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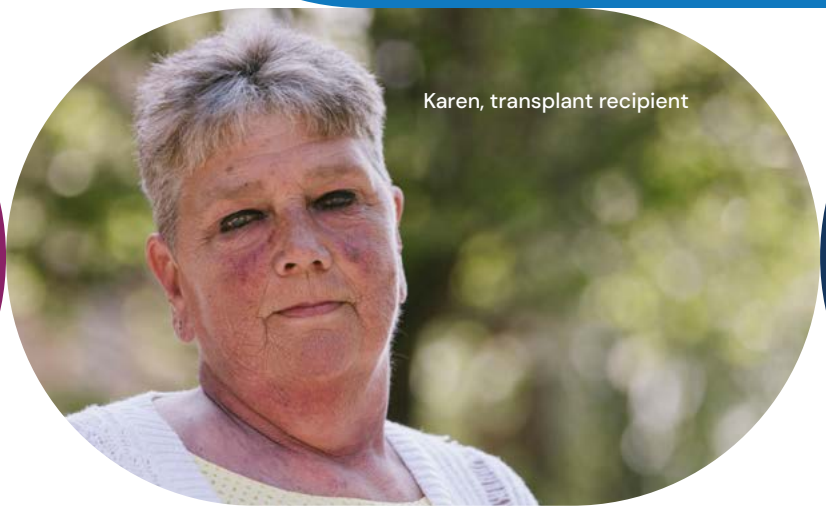
FIND CURES. SAVE LIVES.

Living Now: For Patients

Your guide to life after a blood or marrow transplant (BMT)



Karen, transplant recipient

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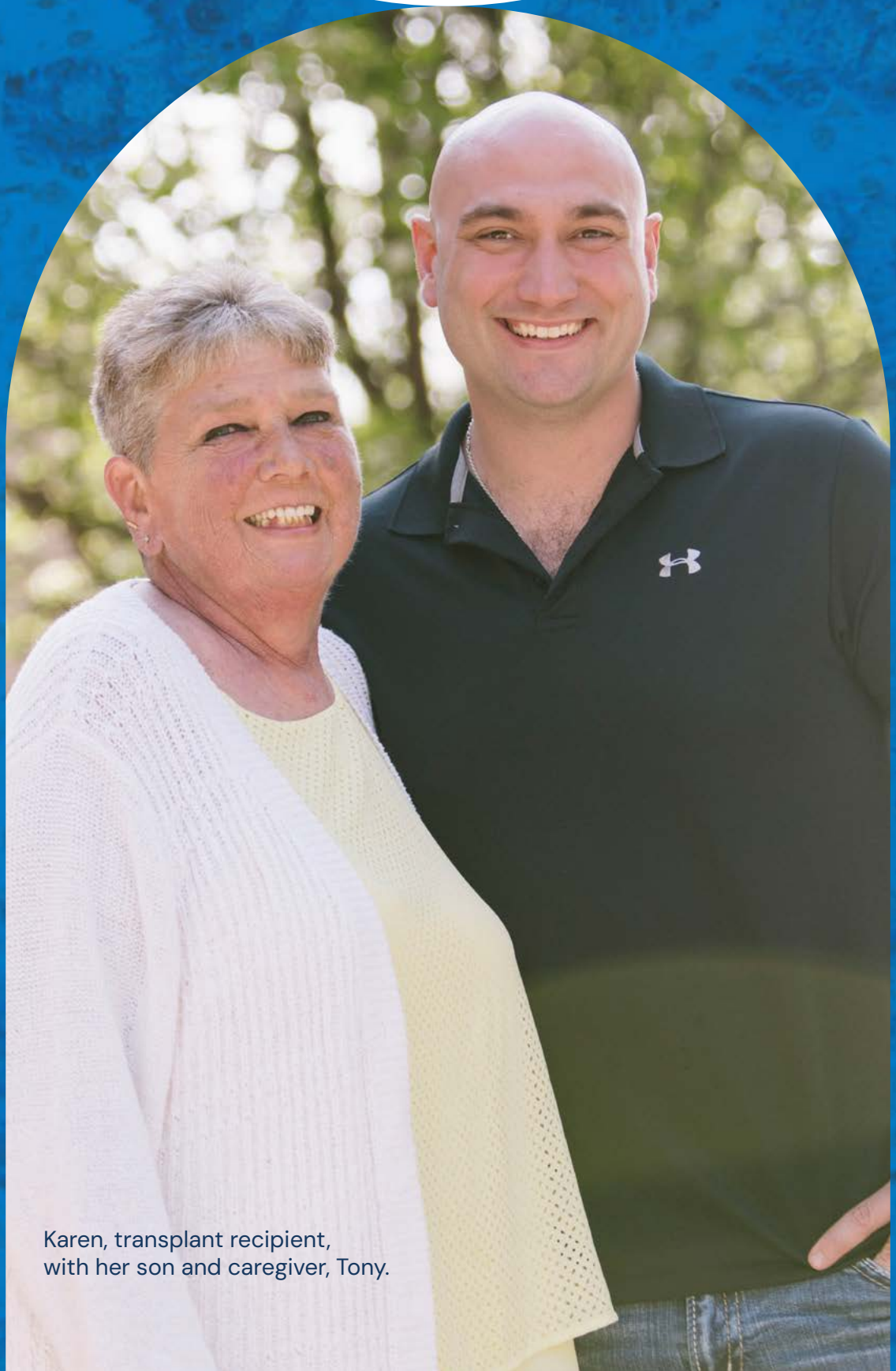

Karen, transplant recipient,
with her son and caregiver, Tony.

You and your loved ones will likely have highs and lows after transplant. During this time there are things you can do to help your recovery. This booklet from the NMDP℠ Patient Support Center includes important information, tips and resources for you.

If you're feeling alone, unsure or worried, we will listen and provide support. If you need help navigating your health care or paying bills, we have resources to help. And, if you'd like to give back or connect with your donor, we will guide you through the process.

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We are here to help you at every step.

Connect with us:

Call or text
1 (888) 999-6743

Email
patientinfo@nmdp.org

Visit
nmdp.org/one-on-one

Watch for signs of graft-versus-host disease (GVHD)

Even while you're being cared for by your health care team and following their instructions, it's likely you'll have some setbacks during your recovery. If you had an allogeneic transplant, GVHD may be one of those setbacks.

What is GVHD?

GVHD is a common side effect of an allogeneic transplant. An allogeneic transplant uses blood-forming cells donated by someone else. GVHD can range from mild to severe.

GVHD happens because of differences between the donated cells (graft) and your body's cells (host). Your new cells from your donor might see your body's cells as different and attack them.

Having a little GVHD isn't always bad. If your transplant was for a blood cancer, your doctor may see mild GVHD as a sign that the donor's immune system is working to destroy any remaining cancer cells. If you had leukemia, you may hear your doctor call this the "graft-versus-leukemia effect".

Types of GVHD:

- **Acute:** Typically develops in the early weeks and months after transplant. It's called late acute GVHD when it develops 3 or more months after transplant.
- **Chronic:** Typically develops within 1 year of transplant but can happen later. It's called overlap chronic GVHD when symptoms of chronic and acute GVHD appear together.

"Expect a forever life change. Accept that you will have difficulties. Learn to be thankful for each day no matter what."

—Tiffany, transplant recipient

"Listen to your body. Every day is different. Everyone's experience is different, even if you had the same type of disease or treatment, so never compare."

—Troy, transplant recipient

Watch for signs of GVHD

Not everyone experiences all these warning signs, but many experience some.

