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Graft-Versus-Host Disease

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These NCCN Guidelines for Patients are based on the NCCN Guidelines® for Hematopoietic Cell Transplantation (HCT): Pre-Transplant Recipient Evaluation and Management of Graft-Versus-Host Disease, Version 5.2021 – September 30, 2021.

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GVHD basics

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Graft-versus-host disease (GVHD) is a complication that may occur after a donor stem cell or bone marrow transplant. GVHD occurs when the donor cells mistakenly attack your body. Symptoms can be mild or severe.

Blood

Blood is made up of red blood cells, white blood cells, platelets, and plasma. Plasma is the largest part of your blood. Plasma is made up of mostly water. Blood cells float in plasma. Blood takes oxygen and nutrients to your body's tissues, and carries away waste.

There are 3 types of blood cells:

- Red blood cells (RBCs)
- White blood cells (WBCs)
- Platelets (PLTs)

Blood cells do not live forever. Most normal red blood cells live for 120 days. Normal white blood cells live for 8 to 14 days. Normal platelets live for about a week (7 days). After cells reach these ages, they die off and are replaced by new cells. Your blood cells are being replaced in your body all the time.

Blood has many functions; they include:

- **Transportation** – Blood takes oxygen from the lungs to the rest of the body. It takes carbon dioxide, a waste product, from the body's cells to the lungs where it is breathed out. Blood also carries nutrients, hormones, and other waste products around the body.
- **Regulation** – Blood helps to keep the acid-base balance of the body in check. It also plays a part in regulating body temperature. Increasing the amount of blood flowing close to the skin helps the body to lose heat.
- **Protection** – White blood cells attack and destroy invading germs (such as viruses and bacteria). Blood clots form after an injury, which protects the body from losing too much blood.

How blood cells are formed

Bone marrow is the sponge-like tissue in the center of most bones. Inside your bone marrow are early blood-forming cells called blood stem cells (hematopoietic stem cells). All types of blood cells start as blood stem cells. Once blood cells mature, they are released in your bloodstream. Normal stem cells grow and divide to make new red blood cells, white blood cells, and platelets.

Stem cell transplant

A stem cell transplant (SCT) destroys cells in the bone marrow and replaces them with new, healthy blood-forming cells. These healthy stem cells form new marrow and blood cells. An SCT may also be called a hematopoietic cell transplant (HCT) or bone marrow transplant (BMT).

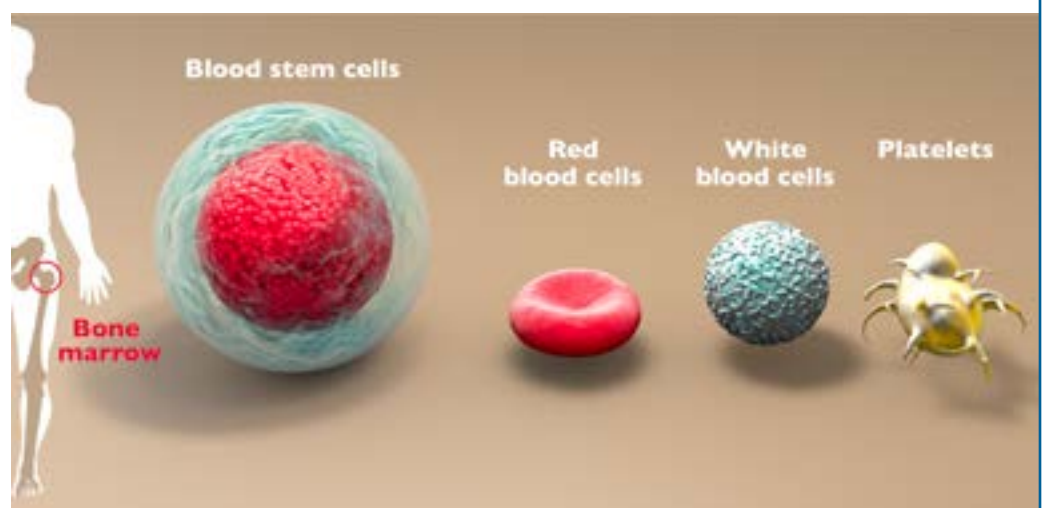
Before an SCT, you will receive a procedure called conditioning. Conditioning uses chemotherapy (and/or radiation therapy) to destroy bone marrow cells. This procedure creates room for the healthy stem cells, and weakens the immune system so your body does not kill the transplanted cells.

After conditioning, you will receive the healthy stem cells through a transfusion. A transfusion is a slow injection of blood products into a vein. This can take several hours. The transplanted stem cells will travel to your bone marrow and grow. New, healthy blood cells will form. This is called engraftment. It usually occurs about 2 to 4 weeks after the transplant.

Until the new, healthy blood cells form, you will have little or no immune defense. You may need to stay in a very clean room at the hospital or be given antibiotics to prevent or treat infection. You may receive immunosuppressants to prevent graft-versus-host disease (GVHD). While waiting for the cells to engraft, you will likely feel tired and weak.

Blood stem cells

Bone marrow contains stem cells. A blood stem cell is an immature cell that can develop into a red blood cell, a white blood cell, or a platelet.



GVHD

Graft-versus-host disease (GVHD) is a complication that occurs in those who have an allogeneic stem cell transplant (alloSCT). An alloSCT replaces stem cells with those of a donor that may or may not be related to you.

In GVHD, donor blood stem cells see your normal, healthy tissues as foreign and attack them. Any area of the body can be affected. The most common areas affected include the skin, liver, and digestive tract. Other areas of the body may also be involved, such as the lungs, eyes, mouth, hair, nails, joints, muscles, kidneys, and genitals. Symptoms can be mild or severe and life-threatening.

GVHD disease can occur within the first few months after SCT (acute) or much later (chronic). Treatment aims to manage symptoms and to prevent further damage to your body.

There are 2 types of GVHD:

- **Acute GVHD (aGVHD)** - Typically develops within 3 months after transplant. It can also occur when immunosuppressants are stopped. Acute GVHD primarily affects the skin, gastrointestinal (GI) tract, and liver.
- **Chronic GVHD (cGVHD)** - Typically develops within 1 year after transplant. Chronic GVHD may involve the eyes, mouth, skin, joints, GI tract, lungs, and other organs.

GVHD affects everyone differently. Contact your care team about anything unusual so it can be treated right away.

Each type of GVHD has a different effect on organs and tissues. Although acute and chronic GVHD usually occur during different time periods after transplant, it is possible to have both at the same time called overlap chronic GVHD.

Many organs are affected by GVHD; they include:

- Skin (rashes, thickening, or tightness)
- Mouth (mouth sores)
- Joints (pain or stiffness)
- Liver
- Eyes (dry, gritty)
- GI tract (diarrhea, nausea, vomiting, or difficulty swallowing)
- Genital organs (dryness or ulcers)
- Lungs (cough, wheezing, and shortness of breath)

Risk factors

A risk factor is anything that increases your chance of getting a disease. Having one or more risk factors does not mean you will get the disease.

Risk factors for GVHD include:

- **Mismatched or not fully matched donor** – donor is not a perfect match to your human leukocyte antigens (HLAs). Any difference can cause donor cells to attack your tissues and organs.
- **Unrelated donor** – risk increases if the donor is not related to you, even if they are a perfect match.
- **Age (donor or recipient)** – risk increases with age.
- **Previously having acute GVHD (aGVHD)** - increases the risk of recurrent acute or chronic GVHD.

