Domain 4

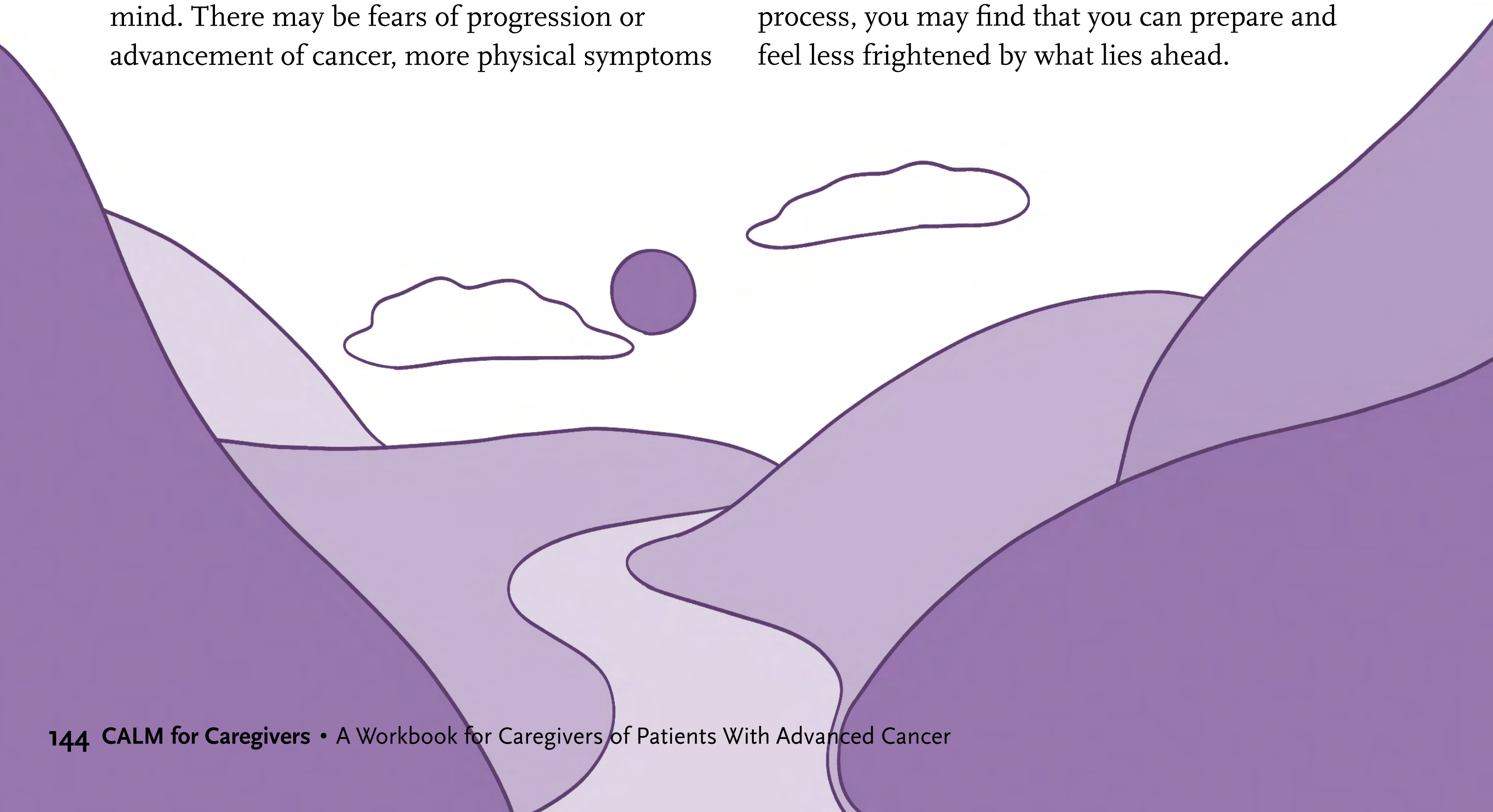
Thinking About the Future

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?

Reflection

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?

Domain ④

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

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?

