

Stem Cell Transplantation and Cellular Therapy Caregiver Guide



Table of Contents

Foreword	3	Continuing Recovery and Returning Home After Transplant.....	15
Introduction	4	Taking Care of	15
What giving care means	4	Communication with the Transplant Team	16
How one becomes a caregiver.....	4	Symptoms to Report	17
What I need to do.....	4	What You Can Do	17
Expectations of the Stem Cell Transplant Caregiver	5	Caring for the Caregiver	18
Pre-Transplant	5	Social and Emotional Impact of Caregiving.....	18
Types of Transplants	5	What You Can Do	19
Taking Care of	5	Spirituality and Caregiving	20
Communication with the Transplant Team	6	Resources and References	22
Symptoms to Report	7	Tips for Stem Cell Transplant Caregivers	22
Inpatient Transplant	8	National and Local Resources	22
Taking Care of	8	Glossary	24
Communication with the Transplant Team	10	Notes	29
Symptoms to Report	10		
What You Can Do	11		
Inpatient Discharge	12		
Outpatient Care After Transplant.....	13		
Taking Care of	13		
Communication with the Transplant Team	14		
Symptoms to Report	14		
What You Can Do	15		

Foreword

We dedicate this guide to all stem cell transplant caregivers. We applaud your strength and courage in helping meet your loved one's needs.

As your loved one begins the stem cell transplant process, your role as a caregiver will have a profound effect on his or her care and recovery. You will be an important part of the health care team and will help manage your loved one's care.

During this journey, you will learn about how to care for your loved one day-to-day, and you will get to know many helpful resources. This guide gives information about how to take care of yourself and your loved one, communicate with the health care team and seek support.

Although being a caregiver can be a positive and rewarding experience, it can also be hard work:

- It is important to care for yourself emotionally and physically.
- Keep in good health and take time for yourself.
- Use the resources that we have provided in this guide.

Sincerely,



Richard Champlin, M.D. Chairman
Department of Stem Cell Transplantation & Cellular Therapy
The University of Texas MD Anderson Cancer Center

Introduction

A caregiver is a person who provides help to someone in need. Often, that help is with necessary activities that the person cannot do on his or her own. Sometimes, helping is just being there in hard times to offer encouragement and support.

There are many kinds of caregivers. Some caregivers, like doctors and nurses, have formal training and devote their lives to caring for others.

Family members, friends and neighbors are caregivers too. This guide is written especially for them because they provide care for their loved ones in many ways:

- Volunteer countless hours of help during tough times
- Help with tasks that their loved ones cannot do on their own
- Are there to offer encouragement and support
- Manage to stay committed and figure out ways to help

What giving care means

Caring for a loved one can mean helping with his or her daily needs. These include going to doctor visits, making meals and picking up medicines. It can also mean helping your loved one cope with feelings and being there for him or her when he or she needs to talk.

How one becomes a caregiver

Being a caregiver for a loved one is a role that no one expects. Just as many people find it hard to accept being a patient, likewise, it can be overwhelming to become a caregiver.

The act of becoming a caregiver nearly always involves change. You might feel like a different person, doing things every day that you have never done before. This is okay, and this is normal.

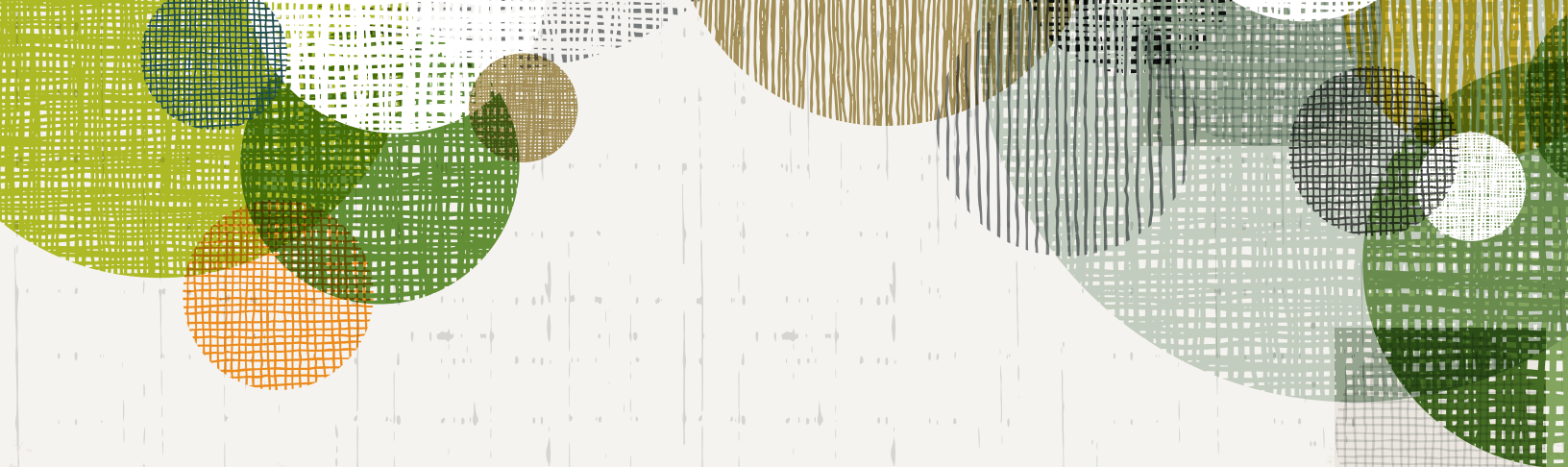
What I need to do

Stem cell transplant is a unique treatment with unique tasks for the caregiver, and these duties may change over time. The transplant timeline occurs in 4 phases: pre-transplant, treatment, initial recovery after transplant (inpatient and outpatient) and long-term recovery.

Throughout each phase, it is important that you take care of yourself. As a caregiver, you are a vital member of the transplant team. It is key to set realistic expectations for yourself and the transplant process.

Keep in mind that much is beyond your control. All we ask is that you do what you are able to do and use the resources that are here for you.

We hope that you find this guide helpful. Use the resources available to help you throughout the transplant process. We are here for you.



Expectations of the Stem Cell Transplant Caregiver

Pre-Transplant

During the pre-transplant phase, caregivers help to get the patient ready for the transplant. You will help your loved one learn more about the transplant process, treatment options, risks and benefits. You also need to make plans for work, home and family, especially if you are moving to the Houston area.

