Stem Cell Transplantation and Cellular Therapy Caregiver Guide

THE UNIVERSITY OF TEXAS
MD Anderson ~~Cancer~~ Center
Making Cancer History®

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What to Expect

A caregiver is a person who provides help to someone in need. Often, that help is with activities that someone can no longer do on their own. Sometimes, helping is just being there in hard times to offer encouragement and support.

Family members, friends and neighbors can all be caregivers. This guide is written for you because you provide care for your loved one in many ways:

- Volunteer to help during tough times
- Assist with tasks that your loved one cannot do on their own
- Offer help and support
- Stay committed and figure out ways to help

What Caregiving Means

Caregiving can mean helping with daily tasks. This includes going to doctor appointments, making meals or picking up medicines. It can also mean helping your loved one cope with feelings and being there for them when they need to talk.

The Role of 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, it can be overwhelming to become a caregiver.

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

Being a Stem Cell Transplant Caregiver

Stem cell transplant is a treatment with unique tasks for the caregiver which change over time. The transplant timeline occurs in 4 phases:

- Before transplant
- Transplant
- Care after transplant
- Recovery and returning home after transplant

It is important that you take care of yourself at each phase. As a caregiver, you are a vital member of the transplant team. Set realistic expectations for yourself since much of the transplant process is beyond your control. Do the things you feel you can do and use the resources to help you throughout the transplant process. The health care team is also here to support you.

Phase 1: Before Transplant

Before the transplant, caregivers help get the patient ready for 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 questions, talk to the transplant team.

How to Prepare Before the Transplant

Your Home

If you are moving to Houston or will be away from home often, consider these things:

- Caring for children and pets
- Having mail delivery to a Houston P.O. box, mail forwarding or hold mail

- Caring for your home and property
- Keeping in contact with the care team by cell phone

Important Forms

Some people need to complete forms for their employer before the transplant. Common forms include the Leave of Absence form and the Family Medical Leave of Absence form. Complete any forms you need and bring them with you to the first clinic visit. Allow the staff 2 weeks to complete and return the forms to you.

Bring copies of advance care planning documents, also called advance directives, such as a living will and health care power of attorney. These documents outline the patient's choices for care. The care team will put this in their medical record. If you need information about completing advance care planning documents, contact your social work counselor.

Caring for 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 nasal vaccine.
  - Refill prescriptions or get written prescriptions to fill at a local pharmacy.
- Learn about available MD Anderson caregiving resources and education.

Caring for Your Loved One

You are an important resource to your loved one. Often, you are the one person who knows everything that is going on with them. Here are some things that will help you:

- Learn about your loved one's cancer and the stem cell transplant process. Read the **Stem Cell Transplantation and Cellular Therapy** patient education guide provided at the first clinic visit.
- Learn about MD Anderson resources and the transplant process:
  - **Transplant Pre-Admission** virtual class
  - **Central Venous Catheter Care** in-person class

Communication With the Transplant Care Team

Contact Information

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

MyChart is a secure web portal and app that connects you to MD Anderson. You can access your account from any computer or download the MyChart app. With MyChart, you can:

- See your appointment schedule and health information.
- Refill prescriptions.
- Access patient education document and video libraries.
- Pay bills.
- Send messages.

You can sign up for MyChart at MyChart.MDAnderson.org. You may also call askMDAnderson at 877-632-6789 if you need help to log in or change your password. Health information specialists answer the phone weekdays, 7 a.m. to 11 p.m. and 8 a.m. to 7 p.m. on weekends and holidays.

Your main contact before the transplant is the transplant coordinator. Your patient services coordinator (PSC) schedules all of the appointments. You can view appointment schedules using MyChart, get a copy from any MD Anderson information desk or from your PSC.

Phone Numbers
The care team needs your cell phone number or local number so that they can reach you at any time. Ask for the care team contact sheet from the transplant coordinator and keep it with you in case you need to make a call quickly. It will have numbers for the clinic nurse, transplant coordinator, business center, PSC, research nurse and social work counselor.

