s skin changes.
    - The doctor may biopsy the skin by using a small tool that removes a piece of skin about the size and shape of a pencil eraser.
    - This most often happens on the BMT unit.
    - Your child will get local anesthesia (numbing medicine injected, or put, under the skin).

- **Gut**: A gastroenterologist (stomach doctor) may do an endoscopy to biopsy the stomach and intestines.
  - The doctor uses a very small, lighted camera on a tube. They put the tube into the stomach through the mouth or into the intestines through the rectum (where stool comes out). Then, they take a small piece of tissue.
  - This is done in a special procedure room.
  - Your child will get general *anesthesia*. Anesthesia keeps them from feeling any pain.

- **Liver**: There are 2 ways to biopsy the liver.
  - Percutaneous (through the skin) liver biopsy: The doctor puts a needle into the liver through the skin on the right side of the belly. They use the needle to remove a small piece of liver tissue.
  - Transjugluar liver biopsy: The doctor puts a catheter into the jugular vein in the neck. A tiny tool is threaded through the vein and into the liver. Then, they take a small piece of tissue from the inside of the liver.
  - Your child will get anesthesia if they have a liver biopsy.

Treatment of acute GVHD

- Your child will get steroids, such as prednisone, if they have acute GVHD.
- Medicines used to treat GVHD work by weakening the immune system. Your child will be on medicines that suppress the immune system longer than first planned.
- Steroids most often work to control GVHD and may cause the GVHD to go away completely.
- GVHD is often harder to treat if steroids do not help. Your child may need other medicines.
- GVHD and its treatment also create a much higher risk for infection.
- Having GVHD may be disappointing and frustrating for you and your child. The BMT team is here to help you and your child through treatment. Talk with your BMT team about your feelings.

Chronic GVHD

Your child may have acute GVHD symptoms that turn into chronic symptoms. They may also develop chronic symptoms without having had any acute symptoms. The parts of the body that may be affected include the skin, eyes, mouth, intestinal tract, lungs, liver, mucous membranes and joints.

Symptoms of chronic GVHD may include:

- Dry, itchy eyes
- Dry mouth with white sores on the tongue and inside the cheeks
- Dry skin with patches of raised, colored spots
- Skin that appears red or blotchy

- Tightening of the skin or muscles
- Brittle nails with ridges
- Hair loss
- Nausea, vomiting, diarrhea, trouble swallowing food, poor absorption of food or weight loss
- Trouble breathing or frequent lung infections
- Jaundice (yellowing of the eyes and skin) and other liver problems
- Stiff and swollen joints
- Low blood counts
- Frequent infections

Diagnosis of chronic GVHD

Doctors most often diagnose chronic GVHD in the same way as acute GVHD (see page 58). One difference is that sometimes an eye exam is done.

- An ophthalmologist (eye doctor) is asked to check your child's eyes. They will look for changes on the lining of the eyeballs and eyelids.
- They may also do a test of your child's tear production called a Schirmer's test. The doctor will place a special strip of paper just inside the bottom eyelid. Then, they measure the distance the moisture travels out on the strip.

Treatment of chronic GVHD

Treatment includes the same medicines that are used to treat acute GVHD or may involve new medicines and treatments.

- Most children need these treatments for many months or years. Sometimes, the treatment may not work.
- GVHD and its treatment will cause your child's immune system to be weak. This means that even though the white blood cell count may be normal, these cells cannot do their job of fighting off infections.
- Call the doctor or nurse **right away** if your child has a fever or signs and symptoms of an infection (see page 66).

Notes

Notes

After Discharge from the Hospital

Leaving the hospital

Leaving the hospital can be both exciting and scary. You may feel that it will be wonderful to be together as a family again. You may also worry that if your child gets sick, you will not have a nurse or doctor with you to give you advice on what to do.

When your child's doctor decides it is safe for your child to leave the hospital, we will make sure you know how to care for your child outside of the hospital. Call us if you ever feel worried about your child. There is a BMT doctor available 24 hours a day, 7 days a week.

Discharge from the hospital

Your child's BMT team will work closely with you to help prepare you and your child to go home. Recovery is not complete when your child leaves the hospital. Your child's doctors and nurses will teach you what to watch for and what to do if your child has a problem.

You will need to bring your child to the Aflac Cancer and Blood Disorders Center outpatient BMT clinic for checkups often. Our BMT team also wants to see your child right away if there are any problems.

Your child will be discharged when they:

- Have a high enough white blood cell count.
- Do not have constant nausea or vomiting.
- Do not have a fever.
- Are able to eat enough food and drink enough fluid. Or if your child cannot eat, you have learned how to give nutrition and fluids through the CVAD or NG tube at home.

You will need to know:

- How to take care of your child's CVAD. This includes dressing changes, injection cap changes and flushing.
- What signs to report as an emergency.
- How to take your child's temperature.
- The phone number to call if your child is sick.
- What medicines your child needs to take at home, why they need them and how to give them.
- Your pharmacy phone number and how to get your child's medicines.

- Where to get home care supplies. You will need to order more before you run out. The outpatient clinic does not stock home care supplies.

Emergency cards

The BMT team will give you 2 emergency cards before your child is discharged from the hospital.

- If your child must go to the emergency department (ED) for any reason, show one of these cards to the staff **right away**.
- Each card explains that your child is a BMT patient and needs care right away. The card lists medicines if your child needs an antibiotic. Your child's allergies are also listed.

Transitional housing

Children who have just had a BMT can get sick quickly. They must be able to get to the hospital right away. We may ask you to stay at Ronald McDonald house, a nearby hotel or other transitional housing for a period of time after discharge if:

- Your child has a central line
- Your child does not have a central line, but you live more than 60 minutes from Children's Healthcare of Atlanta at Arthur M. Blank Hospital

The BMT social worker can help you make plans for your stay.

Preventing infection after discharge

You do not need to sterilize your home or transitional housing before your child is discharged from the hospital. Clean your home regularly and follow these guidelines to help protect your child.

Be sure to:

- Wash your hands often and well. Have your child, other family members and visitors do the same. Hand hygiene is one of the best ways to help prevent infection.
- Clean the toilet with a disinfectant, especially if someone in the family has diarrhea.
- Have your child wear a mask when outside the home and when coming to the outpatient clinic after transplant. Ask your nurse to review how to put the mask on your child.
- Each family member should receive the influenza (flu) vaccine as an injection (shot), not the intranasal (in the nose) form. The intranasal form has live virus and could expose your child to the flu.

Be sure not to:

- Share eating utensils, such as forks or cups.

- Go to public places, such as the bus, store, church, restaurant, school or movie theater. With a weakened immune system, it is easy for your child to pick up harmful germs. Your child is more likely to come in contact with germs where there are lots of people.
- Invite visitors to the house if they have a runny nose, cough, diarrhea, vomiting or sore throat.
- Allow a visitor in your house who has chickenpox or other virus.
- Get a new pet at this time. Talk with the BMT team about the pets you may already have at home.
- Allow a visitor who has recently received a live vaccine.

How long does my child need to wear a mask?

The mask helps protect against infection from other people and the environment. Your BMT team will let you know when it is safe for your child to stop wearing the mask. Until then, have your child wear the mask at all times except inside the home.

The amount of time your child will need to wear a mask depends on the type of BMT they had and what medicines they take.

- If they had an autologous transplant - your child will likely need to wear a mask until the white blood cell count is normal, most often by Day +30.
- If they had an allogeneic transplant - your child will likely need to wear a mask until they are no longer taking medicines that weaken the *immune system*, such as tacrolimus, cyclosporine and steroids.

Outpatient BMT clinic

After leaving the hospital, your child will visit the Aflac Cancer and Blood Disorders Center outpatient BMT clinic many times.

- Before leaving the hospital, the BMT inpatient team will schedule your first clinic visit.
- You may need to come to the clinic as often as each day. This depends on your child's condition and needs.
- Most often, clinic visits decrease after the first few months because problems happen less often. Their visits may follow the schedule below.

Time after discharge	Clinic visit schedule
For 1 to 2 months	2 to 3 times a week to 1 time a week
For 3 to 5 months	Once every 1 to 2 weeks
For 6 to 12 months	1 time every month

You will have many things to remember. Writing things down may help decrease stress and will help keep things organized. Use a calendar or the Notes section of this guide to keep track of:

- Clinic visits
- Medicine changes
- Blood counts
- Other important information

Bring this guide to all of your child's clinic visits. It is also important to keep and look at the discharge instructions you receive after every clinic visit for any medicine changes.

BMT clinic hours

8 a.m. to 5 p.m. Monday through Friday

Clinic phone: 404-785-1200

Clinic location

Aflac Cancer and Blood Disorders Center
Children's Healthcare of Atlanta at Arthur M. Blank Hospital
2200 North Druid Hills Road NE
South Tower, 8th floor
Atlanta, GA 30329

Making an appointment

Call 404-785-1200 during clinic hours to make an appointment.

Getting to the clinic

- Tell the front desk that you are seeing the BMT team.
- Be on time for your clinic visit. Call the clinic if you are running late.
- If you are more than 30 minutes late, you may have to wait to be fit in or you may need to reschedule.

What to bring to the clinic

Bring these items with you each time you come to the clinic:

- Your child's social security number
- Copy of your current insurance card
- New address information if you have moved or are moving soon

- New home, work and cell phone numbers
- This guide
- List of all medicines your child is taking
- All medicine bottles so we can double-check our orders with the pharmacy
- List of medicines that need a new prescription
- Your pharmacy's phone number
- Lunch or snack if you expect to be at the clinic for awhile. Most food cannot be provided.

Visitor and sibling guidelines

- Siblings and other family members may come to clinic with you and your child as long as they are not sick.
- Space is limited in the special BMT clinic area. Limit the number of people that come with your child to the clinic visit.
- If you must bring other children with you to the BMT clinic, bring another adult to watch them in the waiting room.
- Do not bring family members or siblings who are sick. They can infect your child and others in the clinic.
- During flu season, no visitors under the age of 12 will be allowed in the inpatient or outpatient areas.

IMPORTANT

If you think your child may have chickenpox or if someone has chickenpox in your child's day care or school, tell our staff before you enter the clinic. Even if your child has had chickenpox or has had the vaccine, they can get shingles after BMT. Shingles is caused by the same virus that causes chickenpox. Tell us about any new rash your child has, no matter how small it is.

Arriving at the clinic

When you arrive at the clinic, sign your child's name at the front desk. You may be asked to fill out some forms and confirm your address and phone number.

- All children younger than age 18 must have a parent or guardian with them at each visit.
- A parent or guardian must stay for the entire visit.

For your child's safety (unless you have been given permission to stop BMT isolation):

- Take your child directly to the special BMT area of the clinic after you sign in at the front desk.
- Make sure your child is wearing a mask for their clinic visits.
- Your child is not allowed to wait in the regular waiting room or walk around the hospital.