Types of Transplants

There are 2 types of transplants: allogeneic and autologous. Make sure to ask what type of transplant your loved one is having. Some patients receive transplants as outpatients. This means that they do not stay overnight in the hospital. You will visit MD Anderson during the week for check-up appointments, tests and classes.

Other patients receive transplants as inpatients. This means that they stay overnight in the hospital for a period of weeks to months.

During this time before the transplant begins, you will learn:

- Whom to contact and when
- How to treat side effects while away from MD Anderson
- When to go to the hospital

If you have any questions, talk to the transplant team.

Taking Care of ...

Your Home

If you are moving to Houston or will be away from home often, think about plans for:

- Children and pets
- Mail delivery to a Houston P.O. box, mail forwarding or hold mail
- Hold on newspaper delivery
- Care of your home and property
- Keeping in contact with us (cell phone)

Important Paperwork

Some people need to complete paperwork for their employers before the transplant. Common forms include the Leave of Absence form and the Family Medical Leave of Absence form. Bring any paperwork you need completed with you to the first clinic visit and allow us two weeks to complete and return to you.

Also, bring copies of advance care planning documents (also called advance directives), such as a living will and health care power of attorney. This paperwork outlines the patient's choices for care. We will put this in his or her medical record. If you need information about completing advance care planning documents, contact your social worker.



Yourself

Preparing for the stem cell transplant process can be overwhelming and stressful. Here are some things to remember:

- Make a list and ask friends and family to help you. If possible, ask them to help with caregiving duties so that you can plan to take a break for 1 or 2 days. This will allow you time to take care of yourself.
- Arrange your work schedule to attend appointments. Talk to the transplant team about the schedule.
- Have your health insurance cards and medical records ready should you need medical care.
- See your own doctor in order to:
 - Get a regular exam and physical.
 - Get a seasonal flu shot injection (not the nasally inhaled vaccine).
 - Refill prescriptions or get written prescriptions to fill at a local pharmacy.
- Learn about available MD Anderson caregiving resources and education.

Your Loved One

You are a vital resource to your loved one. Often, you are the one person who knows everything that is going on with him or her. Here are some things that will help you:

- Learn about your loved one's cancer and the stem cell transplant process. Read the **Introduction to Stem Cell Transplantation**

patient education manual provided at the first clinic visit.

- Attend the following classes to learn about MD Anderson resources and the transplant process:
 - Pre-Admission Class
 - Central Venous Catheter Care
- Visit The Learning Center on Floor 4, near Elevator A, for additional resources.

Communication with the Transplant Team

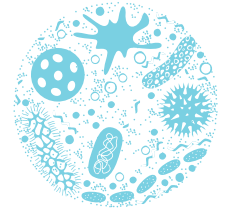
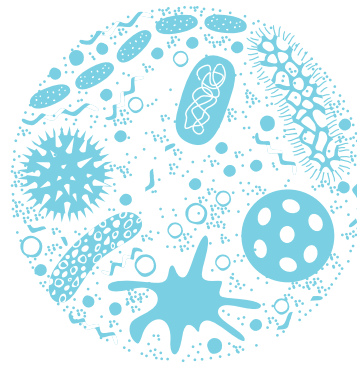
Contact Information

Communication with the transplant team is necessary to prepare you and your loved one for the transplant.

MyChart is a web portal that connects you to MD Anderson. You can access from any computer or download the MyChart app:

- Appointment schedule and personal health record
- Prescriptions
- Patient education information and video library
- Billing statements
- A messaging system to email questions

We encourage you to sign up for MyChart at MyChart.mdanderson.org. You may also call



- Contact myCancerConnection to speak with other caregivers who have gone through this treatment process. Call 713-792-2553 or 800-345-6324.
- Talk with your loved one about advance care planning and have him or her complete the forms before they begin treatment.
- Meet with your social worker to discuss housing and financial assistance options that may be available.
- Become familiar with the Houston area if you are moving.
- Use a journal to write down questions you want to ask or information you want to discuss. Also use your journal to write down important information, phone numbers, appointments, etc.
- Budget money for food, transportation, housing and insurance co-payments.
- Give a current phone number to your transplant team.
- Do not feel like you need to know everything. We have several resources to help you throughout the transplant process. Also, we welcome your questions.
- Do not hide your emotions. You may feel sadness, anger, guilt, frustration and grief. Let us know. We are here to help.

Inpatient Transplant

The treatment phase is a time when we encourage you to rest. During the treatment phase, your loved one will be in the hospital, and our staff will do much of the daily care. This will allow you to focus on giving emotional support.

If you ever have any questions while your loved one is in the hospital, talk to a member of the medical team.

Taking Care of ...

Yourself

Take good care of yourself while your loved one is in the hospital:

- Take time for yourself. Plan to spend some nights away so that you get a full night's sleep.
- Bring comfortable clothes, bedding (clean blanket and pillow) and personal electronic devices, such as laptop or tablet.
- Use services like the Integrative Medicine Center, which offers daily programs in relaxation, yoga, exercise and more.
- Eat well. You may bring food into the hospital for you or your loved one, but it must be labeled with the date and name. Store leftover food in the refrigerators located in the family rooms. We will throw away all food after 3 days or sooner if it is not labeled.

-

Your Loved One

Do the following to help care for your loved one. If you have any questions or concerns, ask your nurse.

- Follow handwashing guidelines. Use the hand gel units outside the room, or wash with soap and water. Check with the nurse to see which method to use.

- Take advantage of quiet time. We dim the lights on the unit every day for an hour. We only enter your loved one's room if needed to allow patients and caregivers time to rest.
- Encourage your loved one to use the incentive spirometer every 2 hours while awake. This helps to keep the lungs healthy and prevents breathing problems while in the hospital.
- Be aware that we do blood tests each morning around 4:30 a.m. We run the lab tests early so that the doctor can act on the results. For example, your loved one may need a blood transfusion, medicines or an infusion of fluids.
- Expect staff to enter your loved one's room often. We do tests and exams, take vital signs and give medicines. At night, we try to limit how often we enter the room.

Communication with the Transplant Team

Contact Information

We need your cell or local phone number on file so that we can contact you any time.

Daily Rounds

An inpatient stem cell transplant team will visit your loved one daily, usually before noon. This is a team of physicians, nurses, pharmacists and others. The stem cell transplant inpatient physician may not be the clinic physician. You may ask questions and talk about any changes or concerns. Use a journal to write down your questions.

If you have a question or concern, talk to your nurse. If necessary, he or she will contact a member of the team. Physician assistants and advanced practice nurses are here throughout the day to help. Often, the advanced practice nurse will follow up with you. Also, a team of health care providers are on call at night, weekends and holidays.

