This book belongs to:

____

This patient guidebook is a great resource and an important tool to help you as you receive care. Please bring it with you to all your appointments and treatments.

The UW Health Blood and Marrow Transplant program is:

- Accredited with the Foundation for the Accreditation of Cellular Therapy (FACT)
- A participant in clinical trials initiated by the NIH funded Bone Marrow Transplant Clinical Trials Network
- An approved allogeneic and autologous transplant center by the Eastern Cooperative Oncology Group
- An approved Transplant Center, Marrow Collection Center and Apheresis Center for the National Marrow Donor Program

If found, please return to the

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Allogeneic Transplant Binder

Important Phone Numbers

UW Health Carbone Cancer Clinic Nursing Triage	608-265-1700 or 1-800-323-8942
After 4:30pm and on weekends contact	608-262-0486
Bone Marrow Transplant Coordinators	
Bethaney Campbell, RN, Program Manager:	608-262-0455
Jan McMannes, RN	608-263-0501
Lauren Racki, RN	608-263-7673
Karen Krantz, RN	608-890-5923
Brett Welhouse, RN	608-263-8628
Mandy Swiecichowski, RN	608-890-5922
Clinic Social Worker	
Kristin Arnold	608-262-7894
Nutrition	
Darcy Stagman	608-263-8248
Kelly Nuckolls	608-890-5295
Case Manager:	
Mary Santarius	608-265-8673
Spiritual Care Services	608-263-8574
Bone Marrow Transplant Pharmacist	608-263-1284
Guest Services	608-263-0315

Housing

UW Health patients and visitors can reserve a room at a local hotel at a discounted rate through Guest Services at **608-263-0315**, or you can stop at the UW Health Information Desk at the hospital entrance.

Restoring Hope Transplant House (RHTH), in Middleton, WI, offers a comfortable, very affordable and caring environment for transplant patients and their families to call their "home away from home" during their stay in Madison. RHTH has sleeping rooms and common areas including a kitchen and living area. Learn more about RHTC at www.restoringhope.org. To reserve a room at the RHTH call UW Health Guest Services **608-263-0315**. Tell the Guest Services staff that you or your family member will be receiving transplant-related care at UW Health, and that you would like to stay at the Restoring Hope Transplant House.

UW Health University of Wisconsin Hospital and Clinics
Allogeneic Stem Cell Transplant Process

Dealing with a severe illness changes your life and the lives of people around you. Choosing the right treatment option can be hard. A UW Health stem cell transplant doctor has told you that a stem cell transplant is an option to treat your disease. This booklet tells you about the transplant process. There is a lot you need to know about stem cell transplant. Transplant is a process and your transplant team is here to help you learn along the way. This book was written for you, but it may also help those people who are close to you.

Stem Cell Transplant Providers
When you come to our clinic for your consult with our stem cell transplant team, you will meet one of the attending doctors.

The primary stem cell transplant doctor will be your primary doctor while you are going through the transplant. Your care team will consist of a team of doctors. These doctors rotate on a schedule. All the doctors are transplant experts and will be helped by fellows and residents.

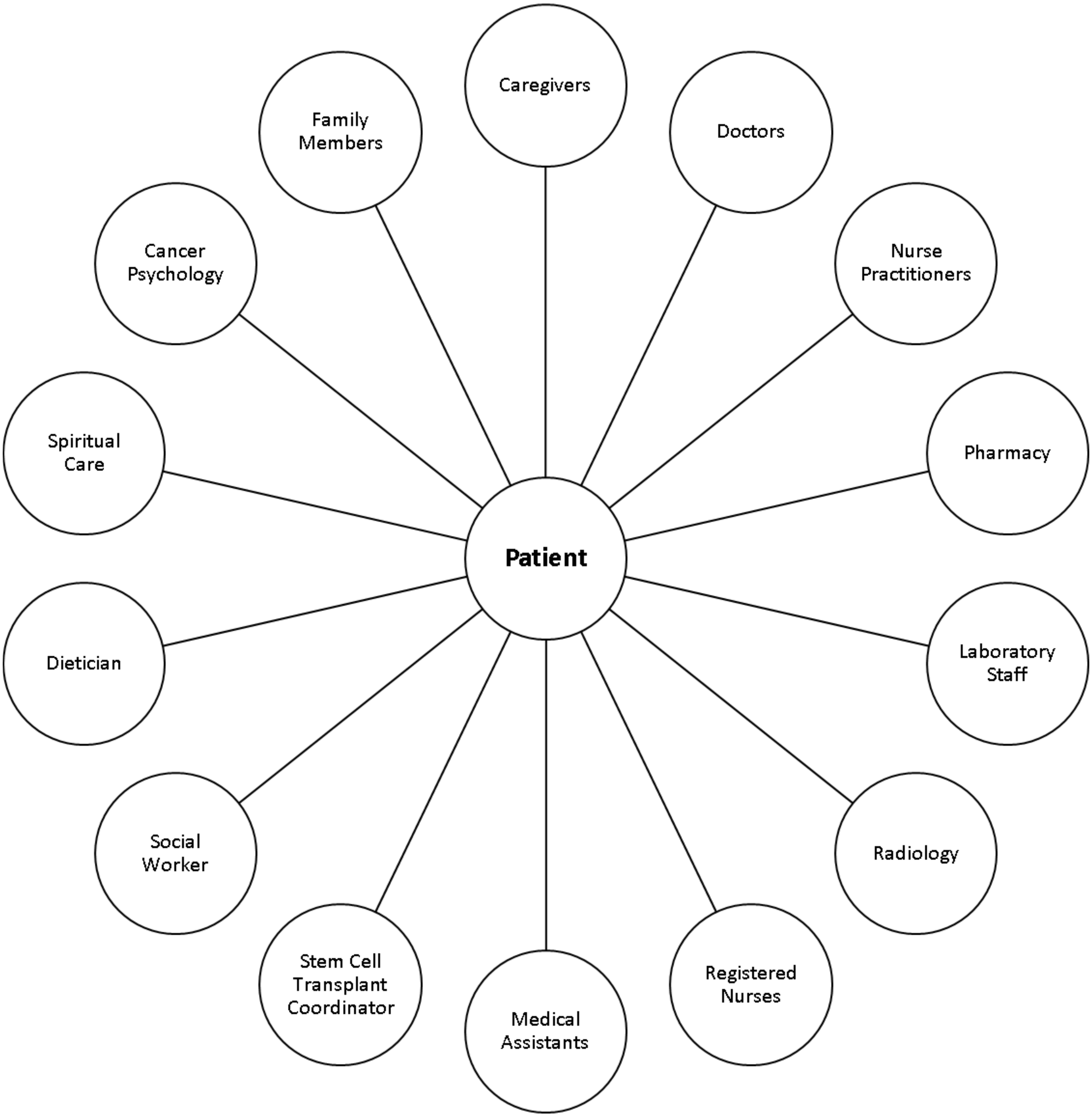
Residents and fellows are doctors in training. Residents are doctors who have worked in internal medicine for 1-3 years. Fellows are doctors who are done with residency and are focused on a field of medicine (cancer).

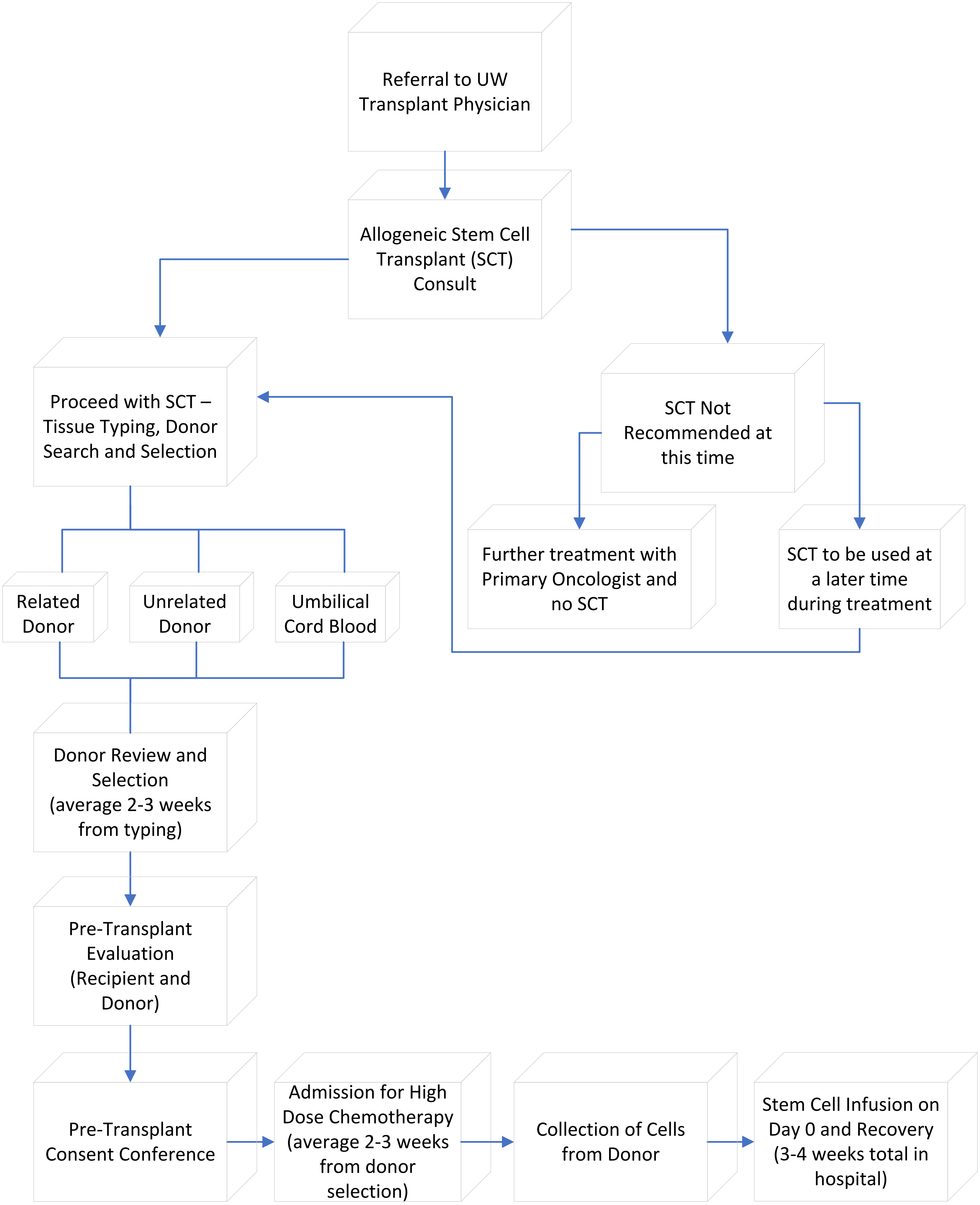
Nurse practitioners are nurses with advanced nursing degrees. They are trained to diagnose and treat illness. They also are trained to care for stem cell transplant patients. They will work with your doctors to provide your care.

In our clinic, you will see your primary stem cell transplant doctor or a nurse practitioner. A fellow or resident may also see you as part of their training.