Whole body

- Bleeding
- Chest pain
- Confusion or less alert
- Faster pulse or feeling like your heart is "racing"
- Feeling lightheaded
- Fever or chills
- Severe headache
- Severe fatigue (tiredness)

Joints and muscles

- Arthritis-like symptoms (pain and stiffness)
- Joints don't move properly
- Muscle pain, cramps or weakness

Skin and nails

- Blisters
- Itchy skin
- Nail changes
- Skin looks red or discolored
- Skin thickening
- Rashes: very faint to severe (like a sunburn)
- Unusual hair loss or thinning

Eyes

- Blurred vision
- Dry or teary eyes
- Pain or sensitivity to light
- Redness or irritation that doesn't go away

Mouth

- Chapped lips or dry mouth
- Difficulty swallowing or sore throat
- Irritation or pain that doesn't go away
- Sores
- Trouble opening your mouth

Lungs

- Cough that doesn't go away
- Less able to exercise
- Shortness of breath or trouble breathing

Liver

- Dark (tea-colored) urine
- Jaundice (your skin or eyes look yellow)
- Pain in the upper part of your belly
- Swelling in your legs or belly

Stomach/digestive system

- Belly pain or cramping
- Bloating or feeling full of gas
- Blood in your stool
- Loss of appetite
- Nausea, vomiting or diarrhea
- Pain with a bowel movement
- Stool that is dark green
- Weight loss

Urinary

- Blood in your urine
- Going to the bathroom (urinating) often
- Having pain with urination

Genitals

- Irritation, dryness or itching
- Rash
- Redness, sores, swelling or burning
- Pain with sexual activity

Do not ignore the early warning signs of GVHD.

Many of the early warning signs for GVHD could also be caused by infection or another side effect. If you have any warning signs:

- Call your transplant team immediately.
- Give your transplant team as many details as you can. Tell them when the symptoms started and what you're experiencing. This can help them figure out the cause and the best way to treat it.

Anytime you feel seriously ill, call your transplant team right away.

Also, wear a medical alert bracelet to tell others that you had an allogeneic transplant. Keep a short treatment summary and your doctor's phone number in your wallet. Then, in case of an emergency, anyone helping you will have this medical information.

"It was helpful to have someone to talk to about all the hardships. Especially someone who understands the process."

—Transplant recipient

MY NMDP APP

Track your wellness and symptoms in the **FREE My NMDP** app.

Available in a mobile app or online: Search for My NMDP in the app store or visit my.nmdp.org.

How to lower your risk

Most people who had an allogeneic transplant will have some symptoms of GVHD. There are some steps you can take to help lower your risk. Ask your doctor about your risk for GVHD after transplant.

1. Take your medicine.

Your doctor will give you medicine to help prevent GVHD. Take it as directed, even if you feel healthy. Call your doctor if you:

- Can't take the medicine for any reason.
- Miss a dose.
- Vomit soon after taking it.

2. Watch for early warning signs.

Tell your doctor right away if you see or feel anything new with your body.

3. Protect yourself from the sun.

Exposing yourself to the sun's ultraviolet (UV) rays increases your risk of getting GVHD. Don't forget, even on a cool, cloudy day the sun is just as harmful as on a hot, bright day. To limit your exposure to the sun:

- Avoid the sun as much as possible.
- Use an umbrella when you're in the sun.
- Wear a hat, sunglasses, long-sleeve shirts and pants when you go outside.
- Apply SPF 50 or higher sunscreen on skin that is not covered. You can also wear SPF clothing.

Treatment for GVHD

Early treatment of GVHD, infections and other side effects can help you recover faster.

- Treatment typically includes medicines that hold back your immune system, also called immunosuppressants. These medicines help your new donor cells accept your body. Many times, the first treatment is a steroid, like prednisone.
- During treatment for GVHD you may be limited on what you can do, even if your transplant was over 1 year ago. For example, you may need to avoid yard work or large crowds. Ask your transplant team what you may need to avoid.
- Follow your doctor's instructions carefully when taking GVHD medicines. If you can't take them for any reason, tell your doctor.
- Treatment for GVHD takes time. You may need to take GVHD medicine for many months. It can take time to find the best type and dose of medicine with the fewest side effects to treat your GVHD.

Resources for you

Find more information on GVHD prevention, signs, symptoms and treatment at **nmdp.org/PatientGVHD**.

If you have GVHD after transplant, a clinical trial may offer a treatment option for you. We can help you learn about and find clinical trials.

Visit **ctsearchsupport.org** or call **1 (888) 814-8610**.

NMDP Survivorship Program

You and your loved ones can receive free support. Our team can:

- Listen and answer questions
- Connect you to resources based on your needs
- Offer virtual appointments with our medical staff

CALL
1 (866) 301-4650

EMAIL
survivorship@nmdp.org

Protecting yourself from infection

Your immune system can't protect you fully right now from germs that cause infections. While some infections can be minor, others can be serious.

These tips can help you lower your risk of infection as your immune system gets stronger. Remember, always follow the advice of your transplant team.

Take your medicines and get vaccines

Take your anti-infection medicines (like antibiotics, antivirals and antifungals) as instructed by your doctor. Over the next several years you may need to be re-vaccinated (re-immunized). Ask your doctor what vaccines you'll need and when it will be safe for you to get them.

Keep your hands and body clean

Washing your hands is one of the best ways to lower your risk of infection. You and others around you should wash hands:

- When you come home after going out
- After you use the bathroom, take out the garbage, touch an animal, cough or blow your nose
- After you touch a shared object, like a phone, doorknob or money
- Before and after preparing food
- After eating food or taking medicines

Avoid changing diapers or wiping noses of children. If you do, use disposable gloves when available and wash your hands afterwards.

Don't be shy about keeping a strict hand-washing policy with family, friends and visitors. Ask them to wash their hands as soon as they come into your home. Buying antibacterial soaps in fun dispensers can help kids get in the habit of handwashing. Use hand sanitizer when washing is not available.

Other tips for keeping your body clean:

- Take a daily bath or shower using mild soap. Your doctor can give you advice on soaps and shampoos.
- Don't share towels or washcloths.
- Change your clothes and towels every day.
- Change your sheets once a week.

"You have to find a way to let go of the life you no longer have in order to be able to embrace the life you do have now."

— Esther, transplant recipient, with her daughters

Keep your mouth clean

Taking good care of your teeth and gums can help protect you from infection and mouth sores. Some general tips include:

- Brush your teeth at least two times a day with a soft toothbrush.
- Check with your doctor to see when it's safe for you to floss.
- Use an alcohol-free mouth rinse or fluoride treatment as recommended by your doctor.
- Ask your doctor if you need to take antibiotics before going to the dentist.
- See your dentist every 6 months.

Keep your environment clean

Until your immune system is back to full strength, you'll need to avoid dust, dirt, soil and plants as much as possible. To lower your risk of infection:

- Stay inside when anyone is mowing the lawn, using a leaf blower or anything else that stirs up dust.
- Have someone help keep your house clean by mopping instead of sweeping.
- Avoid being in a room while it's being cleaned.
- Don't bring any new live plants or flowers into your house.
- Avoid live Christmas trees or other holiday plants.
- Avoid gardening, yard work, or farm work.

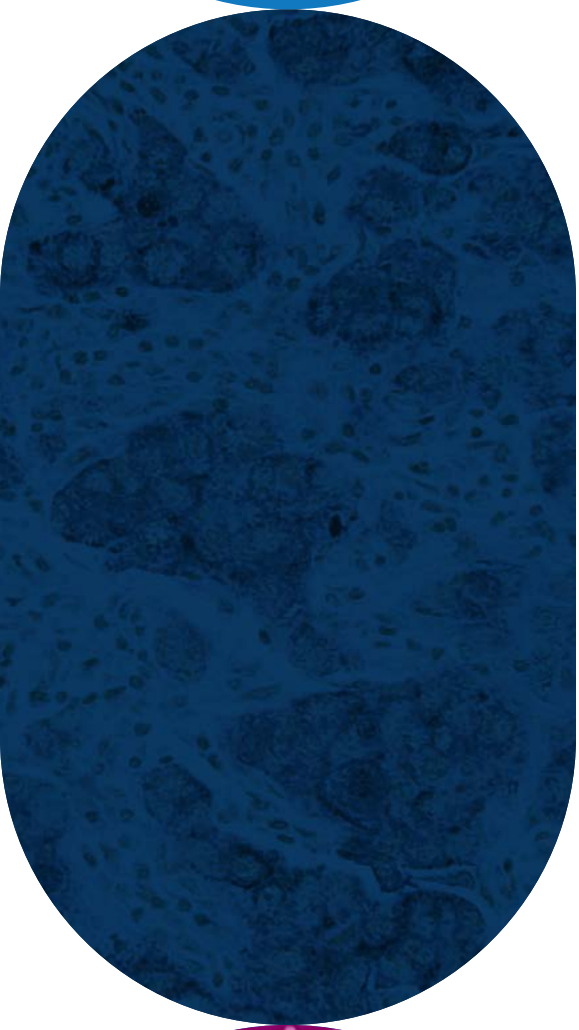
Take special precautions for children

- Avoid toys and games that can't be washed or cleaned.
- Don't let your child share toys with other young children who put toys in their mouths.
- Wash hard plastic toys and games regularly in the dishwasher, washing machine or with hot soapy water.
- Avoid using bath toys that retain water, like rubber ducks that suck in and squirt out water.
- Encourage your child to talk to you about how they're feeling and tell you if they have any infection symptoms.

