



END-OF-LIFE CARE

A guide for
LYMPHOMA AND CLL PATIENTS



LYMPHOMA
CANADA



WHEN TO START END-OF-LIFE CARE?

Deciding when to start end-of-life care is one of the most difficult and emotional stages for lymphoma patients and their loved ones. Realistically this should begin when life expectancy is less than 1 year, regardless of current therapy. During this stage, treatment may be discontinued which is a challenging transition for most patients. This stage of the lymphoma journey can invoke a wide range of emotions including denial, grief, anger, fear and despair, which are very challenging to deal with without the appropriate planning and support. Furthermore, this period of time can create a large amount of uncertainty regarding finances and medical care or even discomfort when talking to family and friends about death and decisions regarding end-of-life. To help lymphoma patients and their family members navigate through this incredibly difficult time, this resource aims to identify the challenges faced by patients at this stage of their lymphoma journey and outlines a collaborative approach to coping with these challenges. **Information in this resource include the following:**

- + **Signs and symptoms of advanced lymphoma**
- + **Considerations when stopping lymphoma treatment**
- + **Understanding palliative care**
- + **Talking to your loved ones about death**
- + **Mental health support options**
- + **Financial and legal resources/advance planning for end-of-life**

SIGNS AND SYMPTOMS OF ADVANCED LYMPHOMA

General symptoms of lymphoma may become more pronounced closer to the end-of-life. The experienced symptoms may vary depending on how aggressive the lymphoma is and which parts of the body are affected, as well as individual factors such as overall health and treatment history. The manifestation of symptoms will differ based on the organs impacted. **Common end-of-life symptoms for lymphoma patients may include, but are not limited to:**

- + **Loss of appetite:** Leads to weight loss, and increased weakness.
- + **Infections:** As the immune system becomes compromised, individuals with advanced lymphoma may be more susceptible to infections, leading to fever, chills, and other symptoms.
- + **Fatigue and drowsiness:** Your lymphoma may cause a shortage of oxygen to your organs, and a decline of red blood cells which contribute to increased fatigue and drowsiness. You could find yourself needing more rest or sleeping a significant amount as you near end-of-life.
- + **Difficulty swallowing:** If your lymphoma affects the throat or esophagus, swallowing difficulties can occur.
- + **Changes in breathing:** You may experience shortness of breath/difficulty breathing. Breathing may be louder, sometimes referred to as rattling.
- + **Neurological symptoms:** Depending on the involvement of the central nervous system, symptoms such as confusion, seizures, or weakness may occur. You may experience restlessness and hallucinations.

- + **Withdrawal and loss of interest:** Patients may withdraw from activities and lose interest in their surroundings, reflecting a decline in physical and emotional energy.
- + **Loss of bladder and bowel control (incontinence):** It can vary in severity from occasional leaks to complete loss of control.
- + **Feeling cold:** Slowed blood circulation results in increased sensitivity to cold temperatures.
- + **Changes in skin:** Lymphoma involvement in the skin can cause rashes, itching, or discoloration.
- + **Swelling and pain:** Swelling of lymph nodes, abdomen (due to spleen or liver enlargement), or other areas of the body can cause discomfort. Your medical team will assess your condition and administer medications to help ease any pain as much as possible.
- + **Sleep difficulties:** Various factors such as physical discomfort, medication, stress, emotional upheaval, or the fear of not awakening may disrupt your typical sleep patterns.
- + **Psychological and emotional distress:** Anxiety, depression, and other psychological symptoms may intensify as the end-of-life approaches.

It is important to note that not all patients will experience all of these symptoms, and some individuals may have a relatively peaceful end-of-life experience. Palliative care and hospice services can provide support to manage symptoms and improve quality of life for patients and their families during this challenging time. Additionally, each person's experience is unique, so symptoms may vary widely from one individual to another.

