

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

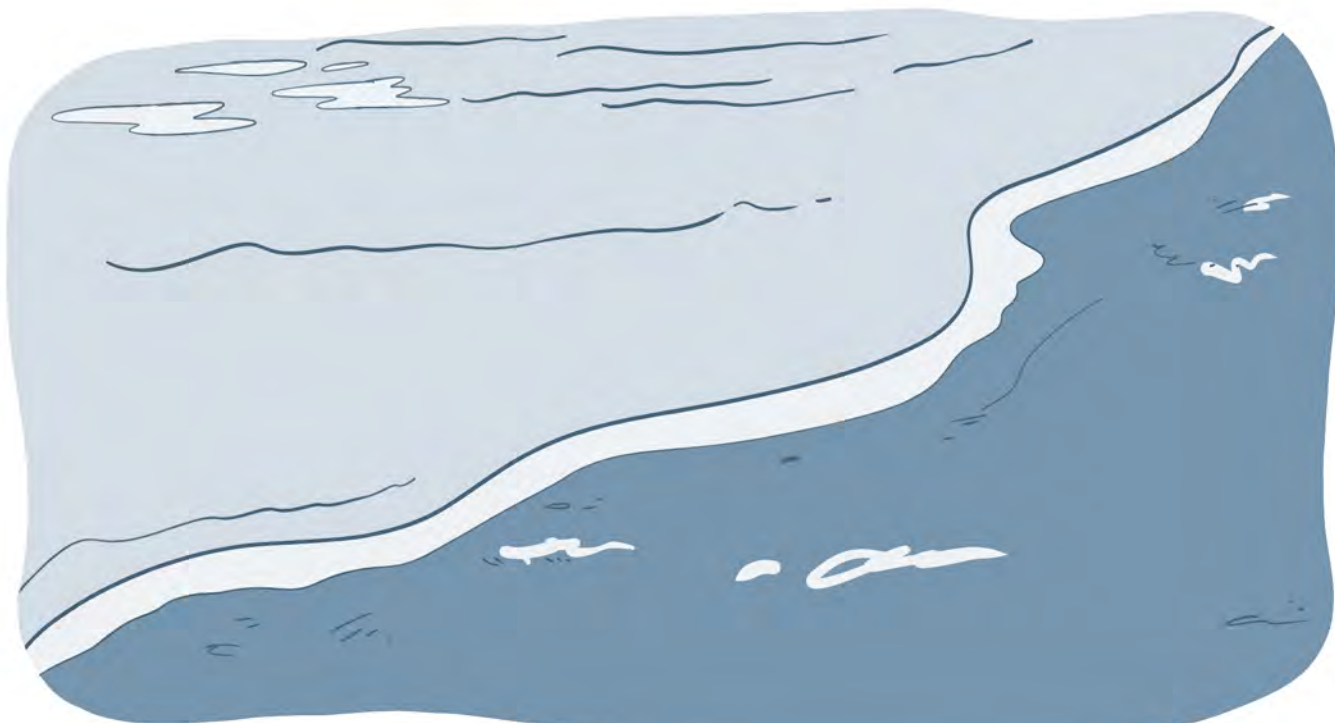
Lastly, we will offer various ways and tools to manage emotions, **pg.29**

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.

