Domain 4

Planning for the Future

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.

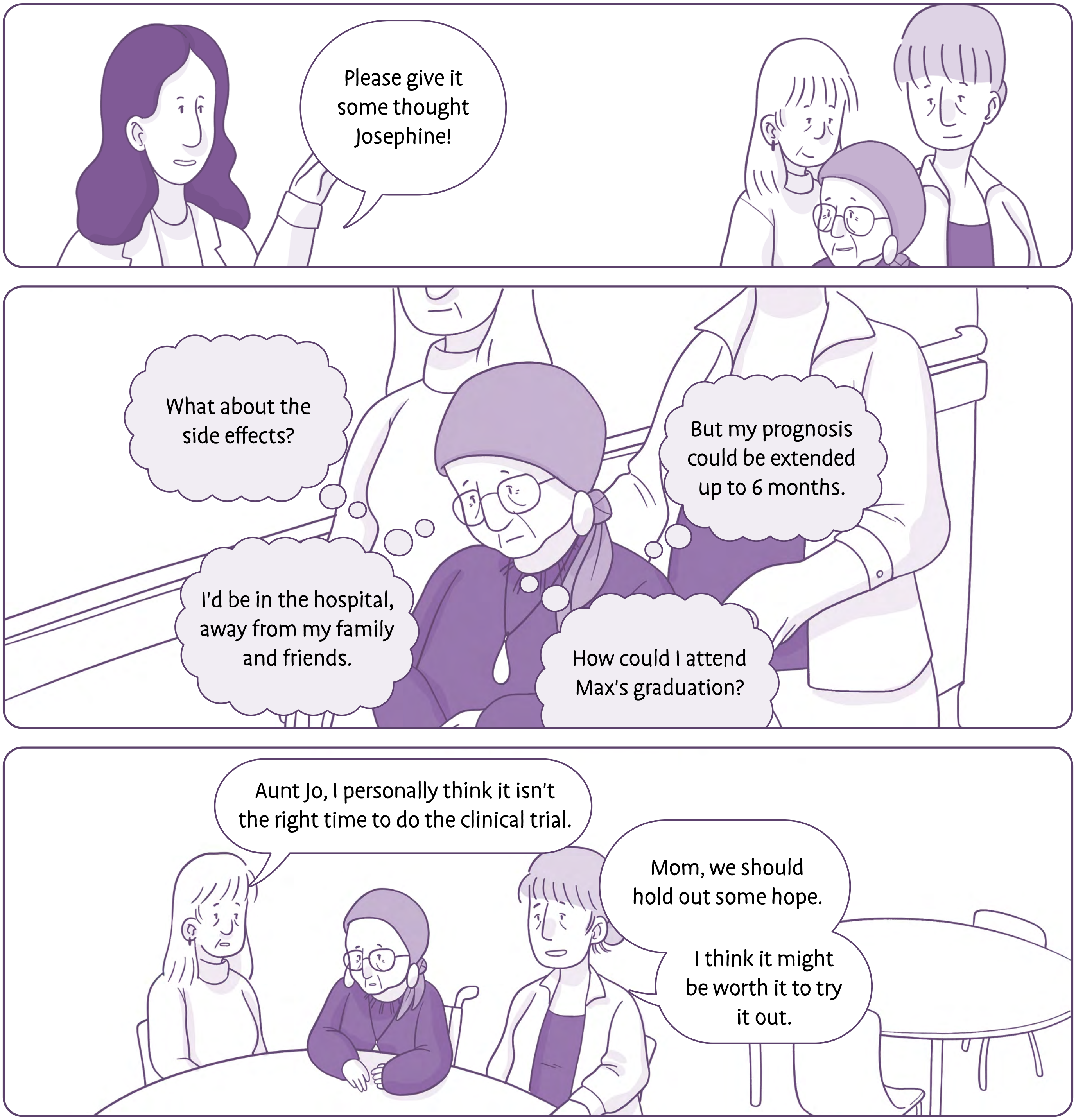
Are there aspects of future planning that are particularly challenging to discuss with the person you are caring for? If so, what are they?

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

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).