Lower your risk

There are things you can do to lower your risk for GVHD; they include:

- **Take your prescribed medicines** – It is important that you continue taking them even if you feel better.
- **Be alert for warning signs** – Tell your doctor about any changes to your body. Your transplant team will give you a list of signs and symptoms for GVHD.

HLA typing

Human leukocyte antigens (HLAs) are proteins found on the surface of most cells. They play an important role in your body's immune response.

HLAs are unique to each person. They mark your body's cells. Your body detects these markers to tell which cells are yours. Each person's set of HLAs is called the HLA type or tissue type.

HLA typing is a blood test that detects a person's HLA type. This test is done before a donor (allogeneic) blood stem cell transplant. To find a donor match, your proteins will be compared to the donor's proteins to see how many proteins are the same.

- **Share information with your care team** – Other types of providers (such as primary care providers) may not be as familiar with GVHD. It is ok to ask your doctors to speak to each other.

Key points

- Blood is made up of plasma and the cells that float within it. These include red blood cells, white blood cells, and platelets.
- Inside your bone marrow are early blood-forming cells called blood stem cells (hematopoietic stem cells).
- An allogeneic stem cell transplant (alloSCT), also called hematopoietic cell transplant (HCT) or bone marrow transplant (BMT), is a type of treatment that destroys cells in the bone marrow then replaces them with new, healthy blood-forming cells from another person.
- Graft-versus-host disease (GVHD) is a complication that may occur after an alloSCT.
- In GVHD donor cells attack your healthy, normal tissue.
- GVHD can occur within the first few months after SCT (acute) or much later (chronic). Treatment aims to manage symptoms and to prevent further damage to your body.

Seek treatment
at a center that
specializes in stem
cell transplants.

2

Testing

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Treatment planning starts with testing. Accurate testing is needed to diagnose and treat GVHD. This chapter presents an overview of the tests you might receive and what to expect.

Test results

GVHD may be diagnosed based on blood tests, a skin exam, physical exam, biopsy, stool sample, and possible imaging studies. Your diagnosis will determine your treatment plan. It is important you understand what these tests mean.

Keep these things in mind:

- Bring someone with you to doctor visits, if possible.
- Write down questions and take notes during appointments. Don't be afraid to ask your care team questions. Get to know your care team and help them get to know you.
- Get copies of blood tests, imaging results, and reports.
- Organize your papers. Create files for insurance forms, medical records, and test results. You can do the same on your computer.
- Keep a list of contact information for everyone on your care team. Add it to your phone. Hang the list on your refrigerator or keep it in a place where someone can access it in an emergency. Keep your primary care physician informed of changes to this list.



Create a medical binder

A medical binder or notebook is a great way to organize all of your records in one place.

- Make copies of blood tests, imaging results, and reports about your specific type of cancer. It will be helpful when getting a second opinion.
- Choose a binder that meets your needs. Consider a zipper pocket to include a pen, small calendar, and insurance cards.
- Create folders for insurance forms, medical records, and tests results. You can do the same on your computer.
- Use online patient portals to view your test results and other records. Download or print the records to add to your binder.
- Organize your binder in a way that works for you. Add a section for questions and to take notes.
- Bring your medical binder to appointments. You never know when you might need it!

General health tests

Medical history

A medical history is a record of all health issues and treatments you have had in your life. Be prepared to list any illness or injury and when it happened. Bring a list of old and new medicines and any over-the-counter medicines, herbals, or supplements you take. Tell your doctor about any symptoms you have. A medical history will help determine which treatment is best for you. It is sometimes called a health history.

Family history

Some cancers and other diseases can run in families. Your doctor will ask about the health history of your family members who are blood relatives. This information is called a family history. Ask family members about their health issues like heart disease, cancer, and diabetes, and at what age they were diagnosed.

Physical exam

During a physical exam, a health care provider may:

- ▶ Check your temperature, blood pressure, pulse, and breathing rate
- ▶ Check your weight. Weight loss may be a sign of GVHD.
- ▶ Listen to your lungs and heart
- ▶ Look in your eyes, ears, nose, and throat
- ▶ Feel and apply pressure to parts of your body to see if organs are of normal size, are soft or hard, or cause pain when touched. Tell your doctor if you feel pain.

- ▶ Feel for enlarged lymph nodes in your neck, underarm, and groin. Tell your doctor if you have felt any lumps or have any pain.
- ▶ Conduct a complete skin exam.

Blood tests

Blood tests check for signs of disease and how well organs are working. They require a sample of your blood, which is removed through a needle placed into your vein.

Complete blood count

A complete blood count (CBC) measures the levels of red blood cells (RBCs), white blood cells (WBCs), and platelets (PLTs) in your blood. Your doctor will want to know if you have enough red blood cells to carry oxygen throughout your body, white blood cells to fight infection, and platelets to control bleeding.

A basic metabolic panel checks kidney function and electrolytes (salts) in the blood. Kidney function and electrolytes can be affected if you are dehydrated from having diarrhea or can be affected by side effects from medicine.

Liver function tests

Liver function tests (LFTs) look at the health of your liver by measuring chemicals that are made or processed by the liver. Levels that are too high or low signal that the liver is not working well and can be a sign of GVHD.

One LFT measured is bilirubin, a chemical that gives bile its greenish color. There may be too much bilirubin in the blood if the liver is not working as well as it should. Too much bilirubin causes a yellowing of the eyes and skin called jaundice. It might cause itchy skin and dark-colored urine. Elevated bilirubin levels can be a sign of GVHD.

Hepatitis panel

Hepatitis is inflammation of the liver. Sometimes, this inflammation is caused by viruses such as hepatitis A, hepatitis B (HBV), and hepatitis C (HCV). Hepatitis causes the liver to not work as it should.

A hepatitis panel will tell your treatment team if you had hepatitis in the past or if you have it today. Certain treatments such as immunosuppressive therapies can reactivate HBV in the blood.

Skin exam

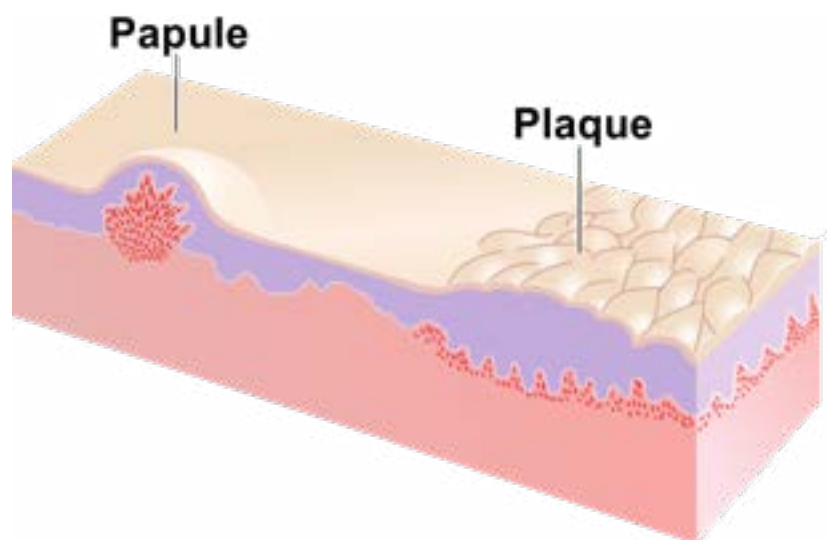
It is important to find an experienced health care provider to conduct a thorough skin exam. Expect a head-to-toe skin exam that includes review of the scalp, face, mouth, hands, feet, torso and extremities, eyes and eyelids, ears, fingers, toes, and toenails. Skin conditions such as rashes, lesions (bumps), and dry or peeling skin are common in GVHD.

