"This is the second most important chapter in the manual ... after attitude."
— BMT Survivor

CHAPTER 15

Survivorship
Survivorship Care Plans
Concerns After Treatment
  Physical        Spiritual
  Sexual         Financial
  Emotional      Work
  Social         Staying Healthy
Chapter 15
Survivorship

The term “cancer survivor” includes anyone who has been diagnosed with cancer, from the time of diagnosis through the rest of his or her life. Family members, friends and caregivers are also part of the survivorship experience. The word “survivor” helps many people think about embracing their lives beyond their illness.

The end of cancer treatment is often a milestone. You are probably relieved to be finished with the demands of treatment and are ready to put the experience behind you. Yet at the same time, you may feel sad and worried. It is common to be concerned about whether the cancer will come back and what you should do after treatment. When treatment ends, you may expect life to return to the way it was before you were diagnosed with cancer. However, it can take time to recover. You may have permanent scars on your body or you may not be able to do some things you once did easily. Or you may even have emotional scars from going through so much. You may find that others think of you differently now — or you may view yourself in a different way.

While cancer is a major event for all who are diagnosed, it also brings with it the chance for growth. As hard as treatment can be, many cancer survivors have told us that the experience led them to make important changes in their lives. Many say they now take time to appreciate each new day. They also have learned how to take better care of themselves and value how others care for them. Others draw from their experience to become advocates to improve cancer research, treatment and care.

Those who have gone through cancer treatment describe the first few months as a time of change. It is not so much “getting back to normal” as it is finding out what is normal for you now. People often say that life has new meaning or that they look at things differently now. You can also expect things to keep changing as you begin your recovery. Your new “normal” may include making changes in the way you eat, the things you do and your sources of support.

Many cancer survivors have told us that while they felt they had lots of information and support during their illness, once treatment stopped they entered a whole new world — one filled with new questions. Many survivors of cancer and their family members have questions about what to expect. You may have some of the same questions. In this section, we will give you information that can help answer some of the questions that people with cancer and family members ask about what to expect with survivorship. We will discuss key concerns during survivorship, how to talk about the concerns with your doctor/nurse practitioner and coping tips that you can use to manage your survivorship concerns.
At City of Hope, we have many services that are provided to help patients with survivorship concerns. The Sheri & Les Biller Patient and Family Resource Center offers a number of support services, including patient navigators, pain doctors, psychiatrists, psychologists, social workers, chaplains, physical therapists, healing arts workshops, peer support groups, health information, complementary medicine, nutrition education and much more.

Survivorship Care Plans

Key Things to Know

The most important part of a survivor’s life after treatment becomes follow-up care. One helpful way of managing your follow-up care is to use a treatment summary and survivorship care plan. This document includes a summary of your diagnosis and all the treatments you received, as well as a follow-up plan of the steps you need to take to achieve the best health and well-being possible. It also helps you to work effectively with all your doctors, including your primary care doctor, as well as other members of your health care team.

How to Communicate Your Survivorship Needs

Many cancer survivors choose to continue follow-up care with their oncologist and others may return to their primary care doctor or family doctor. If you are returning to your primary care doctor, give him/her a copy of your treatment summary and survivorship care plan. This information is important to your primary doctor, who may not have been involved in your cancer treatment.

Things to Ask Yourself

• What are your concerns and questions about survivorship?
• What are your personal goals in terms of healthy living after treatment?
• How can your doctor/nurse practitioner help you achieve these goals?

Self-care Tips

• Make a list of your questions about survivorship before talking to your doctor.
• Keep a copy of your survivorship care plan for your own records.
• Always tell any new doctors you see about your history of cancer because this may affect decisions about your care in the future. They may not know about your cancer unless you tell them.
• Check your health insurance plan to see what follow-up care it allows and, if necessary, who should be in charge of your follow-up care.
Physical Concerns After Treatment

**Key Things to Know**

Many cancer survivors have a risk of developing late effects from cancer treatment.

A late effect is a side effect that does not occur during present therapy but starts approximately one year after treatment ends.

When or if a person develops a late effect, and the type of late effects that may develop, is different from person to person.

Treatment of late effects is an important part of cancer care because cancer survivors are living longer after cancer treatment than in the past.

**Some common late effects after cancer treatment include the following:**

- Chemotherapy and radiation therapy to the chest may cause additional lung problems. Cancer survivors who received combination treatment of chemotherapy and radiation therapy may have a higher risk of lung injury. People with a history of lung disease and older people may be at higher risk.

