Unpacking the Principles of a Palliative Approach to Care Series

Identifying people who would benefit from a palliative approach

Presenters:

Jan Vandale, MN RN CHPCN(C), Clinical Nurse Specialist with Palliative Home Care, and CAMPP (Community Allied Mobile Palliative Partnership), Alberta Health Services

Host and Moderator: Jennifer Campagnolo, CHCA
Date: May 28, 2024

Project ECHO® Palliative Care - Canada BY Pallium Canada

Canadian Home Care Association

Land Acknowledgement

We recognize with humility and gratitude that Canada is located in the traditional, historical and ceded and unceded Lands of First Nation, Inuit and Metis Peoples. On behalf of us all, we acknowledge and pay respect to the Indigenous peoples past, present and future who continue to work, educate and contribute to the strength of this country.

Learning Objectives

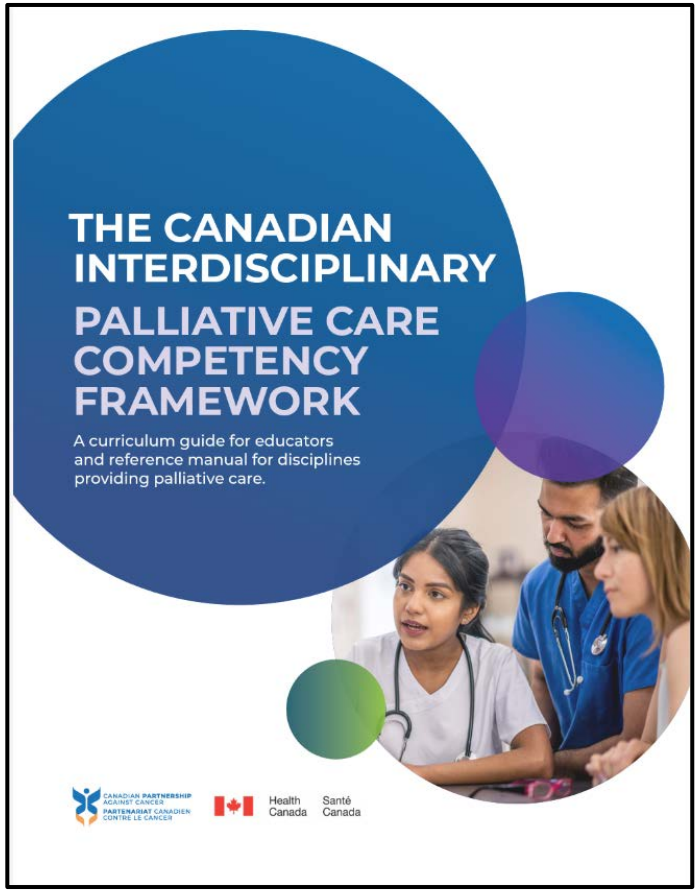
By the end of the session, participants will be able to:

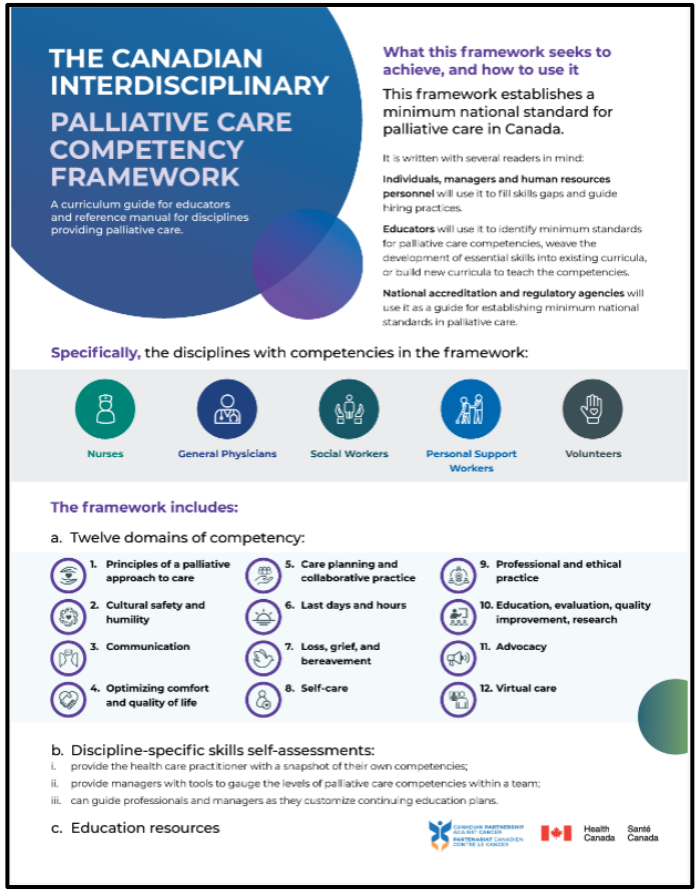
Describe how early identification and integration of a palliative approach enhances care and outcomes

Recognize opportunities to optimize care and QOL through early initiation of a palliative approach

Reflection on skills, knowledge and attitudes needed to identify people who would benefit from a palliative approach

THE CANADIAN INTERDISCIPLINARY PALLIATIVE CARE COMPETENCY FRAMEWORK





Unpacking the Principles of a Palliative Approach to Care

Domain 1: Principles of a palliative approach to care

Palliative care aims to improve the quality of life of people with life-limiting conditions and their designated families or caregivers. This person-centred care ideally begins at diagnosis, continues into bereavement, and is for people of any age. [1]

[1] Canadian Partnership Against Cancer & Health Canada. *The Canadian Interdisciplinary Palliative Care Competency Framework.* Toronto, ON: 2021.

Unpacking the Principles of a Palliative Approach to Care

Competency 1.2 Identifying people who would benefit from a palliative approach[1]

For Interdisciplinary team members (nurses, SW, PSWs, generalist physicians and volunteers) this means recognizing, understanding and integrating:

- “Life-limiting conditions" and a person’s complex and changing multidimensional care needs
- Advocating for early initiation of a palliative approach
- Communicating with families or caregivers about the continuum of care, disease trajectory, and the principles of a palliative approach to care
- Collaborating with the care team and using evidence-based tools to identify people who could benefit from a palliative approach

[1] Canadian Partnership Against Cancer & Health Canada. *The Canadian Interdisciplinary Palliative Care Competency Framework.* Toronto, ON: 2021.

Introductions

Jan Vandale, MN RN CHPCN(C)
Clinical Nurse Specialist with:
Palliative Home Care, and
CAMPP (Community Allied Mobile Palliative Partnership)

Janet Vandale (RN, MN)
Clinical Nurse Specialist
Palliative Home Care (Calgary Zone)
CAMPP

Palliative Care:

The Early Approach

Alberta Health Services

We recognize that our work takes place on historical and contemporary lands of many indigenous peoples, including the **Blackfoot, Stoney Nakoda, Tsuu'tina, Piikani, Cree, Dene, Inuit and Métis peoples**, as identified in Treaty 7, and the Métis Nation within Alberta

Alberta Health Services

This acknowledgement is made in the spirit of reconciliation and gratitude to those whose territory we reside on and work on.

