Health Facts for You

Stem cell transplant – Day 100 and beyond

UWHealth | Carbone Cancer Center

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Welcome to the UW Health Stem Cell Transplant and Cellular Therapy program. Our team takes pride in building a care plan tailored to your needs and your success.

It can be overwhelming to learn about stem cell transplant. Transplant is a process, and your transplant team is here to help you learn along the way.

The names used to refer to a transplant have changed over the years. The names you might hear include bone marrow transplant, stem cell transplant, hemopoietic stem cell transplant, peripheral blood stem cell transplant, and cellular therapy. Cellular therapy is an umbrella term that includes stem cell transplant (SCT) and CAR-T therapy.

The first year after transplant can be tough. You've likely had some problems along the way. We hope you are starting to feel better and are getting stronger.

Recovery from transplant takes time. You may notice a lack of stamina for months after going home. For some people it may take a year or two to fully recover strength and stamina. Part of recovery is learning to trust your body again. It is hard to know which aches, pains, and symptoms are normal, and which ones should be reported to the Stem Cell Transplant (SCT) team. If in doubt, call the SCT team.

Healthy Habits

Exercise
Studies have shown that regular exercise can:

- Help prevent cancer recurrence, new cancers, and other chronic diseases.
- Improve cardiovascular fitness and muscle strength.
- Decrease fatigue, anxiety, and depression.
- Improve memory and brain function.
- Scan the QR code to learn more about the benefits of exercise.

It's best to start slow. Slowly increase the time and intensity of your exercise. Even a small increase of activity can help decrease fatigue and build stamina. This can help you feel better. Ask your team if you have any restrictions on your activity. Let them know if you have any problems or pain with activity.

Fatigue
Fatigue (feeling tired) is common after transplant. It's hard to start exercising when you are feeling tired. Staying inactive will cause you to feel more tired! Studies of cancer patients show that exercise is one of the **best ways** to fight fatigue.

- Occupational therapy can help you make a plan to manage fatigue and conserve energy.
- Ask friends or family to support you in your efforts (or to exercise with you)
- Everyone has lapses due to illness, travel, or other reasons. Be mindful of when a lapse occurs. This is okay. Get back to your routine as soon as you are able. You may find that you need to start slowly if you have not been able to exercise for a while.

Goal Setting
Start by setting small goals, then revise them as you become more active. Choose realistic goals and remember that even a little bit of activity is better than none.

The goal is exercising at least 150 minutes per week (for example 30-minute brisk walk

5 days a week). This will help to keep your whole body healthy. Choose activities that you enjoy and that increase your heart rate and breathing. Include strength-building exercises 2 days per week.

To learn more, review the American Cancer Society Website's Guidelines on activity. Talk to your team if you want a referral to Physical or Occupational Therapy.

Sun Protection
All patients are at a higher risk of getting skin cancer after transplant. For allogeneic patients, **sun exposure can trigger GVHD.**

All patients should follow these tips to protect yourself from the sun:

- **Stay out of the sun**. The sun is strongest between 10 am and 4 pm. Wear clothing that will cover most of your skin. Wear a broad-brimmed hat and UV-blocking sunglasses.
- Use a sunscreen with "broad spectrum" on the label with a SPF of 30 or higher. This protects from both UVA and UVB rays.
    - Apply 1 ounce (2 tablespoons) of sunscreen to your entire body 30 minutes before going outside.
    - Reapply every two hours or right after swimming or a lot of sweating.
    - Use a lip balm with SPF.

For a list of sunscreens, sun protective clothing and other products that have received the Skin Cancer Foundation Seal of Recommendation, go to: https://www.skincancer.org/skin-cancer-prevention/seal-of-recommendation/

Oral and Dental Care
Oral care and routine dental visits are important in your overall health. You should go back to the dentist 6 months to 1-year after transplant to restart routine dental care.

Always bring a current list of all the medicines that you are on. Some transplant medicines have specific oral side effects.

- If you are on a steroid, like prednisone, we recommend that you take an antibiotic 1 hour before for any dental cleanings or dental work.
- Tell your dentist if you have received bisphosphonate therapy (e.g. Zometa, Reclast). These are used to treat multiple myeloma or osteoporosis. This medicine has a risk for jawbone issues if you need to have a tooth removed.

