PALLIATIVE CARE APPROACH
DESIGN YOUR HOME'S PROCESS

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Faculty/Presenter Disclosure

- **Faculty: Benoît Robert**

- **Relationships with financial sponsors:**
  - **Grants/Research Support:** N/A
  - **Speakers Bureau/Honoraria:**
    - OMA Speakers Bureau, Pallium, OLTCC
  - **Consulting Fees: N/A.**
  - **Patents: N/A**
  - **Other:**
    - Past President of the OLTCC
    - Employee of Perley Health (Chief Medical Officer)
    - Ontario Health East – Palliative Care Co – Lead

Disclosure of Financial Support

- **This program has not received financial support from any organization.**

- **Potential for conflict(s) of interest:**
  - Benoît Robert has received a stipend for presenting – through the OLTCC.
  - I am associated with Pallium – as a facilitator trainer, as a content expert (LEAP – LTC)
  - I may promote the Ontario Health approach to palliative care (through the Ontario Palliative Care Network action plan
  - I may showcase approaches used at Perley Health.

Faculty/Presenter Disclosure

- **Faculty: Sandy Shamon**

- **Relationships with financial sponsors:**
  - **Grants/Research Support:** CIHR
  - **Speakers Bureau/Honoraria:**
    - OLTCC
  - **Consulting Fees: N/A**
  - **Patents: N/A**
  - **Other:**
    - VP - OLTCC board

Disclosure of Financial Support

- **This program has not received financial support from any organization.**
- **Potential for conflict(s) of interest:**
  - Previously received stipend to present/ speak with OLTCC

Mitigating Potential Bias

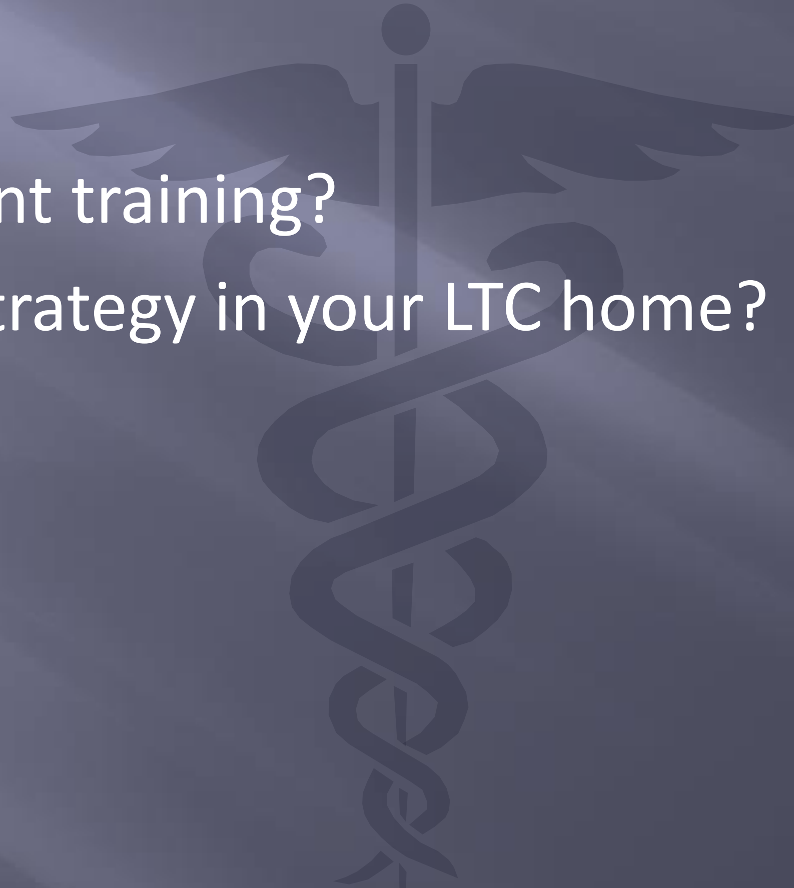
- None perceived
- We will clearly state when potential CoI may exist as it may arise during the presentation, or with discussions

Objectives

- Define the palliative approach to care (PAC) from an evidence-based , legislative and system perspectives
- Apply QI lens to your PAC design
- Discuss tools and processes to help implement the PAC
- Use case examples to discuss leadership and team factors that enable an effective PAC

