

Essential Conversations

A Guide to Advance Care Planning
in Long-Term Care Settings

Spring 2021



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This report was informed by the work of the Strengthening a Palliative Approach in Long-Term Care (SPA-LTC) pan-Canadian team of health and social science researchers. SPA-LTC is about making sure that people with life-limiting illnesses have more opportunities to experience a high quality of life from the moment they enter long-term care to the day of their death. Shaped by clinical experience and through original research, SPA-LTC was developed as an approach to care that draws together best practices in a palliative approach to care within long-term care settings across the globe. The SPA-LTC provincial leads are: Dr. Sharon Kaasalainen (McMaster University), Dr. Tamara Sussman (McGill University), Dr. Paulette Hunter (St. Thomas More College, University of Saskatchewan), Dr. Lynn McCleary (Brock University), Dr. Genevieve Thompson (University of Manitoba), Dr. Abigail Wickson-Griffiths (University of Regina) and Dr. Lorraine Venturato (University of Calgary).

*Production of this guide has been made possible through a financial contribution from Health Canada.
The views expressed herein do not necessarily represent the views of Health Canada.*

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Why Essential Conversations and Advance Care Planning are Important in Long-Term Care

Residents of long-term care homes deserve to receive care that reflects their values and wishes, and to participate in decisions about their lives and care. Most long-term care residents are frail or have a serious illness or disability. They move into long-term care because they can no longer manage in their homes, and their health is likely to deteriorate over time. Even though some will have illnesses (e.g. dementia) that may limit their ability to communicate, all should have an opportunity to engage in essential conversations about what is important to them.

Long-term care teams are in an ideal position to:

- help residents and families talk about what gives meaning to their lives and the kind of care they want
- provide information to help residents and families understand their health issues and which treatments may be effective and which ones may not be
- provide care that reflects their values and wishes.

When long-term care homes take a coordinated approach to Advance Care Planning, they can significantly improve communications between staff and residents/families, and the care and support of seriously ill or frail elderly residents and their caregivers. They can also help staff anticipate residents' care needs at end-of-life and avoid undesired hospital transfers.^{1, 2, 3}

Integrating Advance Care Planning conversations into long-term care can help reduce pressure on staff, avoid misunderstandings and conflict, increase resident, family and health care provider satisfaction, and improve both quality of life and quality of care.

About this Guide

This guide is designed to help those involved in planning for and providing long-term care — health care providers working in long-term care settings, administrators, regional health authorities and policy makers — understand and implement best practices in **Advance Care Planning**. It is one of a number of resources that long-term care settings can use to actively encourage long-term care providers, residents and families to have essential conversations about their values, and document their wishes and preferences for care.

Advance Care Planning is about having the kind of essential conversations that:

- empower residents and families
- make life more meaningful
- make sure everyone in a person's circle of care understands what the person wants and is "on the same page"
- help residents and families make decisions about care that reflect the resident's values and are right for them
- help residents avoid unnecessary, ineffective or unwanted treatments and interventions.

1 Strengthening a Palliative Approach in Long-Term Care. spaltc.ca/about-spa-ltc/

2 Kaasalainen, S., Sussman, T., Thompson, G. *et al.* A pilot evaluation of the Strengthening a Palliative Approach in Long-Term Care (SPA-LTC) program. *BMC Palliative Care* 19, 107 (2020). doi.org/10.1186/s12904-020-00599-w

3 Strengthening a Palliative Approach in Long-Term Care Project Overview. www.chpca.ca/knowledge/strengthening-a-palliative-approach-in-long-term-care-spa-ltc-project/

Integrating Advance Care Planning into long-term care involves:

- Having essential conversations about the person’s values, which can be initiated by the resident, family or a staff member
- Sharing information about the resident’s health condition/illness so the person and their family, friends and Substitute Decision Maker(s) understand what to expect as they age and their health changes (a national guide is in the early stages of development)
- Providing clear, accurate information about the benefits and risks of different treatment options given their health issues
- Supporting residents, families and Substitute Decision Maker(s) as they work through the ongoing process of Advance Care Planning
- Documenting the resident’s wishes and preferences for care
- Ensuring staff have the training and resources to engage residents and families in Advance Care Planning conversations, and support them as they work through the process
- Taking concrete steps to provide care that reflects the resident’s and families’ wishes.

Advance Care Planning is an integral part of a **Palliative Approach to Care**, which focuses on meeting a person’s and family’s full range of needs – physical, psychosocial and spiritual – at all stages of frailty or chronic illness, not just at the end of life. It reinforces the person’s autonomy and right to be actively involved in his or her own care – and strives to give individuals and families a greater sense of control. It sees hospice palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of an integrated approach to care that can enhance their quality of life throughout the course of their illness or the process of aging.

See Appendix I.

How to Integrate Advance Care Planning into Long-Term Care

Advance Care Planning is a lifelong process of thinking and talking about the kind of health and/or personal care you would want if — at some point in your life — you cannot speak for yourself. The process should include the people you have chosen to speak for you — your Substitute Decision Maker(s)⁴ — and may also include health care providers, lawyers, and/or other professionals helping you with your life and care planning. It is about sharing your values, beliefs, and wishes, and making sure the people you’ve chosen to speak for you understand what matters most to you.⁵

In an ideal world, people would start the Advance Care Planning process early in their adult lives and revisit it at key points, such as when they have a child, as they age, if they develop a disability or are diagnosed with a chronic condition, or when their idea of a meaningful life changes.

In an ideal world, people moving into a long-term care setting would already have engaged in Advance Care Planning. They would have appointed a Substitute Decision Maker and their families would know what they want in terms of their care.

4 Substitute Decision Maker is a generic term and the term used varies across Canada. For example, in some jurisdictions, it is referred to as a “proxy”.

