Mental Well-Being and Relapse: A Resource Guide for People Living With Myeloma

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Experiencing a relapse in your multiple myeloma can be very stressful, and while you may have lived with multiple myeloma for some time, relapse and disease progression can be a devastating emotional blow.

You may experience feelings of distress or fear, mixed with hope, as you navigate this stage of the disease, while also exploring options for new treatments and planning for the future.

Myeloma Canada has created “Mental Well-being and Relapse: A resource guide for people living with myeloma” for you and your loved ones as a support to your mental health and to help you determine how wellness strategies fit into your overall cancer treatment plan.

There are two parts to this document:

1. Questions and prompts to help you navigate a relapse – this is an opportunity for self-reflection for you to better understand how to manage your mental and emotional health through a relapse
2. A brief guide to psychosocial support in Canada

We have also included a list of questions that you can print out and bring to your next appointment with your healthcare team. These questions are meant to help ease discussions about mental health and what mental health (psychosocial) support is available to you during your relapse.

PART 1

Questions and prompts to help you navigate a relapse

Questions and prompts to help you navigate a relapse

Together with medical treatment, understanding and exploring the psychological burden associated with a relapse is a vital part of your treatment plan. The following questions are designed to help you think through the impact of a relapse on your well-being and to help you understand what next steps to take to ensure a whole-person approach to your care.

Everyday stressors and your well-being

- What emotions am I feeling given the news of my relapse?
- What thoughts are evoked by this news? What words would I use to describe what it is like to experience a relapse?
- What specific things are causing me to feel this way? It might be any or all of the below:
    - Do I experience this as a loss? If so, what have I lost?
    - Do I experience this as a threat? If so, what is the threat? Is it a source of worry or anxiety?
    - Do I believe this is unfair? If so, what is unfair for me?
- What am I most worried about?
- Who am I most worried about?
- Does this feel different from the last diagnosis?
- If so, in what way(s) is it different and in what ways does it feel different?

Action-focused questions

- What are my thoughts and feelings about having renewed conversations with my hematologist or healthcare professional about starting a new treatment?
- Who do I have in my family and/or my friendships that I can talk to about how I'm feeling about my relapse?
- Do I feel comfortable being open about my feelings and experiences with my hematologist and cancer care team?
- What are my thoughts about and feelings concerning the options in front of me?
- Am I pushing my feelings away (avoiding) or allowing myself to have these feelings without getting overwhelmed?

- What can I do to discharge negative feelings (not let them be bottled up) in a healthy way?
- Am I confident in my healthcare team to provide me with information and guidance?
- Am I confident that my healthcare team will support the decisions I will have to make around this new stage of my disease?
- Should I look at getting more psychological and emotional support? Do I know where to go for that support? Do I understand my options?

What next?

Though psychological and emotional cancer support (called psychosocial oncology) can differ from region to region, there are multiple options available to support your psychological, emotional and mental health, both off- and on-line.

Here are a few steps you can consider when bringing psychosocial support into your wellness plan:

1. Discuss having more psychosocial support as part of your treatment plan with your hematologist or cancer care team.
2. Find out what different specialist supports are available to you through the coordinators at your cancer centre.
3. Connect with a peer support, community support, or virtual support group.
4. Explore the programs available at community organizations like Myeloma Canada or local chapters.
5. Investigate options that may be available through your employer or your spouse/family member's employer or insurance plans.

PART 2

A guide to psychosocial oncology support available in Canada

A guide to psychosocial oncology support available in Canada

Cancer Care Ontario identifies eight different types of psychosocial specialists available to people experiencing a relapse. Below is a short description of each to make it easier for you to decide which one might be the best fit for you and your specific needs.

Note: These specialists are not specific to only psychosocial oncology, but are outlined in accordance with Cancer Care Ontario's descriptions.

