Graft-versus-Host Disease

What to Know, What to Do

30 YEARS EMPOWERING PATIENTS

BMTinfonet.org

BLOOD & MARROW TRANSPLANT INFORMATION NETWORK

Graft-versus-Host Disease

What to Know, What to Do

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This booklet is a helpful guide about graft-versus-host disease (GVHD) and its management but is not a substitute for medical advice from your doctor. Consult your transplant team about appropriate GVHD treatments for you.

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Graft-versus-Host Disease

What to Know, What to Do

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Dear Friend,

Graft-versus-host disease (GVHD) is a rare disease, but common in transplant recipients. GVHD can be challenging, both physically and emotionally. Fortunately, there are many resources available to help people living with GVHD.

This booklet will help you understand how GVHD may affect your body and explain some of the treatment options.

BMT InfoNet has several other resources to help you understand and manage GVHD:

- Read current information about GVHD on our website.
  bmtinfonet.org/gvhd-basics
- Watch videos about GVHD.
  bmtinfonet.org/gvhd-videos
- Find a GVHD clinic or specialist.
  bmtinfonet.org/gvhd-directory
- Talk one-on-one with another person who's living with GVHD.
  bmtinfonet.org/caring-connection
- Join an online support group for GVHD patients or caregivers.
  bmtinfonet.org/gvhd-support-group
- Find a mental health specialist who can help you manage the challenge of living with GVHD.
  bmtinfonet.org/mh-directory

Our mission is to empower you with factual information and emotional support so that you can take a more active role in managing your health.

Contact us at **help@bmtinfonet.org** or phone 888-597-7674 and let us know how we can help you!

Warm regards,

Sue Stewart

Sue Stewart
36-year Transplant Survivor, Founder and Executive Director, BMT InfoNet

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bandell

CHAPTER 1

WHAT IS GRAFT-VERSUS-HOST DISEASE?

Graft-versus-host disease is like a roller coaster ride: some days you're up, and others you're down. You just have to be patient with yourself and the disease until it burns itself out.

Susie S.

Graft-versus-host disease (GVHD) is a common complication following a transplant using stem cells provided by a related or unrelated donor (an allogeneic transplant).

GVHD occurs when the new immune system cells from the donor (the graft) recognize the patient's organs and tissues (the host) as unfamiliar cells that should be destroyed. The donor cells that trigger this reaction are a type of white blood cell called T-cells.

Most cases of GVHD are mild or moderate and resolve over time. However, GVHD can also be more severe and, in some cases, life-threatening.

Patients who develop GVHD usually do so during the first year after transplant. However, GVHD can also occur months and, rarely, years later.

Types of GVHD

There are two types of GVHD:

- acute GVHD
- chronic GVHD

A patient may develop one, both, or neither. Each type has a different effect on organs and tissues.

Although acute and chronic GVHD usually occur during different time periods after transplant, it is possible for a patient to have both at the same time.

Watch the video **Introduction to Graft-versus-Host Disease** at **bmtinfonet.org/2024-video/Intro-GVHD.**

CHAPTER 2

ACUTE GRAFT-VERSUS-HOST DISEASE

*I've experienced all sorts of setbacks since my diagnosis. Now I am living with GVHD, **living** being the key word. No matter the setback, I never stop making plans.*

Jon S.

Acute GVHD typically occurs during the first three months after transplant although it can also occur later, such as when immunosuppressive medicines are being tapered down.

Risk factors for developing acute GVHD include:

- total body irradiation given prior to transplant
- advanced patient and donor age
- how well-matched the donor is for the patient

Preventing Acute GVHD

To reduce the risk of developing acute GVHD, patients are usually given medications starting a day or two before transplant or shortly after, such as:

- abatacept
- antithymocyte globulin

- cyclophosphamide
- cyclosporine
- methotrexate
- mycophenolate mofetil
- sirolimus
- tacrolimus

These drugs suppress the donor's immune system, which has been transplanted into you, making it more difficult for the donor's cells to attack your organs and tissues. You may need to continue taking these drugs for several months after transplant and, in some cases, for life.

Recently, doctors found that giving patients a chemotherapy drug called cyclophosphamide (Cytoxan®) a few days after transplant significantly reduces the likelihood of developing acute and chronic GVHD. This strategy is now being used at many transplant centers.

At some transplant centers, the T-cells that cause GVHD are removed from the donor's cells prior to transplant. This procedure is called T-cell depletion.

Although T-cell depletion reduces the risk of developing GVHD, it can increase the risk of relapse or infections. Researchers are exploring whether removing a subset of T-cells from the donor's cells will protect patients against GVHD without increasing the risk of relapse and infection.

T-cells are a type of white blood cell. They help protect the body from infection and fight cancer but can also cause GVHD.

Symptoms of Acute GVHD

Skin is often affected by acute GVHD. It may start as a faint rash that can be itchy. The rash may appear on the:

- back, shoulders, ears, or neck
- chest or abdomen
- legs or arms
- palms of the hands or soles of the feet

It typically resembles a heat rash, but in severe forms it may look like a sunburn with blisters. The rash usually starts on a small area of skin and often spreads to more areas.

Acute GVHD can also affect the gastrointestinal tract, causing:

- persistent nausea and/or vomiting
- loss of appetite or feeling full after eating only a little food
- abdominal pain and cramping
- watery or bloody diarrhea

Sometimes acute GVHD affects the liver causing:

- elevated liver enzyme levels
- jaundice (yellowing of skin and eyes)
- dark urine

Treatment for Acute GVHD

If you develop acute GVHD, steroids such as prednisone or methylprednisolone may help control the disease. If your GVHD does not respond to these drugs, your doctor may try other treatments such as:

- antithymocyte globulin
- extracorporeal photopheresis
- mycophenolate mofetil
- ruxolitinib
- sirolimus

Your doctor may also recommend that you enroll in a clinical trial that is testing a new therapy for GVHD. (See Chapter 5 for information about clinical trials.)

Once it appears that your acute GVHD is under control, your doctor will start tapering down the dosage of steroids or other drugs. It's possible, however, for acute GVHD to return or get worse during the tapering process. You may need to continue the medication for a longer period of time until the disease is no longer active.

Take Action!

Tell your transplant doctor immediately if you develop a skin rash or other symptoms of acute GVHD. Although these symptoms may be caused by other health problems, early detection and treatment of acute GVHD is important to prevent additional, serious complications.

CHAPTER 3

CHRONIC GRAFT-VERSUS-HOST DISEASE

One of the hardest things about chronic GVHD is that people don't understand what you are dealing with. You can look healthy and appear to have no problems whatsoever, so people give you quizzical looks when you can't do what it seems you should be able to do. It's tough at times.

Dan G.

Chronic GVHD is different than acute GVHD. It usually develops later than acute GVHD, typically five-to-six months after your transplant, and can affect more organs and tissues. Chronic GVHD occurs most often in patients who:

- previously had acute GVHD
- are older
- were transplanted with cells from an unrelated donor or a donor who was not a perfect match
- were transplanted with donor stem cells collected from the bloodstream (peripheral blood stem cells), rather than bone marrow or cord blood
- are male and received cells from a female donor
- received cells from a female donor who previously bore children

Most cases of chronic GVHD are mild or moderate. However, some patients develop symptoms that are more severe.

