



Life Beyond Lymphoma

LYMPHOMA CANADA

GUIDE



A COMPANION HANDBOOK TO:

www.lifebeyondlymphoma.ca

Welcome

Life Beyond Lymphoma is a support portal that has been created for lymphoma patients, such as yourself, who are in the off-treatment phases of their experience.

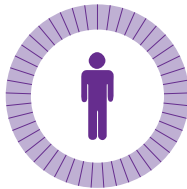
This **Life Beyond Lymphoma (LBL) Guide** is a companion to this portal. You can record your medical history with lymphoma as well as your follow-up care plan. In addition, many lymphoma survivors find that they have feelings of uncertainty and don't always know where or how to move forward. For this reason, we have included some questions in the **LBL Guide** that others have thought about as they began to move beyond their lymphoma and integrate their experiences into their "new normal".

These questions are meant to serve as a starting point for your consideration and reflection. You may find that some of the questions may not resonate with you while others may strike a chord. Either way, taking a closer look at them may help you to determine areas that require further thought, exploration, or action in order to help you plan for your future.

To make things easier, the **LBL Guide** is organized into four key areas of survivorship just like the **Life Beyond Lymphoma** portal:



My Disease



My Body



My Mind



My World

Take some time to examine each area, and reflect on the relevance it has to you. As you work through each section, feel free to make notes where applicable.

You also have the option to download this **LBL Guide** from www.lifebeyon.lymphoma.ca.



My Disease

My Disease

Follow-up Care After Treatment

Once you have completed active treatment, you will likely be given a follow-up care plan to monitor your progress and recovery as well as to watch for a potential recurrence. It is very important to go to all of your follow-up appointments. Your schedule of visits and the tests and procedures that you will undergo during follow-up are tailored to your individual situation. At this point in time, you will continue to be under the care of your current lymphoma healthcare team.

As you move forward, your care may be transitioned back to your family doctor. In addition, you may start to see new or additional healthcare professionals such as a dentist, neurologist, physiotherapist, or naturopath for other health-related issues.

Regardless of who you see, you will need to ensure that they are all aware of your medical history so that you can continue to receive the best care possible. In this section you can record your healthcare team's contact information, follow-up care plan, and medical history to take with you to your future appointments.

Questions to think about as you plan ahead:

Do you know who to call if you have questions about your lymphoma, your health, or any concerns you may have?

Have you gathered copies of all of your health records, and outlined the details of your diagnosis, tests, and treatments into one place for easy reference?

Have you discussed a plan for next steps with your healthcare team?

Have you made a list of the follow-up appointments (and dates) as well as tests that are required?

Do you know what your doctor would like you to watch for with respect to new symptoms or changes in your body/health?

Tools in the LBL Guide to help you:**My Healthcare Team:**

Record the contact information of your entire healthcare team and go over their roles moving forward as you meet with them.

My Lymphoma History:

Capture key notes of your lymphoma history including diagnosis and treatments.

Follow-up Care Plan:

Describe the plan you already have or will have discussed with your healthcare team.

Future Appointments:

Record upcoming appointments in the table provided.

Symptoms to Watch for and Report:

Record your symptoms in the table provided for review with your healthcare team.

My Healthcare Team

Your healthcare team may be made up of a number of different individuals, many of whom are listed below. Use this section to keep track of all of their contact information.

| Role | Contact Information (Include: name, address, phone #, fax #, and email) |
|--|---|
| Lymphoma Doctor (eg, Hematologist or Oncologist) | |
| Radiation Oncologist | |
| Surgeon | |
| Primary Care Nurse | |
| Family Doctor | |

Hospital Pharmacist

Community Pharmacist

Psychosocial Support
(eg, Psychologist,
Psychiatrist, Counsellor, etc.)

Drug Access Navigator

Other Medical Professional
(eg, Obstetrician/Gynecologist,
Urologist, Endocrinologist, etc.)

Complementary Specialist
(eg, Nutritionist, Acupuncturist,
Naturopath, etc.)