5 Canadian Hospice Palliative Care Association. 2020. Advance Care Planning in Canada: A Pan-Canadian Framework.

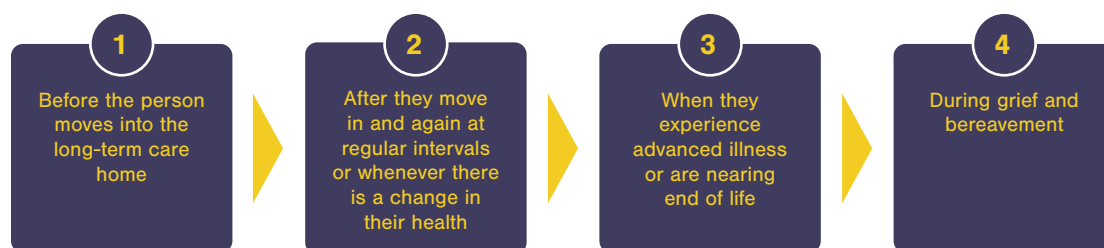
However, for some residents, that is not the case. Some have thought about it, but not written it down or told their families. And, even when a resident and family has gone through a process of Advance Care Planning, the long-term care setting still has a responsibility to:

- understand the resident’s values, goals and wishes, and know who their Substitute Decision Maker is
- create ongoing opportunities to have essential conversations about Advance Care Planning, particularly as the resident’s health changes
- make sure the resident and family have all the information they need about the resident’s health condition(s) as well as the benefits and risks of treatment options so they can think about what’s important to them and make informed care decisions
- revisit the resident’s care plans regularly (e.g. twice a year) and whenever the resident’s health or wishes change
- provide care that reflects the resident’s values, goals and wishes
- integrate a Palliative Approach to Care, which includes Advance Care Planning, with all residents beginning on move-in day.

Within long-term care settings, the Advance Care Planning process may have to be adapted to reflect both the resident’s health, needs and wishes, and the setting’s responsibility to provide person-centred care.

I. When and How Should Advance Care Planning Happen in Long-Term Care?

Advance Care Planning is part of a holistic Palliative Approach to Care with residents in long-term care settings and their families. This supportive, person- and family-centred approach to care can be integrated into long-term care in four phases:^{6, 7, 8, 9}



The following pages describe best practices at each phase and offer tips and tools to help integrate Advance Care Planning into routine long-term care practices, as one element of a Palliative Approach to Care.

6 Strengthening a Palliative Approach in Long-Term Care. spaltc.ca/about-spa-ltc/

7 Kaasalainen, S., Sussman, T., Thompson, G. *et al.* A pilot evaluation of the Strengthening a Palliative Approach in Long-Term Care (SPA-LTC) program. *BMC Palliative Care* 19, 107 (2020). doi.org/10.1186/s12904-020-00599-w

8 Kaasalainen, S., Sussman, T., McCleary, L., Thompson, G., Hunter, P. V., Wickson-Griffiths, A., Cook, R., Dal-Bello Haas, V., Hill, C., Venturato, L., Papaioannou, A., You, J., & Parker, D. (2019). A Stakeholder Analysis of the Strengthening a Palliative Approach in Long-Term Care Model. *Nursing Leadership*, 32(3), 27-39. doi.org/10.12927/cjnl.2019.25974

9 Strengthening a Palliative Approach in Long-Term Care Project Overview.

www.chpca.ca/knowledge/strengthening-a-palliative-approach-in-long-term-care-spa-ltc-project/

Many people moving into a long-term care setting may have complex health issues, such as neurocognitive problems or dementia, already be relying on a Substitute Decision Maker to help communicate their wishes and make care decisions. However, it's still important to have these conversations with the Substitute Decision Maker and engage the resident as much as possible.

If the person who does this assessment (before the person moves into long-term care) is the community or hospital-based care coordinator, ensure the results are documented and shared with the long-term care home.

Depending on the province or territory, documents may include:

- financial planning documents, such as an enduring power of attorney
- health and personal planning documents, such as an advance directive, a speak up workbook and documents related to loss of capacity and guardianship
- estate planning documents, such as a will.

Phase 1. Before Moving into Long-Term Care

The decision to move to a long-term care setting is usually triggered by a deterioration in a person's health or ability to manage in their own home (e.g. a fall, surgery, increasing frailty, worsening chronic condition, neurocognitive problems, dementia). The decision is often highly emotional — for both the person and family members. They may experience an overwhelming sense of loss, grief, and uncertainty about the future.

When a person is moving into a long-term care setting, staff should focus on asking the person and their family about any previous Advance Care Planning conversations and decisions. This role usually falls to the professional coordinating the person's care in the community or to the long-term care staff person in charge of supporting the person's transition to long-term care. That person will either start the essential Advance Care Planning conversations (if none have taken place) or re-visit previous conversations. The goals are to understand the resident's and family's values, goals and wishes, develop a common understanding of the resident's condition or illness, and talk about how the care provided in the long-term care home will provide the support they need to live well.

Best practices in integrating Advance Care Planning and a Palliative Approach to Care into the transition into long-term care include:

Assess

- Assess the resident's needs using a holistic model, such as the **Clinical Frailty Scale** (developed at Dalhousie as part of the Canadian Study of Health and Aging)

The Clinical Frailty Scale assesses the person's existing chronic diseases and frailty and identifies where they are along the scale from "very fit" (1) to "living with mild frailty" (5) to "terminally ill" (10). The results can help determine whether the person would benefit from a serious illness conversation (SIC). SIC conversations are for those residents who have 1-2 years prognosis.

- Ask about and review any ACP documents the resident might have already completed. Ask whether the person has selected a Substitute Decision Maker or proxy, and engage that person in the assessment conversations. Ask the Substitute Decision Maker if they feel prepared for their role. (see the section **Confirm the Resident's Substitute Decision Maker** on page 10 for more information)

If the person doesn't have a Substitute Decision Maker, talk with the person and family about who will play that role (see www.advancecareplanning.ca/resource/living-well-planning-well-resource/ for the list of people in each Canadian jurisdiction who could be considered a Substitute Decision Maker if the person has not chosen one).

