

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

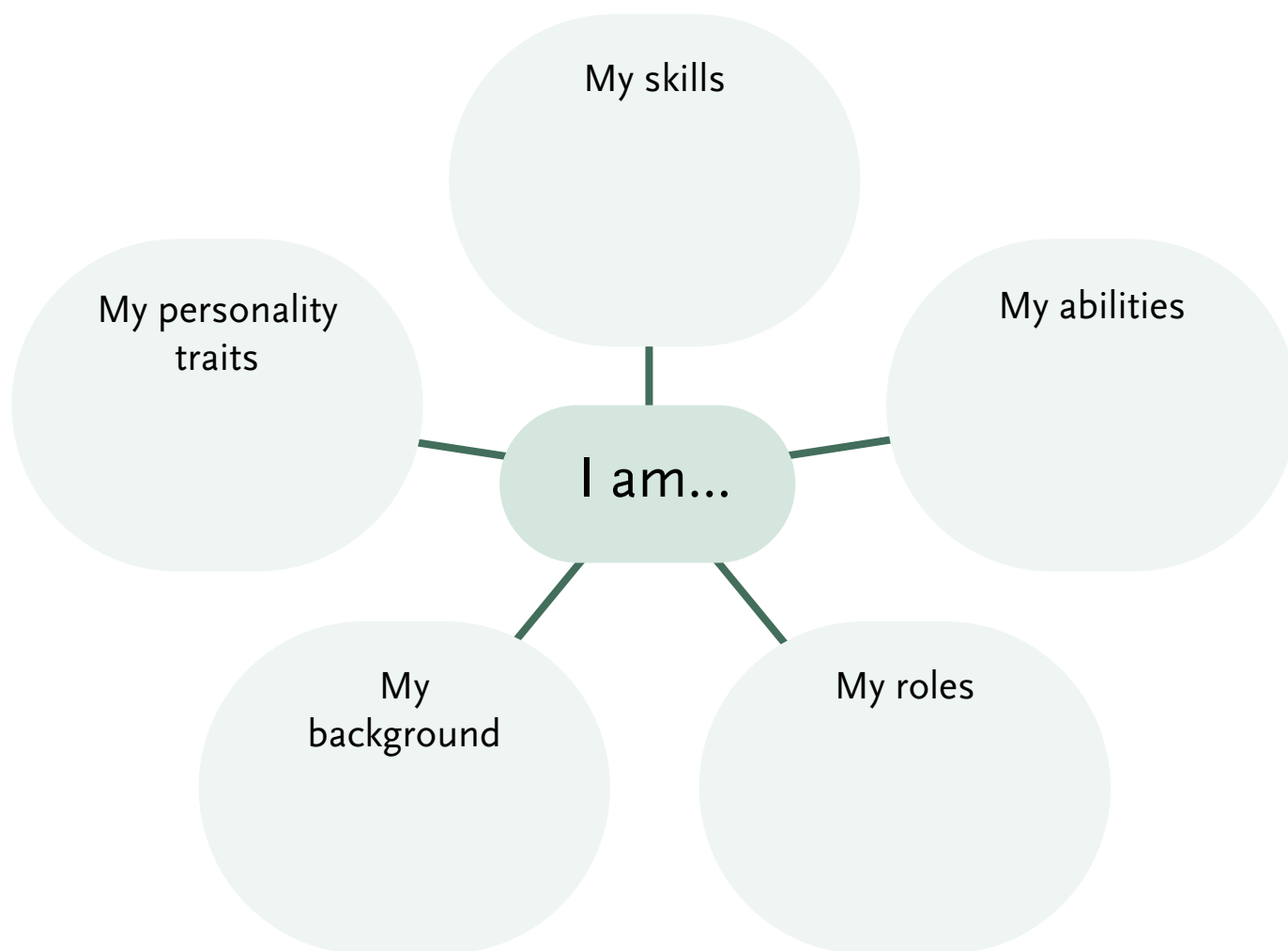
One-page summary for this section, **pg.91**

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?