Lung-related late effects may include the following:

- A change in how the lung functions
- Thickening of the lining of the lungs
- Inflammation of the lungs
- Difficulty breathing

*Heart problems* are most often caused by radiation therapy to the chest and/or chemotherapy. People age 65 or older or those who already have heart problems before cancer treatments may be at higher risk.

Chemotherapy and radiation therapy may cause changes to hormone levels, which may result in *endocrine (hormone) system problems*. Chemotherapy may cause the following late effects:

- Damage to a woman's ovaries, which may result in hot flashes, sexual dysfunction, osteoporosis (weakness of the bones) and early menopause.
- Infertility for both men and women. Specifically for women an inability to conceive a child or maintain a pregnancy.
Osteoporosis

Osteoporosis is the most common late effect of cancer treatment and is more common in cancer survivors. Risk factors for osteoporosis include the following:

- Chemotherapy
- Steroid medicines
- Low levels of physical activity

Other Health Issues to Consider

Hearing loss from chemotherapy, such as cisplatin.

Dental problems may happen, because chemotherapy may affect tooth enamel.

Symptoms that you may have experienced during treatment can continue after treatment as well. These include:

- **Fatigue** is one of the most common complaints during the first year of recovery.
  - The causes of fatigue are different for people who are receiving treatment than they are for those who have finished.
  - For some, fatigue gets better over time. Some people may still feel energy loss years later.
- **Pain or neuropathy (nerve pain)** can continue after treatment, chemotherapy or surgery due to damaged nerves. You may have pain or numbness in your hands and feet and/or around your surgical scar.
- **Cognitive (thought process) problems** can continue after treatment. This can lead to problems paying attention, finding the right word or remembering new things.
- **Weight loss.** Some cancer survivors may continue to have problems with weight loss. You may have a decreased appetite, which can lead to weight loss.

How to Talk About Physical Concerns After Treatment

Here are some questions that may be useful when you talk with your doctor about physical concerns after treatment:

- What are the late effects from my cancer treatments?
- What tests will I need to screen for these late effects?
- How often should I be screened for these late effects?
- What signs or symptoms should I be looking for after my cancer treatment is completed? What should I do if I notice one of these symptoms?
- Do I need to be referred to a specialist?
Keep track of any new symptoms or old symptoms that are getting worse and let your doctor/nurse practitioner know right away:
• When the symptom started
• What makes the symptom better/worse
• How long the symptom lasts

Self-care Tips
• Keep an active, healthy lifestyle
• Supportive care professionals that can help:
  • Pain doctors
  • Physical/Occupational therapist
  • Pulmonary rehabilitation doctor
  • Dietitian
  • Pharmacist
• Follow directions when taking any medicine. Call your doctor/nurse practitioner if you:
  • Have questions about how to take your medicine
  • Have problems getting your medicine
  • Feel that your medicine doesn’t work
• Be aware of what is recommended for your follow-up care after treatment.
What You Need to Know About Changes Related to Intimacy and Sexuality Following Blood and Marrow Transplant

High-dose chemotherapy and/or blood and marrow transplant (BMT) may cause a variety of changes related to intimacy and sexuality. How you feel about sexuality is influenced by hormones, the functioning of the sexual organs, energy level, feelings of love and closeness, how you were raised, and how you feel about yourself and your partner. Having conflicts and miscommunication with your partner, concerns with body image, can also disrupt intimacy and sexual satisfaction. When you have a BMT your normal intimacy routine may change.

How can chemotherapy affect intimacy?

- Men and women may experience hormonal changes for several months after chemotherapy is completed. Lower testosterone and estrogen levels can cause less desire for intimacy as well as physical changes.
- It is important to talk to your doctor about possible side effects of infertility BEFORE and after chemotherapy and/or BMT. Chemotherapy can, but not always cause infertility. Problems with infertility will depend on the type of chemotherapy drugs used, your age, and overall health.
- If you are of child-bearing age discuss your concerns and questions with your doctor before and after having a BMT. Immunosuppressant drugs (drugs that calm your immune system) may cause birth defects. You will want to avoid having children until no longer taking these drugs.

Are there physical changes following BMT?

Following BMT, some people may find it difficult to return to being intimate with their partner. It is important to recognize and inform your doctor about any changes early because they can often be treated.

