

Palliative Perspectives

NEWSLETTER OCTOBER 2021

Palliative and End of Life Care Program

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“Who I am is as important and instrumental as what I do. It is when I am highly skilled and deeply attuned that I do my best work. It is when I integrate my practice and my presence that I truly practice the art of Hospice Palliative Care nursing. I bring to the patient and family more than I often realize. I know that:

- If I bring confidence – they are less afraid.
- If I bring compassion – they are comforted.
- If I bring sensitivity – they know I care for THEM.
- If I bring creativity – they know possibilities.
- If I bring a centered and peace-filled presence – they touch the spiritual in time and space.
- If I bring information – they feel respected and involved.” **By Janis Brown RN MS MDiv**

This nurse’s reflection had a big impact on me. I feel it applies to all the members of the team, not just nursing. ***“I bring to the patient and family more than I often realize.”***

When I was a younger nurse, I worked in CHS and cared for a woman in her 40’s with 4 kids. This woman persisted in carrying out her mother duties, even organizing birthday parties for her children as she approached the end of her life. All the while, she had severe pain due to advanced breast cancer that left her with a very painful wound and a great deal of edema. She fought so hard. And we fought with her to try to give her adequate pain relief so she could continue her role as mother without being too sedated. Late on a Saturday, I met the palliative care physician at the woman’s home because she was in excruciating pain. When we walked in the door, the woman and her husband were sitting on the couch and the husband was holding the woman’s head up. You see, her wound and her edema made it that she could not hold her head straight without pain. And if she let it hang forward, it impeded her breathing... if she let it hang back, it pulled on her painful wound. The physician started to assess her pain and I looked to see what I could do that would be the most helpful. I could see the fatigue on the husband’s face and so I took his place on the couch and held the woman’s head up. I held her head up. I was inches from her face and felt like an extension of her body and her experience. It was nothing and everything at the same time. I was deeply struck by it. It did not require me to know the symptom assessment guidelines or how to titrate opioids. It called for me to just allow myself to step in close. I supported her in that way for the rest of the visit, until she went to lie down. The next day she died suddenly from a pulmonary embolism related to her wound. I was so honoured to have had the opportunity to support her the night before. ***You already have what you need to move into the space where you are most helpful.***

Carolyn Wilkinson, Manager Palliative & End of Life Care Program



DELIRIUM IN PALLIATIVE CARE



Ms. X is a 79-year-old woman with metastatic lung cancer to liver and bone, living at home supported by her husband. She has been getting progressively weaker, is spending most days resting, getting up with effort. Pain has been escalating, and she has been started on scheduled morphine to aid in symptom management. Her last bowel movement was one week ago, and her husband calls to report that in the past 24 hours she has been disoriented, shifting restlessly in her bed, tugging at her blankets, and seems distressed.

Delirium is defined as an acute, fluctuant change in cognition, characterized by disorganized thinking, inattention, and an altered level of consciousness. It is often the result of an underlying medical abnormality, or can be caused by medication. Although it may be reversible if the underlying cause is identified and treated, delirium in patients facing a life-limiting illness is often the result of multiple factors, is not always reversible, and is a poor prognostic indicator. Delirium is very common when patients are close to the natural end of their lives, and can cause significant distress to the patient, family, and caregivers. It is often under-recognized by clinicians, however early identification and treatment can reduce suffering.

Delirium is classified as hyperactive or hypoactive. Hyperactive is generally easier to identify, characterized by hallucinations, agitation, restlessness, whereas hypoactive delirium is often more subtle, with symptoms such as apathy, disorientation, or slow speech.

Assessment methods include a mental status examination and may include use of the Confusion Assessment Method (CAM) linked below. A prompt assessment should be undertaken to identify if there any reversible or treatable potential underlying medical causes. This includes a focused history and examination, and may include diagnostics if indicated and within goals of care. Symptom-directed care of distressing delirium is also an important part of management. Optimize pain or physical discomfort, bowels, environment. Judicious use of low dose antipsychotic medication such as haloperidol is often indicated in distressing delirium, and benzodiazepines should generally be avoided. Consequential sedation is sometimes required to manage severe distress related to delirium, in consultation with a palliative care specialist.

