

CHCA Project ECHO Integrated Seniors Care

All Teach, All Learn

Bridging the Knowledge Gap in
Home and Primary Health Care



Optimizing Comfort and Quality of Life: Integrated Palliative Approaches to Symptom Management in Complex Chronic Conditions

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Land Acknowledgement



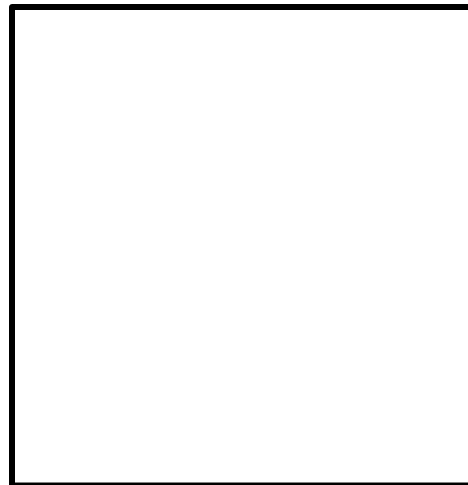
Artist Credit: Patrick Hunter

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.

Introductions



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Mallory Peters
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Optimizing Comfort and Quality of Life: Integrated Palliative Approach to Symptom Management in Complex Chronic Conditions

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Context - My Palliative Practice

- ▶ Group of 12 physicians providing palliative care in patient homes, hospice, and long-term care facilities
- ▶ 24/7 on-call coverage for patients with physician as 1st call
- ▶ Interdisciplinary → homecare and hospice coordinators, nurses, PSWs, PT, OT, grief counsellors, volunteers, family physicians
- ▶ Cancer and non-cancer diagnoses in adults and children
 - ▶ Significant rise in referrals for end-stage dementia, CHF, COPD, renal failure, neurodegenerative illness (ALS, Parkinson's, progressive supranuclear palsy, corticobasilar degeneration)

Edmonton Symptom Assessment Scale (ESAS)

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness (Tiredness = lack of energy)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness (Drowsiness = feeling sleepy)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression (Depression = feeling sad)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety (Anxiety = feeling nervous)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing (Wellbeing = how you feel overall)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing

- intended to capture the patient's perspective on symptoms
- provides a profile of symptom severity at a point in time
- repeated assessments may help to track changes in symptom severity over time
- ***what is the impact of each symptom on patient's quality of life?***

OPQRSTUV Evaluations

Assessment using Acronym O, P, Q, R, S, T, U and V ^(1,2,3,4,5,6,7,8,9)

O Onset	When did it begin? How long does it last? How often does it occur?
P Provoking / Palliating	What brings it on? What makes it better? What makes it worse?
Q Quality	What does it feel like? Can you describe it?
R Region / Radiation	Where is it? Does it spread anywhere?
S Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right now? At best? At worst? On average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?
T Treatment	What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?
U Understanding / Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and / or your family?
V Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

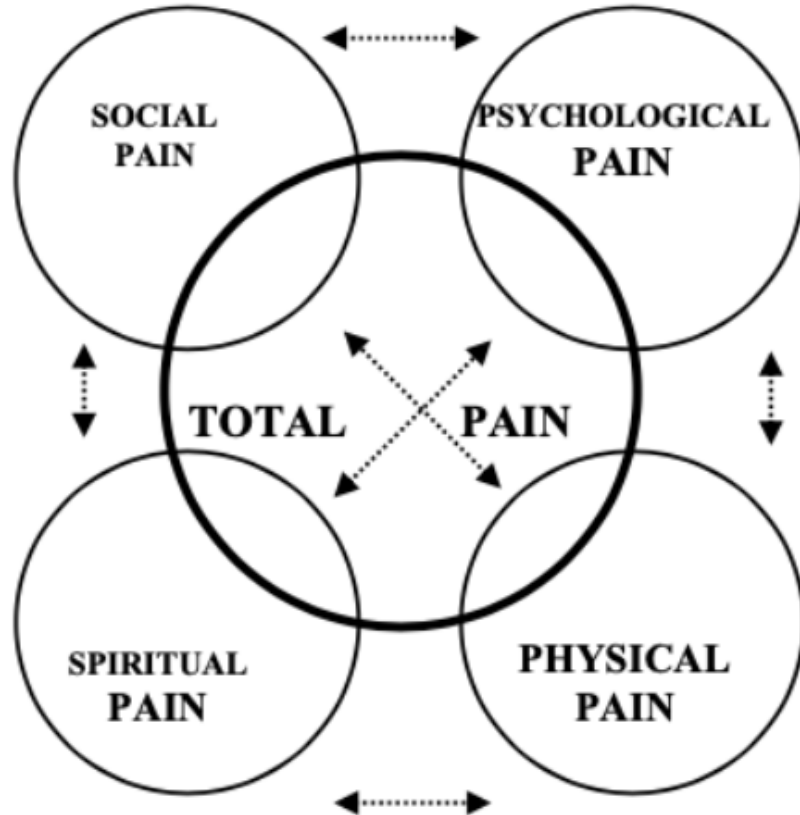
<https://www.albertahealthservices.ca/info/Pages/e14546.aspx>