- Women will need routine vaginal exams to check the skin inside the vagina and lab tests to check hormone levels.
- Men will need routine exams by a doctor who specializes in male reproductive organs (Urologist) to check hormone levels, manage erectile dysfunction, and treat any skin changes to the penis.

Physical changes following a BMT may include:

- Women may experience physical changes such as shortening or narrowing of the vagina, decreased softness or flexibility of the skin, and vaginal dryness. These changes can cause pain during sex and may make vaginal examinations difficult when seeing your doctor.
• Men, especially those who are uncircumcised, are at risk for changes to the skin of their penis. Skin may become hard and stiff. Nerve damage, caused by chemotherapy and/or radiation, may lead to erectile dysfunction (the inability to have an erection).

**Important intimacy guidelines to follow when you resume sexual activities**

There are important steps you are encouraged to follow when you resume sexual activities. Talk to your doctor about any concerns or questions you may have about the following information.

• Sexual activities should be avoided until platelet counts are above 50 without transfusions and until absolute neutrophil counts are above 500. If you are not sure, please speak with your BMT doctor before resuming sexual activities.

• Kissing is acceptable if you and your partner maintain good mouth hygiene (brush teeth twice daily, regular dental checkups) and do not have any mouth sores or bleeding gums.

• Maintain good overall hygiene for you and your partner. Shower or wash your hands and genitals before and after sexual activity.

• Condom/barrier protection must be used while you are on immunosuppressant drugs, chemotherapy, or other medications which might put you at risk for infection. Please check with your doctor regarding the medications you are on that may increase your risk.

• Use a water-soluble lubricant to decrease irritation during sexual activity.

• If possible, urinate before and after intercourse.

• Oral sex is permitted; however, should be avoided if you or your partner has mouth sores, bleeding gums, or genital sores. Barrier methods can help lower the risk of infection from oral sex. A latex or plastic condom may be used on the penis and a cut-open condom or a dental dam can be used between the mouth and the vagina or anus.

• Anal sex is permitted but places the patient at higher risk for bleeding and infection and shall be performed only with condom use, platelet count greater than 100 without transfusions, and ANC greater than 1000.

• Avoid sexual practices that result in the mouth coming in contact with stool.
Online resources you can visit for more information

- **National Bone Marrow Transplant Link (nbmtLINK)**  [www.nbmtlink.org](http://www.nbmtlink.org)
  The mission of the nbmtLINK is to help patients, their caregivers, families, and the health care communities meet the many challenges of bone marrow/stem cell transplantation by providing vital information and support services.

- **American Cancer Society (ACS)**  [www.cancer.org](http://www.cancer.org)
  The American Cancer Society (ACS) is a national community-based voluntary health organization whose mission is to eliminate cancer as a major health problem through research, education, advocacy, and service.

- **Blood and Marrow Transplant Information Network**  [www.bmtinfonet.org](http://www.bmtinfonet.org)
  BMT InfoNet is a not-for-profit organization that serves families facing a bone marrow, stem cell or cord blood transplant, and survivors. This site includes easy-to-understand information about bone marrow, peripheral blood stem cell and cord blood transplants.

- **Bone Marrow Foundation (BMF)**  [www.bonemarrow.org](http://www.bonemarrow.org)
  The mission of The Bone Marrow Foundation is to improve the quality of life for bone marrow and stem cell transplant patients and their families by providing financial aid, education, and emotional support.

- **Centers for Disease Control and Prevention**

Original content for this handout was obtained from H. Lee Moffit Cancer Center & Research Institute-Tampa, FL (2014)
Emotional Concerns After Treatment

Key Things to Know

It is normal to have many different feelings after treatment ends. Just as you need to take care of your body after treatment, you need to take care of your emotions. For many cancer survivors, it is a stressful time filled with new routines to learn, as well as mixed feelings about what they have just gone through. Many people find themselves unsure of how to move forward, wondering, “Now what?” It is common for many cancer survivors to have a complex and often conflicting feelings about their diagnosis, treatment and recovery.

It is normal to feel relieved that treatment is over, yet angry or sad about having gone through such a serious illness.

You may feel guilty about surviving a diagnosis when other people have not survived.

You may also feel anxious and fearful about the cancer coming back or worried that the treatment did not work.

Realizing that life after diagnosis and treatment never really goes back to what it was before cancer. Many survivors find they are not able to return to their old “normal” life but must adapt to a “new normal.”

