



Allogeneic

A Guide to Protecting Your Health After Transplant:

Recommended Tests
and Procedures



Introduction

Congratulations!

You have completed your transplant. Now, your recovery begins. It can take time, but there are many things you can do to improve your health. There are also things you can do to prevent or treat problems that might show up later.

This guide will help you and your doctors know which tests and evaluations are needed to help detect problems that may occur after your transplant. It also includes medications that you may need to take to help prevent or treat problems.

This guide is based on published recommendations written by physicians in leading transplant organizations. Your transplant doctor may make other recommendations like having some tests done more often, or eliminating tests you don't need. Your transplant doctor knows you best, so follow his or her recommendations carefully.

moving forward

In this guide you will find:

- Information about side effects that may occur months or years after transplant
- Charts with recommended tests and procedures for your six-month, twelve-month and yearly post-transplant check-ups
- Space for recording important information about your post-transplant care
- Information for your physicians about the tests and procedures you will need after your transplant (in the back pocket)

Give all of your doctors a copy of the chart in the back pocket and ask them to put it in your medical records. Each time you visit your doctor, remind him or her about the chart. Your reminder will help make sure that tests are done at the proper times. You and your doctor can get more information about these guidelines at www.cibmtr.org/posttransplant or by contacting your transplant center.

The recommendations contained in this guide were developed by:

- The Center for International Blood and Marrow Transplant Research
- The European Group for Blood and Marrow Transplantation
- The American Society for Blood and Marrow Transplantation

The doctors who belong to these organizations are recognized experts on bone marrow, blood stem cell and cord blood transplant.

Questions you may have

Why do I need all these tests and procedures?

Side effects from your transplant can occur many months or even years after transplant. Some can be mild, others can be more serious. The tests and procedures recommended in this guide help detect problems early so that they can be promptly treated. If needed, your doctor may also recommend more frequent appointments or additional follow-up tests.

Do I still need these tests even if I feel healthy?

Yes! Even if you feel fine, you may have problems that do not have any symptoms yet. It is often easier to treat problems when they are detected early, before you notice symptoms.

How many years after transplant are these tests and procedures necessary?

You will need to be checked for possible side effects of transplant for the rest of your life. Most of the tests described in this guide are not difficult or time-consuming. Some only require a physical examination or a simple blood test. Keep in mind that these tests are for problems that **may** occur after transplant. It's possible you will never experience any of these problems, or experience only a few.

What if my doctor needs more information?

If you or your doctor have questions about your post-transplant care, contact your transplant center. You can also get more information about these guidelines online at www.cibmtr.org/posttransplant.

Early detection and treatment improves recovery

Every person's transplant experience is unique. Some survivors have few problems, while others experience more severe complications. Treatment and recovery depend on diagnosis, age, donor and other health factors. The complications listed below are those that may develop several months or years after transplant. You and your doctor can take steps to prevent or treat complications if they develop.

Liver—Chemotherapy, radiation therapy, viral infections, some medications and graft-versus-host disease (GVHD) can cause liver problems. Rarely, patients who receive many blood transfusions accumulate iron in their liver.

Lungs—Radiation and some chemotherapy drugs can cause breathing problems.

Bones—Steroids and other medications to control GVHD may cause bones to become weaker. Joint pains may also occur in patients who have GVHD.

Muscles—Patients who take steroids to control GVHD may develop muscle weakness.

Kidneys—Radiation and chemotherapy drugs such as cyclophosphamide or those that contain platinum can cause kidney or bladder problems. Infections caused by adenovirus or cytomegalovirus (CMV) can also cause kidney or bladder problems.

understanding

Nervous System—Radiation to the brain or chemotherapy can cause nervous system problems including poor memory, short attention span or trouble remembering words. Children may have learning disabilities or delays in growth. Some chemotherapy can cause loss of sensation in fingers or toes.

Growth and Fertility—Chemotherapy and radiation therapy may alter normal hormone levels in all patients and may affect growth and sexual development in children. Most adults who have received radiation or chemotherapy are unable to conceive children. Prolonged use of corticosteroids may also affect normal hormone levels.

Heart and Blood Vessels—Although rare, chemotherapy and radiation therapy can cause damage to blood vessels or increase the risk of blood clots.

