Domain 1

Disease Management

The Cancer Story

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The Cancer Story

Your experience of someone else's cancer

Being diagnosed with and treated for cancer can be difficult for many patients and the individuals around them. Exploring your experiences of caring for someone with cancer may give you insight into the various ways it has impacted you.

What additional supports might have been helpful to you in your role as caregiver?

How has someone else's cancer changed your roles and other aspects of your life?

How has it impacted your desire and ability to engage in work, physical and leisure activities?

How has their diagnosis of cancer affected your relationship with the person diagnosed?

Have you ever been a caregiver before? What was that like for you?

Do you feel prepared and supported for the caregiver role? How so? If not, what do you think you might need to feel prepared and supported?

Important Moments in the Cancer Journey

Many people say that there were particular moments in the cancer trajectory that were more important than others, were challenging, or very emotional. These could include receiving the initial diagnosis of cancer, or times when cancer status or new treatments were discussed. There may have been times when you and the person you are caring for were less able to do many of the things you previously enjoyed.

Take a moment to reflect on your experiences in the space below.

What are some of the important moments related to your family member/friend's cancer experience? For example:

- Events that have been stressful in the cancer experience.
- Events or experiences that have been positive or given you hope.
- What you may have learned from these experiences.

Consider returning to this section to add new reflections and experiences when you feel ready.

Domain ❶

Cancer Overview

When you think back to when you first learned about this cancer diagnosis, it may have felt like you were entering a new country where you couldn't read the signs or speak the language. For people with cancer, especially those who are newly diagnosed, many experiences can be puzzling or confusing. As a partner or family member you may experience similar feelings.

In the following section, we present information about cancer including possible symptoms, treatments including clinical trials, and the roles of different healthcare providers. It can help you understand what is happening, how to interpret symptoms and changes, and to plan ahead. It can also help you to be more informed during meetings with the healthcare team and to support your person in making decisions about their care.

Basic Information

There are many forms of cancer. They may vary based on location of the cancer, cancer type, and stage of disease. The stage refers to whether the cancer is localized or has spread beyond its original or primary location. These factors may affect the type of treatment that is recommended. They may also affect the prognosis of the disease although this may vary and can be difficult to determine at times. You and the person you are caring for may benefit from discussing these topics with your oncologist.

Tumor

A general term for swelling of body tissue caused by abnormal cell growth. Not all tumors are cancers. Non-cancerous tumors (called benign tumors), divide and multiply, but do not move to other parts of the body. Cancerous, or sometimes called malignant tumors happen when the body forms new cells that divide, multiply, and grow into nearby tissues. Cancer cells sometimes spread to other parts of the body and form secondary tumors, called "metastases."

Cancer staging

Cancer staging describes how much cancer is in the body, where it is located and the severity of the disease. The TNM system is the most widely used cancer staging system for solid tumour cancers and has three indicators: T = size and extent of the primary tumour; N = number of nearby lymph nodes with cancer; M = presence of cancer outside the primary tumour site or to other parts of the body.

Primary tumor (T): Refers to the size of the main tumor.

- **T0:** Main tumor cannot be seen.
- **T1, T2, T3, T4:** The higher the number, the larger the tumor or the more it has grown into nearby tissues.

Lymph nodes (N): Refers to the number and location of lymph nodes with cancer.

- **N0:** There is no cancer found in nearby lymph nodes.
- **N1, N2, N3:** The higher the number, the more lymph nodes that contain cancer.

Distant metastasis (M): Refers to whether or not the cancer has spread to other parts of the body.

- **M0:** Cancer has not spread to other parts of the body.
- **M1:** Cancer has spread to other parts of the body.

Some types of cancer use a different staging system. For example, Hodgkin lymphoma uses the Cotswold staging system, non-Hodgkin lymphoma uses the Ann Arbour Staging System, multiple myeloma uses the International Staging System and the Durie-Salmon staging system, and some gynecological cancers are staged using the Federation of Gynecology and Obstetrics staging system (FIGO for short). If you want to know more about the staging systems that are used for specific types of cancers, you can read more through your country/regions cancer society website i.e. Canadian Cancer Society.

Cancer grading is usually described from 1 to 4; the higher the number, the more that the cells look different from healthy cells, the faster they are growing, and the more likely they will spread. Doctors often use cancer grading to determine the stage of the cancer and the prognosis. A prognosis is a health professional's opinion about whether the disease will get better, get worse, or stay the same; a prediction for how things will be in the future.

