What Does A Palliative Care Approach Look Like In Residential Care?

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Overview

- Foundations of a palliative approach
- Application of a palliative approach
- Focus on residential care

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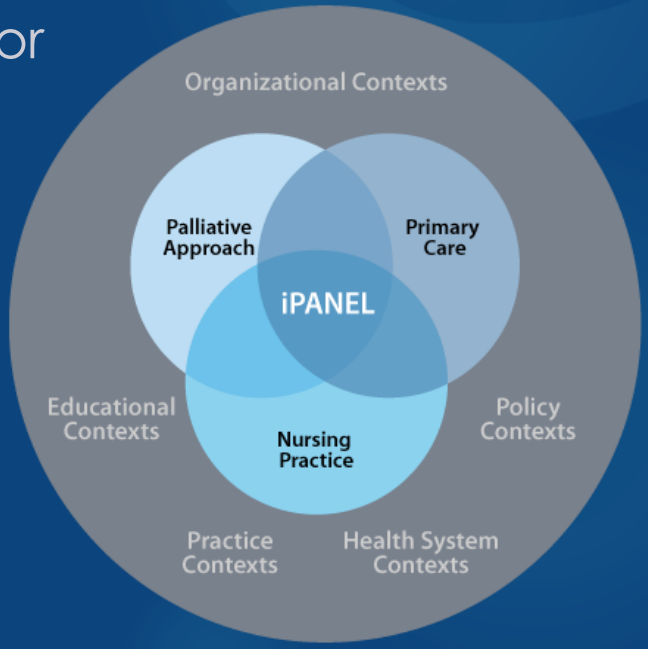
INITIATIVE FOR A
PALLIATIVE APPROACH IN NURSING:
EVIDENCE & LEADERSHIP

Emphasis on integrating a palliative approach across sectors of healthcare for all people who have life-limiting chronic illnesses

* Residential care
* Hospital-based care
* Community-based primary care



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iPANEL

As researchers, clinicians, and administrators, we work collaboratively to synthesize evidence and conduct research on integrating a palliative approach into the care of those facing advancing chronic life-limiting illness.

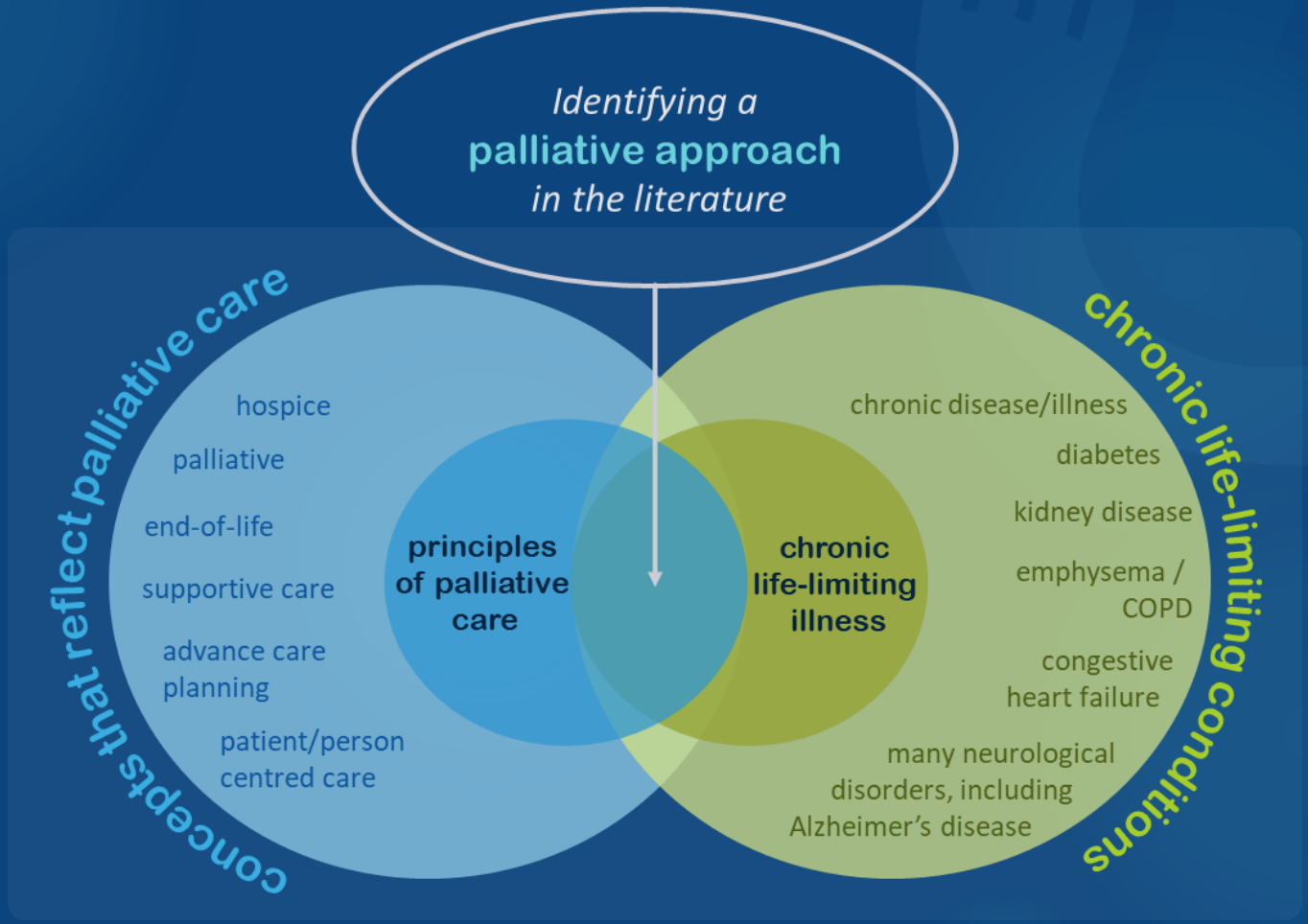
Chronic Disease Management and Palliative Care

Implications of life-limiting illness while acknowledging the uncertainty/lack of prognostic clarity

