

Health Facts for You



**Stem cell transplant
social services, resources,
and references**

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 an allogeneic 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.

Stem cell transplant is life changing treatment. It affects people physically, emotionally and financially. There are many resources and services to help you and your family during this time.

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

Social workers can help with:

- Social Security Disability Benefits
- General insurance guidance for questions or concerns
- Review available financial assistance programs
- Advance care planning
- Review support and mental health resources
- Travel, lodging, and transportation concerns
- Time off work/FMLA

- Going back to work after transplant
- Alcohol and drug addiction
- Caregiver support

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.

Transplant can have many costs that are not covered by your health plan. Some plans do not cover the cost for certain parts of transplant. Other plans may have large deductibles or co-pays. Some drugs that you need may not be approved by your insurer. Other costs might include lost wages, gas, hotel and meal costs, childcare expenses, pet boarding, and more.

Financial Counselors

UW Health has financial counselors. They check your insurance plan before you come for your first visit. If you want to talk to a financial counselor, please call the UW Admissions Department at **(608) 263-8770**.

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. They can help you learn about transplant costs that may not be covered by your plan. There are also helpful tools, like a transplant cost planning worksheet and information about financial assistance.

Raising Money

There are ways to get financial 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. 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 provide help.

There are grants available for people living with cancer or having a stem cell transplant that can help with costs. This includes help with rides, hotels, meals, co-pays, prescriptions and other costs. Your social worker can help you find grant sources.

If you cannot afford certain medicines, let your team know. Our Medication Assistance Program (MAP) can help you find discount medicine programs to apply for.

Coping with Your Diagnosis

Getting a diagnosis of cancer usually comes as a big shock. For many people the time between getting their diagnosis to transplant is a whirlwind of activity and emotions. The news of needing a stem cell transplant can leave people feeling overwhelmed. It is important to remember that these emotions are normal, and you are not alone.

You may feel a wide range of emotions during and before SCT, from sad or angry to fearful or anxious.

Use the support of others and your health care team. Talk through your emotions, find coping strategies that work for you and help locate resources.

It can be helpful to have a list ready of things to do and people to call for help. Make a list of activities that calm and relax you. Also, write down family members or friends that you can call when needed. Think about who is most helpful to you. Keep this list nearby. When you are depressed or

feeling sad, it is good to think about things you can do for yourself.

- Eat well. A well-fed body helps to keep a healthy mind.
- Avoid alcohol. It is a depressant and can make you feel worse.
- Be more active when you are having trouble staying focused or remembering things.
- Take time to do things you enjoy.
- Writing things down may help.
- Meditation: Pick a small, easy task like sweeping the floor. Focus on the present moment. Try not to judge your thoughts.
- If you might be a danger to yourself, don't be alone. Find someone to talk to. If there is no one you can call, suicide hotlines can provide the support you need.

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 affect 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 interfere with your daily life or are hard to manage on your own.

It may be helpful to see a counselor or health psychologist throughout the transplant process. You will see a health psychologist as part of your pre-transplant work up. Follow up visits can be scheduled. Check with your insurance to see if you have coverage. Below are some ways a health psychologist can help you.

- Help cope with your diagnosis and other long-term illnesses.
- 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 with making hard decisions.
- Adjust to a new diagnosis, treatment, or survivorship.
- Teach behavior treatments for insomnia, pain, and nausea.

Spiritual Care Services

UW Health’s Spiritual Care Department is available to patients, loved ones, family members and staff. They offer spiritual and emotional support during unstable times. Chaplains are specially trained ministers who work as part of a patient’s health care team. They believe that a person’s spiritual and emotional well-being plays an important part in overall health.

At University Hospital, Spiritual Care is located in E5/620. You can also call them at **(608) 263-8574**. The chapel is located directly off the skywalk as you cross from University Hospital into American Family Children’s Hospital.

Disability

After transplant, it may be 6-12 months or more that you will be unable to work. A disability is an illness or injury that prevents you from working, like receiving a SCT. Disability payments can help to support you and your family while you are unable to work. Each program below requires medical verification of your disability. You may have long, or short-term “private” disability plans through your job or supplemental plan. To find out more about these plans, call the Human Resources (HR) office where you work.

The disability application process is complex. It can take several months to complete. It is important to start the application process early. The best way to apply is online at www.ssa.gov. Click on

“Apply for Disability Benefits.” Complete the Adult Disability Report. A social worker can help you with this process if needed.

There are two types of government disability benefits that provide monthly income.

- **Social Security Disability Income (SSDI):** You must have worked at a job where you paid into the program. It includes Medicare after you get SSDI checks for 2 years.
- **Social Security Income (SSI):** You are eligible if you have low or no income and minimal assets. Aside from the home you live in and one car or truck, you cannot have more than \$2,000 in assets for a single person or \$3,000 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). It may cover health costs as far back as 3 full months from the date you applied.