Lymphoma History

Symptoms before diagnosis:

Describe type of lymphoma:
(stage/grade)

Date of diagnosis:

Age at diagnosis:

Treatment: (check all that apply and describe)

Chemotherapy (include type of drugs, regimen, and doses)

Start date:

Completion date:

Details:

Side effects/complications:

Start date:

Completion date:

Details:

Side effects/complications:

Start date:

Completion date:

Details:

Side effects/complications:

Biological therapy (include type of drug, regimen, and doses)

Start date:

Completion date:

Details:

Side effects/complications:

Start date:

Completion date:

Details:

Side effects/complications:

Start date:

Completion date:

Details:

Side effects/complications:

Radiation therapy (include specific location and dose)

| | |
|-----------------------------|------------------|
| Start date: | Completion date: |
| Details: | |
| Side effects/complications: | |

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|-----------------------------|------------------|
| Start date: | Completion date: |
| Details: | |
| Side effects/complications: | |

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|-----------------------------|------------------|
| Start date: | Completion date: |
| Details: | |
| Side effects/complications: | |

Surgery (include specific location)

| | |
|-----------------------------|------------------|
| Start date: | Completion date: |
| Details: | |
| Side effects/complications: | |

Complementary therapy (eg, acupuncture, homeopathics, herbs, physical therapy, etc.)

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|-----------------------------|------------------|
| Start date: | Completion date: |
| Details: | |
| Side effects/complications: | |

Other: _____

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|-----------------------------|------------------|
| Start date: | Completion date: |
| Details: | |
| Side effects/complications: | |

Other: _____

| | |
|-----------------------------|------------------|
| Start date: | Completion date: |
| Details: | |
| Side effects/complications: | |

Follow-up Care Plan

Record the follow-up care plan that your primary lymphoma doctor has laid out with you. Include details about upcoming appointments and medical recommendations. Use the table below to record upcoming diagnostic tests that will help in screening for recurrence or other future concerns. Note that not all of the tests listed will apply to you.

Plan overview:

Future Appointments

| Date | Healthcare Professional | Reason |
|-------|-------------------------|--------|
| _____ | _____ | _____ |
| _____ | _____ | _____ |
| _____ | _____ | _____ |
| _____ | _____ | _____ |
| _____ | _____ | _____ |
| _____ | _____ | _____ |
| _____ | _____ | _____ |
| _____ | _____ | _____ |
| _____ | _____ | _____ |
| _____ | _____ | _____ |
| _____ | _____ | _____ |

Visit the **Follow-up Care After Treatment** section of www.lifebeyondlymphoma.ca to learn more about follow-up care.

Follow-up Diagnostic Tests

| Type | Date | Results |
|--|------|---------|
| Physical exam | | |
| Blood tests (eg, tumour markers, blood counts) | | |
| X-ray | | |
| CT scan | | |
| MRI | | |
| PET scan | | |
| Bone scan | | |
| Colonoscopy/ sigmoidoscopy | | |
| Heart tests (ECHO, EKG) | | |
| Lung function tests | | |
| Thyroid tests (function, scan, biopsy) | | |
| Mammogram | | |
| Pap smear | | |
| PSA levels | | |

CT: computerized tomography; ECHO: echocardiogram; EKG: electrocardiogram;
MRI: magnetic resonance imaging; PET: positron emission tomography; PSA: prostate-specific antigen.

General Health History

Have you had other health issues in the past?

(eg, other cancers, past injuries, asthma, lung issues, skin issues, heart concerns, gastrointestinal problems, genitourinary issues, diabetes, sexual/reproductive concerns, severe infections, osteoporosis, seizures, psychosocial issues, etc.)

| Health Issue | Date | Treatment |
|--------------|------|-----------|
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Current Medications and Supplements

| Medication* | Dose | Reason for Use |
|-------------|------|----------------|
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* Please note that many medications have side effects. You may want to familiarize yourself with the common side effects and report anything unusual to your doctor.

Symptoms to Watch for and Report

Your healthcare team may advise you on symptoms to watch for and to report, especially those that may be related to signs of potential relapse.

Keep in mind, if you have received lymphoma treatment, there may be late effects of treatment. Take this into consideration as you adjust to your new normal.

It is natural to feel as though you are on high alert looking for symptoms and it may be difficult to know if a symptom is related to a relapse or recurrence. Any symptom that you are concerned about should be brought to the attention of your healthcare team.

Use this section to write down **any** symptom that you would like to discuss with your healthcare providers.

