

BCHPCA FORUM | 2014

FRIDAY MORNING SESSION MAY 9, 2014 9:30-10:30

Opening Conversations to engage, inform and educate the public on death and dying, and to initiate discussion on future care for themselves and their loved ones.

ROUNDTABLE ①

Public Health Conversations

MODERATOR: MEG MILNER, BCHPCA President [Outgoing]; Vice President, Quality Assurance, Park Place Seniors Living

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 of public health professionals in engaging and educating the public about death and dying, and advance care planning
- the potential for public health organizations to partner with hospice palliative care organizations to promote public and personal conversations on death, dying and advance care planning
- the potential for public health organizations to partner with hospice palliative care organizations to advocate for hospice palliative care in British Columbia

MEG MILNER: Good morning everyone. I'm Meg Milner. I'm the outgoing President of the BC Hospice Palliative Care Association. And it's my great pleasure to moderate this Forum [roundtable] on public health. And we're talking about opening conversations right now. We're talking about engaging and informing and educating the public on death and dying so that they and their loved ones can start talking about their wishes and their hopes. And we're talking about all of this – opening conversations – from the public health perspective. So our expert, content experts, whatever it's called, our presenters: Dr. Paul Gully is the [a] director of the Canadian Public Health Association, Adjunct Professor, Population and Public Health, UBC Medicine and Dr. Gully was Deputy Chief, formerly, the Health Officer and Public Health Service Canada and a representative to the Executive Board [on] the World Health Organization. Dr. Gully.

PAUL GULLY: Thank you.

MEG MILNER: And beside me is Dr. Charmaine Enns, Medical Health. And she is with Island Health, [and] Past Chair of the Health Officers Council of BC. Welcome.

CHARMAINE ENNS: Current Chair.

MEG MILNER: Current Chair. Okay. See, it says Past Chair but it's okay. Current Chair.

INVITED EXPERTS

- DR. PAUL GULLY, Director, Canadian Public Health Association; Adjunct Professor, Population and Public Health, UBC Medicine [Former Deputy Chief Public Health Officer, Public Health Agency of Canada; Canadian representative, Executive Board, World Health Organization]
- DR. CHARMAINE ENNS, Medical Health, Island Health; Chair, Health Officers Council of BC
- MAYLENE FONG, BC Director, Community Health Nurses of Canada; Manager, Home Health, Vancouver Coastal Health; Adjunct Professor, UBC Nursing

CHARMAINE ENNS: Current Chair. I'll be Past [-Chair] soon.

MEG MILNER: Me too. And then Maylene Fong. Maylene is the BC Director of Community Health Nurses of Canada and the Clinical Practice Leader, Chronic Disease Prevention and Management. Vancouver Coastal Health, and Adjunct Professor at UBC Nursing. So welcome to all three of you.

MAYLENE FONG: Just so you know. My role has actually changed. I'm actually a Manager in Home Health in Vancouver Coastal Health.

MEG MILNER: All right. There we go. Lovely. And welcome to all of you. What I would ask is, I know that this whole conversation is being taped and if any of you are going to speak or ask a question, please come and get the mic because I have expert opinion on how to turn it on and off now. So then we would have this mic will also tape what you've asked and/or comments.

So this is about a conversation. Therefore, I have some questions to start the conversation and then would ask all of you to comment. I hear from Charmaine that she's already reformatted the questions which I think is a great approach. And so we'll work from there and see where we end up. So to start with, the first question, or the first comment is: the BCHPCA invites you to share your perspectives on the following questions and we welcome your personal experience in this discourse. What are, what is the current nature of public conversations on death, dying and planning for care, and the paths to opening these conversations from the public health perspective.

PAUL GULLY: Who goes first?

MEG MILNER: Go ahead.

CHARMAINE ENNS: Do we need to use the mic?

MEG MILNER: You don't. No. You're getting taped.

CHARMAINE ENNS: Oh, okay, And everybody can hear okay? So in answering this, I'm just going to re-jig a little bit. So the question is what is the level, the current nature of the conversation. And I think the current nature of the conversation is probably at a low level. And we want to speak generally from a population perspective that as a consumer society where there tends to be a denial of death, yet none of us have an opt-out plan. And it is inevitable that death will knock on all of our doors. So it is always interesting to me when people are surprised that either death is affecting someone in their family or potentially affecting them. While it's sad, it shouldn't be a surprise.

