

Strengthening a Palliative Approach in Long Term Care (SPA-LTC): Tools, Resources, and Evaluation

January 13th, 2022

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Outline of Presentation

- Why a palliative approach to care is needed in LTC
- Overview of different models to guide implementing a palliative approach in LTC
- Key components of the Strengthening a Palliative Approach in LTC (SPA-LTC) program
- Evaluation of SPA-LTC tools and resources
- Next steps & final thoughts



Need to Implement a Palliative Approach in Long Term Care

- In Canada, current average stay in LTC is <18 months
- Over 1 in 4 residents die each year
- Frail and marginalized population – multiple chronic conditions, social isolation
- Includes dementia and mental illness – unique approach to care using a palliative approach required
- Decision making often occurs too late and in crisis mode



Key issues

Editorial



Palliative Medicine
2020, Vol. 34(5) 555–557
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DOI: 10.1177/0269216320916118
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**Current issues with implementing a palliative approach in long-term care:
Where do we go from here?**

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1. Need for training and education
 ➔ limited reach
2. Grow capacity by leveraging internal and external facilitation
3. Right outcomes?



COVID-19 National Long-Term Care Environmental Scan: Implementing a Palliative Approach to Care

Home > Resources and Tools > Health Care Professionals > COVID-19 National Long-Term Care...

Last Updated: July 22, 2021 Group: Health Care Professionals Topic: Education

- Impact of COVID-19 on a Palliative Approach to Care
- Tools & Resources

<https://www.advancecareplanning.ca/resource/covid-19-national-long-term-care-environmental-scan-implementing-a-palliative-approach-to-care/>



Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs



SPA-LTC
Strengthening a Palliative Approach
in Long-Term Care

Palliative Models in LTC

4 main types of palliative models/programs in LTC:

- External specialist end-of-life care model
- In-house end-of-life care
- In-house capacity building within a palliative approach
- In-house capacity building with external support from palliative specialists



SPECIAL FOCUS ON NURSING LEADERSHIP AND PALLIATIVE CARE

Canadian Journal of Nursing Leadership, 2019, 32(3):8-26

Palliative Care Models in Long-Term Care: A Scoping Review

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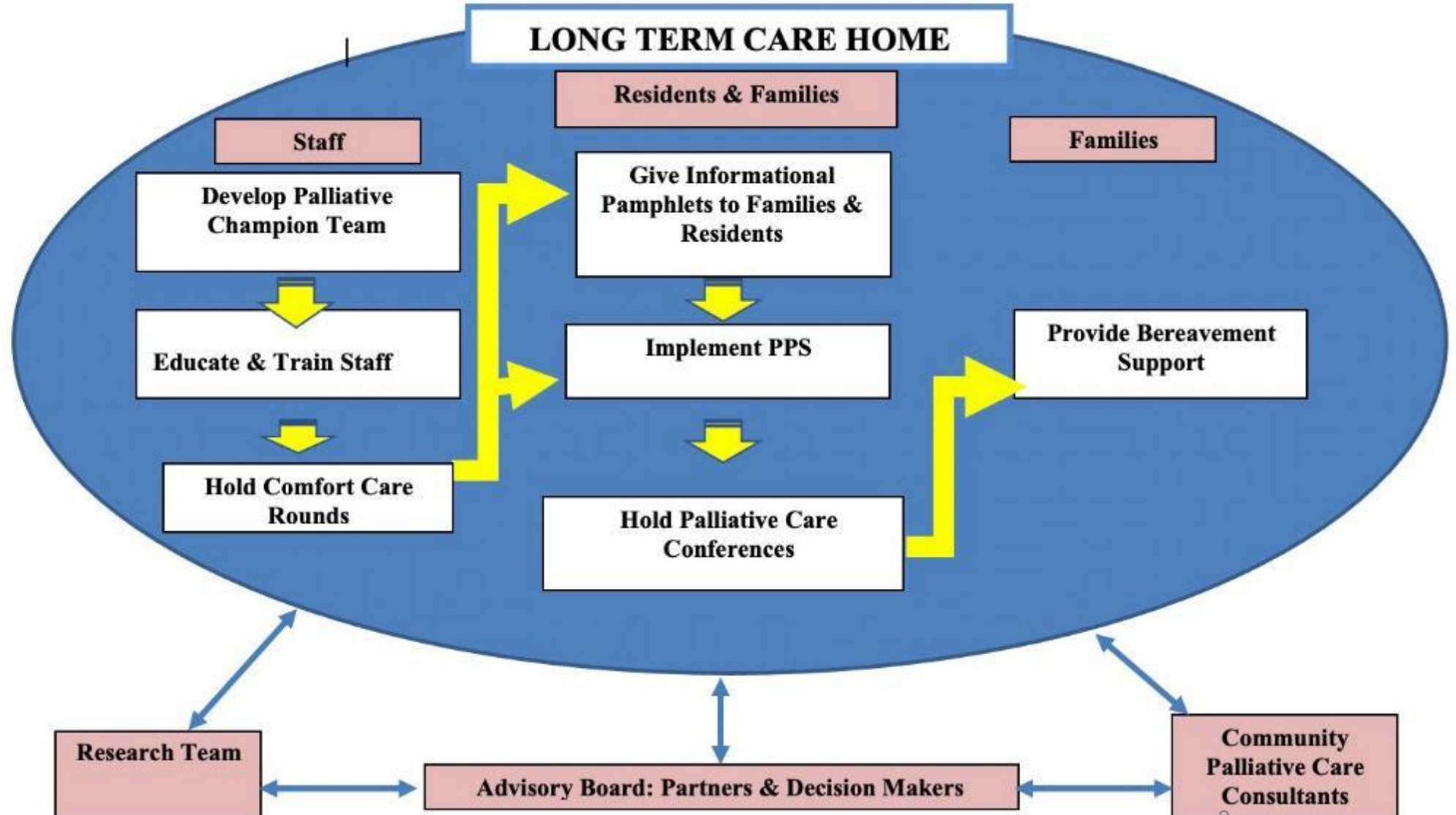
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Strengthening a Palliative Approach in Long Term Care (SPA-LTC) Program



SPA-LTC

Strengthening a Palliative Approach in Long-Term Care

Preparedness

- II' Advance care planning resources
- II' Healthcare decision-making resources
- II' Illness trajectory pamphlets for residents and families

Symptom management

- II' Assessment tools
- II' Education for the whole care team
- II' Video education for residents and families

Caring relationships

- II' Care conferencing resources
- II' Bereavement care resources for families
- II' Bereavement care resources for residents and staff

Organizational capacity

- II' Self-assessment resources
- II' Resource mapping tools to identify external consultants
- II' Terms of reference to build your champion team
- II' Resources to support practice
- II' Education for the whole care team

Our Strategy

- Informed by Participatory Action Research (PAR)
- Balances action (change) with research (understanding)



RESOURCE LIBRARY

Search Library by Topic

FILTERS

Reset Filters

A - Z

Z - A

Newest to Oldest

Oldest to Newest

CATEGORIES

Resource Type

Clinical form/process

Informational Print Resource

Informational video

Research report

Role

Family/Caregiver

Healthcare Provider

Researcher

Topic

Advance care planning

Bereavement

Better communication

Learning about dying

Learning about illness

Symptom management



Re-establishing the Role of Families in LTC after the COVID-19 Pandemic

Saskatchewan

A conversation with members of the Saskatchewan Long Term Care Network.



Family relationships sustain us

Saskatchewan

A conversation with members of the Saskatchewan Long Term Care Network about the importance of family members in Long Term Care.



mySupport Study

This video explores the mySupport study which brings together an international team of healthcare researchers and clinicians to support healthcare staff to have end-of-life care discussions with family carers of people living with advanced dementia.