- **Psychiatry:** Medical practitioners who provide specialty care to patients and are experts in the assessment of psychiatric and emotional disorders.
- **Psychology:** Scientist-practitioners who obtain competency in one or more of clinical psychology, health psychology, rehabilitation psychology, and neuropsychology. They are experts in the assessment, diagnosis and treatment of mental and emotional disorders and syndromes.
- **Social work:** Social workers deliver a wide range of psychosocial oncology support services to patients and families, including conducting psychosocial assessments, intervening with distress, supportive interventions for family adjustments, and providing therapy or education to patients with concerns related to cancer treatments, such as cognitive changes, fatigue, sexual health, insomnia, caregiver distress and other presenting psychosocial problems.
- **Spiritual care:** Practitioners that play a critical role supporting the spiritual health, emotional needs and well-being of patients and their families.
- **Occupational therapy:** Practitioners who assist people to maximize their function in the face of cancer-related functional decline. Occupational therapists work collaboratively with people with cancer to enable them to participate in the occupations that give meaning and purpose to their lives. This includes assessment and intervention in the areas of self-care, productivity and leisure.
- **Physiotherapy:** Practitioners who design and conduct rehabilitation programs aimed at assisting people across the cancer care continuum to achieve their maximum function. Physiotherapists create individualized treatment plans that can include exercise, patient education, provision of walking aids, and hands-on physiotherapy assistance that helps improve function.
- **Dietetic care:** Registered dietitians work as part of an interdisciplinary care team and play a role in caring for cancer patients through the identification, prevention and management of malnutrition, cancer cachexia, nutrient deficiencies and dehydration.
- **Speech language pathology:** Practitioners who help patients manage temporary or long-term communication and swallowing issues that can result from cancer and its treatments (i.e., eating, voice, speech, and overall quality of life).

Support from Canadian provincial cancer centres coast-to-coast

The following is a list of psychosocial oncology support services provided by each province and includes the full list of the main cancer centres. Please note that this is not an exhaustive list of resources, and your closest cancer centre may not offer the breadth of psychosocial support listed. Since each province manages their healthcare system differently, each will have differing levels of psychosocial access and support. Click on the program names for more information.

Note: Territories in Canada currently do not offer extensive psychosocial oncology care and any related services have been listed for reference.

Support by province

Alberta

Provincial Cancer Care Organization: Alberta Health Services (AHS)

Alberta Health Services Resources:

- AHS Psychosocial Oncology
- AHS Supportive Care and Living Well

Alberta has 17 cancer centres. 3 offer comprehensive (tertiary) cancer centres. There are also 4 regional cancer centres.

Major cancer centres:

1. Arthur J.E. Child Comprehensive Cancer Centre, Calgary, AB
    - Psychosocial Oncology
2. Cross Cancer Institute, Edmonton, AB
    - Psychosocial Oncology

Regional cancer centres:

1. Grand Prairie Cancer Centre, Grand Prairie, AB
    - Psychosocial Oncology
2. Jack Ady Cancer Centre, Lethbridge, AB
    - Psychosocial Oncology
3. Margery E. Yuill Cancer Centre, Medicine Hat, AB
    - Psychosocial Oncology

4. Central Alberta Cancer Centre, Red Deer, AB
    - Psychosocial Oncology

Alberta also has 11 community cancer centres. Click here to access the full list of cancer centres in Alberta.

British Columbia

Provincial Cancer Care Organization: BC Cancer

British Columbia has 6 cancer centres:

1. BC Cancer - Abbotsford, Abbotsford, BC
2. BC Cancer - Kelowna (Sindi Ahluwalia Hawkins Centre), Kelowna, BC
3. BC Cancer - Prince George (Centre for the North), Prince George, BC
4. BC Cancer - Surrey, Surrey, BC
5. BC Cancer - Vancouver, Vancouver, BC
6. BC Cancer - Victoria, Victoria, BC

British Columbia's healthcare system is integrated under BC Cancer.
Access their resources here:

- BC Cancer - Emotional Support
- BC Cancer - Cancer Care Support Resources

Manitoba

Provincial Cancer Care Organization: CancerCare Manitoba (CCMB)

CancerCare Manitoba is the primary cancer agency in Manitoba, offering psychosocial oncology support in Winnipeg at its McDermot and St. Boniface sites. More information about their resources can be found here:

- CCMB Support Programs and Support Groups

CancerCare Manitoba also has a Community Cancer Programs Network (CCPN) that enables quality cancer care to patients who live outside of Winnipeg. Click here for a full list of CCPN regional and community cancer programs.