Record their wishes and decisions (required documentation may vary by location and healthcare setting)

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.

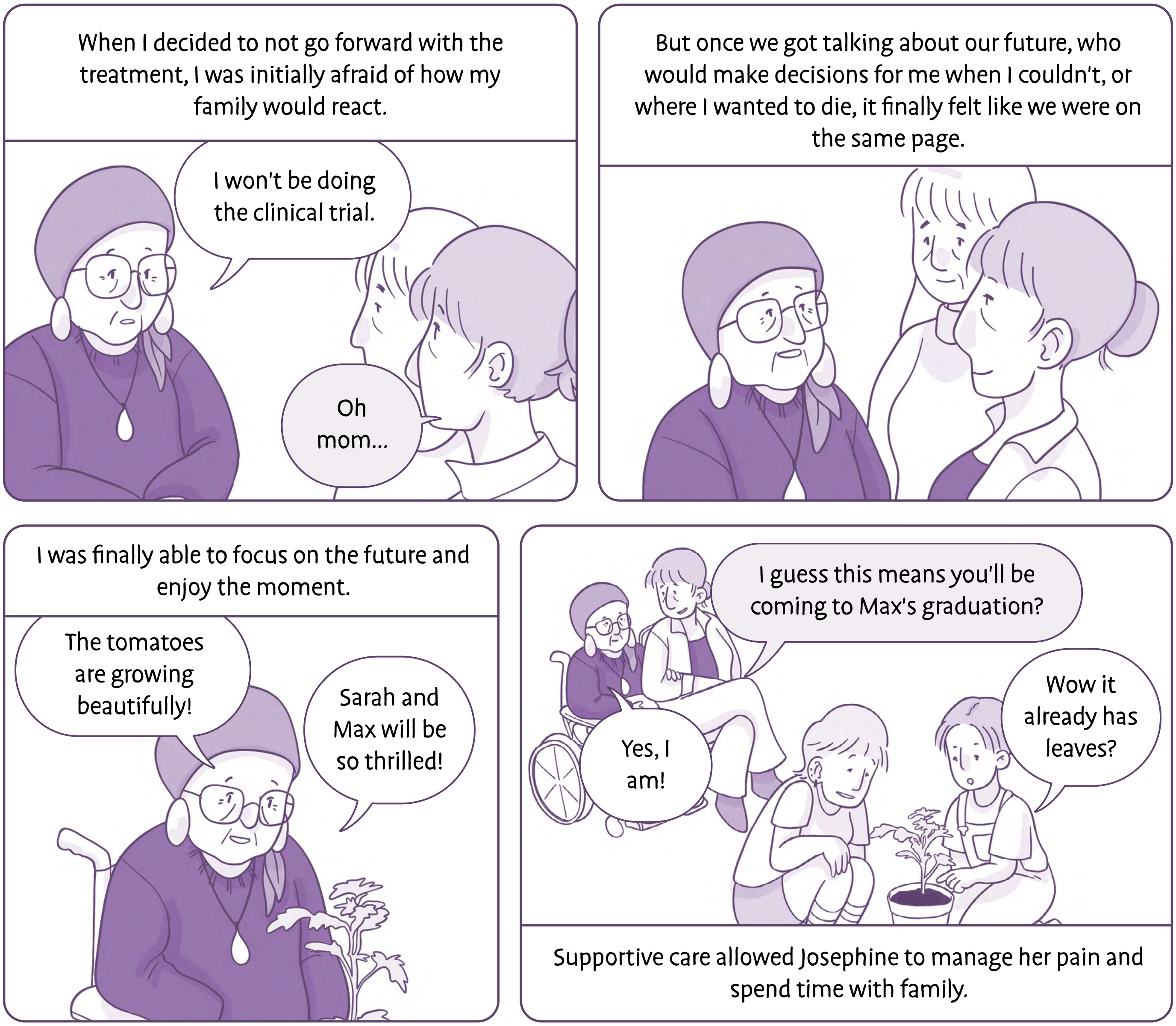
Advance Care Planning

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.