Breathe clean air

There are many steps you can take to help improve the quality of the air you breathe:

- Have someone change the air filters in your furnace regularly. Ask your doctor how often they should be changed.
- Don't smoke anything and avoid second-hand smoke. Both tobacco and marijuana smoke can increase your chances of getting a lung infection.
- Don't use fireplaces, candles, oil lamps or incense. If you enjoy candles, consider battery-operated LED candles.
- Avoid new construction, sawdust and environmental chemicals like paint and glue.
- Check with your doctor before using a humidifier or diffuser.



Protect yourself when you go out

Here are some tips for when you go out:

- Visit places like stores, restaurants and movie theaters when they're less busy.
- Use protective gloves or disinfectant wipes in public places.
- Avoid swimming in pools, hot tubs, lakes, rivers or oceans until your doctor says it's safe.

Take precautions around visitors

Before anyone comes for a visit, tell them about your needs, and:

- Don't let anyone visit who has a rash or symptoms of a cold, flu or COVID-19.
- Don't allow visitors who have been in close contact with sick children.
- Avoid contact with anyone who has had a live vaccine (immunization) in the past 2 to 4 weeks, as recommended by your doctor.

Use caution around pets and animals

Having pets around can be important for your emotional well-being. If you already have cats, dogs or fish, they can stay in your home. But no new pets should be brought in.

While you're recovering, arrange for someone to feed and clean up after your pet.

Cats and dogs: Don't let them lick you. Wash your hands after any contact. Keep cats inside. Keep all pets away from areas where you eat, sleep or spend long periods of time. Tell your doctor right away if a pet scratches you and causes you to bleed.

Fish: It's okay to have a home aquarium if someone else cleans it regularly.

Birds and reptiles: You shouldn't have birds or reptiles in your home.

Patients in rural areas: Avoid barns, fields and contact with farm animals. If you live in a rural area and farmers are working in nearby fields, ask your doctor if you can be outside.

Ashley,
transplant recipient,
with her dog

Remember, even if you do everything "right" you may still get an infection. If you experience anything that doesn't seem quite right, tell your doctor. It could be an infection, a sign of GVHD or other side effect.

Managing complications after transplant

Even if you're feeling well, checkups are important because complications can happen any time after transplant. During your checkups, your doctor will:

- Look for any signs and symptoms.
- Talk with you about what tests you may need.
- Ask you about your quality of life, including your emotional and sexual health.

If you have no signs of GVHD, your doctor may slowly lower the dose and eventually stop your immunosuppressants (medicines that hold back your immune system). When that happens, you may have new symptoms of GVHD. Tell your doctor right away if you have any new or worsening symptoms.

Tips to manage complications

Depending on the problem, you may need to have 2 to 3 different treatments before finding what works best for you. Here are some tips to manage complications:

Eyes

- **Cataracts:** For early or mild cataracts, try new glasses or better lighting. If your vision gets much worse, ask your doctor about cataract surgery.
- **Dryness, itching, irritation:** Avoid eye strain and rest your eyes. Use preservative-free artificial tears or warm compresses. A humidifier may also help but check with your doctor first.
- **Severely dry eyes:** Ask your doctor about specially made eye drops or contact lenses.

Heart and blood vessels

- **High cholesterol or high blood pressure:** Eat a well-balanced diet with less fat. Do physical activity, like walking, most days. Take your medicines as prescribed by your doctor.

Mouth

- **Pain and dryness:** Avoid eating spicy and acidic foods. Ask your doctor about rinses and lubricants, which may help with mouth sores.

Skin, bones and joints

- **Osteopenia (weak bones):** Ask your doctor if you should take calcium and vitamin D supplements or have a test for weak bones. Weight-bearing exercise, like walking, can build bone strength.
- **Rashes:** When going outside, wear hats and long sleeves to protect your skin. Check with your doctor before using any new skin creams or lotions.
- **Skin and joint changes, such as tightening or thickening:** Medicines, exercise and physical therapy may help increase blood flow, strength and flexibility.

"Several years after my transplant, I came to a startling realization. I was living my life 70% of what I used to be. I compared virtually everything I did to my pre-sickness self. That misguided attitude frequently left me disappointed, overshadowing the amazing gains I had made. From that very moment on, I began living my life 100% of what I am now. Imagine that for a moment and feel the difference. Trust me—do that and it will change your life."

