Allogeneic Transplant Handbook

DukeHealth

Welcome to the Duke Adult Blood and Marrow Transplant (ABMT) Program

The Duke ABMT Program began in 1983. We have performed over 5000 transplants. We do about 250 adult transplants every year. Right now, the most important transplant is **your** transplant. Preparing to get a transplant can be very scary for patients and families. Your safety is a priority for our team. We are ready to help you with each step of your transplant journey.

This patient handbook will give you information about what to expect before, during, and after your allogeneic transplant. It will add to the information you receive from the doctors, advanced practice providers, nurses, social workers, pharmacists, and other staff in the program. Bring this handbook to all of your appointments, to the hospital, and to the ABMT clinic. Your healthcare team will refer to the handbook to explain your care. You will get more information about your disease and treatment plan to add to the handbook. You may still have questions for your team, so please write them down. We will be happy to answer them for you.

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☑ “To Do List” before transplant:

- ☐ Read the ABMT handbook.
- ☐ Identify a caregiver and a backup caregiver.
- ☐ Arrange transportation. You may not drive during your treatment.
- ☐ Arrange housing in Durham.
- ☐ Review consent forms.
- ☐ Have a dental exam if you have not had one in the past six months.
- ☐ Change the air filters in your home.
- ☐ Check your prescription coverage and locate a Durham pharmacy you can use.
- ☐ Speak with your doctor about your ability to have a family.
- ☐ Make arrangements for child care and household maintenance.
- ☐ Arrange for pet care. You may not keep pets with you during your transplant care.
- ☐ Get prescription eyeglasses. You will not be able to wear contact lenses.
- ☐ Bring a signed, notarized copy of your medical power of attorney or advanced directive. For more information, ask your nurse.
- ☐ Purchase a large 4-slotted pillbox and a tote bag or rolling bag for the clinic.
- ☐ Attend the New Patient Class.
- ☐ Purchase a digital oral thermometer and a food thermometer.

Who will care for me during my transplant?

The Adult Blood and Marrow Transplant (ABMT) team of health care providers is dedicated to helping you through your treatment. They will decide if you are a candidate for a transplant. They will give you information to help you decide if it is the right treatment for you.

- **Attending Physician or Doctor (MD)**
  The attending physician is an MD who specializes in caring for blood and marrow transplant patients. They will oversee your care. Even though you have one primary ABMT doctor, different ABMT doctors will care for you during your transplant. We will keep the doctor who referred you to Duke informed of your treatment.
- **Transplant Coordinator**
  The coordinator will be your primary contact while preparing for transplant. They will arrange testing before your transplant and will give you a calendar to outline your treatment. Your coordinator may be a registered nurse (RN), nurse practitioner (NP), or physician assistant (PA).
- **Acute Care Nurse Practitioners (NPs) and Physician Assistants (PAs)**
  This team of NPs and PAs will care for you every day in the ABMT clinic or on the hospital unit. They will check on you daily for side effects and help manage your symptoms.
- **ABMT Hospital and Clinic Nurses**
  The nurses in the ABMT program are RNs with special education to care for transplant patients. There are also nursing care assistants (NCAs) and registered medical assistants (RMAs) who will help care for you.
- **Pharmacists**
  The pharmacists in the ABMT program have special training to care for transplant patients. They will make daily rounds with the team to teach you about your medicines and help watch for side effects. The pharmacist will teach you how to take your medicines safely.
- **Clinical Nurse Specialist (CNS)**
  The CNS is an RN who is an expert in transplant nursing. She will round with the team and be a resource to you and your family.
- **Clinical Social Worker (CSW)**
  The CSW helps you and your loved ones manage the stress that comes with the transplant process and cancer treatment. They provide counseling and education to help you and your caregivers cope during the transplant. Your social worker can help find resources you need during treatment. There is a weekly caregiver support group in the clinic and on the hospital unit.

- **Registered Dietitian (RD)**
  The RD will teach you about nutrition and your diet plan during transplant. They will help you and the team manage your nutrition during your treatment.

- **Financial Care Counselor (FCC)**
  The FCC works with you and your insurance company. They help with authorization and tell you about your transplant insurance benefits.

- **Physical Therapist (PT) and Occupational Therapist (OT)**
  The PT and OT work with your team to keep you as active and independent as possible during your transplant care.

- **Oncology Recreation Therapist**
  The oncology recreation therapist is here to help you and your caregiver cope with your illness and treatment. This may be through crafts, low intensity exercise, and counseling.

How do the staff make sure that I am cared for safely?

Your safety is a priority for our team. Providing safe care involves you and your caregiver, too. Some of the treatment you will get is very complex. To provide safe care, sometimes your team may need to take many steps behind the scenes before your direct care can begin. For example, waiting for your medicine or blood products to be prepared may take several hours as doctors, pharmacists, and nurses all check to make sure your lab values are safe.

In the ABMT clinic, safety checks begin with the check-in process and continue through to the treatment room. Wherever you are cared for, your identity will be checked using two identifiers. Your name, date of birth, or Duke medical record number (MRN) may be used. Before you get your chemotherapy, two RNs will double check your height and weight. On the hospital ABMT unit, an RN or NCA will complete a safety check every hour during the day and every two hours at night. The safety check assures that you can walk safely to the bathroom, your call bell is in reach, and you are as comfortable as possible.

There may be times when it seems like nothing is happening fast enough. Often, we are working behind the scenes to make sure you are cared for safely. Please let us know if you have any concerns during your treatment.

What is an allogeneic transplant?

Allogeneic means you will receive stem cells from a healthy donor. Stem cells become white blood cells (that protect you from infection), red blood cells (that carry oxygen), and platelets (that keep you from bleeding). Your disease keeps your body from making these healthy cells. Before your transplant, you get chemotherapy (and possibly radiation) to kill unhealthy cells. Healthy cells are also destroyed during this treatment. This part of the treatment is called the conditioning or preparative regimen.

After your conditioning or preparative regimen, stem cells from a donor are given to replace the healthy cells killed. The stem cells can come from the donor's bone marrow or blood. The stem cells can also come from umbilical cord blood donated by a mother after a healthy birth.

The conditioning or preparative regimen can be given in different doses:

- Myeloablative: high doses of chemotherapy with or without radiation
- Reduced intensity: medium doses of chemotherapy with or without radiation
- Non-myeloablative: low doses of chemotherapy with or without radiation

Your ABMT doctor will decide what doses you will receive based on your health, your age, and your disease.

What is a preparative or conditioning regimen?

The combination of chemotherapy or radiation you get before your transplant is the preparative or conditioning regimen. Your ABMT doctor will choose your regimen, based on your diagnosis, previous treatments, and health. Your ABMT provider and coordinator teach you about the medicines in your preparative regimen. You may get this in the hospital or the ABMT clinic. Your ABMT doctor decides where you get your treatment. Your ABMT coordinator tells you the time of your treatment.

We use special wording to describe the timeline of your treatment course. The preparative regimen starts on a "negative-numbered" day. You will hear your regimen days referred to as "DOT" (day of transplant). Your transplant always takes place on "DOT 0." Every day after that is a "positive-numbered" day.