Once you are in the special BMT area:

- A nurse or patient care technician (PCT) will check your child's vital signs, height and weight.
- They will take you and your child to an exam room and draw blood for tests. You will wait for your child's nurse and doctor.
- Your child must wear a mask at all times except in the BMT exam room.

Your child may get these blood tests during BMT clinic visits:

- **Complete blood count (CBC)**: This test will check the red blood cell count, white blood cell count and platelet count to see if a transfusion is needed. It also checks to see if your child needs growth factor (such as G-CSF) to raise the white blood cell count.
- **Chemistry panel (CMP)**: This test checks salts, such as potassium and sodium. It also checks your child's kidney and liver functions.
- **Magnesium level (Mg)**: This test checks the level of magnesium in the blood. Magnesium may be low if your child is taking tacrolimus or cyclosporine, or if they have taken medicines, such as carboplatin or cisplatin. A normal magnesium level helps keep blood pressure normal.
- **Tacrolimus or cyclosporine level:** If your child is taking one of these medicines, this test checks the level of tacrolimus or cyclosporine in your child's blood. We will use this level to adjust your child's tacrolimus or cyclosporine dose. **Unless you are told differently, do not give your child the morning dose of tacrolimus or cyclosporine before coming to clinic. Bring the dose with you. Give it to your child right after the blood is drawn.**

Common treatments during BMT clinic visits

During many clinic visits, your child may need treatment with transfusions or medicines that may take several hours to infuse. Sometimes you will know ahead of time about these long days, but not always.

- **IVIG**: Your child may need immunoglobulin (IVIG) in the first few months after transplant. This medicine is given through the CVAD to help prevent infection. These infusions most often take 3 to 4 hours. Your child will likely need them once a month.
- **Blood transfusion**: A red blood cell transfusion most often takes 3 to 4 hours. Allow extra time to find a correct unit of blood for your child.
- **Platelet transfusion**: A platelet transfusion most often takes 1 hour. Allow extra time to find a correct unit of platelets for your child.
- **Other medicines**: Your child may need other I.V. injections or inhaled medicines. The time this takes varies. Ask your BMT nurse how to plan for these days.

Procedures

If your child will be getting sedation or anesthesia for a procedure:

- They may have solid foods and regular liquids up to 6 hours before the procedure. They should not chew gum or have hard candy after that.
- They may have breast milk up to 4 hours before the procedure.
- They may drink clear liquids up to 2 hours before the procedure.
  - Some clear liquids include apple juice, water and Jell-O.
  - Your child may not drink milk or milk products, grape juice or orange juice.

Having an empty stomach helps to prevent vomiting. If your child chokes when they vomit, it can lead to pneumonia and they could get very sick. That is why your child has to stop eating and drinking before the procedure.

If your child needs EMLA cream before the procedure:

- Place it on your child's skin 1 hour before your visit. Place a clear dressing over the EMLA. Some places to put EMLA include the:
  - Port-a-cath site.
  - Lower back if your child is getting a spinal tap or lumbar puncture.
  - Back of the hip bones if your child is getting a bone marrow aspirate or biopsy.
- Ask your child's nurse if you have questions about where to put the EMLA cream.
- Tell the BMT team when you get to clinic if you forgot to put on EMLA cream.

Emergencies

Life-threatening emergencies: Call 911

Life-threatening emergencies include:

- Loss of consciousness (you are not able to wake up your child)
- Seizure
- Breathing problems

Contacting the BMT team

Other emergencies

Other emergencies include:

- Fever (temperature of 101° F once or 100.5° F for 1 hour)
- Shaking chills - with or without fever
- Severe headaches
- Bleeding that does not stop within a few minutes
- Changes in behavior, such as trouble walking or sleepiness
- Rash or blisters on the skin
- Pain when urinating or having bowel movements
- Drainage, redness, swelling or pain at the CVAD site
- Broken, cracked or leaking CVAD
- Not able to eat or drink for more than 1 day
- Not able to take medicine
- Not able to drink and has vomiting or diarrhea
- Your child is not acting right - your instincts are very important. You know your child best.

If any of these emergencies happen during clinic hours:

- Call the clinic at 404-785-1200 and press 1.
- Ask to talk with a BMT nurse or team member **right away**. Be as specific as possible about your child's illness.
- The BMT team will tell you to either:
  - Manage the problem at home. They will give instructions on how to do this.
  - Come to the clinic.
  - Go to the emergency department.

If any of these emergencies happen after clinic hours:

- Do not wait for the clinic to open. Call the after-hours number **right away**. That number is 404-785-1200.
- Ask for the pediatric BMT doctor on-call **right away** - even if you have an appointment later that day.

If your child has any of these emergency symptoms, they may have an infection in their blood or other serious problem. Infections can be deadly if antibiotics are not started **right away**.

Nonemergency problems

If any of these nonemergency problems happen after clinic hours, it is most often OK to wait to call the BMT clinic at 404-785-1200 on the next clinic day:

- Small amount of vomiting or diarrhea
- Poor appetite
- Mood changes
- Feeling tired
- Nosebleed that stops within a few minutes

Prescription refills

For prescription refills, call your pharmacy first to check for refills.

If no refills are available:

- Call the clinic at 404-785-1200. Press 3 and leave a message for your BMT nurse. You may also send a message through MYchart. Be sure to provide:
  - Your child’s name.
  - Their date of birth.
  - Medicines needed.
  - Pharmacy name and phone number.
- Calls for prescription refills are returned within 24 hours.
- If you are running low on medicine:
  - Call us at least 2 to 3 days before the medicine runs out.
  - Letting us know 2 to 3 days ahead of time gives the clinic and your pharmacy enough time to refill your child’s medicine.

Routine questions

For routine questions:

- Call the clinic at 404-785-1200. Press 3 and leave a message. You may also send a message through MYchart.
- A nurse will call you back as soon as possible**.**
- **Do not leave a message if your child is sick and needs immediate attention**. Ask to talk with a doctor or nurse **right away**.

You may have routine questions about:

- Isolation and food safety.
- Exposure to a sick child.

- Results of a blood test.
- Medicine instructions.
- Referrals to other specialists.

MYchart

MYchart is another way to communicate with your primary healthcare team about your child's care. MYchart can be used for:

- Routine questions.
- Prescription refills.
- Obtaining limited lab results and medical information.

You can sign up for a MYchart account during your clinic visit or from home at any time. Please visit choa.org/MYchart to learn more. If you have urgent issues, please contact your child's doctor right away. Do not use MYchart for urgent issues or concerns.

What to expect after the transplant

Readmission to the hospital

If you think that your child is sick, call to talk with a BMT doctor or nurse. They will advise what to do (see page 69).

- Your child may need to be readmitted to the hospital for problems, such as:
    - Fever
    - Infection
    - Dehydration (not enough fluid) due to vomiting or diarrhea
    - Graft-versus-host disease (GVHD)
- Most readmissions happen within 100 days after the transplant (before Day +100).
    - If your child needs to be readmitted during the day on Monday to Friday, you may be asked to go to the Aflac Cancer and Blood Disorders Center clinic.
    - If it is nighttime or the weekend, you will be asked to go right to the emergency department at Children's Healthcare of Atlanta at Arthur M. Blank Hospital.
    - If you and your child live far from Arthur M. Blank Hospital, you may be asked to go to your nearest emergency department to be treated first. Your child will be transferred to Children's from there if needed.

Physical changes and body image

BMT can cause many changes in the body. *Chemotherapy*, *radiation* or other medicines may cause your child to:

- Lose weight.
- Gain weight
- Have changes in skin color.
- Get acne or stretch marks.
- Lose hair.
- Have increased body and facial hair.

Talk with your child and listen to their concerns. Help them understand the changes are normal and most often not permanent. Most of these changes will go away as time goes on and medicines are changed. These things may help:

- Loose, drawstring clothes will adjust to rapid weight gain or loss.
- Hats, scarves or wigs will hide hair loss and may help your child feel better.
- You may be able to think of other ways to help give your child a sense of control.

Central venous access device care

Your child will have a central venous access device (CVAD) throughout their transplant process. The CVAD needs to be flushed and cleaned often. Nurses will teach your child's primary caregiver how to take care of the CVAD. You will also receive teaching sheets as guides.

Sun protection

Your child needs sun protection after BMT. The sun can cause skin cancer. It can also trigger GVHD or make it worse. Have your child:

- Wear a hat and clothing that protects the skin when outdoors, such as long pants and long sleeves.
- Use sunscreen with a sun protection factor (SPF) of 30 or higher when going outside.

Returning to school

Going back to school is an important part of returning to normal life. School gives your child the chance to learn, be with friends and feel independent. We want your child to return to school as soon as it is medically safe.

- You will use homebound school services when your child returns home. If you need to stay near the hospital after discharge, the Aflac Cancer and Blood Disorders Center hospital teacher can arrange for school services.
- If your child had an *autologous transplant* (received their own cells): Your child's *oncologist* will decide when your child can go back to school.
- If your child had an allogeneic transplant (received cells from a donor): The decision to return to school will be made by the BMT doctor. Most children can return to school 6 months to 1 year after *allogeneic transplant*.

Immunizations (vaccines)

Most immunizations are not given until at least 1 year after transplant. This delay gives your child's *immune system* time to recover.

- Your child should not get any vaccines unless advised by the BMT doctor.
- When it is time to begin vaccines, the BMT team will give you and your child's primary care doctor a vaccine schedule to follow.
- You and other children in your family should get all regular vaccines except the live polio vaccine and the live flu (influenza) vaccine, such as Flumist.

The flu is contagious. It can be deadly for any child, especially for a child with a weak immune system. Your child will be at high risk for getting the flu during the first year after transplant. Vaccinating the family against the flu will help protect both your family and your child.

- Your family will need to get the injection (shot), not the nasal form (such as Flumist, a live vaccine). The nasal vaccine could make your child sick.
- You and your child cannot catch the flu from the flu shot.
- If your child had a BMT 6 months ago or longer, the BMT team may advise a flu shot for your child.
- Ask your BMT team about flu shots as soon as the vaccine becomes available each year. This most often happens in September or October.
- Ask your *pediatrician* or primary care doctor to call the BMT team with any questions about the flu vaccine for your family.
- Every member of your family who is older than 6 months should get the flu shot (unless they are not medically able).

Taking your child's temperature

You do not need to take your child's temperature each day. If your child feels warm or looks sick, take their temperature.

- Do not use a rectal thermometer. Use a thermometer in the mouth or under the arm.
- Call the BMT doctor or nurse if your child's temperature is:
  - 101° F (38.3° C) or greater 1 time, **<u>or</u>**
  - 100.5° F (38.0° C) for more than 1 hour
- If your child has shaking chills or looks sick but does not have a fever, you should still call the BMT team.

Do not give any fever reducing medicines unless advised by your BMT team.

- Ibuprofen (Motrin, Advil or less costly brands) can keep platelets from working and can mask (cover up) a fever.
- Acetaminophen (Tylenol or less costly brands) can mask a fever.