Infection—Changes to the immune system after transplant or GVHD can lead to increased infections. Some of these infections can be severe or life-threatening.

New Cancers—Sometimes radiation and chemotherapy can cause cancers later in life.

Emotional Health/Quality of Life—Some survivors become depressed, anxious or tired after transplant. Medications may also contribute to some of these feelings. This can affect work, school, behavior or sexual relationships.

Mouth—Radiation therapy or GVHD can cause dry mouth, tooth decay and other dental problems.

Eyes—GVHD can cause dry eyes and other eye problems. Steroids, radiation, chemotherapy and other drugs may increase development of cataracts.

Important information to share with your doctor:

Usually, your transplant center will send a copy of your medical records to the local doctor who will care for you after your transplant. If your doctor has not received a copy of your records, ask him or her to contact your transplant center and include the records in your health file. It is also a good idea to record the following information for your records in case you need it in the future.

Where were you transplanted? _____

What year were you transplanted? _____

What is the phone number of your transplant center? (_____) _____

Who was the transplant doctor most involved with your care? _____

What was your diagnosis? _____

Who was your donor?

Brother or sister Other relative Unrelated donor Cord blood

What conditioning (preparative) regimen did you receive with your transplant?

Chemotherapy Radiation Both Unsure

Have you ever had graft-versus-host disease (GVHD)?

- Yes, currently Yes, in the past No

If yes, what medications did or do you take to control it?

- Steroids (Prednisone) Cyclosporine (Neoral) FK506 (Tacrolimus)
 Mycophenolate mofetil Rapamycin (Sirolimus) Unsure Other:

What complications, if any, have you experienced post-transplant?

- | | |
|---|---|
| <input type="checkbox"/> Anxiety | <input type="checkbox"/> Joint/muscle problems |
| <input type="checkbox"/> Bone pain | <input type="checkbox"/> Kidney problems |
| <input type="checkbox"/> Cataracts | <input type="checkbox"/> Liver problems |
| <input type="checkbox"/> CMV infection | <input type="checkbox"/> Lung problems |
| <input type="checkbox"/> Depression | <input type="checkbox"/> Memory/learning problems |
| <input type="checkbox"/> Eye problems | <input type="checkbox"/> Other infection: _____ |
| <input type="checkbox"/> Fatigue | <input type="checkbox"/> Shingles |
| <input type="checkbox"/> Fungal infection (Aspergillus) | <input type="checkbox"/> Skin problems |
| <input type="checkbox"/> Growth problems | <input type="checkbox"/> Sleep problems |
| <input type="checkbox"/> Hearing problems | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Heart problems | _____ |



Allogeneic Transplant

An allogeneic transplant uses cells from a person other than the patient. The donated cells can come from a related or unrelated donor, or a cord blood unit.

The charts on the following pages list steps to take that will help keep you healthy after your transplant. Your doctor may also perform different tests to check the status of your disease. Unless your transplant doctor gives you different instructions, you should follow these guidelines.

Use the charts on the following pages to keep track of tests and treatments that are completed at six months, one year and yearly after receiving your transplant. On the notes pages after each chart, record your doctor's recommendations, medications, follow-up appointments or other important information.

information

Six-Month Check-Up

| Done (✓) | Recommended Tests and Procedures |
|-----------------------------|--|
| Liver | |
| | Liver function tests |
| Lungs | |
| | Lungs evaluated |
| | Discussion about not smoking |
| | Chest X-ray is recommended if earlier chest X-ray showed lung problems |
| Muscles | |
| | Evaluation of physical therapy needs for patients taking immunosuppressive medications |
| | Evaluation of muscle weakness for patients using corticosteroids more than 3 months |
| Kidneys | |
| | Test blood pressure |
| | Test urine protein levels |
| | Test of kidney filtration (BUN/creatinine) |
| Growth and Fertility | |
| | Blood test to check sex hormone level in children who have not yet reached puberty |

Six-Month Check-up (Continued)