Summary of process

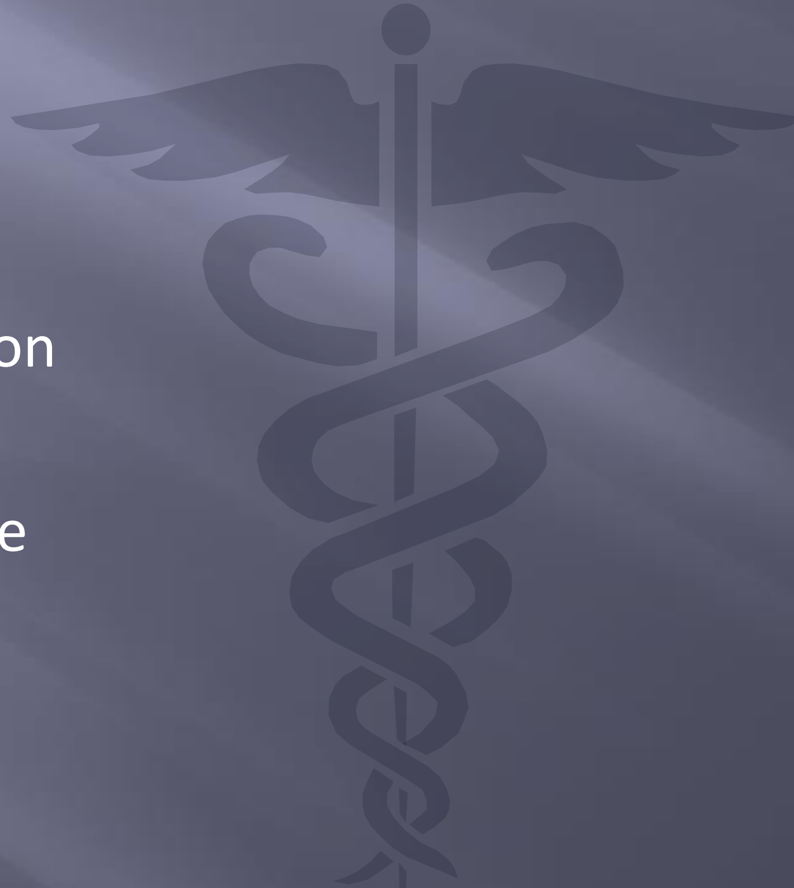
Survey Audience



- Pall Care training?
- Program development training?
- Do you have a PAC strategy in your LTC home?

Summary of Content

1. Basics of PAC
2. Needs assessment
3. Plan
4. Identify resources
5. Training and Education
6. Partnerships
7. Monitor and evaluate



Title and Content Layout with List

BASICS

- Is there a solid foundation in the principles of Palliative Care
- Key concepts include:
  - Early identification (ACP/ GoC/ SIC)
  - Pain and Symptom management
  - Communication skills
  - Psychosocial care
  - Spiritual care/ grieve and bereavement support

Palliative Approach to Care

- **WHO:** **Palliative care** is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual
- Touzel and Shadd (2018): **palliative approach** exists when care provided simultaneously address the following:
  - Whole-person needs
  - Enhances quality of life
  - Acknowledges mortality
  - Family within unit of care

Regulations (FLTCA, Reg 61)

- 61. (1) Every licensee of a long-term care home shall ensure that a resident's palliative care needs are met in accordance with this section.
- (2) The licensee shall ensure that the interdisciplinary assessment of the resident's palliative care needs for their plan of care considers the resident's physical, emotional, psychological, social, cultural, and spiritual needs.
- (3) The licensee shall ensure that the resident, the resident's substitute decision-maker, if any, and any other person or persons designated by the resident or their substitute decision-maker are provided with an explanation of the palliative care options that are available based on the assessment of the resident's palliative care needs, which may include, but are not limited to, early palliative care and end-of-life care.
- (4) The licensee shall ensure that, based on the assessment of the resident's palliative care needs, the palliative care options made available to the resident include, at a minimum,
  - (a) quality of life improvements;
  - (b) symptom management;
  - (c) psychosocial support; and
  - (d) end-of-life care, if appropriate.
- (5) For greater certainty, the licensee shall ensure that the resident's consent is received pursuant to section 7 of the Act before taking any actions set out in this section and before palliative care is provided to the resident.

Palliative Approach Design Process

Needs Assessment

- What are the goals and the specific needs
  - Needs assessment
  - Review existing data (or start collecting data)
  - Engage with stakeholders to determine what is needed most
    - Staff
    - Volunteers
    - Family and Friends Council
    - Residents

Access to an Interdisciplinary Palliative Care Team

The model of care describes "team" from the resident (or family/caregiver) perspective and matches **how they can best receive care** from an Interdisciplinary Palliative Care Team

The interdisciplinary palliative care team:

- Includes a **core team** of a physician or nurse practitioner and a designated care coordinator and, often, a nurse
- Often includes other interdisciplinary providers (**extended services**)
- Have an established connection with **palliative care specialist(s)** for consult with team members and providing direct resident care as needed

Prioritized Recommendations for LTCH*

Implementation should begin with prioritized recommendations and will build upon existing high-quality services and programs.

10.1 Identification & assessment of its residents who would benefit from palliative care will be managed using internal resources & processes.

10.2 Staff within the LTC Home will assume the role of the **Care Coordinator**.

10.4 The Care Coordinator will leverage established relationship with external partners to access outside resources (e.g., psychosocial providers, spiritual counsellor) for **additional supports**.

10.5 The Core Team within the LTC Home will access **providers with expertise in palliative care**.

10.6 Advance care planning & goals of care discussions will take place soon after admission with residents or their SDM, as appropriate. Goals of care discussions will be revisited at regular intervals with the resident or SDM and when there been changes in the resident's health status.

10.8 The resident will receive **pain & symptom management** both during ongoing care and at end of life that is based on best practices utilized in other community settings.

* Priorities established through consultation with LTCH

Implementation Strategy - Goals

Increase Awareness & Desire

- Develop messaging and tools for specific audiences to **promote the existing OPCN resources** that emphasizes the benefits of optimal access to palliative care for residents