How Chronic GVHD is Managed

How your doctor manages your chronic GVHD depends on which organs and tissues are affected, the severity of the symptoms, and the impact GVHD is having on your daily life.

If chronic GVHD is affecting only one or two organs or tissues, your doctor may choose a localized therapy, like an ointment, mouth wash, or eye drops to provide symptom relief.

If chronic GVHD is affecting many different parts of your body, or if the symptoms are severe, your doctor may need to treat it with drugs that suppress your immune system such as:

- prednisone
- prednisone with cyclosporine or tacrolimus
- sirolimus

If your chronic GVHD does not respond well to these treatments, your doctor may try other treatments such as:

- abatacept
- axatilimab
- belumosudil
- extracorporeal photopheresis
- ibrutinib
- low dose interleukin-2
- methotrexate

Patients with chronic GVHD typically require treatment for three-to-five years. Approximately 15 percent of patients require treatment for a longer period of time. Occasionally, patients need life-long immunosuppressive drugs.

Take Charge! Monitor Yourself for GVHD Symptoms

Chronic GVHD usually develops more than 100 days after transplant when you are no longer having weekly visits with the transplant team. Therefore, it's important that you examine your body weekly for signs of GVHD.

Carefully inspect your mouth, eyes, skin, joints, and genitals for any changes. Don't ignore subtle changes. Report anything unusual to your doctor immediately.

Don't be afraid to ask questions. If you notice a change, don't assume it's nothing to worry about. Ask your care team to be sure.

Watch a video about **monitoring yourself for symptoms of GVHD** at **bmtinfonet.org/video/GVHD-symptoms.**

How Chronic GVHD Affects Skin, Nails, Hair, and Sweat Glands

Chronic GVHD most often affects the skin. Symptoms may include:

- a dry, itchy rash
- a burning sensation when exposed to sun or heat
- taut skin, a tightening or pulling sensation
- change in skin color
- thickening of the skin that may restrict joint movement
- cellulite-like appearance on skin
- thinning of the skin
- scarring
- swelling
- sores or wounds

GVHD may also cause:

- brittle or splitting fingernails and toenails
- hair loss or thinning hair on the scalp, face, and/or body
- changes in hair color or texture

- difficulty opening your mouth fully due to taut skin around the mouth
- an inability to sweat or handle heat for long periods of time due to damaged sweat glands
- difficulty breathing due to tight skin around the chest
- feeling full quickly because skin on the abdomen is taut

Topical treatments such as corticosteroids, pimecrolimus cream, or tacrolimus ointment, combined with systemic treatment, may relieve some of these symptoms.

Extracorporeal photopheresis or phototherapy with ultraviolet radiation, given under medical supervision, is sometimes used to treat certain types of skin GVHD.

Watch a video about **Extracorporeal Photopheresis** at **bmtinfonet.org/video/ECP**.

How Chronic GVHD Affects Joints, Fascia, and Muscles

Chronic GVHD sometimes affects the joints, fascia, and muscles. The fascia is the connective tissue under the skin that attaches to and stabilizes muscles and internal organs. Symptoms include:

- joint stiffness or pain
- difficulty fully extending or flexing arms, feet, wrists, or finger joints
- contractures (joints remain in a fixed, flexed position)
- tight muscles and tendons
- muscle cramps or spasms
- muscle weakness
- tightening of tissue under the skin (the fascia) which can look like cellulite

Some symptoms can be relieved by deep tissue massage or stretching exercises under the supervision of a physical therapist.

An occupational therapist can create special splints or casts to help stretch muscles, and recommend assistive devices to make it easier to perform daily activities like reaching items, dressing, and toileting.

Watch the video **Chronic Graft-versus-Host Disease of the Skin and Connective Tissue** at **bmtinfonet.org/2024-video/GVHD-skin.**

Watch the video **Rehabilitation Therapies to Manage Side Effects of GVHD** at **bmtinfonet.org/video/2022-GVHD-rehab**.

Take Action!

Inspect your skin weekly and tell your doctor right away if you have any symptoms of skin GVHD. Early detection and treatment can speed up recovery and improve long-term results.

Use fragrance-free ointments or creams daily to keep your skin moist. Ointments and creams work better than lotions.

Skin GVHD increases your risk for developing skin cancer. Report any new or changing spots on your skin to your doctor.

Protect your skin from exposure to the sun. Remember that the sun’s rays can be just as damaging on a cool, cloudy day as they are on a hot, sunny day.

When outside:

- wear a hat, long sleeves, and pants
- use a strong sunscreen (SPF30 or higher)
- avoid being in the sun between 10 AM - 3 PM, the peak UV hours
- use UV window filters

Companies like Sun Precautions® and Coolibar® offer sun protective clothing that can help shield your skin from the sun’s harmful ultraviolet rays. A laundry additive called SunGuard™ adds sun protection to your everyday clothing.

Your Mouth and Chronic GVHD

Chronic GVHD often affects the mouth and salivary glands. Symptoms may include:

- redness and lacy white patches in the mouth, and on the tongue, inner cheeks, or lips
- painful sores anywhere in the mouth or on the lips
- small, painless, fluid-filled bumps that come and go throughout the day
- sensitivity to spicy, acidic, or crunchy foods, carbonated beverages, or mint-flavored toothpaste
- a very dry mouth
- changes in how some foods taste
- difficulty eating and swallowing food
- swelling, redness, pain, or bleeding gums
- rough feeling in the mouth, like a scalded mouth

Chronic GVHD in the mouth is usually treated with:

- an oral rinse containing steroids
- a topical steroid gel or cream such as fluocinonide or clobetasol
- tacrolimus as a topical ointment for the lips
- pilocarpine or cevimeline for dry mouth
- steroid injections into mouth sores

Some over-the-counter products can help stimulate saliva such as Biotène® Dry Mouth toothpaste and mouth rinse, Mouth Kote® or Biotène® oral moisturizing spray, and Xylimelts® or Sparx®

xylitol candy.

Medications such as lidocaine or magic mouthwash may be prescribed to control pain. A dietitian can help you plan meals that avoid foods that may cause pain.

Take Action!

Tell your doctor right away if you have symptoms of chronic GVHD in your mouth.

Since a lack of saliva can lead to tooth decay, it is important to practice good brushing and flossing.

See a dentist twice a year for a thorough cleaning and check-up. Ask your dentist if you need a fluoride prescription or in-office fluoride varnish therapy to prevent cavities.

Patients with oral chronic GVHD have an increased risk of developing cancer in their mouth. You should be checked annually, preferably by a specialist who is familiar with both GVHD and oral cancer, to examine any unusual lesions.

