

Advance Care Planning Module

Support Long Term Care Staff with Advance
Care Planning Conversations

Quality Palliative Care in
Long Term Care Alliance (QPC-LTC)



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Please copy and share this document. We would appreciate you referencing the source of this work as:

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For more information regarding the project please visit www.palliativealliance.ca or email our team at palliativealliance@lakeheadu.ca

Introduction

Long-term care homes care for residents until the end of their lives. A Palliative Approach is resident-centred care, within the long-term care home, that aims to relieve suffering and improve the quality of life for a resident and his or her family. A palliative approach should be implemented when death of a resident would be expected within the next year. A plan of care that has a palliative approach would address the physical, psychological, social, spiritual and practical issues of both the resident and family and continues to provide support into bereavement.

Advance care planning is a voluntary process where a resident reflects on values beliefs and traditions and communicates wishes for future care that can inform the resident's Substitute Decision Maker (SDM). Therefore if or when the resident becomes unable or not capable of making his her own decision the SDM can make informed decisions on the residents behalf. Having these advance conversations, and documenting residents' requests ensures that their wishes are honoured at the end-of-life. Advance care planning in long-term care can alleviate stress for residents, family members, loved ones, and all staff involved in the resident's care. Advance care planning wishes need to be discussed across disciplines in long-term care and should be revisited frequently or when there is a change in the resident's health.

Sometimes advance care planning conversations are difficult for residents and their families as it is hard for individuals to talk about their mortality. By having these conversations staff can meet the care needs and wishes of residents. It would benefit staff to take time to explore the resident's life, healthcare goals and get to know the resident well. This can enable staff to safeguard that a residents care wishes are met till end-of-life. Advance care planning can also lesson unwanted transfers of residents to the hospital and aggressive medical treatments at end-of-life.

This advance care planning module was designed to provide important information for long-term home management and staff having these important conversations and the value these conversations have for providing care. It contains tips on communication to engage the resident in communicating end-of-life wishes, checklists for staff and valuable key terms.

Organizational Checklist

Policies and Procedures in the Long-term Care home

1. Does the long-term care home have written policies and procedures for an advance care planning process?
 - Is there a statement of any procedure that the long-term care home is unable to provide or withhold?
 - Is there designated staff who coordinate the advance care planning process?
 - Are there time frames in which advance care planning discussions and documentation occur: Upon __ days of admission, OR with a change of condition, quarterly, every six months OR yearly?
 - Is there policy reflecting the right to make decision concerning care including the right to accept or refuse care?
 - What is the policy regarding where the resident's Advance Directive, Power of Attorney for Personal Care or Do Not Resuscitate order are located? (These forms should be included in resident's clinical record.)
2. Does the long-term care home provide all front line staff basic education concerning advance care planning?
3. Does the long-term care home have educational materials that are provided to residents and their families containing information about advance care planning?
4. Does the long-term care home have written procedures that include how advance care planning information is presented to individuals and family members?
5. Does the long-term care home has a policy and procedure stating how the family member or substitute decision maker will be contacted for an advance care planning meeting.
6. Does the long-term care home have a procedure for clearly identifying the decision maker in the medical record?
7. Can all advance care planning be located immediately in the medical record?
8. Does the long-term care home systematically evaluate the quality of end-of-life care and revise its advance care planning process?

Adapted from: Texas Department of Aging and Disability Services (2012). Advance Care Planning Policy and Procedure Checklist. Retrieved from <http://www.dads.state.tx.us/qualitymatters/qcp/advancecare/acp-checklist.pdf>

What Are The Differences Between Care Planning and Advance Care Planning?

Advance Care Planning...

- Is a conversation where a person reflects upon his/her values, beliefs, traditions and expression of wishes about future care. This conversation can lead to the person expressing his/her wishes for treatment and care needs in the event that he/she becomes unable to make those decisions for him/herself (care needs can include but are not exclusive to physical, spiritual, social and emotional needs).
- Occurs PRIOR to Care Planning.
- Involves staff, family members and loved ones getting to know the resident's care and treatment wishes.
- Involves discussions around those wishes (treatment direction, medical, and individual end of life preferences).
- Wishes may be expressed in any form (verbal, writing, audio, video tape)

Care planning...

