Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

Strengthening a Palliative Approach
SPA LTC
in Long-Term Care

Case Scenarios for Personal Support Workers

Facilitator Guide

Welcome!

Dear facilitator,

This is your manual. Please feel free to print it, add notes to it, and make it your own. Please also have it on-hand while you facilitate.

The manual contains three diverse scenarios that are derived from lived experiences in Long Term Care (LTC) homes. To maintain anonymity, all identifying information has been changed.

Each scenario is a stand-alone scenario and can take up to 20-30 minutes to complete or less depending on the group's level of knowledge and engagement.

The scenarios are not meant to be presented in any particular order. Personal Support Workers (PSWs) also do not have to take part in all three to engage in knowledge translation and skill development.

At the beginning of each scenario, you will find a brief introduction and definition of a *Palliative Approach to Care* and the *Domains of Issues Tool*. If you are presenting more than one scenario to the same group of PSWs, you must only present this section once.

Each scenario is linked to the SPA-LTC HEALTH CARE WORKER (HCW) AND PALLIATIVE EDUCATION PROGRAM (PEP) – SPA LTC. Please remind participants to complete the online modules if they have not yet done so.

We thank you for your interest in leading these case scenarios and for your commitment to becoming an active role model for change in our community to best support older adults living in Long Term Care homes and who are at end of life.

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Facilitator Role and Objectives

As a facilitator, you play an instrumental role in knowledge translation. Whether you are facilitating online or in person, when you are able to foster an inclusive, respectful and open space where participants can share and learn together, personal and professional development can occur.

The role of a facilitator is to:

- Guide the group through the curriculum and to help participants feel comfortable sharing and participating.
- Be a timekeeper.
- Help build and foster relationships and group synergy.
- Manage group discussions so that everyone has a chance to share and contribute to the discussion.
- Be aware of messages that come through the chat box (if you're facilitating online).
- Engage in active listening.
- Draw out knowledge from the group as a way to assist with shared learning.
- Summarize and clarify what participants/the group is saying – use their contributions to convey points of the workshop. You can do this by saying "What I'm hearing is''…" or "Do you mean… (paraphrase what you've understood)?"
- Be engaging.
- Answer questions. If you don't have the answer - don't make it up! Be honest and say that you'll get back to them with a resource or more information.
- Keep asking yourself, "What does the group need most at this moment?" And then try to do that.

Co-facilitation:

- If you are facilitating in a pair, this gives you an opportunity to be twice as aware of what's going on in the workshop, to complement each other's facilitator styles, and to have support if any challenging situations arise.
- Teamwork is key when working with a co-facilitator.
- Before the workshop, meet with your co-facilitator to:
    - Share how you tend to or like to facilitate (your facilitation preferences and style i.e., active, intense, light-hearted, quiet energy...)
    - It makes for a smoother and better workshop when facilitators have planned out how they would like to work together. It is crucial that you meet to find out who is more comfortable doing which parts and so forth. If you don't, the participants will be able to tell!

- Talk about your strengths/weaknesses as a facilitator.
- Discuss your comfort level with different parts of the workshop.
- Divide the tasks/sections.
- Develop strategies for how to address challenging points during the workshop.
- Brainstorm signals to use to communicate during the workshop.
- Prepare your responses and have supporting documents available if you choose to use scenarios outside of the ones provided.

The following are things to consider as you begin the discussion. Please use your judgment and take what fits best with you, the context, the group settings, and leave the rest.

At the beginning you may want to:

Section	**Confirm attendance**
Time	**1 minute**
Note	If this is required, make sure you or your co-facilitator is documenting the names of the participants in attendance.

Section	**Host introductions**
Est. Time of Delivery	**5 minutes**
Note	Introductions help to build connections, break the ice and encourage group discussion. If appropriate and you have the time, take a couple of minutes to introduce yourself in any of the following ways. Name, your role/training/profession/favorite (food, colour, or song, etc.) If you have a short ice breaker that you prefer to use, feel free to add it here - just be mindful of the time!