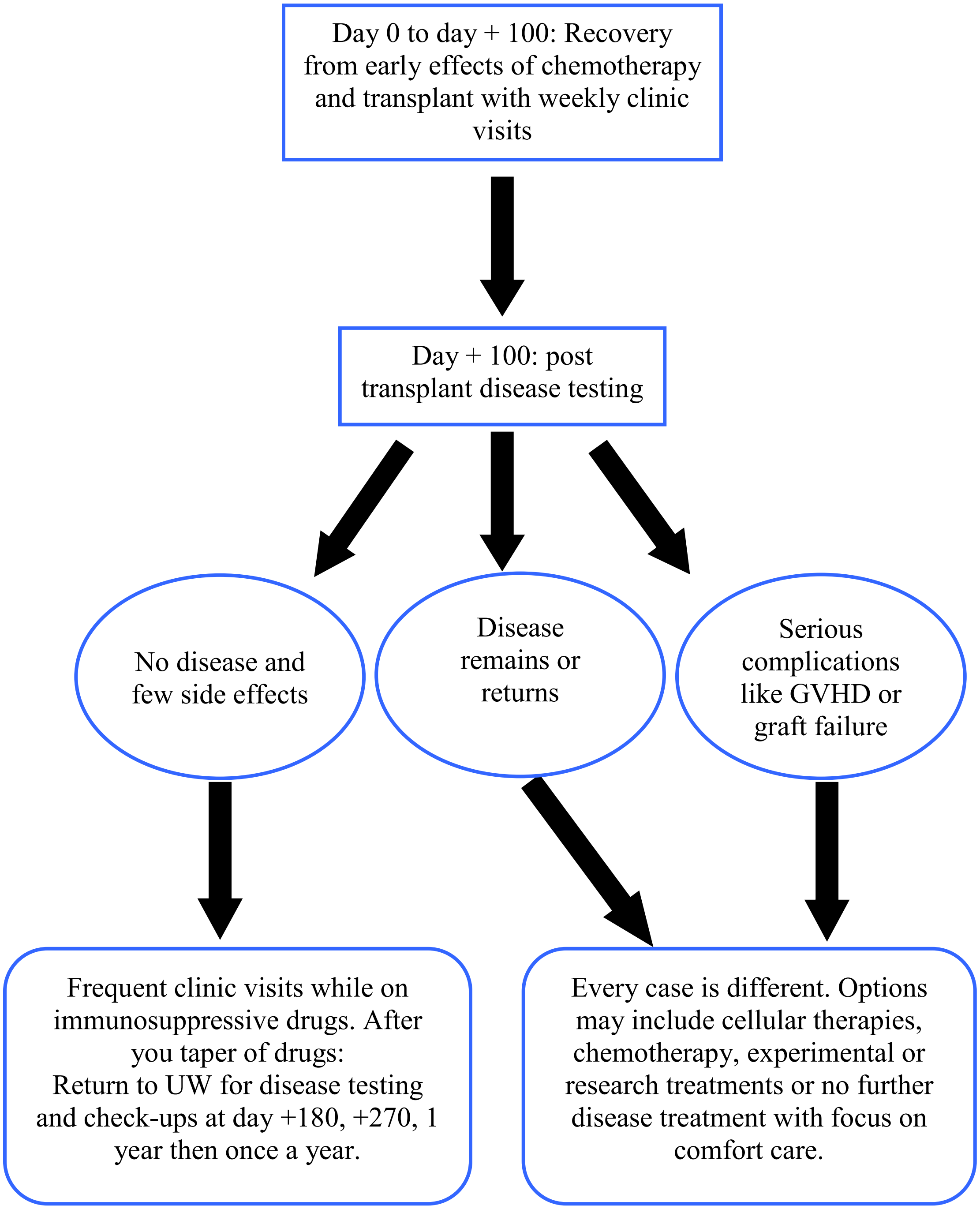
Throughout the binder, you will see boxes. These boxes include special information for your family member or caregiver.

The Stem Cell Transplant Team




Referral to UW Transplant Physician
Allogeneic Stem Cell Transplant (SCT) Consult
Proceed with SCT – Tissue Typing, Donor Search and Selection
SCT Not Recommended at this time
Further treatment with Primary Oncologist and no SCT
SCT to be used at a later time during treatment
Related Donor
Unrelated Donor
Umbilical Cord Blood
Donor Review and Selection (average 2-3 weeks from typing)
Pre-Transplant Evaluation (Recipient and Donor)
Pre-Transplant Consent Conference
Admission for High Dose Chemotherapy (average 2-3 weeks from donor selection)
Collection of Cells from Donor
Stem Cell Infusion on Day 0 and Recovery (3-4 weeks total in hospital)

After Transplant



The Transplant Process

What is stem cell transplant?
A stem cell transplant is one treatment option for patients with blood cancers and immune system or genetic disorders. Doctors often suggest this option because the disease does not respond to standard treatment, or because the disease has returned after standard treatment. In allogeneic (a-lo-jen-ay-ic) transplant, stem cells come from a donor. There are two major types of allogeneic transplant, nonablative and ablative.

What is nonablative stem cell transplant?
This stem cell transplant uses chemotherapy and sometimes total body irradiation (TBI). The doses of TBI are lower than those used in ablative transplant. This type of transplant prepares the body to accept the donor stem cells. Doctors may suggest this type of transplant for older patients or patients with heart, lung or other problems.

In most cases, the early side effects are less than those of ablative transplant. The risks of long-term problems, like graft vs host disease (GVHD), are the same. Read more about GVHD under the Long-Term Complications section in this binder. **You may only be in the hospital for a few days or may even be closely followed in the outpatient BMT Clinic**. These patients will need to stay in or near Madison for the first month after transplant. If you have complications, you may need to stay longer.

What is ablative stem cell transplant?
This type of transplant uses high dose chemotherapy and sometimes total body irradiation (TBI). This transplant treats the disease and prepares your body to accept the stem cells. The risks of early side effects are higher than with nonablative transplant. The risks of long-term problems are the same. If you have this type of stem cell transplant, you will be in the hospital about 3-4 weeks and could stay longer if you have complications.

What is the goal of stem cell transplant?
The goal of this process is to control or cure your disease. Your doctor will discuss the risks and benefits of transplant to treat your disease.

What is a stem cell?
Stem cells are blood forming cells found in bone marrow which is inside the bones and in the umbilical cord blood. Stem cells are the “parent” cells of the main parts of blood: red blood cells, white blood cells and platelets.

- **Red blood cells** carry oxygen to the body’s tissues.
- **White blood cells** fight infection.
- **Platelets** help prevent bleeding.

How does someone donate stem cells?
There are three sources of stem cells used in this type of transplant.

- **Bone marrow from a family member or unrelated donor.** While under general anesthesia, bone marrow is withdrawn with a needle from the donor’s hip bone in the operating room.

- **Peripheral (circulating) blood stem cells from a family member or unrelated donor.** The donor takes injections of filgrastim, a white blood cell growth factor. These shots make the body release stem cells out of the marrow and into the blood. Stem cells are taken from the donor's blood. An IV is placed in both donor's arms. Blood travels from one IV, about ½ cup at a time and travels through a machine to collect the stem cells. The rest of the blood is returned to the donor through the other IV line.
- **Donated umbilical cord blood stem cells.** Cord blood banks collect and store stem cells that have been removed from donated umbilical cords.

Searching for a Donor

If you and your transplant doctor decide that this type of transplant is right for you, the next step is to find a donor. We may look at your family members. Each sibling with the same parents has a 25% chance of being your full match. Your children may be a half match to you. They can be tested by giving a small blood sample. There may be times where half-matched relatives are an option.

Your transplant coordinator will organize the collection of donor blood samples. Please give us complete contact information for them including name, date of birth, address and phone number.

If you do not have a potential related donor, then we may search the National Marrow Donor Program® registry. This search alone can take two months or more to complete. There are many tissue types, some are common, and some are not common. Even though there are a lot of people on the registry, not everyone finds a match.

Searching for a Cord Blood Unit

Your transplant coordinator will contact the National Marrow Donor Program® and other cord blood registries to search for cord blood units. For adults, we must find two cord blood units to provide enough stem cells for transplant.

Finding a Donor

HLA (Human Leukocyte Antigens) are proteins found on most cells in your body. These proteins serve as markers that your immune system uses to figure out the cells that belong in the body from cells that don't (viruses, bacteria, cancer). Your blood will be tested for HLA proteins and compared against the HLA proteins of donors to see if your HLA matches. If there is a close match between your HLA proteins and your donor's HLA proteins, there is less of a chance of getting GVHD. We will search and select the best match for you.

Pre-Transplant Testing

If a matched donor is found, you will have at least 2-3 days of testing before transplant, called the pre-transplant evaluation. You have these tests to see whether you are ready for transplant. In most cases, you will not meet with the doctor on the pre-transplant testing day. Your transplant coordinator will set up the tests. Tests will include:

- Blood and urine testing
- CT and/or PET scans
- Heart and lung tests
- Bone marrow biopsy and maybe a lumbar puncture
- Check of your mental health

You will not need to stay overnight in the hospital for the tests. If you live far away, you can find a place to stay through UW Health Guest Services. Please call **608-263-0315**, or stop by the Information Desk at the hospital entrance.

The results of your pre-transplant testing will take a few days. The results are sent to your health insurance company for review before they will cover the transplant. Insurance must approve transplant.

Dental Check-Up

See your local dentist if you have not had a recent dental check-up. If you do not have a dentist, please tell your coordinator. If you have low blood counts, make sure to tell your dentist. Your dentist may require that counts be high enough to avoid bleeding and infection before they will do dental work. Ask your dentist to look for any sites of infection in your teeth and mouth. Unhealthy teeth and gum tissue can become a bad infection during transplant. You may need to have infected teeth removed.

Smoking

Smoking can cause many severe problems for transplant patients. This includes mouth sores and lung problems that could lead to death. If you smoke, you must stop. Your transplant doctor and coordinator can help you and, in some cases, prescribe medicine to help you stop. When you are in the hospital for your transplant you are not allowed to leave the unit to smoke. UW Health is a smoke-free campus. Smoking is not allowed.

Other tools to help you quit are listed below.

- UW Center for Tobacco Research & Intervention – Community Guide to Quit-Tobacco Resources: http://www.medicine.wisc.edu/quitline/programs/index.php.
- The American Lung Association – Freedom from Smoking has a free online self-help program: lungusa.org.
- The U.S. Public Health Service provides a You Can Quit Smoking information kit: surgeongeneral.gov/tobacco.
- You Can Quit Smoking Now at: smokefree.gov.

Pre-Transplant Testing and Consent Conference

When the results of the pre-transplant and donor's evaluations are complete, you will meet with your doctor to review the results. Your doctor will again talk about the pros and cons of transplant. You will talk about both pre- and post-transplant care.

The consent conference is next. The consent conference reviews the chemotherapy plan, gives you information about your care, and gives you a chance to ask questions. This is the time to review the consent form and the goal of transplant for you. You must sign a consent if you wish to have a transplant. After this, your transplant will be planned.

Fertility Concerns

Though infertility does not occur in all transplant patients, it is common. Those who receive high dose chemotherapy or total body irradiation (TBI) often become infertile due to their treatment. Often, patients have already had treatment that has damaged eggs or sperm. Before your treatment, there may be options to help preserve your fertility. These options are not for everyone and do not always work. Make sure you talk about this with your doctor before your transplant. Your doctor can refer you to UW fertility specialists who can talk to you about your options.

For Men

You may want to think about sperm banking. This involves freezing and storing your sperm. You can talk to your doctor about your options. Many health insurance plans do not cover the cost of this service.

For Women

If there is time, you may be able to freeze your eggs before you start your treatment. This process can take up to a month or more so think about this option long before your treatment. Many health insurance plans do not cover the cost of this service.

Pregnancy Concerns

You should not become pregnant or father a child at any time during your treatment. The treatments can harm an unborn child. Talk to your doctor about birth control options.

The Role of the Transplant Caregiver

Having a transplant is a complex process for anyone to go through. You will need to have a support person who can help you through this process. This can be anyone close to you, such as a parent, spouse, partner or other close friend. They will help you as you recover from your transplant, both in the hospital and after you come home. Each patient should have someone to help because there may be times when you will be too ill to care for yourself.

How do I choose a caregiver?

Your support person may need to stay with you in your home for at least the first 1-4 weeks after transplant. Choose someone that you would be okay living with for that amount of time. Choose someone you would trust to help you with your medicines.

Will your caregiver support your health care choices, and speak up for you? They will need to be present to learn, help create a plan for your care at home, and prepare for your discharge. Your caregiver should be able to take you to and from your appointments after discharge.

For the Caregiver…
Questions to ask yourself before you say 'yes, I will be your caregiver':

- What will I need to do?
- What do I have to know?
- How long will I need to provide care?
- Can I afford to be away from work for a long period of time?
- Does the FMLA apply to me?
- Do I have others who can help me?
- How will I take care of my own duties?

Your caregiver may have to be away from work for a long period. Are they able to take a leave of absence (this could range from weeks to months) from work? Make sure that FMLA (Family Medical Leave Act) paperwork is filled out and submitted for both you and your caregiver. If approved, FMLA allows you to take unpaid, job-protected leave for family and medical reasons. This leave also allows you to keep your group health insurance under the same terms as if you had not taken leave. Think about how much time your support person can take away from work and what the best way to use it is. They may want to work while you are in the hospital, and use FMLA after you leave to go home. Can they afford to take unpaid leave?

You may choose to have more than one helper. Ask your social worker to help you set up a care team for after your transplant.

"It is incredibly difficult to be a caregiver, and oftentimes, the real issues associated with caregivers are overlooked, as the focus is entirely on the patient …You shouldn't feel guilty about taking some time for yourself, and addressing your own needs."
-SCT Patient

For the Caregiver…
Your role will change over time. At first, you will help the patient plan for the transplant process. Think about what the patient needs while away from home. Once in the hospital, spend time with the patient and make sure the doctors and nurses know the patient's needs and concerns.

Your main role will be to help the patient to recover at home after discharge. It may take several weeks for the patient to be strong enough to stay on their own for long periods of time. You will need to:

- Help patient with their scheduled medicines.
- Look for any changes or new symptoms.
- Know what to do in an emergency.
- Call for help when needed.
- Keep the home clean and comfortable.
- Shop for groceries and make meals and snacks.
- Drive patient to and from the clinic or find rides.