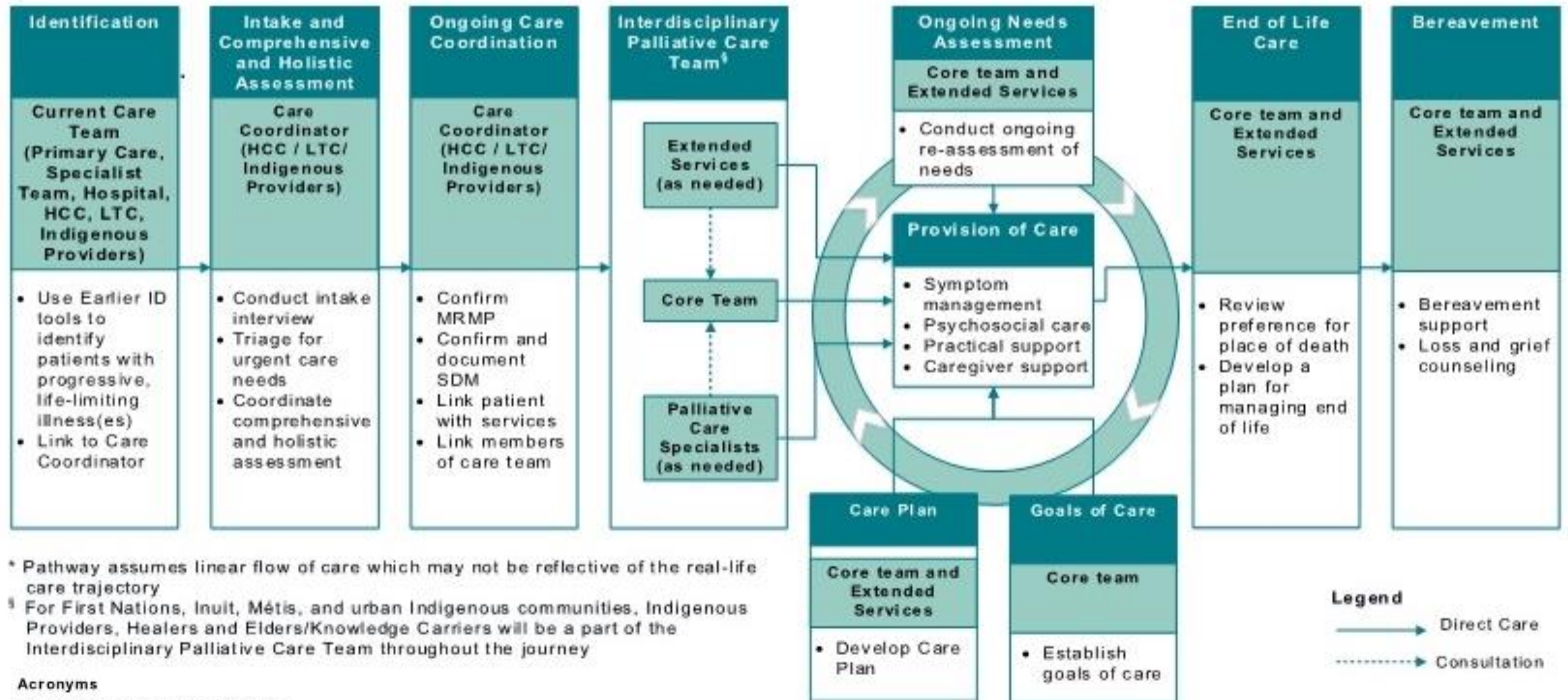
Build Knowledge

- Develop **new webinars, resources, and tool kits** to guide action on the Delivery Framework
- Develop a **provincial education strategy** to increase the number of providers with Level 1 competency in palliative care

Increase Ability & Reinforce Change

- Coordinate change management and QI to affect **practice change** aligned to Delivery Framework
- Implement provincial education strategy
- Measure and monitor **performance and evaluation**
- Supplement regional and local HHR to **support implementation**

The Patient Pathway



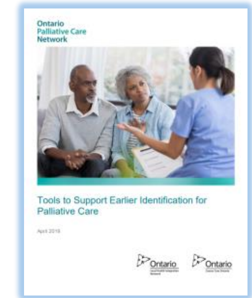
The OPCN Has Created Resources to Support Change

[Palliative Care Quality Standard]

Describes what high-quality palliative care should look like

[Competency Framework]

A comprehensive guide to palliative care competencies required for every type of care provider, from specialists to volunteers



[Tools for Earlier Identification]

Tools to support earlier identification of patients who would benefit from palliative care

Goals of Care Resources

Four resources to enable better provider-patient conversations about goals of care

- Person-Centred Decision Making
- Making Decisions about Your Care
- Approaches to Goals of Care discussions
- Advance Care Planning FAQ

[Palliative Care Toolkit]

Best-practice tools from around the world to support primary care providers with palliative care delivery

HQO/ OPCN Standards

Palliative Care Quality Statements

Quality Statement 1: Identification and Assessment of Needs

People with a progressive, life-limiting illness have their palliative care needs identified early through a comprehensive and holistic assessment.

Quality Statement 2: Timely Access to Palliative Care Support

People with identified palliative care needs have access to palliative care support 24 hours a day, 7 days a week.

Quality Statement 3: Advance Care Planning—Substitute Decision-Maker

People with a progressive, life-limiting illness know who their future substitute decision-maker is. They engage in ongoing communication with their substitute decision-maker about their wishes, values, and beliefs, so that the substitute decision-maker is empowered to participate in the health care consent process if required.

Quality Statement 4: Goals of Care Discussions and Consent

People with identified palliative care needs or their substitute decision-makers have discussions with their interdisciplinary health care team about their goals of care to help inform their health care decisions. These values-based discussions focus on ensuring an accurate understanding of both the illness and treatment options so the person or their substitute decision-maker has the information they need to give or refuse consent to treatment.

Quality Statement 5: Individualized, Person-Centred Care Plan

People with identified palliative care needs collaborate with their primary care provider and other health care professionals to develop an individualized, person-centred care plan that is reviewed and updated regularly.

Quality Statement 6: Management of Pain and Other Symptoms

People with identified palliative care needs have their pain and other symptoms managed effectively, in a timely manner.