It is normal, too, to feel confused about what you have been through and to be concerned about the future.

Sometimes these emotions can be overwhelming, interfering with your day-to-day activities and even your health.

Some common psychological concerns after cancer treatment include the following:

- Worrying about your health
- Feeling stress
- Depression
- Anger
- Feeling alone
- Guilt

Feelings After Treatment

In many ways our emotions are what make us uniquely human. Our feelings enrich our lives. When someone we love is diagnosed with a serious illness, emotions will run high.

Emotions (stress, anxiety, sadness, frustration) may not always feel pleasant. When directed they can always be helpful. The first step for, all of us, is to understand how we can regulate and direct our emotions. Once you learn to manage your emotions, you will begin to feel less overwhelmed (stressed).
Take Action!

Recognize the signs of emotional distress. Being exhausted much of the time, not sleeping enough or feeling impatient, irritable or forgetful.

Take care of your body, mind and spirit. Some people develop or increase unhealthy habits, such as smoking, drinking too much alcohol or using prescription medicine improperly. If you notice that you are doing these types of things, seek professional help.

Meet with an expert such as a psychiatrist, psychologist or social worker. They will listen to your concerns. They can even help you create a plan for how to share your concerns with your partner.

Self-care Tips

Call your doctor/nurse practitioner if you:

- Have questions about how to take your medicine.
- Have problems getting your medicine.
- Feel that your medicine does not work.

Understanding what your new normal is can take time. Here are some tips that you can use:

- Reflect on what you have been through.
- Identify changes you might want to make in your life.
- Recognize what you have learned and what is changed about yourself.
- It is healthy to take time for yourself and to reflect about what matters most in your life.
- It is also okay to surround yourself with people who are close to you.
- Keep an active, healthy lifestyle.
- Join a support group.
- Consider volunteering as a “peer” for cancer patients who are still receiving treatments. At City of Hope, we have “peer support” programs through the Sheri & Les Biller Patient and Family Resource Center that match survivors with patients.
- Medicines can be used for anxiety and depression.
- Supportive care professionals that can help:
  - Spiritual counselors (chaplains)
  - Psychologist/Psychiatrist
  - Social workers
  - Grief counselors
  - Support groups
Social Concerns After Treatment

**Key Things to Know**

Having cancer can change relationships with the people in your life. It is normal to notice changes in the way you relate to family, friends and other people that you are around every day — and the way they relate to you. When treatment ends, families are often not prepared for the fact that recovery takes time. Families also may not realize that their relationships and communications may have changed permanently as a result of cancer. You and your family may need help to deal with the changes and keep the “new” family strong.

Some survivors say they would not have been able to cope without their family members and the help they offered. In addition, even though treatment has ended, you may face problems with your family. Problems that were present before the cancer may still exist, or new ones may develop. You may still need to depend on others during this time, even though you want to get back to the role you had in your family before. At the same time, your family may still be adjusting.

Some common late effects related to cancer treatment include the following:

- Relating to others
- Changes in sex life
- Communication

Reach out to professional who can help you. You may consider:

- Spiritual counselors (chaplains)
- Psychologist/Psychiatrist
- Social workers
- Grief counselors
- Support groups

Understanding what your new normal is can take time. Here are some tips that you can use:

- Reflect on what you have been through.
- Identify changes you might want to make in your life.
- Recognize what you have learned and what is changed about yourself.
- Keep an active, healthy lifestyle.
- Join a support group.
Spiritual Concerns After Treatment

Key Things to Know

Survivors often express the need to understand what having had cancer means to their lives now. In fact, many find that cancer causes them to look at life in new ways. They may reflect on spirituality, the purpose of life and what they value most. Cancer survivors often report that they look at their faith or spirituality in a new way. For some, their faith may get stronger or seem more vital. Others may question their faith and wonder about the meaning of life or their purpose in it. Many say they have a new focus on the present and try to live each day to the fullest.

Many survivors have found that their faith, religion or sense of spirituality is a source of strength. They say that through their faith they have been able to find meaning in their lives and make sense of their cancer experience. Faith or religion can also be a way for survivors to connect with others in their community who may share similar experiences or outlooks or who can provide support. Studies have also shown that for some religion can be an important part of both coping with and recovering from cancer. It is common to question your beliefs after cancer. These questions can be difficult, but for some, seeking answers and searching for personal meaning in spirituality helps them cope.