Paperwork

On the day that we admit your loved one to the hospital, bring a current copy of your loved one's advance directives to place in the medical record.

Symptoms to Report

Chemotherapy often causes symptoms during inpatient care. Tell the team if your loved one is having any of the following:

- Nausea or vomiting
- Fatigue
- Diarrhea
- Pain
- No appetite
- Mouth sores
 - Certain chemotherapy can cause extreme mouth sores that may extend down the throat. This makes it hard to drink or eat.



“I know when we go home; I know that we will come back in April for the checkup and blood work. I know that we will get a written schedule on when to get her shots, her vaccinations and all this again. That is perfect. That is really well done. They just weren’t, ‘All right, go home.’ We didn’t get that. . . I felt 100% comfortable.”

— Caregiver

- Avoid moving, touching or trying to work any medical equipment. Ask your nurse for help.
- Do not turn off the bed check button. This safety feature alerts your nurse to help your loved one get out of bed safely.
- If you feel that he or she is uncomfortable, or if you are concerned about the amount of pain medicine, tell your nurse right away. Do not push the button on the patient-controlled analgesia pump if your loved one has one. This pump should only be controlled by the patient.
- Let your loved one answer questions if he or she is awake and alert. Your input is important, but we want to let your loved one speak first.
- Do not feel you need to be at the hospital 24 hours a day. Let the inpatient team attend to your loved one when you need time for yourself.
- Have an absolute neutrophil count (ANC) of at least 1500.
- Have no fever for 72 hours (3 days).
- Be able to swallow pills and drink at least 8 to 10 cups (2 liters) of fluid each day.
- Do simple activities, such as walking, dressing, brushing their teeth, using the bathroom and feeding themselves.
- Have local housing and a caregiver.

Also, do the following before your loved one is discharged from the hospital:

- Watch the stem cell transplant discharge video. There is one for autologous patients and one for allogeneic patients.
- Attend the Central Venous Catheter Care class to learn how to clean and care for the CVC.
- Prepare and clean the home, apartment or hotel room.
- Fill and pick up prescriptions. You may use the MD Anderson pharmacy or a local pharmacy.
- Discharge time is 11 a.m. It is helpful to pack and move your loved one’s personal items ahead of time if possible. If needed, ask for a cart to help transport these things.
- Take your loved one’s discharge paperwork to their next Fast Track or Ambulatory Treatment Center (ATC) appointment.

Inpatient Discharge

To help you plan and prepare for your loved one’s discharge, a white dry erase board is located in the hospital room. Your loved one’s expected discharge date and goals are listed here. If they are not, tell your transplant team and they will provide you with that information.

The attending physician will tell you when your loved one is ready to be discharged. Before your loved one is discharged, he or she must meet the following requirements:



Outpatient Care After Transplant

After your loved one is discharged from the hospital, you will be his or her primary caregiver. This means that you must care for your loved one around the clock and be aware of what is going on with him or her at all times.

It is common for transplant patients to be readmitted to the hospital for care during this phase. It is okay and should be expected. Do not view this as a setback.

Taking Care of . . .

Youself

Because outpatient care requires that you be with your loved one at all times, we encourage you to do the following:

- Have a schedule of other caregivers to allow you some time off, either daily or weekly.
- Use MD Anderson resources such as support groups, counseling services and caregiving resources.
- Ask questions. Use a journal to write down questions, concerns or notes.
- Do errands, attend a class at the Integrative Medicine Center, rest or enjoy time to yourself while your loved one is in the clinic. However, wait until after your loved one has been seen by the advanced practice nurse or physician

so you can ask questions and receive current updates and instructions.

- Ask for help for yourself or your loved one.
 - Protect yourself from infection by washing your hands frequently and staying away from people who are sick.
 - Exercise daily to help clear your mind and relieve stress. Exercise will also help you sleep better.
 - Take your prescribed medicines.
 - Eat well to keep your energy level up. This includes lean meats, fruits, vegetables and whole grains. Get plenty of rest and take a nap when you can, especially if you stay up at night to help your loved one.
 - Find a local health care provider, if needed.
- Visit www.utphysicians.com or call 888-488-3627.

Your Loved One

Your loved one will have follow-up appointments at MD Anderson. How often these occur depend on the type of transplant and how well he or she is recovering.

Autologous transplant patients:

- Must stay within 30 minutes of MD Anderson for 30 days after transplant.
- Will have follow-up appointments in the Fast Track Clinic on Floor 8, near Elevator B.

“Oh no, I never thought I would ever see this day, but I kept the faith and it was all worth it. We are all going home cancer free.”
— Caregiver

Allogeneic transplant patients:

- Must stay within 30 minutes of MD Anderson for 100 days or more after transplant.
- Will have follow-up appointments in the Ambulatory Treatment Center (ATC) on Floor 10, near Elevator C.
- May sometimes have follow-up appointments in the Fast Track clinic.

At follow-up appointments, your loved one is seen by a physician, a physician assistant or an advanced practice nurse (APN), pharmacist, nurse and other care providers as needed. Plan to spend a full day in the clinic, especially the first few weeks after your loved one is discharged from the hospital. This is the time where he or she may require blood transfusions and fluids.

Do the following to help care for your loved one after transplant:

- Be with the patient at all times. It is okay to take breaks or run errands when the patient is in the clinic for appointments or at the ATC or Fast Track Clinic for transfusions or fluids.
- Continue to clean the home, apartment or hotel room as instructed.
- Bring your loved one to and from clinic appointments.
- Help with activities of daily living, such as cooking, bathing, dressing and laundry.

- Help with central venous catheter (CVC) care using the information you learned in class and any instructions given to you by the transplant team.
- Keep track of your loved one's medicines and contact the MD Anderson pharmacy or your local pharmacy for refills, as needed.
- Watch for and keep a record of any symptoms or changes, such as fever, nausea, vomiting, diarrhea, skin rash, mood or behavior.

Communication with the Transplant Team

Phone Numbers

Keep your preferred pharmacy telephone and fax numbers available so the care team can send prescriptions quickly and easily.

Symptoms to Report

When to call the Fast Track Clinic or Ambulatory Treatment Center

During business hours (7:30 a.m. to 4 p.m.), call the Fast Track Clinic for autologous patients or the Ambulatory Treatment Center for allogeneic patients if your loved one has any of the conditions listed below. After business hours, call their physician.