As a guide, watch out for symptoms that are:

- 1. Unexplainable:** when symptoms appear with no logical explanation (eg, fever without an infection)
- 2. Persistent:** when symptoms do not go away within a reasonable amount of time (eg, cough that does not go away)
- 3. Progressing:** when symptoms worsen over time (eg, continuing weight loss in the absence of a change in physical activity or nutrition)

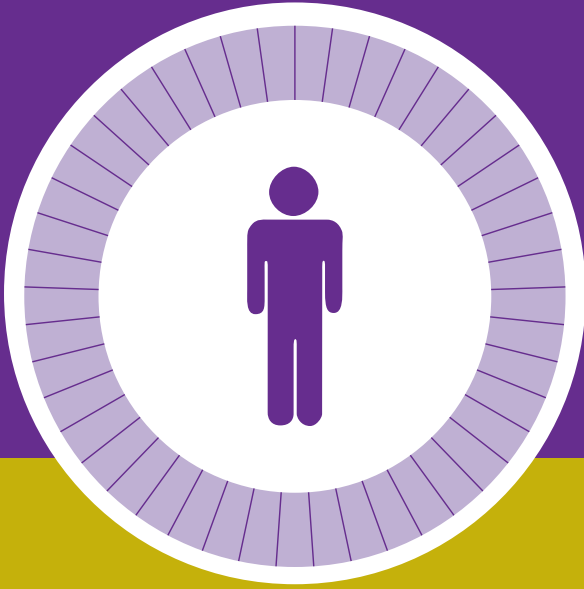
These signs and symptoms can be general (eg, fatigue, night sweats, weight change, infections) or organ-specific symptoms (eg, musculoskeletal-, lung-, nerve-, heart-, gastrointestinal-, and genitourinary-related symptoms).

Start Date**Symptom Details**

| Start Date | Symptom Details |
|-------------------|------------------------|
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Visit the **Disease Concerns After Lymphoma** sub-section of the **My Disease** section at www.lifebeyondlymphoma.ca to learn more about future disease concerns.

Go to the **Late Effects of Treatment** sub-section of the **My Body** section at www.lifebeyondlymphoma.ca to learn more about potential side effects that you may have developed as a result of your treatments for lymphoma.



My Body

My Body

Late Effects of Treatment

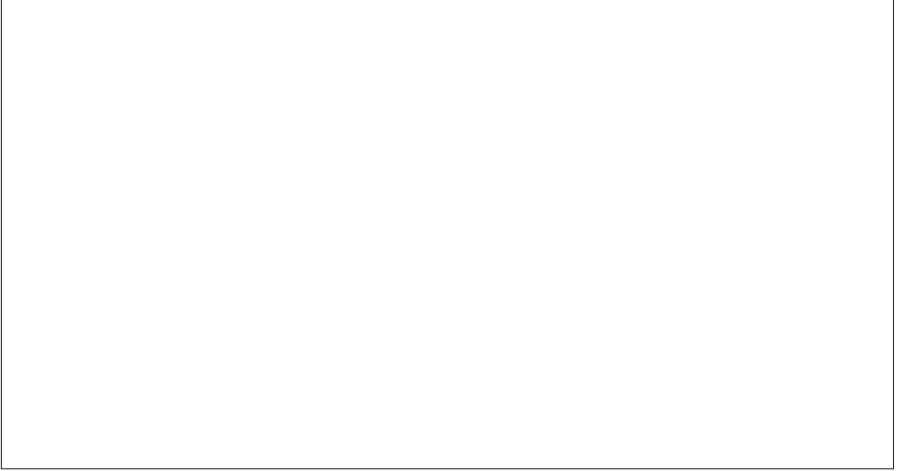
If you have completed lymphoma treatment, now is the time to focus on healing. However, you may notice some side effects continuing for months or even years after your treatment ended, or you may develop new side effects well after treatment. The types of late effects and the chances of developing these late effects of lymphoma treatment will depend greatly on the type of treatment you received.

Other factors that have a role in determining whether or not you develop late effects of treatment include treatment duration, age at the time of treatment, your current age, family health history, and overall health and lifestyle.

