

Introducing Early Palliative Care: Tips for Healthcare Professionals

This document has been created to support the clinical practice guideline: "Integrating an Early Palliative Approach into Advanced Cancer Guideline"





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DISCLAIMER: The following are only shown as examples of how palliative care specialists introduce palliative care to patients/caregivers. These have been provided for clinicians who are looking for wording suggestions. Note though that when and how to introduce it will still ultimately depend on the individual patient context, familiarity of the patient by the clinician as well as experience of the clinician in discussing palliative care. It's expected that as clinicians use this more, they will develop their own words and phrases that fit their personal communication style, rather than using these tips verbatim.

MOMENTS TO INTRODUCE PALLIATIVE CARE

Introducing Palliative Treatments: Chemotherapy, Radiation Therapy, and Primary Palliative Care

When describing palliative therapy (e.g. chemotherapy) explain there are other palliative therapies that you do (primary palliative care):

"In addition to the therapy that is trying to help you live as long as you can, I'm also here to help you live as well as you can."

Name this as palliative care...

"We call this palliative or supportive care, and it is a part of your cancer care."

"I've already been doing some elements of palliative care (such as pain medicine, supportive services like psychosocial oncology, and this chemotherapy which is to help your quality of life)."

"To support you in coping with cancer, I've already been implementing a palliative approach to care. This palliative chemo has been to help you with your quality of life."

"One such source of support, which I recommend people use at the same time as receiving chemotherapy/cancer treatment, is from your Palliative Care Team."

"Patients who have received both chemotherapy and palliative care together have found it beneficial. In fact, some research suggests that introducing palliative care early, in combination with chemotherapy, allows people to not only to live better (which is the expected outcome), but also longer than with chemo alone."

"There are other things we do beyond palliative chemo; we look after you as a person."

Shared Care Letter

When providing the shared care letter explain that the Family Physician and Medical Oncologist are sharing the care with others, including Palliative Care:

Working as a team...

"It will be important for us as we work together to make sure your family doctor is up to date with what is happening. So, I'm going to be sending him/her the same information as I've told you."

Naming shared care...

"We call this shared care."

Including the patient...

"We've also got this letter here about shared care. On this letter are some other teams and services that can be of support to you. Would you like me to go through those? [describe]"

Palliative care as part of shared care...

"I'd like to introduce you to a team who specialize in helping to manage symptoms. In our center we share this support with the Palliative Care Team."

Watch these short videos to see how one oncologist uses the shared care letter in practice:

- 1. Part 1: Introduction to Shared Care Letters (youtube.com)
- 2. Part 2: Discussing the shared care letter (youtube.com)
- 3. Part 3: Reflections on Shared Care Letters (youtube.com)
- 4. Part 4: Ordering the letters (youtube.com)

Referring to Specialist Palliative Care

Palliative Care as an added layer of support:

- "One such added source of support, which I recommend people use at the same time as receiving chemotherapy/cancer treatments, is from our Palliative Care Team."
- "I find people do better when they have an opportunity to plan for some of the practical and emotional challenges of living with cancer."
- "It's best to meet a Palliative Specialist early on and that's why I'd like to refer you today."
- "Knowing what help is available can help you feel more in control both now and if your illness doesn't go as you and I are hoping."

Introduce it through the patient's symptoms:

Make it clear to the patient and family what the referring clinician's role will be going forward...

- "When managing symptoms, I'd like to get some other people involved to help like, the Palliative Care Team. They help people live as long as they can, and as well as they can. They are the experts in managing pain and that's why I'm getting them involved today."
- "I know we have been working together on improving your [pain] over this [time frame], I feel it is not improving the best it could be. I'd like to bring in a team who specialize in helping to manage symptoms. In our center, we use the Palliative Care Team [describe palliative care]."
- "I'm going to get Palliative Care to come and see you. We work as a team, and they will assist with your care and in particular help manage any pain or other symptoms you may have related to your cancer and support you and your family on this journey."
- "Some people think palliative care is about all narcotics, but pain management is only one piece. Palliative care is really care for the whole person and the whole family."
- "We spend a lot of time discussing your physical symptoms (i.e. pain), but cancer is also an emotional and spiritual journey. And our physical experience and our emotional and spiritual experiences are interdependent. So, if we are going to ensure you are comfortable and able to achieve your goals, we need to attend to your emotional, social, and spiritual needs as well as your physical needs. That is what palliative care is about, a holistic approach to care."

Functional ability decline:

Talk about where they are and your worry...

"I think it's getting harder for you around the house, and I want to get you some extra support at home."

How Palliative Care can help...

"In Calgary we use the Palliative Home Care Team to provide that added layer of support at home."

Normalize and address concerns...

"A lot of people worry that means they are dying soon, but we use Palliative Home Care early because they can help you set your home up (i.e. equipment) to make it easier for you; and in collaboration with me, and your family doctor, they help to manage your symptoms so you can spend your energy on the things you want."

When prognosis is changing or there is uncertainty, or when there is significant change or change in clinical information that suggest prognosis is poorer than anticipated:

"Some people worry that accepting palliative care support means that they are giving up on (their hope to live, treatment, etc.). We don't think that. In fact, I find that when patients have that added layer from Palliative Care, they can focus on what matters to them."

"Some people worry that palliative care is just end of life care for people who are dying, but in fact Palliative Care Providers help people and their families manage their symptoms, cope with worries or day-to-day practical issues, and help people live life to the fullest throughout the course of a serious illness."