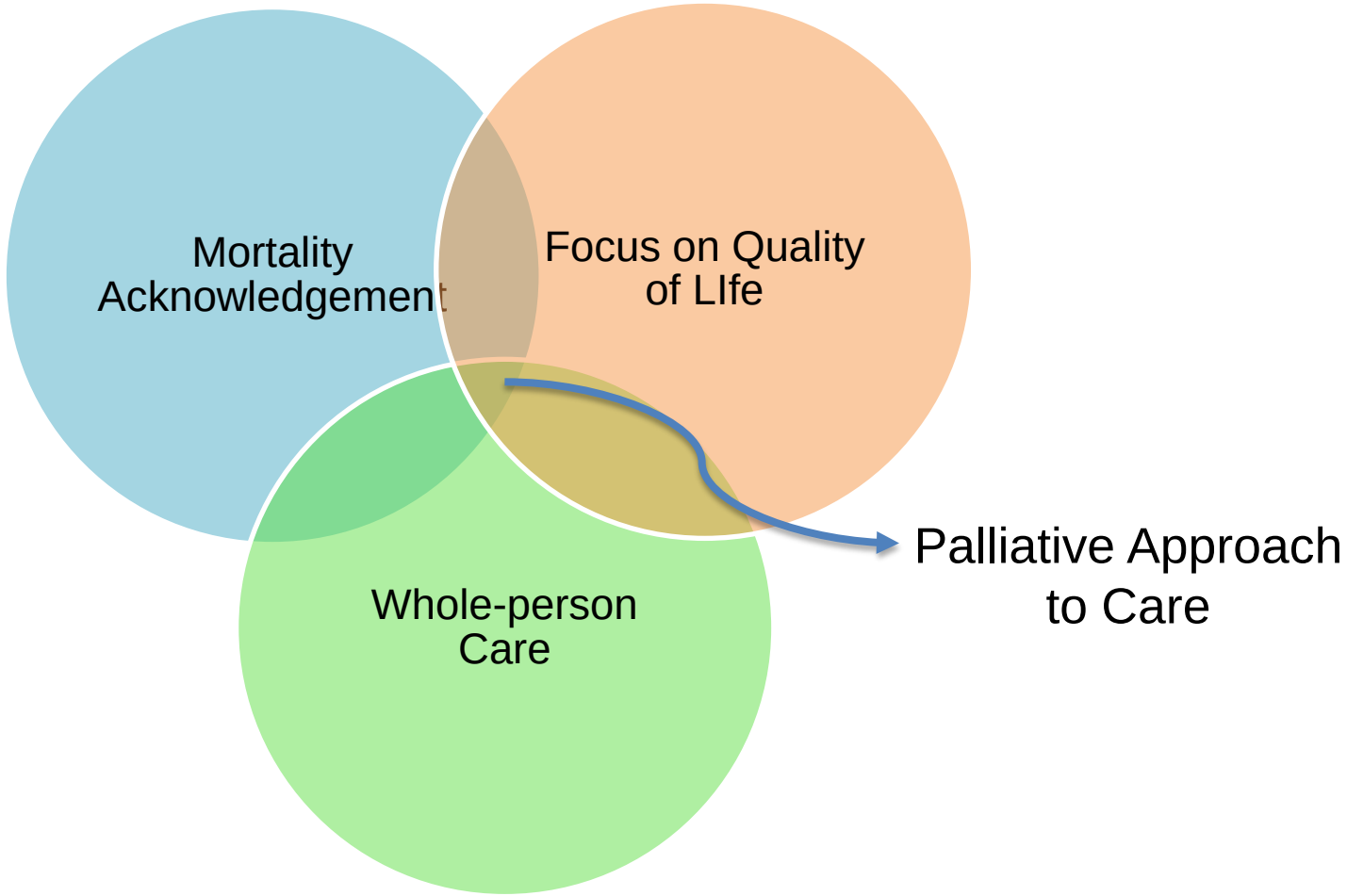
Thank you.

Alberta Health Services

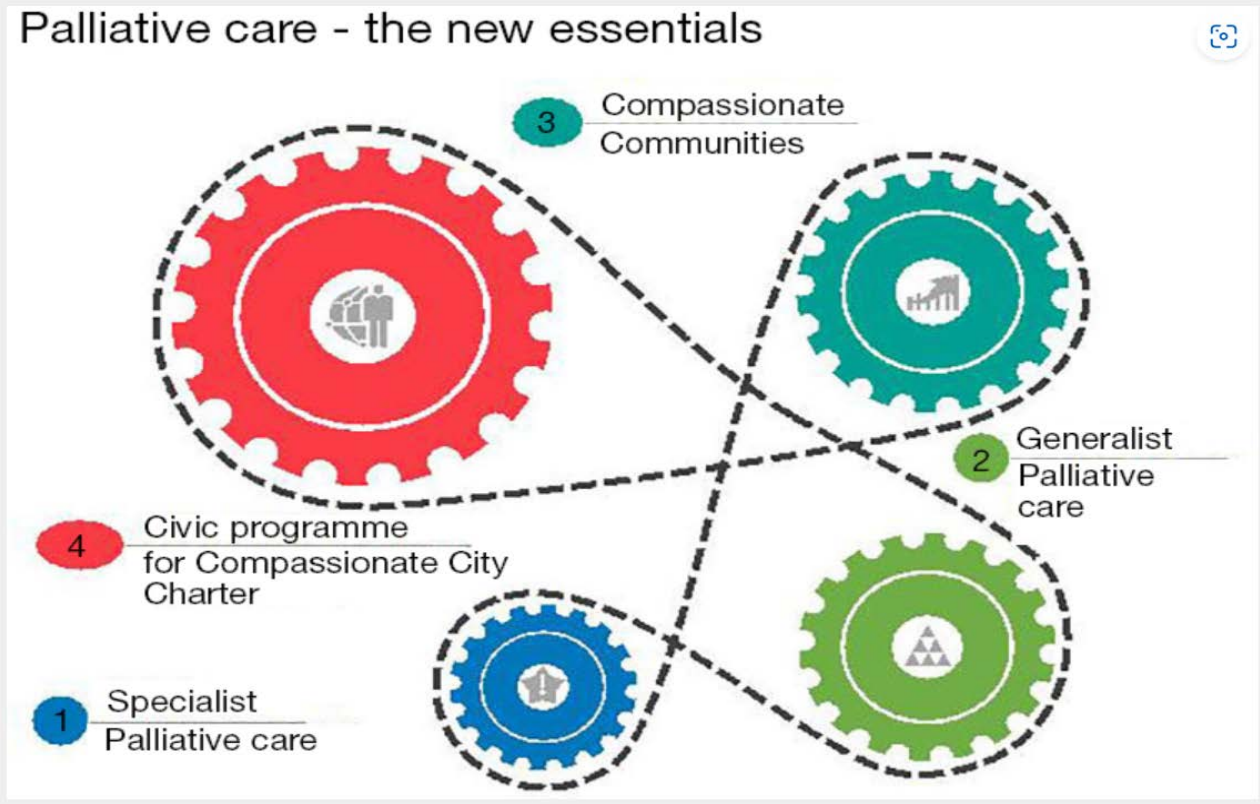
Outline for today:

Frame	Palliative Approach as a concept Principles When, where, how?
Share	PaCES work – early and systematic PC in the context of a palliative approach in advanced cancer care
Explore	Who would benefit, and how do we find them?
Discuss	Your own experiences Questions and comments

Conceptual Model (Touzel & Shadd, 2018)



Public health model



Meet Chris:

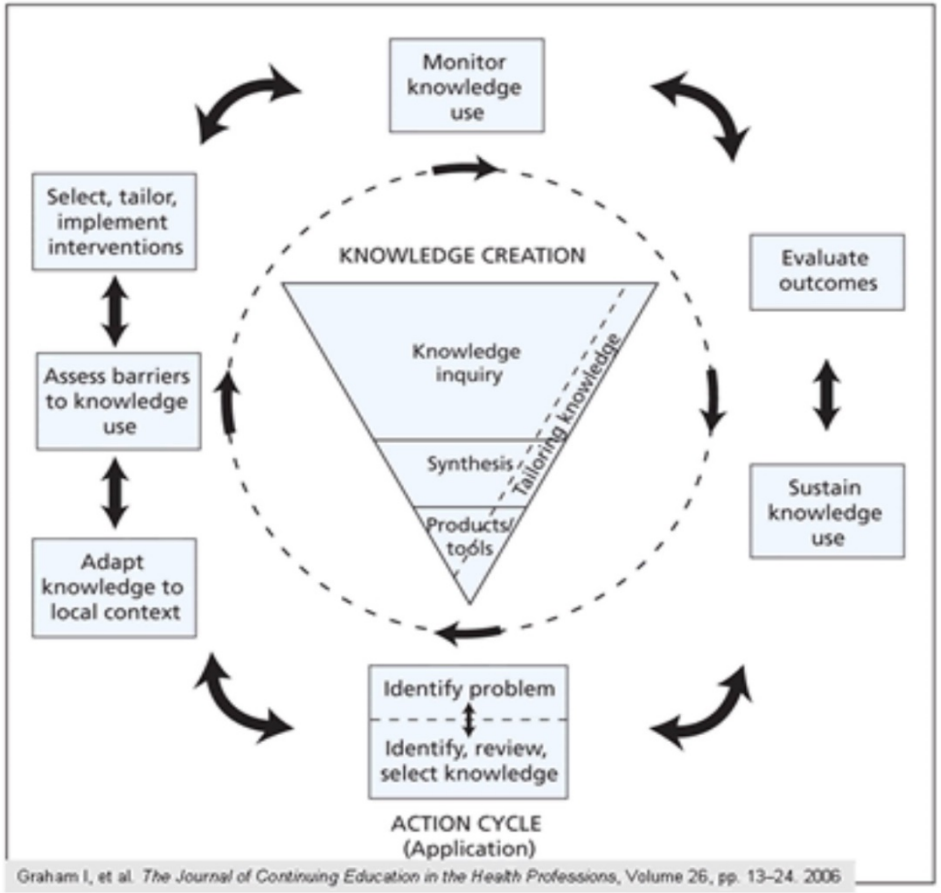
- 48, very advanced salivary gland cancer
- Homeless since early 20’s
- EtOH central to his life
- Dan – caregiver, “life partner”

