CALM

for caregivers

an illustrated workbook for caregivers
of patients with advanced cancer

The Princess Margaret Cancer Foundation UHN
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We wish to acknowledge that this workbook was created on the traditional territory of many nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples. It is now home to many diverse First Nations, Inuit and Métis peoples. We also acknowledge that Toronto is covered by Treaty 13 with the Mississaugas of the Credit. We are grateful for the opportunity to work on this land.

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CALM for Caregivers

An Illustrated Workbook for Caregivers of Patients with Advanced Cancer

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Acknowledgments

Many individuals have contributed at various stages to the development of this workbook.

The theoretical framework, content topics, and general approach are based on the brief, semi-structured psychotherapeutic intervention Managing Cancer and Living Meaningfully (CALM), designed specifically for patients with advanced cancer and their family caregivers.

CALM was developed by Dr. Gary Rodin and Dr. Sarah Hales and shaped by the valuable input of many clinical and research collaborators. CALM was adapted into material for a self-directed online intervention that served as a foundation for this workbook.

We would like to acknowledge the input of the many individuals who helped to develop that original online material including clinician advisors (Dr. Froukje DeVries, Loreto Fernandez, Dr. Lindsay Hurlburt, Dr. Ebru Kaya, Dr. Chana Korenblum, Dr. Jenny Lau, Dr. Andrew Matthew, Kelly McGuigan, Dhara Moddel, Dr. Pamela Mosher, Patricia Murphy-Kane, Ashley Patterson, Dr. Christian Schulz-Quach, Dr. Gilla Shapiro, Dr. Jungmin Woo), research team members (Twinkle Aurora, Emily Barca, Natalie Bauereiss, Lesley Chalklin, Alanna Chu, Valerie Heller, Cheryl Kanter, Laurice Karkaby, Argin Malakian, Carmine Malfitano), and patient and family advisors (John Dodds, Diane Boyes, Pierrette Comtois-Heino).

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This final version of this workbook was created by Dr. Rinat Nissim, Dr. Sarah Hales, and research coordinator Karley Wulf. Content was illustrated and designed by Emily Huang, a biomedical communications graduate student (MScBMC) at the University of Toronto, who was supervised under Dr. Shelley Wall, associate director and associate professor at the MScBMC program.

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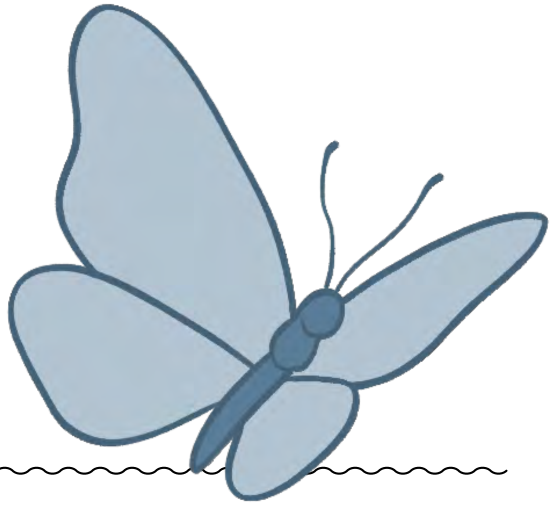
Introduction



All of us may have different roles in life, as family members, friends, partners, professionals, etc. These roles may fulfill us in different ways. Some we may take on by choice and some not.

The role of a caregiver sometimes comes suddenly and sometimes gradually. It may be a role we take on naturally without much thought, or it may be one that we resist or struggle to adjust to. Depending on different life circumstances, caregiving duties may be shared but often the burden falls mostly on one family member.

Most of the roles we have in our lives come with training, whether formal (schooling, on the job experience, etc.) or informal (learning through experience or watching others) but most of us do not have the opportunity to be trained for the role of a caregiver.

The purpose of this workbook is to support caregivers of people with advanced cancer. Through research into caregiver experiences, and through years of working with caregivers in 1:1 therapy and clinical settings, it has become clear that caregivers need and deserve support for the unique situations they face. Unfortunately, up until now there have been limited resources to support caregivers, and research shows that caregivers can often be reluctant to reach out for help resulting in underutilization of support services. This workbook has been designed to provide caregivers with a self-paced, 'choose your own path' approach to support for the emotional and practical challenges of cancer, allowing caregivers to be in control of their experience, accessing the information they want, when they are ready.

Of note, we recognize that the close support around someone with cancer can include spouses, relatives, and/or friends. Throughout this workbook we use the word "family" to include anyone in the close circle around the individual with cancer.

Managing Cancer and Living Meaningfully (CALM)

CALM for Caregivers is based on components of **CALM** therapy ("Managing **C**ancer **a**nd **L**iving **M**eaningfully"). Developed in Canada and used in many countries around the world, CALM is focused not only on the practical challenges of cancer, but also the range of emotions that may be experienced and how to manage them, as well as common challenges to identity, relationships, meaning, and planning that may arise during this time.

This workbook begins with a primer on emotions and then explores four CALM domains: 1) symptom management and relationships with healthcare providers; 2) changes in self and relationships with close others; 3) sense of meaning and purpose; and 4) mortality and future-oriented concerns. Each section has a different focus, but you will notice some similarities throughout. We start each section by highlighting what you can expect, and then information will be presented with real caregiver stories to illustrate the material and reflective exercises woven throughout to help connect what you are reading to your life experiences and circumstances.

The stories are based on real situations. For this reason, names and other personal information may have been changed to protect privacy. You may relate to these stories or you may not. Each story is meant to provide an example, relevant to the particular domain or topic, but is not intended to represent all experiences. For some people, learning through someone else's story can be helpful and allow for deeper insights into their own story and experience. If this is not beneficial for you, we have tried to ensure that the reflective exercises which typically follow can still be completed from your own perspective.

How to Use this Workbook

This workbook is meant for you to use in any way that benefits you.

The various sections of this workbook have no intended order and can be worked through in many ways. You should feel free to decide what content interests you and focus your attention there. It can be helpful initially to familiarize yourself with all the content of this workbook, even if a topic or exercise is not of interest/importance now. Reviewing the content now will help you recall and return to it later.

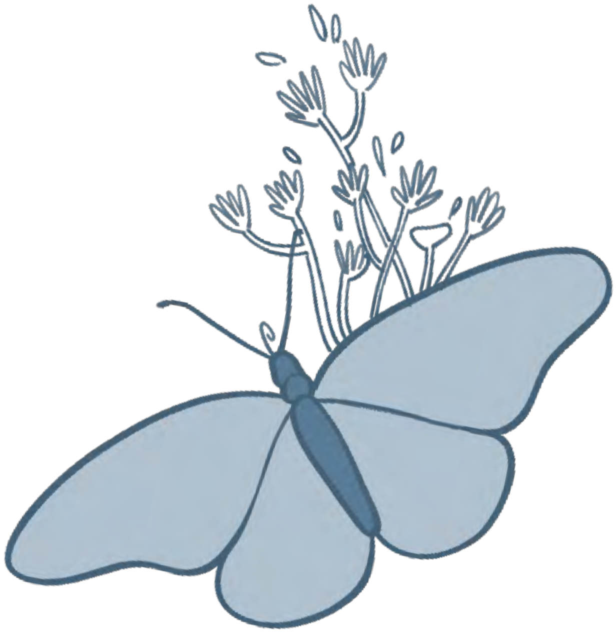
For individuals who prefer to navigate the workbook by jumping from section to section, simply note that some information may be introduced in previous section, so you may need to flip back to the to familiarize yourself with a strategy or concept. However, this should not deter you from freely navigating the workbook as you prefer.

Many people may prefer to use this workbook with the support of a therapist or mental health professional. Bringing difficult topics or emotions to a session with a professional can help support your understanding and the process of self-reflection but is not required.

Additional Supports to Consider

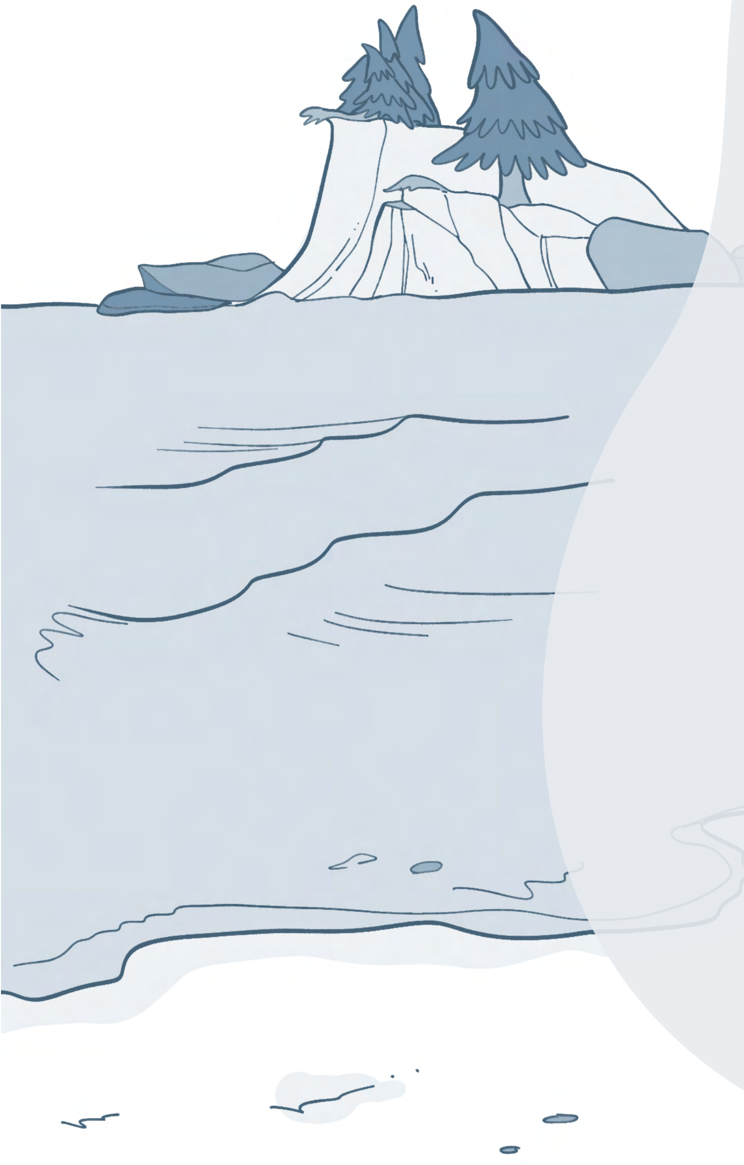
This workbook is not intended as a substitute for professional support. When navigating a challenging time, looking for professional help can be beneficial. If you feel you need more support, consider contacting your family doctor who may be able to connect you with mental health resources in your community. The cancer treatment centre may also offer counseling and support that can help you. If you feel you could benefit from speaking with a mental healthcare professional, let the treatment team know. Asking to be referred to a social worker can often be a good starting point to tap into the support you need.

If you need immediate support, or if you have thoughts of hurting yourself or someone else, dial 911 or go to your nearest emergency room. There is help available to you.



Introduction

Primer on Emotions



What Are Emotions and Why Are They So Important

We invite you to think about emotions from different perspectives, including what elicits strong emotions in us, and how they may manifest, **pg.13**

Common Emotions for Caregivers

We will explore commonly experienced emotions that caregivers often describe: helplessness, fear, grief, guilt and anger, **pg.15**

Managing Our Emotions

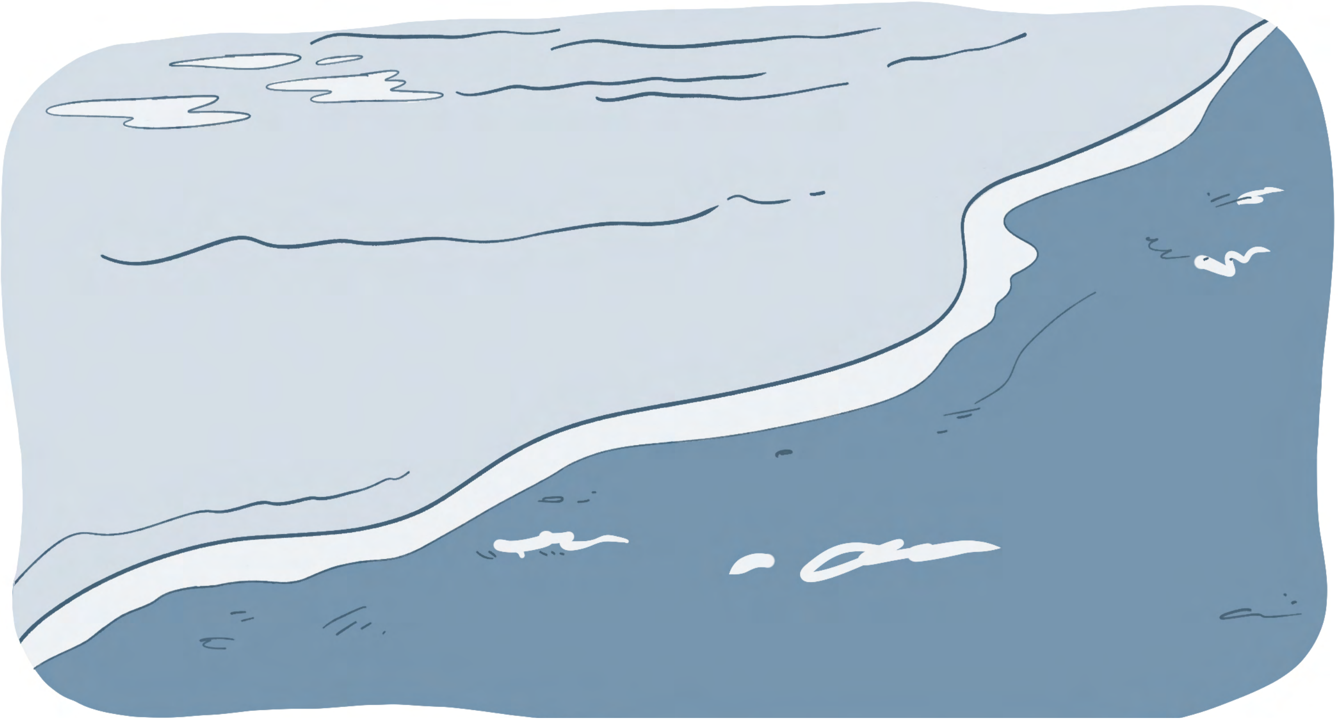
Lastly, we will offer various ways and tools to manage emotions, **pg.29**

Summary

One-page summary for this section, **pg.32**

To Start...

A cancer diagnosis brings with it many challenging emotions. People facing advanced cancer (both patients and their family members) can experience very difficult emotions, including fear, helplessness, sadness, grief, guilt and anger.



Often, the focus is on the patient's experience. However, research consistently shows that advanced cancer can be more distressing to caregivers than to patients. One of the first studies to compare the emotional distress of patients and their family caregivers was conducted at the Princess Margaret (PM) Cancer Centre, in Toronto, Ontario, Canada. In this study, Braun and colleagues found that almost 40% of spousal caregivers experienced depressive symptoms, compared to only 23% of their advanced ill spouses.

This is why we chose to begin this workbook with a Primer on Emotions, helping you understand your emotions (both pleasant and unpleasant) as a family caregiver and how your family member's cancer is impacting your emotional wellbeing.

What Are Emotions and Why Are They So Important?

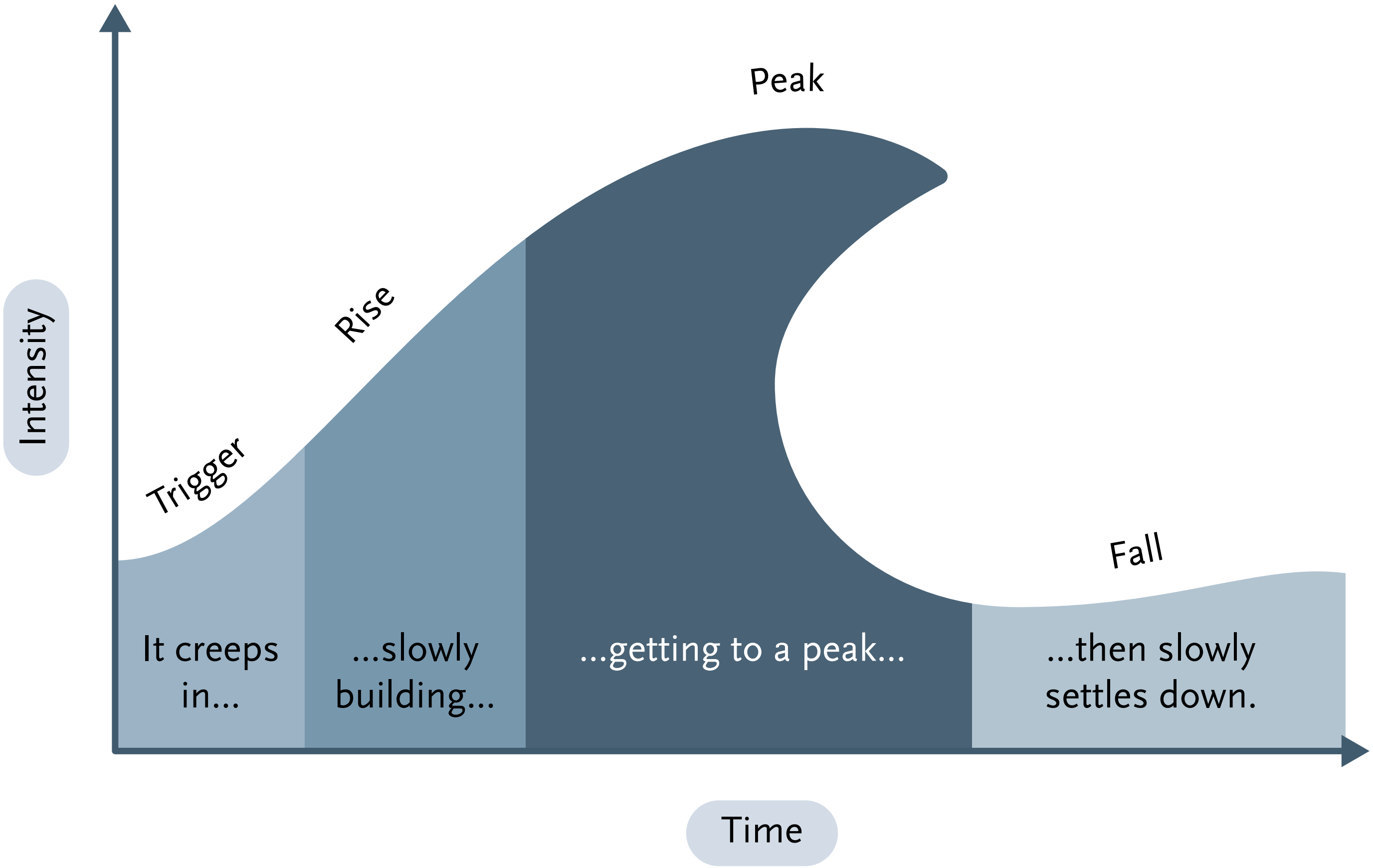
Emotions are an important component of the human experience and help us make sense of the world. Joy helps us understand what is pleasurable and good for us; fear signals when there is a possible danger; anger motivates us; sadness helps us process loss.

We tend to judge ourselves for certain emotions or the thoughts that they bring. However, it is more productive to think of emotions as a source of information – they can help you figure out what you need or want. Our hope is that our description of common emotions for family caregivers will encourage you to move from "I shouldn't feel this way" to "this is why I sometimes feel this way."

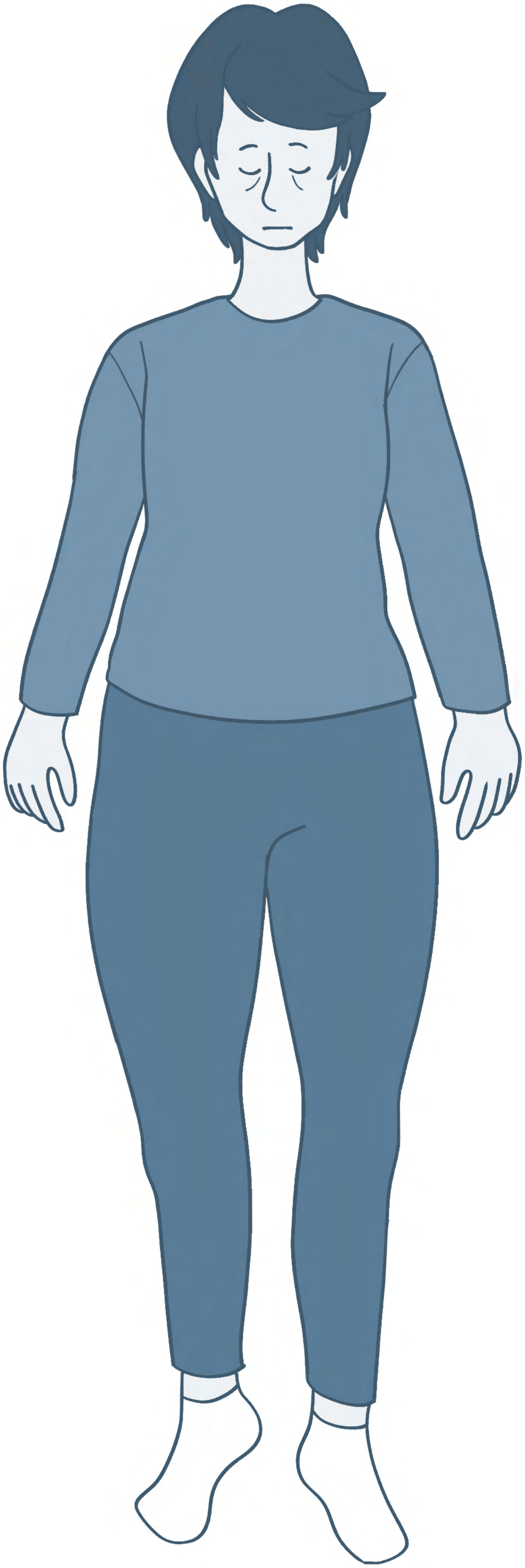
Another important thing to know about emotions, is that they are like waves – and all emotions, pleasant or unpleasant, will always pass.

Here is a picture to remember as you progress through this workbook and beyond. It is the wave of emotion/emotions. Depending on the feeling and circumstances around that feeling(s), this wave may take minutes or hours or sometimes even days to pass.

Wave of Emotion



Lastly, it is important to know that we can experience several emotions atonce, and these emotions might not always agree with each other. For example, you might feel happy and sad at the same time about differentaspects of a situation. This is especially true for family caregivers of individuals with advanced cancer. Being a caregiver for someone with advanced cancer can bring about many emotions. Sometimes it may feel like being on a rollercoaster. You may move between intense alternating emotions or between feeling numb and feeling intense emotions. You may feel emotions that seem conflicting. For instance, feeling hopeful if the doctor gives another treatment option but also worried or fearful knowing that another round of treatment might mean pain or have negative side effects. This can be confusing and make it difficult to understand what we are feeling.



Where Do You Notice Emotions in Your Body?

Part of feeling and understanding our emotions is knowing where they happen in our bodies. As a wave of emotion begins, we may feel it in our body—a lump in the throat, heat or fire in the belly, faster breathing, racing heart, feeling flushed. Physical changes can be cues to help us recognize our emotions.

Common Emotions for Caregivers

Cancer is often experienced as not just a physical trauma, but also a psychological trauma, and in that respect, the trauma is shared and is not limited to the individual with the physical trauma. Therefore, people facing advanced cancer (both patients and their family caregivers) can experience very distressing emotions, including fear, helplessness, sadness, grief, and anger.

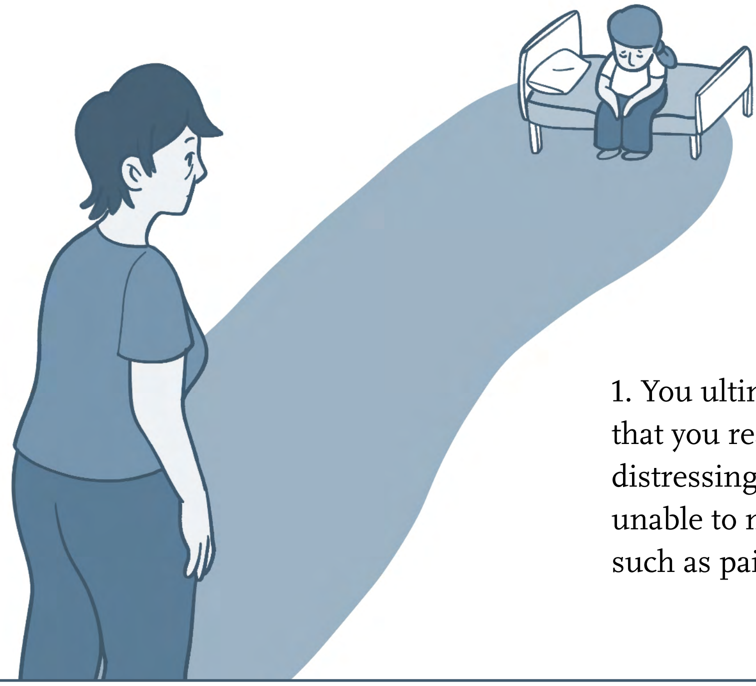
At the same time, while a traumatic experience is distressing, it also may have the potential to lead to what we call "post-traumatic growth." Post-traumatic growth refers to the positive psychological changes that individuals experience while facing highly challenging experiences and it is often associated with many positive emotions, such as deeper joy and gratitude for life and relationships, pride in one's newfound strength and resilience, or greater compassion for others. These more positive emotions often coexist with the distressing emotions.

There are some emotions, pleasant and unpleasant, which tend to be commonly felt in caregivers that we are listing on the following pages. This is by no means an exhaustive list or meant to tell you what you should be feeling but perhaps there may be times when you have or will experience some of the emotions outlined here. All of your feelings are valid and make sense. We hope that by reviewing the list we provide you will better understand what you may feel and recognize that others may have similar feelings.

Helplessness

As a caregiver, it is very likely that you will feel helpless from time to time.

2 main conditions contribute to this:



1. You ultimately can’t fix the problem that you really want to fix. It may be distressing to see someone suffer and be unable to make the illness or side effects, such as pain or fatigue, disappear.

2. Ultimately, the patient has more control than the caregiver. The patient has more control over their situation, knowing their own pain and discomfort levels, while you do not. You might also face disagreements about decisions like what they should eat or drink and when, or what to tell the doctor(s) and when to call the doctor. Additionally, as a caregiver, you may not have direct access to the patient’s medical record or medical team to ask your own questions. This lack of direct communication can leave you feeling out of the loop and powerless, as you rely on second-hand information from the patient.

Reflecting On: Helplessness

Can you recall a specific moment when you felt helpless as a caregiver? What was the situation? What other emotions, if any, did you experience? And how did helplessness shape your behaviour?

Is there a pattern to your helplessness? Do you feel it more with certain people, situations, or in relation to specific issues?

How comfortable do you feel expressing your helplessness to others, whether it's the patient, friends, or family members?

Fear

A cancer diagnosis in the family shakes up our sense of certainty and control. It makes us face the reality that we can't always predict or control what will happen. This uncertainty, by default, brings both hope and fear. Therefore, many caregivers alternate between feeling hope and fear, with fear being more in the forefront when there is less stability and more uncertainty. For example, when the patient has new symptoms or side effects, or when the patient is about to begin or finish treatment.

Not knowing what each day will bring, how the patient will respond to treatment, or whether there will be unexpected complications can leave some caregivers feeling on edge and perpetually anxious about what the future holds. Many caregivers also experience fear in relation to what life will look like after the patient dies. In addition, intimate exposure to illness, particularly cancer, may evoke fears about one's own health or the health of other family members.

Remember – while fear is unavoidable, it will always be a wave that passes, and in the next section, we will suggest a few strategies that can help you "ride the wave" of fear when it comes.

Reflecting On: Fear

Can you recall a specific moment where you felt fear as a caregiver? What were the circumstances? Was it in relation to a specific concern? How did you experience the fear in your body? And how did the fear shape your behaviour?

Do you find that your fear fluctuates over time? Are there certain times or events that intensify or alleviate your fear?

How comfortable do you feel expressing your fear to others, whether it's the patient, friends, or family members?

How do you usually react to uncertainty in your life?

Grief

Caregivers are often surprised to realize how much grief they are carrying. We usually think about grief as something that only happens after someone important to us dies. However, grief often starts with the diagnosis of cancer. This is because the diagnosis of cancer brings about many different losses. Some are tangible losses like changes in finances or family dynamics. Some are intangible, such as the loss of the vision you may have had for the future. In addition, sometimes, it may feel like you're grieving not only for what has already changed, but also for what may lie ahead, a phenomenon known as anticipatory grief.

Reflecting On: Grief

Can you recall specific moments where you've experienced grief as a caregiver, or upon reflection, recognize instances where you may have felt grief? What triggered this grief? Where do you feel it in your body?

Do you find that your grief fluctuates over time? Are there certain times or events that intensify or alleviate your feelings of sadness?

Have you experienced anticipatory grief, where you mourned potential losses or changes before they occurred?

How comfortable do you feel expressing your grief to others, whether it's the patient, friends, or family members?

Guilt

It's common for caregivers to carry around a heavy load of guilt. They might replay moments in their minds, wondering if they could have handled things better or made different choices, even to the point of being convinced that different choices or actions could have prevented the cancer from happening in the first place.

Sometimes, caregivers also feel guilty for perfectly normal thoughts or feelings, like the wish for this experience to end, or like having moments of happiness while the patient is sick.

If you struggle with guilt, we would like you to consider the idea that beneath the weight of guilt you're carrying, there might be a deeper longing – the wish to regain a sense of control and certainty. As humans, it's less painful to believe that if we had acted differently, things might have turned out better, than to confront the reality that we don't always have as much control as we'd like. Admitting this can be tough because it means accepting the unpredictable nature of life and the vulnerability that comes with it.

Reflecting On: Guilt

Can you recall specific moments where you've experienced guilt? What triggered this guilt? Where did you feel it in your body? How did the guilt shape your behaviour?

Are there certain times or events that intensify or alleviate your feelings of guilt? Have you noticed any patterns or triggers that consistently lead to feelings of guilt?

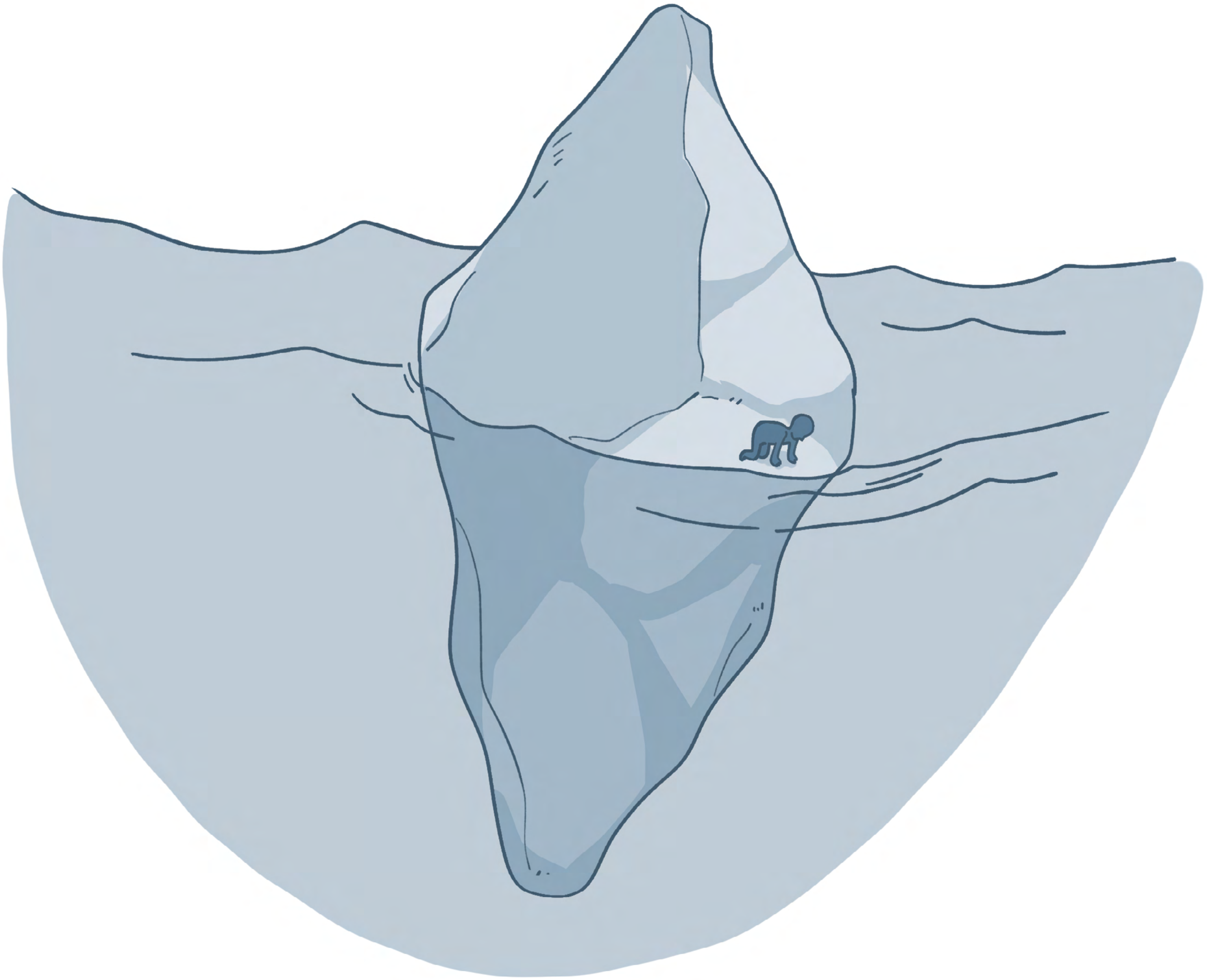
How comfortable do you feel expressing your guilt to others, whether it's the patient, friends, or family members? Have you ever discussed your feelings of guilt with others, such as friends, or family members? If so, how did these conversations impact your perception of guilt?

Anger

Similarly to guilt, many caregivers find themselves struggling with waves of anger, feeling frustrated or resentful when they believe others could have or should have handled situations differently.

Anger is often a great source of information about your unmet needs. Anger can be like a signal, trying to tell us something important. For example, it might be telling us that we're burned out, or that we're feeling overlooked or unappreciated, like no one sees all the hard work we're doing.

But here's the thing about anger: it's often not the whole story. It's the tip of the iceberg – what you see on the surface. Beneath that anger, there are usually deeper emotions lurking, like grief, fear, or helplessness. As humans, it's often easier and less painful to feel anger than to feel the emotions that are underneath.



Reflecting On: Anger

Can you recall specific moments where you've experienced anger as a caregiver? What triggered this anger? Where did you feel it in your body? How did the anger shape your behaviour?

Are there certain times or events that intensify or alleviate your feelings of anger? Have you noticed any patterns or triggers that consistently lead to feelings of anger?

How comfortable do you feel expressing your anger to others, whether it's the patient, friends, or family members? Have you ever discussed your feelings of anger with others, such as friends, or family members? If so, how did these conversations impact your perception of your anger?

Hope

Fear and hope always coexist. A cancer diagnosis, by default, brings about uncertainty, and uncertainty brings about both hope and fear. Therefore, as we discussed when we explored the common emotion of fear, many caregivers alternate between feeling hope and fear.

Sometimes, caregivers might doubt their sense of hope, worrying that it means they're ignoring the seriousness of the situation. But it's important to realize that feeling hopeful doesn't mean you're in denial. It's completely normal, and can be very nourishing, to have moments of hope. We encourage you to enjoy this feeling, rather than question it.

Dealing with the mix, or duality, of hope and fear can be tough. Often, we end up splitting these emotions between ourselves and the person we are caring for. For example, the patient might hold onto hope while the caregiver feels overwhelmed by fear, or vice versa. This division is very common, and we will explore how to manage it in the next section.

Reflecting On: Hope

Reflect on a time when you felt a sense of hope as a caregiver? What inspired or nurtured that feeling? Where did you feel it in your body? How did it shape your behaviour?	Have you ever doubted your sense of hope, questioning whether it was realistic or appropriate given the circumstances?
How do you express or share your hope with others? How do their responses impact your own sense of hope?	Do you find that your hope fluctuates over time? Are there certain times or events that strengthen or diminish your hope?

Joy and Gratitude

Every society and culture have their own phrases emphasizing finding beauty or growth through adversity. For example: “no mud, no lotus”, "every cloud has a silver lining" or "diamonds are created under pressure." This is because, universally, even when the hard times feel like they're weighing you down, they can also make us stronger and bring some unexpected positives into our lives.

For you, as a caregiver, this might mean feeling even more joy and gratitude for the little things – like spending time with the person you are caring for, feeling proud of how strong you've become, or grateful for the support you receive from others. Going through tough times can also make you more compassionate and understanding towards others who are going through similar struggles. It's like walking in someone else's shoes – you get a whole new perspective on what they're going through, and that can lead to a deeper sense of connection.

Reflection

Reflecting On: Joy and Gratitude

Reflect on a time when you felt a sense of joy or gratitude as a caregiver? What inspired or nurtured these feelings? Where did you feel it in your body? How did it shape your behaviour?	How do you express or share these feelings with others?

Managing Our Emotions

Managing our emotions begins with awareness of them and naming them. We hope that the list above of common emotions in caregivers can help you name your emotions, especially ones, like grief or helplessness, that tend to hide behind emotions that are easier for us to feel, like anger or guilt.

Often, managing our emotions can be done just by reminding ourselves that all emotions, pleasant and unpleasant, are like waves. Just as waves in the ocean rise and fall, our emotions, both pleasant and unpleasant, come and go. It's crucial to remember this because we often fear being "stuck" in our unpleasant emotions, believing they'll never pass. Similarly, we may fear the fleeting nature of pleasant emotions, not wanting them to end. But like waves, emotions always shift and change, even without us trying to “manage” them.