Look at the example of a transplant calendar below:

THURS	FRI	SAT	SUN	MON	TUES	WED
DOT-5	**DOT-4**	**DOT-3**	**DOT-2**	**DOT-1**	**DOT 0**	**DOT+1**
Preparative regimen	Preparative regimen	Preparative regimen	Preparative regimen	Rest	Stem cell infusion	Supportive Care

How does my team evaluate me for transplant?

To prepare for transplant, you will make several trips to Duke. At your first visit (New Patient Evaluation), you will meet members of your ABMT team. Your team will check your overall health and physical condition. Your ABMT doctor will talk to you about your treatment plan.

After your first visit, you may need to have more tests at Duke or with your local doctor. This is your "work up" or "restaging" time. Work up may take several weeks or months. You may need additional therapy to keep your disease in check during this time.

The following tests may be part of your work up:

- **HLA typing:** We search for donors based on your HLA typing. This blood test is repeated at the Duke HLA lab even if you have had it checked before. It is our responsibility to verify your typing. Any possible donors will also have HLA typing done and compared to your typing.
- **Lab Studies:** We draw blood from a vein or from your central venous catheter. The results tell us about your history of infections and help us treat you before, during, and after your transplant.
- **Chest x-ray and EKG:** These tests look at your heart and lung health. You will likely have these tests more than one time before your transplant to track any changes and keep you safe.
- **Echocardiogram:** This test tells us the pumping ability of your heart. We place a wand on your ribs near your breastbone that transmits sound waves. The machine picks up echoes of sound waves from your heart and converts them to moving pictures of the heart.
- **Pulmonary Function Test:** This checks your lung function. You breathe into a machine that measures the amount of air your lungs hold and how fast the air enters and leaves your lungs.
- **CT scans, PET scans and MRI scans:** These tests are similar to x-rays but use computers to make pictures of the body part we are checking. Some scans use contrast dye that you drink or have given into a small IV. **Please alert your nurse or doctor if you have a known allergy to contrast dye, iodine, or seafood.** If you have an allergy, you need a medicine before your scan to prevent a reaction.
- **Bone marrow biopsy and aspirate:** A bone marrow aspiration removes a small sample of marrow from the back of your hip. You lie down on your stomach, and we numb the back of your hip with lidocaine. The provider inserts a needle into the bone marrow and removes a small amount of liquid marrow. A bone marrow biopsy uses the same process to remove a small amount of bone tissue. This test shows how well you are making cells and looks for signs of your disease in the bone marrow. After your transplant, bone marrow tests check your response to the treatment.

The work up and review can take several weeks or longer. We understand that it is stressful to wait for test results. The test results help us decide if transplant is the best option for you.

How do I find a donor?

We find a donor by comparing your human leukocyte antigen (HLA) typing to your family members and anonymous donors in the National Marrow Donor Program (NMDP) registry or cord blood registry. Your HLA typing is done by a blood test.

There are 4 sources for healthy donor stem cells:

- **Matched related donor:** You and your brothers and sisters receive half of your HLA cells from your mother and half from your father. There is a 1 in 4 chance (25%) that your brother or sister will be a full or "perfect" match to you. If your brothers or sisters are not able to come to Duke to have their HLA blood test drawn, we will send them a kit to have blood drawn and sent to us for testing.
- **Mismatched related donor:** If you do not have a fully matched brother or sister, your ABMT doctor may consider using a family member who is not a full match. This may be one of your other brothers or sisters, your child, or your parent.
- **Unrelated donor:** If none of your family members is a suitable match for you, we will search for an unrelated donor in the NMDP registry. We will compare your HLA typing to those in the registry. Donors in the NMDP registry are volunteers who are willing to donate stem cells to a person in need. There are millions of volunteers in the registry. We will start the search process very quickly and keep you informed of the progress. It can take several weeks to several months to find a donor in the registry. Some patients cannot find a donor in the registry. Donors in the registry remain anonymous throughout the process.
- **Umbilical cord blood:** Umbilical cord blood stem cells are blood cells donated after a mother has a healthy birth. The umbilical cord blood is very rich in stem cells. The stem cells are removed from the umbilical cord after the birth, HLA typed, and safely frozen and stored in a bank. When we start your unrelated donor search, we also do an umbilical cord blood search through the NMDP. These cells are available more quickly than a donor through the NMDP registry. These donors are anonymous.

What does my donor need to do?

Our Duke ABMT team will see your family member donor. They will have a chest x-ray, EKG (electrocardiogram), physical exam, and a health history. This is to make sure it is safe for your family member to be a donor. Your family member donor will receive written information about the donor process. Your donor will make several trips to Duke during the evaluation and stem cell donation.

If we find your donor through the National Marrow Donor Program (NMDP), a BMT center closer to their home will evaluate them and collect their stem cells. If umbilical cord blood is your donor, it is tested, HLA typed, and frozen in storage at the time it is donated.

What is informed consent?

Informed consent is the process where you learn about the risks and benefits of a therapy or procedure, ask questions about it, and decide if it is right for you. Before starting your transplant journey, you get important information, including risks and benefits of the transplant treatment. Your transplant treatment may be routine care or part of a clinical trial. A clinical trial studies new ways of treating patients. Clinical trials follow a plan called a protocol. Whether your transplant treatment is part of a clinical trial or considered routine, you get a consent form to sign.

Read the informed consent form, and write down any questions you have. By signing the consent form, you are saying that the ABMT team told you about all the risks and benefits of the treatment, you have asked all your questions, and we have answered them.

How do I pay for my transplant?

Transplant is a very expensive treatment. The medicines and treatments you get are costly. You have many days of care in the hospital, ABMT clinic, or local housing. We communicate with your insurance company to let them know of your planned treatment. Your insurance may cover some or all of your treatment. You may have co-pays for days that you get care in the clinic. You meet your FCC on your first visit to the Duke ABMT program. They give your insurance company medical information to evaluate your transplant approval request.

If you have private insurance or a managed care plan, get a copy of your insurance policy. Every policy is different. Review your policy so you understand which services your insurance policy covers. Your policy also tells you what your financial responsibilities are including co-pays, services not covered, deductibles, and medicine coverage. Your policy may require a co-pay with each daily visit to the ABMT clinic during your treatment. You can get a copy of your insurance policy by calling the Member Services Department of your insurance company. You can also call the Human Resources Department of your employer or your spouse’s employer if they insure you.

Many insurance companies have special case managers that work with transplant patients. They can answer your questions about your insurance and your transplant benefits.

Before starting your transplant care, your insurance company must authorize payment for all your treatments. Unfortunately, there are times when they may deny or limit your coverage or benefit. If your insurance company does not pay for your transplant care, or only part of your treatment, you are responsible for payment to Duke. If this happens, your FCC or CSW will talk to you about fundraising and refer you to other resources.

It is important to let your FCC know immediately if there are any changes to your insurance. We strongly encourage you not to change insurance coverage during your transplant care or while seeking approval, unless your employer or your spouse's employer gives you no other option.

What can I do to get ready for my transplant?

A transplant means new responsibilities. Leading a healthy lifestyle is one of the most important responsibilities. Some harmful habits damage your immune system. We will not offer transplant to people who are using tobacco products, vaping, or who are dependent on drugs or alcohol. We require you to be substance-free before treatment. We want to help you and your loved ones prepare for transplant. Making plans to deal with your needs before your transplant reduces your stress. If changes occur in your home or health situation, please let us know.