Some common spiritual concerns after cancer treatment include the following:

- Finding comfort and meaning
- Finding purpose in life
- Uncertainty
- Positive changes

How to talk about spiritual concerns after treatment

Supportive care professionals that can help include:

- Spiritual counselors (chaplains)
- Psychologist/Psychiatrist
- Social workers
- Support groups
- Spiritual directors
Coping Tips:

Understanding what your new normal is can take time. Here are some tips that may help:

• Reflect on what you have been through.
• Identify changes you might want to make in your life.
• Recognize what you have learned and what is changed about yourself.
• Pray or meditate to help you gain perspective.
• Seek spiritual support.
• Keep an active, healthy lifestyle.
• Join a support group. Talk with others who have had similar experiences.
• Keep a journal and write about your experience and where you want to go in life now.
Financial and Work Concerns

Key Things to Know:
Many cancer survivors are able to continue working through and beyond their treatment. Others may have to stop working during treatment and return later. Whether returning to their old jobs or beginning new ones, some survivors are treated unfairly when they return to the workplace. Employers and employees may have doubts about cancer survivors’ ability to work. Employers may regard making any special arrangements as a hardship on the business. Research shows that cancer survivors who continue to work are as productive on the job as other workers.

How to talk about financial and work concerns after treatment
Supportive care professionals that can help include:
• Social workers
• Hospital financial counselors

Coping Tips:
• Learn about your company’s rules and policies related to sick time. It is important to know that there are laws that protect you in the workplace.
• Develop a plan to cope with changing financial needs for daily expenses (e.g., medicines, housing, rent/mortgage, transportation, insurance, groceries).
• Organize a financial record-keeping system.
• Join a support group. Talk with others who have had similar experiences.
Staying Healthy After Treatment

**Key Things to Know:**

Once treatment is over, people who have had cancer often want to know what they can do to stay healthy.

Cancer survivors find that this is a time when they take a good look at how they take care of themselves. This is an important start to living a healthy life.

Cancer survivors often look for information and advice about food choices, physical activity, and dietary supplements to improve their quality of life and survival.

Cancer rehabilitation helps a person with cancer obtain the best physical, social, psychological, and work-related functioning after cancer treatment.

The goal of rehabilitation is to help a person regain control over many aspects of their lives and remain as independent and productive as possible.

Rehabilitation can be valuable to those recovering from cancer treatment.

**How to Talk About Staying Healthy After Treatment:**

As part of your follow-up care, ask your doctor/nurse practitioner about developing a wellness plan that includes ways you can take care of your physical, emotional, social and spiritual needs.

Ask your doctor/nurse practitioner to suggest other members of the health care team for you to talk with, such as a social worker, dietitian or physical therapist.

Call your doctor/nurse practitioner if you have any ongoing symptoms such as pain, fatigue, cough, etc.

**Self-care Tips:**

Supportive care professionals that can help include:

- Physical/Occupational therapist
- Dietitian
- Social worker
- Psychologist

Be aware of what is recommended for your follow-up care after treatment, including your wellness plan.
Stay as active as possible.

- Maintain a healthy weight
- Work at your own pace
- Consult a physical therapist about what types of exercises are best for you.
- Check with your doctor before starting any exercise program.

Maintain a healthy diet.

- Try to get all of your nutrients from foods instead of from supplements.
- Check with your doctor regarding any food or diet restrictions.
- Ask your dietitian to help you create a nutritious, balanced eating plan.
- Choose a variety of foods from all the food groups. Try to eat at least five to seven servings a day of fruits and vegetables, including citrus fruits and dark-green and deep-yellow vegetables.

Seek counseling from psychologist/psychiatrist, chaplains or social workers, if needed.

Reduce stress by exercising, using meditation and relaxation.