Legal Resources

Make sure that you are treated fairly by your workplace. They cannot discriminate against you because of your health. If you feel that you are being treated unfairly at your work because of your illness, reach out to the SCT social worker who can connect you with the right resources.

Legal Planning and Getting the Care You Want

We strongly encourage you to fill out Advance Medical Directives. This is a legal document that allows you to name another person to make health care decisions for you if you are unable to make those decisions yourself. It’s the best way to make sure that you will be getting the care you want, even if you’re unable to communicate. The social worker can tell you more about advanced

medical directives and can also help you fill one out. If you already have an advance health care directive, make sure a copy of it is in your medical record.

The Center for Patient Partnerships at the University of Wisconsin-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. You can reach them at **(608) 890-0321**.

The Cancer Legal Resource Center 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. Please call **(866) 843-2572**.

Other Trusted Support Options

Lodging

Local hotels provide reduced rates to UW Health patients and can be scheduled by calling Guest Services at **(608) 263-0315** or stopping at the Information Desk at the University Hospital entrance.

Restoring Hope Transplant House located in Middleton, WI, offers a comfortable, affordable and caring environment for transplant patients and their families. It has sleeping rooms and common areas including a kitchen and living area. Learn more at <https://www.restoringhope.org>. Reservations must be made through UW Health Guest Services at **(608) 263-0315**.

Gilda's Club Madison offers **free** support for everyone touched by cancer along with their families and friends. They provide support groups, workshops, education, social activities and a way to connect with others.

<https://www.gildasclubmadison.org>

7909 UW Health Court, Middleton, WI

Phone: **(608) 828-8880**

Email: info@gildasclubmadison.org

National Marrow Donor Program (NMDP), formerly known as "Be the Match," it provides information and one-on-one support to patients and families. They can help you get the support and information you need to learn about your disease and treatment options, prepare for transplant and thrive after transplant.

- **Peer Connect Program:** The Peer Connect program can 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:** They host monthly "Survivorship Chats" for those who are post-transplant. These are telephone support groups. Each month there is a new topic.

<https://www.nmdp.org/>

(888) 999-6743

Email: patientinfo@nmdp.org

BMT InfoNet is a leading advocacy organization for transplant and CAR T-cell therapy recipients before, during and after treatment. In addition to education materials, BMT InfoNet also hosts a yearly Survivorship Symposium and has patient and caregiver support services.

The Caring Connections program links patients who are new to transplant with trained transplant survivors who can listen to their concerns and offer insights on the transplant journey. This one-on-one peer support is also available to family members of transplant patients.

<https://bmtinfonet.org/>

(888) 597-7674 or (847) 433-3313

Email: @bmtinfonet.org

CancerCare provides 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.

<https://www.cancercare.org/>

(800) 813-4673

Cancer and Careers 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.

<https://www.cancerandcareers.org/en>

Caring Bridge helps you connect with people **you choose**, to keep informed about your progress and your needs. You can journal your transplant journey, get guestbook messages from your circle of friends, receive e-cards and more.

<https://www.caringbridge.org/>

Crisis Text Line is a free, 24/7, confidential text message service for people in crisis.

<https://www.crisistextline.org/>

Text HOME to 741741.

GVHD Alliance

www.gvhdalliance.org

The GVHD Alliance is committed to supporting every person, in every community, throughout their experience with GVHD. The GVHD Alliance is

empowering voices in the Graft-versus-host disease (GVHD) community to increase awareness and help improve the lives of people living with GVHD. Collection of resources from reputable sources.

Imerman Angels 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.

imermanangels.org

(877) 274-5529

Leukemia and Lymphoma Society (LLS) provides free information and support.

<https://bloodcancerunited.org/>

Look Good...Feel Better is a free service that teaches beauty techniques to cancer patients to help them deal with the side effects of cancer treatment. They will learn about makeup techniques, skincare, nail care, and hairless options. Meetings are at the UWCCC and Gilda's Club in Middleton. Each group program member receives a free makeup kit.

<https://lookgoodfeelbetter.org/>

(608) 266-6025 or 1-800-ACS-2345

Lotsa Helping Hands 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.

<https://lotsahelpinghands.com/>

LiveStrong at the YMCA. Call your local YMCA to see if they offer LiveStrong. It 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 12-week small group program free of charge.

MyLifeline 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.

<https://www.mylifeline.org/>

National Suicide Prevention Line

Text or call **988** or **1-800-273-8255**

<https://988lifeline.org/>

Share the Care www.sharethecare.org

A website 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.