Patient History Form
If needed, help your loved one complete a patient history form when they arrive for their appointment. The transplant team needs the medical history about their cancer in order to plan the best treatment.

Clinic Appointments
Ask questions if there is something you do not understand or if you are not sure what to do next.

Symptoms to Report

Sometimes the care team needs to treat symptoms before the transplant. These symptoms are often caused by other treatments or infection. Tell the care team if your loved one has:

- Fever of 100.4°F (38°C)
- Flu-like symptoms or other symptoms that may be a sign of infection
- Fatigue
- Bone pain
- Nausea
- Vomiting
- Diarrhea
- Loss of appetite
- Any other pain, or if there are any changes in pain level.

What You Can Do

- Report any of your loved one's symptoms to the care team.
- Ask for support when you need it. Caregiving can be tough and there are many resources to help you.
- Visit MDAnderson.org to learn about MD Anderson resources.
- Contact myCancerConnection if you would like to speak with other caregivers who have gone through the transplant process with a loved one. Call 713-792-2553 or 800-345-6324.
- Meet with your social work counselor to discuss housing and financial assistance options.
- Become familiar with the Houston area if you are moving.
- Write down questions you want to ask or information you want to discuss. Also write down important information, phone numbers and appointments.
- Budget money for food, transportation, housing and insurance co-pay fees.
- Do not feel like you need to know everything. The care team will tell you about many resources to help you throughout the transplant process.
- Do not hide your emotions. You may feel anger sadness, guilt, frustration and grief. Let the care team know how you are feeling.

Phase 2: Transplant

The transplant treatment phase is a time when the care team encourages you, the caregiver, to rest. During the transplant phase, your loved one will be in the hospital and the staff will do much of the daily care. This will allow you to focus on providing emotional support.

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

How to Prepare for Inpatient Transplant

Caring for 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 such as a clean blanket and pillow and electronic devices with their charging cords like a laptop or tablet.
- Use services like the Integrative Medicine Center, which offers programs in relaxation, yoga, exercise and more.
- Eat well. You may bring food into the hospital for yourself or your loved one. You may store leftover food in the refrigerators located in the family rooms. The staff will throw away all food after 3 days or sooner if it is not labeled with the date and your name.
- Call 713-792-3463 to order guest meals. Guest meals are delivered directly to the room and must be paid for at time of delivery.
- Keep your clothes clean. A laundry room is available in the Main Building on Floor 6. Machines and soap are provided free of charge.
- Protect yourself from infection. Wash or sanitize your hands often and stay away from people who are sick.
- Organize your own medicines and remember to take them as prescribed. The hospital staff cannot give you medicine, prescriptions or help you with your medicines.
- Take part in caregiver support resources. Ask the care team for more information.

Caring for Your Loved One

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

- Follow hand washing guidelines. Use the hand sanitizer outside the room or wash with soap and water. Ask the nurse which method you should use.
- Wear a mask and gloves if you are not feeling well or are getting over a cold. **Do not** stay with your loved one if you are sick or coughing, sneezing or have a fever.
- You may use the shower in the hospital room only after your loved one has finished showering. If you use it first, tell your loved one's nurse so arrangements can be made to have it cleaned.
- It is OK use the toilet in your loved one's room, but you are strongly encouraged to use the visitor toilets located throughout the unit.
- Remind family and friends that plants or flowers are not allowed in the transplant unit. Cards, candy and stuffed toys are OK.
- **Do not** help your loved one out of bed. Call the nurse for assistance to help prevent a fall.
- Allow your loved one to do as much as possible, such as eating, dressing and showering. This will help maintain their strength.
- Motivate your loved one to be active at least 3 times a day if possible. Encourage them to walk, attend an exercise class or use the exercise bike. Exercise helps maintain strength and energy during treatment.
- Take advantage of quiet time. The staff will dim the lights on the unit every day for 1 hour. Staff only enter your loved one's room during this time if needed so patients and caregivers have time to rest.
- Encourage your loved one to use the incentive spirometer every 2 hours while awake. This helps keep the lungs healthy and prevents breathing problems while in the hospital.
- The care team will do blood tests each morning around 4:30 a.m. Lab tests are done early so 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. The care team will do tests and exams, take vital signs and give medicines. At night, the staff will try to limit how often they enter the room.