And so, I also have the benefit in my own personal experience of working regularly in Africa, particularly in Uganda and Kenya. And those life experiences over many years of working cross-culturally in societies where death is normal, is truly a normal part of life, it's truly that cycle of life and it's not separated from people's daily lives in that when a loved one dies, there is that visual, that tactile, that contact with death in a way that I think in our society, and I know from my own family, we tend to be distanced. The word I heard recently is that funeral services have become corporatized. It's... we've separated death from our daily life. We've separated it from our understanding of the cycle of life and so that's why then the conversation can

become difficult or painful when really it's something that's actually quite beautiful when it's talked about and planned for in a good and healthy way and that people's wishes can be honoured.

So in saying all of that, then we get to look at the conversation from a public health perspective and that conversation can happen from that public health approach. If I could just take a second of your time to say why I think the conversation from a public health approach has a lot of benefits for us as a, in a society. And why there is a real value in us looking at this topic from a public health perspective. The benefit – why do we need a public health approach? Why do we need to talk about it from that perspective – is because we ultimately want to achieve good dying for all. Because we all will die. And that, up till now, the concept of palliative care and dying, at least in our society, has been built around cancer and that malignant process. And it's time for us to apply those public health approaches of understanding why people are, what are people dying from. Who are the demographics? Who, what's the epidemiology? What are the equity issues or inequity issues? Who's being underserved? Who is being most impacted? How are the social determinants affecting this, the process of death and dying? How are we dealing with underserved groups or populations? Do we understand what the needs of the population are and what's actually happening in that disconnect? Do we, are we able then to apply that knowledge to our policies, to our decision-making, to our health service allocations? So those are all public health tools and all from a public health perspective. So I just say that to whet our appetite, that there's real value in us looking at it from that bigger perspective.

MEG MILNER: Thank you.

CHARMAINE ENNS: You're welcome.

MAYLENE FONG: Can I interject? I really agree with everything that you're saying. I think it's a very important issue. Back to the current nature of the conversation. I would say that there is actually from a public health nursing perspective, because that's the perspective that I'm coming from, there really is no discussion or conversation right now. Not to say that it isn't needed. I think as a community health nurse, there's actually several or two main distinctions of the care. One is home health nursing; another one is public health nursing. I know some of the roles interchange but for home health where we are dealing directly with the clients, there is very, very good hospice and palliative care, clinical management and the conversation is there. It's not an easy conversation but it requires a lot of training, it requires a lot of practice and a lot of support. And you need that support up to teams to help you facilitate that conversation.

When you talk to our public health colleagues, the nurses that are involved with the immunizations, in the water, in the new baby visits and infant health, that conversation does not happen at all. The only time that conversation will ever happen and often it's a referral to the home health [nurse], or to the team, is when there's a dying child or when they're involved in the care of the family as a unit. There might be a mother or a grandmother that has been diagnosed with cancer and they need to have that conversation, so there's that referral. I've actually had an opportunity to scan all my colleagues across the country in Canada to say, and pose these questions actually and got some responses and the responses were all the same from here all the way to the East Coast, is that "That's not a conversation we have." It's not that it's, we don't want to have it, but it's a capacity issue. So how can we do this with the limited resources we have and it's never been on our radar. Our mandate has been immunization, infant/child healthcare, education – that perspective. So that conversation in the public health, from the community health nurses' perspective is not happening. Not to say that it isn't. This is the beginning conversation. It's never been on the table and never been identified as a mandate.

MEG MILNER: What I've heard so far is there's a great role for public health and community nursing and that it isn't happening at all, all the way across Canada.

MAYLENE FONG: In public health. But in community health, in home health – there's the two distinctions, at least in BC anyway. That's how we separate the care.

PAUL GULLY: If I could add ... certainly I want to complement what the two other panellists have said. Certainly in my experience at the federal level, I'm aware that Senator [Sharon] Carstairs wanted to try and raise this, certainly to the level of the Senate, the Government of Canada. I'm not sure it got very far. I certainly never heard a conversation at the level of the Public Health Agency of Canada, which is perhaps not surprising and especially with the wishes of the current government which would say "health services and public health are provincial responsibilities". And then also, as a director of the Canadian Public Health Association, there's never been a position taken by the CPHA on death and dying.

