

Chronic GVHD

Chronic Pain

Chronic Fatigue

Chronic Fibrosis

Thankfully, you also have

Chronic Determination

What is chronic graft-versus-host disease (GVHD)?

Definitions of terms in **bold** can be found in the glossary at the back of this brochure.

Blood stem cell transplants are used to treat many types of blood cancer and other conditions. The transplanted cells may come from your own body (**autologous hematopoietic cell transplant**, or **auto-HCT**), or they may be healthy cells from a donor with a similar genetic makeup (**allogeneic HCT**, or **allo-HCT**).

The transplant contains immune cells, which are important for keeping you healthy and fighting infection. However, immune cells from another person (the graft) can sometimes attack your own body (the host) because they see it as foreign and a threat.

Graft immune cells attacking normal host organs and tissues is called GVHD. GVHD may be classified as acute or chronic, based on timing and clinical presentation. In this material, we will discuss chronic GVHD.

Chronic GVHD is a serious condition that can result in permanent damage to your body, disability, or death. Appropriate and timely treatment may help people with chronic GVHD maintain their quality of life.

Who is affected by chronic GVHD?

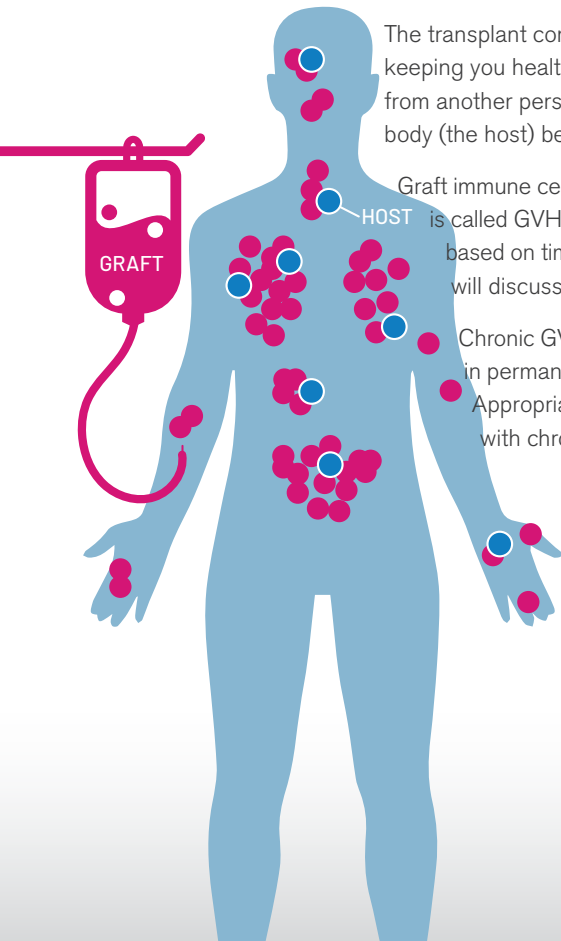
Chronic GVHD is a serious and common complication of allo-HCT. It occurs in 30–70% of people who receive an allo-HCT.

There are some factors that may put you at higher risk of developing chronic GVHD after allo-HCT.

These include:

- **Incomplete genetic match.** A donor's cells may not be a perfect genetic match, which may make the donor immune cells more likely to attack your own organs.
- **Older recipient age.**
- **History of acute GVHD.**
- **Male recipient of female donor cells.**
- **Use of post-transplantation donor lymphocyte infusion.**
- **Use of peripheral blood cells.**

Before receiving an allo-HCT, the health care team will take measures to try to prevent chronic GVHD. They will ensure the donor is as close a genetic match as possible.



All cancers

How common is blood cancer, allo-HCT, and chronic GVHD among all cancers?

Blood cancer **10%**

Allo-HCT **<4%**

Chronic GVHD (You) **<2%**

What does chronic GVHD look like?

Chronic GVHD is a complex condition that may affect many different parts of your body.



