

BCHPCA FORUM | 2014

FRIDAY AFTERNOON SESSION MAY 9, 2014 4:00-5:00

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

ROUNDTABLE ①

Chronic Illness | New Palliative Diagnosis

MODERATOR: WENDY WAINWRIGHT, BCHPCA Past-President, [Outgoing]; Past-President, CHPCA; Director of Clinical Services, Victoria Hospice Society

QUESTIONS

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

- the current challenges health care professionals have in opening conversations about death, dying and planning for care with patients in chronic care and/or with a new palliative diagnosis
- the current challenges health care professionals have in opening conversations about death and dying, and planning for care with loved ones of patients in chronic care and/or with a new palliative diagnosis
- the potential for general and specialty practice organizations to partner with hospice palliative care organizations to promote public conversations on death, dying and advance care planning
- the potential for general and specialty practice organizations to partner with hospice palliative care organizations to advocate for hospice palliative care in British Columbia

WENDY WAINWRIGHT: Okay everybody. Can we get started please? So here we are, the last session of the day. You survived it. We've had multiple conversations I think about advance care planning and having conversations. And so this is one more conversation that we're having before we bring the day to a close. And it's called Chronic Illness | New Palliative Diagnosis, just so you know whether or not you're in the right place. So my name is Wendy Wainwright. I'm here as the Past President of BCHPCA. I was just saying to somebody this is my second last duty on the BCHPCA Board, for about the third time.

PAUL SUGAR: What's your last?

WENDY WAINWRIGHT: The AGM tomorrow.

ROMAYNE GALLAGHER: Your funeral.

WENDY WAINWRIGHT: The AGM is my last. A new Board.

INVITED EXPERTS

- DR. ROMAYNE GALLAGHER, Geriatrics and Palliative Care Committee, Council on Health Promotion, Doctors of BC; Founding Director and Clinical Professor [Policy], Division of Palliative Care, UBC Medicine; Head, Residential Care and Palliative Care, Community and Family Medicine, Providence Health Care; Physician Program Director, Palliative Care Program, Providence Health Care
- DR. PAUL SUGAR, Paul Sugar Palliative Support Foundation; Palliative Physician, Lion's Gate Hospital; Member, Advance Care Planning Project Group, Council on Health Economics and Policy, Doctors of BC
- DR. MARY JANE O'LEARY, Palliative Care Fellow, UBC Medicine; Specialist Registrar, Palliative Medicine, Marymount University Hospice, County Cork, Ireland

ROMAYNE GALLAGHER: She has to manage her own funeral.

WENDY WAINWRIGHT: So that's what I'm here for. In my work life, I work for Victoria Hospice [Society] and I'm Director of Clinical Services there which means everything except medical services. And we have three guests here with us today at the end of the day. And so first we have Mary Jane, and I'm forgetting your last name Mary Jane ... O'Leary. That's a good Irish name. I should be able to remember that. And Mary Jane is here – she's an Irish trained physician and currently here in Vancouver, she's working with Fraser Health doing non-clinical projects; about to go home to see her family in Ireland next week which is pretty exciting. So we have Mary Jane. And then Paul Sugar. If you were at lunch you will know all about Paul because we heard all about him in the presentation of his [BCHPCA] Award of Excellence. So congratulations on that. And Dr. Romaine Gallagher. And Romaine has been a palliative care doc for just about as long as I can remember. She looks like she's only about 30 but really and truly she's a little older than that.

ROMAYNE GALLAGHER: That's kind of you.

WENDY WAINWRIGHT: You're welcome. And Romaine, her involvement with palliative care, she works as a palliative care doc with Providence Health and she's also involved with the Division of Palliative Care at UBC in UBC Medicine. And she's also involved with the newly titled Doctors of BC. Is that right?

ROMAYNE GALLAGHER: Yeah. It wasn't my idea [the title].

WENDY WAINWRIGHT: No, it's kind of an odd title but there we go. So we thought we'd like to, because we've had so many conversations already, and so we thought we'd like to start with a bit of a case presentation, talking about someone who has been living with ongoing co-morbid diseases – chronic illnesses – and the challenges that perhaps we face as they move into a palliative phase of their illness. So we thought that would be a good way to kick off the conversation. I would invite you if you need to make comments, please do so and you know by now that you have to speak into this [the microphone] because everything is being recorded. And so I'll run around. And let's get started. Does that seem okay with everyone? So Romaine do you want to start?

ROMAYNE GALLAGHER: Sure and before we start, I recognize some of you but do we have a mixture, do we have health care providers here as well as ...? Okay. But volunteers and various things? Okay. So I was going to present a case, a story of a person who I think represents our greatest challenge in health care these days and that's the person with more diseases than you can count and who is the typical person that we get called to see. And this is ... she was a lovely lady ... well is still a lovely lady when I saw her, I was noticing that she still dyed her hair that flaming red colour. [laughter; the moderator has red hair]

WENDY WAINWRIGHT: That would be me.

ROMAYNE GALLAGHER: No, no. This is the impossible color if you know what I mean. And you could tell that she, how long she'd been in hospital from the grey that was showing. Sort of an indicator of, a bad indicator. And so her major problem was dementia. She had been actually known to have dementia since 2006 and had, was living in a facility downtown. And she had been in and out of hospital numerous times for the last little while and she had atrial fibrillation, which is an arrhythmia of the heart which can lead to clotting. So she was on clotting medications. She had heart failure. She had started having some vaginal bleeding and they thought she probably also had a cancer of the uterus. But they were wondering whether they should do anything about that. She also had high blood pressure, depression, anaemia.

