Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

Strengthening a Palliative Approach in Long-Term Care
SPA LTC

Illness Trajectory Complementary Conversation Guides Booklet:

A Communication Aid

Contents

Introduction to the Illness Trajectory Complementary Conversation Guides Booklet

The purpose of this conversation guide booklet is to assist healthcare providers in facilitating conversations with residents and family caregivers; and offer guidance on how to respond to questions regarding **an illness trajectory and providing a palliative approach to care**. The complementary conversation guides are designed to accompany any of the corresponding Illness Trajectory Pamphlets but may be used independently as deemed appropriate by the healthcare provider. See the Supporting a Palliative Approach in Long-Term Care (SPA-LTC) website for additional resources https://spaltc.ca/ [1]

Using the Booklet

Common Terms

Resident: The person residing in a long-term care home with a life-limiting illness.
Family caregiver: "Any person who takes on a generally unpaid caring role providing emotional, physical or practical support in response to an illness, disability or age-related needs".[2] Although the term family is identified, this person may be a friend, neighbour, or another close person to the resident.
Healthcare provider: A member of the healthcare team, providing care to the resident and/or family caregiver.

Highlighted text and Icons

Throughout this guide booklet, readers will note that some text is highlighted. This highlighted text alerts the user to the opportunity to individualize the message.

📣 The megaphone icon indicates an example of an adaptable script to guide responses to questions, share information or invite input from residents and/or their family caregivers.

Key Features

Many individuals residing in long-term care homes are living with chronic, progressive life-limiting illnesses. Healthcare providers are encouraged to promote advanced care planning conversations with residents and/or their family caregivers. This booklet contains ideas about and suggested/adaptable wording for:

- initiating conversations about life-limiting conditions and planning for care as the illness progresses;
- explaining a palliative approach to care and considerations for end-of-life care planning;
- exploring ways in which residents and family caregivers can spend quality time together; and
- describing advanced disease progression and invitation for further discussion. The topics include **frailty, and advanced dementia, heart failure, lung disease and kidney disease** as well as **falls**. Although the topics are presented individually, healthcare providers should consider the impact of co-morbidities and impact of frailty on the primary illness being discussed.

Initiating the Conversation

As the complementary conversation guides are intended to accompany the corresponding illness trajectory or falls pamphlets, you can initiate a conversation by offering the pamphlet to the resident and/or their family caregiver. It is important to remember that the pamphlet may not be appropriate for all persons due to the literacy and/or cognitive ability of the reader. If this applies, suggest a time and environment that you can review the pamphlet together. Depending on the situation (e.g., the resident's health is changing/declining, the resident and/or family caregiver have questions about health status or quality of life, an advance care planning conversation has not taken place), it may be appropriate to coordinate a meeting with the primary care provider and larger healthcare team. This conversation may be face-to-face or arranged through a telephone call or videoconference.

Examples of Conversation Starters

Perception Check: It is important to confirm that the resident and/or family caregiver has received the diagnosis of the life-limiting illness you wish to discuss. Healthcare providers can open a conversation about the diagnosis using the following examples. **If the resident and/or family caregiver is not aware of a diagnosis, pause the conversation to follow up with primary care provider**.[1]

"What has your/your family member's health care team told you about the diagnosis?"
"What is your/your family member's understanding of the diagnosis(es)?"

Offering the Illness Trajectory Pamphlet(s): If the resident and/or family caregiver is aware of the diagnosis, use your judgement to offer them information through the appropriate pamphlet(s).

"I understand there is a lot of information to learn/review, so we can start with a pamphlet. Take some time to look through it and consider the questions you may have or points you would like to discuss. Let's arrange a time so that we can meet to discuss with the larger healthcare team."

"What is your understanding of the term 'palliative care'?" I understand this may be a new term to consider when thinking about your/their life-limiting illness. Here is a pamphlet highlighting the information we have discussed so far. Take some time to look through it and consider additional questions you may have or points you would like to discuss. Let's arrange a time so that we can meet to follow-up."

Following-up with the Resident and/or Family Caregiver: After the resident and/or family caregiver has reviewed the pamphlet information, the healthcare provider may opt for one of the following prompts to initiate the follow-up conversation with the healthcare team.

"Do you have any questions about the pamphlet?"
"Did you find any of the material confusing or unclear?"
"Do you have any fears about the illness or how it will progress?"
"Let's arrange a time to discuss or revisit your/your family member's wishes for care."

Key Communication Principles

When responding to questions and conversing with residents and/or family caregivers, consider and incorporate the following key communication principles: [1-3]

- Ensure that you offer the participants your full attention.
- Provide an environment which has minimal distractions and offers a reasonable level of privacy.
- Offer information in easy-to-understand language.
- Watch for non-verbal communication cues such as body language and tone. For example, be aware of cues that may indicate confusion, such as furrowed brows. Provide additional details if needed.
- Be aware of the non-verbal messages you send to the resident or their family caregiver, too. Your body language and tone should match the message you are sending.
- Avoid using metaphors or euphemisms to soften language (e.g., drift away, pass, nearing the end). For example, use terms such as end-of-life care, advanced-stage, and life-limiting illness. Terms such as “death” or “dying” should be used as they provide a clear definition.
- Offer factual information based on clinical evidence and assessment. Invite the resident and/or family caregiver to share their experiences and observations, too.
- Remain respectful of cultural, spiritual, and societal expectations and how they may influence the conversation.
- End conversations with a confirmation of any follow-up required, as well as an invitation to continue the conversation with the healthcare team or appropriate individual (e.g., primary care provider, pharmacist, recreationist, dietitian).