As the patient begins to get better, step back and allow them to take over their own care. There may be setbacks along the way, but most patients are able to handle their own care within a few weeks at home.

Learn what to expect. Learn about the disease and treatment plan. Make sure you learn what the patient will need help with at home. Be in the hospital a day or two before discharge to learn about the patient's care needs.

Working with Insurance

UW Health must have proof of insurance for all care. This must be done **before** you are seen for a transplant consult. Most insurance plans assign a transplant case manager who can talk to you about what your plan covers.

If you do not have health insurance or government coverage like Medicare or Medicaid, or are underinsured, you may not be able to have a transplant at UW Health. You may be able to find a plan through the HealthCare Marketplace. A social worker can help you find where to apply. Call the UW Health social worker at **608-262-7894** for help.

After a transplant, you have many medicines to keep you healthy. These are required. **You could be at risk for serious problems if you do not take your medicines.** If your plan does not cover your medicines, tell your pharmacist, or call the UW Health social worker at **608-262-7894**.

If your insurance plan covers you, coordinators from your UW transplant team will send them your health records and written treatment plans. Not all plans cover the same things. Make sure that you know and understand your plan.

UW Health has financial counselors. They can help you. They check your plan before you come for your first transplant consult. You may meet with them when you are here for your pre-transplant visit.

To talk with a financial counselor, please call the main number for the UW Admissions Department at **608-263-8770**.

Disability

These payments can be a great way to help with the costs of stem cell transplants (SCT). SCT patients are often approved. This process is long, and some patients do not go back to full-time work for a year or more. It is a good idea to file for disability and tell your employer what is going on.

For the Caregiver…

You may need to help the patient with their insurance. Work with their transplant case manager through their insurance and the UW Transplant Coordinator to find out what you need to know. If you have the same plan, know that your coverage cannot be reduced because of the patient's health. It is against the law.

While the health plan may cover the cost of the hospital stay and transplant, there can be other costs (i.e. gas for trips to UW Health or hotel bills and meals to stay in Madison). Plan ahead so you do not worry later.

How will I support my family and myself during treatment? Can I get disability payments?

Some patients have long or short-term "private" disability plans through their job. If you want to find out more about these plans, call the Human Resources (HR) office where you work.

There are two types of government disability benefits. Social Security Disability Income (SSDI) is a monthly income you could get. You must have worked long enough and the Disability Bureau needs to agree that you are disabled to get it. It includes Medicare after you get SSDI checks for 2 years.

Social Security Income (SSI) is a monthly income you can get if you have low or no income and the Disability Bureau agrees that you are disabled. Aside from the home you live in and one car or truck, you cannot have more than $2000 in assets for a single person or $3000 for a couple. This includes money in the bank and other accounts and assets.

In Wisconsin, SSI includes Medicaid (also known as Medical Assistance or MA) which may cover health costs as far back as 3 full months from the date you applied. Illinois does not have Medicaid with this program. Instead, you will have to apply through your county.

For the Caregiver…
The patient may need your help filing for disability.

Family Medical Leave Act (FMLA)- You can get a form to apply for FMLA from the HR office where you work. FMLA allows you to take unpaid time off to care for the patient.

How to Apply for SSDI
You may apply on your own. If you have questions, social workers at UW Health can help.

The best way to apply is online at www.ssa.gov. Click on "Apply for Disability Benefits." Complete the Adult Disability Report. You must also have a phone or office interview. Before you call, make sure you have the correct social security number and birth date. Call toll free at **1-800-772-1213**. For Dane and Iowa counties, call **(608) 270-1141**. Listen to the message and follow the prompts.

Ask to set up an interview by phone or at the Social Security Administration (SSA) office. SSA asks questions to figure out which program you could apply for. If you have disability insurance through your job, ask about when to apply for SSDI/SSI.

Sign the Authorization to Disclose Information forms. Return them to SSA. It may take a few months to hear if you have been approved. In some cases, the type and how serious your health is results in a quicker response.

Medical Assistance (MA)
Some people may be able to get MA. You must apply at your local county social services office. Ask your social worker to find out if you should apply.

Raising Money
There are many ways to get help if you need it. If you ask for help, it can broaden your support group and lessen stress while you heal. A lot of patients need help, so do not feel like you are alone.

Sometimes the place you work may give out grants and help raise money. Ask your HR office or boss if your company can help you in any way.

If you are active in a service, union, or religious group, see if they can raise money or help in any way.

Grants for people living with cancer or having a stem cell transplant can help with costs. This includes help with rides, hotels, meals, co-pays, prescriptions and other costs. The Leukemia and Lymphoma Society is one place to check. Your social worker can help you find other grant sources.

Legal Planning
Fill out Advance Medical Directives. Make sure that you update your will to state any wishes you may have. Keep all legal papers your family might need in one place so that they know where to find them.

Make sure that you are treated fairly by your place of work. They cannot discriminate against you because of your health. Your insurance benefits cannot decrease (whether you are on your own insurance or someone else's) because of your health. It is illegal.

Other Planning
This process can be stressful in many ways. If you worry about money, it can add to your stress. Please ask for help when you need it. If you plan ahead, it helps lessen some of this stress.

For the Caregiver…
Before the patient is in the hospital, make a binder or folder where you can keep the receipts for treatment. This way it will be easy to find. Mark all costs that insurance has not covered. You may be able to deduct these costs on your taxes.

This is a good time to make, or update, your own will and living will. It is a good idea to ensure that all insurance and legal paperwork is in order.

Preparing for the Transplant and Your Absence from Home

"I've learned that I can deal with a crisis like this." - SCT Patient

Preparing for Transplant

Ask your doctor or transplant coordinator about your treatment plan. You will get an education sheet that shows your treatment plan along with a list of side effects. This sheet will show how many days of chemotherapy you will have and, in some cases, will include total body irradiation (TBI).

The amount of time spent in the outpatient clinics or in the hospital varies. Think about how your hospital stay will affect your home routines. Think about how your bills are going to be paid or who will care for your children or pets. This will make things easier for your family when you are in the hospital and lessen your stress and allow you to focus on recovery.

If you live far away, you may need to stay close to the hospital for the first few weeks after discharge. You will have frequent follow-up appointments after discharge. If you have complications like a fever, you will be admitted to the hospital again.

For the Caregiver…

The patient is not the only person who will be spending more time away from home. This is a good time to plan for your absence as well.

- If you need to stay at a hotel while the patient is getting care, your transplant coordinator can help you find a place to stay. See important phone numbers page for Guest Services.
- If you live far away from the hospital, make sure the patient's and your bills and mail are forwarded to the hospital or to a trusted family member.
- Write a list of chores you will need help with while you care for your loved one.

Checklist

- ✓ Make sure your family knows where financial and legal documents are kept.
- ✓ Talk about the benefits of making a Durable Health Care Power of Attorney with a social worker.
- ✓ Provide a medical release granting a caregiver, family member or friend permission to approve medical care for your children in your absence.
- ✓ Ask your coordinator for a verbal release of information form if you wish to allow medical information to be shared with other people.
- ✓ If you have children make sure there are plans for how they will be cared for while you recover. Make plans for how and when they can visit you in the hospital. Keep them informed of plans and changes.
- ✓ Organize how your bills will be paid while you are away. Make sure your health insurance premiums are paid on time, even while you are in the hospital.
- ✓ Write down a list of regular chores you do so that your family is prepared to do those during your absence.
- ✓ Leave a list of numbers that your family can call if they need help fixing things so they do not have to rely on you.
- ✓ Family and friends will want to help. Let them know in advance what would help you, like a meal calendar or yard work.

After about 100 days, most transplant patients can do daily tasks, with only a little bit of help. If you have serious complications, you could need a caregiver to help you for a much longer time. In very rare cases, some patients need nursing home or rehab care.

Preparing Your Children

You will need to help your children prepare for and understand what will happen during your treatment and hospital stay. The process can seem overwhelming but if you take the time to talk with your children it will make it easier. Below are some tips to prepare your children for your treatment.

Talk to your children about what will happen while you are going through your treatment.

- Let them know who will be taking care of them.
- Let them know how you will talk with them while you are away.
- Set up schedules to help organize their day.
- Keep children informed of plans and changes.
- Children can visit you on the inpatient unit, B6/6. They must be updated on their vaccines and have not recently been exposed to chickenpox.

Talk to your children in words they can understand.
Describe why you are going to the hospital and how long you will be away. Use books, photos, or videos. Keep a journal to stay connected throughout the transplant process.

Provide a medical release.
Give the caregiver a medical release that allows them to get medical care for your children in your absence.

Resources
Kids Konnected
http://www.kidskonnected.org provides friendship, understanding, education and support for children who have parents with cancer.

For the Caregiver…
If you have children, you should also talk to them about what is going on and explain why the patient needs you.

You may be asked to care for the patient's pets as well. If you are not able to do this, it is a great time to use a support website.

Pets
As you prepare for transplant, you will need to make plans for your pets. Pet illnesses can be transferred to you as you recover from transplant. All pets should be healthy. Check to see if your pet is missing any vaccines and make sure he is up to date on his checkups. Follow the tips below for the first 6 months after transplant.

If you plan to keep healthy pets in your home as you recover from transplant:

- Reduce contact with pets as much as you can (for example, do not allow pets to sleep with you).
- Use alcohol-based hand gel or antibacterial soap and water after each contact with pets.
- Keep litter boxes in a separate room or area of the house. Even when cats seem healthy, cat feces can carry a disease called toxoplasmosis.
- Do not clean fish tanks, bird cages, or litter boxes. Animal waste can carry disease. Do not touch or dispose of animal waste. Ask a friend or family member to clean the litter box or cage and dispose of waste.

If you are not able to avoid these tasks, be very careful. Wear gloves that you can throw away after each use. Make sure to wash hands with antibacterial soap and water.

Preparing the Home

You will need to have a clean home to return to after your treatment because your immune system will not be normal. To reduce the risk of illness after you come home, your family and friends should follow these steps:

- Vacuum carpets and rugs well. Only very dirty carpets need to be shampooed.
- Change filters in air conditioners and furnaces. You are not required to buy an air filter unit.
- Clean all toilets, showers, counters, sinks, and tubs.
- Make sure rooms are free of mold and mildew. Do not remodel your home now as this can cause mold spores to be released into the air.
- Remove fresh or dried flowers from your home.
- Limit house plants to one room in the house.

Once you are home, follow these guidelines:

- Have someone else vacuum, dust, and clean the bathrooms. If you clean, wear gloves and wash your hands when done.
- Be careful when you handle household trash. Have someone else handle the trash or make sure to wear a mask and gloves.
- No one should smoke in your house.

Guidelines for Visitors

- All visitors must wash their hands.
- Avoid contact with people who are sick.
- When you cannot avoid contact, both you and the sick person should wash your hands often. You may wish to wear a mask.

For the Caregiver…

- Have a sign on the door to remind visitors to wash their hands.
- Screen visitors to be sure that they haven’t been exposed to a cold or the flu.

Guidelines for Children

Teach your children about cleanliness before you return home. They need to know how important it is to reduce your risk of infection and illness. Follow these guidelines:

- Children need to wash their hands often.
- Avoid changing diapers. If you must, wear disposable gloves and a mask.
- If a child is ill, arrange for someone else to care for them. Avoid contact with the child as much as you can. The child should wear a mask if they can.
- Household members should have current vaccines. This will prevent illness and reduce your risk of getting sick.
- No one in your home should receive live vaccines during the first year after your transplant.

Patients who are recovering from transplant should **not** have:

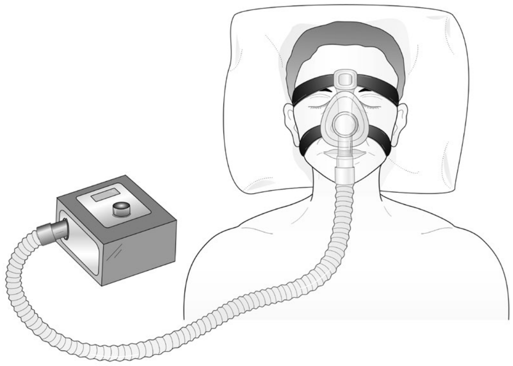
- Young pets (pets that are less than 6 months old).
- Stray animals.
- Unhealthy pets, or pets without current vaccines.
- Reptiles (snakes, lizards, turtles, iguanas).
- Ducklings and chicks.
- Exotic pets like monkeys.

Cleaning Your CPAP/BIPAP

You must clean your mask, headgear, and tubing of your CPAP/BIPAP machine often to protect yourself and your device.

When you use your CPAP/BIPAP, moist, exhaled air goes back into the mask, tubing and machine. If you do not clean your equipment it could begin to grow bacteria. This may cause your equipment to smell and breakdown. To prevent these problems:

- Rinse the equipment with water and allow it to dry.
- Make sure that standing water drips out of the tubing.
- Replace supplies yearly or sooner.
- Replace filters monthly. Replace your filter more often if you live in a dusty area.
- Check the manual for your home device before using any products for cleaning. You can also call your home medical equipment provider for cleaning instructions.