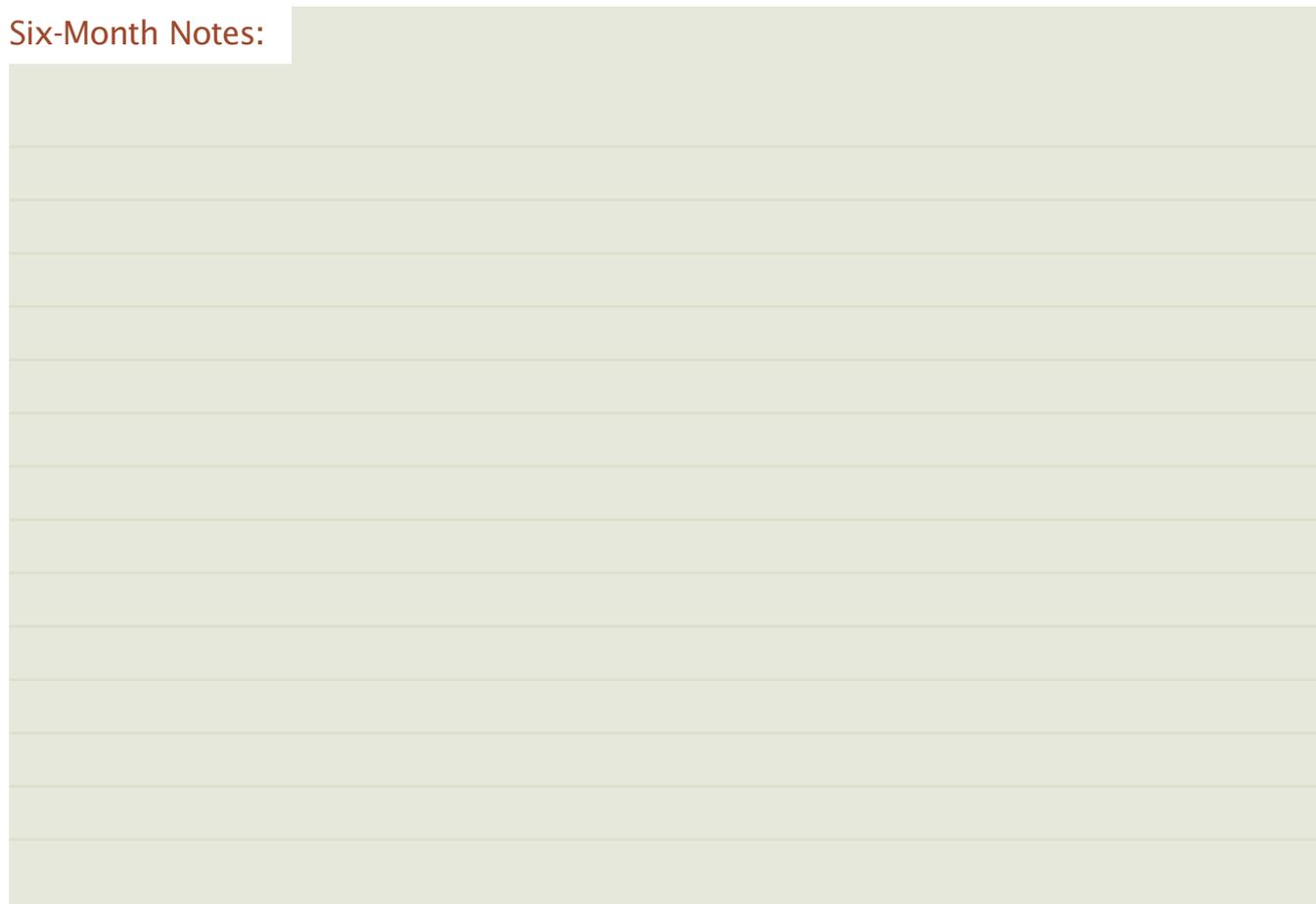
| Done (✓) | Recommended Tests and Procedures |
|---|---|
| Infection | |
| | Medication to prevent infections with bacteria that cause meningitis and pneumonia for patients taking immunosuppressive medications or those with ongoing GVHD |
| | Medication to prevent <i>Pneumocystis carinii</i> pneumonia (PCP) |
| | Test for cytomegalovirus (CMV) for patients taking immunosuppressive medications or those with ongoing GVHD |
| | Medication to prevent fungal infection is recommended by some experts for patients taking steroids (Prednisone) |
| | Medication to prevent herpes simplex virus (HSV) is recommended by some experts for patients taking immunosuppressive medications or those with ongoing GVHD |
| Emotional Health/Quality of Life | |
| | Discuss emotional health and quality of life |
| | Discuss sexual health |
| | Discuss counseling and support groups |
| Mouth | |
| | Regular dental check-up |
| Eyes | |
| | Screening for visual symptoms (pain, dryness) or vision loss (by internist or oncologist) |

Record important notes on the following page.

six-month

Use this space to record notes about your check-up and doctor recommendations.

