

 **Sutter Health**
Sutter Cancer Centers

sutterhealth.org/services/smcs-cancer



Autologous Stem Cell Transplant

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How To Contact Your Transplant Team

Transplant Doctor: _____

Phone Number: _____

Medical Coordinator: _____

Phone Number: _____

Social Worker: _____

Phone Number: _____

Financial Coordinator: _____

Phone Number: _____

Welcome to the Sutter Health Cellular Therapy Program

Deciding whether to have an autologous stem cell transplant is difficult. You and your loved ones will likely experience mixed emotions about the process – perhaps both eagerness and anxiety – and have many questions.

This guide provides information regarding autologous stem cell transplant, including the time before and after the blood or marrow transplant (BMT) itself, and all the ways we'll support you throughout.

The BMT team shares a commitment to quality in medical and nursing care, lab services, rehabilitative therapy, social service support and clinical research, so you have access to the latest treatments and therapies. The team will also keep in close communication with your primary care doctor to help ensure coordinated care.

Keep this guide with you to review with your care team members and later, to help with new questions. There's a lot to learn, and you don't need to learn it all at once. Pace yourself and please reach out to your transplant team when you need us.

Autologous Blood and Marrow Transplantation: Frequently Asked Questions

What are stem cells?

Stem cells are “baby” blood cells, or blood-forming cells, produced in your bone marrow. These stem cells eventually become adult blood cells, particularly red blood cells, platelets and white blood cells. Each of these cells has a specific task:

- **Red blood cells** carry hemoglobin, which supplies oxygen throughout your body to tissues and organs.
- **Platelets** clot the blood and prevent bleeding.
- **White blood cells** fight infection.

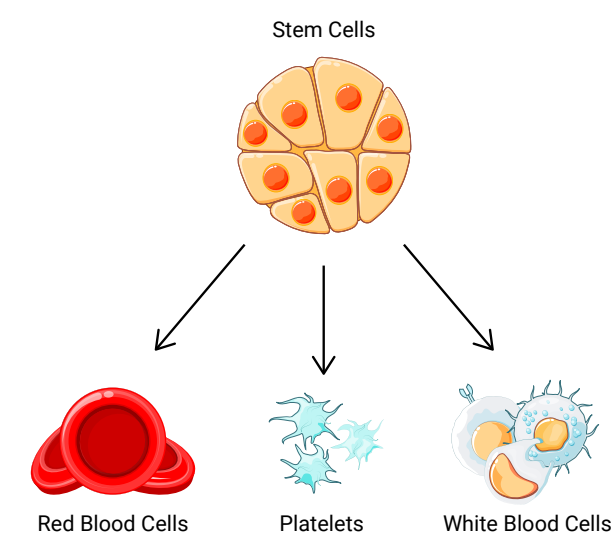
What is a blood or marrow stem cell transplant?

The term “stem cell transplant” describes a transplant using bone marrow or stem cells found in the blood. A blood or marrow stem cell transplant provides a possible cure for blood cancer, or a longer period of disease-free survival. The transplant starts with chemotherapy, radiation or both to deplete the cancer or diseased blood cells. The patient then receives an infusion of their own cells into the bloodstream.

Why are stem cell transplants performed?

A stem cell transplant is used when:

- Your body's bone marrow cannot or fails to make the blood cells your body needs.
- Disease compromises your bone marrow or blood cells.
- You've received high doses of chemotherapy or radiation, and your body needs a replacement of cells lost during these treatments.
- Your body's stem cells don't develop into the blood and other components your immune system needs to function.
- Your cancer returns after previous treatment.
- Transplant is the best treatment for disease control.



Your Transplant Team

A blood or marrow transplant is more than just a series of medical procedures. It's a challenging experience for you and everyone you're close to. Our goal is to create a partnership of care with you, your family and other loved ones. That's why we gather a team of skilled professionals to help meet your needs.

Below are the team members who may contribute to your care.

BMT RN Coordinator

The BMT registered nurse (RN) specializes in stem cell transplants. You'll be assigned a BMT RN coordinator early in the pretransplant phase. Their primary role is to teach both you and your caregivers about the stem cell transplant before, during and after the procedure. They'll also help guide and support you and your care team throughout the transplant process.

Social Worker

A social worker will be available to support your mental health during all stages of your transplant. They'll meet with you to assess any barriers to care and be sure you're managing well. They may:

- Help you establish housing in the area if needed and create a caregiving plan.
- Perform a required mental health assessment as part of the insurance authorization process.
- Help you complete an advanced care plan, which may include a Physician Orders for Life-Sustaining Treatment (POLST). This form gives your doctor specific instructions about what treatments you'd like at the end of life.
- Assist you and your caregiver with the Family Medical Leave Act or Paid Family Leave process.

Our goal is to create a partnership of care with you, your family and other loved ones.

Financial Coordinator

The financial coordinator's role is to help you understand the cost of a transplant and what your insurance covers. They'll work with you to provide guidance between the hospital and your insurance company. Call the financial coordinator with any questions or concerns about your potential financial needs.

Transplant Nurse

Your transplant nurse is specially trained and is there to guide and care for you while you're undergoing treatment. They collaborate with the transplant doctor and other transplant team members to ensure your needs are met.

Case Manager

If you're in the hospital, the case manager helps anticipate needs in advance of your discharge to help ensure a smooth transition home.

Pharmacist

The pharmacist reviews all medication and treatment orders your doctor provides and can answer any medication questions you might have.

Radiation Oncologist

If your treatment plan includes radiation therapy, you'll meet with a radiation oncologist to discuss it.



Clinical Dietitian

Healthy foods are an important part of recovery. A dietitian is available to meet with you before, during and after your transplant to help you meet your nutritional needs. If you're a hospital inpatient and don't have a good appetite, the dietitian will work with your doctor to determine the best way to get your body the nutrition it needs to heal. After transplant, if you have problems with eating or drinking, you may continue to see a dietitian as an outpatient.

Physical Therapist

Exercise is important before, during and after treatment. The physical therapist will design an individual exercise program to help you maintain strength and endurance during your treatment.

Chaplain

If you'd like, you may talk with a chaplain. They're available for people of all religious and spiritual backgrounds, including those who follow no traditional spiritual practices.

Music Therapist

Many people find music to be very healing. A certified music therapist can visit and play music for you. (Ask about availability.)

Massage Therapist

Like music, touch can be therapeutic. A licensed massage therapist can offer relaxation techniques to help you work through any anxiety or pain. (Ask about availability.)