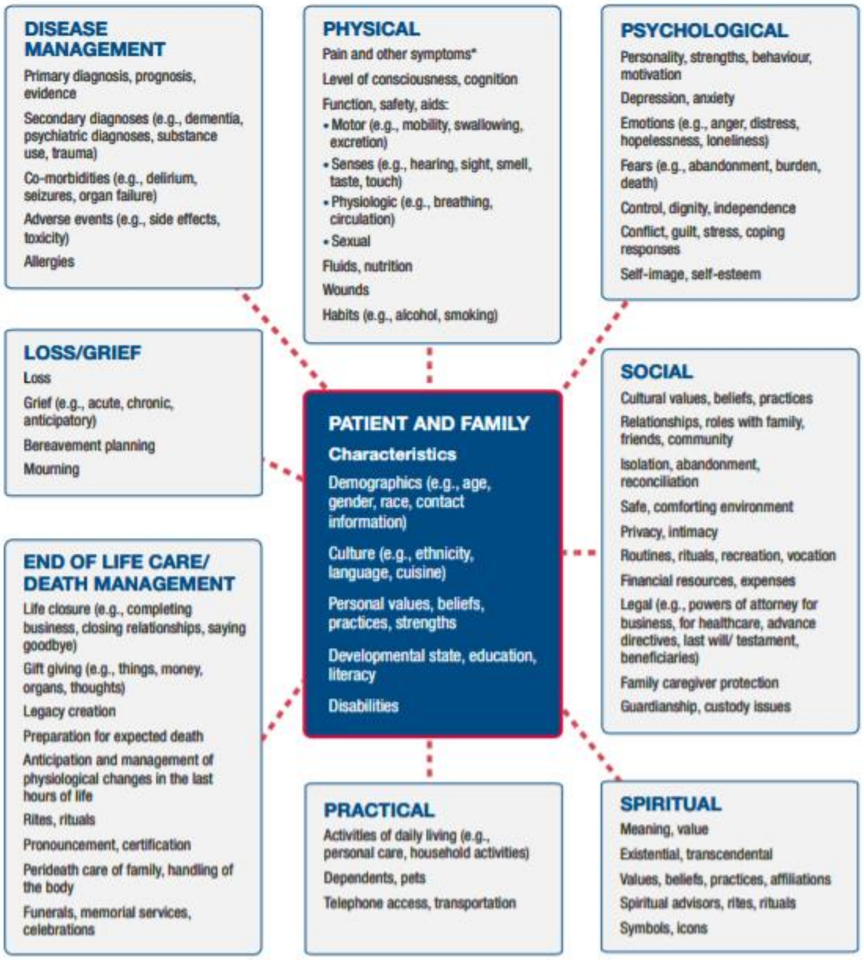
Section	**Additional things you might want to say at the beginning.**
Est. Time of delivery	**1-2 minutes** (if saying all points)
Do & Say	[***Facilitator note***: In this session, the facilitator(s) strive to create an inclusive, open space where participants can learn, share and explore possible situations that may arise in your place of work. We encourage participation. At the same time, to ensure confidentiality and respect for one another, please remind participants that if they are sharing a story to always maintain confidentiality (don't share details that can give away someone's identity). Additionally, due to the amount of material you will be covering, you may have to cut conversations short at certain times.] **Do:** 1. Introduce yourself and thank everyone for being here today. 2. Host 'Round-table' introductions (if time permits) 3. Inform participants of your role as timekeeper and how you will strive to create an inclusive, open space where participants can learn, share and explore together. 4. Acknowledge that there are people with different levels of knowledge in the session – and that we are all here to learn together. **Things to consider saying:** • As facilitators of this discussion, we know a lot but not everything. • It is important to remember that all experiences are diverse, unique, and can be experienced differently by different individuals. • If you, as a participant, choose to disclose a personal experience, consider the effects that this may have on the group now and after we leave the workshop. • When sharing a story, please make sure that no identifying information is given. That includes avoiding the use of other peoples' names or identifying remarks that could link a person back to an event • Respect what is said and build on discussion. • I (the facilitators) will stick around after the session in case anybody wants to ask questions, debrief, reflect, or share your thoughts with us.

Scenarios

	Balancing Risk and Independence Scenario Mrs. Elsa
Time	The scenarios can take roughly ***25-30 minutes*** to complete depending on participant engagement and group discussion.
Say	***Purpose of the case scenario****:* To offer Personal Support Workers the opportunity to identify resident concerns and communicate them to the health care team. PSWs will also gain a deeper understanding of how to incorporate a resident's values and beliefs into their individualized care plans, thereby promoting a more resident-centered approach to care.
Say	This case scenario is an extension of the SPA-LTC HEALTH CARE WORKER (HCW) AND PALLIATIVE EDUCATION PROGRAM (PEP) – SPA LTC E-Learning modules. If you have not yet completed the online modules, it is highly encouraged that you do so by visiting https://spaltc.ca/courses/spa-ltc-health-care-worker-hcw-and-palliative-education-program-pep/. This scenario relates to the modules on: ● Supporting Loss and Grief for Residents, Families, Staff, And Yourself. ● Providing Daily Comfort and Supporting Quality of Life. ● Communicating with Residents, Families and LTC Staff. ● Understanding Advance Care Planning (ACP) and Goals of Care.
Optional **Section** **5 minutes**	**Exploring a Palliative Approach to Care: A Brief Introduction**. **This section is optional depending on participants' level of knowledge and if you've already presented this in other case scenarios.

Say	To help ground our session today, I would like to start off with a short introduction on the use of the words “palliative” and “palliative care” in LTC. When using these words, health care workers and staff are often referring to the last hours to days of a resident’s life. However, a palliative approach to care aims to **relieve suffering and improve quality of life for any person living with or at risk of developing a life limiting illness**. A Palliative approach to care is best delivered by a multidisciplinary team and identifies and addresses issues in various domains of a person’s life. A Model to Guide Hospice Palliative Care: **Based on National Principles and Norms of Practice** was created by the Canadian Hospice Palliative Care Association and is a “model for delivering quality hospice palliative care based on a broad understanding of how people experience health and illness, and how the health care system responds to them” (p.3). Within this model is the ***Domains of Issue tool***. It is one way to conceptualize a palliative approach to care. You may also know this concept as a holistic/whole-person/resident-centered approach to care. ***Show/bring on screen the image of the model found below.***
Say	*[Facilitator note: show the Domains of Issue tool and briefly explore each category: disease management, physical, psychological, loss/grief, end-of-life care/death management, practical, spiritual, social, psychological.* ***Ask if participants are familiar with this model or a similar model?*** *Note: the issues in each domain (Figure 1 below) are examples and not an exhaustive list.]* According to the Canadian Hospice Palliative Care Association, “(t)o relieve suffering and improve quality of life, caregivers must be able to identify and respond to all the complex issues individuals and families may face, which can be categorized into eight equally important domains. If one or more issues are missed, they can compound one another, leading to distress. Each issue identified by the person and family also comes with expectations, needs, hopes and fears. For example: how will the illness affect my relationships with others? What can be done to change the experience and the way it will evolve? How can I restore or maintain my capacity for meaningful and valuable relationships with others for as long as possible? While each of these issues and its associated expectations, needs, hopes and fears can be challenging and stressful, they are also opportunities for growth” (p.4).