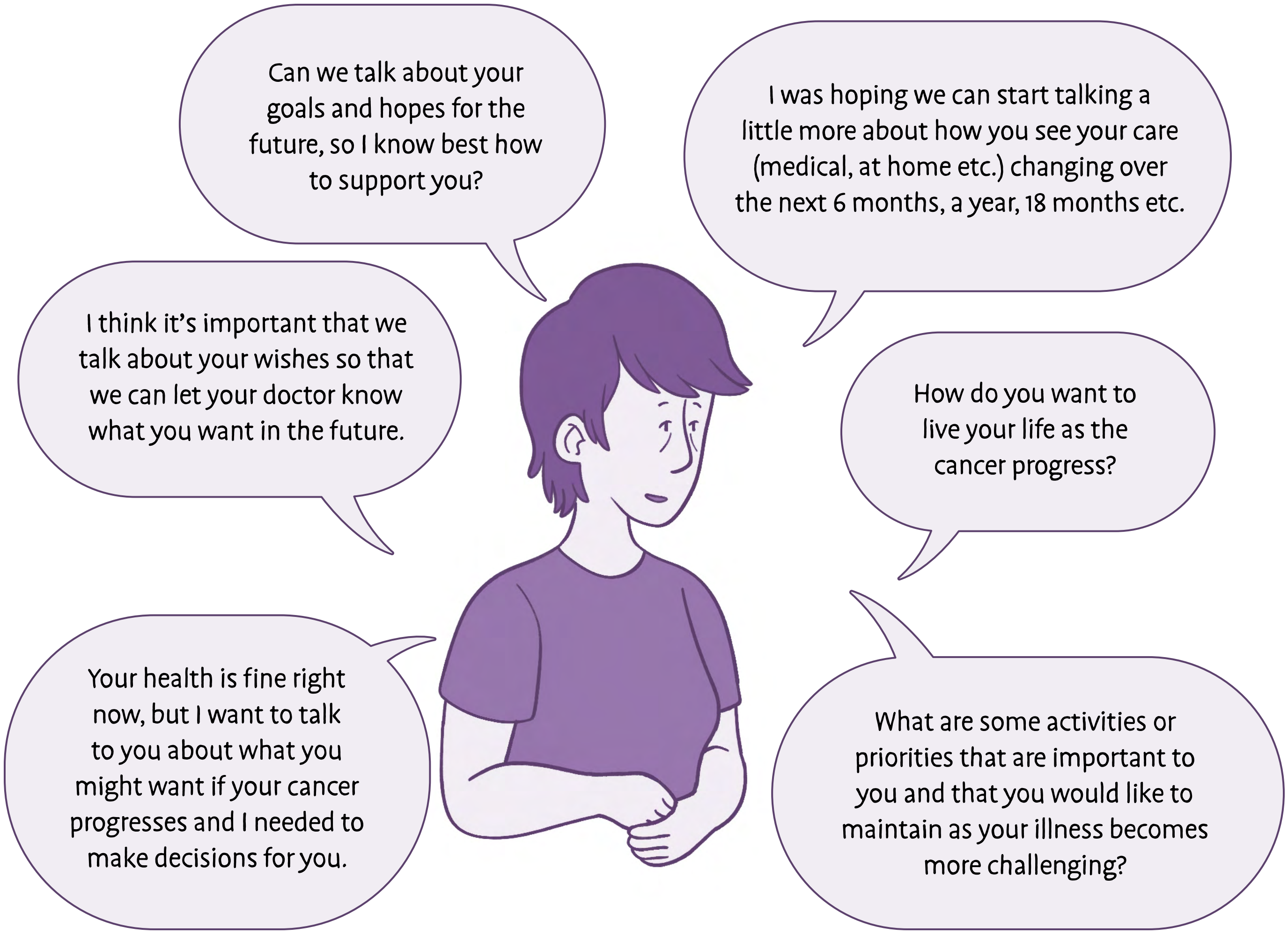


Initiating Advanced Care Planning Discussions

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?