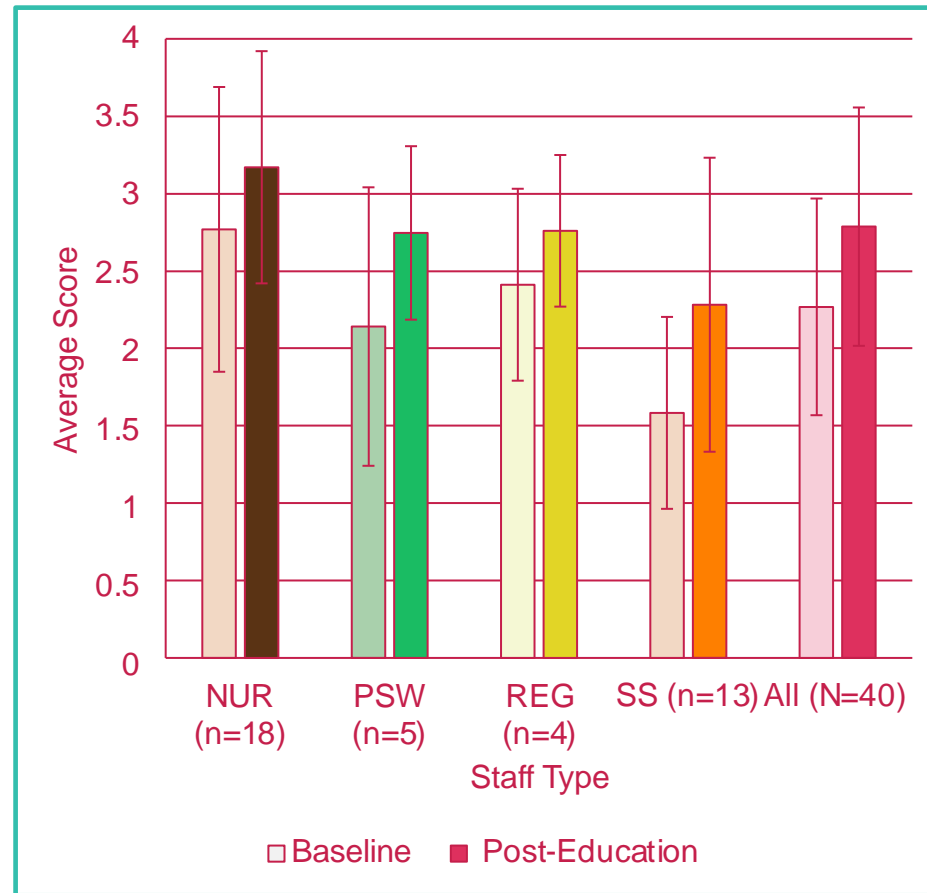


For Staff



Need for Education & Training

- LTC staff reported higher comfort levels ($t=5.08$, $p=0.003$) with caring for residents at end of life after attending an educational workshop about effective communication at end-of-life
- PSWs and support staff reported the lowest comfort level before attending the workshop and improved the most after attending the educational workshop



Growing Capacity: Comfort Care Rounds

- A strategy for addressing staff's palliative and end-of-life care educational and support needs
- Met monthly
- Include all team members
- Reflect on resident deaths and emerging resident EOL issues



Wickson-Griffiths, A., Kaasalainen, S., Brazil, K., McAiney, C., Crawshaw, D., Turner, M., & Kelley, ML. (2015). Comfort Care Rounds: A qualitative evaluation of an innovative palliative care improvement strategy. *Journal of Gerontological Nursing*, 18:1-7. doi: 10.3928/00989134-20140611-01

Resources for implementing comfort care rounds:

http://www.palliativealliance.ca/assets/files/Alliance_Resources/Communication/Comfort_Care_Rounds-Jan_162013.pdf



Comfort Care Rounds



Comfort Care Round Scenarios



Instructions Page

Purpose of this resource: To increase the confidence and knowledge of staff caring for residents who are living and dying in Long-term Care.

Intended Audience: Staff who assist in the end-of-life decision-making within long-term care. Please encourage all staff (i.e., cleaning staff, recreation staff, etc.) to join. Encouraging an interdisciplinary team approach in learning strengthens teamwork, awareness, and overall quality of care for residents in LTC.

Teaching Plan:

1. **Visual Aide:** Distribute a copy of the Comfort Care Rounds booklet for everyone to have a visual learning guide (either electronically or a physical copy) (OR if this cannot be distributed) Display the Care Scenarios on a PowerPoint presentation or create a concept map of main points from the scenario on a board.
2. **Introduction:** Introduce the purpose of this resource to the audience and encourage optimism in learning.
3. **Introduce the Scenario:** Read each Resident scenario as a group (encourage the audience to participate in reading the scenarios).
4. **Discussion/Facilitating questions:** When facilitating questions note words of emphasis on a board (i.e., similar thoughts, outlying thoughts, etc.) to assist staff in recognizing learned experiences from the discussion.
5. **Inform Practice:** Review listed descriptions where opportunities to inform practice relating back to the specified scenario arise. Relate informed practice discussed during the comfort care round to current practices within the staff's scope of knowledge.
6. **Roleplay:** In this section, you will be practicing as if this scenario would arise in the practice setting. Encourage the group to openly collaborate and partake unilaterally as the 'staff' that will help in the decision-making process within the specified scenario. You could also have one member of the group become the family or resident. In this way, they are able to feel how staff approach this situation.
7. **Feedback:** Provide feedback to the group throughout the Comfort Care Rounds. Both constructive and positive feedback is beneficial for learning. Always encourage ongoing learning and support among staff members.
8. **Follow-up:** At end of days follow up with any areas that group members would like to review. Ensure emotional support is provided through the rounds as this can be a sensitive topic for certain individuals.

Notes:

1. Encourage the group to openly discuss each scenario and not to worry if they are uncertain of what to say. Remind the group this is a learning experience.
2. Create an environment where the group members feel comfortable in expressing themselves. At times, members of the group may be uncertain of how to approach a question. The facilitator can encourage them optimistically by, stating phrases such as, "This is a great opportunity for growth and although you may not know the answer, you can begin to explore what you may already know or have felt in practice here, and with a safe, supportive group setting".

References:

For additional learning and tips please visit the palliative alliance toolkit at:

<https://www.palliativealliance.ca/>

and review the following publication:

Wickson-Griffiths A., Keselainen S., Brazil K., McAney C., Crawshaw D., Turner M., & Kelley M. L. (2015). Comfort care rounds: A staff capacity-building initiative in long-term care homes. *Journal of Gerontological Nursing*, 41(1), 42-48.

Using Scenarios for CCR Training

Scenario 2

Section Type: Reflection and Action

Description of Resident Scenario

Last evening, EB, a 70-year-old male with end-stage cardiac disease and a history of depression and anxiety passed away. EB's Palliative Performance Scale score was PPS10% for the last 3 days of his life. The evening shift nurse reported that EB's breathing remained shallow but regular, and his family was at the bedside at the time of his passing. The nurse reported that EB appeared comfortable and was receiving 0.5mg of hydromorphone subcutaneously, every 4 hours.

Purpose of Comfort Care Round

Reflect on a recent 'good' resident death.

Questions for Facilitator to Start Discussion

- Does this scenario reflect the experiences of residents and family members that you currently cared for?
- What does a 'good death' or 'successful dying' look like in your practice?

Additional Discussion Questions

- What are the primary objectives for someone who is facing imminent death?



New Education Series



Palliative e-Learning Modules for All LTC Staff

☰ Course Introduction

RESOURCES

What are the eight learning modules about?