- A sore mouth that stops your loved one from taking medicine or drinking liquids
- Nausea or vomiting that is not relieved with the prescribed medicine

- Diarrhea that does not stop
- A skin rash or red areas on the skin
- A cough that does not go away
- Burning feeling or pain when he or she urinates or a decrease in the amount of urine

When to Seek Emergency Care

MD Anderson's Acute Cancer Care Center is open 24 hours a day, every day. From Holcombe Boulevard, turn at Entrance Marker 3. The entrance is on Bates Street near Garage 2. From inside the Main Building, go to Floor 1, near the Pavilion entrance.

Go to the MD Anderson Acute Cancer Care Center **right away** if your loved one has any of these symptoms:

- A temperature of 100.4°F (38°C) or higher, unless otherwise instructed
- Chills or shaking
- Any bleeding that does not stop after 10 minutes of applying light pressure
- Vomiting that does not stop
- Shortness of breath when resting
- Feeling dizzy, lightheaded, or faint
- A rapid heartbeat (palpitations)

Keep in mind that your loved one may not notice these symptoms or may try to tolerate them before telling you. It is very important to watch for these symptoms. Talk to your loved one about how they feel. Call the care team or go directly to the MD Anderson Acute Cancer Care Center as directed.

What You Can Do

- Be with the patient at all times.
- Wash your hands often and encourage the patient to do the same. This helps to reduce the risk of infection.
- Take time for yourself when the patient is in the clinic or when another caregiver is available.
- Bring any forms that need to be completed or updated for your work leave, such as Leave of Absence or Family Medical Leave of Absence.

- Learn and use MD Anderson and community resources.
- Report any changes in your loved one's condition to the care team **right away**.
- Go to the MD Anderson Acute Cancer Care Center **right away** for certain symptoms as directed.
- Do not let anyone with signs or symptoms of illness visit with the patient.
- Do not allow family, friends and children who have had recent vaccinations visit with the patient.

Continuing Recovery and Returning Home After Transplant

As your loved one continues to recover, our hope is that he or she can return to a new normal after the initial recovery phase. It is important to be cautious even after returning home. Surviving a transplant does not mean that your loved one is immune to other health problems. In many cases, he or she may have an increased risk for other problems because of what their body has been through. The outpatient care team is the best resource during this phase.

Taking Care of ...

Yourself

Transitioning home can be a challenge since your loved one will no longer need daily care at the hospital and clinic. You may have some fears or concerns about problems that could occur or about returning to day-to-day life. During this time, it may be helpful to:

- Contact family or friends who can help you. This is very important as you begin to transition back to work or other duties.
- Do activities that you enjoy. Be sure you continue your interests and activities to give yourself a break from your caregiver role.

Your Loved One

- Allogeneic patients and caregivers must attend a survivorship appointment.
 - This appointment is usually scheduled between day 60 and 80 after transplant.
 - The visit covers details for continuing recovery at home as well as things to be aware of that can affect your loved one's health or quality of life months and years after transplant.
- If your loved one received an autologous transplant, he or she will receive instructions from their stem cell transplant physician and advanced practice provider before leaving the Houston area.
- Your loved one will need to travel to Houston for routine follow-up appointments. A follow-up plan is recommended by the stem cell transplant physician based on your loved one's care needs and the available medical care in their home community. Expect to come back to MD Anderson about 1 to 3 months after returning home.

Continue to help your loved one with activities of daily living, such as medicines, meals, personal hygiene and chores. Here are some other ways you can support your loved one.

- Encourage your loved one to do more as he or she gets stronger.
- Drive until your loved one is cleared to drive again.

- Encourage safe activity. It may take a few months before he or she can resume normal activity levels. Expect that he or she may tire easily.

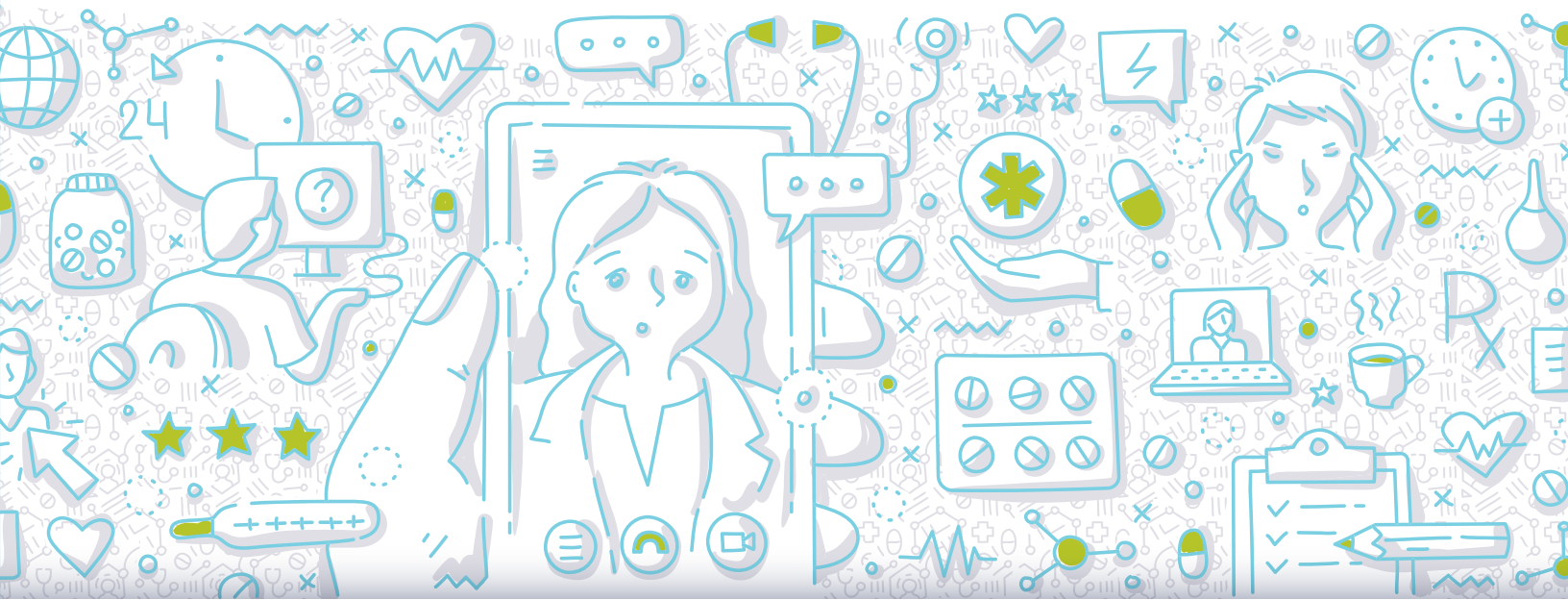
To help your loved one build strength, endurance and energy:

- Make weekly goals to increase activity, such as 30 minutes of walking a day.
- Take a short rest after big activities.
- Walk to and from all clinic appointments. Try not to use a wheelchair unless needed.
- Limit daytime naps to 1 hour or less.
- Ask for a physical therapy consult if he or she is not making progress with strength building or independence.