In any conversation with residents and/or their family caregiver(s), it is essential to remember that communication is a two-way street. Be mindful of taking opportunities to check on the resident’s and family caregiver’s understanding of the information that you have communicated to them. **As resident and family caregivers are partners in care, invite them to share their feelings, experiences, and observations during the discussion**.

Introduction to a Palliative Approach to Care

Residents and/or their family caregivers may wish to learn more about a palliative approach to care. The following provides examples of questions and suggested/adaptable responses that healthcare providers can tailor to the resident and/or family caregiver's needs.

What is a palliative approach to care?

"Palliative care focuses on maintaining and improving the quality of life of the resident and supporting their family caregiver when faced with a life-limiting illness. A palliative approach shifts the focus from "curing" or treating the life-limiting illness towards symptom management. The goal of palliative care is to ensure that the resident remains comfortable (e.g., physically, emotionally, socially and spiritually) as the illness progresses."[1]

"A palliative approach to care includes treating conditions deemed appropriate, managing pain and other symptoms, as well as focusing on emotional, social and spiritual support-all to promote quality of life."[1,2]

When can a palliative approach to care be initiated?

"A common misunderstanding is that palliative care is only offered to people who are actively dying, or in their last month or days of life.[3] This is not the case. A palliative approach to care is appropriate for anyone who has been diagnosed with either a life-limiting, or terminal illness[1,4]

"Essentially, this approach is appropriate for illnesses that people die from (or with). It can be initiated at any point of the diagnosis, with early activation showing better outcomes in terms of quality of life and comfort.[3,4]

Family Caregivers & Supporting a Palliative Approach to Care

The following provides potential questions and suggested adaptable responses to family caregivers about supporting a palliative approach and end-of-life care considerations.

When do I begin to provide support to my family member?

"Family caregiving can begin at any point of the diagnosis. Acting as a caregiver can be more than providing physical care or making health care decisions (when appropriate/as named Substitute Decision Maker), it can involve offering emotional support and comfort."[5,6]

"However, making decisions on behalf of your family member can only occur if they have asked you to, or when their primary care provider determines they are no longer capable of making decision on their own behalf."[6]

For the named Substitute Decision Maker: "How does the responsibility of making medical decisions sit with you? Let's identify any questions you might have to inform your decision making on behalf of your family member. The primary care provider/healthcare team is here to provide information about your family member's condition and support you in decision making."[6]

Suggestions for Enhancing Quality of Life & Time Together

Sometimes family caregivers appreciate suggestions on spending time and providing emotional support to their family member living in long-term care. Healthcare providers can ask questions of caregivers to learn more about their family member's favourite past times, cherished memories, and relationships. Healthcare providers can also share their observations and experiences in how the resident enjoys spending their time. Healthcare providers can suggest ways in which family caregivers can support their family member and spend time with them. Here are a few examples:

1. You have mentioned that your grandma used to be quite the cook. Maybe you would like to try one of her famous recipes and bring a plate next time you come to visit.
2. Your great aunt mentioned that she felt homesick, and that she misses her mom's Sunday baking. Together we can set-up an automatic bread maker in the hall. She may find the smell of fresh bread comforting.
3. You have mentioned that your husband was an avid gardener back home. There are a couple of great windows in the common room. Maybe next time you come to visit, you two could plant a couple vegetables in planters? That way he'll be able to continue gardening here.
4. Your friend loves to talk about his life when he was a young man. Do you have any old photos that you could bring in? He seems to enjoy reminiscing about all that he has lived.
5. I know your wife loves to dance. We could put on some of her favorite music in her room, and clear away a spot for a dance floor. She might enjoy that.
6. The care home may be unfamiliar for your brother, as it is something new and always changing. Does he have any paintings, photos, or anything else from back home that we could place in his room here? It might help the place seem more familiar.
7. You have mentioned your dad loved dogs and has had a pet for most of his life. Maybe you could bring your dog with you the next time you visit?
8. Your grandma seems to really enjoy doodling in her sketchbook. Next week we are holding a paint night for the residents, would you like to join?
9. Does your dad have a favorite blanket from back home? We could put it on his bed to help him sleep.
10. Do you have any mementos or photos from your uncle's working life? We use them to decorate their room.

End-of-Life Considerations

How do I know my family member is dying?

The following may be indicators that someone diagnosed with a life-limiting illness is nearing death. When describing end-stage changes to family caregivers, offer examples which relate to the individual as well as those they might anticipate.[7,8]

- **Circulation**: The resident's hands and feet may feel cool to touch; lips and nails may appear grey or blue-ish.
- **Skin**: They may have an increase in skin breakdown (e.g., open wounds on the skin, or pressure ulcers).
- **Diet**: The resident may no longer desire to eat or drink; they are not starving or thirsty but simply do not require the same amount of energy as before.
- **Sensation**: They may experience the presence of discomfort, or pain, although awareness of pain will decrease.
- **Consciousness**: The resident may experience a decreased level of wakefulness (e.g., increased periods of sleep with the resident being difficult to rouse or unresponsive), and increased confusion.

- **Breathing**: Their breathing may change in rate, depth, and rhythm. Breaths may appear delayed, slow and/or sporadic. These signs can be present even with oxygen support.
- **Senses**: The resident may experience a decrease in vision and hearing; however, hearing can remain up until the last hours of life even when the resident has become unresponsive.
- **Affect**: The resident may experience an increase in agitation and restlessness.