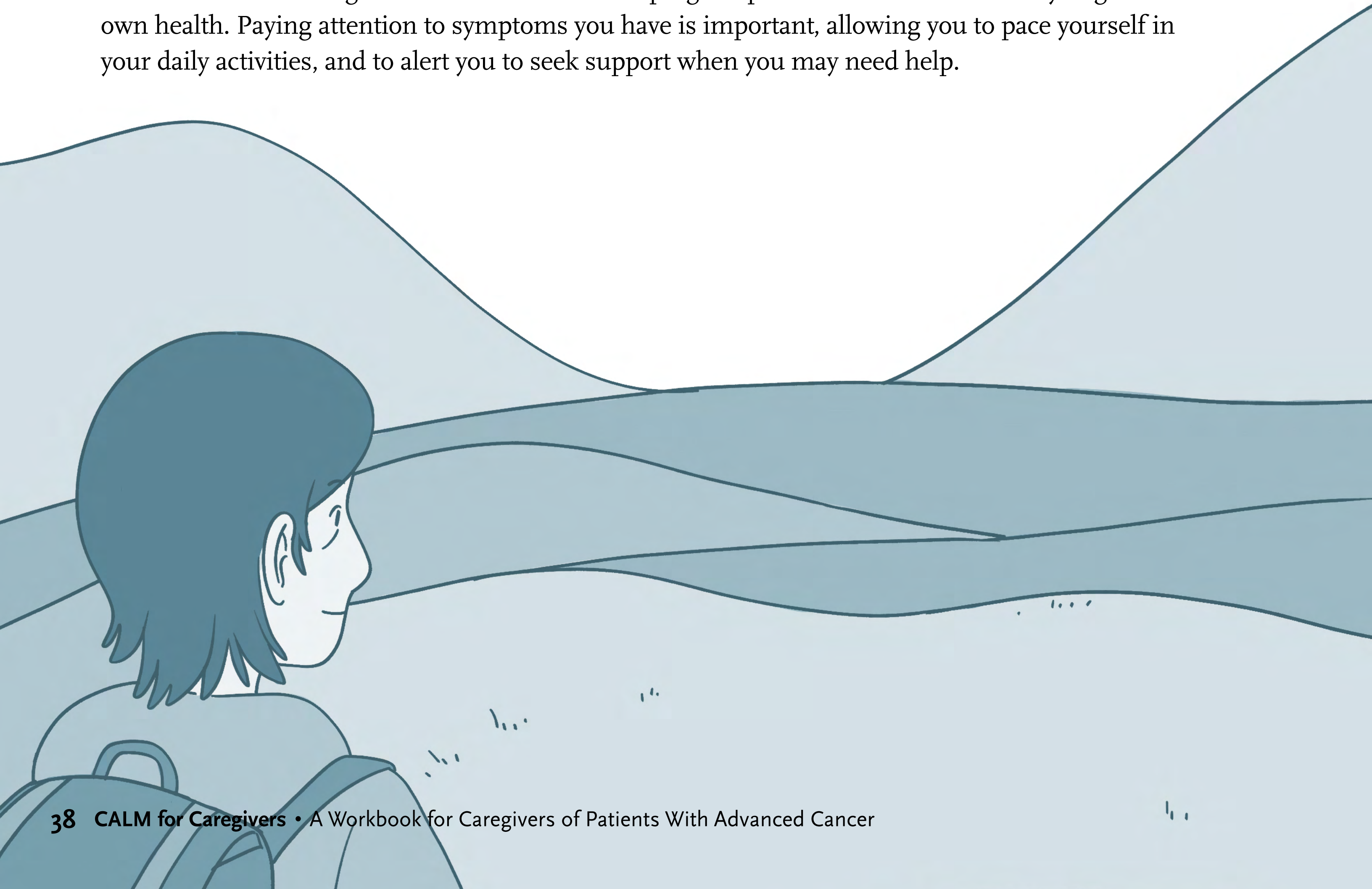
Understanding the Symptoms

Cancer is often accompanied by a variety of physical and psychological symptoms and side effects. These symptoms can have an impact on both the person with cancer and the people around them. Symptoms may be the result of the cancer, the cancer treatment, or other medical or psychological conditions. They also may have more than one cause and may interact with each other. Symptoms can also cause an emotional response. Sometimes it can be difficult to determine exactly what is causing symptoms and this uncertainty can be distressing for some people. For instance, sleep difficulties can result from the cancer, the treatment, or the stress of the situation. Sleep difficulties, in turn, can lead to low energy and emotional challenges such as low mood or anxiety.