The eight learning modules clearly identify the focus and topic area related to a palliative approach.



||



< PREV

NEXT >



SPA-LTC HEALTH CARE WORKER (HCW) AND PALLIATIVE EDUCATION PROGRAM (PEP)

0% COMPLETE Last activity on November 28, 2021 11:37 pm

COURSE CONTENT

Expand All

Prerequisites

1 Quiz

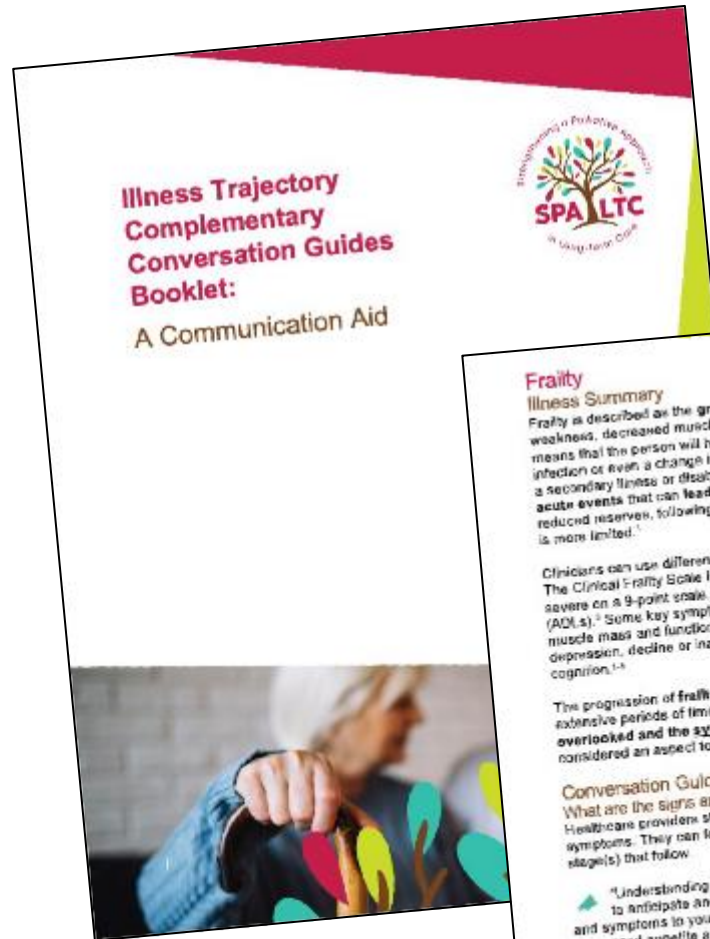
Expand

Introduction

Bringing a Palliative Approach to Resident Care

Communicating with Residents, Families and LTC Staff

SPA-LTC Conversation Guides



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.** 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.¹

Conversation Guide
What are the signs and symptoms of frailty?
Healthcare providers should tailor the information to acknowledge the resident's current frailty stage(s) that follow.

▶ "Understanding the symptoms that you, your family member, my 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

Illness Trajectory Complementary Conversation Guide Booklet: 8



<https://vimeo.com/656165692>



Need to Support Staff

CONTRIBUTORS OPINION

Moral distress: Let's take this time to help the helpers during Nurses Week

SK

By Sharon Kaasalainen
Fri., May 15, 2020 | 3 min. read



Reflective Debriefing



<https://www.youtube.com/watch?v=Du0orYXX8MI&t=2s>



We Hear You Toolkit



Saskatchewan Project (Hunter et al.):
<https://appliedinterprofessionalresearch.com/>



For Residents & Family



Preparing Residents & Family

- Many families are unaware that dementia is a terminal condition
- There are other gaps in knowledge about EOL
- Our team developed “illness trajectory pamphlets” to support discussion about these issues
- We are in the process of developing other communication aids, including animated videos to explain end of life issues and facilitate decision making



DIGITAL VERSION



The Palliative Approach for Advanced Frailty in Long Term Care

A RESOURCE FOR RESIDENTS, FAMILY AND FRIENDS

What is a Palliative Approach?

The pamphlet was made to help people with Advanced Frailty and their families know what to expect at the end of life, so they can start ahead. Talking about preferences early on is an important first step to a Palliative Approach to Care.

A PALLIATIVE APPROACH:

- Is for residents in long term care (LTC) with conditions that have no cure
- Shifts focus from prolonging life to making it as good as life
- Is an active approach that can start at any stage of chronic illness
- Is not a last-ditch effort
- Does not require a referral



What is Frailty?

It is a condition where the body is weak. It is not a disease, but it can lead to health problems.

FRAILTY IS:

- A condition that can be prevented
- A condition that can be treated
- A condition that can be managed

FRAIL RESIDENTS:

- Are at greater risk of falls, hospitalizations, and death
- Have more health problems
- Have more difficulty with daily activities

A PALLIATIVE APPROACH INCLUDES:

- Assessment of care needs
- Pain management
- Symptom management
- Emotional support
- Spiritual support
- Social support
- Support for family and friends



How Does Frailty Progress?

As a person's frailty progresses, they will experience more health problems and have more difficulty with daily activities.



Living with Frailty

The impact of frailty can be overwhelming and hard to cope with. It is important to seek support from family and friends.

FRAIL RESIDENTS MAY SHOW A DECLINE IN:

- Mobility
- Energy
- Appetite
- Ability to perform daily activities
- Ability to manage medications
- Ability to manage health conditions
- Ability to manage social relationships
- Ability to manage emotional health

THE PROGRESS OF FRAILTY IS CALLED 'DECLINE IN HEALTH'. IT IS NOT RELATED TO ONE SPECIFIC DISEASE.



Tips for Family & Friends

BEFORE A CARE DECISION IS MADE:

- Consider your relative or friend's end-of-life values and preferences
- Stay informed and ask questions
- Encourage your relative or friend to be as independent and participate in as many decisions as he or she is able

WITH A HEALTH CARE PROVIDER, EXPLORE AND DISCUSS OPTIONS:

- To prevent or reduce injury from falling
- To prevent or reduce confusion (e.g. discontinue unnecessary medications)
- To manage symptoms from multiple chronic conditions
- For older (e.g. supplements to deal with swallowing problems or weight loss)
- For dealing with fatigue (e.g. increase physical activity)



Your health is important too. If you are feeling overwhelmed, seek support from your health care provider and from the Family Councils of Ontario www.fco.org (416) 487-4355 or 1-888-953-8804.

WHAT SHOULD I ASK ABOUT?

- What are my or my relative or friend's biggest fears about my/their health?
- How can I help maintain my or my relative or friend's quality of life?
- When should I accept when I am or my relative or friend is dying?

Online Resources

1. Canadian Policy Network <http://www.cpn-npc.ca>
2. See SPA-LTC website for more resources: www.spaltc.ca/resource-library/

Contact Us

Strengthening Palliative Approach in Long-Term Care (SPA-LTC) Network (1-monthly, 30-min of learning)

www.spaltc.ca
416-487-4355



DIGITAL VERSION



The Palliative Approach for Advanced Heart Failure in Long Term Care

A RESOURCE FOR RESIDENTS, FAMILY AND FRIENDS

What is a Palliative Approach?

This pamphlet was created to help persons with Heart Failure (HF) and their family/friends understand the goals of the palliative approach and what it means to have a Palliative Approach to Care.

A PALLIATIVE APPROACH:

- Is for residents in long term care (LTC) with conditions that have a limited life expectancy
- It's focused on providing life to maintaining quality of life
- Is an active approach for an individual's stage of illness/disease
- Is part of usual care
- Does not require a referral



A PALLIATIVE APPROACH INCLUDES:

- Treatment of medical conditions
- Personalized care management
- Social and spiritual support

For more information, please visit: www.virtualhospice.ca or advancecareplanning.ca or www.spa.ltc.on.ca

What is Heart Failure?

Heart failure is a chronic progressive **lifelong illness**. This means that symptoms worsen over time and may affect how you live.

HEART FAILURE:

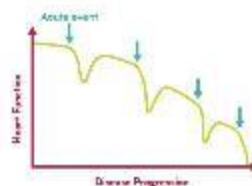
- Occurs when the heart is not pumping or circulating blood well
- Occurs fluid to back up from blood vessels into the lungs and legs

RESIDENTS WITH HEART FAILURE:

- Will have feelings of stress, worry and good days (just sleeping)

How Does Heart Failure Progress?

Heart failure is a gradual condition, someone with heart failure will feel well to good to help for the best one part for the worst.



Living with Heart Failure

The long-term of heart failure can be overwhelming and there is no cure. Being well-informed will help you to make good decisions if you're able.