Communication with the Transplant Team

When you return home, all medical issues for your loved one should be reported to their home community doctor. We prefer that your loved one be seen by an oncologist or hematologist first for their care. If a medical issue occurs, contact your home community doctor to address the issue. Then, you may update the transplant team.

If you live in the Houston area, use your transplant doctor and team for all medical issues until told otherwise. Continue to use the MD Anderson Acute Cancer Care Center as instructed.



“I think talking to each other when we see other caregivers in the room or on the bus helps. We’ve made some of the best friends that will continue to be friends.”
— Caregiver

Caring for the Caregiver

Social and Emotional Impact of Caregiving

While caring for a loved one can be fulfilling, it can also be stressful and tiring. Sometimes, caregivers may feel angry, anxious, frustrated and isolated. While these feelings are normal at times, they should not fill your day. We do not want these feelings to grow into serious problems.

Review the Resources section in this guide to learn more about available services to support you. Feel free to contact these groups, even if you do not feel like you need help. You may learn about something of benefit to you.

If you feel overwhelmed at any time, talk to us. We will work with you to get the support and help you need.

Anxiety and Stress

Feeling anxious and stressed are normal when faced with challenges, uncertainties or dangers. As you care for your loved one, you may worry about being a good caregiver. You may also start to feel anxious and stressed about work, family issues, money and being away from home and other loved ones.

Often, you may be the main support for your loved one and have many demands placed on you. Your family role may change too. You may be expected to do tasks that you are not used to doing, such as managing finances, childcare, cooking and cleaning.

How you respond to stress and anxiety affects your life and your loved one. The key is to learn how to cope and manage in a healthy way. If you need help coping, ask to speak with your social worker or anyone from the transplant team. We offer many resources to help.

Communication and Sharing

If you have a hard time talking about your loved one’s treatment with family or friends, ask your social worker for help. We can suggest ways to share information. For example, some caregivers hold regular family meetings.

It is also important to be open with the transplant team. Speak with the transplant coordinator if you feel communication is an issue. Your social worker and patient advocate can also help.

Emotions*

Being sad or moody is normal. Sometimes, how you feel that day is related to how well your loved one is doing with their emotions. Each person

has different feelings. There is no right way for you to feel. Speak with the transplant team if these feelings or changes start to affect your daily activities or if you feel you are unable to do things that are normal for you. Some feelings that may come and go include:

- **Sadness.** It is okay to feel sad. But if it lasts for more than 2 weeks and it keeps you from doing what you need to do, you may be depressed.
- **Anger.** You may be angry at yourself or family members. You may be angry at the person you are caring for. Or you may be angry that your loved one has cancer. Sometimes, anger comes from fear, panic or stress. If you are angry, try to think of what makes you feel this way. Knowing the cause may help.
- **Grief.** You may be feeling a loss of what you value most. This may be your loved one's health. Or it may be the loss of the day-to-day life you had before the cancer. Let yourself grieve these losses.
- **Guilt.** Feeling guilty is common, too. You may think you are not helping enough. Or you may feel guilty that you are healthy.
- **Loneliness.** You can feel lonely, even with lots of people around you. You may feel that no one understands your problems. You may also be spending less time with others.

**Adapted from the National Cancer Institute's Caring for the Caregiver.*

Talk to your social worker or anyone from the transplant team. We are here to support you and can refer you to local services and resources.

Fatigue

Fatigue is more than just feeling tired. It can have a major effect on your quality of life.

The emotional and physical stress of taking care of someone can cause fatigue. Sometimes, you can become mentally fatigued, and may have a hard time thinking and doing daily tasks. Also, you may have fatigue if you are not sleeping, eating

well or are worrying too much. Be sure to get enough sleep, eat healthy foods, take short walks and exercise daily. Try to keep a normal routine as much as possible.

Take time for yourself and your needs. Speak with the transplant team to find out when you need to be at the hospital and when you can take a break. Ask family members and friends for help.

Fear

It is important to remember that some things are beyond your control and not knowing the outcome can be scary. Some caregivers feel afraid because they have never been a caregiver before and do not want to fail. It is okay to feel afraid. Make a list of things you do well, and ask for help with things that are more challenging. Journaling and talking to other caregivers may help.

Resentment

Sometimes, caregivers feel so burdened or weighed down by all that they have to do. Being a caregiver can take a toll on your work and personal life. You might even have feelings of resentment towards your loved one. Sometimes this is caused because of a conflict between meeting your loved one's needs and your own.

Be realistic and set limits as to what you can or cannot do. The important thing to remember is to ask for help.

What You Can Do

- Ask your transplant coordinator about pre-transplant scheduling.
- Talk to the transplant team if you are feeling overwhelmed, anxious or stressed.
- Use MD Anderson resources, such as myCancerConnection, the Integrative Medicine Center, Spiritual Care and Education and The Learning Center.
- Ask about community resources. Your social worker will help you find what resources are available in your community.

“We were able to get some literature from the librarians in The Learning Center. Several of them had expertise in the particular cancer in my family’s case. We felt very grounded, very armed with information and very connected throughout the process.”

— Caregiver

- Join a support group. Ask your social worker for a list of MD Anderson and community support groups.
- Ask questions about the treatment plan or your role as caregiver.
- Express your feelings about caregiving. Many people at MD Anderson are trained to support you through the process.
- Do not feel like you have to do everything on your own.
- Try not to be too hard on yourself. Caregiving can be a challenge, and some days you might wish you did not have to do it.
- Take time for yourself. You need breaks to rest and recharge. Check with the health care team to find out when your loved one is safe to be left with medical caregivers.

Remember, always ask us for help. We are here for you!

Spirituality and Caregiving

Spirituality is not easy to define. Many say it is a connection to something larger than they are. Some explain it as a personal relationship with God or a higher power.

People grow spiritually based on many things. Families have unique histories and cultures, and personal experiences play a role, too. Some people

practice public worship, while others pray or meditate alone. Others look to nature or art. Many people find their spirituality to be a source of strength, comfort and purpose.