If you have questions, please contact one of the resources below:

- City of Hope (626) 256-HOPE (4673)
- Spiritual Care Services: ext. 63898
- Sheri & Les Biller Patient and Family Resource Center: ext. 32273
- Division of Clinical Social Work: ext. 62282
Congratulations—on the upcoming 6-month 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 6-month appointment. It is the first in the series of 3 (12-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 six-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, anywhere
• Make a list of tests and evaluations customized to your unique situation
• Email information to yourself, or your healthcare team

Take action: prepare for your checkup

Schedule 6-month checkup appointment with your transplant doctor or 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 doctors 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 BeTheMatch.org/guidelines for free clinical guidelines in print or through a mobile app

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

Available on iPhone®, iPad®, and Android™

Online at BeTheMatch.org/patient-survive

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Free mobile app

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- 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
SIX-MONTH CHECKUP GUIDE

Below, you’ll find information on the physical exams and tests that are recommended 6 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
• Check how well you can see (vision screening)
• If you have eye symptoms or problems seeing, ask to see an eye specialist (ophthalmologist)

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

If you have GVHD you may need:
• To have exams of the mouth and teeth, and oral cancer screening more often

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

• 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

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Check how well you can see (vision screening).

Tell your doctor about harmful habits (like tobacco use or smoking). Ask for help quitting.

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Learn how to do a routine self-exam of your skin.

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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 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.

Words in bold are defined in the glossary.
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, fascitis 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 have GVHD or are taking immunosuppressants you may need:*  
- Bone density measurement (using dual photon densitometry)

Skin and Genital

- Learn how to do a routine self-exam of your skin  
- Discuss risks of being in the sun without proper protection

*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
Fertility

- Ask your doctor about birth control options

Immune System

- Medicine to prevent an infection called pneumocystis
- 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
- Blood tests to screen for cytomegalovirus (CMV)

Endocrine System (thyroid, growth, sex hormones)

Tests for children:

- Talk to your child’s doctor about sexual development. 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

If you have GVHD you may need:

- Clinical and dental exams
- Oral cancer screening
Fascitis—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.

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 6-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 for free clinical guidelines in print or through a mobile app

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-enews
• FACEBOOK: facebook.com/BeTheMatchPatient

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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, anywhere
- 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

* Majhail NS, Rizz o JD , Lee SJ , et al. Rec ommended scr eening and pr ev entiv e pr actic es for long-t erm surviv ors aft er hemat opoietic c ell tr ansplantation; Cent er for Int ernational Blood and Marr o w T r ansplant Resear ch (CIBMTR), American Society for Blood and Marr ow Tr ansplantation (ASBMT), Eur opean Gr oup for Blood and Marr o w T r ansplantation (EBMT), Asia-Pacific Blood and Marr o w T r ansplantation Gr oup (APBMT), Bone Marr o w T r ansplant Society of Austr alia and Ne w Z ealand (BMTSANZ), East Medit err anean Blood and Marro w Tr ansplantation Gr oup (EMBMT) and Sociedade Br asileir a de T r ansplant e de Medula Ossea (SBTMO ). Co-published in Biol Blood Marr o w T r ansplant. 2012; 18(3): 348-3 71; Bone Mar -
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
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.

**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, fascitis 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.

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

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**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

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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

Notes:

Just for you—recipient resources

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• FACEBOOK: facebook.com/BeTheMatchPatient
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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 yearly 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.

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Checkup
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24+
MONTH
checkup
Helping you prepare for your appointment


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YEARNLY CHECKUP GUIDE
Below, you’ll find information on the physical exams and tests that are recommended every year after transplant starting 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. 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
Below, you'll find information on the physical exams and tests that bold are defined in the glossary.

If you have

• Tell your doctor about tobacco use or smoking. Ask for help
eat healthy foods, and don’t smoke)

Lung exams and

Ask if you need to take an antibiotic before having dental work
done. The antibiotic prevents a bacterial infection of the heart
valves

GVHD

CHECKUP GUIDE

• Bone density measurement (using
dual photon densitometry)

• Urine protein levels test

If your kidneys aren’t working well, you may need more tests
to see how well your kidneys are working

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
Heart and Blood Vessels

Check for heart and blood vessel risk factors, such as high cholesterol, high blood pressure, obesity, history of smoking or had total body irradiation, you may need to:

- Pulmonary (lung) function tests
- Kidney filtration levels test
- Blood pressure test

To see a physical therapist if you have myopathy

To see an eye specialist more often if you had red blood cell transfusions, you may need a blood test to measure bone density loss. The antibiotic prevents a bacterial infection of the heart valves.

Liver

Learn how to test your own range of motion

If you are a woman, allogeneic transplant recipient, have hepatitis B or C, your doctor will watch it closely. Ask if you may need: vaccines to prevent infection and disease.

Immune System

Endocrine System

Learn how to do a routine self-exam of your skin

Fertility

Additions for children:

Kidney filtration levels test

Graft-Versus-Host Disease (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.

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