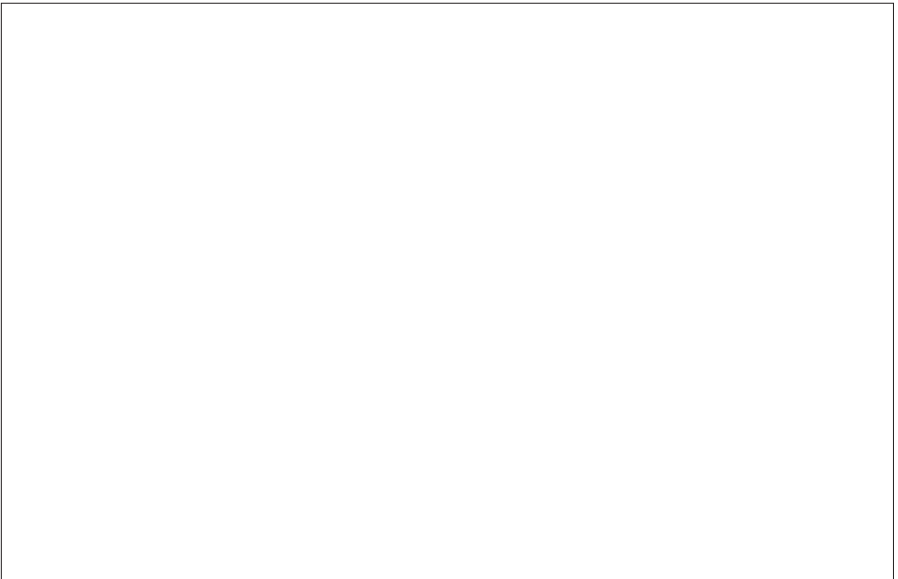
In this section you will find questions that will help you identify different late effects of treatment and document how they affect your daily life.

To learn more about fatigue, nerve damage, reduced glandular function, memory problems or confusion, infections, sexual issues, reproductive issues, heart disease and stroke, lung scarring, eye problems, bone complications, and secondary cancers visit the **Late Effects of Treatment** sub-section of the **My Body** section at www.lifebeyondlymphoma.ca.

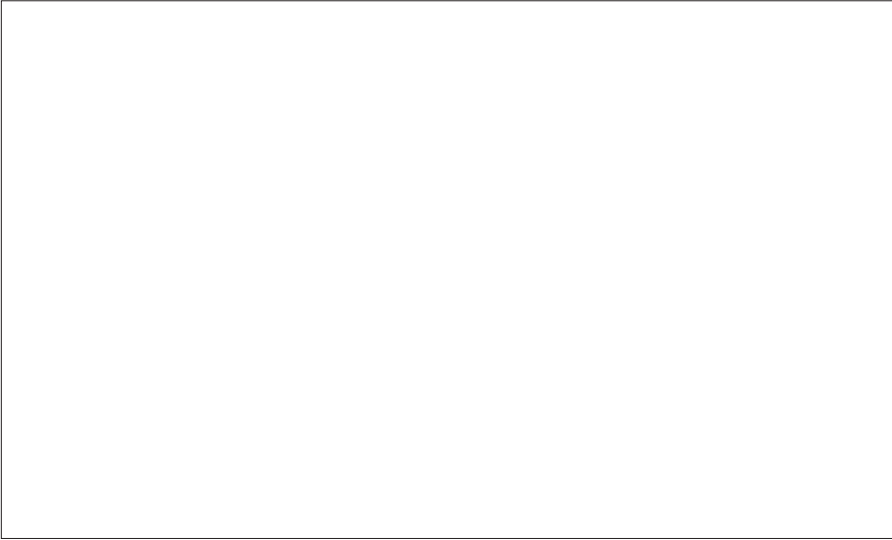
What type of visible/non-visible changes to your body are you dealing with as a result of lymphoma treatment (eg, hair loss, scarring, pain, numbness, infertility, etc.)?



How have these late effects of treatment affected your daily functioning?



Have physical changes to your body affected your willingness or ability to engage in some of your previous activities or relationships? Use this space to jot down some thoughts.



Have your sleep habits or has your quality of sleep been affected?
How so?



Identify the appropriate healthcare team member with whom to discuss these changes and/or effects that you are experiencing.

Make note of these effects in the **Symptoms to Watch for Report** and **Future Appointments** sections of the **My Disease** tab of the **LBL Guide** to remind you to discuss these issues at a future appointment.

Have you explored ways to manage these effects? What resources have helped?

Healthy Lifestyle

As you regain your health following your treatment, it is important to maintain a healthy lifestyle.

Visit the **Healthy Lifestyle** sub-section of the **My Body** section at www.lifebeyondlymphoma.ca to learn more about physical activity, nutrition, maintaining a healthy weight, and environmental exposure.

Current Lifestyle Choices

| Type | Details |
|--|--|
| Tobacco use | _____ |
| Alcohol use | _____ |
| Recreational drug use | _____ |
| Special diet (eg, vegetarian, gluten-free, reduced sodium, etc.) | _____ _____ |
| Exercise routine | Types of light-intensity exercises: _____ _____ |
| | Types of moderate-intensity exercises: _____ _____ |
| | Types of high-intensity exercises: _____ _____ |

Identify changes to your lifestyle that you would like to make to help you manage specific physiological effects you are experiencing (eg, eating, sleeping, exercise, complementary support).