She had fallen multiple times because part of her dementia actually came from alcohol and it tends to affect the whole brain including the cerebellum so she, which is the balance centre, so she was falling a lot. And had fallen and fractured her leg and then they had to do, they had to put in a plate. And lo and behold, the plate had got infected.

And here she was. She was at her facility and she was found to be, to have low blood pressure and be kind of drowsy. And they decided that they should send her to hospital. And so we were called to see her because her family doctor was a bit frantic that they were going a bit crazy. And she had a cardiologist involved, she had infectious diseases involved, she had orthopaedics involved because of course she had infected hardware. Who else did she have involved? Everybody else.

And her major co-morbidity, which I'm sort of thinking we need to highly mark it, was no family. So she had no one to get after the health care people and say "What's going on here?" And so these are the kind of people that we're seeing increasingly. And I'm wondering if this rings a bell to anyone of you ... yeah, as to the kind of people ... And I feel like what I'm seeing as a health care professional is that we've got lots of attention to individual organs, but nobody's looking after the whole person.

WENDY WAINWRIGHT: And so where are those conversations happening?

ROMAYNE GALLAGHER: Where are the conversations? Well I find the conversations just aren't happening.

PAUL SUGAR: Well I think that's a major fall, a major problem with our health care system right now. I think that so few people have somebody at the helm. GPs [general practitioners] that take a real interest in patients, see them in hospital. It's so divisive the way things are here now. Twenty-five years ago, I don't think we saw nearly as many people like that. And I think in the future we won't see as many either because I think that the BCMA or what are they, Doctors of BC, in their wisdom are trying to get, make general practice look more attractive. And I think there are more GPs coming through that are generally interested in medicine, at least that's my impression with students.

ROMAYNE GALLAGHER: Do you think though, because I've run across a number of GPs who've said "Oh my God. Look at how complicated this lady is. I don't know if I can manage this."

PAUL SUGAR: Well if you need to get an internal medicine consult for, maybe you're not, the patient's not responding to a congestive heart failure or her AF [atrial fibrillation] is rapid and you can't get it slowing down, you can ask people that. But I'm talking about somebody who knows the whole patient, somebody who either looks after them in their facility, someone who looks after them in the community and visits the facility. There's no substitute for that and we know how many times people like this land up in the emergency department. They see person after person after person. They get drugs for, because they get a little bit confused. Maybe they've got some early dementia. Then they end up on Seroquel or some other drug because they're not sleeping. And before you know it, even if they've come from home, they're a long term care patient. And I think it's because of the lack of continuity of care. And I think that's one of the biggest problems that's going to exist for the majority of us as we get older. Not you [pointing]. [Laughter]

WENDY WAINWRIGHT: We'll have it all sorted out by the time you need it. [laughter]

PAUL SUGAR: No, and I think it's a real problem. I'm old fashioned that way and I've always been that kind of a GP before palliative care. And I knew my patients when they went into emerg and so did a lot of other people at Lion's Gate Hospital. They knew their patients, they looked after them, they took them through whatever was happening, they knew what their

baseline was. And they also had a perspective on just whether or not to treat them, whether they should be someone who's transferable to an acute care facility or not. And there was that continuity. And that, I think, is a big problem.

MARY JANE O'LEARY: I'd have to agree with Romaine. And a lot of the time I think the GPs kind of take a little bit of a step back and say, "They've been in and out of the hospital a couple of times. I haven't seen them in this many months. I don't know what's going on with their care and lots of things have happened and I'm probably not the best person to decide for them or to help them in that decision." I think a lot of the time it ends up falling on the palliative care team because they're the only people that step back and say, "Hang on a second. What is going on? How are we going to coordinate all the services within the hospital and in the community?" They look at the bigger picture of the whole person. There is a great degree of satisfaction out of that when you are the palliative care team involved and you are thinking, "What would they do only for us?" Should it be the palliative care team coordinating all the services? Probably not. But I think a lot of the time it does fall on the palliative care team.

PAUL SUGAR: I agree. I agree that it does fall ...

ROMAYNE GALLAGHER: If you've got a palliative care team.

PAUL SUGAR: ... onto a palliative care team. I agree that it does but I think that the palliative care team is also new to the situation and most palliative care docs that I know do step back and look at the whole picture. But it's a shame that there aren't GPs around to do the same. And GPs aren't encouraged to do the same either.

ROMAYNE GALLAGHER: But I guess I think there aren't going to be many old dogs like us anymore. Really I don't think so.

PAUL SUGAR: No? That's a shame.

ROMAYNE GALLAGHER: I think people want to practice differently. And I think it's a bit ... I don't think we're going to have the same kind of people doing primary care that go to the hospital first in the day and then go their office. I just don't ... we teach lots of people and they sort of say, "That's not for me." I don't know. So I think we have to find some way to build it into the teaching. Because I can't understand, even though you're seeing someone for atrial fibrillation, why you can't ... And I raise this because one doctor, the gynecologist actually, was the one who said, "Now, typically this is what I would do. But hold on a second here. This person has a, b, c, d, e, f, g, and I'm not sure it's in their best interest for me to do this." And I thought, "Well somebody has done that."