Communication With the Transplant Care Team

Contact Information

The care team needs your cell or local phone number on file so they can contact you at anytime.

Important Forms

Keep a copy of your loved one's advance directives and confirm that copies are in the medical record.

Daily Rounds

An inpatient stem cell transplant team will see your loved one daily, usually before noon. This is a team of doctors, nurses, pharmacists and others. The stem cell transplant inpatient doctor may not be your clinic doctor. You may ask questions and talk about any changes or concerns. It helps to write down your questions so you do not forget what you want to ask them.

If you have a question or concern before or after the daily round, talk to the nurse. If needed, they will contact a member of the care team. Advance practice providers, such as physician assistants and advanced practice nurses, are available throughout the day to help. Members of the care team are also on call at night, weekends and holidays.

Symptoms to Report

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

- Nausea or vomiting
- Fatigue
- Diarrhea
- Pain
- No appetite
- Mouth sores
  - Certain chemotherapy can cause extreme mouth sores that may spread down into the throat, which makes it hard to drink or eat.
- Fever, chills or coughing, which are signs of possible infection
  - After the stem cell transplant, the white blood cells may go down to 0. This means that your loved one would not be able to fight an infection, including pneumonia.
- Graft versus host disease (GVHD)
  - With an allogeneic transplant, your loved one may feel the effects of GVHD, such as a rash, extreme diarrhea or yellowing of the skin and eyes. This is called jaundice.
- Side effects of filgrastim
  - After the transplant, the care team will give your loved one a medicine called filgrastim. This medicine may cause fatigue, bone pain and lower back pain.

The care team can give medicine to help your loved one feel more comfortable if they start having symptoms and side effects. Refer to MD Anderson's **Chemotherapy Guide** bit.ly/ChemoGuide-MDAnderson for more information.

What You Can Do

- Support your loved one on the day of transplant.
- Be in the room when the inpatient team sees your loved one every day.
- Expect your loved one to have nausea, vomiting, fatigue or a low appetite.
- Report any changes in your loved one's condition to the care team **right away**. You may be the first to notice changes. Signs and symptoms of infection include:
  - Chills.
  - Fever of 100.4°F (38°C) or more.
  - Redness or irritation around the IV site.
  - Discharge from a wound, incision or IV site.
- Measure, save or tell the nurse about any food and liquids your loved eats and drinks, also known as "intake" and when your loved one urinates, has stool or vomits, also known as "output." The care team needs to make sure your loved one is eating and drinking enough.
- Expect your loved one's blood counts to be very low during a time called nadir. This is when they are most at risk for infection and may need blood transfusions more often.
- Consider donating blood or platelets. Call the MD Anderson Blood Bank at 713-792-7777 for an appointment.
- Tell the care team about your loved one's choices for care, any concerns about the transplant process or your need for support. The care team can connect you with caregiver resources at MD Anderson.
- **Do not** give your loved one any medicines, supplements or vitamins that have not been approved by the doctor and pharmacist. Always check with your loved one's doctor before giving them any medicines. Even over-the-counter medicines can affect the transplant.
- **Do not** move, touch or try to work any medical equipment. Ask your nurse for help.
- **Do not** turn off the bed check alarm. This safety feature alerts your nurse to help your loved one get out of bed safely and prevent a fall.
- If you feel your loved one is having pain, or if you are concerned about the amount of pain medicine, tell your nurse **right away.** **Do not** push the button on their pain pump if they have one. This pump should only be controlled by the patient.
- Let your loved one answer questions if they are awake and alert. Your input is important, but the care team wants to let your loved one speak first.
- You do not need to be at the hospital 24 hours a day. Let the inpatient care team attend to your loved one when you need time for yourself.