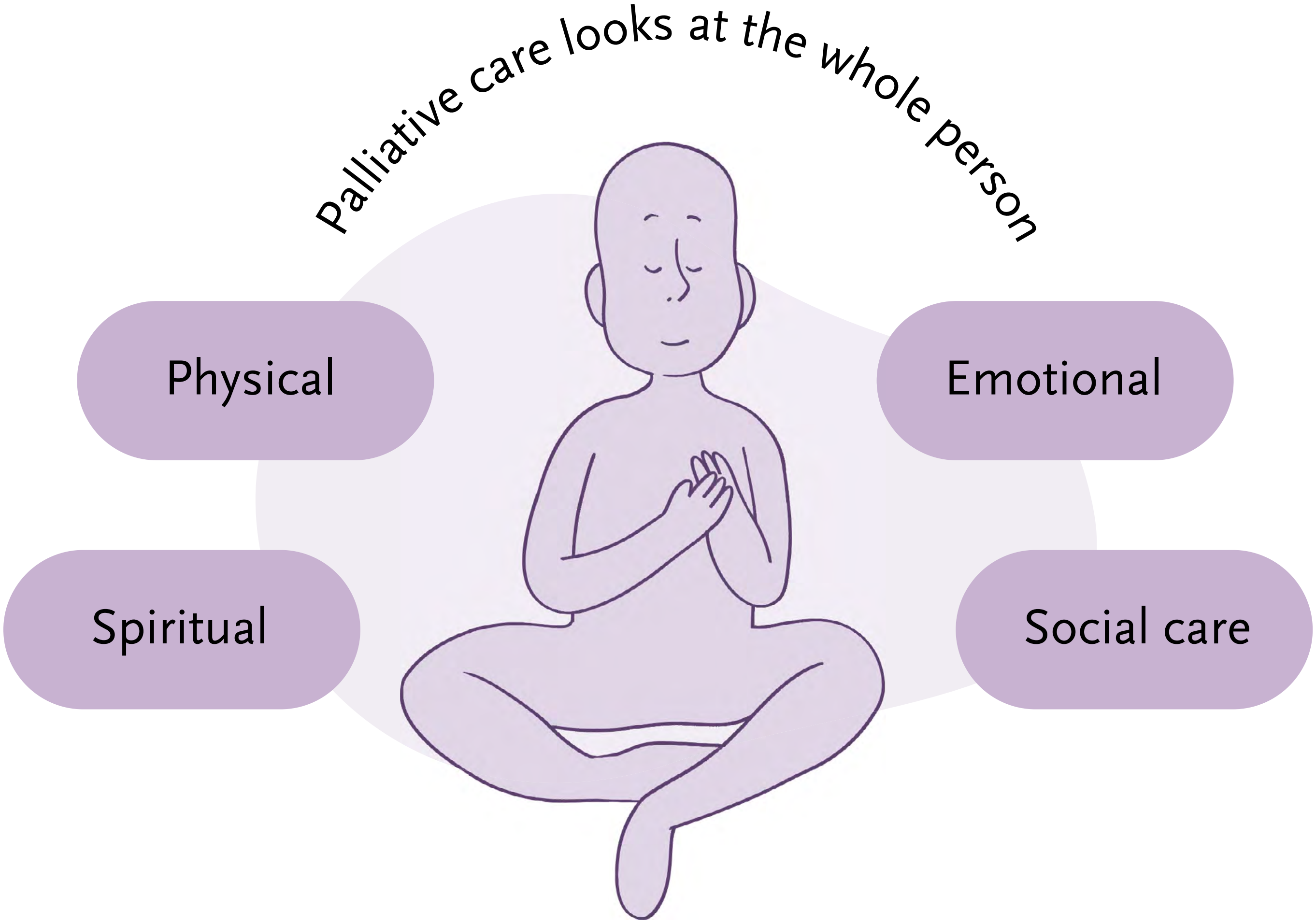
Do you feel prepared for this? If not, what would help you to feel more prepared?

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?