So how do we get that built into people's training so that no matter which nanoparticle of the human body they're looking after, they can step back and look at it. Because I think ... I'm afraid a lot of doctors would look at this poor lady's list of problems and say "Oh, dear." And the problem is this poor lady was incapable of voicing ... I was saying to her "I think you might be coming near the end of your life. Are you worried about that?" And she said 'Oh no. Not at all.' But then she couldn't, she did later say to her GP, "Oh, I wish I could just die." That kind of came out of her mouth.

But this is after, I'm thinking, we've had multiple interventions, tons of blood work, a one on one care provider to stop her climbing out of the bed. And I'm thinking that she's been trying to die numerous times and nobody has let her. And I'm not sure how to build that aspect into the care. Because I think we're trained to also look ahead and think about quality of the dying too. And often times I think people are just built to keep treating until it's obvious you have to stop. I don't know. What about other people?

WENDY WAINWRIGHT: Marylene, I saw you wanted to say ... okay, can I do Marylene and then?

COMMENTOR 1 [Dr. Marylene Kyriazis, BCHPCA Regional Director – Vancouver Coastal]: So I think when we are looking at chronic illness and new palliative diagnosis, I think the key here is continuity because for, at least from a pharmacist's perspective, we see a lot of multi-doctoring because there's no one in charge of the patient which leads to polypharmacy. So at the end of the day, what we are really treating is iatrogenic illnesses. And then with a palliative diagnosis, it's just compounded and we are doing a disservice to the patients.

COMMENTOR 2: No, I've heard this story so many times having worked in an extended care facility. But being a nurse and watching this happen to a patient, not just once but twice, many times. And wherever I've worked, we've never had physicians who do rounds. Your patients are there. If they get to see a doctor once in a year, they're lucky. That's changed now fortunately, recently with a new manager in our facility. But one of the things as Marylene indicated, it's polypharmacy. They kept just piling on more meds without looking at the interactions. And we did discover in a couple of incidences that there was problems with interaction. And so we'd fix it, right? Or even giving an antidepressant when really she didn't need the antidepressant. She just needed some company or a ... But no, it's a huge problem. It is.

We're all concerned about what is happening to these patients if they don't have family. And one of the things, I don't know, I'm sure all of you are advised, but there is the health representative role now. I've been called in that capacity twice now. Because it helps. The person who's left completely alone can have a health representative appointed so that they have that contact with someone.

COMMENTOR 3: Thank you. MaryAnn Deacon from Cowichan [Cowichan Valley Hospice Society]. I'm wondering, had there been an advance care directive, would that have helped? Could it somehow be legislated at the beginning of a dementia that they be asked these questions so that there's some help for everyone.

ROMAYNE GALLAGHER: Well I think there's two issues to that: one is that the way people arrive at their dementia differs. In this lady's case, it was probably diagnosed when she was really grossly incapable of decision-making. And because she was living in a downtown hotel. And so a decision would have had to be made on her behalf because she was then incapable.

But I also think it must be incredibly hard to know what you're going to want down the line. And I've had, because I'm all for advance care planning, but I have seen a number of cases, and I'll never forget a fellow who had said to his family, "If I have a second stroke, whatever you do, don't feed me, don't let them put a feeding tube in. Just let me go." And he had his second stroke and it was a lot worse. He couldn't speak and the family was abiding by his wishes. But then when I said to him, I thought well, the man can still hear me and understand me. I should raise this issue with him. So I explained everything and he very difficultly wrote out, "Different now."

And so I find myself now thinking, it's difficult isn't it. It's not as simple as "Tell us what you want and we'll carry it out five years later." So it's really challenging. I think the best thing really is a health representative who has some knowledge of you and what makes you tick and what you like to do. But then has some leeway in deciding at the time under the given circumstances, what seems to be the right thing to do.

PAUL SUGAR: When I get a call from a long term care facility and they say "We've got Mrs. So and So here and she's got this happening and this happening." And I ask them, do they, are they an aware person and "Well, she's palliative, she's this,

she's that." And people are from the point of view of someone who's coming on the scene, who's parachuting into somebody totally new, and I'm going back to this same sort of thing, this continuity thing, it's a knee jerk response when someone hears palliative is "Well, just do this."

But there's so many people on a palliative program who are really ... they're elderly, they've got some early dementia. Maybe they've got some congestive heart failure. They're on a palliative program. But those people get treated differently. Because someone's on call who doesn't know them and I think they get the short end of a stick. And unless you're willing to take the time to question the nurse who knows the patient well, then you're going to get, you're going to ... you're not going to perform a good function there. And someone's going to get sold short. And that happens quite often.

And I guess again I'm coming back to there needs to be somebody who knows the patient, who has a history of the patient and what their baseline is like. And that's the key person that you need to speak to. And it's true. People change their minds all the time. They do. And just because someone is demented, doesn't mean ... "someone here's dementia and someone here's palliative or someone here's ..." and that brands them in a way that's, in my mind, ethically not appropriate. And because they're treated by people who don't know them, that's a problem.

WENDY WAINWRIGHT: Oh that Marylene wants to talk again.

COMMENTOR 1 [Marylene Kyriazis]: So well I was just going to say what Dr. Sugar said. When it comes to treatment, it's really important to have the baseline and the perspective and to avoid a knee-jerk response, you need that perspective. So someone who knows the patient really well or a physician that's been the patient's primary physician for many years will know whether or not it's important to take the next step.

WENDY WAINWRIGHT: I guess it just kind of strikes me though, because I'm hearing, the family physician filled that role for people very, very often. I'm also hearing that's likely not the wave of the future in terms of family physicians. So it makes me think, so who are people having those conversations with so that's somebody knows them well?