The transplant increases your risk of other cancers. Dentists will screen you at every visit to look for signs of oral cancer.

Tell both your transplant team and your dentist about any problems that occur in your month. Discuss any oral pain, sensitivity, or dry mouth.

Allogeneic patients may be on immune suppressant drugs for some time after transplant. These can make it more likely for problems to develop in your mouth.

Diet
It is important to eat a healthy diet and be at a healthy weight. A healthy, well-balanced diet will help you get the proper nutrition you need for good health. You should avoid restrictive or extreme diets. They can lead to vitamin and mineral deficiencies and malnutrition.

Talk to your dietitian or doctor about any concerns about your health. Discuss any diets with them before trying.

You are less likely to have your cancer come back or develop new cancer if you follow these guidelines:

- 2/3 (or more) of daily foods are vegetables, fruits, whole grains, or beans.
- 1/3 (or less) of daily food is animal protein. Limit red meats and **avoid** cured meats.
- Limit salty foods.
- **Stay away from sugary drinks, high fructose corn syrup and added sugars.**
- If you choose soy foods, eat them in moderation, 3 servings or less per day.

There have been no studies to look if organic produce is better in preventing cancer than non-organic produce. Buy what you like and rinse well.

It is always important to keep food safety in mind.

- **Clean:** Wash your hands (20 seconds with soap and running water) and surfaces often.
- **Separate:** Separate raw meat and poultry from ready-to-eat food.
- **Cook**: Cook food to the right temperature.
- **Chill:** Chill raw meat and poultry, as well as cooked leftovers, right away.

To learn more, check out the American Cancer Society Guidelines on nutrition. You can scan the QR code or visit this link www.foodsafety.gov.

You can also ask your care team to meet with a nutritionist or scan the QR code to visit the UW Health Cancer Center Nutrition Therapy website. https://www.uwhealth.org/treatments/cancer-nutrition

Alcohol

Alcohol increases the risk of cancer. The type of alcohol (wine, beer, or liquor) does not matter. There is no clear evidence that drinking red wine helps to prevent cancer.

You should avoid alcohol to reduce your cancer risk. If you choose to drink alcohol, limit to no more than 1-2 drinks per day.

For more information, visit http://www.cancer.org and search ‘alcohol’.

Tobacco and Nicotine

There are many different types of products that contain tobacco or nicotine **No amount of tobacco use is safe.**

- Smoking harms nearly every organ of the body.
- Cigarette smoking remains the leading cause of preventable disease, disability, and death.
- Vaping oils can cause lung injury and irritation from the chemicals and/or flavorings in the oil.

Quitting is hard. Dependence on tobacco happens because of the addiction to nicotine in the tobacco. Often people need long-term support. There are many over the counter products and prescription options to help you quit. Often, people need try more than one. Talk to your health care team about which quitting aids might work for you.

Marijuana and CBD
Marijuana, CBD and hemp products are unregulated, which can be very dangerous to your health. While legal in some states, in Wisconsin it is an illegal substance.

Marijuana smoke contains many of the same cancer-causing agents as tobacco smoke, often at much higher amounts. They can cause airway swelling, bronchitis and increased airway resistance. They also can cause lung, oropharyngeal, prostate, and cervical cancers.

Cannabidiol (CBD) is a part of marijuana that does not cause a high. There are many products on the market which may be swallowed, inhaled, or rubbed onto the skin. There is no strong evidence to show that it works. We do not recommend that you use CBD to treat or prevent any conditions or diseases. Please talk to your team. We can talk with you about the risks and benefits of CBD products.

Dietary Supplements
Dietary supplement is a general term for products that you can buy online or over the counter (OTC). They include:

- Vitamins (like vitamin D and B12)
- Minerals (like calcium and iron)
- Herbs (like echinacea and garlic)
- Other non-prescription products (like glucosamine, probiotics, and fish oils)

Supplements can come in many different forms. Examples include pills, powders, ointments, drinks, or energy bars. Supplements are not medicines and are not intended to treat, prevent, or cure diseases.

Always let your care team know about any supplements you're taking. We need to make sure they don't interact with the medicines that are taking. Your team may recommend some supplements such as calcium or vitamin D to support bone health.

Supplements do not have to go through FDA testing or approval before they are sold. There is not regulation to make sure they are safe.

