24+ months checkup

Post-transplant care guide

BE THE MATCH®

Patient support for **your** life.

1.888.999.6743 | BeTheMatch.org/patient

Congratulations—on the upcoming anniversary of your transplant! To help you understand and prepare for your follow-up care, this guide includes an easy-to-understand list of tests and evaluations for your 2-year and beyond annual appointments. This guide is the third in the series of three (6 month and 12 month also available), based on recommendations from experts in post-transplant care[1], and brought to you by Be The Match®.

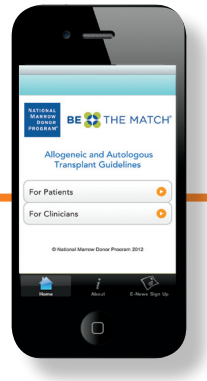
Why your annual checkup matters

As a transplant recipient, your health needs monitoring and protection. Your health care team needs to regularly check how you are improving and look for potential issues. 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, post-transplant checkups are very important to managing your health and staying healthy.

About this guide

This guide is based on a publication of post-transplant care recommendations[1] 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
- Generate 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®, Android™, and BlackBerry®
Online at m.marrow.org/HCT

Scan QR Code
to download app

Take action: prepare for your checkup

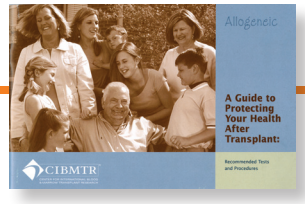
- ☐ Schedule annual checkup appointments with your transplant doctor or your hematologist/oncologist
- ☐ Review the tests and procedures listed on the pages inside
- ☐ Write down questions or issues you'd like to discuss at your appointment
- ☐ Ask your transplant team if there are other recommendations unique to your situation (if you aren't going back to your transplant center for checkup)
- ☐ Bring this guide to your appointment
- ☐ At your appointment, ask your doctor if you need to schedule appointments with other health care professionals (ophthalmologist, dentist, physical therapist, OB/GYN, other specialists)

Share with your doctor

There are two easy ways to share these guidelines with your doctor, dentist or any other health care provider:

- Review this guide with them at your next appointment
- Point them to **marrow.org/md-guidelines** for free clinical guidelines in print or through mobile app

This version replaces: *A Guide to Protecting Your Health After Transplant* from CIBMTR®. CIBMTR is the research arm of the National Marrow Donor Program, which operates Be The Match.



[1] 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.

Annual checkup guidelines

Below, you'll find information on the tests and evaluations that are recommended every year following transplant beginning at 2 years. This information will help you understand what to expect and prepare any questions or concerns you have to discuss with your doctor.
Items in bold are found in the glossary.

Eyes

- Visual symptom evaluation (checking for pain, dryness)
- Vision screening (checking how well you can see) and retina exam by an ophthalmologist may be required

*Additional test for patients with **GVHD:***

- **Ophthalmologic exam** may be required more often

Mouth

- Clinical exam of the mouth and teeth
- Oral cancer screening
- Discuss history of dry mouth
- Discuss high-risk habits (e.g., smoking) and oral health practices that can help protect your mouth
- Dental checkup—a complete head, neck and dental exam

*Additional test for patients with **GVHD:***

- Oral and dental checks, and oral cancer screening may be required more often

Additional test for children:

- Dentist will check how well teeth are developing

Lungs

- Routine lung exam
- Discuss tobacco use and quitting smoking
- **Pulmonary function tests** and imaging studies (e.g., chest X-ray, CT scan) for patients who currently have breathing problems or a history of breathing problems

*Additional test for patients with **GVHD:***

- Lung exams and **pulmonary function tests** may be needed earlier and/or 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
- Discuss a "heart healthy" lifestyle (regular exercise, healthy weight, no smoking, dietary counseling)
- Early treatment of risk factors such as diabetes, high blood pressure and high cholesterol
- When you have a dental procedure, you may need medication to prevent bacterial endocarditis, a bacterial infection of the heart valves

Liver

- **Liver function blood tests** to see if the liver is working properly
- If you have hepatitis B or C, the severity of the viral infection will be monitored (an appointment with a specialist may be needed)
- If you received red blood cell transfusions, you may need a blood ferritin test, a liver MRI or liver biopsy to check for iron overload

Kidneys

- Blood pressure test
- If you have high blood pressure (hypertension), prompt treatment and regular follow up is recommended
- **Urine protein levels test** to check if kidneys are working properly
- **Kidney filtration levels test** (blood BUN/Creatinine test) to check if your kidneys are filtering properly
- If you have **renal dysfunction**, further testing (kidney biopsy or ultrasound) may be needed
- If you have chronic kidney disease that is worsening, you should avoid medications/substances that can harm the kidney and may need to see a kidney specialist

Muscles

- Discuss current exercises and physical fitness activities

*Additional tests for patients with **GVHD** or taking immunosuppressive medications:*