Similarly, often, managing our emotions can be done just by reminding ourselves that all emotions are normal and valid, and by giving ourselves permission to feel them all when they arise, without judging the emotions or ourselves. Judging is not helpful (ever, but especially when it comes to emotions). Emotions, although sometimes very unpleasant, are always valid and are never “wrong” “false” or “bad”. Instead of judging, try giving yourself a little pep talk, reminding yourself that whatever you are feeling is totally okay and normal. You don't have to push your feelings away or pretend they're not there. Paradoxically, this attitude will help you “ride out” the wave of distressing emotions faster because the more we are willing to feel the emotion, truly ‘sit in it’, the more quickly the feeling becomes less intense and more tolerable.

Reflection

We tend to judge our emotions. Think about an intense emotion that you had as a caregiver.

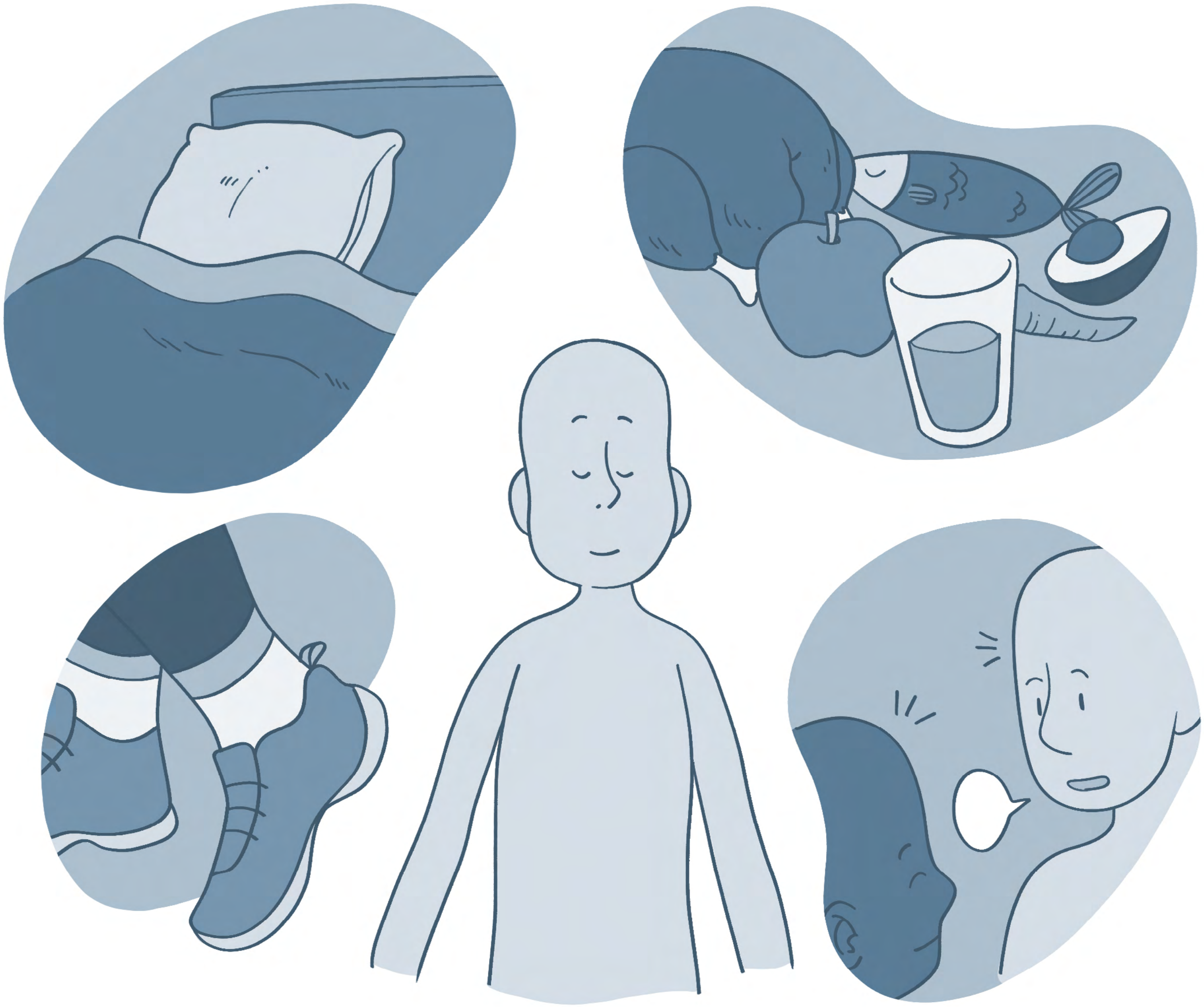
How did you judge it? Here are some common examples: “I shouldn’t feel this way”, “it's selfish to feel this way”, “I will jinx things if I feel this way”, “feeling this way means I’m in denial”, or “feeling this way means I gave up”.

A Note on Self-Care

Self-care is taking the time to do things that help you take care of your physical and emotional health. It can be simple activities like getting enough sleep, eating healthy meals, taking a walk, or spending time with friends. It's about making sure you're feeling well so that you can better handle the challenges in your life.

Self-care is essential to managing your emotions and can help you stop your unpleasant emotions from getting too intense. Think about it like this: when you're tired or hungry, you might notice your feelings are more unpleasant and intense. That's because our basic needs, like sleep and food, affect how we feel. So, it's important to take care of those needs to keep our emotions in check.

Remember, self-care is *never* selfish. Being a caregiver to someone with advanced cancer is like running a long marathon alongside them – you need to take care of yourself to keep going strong and support them throughout the journey.



Self-Care

What are some activities that make you feel relaxed and recharged?

How often do you take time for yourself, even if it's just a few minutes each day?

Have you noticed any physical or emotional signs that suggest you might need more self-care?

What barriers do you face when trying to prioritize self-care, and how might you overcome them?

How does taking care of yourself impact your ability to care for someone?

Can you think of a recent time when you felt particularly stressed or overwhelmed? What self-care activities could have helped you in that moment?

How do you feel about the idea that self-care is not selfish but essential for being an effective caregiver?

Summary of Primer on Emotions

- Emotions help us interpret the world and provide useful information about our needs and experiences.
- Multiple conflicting emotions can coexist (e.g., hope and fear), especially in caregiving situations.
- All emotions are okay – they are natural signals rather than problems to fix or judge.
- Emotions are like waves: they rise, peak, and eventually pass – even the most intense ones.
- Emotions are also felt physically in the body (e.g., tight chest, racing heart), and recognizing these signals can help identify what we're feeling.
- Common emotions for caregivers include helplessness, fear, grief (including anticipatory grief), guilt, anger, hope, joy, and gratitude.

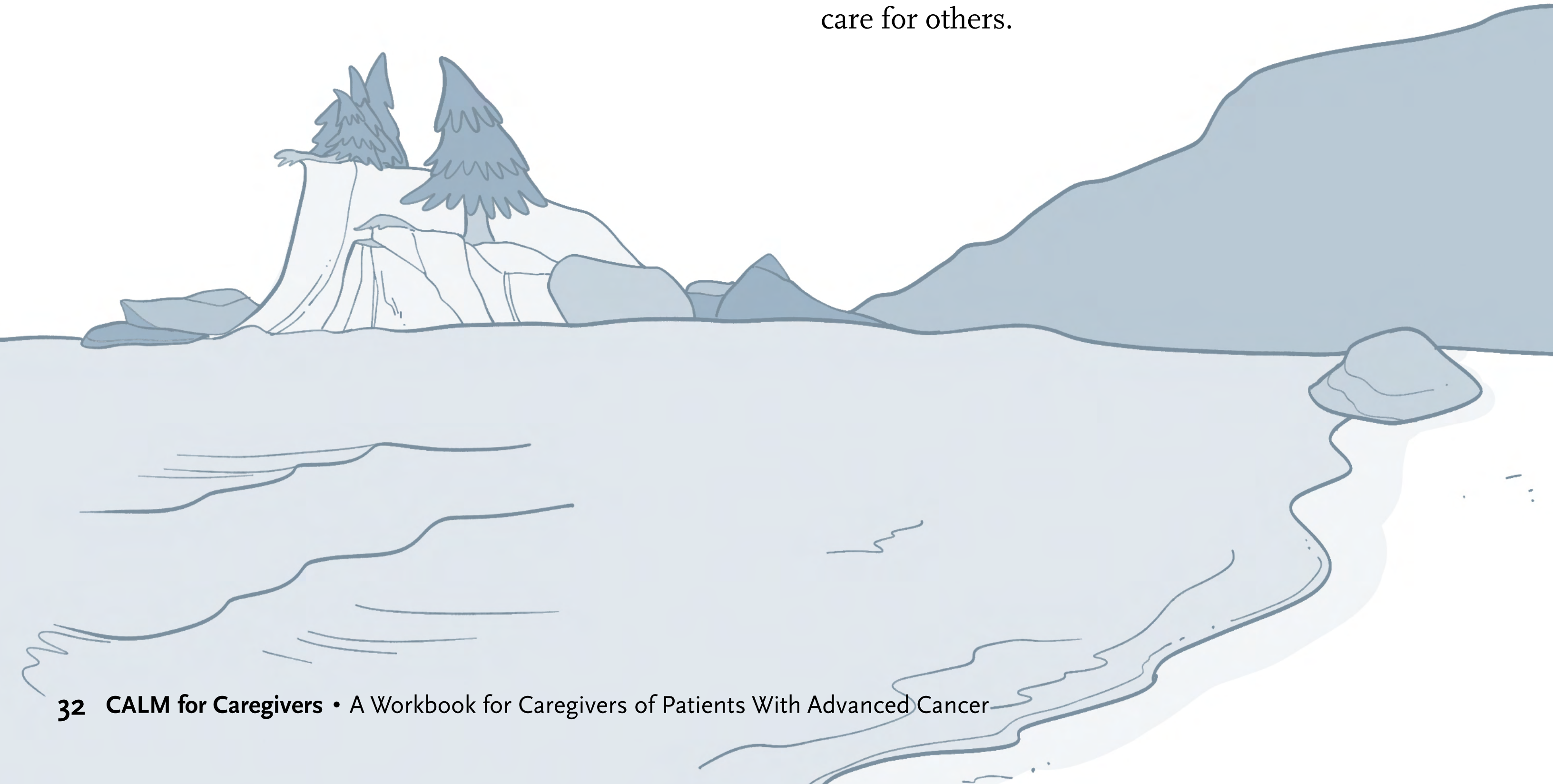
Managing Emotions

- Starts with awareness and naming emotions - this can help with making them feel less intense.
- Accepting all emotions without judgment allows them to pass more easily.
- Emotions are never wrong - avoiding self-judgment is crucial.
- "Ride the wave" - let emotions come and go rather than resisting or suppressing them.

Self-Care

Self-care is essential for caregivers, not selfish.

- Includes basic needs (sleep, food, rest) and emotional nurturing (social connection, joy, downtime).
- When caregivers neglect self-care, emotional intensity increases.
- Taking care of yourself allows you to better care for others.



Domain 1

Disease Management

The Cancer Story

We invite you to share your experience of having someone you know diagnosed with cancer, receiving treatment, and coping with symptoms, **pg.34**

Cancer Overview

We will review some basic information about cancer, **pg.36**

Understanding the Symptoms

You can read about common cancer symptoms, reflect on the meaning of these symptoms, and learn a simple way to track cancer symptoms over time, **pg.38**

Treatment Plans

We invite you to share your experience of treatment planning for the person you are caring for and reflect on how you can actively participate in this process, **pg.43**

Summary

Two-page summary for this section, **pg.51**

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.

Domain ❶

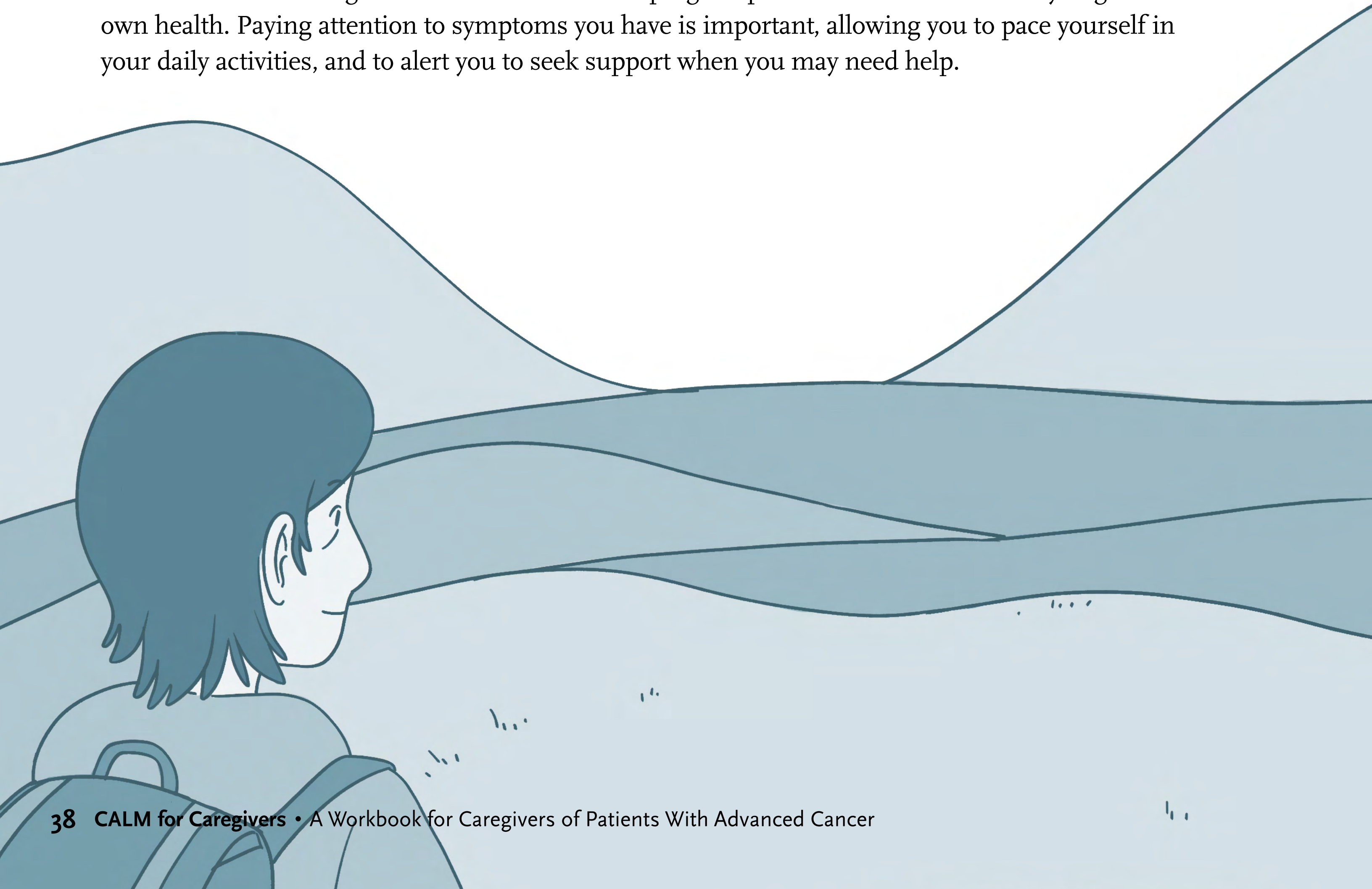
Understanding the Symptoms

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 ①

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.

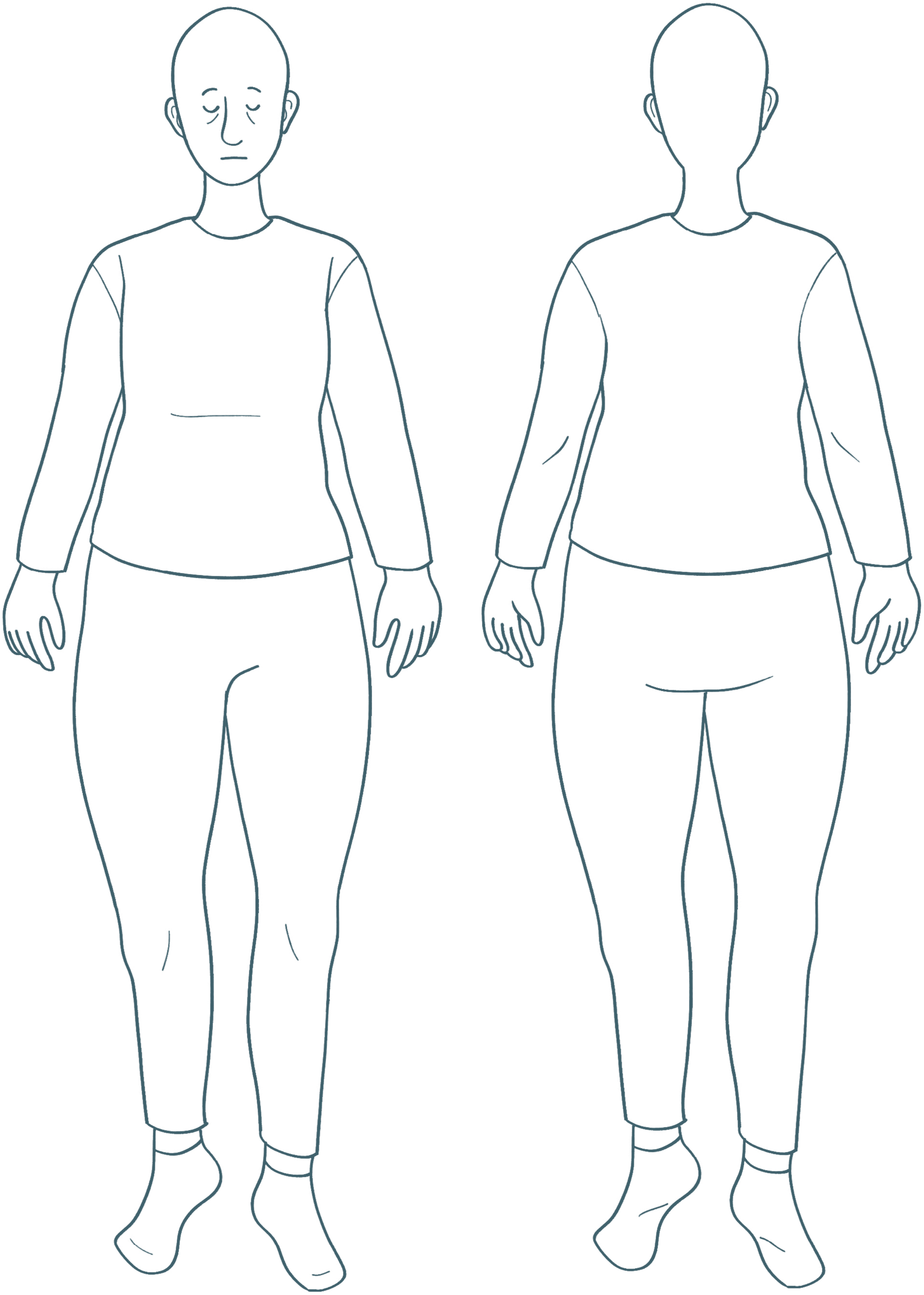
Please circle the number that best describes how you feel NOW:

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 ________

---

[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.

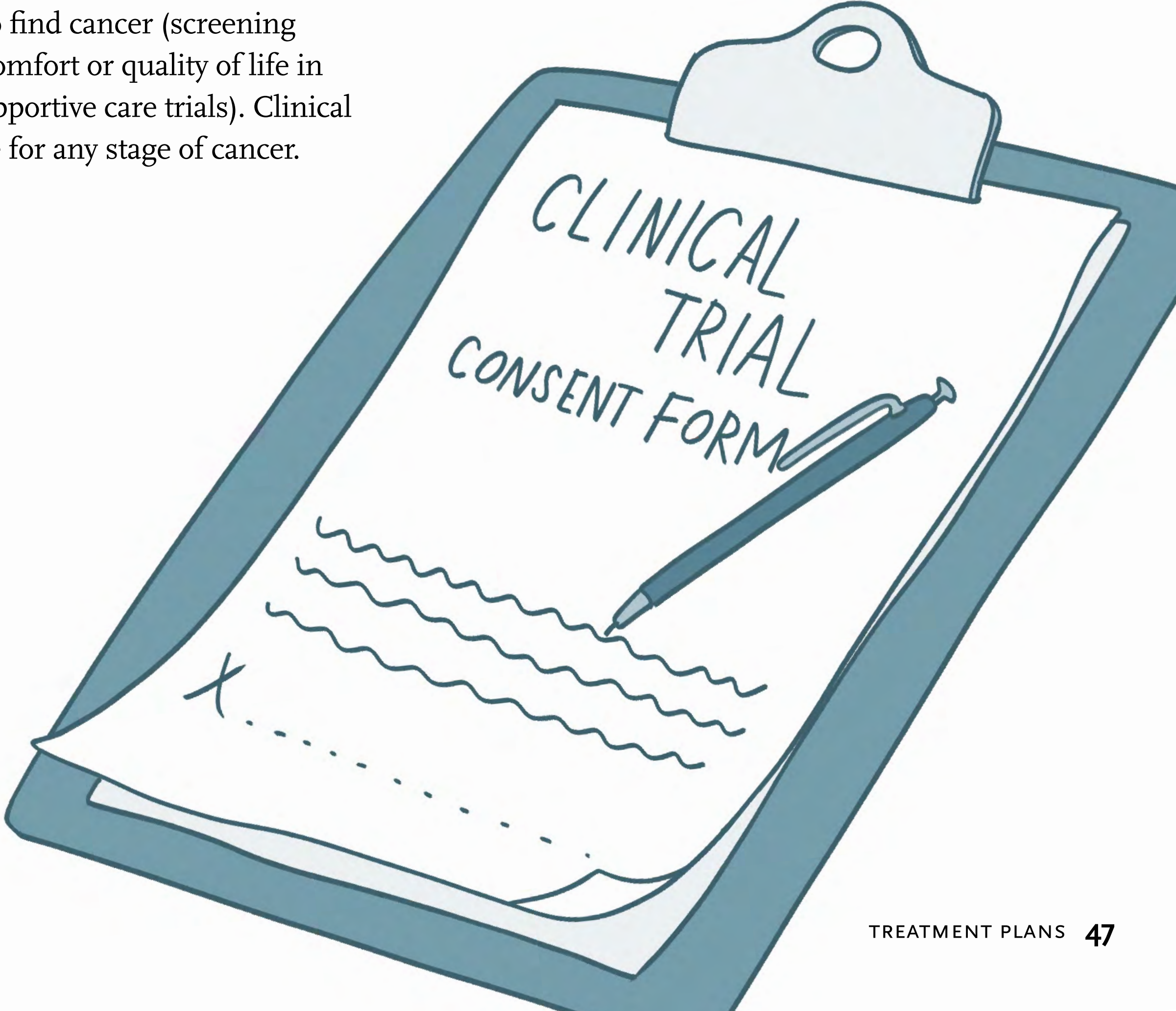
What is the purpose of a clinical trial?

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.



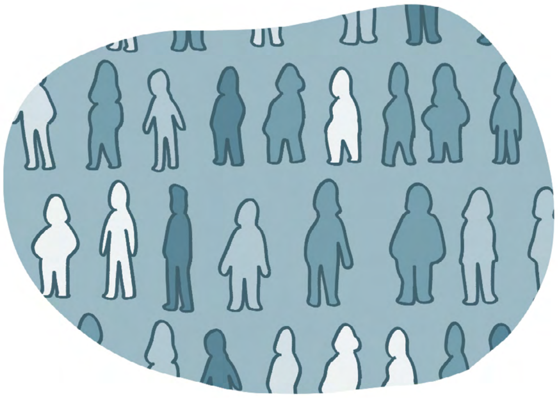
Phases of Clinical Trials

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

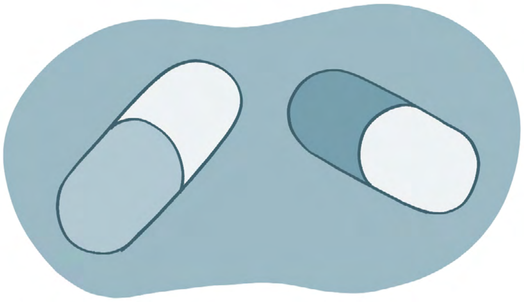
A **phase I clinical trial** is often the first time a new treatment is tested in people. The goals are typically to test the safety of the new therapy and determine the best dose of the drug, if applicable. These trials are typically very small (e.g., 15-30 people) and often only available to people 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).

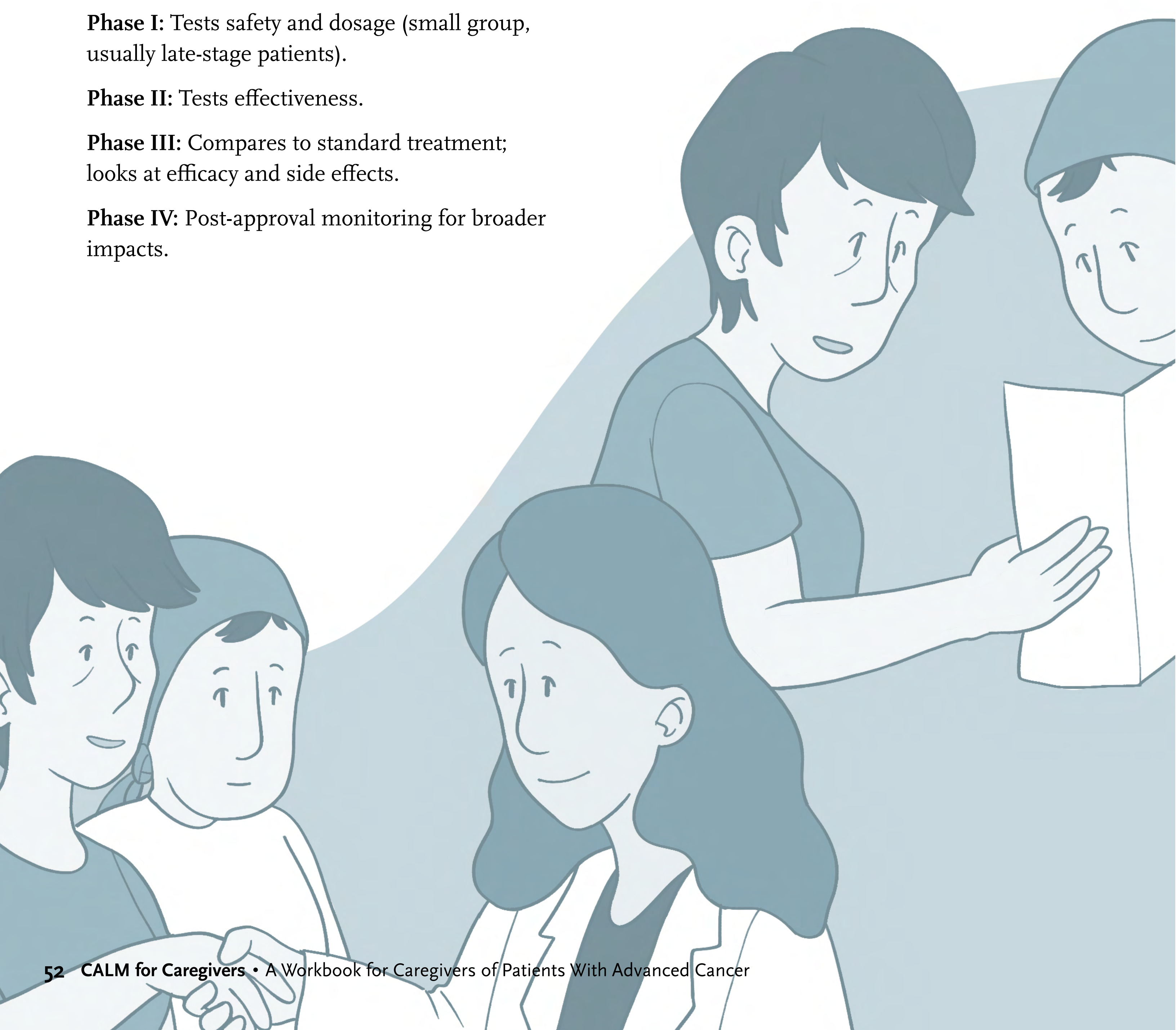
Phase II: Tests effectiveness.

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

Phase IV: Post-approval monitoring for broader impacts.

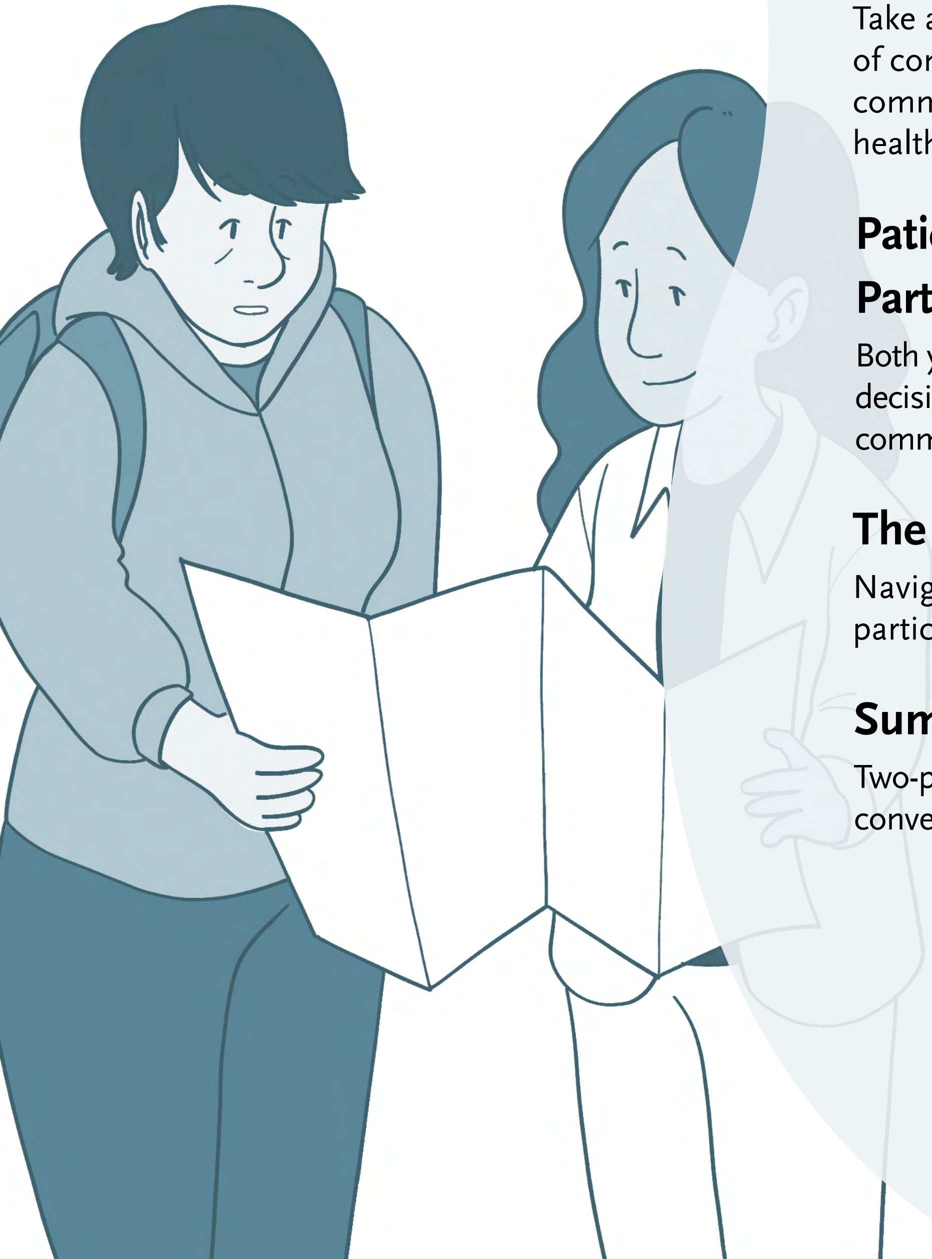
Considerations Before Joining

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



Domain ①

Communication with Healthcare Providers



The Healthcare Team

Learn about the different roles of the members of the healthcare team, **pg.54**

Communication with Healthcare Providers

Take a moment to reflect on the importance of communication and learn about some common communication barriers in healthcare settings, **pg.57**

Patients and Caregivers as Care Partners

Both your roles in the healthcare team, your decision-making styles, and pattern of communicating with healthcare providers, **pg.64**

The Caregiver Role

Navigating the healthcare system and participating in treatment decisions, **pg.71**

Summary

Two-page summary with starters for difficult conversations, **pg.75**

Domain ❶

The Healthcare Team

Patients and their caregivers speak to many healthcare providers during cancer care. This may include healthcare providers from many different specialities. They may be responsible for helping patients manage their treatments, symptoms, and treatment side effects, emotional concerns, and offering information and resources related to cancer.

Members of Your Healthcare Team

Oncologists

Oncologists are medical doctors (physicians) who specialize in the treatment of cancer. They have received training in the treatment of cancer using different types of treatment. An oncologist is usually the main healthcare provider for someone with cancer.

There are different types of oncologists, including a radiation oncologist who specializes in using radiation to treat cancer, a surgical oncologist who specializes in performing surgery to treat cancer, and a medical oncologist who specializes in diagnosing and treating cancer with chemotherapy and other drugs. Your oncologists may also consult with other medical specialists to treat non-cancer related problems.

If you are getting treatment at a teaching hospital, your oncology team may also include medical learners that may be called medical students, residents, or fellows.

Palliative Care Physicians

The palliative care service is focused on symptom management and advance care planning. Palliative care is a medical speciality, but palliation can be provided by family doctors or other health care providers. The palliative care team may follow patients while they're also receiving cancer-focused treatment.

Nurses

This group of professionals includes Registered Nurses (RN), Registered Practical Nurses (RPN), Advance Practice Nurses (APN), Nurse Providers (NP) or Clinical Nurse Specialists (CNS). They each have different qualifications, training, and responsibilities.

Nurses will be at your side throughout your experience with cancer. They can provide you with daily care in the hospital, in the community or at home, answer questions about your care and provide emotional support. Depending on their level of training they may also be able to diagnose and prescribe medications. Some nurses receive special training in particular areas. For example, you may meet Clinical Nurse Specialists who focus their practice on working with patients in palliative care.

Social Workers

Social workers can help you and your family with emotional and practical needs. This includes emotional support, strengthening coping strategies, communicating with your family, the person you're caring for or health team, planning finances, and more. They can also give you information about services and supports in your community.

Psychiatrists

Psychiatrists are medical doctors who specialize in the treatment and prevention of mental, emotional, and behavioural problems. They can provide counselling, consultations, and drug therapy for both patients and their family members.

Psychologists

Psychologists are mental health professionals with a graduate degree in clinical psychology. They specialize in assessing and providing treatment for mental health conditions, emotional distress, and behavioural disorders. They can also help you with treatment planning and give you strategies to overcome cancer-related challenges.

Music and Art Therapists

Music and Art Therapists can help you express your feelings and cope with your diagnosis in creative ways.

Spiritual Care Providers

Spiritual care providers help people explore their sources of meaning in life and hope. They can help you cope with difficult times, to find meaning and value in life, and connect with others.

Dietitians

A dietitian is a health professional trained in nutrition and diet. They can teach you about choosing the right foods, including giving advice on recommended dietary changes due to cancer or cancer treatment.

Pharmacists

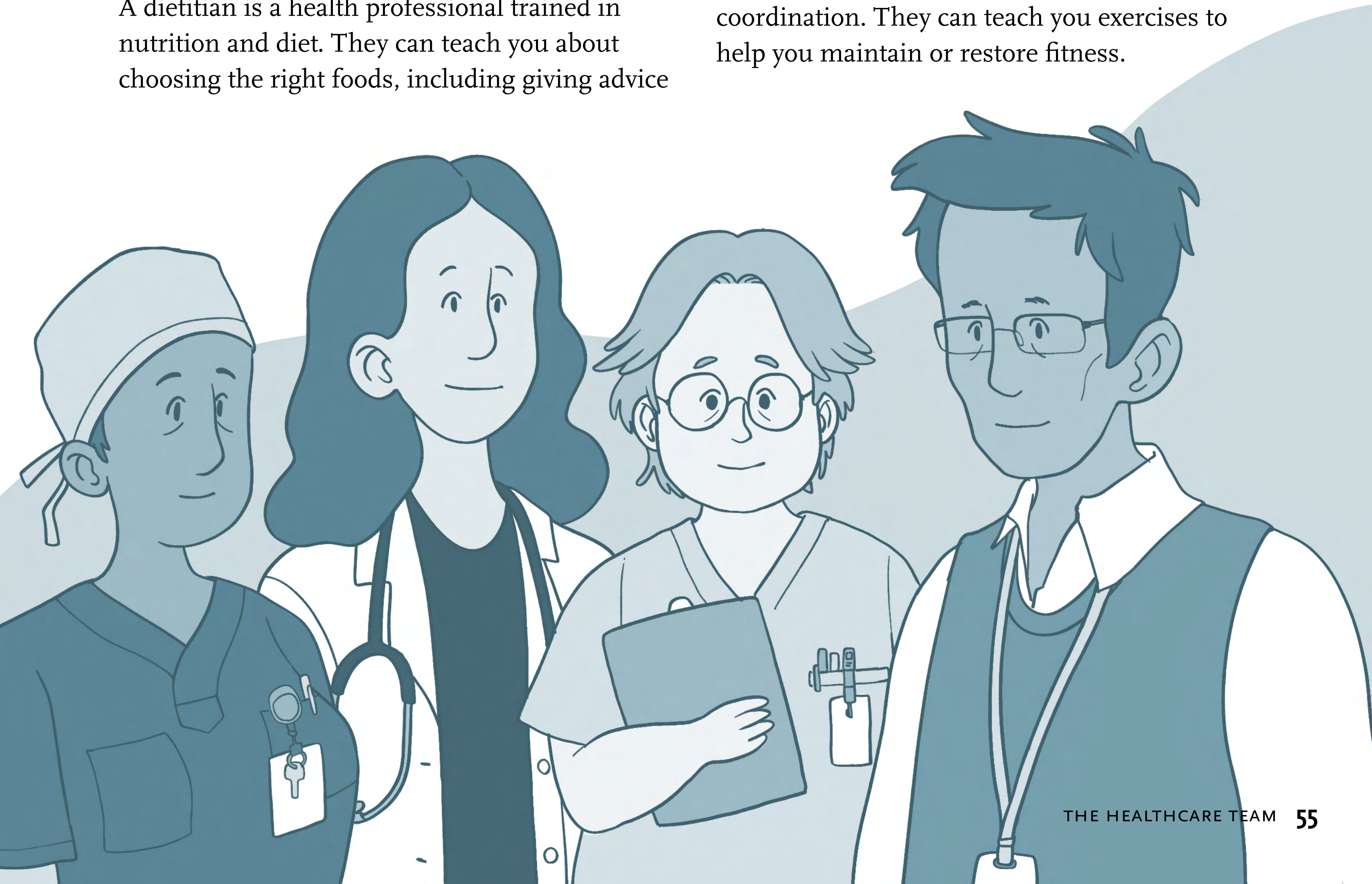
Pharmacists prepare medication, such as cancer drugs or pain medication. They can explain how to take the drugs, how they work, and their potential side effects. Sometimes they can also administer certain vaccines.