Six-Month Notes:

A large, light green rectangular area with horizontal lines, intended for taking notes. The lines are evenly spaced and run horizontally across the entire width of the area. The background is a solid light green color.

One-Year Check-Up

| Year 1 Done (✓) | Recommended Tests and Procedures |
|-----------------|---|
| Liver | |
| | Liver function tests |
| | Blood test for iron level in bloodstream (ferritin) |
| Lungs | |
| | Routine lung exam |
| | Discussion about not smoking |
| | Chest X-ray is recommended if earlier chest X-ray showed lung problems |
| | Pulmonary function test for patients who received radiation or medications that damage lungs, or have had trouble breathing in the past |
| Bones | |
| | Bone density test for all women |
| | Bone density test recommended for men who have used steroids or a calcineurin inhibitor for more than 3 months to control GVHD |
| | Bisphosphonates for patients who have taken steroids for more than 3 months |
| Muscles | |
| | Evaluation of physical therapy needs for patients taking immunosuppressive medications |
| | Evaluation of muscle weakness for patients who have taken corticosteroids for more than 3 months |

one-year

One-Year Check-Up (Continued)

| Year 1 Done (✓) | Recommended Tests and Procedures |
|--------------------------------|--|
| Kidneys | |
| | Test blood pressure |
| | Test urine protein levels |
| | Test of kidney filtration (BUN/creatinine) |
| Nervous System | |
| | Routine nervous system exam |
| Growth and Fertility | |
| | Blood test to check thyroid function |
| | Evaluate growth rate for children |
| | Blood test to check sex hormone levels — in women of any age — in children, both male and female, who have not yet reached puberty |
| Heart and Blood Vessels | |
| | Routine heart and blood vessel evaluation |

one-year

One-Year Check-Up (Continued)

| Year 1 Done (✓) | Recommended Tests and Procedures |
|--------------------|--|
| Infection | |
| | Medication to prevent infections with bacteria that cause meningitis and pneumonia for patients taking immunosuppressive medications or those with ongoing GVHD |
| | Medication to prevent <i>Pneumocystis carinii</i> pneumonia (PCP) for patients taking immunosuppressive medications or those with ongoing GVHD |
| | Regular flu vaccine and re-immunization for diseases like pneumonia, hepatitis, tetanus and other diseases as recommended by the Centers for Disease Control (CDC) or EBMT |
| | Medication to prevent fungal infection is recommended by some experts for patients taking steroids (Prednisone) |
| | Medication to prevent herpes simplex virus (HSV) is recommended by some experts for patients taking immunosuppressive medications or those with ongoing GVHD |
| | Medication to prevent infection of the heart (endocarditis) with dental procedures |
| New Cancers | |
| | Discuss ways to reduce risk of cancer later in life |
| | Learn how to perform breast self-exam |
| | Learn how to perform testes self-exam |
| | Learn how to perform skin self-exam |
| | Screen for cancers that may be caused by drugs or radiation used during transplant |
| | Pap smear for women |
| | Mammogram for women over age 40—some experts recommend mammograms for women under age 40 who have had radiation therapy |

One-Year Check-Up (Continued)

| Year 1 Done (✓) | Recommended Tests and Procedures |
|---|--|
| Emotional Health/Quality of Life | |
| | Discuss emotional health and quality of life |
| | Discuss sexual health |
| | Discuss counseling and support groups |
| Mouth | |
| | Regular dental check-up |
| Eyes | |
| | Screening for visual symptoms (pain, dryness) or vision loss (by internist or oncologist) |
| | Test for dry eyes (Schirmer's test) for patients taking immunosuppressive medications or those with ongoing GVHD |

Record important notes on the following page.

one-year

Use this space to record notes about your check-up and doctor recommendations.

One-Year Notes:

A large, light green rectangular area with horizontal lines, intended for writing notes. The lines are evenly spaced and extend across the width of the area. The area is positioned to the right of the 'One-Year Notes:' label.