PAUL SUGAR: Yeah, well and I think, like I say, it can be a nurse. It can be a nurse practitioner. It can be a social worker. Someone who knows the patient, knows what their baseline is. Was this person living at home, marginally, then they found themselves in the emergency department being overdosed on Seroquil? Someone's got to know who that person is and I think that's really important and it's a real problem in the system we have.

WENDY WAINWRIGHT: Well two pieces for you: comment that you're going to make, but I'm also interested to hear, with your perspective as an Irish trained physician who comes with fresh eyes to this, I would be interested in your reflections or comments as well. So you do what you're doing first and then ...

MARY JANE O'LEARY: Okay. Well the first bit is just a comment that Romaine mentioned earlier. The educational piece. And I think there is a huge, and it's universal from what I've seen in Ireland, the UK and here, is the piece that's missing in the education of the specialists. So the Journal of the American Heart Association recently, very recently published a qualitative piece with eighteen cardiologists. And they asked them a structured interview. One of the first questions was would they endorse palliative care involvement in the patient's care for patients with heart failure. And they all endorsed it. Universally, globally, they all said yes, absolutely, it's a great idea, we should get palliative care involved.

And then they went on and they couldn't distinguish the difference between end-of-life care, hospice end-of-life care and palliative care. They couldn't tell them or they didn't realize that there could be concurrent care – palliative care plus life modifying treatments couldn't go side by side. The majority of them couldn't tell you how to refer to the palliative care team. So I think there's a huge gap in educating our colleagues. And I think certainly us as palliative care do have a certain role in that. And obviously it's better in some centres with well-established palliative care teams than it is in others. But certainly I think we have a huge educational piece to do with specialties. Maybe with the recognition of palliative care becoming a subspecialty of internal medicine within the Royal College, that might help things and improve things. Who knows?

Again I think this is the type of person who falls between the cracks in every health care system. And unfortunately from what I see is either the primary care physician or the palliative care team picking up the pieces. How do you prevent this from happening? Part of it I suppose should be that the care centres and the residences that these patients, people are staying in, there should be ... they have social workers and people looking out for them and the people in charge of the facilities certainly should be made more aware and maybe have contact information for primary health care workers to contact in these situations. But I think that certainly it's a global thing and I don't think it's unique to here.

WENDY WAINWRIGHT: So you don't have an answer for us then? [laughter]

COMMENTOR 4: I do have a question and that's what's the role of medical charts, especially in 2014 with electronic charts? Can you not get access to a chart that's got all that information in it?

ROMAYNE GALLAGHER: Oh yes, you've got access to more information than you'd ever want. [laughter] But you don't have access to the key information like how did this person function, what did they like to do, how was their day to day life. That kind of stuff doesn't really come in. It does to some extent in what's called the MDS [Residential Assessment Instruments - Minimum Data Sets] in residential care. I think gives you some idea of their cognitive function and some idea of, are they independent and whatever. But whether they value independence or not, that's not going to be in the MDS.

What I wanted to say though was one thing that I think would help in residential care, because I think just about everybody does a yearly review don't they? Or a yearly case conference? And I often have seen that the case conferences seem to be everybody reporting in about how the patient is now. But I really think they should be reporting in about what's going to happen down the road and how we need to prepare for this and the kind of decisions that might have to be made.

I see them as conferences that should be looking to the future rather than just ... If you're a family member that visits every day, you kind of know how things are going. And I wonder if they couldn't be better used to try and prepare families for what's coming down the line. I don't know. Are there many people from residential care here? What do you think? It's a small part of the health care system. But these are people with ... I hate the way people refer to them as jamming up the emergencies and everything like this because I think a) it's not true and b) why shouldn't they deserve some health care too. But I'll throw that open.

COMMENTOR 2: Yeah, it's Gayle. I, like I said, my experience and this is, I've taken this out of my, I've retired as an LPN, taken it into my retirement. But the advocacy piece for residential care residents is really, really important. That you don't ... nurses need to take a better role in that I believe. Just because you're a nurse, you've got your duties to do. But it doesn't, it can't stop at the clinical side. If you see your patient in need, I think part of our roles as nurses is advocacy.

PAUL SUGAR: Absolutely.

COMMENTOR 2: It's huge. And I don't, and I'm not criticizing, but I think a lot of the politics in medicine and in the hospitals doesn't support that.

PAUL SUGAR: Agreed completely.

COMMENTOR 2: And we need to stop it. We need to say and encourage our nurses to do more of that advocacy. I've taken it on because I saw a patient suffering. I saw her meds being, because I'm still a nurse, I don't stop just because I walk out the door and say "I'm not working here anymore." And I saw things going on because I was a friend. And so I went to the family and said, "You know, I'm available. Why don't you hire me as the health representative because I advocate for seniors?"

And so it changed. Her health changed. She got better because I was able to intervene and make some suggestions to the nurses to change her care. But everybody needs to do that. I really think it's so important. We can't, we've got to carry that advocacy role. She doesn't have to be palliative or not in a special slot, but if a patient's a patient and they're elderly and they need that care because they're aging and they lose a lot of capacity, let's support that and let's come up behind that patient and support it and help them through that.