UW Health Services

Nutrition
Registered Dietitians can help you recover after your transplant. If you would like to set up a meeting, please call **608-265-1700**, or ask clinic staff.

Social Work
You will meet with a transplant social worker before transplant to talk about your needs. This meeting will last about an hour. You can request to speak with a social worker any point before, during or after the transplant. Call Social Work at **608-262-7894**.

Social workers can help with:

- Making referrals for disability
- Insurance
- Financial needs
- Grants
- Advance care planning
- Emotional needs
- Travel, lodging
- Understanding benefits
- FMLA
- Going back to work after transplant
- Alcohol and drug addiction
- Caregiver support
- Peer-to-peer support and other problems or needs

UWCCC/American Cancer Society Navigator
They provide a link between cancer survivors and resources in the area. They can help with travel, lodging, and other programs. Call **(608) 266-6025** or **1-800-ACS-2345**.

UW Carbone Cancer Center Health Psychology Service
Our staff is trained to help cancer patients. Most transplant patients will meet with them as part of the pre-transplant visit. You will discuss many aspects of the transplant journey. Extra sessions are based on your needs and are offered both during your inpatient stay and after transplant. Please call **608-265-1700** for an appointment or ask your doctor. This service can:

- Help you cope with and adjust to your disease, treatment, and recovery.
- Assess and treat issues like anxiety and depression.
- Teach you (non-medicine) ways to cope with trouble sleeping, fatigue, and pain.
- Improve your health habits.
- Improve how you talk with loved ones or your health care team.
- Teach you ways to deal with stress and help you relax.
- Help you figure out tough decisions

Spiritual Care Services
They offer spiritual and emotional support for patients with cancer. Talk to your nurse if you would like to meet with a chaplain.

For the Caregiver…
The patient is not the only one who may need support. The counseling groups at the hospital and online resources are open to caregivers as well.

UW Integrative Health
They help remove barriers that may be blocking your ability to heal. To find out more about programs and fees, call
(608) 262-9355.

Below are safe options you can add to help manage symptoms.

- **Inpatient Services** includes healing touch, massage therapy and acupuncture. These can help you deal with many issues that patients have during a hospital stay like pain, anxiety, nausea and trouble sleeping. There may be a fee for service.
- **Healing Touch** is a non-invasive therapy that may help calm you and improve your sense of well-being.
- **Massage therapy and bodywork** can reduce stress, increase blood flow, relieve muscle tension and chronic pain.
- **Mindfulness-Based Stress Reduction** teaches you ways to meditate to reduce stress and gain greater balance, control and fuller participation in your life.
- **Acupuncture** may help with many acute and chronic illnesses. It promotes the natural healing process of the body to restore health and healing.
- **Feldenkrais® Method** may increase your ease and range of motion.
- **Integrative Health Physician consults** are done by doctors who are trained to use both traditional and complementary techniques to promote health and healing. Your consult will allow us to find the best treatment options for you.

Local Places and Resources

Gilda's Club Madison
www.gildasclubmadison.org
7909 UW Health Court, Middleton, WI
53562 Phone: **(608) 828-8880**
Email: info@gildasclubmadison.org
Gilda's Club Madison offers **free** support for everyone touched by cancer—men, women, teens and children—along with their families and friends. Their program is a great resource. It provides support groups, workshops, education, social activities and ways to connect with others.

UW Health Blood and Bone Marrow Transplant Support Group meets the third Wednesday of each month from 2:30 - 4:30 pm at Gilda's Club, 7909 UW Health Court, Middleton, WI 53562. There is no fee to attend. We invite all patients or caregivers as they think about, recover from or live with transplant. This is a way to meet with others, share resources, learn together and offer support during your journey. To find out more contact Gilda's Club.

Look Good… Feel Better
lookgoodfeelbetter.org
This is a free service. It teaches beauty techniques to cancer patients to help them deal with the side effects of cancer treatment. Women learn about makeup techniques, skincare, nail care, and hairless options. They meet at the UWCCC and at Gilda's Club in Middleton. Each group program member receives a free makeup kit. Call **608-266-6025** for the UWCCC Navigator. If calling long distance, **1-800-ACS-2345** and ask for your Regional Navigator.

LiveStrong at the YMCA

LiveStrong partners with the YMCA to help meet the physical needs of cancer survivors. They offer free training. You are given access to trainers for a free 12-week small group program. Call your local YMCA to see if they offer this program.

Connecting with Others Resources

Connecting with others can help you remain hopeful and positive while you recover. Also, you will learn helpful tips about the recovery process. It is also a good way to find support and a shoulder to lean on. These tools have helped many patients and caregivers find support and given them chances to unite with stem cell transplant survivors.

BMT InfoNet

BMTinfonet.org

Whether you are just starting the transplant journey or learning to manage being a survivor, BMT InfoNet is here to help.

Caring Connections Program

Survivors and their family members provide support to others facing a transplant. For patients, it can help to talk with others who have been through this process and know how you feel. They can, provide information and support and can offer tips for coping. If you are a family member of a patient, or a donor, you can use this program to find others like you. To request a link with a survivor, family member or donor, simply fill out the form on their web site http://www.bmtinfonet.org/services/support or call **888-597-7674**.

National Marrow Donor Program

bethematch.org

This program, also known as “Be the Match,” provides information about stem cell transplant. It also includes survivor stories and tips to prepare for a stem cell transplant. Be the Match is also on Facebook.

Peer Connect Program Through Be The Match

If you have questions about transplant and would like to talk with someone who has been there, the Peer Connect program can help. They will connect you with other transplant recipients or caregivers to answer your questions and share their own transplant stories. This program is for both transplant patients and caregivers.

Survivorship Chats

Be The Match hosts monthly "Survivorship Chats" for those who are post-transplant. These are telephone support groups. Each month there is a new topic. If you would like to join, call the Patient Support Center at **1-888-999-6743** or by email patientinfo@nmdp.org.

Leukemia and Lymphoma Society (LLS)

www.lls.org

LLS provides free information and support.

For the Caregiver…

Support is just as vital as it is for the patient. If you are fatigued, these support services can help. It is vital for the patient’s health that you stay healthy as well.

CancerCare
cancercare.org
They provide free support and information to help people manage cancer. It offers counseling and support groups over the phone, online and in-person. They also offer workshops, and financial help. Visit them online or call **(800) 813-4673**.

Cancer and Careers
cancerandcareers.org
This is for employees with cancer and their healthcare providers and coworkers. They provide expert advice, helpful tools and education. Through their website you can access free career coaching, resume review and other tools.

Resources to Share Information or Coordinate Care

Caring Bridge
www.caringbridge.org
You can create a secure website to connect with people **you choose**, to keep them informed about your progress and also your needs. You can journal your transplant journey, get guestbook messages from your circle of friends, receive e-cards and more.

Lotsa Helping Hands
www.lotsahelpinghands.com
This helps caregivers plan care in a private and secure website. Through a simple website, friends and family can view and sign up for tasks, review their current tasks and receive email reminders of duties.

Share the Care
www.sharethecare.org
This is a website that you can use to form a group to care for someone who is very ill. It can help you create a unique caregiver "family" from friends, relatives, neighbors, co-workers, and other people you know.

MyLifeline.org
This website was created by and for cancer survivors. It is your one-stop-shop for blogging, creating a "helping calendar," personal fundraising and more. Make it public or invite only who you would like to be able to view your page.

Imerman Angels
imermanangels.org
This website provides peer-to-peer support for cancer patients and caregivers. Matches are made based on type of cancer and treatment, as well as your life-stage, interests, and roles in life. You can access this free service by going to their website or calling **(877) 274-5529**.

Financial and Legal Resources

Financial Resources

To have a transplant at UW, you must have proof that you can pay hospital and doctor bills. In most cases, health insurance covers the major costs of transplant. You are responsible for your bills.

A stem cell transplant can have many costs that are not covered by your health plan. Some plans do not cover the cost of the donor search or the cost of getting the stem cells. Others have large deductibles or co-pays. Long-term problems like GVHD can add to costs. Some drugs that you need may not be approved by your plan. Other costs might include lost wages, gas, hotel and meal costs, childcare, pet boarding, and more.

Transplant Financial Counselors

Before transplant, the transplant financial counselors, confirm your insurance plan and talk with your case manager. They know about transplant insurance contracts, Medicare, Medicaid and other payors.

Health Insurance Transplant Case Managers

Most group and individual health insurance companies have transplant case managers who know the details about your plan. Your insurance company's customer service office may give you the name and phone number of your transplant case manager. Contact your case manager to discuss questions about your plan and access to services within the plan. Many have rules about where you can and cannot receive care.

The National Marrow Donor Program

www.bethematch.org

This website can help you plan for transplant costs. They have a list of questions to ask your insurer and can help you learn about transplant costs that may not be covered by your plan. There are also helpful tools, like a transplant costs planning worksheet and information about financial assistance.

Legal Resources

The Center for Patient Partnerships at UW-Madison serves patients with life-threatening and serious chronic illnesses and their families. Patient advocates work with clients to help them make more informed decisions, access care, find their way through employment issues, find support, and build their own skills. The center trains professional and graduate students in many fields who will work in or around the health care system. Call **(608)-890-0321**.

The Cancer Legal Resource Center (CLRC) is a joint program of Disability Rights Legal Center and Loyola Law School, Los Angeles. The CLRC can inform and teach you about legal issues through its national telephone help line. When information is easy to access, we believe it improves the patient's quality of life and decreases stress and anxiety. Call **(866) 843-2572**.

Nutrition

Good nutrition before, during, and after transplant can help you heal. It helps:

- Improve how you respond to treatment by helping grow healthy blood stem cells.
- Reduce swelling which impacts GVHD for patients whose cells came from another donor.
- Fight infection.
- Reduce side effects from treatment.
- Fix tissue hurt by treatment.
- Keep up your strength and energy.
- Keep a healthy body weight.
- Prevent muscle loss.

When your immune system is weak, you are at risk of getting sick from foods with bacteria, viruses, and mold. You need to follow special diet guidelines during and after transplant. Follow these guidelines until you no longer take any drugs that suppress your immune system. Avoid drinks with alcohol for at least the first six months after transplant. Talk to your doctor before you start drinking. The harmful effects of alcohol increase after transplant and can be unsafe when used with medicines.

Types of Food	High Risk Foods to Avoid
Meats, Poultry and Seafood	• Raw, dehydrated, or undercooked meat, poultry, fish or shellfish • Refrigerated smoked fish
Milk	• Unpasteurized (raw) milk • **Kefir and yogurt are safe to eat. This includes those with live cultures**
Eggs	• Foods with raw or undercooked eggs like homemade Caesar salad dressing, homemade raw cookie dough, and homemade eggnog
Fruits/Vegetables	• Unwashed fruits and vegetables • Fresh produce that cannot be cleaned well like strawberries, blueberries, grapes, blackberries and raspberries • Non-pasteurized fruit and vegetable juice • Raw sprouts (alfalfa, bean or other sprouts) • Fresh mushrooms • **Packaged, frozen fruits and vegetables are safe to eat**
Cheese	• Soft cheeses made from unpasteurized (raw) milk like feta, brie, camembert, blue-veined, queso fresco • **These cheeses are safe to eat if cooked**
Hot Dogs and Deli Meats	• Hot dogs, deli meats, and luncheon meats that have not been reheated to steaming hot or 165°F
Other	• Unpasteurized pâtés or meat spreads, raw honey
Drinks/Water	• Sun tea • Homemade Kombucha • Well water • Water from lakes, rivers, streams, or springs

You can find out more online at https://www.foodsafety.gov/. Here are food safety guidelines:

- Follow good food safety habits. Wash hands, utensils and your work surface often.
- Cook meats to the right temperature.
- Avoid foods from delis, buffets, salad bars, bulk food bins and free food samples.
- Do not buy opened or damaged packaged foods, expired foods, or canned foods that are rusted, bulging or dented.
- Choose produce that looks and smells fresh and are free of bruises and damaged skins.
- To clean fresh produce, run under cold water or let soak in a basin of water and then dry off with a clean towel. Do not use soaps.
- Thaw meat, fish, and poultry in the fridge or microwave, not on the counter.
- When in doubt, throw it out.
- Keep cold foods cold and hot foods hot.

When you are in the hospital, you may find it hard to eat. You may have side effects like nausea, vomiting, diarrhea, poor appetite, taste changes and sore mouth or throat. A registered dietitian can help you meet your nutrition goals any day of the week. You can ask your doctor or nurse for a consult.

After discharge, a registered dietitian can still help you as you recover. Ask clinic staff to make an appointment for you or call **(608) 265-1700**. There is no extra cost for this service.