Engage

- ✓ Use a Conversation Starter Kit or a Serious Illness Conversation Guide (SICG) to have a “listening” conversation. Use this conversation to build the relationship with the person and/or Substitute Decision Maker, give the person a sense of control, and tailor information about the person’s illness to their readiness to receive it. The tools can also help staff explore the person’s, family’s and Substitute Decision Maker’s understanding of the person’s values, their wishes for their life as well as their condition and how much information they would like to receive about the impact of that condition on their health.

Reinforce that the purpose of the conversation is to talk about what may lie ahead with their illness and think about what’s important to them so the long-term care setting can provide the care they want.

- ✓ If the resident is not able to communicate easily, explore ways to overcome communications barriers (see page 13) and to understand a person’s wishes.
- ✓ Introduce the person and family member to a Palliative Approach to Care and prepare them for what they can expect given the resident’s health issues/chronic conditions (i.e. expected changes over time).

Document/Plan

- ✓ Use the information from the essential conversations and the assessments to document the person’s values and preferences.

This documentation should reflect what is important to the resident, activities that give meaning to their life, and the kind of care they want.

- ✓ If the person’s long-term care stay is likely to be time-limited (e.g. the person is recovering from surgery or a fall), plan for the resident to be able to move easily into long-term care and back out.
- ✓ If the person is on a waiting list for a place in the long-term care setting, identify what the long-term care setting can offer to help them maintain their health and avoid a crisis admission.

For example, working with the family to complete any documents or apply for subsidies, and coordinating with the person’s primary care or specialist provider to ensure they have access to home care or other supports.

Phase 2. After Moving into Long-Term Care Home and at Regular Intervals

Essential conversations continue when the person is in the long-term care setting. The long-term care team is responsible for having those conversations with the resident and family when the person moves in and again at regular intervals (e.g. twice a year) or whenever the resident’s health deteriorates. The roles of members of the team in Advance Care Planning vary depending on their training and scope of practice. For example, some tasks, such as explaining what Advance Care Planning is can be done by anyone involved in the resident’s care, while some tasks should be done by a trained interprofessional Advance Care Planning professional who could be a social worker, ethicist, nurse, nurse practitioner or physician, and others can only be done by a physician or nurse practitioner.

Role of Interprofessional Providers in Advance Care Planning

	ANYONE INVOLVED IN RESIDENT CARE	TRAINED INTERPROFESSIONAL ADVANCE CARE PLANNING PROFESSIONAL*	PHYSICIAN/ NURSE PRACTITIONER
Ask about Substitute Decision Maker	✓	✓	✓
Explain what Advance Care Planning is	✓	✓	✓
Discuss illness understanding		✓	✓
Clarify illness understanding			✓
Discuss values, beliefs, quality of life and wishes		✓	✓
Determine capacity for treatment or treatment plan			✓
Discuss values, life goals with capable resident or Substitute Decision Maker		✓	✓
Discuss treatment plan and options			✓
Obtain consent for treatment or plan			✓

* e.g. social worker, ethicist, nurse

Importance of an Equity, Diversity and Inclusion Lens

When exploring a resident's care preferences, it's important for long-term care settings to incorporate an equity, diversity and inclusion lens. Staff should recognize that culture may affect people's willingness to engage in the conversations as well as how families make decision. They should ask the resident, family and Substitute Decision Maker about their religious/spiritual beliefs, their routines, and their hobbies and activities. Staff can use this information to tailor activities for the individual and provide social and spiritual support.

On admission:

- Complete a full resident assessment upon admission, including advance care planning documents (see above), along with the review of medication and level of frailty used to inform the resident's comprehensive plan of care.
- Support the resident and family members as they adjust to living in a long-term care setting, including coping with the grief and "losses" (e.g. home, independence, familiar routines, contact with friends and neighbours) they may experience.
- Have the physician, nurse practitioner or social worker meet the resident and family on move-in day (if they don't already know the person) or shortly after to provide medical information that will help the resident or Substitute Decision Maker make informed health care decisions.

At regular intervals (i.e. no changes in the resident's health):

- Continue to have conversations at regular intervals (e.g. every six months or at care conferences) about the course of the person's illness and whether the resident's wishes have changed

Routinely assess long-term care residents for any significant decline in health or new symptoms of advanced chronic illness using one or more of the following:

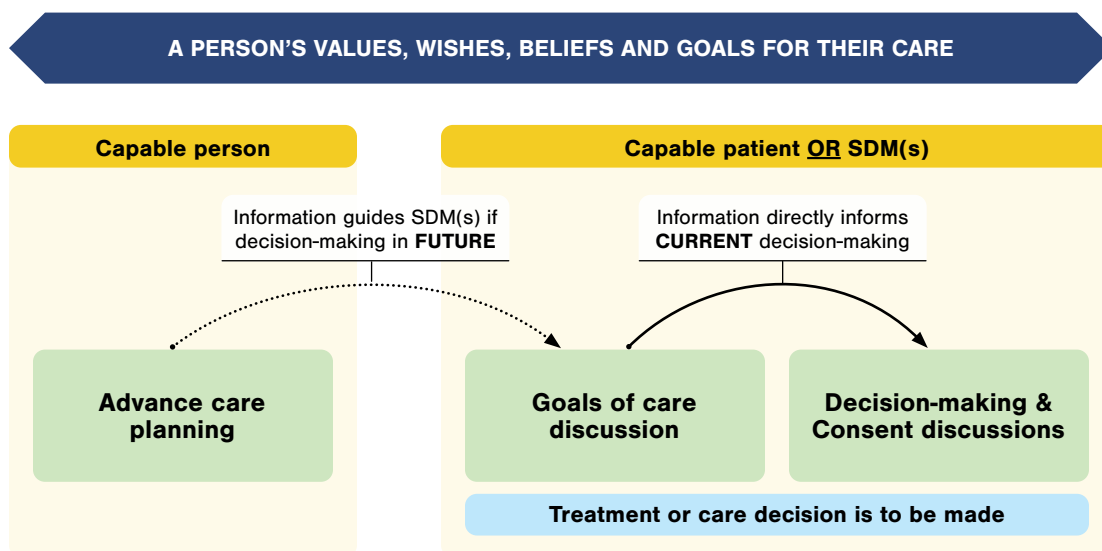
- 2 or more indicators checked on the Supportive Palliative Care Indicators Tool (SPICT)
- a score of <30 on the Palliative Performance Scale (PPS)
- J5 checked or CHES score on the RAI MDS
- ‘No’ to the question: “Would you be surprised if the resident died within 6 months?”
- Determine the patient’s goals of care, if clinically appropriate and part of your health system’s care planning.
- **Document conversations** related to determining or changing a goals of care medical order. In some jurisdictions, long-term care homes have to complete consent forms; in others they just have to document the conversation in the resident’s file or health regional forms

At any sign that the resident’s health is deteriorating:

- Have proactive conversations with the resident, family and Substitute Decision Maker
- Revisit their wishes and values
- Provide any new information about how the change will affect the person and the different treatment options, benefits and risks (**including CPR**). The Serious Illness Conversation Guide can be a useful tool.
- If indicated, revise the person’s plan of care.