As the resident approaches death, healthcare providers can take the opportunity to prepare family for these common signs and symptoms of the dying process. This is a good time to reinforce a holistic approach to managing symptoms, including physical needs, but also emotional, social, and spiritual support. As such, pharmacological and non-pharmacological supports can be discussed as appropriate.

Frailty

Illness Summary

Frailty is described as the **gradual decline in the body's state,** characterized by increased weakness, decreased muscle mass, and overall reduced physical and/or cognitive health**.** This means that the person will have increased vulnerability to various stressors, such as illness, infection or even a change in medication.[1] Frailty can be a standalone diagnosis or coincide with a secondary illness or disability, such as dementia or respiratory disease.[2] Stressors can cause **acute events** that can **lead to a sudden or drastic decline in health**.[1] Given the body's reduced reserves, following an illness, recovery to the person's normal level of health and ability is more limited.[1]

Clinicians can use different clinical indicators to diagnose or stage frailty, from mild to severe. The Clinical Frailty Scale is one such tool that pictorially categorizes frailty from very mild to very severe on a 9-point scale, using the person's fitness or ability to perform activities of daily living (ADLs).[3] Some key symptoms of frailty can include (but not limited to) sarcopenia (loss of muscle mass and function), anorexia (lack of appetite), fatigue/exhaustion, low mood or depression, decline or inability to perform activities of daily living (ADLs), and a decline in cognition.[1-3]

The progression of **frailty is gradual**, with those diagnosed experiencing symptoms for extensive periods of time. **This gradual but slow decline results in frailty being oftentimes overlooked and the symptoms being incorrectly attributed to aging**.[1] Frailty is not considered an aspect to normal aging; however, frailty is more commonly seen in older adults.[2]

Conversation Guide

What are the signs and symptoms of frailty?

Healthcare providers should tailor the information to acknowledge the resident's current frailty symptoms. They can focus on symptoms which relate to their present stage in addition to the stage(s) that follow.

"Understanding the symptoms that you/your family member may experience can help you to anticipate and prepare for what is to come. I can explain some of the common signs and symptoms to you. **Physical symptoms** include loss of muscle mass or muscle wasting, decreased appetite and weight loss, and feeling tired, fatigued or even exhaustion.[1] While these physical symptoms are important to anticipate, it is also important to understand how they **influence overall health and quality of life**. In mild stages of frailty, you/your family member will be able to do personal care and be more likely to recover from minor illness. As frailty progresses, you/your family member can become fully dependent on others for personal care and may be very susceptible to minor illnesses.[1-3] Recovery from minor illnesses may take longer and you/your family member may not recover to the previous level of ability or wellness prior to the illness."

"I would like to invite you/your family member to consider a conversation with the primary care provider and larger healthcare team to discuss how we can manage the symptoms as they progress. What changes are you noticing? What symptoms are you most concerned about?"

How does frailty progress?

"It can be difficult to predict the transition to the end-of-life period, given the gradual decline in functional abilities and overall health.[1] While the progression of frailty is often very gradual, acute events (e.g., pneumonia, fall) add a degree of uncertainty, increasing the risk for mortality and making each person's experience is unique."

What strategies can delay the progression of frailty?

"Steps can be taken to improve overall health and reduce the risk of acute events. Increasing physical activity, staying up to date on vaccinations, medication optimization, and promoting a healthy diet may be beneficial.[1,4] If you have more questions regarding treatment, we can help facilitate a discussion with your/your family member's primary care provider, pharmacist and dietitian."

How do I know frailty is progressing?

"Understanding the progression of frailty and may help you prepare for what is to come." Example: You have mentioned that you think your family member has lost a visible amount of weight. As frailty progresses, you may notice loss of muscle mass and progressive weight loss. You may have also noticed that your family member may need help with things that they didn't need help with before (e.g., moving from their bed to the chair). These changes might be difficult to accept; however, as frailty progresses you may notice that they have a decrease in mobility and become more dependent on others for care.[1,3]

"I would like to invite you/your family member to consider a conversation with the primary care provider and larger healthcare team to discuss how we can manage the symptoms as they progress. What have you/your family member done in the past to manage symptoms? How effective were those interventions in managing the symptoms?

How can we support a palliative approach together?

"In supporting a palliative approach, the primary care provider and healthcare team can offer guidance on medical and complementary therapies. In partnership with the team, you can advocate for yourself/your family member to ensure healthcare wishes are communicated.

Together we can explore managing symptoms as well as promoting quality of life. Some of the areas we might want to explore include:

- assessing for and managing pain
- psychological support to address any anxiety or fear related to an advanced illness and progressing symptoms

- movement therapy to promote range of motion and physical comfort
- nutrition and hydration support for comfort and socialization
- recreation therapy to promote socialization and entertainment
- social and spiritual support”

Healthcare providers can also take this moment as an opportunity to offer specific guidance on how family caregivers can offer comfort and joy in support of their family member. They can appeal to the interests of the family caregiver and resident to offer suggestions on safe activities that they can do together. See suggestions on **Enhancing Quality of Life and Time Spent Together** section.

“I have heard your grandma loved reading. While she may not be interested in reading herself, maybe next time you come to visit you can read her favorite book to her?”

Where can I go for more information?

“We covered a lot of information, and I can understand that you’ll likely have more questions. If you have any more questions you can speak with the primary care provider, or any other member of their care team. I also recognize many people access additional information online. The Canadian Frailty Network is a good resource to access.[5]

Dementia

Illness Summary

Dementia is a disorder characterized by **significant decline in cognitive ability,** due to neurodegeneration.[1] Alzheimer’s disease is the most common form of dementia, especially in those over 65 years old.[2] Alzheimer’s disease is often characterized by severe cognitive decline, memory loss, frailty, and an overall decline in physical health.[1] Currently, there are no curative treatments; therefore, dementia is considered a life-limiting condition.

