



Survivorship

and post-transplant care guide



Routine checkups are a vital part of your recovery after a blood or marrow transplant. This booklet has a list of tests and questions that will help you prepare for your checkups. These recommendations come from doctors who specialize in post-transplant care.*

Why routine checkups matter

Whether you had an autologous or allogeneic transplant, checkups are important. They help your doctors find any changes in your health, such as:

- The disease coming back (relapse)
- Problems due to your treatment

During your appointment, you can discuss any symptoms that may be affecting your quality of life. When issues are caught early, there may be more options for treatment, and those treatments may work better.

Even if you're feeling well, routine checkups are important to help you stay healthy. You should have checkups for the rest of your life because sometimes changes related to treatment can happen many years after your transplant.

About this guide

This guide is based on recommendations from doctors and researchers around the world.*

This information is not intended to replace the recommendations of your transplant doctor. You may need different tests or evaluations based on your unique situation. Your transplant doctor knows you best, so follow their recommendations.

Our free My NMDPSM app offers a secure tool to help you manage your health after transplant.

Use it to:

- Track symptoms
- Manage medications
- Get support from NMDP patient navigators

Download the app from the Apple or Android app store or visit my.nmdp.org.



Prepare for your checkup

- Talk with your transplant doctor and primary care provider to create a checkup schedule. They can also decide if you should go to the transplant center or a local hematologist/oncologist.
- Review the tests in this guide.
- Write down questions or concerns you'd like to talk to your doctor about.
- Ask your doctor if they have other suggestions unique to your treatment.
- Ask your doctor if you need appointments with other doctors like an eye doctor, dentist, physical therapist, gynecologist or other specialists.
- Bring this guide to your checkup.

Share with your doctor

There are 3 easy ways to share these guidelines with your doctors or dentist:

- Review this guide with them at your next appointment.
- Point them to **network.nmdp.org**. Click on Services & Support, then Post-transplant care.
- Ask them to download the NMDP Transplant Guidelines app for medical professionals.

Get support from caring experts

Our NMDP team can:

- Review post-transplant care guidelines
- Listen to your experiences and answer questions
- Connect you to resources specific to your needs
- Offer telehealth appointments with our medical staff (not available in every state)

Call:
1 (866) 301-4650

Email:
survivorship@nmdp.org

Website:
nmdp.org/survivorship

* Rotz SJ, Bhatt NS, Hamilton BK, et al. International recommendations for screening and preventative practices for long-term survivors of transplantation and cellular therapy: A 2023 update. *Transplantation and Cellular Therapy*. 2024;30(4):349-385. doi: 10.1016/j.jctc.2023.12.001.

Routine checkup guide

Checkups are important to staying healthy, even if you feel well. Below, you'll find exams and tests you may get after transplant. This information can help you prepare questions or concerns to discuss with your doctor. You may need more monitoring or treatment based on your situation, so ask your doctor what they recommend for you.

Words in **bold** are defined in the glossary.

Blood

- Blood test to check your complete blood count.
- Bleeding risk assessment.
- If you had blood transfusions, you may need a blood test or liver MRI to check your iron levels.
- If you have a hemoglobinopathy or a bone marrow failure syndrome, you may need more frequent monitoring.
- If you have multiple myeloma and are receiving immunotherapy, you may need medicine to prevent blood clots.

Bones

- Get regular checks of your bone density (using **DEXA scan**).
- Talk about ways to prevent **bone density loss**—including exercise, vitamin D and calcium supplements.
- You may need additional monitoring and treatment if you have avascular necrosis or Hurler Syndrome.

Cancer screening

- Talk to your doctor about your risk of getting a cancer after completion of therapy.
- Get regular cancer screening. Screening frequency may vary based on your individual risk factors (such as a history of radiation or **GVHD**). Screenings may include:
 - Blood tests
 - Breast imaging
 - **EGD** and colonoscopy
 - Oral exam
 - **Pap smear**
 - Skin exam
 - Thyroid exam
- Learn how to do self-exams for cancer, including skin, breast or testicular exam.
- Ask your doctor if you need a **mammogram** or other breast screening tests and how often they should be done.
- Additional screening may be needed if you had Fanconi anemia or Epstein Barr virus infection.