Other things to consider:

- **Daily Clinic visits:** You may get your treatment in the ABMT Clinic, in the hospital, or in local housing. **You should expect to stay locally for about 100 days. Talk about housing arrangements with your team.**

- **Medicines:** After your transplant, you take medicines for many months. These medicines may be expensive and may have side effects. The ABMT team helps you find financial resources.

- **Follow up testing:** After your transplant care at Duke, you will go back home to the care of your referring doctor. From time to time, you need to have tests to check your response to the transplant. We also watch for late side effects. You will return to see your ABMT provider at certain times too.

- **Healthy habits:** After transplant, you need to maintain a balanced diet and exercise regularly to help you recover.

What is the role of my caregiver?

During your treatment, you must have a caregiver with you at all times. If one person cannot be with you during your entire treatment, different caregivers may share the job. Your caregiver should be dependable and reliable. **Caregivers should get a flu shot.**

Some caregiver roles include:

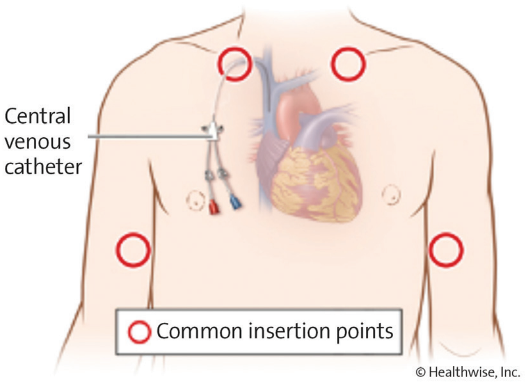
- Bringing you to and from appointments on time. They should have a valid driver's license and a reliable vehicle
- Providing emotional support
- Providing physical care
- Helping with your medicines
- Keeping track of when you take medicines
- Keeping the team informed of any changes in your health
- Preparing your meals and keeping your environment clean
- Keeping family and friends informed
- Getting you emergency care if needed
- Running errands like grocery shopping or picking up medicines
- Encouraging you to eat and drink
- Encouraging you to exercise

Some helpful tips for your caregiver are:

- Accept help from others
- Be specific about what you need
- Write down your questions to ask the ABMT team
- Take rest breaks.
- Educate yourself about your role and your loved one's illness
- Stay hydrated
- Get some exercise every day

Scan the QR code for more information on taking care of yourself:

What is a central venous catheter (CVC)?



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A tunneled central venous catheter (CVC) is a tube that is placed under the skin in the upper chest and exits from a tunnel under the skin. The catheter is sometimes called a Hickman®. The doctor uses an x-ray machine to guide the placement of the CVC. You get medicine to make you sleepy but no general anesthesia. The procedure takes about one hour, and you rest in a recovery room for several hours after the procedure. You must have a driver with you. You may have pain and bruising over the area for several days. You receive pain medicine afterwards.

You will have one small suture after insertion. A part of the CVC is outside of your body with one or more lumens (tubes) to get more than one medicine at a time. You can hide the catheter underneath your clothes when you are away from the hospital. Once you have a tunneled catheter, it is important to know how to care for it. Your ABMT nurse reviews how to care for your CVC when you are in the clinic. **When showering or bathing, cover your dressing with plastic wrap and tape to keep the dressing dry. Set aside a clean area in your bathroom with supplies.**

During your transplant treatment, the staff cares for your catheter. You must care for your CVC when you are away from the clinic for an extended time.

When you have a CVC, infection is the most serious complication. Look at your catheter site every day.

Call your healthcare provider if you notice:
- Redness, swelling, or drainage at the catheter site
- Pain or tenderness at or around the catheter site
- **Fever greater than or equal to 100.5°F or 38°C**
- Flu-like symptoms or chills

Other CVC-related problems to call your healthcare provider about right away:
- You are unable to flush the catheter
- You see a hole or break in the catheter or leaking fluid
- Swelling or pain in your face, neck, shoulder, or arm on the same side of your body as the catheter

Scan the QR codes below for more information on caring for and treatment through a CVC:

What happens on the day of my transplant?

You may get your transplant in the hospital or in the ABMT clinic. Your transplant occurs on “DOT 0.” A lab technician and two RNs check your stem cells. You get medicine before the infusion to prevent any reaction. If your cells are frozen, you may have a reaction to the preservative in the cells that protects them from damage in the freezing process. Reactions may happen while the RN is giving you your cells.

Please let your RN know right away if you have any of these reactions:

- Slow heartbeat
- Chest pain
- Rash or hives
- Feeling chilled
- Nausea

Other reactions are:

- Fatigue
- An unusual taste in your mouth (hard candy reduces the unusual taste)
- Blood-tinged urine for 48 hours
- A strange body odor (not harmful to anyone around you)

How do I know the cells are working?

When the stem cells start to make healthy cells, this is engraftment. Engraftment means your stem cells are re-growing. White blood cells (WBCs) are usually the first to grow. Your white blood cell count will start to grow in 2 to 4 weeks. Platelet cells and red blood cells (RBCs) take a little longer to grow. During the time you wait for engraftment, you need support with RBC and platelet transfusions. While your WBCs are low, you have a higher risk for infection. Good handwashing is your best defense against infection.

Common symptoms as your cells start to engraft are:

- Bone pain
- Rash
- Fever or chills

If I need to stay in the hospital, what should I bring?

☐ Bring all your medicines to the hospital. After we have reviewed them, we will send them back home. You will not need to take any of your own medicine in the hospital.

☐ New toiletries

☐ New or washable slippers and socks

☐ Prescription eyeglasses **(you may not wear contact lenses)**

☐ Pictures of family and friends

☐ Clean or new bathrobe and lightweight blanket

☐ Front button pajamas, which provide easier access to your CVC

☐ Comfortable lounging clothes

☐ Sturdy walking shoes

☐ New, soft toothbrush and new toothpaste

☐ Tablet, computer, cell phone, chargers

☐ **Your ABMT handbook**

☐ Books, magazines, cards, journal, writing utensil

The storage space in your room is limited. Any large suitcases need to be sent home. We ask that you keep surfaces clear as much as possible. The room is best cleaned when there is little clutter. Each room has a HEPA (High Efficiency Particulate Air) filter system that removes germs and dust from the air. Each room and the hospital unit itself are under positive pressure so that air exits when the door opens. This stops outside air from entering your room.

- Fresh flowers and live plants are not allowed in the rooms or on the hospital unit. These can hold germs that are unsafe for transplant patients.
- Please do not bring any knives, firearms, or other weapons to the hospital.
- Please do not bring any valuables to the hospital.

What is the visitor policy on the hospital unit?

Although the Duke Health System visitor policy allows support persons to visit anytime, the ABMT unit has some special restrictions to protect our patients.

