Caregiver Education

The Caregiver Role

Information for Caregivers

Read this guide to learn:

- What is a caregiver
- About the role and responsibilities of a caregiver
- About caregiver resources

The Leukemia/Bone Marrow
Transplant Program of BC

Important Phone Numbers:

The Leukemia/BMT Daycare Unit Hours:
6th Floor Leon Blackmore Pavilion, VGH
Monday to Friday 7:00 am – 7:30pm
Weekends 8:00 am – 6:00 pm
Holidays 7:00 am – 7:30 pm

604 – 875 - 4073

If the patient does not have a scheduled appointment, please call the unit and speak to a Triage Nurse prior to showing up to the Leukemia/BMT Daycare Unit.

Hematology Apheresis Unit (HAU):
6th Floor Leon Blackmore Pavilion, VGH
Monday to Friday 7:00 am – 7:00 pm
Weekends & Holidays Closed

604 - 875 - 4626

BMT Daycare and Apheresis After Hours:
BMT Daycare and Apheresis units close every night; for issues afterhours please call the Leukemia/BMT Inpatient Unit
15th & 16th Floor
Jim Pattison Pavilion, VGH

604 - 875 - 4343

Call us immediately if the patient has:

- Fever: a temperature of 38°C or higher
- Flu-like symptoms, chills or shaking
- Yellow or green mucus when they cough
- Shortness of breath or a bad cough
- Diarrhea, nausea or vomiting that doesn’t stop
- Impaired speech, memory loss, confusion
- New bad bruising and/or bleeding
- Difficulty taking their pills
- New pain or a bad headache
- Concerns about their CVC line
- Dizziness, unsteadiness when walking or has fallen down
- Rash, blisters, allergic reactions

In Case of Emergency – Call 911

If you are caring for someone that is having severe chest pain, can’t breathe, or requires urgent medical care – **Call 911**. An ambulance will take them to the closest hospital. Tell the staff they are a Leukemia/BMT patient and to contact our Doctor on call. These symptoms cannot be managed over the phone.

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What is a Caregiver?

The main responsibility of a caregiver is to make sure the person within their care is safe and healthy. A caregiver needs to be available to help with basic day-to-day medical and practical issues as well as provide emotional support.

When the patient is admitted to the hospital, the healthcare team will provide care. In the time before they are admitted to hospital and after they are discharged from the hospital a caregiver will be needed.

It is important for a caregiver to stay positive, calm, and flexible while providing the patient with the support and encouragement they need. The caregiver role is challenging and you might at times feel overwhelmed by the responsibilities.

Caregiver(s) can be:

- Family members
- Close friends
- More than one person

Additionally, the primary caregiver is required to be:

- Aged 19 years or older.
- Someone who can commit to being with the patient 24 hours a day, 7 days a week, if required (check with the healthcare team).
- Able to understand what is required of them.
- Someone who is responsible.
- Physically, mentally, and financially able to commit to the role.
- You must be able to communicate with the healthcare team. Translation and interpretation services can be provided.

Caregiver Responsibilities:

Caregiver duties and responsibilities depend on what your loved one needs. You can help by:

- Coordinating services, such as transportation to and from the clinic.
- Attending appointments, taking notes, asking questions, keeping track of the patient’s schedule.
- Providing emotional support.
- Providing support at home:
  - *Reminding the patient to take oral medications.*
  - *Identifying changes in the patient’s condition to the clinical team.*
  - *Calling the BMT triage nursing line or obtaining urgent medical care, if needed.*
- Maintaining the home environment (e.g., household cleaning, pet care, laundry).
- Activities of daily living (e.g., grocery shopping, preparing food, picking up prescriptions).
- Serving as a communication link with other family members and friends.