What are some specific and attainable changes/goals that you can make to your lifestyle that will help to improve your overall health?

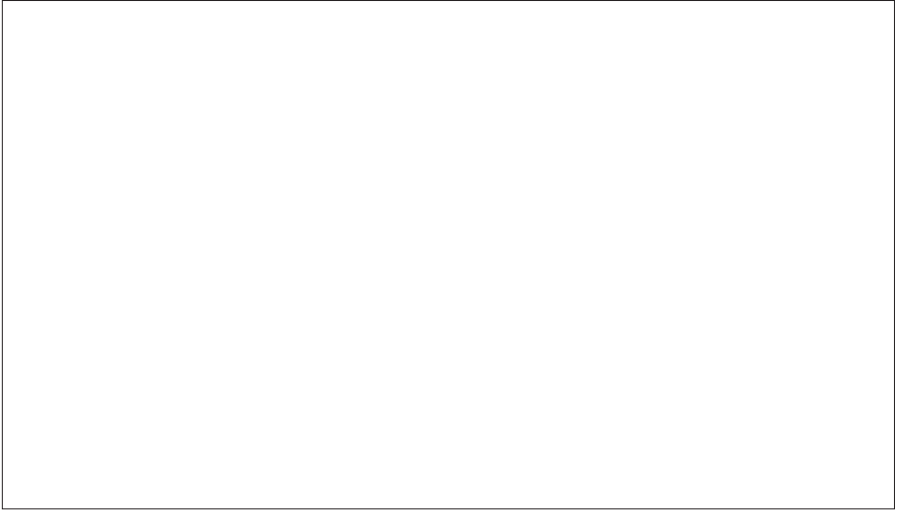
Identify specific complementary approaches that you plan to incorporate into your regime or diet that will need to be discussed with your healthcare team.

Make note in the **Future Appointments** section of the **My Disease** tab of the **LBL Guide** to remind you to discuss these approaches with your healthcare team.

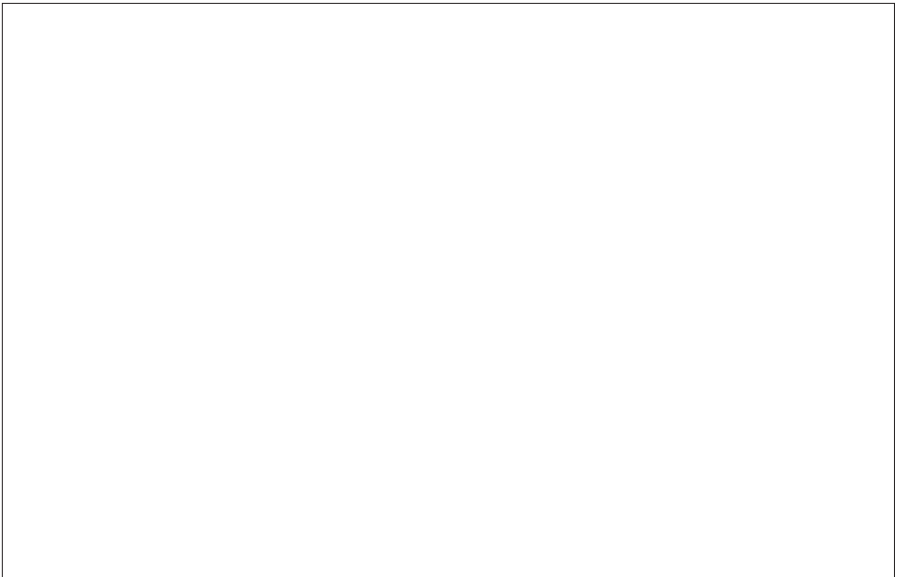
What is your current level of physical activity? Do you plan to try to increase it as you move forward? Identify specific examples.

Make note in the **Future Appointments** section of the **My Disease** tab of the **LBL Guide** to remind you to discuss these activities with your healthcare team.

Identify mentors who can help you plan out how you can achieve your goals (eg, support group leaders, counsellors, etc.).



Are there people that you know who can work with you to reach common lifestyle goals and fitness goals or be an “accountability partner” for you (eg, family, friends, neighbours, coworkers, etc.)? List them here and discuss your plan with them.





My Mind

My Mind

After your treatment for lymphoma is over, it is not uncommon to experience a variety of emotions. Some of these emotions or experiences may be familiar to you and some may be new. You may expect some of these emotions, while others may take you completely by surprise. Remember that you are an individual and your situation is unique to you. There is no right way to feel when going through this process. Remember to take one day at a time and that you are not alone. There are people who can help.