Physical Activity and Exercise

Before Your Transplant

For most people with cancer, it helps to stay active. It can make you feel better and help you:

- Improve your quality of life.
- Increase your sense of control and well-being.
- Decrease your fatigue.
- Increase energy.
- Depend less on others.
- Gain muscle strength and range of motion.
- Reduce your risk of blood clots.
- Improve your social life.

How much you can stay active before, during and after treatment varies. If you are active now, stay that way. Treatment can affect energy and muscle function and increase the need for fluids and rest. Those who stay active may find that they need to adjust their routine during treatment. If you are not active it is a great time start! Walking is a great way to stay active.

During Your Stay

Rehab staff will work closely with your health care team to provide the best results. Their focus is to restore function to the highest level.

Physical therapists work on walking, balance, strength and other movements. They decide if you will need any tools to help you with walking or moving.

Occupational therapists work with arm function, daily living and self-care skills. They will figure out if you will need any tools to help you in your daily routine. Rehab improves pain, function, and quality of life.

For the Caregiver…

- Get the patient to walk at least three times daily.
- Help the patient use their assist device (if needed).
- Have the patient **slowly** increase their activity level.
- You may have to be with the patient 24/7 until they are stronger.

Activity Level and Blood Counts

Patients with **low platelet counts** should avoid heavy weight training and activities that are hard on the joints. Low impact exercise is okay, if cleared by your doctor.

Patients with **low RBC** counts can have increased fatigue. Your resting heart rate may be higher, and you may need to adjust your level of activity. Your rehab therapist can suggest a program that is right for you.

Getting Ready for Discharge

Your blood count may have improved, but will not be normal for a while. Once you get home make sure you adjust your activity level.

Fatigue is common and you may need to adjust your activities for a while. There are some steps you can take to help.

- Get good rest.
- Keep active. If you are active each day, it can increase your strength and help you sleep better.
- Understand how and when fatigue affects you.
- Plan ahead. You may not have the energy to do things you want.
- Let your friends and family help you.

Emotional Health After Transplant

Fighting a severe illness is hard on all involved. Stress from your illness and treatment, as well as many other factors can impact your mood. Getting help can improve the recovery process. Transplant patients sometimes refer to their lives after treatment as “the new normal.”

Emotional Well-Being and Common Feelings
Some of the changes you may feel are discussed below. You may feel all or none of these. Each person reacts differently.

Fatigue is common after transplant. Most survivors feel weak, tired, or slow. Fatigue is not the same as feeling tired. It is not caused by too much activity, but from your treatment. It can also be caused by stress.

Depression is more than just feeling sad or “down.” Many symptoms of depression overlap with the side effects of your transplant. Talk to your doctor or cancer psychologist about any long-lasting mood changes.

Guilt or shame about asking for help. You may also feel bad about having fewer problems than other transplant families. These are normal feelings.

Fear or anxiety is common. Many patients find themselves asking “what happens next?” and “when will life return to the way it was?” It is common to have a fear that the illness will return or that you’ll have problems. Finding a support group or a therapist to share your feelings with may help.

Changes in sleep pattern is common due to medicine and hospital stays. If it is an ongoing problem, talk to your doctor. The changes can affect your moods.

Trouble with memory, concentration, or planning is common. These changes often do not last and improve as you recover. Please let your health care team know if these problems persist and get in the way of your daily routine.

When to Seek Help
Depression, anxiety, and stress are a normal part of the transplant process. Sometimes these emotions can be hard to manage. They may impact your recovery or quality of life. There are good treatments and support options that can help you manage.

Contact your doctor if the problems below are ongoing, affect your daily life, or are hard to manage on your own.

- Feeling overwhelmed
- Anxiety that is hard to manage
- Insomnia, pain, fatigue, nausea, or vomiting
- Sudden change in mood, memory or concentration
- Have memories of a major trauma earlier in life

For the Caregiver…
Caregivers have the same anxiety and signs of depression as survivors. They are less likely to have their symptoms noticed and addressed. Caregivers should have someone for support. Talk to your own doctor about options to help you cope.

You can see a cancer psychologist throughout the process. Below are some ways they can help you.

- Help you cope with cancer and other long-term illnesses.
- Check and treat issues such as anxiety and depression.
- Improve how you talk with loved ones and your health care team.
- Provide stress management and relaxation techniques.
- Help make hard decisions.
- Help you adjust to a new diagnosis, treatment, or survivorship.
- Teach behavior treatments for insomnia, pain, and nausea.

After 100 days post-transplant many patients won't have to come back as often. While your life may be slowly getting back to normal, you and your caregiver may still need more support. Your cancer psychologist can help you find more support options and can refer you to a mental health clinic near you.

Fatigue

Chronic fatigue is the most common side effect. Tips for dealing with fatigue include getting extra rest but also keeping active so that you can build strength. Take time to relax when you need it but push yourself to stay active as much as you can.

Memory and Concentration Changes

Some patients have problems with short term memory or focusing. Most survivors find ways to adjust to these changes. They may make lists or put reminder notes where they need them. It can help to repeat things that you want to remember, like names.

Sometimes transplant can change the way you process information. Memory lapses, poor concentration, or trouble multi-tasking affect some transplant patients. If you have these issues there are things you can do to help. In most cases, these problems resolve or decrease over time. Speech-language pathologists can help you improve this process.

For the Caregiver…

Often the patient is the last to notice the difference between normal cancer stress and the onset of clinical depression. You can help by noting changes in feelings and behavior.

Be sure that you take care of **your own** health as well. Find someone who can listen to and support you.

The Hospital Stay During Transplant

The Unit

The Stem Cell Transplant Unit is B6/6, on the 6th floor. You could be here as little as a few days to as long as a month or more.

Items to Bring

The hospital rooms are small. You need to keep your room free of clutter, so nurses can safely care for you and housekeeping can clean. Please **do not** bring pillows, blankets, stuffed animals, plants or silk flowers. These items can carry germs back home that can cause infection and make you sick. Your nurse will give you a toothbrush, toothpaste, shampoo, soap and skin lotion. During your treatment, do not use aftershave, deodorant, perfume, tampons, contact lenses, toothpicks, or bladed razors. You will need to remove any earrings, nose rings, or other body jewelry. Do not get any tattoos during the pre-transplant phase.

Here are some items to bring:

- Loose fitting, comfortable clothes
- Shoes for walking in the halls
- A list of your current medicines
- Pictures, posters, and other small items to make your room cozy
- CD player, iPod, or laptop computer and chargers
- Something to read
- Cell phone and charger; you will only be able to make local calls from your room phone
- Leave all jewelry at home
- Snacks and nutrition supplements that will not spoil

For the Caregiver…

If you need to stay overnight, call **608-263-0315** to find a hotel at a discount. We do not encourage the caregiver to stay overnight in the patient's room due to the size of the rooms and risk of infection.

Please do not bring pillows, blankets, stuffed animals, plants, or silk flowers to the patient's room. Talk to the nurses about bringing in outside food and proper storage.

Each patient is assigned a nurse. The nurse is a great resource for any questions or concerns you may have.

Your Room

All rooms on this unit are private and have a TV/DVD player. The air in the B6/6 unit is HEPA filtered. There are phones in each patient room. Local calls are free. You will need to use your own cell phone or a calling card to make long distance calls.

A few days before your transplant, you will have a sign (like the one on the next page) placed outside your door listing guidelines for visitors. These guidelines help protect you when your immune system is weakened.

You will have to wear a mask each time you exit your room to protect you from things in the air that may harm you. Family and friends can visit if they are healthy. They cannot bring in flowers or items that cannot be cleaned. Visitors **cannot** use your bathroom or sit on your bed.

Good handwashing is one of the best ways to reduce the risk of infection.

PROTECTIVE PRECAUTIONS

VISITORS: Report to nurse's station before entering.

ILL visitors not permitted to visit the patient.

Wash hands or sanitize with alcohol hand gel upon entry.

Healthcare providers must wear gloves upon entry.

Protective Environment Room with positive-flow ventilation required. Door must remain closed.

Plants and flowers prohibited.

Patient must wear a properly fitting filtration mask when leaving the protective environment.

The Staff
You will be assigned one nurse who will function as your "primary nurse." The nurse is a great resource for you and your loved ones. We try to assign a nurse to you who knows you. You will also have a nursing assistant to help you with daily cares like washing, going for walks, and ordering meals. **B6/6 nurses station phone number is 608-263-8196.**

Protecting Your Privacy
When you come for your stay, we will give you a code number to share with family or friends who you want to be able get updates about you and your health. To protect your privacy, callers who ask to speak with your nurse will need to provide the code number.

For the Caregiver…
UW Health supports a patient and family-centered approach to care. If the nurse and the patient approve, you can come to the hospital at any time. Make sure you balance your time with the patient and make time to care for yourself as well.

Visitors
Visiting Hours are 8:00am – 9:00pm. **All** visitors must be healthy. Even colds and minor illnesses can be very harmful for transplant patients. **All** visitors must wash their hands well at sinks in the B6/6 hallway before visiting the patient. Children can visit but need to be healthy and up-to-date on their vaccines. Children with colds or other minor illness should not visit. They cannot visit if they just had a live vaccine injection, chicken pox or have been exposed to chicken pox. Children younger than 16 must come with an adult. They cannot be left alone on the unit.

The patient may choose a few primary support persons who can visit anytime the patient wishes. Those who will be staying after 9:00 pm must have after-hours badges. Visitors must request an after-hours badge at the B6/6 nursing unit desk.

Patient Letters
You can send letters to:

Patient's name
B6/6
University of Wisconsin Hospital & Clinics
600 Highland Avenue
Madison, WI 53792-6718

Internet Access

You can get free Wi-Fi access in the hospital. To use, select the "Free WiFi UWHealth" network on your device. Users who need help may call the Help Desk at **265-7777**.

Care pages are free, private patient web pages that help families share updates, and provide support. Go to www.uwhealth.org and click on Care Pages.

There is a computer you can use in a private lounge. You may use this computer to update your friends and family.

Housing

The information desk inside the hospital entrance can help with housing. Stop by or call **608-263-0315.** Patients who live far away may need to stay nearby after discharge. Staff at the desk can help you or your family get a reduced rate at local hotels. Some health insurance plans may cover the cost of a hotel. Medicare and Medicaid do not. Talk to your social worker if you cannot afford a hotel.

You may also stay at the Restoring Hope Transplant House (RHTH). This house provides a room for transplant patients and their families. Rates are very cheap. Contact the housing desk at **608-263-0315** if you want to stay here. To learn more about this house, see www.restoringhope.org.

Parking

You will be given one free parking pass. It can be used by a family member or a friend for the entire time you are in the hospital. Pick it up from the Admissions desk, inside the Hospital entrance. They must be renewed every seven days. Other visitors can park in the ramp and will need to pay the hourly parking fee.

Lounge

There are small lounges at the end of the hallways. In the lounges, you may find a television, DVD player, microwave, fridge, exercise bike, vending machine and game cupboard. Your family and friends may use any of these items. You can bring DVDs from home or borrow them from the nursing unit.

Daily Activities in the Hospital

The things listed below are the daily routines that you can expect during your stay. These things are done to ensure your safety during your stay.

Transplant Team Rounds

The transplant team will come to your room each morning to see how you are feeling. They will discuss and explain any changes in your care plan. This is a chance for you or your caregiver to ask questions and express concerns.

Blood Tests

Blood tests are drawn most days.

Weight

You will be weighed daily.

Vital Signs and Health Assessment

You will have your vital signs taken often. A nurse will listen to your lungs, heart, and bowel sounds. The nurse will also look for any swelling in your hands or feet, look over your skin and check the inside of your mouth with a flashlight. You may have other tests if you are having complications. Your nurse will keep you informed about new tests or procedures that your doctor has ordered for you.

Showers

You must take a shower every day to reduce the risk of infection and to help you stay healthy. The nurses or nursing assistants will help you cover your PICC line and prepare for showers. Your shower is a vital part of your daily care plan. Your nursing staff will teach you how to use a soap that will help protect you from infection. You will need to use the lotion that is given to you, it works with the soap. This is why we ask you to leave your bathing products at home.

PICC Line Care

You will have a PICC line placed in your arm. The nurse will take care of flushing the lines every day if it is not hooked up to an IV line. If you are hooked up to an IV line, the staff will limit the times you are unhooked from the tubing. This will decrease your risk of infection. The PICC dressing will be changed every 7 days or sooner if the dressing is soiled or comes loose. You and your caregiver will learn how to take care of your catheter before you are discharged. In most cases, the catheter is removed before you go home, so you will likely **not** need to care for the PICC line at home.

Activity

You will need to be up in a chair and walk the halls at least 3-4 times a day. Doing this is crucial to reduce risk of infection and promote healthy recovery. Taking a walk when your room is being cleaned every day is a good idea. You will also see a physical therapist 2-3 times during your stay. Do your best to follow the exercises they give you.