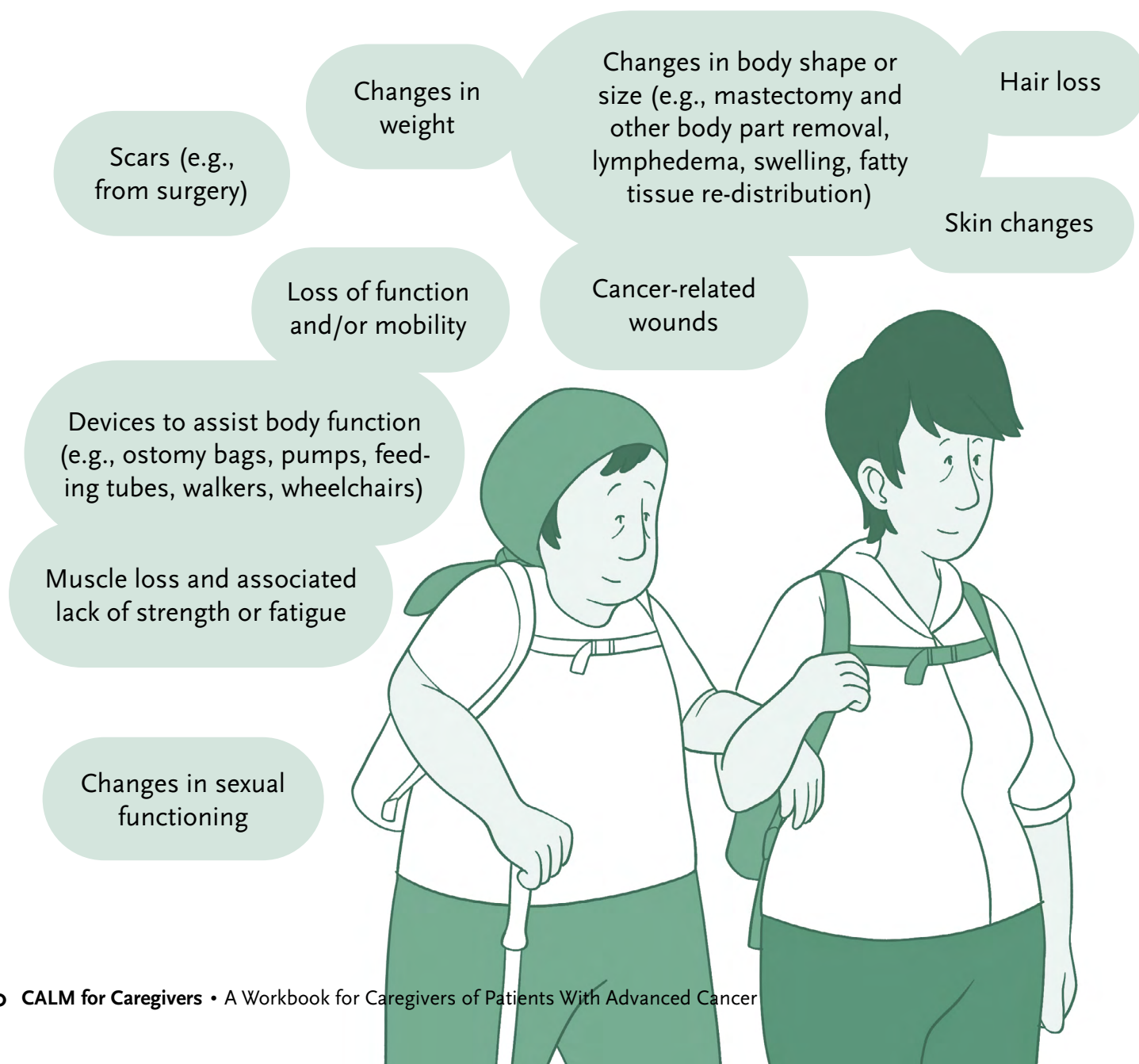
Has your family member's cancer experience changed how you see yourself in any way?

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.