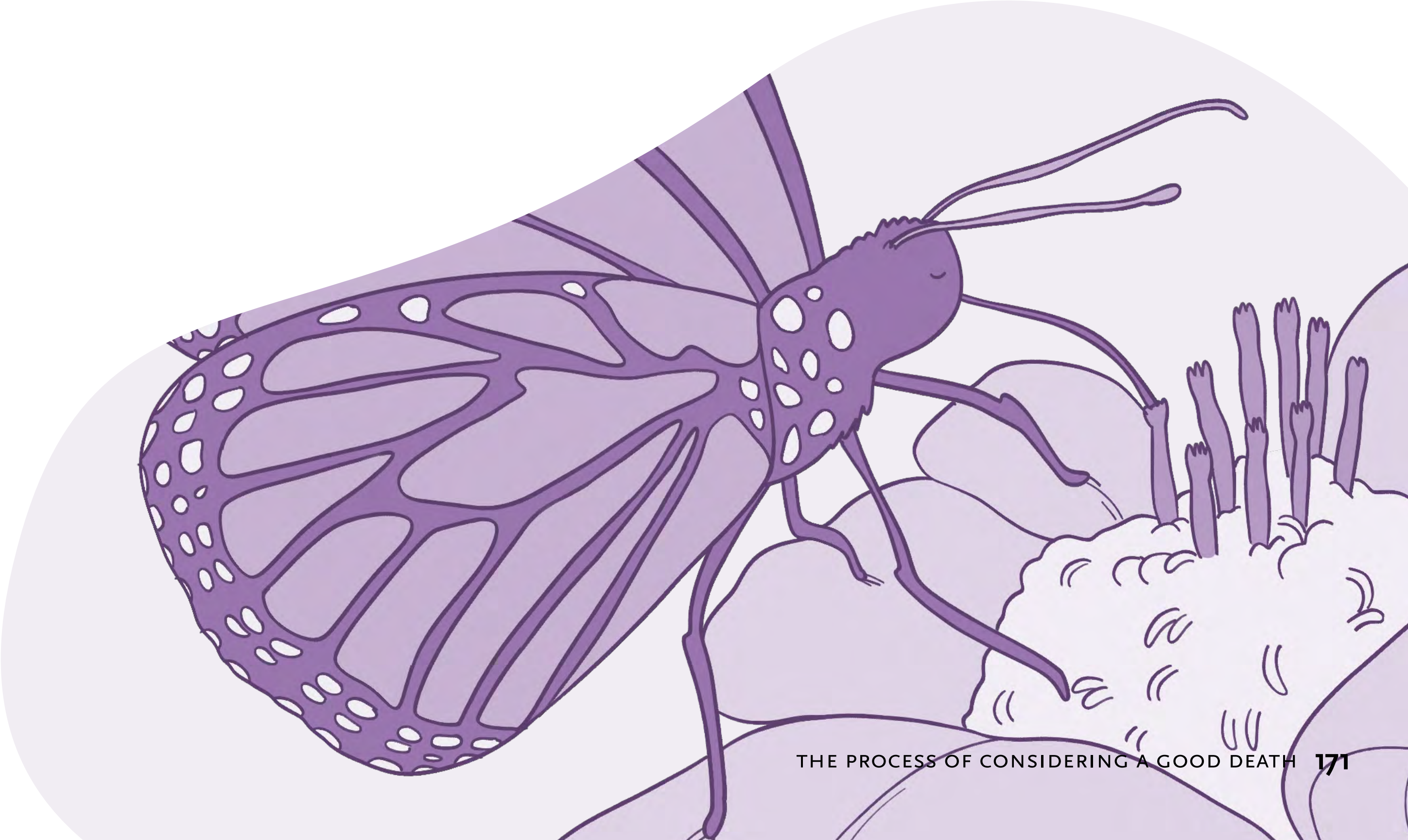
What do you and the person you are caring for hope to get from palliative care?

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.



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).