Occupational Therapists

Occupational therapists can help you maintain your daily activities, such as adjusting your work activities based on your abilities. They can also help you make changes to your home based on your changing needs.

Physiotherapists

Physiotherapists or physical therapists are trained to treat people with conditions or injuries that affect their ability to do physical activities. They can help you with strength, balance and coordination. They can teach you exercises to help you maintain or restore fitness.



Your Relationship with the Healthcare Team

Why do some people feel supported and understood by their healthcare team while others may feel they cannot count on their team or speak freely?

Where is the person you are caring for receiving care for their cancer and who are the most important members of their cancer care team?

Are you involved in communication with their healthcare team? If so, how or how not? How might you like to be involved?

Communication with Healthcare Providers

In any relationship, effective communication is important and the ability to feel comfortable talking openly with the team is important when discussing the cancer diagnosis and cancer treatment. The members of the healthcare team have a major role in managing the patients' health.

Take a moment to reflect on your communication with the healthcare team.

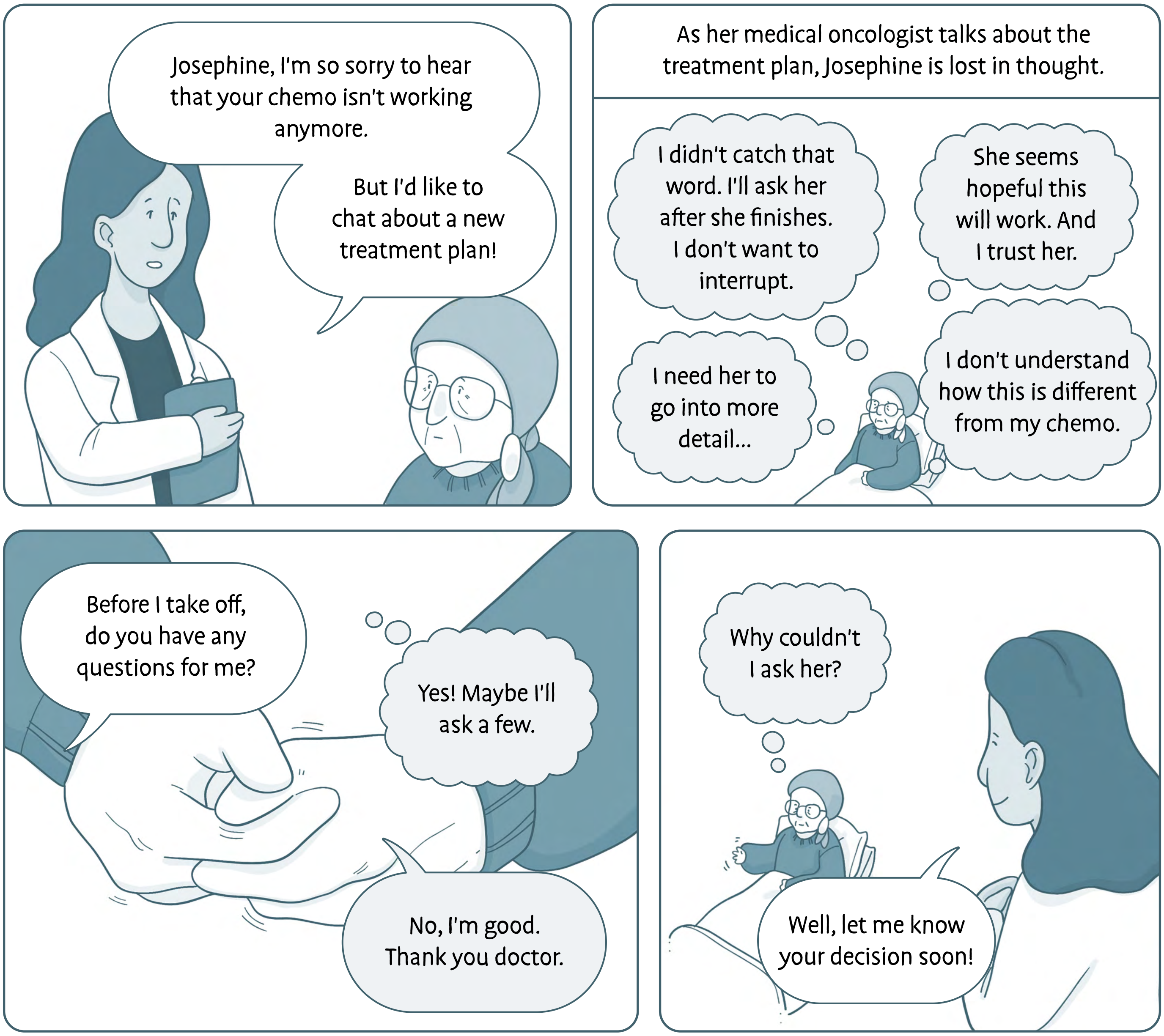
Are you and the person you are caring for able to have conversations with the team that help you understand their disease, symptoms and make treatment decisions? If not, can you think of what the barriers or obstacles may be?

You may find some individuals easier to approach than others, and if so, can you say why?

Think of a time when difficult or positive news was communicated to you both? How did you feel at the end of the interaction? Can you identify what helped or did not help that interaction?

Josephine's Story

Josephine is a 72-year-old woman who has recently been diagnosed with stage four breast cancer with bone metastases. She recently discovered that her chemotherapy is no longer working.



Reflection

Please take a moment to reflect on any communication problems with the healthcare team.

What kind of communication problems has the person you are caring for experienced?

What kind of communication problems have you experienced?

What did either of you do about them?

Is there anything you or the person you are caring for might do differently if these problems are experienced again?

Did experiencing these problems affect how you were feeling about your care?

Domain ❶

Communication Challenges

Most people have experienced long wait times to see their doctor, only to find that their appointment is quite short. Doctors on the care team may not always be able to spend as much time with you as either of you would like. It may be helpful if you clearly communicate your most important concerns first. Nurses and other health care providers can also be important sources of information.

Most people do not have a background in medicine. Learning about cancer can be like learning a new language. Healthcare providers use words that many people may not be familiar with.

Many patients don't feel confident in their ability to understand information. Some people question their own personal knowledge and the value that they can bring to the conversations with their healthcare team.

You, the person you are caring for and the healthcare providers may have certain styles or approaches to communication that may be more or less effective.

Some people want as much information as possible, but others prefer to only receive information that is necessary to make decisions about their care in that moment. Healthcare providers can sometimes make assumptions about what and how much information people want.

Some people find it intimidating to speak to healthcare providers. They may find it hard to speak up when they have questions or do not agree with their care provider. This can be because there is a power imbalance between provider and patient. It might surprise you to learn that research has shown that even doctors can have trouble speaking up when they are the patient themselves.

Having a good relationship with their healthcare team is important to many people. But some patients might worry about upsetting their provider if they play a more active role in their care. Some people even worry that they will be seen as difficult or risk receiving lower quality care. This may be even more true for certain groups, such as older adults who grew up at a time when it was not culturally acceptable to question your physician.

The system where you are receiving care may not be as patient centred as it could be. It's not always clear who you should be speaking to or how to get the support you need.

As healthcare becomes busier and more technological, many patients and families don't feel their healthcare team addresses their emotional needs or understands who they are as a person.

Some clinicians and patients may avoid or find it difficult to talk about topics which are distressing or uncomfortable (including sexuality, disease progression, fear of death and dying and mental health issues). Because of this, some important issues may never be discussed.

Can you relate to any of these barriers?

Communication Challenges for Caregivers

Communicating with healthcare providers as a caregiver can have additional difficulties. Here are some communication challenges that other caregivers have reported:

▲ Having different information needs than the patient.

▼ Not feeling entitled to ask the healthcare team their own questions during clinic visits.

◄ Mediating the relationship between the patient and the healthcare team.

Your role in communication with the healthcare team may also change over the trajectory of the cancer care. Earlier on, it may be a more supportive role. However, as the cancer progresses and if they become unable to make decisions on their own, you may need to play a more active role in decision-making.

This can be a difficult role to play. Your opinions and attitudes may be helpful to the person you are caring for. Patients often rely on their caregivers to aid in decision making. There may be times when you both do not agree on their healthcare decisions, and it may become challenging to support the person you are caring for while not taking over the decision-making process. It is often helpful to provide your input and discuss treatment decisions openly. Ultimately, it may sometimes be necessary to set aside your opinions to best support your friend/family member/loved one with cancer.

Tips for Communicating with Healthcare Providers

Research has found that patients and their caregivers who communicate with their healthcare team tend to have positive outcomes, including more satisfaction with care, a greater sense of control, being more informed and receiving more responsive care. It's important that you are clear with your healthcare team about the amount of information you want and what your expectations are for treatment. Here are some tips which may help improve communication with the healthcare team.

Here are some tips which may help improve communication with the healthcare team.

Be open, honest, and direct.

If you feel safe to do so, share your feelings, fears, and concerns with the healthcare team. This includes information about your physical, emotional, and social well-being, practical issues (e.g., work, money, etc.), values, goals and hopes.

These topics can be difficult to bring up with your healthcare team, but being honest with your healthcare team might help them understand and support you better.

Tell your healthcare team how much you want to know.

You can let your healthcare team know, at any time, whether you want more or less information, and how you would like to receive information. For example, some people want to know a lot of detail about their cancer and treatments because it helps them feel more in control. Other people only like to know what is necessary because too much information can be overwhelming and upsetting. Telling your doctors how much information you want can help make your visits more satisfying to you.

Ask for clarification.

Let your team know if you want more details or don't understand something that was explained to you. There is nothing wrong with telling your team that you do not understand something. Remember, it is part of their training to learn how to explain medical information to patients. So, by saying you don't understand, you are helping healthcare professionals become better providers.

Don't hesitate to ask your healthcare provider to spell, repeat, or explain specific terminology.

Prepare a list of questions in advance.

It can be helpful to write down questions before you meet with your healthcare providers. Ask how much time you will have during your appointment and ask your most important questions first.

Try not to worry about asking questions that you think are silly or embarrassing. Don't be afraid to ask them to simplify things for you or to ask questions multiple times. Your questions deserve answers, and your healthcare providers should do their best to answer them. It can be difficult to know what questions to ask. On the next page, we have examples of some common questions that you can write down.

If you did not have enough time during your appointment, you can ask for another meeting. Do not feel pressured to make a decision about your care at your clinic appointment if you need more time to think about it.

Take notes or ask to record your conversations with your healthcare team.

It can be challenging to remember everything during your conversations with your healthcare providers, especially if you are nervous or scared. Taking notes may help you remember what is said and help make sure you've understood. You can review these notes after your appointment and think of any questions you may want to ask at your next appointment. If you are thinking about recording your conversation, ask ahead of time if it's okay because there can be hospital rules about recordings.

Discuss appointments beforehand.

It can be very helpful for patients to have someone come to appointments with them. They can help you take notes, ask questions, listen, and/or give support. Caregivers may want more information than the patient. Before the appointment, caregivers and patients could discuss how much the patient wants to know and could help communicate this to the healthcare team.

Keep a binder or a diary.

A binder or diary is a good way of storing all important information, such as contact information for your healthcare team, list of medication and their potential side effects, information about community and medical services, appointment calendars, diagnoses, scans, a list of questions, etc.

Ask the health care team how to contact them between appointments.

It is not always obvious how to contact the members of your healthcare team so it's a good idea to ask. You can keep a contact sheet in your binder or diary with all their information.

Some clinics have phone lines staffed by nurses to answer patient questions between appointments so be sure to ask if this service is available. Also, make sure to ask who to contact in the case of an emergency.

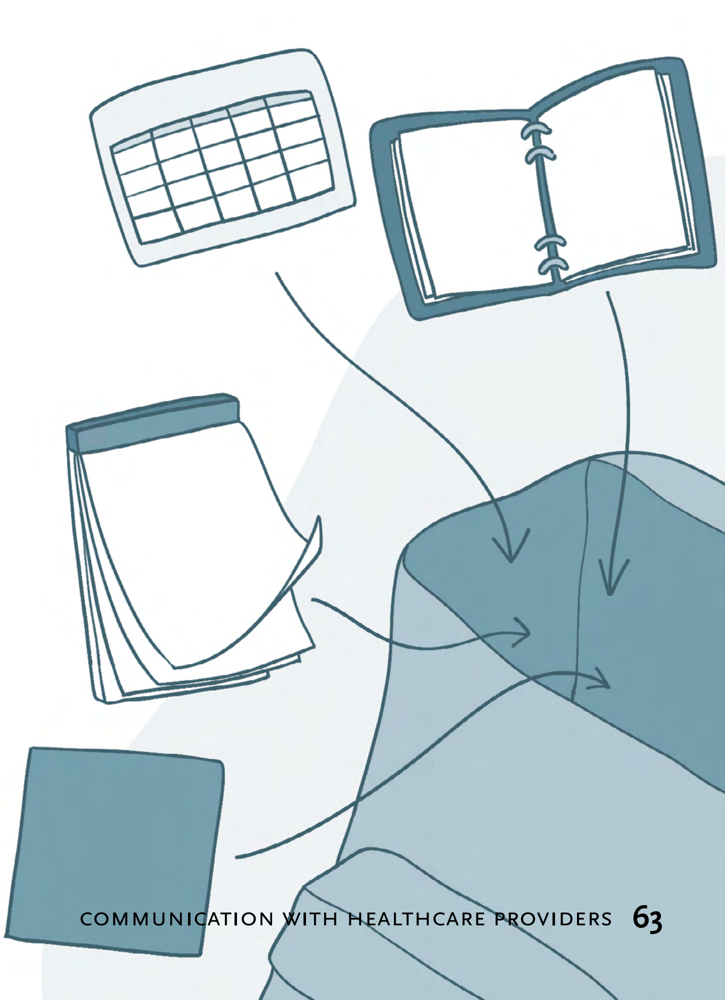
Coping with complex healthcare systems.

There is usually one person responsible for coordinating cancer care within the healthcare team. This may be their general practitioner, their oncologist or palliative care physician, or a care coordinator. It is useful to know who is coordinating their care, so you have a main point of contact. You can ask anyone in your healthcare team, and they will be able to tell you who this person is.

If available, you could seek out a nurse navigator, patient advocate, or social worker if you are having trouble navigating the healthcare system. They can work with both of you and point you in the right direction.

Some final thoughts

It's helpful to remember that a healthcare team might not be able to meet all of your needs, all of the time. You may work hard to improve your relationship, but the actions and behaviours of the health care team is not your responsibility. In some cases, if the relationship is not satisfactory, you may be able to ask to switch providers, if this option is available.



Domain ❶

Patients and Caregivers as Care Partners

In many healthcare systems, patients are encouraged to be involved as much as possible in making decisions about their care. This was not always the case, and in some places, it is not usual practice.

This approach has become more widely accepted over time. You might hear it referred to as "**shared decision making**."

The goals of shared decision making are to:

1. Fully inform patients about different treatment options and their risks and benefits.

2. Consider patients' values and preferences when making choices about various treatments.

In shared decision making, patients are encouraged to consider their own personal values and their quality of life. This is an important step towards making treatment goals with your healthcare team.

As a caregiver to someone with cancer, you may be involved in the decision making about their cancer care. Caregivers often play an important role in understanding the patient's wishes and values and advocating for them within the healthcare system.

Shared decision-making may seem like a simple idea, but it can be a complex process in practice. Here are some common difficulties:

- Patients and caregivers are required to learn a lot of new information in a short period of time
- Sometimes there is not a clear choice between the options being presented
- There can be disagreement between the treatment goals of the healthcare provider, the patient, and/or their loved ones
- These decisions come with a lot of uncertainty
- There is often a time pressure in making a decision

Even with the potential challenges, research has shown that increasing patient participation in decision making can improve health outcomes.

Shared Decision-Making

Take a moment to think about your experience with ‘shared decision-making' and caregivers as partners in health care. Here are a few prompts and some space below to make notes if that’s helpful to you.

Does your medical team involve you and the patient in decision-making? If so, what has this experience been like?

What is your role as the caregiver in the decision-making process?

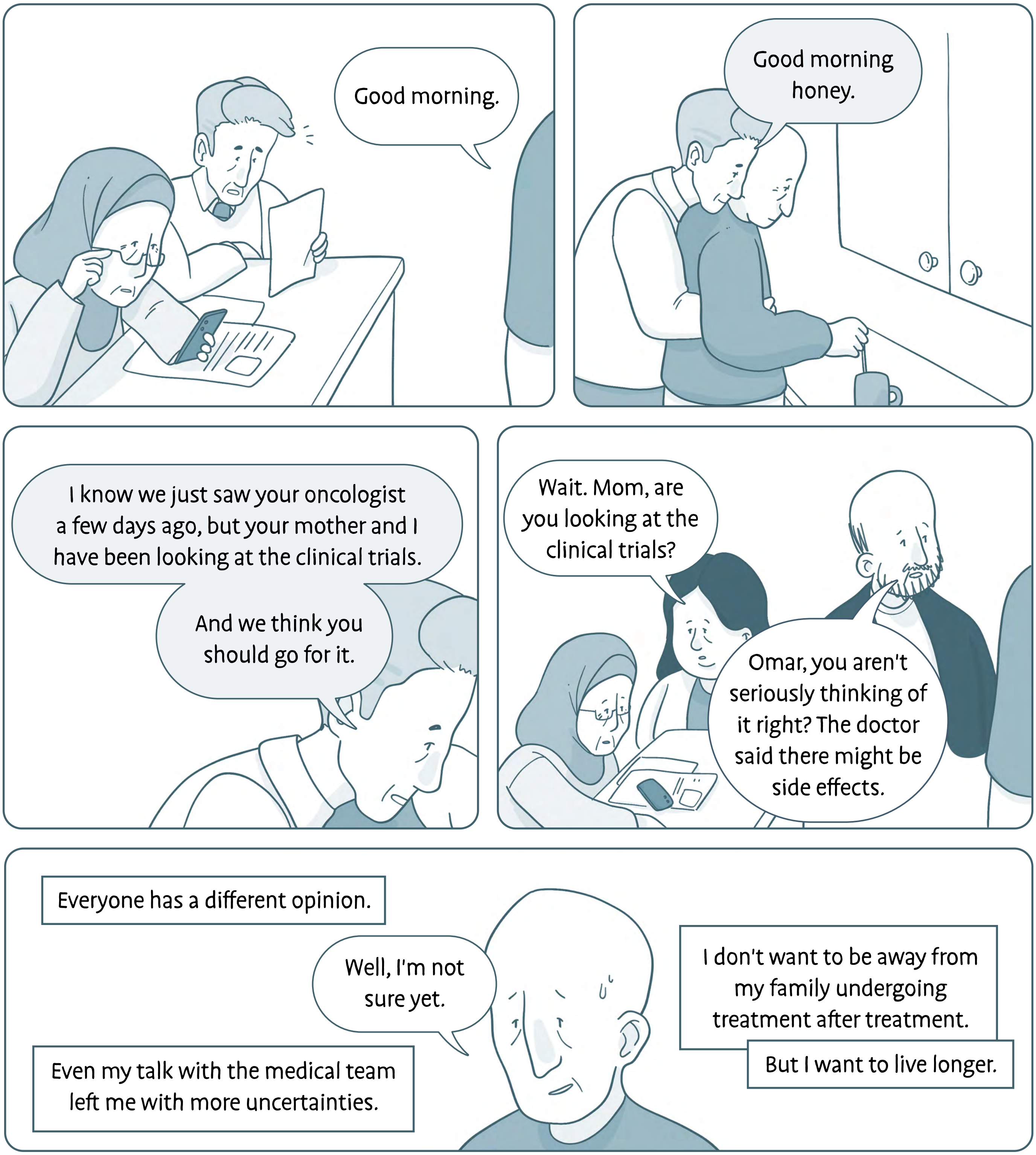
What has the person you are caring for communicated to you about their goals and wishes?

What have your communicated to the person you are caring for about your goals and wishes for their care?

How do you see your role in facilitating communication with the healthcare team?

Omar's Story

Omar has metastatic lung cancer and has been managing his cancer with chemotherapy for the past two years. His oncologist recently told him that they have exhausted all standard treatments for his disease. His doctor told him about a clinical trial, which has potential benefits (i.e., extended survival) as well as side effects (i.e., worsening fatigue, nausea). The alternative option would be a watch-and-wait approach.



Factors in Shared Decision-Making

In a situation like Omar's, how would you order these factors impacting decision-making from least to most important (0=least importnant to 8=most important)? How do you think the person you are caring for would order these factors when making medical care decisions?

There is no right answer, just different opinions.

You	Factors	Them
	Quality of life	
	The opinion of the medical team	
	The opportunity to spend with family and friends	
	The opinion of family	
	The potential to contribute to medical science	
	My own opinion	
	The possibility of benefit from a clinical trial (i.e., extended survival)	
	The possibility of risks associated with a clinical trial (i.e., worsening fatigue, nausea)	

Shared Decision-Making

How do you make decisions?

What kind of information have you found helpful to make treatment decisions to date?

Do you both discuss these factors when making treatment decisions?

Are there other important factors that you consider which are not listed above?

Have you considered other sources that influence treatment decisions (e.g., friends, family, medical team, your own research)? How much weight do you give to their opinions?

Here are some common questions to consider in treatment decision-making. Reflect while answering these questions.

What do you hope from treatment?	What is the purpose of the treatment?
What are the possible risks of the treatment and how likely are they to occur?	Are the possible benefits from treatment greater than the possible risks?

Beliefs, Values and Decision-Making

A **belief** is an idea that a person (or group of people) accepts as being true. **Values** are ways of thinking about the world and our choices in terms of what is right and wrong, or positive and negative. Our society, culture, and our different social groups, can all influence our beliefs and values.

Our beliefs and values play an important role in decision-making. However, some people find it difficult to know what their preferences are. In Omar's case, he was having trouble making decisions because his family members were weighing possible outcomes differently based on different values. He wasn't sure which position he wanted to take or which course to pursue.

The following questions can help you reflect and think more about your own beliefs and values and the beliefs and values of the person you are caring for:

What do you consider "good quality of life"? What about the person you are caring for? Are the answers similar or quite different? How so?

What are your goals for treatment and care (e.g., to cure the cancer, trying all available options, maintaining quality of life, maintaining hope, providing pain or symptom relief, etc.)? Do both of you have the same goals of care?

Are these goals reflected in the current treatment plan?

The Caregiver Role

Caregivers play an important role throughout the cancer experience, including supporting the patient with medical decision-making.

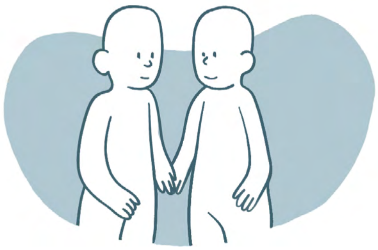
It is common for patients and their family, friends and caregivers to have different beliefs and values and thus different opinions about what to do moving forward. It can be tricky to deal with these differences and there are no universal rules for the right way to resolve conflict about a patient's medical care. Some caregivers have strong opinions on what should be decide moving forward, where others may not know which direction to take. In general, it's important to recognize and understand your own needs and desires as a caregiver and separate those from the desires of the person you are providing care to.

While the patient is doing well and can make their own decisions, you may play a more collaborative role in decision making. However, as the disease advances and if they are no longer able to decide for themselves, you may become more involved in their decision-making. Thus, it's important to discuss and understand their wants and beliefs in advance so that you can make decisions that would best reflect their wishes.

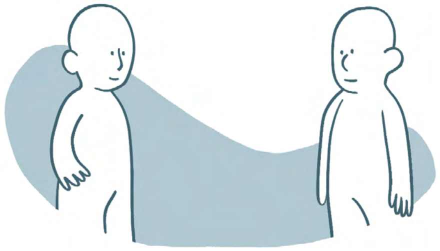
Your Style of Relating to Healthcare Providers

Recognizing our patterns can help us understand ourselves and others better. It can also help us make adjustments to work together more effectively.

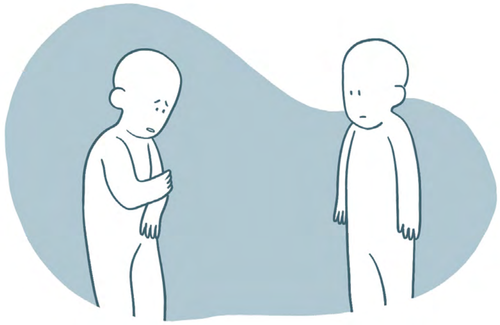
Here are some common patterns for relating to other people. Please keep in mind that these are simplified examples to help you think about your own tendencies in relationships. You may have different relationship patterns with different people, and your patterns may change over time and depending on the situation.



Some people tend to create intimate (close) relationships with others.



Some prefer more space and distance in their relationships.

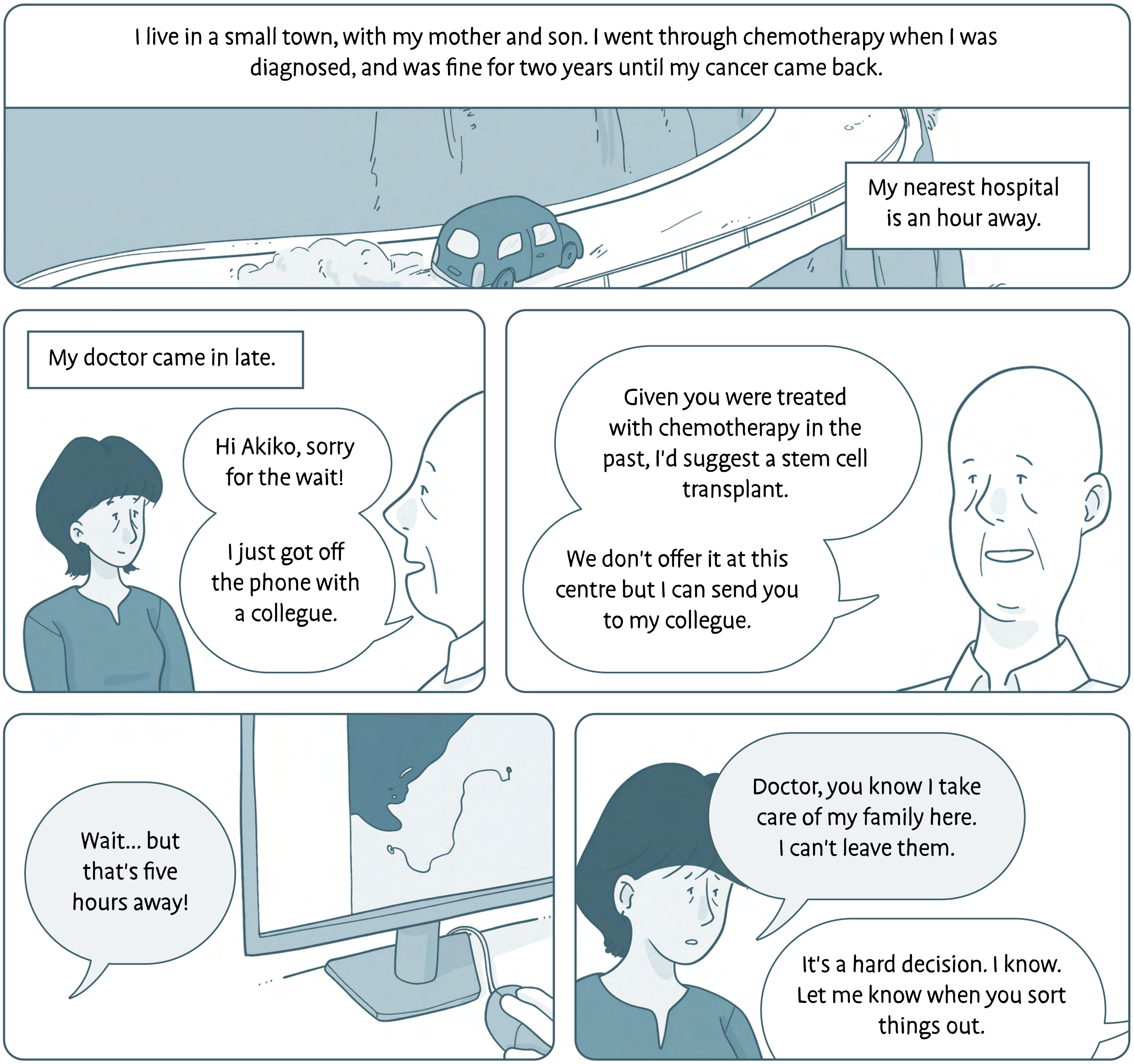


Other people desire closeness but live with a great deal of anxiety about the solidity of their relationships.

Domain ①

Akiko's Story

Akiko is 49 years old and has Refractory Acute Myeloid Leukemia(AML). She is divorced and shares custody of her 12-year-old son with her ex-husband.



Notice how in the example above, Akiko felt dismissed by her oncologist, who may have been focused on her treatment without considering what this could mean for her. Akiko may feel scared about the possible side effects, how the treatment will affect her everyday life, how she'll be far from her loved ones and how that might burden them.

While communication with the healthcare provider may be focused on the cancer and treatment, this is also a human relationship. Patients and families may also have a need for emotional support and an understanding of the patient as a whole person and their broader situation.

Considering what you have read so far...

How do you think you and the person you are caring for relate to the healthcare team?

Do you feel that you can count on them during difficult times?

Do you worry about whether they will be there for you?

What do you think would improve this relationship?

Your Relationship with the Healthcare Team

Sometimes people will have transitions and different clinicians involved in their care at different times.

How have these transitions worked for you in the past? Have you felt that you've fallen through the cracks, unsupported, or neglected? Are you anticipating or worried about transitions in the future?

Do you feel like the healthcare team knows and understands both of you? Is there anything you wish that your healthcare team knew about you (e.g., background, specific needs or challenges, your current circumstances or stressors)?

Have you had past experiences with medical care that are shaping your current experiences?

Beyond your oncology team, do you have other healthcare providers (e.g., family healthcare team, naturopath, complimentary/ alternative healthcare providers) that are supporting you? Do you feel there is communication and collaboration between these providers?

There is a lot of information about cancer and cancer care available through the internet, social media, or other routes that is sometimes overwhelming or contradictory. How are you sorting through this information and making sense of it for yourself?

Summary of Domain 1: Communication with Healthcare Providers

Communication Challenges for Caregivers

Caregivers may...

- feel unsure about their right to ask questions or engage during appointments.
- have different information needs than the patient
- act as mediators between the patient and healthcare team, adding emotional and logistical complexity.
- The caregiver role changes — often from supportive to primary decision-maker, especially as an illness progresses.
- Balancing involvement and respect for the patient's autonomy can be challenging, especially when opinions differ.

Tips for Improving Communication

- **Be open and seek understating:** Share all concerns with the health care team and don't hesitate to ask questions or for clarification
- **Clarify and communicate preferences:** Let providers know how much information you want and how you prefer to receive it.
- **Be prepared:** bring a list of key questions to appointments and take notes, or request to record conversations (with permission).
- **Bring support**: if you are unable to attend an appointment have a trusted individual accompany the person you are caring for to the appointments.
- **Try to stay organized and connected:** Keep important info in one place, know who coordinates care, and ask how to reach providers between visits.

Shared Decision-Making

- **Goal:** that patient and caregiver are care partners, participating in decision-making that is fully informed and takes into account values and preferences.
- Shared decision-making may seem like a simple idea, but it can be a complex process in practice.
  Here are some common difficulties:
  - Information overload and time pressure can feel overwhelming for patients and caregivers especially when it comes time to make decisions.
  - Uncertainty and lack of clear options can complicate treatment choices.
  - Conflicting goals between patients, providers and caregivers may lead to disagreements during care planning.

Starters for Difficult Conversations

Important relationships take effort from both parties. Clear communication on your part may help facilitate better understanding and care from your team.

If you would like some suggestions on how to initiate discussion about communication difficulties, here are some prompts below. Some of these suggestions are from the American Cancer Society[2].

I'm worried that we aren't communicating well, and here's why...

Cancer has affected my life in a lot of ways and I don't have anyone to talk to about it — can you recommend someone?

I have some concerns about ________, and I'm finding it difficult to talk about.

I'm having trouble understanding ___________. Can you help me?

I feel like the members of my health care team are not all on the same page. I'm wondering if there is anything we could do about that.

I was hoping to discuss ______, _________, and ________ today. Do you think there will be time to talk about everything, and if not, can I make a second appointment?

---

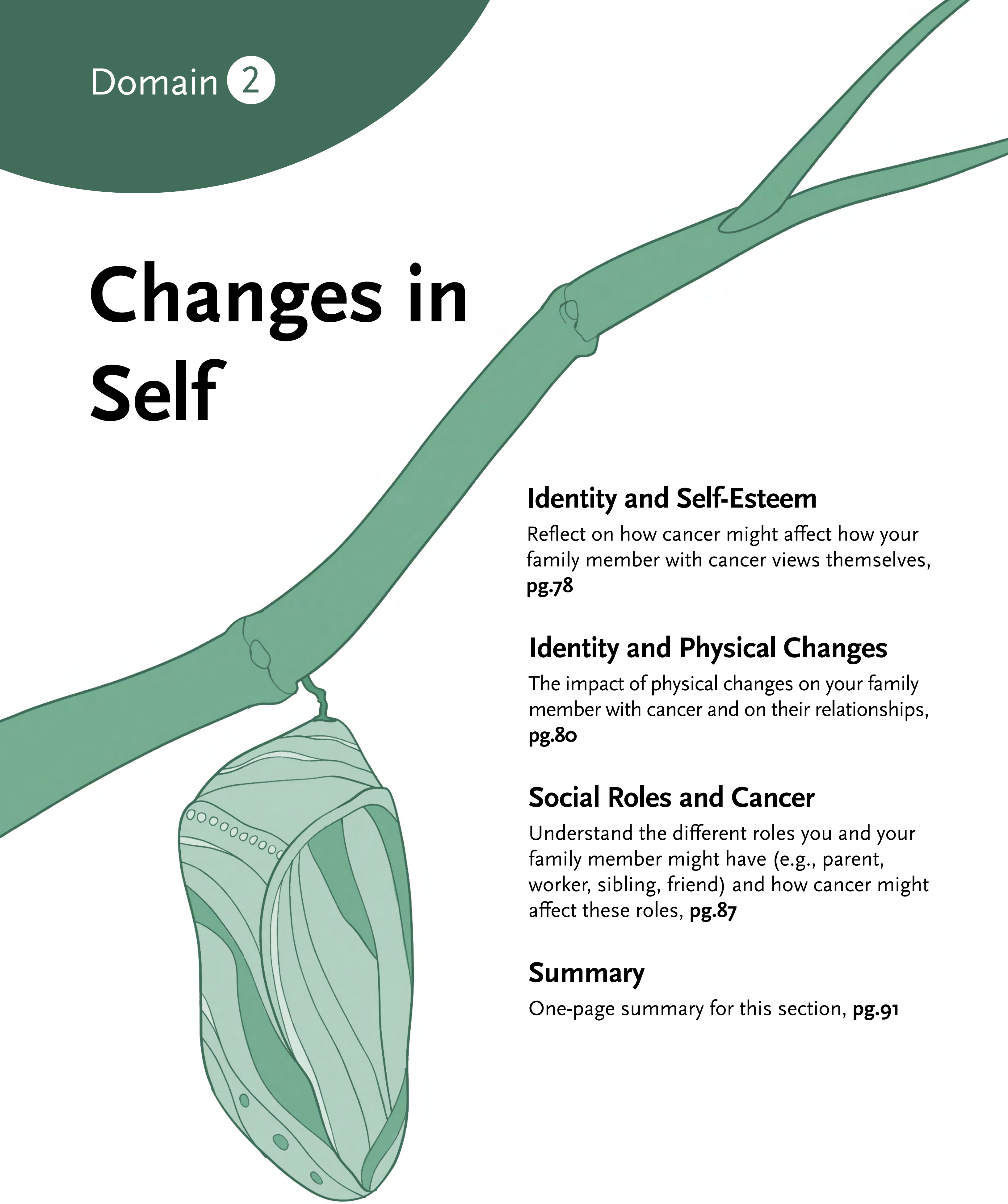
[2] American Cancer Society. (2025). Cancer Research. Caregiver and Family. What a Cancer Caregiver Does. How to Communicate as a Caregivers How to Communicate as a Caregiver | Caregivers and Family | American Cancer Society http://cancer.org/cancer/caregivers/what-a-caregiver-does/communication.html

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?*

Domain 2

Changes in Self



Identity and Self-Esteem

Reflect on how cancer might affect how your family member with cancer views themselves, **pg.78**

Identity and Physical Changes

The impact of physical changes on your family member with cancer and on their relationships, **pg.80**

Social Roles and Cancer

Understand the different roles you and your family member might have (e.g., parent, worker, sibling, friend) and how cancer might affect these roles, **pg.87**

Summary

One-page summary for this section, **pg.91**

Identity and Self-Esteem

Over time, we develop a sense of ourselves and learn what defines us as individuals. This is our identity. It includes an understanding of our physical self (e.g., our body shape, our eye or hair colour), our individual characteristics and abilities (e.g., "I am easy going," "I am an artist," "I am good at sports"), and our roles, history, and life experiences (e.g., "I am a parent", "I have traveled", etc.).

