

Support and Resources

for Patients and Caregivers

Included in this booklet:

- Support Groups and Resources
- Caregiver Supports
- Cancer Support Services
- Finances and Travelling
- Volunteer Drivers
- Helpful Websites
- Young Adult Resources
- Palliative Care Supports



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To our Patients and their Caregivers

When you have cancer, the focus is often on the physical side effects of your illness – on symptoms, treatment choices, side effects and what the test results show. But your emotional health – your feelings and how you cope with them over time – is also important. It deserves as much care as your physical health.

There is really no right or wrong way to feel when you or your loved one has cancer. Everyone will react to the diagnosis in their own way. This booklet is to inform patients and caregivers on the supports and resources that are available for those dealing with a new diagnosis or in active treatment for a blood cancer.

Remember that you are never alone. There are people to help and support you. Some of them are in your home and community; others are at your hospital, place of worship or cancer centre.

For a helpful book that can help you manage the many emotions of a cancer diagnosis, we recommend:

- ***Coping When You have Cancer. Canadian Cancer Society 2017.***

Copies can be found:

- **Online:** Read or order a free printed copy at:
www.cancer.ca/en/support-and-services/resources/publications
- **The Inpatient Unit:** on T15 near the public washrooms (room 15020)
- **The Outpatient Daycare Unit:** on LB6 in the patient library (room 631)

Who are My Health Care Team Members? What Do They Do?

Attending Doctor (Hematologist): The “head doctor” in charge of your care. Hematologists specialize in blood diseases and disorders. This doctor is usually on duty for two weeks at a time on the inpatient and outpatient units. All attending doctors meet regularly to discuss your case.

Clinical Associate Doctors and Fellow Doctors: Doctors with advanced training in blood diseases and stem cell transplant. They will assess you every day (or every visit in Daycare) and discuss your progress with the Attending Doctor.

Registered Nurse (RN): Nurses assess your condition and progress, give your medications and assist with all aspects of your care. Your nurse is your main contact through treatment; and monitoring and supporting you 24hr/day on the inpatient unit.

Pharmacist: Pharmacists monitor and prevent problems related to the medications your doctors order for you. They help you understand how to take medications at home.

Social Worker: Social Workers help you cope with your diagnosis and how it may affect you, your family, your living arrangements, your finances and other practical matters.

Registered Dietitian: Dietitians are experts in nutrition. They help you manage symptoms and make the best food choices, especially when your appetite is low.

Physiotherapist (PT): This team helps you maintain and regain your strength through treatment and recovery. They help you design an activity program based on your needs.

Occupational Therapist (OT): This team helps you manage everyday activities, moving safely, coping with symptoms and any equipment needs you may have to get you through the day.

Spiritual Care Counsellor: A chaplain is available for all religious and spiritual needs, regardless of your beliefs. They provide spiritual care to people of all faiths and can arrange care by clergy in the community. Speak with your nurse to arrange a visit.

Nurse Navigators: This team arrange all the planning, testing and appointments needed if your doctor recommends a stem cell transplant or bone marrow transplant.

Patient Care Coordinator (Charge Nurse): Charge nurses supervise each unit and are available to discuss nursing care, hospital services and your needs and concerns.

Patient Services Manager: Each Nursing Manager is responsible for the BMT units within the program, including patient care & policies.

The Leukemia and Lymphoma Society

The Leukemia and Lymphoma Society of Canada mission is to support patients and their families who are facing the diagnosis of a blood cancer. Find more details at:

www.llscanada.org/bc

For those wanting to learn more about their diagnosis and treatment, this group offers the following booklets. “Guides” generally use simpler language.