Quality Statement 7: Psychosocial Aspects of Care

People with identified palliative care needs receive timely psychosocial support to address their mental, emotional, social, cultural, and spiritual needs.

Quality Statement 8: Education for Patients, Substitute Decision-Makers, Families, and Caregivers

People with a progressive, life-limiting illness, their future substitute decision-maker, their family, and their caregivers are offered education about palliative care and information about available resources and supports.

Quality Statement 9: Caregiver Support

Families and caregivers of people with identified palliative care needs are offered ongoing assessment of their needs, and are given access to resources, respite care, and grief and bereavement support, consistent with their preferences.

Quality Statement 10: Transitions in Care

People with identified palliative care needs experience seamless transitions in care that are coordinated effectively among settings and health care providers.

Quality Statement 11: Setting of Care and Place of Death

People with identified palliative care needs, their substitute decision-maker, their family, and their caregivers have ongoing discussions with their health care professionals about their preferred setting of care and place of death.

Quality Statement 12: Interdisciplinary Team-Based Care

People with identified palliative care needs receive integrated care from an interdisciplinary team, which includes volunteers.

Quality Statement 13: Education for Health Care Providers and Volunteers

People receive palliative care from health care providers and volunteers who possess the appropriate knowledge and skills to deliver high-quality palliative care.

Note: This resource can be used to support health care providers in the provision of care. It does not override the responsibility of health care providers to make decisions with patients, after considering each patient's unique circumstances. Grouping/directionality of statements may not be applicable for every patient, and clinical judgment should be used.

Palliative Approach Design Process

Develop a plan

- Outline the goals, objectives, and strategies for developing the program
- Identify stakeholders
- Establish timeline
- Define the roles and responsibilities of each team member

Palliative Approach Design Process

Identify resources

- Funding
- Staffing
- Training
- Equipment

Palliative Approach Design Process

Training and education

- Principles of palliative care
  - Ensure cultural appropriateness (apply DEI lens)
- Specific skills
  - Assessments, serious illness communication
- Specific knowledge
  - Ex. Palliative sedation, basic data management

Palliative Approach Design Process

Establish partnerships

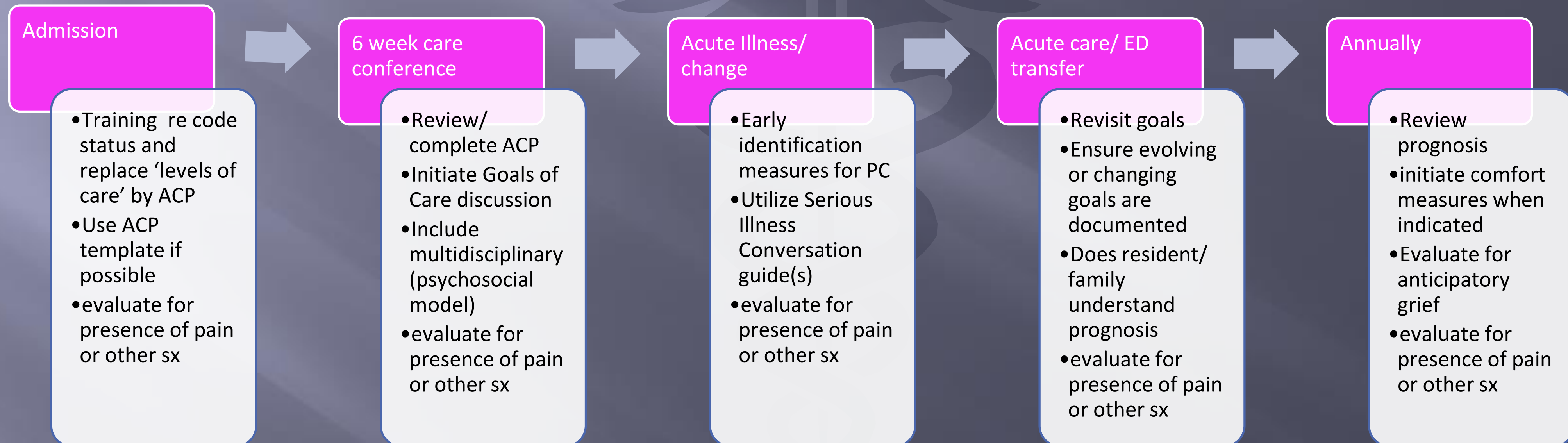
- Local specialists, hospices, hospital
- Home and community care resources
- Volunteer groups
- Virtual e-learning resources