Use this section to reflect on your feelings. Sometimes writing your feelings down can help you figure out a way to deal with them.

To learn more about what emotions to expect after your lymphoma experience, suggestions on how to deal with them, and where to get support, visit the **My Mind** section at www.lifebeyondlymphoma.ca. You will also find suggestions on how to take positive action as you recover.

Have you experienced a change in how you feel about yourself after your lymphoma experience? What do you feel has changed? How is it a positive or negative change?

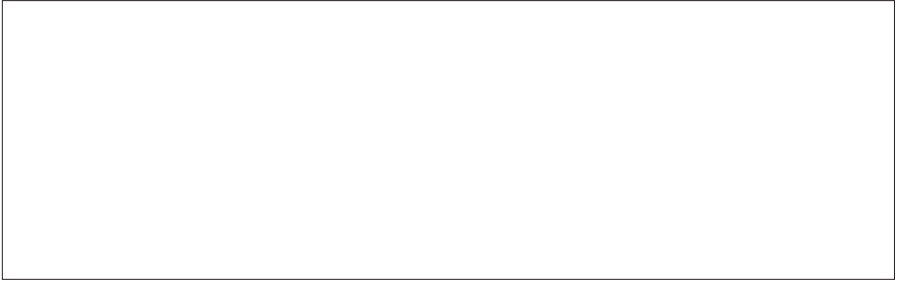
What is your current attitude about your illness?

What are your primary emotions currently? Are your emotions helping you to move forward or holding you back?

What are the things that have given you strength during your diagnosis and/or treatments? How can you draw upon these things now to help you move forward?

Has a spiritual or religious affiliation been a part of your lymphoma experience? How has it helped you to cope with all that you have been through?

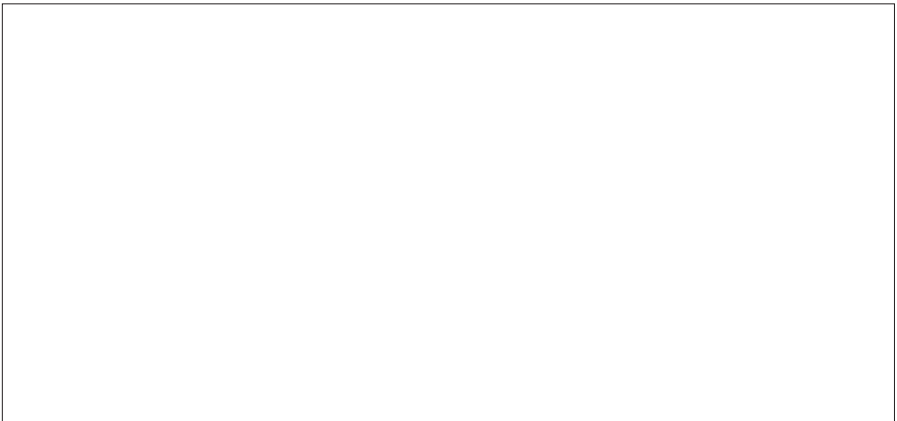
Have you made peace with the “Why me?” question? How did you go about doing this?



Are there negative feelings that you feel need to be addressed (eg, guilt, blame, sadness, anger, etc.)? What steps can you take to begin addressing them?



Do you fear the “unknown cause” of your illness? What steps have you taken or will you take to address your fears?