Palliative Care Early and Systematic: CRC

Complex system change

Complex conceptual change

Knowledge to Action Cycle



Graham I, et al. *The Journal of Continuing Education in the Health Professions*, Volume 26, pp. 13–24. 2006

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Local Context: “The saddest place on earth…”

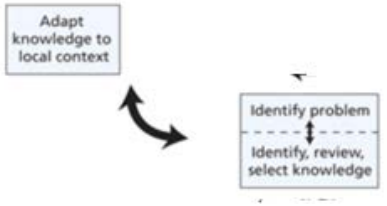

Photo credit: CTV news

Slide courtesy of
Dr. Jessica Simon

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Our challenge: Late & non-integrated PC

EVIDENCE SUGGESTS INITIATE PALLIATIVE CARE WITHIN 2 MONTHS *OF DIAGNOSIS*

2010 RCT Early Palliative Care significant improvement in quality of life, mood and longer survival

2017 Multiple systematic reviews confirm better quality of life, symptom burden and survival

2017 ASCO Guideline suggests early palliative care involvement within 8 weeks of diagnosis of advanced cancer

BUT IN CALGARY PALLIATIVE CARE WAS USED A MEDIAN OF 2 MONTHS *BEFORE DEATH*

Temel JS. N Engl J Med 2010; Smith TJ. J Clin Oncol 2012;
Ferrel B. J Clin Onc 2017;
Haun MW. Cochrane Database Syst Rev 2017;

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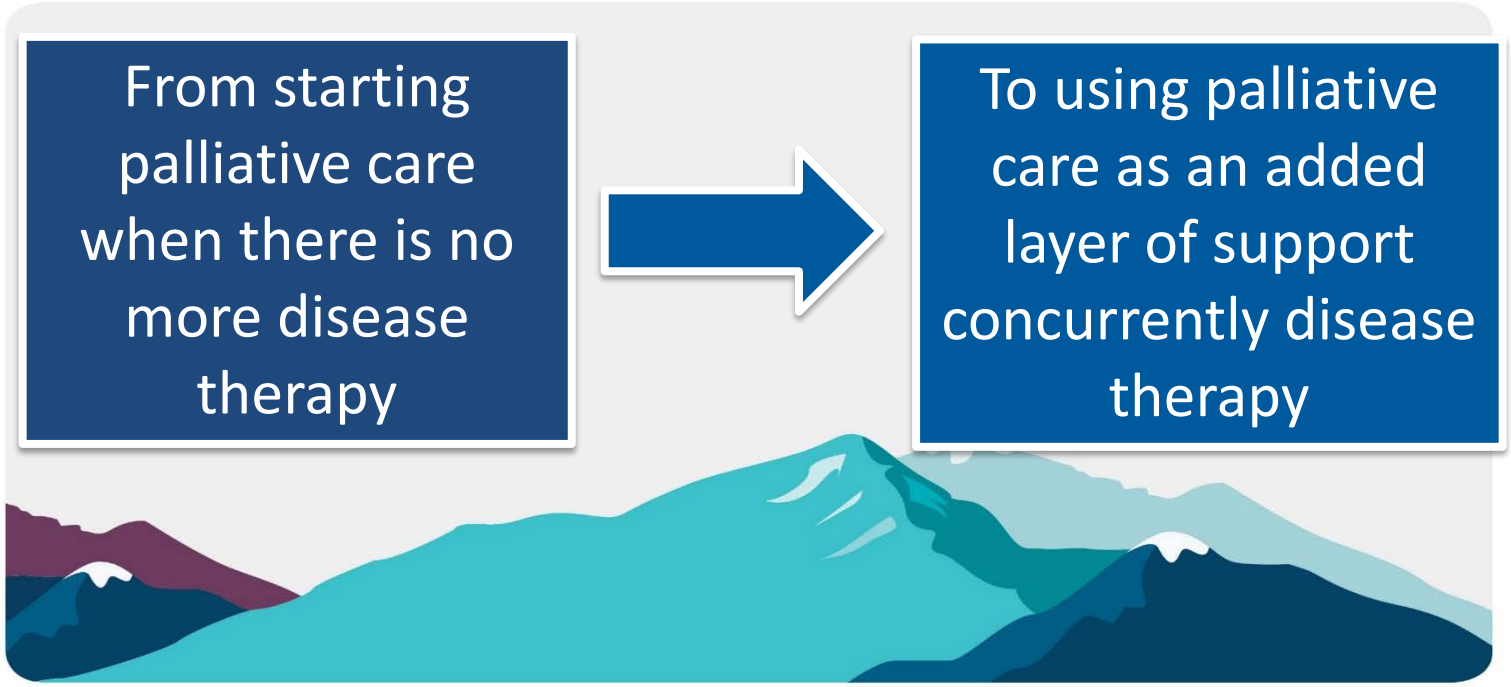
What are we trying to change?

SHIFTING CULTURE AND PRACTICE & SYSTEMS



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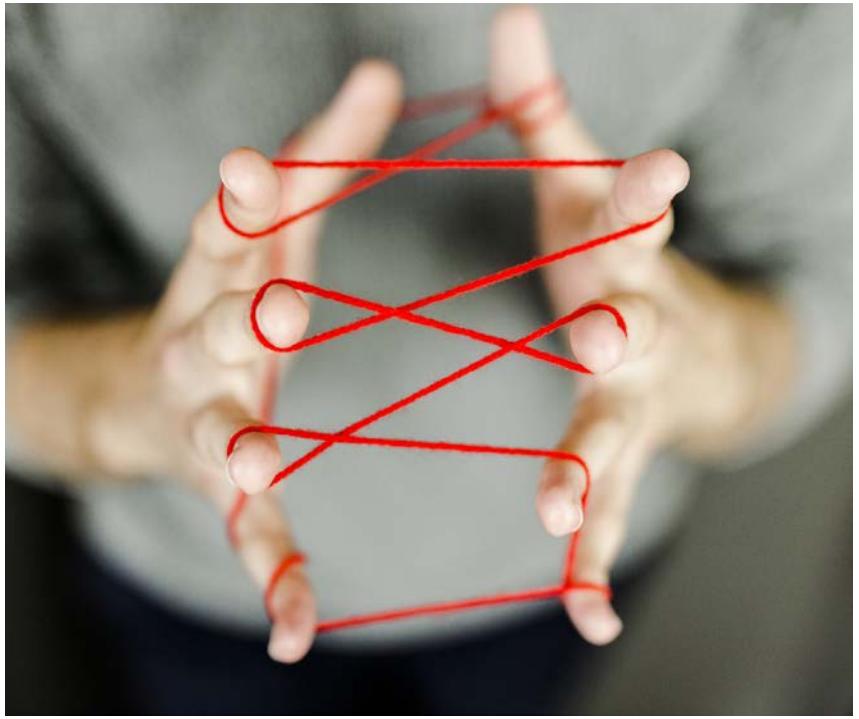
What kind of timely Palliative Care?