The Role and Responsibilities of a Caregiver:

The healthcare team may provide information about the caregiver role and responsibility. Some of these responsibilities will include, but are not limited to, the following tasks:

Medical Support	Emotional Support	Practical Support
• Gathering information • Helping the patient take their medications • Taking the patient's temperature twice a day (morning and evening and whenever they are feeling unwell) • Keeping track of the patient's temperatures, and calling the nursing triage line if the patient's temperature is ≥ 38ºC • Helping ensure the patient is drinking enough water and getting enough nutrition • Monitor how often the patient is peeing and passing stool • Noticing changes in the patient's condition and calling the triage nursing line when needed • Notifying the healthcare team about changes in the patient's condition and new symptoms they are experiencing • Calling for medical help in an emergency	• Paying attention to the patient's moods and feelings • Communicating with and listening to the patient • Supporting the patient to talk with the healthcare team about their emotional state • Feeling comfortable talking to the healthcare team if you are concerned about their emotional state • Helping the patient keep a list of questions for the healthcare team • Helping the patient access emotional support resources	• Keeping track of the patient's appointment schedule • Managing the patient's daily routine so they can focus on recovery • Helping the patient with daily activities such as toileting, bathing, getting dressed, brushing hair • Assisting with transportation to and from appointments • Dealing with financial and insurance issues • Assisting with arranging lodging prior to treatment • Cooking or providing meals • Handling food safely to prevent foodborne illness (food poisoning) • Keeping the home or living area clean to minimize risk of infection • Keeping family members and friends up to date about the patient's condition • Managing the number of visitors the patient has • Keeping the patient away from anyone that is sick

Caregiver Review and Checklist

Being the primary caregiver is an important role, and no one expects you to do it alone. Use the checklist below to start preparing for the role.

	Questions:	Notes
☐	Can I take the time off from work?	
☐	Will I be able to travel with my loved one to their different appointments (doctor, tests, treatment, follow-up, etc...)?	
☐	How will I cover my expenses if I am taking time off from work?	
☐	Do I need to apply for family medical leave or family caregiver benefits?	
☐	Do I have someone who can care for my/our other family members?	
☐	Do I have someone to check on the house or care for the pets while we are away from home or in the hospital?	
☐	Am I emotionally able to support my loved one during their treatment and recovery?	
☐	Who will I reach out to for support?	
☐	What do I need to learn about my loved one's treatment to be a good caregiver?	
☐	What concerns and questions do I have, and who can I contact to clear them up?	
☐	Where will I stay while my loved one is being treated in hospital?	
☐	What will I do for meals while my loved one is receiving treatment in hospital?	
☐	What do I need to bring to the hospital in the case of an emergency?	
☐	Who can take care of my loved one if I am unavailable?	
☐	Can I commit to staying with my loved one during their treatment?	
☐	Can I commit to only part of the duration of their treatment and recovery?	
☐	If so, how long and for what part?	
	Other questions:	

Delegating Tasks:

When a patient is going through treatment they will not feel well. It is a good idea to plan to have help. The chart below can help the patient decide what they would prefer to do themselves and what other people can do to help. Please have the patient fill out this chart.

Tasks that need to be done	This is something I prefer to do myself	This is something I would like help with	Person that may be able to help	Contact information
	☐	☐		
	☐	☐		
	☐	☐		
	☐	☐		
	☐	☐		
	☐	☐		
	☐	☐		
	☐	☐		
	☐	☐		

The Caregiver Experience

Being a caregiver for a loved one can be very rewarding. Most caregivers agree the experience changes their lives. Some caregivers have reported:

- Feeling a closer bond with the person with cancer
- Finding added meaning in life
- Finding new strength
- Developing a new appreciation for family and friendships

Nonetheless, the responsibility of being a caregiver can be overwhelming and stressful. Caregivers can have physical, emotional, social, spiritual, and financial distress.

Caregiver burnout is very common; it is a state of physical and emotional depletion resulting from prolonged stress and strain. Studies show that more than 60% of caregivers experience symptoms of burnout. Caregiver burnout can occur with role ambiguity, high expectations, difficulty saying "No", and lack of additional help.

What are the signs and symptoms of caregiver burnout?

Your health and well-being matter just as much as the person you are caring for. It is important to know the signs and symptoms of caregiver burnout. The signs and symptoms of caregiver burnout are similar to stress and depression. They can include:

- Emotional and physical exhaustion.
- Withdrawal from friends, family and other loved ones.
- Not taking time for yourself.
- Loss of interest in activities previously enjoyed.
- Feeling hopeless and helpless.
- Changes in appetite and/or weight.
- Changes in sleep patterns.
- Long-term fatigue.
- Unable to concentrate.
- Getting sick more often.
- Irritability, frustration, anger, or resentment toward others.
- Feeling isolated, stressed, or withdrawn.