Watch the video **Your Mouth and Chronic Graft-versus-Host Disease** at **bmtinfonet.org/2024-video/GVHD-mouth.**

Your Eyes and Chronic GVHD

Chronic GVHD can affect the surface of your eyes and/or the inside of your eyelids and can damage tear glands. Symptoms include:

- tired, gritty, itchy, or burning eyes
- difficulty keeping your eyes open
- sensitivity to bright light or wind

- intermittent blurry vision
- red and swollen eyelids
- crusting on the eyelids
- excessive tears and discharge without much discomfort

The treatment for GVHD in the eyes depends on the severity of the symptoms. Most cases can be managed with:

- preservative-free artificial tear drops or ointments
- steroid drops or ointments
- cyclosporine eye drops
- plugging tear ducts so that moisture remains in your eyes
- adding humidity to your home
- wearing goggles or glasses with gaskets to limit exposure to wind (see **7eye.com/collections/dry-eye** or **zienaeyewear.com** for examples)

If the problem is more severe and is affecting your vision, your doctor may recommend:

- eye drops made from your blood serum (autologous serum drops)
- a bandage contact lens that protects the surface of the eyes, sometimes with an amniotic membrane to promote healing
- a scleral lens, such as the PROSE system offered by BostonSight®, which can relieve symptoms and improve vision

If you have GVHD in your eyes:

- do not wear regular contact lenses
- avoid rubbing your eyes
- only use eye drops that do NOT contain a preservative
- do not dig crusted mucous from the corner of your eyes with your fingernail or a tissue. Instead, use warm, wet compresses to soften and remove it. Applying warm compresses for 5-10

minutes at night may help prevent morning crusting

- avoid using redness relievers such as Visine®, Opcon A®, Naphon A®, or Clear Eyes® which can make dry eyes worse
- do not use allergy eye drops such as Alaway® or Zaditor® because they will not treat the root problem.

Take Action!

Tell your doctor immediately about any eye discomfort or vision changes you experience. Prompt treatment may prevent severe damage to the eye.

When in the sun, be sure to wear sunglasses with UV protection to protect your eyes from further damage. Use wrap-around sunglasses for added protection.

Take frequent breaks from viewing screens on electronic devices.

Be careful when applying make-up near your eyes and avoid unnecessary eye surgeries such as cosmetic eyelid surgery and lash extensions.

Ask your transplant team to recommend an ophthalmologist who is familiar with symptoms of ocular GVHD or consult BMT InfoNet's GVHD Directory for a specialist near you at **bmtinfonet.org/gvhd-directory**.

Watch the video **Your Eyes and Chronic Graft-versus-Host Disease** at **bmtinfonet.org/video/2023-GVHD-eyes**.

Your Gastrointestinal Tract and Chronic GVHD

Chronic GVHD can affect the esophagus, stomach, and colon. Symptoms include:

- difficult or painful swallowing
- no desire to eat
- abdominal pain, bloating, cramping
- greasy stools, undigested food in stool
- weight loss
- nausea, vomiting, and diarrhea

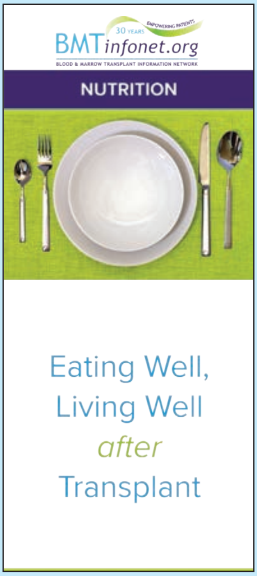
If chronic GVHD affects your gastrointestinal tract, your doctor may recommend treatment with drugs that suppress the immune system or medications that coat the gastrointestinal tract with steroids. Extracorporeal photopheresis may also help control symptoms. If there are obstructions in the esophagus, called strictures or webs, an endoscopy may be used to clear them.

Take Action!

Tell your doctor right away if you have symptoms of gastrointestinal GVHD. Other health issues can cause similar symptoms. It is important to rule these out so that you get proper treatment.

If weight loss is a problem, talk with a dietitian to develop a diet that will provide you with the calories, protein, and nutrients you need to recover.

Order the free brochure **Eating Well, Living Well after Transplant** online at **bmtinfonet.org/eat-well** or phone 888-597-7674.



Your Liver and Chronic GVHD

Chronic GVHD sometimes affects the liver. Symptoms include:

- elevated liver enzyme levels
- jaundice (yellowing of skin and eyes)
- dark urine
- nausea and vomiting
- no desire to eat

If you are diagnosed with chronic GVHD of the liver, your doctor may add ursodeoxycholic acid to the other drugs you are receiving to treat chronic GHVD.

Take Action!

Work with your doctor to rule out other possible causes of liver abnormalities such as drugs you are taking, infection, or gallbladder problems.

Watch the video **Graft-versus-Host Disease of the Gastrointestinal Tract and Liver** at **bmtinfonet.org/2024-video/GVHD-GI-liver**.

Your Lungs and Chronic GVHD

Chronic GVHD sometimes affects the airway passages in the lungs. It sometimes occurs after a cold or lung infection.

Lung GVHD, also called bronchiolitis obliterans syndrome, usually has no obvious symptoms in its early stage. It is therefore very important to have periodic pulmonary function tests done in the first few years after transplant so that lung GVHD can be detected early when treatment is most effective.

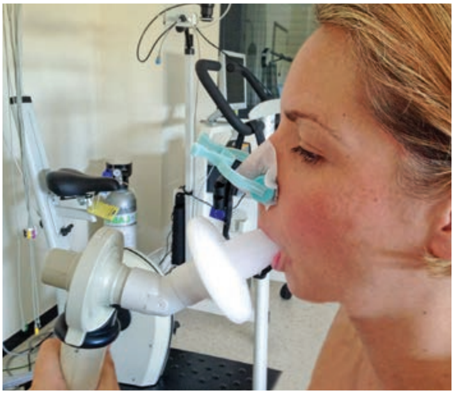
Symptoms of lung GVHD may include:

- a dry cough

- a cough that persists after a cold for longer than 2-4 weeks
- wheezing
- shortness of breath, even with light activities
- feeling like you can't take a deep breath

If you develop lung GVHD, your doctor may treat you with:

- azithromycin
- belumosudil
- bronchodilators
- montelukast
- prednisone
- ruxolitinib
- steroid inhalers



Take Action!

Talk to your doctor about scheduling periodic pulmonary function tests to monitor for lung GVHD, particularly during the first two years after transplant.

If you are having breathing difficulties, let your doctor know immediately. The sooner treatment begins, the better the outcome.

Avoid smoking tobacco products, e-cigarettes, and marijuana, as these can make the symptoms worse.

Protect against lung infections. Be sure your vaccinations are up to date and that you get your yearly flu shot and the COVID vaccine, unless your transplant doctor recommends otherwise.

Watch the video **Take a Breath! Managing Lung Problems after Transplant** at **bmtinfonet.org/2024-video/GVHD-lungs**.

Your Genitals and Chronic GVHD

Sometimes, chronic GVHD affects the genitals. Genital GVHD can cause difficulties with sex and intimacy.

In women, chronic GVHD may cause:

- vaginal itching, burning, dryness
- white lines, scarring, and adhesions in the vagina
- loss of elasticity in the vagina or narrowing of the vaginal canal
- painful intercourse
- pain when urinating
- bleeding

Treatment options may include:

- dilators to expand the vaginal canal
- hormone replacement therapy
- tacrolimus or cyclosporine ointment
- topical steroids
- vaginal suppositories
- water-based lubricants

A pelvic floor physical therapist can help relieve symptoms. Find a pelvic floor physical therapist at **PelvicRehab.com**.

In men, GVHD can affect the penis. Symptoms include:

- a change in skin color on the head of the penis
- redness, white lines, burning, or pain on the head of the penis
- difficulty or pain when retracting the foreskin
- scarring or adhesions on the foreskin
- curvature of the penis when it is erect
- in rare cases, scarring on the meatus (where the urine comes out)

Topical steroids and tacrolimus are the usual treatment options.