Any significant decline/change in a resident’s health should trigger an essential conversation about their wishes.

Components of Person-Centred Decision-Making and Consent



Source: Hospice Palliative Care Ontario

The Difference Between Advance Care Planning Conversations and Treatment Decisions

If the change in the person's health means they are faced with a treatment decision (e.g. go to hospital, have a feeding tube), then it is time for a different, more specific conversation about the person's goals of care and consent to treatment.

In earlier conversations, the resident may have indicated that enjoying life mattered most to them and that they did not want intrusive interventions that would affect their quality of life. However, in the moment when a treatment decision has to be made, it is the responsibility of the physician or nurse practitioner to talk with the resident, family and/or Substitute Decision Maker about the person's goals of care and seek consent for any particular course of action.

Faced with a treatment decision, some residents and families may ask about invasive measures, such as CPR, and hospital and ICU admission. If these measures are not medically indicated, it's important for care providers to have conversations with the family about the likely outcome of these measures and about how the issues can be managed without those measures, as part of decision making.

Physician or nurse practitioner treatment orders (called the Medical Orders for Scope of Treatment or MOST form, or Goals of Care Designations in some provinces and territories) can help health care providers: understand the focus of care that is medically indicated given the resident's illness (ranging from comfort care to intensive care); and talk with the resident, family and Substitute Decision Maker and other health care providers about how best to achieve their goals.

Note: these types of medical orders are usually reviewed with the person, family and Substitute Decision Maker whenever there is a change in the person's health or care setting.

Phase 3. Advanced Illness/End of Life

As a resident's illness advances, the care team will continue to reassess their needs and their care plan. Best practices include:

- Use the **Clinical Frailty Scale** and the **Pictorial Fit-Frail Scale** to continually assess the resident's health.
- As the person's health declines, continue to have Advance Care Planning and Palliative Approach to Care conversations, and revisit the resident's wishes and values, including where they prefer to receive care.
- When the resident's illness is advancing and they are nearing end of life, arrange a **Family Care Conference**, talk about the changes in the resident's illness/health and their prognosis, identify goals of care, and ensure resident and family questions are answered.
- Begin to provide grief and bereavement support (part of a Palliative Approach to Care), including spiritual support for the resident and family. Provide access to helpful resources, such as "**A Caregiver's Guide – A Handbook About End-of-Life Care**" published by the Order of St. Lazarus in association with The Canadian Hospice Palliative Care Association, as well as **guidance about funeral arrangements**
- Review medications in consultation with the physician or nurse practitioner, pharmacist and nurse; continue only those that are symptom relieving and medically indicated.

- Ensure medications are proactively prescribed and dispensed for residents early (i.e. at the beginning of this phase) and not right at the end of life.
- Continue to monitor and manage symptoms especially fever, pain, anxiety, dyspnea, constipation, and secretions.
- Help prepare the resident and family members for any changes the resident may experience, especially physical changes, in the last hours of life.
- Support the resident and family through life review, emerging issues, and final separation.
- Help the resident, family members and Substitute Decision Makers be at peace with difficult decisions.

Phase 4. Grief & Bereavement

A Palliative Approach to Care in long-term care includes supporting the family after a resident's death. It should also include grief and bereavement support for staff and other residents. This role usually falls to a social worker or spiritual care provider on the team. Best practices include:

- Continue to provide grief and bereavement support for families, including written materials and other resources
- Talk to family members about how to tell children about the resident's death and how to provide age-appropriate grief support.
- Offer bereaved family members the opportunity to attend a peer support group
- Tell other residents about the person's death and provide support
- Acknowledge the death and celebrate the person's life (i.e. send a sympathy card to the family, hold a memorial service for staff and residents)
- Provide grief and bereavement support for staff

II. Tips and Tools for Integrating Advance Care Planning into Long-Term Care

1. Confirm the Resident's Substitute Decision Maker

Some residents may already have designated a Substitute Decision Maker(s) as part of their life planning. During the initial assessment/admission process, the staff person responsible for supporting the transition to LTC should obtain and document information on the person's Substitute Decision Maker(s). It is also important that SDM information is current and staff ask the Substitute Decision Maker(s) how prepared they feel for their role. For example, do they know the person's values and goals? Do they feel confident making care decisions? If not, what other support do they need?

A substitute decision maker provides consent for treatment and guides health-care decision making when a person is not capable of making decisions for themselves.

If the person has not already chosen a Substitute Decision Maker, staff can help them think through the following questions:

- Who will understand and follow your wishes?
- Who will honour your wishes, goals and be willing to make difficult decisions on your behalf if you are not able to make decisions for yourself?
- Is the person a capable adult?
- Do you trust this person to make decisions regarding your life, comfort and well-being?
- Will the person make decisions consistent with your faith and cultural values?
- Are you comfortable talking to this person about sensitive and difficult issues?
- Can this person handle differing opinions of family members and health care providers and come to a decision that reflects your wishes and discussions?
- Is this person available and able to make the time commitment that may be required?

If the resident is not capable of making an informed decision about their Substitute Decision Maker, staff should have the conversation with the family. The discussion should include: the list of people legally able to serve as Substitute Decision Maker(s) in that jurisdiction as well as conversations that would consider all the factors highlighted in the questions above — particularly the ability to follow the person’s wishes, act in their interests, make difficult decisions, and be available. For more information, download the [ACP in Canada Living Well, Planning Well resource](#).