COMMENTOR 5: Barb Warren from the Comox Valley [Hospice Society]. I just wanted to suggest that some nurses in facilities are taking on that role. I live with my mother in law who has severe dementia and she goes into respite three times a year. And the nurses there are very serious about their role. And they have been wonderful advocates for her. They help us to understand because sometimes we've got her messed up by the time we take her back into respite again. Because we've missed something or we haven't responded. And the nurses on admission have been absolutely fabulous in my eyes in helping us to clear some things up. She comes home always better from respite than when she went in, and we're thrilled with that. So I think that nurses in facilities, at least some facilities, are taking that seriously. And so I just want to support that they are doing it in some places.

COMMENTOR 6 [Ruth Edwards, BCHPCA Regional Director – Interior, Incoming; North Okanagan Hospice Society]: I'm from Vernon. We have a twelve bed residential hospice in Vernon where we also do respite care. We have weekly rounds. And as I'm listening through here, I realize now how absolutely fortunate our clients are. We have a psychiatrist, we have a pharmacist, we have a family doctor, a social worker, a nurse and a nurse manager all in those rounds. And the care that they receive is exceptional, absolutely exceptional. But we fundraise for that. It's not government money that pays for that. It's all fundraised dollars. And/but those clients, as you see them progressing from respite admissions through to final admissions in hospice and you see the transition with the families and how the nurses interact with those families, it's just exceptional care. And it's unfortunate that isn't available throughout the province.

ROMAYNE GALLAGHER: I often think why, we certainly, I would certainly support that. For example, we've found in our hospice people, bereaved relatives rated the care there the highest in the whole organization. But I often wonder if that isn't because the philosophy of the patients and philosophy of the staff line up perfectly. And that's why it works so well, whereas in, that's not the case if someone comes to ICU after a trauma or whatever or families are just not inclined to think that way. I think we're lucky in hospice to be able to do that and it results in wonderful care. But I'm not sure how to integrate that into a system that has never been very good at dealing with chronic illness.

MARY JANE O'LEARY: It's all about bridging the gap between expectation and reality. The closer they are the better perceived are the quality of care and the quality of life for patients as well.

COMMENTOR 1 [Marylene Kyriazis]: So and unfortunately, so the system is moving further away from chronic patients with chronic illnesses.

ROMAYNE GALLAGHER: In what way?

COMMENTOR 1 [Marylene Kyriazis]: In terms of I guess encouraging more walk-in clinics as opposed to family physicians looking after patients with chronic illnesses.

PAUL SUGAR: That's been true for about twenty years though. And I think the BCMA is now realizing that they practically decimated family practice by some of their, the way they've done things. I think they're making some big changes.

COMMENTOR 1 [Marylene Kyriazis]: Well they're adding some incentives to try and, for family physicians to take on chronic pain patients. But we often hear "This patient is too complex for me. I cannot take them on."

MARY JANE O'LEARY: And sometimes I think that's the importance of a joint approach. So for example, St. Paul's [Hospital] with the chronic heart failure clinics, the conjoint clinics with the palliative care. I'm currently working with the newly established BC Centre for Excellence [BC Centre for Palliative Care]. And one of the new projects that we're initiating is developing a COPD [chronic obstructive pulmonary disorder] framework. Again, trying to improve the care for patients with chronic illness. And realizing that it can't be just one person that provides this care, it can't be just the GP or the cardiologist but it has to be combined care and multi-disciplinary. And there have been strides I think recently in heart failure and in renal and hopefully now in COPD as well to try and improve the care for those people.

WENDY WAINWRIGHT: I heard of a study a number of years ago and I'm sorry, I don't remember the details precisely. But the researchers spoke to, interviewed a very large number of seniors. So potentially folks living with chronic diseases and multiple illnesses. And their interest was, if you had a choice, would you want these interventions. And at the end of the day, a huge number of these people said "No, I don't want all of that stuff." And yet it was happening. So I think that's part of the challenge of how do we stay current with people's thinking, because people's minds will change of course. But how do we really find out what people value and what's important to them as they think of their own health care.

And then when you're working with populations who aren't able to articulate that for themselves, or they haven't had the conversations with their families or their friends to be able to articulate, or their physicians. I don't care who really, it ... I think it must be incredibly hard in fact to be a physician trying to care for someone at this point in their lives and trying to ... "What's the best decision here? What's the direction that we should be going in? How do we make those kinds of decisions?" I think we're in fact somewhat abrogating our responsibility as people and members of our society that we're perhaps leaving it to a small group of people to be making decisions on our behalf. And is that okay?

PAUL SUGAR: I think sometimes there's no choice. But it's really preferable that it's someone who knows you, knows what you're about, knows what you might want. At least you can get closer to the mark. Maybe you're not going to get a bullseye but you can get closer.

COMMENTOR 7 [Lois Brummet, Desert Valley Hospice Society, Oliver]: From my years in complex care, I found that we often had residents who were mentally very astute. They knew exactly what they wanted. They could articulate that. And if something came along, "Do you want to go to hospital?" "No." We had one situation where a man didn't want to go to

hospital but his family arrived and so off to hospital he went. Which is where he died, very suddenly. And if he'd stayed where he was, he may still have died but I think he may have been more comfortable. But the whole point is we get seniors to articulate what we [they] want and lay out how we [they] want it done and leave that wriggle room for people. And then others come along and say "Oh well, the family has last say." "Well then why the hell am I filling out all these papers" if some hysterical kid can take ... Or they turn to the physician and put the load on the physician and if it happens to be somebody who's a little fearful of death or failure or whatever they want to see it, "What am I going to be subjected to?" So when people see those kinds of things happen, they're going to be reluctant.