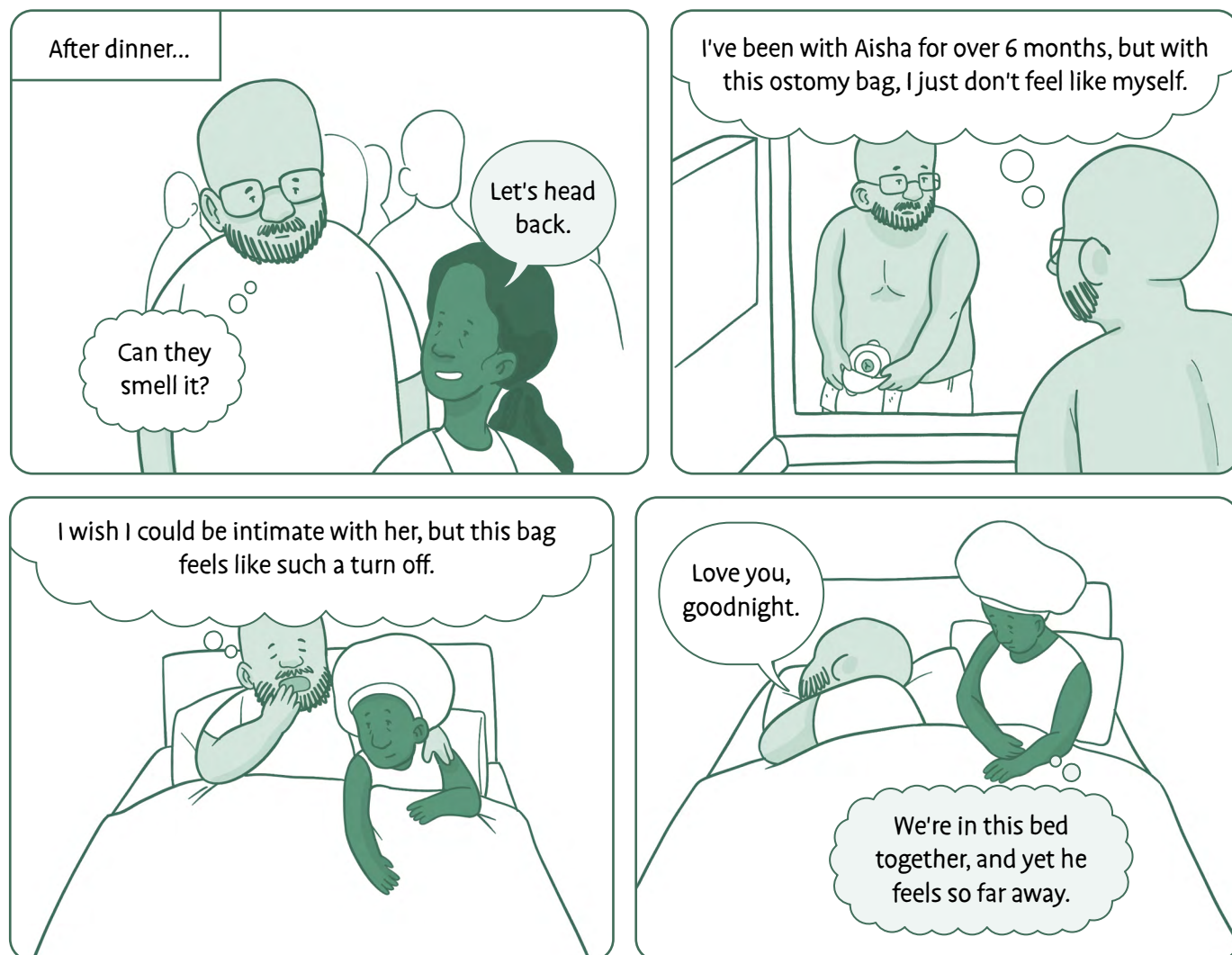
People living with cancer may experience many changes to their bodies, such as how their body looks, feels, and functions. These changes are often caused directly by the cancer or its treatment. These changes may be visible or hidden from other people; some may be temporary, while others are permanent. 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.