We are here to support you in your spiritual needs and to provide resources that you might find helpful. Ask to speak to a chaplain to learn more.

Pre-transplant Spiritual Preparation

When preparing for your loved one’s transplant, you may consider these questions.

Spiritual Resources

- What are my spiritual resources at home?
- What will my spiritual resources be at MD Anderson?
- Where are the places of worship and other reflective spaces in Houston?
- While at MD Anderson, how do I arrange certain ceremonies or rituals?

Community Help

- How can community members at home support me?
- How do I contact a religious or spiritual community in Houston?
- How do I get in touch with support groups at MD Anderson and at home?

Items to Bring

- What spiritual items do I need to pack?
- Should I bring religious books, prayer books, other spiritual or meaningful writing, prayer beads, spiritual symbol, pictures or music?

Spiritual Support at MD Anderson

Chaplains through Spiritual Care and Education are available 24 hours a day for spiritual support. Also, the Stem Cell Transplant Program has its own chaplain who is available to you. If you would like to speak with a chaplain, ask your nurse to page the chaplain for you.

Our chaplains serve people of many spiritual backgrounds. They help you make the most of spiritual resources. They can also respond to requests, such as reading sacred texts or meeting with a religious leader or representative.

The following resources are also available to you:

- Prayer and meditation rooms. Many are open 24 hours a day.
- Scheduled services in the Freeman-Dunn Chapel, located in the Main Building, Floor 1, near Café Anderson.
- Worship services, nature scenes, music, guided meditation and other spiritual programs on TVs in inpatient rooms. Ask for a copy of the **Patient Education Video Guide: MDA-TV** for a list of programs and channels.
- Spiritually supportive reading materials. Ask your chaplain for more information.
- Support groups through Spiritual Care and Education and Integrative Medicine Center.
- Many people find comfort in listening to music. Relaxation music CDs are available at The Learning Center.

Your Spiritual Expectations

Cancer might cause changes in your spiritual life. Having good days and bad days is normal. Ask for support and remember:

- Be gentle and patient with yourself. Being a caregiver is hard physically, emotionally and spiritually.
- Holding something that represents your loved one, your hope or faith can be a type of prayer. If it helps, carry a photo, wedding ring, spiritual symbol – even a copy of daily lab results or medical reports.
- Sometimes, it may be too hard to turn to your usual spiritual practices. Prayer may not come easily, or it may be hard to read or focus. The usual feelings you have from spiritual support and guidance may change or disappear. While you might feel like you are losing your faith, this struggle is okay and normal. Talk with a chaplain for help with these feelings.
- Focus on the goal, but live in the day-to-day. Each day contains small gifts. It might be a smile, word or act of kindness from someone. You might find joy in an email, phone call, card or an unexpected quiet moment. Enjoy these daily comforts.



Resources and References

Tips for Stem Cell Transplant Caregivers

Here are some helpful tips for you:

- Take care of yourself. Know your limits and take everything one day at a time. The transplant process can be long and challenging. Let us help support you.
- Contact the social worker for housing and support information after the first clinic visit.
- Attend all admission, discharge and educational classes with your loved one so you have the information you need.
- Keep a journal to write down questions, instructions and information.
- Make sure you are available when the patient is discharged.
- Arrange for a back-up caregiver in case you need a break.
- Check your loved one's schedule often for any new appointments or changes.
- Keep the stem cell transplant team's contact sheet with you in case you need to call.
- Sign up for MyChart, a secure, personal website for patients.
- Use MD Anderson resources, such as Integrative Medicine Center and myCancerConnection. Also, support groups, one-to-one counseling and other resources are available especially for caregivers.

- Visit the Learning Center for the **Stem Cell Recommended Resources**, mdandersontcl.libguides.com/stemcell

For a complete list of MD Anderson Services and resources, ask the care team for a copy of the Resources and Services guide

National and Local Resources

Be The Match (National Marrow Donor Program)
<http://bethematch.org>
800-627-7692

This site provides updates and facts about unrelated marrow, cord blood and peripheral blood stem cell transplantation.

Blood & Marrow Transplant Information Network
<http://bmtinfonet.org>
847-433-3313 or toll-free 888-597-7674

A non-profit organization dedicated exclusively to serving the needs of persons facing a bone marrow, blood stem cell or umbilical cord blood transplant.

Bone Marrow Donors Worldwide
<https://www.wmda.info/>
+31-88-505-7900

This organization collects the HLA phenotypes (tissue types) of volunteer bone marrow donors and cord blood units, and coordinates their worldwide distribution.

Bone Marrow Foundation

<http://www.bonemarrow.org>

212-838-3029 or toll-free 800-365-1336

A nonprofit organization created to provide financial assistance, education and support to bone marrow transplant patients and their families. Two unique parts of this site include a “Support Line” and “Ask the Expert” features.

CancerCare

<http://www.cancercare.org>

800-813-4673

A national nonprofit organization that provides free professional support services to anyone affected by cancer, people with cancer, caregivers, children, loved ones and the bereaved. CancerCare programs include counseling and support groups, education and financial assistance.

Dan’s House of Hope

4917 Jackson St

Houston, TX 77004

713-239-3464

info@danshouseofhope.org

Dan’s House of Hope offers the warmth and comfort of home in a B and B-style accommodation for young adult cancer patients and caregivers receiving treatment at hospitals in the Texas Medical Center. A caregiver is required for each patient guest. Patient-guests must provide contact information for their doctor and HCF. There is no nightly stay fee charged, but donations are gratefully accepted.

Dream Foundation

<http://www.dreamfoundation.org>

888-437-3267

A nonprofit organization that grants final wishes to terminally ill adults.

Fertile Hope

<https://www.livestrong.org/tags/fertile-hope>

Fertile Hope is a national, nonprofit organization dedicated to providing reproductive information, support and hope to cancer patients whose medical treatments present the risk of infertility.

Help Hope Live - National Transplant Assistance Fund

<https://helphopelive.org/>

800-489-3863

This nonprofit organization’s home page provides financial, social and emotional support to transplant candidates.

Hendrick Marrow Program

<http://bethematch.org>

800-627-7692

A grant program to help patients pay for post-transplant costs that support the success of the transplant and relies on the social workers to screen patient finances and request assistance when needed.

Leukemia and Lymphoma Society

<http://www.lls.org>

800-955-4572

This organization supports cancer research and provides information and financial help to patients with leukemia. It also offers support groups for patients and their families and provides referrals to other sources of help in the community.

