

BCHPCA FORUM | 2014

FRIDAY AFTERNOON SESSION MAY 9, 2014 2:30-3:30

Planning Conversations to inform and educate people about personal advance care planning and to encourage them in documenting their plans.

ROUNDTABLE ②

Nursing and Allied Health Perspectives

MODERATOR: SANDI ARMITAGE, BCHPCA Regional Director – North, BCHPCA; Retired Palliative Care Nurse Consultant, Northern Health

QUESTIONS

BCHPCA invites you to share your perspectives on the following questions. BCHPCA welcomes your personal experience in this discussion.

- the current nature of public conversations on death, dying, and planning for care and the paths to opening these conversations
- the current and potential role health care professionals have in engaging and educating the public about death and dying, and advance care planning
- the potential for your professional organizations to partner with hospice palliative care organizations to promote conversations on death, dying and advance care planning
- the potential for your professional organizations to partner with hospice palliative care organizations to advocate for hospice palliative care in British Columbia

SANDI ARMITAGE: Okay, so I think we will get started because we are running just a little wee bit late. So most of you I've actually seen in other conversations today. So we all know that today and tomorrow is about conversations, having conversations, starting conversations, planning conversations. So we'll continue the conversation here. So the perspective from, for this group is Nursing and Allied Health Professionals. And we're going to ask a series of questions with our experts that are sitting here at our table.

So I'd like to start with some introductions. So Julie on my far right here is the current President of the Association of Registered Nurses of BC and on the Canadian Nurses Association [board] as well. And a Clinical Nurse Specialist, Home Nursing Care and Home Plan for Fraser Health. Next to me is Kathy who is a former President of the BC Society of Occupational Therapists. So the allied health [professionals] are occupational therapists, pharmacists, respiratory techs, all those kinds of people. So Kathy is here representing occupational therapists. Miguel beside me here is representing pharmacists. So Miguel is a Vice-President and Director, British Columbia and the Yukon, Canadian Pharmacists Association. And do you do the Yukon?

MIGUEL LOPEZ-DEE: Yes, I've been there once. Yes we do represent, we have a few pharmacist members in the Yukon.

INVITED EXPERTS

- JULIE FRASER, President, Association of Registered Nurses of BC; BC Director, Canadian Nurses Association; Clinical Nurse Specialist, Home Care Program, Fraser Health
- TERRY WEBBER, Clinical Resource Nurse, Hospice Palliative Care Consult Team, Surrey Memorial Hospital
- MIGUEL LOPEZ-DEE, Vice President & Director, British Columbia and Yukon, Canadian Pharmacists Association
- KATHY SCALZO, Former President, BC Society of Occupational Therapists; President, K. Scalzo & Associates

SANDI ARMITAGE: Okay. And Terry at the far end there is a clinical nurse specialist with Fraser Health working in Langley, White Rock, Ladner in the palliative care. Also nursing. So as with the other conversations that you may have attended, it is being recorded here. So all of the conversations are being recorded so that they can be summarized and compiled at the end of all our sessions. The intent of this Forum is to help BC Hospice ... Oh I should tell you I'm Sandi Armitage and I'm one of the directors with BC Hospice Palliative Care Association. I represent the North, so Prince George and North and the Yukon, That's my territory. And I actually live in Dawson Creek.

So the Association [BCHPCA] is looking at their strategic plans and what direction they want to go. So part of our plan is to find out what other people are thinking and how they are working towards improving palliative care in British Columbia. And the first step towards this is just starting to talk about palliative care and to open the communications. So we've asked a variety of people how they've been involved in palliative care and opening up their discussions. So we're going to start today and ask that question of our experts. And so we would like their perspective on what they think the culture out there is and how the public is actually talking about palliative care from their professional perspective. So Julie, we'll start with you.

JULIE FRASER: Alright. Great. So I would say actually there's been a nice shift that I've seen in my career, which has been about sixteen years where there is some more openness actually to talk about end-of-life conversations. And I think a lot of that has got to do with the great work that various associations have done. And to open it up and not to label it for certain population groups or diagnoses, is that it's just part of our societal responsibilities. It's not something that is a selfish thing to do actually. It's something, it's a gift that we can give our families and the communities that might be supporting us by letting people know what we want at end of life.

SANDI ARMITAGE: We are open for questions. If anyone in the audience would like to ask a question, I'm going to ask you to pick up the mic. The mic is not for volume; it's [also] to record your questions. So maybe Kathy, you could speak about it from your perspective.

KATHY SCALZO: Sure. I've spent a lot of my career in cancer care and working with survivors and people at the end of life. And one of the things that I've found too is that more and more people have friends have embraced the role of what is it like to be a friend of someone who is living with a life-threatening illness and that's I think changed the social perspective too. It's the stigma of a lot of things people used to not talk about, they do talk about.

And I think the other thing that I'm finding that's changed in terms of my professional background is that as more and more the professions have embraced this is a specialty area for us to train our students in and do research in, that's also, I think, put more ambassadors out there into the world that people find out "Oh my neighbour, Sarah, is an OT [occupational therapist], PT [physiotherapist], social worker, pharmacist working in end-of-life care" and they're like "Oh really? There's a role for rehab in end of life?" So that conversation has gotten bigger just by our own students and clinicians being in that work. So I'm just throwing that out too.