Skin

Thickened or tight skin, with changes in texture or colour



Mouth

Appearance of lacy white lines, painful ulcers



Eyes

Dryness, grittiness, pain



Muscles and joints

Stiffness, pain



Scalp and body hair

Loss of hair



Lungs

Shortness of breath, dry cough



Genitals and sex organs

Painful rash, dry skin



Digestive system

Pain, difficulty swallowing



Nails

Brittleness, thinning

Chronic GVHD is difficult to diagnose because it can appear differently in different people, and it can look similar to other conditions. If your health care team thinks you might have chronic GVHD, they may be able to confirm the diagnosis with a detailed physical examination. However, they may need to do further tests, like blood tests, scans, or, less commonly, a tissue biopsy.

If you have been diagnosed with chronic GVHD

Some cases of chronic GVHD are mild, while others are moderate or severe. Chronic GVHD is considered more severe if there are more organs involved (for example, lungs, skin, and nails), or if the symptoms in any one organ is particularly severe. Your health care team will use a scoring system to assess how severe your chronic GVHD is.

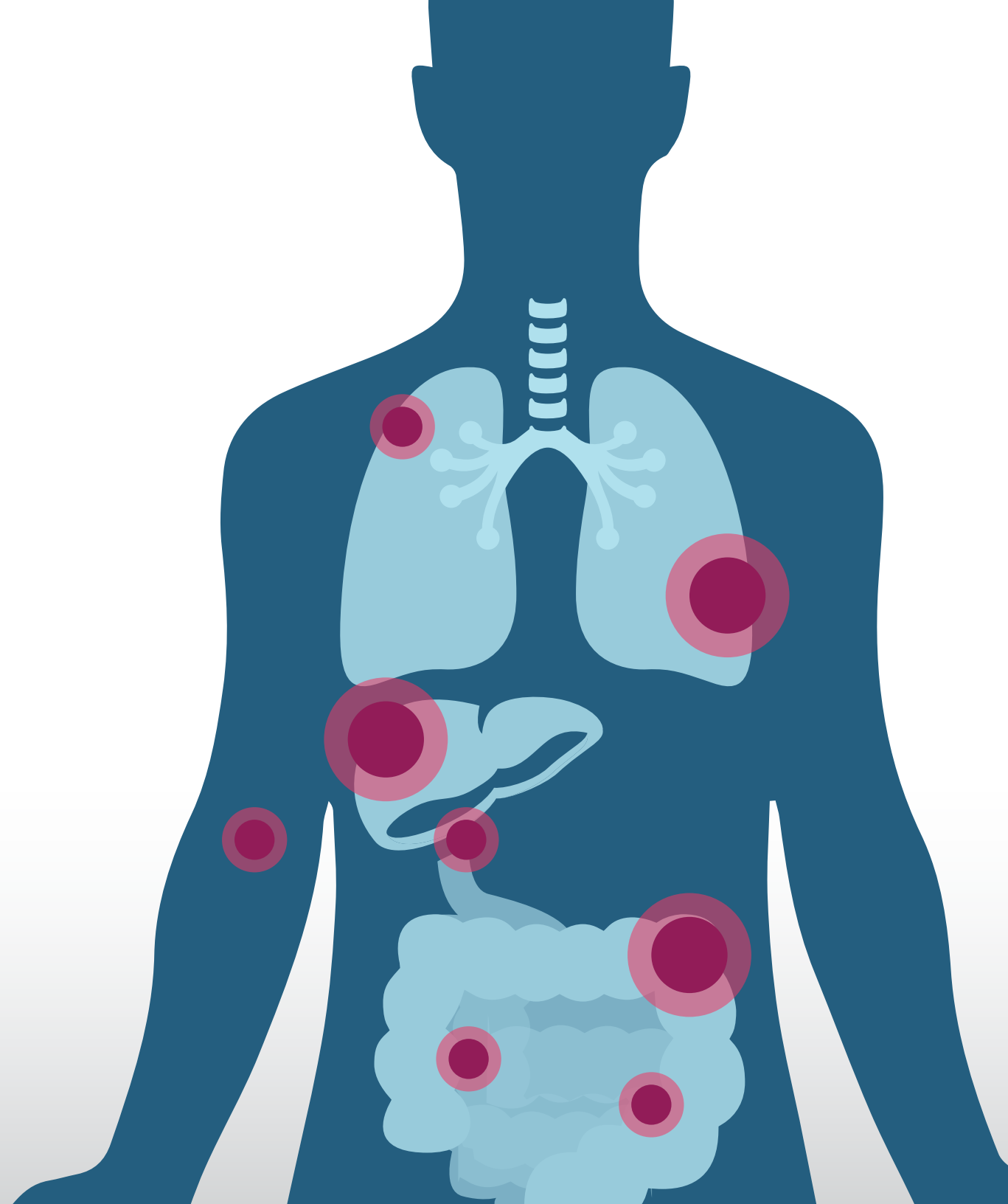
Many symptoms of chronic GVHD are caused by **inflammation** and **fibrosis**. Chronic inflammation damages tissues, which are then repaired by the body creating new connective tissue. When this damage-and-repair cycle happens too often, there is too much connective tissue, and permanent scarring can destroy normal tissue.