National Bone Marrow Transplant Link

<http://www.nbmtlink.org/>

800-546-5268

This site provides information on bone marrow transplants and publications designed to help you understand and deal with the logistics of bone marrow transplantation, finances and medical insurance. It includes frequently asked questions, BMT survivor stories and peer support program information.

Stupid Cancer

<http://stupidcancer.org>

Stupid Cancer, a nonprofit organization, is a leader in young adult cancer advocacy, research and support. We offer a lifeline to the young adult cancer community by helping those in need feel normalized and connected to their peers.

Glossary

Absolute neutrophil count (ANC): The actual number of neutrophils (a type of white blood cell) in the blood.

Advance directive: A legal document outlining your wishes should you be unable to communicate. Examples of documents that make up an advance directive include Directive to Physicians (Living Will), Power of Attorney for Healthcare, and Out-of-Hospital Do Not Resuscitate (DNR).

Allogeneic (A-loh-jeh-NAY-ik): A graft or tissue from someone other than the patient, usually a matched sibling (a brother or sister), but may be a matched unrelated volunteer donor.

Allogeneic bone marrow transplant: Transplants of bone marrow from one person to another person who is of the same tissue type.

Allogeneic stem cell transplant: A procedure in which a person receives blood-forming stem cells (cells from which all blood cells develop) from a donor who has similar, but not identical, genes. It is often a sister or brother, but could be an unrelated donor. Stem cells can be harvested from a newborn's umbilical cord.

Antibody: A protein produced by the white blood cells (leukocytes) to battle foreign substances, such as bacteria, that enter the body.

Antigen: A foreign substance that causes the production of antibodies.

Apheresis (af-uh-REE-sis): A procedure in which peripheral blood stem cells (PBSC) are collected from the circulating blood. Blood is drawn from a donor/patient and then circulated through a machine that separates stem cells. The remaining blood is given back to the donor/patient. This procedure is done prior to treatment.

Autologous (aw-TAH-luh-gus): A graft or tissue that is taken from the patient and then returned to the patient.

Autologous bone marrow transplant (ABMT): A patient's own bone marrow is used for transplant after treatment.

B cells: Another term for B lymphocytes. These cells develop from stem cells and are involved in immunity and the secretion of antibodies.

Biotherapy: A type of treatment that uses biological agents that are natural or man-made substances that help your normal defenses fight cancer or cause the cancer cells to become normal cells.

Blood cell separator: An apheresis machine that spins blood and separates out the stem cells from the blood.

Bone marrow: A spongy tissue found in large bones of the body, such as the hip bones and breastbone that produces blood cells.

Bone marrow collection (harvest): A procedure that is performed while the donor is under general anesthesia. Multiple punctures are made into the posterior hip bone, and marrow is aspirated into a syringe and placed in the collection bag.

Clinical trials: Medical research studies conducted with volunteers. Each study is designed to answer scientific questions and to find better ways to prevent, detect or treat cancer.

Conditioning: A phase in the transplant process that involves combining high doses of chemotherapy and/or radiation to destroy cancer cells more effectively than standard doses of chemotherapy.

Cord blood: Stem cells that are removed from the umbilical cord of a newborn baby.

Cryopreserve: A process that involves freezing items such as cells, sperm or embryos and preserving them for later use.

Cyclosporin (SY-klo-spor-een): A drug used to help reduce the risk of organ or bone marrow rejection (graft vs. host disease) by the body. It is also used in clinical trials to make cancer cells more sensitive to anticancer drugs.

Cytokine (SY-toh-kine): A substance that is produced by cells of the immune system and can affect the immune response. Cytokines can also be produced in the laboratory using DNA technology and is given to people to affect immune responses.

Day 0: The day the patient receives a transplant.

Day - 1, 2, 3, etc.: The number of days prior to the day of transplant.

Day + 1, 2, 3, etc.: The number of days after the day of transplant.

DNR: Do not resuscitate. Used as a directive to the health care team not to perform CPR (cardiopulmonary resuscitation).

Engraftment: When the transplanted stem cells start to grow and make healthy levels of new blood cells.

Engraftment syndrome: Symptoms associated with engraftment (e.g., fever, red rash).

Erythrocytes (eh-RITH-roh-site): A cell that carries oxygen to all parts of the body. Also referred to as a red blood cell (RBC).

Graft failure: A complication of stem cell transplant. The transplanted stem cells do not grow in the recipient's bone marrow and do not produce enough new white blood cells, red blood cells and platelets.

Graft-versus-host disease (GVHD): A reaction of donated bone marrow or peripheral stem cells against the recipient's tissue. A common occurrence with allogeneic transplant. Signs and symptoms include skin rash, redness, yellowing of the skin, cramps, diarrhea and fever.

Granulocytopenia (GRAN-yoo-loh-SY-toh-PEE-nee-uh): A decrease in white blood cells.

Growth factor: Substances given to transplant patients to stimulate the production of blood cells. It is also given to stem cell donors to mobilize stem cells into the bloodstream for collection.

Haplo-identical: When a donor is the parent or child of the patient, and therefore only half of the human leukocyte antigens (HLA) match.

Hematopoiesis (hee-MA-toh-poy-EE-sus): The forming of new blood cells.

Hematopoietic growth factors (hee-MA-toh-poy-EH-tik): A group of proteins that causes blood cells to grow and mature.

Hematopoietic progenitor cell: Stem cells obtained from marrow or blood, not embryo tissue.

Hemoglobin (HEE-moh-GLOH-bin): A protein inside the red blood cells that carries oxygen from the lungs to the rest of the cells in the body.

Histocompatibility (his-toh-kum-pat-uh-bil-i-tee): Similarity between the donor tissue and the patient or recipient tissue.

Human Leukocyte Antigen (HLA) typing: A special blood test that is done to identify a person's key antigens and then compared with a donor's results to determine compatibility.

Hospice care: A program that provides special care that is focused on physical, emotional and spiritual comfort for people who are near the end of life and for their families. Care can be at home, in a hospice facility or within a hospital.

Human Leukocyte Antigens (HLA): Proteins that are found in white blood cells that make each person's tissue typing unique. HLA plays an important role in activating the body's immune system to respond to foreign organisms.

Immunocompromised: An immune system that has been weakened or impaired by disease or treatment.

Immune system: Special cells, proteins, tissues and organs make up the immune system. It is the body's defense against disease and infections.

Immunosuppression (IH-myoo-noh-suh-PREH-shun): Suppression of the immune system by using drugs or radiation to prevent the rejection of grafts or transplants, or to control autoimmune diseases.