- Aspirin or products with aspirin in them can keep platelets from working, mask a fever and cause a condition called Reye's syndrome.
- Salicylate medicines, such as Pepto Bismol, can keep platelets from working.

Mouth care

Mouth care is important and can help to prevent infection.

- Use a soft toothbrush if the platelet count is below 50,000.
- Use toothpaste with fluoride to help prevent cavities.
- The BMT team may advise to use special mouthwash.

Skin care

Skin is the body's first defense against infections. Your child's skin may be sensitive and dry for many months after transplant. Many BMT patients also notice darkening of the skin after BMT. This darkening is most often due to the *preparative regimen* and most often goes away over several months.

- Have your child use hypoallergenic soaps, shampoos and lotions, such as Cetaphil, Aquaphor or Eucerin. You can find these products at your local pharmacy or grocery store.
- Avoid fragrances (perfumes), dyes or harsh chemicals. They can dry out the skin and cause irritation.
- Put on sunblock every day. Use SPF 30 or higher.
- Tell the BMT team if your child has a new rash, no matter how mild it is. Call them **right away.** Do not wait until your next clinic visit.

Sexuality

If your child is sexually active, be sure to talk about safe sex practices. Teach your child to:

- Use birth control. Even though chemotherapy or radiation therapy may cause sterility, it is not a certainty.
- Use a condom to avoid sexually transmitted diseases (STDs).
- Avoid sexual intercourse if the white blood cell count or the platelet count is low due. There is a risk of bleeding or infection. Infections can be more serious for a recent BMT patient.

Animals and BMT

You probably do not need to get rid of a family pet before BMT. Most often, healthy pet dogs and cats do not put your child at high risk for infection. Talk with your BMT doctor about your pets. Make sure:

- Your child wears shoes when outdoors and washes their hands after contact with a pet.
- Your pet has routine veterinary care with tests for parasites.
- Your pet gets regular vaccines as advised by your veterinarian (vet).
- Your vet knows about your child's transplant and the need to keep your pet healthy.

There are certain pets that your child should avoid after BMT. These pets carry a high risk for infections that can make your child sick.

Unsafe pets include:

- Fish
- Turtles
- Snakes
- Lizards and other reptiles
- Chickens
- Birds
- Rodents (rats, gerbils and hamsters)
- Ferrets

Talk with your BMT doctor about animals in your home. You may need to keep animals out of the home or simply keep them away from your child. You may also need to keep your child from helping with pet care.

Other tips for pets include:

- Do not get a new puppy or kitten just before, during or right after transplant. Young animals are at a high risk for diseases, such as parvovirus, parasites and diarrhea.
- Your child should not clean cat litter boxes, turtle or bird cages, or dog stool. Stool from animals may have germs that could make your child sick.
- Visit the Centers for Disease Control and Prevention at cdc.gov/healthypets for more information.

Nutrition

Good eating habits are an important part of your child's recovery after a BMT. It is also very important that you follow the food safety instructions from your child's BMT team very closely to help protect your child from infection (see page 44).

Medicines

Helping your child take medicines can be hard. A young child may refuse to take medicine if it has a bad taste or if they do not feel well. A teen may feel tired of following rules and taking medicine. There are medicines that your child must take for at least several months after the transplant. Some ideas to help with taking medicines include:

- Mix the medicine in a small amount of food that tastes good. Let your child choose what food or drink to take with the medicine.
- Talk with your BMT team about which medicines need to be taken at very specific times. There may be a few medicines that your child can take when they want to. Letting your child choose the time of day they take certain medicines may give them a sense of control.

- Offer small rewards for taking medicine, such as stickers.
- Your child life specialist can help with ideas.

NOTE: There are some medicines that cannot be mixed with certain foods or drinks. There are also some that cannot be taken together or taken with vitamins, herbs or supplements. Always check with your child's doctor or pharmacist about how and when to give your child medicines.

Common transplant medicines and their side effects

Your child may need some or all of the medicines listed below. Your BMT team will decide on the best medicines for your child. Expect your child's medicines to change often after BMT. If your child is unable to take medicine by mouth (to swallow), they may get an NG tube. Some medicines can be given through the tube.

Brand name medicine (generic name)	**Use**	**Most common side effects**
• Zovirax (acyclovir) • Valtrex (valacyclovir)	• Prevents or treats certain viral infections	• Decrease in kidney function
• Bactrim or Septra (sulfamethoxazole and trimethoprim; cotrimoxazole)	• Helps prevent a type of pneumonia	• Rash
• Cellcept (mycophenolate)	• Prevents or treats graft-versus-host disease (GVHD)	• Low blood counts • Diarrhea • Upset stomach
• Diflucan (fluconazole)	• Prevents or treats fungal infections	• Increase in liver enzyme levels
• Gammagard (IVIG)	• Antibodies to help prevent infections	• Fever, chills and other reactions during or after infusion • Headache
• Keppra (levetiracetam)	• Prevents seizures	• Drowsiness
• Magnesium oxide	• Prevents or treats low magnesium	• Diarrhea

Brand name medicine (generic name)	**Use**	**Most common side effects**
- Neoral or Gengraf (cyclosporine)	- Prevents or treats GVHD	- High blood pressure - Decreased kidney function - Upset stomach - Seizures and changes in the nervous system - Low magnesium - Increased body and facial hair
- Prednisone - Orapred (prednisolone)	- Prevents or treats GVHD	- High blood pressure - Weight gain and fluid retention - Increased appetite - Acne - Behavior and mood changes - Trouble sleeping - Upset stomach - Stretch marks
- Prevacid (pantoprazole) - Nexium (esomeprazole)	- Blocks acid in the stomach	- Gassy stomach
- Procardia (nifedipine) - Norvasc (amlodipine)	- Prevents or treats high blood pressure	- Swelling of feet and legs
- Prograf (tacrolimus)	- Prevents or treats GVHD	- High blood pressure - Decreased kidney function - Seizures and changes in the nervous system - Low magnesium
- Vasotec (enalapril)	- Prevents or treats high blood pressure	- Cough

Returning to your primary care team

The transplant team will care for your child until they have fully recovered from the transplant.

- The amount of time it takes depends on your child's disease and type of transplant. Your child's BMT doctor will talk with you and let you know when your child is ready to go back to their primary care team.
- The transplant team will give your child's primary care team a report of their medical care during the transplant process.

1 year post-BMT

Allogeneic BMT patients will return to see the BMT team in the Aflac Cancer and Blood Disorders Center clinic 1 year after their transplant. Autologous BMT patients most often do not need to return to see the BMT team.

Your child may need these special tests close to their 1 year visit:

- **Echocardiogram (echo)**: This test measures the size and function of the heart. A sensor is moved over the skin above the heart. Sound waves are sent to the heart and a picture of the heart can be seen on a screen. This test does not hurt.
- **Pulmonary function test (PFT)**: This test measures how well the lungs work. Babies and young children may be too young to take this breathing test. This test does not hurt.
- **Thyroid function**: This is a blood test to see if the thyroid gland is making the right amount of hormones. The thyroid gland may have been hurt by the preparative regimen or by GVHD.
- **Engraftment studies (allogeneic transplants only)**: These tests will find out the percent of donor cells in your child's blood.
- **Other hormone tests**: These tests can help tell if your child's sexual development is normal. This may include tests called FSH, LH, testosterone and estradiol.

Long-term follow-up care

Late effects

BMT treatment can cause side effects that happen years later. These side effects are known as late effects. The risk of late effects depends on:

- The type and amount of treatment your child receives.
- Your child's gender and age at transplant.

To look for late effects, your child needs follow-up care:

- Throughout adulthood.
- From doctors who know about your child’s transplant and the treatment of your child’s primary disease.

A helpful resource is the National Marrow Donor Program's Post-Transplant Guidelines for Patients at bethematchclinical.org/medical-education-and-research/materials-catalog/#/care%20guides.

Common late effects

Cataracts

Cataracts are clouding of the lens in the eye and can cause poor vision. There is a risk of cataracts if your child received steroids, busulfan or total body irradiation. Cataracts can be corrected by a simple surgery.

MAKE SURE:

- Your child sees an optometrist or ophthalmologist each year to look for cataracts, GVHD or other eye problems.
- The eye care doctor knows your child had a BMT. They should also know if your child received steroids, busulfan or total body irradiation.

Teeth and mouth problems

BMT may cause mouth problems, such as poor enamel and increased risk of cavities. If your child has had an allogeneic BMT, they may also get chronic graft-versus-host disease (GVHD) of the mouth (see page 60).

- Have your child get dental care at least 1 to 2 times each year.
- Make sure the dentist knows your child had a transplant.
- If the dentist has concerns, ask them to call your BMT doctor to talk about the possibility of GVHD.

Cardiac (heart) problems

Radiation and high doses of chemotherapy may cause the heart to get weak over time.

- Your child may need to have an echocardiogram sometimes to check for changes in heart function.
- Your child should make healthy lifestyle choices to help protect the heart. These choices include a healthy diet, regular exercise and not smoking.
- Your child may need to avoid certain activities, such as power lifting and scuba diving. Ask your child’s doctor if they should avoid any activities.

Pulmonary (lung) problems

Many parts of the BMT process may cause problems with the lungs. These problems may include lung scarring, asthma-like symptoms or poor tolerance of exercise.

- Your child may need to have pulmonary function tests sometimes to check for lung problems.
- Your child should make healthy lifestyle choices to help protect the lungs. These choices include a healthy diet, regular exercise and not smoking.
- Your child may need to avoid certain activities, such as scuba diving. Ask your child's doctor if they should avoid any activities.

Infertility (sterility)

Chemotherapy and radiation may cause infertility. Infertility means that it is either difficult or not possible to get pregnant (for females) or cause a pregnancy (for males).

Risk of infertility depends on:

- The type and amount of treatment during the BMT.
- The treatment given before the BMT.
- Your child's gender and age at time of transplant.

Talk about the risk for infertility with your child.

- If your child is male, they may want to have their sperm tested when they are ready to start a family or if they have trouble starting a family. This test can help find out the sperm count and quality.
- If your child is female, there is not an easy way to test for damage to the eggs. Hormone testing may provide some information on how well the ovaries work. They may want to talk with a fertility specialist.
- Never tell your child that it is impossible to get pregnant or cause a pregnancy. Even when risks of infertility are very high, pregnancy does sometimes happen.

Endocrine problems

Some BMT treatments may cause endocrine problems, which involve the body's hormones.

- These problems may include hypothyroidism. This is when the thyroid gland does not make enough of its hormones. Blood tests can show hypothyroidism. The treatment is taking certain medicine every day.
- Other endocrine problems may involve the sex hormones. The ovaries or testes may not make the right amounts of estrogen, testosterone and other sex hormones. This can cause a delay or other problems in sexual development. Blood tests and a physical exam can show problems with the sex hormones.
- Your child may need to see an endocrinologist if hormone problems happen.