The nurse attends Ms. X and conducts a head-to-toe assessment. A suppository is provided to help evacuate the bowels and she is started on a regular laxative by mouth. Her opioid is rotated to hydromorphone at a slightly lower dose, and gentle oral hydration is recommended. She requires two doses of haloperidol 0.5 mg for agitation and distress overnight, however within 24 hours has become more oriented and comfortable. Anticipatory guidance was provided to family on what symptoms to look for and an in-person follow-up was arranged for later in the week.

For further information click on the links provided:

[Delirium - Symptom Management Guidelines – BC Centre for Palliative Care](#)

[Confusion Assessment Method \(CAM\)](#)

Submitted by: Dr. Sabrina Gustafson-Vickers, MC, CCFP(PC) Geo 4



[Salt Spring Island Hospice Society](#) may serve a small community, but their programs are diverse and meet the needs of these island folks. The COVID pandemic has of course curtailed some services, just as it has in larger centers, but during normal times this organization that is completely volunteer driven, provides much needed comfort care and support. These programs include bed-side vigils, one-to-one palliative and bereavement support, elder care facility visiting, a listening circle, ACP education, four education sessions annually for the public on various topics with guest speakers and panel discussion, and volunteer training in the spring and fall.

Recently we had a request for a vigil for one of the residents at a local care facility. The volunteer mistakenly arrived mid-afternoon instead of in the evening. Rather than leave, they decided to sit with the person as the nursing staff were very busy. It just so happened that the volunteer was present when the person slipped away peacefully. “You are not alone” is a credo these volunteers adhere to and they make a very positive difference to individuals and families facing end of life issues including dying, caregiving and bereavement. *For more information on hospice services in your community please visit [Vancouver Island Federation of Hospices](#)*



You Are Not Alone



Salt Spring Hospice Volunteer Trainers

Submitted by: Wendy Pratt, Coordinator V.I. Federation of Hospices

QUESTION OF THE MONTH



I have just given my client their regular opioid but they are having pain. Should I wait to see if it is effective before I give a Breakthrough (BT) dose?

A regular opioid regime provides a steady state of medication in the system. Pain may still breakthrough for various reasons. Breakthrough pain can happen at anytime, so a BT dose can be given at any time regardless of the timing of the regular dose. So YES! You can give a BT dose at the same time as a regular scheduled opioid dose if needed. Remember to assess the pain though: Same pain, or new? Severity? What helps? What brings it on? What does he/she think is going on?

NOTE: Palliative clients on regular opioids should have a BT dose ordered q1h prn – usually 10% of the total daily opioid dose. If 4 or more BT doses are required in 24 hours for a couple days or more, an increase in the regular daily dose may be required.

For more information: [Pain – Symptom Management Guideline](#) BC Centre for Palliative Care

Submitted by: Necia Kaechele RN MN CHPCN(c) Palliative Care Coordinator Comox Valley

DYING AT HOME IN A REMOTE COMMUNITY



In a place with no home care nurses, no physicians, no pharmacy, and a long rough drive, or even boat journey from the nearest hospital, supporting a dying person can be difficult. More difficult than usual.

All the services that are often wrapped around a person at end-of-life – equipment (such as a hospital bed or commode), Community Health Workers (for personal care or medication administration), and nursing or physician home visits (to manage symptoms and guide folks through their losses), may manifest in unusual ways. Some assessments can be done through virtual technologies, and with teaching, families or friends can give injectable medications. In one instance, a community purchased a hospital bed frame, to be kept in a central location, and shared as needed. A loaned mattress was then sent by boat, this effort coordinated by multiple paid and unpaid helpers.

Planning is key, and flexibility essential. The larger system of health care delivery does not always have an answer to a sketchy power supply, or the logistics of getting a hospital bed up 20 steps from a floating dock.