Common Cancer Symptoms

On the next page is a list of **common** cancer symptoms and side effects. Symptoms are an individual experience - this means that the way people experience symptoms are unique to the person. This list is not meant to be complete or be used to diagnose. Your healthcare providers can support you and the person you are caring for in managing any physical or psychological symptoms.

Caregivers may experience a variety of physical and psychological symptoms of their own. These may include depression and fatigue, and/or could include symptoms related to their own medical conditions. Some caregivers are so focused on helping the person with cancer that they neglect their own health. Paying attention to symptoms you have is important, allowing you to pace yourself in your daily activities, and to alert you to seek support when you may need help.



Psychological distress (depression and anxiety)

People with cancer and those who care for them often experience many difficult emotions including sadness, worry, fear, hopelessness, anger, frustration, and guilt. These feelings can be normal and understandable reactions to the difficulties associated with cancer. However, some people develop severe and persistent distress, such as depression or chronic anxiety, and may need professional support or treatment (e.g., talk therapy or medication).

Fatigue

Physical and mental fatigue is very common amongst patients and caregivers. This can include the feeling of being tired, foggy, depleted or burnt out. For caregivers, it may be related to many aspects of caregiving, including the physical demands of caregiving, the psychological, practical or financial concerns around the diagnosis, treatment, and/or prognosis.

Pain

Pain is a common symptom of cancer. There are many types of pain, which can be related to the cancer itself, treatments, or tests. It can have both physical and emotional roots. It is important to understand the type of pain and to talk to your healthcare team so they can help you and the person you care for to best manage and control the pain.

Difficulty Sleeping

Many people with cancer and caregivers have difficulty with sleep. Sleeping difficulties can include sleeping too much, sleeping too little, and/or sleeping at the wrong time. For patients, this may be related to physical symptoms related to their cancer, such as pain, nausea, and shortness of breath. For patients and caregivers, it may be related to emotional challenges such as stress, worry or low mood.

Appetite changes

Appetite changes are a common side effect of cancer and cancer treatments, stress, and low mood. Some people may want to eat more than usual, and some individuals may lose their appetite. This change may cause weight gain or loss.

Changes in physical appearance

There may be changes to a person's physical appearance because of cancer or cancer treatments. These may include hair loss, weight changes, skin changes and more. Changes to appearance are common concerns and can be distressing. These feelings are normal and may get better with time. It can help to talk to the person you are caring for about changes in physical appearance to understand how they are feeling.

While these symptoms can be distressing and impact quality of life, there are healthcare professionals who have expertise in managing these symptoms. Do not hesitate to bring up concerns about symptoms with your health care team. They will be able to help you treat these symptoms, understand what to expect in terms of potential future symptoms, or refer you to someone who can.

Domain ❶

Understanding cancer symptoms

As a routine part of cancer care, many health care providers will regularly screen for symptoms to be sure that they are promptly and well managed. You may have seen your family member/friend complete symptom screening questionnaires during visits to the clinic or the hospital. Some clinics will have similar questionnaires for caregivers that routinely ask about emotional symptoms, coping, and practical needs.

Here is a copy of the Edmonton Symptom Assessment System (revised) ESAS-R[1] for short. You may want to consider how the person you are caring for would answer these questions.

Please circle the number that best describes how you feel NOW:											
Pain											
no pain	0	2	3	4	5	6	7	8	9	10	worse possible pain
Tiredness (i.e., lack of energy)											
no tiredness	0	2	3	4	5	6	7	8	9	10	worst possible tiredness
Drowsiness (i.e., feeling sleepy)											
no drowsiness	0	2	3	4	5	6	7	8	9	10	worst possible drowsiness
Nausea											
no nausea	0	2	3	4	5	6	7	8	9	10	worst possible nausea
Lack of appetite											
no lack of appetite	0	2	3	4	5	6	7	8	9	10	worst possible lack of appetite
Shortness of breath											
no shortness of breath	0	2	3	4	5	6	7	8	9	10	worst possible shortness of breath
Depression (i.e., feeling sad)											
no depression	0	2	3	4	5	6	7	8	9	10	worst possible depression
Anxiety (i.e., feeling nervous)											
no anxiety	0	2	3	4	5	6	7	8	9	10	worst possible anxiety
Wellbeing (i.e., how you feeling overall)											
best wellbeing	0	2	3	4	5	6	7	8	9	10	worst possible wellbeing
Other problem (e.g., constipation)											
no ____________	0	2	3	4	5	6	7	8	9	10	worse possible ____________