The process of confirming the resident’s Substitute Decision Maker provides an opportunity for staff to reinforce the Substitute Decision Maker’s obligations and responsibilities (i.e. to make decisions based on the resident’s instructions, wishes, values and beliefs).

If the resident is not capable of having the conversation about their understanding of their illness, then staff should cover these issues with the Substitute Decision Maker(s). Fraser Health has adapted a version of the [Serious Illness Conversation Guide \(SICG\) specifically for use with Substitute Decision Makers](#). Nationally, there is a SICG in development.

As people age, become frailer and have more complex health problems, they are less likely to survive interventions that can be helpful in younger healthier people.

For example:

- 98 out of 100 people who have a critical illness and are admitted to an intensive care unit will die
- Among all people over 75, only 15 of 100 survive CPR.

2. Engage the Resident, Family and SDM in a Discussion about What to Expect

Advance Care Planning conversations are particularly important in long-term care settings because, in the last year of life, 30% of frail long-term care residents are admitted to an intensive care unit and 50% are admitted to hospital — even though these interventions may not extend their lives, and often cause anxiety, pain or discomfort. For residents and families to make informed decisions, it’s important for residents, families and Substitute Decisions Maker(s) to understand the benefits and risks of these interventions.

A resident’s care decisions will depend to a great extent on their overall health and any chronic conditions they have. One of the most useful ways to talk about the impact on their health and lives — that is, what to expect — is to focus on their specific illness. Residents and families often find it easier to talk about the specifics of a condition than about wishes and preferences in general.

The Illness Trajectory Pamphlets provide information for the following conditions:¹⁰

- **Frailty**
- **Heart disease**
- **Lung disease**
- **Kidney disease**
- **Dementia**

The pamphlets also help members of the care team talk to residents and families about a Palliative Approach to Care and how Advance Care Planning can support quality end-of-life care. Family members report that they are more comfortable talking about Advance Care Planning after they have read one of the pamphlets.^{11, 12, 13}

Note: In addition to providing the general pamphlets, certain members of the care team (e.g. physicians, nurse practitioners – depending on the jurisdiction) can talk to the resident, family members and Substitute Decision Maker in more detail about the resident’s specific prognosis and the benefits, risks and effectiveness of different treatment options.

Work with your team to encourage conversations tailored to the person, their Substitute Decision Maker and family.

3. Ask the Resident, Family and Substitute Decision Maker About and Document their Preferences for Care

Given what the resident and family now know about what to expect from the resident’s illness, it’s important to talk about what gives meaning to their lives and what type of care may be medically indicated under what conditions.

There are a number of tools that can be used to help long-term care staff ask about and record the resident’s preferences for care including:

- The Serious Illness Conversation Guide
- The Conversation Starter Kit
- The Advance Care Planning Record
- Sample Questions to Guide Essential Conversations

The resident’s preferences should be documented in their file and available to all staff. A copy should be also shared with the family and Substitute Decision Maker. **Make sure you know how these conversations are documented in your region.**

10 Illness Trajectory Pamphlet links are to the Ontario versions. Illness Trajectory Pamphlets for five Canadian provinces are available at the SPA-LTC Resource Library in both print and online versions www.spaltc.ca/resource-library/

11 Strengthening a Palliative Approach in Long-Term Care: Illness Trajectory Pamphlets. spaltc.ca/illness-trajectory/

12 Sussman, T., Kaasalainen, S., Lee, E., Akhtar-Danesh, N., Strachan, P. H., Brazil, K., Bonifas, R., Bourgeois-Guérin, Durivage, P., Papaioannou, A., & Young, L. (2019). Condition-specific pamphlets to improve end-of-life communication in long-term care: Staff perceptions on usability and use. *JAMDA*, 20(3), 262-67. doi.org/10.1016/j.jamda.2018.11.009

13 Sussman, T., Kaasalainen, S., Bui, M., Akhtar-Danesh, N., Mintzberg, S., & Strachan, P. (2017). “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. *Gerontology and geriatric medicine*, 3, 1-11. doi.org/10.1177/2333721417747323

4. Overcome Communication Barriers

Advance Care Planning is about conversations and communication. Many residents may have communication barriers related to loss of hearing and sight, neurocognitive issues and dementia, and/or the impact of other health conditions or developmental issues. However, even people who are non-verbal or struggle to communicate can still be involved and engaged in conversations and decision making.

- **This resource** will help staff engage residents with dementia
- This resource will help staff engage residents with intellectual or developmental disabilities: **Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities**

5. Ensure Equity, Diversity and Inclusion

When having essential conversations with residents, families and Substitute Decision Makers, it is extremely important to consider their culture and how it may affect their comfort talking about values and preferences, and their approach to decision making.

The following resources can help staff understand the impact of culture and initiate conversations in culturally appropriate ways:

- **Fraser Health Advance Care Planning**
(18 minutes; shows other cultures/ ethnicities)
- **Equity in Palliative Care**
- **Advance Care Planning for Culturally Diverse Communities**

There are also a number of resources that can help support Advance Care Planning conversations and a Palliative Approach to Care with Indigenous Peoples:

- www.fnha.ca/what-we-do/healthy-living/advance-care-planning
- livingmyculture.ca/culture/first-nations/
- **Talking to my community**

6. Revisit the Advance Care Planning Conversation Regularly or Whenever a Resident's Health Changes

At regular intervals (annually or bi-annually) and when there is any change in a resident's health (e.g. deterioration, new loss of function), staff should have an Advance Care Planning and Palliative Approach to Care discussion with the resident, family and Substitute Decision Maker.

If there has been a change in a resident's health, staff should:

- describe to the resident, family and Substitute Decision Maker what the person can expect now in terms of illness trajectory
- ask the resident and Substitute Decision Maker(s) whether any of their wishes or preferences for care have changed
- discuss the steps the long-term care home will take to provide the type of care that will help manage the illness and side effects.
- document the person's wishes and preferences for care.