TALK TO YOUR OR YOUR RELATIVE OR FRIEND'S HEALTH CARE PROVIDER IF YOU NOTICE:

- More swollen or tired than before
- More shortness of breath with little activity or at rest
- Weight gain (fluid retention) or weight loss (decrease in food intake)
- More swollen legs (lower leg swelling) or in abdomen (bloating)
- Coughing, phlegm, or wheezing (as if your chest is congested or when lying down)
- Rapid or irregular heart rate or chest pain
- More problems with sleeping than before



Tips for Family & Friends

BEFORE A CARE DECISION IS MADE:

- Consider your relative or friend's wish of life and end preferences
- Stay informed and ask questions
- Encourage your relative or friend to be or involve in care decisions in as many decisions as he or she is able

WITH A HEALTH CARE PROVIDER, EXPLORE AND DISCUSS OPTIONS:

- Be willing to talk with the medical team and I and relatives
- Before you give your relative or friend any care, the doctor is getting advice or medical health decisions
- How do you want to be cared for (living with symptoms vs. hospitalization)
- Be willing to talk with the medical team and I and relatives



Your health is important too. If you are feeling overwhelmed, seek support from your health care provider and from the Family Council of Ontario www.fco.on.ca (416) 467-4336 or 1-800-263-1006.

What should I ask about?

- What are my or my relative or friend's biggest concerns about their health?
- How can I be a medical proxy or my relative or friend's quality of life?
- What symptoms or my relative or my friend have that are related to heart failure?
- What are the options when someone is unable or unable to make decisions regarding their health care needs and care?
- What should I expect when I am caring for my relative or friend's care? © 2014 SPA-LTC

Online Resources

1. Canadian Heart Failure Society <https://heartfailure.ca>
2. See SPA-LTC website for more resources www.spa.ltc.on.ca/resource-library/

Contact Us

Strengthening a Palliative Approach
through Long Term Care (SPA-LTC)
Website: www.spa.ltc.on.ca

www.spa.ltc.on.ca
SPA-LTC@ontario.ca

SPA-LTC
Strengthening a Palliative Approach



DIGITAL VERSION

The Palliative Approach for Advanced Kidney Disease in Long Term Care

A RESOURCE FOR RESIDENTS, FAMILY AND FRIENDS



What is a Palliative Approach?

This pamphlet was made to help persons with **Advanced Kidney Disease (AKD)** and their family to know when to expect at the end of life as they cope with it. Talking about preferences early on is an important first step in a **Palliative Approach to Care**.

A PALLIATIVE APPROACH:

- Is for residents in long term care (LTC) with conditions that have no cure
- Shifts focus from prolonging life to maintaining quality of life
- Is an active approach that consults at any stage of chronic illness
- Is part of usual care
- Does not require a referral



A PALLIATIVE APPROACH INCLUDES:

- Good care of chronic conditions
- Pain and symptom management
- Social and spiritual support

For more information, visit our website: www.spa-ltc.ca or call us at [416-291-2222](tel:416-291-2222) or [1-800-387-2222](tel:1-800-387-2222).

What is Advanced Kidney Disease?

Advanced Kidney Disease is a **progressive life-threatening illness**. This means that symptoms worsen over time and may affect how long one lives.

ADVANCED KIDNEY DISEASE:

- Is a medical condition that leads to:
- Loss of kidney function
- Depression, fatigue, or weakness
- Swollen ankles, chest, or lungs
- Trouble with blood, kidney function, blood pressure

RESIDENTS WITH ADVANCED KIDNEY DISEASE:

- Have an average life expectancy of 3-5 years



How Does Advanced Kidney Disease Progress?

Think of the water level in a glass of milk. As you drink, the level goes down. In a similar way, as kidney disease progresses, the level of kidney function goes down.



Living with Advanced Kidney Disease

The progression of Advanced Kidney Disease will be reviewed at the clinic. Consulting with informed staff in a year or more can help you make care decisions if you wish to.

TALK TO YOUR OR YOUR RELATIVE OR FRIEND'S HEALTH CARE PROVIDER IF YOU NOTICE:

- Weight changes
- Confusion and sleep problems
- Lack of energy and feeling fatigued
- Muscle weakness
- Low appetite and weight loss
- Itching and swelling
- Enlarged feet
- Frequent urination
- Fatigue or coldness (low heat)



Tips for Family & Friends

BEFORE A CARE DECISION IS MADE:

- Consider your relative or friends and all the values and preferences
- Stay informed and ask questions
- Encourage your relative or friend to be as independent and participate in as many decisions as he or she is able

WITH A HEALTH CARE PROVIDER, EXPLORE AND DISCUSS OPTIONS:

- For drug levels, signs of lab or x-rays (e.g. calcium level or chest) to help with treatment
- For starting to help reduce itching (e.g. cream)
- For diet (low, low protein and eat food to deal with low appetite/ thirst)
- For dealing with fatigue (e.g. promote physical activity)



Your health is important too. If you are feeling overwhelmed, seek support from your health care provider and from the Family Council of Ontario www.fco.org (416) 487-4366 or 1-888-283-8806.

WHAT SHOULD I ASK ABOUT?

- What can my relative or friend's biggest fears about death or health be?
- How can I help maintain my or my relative or friend's quality of life?
- What symptoms do I, my relative or my friend have that are related to Advanced Kidney Disease?
- What are the options when I am or my relative or friend's disease is too late to respond to medication?
- What should I expect when I am or my relative or friend is dying? 10-15 min

Online Resources

1. Kidney Foundation of Canada: <https://kidney.ca>
2. See SPA-LTC website for more resources: www.spa-ltc.ca/resource-library/

Contact Us

Strengthening Palliative Approach in Long-Term Care (SPA-LTC) at www.kidney.ca or www.spa-ltc.ca

SPA-LTC
Strengthening Palliative Approach in Long-Term Care



DIGITAL VERSION

The Palliative Approach for Advanced Lung Disease in Long Term Care

A RESOURCE FOR RESIDENTS, FAMILY AND FRIENDS



What is a Palliative Approach?

This document was made to help persons with Advanced Lung Disease (ALD) and their families know what to expect at the end of life so they can plan ahead, taking about preferences early on as an important first step to a Palliative Approach to Care.

A PALLIATIVE APPROACH:

- Is for residents in long term care (LTC) with conditions that have no cure
- Shifts focus from prolonging life to maintaining quality of life
- Is an active approach that can start at any stage of chronic illness
- Is part of usual care
- Does not require a referral



A PALLIATIVE APPROACH INCLUDES:

- Treatment of curable conditions
- Pain and symptom management
- Emotional and spiritual support

For more information, please visit www.ontariospa.ca, info@ontariospa.ca or www.spa-ltc.ca

What is Advanced Lung Disease?

Advanced Lung Disease is a chronic progressive life-threatening illness. This means that symptoms worsen over time and may affect how long you live.

ADVANCED LUNG DISEASE:

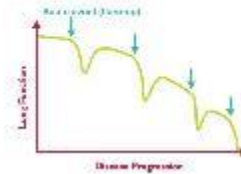
- Occurs when damaged lung tissue makes it hard to breathe and can lead to death
- Is a group of chronic lung illnesses (eg. emphysema, chronic bronchitis, bronchiectasis, and asthma)

RESIDENTS WITH ADVANCED LUNG DISEASE:

- Will have bad days (more symptoms) and good days (few symptoms)
- Can live for months or years

How Does Advanced Lung Disease Progress?

A graph that shows how lung function declines over time. The graph shows a downward trend with some fluctuations, indicating that lung function generally decreases over time but may have some periods of stability or slight improvement.



Living with Advanced Lung Disease

Living with advanced lung disease can be challenging. You may experience symptoms like coughing, wheezing, and shortness of breath. It's important to talk to your healthcare provider if you notice any changes in your symptoms.