- Understanding Leukemia
- Acute Lymphoma Leukemia (ALL)
- Acute Lymphoblastic Leukemia: A Guide for Patients and Families
- Chronic Myeloid Leukemia (CML)
- Chronic Myeloid Leukemia: A Guide for Patients and Families
- Acute Myeloid Leukemia (AML)
- Acute Myeloid Leukemia: A Guide for Patients and Families
- Chronic Lymphocytic Leukemia (CLL)
- Chronic Lymphocytic Leukemia: A Guide for Patients and Families
- Myelodysplastic Syndromes
- The MDS Guide
- Myeloma
- Myeloma: A Guide for Patients and Families
- Hodgkin Lymphoma
- Lymphoma: A Guide for Patients and Families
- Non-Hodgkin Lymphoma

Much more information on specific blood cancers and disorders are available online ↓

Copies can be found:

- **Online:** Read or order a free printed copy at:
www.llscanada.org/resource-center/download-or-order-free-publications
- **The Inpatient Unit:** on T15 near the public washrooms (room 15020)
- **The Outpatient Daycare Unit:** on LB6 in the patient library (room 631)

Please refer to the website link if copies are not available on the units.

Canadian Cancer Society

In addition to excellent online resources, the Canadian Cancer Society has telephone assistance for questions on cancer treatments, side effects, clinical trials, coping, emotional support services, prevention, community supports and approved complementary therapies. Find more details at:

www.cancer.ca or call 1 888 939 3333

Among the many booklets this group offers, you may be interested in:

- Life After Cancer Treatment
- Advanced Cancer
- Canadian Cancer Statistics
- *Chemotherapy and Other Drug Therapies
- Clinical Trials
- *Coping When You Have Cancer
- *Eating Well When You Have Cancer
- Listen First: And 9 other ways to support someone with cancer
- Pain Relief: A guide for people with cancer
- Questions to Ask When You Have Cancer
- Radiation Therapy: A Guide for People with Cancer
- Sex, Intimacy and Cancer
- When Your Child Has Cancer

*recommended booklets applicable to all patients and family members

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We try to keep our supplies stocked on the units, please refer to the website link if copies are not available.

BC Cancer

BC Cancer is the overall cancer treatment for BC and Yukon. In addition to the physicians, nurses and technicians, there are others on the healthcare team to assist you. Find more details at:

www.bccancer.bc.ca

Resources for emotional support, practical support, exercise, nutrition, managing side effects and more can be found at: www.bccancer.bc.ca/health-info/coping-with-cancer

BC Cancer Locations:

Abbotsford	604-851-4710
Kelowna	250-712-3900
Prince George	250-645-7300
Surrey	604-930-2098
Vancouver	604-877-6000
Victoria	250-519-5500

There may be additional community cancer support programs near you, please check your local listings or go to www.bccancer.bc.ca/our-services/centres-clinics/locations

BC Cancer Patient and Family Counselling

Counsellors are available to talk with at your regional cancer centre and over the phone. www.bccancer.bc.ca/our-services/services/patient-family-counselling

BC Cancer Support Programs

BC Cancer locations offer programs to help you and your caregivers cope with your diagnosis and the impact it has on the lives of you and your loved ones.

www.bccancer.bc.ca/our-services/services/support-programs

BC Cancer Libraries

BC Cancer has patient education materials in various locations and a full library at 675 West 10th Ave. in Vancouver. Librarians are there to assist you.

www.bccancer.bc.ca/Library or call 604.675.8001 or toll free 1.888.675.8000 ext. 8001

Canadian Blood Services

Please encourage friends, family and associates to donate blood and register as a stem cell donor with Canadian Blood Services. More information about this and the process of searching for an unrelated stem cell donor can be found at:

www.blood.ca or call 1 888 236 6283

Blood Cancer Support Groups

See below for telephone peer-to-peer programs that connect you and your family with trained volunteers who have experienced cancer:

- **Leukemia & Lymphoma First Connection 1-877-662-8326 ext. 5198**
www.llscanada.org/support/first-connection
- **Canadian Cancer Group Peer Support Program 1-888-939-3333**
<https://match.cancer.ca/>

Contact the links below for information on online and face to face support groups for patients and caregivers and what is available to you close to home.

- **Myeloma Canada 1-888-798-2242**
www.myeloma.ca/en/find-support/find-support-group
- **Leukemia & Lymphoma Society 1-833-222-4884**
www.llscanada.org/support/patient-education-programs

Cancer Chat <https://cancerchat.desouzainstitute.com>

This organization provides links to free and professionally-led online support groups for Canadian patients, caregivers and survivors affected by cancer.