- Testing if your muscles are weak (**myopathy**) by monitoring your ability to go from sitting to standing position
- If you have **myopathy**, **fasciitis** or **scleroderma**, an appointment with a physical therapist is recommended
- **Range of motion** evaluation will detect **sclerotic changes**
- Learn how to perform a self-assessment of **range of motion**

Bones

- Discuss ways to prevent **bone density loss**—including physical activity, vitamin D and calcium supplements

*Additional test for women, allogeneic transplant recipients, patients with **GVHD**, taking immunosuppressants, or at high risk for bone loss:*

- Bone density measurement (using **dual photon densitometry**) may be required

Skin and Genital

- Learn how to perform routine self-exam of skin
- Discuss risks of being in the sun without proper protection
- Annual gynecologic exam

*Additional test for women with **GVHD** or total body irradiation recipients:*

Discuss how often gynecologic exams should happen

Nervous System

- Nervous system exam and testing may be needed
- Testing of mental function may be needed if you have trouble with things such as memory, concentration, decision-making, etc.

Additional test for children:

- Evaluate cognitive development

Fertility

- Discuss birth control options
- If you and your partner are considering pregnancy, an appointment with a fertility specialist is recommended

Immune System

- Post-transplant immunizations

*Additional tests for patients with **GVHD** or taking immunosuppressive medications:*

- Medication to prevent infections such as **meningitis** and **pneumonia**
- Medications to prevent **pneumocystis pneumonia** (PCP) for the duration of immunosuppressive therapy
- **Cytomegalovirus** (CMV) screening, if you are at an increased risk for CMV to become active again

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

- Blood test to check **thyroid** function
- Blood tests to assess sex hormone levels may be required
- Additional tests for women who are not menopausal after transplant may be needed

Additional tests for children:

- Blood tests to assess sexual development and sex hormone levels for children who have not reached puberty at the time of transplant
- **Growth rate evaluation**
- Blood test to check **thyroid** and **growth hormone function** may be needed

*Additional tests for patients with **GVHD** or taking immunosuppressive medications:*

- If you have received corticosteroids for some time, you may need additional doses of this medication if you become severely ill
- If you have received corticosteroids for some time, the dose of this medication may be lessened gradually when you are ready to stop it

Emotional Health

- Discuss your general well-being (quality of life)
- Discuss your feelings (emotional health)
- Discuss family and caregiver emotional health
- Discuss counseling and support groups
- Discuss sexual health

General Health

- General recommended screenings including high blood pressure, high cholesterol, diabetes, depression, sexually transmitted diseases, osteoporosis (in women), cancer

New Cancers

- Discuss risks of new cancers
- Learn how to perform self-exam for cancers
- Follow cancer screening recommendations of general population
- **Mammogram** in women may be required depending on age and length of time after radiation exposure

Glossary

Bone density loss—Bones become more porous and brittle, and have a higher risk of fracture.

Cytomegalovirus (CMV)—A type of herpes virus that can cause infections (e.g., pneumonia)

Dual photon densitometry—A tool to measure bone mineral density. Often referred to as a DEXA or DXA scan.

Endocrine system—Glands that release hormones into the bloodstream to regulate bodily functions. Endocrine glands include the thyroid, pituitary, and pancreas.

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

Graft-Versus-Host Disease (GVHD)—A post-transplant condition where the transplanted donor cells attack the patient's tissues or organs.

Growth hormone function—Test to determine if there is enough growth hormone in a person's body to result in normal growth.

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

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 detect liver dysfunction.

Mammogram—A test to detect breast cancer.

Meningitis—Inflammation of the membranes covering the brain and spinal cord. Can be caused by viruses, fungi or bacteria.

Myopathy—Muscle disease. Steroids used for chronic GVHD may result in muscle weakness, especially in the lower body.

Ophthalmologic exam—Examination of the eye by an ophthalmologist, a medical doctor who treats diseases that affect the eyes.

Pneumonia—Inflammation of the lungs caused by viral, bacterial, or fungal infection.

Pneumocystis pneumonia (PCP)—A form of pneumonia caused by a yeast-like fungus.

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

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

Renal dysfunction—When the kidneys don't properly filter toxins and waste products from the circulating blood.

Scleroderma—Hardening, thickening, and tightening of skin and underlying tissue that can lead to muscle weakness, joint pain, and stiffness.

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

Thyroid—A gland that controls the body's metabolism (how quickly the 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

Be The Match has a team 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**

Were these guidelines useful?
Share your feedback at BeTheMatch.org/careguide

Notes: _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Just for you—survivor resources

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

BE THE MATCH®

Patient Services, National Marrow Donor Program
3001 Broadway St. N.E., Minneapolis, MN 55413-1753
1 (888) 999-6743 | BeTheMatch.org/patient

©2012 National Marrow Donor Program

418; MAY 2012