Emotional health

- Tell your doctor about your general well-being or quality of life.
- Talk about your feelings. Ask your doctor if or how often you need screenings for anxiety and depression.
- Talk about healthy lifestyle choices including nutrition and exercise.
- Talk about your family and caregiver's emotional health.
- Ask about counselors and support groups in your area.
- Ask questions about your sexual health.

Endocrine system

(thyroid, growth, sex hormones)

- Blood tests to check your **thyroid**, adrenal glands and hormone levels.
- Blood test to check for diabetes. Begin treatment if needed.
- Additional tests may be needed after menopause.

Additional tests for children:

- **Growth rate** and puberty evaluation.

If you have **GVHD** or take **immunosuppressants**, you may need to:

- Take higher doses of steroids (like prednisone) if you become sick.
- Gradually lower your dose of steroids when it is time to stop taking them.

Eyes

- Check for symptoms like:
 - Dryness
 - Excessive tearing
 - Pain
 - Redness and swelling
 - Sensitivity to light
 - Vision changes
- Have an eye specialist (**ophthalmologist**) perform a vision screening and retina exam.

If you have **GVHD**, you may need to:

- See an eye specialist more often.

Heart and blood vessels

- Talk about a heart healthy lifestyle, including nutrition and exercise.
- Check for high blood pressure and high cholesterol. Get treatment if needed.
- You may need a heart ultrasound or additional testing.
- You may need to see a heart specialist if you have one or more risk factors (like obesity or history of smoking), or if you have abnormal test results.
- If you have Hurler syndrome or amyloidosis, you may need close monitoring of your heart.

Immune system

- Talk about vaccines to prevent infection and disease.
- Talk about special precautions if you:
 - Have hypogammaglobulinemia
 - Have inborn errors of immunity
 - Have multiple myeloma
 - Don't have a spleen or if your spleen does not work

If you have **GVHD** or take

immunosuppressants, you may need:

- Medicine to prevent infection while you take immunosuppressants.
- Blood tests to screen for cytomegalovirus (CMV).

Kidneys

- Blood pressure test. If needed, start treatment and follow-up care.
- **Urine protein levels test** to see how well your kidneys are working.
- **Kidney filtration levels test** (BUN/creatinine test) to see how well your kidneys are working.
- If your kidneys aren't working well, you may need more tests (like kidney ultrasound or biopsy).
- If you have chronic kidney disease, don't take medicines, herbs or supplements unless directed by your doctor. You may need to see a kidney doctor.
- If you have multiple myeloma or amyloidosis, you may need more frequent monitoring.

Liver

- **Liver function blood tests** to see if your liver is working properly.
- If you have hepatitis B or C, your doctor will watch it closely. Ask if you need to see a liver doctor.
- If you have cirrhosis or dyskeratosis congenita, you may need a referral to a liver doctor.
- If you had red blood cell transfusions, you may need a blood test, a liver MRI or liver biopsy to check for too much iron.

Lungs

- Have your doctor listen to your lungs every year or more often if your breathing changes.
- Tell your doctor if you have shortness of breath or a cough that doesn't go away.
- Have **pulmonary function tests (PFTs)** to measure how well your lungs work.
- You may need to repeat PFTs and have imaging tests (such as chest X-ray, CT scan) if you have breathing problems or abnormal test results.
- Tell your doctor if you use tobacco, smoke or vape. Ask for help quitting.

If you have **GVHD**, you may need:

- Lung exams and **pulmonary function tests** earlier and more often.