Palliative Approach Design Process

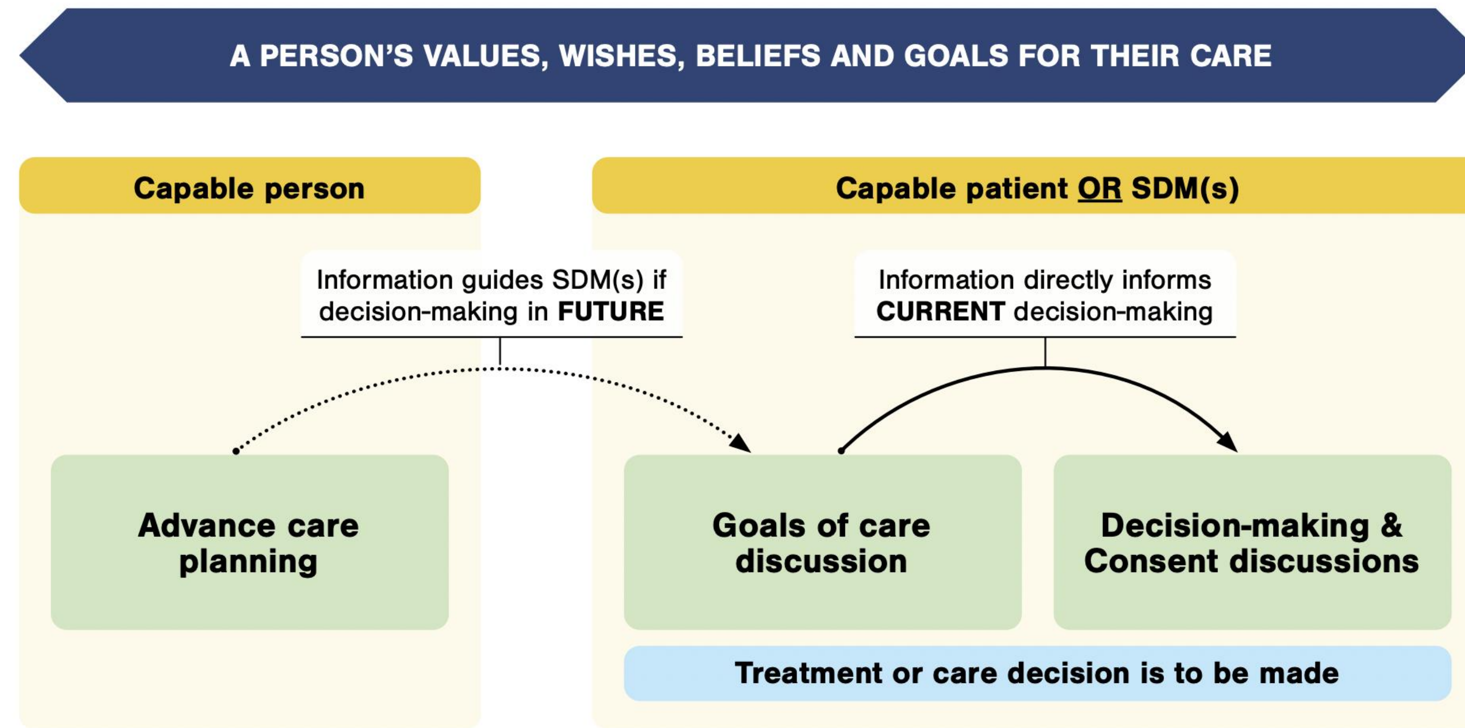
Monitor and evaluate

- Which measures to use
- Developing ongoing data collection
- Satisfaction surveys
- Metrics tracking

Examples of Intervention Points



HPCO: Person Centered Decision Framework



https://www.advancecareplanning.ca/wp-content/uploads/2021/06/LongTermCare-Toolkit_EN.pdf

Processes, Resources, Tools

- ACP/ GoC template utilized upon admission or at 6 week care conference
  - Update GoC at every care conference
- Changes in condition (decline) identified with MDS collection q3m trigger care conference or re-evaluation
  - RAI team can flag with MRP
- Champions involved and identified from every discipline
  - RAI team coordinator informs MRP if changes in PSI/ CHESS/ ADL
  - PSW informs RN if noted changes and any family concerns re care at EOL
  - Chaplain/ spiritual care or social worker engages families to ensure early grief bereavement support

Processes, Resources, Tools

- Use pre-existing useful resources for every stage
- Can modify for your own organization
- Ensure consistency in using these tools and revise with time

Tools : explaining frailty

Clinical Frailty Scale*

1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 Well – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 Managing Well – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 Vulnerable – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 Mildly Frail – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 Moderately Frail – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

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7 Severely Frail – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. Terminally Ill - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

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DALHOUSIE UNIVERSITY *Inspiring Minds*

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SIC Guide

SERIOUS ILLNESS CONVERSATION GUIDE
SUBSTITUTE DECISION-MAKERS
A CONVERSATION TOOL FOR CLINICIANS

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. Set up the conversation • Introduce ideas and benefits • Prepare of future decisions • Ask permission	"I'd like to talk about what is ahead with your _______'s illness and do some thinking in advance about what is important to him/her so that I can make sure we provide him/her with the care that they'd want - **is that okay?"**
2. Explore prior advance care planning conversations and documentation	"How much has your ______ discussed with you about about his/her priorities and wishes, especially about his/her health and illness?" "Does he/she have any previous advance care planning documents?"
3. Assess illness understanding and information preferences	"What is your current **understanding** of your ______'s illness now and how it might change over time?" "How much **information** about what is likely to be ahead with your _______'s illness would you like from me?"
4. Share prognosis and medical information • Tailor information to expressed preferences • Allow silence, explore emotions • Provide a warning: "I have some bad news.", or "The news is not good." • Frame as "wish.., worry..."	"I want to share with you **my understanding** of where things are with your ______'s illness..." *Uncertain:* "It can be difficult to predict what will happen with your ______'s illness. I **hope** he/she will continue to live well for a long time but I'm **worried** that he/she could get sick quickly, and I think it is important to prepare for that possibility." **OR** *Time:* "I wish we were not in this situation, but I am **worried** that time may be as short as _____ *express as a range, eg. days to weeks, weeks to months, months to a year*)" ***OR*** *Function:* "I **hope** that this is not the case, but I'm **worried** that this may be as strong as your _______ will feel and things are likely to get more difficult.
5. Explore key topics • Goals • Fears • Strengths • Functions • Trade-offs	"What would your ________ say would be his/her most important **goals** if/when his/her health worsens? "What would your ______say are his/her **biggest fears and worries** about his/her health?" "What gives your ________and you **strength** as you think about the future and your ______'s illness?". "What do you think your ______ would say are **abilities** that are so critical to him/her that he/she couldn't imagine living without them?" "If your ______ becomes sicker, how much would he/she say he/she would be **willing to go through** for the possibility of gaining more time?
6. Close the conversation • Summarize what you've heard • Make a recommendation • Check for alignment • Affirm commitment	"It sounds like __________ (sumarize goals and fears) is very important to your __________." "Given your _______'s goals and priorities and what we know about his/her illness at this stage, I **recommend**.... "How does this plan seem to you?" **"We're in this together."**
7. Document your conversation on the ACP record	
8. Communicate with key clinicians	