SANDI ARMITAGE: I think that it has. It's become a specialty that been more widely accepted as something that health care professionals deal with, not just on the side of a desk.

KATHY SCALZO: No. It's a choice.

SANDI ARMITAGE: Okay. Miguel?

MIGUEL LOPEZ-DEE: Thank you. I'm at a bit of a loss for words here to be called an expert on the subject at hand. But certainly speaking from my personal experience, I'm a community pharmacist primarily. So I'll do in a local community. Meeting patients who express certain needs, obviously we in the pharmacy setting, the primary goal or intention when they come to visit with us would be for any medication related issues. But also there are some practices that I've been in where they, either there's a – I'm not sure what they call it, the palliative care box that's assembled for patients for end-of-life care – and there's interaction there with the nursing and that is provided for the patients, as well as relatives and family.

Pharmacists are perhaps one of the most accessible health care providers in the community. And I think what I hear from the discussions here and just looking at the materials, the key word is 'opportunity'. I think there's certainly an opportunity to explore with each of the health professions, their skills, their talents, their abilities – what we would be able to do in a more consistent and coherent manner. Speaking from my other hat as a member of the Canadian Pharmacists Association, our Association actually has supported and endorsed your national organization for the Canadian Hospice [Palliative Care] Association. And endorsed "The Way Forward" plan. And certainly we actually have a blog on the CHPCA website that points to "The Way Forward" and certainly the other good things that are being done to initiate that discussion.

SANDI ARMITAGE: Excellent. So if any of you are not familiar with the Canadian Hospice Palliative Care Association, their website and this resource "The Way Forward". It is something that you should take a moment and look up because it is the advancement of palliative care not just as strictly end-of-life care but through the lifetime over many diseases basically. Thank you. And Terry?

TERRY WEBBER: And first of all, Miguel, I don't feel like an expert too. I'm looking at the faces out here that I learn from so I think I got the tag because I agreed so that's why I'm here today. [laughter] Though but I do have to agree with Julie. I think it's really important to look on the broader spectrum about, we can be so critical of other things going on now and what the needs are but if we look on a broader spectrum, yes, things have improved. And one thing is we were, as I was listening to you, was I'm hearing more acceptance and actually a looking forward to going to hospice. And I hear that more from families and patients that have had loved ones going into hospice because they better understand what palliative care is all about. That is really isn't no care. It really is a different shift of care and it's wonderful care that they get because they all come away saying they're really cared about as human beings.

My perspective though is coming from a clinician and part of my role is I am doing end-of-life conversations all, every day, all day long. Whether it's for patients that are in the hospital – they get referrals – or going out to the community. It's about reaffirming what the goals of care are and what's important to people. That's really what it's all about. And from a medical perspective, where are they in that slippery slope, in their slide looking at where they are in their disease? So for me it's kind of putting two and two together. And helping them to go from here and get them through to here knowing that we can take them to that next place and it's going to be safe, that regardless of whether or not there are the kinds of interventions they are used to – active treatment that actually a shift of focus that is one, that they're still getting excellent care.

But of course I couldn't help think, because I'm doing this all day long, of some of the barriers. And I hope you don't mind me sharing what some of those are. And they still continue to be and that is no. 1, an individual belief. So often they're just not sure what the word "palliative" means. And so for them, again, the word "palliative" means no care at all. I can think of one example within the last week of a family bringing their loved one into the emergency department always knowing that in the past that they've had intervention. No matter how small or large, they'd receive it. But to come to the emergency department and then finding the doctor to say, "I'm sorry but we can't do anything for you. It's time to go home." I think that is probably, if there was a need identified right there, it's actually that we all need to learn that it may be a different kind of care but it's still

a form of care. Perhaps not for the emergency physician, they're not used to ... they're used to intubating and resuscitating and giving all kinds of medications. So, no, it's about learning that, it's about the language again, about helping people go from one level of treatment into the other.

And the other thing is around, I think there is an acceptance that their age has a great deal to do with it. I find that the younger population – it is harder for them and rightfully so. It's not normal for a 40 year old who's got a brand new baby that's just been born to be saying "I'm going to stop any chemo." And so we see people dying, they're actually still fighting in their dying days. Its, not ... I worked at Surrey Memorial [Hospital] and going to the oncology ward and looking at someone who is quite cachectic or very thin, jaundiced or yellow – completely yellow – and to be barely able to breathe. But no he was determined that he was going to still fight. I think there's some, that is part of their developmental task, is they're going to in that fighting mode. And if we get that, if we understand that, then we know how we need to support the family. So end-of-life discussions sometimes isn't, it's not right, it's just what can we do for the person in the moment, it's working with the families at that time.