Transplantation: Step by Step

Step 1: Planning Ahead

- Meet your transplant team.
- Assess financial coverage and other financial resources.
- Assess options for sperm banking (males) and egg or embryo freezing (females).
- Meet with BMT social worker.
- Complete financial applications (see page 26). Social worker to assist.
- Select one or more caregivers.
- Make decisions about childcare and schooling.
- Arrange transportation to and housing near your transplant center if needed (see pages 26–27). Decide on arrival date with assistance from BMT RN coordinator.
- Complete an advance directive and POLST. (Social worker will assist.)
- Decide if you need special preparations — for example, dental, nutrition or fertility.

Step 2: Preparation for Transplant

- Arrive at your transplant center.
- Meet with the BMT RN coordinator for education.
- Complete medical evaluation with BMT team.
- After completing evaluation studies and obtaining insurance authorization, schedule an appointment to sign consent forms.
- Receive placement of a central venous catheter, which collects your cells from you.
- Stay active by walking or other mild exercise as suggested by your doctor.
- Ask questions and talk with staff regarding any concerns.

Step 3: Preparative Regimen (Conditioning)

- Admit to transplant center or hospital.
- Receive pretransplant chemotherapy through your central venous catheter.
- Your cells are collected from you through your central venous catheter.
- Activities: frequent mouth rinses, daily showers, walking three times per day.
- Take medication to help prevent symptoms and keep you comfortable.
- Let staff know how you're doing and what you need.



Step 4: Transplant

- It's a big day! Infusion of stem cells.

Step 5: Waiting for Engraftment

- Nursing staff monitors your blood counts daily.
- Receive transfusions of red blood cells and/or platelets if needed.
- Tell your doctor and nurse about any side effects: nausea, diarrhea, taste alteration, sores in mouth or anything else that isn't normal for you.
- Talk with the support services team for your mental health. The team includes a nondenominational chaplain for spiritual needs, a social worker for problem solving and counseling, a physical therapist and a dietitian.
- Stay active. Talk with a physical therapist about exercises you can do in your room.
- Set goals for each day and cheer yourself on when you meet them.

Step 6: Recovery

- Your caregiver will be responsible to help you manage your medicines, watch out for symptoms, drive you to doctor appointments and more.
- You'll have frequent or daily appointments in the transplant center, including blood draws and transfusions.
- Focus on food. Encourage yourself to eat the foods your dietitian suggests.
- Increase your activity. Talk with a physical therapist about how you can get stronger.
- Relax and nap during the day. Rest is important.
- Take things one day at a time and keep track of your daily goals to see your progress.
- Follow up with your BMT doctor at 30, 100 and 180 days after transplant, one year after transplant and then annually for evaluation.

Caregivers

People usually pick a family member or close friend as a caregiver to help before, during and after transplant. Your caregiver will provide emotional support, care for you when you're not feeling well and work with your team to report any of your side effects or concerns before, during or after treatment.

Before you can start the transplant process, you must identify at least one person to be your caregiver. Your caregiver will need to be available 24 hours a day, seven days a week for general care, emergencies and transporting you to and from appointments. You may also choose two or three backup caregivers who may take turns staying with you. **Due to your increased risk, your caregivers must agree not to receive any live-virus vaccinations during and after your transplant for 100 days.**

Caregiver Role Before Transplant

- Participate in any pretransplant education meetings with the BMT RN coordinator.
- Participate in the consent signing process and sign the caregiver contract.
- Accompany you to doctor and evaluation appointments as needed. This will include the day of central line placement as well as chemotherapy administration. (You'll receive a calendar with these dates.)
- Provide 24/7 observation and support.
- Provide or arrange transportation to and from the clinic or infusion center daily.
- Keep track of appointments.
- Keep track of symptoms daily.
- Record and refill medications.
- Assist you with taking medications on schedule.

Caregiver Role After Transplant

- Be available 24/7 to assist with post-transplant recovery.
- Encourage fluids and food as tolerated.
- Live or stay within 20 minutes of the clinic or infusion center.
- Provide or arrange transportation to and from the clinic or infusion center daily.
- Take notes during appointments.
- Perform housecleaning before and after discharge.
- Handle meal management. They'll prepare meals and snacks, encourage eating and do meal cleanup.
- Monitor symptoms daily with the Stoplight Tool that the coordinator provides. They'll take your temperature twice a day or more often if needed, record it and notify your doctor if your temperature is higher than 100.4°F (38°C) or you experience dehydration, diarrhea, nausea or vomiting.
- Monitor and screen visitors.
- Take you to the emergency room or hospital if needed.

If you need to go to the emergency room, you or your caregiver should notify your coordinator. The coordinator should alert the staff that you're a BMT patient currently under a transplant doctor's care.

Take a list of your current medications, transplant information and the contact information for your doctor and coordinator with you to the hospital.

Your Transplant Evaluation

Before your transplant, you'll undergo several tests and procedures to ensure you're in good physical condition. These may include:

Central venous catheter. A surgeon or radiologist will insert a catheter — a small flexible tube — into a large vein in your chest, just above your heart. The catheter provides a route to administer all chemotherapy drugs, blood products and other intravenous fluids. It's also used to withdraw blood for the many samples needed throughout your stay.

Chest X-ray. This test evaluates your lungs.

Dental exam. If you haven't seen your dentist in the past six to nine months, you'll need an exam and/or dental clearance. Simple cavities may be filled, but if you need any major work, you'll need to get approval from your transplant doctor. You may need antibiotics prior to any dental work, or you may need to wait until well after the transplant to have dental work done.

Electrocardiogram, known as EKG or ECG. This test examines the heart's electrical activity.

Multigated acquisition. This test measures how well your heart pumps blood through your body.

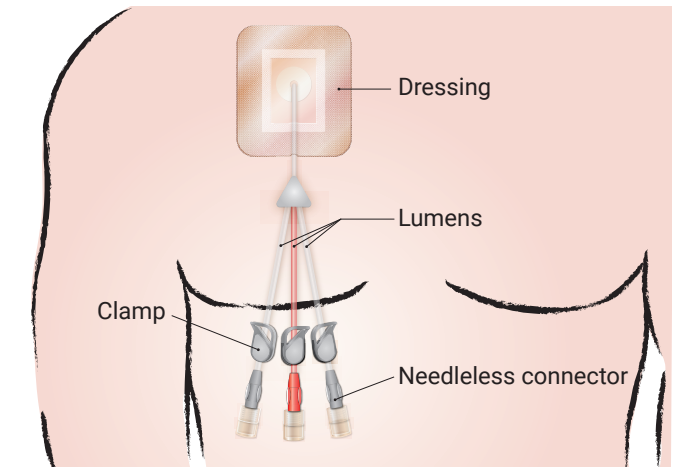
PET/CT or CT scan. A full-body scan looks for any additional disease in other areas.