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Conversation Guides:

Frailty Informed Care - The Perley, Ottawa

Care Conference Agenda

Date	
Time	
Location	
Attendees	

Resident Sticker

Items For Discussion	Objectives	Action Items (If Identified)
1. Welcome And Introductions	Set the tone for the meeting and plan for attendees that will be leaving before the end. Resident/family highlights most important issue(s) they would like to address during the meeting.	
2. Interdisciplinary Care Overview **Quality Of Life Discussion**	Understand how the resident is doing from a holistic perspective, including challenges and risks. Discuss changes observed since admission, last care conference. Discuss 3 most important issues impacting quality of life.	
Goals Of Care And Future Health Preferences Discussion		
3. Medical Overview	Understand illness/frailty and decline. Discuss most likely future trajectory/prognosis.	*[Information from these sections to be recorded in the **Goals of Care/Future Health Preferences** assessment in PCC]*
4. Resident Values, Beliefs	Understand the resident's story, and what is most important to the resident and family.	
5. Goals Of Care/ Future Health And Personal Care Preferences	Discuss goals of care in light of current condition, beliefs, and values. Discuss impact of treatment/care decisions on goals.	
6. Follow-Up, Most Responsible Person(S) And Timelines	Summarize actions arising from the care conference and identify timelines for follow-up.	

https://www.perleyhealth.ca/seeme

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Conversation Guides : SPA-LTC Toolkit

PALLIATIVE CARE TOOLKIT

ONTARIO PAMPHLETS

- Advanced Frailty
- Dementia
- Advanced Lung Disease
- Heart Failure
- Advanced Kidney Disease
- After Death
- Grief and Loss
- Resources – Grief, Bereavement and Loss

DIGITAL VERSION

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 to help persons with **Dementia** and their families know what to expect at the end of life so they can plan 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 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

https://spaltc.ca/wp-content/uploads/2021/09/SPA-LTC1985_ON_Dementia-1.pdf

Setting up palliative care committee
WW HPC Resource

Palliative Care Committee
Terms of Reference

In alignment with the *Fixing Long Term Care Act, 2021, S.O. c. 39 and its regulations, the* committee:

- supports all team members in providing a palliative approach to care for residents with life-limiting conditions and,
- supports all team members in providing end of life care to all residents.

CHAIRPERSON

Due to the wholistic nature of a palliative approach to care, it may be beneficial to select a chairperson(s) with a role that are responsible for and accountable to residents' complete care plan i.e. physicians, nurses.

https://hpcconnection.ca/wp-content/uploads/sample-ltc-pc-cttee-tor-2022-final.pdf

Setting up palliative care committee

MEMBERSHIP

Interdisciplinary representation is key to ensuring that a team is providing a wholistic palliative approach to care and wholistic end of life care for residents.
Some members participation may be ad hoc depending on the LTCH's and individual resident's needs.
Committee members can be edited to suit the individual needs of the home.

- Director of Care/Assistant Director of Care (or delegate)
- Administrator
- Physician/Nurse Practitioner
- Nursing
- RAI Coordinator
- Personal Support Workers
- Registered Dietitian
- LTCH-specific allied providers (i.e. Pharmacy, Spiritual Care, Social Work, Recreational Therapy, Physiotherapy, Occupational Therapy, Music Therapy, Wound Care, etc)
- LTCH Volunteer
- External Palliative Nurse Consultant
- External Contracted Providers (i.e. Pharmacy, Spiritual Care, Social Work, Recreational Therapy, Physiotherapy, Occupational Therapy, Music Therapy, Wound Care, etc)
- External Hospice Volunteer

Members with additional education and training in hospice palliative care can be of benefit to the Palliative Care Committee. For information on Palliative Care education, contact your Palliative Nurse Consultant or check our website's Courses page.

SAMPLE

https://hpcconnection.ca/wp-content/uploads/sample-ltc-pc-cttee-tor-2022-final.pdf

Perley Health

Place resident sticker here

End-of-Life Order Set

Diagnosis of terminal illness: ______________________

Procude: **All orders must be initialed and signed by the RN/RPN** **Fax to Pharmacy 613-526-0330**
Telephone Order:
Nurse Signature: **Date/Time:**
Nurse #1 Check Signature: **Date:**
Nurse #2 Check Signature: **Date:**
POA Consent Received (Nurse signature once completed):
Physician Signature:

Referrals	
☐ Palliative care volunteer ☐ Spiritual health ☐ Occupational therapy ☐ Recreation therapy ☐ Music therapy	
X	**Update EOL focus in care plan**
X	**Subcutaneous line change Q 7 Days & PRN**
	D/C all medications (except new orders as per EOL order set)
	Discontinue bloodwork, O2 Sat, Accucheck
	Comfort Care feeding
	Foley catheter for comfort: 14 fr
	MAXIMUM 2-3LPM O2 FOR COMFORT ONLY. **If >3LPM required, see PRN order for dyspnea**