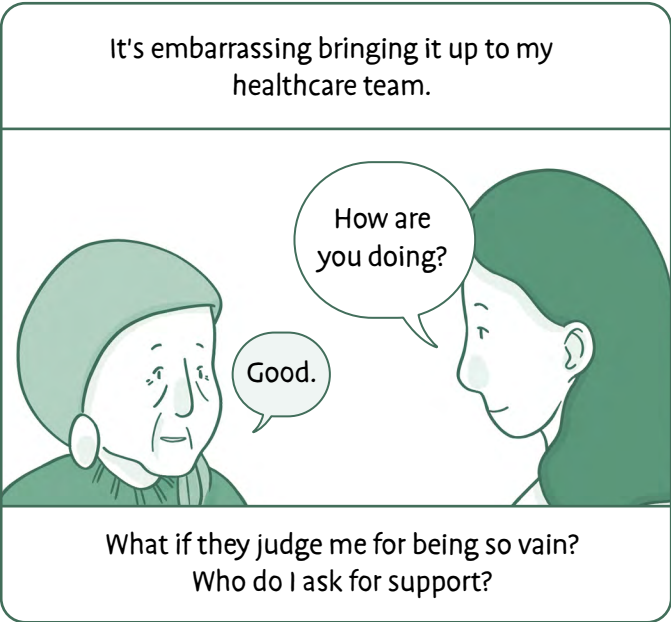
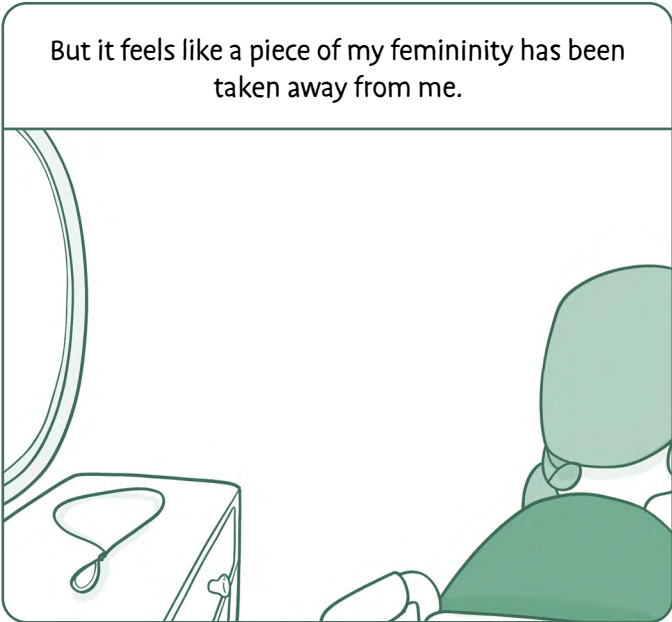
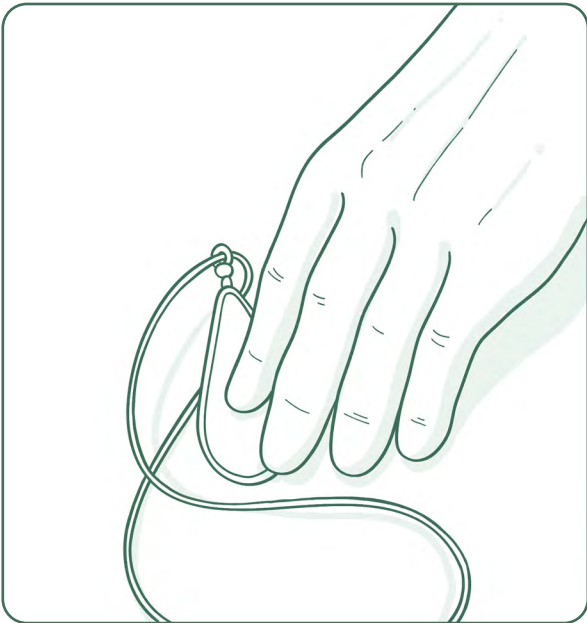
Simon's Story

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.