Look Good Feel Better Program 1-800-914-5665

Free programs that help women cope with any appearance-related effects of their cancer and treatment with confidence. They strive to treat the whole person through workshops, online forums and peer support. www.lgfb.com

Cancer Support Services

InspireHealth Supportive Cancer Care 1-888-734-7125

With centres located in Vancouver, Victoria and Kelowna, they offer practical and personalized exercise therapy, stress management, nutrition and counselling services at no cost. Their live online meditation sessions are especially helpful for those with low immune systems and low energy. www.inspirehealth.ca

Family Caregivers of British Columbia 1-877-520-3267

This program is dedicated to supporting caregivers looking after loved ones. It offers free webinars, newsletters, workshops and support groups. www.familycaregiversbc.ca

Callanish Society 604-732-0633

An organization in Vancouver with outreach programs, counselling, retreats and group programs for people living with cancer. www.callanish.org

Finances and Travelling

Please see **BC Cancer's Financial Information for Cancer Patients booklet**

Online version: www.bccancer.bc.ca/health-info/coping-with-cancer/practical-support

The Travel Assistance Program (TAP) helps reduce your travel costs (i.e. free passage on BC ferries, guaranteed boarding, and reduced air travel rates through Harbour Air) This form needs to be completed by your doctor. Call 1 800 663 7100 or www2.gov.bc.ca/gov/content/health/accessing-health-care/tap-bc

Save your receipts: You and your partner may be able to use them to claim costs on your income tax. If your family helps you pay for medical costs, they may be able to claim these costs too. Examples: receipts for getting to the hospital, parking, gas, taxis, prescription medication costs you have to pay, medical/mobility devices (canes, wigs, raised toilet seats, etc.). Type "medical expenses" on www.canada.ca to learn about medical expenses you can claim on your tax return.

At Vancouver General Hospital

The **volunteer help desk** located in the main entrance of Jim Pattison Pavilion can help you with any questions about resources and locations in the hospital.

Translators/Language Interpreters

Spoken language interpreters are available to help with communication between staff and patients who have limited English. These interpreters can only be requested by our staff, please speak to us if you or your family needs the help of an interpreter.

Spiritual Care at VGH 604-875-4151

Ask your nurse for a referral to our Spiritual Care services; non-denominational professionals can meet with you, regardless of your beliefs. There is a Sacred Space on the ground floor of Leon Blackmore Pavilion near the elevators. This is a quiet room, open to everyone, for prayer, meditation, reflection and ceremony.

www.vch.ca/your-care/cultural-spiritual-services/spiritual-care-multifaith-services

VGH Centre for Patients and Families 604-875-5887

Located in VGH's main lobby, this is a quiet area where caregivers can access computers, phones, printers, copiers, fax machines and reading/media rooms. A librarian is also available to help recommend books & resources.

<https://centreforpatients.vch.ca/practicalresources/about-us>

Aboriginal Patient Navigator Program at VGH 1-877-875-1131

Ask for a referral to the Aboriginal Patient Navigator Program for requests for traditional ceremonies such as smudging, cedar and elder fan brushings or blanketing. See the link for the First Nations Health Authority's "Living with Cancer" Guide.

www.fnha.ca/wellnessContent/Wellness/Living-With-Cancer.pdf

Volunteer Drivers

There may be free services available to help you find your way to cancer appointments.
Please always book two days ahead if possible

Freemasons Volunteer Drivers (no charge) 604 872 2034 or 1- 800-663-2524

Covers Vancouver, Burnaby, New Westminster, Richmond

Operates Monday – Friday

Volunteer Cancer Drivers Society (no charge) 604 515 5400

Covers North Shore, Tri-cities, Coquitlam, Port Coquitlam, Port Moody, Surrey, Delta, Langley, White Rock