- Primary PC (palliative approach)
- Specialist PC

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Alberta Health Services

SMART Goal

Increase by 20%, access to early specialist palliative care (more than 90 days before death) over 2 years

SMART goal = Specific, Measurable, Achievable, Relevant, and Time-Bound

Assess Barriers: Oncology providers' challenges

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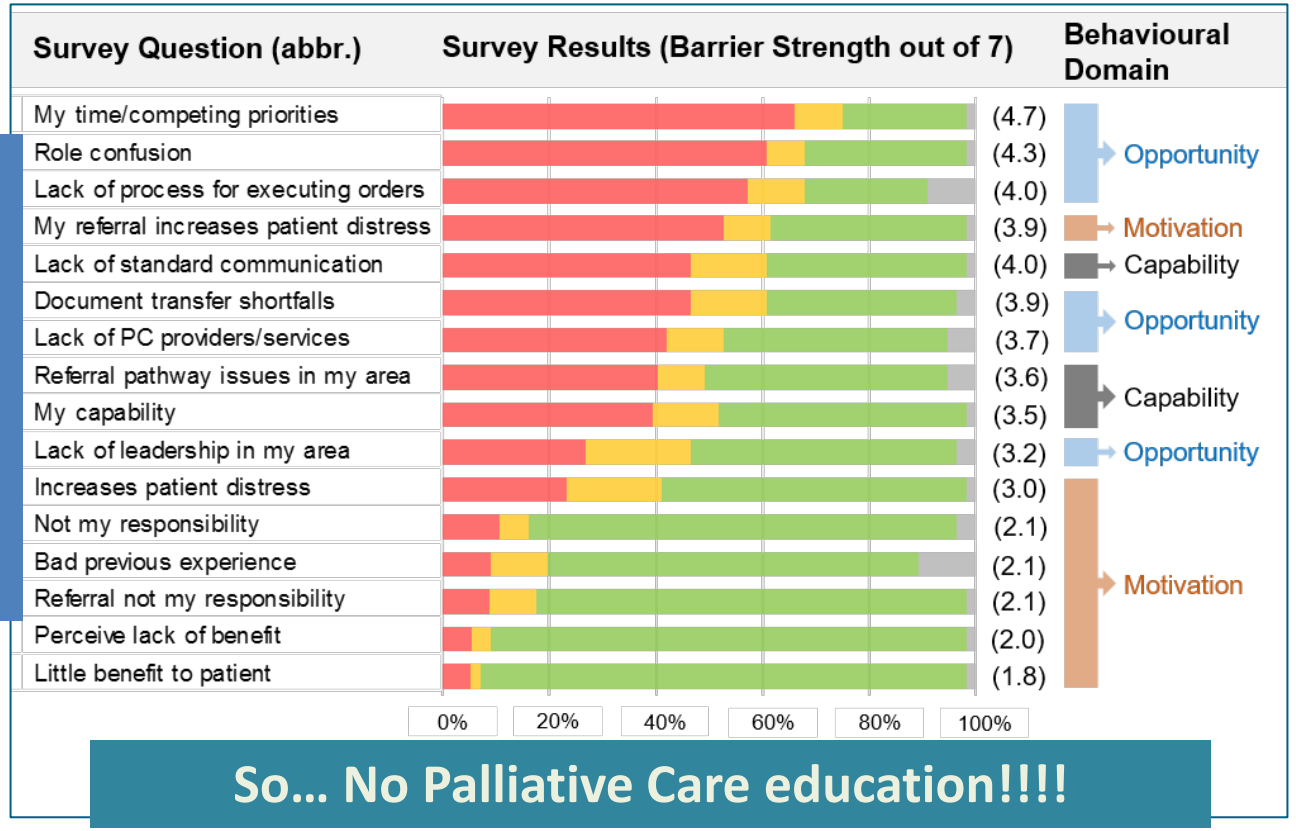
sion
ocess for executing

ut patient distress



So… No Palliative Care education!!!!

Select & Tailor Interventions: Visioning Together

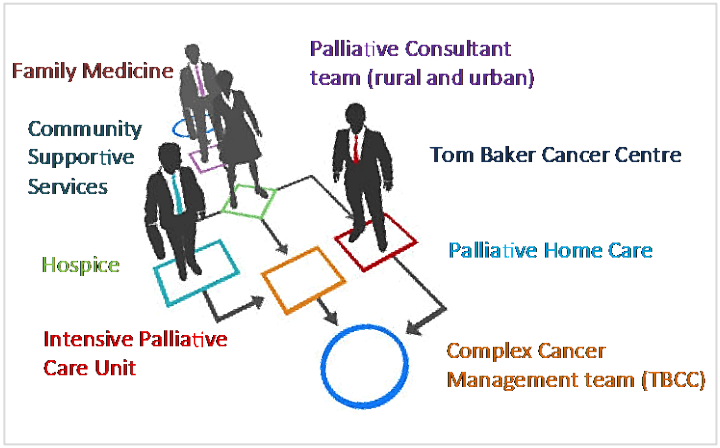
Improving quality of life for Albertans with advanced cancer

Grounded in Patient Experience

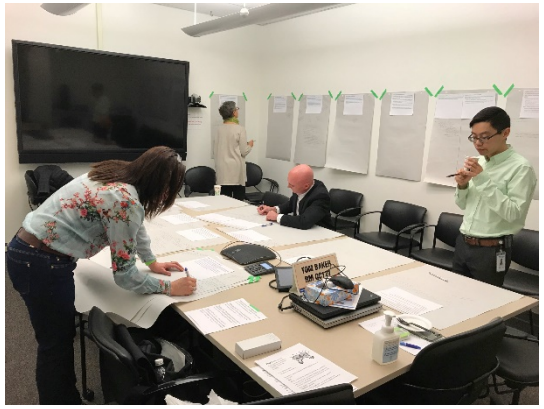
"I will be forever grateful for the many acts of kindness, both big and small — that reassured both of us that we weren't alone, that others cared." — PaCES Family Advisor

Stakeholders Generated the Solutions

AHS AIW Methods



Broad stakeholders Involved



E.g. Drop-in session

Staff Identified 101 Gaps
and Generated 136 Actionable Solutions

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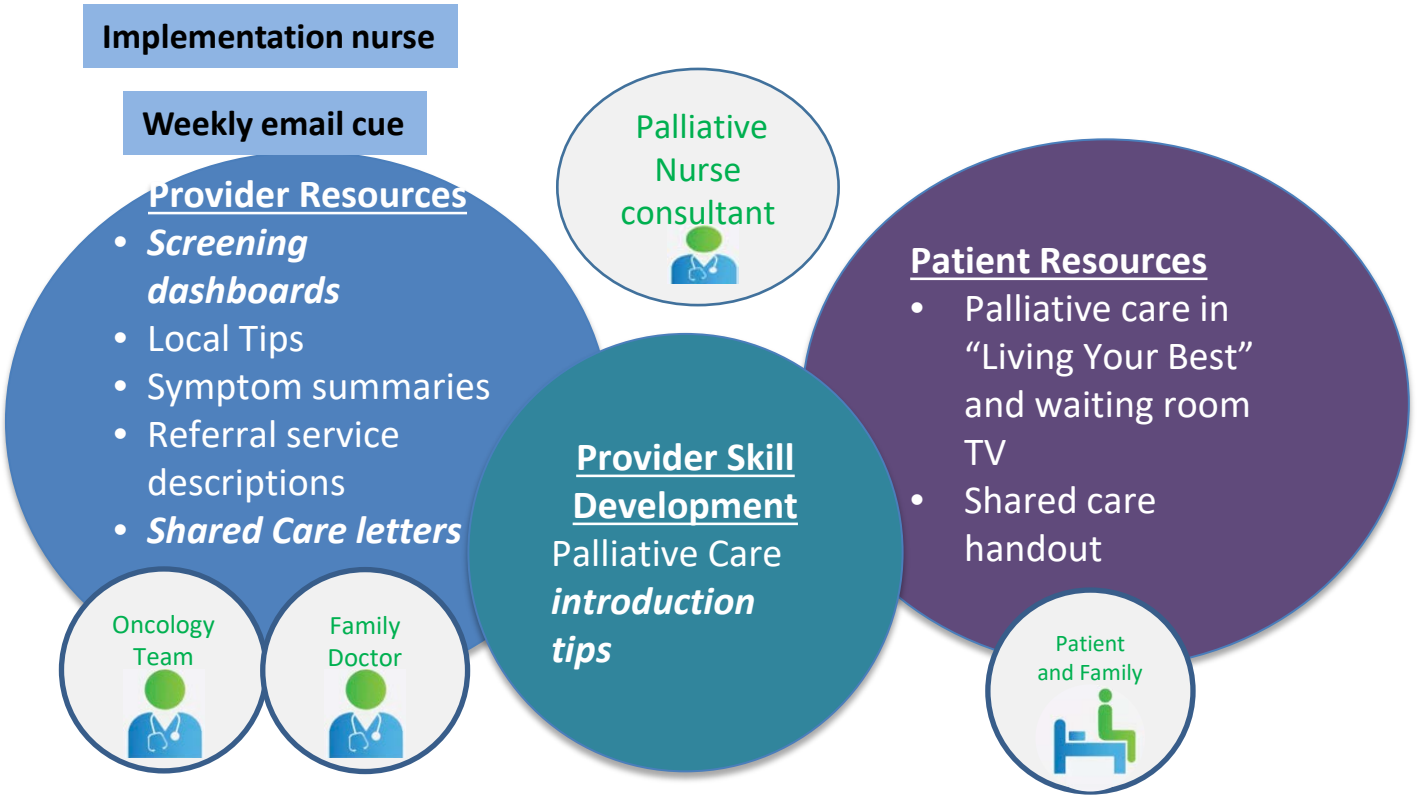
Intervention Resources