Osteopenia

BMT treatment may cause osteopenia. Osteopenia means your child has weakened or not enough bone substance. Osteopenia can increase the risk of fractures and certain joint problems. Patients who take steroids for a long time and certain other medicines are at high risk for osteopenia. You can help your child improve bone health by:

- Making sure they take enough calcium and vitamin D. Your child’s nutritionist and BMT team can give you advice on how to make sure they get enough.
- Having them do regular, weight-bearing exercises. Your child’s physical therapist and BMT team can teach you about exercise.

Cognitive problems

Some BMT treatments may cause cognitive problems. Cognitive problems are problems with thinking and learning. This may cause trouble at school or work.

- The types and amount of problems depend on your child’s:
  - Disease.
  - Treatment before, during and after the BMT.
- It also depends on their ability to think and learn before the BMT.
- The problems may last a short or long time.
- Many children who have a BMT have problems thinking and doing schoolwork for the first year after transplant. Then, things most often go back to the way they were before the transplant.

You may want to meet with a neuropsychologist if your child has these problems. They can do testing that often helps find problems. They can also give you ideas for improvement. Your BMT team can help arrange this testing.

Secondary cancers

BMT treatment involves chemotherapy and sometimes radiation. Both treatments can increase the risk of cancer. Be sure your child’s primary care doctor knows they had a transplant and is at increased risk for cancer. Then, proper screening and teaching can take place. Help your child make smart life choices to avoid the risk of cancer by teaching them to:

- Avoid smoking.
- Drink alcohol in moderation.
- Protect their skin from the sun.
- Eat a healthy diet.
- Get physical exams each year.

Your child should learn how to:

- Do regular breast or testicular exams.
- Check their skin for unusual changes that a doctor may need to see.

Cancer Survivor Program

Advances in treatment cure nearly 80 percent of children with cancer. Today's cancer treatments result in greater success rates and longer lives, but they can also create unique problems later in life for survivors. Medical treatment can help with many of these late effects.

The Cancer Survivor Program at the Aflac Cancer and Blood Disorders Center helps with these needs. A team of childhood cancer survivor experts:

- Treats survivors in the program.
- Offers support and education to help them have the best possible quality of life.
- Works to address the health and psychosocial needs of the cancer survivor.

As leaders in providing care to childhood cancer survivors, our goals include:

- **Specialty clinics**: Survivors should meet with a team of childhood cancer survivor experts each year.
- **Research**: Research helps us better understand how to help survivors today and help prevent late effects.
- **Teaching**: Survivors need to know the risks of cancer treatment and how to have good health and a better quality of life.
- **Increased awareness**: Healthcare workers and other members of the community need to know more about the challenges childhood cancer survivors may have. With this knowledge, we can provide better health care and programs to help with social or financial problems.

What we can do for your child

- Provide a special clinic at Children's.
- Review your child's health history and suggest a plan of care.
- Do a complete evaluation. This includes a physical exam, blood tests and any other tests needed.
- Teach your child about risks with the specific cancer treatment they received.
- Teach ways to improve your child's health and quality of life.
- Help with school, job or insurance problems.
- Provide support for physical or emotional changes or problems.

Any survivor of childhood cancer who has been off treatment for 2 years can join the program.

Late effects screening for noncancer survivors of BMT

The Cancer Survivor Program sees children without cancer 2 years after their transplant. During the visit, staff can provide advice on future care.

Ex-Sickle Cell Clinic

Many children from the Aflac Cancer and Blood Disorders Center have been cured of their sickle cell disease through BMT. These children need special follow-up to look for long-term effects, just like cancer patients. They also need special care for conditions like iron overload, stroke and acute chest syndrome from their sickle cell disease. Survivors of BMT for sickle cell disease begin yearly visits to the Ex-Sickle Cell Clinic 1 year after their transplant. Call 404-785-1200 to make an appointment.

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Research Studies

What is clinical research?

Research means doing a study to learn something new or answer a question and then sharing the answers with others. *Clinical research* is research on human patients. Pediatric blood and cancer specialists have relied on clinical research to make great advances in treating diseases. Without families who will take part in clinical research studies during treatment, it would be impossible to answer important questions about how to best treat children with cancer and blood disorders.

New research studies build on the results of past research studies and current treatments. Research studies are the building blocks of medical breakthroughs and cures.

Why is research important?

Research studies can help to improve the health, medical care and quality of people's lives. This may include:

- New drugs or therapies to help treat cancer and other illnesses.
- New ways to do surgery that are safer and help the body heal faster.
- New machines that help find cancer and other illnesses sooner.
- Better understanding of diseases and treatments

There is no guarantee that a research study will help your child. However, what is learned could help others who have the same illness.

You and your child have a choice

Taking part in clinical research is always your choice. Your child does not have to take part in a clinical research study to be treated at the Aflac Cancer and Blood Disorders Center.

Your choice will not affect how the Aflac Cancer and Blood Disorders Center staff feels about or treats you or your child. Your child will still get the same quality of care.

You may talk with your child, your child's doctor, your family or others before you decide to take part in a research study.

- You and your family can ask questions at any time during the study.

- You can take your child out of the research study at any time. The care your child gets will not change in any way if you decide to take your child out of the study.
- During the study, researchers will review what is learned from the study. They will tell you if they find that it is not safe for your child to stay in the study. If this happens, your child will be taken out of the study.

Types of clinical research

Clinical trials

A *clinical trial* is a research study that involves a medical treatment.

- Clinical trials provide a standard way (a *protocol*) to treat a disease. They also collect information about how well the treatment works.
- A clinical trial tries to learn more about the safety or success of a drug, device or medical procedure.
- The goal is that what is learned from a clinical trial will help improve care or even find a cure for an illness.

Cancers and blood disorders in children are rare when compared to diseases such as diabetes or asthma. For that reason, pediatric blood and cancer specialists from around the world work together to carry out clinical trials. Pediatric blood and cancer clinical trials often take what has already been learned to lay out the best known treatment and then put in a question to be answered during the treatment.

- If your child is enrolled in a clinical trial, they would be treated the same way as every other child enrolled in that clinical trial. This is true even if they receive treatment at another center.
- Many clinical trials in BMT outline the entire BMT treatment. Or, they may involve just part of the treatment, such as how to treat a certain problem.
- A child may be enrolled in more than 1 clinical trial.

Registry studies

Registry studies do not involve treatment, so they are called nontherapeutic studies. Instead, the research collects information or data about your child’s disease, transplant and in some cases, donor.

- The information is collected from the medical record. It may be put into a list (registry) that is shared with researchers outside of Children’s.
- For rare diseases, such as pediatric cancers and blood disorders, there are organizations that collect data. They collect data in a certain way so that researchers can then answer questions using that information.

In BMT, the most common registry study is through the Center for International Blood and Marrow Transplant Research (CIBMTR).

- Every patient at our center who is going to have a BMT is asked to take part in this registry, no matter what type of BMT.
- If you and your child decide to take part, a research staff member will:
    - Fill out forms about your child's disease and transplant.
    - Send these forms into the CIBMTR.

Other registry studies you and your child may be asked to take part in include:

- Pediatric Blood and Marrow Transplant Consortium (PBMTC)
- National Marrow Donor Program (NMDP)
- Cord blood registries
- Rare disease registries

Other types of research

There are other nontherapeutic clinical research studies that do not involve treatment. This may include a biology study.

- Extra blood samples are taken, or leftover tissue from a biopsy is collected, to do tests that would not normally be done.
- These tests are then compared with information about how the patient is doing.
- In this way, a researcher can find out whether or not a new way of testing is useful.

Other nontherapeutic research may look at the psychosocial aspects of a disease or treatment. For example, a study may use questionnaires given to families going through transplant that include questions about how each family member is coping with the stresses of transplant.

Randomization

After a new treatment has gone through studies and found to work and be safe, a *randomized* clinical trial is done to compare the new treatment to 1 or more standard treatments. A randomized clinical trial is one in which the patients are assigned randomly (by chance) to different treatments. Randomization ensures each child has a fair and equal chance of being assigned to any of the treatments. The results of the treatments are then compared to find out which one works best. Randomization is an important part of clinical research.

- At the start of the trial, it is not known whether the standard treatment or the new treatment is best.
- If there are 2 treatments on a clinical trial, randomization is like flipping a coin.
- If there are 3 treatments, randomization is like drawing straws.

- In some randomized clinical trials, neither the patient nor the doctor knows which treatment a child is getting. This is called a double blinded study. Blinded studies help prevent *bias* in the research and help make sure the groups can be compared fairly.

Benefits of clinical research

Children treated on clinical trials may benefit by getting the:

- Most up to date treatment.
- Follow-up that clinical trials require.

But there may not be a direct benefit to your child. Benefits will vary among different studies. In some cases, such as taking part in a registry, your child will not get any direct benefit. Instead, other children in the future may benefit from what is learned from your child's data.

Your BMT doctor can answer questions about the possible benefits of taking part in a clinical research study. Talk with your child, your child's doctor, your family and others before you decide to take part in research.

Some questions you may want to ask about a treatment include:

- Which treatment do you advise and why?
- What is the chance that the treatment will work?
- How will we know if the treatment works?
- What are the risks of the treatment?
- How long will the treatment last?
- What do I need to do as a part of research study that is different from the care my child would most often get?
- How much will the treatment cost? Who pays for the cost?
- How can I help prepare my child for the treatment?
- What are other alternatives?
- Are there any things that my child or I will be asked to do as part of the study?

How is your child protected?

One of the main goals of a research study is to ensure the safety, privacy and confidentiality of the patient. To achieve these goals, we use:

- **Scientific review**: Studies are reviewed by groups of experts at many levels who provide guidance and advice.
    - They look to see that the study makes sense and is designed well.

  - If the study is funded by the government, it will be reviewed by the National Cancer Institute (NCI) at the National Institutes of Health (NIH).
  - At Children's, all cancer and blood disorders studies are reviewed by the doctors and staff at the Aflac Cancer and Blood Disorders Center.
  - If a study involves patients with cancer, it is also reviewed by the Winship Cancer Institute at Emory University.
- **Institutional Review Board (IRB)**: An IRB is a committee of doctors, scientists, people who are not scientists and community members who review research on humans. Every center that does clinical research has an IRB. This is required by the federal government.
  - The IRB makes sure the patient's rights and welfare are protected. They also ensure that patients and families are informed about the study before giving consent.
  - The IRB must approve a study before it is started, and at least yearly, while the study is being carried out.
  - The IRBs of both Children's and Emory University review studies from the Aflac Cancer and Blood Disorders Center.
- **Protecting privacy and confidentiality**: Taking part in a clinical research study often involves sharing private health information. Researchers are required to protect your child's privacy when possible. They share information only with those who need it and authorized to receive it. There are many ways that sensitive information is protected:
  - Research data may be stored in a locked file cabinet or password-protected computer file.
  - Information may be coded so that a Study ID or number, rather than your child's name, is attached to the research data.
  - The Health Insurance Portability And Accountability Act (HIPAA) passed by the federal government directs how to share protected health information (PHI).
    - You were asked to sign a HIPAA form when your child was first seen at the hospital. This form allows us to use the information to care for your child.
    - We must have other permission from you if the information will be used in any other way, including research. If your child is part of a research study, you will be asked to sign a HIPAA form for that study.
- **Other ways of protecting your child**: Large treatment studies often have a special committee called a Data and Safety Monitoring Board (DSMB).
  - The DSMB is made up of experts who are not involved in the study.
  - The DSMB checks the progress of a study while it is being carried out and makes any needed changes to protect patient safety. For example, the DSMB may find that 1 treatment appears to be working better than another. The DSMB can stop the study so that all patients can be treated with the best treatment.