Figure #1: Domains of Issues Associated with Illness and Bereavement



* Other common symptoms include, but are not limited to:

Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns

Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia

Oral conditions: dry mouth, mucositis

Skin conditions: dry skin, nodules, pruritus, rashes

General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

Image reference: Canadian Hospice Palliative Care Association. (2013). *A model to guide hospice palliative care: based on national principles and norms of practice.*

Section	**Introducing Mrs. Elsa**
Say	Mrs. Elsa is a resident of a long term care home. She values her independence very much. However, Mrs. Elsa has had a few falls lately, often when she is walking on her own. She also does not like to use her walker for short trips within her room stating she doesn't feel she needs it. During her night shift rounds, Marie, a PSW, finds that Mrs. Elsa is in her bathroom on the toilet with the lights off. Marie goes in and turns on the lights and says to her "Mrs. Elsa, you are supposed to ring your bell for help to go to the bathroom. You're not safe to do it on your own!" Mrs. Elsa responds to Marie saying "I am 91 years old, and I've made it this far without your help! And you better not try to give me one of those bed alarms because I know how to turn it off! I've walked to the bathroom before, and I haven't fallen yet." Marie is distressed by this. She feels like it will be her fault if Mrs. Elsa falls on her shift.
Section	**Group discussion questions**
Ask	1. Does this scenario reflect the experience of residents that you have previously or currently care for? 2. What do you think Marie should do now? 3. Honouring personhood is important when providing a resident-centered approach to care. At the same time, Marie is concerned that if Mrs. Elsa falls, she will be at fault. How can the multidisciplinary team, LTC home and resident work together to bridge this divide? 4. (Optional question) How does Mrs. Elsa's scenario tie into the Domains of Issues tool? Possible ***suggestions*** to assist with problem solving and brainstorming responses to the scenario include: ● Talk with the RN about the situation. ● Engage Mrs. Elsa and perhaps her family in a discussion about her values, wishes and desires. Explore what it means for Mrs. Elsa to use a walker and any fears or concerns she may have about physical decline, loss of independence, accessing the staff when she needs help, etc. ● Find someone on her team to talk to about her distress over a possible fall and what that could mean for both Mrs. Elsa and Marie. ● Please add other suggestions that you have to share.

Say	**Mrs. Elsa's Story Continued** Marie reports her interaction to the RN and finds this is a regular recurrence. A care conference is held with the multidisciplinary team, Mrs. Elsa and her family to discuss her values and goals of care. The decision was made for the team to continue to offer support to Mrs. Elsa for ambulation to and from the bathroom, but to respect her decision if she declines. She and her family accept the risk for falls and are aware of the potential outcomes. No bed/chair alarms will be put into place as fall prevention interventions.
Section	**Group discussion questions**
Ask	● What concerns, if any, do you have about this care planning approach? ○ If you have concerns about the care planning approach, how can you communicate and/or address your concerns to the RN or the team so that the resident is able to enjoy their highest level of independence? ● What are some ways in which Mrs. Elsa's preferences and care plan can be communicated to the team so that everyone involved in her care is aware?
Section	**Personal Reflection Questions**
Say & Ask	Should a situation arise like this in the future, you might want to take some time after this session to further think about and reflect on this scenario. Questions to explore could be: ● How might you feel if Mrs. Elsa falls and breaks her hip and needs to go to hospital for surgery? ● How might you be able to address those feelings? ● What supports are available to you to help you through an experience like this? Consider the support of your colleagues, manager, the RN, other support networks, etc. ● What would you need, if anything, from your team to feel confident supporting Mrs. Elsa in her care plan?

Section	**Inform Practice – Discussing Values, Wishes and Beliefs**
Say	*[Facilitator note: read the following suggestions to the group and invite participants to give their suggestions as well.]* To provide the best possible resident-centered approach to care, staff need to get a sense of what is most important to the residents and use that information in their

	care plan. This can be achieved by creating a space free of judgment where residents can talk openly and honestly about their values, preferences, wishes and beliefs. As a PSW, you typically spend the most one-on-one time with residents each day during personal care. This provides you with a unique opportunity where you can work on relationship building and get to know the resident further (their values, wishes and beliefs). In the case of Mrs. Elsa, it is clear that she values her independence and is willing to accept certain risks (risk of falls resulting in injury). It will be important to learn more about her perspective on risk versus independence to ensure that her wishes and preferences are better understood and communicated amongst the team. **Suggested ways to open-up the discussion with a resident can include:** ● I can see independence is important to you. Can you tell me more about what independence means to you and what it resembles in your day-to-day life? ● Are there other times in your life where taking a risk was something that you were willing to do for independence? Tell me about them? ● Are there some risks that are too big to take and what might they be? **Broader questions used to get to know a resident can include:** ● Tell me a little bit about yourself. ● What do I need to know about you to give you the best care possible? ● Who supports you? ● Mrs. Elsa, at this time in your life, what is important to you? Even asking about things such as favorite hobbies, past career or travel experiences, favorite foods, can start a conversation about a resident's values, wishes and beliefs. Doctors and nurses often engage in goals of care discussions with residents in order to guide treatment decisions (when testing or medication changes are needed, for example) and ensure that their care is based on the residents' expressed wishes. As a PSW, the conversations that you have with your residents allow you to learn about who the resident is as a whole-person and to make great contributions to resident-centered care planning.
Section	*This is the end of the case scenario. Thank you for taking part and for sharing in the discussion. If you have other questions, please let me know!*