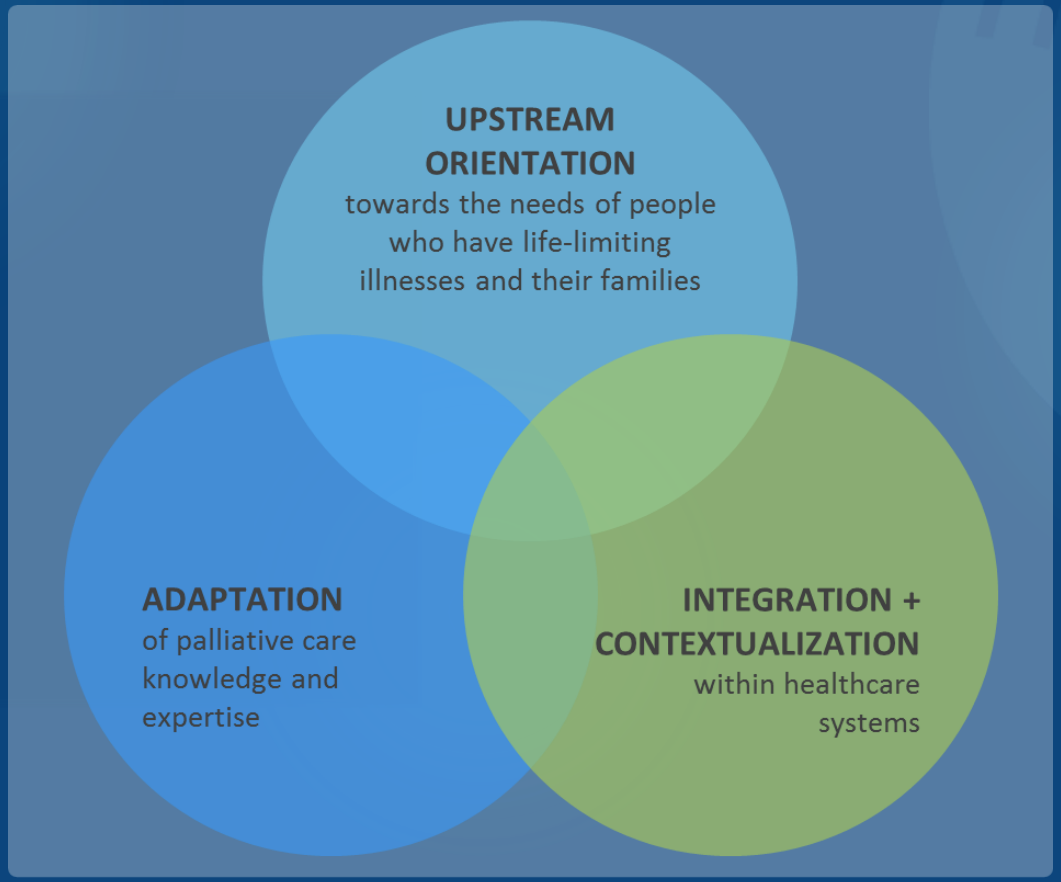
"*The healthy optimism of self-care management with profound compassion of a person-centred approach*"

Thorne, S., Roberts,D., & Sawatzky, R. (2016)

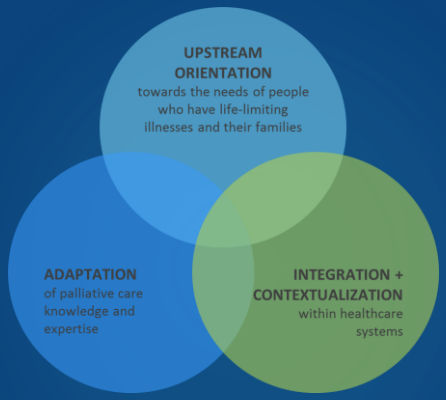
Knowledge Synthesis:
Conceptual foundation of a palliative approach



Palliative Approach:
Knowledge Synthesis



1.Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., Roberts, D., Tayler, C., Voth, J., & Stajduhar, K. (2016). Conceptual foundations of a palliative approach: A knowledge synthesis. BMC Palliative Care, 15(5). doi: 10.1186/s12904160076



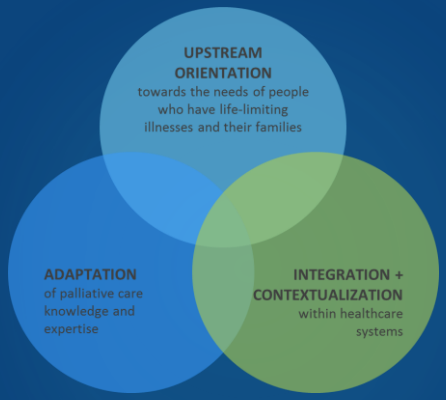
ADOPT AN UPSTREAM ORIENTATION

towards the needs of people who have life-limiting illnesses and their families

A Palliative Approach is not focused on or limited to care for the imminently dying

Two conditions required of care providers to achieve an upstream orientation:

1. Understanding different chronic life-limiting illness trajectories
2. Identifying where people are on those trajectories - ongoing process

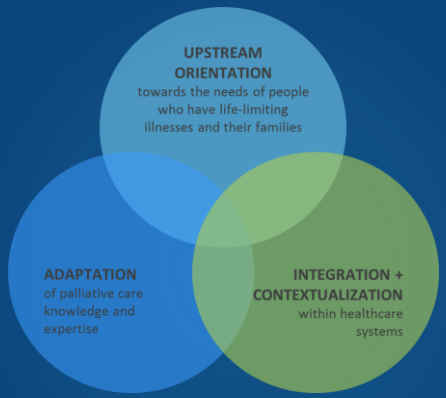


ADAPT PALLIATIVE CARE KNOWLEDGE AND EXPERTISE

Two questions guide this adaptation:

1. Which principles and practices from palliative care should be applied to people with chronic life-limiting illnesses more generally?

2. How do these principles and practices need to be adapted to ensure their fit with the needs of disease-specific patient populations?