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Facilitated Implementation Interventions

Weekly: identify pts with P. needs + cueing reminders to Oncologists

Facilitated implementation in Clinics

Dedicated Early Palliative Care Nurse Specialist

SHARED CARE

Meet Sue…

Susan's journey:

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4 Elements of PaCES-brand EPC

- Illness understanding and coping
- Symptoms and Function
- Advance care planning
- Care Coordination

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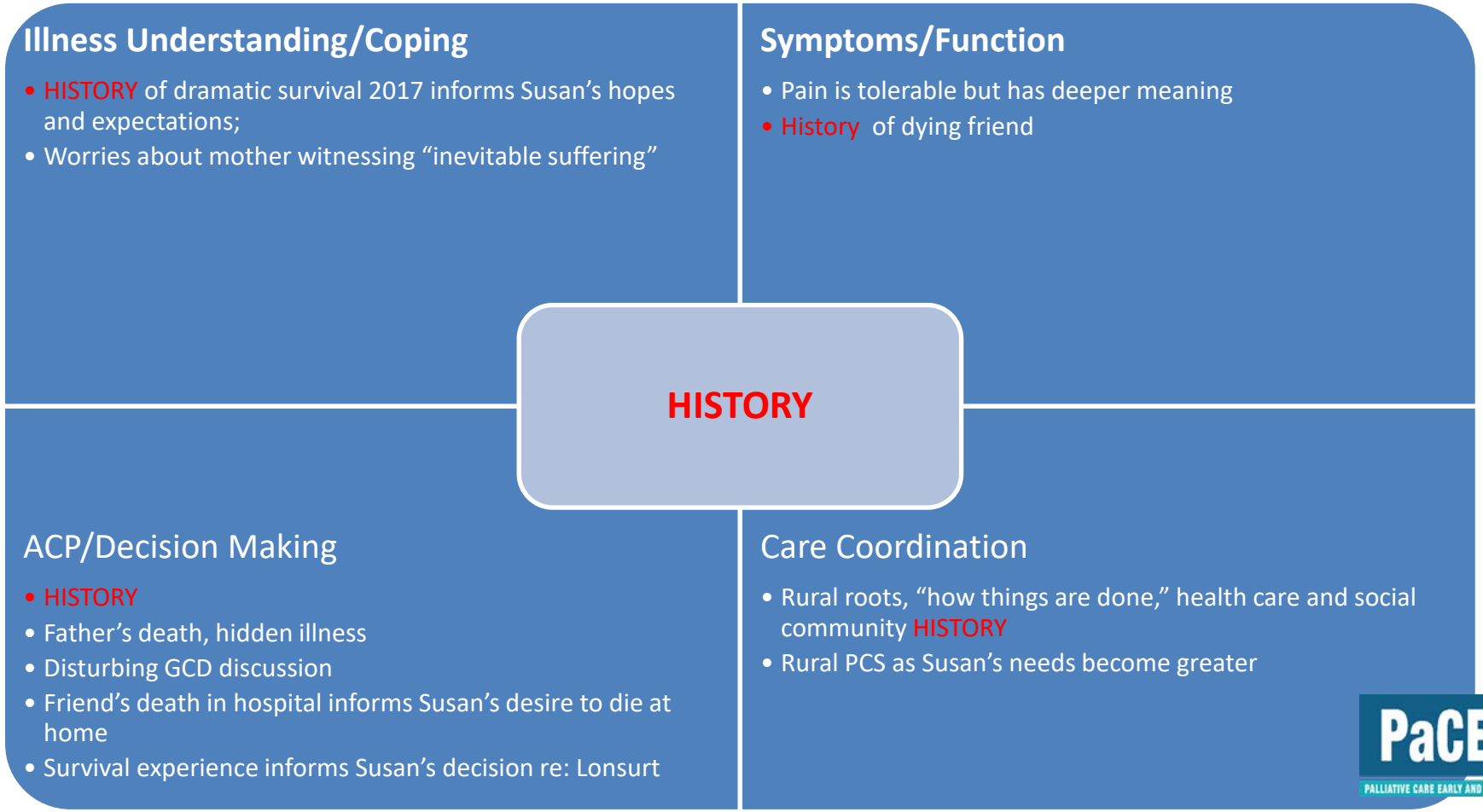
Sue's elements :



“Why would I plant a tree in my garden if I didn’t expect to see it grow?”

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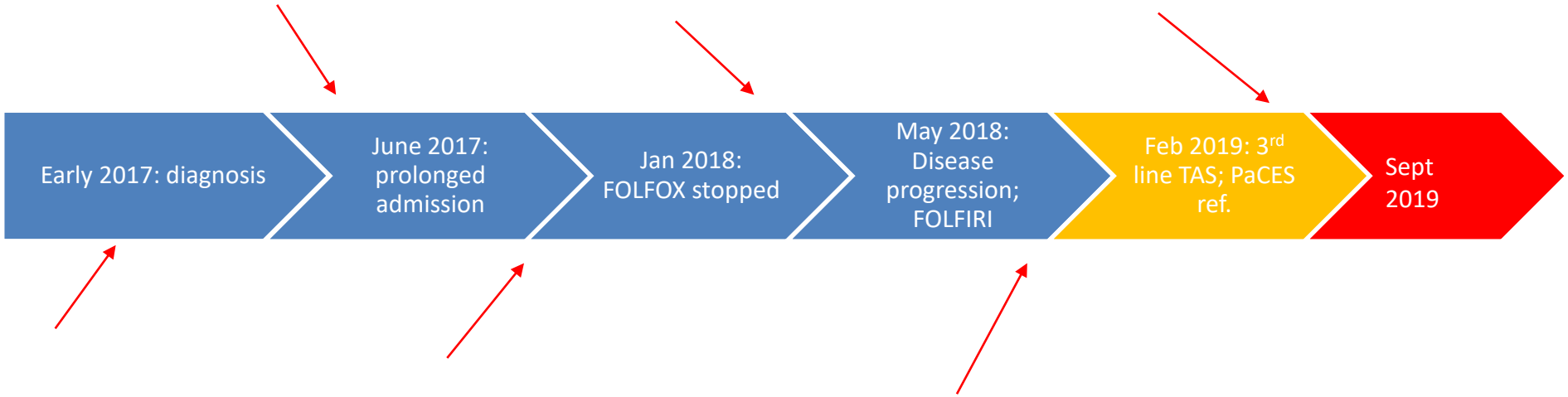
Susan's journey:



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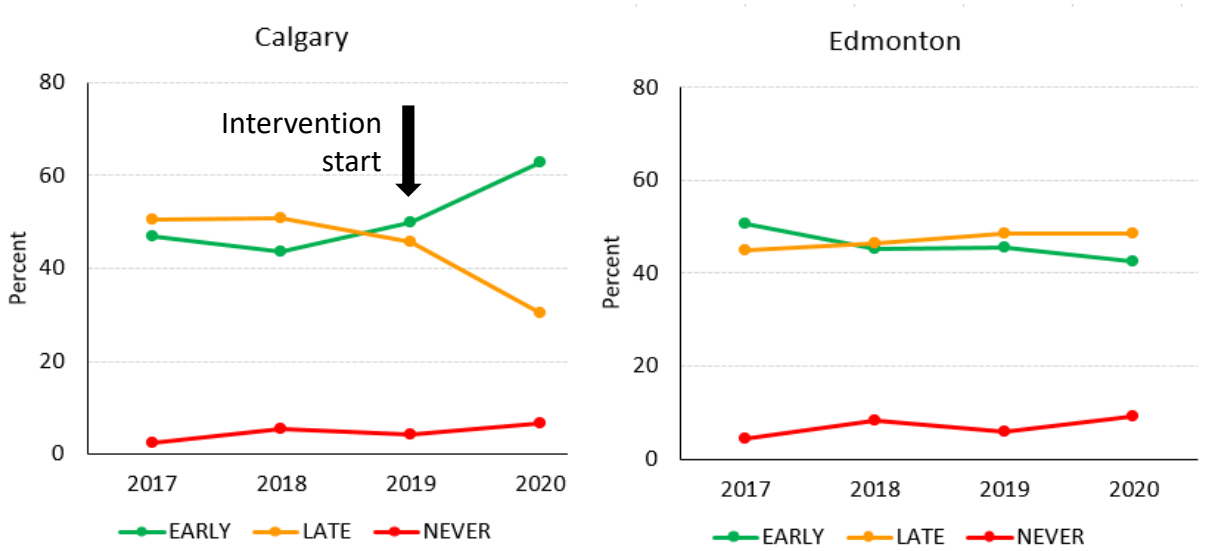
Evaluate Outcomes:
More Calgary decedents received early PC