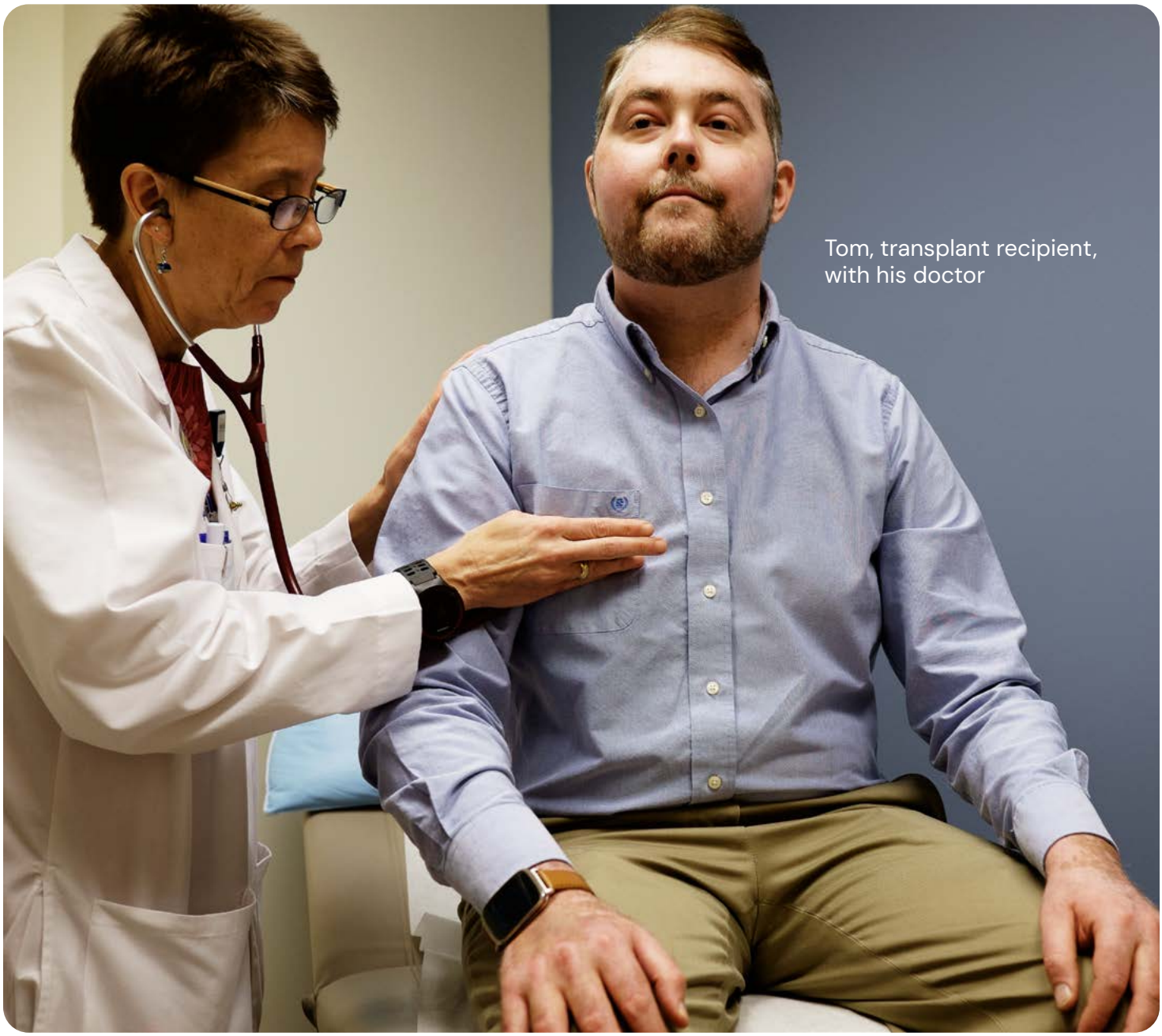
—Ted, transplant recipient

Screening for cancer

A new cancer could be a complication from your treatment. Talk to your doctor about your risk. You can also:

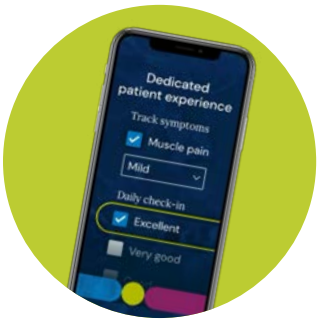
- Follow cancer prevention recommendations (go to **aicr.org** and click on Reduce Your Cancer Risk).
- Ask your doctor if you need cancer screenings (like a mammogram).

When a new cancer is caught early, there may be more treatment options and they may work better.



Tom, transplant recipient, with his doctor

Resources for you



My NMDP app

My NMDP is a free mobile app that helps you manage your care after transplant, including:

- Tracking your wellness and symptoms
- Connecting with others going through their own transplant journeys
- Accessing education articles
- Getting support from our Patient Support Center

Available in a mobile app or online:
Search for My NMDP in the app store or visit **my.nmdp.org**.

Post-transplant care guides

We offer free post-transplant care guides for you and your health care team. They include information on routine tests and lifestyle tips.

You can access the guidelines at **nmdp.org/CareGuide**.

Your doctor can download our free mobile app by searching "NMDP transplant guidelines" in the app stores.

MY NMDP APP
my.nmdp.org

POST-TRANSPLANT CARE GUIDELINES
nmdp.org/CareGuide

Eating well after transplant

Good nutrition is a key part of gaining strength after transplant. But transplant changes things. Nutritional needs and tastes may change, sometimes making it hard to eat healthy.

Follow your transplant team's instructions on how to safely choose, prepare and handle food. Use the menus and recipes they give you. Your dietitian (a nutrition expert) might also be able to help you create more recipes. The following tips are meant as a guide to help you as you make food choices. However, **always listen to your transplant team's instructions.**

Healthy food basics

A healthy diet after transplant includes a variety of foods that you already enjoy such as:

- Fats
- Carbohydrates (carbs)
- Proteins
- Fruits
- Vegetables

Limit of the amount of highly processed, packaged and sugary foods you eat. But you don't need to cut them from your diet entirely. Carbs and fats sometimes get a bad reputation, but they are good in moderation.

Ideas to make eating easier and more enjoyable

You may find that you have less of an appetite or a change in your taste buds. These side effects are usually temporary. Work with your dietitian to plan meals that are satisfying and healthy for you.

Helpful tips:

- **If your mouth is dry:** Rinse your mouth with a mixture of 1 cup water and ½ teaspoon baking soda before eating.
- **If your mouth is sore:** Try eating chilled or frozen foods, like cottage cheese or frozen yogurt.
- **If foods taste metallic:** Use plastic utensils and try mint or ginger.
- **If your stomach is upset:** Avoid fried, fatty, spicy and acidic foods, like tomato juice.
- **To help prevent diarrhea:**
  - Eat low-fiber foods like white bread, white rice, eggs, potatoes, cooked fish and chicken without skin.
  - Avoid lactose by using lactose-free milk, soy milk or yogurt instead.
  - Avoid ingredients like sorbitol, mannitol and xylitol, which are in many sugar-free products.
  - Eat small meals throughout the day instead of larger meals.

Jody,
transplant recipient

When you're choosing something to eat

These foods are low risk and generally safe to eat:

Dairy and eggs

- Pasteurized foods like milk, eggs, yogurt, cottage cheese, tofu and refrigerated juice (look for the word "pasteurized" on the label)
- Commercially packaged hard and semisoft cheeses, including cheddar, mozzarella, parmesan, Swiss and Monterey Jack

Fruits and vegetables

- Washed fresh fruits and vegetables
- Cooked vegetables, including sprouts

Meat and seafood

- Meat or poultry cooked to a safe internal (inside) temperature (find the safe temperatures listed on page 22)
- Seafood, when handled properly and cooked to a safe internal temperature

Packaged foods

- Prepared, packaged foods in boxes, cans or frozen, like fruits and vegetables
- Roasted and shelled nuts (look for the word "roasted" on the label)
- Commercially packaged peanut, almond and soybean butter
- Commercially packaged breads and cereals
- Prepackaged snack foods like pretzels, popcorn and tortilla chips
- Honey

These foods are high risk and generally not safe to eat:

Dairy and eggs

- Unpasteurized (raw) milk
- Soft cheeses made from unpasteurized (raw) milk, such as feta, Brie or queso fresco
- Foods that contain raw or undercooked eggs, such as homemade raw cookie dough, homemade eggnog or homemade Caesar salad dressing

Fruits and vegetables

- Unwashed fresh fruits and vegetables
- Fruits and vegetables with bruises or bad spots
- Raw sprouts, such as alfalfa or bean sprouts

Meat and seafood

- Raw or undercooked fish or shellfish, including sashimi
- Refrigerated smoked fish
- Partially cooked seafood
- Hot dogs, deli meats and luncheon meats that have not been reheated

Packaged foods

- Frozen foods that are not frozen solid
- Foods in damaged packaging (packages with dents or cracks)
- Expired foods (check the expiration date on the packaging)
- Bulk foods or items from self-service bins
- Unroasted nuts or nuts in the shell

When you're choosing something to drink

- **Water:** It's important to drink water throughout the day to stay hydrated. Most tap water is safe to drink. If you get your water from an uncertified well or are worried about your water quality, boil your water before drinking it or using it in food preparation. Or use bottled water instead.
- **Alcohol:** Alcohol could interact with your medicines. Talk to your doctor before having a beer, glass of wine or other drinks with alcohol.

When you're eating away from home

If you go out for a meal, there are extra precautions you may need to take. But first, talk with your doctor about when it's safe for you to eat away from home.