INTEGRATE & CONTEXTUALIZE WITHIN HEALTH CARE SYSTEM

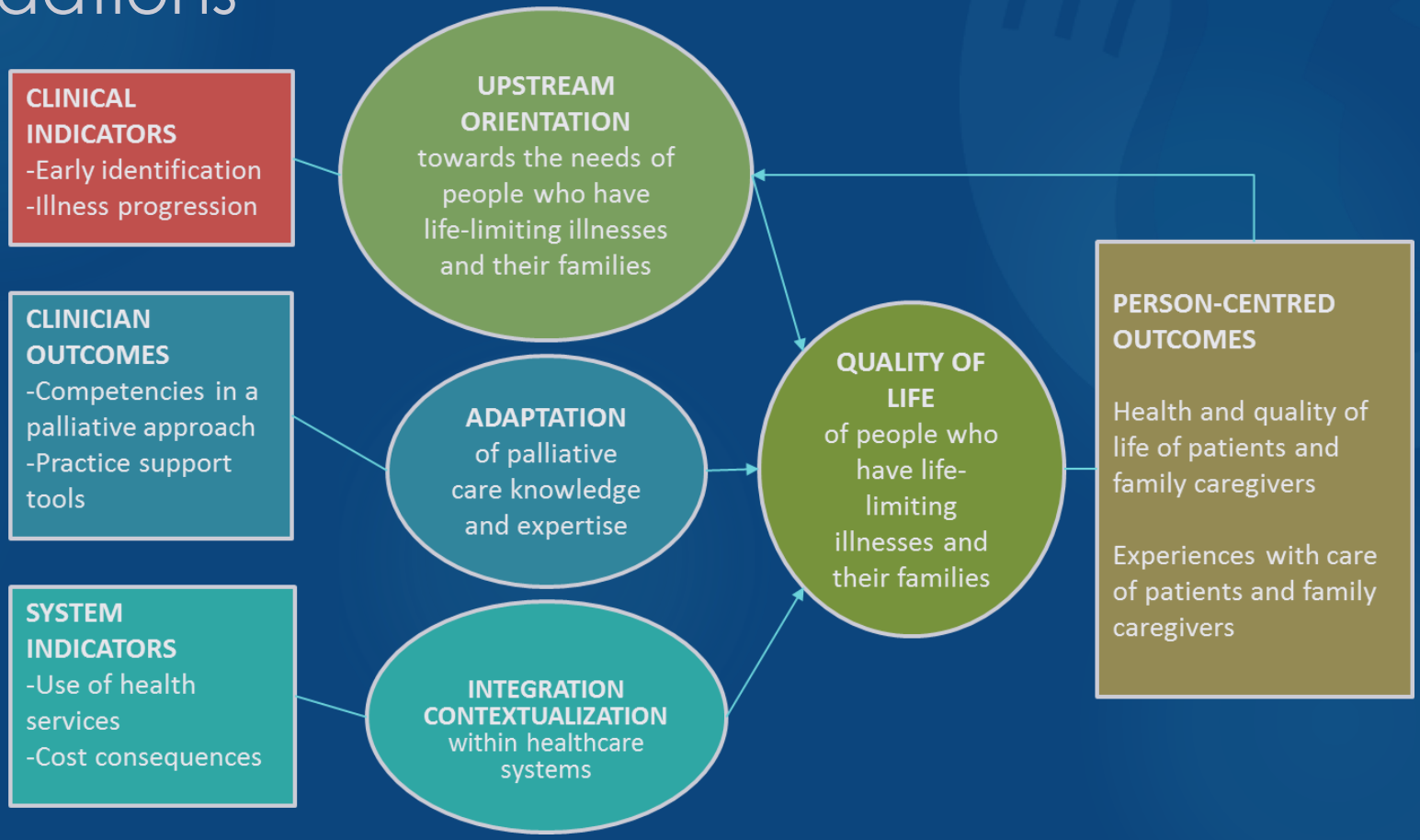
Models for Integration & Contextualization

- "Early" palliative care
- Integration into generalist practice
- Disease/condition-specific models for care delivery

Two requirements:

1. Greater capacity within the healthcare system to fully address the evolving end of life care needs of people with chronic life-limiting illnesses
2. Partnerships with a range of healthcare providers—generalists, pc specialists, chronic disease specialists, community partners, people with lived experience

Relating outcomes and indicators to palliative approach conceptual foundations



Further information

- Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., Roberts, D., Tayler, C., Voth, J., & Stajduhar, K. (2016). *Conceptual foundations of a palliative approach: A knowledge synthesis.* BMC Palliative Care, 15(5). doi: 10.1186/s129040160076

- Sawatzky, R., Porterfield, P., Roberts, D., Lee, J., Liang, L., Reimer-Kirkham,S., Pesut, B., Schalkwyk, T., Stajduhar, K., Tayler, C., Baumbusch, J. & Thorne, S. (2016). *Embedding a palliative approach in nursing care delivery: An integrated knowledge synthesis.* Advances in Nursing Science, online first. doi: 10.1097/ANS.0000000000000163

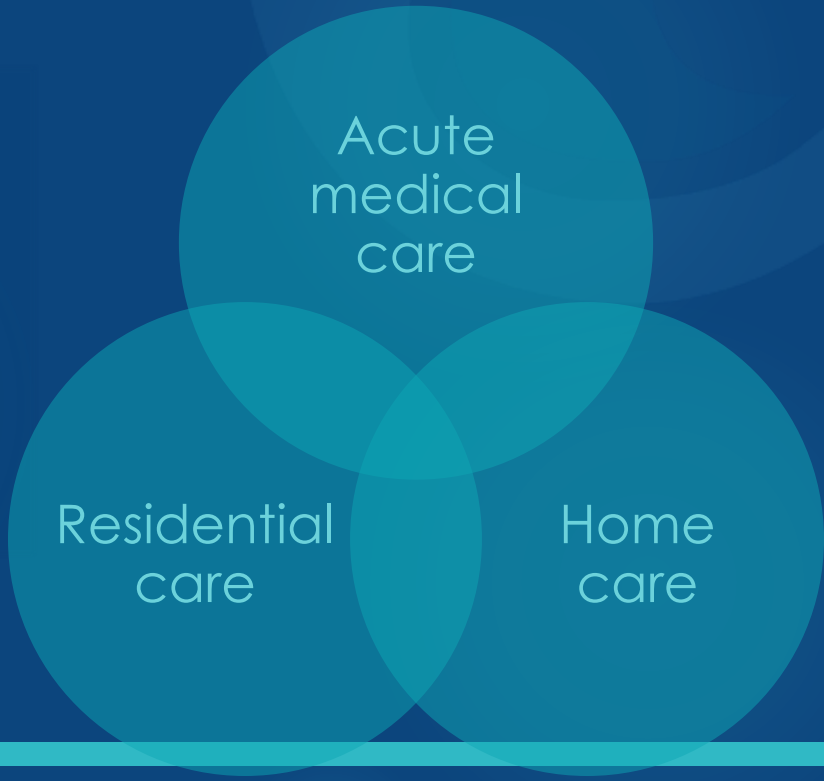
Provincial Survey of nurses and healthcare workers