7. Support the Resident through Advanced Illness/ End of Life

In a Palliative Approach to Care, the focus shifts more to comfort care as a resident's illness advances and the person nears end of life. Comfort care involves managing pain and symptoms, providing psychosocial support for residents and families, and supporting residents to engage as much as possible in activities that give meaning to life.

Comfort Care Rounds are an effective way to help all members of the long-term care team focus on the residents' wishes for care at the end of life. In these rounds, usually held monthly, interdisciplinary teams use case-based learning to problem solve for different residents' care. Common issues discussed include: navigating complex family dynamics, balancing the divergent needs of families and residents, managing sudden resident deaths, and addressing the moral distress that staff may experience as part of their work.

Depending on the residents' needs, it may be helpful to include social work, spiritual care, palliative care or other medical specialists in Comfort Care Rounds.

Long-term care settings that focus on residents' wishes and provide effective comfort care report that residents have fewer ER visits and hospital admissions in the last weeks and months of life. Residents, family members and staff also report better communications and greater comfort talking about and managing end-of-life issues.^{14, 15, 16}

14 Strengthening a Palliative Approach in Long-Term Care "About SPA-LTC." spaltc.ca/about-spa-ltc/

15 Strengthening a Palliative Approach in Long-Term Care Project Overview www.chpca.ca/knowledge/strengthening-a-palliative-approach-in-long-term-care-spa-ltc-project/

16 Kaasalainen, S., Sussman, T., Thompson, G. *et al.* A pilot evaluation of the Strengthening a Palliative Approach in Long-Term Care (SPA-LTC) program. *BMC Palliative Care* 19, 107 (2020). doi.org/10.1186/s12904-020-00599-w

8. Support Family Members and Staff with Grief and Bereavement

Support with grief and bereavement is an integral part of a Palliative Approach to Care. Family members who feel that the resident received good care that reflected their wishes report that the resident experienced less emotional distress at end of life. Family members who receive support from long-term care staff also report that both they and the resident experience less emotional distress at end of life.^{17, 18, 19, 20} How those close to us die and how we are supported at that time are part of each of our never forgotten stories. A family member's experience in this phase influences them later when they are making or revising their own advance care plans or when acting as Substitute Decision Makers for other family members.

One of the most effective ways to provide support for both residents and families before the resident's death is Family Care Conferences. Long-term care staff meet with the resident, Substitute Decision Maker(s) and family members to discuss preferences for care, answer questions family members may have, prepare them for the changes they may see in the person, and provide support with grief and bereavement. Most families who participate in care conferences report that:

- their concerns and issues around end-of-life care were addressed
- the conferences supported good communication with staff.²¹

Some long-term care settings provide simple, practical supports for families that can make a difference, such as a basket of toiletries, toothbrushes and refreshments for families keeping vigil. Others have after death rituals that help the other residents, staff and family remember, celebrate and grieve the person who has died.

In terms of grief and bereavement support for long-term care staff, see the following resource:

- **Reflective Debriefing**

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- 17 Lee, E., Sussman, T., Kaasalainen, S., Durepos, P., McCleary, L., Wickson-Griffiths, A., & Bimman, R. (2020). The relationship between caregivers' perceptions of end-of-life care in long-term care and a good resident death. *Palliative & Supportive Care*, 1-8. doi.org/10.1017/S1478951520000292
- 18 Thompson, G., Shindruk, C., Wickson-Griffiths, A., Sussman, T., Hunter, P.V., McClement, S., Chochinov, H., McCleary, L., Kaasalainen, S., & Venturato, L. (2019). "Who would want to die like that?": Perspectives on dying alone in a long-term care setting. *Death studies*, 43(8), 509-520. doi.org/10.1080/07481187.2018.1491484
- 19 McCleary, L., Thompson, G. N., Venturato, L., Wickson-Griffiths, A., Hunter, P., Sussman, T., & Kaasalainen, S. (2018). Meaningful connections in dementia end of life care in long term care homes. *BMC Psychiatry*, 18(1), 307. doi.org/10.1186/s12888-018-1882-9
- 20 Smith-MacDonald, L., Venturato, L., Hunter, P., Kaasalainen, S., Sussman, T., McCleary, L., Thompson, G., Wickson-Griffiths, A., & Sinclair, S. (2019). Perspectives and experiences of compassion in long-term care facilities within Canada: a qualitative study of patients, family members and health care providers. *BMC geriatrics*, 19(1), 128. doi.org/10.1186/s12877-019-1135-x
- 21 Durepos, P., Kaasalainen, S., Sussman, T., Parker, D., Brazil, K., Mintzberg, S., & Te, A. (2017). Family care conferences in long-term care: Exploring content and processes in end of life communication. *Palliative and Supportive Care*, 0:1-12. [doi:10.1017/S1478951517000773](https://doi.org/10.1017/S1478951517000773).

III. Training and Supporting the Long-Term Care Team

The long-term care team is responsible for integrating Advance Care Planning and a Palliative Approach to Care into residents' care. To have essential conversations with residents and families and provide care that reflects what matters to each resident, all staff — physicians, nurse practitioners, nurses, social workers, spiritual care providers, personal support workers (PSWs) and support staff — should:

- understand the importance of Advance Care Planning and a Palliative Approach to Care
- be comfortable having conversations about Advance Care Planning and end-of-life care that are culturally sensitive and inclusive
- be comfortable working with residents whose illness is advancing or who are dying.

Here is an example of the kinds of resources that are being developed to address training and support to address the needs of long-term care teams:

www.pallium.ca/taking-ownership/

Research in long-term care settings has shown that, in general, personal support workers are less comfortable working with dying residents than nurses, and less accustomed to working as part of a coordinated interdisciplinary team.²²

Strategies that help educate and support all staff in integrating Advance Care Planning and a Palliative Approach to Care include:

- Having designated people who champion a Palliative Approach to Care and Advance Care Planning
- Clarifying roles. Who will be responsible for having ongoing essential Advance Care Planning conversations with residents and families? Who will be responsible for talking to them about any changes in their health?
- Providing opportunities for all staff to receive training in and have opportunities to discuss a Palliative Approach to Care and Advance Care Planning, and how it changes practice, including tips and techniques on how to communicate with residents and families

Long-term care staff who gain more experience in a Palliative Approach to Care (including Advance Care Planning), feel they are more effective in their work with residents.