Leaving the Hospital

An information board is located in the hospital room to help you plan and prepare for your loved one's hospital discharge. It will list their expected discharge date and goals. If this information is not listed, ask your transplant care team for information.

The doctor will tell you when your loved one is ready for discharge. They must meet certain conditions before they can be discharged:

- Have an absolute neutrophil count (ANC) of at least 1500
- No fever for 72 hours
- Be able to swallow pills and drink at least 8 to 10 cups or 2 liters of fluids each day
- Do simple activities, such as walking, dressing, brushing their teeth, using the bathroom and feeding themselves.
- Have local housing and a caregiver

Before your loved one is discharged from the hospital, you will need to:

- Watch the stem cell transplant discharge videos. There are specific videos for autologous patients and 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.
- Pick up prescriptions at the MD Anderson pharmacy or arrange with the nurse to have them delivered to the hospital room. You can also choose to use a local pharmacy.
- Pack your loved one's personal items ahead of time if possible. If needed, ask for a cart to help bring these things to your car. The care team's goal is to have your loved one discharged from the hospital before noon.
- Make sure you have a copy of your loved one's discharge paperwork so you can bring it to their next Fast Track or Ambulatory Treatment Center (ATC) appointment.

Phase 3: Care After Transplant

After your loved one is discharged from the hospital, you will be their primary caregiver. This means that you must care for them 24 hours a day, 7 days a week. You need to be aware of what is going on with them at all times.

It is common for transplant patients to be readmitted to the hospital for care during this phase. It is OK and should be expected. This is not considered a setback.

How to Prepare for After the Transplant

Caring for Yourself
Outpatient care requires that you be with your loved one at all times. The transplant care team encourages 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.
- Take notes. Write down questions or concerns.
- Do errands, 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 provider or doctor 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 or sanitizing your hands often. Stay away from people who are sick.
- Exercise every day 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 doctor for yourself, if needed.

Caring for 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 they are 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.
- 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).
    - May sometimes have follow-up appointments in the Fast Track Clinic.

At follow-up appointments your loved one is seen by a doctor, an advanced practice provider, which is a physician assistant or an advanced practice nurse, pharmacist, nurse and other members of the care team 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 they may require blood transfusions and fluids.

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

- Be with them at all times. It is OK to take breaks or run errands when they are 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 directed.
- Bring them to and from clinic appointments.
- Help with activities of daily living, such as cooking, bathing, dressing and laundry.
- Help with their central venous catheter (CVC) care using the information you learned in class and any instructions given to you by the transplant care team.
- Keep track of their medicines and contact the MD Anderson pharmacy or your local pharmacy for refills, as needed.
- Watch for and keep a record of any symptoms such as fever, nausea, vomiting, diarrhea, skin rash, mood or behavior changes.

Communication with the Transplant Care Team

Phone Numbers

Keep the phone numbers to your preferred pharmacy available so the care team can send prescriptions quickly.

Symptoms to Report

When to Call the Fast Track Clinic or ATC

For any of the following symptoms or conditions, call the Fast Track Clinic if your loved one had an allogeneic transplant or call the Ambulatory Treatment Center if your loved one had an autologous transplant. After business hours, weekends and holidays, call 713-792-2121 to speak to a nurse with askMDAnderson.

- A sore mouth that stops them from taking medicine or drinking liquids
- Nausea or vomiting that does not get better 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 they urinate or a decrease in the amount of urine

When to Seek Emergency Care

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

- A fever of 100.4°F (38°C) or higher, unless you were given different instructions
- 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, also called 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.

The MD Anderson Acute Cancer Care Center is open 24 hours a day, 7 days a week. From Holcombe Boulevard, turn at Entrance Marker 3. The entrance is on Bates Street for patient drop off only. You can park in Garage 2.

What You Can Do

- Have someone with the patient at all times.
- Wash or sanitize your hands often and encourage them to do the same. This helps to reduce the risk of infection.
- Take time for yourself when they are 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 about and use MD Anderson and community resources.
- Report any changes in their 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 the patient.