There are several types of neurodegenerative dementia which may vary in clinical presentation; however, they can share common symptoms.[1] For example, while different clinical tools can be used to stage dementia, Alzheimer’s Disease can be classed into three primary stages: early, middle, late or advanced. Each stage is characterized by cognitive and physical decline. The following table offers some examples (although not exhaustive) of changes that occur as dementia progresses.[3,4]

Description of Symptoms of Dementia Progression

	Stage		
	Early (Mild)	Middle (Moderate)	Late (Advanced Stage)
Memory	Short-term memory loss (e.g., unable to recall recent events/forgetful, misplace items, repeat questions and previous conversations)	Short-term and medium-term loss (e.g., less ability to remember new information, difficulty remembering family/friends)	Extensive memory loss (e.g., unable to recognize immediate family, unable to complete familiar activities like bathing or feeding oneself)
Cognition	Difficulty completing basic math and/or understanding	Moderate decline in ability to problem-solve and plan/carry out	Extensive decline in cognition (e.g., inability to plan/carry out actions);

	messages (e.g., telling the time)	actions; disorientation to current environment;	complete disorientation to current environment
Communication	Vague expression, mild aphasia (e.g., difficulty word finding or using the wrong word)	Speech slows; difficulty word finding or using the wrong word, decline in ability to understand/follow conversation and instruction (spoken and written)	Loss of vocabulary; non-verbal communication present; inability to understand/follow conversation and instruction
Motor Skills	Slower to respond to stimuli (e.g., touching a hot plate out of the oven, reaction time while driving); walking speed starts to slow	Continued decline in response time to stimuli; disconnect between intention and actions in movement; decline in coordination	Decline in ambulation; inability walk, stand or sit independently; difficulty swallowing
Mood and behaviour	Mood swings to apathy and/or depression; lack of facial expression; less interest/ability in connecting with others	Delusions, hallucinations, mood swings to depression may be present; decreased understanding of relationships and others	Agitation/mood swings, aggression, delusions, hallucinations may be present; socially withdrawn from others
Daily activities	Decline in ability/desire to perform activities or personal care (e.g., bathing)	Continued decline in ability to perform personal care	Mostly or completely dependent on others for personal care

Conversation Guide

What are the signs and symptoms of dementia?

Healthcare providers should tailor the information to the resident's current stage of dementia. They should focus on symptoms which relate to the present stage in addition to the stages that follow.

"Understanding the symptoms that you/your family member may experience can help you anticipate and prepare for what is to come. While we can't be certain when symptoms might occur, I can explain some of the common ones to you. In the moderate to advanced stages of dementia, symptoms move beyond short-term memory loss and include communicative and physical symptoms, like the loss of the ability to find words or understand instructions, or to do personal tasks independently like grooming or getting dressed.[1,3,4] In advanced dementia, memory loss and cognitive decline are significant and may include not recognizing long-term friends or family, the inability to verbally communicate or carry out personal care. These are just a few examples, so that you can anticipate some of the likely changes".

"I would like to invite you/your family member to consider a conversation with the primary care provider and healthcare team to discuss how we can manage the signs and symptoms as they progress. What changes are you noticing? What symptoms are you most concerned about?"

How does dementia progress?

"It can be difficult to predict exact life expectancy. What we do know is that dementia is a chronic and life-limiting disease.[1] Dementia will progress through stages of severity, ultimately leading to death. Some days may be better than others, with less confusion, but physical and cognitive changes are ultimately permanent and cannot be reversed."

How do I prepare and deal with the changes in behaviour?

When describing behaviour changes to the resident/family caregiver offer examples which relate directly to the individual.

"Experiencing/watching family member's behaviour change can be upsetting and difficult to accept.

For family caregiver: Last night, a friend accused your family member of stealing their wallet. While it may be odd or even confusing, it is a fairly typical behaviour change that we see in those with advanced dementia. People living with dementia, especially in the advanced stages, can experience hallucinations and confusion.[3,4] This means that they may not be experiencing the world in the same way that we are, and that's okay. So, while these behaviours may be shocking, they are nothing to be embarrassed or ashamed of. Let's meet with the larger healthcare team to discuss ways to support your family member with these changes."

What strategies can delay the progression?

"There are medications such as acetylcholinesterase inhibitors which may help to stabilize and/or slow the progression of dementia, but they do not offer a cure.[5] Additionally, there are medications and other therapeutic interventions that can help treat other symptoms such as agitation, depression, difficulty sleeping, etc. There are also many strategies which may delay the progression of dementia such as social activity, smoking cessation, movement/exercise, reading or playing games.[5] If you have more questions regarding treatment, we can help facilitate a discussion with your/family member's primary care provider and/or their pharmacist."

How do I know dementia is progressing?

"Knowing what the symptoms of advanced dementia are important to preparing for and understanding what you/your family member will experience.
Example: Previously, you have mentioned that your family member has been confused about who you are and cannot remember their grandchildren. That memory loss must be hard for you to experience. As dementia progresses, declining and severe memory loss is anticipated.[3,4] In addition to their decline in memory, you may have also noticed that they need help moving to their wheelchair and find it difficult to speak or find the right words."

"I would like to invite you/ your family member to consider a conversation with the primary care provider and larger healthcare team to discuss how we can manage the signs and symptoms as they progress. What changes are you noticing? What changes are you most concerned about managing?"