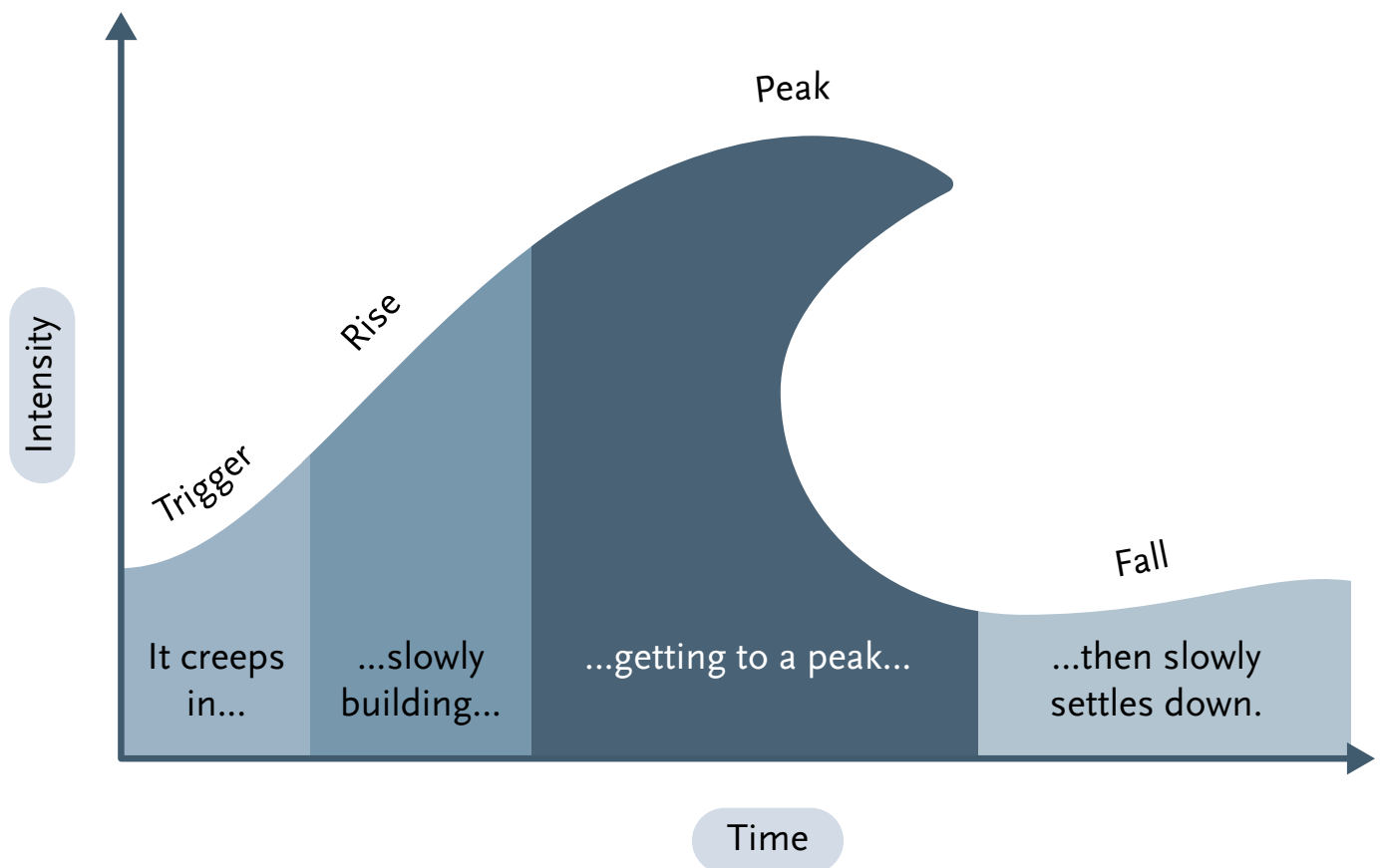
We tend to judge ourselves for certain emotions or the thoughts that they bring. However, it is more productive to think of emotions as a source of information – they can help you figure out what you need or want. Our hope is that our description of common emotions for family

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.