Mixed-methods provincial survey

To obtain baseline descriptive information relevant to the integration of a palliative approach in a variety of nursing care settings that do not specialize in palliative care

Survey includes:

- Registered nurses
- Licensed practical nurses
- Health care workers



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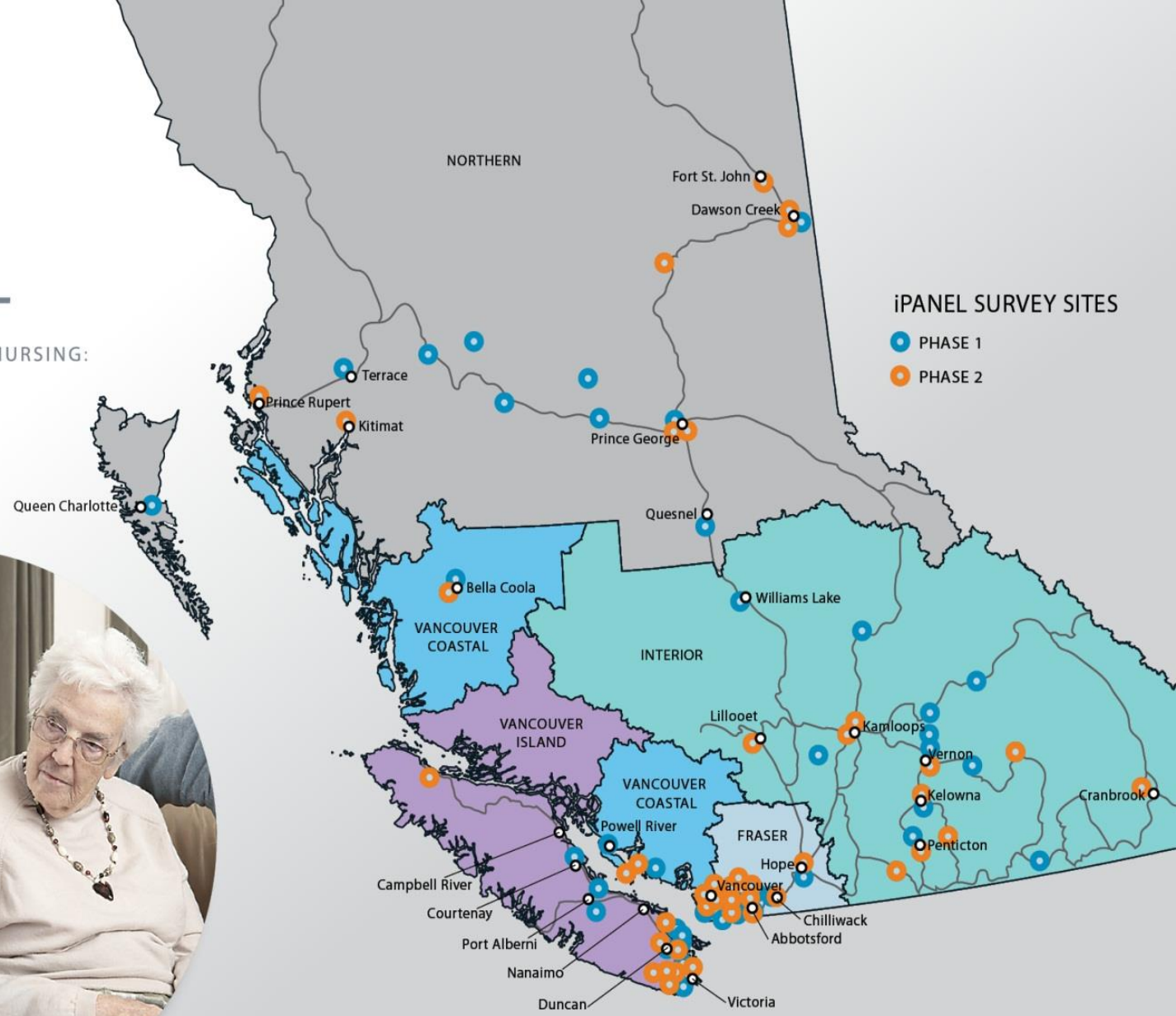