New Brunswick

Provincial Cancer Care Organization: New Brunswick Cancer Network (NBCN)

New Brunswick has 2 tertiary level cancer centres, each respectively under New Brunswick's two Health Networks:

1. Vitalité Health Network
    - Dr. Léon-Richard Oncology Centre, Moncton, NB
2. Horizon Health Network
    - Saint John Regional Hospital, Saint John, NB

Please note that New Brunswick currently does not offer specific psychosocial oncology support. For community resources, please visit: New Brunswick Support Centres.

Newfoundland and Labrador

Provincial Cancer Care Organization: Eastern Health Provincial Cancer Care Program

Newfoundland & Labrador has 1 major cancer centre:

1. Dr. H Bliss Murphy Cancer Centre, St. John's, NL

For additional resources, please visit Newfoundland & Labrador Support Centres.

Nova Scotia

Provincial Cancer Care Organization: Nova Scotia Health Authority (NSHA) Cancer Care Program

Nova Scotia has 2 cancer centres:

1. QEII Cancer Centre, Halifax, NS
2. Cape Breton Cancer Centre, Sydney, NS

The Nova Scotia Health Authority provides many services including:

- Psychosocial Oncology
    - Patient and Family Comfort Rooms
    - Emotional and Practical Support
    - Support Groups

Ontario

Provincial Cancer Care Organization: Cancer Care Ontario (CCO)

Cancer Care Ontario has a Psychosocial Oncology Support Program.

Ontario has 14 regional cancer centres:

1. Cancer Centre South East, Kingston, ON
    - Care team

2. Carlo Fidani Regional Cancer Centre, Mississauga, ON

3. Waterloo Wellington Regional Cancer Centre, Kitchener, ON

- Supportive Care Team

4. Juravinski Cancer Centre, Hamilton, ON

- Psychosocial Oncology Program

5. London Regional Cancer Program, London, ON

6. Shirley & Jim Fielding Northeast Cancer Centre, Sudbury, ON

- Supportive Care Program

7. Princess Margaret Cancer Centre, Toronto, ON

- Psychosocial Oncology Clinic

8. Regional Cancer Care Northwest, Thunder Bay, ON

- Patient and Family Handbook
- Ask a member of your healthcare team about programs and services available

9. R.S. McLaughlin Durham Regional Cancer Centre (Lakeridge Health), Oshawa, ON

- Psychosocial Oncology Team (Dietitian, Speech Language Pathologist, Social Worker, the BETTER Clinic)

10. Simcoe Muskoka Regional Cancer Centre (Royal Victoria Regional Health Centre), Barrie, ON

- Patient and Family Support and Resources

11. Stronach Regional Cancer Centre at Southlake, Newmarket, ON

- Ask a member of your healthcare team about programs and services available. Learn about what is available on page 13 of their patient education booklet.

12. Sunnybrook Odette Cancer Centre, Toronto, ON

- Patient and Family Support Program

13. The Ottawa Hospital Cancer Centre, Ottawa, ON

- Programs and Clinics
- Patient & Family Support (Psychosocial Oncology) Program

14. Windsor Regional Cancer Centre, Windsor, ON

- Patients, Families, and Caregivers

Prince Edward Island

Provincial Cancer Care Organization: PEI Cancer Treatment Centre

PEI Cancer Treatment Centre is the only cancer centre in Prince Edward Island.

Access their services here: PEI Cancer Care Support & Resources

Quebec

Provincial Cancer Care Organizations:

- Integrated Health and Social Services Centres (CISSS) and Integrated University Health and Social Services Centres (CIUSSS)

Beyond these integrated centres, Quebec has 4 university hospital centres and 3 university institutes that provide specialized and highly specialized services beyond their health region border.

Quebec's cancer centres run under 22 integrated health and social service centres that manage numerous healthcare establishments within its 16 regions.