Operates Monday – Friday

Blood Cancer and General Cancer Websites

Blood Cancer Videos: <https://bloodcancerclips.wordpress.com>

The Aplastic Anemia & Myelodysplasia Association of Canada: www.aamac.ca

CLL Patient Advocacy Group: <http://cllpag.ca>

Lymphoma Canada: www.lymphoma.ca or call 1 866 659 5556

Myeloma Canada: www.myelomacanada.ca or call 1 888 798 5771

International Myeloma Foundation: www.myeloma.org

International Waldenstrom's Macroglobulinemia Foundation: www.iwmf.com

Myeloproliferative Neoplasms: <http://mpninfo.org/mpns>

Canadian Blood and Marrow Transplant Group: www.cbmtg.org/page/Patients

Coping with Cancer (Canadian): www.copingwithcancer.ca

General Cancer Information (American): www.cancer.net

General Cancer Information (American): www.cancer.gov

General Blood Cancer Information (UK): <https://bloodwise.org.uk/>

General Cancer Information (UK) www.macmillan.org.uk/information-and-support

Stem Cell Transplant Information (UK): www.anthonynolan.org/patients-and-families

Blood and Marrow Transplant Information Network: www.bmtinonet.org

Helpful BC Resources and Websites

My eHealth

Access your test results online from Vancouver Coastal Health (outpatient results only), Lifelabs & other health centers in BC. www.myehealth.ca

Quit Smoking

There are many reasons to quit smoking, please ask us for more information.

www.quitnow.ca 1-877-455-2233 www.smokershelpline.ca 1-877-513-5333

Healthlink BC (Call 8-1-1)

Call 811 for general questions regarding your health. Offers online support and telephone access to nurses, dietitians, exercise professionals, pharmacists and translators. www.healthlink.ca

Fertile Future

This is a Canadian website with valuable information regarding fertility issues and options for men and women diagnosed with cancer. Check their services and assistance with costs related to fertility services. www.fertilefuture.ca

Nidus www.nidus.ca or call 604 408 7414 or 1 877 267 5552

This is a non-profit resource center to inform people about health and personal care, legal and financial affairs, and to help people understand and make arrangements for representation agreements, power of attorney, advanced directives and estate planning.

Kelty's Key Online Mental Health

Free and confidential online cognitive behavioural therapeutic courses that can provide you with the support you need to feel better. www.keltyskey.com

Online Videos and App

Cancer Related Fatigue Video: www.youtube.com/watch?v=YTFPMYGe86s

This video is part of a series of excellent health related videos made by Canadian Dr. Mike Evans.

Alberta MyHealth Video Series

<https://myhealth.alberta.ca/health/Pages/healthvideoplayer.aspx>

Browse “Cancer” and other health related videos

MacMillan Cancer Support Videos (United Kingdom)

www.macmillan.org.uk/information-and-support/resources-and-publications/videos

An excellent series of videos covering cancer information and coping

Tired of Cancer App www.tiredofcancerapp.com

There is a lot of information on the internet. How do you know what health websites are reliable? Learn more at <https://medlineplus.gov/webeval/webeval.html>

What other websites and videos have you found helpful? Let us know at **bmtpatienteducator@vch.ca**

Disclaimer:

The websites listed in this manual are created by organizations outside our program. They are meant to be used as information only and should not replace the advice given to you by your health care team. Information and policies change frequently and we cannot guarantee any websites contain the most up to date information. We do not endorse the content on any third party websites.

Contact bmtpatienteducator@vch.ca to offer feedback and to report any websites that are no longer working.

Young Adults

YAConnect: Young Adults Living with Leukemia, Lymphoma and Myeloma (LLS)

A chat group for young adults (age18-39) to discuss any issue related to living with a blood cancer: a new diagnosis, treatment decisions, relapse, treatment side effects, emotional toll, fatigue, interpersonal relationships, clinical trials, living with uncertainty and other survivorship issues. www.lls.org/childhood-blood-cancer/about-childhood-bloodcancer/teens-and-young-adults

The Callanish Society has a young adult program, see page 9.

Young Adult Cancer Canada (YACC)

A Canadian organization for young adults affected by any type of cancer. They offer information, retreats, workshops, support during treatment, goal-setting strategies for life after treatment and connection to other young adults. www.youngadultcancer.ca

Food and Nutrition

Most major grocery stores allow you to enter your grocery list over the phone or online. You can pick up your order in the store for free (or have it delivered for a fee).

Try safe take-out food restaurants. Download food delivery apps (i.e. DoorDash[®], Skip the Dishes[®] in Vancouver) for easier access to online menus.