Take Action!

If you have symptoms of genital GVHD, ask for a referral to a gynecologist or urologist familiar with GVHD.

To minimize irritation and pain:

- wash your genital area with warm water and soap
- don't use perfumed products in the genital area
- wear loose cotton or cotton-lined underwear

GVHD can affect your sex drive and sexual functioning even if it does not directly affect your genitals. Ask your doctor for help if you are having sexual difficulties.

Watch the video **Graft-versus-Host Disease: Genitals** at **bmtinfonet.org/video-2023/genital-GVHD**.

Your Nervous System and Chronic GVHD

Sometimes chronic GVHD affects the nervous system. Symptoms include:

- numbness or a painful, tingling sensation in your hands and feet
- shooting pains in your hands and feet
- lack of coordination

These problems, caused by nerve damage, are called neuropathy. Depending on the severity, neuropathy may be treated with:

- topical medications such as a lidocaine patch or gel
- oral medications such as amitriptyline, gabapentin, or pregabalin
- physical and occupational therapy
- soaking feet in cool water

Take Action!

Talk to your doctor if you have symptoms of neuropathy. A consultation with a neurologist can help.

Wash your feet daily with lukewarm water and fragrance-free soap.

Inspect your feet daily for cuts, bruises, cracking, or other changes that may require attention.

Always wear sturdy shoes or slippers.

Do not apply direct heat to your feet and legs.

Avoid falls:

- Keep your home free of clutter and slippery surfaces.
- Consider using devices, such as handrails and canes, to help maintain your balance.

Watch the video **Managing Neuropathy after Transplant** at **bmtinfonet.org/2024-video/neuropathy**.

Other Rare Symptoms of Chronic GVHD

Very rarely, chronic GVHD may cause other symptoms including:

- Raynaud's Phenomenon (poor blood flow to skin, fingers and toes)
- extra fluid around the heart or lungs
- an abnormal accumulation of fluid in the belly
- too much protein in your urine

Your doctor will rule out other more common causes of these symptoms before concluding they are caused by chronic GVHD.

Find a GVHD Specialist

Sometimes patients have difficulty finding doctors to help them manage their GVHD. This is particularly true if you no longer live near your transplant center.

Ask your transplant team to refer you to a doctor familiar with GVHD or consult BMT InfoNet's GVHD Directory at **bmtinfonet.org/gvhd-directory**. In addition to GVHD clinics and doctors who specialize in manging GVHD, the directory includes subspecialists who can manage GVHD symptoms such as:

- dermatologists
- ophthalmologists
- pulmonologists
- oral medicine specialists
- gynecologists/urologists
- physical and occupational therapists
- GI specialists
- endocrinologists

CHAPTER 4

INFECTION AND GRAFT-VERSUS-HOST DISEASE

My wife was the sanitizer queen after my transplant. She carried alcohol-based wipes with her wherever we went so I wouldn't touch anything that might cause an infection. It looked a little crazy, but it was a small price to pay to keep me out of the hospital while I had GVHD.

William B.

Many drugs used to treat GVHD weaken your immune system. This increases your risk of developing a serious infection.

To protect against a serious bacterial infection, your doctor may put you on antibiotics or give you antibiotics to keep on hand in case you develop a fever. You may also be asked to take medications to prevent viral and fungal infections.

Your transplant team will give you guidelines to help prevent infections until your immune system recovers. The most important of these is frequent, thorough handwashing with soap and water before:

- eating or preparing food
- taking medications

Be sure to wash your hands after:

- touching catheters and wounds
- changing diapers (if you are permitted to do so)
- touching plants or dirt (if you are permitted to do so)
- going to the restroom
- touching animals
- touching bodily fluids or items that might have come in contact with bodily fluids such as clothing, bedding, or toilets
- going outdoors or to a public place
- removing gloves
- collecting or depositing garbage (if you are permitted to do so)

Avoid Exposure to Infectious Agents

While your are taking immunosuppressive drugs, you'll want to avoid exposure to sources of infection. Your transplant center may recommend that you avoid:

- crowds, especially during cold and flu seasons
- people who have, or have been exposed to, an infection

- gardening or digging in dirt
- smoking or being around people who smoke tobacco products, e-cigarettes, or marijuana
- walking, wading, swimming, or playing in ponds or lakes
- construction sites and remodeling projects

Cleaning kitchen counters and bathrooms daily with a solution of one part bleach to 10 parts water can help reduce sources of infection.

If you live in a rural area, you may need to treat your well water before drinking it.

Ask Your Transplant Team about Pets

Rules vary among transplant centers as to whether or not you can have pets in the home while your immune system is suppressed.

Your transplant center may ask you to avoid:

- adopting ill or juvenile pets
- animals that are sick
- reptiles such as lizards, snakes, turtles, and iguanas, and items they touch
- chicks and ducklings
- exotic pets such as monkeys or chinchillas
- cleaning litter boxes or cages, disposing of animal waste, or other activities that put you in touch with animal feces
- bird droppings
- cleaning fish tanks

Your doctor may also recommend:

- keeping cat litter boxes away from areas where food is prepared or eaten
- keeping cats indoors

- not adopting stray cats
- covering backyard sandboxes to prevent cats from using them as a litter box

Take Action!

Avoid potential sources of infection until you are no longer on drugs that suppress your immune system.

At the first sign of infection, contact your doctor so that you can get prompt treatment and avoid serious complications. Infections are often easier to treat if detected early.

Be sure your vaccinations are up to date, and that people you live with, as well as those with whom you have frequent contact, are vaccinated, too.

Watch the video **Infections after Transplant** at **bmtinfonet.org/2024-video-infection**

CHAPTER 5

CLINICAL TRIALS

I currently have GVHD in my lungs and have tried several treatments with no success. I agreed to participate in a clinical trial testing a new medication to see if it helps. I know how important it is to get new drugs approved, and I feel I have a duty to help others.

Barbara G.

If current therapies are not controlling your graft-versus-host disease well, consider participating in a clinical trial. Clinical trials are carefully monitored research studies that test new drugs and therapies.

Patients who participate in a clinical trial have early access to new medications, although there is no guarantee that the drug or therapy being studied will be effective.

Ask your doctor if there is a clinical trial that might be appropriate for you. You can also contact the NMDP® Jason Carter Clinical Trials Program online at **ctsearchsupport.org**.

The Leukemia & Lymphoma Society at **lls.org** also has navigators who help you find a clinical trial that's right for you.

Clinicaltrials.gov, a website hosted by the National Institutes of Health, provides details about clinical trials worldwide.

National Cancer Institute Chronic GVHD Study

An important clinical trial for people living with chronic GVHD is the National Cancer Institute's chronic GVHD study. Patients between the ages of one and 75 can schedule an appointment for a free comprehensive evaluation of their chronic GVHD.

Specialists familiar with how chronic GVHD affects every part of the body conduct a four-day physical examination and make recommendations on how best to manage your disease.

The medical evaluation is free of charge and takes place in Bethesda, Maryland. The program is designed to gather a national database of information about chronic GVHD so that better treatments can be developed.

For details call 240-858-3681 or go to **bit.ly/ncigvhd**.

CHAPTER 6

COPING WITH THE STRESS OF GRAFT-VERSUS-HOST DISEASE

GVHD is the gift that keeps giving, though you wish you could exchange it for a waffle maker or at least a store credit.