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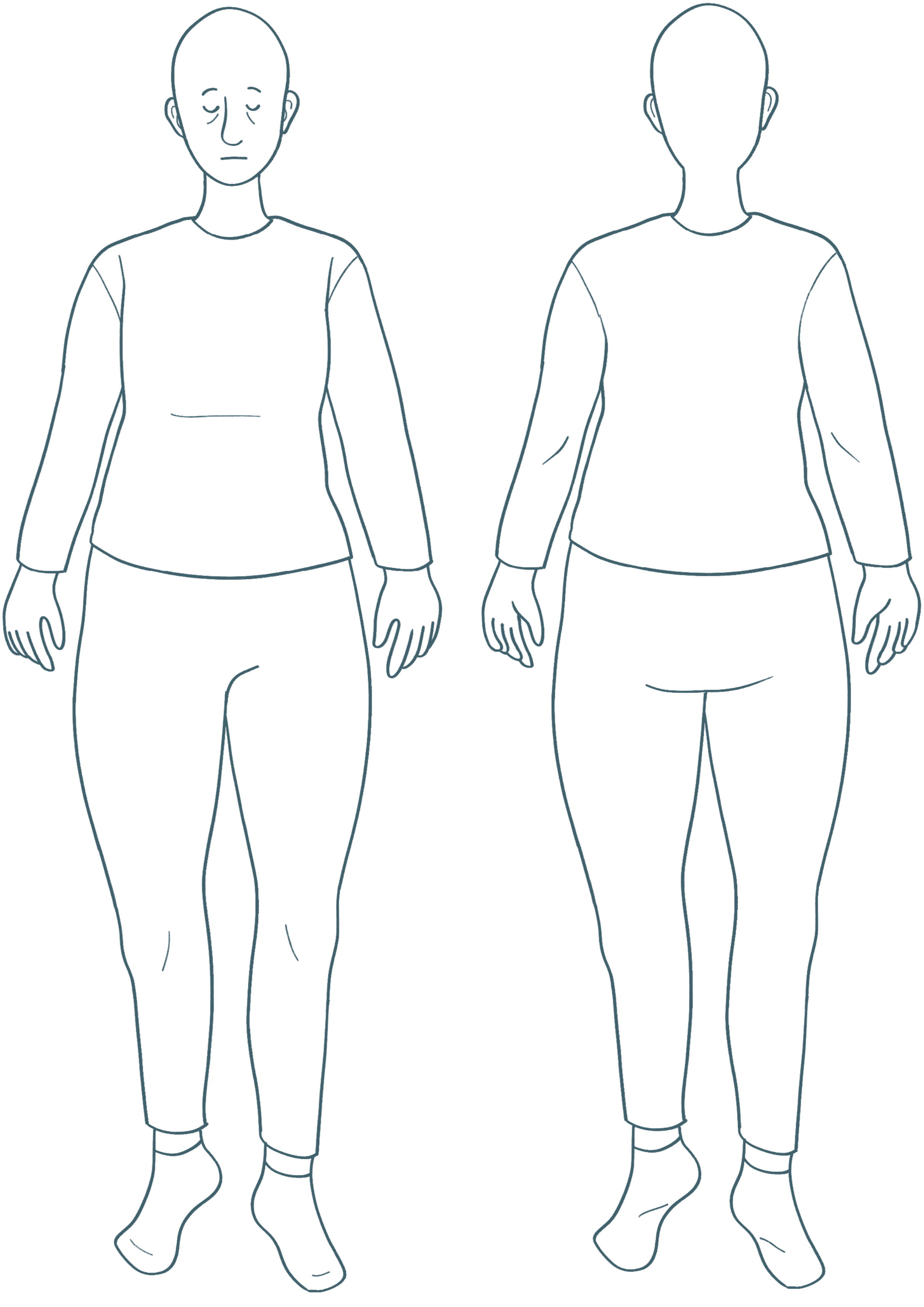
[1] Watanabe SM, Nekolaichuk C, Beaumont C, Johnson L, Myers J, Strasser F. A multi-centre comparison of two numerical versions of the Edmonton Symptom Assessment System in palliative care patients J Pain Symptom Manage 2011; 41:456-468.