Caregiver Support

To best support the patient, a caregiver will need their own community of support. A caregiver should seek and identify friends or family members they can turn to. Resources and support are available to help manage the many responsibilities that come with caring for a patient undergoing treatment. Caregivers can also join a caregiver support group or look for support groups online. See *Caregiver Resources* on Page 9. The Leukemia/BMT program's Social Workers can help support you and provide resources and information.

Tips for Self-Care

1. **Set aside a regular time to do something you enjoy.** Take a bath or visit a friend. Watch a TV show from start to finish. Read a book. Get your hair done. Listen to music. Catch up on your sleep. Remember this is your time to rest and recharge your batteries. If your loved one has an appointment at the Leukemia/BMT Daycare unit, check in with the Nurse to see if you can leave the unit and take some time to have a break.
2. **A good way to reduce stress is to get some exercise.** Walk, swim, jog, play golf. Work in the garden. Do some stretching. Try Tai Chi or Yoga.
3. **Eat a well-balanced diet.** Good nutrition is important to your health.
4. **Have regular check-ups.** Talk to your doctor about any health problems.
5. **Try to get enough sleep.** Sleep is important for staying healthy. If you have trouble getting to sleep, try breathing or relaxation exercises (there are books or apps to help). You may want to use your time off to catch up on sleep.
6. **Take part in activities you have enjoyed in the past.** Or try something new.
7. **Keep in touch with friends.** You need a life apart from your caring role. If you cut yourself off, you are also cutting off the support that friends will give you. And you will find it hard to pick up the pieces of your life when you are no longer spending so much time caregiving. You might like to join a support group. It is a good way to meet new people who have the same experiences as you do.
8. **Don't try to be a superhero.** Be realistic. Think about what really matters most to you. Let the less important things wait. Learn to say "No".
9. **Reward yourself.** Remember to congratulate yourself for all your successes.

Caregiver Resources

Leukemia & Lymphoma Society of Canada. Go to **www.bloodcancers.ca** Search "Caring for a loved one with a blood cancer" or "Learning to be a caregiver" or "Taking care of yourself". Click on the result. Search "First Connection Peer Support Program". Click on the second result with the same name.

Canadian Cancer Society. Go to **www.cancer.ca** Search "caregiver". Click on any of the results you feel apply to your situation.

BC Cancer. Go to **www.bccancer.bc.ca** Search "patient and family counselling". Click on the first result "Patient & Family Counselling". Individuals, couples, caregivers and family can talk to BC Cancer counsellors in-person or over the phone.

Family Caregivers of BC. Go to **www.familycaregiversbc.ca** Click on Caregiver Support Groups. They are a non-for-profit organization that supports caregivers by providing access to information, education and support.

Leukemia/BMT Social Workers. They can support you to explore various programs for emotional support and practical (financial and travel) assistance.

PATIENT TREATMENT CALENDAR

Note upcoming appointments in this calendar. If your loved one misses an appointment, reschedule as soon as possible

JAN FEB MAR APR MAY JUN JUL AUG SEP OCT NOV DEC

SU	M	TU	W	TH	F	SA
SU	M	TU	W	TH	F	SA
SU	M	TU	W	TH	F	SA
SU	M	TU	W	TH	F	SA
SU	M	TU	W	TH	F	SA

Key dates you may want to write down:

Notes:

References

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Vancouver Coastal Health. (2020, May). Take Care: A handbook for family caregivers [Pamphlet].

Please note: the information contained in this manual is not intended to replace the advice of the patient's healthcare team. Use this as a reference and education guide. Consult the patient's healthcare team if you have any questions or concerns. Creators and Authors: Danae Lohrenz 08/2024, Marie Scott 08/2024, Sally Moore 06/2026. Editors: Nogol Salehi 06/2026, Jennifer Miller 06/2026, Tanisha Bors 06/2026, Patsy Vanee 03/2026, Mona Walia 06/2026, Tessa Veikle 06/2026.