



BE  THE MATCH®

12

MONTH
checkup

Helping you prepare
for your appointment

Congratulations—on the upcoming 1-year anniversary of your transplant. This guide will help you understand and prepare for your medical checkups after transplant (follow-up care). This guide has a list of tests and evaluations for your 12-month appointments. It is the second in the series of 3 (6 month and 24+ month guides are also available). The recommendations in the guides are based on recommendations from doctors who specialize in post-transplant care*, and brought to you by Be The Match®.

Why your 12-month checkup matters

Whether you received 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)
- New cancers
- Problems due to your treatment
- Quality of life

When issues are caught early, there may be more options for treatment, and those treatments can be more effective.

Even if you are feeling well, checkups after transplant are very important to staying healthy.

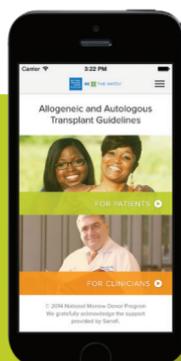
About this guide

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 his or her recommendations carefully.**

Free mobile app

Use our free mobile app to:

- Access these guidelines anytime, anyplace
- Make a list of tests and evaluations customized to your unique situation
- E-mail information to yourself, or your health care team



Available on iPhone®, iPad®, and Android™
Online at BeTheMatch.org/patient-survive

TWELVE-MONTH CHECKUP GUIDE

Below, you'll find information on the physical exams and tests that are recommended 12 months after transplant. This information will help you understand what to expect and prepare any questions or concerns you have to discuss with your doctor. **Words in bold are defined in the glossary.**

Eyes

- Check for eye symptoms like pain or dryness
- Have an eye specialist (**ophthalmologist**) check how well you can see (vision screening) and do a retina exam

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

- To see an eye specialist more often

Mouth

- Exam of the mouth and teeth
- Oral cancer screening
- Talk about symptoms like dry mouth
- Tell your doctor about harmful habits (like tobacco use or smoking). Ask for help quitting
- Have a complete dental checkup (exam of your head, neck, mouth and teeth)

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

- To have exams of the mouth and teeth, and oral cancer screening more often

Additional test for children:

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

Lungs

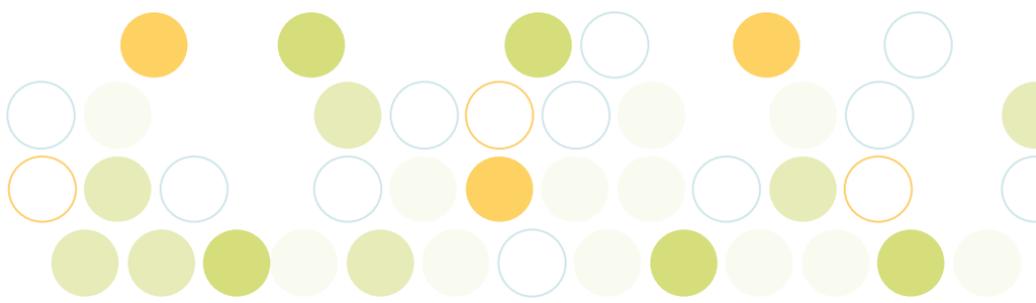
- Regular lung exam
- Tell your doctor about tobacco use or smoking. Ask for help quitting
- **Pulmonary (lung) function tests** and imaging tests (such as chest X-ray, CT scan) if you have or had breathing problems

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

- Lung exams and **pulmonary (lung) function** tests earlier and more often

Heart and Blood Vessels

- Check for heart and blood vessel risk factors, such as high cholesterol, high blood pressure, obesity, history of smoking
- Talk about a "heart healthy" lifestyle (exercise, healthy weight, eat healthy foods, and don't smoke)
- Get treatment for diabetes, high blood pressure, and high cholesterol
- Ask if you need to take an antibiotic before having dental work done. The antibiotic prevents a bacterial infection of the heart valves



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 ferritin test, a liver MRI, or liver biopsy to check for too much iron