Rodney C.

Living with GVHD can be an emotionally difficult experience for both you and your family. After transplant, everyone wants to resume a normal life, but GVHD can make that difficult for a time.

It's normal to feel sad or anxious while dealing with GVHD. Physical changes, some of the drugs used to treat GVHD, fatigue, or sleep problems can cause depression, confusion, anxiety, mood swings, or exaggerated feelings of anger, excitement, or sadness. It's important to let your doctor know if you are experiencing any of these symptoms.

Sometimes, medications are offered to GVHD patients to stabilize mood swings and reduce anxiety. This is very common. Short-term use of these drugs does not mean you will be dependent on them long-term.

Living with Uncertainty and Change

Living with GVHD sometimes feels like riding an emotional roller coaster, with ups and downs and unexpected twists and turns. It can be challenging to have to deal with a new problem after having made it through transplant.

It's especially hard not knowing what's next around the corner, whether things will get worse or better, and how long the GVHD will last. This is why we often hear, 'it is a marathon, not a sprint'!

Figuring out how to adjust to physical, social, and emotional changes takes time. The goal is to learn to manage GVHD without being defined by it. Try to:

- take each day as it comes, one day at a time
- focus on what you can do rather than what you can't do
- build flexibility into your plans since you don't always know how you will feel
- notice small things that bring you joy and pleasure
- engage in non-medical activities that help you feel a sense of normalcy and remind you of who you are as a person

Talk about Your Feelings

If you have GVHD, it's important not to ignore or downplay your feelings. Finding an outlet to express and process your feelings can decrease stress, facilitate problem-solving, and help you move forward in a healthy manner.

Talking with a social worker, psychologist, psychiatrist, or pastoral counselor often helps, especially one who has experience working with transplant survivors.

It can be especially helpful to talk with others who have been down the same path. Speaking with other survivors who ‘get it’ may make you feel less alone. In addition, they can share with you information and coping strategies that they found useful.

Take Action!

If sadness, anxiety, mood swings, or depression are affecting your quality of life, don’t ignore those feelings.

- Ask your healthcare team for a referral to a mental health provider or find one through BMT InfoNet’s Mental Health Directory at **bmtinfonet.org/mh-directory**.
- Seek support from others who have had GVHD through BMT InfoNet’s Caring Connection Program at **bmtinfonet.org/caring-connection** or phone 888-597-7674.
- BMT InfoNet also offers online support groups for GVHD patients and their caregivers. Call 888-597-7674 or go to **bmtinfonet.org/GVHD-support-group** for details.
- NMDP® offers free counseling to GVHD patients and their caregivers. Phone (888) 999-6743.
- Ask your doctor whether medication may help stabilize mood swings and reduce anxiety.

Other Ways to Reduce Stress and Anxiety

Patients with GVHD often find that meditation, guided imagery, and relaxation techniques help them manage the stress of living with GVHD. Practicing living in the moment, acknowledging and accepting your feelings, and using techniques like slow, deep breathing to calm yourself can also help.

Journaling and creating works of art are wonderful ways to identify, express, and process feelings you may be experiencing.

Exercise can help improve strength, stamina, and sleep, and reduce fatigue, anxiety, and depression. Walking or gentle stretching, such as chair yoga, can make a difference.

Take Action!

Explore whether your hospital or a local cancer wellness group offers classes in meditation, guided imagery, and relaxation techniques. Try some apps designed to help you relieve stress. **Calm.com** and **Headspace.com** are two worth exploring.

Consider creating a ‘gratitude diary’ to record and remember positive events and things for which you are grateful.

Explore opportunities to relieve stress creatively through journaling, art projects, or music.

Ask your doctor if it is safe for you to begin an exercise program either under the supervision of a physical therapist or at a local gym. Some YMCAs have partnered with LIVESTRONG to offer a free 12-week exercise program to help cancer patients build endurance and reduce fatigue. Go to **livestrong.org/ymca-search** or call 855-220-7777 to find a participating YMCA near you.

Watch the video **Riding the Emotional Roller Coaster of Survival** at **bmtinfonet.org/video/2024/emotional-challenges**.

Watch the video **Living Well: Exercise/Strategies to Improve Endurance and Strength** at **bmtinfonet.org/video/2023-exercise**.

Growth and Positive Change

Going through transplant and dealing with GVHD causes many survivors to re-evaluate aspects of themself, their relationships, and their life. Many GVHD survivors find that they have grown and experienced positive changes, such as:

- learning new ways to do old things
- recognizing their own strength and ability to do things they didn't think they'd be able to do
- making new or stronger connections with others
- finding new meaning in life

Taking time to find something positive each day can help counterbalance the challenge of living with GVHD.

Some GVHD survivors find it gratifying to 'give back' by supporting others in a support group, volunteering, or participating in a research study that could provide valuable information for future survivors. Helping others can be a great way to help yourself.

CHAPTER 7

THE ROLE OF THE CAREGIVER

My husband is just now starting to experience some long-awaited health stability. It's wonderful news and provides hope that the roller coaster of GVHD will settle into a calmer, more stable path. But it also brings a new set of adjustments. I'm wondering whom I'll be when my role as caregiver is no longer needed. Having spent so long 'holding up the sky' I'm now feeling the labor pains of a new self emerging.

Bethany Z.

Caring for a loved one who has GVHD is a big job. Caregivers must juggle many tasks including:

- some of the medical duties that nurses previously handled
- ensuring that the patient follows the treatment plan prescribed by the medical team
- acquiring and dispensing the many medications that the patient needs daily
- scheduling and coordinating transportation to the many clinic and specialist visits
- monitoring the patient for new or worsening symptoms
- communicating any change in the patient's condition to the healthcare team

- protecting the patient from sources of infection
- preparing nutritious meals
- providing the patient with emotional support
- managing usual household chores such as paying bills, childcare, home maintenance, running errands, as well as going to work.

The course of GVHD can be uncertain, with lots of ups and downs and unexpected twists and turns. Sometimes it becomes a chronic disease you have to manage and adapt to for longer than anticipated. It's important to build resilience and take care of yourself so that you remain well and strong through the weeks and months ahead.

Take Care of Your Physical Well-Being

To be an effective caregiver, you will need to keep yourself in good physical condition. This includes eating well-balanced meals, getting daily exercise, and getting sufficient sleep each night.

Although it can be hard, try to prioritize your own health. Remember, if you become ill, you will not be able to care for your loved one.

Create a daily routine, with time built in to do things that will keep you strong and healthy, both mentally and physically. Think about ways to 'burn off' stress with physical movement, such as walking or yoga, and 'turn off' stress with meditation or prayer, spending time in nature, listening to music, or watching a favorite show.

If you have any health issues, don't ignore them or put them off. Keeping yourself strong and healthy is important for both you and your loved one.

Gather a Team of Helpers

Don't try to go it alone. It is hard to do all the things you need to do for the patient, as well as address your own needs. A good support network is essential.

People are often eager to help if they know exactly what you need. Make a list of all the activities that could be done by someone else, and then reach out to family and friends to see who can help. Build in ongoing support, if you can, so that you don't have to keep asking for help.

Can someone occasionally or routinely do shopping for you? Pick up medications? Take the children to activities? Mow your lawn? Make a dinner? Walk the dog?