Yearly Check-Ups for Life

| Year 2 | Year 3 | Year 4 | Recommended Tests and Procedures |
|-----------------|--------|--------|--|
| Done (✓) | | | |
| Liver | | | |
| | | | Liver function tests—if previous results were abnormal |
| | | | Serum ferritin test—if previous results were abnormal |
| Lungs | | | |
| | | | Routine lung exam |
| | | | Discussion about not smoking |
| | | | Chest X-ray is recommended if earlier chest X-ray showed lung problems |
| | | | Pulmonary function test is recommended by some experts for patients receiving radiation or medication that damage lungs, or have had trouble breathing in the past |
| Bones | | | |
| | | | Bone density test for all women taking immunosuppressive medications or those with ongoing GVHD |
| | | | Bone density test recommended by some experts for men who have used steroids or calcineurin for more than 3 months to control GVHD |
| | | | Bisphosphonates recommended by some experts for patients who have taken steroids for more than 3 months |

Yearly Check-Ups for Life (Continued)

| Year 2 | Year 3 | Year 4 | Recommended Tests and Procedures |
|--------------------------------|--------|--------|--|
| Done (✓) | | | |
| Muscles | | | |
| | | | Evaluation of physical therapy needs for patients taking immunosuppressive medications |
| | | | Evaluation of muscle weakness for patients using corticosteroids more than 3 months |
| Kidneys | | | |
| | | | Test blood pressure |
| | | | Test urine protein levels—if previous results were abnormal |
| | | | Test of kidney filtration (BUN/creatinin)—if previous results were abnormal |
| Nervous System | | | |
| | | | Test function of nervous system—if previous results were abnormal |
| Growth and Fertility | | | |
| | | | Blood test to check thyroid function—if previous results were abnormal |
| | | | Evaluate growth rate for children |
| | | | Blood test to check sex hormone levels |
| | | | — in women of any age |
| | | | — in children, both male and female, who have not yet reached puberty |
| Heart and Blood Vessels | | | |
| | | | Routine heart and blood vessel evaluation |

yearly

Yearly Check-Ups for Life (Continued)

| Year 2 | Year 3 | Year 4 | Recommended Tests and Procedures |
|--------------------|--------|--------|--|
| Done (✓) | | | |
| Infection | | | |
| | | | Medication to prevent infections with bacteria that cause meningitis and pneumonia for patients taking immunosuppressive medications or those with ongoing GVHD |
| | | | Medication to prevent <i>Pneumocystis carinii</i> pneumonia (PCP) |
| | | | Test for cytomegalovirus (CMV) |
| | | | Regular flu vaccine and re-immunization for diseases like pneumonia, hepatitis, tetanus and other diseases as recommended by the Centers for Disease Control (CDC) or EBMT |
| | | | Medication to prevent fungal infection is recommended by some experts for patients taking steroids (Prednisone) |
| | | | Medication to prevent herpes simplex virus (HSV) is recommended by some experts for patients taking immunosuppressive medications or those with ongoing GVHD |
| | | | Medication to prevent infection of the heart (endocarditis) with dental procedures |
| New Cancers | | | |
| | | | Discuss ways to reduce risk of cancer later in life |
| | | | Reminder to perform breast self-exam |
| | | | Reminder to perform testes self-exam |
| | | | Reminder to perform skin self-exam |
| | | | Screen for cancers that may be caused by drugs or radiation used during transplant |
| | | | Pap smear for women |
| | | | Mammogram for women over age 40—some experts recommend mammograms for women under age 40 who have had radiation therapy |

Yearly Check-Ups for Life (Continued)

| Year 2 | Year 3 | Year 4 | Recommended Tests and Procedures |
|---|-----------|-----------|--|
| Done (✓) | | | |
| Emotional Health/Quality of Life | | | |
| | | | Discuss emotional health and quality of life |
| | | | Discuss sexual health |
| | | | Discuss counseling and support groups |
| Mouth | | | |
| | | | Regular dental check-up |
| Eyes | | | |
| | | | Screening for visual symptoms (pain, dryness) or vision loss (by internist or oncologist) |
| | | | Test for dry eyes (Schirmer's test) for patients taking immunosuppressive medications or those with ongoing GVHD |
| | | | Examination of the retina (Ocular fundus exam) is recommended by some experts—if previous results were abnormal |

Record important notes on the following pages.