TALK TO YOUR OR YOUR RELATIVE OR FRIEND'S HEALTH CARE PROVIDER IF YOU NOTICE:

- More shortness of breath with little activity or at rest
- More weakness or tiredness (fatigue)
- Coughing or wheezing with more sputum
- Excessive daytime sleepiness
- Ankle and/or leg swelling
- Losing weight or appetite
- More hospital visits or emergency room visits
- More problems with cognitive function



Tips for Family & Friends

BEFORE A CARE DECISION IS MADE:

- Consider your relation to friend's and/or relative's and preferences
- Stay informed and ask questions
- Encourage your relative or friend to be as independent and self-reliant as possible in as many decisions as he or she is able

WITH A HEALTH CARE PROVIDER, EXPLORE AND DISCUSS OPTIONS:

- To help with shortness of breath and coughing (eg. spirometry, oxygen therapy, breathing room care)
- To ease or relieve (eg. hand washing, flu and pneumonia shots, dental hygiene, foot)
- For diet (eg. eating with low appetite)
- For dealing with fatigue (eg. promote physical activity)



Your health is important too. If you are feeling overwhelmed, seek support from your health care provider and from the Family Councils of Ontario www.fco.orgo (416) 487-4355 or 1-888-285-8904.

What should I ask about?

- What do my or my relative or friend's biggest fears about my/their health?
- How can I help maintain my or my relative or friend's quality of life?
- When symptoms do, my relative or my friend have that are related to Advanced Lung Disease?
- What are the options if I develop or my relative or friend develops end of life care as a result of Advanced Lung Disease?
- What should I expect when I am or my relative or friend is dying?

Online Resources

1. Lung Association www.lung.ca
2. See SPA-LTC website for more resources www.spa-ltc.ca/resource-library/

Contact Us

Strengthening Palliative Approach in Long-Term Care (SPA-LTC)
McMaster University School of Nursing

www.spa-ltc.ca
spa@spa-ltc.ca

SPA-LTC
Strengthening Palliative Approach in Long-Term Care



The Palliative Approach for Advanced Dementia in Long Term Care

A RESOURCE FOR RESIDENTS, FAMILY AND FRIENDS

What is a Palliative Approach?

This pamphlet was made for people with dementia and their families to help them understand what to expect at the end of life and how to plan ahead. Talk to your doctor or care worker on an important first step to a Palliative Approach to Care.

A PALLIATIVE APPROACH:

- Is for residents in long term care (LTC) with conditions that have no cure
- Helps focus on prolonging life to maintaining quality of life
- Is an end-of-life approach that can start at any stage of chronic illness
- Is part of usual care
- Does not require a referral



DIGITAL VERSION



A PALLIATIVE APPROACH INCLUDES:

- Treatment of acute conditions
- Pain and symptom management
- Social and spiritual support

For more information, please visit:
www.virtualhospice.ca/advancescareplanning.ca
www.speakupontario.ca



What is Dementia?

Dementia is a chronic progressive life-limiting illness. This means that symptoms worsen over time and may affect how long one lives.

DEMENZA:

- Affects a person's thinking, mood, language and behaviour
- Is a group of illnesses (e.g. Alzheimer's, vascular, frontotemporal, Lewy Body, Parkinson's dementia)

RESIDENTS WITH DEMENZA:

- Will have bad days (when confused and agitated) and good days (less confused)
- Can live for years

How Does Dementia Progress?

It is difficult to predict how long someone with dementia will live, as it is good to hope for the best and plan for the worst.



Living with Dementia

The progression of dementia cannot be reversed and there is no cure. Being well-informed will help you to make care decisions.

LATE OR ADVANCED STAGE SIGNS

- Shows memory loss (e.g. names, events)
- Loss of concept of time and space
- Difficulty with speech or language (aphasia)
- Loss of ability to use toilet, bathe, and walk without help
- Difficulty swallowing (dysphagia or risk)
- Reduced interest in activities

END OF LIFE STAGE SIGNS

- Change in circulation (e.g. cold hands or feet, skin breakdown)
- Gradual organ failure
- Pain, discomfort, breathlessness



Tips for Family & Friends

BEFORE A CARE DECISION IS MADE:

- Consider your role and the role of family and friends
- Stay informed and ask questions
- Encourage your relative or friend to be as independent and participate in care as much as possible or hold the hand

WITH A HEALTH CARE PROVIDER, EXPLORE AND DISCUSS OPTIONS:

- Talk about how you relative or friend expresses feelings through their behaviour
- For communication (e.g. pleads, shrugs, pictures, dramas) and help comforting stories
- For eating, if you or relative or friend can no longer swallow food
- To maintain private and social activities



Your health is important too. If you are feeling overwhelmed, seek support from your health care provider and from the Family Council of Ontario www.fco.on.ca (416) 487-4366 or 1-888-283-8806.

What should I ask about?

- What are the role of my relative or friend's biggest fears about their life or health?
- How can I help maintain their mental or physical quality of life?
- How long can someone be in the end stage of dementia?
- What end-of-life options when I am or my relative or friend is dying?

SPALTC 2021

Online Resources

1. Alzheimer Society of Canada <http://www.alzheimer.ca/en/Home>
2. Seniors-TO website for more resources www.seniors-to.ca/resource-library/

Contact Us

Providing Palliative Approach in Long Term Care (SPA-LTC) at McMaster University School of Nursing
www.spa-ltc.ca
spal@mcgill.ca

SPA-LTC
 Supporting Palliative Approach in Long Term Care



Our Results

Residents and family reported the pamphlets:

- encouraged reflection (84%)
- helped to clarify what to ask (70%)
- increased comfort talking about EOL (63%)



JAMDA

journal homepage: www.jamda.com

Original Study

Condition-Specific Pamphlets to Improve End-of-life Communication in Long-term Care: Staff Perceptions on Usability and Use

Tamara Sussman PhD^{a,*}, Sharon Kaasalainen PhD^b, Eunyoung Lee MSW^a, Noori Akhtar-Danesh PhD^b, Patricia H. Strachan PhD^b, Kevin Brazil PhD^c, Robin Bonifas PhD^d, Valérie Bourgeois-Guérin PhD^e, Patrick Durivage MSc^f, Alexandra Papaioannou MD^g, Laurel Young PhD^h

Article

“Now I Don’t Have to Guess”: Using Pamphlets to Encourage Residents and Families/Friends to Engage in Advance Care Planning in Long-Term Care

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Your Conversation Starter Kit



Your Conversation Starter Kit

When it comes to end-of-life care, talking matters.



Institute for
Healthcare
Improvement

the conversation project

CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT



Your Conversation Starter Kit

For Families and Friends of People
with Alzheimer's Disease or Other
Forms of Dementia



Institute for
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CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT



Your Conversation Starter Kit

Step 1 Get Ready

You will have many questions as you get ready for the conversation. **Here are two to help you get started:**

1 What do you need to think about or do before you feel ready to have the conversation?

2 Do you have any particular concerns that you want to be sure to talk about? (For example, making sure finances are in order; or making sure a particular family member is taken care of.)

REMEMBER:

- You don't need to have the conversation just yet. It's okay to just start thinking about it.
- You can start out by writing a letter—to yourself, a family member, or a friend.
- You might consider having a practice conversation with a friend.
- Having the conversation may reveal that you and your family members or friends disagree. That's okay. It's important to simply know this, and to continue talking about it now—not during a medical crisis.
- Having the conversation isn't just a one-time thing. It's the first in a series of conversations over time.

Step 2 Get Set

What's most important to you as you think about how you want to live at the end of your life? What do you value most? **Thinking about this will help you get ready to have the conversation.**

1 Now finish this sentence: **What matters to me at the end of life is...**
(For example, being able to recognize my children; being in the hospital with excellent nursing care; being able to say goodbye to the ones I love.)

Sharing your "what matters to me" statement with your family member or friends could be a big help down the road. It could help them communicate to your doctor what abilities are most important to you—what's worth pursuing treatment for, and what isn't.

WHERE I STAND SCALES

Use the scales below to figure out how you want your end-of-life care to be. Select the number that best represents your feelings on the given scenario.

As a patient, I'd like to know...