If you notice any of the signs or symptoms listed after receiving an allo-HCT, speak with your health care team immediately.

How could chronic GVHD affect my life?

Chronic GVHD is a very serious complication and can affect your ability to carry out everyday tasks and activities and may even lead to death. If you have chronic GVHD, you may experience limitations on what you can do in your everyday life. People with chronic GVHD are less likely to be fully active in school, work, or home activities. Fibrosis in particular can affect your joints, lungs, liver, and skin, which may limit your ability to do your regular activities.

Going through a blood stem cell transplant and chronic illness is difficult. Many people who receive HCT also experience depression or anxiety. Talk to your doctor about your next steps with chronic GVHD.



How is chronic GVHD treated?

The primary goal of treatment for chronic GVHD is to manage symptoms. There are a number of options used in treatment of chronic GVHD.

Corticosteroids

- Used to provide relief from inflammation
- Works by lowering the activity of your immune system
- Side effects may include: increased appetite; weight gain; bloating; change in taste; abnormal fat deposits; nausea; vomiting; diarrhea; abdominal pain; indigestion; hiccups; thinning hair; unusual hair growth; feeling of general discomfort or uneasiness, dizziness, forgetfulness, confusion, tired, irritated, euphoria (intense feelings of wellbeing, elation, happiness, excitement and joy); nervousness or restlessness; trouble sleeping; change in strength (loss of muscles) and reflexes; rounder face; increased sweating; sore throat; headache; increased or decreased motility and number of sperm; irregular periods; black or tarry stools; skin problems: thin, fragile, dry, or itchy; tingling, tickling, prickling or burning; spots containing blood or caused by broken blood vessels; lightening or darkening of an area of skin; rash; acne or an area of pus that is red, warm, and swollen (abscess); gastrointestinal problems; liver problems; eye problems

Cyclosporine

- Used after organ or bone marrow transplantations to help prevent organ rejection
- Belongs to a family of drugs known as immunosuppressants
- Works to suppress or reduce the body's immune response
- Side effects may include: high blood pressure; kidney or liver problems; headache (including migraine); increased levels of lipids (e.g. cholesterol) in the blood; loss of appetite, nausea, vomiting, constipation, or diarrhea; acne or oily skin; slight trembling of the hands; increased growth of fine hairs on the body; muscle or joint pains or cramping; weakness, anxiety; tingling in the fingers, toes, or mouth; night sweats; hearing loss; swelling of the face; increased potassium in the body; tender or swollen gums; decreased ability to fight infection; low level of white blood cells; high level of sugar in the blood; hot flushes; stomach ulcer; rash

Ibrutinib

- Used to treat adults with chronic GVHD when corticosteroid therapy did not work and additional therapy is needed
- Used to treat children 1 year of age and older with chronic GVHD who have received at least one line of therapy that did not work
- Blocks a specific protein in the body called Bruton's Tyrosine Kinase

- Side effects may include: heart problems like arrhythmia or heart failure, increase in the number of white blood cells (lymphocytosis), as seen on blood tests; diarrhea; viral, bacterial, or fungal infections (infections can be serious and may lead to death); fatigue, lack of energy, anxiety, difficulty falling or staying asleep; common cold, cough, stuffy or infected nose, sinuses or throat; chills; muscle aches/pain/spasm, joint aches/pain; headache, dizziness, weakness, anxiety; rash, itching, dry skin, skin infection; inflammation of the fatty tissue underneath the skin; nausea, sore mouth or throat, constipation, vomiting, loss of appetite, stomach pain, indigestion, mouth sores; nail changes such as brittle fingernails and toenails; inflamed blood vessels in the skin, which may lead to a rash (cutaneous vasculitis)