Difference in difference estimator: 17.0%

Time Period	Intervention zone (Calgary)		Comparator zone (Edmonton)			
	Pre-intervention (Apr '17 – Dec '18)	Intervention (Apr '19 – Dec '20)	Pre-intervention (Apr '17 – Dec '18)	Intervention (Apr '19 – Dec '20	Difference in difference estimator (95% CI)	p
Total number of deaths	188	209	153	145		
Referral to specialist PC >90 days before death (proportion, n)[a]	44.7% (84)	57.4% (120)	47.7% (73)	44.1% (64)	17.0% (2.0%-32.0%)	0.027

Dominant Intervention Effect: Lower healthcare costs

	Calgary (Intervention)		Edmonton (Control)	
Outcomes of interest in economic analysis	Preintervention n=188	Intervention n=209	Preintervention n=153	Intervention n=145
Days spent at home in the last 90d life (Limited definition: hospital, hospice, ED)	61.7	68.1	63.6	67.9
Days spent at home in the last 90d life (Extended definition: includes out-pt cancer clinic)	55.2	60.4	54.6	57.5

Incremental Cost-Effectiveness Ratio	Calgary	Edmonton	Difference	ICER
Incremental Cost (Post - Pre)	-$2,273	$2,194	-$4,467	
Incremental Effect (Post - Pre) - Short Definition	6.4	4.3	2.1	-$2,127.14
Incremental Effect (Post - Pre) - Extended Definition	5.2	2.9	2.3	-$1,942.17

Lessons Learned: Process

WE WANT TO DO THE RIGHT THING BUT IT NEEDS TO BE QUICK AND EASY TO DO

Engagement	*Meeting 1:1 with leaders and GI oncologists before implementation*
Investment in Facilitator	*Achieved uptake through "at shoulder" training*
Patient Advisors	*Patients' enthusiasm was sustaining drive*
CNS presence	*Essential influence for patients and providers*
Sustained Cueing Needed	*Effortful, Connect Care may help*

Lessons Learned: Care

- Presence
- Language
- Ongoing conversation
- Cultural shift

Who would benefit, and how do we find them and when do we find them?

Explore

Who would benefit, and how do we find them?

British Journal of General Practice, May 2018

Bruce Mason, Kirsty Boyd, John Steyn, Marilyn Kendall, Stella Macpherson and Scott A Murray

Computer screening for palliative care needs in primary care:

a mixed-methods study

THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT™)

NHS SCOTLAND

The SPICT™ is used to help identify people whose health is deteriorating.
Assess for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (Person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems. The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.

SPICT TM

https://www.spict.org.uk/e-spict/

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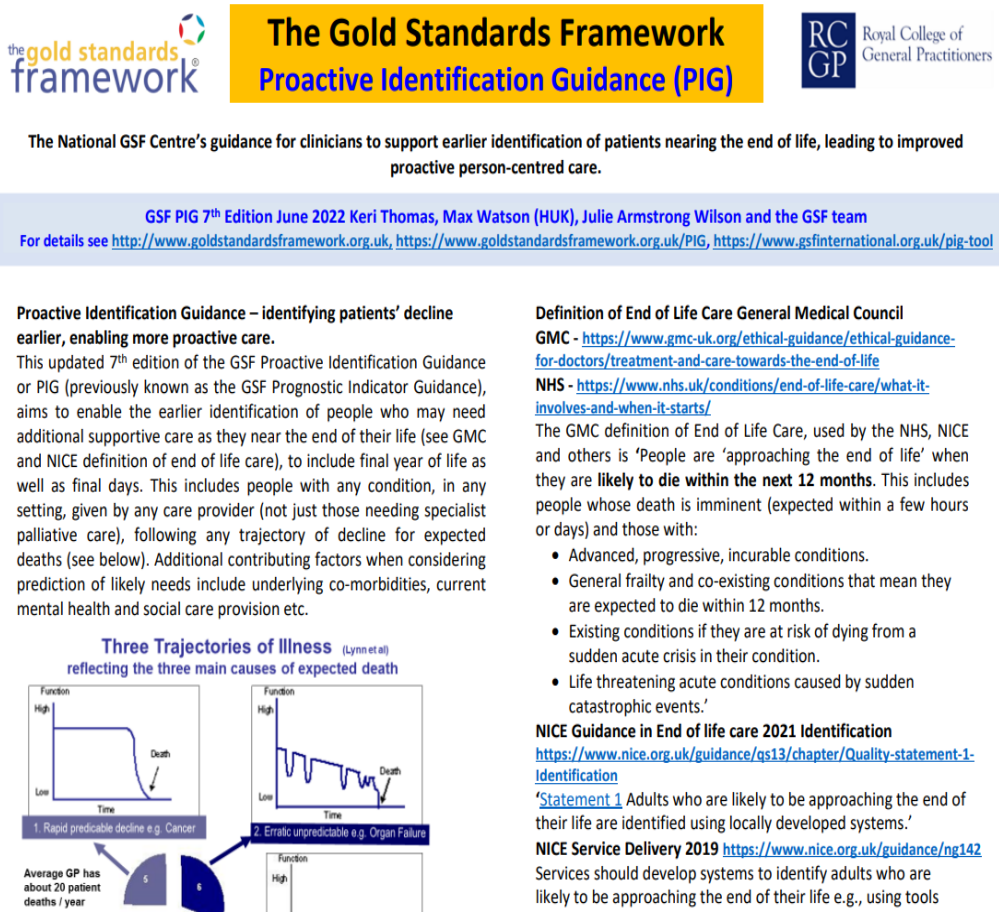
PIG – Proactive Identification Guidance



The Gold Standards Framework
Proactive Identification Guidance (PIG)

The National GSF Centre's guidance for clinicians to support earlier identification of patients nearing the end of life, leading to improved proactive person-centred care.

GSF PIG 7th Edition June 2022 Keri Thomas, Max Watson (HUK), Julie Armstrong Wilson and the GSF team
For details see http://www.goldstandardsframework.org.uk, https://www.goldstandardsframework.org.uk/PIG, https://www.gsfinternational.org.uk/pig-tool

Proactive Identification Guidance – identifying patients' decline earlier, enabling more proactive care.
This updated 7th edition of the GSF Proactive Identification Guidance or PIG (previously known as the GSF Prognostic Indicator Guidance), aims to enable the earlier identification of people who may need additional supportive care as they near the end of their life (see GMC and NICE definition of end of life care), to include final year of life as well as final days. This includes people with any condition, in any setting, given by any care provider (not just those needing specialist palliative care), following any trajectory of decline for expected deaths (see below). Additional contributing factors when considering prediction of likely needs include underlying co-morbidities, current mental health and social care provision etc.