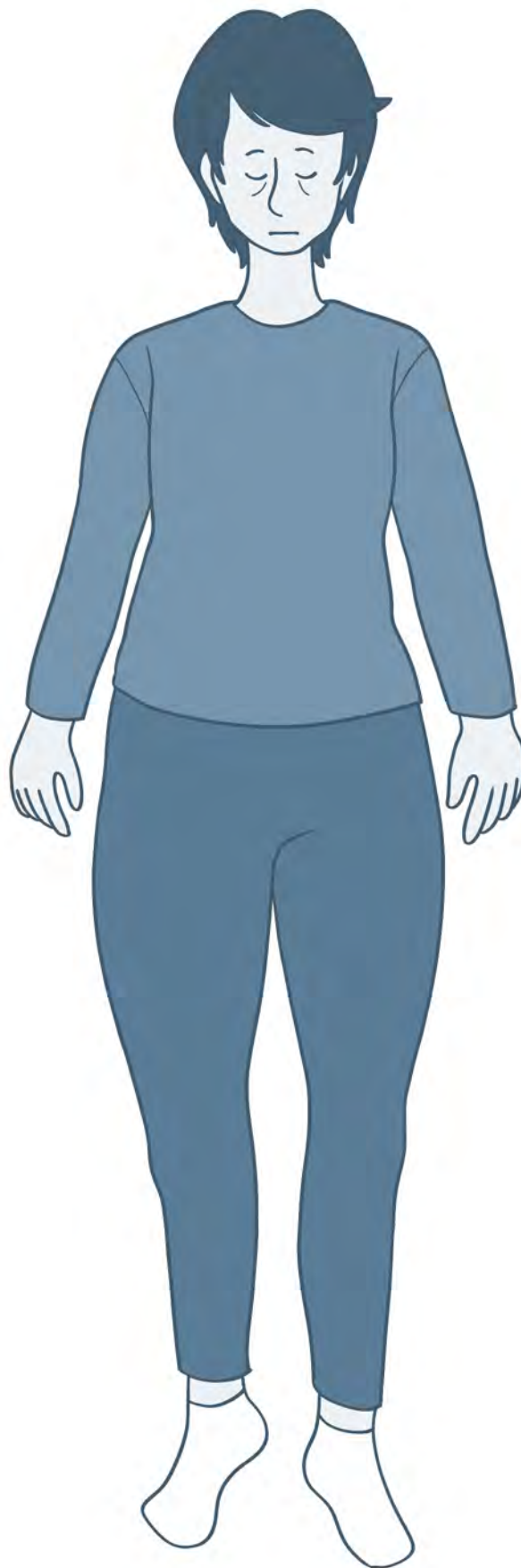
Wave of Emotion



Lastly, it is important to know that we can experience several emotions at once, and these emotions might not always agree with each other. For example, you might feel happy and sad at the same time about different aspects 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.

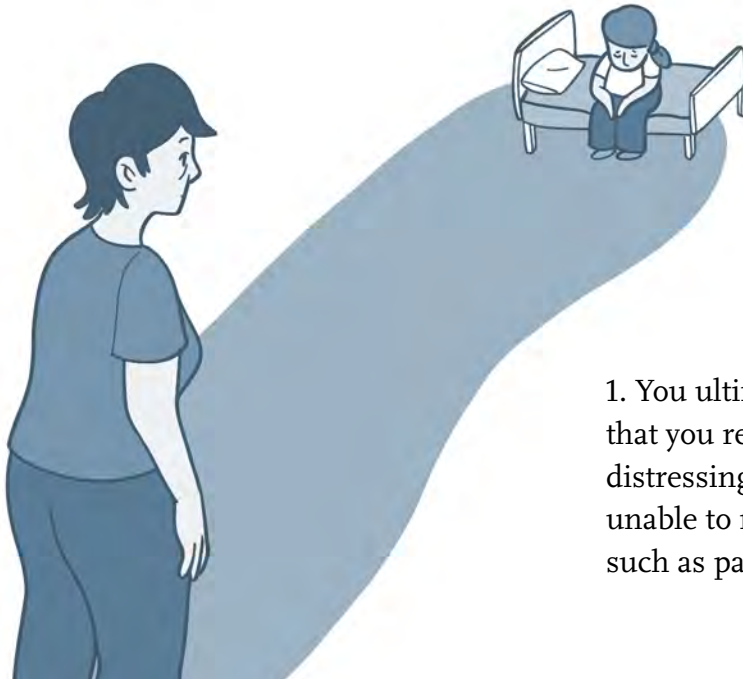
There are some emotions, pleasant and unpleasant, which tend to be commonly felt in caregivers that we are listing on the following pages. This is by no means an exhaustive list or meant to tell you what you should be feeling but perhaps there may be times when you have or will experience some of the 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?