The other thing is about lack of knowledge about what effects of treatment are. And I hope I'm not offending anybody. But I find that often and I'll speak as an independent rather than speaking, claiming I'm from any health authority or whatever, but I do have to wonder about, I know that there are wonderful chemotherapy drugs and treatments but you have to wonder at some point, when is it time to stop? We are not fully informing, giving informed decisions for family members about what the outcomes [are] for a certain medication. And statistics have found that we're not actually adding quality. We might be adding a little bit more time but we're not adding quality of time with the kinds of treatments that we're giving. Those were just some of the thoughts for me about barriers during end-of-life conversations.

SANDI ARMITAGE: So it's very interesting from a professional perspective here on how people in our societies are actually talking about death with Julie saying that over sixteen years, she feels that people are talking more about death and are more easily talking about death; Miguel said he works in a position where there is now an opportunity, so people are coming for drug boxes that are related to death, so you have an opportunity. And then Terry says we're maybe not necessarily taking about the right things about death at the right time. So the topic of conversations around death, dying and advance care planning is huge and it's so varied where everyone is in there. And as Kathy says, there's people who don't realize all the services you can get and that someone like an occupational therapist could help.

So the second part of the first question is: As a professional, how could you open that path to promote this communication in there? So we'll start the other way.

TERRY WEBBER: So no. 1 is trust because oftentimes trust has been really broken along the way. Mixed, you get different care providers who are saying one thing "You need to go to hospice"; another one is saying "You need to go for more chemotherapy or another treatment." So I think establishing trust and actually letting the person know that you're here for them. You're not representing a system that's trying to save dollars. They have to know that you really care about what it is that they're going through. So trust is the big one.

That's my ... and listen to the story. That's the other piece – not coming with an agenda but listening to the story. And seeing what other goals and how can you help to move along with end-of-life discussions and end-of-life discussions is really about what's important to them and whatever concerns them the most. We may think it's about symptom management. Maybe it's an itch on their foot that day that's really bothering them or a sore, an ache or a pain that just doesn't allow them to get out of bed that day. So we really have to look at what are their symptoms of concern, not ours.

SANDI ARMITAGE: So building trust. Miguel, what would you say would open the path to ... you mentioned opportunity.

MIGUEL LOPEZ-DEE: Yeah definitely. And I think as what Terry has mentioned, trust is a big component of that – opening the door for conversation. As pharmacists, as a pharmacist, I've seen or I've heard many interesting stories. People inherently when they come to the pharmacy have this trust. There have been surveys that have said that pharmacists are one of the most trusted health professions. And so they tell us funny, strange, interesting things all the time. And even before you feel you've known them that well as an individual. But certainly I guess that's one of the benefits of the profession.

But I go back to something that Kathy mentioned earlier about doing this early on in education, when we're training our health professionals. And training them in communication skills. Being able to pick up on certain cues, whether its body language, tone, things that they're saying to you when they're interacting with you. To be able to move forward from those little clues and then take the conversation to where the patient is being provided information. And so as a resource, it's our responsibility as pharmacists to be aware of what community resources are available to patients and perhaps point them in the right direction if it's something beyond our scope. And it all begins with that. Just those conversations and being able to communicate effectively and listening to our patients effectively.

SANDI ARMITAGE: I'm sure all of you notice how drugstores now have private little places to speak. So I can see why people go in to see the pharmacist.

MIGUEL LOPEZ-DEE: Absolutely.

COMMENTOR 1 [Lynn Wood, Oceanside Hospice Society]: In response, you were saying we can all ... locally where I work, pharmacists have asked us to provide some psychosocial training for their group because they're faced with very often people at their counter apply, coming for drugs, but then there's a breakdown or an emotional moment and they don't feel equipped to deal with the emotional piece of it. So they actually come to hospice to get some training in how to deal with that prognosis or whatever the issue might be, and then connect people to the services. I don't know if that's been your experience. Not everybody that's a pharmacist for instance might feel comfortable dealing with the psychosocial piece of it.

MIGUEL LOPEZ-DEE: There's certainly, when you look at the various practice settings and even the demographic of where a pharmacist might practice, you will find a great, there's a fair bit of variation. And as you say, there may be some pharmacists that don't get that type of an encounter on a regular basis, where you might find another pharmacy might. And so, when it comes to training as well, I was trained pre-2000 and I kind of feel old saying that [laughter] but a lot of the students, but we're all certainly when I look at the training that was done at pharmacy school at the time, it's very different from some of the things that they are teaching in the curriculum today. There's certainly been a greater focus on certain things, with interpersonal skills and coping mechanisms and even change management – behavioural skill sets. Many different things that have changed over the years. And I think that is an important component of education. So certainly pharmacists that have, didn't get that in their formal training, there's an opportunity for other health professions who are more skilled in that area to assist us.

SANDI ARMITAGE: That's a great partnership then that you have.

COMMENTOR 1 [Lynn Wood]: Yes actually it worked out. It was sort of fortuitous. We gave a tour of the hospice for all the local pharmacists and then they said, "Gee, we didn't know you did all that." And then, "Gee, I've had some really upsetting

circumstances right at the front counter and I feel ill-equipped to deal with that. So could we get some training from you.” And of course we were happy to provide it. And it really increased the connection also between the two services.

SANDI ARMITAGE: I forgot to give you the mic – sorry. Okay, so Kathy.