Despite this, there are several independent groups that offer quality testing. If a product passes their tests, it displays a seal of quality assurance. This seal means that the product was properly made, contains the ingredients listed on the label, and does not contain harmful levels of contaminants. These seals do not guarantee that a product is safe or effective. Look for these seals:



Autologous patients, skip to page 8

Allogeneic patients only: Chronic Graft vs Host Disease (cGVHD)

As you get farther out from transplant, your risk for developing GVHD decreases. If you had acute GVHD, you are more likely to have chronic GVHD. You may still get chronic GVHD even if you didn't have acute GVHD. Chronic GVHD can occur any time after transplant. Your highest risk of having GVHD is within the first 2 years after transplant.

Like acute GVDH, chronic GVHD happens because the donor's cells don't recognize your cells. The donor cells think your body is foreign and attack it. We don't know why some people get chronic GVHD and others don't.

The difference between acute and chronic GVHD is where it affects you. Chronic GVHD can affect **any** system in the body.

Chronic GVHD can affect the same organs that were affected by acute GVHD (skin, liver, GI). It can also affect the:

- Joints and/or muscles
- Mouth
- Esophagus
- Lungs
- The glands that make saliva
- The glands that make tears
- Genitals

GVHD can range from mild to life-threatening. It can last from weeks to months to years.

Preventing Chronic GVHD:

- **Protect yourself from the sun:** UV rays in sunlight can trigger a reaction in the skin that causes GVHD. Sun protection is most important for the first 2 years, but it is also a good lifelong habit.
- **Preventing infections**: Infections can sometimes trigger GVHD. Getting your post-transplant vaccines, along with your yearly flu and COVID vaccines, are one way to help protect yourself from infections.

There aren't many other ways to prevent chronic GVHD. The best thing that you can do is monitor yourself. Let us know if you notice any changes. Earlier treatment can help minimize the damage that GVHD can cause.

Chronic GVHD Monitoring

Chronic GVHD can start with subtle symptoms. At your clinic visits after transplant, you will be asked about these symptoms. Symptoms do not always mean that you have chronic GVHD. Watch for any of the symptoms listed.

Skin: Look at your skin on a regular basis. Pay close attention to the lower legs and places where there is a lot of friction, such as the waistline or bra line. Talk to your doctor if you notice any of these changes:

- Skin is tight or hard.
- Skin is very dry or very itchy.
- New rashes or changes in the color of your skin. A rash may be hard to see if you have a dark skin tone. A rash may be red, brown, purple, or gray. Let the team know if the skin is swollen, itchy, bumpy or very sensitive.
- You are unable to sweat or unable to keep your body warm.
- Recent loss of hair to your scalp or body that is not due to chemotherapy.
- Changes to your nails.

Eyes: Tell your care team if your eyes are dry, painful, gritty, light sensitive or if you have excess tearing, red, or any changes in vision. You should have an eye exam every 3-12 months, depending on your symptoms.

Mouth: Be aware of any changes in your mouth. Tell your care team if:

- Your mouth is dry, sensitive to hot/cold or strong flavors.
- You have ulcers, sores or taste changes (not due to chemotherapy).
- Food or pills get stuck when you swallow.

Lungs: You will have frequent pulmonary function tests (PFTs) after transplant to screen your lungs for changes. Tell your care team if you:

- Are you short of breath at rest.
- Are short of breath when you are active.
- Have a cough or wheeze.

Body: Do you have new swelling to your arms or legs? Muscle cramping or pain? Loss of flexibility? Skin/muscle/joint tightness?

Genitals: You should monitor your genital area. Tell your care team if you have:

- Pain with sex.
- Vaginal dryness or itching.
- Burning or trouble urinating.
- Genital pain.

Weight: You should weigh yourself on a regular basis and monitor for any changes. Tell your care team if you have:

- Any unexplained weight loss.
- Trouble gaining weight.

Joints: It's also important to monitor your range of motion to your joints. Let us know if you have any tightness or pain in your skin, muscles, or joint.

Let your care team know if you're noticing:

- Your range of motion is getting worse.
- Pain or tightness at the end of your range of motion.