But I still ... listen ... but I still maintain that what we see in palliative care, come end-of-life care, is that it's very person-centered. It's person-family centered. And if we could take acute medicine and say, "You know, you're looking at a person and a family who are being affected by this sudden onset of whatever it is which makes it acute." So if that mentality of keeping the person-centered, so that when as life goes on and they end up in complex care and I'm standing up and saying to new staff, "Now, the resident and their family are at the centre of our care, as we say in palliative care, and when there's problems, who's in the centre of your care? And if it's not the resident family, if it's you, that's why there's problems." But I don't know why that philosophy ... it works well. We know it works well with the elderly, with infirm, with palliative care, why can't it work in acute care? Now I know on occasion it does because I have worked in acute care as well. And I've seen nurses who have demonstrated that. And I've seen physicians who have demonstrated that. But it needs that support. It needs that advocacy to carry it on, to carry it over.

PAUL SUGAR: Exactly. Sure. Well I'm stumped. [laughter]

WENDY WAINWRIGHT: Anything else? It kind of feels like that was a really nice wrap up.

ROMAYNE GALLAGHER: But Lois, who would do the advocacy? Do you, because I've been thinking a lot about this. And thinking about how we've set up the system to almost work against itself. Because we choose people to be physicians who have a higher death anxiety than the general public. And then we expect these people to talk about death and dying when actually they're more frightened of it than the average person. And so I've been thinking a lot about that. And what are your thoughts? And the family is vulnerable. They just want to see their loved one get better.

COMMENTOR 7 [Lois Brummet]: It takes a team. It takes ... what did Steven Garrett say ... it takes a village to raise a child. It takes a community to have someone die comfortably and peacefully with celebration. So I think it needs to be a team. And I think that often nurses will find themselves quite isolated in their practice because they're in the boonies. Or you can be in the boonies and be in the South Okanagan too. I'm sure physicians find themselves very isolated and singular. And when it's only your own thoughts that are going around, it gets scary.

So the team. I made headway or I should say, we may headway with advance care planning and those kind of things in our facility because the social worker at the time and I worked very well together. And so, and we worked off one another. And we could support one another if we had to fight with administration to get something that was needed. So it was that team thing. And we have the rudiments of a palliative care team in South Okanagan. There's a lot of things missing on it. But over the last year and a half, I've seen things change and happen because people are realizing that they don't have to carry it all themselves. That there's somebody else on that team that will share the load with them.

COMMENTOR 5 [Barb Warren]: I think we have to back it up too. What we've done in the Comox Valley is that we've backed it up into the community. So we are meeting with people who don't have chronic illnesses, who know that their neighbour does.

And so the people that we're talking to go and bring their neighbour to the next session. We're talking with people who have nobody, absolutely nobody that they can rely on. And what those people are doing then, is if they have ... we've had a couple of people who have absolutely nobody who've written their advance directive. "This is my consent now" recognizing that they don't have somebody.

We've met with people ... I had one woman come recently to one of our advance care planning sessions that wanted to talk to me about who she could identify as her [care] representative. She was going travelling. So we chatted about who was important in her life, who would make decisions for her. And she identified it was her brother in Toronto. So she's putting that in her passport. It's her brother, this is his number and he's chatted, he knows what to do. So the lady that you've described could be this woman. But she knows that her brother even though she hasn't, they're not seeing each other, they're not in their back pockets, but she knows that he will make the decisions that she's identified are important to her. So I think that, I honestly think if we don't back this conversation up and start it early when we haven't got illnesses.

So it's happened in my family and my 21 year old grandson has already started thinking about advance care planning. Because, as I said to him, "Who knows? You might be the one that they reach when I'm in trouble." So he had to be part of the conversation. He's over 19, he could make the decisions. If you look at the temporary substitute decision maker list, he's third on the list. So he had to be included. So his friends have started thinking about it because I forced him to think about it. And he goes and says, "You know what my grandma made me talk about?" They're talking about it at the bar. We've got to back it up guys. We can't be waiting until people are palliative.

WENDY WAINWRIGHT: So it's the bar.

COMMENTOR 4: What happened to the concept of case managers? For example, I've been involved in training people to be patient navigators at the BC Cancer Agency. It's well developed now in Nova Scotia and Quebec; not as well here. But those concepts are around and they sound like at least partial solutions. Have they all disappeared because they've turned out to be [inaudible] ...

PAUL SUGAR: Is this patient navigators? These are like patient advocates right?

COMMENTOR 4: Well, there are different definitions depending on what label you use and how you define ... there's a lot of debate about that one.

PAUL SUGAR: But what do you do?

COMMENTOR 4: But the basic idea is to have one person who the patient goes to for help, who knows the system and makes the connections. That you could rely on for physicians to say, "You seem to know what services this patient has seen and can help along." Have these things all disappeared or ...?

PAUL SUGAR: Well I think social work ... it falls to social workers. There's a social worker in the chemotherapy unit and there's a social worker on every, on the palliative care unit. And I think it falls to them to do some of that, some of what you're saying at least.

WENDY WAINWRIGHT: Certainly the [BC] Cancer Centre in Victoria has patient navigators – volunteers that they train to fill that role.

PAUL SUGAR: So is that different than social workers?

ROMAYNE GALLAGHER: No it's meant well, our social workers would

WENDY WAINWRIGHT: It's helping people understand the system and how to make their way through it.

PAUL SUGAR: So it's not nearly as specialized, it's more to navigate ...

WENDY WAINWRIGHT: No, but it's just a piece of it.