KATHY SCALZO: Well I would like to pick up on Terry’s point about lack of knowledge because certainly in the allied health profession, many people refer or call an OT or PT because they see the need for physical mobility or independence in a more traditional zone, like activities of daily living. But where we need to do more education is on the whole idea of fostering participation in the activities that made people who they were. That creative expression, the idea of combatting boredom, what symptoms are controlled. All of those are equally as important to people who are living while dying. And we need to as professionals educate our colleagues as well as clients and their families about “It’s not just ADL [activities of daily living] and safety and comfort in people’s beds”. It’s also about helping them engage in life as long as they want to. So I’m kind of blaming my profession in that we still need to do more education and build on the lack of knowledge about how to use us. And that said I think some of the forms would be a good commercial, when you’re out in the community, do good work. And I think there’s nothing like that, that helps spread ...

SANDI ARMITAGE: Yeah. So one of the things you mentioned is it’s more than ADLs. It’s getting them to live and they’re comfortable and they’re mobile to the best of their abilities, that makes them more likely to have a conversation, isn’t it? And if they’re still, if their symptoms are not managed, it’s hard. So that’s a good way to open up

KATHY SCALZO: Yes. It’s hard work. Well just an example. One client that I had, she was, you mentioned, she was 48 [years of age] and dying with melanoma and it was very important to her to make her high school son’s lunches. But energy management, most people make lunch for the next day at the end of the day or in the morning. Those were the two times of the day that didn’t work for her. So we had to set it up like it was a simple task but it would take her an hour to make the kid’s lunches. And she needed to learn how to do that at 3:00 in the afternoon after she’d had a rest, before they even came home. So it’s that kind of simple stuff. Someone identifies, “That’s a role I want to hold onto – being Mom until the very end.” And that was a tangible way she could still do it, as to make those sandwiches. So it’s a small but important milestone.

SANDI ARMITAGE: Julie?

JULIE FRASER: I think what I’ll add to what my colleagues have said is building on that piece about trust. So your question is about opening paths and I think that nurses have a privilege where they really do bear witness to clients when they’re, when they have a life-limiting illness. And that bearing of witness, you do establish trust and you have the opportunity to take time for that conversation. So just like any of us in our normal day, sometimes we get rushed and we get in our pace, so we have getting through our assessments and our interventions and it can speed up. And so it’s that importance when you see that timing, that you have that opportunity for that conversation, that you create that space. So building on your comment about the therapeutic communication techniques, the importance of silence and pausing. The allowing of the digestion of the information that they’ve just received. Bearing witness to that moment and just sitting in that, and that creating the time to then, sucking up that courage from their baby toe to actually act the question. Say “I really would like to begin to have the conversation with you about advance care planning.”

SANDI ARMITAGE: We live in a world where it’s hard to stop. Just stop. Stop, sit and listen.

So the second question is about the role of health care professionals in advancing conversations. So we've kind of covered it in here. So I'm just going to skip down to the third question which is how professionals or allied health care providers can partner with hospice societies to encourage people to have these conversations. So how could you in your role work with someone from a hospice society to encourage people to plan and work through their death and dying. So I'm going to start with you. I'm going to mix it up here.

MIGUEL LOPEZ-DEE: Sure. To me it really all begins with again, we mentioned this word a lot, "conversation". When you look at that, there was that Harris-Decima survey done recently where they had talked about the awareness of planning for end of life. And while a lot of people may have thought about it – I'm trying to think of the statistic here, if I remember this correctly – but only about 13% of people have actually done tangible end-of-life planning. The awareness is still there. It's gone up from something like two-thirds to about 75% of people that have discussed it or thought about it.

But to me, at least from maybe a personal experience, when, it's only when someone needs to use something in a system, use, avail of what resources are out there, you actually start to do the background work and the research and go into it. And so working together with hospice, when I look at pharmacists and pharmacies in general, it's really about beginning those conversations and trying to find out how do people access, how do they get to you: is it through referral, is it through friends, is it through the Internet, is it through a health authority? What are the touch points and how would, based on what we would say would be our part of the conversation would be, "Well, pharmacists offer these services. Pharmacists are able to do these things."

Certainly I was speaking earlier with Kathy before our session began and how exciting a time it is for pharmacy because our scope of practice is expanding. There's certain things that pharmacists weren't able to do five years ago that now they're able to do. And it's a bit of a patchwork if you look across Canada. There are certain things that can occur, that are occurring and pharmacists are able to do in one province but maybe not in another province. But trying to harmonize everything so that regardless of which part of the country you're in, you'd be able to receive those services. It's really being able to let the health care world, if that is such a term, know that we're able to offer these services and support other health care professions. But we also need to know how patients access the services, that how they access hospice, how do they fit in.

SANDI ARMITAGE: So it's a little bit of navigation ...

MIGUEL LOPEZ-DEE: So I think there's a lot to be done there in terms of, before we can create tangible plans, is to get a better understanding of where everyone is at and what everyone is able to offer.

SANDI ARMITAGE: And Julie. Do you have any ideas on partnering with hospice societies?