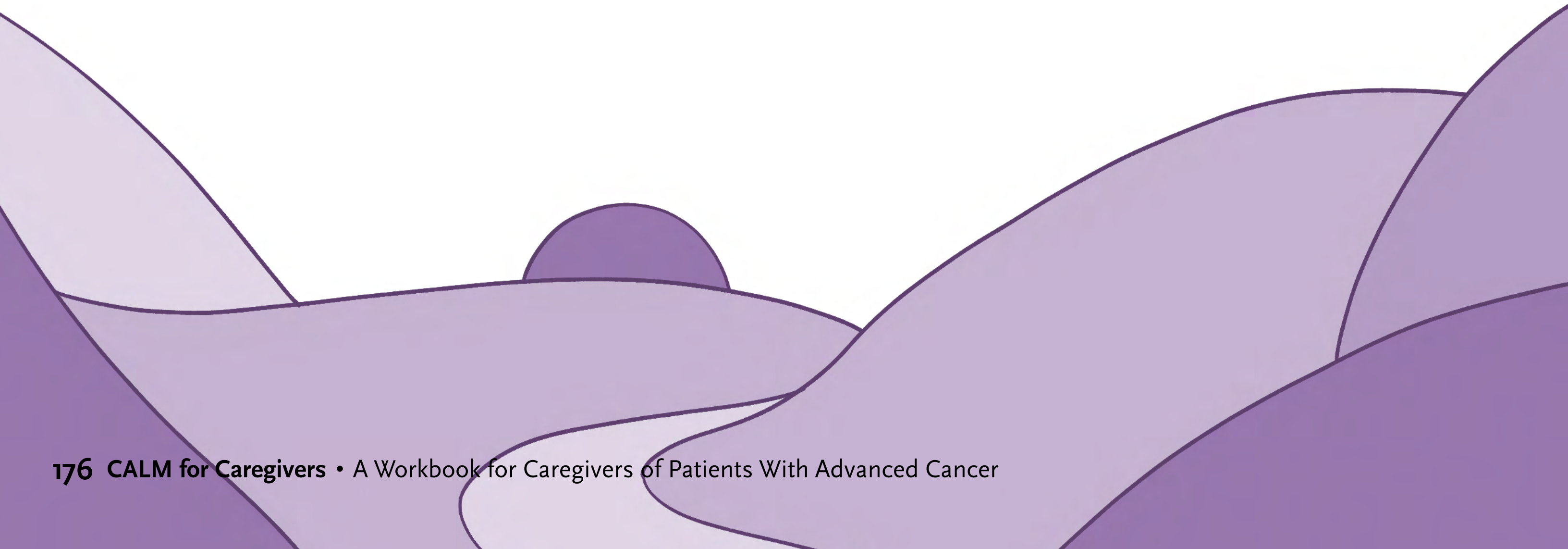
If you feel like you need more help with your emotions, please ask the health care team, they can tell you about hospital and community supports available to you.

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?