ROMAYNE GALLAGHER: But don't social workers get a terrible lot of paper work to do and I feel like saying what they'd like to do is help people navigate but ...

COMMENTOR 8 [Gretchen Hartley, BCHPCA Regional Director – Vancouver Island, Incoming; Cowichan Valley Hospice Society]: It's something we're starting to talk about in Cowichan. I think part of the difference between someone like a social worker is they're not site specific, that they can travel. They're available to the patient whether they're at home, whether their travelling in our case over the mountains to the [BC] Cancer Agency. There's someone there along the whole journey. But yeah, it maybe doesn't entirely answer that question of being that person's who's known you, who you are since before you were ill. But at least it's somebody that can pull together some pieces. But we're not sure ...

PAUL SUGAR: Yeah, I had a patient this morning who was in the chemotherapy unit: 39 year old lady with breast cancer and she's got bone pain. And she missed her CT scan and she needs some radiation badly. And she's not going to get referred to the [BC] Cancer Agency without a CT scan because that doesn't make much sense. And she had missed it because her telephone doesn't work because she doesn't have much money. So the bottom line for her was, if I didn't, if we just put in a requisition and sent it down to x-ray, well she'd get that x-ray, that CT in three weeks. So unless you take that thing in your hand, go downstairs, talk to either the radiologist or somebody, you're not going to get that done. And maybe that's what a navigator does or I don't know? But I do it for my patients because sometimes people, you need somebody to navigate the system. When something's urgent, you need somebody to push it.

COMMENTOR 8 [Gretchen Hartley]: And I think that's what we're acknowledging in Cowichan is that some of the really good palliative docs are navigators that ... the palliative nursing coordinator has been in many cases the navigator so maybe you don't need that distinct role. And yet there's, there are so many stories of people that just for whatever reason don't get one piece or another of the story. You don't hear about home care nursing until very late, they don't know about the hospice services or they get told that "We can't help you anymore at the Cancer Agency" and they don't know where to go.

WENDY WAINWRIGHT: Health care is very complex. And so if, as someone who understands to some degree the health care system, I still find it complex. And I cannot imagine how someone who has had no previous experience with the health care system even knows where to begin, never mind dealing with some kind of crisis that makes it hard to know what to ask and hear information and all that kind of stuff, so it's very complex for people.

COMMENTOR 8 [Gretchen Hartley]: People do speak highly of the breast cancer navigators I have to say that for those very simple reasons. They're there at a critical time and they do know the system.

PAUL SUGAR: Well maybe we need just a few people on a phone line all over BC. One line that says, "What do you do if?" You've got bone pain from your breast cancer and you're trying to get a CT scan. And someone will sit there and say, "Okay. Who's your doctor, who's your this, who's your that?" And they'll kind of go through it for them and tell them "This is what you do."

ROMAYNE GALLAGHER: We have a Nurse Line. They have all kinds of ... well has anybody here worked for the Nurses Line? I think they have a remarkable number of protocols that they have to go through.

COMMENTOR 9: I haven't worked for it but I've used it and it's absolutely amazing I have to say. The responsiveness of the team is unbelievable. Our adult son came home to visit and his face blew up and it swole in a matter of two hours.

WENDY WAINWRIGHT: Such an image. [laughter]

COMMENTOR 9: It did that but it didn't explode. It wasn't like the whale. It didn't explode. Anyhow he really, he was here to go to a conference and he didn't really want to do anything about it. So I thought "I think I'll phone the Nurse Line" because the mother has to do something. She won't be happy. So I phoned and they said, "No, no. He needs to go to emerg." So I said to him, "You know what, you need to go to emerg, so I'll take you there." They actually phoned the next morning to make sure that we had followed through.

So I actually did suggest that they have a phone line in Richmond because I'm with Richmond Hospice in there and we were meeting with the palliative team and I was saying "Well, why don't we have a phone line, and even, why don't we have a face time? Why can't people see them face to face?" It's like a face time meeting over Skype, whatever protocol they want to use. Because there's more comfort for people when they see a face. Because there is actually a startup medical unit in New York that's using that now for seeing patients and saving companies time because patients don't have to leave work. They can have this face meeting with their doctor.

PAUL SUGAR: I think there's a lot of people like me who don't know how to use it though.

COMMENTOR 9: We could teach you really quickly. Just get a teenager to come in.

MARY JANE O'LEARY: Taking an idealistic point of view, but I think that's very sad that a person of 39 years old with known breast cancer who has bone metastases and who is now in pain has to go and call a complete stranger on a line to see what they do next. Surely there should be a port of contact at the [BC] Cancer Agency, with their GP, with somebody they know to say "I'm in pain. Can you sort this out for me?"

COMMENTOR 9: But I think, if it's after hours, then what? You're still, it's still a stranger. Maybe the person who's taken over your case. But it's still a stranger. So I agree with you. It is sad but ...

Wendy Wainwright: Okay. We have time for a couple more comments and then it's a wrap.

COMMENTOR 6 [Ruth Edwards]: I just wanted to say that there is a palliative line. It has just started. So it is after hours. It has started. BC wide.

WENDY WAINWRIGHT: It's part of the Nurse Line so the nurses have trained to be palliative responders.

COMMENTOR 10 [Terry Webber, Fraser Health]: I can speak to that Wendy. Because as a palliative care clinician, I am one of the palliative response nurses. And so what happens, just for general information. People with a palliative, that are known to the palliative care team and home health care team, if they have a problem in the middle of the night, and the whole purpose of the line is to support patients and families in the middle of the night to avoid crises so they don't have to go to the hospital if they don't need to. But to provide that support because often, problems don't happen just in the daytime.