Pulmonary function test. This test examines how well your lungs are working. You'll also have blood drawn from your wrist to measure arterial blood gas.

Social work assessment. This evaluation helps your team better understand your readiness and understanding of the transplant and support you may need.

Preparative Regimen (Conditioning)

Pretransplant preparation destroys healthy and unhealthy cells. This process includes chemotherapy with or without total body radiation and is based on a specific treatment protocol designed for you. The length of time may vary from one to eight days before transplant.



Transplant Medications

Reactions vary when receiving chemotherapy. The most common complaints are nausea with or without vomiting plus fatigue. Other side effects may include diarrhea, hair loss, infertility, loss of appetite and mouth sores.

Medications can address many of these side effects. You may be taking these medications during your transplant and when you go home. Since they work better when taken early, ask for them when you begin to experience nausea or pain, rather than waiting until you're vomiting or feeling acute pain. Many of these medications can make you sleepy, and you may experience anxiety or depression as well.

In addition to chemotherapy or fluids, medications used during your stay may include:

- Antibiotics to prevent or treat infections.
- Antifungals to prevent or treat fungal infections.
- Antinausea medicine to prevent or treat nausea.
- Antivirals to prevent or treat viral infections.
- Narcotics to relieve pain.
- Electrolyte replacement

Transplant in the Hospital

If you're being admitted to the hospital for transplant, follow these guidelines to ensure your safety, promote a healing environment and support a quality healthcare experience.

BMT Unit Guidelines

The BMT unit is a positive-pressure unit with high efficiency particulate air, or HEPA filters. Visits are limited to two guests at a time. Hospital visiting guidelines may change according to state mandates and other circumstances. Children may visit when accompanied by an adult.

No guests may enter the BMT unit if they have symptoms of illness, such as cough, fever, running nose, malaise, nausea or vomiting. Everyone must wash their hands before entering and when leaving the BMT unit and patient rooms. Hand sanitizer and handwashing sinks are readily available. Latex balloons, fresh flowers, plants and pets aren't allowed.

One visitor over age 18 may stay overnight in your room on the couch or recliner. Visitors may not use patient restrooms. Visitor restrooms are in the family waiting room.

Expectations During Your Stay

- To decrease infection risk, you'll receive a daily shower followed by chlorhexidine gluconate wipes.
- Wash hands or use hand sanitizer before every meal, before and after using the restroom, and when entering or leaving your room.
- Brush your teeth and/or use a mouth rinse at least four times a day, typically after meals and before bed. This reduces infection risk.
- You'll receive nurse visits every hour to deliver medications, provide treatments and perform assessments. You'll have a blood draw between 4 and 5 a.m. daily.

- The vascular access team checks your central line every day to assess its condition and prevent infection.
- The hematology-oncology team will visit daily. This is a good time to discuss your care and ask questions.

How To Promote Your Health and Comfort

- Bring comfortable shoes. Walk the length of the BMT unit three times a day to maintain muscle strength.
- Bring clothing that allows easy access to your central line. You can wear these clothes or a hospital gown.
- Bring personal items such as books, computer, gaming devices or games to pass the time. We aren't responsible for items that may become lost or stolen.
- The unit has a cart-mounted TV you can check out for personal gaming, and you can access the internet through SHGuestNet.
- A charge nurse is always available to manage any concerns or questions.
- Your medications may alter the taste of food. Your family may bring in food or have it delivered, and you can talk with the dietitian for help with food selection. Avoid raw or undercooked meats and unwashed fresh fruits and vegetables. Make sure foods are freshly prepared and stored properly. Label all food stored in the family room refrigerator with your name and the date.



How To Reach You in the Hospital

Your room phone can receive direct calls from 7 a.m. to 10 p.m. Because nurses are usually in patients' rooms and unable to answer calls, family and friends should not call the nurses' station but instead call your room directly, unless they have a specific problem or issue to address with the staff.

We won't release any information about you to any caller without your permission. Please identify one family member or friend as the primary person to call for information. If you'd prefer not to receive calls in your room, simply let the nursing staff know to hold your calls.

Hospital Admission: Registration and Arrival

On admission day, please arrive by 7:30 a.m. Register at the desk in the lobby of the Anderson Lucchetti Women's and Children's Center on the main campus. From there, you'll be escorted to the 4th floor BMT unit. Upon admission to the transplant center, the nursing staff will take your vital signs and orient you to your room and unit. Your transplant doctor will visit to ensure you're ready to proceed.

Your nursing staff will keep you informed about your care and provide hourly safety rounds while you're in the hospital. At the beginning of each shift, your nursing team will discuss your care during a bedside report. We encourage you to bring up any questions or concerns.

Transplant Day: Infusion of Stem Cells

Stem cell infusion is like blood transfusion. The total time may vary, depending on the volume of stem cells, how well your body tolerates the infusion and whether the cells are fresh or frozen.

At least two nurses will be with you before and during the infusion to monitor your vital signs. Your transplant doctor will also be available during the infusion. If you have any questions or concerns, ask your nursing staff.

Frozen Stem Cells

Cells may have been collected, preserved with the chemical dimethyl sulfoxide (DMSO) and delivered to the transplant unit frozen. Nurses thaw the frozen cells in a lukewarm water bath. Once thawed, the cells can be infused like any other blood product. DMSO enters your bloodstream during the infusion. Your body removes it through breathing, so take deep breaths in and out to help this process along.

Patients commonly report that DMSO has a strong, garlic-type taste, while others report a sweet corn taste. You might want to have hard candy (preferably on a stick) at your bedside during the infusion. It's also common for you, your room and the unit to smell like garlic for a while after the infusion.

Possible Side Effects

You'll receive medicine prior to the infusion to help reduce possible side effects, such as:

- Nausea
- Vomiting
- Fever or chills
- Fever or chills
- Shortness of breath or change in oxygen level
- Low or high blood pressure
- Increased heart rate
- Rash or hives
- Discolored or reddish urine

You'll see a special supplies cart placed outside or near your room or chair.

Post-Transplant: What To Expect

For many people, the most difficult time of the transplant process is between infusion and discharge.

Engraftment

Approximately 10 to 28 days after transplant, your medical team expects to see signs that new bone marrow or stem cells are growing (engrafting) and beginning to produce blood cells. The medical team usually monitors blood counts daily. A rising white blood cell count is often the sign of a successful transplant, or graft. You may want to keep a daily record of your blood counts to track your progress.