22 Kaasalainen, S., Sussman, T., Bui, M., Akhtar-Danesh, N., Laporte, D., McCleary, L., Wickson-Griffiths, A., Brazil, K., Parker, D., Dal Bello-Haas, V., Papaioannou, A., & O'Leary, J. (2017). What are the differences among occupational groups related to their palliative care-specific educational needs and intensity of interprofessional collaboration in long-term care homes? *BMC Palliative Care*, 16(1), 33. doi.org/10.1186/s12904-017-0207-y

- Holding interdisciplinary education sessions (i.e. with physicians, nurse practitioners, nurses, social workers, spiritual care providers) on “Being Comfortable with Palliative Care” for staff and for members of resident and family councils
- Developing a process to document all essential conversations with residents and families so the whole team is aware of the residents’ values and wishes
- Creating regular opportunities, such as Family Care Conferences and Comfort Care Rounds, for staff to come together to talk about resident and family needs, and the best way to meet those needs
- Measuring resident and family satisfaction with a Palliative Approach to Care and Advance Care Planning, and sharing the findings with all staff
- Measuring the impact of integrating Advance Care Planning and a Palliative Approach to Care into long-term care on quality of care indicators (e.g. number of residents who receive care that reflects their wishes, number of ER visits avoided, number of hospitalizations avoided, resident satisfaction, family satisfaction), and sharing that information with staff. One approach to measuring change is using the Plan-Do-Study-Act (PDSA) as an example.

Appendix I: Definitions

Advance Care Planning

Advance Care Planning is a lifelong process of thinking and talking about the kind of health and/or personal care you would want if — at some point in your life — you cannot speak for yourself. The process should include the people you have chosen to speak for you — your Substitute Decision Maker(s)²³ — and may also include health care providers, lawyers, and/or other professionals helping you with your life and care planning. During the conversations that are part of Advance Care Planning, you share your values, beliefs, and wishes, and make sure the people you've chosen to speak for you understand what matters most to you.²⁴

Advance Care Planning is part of life planning, which includes financial, estate, and health care planning. People plan for tomorrow so they can live for today.

Advance Care Planning is important because it:

- gives people a greater sense of control over their health care decisions
- makes people feel less anxious if/when they or a loved one experiences a health crisis
- improves communication and can reduce conflict, strengthen relationships and help family, friends and health care providers work together to provide the kind of care people want.

Advance Care Planning means people are more likely to feel confident that others understand their wishes, and to live and die how and where they want.

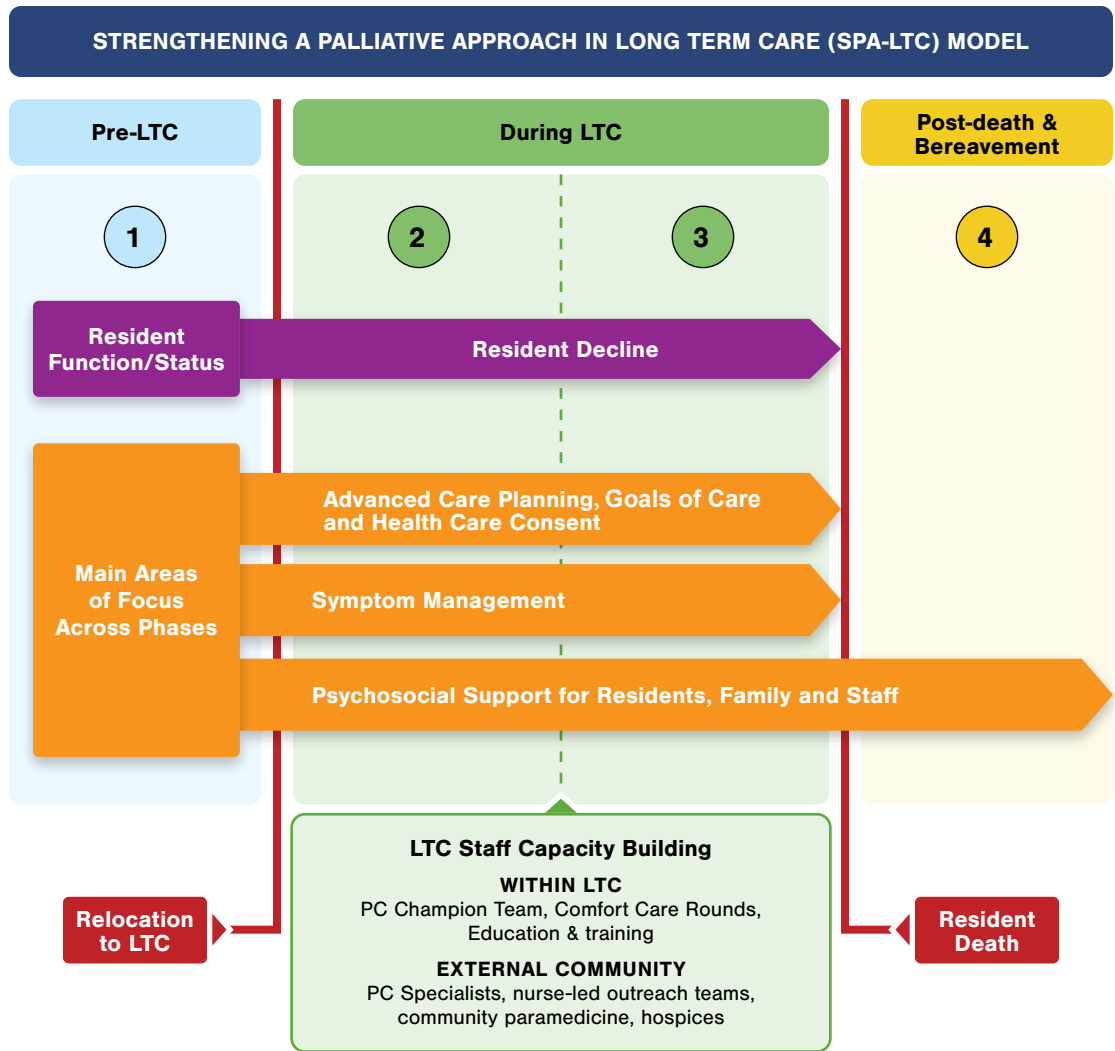
Advance Care Planning is not a one-time event. At regular intervals (i.e. once or twice a year) or whenever there's a change in a person's life or health, it's a good idea for them to go back and review any or all of the Advance Care Planning steps to make sure what they decided still reflects their values, goals and wishes.