How can we support a palliative approach together?

"In supporting a palliative approach, the healthcare team can offer guidance on medical and complementary therapies. In partnership with the team, you can advocate for yourself/your family member to ensure healthcare wishes are communicated.

Together we can explore managing symptoms as well as promoting quality of life. Some of the areas we might want to explore include:

- assessing for and managing pain
- psychological support to address any anxiety, fear or responsive behaviours related to an advanced illness and progressing symptoms
- movement therapy to promote range of motion and physical comfort
- nutrition and hydration support for comfort and socialization
- recreation therapy to promote socialization and entertainment
- social and spiritual support"

Healthcare providers can also take this moment as an opportunity to offer specific guidance on how family caregivers can offer comfort and joy in support of their family member. They can appeal to the interests of the family caregiver and resident to offer suggestions on safe activities that they can do together. See suggestions on **Enhancing Quality of Life and Time Spent Together** section.

I know your mom really enjoyed the companionship of her dog before moving into this home. Would you like to visit when we have our bi-weekly pet therapy session and spend time together with the animals?

Where can I go for more information?

"We covered a lot of information, and I can understand that you'll likely have more questions. If you have any more questions you can speak with the resident's primary care provider, or any other member of their care team. I also recognize many people access additional information online. The Alzheimer's Society of Canada has several resources to learn more about dementia including services and support programs for you, family members or caregivers."[6]

Advanced Heart Failure

Illness Summary

Heart failure is caused by conditions such as hypertension (**high blood pressure**) or coronary artery disease (**narrowing of the blood vessels**), which can contribute to abnormal heart function or structure. In heart failure, the heart is **unable to effectively pump oxygenated blood throughout the body**.[1] Advanced heart failure is characterized by chronic and persistent symptom presentation despite pharmacological interventions and typically resulting in death.[2] Heart failure is classified according to the severity of symptoms. The New York Heart Association (NYHA) Functional Classification is used in Canada to classify heart failure from no symptoms (Class I), to mild (Class II), to moderate (Class III) and severe (Class IV).[1]

Symptoms of advancing heart failure can include but are not limited to:

- dyspnea (shortness of breath or difficulty breathing),
- weight gain (due to fluid retention),
- bloating,
- cough or cold symptoms lasting greater than a week,
- extreme fatigue
- loss of or change in appetite,
- edema (swelling) in ankles, feet, legs, sacrum (buttocks), or abdomen,
- limited or inability to participate in any physical activity,

- chest pain, and
- nocturia (waking up to urinate at night).[3,4,5]

Conversation Guide

What are the symptoms of heart failure?

Healthcare providers should tailor the information to the resident's current class of heart failure. Focus on symptoms which relate to their present class in addition to those that follow.

"Understanding the symptoms that you/your family member may experience can help you anticipate and prepare for what is to come. In mild heart failure, symptoms might not be obvious; however, there are structural/functional changes impacting the heart. As these changes to the heart progress, we may begin to see a decline in the ability for the heart to pump blood resulting in mild tiredness, and shortness of breath. In severe or advanced heart failure, symptoms such as shortness of breath, chest pain, fatigue, fluid retention, persistent cough, swelling and bloating may be present.[3,4] These are just a few examples of changes."

"I would like to invite you/your family member to consider a conversation with the primary care provider and larger healthcare team to discuss how we can manage the signs and symptoms as they progress. What changes are you noticing? What symptoms are you most concerned about?"

How does heart failure progress?

"It can be difficult to predict the exact path that the heart failure condition will take. However, heart failure typically includes a period of successful responses to treatment that eventually lose their effectiveness as the disease progresses. It is important to know that each person's experience is unique, as progression of the disease is variable depending on lifestyle and other related comorbidities and respective management and compliance with the same."[1]

Can the progression be delayed?

"There are many pharmacological treatment options that have shown to be effective with managing symptoms and delaying the progression of disease. In addition, other lifestyle interventions such as smoking cessation, weight loss, reducing sodium intake and managing other chronic diseases such as diabetes are also beneficial.[4] While these interventions may delay the progression of disease, they do not offer a cure.[5] If you have more questions regarding treatment, we can help facilitate a discussion with your/your family member's primary care provider or their pharmacist."

How do I know that the heart failure condition is progressing?

"Knowing the symptoms of advanced heart failure is important to preparing for and understanding what you/your family member will experience."

Example: Previously, you have mentioned that your family member appears to be struggling to breathe when laying down. This symptom is caused by fluid buildup in the lungs. You have also mentioned that they have been getting tired more easily and have no interest in eating meals, even when family visits. As heart failure progresses, you may have also noticed that your family member seems more confused and agitated. This can be distressing to see but do know that these symptoms and related behaviors are common in advanced heart failure."[3-5]

"I would like to invite you/your family member to consider a conversation with the primary care provider and larger healthcare team to discuss how we can manage the signs and symptoms as they progress. What changes are you noticing? What changes are you most concerned about managing?”

How can we support a palliative approach to care together?

“In supporting a palliative approach, the primary care provider and healthcare team can offer guidance on medical and complementary therapies. In partnership with the team, you can advocate for yourself/your family member to ensure healthcare wishes are communicated.