See if a family member or friend will organize the help for you. There are many online programs available to schedule meals and other help for people with chronic health issues. Some to check out include:

- **LotsaHelpingHands.com**
- **MealTrain.com**
- **CaringBridge.org**

Dealing with Uncertainty

One of the most challenging aspects of being a caregiver for someone with GVHD is the uncertainty - not knowing:

- how long the GVHD will last
- whether it will get better or worse
- how long your loved one will depend on you for help

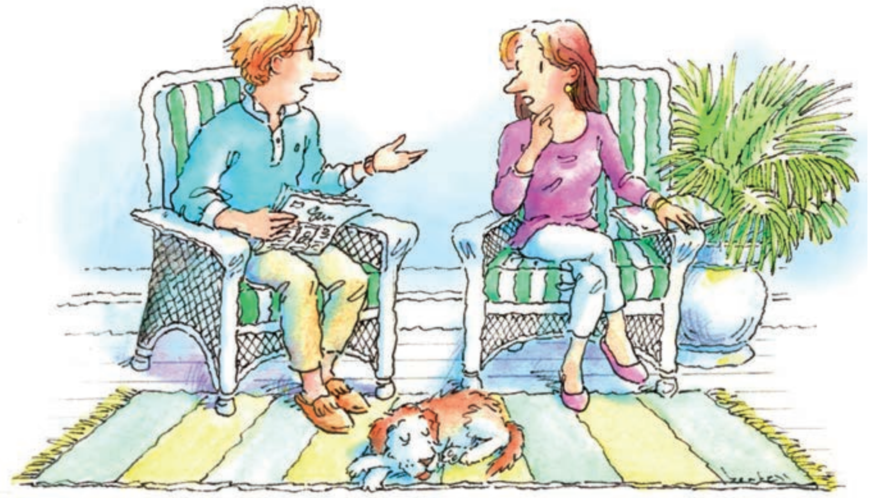
Some caregivers view 100 days after transplant as the finish line, but it's often just the start of a new phase of caregiving. Chronic GVHD usually begins five-to-six months after transplant, so treatment and caregiving duties may be needed much longer than expected.

It is good to be optimistic but realistic as well. Your loved one may get a mild case of GVHD that resolves in a few months. But just in case, prepare yourself mentally for the possibility that you may need to deal with GVHD and caregiving for a much longer period of time.

Changing Relationships

The role of caregiver can create a different type of relationship between you and the person with GVHD, at least for a time. If you are caring for a spouse or partner, you may find yourself in a nurse/patient role instead of being equal partners. It's common for differences to arise over how much care you should be providing or how much you should be pushing the patient to do various activities, which can lead to frustration, resentment, and anger for both parties.

Communication is key. Bottling up frustration is not healthy. Try using 'I' statements, such as 'I am feeling frustrated' rather than 'You' statements such as 'You make me mad'.



Think about caregiving as ‘care-partnering’. Work together to name challenges and problem-solve them together.

Encourage the patient to do what he or she can without help so you both maintain as much independence and self-identity as possible. Don’t forget to spend time together doing things you enjoy that are not medical in nature.

Sometimes, relationships with extended family members or friends can become strained as well. It is difficult for people who are unfamiliar with GVHD to understand how much GVHD can impact daily life and health, particularly if the patient is not showing obvious symptoms. Describing GVHD as a chronic disease, like diabetes or multiple sclerosis, may help others understand that issues are ongoing.

Your Emotional Well-Being

Caring for someone with GVHD is stressful. Fear of the unknown, frustration over things like getting appropriate medical help, wanting support from family and friends, and just plain exhaustion can put your emotional health in jeopardy.

Don’t ignore your feelings. If you don’t deal with them, they will deal with you. Emotional burnout is common after extended

periods of caregiving. It's best to seek help before distress causes other health problems.

Find a person with whom you can honestly express your feelings and discuss your worries. This could be a:

- trusted family member, friend, or religious counselor
- caregiver for another GVHD patient (see Caring Connections Program at **bmtinfonet.org/caring-connection**)
- GVHD support group (see BMT InfoNet Support groups at **bmtinfonet.org/gvhd-support-group**)
- mental health professional (find one at **bmtinfonet.org/mh-directory**)

Give Yourself the Credit You're Due

You are a vital member of the healthcare team working to help your loved one recover. Acknowledge the hard work you are doing and take pride in mastering the many tasks that you once may have thought you'd be unable to do.

Sometimes, despite your best efforts, problems like an infection may occur, or things don't go as planned. It can be easy to question yourself and wonder if something you did caused the problem.

Resist the urge to blame yourself. Like everyone involved in patient care, you are doing your best and not everything is within your power to control. Try to show yourself the same compassion as you would for a friend.

Silver Linings

Despite the difficulty of living with GVHD, many people say the experience has some silver linings. Caregiving can feel rewarding and meaningful.

Some couples grow closer together. Some caregivers find a new sense of how capable they are, despite adversity. Some learn new ways of problem-solving or make new friendships. Many describe changes in their perspective and have a new appreciation for life.

Watch the video **GVHD Caregivers are Survivors, Too!** at **bmtinfonet.org/video/2023-GVHD-Caregiver**.

CHAPTER 8

STEROIDS AND THEIR SIDE EFFECTS

Although I was forewarned before my transplant that I could experience GVHD, I was mostly focused on trying to survive, not on what was to follow. GVHD and the side effects of steroids make it hard to establish a 'new normal' after transplant. Still, it's better than the alternative and worth the struggle.

Liz M.

Steroids, such as prednisone and methylprednisolone, are used extensively to treat both acute and chronic GVHD. You may need to take steroids for several months or longer to keep your GVHD under control.

When it looks like your GVHD is improving, your doctor will slowly start reducing the dosage of steroids over several weeks or months. However, it is common for GVHD to flare up during this tapering process. You may need to resume taking a higher dosage for a while or slow down the tapering process.

Although steroids are an important tool for managing GVHD, they can also cause significant side effects.

Be Alert for Signs of an Infection

Because steroids weaken your immune system and can suppress a fever, you will have a higher risk of developing a serious infection.

Be sure to tell your healthcare team immediately if you have:

- a fever over 100.4 degrees
- are experiencing chills

It's important to avoid anyone who is sick, or who has been near someone who is sick.

Ask your transplant team for guidance on how to reduce your risk of infection while on steroids. (See Chapter Four – Infection and GVHD.)

Physical Side Effects of Steroids

Steroids can cause side effects that temporarily alter your appearance, weaken your muscles and bones, and/or affect how your organs perform. Side effects can include:

- high blood sugar that can lead to diabetes
- increased appetite and weight gain
- fluid retention that causes puffiness or swelling in the arms, legs, and/or face
- muscle weakness, fatigue, or tremors that can affect strength and balance
- delayed wound healing
- difficulty sleeping
- upset stomach or ulcers, loss of appetite
- increased fat around the midsection, upper back, neck, or face
- high blood pressure

Long-term use of steroids can lead to additional problems, such as:

- weakened bones, that can lead to osteoporosis or avascular necrosis
- thinning, fragile skin that may bruise easily
- vision problems such as glaucoma or cataracts

Tell your healthcare team if you develop any of these side effects. Most are temporary and resolve once your doctor begins reducing your dosage of steroids.