To download additional copies of this guide, visit www.cibmtr.org/posttransplant

yearly

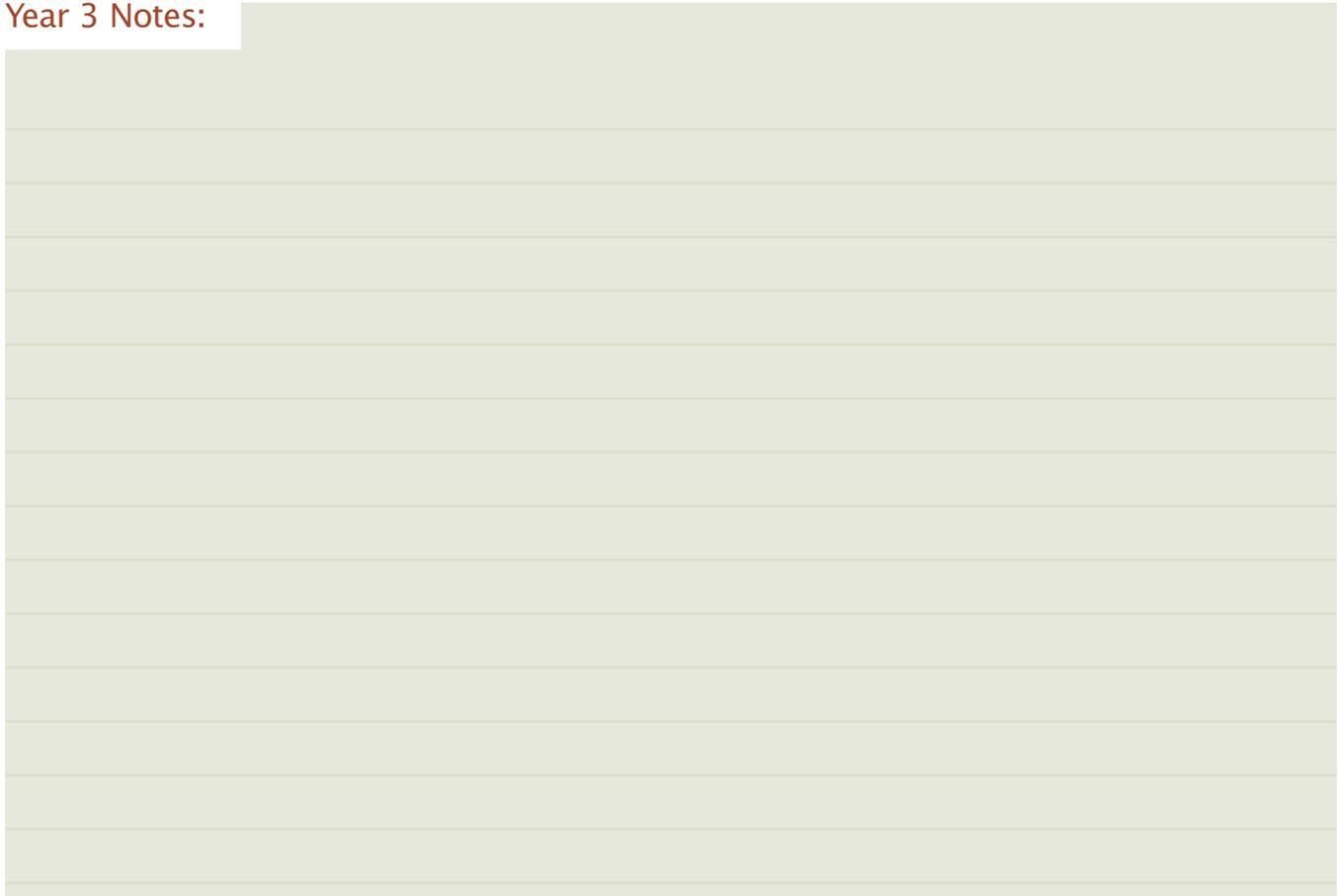
Use this space to record notes about your check-up and doctor recommendations.

Year 2 Notes:

A large, light green, lined area for taking notes. The lines are horizontal and evenly spaced, providing a structured space for writing.

Use this space to record notes about your check-up and doctor recommendations.