Self-esteem describes the value we place on ourselves. Similar to our identity, self-esteem starts to develop during childhood and changes throughout our lifetime. Our actions, thoughts, beliefs, relationships, and emotions all influence our self-esteem. Our environment also affects our self-esteem, including our social environment and interactions with other people. For example, feeling capable at your job may make you feel good about yourself. On the other hand, not being able to function as well at work or at home may negatively impact how you see yourself.

What are 5 words that you would use to describe yourself (e.g., personality traits, skills and abilities, roles, background)? (For example, Gregory, Omar's husband and caregiver, would describe himself as "Buddhist, husband, father, introverted, introspective").

This section focuses on how you see yourself. It's okay to include positive, neutral, and/or negative descriptors.

How do you generally feel about yourself?

What are some qualities that you are most proud of? What are some personal qualities that create challenges for you?

What are some achievements or experiences that you feel good about?

How do you think your friends and/or family would describe you?

Has your family member’s cancer experience changed how you see yourself in any way?

Domain ②

Identity and Physical Changes

The way we feel about our bodies may be part of identity, and this may also impact our self-esteem. Some of us have positive feelings about our bodies and this may help us feel better about ourselves. At the other times, we may be critical of our bodies, and this can negatively impact how we feel about ourselves.

People living with cancer may experience many changes to their bodies, such as how their body looks, feels, and functions. These changes are often caused directly by the cancer or its treatment. These changes may be visible or hidden from other people; some may be temporary, while others are permanent. Even if these changes are temporary, they can affect identity and self-esteem. They can have different meanings or cause different reactions in different people.

You may notice changes in your loved one's physical appearance or function, and changes in their self-perception and self-esteem as a result.

Scars (e.g., from surgery)

Changes in weight

Changes in body shape or size (e.g., mastectomy and other body part removal, lymphedema, swelling, fatty tissue re-distribution)

Hair loss

Skin changes

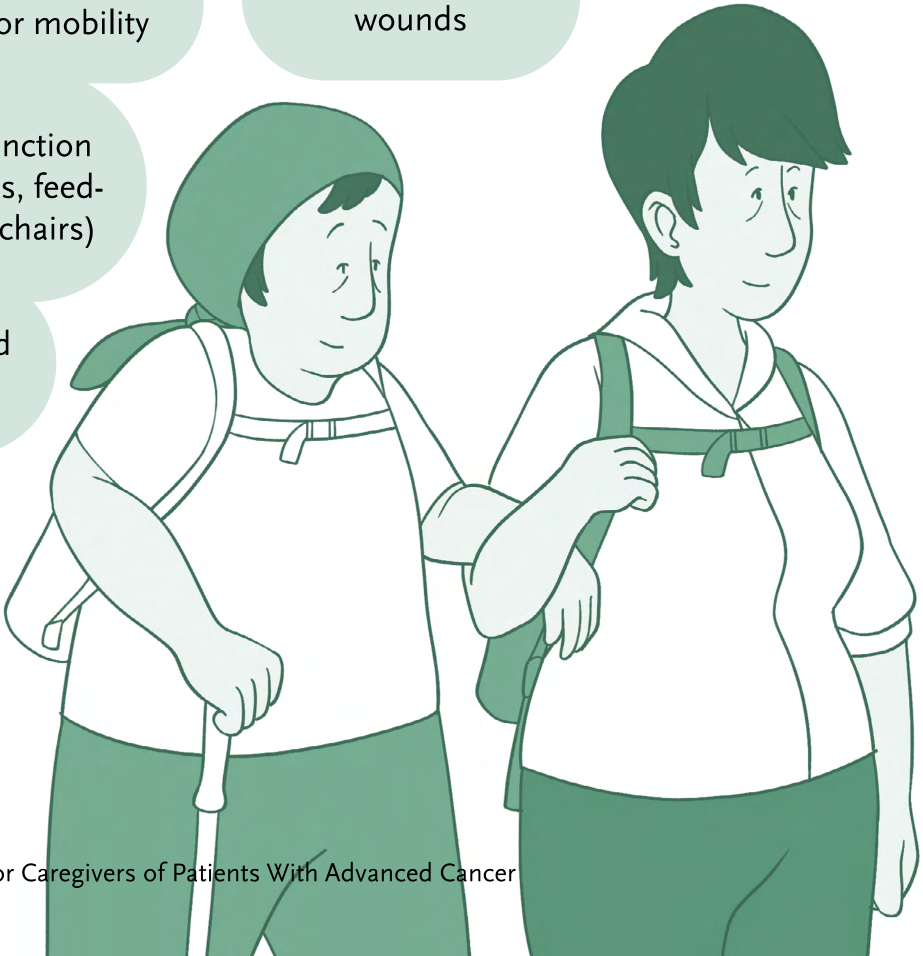
Loss of function and/or mobility

Cancer-related wounds

Devices to assist body function (e.g., ostomy bags, pumps, feeding tubes, walkers, wheelchairs)

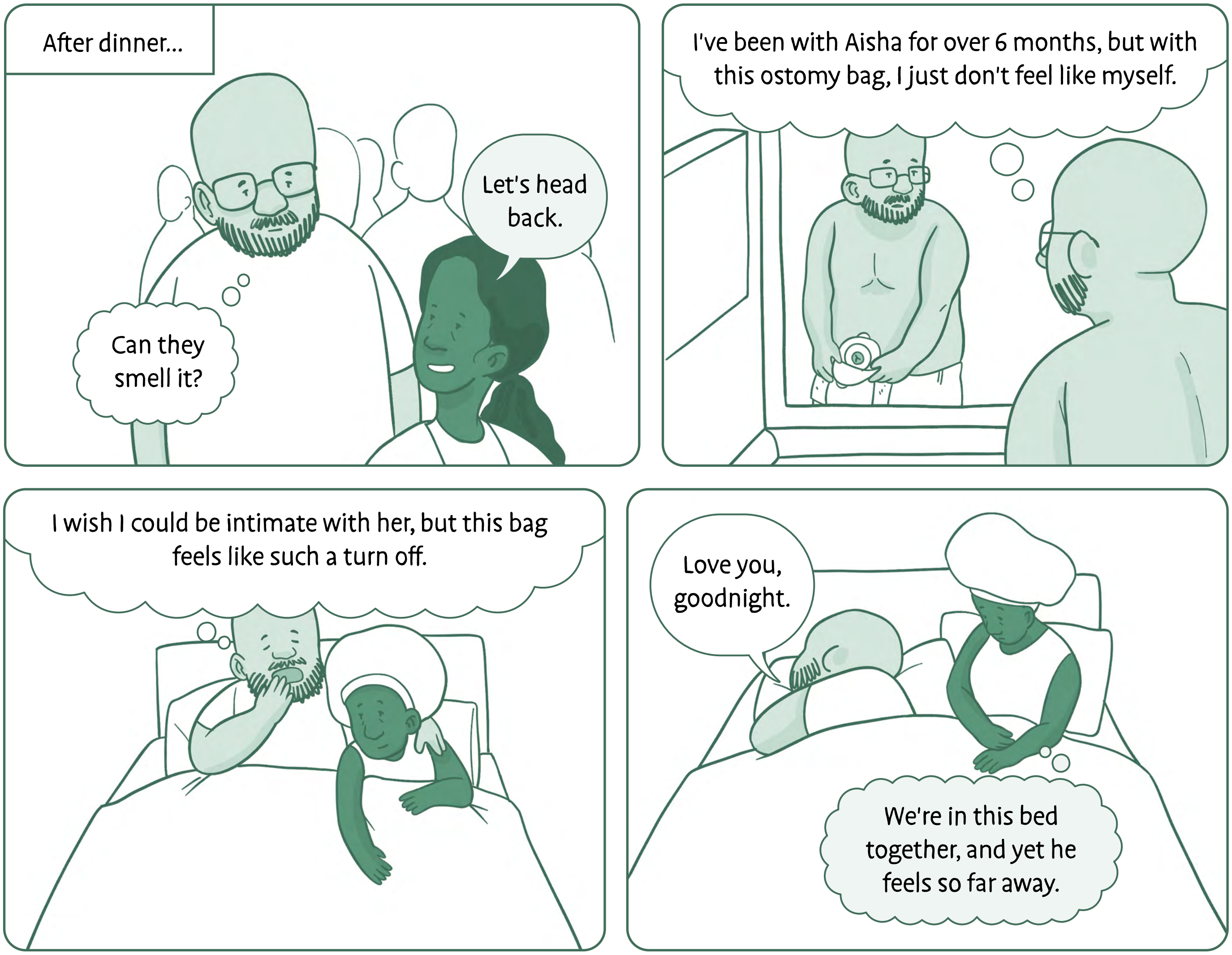
Muscle loss and associated lack of strength or fatigue

Changes in sexual functioning



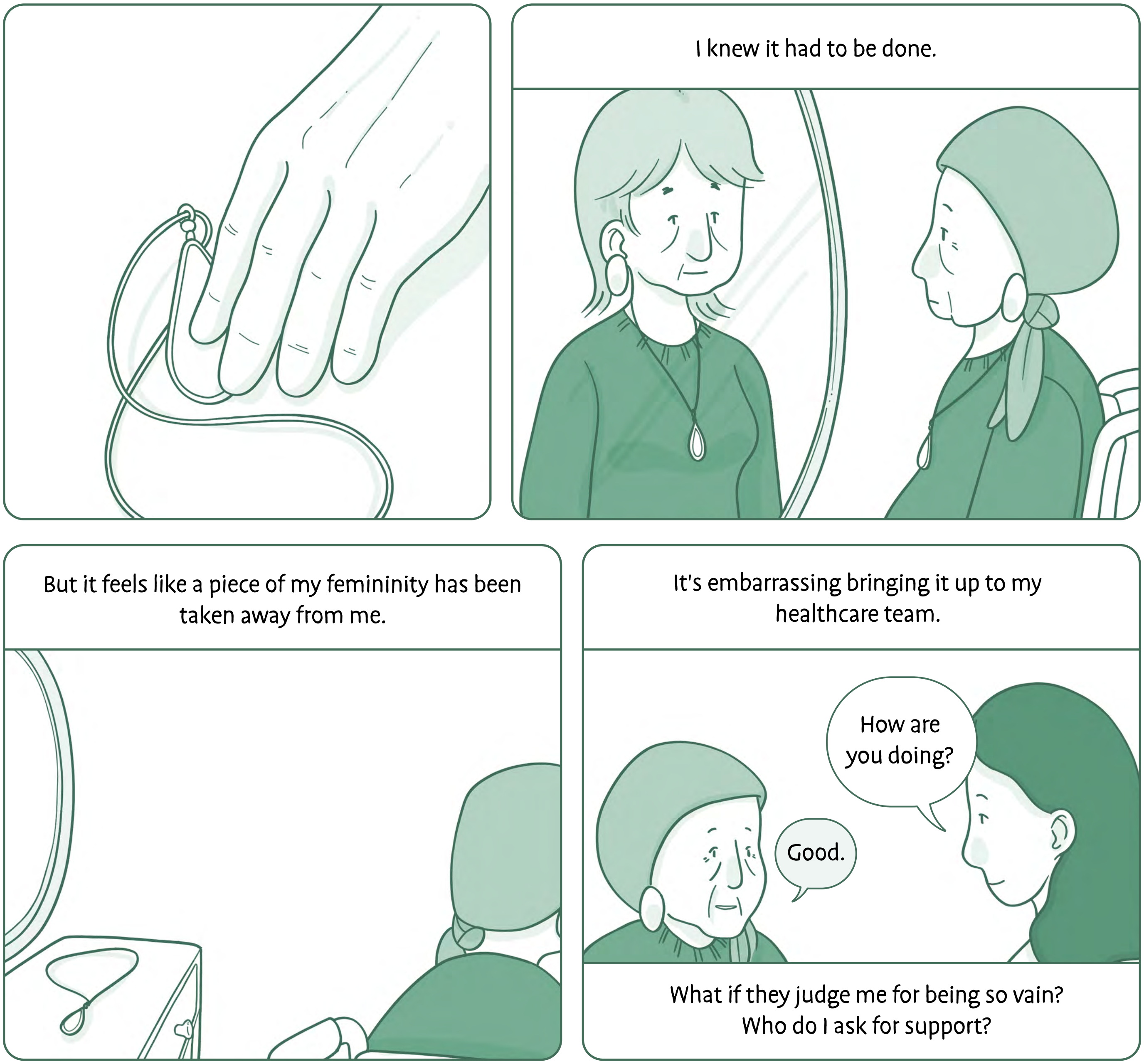
Simon's Story

Simon is a 37-year-old man with advanced colorectal cancer. Part of his treatment plan involved surgery to remove some of the cancer from his colon and now Simon has a stoma (an artificial opening into an organ that can be seen from the surface of the skin) and an ostomy bag.



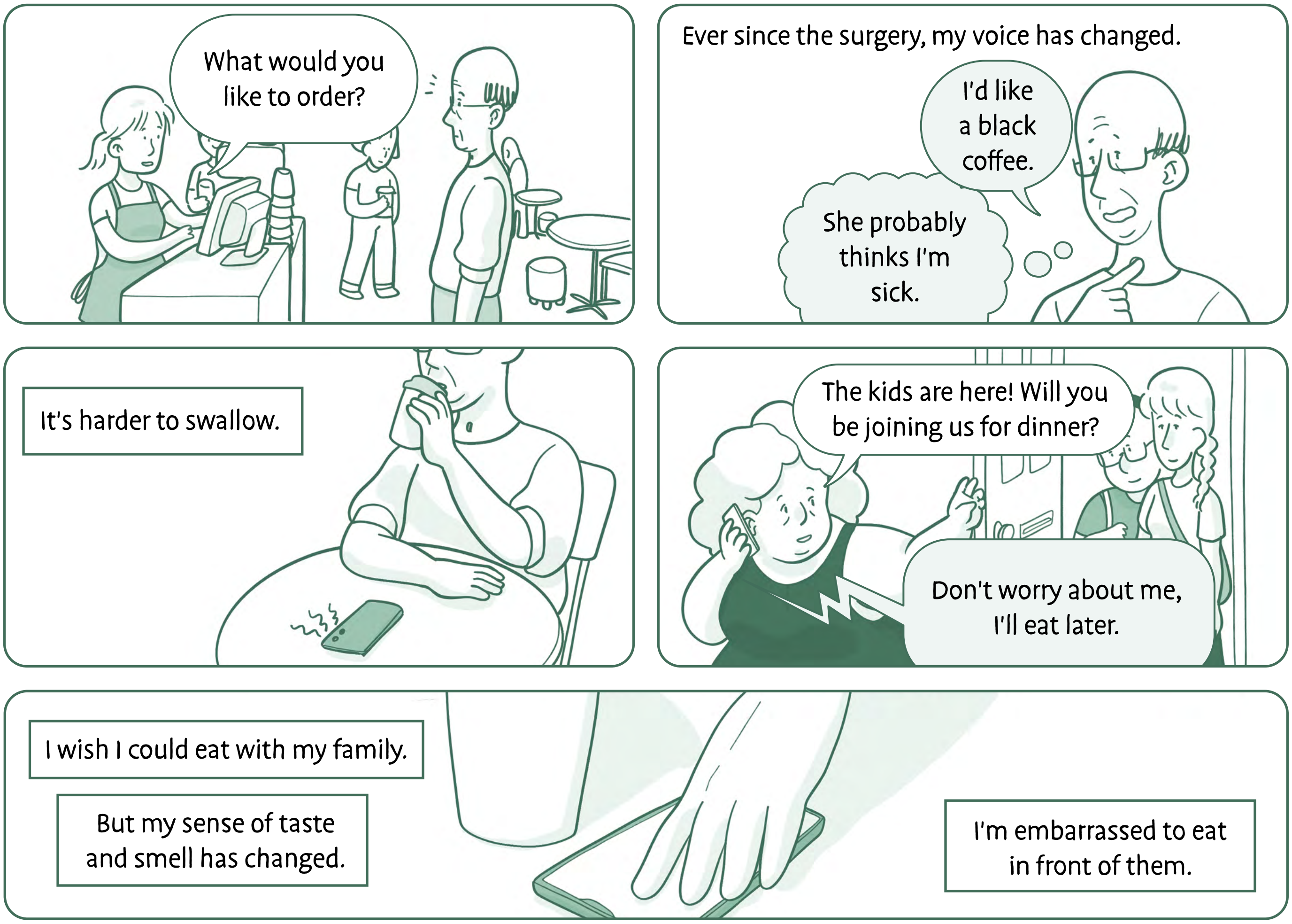
Josephine's Story

Josephine is a 72-year-old woman with stage IV metastatic breast cancer. When she was first diagnosed, she received chemotherapy and had a double mastectomy.



John's Story

John is a 65-year-old man recently diagnosed with pharyngeal (throat) cancer. John had a laryngectomy to remove his voice box and is undergoing chemotherapy and radiation. John had a tracheostomy and now has a permanent stoma (an artificial opening into an organ that can be seen from the surface of the skin).



Changes to physical appearance can affect sense of identity or self-esteem. People with cancer may feel self-conscious about changes in their appearance or abilities. They may be concerned about how they look to other people, including their partner, children, friends, or strangers.

Some people feel that they have lost a sense of their masculinity or femininity, particularly when changes to their body affect organs that we commonly associate with sex (e.g., breasts or testes) or sense of attractiveness to sexual partners. Younger patients may have to cope with body changes that are not typical for their age group (e.g., early menopause, loss of fertility).

Some people are very concerned about anticipated body changes, and this may even affect their treatment decision making (e.g., fear of hair loss associated with chemotherapy). For some, this may be the first time in their life that they have experienced a major change to their body that may limit their abilities. Others may have already gone through changes due to illness, injury, or aging. It is common to experience fluctuating or temporary feelings of loss, grief, sadness, frustration, shame, and anger in response to these types of changes. All these feelings are understandable, normal and valid.

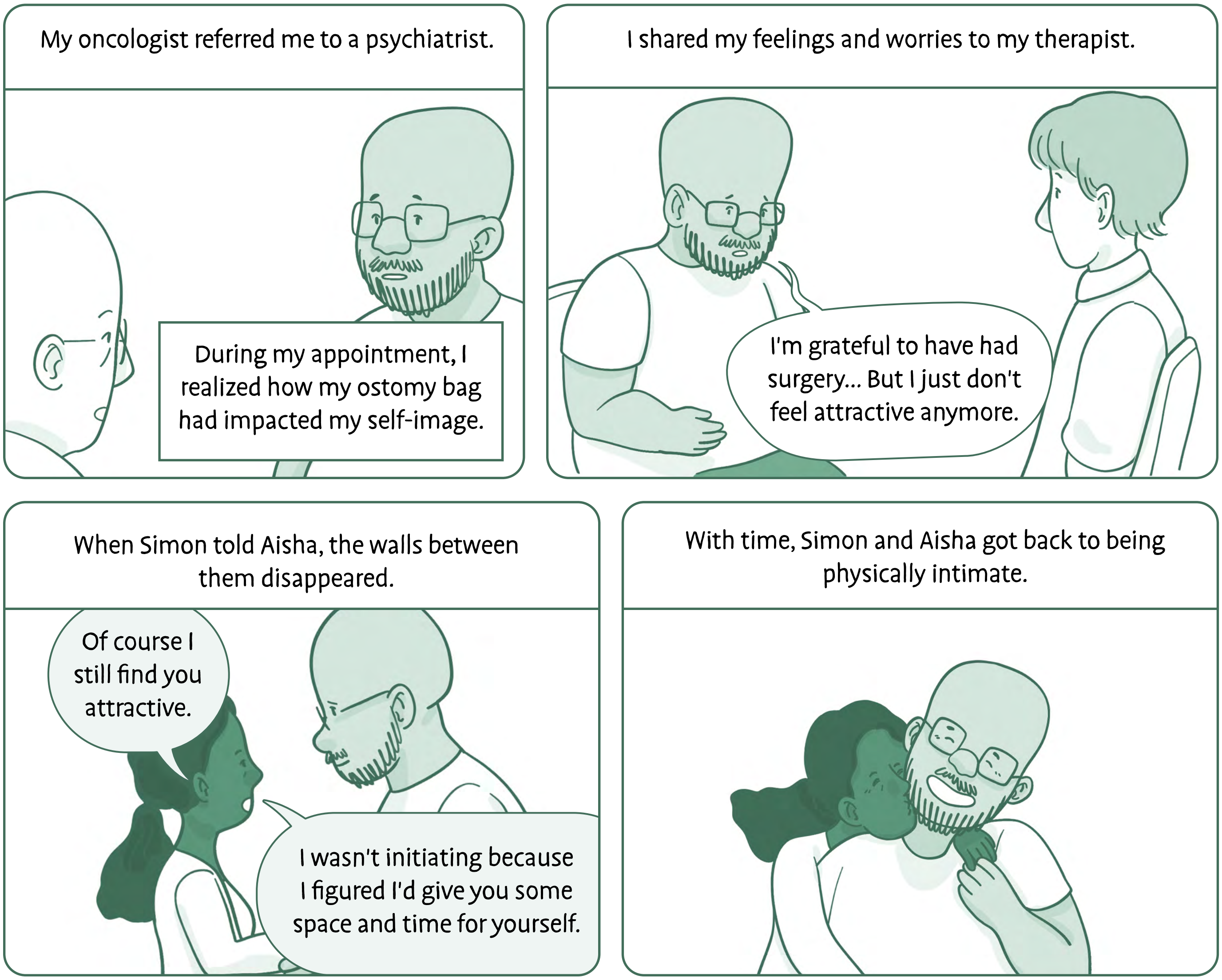
Identity and Physical Changes

Has your family member experienced any physical changes from their illness? How do you think these physical changes have affected the way they feel about themselves?

How have these physical changes affected the way you see your family member? How have they affected you?

Has your family member talked to you about changes in their physical appearance, self-image and/or self-worth? What have these conversations been like? What do they bring up for you?

Simon’s Story continued



If your family member is experiencing physical changes from their cancer and is finding these distressing, they do not need to suffer alone.

These are some options to consider:

- Speak to their nurse or doctor about their concerns. Their healthcare team can give them information about the medical reason for these changes, what to expect in the future, and how to optimize symptom management and functioning.
- Reflect on how these changes are impacting their life on their own, with you, or with a someone else they trust.
- Depending on where they are treated, their hospital or cancer centre may have programs that can help them manage the physical changes associated with cancer (e.g., using wigs, make-up, tips for dressing, use of prosthetics, etc.)
- If they would like further support, they can ask their healthcare team about a referral to a supportive care or mental health professional (e.g., social worker, occupational therapist, physiotherapist, psychologist, psychiatrist) or join a support group for people experiencing similar changes.

Supporting Someone with Physical Changes Due to Cancer

As a caregiver to a person with cancer, you may notice their physical changes. Their emotional response to physical changes may relate to the impact on identity and self-concept, fears of not being accepted or desirable, or what these changes represent to them (e.g., mortality, potential further losses or disability in the future).

Feeling loved, validated, and connected to others can help. Like many aspects of supporting someone with cancer, the kind and amount of support someone needs depends on the individual and the relationship. These changes may also bring up emotions for you, as the caregiver. Watching someone you care about undergo changes related to their cancer and cancer treatment can be challenging.

Here are some suggestions for supporting them through these changes:

Consider your own feelings.

Seeing someone you care about experience changes related to cancer may be difficult. It may be important for you to take time to acknowledge and explore your own emotional reactions first. This may allow you to then be more engaged and responsive to their needs.

Support and validate their true feelings (even the negative ones).

Many patients with cancer feel the need to be positive for their loved ones and avoid negative feelings. Allowing for expression of both positive and negative feelings may reduce feelings of isolation for both of you.

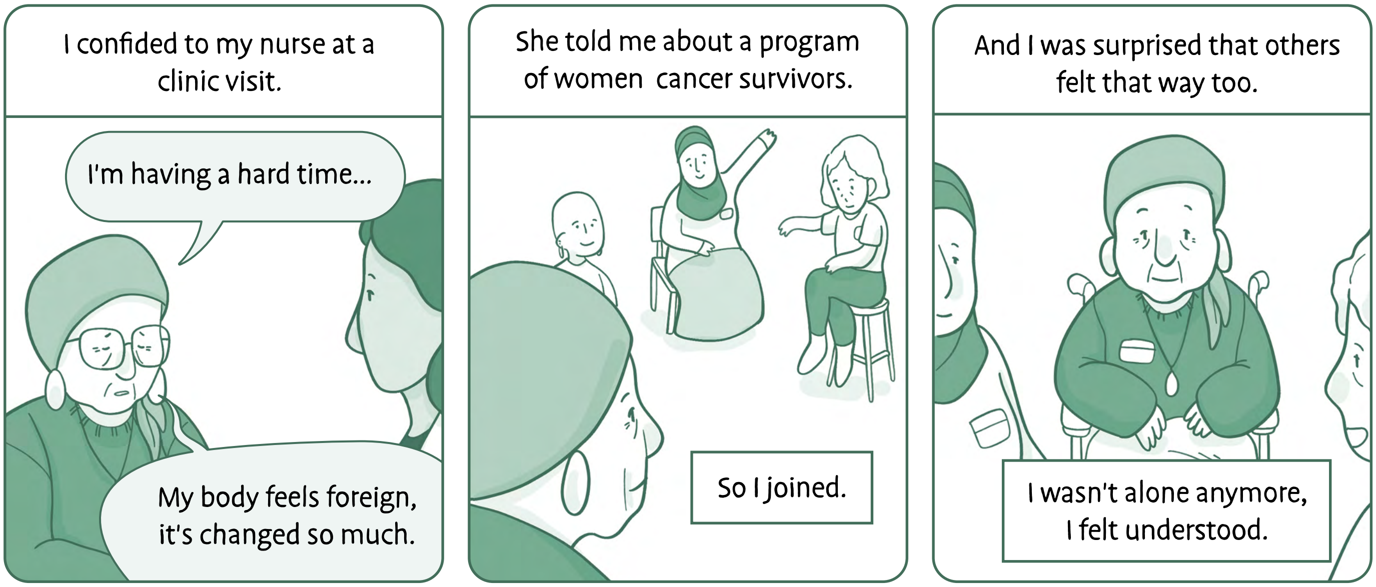
Ask how they are feeling and what they need from you.

You may assume that your loved one is feeling the same way as you; however, it can be helpful to ask how they are feeling and specifically what they need from you.

Check in over time.

Your concerns and needs may change over time. It's important to continue to check-in to make sure that you are both aware of each other's feelings and needs which may evolve and change.

Josephine's Story continued



Social Roles and Cancer

A **social role** is a set of expectations, duties, norms, and behaviours. As an employee, we may be expected to show up to work, perform our duties, listen to our boss or manager, and act professionally towards our coworkers. As a parent, we may be expected to provide for our children's emotional, practical, physical, and spiritual needs.

Reflection

Take a moment to reflect on how you see and experience the role of caregivers.

Which roles do you take on in your everyday life and how might they have changed due to your family member's cancer?

What roles have changed for your family member through cancer?

Grief Around Changing Social Roles

When we are young, we often have expectations about how our life will unfold. We might have particular dreams, goals, and desires. Over time, our goals and priorities may shift, and we may find that life takes us down a different path than the one we thought we would take. We might not always end up accomplishing the goals we started with, but we may find other ways to be contented, feel successful, and find meaning in life. We may take pride in watching our family grow up, developing ourselves professionally, becoming a valuable member of the community, and/or deepening our friendships.

A cancer diagnosis may change one's ability to perform our social roles. In a very short period, someone with cancer may lose their ability to function as an employee, breadwinner, partner, and/or caregiver. They may also become aware of how precious time is. They may feel that they are missing out on certain opportunities such as retirement, career advancement, watching children grow or having children, growing old with a partner, finding a partner, spending time with close family and friends, caring for parents and other loved ones. After a cancer diagnosis, and particularly advanced cancer, there may also be new social roles such as being a patient and receiver of care.

A sense of loss may be a common and normal part of this process of role change. For many people, adjusting to new realities can be challenging and may take time.

The Role of Being a Cancer Patient

We often think of people trying to "fight" cancer. While there is nothing wrong with this idea, there are many different ways of living with and thinking about cancer.

Some people feel very connected to their identity as a cancer patient. They may embrace the role and feel comfortable speaking about their experience with their family, friends, and colleagues.

Others may feel limited by being seen as a cancer patient. They may wish that people would focus on other aspects of their identity and not focus only on their diagnosis. They may feel cancer has taken over and that they are not being seen as a whole person.

Reflection

Take a moment to reflect on how you see and experience the role of patient.

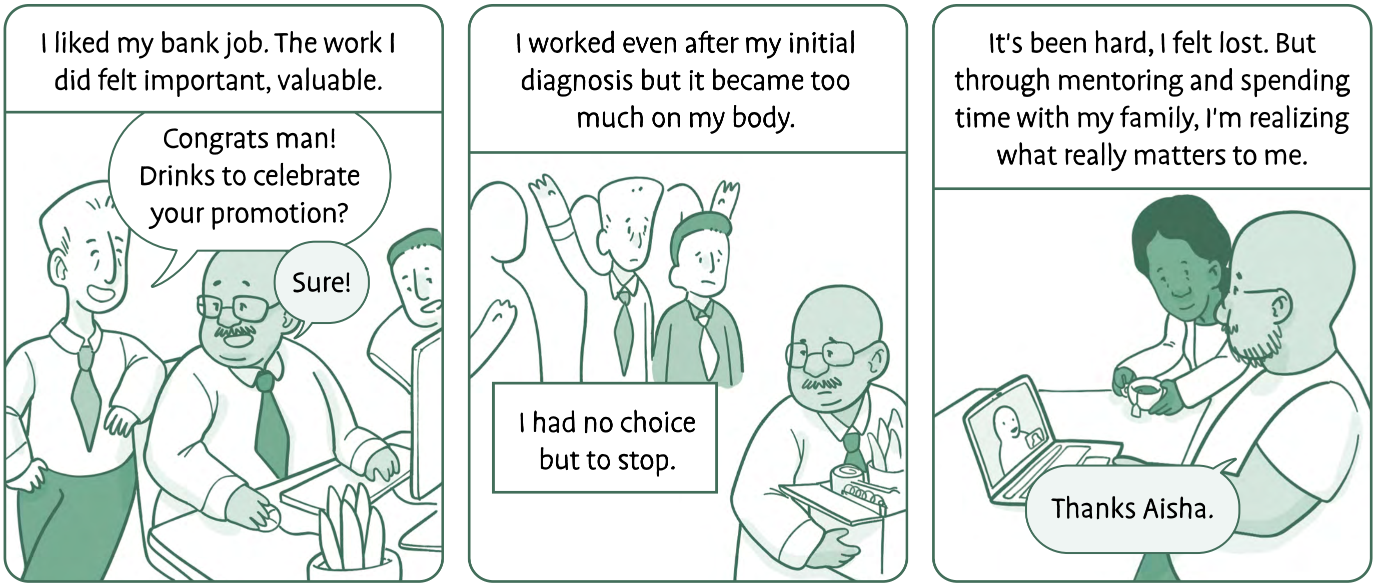
How do you think your family member experiences being a cancer patient?

Does your family member having cancer change the way you see them, what you expect from them, or how you interact?

We have discussed how cancer can affect one's physical appearance and social roles and how these changes can in turn affect how one sees and feels about oneself. What previously strengthened self-worth (e.g., feeling attractive, having a unique ability or specific skill) may have been taken away, leaving loss, grief, or demoralization. However, some people say that having advanced cancer offers an opportunity to re-examine their beliefs about what makes them valuable.

Simon's Story continued

Simon is 37 years old and has advanced colorectal cancer.



Caregivers may have similar experience of struggling to adjust when changes occur in life that challenge what we had planned. Being a caregiver may be a new role for you, or perhaps you have been a caregiver for a child or an adult with an illness or disability before. No matter what your past experiences or the circumstances, you will likely face competing demands and different thoughts and feelings about the changes that are occurring in your life.

Some people have an idea of what being a caregiver might mean and the types of expectations or responsibilities that may come with this role. Caregiving can take many different shapes and forms. For example, parents may become re-involved in the lives of their adult children with cancer, adult children may take on responsibility for elders with cancer, spouses or partners may experience a shift in the nature of their partnership when one has cancer, friends may find their relationship deepens and becomes more intimate as they care for a friend with cancer. Regardless of the specific change, it's common for transitions to bring up feelings at times of stress, confusion, grief, and sadness.

On the other hand, caregiving can also be a source of satisfaction, meaning and purpose for many individuals. It is okay and normal to have multiple and changing perspectives on the caregiving role.

Reflection

Take a moment to reflect on how you see and experience the role of caregivers.

What expectations, duties, and behaviours do you associate with your caregiving role?	How do you feel about this role, the expectations and duties? Allow yourself to think and write freely about this, try to soften any judgments and don't hold back.

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 2: Changes in Self

Understanding Identity and Self-Esteem

- **Identity** is our evolving understanding of who we are and is shaped by our physical traits, personal qualities, abilities, roles, and life experiences.
- **Self-esteem** is an evolving sense of self-worth that is shaped by our experiences, relationships, environment, and how we perceive our abilities and roles in daily life.
- Physical changes, emotional and life experiences (like illness) can affect both identity and self-esteem over time.

Impact of Physical Changes from Cancer

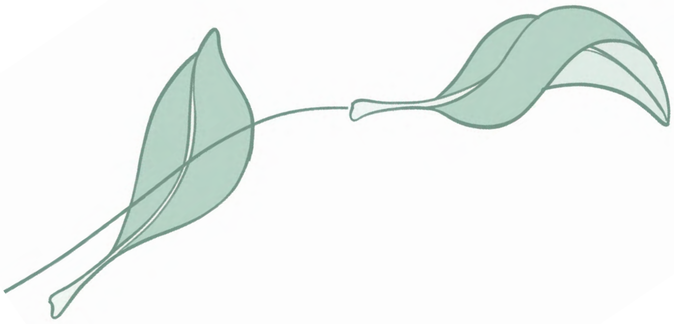
- Cancer and its treatments can lead to visible and invisible physical changes (e.g., scars, hair loss, weight changes, loss of function, mobility aids).
- These changes may temporarily or permanently affect how someone sees themselves and how they feel about their body.
- Each person reacts differently to physical changes, which may cause grief, self-consciousness, or shifts in self-worth.

Navigating Physical, Social and Emotional Changes

- **Acknowledge your own emotions** before offering support; caregiving can be challenging, and you might not always have the capacity to support someone else.
- **Communicate openly**—ask how they feel and what they need, without making assumptions.
- **Validate feelings**, both positive and negative, to reduce isolation and foster connection.
- **Check in regularly**—emotions and needs can evolve over time.
- **Social roles** (e.g., employee, parent, partner) may shift after a cancer diagnosis, sometimes suddenly.
  - Loss of ability to fulfill previous roles can cause grief, frustration, or a sense of missing out on life milestones.
  - New roles, such as being a patient or caregiver, can emerge and be both challenging and meaningful.

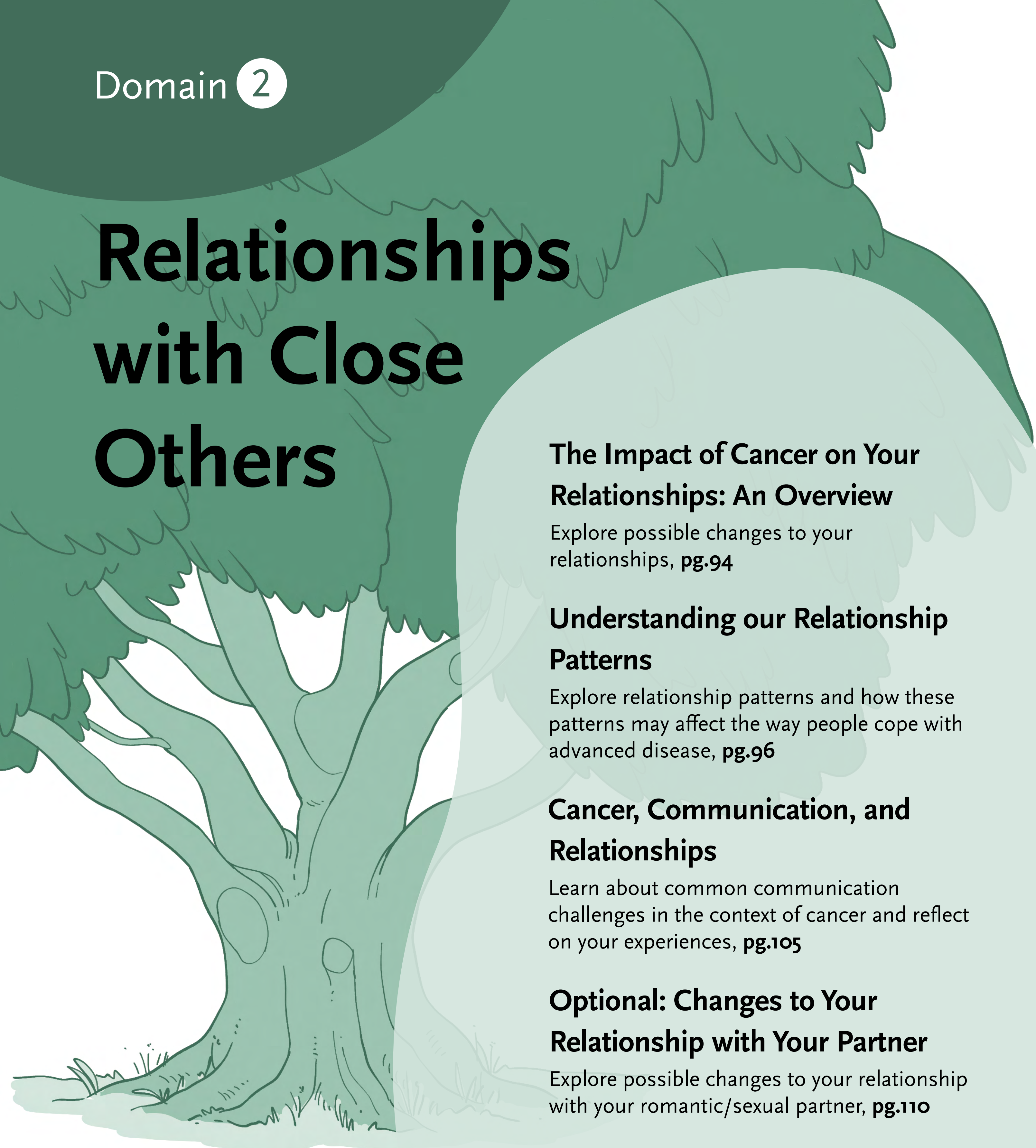
Caregivers

- Caregiving may be a new or evolving role and often involves complex emotions and competing demands.
- It’s normal to experience a mix of emotions—grief, stress, fulfillment etc.
- Caregiving dynamics can vary widely (e.g., parent-child, partner-partner, friend-friend) and may reshape relationships.