	Supporting Quality of Life in Advancing Illness Scenario Mr. Jay
Time	The scenarios can take roughly ***25-30 minutes*** to complete depending on participant engagement and group discussion.
Say	**Purpose of the case scenario:** Personal Support Workers will briefly learn about a palliative approach to care in long term care settings to support resident overall wellbeing, become familiar with the *Domains of Issue* tool used to help identify and address issues that may arise in the various domains of a person's life, and be provided with an opportunity to explore how social and recreational activities contribute to a resident's wellbeing.
Say	This case scenario is an extension of the SPA-LTC HEALTH CARE WORKER (HCW) AND PALLIATIVE EDUCATION PROGRAM (PEP) – SPA LTC E-Learning modules. If you have not yet completed the online modules, it is highly encouraged that you do so by visiting https://spaltc.ca/courses/spa-ltc-health-care-worker-hcw-and-palliative-education-program-pep/. This scenario relates to the modules on: ● Supporting Loss and Grief for Residents, Families, Staff, And Yourself ● Providing Daily Comfort and Supporting Quality of Life ● Recognizing Pain, Suffering & Common Symptoms of Advancing Illness ● Understanding Advance Care Planning (ACP) and Goals of Care.
Optional **Section** **5 minutes**	**Exploring a Palliative Approach to Care: A Brief Introduction**. **This section is optional depending on participants' level of knowledge and if you've already presented this in other case scenarios.

Say	To help ground our session today, I would like to start off with a short introduction on the use of the words “palliative” and “palliative care” in LTC. When using these words, health care workers and staff are often referring to the last hours to days of a resident’s life. However, a palliative approach to care aims to **relieve suffering and improve quality of life for any person living with or at risk of developing a life limiting illness**. A Palliative approach to care is best delivered by a multidisciplinary team and identifies and addresses issues in various domains of a person’s life. A Model to Guide Hospice Palliative Care: **Based on National Principles and Norms of Practice** was created by the Canadian Hospice Palliative Care Association and is a “model for delivering quality hospice palliative care based on a broad understanding of how people experience health and illness, and how the health care system responds to them” (p.3). Within this model is the ***Domains of Issue tool***. It is one way to conceptualize a palliative approach to care. You may also know this concept as a holistic/whole-person/resident-centered approach to care. ***Show/bring on screen the image of the model found below.***
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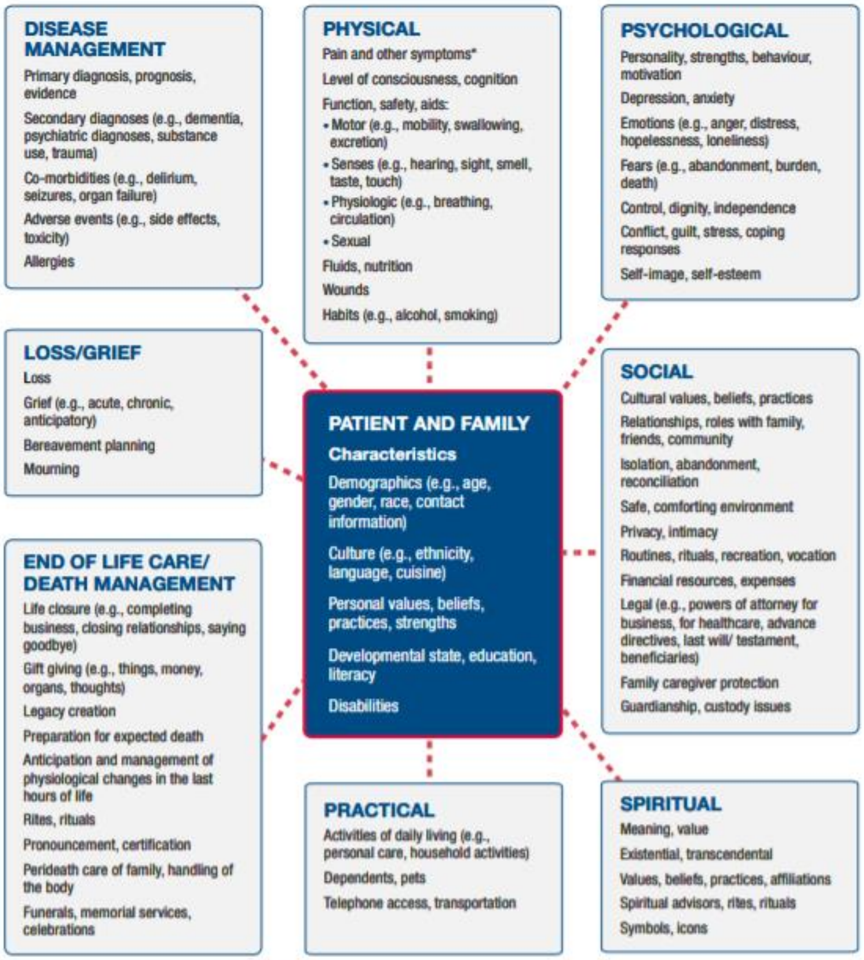


DISEASE MANAGEMENT

Primary diagnosis, prognosis, evidence

Secondary diagnoses (e.g., dementia, psychiatric diagnoses, substance use, trauma)

Co-morbidities (e.g., delirium, seizures, organ failure)

Adverse events (e.g., side effects, toxicity)

Allergies

PHYSICAL

Pain and other symptoms*

Level of consciousness, cognition

Function, safety, aids:
- Motor (e.g., mobility, swallowing, excretion)
- Senses (e.g., hearing, sight, smell, taste, touch)
- Physiologic (e.g., breathing, circulation)
- Sexual

Fluids, nutrition

Wounds

Habits (e.g., alcohol, smoking)

PSYCHOLOGICAL

Personality, strengths, behaviour, motivation

Depression, anxiety

Emotions (e.g., anger, distress, hopelessness, loneliness)

Fears (e.g., abandonment, burden, death)

Control, dignity, independence

Conflict, guilt, stress, coping responses

Self-image, self-esteem

LOSS/GRIEF

Loss

Grief (e.g., acute, chronic, anticipatory)

Bereavement planning

Mourning

PATIENT AND FAMILY

Characteristics

Demographics (e.g., age, gender, race, contact information)

Culture (e.g., ethnicity, language, cuisine)