JULIE FRASER: Yeah. I think that the idea of coalitions are really important, particularly when we're talking about professional perspectives. To me that's just a portion of the picture. So my learning, because I do feel like I'm learning in my leadership role in the Nursing Associations, is that it's not just a primary nursing perspective. In some aspects we are going to be partnering with our colleagues in allied health and having an inter-professional perspective. But there's also that coalition with patient advocacy groups that's really important. And what strikes me when I talk about those two sides to the coin is that we ourselves are patients as well as health professionals.

So there's two parts of it. There's partnership around promoting the hospice palliative care week through our social media that we can do. We have a blog on our website where nurses actually share their personal stories and they can share actually

their successes and their real challenges from a mentorship perspective to other nurses. And that can be done again in partnership.

But the other piece is that when our nurses ourselves are needing support. And they, those roles switch. Whether it's themselves or that term you may have heard of "the double duty caregiver" whereas us as nurses or health professionals, indeed we have family members that we're caring for that there's a role for us to work together to support those individuals as well too.

KATHY SCALZO: I was just thinking. Education forums like these are wonderful but right now, certainly in Vancouver, real estate is the hot topic. You read about it all the time and I've notice more and more because it is a hot topic, the community centres are offering free lectures on "Do you really want to sell your house?" or whatever. And I thought "Ah-ha! What a wonderful forum for hospice!" We could partner and do "Have you thought about dying?" like in a forum that's public. Like people go for, all ages – painting, daycare, whatever ... fitness. Why don't we do that more often in a place where it's normalized?

SANDI ARMITAGE: I think that's a very good question. Why don't we do that? Question?

COMMENTOR 2 [Joyce Kuhn, Comox Valley Hospice Society]: Yes. Hi there. I'm a hospice volunteer in the Comox Valley. And I'm a registered nurse and I come from a critical care background. And after many years from that perspective, then shifting to a hospice perspective, is such gratifying work. It's very motivating for me. And I'm one of the facilitators for workshops on advance care planning through hospice. So when we're talking about how do the health professionals link up with hospice and what not, there's, we do need to find out about each other.

In our community, our little advance care planning committee is always trying to figure out how we can target other groups besides old people and sick people. We want to get to young people and mothers of young families and all kinds of different target groups. And we're there and we're offering workshops. The "My Voice" booklet – that yellow booklet that's fifty three pages and everybody look at and goes "Uhhh!" We have a two part workshop and the first part is about having the conversation and the second part is really going through that book page by page and making it not so intimidating. So just for people knowing that there's those kinds, that we're each – knowing about each other. And I think we're certainly not the only hospice organization carrying the ball forward with advance care planning and offering workshops. So we're just trying to

SANDI ARMITAGE: Actually, the Island [Vancouver Island] is very much further advanced. The societies on the Island for doing that very thing. You guys are ... it's very organized.

ROUNDTABLE EXPERTS: That's great. It's really great to hear.

COMMENTOR 2 [Joyce Kuhn]: It's snowballing and we're very excited about it but also just, it's amazing how many health care professionals have no idea that these workshops are available, including doctors' office nurses and doctors. Just hand people this booklet ["My Voice"] and say "You need to do this" and people go "Huh?" So then we're there to help guide people through exactly that process.

SANDI ARMITAGE: Perfect.

COMMENTOR 3 [Geri Arkell, Campbell River Hospice Society]: So I'll just take a second. I'm Geri. I'm from Campbell River. I'm doing the exact same thing she is in Campbell River. We're doing a session every month. We go through the nuts and bolts of it at one time and then we go invite people back if they have questions and answers before they fill in their paperwork. It's interesting though ... the docs do all this. They get stuff through the BCMA [BC Medical Association]. There is all kinds of education out there. So we just need to all get together to do this. I'm not sure how we're going to partner with pharmacy. I can go to my local pharmacies and say "Look I'm doing these classes." But really honestly I'm not sure how much time he's going to have in his day to say "Look, you need to do your advance care plan."

COMMENTOR 1 [Lynn Wood, Oceanside Hospice Society]: We had to do them after work. So we had an invitation to hospice. They came and we provided food. It was very pleasant and it was a good sociable interaction as well. And most of them in Parksville | Qualicum came to the meeting.

COMMENTOR 3 [Geri Arkell]: The pharmacists?

COMMENTOR 1 [Lynn Wood]: The pharmacists. I think it was really worthwhile. And we have a speakers bureau of volunteers who disseminate the advance care planning. But this is the Island again. We're kind of united in our approach.

SANDI ARMITAGE: And advanced.

COMMENTOR 4: If I may. My name is Stephen Roberts. I'm from Salt Spring Hospice and from Vancouver Hospice Society where on April 1st, we opened a new six bed stand-alone hospice on Granville Street. And my question is really for you professionals is, your perspective as professionals, I heard in an earlier session today that in some quarters, nursing used to think of palliative as the end of the road. It was going to the dark side as a professional. How do we attract nurses and how do we interest them in what we are doing? How do we attract pharmacists to be interested in the specific type of drug treatments that we're going to need in a hospice home sort of environment? And also the therapists? How do we interest them in and what's the perspective actually from your various fields on the hospice as a home, as the last place. We also have the operational services hospice, the outreach, but then we have the in-house, the home-based hospice systems or like we have just built. You've got a new dimension to that as well. And we're very eager of course to partner with professionals in the field with the specific needs of the people that are going to be spending their final days in our home.