Three Trajectories of Illness (Lynn et al)
reflecting the three main causes of expected death

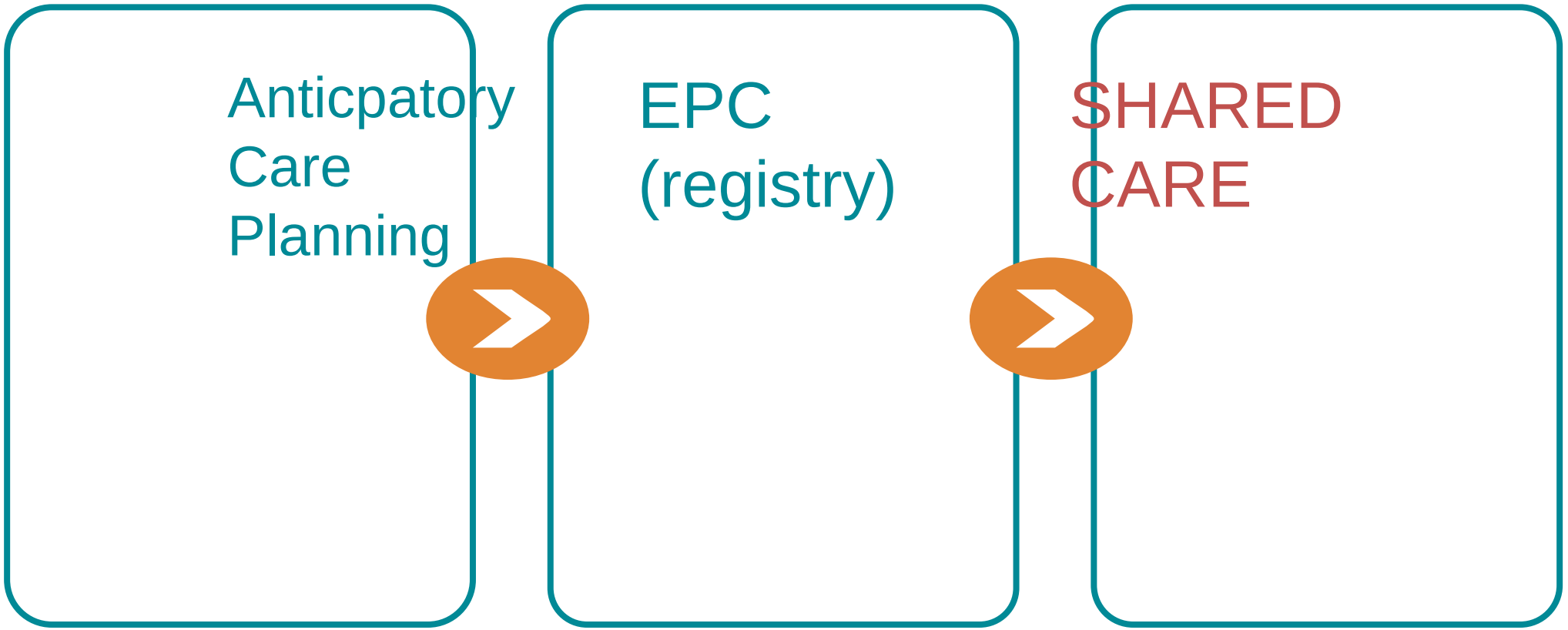
Definition of End of Life Care General Medical Council
GMC - https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life
NHS - https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/
The GMC definition of End of Life Care, used by the NHS, NICE and others is 'People are 'approaching the end of life' when they are **likely to die within the next 12 months**. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions.
- General frailty and co-existing conditions that mean they are expected to die within 12 months.
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- Life threatening acute conditions caused by sudden catastrophic events.'

NICE Guidance in End of life care 2021 Identification
https://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-1-Identification
'Statement 1 Adults who are likely to be approaching the end of their life are identified using locally developed systems.'
NICE Service Delivery 2019 https://www.nice.org.uk/guidance/ng142
Services should develop systems to identify adults who are likely to be approaching the end of their life e.g., using tools

https://goldstandardsframework.org.uk/cd-content/uploads/files/PIG/Proactive%20Identification%20Guidance%20v7%20(2022).pdf

Early Primary PC in Scottish NHS



MSR: My Symptom Report

- Flowsheet
- Questionnaire

Onc Msr

Question	08/05/2024 13:22 MDT - Filed by Karen Anne Russell, RN
For urgent symptoms or concerns, talk with your care team or call Health Link at 811. If this is an emergency, call 911 or go to your nearest emergency department.	
Pain	8!!
I have pain in:	Back Other
I take medications or other substances to manage pain.	Yes
Tiredness	8!!
I spend more than half of my day resting or sleeping.	Yes
Drowsiness	9!!
I take medications or other substances that may cause me to feel drowsy.	Yes
Nausea	6
I am vomiting.	No
I take medications or other substances to manage nausea.	No
Lack of Appetite	7!!
I currently eat _____ of my normal diet.	Less than half
Shortness of Breath	6
I am short of breath:	Climbing one flight of stairs Walking short distances
Depression	7!!
I work with a professional for depression.	No
I have thoughts of harming or killing myself.	No
Anxiety	7!!
I work with a professional for anxiety.	No
Well-Being	7!!
Diarrhea	10 = worst!!
I have _____ diarrhea bowel movements per day.	More than 6
I take medications or other substances to manage diarrhea.	Yes

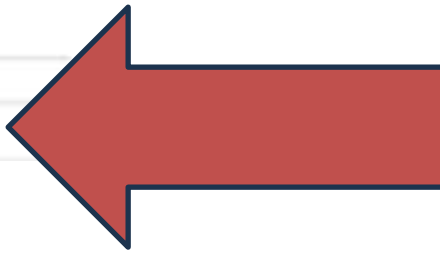
PROBLEMS SQUARE

Somatic	Social context and finances
Policy	Policy
Actual problems:	Actual problems:
Expected problems: Dying scenario:	Expected problems: Dying scenario:
Caregiving and daily living activities	**Existential and psychological issues**
Policy	Policy
Actual problems:	Actual problems:
Expected problems: Dying scenario:	Expected problems: Dying scenario:

Possible future problems: Pain, Dyspnoea, Ileus, Delirium, Anxiety, Depressed mood, Coma Liver/kidney failure, Caregiver burden, Specific technical care needs	
Disease-specific aspects: heart failure: anaemia, weight, stopping defibrillator COPD: drug and other therapy when dyspnoea	

Fig. 2 Problems square to make a structured actual and possible future multidimensional problems analysis

It has been _____ days since my last bowel movement.	1 to 2 days
I take medications or other substances to manage constipation.	Yes
Numbness or Tingling	9!!
I have numbness or tingling in:	Toes Feet
Sleep Problems	10 = worst!!
I have these sleep problems:	Restless sleep
I take medications or other substances to manage sleep problems.	No
Thinking Problems	8!!
I have trouble remembering or concentrating on a daily basis.	No
Mobility Problems	7!!
I have fallen in the last month.	
I work with a professional for mobility problems.	No
I have these additional physical symptoms:	Chills Bladder problems Sexual function changes
The most important item to discuss with my care team is:	Pain
Some cancer treatments could negatively impact fertility or reproductive health and the ability to have biological children now or in the future. I would like to speak to a healthcare professional about this.	No
I have vaped, smoked or chewed tobacco in the last 30 days.	Yes
MSR Symptom Complexity Score (range: 0 - 170)	135 (High)!!



PALCOM Scale

PALCOM: Complexity Scale of Palliative Care Needs in People with Advanced Cancer

Would you be surprised if the patient died in the next 12 months? If the answer is no, the PALCOM scale can determine the complexity of palliative care needs and allows managing the intervention of specialized Palliative Care teams.

1. **Is a high symptom burden detected?**
   Presence of ≥5 chronic symptoms with at least a moderate intensity (Visual Analogue Scale or Numeric Ratting Scales ≥4/10) out of 10 systematically recorded symptoms:
   * Pain * Anorexia * Weakness * Nausea-vomiting * Constipation * Dyspnea or cough * Insomnia * Drowsiness * Anxiety
   * Sadness * Others...
2. **Are there any markers of difficult pain control?**
   Any of the following characteristics can lead to potentially difficult pain:
   * Neuropathic pain * Mixed pain (nociceptive and neuropathic) * Breakthrough cancer pain * Pain associated with cognitive impairment
   * Pain associated with a history of addiction to alcohol or other substances of abuse
3. **Is there functional impairment?**
   Person who requires relevant assistance for activities of daily living. (e.g. Barthel index ≤60 or Karnofsky index ≤50-60%)
4. **Any socio-familial risk factors**
   * Absence of identified caregiver * Caregiver limitations due to advanced age, health problems, or socio-family or economic burdens
   * Minors or more than one member of the nuclear family who needs support * Risk of severe family burnout. * Other complexity situations (social vulnerability, poverty, domestic violence, addiction of abuse substances...)
5. **Any ethical or existential conflict?**
   * Conflicts related to information (denial, conspiracy silence, ...) * Healthcare team disagreement * Disagreement between patient/family and healthcare team
   * Loss of meaning in life or existential distress * Desire to advance death, demand for euthanasia or assisted suicide * Spiritual distress. * Others...