Places to avoid:

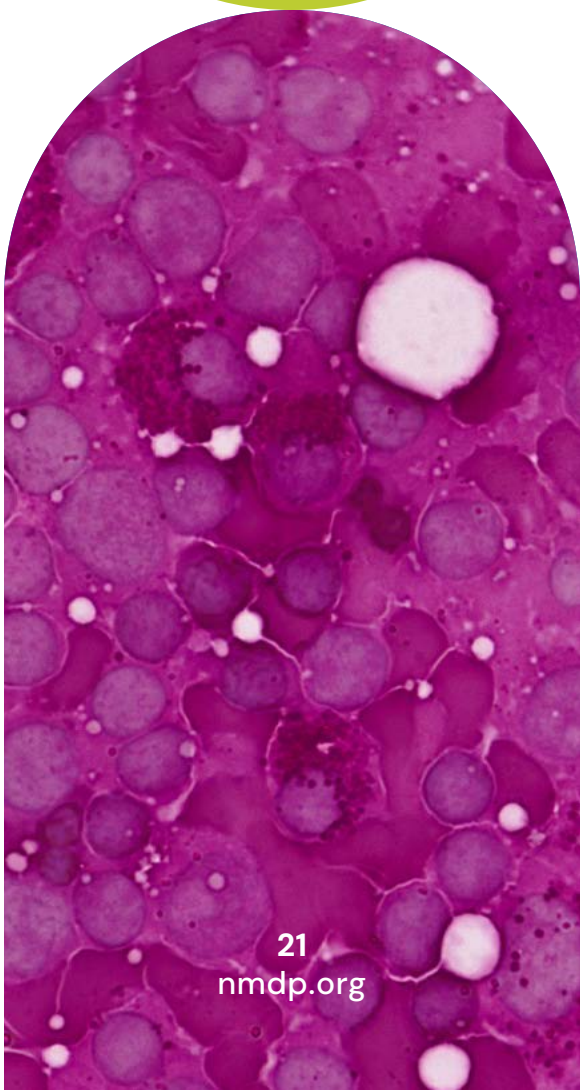
- Delis
- Salad bars, buffets and potlucks
- Street or sidewalk vendors (food trucks, food stands, etc.)

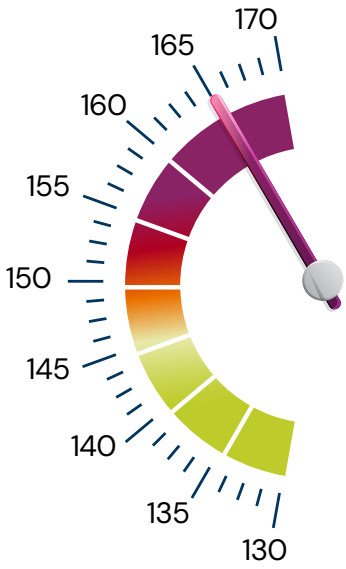
Restaurant tips:

- Avoid crowds by calling ahead and visiting during less busy times.
- Ask how your food will be prepared and if it contains raw eggs, meat or fish.
- If you order meat, ask that it be cooked until well done.

"There are many stages of recovery. The one you're in now ... it's temporary."

—James,
transplant recipient





Safe temperature recommendations

Use a meat and poultry thermometer to make sure the internal temperature of your food is high enough to kill bacteria. Simply looking at color and texture is not reliable enough. If you don't have a thermometer, make sure to buy one designed for meat and poultry.

165° F

Chicken, turkey and duck (whole, pieces and ground)

160° F

Ground beef, pork, veal, egg dishes

145° F

Beef, pork, veal, lamb (steaks, roasts and chops), fish

Tips for safe food preparation:

- Wash your hands with warm, soapy water before and after handling food.
- Use hot, soapy water with disposable sponges and paper towels for washing dishes. To clean areas where food is prepared, you can also use disinfecting wipes.
- Thaw frozen foods (including meat) in the refrigerator, not on the counter or in the sink.
- Wash fruits and vegetables before cutting them, even those that you peel. The best way to wash fruits and vegetables is with running water. You can also scrub them with a produce brush. Don't use produce washes, soap, bleach, peroxide or vinegar. Don't soak fruits or vegetables.
- Wash the top of cans and can opener with hot, soapy water before use.
- Use a side-opening can opener so lids don't fall inside.
- Avoid touching raw meat. Or wear disposable gloves and wash your hands before and after touching raw meat.
- Use separate cutting boards, plates and utensils for raw foods and cooked foods. Be careful to avoid contact between cooked and raw meat juices.
- Clean cutting boards in the dishwasher or use a mixture of 1 tablespoon of bleach for every gallon of water.
- Cook meat to a safe internal (inside) temperature. See the image to the left for safe temperatures.
- Cook hot dogs and lunch meat until they are steaming.

When you're storing and preparing food

Handling food safely helps you avoid getting sick. It's especially important when you have a weaker immune system.

Storing and preparing food in the right way is just as important as the foods you eat. If you have any questions about storing or preparing your food safely, talk to your dietitian.

Tips for safe food storage:

- Bring your groceries home right after leaving the store and put them away immediately.
- Make sure refrigerated foods stay cold and frozen foods stay frozen until use.
- Throw away expired food and pay close attention to freshness.
- Make and store foods in small portions so they are used up quickly.
- Do not eat leftovers that have been in the refrigerator for more than 2 days. Put a date on containers so you know how long they've been there.
- Do not eat foods that have been left out of the refrigerator for 2 or more hours.

Nutrition and steroids

Steroids are often the main treatment for GVHD. But they can cause side effects like high blood pressure, high blood sugar and swelling. If you're taking steroids, adjusting your diet may help you avoid or reduce some of these side effects. Eating fruits and vegetables while avoiding sugary drinks and sweets can help.

Resources for you

READ
more about food safety:
nmdp.org/FoodSafety

CALL
1 (866) 301-4650

EMAIL
survivorship@nmdp.org

Emotional highs and lows after transplant

You've been through a lot. Even if you were very upbeat during treatment and recovery, it's normal to sometimes feel down or worried after transplant. At the same time, you may also find meaning and growth from your experience.

Emotional highs and lows after transplant happen. But when feelings of anxiety, worry or feeling down won't go away or get in the way of activities of everyday life, it's time to ask for help.

Recognizing anxiety

Sometimes anxiety is helpful. For example, a little bit of worry about infection after transplant can be a reminder to wash your hands. But too much worry about infection can slow your recovery if it limits your normal daily activities.

Some symptoms of anxiety include:

- Difficulty falling or staying asleep
- Dizziness
- Feeling so restless you can't sit
- Irritability
- Muscle tension
- Nervousness
- Trouble concentrating
- Upset stomach

Recognizing PTSD

Sometimes anxiety is so intense after a difficult experience that a person develops post-traumatic stress disorder (PTSD). If untreated, PTSD may affect your relationships and your ability to function at home, school or work.

Some symptoms of PTSD include:

- Bad dreams
- Scary thoughts
- Reliving your experience over and over
- Feeling emotionally numb, guilty, depressed or worried
- Feeling easily startled, tense or "on edge"

These symptoms may come early in your recovery or later on. If any of these symptoms last more than a few weeks, they might be PTSD. Tell your doctor about your symptoms.

Many people with PTSD get better with medicines, counseling and/or group therapy.

"For the first 3 months after transplant, I was severely depressed. I was in a 'why me' state for a while. I didn't want to get out of bed. My doctor prescribed antidepressants. That, along with the support of my mom, really helped."

—Danielle,
transplant recipient

Recognizing depression

Some symptoms of depression include:

- Feeling sad, irritable or an "empty" mood that won't go away
- Sleeping more or less than usual or not being able to sleep
- No longer interested or enjoying activities you used to enjoy, including sex
- Having trouble concentrating, remembering or making decisions
- Feeling guilty, hopeless, helpless or worthless
- Thoughts of hurting or killing yourself

If you've had any of these symptoms most days for 2 or more weeks, you may need to ask for help. Tell your doctor about your symptoms and ask about what could help you. Your doctor might suggest a prescription medicine, talking to a therapist or both. Ask to see a therapist or counselor who has experience helping people who are recovering from a life-threatening illness or helping caregivers.

If you are having thoughts of hurting yourself or others, get help immediately. Call 988, the national suicide or crisis lifeline, any time—24 hours a day, 7 days a week—to talk with someone who can help.
You can also dial 911 or go to your local hospital emergency department (ER).

Starting the conversation

If you think you're depressed or have anxiety, or you're concerned about a loved one, it can be hard to talk about it. Try these tips to get the conversation started.

With your doctor:

- "I haven't been feeling like myself lately. I'm concerned that I'm depressed or overly anxious."
- "What do you recommend so I don't feel like this all of the time?"
- "My friend told me they're worried about me. They wondered if I was depressed."