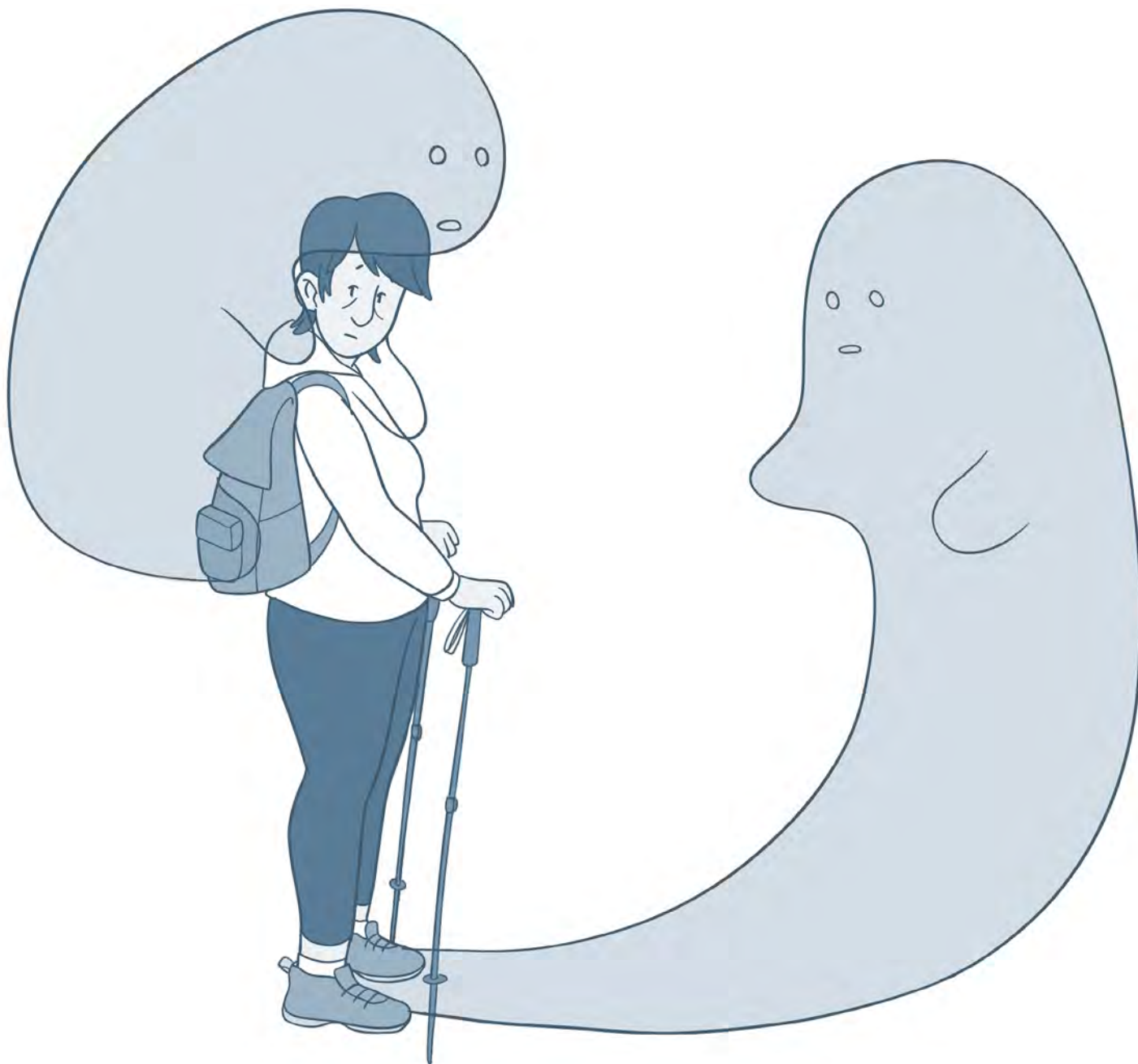
Do you find that your fear fluctuates over time? Are there certain times or events that intensify or alleviate your fear?

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?