You may start experiencing side effects the first week you begin taking steroids or several weeks later. The side effects can persist for up to two months after you stop taking steroids. Some side effects, such as osteoporosis, are permanent.

Do not stop taking steroids unless your doctor tells you to do so. Stopping steroids abruptly can cause serious medical problems.

If you have been on steroids for several weeks, your body may become dependent on them and will stop making your own steroid-like proteins. This is called adrenal insufficiency. Stopping steroids abruptly or lowering the dosage too quickly can also cause your blood pressure to fall to a very low level, causing lightheadedness, diarrhea, and nausea.

If you become very sick, be sure your healthcare providers know that you are taking steroids.

How Steroids Affect the Brain

Steroids can impact your mood as well as how you process information. It is common to feel stronger emotions than usual while on steroids, such as extreme anxiety or sadness.

Approximately one-third of patients on steroids experience mild to moderate psychiatric problems such as:

- anxiety
- irritation
- mood swings
- agitation
- being easily distracted
- irritability
- feeling down, lacking energy and enthusiasm
- restlessness
- tearfulness
- memory problems

A small percentage of patients experience more severe problems such as:

- seeing or hearing things that are not there
- having beliefs that are strange or magical
- delirium
- mania
- suicidal thoughts

Tell your healthcare team if you are experiencing any of these side effects. They can recommend strategies to help you manage them until you no longer need steroids.

Tips to Minimize Steroid Side Effects

- Keep healthy snacks readily available for when your appetite surges. Avoid filling the pantry with salty and fatty snack foods that can cause weight gain.
- Eat a diet high in calcium and stick to foods with a low glycemic index. This can help control your blood sugar.
- Ask your doctor whether you should take calcium and vitamin D supplements, or medications that reduce your risk of developing osteoporosis.
- Take your steroids with food to minimize heartburn and nausea. If you experience heartburn or nausea, let your health-care team know. Antacids or other prescription medications can be helpful.
- Stay well hydrated. Drink at least 64 ounces of fluid a day.
- Take your steroids in the morning rather than in the evening so they don't interfere with your sleep.
- Exercise daily, even if it is a just a short walk. This will help keep your muscles strong.

- Practice healthy sleep hygiene habits. Watch a video about improving your sleep at **bmtinfonet.org/2024-video/sleep**.
- Try meditation in the evening to reduce stress and restlessness and improve the quality of your sleep.
- Ask your transplant team whether physical therapy can help you manage the side effects of steroids.
- Avoid caffeine, alcohol, and spicy foods that may cause hot flushing.
- Learn how to monitor your blood pressure and blood sugar at home. Record the results and report them to your healthcare team.
- Share the potential side effects of steroids with your family and friends to help them understand that unusual behavior or outbursts may be due to the steroids.

CHAPTER 9

DRUGS USED TO PREVENT AND TREAT GVHD, AND THEIR SIDE EFFECTS

> *Check with your doctor before you take any over-the-counter medicine or supplements. I thought about taking turmeric pills while I was on medicines for my GVHD. When I checked with my doctor, he said turmeric could increase the amount of the GVHD medication absorbed by my body to a dangerously high level. Better to be safe than sorry. Always ask.*
>
> *Tamir O.*

The drugs commonly used to prevent and treat GVHD and its symptoms have side effects. Most are temporary and end when the drug is no longer needed.

The following pages describe the most common side effects that have been reported. Other less common side effects may also occur. Consult your doctor for details.

New drugs and therapies are constantly being developed to prevent or treat GVHD. If a drug you are taking is not on this list, consult your doctor or pharmacist for a list of potential side effects.

Caution: Herbs, Supplements, and Botanicals

Be careful about using herbs, supplements, botanicals, and mega-doses of vitamins while taking medications for GVHD. Some can reduce the effectiveness of your GVHD medication or cause serious side effects.

For example:

- Turmeric and curcumin supplements can change how your body processes tacrolimus. When they are applied to the skin, they can cause sun sensitivity and/or a rash.
- Garlic supplements can decrease the effectiveness of cyclosporine and increase your risk for bleeding. (Cooking with garlic is fine.)
- Omega-3 supplements can interfere with the effectiveness of steroids and increase the risk of bleeding.
- Milk thistle can interfere with how your liver processes sirolimus and some antifungal drugs.
- St. John's wort can interfere with the effectiveness of cyclosporine and tacrolimus, as well as some blood pressure medications.

Check with your doctor before starting or continuing to use any non-prescription medicine, herb, or other supplement.

Abatacept (Orencia®)

- headache
- infection
- nausea
- infusion reactions, such as chills and fevers
- high blood pressure

Afinitor® (see everolimus)

Antithymocyte globulin (ATGAM or Thymoglobulin®)

- infusion reactions: fever, chills, low blood pressure, skin rash
- joint pain
- headache
- nausea, vomiting, diarrhea
- night sweats
- dizziness
- shortness of breath
- low platelets and white blood cells
- infections

ATGAM (see antithymocyte globulin)

Axatilimab (Niktimvo®)

- muscle, bone or joint pain
- low energy
- headache
- diarrhea

Belumosudil (Rezurock®)

- infection
- feeling tired or weak
- nausea, diarrhea
- shortness of breath
- cough
- swelling caused by excess fluid
- bleeding
- muscle, bone, tendon or nerve pain
- stomach pain
- high blood pressure
- headache, fever

CellCept® (see mycophenolate mofetil)

Cyclophosphamide

- nausea, vomiting, diarrhea
- mouth sores
- kidney problems
- bleeding from bladder
- bloody urine
- low blood cell counts
- infections

Cyclosporine (Gengraf®, Neoral®, Sandimmune®)

- kidney problems
- headaches
- tremors, muscle cramps
- increased body hair
- seizures
- nausea, diarrhea, abdominal discomfort
- high blood pressure
- gum overgrowth
- swelling due to fluid retention
- endocrine problems
- abnormal kidney function test
- stomach pain

ECP (see extracorporeal photopheresis)

Enbrel® (see etanercept)

Etanercept (Enbrel®)

- respiratory infections
- reactions at the site of injection
- headache

Everolimus (Afinitor®)

- constipation
- slowed healing of wounds
- nausea, vomiting, diarrhea
- anemia
- urinary tract infection, pain when urinating, blood in urine
- other infections
- high blood pressure
- headache

Extracorporeal photopheresis (ECP)

- sensitivity to sunlight and other sources of UV light
- skin redness
- fever
- low blood pressure, rapid heart rate
- low red cell and platelet count
- iron deficiency
- fatigue

Gengraf® (see cyclosporine)

Ibrutinib (Imbruvica®)

- fatigue
- bruising, rash
- diarrhea, nausea
- low platelet count
- muscle spasms
- mouth sores
- pneumonia
- brittle nails
- abnormal heart rhythm

IL-2 (see interleukin-2)

Imbruvica® (see ibrutinib)

Interleukin-2 (IL-2, Proleukin®)

- Infusion reaction: fever, chills, low blood pressure
- flu-like symptoms, general aches and pains
- redness on the face and body, rash
- nausea, vomiting, diarrhea
- low blood counts
- confusion, drowsiness, or temporary memory loss
- fast heart beats
- low urine output
- swelling of the face, ankles, or legs
- respiratory issues, difficulty breathing