A skin lesion is a change in color or texture. In GVHD, these areas are measured using the size of your hand. One hand is equal to 1 percent (1%) of your total body surface area (BSA). Keeping a photo journal might help track your skin changes.

Skin lesions

A papule is a very small, solid bump. A plaque is a raised or hardened lesion that forms on the skin, larger than a papule.

Credit: https://commons.wikimedia.org/wiki/File:Papule_and_Plaque.svg



Some words to describe skin lesions might include patch, papule, plaque, nodule, and erythroderma.

Erythroderma

Erythroderma is redness of over 80 percent (80%) of the body's skin surface. Erythroderma can look like a sunburn or large blotches on the skin.

Papule

A papule is a very small, solid lump that might look like a very small pimple. Papules are usually found in groups. They may be red, purple, brown, or pink.

Papulonodular

Papulonodular is a combination of papules and nodules found on the skin. Nodules are more raised than papules.

Patch

A patch is a flat, thin, pink or red lesion of any size that forms on the skin. Patches may be dry, scaly, or itchy, and may look like eczema or psoriasis. They can be lighter than surrounding skin or brown in people with darker skin. The patches may sometimes become plaques (hard, raised lesions) on the skin.

Plaque

A plaque is a raised (elevated) or hardened (indurated) lesion of any size that forms on the skin. Plaques may be red, scaly, or itchy, and may look like eczema or psoriasis.

Ulcer

A skin ulcer is an open sore or wound on the skin caused by poor blood flow. Ulcers caused by GVHD can also be found on the genitals or in the mouth.

Stool sample

Stool, also called feces or poop, is made up of undigested food, bacteria, mucus, and cells from the lining of the intestines. Since GVHD might affect the digestive tract, symptoms such as diarrhea or abdominal pain are concerning for GVHD. Infection in the bowels can also cause similar symptoms. Therefore, it is important to test for infections if you are having diarrhea and GVHD is suspected. A stool sample will be checked for different infections.

For this test, you will need to provide a sample of your poop. You will be given a special container with a lid to take home. Speak with your doctor about how you should collect the stool sample and any special instructions.

Biopsy

A biopsy is the removal of a sample of tissue or group of cells for testing. It is an important part of an accurate diagnosis. Your sample should be reviewed by a pathologist who is an expert in the diagnosis of GVHD. This review is often referred to as histology, histopathology, or hematopathology review. The pathologist will note the overall appearance and the size, shape, and type of your cells. Tests will be done on the biopsied cells.

Biopsies of the skin, gastrointestinal (GI) tract, liver, or other organs might be done to confirm GVHD.

Skin biopsy

If you have skin lesions, a sample of your lesion may be removed and tested to plan treatment.

Liver biopsy

In a liver biopsy, a needle may be inserted through your skin to remove a liver sample. It also may be inserted through a large vein in your neck (jugular), and threaded down to a vein (inferior vena cava) near your liver.

Testing takes time.
It might take days
or weeks for all test
results to come in.

GI biopsy

A GI biopsy is often performed to confirm a diagnosis of GI acute GVHD. A biopsy might be done during an endoscopy (EGD), colonoscopy, and/or flexible sigmoidoscopy.

In an EGD, a device is guided down the throat into the esophagus, stomach, and upper parts of the small intestine (duodenum). An EGD is used to inspect the lining of these organs and to look for any signs of cancer or other abnormalities such as dilated blood vessels or ulcers. An EGD can also be referred to as an upper GI endoscopy or duodenoscopy.

In a colonoscopy and flexible sigmoidoscopy, a device is inserted into the rectum to inspect the colon.

Imaging

Imaging tests take pictures of the inside of your body. A radiologist, an expert in interpreting test images, will write a report and send this report to your doctor. Your test results will be discussed with you.

CT scan

A computed tomography (CT or CAT) scan uses x-rays and computer technology to take pictures of the inside of the body. It takes many x-rays of the same body part from different angles. All the images are combined to make one detailed three-dimensional (3D) picture.

In most cases, contrast will be used. Contrast material is used to improve the pictures of the inside of the body. Contrast materials are not dyes, but substances that help enhance and improve the images of several organs and structures in the body. It is used to make the pictures clearer. Contrast might be taken by mouth (oral) or given through a vein (IV). The contrast is not permanent and will leave the body in your urine immediately after the test.

Tell your doctors if you have had allergic reactions to contrast in the past. This is important. You might be given medicines, such as diphenhydramine (Benadryl®) and prednisone (a steroid), to avoid the effects of those allergies. Contrast might not be used if you have a serious allergy or if your kidneys aren't working well.

MRI scan

A magnetic resonance imaging (MRI) scan uses radio waves and powerful magnets to take pictures of the inside of the body. It does not use x-rays. Contrast might be used.

Ultrasound

An ultrasound (US) uses high-energy sound waves to form pictures of the inside of the body. A probe will be pressed onto your abdomen. This is similar to the sonogram used for pregnancy. Ultrasound is painless and does not use x-rays, so it can be repeated as needed. Sometimes, an ultrasound or CT is used to guide a biopsy.

X-ray

An x-ray uses low-dose radiation to take one picture at a time of the inside of the body. A chest x-ray is used to check for infection in your lungs.

Performance status

Performance status (PS) is a person's general level of fitness and ability to perform daily tasks. Your state of general health will be rated using a PS scale called the ECOG (Eastern Cooperative Oncology Group) or the Karnofsky Performance Scale (KPS).

ECOG PS

The ECOG PS scores range from 0 to 4.

- PS 0 means you are fully active.
- PS 1 means you are still able to perform light to moderate activity.
- PS 2 means you can still care for yourself but are not active.
- PS 3 means you are limited to a chair or bed more than half of the time.
- PS 4 means you need someone to care for you and are limited to a chair or bed.

PS might be referred to as good or poor. Good PS is usually PS 0 or PS 1.

Karnofsky PS

The KPS score ranges from 0 to 100.

- 10 to 40 means you cannot care for yourself.
- 50 to 70 means you cannot work and need some help to take care of yourself.
- 80 to 100 means you can carry out daily tasks.

Performance status

Performance status (PS) is a person's ability to perform daily tasks.



Key points

- Accurate testing is needed to diagnose and treat GVHD.
- Blood tests check for signs of disease and how well organs are working.
- Skin conditions such as rashes, lesions, and dry or peeling skin are common in GVHD.
- A biopsy is the removal of a sample of tissue or group of cells for testing. It may be an important part of diagnosing GVHD.
- Depending on your symptoms, a biopsy of the skin, liver, gastrointestinal (GI) tract, or other organs is possible.
- Imaging tests take pictures of the inside of your body.
- Performance status (PS) is a person's general level of fitness and ability to perform daily tasks.
- Online patient portals are a great way to access your test results.

Need help paying
for medicine or
treatment?

Ask your care team
what options are
available.