Quebec's 10 major cancer centres are:

1. Hôpital Maisonneuve-Rosemont - Cancérologie, Montreal, QC
2. Cedars Cancer Centre (McGill University Health Centre), Montreal, QC
    - Psychosocial Oncology Program
3. Centre intégré de cancérologie – CHUM, Montreal, QC
    - Physical and psychological resources
4. St. Mary's Hospital Center, Montreal, QC
    - Psychosocial Oncology Support
5. Segal Cancer Centre (Jewish General Hospital), Montreal, QC
    - Psychosocial Oncology Program
6. Hôtel-Dieu de Québec (CHUQ), Québec City, QC
    - Psychosocial and Spiritual Oncology
7. Centre intégré de cancérologie de Laval (CICL), Laval, QC
8. CIUSSS de l'Estrie – CHUS, Sherbrooke, QC
9. Hôpital Charles-Le Moyne, Greenfield Park, QC
10. CISSS du Bas-Saint-Laurent, Rimouski, QC

For further community services, please visit Local Community Services Centres (CLSCS) or community psychosocial services.

Saskatchewan

Provincial Cancer Care Organization: Saskatchewan Cancer Agency

Saskatchewan has 2 cancer centres:

1. Allan Blair Cancer Centre, Regina, SK
2. Saskatoon Cancer Centre, Saskatoon, SK

The Saskatchewan Cancer Agency provides a program called The Community Oncology Program of Saskatchewan (COPS), coordinated by the Saskatoon Cancer Centre and the Allan Blair Cancer Centre in partnership with hospitals across the province. The goal of the program is to treat patients close to their home communities.

Territorial psychosocial support

- Northwest Territories: Cancer Navigation Program through the Northwest Territories Health and Social Services Authority (NTHSSA)
- Yukon: Cancer Care

Community resources

Myeloma Canada

- Local support groups: Meet other people living with myeloma, their caregivers and families at a local myeloma support group. There are over 40 local myeloma support groups across Canada. Support groups can help you cope with a myeloma diagnosis or relapse and provide important information about the disease and treatment.
- Virtual support groups: This online offering gives you the opportunity to connect, ask questions and participate in discussions with other Canadians impacted by multiple myeloma, all from the comfort of your own home. There are currently 4 virtual Facebook support groups on Facebook available to join, all of which are closed and monitored for your safety and comfort:
    - Virtual Support Group for Caregivers
    - Virtual Support Group for Young Patients and Caregivers
    - Virtual Support Group for Patients and Caregivers of All Ages
    - Virtual Support Group for Francophones
- Myeloma Peer Support Program : This program offers a chance to connect with a Myeloma Peer Support Volunteer. Peer Support Volunteers are individuals within the Myeloma Canada community who have first-hand experience either living with myeloma, or as caregivers to someone with the disease. There is no fee to participate in this program.
- Educational resources: These resources from Myeloma Canada contain essential, current information that zero in on specific topics pertaining to myeloma. Myeloma Canada offers an array of publications on various topics that impact Canadians living with myeloma. In addition, there are videos on the latest myeloma research and disease management, as well as shared experiences from those living with the disease.

This guide was made possible by a member of Innovative Medicines Canada. For more information on myeloma or myeloma resources and support, visit Myeloma Canada at myeloma.ca or call toll-free 1-888-798-5511.

Discussion guide on psychosocial support for people experiencing a relapse

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Supplemental questions for your next visit with your hematologist or healthcare provider

The questions below complement Myeloma Canada's Discussion Guide for People Experiencing a Relapse: Making the most out of your medical visit, available at myeloma.ca. The guide, which can be printed, focuses on developing meaningful conversations around treatment options at your next visit with your healthcare team.

Feel free to print the questions that follow and use them to facilitate a conversation with your healthcare team about incorporating psychosocial care as a part of your overall treatment plan.

1. Emotionally, are there any differences I can expect to feel between my initial diagnosis and a relapse?

2. When is the best time in the treatment process of a relapse to reach out for psychosocial support?

3. In your experience, how have other patients dealt with a relapse?

4. What's the best way for my caregiver to emotionally support me?

5. Who should I turn to for questions about how I'm feeling both emotionally and physically?

6. What psychosocial support services are available to me at the hospital, and how can I access them?

7. Are there any government support programs in place that I can look into?

8. Are there any programs in place either at the hospital, or another place, specifically for caregivers?



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