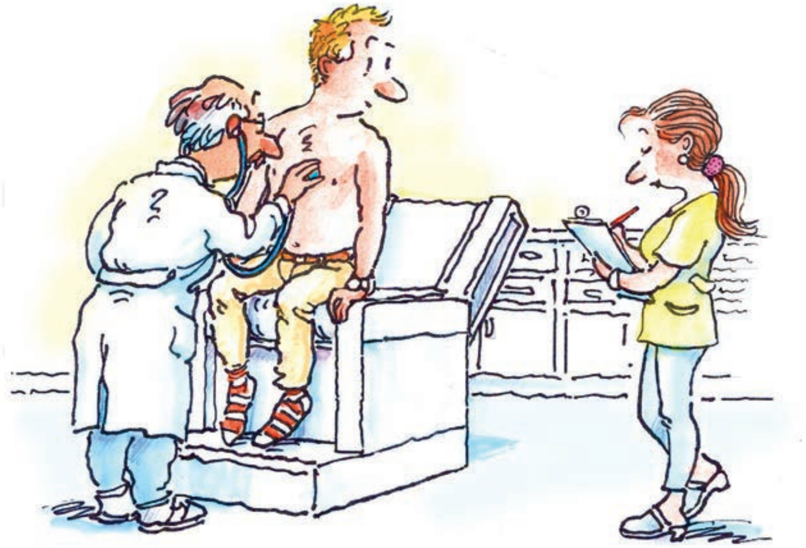
Jakafi®/Jakavi® (see ruxolitinib)

Methotrexate (Rheumatrex®)

- mucositis
- skin redness
- nausea, vomiting, diarrhea
- elevated uric acid
- kidney problems
- liver problems
- low blood counts

Methoxsalen (Oxsoralen®, psoralen with ultraviolet A light)

- nausea
- itching of the skin
- sensitivity to the sun



Montelulast (Singulair®)

- headache

Mycophenolate mofetil (CellCept®)

- nausea, vomiting, diarrhea
- bleeding
- increased risk of infection
- anemia
- high blood sugar
- high cholesterol
- low calcium and magnesium
- high potassium
- cough, breathing issues

Myfortic® (see mycophenolate mofetil)

Neoral® (see cyclosporine)

Niktimvo®(see axatilimab)

Orencia® (see abatacept)

Oxsoralen® (see methoxsalen)

Prednisone and Prednisolone

- osteoporosis (weak and brittle bones)
- joint deterioration
- infection
- cataracts
- weight gain
- moon face
- mood swings
- depression
- high blood sugar
- high blood pressure
- gastric ulcers

- muscle weakness
- bleeding

Prograf® (see tacrolimus)

Proleukin® (see interleukin-2)

Psoralen with ultraviolet A light
- nausea
- itching of the skin

PUVA (see psoralen with ultraviolet A light)

Rapamune® (see sirolimus)

Rezurock® (see belumosudil)

Rheumatrex®
(see methotrexate)

Rituxan® (see rituximab)

Rituximab (Rituxan®)
- Infusion reaction: fever, chills, rigors, low blood pressure
- rash, itching skin
- swelling of soft tissues
- infections
- muscle pain
- diarrhea, nausea, vomiting
- low blood counts
- low immunoglobulin levels
- reactivation of hepatitis B

Ruxolitinib (Jakafi®/Jakavi®)
- low blood counts
- bruising
- dizziness
- headache
- elevated liver enzymes
- elevated cholesterol

Sandimmune® (see cyclosporine)

Sirolimus (Rapamune®)
- infection
- bleeding
- elevated glucose (sugar) in the blood
- elevated triglycerides (blood fats)
- swelling
- fever
- headache
- low blood counts
- kidney problems
- constipation, diarrhea
- sepsis

Tacrolimus (Prograf®)

- diarrhea
- abdominal pain
- nausea
- kidney problems
- headache
- tremors
- high blood sugar
- high cholesterol
- high potassium

Thymoglobulin® (see anti-thymocyte globulin)

Ursodeoxycholic acid

- headache
- dizziness
- nausea, vomiting, gastric discomfort
- back pain
- respiratory infection

RESOURCES FOR GVHD PATIENTS AND CARE PARTNERS

GVHD Information Online

- BMTInfoNet.org/GVHD-basics
- NMDP.org
- Leukemia & Lymphoma Society (lls.org)
- nbmtLINK.org
- GVHDAlliance.org
- GVHD*now*.com

Financial Assistance

- **BMT InfoNet**
    - bmtinfonet.org/financial-aid
    - Email: help@bmtinfonet.org
    - 888-597-7674
- **Bone Marrow & Cancer Foundation**
    - Bonemarrow.org
    - Email: BMCF@Bone Marrow.org
    - 800-365-1336
- **Leukemia & Lymphoma Society**
    - lls.org/support-resources/financial-support
    - 877-557-2672

Locate GVHD Clinics, Specialists and Subspecialists

- **BMT InfoNet**
  bmtinfonet.org/gvhd-directory
  888-597-7674
  Email: help@bmtinfonet.org

Peer Support/Support Groups/Counseling

- **BMT InfoNet**
  888-597-7674
  Email: help@bmtinfonet.org
  - o **Online GVHD support groups**
    bmtinfonet.org/gvhd-support-group
  - o **One-on-one peer support**
    bmtinfonet.org/caring-connection
  - o **Directory of Mental Health Providers**
    bmtinfonet.org/mh-directory
  - o **GVHD Wall of Hope**
    bmtinfonet.org/wall-of-hope
- **NMDP**
  888-999-6743
  Email: patientinfo@nmdp.org
  - o Individual counseling with social worker

Videos/Podcasts

- **Introduction to GVHD: It Takes a Village**
  bmtinfonet.org/video/2022-intro-GVHD
- **GVHD: Advances in Prevention and Treatment**
  bmtinfonet.org/video/2024-GVHD-progress
- **GVHD: Skin, Hair and Nail**
  bmtinfonet.org/video/2024-GVHD-skin

- **GVHD: GI Tract and Liver**
  bmtinfonet.org/2024-video/GVHD-GI-liver
- **GVHD: Eyes**
  bmtinfonet.org/video/2023-GVHD-eyes
- **GVHD: Mouth**
  bmtinfonet.org/video/2023-GVHD-mouth
- **GVHD: Lungs**
  bmtinfonet.org/2024-video/GVHD-lungs
- **GVHD: Genitals**
  bmtinfonet.org/video/2023-GVHD-Genital
- **GVHD: Caregivers**
  bmtinfonet.org/video/2023-GVHD-caregiver
- **Rehabilitation Therapies to Manage GVHD Side Effects**
  bmtinfonet.org/video/2022-GVHD-rehab
- **GVHD Podcasts**
  nbmtlink.org/marrow-masters-podcast

Celebrating a Second Chance at Life Survivorship Symposium

The annual Celebrating a Second Chance at Life Survivorship Symposium is a wonderful opportunity to learn from nationally recognized experts how to manage the many challenges that can arise after transplant.

Workshop topics include:

- How to Protect Your Health Long-Term
- Graft-versus-Host Disease
- Learning and Memory Problems after Transplant
- Managing Fatigue
- Sexual Health after Transplant
- Caregiver Challenges

and much, much more.

Join us online at our next symposium and take charge of living!

For information email **help@bmtinfonet.org** or phone 888-597-7674.

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