

Introducing Early Palliative Care – Tips for Health care professionals

This document has been created to support the clinical practice guideline “Integrating an Early Palliative Approach into Advanced Colorectal Cancer Care” (www.ahs.ca/GURU)

DISCLAIMER: *The following are only shown as examples of how palliative care specialists introduce palliative care to patients/caregivers. These have been provided in case clinicians 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.*

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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)	<p>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.</p> <p style="text-align: center;"><i>Name this as palliative care</i></p> <p>We call this palliative or supportive care, and it is a part of your cancer care.</p> <p>I've already been doing some elements of palliative care (such as... pain medicine, supportive services like psychosocial, this chemo which is to help your quality of life)</p> <ul style="list-style-type: none"> • To help you live with this serious illness, I've already been providing a palliative approach to care • This palliative chemo has been to help with your quality of life
	<p>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.</p> <p>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 not only to live better (which was the expected outcome) but also longer than with chemo alone.</p> <p>There are other things we do other than palliative chemo, we look after you as a person.</p>

Shared Care Letter	
When giving shared care letter explain that Family Physician and Medical Oncologist are sharing the care and others include PC	<p style="text-align: center;"><i>Working as a team</i></p> <p>It will be important for us as we work together is 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.</p> <p style="text-align: center;"><i>Naming shared care</i></p> <p>We call this shared care.</p> <p style="text-align: center;"><i>Including the patient</i></p> <p>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]</p>

	<p style="text-align: center;"><i>Palliative care as part of shared care</i></p> <p>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.</p>
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Referring to Specialist Palliative Care	
Palliative care as an added layer of support	<p>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.</p> <p>I find people do better when they have an opportunity to plan ahead for some of the practical and emotional challenges of living their cancer.</p> <p>It's best to meet a palliative specialist early on and that's why I'd like to refer you today.</p> <p>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.</p>
Introduce it through the patient's symptoms	<p><i>Make clear to the patient and family what the referring clinician's role will be going forward.</i></p> <p>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.</p> <p>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 [then describe palliative care].</p> <p>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.</p> <p>Some people think palliative care is about all narcotics... Pain management is only one piece. Palliative care is really care for the whole person and the whole family.</p> <p>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</p>

	<p>and spiritual needs as well as your physical needs. That is what PC is about, that holistic approach to care.</p>
<p>Functional ability decline</p>	<p style="text-align: center;"><i>Talk about where they are and your worry</i></p> <p>I think it's getting harder for you around the house and I want to get you some extra support at home.</p> <p style="text-align: center;"><i>How PC can help</i></p> <p>In Calgary we use the palliative homecare team to provide that added layer of support at home.</p> <p style="text-align: center;"><i>Normalize and address concerns</i></p> <p>A lot of people worry that means they are dying soon, but we use Palliative care home care early because it helps you setting your home (like equipment) up to make it easier for you and they help in collaboration with me and your family doctor manage your symptoms so you can spend your energy on the things you want.</p>
<p>When prognosis is changing or there is uncertainty.</p> <p>When there is significant change or change in clinical information that suggest prognosis is poorer than anticipated</p>	<p>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 patient have that added layer from palliative support they are able to focus on what matters to them.</p> <p>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 full throughout the course of a serious illness.</p> <p>You may think that PC is something to do with end of life, but we think of PC 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.</p> <p>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 seems to be in that unpredictable phrase. Things have been changing this week and suggest that you'll continue to have unpredictable changes and complications related to your cancer. The PC team will learn to know you and help respond to those unanticipated changes. <i>(Normalizing the uncertainty of it)</i></p> <p>Some cancers are hopefully curable and others aren't – we like to get the palliative care team involved in either situation, when symptom management is likely to be challenging. But even when cure is the intent, palliative care can be helpful with pain and symptom management.</p>

	<p>Reflecting on what has been happening (i.e. significant clinical change) it is important that your care team looking after you understand your goals. Some people in this kind of situation sometimes choose to do whatever they can to prolong their life, and 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?</p> <p>While your cancer is not likely to be cured, we will still do things to help you. Palliative therapies as one of the ways we manage this illness (in addition to the therapy offered by the oncologist) or as a part of ongoing management.</p> <p>Some people describe having cancer (or serious illness) as travelling through uncharted territory. You don't always know what is coming up around the next bend in the road. The PC 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.</p>
<p>Linking the patient's own expressed concerns to how palliative care can be an added layer of support.</p>	<p><i>Align PC with identified issues and the patient's goals, elicit patient concerns</i></p> <p>"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?"¹</p>

¹ Dr Mike Harlos: http://www.wrha.mb.ca/prog/palliative/files/Education_Presentation-Rounds.pdf