Medication for Symptom Management

Pain Management		Hydromorphone (DILAUDID) ____mg subcutaneously q __ hours straight
		Continue Transdermal analgesia:
Breakthrough Pain & Dyspnea		Hydromorphone (DILAUDID) ____mg subcutaneously q __hours PRN for Pain and/or dyspnea
Delirium		Methotrimeprazine (NOZINAN) ____mg subcutaneously q__ hours PRN for agitation, restlessness, hallucinations, nausea, vomiting
Pre-Care/ procedure Anxiety		Midazolam (VERSED) ____ mg subcutaneously q __ hours PRN for pre-care**, pre-procedure, or anxiety (LU 495) *** Includes all aspects of care, including repositioning and movement.* ***NOTE**: This medication is only effective for 30 minutes from administration*
Upper Airway Secretions		Scopolamine 0.4 mg/ml subcutaneously Q4H PRN (LU 481)
Lower Airway Congestion		Lasix 20mg subcutaneously or IM once DAILY PRN (for residents with confirmed/suspected COVID-19) **TO BE RE-ASSESSED DAILY**
Eye Care		ISOPTO TEARS 0.5% Solution to both eyes Q4H PRN
		LID CARE wipes to both eyes PRN
Mouth Care		MOI-STIR Solution Q2-4H PRN (May keep at bedside)
Fever		Acetaminophen (ABENOL) 650 mg Suppository - Insert 1 suppository rectally Q4H PRN
OTHER(Specify)		

10 Min Group Exercise

- Discuss within your group whether you have processes that
  - Meet OPCN quality standards
  - Can you identify/ create/ suggest 3 new processes or tools which you may consider implementing to design or improve you PAC

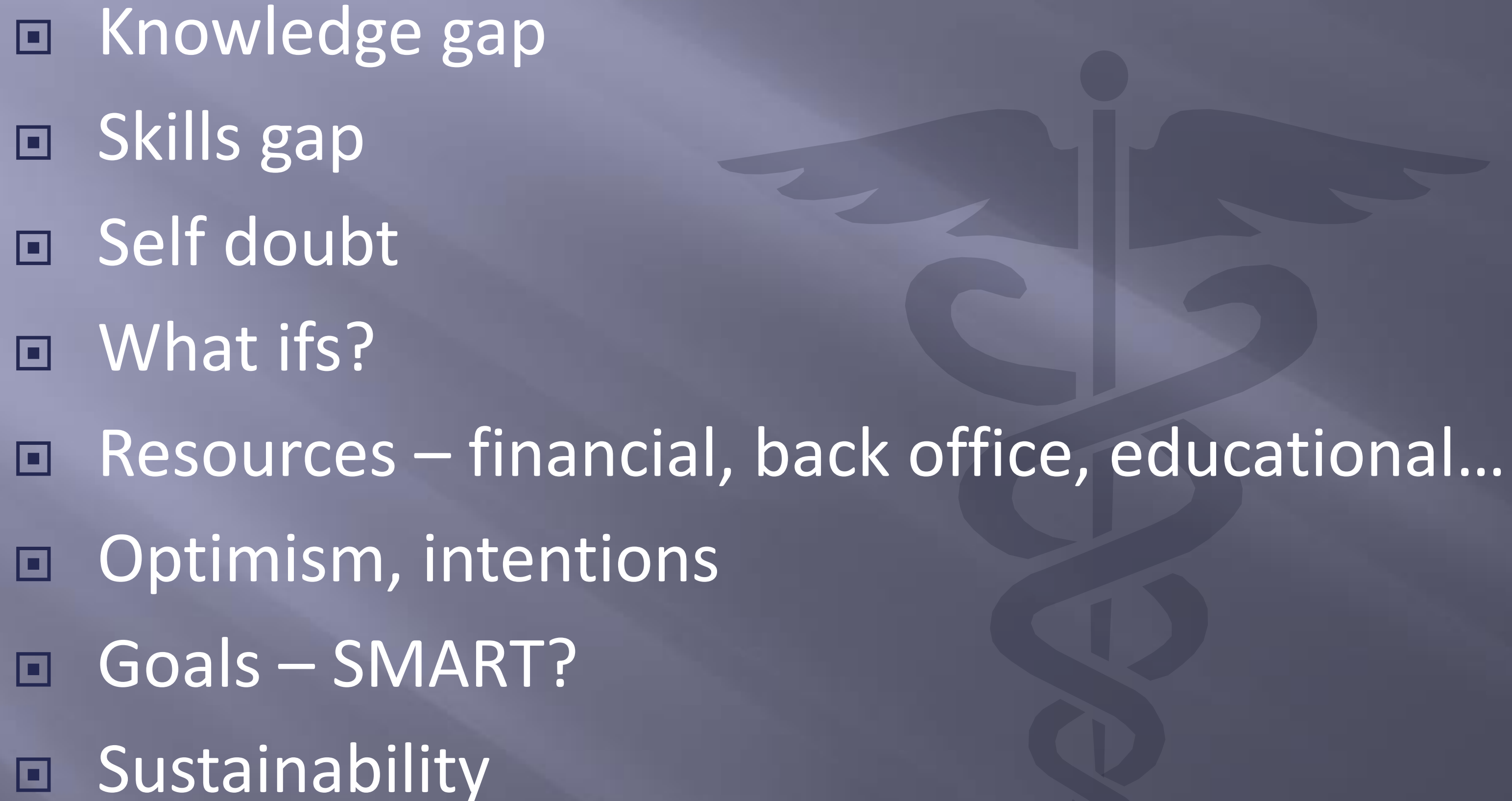
Possible case discussion

- Mr. Stanley is a new resident who moved into your LTC home last week
  - You are completing his admission physical during rounds
    - What do you expect to see vs reality in his completed admission paper work?
    - Is SDM clearly documented
    - Are there any documentation of ‘goals of care’
    - Do you still use ‘levels of care’
- Is the 6 weeks care conference an opportunity to introduce ACP?
  - How?
  - What are some ‘indiators’ you could use to discuss with family and assist with ‘prognosis’
- Two months later, Mr. S develops aspiration pneumonia
  - His swallowing is getting worse
  - Do you have SIC protocols? When do you address sx mgmt? Grief?