In addition to watching for the first signs that your new immune system is working, your medical team will monitor you closely to detect any complications. If complications arise, treatment begins promptly. Until the new cells engraft, you're very susceptible to infections. During this time, your doctor may give you antibiotics. You may experience fever and will be monitored closely for any symptoms of infection.

Because your hemoglobin may be low, you may feel tired. Because your platelets may be low, you may experience bleeding; if so, please notify your nurse and doctor immediately. Your medical team will monitor all your lab values closely, and you'll be given either red blood cells or platelets as needed. Despite fatigue, it's important to maintain activity to prevent complications.

Be prepared for the possibility of an emotional roller coaster.



Maintaining Your Well-Being

During transplant and after, be prepared for the possibility of an emotional roller coaster. You may feel:

- Vulnerable and anxious while you're waiting for engraftment and not protected by a fully functioning immune system.
- Intense concerns about physical symptoms.
- Worry about making it through transplant.
- A loss of personal control as you cope with the daily monitoring and medical procedures.

All these feelings are common but coping with them can be a challenge. It may help to talk with others, keep active and engage in activities that help take your mind off treatments. You may find that working out the details of your day, such as time of bathing, walks and treatments, helps you maintain control and give structure to this period.

Potential Side Effects

It's important to understand the risks. You may or may not experience any of these but be aware of what to look for and what to report.

- **Bleeding** – The transplant process stops the body's platelet production. Platelets are essential to prevent bleeding and aid in the clotting process. The staff will monitor your platelet count daily and administer a platelet transfusion when needed. They'll also monitor your urine, stool and any vomit for early signs of bleeding. To prevent bleeding from injury and for your safety, always call your nurse for help when you want to get out of bed.
- **Cataracts** – Your eye lenses may become cloudy after your transplant. If left untreated, this can cause partial or complete blindness. Establish regular care with an eye doctor before, during and after transplant.
- **Early Menopause** – Many women go into early menopause after transplant because chemotherapy or radiation can cause the ovaries to stop producing eggs. This is especially likely if you've been on estrogen therapy. Side effects may include hot flashes, irritability or night sweats. You'll also be at a higher risk for osteoporosis (bone thinning).
- **Graft Failure** – There's a very rare (less than 1%) possibility that your stem cells won't grow back to a fully functioning bone marrow. This can affect all the blood cells or only specific types. You'll receive lab tests daily to monitor engraftment.
- **Hemorrhagic Cystitis** – Your bladder lining may become irritated and bleed. Symptoms are similar to a urinary tract infection. You'll receive large volumes of intravenous (IV) fluids to protect your bladder. The nurses will also monitor how much urine you produce and will check urine for blood. In severe cases, your doctor may ask for a bladder catheter to help keep you comfortable.
- **Infection** – Because your immune system is compromised, infections can develop. Your medical team will monitor your temperature and other vital signs frequently, even through the night. If you develop signs of an infection, you'll receive additional medications to treat it. It's possible that an infection may threaten to overwhelm your system, a condition called sepsis or septicemia that can be life threatening.
- **Lung Complications** – The lungs are a common infection site in blood marrow transplant patients, in part because most patients spend a great deal of time in bed. While full-blown pneumonia can be life threatening, it can be prevented. The nurses and physical therapists will constantly encourage you to get out of bed, sit in a chair, walk in the hallway, exercise, breathe deeply and use an incentive spirometer (a breathing exerciser). Your own hard work can help prevent a serious complication.
- **Secondary Cancers** – Transplant patients are at higher risk for secondary cancer — usually leukemia (cancer of the blood cells). This can be related to chemotherapy or radiation treatment.
- **Short-Term Memory Loss** – Many transplant patients complain of short-term memory loss, which may be temporary or permanent. Some people find it helpful to keep a small notebook.
- **Sterility** – Your ability to have children may be affected by your treatment and transplant. Refer to page 6 for information about fertility preservation.
- **Veno-Occlusive Disease** – Chemotherapy or radiation therapy may affect your liver. Your belly may become tender and swollen, and your skin and eyes may turn yellow (jaundice). This condition usually heals on its own; however, severe cases can be life threatening. To monitor this, you'll be weighed twice a day if you're in the hospital.

You may not experience any of these risks, but be aware of what to look for.

Transition: Returning Home

Discharge

Immediately after discharge, you'll need to stay within a 20-minute drive of the transplant center or hospital. Your BMT team includes a financial coordinator, social worker and BMT coordinator to assist you with housing or transportation.

You may feel a wide range of emotions as you think about going home. Though you look forward to returning:

- You may feel anxious about leaving the protected environment of the transplant center or hospital and the security of the staff.
- You may be worried about caring for yourself at home.
- Your family or caregiver might have concerns about their ability to handle responsibilities that were once those of the transplant staff.
- You may wonder how other people will relate to your physical and other changes. Some people may not understand what you've gone through and how it's changed you, and you may miss the support system you had in the transplant center or hospital.
- You'll probably feel frustrated or down at times because of your isolation and limited activity. These feelings are normal, and you may wish to seek out a supportive friend or relative who's able to provide the understanding you need. Your BMT team can also help. Above all, as you make this transition from hospital to home, remember to be patient, pace yourself and set small goals for yourself and others.

You, the patient, should not change cat litter, pick up pet poop, dig in soil, tend to farm animals or engage in house renovations. Your home needs to be a safe place for you. Don't visit with anyone who has illness symptoms or who has been near anyone who's ill.

Medications

You'll have thorough medication instructions, including a written schedule, and all your medications in hand. Take your medications as directed and bring your medications with you to each clinic or infusion center appointment.

Home Environment

Your caregiver should ensure that your recovery location has been thoroughly cleaned. Someone other than you will need to be responsible for keeping the house picked up, especially the bathroom and kitchen. The goal is to reduce your exposure to germs while your immune system recovers. While it's important to keep the house clean, it shouldn't take more than a few minutes a day.

Your caregiver needs to:

- Vacuum every day.
- Wipe down kitchen counters with a disinfectant or bleach cleaner daily.
- Use dish brushes (not dishrags) and wash them frequently.
- Wipe down bathroom countertops and sinks with a disinfectant or bleach cleaner daily.
- Wipe down and clean toilets with disinfectants daily.
- Designate a bathroom for you to use and another bathroom for use by others. If that's not possible, the caregiver needs to wipe down the toilet and shower after each use.
- Disinfect and clean the shower weekly.
- Change bed linens weekly and as needed.