Reframing and hope	
To reframe hope	<p>We are not giving up on you, we think of it as adapting the treatment to what your body can take now.</p> <p>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 are able to focus on what matters to them.</p> <p>You can still be committed to you goal of combating/fighting/etc. but accepting palliative care does not lessen that, nor does it take away from that goal.</p> <p>I understand that your goal is for your cancer to be cured, PC 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.</p>

Family and Caregiver Support	
	<p style="text-align: center;"><i>Present it as a level of family support</i></p> <p>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.</p> <p>Palliative care teams can talk to [name] and help support them.</p> <p>When Palliative home care comes to the house they can talk to them and see how they are doing and other supports they may need as a caregiver.</p> <p style="text-align: center;"><i>Present PC to help identify needs</i></p> <p>Palliative Care Specialists can help the patient and family to anticipate their needs</p> <p>I find people do better when they have an opportunity to plan ahead for some of the practical and emotional challenges of living their cancer.</p>

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 again (i.e. your oncologists or GI surgeon) at follow up in a week of two (we are the "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).²

² Dr. Hubert Marr personal communication

What it means to have a serious illness

Advance Care Planning / Goals of Care

Visit www.conversationsmatter.ca for patient, family and provider information of Advance Care Planning. Health Professionals link includes forms, policy and procedures, and resources.

Serious Illness Care 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.

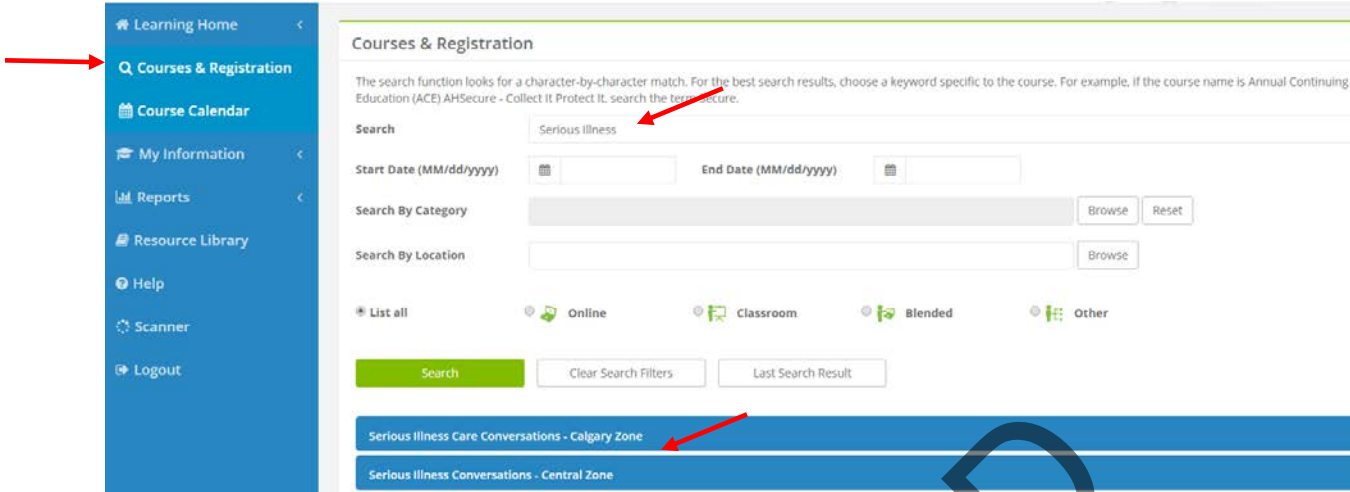
To learn more visit <https://www.ariadnelabs.org/areas-of-work/serious-illness-care/>

This course is accessible via Insite (AHS users). To register please go to:

<https://mylearninglink.albertahealthservices.ca/elearning/bins/index.asp>

Log in with your AHS account user name as password (same one as your email). Go to Courses & Registration then:

- Search "Serious Illness"
- Select by zone
- Once selected zone is open, choose the course session you prefer



The screenshot shows the 'Courses & Registration' page of an LMS. A red arrow points to the 'Courses & Registration' menu item in the left sidebar. Another red arrow points to the search input field containing 'Serious Illness'. A third red arrow points to the search results, which include 'Serious Illness Care Conversations - Calgary Zone' and 'Serious Illness Conversations - Central Zone'. The interface includes search filters for Start Date, End Date, Search By Category, and Search By Location, along with buttons for 'Search', 'Clear Search Filters', and 'Last Search Result'.

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.

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

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Vision: Improving quality of life for Albertans with advanced cancer.

