

Long-Term Follow-Up Care After Your Stem Cell Transplant

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What is long-term follow-up care?

- This is follow-up care for a period of time after a treatment, surgery, or other health care procedure.
- Long-term follow-up care after your stem cell transplant will include:
 - › Appointments with your transplant doctor and clinic nurse
 - › Blood work
 - › Pulmonary (lung) function tests
 - › Other tests, as needed
 - › Following your vaccination schedule
 - › Social and emotional support

Why do I need long-term follow-up care?

- The stem cell transplant and other therapies you needed to treat your cancer have put you at a higher risk for other health problems.
- Long-term follow-up care is very important to help you:
 - › Manage these risks
 - › Have the best health that you can after your transplant

Follow-up care team

- Your follow-up care team includes:
 - › Your transplant doctor
 - › Registered nurses (RNs)

My transplant doctor: _____

Follow-up care plan

Year 2

- › Follow-up visit with your transplant doctor and clinic nurse every 3 to 6 months

Years 3 to 6

- › Follow-up visit with your transplant doctor or clinic nurse every 6 to 12 months
- You may have more or fewer appointments. This will depend on your care needs and health.

After year 6

- If you do not have **chronic graft-versus-host disease** (GVHD) (see page 7) or any other active concerns, we will transfer your follow-up care to your primary health care provider (family doctor or nurse practitioner), if you have one. We will give them a letter with recommendations for your care.

Where do I go for my appointments?

Hematology Clinic

Victoria Building, 4th floor

Victoria General (VG) site, QE II

- Be sure that you have enough time to park before your appointment. Parking at the VG site is limited.

If you will be late or you need to change your appointment:

› Phone: 902-473-3127

- If you cannot attend your appointment in person, you may be able to have a phone appointment instead.
 - › This may not be possible if you need to be assessed in person (for example, if you are having active symptoms).

How do I get ready for my follow-up appointments?

- Have blood work done before your appointment, if needed.
 - › If you have problems booking an appointment or you have questions about what blood work you need, please call your clinic nurse.

My clinic nurse: _____

Phone: _____

If you are having blood work done at a clinic outside of Nova Scotia, ask clinic staff to fax your results to:

- › Fax: 1-902-473-7098
- Bring an up-to-date list of all your medications (including prescription and over-the-counter medications, inhalers, creams, eye drops, patches, herbal products, vitamins, and supplements) and the doses (amounts) you are taking with you to your appointment.
- Check if you need any prescription refills.
- Make a list of any questions or concerns you have so you can ask about them at your appointment.

Types of follow-up care you may have

Follow-up care for your immune system

- Because you lost your immune system as part of your transplant, it is easier for you to get infections that could be dangerous.
- You may need to take medications to prevent infections if your immune system is lowered.
- You may need to get intravenous (I.V.) antibody (immunoglobulin) replacements if you have infections often.
- You will need to keep up your vaccination schedule. Please talk to a member of your health care team if you have any questions about vaccines.
 - › Keep a record of the vaccines you have had. Give this record to your nurse at your next appointment.

Follow-up care to watch for other cancers

- People who have had a transplant are 2 to 5 times more likely to get another cancer than people who have not had a transplant.
- Some of the more common types of cancer people can get after a transplant are skin, thyroid, breast, gastrointestinal (gut), and other blood cancers.

- It is important to follow cancer screening guidelines. If you **do not** have a family history of cancer, follow these guidelines:
 - › If you are between the ages of 50 and 75, you should get regular colon cancer prevention screenings.
 - › If you have breasts and are 40 years old or older, get a mammogram every year.
 - › If you have a cervix, are sexually active, and are between the ages of 25 and 70, get a Pap test every 3 years.
 - › If you have a prostate and are between the ages of 50 and 75, talk about the benefits of prostate screening with your primary health care provider.
- It is important to check your skin often. Tell your primary health care provider about any new lumps or bumps on your skin or changes to any freckles or moles.
 - › Practice sun safety and make sure you wear sunscreen with SPF 30 or higher when you are out in the sun.
- Have a dentist check your mouth for oral (mouth) cancers 2 times a year.

Follow-up care for bone density

- The treatments you had for your transplant can make your bones weak. You may be asked to have a bone density test to check your bone health.
- Depending on your test results, you may be asked to:
 - › Take vitamin supplements
 - › Take medications
 - › Receive I.V. medication

This will help to make your bones stronger.