SANDI ARMITAGE: So who would like to answer Stephen?

TERRY WEBBER: Well thanks Stephen. A couple of things come to mind. How do we attract nurses who want that kind of nursing? And I do think it takes a special kind of nurse. We actually have to find more ways to empower nurses to be the kind of caring people I think that often times go into their professions. So empowering them around their voice, around being able to have those conversations with their patients' families.

And I have to say that I've been a nurse for, I don't know, forty odd years and it only came to me maybe within the last decade, that caring is actually a component of nursing, that is, it is a gold standard. And I just thought it was something that I just did because it felt good for me and I knew it felt good for the patient. But it actually is one of the basic foundations. And if we can just empower nurses that it is, like the physician [Dr. Trevor Janz] spoke in the last session, it is one of the greatest gifts that we can offer people, that connectedness.

And I think if we focus in on that part, they say “Yes. That’s what we want” in the kind of nursing, then that will pave the way for not just end of the road kind of nursing but also what I’m seeing is, there’s more chronic illness. And there’s a better understanding about chronic illness in that palliative care is not just for people at the end, the end days. Because actually, and I know Judy [Lett, BCHPCA Regional Director – Fraser, Incoming] has done extensive work with the iPanel. It’s a research panel that did work on what we call the “palliative approach”. And it is around educating people that sometimes there is no cure, but where there may be lots of time left, more than just a few weeks or months. So a palliative approach meaning comfort measures is the right thing. So actually it isn’t for people just at the end but we are seeing that in the acute care setting even now. Although they may come in for a pneumonia that can be treated, their underlying disease is a non-curable one. So we actually need to teach more to that to nurses about what the palliative approach means.

COMMENTOR 4 [Stephen Roberts]: Because often we have a task oriented society and our jobs are very task oriented, we can lose the care element of that in this rush to accomplish specific things.

TERRY WEBBER: Absolutely. Sorry Stephen, I don’t know if I answered. Were there other pieces of that question?

COMMENTOR 4 [Stephen Roberts]: No, I think from your perspective that’s correct and how do we engender that kind of sensitive care in nurses? Do we see that as a growing sense of care? Is there more interest from your profession, I guess Julie, in working specifically in this field?

JULIE FRASER: Yeah. I get the privilege of working with students and new graduates and talking to them and so they just bubble over with care. They’re fresh and new and it’s absolutely wonderful. And I think one way from a professional perspective that we can, we don’t usually use [the word] engender, but socialize or make normal is the idea of specific competencies and recognize end-of-life care as one of those specialties, just like critical care or renal care. I know that there is CMA [Canadian Medical Association] certification for that.

But as a professional association, we can give opportunity for nurses to tell their story about satisfaction of that. And nurses in from all sorts of generations and to not necessarily talk about the tasks. So I remember one of the mentors came back when I was in an educator role. I overheard him talking to another nurse and he said “Success with clients at end of care may be that you go into the home and you do not do anything except just presence and be there.” And this was a nurse who was transitioning from the hospital setting into the homecare setting. And just really understanding it isn’t just about the task. So I think it happens at a mentorship level but we can as an association provide some leadership there too.

SANDI ARMITAGE: So I would ask a question of the group. Do you think there is a partnership between professionals and hospice societies?

COMMENTOR 1 [Lynn Wood, Oceanside Hospice Society]: I would go farther than a partnership. On the Island we have a team and so that doesn’t have a separate group of professionals and non-professionals, but rather the team members have specific functions in that group. And I think the team approach is working because it balances off all of one’s needs.

SANDI ARMITAGE: And I think that’s really encouraging to hear because then it’s not like the feeling you expressed Stephen that palliative care is down at the end where you go and you can’t do anything else. It’s actually a functioning team that it’s a priority for, that they’re doing.

COMMENTOR 5 [Judy Lett, BCHPCA Regional Director – Fraser, Incoming]: I just have a couple of comments I'd like to make too. I have a soft voice so

SANDI ARMITAGE: It doesn't make it louder. It just records it.

COMMENTOR 5 [Judy Lett]: Oh does it? Maybe I should put it back on the table. [laughter] Anyways, my name is Judy Lett. I'm a clinical nurse specialist with Fraser Health and I work with Terry and I work in collaboration with Julie. I have a couple of comments I'd like to make and one has to do with the discussion we were having just a little bit earlier. I think we have a real strong professional responsibility. When you see that the miracles of modern medicine where we've helped people to live beyond all expectations, we all have a professional responsibility not to abandon our patients where they get to that point where quote | unquote "There's nothing more we can do." There's so much more we can do. We can help to transition people from the focus on cure to the focus of quality of life. And that is so, so important.

The other thing I wanted to mentioned is that we already, in terms of how we collaborate together, we do already. We, the hospice palliative care teams throughout Fraser Health have hospice society people on all of the clinical teams. And so we work as integral partners and we're constantly collaborating and we depend on them quite heavily actually in terms of supporting patients and families in those conversations and helping us as well around the grief and bereavement and they're so excellent on that.

