



Flexing Your Core: the Palliative Workout ECHO

Optimizing Comfort & Quality of Life and Last Days & Hours

July 29, 2025

AGENDA ITEM	NOTES				
Introductions,	Session Facilitators: Sue Bartnik, RN and Tammy Dyson, MSW				
Opening reflection	Opening questions for participants to reflect on: 1) What do you think or feel is important in optimizing comfort and supporting last days and hours for the people you support? • Creating a culture of safety to bring forward concerns and ideas to promote quality of death • Open dialogue, inviting questions, empathy and compassion • Sometimes we need to unlearn because of our own assumptions • Approaching death is sacred space, memories can be vivid and very detailed of these moments • People receiving healthcare not often used to being asked what matters to them until closer to death • If the patient does not have anyone to be with them and you can, sit with them, play their favorite music, read to them 2) And for yourself? • What I think is important may not be the same as what may be important to the patient				
Session Key Points and discussion	 Optimizing Comfort: Steps of Care Observe and pay attention to what you are seeing, what's being said and not said Goals of care conversation – people need to be aware what their options are for comfort. How can we make the transition in your health journey as comfortable and stress free as we can? Listening and being present. Asking about religion/culture with this Assessment – wholistic approach listening with heart, eyes, ears, brain and mouth Interventions – all disciplines have different tools and perspectives to bring We may wrongly assume people near end-of-life want to have these conversations but some people, though their death is imminent, may not want to talk about it. We can gently explore this by asking, "If you were in your final days what would you want to do? https://www.bc-cpc.ca/publications/symptom-management-guidelines/ 				



Rallium Canada



Palliative Performance Scale & Psychosocial Support: Palliative Performance Scale PPSv2

- Tool for quickly describing a patient's current functional level. Provides a framework for measuring progressive decline over the course of illness.
- Supports anticipatory planning. Helps inform conversations with care team and pt & family
- Transitions on the scale are important. Focusing in on the change in roles the patient and family experience as things change. PPS of 60-50% is where we generally see the change in roles:

PPS %	PPS – Victoria Hospice model*	Shift in focus	Possible responses	For Healthcare providers
60-50	Shift to Palliative Care Struggling to engage in activities, occasional or considerable assistance required	From managing disease, to managing one's life	Patient: Shrinking world, reviewing one's life. Loved ones: Changing roles, feeling abandoned, fears regarding ability to manage	Explore emotions and support difficult conversations; family differences
40-30	Illness Predominates Unable to do most activities, either mostly or always in bed	Focus on physical care, preparing for increased care	Patient: Feeling worn out, thinking of death, loss of control Loved ones: Reality of death approaching, strengths and struggles intensify, assume decision making	Facilitate discussions about sources of strength, stress, and support
20-10	As Death Approaches Totally bedbound, Total Care	Connection and expectation	Patient: Little or no communication with others Loved ones: Sitting vigil, relief/sadness and/or anger.	Provide people with simple information about what they may see and hear and do when the person is dying.
0	Time of Death	Nature of death	Questions and concerns about death, expected yet still shocking, may have rituals/beliefs that comfort (or not)	Normalize & support the range & depth of people's reactions and needs

- Calls inquiring about MAiD generally occur around PPS of 30%
- At each level/score it's important to share options and ask questions to engage patient and family
- <u>Resource</u> book called *Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying* (1992) by Maggie Callanan and Patricia Kelley (hospice nurses)

Last Days & Hours

- Refer again to https://www.bc-cpc.ca/publications/symptom-management-guidelines/
- We want to normalize symptoms, optimize comfort
- Most health authorities have patient-oriented info on what happens to the body at end-of-life
- Assess with all your senses





- Body changes we see: breathing shifts (educate family this is normal but may sound alarming, they are not in distress or discomfort), skin changes that are normal
- Eating/drinking a common conversation to have with family. They may want to feed to connect with family member or feel they need to keep them alive. Gently educate that the body doesn't need much or any in last few days. You can play music, massage them, talk to them to connect.
- Share knowledge about what is happening and what to expect in a gentle and honest way
- Hearing is one of the last senses to go at end of life. Ensure what you as care provider preserves their dignity to the end.