"You may think that Palliative Care is something to do with end of life, but we think of Palliative Care as an added layer of support for people and their families living with serious illness. When we talk about palliative care, we mean looking after people's symptoms, making sure their pain and symptoms are controlled, and maximizing quality of life."

"One of the things about living with cancer is that it is often an unpredictable and uncertain journey. Given the ways things have gone recently, your cancer appears to be in that unpredictable phase. Things have been changing this week which suggests that you'll continue to have unpredictable changes and complications related to your cancer. The Palliative Care Team will get to know you and help respond to those unanticipated changes [normalizing the uncertainness of it]."

"Some cancers are curable, and others are not – we like to get the Palliative Care Team involved in either situation when symptom management is likely to be challenging. However, even when the focus is on a cure, palliative care can be helpful with pain and symptom management."

"Reflecting on what has been happening (i.e. significant clinical change) it is important that your care team understand your goals as they look after you. Some people in this kind of situation choose to do whatever they can to prolong their life, while others choose to focus more on quality of life than on treatments that prolong their life. Have you thought about this question, about what is right for you?"

"While your cancer is not likely to be cured, we will still do things to help you. Palliative therapies are one of the ways we manage this illness, in addition to the therapy offered by the oncologist, or as a part of ongoing management."

"Some people describe having cancer (or a serious illness) as travelling through uncharted territory; you don't always know what is coming up around the next bend in the road. The Palliative Care Team can help you navigate the twists and turns. They help you to see where you are on the map, and help you get to where you want to go."

Linking the patient's own expressed concerns to how Palliative Care can be an added layer of support.

Align palliative care with identified issues and the patient's goals, elicit patient concerns...

"I'd like to talk to you about how things are going with your condition, and about some of the treatments that we're doing or might be available. It would be very helpful for us to know your understanding of how things are with your health, and to know what is important to you in your care...what your hopes and expectations are, and what you are concerned about. Can we talk about that now?"

Reframing and Hope

To reframe hope:

"We are not giving up on you, we think of it as adapting the treatment to what your body can take now."

"Some people worry that accepting Palliative Care support means that they are giving up on (their hope to live, treatment, etc.). We don't think that. In fact, I find that when patients have that added layer of palliative support, they can focus on what matters to them."

"You can still be committed to your goal of combating/fighting/etc., but accepting palliative care does not lessen that, nor does it take away from that goal."

"I understand that your goal is for your cancer to be cured, palliative care is about supporting you (your physical, psychosocial, and spiritual needs) in such a way that you're able to focus on the management of your cancer and achieving your goals as well as optimizing your quality of life as you work to those goals."

Family and Caregiver Support

Present it as a level of family support...

"I know that you worry about how your illness affects your loved ones, the Palliative Team is another layer of support for both you and your loved ones."

"Palliative Care Teams can talk to [name] and help support them."

"When Palliative Home Care comes to the house, they can talk to your family, see how they are doing, and provide them with other supports they may need as a caregiver."

Present Palliative Care to help identify needs...

"Palliative Care Specialists can help anticipate your needs as well as the needs of your family."

"I find people do better when they have an opportunity to plan for some of the practical and emotional challenges of living with cancer."

"The Football Analogy: We are all on the same team. The palliative team are more the short yardage guys to get the yard or two to the get the pain taken care of, easier breathing, less side effect combo of Meds, to get "the first down,". They are also team players, that can sometimes help with third opinion to enlighten you to the big picture, so when that first down is won, when your function improves enough to get home, eat a bit more...when you come back to see us [your oncologists or GI surgeon] again at follow up in a week or two (we are "the long bomb big play guys"), you can ask the right questions to pick the right play for you since you are still the Quarterback."

Marr, H., personal communication

WHAT IT MEANS TO HAVE A SERIOUS ILLNESS

Advanced Care Planning & Goals of Care

Visit <u>www.conversationsmatter.ca</u> for patient, family, and provider information on Advance Care Planning. The Health Professionals link includes forms, policy and procedures, and resources.

Serious Illness Program (SICP)

The Serious Illness Care Program (SICP), centered on the Serious Illness Conversation Guide, assists providers to:

- 1. Utilize an evidence-based, structured approach to Serious Illness Communication
- 2. Recognize ways that improving communication about serious illness goals and values improves the quality of care received by patients with advanced illness and their families.

The conversation guide helps providers have compassionate and effective conversations to learn patients' values, goals, and preferences. The guide provides suggested conversation framework with patient tested language. There is also a section with suggested ways to address emotions, including provider example language.

The **Serious Illness** course is accessible via Insite (AHS users). To register please go to https://mylearninglink.albertahealthservices.ca/elearning/bins/index.asp and follow the steps below.

- Log in with your AHS account username and password (same one as your email)
- Go to Courses & Registration, then:
- Search "Serious Illness"
- From the two course selections, choose the course session you would prefer.

To learn more visit: https://www.ariadnelabs.org/areas-of-work/serious-illness-care/

Note that this Group Learning program has been certified by the College of Family Physicians of Canada for up to 7.0 Mainpro+ credits and by the RCPSC for up to 3hrs of section 3 credits.

Nurses should consider applying to use a professional development (PD) day (UNA employees) to be paid while taking the course.

*Non-AHS EMPLOYEES email calgaryconversations.matter@ahs.ca

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