Mouth Care

You will need to take care of your mouth to help prevent infection. Your nurse will instruct you on what to use.

Nutrition

You need good nutrition for your recovery. We offer room service for patients. You may order your meals from a menu from 6:30 am until 9:00 pm. You can also get nutrition supplements, such as Boost®.

For the Caregiver…

Talk with your patient about each other's comfort level with being in the room during the rounds and other daily tasks.

You will need to learn how to care for the patient after discharge. You may need to track medicines, help the patient check for fevers or side effects. You will also need to know about diet and visiting guidelines for home.

Your nurse is a resource to help you learn how to care for the patient after discharge. As the patient's discharge gets closer, the nurse will begin training you and the patient in post-discharge care.

Transplant Conditioning Regimen and Day '0"

Transplant Conditioning Regimen

You will first have an IV or PICC line put into a vein. A PICC is a small flexible tube which can be used for drawing blood and giving medicines. Then you will start the conditioning (also called "preparative") regimen of chemotherapy (chemo). Some patients may also have total body irradiation (TBI) or total nodal irradiation (TNI). These regimens vary, but most often are about 5-7 days long. All are followed by infusion of the donor stem cells. The day of stem cell infusion is "Day 0" and each day after will be day +1, +2, and so on.

Chemotherapy

Chemo will be given into your PICC line. It affects cells that grow quickly, like cancer cells, but it can also affect healthy cells. This treatment may be used alone or with TBI or TNI.

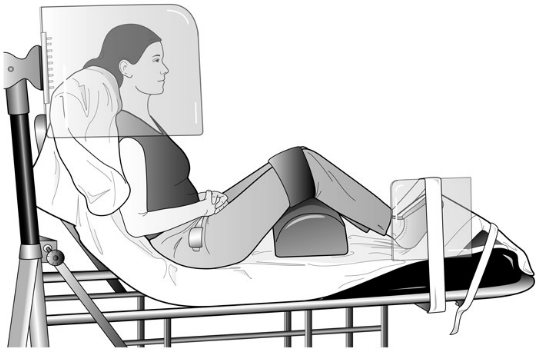
The purpose is to:

- Destroy cancer cells.
- Suppress the immune system to decrease the risk of rejecting the new stem cells.

TBI or TNI (not all patients will have this treatment)

The purpose is to kill cancer cells and suppress your immune system before you receive the stem cells. It can reach areas where chemotherapy does not work very well. You will receive 1-8 treatments.

- Each treatment is done in the Radiotherapy Clinic for about 20 minutes.
- Treatment can be over 1-4 days. Family members or a friend can go with you to this clinic, but cannot go into the treatment room.
- Before each treatment you can receive medicine to prevent nausea.
- Small plastic squares will be taped to different parts of your body to tell the amount of radiation you have received.
- During your treatment you will be in a room by yourself. The technician and the nurse will be in the next room and can see you on a monitor. You will be able to talk to them through an intercom.



TBI Treatment Guidelines

- Keep your skin clean and dry. Wash your skin with mild perfume free soap.
- Use a mild shampoo such as baby shampoo. Avoid blow dryers, hairpins, rollers, or hairspray.
- Follow your mouth care routine as your nurse taught you.
- Do not use powders, perfumes, aftershave, deodorant, or make-up on your skin.
- You can use unscented lotions and creams, but do not apply for at least two hours before your treatment.
- Remove all jewelry, dentures, or any metal objects before each treatment. This includes clothing that contains metal like a bra or jeans.

Transplant: Day ‘0’

The day you receive your stem cell infusion is often called Day ‘0’. Some patients feel anxious or nervous on day ‘0’. For others, it is a happy day. These are normal feelings. Your family and friends can be with you if you want them to.

Day ‘0’ comes about 1-2 days after you complete the conditioning regimen. You may be tired or have other early side effects. If you receive cells from an adult donor, he or she completes their donation either on Day ‘0’ or the day before.

The stem cells arrive in either a blood bag or syringes. The stem cells enter the blood through your IV, much like a blood transfusion, and will float through the blood stream and settle into the bone marrow space inside your bones. The donated cells will begin to grow and produce new red blood cells, white blood cells and platelets.

This process can take a few minutes to a few hours. The time will depend on the type and volume of stem cells. It does not hurt and is much like getting a blood transfusion. A nurse will watch your blood pressure and pulse for any reactions.

Some symptoms you may have during the infusion are listed below. Not all patients have these symptoms.

- Feeling short of breath
- Chest pain or chest heaviness
- Nausea and vomiting

You may receive medicine before the transplant to help prevent these side effects.

Engraftment

This is when the stem cells begin to grow in your body and start making blood cells. It is an important milestone in your progress. This will likely occur 2-3 weeks after the transplant day. Until then, you may receive red blood cell or platelet transfusions. You may also receive growth factors to help cells engraft more quickly. We will take your blood cell count to figure out if your body is making blood cells. Your nurse will keep record of all your counts. Your counts may vary at first, though you may start to show signs of healing, such as healing of mouth sores. You will also gain more energy.

Side Effects of the Conditioning Regimen

Common Side Effects

High doses of chemotherapy and TBI or TNI can cause some short-term side effects like:

- Fatigue
- Mouth sores
- Hair loss
- Nausea, vomiting and lack of appetite
- Diarrhea
- Low blood counts
- Fevers

For the Caregiver…

- Day ‘0’ is an exciting time for you and family members. It is a big milestone.
- Transplant is a new chance at health for the patient and for you and your family.
- If your loved one feels up to having friends and family present, today is a good day to do so.

Side effects can vary from mild to severe and are likely to be more severe if you smoke. A mild side effect could be nausea and diarrhea which often goes away a few days after the chemo is complete. We will offer you anti-nausea and pain medicines to help control symptoms. It is usually not possible to completely get rid of symptoms. You will have low blood counts and need transfusions. Almost all patients have fevers that we treat with IV antibiotics. Some of these side effects can be life threatening, but your transplant team will watch you closely and treat the effects if they occur.

More Serious Side Effects

There is a chance that a high dose of chemotherapy or TBI or TNI can cause severe side effects. Some severe side effects include:

- **SOS or sinusoidal obstruction syndrome** causes the blood vessels in the liver to swell and block the blood flow. As a result, the liver cannot remove waste products from the bloodstream. Symptoms can include pain in your upper right abdomen, weight gain and jaundice. There is no way to prevent SOS, but if you get it, your transplant team will act to ease your symptoms. You may be asked to take a pill called ursodiol to help decrease the risk of SOS.
- **Lung damage** that makes it hard to breathe. Lung damage can range from mild to severe. You might need oxygen or, if it is severe, you might need a ventilator to help you breathe. In some cases, lung damage is long-term.
- **Heart muscle damage** (cardiomyopathy) which makes the heart unable to work well enough to pump blood through your body. This is life-threatening, but it is rare.

Infection

While you are in the hospital, we will take steps to protect you from infections. We will give you antibiotics and closely watch you for signs of infection. If you get an infection, we will treat you with antibiotics through your IV. Common sites for infection include the central venous catheter, blood, lungs, mouth, urinary tract and rectal area.

Washing your hands well is one of the best ways to reduce the risk of infection.

Wash your hands well using soap and water and follow these guidelines:

- Have a dry cloth towel near you before you start. Avoid using damp towels due to germs.
- Wet your hands with water.
- Put soap on your hands. Use liquid soap if you have it. Liquid soaps are better than bar soaps because germs can live on bar soap.
- Rub your hands together for at least 15 seconds. You may say the ABCs or sing “Row, Row, Row Your Boat” to make sure you’ve washed long enough.
- Clean all parts of your hands, fingers, thumbs, nails, and wrists.
- Rinse your hands well to remove soap.
- Dry your hands gently with soft paper towels or a dry cloth towel.
- Use a towel or your elbow to turn off the faucet.

How to Use Alcohol Hand Gels

- Put the alcohol hand gel in the palm of one hand.
- Rub your hands together. Clean all parts of your hands, fingers, thumbs, nails, and wrists.
- Rub your hands until they are dry. It should take 25-30 seconds to dry your hands.

When to Use Alcohol Hand Gels

- Anytime you are cleaning your hands when they don't look dirty.
- Before and after you have contact with someone who is sick.
- After shaking or holding hands.
- After coughing, sneezing, or blowing your nose.

All healthcare staff should gel coming in and gel going out of your room.

Longer Term Complications of Transplant

Infection

While you are in the hospital, we will take steps to protect you from infections. Your risk of infection does not end when you go home. If you get GVHD (see below to find out more), treatment involves taking medicines that weaken the immune system. The more the immune system is weakened, the higher the risk of infection. Some infections can be life threatening.

Your risk of infection from bacteria decreases after engraftment (once the donor's cells start making cells in your bone marrow), but, your immune system will still be weak. It takes many months or longer for it to get better. The time it takes depends upon the type of transplant you had. During this time, you remain at an increased risk for infection. You are at highest risk of infection caused by viruses, fungus and mold. Your doctor will keep you on medicines to try to prevent infections until your immune system has recovered. We will also watch you closely for signs of infection and teach you what symptoms to report to your transplant team. If you are on steroids, like prednisone, it may mask a fever. Please call if you have any concerns of infection, even if you do not have a fever.

Failure to Engraft

In less than 5% of patients, there is a chance that the new stem cells will not grow after they are infused. This is called failure to engraft or "non-engraftment." This can happen for many reasons. We might give you medicines to help make the stem cells grow, but in most cases the only treatment for graft failure is a second transplant using stem cells from the same or a different donor. This may not always be an option. If it is, you should know that having two allogeneic transplants is risky and often does not work. If you have failure to engraft, your transplant doctor will discuss options with you, which may include no further treatment.

Graft Versus Host Disease (GVHD)

In Graft Vs Host Disease (GVHD), some of the donor's stem cells (graft) attack the body of the transplant patient (the host). This is a common problem that can range from mild to serious and can, sometimes, even be life threatening. A "little bit" of GVHD is a good thing because the same cells that attack your body may also attack cancer cells. Patients who get GVHD may be less likely to have a relapse of their disease. Treatment for GVHD involves taking medicines that weaken the immune system. This treatment will put you at a higher risk of getting an infection. Some infections can be life threatening. If you get GVHD, we will talk about treatment options, ways to prevent infections, and how to manage symptoms.

How to Prevent GVHD

There are many factors that impact if you will get GVHD, many that we do not yet understand. There are still ways to try and prevent GVHD.

- **HLA match** – In most cases, a complete HLA match between you and your donor results in the lowest risk of getting GVHD after transplant. There are other factors, like the age of the donor, that also affect the chance of getting GVHD. Your BMT team works very hard to think about all the factors for each donor option to find the best match for you.
- **Medicines** – We will give you medicines to prevent GVHD that weaken the immune system. Please

refer to your consent form to find out which ones you will receive.
- **Preventing Infections** – Getting an infection can lead to GVHD. Your medicines that prevent GHVD also increase your risk of getting infections. We will suggest other medicines and safety measures to decrease your risk.
- **Protection from Sunlight** – the UV rays in sunlight can trigger a reaction in the skin that causes GVHD.

Acute GVHD

Acute GVHD happens most often within the first six months after transplant. It can range from mild to moderate to severe or even untreatable. Symptoms depend on which part of your body it affects and how severe your case is. Acute GVHD can affect the skin, gut or liver.

We will give you medicine to try to prevent acute GVHD for the first months after transplant. Some patients may still get acute GVHD. If you do, your doctor will likely try treatment with steroid medicines first. If steroids do not help, there are other treatments. Sometimes, acute GVHD can be so hard to control that none of the treatments work. Severe, acute GVHD that does not respond to treatment can result in death.

Acute GVHD affects 3 systems.

- **Skin Acute GVHD:** This consists of a rash on your skin. It can start on the palms of the hands or soles of the feet and can spread later to other parts of the body. This can range from a mild rash to a full body rash that can blister, peel and be painful. Treatment may range from steroid creams to systemic steroids or other medicines. It is very important to let your team know right away if you get a rash.
- **Gut Acute GVHD:** This can affect the stomach and intestines. It can cause cramps, diarrhea and nausea. In severe cases, there can be large amounts of diarrhea which can become bloody. Sometimes the symptoms can be controlled with medicines. In severe cases, medicines might be unable to control the symptoms. Let your team know if you have diarrhea. It is helpful to keep track of how many episodes of diarrhea you have each day.
- **Liver Acute GVHD:** Your liver will not function as it should and your doctor will see that in lab test results. You could also have yellow skin and eyes. In severe cases, liver failure can occur.