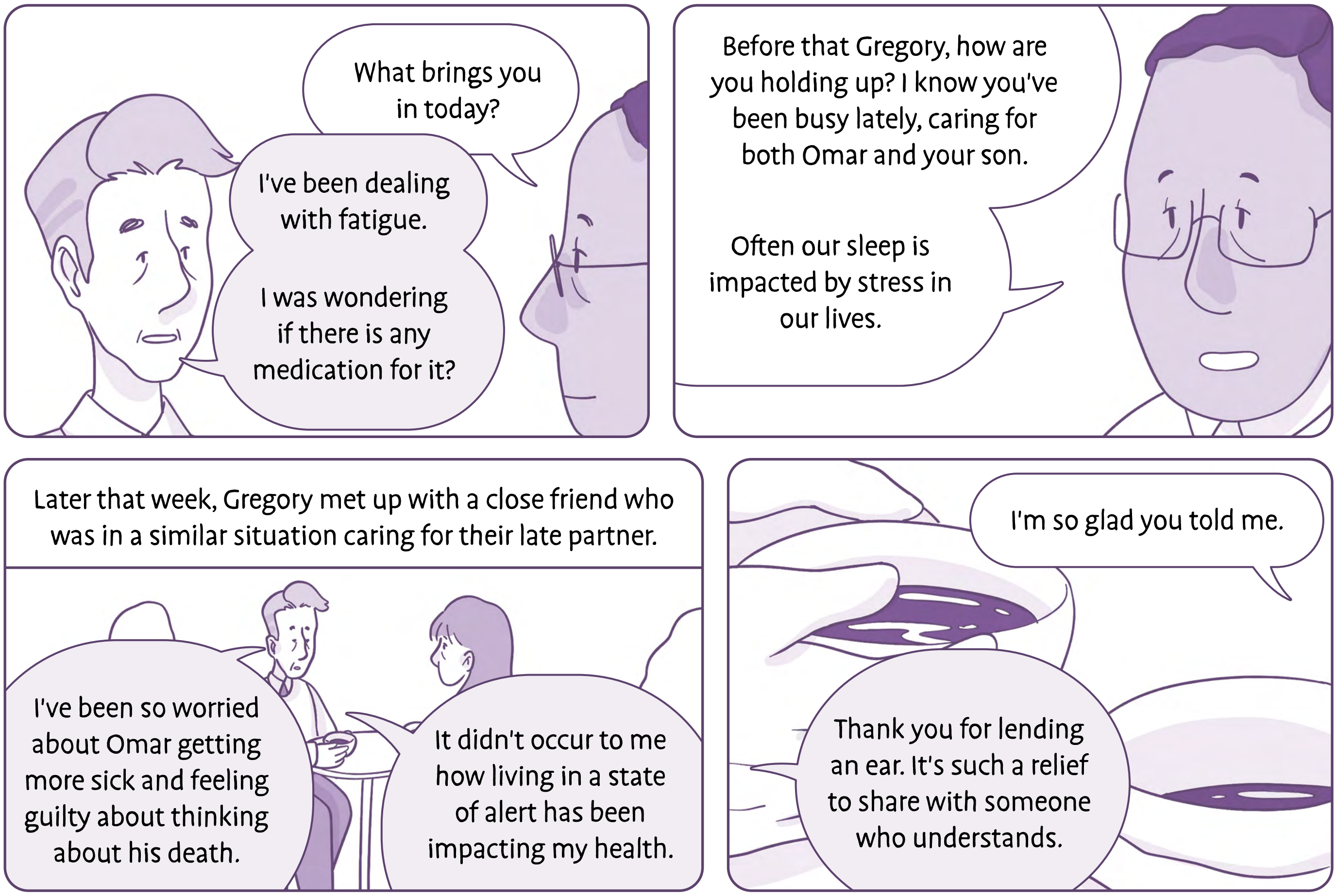
Grief and Bereavement

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.

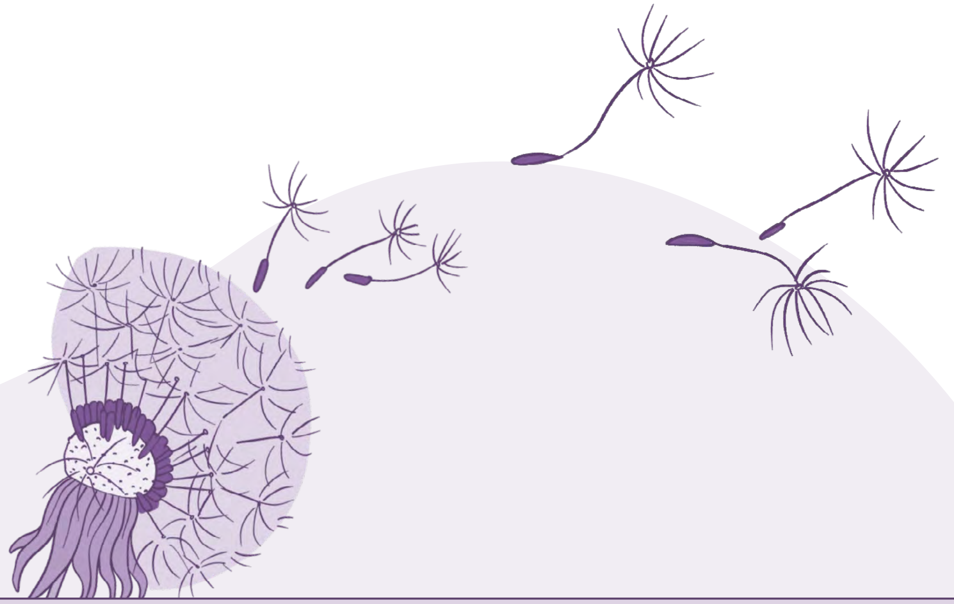
Domain ④

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.