Follow-up care for chronic GVHD

- GVHD is a condition that can happen when you receive stem cells or bone marrow from a donor. It is when the donor's white blood cells attack your tissues.
- GVHD usually happens after engraftment (when the donor's stem cells start to make new white blood cells, red blood cells, and platelets). Chronic GVHD usually starts more than 100 days after transplant.
- If your donor is your sibling (brother or sister) or another relative, the chance of moderate to severe (very bad) GVHD is about 30 to 50%. If you are not related to your donor, the chance is 80%.

Symptoms of chronic GVHD

- Your transplant doctor or clinic nurse will check for chronic GVHD. The symptoms may be mild or severe.
- If your GVHD does not get better, you may need to be admitted to the hospital or take medication long-term.
- Chronic GVHD can affect any organ in your body. Symptoms include:

Skin

- › New areas of dry, red, itchy skin (especially on the palms of your hands, bottoms of your feet, or behind your ears)
- › Dryness, itching, tightness, or thickening of the skin
- › Dry or brittle nails
- › Nail loss

Eyes

- › Dry or runny eyes
- › Redness
- › Feeling sensitive to light
- › Feeling like there is something in your eye

Mouth

- › Ulcers or open areas on your tongue, the insides of your cheeks, or the roof of your mouth
- › Dry mouth
- › Being sensitive to hot, cold, spicy, or minty foods and products

Liver

- › Jaundice (yellow colour) in your skin or eyes
- › Fluid buildup in your abdomen (stomach area)
- › Abnormal blood work results of your liver function tests

Gastrointestinal (G.I.)

- › Nausea (feeling sick to your stomach), throwing up, or diarrhea (loose, watery poop) that is different than usual
- › Weight loss that does not seem to have a cause or that you cannot explain
- › Loss of appetite (do not feel hungry) or feeling full early
- › Tightening of your esophagus (tube that connects your mouth to your stomach)
- › Trouble swallowing

Vagina

- › Dryness
- › Burning
- › Itching
- › Having infections often
- › Pain during sex

Lungs

- › A cough that is new or getting worse
- › Trouble breathing that is new or getting worse
- › Wheezing

Muscles and joints

- › New joint or muscle pain that is not related to a recent injury
- › Less joint mobility (movement) or contractures (when muscles, tendons, or other tissues get short and hard)

Chronic GVHD assessment

- At each appointment, your nurse will do a physical exam to check for chronic GVHD.
- We will also monitor your blood work for signs of chronic GVHD.
- For the first 2 years after your transplant, you will have a pulmonary function test every 3 to 6 months. This is to check how well your lungs are working. After 2 years, you will have this test as needed.
- Depending on your symptoms, you may need other tests (like a colonoscopy or a bronchoscopy) to diagnose chronic GVHD.

Chronic GVHD treatment

- The goal of chronic GVHD treatment is to lower your new immune system to protect your body's healthy tissues.
- Your transplant doctor may prescribe medication, like an oral (taken by mouth) steroid, a steroid ointment, or eye drops.
- Depending on how you respond to treatment, your doctor may start other therapies to lower your immune system (like cyclosporine, tacrolimus, or Jakavi®).

Important

All treatments for chronic GVHD have side effects. The choice to start any treatment will be based on:

- › Your symptoms
- › Possible side effects of the treatment
- › How the treatment may affect your quality of life

Healthy living after your transplant

Mental health

- Having a stem cell transplant can be hard physically and emotionally.
 - › You may feel worried, anxious, sad, or depressed.
 - › You may find it hard to cope with the changes to your daily life after your transplant.
 - › You may worry that your disease will come back or that you will get GVHD.
- It may help to talk with a counsellor or a therapist. They can help you understand your feelings and find ways to manage them.

Things that can help

- Do things that you like and find relaxing, even if you do not feel like it. This can help to improve your mood.
- Be physically active. You may not be able to be as active as you were before your transplant, but you can add activities (like short walks) to your daily routine. This can help with your recovery, and with any aches and pains you may have.
- Pay attention to what triggers (brings on) your anxiety or sadness. Once you know your triggers, you can try to plan ahead to help manage your feelings.
- Express your feelings. Talk openly about your struggles with your support persons or your health care team.
- Get more light. Being in rooms or spaces that have lots of light and air can help improve your mood.
- Surround yourself with people who support you (like family, friends, or supportive peers).
- Find purpose in your life after your transplant. You may wish to volunteer, go back to work or find a new job, or find a new hobby.
- Make plans. Having things to look forward to can help improve your mood.