1 2 3 4 5

Only the basics about my condition and my treatment

All the details about my condition and my treatment

As doctors treat me, I would like...

1 2 3 4 5

My doctors to do what they think is best

To have a say in every decision



Your Conversation Starter Kit

Step 3 Go

When you're ready to have the conversation, think about the basics.

MARK ALL THAT APPLY:

1 WHO do you want to talk to?

- | | |
|---|---|
| <input type="checkbox"/> Mom | <input type="checkbox"/> Faith leader (Minister, Priest, Rabbi, Imam, etc.) |
| <input type="checkbox"/> Dad | <input type="checkbox"/> Friend |
| <input type="checkbox"/> Child/Children | <input type="checkbox"/> Doctor |
| <input type="checkbox"/> Partner/Spouse | <input type="checkbox"/> Caregiver |
| <input type="checkbox"/> Sister/Brother | <input type="checkbox"/> Other: <input type="text"/> |

2 WHEN would be a good time to talk?

- | | |
|--|---|
| <input type="checkbox"/> The next holiday | <input type="checkbox"/> Before the baby arrives |
| <input type="checkbox"/> Before my child goes to college | <input type="checkbox"/> The next time I visit my parents/ adult children |
| <input type="checkbox"/> Before my next trip | <input type="checkbox"/> At the next family gathering |
| <input type="checkbox"/> Before I get sick again | <input type="checkbox"/> Other: <input type="text"/> |

3 WHERE would you feel comfortable talking?

- | | |
|---|--|
| <input type="checkbox"/> At the kitchen table | <input type="checkbox"/> Sitting in a park |
| <input type="checkbox"/> At a favorite restaurant | <input type="checkbox"/> At my place of worship |
| <input type="checkbox"/> In the car | <input type="checkbox"/> Other: <input type="text"/> |
| <input type="checkbox"/> On a walk | |

4 WHAT do you want to be sure to say?

If you wrote down your three most important things at the end of Step 2, you can use those here.

Step 4 Keep Going

Congratulations! You have had "the conversation" — hopefully, the first of many. You can use the following questions to collect your thoughts about how your first talk went, and to think about what you'd like to talk about in future conversations.

1 Is there something you need to clarify that you feel was misunderstood or misinterpreted?

2 Who do you want to talk to next time? Are there people who should hear things at the same time (like siblings who tend to disagree)?

3 How did this conversation make you feel? What do you want to remember? What do you want your family members and friends to remember?

4 What do you want to make sure to ask or talk about next time?



Evaluating the Implementation of the CSK Booklet

Residents with capacity (N = 44) reported higher engagement in ACP after completing the CSK relative to before. Particularly, in *asking questions* to health care providers about health care issues.

Scale	T1 mean (SD)	T2 mean (SD)	T2 - T1) mean difference (SD)	t (p)
Decision Maker	3.85 (1.04)	4.07 (0.84)	0.22 (0.96)	1.51 (0.14)
Quality of Life	2.95 (1.13)	3.03 (1.11)	0.07 (1.25)	0.39 (0.70)
Ask Questions	2.76 (0.90)	3.18 (1.17)	0.41 (1.28)	2.15 (0.04)*
Flexibility	3.51(1.42)	3.98 (1.42)	0.47 (1.52)	2.01 (0.05)*
TOTAL	3.36 (0.93)	3.59 (0.81)	0.23 (0.88)	1.69 (0.09)



Evaluating the Implementation of the CSK Booklet

Baseline: family members reported feeling very certain that they would be able to make decisions on behalf of the resident

Post: family members reported feeling less certainty after completing the CSK

- ▶ CSK raised awareness of the decisions they might need to make — hopefully triggering contemplation and preparation



Residents Nearing End of Life



Palliative Care Conference

- A meeting held with staff, family, and residents (if possible) to discuss end-of-life care
- Can be triggered by PPS score, change in function/status, or request
- Designed to help family and residents to:
 - Access important information
 - Clarify goals and preferences for care
 - Feel supported in decision-making
 - Consider the site of care options (LTC, home, or hospital)
 - Obtain informed consent about goals of care



Our Results

- increased family satisfaction
- 82% of participating residents had a palliative care conference before they died
- 55% reduction in ER visits in last year of life
- 72% decrease in resident deaths in hospital

Kaasalainen et al. *BMC Palliative Care* (2020) 19:107
<https://doi.org/10.1186/s12904-020-00599-w>

BMC Palliative Care

RESEARCH ARTICLE

Open Access

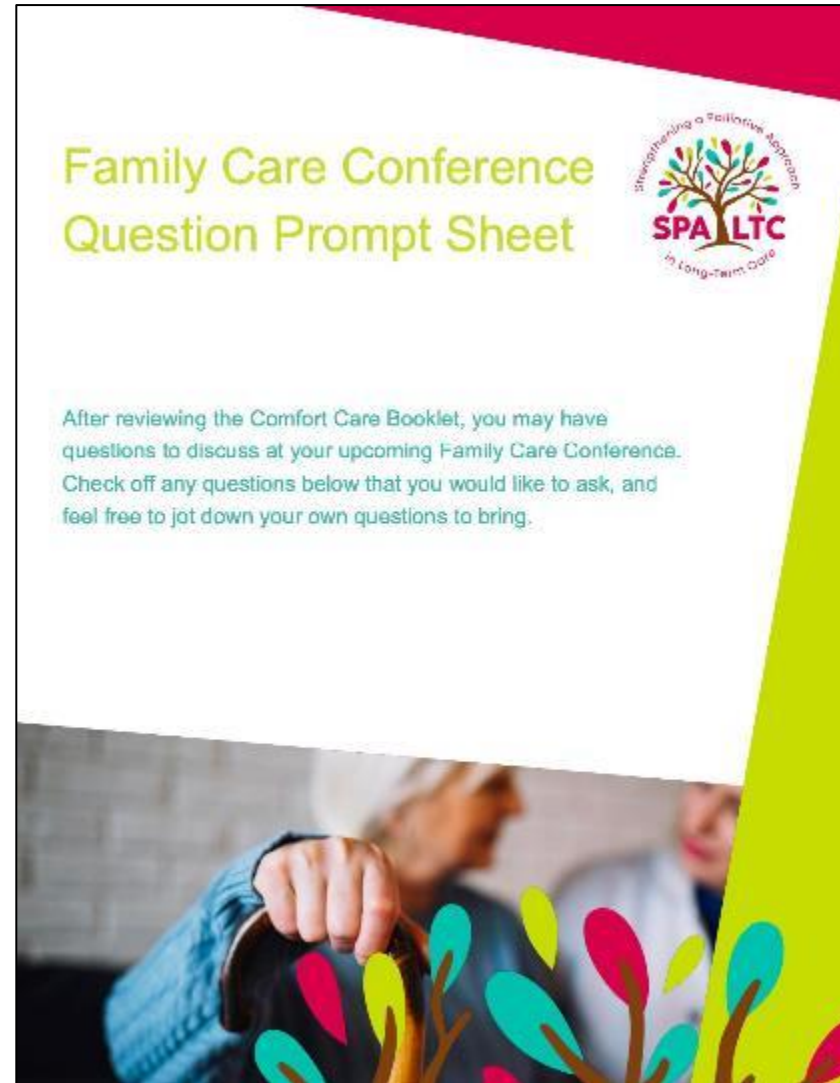
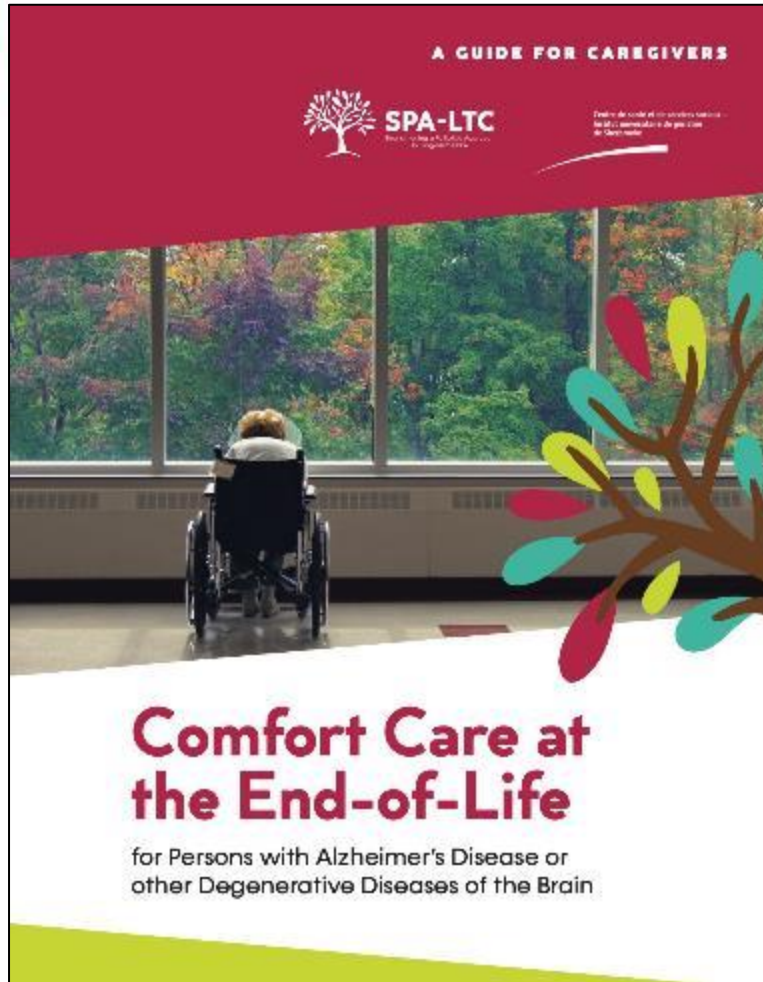
A pilot evaluation of the Strengthening a Palliative Approach in Long-Term Care (SPA-LTC) program