Mouth

- Exam of the mouth, head and neck.
- Oral cancer screening.
- Talk to your doctor about high-risk habits, like tobacco or alcohol use.
- Talk to your doctor about symptoms like dry mouth.
- See your dentist for a complete dental checkup at 6- and 12-months post-transplant and then at least once a year.
- Ask if you need to take an antibiotic before having dental work done. The antibiotic prevents a bacterial infection of the heart valves.

Mouth (continued)

If you have **GVHD**, you may need to:

- Have exams of the mouth and teeth and oral cancer screenings more often.

Additional test for children:

- A dentist will check how well your child's teeth are growing.

Muscles

- Tests of your **range of motion**. Learn how to check your own **range of motion**.
- If you take steroids (like prednisone), you will need more tests.
- Tell your doctor if you have muscle weakness. You may need more tests including blood tests, imaging and electrical activity testing.
- See a physical therapist if needed.

Nervous system

(brain, spinal cord and nerves)

- Tests of your **nervous system** like your hearing, thinking and reasoning.
- If you have trouble with memory, concentration or decision-making, you may need more tests.

Additional test for children:

- Check cognitive development (ability to think and reason) for your child's age.

Sexual health, fertility and pregnancy

- Talk to your doctor about birth control and safe sex practices.
- Tell your doctor if you have pain or other problems with sexual activity.
- Get regular screenings for sexually transmitted infections (STIs).
- Get a **gynecologic exam** every year.
- If you want to have a baby, ask to see a fertility specialist.

If you have **GVHD** or had total body irradiation:

- Ask your doctor how often you need gynecologic or genital exams.

If you are pregnant:

- See a doctor who specializes in high-risk pregnancy.
- You may need to see a heart specialist.

Skin

- Discuss your risk of skin complications.
- Have regular skin exams based on risk factors like:
 - History of GVHD
 - History of skin cancer
 - History of radiation
 - Sun exposure
- Learn how to do routine self-exams of your skin.
- Talk about the risks of being in the sun and ways to protect yourself.
- Talk to your doctor immediately if you have sores that don't heal, skin tightening or other changes.

Screening for chronic GVHD

Chronic graft-versus-host disease (**GVHD**) is a serious, potentially life-threatening post-transplant complication. Early diagnosis can help prevent organ damage and increase your quality of life. If you notice any of the following symptoms, please tell your transplant doctor and primary care provider right away.

Digestive system

- Bloating
- Cramping or pain in belly
- Diarrhea
- Loss of appetite
- Nausea or vomiting
- Weight loss
- Painful or difficulty swallowing

Eyes

- Dry, burning, gritty eyes
- Excessive tearing
- Itching
- Pain
- Sensitivity to light and wind
- Trouble opening eyes in the morning
- Vision changes

Genitals

- Burning
- Dryness
- Itching
- Pain during intercourse or urination

Hair

- Hair loss
- Itchy scalp
- Premature gray or thinning hair

Liver

- Fatigue
- Feeling unwell
- Itching
- Yellowing of the skin and eyes

Lungs

- Difficulty breathing
- Dry cough
- Shortness of breath
- Wheezing

Mouth

- Chapped lips
- Dryness
- Pain
- Redness
- Sensitivity to spicy food, soda or toothpaste
- Swollen, red or bleeding gums
- Ulcers (painful sores)

Muscles and joints

- Cramps or pain
- Lower **range of motion**
- Tightness or stiffness
- Weakness

Nails

- Brittle or splitting nails
- Nail loss
- Ridging in nails

Skin

- Changes in skin color or texture
- Dry, itchy skin
- Rash
- Sores
- Swelling
- Tightening

Vaccines

Your immune system may be weak for more than 2 years after transplant. To prevent infection, it's important that you get re-vaccinated. Below is a list of recommended vaccines and what they protect against. Your doctor will manage your vaccination schedule for you.