Informed consent

Informed consent is more than just signing a consent form. It is a process that includes talking with your doctor, reading information, taking time to think and getting answers to your questions. The process should help you know enough about the study to decide whether or not you want your child to take part.

- Informed consent for research starts with talking to your doctor or other member of the BMT research team. They will tell you about the benefits and risks of the study, as well as other options. They will also answer your questions.
- They will give you an informed consent form to read. The form often gives more details about the study. The form will include the:
    - Purpose of the study.
    - Procedures that your child would take part in.
    - Risks and benefits of taking part in the study.
    - Costs of taking part in the study.
    - Rights of people who take part in the study .
    - Person to contact if you have questions or if there are problems.
- Once you have read the form, you will have a chance to ask more questions and talk about other options.
- If you decide that you want your child to take part, most studies have you sign the informed consent form. By signing the form, you are giving permission for your child to be in the study.
- You should be given a copy of the form whether you sign it or not. Keep the consent form so that you can refer to it during the study.
- Patients 18 years of age or older are asked to give their own informed consent for research. If your child is younger than 18 years, you will need to sign for them.

The informed consent process does not stop when you sign the informed consent form. You may have questions later. We encourage you to talk with the BMT team.

Informed assent

Children younger than 18 years are not legally able to give informed consent on their own. A parent or legal guardian must give permission for the child to be in the research. Still, the child does have a say in the decision. If your child is younger than 18 years:

- They should be involved in the decision at a proper level for their age, development and thinking ability. This involvement is called informed assent.
- The assent process can give your child a sense of empowerment and control.
- Assent may come in the form of talking with a young child about what is involved and asking for their OK.

- Older children are asked to read and sign a short version of the informed consent form called a written assent form.
- Older teens are asked to read the full informed consent form. They are expected to be more involved in the discussion about it and the decision to take part.

Notes

Caring for the Whole Family

Feelings

Your family life will be different before, during and after your child's BMT. There will be many new stresses. Every family is different, but many families have said that they feel fear, anger, guilt and depression. Share these feelings. Your child's BMT team is here to listen to and help you and your family.

- **Fear**: You may fear the unknown. This may be the first time your child has been in the hospital. It may be hard to see your child getting used to new and sometimes scary surroundings. You may also worry about treatment, expenses or how to help your child deal with treatment. It often helps to talk about these worries.
- **Anger**: At times you may feel angry at what is happening to your child and your family. Some parents feel angry at the BMT team for not finding out what is happening with their child. You may even feel angry with your child for getting sick and turning your life upside down. Feeling angry is normal. It may help to take a walk or talk with a friend, family member or the BMT family support team.
- **Guilt**: Many parents feel guilty that they did not know their child was sick. Others wonder if they did something to make their child sick. Family members may feel guilty that they are healthy. Young children often feel that they caused the illness. It is important to let everyone in your family know that they did not make your child sick and they could not have done anything to prevent it.
- **Depression**: Feeling sad is a normal reaction. You may have changes in family routines. You may feel alone. These changes can cause feelings of depression:
  - Crying
  - Eating more or less
  - Lack of interest
  - Low energy
  - Tightness in the chest
  - Headaches
  - Poor sleep or sleeping too much
- **Isolation or boredom**: BMT patients are not allowed to leave the inpatient unit after their BMT for many weeks because of their immune system. This can lead to feelings of isolation and boredom.

All of these feelings are normal. Your child is not alone. Most families can work through these feelings with the support of family, friends and your child's BMT team.

Ideas to help you cope with your child's BMT

- Find private time to talk with your partner, or a close friend or family member. Try to talk about things other than your sick child.
- Do not talk about your child in front of them unless they are included.
- Find ways to reduce stress. You know what works best for you. You may try exercise, reading, massage or shopping.
- Take turns with your partner or another support person who can stay with your child at the hospital or go to clinic visits. This helps everyone be involved with your child's care. It also helps parents feel closer if they are both involved in their children's care.
- Ask your child's BMT team for help and support.
- Talk with other parents whose children had BMTs.
- Go to a support group.

Sometimes feelings are overwhelming. This can be especially true when there are other stresses like:

- Death of a loved one.
- Loss of a job.
- Marriage problems.
- Divorce.
- Mental health problems.
- Substance abuse.

You may need mental health counseling or medicine. Share your feelings with the BMT team so you can get the help you need.

Teens and young adult patients

Teens and young adults have different questions and fears than younger children. They may worry about dating, fitting in at school, sports and other activities, or fertility problems. Talk with your child's BMT team about these kinds of questions or worries.

These websites and programs may also help you and your child share your feelings of anger, frustration, fear and hope.

The Young Adult Group at Camp Sunshine House

A program for teens who want to take part in the everyday experiences of growing up

mycampsunshine.com

Planet Cancer

An online forum for teens and young adults with cancer

planetcancer.org

Fertile Hope

A website dedicated to helping cancer patients with infertility

fertilehope.org

Impact on marriage or relationship

An illness can turn a family's life upside down. You may feel emotionally and physically tired. Often, parents keep working and try to keep a normal home routine. Many parents feel the strain on their marriage or relationship. They feel angry and upset about what has happened to their child. They often say that they do not have time for their partners.

Ideas that may help prevent marriage or relationship problems

- **Knowing coping styles**: It is important to know how your partner deals with stress. Each person shows feelings in different ways. Some people pull away, cry or get angry. Some people try to learn as much as possible. Be aware of how your partner deals with their feelings.
- **Talking with each other**: The key to a good relationship is talking. It is important to talk about feelings, fears and information during times of stress. Silence can make you feel distant from your partner. Sharing feelings and facts can help you know what your partner is thinking. Sharing and talking may help with making decisions.
- **Changing roles when needed**: The stress of an illness can change the roles of family members. One parent who took care of the home may now be too busy. The other parent may have made most decisions in the past. If one parent is with the sick child more than the other, they may now make many decisions. Changing roles can cause stress in a relationship. In their book, "Coping with Childhood Cancer," authors David Adams and Eleanor Deveau list 6 ways that parents can work together:
    - Show your partner kindness and understanding. Do not blame or criticize.
    - Make your sick child a priority. Both parents need to learn about the diagnosis and treatment.
    - Continue to share in caring for and loving your other children.
    - Share your feelings of anger, sadness and hope with each other.
    - Accept the help of family, friends and neighbors.
    - Be loyal to each other if family members criticize or blame one of you for decisions that are made.

Divorced parents

Divorce is hard on most families. Problems may get worse when a child is sick. Sometimes children may try to use the BMT to bring together divorced parents. Other times, they may try to play 1 parent against the other to gain some feeling of control. Try not to let the stress of divorce affect your child's care. Though the marriage has ended, the job of parenting continues. Good communication can help you both provide the best care for your child.

Here are some tips to help avoid problems:

- Talk with the BMT team if your child is having behavior problems.
- Provide copies of divorce decrees, custody agreements and visitation rights for your child's medical record.
- Meet together with your child's BMT team to help avoid confusion about the plan of care.
- Ask for 2 copies of all teaching materials so both parents can have the same information.

Siblings

Brothers and sisters have many feelings. They may have some of the same needs as their sick brother or sister. They may feel upset, scared and unsure of the future. They may worry about death. Children of any age will see a change in their family life.

Siblings may feel sad and worried about their sick brother or sister. They may also feel anger or jealousy. Their parents may spend all of their time with or talking about the sick child. Friends and family send gifts and money. Siblings may feel sad and cry easily. They may have trouble sleeping, physical complaints or problems in school. Siblings may also feel they are being left out of what is going on and the latest updates.

Some tips to help siblings include:

- Try to spend time alone with your other children, doing things that they like.
- Let them know that you love them and they are special.
- Talk with them about the BMT in a way that they can understand. Help them understand their brother or sister's illness and treatment. Let them know that the illness is not contagious and they did not cause their brother or sister to get sick. Ask your child life specialist for helpful tips.
- Ask a loving friend or family member to stay in your home. Try to avoid sending your children somewhere else to stay.
- Ask your children to help with chores at home. Including your other children makes them feel needed and helps you, too.
- Talk with their teachers. Teachers can support your children and let you know if there are any problems at school.
- Ask for help from the BMT team.

Special programs

There are programs to help with your child's physical, emotional, mental and spiritual needs. Your child's life is centered on their family. Your family's involvement is an important part of their recovery. The following information about support groups and special programs can help heal your child. Social workers can provide more information on these programs, as well as applications.

Camp Sunshine

Camp Sunshine was founded in 1983 as a summer camp for children with cancer. Today, Camp Sunshine is more than a summer camp program. It is a place where kids can be kids. Year-round programs include:

- An outward bound trip and a trip to Washington, D.C., for teens.
- A snow ski clinic and ski trip for children who have physical disabilities from their cancer.
- Sibling camp and family camp weekends.

The goal of each program is to:

- Promote self-confidence and personal growth.
- Make friends and enjoy the daily activities of growing up.

BMT patients cannot take part in camp activities until it is a safe time after the BMT. Talk with your child's doctor before planning any camp activities.

mycampsunshine.com
404-325-7979
1850 Clairmont Road, Decatur, GA 30033-3405

Camp Sunshine House

Completed in 2003, Camp Sunshine House is a place that provides year-round emotional and social support for children with cancer and their families. They have:

- Support groups.
- Networking opportunities.
- Workshops.
- Special events.

It provides a familiar, central place for families from out of town where they can go to receive support services. The house makes Camp Sunshine services more accessible to more families, including those who live outside Atlanta or have to work on weekends.

The Children’s Connection

The Children’s Connection is a school re-entry program for children at the Aflac Cancer and Blood Disorders Center. This program helps students with cancer or sickle cell disease make a smooth shift back to school.

Members of the care team visit the student’s school to talk about:

- The disease and treatment.
- The emotional side of the student’s illness.
- How classmates and teachers feel and how to support the student.

Talk with your child life specialist to set up a visit to your child’s school.