Personal values, beliefs, practices, strengths

Developmental state, education, literacy

Disabilities

SOCIAL

Cultural values, beliefs, practices

Relationships, roles with family, friends, community

Isolation, abandonment, reconciliation

Safe, comforting environment

Privacy, intimacy

Routines, rituals, recreation, vocation

Financial resources, expenses

Legal (e.g., powers of attorney for business, for healthcare, advance directives, last will/ testament, beneficiaries)

Family caregiver protection

Guardianship, custody issues

END OF LIFE CARE/ DEATH MANAGEMENT

Life closure (e.g., completing business, closing relationships, saying goodbye)

Gift giving (e.g., things, money, organs, thoughts)

Legacy creation

Preparation for expected death

Anticipation and management of physiological changes in the last hours of life

Rites, rituals

Pronouncement, certification

Perideath care of family, handling of the body

Funerals, memorial services, celebrations

PRACTICAL

Activities of daily living (e.g., personal care, household activities)

Dependents, pets

Telephone access, transportation

SPIRITUAL

Meaning, value

Existential, transcendental

Values, beliefs, practices, affiliations

Spiritual advisors, rites, rituals

Symbols, icons

* Other common symptoms include, but are not limited to:

Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns

Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia

Oral conditions: dry mouth, mucositis

Skin conditions: dry skin, nodules, pruritus, rashes

General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

Image reference: Canadian Hospice Palliative Care Association. (2013). *A model to guide hospice palliative care: based on national principles and norms of practice*.

Section	**Introducing Mr. Jay**
Say	Mr. Jay has lived at a long term care home for the past five years. He is very involved in the residents' council and often takes the lead on planning the home's social activities. His favourite role is to call out the bingo numbers at the biweekly bingo night. Lately, Mr. Jay's COPD has been worsening. He has been admitted to the local hospital twice in the past six months due to worsening shortness of breath and chest infections. He is now unable to tolerate much activity at all without easily becoming breathless. One evening after dinner, Peter, a PSW, goes to Mr. Jay's room to ask him if he would like some help getting ready for bingo as Peter knows this is Mr. Jay's favourite activity. Mr. Jay tells Peter he doesn't want to go to bingo anymore because he can barely speak without getting winded and feels he would be ruining the game for everyone else if he needed to take breaks between calling numbers. Peter tries to tell Mr. Jay that everyone would miss him, but Mr. Jay still refuses to come. Peter is concerned because Mr. Jay seems really down. He decides to speak with the recreation staff about his conversation with Mr. Jay to see if there would be any way to support him to engage in his usual social activities.
Section	**Group discussion questions**
Ask	1. How do social and recreational activities contribute to a resident's wellbeing? 2. How are resident's social and recreational preferences being addressed in your workplace? 3. A holistic/resident-centered approach to care means **to provide support that looks at the whole person**. Considering this, what are some diverse ways that you, your team and the LTC home can support Mr. Jay continue in this social role? a. To help reduce risks of isolation b. To help maintain relationships with friends and community c. To help maintain a comforting environment. Possible ***suggestions*** to assist with problem solving and brainstorming responses to the scenario include: ● Having access to a speaker to emphasize his voice/call out the numbers so he doesn't have to exert so much? ● Exploring the possibility of pacing – could Mr. Jay attend bingo half time, find a partner that he could mentor to help him out and cover in his absence? ● Consider the use of medication for dyspnea, especially proactively to a planned event. ● Further explore how Mr. Jay understands and thinks about the progression of his illness so you can best support him.

Section	**Mr. Jay story continued**
Say	A care conference is held with Mr. Jay and the multidisciplinary team. Mr. Jay is receptive to the idea of putting extra supports in place so he can continue attending Bingo. Some of the strategies include: portering Mr. Jay to activities in a wheelchair to conserve energy, ensuring he has access to portable oxygen, having recreation staff assist with his bingo calling duties should he become short of breath, and giving him time to express his thoughts and opinions. The next week, Peter notices that Mr. Jay is attending social activities more regularly and is in great spirits. Given the responses we've discussed and the solutions provided in this scenario, we can see that there are many diverse ways that a multidisciplinary team and LTC home can work together to support residents as they progress through their illness to ensure social wellbeing is maintained. In this scenario, you may have alternative suggestions to propose to help Mr. Jay. We encourage you to keep reflecting on these options, how they would play out in your home and what steps would need to be taken to ensure these resources are put in place and these discussions are had with residents.
Section	**Alternative ending to Mr. Jay's story**
Say & Ask	*[Facilitator note: read the following suggestions to group and invite participants to share their input before providing suggestions.]* Now let's explore what would happen if during the discussion with the team, Mr. Jay said no to the offer of support and expressed that Bingo is no longer worth the energy. What might you do then? And how would you open up the discussion with him? *Suggestions for opening up the discussion with Mr. Jay can include exploring*: ● What does Mr. Jay like about Bingo that gives him pleasure and pride? ● How might he get this in other ways? ● What else might be comforting to him if he can no longer attend bingo and other social activities and events? ● Are there some residents he feels connected to and who he would want to have over for a visit if he no longer went out to these events? ● This might be a time to discuss, as Mr. Jay's health deteriorates, what are his social needs should he become less and less able to engage in social activities and what are the things that are important to him (social, environmental, physical, intellectual, emotional, etc.).