Post-Transplant Follow-Up

Doctor Visits

You'll remain under your transplant doctor's care for a while. You'll visit with the doctor approximately two to three times each week for a couple of weeks. During these appointments, ask questions or discuss concerns with your care team.

Contact your transplant team if you experience:

- Any type of bleeding.
- Burning, pain, increased frequency or urgency with urination.
- Discharge or odor from the vagina or penis.
- Headache or neck pain.
- Mouth sores, sore throat or trouble swallowing.
- New or persistent cough.
- New or persistent diarrhea or constipation.
- Physical changes or any other differences that concern you.
- Rectal soreness or abscesses.
- Redness or swelling on your skin.
- Redness, swelling or drainage at your catheter site.
- Shortness of breath while at rest or when exercising.
- Temperature of 100.4°F (38°C) or higher.

If you need to go to an emergency department, please contact your transplant team so you'll be treated as a post-transplant patient and possibly admitted to the hospital.

Infusion Center

You'll make daily visits to the infusion center for a period of time. The visits usually last at least one to two hours but may be as long as six hours. Your team will schedule your first infusion-center appointment before your discharge. At your visits, infusion center nurses will check your lab values, check your vital signs and administer IV fluids, medications or blood products as needed.

Caring for Your Tunneled Catheter*

If your central infusion line gets damaged, it won't work correctly and could raise your chance of getting an infection. To protect the central line at home:

- **Use good hand hygiene.** (See Hand Hygiene, page 16.) Don't touch the catheter or dressing. Always clean your hands before and after you touch any part of the central line. Your caregivers, family members and any visitors should use good hand hygiene, too.
- **Avoid damage.** Don't use any sharp or pointy objects around the catheter. This includes scissors, pins, knives, razors or anything else that could cut or puncture it. Don't let anything pull or rub on the catheter, such as clothing.

Call your healthcare provider right away if:

- Your dressing is damaged, dirty, wet or peeling off.
- You have redness, swelling, tenderness, leakage, bleeding or drainage around your catheter exit site.
- Your needleless connector falls off.
- You have chills or a fever of 100.4°F (38°C) or higher.
- You have a break or leak in your catheter.

* See page 9 for diagram.

Guidelines at Home

Hand Hygiene

You must follow certain procedures at home to help prevent infection. Wash your hands frequently, and encourage visitors and family members to do so, particularly:

- Before and after using the bathroom.
- Prior to eating.
- Before and after preparing food.
- After coming home from a public place.

To clean hands, follow these steps.

- Wet hands with clean, running water and apply soap.
- Lather hands by rubbing them together with the soap. Lather the backs of your hands, between your fingers and under your nails.
- Scrub hands for at least 20 seconds. Need a timer? Hum the "Happy Birthday" song from beginning to end twice.
- Rinse hands well under clean, running water.
- Dry hands using a clean paper towel, or air dry them.
- When you can't use soap and water, use an alcohol-based hand sanitizer that contains at least 60% alcohol.



Showering

You can shower with your catheter in place. Don't submerge your catheter in water, such as in a bath, pool or hot tub.

Each time you shower, cover your dressing completely with plastic wrap and tape or with a new, single-use waterproof cover, such as Aquaguard®, which you purchase online. To use the waterproof cover:

- Peel off the top and side strips.
- Place the top edge above your dressing. Don't let the tape touch your dressing. Smooth the cover down over your dressing.
- Peel off the bottom strip. Make sure the bottom edge of the waterproof cover is below your dressing and the catheter lumens are tucked in and completely covered. Smooth down the bottom edge.
- After your shower, dry the waterproof cover before you take it off.

Temperature Checks

Take your temperature twice a day at home. If you don't have a working thermometer, please tell the BMT staff.

- Take your temperature at the same times each day.
- Anytime you feel sick or think you have a fever, check your temperature. If you notice your temperature increasing, check it again within 30 to 60 minutes.
- Don't drink anything hot or cold for at least 15 minutes before taking your temperature.
- Always take your temperature before taking fever-reducing medications.
- If your temperature is 100.4°F (38°C) or higher with or without fever-reducing medications, notify your team immediately.
- **Don't use aspirin, ibuprofen, acetaminophen** or products that contain them unless advised by your transplant doctor.

Bleeding Prevention

It's normal to need platelet transfusions for a while after transplant. Notify your transplant doctor if you notice any bleeding (including your mouth, gums, urine or stool) or red dots or bruising on your skin.

TO HELP PREVENT BLEEDING:



Use a soft toothbrush or dental swabs.



Wear a seatbelt with shoulder harness when in the car.



Do not use rectal thermometers, rectal suppositories or enemas. Use stool softeners or dietary fiber to prevent constipation.



Use an electric razor until platelet count is over 50,000 without transfusions.



Don't use dental floss until platelets are over 50,000 without transfusions.



Avoid forcefully blowing your nose.



Avoid contact sports and other activities that may cause bleeding or bruising.



Use proper lubrication during sexual activity (see page 18).

Schedule out-of-home activities at nonpeak hours.

Skin Care

Showering daily helps reduce potentially harmful bacteria that live on your skin. Keep your skin hydrated by avoiding hot showers and using unscented lotion daily.

Your skin will be very sensitive to sunlight and will burn easily. Avoid exposure to bright sunlight for at least six months after your transplant. When you're out in the sun, wear protective clothing such as long sleeves, pants and a hat with a brim. Use sunscreen with an SPF of at least 15 on exposed skin.

It's fine to wear makeup. Use new, unopened products and don't share them. Chipped nail polish and artificial nail products encourage the growth of bacteria and fungus, so we don't recommend their use.

Mouth Care

Continue with good mouth cleaning after meals and at bedtime. Get regular dental cleanings, but avoid dental work (fillings, bridges, etc.) for six months after your transplant. If you must get dental work, your doctor may recommend antibiotics.

Contact Lenses

Don't wear contact lenses during your treatment. Discuss with your doctor when you can resume wearing them.

Vaccines

Don't get any vaccines unless ordered by your transplant doctor. Check with your doctor before visiting with adults or children who've recently received vaccines.

Physical Exercise

It's common to feel fatigue after a transplant. Physical activity plays a vital role in your recovery. Most of your waking time should be spent out of bed. Maintain your activity level by developing a regular exercise routine. This may be as simple as taking a short walk. Talk to your healthcare team about appropriate physical activities.

Sexual Activity

After your transplant, you might feel very tired and hesitant about intimacy with your partner. You can hug, cuddle, snuggle, kiss, touch each other and sleep in the same bed with your partner unless your partner is ill. As you start to exercise and eat better and your blood counts improve, your sexual desire should return. You may have gentle sexual intercourse when your platelet count is above 50,000 without the need for transfusions. Discuss any questions with your transplant doctor. Your partner may also have questions.