Please mark on these pictures where it is that you hurt ▼



The Meaning of Symptoms

The following exercises are meant to help you reflect on symptoms and think more clearly about these challenges. These exercises will help you to communicate and prepare for future meetings with the healthcare team. Since visits are often brief, it may be helpful to plan ahead and write down concerns that you wish to communicate.

Which symptoms have been most distressing for the person you are caring for? These symptoms may be physical, psychological or both.

Have you been experiencing physical or psychological symptoms yourself?

What has made it possible or difficult to discuss any symptoms with your healthcare team?

Can you reflect on what makes interactions with the healthcare team successful, difficult or challenging?

If either of you are experiencing distressing symptoms, it is ok to bring it up with the healthcare team (including the oncologist), even if it's not directly related to the cancer. They may be able to help lessen the severity of these symptoms or arrange for another specialist to address these needs.

As a caregiver, you may experience your own distress brought on by the various challenges of caring for someone with cancer. Your primary care provider may be a good start when seeking help in managing your own symptoms.

Treatment Plans

Making treatment decisions can be a challenging for you and the person you are caring for. There is a lot to learn and think about and it's common to feel overwhelmed and even confused. Treatment decisions can be complicated, and you both may need time to think and reflect on what is best.

The type of treatment the doctor(s) and health care team propose depends on the type and stage of cancer, and other medical conditions. Treatment decisions require patients and families to learn about the risks and benefits of treatments or of clinical trials (which we will discuss later). There may be situations where the oncologist's recommendation for treatment is clear. In these circumstances treatment decisions are often more straightforward. In other cases where the benefits of one treatment over another are less clear, the decisions may be more complicated.

Treatment decisions are often easier to make when patients, families and healthcare providers are all in agreement. It may be more difficult when the opinions of family members, patients and their healthcare providers differ. Gathering and discussing information may help to resolve these differences. In other situations, patients may decide on a course of treatment which some in their circle do not agree with.

Common Types of Cancer Treatment

Radiation therapy

Sometimes called radiotherapy or radiation uses high-energy radiation to cause the cancer cells to die. The goals of radiation therapy can be curative (to cure the cancer), adjunctive (used with other treatments such as surgery), or palliative (to manage symptoms or reduce pain). Side effects may include fatigue, weight loss, nausea, inflammation, and skin and hair changes.

Chemotherapy

This involves taking medication that inhibits the growth and division of cancer cells. Chemotherapies treatment goals can include curative, adjunctive, or palliative. Chemotherapy can cause many side effects like skin changes, hair loss, lowered immune response, fatigue, nausea and vomiting, appetite changes, nerve damage, and damage to the reproductive system.

Surgery

Cancer surgeries remove tumor tissue. Surgery is usually done to prevent, diagnose or stage, cure the cancer, or lessen symptoms and improve quality of life. Surgical procedures range in how complex or invasive they are, as well as the risks that might be involved (with pain and infection being most common).

Hormone therapy

Hormone therapy works by slowing or stopping the growth of cancer cells which rely on hormones in the body to grow (e.g., gynecological, breast, and prostate cancers). Hormone therapy can have physical (e.g., nausea), sexual (e.g., loss of interest in sex), and emotional (e.g., depression) side effects.

Immunotherapy

Immunotherapy works by enhancing or boosting the body's own immune system to find the cancer and attack it. There are many types of immunotherapies (e.g., monoclonal antibodies, immune checkpoint inhibitors, conjugated monoclonal antibodies) which all work differently to attack different types of cancer. Immunotherapy can be administered in different ways such as a pill (orally), needle to the vein (intravenously) or applied to the skin (topically).

Targeted therapy

Sometimes called molecularly targeted therapy, uses specialized drugs to target specific cancer molecules. The goal of targeted therapy is typically to slow the growth of cancer, relieve symptoms caused by cancer and to destroy cancer cells.

Early palliative care

This is an approach that can be helpful to many patients with advanced cancer. The modern use of this term refers to psychological, physical, social, and spiritual care that is delivered in a patient-centred way. Some people become concerned because they believe this refers only to end of life care, but palliative care can also be involved in early stages of disease and help improve symptom control, quality of life and help in planning for the future.

Complementary and alternative therapies

Some people consider complementary and alternative therapies, instead of or in addition to conventional cancer treatment options. All options may have benefits and risks, including alternative or 'natural' therapies. Some complementary and alternative therapies can reduce the effectiveness of traditional treatment options, for this reason it is important that the healthcare team know all the therapies a patient is receiving or considering.