Mental health supports

Social work support

- Social workers are available for counselling and support. Ask your clinic nurse to refer you, or call the self-referral line:
 - › Phone: 902-240-8129

Wellspring online programs

- Access free, downloadable programs, interactive group programs, and self-paced information sessions:
 - › <https://wellspring.ca>

Group learning sessions for cancer-related sadness and depression

- To register for an upcoming session:
 - › Phone (toll-free): 1-866-599-2267, option 2
- You can also watch a video of each group learning session:
 - › <https://vimeo.com/showcase/cancereducation>

Fatigue (tiredness)

- After a stem cell transplant, it is common to feel fatigue that is **not** caused by activity or effort.
- The amount of fatigue, how often it happens, and how long it lasts will be different for each person. Some people may never have the same amount of energy as they did before their transplant.

Things that can help

Physical activity

- It can be hard to be active when you feel tired, but resting more can make transplant-related fatigue worse.
- Regular, moderate activity can:
 - › Lower fatigue and give you more energy
 - › Improve your sleep
 - › Help improve your mood and sense of wellbeing
- Start slowly and increase your activity slowly over time, as you are able. Remember that any movement is better than nothing.

You may wish to start with:

- › Sweeping the floor
- › Carrying and sorting laundry

- › Taking the dog outside for a walk
- › Going for a walk while talking on the phone
- › Parking farther away from the entrance of a building so you have farther to walk

Physical Activity and Cancer (PAC) Lab

- Exercise programs for people affected by cancer. For more information:
 - › www.thepaclab.com
 - › Email: EXCancer@nshealth.ca

Healthy eating

- Eat foods that are high in nutrients, like:
 - › Nuts and seeds
 - › Fresh or dried fruit
 - › Yogurt
- Eat a variety of foods.
- Protein is important for healing. Good sources of protein include:
 - › Meat
 - › Fish
 - › Milk products
 - › Beans
- Drink lots of fluids. Dehydration (not having enough fluids) can make fatigue seem worse.

- Tell a member of your health care team that you would like to talk with a dietitian if you:
 - › Are losing weight without trying
 - › Have a low appetite
 - › Have a condition that limits what you can eat

Sleep and rest

- Resting a lot will **not** help this type of fatigue. It is important to focus on improving the quality of your sleep and rest.
- To improve your sleep quality:
 - › Try to limit how long you nap during the day. Your longest sleep should be at night.
 - › Try not to lay in bed, except when you are sleeping. Do activities like reading or watching TV in a different room.
 - › Try to relax at bedtime (for example, try having a warm drink with no caffeine, meditate, or take a warm bath).
 - › Limit screen time (like computers, phones, or ebooks) before bed.
 - › Avoid eating, having drinks with caffeine or alcohol, and smoking before bed.

- › Follow a sleep routine: wake up at the same time and go to bed at the same time every day.
- › Within 60 minutes (1 hour) of waking up, get some bright light (natural or artificial). This will improve your energy and mood.

Managing new levels of energy

- Your energy levels may never go back to what they were before your transplant.
- To manage your energy:
 - › Figure out when your energy is highest and lowest. Plan your day around those times.
 - › Spread tasks throughout the week.
 - › Organize your time to avoid rushing.
 - › Pace yourself with balance and rest.
 - › Ask your support persons for help with things you no longer have the energy to do.

Going back to work

- Many people start to think about going back to work around 1 year after their transplant.
- The thought of going back to work can be stressful. You may worry that your work will be harder to do than before your transplant.
- It is important to talk with your employer about your concerns. They may be able to help you find ways to deal with your concerns and ease back into work.
- Please tell your nurse if you would like to talk with other people who have gone through this, or with a social worker.
- For more information about going back to work after cancer treatment, visit:
 - › www.cancerandwork.ca

Returning to Work online program

- This is a 5-week online group program from the Canadian Cancer Society and Wellspring Cancer Canada about going back to work after cancer treatment. To learn more and to register, visit:
 - › <https://library.nshealth.ca/returning-to-work>

This pamphlet is for educational purposes only. It is not intended to replace the advice or professional judgment of a health care provider. The information may not apply to all situations. If you have any questions, please ask your health care provider.

Find this pamphlet and all our patient resources here:
<https://library.nshealth.ca/Patients-Guides>

Connect with a registered nurse in Nova Scotia any time:
Call 811 or visit: <https://811.novascotia.ca>

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