Remember that your body is still adjusting to the effects of treatment. Practice good hygiene before and after sexual activities. Use proper lubrication during sexual intercourse to avoid irritation and possible bleeding or infection — a water-soluble, nonirritating lubricant can help. Urinate after intercourse to prevent urinary tract infections.

Although women may go into early menopause after transplant, that doesn't always happen and shouldn't be counted on for birth control. Safe sex practices, including condom use, are always encouraged to prevent sexually transmitted diseases. Speak to your doctor about contraceptive options, pregnancy concerns or any other questions you may have.



Activities Away From Home

Schedule out-of-home activities at nonpeak hours. For example, shop early in the morning when most people are at work. Avoid areas like construction sites, which may have mold, fungus or bacteria.

Return to Work or School

You may require a longer time to be able to resume work or school, especially if you require further treatment after transplantation. Discuss this with your transplant team.

Children

Children are wonderful, but they can be little germ carriers, especially if they attend school. Reduce visits from children when possible. If your home includes schoolchildren, ask the school to notify you if there are any outbreaks of chicken pox, mumps or measles. The transplant doctor might want you to keep your child out of school for a short time. If you must change a soiled diaper, wear disposable gloves, and always wash your hands afterward.

Animals

Animals can be therapeutic, but all animals carry some risks. Avoid any aggressive animal that may bite, scratch or cause a fall. Don't handle any animal waste tasks, including poop scooping or cleaning litter boxes, fish tanks and bird cages. Always wash your hands after any animal contact.

Hospital Admission

You may need to be admitted to the hospital if you're experiencing fever, infection or inability to drink or eat. This isn't uncommon and doesn't necessarily mean you're not progressing as you should.

Nutrition Recommendations

After your transplant, you may discover that foods still taste different, and your appetite hasn't returned to normal. Maintain a well-balanced diet with adequate calories and protein to continue to help your bone marrow and immune systems recover. To prevent dehydration, try to drink at least eight to 10 glasses of fluid each day.

Most of the nausea and vomiting associated with your transplant should be over. If not, your transplant doctor can prescribe an anti-nausea medication. It might be easier for you to eat several small meals and snacks rather than three large meals.

Use these neutropenic diet recommendations, specific for people with weakened immune systems.

Eat any food products prior to their expiration dates. If you aren't sure whether you should eat something, don't.

"Shelf stable" refers to unopened canned, bottled or packaged foods that can be stored at room temperature before opening; the container may require refrigeration after opening.

	RECOMMENDED	NOT RECOMMENDED
Beverages	<ul style="list-style-type: none"> • Tap water • Commercial bottled distilled spring water • All canned, bottled, powdered beverages • Instant and brewed coffee or tea • Beer pasteurized after fermentation • Brewed herbal teas using commercial packaged tea bags • Liquid or powdered nutritional supplements and baby formula 	<ul style="list-style-type: none"> • Maté tea • Unpasteurized beer • Well water, unless tested yearly for safety
Breads, Grains, Cereals	<ul style="list-style-type: none"> • All breads, bagels, rolls, crackers, muffins, sweet rolls, biscuits, pancakes, waffles and French toast • All cooked and ready-to-eat cereals • All chips, pretzels, popcorn, tortillas • Cooked rice, pasta, beans and other grains 	<ul style="list-style-type: none"> • Raw grain products
Fruits and Fruit Juice	<ul style="list-style-type: none"> • Any canned, stewed or frozen cooked fruit • Well-washed raw fruit (except as noted) • Dried fruit • Pasteurized fruit juices 	<ul style="list-style-type: none"> • Unwashed raw fruit • Unpasteurized fruit juices • Fresh strawberries and other berries • Fresh grapes
Vegetables and Vegetable Juice	<ul style="list-style-type: none"> • All cooked frozen, canned or fresh vegetables • Well-washed raw vegetables • Fresh, well-washed herbs and dried herbs and spices • Pasteurized vegetable juices • Bottled and canned salsa, refrigerated after opening 	<ul style="list-style-type: none"> • Unwashed raw vegetables and herbs • Vegetable sprouts

	RECOMMENDED	NOT RECOMMENDED
Meat and Meat Substitutes	<ul style="list-style-type: none"> • All well-cooked or canned meats (beef, pork, lamb, ham, bacon, sausage, hot dogs), poultry, game, fish and shellfish • Well-cooked eggs (white cooked firm with thickened yolk) • Pasteurized egg substitutes • Commercially packaged salami, bologna and other lunch meats • Canned and commercially packaged hard-smoked fish, refrigerated after opening • Cooked tofu. 	<ul style="list-style-type: none"> • Raw or undercooked meats • Raw or undercooked poultry, game, fish (including, sushi, sashimi, ceviche, pickled fish, cold smoked salmon lox) • Raw or undercooked tofu or eggs (and foods containing them) • Deli meats, unless further cooked • Fermented soybean products such as tempeh
Milk and Milk Products	<ul style="list-style-type: none"> • All pasteurized Grade A milk, milk products, commercially packaged cheese and cheese products • Pasteurized yogurt and sour cream • Dry, refrigerated and frozen pasteurized whipped topping 	<ul style="list-style-type: none"> • Unpasteurized or raw milk, unpasteurized cheese, yogurt and other milk products • Cheese with molds (blue stilton, Roquefort, gorgonzola)
Fats and Oils	<ul style="list-style-type: none"> • Canned or bottled nuts • Nuts in baked products • Commercially packaged peanut butter and other nut butters • Oils, shortening • Refrigerated lard, butter, margarine • Commercial, shelf-stable mayonnaise and salad dressings, refrigerated after opening • Cooked gravy and sauces • Nondairy creamers • Nondairy whipped topping 	<ul style="list-style-type: none"> • Unroasted raw nuts • Roasted nuts in the shell • Raw or natural nut butters • Salad dressings containing raw eggs or cheese with molds
Desserts	<ul style="list-style-type: none"> • Refrigerated commercial and homemade cakes, pies, pastries and puddings • Refrigerated, cream-filled pastries. • Homemade and commercial cookies • Ices, popsicles, gelatin desserts • Candy, gum • Shelf-stable, cream filled cupcakes, fruit pies and canned pudding • Commercially packaged ice cream, frozen yogurt, sherbet, ice cream bars • Homemade milkshakes 	<ul style="list-style-type: none"> • Unrefrigerated, cream-filled pastry products (not shelf stable)
Soups	<ul style="list-style-type: none"> • All canned and homemade cooked soups 	<ul style="list-style-type: none"> • All miso products (miso soup)
Miscellaneous	<ul style="list-style-type: none"> • Salt, sugar, brown sugar • Jam, jelly and syrups, refrigerated after opening • Commercial (heat treated) honey • Ketchup, mustard, BBQ sauce, soy sauce, pickles, pickle relish, olives, and other condiments, refrigerated after opening 	<ul style="list-style-type: none"> • Raw or unpasteurized honey • Herbal and nontraditional nutrient supplements • Brewer's yeast, if eaten uncooked (avoid contact with raw yeast)

Wash fruits and vegetables thoroughly under running water before peeling and cutting.