CONSIDERATIONS WHEN STOPPING LYMPHOMA TREATMENT

There are several factors that need to be considered by you and your health care team when deciding on whether you should stop treatment including:

- + Your age and general health status
- + The exact type, stage, and growth rate of your lymphoma
- + Which parts of your body are affected by lymphoma and related symptoms
- + How your lymphoma responded to previous treatment
- + Whether there are additional treatments available for your type of lymphoma
- + Your body's tolerance of prior treatments and your willingness to experience more side effects
- + You may want to consider the support you have available to you at home and from those around you

Take the time to discuss your needs and preferences with your health care team and family members to ensure you are making an informed decision.

UNDERSTANDING PALLIATIVE CARE

Choosing the care and treatment you receive for advanced lymphoma is a personal process. Some people explore every option that might help them live longer — others are more concerned with quality of life. Along the way, many people will offer suggestions and advice but only you can decide on your treatment and care.

You may have doubts or fears about palliative care because of misunderstandings about what it means. Palliative care is a special type of care that provides physical, emotional, social and spiritual care for people with cancer and their families. It does not mean that doctors are giving up. Palliative care does not speed up or delay death. The aim of palliative care is to relieve suffering and improve the quality of living and dying for people whose condition cannot be cured.

Palliative care supports the principle that it is important for people to be given the opportunity to live out their days with meaning and with as little distress as possible. It may complement and enhance disease modifying therapy or it may become the total focus of care. **Care focuses on:**

- + Embracing life and regarding death as a normal process
- + Making you as comfortable as possible
- + Helping to relieve pain and symptoms
- + Keeping quality of life
- + Providing support during this time (it may be months or years) and this support can include psychological and spiritual support
- + Offering a support system to help patients live as well as possible until death
- + Offering a support system to help families cope with their loved one's death and to help them cope afterward with their own bereavement

Palliative care helps patients receive the care they need in the surroundings they prefer, whether it be at home, in a hospice, a long-term care facility or in a hospital. Palliative care is planned and delivered through the collaborative efforts of many people including the patient, their caregivers (family and friends) and service providers (lymphoma care team and community healthcare providers). Treatments can include radiation or medicines for pain or other symptoms. These treatments are not intended to cure the lymphoma, but to relieve symptoms, shrink the cancer if possible and improve quality of life.

GETTING PALLIATIVE CARE SERVICES WHEN YOU NEED THEM

Access to palliative care services varies by province and community and waiting lists are common in many areas. Ask early and talk to your doctor, social worker, or other member of your healthcare team for more information.

CHOOSING TO STAY AT HOME

Some patients want to or feel most comfortable receiving treatment at home near the end-of-life. Caregivers may also want this option – even though it means more responsibilities. When making this choice, discuss it with members of your healthcare team so that you are both prepared. You may be able to arrange for home visits by palliative care nurses, doctors, social workers, home health aides, occupational therapists, and volunteers.

Even with the right support, there may come a time when it is no longer possible to continue home care. It's important to recognize that this is not a failure. Try to talk openly about your doubts or concerns and focus on what will improve quality of life for the patient.

TALKING TO YOUR LOVED ONES ABOUT DEATH

It can be emotionally challenging telling your loved ones about your decision to forgo active treatment. This is particularly the case when individuals have a difficult time coming to terms with your decision.

Some tips to navigate this situation include:

- + Practise what you will say in advance and explain how you reached your decision
- + Consider talking with your health care team about what you may say or how to approach your loved ones
- + Keep in mind that everything doesn't have to be settled immediately, and your family/friends might need or want to talk about this more than once
- + Speak from the heart and remember that open communication is most essential

Friends and family should also take the time to listen as a sign of support and understand that the patient has the right to choose how to live the rest of their life.