Phase 4: Recovery and Returning Home After Transplant

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

How to Prepare for Recovery and Returning Home

Caring for Yourself

The transition to home can be a challenge since your loved one will no longer receive 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 go back to work or other duties.
- Do activities that you enjoy and continue your interests and activities to give yourself a break from the caregiver role.

Caring for 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 appointment covers information on continuing recovery at home and 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, they will receive instructions from their stem cell transplant doctor 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 doctor 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 them.

- Encourage your loved one to do more as they get stronger.
- Drive until your loved one is cleared to drive again.
- Encourage safe activity. It may take a few months before they can resume normal activity levels. Expect that they 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 clinic appointments, as you are able.
- Limit daytime naps to 1 hour or less.
- Ask for a physical therapy consult if they are not making progress with strength building or independence.

Communication With the Transplant Care Team

When you return home, all medical issues for your loved one will be reported to their local doctor. The MD Anderson transplant care team prefers that your loved one be seen by a cancer doctor, also called an oncologist, or a hematologist, which is a doctor that treats blood diseases, for their care. If a medical issue occurs, contact your local doctor to address the problem. Then, you may update the transplant care team.

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

You may message the transplant care team on MyChart about non-urgent issues and updates.

You may also call the Stem Cell Transplant Center at 713-792-6100, Monday through Friday, 7:30 a.m. to 5 p.m. to reach your transplant care team.

Ask your loved one's local doctor to sign up for EpicCare so they may access their medical records online. To sign up, your local doctor can email MD Anderson's Physician Relations department at PhysicianRelations@MDAnderson.org or call Physician Relations at 713-792-2202 or 800-252-0502. For more information, visit MDAnderson.org/PhysicianRelations.

Symptoms to Report

Report any of the following signs and symptoms to your local doctor or the transplant care team:

- Nausea, vomiting or diarrhea
- Not eating
- Cannot take medicines by mouth
- Mouth sores
- Pain
- Fatigue
- GVHD symptoms such as rash, severe diarrhea or yellowing of the skin or eyes.

Go to the MD Anderson Acute Cancer Care Center or the nearest hospital emergency center **right away** if your loved one has a temperature higher than 100.4°F or 38°C.

What You Can Do

- Read the **Stem Cell Transplantation and Cellular Therapy** patient education guide. It provides information about caring for your loved one at home. Care instructions are different for autologous and allogeneic transplant patients.
- Get a flu vaccine injection every year. **Do not** receive the nasal vaccine because it is a live virus.
- Follow up with your own doctor so you can stay healthy.
- Tell the transplant doctor before traveling out of the country and discuss any precautions, medicines or vaccines that your loved one may need.
- Keep a list of your loved one's medicines and doctors' phone numbers.
- Help your loved one plan for someone to go with them to MD Anderson for follow-up appointments, especially if they are driving or flying long distances. Someone should be with them in case of an emergency.

Caring for the Caregiver

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. The transplant care team does not want these feelings to grow into serious problems.

Anxiety and Stress
You may worry about being a good caregiver. You may also be the main support for your loved one and start to feel anxious and stressed about balancing caregiving duties, work, family issues, money and being away from home and other loved ones. How you respond to stress and anxiety affects your life and your loved one. The key is to learn how to cope with the demands of caregiving and manage in a healthy way.

If you feel overwhelmed at any time or need help coping, talk with your loved one's care team or ask to speak with a social work counselor. They will work with you to get the support and help you need.

Communication and Sharing

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

Be open with the transplant care team and if you feel communication is a problem, speak with the transplant coordinator, your social work counselor or patient advocate.

Emotions
It is normal and okay to experience a wide variety of feelings that likely range from uncertainty to hope. You may also feel sadness, anger, grief, guilt or loneliness. Sometimes, how you feel that day is related to how well your loved one is doing with their emotions. Share your feelings and concerns with the care team, a counselor, support group or friend.