With a loved one:

- "You don't seem like yourself. How are you feeling?"
- "It's okay to ask for help. Your doctor would want to know about these feelings so they can help you."
- "I'd like to help you get treatment. Would you like me to be with you when you make an appointment with your doctor?"

Resources for you

Sometimes talking to someone who's been there can help. The NMDP Peer Connect program can put you in touch with one of our trained volunteers—who are all transplant recipients or caregivers. Learn more at **nmdp.org/PeerConnect**.

For free, confidential support, contact the NMDP Patient Support Center:

CALL
1 (866) 999-6743

EMAIL
patientinfo@nmdp.org

VISIT
nmdp.org/one-on-one

Redefining your relationship with your caregiver

Once you return home after transplant, it can be hard to determine when and how to get back to when you weren't a "patient" and a "caregiver."

Talk it out

When you come home from transplant, it's normal to feel a mix of emotions. Talking through these emotions with your caregiver can help you connect and cope with them together. Wendy, a transplant recipient, says, "Talk with your caregiver about how you're doing, how they're doing, and how things are changing. Try to have these conversations when you're both calm."

If you're not sure how to bring this up, here are a few ideas to help you start the conversation:

- "We've been through a lot recently. Can we talk about how our relationship has changed?"
- "I know you've taken on a lot as my caregiver. As I start to feel better, I'm hoping you'll have less caregiving to do. Can we talk about this transition?"
- "I feel like our roles have changed through transplant and I'm looking forward to not feeling like a patient. How do you feel?"

"All of a sudden you're turned loose into the world and reality really hits."

—Clark, caregiver

"We had a lot to celebrate and made a point of acknowledging every milestone we could."

—Brian, caregiver, with his wife, Betsy, transplant recipient

"There may also be books or other resources out there that can help you, but don't be afraid to ask for help."

—Clark, caregiver

Hailey Hassel, MSW, LICSW, BMT Social Worker for NMDP

Take it slow

When you're ready to get back to your pre-transplant routine, it may be helpful to talk with your caregiver about setting boundaries and how your expectations for one another are changing. Your caregiver may feel hesitant because they're still protective of you.

For example, if your normal routine includes:

- **Working:** Consider volunteering or working part-time before going back to work full-time.
- **Grocery shopping:** Try going to the store on days and times when there are fewer people there.
- **Going out with friends:** Avoid going to crowded areas. Instead, try walking at the park. Talk with your friends about staying home when they feel sick.

Ask for help

If you don't feel comfortable talking about this with your caregiver, ask someone to sit in and help with the conversation. It could be a counselor, someone from your church or a trusted friend.

One of our BMT Social Workers, Hailey Hassel, MSW, LICSW, offers some advice. "You don't have to be perfect at communicating," she says. "The goal isn't to have the perfect words or the right answers, but to talk and figure it out together. It's OK to make mistakes along the way."

Resources for you

You can connect with a BMT social worker like Hailey to talk about life after transplant, including:

- Transitioning away from being a “patient”
- Setting boundaries and expectations with your caregiver
- Changes in your relationships

You can also:

Join a group of peers:

- Virtual support group: **nmdp.org/SupportGroups**
- My NMDP app: Search MyNMDP in the app store or visit **my.nmdp.org**
- Facebook: **Facebook.com/NMDPPatient**

Connect with someone who’s been through it:

- **nmdp.org/PeerConnect**

Free confidential support

Contact our Patient and Caregiver Emotional Support (PACES) program:

CALL
1 (866) 999-6743

EMAIL
patientinfo@nmdp.org

Coping with changes in sexual health

Many people find that their sex life changes after transplant. And it may be hard for you and your partner to adjust. You're not alone. And there is help available. Your sexual health is just as important as your blood and immune system recovery. Returning to sexual activity is an important part of life after transplant.

Common sexual problems and possible solutions

Some sexual problems after transplant may be temporary side effects from treatment. Others may be long-lasting or signs of a more serious complication.

Tell your doctor or nurse about any new sexual problems you experience and how you are feeling. They can help make sure sexual problems aren't early signs of complications, like GVHD or infection. They can also suggest solutions.

Here are some common sexual problems after transplant:

Loss of interest in sexual activity

If you have lost interest in sexual activity, talk to your doctor or nurse. For some patients, hormone replacement may be an option. You might also find it helpful to see a professional sex therapist or counselor.

Vaginal changes

Many patients have vaginal dryness, which can cause discomfort or pain during intercourse. Over-the-counter water-based lubricants or vaginal moisturizers can help reduce pain. Prescription medicines, like vaginal estrogen, may help. Ask your doctor or nurse what is best for you.

After transplant, some patients may have vaginal infections. Symptoms include a creamy-white discharge or itchiness that gets worse if you scratch. This may be treated with medicines.

Erectile issues

Many patients have difficulty getting or keeping an erection during their recovery. Talk to your doctor about options for dealing with erectile dysfunction. You might also try other sexual activities for pleasure, including oral or manual sex, using sex tools and masturbation.

Pain during sex

If sex is painful, tell your doctor or nurse. They can help find out what is causing the pain and recommend the best treatment.

But even with treatment, some people still have pain with sex. Talk to your partner about what hurts. Explore other positions or ways of sharing intimacy. You might experiment with less strenuous activities, such as mutual masturbation, side-by-side positions or quicker rather than longer sexual encounters.

Plan times for intimacy after you have taken pain medicines and explore pain relieving lubricants (such as CBD). Use pillows and cushions to get more comfortable. Allow the person who has the pain to control the depth, speed and duration of penetration.

Practice safe sex

Remember to practice safe sex even if you have been in a long-term, committed relationship. Your immune system is weaker than normal right now, so your risk for infection is higher. Ask your doctor if there are any sexual practices that you should avoid.

You should always use a condom during sex. Condoms help lower your risk of getting a sexually transmitted disease (STD).

Be sure to use condoms or other forms of birth control to prevent pregnancy. It may still be possible for you or your partner to become pregnant without birth control. Preventing a pregnancy is important because the medicines you are taking might hurt an unborn baby.

Connect with your partner

It may not be easy, but it's important to talk with your partner about any sexual problems. Talk openly and encourage your partner to do the same. If you understand each other's experiences, you can help each other cope with any changes.

Take time to be intimate, even as you work through problems. Remember, intimacy doesn't just mean having sex. Explore other ways to be intimate, such as cuddling, giving each other a massage or having a romantic dinner.

Help is available

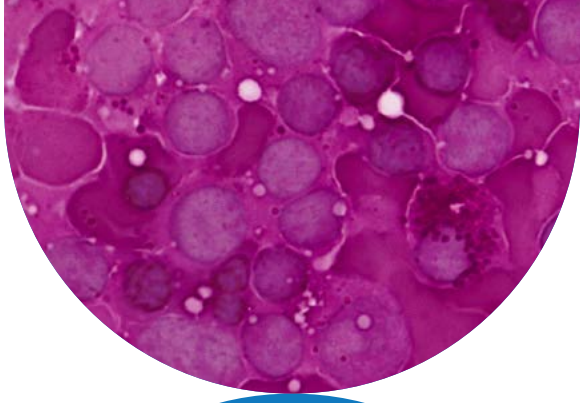
Talk to your doctors about any sexual problems you're having. This might feel embarrassing, but most doctors are used to talking about it and want to know. You may find it helpful to write down your questions before meeting with your doctor. If you feel uncomfortable talking about this with your doctor, talk with someone you are comfortable with, like a nurse or social worker. They can help you get the care and support you need.

"In my personal experience, doctors are comfortable talking about sex, but you may have to bring it up."

—Wendy, transplant recipient

Fertility after transplant

Fertility is the ability to have children. Some people freeze eggs, embryos or sperm before transplant to help them have children after transplant. If you haven't already done so and think you want to have children, talk to your doctor about your options.



Risks for infertility

When patients are not able to become pregnant after 1 year of trying, it's called infertility. Chemotherapy and radiation before transplant lowers your ability to have children. Not all preparative regimens have the same risk.