3

Treatment

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This chapter presents an overview of the different types of treatment for GVHD and what to expect. Please note, not everyone will receive the same treatment. Together, you and your doctor will choose a treatment plan that is best for you.

Treatment team

Treatment decisions should involve a multidisciplinary team (MDT). An MDT is a team of doctors, health care workers, and social care professionals from different professional backgrounds who have knowledge (expertise) and experience with GVHD. This team is united in the planning and implementing of your treatment. Ask who will coordinate your care.

Get to know your care team and help them get to know you.

Your team might include the following specialists:

- **A hematologist** is an expert in blood diseases and cancers.
- **A dermatologist** specializes in the diagnosis and treatment of skin diseases.
- **A pathologist** analyzes the cells, tissues, and organs removed during a biopsy and provides information about biomarker and genetic testing.
- **A diagnostic radiologist** reads the results of x-rays and other imaging tests.
- **An interventional radiologist** performs needle biopsies and places ports for treatment.
- **A medical oncologist** treats cancer in adults using systemic therapy.
- **A radiation oncologist** prescribes and plans radiation therapy to treat cancer.
- **An anesthesiologist** gives anesthesia, a medicine so you do not feel pain during procedures.
- **Oncology nurses** provide your hands-on care, like giving systemic therapy, managing your care, answering questions, and helping you cope with side effects. Sometimes, these experts are called nurse navigators.
- **Palliative care nurses and advanced practice providers** help provide an extra layer of support with your cancer-related symptoms.
- **Residents and fellows** are doctors who are continuing their training, some to become specialists in a certain field of medicine.
- **Nutritionists and dietitians** can provide guidance on what foods are most suitable for your condition.
- **Psychologists and psychiatrists** are mental health experts who can help manage issues such as depression, anxiety, or other mental health conditions that can affect how you feel.
- **Social workers** help people solve and cope with problems in their everyday lives.
- **Research team** helps to collect research data if you are in a clinical trial.

Your physical, mental, and emotional well-being play an important role in your recovery from GVHD. You know your body better than anyone. Help other team members understand:

- How you feel
- What you need
- What is working and what is not

Keep a list of names and contact information for each member of your team. This will make it easier for you and anyone involved in your care to know whom to contact with questions or concerns.

Get to know your
care team and help
them get to
know you.

Skin-directed therapy

Types of therapy focused on the skin include topical therapy and phototherapy.

Topical therapy

Topical treatments are put on the surface of the skin. They might be a lotion, cream, gel, or ointment.

Topical steroids used to treat GVHD include:

- Clobetasol propionate
- Hydrocortisone
- Triamcinolone acetonide (Triderm™)

Tacrolimus (Protopic®) is an ointment form of the immunosuppressant drug tacrolimus.

Phototherapy

Phototherapy uses ultraviolet (UV) light wavelengths to treat skin lesions in GVHD. Photochemotherapy ultraviolet light A (or PUVA) combines psoralen (P) with UVA. Psoralen is a type of medicine taken by mouth (orally) that causes your skin to be sensitive to light. After taking psoralen, the skin is exposed to long-wave UV light. PUVA might be given to treat severe skin-only GVHD.

UV can increase your risk of some skin cancers. Phototherapy may not be favored in those with a history of squamoproliferative skin neoplasms, basal cell carcinomas, or who have had melanoma.

For more information, see *NCCN Guidelines for Patients: Basal Cell Skin Cancer* or *NCCN Guidelines for Patients: Melanoma*, available at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines).

Systemic therapy

Systemic therapy is treatment that affects the whole body. It is usually given by mouth (oral) or through a needle inserted into a vein (intravenously or IV).

Types of systemic therapy used to treat GVHD include:

- Antibiotics
- Antihistamines
- Biologics
- Chemotherapy
- Immunosuppressants
- Steroids
- Targeted therapy

A biosimilar might be used in place of some drugs. A biosimilar is a drug that is very much like one that has been approved by the U.S. Food and Drug Administration (FDA). It must be used in the exact same way and at the same dose as the other drug.

Ask your doctor about the goal of systemic therapy and why one therapy might be chosen over another. The reason might be related to your symptoms, cost, toxicity, or availability. Your wishes are also important.

Systemic therapies can fall into more than one category. The types described on the following pages provide a general overview. Not all possible drugs are listed.

Antibiotics

Opportunistic infections (OIs) are infections that occur more frequently and are more severe in those with a weakened immune system. A stem cell transplant (SCT) weakens the body's natural defense against infections. If not treated early, infections can be fatal. Infections can be caused by viruses, fungus, or bacteria. Antibiotics can treat bacterial infections. Antifungal medicines can treat fungal infections. You may be given antiviral drugs to prevent viral infections.

Azithromycin (Zithromax[®]) is an antibiotic that might be used to treat lung issues in chronic GVHD.

Antihistamines

Antihistamines are a type of drug that blocks the action of histamines, which can cause fever, itching, sneezing, a runny nose, and watery eyes. Antihistamines can control itchy skin, watery eyes, and other symptoms of GVHD.

AAT

Alpha-1 antitrypsin (AAT) is a protein that protects the lungs and liver from damage. It may be used for GVHD.

Biologics

A biologic is made from a living organism or its products. Etanercept (Enbrel[®]) and infliximab (Remicade[®]) are biologics that stop or slow inflammation. Other examples of biologics used for GVHD include ATG, basiliximab (Simulect), tocilizumab (Actemra[®]), and rituximab (Rituxan[®]).

Chemotherapy

Chemotherapy kills fast-growing cells throughout the body, including cancer cells and normal cells. Methotrexate stops the cells from dividing and making new cells. Methotrexate is used to prevent GVHD following bone marrow or SCT. Since this medicine may cause mouth sores, good oral care is very important. Melphalan (Alkeran®) is an example of a chemotherapy. Cyclophosphamide (Cytosan®) is a chemotherapy that may be used for GVHD prevention.

Steroids may cause dizziness, headache, trouble sleeping, depression, or mood swings, among many other effects. Speak to your doctor about potential side effects.

Immunosuppressants

Immunosuppressive therapy (IST) uses materials made either by the body or in a laboratory to improve, target, or restore immune system function. IST is a type of drug therapy that lowers the body's immune response to prevent the donor immune cells from attacking your healthy tissues. Immunosuppressants can be topical or systemic.

Some ISTs used to treat GVHD include:

- Calcineurin inhibitors (such as cyclosporine and tacrolimus)
- Cyclosporine (Neoral®)
- Hydroxychloroquine (Plaquenil)
- Mycophenolate mofetil (CellCept®)
- Sirolimus (Rapamune®)
- Steroids

Calcineurin inhibitors

A calcineurin inhibitor (CNI) is used for prevention and treatment of GVHD. Types include cyclosporine, tacrolimus ointment (Protopic®), tacrolimus (Prograf®), and pimecrolimus (topical only). They can be used as a pill, intravenously (IV), or as an ointment.

Steroids

Corticosteroids or steroids are lab-made immunosuppressants used to reduce inflammation in many conditions. In GVHD, they are used to stop activated donor immune cells from harming your body. Steroids can be placed on the skin as an ointment or gel, inhaled through the mouth, used as a mouth (oral) rinse, taken as a pill, or given as an infusion through an IV needle. They each work differently to treat side effects of GVHD.

Steroids can cause short-term and long-term side effects. Ask your care team about possible side effects.