- Is a process of information sharing between the resident, their SDM and the members of the health care team.
- It leads to the development of treatment and course of treatment and can include component in addition to medical treatment such as personal care and support requirements including nutrition and daily activity needs or recreation.
- Informs treatment direction, medical, individual end-of-life preferences.
- Is about the present care the resident is receiving.

Establishing Relationships and Advance Care Planning

- Before having advance care planning conversations, a relationship must be established between the individuals having the conversation. This can lessen anxiety and stress for everyone involved when talking about end-of-life issues. Getting to know a resident and their family members well will establish rapport, and create needed trust to have the conversation.
- Having advance care planning conversations can also strengthen interpersonal relationships.
 - It can enhance family relationships and help resolve conflicts between families, long-term care staff and health care professionals about end-of-life decisions for the resident.
 - Advance care planning conversations can also foster and improve trust between residents, family members and staff.

Advance Care Planning Guide for Staff

Knowing the Resident

- Get acquainted with residents' personal, medical and social history.
- Knowing the history of the resident will help prepare staff for the Advance Care Planning conversation and increase their knowledge of the resident and their wishes
- Conversations with the resident, family members and loved ones can aid in establishing how open they are to having advance care planning discussions.

Education

- Use this Advance Care Planning Toolkit as a guide. If you feel you need more information there are great advance care planning resources that can be found online:
- *Speak Up Website*: <http://www.advancecareplanning.ca/>
- *Healthcare Professionals*: <http://www.advancecareplanning.ca/health-care-professionals.aspx>
- *Consent in Ontario*: <http://advancecareplanning.ca/making-your-plan/how-to-make-your-plan/provincial-territorial-resources/advance-care-planning-in-relation-to-health-care-consent-training-materials.aspx>
- L-SAA HCC e learning health care consent and advance care planning module by Judith Wahl and Heather Westaway http://hnhblhin.on.ca/HC_ELearning.html

Communication Tips for LTC Staff

Listen To the Resident and Family Member

- Choose a quiet private space to ensure a safe environment
- Do *not* interrupt
- Sit down together with the resident/family (i.e., be at the same level)
- Allow for pauses and silence in the conversation
- Make eye contact
- Keep an open posture
- Do *not* multi-task during the discussion
- Nod occasionally
- Let the resident/family sit closest to the door

Adapted from: Fraser Health, British Columbia. (n.d.). Advance care planning communication and follow up. Retrieved from http://www.gpsc.bc.ca/system/files/50_EOL_PSP_%

Checklist for LTC Staff

Part 1: Are you Ready?

- Educate yourself on the policies and procedures in your long-term care home on the advance care planning process.
- Become aware of the differences between advance care planning and care planning.
- Become aware of treatment directives, also known as advance directives, and/or the do not artificially resuscitate order (DNAR) in the long-term care home
- Become aware of where all the advance care planning documents are located in your home. Can you locate them within 30 seconds?
- Become aware of any other home specific procedures related to advance care planning.
- Ask yourself “What is my scope of practice around advance care planning?”

Part 2: Points to Cover with Resident/Substitute Decision Maker

- First, ask the resident if they have ever talked to anyone about their care wishes or care needs. This can open up the conversation to discuss care needs or to start reflection for future conversations.
- Remind family that staff are there to support the resident and family.
- Ask yourself if the resident at that time is able to have a conversation about advance care planning.
- Tell the necessary staff involved in the residents care about the conversation and document all information pertaining to care needs or wishes.
- Include family members, substitute decision makers and love ones in the advance care planning conversation.

Part 3: Conversation Starters

- Have you ever talked to anyone about their treatment wishes or care needs?
- If you weren't able to make your own health care decisions, who would make them for you?
- What activities or experiences are most important for you to live well?
- How much intervention do you want? (i.e., Artificial resuscitation, no assisted ventilation? Invasive or non-invasive treatments? Assisted hydration and feeding?)
- What do you know about the possible complication of _____ ?
- Are there any other concerns you have about your health care wishes?