TERRY WEBBER: Judy, if I can add to that. While great work has been done again, and we sit in it all the time of course. One thing that came to mind is the great need. There is so much research that's been done out there. We have some wonderful tools out there. But we have not been able to take it from that piece of paper and sometimes move it into action. So I'm thinking for example ... I was involved in a caregiver coping study with Dr. [Doris] Barwich [Executive Director, BC Centre for Palliative Care; Former Program Medical Director, End-of-Life Care, Fraser Health Authority] a few years ago. And it looked at family caregivers who are caring for their loved ones in the home. What was it that they needed? And one of the outcomes of the research project was that they wanted to feel prepared. It comes a time – family caregivers say at the beginning of the illness say "We're going to do this. I'm going to get through this. We might even be this but we're going to get through this." At one point when the care needs are escalating out of control, the family caregiver has a hard time to keep up. But what they still want is that they want to feel prepared along the way.

So if we know that this is one of the outcomes, what about, what are we doing with it? It's sitting on a piece of paper. We need to be taking it to disease specific organizations: congestive heart failure, Heart and Stroke Foundation, caregiver hospice societies ... where a lot of work is, where you are doing support groups already. And to say if that's what caregivers need from a specific standpoint, and again we cannot standardize the kind of teaching. We have to make it specific to the disease. So to say you know what? We know that caregivers need to be prepared and say "Julie, your husband had congestive heart failure, what is it you're going through now and what is it that you need to be prepared?" Ah, in my nursing light it tells me that this is what I need to do for you next.

So these are very, very specific things again. It's, and we call this knowledge, is it called translation? It's a transferring of knowledge that we already have and that research says, I can't remember how many, for the health professional to stay on top of her competency she'd have to read five to twenty articles a day. It's just not possible. But let's use that information and somehow transfer it to the disease specific organizations.

COMMENTOR 5 [Judy Lett]: And so in some ways, it's really important that we have these partnerships. We need the people in the hospice society to be engaged and to support conversations. But it's more than just conversations about preferences and values. We also need to have those bodies involved where there is that very specific knowledge around those diseases in terms of well, what kinds of decisions do I actually have to make? So that is so important. So we really all need to work together.

COMMENTOR 6 [Mary Ann Deacon, Cowichan Valley Hospice Society]: And I'm just wondering – Mary Ann Deacon, Cowichan – a former nurse as well. I'm wondering now that nurses have more of a supervisory role than hands on, how much time they will have with patients to do the patient teaching that we used to do while we were rubbing a back or doing afternoon nourishments or whatever we fit in to all the other things – the treatments and the medications and all that. I'm wondering how that's going to happen in today's efficient way of doing things.

TERRY WEBBER: Well it just speaks to me that we've really shifted our priorities. Like you say Stephen, it's become very task focused. And when you talk about end-of-life discussions, it may be wonderful to think the potential's there but the mandate is not given to us. I think of the times when even going down, we get a referral for example to go down to the day care because there's a lady who's thinking about stopping her transfusions. And so you have a spare moment but actually it's really not. You're just going from A to B and the clerk stops you and says, "We've got a call. Do you think you can go down?"

And you know what? This gives me a lot of joy. So I go down and I talk to a lady who is in her 80s and nobody's had end-of-life discussions with her. So somewhere along the line, and where she's learning about what palliative care really means, about the shift of care ... Transfusions? We might be able to keep going with them because she knows that living alone, she can't live by herself at home. So going into hospice – yes, maybe one or two transfusions. But again it's not really about the transfusions. It's about how your body's going to be. And it's about what's important to you in that moment. You may not want to go thinking about spending time getting on and off stretchers to go down for your transfusions. Maybe it's just about being and sitting with your granddaughter and so forth. So, ahh. So she gets it.

So what I'm saying is, there's no time. It's become so task orientated. And because the capacity. We are kind of, and we talked about this, we are over our capacity. We've reached our capacity unfortunately. So it should not sit within the professionals' level. It has to sit at a different level. But the mandate unfortunately isn't there. And somehow I wonder if we changed our priorities from a health system level to make measurements feel a little bit different. That it's not about who goes in and out of hospital but it's about the work that gets done. That's how we would measure success, of there being good end-of-life discussion because maybe they wouldn't come back the next time. Do you know what I mean? It's about what the kind of work that we actually do to help people when they're in the setting, when they're within our reach and we can be with them.

COMMENTOR 5 [Judy Lett]: And is it really our job to do the conversations or is it our job to prompt the conversation?

SANDI ARMITAGE: The heart yeah. And actually and that goes to your opportunity. It may not be your job to do the conversation, but if the opportunity is there, if you do it.

COMMENTOR 5 [Judy Lett]: Yeah, because Dr. Janz said when we was having his little ... anyways, he had an end-of-life planning conversation with you that took two or three minutes. And I've had the same kind of experiences when you walk into somebody's room and upset "What's going on? What's the matter?" And they'll tell you. And you have this very short, satisfying conversation where that person is given permission to do, "Well what do you want to do? What do you want?" Not

“What does your family want you to do.” And so giving people permission to let others know what is that they want is so important. And it doesn’t take a lot of time. I think a lot of us are so afraid because “Oh my God, we have to be somewhere else in five minutes.” But it doesn’t always take very much time.