Wisconsin Tobacco Quit Line

800-QUIT-NOW or text **READY** to 200-400. www.wiQuitLine.org. They offer free services that are available 24/7, including:

- Telephone coaching and phone support for Wisconsin residents who want to quit tobacco use.
- Personalized advice on how to quit, information on medicines, and assistance with creating a quit plan.
- Two weeks of free medicine (nicotine patch, nicotine gum or nicotine lozenge) and self-help materials.
- A secure Web Coach where tobacco users can interact with others trying to quit, get support, develop personalized quit plans and track results.
- Information for those concerned about a tobacco user.

The Stem Cell Transplant Team

There will be many medical staff members who will be part of the team that cares for you and your family.

Treatment Team Member Roles and Responsibilities

Your **primary transplant doctor** is the attending doctor you meet at your consult visit.

- They will be your primary provider who will care for you before and after transplant at clinic appointments.
- They will discuss your treatment options, the benefits and risks of the available treatments and will decide which therapy plan and donor is best for you.

Nurse practitioners (also known as Advance Practice Providers, or APPs) are nurses with an advanced nursing degree and will provide you medical care throughout the transplant process.

The inpatient APPs care for you when you are in the hospital. The clinic APPs will see you at clinic appointments. Both work closely with your primary transplant doctor.

You will be assigned a **nurse navigator** at your referral to the transplant program. They are your primary contact for transplant related care and will:

- Help coordinate care with local providers and UW SCT team.
- Provide emotional support, education, and prepare you and your family for your upcoming transplant.

The SCT **social worker** can help in many ways. Everyone meets with the social worker before transplant.

- They will assess your support system and help develop a caregiver plan.
- Provide emotional support to you and your family.
- Connect you with support and mental health resources.
- Provide resources to help with transportation and transplant costs.
- Help with lodging.
- Help with work-related issues, disability, and leave programs.
- Help you write an advance health care directive.
- Help with housing and food insecurities.

Medical assistants (MA) will room you in clinic and ask you questions before you see your doctor or APP. They work with your clinic nurse and can give injections, like vaccines.

Pharmacists will meet with you pre-transplant to review transplant related medicines. If admitted to the hospital, they will review all your medicines on admit. On your discharge day, they will again review your medicines and teach you about any changes or new medicines.

Registered dietitians can meet with you before, during or after your transplant to help address your nutrition concerns. There is an inpatient and outpatient registered dietitian. You can request to meet with them at any point.

All of the transplant doctors and nurse practitioners rotate on a schedule to care for the transplant patients in the hospital. Even though the team you see may change, everyone communicates regularly with each other.

An **attending physician** has completed all their training and will oversee your inpatient care while teaching and supervising doctors in training.

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 will stay in the cancer specialties.

You also may meet medical students who are in training to be doctors. They help your doctor with your care and learn from you as a patient.

Inpatient nurses will have the most contact with you during your stay in the hospital. You can expect have 2-3 nurses assigned to your care over a 24-hour period.

- Your **primary nurse** will provide consistent nursing care and will help coordinate your care with all members of the health care team.
- **Team nurses** are assigned to care for you around the clock during your inpatient stay so you will receive consistent nursing care. They will:
 - Assess body systems, pain, and other symptoms or changes.
 - Provide medicine, transfusions and chemotherapy.
 - Help with supportive care to reduce the side effects of treatment.
 - Provide education and updates on your inpatient treatment plan.
 - Provide emotional support for you and your family.

Nursing assistants (NA) work directly with your nurse to help care for you by taking vital signs, walking, bathing, and helping you use the bathroom. You will have 2-3 NAs assigned to your care over a 24-hour period.

Physical and occupational therapists (PT and OT) will see you while you are inpatient. If needed, your team can make a referral so you can see them in clinic.

- **Physical therapists** work on walking, balance, lower body 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 and strength, daily living and self-care skills, cognitive functions for daily life tasks. They will figure out if you will need any tools to help you in your daily routine.

Inpatient case management staff include a nurse case manager and social worker who:

- Help with your discharge process and create a discharge plan, if needed.
- Assist with insurance needs.
- If needed, they will help with getting special equipment, arranging home health care, and skilled nursing facility placement.

Transplant Dictionary

Allogeneic transplant: A stem cell transplant that uses donor stem cells.

Alternative medicine: Medicine used **instead of** standard medical treatment. One example is using a special diet to treat cancer instead of cancer drugs that are prescribed by an oncologist.

Anemia: A low number of red blood cells. You may have symptoms of feeling tired, weak, and short of breath if you are anemic.

Apheresis: The process used to collect stem cells from the blood. A machine is used that can separate the stem cells from the blood.