Sample ACP Questions for LTC Staff

How to get the conversation started?

- Tell me about your health/illness?
- What have the doctors told you about your health/illness/condition?
- What do you understand about your health condition? What does your family understand?
- What fears or worries do you have about your health/illness or medical care?
- How has your illness interfered with your daily activities?
- What treatments/medications interfere with your quality of life?
- Tell me about what you understand about the options for treating your illness?

Care Planning and Wishes at End of life

- Tell me about your health?
- Has this changed what you value and believe? Tell me about that.
- What fears do you have now and for the future?
- What decisions do you feel may need to be made in the future?
- Have you thought about what those decisions might be?
- Who have you talked with about those decisions?
- Have you talked with your family about your wishes for future medical care?

Reflecting Back

These are situations when it might be helpful/appropriate to initiate ACP conversations:

Checking for understanding:

- You seem to be saying that you might need some help talking with your family. Am I right?
- I just want to make sure I heard you. You would want life sustaining treatments if you had a good chance of recovering to the point where you would recognize your family?

Inviting others to participate:

- You said that your daughter asks lots of questions about your appointments and helps you with decisions. I feel it would be important for her to come to the next appointment, what do you think?

Adapted from: Fraser Health, British Columbia. (n.d.). Advance care planning communication and follow up. Retrieved from http://www.gpsc.bc.ca/system/files/50_EOL_PSP_%

Scheduling an Advance Care Planning Meeting

- Recognize that admissions is a stressful time for residents and their family members, this is often not the time to discuss advance care plans.
- Give the resident/family member/substitute decision maker information on advance care planning.
- Plant the seed upon admission. During admission staff can aid in reflection of advance care plans by recommending a meeting or conference six to eight weeks post admission to have this discussion.
- Establish who the resident's Power of Attorney for Personal Care or SDM is .
- Ensure that everyone (health care providers, family members, POA, SDM) who needs to attend is aware time, place, date and clarify the goals of the meeting.

Points to consider for an advance care planning meeting:

- Clarify with everyone that is involved the purpose of the meeting.
- Be aware of your own value and beliefs and understand that some cultures are not willing to discuss end of life issues.
- Request a meeting if there is a significant change in the resident's health.
- Ask if care needs are being met and if not, what can be done differently, what are the residents wishes or expectations for his/her care?
- Address any concerns and issues with present care needs with the necessary staff/disciplines.
- Insure that the resident/family members have all information regarding treatment and end-of-life care that the long-term care home can offer.
- Scheduling a follow-up contact to confirm care needs are being met. This can ensure successful communication and create consistency with care

(Adapted from the Registered Nurses Association of Ontario, Clinical Best Practice Guidelines, 2011)

Tip:

- Completing your own advance care plan can aid in your understanding of the process and reflection that an individual will need to go through when completing their advance care plan. While reflecting on your advance care plan some questions to consider are:
 - 1) What does quality of life mean to me? Think about your values and beliefs? What matters to you and what doesn't?
 - 2) What choices would I make for myself regarding my care or treatment needs?
 - 3) Who would I want to speak for me if I was unable? Who would
 - 4) If I am at end-of-life what kind of care would I want? Try to think holistically. What care or treatment you would want physically, mentally, emotionally and spiritually?