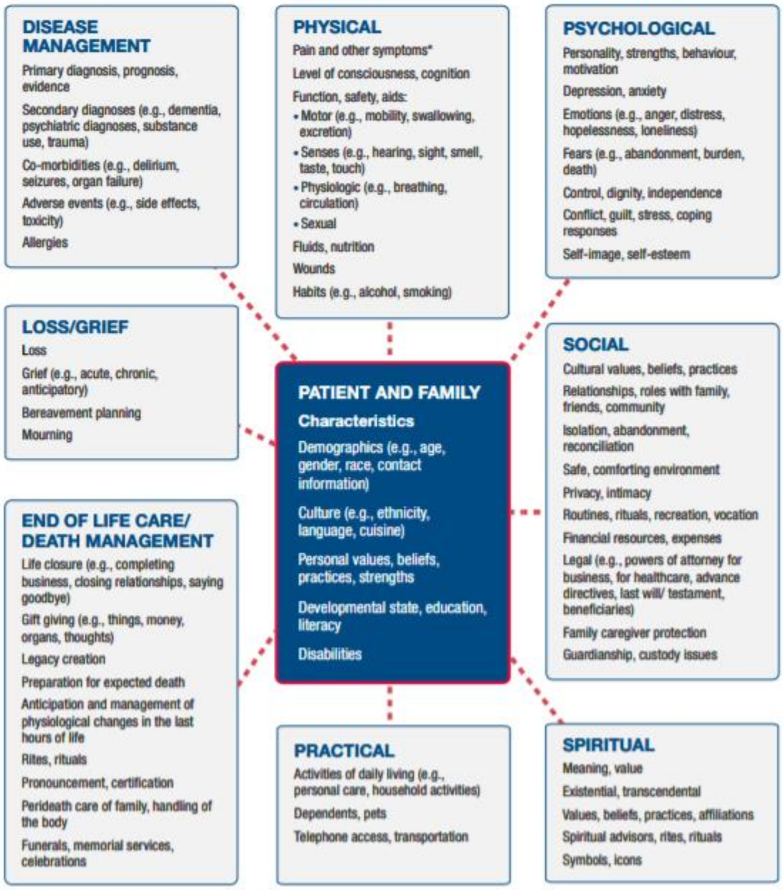
Optional Section	**Connecting lived experience of advancing illness and the important work that you do in your LTC home.**
Say & Ask	Now let’s go back to the *Domains of Issue Tool*. When you think of someone living with an advancing (or progressive) life-limiting illness, like Mr. Jay: 1. What are some of the other ways that the advancing illness impacts his everyday life? What might he be experiencing? 2. Would a palliative approach to care be appropriate for Mr. Jay? Why or why not? 3. What are some of the ways that you can best help Mr. Jay as his illness progresses? 4. How can you help to address resident concerns related to their health conditions that are NOT physical symptoms?
Section	*This is the end of the case scenario. Thank you for taking part and for sharing in the discussion. If you have other questions, please let me know!*

	Honouring Cultural Needs Scenario Mr. Sanjay & Daughters
Time	The scenarios can take roughly ***25-30 minutes*** to complete depending on participant engagement and group discussion.
Say	**Purpose of the case scenario:** To provide PSWs with an opportunity to gain a deeper understanding of how cultural and social aspects of food and nutrition are related to advance care planning and goals of care discussions. Learn about the importance of communication with residents and family members to gain a better understanding of traditional and cultural practices, values, wishes and goals to form a resident-centered care plan.

Say	This case scenario is an extension of the SPA-LTC HEALTH CARE WORKER (HCW) AND PALLIATIVE EDUCATION PROGRAM (PEP) – SPA LTC E-Learning modules. If you have not yet completed the online modules, it is highly encouraged that you do so by visiting https://spaltc.ca/courses/spa-ltc-health-care-worker-hcw-and-palliative-education-program-pep/. This scenario relates to the modules on: ● Understanding Advance Care Planning (ACP) and Goals of Care ● Communicating with Residents, Families and LTC Staff ● Bringing a Palliative Approach to Resident Care
Optional Section **5 minutes**	**Exploring a Palliative Approach to Care: A Brief Introduction**. **This section is optional depending on participants' level of knowledge and if you've already presented this in other case scenarios.
Say	To help ground our session today, I would like to start off with a short introduction on the use of the words "palliative" and "palliative care" in LTC. When using these words, health care workers and staff are often referring to the last hours to days of a resident's life. However, a palliative approach to care aims to **relieve suffering and improve quality of life for any person living with or at risk of developing a life limiting illness**. A Palliative approach to care is best delivered by a multidisciplinary team and identifies and addresses issues in various domains of a person's life. A Model to Guide Hospice Palliative Care: **Based on National Principles and Norms of Practice** was created by the Canadian Hospice Palliative Care Association and is a "model for delivering quality hospice palliative care based on a broad understanding of how people experience health and illness, and how the health care system responds to them" (p.3). Within this model is the ***Domains of Issue tool***. It is one way to conceptualize a palliative approach to care. You may also know this concept as a holistic/whole-person/resident-centered approach to care. ***Show/bring on screen the image of the model found below.***
Say	*[Facilitator note: show the Domains of Issue tool and briefly explore each category: disease management, physical, psychological, loss/grief, end-of-life care/death management, practical, spiritual, social, psychological.* ***Ask if participants are familiar with this model or a similar model?*** *Note: the issues in each domain (Figure 1 below) are examples and not an exhaustive list.]*

According to the Canadian Hospice Palliative Care Association, “(t)o relieve suffering and improve quality of life, caregivers must be able to identify and respond to all the complex issues individuals and families may face, which can be categorized into eight equally important domains. If one or more issues are missed, they can compound one another, leading to distress. Each issue identified by the person and family also comes with expectations, needs, hopes and fears. For example: how will the illness affect my relationships with others? What can be done to change the experience and the way it will evolve? How can I restore or maintain my capacity for meaningful and valuable relationships with others for as long as possible? While each of these issues and its associated expectations, needs, hopes and fears can be challenging and stressful, they are also opportunities for growth” (p.4).