Ruxolitinib

- Used to treat adults and children 12 years of age and older with GVHD, which can happen after a blood or bone marrow transplant
- Chronic GVHD can happen weeks to months after a transplant. These patients will have received other medicines for their GVHD but these did not work well enough
- Blocks the action of certain enzymes in the body called Janus Associated Kinases (JAK1 and JAK2)
- Side effects may include: dizziness; bruising; headache; weight gain; frequently passing gas; diarrhea; nausea; constipation; muscle spasms; ringing in the ears; back pain; numbness; anxiety; cough, pain in the mouth and/or throat; nose bleeds; high blood pressure may also be the cause of dizziness and headache; BK virus infection (fever, pain, redness, and/or difficulty breathing); fever

Belumosudil

- Used to treat patients, 12 years of age and older, with chronic graft-versus-host disease (GVHD) after two or more prior treatments that did not work
- Blocks a specific protein in the body that is involved in inflammation and fibrosis
- Side effects may include: infections; tiredness or weakness; nausea or vomiting; difficulty swallowing; diarrhea or constipation; cough; shortness of breath; cold symptoms; swelling; bleeding; stomach pain; muscle, bone, or joint pain; muscle spasms; headache; high blood pressure; itchy skin, rash

Ask your doctor to learn more

How can I ease my symptoms?

Here are some tips and tricks to manage your chronic GVHD:



Eyes

- Keep eyes moist with preservative-free artificial tears
- Keep your eyes moist while you sleep using an eye gel or ointment
- Stay out of wind, air conditioning, and dry environments



Mouth

- Drink water often to keep your mouth moist
- If you have difficulty swallowing, take small bites and chew food completely
- Keep teeth clean (brush twice daily, floss once daily) and visit a dentist regularly



Skin

- Apply fragrance-free ointments or creams right after you shower or bathe
- Protect your skin from sun exposure by wearing a hat, long-sleeves and pants, and using sunscreen
- If skin or tissues are tight, gentle stretching, massage or physical therapy may help loosen thickened or hardened skin



Genitals

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
- Use a water or silicone-based lubricator before sex



Digestive System

- Keep a list of what you eat and symptoms
- Spicy, oily, or fatty foods and dairy products are more likely to cause problems
- See a dietician if you're losing weight



Lungs

To lower your risk of lung infections:

- Wash your hands often
- Avoid sick people
- Get vaccines recommended by your doctor
- Avoid yard work or exposure to dirt, soil, or plants



Muscles and Joints

- Ask your doctor if seeing a physical therapist could help
- Avoid positions that decrease blood flow to your legs (for example, crossing your legs or sitting for a long time)

Chronic GVHD can cause new symptoms, even many years after you start treatment. Report any new symptoms to your doctor immediately.

Support Resources

Myeloma Canada

Provides downloadable educational guides, videos, and additional resources to those affected by multiple myeloma (including access to virtual support groups, local support groups, and more).

Learn more: myelomacanada.ca

Leukemia and Lymphoma Society of Canada

Provides educational information, resources, and support to those affected by blood cancers (including access to one-on-one personal support, peer-to-peer support, educational events, and more).

Learn more: lls.org/support-resources

Canadian Cancer Society

Provides cancer and cancer side effect information and various support services (including access to a National Cancer Information Helpline, a community service locator, and more).

Learn more: cancer.ca/en/living-with-cancer/how-we-can-help

Glossary

Allogeneic hematopoietic cell transplant (allo-HCT):

A procedure where a person receives healthy blood stem cells from a donor to replace their own stem cells.

Autologous hematopoietic cell transplant (auto-HCT):

A procedure where a person's healthy cells are collected before they receive their cancer treatment and then given back to the person.

Corticosteroids:

An anti-inflammatory medication used to suppress the immune system for a wide range of conditions.

Fibrosis:

Overgrowth, hardening, and/or scarring of various tissues.

Inflammation:

A protective reaction to injury, disease, or irritation that results in redness, swelling, pain, and/or a feeling of heat.