- guides a consistent and comprehensive symptom assessment in palliative and end of life care

Palliative Performance Scale (PPS)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity <i>with</i> Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Total Pain



- interplay of physical, psychological, social and spiritual distress. Each domain can amplify the others
- clinicians cannot fully care for patients with life-limiting illnesses without assessing for all domains of total pain
- since no one person or discipline can manage total pain, interdisciplinary teams (IDTs) are vital to address *total pain*
- <https://www.mypcnow.org/fast-fact/total-pain/?print=print>

Total PainComponent	Description	Manifestation	Example
Physical	Nociceptive, visceral, or neuropathic pain from known tissue injury (1)	Pain leads to impaired function and social isolation from fear of exacerbations away from home	Epigastric pain radiating to the back from unresectable pancreatic cancer
Psycho-logical	Anxiety, hopelessness, helplessness from medical uncertainty (15,18).	Adjustment reactions, despair.	Disengaging from clinical care plan, spending excessive time searching the web
Social	Fear of dependency on family; loss of role as provider to family (19);	Loss of dignity and sense of worth (13).	Family conflict as the patient declines recommended care and voices an urgency to return home.
Spiritual	Despair from inner realization that life is finite and without meaning (16)	Feelings of disconnection and abandonment by community/God.	Questioning the meaning of life and the dying process – “ <i>Why me?</i> ” (20)