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Comfort Care Booklet & Question Prompt List



Supporting Families, Staff & Residents After a Resident Dies



Grief and Loss

"OUR GRIEVING IS AS INDIVIDUAL AS OUR LIVES"
- ELISABETH KÜBLER-ROSS

What is Grief?

Grief is a natural way we learn to live without someone we cared about after their death.

Grief can be intense and uncomfortable. We sometimes try to avoid our grieving through distractions and keeping busy.

GRIEF ACROSS CULTURES:

You may have unique cultural beliefs and rituals around death and grief. This may include how to handle the deceased person's body.

It is important to learn how about these beliefs and rituals as they can honour them.

It may help to talk to a spiritual or cultural leader to discuss your own beliefs in your culture or religion.

For more information, please visit:
www.virtualspalife.ca
advice@speaking.ca
www.speakupontario.ca



DIGITAL VERSION



What if I am More Relieved than Sad?

We have met with many people who feel their relative or friend died such as:

- Seeing the death as a relief
- Wishing their age
- Feeling a final closure
- Living separately from them

Given this, you may initially feel relief for a family member or friend to end their suffering.

With time however, the absence of your relative or friend will feel a little more. It may lead to many of the reactions described under Reactions to Grief.

How Long Do People Grieve?

People can feel profound grief for six months and up to two years.

DURING THIS TIME, YOU MAY HAVE:

- Bad days, when you know how bad you feel and just trying to get through the day
- Good days, when you have more energy and feel positive

Having a bad day after just starting to feel better does not mean you are slipping back into intense grief. Over time, the good days, then to outweigh the bad days.

Reactions to Grief:

There is no "right" way to grieve.

Common reactions following the death of a loved one relative may include:

PHYSICAL/PSYCHOLOGICAL REACTIONS:

- Loss appetite
- Irritability
- Difficulty focusing
- Loss energy
- Seeking or fearing the person who has died

EMOTIONAL REACTIONS:

- Anger
- Intense sadness
- Numbness
- Anxiety
- Guilt

SOCIAL REACTIONS:

- Isolation/withdrawal
- Lack of enjoyment
- Longing for the person who has died



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Planning Ahead

Grief may rear its head suddenly, even when you feel you are coping. To live without your relative or friend. This often happens during holidays, events and anniversaries.

Being prepared for these periods can help you cope better when they happen.

YOU MAY WANT TO:

- Plan to be with close family or friends
- Plan ahead to honour the person who has died
- Take time for yourself

Taking Care of Yourself

It is important to take care of yourself while you grieve:

- Spend time with your family and friends. This will help prevent isolation and provide support to you in coping with your loss.
- Reach out for help and support. Speak daily with other survivors of loved one's death.

Your health is important too. If you are feeling overwhelmed, seek support from your health care provider and from the Family Councils of Ontario www.fco.org (416) 467-4355 or 1-888-283-8806.

Reaching Out for Help

Sometimes our feelings of grief are overwhelming. These feelings may give us trouble in our daily lives.

AFTER 6 MONTHS, YOU MAY WANT TO SEEK HELP IF:

- You cannot feel happy or relieved
- You see no hope for the future
- You are preoccupied with anger or guilt

Refer to the pamphlet *Surviving the Bereavement, Grief and Loss* to learn about services and resources to help you understand and cope with your grief. Refer to the pamphlet *What to Do After a Death* for a list of funeral services you may need to complete following the death of a family member or a friend.

SPALIFE

Online Resources

- 1. See SPA-LTC website for more resources www.spalife.ca/resource-library/

Contact Us

Strengthening Palliative Approach
In Long-Term Care SPA-LTC
McMaster University School of Nursing
www.spalife.ca
spa.ltc@mc.mcmaster.ca

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Strengthening Palliative Approach
In Long-Term Care



DIGITAL VERSION

What to Do After a Death

A GUIDE TO LEGAL, FINANCIAL AND GOVERNMENTAL FORMALITIES



Transferring the Body

When someone dies, their body must be transferred. If you have private care or a funeral service, you or the funeral home will call them immediately to advise the body is ready for transfer. If you are not sure, you will need to select one immediately.

If you are unsure how to be with a loved one, bereavement services are available. You can contact the Bereavement Authority of Ontario at: <https://thebao.ca/>, 416-493-2646 or 1-844-493-2646 (toll free); email: info@thebao.ca

Consulting a Will

If you know there is a will, you will be responsible for finding out the deceased person's wishes. If you are not sure if there is a will, you can contact the estate division of the local court in the area. The person has to submit a will to be verified. If there is no will, you will be required to appoint someone to decide who administers the estate of the deceased person's final testament.



FOR MORE INFORMATION ON WILL AND LEGAL ISSUES FOLLOWING THE DEATH OF SOMEONE, CONTACT:

Law Society of Ontario
www.lso.ca/home
1-800-465-8588 (toll free) or 416-947-8900 (toll)

Legal Aid Ontario
www.legalaid.on.ca
1-800-465-8588 (toll free) or 416-977-8888 (toll)

Notifying Federal and Provincial Agencies

When someone dies, there are a number of organizations that need to be informed. Most of these organizations will need a death certificate, which can be obtained online at www.ontario.ca/ageof-death-certificate-online. Phone: 1-800-465-8588 (toll free) or 416-977-8888 (toll free only).

PROVINCIAL

Ministry of Health
Coronavirus (COVID-19) 1-800-268-1183
Toll-free or 416-327-4327

Ministry of Community and Social Services
Family Financial Services and Support
1-800-386-4188 (toll-free) or 416-325-5444

Ministry of Transportation
22 Ave. Road, Mississauga, ON L4R 1A7
1-800-387-3449 (toll-free) or 416-238-2999 (TTS)

Ontario Ministry of Finance
Notify Financial Institutions of the Death
800-387-3449 (toll-free) or 416-325-5444

FEDERAL

Service Canada

Canada OAS and CPP benefits
Check if you qualify for a benefit. A death certificate is required.
1-800-273-9914

Canada Revenue Agency

Final and income tax return
1-800-959-6391

Veterans Affairs Canada

Control a Veterans pension and more
If you qualify for death benefits
1-888-823-2133

Canada Post

Return incoming mail to sender
1-844-997-6801

Citizenship and Immigration Canada

Convince a visa sponsor
1-800-969-6868

Refer to the people or institutions to learn about life insurance and common expenses related to grief.