Together we can explore managing symptoms as well as promoting quality of life. Some of the areas we might want to explore include:

- Assessing for and managing pain
- Psychological support to address any anxiety or fear related to an advanced illness and progressing symptoms (e.g., dyspnea, pain, reduced mobility, fatigue, edema)
- Movement therapy to promote range of motion and physical comfort
- Nutrition and hydration support for comfort and socialization
- Recreation therapy to promote socialization and entertainment
- Social and spiritual support”

Healthcare providers can also take this moment as an opportunity to offer specific guidance on how family caregivers can offer comfort and joy in support of their family member. They can appeal to the interests of the family caregiver and resident to offer suggestions on safe activities that they can do together. See suggestions on **Enhancing Quality of Life and Time Spent Together** section.

“I’ve heard your grandma loved music and was particular fan of Elvis. Maybe next time you come to visit you can bring a recording of her favorite songs?”

Where can I go for more information?

“We covered a lot of information, and I can understand that you’ll likely have more questions. If you have any more questions you can speak with your family member’s primary care provider, or any other member of the care team. I also recognize many people access additional information online. The Heart and Stroke Foundation of Canada and the Canadian Heart Failure Society has several resources to learn more about heart failure.[6,7]

Advanced Lung Disease

Illness Summary

Advanced Lung Disease (ALD), also known as **chronic obstructive pulmonary disease (COPD)**, is a **chronic condition** which is characterized by a progressive limitation and decline in airflow within the lungs.[1] The limitation in airflow results from the **narrowing of small airways** within the lungs (e.g., from chronic inflammation) and the destruction of the lung parenchyma (e.g., from emphysema), or the region which is responsible for gas exchange.[1,2]

Symptoms of advancing COPD may include but are not limited to:

- dyspnea (shortness of breath or difficulty breathing),
- cough/persistent cough,
- sputum production,
- fatigue/exhaustion,
- anorexia and weight loss, and

- psychological symptoms of anxiety and depression.[1]

COPD severity can be classed using the **Global Initiative for Chronic Obstructive Lung Disease (GOLD)** staging criteria. The GOLD system has 4 stages, which are based on post-bronchodilator spirometry, with the volume of air exhaled within the first second of a forced breath. The 4 stages are described as mild, moderate, severe, and very severe, with increased symptom burden as COPD progresses.[1,3]

As COPD progresses, the **frequency of acute exacerbations** (e.g., worsening of respiratory symptoms) **will likely increase**. Exacerbations are characterized by a sudden increase in symptoms (from baseline), which require additional treatment and management.[3] Exacerbations can be caused by infection and illness, environmental factors, irritants, or exercise, etc.[1,3] **An increase in severity of exacerbations may lead to respiratory failure**.[2]

Conversation Guide

What are the symptoms of advanced lung disease?

Healthcare providers should tailor the information to the resident's current symptoms of advanced lung disease. They should focus on symptoms which relate to their current condition in addition to what they can anticipate.

"Understanding the symptoms that you/your family member are likely to experience can help you anticipate and prepare for what is to come. While we can't be certain when symptoms might occur, I can explain some of the common ones to you. As you/your family member have likely experienced/observed, in the early stages of COPD, symptoms are typically milder and include a cough. As COPD progresses, the persistent cough continues, along with increasing shortness of breath (even with mild exertion), fatigue, loss of appetite and weight loss, and psychological symptoms like anxiety (worry) or depression.[1,4]

"I would like to invite you/your family member to consider a conversation with the primary care provider and larger healthcare team to discuss how we can manage the signs and symptoms as they progress. What changes are you noticing? What symptoms are you most concerned about?"

How does lung disease progress?

"It can be difficult to predict your/your family member's exact life expectancy. COPD can follow a relatively slow progression, but unexpected exacerbations can lead to disease progression and respiratory failure.[1,3] An exacerbation can be caused by infection, cigarette smoke or environmental irritants. As COPD progresses, exacerbations can become more frequent. The exact life expectancy can be hard to predict as disease progression is influenced by overall health, smoking history, etc. While it is important to know that each person's experience is unique, the fact that COPD is life limiting remains the same."

What strategies can delay the progression?

"While COPD is progressive and can't be cured, steps can be taken to potentially slow the progression and help prevent exacerbations. Keeping up to date on vaccinations, smoking cessation, avoiding environmental irritants, and managing other chronic conditions is essential.[1,3] In addition, pharmacological interventions may also be an option to improve breathing, decrease secretions, reduce inflammation, and manage symptoms.[3] If you have more questions regarding treatment and quality of life considerations, we can help facilitate a discussion with your/your family member's primary care provider, pharmacist and other members of the team."

How do I know the lung disease is progressing?

"Understanding the progression of COPD and what it will look like may help you emotionally prepare for what is to come."

Example: You mentioned that your family member appears to be anxious and is struggling to catch their breath when she walks to the washroom. I can see that this is distressing for both of you. As COPD progresses, you may begin to see them become increasingly more tired with movement, to a point where personal care become more difficult, and they may not feel like eating."[1,4]

"I would like to invite you/your family member to consider a conversation with the primary care provider and larger healthcare team to discuss how we can manage the signs and symptoms as they progress. What changes are you noticing? What symptoms are you most concerned about?"

How can we support a palliative approach to care together?

"In supporting a palliative approach, the primary care provider and larger healthcare team can offer guidance on medical and complementary therapies. In partnership with the team, you can advocate for yourself/your family member to ensure healthcare wishes are communicated.