Usually, steroids are used as a first-line treatment for both acute and chronic GVHD.

Steroids taken by mouth as a pill or liquid:

- Prednisone
- Methylprednisolone (Solu-Medrol®)
- Beclomethasone dipropionate
- Budesonide (Entocort® EC, Ortikos, Uceris)

Steroids given via IV needle:

- Methylprednisolone (Solu-Medrol®)

Steroids inhaled through the mouth:

- Budesonide (Pulmicort Flexhaler™, Pulmicort Respules®)
- Fluticasone (Flovent HFA, Flovent Diskus) for lung involvement

Steroid creams:

- Hydrocortisone cream or ointment (1% or 2.5%)
- Triamcinolone cream or ointment

Steroids given as an oral rinse (swish and spit):

- Dexamethasone

Prednisone

Prednisone helps treat and prevent GVHD by weakening your new, transplanted immune system. This gives the new immune system more time to get used to and tolerate your body. The goal is for your new immune system to accept your body, not attack it. You might be on prednisone for a long period of time, depending on the severity of the GVHD. Long-term use can cause side effects.

Extracorporeal photopheresis

Extracorporeal photopheresis (ECP) is a type of immunotherapy used to treat GVHD. In this procedure, your blood is circulated outside the body through a filter. This filter separates the white blood cells from the rest of your blood. The white blood cells are combined with a light-sensitive agent (8-methoxypsoralen) and exposed to ultraviolet A (UVA) light to activate the medicine, which kills the immune cells. Then, the treated cells are reinfused back into your body.

Targeted therapy

Targeted therapy works throughout the body. It is drug therapy that focuses on specific or unique features of cells. Ibrutinib (Imbruvica™), ruxolitinib (Jakafi®), and belumosudil (Rezurock™) are targeted therapies. Jakafi is used in both acute and chronic GVHD that did not have good response to steroids. Imbruvica and rezurock are used in both acute and chronic GVHD.

Clinical trials

A clinical trial is a type of medical research study. After being developed and tested in a laboratory, potential new ways of fighting cancer need to be studied in people. If found to be safe and effective in a clinical trial, a drug, device, or treatment approach may be approved by the U.S. Food and Drug Administration (FDA).

New treatments of GVHD are being studied in clinical trials. Talk to your doctor about whether a clinical trial may make sense for you.

Phases

Most cancer clinical trials focus on treatment. Treatment trials are done in phases.

- **Phase I trials** study the dose, safety, and side effects of an investigational drug or treatment approach. They also look for early signs that the drug or approach is helpful.
- **Phase II trials** study how well the drug or approach works against a specific type of cancer.
- **Phase III trials** test the drug or approach against a standard treatment. If the results are good, it may be approved by the FDA.
- **Phase IV trials** study the long-term safety and benefit of an FDA-approved treatment.

Who can enroll?

Every clinical trial has rules for joining, called eligibility criteria. The rules may be about age, transplant type, GVHD treatment history, or general health. These requirements ensure that participants are alike in specific ways and that the trial is as safe as possible for the participants.

Informed consent

Clinical trials are managed by a group of experts called a research team. The research team will review the study with you in detail, including its purpose and the risks and benefits of joining. All of this information is also provided in an informed consent form. Read the form carefully and ask questions before signing it. Take time to discuss with family, friends, or others whom you trust. Keep in mind that you can leave and seek treatment outside of the clinical trial at any time.

Start the conversation

Don't wait for your doctor to bring up clinical trials. Start the conversation and learn about all of your treatment options. If you find a study that you may be eligible for, ask your treatment team if you meet the requirements. If you have already started standard treatment you may not be eligible for certain clinical trials. Try not to be discouraged if you cannot join. New clinical trials are always becoming available.

Frequently asked questions

There are many myths and misconceptions surrounding clinical trials. The possible benefits and risks are not well understood by many with cancer.

Will I get a placebo?

Placebos (inactive versions of real medicines) are almost never used alone in GVHD clinical trials. It is common to receive either a placebo with a standard treatment, or a new drug with a standard treatment. You will be informed, verbally and in writing, if a placebo is part of a clinical trial before you enroll.

Are clinical trials free?

There is no fee to enroll in a clinical trial. The study sponsor pays for research-related costs, including the study drug. You may, however, have costs that are indirectly related to the trial, such as the cost of transportation or child care due to extra appointments. During the trial, you will continue to receive standard cancer care. This care is billed to—and often covered by—insurance. You are responsible for copays and any costs for this care that are not covered by your insurance.



Finding a clinical trial

In the United States

NCCN Cancer Centers

[NCCN.org/cancercenters](https://www.nccn.org/cancercenters)

The National Cancer Institute (NCI)

[cancer.gov/about-cancer/treatment/clinical-trials/search](https://www.cancer.gov/about-cancer/treatment/clinical-trials/search)

Worldwide

The U.S. National Library of Medicine (NLM)

clinicaltrials.gov

Need help finding a clinical trial? NCI's Cancer Information Service (CIS)

1.800.4.CANCER (1.800.422.6237)

[cancer.gov/contact](https://www.cancer.gov/contact)

General supportive care

Before your stem cell transplant (SCT), you likely had many rounds of systemic therapy and possibly radiation therapy to treat your cancer. This weakened your body. An SCT further weakens your body. You may also have other serious health issues like high blood pressure or diabetes that may complicate recovery.

It is critically important to take care of yourself by eating well, drinking plenty of fluids, exercising, and doing things that make you feel energized. Strength is needed to sustain you while being treated for GVHD.

Supportive care is health care that relieves symptoms caused by GVHD and improves quality of life. It might include pain relief (palliative care), emotional or spiritual support, financial aid, or family counseling. Tell your care team how you are feeling and about any side effects.

Diarrhea

Diarrhea is frequent and watery bowel movements. Your care team will tell you how to manage diarrhea and may recommend medicines to stop the diarrhea. It is important to drink lots of fluids. Changes to your diet might help.

Distress

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect how you feel, think, and act. Distress might include feelings of sadness, fear, helplessness, worry, anger, and guilt.

Depression, anxiety, and sleeping problems are common in those with GVHD. Talk to your doctor and with those whom you feel most comfortable about how you are feeling. There are services and people who can help you. Support and counseling services are available.

For more information, see *NCCN Guidelines for Patients: Distress During Cancer Care*, available at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines).

Disability and GVHD

A disability is a condition that interferes with or limits your ability to do daily tasks like bathe, cook, think, work, or enjoy time with others. It might affect your quality of life. Many people with GVHD have some type of disability. There are resources and support available for those with short-term and long-term disability as a result of GVHD.

Your physical, mental, and emotional well-being play an important role in your recovery from GVHD. You may want to speak with a nurse navigator, social worker, or someone at your local library for more information on state or federal disability benefits and how to access the forms.

Social Security Administration

[ssa.gov/applyfordisability](https://www.ssa.gov/applyfordisability)

Fatigue

Fatigue is extreme tiredness and the inability to function due to lack of energy. Fatigue may be a sign of GVHD. There are treatments for fatigue. Let your care team know how you are feeling and if fatigue is getting in the way of doing the things you enjoy. Eating a balanced diet, exercise, yoga, and massage therapy can help. You might be referred to a nutritionist or dietitian to help with fatigue.

Nausea and vomiting

Nausea and vomiting might be a sign of GVHD. You will be given medicine to treat nausea and vomiting.