- Visiting hours are from 8 a.m. to 11 p.m.
- **Quiet hours on the unit are from 2 p.m. to 4 p.m. This is a time for patients to have uninterrupted rest. There is a quiet period during the night as well.**
- You may have two visitors in the room at one time.
- Handwashing is required when entering the unit. **Handwashing or using foam sanitizer is also required before entering the room and when leaving the room.** Frequently washing with soap and water for 20 seconds or using approved hand sanitizer protects you and your loved ones. Please note there may be other precautions. Look for signs on the door and ask your nurse if you have questions.
- Your visitors may not to use your shower or toilet.
- Your visitors may not eat in your room.
- Your visitors may not spend the night in your room.
- Ask your visitors not to visit if they have any signs of a cold, the flu, or have been around anyone who is sick. **All visitors of ABMT patients must have the seasonal flu shot.**
- Children under six years old may not visit the unit. This restriction may change during high-risk seasons.

How do I get ready for discharge from the hospital?

After discharge from the hospital unit, your care continues at the ABMT clinic or in your local housing. Before discharge, you and your caregiver learn how to continue your care safely. The pharmacist and RN will give you instructions.

You can help by:

- Having your caregiver available between 11 a.m. and 3 p.m. to join you for teaching.
- Having all of your outpatient medicines with you. The team will call these in several days before your discharge. **You cannot be discharged from the unit unless you have your medicines with you.**
- Having your ABMT handbook with you.

How do I get ready for treatment in the ABMT clinic or in my local housing?

You may have long days in the clinic. Think of it as a day hospital where we provide the same care you get in the hospital, but you do not spend the night. The clinic has a resource room and meditation room across from the security desk. You and your caregiver are welcome to use either during the day.

Some tips to help in the clinic and in your local housing are:

- **Bring food and snacks to clinic. We have very few food options at North Pavilion.**
- **Bring all your medicines to the clinic each day.**
- Drink healthy drinks like nutrition supplements, fruit juices, and water.
- Eat small, frequent, healthy meals. These are usually more appealing than a big meal while you recover.
- Walk at least one mile every day. You can take several shorter walks if it is easier. You can walk outside wearing a surgical mask. Avoid areas of construction or yard work. Wear sunscreen of SPF 30 and a hat.
- Wear socks and closed-toed shoes to protect your feet.
- Do not use tobacco or vaping products, and avoid being around anyone using them.
- Always wear your seat belt when riding in a vehicle.
- Do not wear make-up, perfumes, nail polish, or harsh deodorants. Use unscented moisturizers for your skin. You may wear newly purchased lip balm or lipstick if you do not have sores on your lips or mouth.
- Do not drink alcohol. Some of your medicines may interact with alcohol.

What medicines will I take?

You will take many medicines while getting transplant care. Some of the medicines are pills; you get others through your CVC. The medicines you get may have side effects different from transplant side effects. You may get other medicines in addition to those listed below.

- **Immunosuppressants:** Immunosuppressants are medicines to suppress your immune system and help your donor cells "find a home" in your body. These medicines help prevent graft versus host disease (GvHD). You take these medicines for many months after transplant.
- **Antibiotics:** During transplant, you are at risk for many different bacterial infections. Antibiotics help protect you from infection while your immune system is not strong. You will take antibiotics as long as you are on immunosuppressants.
- **Antivirals:** During transplant, you are at risk for different viral infections. Antivirals help protect you from viral infections while your immune system is not strong.
- **Antiemetics:** Antiemetics are medicines to prevent or treat nausea and vomiting.
- **Antidiarrheals:** Antidiarrheals are medicines to prevent or treat diarrhea or loose stools.
- **Electrolytes:** Electrolytes are minerals that help keep your body in balance and working well. During transplant, your electrolytes may be low due to medicines or not eating and drinking enough. You may get electrolytes for many months after your transplant.

How will I manage my medicines?

You get prescriptions to fill during your outpatient treatment in the ABMT clinic or your local housing. These medicines are in addition to your routine medicines. You may need to stop some of your routine medicines. Your ABMT team will instruct you.

To help keep track of your medicines, you get sheets to add to your handbook behind the "Medicine" tab. The sheets list your medicines and the time of day they are due. Mark the time you take the medicine on the sheet with a check mark or an "X." Every day, one of the team checks your medicine sheets to make sure you are taking your medicines as directed.

Do not take any over-the-counter (OTC) medicines that we do not prescribe for you. This includes:

- Aspirin, ibuprofen, naproxen, acetaminophen
- Herbal products
- Vitamins
- Antioxidants

What are possible side effects from transplant?

There are many possible side effects during your treatment. Some side effects may happen early on in your treatment, and some may occur weeks to months after your treatment.

Common side effects include:

- Neutropenia (low white blood cell count)
- Infection
- Anemia (low red blood cell count)
- Thrombocytopenia (low platelet count)
- Lung problems
- Liver and kidney problems
- Fatigue (feeling tired)
- Nausea and vomiting
- Anorexia (loss of appetite)
- Diarrhea
- Constipation
- Mucositis (mouth sores or sore throat)
- Pain
- Acute Graft versus Host Disease (acute GvHD)

Neutropenia and Infection

Neutropenia: Neutropenia is a low number of the white blood cells (neutrophils) that fight infection. Your neutrophil count may be low for several weeks. **During this time, you are at the greatest risk for infection.**

Infection: One of the first signs of infection may be a fever or chills. **Your caregiver should check your temperature every four hours while you are awake.**

If you have a temperature of 100.5°F or 38.0°C or greater, call the ABMT Clinic or hospital unit immediately.

Viral, bacterial, and fungal infections can happen after a transplant.

- Viral infections occur in transplant patients because of a weakened immune system. Viral infections can happen during the first year after transplant or later. Viruses that you have come into contact with during your life "lay asleep" in your body and can "wake up" during your transplant.

  These viruses include:

  - Herpes virus (HSV), which causes cold sores or genital lesions.
  - Zoster virus, which causes chickenpox in children. This virus can cause shingles if it becomes "awakened" in adults. Shingles is a painful rash on one portion of your body. The rash may stay for several weeks, and the pain may last much longer than the rash.
  - Cytomegalovirus (CMV) can cause infections. We will test your blood every week to make sure your CMV is still "asleep.

You will get medicine to keep the viruses "asleep" during and after your transplant treatment.

- Normally, you have bacteria on your skin, in your mouth, and in your stomach and bowels. When your white blood cell count is low, these normal bacteria may grow too much and cause infection.
- Fungus is also in our bodies and in the environment. The bacteria in your body keep the fungus from causing infection. When your immune system is not strong, you are at risk for a fungal infection.

How can I reduce my risk for infection?

- **Wash your hands with soap and water or use hand sanitizer frequently.**
- Avoid touching your face.
- Avoid artificial nails and nail polish.
- Avoid crowds.
- Follow safe food and water rules.
- Avoid people with cough, fever, or runny nose.

Where can infections occur?

