12+ MONTH

After 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 after-transplant care.*

Why your yearly checkups matter
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
• Differences 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 after-transplant care recommendations developed by doctors and researchers from around the world.* This information is not meant to replace the recommendations of your transplant doctor. You may need different tests or checkups based on your unique situation. Your transplant doctor knows you best, so follow their recommendations carefully.

FREE MOBILE APP

Use it to:
• Access our guidelines anytime, anywhere
• Make a list of tests and evaluations customized to your unique situation
• Email information to yourself or your health care team
• Identify possible symptoms of chronic GVHD
• Set reminders, like appointments, taking medicines and exercising

Search “transplant guide” in the Apple® or Android™ app stores to download.
Available online at BeTheMatch.org/CareGuide
Take action: Prepare for your checkup

Schedule 12-month checkup appointment with your transplant doctor or your hematologist/oncologist

Review the tests listed on the pages inside this brochure

Write down questions or issues 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 BeTheMatchClinical.org/guidelines for free clinical guidelines in print or through a mobile app

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’re a woman, an allogeneic transplant recipient, have GVHD, are taking immunosuppressants or are at a high risk for bone loss, 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 and testicular exams
- Follow cancer screening recommendations for the general population
- If you’re a woman, 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 any questions you may have 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 for women who haven’t gone through menopause

*Additional tests for children:*
  - Blood tests to measure sex hormone levels
  - **Growth rate evaluation**
  - Blood tests to check thyroid and growth hormone function (which an endocrine doctor can perform)

*If you have GVHD or are taking immunosuppressants, you may need to:*
  - Take more doses of steroids (like prednisone) if you become very sick
  - Have your dose of steroids gradually lowered 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 (i.e., exercise, healthy weight, healthy foods, smoke-free)
• If needed, get treatment for diabetes, high blood pressure and high cholesterol

Immune System
• Ask if you need 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)

Kidneys
• Blood pressure test
• If you have high blood pressure, start treatment and have regular follow-up
• 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 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

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
Lungs
- Have your doctor listen to your lungs at least 1 time every year
- 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
- Tell your doctor about tobacco use or smoking. Ask for help quitting
- See your dentist for a complete dental checkup (exam of your head, neck, mouth and teeth)
- 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 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

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 without proper protection
- Have a yearly gynecologic exam if you’re a woman
- 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

Be The Match® 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, DVDs, newsletters and fact sheets
- Information and support in many languages

Contact us at [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org) or **1 (888) 999-6743**

Notes:

Resources just for you

**ONLINE:** [BeTheMatch.org/AfterTransplant](http://BeTheMatch.org/AfterTransplant)

**E-NEWS:** [BeTheMatch.org/patient-enews](http://BeTheMatch.org/patient-enews)

**FACEBOOK:** Facebook.com/BeTheMatchPatient

---

©2018 National Marrow Donor Program