But for those people who have chosen to live in the wilder corners, illness and death still come. And this can mean intensive physical, emotional and psychological support from those caring for the dying person. Sometimes, if there are family or friends willing to do the hard work, it is possible to have a planned home death in a remote community. And, as with most “good deaths” this is more likely with early, frequent, and clear communication among all members of the care team – with the dying person at the centre.

Submitted by: Jessica Blackburn RN BSN Palliative Care Coordinator Port Alberni/West Coast

Empowering Patients and Their Families

“An illness experience can be profoundly impacted by a number of different factors. In order to help you prepare for a better experience we encourage you to be **In The Know**. Balance positivity and planning. You can only plan if you know what to plan for. Hope matches what you are planning for. Listen to these podcasts by Dr. Hsien Seow and Dr. Samantha Winemaker talking about the 7 keys that can make a difference between being **In the Dark** and an **In The Know** experience. In our experience, being proactive and doing some planning can change the experience for the better.” - quote from [The Waiting Room Revolution](#). (click on the link to subscribe to the podcast and receive updates on new episodes and events – open in Chrome)

Episode 1: [The Origin of the Revolution](#) (20 mins)
(open in Chrome)

Unlocking the keys to a better illness experience



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HOSTED BY DR. SAMANTHA
WINEMAKER AND DR. HSIEN SEOW



STAFF SPOTLIGHT!

Jacinta Slobodan MSW, RSW
Coordinator Advance Care Planning & MOST

What is your role within the palliative care team?

My position sits in the palliative care team, but my role is regional and it really touches all areas of care- primary care, acute care, long term care, community care because advanced care planning isn't just for end of life. It certainly helps provide good end of life care, it helps us to know what people want and don't want but really we should know all about that where ever we are providing care.

What does ACP mean?

Advance Care Planning is understanding a person's values, goals and preferences for their care and making sure that the care we are providing is aligned with that. In healthcare we can get really focused on paperwork such as who is the substitute decision maker. Those are important pieces of information but they are not the only part. When you think of advance care planning, appointing a substitute decision maker is a choice in that process but really it is about thinking about who you are, what do you value, what gives you quality of life? If you couldn't speak for yourself what would you want your care team and the people who would speak for you to know? Are there any cultural, religious or spiritual considerations to take into account? Do you have any particular goals you are trying to reach, like making it to a grandchild's birth or taking a special trip? I think we need to stop thinking of advance care planning as paper work. We need to think about it as who is this person in front of me? What do they value and how can I provide care that is in line with their wishes?

What drew you to this type of work and what is your favorite aspect of it?

As a social worker I have always really been invested in patient autonomy, making sure the patient's voice is heard. I have seen both the benefits of having ACP conversations and then I have seen the difficulty that arises when we don't have those conversations. That is what motivates me and I truly believe that every adult should have a voice and a say in their care. This really aligns with both my social work values of patient autonomy, and personal value around people being involved in their own care, and having a say in what happens to them. I think all of us want that!

One of the favourite parts of my job is when I get to interact with other people throughout the Health Authority who are really enthusiastic about advance care planning. goals of care conversations and providing good quality care to people. When I have those conversations it's like realizing we have so many people within the Health Authority who value the people they are caring for. In their true heart that is what they want. They want to be caring in the truest sense of the word. For me having those conversations with people inspires me to keep going and doing the work.

What is something about you that we don't know?

I am pretty quiet and reserved. When I am at work I am in work mode. What might surprise people is that when I was 25, I went sky diving. It was a solo jump with a line that is attached to your pack and when you fall a certain distance your parachute opens. It was on my bucket list as a young adult to jump out of a plane someday and I did it and it was amazing! I have never felt more free in my life but once was enough especially now that I have kids. It's like hmm... maybe I shouldn't be jumping out of a plane!