Domain ②

Relationships with Close Others



The Impact of Cancer on Your Relationships: An Overview

Explore possible changes to your relationships, **pg.94**

Understanding our Relationship Patterns

Explore relationship patterns and how these patterns may affect the way people cope with advanced disease, **pg.96**

Cancer, Communication, and Relationships

Learn about common communication challenges in the context of cancer and reflect on your experiences, **pg.105**

Optional: Changes to Your Relationship with Your Partner

Explore possible changes to your relationship with your romantic/sexual partner, **pg.110**

Summary

One-page summary for this section, **pg.115**

The Impact of Cancer on Your Relationships: An Overview

Living with a cancer may lead to changes in relationships. It can be difficult to know how to manage these changes for both the patient with cancer and their circle of friends and family. Reflecting on and talking about these changes may help people manage them better.

Here are some examples of how relationships may change in the context of advanced cancer. Each area includes an example from one of our patient partners.

Family

Omar was always close to his parents. He helped care for his father when he was sick and used to help support his mother. Every Sunday, he took her to buy groceries, and he helped her around the house every few weeks. Now that he is sick himself, he can't do this anymore. His sister has taken on a greater role caring for Omar's mother. He is grateful but also feels guilty because he knows how busy his sister is taking care for her children.

For Gregory, Omar's husband, Omar's cancer has caused significant changes in his life and in their relationship. Omar was always the organizer and planner, and Gregory was always the spontaneous one. However, since Omar has become sick, Gregory has had to make adjustments and become the organizer – for both Omar and their teenage son. Additionally, Gregory and Omar's mum have always had a good relationship; however, Omar's mum has become more involved in Omar's care over time. Although Gregory appreciates the help, it's been challenging to negotiate how they share the care. Gregory sometimes struggles to manage the feelings of different family members, fulfill his role as a caregiver, as well as cope with his own feelings of grief and sadness.

Community Relationships

Josephine was an active member of the local gardening club. Being part of the club allowed her to pursue her hobby, and form friendships with her neighbours. However, after her cancer diagnosis she didn't have the energy to attend club meetings. This was a real loss to Josephine, especially as these relationships had become very important to her after she lost two of her childhood friends to cancer five years ago.

Isabella, Josephine's daughter, has always been close with her mother, but for the first time in their lives, Isabella is taking care of Josephine. In some ways, Isabella feels grateful to be able to provide care to Josephine who was a dedicated mother to her growing up. However, as Josephine has started to pull away from her other supportive friends and gardening community, it's felt like she is dependent on Isabella for more and more. Although Isabella is happy to support her mum, it's also meant Isabella has had to re-prioritize some things in her life.

Work Relationships

Akiko lives with her mother and son in a small town outside of the major city where she is being treated. Akiko worked as a human resources specialist for the federal government. Her coworkers felt like family and were a real source of support for her when she was going through her divorce. After she got sick, she had to stop working and moved out of the city, back to the small town an hour away to live with her mom. Akiko still regularly sees Lydia, her closest friend, who she met at work, but it's harder to see her other "work family" on a regular basis because everyone lives in different places.

Lydia and Akiko worked together for four years. They used to eat lunch together almost every day and talk on the phone in the evening at least once a week. Since Akiko got sick, Lydia has been trying to support her in her transition away from work. Their relationship has changed from “work wife” to closer friendship.

Friendships

Beth is single and was living with a roommate until she recently made the decision to move back in with her parents for more support. After Beth moved back home, she found it harder to meet up with friends. Most of her friends live downtown, but her parents live in the suburbs. What was even more difficult for her was how some of her friends seemed to disappear. She realized that they were so uncomfortable with her illness that they were avoiding her. Beth did reconnect with an old friend, Rachel, who recently moved back home as well after a relationship ended. Beth and Rachel found that they could relate to each other with respect to having to be more reliant on their families.

Reflection

Cancer and Relationships

In the face of cancer, what aspects of your relationship with your family member have changed?	What other relationships in your life have changed because of this cancer?

Understanding our Relationship Patterns

The relationships we had while growing up, and the experiences we have throughout our lives, influence how we now relate to other people in the here and now. We have found that many people benefit by becoming aware of their relationship patterns (sometimes called "attachment styles"). In times of crisis, if these patterns are inflexible, this may add to our distress. Often, small adjustments to our expectations, attitudes, and behaviours may help us to feel better supported.

What are Attachment Styles?

Humans are complicated and there is no one theory that can explain all of human behaviour. However, one very popular and well-researched theory on relationship patterns is called attachment theory.

Attachment theory was originally proposed by John Bowlby and was used to understand relationships between young children and their mothers. Since then, it's been expanded and modified to help us understand adult romantic and non-romantic relationships. Attachment theory proposes that humans are hardwired to seek out caregivers and/or to provide care, particularly when under threat or during times of crisis. We see some general differences in the ways that individuals interact with caregivers and as caregivers during these times.

Read about some of these common "attachment styles" below and as you read, please keep in mind that these are simplified examples. In reality, relationships are very complex, and you may have different relationship patterns with different people, and your patterns may change depending on the time and place. We can also see "anxious attachment" and "avoidant attachment" as on a continuum, rather than as discrete categories.

Secure attachment

If we tend to see others as reliable, we may find it easier to ask for and receive help when needed.

Avoidant Attachment

If we tend to see others as not reliable and believe we must deal with difficulties on our own, we may prefer more space and distance in our relationships.

Anxious Attachment

If we feel like we need others to cope, but we also tend to believe others may walk away or abandon us in times of need, then we may seek reassurance in our relationships.

Anxious-Avoidant Attachment

If we struggle with our own ability to manage distressing situations and are unable to rely on and trust others, then we may be both help-seeking and help-rejecting.

See the next page for a model of the four types of attachments styles[3] ▶

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[3] Bartholomew, K., & Horowitz, L. M. (1991). Attachment styles among young adults: A test of a four-category model. *Journal of Personality and Social Psychology, 61*(2), 226–244. https://doi.org/10.1037/0022-3514.61.2.226

Attachment Styles and Coping with Cancer

Our ways of relating are usually adaptive and work well. However, in stressful times such as dealing with cancer, these patterns may become more prominent and less flexible. Our patterns of relating to others may affect our ability to access support and cope in difficult times.

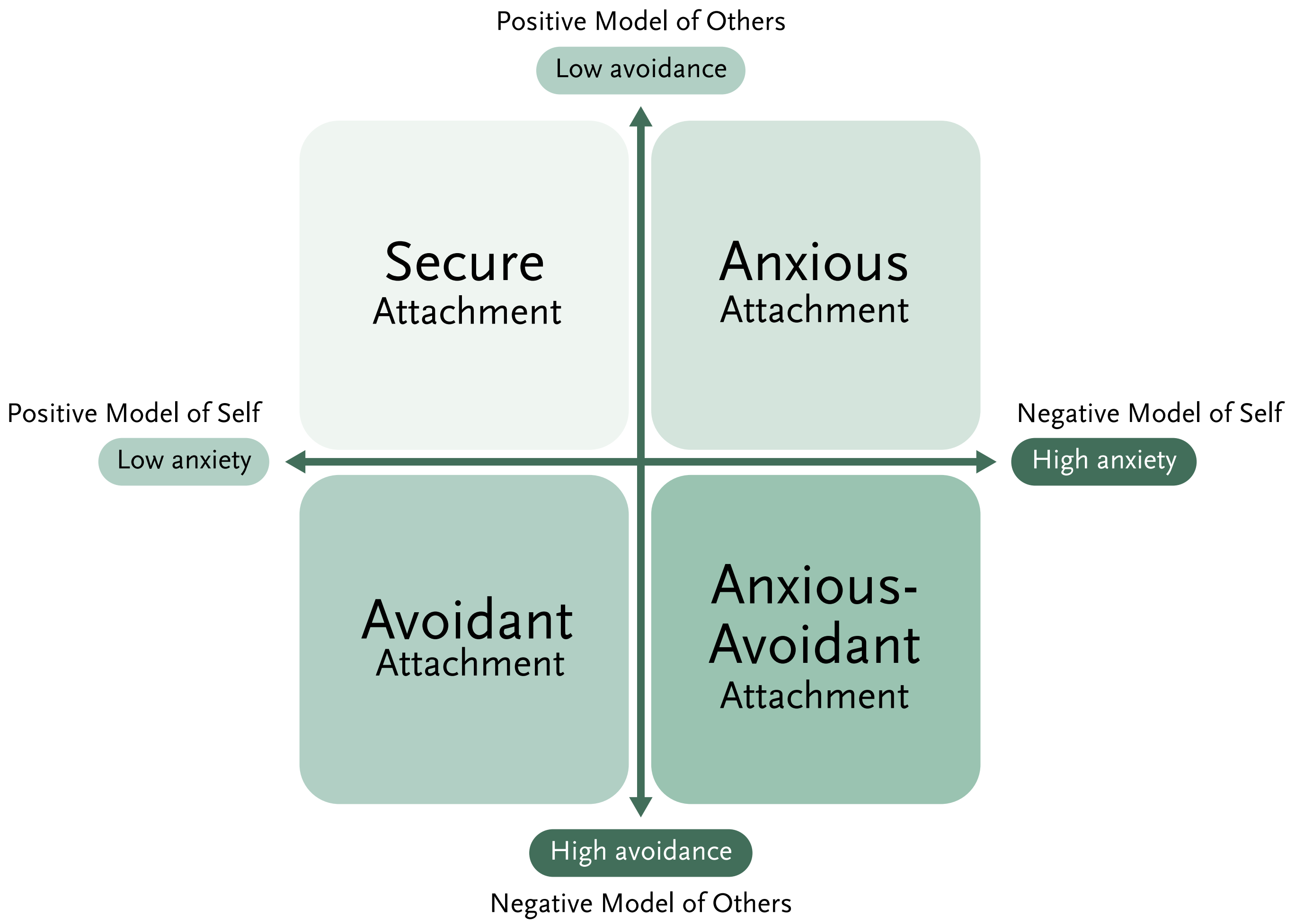
Some people have strong worries that their needs (practical and/or emotional) will not be met by their caregivers. This can include their healthcare team. They may doubt their own ability to cope with the challenges brought on by advanced cancer. They can become anxious that people will abandon them when they need them the most.

Some other people, who have always relied on themselves and prefer to solve their day-to-day problems on their own, may experience a lot of distress when they become more dependent on others in challenging times.

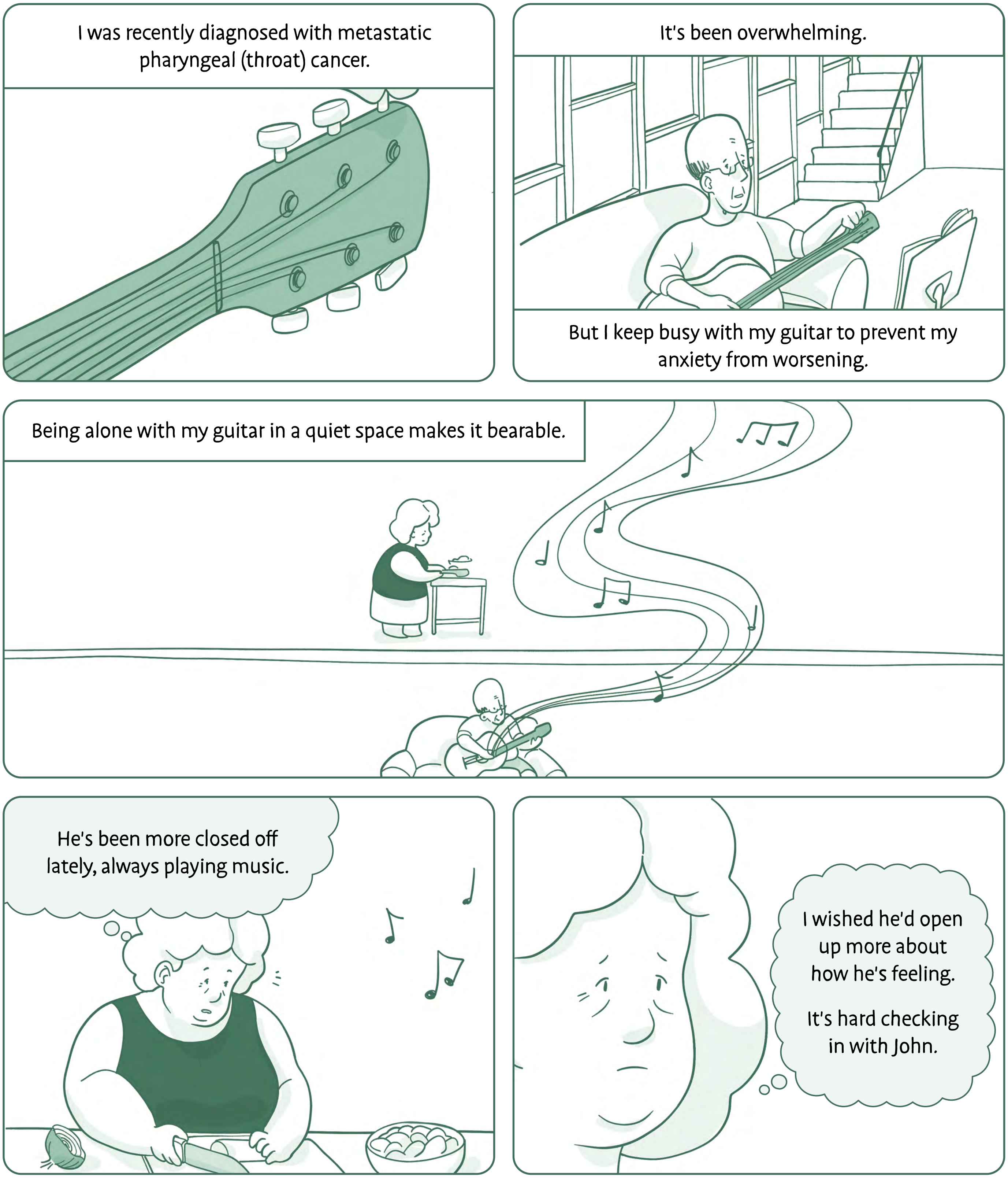
People who feel confident in their ability to reach out for and use support, who believe they can depend on others, that others are reliable and will be there for them when they need help, may cope better with crisis.

We have found that many people benefit by becoming aware of their relationship patterns, and this is particularly true when dealing with a major challenge like cancer.

Attachment Theory



John's Story


I was recently diagnosed with metastatic pharyngeal (throat) cancer.
It's been overwhelming.
But I keep busy with my guitar to prevent my anxiety from worsening.
Being alone with my guitar in a quiet space makes it bearable.
He's been more closed off lately, always playing music.
I wished he'd open up more about how he's feeling.
It's hard checking in with John.

What are Your Relationship Patterns?

The following questionnaire is called Experiences in Close Relationships (ECR-R)[4,5] and is an opportunity for you to reflect on your relationship patterns. We encourage you to choose the answer that is the best reflection of how things are for you right now. Our relationships are always changing so you may have felt differently at different times.

The following statements are about how you feel in close relationships with others. In the following statements, the term "other people" refers to people with whom you feel close.

Using a scale from 1 (Strongly Disagree) to 7 (Strongly Agree), indicate how much you agree or disagree with each statement below.

I get uncomfortable when other people want to be very close to me.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

I worry about being abandoned.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

I tell people with whom I feel close just about everything.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

I need a lot of reassurance that I am loved by people with whom I feel close.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

I don't feel comfortable opening up to other people.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

I worry a lot about my relationships.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

I usually discuss my problems and concerns with people with whom I feel close.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

I find that other people don't want to get as close as I would like.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

I try to avoid getting too close to other people.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

I worry that other people won't care about me as much as I care about them.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

I don't mind asking other people for comfort, advice, or help.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

I get frustrated when other people are not around as much as I would like.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

I prefer not to be too close to other people.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

I worry a fair amount about losing people with whom I feel close.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

It helps to turn to other people in times of need.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

I resent it when people with whom I feel close spend time away from me.

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

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4. Brennan, K. A., Clark, C. L., & Shaver, P. R. (1998). Self-report measurement of adult attachment: An integrative overview. In J. A. Simpson & W. S. Rholes (Eds.), Attachment theory and close relationships (pp. 46-76). Guilford Press.

5. Fraley, R. C., Waller, N. G., & Brennan, K. A. (2000). An item-response theory analysis of self-report measures of adult attachment. *Journal of Personality and Social Psychology, 78*, 350-365.

Has answering these questions helped you to see any patterns in your relationship styles?

1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

Is there anything else you'd like to add or that you think is important in explaining how you tend to interact with others?

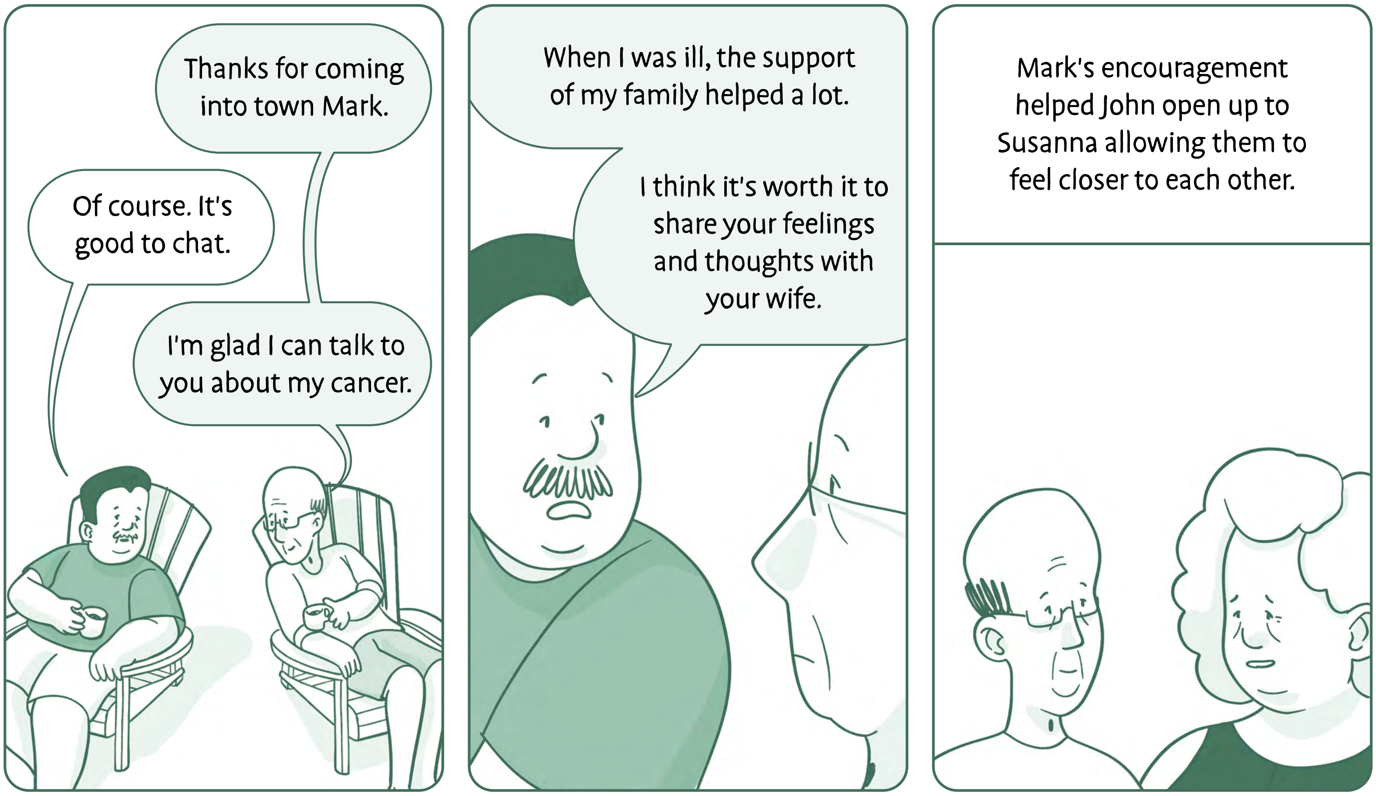
1	2	3	4	5	6	7
strongly disagree			neutral			strongly agree

Understanding Your Results

It is enough to simply reflect on how you answered this questionnaire. However, you can add up your answers from each question to calculate your total score. Total scores will range from 18 –126 (if you answered all the questions) and have general interpretations.

18-50	**51-85**	**86-126**
A score in this range suggests a secure attachment style	A score in this range suggest a mixed attachment style	A score in this range suggest an anxious, avoidant or anxious/avoidant attachment style

John's Story continued



Changing Relationships, Changing Needs

When someone has advanced cancer, their needs (e.g., physical, practical, and emotional) may change and they may require more or different support than they did in the past. Additionally, this loss of independence can be uncomfortable and upsetting for some people.

Similarly, cancer is a challenge that affects caregivers. As a caregiver, you may need to support your loved one in different or more ways than before. At the same time, you may also have more responsibilities in other areas (e.g., childcare, housekeeping, financial), while also trying to manage your own feelings. It can be tremendously challenging to cope with your loved one's changing needs while also taking care of your own.

We have found that these shifts in relationships can be a source of difficulty for individuals with cancer and their caregivers. It may be helpful to reflect on whether our usual patterns and strategies are still working for us.

Attunement is the process of understanding another and being able to respond or react to their unique needs. Learning to attune to your loved one, being flexible, and make adjustments accordingly, can help support transitions in your relationship and help ease cancer-related challenges. We find that when two people can reflect on their patterns that are problematic, they can often make small adjustments that can make a positive difference. This process may help us develop more fulfilling relationships. There may be times of feeling abandoned, misunderstood, neglected, but there may also be the possibility of new closeness and positive growth in your relationships.

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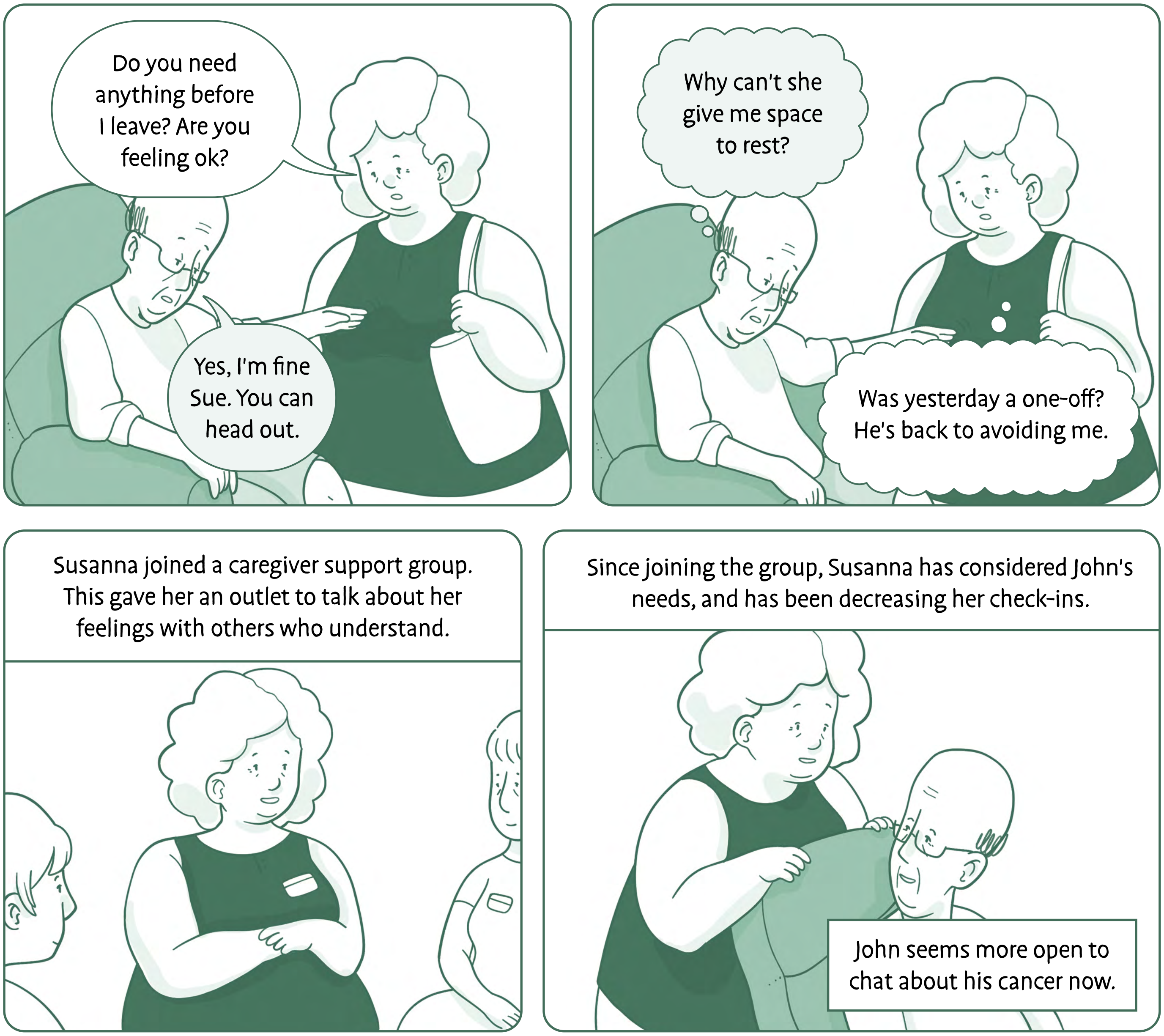
6. Levine, A. & Heller, R. (2018). Attached: the new science of adult attachment and how it can help you find-and keep-love. Penguin Publishing Group. 2012

John's Story continued



Akiko's Story continued

Akiko is a 49-year-old woman with acute myeloid leukemia. She is divorced and shares custody of her 12-year-old son with her ex-husband. Akiko lives with her mother in a small town outside of the major city where she is being treated. One of Akiko's biggest supports is her best friend, Lydia. Akiko tends to panic when she can't get in touch with Lydia. She calls and calls until she can reach her. Lydia loves Akiko like a sister and wants to support her, but at times she feels overwhelmed by this situation.

Cancer, Communication, and Relationships

Living with advanced cancer may mean difficult conversations are necessary at some points. Some individuals feel more comfortable speaking openly about their hopes and fears than others. Akiko, John, and Omar are examples of individuals with different communication styles. Both Akiko and Omar prefer to have open and frequent communication. Akiko feels more comfortable when she has a lot of reassurance from her network. John, on the other hand, sometimes avoids speaking with the people closest to him because he feels that he can handle everything on his own.

You may also have noticed that some people in your life prefer to be more direct, and others are more indirect. There may be many factors that contribute to different communication styles, including personality, family norms, culture, and context.

Can you think of a crisis that you and your family member faced in the past and reflect on how you communicated about it?

Do you notice any of the above patterns in your communication with your family member?

What has your family member told others in their life about their cancer?

What would you like to tell close other(s) about the cancer?

Reflection

Are there issues or problems that you think you and your family member should discuss but have not?

What do you imagine the person you are caring for is thinking or feeling about their illness?

What are your fears about discussing these issues, if any?

Are there any topics you are having particular trouble discussing and why (e.g., treatment decisions, discussion of death and dying, talking about intimacy and sexuality)?

Common Fears

From our experience working with people living with cancer, one of the biggest barriers to open communication about the cancer experience is fear.

Some common fears may include:

Fear of disconnection or being abandoned

Fear of being a burden on loved ones

Fear of seeing others overwhelmed by emotion when talking about difficult topics

Fear of being overwhelmed by your own emotions when bringing up difficult topics

Caregivers additionally may feel that they cannot speak openly about:

Fears of their family member becoming more ill and dependent

Fears about how they will cope should their family member die

Fears of how they will manage increasing demands and responsibilities

Avoiding talking about our fears can lessen our distress in the short-term. However, we have found that having a safe place and support to explore these fears may help decrease some distress and assist with planning and preparation for the future.

If you find you are unable to speak with your family member about these issues, try talking to a friend or healthcare provider first.

Suggested Openers for Difficult Conversations

Here are some suggestions for how you might start a conversation with the person you are caring for about the cancer experience:

Potential Benefits of Caregiving

Being a caregiver for someone with cancer is an experience that can change us. Although some aspects of this experience can be difficult, many people find they have also learned new things about themselves or the person they are supporting in the process. Some caregivers say that cancer has brought them and their family member closer together and allowed them to work as more of a team. Some people may even feel a greater sense of intimacy.

Has the experience of caregiving shown you anything new about yourselves or your relationship?

Do you find that there have been any benefits of the caregiving role to yourself or your relationships?

Changes to Your Relationship with Your Partner

If the person with cancer you are supporting is your partner, you probably play the most important role in their cancer journey. While you may have experienced hardships together in the past, many couples find this to be a uniquely challenging experience.

Before your partner became ill, your relationship may have worked well in a particular way. Many couples experience changes in their relationships after one partner is diagnosed. For example, it may have worked well in the past for you to be very independent from each other and now your partner may now need more support practically and/or emotionally. Or perhaps your partner had been used to taking on a caregiving role in the partnership or family and now they may no longer be able to do this in the same way and may find it difficult to ask for help and support.

This new experience may be challenging for both of you. While you take on a new role as a caregiver, you may also be managing other increased responsibilities and worrying about the future. In fact, research shows that partners experience levels of distress similar to that of patients.

Sexuality and Intimacy

The following section aims to offer you a place to reflect on sexuality and intimacy in the context of cancer. As always, you can engage with the material if you feel it is relevant to you and this is the right time. If you do not feel comfortable completing the exercises that is ok. Many people feel uncomfortable speaking about sexuality and intimacy in a medical setting. While some people with advanced cancer wish they had a place to talk about it, others may feel it is not a priority.

One's sexuality includes sexual activity [on your own or with a partner(s)] but can also include experiences such as erotic feelings for other people. Intimacy can refer to sexual relationships but also can refer more generally to a sense of closeness. In the following reflection section, we focus on sexual intimacy, although intimacy may also refer to feelings between close friends.

What is your experience of sexuality and intimacy since your partner was diagnosed with cancer?

Has your desire to be intimate or sexual on your own or with your partner changed since your partner's diagnosis (e.g., sexual activity, cuddling, handholding, having intimate conversations)?

Has the frequency, quality or your ability to participate in these experiences changed?

How do you feel about these changes?

Common Changes in Sexuality and Intimacy

The following are some common changes that individuals with cancer experience related to their sexuality. Some of these changes may be interrelated.

Body Image

If you have completed *Domain 2 Changes in Self*, you will have read about cancer and body image. People with advanced cancer often experience physical changes that affect how they feel about their body. When people feel negatively or ashamed of their bodies, they may feel less comfortable being intimate with another person.

Decreased Desire

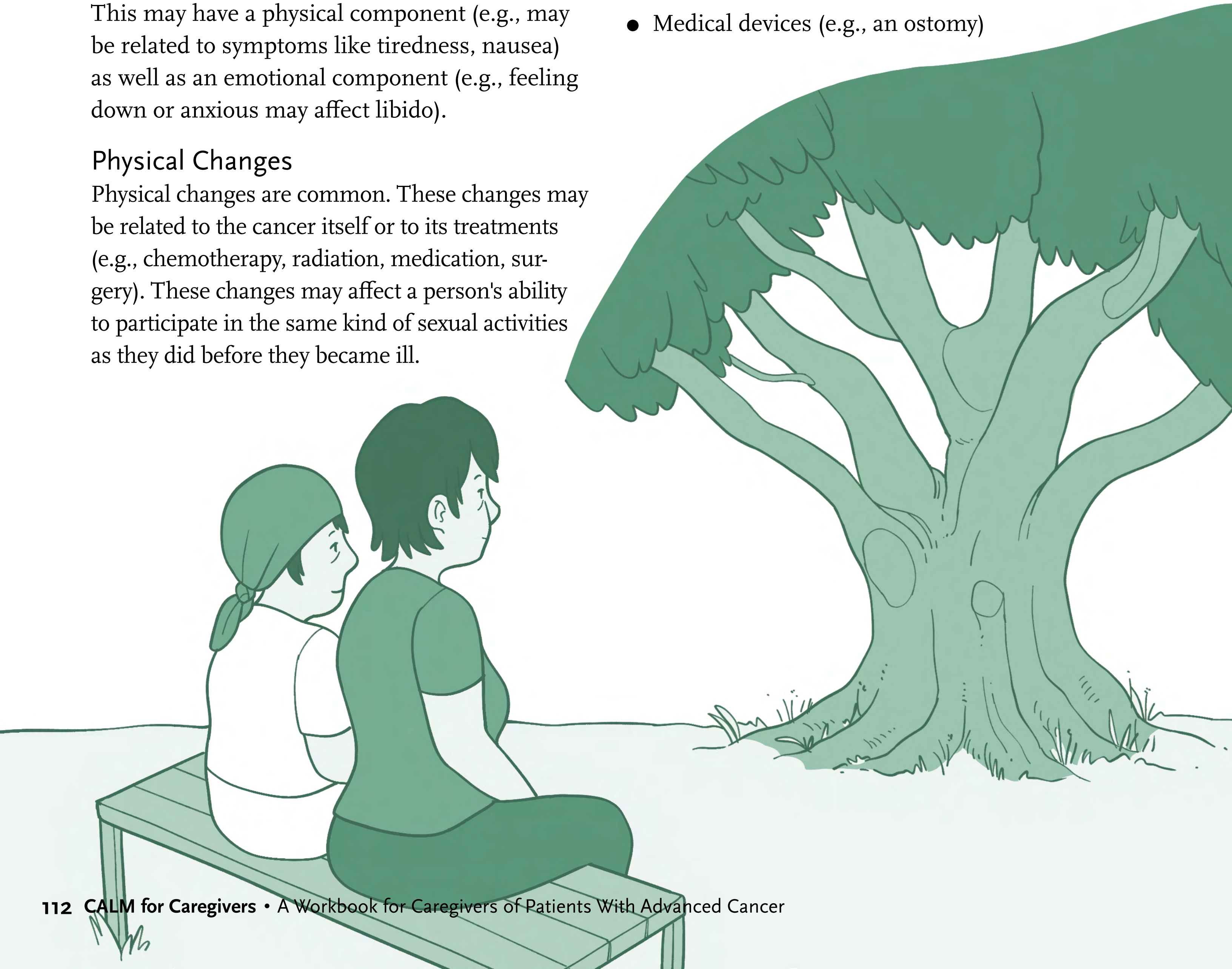
People with advanced cancer may experience less desire to engage in certain sexual activities. This may have a physical component (e.g., may be related to symptoms like tiredness, nausea) as well as an emotional component (e.g., feeling down or anxious may affect libido).

Physical Changes

Physical changes are common. These changes may be related to the cancer itself or to its treatments (e.g., chemotherapy, radiation, medication, surgery). These changes may affect a person's ability to participate in the same kind of sexual activities as they did before they became ill.

Physical changes can include:

- Changes to one's genitals (e.g., vaginal dryness)
- Sexual response (e.g., erectile dysfunction)
- Vasomotor symptoms (i.e., related to the part of the brain that controls blood pressure) including night sweats and hot flashes
- Loss of a body part especially a body part associated with sexuality (e.g., breasts)
- Medical devices (e.g., an ostomy)



Changes to Your Relationship

As described above, cancer may cause changes in relationships, sense of felt security, and intimacy.

What can be done to help manage these changes? There are ways to manage these changes if you are experiencing them and they bother you. Despite living with cancer, it is still possible to be sexual, having satisfying sexual experiences, and to experience intimacy.

Depending on what your concern is, options for help include:

- Counselling with or without a partner
- Reading psychoeducation material
- Other therapies, medications, or devices

Speaking to your healthcare provider about your concerns. Some people find it uncomfortable to speak to their doctor, nurse or other healthcare provider about their sex life. However, they can provide advice or refer you to other clinicians who have more expertise and knowledge in this area.

Some tips for speaking to your healthcare provider about sexual concerns:

- Write down your questions beforehand and take notes while they are speaking.
- If your partner is going with you to your appointment, it may help to talk about it together beforehand.
- Remind yourself that not every healthcare provider has expertise in this area, however, sexual health is an important component of wellbeing and a legitimate health concern and topic for clinic appointments.
- If your healthcare provider isn't able to help address your concerns, consider asking them if there is someone they can refer you to who can.