Some people will notice a change to their hip range of motion or ability to squat. The best way to test your hip flexibility is to stand. Hold onto a counter, table or chair to steady your balance. Lift a knee up. If you notice changes or weakness to your hips, let your team know.

Chronic GVHD Treatment

Where your GVHD occurs and how bad it is will help your team decide what treatment you need. GVHD treatment may range from steroid creams, oral steroids, or other medicines. Treating GVHD involves taking medicines that weaken the immune system. This treatment will put you at a higher risk of getting an infection. Some could be life threatening.

Treatment starts with steroids for most people (see acute GVHD section in the 0 to Day 100 booklet to learn more). Non-steroid medicines to treat GVHD are often slow to show results. This can be frustrating. It is important to stick to your treatment plan.

The first goal of treatment is to control the symptoms. Another goal is to prevent long-term damage that can result from GVHD. Your doctor will decide which medicines and dosages are right for you. Your doses of will be slowly decreased over time. This allows the new immune system time to adjust at its own pace.

Sometimes we need to increase the doses or to change medicines. GVHD can come back if treatment is stopped too soon. Half of patients can complete their treatment within two to four years after starting. In other patients, it takes longer to complete the treatment.

Emotional Health After Transplant

Getting through treatment for a severe illness is hard on everyone involved. Stress from your illness and treatment can impact your mood. Each person reacts differently. There is no magic formula for dealing with these wide range of emotions. Try to recognize these emotions and talk to your family, friends, or care team. Getting emotional support can help with your recovery and healing. Emotional recovery from transplant is a slow process that takes time.

Fatigue: Most survivors feel weak, tired, or slow. Fatigue is not the same as feeling tired. It is caused by your treatment or stress, not from a lot of activity.

Balance extra rest with keeping active so that you can build strength. It's important to take time to relax when you need it but also push yourself to stay active as much as you can.

Depression: This 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: Some patients may feel guilty if they have fewer problems than other transplant families. These are normal feelings.

Fear or anxiety: 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 may help.

It is common to have anxiety about a relapse. The anxiety seems to be worse just before and during follow-up visits.

Changes in sleep patterns: Changes can happen from medicine and being in the hospital. If it is an ongoing problem, talk to your doctor. Poor sleep can affect your mood.

Trouble with memory, concentration, or planning: These changes often do not last and improve as you recover.

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. Let your team know if depression, anxiety and/or stress affect your daily life. Seeing a counselor or cancer psychologist may help. Check with your insurance to see what mental health services are covered.

While your life may be slowly getting back to normal, you and your caregiver may still need more support. Your care team can help you find more support options and can refer you to a mental health clinic near you.
Part of recovery is also learning to trust your body again. It is hard to know which aches, pains, and symptoms are normal. If in doubt, call your care team.

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, sometimes making you self-conscious. These feelings are normal. You should be open and honest about your feelings with your partner and your care 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 team about any concerns you may have. They can:

- Treat side effects of therapy and transplant
- Prescribe medicine
- Teach you exercises
- 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.
- Empty your bladder after sex to reduce the risk of a urinary tract infection.
- Water-based lubricants can enhance comfort during sex.

You can find more resources online through A Woman's Touch website at https://sexualityresources.com/.

Patients Assigned Male at Birth (AMAB)

AMAB 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 chemotherapy.

You may also notice aching or pain in the testicles. These issues should pass after the first few times you have sex.

Report any brown discharge, pain that does not go away, or trouble getting erections to your healthcare team.

Low Testosterone

If after 6 months, your interest in sex is still low or you are having problems with erections again, consult your SCT 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.

Patients Assigned Female at Birth (AFAB)

AFAB may have symptoms of early-onset menopause because of treatments. Symptoms can include:

- Hot flashes
- Vaginal dryness
- Mood changes
- Trouble sleeping
- Weak bones (osteoporosis)
- Irritability

Ask your doctor if hormone-replacement therapy is an option for you, to help offset some of these symptoms.

Vaginal Health
Hormone changes and/or chronic GVHD can affect the genitals and cause vaginal dryness, itching, burning, painful urination, and pain with sex. Let your care team know if you are having those symptoms.

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

Allergens and Irritants
The allergens and irritants listed below can cause symptoms or make GVHD symptoms worse. **Avoid** these ingredients.