Summary of steps

- Plan for change
  - Leadership
  - Change management
- Form a team
- Focus your priorities
  - Use HQO standards, gap analysis, etc
  - Consider FFC as an ally
- Measure change
  - What metrics – who's responsible

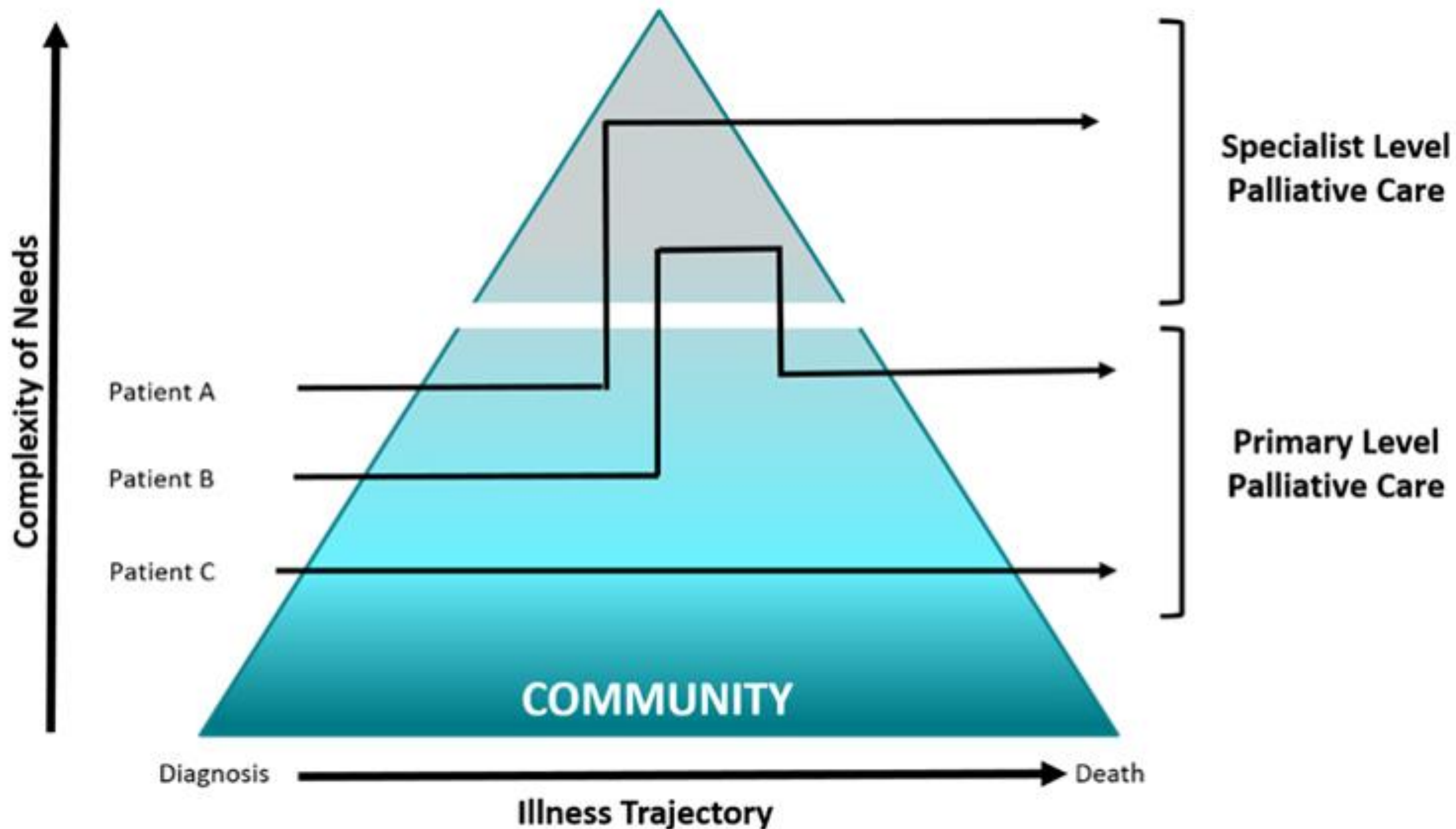
Challenges to anticipate



- Knowledge gap
- Skills gap
- Self doubt
- What ifs?
- Resources – financial, back office, educational…
- Optimism, intentions
- Goals – SMART?
- Sustainability

Figure 1.3: 3 phases of a palliative approach to care in LTC

Palliative care is offered by two levels of care providers: primary and specialist. These levels are based on the knowledge and skills of the provider.



COVID-19: Get the latest updates or take a self-assessment.

Methodology

- Palliative Home Visits in the Last 90 Days of Life
- Emergency Department Visits in the Last 30 Days of Life
- Deaths in Hospital
- System Level Measures Targets
- Acknowledgements