Food-Handling Guidelines

People with a compromised immune system are at greater risk for food-borne illness. Most food-borne disease results from poor food handling.

To handle food safely:

- Keep food at safe temperatures. Bacteria grow quickly between 40° and 140°F (4° and 60°C). Keep cold foods below 40° (4°C) (refrigerated) and hot food above 140°F (60°C).
- Don't defrost food at room temperature. Defrost food in the refrigerator or place in cold water in a watertight bag; change the water every 30 minutes. You can thaw food in the microwave if you cook it immediately after thawing.
- When thawing in the refrigerator, make sure meat juices don't contaminate other foods.
- Cook all meat and poultry thoroughly, to an internal temperature of 165°–180°F (73°–82°C). Use an instant-read thermometer. If you don't have one, visually assess doneness; ground meat shouldn't be pink and poultry juices should run clear, without any trace of red, pink or cloudiness.
- Use up leftovers within two days.
- Keep foods covered, wrapped or in airtight containers.
- Don't eat raw eggs or foods containing them. Eat thoroughly cooked eggs only.
- Don't leave hot or cold food out at room temperature for more than two hours.
- You may eat meats that have been appropriately refrigerated or frozen as long as they're cooked adequately.
- Avoid cross-contamination of cooked meats with raw foods.
- Divide large amounts of food into small, shallow (2–4 inch) containers for quick cooling in the refrigerator. Cool hot foods uncovered in the

refrigerator; cover once cooled.

- Refrigerate only as much as can be eaten in two to three days. Freeze the rest.
- Wash fruits and vegetables thoroughly under running water before peeling and cutting. Avoid any produce with mold.
- Wash tops of canned foods before opening and clean the can opener after each use.
- Never taste food that looks or smells strange. When in doubt, throw it out.

Kitchen Hygiene

- Clean cutting utensils, countertops and cutting boards thoroughly before and after each use.
- Use paper towels (not sponges) to clean up juices from raw meat or poultry. Sanitize the area.
- Use separate cutting boards (plastic, glass or wooden) for cooked or ready-to-eat foods and raw foods. Wash cutting boards after each use in hot soapy water or in the dishwasher.
- After cleaning, sanitize equipment and surfaces, including cutting boards, with dilute bleach solution: 1 to 3 teaspoons bleach in 1 quart or liter of water.
- Keep appliances, kitchen counters and other preparation areas free of food residue and particles.
- Dry hands with paper towels. Replace dishcloths and dish towels daily and sponges at least weekly. To reduce bacteria on moist sponges or dishcloths, microwave them on high for one to two minutes, wash them in the dishwasher or soak them in a dilute bleach solution.
- Allow dish sponges, cloths and towels to air-dry between uses.
- Don't share eating utensils.

Microwave Cooking

Microwave cooking can leave cold spots in food where bacteria can survive. If your microwave doesn't have a turntable, rotate the dish a quarter turn once or twice during cooking. When heating leftovers, partially cover food with a microwave-safe lid for thorough heating; stir several times during heating.

Refrigerator and Freezer

- Keep shelves and doors sanitized.
- Maintain refrigerator temperature at less than 40°F (4°C) and freezer temperature less than 0°F (-17°C).
- Discard foods that have exceeded their expiration dates. Discard all prepared foods after three days (72 hours).
- Discard any package or container that has moldy foods.

Cupboards and Pantry

- Discard without tasting any food that comes in a can or jar that is bulging, leaking, cracked or damaged at the seam.
- Discard any items past the expiration date.
- Make sure food storage areas remain reasonably clean, without insect or rodent contamination.
- Review the processing procedure and conditions of any home-canned foods to ensure they were appropriate for the type of food. If you're unsure about any item, discard it.

Grocery Shopping

- Avoid unlicensed sidewalk or roadside vendors.
- Check sell-by and use-by dates. Check packaging dates on fresh meats, poultry and seafood.
- Select undamaged produce. Check for unusual odor and mold or insect contamination.

- Reject swollen, rusted or deeply dented cans.
- Check that packaged and boxed foods are properly sealed.
- Avoid taste-testing food samples.
- Purchase frozen and refrigerated foods last, especially during the summer.
- Store perishable foods promptly in the refrigerator or freezer.

Vitamins and Herbal Remedies

If you're currently taking any vitamins, nutritional supplements, cannabidiol/tetrahydrocannabinol (CBD/THC), or any herbal remedies, discuss them with your transplant doctor.

Don't take these herbal or botanical medications under any circumstances:

- | | |
|--------------------------|-------------------------|
| • Alfalfa | • Heliotrope |
| • Borage | • L-tryptophan |
| • Chaparral | • Lobelia |
| • Coltsfoot | • Mate tea |
| • Comfrey | • Sassafras |
| • Ephedra or Ma Huang | • Yohimbe and Yohimbine |
| • Groundsel or Life Root | |

Dining Out

- Be sure that any food you eat is adequately cooked and freshly prepared. Avoid uncooked foods (sushi, steak tartare). All meat should be thoroughly cooked. Avoid raw or uncooked and undercooked foods.
- Don't order anything containing fresh fruits or vegetables — for example, avoid salad bars. Order hamburgers with a bun, meat and cheese only.
- Use condiments like ketchup and mayonnaise from individually wrapped packages.
- Pizza and fried foods are fine.

Long-Term Follow Up

Clinic Visits

Your doctor may ask you to remain near your transplant center for a while after your treatment. You'll return to see your transplant doctor at days 30, 100 and 180, and then annually. Please keep your scheduled clinic appointments. If for any reason you're unable to attend, call the transplant doctor's office.