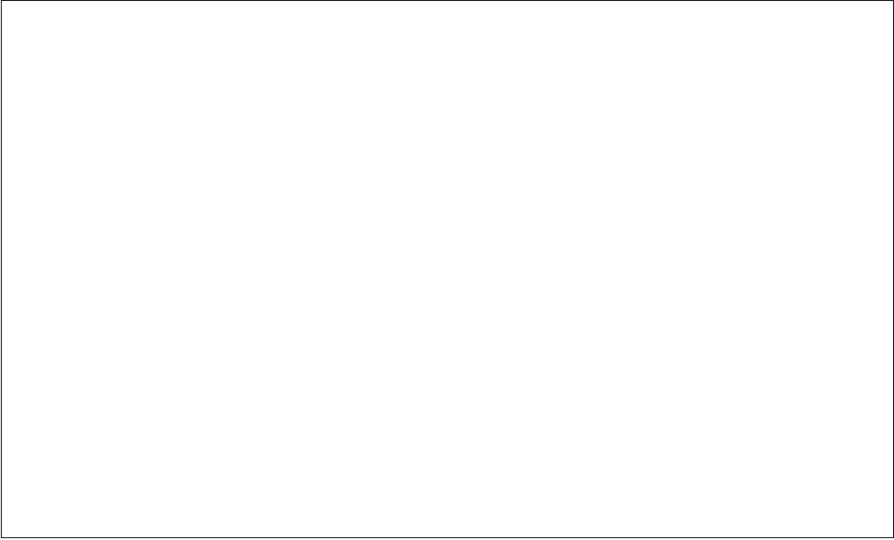


If you are experiencing fear of recurrence, what is the intensity of the fear?
Is it disruptive to your activities of daily living?

Take time to reflect on your lymphoma experience and how it has affected your life. Have you thought about what is important to you now, and what you might like to change?

If you have a desire to give back, reflect on the ways you can share your lymphoma experience with others to help them in their journey.

In what ways have your thoughts or beliefs been influenced by others?
Describe what they have said or done.

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How do you feel about your future as you move beyond your lymphoma experience?

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My World

My World

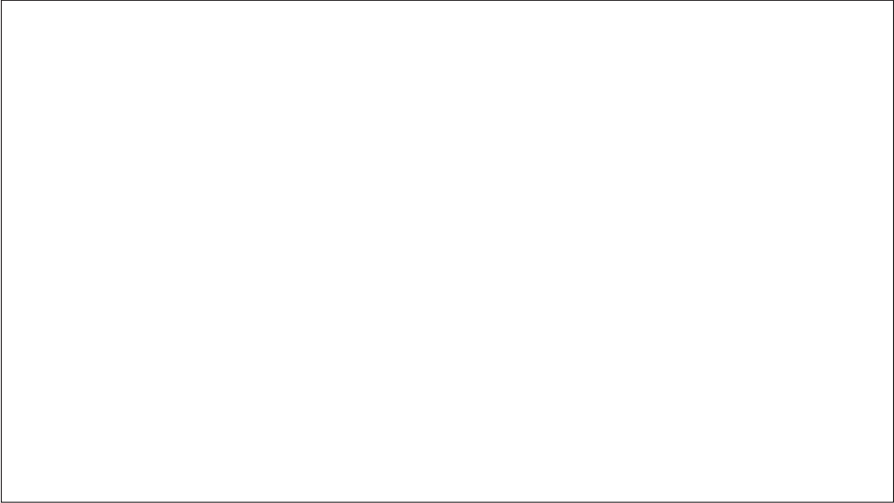
As part of life after diagnosis and possible treatment for lymphoma, there is a realization that life may never return to the normal that you were accustomed to before you were diagnosed. You are now faced with creating a “new normal” for yourself. Part of this process involves re-evaluating personal relationships and professional and financial goals.

Use this section to think about your relationships, as well as to plan for your return to work or school, if this applies to you.

To learn more about the changes to relationships you may expect, as well as how to plan to return to work or school, visit the **My World** section at www.lifebeyondlymphoma.ca. You will also find information about work- or school-related benefits for which you may qualify.

Are there things that are holding you back from feeling positively about your relationships with others (eg, family, friends, acquaintances, co-workers)? How can you address them?

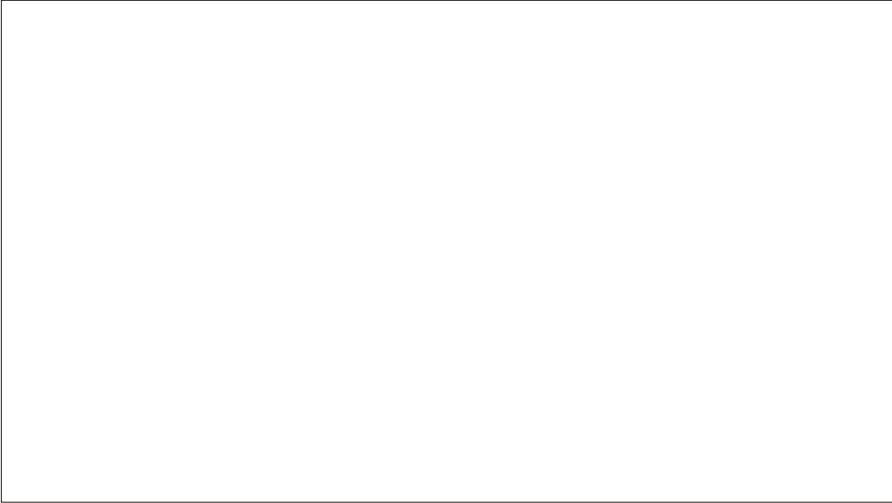
Have you identified any important issues that you want to discuss with your loved ones as you work to re-establish your routines (eg, roles and responsibilities, limitations, concerns)?