Each of these 5 domains is scored dichotomously, 0 absence or 1 presence of any of the variables, the sum, between 0 and 5, is the total score of the PALCOM scale.

0-1 Low complexity: Basic palliative care is recommended. Referring team to get back in contact if patient becomes more complex. In some cases, timely consultation with specialist palliative care may be needed for a comprehensive assessment or management of difficult isolated symptoms.
2-3 Medium complexity: Specialised palliative care is systematically recommended (hospital teams, home support teams or palliative care services).
4-5 High complexity: Intensive specialised palliative care is systematically recommended (teams in the hospital, support teams in the home or palliative care services).

Time to Reflect:
Competency = Skills, Knowledge and Attitude

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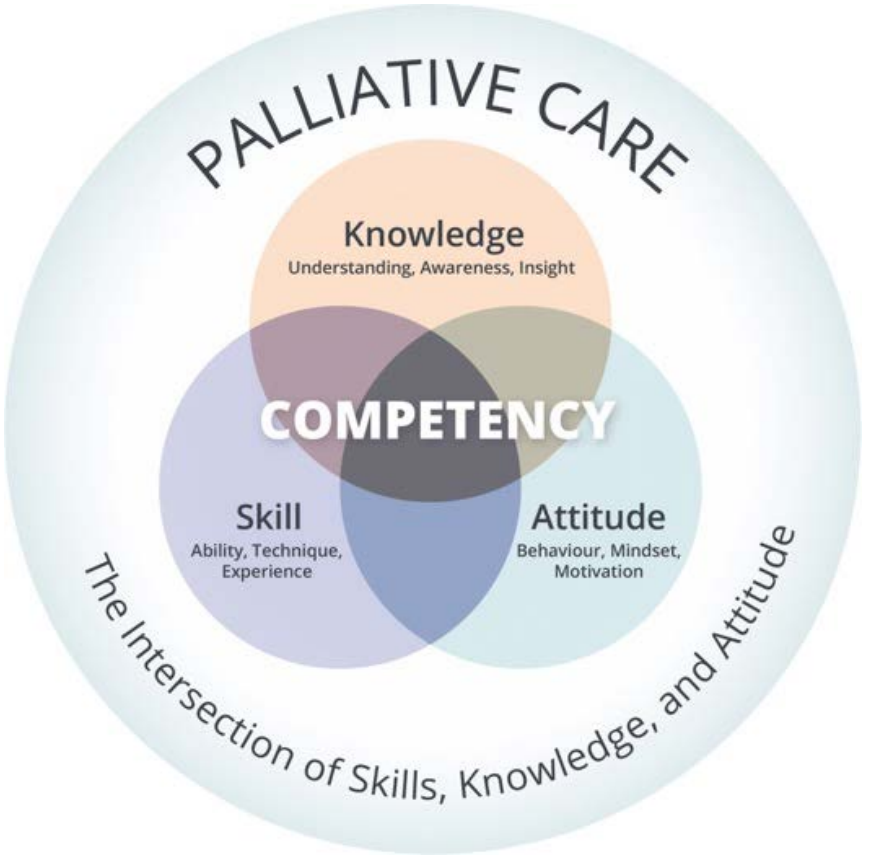
Canadian Home Care Association

THE CANADIAN INTERDISCIPLINARY PALLIATIVE CARE COMPETENCY FRAMEWORK



[1] Canadian Partnership Against Cancer & Health Canada. *The Canadian Interdisciplinary Palliative Care Competency Framework.* Toronto, ON: 2021.

THE CANADIAN INTERDISCIPLINARY PALLIATIVE CARE COMPETENCY FRAMEWORK

Competency 1.2 Identifying people who would benefit from a palliative approach[1]

For Interdisciplinary team members (nurses, SW, PSWs, generalist physicians and volunteers) this means recognizing, understanding and integrating:

- “Life-limiting conditions" and a person’s complex and changing multidimensional care needs
- Advocating for early initiation of a palliative approach
- Communicating with families or caregivers about the continuum of care, disease trajectory, and the principles of a palliative approach to care
- Collaborating with the care team and using evidence-based tools to identify people who could benefit from a palliative approach

Competency = SKILL + KNOWLEDGE + ATTITUDE

[1] Canadian Partnership Against Cancer & Health Canada. *The Canadian Interdisciplinary Palliative Care Competency Framework.* Toronto, ON: 2021.

Time to reflect on the elements of Competency

Apply knowledge of life-limiting conditions to respond to complex and multidimensional care needs, and comprehensively identify current and prospective issues in palliative care at the system level.

To effectively identify patients who may benefit from a palliative approach to care, what skills do you believe you need to strengthen?

- Communication Skills
- Emotional Self-Awareness
- Clinical Assessment Skills
- Knowledge of Palliative Care Principles
- Multidisciplinary Collaboration

Apply knowledge of life-limiting conditions to respond to complex and multidimensional care needs, and comprehensively identify current and prospective issues in palliative care at the system level.

How well do you understand the term "life-limiting condition" and its implications for patient care?

- Not at all
- Slightly
- Moderately
- Very well
- Extremely well

Apply knowledge of life-limiting conditions to respond to complex and multidimensional care needs, and comprehensively identify current and prospective issues in palliative care at the system level.

How aware are you of how your emotions may impact your ability to identify patients who may benefit from palliative care?

- Not aware at all
- Slightly aware
- Moderately aware
- Very aware
- Extremely aware

Identify and initiate, early in the illness trajectory, people who would benefit from a palliative approach.

Consider the following prevalent life-limiting illnesses among home care patients. Choose which diagnosis you have the most confidence **in recognizing common trajectories and transition points to trigger the early initiation** of a palliative approach to care, and which diagnosis you have the least confidence in.

Most Confident:

- Advanced Cancer
- End-Stage Heart Failure
- Chronic Obstructive Pulmonary Disease (COPD)
- Advanced Dementia
- End-Stage Renal Disease

Least Confident:

- Advanced Cancer
- End-Stage Heart Failure
- Chronic Obstructive Pulmonary Disease (COPD)
- Advanced Dementia
- End-Stage Renal Disease

Identify and initiate, early in the illness trajectory, people who would benefit from a palliative approach.

Surprised?

Advanced Cancer
- Range of Certainty: High
- Trajectory: Often clear; progressive symptoms and/or poor prognosis

COPD
- Range of Certainty: Moderate
- Trajectory: Challenging; variable with periods of stability

End-Stage Heart Failure
- Range of Certainty: Moderate
- Trajectory: Varies; fluctuating symptoms and potential for sudden decline

Advanced Dementia
- Range of Certainty: High
- Trajectory: Fairly high; progressive cognitive decline and inability to perform daily activities make identification clearer

End-Stage Renal Disease
- Range of Certainty: High
- Trajectory: Generally clear when patients opt out of dialysis or show significant decline despite treatment

Communicate to people and families or caregivers the continuum of care, disease trajectory, and optimal time to refer to palliative care.

How comfortable are you initiating conversations with patients and their families or caregivers about their diagnosis, disease trajectory, and a palliative approach to care?

- Not comfortable at all
- Slightly comfortable
- Moderately comfortable
- Very comfortable
- Extremely comfortable

Use appropriate evidence-informed tools, from diagnosis throughout the illness trajectory, to help the interdisciplinary care team identify people who could benefit from a palliative approach (e.g., psychosocial concerns, screening for distress).

How important do you believe it is to collaborate with the care team to identify patients who could benefit from a palliative approach?

- Not important at all
- Slightly important
- Moderately important
- Very important
- Extremely important

Use appropriate evidence-informed tools, from diagnosis throughout the illness trajectory, to help the interdisciplinary care team identify people who could benefit from a palliative approach (e.g., psychosocial concerns, screening for distress).

How often do you use evidence-informed tools to help the interdisciplinary care team identify patients who could benefit from a palliative approach?

- Never
- Rarely
- Sometimes
- Often
- Always

Questions & Discussion

Project ECHO® Palliative Care - Canada BY Pallium Canada

Canadian Home Care Association

CHCA ECHO Hub

https://cdnhomecare.ca/palliative-care-echo-hub/

For taking a few moments to complete the feedback survey

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