Treatment Plans

What treatment are they currently receiving, including supportive care and/or palliative care?	How did they make the decision about their current plan? Who was involved in making that decision? Were options well explained before any decisions were made?
What do you understand about the goals of their treatment(s)?	Would you have liked to be more involved in the treatment decision process? If so, what barriers to involvement are you experiencing?

It is strongly encouraged that you and your loved one talk to your healthcare team and ask questions before making decisions about treatments (including clinical trials). If either of you are having difficulty speaking with your team, you will find more support in the second section of Domain 1, Communication with Healthcare Providers.

Treatment Plans

Do you and the person you are caring for know who to talk to about future treatment decisions? Do you feel like your/their values, goals, and needs have been considered in the treatment decision-making process?

Take a moment to reflect on your experiences of supporting this person throughout the decision-making process to date. What are some key moments that come to mind that were either positive or negative?

Do you think there will be challenging decisions you will have to make in the future? What might those be?

Clinical Trials

At some point during treatment, someone from the healthcare team may suggest participation in a clinical trial. You or the person you are caring for may have even actively searched for one. It is important to understand what a clinical trial is when you make your decision about whether to participate.

What is a clinical trial?

A clinical trial refers to a research study in which a new treatment is being evaluated. These treatments are still under investigation and may not have been proven to be safe or effective.

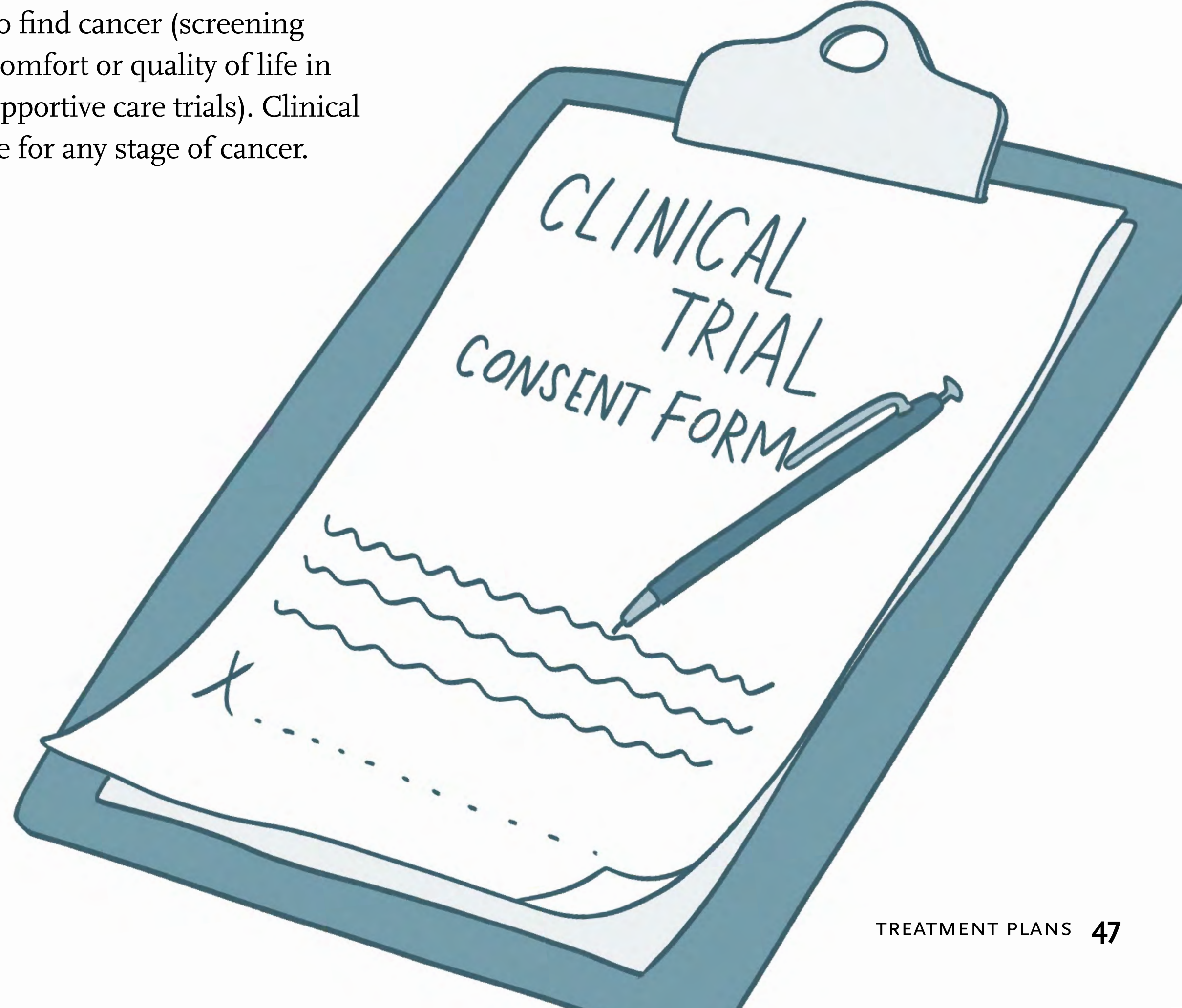
What is the purpose of a clinical trial?