| Vaccine | What it does | Months post-transplant to start vaccine | Doses |
|-----------------------------------|--|---|-------|
| COVID | Protects against COVID-19, which can cause severe respiratory illness | 3 | 3-4 |
| PCV20 | Protects against serious bacterial infections that can cause pneumonia, meningitis and bacteremia | 3-6 | 3-4 |
| Influenza (inactivated) | Protects against the flu | 4-6 | 2+ |
| DTaP | Protects against 3 serious diseases called diphtheria, tetanus and pertussis (whooping cough) | 6-12 | 3 |
| Hepatitis B | Protects against hepatitis B, which can cause liver damage and liver cancer | 6-12 | 3-4 |
| Hib | Protects against serious bacterial infections that can cause pneumonia, meningitis and bacteremia | 6-12 | 3 |
| HPV9 | Protects against 9 types of HPV that can cause many different types of cancer | 6-12 | 3 |
| IPV | Protects against polio, which can cause permanent paralysis | 6-12 | 3 |
| MCV4 | Protects against a serious bacterial infection that can cause meningitis and septicemia (sepsis or blood poisoning) | 6-12 | 2 |
| Zoster | Protects against shingles, which can cause painful rash and blisters | 12 | 2 |
| MMR | Protects against measles, mumps and rubella | 24 | 2 |
| Varicella | Protects against chickenpox, which can cause itchy rash and blisters | 24 | 2 |

Glossary

Bacteremia—An infection in your bloodstream. It can be mild to severe.

Bone density loss—Bones become weak and brittle. Bones can break more easily.

Cytomegalovirus (CMV)—A type of herpes virus that can cause infections (like **pneumonia**).

DEXA scan—A test to measure bone density. Often called a dual photon densitometry or a DXA scan.

Diphtheria—A serious bacterial infection of the nose and throat. It can cause serious complications.

Endocrine system—Glands that release hormones into your body. Hormones affect your mood and growth.

Esophagogastroduodenoscopy (EGD)—A test to look for problems in your upper GI tract.

Graft-versus-host disease (GVHD)—A common side effect after an allogeneic transplant when the new donor cells attack your body's cells.

Growth rate evaluation—Comparing a person's growth to average growth in the general population in people of the same age and sex.

Gynecologic exam—An exam of the female reproductive organs. It checks for infection and other problems.

Immunosuppressants—Medicines that lower your body's ability to fight infection. These medicines also help to prevent and treat GVHD.

Kidney filtration levels test—Measures the flow rate of filtered fluid through the kidneys. Used to detect chronic kidney disease.

Liver function blood tests—Tests to see how well your liver is working.

Mammogram—A test to detect breast cancer.

Measles—A viral infection causing symptoms like a rash, fever and cough. It can cause serious complications.

Meningitis—Inflammation (redness and swelling) of the membranes covering your brain and spinal cord (inside the back bone). It can be caused by infection.

Mumps—A viral infection causing inflammation (swelling) of the salivary glands. It can cause serious complications.

Nervous system—The parts of your body that control your movements and thinking. The nervous system includes your brain, spinal cord (inside the back bone) and nerves.

Ophthalmologist—A medical doctor who treats diseases that affect the eyes.

Pap smear—A test to detect cervical cancer.

Pneumonia—Inflammation (redness and swelling) of the lungs caused by infection.

Pulmonary function tests—A group of tests to measure how well your lungs are working.

Range of motion—A test to find out if a joint (such as elbow, hip, wrist) can move properly and in all normal directions.

Rubella—A viral infection that causes symptoms like rash and fever. It's also called German measles or 3-day measles.

Tetanus—A serious bacterial infection that affects your nervous system. It causes muscle spasms and stiffness.

Thyroid—A gland that controls your body's metabolism (how quickly your body uses energy).

Urine protein levels test—Measures the amount of proteins found in a urine sample. Used to detect kidney disease.

Resources just for you

Information:
nmdp.org/patient

Health tracker:
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Contact us at patientinfo@nmdp.org or 1 (888) 999-6743



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