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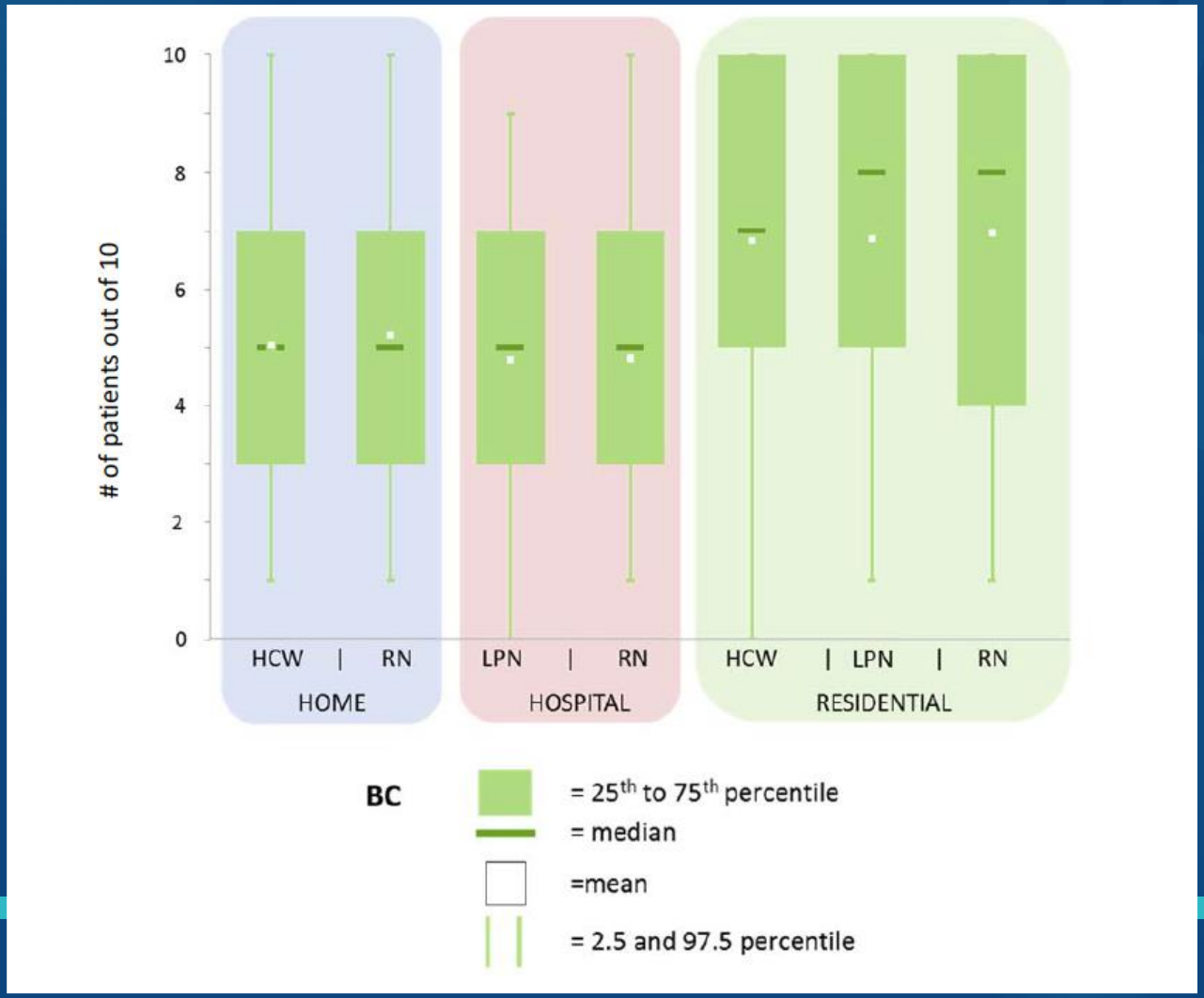
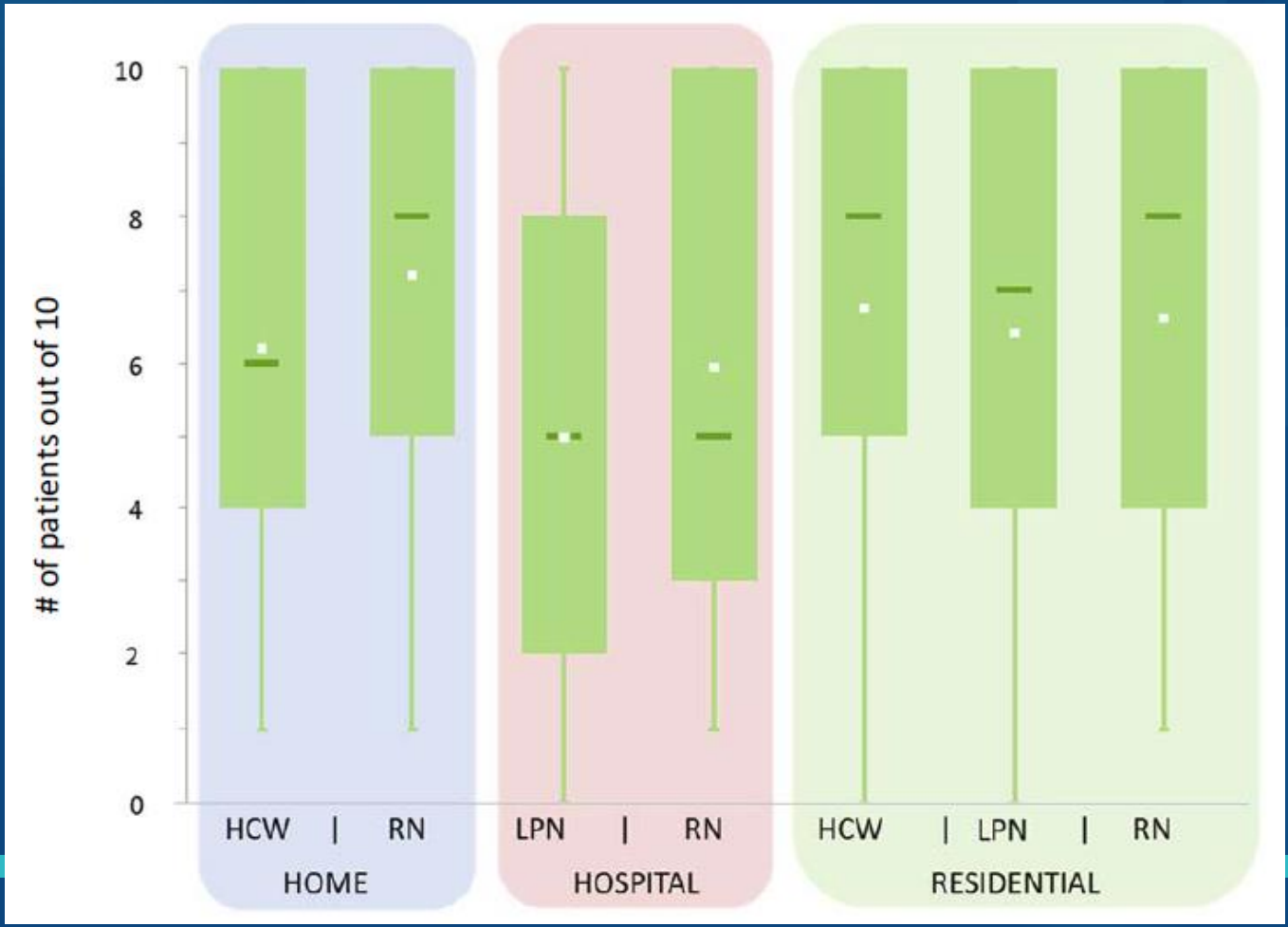
In your practice, how many patients out of 10 have a life limiting condition?



In your practice, how many patients out of 10 with life limiting conditions would benefit from a palliative approach?



Application of a palliative approach

Key findings

- Improved recognition of the life-limiting nature of chronic conditions is needed
- There is a need for consistent application of a palliative approach for people with chronic life-limiting conditions in all settings
- There is a need for improved confidence and knowledge regarding a palliative approach

iPANEL Knowledge Translation

GOAL:

- Translate key iPANEL findings into action
- Help care practitioners and health systems to embed a palliative approach into current care delivery systems, part of the core service.

GUIDED by our findings & beliefs "Knowledge-As-Action"[1]:

- Evidence becomes knowledge when it is enacted ("actionable").
- Research-derived knowledge and practice-embedded knowledge come together in KT; both are invaluable and must be merged "in the gap" between knowing and doing.