The purpose of clinical trials can be to test new or modified treatments (treatment trials), to find ways to prevent cancer (prevention trials), look for better ways to diagnose cancer (diagnostic trials), look for better ways to find cancer (screening trials), and improve comfort or quality of life in those with cancer (supportive care trials). Clinical trials may be available for any stage of cancer.

Treatment vs. Research

A standard of care, or "best practice," follows guidelines that are generally accepted in the medical community for the treatment of a condition. Clinical trials, in contrast, are research studies of treatments that are not yet established as standard care.

If someone decides to participate in a clinical trial, they will receive a consent form with all the information about the study, the treatment and tests, the potential benefits and risks, and the research process. They may also withdraw from participating in a clinical trial at any time, even after they sign the consent form.



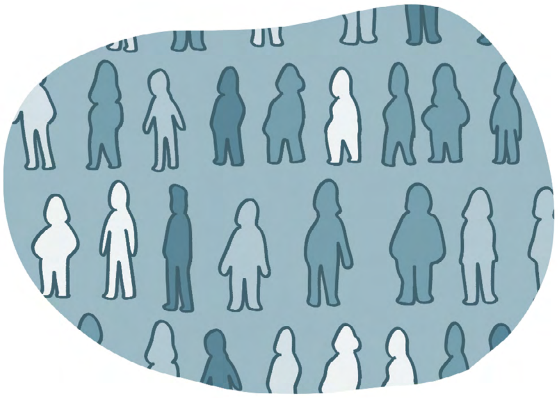
Phases of Clinical Trials

Clinical trials are part of a long process of developing treatment (sometimes called interventions). Most new treatments start in the laboratory and are then tested on animals. If the results of those studies look promising, the researchers will move onto clinical trials.

There are usually four phases of clinical trials, and each phase has different goals.

Phase 1

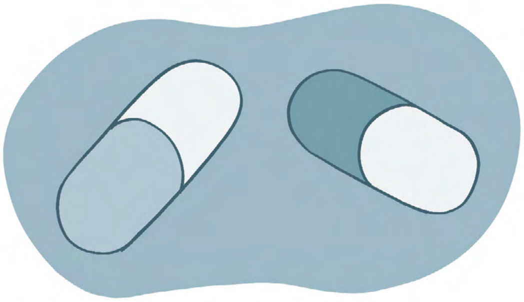
A **phase I clinical trial** is often the first time a new treatment is tested in people. The goals are typically to test the safety of the new therapy and determine the best dose of the drug, if applicable. These trials are typically very small (e.g., 15-30 people) and often only available to people with advanced cancer who are not responding to other treatments.



Phase 3

A **phase III study** compares the new treatment to the current best or commonly used treatment (sometimes called the “gold standard”).

Typically, the goal of this phase is to see whether or not the new treatment is better or at least as effective (but better in some other way such as associated with fewer side effects) than the current best treatment.



Phase 2

A **phase II clinical trial** determines if a new treatment is effective. The goal of a treatment study might be to determine if the treatment is effective at treating the cancer, while the goal of a palliative care study might be to determine if the treatment reduces pain or improves quality of life.

Phase 4

A **phase IV study** is the final stage in a clinical trial. The purpose of a phase IV study is to gather more information about possible effects after the treatment is approved to be used in patients. These studies are often very large, with hundreds to thousands of participants.