CURE Childhood Cancer

CURE is a nonprofit organization whose mission is to conquer childhood cancer through research and education while supporting patients and their families. CURE was founded in 1975 by parents of children with cancer; the work continues today with the help of their community of donors and volunteers. There are many programs that have been organized by CURE. Some are:

- **Open Arms Meal Program:** CURE serves meals to children and families who are inpatient in the Aflac Cancer and Blood Disorders Center at Children’s Healthcare of Atlanta at Arthur M. Blank Hospital on 3 days each week. CURE also visits the outpatient clinic 2 times each week with Chick-fil-A. Your child’s social worker will give you a schedule.
- **Off-Therapy Celebration:** This is a picnic at a local attraction that happens each year. Children who have survived cancer and their families are invited. More than 1,500 children are invited, but the list keeps growing. Talk with your child’s BMT team about whether they can go to the next Off-Therapy Celebration.
- **CURE’s Counseling Program:** This program helps address the unique psychological needs of families affected by childhood cancer. CURE’s family-centered approach to addressing these needs includes partnering with a network of licensed community-based therapists to offer counseling to CURE families.
- **Holiday and Summer Parties:** CURE hosts a holiday and summer party to bring families together in community and have fun outside of the hospital.

curechildhoodcancer.org

770-986-0035

CarePages

Children’s makes it easy to keep family and friends informed of your child’s progress while in the hospital. We have partnered with CarePages for a free, easy-to-use program that allows you and your child to create a webpage to:

- Share news about your child’s health.

- Provide updates.
- Post visiting hours and contact information.
- Share pictures.
- Create a guest message board where family and friends can build an online support network.

Visit choa.org to set up your child's webpage.

Lighthouse Family Retreat

The Lighthouse Family Retreat provides seaside retreats for families living through childhood cancer. Retreats are held in Florida from April to October each year. Each retreat includes 8 to 12 families. There are 25 to 35 volunteers who serve them by cooking, cleaning and taking care of daily responsibilities so the retreat families can focus on having fun together. The Lighthouse was designed to bring joy to children with cancer and their families, while renewing their strength, hope and love.

lighthousefamilyretreat.org
678-455-5115

Hilton Head Heroes

The mission of Hilton Head Heroes is to bring together children between the ages of 4 and 12 who have been diagnosed with a serious illness, along with their families, to Hilton Head Island for a free resort vacation. It must also be determined that the family's financial capabilities would make a vacation impossible otherwise.

hiltonheadheroes.org
843-671-4939

Deliver the Dream

Deliver the Dream is a mountain retreat center for children, families and individuals faced with serious illness or other crisis. Deliver the Dream offers relaxation, recreation and fun in a tranquil mountain setting, and the chance to share with others who are coping with similar experiences.

deliverthedream.org
888-OUR-DREAM

Notes

Resources

Financial assistance resources

The Bone Marrow Foundation

This patient aid program helps patients with transplant-related costs, such as donor search, compatibility testing, bone marrow harvesting, medicines, home and childcare services, medical equipment, transportation and housing expenses.

bonemarrow.org

800-365-1336

Cancer Care

This program is staffed by oncology social workers. They provide emotional support, information and financial assistance to cancer patients and their loved ones.

cancercare.org

800-813-HOPE

Children’s Organ Transplant Association (COTA)

COTA provides fundraising assistance for children and adults needing lifesaving transplants. Staff members and advocates work with the family to set up the initial organization and campaign goals prior to an on-site visit. Volunteers, family members and staff work as a team to raise the necessary funds.

cota.org

800-366-2682

The Leukemia and Lymphoma Society

This organization provides education, sponsors, research and limited financial assistance to patients who need treatment for leukemia, lymphoma, Hodgkin’s disease or myeloma. Contact your local Leukemia and Lymphoma Society chapter for more information.

leukemia-lymphoma.org

800-955-4572

Lymphoma Research Foundation

This foundation provides reimbursement grants to lymphoma patients in need of financial assistance. The grants are for uncovered expenses that happened during treatment. This may include childcare, travel costs (needed to get treatment), medical aids and devices, educational and support meetings, camps, cosmetic aids (such as wigs and scarves) and hygiene products.

Grants must be used within 1 year from the award date.

lymphoma.org

800-235-6848

Be the Match

This organization, along with the National Marrow Donor Program (NMDP), helps patients afford BMT, find a matching donor and build a future as advances in medical research are made.

marrow.org

202-638-6601

Medicaid

Medicaid is a medical assistance program that helps eligible people who cannot afford medical care pay for some or all of their medical bills. Medicaid can be obtained through a variety of programs administered by the Department of Family and Children Services (DFCS) and the Social Security Administration. Talk with the transplant financial counselor or social worker for more information.

The National Children's Cancer Society

This organization supports children with cancer and their families. It provides financial assistance for blood stem cell transplant and emergency ancillary expenses, education, information, advocacy and emotional support for children and families dealing with a child's cancer.

thenccs.org

800-532-6459

Travel and housing resources

Angel Flight of Georgia

This organization provides free transportation for people who have a medical need that cannot be filled in their local area. Pilots donate time and expenses to provide air travel to treatment centers.

angelflight-ga.org

877-452-7958 or 770-452-7958

Local hotels

The social work department has a list of hotels in the area. Some of these hotels provide a hospital discount. The transplant social worker can suggest which hotels will best fit your needs (short-term, long-term, necessary amenities, location).

Medicaid nonemergency transportation

Nonemergency transportation services, subsidized by Georgia Medicaid, are provided for patients who have Georgia Medicaid coverage. Talk with the transplant social worker for information about services provided in your local area and phone numbers. You can also call your local Department of Family and Children Services (DFCS) office.

National Patient Air Transport HELPLINE (NPATH)

This organization gives information and referrals to patients in financial need of air transport to distant locations for specialized treatment or recovery. If charitable means cannot meet the patient's financial need, NPATH will provide information on discounts from all known commercial services.

patienttravel.org

800-296-1217

Ronald McDonald House

This facility provides lodging for patients and their families during medical treatment. The initial referral must come from the transplant social workers. A donation of $10 each day is requested.

armhc.org

404-315-1133

Web resources

These websites can help you and your family before, during and after your child's BMT.

American Cancer Society

cancer.org

American Institute for Cancer Research

aicr.org

American Society for Blood and Marrow Transplantation

asbmt.org

American Society of Clinical Oncology

asco.org

Aplastic Anemia and MDS International Foundation

aamds.org

Association of Cancer Online Resources

acor.org

Association of Pediatric Hematology/Oncology Nurses

aphon.org

Association of Pediatric Oncology Social Workers

aposw.org

Be the Match

marrow.org

Blood and Marrow Transplant Information Network and Newsletter

bmtinfonet.org

Bone Marrow Donors Worldwide

bmdw.org

Bonetumor.org

bonetumor.org

Camp Sunshine

mycampsunshine.com

Cancer.net

cancer.net

Cancer Index

cancerindex.org

Candlelighters

candlelighters.org

Centers for Disease Control and Prevention

cdc.gov

Chai Lifeline

chailifeline.org

Childhood Cancer Center

childhoodcancerguides.org

Children's Brain Tumor Foundation

cbtf.org

Children's Cause Cancer Advocacy

childrenscause.org

Children's Oncology Group

childrensoncologygroup.org

Children's Organ Transplant Association

cota.org

Clinical Trials

clinicaltrials.gov

Consumer Credit Counseling Service of Atlanta

cccsatl.org

CURE Childhood Cancer

curechildhoodcancer.org

CURE Search

curesearch.org

Deliver the Dream

deliverthedream.org

Leukemia and Lymphoma Society

leukemia.org

Locks of Love

locksoflove.org

Lotsa Helping Hands

lotsahelpinghands.com

Make-a-Wish Foundation

wish.org

National Bone Marrow Transplant Link

nbmtlink.org

National Cancer Institute

cancer.gov

National Center for Complementary and Alternative Medicine

nccam.nih.gov

National Children's Cancer Society

thenccs.org

National Coalition for Cancer Survivorship

canceradvocacy.org

National Comprehensive Cancer Network

nccn.org

National Health Information Center

health.gov/nhic

National Institutes of Health

nih.gov

National Marrow Donor Program

marrow.org

National Organization for Rare Disorders

rarediseases.org

Neuroblastoma Children's Cancer Society

neuroblastomacancer.org

Parent-to-Parent of Georgia

www.p2pga.org

Partnership for Prescription Assistance

pparx.org

Pediatric Brain Tumor Foundation of the United States

pbtfus.org

Sickle Cell Information Center

scinfo.org

Social Security Administration

ssa.gov

Songs of Love

songsoflove.org

Starlight Children's Foundation

starlight.org

Survivorship Guidelines

survivorshipguidelines.org

Notes

Glossary

Abdomen: The area of the body that lies between the chest and the pelvis.

Absolute neutrophil count (ANC): Total count of neutrophils in the blood. It shows a person's ability to fight infection. To calculate the ANC, add the percent of segmented neutrophils (segs) and banded neutrophils (bands), divide by 100 and multiply by the total white blood count.

Acute: Happens over a short period of time.

Alkylating agents: A family of anticancer drugs that work by interfering with the DNA of a cell to prevent normal division.

Allogeneic transplant: A type of blood and marrow transplant in which the blood stem cells are donated by another person.

Alopecia: Hair loss; a common side effect of chemotherapy.

Ambulatory: The ability to walk.

Analgesic: A drug that relieves pain.

Anaphylaxis: An acute allergic reaction that can be life-threatening.

Anemia: A condition that reduces the number of circulating red blood cells.

Anesthesia: Partial or total loss of sensation, with or without loss of consciousness, induced by giving a medicine.

Anesthesiologist: A doctor who specializes in the study and giving of anesthesia.

Anorexia: Loss of appetite.

Antibiotic: A medicine that treats bacterial infections.

Antibody: A protein that defends the body against bacterial and viral infections.

Antiemetic: A medicine that prevents or reduces nausea and vomiting (throwing up).

Antigen: A foreign substance that stimulates the lymphocytes to produce antibodies.

Antihistamine: A medicine that treats allergic reactions.

Apheresis: The collection of blood components from a patient or donor in which desired elements are removed and the rest is returned to the body.

Artery: A blood vessel that carries oxygen-rich blood from the heart to other tissues.

Ascites: An abnormal collection of fluid in the abdomen (belly).

Asepsis (aseptic): No infection.

Asymptomatic: No symptoms.

Ataxia: Loss of balance.

Attending physician: A hospital doctor who finished medical school, specialty residency and subspecialty fellowship.

Atypical: Not usual or ordinary.

Autologous: From the same person. An autologous blood and marrow transplant is a procedure in which blood stem cells that are removed from a patient are given back to the same patient.

Axilla: The armpit.

Bacteria: A group of 1-celled organisms that you can only see with a microscope. Most bacteria do not cause harm. Some can cause disease in a weak immune system.

Basic research: Research done to increase knowledge of basic principles.

Benign: Not cancerous.