Chronic Graft vs Host Disease (cGVHD)

Chronic GVHD can begin any time after transplant, but most often begins during or after the third month post transplant. Sometimes patients have their first symptoms of chronic GVHD when they stop medicines to prevent GVHD. If you have acute GVHD, you are more likely to have chronic GVHD. Unlike acute GVHD, which only affects 3 systems, chronic GVHD can affect **any** system in the body. One way it can affect someone is a dry mouth. The dry mouth happens because the donor's immune system destroys part of the salivary gland so it cannot produce enough saliva. Another example of more severe chronic GHVD is joint damage. This could limit range of motion of your joints and may make physical activity harder. Other effects can include severe fatigue or weight changes.

The extent of chronic GVHD and how severe it is varies from patient to patient and can range from mild to life-threatening. It can last from weeks to months to years. Medicines to treat chronic GVHD are often slow to show results. This can frustrate patients. It is important to stick to your treatment plan. Chronic GVHD can start with subtle symptoms. At your clinic appointments after transplant, we will ask you about these symptoms to help us spot it early.

- **Skin**: Is your skin tight or hard, very dry or very itchy? Do you have new rashes or changes in the color of your skin? Are you unable to sweat or unable to keep your body warm? Have you had a recent loss of hair to your scalp or body that is not due to chemotherapy? Are you having nail changes?
- **Joints:** Do you have stiffness in the wrists, fingers or other joints? Do you have pain in the wrists, fingers or other joints?
- **Eyes**: Are your eyes dry, painful, gritty or sensitive to wind or air conditioning?
- **Mouth**: Is your mouth dry, sensitive to hot/cold or strong flavors? Do you have ulcers, sores or taste changes (not due to chemotherapy)? Does food or pills get stuck when you swallow?
- **Lungs**: Are you short of breath at rest? Are you short of breath when you are active? Do you have a cough or wheeze?
- **Females**: Do you have discomfort or pain with sex? Vaginal dryness or itching?
- **Males**: Do you have burning or trouble urinating? Genital pain?
- **Weight**: Any unexplained weight loss? Having trouble gaining weight?

These symptoms do not always mean that you have chronic GVHD, but you should talk about these issues with your doctor or nurse.

Cataracts

You may start to get cataracts about a year after transplant. They are most likely to occur in patients who have had total body irradiation or long use of steroid medicines. If cataracts change your vision, you can have them removed.

Bone Pain

If you have bone pain after transplant, do not ignore it. There are two main causes of bone pain after transplant.

- **Osteoporosis -** Older adults, patients with multiple myeloma, and young women who go through early menopause after transplant are at higher risk for osteoporosis. Bones may become weak due to disease, use of steroids, lack of calcium, or early menopause. Estrogen replacement therapy, calcium supplements, and regular exercise can improve bone density. Your doctor may also suggest other medicines.
- **Avascular Necrosis** -This may be seen in younger patients who have received a lot of steroid medicines. You may have pain in the hips, knees, or shoulders. Often patients say that the pain is worse when sitting, lying down, or being still for a long period. The pain is often less when walking. In severe cases, the patient may need to see a surgeon to discuss hip, knee, or shoulder replacement.

Heart Disease

Chemo and radiation increase the risk of heart disease, unusual heart rhythms and heart attack. The bone marrow transplant process may also result in diabetes and high cholesterol, which can affect your heart health. Have your primary care doctor keep track of your cholesterol and blood sugar levels, as well as your overall heart health.

Cognitive Changes

Many patients say that they have changes in the way they think after transplant. Mental changes may include:

- Memory lapses.
- Poor concentration.
- Stuttering.
- Trouble spelling.
- Not able to perform jobs that they had been able to do before.
- Trouble learning new tasks.

Most survivors find ways to adjust to these changes by making lists and leaving notes around the house to remind them of things that need to be done.

Increased Risk for Other Cancers

Chemo and radiation increase your risk for having other kinds of cancer later in life. These cancers are called "secondary" cancers. People who have had total body irradiation or GVHD are at higher risk. The most common are cancers of the skin and mouth, but other kinds of cancer also occur.

For the Caregiver…

- You may notice symptoms before the patient does.
- It is important for you to talk with the patient about reporting these to the nurse or doctor.
- Delaying reporting of symptoms may make treatments less effective.
- Sometimes the best way to treat these complications is in the hospital.

Staying Healthy

Talk to your doctor to stay current with your health maintenance tests, including cancer screening (high cholesterol screening, colonoscopy, mammogram, etc). There may be reason to delay some of these tests, but in most cases, you can have these tests at the suggested times for you.

You've worked so hard to fight your disease. Keep up with your health prevention and maintenance to make sure your whole body stays as healthy as it can!

Leaving the Hospital

Discharge Day

Discharge day is both exciting and a little overwhelming. A pharmacist will review all your medicines with you, and a nurse will make sure you know any safety measures you need to follow while at home.

Most patients can leave the hospital after transplant when they have met these goals:

- Free of fever and active infection.
- Able to take medicine by mouth.
- Able to eat and drink enough.

If you had a reduced intensity transplant, you could be discharged after chemo and stem cell infusion. Your transplant coordinator and primary nurse can tell you more.

Be sure that your caregiver is present for discharge day to ask questions and take notes.

Wear a mask on the way to your car and each time you come to the clinic. Your doctor or nurse will talk to you about other times to wear a mask. We will give you a supply to take home with you.

For the Caregiver…

- Assign chores to family members so that you can be with the patient on discharge day.
- Talk with the patient about what they want in the house upon their return.
- Talk to your family members and make sure everyone is on the same page. It can be much easier to care for a loved one when there are more hands to help.
- Keep hand sanitizer around the house.

Coming to the BMT Clinic

The best way to manage your health is to come to your clinic appointments. Most patients come to the clinic once or twice a week for 1-3 months after discharge. You should wear a mask each time you come to clinic. You will have labs drawn one or more times weekly. We are looking to see if you need any blood products, IV fluids, or adjustments to your medicine. We will ask you how you are eating and drinking, if you are having regular bowel movements, and if you are sleeping well. We will check your skin for any rashes. Please bring a list of your current medicines with you.

At about Day +90 to Day +100 after transplant, we will schedule you for a complete disease staging. This is to see how well the transplant has worked. You may have a bone marrow biopsy, CT or PET scan, labs and a doctor visit. If you have had lung or heart problems, you could have other tests. If all goes well, you might be scheduled for follow ups at 6, 9 and 12 months post transplant. If you have complications, you will come to the clinic more often. Your doctor will discuss your follow up plan with you.

If you do not live near UW Hospital, we may ask you to stay in a hotel nearby for the first few weeks after discharge. This will allow you to access help more quickly. Based on your recovery, you may be allowed to return home shortly after transplant.

We kept a notebook…and during the course of the chemo and afterwards we would both have questions and write them down. So that when you come in, you can remember to ask the doctor the questions you wanted to ask. It's amazing how things can slip your mind in that clinic visit. – BMT Patient

Staying Healthy After Your Hospital Stay

Signs of Infection

Even when your white blood cells return after transplant, you are still at high risk for infection. Transplant patients are at risk for bacterial, fungal, viral, and parasitic infections. Most transplant patients have a weakened immune system for 6-12 months after transplant. If you are taking steroid medicines or have GVHD, it may be longer. During the first 6-12 months it is very important to follow the directions below.

Tell your doctor about any signs of infection, which often include a fever, redness, swelling, or tenderness. Infections can occur throughout the body but are most common in:

- The lungs
- The urinary tract
- The PICC line site
- The mouth
- On or near the rectum
- The blood
- Any open wounds on your body

Wash your hands often with warm water and soap. You may also use alcohol-based hand gels (such as Purell®). Wash your hands:

- Before preparing or eating food.
- After going to the bathroom.
- After touching plants or dirt.
- After touching animals.
- After touching body fluids or things that might have had contact with human or animal feces.
- After going to public places or crowded areas, such as the grocery store or shopping mall.
- After spending time outdoors.
- After taking out the garbage.
- Before and after touching catheters or wounds.
- After taking off gloves.

For the Caregiver…

- Watch for infection. Signs include rashes, fevers of 100.4°F, or over and sores.
- Make sure you keep a copy of the “When to Call the Doctor” document, at the back of the binder, with you.
- When in doubt, call. The triage nurses can help you and the patient solve problems, stay safe, and decide which symptoms are serious enough to see the doctor.

For the first six months, avoid:

- Close contact with people who have colds and the flu.
- Working in the garden or direct contact with soil and plants.
- Water sources, such as ponds or lakes.
- Dust or airborne particles, such as those present at construction areas or around farms.
- Mowing the lawn, working on the car, and painting.

If you cannot avoid contact with the above, wash or gel your hands often and be sure to cover your mouth and nose with tissues or a mask.

Caring for Your Teeth

- Caring for your teeth is a key way to prevent infections and mouth sores.
- Brush your teeth twice a day with a soft toothbrush.
- Tell your dentist if you have sensitive gums. The dentist can suggest a special toothpaste or toothbrush type.

- Do not floss unless your platelet count is high and your transplant team tells you it is okay. Flossing can increase the risk of infection in your mouth when your immunity is weak.
- Do not eat foods that irritate your mouth.

If you have mouth sores, use a mouth rinse that your doctor suggests. If you have dry mouth, try over the counter dry mouth products and drink water throughout the day. Constant dry mouth can lead to dental problems. Ask your dentist about fluoride treatments or other ways to keep your teeth healthy. It is important to see the dentist every 6 months.

Caring for Your Skin

Your skin may be dry or sensitive. To prevent this, put on lotion that your doctor suggests after you bathe. Your skin may be lighter or darker in patches after your transplant. This is normal and will go away in time. If you see signs of a rash (which can be a sign of GVHD), contact your transplant team.

One of the things that can trigger skin cancer is sun exposure. Because of this, it is very important to stay out of the sun as much as you can. If you are going outside during the day make sure you:

- Wear long pants, long sleeves and a wide brimmed hat that covers your face to protect your skin.
- Try to avoid going outside during the middle of the day when the sun's rays are strongest.
- Use a sunscreen with "broad spectrum" on the label (this means it protects from both UVA and UVB rays). Choose one with a SPF of 30 or higher.
- Apply 1 ounce (2 tablespoons) of sunscreen to your entire body 30 minutes before going outside. Use a lip balm with SPF in it.
- Reapply every two hours or right after swimming or a lot of sweating.

Remember that the sun's rays can affect you whether it is sunny or not, so follow these tips even if it is cloudy.

For the Caregiver…

- Biotene® is a helpful mouth rinse for dry mouth.
- Make sure the patient always has plenty to drink – ice cream and popsicles help.
- Keep sunscreen, wipes, and hand sanitizer handy when you go out.

Vaccines

All patients who have had a transplant should receive vaccines starting about 6 months after transplant. Talk to your Transplant team about your vaccine schedule. Vaccines may be given at UWHC or at your local doctor's office. If a household member needs to receive the polio vaccine within the patient's first year after transplant, they should use the inactivated (Salk) vaccine. Avoid live virus vaccines such as the nasal flu vaccine "FluMist." They carry risks. It may be harmful to get the shingles vaccine, we do not ever suggest it for transplant patients. Not all insurers, such as Medicare, pay for vaccines. You might have to pay out of pocket to be able to receive vaccines.

Nutrition

During and after cancer treatment, you should eat well and fuel your body. Food helps you keep your strength up, maintain your weight, and support your immune system. During your stem cell transplant, you will be at risk for food-borne illnesses. See the nutrition chapter to find out more.

Health Facts for You UWHealth

Vaccines After Bone Marrow Transplant

After your transplant, you will no longer have the immunity from your childhood vaccines. Vaccines lower your chance of getting certain diseases (like cancers, or other health conditions) or there complications. Vaccines work with your body's natural defense system to help you safely gain immunity to disease. For instance:

- Hepatitis B vaccine lowers your risk of liver cancer.
- HPV vaccine lowers your risk of cervical cancer, head and neck cancers.
- Flu vaccine lowers your risk of flu-related heart attacks or other problems.

Vaccines are vital for people who have a weakened immune system, such as after bone marrow transplant.

Vaccination Schedule

You will need to follow a vaccination schedule for getting revaccinated. You will start your vaccines about 6 months after transplant and complete them about 2 years after transplant. Get the vaccines during the time frame listed on your schedule. All BMT patients should follow this schedule to receive their vaccines.

Vaccines

The BMT staff can provide the full vaccination schedule and details to your local health care team.

- **Flu (influenza):** You will need a yearly flu shot as the flu can be deadly for transplant patients. Avoid live flu vaccines.
- **Shingles:** Talk to your BMT team about your safe vaccine options. Avoid the live shingles vaccine.

Live Virus Vaccines

Talk to your BMT team **before** getting any live vaccines, as they may be harmful.