Infections can happen even if you are doing everything possible to prevent them.
Pay special attention to your:

- **Mouth:** You may develop mouth sores. Watch for white patches in your mouth or in the back of your throat. You may experience "cold sores" in or around your mouth and lips.
- **Sinuses:** You may develop infection in your nasal passages. You may have nose drainage, headache, or a sore throat.
- **Skin:** Skin infections may occur. Shower daily with a mild soap and water. Keep your skin healthy by using a gentle lotion to moisturize. Avoid perfumed soaps and lotions. If your skin is cracked or you have a wound, let your team know. Keep your nails filed to avoid scratching your skin.
- **Central Venous Catheter (CVC):** Keep your dressing dry and secure. Notify your team if you see redness or drainage at the site or if the site is painful.
- **Lungs:** Report any new cough or increase in cough, shortness of breath, chills, or fever. Walking at least one mile during the day, helps prevent lung problems. Sitting upright during the day and taking slow deep breaths help keep the lungs clear.
- **Bladder:** Report any problems passing urine such as pain, burning, urgency, or frequency of urination. A fever may also be a sign of a urinary tract infection.
- **Rectal pain or pressure:** Report any burning, pain, or itching around your rectum.
- **You and your caregiver should wash your hands often to prevent infection.**

Anemia

Anemia is another name for low red blood cells (RBCs). RBCs carry oxygen through your body. When you are anemic, there are fewer RBCs to bring oxygen to your body's cells. Anemia can make you feel tired, weak, or dizzy. You may be anemic before, during, or after your transplant for a number of reasons. Your ABMT team will monitor for anemia by checking your blood counts. You may need RBC transfusions or medicine to increase your RBC count.

Thrombocytopenia

Thrombocytopenia is another name for low platelets. Platelets help your blood to clot. When your platelet count is low, there is a risk of bleeding, so you may need a transfusion.

Steps to help prevent bleeding include:

- Avoid dental floss unless you floss regularly. If your gums bleed, stop flossing.
- Use a soft toothbrush, and avoid water pick machines and electric toothbrushes.
- Do not strain when moving your bowels.
- Avoid suppositories and laxatives unless prescribed by your ABMT team.
- Avoid sexual intercourse if your platelet count is less than 50,000.
- Avoid tight-fitting clothing.
- Use an electric razor for shaving.
- Use a nail file to file nails, and avoid cutting your nails.
- Avoid nose blowing.
- Avoid medicines that can make it more difficult for your blood to clot, such as aspirin, ibuprofen, or naproxen.
- Avoid blood thinners unless told otherwise by your ABMT team.
- Avoid strenuous activity.
- Do not lift objects heavier than a gallon of milk (10 pounds).
- Keep your lips moisturized.

Lung problems

After transplant, you are at risk for lung problems like pneumonia. Chemotherapy and radiation can cause some lung problems while other problems are caused by bleeding in the lungs. If you notice any shortness of breath, cough, or fever, report them **right away** to the ABMT team.

Liver and kidney problems

You get many medicines during your transplant care. Chemotherapy and other medicines pass through your liver and kidneys before they leave the body. Sometimes the kidneys and liver have to work harder. We will perform blood work to tell us how your kidneys and liver are working and what dose of some medicines to give you. You may take medicines to protect your liver and kidneys. We may ask you to write down what you are drinking to monitor your fluid intake. This is important to help us keep your kidneys and liver healthy.

Fatigue

Fatigue is a feeling of tiredness. Cancer and its treatment can cause you to become inactive. Being inactive may cause fatigue because your muscles become weak and shrink a little when they do not get enough exercise.

Some causes of fatigue during transplant are:

- Chemotherapy and radiation
- Not eating well
- Not sleeping well
- Sleeping too much
- Lack of activity
- Dehydration
- Anxiety and stress
- Anemia
- Depression

Fatigue may continue after your transplant care for several weeks or months and will improve slowly.

Some things you can do to help fatigue during and after your treatment are:

- Exercise every day even when you do not feel up to it. You should try to walk one mile every day. You can break the mile up into several shorter walks.
- If you need a nap, take a short one that is no longer than 60 minutes.
- Try to get a good night's sleep without distractions from phones or TV.
- Avoid caffeine after 5 pm because it can keep you awake.
- Tell us about your fatigue. There may be a medical cause for it, such as anemia.

Nausea and vomiting

Chemotherapy and radiation can cause nausea and vomiting. Chemotherapy acts on a part of your brain that triggers nausea. You may feel nausea right after your treatment or several days after treatment. Every patient has different levels of nausea. You will get medicine to prevent nausea and vomiting before your chemotherapy or radiation. You will also have medicine to take after your treatment. The nausea usually lessens days after chemotherapy and radiation. Other medicines that you take during your treatment may cause nausea, too. Your ABMT team works with you to prevent and treat nausea. Let us know if the medicines we give you do not help you feel comfortable.

Anorexia

Anorexia is a loss of appetite. This can occur for several reasons:

- Chemotherapy or radiation can cause anorexia.
- The treatments can cause a metallic taste in your mouth or decreased taste.
- You may feel full more quickly.
- You may experience dry mouth, mouth sores, or a sore throat.

During this time, you need more calories than you usually do so that you can heal after the transplant. This can be hard if you have anorexia. If you do not consume enough calories and are losing weight, your ABMT team will talk about options to help with nutrition.

Some things you can do to help anorexia are:

- Eat frequent small meals.
- Eat in a pleasant setting, such as sitting up in a chair instead of your hospital bed.
- Suck on sugar-free hard candy or chew sugar free gum to help keep your mouth moist.
- Rinse your mouth with salt-water rinses after you eat meals and at bedtime.
  - Mix ½ teaspoon of salt in 8 ounces warm water or purchase saline rinse.
- Exercise can stimulate the appetite.
- Cooler foods are usually more appealing than hot foods.

Diarrhea

Diarrhea is frequent, loose, or watery stools. Diarrhea can occur because of:

- Chemotherapy
- Radiation
- Other medicines
- Stress
- Infection

Diarrhea causes loss of fluids, minerals, and electrolytes in your blood. You may have belly cramping, pain around your rectum, or skin break down around your rectum. It is important to tell us if you are having diarrhea. Do not treat the diarrhea with OTC medicine unless directed by your ABMT team. It is important to identify the cause of the diarrhea to treat it correctly.

Constipation

Constipation occurs when your stool is hard and dry. Constipation can occur because of:

- Not eating or drinking enough (dehydration)
- Pain medicine
- Inactivity
- Some chemotherapy

Tell your ABMT team if you are having constipation.

Some things you can do to prevent constipation are:

- Drink 6 to 8 glasses (at least 8 ounces) of healthy fluid every day. These include juices, water, and protein drinks.
- Be active every day.
- If you are taking pain medicine, take a stool softener, too.

Mucositis

Mucositis is pain and inflammation of the tongue, gums, or lining of the mouth or throat. This can happen after chemotherapy and radiation. Mucositis can be mild with a few tender areas in your mouth, or it can be more severe, causing painful swallowing and excessive mucus.

Tell your ABMT team if you are having:

- Redness, tenderness, or burning in your mouth
- Sores, blisters, or white patches in your mouth
- Bleeding gums
- Pain that keeps you from eating and drinking
- Difficulty swallowing due to sore throat
- Your ABMT team will give you medicine to help with mouth discomfort.

Mouth Rinse Recipes

Saline (Salt Water) Rinse:

1 teaspoon salt in 8 ounces of warm water

Baking Soda Rinse:

1 Teaspoon of baking soda in 8 ounces of warm water

How should I care for my teeth and gums during treatment?