Year 3 Notes:



Use this space to record notes about your check-up and doctor recommendations.

Year 4 Notes:

A large, light green, lined area for taking notes. The lines are horizontal and evenly spaced, providing a structured space for writing.

Maintain a healthy lifestyle

While living a healthy life is important for everyone, following these guidelines is especially important for transplant survivors.

Transplant survivors should:

- Avoid smoking or chewing tobacco
- Eat a healthy diet
- Be physically active 20–30 minutes most days of the week
- Maintain a healthy body weight
- Avoid alcohol or use alcohol only in moderation, usually less than 2 drinks per day
- Wear sunscreen and avoid excessive exposure to the sun
- Wear helmets, seatbelts and other safety equipment when riding a bike or motorcycle, riding in a car, or playing sports
- Avoid use of illegal drugs
- Discuss **all** medications with your doctor, including herbal or alternative medications you may be taking and medications you can get without a prescription. Any of these may cause problems for some transplant survivors.

In addition, survivors and their family members should be asked about depression and offered help when needed.

If you need help finding a mental health expert, contact your transplant center, a local cancer center, or the American Psychological Oncology Society at (866) 276-7443 or www.apos-society.org

Routine check-ups

While it is important to watch for complications that might happen as a result of your transplant, you also need to follow the same health guidelines that apply to the general public. Be sure to schedule routine check-ups with your primary physician to monitor for:

- High blood pressure
- High cholesterol
- Diabetes
- Colon cancer
- Prostate cancer (for men)
- Breast and cervical cancer (for women)
- Sexually transmitted diseases
- Osteoporosis (for women)

Details about recommended health guidelines for the general public can be found at: www.ahrq.gov/consumer

healthy lifestyle



living life

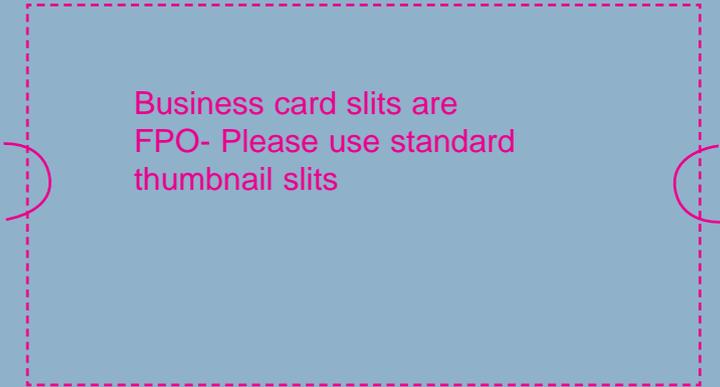
Additional Notes:

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Additional Notes:

Lined area for taking notes.

Additional copies of the physician guidelines can be downloaded from:
www.cibmtr.org/posttransplant



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Center for International Blood & Marrow Transplant Research®

About the CIBMTR

The Center for International Blood and Marrow Transplant Research (CIBMTR) combines the expertise and unique resources of two leaders in the field of blood and marrow transplant: the National Marrow Donor Program and the Medical College of Wisconsin's International Bone Marrow Transplant Registry and Autologous Blood and Marrow Transplant Registry.

These organizations conduct and support clinical studies that involve large numbers of patients from multiple transplant centers. These studies will help improve outcomes for blood and marrow transplantation. The goal is to help more transplant patients live longer, healthier lives.

This patient guide was developed by the Consumer Advocacy Committee of the CIBMTR. The Consumer Advocacy Committee provides a consumer perspective on the research agenda of the CIBMTR, and brings important publications of the CIBMTR to patients and the public.

Thanks to the National Marrow Donor Program for their assistance in producing this booklet.

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Physicians' Guidelines

Protecting your patient's health after transplant

Recommended screening and preventive practices

The guidelines, *Recommended Screening and Preventive Practices*, were developed by a consensus panel formed by members of the Center for International Blood and Marrow Transplant Research (CIBMTR), the European Group for Blood and Marrow Transplantation (EBMT), and the American Society for Blood and Marrow Transplantation (ASBMT).¹

Complications from hematopoietic cell transplantation can develop long after a patient leaves the transplant center and returns to his or her primary care physician. To prevent late complications from increasing morbidity in these post-transplant patients, physicians need to be aware of the specialized care these patients require.