Allergens	**Irritants**
Benzocaine	Alcohol
Chlorhexidine (in KY jelly)	Chemicals in toilet paper or clothing
Disinfectants	Douches
Ethylene diamine (in neomycin)	Medicines used on the vulva or vagina
Imadazole	Methylated spirits
Lanolin	Nylon underwear
Latex (in condoms or diaphragms)	Pinetarsol
Nickel	Sanitary pads, incontinence pads or tampons
Propylene glycol or other preservatives	Spermicide or contraceptive sponges
Semen	Soap, bubble bath, shampoo, hair conditioner
	Sweat or urine
	Talcum powder
Perfumes, dyes or deodorants	
Tea tree oil	

Healthy Habits
Good habits to keep the vagina and vulva healthy:

- **Avoid** scented soaps, bubble bath, detergents, lotions, powders, baby wipes and douching.
- **Clean with warm water only.** You do not 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 to allow 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.
- Wipe front to back when going to the bathroom. 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.
- Drink plenty of fluids (without caffeine) throughout the day.

Vaginal Moisturizers
These are products that you can use on the vulva and vagina. 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. Use the same way you would use lotion on your hands or face. You could also use any other water-based lubricant. “Replens” is a product that is easy to find but can cause a burning feeling.

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
It’s important to keep your vagina stimulated. Doing so helps you to avoid stenosis. Stenosis is when your vagina closes due to lack of stimulation.

If you can, try to have sex twice weekly to **avoid** stenosis.

Some patients don’t have sex or find sex to be painful. A vaginal dilator or a vibrating wand also works. These products help to keep the tissues open and bring blood flow to the area. This keeps the tissues healthy. Always use a good water-based lubricant with these.

Topical Estrogen
Some 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.

Let your SCT team know if none of these options work, they will refer you to the WISH clinic (Women’s Integrative Sexual Health) at University Hospital.

Returning to Work or School

The timeframe that you can safely return to work varies greatly. It may take up to a year or longer for your immune system to become normal. The decision to return to school or to full-time work depends upon your immune function, medical status, and the nature of your work.

Some patients return to work about 6 to 12 months after a transplant. This timing can depend on your transplant course and the job that you have.

For others, we may recommend waiting longer. These cases may include:

- Those treated for GVHD
- Those in different fields of work such as
    - Farming
    - Ranching
    - Jobs where you are exposed to chemicals or micro-organisms.

It’s important to talk over your work plans with your transplant team early. Discuss this before you make any work commitments.

In some cases, it may not be safe for you to go back to the same job you had pre-transplant. If so, we may recommend you find another type of job. Your social worker can talk to you about job re-training programs.

If you have been getting SSDI benefits, contact the Social Security Administration before you return to work. If you are thinking of going back to work, look into the ticket to work program. https://choosework.ssa.gov/about/how-it-works/

Vaccines After Stem Cell Transplant

During the SCT therapy process, you will lose the cells involved with immune memory. This means that you will no longer have the immunity from your childhood vaccines. In the US, vaccines have reduced or gotten rid of many diseases. The viruses and bacteria that cause these diseases still exist and you can still get them if you are not vaccinated. Vaccines are very important, especially for people who have a weakened immune system. Getting vaccines will help you prevent getting and spreading infections.

We strongly recommend you get a yearly flu shot and the COVID series and boosters. Getting these vaccines can greatly decrease your risk of severe illness or death.

You will start your vaccines about 3 to 6 months after transplant and continue until about 2 years after. A schedule of vaccines is located at the end of this booklet.

Some patients do not make enough antibodies after getting a vaccine after transplant. A lab that can measure how well you responded to a vaccine is called a titer. If the titer is low for a vaccine, you may need a booster shot.

Vaccine Insurance Coverage

You may be able to get your vaccines closer to home or you may have to receive them at the UW pharmacy. Your insurance will decide where you can get your vaccines. Your team will help you coordinate this.

Scan the QR code or visit patient.uwhealth.org/healthfacts/8186 to review your revaccination plan.

Vaccine Information for Family Members and Household Contacts

Members of your household should be up-to-date on their vaccines. We recommend that **all** household members get the flu vaccine yearly and the COVID vaccine and boosters. These vaccines can greatly decrease your risk for getting a severe illness that can lead to death. If your family or household contacts receive a live vaccine, there may be a small risk to you.