WAYS TO RECEIVE MENTAL HEALTH SUPPORT

There are many professionals that can provide you with mental health support during this challenging time. **This includes but is not limited to you:**

- + **Palliative care team:** usually made up of doctors, nurses, pharmacists, dietitians, physiotherapists and occupational therapists
- + **Spiritual care workers:** support you and your family by providing spiritual counselling

- + **Social care team:** support, counsel and help you and your family deal with your lymphoma and the impact it may have on your lives. They provide emotional support and can also advise you on financial concerns

FINANCIAL AND LEGAL RESOURCES / ADVANCE PLANNING FOR END-OF-LIFE

You may not feel up to thinking about end-of-life planning such as wills and funerals, but if you are able to discuss practical matters openly and early on with family, it can bring some peace of mind for everyone involved. It can help the person with advanced lymphoma to know that their wishes are understood, and it can relieve some of the stress and uncertainty for caregivers and family.

TIPS FOR ORGANIZING IMPORTANT PAPERS

- + Make a list of where your family can find important papers/ items, or gather them together yourself if you are able
- + Keep your papers in a fireproof box, with your lawyer or in a safety deposit box. Make sure that a family member or friend has access
- + Although original documents are needed for legal purposes, give family members copies
- + If you need help ask a doctor, social worker or lawyer. You can also give copies of any legal documents related to medical care to members of the healthcare team

ADVANCE DIRECTIVES

Advance directives are legal documents that describe what a person wants for their medical care, finances, or estate. They allow people to clearly describe their decisions about end-of-life care and who will act on their behalf when necessary. They take effect only if the person becomes unable to make decisions.

LIVING WILLS

A living will be a set of written instructions about a person's wishes for medical care. If a person later becomes unable to communicate or make decisions, doctors and caregivers will know what their wishes are about the following:

- + Use of breathing machines or ventilators
- + Use of cardiopulmonary resuscitation (CPR) if breathing or heart-beat stops
- + Artificial feeding such as tube feeding
- + Continuing or not continuing with medical treatments

These types of medical care can be used to delay death. As the person with advanced lymphoma, it is always your right to refuse treatment and to make this wish known.

POWER OF ATTORNEY

You can choose someone to act as your power of attorney to make healthcare or financial decisions for you if you become unable to do so. Sometimes, one person is chosen to make financial decisions and another person to make healthcare decisions. A power of attorney should be someone you know well and trust. They will have legal authority to act for you on your behalf.

WILLS

You may want to change an existing will or create a new one. A will gives legal instructions about how people want their money, property, and other assets to be handled when they die. It can also include information about who might look after a person's children (under age 18) after death or who should look after pets. When writing a will, get advice from a lawyer to make sure that the document is legal.

FUNERAL PLANNING

Some people want to plan their own funeral, memorial service or other special tribute or event. Others may not. If you're ready, talk to a funeral director, spiritual advisor, or social worker. If you have specific religious or cultural customs, be sure to make these known. Planning ahead means others will not be left to make decisions for you.

The end-of-life stage of a lymphoma patient's journey can be difficult to navigate. There is no right or wrong choices to be made, only those that best fit the patient's want and needs.

When planning for the future, more information can be found on our website at www.lymphoma.ca/patient-experience/coping-with-cancer/

NOTES

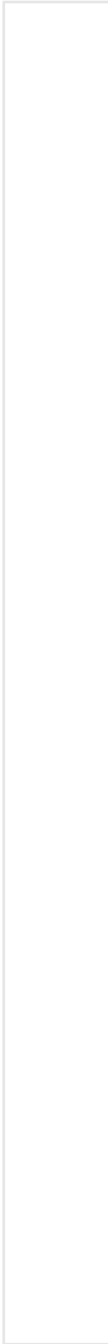
The following pages are provided to help you keep notes about any items you may want to discuss or review with your healthcare team, and/or loved ones.

DISCUSS WITH...	TOPIC FOR DISCUSSION
<i>healthcare team</i>	<i>loss of appetite, drowsiness, etc.</i>

DISCUSS WITH...	TOPIC FOR DISCUSSION

DISCUSS WITH...	TOPIC FOR DISCUSSION

DISCUSS WITH...	TOPIC FOR DISCUSSION





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