Reflection

If you and your partner are experiencing a sexual difficulty, what are some questions you might like to ask your healthcare provider?

Your Partner and Communication

It can be difficult for both you and your partner to cope with the changes to sexuality and intimacy because of cancer. Additionally, you may be coping with many other changing responsibilities as a caregiver, including perhaps more parenting duties, increased responsibilities at home or within your family. Research also shows that many caregivers neglect their own sexual needs.

Have you and your partner been able to speak about changes in your sex life or intimacy? If yes, how did these conversations go? If no, and you would like to, do you have any idea what's getting in the way?

Even though having these discussions can be challenging, not speaking about these topics can lead to other difficulties in the relationship.

These might include:

- Feeling down
- Resentment
- Guilt
- Shame
- Loss of emotional intimacy
- Decrease in confidence

Often, the most important thing is just checking in with your partner. Your partner may have different or similar feelings. Even if you may not be on exactly the same page, having the opportunity to acknowledge and talk about those feelings can go a long way.

Tips for a successful conversation

Choose the right time and place

Put away any distractions

Really listen to what they are saying

Remember everything you like about your partner and all that you have shared

Remember everything you like about your partner and all that you have shared

Let your partner know what you like about them, and (if appropriate) what's still going well for you

If your partner is having a hard time speaking about this issue, start off by sharing your experiences first. They may feel more comfortable sharing if you set the tone.

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 2: Relationships with Close Others

Changing Caregiver Roles & Responsibilities

- You may be taking on new roles (organizer, caregiver etc.) which can be emotionally and physically demanding.
- Relationship dynamics may change, requiring adjustment and flexibility.
- Balancing caregiving with other responsibilities (children, work, finances) often increases stress.

Changing Relationship Dynamics

- Family, Friends and Social Connection
  - ○ People may want to help, but aren't sure how, or there can be tension over
  - ○ caregiving roles.
  - ○ Caregiving can limit time and energy for friendships and hobbies.
  - ○ You might feel disconnected (isolated) from work/friends/social circles etc.
- Intimate/Partner Connection
  - ○ Changes in body image, emotional closeness and sexual intimacy may occur.
  - ○ Open communication, even when difficult is important to maintaining connection.

Understanding Attachment & Relationship Patterns

- Your personal relationship style (secure, avoidant, anxious, or mixed) affects how you give and receive support.
- Stress can magnify relationship patterns but being aware and compassionate with yourself can help you respond with flexibility.
- Reflecting together about relational needs may reduce misunderstandings and increase closeness with the people you care about.

Coping & Emotional Growth

- Guilt, grief, fear, isolation and sadness are common for caregivers and often go unspoken – having open conversations can ease the emotional strain.
- Reflecting on your relationship patterns and needs can help build emotional growth and resilience.
- Managing the emotions of others (children, in-laws, other family/friends) while coping with your own emotions can be overwhelming.
- Many caregivers suppress their own needs to support the needs of others (children, in-laws, other family friends) – this can lead to overwhelm and burnout.
- Seeking counseling, support groups, or trusted healthcare professional may provide needed relief of the emotional burdens.

Supportive Communication Starters

“I have some things on my mind about your cancer… Can we find a time to talk?”

“How has this experience been for you?”

“What support would be most helpful for you right now?”

Domain 3

Meaning, Purpose, Values and Goals

Cancer and Meaning in Life

This section will explore questions cancer might bring up about how to live a meaningful and satisfying life, **pg.119**

Sources of Meaning

Here we will explore some common sources of meaning in life. You will have an opportunity to reflect on what gives you strength and a sense of direction in your everyday life, **pg.123**

Spirituality and Faith

This section explores your spiritual or religious beliefs and values, which for some people can be a source of support when facing cancer, **pg.128**

Summary

One-page summary for this section, **pg.129**

Tell Your Story

Everyone has a story to tell. This is a space to tell a story about you. The purpose of this exercise is to reflect on experiences in the past that may have shaped you. It is possible that reflecting on these past experiences might help provide useful direction around how to cope with the present moment and plan for the future.

Your story can take any format, order or structure you like. It can include an array of memories and experiences or can be focused on something pivotal in your past. You can write about your childhood, youth, or adult life. These stories do not need to be in any particular order. We have included some prompts below, but we hope you feel free to deviate from these if you wish.

Which activities or projects have you been the proudest of in your life? These might have involved your role as parent or family member or friend, a job you had, learning you pursued, a hobby or pastime that engaged you.

Which people have played an important role in shaping the way you think and the choices you have made in life and what was the influence they had on you? These may have been role models or people you admire, family members, teachers, community leaders, friends, or religious or spiritual leaders.

Have you ever faced a challenge, illness, or crisis, or have you had someone close to you who has? What helped you get through those difficult periods of your life?

How have these experiences influenced how you are facing your family member's cancer today and in what way?

Cancer and Meaning in Life

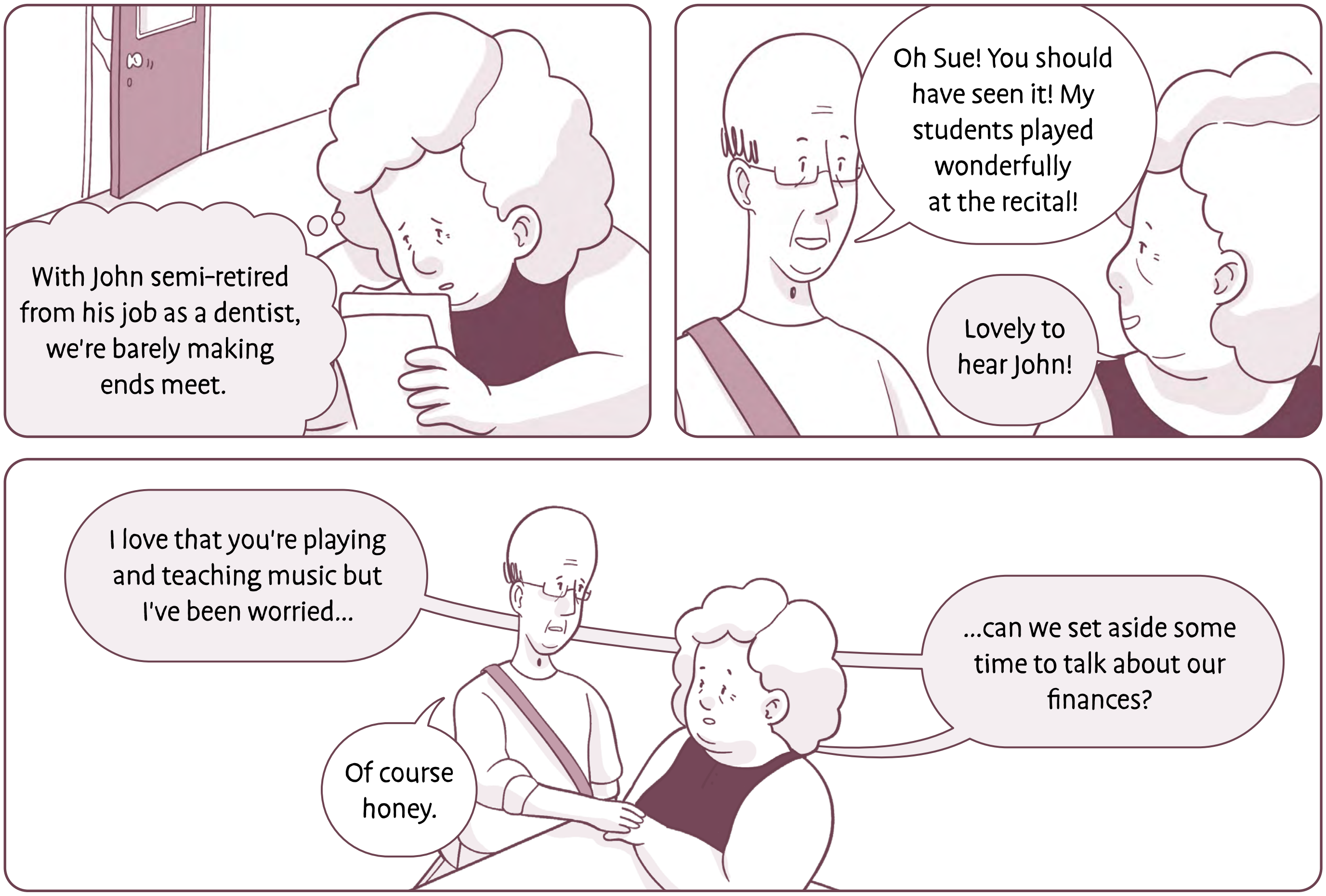
Cancer may cause us to pause and consider the road we have been on and the direction in which we are heading. There may be common questions that patients may ask themselves, such as: Why did the person I care for get this disease? Does our life still make sense? Have we lived our lives "properly" so far? What am I supposed to do now? What is the right way to approach cancer?

Many people find that cancer causes them to reflect on how they have lived their lives and what meaning their lives have now. Some people feel distressed at the thought that their previous goals in life may no longer be achieved, while others may feel that cancer has helped them to clarify what is really important. Some set new priorities and value different things than before.

For caregivers of patients with cancer, similar questions may arise. Cancer can change the trajectory lives significantly. For example, shared and personal goals may no longer be a priority or be possible. For many caregivers, cancer has caused them to step back and re-evaluate their values and priorities.

John and Susanna's Story

John is a 65-year-old man with cancer of the throat that was diagnosed a few years ago. At first, he was treated with surgery and chemotherapy. He is now off treatment and monitored by his oncology team every few months.



Beth, Janice & Tom's Story

Beth is 25 years old and has metastatic sarcoma. She was diagnosed in childhood and her cancer recurred in the last year. She recently graduated from university and was about to start an accelerated nursing degree. Beth is single and was living with a roommate but recently made the difficult decision to move back to her parents' home for additional support.

Reflecting on these stories and your life...

How have important areas in your family's life been affected by cancer?

Since the person you care for was diagnosed with cancer, what changes have they made to their day-to-day life and how they spend their time? Do they spend more or less time with their family and friends? Did they continue to go to work or school? What significance does this hold for them? Have their hobbies or other past times become more or less important since their illness? How so?

How about you? How have important areas in your life changed?

Reflection

Did cancer raise questions about your family member's priorities?

How about you? Did their cancer raise questions about your own priorities?

In response to these questions, have you found any useful answers, conclusions, or new directions? This might be an evolving process but take this opportunity to write down whatever comes to mind.

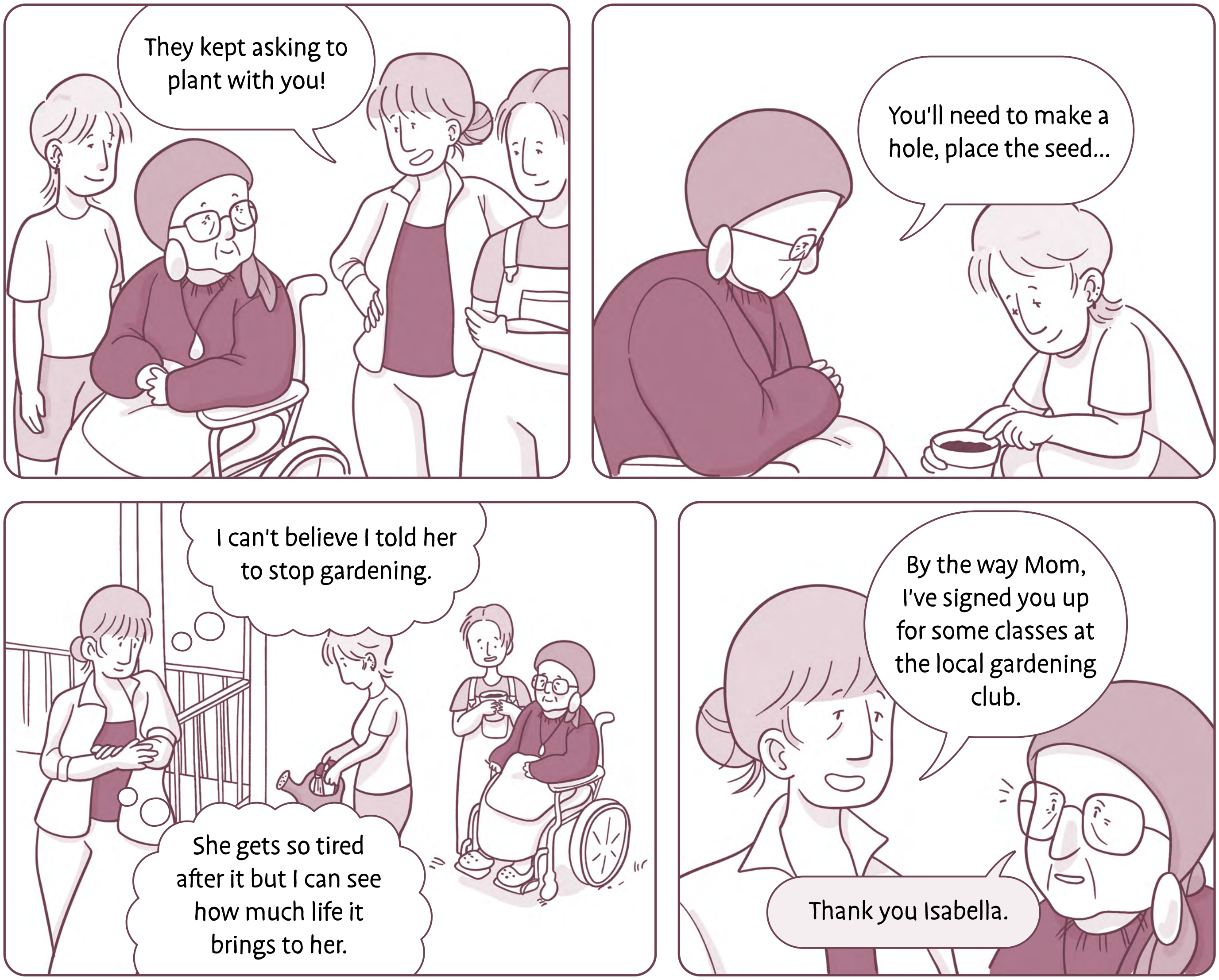
There is no right way to feel in the face of cancer. Each person copes in their own way and this may change over time. Many people find it helpful to pause to think and reflect about what is important to them in life, especially during a challenging time, even if there are no quick or easy answers.

Sources of Meaning and Purpose

Activities, experiences, projects, and relationships that are most meaningful may be different for each person. For example, working on a piece of art may bring meaning and joy to one person. And for another it can be volunteer work or time spent together with family. Others may find a lot of meaning from their job or from simple pleasures such as a beautiful view or a good meal.

Josephine and Isabella's Story

Josephine is 72 years old woman and lives with stage four breast cancer. Since she learned her chemotherapy is no longer effective, she often thinks about her garden. Josephine has spent most of her life in the garden. Every year she planted new flowers, cared for the perennials, and harvested tomatoes and vegetables. She does not always have the strength now to care for her garden due to her disease, but she still enjoys putting her hands in the earth and breathing the fresh air.



Domain ③

Here are some sources of meaning and purpose...

Creativity

contributes to feelings of satisfaction and wellbeing.

Gardening

Repairing a car

Woodworking

Writing

Playing music

Cooking

Painting

...& much more!

Satisfaction and well-being

may also stem from...

taking a vacation

a stimulating conversation

seeing something beautiful

encounters with a special person

being physically active

a great concert

A feeling of belonging and connection

to something greater than ourselves can be an important source of meaning for some people. A sense of connection to...

Nature

Spiritual, religious or cultural beliefs

Community

Values and outlook

on life play an important role in how we experience life.

Accomplishments

Pursuit of knowledge

Dedication to others

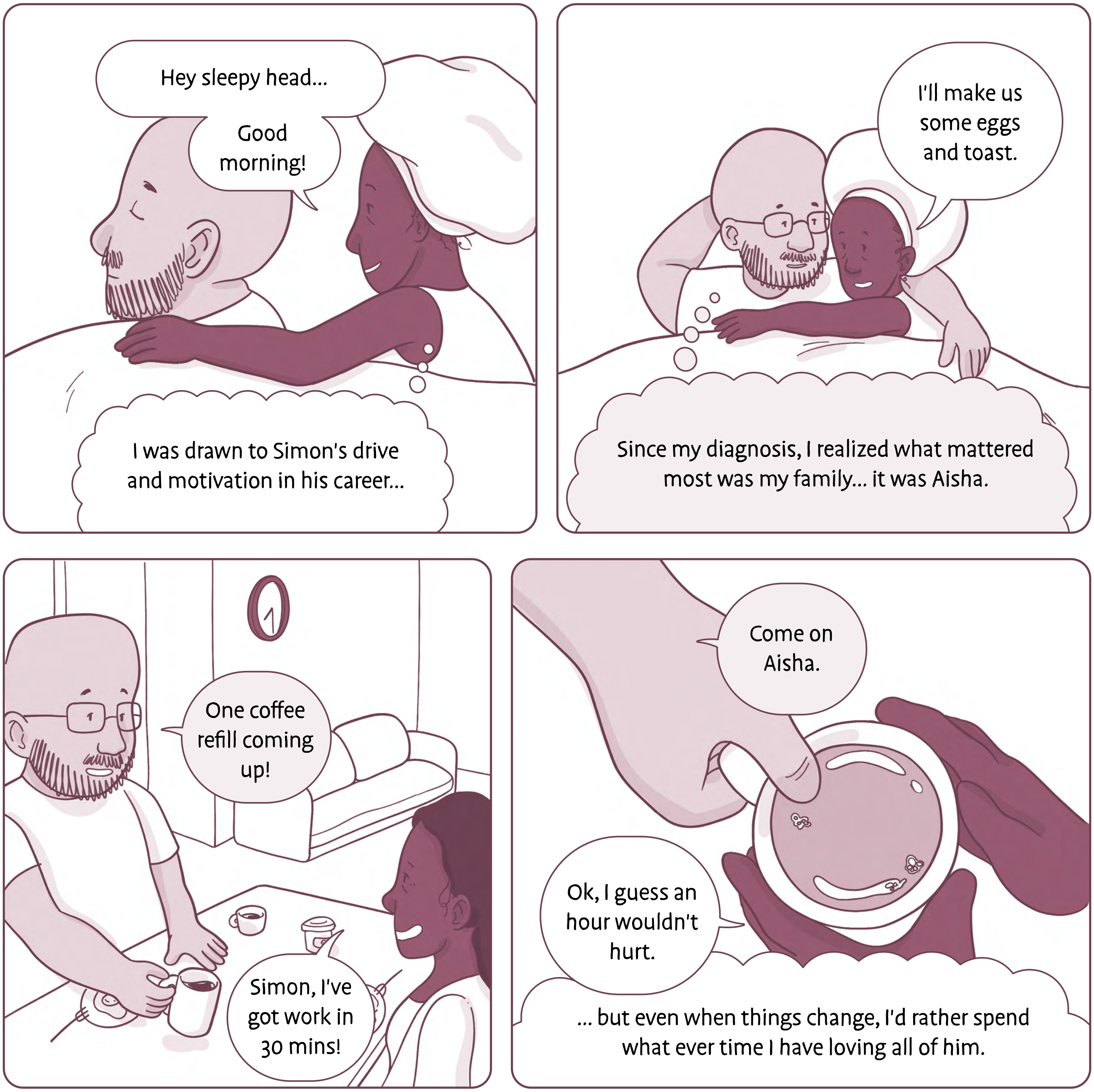
Hardwork

Care

Respect

Simon and Aisha's Story

Often, when faced with cancer both patients and caregivers may reflect on sources of meaning and purpose in life. It can also be a useful exercise to reflect and reassess what brings us meaning, purpose, joy, fulfillment, values and goals.



Domain ③

Reflection

Many people find that reflecting on areas of life that bring meaning and purpose can provide strength in challenging times.

Consider some of these examples when thinking about past or current goals as well as what brings meaning, purpose and joy to your life.

- Relationships/Connection to others (friendships, partners, family, etc.)
- Career
- Creativity
- Education and personal development
- Connection to nature
- Pleasurable activities
- Appreciation of beauty
- Physical well-being/ exercise/ sport
- Connection to a higher power
- Spirituality and/or faith

Which activities, experiences, projects, relationships, roles or ideas bring meaning purpose and joy to your life now?

In your past, were there sources of meaning and purpose that you might want to return?

Have there been shifts in priorities as a result of facing cancer? What are the shifts have you noticed?

What areas do you now draw strength from and give meaning to your life?

What about for the person with cancer that you care for?

Spirituality and Faith

Philosophy, spirituality and religion can provide an understanding of the way the world works and what is important, as well as a sense of connection to a higher power, 'source' or something beyond oneself. We invite you to reflect on your own values and beliefs which you may describe as spiritual or religious. Cancer often brings up important questions, such as: Why did this happen? What has my life meant? What else can I hope for? Some people find answers to these questions in their philosophy, their beliefs, or their faith.

Consider what experiences you have had with spirituality and belief.

Do you see yourself as a spiritual person? If yes, how so? If no, why not?	Do you belong to a religious or faith community? What about this community/faith brings you support/comfort/meaning/joy?
Have you questioned beliefs/faith/existential ideas due to someone else's illness?	Consider how the person you care for might answer these questions?

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 3: Meaning, Purpose, Values and Goals

Cancer, Life's Meaning and Telling Your Story

Cancer often prompts deep questions:

- Why did this happen?
- What matters now?
- Have I lived aligned with our values?
- What is the way forward?

You may find yourself rethinking personal and shared life goals that are now uncertain or out of reach.

It's normal for your sense of purpose or direction to shift; values may evolve as your caregiving role deepens.

Reflection Can Be a Tool for Coping

- Looking back can help you understand how past experiences shaped who you are now and what matters most to you.
- Taking time to reflect doesn't mean having all the answers—it's about reconnecting with what gives your life meaning today.

Sources of Meaning & Joy

Everyone finds meaning in different ways:

- **Relationships** (e.g., time with family, caregiving itself)
- **Creative work**, hobbies, or nature
- **Professional roles** or volunteer efforts
- **Everyday joys** (e.g., a shared meal, music, a quiet walk)

Identifying what brings you meaning—even small things—can sustain you through hard days.

Spirituality, Faith & Beliefs

Faith, spirituality, or beliefs can offer comfort and perspective:

- Connection to something larger than yourself
- A framework for making sense of suffering or change
- A place to find hope, peace, or acceptance

Reflecting on what you believe may help you feel more grounded and less alone.

Domain ③

Re-evaluating Meaning, Purpose, Values and Goals

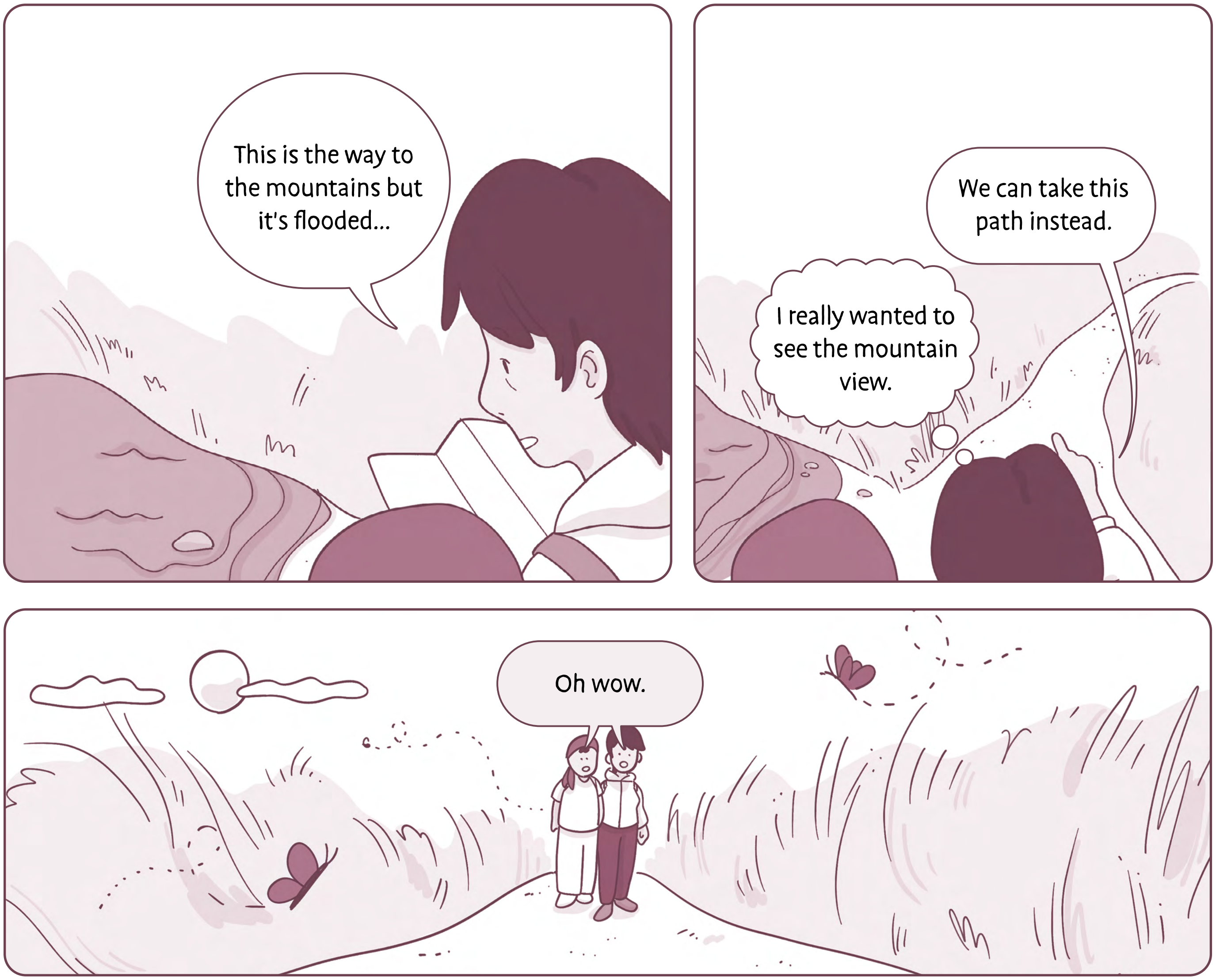
Domain ③

Re-Evaluation of Life Goals

Many people find that there are drivers that guide them through life. For some, this might be achieving success at work, maintaining friendships, or completing projects, such as building a house or creating works of art. Others may dream of traveling the world or starting a family. These dreams and wishes may become short-term or the long-term goals.

However, cancer can affect one's ability to work towards these goals. What may have seemed important before the diagnosis may move into the background or become beyond more difficult to achieve over the course of the disease. On the other hand, other aspects of life may come to the forefront, and new goals and opportunities may emerge.

Within the *Meaning, Purpose, Values and Goals* section, there was an opportunity to reflect on how your family member's life goals may have changed over the course of cancer. Depending on your level of involvement in caregiving, you may have had to make changes to your own goals and plans as well.



Akiko's Story

Akiko is a 49-year-old woman with acute myeloid leukemia that is not responding to treatment. Akiko lives with her mother in a small town and has a 12-year-old son, Nathan (from a former marriage). Akiko has always had a lot of stuff on the go. She likes to be busy with travel, exercise, and spending time with family and friends. However, since Akiko got sick, she has had to cut back on her busy schedule.

Domain ③

Reflection

What have you and the person you care for already achieved and what were some of goals, wishes and dreams for the future?

Here are some examples to think about:

Relationships. e.g., connection or reconnect with loved ones (friends, sibling, child, spouse, self, etc.), find life partners/marriage

Profession and career. e.g., a new job, participate in advanced training, career advancement, retirement

Social engagement. e.g., volunteer work, political engagement

Education and further development. e.g., complete school, vocational training, study, develop a skill

Health and well-being. e.g., living a healthy lifestyle, managing stress, self-care, meditation, religious practices

Leisure and activities. e.g., travel, new pet, time to enjoy a hobby

Movement and sport. e.g., regular exercise, dance classes, tai chi

Creativity. e.g., learn an instrument, paint, write stories/poems

Closeness to nature. e.g., more time in nature, gardening, hiking

Achievements	Goals, wishes and dreams

Re-Evaluation of Life Goals

The cancer experience may interfere with life plans for both patients and their caregivers, although new opportunities and goals may emerge. It may be upsetting when long held dreams and goals do not seem in reach because of illness. Identifying new and achievable goals may create a sense of new hope and direction.

Have you found that some activities and goals are less possible due to cancer? If so, what are they?

What thoughts and feelings do you and the person you care for experience in connection with these activities or goals that now seem difficult or impossible?

What new goals, wishes or dreams might have emerged for you both?

How Values Can Shape Life Plans

Values are qualities or principles that may guide our actions and decisions.

Here are some examples of values:

- Honesty
- Reliability
- Respect
- Prosperity
- Loyalty
- Enjoyment
- Curiousity
- Creativity
- Love
- Humour
- Self-realization
- Partnership
- Safety
- Solidarity
- Career Pursuits
- Hard work
- Friendship
- Health
- Modesty
- Independence
- Family
- Authenticity
- Caring
- Order
- Learning
- Responsibility
- Openness
- Sincerity
- Tradition
- Kindness
- Security
- Tolerance

Values can be integral to your identity, give direction in life, and be helpful in navigating challenges.

What values are most important to your identity? What top three values provide a guiding influence in your life (consider the above list or feel free to come up with your own)?

Your values can change over the course of your life, perhaps in response to challenges. Has cancer caused you to change or reprioritize what you value? What about your experience caregiving?

You've been focusing on your own goals and values. You can now take a moment to reflect on the values of the person you are caring for and what might be important to them, and how the illness experience has influenced their values. Perhaps you both share some values and perhaps some are different.

Communicating Values and Goals

Being aware of your life goals and underlying values can help to guide you during times of significant life changes. These values can act as a compass to point you in the right direction. Patients with cancer may have found new ways to reach goals or may form new goals. Some people find that their previous goals are not as important as before. This is the same for caregivers in the face of another's illnesses, especially when it comes to shared goals or plans for the future. Discussing values and life goals with people close to us may make them clearer to us and may allow others to join with us in achieving them.

For patients, it can also be helpful for their medical team to understand their personal values and goals so that they can better support them in treatment plans and decisions. It is often beneficial to speak with the person you care for about their values and goals prior to making treatment decisions.

Do you feel that the people close to you understand your values and goals?

Are there goals or values that you share with people close to you? Reflect on why or why not?

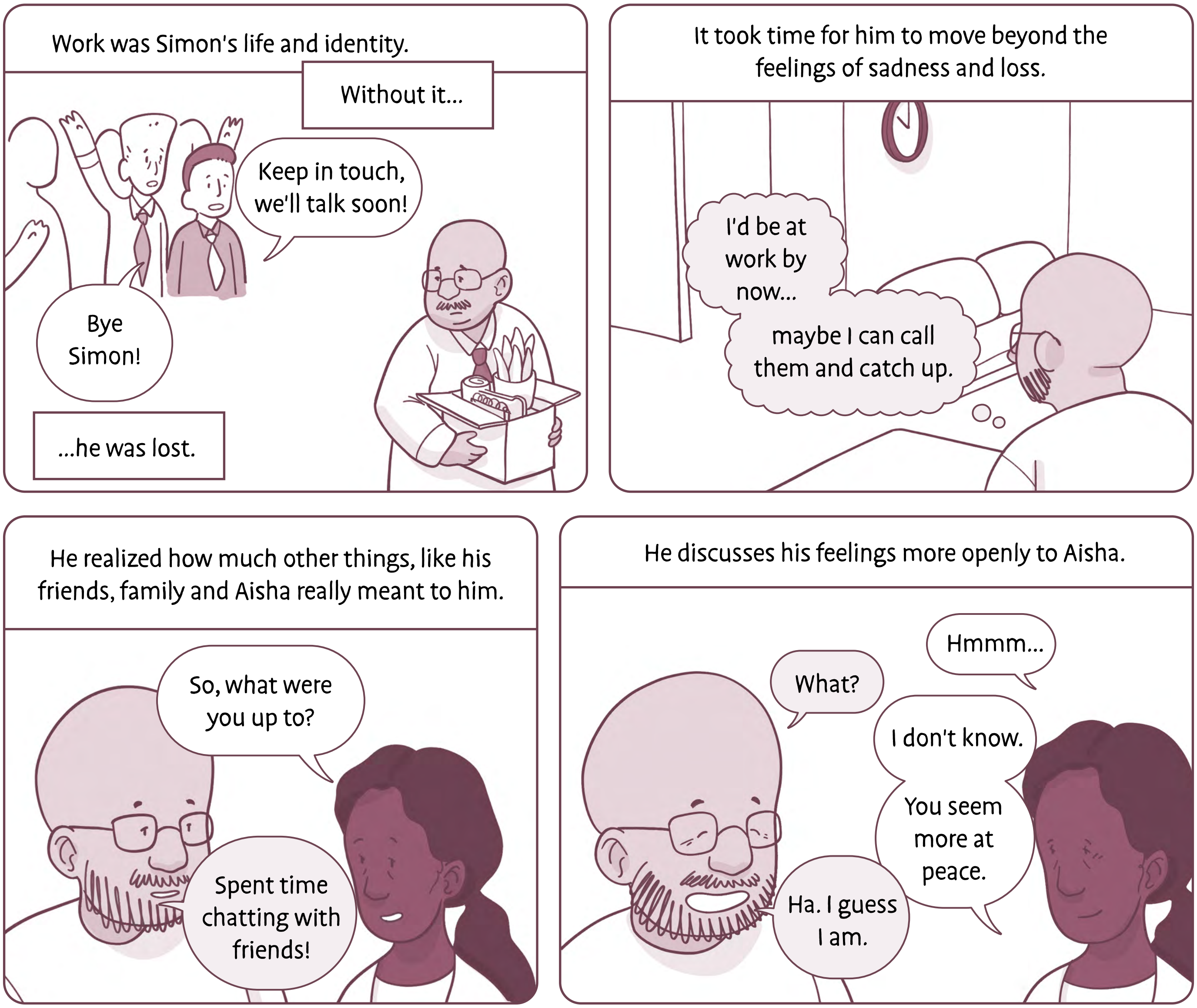
How do people close to you help you to achieve your goals?

Do your values and goals sometimes differ significantly from them?

Have you and the person you care for ever talked to the health care team about values and life goals? Do you think this could be helpful? Why or why not?

Simon's Story

Simon is 37 years old and has advanced colon cancer. Before being diagnosed, he worked in asset management at a bank.



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 3: Re-evaluating Meaning, Purpose, Values and Goals

Life Goals Before and After Cancer

- A cancer diagnosis often disrupts long- and short-term goals, shifting what feels important or achievable.
- What once felt like a priority may fade, while new goals or values may rise to the surface.
- This shift affects both the person with cancer and their caregiver, especially if goals were shared.

Adjusting to Change

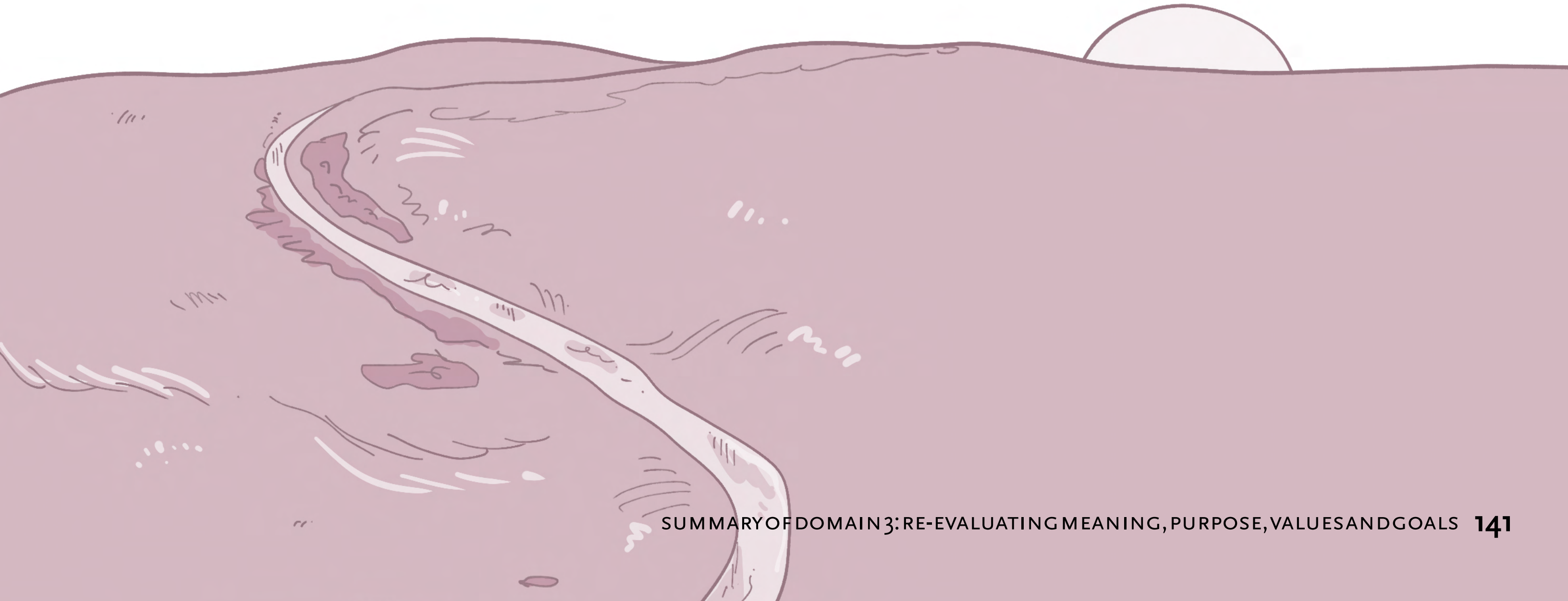
- Caregiving may require you to put personal goals on hold or redefine your future plans.
- It's natural to feel a sense of loss or sadness when long-held dreams seem out of reach.
- Creating new, realistic goals can offer a sense of hope, motivation, and renewed direction.