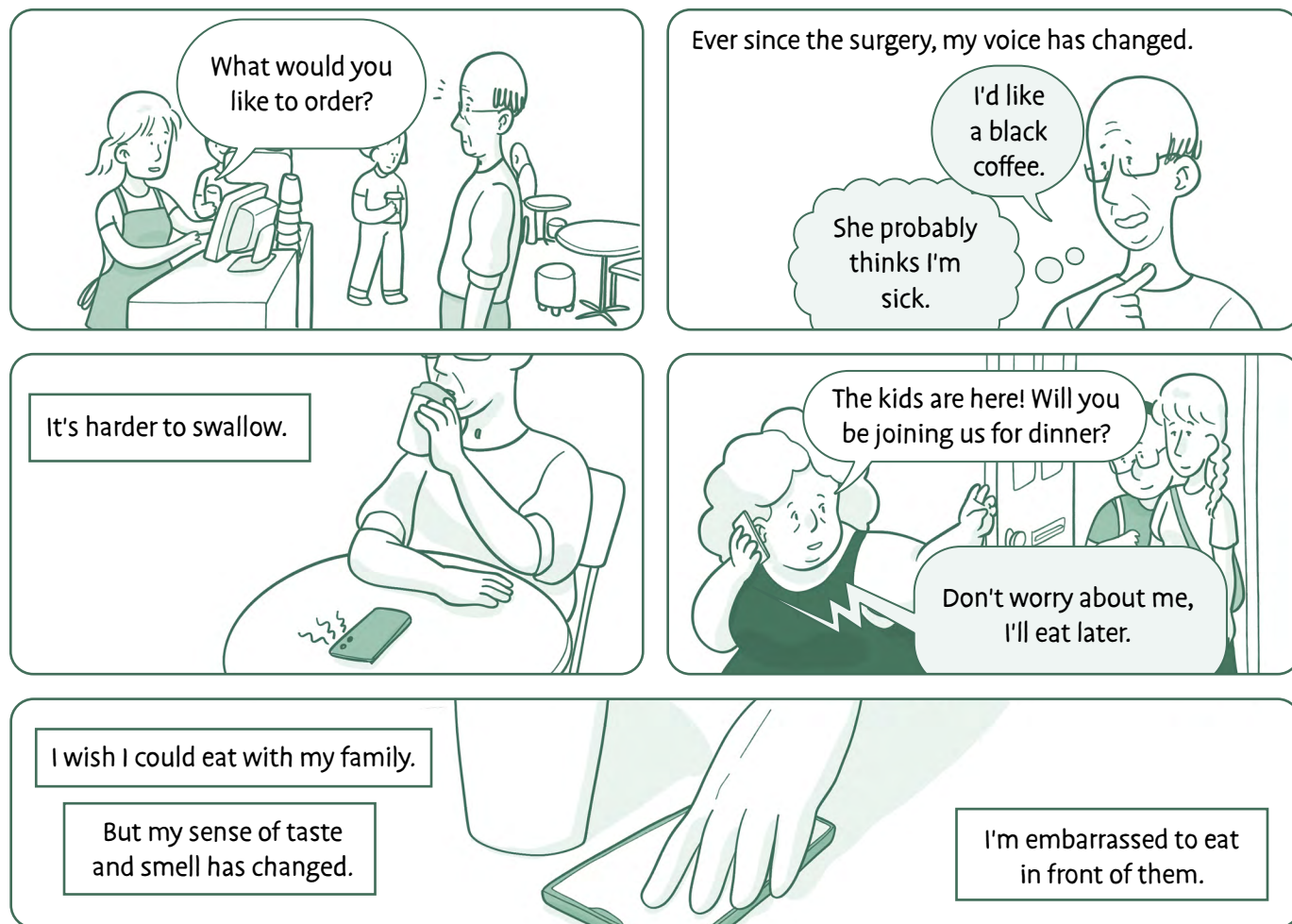
Josephine's Story

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

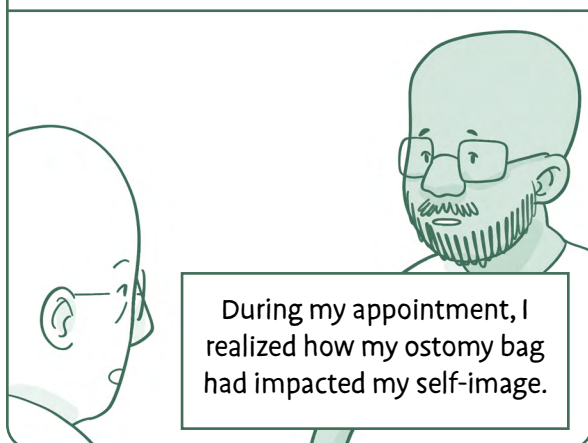
Has your family member experienced any physical changes from their illness? How do you think these physical changes have affected the way they feel about themselves?