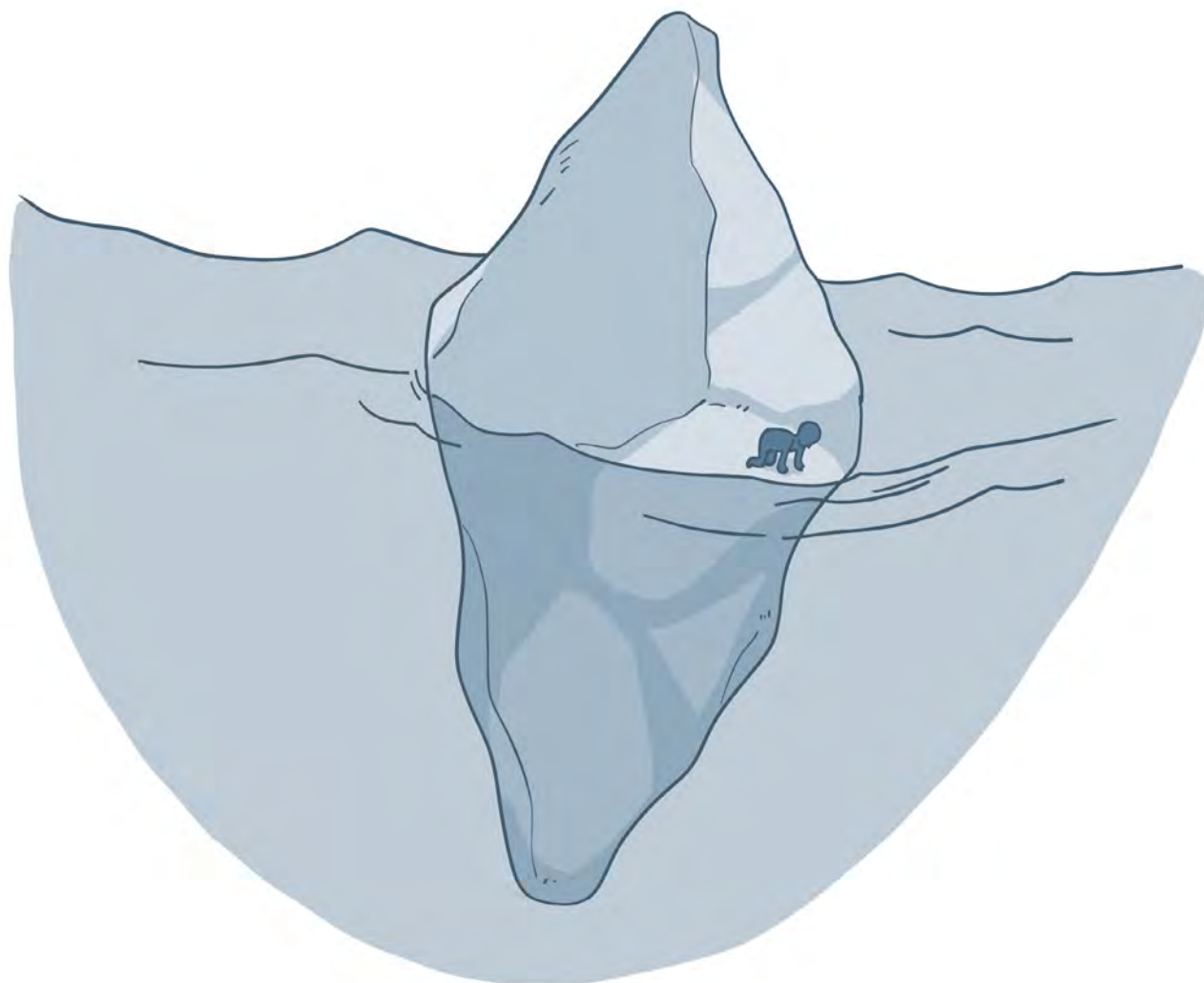
How comfortable do you feel expressing your guilt to others, whether it's the patient, friends, or family members? Have you ever discussed your feelings of guilt with others, such as friends, or family members? If so, how did these conversations impact your perception of guilt?

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.