Depression
Depression is common for caregivers. It can occur during your loved one's treatment or years after. Depression is a medical condition. It is not a sign of weakness or failure and affects everyone differently. Signs of depression include:

- Feeling sad, blue or crying a lot for no reason.
- Feeling guilty, unworthy, helpless and lacking self-confidence.
- Seeing life as meaningless or feeling like nothing good will ever happen again.
- Losing interest in hobbies or activities.
- Wanting to be left alone most of the time.
- Having problems making decisions, remembering things or trouble concentrating.
- Being irritable often, getting mad over little things and over-reacting.
- Having a problem falling asleep or sleeping too much.
- Waking up earlier or later than normal.
- Eating too much or too little so you are losing or gaining weight.
- Feeling restless and tired most of the time.
- Thinking about death or suicide.

It is very important to get help. If you would like to speak with someone about your feelings, call Social Work at 713-792-6195. You can also call, text or chat 988 with the Suicide & Crisis Lifeline for free mental health support 24 hours a day, 7 days a week.

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 experience mental fatigue and may have a hard time thinking and doing daily tasks. You may also have fatigue if you are not sleeping, eating well or if you are worrying too much. Be sure to:

- Get enough sleep.
- Eat healthy foods.
- Take short walks and exercise daily.
- Keep to 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 OK 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
Caregivers may feel 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 may even have feelings of resentment towards your loved one if you are struggling to meet 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 schedules and appointments before the transplant.
- Ask questions about the treatment plan and your role as caregiver.
- Talk to the transplant care team if you are feeling overwhelmed, anxious or stressed.
- Use MD Anderson resources such as myCancerConnection, Spiritual Care and Education and The Learning Center library.
- Ask about community resources. Your social work counselor can help you find what resources are available in your community.
- Join a support group. Visit MDAnderson.org/SocialWork for a list of MD Anderson support groups.
- Express your feelings about caregiving. Many MD Anderson staff and volunteers are trained to support you through the process.
- Remember, you do not have to 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 care team to find out when it is safe to leave your loved one with other caregivers.

Spirituality and Caregiving

Spirituality has many meanings. For some people it means finding a purpose. Spirituality also could be connecting to nature. Others may relate it to formal organized religion. Spirituality is personal.

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?

Items to Bring

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

Spiritual Support at MD Anderson

Chaplains through Spiritual Care and Education are available 24 hours a day, 7 days a week for spiritual support. The stem cell transplant program has its own chaplain who is available to you and your loved one.

The chaplains at MD Anderson 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, open 24 hours a day
- Scheduled services in the Freeman-Dunn Chapel, located in the Main Building
- Worship services, nature scenes, music, guided meditation and other spiritual programs are available on the inpatient MD Anderson TV system.
- Spiritual reading materials
- Support groups through Spiritual Care and Education
- Many people find comfort in listening to music. Relaxation music CDs are available at The Learning Center patient library.

If you would like to speak to a chaplain or learn more about spiritual support and resources, ask the care team to page the chaplain for you.

Spiritual Practices

- 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 or spiritual symbol – even a copy of daily lab results or medical reports.
- Sometimes, it may be too hard to turn to your regular 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 OK 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.

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 the care team help support you.
- Contact Social Work for housing and support information after the first clinic visit.
- Attend all admission, discharge and education 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 your loved one is discharged from the hospital.
- Arrange for a back-up caregiver when you need a break.
- Check your loved one's schedule often for any new appointments or changes.
- Keep the care team's contact information on your cell phone in case you need to call.
- Ask your loved one for proxy access to their MyChart account so you can see their appointments.
- Use MD Anderson resources such as myCancerConnection. Support groups, one-to-one counseling and other resources are available for caregivers.
- View the Learning Center's **Recommended Resources for Bone Marrow and Stem Cell Transplant** at MDAndersontlc.Libguides.com/StemCell.

For a complete list of MD Anderson services and resources, view the **Resources and Services Guide** at bit.ly/ResourcesGuide-MDAnderson.

Notes

Stem Cell Transplantation and Cellular Therapy Caregiver Guide

Revised 07/2025, Patient Education