- After a period of reflection, you can then begin the process of completing an advance care plan. Here are a few different websites that can aid in completing your advance care plan.
 - 1) My Voice-Fraser Health Authority <http://www.fraserhealth.ca>
 - 2) A Guide to Advance Care Planning– Ontario Seniors' Secretariat www.seniors.gov.on.ca
 - 3) Planning in Advance for Your Future Healthcare Choices– Fraser Health Authority: <http://fraserhealth.ca>
 - 4) Advance Care Planning Workbook- Speak Up– Canadian Hospice Palliative Care Association <http://www.advancecareplanning.ca/>

Key Terms

A “Good” Death

- A good death may mean very different things to individual but may include but not be exclusive to:
 - ⇒ Being treated with dignity and respect
 - ⇒ Living without pain and other symptoms
 - ⇒ Being able to be in their own environment at end-of-life
 - ⇒ And being with their loved ones
- (Alzheimer's Society, 2012)

Advance Care Planning

- Is a process of reflection and communication in which a person who is capable, makes decisions about future health and personal care in the event that they become incapable of giving informed consent. It involves:
 - Thinking about what gives life meaning;
 - Learning about medical procedures that can be offered at the end of life;
 - Talking to health care providers, family and friends about future health care wishes;
 - Choosing a person would like to speak for them, when they cannot speak for themselves; and
 - Informing oneself of ACP regulations for their geographical area, as every province/territory has its own legislation
 - Recording goals and wishes.

(Canadian Hospice Palliative Care Association, 2013)

Advance Directive

- Is a written document that expresses an individual's wishes for future care or treatments. Every province and territory has their own legislation regarding the preparation of advance directives.

(Canadian Hospice Palliative Care Association, 2013)

Allow Natural Death

- Refers to decisions NOT to have any treatments, care, and procedures that will delay the moment of death. This applies only when the death is about to happen from natural causes.

(Canadian Hospice Palliative Care Association, 2013)

Capable

- A resident is “capable” when she or he can understand the information that is pertinent to making a decision about their care or treatment being proposed , and that he/she can also realize the consequences of that decision or lack of that decision.

(College of Nurses of Ontario, Practice Guidelines, 2009)

Comfort Measures

- Is the care or treatment an individual receives to ensure their comfort (e.g., pain and symptom management, psychological support, or spiritual care)

(Canadian Hospice Palliative Care Association, 2013)

End-of-life Care

- Refers to treatment and the care that is provided at the end of an individuals’ life. This type of care is focuses on an individuals choice for care during the last days of life till death.

(Canadian Hospice Palliative Care Association, 2013)

Informed Consent

- Is the consent given by a resident/client/patient only after the said person has received information about a treatment (including the nature of the treatment, expected benefits, material risks and possible side effects of treatment, alternate course of treatment and the possible/likely consequences of not receiving the treatment).

Consent Must:

- Relate to the treatment
- Be informed
- Be given voluntarily
- Not be obtained through misrepresentation or fraud

(Health Care Consent Act, 1996, c. 2, schedule A, s. 11 (1)., 2010)

Palliative Care

- Is the care that individuals receive who have a life limiting illness, and it focuses on providing quality of life care. Palliative care is about keeping individuals as comfortable and free of pain or other symptoms as possible. Palliative care is also about meeting the holistic (physical, mental, emotional and spiritual) care and treatment needs of an individual.

(Canadian Hospice Palliative Care Association, 2013)

Power of Attorney for Personal Care

- Is a document in Ontario where an individual can appoint a substitute decision maker. This document gives the substitute decision maker the power to make decisions for an individuals personal care (i.e. health care, clothing, nutrition, shelter) should an individual become incapable of making these decisions.

(Ontario Seniors’ Secretariat, 2013)



Substitute Decision Maker

- Is an individual who is chosen by a person or who is appointed that provides consent or refusal of treatment, or the withdrawal of treatment on behalf of another person when that person is incapable of making decisions about treatment or care. The substitute decision maker must act in the best interest of the individual who is incapable of making decisions for themselves.

(Canadian Hospice Palliative Care Association, 2013)

Best Interests

- When making a “best interests” decision for a person who is incapable to give informed consent, the POA/SDM must consider any wishes the person made while he/she was capable which are not binding upon the POA/SDM. The POA/SDM must also consider these wishes with respect to any treatment being proposed.

(Health Care Consent Act, s21, 1996)

Quality of Life

- an individual (s) viewpoint of their position in life in the perspective of the culture and value systems in which they live, and in relation to their expectations, goals, values and concerns.

(World Health Organization, 2013)

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