Are others expecting more or less of you now that you are recovering, and how does this fit with your expectations of yourself?



What will you share with others? How much will you say about your lymphoma experience and what you have gone through?



When you return to work/school/social situations, how will you handle questions that you might not feel comfortable answering?



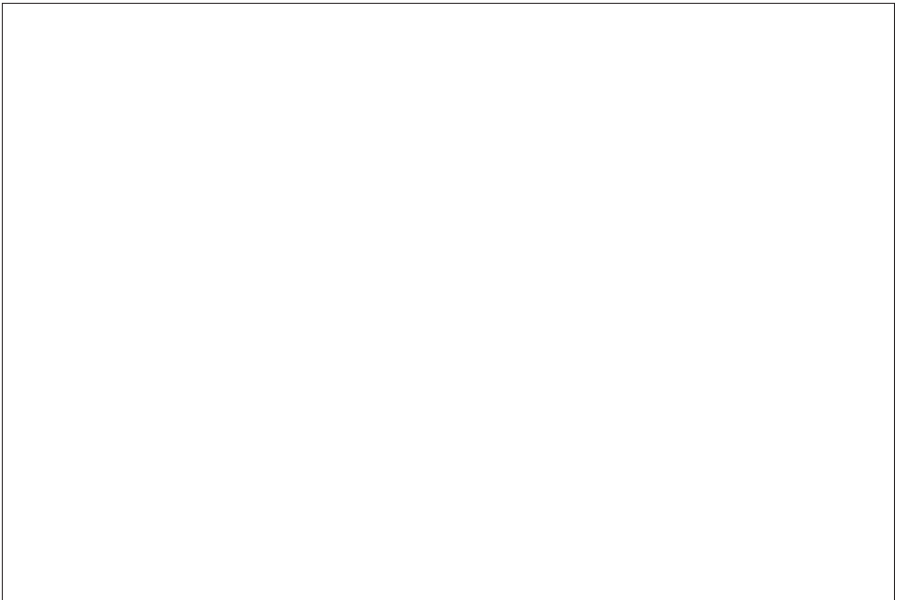
Do you have a plan for your re-entry to work or school and will you require any modifications (eg, gradual entry, modified responsibility, incorporating appointments)?

Have you identified the point person at your job or school who will assist you with your re-entry?

Are you aware of your employment rights or school attendance expectations?



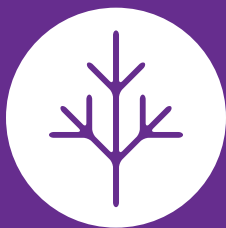
Are you aware of the benefits and services available to you (eg, workplace health benefits, provincial insurance, employment insurance, community resources)?



References and Resources

You may find more information about the topics covered in the **LBL Guide** in the references and resources below:

1. Anderson, G. (2013). *Cancer: 50 Essential Things to Do*. New York: Penguin Books Ltd.
2. Cancer Care. (2012). *After Treatment Ends: Tools for the Adult Cancer Survivor*. http://media.cancer.org/publications/original/25-ccc_survivor.pdf?1302556249. Accessed October 2, 2014.
3. Cure. (February 23, 2012). *Survivorship Experts Agree on Essential Elements of Survivorship Care*. Kathy Latour. http://www.curetoday.com/index.cfm/fuseaction/journey.showArticle/id/9/enableStageSubMenu/5/article_id/1852. Accessed October 2, 2014.
4. Holland, JC & Lewis, SL. (2000). *The Human Side of Cancer: Living with Hope, Coping with Uncertainty*. New York: Harper Collins.
5. Magee, S & Scalzo K. (2006). *Picking Up the Pieces*. Rutgers University Press.
6. Oncology Nurse Advisor. (January 15, 2013). *Coping With Cancer as a Young Adult*. <http://www.oncologynurseadvisor.com/coping-with-cancer-as-a-young-adult/article/276167/>. Accessed October 2, 2014.
7. Silverman, D. (2009). *Your Brain After Chemo: A Practical Guide to Lifting the Fog and Getting Back Your Focus*. PA: Da Capo Press.



LYMPHOMA
CANADA

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