Immunization Schedule

Your immune system is your body's defense against infection and disease. After having a stem cell transplant, you'll probably have a weakened immune system and at higher risk for infection and disease. Your team will give you your vaccine plan when you're ready. You'll receive these immunizations:

- COVID-19
- Diphtheria, tetanus, pertussis (DPT)
- Haemophilus Influenzae Type B
- Hepatitis B
- Influenza
- Measles, mumps, rubella
- Pneumococcal
- Pneumovax (or Prevnar if immunosuppressed and chronic graft-versus-host disease)
- Poliovirus
- Shingles (Shingrix)

Exposure to the live polio vaccine is dangerous. Avoid contact with children or adults who've received the live polio vaccine in the previous three months.

Online and In-Person Support

Everyone has different needs as they progress through the BMT process. In this guide, we've provided many different programs and resources for you to choose from. Your BMT team is available for questions and to help you to secure resources. Your social worker, financial coordinator and transplant coordinator are also reliable sources of guidance and support.

My Health Online: mho.sutter.org

- Access your Sutter Health electronic health record.
- Request medical appointments.
- Message your care team.
- View lab test results.
- Request prescription renewals.
- Access health information.

Information and Education

- American Cancer Society: cancer.org
- American Society for Blood and Marrow Transplantation: asbmt.org
- Association of Cancer Online resources: acor.org
- Blood and Marrow Transplant Information Network: bmtinfonet.org
- Bone Marrow Foundation: bonemarrow.org
- Cancer Care: cancercares.org
- Cancer Net: cancernet.org
- International Myeloma Foundation: myeloma.org
- Leukemia and Lymphoma Society: leukemia-lymphoma.org
- National Bone Marrow Transplant Link: nbmtlink.org
- National Cancer Institute: cancer.gov
- Sutter Cancer Services: sutterhealth.org/cancer



Peer Support

- **Sutter BMT Patient Contact Coordination.** For one-on-one contact with a previous Sutter BMT patient or caregiver, please call your BMT social worker or transplant coordinator to match you with an appropriate candidate. This might include contacting someone by phone or in person depending on your comfort level.
 - **Sutter Support Groups.** Sutter Cancer Services offers support groups for cancer patients, their family and caregivers, plus bereavement and art therapy for adults and children. For a complete list of groups, locations and times, visit sutterhealth.org/cancer and click "Special Services and Support."
 - **Counseling Services.** Sutter Cancer Services provides free counseling with a licensed professional who specializes in cancer patients and their families. Ask your social work team for more information.
 - **On-Call Peer Support.** Get free, one-on-one support from trained peer support volunteers who have had BMT transplants, caregivers and donors. To request this, call **800-LINK-BMT (800-546-5268)** and ask for peer support.
- **Supportline.** Receive free online or phone support from a BMT patient or caregiver through the Bone Marrow Foundation. Call **800-365-1336** or fill out a request at bonemarrow.org/supportline.
 - **ACOR Online Communication Forums.** The Association of Cancer Online Resources (ACOR) offers multiple online communication forums, including lists specific to BMT and caregivers. After creating a login, you'll have access to monthly newsletters and a listserv for posting and communication. Go to acor.org to start.

Create Your Own Website or Blog

- [CaringBridge.org](https://caringbridge.org)
- [LiveJournal.com](https://livejournal.com)
- [MyLifeline.org](https://mylifeline.org)

Financial Resources

Several local and national organizations offer financial assistance for eligible patients with a cancer diagnosis. In addition, many pharmaceutical companies have programs for those who can't afford medications. Income replacement options for you and your caregivers include Paid Family Leave, Social Security Disability or State Disability Insurance. Ask your employer for information about your benefits and eligibility for Family and Medical Leave Act.

Many programs require documentation of your diagnosis or treatment plans as well as proof of your financial need. Your BMT social worker or financial coordinator can offer information about these programs, including private fundraising, and assist with applications.

- American Cancer Society: [cancer.org](https://www.cancer.org), **800-277-2345**
- The Bone Marrow and Cancer Foundation: [bonemarrow.org](https://www.bonemarrow.org)
- California Employment Development Department (EDD): [ca.edd.gov](https://www.ca.edd.gov)
- CancerCare: [cancercare.org](https://www.cancercare.org), **800-813-4673**
- Leukemia and Lymphoma Society: [lls.org](https://www.lls.org)
- Social Security Administration (SSA): [ssa.gov](https://www.ssa.gov), **800-722-1213**

Applications for Financial Assistance

Please tell your transplant coordinator if you need any of these forms. Some require a healthcare provider's signature.

- American Cancer Society Patient Referral Form.
- The Bone Marrow Foundation Patient Aid Program Application.
- Department of Motor Vehicles Application for Disabled Person Placard or License Plates.
- Your local utilities may also offer financial assistance. Contact them directly.

Transportation

Ask your transplant coordinator for local resources to assist you with any transportation needs.



Local Housing

If you can't remain at home through the transplant process, please discuss your needs with your social worker. Your BMT team can help if you need proof of hospitalization or treatment.

The American Cancer Society collaborates with hotels around the county to offer temporary, free or discounted rates for cancer patients who need to travel for treatment. Call **800-227-2345** for additional information.

The Cancer Support Community collaborates with Airbnb to offer temporary, free housing for income-eligible cancer patients who need to travel more than 50 miles from home for treatment. Discuss this option with your social worker, call **877-793-0498** or email helpline@cancersupportcommunity.org for more information.

Sutter has negotiated discount rates for our patients at several local hotels near Sacramento. Go to [suttermedicalcenter.org/housing](https://www.suttermedicalcenter.org/housing) for a current list of hotels and rates.

Visit Joe's House, a Lodging Guide for Cancer Patients, at [joeshouse.org](https://www.joeshouse.org) for links to local hotels that offer discounts to cancer patients.

For rental apartments, RV accommodations and other options, talk to your BMT social worker.

If you can't remain at home through the transplant process, talk to your social worker.

Recommended Books

The Anatomy of Hope: How People Prevail in the Face of Illness

Jerome Groopman, M.D.

Becky and the Worry Cup: A Children's Book About a Parent's Cancer

Wendy S. Harpham, M.D.

Climb Back from Cancer: A Survivor and Caregiver's Inspirational Journey

Cecilia Hobson and Alan Hobson

Everyone's Guide to Cancer Supportive Care: A Comprehensive Handbook for Patients and Their Families

Ernest Rosenbaum, M.D., and Isadora Rosenbaum

The Human Side of Cancer: Living with Hope, Coping with Uncertainty

Jimmie C. Holland, M.D., and Sheldon Lewis

My (So-Called) Normal Life

Erin Zammett

Picking Up the Pieces: Moving Forward After Surviving Cancer

Sherri Magee, Ph.D., and Kathy Scalzo, M.S., O.D.

When a Parent Has Cancer: A Guide to Caring for Your Children

Wendy S. Harpham, M.D.