Bias: An unfair or unproven belief in something. Research should be done based on facts, not bias.

Bilateral: Happens on both sides of the body.

Bilirubin: A pigment made by the liver as it processes waste products. When elevated, bilirubin causes yellowing of the skin.

Biopsy: Removal of a small tissue sample to be looked at under a microscope.

Blood type: Identification of the proteins in a person’s blood cells so that transfusions can be given with compatible blood products. Possible blood types are A+, A-, B+, B-, AB+, AB-, O+ and O-.

Bone marrow: Soft, inner part of large bones that makes stem cells.

Bone marrow aspiration: Process in which a sample of fluid and cells is withdrawn from the bone marrow using a hollow needle.

Bone marrow biopsy: The removal of a sample of solid tissue from the bone marrow.

Blood and marrow transplant: A procedure in which doctors replace bone marrow that has been destroyed by high doses of chemotherapy and/or radiation.

Cachexia: The wasting away of the body; extreme weight loss, most often from disease or malnutrition.

Cancer: A term for diseases in which abnormal cells divide without control.

Carcinogen: A substance or agent that produces cancer.

Cardiac: Has to do with the heart.

Catheter: A tube that can be placed into the body to give fluids or medicines, or to drain fluid.

Cell: The basic building block that makes up all the tissues and organs in the body.

Centigray: A measurement of radiation-absorbed dose; same as a rad.

Central nervous system (CNS): Brain, spinal cord and nerves.

Cerebrospinal fluid (CSF): Fluid which surrounds the brain and spinal cord and provides a cushion from shocks.

Chemotherapy: A treatment of disease with drugs. The word most often has to do with cytotoxic drugs that treat cancer.

Chromosome: A structure in the nucleus of a cell that has genetic material. Normally, 46 chromosomes are inside each human cell.

Chronic: Lasting over a long period of time.

Clinical research: Research done to find out if medicines, equipment, tests and treatments are safe and effective in people. The results are used to help prevent, find or treat diseases in the best possible way.

Clinical trial: A carefully designed and executed investigation of a drug, drug dosage, combination of drugs or other way of treating disease. Each trial is designed to answer 1 or more scientific questions and to help prevent or treat disease.

Colony-stimulating factors: A substance that is used to stimulate the production of some types of bone marrow cells.

Coma: A deep, prolonged state of unconsciousness.

Combination chemotherapy: Using 2 or more chemotherapy drugs at the same time.

Combined modality therapy: Treatment that includes 2 or more types of therapy, such as chemotherapy with surgery, radiotherapy or immunotherapy.

Complete blood count (CBC): A measurement of the numbers of white cells, red blood cells and platelets in a cubic millimeter of blood.

Conditioning: The treatment given before a bone marrow or stem cell transplant. Conditioning can include high-dose chemotherapy with or without total body irradiation. It is also called a preparative regimen.

Congenital: Any condition present at birth.

Culture: To grow in a test tube; cultures come from blood, urine and throat secretions.

Cytokine: Proteins secreted by immune system cells which enable them to communicate with each other.

Cytomegalovirus (CMV): 1 of a group of herpes viruses that can cause life-threatening infections in immunosuppressed patients.

Cytotoxic: Causing the death of cells.

Differentiation: The process by which cells mature and become specialized.

Distal: Further away from any point (the opposite of proximal).

Diuretics: A medicine that causes the kidneys to make more urine. This helps to get rid of extra water in the body.

Dysphagia: Trouble with swallowing.

Dysplasia: Abnormal changes in a cell which sometimes mean that cancer may happen.

Dyspnea: Shortness of breath.

Dysuria: Pain with or trouble urinating.

Edema: The abnormal collection of fluid within tissues.

Emesis: Vomiting (throwing up).

Engraftment: During bone marrow or stem cell transplant, the point at which the infused marrow is accepted by the patient and begins to produce blood cells.

Enteral feeding: Giving nutrients through a tube that is put into the stomach or intestine.

Epidural: The space right outside the spinal cord.

Erythrocytes: Red blood cells.

Excision: Surgery to remove tissue.

Exposure (to disease): To be exposed to, or open to, the risk of germs, viruses or disease.

External catheter: Indwelling catheter in which 1 end of the tubing is in the heart and the other end of the tubing sticks out through the skin (for example, a Hickman catheter).

Febrile: A fever.

Fellow: A doctor who has finished medical school and several years of residency, and is getting specialty training.

Fine needle aspiration (FNA): Removing small samples of tissue, most often with numbing medicine, through a very small needle.

Finger poke: When a lab technician pricks the fingertip to get a small sample of blood.

Gastritis: An inflammation of the stomach.

Gastrointestinal: Has to do with the stomach and intestines.

Gene: A unit of DNA that transmits a single trait from a parent to a child.

Graft: Tissue or cells taken from a donor and given to another person (recipient or host).

Graft-versus-host disease: A condition that may happen after an allogeneic blood and marrow transplant in which the transplant marrow (graft) attacks the patient's (host's) organs.

Granulocytes: A type of white blood cell which destroys foreign substances in the body, such as viruses, bacteria and fungi.

Hematocrit: The measurement of the proportion of cells to plasma in a sample of blood; sometimes called packed cell volume (PCV).

Hematologist: A doctor who specializes in the diagnosis and treatment of disorders of blood and blood-forming tissues.

Hematoma: A collection of blood in 1 spot.

Hematuria: Blood in the urine.

Hemoglobin: The protein found in red blood cells that carries oxygen.

Hemorrhagic cystitis: Bleeding from the bladder, which can be a side effect of the drug Cytoxan.

Hepatic: Has to do with the liver.

Hepatitis: Inflammation of the liver by virus or toxic substance. A patient most often has a fever and jaundice. Sometimes the liver is bigger than normal.

Hickman catheter: An indwelling catheter that has 1 end of the tubing in the heart and the other end outside the body.

Histology: What the tissue looks like under a microscope.

HIV (human immunodeficiency virus): The virus that causes AIDS.

Host: The person who receives the marrow during a blood and marrow transplant.

Human leukocyte antigen (HLA): Proteins on the surface of cells that are important in a transplant and transfusion. For a bone and marrow transplant, the HLAs on white blood cells of the patient and possible donor are compared.

Hyperalimentation: Artificial feeding which gives nutrients through a special catheter or through an I.V.

Hypercalcemia: Abnormally high levels of calcium in the blood.

Immune system: Complex system by which the body protects itself from foreign substances.

Immunosuppression: Suppression of the immune system, which increases the risk for infection.

Immunotherapy: A type of cancer therapy that uses the body's own immune system to attack cancer cells.

Informed consent: Giving permission to start treatment.

Infusion: Giving fluids or medicines through a vein over a period of time.

Infusion pump: A small, electronic device that allows medicine to be given at home through an I.V. or indwelling catheter.

Institutional review board (IRB): A group of people made up of scientists, people who are not scientists, doctors and community members that approves and reviews all research on humans taking place at an institution.

Intern: A doctor who has recently finished medical school and is getting their first year of supervised training in medical and surgical care of patients in hospitals.

Intramuscular (IM): Injection of medicine into the muscle.

Intraocular: Happens within the eye.

Intrathecal: Injection of medicine into the cerebrospinal fluid (CSF) during a spinal tap.

Intravenous-access line (I.V.): A hollow metal or plastic tube that is inserted into a vein and attached to tubing. This can be used to give solutions or medicines into the blood.

Jaundice: A yellowing of the skin and the whites of the eyes caused by too much bilirubin in the blood. Jaundice can be a sign of liver problems.

Laparotomy: A surgery to open the abdominal cavity.

Lesion: A tissue abnormality.

Leukocytes: White blood cells.

Leukopenia: A below-normal number of white blood cells.

Localized: Cancer that has not spread to other areas in the body.

Lumbar puncture (spinal tap): A procedure in which a needle is inserted between the vertebrae of the back to get a sample of cerebrospinal fluid (CSF) and/or inject medicine.

Lymph: A clear, colorless fluid found in lymph vessels throughout the body that helps filter out bacteria.

Lymph nodes: Rounded bodies of lymphatic tissues found in lymph vessels.

Lymph system: A system of vessels and nodes throughout the body that helps filter out bacteria.

Lymphocytes: A type of white blood cell formed in the lymphoid tissues that prevents infection and helps provide immunity to disease.

Malaise: Tiredness.

Malignant: Cancerous.

Mediastinum: The middle chest area.

Medical student: A student who has completed 4 years of college and is in medical school.

Metastasis: The spread of cancer from 1 area of the body to another through the lymph system of the blood.

Modality: A type of treatment.

Monocytes: A type of white blood cell.

Mucositis: Inflammation of the mucous membranes.

Multifocal: Coming from more than 1 location.

Myeloablative transplant: Patients are given high doses of chemotherapy and/or irradiation that destroys the patient's bone marrow. This process eliminates most or all of the patient's own stem cells, which are to be replaced with the donor's stem cells.

Myelosuppression: Low blood counts caused by chemotherapy or radiation.

Nadir: The lowest point that blood counts will fall after chemotherapy.

Necrosis: The death of tissues caused by chemotherapy, radiation or a lack of blood supply.

Neoplasm: A new abnormal growth that may be benign or malignant.

Neuropathy: A condition sometimes caused by chemotherapy. Neuropathy is the malfunctioning of a nerve, which can cause numbness or weakness.

Neurotoxic: A substance that is poisonous to the brain, spinal cord and/or nerve cells.

Neutropenia: A condition that happens when the body does not have enough neutrophils (a type of infection-fighting white blood cell).

Neutrophils: The most numerous of the granulocytic white blood cells. These cells move through the bloodstream to the site of infection, where they ingest and destroy bacteria.

Nonmyeloablative transplant: This transplant is sometimes called a mini- or reduced-intensity transplant. Lower doses of chemotherapy and/or radiation are used, relying more on drugs that suppress the immune system. The donor's cells coexist in the body for a period of time before the donor's cells take over. This type of transplant is a promising option for patients who may not be able to tolerate full-dose myeloablative treatment.

Nutritionist: A professional who analyzes nutrition requirements and gives advice on how to eat an appropriate diet for any condition; also called a registered dietician.

Oncogenes: Any gene that contributes to the transformation of a normal cell into a cancer cell.

Oncologist: A doctor who specializes in cancer treatment.

Oncology: The study of cancer.

Ototoxicity: Damage to the ears that can cause ringing or permanent hearing loss.

Palliative: Treatment that helps control pain.

Palpation: Examining an area of the body, such as the abdomen, by feeling with the fingers to find abnormalities.

Pancreatitis: Inflammation of the pancreas, which can cause extreme pain, vomiting, hiccoughing, constipation and collapse.

Pathologist: A doctor who specializes in examining tissue and diagnosing disease.

Pediatrician: A doctor who specializes in the care and development of children and the treatment of their diseases.

Petechiae: Small, reddish spots under the skin caused by hemorrhage.