- **MMR vaccine:** Patients with chronic GVHD or patients on medicines to suppress the immune system should **not** get this vaccine. It may be safe for other patients. Please talk with the BMT team for details.
- **Chickenpox vaccine:** The BMT team does not suggest this vaccine, though it may be safe for some patients. Please talk with the BMT team for details.
- Avoid other live virus vaccines like flu mist (live flu vaccine), live shingles vaccine, Sabin oral polio vaccine (OPV), BCG, yellow fever and smallpox as they carry risk for BMT patients.

Insurance Coverage for Vaccines After Transplant

Medicare patients: Medicare **does not** cover vaccines as a part of preventative care (except for yearly flu shots). This means that any vaccines given in-clinic will **not** be covered by Medicare. If Medicare is your **primary** insurer, you should get your vaccines at a retail pharmacy so they are cheaper. The vaccine will be processed through your pharmacy benefit (if you have a supplemental insurance plan). You may still have a co-pay for each vaccine.

Non-medicare patients: Most other insurers view vaccines as preventative. These patients can receive the vaccine in clinic.

Vaccines for Family Members

Members of your household should also be up-to-date on their vaccines. While some vaccines can help to protect you, other vaccines can put you at risk.

- **Flu:** Members of your household should get the flu vaccine yearly. This will help prevent them from spreading the flu.
- **Polio:** Within the first year after your transplant, members of your household should not receive the live vaccine.

Vaccines Family Members Should Avoid

- **Live polio vaccine:** If someone in your household gets the live polio vaccine, avoid close contact for about 2 months. They must practice good personal hygiene to avoid exposing you.
- **Varicella:** If a household member receives the varicella vaccine and then gets lesions, you need to avoid them while the lesions are still present.

To find out more about vaccines and vaccine safety, go to the Center for Disease Control's website at www.cdc.gov/vaccines.

This is only a summary of the vaccines you need. Have your provider ask for the complete UW Health post-transplant vaccine schedule.

Who to Call

Please call with questions.

BMT Clinic
608-265-1700

Table 1- Vaccines for Adults After Transplant

Time After Transplant	6 months	9 months	12 months	2-4 weeks later	14 months	2-4 weeks later	24 months	2-4 weeks later
Diphtheria Tetanus and Pertussis toxoid (DTaP)			X		X		X	
Inactivated poliovirus (IPV)				X		X	X	
Pneumococcal conjugate**	**PCV-13**	**PCV-13**	**PCV-13**		**PCV-13 OR PPSV-23**			
Haemophilus influenzae (HIB)				X		X		X
Hepatitis B				X		X		X
Influenza	X	Then yearly						
MMR (measles, mumps, rubella)								X
Human papillomavirus vaccine (HPV) (Only for those under 45 years old)	X	X	X					
Meningococcal conjugate			X		X			

** PCV-13 should be given for the first three doses of the pneumococcal vaccination series. For patients without GVHD, the fourth dose should be PPSV-23. For patients with GVHD, the fourth dose should be PCV-13.

Pneumococcus booster for patients 65 years of age or older: repeat dose of PPSV-23 5 years after last dose, or 6-12 months after 4th PCV-13 (those with active GVHD) and then 5 years later.

Carbone Cancer Center UNIVERSITY OF WISCONSIN SCHOOL OF MEDICINE AND PUBLIC HEALTH	**Blood and Marrow Transplant (BMT) Clinic** 8:00AM to 4:30PM Monday through Friday: 608-265-1700 or 800-323-8942 - ask for 5-1700 After Hours: 608-262-0486 or 800-323-8942 - ask for the BMT Physician on call

Guidelines for Symptoms
Call 911 for anything worse than what is listed below.

Areas of Concern	**Urgent Medical Help Needed** **Call Now** See Numbers Above	**Important Information for Clinic** **Call Within 24 Hours** See Numbers Above
Alertness, Consciousness, Activity	• New or increased confusion • Change in level of alertness • Change in vision • Falling down • Numbness, tingling in limbs • Dizziness	• Mood changes: irritable, tearful • Sleeplessness • Lethargic • Change in energy level • Tremors/Shakiness • Not able to get around • Problems swallowing
Bleeding	• New or increased bleeding • Bloody urine • Unable to stop nosebleed • Bloody diarrhea • Vomiting blood • Patient falls or is injured • 1 or more feminine pad used per hour	• Frequent controlled nose bleeds • New bruising • Little red or purple spots on the skin
Breathing	• Trouble breathing • Feeling as if they can’t get enough air • Trouble breathing when laying flat • Wheezing with breaths • Persistent continuous cough • Coughing blood or green/yellow material	• Gets “winded” more easily with little activity • New or recurrent cough
Diarrhea	• Constant or uncontrolled diarrhea • Diarrhea with fever and abdominal cramping • Stool is bloody, burgundy, or black	• Mild abdominal cramping • New onset diarrhea • Whole pills passed in stool • Greater than 5 times each day
Fatigue	• Dizziness • Too tired to get out of bed or walk to the bathroom	• Fatigue is getting worse • Staying in bed all day • Other symptoms occur with increased fatigue

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Areas of Concern	**Urgent Medical Help Needed** **Call Now** See Numbers Above	**Important Information for Clinic** **Call Within 24 Hours** See Numbers Above
Fever/Chills	• Shaking chills, temperature may be normal • Temperature 38.2⁰C or 100.4⁰F or above taken by mouth • Fever 1 degree higher than usual	• New redness or swelling on skin or at central line site • Cold symptoms (runny nose, watery eyes, sneezing, coughing) • New abdominal or back pain • Toothache
Mouth Pain/ Mucositis	• Having trouble breathing • Cannot swallow • Bright red blood in mouth • Pain not controlled by medicine	• White patches or sores appear on gums or mouth • Problems swallowing food or fluid
Nausea/ Vomiting	• Uncontrolled, constant nausea/vomiting • Blood or “coffee ground” appearing material in the vomit • Medicine not kept down because of vomiting • Weakness or dizziness along with nausea/vomiting • Severe stomach pain while vomiting	• Nausea persists without control from anti-nausea medicines • Vomit shoots out for a distance (projectile vomiting)
Pain	• New or uncontrolled pain in body • Headaches not relieved with Tylenol® • Chest discomfort • Pounding heart • Heart “flip-flop” feeling • Burning in chest or stomach • Pain or burning while urinating • Strong stomach pain	• Sores or painful areas on skin or mouth • New pains relieved with pain medicines • Painful central line site or area around catheter • Pain with infusion of medicines or fluids into central line
Rash	• Sudden onset body rash • Rash with severe pain	• New, or changes in skin rash
Swelling	• Sudden swelling with or without pain	• Swollen legs, hands • Swelling around central line
Urination	• Unable to urinate for more than 8 hours • Bloody urine • Painful urination	• Strong odor of urine • Change in color of urine

Intimacy and Sexuality

Some people resume having sex soon after transplant. Others find that their sex life has changed a lot. This can be due to fatigue, nausea, or the effects of treatments. Medicines and side effects of treatments may change your body, making you self-conscious. These feelings are normal, and you should be open and honest about your feelings with your partner and healthcare team. Sex is not the only way to be intimate with your partner. You can also try holding hands, cuddling, massage, and kissing.

You may find it hard to talk to your doctor about these issues. Sex is an important part of many patients' overall well-being and recovery. Talk to your doctor about any concerns you may have. Your doctor can help you treat side effects of therapy and the transplant process. They can help you get medicines, exercises, or refer you to sexual health clinicians.

Guidelines for Sex

- Talk to your doctor about your fertility, desire or plan for children, and safe forms of birth control.
- If your platelet count is low discuss your risk of bleeding.
- Practice cleanliness and safe sex with a single healthy partner.
- Avoid sexual contact with someone who has an open sore, wound, cold sore, or herpes outbreak.
- Avoid oral sex and anal sex for the first 6 months.
- Women should empty their bladder after sex to reduce the risk of a urinary tract infection.
- Water-based lubricants can enhance comfort during sex (see next page).

Women

Women may have symptoms of early-onset menopause because of treatments. Symptoms can include hot flashes, vaginal dryness, mood changes, trouble sleeping, weak bones (osteoporosis) and irritability. Ask your doctor if hormone-replacement therapy is an option for you to help offset some of these symptoms.

Make sure you have a gynecologist in your health care team. You should resume routine care with them between 6 months and one year after transplant.

Men

Men with low blood counts may have trouble getting an erection. Talk to your doctor if this is a concern for you. The first few times you ejaculate, you may notice a brown or burnt orange color. This is due to the chemo. You may also notice aching or pain in the testicles. These issues should pass after the first few times you have sex. Please report any brown discharge or pain that does not go away, or trouble getting erections to your healthcare team. If 6 months after transplant, you find your interest in sex is still low or you are having problems with erections again, consult your BMT team or primary care doctor. Your testosterone level may be low. You can have this checked with a blood test and take medicine to increase it.

One resource that you may find helpful is the book titled “Sexuality for the Woman with Cancer and her Partner” and “Sexuality for The Man with Cancer and His Partner.”

If you would like more help, talk to your transplant coordinator, who can provide education and resources:

- Personal lubricants
- Pelvic Floor Health for Men
- Pelvic Floor Health for Women
- Libido
- Healthy Sexuality After Cancer

You can also access these online through A Woman's Touch website at https://sexualityresources.com/

Vaginal Health After Stem Cell Transplant

Some people who have a transplant with cells from another donor get graft versus host disease (GVHD) after stem cell transplant. This can affect many body systems, such as the skin, mouth, and eyes. About 25-50% of women may also get symptoms in the genital area, like vaginal dryness, itching, burning, painful urination, and pain with sex. These symptoms may show up within 7-10 months of the transplant, or may not show for up to 2 years. These allergens and irritants may make symptoms worse:

Allergens

- Benzocaine
- Latex (in condoms or diaphragms
- Ethylene diamine (in neomycin)
- Chlorhexidine (in KY jelly)
- Perfumes
- Propylene glycol or other preservatives
- Tea tree oil
- Imadazole
- Nickel
- Semen
- Disinfectants
- Dyes
- Lanolin

Irritants:

- Soap, bubble bath, shampoo
- Sanitary pads or tampons
- Incontinence pads
- Nylon underwear
- Sweat or urine
- Talcum powder
- Douches
- Spermicide or contraceptive sponges
- Perfumes or deodorants
- Hair conditioner
- Medicines used on the vulva or vagina
- Tea tree oil
- Pinetarsol
- Alcohol
- Methylated spirits
- Chemicals in toilet paper or clothing

Some things we suggest to keep the vagina and vulva healthy:

- Avoid scented soaps, bubble bath, detergents, lotions, powders, baby wipes and douching. Clean with warm water only. There is no need to use soaps or other products.
- Avoid shaving or waxing the vulva. This can make any irritation worse.
- Avoid scrubbing the vulva. This can cause healthy skin to break down.
- Keep the area dry.
- Wear cotton underwear. Non-cotton underwear traps moisture, which can lead to infection.
- Sleep with your underwear off at night. This allows the area to breathe.
- Avoid wearing wet or tight-fitting clothing. Change your workout clothes and swimsuit as soon as you are done with activity.

- After going to the bathroom be sure to wipe front to back. Wiping back to front can bring bacteria from your rectum into the vulva and vagina and lead to infections.
- Avoid wearing panty liners. They create a "wicking" effect, which can take out moisture that you need. If you have a lot of discharge, change your underwear more often.
- Urinate right after sex and when you feel the urge. This will help reduce the number of bacteria in the bladder and help prevent infections.
- Make sure you are drinking enough fluids without caffeine throughout the day.

Vaginal Moisturizers

These are products that you can use on the vulva and vagina the same way you would use lotion on your hands or face. They do not contain hormones and can be used as often as needed. "One Oasis Silk" is a high-quality one that you can get in the oncology pharmacy. Apply to the vulva and vagina gently with a finger. You could also use any other water-based lubricant. "Replens" is a product that is easy to find but may cause a burning feeling for some women.

Sexual Lubricants

Use lubricants that are mostly water-based. Some of the best ones are found online or at "A Woman's Touch" in Madison. "One Oasis Silk" and "Sliquid Organics Silk" are good choices. Avoid ones with colors, flavors, warming ingredients, and spermicides. These can irritate vaginal tissues.

Vaginal Stimulation

If you are able to have sex, you should have sex twice weekly to avoid what is known as "stenosis" or closing of the vagina. If you do not have a partner, or sex causes pain, you could also use a vaginal dilator or a vibrating wand. These products help to keep the tissues open, and to bring blood flow to the area. This keeps the tissues healthy. Always use a good water-based lubricant.

Topical Estrogen

Some women may want to use a form of estrogen that is applied to the vagina. These come in creams, tablets, or a vaginal ring. This may be an option for you if you do not have a history of estrogen-sensitive cancer.

What if you follow all these tips and you still have problems?

Contact your doctor's office right away. The WISH clinic (Women's Integrative Sexual Health) at the UW Hospital can help you.