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

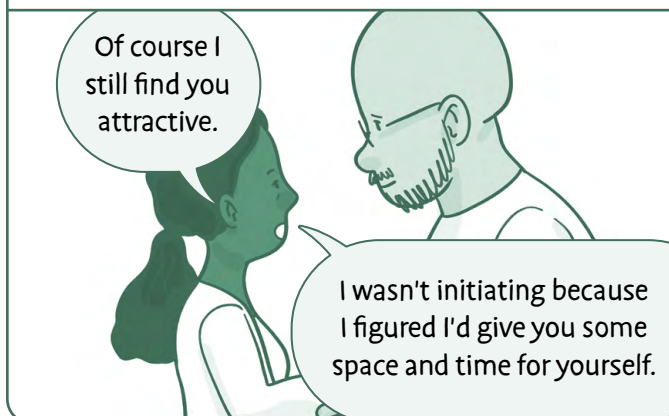
My oncologist referred me to a psychiatrist.



I shared my feelings and worries to my therapist.



When Simon told Aisha, the walls between them disappeared.



With time, Simon and Aisha got back to being physically intimate.



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.

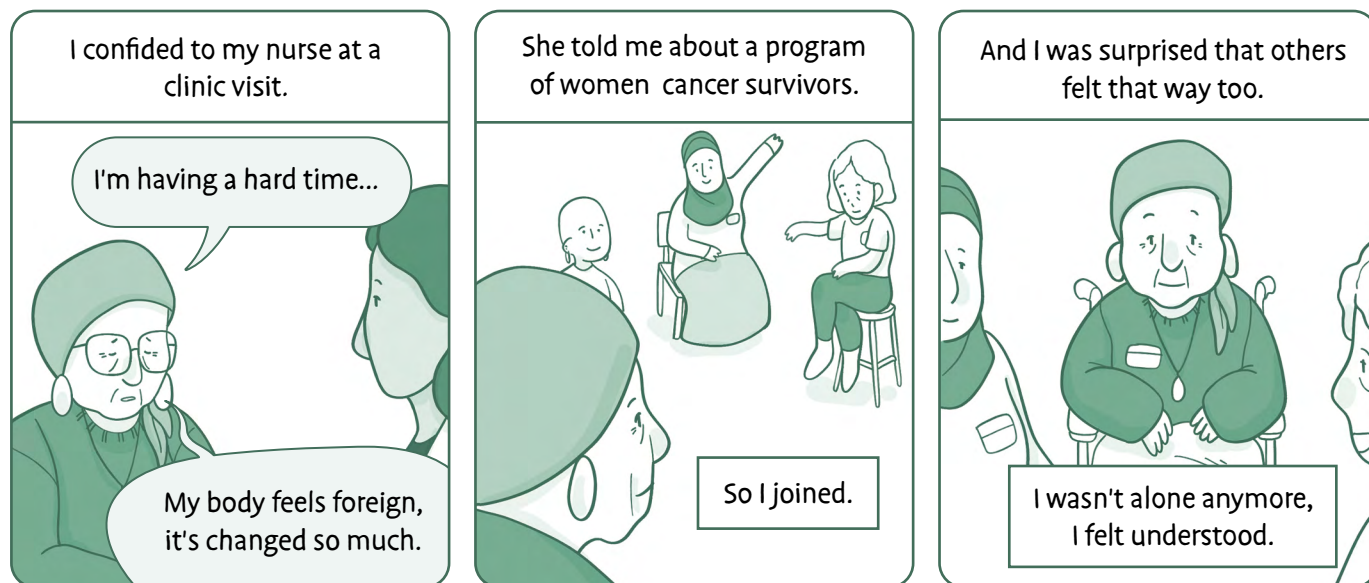


Check in over time.

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.

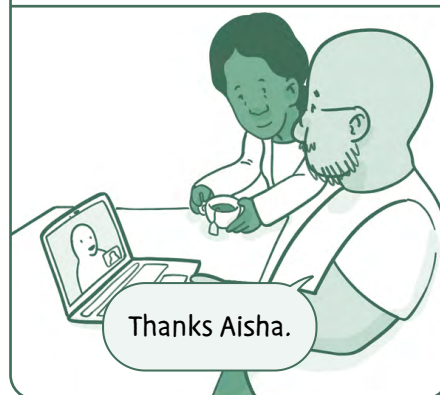
I liked my bank job. The work I did felt important, valuable.



I worked even after my initial diagnosis but it became too much on my body.



It's been hard, I felt lost. But through mentoring and spending time with my family, I'm realizing what really matters to me.



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.