Trouble eating

Sometimes side effects from GVHD might cause you to feel not hungry or sick to your stomach (nauseated). You might have a sore mouth. Healthy eating is important during treatment. It includes eating a balanced diet, eating the right amount of food, and drinking enough fluids. A registered dietitian who is an expert in nutrition and food can help. Speak to your care team if you have trouble eating or maintaining your weight.

Pain

Pain is common in GVHD. It might be caused by nausea and vomiting or abdominal cramps from diarrhea. Other sources of pain can be the eyes, joints and muscles (musculoskeletal), or mouth. Tell your care team about any pain or discomfort you have. You might meet with a palliative care specialist or pain specialist to manage your pain.

Keep a pain diary

A pain diary is a written record that helps you keep track of when you have pain, how bad it is, what causes it, and what makes it better or worse. Use a pain diary to discuss your pain with your care team. You might be referred to a specialist for pain management.

Include in your pain diary:

- The time and dose of all medicines
- When pain starts and ends or lessens
- Where you feel pain
- Describe your pain. Is it throbbing, sharp, tingling, shooting, or burning? Is it constant, or does it come and go?
- Does the pain change at different times of day? When?
- Does the pain get worse before or after meals? Does certain food or drink make it better?
- Does the pain get better or worse with activity? What kind of activity?
- Does the pain keep you from falling asleep at night? Does pain wake you up in the night?
- Rate your pain from 0 (no pain) to 10 (worst pain you have ever felt)
- Does pain get in the way of you doing the things you enjoy?

Key points

- Treatment decisions should involve a multidisciplinary team (MDT) of doctors, other health care workers, and social care professionals from different professional backgrounds who have knowledge (expertise) and experience with GVHD.
- Usually, steroids are used as first-line therapy in GVHD.
- Skin-directed therapy focuses on the skin. It includes topical therapy and phototherapy.
- Systemic therapy is a treatment that affects the whole body. It is usually given by mouth or through a needle inserted into a vein (intravenously or IV).
- Chemotherapy kills fast-growing cells throughout the body, including cancer cells and normal cells.
- Immunosuppressants are drugs or biologic products used to prevent or stop the donor's immune system from harming your body.
- A clinical trial is a type of medical research study that tests new treatments.
- Supportive care is health care that relieves symptoms caused by GVHD and improves quality of life. Best supportive care, supportive care, and palliative care are often used interchangeably.

It is very important to take medicine on time and exactly as prescribed. Don't miss or skip a dose!

4

Acute GVHD

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Acute graft-versus-host disease (aGVHD) is a complication from a donor stem cell transplant. It typically develops soon after a transplant. Treatment aims to suppress the immune response and manage symptoms.

Diagnosis

In acute GVHD (aGVHD), the donor cells attack areas of your body such as the skin, liver, and gastrointestinal (GI) tract. You might have a skin rash, diarrhea, nausea, vomiting, and liver function issues. Tests will be done to rule out non-GVHD causes. Biopsies of the skin, GI tract, liver, or other organs might be done to confirm GVHD.

Stage

After diagnosis, your GVHD will be given a stage. A stage is used to identify the extent of the disease at the time of diagnosis. The stage will be used to make treatment decisions.

In acute GVHD, each organ is staged individually. The skin is given a stage based on the amount of body surface area (BSA) involved. The GI tract is given a stage based on the amount of diarrhea or number of bowel movements per day. And, the liver is given an individual organ stage based on the rise in your bilirubin level.

Erythroderma

Erythroderma is severe inflammation of most of the body's skin surface. It can look like sunburn or large splotches.

Credit: <https://commons.wikimedia.org/wiki/File:Sezery2.jpg>



Stage 1

In stage 1 aGVHD, you have one of the following:

- Rash on less than 25% (or one quarter) of your skin
- Bilirubin levels between 2 and 3 mg/dL
- Persistent nausea or greater than 500 mL of diarrhea

Treatment

Treatments for stage 1 aGVHD include continuing or restarting an immunosuppressive agent with topical steroids, or observation. Observation may be used if no symptoms are found or your rash is stable (unchanged).

Response

If symptoms (including rash) improve with treatment, you will be tapered off the immunosuppressive agent.

No response

If symptoms do not improve with treatment, your doctor may refer you to a clinical trial or continue topical steroids.

Progression

If there is no response or your symptoms worsen, you may develop higher stages of GVHD or require more intensive treatments.

Stages 2, 3, and 4

In stage 2, you have one or more of the following:

- Rash on up to half of your skin
- Bilirubin levels between 3 and 6 mg/dL
- Diarrhea greater than 1000 mL/day

In stage 3, you have one or more of the following:

- Rash on over half of your skin
- Bilirubin levels between 6 and 15 mg/dL
- Diarrhea greater than 1500 mL/day

In stage 4, you have one or more of the following:

- Erythroderma with blisters
- Bilirubin levels greater than 15 mg/dL
- Severe abdominal pain

Treatment

Treatment for aGVHD stage 2 through 4 may include the following:

- Continue or restart original immunosuppressive agent
- Clinical trial
- Systemic steroids with or without topical steroids
- Sirolimus (a drug used to prevent organ transplant rejection)

Depending on your symptoms, you may be given steroid pills or creams to use at home,

or you may be admitted to the hospital for intravenous (IV) treatments.

Response

If symptoms improve, then you will be tapered off steroids. Since long-term steroid use causes health issues and risk for infection, you will be tapered off steroids when possible. Some people may remain on low-dose steroids.

No response

If symptoms do not improve, your doctor might:

- Refer you for a clinical trial
- Add another systemic agent to corticosteroids

If aGVHD does not respond to treatment, then you will be treated for steroid-refractory disease.

Steroid-refractory disease

Steroid-refractory disease happens in about 1 out of every 2 people with acute GVHD. Steroid-refractory acute GVHD (SR-aGVHD) is very serious and can be life-threatening. Participation in a clinical trial is encouraged, if available.

In steroid-refractory disease, GVHD stops responding to or worsens on steroid treatment. SR-aGVHD is treated with a steroid and additional systemic therapy that may be given as a pill or IV. Often, your original immunosuppressant will be combined with systemic therapy found in [Guide 1](#).

Guide 1 SR-aGVHD systemic therapy

Ruxolitinib

Alemtuzumab

Alpha-1 antitrypsin (AAT)

Anti-thymocyte globulin (ATG)

Basiliximab

Calcineurin inhibitors

Etanercept

Extracorporeal photopheresis (ECP)
(PUVA may be an option in some cases)

Infliximab

mTOR inhibitors

Mycophenolate mofetil

Pentostatin

Tocilizumab

Key points

- Acute graft-versus-host disease (aGVHD) is a complication from a donor stem cell transplant. It typically develops soon after a transplant.
- In aGVHD, the donor cells attack areas of your body such as the skin, liver, and gastrointestinal (GI) tract. You might have a skin rash, diarrhea, nausea, vomiting, and liver function issues.
- In aGVHD, each organ is staged individually.
- Treatment options for stage 1 aGVHD may include an immunosuppressive agent and/or topical steroids or observation.
- Treatment options for aGVHD stages 2 through 4 may include immunosuppressive agents, a clinical trial, systemic steroids with or without topical steroids, or sirolimus.
- In steroid-refractory disease, GVHD stops responding to or worsens on steroid treatment. Steroid-refractory acute GVHD (SR-aGVHD) is treated with a steroid and additional systemic therapy.
- Depending on the severity (how bad) of your symptoms, you may be treated at home with pills and topical creams, or you may need to be admitted to the hospital for IV treatments.