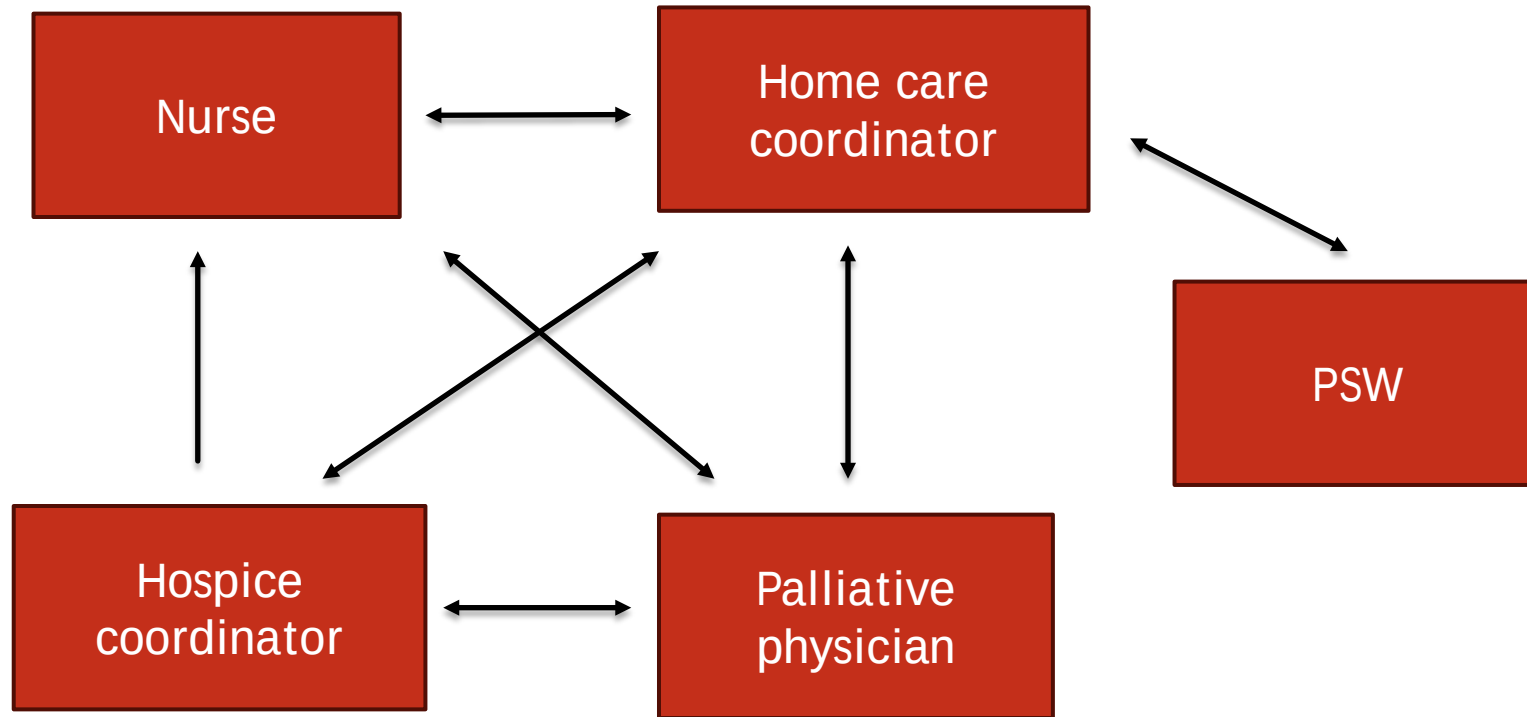
Interdisciplinary Team

► Clear role definitions

1. Physician - assess, diagnose, prescribe, goals of care conversations
2. Nurse - assess, monitor, teach, coordinate
3. Personal support worker - assess, monitor, support ADLs
4. Homecare coordinator - coordinate services and equipment
5. Hospice coordinator - psychosocial support, system navigation, coordinate hospice services (volunteers, wellness, art + music therapy, grief and bereavement)
6. Social worker - assess, coordinate social determinants of health

Interdisciplinary Team

- Clear communication pathways within the team:



Psychological Safety

- ▶ An environment where individuals feel supported to take risks, make mistakes, seek help, and voice their thoughts and opinions without fearing negative repercussions such as judgment or embarrassment.
- ▶ This concept promotes a climate of mutual respect and trust, facilitating open communication and teamwork.
- ▶ Is the #1 most important factor to ensure successful team function.

Helpful Resources

- ▶ Caregiver burnout <https://canadiancaregiving.org/resources/caregiver-resources/>
- ▶ Dignity Therapy (Dr. Harvey Chochinov) <https://www.dignityincare.ca/en/>
- ▶ End-of-life Planning <https://www.advancecareplanning.ca/>
- ▶ Symptom assessment tools <https://www.albertahealthservices.ca/info/Page14546.aspx>
- ▶ Canadian Virtual Hospice
https://www.virtualhospice.ca/en_US/Main%20Site%20Navigation/Home.aspx

Meet Carole Carter*

Background and Living Situation

- 79-year-old woman; retired postal worker living in Charlottetown, PEI with her husband David, who is her primary caregiver.
- A son Michael helps most days, while daughter Sarah participates by phone.
- Declining health and independence, breathlessness, fatigue and pain are limiting daily activities and increasing her isolation.
- Carole's goals of care: comfort at home, meaningful family time and her granddaughter's wedding in six weeks.

Medical History and Functional Status

- Advanced COPD, heart failure, CKD and osteoarthritis.
- Two ED visits in three months for breathlessness/fluid overload; recent medication changes.
- Continuous oxygen at 2 L/min plus inhalers; SpO₂ 91–93% at rest, 86–88% with exertion.
- Walks 10–15 m with a walker; breathing and SpO₂ recover after 3–5 minutes' seated rest.
- Needs help with personal care, meals, housekeeping and medication organization; no recent PT/OT reassessment.
- Nursing twice weekly; personal care three mornings weekly. Care team includes family physician, respirologist, home care and pharmacist.

* This case study is based on real-world events and experiences but is a composite scenario, with names and identifying details changed to protect privacy and confidentiality.

Meet Carole Carter^{*}

Current Concerns

- Symptoms: Breathlessness 4–8/10, fatigue 8/10 and pain 3–6/10, with limited relief; poor sleep/intake, 4 kg weight loss and constipation.
- Distress: Anxiety 7/10, fears of isolation/hospitalization, feeling burdensome and spiritual concerns; “not worth the effort” remains unexplored.
- Care gaps: No clear symptom/escalation plan, comprehensive pain reassessment or shared holistic care plan.

Caregiver and Team Perspective

- David is committed to Carole’s goals of care, but exhausted by overnight monitoring and unsure whom to call when symptoms worsen.
- Michael worries that his father is overwhelmed and wants clear guidance and one plan for the family to follow.
- Sarah views hospital as the safest response to worsening breathlessness, while Carole wants to avoid hospital when symptoms can be managed safely at home. This is creating family tension.

Challenge

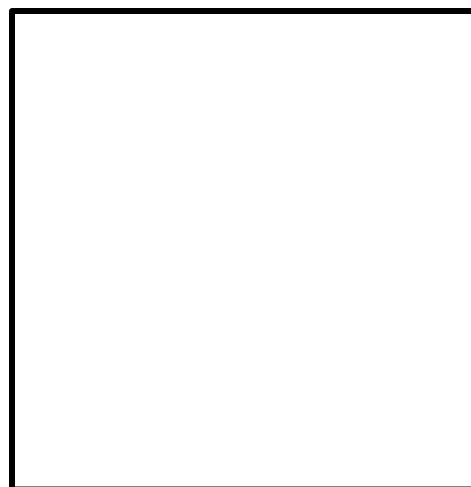
How can the interdisciplinary team address Carole's total pain, align symptom management with her goals for comfort and quality of life, and give her family clear guidance as her condition changes?

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Q&A Discussion



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Upcoming TeleECHO Clinics

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cdnhomecare.ca/chca-project-echo-integrated-seniors-care

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