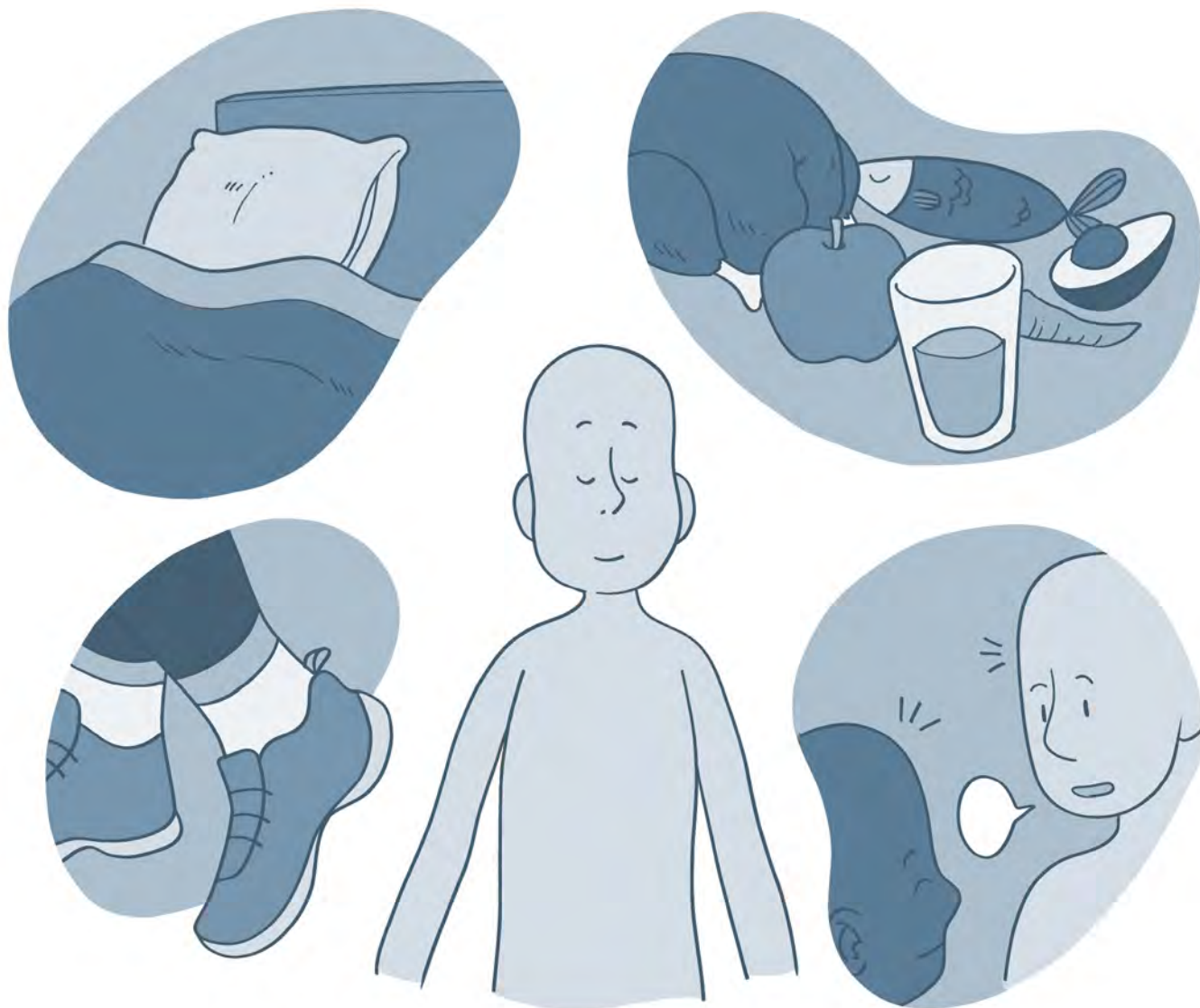
How did you judge it? Here are some common examples: "I shouldn't feel this way", "it's selfish to feel this way", "I will jinx things if I feel this way", "feeling this way means I'm in denial", or "feeling this way means I gave up".

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.