Refer to the people or institutions for bereavement services and resources to help you understand and cope with your grief.



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PRIVATE PENSIONS AND FINANCIAL INSTITUTIONS

- If you are unsure if the deceased had private life insurance or a private pension, contact their most recent employer. You can also reach the a member of health insurance company that he or she engaged.
- Contact the bank or other financial institutions with which the deceased was involved.
- If you are unsure if the death occurred, maximize substantiating evidence when you contact them. You can file a "Notice to Creditors" in the local paper. This is for notifying creditors that he or she has died, and it gives them a deadline to make any claim against the estate.

Finding Out About Benefits

You may be eligible for Survivor's Allowance, Allowance for the Survivor and/or CPP Death Benefit. You can also check out the website for your Service Canada OR all the following websites:



Your health is important too. If you are feeling overwhelmed, seek support from your health care provider and from the Family Councils of Ontario www.fco.org (416) 487-4955 or 1-888-255-8804.

Survivor's Pension

www.csis.gc.ca/en/cpp/survivor_pension.page

CPP Death Benefit

www.canada.ca/en/services/benefits/publicpensions/cpp/cpp-death-benefit.html

Allowance for the Survivor

www.csis.gc.ca/en/cpp/allowance_survivor.page

Online Resources

- 1-800-969-6868 (toll free) or www.spa-ltc.ca/resource-library/

Contact Us

Strengthening Palliative Approaches in Long-Term Care (SPA-LTC)
McMaster University School of Nursing
www.spa-ltc.ca
info@spa-ltc.ca

SPA-LTC
Strengthening Palliative Approaches in Long-Term Care



Resources

ON BEREAVEMENT,
GRIEF AND LOSS



What is Grief and Bereavement?

Grief is a natural response to loss, without someone we cared about after their death.

As a service user part of grief is the loss of a staff member or friend.

Bereavement Resources

Hamilton, Niagara, Halton and Front (HNHF): The link below are online bereavement support groups and advice call for the area www.hnhfhaalthline.ca/healthservices.aspx?tbl=10162

Bereaved Families of Ontario: Help and support for those who have lost a loved one. Help is connected you to other people for practical or personal support. All programs are run by volunteers who have grieved the death of their loved one. www.bereavedfamilies.net



For more information, please visit:
www.elfhealthpress.ca
www.spahealthpress.ca

SELF-HELP BOOKS ON GRIEF AND LOSS

Healing After Loss: Daily Meditations for Working Through Grief.
Marie Perle (October 2011)

This book will give you a sense of calm, quiet and peace in your life. Each day you will be able to cope with grief and loss. It is written by a grief survivor. It is also available in audio form.

How to Go on Living When Someone You Love Dies.
Harold G. Koenig (1997)

This book is written by a psychologist who has discussed many people through grief. The book provides a link to help you cope with grief and will be a support and for coping with grief.



Understanding Your Grief: Ten Essential Touchstones for Finding Hope and Healing Your Heart.
Kathleen Kuhlman (2002)

This book is written by a grief counselor. The book is designed to be read in short segments with each chapter providing a thought provoking exercise to complete on your own.

Healing A Spouse's Grieving Heart: 100 Practical Ideas after your husband or wife dies.
Muriel D. Mahler, Ph.D. (2007)

This book is specifically geared towards dealing with the loss of a spouse in later life. Simple and brief ideas on how to move through your grief are offered.

Life After Loss.
Liz Kirkpatrick

This book offers some practical information on coping with the loss of a loved one. It is written by a grief counselor and is available in audio form.

Good Grief.
George Weitz (2010)

This book offers a practical approach to grief and loss. It is written by a grief counselor and is available in audio form.



Informational Web Sites

FAMILY CAREGIVER ALLIANCE

The web site below offers some specific information for those who are providing care for someone who is frail. It is an American site but some of the information may be applicable to you.

www.caregiver.org/grief-and-loss

BAYCREST

This web site below offers the different ways you can get help and support. It is written by a grief counselor and is available in audio form. It is a good resource for those who are providing care for someone who is frail.

www.baycrest.org/Baycrest/Education-Training/Educational-Resources/Late-Life-Depression

Your health is important too. If you are feeling overwhelmed, seek support from your health care provider and from the Family Doula in Ontario www.fdo.org (416) 497-4356 or (888) 283-8363.



HELP GUIDE

The web site below offers a list of grief and loss resources. It is a good resource for those who are providing care for someone who is frail. It is a good resource for those who are providing care for someone who is frail.

www.helpguide.org/articles/grief-and-loss/grief-and-loss.htm

Next Steps...

Refer to the pamphlet *How to Deal with Grief and Loss* to learn more about grief and loss.

Refer to the pamphlet *How to Deal with Grief and Loss* to learn more about grief and loss.

21 April 2013

More Resources

1. See SPA-LTC website for more resources
<http://spa.ltc.ca/resources/files/>

SPA-LTC
STRENGTHENING A PALLIATIVE APPROACH
IN LONG-TERM CARE

Contact Us

Strengthening a Palliative Approach
in Long-Term Care
McMaster University School of Nursing
www.spa.ltc.ca
508-250-1100





Strengthening Bereavement Care

in Long-Term Care Settings



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Final Thoughts

- Need to build capacity in LTC to implement a palliative approach to care
- Need stronger focus on caring relationships within a psychosocial model
- Need to break down the walls of LTC homes and integrate them more within the larger community



SPA-LTC Alliance

Funded by Health Canada (2021-2026) to roll out a palliative program in LTC across Canada in partnership with:

- CHPCA
- CVH
- Pallium

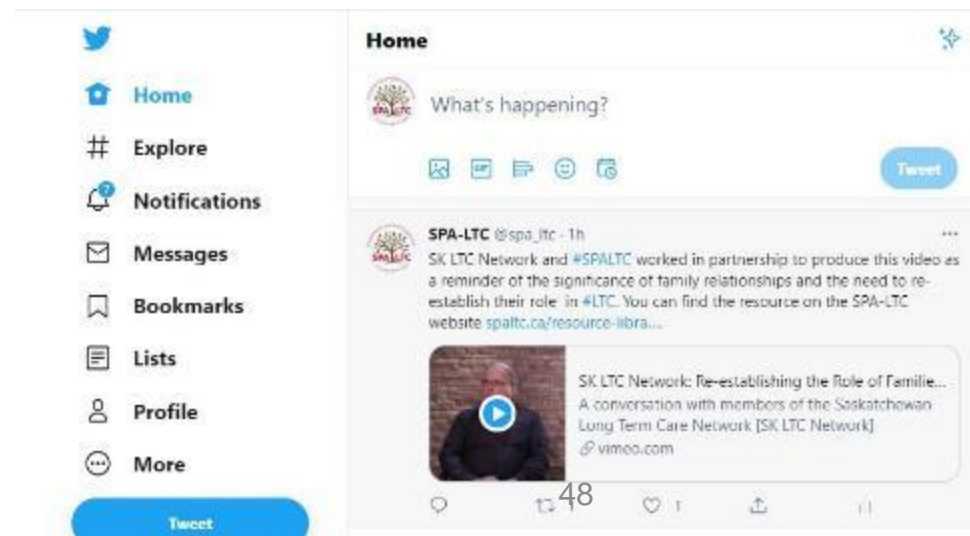
- If you are interested in joining our Alliance please email:

kaasal@mcmaster.ca



Website & Social Media

- Website: www.spaltc.ca
- Twitter: @spa_ltc
- Facebook
@strengtheningapalliativeapproach
- LinkedIn
<https://www.linkedin.com/company/spa-ltc/about/?viewAsMember=true>



SPA-LTC

Strengthening a Palliative Approach
in Long-Term Care

Website:

www.spaltc.ca