Recognizing complications early, while therapeutic options are more numerous and treatments more effective, is critical to the well-being of transplant recipients.

Physicians can use the chart on the back to:

- Become aware of the specialized care required by transplant recipients
- Track treatments administered and tests completed
- Trigger discussions with patients on proper self-care

Patients have received a similar chart to help guide them in requesting appropriate care from their primary care physicians.

To access the full publication visit www.cibmtr.org/posttransplant

To order more copies of this guide visit CIBMTR.org



References:

¹Rizzo JD, Wingard JR, Tichelli A, et al. Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation: joint recommendations of the European Group for Blood and Marrow Transplantation, Center for International Blood and Marrow Transplant Research, and the American Society for Blood and Marrow Transplantation (EBMT/CIBMTR/ASBMT). *Bone Marrow Transplantation* 2006; 37(3): 249-261. (Published concurrently in *Biology of Blood and Marrow Transplantation* 2006; 12(2): 138-151.)

Recommended screening and preventive practices for post-transplant patients

Physicians: See back for important information

Key:

- 1 = Recommended for all transplant patients
- 2 = Recommended for allogeneic patients only
- 3 = Recommended for any patient with ongoing chronic GVHD or immunosuppression
- + = Reassessment recommended for abnormal testing in a previous time period or for new signs/symptoms

| Six Months | One Year | Annually | Recommended Screening/Prevention |
|---------------------------|----------|----------|--|
| Liver | | | |
| 1 | 1 | + | Liver function testing |
| | 1 | + | Serum ferritin testing |
| Respiratory | | | |
| 1 | 1 | 1 | Clinical pulmonary assessment |
| 1 | 1 | 1 | Smoking tobacco avoidance |
| | 2 | + | Pulmonary function testing |
| + | + | + | Chest radiography |
| Musculoskeletal | | | |
| | 1 | + | Bone density testing (women and patients with prolonged corticosteroid or calcineurin inhibitor use) |
| 3 | 3 | 3 | Screen for corticosteroid-induced muscle weakness |
| 3 | 3 | 3 | Consider need for physical therapy consultation |
| 3 | 3 | 3 | Osteopenia prophylaxis with bisphosphonates is recommended by some experts |
| Kidney | | | |
| 1 | 1 | 1 | Blood pressure screening |
| 1 | 1 | + | Urine protein screening |
| 1 | 1 | 1 | BUN/creatinine testing |
| Nervous System | | | |
| | 1 | + | Neurological clinical evaluation |
| Endocrine | | | |
| | 1 | + | Thyroid function testing |
| | 1 | 1 | Growth velocity in children |
| 1 | 1 | 1 | Gonadal function assessment (prepubertal boys and girls) |
| | 1 | 1 | Gonadal function assessment (postpubertal women) |
| Vascular | | | |
| | 1 | 1 | Cardiovascular risk factor assessment |
| Immune System | | | |
| 3 | 3 | 3 | Encapsulated organism prophylaxis |
| 1 | 3 | 3 | PCP prophylaxis |
| 3 | 3 | | CMV testing |
| | 1 | 1 | Immunizations |
| 3 | 3 | 3 | Antifungal prophylaxis is recommended by some experts |
| 3 | 3 | 3 | Prophylaxis for HSV is recommended by some experts |
| | 2 | 2 | Endocarditis prophylaxis with dental procedures following AHA guidelines |
| Second Cancers | | | |
| | 1 | 1 | Second cancer vigilance counseling |
| | 1 | 1 | Breast/skin/testes self-exam |
| | 1 | 1 | Clinical screening for second cancers |
| | 1 | 1 | Pap smear/mammogram (over age 40) |
| Psychosocial | | | |
| 1 | 1 | 1 | Psychosocial/QOL clinical assessment |
| + | + | + | Mental health counseling for patients with recognized psychosocial problems |
| 1 | 1 | 1 | Sexual function assessment |
| 1 | 1 | 1 | Maintain robust support networks |
| Oral Complications | | | |
| 1 | 1 | 1 | Dental assessment |
| Ocular | | | |
| 1 | 1 | 1 | Ocular clinical symptom evaluation |
| | 3 | 3 | Schirmer testing |
| | 1 | + | Ocular fundus exam |