- Avoid using an electric toothbrush or water pick.
- Brush your teeth gently after each meal and at bedtime. Use a soft toothbrush and gentle toothpaste. Replace it weekly.
- Do not use a whitening toothpaste or toothpaste with lauryl sulfate. If your mouth is sore, use moistened toothbrush with saline (salt water) to brush. See recipe in box above. Bristles can be softened with hot water first.
- Clean your tongue gently with a soft toothbrush or with a piece of gauze moistened with saline rinse. See recipe in box above.
- Rinse twice daily with chlorhexidine oral rinse as tolerated.
- Rinse with saline (salt water) after every meal or snack. See recipe in box 1.
- Avoid mouthwash that contains alcohol, citric acid, or glycerol.
- Avoid hard, sharp, spicy, or acidic foods.

How can I help my dry mouth?

- Rinse your mouth several times a day with saline or baking soda rinse. See recipe in box above.
- Use mouth lubricants to keep your mouth moist and to help with eating.
- Take small, frequent sips of water, or suck on ice chips.
- Use sugar-free gum or hard candy.

How should I care for my dentures during treatment?

- Remove dentures, bridges, and oral plates. Only wear them during eating and drinking.
- Avoid denture adhesives.
- Store dentures in a dry container overnight.

Pain

Pain can be a side effect of your treatment. Everyone experiences pain differently. Tell the ABMT team if you are having pain. Describe your pain (dull, sharp, burning, aching), and rate it on a scale of 0-10 with 0 being no pain, and 10 being your worst pain. Your ABMT team will also ask about where the pain is, how long it lasts, and if there is anything that makes it worse or better. Describing the pain will help us choose medicines and treatments that are most effective for you.

Acute Graft versus Host Disease (acute GvHD)

Acute Graft versus Host Disease (GvHD) is a common complication of transplant. T-cells in your immune system recognize anything foreign, from a cold virus to human tissue, and attempt to reject it to keep your body safe. GvHD happens when your donor T-cells recognize you as foreign and attempt to reject you. GvHD may happen in up to 5 out of every 10 patients and may be mild to severe. Your ABMT provider will talk you to about your risk of GvHD.

During your transplant care, you will receive 1 or more medicines to prevent GvHD. It is important to take these medicines as directed. You may take these medicines for many months after your discharge home.

Acute GvHD can appear as a flat red rash on your skin. The rash may occur on your palms, soles of your feet, chest, back, or occur all over your body. Sometimes the rash itches. We will carefully watch your skin for signs of acute GvHD.

Acute GvHD may affect your liver. We will carefully watch your liver through blood tests. If acute GvHD affects your liver, you may feel tiredness, tenderness on the right side of your belly, or have yellowing of your skin or eyes.

Acute GvHD may affect your digestive system. You may have nausea, vomiting, or watery diarrhea. Sometimes you can have belly cramping with the diarrhea. You also may have weight loss and loss of appetite.

If you have any of these symptoms, tell your ABMT team right away.

When should I call right away?

- Temperature of 100.5°F (38.0°C) or greater
- Shortness of breath
- Severe nausea or vomiting that keeps you from drinking fluids
- Severe diarrhea
- Change in thinking or headache
- Any other questions or concerns, or any new changes

Why is exercise important during my transplant?

Exercise is an important part of your recovery after transplant. Exercise helps your muscles stay strong, can improve your appetite, and helps you manage stress. It is good for your lungs and your heart while receiving your transplant treatment.

If you get your care on the hospital unit, you will see a PT and an OT. They design an exercise program for you. You should walk the halls of the hospital unit at least 3 times every day. Your PT or OT may also give you special exercises to do. If they do not recommend walking, they will help you with gentle movements in the bed and help you get to the chair.

If you receive your care in the ABMT clinic, you may see a PT and an OT there. When not in the clinic, you should walk outside. If it is sunny, wear sun protective clothes or sunscreen with SPF 30 and a hat. Wear a surgical mask if walking outside, and avoid areas of construction or yard work. It may not seem important, but exercising every day, even when you do not feel up to it, can help you recover.

What food safety guidelines should I follow?

After allogeneic transplant, you take medicines that suppress your immune system to keep your new donor cells from overreacting. You have a higher risk for infections due to these medicines. You will take these medicines for many months following your transplant. Hygiene is important for food safety.

Some tips are:

- Wash hands with antibacterial soap and warm water for 20 seconds before and after every step when preparing food.
- Wash hands before eating, especially when eating handheld foods.
- Wash hands after using the restroom, handling garbage, or touching pets.
- Wash cloth towels daily in a washing machine with hot water, or use paper towels instead of cloth ones.
- Your caregiver should handle all food preparation.
- Keep kitchen appliances clean (toaster, stove, coffee maker).

Food safety is important for everyone, especially for transplant patients. These guidelines are a summary of the US Department of Agriculture's Food Safety for Transplant Recipients. The full booklet in English and Spanish is available by clicking on the link below:

https://www.fda.gov/food/people-risk-foodborne-illness/food-safety-transplant-recipients.

USDA Recommended Safe Minimum Internal Temperatures

Steaks & Roasts	Fish	Pork	Ground Beef	Egg Dishes	Chicken Breasts	Whole Poultry
145 °F	145 °F	160 °F	160 °F	160 °F	165 °F	165 °F

After an allogeneic transplant you will follow these guidelines for one year or until you are off all immunosuppressive medicines or treatments.

Four Basic Steps to Food Safety

1. **Clean:** Wash your hands and surfaces often. Bacteria can spread throughout the kitchen and get into cutting boards, utensils, counter tops, and food.
   - **a.** Wash hands with antibacterial soap and warm water for 20 seconds before and after handling food and after using the bathroom
   - **b.** Wash cutting boards, dishes, utensils, and counter tops with hot soapy water often, sanitize with a bleach cleaner, or run plastic cutting boards through the dishwasher.
   - **c.** Use paper towels or disposable wipes to clean surfaces, or wash cloth towels frequently in the hot cycle of the washing machine.
   - **d. Wash all produce. Rinse fruits and vegetables, and rub firm skin fruits and vegetables under running tap water, including those with skins and rinds not eaten.**
   - **e.** Clean tops of cans before opening.
2. **Separate:** Keep food and their juices away from ready to eat foods.
   - **a.** Separate raw meat, poultry, seafood, and eggs from other foods in your grocery cart.
   - **b.** Never place cooked food on a plate that held raw meat, poultry, or seafood.
   - **c.** Do not reuse marinades used on raw food.
   - **d.** Use separate cutting boards for raw foods and ready to eat foods.
3. **Cook:** Cook foods to safe temperatures.
   - **a.** Use a food thermometer to measure the internal temperature of cooked foods.
   - **b.** When cooking in a microwave oven, cover food, stir, and rotate for even cooking. Always allow standing time, which completes cooking, before checking the internal temperature with a food thermometer.
4. **Chill:** Refrigerate quickly. Cold temperatures slow the growth of harmful germs. Keep a constant refrigerator temperature of 40°F or below and the freezer temperature 0°F or below.
   - **a.** Refrigerate or freeze meat, poultry, eggs, seafood, and other perishables within 2 hours of cooking or purchasing.
   - **b.** Never thaw food at room temperature. Safely thaw food in the refrigerator, in cold water, or in the microwave. If you thaw food in cold water or the microwave, cook it immediately.

What foods are off limits during this time?