Submitted by: Julie Horwood RN BSN CHPCN(c) Palliative Care Coordinator Cowichan

Conversations About Eye Donation

Gift of Sight



One of the many things that I value about working in palliative care is the opportunity to have deep conversations with patients and families. I love asking about joys, regrets, meaning and love. Depending on the readiness of the patient or family, I also explore the practical, though delicate, issues of wills and funeral plans. I welcome speaking the truth at a time when, perhaps, honest information is being kept at the periphery. Working in palliative care has taught me to be brave and curious and gentle in my conversations. I value the role modeling of a nurse I worked with at Victoria Hospice who was an advocate and champion for eye donation.

Here are some examples of phrases I have used to introduce the idea of eye donation:

“I have a big question to ask. I want you to know that there’s no right or wrong answer – this is about what’s right for you and your family. Knowing your mom as you do, do you think she would want to donate her eyes?”

Sometimes there is a clear yes or no. If there is a clear no, I thank them for being honest and for knowing their mom so well.

If they’re thinking about it, I might add something like this: “From what you’ve told me about her, I get the sense that beauty was really important to her. I wonder if she would like the idea that this could give someone else the possibility to see. ”

If they say “yes” or are interested, I add more information, specific to my setting: “This happens on our unit. After your mom dies, her nurse will put drops in her eyes and an ice pack over her eyes. A trained nurse will come to the unit within 8 hours of death to do the procedure. After this is done, she will be transferred to the funeral home.”

For more information please visit: [The Eye Bank of BC](#) to learn how to [become an eye donor](#), print [Gift of Sight Pamphlets](#), and find [Professional Resources](#). Watch this 9 min. video [Request for Consent](#)

Submitted by: Michelle Dale MSW Palliative Care Unit (RJH)

Can You Feel The Pain In My Heart Too? – [Barbara Morningstar](#)



If we are lost, we are lost together ~ Blue Rodeo

When a person is facing a life limiting illness, they rely on their community. Their people: family, friends, primary practitioner, health care team, any one that steps into this circle of care. These people can have the opportunity to have the most profoundly rewarding, yet at times overwhelming, personal experiences of life.

While caring for someone at end of life can be a struggle, it is important to know that no one is doing it wrong. It is an act of love, which often looks different for each individual.

As a caregiver or health professional, it is recommended that you reach out to others and allow them to help. Friends, family & colleagues often don't know how to help, so it works to be directive. When someone asks "what can I do to help? Prepare a list of choices and answer "I really need ...fill in the blank". This avoids miscommunication of needs and isolation. Put your needs on the list too. You require regular breaks, which is part of self care.

Some other important self care considerations especially if you are struggling:

- Get enough sleep
- Eat nutritious foods
- Read fiction or non fiction about people who are going through similar or more difficult challenges to provide a little perspective
- Enjoy the sunshine or a walk in the outdoors which can provide some opportunity for reflection in order to process what you are witnessing
- Get a hug
- Talk to caring friends, persons who can lighten your burden
- Write in a journal or draw, doodle
- Listen to music, podcasts, or audio books while doing your chores

We have all endured some very difficult times this year but while caring for others we must also maintain steps to care for ourselves and build up personal resilience.

Submitted by: Robyn Dunstan RN BSN CON(c) CHPCN(c) Palliative Care Coordinator Oceanside & Julie Horwood RN BSN CHPCN(c) Palliative Care Coordinator Cowichan

A palliative approach to care improves quality of life for persons living with a life-limiting illness. Our goal is to inspire and support staff across all health care settings to be able to embed this philosophy of care into their everyday practice.

If you have feedback for us or an article you would like to submit please contact us at:

PalliativeNewsletter@islandhealth.ca

Archived editions of Palliative Perspectives Newsletters can be found on the PEOL site under

[Learning Resources](#)

[Palliative Care Services and Teams Across Island Health](#)



As we head into Thanksgiving, I am reminded of all the people, experiences and “things” I am grateful for. Music is one of them. As always, we like to leave you with a song, one that I hope reminds us to live our best life and not take anything for granted. In Tim McGraw’s words.....[Live Like You Were Dying](#). Sit back, close your eyes and take 4 mins. to reflect. Thank you for the care you provide. Remember Carolyn’s words at the beginning, *You already have what you need to move into the space where you are most helpful.*