



12+ MONTH

Post-Transplant Care Guide



The 1-year anniversary of your transplant is an important milestone in your recovery. This guide has a list of tests and questions to ask to help you prepare for your yearly checkups. These recommendations are from doctors who specialize in post-transplant care.*

Why your yearly checkup matters

Whether you had an **autologous** or **allogeneic** transplant, follow-up care is important. It helps your doctors find any changes in your health, such as:

- The disease coming back (relapse)
- Problems due to your treatment
- Changes in 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, checkups after transplant are very important to staying healthy.

About this guide

This guide is based on post-transplant care recommendations developed by doctors and researchers from 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 NMDP app** offers a secure tool to help you manage your health after transplant.

Use it to:

- Track symptoms
- Manage medications
- Join community groups & discussions
- Get support from Patient Navigators

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



Prepare for your checkup

- Schedule a 12-month checkup appointment with your transplant doctor or your hematologist/oncologist
- Review the tests inside this brochure
- Write down questions or concerns you'd like to talk to your doctor about
- Ask your doctors if there are other suggestions unique to your situation
- At your checkup, ask your doctor if you need to schedule appointments with other doctors or therapists (eye doctor, dentist, physical therapist, gynecologist or other specialists)
- Bring this guide to your checkup

Share with your doctor

There are 2 easy ways to share these guidelines with your doctors or dentist:

- Review this guide with them at your next appointment
- Point them to nmdpclinical.org/guidelines

Connect with NMDP's survivorship team

We can:

- Listen to your experiences and answer questions
- Connect you to resources specific to your needs
- Offer telehealth appointments with our medical staff

Call: 1 (866) 301-4650

Email: survivorship@nmdp.org

* Majhail NS, Rizzo JD, Lee SJ, et al. Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation; CIBMTR* (Center for International Blood and Marrow Transplant Research*) is a research collaboration between NMDPSM and the Medical College of Wisconsin* (MCW), American Society for Blood and Marrow Transplantation (ASBMT), European Group for Blood and Marrow Transplantation (EBMT), Asia-Pacific Blood and Marrow Transplantation Group (APBMT), Bone Marrow Transplant Society of Australia and New Zealand (BMTSANZ), East Mediterranean Blood and Marrow Transplantation Group (EMBM) and Sociedade Brasileira de Transplante de Medula Ossea (SBTMO). Co-published in Biol Blood Marrow Transplant. 2012; 18(3): 348-371; Bone Marrow Transplant (2012) 47, 337-341; and Hematol Oncol Stem Cell Ther 2012; 5(1): 1-30.

Yearly checkup guide

Below, you'll find information on the physical exams and tests that are recommended yearly after transplant. You can use this information to help you prepare any questions or concerns you'd like to talk about with your doctor. **Words in bold are defined in the glossary.**

Bones

- Talk about ways to prevent **bone density loss**—including exercise, vitamin D and calcium supplements

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

- Bone density measurement (using **DEXA scan**)

Cancer Screening

- Talk to your doctor about your risk of getting another cancer
- Learn how to do self-exams for cancer, including skin, breast or testicular exam
- Follow cancer screening recommendations for the general population
- Ask your doctor if you need a **mammogram** or other breast screening tests and how often they should be done

Emotional Health

- Tell your doctor about your general well-being or quality of life
- Talk about your feelings
- 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**
- Blood tests to check your sex hormone levels
- Additional tests may be needed post-menopause
- If needed, get treatment for diabetes

Additional tests for children:

- Blood tests to measure sex hormone levels
- **Growth rate evaluation**
- Blood tests to check **thyroid** and **growth hormone function** (Your pediatrician or an endocrine doctor may do these)

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 pain or dryness
- 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

Fertility

- Ask your doctor for advice about birth control
- If you want to have a baby, ask to see a fertility specialist

General Health

Get regular screenings for:

- Cancer
- Depression
- Diabetes
- High blood pressure
- High cholesterol
- Osteoporosis
- Sexually transmitted infections (STIs)