1. Reimer-Kirkham, S., Doane, G., Antifeau, E. et al. (2015) Translational scholarship and a palliative approach: Enlisting the Knowledge-As-Action framework. Advances in Nursing Science, 38(3), 187-202.

Shift your care to a palliative approach

[1]

1. iPANEL Knowledge Translation Working Group. iPANEL. (2017, September 14). Shift your care to a palliative approach [video file]. Retrieved from https://www.youtube.com/watch?v=sABo3gZoAcM

Key Features of a Palliative Approach

WHAT?

- Involves life-limiting illnesses such as heart, lung, and kidney disease, dementias, frailty, and cancer
- Integrates chronic disease management and palliative care principles
- Includes conversations about serious illness, personal preferences and goals of care
- Understands where the person is in the course of their chronic illness
- Orients care to the whole person and their family
- Prepared for illness progression, while recognizing uncertain prognosis

WHERE?

- Offered across settings including acute, home, and long term care

WHEN?

- Consults with specialist palliative care providers, as needed

WHY?

- Aligns treatment decisions better with goals and wishes
- Improves quality of life when preferences are known and respected
- Reduces inappropriate or futile treatments
- Encourages health care teams to "get on the same page" as the person and family
- Supports communication and shared care planning among teams caring for the person
- Gives team members permissions to have conversations with the person and family about serious illness

A palliative approach is different than specialized palliative care. It takes the principles of palliative care and ADOPTS, ADAPTS, EMBEDS

SHIFT YOUR THINKING

ADAPT strategies to meet patient and family needs, blend principles of palliative care with chronic disease management

ADOPT principles EARLY (as soon as diagnosis) in the course of a person's life-limiting condition

EMBED practices into usual care in settings not specialized in palliative care

Shift your view on when people with life-limiting illness could benefit from palliative principles:

Home & community care: When they are referred to home & community

Long term care: When they move into care

Acute care: When they are admitted to hospital

A palliative approach takes principles of palliative care and ADOPTS them EARLY in the course of person's life-limiting condition

SHIFT YOUR PRACTICE

ADOPT

HOW?

ADOPT

Ask yourself: "Does this person have a life-limiting condition?" "Would this person benefit from a palliative approach?"

Develop an understanding of the illness course and where the person is along their journey

Open conversations with people and their families to gauge understanding of their illness, what is most important to them, and their preference for care

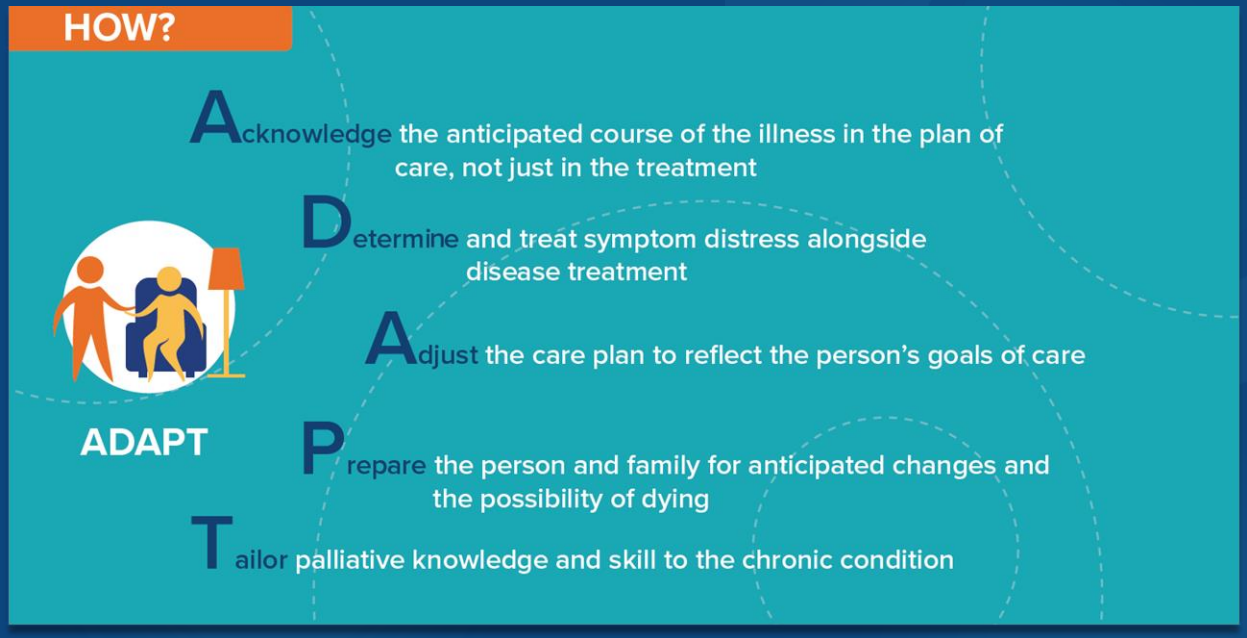
Prioritize care - focus on what is important to people and their families

Tell people and their families about the illness and what can be expected in the future to inform their goals of care

A palliative approach takes principles of palliative care and ADAPTS strategies to meet patient and family needs

SHIFT YOUR PRACTICE

ADAPT



A palliative approach takes principles of palliative care and EMBEDS practices into usual care in settings that do not specialize in palliative care

SHIFT THE SYSTEM

EMBED

HOW CAN LEADERS EMBED A PALLIATIVE APPROACH?

EMBED

Enable support for early integration in and across settings

Mandate processes for patient and family perspectives to be sought and communicated

Build confidence and competence by interactional education, mentorship and peer support

Ensure access to resources, mentors and specialist palliative care teams

Dedicate time for providers to be involved in creating practical tools and processes for their setting

Where?
In all settings, across the continuum of care

When?
Early in the course of a chronic life-limiting condition

Who?
Everyone working with people with life-limiting conditions

Palliative Approach Infographics - now available for download

www.ipanel.ca
or email
ipanel@uvic.ca

Where to find these resources?

Project Overview

Improving End-of-Life Outcomes in Residential Care Facilities: pilot project to enhance palliative care in the long term care setting

In partnership with 4 residential sites in 3 geographies within Island Health, an inter-professional palliative care specialty team co-developed and facilitated the implementation of a 2.5-year quality improvement and knowledge translation pilot project.