Kidneys

- Blood pressure test
- If you have high blood pressure (hypertension), start treatment and have regular follow up
- **Urine protein levels test** to see how well your kidneys are working
- **Kidney filtration levels test** (blood BUN/Creatinine test) to see how well your kidneys are filtering
- If your kidneys aren't working well, you may need more tests (ultrasound or kidney biopsy)
- If you have chronic kidney disease that is getting worse, don't take medicines, herbs or supplements that can hurt your kidneys. Talk to your doctor about what these may be. You may need to see a kidney doctor

Muscles

- Talk about current exercises and physical fitness activities

*If you have **GVHD** or are taking **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**

Bones

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

*If you are a woman, allogeneic transplant recipient, have **GVHD**, are taking **immunosuppressants**, or are at a high risk for bone loss you may need:*

- Bone density measurement (using **dual photon densitometry**)

Skin and Genital

- Learn how to do a routine self-exam of your skin
- Talk about the risks of being in the sun without proper protection
- Have a yearly gynecologic exam if you are a woman

*If you are a woman and have **GVHD** or had total body irradiation, you may need to:*

- Ask your doctor how often you need gynecologic exams

Nervous System

- You may need 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



Fertility

- Ask your doctor about birth control options
- If you and your partner want to have a baby, ask to see a fertility specialist

Immune System

- Vaccines to prevent infection and disease

*If you have **GVHD** or are taking **immunosuppressants** you may need:*

- Medicine to prevent infections such as **meningitis** and **pneumonia**
- Medicine to prevent an infection called **pneumocystis** for as long as you are taking immunosuppressants
- Blood tests to screen for **cytomegalovirus (CMV)**

Endocrine System *(thyroid, growth, sex hormones)*

- Blood tests to check your **thyroid**
- Blood tests to check your sex hormone levels
- Additional tests for women who have not gone through menopause

Additional tests for children:

- Your child may need blood tests to measure sex hormone levels
- **Growth rate evaluation**
- Your child may need blood tests to check **thyroid** and **growth hormone function**

*If you have **GVHD** or are taking **immunosuppressants** you may need:*

- To take more doses of steroids (like prednisone) if you become very sick
- To have your dose of steroids gradually reduced when it is time to stop taking them

Emotional Health

- Tell your doctor about your general well-being or quality of life
- Talk about your feelings (emotional health)
- Talk about your family and caregiver's emotional health
- Ask about counselors and support groups in your area
- Ask any questions you may have about your sexual health

General Health

- Get regular screenings for high blood pressure, high cholesterol, diabetes, depression, sexually transmitted diseases, osteoporosis (in women), and cancer

New Cancers

- Talk to your doctor about risks of new cancers
- Learn how to do self-exams for cancer
- Follow cancer screening recommendations for the general population
- If you're a woman, ask your doctor if you need a **mammogram**

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, a lung infection).

Dual photon densitometry—A tool to measure bone density. Often called a DEXA or 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.

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.

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

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

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

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

Pulmonary (lung) 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.

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 fasciae, 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.

Take action: prepare for your checkup

- Schedule 12-month checkup appointment with your transplant doctor or your hematologist/oncologist
- Review the tests and evaluations listed on the pages inside
- Write down questions or issues you'd like to talk to your doctor about
- Bring this guide to your checkup
- 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 others)

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 **[BeTheMatchClinical.org/guidelines](https://www.bethematchclinical.org/guidelines)** for free clinical guidelines in print or through a mobile app

* Majhail NS, Rizzo JD, Lee SJ, et al. Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation; Center for International Blood and Marrow Transplant Research (CIBMTR), 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 (EMBMT) 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 Cel Ther 2012;5(1):1-30.

We are here to help

Be The Match is dedicated to supporting patients, caregivers and families before, during, and after transplant.

We offer you confidential one-on-one support, financial guidance, and free educational resources — DVDs, booklets, online tools, and more. Our goal is to get you what you need, when you need it. We can help you learn more about transplant as a treatment option, plan for a transplant, and learn what to expect after transplant.

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

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Just for you—recipient resources

- **ONLINE:** BeTheMatch.org/survive
- **E-NEWS:** BeTheMatch.org/patient-eneews
- **FACEBOOK:** facebook.com/BeTheMatchPatient



Patient Services
3001 Broadway St. N.E., Minneapolis, MN 55413
1 (888) 999-6743 | BeTheMatch.org/patient