Heart and Blood Vessels

- Check for risk factors, such as cholesterol, high blood pressure, obesity or history of smoking
- Talk about a heart healthy lifestyle
- If needed, get treatment for high blood pressure and high cholesterol

Immune System

- Talk about vaccines to prevent infection and disease

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

- Medicine to prevent infections such as **meningitis, pneumonia and pneumocystis**
- Medicine to prevent infection while you take **immunosuppressants**
- Blood tests to screen for **cytomegalovirus (CMV)**

Kidneys

- Blood pressure test
- If you have high blood pressure, start treatment and have regular 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 (e.g., 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

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 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 at least 1 time 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
- Tell your doctor about tobacco use or smoking. Ask for help quitting
- **Lung function tests** and imaging tests (such as chest X-ray, CT scan) if you have or had breathing problems

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

- Lung exams and **lung function tests** earlier and more often

Mouth

- Exam of the mouth and teeth
- Oral cancer screening
- Talk to your doctor about symptoms like dry mouth
- See your dentist for a complete dental checkup 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

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

- Talk about current exercises

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

- Test if your muscles are weak (**myopathy**)
- See a physical therapist if you have **myopathy**, **fasciitis** or **scleroderma**
- Have a **range of motion** exam to look for **sclerotic changes**
- Learn how to test your own **range of motion**

Nervous System (brain, spinal cord and nerves)

- Tests of your **nervous system**
- If you have trouble with things such as memory, concentration or decision-making, you may need more tests

Additional test for children:

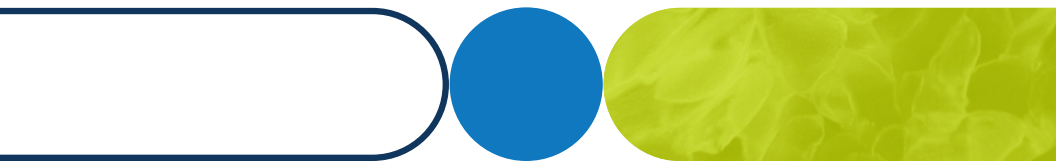
- Check cognitive development (ability to think and reason) for your child's age

Skin and Genitals

- Learn how to do a routine self-exam of your skin
- Talk about the risks of being in the sun and ways to protect yourself
- Have a yearly gynecologic exam
- Tell your doctor if you have any pain or other problems with sexual activity

If you have **GVHD** or had total body irradiation, you may need to:

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



Glossary

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.

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

Fasciitis—Inflammation (redness and swelling) of the connective tissue that surrounds muscles, blood vessels and nerves. Often happens with hardening of the skin (see **scleroderma**).

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

Growth hormone function—Test to see if there is enough growth hormone in your body to grow normally.

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

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.

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

Mammogram—A test to detect breast cancer.

Meningitis—Inflammation (redness and swelling) of the membranes covering your brain and spinal cord. Can be caused by infection.

Myopathy—Muscle disease and weakness. Steroids used for chronic GVHD may cause muscle weakness, especially in your legs and feet.

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.

Pneumocystis—A form of **pneumonia** caused by a yeast-like fungus.

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

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

Scleroderma—When your skin becomes hard, thick and tight. This can lead to weak muscles, stiff joints or pain in your joints.

Sclerotic changes—Hardening of the skin and other tissues such as connective tissues, muscles and joints.

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.

We are here to help

NMDPSM Patient Support Center offers reliable, easy-to-understand information from diagnosis through recovery. All of our programs and resources are free.

Our services include:

- Telephone counseling and confidential, one-on-one support
- Financial grants for patients
- Support groups and telephone workshops
- Caregiver support
- Tips for talking with your health care team
- Educational books, videos, newsletters and fact sheets
- Information and support in many languages
- Survivorship support and telehealth appointments

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

Resources just for you

Information: nmdp.org/AfterTransplant

Health Tracker: my.nmdp.org

Facebook: facebook.com/nmdppatient



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