Figure #1: Domains of Issues Associated with Illness and Bereavement



* Other common symptoms include, but are not limited to:

Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns

Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia

Oral conditions: dry mouth, mucositis

Skin conditions: dry skin, nodules, pruritus, rashes

General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

Image reference: Canadian Hospice Palliative Care Association. (2013). *A model to guide hospice palliative care: based on national principles and norms of practice.*

Section	**Introducing Mr. Sanjay & Daughters**
Say	Mr. Sanjay was recently admitted to a LTC home after a long stay in hospital. He suffered a stroke and has been left with many deficits, including difficulty swallowing and talking. It's been a couple of weeks since his arrival, but the home has noticed that Mr. Sanjay is having trouble at meal time and is not finishing his food. Mr. Sanjay has two daughters who have started visiting their father in the home more and more frequently at dinner time to help with feeding. One day they bump into Julie, the Personal Support Worker (PSW) who usually helps Mr. Sanjay/their father, with his meals at breakfast and lunch. They mention during mealtime, their father has started turning his head away when offered a spoonful of his dinner or closes his mouth tightly when they attempt to feed him. They mention that Mr. Sanjay has trouble expressing his needs after the stroke and communicating with the staff because English is not his first language. The daughters ask Julie if this has been happening during breakfast and lunch as well. Julie nods in agreement. The daughters are very concerned by this. They indicate that their father really enjoys the dishes from his native country such as rice and different kinds of curries, but they have been instructed not to give it to him due to choking and aspiration risk. Julie knows that the hospital reports indicate that Mr. Sanjay's swallowing status is unlikely to improve and that the staff, herself included, are very concerned at what might happen if Mr. Sanjay ate foods other than the prescribed purées ordered by the dietician. The daughters continue to explain to Julie that they feel that Mr. Sanjay does not eat the food here because he does not find it appealing and are distressed by how much weight he has lost and how unhappy he seems. They talk about how much joy he used to experience sitting around the table and eating his favourite foods with his family. The daughters feel that if given the choice, Mr. Sanjay would rather eat the cultural foods he likes and they accept the risk of choking as it would bring him joy and comfort in food once again. Julie feels at odds with this information and unsure of how to proceed.

Section	Group discussion questions
Say & Ask	We are first going to focus on the presenting needs and concerns of Mr. Sanjay and his daughters. We will then explore how to navigate and work through communication barriers, the importance of incorporating culture into treatment decisions, and we will end on the topic of choking risks. 1. What are some of the challenges and issues that Mr. Sanjay and his daughters are experiencing? *Suggestions may include*: ● He is losing weight and not eating. ● He has trouble eating and drinking and needs a lot of support. ● He is at risk for choking and aspiration if the diet is not modified. ● The home is not honouring his cultural and traditional preferences for food. ● The daughters have expressed that their father might respond better to traditional foods and that they want to support him in this regard but they are being prevented from doing so. ● His family thinks he dislikes the food provided at the LTC home. ● The daughters understand their dad's wishes and preferences for care but they are not built into his care plan at this time. 2. Julie is at odds with this information and unsure how to move forward. A. First let's discuss any suggestions you might offer Julie to help her engage further with the family to learn more about Mr. Sanjay's culture, food preferences, and what is important to him and the family so that she can share this with the larger team. *Suggestions may include*: ● This is very important information to know about your dad, thank you! ● I would like to share this information with… [*the nurse and the dietician*] and see if there is some way we could make his more traditional foods safer for him to swallow. ● I would like to ask the nurse/dietician to come speak with you about this matter and see if we can find a solution that will give your dad more pleasure and better nutrition. Is that ok?

- I agree, it is very important to honour your father's culture and traditional foods. Let me bring this information back to the team and we will get back to you.
- I hear you saying that food and culture was a source of joy for your dad and part of his quality of life. Can you tell me more about your culture, holidays, and the food that we should pay attention to in his care plan?
- It sounds like mealtime was a very social and happy time in your house. Can you tell me more about that?
- Tell me more about his traditional foods? Can you give me an example of his favourite dishes to share with the nurse and dietician?

B. Imagine Julie was your colleague, who could she approach in the care team to help her with this situation and assist the family in finding a solution? When providing your response, please include a short description of that person's role (in the care team) and how they play a part in finding a solution for Mr. Sanjay.

Suggestions may include:

- Nurse – provide in the moment discussion and further assessment with the daughters regarding their concerns; can document and make referral to dietician; will receive recommendations from various health team members and be responsible to update the care plan and communicate to the PSW staff.
- Dietician – meet with the daughters and review several favourite dishes and consider how they can be modified to be safe to swallow. Make notes of traditional, ritual or holiday foods associated with Mr. Sanjay's culture; provide dietary direction back to nursing and the care plan on how and who will modify the diet texture (e.g., daughters or kitchen aides or PSW).
- SLP (Speech Language Pathology) Clinician – Advanced swallow reflex assessment, recommendations to dietician and physician regarding limitations of abilities post stroke.
- Social Worker – meet with the daughters to discuss cultural and traditional practices and rituals, which includes knowing about preferred foods, holidays and events that are important to honour with Mr. Sanjay. This will be shared with the dietician and nursing team to ensure a whole-person care plan is created and respected.