Phlebitis: Inflammation of a vein.

Plasma: The liquid part of the lymph and the blood.

Platelet: A disc-shaped blood cell which helps with blood clotting.

Port-a-cath: Indwelling catheter with a small portal under the skin of the chest that is attached to tubing that goes into the heart.

Preparative regimen: See Conditioning.

Primary tumor: The original site where cancer first begins to grow.

Prognosis: Expected or probable outcome.

Progression: A worsening of disease by the continued growth of cancer.

Prophylaxis: An attempt to prevent disease.

Proptosis: A forward projection of the eyeball.

Protocol: A document that outlines the drugs that will be taken, when they will be taken and in what doses. It also includes the dates for procedures.

Proximal: Closest to any point (the opposite to distal).

Pulmonary: Has to do with the lungs.

Purging: A process to remove certain components found in bone marrow or stem cell harvest. In an autologous harvest, purging may be used to remove any remaining cancer cells. In an allogeneic harvest, purging may be used to remove components of the donor collection that can cause graft-versus-host disease (GVHD).

Rad: A radiation-absorbed dose; a unit of measurement of the absorbed dose of radiation. It is the same as a centigray (cGy).

Radiation: High-energy rays that kill or damage cancer cells.

Radiologist: A doctor who specializes in using radiation and radioactive isotopes to diagnose and treat disease.

Radiosensitive: A type of cancer that most often responds well to radiation.

Randomized: Chosen at random. In a randomized research project, a computer chooses which patients receive the experimental treatment(s) and which patients receive the standard treatment.

Recurrence: See Relapse.

Regression: The shrinking or disappearance of cancer cells, most often as a result of therapy.

Relapse: A return of cancer.

Remission: Disappearance of detectable disease.

Renal: Has to do with the kidney.

Resection: The surgical removal of tissue.

Resident: A doctor who has finished medical school and 1 year as an intern, and is still getting supervised training in medical and surgical care of patients in hospitals.

Residual disease: The cancer cells that are left behind after a tumor has been removed in surgery.

Right atrial catheter: Indwelling catheter with tubing that goes into the heart and provides a way to draw blood and give medicine.

Roadmap: A guideline for a patient’s plan of care.

Second-look surgery: An operation that is done after the first surgery. This gives the surgeon a chance to look at the area of the first surgery

Seizure: Uncontrollable shaking of the body, often with loss of consciousness. It is also called convulsion.

Sepsis: Bacterial growth found within the bloodstream.

Side effect: An unintentional or undesirable effect of treatment.

Translational research: A way of translating and using research findings so they can be used in everyday medical practice.

This handbook should not replace instructions given to you by your child's doctor and healthcare team. It is not meant to be medical advice or a complete source of all information about this subject. Your child's doctor is the best source of information about what is best for your child's treatment and care.

Health-related information changes frequently, and therefore information contained in this handbook may be outdated, incomplete or incorrect. This handbook may contain printed material that has been updated by Children's Healthcare of Atlanta. Please talk with a member of your child's healthcare team if you need an up-to-date copy.

Children's Healthcare of Atlanta has not reviewed all of the sites listed as resources and does not make any representations regarding their content or accuracy. Children's Healthcare of Atlanta does not recommend or endorse any particular products, services or the content or use of any third-party websites, or make any determination that such products, services or websites are necessary or appropriate for you or for the use in rendering care to patients. Children's Healthcare of Atlanta is not responsible for the content of any of the above-referenced sites or any sites linked to these sites. Use of the links provided on this or other sites is at your sole risk.

Call 911 or go to the nearest emergency department right away in case of an urgent concern or emergency.

Children's℠
Healthcare of Atlanta

Children's Healthcare of Atlanta Nondiscrimination Statement

Discrimination is against the law. Children's complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability or sex. Children's does not exclude people or treat them differently because of race, color, national origin, age, disability or sex.

Children's Healthcare of Atlanta:

Provides people with disabilities reasonable modifications and free appropriate auxiliary aids and services to communicate effectively with us, such as:

- Qualified sign language interpreters.
- Written information in other formats (large print, audio, accessible electronic formats).

Provides free language assistance services to people whose primary language is not English, including:

- Qualified interpreters.
- Information written in other languages.

If you need any of these services, contact Children's Civil Rights Coordinator at **404-785-4545**.

If you believe that Children's has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability or sex, you can file a grievance with:

Children's Civil Rights Coordinator
1575 Northeast Expressway NE
Atlanta, GA 30329
404-785-4545
section1557coordinator@choa.org

If you need help filing a grievance, Children's Civil Rights Coordinator is available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services Office for Civil Rights electronically through the Office for Civil Rights complaint portal, available at **ocrportal.hhs.gov/ocr/portal/lobby.jsf**, or by mail or phone at:

U.S. Department of Health and Human Services
200 Independence Ave. SW
Room 509F, HHH Building
Washington, DC 20201
800-368-1019
800-537-7697 (TDD)

Complaint forms are available at:
http://www.hhs.gov/ocr/office/file/index.html

This notice is available at **choa.org**.

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Language Assistance Services and Auxiliary Aid Services

English

ATTENTION: If you speak English, free language assistance services are available to you. Appropriate auxiliary aids and services to provide information in accessible formats are also available free of charge. Call 404-785-4545 or speak to your provider.

Spanish

ATENCIÓN: Si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. También están disponibles de forma gratuita ayuda y servicios auxiliares apropiados para proporcionar información en formatos accesibles. Llame al 404-785-4545 o hable con su proveedor.

Vietnamese

LƯU Ý: Nếu quý vị nói tiếng Việt, chúng tôi cung cấp miễn phí các dịch vụ hỗ trợ ngôn ngữ. Các dịch vụ và phương tiện hỗ trợ phù hợp để cung cấp thông tin theo các định dạng dễ sử dụng cũng được cung cấp miễn phí. Vui lòng gọi theo số 404-785-4545 hoặc trao đổi với người cung cấp dịch vụ của quý vị.

Korean

주의: 한국어를 사용하시는 경우 무료 언어 지원 서비스를 이용하실 수 있습니다. 이용 가능한 방식으로 정보를 제공하는 적절한 보조 기구 및 서비스도 무료로 제공됩니다. 404-785-4545 번으로 전화하거나 서비스 제공업체에 문의하십시오.

Chinese

注意：如果您说 中文， 我们将免费为您提供语言协助服务。我们还免费提供适当的辅助工具和服务，以无障碍格式提供信息。请致电 或咨询您的服务提供商。

Gujarati

ધ્યાન આપો: જો તમે ગુજરાતી બોલતા હો તો મફત ભાષાકીય સહાયતા સેવાઓ તમારા માટે ઉપલબ્ધ છે. સુલભ ફૉર્મેટમાં માહિતી પૂરી પાડવા માટે યોગ્ય સહાયક સાધનો અને સેવાઓ પણ વિના મૂલ્યે ઉપલબ્ધ છે. 404-785-4545 પર કૉલ કરો અથવા તમારા પ્રદાતા સાથે વાત કરો.

Language Assistance Services and Auxiliary Aid Services

French

ATTENTION : Si vous parlez français, des services d'assistance linguistique gratuits sont à votre disposition. Des aides et des services auxiliaires appropriés pour fournir des informations dans des formats accessibles sont également disponibles gratuitement. Appelez le 404-785-4545 ou parlez à votre fournisseur de services.

Amharic

ማሳሰቢያ፡- አማርኛ የሚናገሩ ከሆነ፣ የቋንቋ ድጋፍ አገልግሎት በነፃ ይቀርብልዎታል። መረጃን በተደራሽ ቅርጸት ለማቅረብ ተገቢ የሆኑ ተጨማሪ እገዛዎች እና አገልግሎቶች እንዲሁ በነፃ ይገኛሉ። በስልክ ቁጥር ይደውሉ ወይም አገልግሎት አቅራቢዎን ያናግሩ።

Hindi

ध्यान दें यदि आप हिंदी बोलते हैं तो आपके लिए निःशुल्क भाषा सहायता सेवाएँ उपलब्ध हैं। सुलभ प्रारूपों में जानकारी प्रदान करने के लिए उपयुक्त सहायक साधन और सेवाएँ भी निःशुल्क उपलब्ध हैं। 404-785-4545 पर कॉल करें या अपने प्रदाता से बात करें।

Haitian

ATANSYON: Si'w pale Kreyòl, sèvis assistans lang ou disponib pou ou gratis. Èd ak sèvis oksilyè apwopriye pou bay enfòmasyon nan fòma aksesib yo disponib gratis tou. Rele nan 404-785-4545 oswa pale avèk founisè ou.

Russian

Arabic

تنبيه: إذا كنت تتحدث اللغة العربية، فستتوفر لك خدمات المساعدة اللغوية المجانية. كما تتوفر وسائل مساعدة وخدمات مناسبة لتوفير المعلومات بتنسيقات يمكن الوصول إليها مجانًا. اتصل على الرقم 404-785-4545 أو تحدث إلى مقدم الخدمة.

Language Assistance Services and Auxiliary Aid Services

Brazilian Portuguese

ATENÇÃO: Se você fala português do Brasil, serviços gratuitos de assistência linguística estão disponíveis para você. Auxílios e serviços auxiliares, apropriados para fornecer informações em formatos acessíveis, também estão disponíveis gratuitamente. Ligue para 404-785-4545 ou fale com o seu provedor.

Telugu

గమనించండి: మీరు తెలుగు మాట్లాడితే, మీకు ఉచిత భాషా సహాయ సేవలు అందుబాటులో ఉంటాయి. యాక్సెస్ చేయగల ఫార్మాట్‌లలో సమాచారాన్ని అందించడానికి తగిన సహాయక చర్యలు మరియు సేవలు కూడా ఉచితంగా అందుబాటులో ఉంటాయి. 404-785-4545 కి కాల్ చేయండి లేదా మీ ప్రొవైడర్‌తో మాట్లాడండి.

German

ACHTUNG: Sie haben Anspruch auf kostenlose Sprachdienste, wenn Sie Englisch sprechen können. Kostenlose Dienstleistungen und Hilfsmittel, die geeignet sind, Informationen in zugänglicher Form zu vermitteln, werden ebenfalls angeboten. Sprechen Sie mit Ihrem Anbieter oder rufen Sie die Nummer 404-785-4545 an.

Tamil

கவனிக்க: நீங்கள் ஆங்கிலம் பேசுபவராக இருப்பின், இலவச மொழி உதவி சேவைகள் உங்களுக்கு வழங்கப்படும். எளிதில் அணுகக்கூடிய வகையில் தகவல்களை வழங்குவதற்கான பொருத்தமான துணை உதவிகளும் சேவைகளும் இலவசமாகக் கிடைக்கின்றன. இந்த சேவையை பெற 404-785-4545 என்ற எண்ணிற்கு அழைக்கவும் அல்லது உங்கள் வழங்குநரிடம் கலந்துரையாடவும்.