We want your feedback!

Our goal is to provide helpful and easy-to-understand information on cancer.

Take our survey to let us know what we got right and what we could do better:

[NCCN.org/patients/feedback](https://www.nccn.org/patients/feedback)

5

Chronic GVHD

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Chronic graft-versus-host disease (cGVHD) is a complication from a donor stem cell transplant. It typically develops within 1 year of the transplant. Treatment aims to control symptoms, avoid organ damage, and improve quality of life.

Diagnosis

Before starting treatment, a diagnosis of chronic GVHD will be confirmed and a disease grade will be given. While a biopsy may be done to confirm chronic GVHD, a biopsy is not always possible or necessary.

Areas of the body that might be affected by cGVHD:

- Skin
- Nails
- Scalp and body hair
- Mouth
- Eyes
- Genitals
- Gastrointestinal (GI) tract
- Liver
- Lung
- Muscles, fascia, and joints
- Blood, immune system, and other sites

Grade

A grade is a rating or score given to specific signs or symptoms of GVHD. Grading is based on your performance status (PS) and the area(s) of the body affected. A score of zero (0) means there are no symptoms or signs. Severe symptoms or signs are given the highest score of 3.

Oral health care

Chronic GVHD can cause problems in your mouth. Symptoms often include sensitivity and pain, dry mouth, changes in taste, and difficulty opening your mouth. Seek care by a dental professional if symptoms persist or worsen.

There are steps you can take to prevent symptoms, including:

- Dental check-ups every 6 months.
- Brush your teeth, gums, and tongue after meals and before bed.
- Use a toothpaste with fluoride and an alcohol-free mouthwash.
- Floss your teeth gently every day.
- Use mouth rinses (baking soda and salt in warm water, followed by plain water rinse).
- Clean, brush, and rinse dentures after meals.
- Make sure dentures fit well.

Treatment

Treatment for chronic GVHD aims to control symptoms, avoid organ damage, and improve quality of life. Since long-term steroid use causes health issues and risk for infection, you will be tapered off steroids when possible. Some people may remain on low-dose steroids.

Treatment is based on symptoms. Options may include one or more of the following:

- Clinical trial
- Continue or restart original immunosuppressive therapy
- Systemic corticosteroids (methylprednisolone or prednisone)
- Topical steroids as needed (such as triamcinolone or clobetasol), topical estrogen for vulvovaginal GVHD, topical tacrolimus, or dexamethasone mouth rinse for oral GVHD
- Inhaled steroid (examples include budesonide or fluticasone)
- Azithromycin for lung involvement (those with progression or worsening of lung cGVHD following 2 to 3 lines of therapy may be evaluated for lung transplant)

If cGVHD does not respond to treatment, then you will be treated for steroid-refractory disease.

Those with steroid-refractory GVHD are encouraged to participate in a clinical trial, if available.

Steroid-refractory disease

Steroid-refractory disease happens in about 1 out of every 2 people with chronic GVHD. Steroid-refractory chronic GVHD (SR-cGVHD) is very serious and can be life-threatening. Participation in a clinical trial is encouraged, if available.

In SR-cGVHD, GVHD stops responding to or worsens on steroid treatment. To get your disease under control, another systemic therapy is added to the steroid treatment. Often, your original immunosuppressant is combined with a systemic therapy found in [Guide 2](#).

Guide 2 SR-cGVHD systemic therapy

Ruxolitinib

Abatacept

Alemtuzumab

Belumosudil

Calcineurin inhibitors

Etanercept

Extracorporeal photopheresis (ECP)
(PUVA may be an option in some cases)

Hydroxychloroquine

Ibrutinib

Imatinib

Interleukin-2 (IL-2)

Low-dose methotrexate

mTOR inhibitors

Mycophenolate mofetil

Pentostatin

Rituximab or its biosimilar

Key points

- Before starting treatment, a diagnosis of chronic GVHD will be confirmed and a disease grade will be given.
- When possible, a biopsy will be done to confirm GVHD.
- Grading is a rating or score given to any signs of symptoms of GVHD.
- Treatment for chronic GVHD aims to control symptoms, avoid organ damage, and improve quality of life.
- In steroid-refractory chronic GVHD (SR-cGVHD), GVHD stops responding to or worsens on steroid treatment. More systemic therapy will be added to your treatment.
- Participation in a clinical trial is encouraged in anyone with cGVHD.



Let us know what you think!

Please take a moment to complete an online survey about the NCCN Guidelines for Patients.

[NCCN.org/patients/response](https://www.nccn.org/patients/response)

6

Making treatment decisions

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It's important to be comfortable with the cancer treatment you choose. This choice starts with having an open and honest conversation with your doctor.

It's your choice

In shared decision-making, you and your doctors share information, discuss the options, and agree on a treatment plan. It starts with an open and honest conversation between you and your doctor.

Treatment decisions are very personal. What is important to you may not be important to someone else.

Some things that may play a role in your decision-making:

- What you want and how that might differ from what others want
- Your religious and spiritual beliefs
- Your feelings about certain treatments like surgery or chemotherapy
- Your feelings about pain or side effects such as nausea and vomiting
- Cost of treatment, travel to treatment centers, and time away from school or work
- Quality of life and length of life
- How active you are and the activities that are important to you

Think about what you want from treatment. Discuss openly the risks and benefits of specific treatments and procedures. Weigh options and share concerns with your doctor. If you take the time to build a relationship with

your doctor, it will help you feel supported when considering options and making treatment decisions.

Second opinion

It is normal to want to start treatment as soon as possible. While cancer can't be ignored, there is time to have another doctor review your test results and suggest a treatment plan. This is called getting a second opinion, and it's a normal part of cancer care. Even doctors get second opinions!

Things you can do to prepare:

- Check with your insurance company about its rules on second opinions. There may be out-of-pocket costs to see doctors who are not part of your insurance plan.
- Make plans to have copies of all your records sent to the doctor you will see for your second opinion.

Support groups

Many people diagnosed with cancer find support groups to be helpful. Support groups often include people at different stages of treatment. Some people may be newly diagnosed, while others may be finished with treatment. If your hospital or community doesn't have support groups for people with cancer, check out the websites listed in this book.

Questions to ask your doctors

Possible questions to ask your doctors are listed on the following pages. Feel free to use these questions or come up with your own. Be clear about your goals for treatment and find out what to expect from treatment.

Questions to ask about treatment options

1. What are my treatment options?
2. Will my age, health, and other factors affect my options?
3. Am I a candidate for a clinical trial?
4. Is there a better treatment option based on my type, age, and other risk factors?
5. Is there an option that is least time-consuming? Less expensive?
6. How will we know if treatment is working?
7. What are my options if my treatment stops working?
8. What should I expect from this treatment?
9. Can I stop treatment at any time?
10. What will happen if I stop treatment?
11. What support services are available to me?
12. How often will I need follow-up visits after I finish treatment?