High-risk foods you should avoid are:

- **Unpasteurized, raw** milk, cheese, or other dairy products
- "Moldy" or soft cheeses such as blue cheese, brie, feta, or farmer's cheese
- Raw or undercooked meat, poultry, fish eggs, or egg substitute
- Cold, smoked or pickled fish
- Raw tofu or tempeh
- **Unpasteurized** fruit and vegetable juices or ciders
- Raw or uncooked sprouts like alfalfa, mung bean or raw grains
- **Unroasted or uncooked** raw nuts and seeds
- Sun tea and "cold brewed" teas and drinks
- **Unpasteurized** honey
- Fresh prepared salsas, dressings, and salads stored in the refrigerated section of the grocery
- Uncooked brewer's yeast
- **Uncooked** deli meats and hot dogs- all must be heated to steaming
- **Unwashed** fresh fruits and vegetables
  - **Wash all fresh fruits and vegetables with friction under running water**
- Leftovers should be stored for only 48 hours and thoroughly reheated to 165°F only once.

Can I eat in a restaurant during my transplant?

You are not allowed to eat in a restaurant during your transplant treatment. Take out food that follows the above guidelines is allowed. Your caregiver should go into the restaurant and get the food for you.

Please follow these rules when ordering takeout food:

- Check the grade at the restaurant. Look for "A" with a rating of higher than 95%.
- Order only cooked entrees, and reheat at home to 165°F.
- Ask if the food contains uncooked ingredients, if yes, make another choice.
- Avoid fountain drinks from a restaurant.
- Avoid milkshakes made at the restaurant.
- Avoid buffets and salad bars.
- Request single serving condiment packets.
- Avoid garnishes that are uncooked.
- Avoid uncooked fresh fruits and vegetables from a restaurant.

What water is safe for me to drink?

The following water sources are safe for you to drink:

- **Tap water:** Water from a faucet is safe if it is from a city water supply.
- **Municipal water source:** Water from a municipal water supply is safe as the water is tested more than two times per day for bacterial contamination.
- **Bottled water:** Most bottling companies use reverse osmosis to filter water. Most bottling plants run their water through this process before bottling.
- **Distilled water:** Bottled distilled water is a safe source.
- **Boiled water:** Boil well water for 15 to 20 minutes and refrigerate in a clean covered container. Discard after 72 hours.

Throw away opened bottled water after 72 hours. Community or private well water is not a safe drinking source. The FDA recommends you use tap, bottled, boiled, or distilled water instead.

Do I need other treatments after my transplant?

You may need more treatment after your transplant. Sometimes these treatments make your donor cells stronger or help keep your disease away.

- Your doctor may decide to give you medicine to help keep your cancer away. This is called maintenance therapy. It may be a medicine that you have received in the past.
- Your doctor may decide to give your new immune system a "boost" with more donor cells. This can be done by:
    - Donor lymphocyte infusion: Your donor donates more stem cells. You get them like a blood transfusion. You do not need more chemotherapy.
    - CD34+ selected infusion or NK cell boost: Your donor donates more stem cells to make your cells stronger without increasing your risk for GvHD.

Your ABMT team will talk to you about possible treatment after your transplant.

How do I stay healthy when I go home after transplant?

It may take many months to recover. The transplant experience can affect you in many ways. You may need to let go of old ideas about yourself, set some new goals, and make changes as to how you live. You may find yourself adjusting to “a new normal.”

You can help your recovery by:

- **Keeping your healthcare appointments:** In addition to keeping your transplant and cancer provider appointments, you should see your primary care provider (PCP) within 1 year of transplant. Your PCP orders routine cancer screening and health maintenance tests. Pay attention to health changes, and note any skin changes, new sores, lumps, or bumps. Discuss any changes with your provider.
- **Deal with unplanned weight loss or gain:** Treatment side effects, changes in diet, and lack of activity can cause unplanned weight loss or weight gain. Talk to your provider or dietitian to help you manage your weight.
- **Preventing your cancer from coming back:** There are several ways to help prevent new cancer or prevent your cancer from coming back. You can:
    - Keep a healthy weight.
    - Be physically active.
    - Eat a diet rich in whole grains, fruits, and beans.
    - Limit “fast food” and other processed food.
    - Limit red and processed meat.
    - Limit sugar-sweetened drinks.
    - Limit alcohol.
    - Do not use supplements for cancer prevention.
    - Avoid tobacco or vaping products and secondhand smoke.
    - Avoid excess sun and always wear sunscreen with SPF 30.
- **Exercise:** You may not feel like exercising when you go home, but exercise is an important part of your recovery. Start slowly, and increase every day. You may not notice improvement in your energy from day to day. Sometimes the progress is slow. Make exercise enjoyable by walking with a friend or family member, listening to music, or using it as quiet time for yourself.

- **Plan your day and get on a schedule:** A plan for your day helps keep you moving forward. Being active with short rest periods helps you increase your strength, keep your mind active, and sleep at night.
- **Keep a check on your emotional health:** Fatigue and not feeling well can sometimes make you feel sad or depressed. You may feel anxious being at home and away from your doctors and nurses. You may also experience “flashbacks” from your transplant experience. If sad feelings keep you from taking your medicine, exercising, eating well, or generally taking care of yourself or others, you need extra support. Reach out to your ABMT team or your local PCP for help. We can help you find services near your home to support you.

Scan the QR codes below for more information on stress and relationships:

- **Dental care:** Notify your dentist that you have had a transplant. You should wait until you are off immunosuppressant medicine or treatment and 1 year before you see the dentist. You should have your blood counts checked before any dental work, including cleaning.
- **Get a flu shot and other vaccinations:** You should get a flu shot 6 months after your transplant. Do not get the flu mist. Anyone in your household or close family members should also get a flu shot every year. If it is spring or summertime, you may need to wait until the fall. Other vaccinations are given 1 year after transplant. Your ABMT team will coordinate your vaccination schedule.

What limits will I have when I go home after transplant?

- **Avoid driving until approved by your ABMT team.** This is usually after your platelet count has recovered. Make sure your vision is clear and you feel steady in the driver's seat before you drive. You should not drive if you are taking any medicine that makes you sleepy.
- **It is safe to go home to your pets after transplant.** You can walk them, play with them, bathe them, and welcome them back into your life. If you have a cat at home, do not change or clean the litter box. If you have a dog, do not handle the dog's stool. Do not handle or clean birdcages. Do not handle reptiles or snakes. Do not care for or have contact with farm animals. Wash your hands often. **You should avoid handling pet waste until you are off immunosuppressant medicine or treatment and 1 year post tranplant.**
- **General house cleaning and cooking is safe after transplant.** Change your air filters routinely. Normal weekly house cleaning is fine. You do not need to wear a facemask when you use the vacuum cleaner.
- **Avoid yard work. You should avoid working in the yard until you are off immunosuppressant medicine or treatment and 1 year post transplant.** Yard work includes raking, mowing, mulching, planting, pruning, and watering. Yard work is not safe even with a facemask. There are germs in the dirt that get in the air. You cannot see these germs but they are dangerous for transplant patients. These germs can cause serious infections.
- **It is safe to go out to restaurants after discharge. Use these guidelines:**
    - Eat early or late to avoid crowds.
    - **Continue to follow safe food practices when ordering for 1 year after transplant or until you finish taking immunosuppressant medicine or treatment.**
    - Restaurant should have a grading of "A" with a score of 95% or higher.