To find a reputable restaurant, click “VCH Inspection Reports website” at:

www.vch.ca/public-health/environmental-health-inspections/restaurant-food-safety

Meal Preparation Services

Find local companies who will deliver meals ready to prepare. Search “meal prep services” with your city name.

Better Meals 1 888 838 1888

This BC company is available from mid-Vancouver Island to Victoria area and from the Okanagan to Vancouver area. Offers frozen, diet specific meals. www.bettermeals.ca

Meals on Wheels

This hot meal delivery program is available for those requiring temporary assistance during illness. <http://mealcall.org/canada/cities/?state=BC>

Palliative Care and Grief Resources

Nancy Chan Ambulatory Palliative Care Clinic (Vancouver) 604 659 1160

An excellent outpatient clinic that offers consultations to clients and families who are living with a serious illness and may be experiencing symptoms and distress which may be affecting their quality of life. www.vch.ca/Locations-Services/result?res_id=1434

Services may include one or more of the following:

- Palliative specialty consultation by Physician, Nurse, Social Worker and/or Spiritual Care Practitioner
- Symptom assessment and management
- Care planning, documentation, and communication to referral source (specialists, outpatient clinics, home health and GPs)
- Counselling and individualized education
- Spiritual care and counselling
- Self-management support and coaching – clients set goals and participate in action planning for ongoing and crisis-management planning
- Caregiver support/education
- Bereavement risk assessment and follow up

Canadian Virtual Hospice www.virtualhospice.ca

This website has a wealth of information and access to professionals to answer questions related to comfort care in advanced illness and end of life. Practical information, spiritual care, symptom management, decision making, nutrition, communication and other concerns are addressed by this service. They have also launched a new online app that is a comprehensive tool for grief and loss at www.mygrief.ca

British Columbia Hospice Palliative Care Association 604 267 7024

An association dedicated to the providing quality end-of-life care for British Columbians. It is a good place to find local information and resources. www.hospicebc.org

The BC Bereavement Helpline 1 877 779 2223

Trained personnel are available to assist bereaved callers with understanding responses to loss and to inform them of community resources, as appropriate. www.bcbh.ca

Choosing a Caregiver

When do I need a caregiver?

- When you are receiving treatment as an outpatient and have a low immune system, you need at least one family member or friend who can provide you with physical and emotional support 24 hours a day, 7 days a week.
- Patients who do not speak English: **we strongly suggest** these patients need an English speaking caregiver/contact, whether they are an inpatient or outpatient.
- Social workers and Nurse Navigators can help caregivers with requesting compassionate time off work and visa application letters.

How do I choose my caregiver?

- Caregivers should be someone you are comfortable around, is comfortable around you, and is able to help you through your treatment.
- If a patient does not speak English, we strongly suggest that their caregiver speaks English.

How many caregivers do I need?

- One caregiver may only be possible. If this is the case, we suggest arranging visits from family and friends so care-giving tasks do not fall on just one person.
- Having two caregivers allows each one to rest, relax and have time away from the hospital and responsibility. Caregivers can often experience a high degree of anxiety. Some of these stresses and anxieties can be reduced when shared.

If a patient does not speak English, why is it important for caregivers to speak English?

For us to best care for you, communication is extremely important. If patients and caregivers are unable to share their concerns and symptoms with our team, it makes it very difficult to care for you to the best of our ability. Translators are available but need to be booked days in advance.

Caregiver Responsibilities

Caregivers typically help in these ways:

- Making arrangements, such as transportation to and from the clinic
- Attending appointments, recording information, asking questions
- Providing emotional support
- Providing physical care:
 - Helping you take oral medications
 - Helping you care for your central venous catheter (at times)
 - Identifying changes in your condition
 - Obtaining medical care if needed
 - Reporting symptoms to health care staff
- Maintaining the home environment (household cleaning; preparing food)
- Serving as a communication link with other family members and friends

Tips for Caregivers

Here are some valuable suggestions from former patients and families for caregivers:

- Even if you don't think you need help, you do.
- Don't feel guilty about doing something for yourself.
- Sometimes crying is part of being strong.
- Realize that other family members and friends react different ways. Some people may be quiet or distant, others supportive.
- Try not to put your life on hold. Continue to meet with friends, enjoy hobbies or activities, and maintain as "normal" a schedule as possible.
- Be good to yourself. Self-care is not a luxury; it's a necessity! Make and take time away for yourself with the assistance of friends and family.
- Learn to recognize when you are stressed and what makes you stressed.
- Stay active. Go for a walk every day in the fresh air.
- Learn and practice relaxation techniques. (i.e. visualization, meditation, yoga)

- Watch your use of alcohol and/or recreational drugs. You may feel “relaxed” in the short run, but they are depressants and can make you feel worse.
- Learn to recognize the common signs of depression. Find professional help if you think you (or other close contacts) are depressed. Signs include:
 - Constant sadness, anxiety or emptiness
 - Changes in sleep patterns (too much or not enough sleep).
 - Changes in eating habits (unwanted weight gain or loss)
 - Loss of interest in people and/or activities that you once enjoyed
 - Becoming easily agitated, angered, or irritable
 - Overwhelming feelings of guilt, hopelessness or worthlessness
 - Thoughts of death or suicide, or attempting suicide
- Putting one’s legal affairs in order does not mean expecting the worst. It can give you the peace of mind to focus on recovery. This may include preparing wills, powers of attorney, and advanced care planning.
- Don’t do it all yourself! Ask, accept and if necessary, demand for offers of help. Helpful tasks are grocery shopping, cooking, caring for kids and pets.
- Learn to say “NO”. Some people can have good intentions but may further drain your valuable time and energy. Sometimes it is best just to say no.
- Educate yourself and be informed. Write down your questions to ask the health care team. Knowledge is power.
- Trust your instincts. They’re usually right!
- Grieve the many losses that accompany a serious illness, but don’t forget to dream your dreams. Focus on having a goal, something in the future outside of cancer (i.e. family events, vacations, etc.)
- Give yourself credit, this is a difficult role. You are making a big difference!
- Have someone you can talk to. Seek support from family, friends, other caregivers and professionals. Consider participating in a support group.
- Keep your sense of humour. Be around people who make you laugh.

Seattle Cancer Care Alliance’s Caregiver Guide:

www.seattlecca.org/sites/default/files/page_content/2017-05/Caregiver-Guide-5-2017.pdf

Symptoms of Caregiver Burnout

Being a caregiver is a rewarding, yet demanding job. Here are a few thoughts to keep in mind during the caregiver journey. Signs of burnout include:

- Irritability
- Insomnia
- Physical complaints
- Fatigue
- Decreased motivation
- Anger
- Resentment
- Emotional exhaustion

How Does Burnout Occur?

- Lack of clear job role definition
- Poor communication
- High expectations
- Difficulty saying no
- Being a “giver” rather than “receiver”
- Feeling of needing to prove oneself
- Self-sacrifice
- Perfectionism
- Difficulty delegating

Steps to Getting Help

- Recognize that not all tasks are of the same importance
- List all tasks that need to get done
- Group your list into categories
- Review your list of tasks with the intent of sorting
- Write down your worries
- Know what you can and cannot control
- Pat yourself on the back
- Asking for help is not a weakness. Ask someone to help.

Hope...

Hope is being honest with yourself about your situation, while still looking forward to positive outcomes in your future. Hope may not be easy to find. The changes that come with cancer can be overwhelming and cause a great deal of uncertainty. Hope can help you find the strength and courage to face these concerns.

Focus on wellness. Try to be hopeful. Sometimes this means looking for the good even during a bad time. Try to use your energy to focus on wellness and doing things that make you happy. Remember that you are never alone. There are people to help and support you. Some of them are in your home and community; others are at your hospital, cancer centre or place of worship.

There is no right or wrong way to hope.

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Please note that the information contained in this manual is not intended to replace the advice of your health care team. Use this as a reference and education guide. Consult your health care team if you have any questions or concerns. Author: Amy Healy 06/20 19

Adapted from *British Columbia Blood Cancer Resource Guide*. The Leukemia & Lymphoma Society of Canada 2017.

Adapted from *Caregiver Guide*. Seattle Cancer Care Alliance 2017.

Adapted from *Coping When You have Cancer*. Canadian Cancer Society 2017.