Your age affects your risk for infertility too. If you had a transplant closer to age 40, you may have a higher risk of infertility than if you have a transplant closer to age 20.

Other things that can increase your risk for infertility include:

- Hormone changes
- Medicines
- Sexually transmitted infections
- Smoking
- Strenuous exercise
- Weight (overweight or underweight)

Measuring fertility

Even if you've had a transplant, you may still be able to have a baby. It's important to talk to your doctor right away if you want to have children. They can help you meet with a fertility specialist to see if you're able to have children.

Getting your period isn't a sign of fertility. You may have a period but not be able to get pregnant. Or you may be able to get pregnant but not have a regular period. A doctor who specializes in fertility can find out if you can become pregnant.

The chemotherapy or radiation may or may not have affected your sperm. It can take longer for sperm to recover after chemotherapy and radiation. And it's possible that sperm may never recover after transplant. It's important to always use a condom so you don't have a baby while recovering from transplant.

Ask your doctor about measuring your fertility and about birth control options.

Safety of pregnancy

It is safe to have a baby after transplant. Doctors have found that there is no higher risk of birth defects in children born to transplant recipients. But there are risks during pregnancy.

If you are considering having a baby after a transplant be sure to see a doctor who specializes in high-risk pregnancy. This doctor will monitor you and your baby more often throughout the pregnancy.

Survivorship Care Plans for transplant recipients

After transplant, you may have many different doctors, tests and treatments. You may have gotten a Survivorship Care Plan from your doctor or care team to help you manage your care easier.

A Survivorship Care Plan keeps your recovery on track by helping you coordinate your health care between doctors, nurses, social workers and other providers that you'll see after your transplant.

What a Survivorship Care Plan should include

A Survivorship Care Plan is your personal tool—tailored to your specific needs—to help you keep track of your health care information. A Survivorship Care Plan should include:

- A summary of transplant history
- A detailed plan and schedule for ongoing care
- Tests you may need
- Signs and symptoms to watch for
- Contact information for your health care team

How to use your plan

Share your Survivorship Care Plan with your primary care doctor and any other doctors involved in your post-transplant care. This will help everyone communicate with each other.

Take your Survivorship Care Plan with you to all your medical appointments. Use it to:

- Ask questions
- Take notes
- Keep track of test results
- Write down next steps

It's also important to share your care plan with your caregiver. They can help you coordinate appointments, ask questions and notice symptoms that you may not.

"Patients get a Survivorship Care Plan when they transfer care from their transplant center to providers they see at home. The care plan includes your transplant history and gives recommendations for ongoing care. It also lists signs and symptoms to watch for and report to your care team."

—Dekozlymn Anderson, DNP, APRN, FNP-C, Nurse Practitioner for NMDP

Information session at
Gulf Coast Blood Center

What to do if you don't have a Survivorship Care Plan

Your doctor or care team should give you a plan after your transplant. If you don't have one, ask your transplant doctor or care team. Be sure to ask your doctor about anything in your Survivorship Care Plan that you don't understand.

Keep in mind, if your transplant was many years ago, your plan might need updating. Doctors may know more now, and medical guidelines may have changed. Ask your doctor to review it and update if needed.

Resources for you

Our NMDP Survivorship Program offers free support for you. We can help you understand your Survivorship Care Plan and help you navigate your post-transplant journey.

VISIT
nmdp.org/survivorship

EMAIL
survivorship@nmdp.org

Going back to work or school

Going back to work or school can be a big milestone on the road to recovery. You and your doctor or your child's doctor will work together to decide when it's okay to make this transition.

When you do head back to work or school, you or your child may feel a lot of emotions. Excitement about seeing friends or co-workers again. Nervousness about how people will react. Concern about "keeping up."

Read on for tips to make the transition a little easier, and to make sure your rights are protected, too.

When you're going back to work

Doctors usually suggest waiting to go back to work until at least 1 year after an allogeneic transplant. That's because it can take 9 to 12 months for your immune system to recover. Some people may get their doctor's okay to go back to work sooner. For others, it takes longer. You might also wait to go back because you don't feel up to it physically. Or, your job may be demanding or put you at a higher risk for infection (like construction work or working with animals).

Before you return to work:

- ☐ Contact your human resources (HR) department and talk to your supervisor, shop steward or union representative.
- ☐ Discuss any special needs and ask for any changes that would make it easier for you to keep your job (e.g., flexible hours, regularly scheduled breaks, working from home or special equipment).
- ☐ Work out clear expectations about your schedule and workload.
- ☐ Keep a record of each request and the response.
- ☐ Consider asking your employer to tell your co-workers about your situation. Make sure you're comfortable with the information and how they'll share it.
- ☐ Talk to your HR department about your health insurance benefits. There are laws, including HIPAA and COBRA, which protect your health insurance benefits if you had health insurance before your leave.

Social Security benefits

- Talk to your Social Security plan administrator about how returning to work may affect your benefits.
- Look into the resources through the Social Security Administration (SSA) that could help you get back to work, like a trial work period. A trial work period lets you test your ability to work and still get Social Security benefits for up to 9 months, with more help after the trial period if needed.

"When you return to work, you need to take your time. You don't have to impress anyone. Give yourself permission to take it easy, and one day, you'll begin to see that you're accomplishing tasks in a very real and effective way."

—Herschel,
transplant recipient

To learn more about Social Security benefits, go to **ssa.gov/disability**

or call **1 (800) 772-1213.**

"Chemo brain is very real; even now 6 years after treatment. You can make lists, and I make reminders on my calendar. So, you find ways to deal with it."

—Matt, transplant recipient

Dealing with an "employment gap"

Because you didn't work during your transplant recovery, your résumé will show a length of time when you were not employed. This can be difficult to discuss during a job interview.

Your health history can't be used against you when you return to work or look for a new job. And if you're looking for a new job, companies can't ask about your health history. You aren't required to tell them about it unless you choose to do so.

Karen, a transplant recipient, chose to fill the gap in her employment by highlighting her volunteer work. She even put it at the top of her resume. "There are keywords that say 'volunteer work'," says Karen.
"It's what I'm doing, it's where my skills are at, and it's my experience."

Preparing for demands in the workplace

It can be physically and emotionally difficult to return to work after transplant. Many patients worry about whether they will be able to respond to the pace and requirements. Many patients also describe symptoms of "chemo-brain" that can affect short-term memory or make it hard to organize thoughts.

Consider "coping ahead of time" by thinking of situations or aspects of work that may be difficult and prepare for them. For example:

- If you're concerned about managing demands, come up with a plan for setting reminders (post-it notes, a calendar, alarm, etc.)
- To prepare for co-workers asking about your time away, come up with an "elevator speech" that you can use to move quickly through those conversations.

Finding your values

For many people, work not only provides financial stability, it also gives a sense of purpose, identity and belonging. Work provides structure to our days, plus social interaction that plays a major role in our self-esteem.

But even if you want to go back to work, it's not always easy to find the right job for you. If you're struggling to find work after BMT, finding volunteer and networking opportunities can be a great way to build up a resume and open doors to possible jobs.

Now could also be a good time to consider a new type of work. Take stock of your relationships and values—think through what and who is most important to you now. Use that list to guide how you spend your time. Then, consider doing some informational interviews with people in jobs that seem interesting to you.

When your child is going back to school

There are things you can do both before and after your child returns to school to help make it a smoother transition:

- Ask about resources, accommodations and services available to help your child. By law, your child's school may be required to provide some of these.
- Form a support team to help your child, including doctors, child life specialists, teachers, guidance counselors and the principal. Meet with them before your child goes back to school.
- Create a list of your child's medicines and talk to the team about them. If the medicines affect your child's mood or behavior, make a plan for dealing with these issues.
- Explain the plans to your child so there are no surprises. If your child is old enough, involve them in the planning.

Stay involved even when your child is back in school. Your child might not want special accommodations for fear of not fitting in. But it can be just as frustrating if your child feels overwhelmed.

If you think there are issues at school, talk to the teachers and principal right away. Remember, you are your child's advocate. Insist on what's right for your child.