Lead by Palliative Care (PC) Specialist Physician Dr. Leah MacDonald, Medical Director**,** and supported by **Jill Gerke MA, Regional Manager**, both of Palliative and End of Life Care Program within Island Health, members of the Implementation Team were:

Palliative Physician Advisor

- **Dr. Christine Jones** – PC Physician Lead for Victoria
- **Dr. Valorie Masuda** – PC Physician Lead for Duncan
- **Dr. Marlene van der Weyde** – PC Physician Lead for Parksville
- **Dr. Christian Wiens** – PC, Geriatric Psych Specialist Physician, Advisor

Palliative Care Nurse Advisor

- **Della Roberts** CNS - Knowledge, Education and Research Advisor to Project
- **Jamie Linstead** RN - PC Specialist Nurse, Victoria (Link Nurse)
- **Charlotte Robinson** RN - PC Specialist Nurse, Duncan & Parksville (Link Nurse)

Pilot Project Goals

- enhance the care experience of residents with progressive life-limiting illness and their families;
- improve the experience of the care team in providing care for the dying;
- encourage collaborative practice between clinicians in residential care and palliative care; and,
- reduce emergency department use and hospitalizations of residents who are dying (supporting residents' dying in place).

Core Activities

- **awareness** raising about the role of a palliative approach to care in long term care (professional and non-care staff, residents' families or close ones, general public);
- **inter-professional,** care team-based as well as group peer-learning palliative care education adapted for the long term care setting;
- identification of opportunities for **organizational (culture) shift** and system change to support integration or enhancement of a palliative approach to care;
- **engagement of family physicians and specialist physicians** in the conversation about a palliative approach to care as best practice for individuals living with progressive life-limiting illness in the residential care setting.

A Palliative Approach to care is not limited to last days. It is about providing comfort and quality care for all residents living with progressive life-limiting illness and their families.

A PALLIATIVE APPROACH TO CARE

Palliative and End of Life Care Program January 2016

	INCREASING FRAILTY	INCREASING MEDICAL AND FUNCTIONAL DECLINE	LAST WEEKS	ACTIVE DYING	DEATH AND BEREAVEMENT
	For frail people admitted to residential care, this is the last season of their lives.	There are often signs a resident's health is declining. Dying is possible at any time in the coming months.	Dependency and symptoms increase. Death is now expected.		
Key Messages	"We are here to support and care for you to live well until the end of your life."	"Things are changing for you. This seems a good time for a family conference."	"Your mom is more frail now and coming closer to the end of her life."	"Your mom has changed more, and she is in her dying time."	"I'm sorry for your loss. We will miss your mom."
PPS (Palliative Performance Scale)	50–40%	40–30%	30–20%	20–10%	
Prognosis	YEARS	MONTHS	WEEKS	DAYS	DEATH

Ask yourself, "Is this resident at high risk of dying in the next months?"

Integrate a Palliative Approach

Affirm goals of care

Inform and guide

Enhance symptom management

Anticipate care needs

- Discuss with resident and family their understanding of their illness and expected trajectory
- Explore the resident's goals and values to guide their care and inform the Medical Orders for Scope of Treatment (MOST)

- Speak with resident and family about their changing condition and what to expect over time
- Create a plan for worsening symptoms and exacerbations to avoid hospitalizations
- Review medications. Can any be eliminated or decreased?

- Address symptoms along with managing chronic disease
- Reassess resident and family's comfort with the end-of-life plan, including dying "in place"
- Anticipate swallowing difficulties and consider alternative routes for medications

- Activate the Residential Care EOL order set and customize when appropriate
- Support family

- Acknowledge and review death
- Support grieving family
- Consider referral for bereavement support to local Hospice Society

Signs of Transition

- Progressive weight loss
- Significant functional decline with limited reversibility
- Resident and family asking for palliative care or comfort measures only, treatment withdrawal or limitation
- Unplanned transfer(s) to ED or hospital admissions
- Extreme frailty
- Advanced dementia or other neurological disease, advanced cancer diagnosis, severe heart disease, severe respiratory disease

- Increasing fatigue, e.g. not wanting to be out of bed long
- Withdrawing socially, less communicative
- Swallowing difficulties
- Eating and drinking less

- Fluctuating level of consciousness
- May not want any food or fluid
- Congested breathing
- Irregular breathing (apneic spells)
- Body temperature changes

A PALLIATIVE APPROACH TO CARE

Early Identification Tool

There are often signs that a resident's health is declining and that they are at higher risk of dying in the coming months. Ask yourself, "Would I be surprised if this resident died in the next 6 months?" Being attuned to these signs allows health care providers to better inform and guide residents and their families in this final season of their life.

What factors support the care teams impression that the resident is in their last months of life? (check all that are relevant)

- ☐ Progressive weight loss (greater than 10% in 6 months)
- ☐ Progressive, irreversible functional decline
- ☐ Resident or family asking for palliative care or comfort measures only, treatment withdrawal or limitation
- ☐ Unplanned transfers to hospital
- ☐ Extreme frailty (e.g. persistent pressure ulcers, recurrent infections, delirium, persistent swallowing difficulties, falls)
- ☐ Advanced dementia or other neurological disease (e.g. full assistance needed with all activities of daily living, incontinence, unable to communicate effectively, poor oral intake, swallowing difficulties, recurrent UTIs, aspiration pneumonia)
- ☐ Advanced cancer diagnosis
- ☐ Severe heart disease (e.g. breathlessness or chest pain at rest or with minimal exertion)
- ☐ Severe respiratory disease (e.g. breathless at rest or with minimal exertion, on oxygen therapy in place, recurrent hospitalizations)
- ☐ Advanced illness of any cause with progressive function decline or poorly controlled symptoms

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Criteria adapted from Supportive and Palliative Care Indicators Tool (SPICT) www.spict.org.uk and "The Gold Standards Framework Prognostic Indicator Guidance"

Today's Date: _____

Guide for Goals of Care Plan

(following identification of resident for palliative approach to care)

DOMAINS OF CARE	GOALS	ACTIONS
Early Identification	Ensure coordinated team-based support is initiated when resident is identified as in greater need of a palliative approach to care	☐ Complete "Early Identification Tool" ☐ Notify MRP if resident is identified (send form letter if used by this facility) ☐ Communicate to care team that resident has been identified
Information Sharing and Being a Guide to Family	Ensure that the family/ resident have opportunity to discuss the anticipated illness course and the benefits of a palliative approach to care to inform their care plan	☐ Choose a care team member to speak with family/resident about changes the care team has noted ☐ Document wishes and concerns on the Advance Care Planning Notes and Conversation Form (or equivalent) kept in Greensleeve of a resident's chart ☐ Encourage family to make an appointment with the resident's doctor to discuss anticipated illness course, prognosis and MOST ☐ Consider a family meeting with care team and MRP ☐ Provide ongoing check-ins with family
Confirming Goals of Care	Ensure that care provided is in keeping with resident's wishes and values, and is medically appropriate	☐ Revisit "Medical Orders for Scope of Treatment" (MOST) ☐ If MOST designation appears inconsistent with condition notify MRP and encourage family to make an appointment to revisit MOST

CONVERSATION GUIDE for RESIDENTIAL CARE TEAM

A resident's increasing frailty has been identified and the early identification tool for a palliative approach to care has been completed.