Immunotherapy (IH-myoo-noh-THAYR-uh-pee): Treatment of disease by stimulating, enhancing or suppressing an immune response to fight infections and other diseases. It is also used to lessen side effects that may be caused by some cancer treatments. Also referred to as biological therapy, biotherapy or biological response modifier (BRM).

Informed consent: A process in which a person learns about a specific clinical trial or medical procedure, including information about its design and potential risks and benefits, before deciding to participate or have the procedure. Patients are asked to sign a consent form documenting their understanding of the medical procedures or clinical trial.

Leukocytes (LOO-koh-site): Cells that help the body fight infections and other diseases. Also referred to as white blood cells (WBC).

Leukapheresis (LOO-kuh-feh-REE-sis): Removal of the blood to collect specific blood cells. The remaining blood is returned to the body. Usually used in leukemic patients when the white cell count gets too high. This process is performed by using continuous flow cell separators or filtration techniques.

Living Will: A Living Will is an outline of your health care wishes. It gives specific details about what treatment you do or do not want. A Living Will takes effect only when you are in the terminal phase of illness or injury. It may address topics like artificial nutrition, hydration, dialysis, breathing support and comfort care.

Lymphocyte (LIM-foh-site): A type of white blood cell. Lymphocytes have a number of roles in the immune system, including the production of antibodies and other substances that fight infection and diseases. B lymphocytes directly attack virus infected cells.

Matched Unrelated Donor (MUD) transplant: A stem cell or bone marrow transplant from a MUD.

Mobilization: Stimulating the bone marrow to increase the number of stem cells that circulate in the blood through chemotherapy and/or injecting a growth hormone.

Monoclonal antibodies (MAH-noh-KLOH-nul AN-tih-BAH-dee): Antibodies that are made in the lab rather than by a person's own immune system. This type of treatment is considered a form of passive immunotherapy. These treatments do not require the person's immune system to start the fight against the cancer. Once the antibodies are given, they can then recruit other parts of the immune system to destroy the cancer cells. Monoclonal antibodies can be used alone, or they can be used to deliver drugs, toxins or radioactive material directly to a tumor.

Mucositis: A complication of some cancer therapies in which the lining of the digestive system becomes inflamed. Often seen as sores in the mouth.

Myelosuppression (MY-eh-loh-suh-PREH-shun): A condition in which bone marrow activity is decreased, resulting in fewer red blood cells, white blood cells and platelets. Myelosuppression is a side effect of some cancer treatments.

Nadir (NEY-deer): The period of time when an antineoplastic drug has its greatest effects on the bone marrow.

Natural killer cells (NK cell): A type of white blood cell that contains granules with enzymes that can kill tumor cells or microbial cells. Also referred to as a large granular lymphocyte.

Neutropenia (noo-troh-PEE-nee-uh): Neutropenia is when the number of neutrophils in the bloodstream is below normal. If this happens, you may be at high risk for getting an infection.

Neutrophil (NOO-tro-fil): The most common type of white blood cell in the bloodstream, which helps defend against bacterial infections.

Peripheral blood stem cells (PBSC) (peh-RIH-feh-rul): Stem cells that circulate in the blood.

Peripheral blood stem cell transplant: Stem cells are removed from the blood and returned after high-dose chemotherapy. This can be done for both autologous and allogeneic transplant.

Plasma cells: A type of white blood cell that produces antibodies.

Platelet: A type of blood cell that helps prevent bleeding by causing blood clots to form. Also referred to as a thrombocyte.

Protective isolation: All persons entering the patient's room must put on a mask and gloves to protect the patient from potential germs.

Protocol: A detailed plan that explains what will be done in a clinical trial and why. It outlines how many patients will take part in the clinical trial, what medical tests they will receive and how often, and the treatment and monitoring plan. Researchers must follow the protocol approved by the Institutional Review Board (IRB).

Purging: The process by which certain types of cells are removed from bone marrow prior to infusion into the patient. In an allogeneic transplant, the donor stem cells may be purged to remove the cells that cause graft-versus-host disease. In autologous transplants, marrow may be purged of lingering cancer cells.

Red blood cells (RBC): Red blood cells carry oxygen to all parts of the body. Also see "erythrocytes."

Reinfusion: The return of healthy stem cells into the body of the transplant recipient.

Stem cell: The "parent cell." Every type of blood cell in the body begins its life as a stem cell. Stem cells then divide and form the different cells that make up the blood and immune system. Stem cells are found in both the bone marrow and the circulating blood. Also referred to as a hematopoietic progenitor cell.

Stem cell rescue process: Another term for stem cell transplant. Healthy stem cells are reinfused to rescue the marrow after high doses of chemotherapy or radiation.

Stem cell retrieval (stem cell harvest): The process of collecting stem cells from the circulating bloodstream after growth factors are given to increase their numbers.

Stem cell transplant: A method of replacing immature blood-forming cells that were destroyed by cancer treatment. The stem cells are given to the person after treatment to help the bone marrow recover and continue producing healthy blood cells. Also see peripheral blood stem cell transplant.

Syngeneic (SIN-juh-NAY-ik): Graft of tissue that is genetically identical to the patient; an identical twin.

Syngeneic bone marrow transplant: A procedure in which a person receives bone marrow donated by his or her healthy identical twin.

T cell: One type of white blood cell that attacks virus-infected cells, foreign cells and cancer cells. T cells also produce a number of substances that regulate the immune response.

T-cell depletion: Treatment to destroy T cells, which play an important role in the immune response. Removing T cells from a donated stem cell graft may reduce the chance of an immune reaction against the recipient's tissues.

T lymphocytes: Cells within the bone marrow responsible for remembering and fighting bacteria and other substances foreign to the body.

Telemetry (tuh-LEM-i-tree): Monitoring the heart using wires that are attached to the chest to transmit the rhythm of the heart using radio waves.

Thrombocytopenia (THROM-boh-sy-toh-PEE-nee-uh): A decrease in the number of platelets in the blood. This condition can cause a person to bruise easily and bleed excessively from wounds, mucous membranes and other tissues.

Total body irradiation (TBI): Radiation therapy to the entire body. It is usually followed by bone marrow or peripheral stem cell transplantation.

White blood cells (WBC): Refers to a blood cell that does not contain hemoglobin. White blood cells include lymphocytes, neutrophils, eosinophils, macrophages and mast cells. These cells are made by bone marrow and help the body fight infection and other diseases.

**Word pronunciations – www.cancer.gov/dictionary/*

29

Notes

[illegible]

Notes

[illegible]

Notes

[illegible]