"Together we can explore managing symptoms as well as promoting quality of life. Some of the areas we might want to explore include:

- Assessing for and managing pain
- Psychological support for managing anxiety due to shortness of breath and other symptoms
- Pharmacological management and/or breathing techniques to increase oxygen, decrease breathing effort and reduce shortness of breath
- Movement therapy to promote range of motion and physical comfort
- Nutrition and hydration support for comfort and socialization
- Recreation therapy to promote socialization and entertainment
- Social and spiritual support"

Healthcare providers can also take this moment as an opportunity to offer specific guidance on how family caregivers can offer comfort and joy in support of their family member. They can appeal to the interests of the family caregiver and resident to offer suggestions on safe activities that they can do together. See suggestions on **Enhancing Quality of Life and Time Spent Together** section.

"I've heard your mom loved movies. Maybe next time you come to visit; we can set up a movie for the two of you in her room."

Where can I go for more information?

"We covered a lot of information, and I can understand that you'll likely have more questions. If you have any more questions you can speak with your family member's primary care provider, or any other member of your care team. I also recognize people access additional information online. The Lung Association[5] has several resources to learn more about COPD. If you have any additional questions, please let a member of the healthcare team know."

Advanced Kidney Disease

Illness Summary

Chronic Kidney Disease (CKD) is a condition in which the **kidneys lose the ability to effectively filter blood and eliminate waste products from the body**. Advanced kidney disease, or end-stage renal disease results from near to complete loss of the function of filtration.[1]

CKD can be classed according to a specific estimated glomerular filtration rate (eGFR ml/minute per $1.73m^2$), with or without the presence of kidney damage (e.g., presence of protein in the urine). The eGFR indicates the ability in which the kidneys can filter blood and remove waste products; a lower GFR indicates decreased function of the kidneys.[1,2]

Damage to the kidneys is progressive, and kidney failure is ultimately inevitable. Advancing CKD may be managed through dialysis, organ transplant, or through **palliative and supportive care**.[3.4] In older adults, dialysis may be an option; however, the benefits should be considered with the likely impact of existing comorbidities like frailty or heart failure.[3] Prognosis is dependent on treatment and management options.

Symptoms of advancing kidney disease can include but are not limited to:

- pain (may be from other conditions)
- discoloured and/or foamy urine,
- dyspnea (shortness of breath),
- pruritus (itchiness),
- edema (swelling) in the legs and ankles,
- muscle cramping,
- restless legs,
- difficulty sleeping,
- poor appetite,
- fatigue[3,4]

Conversation Guide

What are the symptoms of Advanced Kidney Disease?

Healthcare providers should tailor the information to the resident's current stage of CKD. They can focus on symptoms which relate to their present stage in addition to the stages that follow.

"Understanding the symptoms that you/your family member may experience can help you anticipate and prepare for what is to come. While we can't be certain when symptoms might occur, I can explain some of the common ones to you. Symptoms in mild kidney disease might not be as obvious. At this stage the primary focus is on the presence of damage to the kidney, which can be identified by protein found in the urine, as well as a decline in filtration function.[1,2] In advanced kidney disease, or kidney failure, we see more significant symptoms as the kidney's function is severely limited. Symptoms like pain, muscle cramps, loss of appetite, swelling in hands and feet, shortness of breath, changes in urine output, and difficulties sleeping become evident.[3,4] These are just a few examples."

"I would like to invite you/your family member to consider a conversation with the primary care provider and larger healthcare team to discuss how we can manage symptoms as they progress. What changes are you noticing? What symptoms are you most concerned about?"

How does kidney disease progress?

“It can be difficult to predict the exact path that the illness will take, which is dependent on underlying comorbidities and related management. However, chronic kidney disease typically involves a progressive and irreversible decline in health.”[3]

What strategies can delay the progression?

“Treatment options are dependent on advancement of disease and underlying comorbidities. In some situations, dialysis may be an option; however, further discussion is needed with a specialist (nephrologist). Dialysis does not offer a cure in advanced stages; however, in some situations, dialysis is used to manage symptoms (palliative approach).[3] If you have more questions regarding treatment, we can help facilitate a discussion with you/your family member’s primary care provider and/or specialist (nephrologist).”

How do I know the kidney disease is progressing?

“Understanding the progression of kidney disease and what it will look like may help you prepare for what is to come.”

Example: “You mentioned that your dad appears to be uncomfortable and grimacing like he is in pain. You have also mentioned that he has been avoiding meals and isn’t hungry. It can be distressing to see, but both back pain and loss of appetite are anticipated; let’s discuss ways we can help to manage this experience with the healthcare team. As kidney disease progresses, you may begin to see your dad become increasingly more tired with movement and personal care becoming more difficult. You might notice swelling in the ankles or he may appear short of breath or have difficulty with breathing.”[3,4]

How can we support a palliative approach to care together?

“In supporting a palliative approach, the healthcare team can offer guidance on medical and complementary therapies. In partnership with the team, you can advocate for yourself/your family member to ensure healthcare wishes are communicated.”

Together we can explore managing symptoms as well as promoting quality of life. Some of the areas we might want to explore include:

- assessing for and managing pain
- psychological support to address any anxiety or fear related to an advanced illness and progressing symptoms (e.g., dyspnea, pain, reduced mobility, fatigue, edema)
- movement therapy to promote range of motion and physical comfort
- nutrition and hydration support for comfort and socialization
- recreation therapy to promote socialization and entertainment
- social and spiritual support

Healthcare providers can also take this moment as an opportunity to offer specific guidance on how family caregivers can offer comfort and joy in support of their family member. They can appeal to the interests of the family caregiver and resident to offer suggestions on safe activities that they can do together. See suggestions on **Enhancing Quality of Life and Time Spent Together** section.

“I’ve heard your grandpa loved watching and playing hockey. Maybe next time you come to visit we can put on a rerun of his team winning the Stanley Cup?”