The Role of Values

- Values are the core principles that guide choices and actions—such as honesty, connection, or resilience, like a compass helping you navigate life.
- Reconnecting with your values can help anchor you during uncertain times.

Communicating Goals and Values

- Talking openly with the person you're caring for about both of your evolving goals and values can...
  - ○ Strengthen connection and mutual understanding
  - ○ Help with shared decision-making, especially around care and treatment
  - ○ Allow both of you to align your energy toward what matters
  - ○ It can also be helpful to communicate goals and values to the medical team, so they can tailor care accordingly



Domain 4

Thinking About the Future

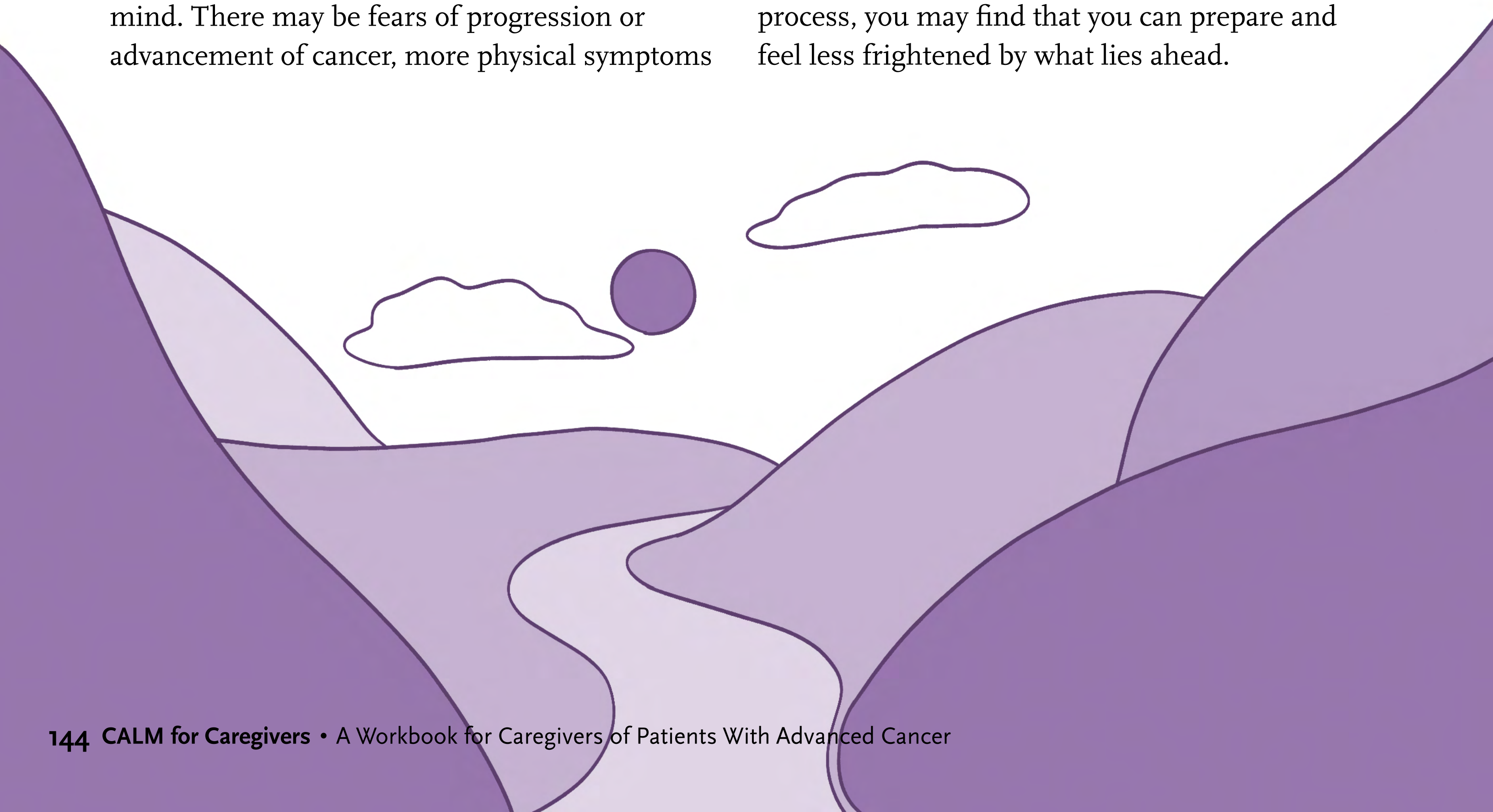
Domain ④

Thinking About the Future

People who are living with advanced cancer, and their caregivers, face many challenges that we have been reflecting upon throughout this workbook. These challenges may include distressing symptoms or the need to make treatment decisions, how to adjust to changes in appearance or physical capacities or in relationships with others, and how to find meaning and purpose while living with cancer. One of the most difficult challenges is looking to the future. This is not only because it may be unknown, and no one is able to predict what lies ahead with certainty, but also because there may be several different aspects of what is imagined ahead that might be frightening. In addition, those we often rely on to help us with our fears (i.e., friends, family, health care providers) might also be uncomfortable with discussing these topics. This can leave those with cancer and their caregivers feeling alone with their worries.

When people facing cancer imagine the future, there may be different scenarios that come to mind. There may be fears of progression or advancement of cancer, more physical symptoms or associated loss of ability, loss of independence, increasing reliance or "burden" on loved ones, a shortened lifespan, or end of life.

Many caregivers find these thoughts distressing. Some may begin to think about the future and then push these thoughts away because they are upsetting and find themselves going back and forth between states of avoidance and states of being overwhelmed. Some people may believe, or may be told, that it is best not to think about these distressing thoughts and that they should "stay positive" but find it impossible to do so. Our intention is not to suggest that people with cancer and their families must think or feel a certain way about their situation. Nor do we want to force people to consider what they are not ready or wanting to consider. What we have found is that these are thoughts and fears that many cannot avoid and that they may feel silenced and alone. We want to reassure you that thinking and wondering about the future is normal and that if you can be supported in that process, you may find that you can prepare and feel less frightened by what lies ahead.



Arriving at a Tipping Point

Concerns about the future, or “anticipatory fears”, may surface for caregivers and people living with cancer for different reasons. We have described this as a “tipping point,” when internal or external factors demand recognition of how advanced cancer is affecting life. To return to the analogy of travel or a trek, there may be various signs that cause us to pause on our journey and challenge us to see the way ahead. Checking the map for information about the upcoming terrain, wondering how much farther we have to go, daunted or even afraid that we might not be able to go on are all normal and common experiences.

When people are not experiencing physical issues such as fatigue or pain that serve as reminders of their cancer, they may carry on at times even forgetting they have a serious illness. We often hear patients say, "I feel so normal, but my doctors are saying that I am dying." When new or worsening symptoms are experienced, however, these may begin to interfere with functioning and also serve as a reminder of cancer, causing more persistent or recurrent worry, sadness, anger, or other negative emotions.

Those with cancer and their caregivers might begin to experience more anticipatory fears because of changes in functioning and/or loss of ability to engage in previously meaningful or distracting activities, increase or spread of cancer, when current cancer-targeted treatments stop being as effective, when family or friends express fears about cancer progression, and/or there are discussions with the oncology team about the course of treatment or referral to palliative care.

It is when caregivers and patients find themselves at this point, thinking and worried about the future either some or all of the time, that we find they may benefit from the sort of reflection and for some, the support of a mental health professional. Hopefully the stories and exercises here will support you in the self-reflection piece. If you feel speaking with a mental health professional would benefit you, we suggest either reaching out to the care team to ask about caregiver supports or getting in touch with your primary care provider (i.e. family doctor, nurse practitioner, naturopath etc.) to discuss what your needs and what resources are available.

Tipping Point

Can you identify a “tipping point” for you or the person you support or can you imagine a potential tipping point in the future?

Were there times since the cancer diagnosis when the person you support was more frightened of the future? What was going on at that time for them and for you?

What do you see when you look ahead? What do you expect your future to look like?

What have you been told about the cancer and the prognosis?

Do you have questions or concerns about what your future will be like?

What are some of the feelings that arise when you think about the future?

The Human Experience of Mortality

Birth and death are probably the two most significant events in a human life. For some, they represent the beginning and the end of our story and yet, while we are living our lives, we often don't think about the potential limits of existence. When we are confronting the reality of dying and death, this may pose questions for which there are no simple answers and this may trigger strong emotions.

When it seems that life may be shortened by serious illnesses such as advanced cancer, this can lead to a sense of urgency to address things we may have long put off. It may also lead to a heightened awareness of the precious and fleeting nature of life. This may bring positive emotions, such as love, hope and gratitude. On the other hand, the prospect of limited time, may also trigger feelings of loss, anger, sadness and worry.

Although these thoughts and feelings are common for caregivers and those they support, everyone's experience may be different. We are not proposing that there is a right or wrong way to feel when confronted with thoughts of dying. Your reactions and your family member's reactions may be complex, may fluctuate, and may contain multiple different and sometimes conflicting aspects at the same time.

Caregivers often also have fears about death and what their life may be like without the person they are caring for. Thoughts and feelings about life and death can be difficult to think about and sometimes even more difficult to speak about with others.

Listed below are several concerns that some caregivers and people with cancer may have at any stage of their disease[7]. The focus of these questions is on “distress” and by “distress”, we refer generally to negative feelings such as being angry, afraid, sad, or anxious. Think about these questions from the perspective of the person with cancer.

If there are many different negative feelings about one concern, choose the answer based on the strongest negative feeling. If you don’t think they have experienced the thought or concern at all, please circle "0-no distress". Please put a circle in one option per line. If you don’t know what they are thinking or feeling, you can leave the question blank.

Over the past 2 weeks, how distressed has your family member with cancer felt about...

Not having done all the things that they wanted to do

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

Not having said all that they wanted to say to the people they care about

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

Not having achieved their life goals and ambitions

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

Not knowing what happens near the end of life

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

Not having a future

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

The missed opportunities in their life

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

Running out of time

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

Domain ④

Being a burden to others

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

The impact of their death on their loved ones

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

Their own death and dying

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

Over the past 2 weeks, how distressed did you/they feel that their death and dying may...

Happen suddenly or unexpectedly

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

Be prolonged or drawn out

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

Happen when they are alone

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

Happen with a lot of pain or suffering

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

Happen very soon

0	1	2	3	4	5
no distress	very little distress	mild distress	moderate distress	great distress	extreme distress

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7. Lo C, Hales S, Zimmermann C, Gagliese L, Rydall A, Rodin G. (2011). Measuring death-related anxiety in advanced cancer: Preliminary psychometrics of the Death and Dying Distress Scale. Journal of Pediatric Hematological Oncology; 33(Suppl 2):S140-5

Debriefing…

How did you find answering these questions? Write down as many thoughts and feeling as you feel comfortable. Are these topics that you and the person you support have discussed?

You may also have thoughts or concerns about your family member's life being shortened by cancer, about the possible dying process, and/or what this means for you.

Considering some of your answers above, are these thoughts or concerns that you have had? If so, which of these is most distressing to you?

Have you shared these thoughts with your family member, anyone close to you, or with health care providers?
If not, why?

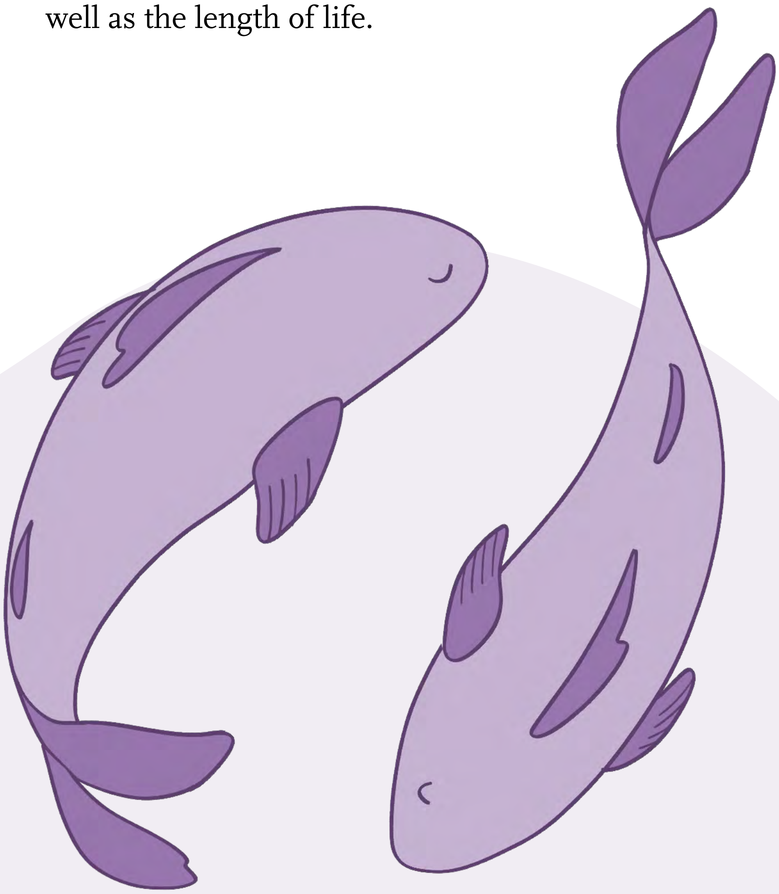
Living with Advanced Cancer: Balancing Hopes and Fears

People living with advanced cancer and their caregivers often feel as if they are living in two worlds at the same time, one within and one outside of the world of cancer. Cancer treatment may require much time and energy focused on appointments, scans, treatments, blood work, treatment side effects, and cancer symptoms. Many patients understandably feel that they must put the rest of their life on hold in order to save physical and mental energy to manage their disease. Others find ways to continue many or some of their former interests and activities and the same can be true for caregivers.

It is understandable that people with cancer may have fears about the future, and about dying and death. Sometimes mortality can be a threat to hope. Some people may feel that if they release their focus on treatments or a cure that they are "giving up hope". However, it is possible to face the future and to maintain hope or to reframe it in a realistic way. Some examples of reframing hope include hoping for meaningful interactions or hoping to engage in pleasurable activities that are still possible.

Double Awareness

It is possible to have sad or distressing thoughts sometimes and at other times feel joy and engagement in life. We use the term "double awareness" to describe the ability to hold both sets of emotions. It also refers to being able to live in the present, to be engaged in life but also to be prepared for what may come in the future. It can sometimes be challenging for people who are immersed in cancer treatment, which may involve many tests, investigations and hospital visits, to continue to be engaged in what is meaningful and satisfying in their life. However, this is a challenge which is important to address in order ensure that quality of life is a focus as well as the length of life.



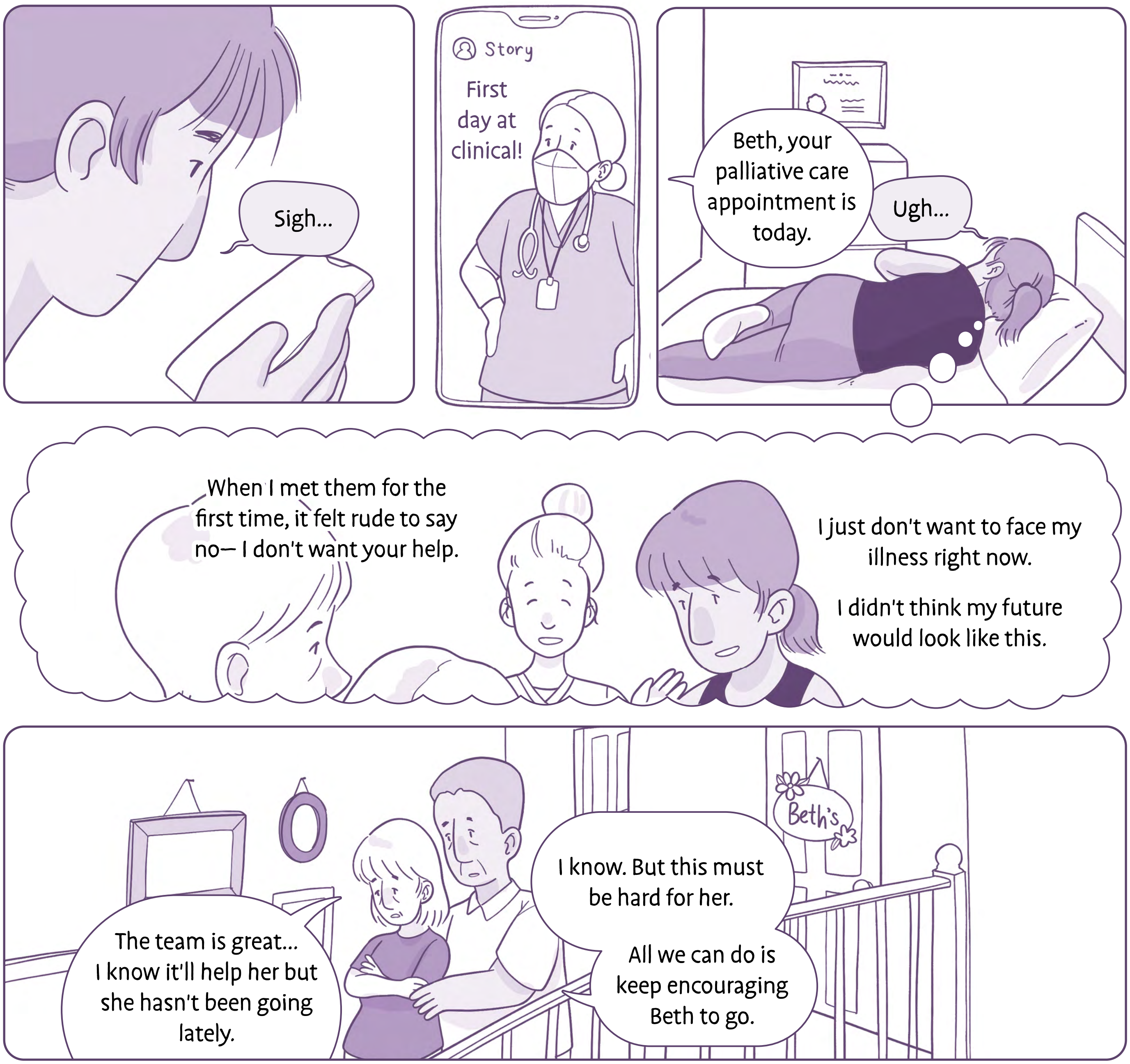
Omar's Story

Omar is a 57-year-old man who is married to his partner Gregory, and they have one teenage son together. He has been living with metastatic lung cancer for the past 2 years. His symptoms have been managed by chemotherapy.

In some ways, they have put their life on hold until Omar's treatment is over. However, some forms of treatment may continue for long periods of time. Many people with cancer ask, "How can I manage cancer and prepare for the future while at the same time engaging in life in a meaningful way?" Holding both goals in mind or moving back and forth between them requires double awareness.

Beth's Story

Beth is a 25-year-old woman with metastatic sarcoma which has recurred since childhood. As a young girl, she spent much of her childhood in a hospital receiving treatment. When her cancer went into remission, she told herself that she would live in the moment as much as possible. Beth is highly social and prioritizes spending her time with friends.



Both Omar and Beth are struggling with holding double awareness. For Omar, he's focused primarily on his treatment and diagnosis while missing out on participating in meaningful activities. On the other hand, Beth is avoiding thinking about advancing disease and potential future care needs.

It can be difficult to hold double awareness. Different members of a family may also hold different perspectives at different times. Although this can be challenging, sometimes talking about these differences together can encourage everyone to consider different perspectives and goals.

Your Experience and Double Awareness

Can you reflect on the concept of double awareness and if it applies to you your experience? If yes or no, how so?

Do you find that the person you support is having difficulty engaging in life now (like Omar) or that they cannot allow themselves to consider the future (like Beth)? Or perhaps their outlook changes or fluctuates depends on their circumstance.

How about you? Do you find it difficult to hold double awareness?

Can you reflect on the ways you and the one you support are currently engaging in life? Is there anything you would want to do differently in order to live life as meaningfully and with as much quality as possible under the current circumstances?

Your Experience and Double Awareness

Can you reflect on ways you both are thinking about the future and preparing for what lies ahead, both practically and emotionally? Do you find it hard to do this?	Do you have concerns about the future? If so, have you discussed your concerns with anyone? Is there anyone that you believe would be able to listen to and support you with your thoughts and emotions?

The challenges we have been exploring in this section (the uncertainty of the future and the difficulty of considering mortality) are problems that all of us face. For those living with an advanced or life-limiting illness, however, they may not be as easily ignored. Working with our patients and their families, we have found that most have benefitted from an opportunity to discuss these concerns in the context of a supportive relationship. We hope these exercises may have helped you to reflect on these concerns and may help you in communicating about these issues with close others.

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 4: Thinking About the Future

Facing the Unknown

Thinking about the future with advanced cancer can feel frightening, uncertain, and isolating—for both patients and caregivers. Thinking and wondering about the future is normal and when supported (by friends, family, medical professionals), you may find that you can prepare and feel less frightened by what lies ahead.

A Tipping Point...

often comes when we're thinking and worried about the future either some or all of the time ("anticipatory fears"). This can be challenging, consider what you may need and if you may benefit from the support of a mental health professional.

Anticipatory Grief

Caregivers often begin grieving before loss occurs. This emotional process may involve sadness, anger, or anxiety about what lies ahead.

Mortality Awareness

Confronting mortality can bring a mix of emotions—urgency, sorrow, gratitude, or love. Everyone processes these feelings differently, and that's normal.

Balancing Hopes, Fears and Quality of Life

It's possible to maintain hope even while acknowledging serious illness. Hope can be reframed—from hoping for a cure to hoping for comfort, or meaningful moments, or peace. Quality of life is a balance of managing illness while maintaining meaningful daily experiences—for both caregiver and patient.

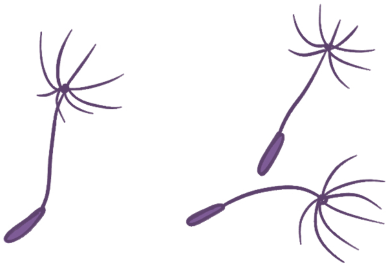
Double Awareness

Refers to being able to live in the present and be engaged in life but also to be prepared for what may come in the future.

Seek Support...

if fears and distress become overwhelming, consider talking to a mental health professional or asking your care team about caregiver resources.

Domain 4



Planning for the Future

Planning for the Future

This section will review the potential challenges and benefits of planning for the future, introduce the idea of advance care planning, and providing an opportunity to consider what you and your family member may want in the future, **pg.160**

What is Palliative Care?

This section will provide information about the scope of palliative care services and what you could expect from involvement with palliative care, **pg.168**

The Process of Considering a Good Death

This section will explore the concept of a good death and what that may look like for the person you support, **pg.171**

Grief and Bereavement

This section will discuss the normal range of responses to anticipated and experienced loss, **pg.179**

Summary

Two-page summary for this section, **pg.183**

Domain ④

Planning for the Future

In the last section, we considered potential fears related to thinking about the future and arriving at "the tipping point" where addressing these fears may be unavoidable.

As mentioned, some people may feel overwhelmed with fears of death, suffering, burdening or hurting loved ones, losing independence or dignity, or what may happen near or at the end of life. Sometimes these fears crowd out positive thoughts about the possibilities of life that remain. At times, these thoughts and feelings can be so scary that people diagnosed with cancer make a conscious (or sometimes unconscious) decision to avoid thoughts about the future at all. This strategy of avoidance may work at times, but as disease advances this may become less feasible.

Similarly, for caregivers of patients with cancer, thinking about the future can be difficult. For some, thinking about the future and making plans about end of life may feel like giving up hope. Some caregivers experience the double burden of anticipating the possible end-of-life phase while also anticipating the future without the person they have been a caregiver to.

Even when people want to discuss this with others, they may feel that it is not possible to do so. Patients and caregivers alike may avoid talking about the future for many reasons, including fears of diminishing hope for the future or causing distress to themselves or others.

In our research and clinical work, we have learned from patients, their caregivers and other loved ones that thinking and talking about fears and difficult feelings can be helpful, especially if done with guidance and support. This process can make these feelings more manageable and help to prepare for what may lay ahead.

Some of us move through life not thinking much about the future while others may be planners, focused more on future goals than the present moment. In the last module, we described "double awareness", which means planning for the future while also living in the present. We reflected on the challenges associated with this for those with advanced disease, their caregivers and other loved ones including the difficulty of confronting mortality-related fears.

In this section, we will further explore steps to planning for the future, including advance care planning and palliative care. We hope this module will give you space to think about the goals and wishes of the person you are caring for, as well as your own. It may also help to facilitate conversations between both of you, and the healthcare team.

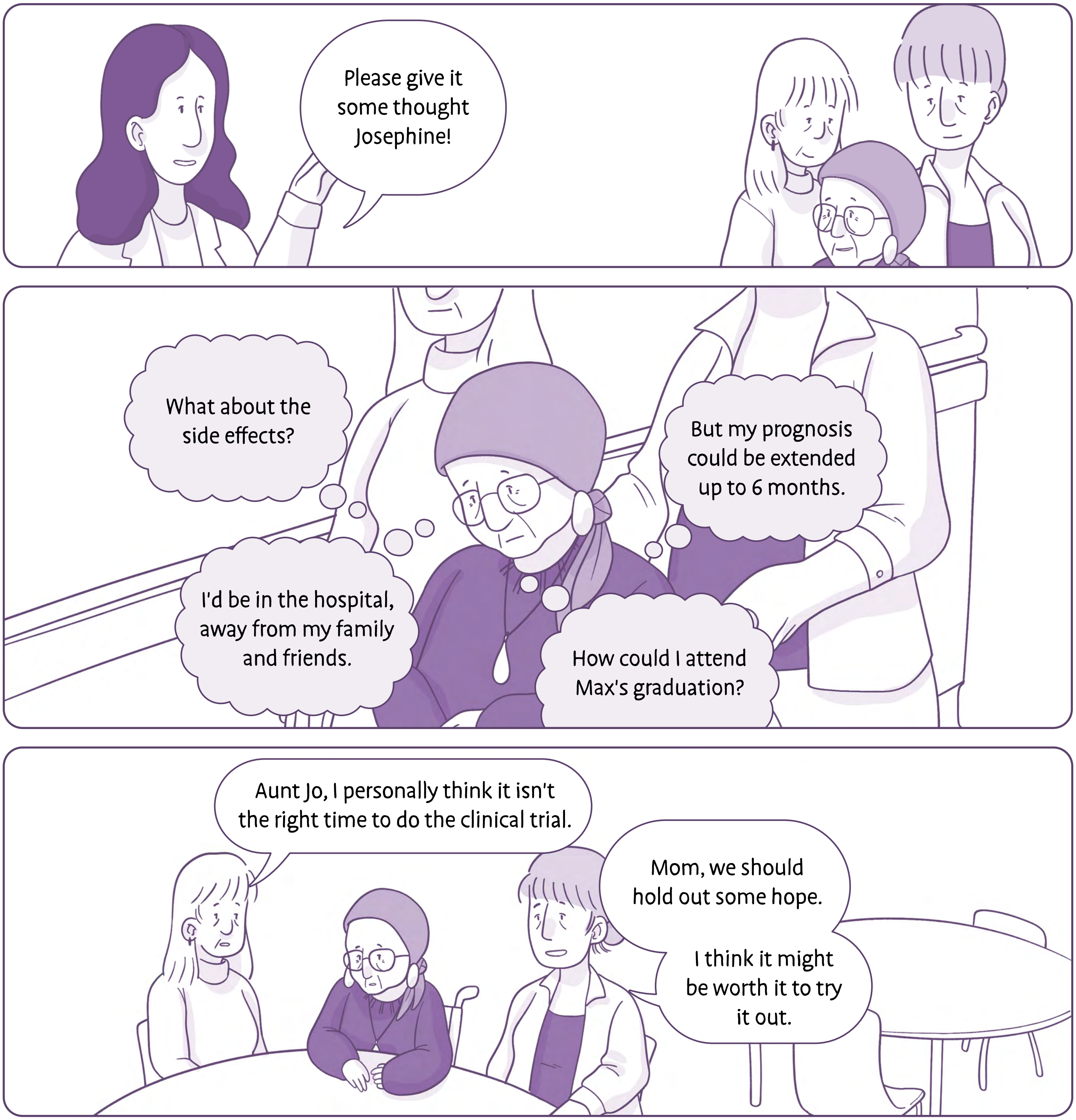
Are there aspects of future planning that are particularly challenging to discuss with the person you are caring for? If so, what are they?

What potential benefits might there be to speaking openly about these issues?

What potential risks might there be to speaking openly about these issues?

Josephine's Story

Josephine is 72 years old and lives with the diagnosis of stage IV breast cancer. Josephine's chemotherapy has stopped working and her oncologist has suggested that she consider a clinical trial. The thought of making these plans feels overwhelming and she isn't sure which path is the right one.



Advance Care Planning

As cancer progresses, the person you are caring for may experience more physical symptoms and become less able to work, travel, care for others, or engage in physical and social activities. In the first domain, we discussed how these changes can affect self-esteem and mood. Thinking about potential future health issues can be difficult but may also reduce some anticipatory anxiety and provide a greater sense of control.

"Advance care planning" is the process of making important decisions about the future while still feeling well and able to engage in these discussions. For patients, planning in advance may include choosing the person who could make decisions on their behalf if they are unable to do so. It may also mean making necessary financial decisions and planning for potential future care needs or having conversations with loved ones and the medical team so that everyone is aware of the patient's goals and priorities.

Here are some suggested aspects of advanced care planning that you and the person you are caring for may wish to consider together. Patients may:

- Think and reflect about what makes their life meaningful
- Discuss their values, wishes and goals with their family and loved ones
- Talk with their healthcare team about their values and goals
- Record their wishes and decisions (required documentation may vary by location and healthcare setting)
- Make decisions about their future care, including: What treatment or care they would or would not want; Who they trust to make these decisions for them if they're not able to speak for themselves (we will talk about this in the next section).

Once these important decisions are made, patients often feel a sense of control about their future because, if they should become more ill, they have already considered how to proceed.

For caregivers, advance care planning may mean supporting the patient to make these decisions in advance and executing these wishes when the time comes. These conversations can bring up difficult emotions and grief about the future; however, having these conversations may help you feel more prepared and lessen the strain in the future.

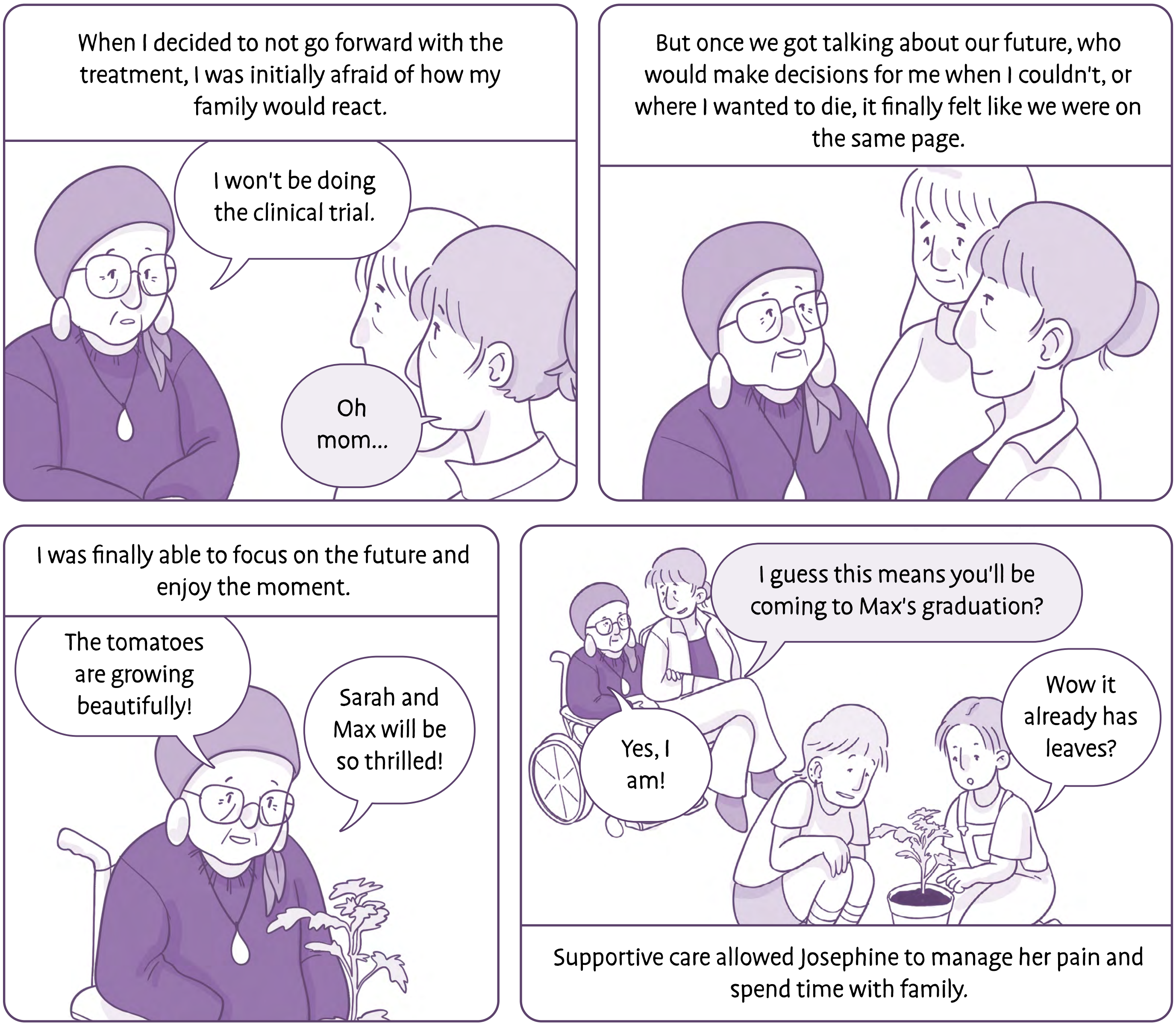
Advance Care Planning

Have you discussed future care wishes with the person you are caring for? If so, what is your understanding of their future care wishes?

Have you discussed which activities or goals are most important if you both learn that there is less time left? And if so, how have these discussions been for you?

Josephine's Story continued

Josephine spent a lot of time weighing the pros and cons of her options.

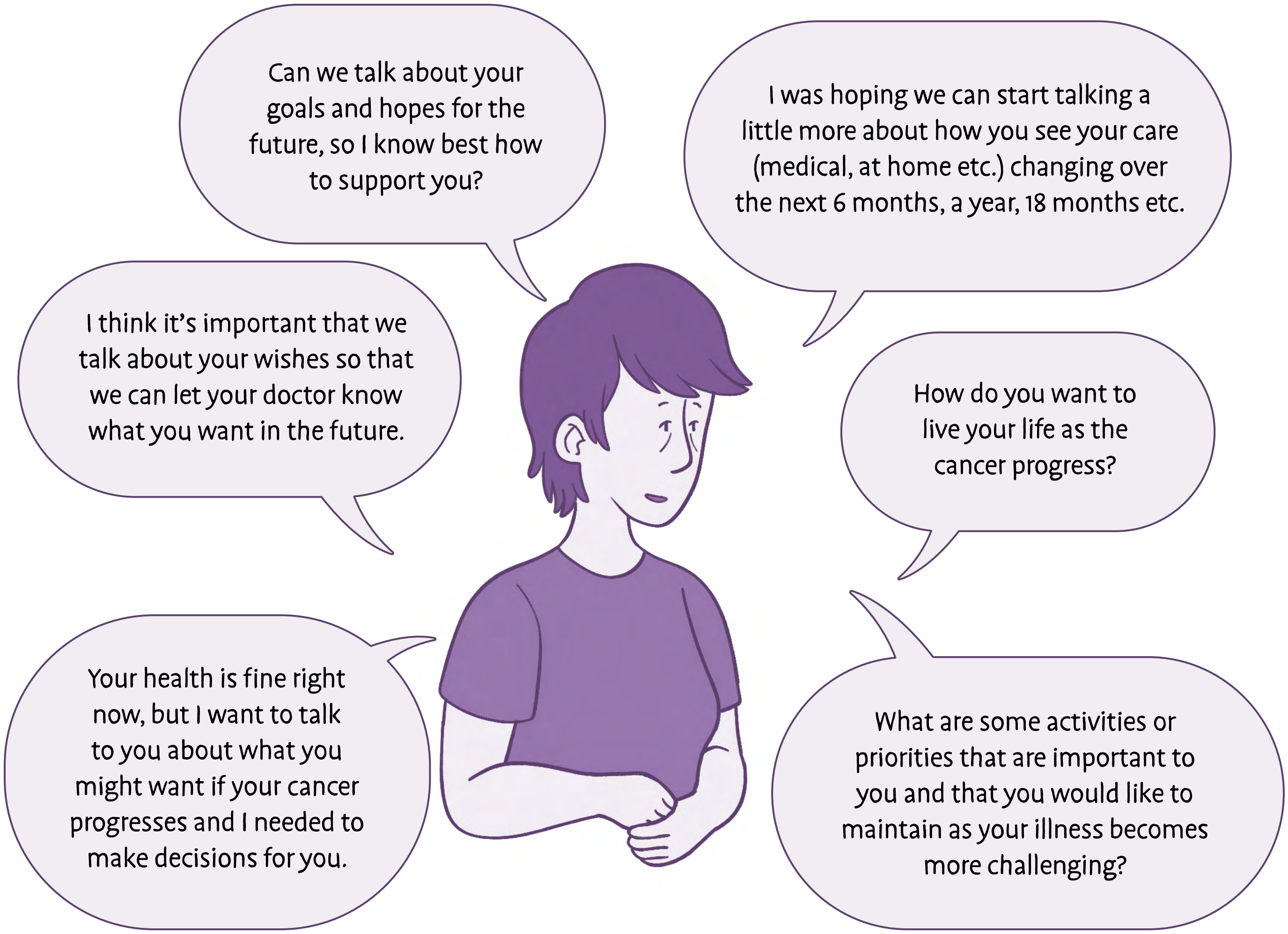


Initiating Advanced Care Planning Discussions

As we've discussed, advance care planning involves understanding the values and wishes for the future that the person you are caring for has and communicating them to important people such as their healthcare team and their circle of care. Sometimes people with cancer, their loved ones, and/or their medical team, are reluctant to discuss such issues, although discussing these topics may relieve anxiety and increase preparation for what the future.