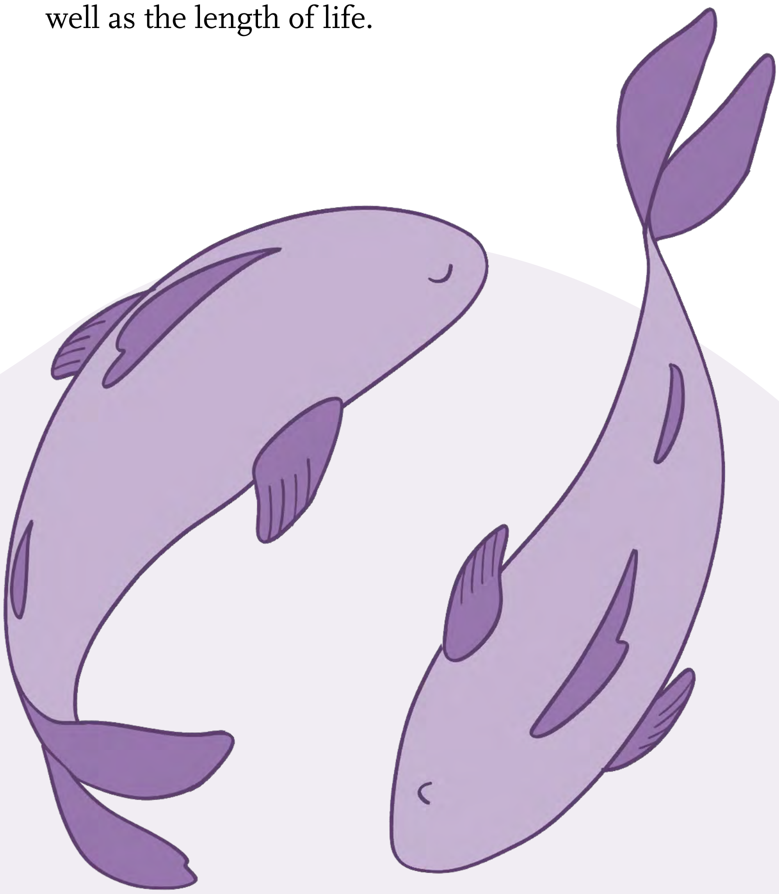
Living with Advanced Cancer: Balancing Hopes and Fears

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.



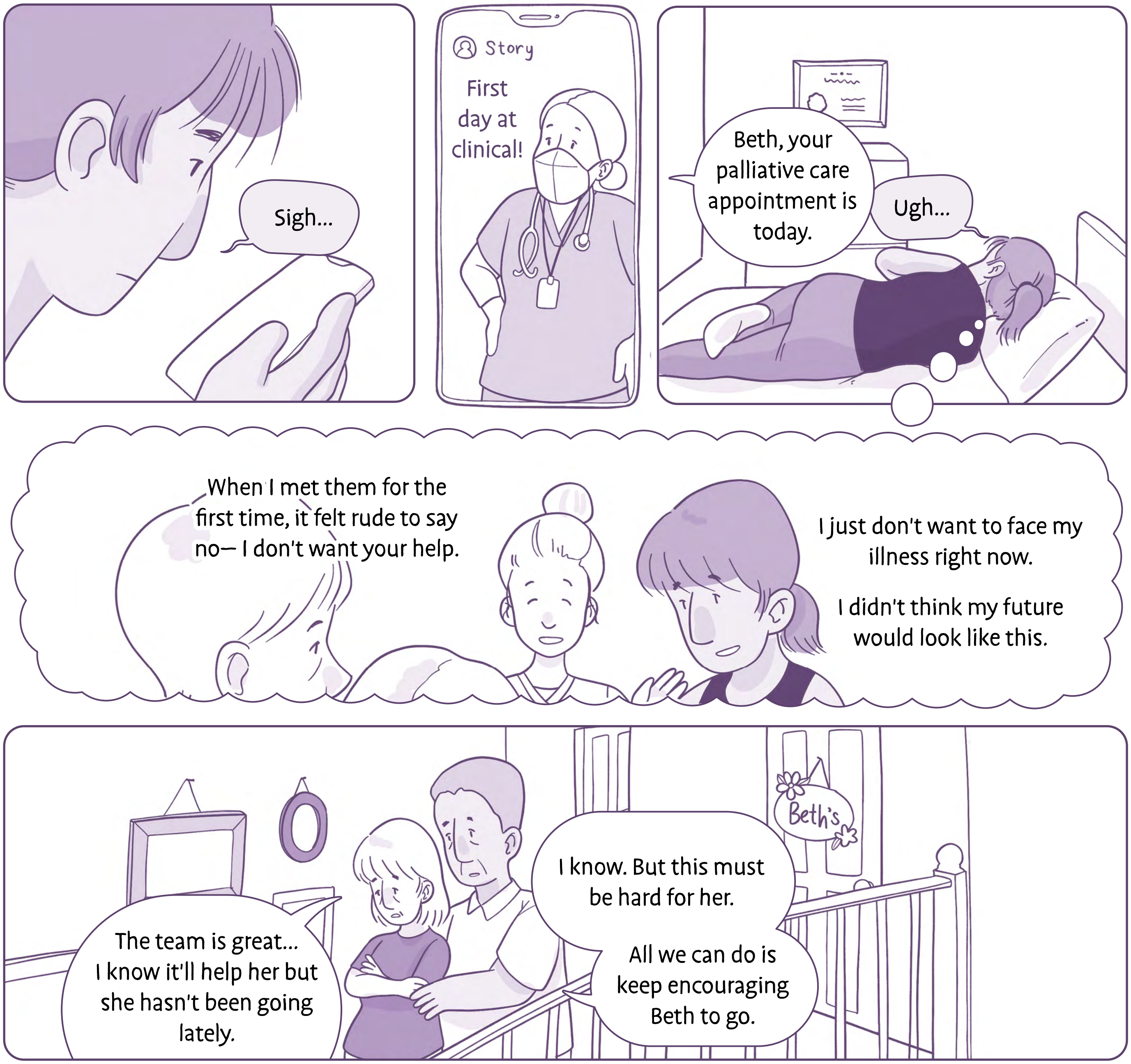
Omar's Story

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.