Where can I go for more information?

"We covered a lot of information, and I can understand that you'll likely have more questions. If you have any more questions you can speak with your/your family member's primary care provider, or any other member of your care team. I also recognize many people access additional information online. The Kidney Foundation of Canada[5] has several resources including a peer support program to learn more about chronic kidney disease and renal failure. Some organizations have support groups; however, not all do. The Kidney Foundation of Canada has a Peer Support Program."

Falls

Falls Summary

Falls are the **primary cause of injury** in older adults,[1] and are a common occurrence for people residing in long term care (LTC) homes.[2] Every year, up to **50% of those living in long-term care homes** experience a fall.[2,3] In long-term care homes, healthcare providers should be mindful of resident's fall risk factors, including a history of previous falls.[2]

The risk of falling increases with age due to typical **age-related** physical and cognitive **changes**. These changes can affect the resident's balance, stability, muscle activation, and visual acuity and perception. In addition, residents may have conditions or multiple conditions (e.g., hypotension, anemia, dementia, frailty, profound sensory loss, arthritis, history of stroke) and/or be on medications that further contribute to their risk of falling.[2,4] Together, these are known as **intrinsic risk factors** for falling. Healthcare providers can determine the modifiable factors, or those that can be managed or adapted, to reduce the risk of falls and promote quality of life.[1,2] In addition, various **extrinsic of environmental factors** (independent or in combination with intrinsic factors) can contribute to falls. Some environmental factors include a cluttered room/common area, poor lighting, wet/slippery surfaces, and a new environment (e.g., moved furniture or room).[2] Falls typically result from a combination of factors.

Injuries from falls can very in nature from being more minor (e.g., bruising or scrape) requiring minimal treatment to more serious (e.g., wrist, leg or hip fracture, head injury) needing more complex intervention, including possible hospitalization for management.[2] Fractures, especially **hip fracture**, are of particular concern due to the potential for hospitalization and **increased mortality rate** in the year following the fall.[2] Even non-injury related falls can impact the resident with fear of mobilizing and resulting functional decline, as well as experiencing social withdrawal and depression.[4]

In partnership with the resident and/or family caregiver, **acceptable prevention measures** should be identified and implemented to reduce the risk of an initial fall as well as subsequent falls. However, not all risk factors can be managed (e.g., are non-modifiable)[1]; therefore, the risk of falling cannot be eliminated. In partnership, the primary care provider and team may wish to explore increased physical therapy and/or exercise programming to address gait and balance concerns; medication reconciliation to improve efficacy and reduce side effects; and using a mobility aid to improve gait and balance. Other interventions may be deemed appropriate following a fall analysis.[1,2,4]

Conversation Guide

Why are falls, even if minor, a concern?

"Falls are unique because they are an **event and not a specific illness**. They can happen to anyone, at any time, whether they are younger or older. However, for older adults, a combination of age-related changes, effects of chronic conditions, multiple medication use, and environmental factors can increase their risk of falling, as well as the severity of a fall related injury.[1,2,4] After suffering one fall, the risk of another fall also increases. While one fall might result in no injury or a relatively minor injury, like a bruise, subsequent falls might result in more of a serious injury, like a fracture of head injury.[2] Together with the primary care provider and larger healthcare team, we can take the information that we learned from the initial fall and strategize about preventative steps to reduce the risk of another fall."

What causes/caused the fall? How can we reduce the risk of falling?

Healthcare providers should focus on factors that relate directly to the resident.

"Understanding, assessing for, and managing (where able) the risk factors that can cause falls are keys to fall prevention. Using standardized tools, we can assess the risk of a fall or falling.[2] Falls can be caused by many different individual factors and factors in combination. The following are factors we can consider:

- A previous history of falls or falling.
- If you/your family member has been diagnosed with a chronic condition(s) that can contribute to falls (e.g., frailty, dementia, peripheral neuropathy).
- Medication use, as the side effects can impact alertness and balance.
- Gait and balance when walking or moving.
- Environmental factors (e.g., lighting and visibility in bedroom and common areas) that can be tripping hazards.
- Environmental factors (e.g., height of bed, location of call bell, use of hip protectors and footwear) that can be protective against falls. [1,2,4]

How serious is a hip fracture? Do we surgically intervene?

"Fractures are a common injury following a fall.[4] Especially in older adults, hip fractures are considered a serious injury. They can impair mobility, lead to depression or social withdrawal, cause chronic pain, or even lead to death.[2,4] Treatment often includes surgical repair of the hip,[5] however, discussing desire for surgery and possible risks associated with surgery are important. We can facilitate a conversation with the primary care provider and/or surgeon to allow you time to discuss all options and decide what is best."

Will use of a cane or a walker help to prevent a fall?

"In general, the use of a mobility aid (such as a cane or a walker) can reduce the risk of a fall.[2,6] For some residents, mobility aides promote greater independence (and quality of life) as they can more easily and safely mobilize. I would like arrange a conversation with you/your family member's primary care provider and/or physical therapist to discuss the safety and suitability of using a mobility aide."

How can we support a palliative approach to care together?

"In supporting a palliative approach, the healthcare team can offer guidance on medical and complementary therapies following a fall. In partnership with the team, you can advocate for yourself/your family member to ensure healthcare wishes are communicated."

Together we can explore managing post-fall symptoms as well as promoting quality of life. Some of the areas we might want to explore include:

- assessing for and managing pain
- psychological support to address potential restricted mobility
- movement therapy to promote range of motion and physical comfort
- recreation therapy to promote socialization and entertainment
- social and spiritual support

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