Complementary medicine: Medicine or treatment used **along with** standard medical treatment but is not considered by itself to be standard treatment. One example is using acupuncture to help lessen some side effects of cancer treatment.

Complementary and alternative medicine (CAM): The term for medical products and practices that are not part of standard medical care.

Central line (PICC, Hickman, Port): An intravenous catheter placed in a vein. The catheter is used to give fluids or medicine and to draw blood. Common central lines are PICC lines, Hickmans or ports.

Conditioning treatment: Chemotherapy given in the days before transplant to prepare the body to accept the donor stem cells. Total body irradiation may be part of the regimen for some people. Also referred to as preparative (prep) regimen. Conditioning treatments have different intensities, ablative, non-ablative and reduced intensity.

Consent form: A document that explains the treatment medicines, and the risks and benefits of a transplant.

Conventional medicine: A system in which health professionals (doctors, nurses, pharmacists, and others) treat symptoms and diseases using drugs, radiation, or surgery.

Donor: The person who donates stem cells used in a transplant.

Engraftment: A time when blood cells recover after the transplant.

Graft: A term used to refer to the donor stem cells. A term used to refer to the donor stem cells.

Graft-versus-host disease (GVHD): A complication of an allogeneic transplant. It happens when the donor cells (graft) don't recognize the recipient patient's body tissues.

Graft versus leukemia (or graft vs tumor): A reaction of the allogeneic donor's cells to the patient's cancer. This is part of the cure in an allogeneic transplant.

Hemoglobin (Hgb): The part of the red blood cell that contains iron. Iron binds to oxygen and carries it to tissues throughout the body.

Human leukocyte antigen (HLA): The human leukocyte antigen is a group of markers on the surface of cells of the immune system. These markers are inherited from parents. The antigens are used to find an allogeneic donor from either your family or the unrelated volunteer donor registries.

Immune system: A system of specialized cells of the body that protect us from bacteria, viruses, and other micro-organisms in the environment that cause infections.

Immunosuppressants: Drugs given to weaken the immune system to prevent or treat graft-versus-host disease.

Inpatient: A person who receives care in the hospital.

Integrative medicine: An approach to medical care that combines conventional medicine with CAM practices that have shown through science to be safe and effective. This approach attempts to address the mental, physical, and spiritual aspects of health.

Mobilization: A process to increase the number of stem cells in the blood. By mobilizing (moving) the stem cells from the bone marrow into the blood, the stem cells can be collected from the blood.

Myeloablative: A preparative regimen of high-dose chemotherapy, with or without radiation, that will completely destroy a person's ability to make blood cells.

Neutropenia: A condition in which a person has a low number of neutrophils. Neutrophils are a type of white blood cell that are important for fighting bacterial infections.

Non-myeloablative: Non-myeloablative means that the preparative regimen consists of low or standard doses of radiation, chemotherapy or immune-suppressing drugs. The purpose of the preparative regimen is to suppress the patient's immune system enough to allow the donor's cells to grow and function.

Platelets: Blood cells that form a clot to prevent or stop bleeding after injury. When the platelet count is low there is a risk of bleeding.

Preparative (prep) regimen: Chemotherapy given in the days before transplant to prepare the body to accept the donor stem cells. Total body irradiation may be part of the regimen for some people. Also be referred to as conditioning treatment.

Prep regimens have different intensities, ablative, non-ablative and reduced intensity.

Stem cell transplant (SCT): A stem cell transplant is a treatment option for patients with blood cancers and immune system or genetic disorders. The goal of a stem cell transplant is to control or cure the disease. A transplant restarts the body's ability to make healthy new blood cells by replacing abnormally forming stem cells with healthy cells.

Standard medical care: Treatment that is accepted by medical experts as a proper treatment for a certain type of disease and is widely used. Also called best practice, standard of care, and standard therapy.

Thrombocytopenia: A low platelet count. A low platelet count increases the risk of bleeding.

Transfusions: The infusion of different parts of the blood to treat specific problems. An infusion of red blood cells is given to reduce the effects of anemia, and an infusion of platelets is given to decrease the risk of bleeding.

Veno-occlusive disease (VOD): Veno-occlusive disease, (sometimes called sinusoidal obstruction syndrome or SOS), happens when the small blood vessels around and in liver become blocked. VOD is caused by high doses of chemotherapy and radiation therapy given before a stem cell transplant. It develops in the first few weeks after a stem cell transplant.

White blood cells (WBC): White blood cells protect the body from infection. There are many types of white blood cells including neutrophils, eosinophils, basophils, monocytes, macrophages and lymphocytes.

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 © 11/2025 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#8457.

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) 265-1700 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 Nutritionist - Caitlyn Leiva	(608) 275-1700
Inpatient Nutritionist - Alyssa Stiles	(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