Some important things to consider when deciding whether or not to participate in a clinical trial are:

1. The type and the phase of the trial
2. The risks and benefits of the trial
3. The costs and time involved in the trial
4. Personal goals and values

Clinical Trial Decision-Making

The decision to participate in a clinical trial is personal. People decide to seek out and participate in clinical trials for many reasons. In addition to individual health benefits, some may wish to contribute to science and help future patients with their type or stage of cancer.

Has the person you are caring for been invited to participate in a clinical trial? If so, what motivated them to do so and how were you involved in the decision making?

Have either of you talked about clinical trials with your healthcare team? Recall those conversations, what stands out to you and why?

If the person you are caring for is currently involved in a clinical trial, what are some of the reasons for their participation?

What is your understanding of the goals, risks and potential benefits of your loved one participating in the clinical trial? Were they explained to you, and do you know who to contact to get more information?

Pros and Cons of Participating in a Clinical Trial

If either of you are considering participating in a clinical trial, one way to focus your thoughts is to make a list of pros and cons.

Pros	Cons

Remember that the person you are caring for has the right to choose whether or not to participate in a research study. They continue to get their current standard care even if they choose not to participate. They may leave the study at any time, without this decision affecting their care.

If you feel that you need extra support for yourself, or if you feel that the person you are caring for requires additional help in managing their physical symptoms, we encourage you to talk to your healthcare team. Also, if either of you needs more psychological or social support, do not hesitate to speak out and explore options with your team.

Pause and Consider

Pause for a moment. *How are you feeling?*

Consider what you need right now. *What might help to support you in the next few minutes, hours, or the coming days?*

Summary of Domain 1: Disease Management

- A cancer diagnosis can feel overwhelming, confusing and distressing for both patients and caregivers
- Understanding cancer helps with symptom interpretation, treatment planning, and communication with the healthcare team.

Basic Cancer Concepts

Cancer Types & Stages: Vary based on location, type, and how far it has spread (localized vs. metastatic).

Tumors

Benign: Non-cancerous, doesn't spread.

Malignant: Cancerous, can invade tissues and spread (metastases).

Cancer Staging (TNM System)

T: Tumor size (T0-T4)

N: Lymph node involvement (N0-N3)

M: Distant metastasis (M0-M1)

Grading: Rates cancer from 1-4, the higher numbers the more abnormal and aggressive the cells are.

Common Symptoms & Side Effects

Emotional: depression, anxiety, fear, guilt and anger can be common in both patients and caregivers.

Fatigue: physical, emotional, or mental, can be common in both patients and caregivers.

Pain: varies by cause (cancer, treatment, tests).

Sleep Issues: Difficulty falling/staying asleep or excessive sleep; may relate to stress, symptoms in patients and caregivers, or treatment(s) in patients.

Appetite Changes: Increase or loss of appetite, impacts patients, can affect weight/strength.

Appearance Changes: Hair loss, skin changes, weight changes, impacts patients.

Caregiver Health: Caregivers can experience neglect of their own needs, fatigue, and emotional burden. There are some tailored clinics that support caregivers' emotional and practical needs.

Cancer Treatment Options

Radiation Therapy: Uses high-energy rays to kill cancer; side effects include fatigue, skin changes, nausea

Chemotherapy: Drug treatment that kills fast-dividing cells; can cause hair loss, fatigue, nausea, immune suppression

Surgery: Removes/reduces the tumor; used for diagnosis, staging, cure, or symptom relief

Hormone Therapy: Blocks hormones that feed cancer (e.g., breast, prostate); can affect mood, sex drive

Immunotherapy: Boosts immune system to fight cancer; may be given via pill, IV, or skin

Targeted therapy: Attacks specific cancer molecules; aims to slow growth or reduce symptoms

Early Palliative Care: Enhances quality of life at any stage, not just end-of-life

Complementary & Alternative Therapies: Should be discussed with healthcare providers due to potential interactions

Summary of Domain 1: Symptom Management & Communication with Healthcare Providers

Clinical Trials

Research studies to test new or modified treatments, often explore options not yet established as standard treatment. Consent is voluntary and can be withdrawal/stopped at any time.

Phases of Clinical Trials

Phase I: Tests safety and dosage (small group, usually late-stage patients).

Phase II: Tests effectiveness.

Phase III: Compares to standard treatment; looks at efficacy and side effects.

Phase IV: Post-approval monitoring for broader impacts.

Considerations Before Joining

- Trial phase and type
- Risks and benefits
- Time and cost commitment
- Alignment with patient's values and goals