Safety Guidelines

Some of the vaccines listed are safe, while others may pose a danger to you. Follow the guidance listed if your family member receives any of these vaccines.

- **Nasal-spray influenza vaccine (FluMist):** Avoid contact with the person for the first 7 days after they received this vaccine.
- **Smallpox**: This should not be given to someone who has a household member or other close contact with a weakened immune system.
- **Polio vaccine**: Within the patient's first year after cellular therapy, the inactivated vaccine should be used for family members and household contacts.
    - If the oral live vaccine is given, you should avoid close contact between you and this household member for 2 months after. **Avoid** exposure to fecal-oral contamination

by practicing good personal hygiene and hand washing.

- **MMR (measles, mumps and rubella):** The viruses in MMR do not spread from a vaccinated person to others. Close contact is okay. A person who has been vaccinated with the MMR vaccine cannot infect other people, even if they develop a rash after getting the vaccine.
- **Varicella:** If the vaccine recipient gets a rash or lesions, **avoid** direct contact with the cellular therapy recipient until the rash is gone.
- **Rotavirus: Avoid** changing diapers for 4 weeks after the child has received the vaccine. Household members should wash their hands after changing diapers of an infant who has received rotavirus vaccine.

Allogeneic patients only: Connecting with Your Unrelated Donor

It is your decision whether you want to connect with or release personal information to your donor. The identities of both the donor and recipient must remain confidential for at least one year after the transplant. Each donor center has their own rules about anonymous correspondence between the donor and recipient.

Any anonymous correspondence will be carefully screened by the transplant nurse navigator and donor center coordinator. They will ensure all personal information (name, photos, school, employer, geographical references) is removed.

There is no guarantee that the donor will respond.

Tips for writing to your donor:

- Your donor may not share the same values about direct contact. Your donor may not want to release their personal information.
- There may be many cultural or lifestyle differences between you and your donor.
- You and the donor have the right to set boundaries and limits on interactions.
- Keep correspondence private. **Do not** share publicly or on social media.

For questions about contacting your donor, please contact your transplant nurse navigator.

Appointments

Autologous patients: You will be transitioned back to your local team around day 100. It's important to re-establish routine care with your primary care provider, eye doctor and dentist.

Allogeneic patients: For at least the first year after transplant, you will be seen often at the UW SCT clinic. After 1-year post-transplant, you might not need to come as often.

As more time goes by after any transplant, there is less focus on relapse and more focus on your overall health and wellness. Transplant was a big event affecting all areas of your life. After your SCT, it's important to work with your health care team to stay as healthy as possible.

It's important that you have a primary care provider (PCP) on your health care team. A PCP practices general medicine and is the first stop for medical care. They will also complete your general health screening. At about a year after transplant, it is important

to re-connect with your primary care provider. They are the best team member to go to for most general health problems. They will help you decide whether the SCT team's input is needed.

Long Term Complications of Transplant

There are long term consequences to your body and organs from receiving chemotherapy. This means you may be at higher risk for some things compared to others. We've listed some of the common long-term issues that you should watch for. Let your team know if you start to have any of these issues.

Numbness and Tingling

Numbness and tingling in the hands and feet is a side-effect that some patients have after chemo. This is called peripheral neuropathy. Some types of chemo can damage nerves and cause changes in feelings. Some patients find that it gets better over time, but it may never go away. Talk to your doctor if your symptoms become painful or they keep you from doing your daily routine.

Bone Pain

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

- **Osteoporosis:** Bones may become weak due to 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 can happen to patients who have received a lot of steroid medicines. Pain may be present 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 a joint replacement.

Cognitive Changes

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

- Poor concentration
- Poor short-term memory
- Foggy thinking or "chemo-brain"
- Trouble learning new tasks

Many patients find that these issues improve after the first year. Symptoms can persist for up to 5 years after.

If you feel like your cognitive changes are getting worse, let you doctor know. Your symptoms from before therapy are not expected to worsen post-transplant.

Heart Disease

Your chemotherapy, radiation and stem cell transplant increase your risk for getting heart disease. Post-transplant patients tend to develop heart disease at an earlier age compared to others. The good news is that there are things you can do to lessen that risk and keep your heart as healthy as possible!