When can I return to work after transplant?

Many patients are able to return to work 6 to 12 months after transplant. Your ABMT team will help you decide when it is safe for you to return to work. If possible, we recommend working from home, or returning to work part time to start out. We understand this may not be possible for all patients. We will help you with any documentation you need to return to work.

Is it safe to have sex?

It is safe to have sex when your platelet count reaches 50,000. You or your partner should use a condom for the first 6 months after transplant to prevent certain viral infections that you can get through sex. Transplant can affect sexuality in many ways. It can change hormone levels and decrease your desire for sex. Changes in body image, worry about infection, and fatigue can lead to a decrease in a desire for sex. As your blood counts, diet, and activity level improve, your sex drive will also improve.

What are common concerns for women?

Chemotherapy and radiation can cause early menopause for many women. Sometimes blood vessel damage can cause a decrease in the ability of the vagina to stretch and a decrease in lubrication. In addition, vaginal graft-versus-host disease can make the vaginal opening sensitive and sore.

- Problems reported by women after transplant include:
    - Decreased interest in sex
    - Decreased physical response or arousal
    - Pain during sex
    - Difficulty reaching orgasm
    - Changes in body image
    - Worries about germs and infection
- There are therapies to help some of these problems including:
    - Vaginal moisturizers
    - Water or silicon based lubricants designed for intercourse
    - Hormone replacement therapy
    - Vaginal dilators
    - If you are experiencing vaginal graft-versus-host disease, topical steroids with estrogen may help. In severe cases, surgical intervention may be required.

Please tell your ABMT team or local PCP if you are having any of these problems. Your health care team can refer you to an expert to help with your symptoms.

What are common concerns for men?

Chemotherapy and/or total body irradiation (TBI) you receive before transplant can reduce testosterone (most men recover normal levels within two years), damage small blood vessels in the penis, or damage nerves over time. In addition, chronic GVHD sometimes affects the genitals creating sores on the penis.

- Problems reported by men after transplant include:
  - Inability to get or maintain an erection
  - Decreased interest in sex
  - Pain with erection
  - Difficulty reaching orgasm
  - Changes in body image
  - Worries about germs or infection
- There are therapies to help some of these problems including:
  - Testosterone therapy
  - Oral medicine to help get and keep an erection
  - Other treatments to help with erections
  - Treatments to increase the blood flow to the penis

Please tell your ABMT team or local PCP if you are having any of these problems. Your health care team can refer you to an expert to help with your symptoms.

What are possible late effects after transplant?

- **Chronic Graft versus Host Disease (chronic GvHD):** Chronic GvHD can happen several months after your allogeneic transplant. Donor t-cells cause both acute and chronic GvHD. Transplant patients who have acute GvHD are more likely to have chronic GvHD later on. Patients who do not have acute GvHD can also get chronic GvHD. Chronic GvHD can be mild to serious. Some patients have chronic GvHD for many years after transplant. If you have chronic GvHD, you may be on several medicines and treatments.

  Getting too much sun on your skin can trigger chronic GvHD. To prevent this:

  - Always wear sunscreen with **sun protective factor (SPF) of 30 or higher** on skin exposed to the sun. This includes your face, back of your hands, and tops of your feet. When you go outside, try to stay in the shade and avoid the hottest part of the day from 10 am to 2 pm.
  - You may choose to wear sun protective clothing.
  - Protect your eyes from the sun with ultraviolet (UV) protection sunglasses.
  - Wear a hat, a long-sleeved shirt, and long pants when possible.

  Common signs of chronic GvHD are:

  - Skin rash, changes in skin color or texture
  - Dry, irritated eyes or watery eyes
  - Nausea, weight loss, diarrhea, mouth sores
  - Dry or irritated vagina
  - Thinning hair and nails
  - Joint stiffness
  - Shortness of breath

If you notice any of these symptoms, tell your ABMT team right away.

- **Cataracts:** Cataracts can develop from radiation or from taking certain medicines. Your vision may become blurry or less clear. You should see an eye doctor if you are having problems with your vision. You should wear sun protective eyewear that block ultraviolet (UV) rays when you are out in the sunlight.

- **Mouth problems:** If you get total body irradiation, you may have gum disease or receding gums. When you are off immunosuppressive medicine, see a dentist and let them know you had high dose chemotherapy or total body irradiation.

- **Infertility:** Most transplant patients are not able to have children after their treatment. Your choices about having children will depend on steps you took before transplant. **Talk to your ABMT team about fertility options before your transplant.**

- **Bone problems:** Some transplant medicines and treatments can cause your bones to become weak. This is called osteopenia or osteoporosis. Both are caused by decreased minerals in your bones that makes them weaker and at risk for fracture. Your ABMT team may give you calcium and vitamin D to help your bones stay strong. If you notice bone pain, tell your ABMT team or local PCP. Medicines, a balanced diet, and exercise can help strengthen bones.

  If you take steroids for a long time, you may develop avascular necrosis (AVN). This happens when the blood supply to the bones are damaged, causing them to break down faster than the body can rebuild them. AVN can cause pain in your joints, like the hips, shoulders, knees, ankles, and wrists. If you notice any joint pain, tell your ABMT team or local PCP. Sometimes the joints need to be repaired with surgery.

- **Heart or lung problems:** Some chemotherapy and radiation can damage your heart and lungs long after your transplant. **You should see your PCP every year to look for signs of damage. You should see a health care provider right away if you have shortness of breath or chest pain.** You may also have high cholesterol or other high blood levels that make you at higher risk for heart problems.

- **Changes in mood or thinking:** Sometimes patients have mental cloudiness before, during, or after treatment. This is known as "chemo brain. " You may feel your memory is not as sharp, or it is difficult to concentrate or multi-task. These symptoms may affect your everyday life and be frustrating. Tell your ABMT team or local PCP if you have these symptoms. There is help and support available.

Before going home, you will get more information about being a survivor and staying healthy after transplant. We hope this handbook is helpful as you travel through your transplant journey. If you have any questions, please ask a member of your ABMT team. We are here to support you.

What are other resources I can turn to if I have questions?

Organization	Website	Phone Number
Duke Cellular Therapy	www.dukecancerinstitute.org	**919-684-8964**
Duke Cancer Patient Support	www.dukecancerinstitute.org	**919-684-4497**
The Leukemia & Lymphoma Society	www.lls.org	**800-955-4572**
National Marrow Donor Program	www.marrow.org	**800-627-7692**
National Bone Marrow Transplant Link	www.nbmtlink.org	**800-546-5268**
BMT Infonet	www.bmtinfonet.org	**888-597-7674**
American Cancer Society	www.cancer.org	**800-227-2345**
International Myeloma Foundation	www.myeloma.org	**800-452-2873**
Multiple Myeloma Research Foundation	www.themmrf.org	**203-229-0464**
National Cancer Institute	www.cancer.gov	**800-422-6237**
National Coalition for Cancer Survivorship	www.canceradvocacy.org	**877-622-7937**
To forward your mail	https://www.usps.com/manage/forward.htm	

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DUHS Patient Education Governance Council approved June 2020
Flesch-Kincaid: 6.6
Allogeneic Transplant Handbook
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