Palliative Approach to Care

Advance Care Planning is an integral part of a Palliative Approach to Care — along with symptom management, supporting function and coping with illness, care coordination and psychosocial support — in long-term care homes. The goal of Advance Care Planning is to help ensure people receive medical care that is consistent with their values and goals while the goal of a Palliative Approach to Care is to enhance quality of life throughout the course of an illness or the process of aging.

²³ Substitute Decision Maker is a generic term and the term used varies across Canada. For example, in some jurisdictions, it is referred to as a “proxy”.

²⁴ Canadian Hospice Palliative Care Association. 2020. Advance Care Planning in Canada: A Pan-Canadian Framework.



Source : A Stakeholder Analysis of the Strengthening a Palliative Approach in Long-Term Care Model.²⁵

A Palliative Approach to Care focuses on meeting a person’s and family’s full range of needs — physical, psychosocial and spiritual – at all stages of frailty or chronic illness, not just at the end of life. It reinforces the person’s autonomy and right to be actively involved in his or her own care — and strives to give individuals and families a greater sense of control. It sees hospice palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of an integrated approach to care that can enhance their quality of life throughout the course of their illness or the process of aging.²⁶

²⁵ Kaasalainen, S., Sussman, T., McCleary, L., Thompson, G., Hunter, P. V., Wickson-Griffiths, A., Cook, R., Dal-Bello Haas, V., Hill, C., Venturato, L., Papaioannou, A., You, J., et Parker, D. (2019). *A Stakeholder Analysis of the Strengthening a Palliative Approach in Long-Term Care Model*. *Nursing Leadership*, 32(3), 27-39. doi.org/10.12927/cjnl.2019.25974

²⁶ Canadian Hospice Palliative Care Association. 2015. *The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care*.

A Palliative Approach to Care strives to enhance both living and dying for people who are frail or who have chronic conditions. It includes:

- open and sensitive communication about the person’s prognosis and illness trajectory, including any changes they may have to make in their lives, such as limiting certain activities
- Advance Care Planning, including discussing the person’s values and wishes
- providing information on the range of treatments available to help residents and goals of care
- psychosocial and spiritual support to help individuals and families struggling with any issues related to their health
- effective pain and/or symptom management.

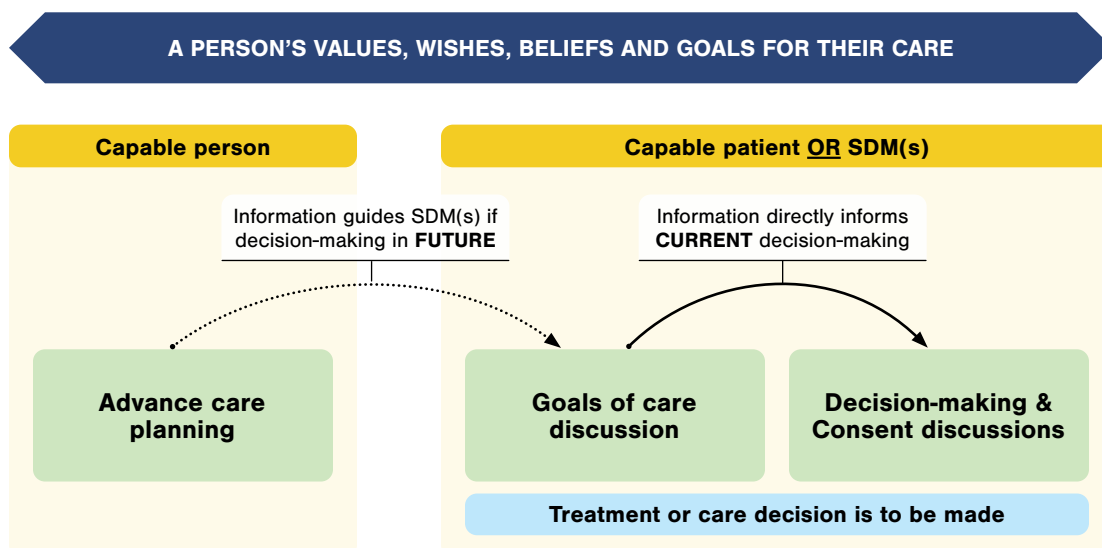
In the later stages of people’s lives, a Palliative Approach to Care also includes:

- regularly reviewing the person’s goals of care and adjusting care strategies to reflect any changes in the person’s values, goals and wishes
- deciding if and when to engage specialized palliative care providers (e.g., for people and families with challenging physical, psychosocial or spiritual symptoms, conflicts over goals of care or decision making, family distress).

Goals of Care

Goals of Care are the aims for a person’s care. They are developed in conversations with the person, family, Substitute Decision Maker(s) and health care team. Goals of Care conversations help health care providers understand the patient’s values and goals for their care. They also ensure that someone living with a life-limiting illness (or, if the person is incapable, the person’s Substitute Decision Maker (SDM)) understands the serious nature of their illness. Goals of care discussions provide the basis for treatment decisions and informed consent. For people who are nearing end of life, their goals of care are likely to change over time. That is why it is essential to revisit the person’s goals of care each time a decision has to be made about the person’s care and treatment.

Components of Person-Centred Decision-Making and Consent



Source: Hospice Palliative Care Ontario

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Advance Care Planning

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