"It took me a long time to believe that I would ever live a normal life again. My children believed in me long before I believed in myself. They encouraged me to try new things and take baby steps."

—Transplant recipient

Tiana,
mother and caregiver
to Demier, transplant recipient

Getting your child help at school

As you're planning for your child's return to school, you may want to ask about special services such as:

- More time to complete assignments and fewer homework demands.
- Help organizing materials.
- Being able to use calculators and recorders.

For children in kindergarten through grade 12, these special services are typically part of an Individual Education Program (IEP) or 504 Plan.

Many schools do a good job meeting students' needs and making accommodations to help them succeed. But if you think your child isn't getting support, you can:

- Bring your concerns from the teacher to the principal or the superintendent, if needed.
- Request other resources—such as tutors—to help your child.
- Learn more about your child's educational rights. Consult with an attorney who specializes in education.
- Change schools or homeschool your child.

To learn more about special education services, talk with the social worker at your child's transplant center or visit **ed.gov/about/contacts/state** to find contacts for the Department of Education in your state.

When you're going back to college

If you're going back to college, you may or may not be ready to take on a full class load, and that's okay. You need to ease back into things just like people who are going back to work.

Before you start your next college semester:

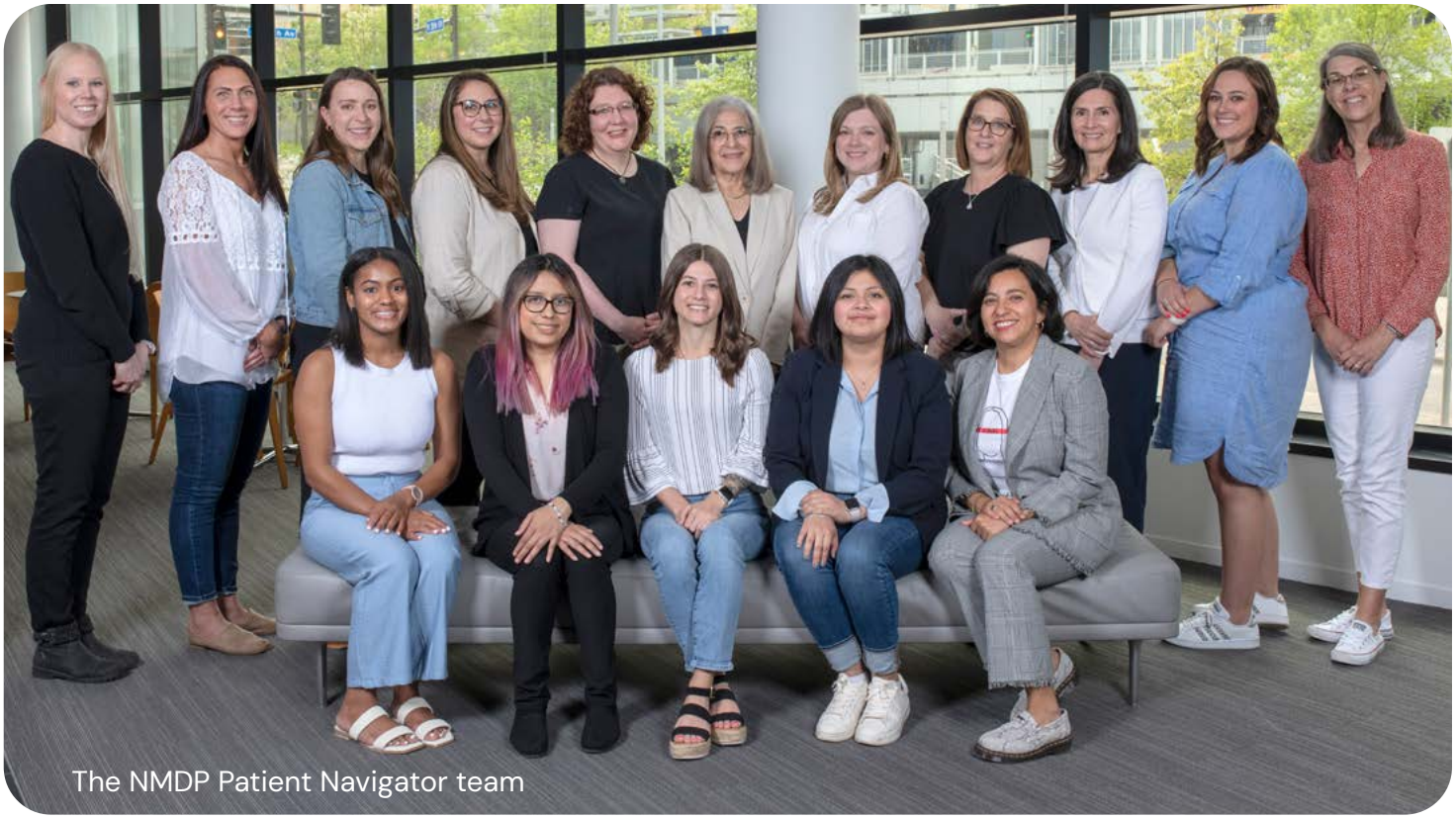
- Meet with the school's disabilities office or academic support center to learn about the resources available to help you.
- If you've already decided on your major, meet with an academic advisor in that area and ask for their support. They may be able to give you advice and be your advocate if needed.
- Talk with your professors before classes start for the semester or soon after. Work with them to set reasonable accommodations for completing your work.

We can help you find resources to help with the transition back to work or school.

Contact our BMT patient navigators at **patientinfo@nmdp.org** or **1 (888) 999-6743**.

"I was getting really tired at school so we switched to a half load. I went to the first 2 classes of the day and then went home. I usually took a nap, ate something and would do the homework for those 2 classes. Then I had a tutor who would come around 3 o'clock to get me caught up."

—Joe, transplant recipient



The NMDP Patient Navigator team

"At NMDP, we believe that every patient and caregiver deserves to be well cared for throughout the treatment journey. Who you are and how your story has unfolded matters to us. Our team of diverse and highly skilled professionals is ready to come alongside you to offer help that is tailored to you. We have bilingual staff members who can provide services in English or Spanish."

—Katie, MSW, LICSW, Sr. Director of Patient Services

We are here to help

As you continue your transplant journey, you're not alone. We are ready to help. We offer many free programs and resources to support you and your loved ones.

If you have questions ... Our BMT patient navigators can provide answers and find resources for you.

If you need to talk ... Our BMT social workers can listen and help you cope with challenges after transplant. We can also put you in touch with a trained volunteer who has been through transplant.

If you want guidance around ongoing care ... Our Survivorship team or clinical trials navigators can help you find and navigate care after transplant.

If you're looking for financial support ... We have financial grants that can help cover the costs of medicines, copays, groceries and other ongoing transplant-related costs.

If you want to give back after transplant... We have many volunteer opportunities, or you can donate financially to give back to future patients.

Connect in the way that works best for you.

- Call: **1 (888) 999-6743**
- Email: **patientinfo@nmdp.org**
- Visit: **nmdp.org/one-on-one**

Caregiver and parent caregiver magazines

Special issues of Living Now are available for caregivers and parents who care for a loved one or child after transplant.

ORDER FOR FREE

nmdp.org/request or by calling 1 (888) 999-6743

VISIT

Information for caregivers and parents is also online at nmdp.org/caregiver.

At NMDP[SM], we believe each of us holds the key to curing blood cancers and disorders. As a global nonprofit leader in cell therapy, NMDP creates essential connections between researchers and supporters to inspire action and accelerate innovation to find life-saving cures. With the help of blood stem cell donors from the world's most diverse registry and our extensive network of transplant partners, physicians and caregivers, we're expanding access to treatment so that **every** patient can receive their life-saving cell therapy.

NMDP. Find cures. Save lives.

Every individual's medical situation, transplant experience and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. This information is not intended to replace, and should not replace, a doctor's medical judgment or advice.

nmdp[SM]
FIND CURES. SAVE LIVES.

OUR MISSION

We save lives through cell therapy.

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