	- Social Workers may also want to gauge values for care risk versus safety; longevity versus quality;and, how decisions about care are made (together versus led by one person). There may be a decision to accept more risk than the staff feel comfortable with, and the Social Worker will explore how that will be negotiated. The daughters may feel more respected and better understand what role they can play to help their father after meeting with the Social Worker. - Physicians – should be informed about all the assessment data regarding diet and nutrition and the potential outcomes. The physician can also speak to what happens when someone chokes, how painful it is and what the outcomes could be. They can also gauge where the family sits on accepting this risk. If a modified diet is not possible or if the traditional diet continues to pose some risk to Mr. Sanjay, then a risk agreement might be carried out. The LTC Facility Administrator should also be informed. A signed risk agreement needs to be in the chart. *[Facilitator note: if it was not brought up in discussion, share with participants that Julie might have limited power in making decisional changes regarding Mr. Sanjay's diet. It would be important for the PSW to convey this to the family while also remaining open to hearing more about Mr. Sanjay's preferences and inviting the daughters to continue engaging with the LTC home team to best support Mr. Sanjay.]*
Section	**Inform Practice: Goals of Care (GOC) Discussions with Residents with Language and Communication Barriers.**
Say	In this section we are going to explore three areas of informed practice. If possible, please keep your questions to the very end when we reach the group discussion section. Make little notes if you need to remind yourself. Exploring approaches to resident feeding and diet preferences may warrant a goals of care discussion with the resident (and substitute decision maker if applicable), their family, and the health care team. These discussions usually occur within a care conference or whenever a change is noticed in the resident's condition. Ideally, this would occur after advance care planning has taken place between the resident and their identified substitute decision maker (in this case, Mr. Sanjay and his daughters) in which the resident's values, wishes and beliefs are communicated with respect to care they may need in the

	future.
	In this scenario, Mr. Sanjay has difficulty expressing himself verbally after his stroke and because English is not his primary language. Although communication with residents who speak a different language may be challenging, it is important to make every effort to include Mr. Sanjay in advance care planning, goals of care discussions and treatment decisions. When we assume that residents with speech or language difficulties are not capable of making their own decisions, we run the risk of violating their right to participate in their own care.
Section	**Inform Practice: Culturally Competent Care (Incorporating culture into ACP, GOC, treatment decisions).**
Say	Food has many symbols and meanings across cultures that will impact ACP, GOC and treatment decisions (e.g., artificial nutrition/hydration vs. comfort feeding) directly. It is often a representation of cultural identity. Culture beliefs/values around food often have religious influences – examples Sikh, Hindu, Muslim faiths. For many South Asian cultures, withdrawing (as in the case of comfort feeding) often can be viewed as hastening of death and prevents a "good death". For example, in Taiwanese culture, if someone is not fed at EOL, they believe the person would die hungry and their soul will be a restless and hungry soul. Therefore, the concept of comfort feeding can be challenging for families to navigate and accept this approach to care, even if the withdrawal of food is due to disease progression and a natural decrease in appetite/intake. Being able to consume food is seen as a measure of well-being and being able to prepare and feed food to a loved one is an expression of affection, a source of comfort for both parties, a show of support and can sometimes be viewed as the caregiver's duty. When specific and special foods are not offered in LTC homes, some care partners may feel an added extra burden to prepare the foods and meals that their loved one prefers to eat.

Section	**Inform Practice – Comfort Feeding at the end of life**
Say	Should Mr. Sanjay be at the end-of-life, another feeding option might be comfort feeding. Mr. Sanjay is showing clear indication that he does not enjoy the foods offered at the long term care home and the hospital reports indicate that his swallowing status is unlikely to improve. Comfort feeding is an approach to feeding residents who have irreversible and life-limiting conditions and who are receiving a palliative approach to care. This approach suggests that a resident would be fed as long as it is not distressing, that the feedings are comfort oriented and are offered in the least invasive and most satisfying way for the resident. With comfort feeding, diet textures and the foods offered might be altered to reflect the resident's preference. Examples of care plan items for comfort feeding include: ● Resident-specific signs that feeding is causing distress (choking, turning head away, difficulty breathing) ● Resident-specific behaviours that indicate that it is safe to feed (nodding, smiling, engaging in eye-contact, opening mouth when food presented) ● Types of food and food textures that are preferable ● Effective feeding techniques ● Times of day that are preferable for feeding to be offered.
Section	**Group discussion questions**
Say & Ask	Before I start with our pre-set discussion questions, does anyone have any questions about the content I just covered? How could we use what we have learned about incorporating culture and comfort feeding to advocate for Mr. Sanjay? ● Going forward, how might you change your approach in caring for residents who experience difficulty communicating? ● If a care conference has occurred to address advance care planning and goals of care with the multidisciplinary team, how can the outcomes be communicated to the PSW staff to ensure consistency of care?

Section	**Section on Choking & Personal Reflection Questions**
Say	Now we are going to explore the part of the scenario that focuses on choking. Although a reality in the places you work, the topic of choking can still be uncomfortable for some people. In this section, I will provide you with personal reflection questions that I encourage you to explore further on your own time in the context of your place of work and in relation to your lived experiences. Feeling at odds about a request that may cause choking is a natural reaction. It's important for the team to have open and honest conversation with families and amongst staff about the resident's values, preferences, risk management, and accountability. The agreed upon care plan should also be effectively communicated to the staff to ensure they feel supported, equipped and more at ease with the decisions that have been taken. A plan of action if choking occurs must also be clearly communicated. Personal Reflection Questions: ● What would you think if the family insisted on feeding even if there was a risk? ● What is your level of comfort with the risk of choking? ● What would you want for the relatives who feel distressed by their loved one's state? Staff may also experience difficulties with this request due to lack of time and availability to help if choking occurs. To help staff navigate these barriers, questions for the team and the family may include ● Can the family agree to a plan if the staff are unavailable to help if there's a problem? ● Can the timing of this be discussed when there are more staff or on the floor? [*Facilitator note: If appropriate - you can invite the group to ask questions about this topic. Remind them to be mindful of the details they share and the impacts it could have on others should they relay a story/account of a situation they've experienced.]*
Say	Thank you for your participation today and for the rich discussions. Your dedication and caring support to persons living in LTC homes makes a difference! As a facilitator, I recognize that engaging in these types of case scenarios and practice work is not always easy. I encourage you to take care of yourself after this session and to reach out for support if you need it.

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