Your cholesterol, blood pressure and blood sugars are very important factors in keeping your heart healthy.

Cholesterol

- Dyslipidemia is the medical term for higher-than-normal cholesterol levels.
- If cholesterol in your blood stays high, it will stick to the inside of the arteries. Making them narrow and less flexible. This increases your risk

of heart disease, heart attack and stroke.
- Your PCP is the best team member to monitor your cholesterol. They will work with you to keep it in a healthy range.

Blood Pressure
- Hypertension is the medical term for high blood pressure.
- When your blood pressure is too high for too long, it damages your blood vessels. Cholesterol will start to stick to these damaged areas in the artery walls. This increases the work of your heart and increases your risk of heart attack, stroke, and heart disease.
- It's important to work with your PCP to manage and treat high blood pressure.

High Blood Sugar
- Diabetes is the medical term for high blood sugars. This condition affects almost 1 in 10 adults worldwide.
- Over time, high blood sugars may damage the eyes, kidneys, nerves or heart. If untreated, diabetes can increase your cholesterol levels and your risk of heart disease and stroke.
- Your PCP is the best person to work with to keep your blood sugars in a healthy range.

You can reduce your risk of heart attack and stroke by controlling the above factors. A healthy lifestyle is also an important part of lowering your risk of heart disease. Regular exercise, maintaining a healthy weight, eating a healthy diet, and not smoking can all help reduce risk.

Cataracts
Your risk for cataracts increases transplant. They are most likely to occur in patients who have had total body irradiation or long-time use of steroids. If cataracts change your vision, they can be removed.

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.

Survivorship for Allogeneic Patients

Between year one and year two post-transplant you will be contacted by one of the UW SCT staff to schedule a survivorship video visit.

The visit can last an hour or longer, depending on your needs and questions.

You are welcome to include caregivers or family in this visit if you wish.

During the visit, we will discuss your survivorship care plan. Because of your cancer and SCT, you will have different health care needs than you did before you were diagnosed.

A survivorship care plan (SCP) is a document that contains your stem cell transplant treatment (treatment summary) and a care plan. The care plan shows how to address future health needs and screenings. It is meant to be used by you and your PCP. This will include possible long-term effects of your treatments, and ways you can stay healthy.

Your follow-up care and health maintenance plan may include:

- Schedule for:
  - Labs and tests
  - Specialty care
  - Health maintenance
  - Vaccines
- Possible future or chronic side effects based on your treatments

As you move beyond the stem cell transplant, you may see the SCT team less or not at all. Your PCP should be able to help manage your long-term health needs. You can always contact the SCT team if needed.

Who to Call	
UW Health Carbone Cancer Clinic Nursing Triage An answering service covers this line after hours and on weekends or holidays. Ask to speak with a Stem Cell Transplant (SCT) doctor on call.	608-915-0100 or 1-800-323-8942
Stem Cell Transplant Nurse Navigators	
Lauren Racki, Program Director	608-263-7673
Nicki Bates-Czyzewski	608-262-0455
Courtney Botteron	608-890-5934
Bethaney Campbell	608-263-0501
Karen Kranz	608-890-5923
Mandy Swiecichowski	608-890-5922
Brett Welhouse	608-263-8628
Clinic Social Worker	
Kristin Studer	608-262-7894
Clinic Pharmacist	
	608-263-1284
Infusion Center	
	608-263-8369
Inpatient Case Managers	
Mary Lynn Kessenich	608-262-0857
Bonnie Nelson	608-267-8105
Inpatient Nurses Station (B6/6)	
	608-263-8196
Nutrition	
Clinic Nutritionists	608-275-1700
Inpatient Nutritionist	608-263-8230
Spiritual Care Services	
	608-263-8574
Guest Services/Lodging	
UW Health patients and visitors can reserve a local hotel room at a discount through Guest Services by calling or stopping at the information desk at the hospital entrance. **Restoring Hope Transplant House (RHTH)** in Middleton, offers an affordable housing option for transplant patients and their families. RHTH has sleeping rooms and common areas including a kitchen and living area. Learn more at https://www.restoringhope.org. To reserve a room, call Guest Services and tell them know that you or your family member will be having transplant-related care at UW Health, and that you would like to stay at the Restoring Hope Transplant House.	608-263-0315

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 8/2025 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8409.