Importantly, advance care planning is an on-going process. These wishes and preferences are not only personal and individual, but also may change with shifts in values, priorities and the experience of advancing disease and treatments. This means that it's important to continue to have these discussions over time.

When initiating conversations about advanced care planning (or any difficult subject) it is always important to ask the person you are caring for if they are wanting and ready to have a conversation and if not, make a plan to have the conversation at a later date. Multiple conversations will be needed, so plan to pace the discussions over time and be prepared to revisit the discussion as often as is needed. It may also be a good idea to make notes that both of you can review, to ensure a solid mutual understanding.



Substitute Decision Maker and Attorney for Personal Care

One important consideration in the advance care planning process is deciding who will be named the substitute decision maker. A **substitute decision maker** is someone who can legally make decisions on a patient's behalf if they are incapable because they are too ill to participate in the informed consent process with the health care team. In many places, there are rules about who is automatically considered a patient's substitute decision maker if that person is not specified in advance. You should check on the rules about the automatically determined substitute decision maker where the person you are caring for lives. This person might be responsible for decisions about treatment, admission to long term care homes, and other aspects of care.

As a caregiver, it's important to have conversations with the person you are caring for about who will be considered the substitute decision maker. If you are named or automatically considered the substitute decision maker, then you will be contacted by the health care team and asked to make decisions on their behalf if they are unable to do so.

Many people feel significant anxiety about being named the substitute decision maker. In most jurisdictions the substitution decision maker is expected to base decisions not on what they would want but on what the patient would want if they were able to decide. Therefore, it's important for substitute decision makers to know the patient well and know what their health care priorities and decisions would be. Having discussed wishes explicitly ahead of time can reduce the pressure on caregivers and ensure that the patient receives the care that they would have wanted.

If you are the advocate or substitute decision maker, how do you feel about your role in treatment decision making?

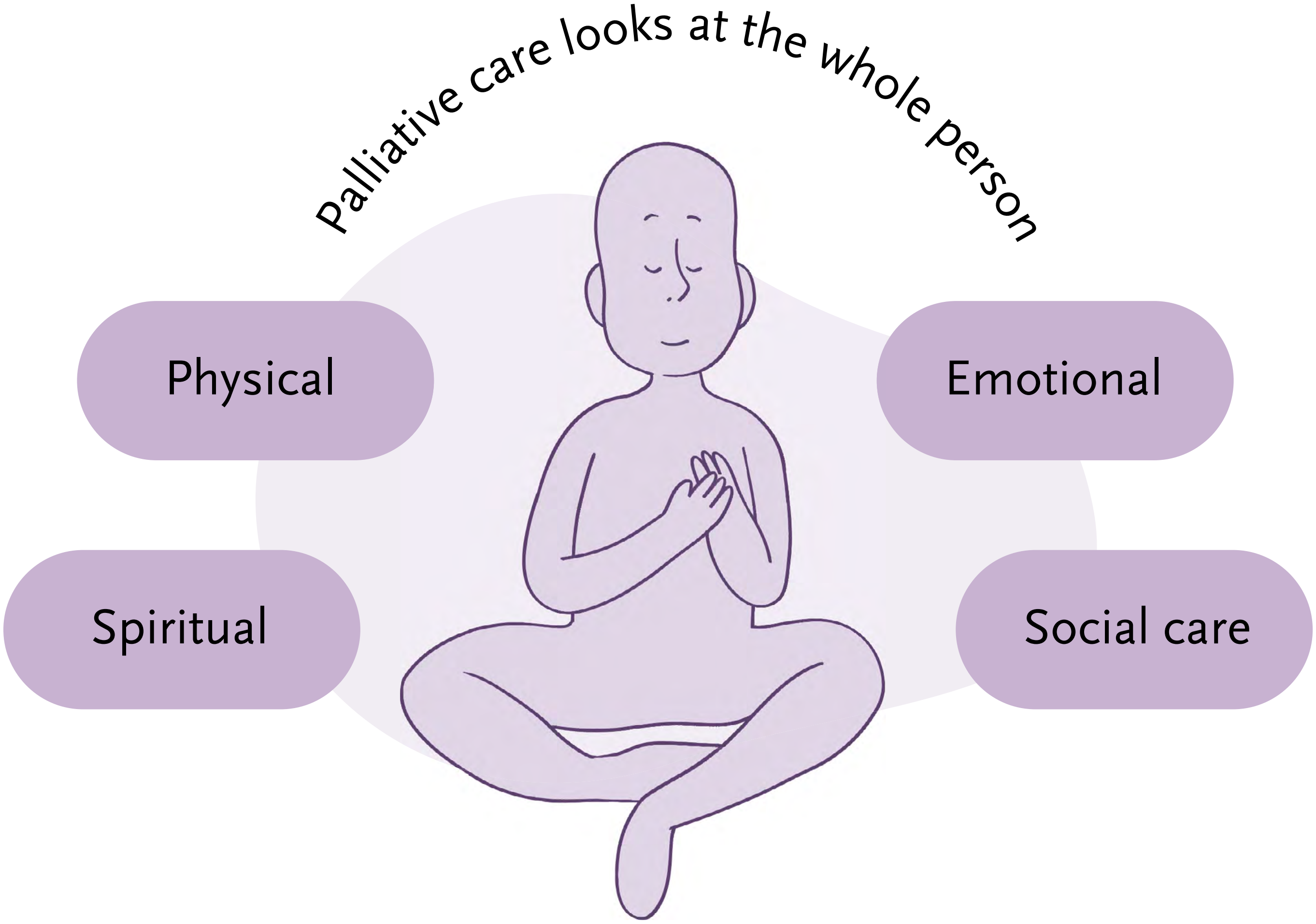
Do you feel prepared for this? If not, what would help you to feel more prepared?

What is Palliative Care?

Palliative care is a type of care that focuses on the **whole person**. This includes physical, emotional, spiritual, and social care, with the primary goal of improving quality of life in patients with serious diseases. Many people know that palliative care can include relief of suffering from pain or other physical symptoms, but it can also attend to emotional/spiritual/social concerns, support treatment planning, and prevent new symptoms from occurring.

For some people, "palliative care" has the same meaning as "end-of-life care". However, modern palliative care may begin from the time of diagnosis. Research has shown that early palliative care can increase quality of life, reduce depressive symptoms, and in some cases can help people live longer.

Palliative care looks at the whole person, including physical and emotional symptoms, considers the needs of the patient and their family, and focuses on how to achieve the best quality of life in the present and on how to plan for the future.



Who, What, Where, When, Why, and How of Palliative Care

Who

Palliative care is for:

- Patients and/or caregivers
- Any stage of illness or any age

Palliative care can be delivered by:

- A primary care team or a palliative care team, which may include: doctors, nurses, social workers, occupational therapists, physiotherapist, pharmacists, spiritual care providers, dietitians, psychiatrists, psychologists, music therapists, respiratory therapists, speech language pathologists, volunteers, home and community care coordinators
- You can read more about the roles of these professionals in Domain 1

What

Palliative care may include, but is not limited to:

- Medical care to reduce or prevent suffering or pain from symptoms, side effects, or from the disease
- Support for medical decision making
- Emotional support such as individual or group therapy or support groups
- Spiritual care
- Practical support such accessing assistance in the home

Where

Depending on the type of support both of you wants or needs, palliative care can be delivered at:

- A medical clinic or unit in the hospital
- A palliative care clinic or unit in a hospital
- A primary care doctor's office
- At your home
- A residential hospice in the community
- A long-term care or nursing home

When

At any time in the course of the disease, and when physical or emotional symptoms are affecting quality of life.

Why

To improve overall quality of life and to help patients and families prepare for the future.

How

There are many ways to access palliative care, depending on where the person you are caring for lives and receive medical care.

- If they are receiving treatment at a hospital or assisted-living facility, you can ask your health care team for a referral to palliative care.
- If they are in your own home or in a retirement residence, you can ask your family doctor.
- You can also call Home and Community Care services and ask about available services

Palliative Care

Have you or the person you are caring for considered palliative care? Why or why not?

If the person you are caring for is currently being seen by a palliative care team, what has your experience with palliative care been like so far? Is there anything needed now that isn't in place?

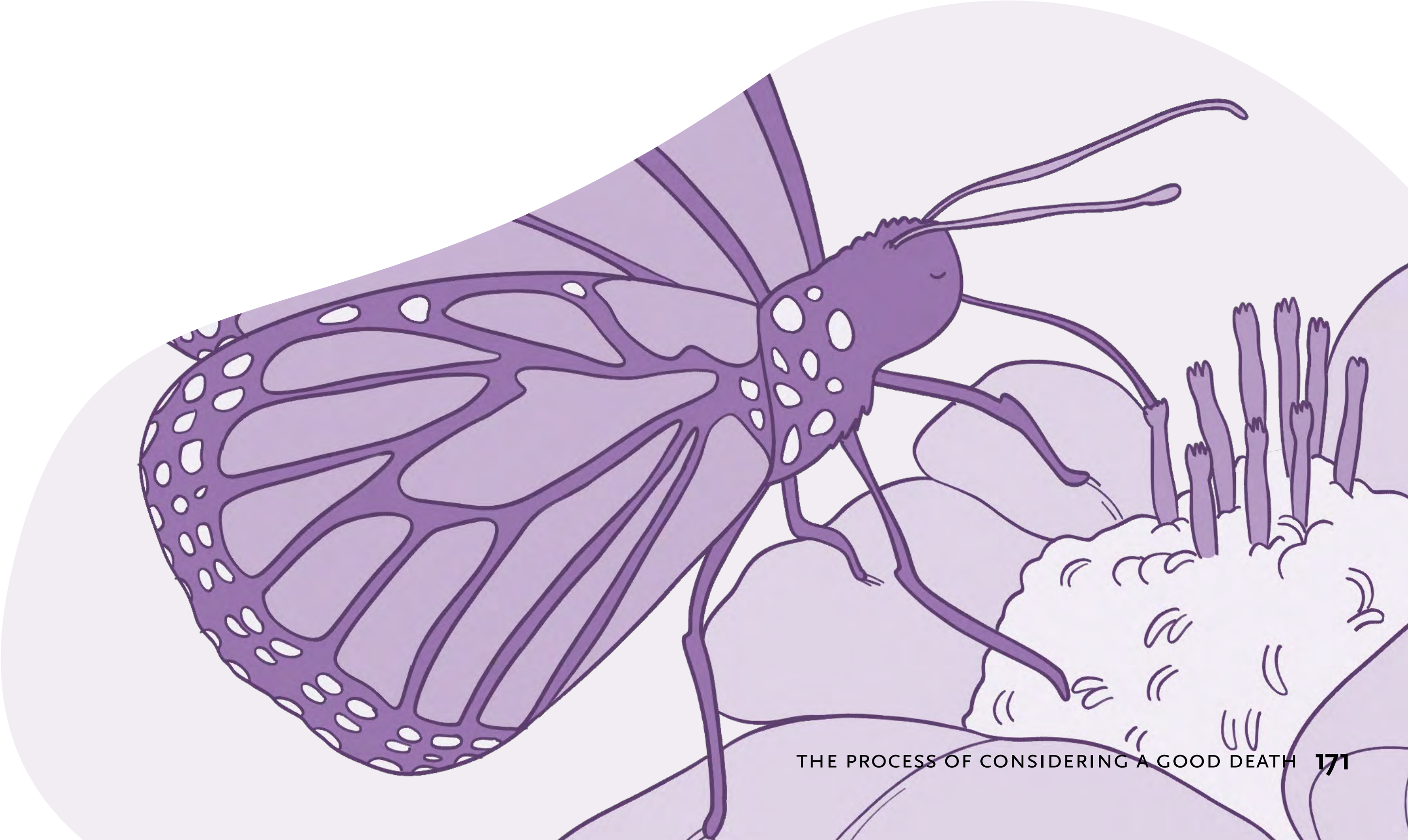
What do you and the person you are caring for hope to get from palliative care?

The Process of Considering a Good Death

The ways that individuals approach end of life, and their wishes and plans for this phase of life, are highly individual. There is no one “right” approach and choices may be influenced by one’s personality, their past experiences, their family, their culture and social context. For instance, some people may prefer to maintain independence as long as possible while others may want to draw their support system close and not be alone. Some people may wish to speak openly about dying with their friends and family, to have an opportunity to say goodbye and have some life closure, while others may be uncomfortable with this kind of communication. It is also possible that wishes and preferences may change over time.

Some people with advanced disease are concerned about what the process of dying and death will be like and they may want to know what to expect and how to plan for this. There are different aspects of end of life that may be of importance to them, including the location of care (for instance whether they want to be at home, hospice, palliative care unit or another location entirely) and who they would like to have involved in caring for them. For some, these wishes and preferences may be influenced by past experiences of dying and death which might have been positive or negative.

Many caregivers feel responsible for helping to facilitate the best possible death for the person they are caring for. This can be a meaningful and positive experience but can also lead to feelings of regret or guilt if end of life does not, end up playing out as everyone had hoped. It is possible that circumstances may limit options in some cases. For instance, many patients indicate they would prefer to die at home, if possible, but if symptoms are not well controlled at home, they may require admission to a palliative care unit or hospice at the end of life. While this may not be what had been planned for, we know from research that these can still be good death and a positive experience for patients and their families.



Domain ④

Reflection

Here are some questions that may help you to discuss end of life with the person you are caring for.

What does a good death look like to you? Some aspects to consider include, where would you want to be? Who would you like to have present? Are there end-of-life religious or spiritual rituals important to you?

In the past, have you experienced death you thought was or was not handled or planned well? What were the aspects that were positive or negative?

Here are some questions that may help you to discuss end of life with the person you are caring for.

Are there conversations to have or arrangements that we could make in order to facilitate the best possible end-of-life experience?

Do they have any requests regarding funeral arrangements, celebration of life of other ceremonies?

Trajectory of Dying

What does dying look like? How long does it take? How will we know how much time is left or when the end is near? These are all common and normal questions to be considering. Although every death is a unique and intimate experience, there are some commonalities that can be helpful and reassuring to know ahead of time. It is hard to assess when the trajectory of dying 'begins'. Many palliative care clinicians see the dying phase as the very end of life when individual's physical state is deteriorating over the course of days or hours. This process does not always follow a straight path but might have twists and turns, hills and valleys and periods of plateau along the way.

Often medical team can provide a **prognosis**, which is an estimate of the likely course of a disease. A prognosis is typically given in hrs to days, days to weeks, weeks to months or months to years and may help you and the person you are supporting know approximately how much time is left but it is not an exact science and can vary because of many factors.

What to Expect?

Knowing that someone you care about is dying can be emotional. Knowing what you can expect to see, feel, and do can give you some comfort and peace of mind. Dying, is a different experience for everyone. However, there are some common things that may happen to the person you are caring for and knowing what they are can help you cope and support them.

Here are some physical changes you might notice and how you can support the person you are caring for:

Pain/Discomfort - may occur, you may also notice swelling in the arms or legs and for some swallowing may become difficult. If you notice signs of pain (e.g., moaning, frowning, restlessness), let the healthcare team know. You can also consider non-medical pain relief methods like massage or relaxation therapy.

Energy – low energy, increased tiredness, reduced talking and moving and increased sleeping are things you may notice. You can offer comfort through gentle touch, being at the bedside, and talking softly or playing calming music. Keeping the noise levels low and pacing any visitors can be helpful.

Vision – maybe reduced or blurry and the person you are caring for may sleep with their eyes slightly open. If this makes their eyes dry, nurse or pharmacist can show you how to give your loved one eye drops. This will keep their eyes moist.

Appetite, Hunger and Thirst – the person you are caring for won't want to eat or drink very much or often and when they do it won't change their energy or strength. You can offer favourite foods, drinks or ice chips when they are awake, and the head of the bed is raised. You can also use mouth swabs or moistures spray to help when their mouth is dry.

Skin - may feel warm at times but become cold as circulation slows, you can adjust blankets to help keep them comfort.

Breathing – will start to change and might be quicker and not as deep and as the person you are caring for nears death, they might have periods where breathing stops, and these periods will get longer as they near death. They may start making noises from your throat because there is extra saliva in their throat or the muscles in their tongue and jaw begin to relax.

Bowel/Bladder - the person you are caring for might urinate less or the colour of their urine might change as their kidney function slows. They may also lose control of their bowl or bladder as muscles become more relaxed. You can let the care team know if you think the person you are caring for needs to go to the bathroom or could benefit from incontinent products.

Confusion and Restlessness – the person you are caring for might experience confusion, seeing things that aren't there and or restlessness. If you find this happening speak calmly and softly, remind them of familiar and comforting details. You can also speak to the care team about medication that can help them feel calmer.

Emotional Changes - It is common for both you, the person you are caring for (and close others like friends, family etc.) to have changing emotions as death nears. Feelings of anxiety, fear, anger, sadness, guilt, embarrassment, grief/loss or the desire to be alone are common. There are some things that you and the person you are caring for can do to help each other feel better, like sharing your feelings with each other, reminiscing about shared times, finding familiar things to have nearby that bring comfort (blanket, photo or music), supporting each other through touch (holding hands, hugging, laying together), utilizing music therapy, social work or spiritual care services or even calming exercises you two can share or do individually (deep breathing, meditation).

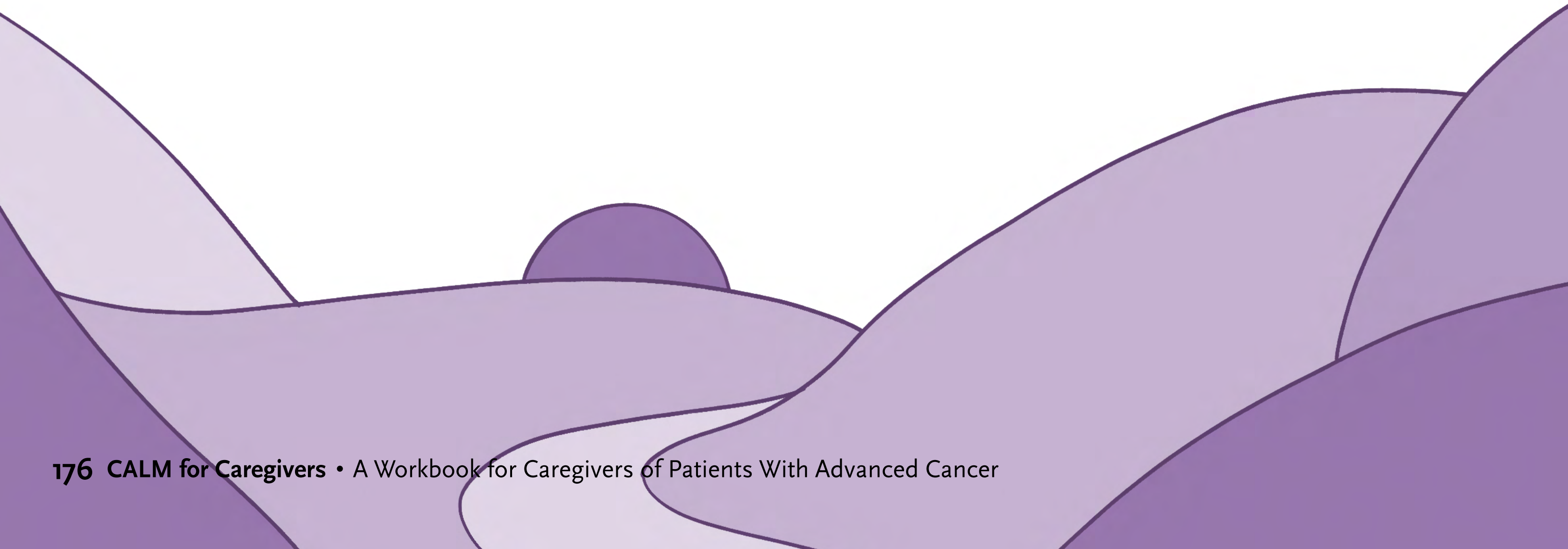
If you feel like you need more help with your emotions, please ask the health care team, they can tell you about hospital and community supports available to you.

Knowing Death is Near - as death nears, your loved one will no longer respond to your voice or touch. You can still talk to them as if they can hear you. They may still be able to understand what you say or recognize your voice. Moaning is common in the last days of life, if you are worried about it make sure to discuss it with the health care team. As the person you are caring for nears death they may stop breathing for several second, this is normal and causes no distress to them. No one can predict exactly when death will occur but asking the health care team about changes you are noticing can help to understand when death is close.

How will I know when they have died – this might be obvious or something that happens without anyone noticing but at some point, breathing will slow to a stop as will their heartbeat, and there won't be a response to voice or touch. Their eyelids may be slightly open with their jaw relaxed. Your loved one’s body will remain in the hospital until the funeral home picks them up. The doctor will complete a certificate of death. This certificate will go with the body to the funeral home. The funeral home will provide you with copies of the death certificate.

It is important to remember that not all these things will be experienced by everyone, and some may be experienced at a different time then what has been indicated above. If you are worried about any signs or symptoms, reach out to their health care team. If you or the person you are caring for would like to know more about what this phase of illness might be like, this may be a conversation to have with your oncology or palliative care team.

Note
The following is an optional section on medical assistance in dying sometimes called MAiD which is legally available in some jurisdictions.



Medical Assistance in Dying (MAiD)

Medically assisted death is a controversial topic. It is legal in several countries with different terminology and different practices depending on the jurisdiction. In most places where it is legally available, there is first a process of assessment during which health care provider(s) assess whether the patient meets the legal criteria for medically assisted death. The assisted dying intervention may involve providing or prescribing a lethal substance that the patient administers themselves or it may involve the direct administration of a lethal substance by a health care provider. This may be offered at home, in hospital, in a palliative care unit or hospice. Thoughts of or consideration of assisted dying is quite common but even where it is legally available, most patients do not die with medical assistance. For some patients, just having this option available as a last resort is reassuring and provides a sense of control.

Assisted dying assessments focus on the wishes of the patient, but as with other health care decisions, family and friends of the patient may have their own thoughts and feelings about this choice. As with other aspects of health care decision-making, open conversation within family/friend networks about different perspectives, hopes and wishes, can often facilitate mutual understanding even if there is not, in the end, agreement on these decisions.

For many patients and families, a medically assisted death allows for planning for the specific time and place of death and more control over who will be there and what will happen. This also gives family and friends time to prepare and an opportunity to say goodbye or share specific thoughts and feelings with one another.

Reflection

Here are some questions that might help facilitate understanding and/or discussion about assisted dying.

Why are they considering assisted dying? And for how long?

What are their thoughts and feelings about it?

When or at what point do they think they would want to pursue this? Do they want any help/support in planning or preparing for this?

Is there anything you would like to say, do or share with the person you are caring for before there death?

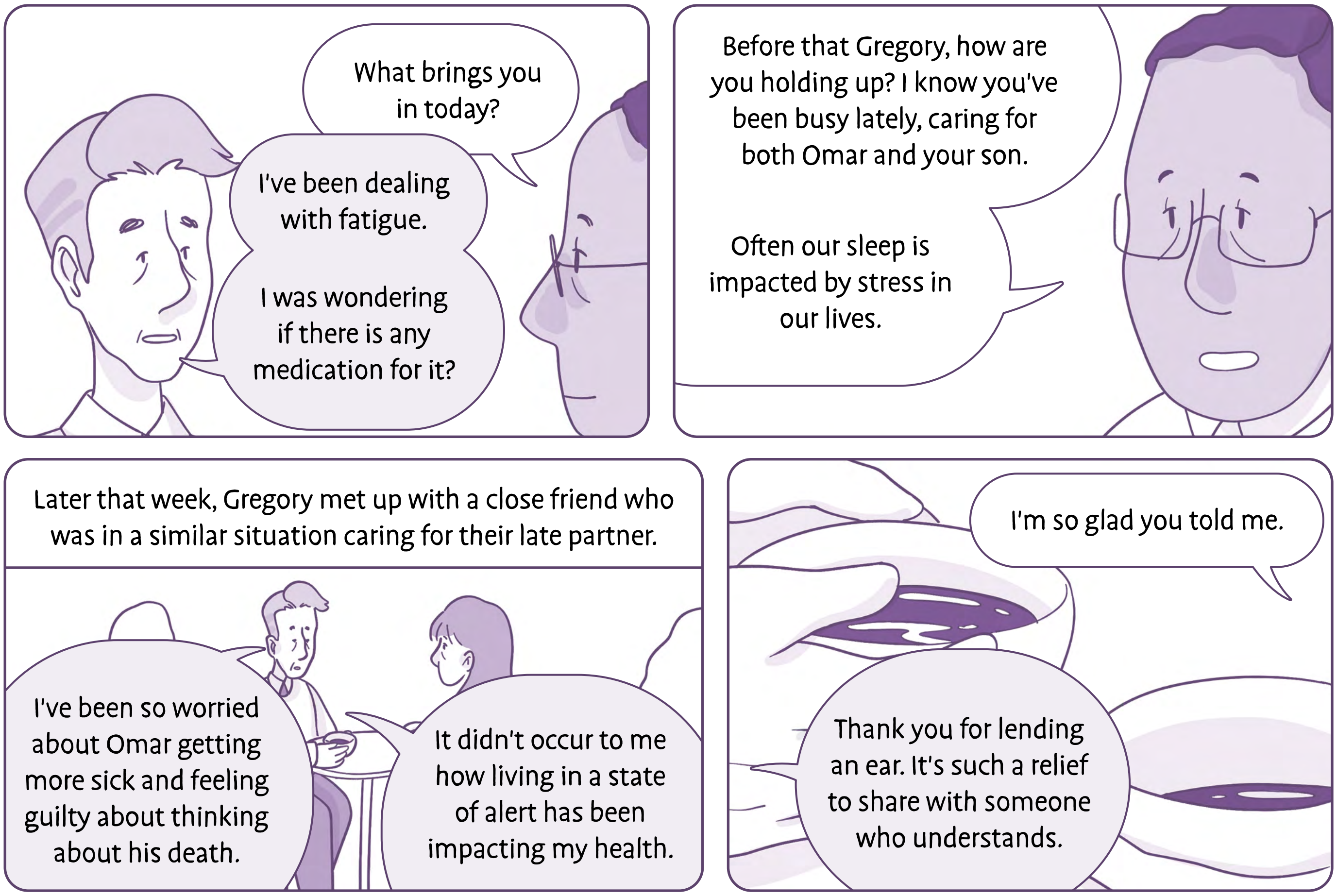
Grief and Bereavement

Grief is a normal psychological response to loss and is a process which often begins even before loss has occurred, like when someone has a life-threatening illness such as cancer. It can involve different fluctuating feelings of anxiety, emptiness, sadness, fear, anger, guilt, yearning, numbness. The intensity of grief-related feelings can vary and may at times feel manageable and at other times intense or overwhelming.

It is normal for caregivers to think about and to emotionally prepare ahead of time for loss. For some people, there may be shame or guilt about having these thoughts or trying to prepare for a future without this person. They may feel alone in these thoughts and unable to share them with others. In the last module we reviewed the concept of "double awareness" which involves thinking about the possibility of dying while also remaining focused on life and living in the present. For caregivers, another kind of "double awareness" involves both preparing for possible loss while at the same time staying connected to the person they are caring for in the present.

Gregory's Story

Omar is a 57-year-old man who is married to Gregory and they have one teenage son together. Omar has been living with metastatic lung cancer for the past 2 years and is maintained on chemotherapy.



Reflection

Here are some optional prompts to help support reflections on grief and bereavement.

If you think about the loss of the person you are caring for, what do you imagine that life will be like for you?

What is most upsetting about this imagined future?

You might want to begin by just jotting down thoughts or ideas or images that come to mind, even in point form. It is also fine if you don't know or do not want to think about this at this time. You do not need to answer these questions and there are no "right" answers. These are prompts to help support reflection about these issues.

Who do you imagine you will lean on or rely on?

Who will be able to help you during this time both practically and emotionally?

How have you coped with other losses or major crises in the past?

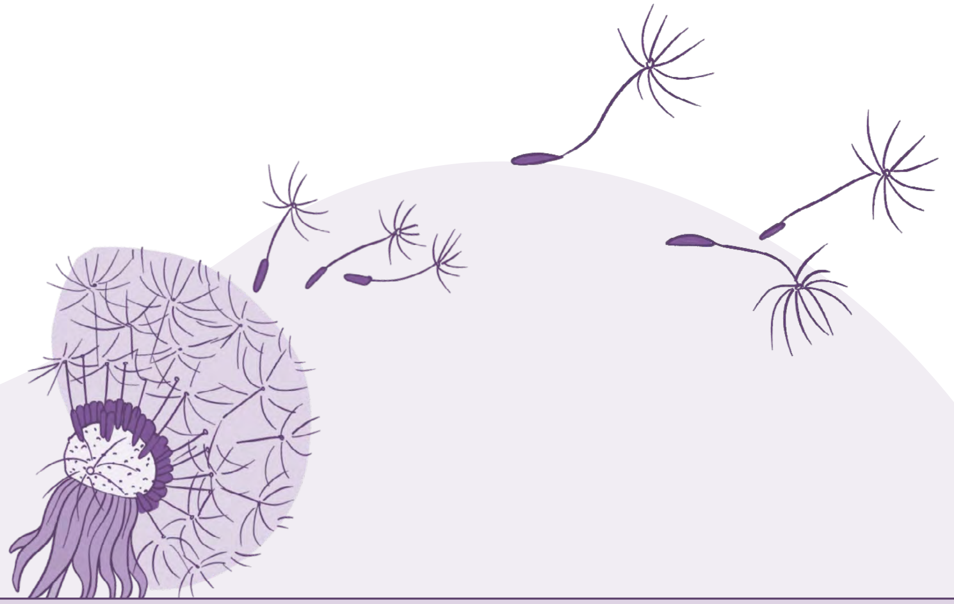
The emotional pain associated with grief can range from normal to severe. Severe emotional pain, when persistent and interfering with functioning, or when there are persistent thoughts of wanting to die, may be a sign of depression. In this case, it is important to talk to your doctor or your supportive care team about how you are feeling.

Bereavement

The time after losing someone is called bereavement. There are many aspects to bereavement but there are two major processes at work, one is mourning loss and one is building and preparing a new future. These are not discrete phases but bereaved persons may move back and forth between these aspects. Most people describe fluctuating, waves of distress that evolve over time. For many, memories and reminders such as anniversaries or important dates can trigger more intense emotions.

There is often both a physical and emotional response to loss and individuals may feel tired, have trouble with their memory or managing tasks. If loss has come after a long period of caregiving, individuals may be exhausted. In the early phase of bereavement there are often a lot of practical tasks to attend to including communicating with others and receiving condolences, planning a funeral or celebration of life, dealing with estate and financial issues. It can be important not to forget to take care of yourself and focus on the basics of wellbeing which include eating regular healthy meals, getting sleep, showering, gentle exercise, etc. These routines will help to provide a sense of stability and help when emotions are high and overwhelming.

There is no one "right" way to face bereavement. Like any major life crisis, individuals cope in different ways that can be considered healthy and adaptive. Some people benefit from bereavement groups in which grieving individuals support one another while other people would prefer sharing their grief just with their circle of friends and family. It is important to remember that while the grieving process can be very painful, it is a natural human response to losing a person you care for and have been close to.



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 4: Planning for the Future

Fears and Avoidance

- Avoiding future-oriented conversations is common but can lead to greater distress as the patient's disease progresses.
- Talking openly can reduce anxiety and foster a sense of control. Some people (caregivers and patients both) can benefit from the support of a professional to guide these difficult conversations.

Advance Care Planning (ACP)

- ACP involves discussing values, wishes, and care preferences before a patient is too unwell to decide.

Key components include:
  - Choosing a substitute decision maker.
  - Deciding on wanted and unwanted treatments in the future
  - Sharing these wishes with family and the healthcare team.
  - Having these decisions and wishes documented.
- See Conversation Starters for ACP

Substitute Decision Maker

- Legally makes healthcare decisions if the patient is unable.
- Should be someone who understands and respects the patient's values.
- Caregivers may need to act in this role—discuss and plan for this ahead of time.

Palliative Care

- Focuses on quality of life (physical, emotional, spiritual, and social aspect of care).
- Provided in hospitals, clinics, at home, hospices, or long-term care.
- Can begin at diagnosis, it's not just for end-of-life.
- Includes symptom management, emotional support, and care coordination.

Caregiver Role

- Your presence, understanding, and advocacy is vital in honoring the patient's wishes.
- Caregivers can initiate and support advanced care planning discussions gradually and compassionately over time.
- Emotions like fear, sadness, anger, and grief are normal and common for both patient and caregiver.

What to Expect at the End-of-Life

Each person's death is unique, but some physical/emotional changes are common:

- Reduced appetite, energy, alertness
- Changes in breathing, skin temperature, bowel/bladder control
- Restlessness, anxiety, confusion and/or emotional shifts
- Comfort can be provided through touch, quiet presence, soft music, comfort item, and/or memory sharing.

Summary of Domain 4: Planning for the Future

Knowing When Death is Near

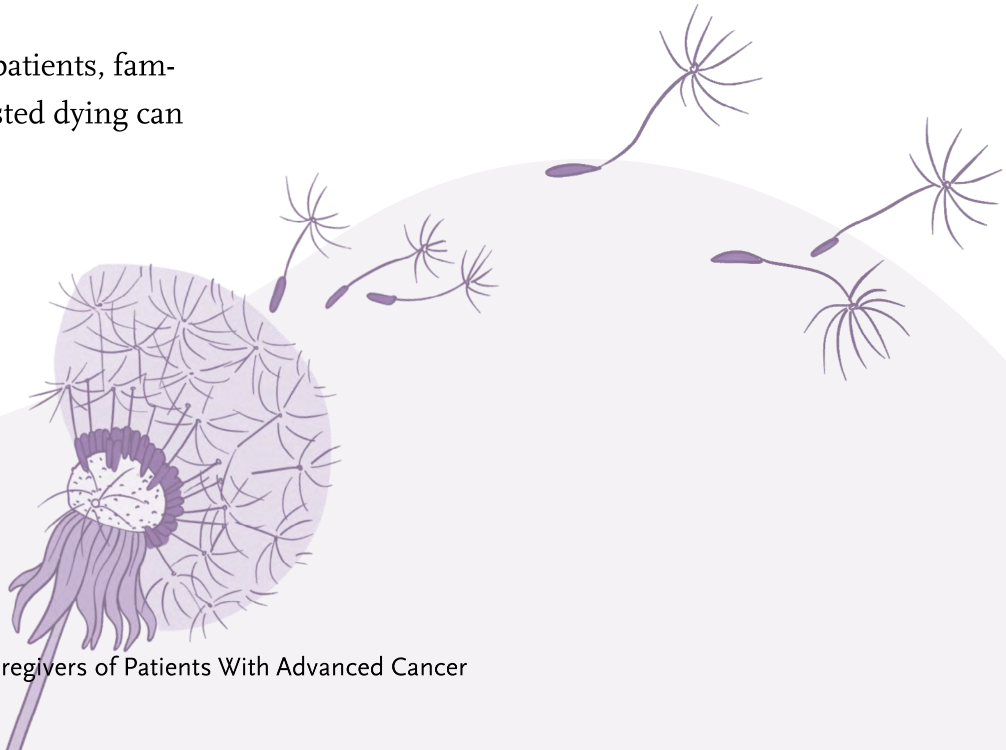
- Signs may include reduced response to voice/touch, long pauses in breathing, and or noisy breathing (gurgling or moaning).
- Final breath and heartbeat stop naturally, sometimes going unnoticed.

Medical Assistance in Dying (MAiD)

- Medical assistance in dying is a process by which a doctor or nurse helps a person who qualifies, to end their life. This is only allowed under strict rules and special conditions set by the law.
- Consideration of assisted dying is quite common, but most patients do not die with medical assistance.
- Many find comfort in knowing the option exists, giving them a sense of control even if they do not pursue it.
- Open communication among patients, families, and caregivers about assisted dying can help foster understanding, even if opinions differ, and for those who choose it, it allows for meaningful planning and goodbyes.

Grief and Bereavement After Death

- Grief in response to a loss can be overwhelming and will fluctuate over time.
- Bereavement involves both mourning and rebuilding, all while experiencing shifting waves of emotion. This is a difficult time, with competing responsibilities and coping capacity will vary.
- Self-Care should be a focus; ensure you take the time you need to make sure your needs are met every day.
- *Seeking Support*—whether from groups, health care professionals or loved ones— support can help foster healing and reduce isolation.



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CALM for Caregivers: An Illustrated Workbook for Caregivers of Patients with Advanced Cancer was created by The Managing Cancer and Living Meaningfully (CALM) team at Princess Margaret Caregiver Clinic from the Department of Supportive Care.

This self-guided reflection workbook is designed to support caregivers of patients with advanced cancer. Inside you'll find information on cancer, symptom management, tips on communicating with healthcare providers, maintaining relationships, reflecting on life, advice on taking care of your mental and physical wellbeing, and thinking for the future ahead.

Each domain is fully illustrated and can act as a standalone to best suit your needs, featuring graphic narrative-based caregiver stories, questionnaires and reflective worksheets.