SANDI ARMITAGE: That leads me to exactly where we need to be in five minutes. But I will ...

COMMENTOR 7 [Louisa Sanchez, Prince Rupert and District Hospice Society]: I just going to mention in terms of the time that we’re talking about. The information that we need and especially it’s wonderful to hear everything that’s happening on the Island. But when we look at where we live, up in the boondocks, in Prince Rupert, it’s very difficult. And we do have dedicated people who really want this work to be done. We’re trying our best to get the volunteers.

But you know something, you mentioned about having all that information that’s there and it’s sitting on those shelves and they’re gathering dust. And the information is not distributed. I’ll tell you how I picked up “Our Voice” – is it “Our Voice”? “My Voice”? Okay, because there’s another one with Peter Topping that I’m involved with. However, the thing of it, I picked it up one day. I was at the hospital. I went to see a specialist. I don’t remember for what. Anyway, and that’s how I picked up that information. See, we get the information but it’s not distributed. And the people who work, we’re volunteers, we’re not paid. And what’s happening is when you question the other people, they said “It’s there.” But we need to have those things in other places than at the hospital sitting on the table.

How can we get that into our libraries? How can we get that into our schools? How can we get that information? And I think that’s one of things that we’re having a hard time with. And I think that’s something that should really be addressed. Because it’s not, I don’t know, like you said, the time limit that people have. It’s a nine to five and then you’re overwhelmed with everything else. But there’s got to be a way. And I know there’s funding. It’s always, the funding, the money is the money. I’ve heard about that. But surely we can do something to help along, to get that information to the whole community. And I’m finding that very frustrating. Thank you.

SANDI ARMITAGE: I can hear, and it is frustrating when you come to forums like this and you hear people who are doing so well and then groups that aren’t doing so well. And communication that isn’t happening and conversations that aren’t happening in there. So it is hard.

COMMENTOR 2 [Joyce Kuhn, Comox Valley Hospice Society]: But those booklets. There was, it was my understanding there were only 60,000 printed in the province. They’re about to run out and that’s all that the tax dollars can support. And so the communities, it’s up to us to have people order them. They’re not around. How do you get one?

COMMENT: The Queen’s Printer.

COMMENTOR 1 [Lynn Wood]: So one the reasons Vancouver Island is kind of organized in this is that we set up a Federation of Hospices. And the Federation has a website on advance care planning. And not everybody is web-friendly. I understand that. But the documents are all linked on the website. And does anybody have one of the little advance care planning cards with you, that you could share? Yeah. The lady in the back with the blue, maybe you could share that with this lady.

COMMENTOR 2 [Joyce Kuhn]: Well not that one. I’ve only got one.

COMMENTOR 1 [Lynn Wood]: No. Just the little card. I can get you one later today if you like. But we worked very long and hard to get it sort of consolidated as an information base and we all contributed to the cost of it.

SANDI ARMITAGE: And so this is really good information because this is what the BC provincial one [BC Hospice Palliative Care Association] is looking to help with and to do. So that we don't have pockets of excellence and pockets of less excellence.

COMMENTOR 4 [Stephen Roberts]: If I could just add to what you were saying. Also with the Vancouver Island Federation of Hospices, we were given a grant by Island Health as it's now called or Vancouver Island Health Authority, to specifically disseminate the information on advance care planning. They gave I think each hospice \$15,000 to undertake that task for them. So basically they're offloading it off to us as volunteers but it gives us an opportunity to have these conversations that we're talking about. And to put these brochures in offices, at doctors' offices and of course in pharmacies and things like that. So the hospice takes it on but we get the grant to be able to do that.

SANDI ARMITAGE: And does your education program extend to professionals? You said that you put them in pharmacies. But do you go to nursing group or physio or occupational [therapists]?

COMMENTOR 4 [Stephen Roberts]: Yes, and it's kind of up to each hospice to decide how they want to work on the dissemination of the information and how they want to get the advance care plan out. You can send some of your team to get the training to give the seminars and the workshops themselves. You can pay, we use the money to pay for people to go and have the training – whatever it is you want to do with it. It's very flexible. They just gave us the grant and said, "Please do this advance care planning for us" and it was pretty [much] without conditions.

COMMENTOR 7 [Louisa Sanchez]: So we apply for a grant?

COMMENTOR: You can apply for a grant and I would certainly approach your health authority for your region and tell them that this is what Island Health has done because there's a precedent there and it's effective for them because it offloads costs that they would otherwise have to ...

SANDI ARMITAGE: Thank you. I'm just going to move you on because that's just a little bit off topic and we're actually done with our time. But good information. And I think if you do talk to these, it will help in the North. The North is a very poor health authority. But I would like to thank you all for coming. I would like to thank our experts in particular for coming to the table and taking an hour out of their day and to share the perspective of a professional. So thank you.

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