So when they call the BC Nurses Line, it's the first point. And of course BC Nurses Line has an algorithm that they follow. And if at any time in their algorithm, the algorithm says "Go to emergency" it triggers them that they must call a palliative response nurse. So there's a group of us with Fraser Health that are on call. We take turns two nights a week and we'll get a call first from the BC Nurses Line. And at that point we take the information and we get back to the family caregiver usually, or sometimes the patient who calls in the middle of the night. And it can anywhere in BC. And wonderful connections.

I envision ... you know it's amazing how quickly you can make connections with people over the phone and zero in right on the problem. And you can provide educational support around the pain management. Because in the middle of the night, pain is such a huge issue and people get muddled up: "What did they take?" So we go through medications, we go through sometimes is just to let somebody in the world know that their loved one is passed away. They need to tell somebody and that's what we do as well.

So it's about helping them to say, "What have you been taught? If you have an expected death at home, you can go ahead and call a funeral home or you can wait for the home care nurse." And just provide general support. Because in the middle of the night, it feels very lonely when you're tackling issues in the home. So I'm very happy to be ... I actually take call, I ask to take call at Christmas time because to me it is so rewarding to be able to connect with patients and families. It's just a really, it's a wonderful feeling to know that you've helped someone across invisible lines. It's wonderful. Thank you.

PAUL SUGAR: So the way people to get to you is the BC Nurses Line and then someone asks for ...

COMMENTOR 10 [Terry Webber]: The BC Nurses Line connects with me and then the BC Nurses Line say to the patient or family, "The palliative response nurse will connect with you in ... so just hold on and she'll call you back."

ROMAYNE GALLAGHER: But do they have to be registered in their program?

COMMENTOR 10 [Terry Webber]: They have to be registered with the palliative care program, home health program. There's a key to that is, because I need to identify something and I need to let the nurse know there are issues and the home care nurse has to call back as soon as she gets in the office so that the family can expect a response and that's what it is, is a telephone call to follow it up. So if I don't have somebody to pass it over to, it's a problem to follow up.

PAUL SUGAR: So what's that number?

COMMENTOR 10 [Terry Webber]: It's only given to the palliative care families.

WENDY WAINWRIGHT: It's a secret.

COMMENTOR 10 [Terry Webber]: What happens is there's a BC Nurses Line and then there's a special line for just people who are on the palliative care program. Those patients and families are given that number and the only, the reason to do that is to protect, because it could be anyone that phones in and perhaps it's a different level of intervention. Maybe there's someone that's actually receiving oncology type of support and really they need to phone the cancer line instead. So the palliative care after-hours program is for people that are registered with the palliative care program.

Of course BC Nurses Line for people that have say palliative type issues that may be more chronic, for those people that have palliative problems of six months or less should be put on the palliative care program. But other patients and families may have more of a longer trajectory or a longer prognosis. So of course if they have problems, they would call BC Nurses Line and BC Nurses Line would give them the support that they're needing and direct them. So they're not without services.

PAUL SUGAR: So they have to be known to home care.

COMMENTOR 10 [Terry Webber]: For people with palliative – six months or less and on the palliative care program.

WENDY WAINWRIGHT: I know what happens in our area is the home care, it's the home care nurse who gives the patient or family that number to call after hours. That's how it happens

PAUL SUGAR: But why am I not, why don't doctors give it to their patients?

WENDY WAINWRIGHT: I don't know.

ROMAYNE GALLAGHER: Because you have to be registered in the program through the home care ...

COMMENTOR 10 [Terry Webber]: Because the doctor has to be with the home care program to follow-up happens the next day with the home care nurses. And it may be a nursing issue ... if there was a medication issue, of course, the nurse, the home care nurse would be connecting with the family physician or palliative care physician.

PAUL SUGAR: So should you register everybody that's on, at least wise palliative. I have palliative patients who are getting chemotherapy and they're looking at possibly a year of survival. Should those people then be known to home care?

COMMENTOR 10 [Terry Webber]: There are two, there are different programs. And I'm not sure there's equal kinds of services across BC. But we have what's called supportive care programs so the same kind of, the same nurse comes to visit you but where the prognosis is longer than six months, whereas the palliative benefits form is meant to be a program for people with, we're looking at months, we're not talking years.

PAUL SUGAR: Alright. So this is available to people who are less than 50% PPS [Palliative Performance Scale]? Is that what we're saying?

COMMENTOR 10 [Terry Webber]: Exactly. That's with a prognosis of, we're looking at four months and again, the general public, we don't want to give stats on how long but certainly not months in years of life. But more, it's typically months. And where the goals are [wanted?] as well. We don't want to be putting people on the program where they're saying "No we don't want this. This is not what we're signing up for." So again, the goals of care have to be over a palliative approach is what people are looking for.

WENDY WAINWRIGHT: Okay. I'm going to have to stop the conversation there because we've gone past 5:00 [p.m.]. And I know some of us have babysitters to get home to. So I would really like to thank Mary Jane and Paul and Romaine for taking the time to come and spend this late part of the day with us so thank you very much [applause]. And thank you all for being so animated and engaged at 4:00 [p.m.] in the afternoon. I'm impressed. So thank you all very much for coming and for all your comments and the discussion.

REFERENCES

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