<u>Last Days & Hours – how do you provide comfort?</u>

- Can be about reorienting loved ones on how they can connect: encourage they continue to talk to their loved one
- Comfort will look different for each person.
- As healthcare providers we may need to reframe the situation. Loved ones may feel it's a time to get better. We're not giving up on the patient, we're providing excellent comfort care and dignity.
- Educating families early on is extremely helpful. There are no "surprises" or shocking moments. People may forget some things of course. Giving written materials for them to review as needed is helpful as well.
- Barbara Karnes has booklets on End of Life Care https://bkbooks.com/collections/booklets

Case Study discussion:

Mrs. Lin is a 68 year-old woman with metastatic lung cancer. Her goal is to stay at home and enjoy time with her family. So far, she has been able to dress and do the household cooking herself. Over the past few weeks, she has noticed that she is getting tired more easily. When climbing stairs to her bedroom, she has to pause several times. She has stopped showering and does a sponge bath instead. Her family is worried she seems "down" and doesn't engage like she used to. She has also complained of nausea and is not eating as much and has lost weight. The family is encouraging her to eat and be active.

- 1) What questions would you want to ask Mrs. Lin and her family?
 - What matters to her most at the moment? We might assume based of things she's previously said (ie. nausea) but we need to check in to see what really matters to her at the time
 - What support from family are you finding most helpful now? this question gives Mrs Lin space to share what is or isn't helpful
 - What is the best way we may help you and your family to cope with your smaller appetite?
 - Is there home support we could explore?





- What does this mean to you (what's happening to you right now)?
- What do you do for self-care?
- 2) What could you suggest to help with her fatigue?
 - Encourage rest periods throughout the day.
 - Refer to: BCCPC Symptom Mgmt Guidelines Fatigue
 - OT any different home set ups that we could do? Equipment to support at home. Perhaps a hospital bed in home would be helpful
 - Speak with a dietician about what best she can eat that is high density, nutrient rich
- 3) How could you support her individual and family's wellness?
 - If your health changes, where would you like to be? Does she want to be home at the end? We will try to support you at home until the end, but what if we can't? Have discussion about possible needs as they relate to changes and as a team (including family), what can each contribute to care
 - Maybe needs help to address nausea as it's something she has brought up
 - Optimize her dignity and choice as these changes in her health occur
- 4) Are there other team members you would like to bring into Mrs. Lin's care?
 - Depends on geographic location and rural vs urban with what would be available
 - Physician/NP re medication, support optimizing quality of life, managing symptoms, serious illness conversations, convos around CPR, death at home MOST
 - Nurses to teach, educate, support comfort care
 - Pharmacy, OT, PT, Palliative care coordinator, home care
 - Dieticians can help with eating strategies
 - Ask about any community groups she's involved in perhaps a spiritual leader or elder
 - What supports family may need community orgs
 - Volunteer to provide peer support, navigation of other supports
 - Ideal when interdisciplinary teams can visit together so pt/family not repeating themselves so much
- 5) What do you anticipate Mrs. Lin and her family needing to prepare for her last days?
 - Asking what options they know about for end of life. While doing assessment making sure they have awareness of
 resources available to them. MAiD access and information processes looks a bit different in each province





	Palliative care is anticipating so as much we can offer info and explore all options with pt/family they have the above.			
	to make decisions when time is nearing the end			
Resources	 Palliative Performance Scale PPSv2 – Victoria Hospice Advance Care Planning: https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning Symptom Management Guidelines: https://www.bc-cpc.ca/symptom-management-guidelines/ Final Days: https://www.interiorhealth.ca/health-and-wellness/palliative-and-end-of-life-care/the-final-days Preparing for the Journey: https://www.interiorhealth.ca/health-and-wellness/palliative-and-end-of-life-care/the-final-days Planning for a Home Death: https://www.interiorhealth.ca/health-and-wellness/palliative-and-end-of-life-care/the-final-days Preparing for the Journey-Booklet.pdf Planning for a Home Death: <a a="" health-and-wellness="" href="https://www.interiorhealth.ca/health-and-wellness/palliative-and-end-of-life-care/the-final-days Preparing for the Journey-Booklet.pdf Planning for a Home Death: <a href=" https:="" palliative-and-end-of-life-care="" the-final-days<="" www.interiorhealth.ca=""> Preparing for the Journey-Booklet.pdf Planning for a Home Death: <a a="" health-and-wellness="" href="https://www.interiorhealth.ca/health-and-wellness/palliative-and-end-of-life-care/the-final-days Preparing for the Journey-Booklet.pdf Planning for a Home Death: <a href=" https:="" palliative-and-end-of-life-care="" the-final-days<="" www.interiorhealth.ca=""> Planning for a			
Next session info	Next Flexing Your Core ECHO Session: Grief Loss & Bereavement Aug 5 th 12pm-1pm PDT. Register here! You may be interested in an upcoming session part of our Grief & Bereavement Literacy series: Experiencing Grief as a Health Care Provider Aug 28 th 12pm-1pm PDT. Register here!			
	Other upcoming ECHO sessions listed <u>here</u>			