CONVERSATION - LISTENING MORE THAN TALKING

Elements of conversation often take place over many small conversations and do not need to happen in one long session.

STEPS	DESCRIPTION	SCRIPT QUESTIONS / Sample Statements
1 **INITIATE** discussion	**Contact** the resident and/or family **Ask** permission for discussing change **Gather information** from the team about the specific changes identified **Plan** what you will say to the resident and/or family	**Q:** I would like to talk with you about the changes in your mom's health. Is that OK? **Q:** Have you been noticing change? What changes have you been noticing?
2 **ASK** the resident and family	**Ask** the resident and/or family what their thoughts are about the resident's current status **Ask** the resident and/or family about what is important to them	**Q:** What do you understand about what is happening for your mom, with her illness? **Q:** What is most important to your mom now? What is most important to you?
3 **TELL** share information about changes	**Ask** permission to share information **Share information** on current status; include changes staff have seen, the increasing frailty, and that more change could happen at any time **Give information** in a straightforward way **Use words** the resident and family will understand Use "I **wish**…", "I **worry**…", "I **wonder**…" strategy	**Q:** Is it okay if I tell you the changes the care team has been seeing? As you noticed, your mom is sleeping more and doesn't go to activities. She is also eating less and has lost 5 pounds over the last 2 months. She is more irritable and is in more pain when moving. These changes are all part of what we expect as someone becomes more frail and … … they become less able to fight off a cold or infection. … they are moving toward the end of life. … life is getting shorter. … I **wish** things were different. I **worry** time is getting shorter. I **wonder** if we could talk about how we can provide care for your mom at this time.

	DESCRIPTION	SCRIPT QUESTIONS / Sample Statements
4 ASK share information about changes	**Explore** what is most important, the concerns	Now that we have talked ... **Q:** What is most important to you at this moment? **Q:** What hopes or concerns do you have?
5 NEXT steps	**Outline** next steps **Record** Advance Care Plan (ACP) notes and conversation. Fax form letter to physician (MRP) and attach progress notes if needed. **Share** with team including physician **Update** care plan	– I will write all this down and let the rest of the care team know so we are all on the same page. – I will (the nurse will) connect with the doctor and ask about changing some of the medications. We can reconnect next week. Does that sound OK? – I think it is important to make an appointment with your doctor and have a good discussion about what to expect and the plan of medical care. – ACP notes and conversations example: "Discussed recent changes in condition with family. Family wishes to have medical information and review plan of care. Asked family to make appointment with GP."
GOALS OF CARE	**CLARIFY GOALS OF CARE** (as appropriate)	**Also refer to Conversation Guide on page 2 of MOST**
Answer questions as they are raised	 Use the same approach: **ASK - TELL - ASK**	**FAMILY QUESTIONS:** How much time do they have? Are they dying? **ASK -** What is your sense? What are you expecting? **TELL -** You could be right. Often we aren't able to predict how much time, but we can see that she frail enough and change could happen at any time. This could be her dying time. **ASK -** Is that what you expected to hear? Does that make sense to you? **FAMILY QUESTION:** Should their family member still go to hospital? **ASK -** What are you thinking? How do you think they would benefit from going to the hospital? What would you hope from your mom going to hospital? **TELL –** It is so important to discuss your worries and hopes. We can care for your mom here, focusing on her comfort. For what she now needs, we have the care available. **ASK –** It sounds like you have more questions. Do you want to talk about this with your mom's doctor? Could you make an appointment?

Early Learnings & Results

- Cultural Shift - Seeing "palliative care" as a process rather than event"
- New confidence levels with "conversations"
- Facility leadership involvement critical - CNL, Medical Co-ordinator, Manager
- Supporting (multidisciplinary) champions (eg. SW, dietician)
- Role of the Health Care Aid
- Across all four sites there was a decrease in hospital admissions in last 14 days of life for those residents who were identified early

Palliative Care Rounds Essential

- To address the staff's educational and emotional needs around palliative and end of life care
- Opportunity to review and "identify" residents early as a team
- An opportunity to reflect on deaths and any emerging concerns or issues.

Evaluation – iPAC - RC

The iPAC-RC project is guided by the following three **objectives**:

- Assess the ***impact of the implementation project*** from the perspective of administrative and clinical personnel (i.e., managers, directors of nursing, physicians, and medical directors), family members, and paid workers (RNs, LPNs, RCAs);
- Assess **indicators of quality of care** at the end of life pre- and post-IEOL implementation; and
- Identify the ***process for successful implementation*** of the project in Island Health, influencing contextual factors (i.e., facilitators and barriers to implementation), and lessons learned for scaling up into other facilities

Data Collection – iPAC-RC

- **Completed:**
  - Nurse/LPN focus groups
  - Care Aide focus groups
  - Family Council focus groups
  - IPEOL team focus group (time 1)

- **In Progress:** (individual)
  - Nurse/LPN surveys
  - Care Aide surveys
  - Bereaved family member surveys
  - Schedule IPEOL team (individual) and Time 2 and Time 3 focus groups

Next Steps

EMBED practices into usual care in settings not specialized in palliative care

- developing evidence-informed recommendations for integrating and scaling up a palliative approach into LTC facilities;
- packaging the suite of practice support tools to facilitate transitions in the care journey; and
- developing an evaluation framework including outcome measures and benchmarks.

Take home messages

- Palliative approach is NOT a service — clarity in understanding & language…
- Understanding a palliative approach (shift your thinking!) before introduction of practice tools — a palliative approach is not an "add on" or a "tick box "
- Empowering staff within a team-based approach
- Communication that is patient - centred — respectful, sensitive, contributes to continuity in care
- Evidence — need for research, especially including patient reported outcomes
- Others… your thoughts and questions?