Questions to ask about side effects

1. What are the side effects of systemic therapy? Topical therapy? Steroids?
2. What are the side effects of GVHD?
3. How long will these side effects last? Do any side effects lessen or worsen in severity over time?
4. What side effects should I watch for? What side effects are expected and which are life threatening?
5. When should I call my doctor? Can I text? What should I do if I need to contact my doctor on weekends and other non-office hours?
6. What emergency department or ER should I go to? Will my treatment team be able to communicate with the ER team?
7. What medicines can I take to prevent or relieve side effects?
8. What can I do to help with pain and other side effects?
9. Will you stop treatment or change treatment if there are side effects? What do you look for?
10. What can I do to lessen or prevent side effects? What will you do?
11. What medicines may worsen side effects of treatment?

Questions to ask about skin

1. Is GVHD contagious? Will it spread to people who touch me?
2. Should I avoid sharing clothes or towels? How often should I change or wash towels?
3. Can I use lotions or oils on my skin or hair other than what you recommend? What are the best types of soap or shampoo to use? Hair dye? Makeup?
4. Is it better to wear long sleeves, pants, or clothing that covers the rash/lesions in some way? Or should I let the rash/lesions be exposed to the air as much as possible?
5. Should I take time to inspect my skin? If so, how often?
6. If I notice any changes in my skin whom should I call? When?
7. Will keeping a diary and photo journal help? What should I include in my diary? How often should I take photos?
8. Can I go out in the sun? Should I wear sunscreen? Long sleeves? Hat?
9. Are there any changes that I can make to my diet? Exercise?
10. What about stress? Will stress worsen my condition?

Questions to ask your doctors about their experience

1. Who will be part of my health care team, and what does each member do?
2. Who will be leading my overall treatment?
3. What is your experience in treating people with GVHD?
4. Who else will be on my treatment team?
5. What other diagnostic tests or procedures will I need?
6. I would like to get a second opinion. Is there someone you recommend?
7. How many patients like me (of the same age, gender, race) have you treated?
8. Will you be consulting with experts to discuss my care? Whom will you consult?
9. How many procedures like the one you're suggesting have you done?
10. Is this treatment a major part of your practice?
11. How many of your patients have had complications? What were the complications?
12. Who will manage my day-to-day care?

Resources

American Cancer Society (ACS)

<https://www.cancer.org/treatment/treatments-and-side-effects/treatment-types/stem-cell-transplant/transplant-side-effects.html>

Be the Match

<https://bethematch.org/patients-and-families/life-after-transplant/physical-health-and-recovery/graft-versus-host-disease-basics>

Blood & Marrow Transplant Information Network (BMT InfoNet)

bmtinfonet.org/transplant-article/graft-versus-host-disease-gvhd

CancerCare

cancercares.org

Cancer Support Community

cancersupportcommunity.org/living-cancer

Chemocare

chemocare.com

Leukemia and Lymphoma Society (LLS)

lls.org/treatment/types-treatment/stem-cell-transplantation/graft-versus-host-disease

MedlinePlus

medlineplus.gov/ency/article/001309.htm

National Bone Marrow Transplant Link

nbmtlink.org

National Coalition for Cancer Survivorship

Canceradvocacy.org/toolbox

National Financial Resource Directory - Patient Advocate Foundation

patientadvocate.org/explore-our-resources/national-financial-resource-directory/

NCCN Reimbursement Virtual Resource

NCCN.org/reimbursement

OncoLink

oncolink.org

Patient Access Network Foundation

panfoundation.org

RareDiseases.org (NORD)

rarediseases.org/rare-diseases/graft-versus-host-disease

Smart Patients

smartpatients.com/communities/gvhd

Testing.com

testing.com



Words to know

allogeneic stem cell transplant (alloSCT)

A cancer treatment that replaces abnormal blood stem cells with healthy donor cells.

baseline

A starting point to which future test results are compared.

best supportive care

Treatment given to prevent, control, or relieve side effects and improve comfort and quality of life.

biopsy

Removal of small amounts of tissue from your body to test for disease.

blood stem cell

A blood-forming cell from which all other types of blood cells are formed. Also called hematopoietic stem cell.

body surface area (BSA)

The total surface area of the human body calculated using weight and height. Different than body mass index (BMI).

bone marrow

The sponge-like tissue in the center of most bones.

chemotherapy

Drugs that kill fast-growing cells, including normal cells and cancer cells.

clinical trial

A study of how safe and helpful tests and treatments are for people.

combination regimen

The use of two or more drugs.

complete blood count (CBC)

A lab test that includes the number of blood cells.

computed tomography (CT) scan

A test that uses x-rays from many angles to make a picture of the inside of the body.

contrast

A substance put into your body to make clearer pictures during tests that take pictures of the inside of the body.

dermatologist

A doctor who specializes in the diagnosis and treatment of skin diseases.

erythema

Reddening of the skin, usually in patches.

erythroderma

A severe inflammation of most of the body's skin surface. It can look like sunburn or large splotches.

hematopoietic cell transplant (HCT)

A type of treatment that destroys cells in the bone marrow then replaces them with new, healthy blood-forming cells from another person. Also called stem cell transplant (SCT) or bone marrow transplant (BMT).

human leukocyte antigen (HLA)

A cell protein by which your body knows its own cells from foreign cells.

imaging test

A test that makes pictures (images) of the insides of the body.

immune system

The body's natural defense against infection and disease.

milliliter (mL)

A metric unit of volume equal to one thousandth of a liter.

palliative care

Specialized medical care aimed at increasing quality of life and reducing pain and discomfort for people with serious, complex illness.

papule

A small, solid, raised bump on the skin that might look like small pimples. Papules may be red, purple, brown, or pink.

patch

A flat, thin, pink or red skin lesion of any size.

pathologist

A doctor who is an expert in testing cells and tissue to find disease.

peripheral blood

Blood that circulates throughout the body.

phototherapy

Uses different ultraviolet (UV) light wavelengths to treat skin lesions or tumors.

plaque

A raised (elevated) or hardened (indurated) skin lesion of any size.

platelet (PLT)

A type of blood cell that helps control bleeding. Also called thrombocyte.

pruritus

Itchy feeling that makes you want to scratch your skin.

radiation oncologist

A doctor who's an expert in treating cancer with radiation.

radiation therapy (RT)

A treatment that uses high-energy rays or related approaches to kill cancer cells.

radiologist

A doctor who is an expert in imaging tests.

red blood cell (RBC)

A type of blood cell that carries oxygen from the lungs to the rest of the body. Also called an erythrocyte.

scale

When the outer layer of skin peels away in large pieces.

side effect

An unhealthy or unpleasant physical or emotional response to treatment.

skin-directed therapy

Treatment focused on the skin. Includes topical therapy, local radiation, and phototherapy.

stem cell transplant

A type of treatment that replaces abnormal blood stem cells with healthy cells. Also called hematopoietic cell transplant (HCT) or bone marrow transplant (BMT).

steroid-refractory disease

GVHD stops responding to or worsens on steroid treatment.

supportive care

Health care that includes symptom relief but not cancer treatment. Also called palliative care or best supportive care.

systemic therapy

Treatment that works throughout the body.

targeted therapy

A drug treatment that targets and attacks specific cancer cells.

ulcerated

A break in the skin.

white blood cell (WBC)

A type of blood cell that helps fight infections in the body. Also called a leukocyte.

NCCN Contributors

This patient guide is based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Hematopoietic Cell Transplantation (HCT): Pre-Transplant Recipient Evaluation and Management of Graft-Versus-Host Disease, Version 5.2021. It was adapted, reviewed, and published with help from the following people:

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