Having said that, I think that there are opportunities. Public health is [inaudible] about health promotion, disease prevention [and] protection. We're that certainly not here to prevent death. But in terms of health promotion, maybe we could, throw it out – start incorporating discussions about death and dying as part of health promotion, as part of the conversation. And also there's increasing recognition of the issues of mental health and the need to promote mental wellness. And perhaps then, that is a way into this too. Because that's certainly come up in other conversations that the Canadian Public Health Association, for example.

The other thing to complement what Charmaine says about information, data analysis, is that being aware of the fact that health promotion has been able to help people to live a lot longer and perhaps hopefully, the end of life experience is not dogged by chronic disease as much. But then that might have a negative side in that people don't actually think about it, wanting to maintain their health. Why I talked about health promotion. But also then, the advantages of increased diagnosis, better treatment, which has meant that there are individuals who otherwise would have died of cancer earlier, who would have died of cardiovascular heart disease earlier, do not now do so. And then maybe that's an opportunity to sort of ... I know it's tough, you've got over a particular acute event but then it enabled you to bring it into the conversation. So it's a few other thoughts.

MEG MILNER: Yes?

CHARMAINE ENNS: When do we get to involve the group or can I say something?

MEG MILNER: The group can be involved whenever and if you want to say something, go ahead, and then we'll ...

CHARMAINE ENNS: If I could just ... I really appreciate what my co-panelists have said and there is I think ... we've heard already the difference between a public health approach versus a public health provider's. So my comments were about a public health approach which should be shared collaboratively across levels, sectors, organizations across society. I was actually advocating that as an approach, as a reasonable consideration at a societal level, not necessarily from the public health workforce. Because I think within the paradigm of public health, we have, we strongly, as Paul has suggested, Paul had said, we use the promote, we want to promote health, we want to prevent disease, we want to prolong life. But I think we can still use the public health approach in a new paradigm. And we need to expand the paradigm, that it's actually about preventing and relieving suffering. No preventing, it's not preventing disease; it's about preventing suffering. And if we can't prevent it, we need to relieve it. That's consistent in a paradigm of public health.

As well as we want to promote wellness. Wellness is not just about the physical body. As we all know, expanding that context of the social, spiritual, emotional, that psychosocial, that really critical part about what makes us well isn't what keeps us healthy. So we need to promote the wellness of the person who's directly impacted as well as the family and then to prevent suffering. And that to me is completely consistent with the public health approach. But a bit of a paradigm shift.

COMMENTOR 1: I just ... thanks for your comments. I work in/with the Langley Hospice Society but I, my role is in communications, so we're doing a large push out in community engagement and awareness for specifically for that reason. We're finding even that our challenges before even starting the conversation with the public and the individuals in the community is really educating service providers and our local dignitaries etc. about who we are and what we do and about how important the conversation is. And so we have communities that are establishing with Fraser Health and other components, healthy living committees, partnerships and committees that are great. But palliative care or end of life is not identified as an area that would be considered healthy living. So you're combatting that and you really have to make, I found, once we have the conversation with those individuals, there's a natural fit for us at the table. But we're having to make that case for support. And we're having to make it up here. So when, our challenge is we're faced within the community is that on the community level, people aren't having those conversations until they absolutely have to. They're often under duress, emotional, and grasping at straws. So yeah, how we get the two to meet, I think, it is part of being welcomed at the table without having to fight for a spot sometimes that will enable us. Because once we've had the conversation, it appears to be much easier. I don't know if that makes sense but

COMMENTOR 2 [Wendy Wainwright, BCHPCA Past-President, Outgoing; Victoria Hospice Society]: I think I would like to broaden the conversation even further because I think so often in public health, preventative health, medical care, the conversation stops at the time of death. And I think bereavement and the mental and well-being of people and how we support them in bereavement has huge implications for public health. But it's not part of the conversation. And I also work at a hospice and I can tell you we've been doing bereavement care for thirty plus years. Never has our health authority contributed a dime to that. It's not a priority. Nationally it's not a priority. It's often the community that supports it because they see the value of it. So I really think that we need to just remember that there's a huge opportunity there for preventative care of our community. So ...

COMMENTOR 3 [Kay Johnson, BCHPCA Regional Director – Fraser, Outgoing]: So I've worked in hospice for a long time too, but five years ... and I did all of this talking about we need to get the conversation going for over twenty years. Five years ago I was diagnosed with a life limiting illness and I have to tell you that that changes everything. And so I think it was what you said – we need to talk to people when they are still not in any kind of crisis situation, way before the fact. Because I can't do it now. I've tried. The "My Voice" has been sitting beside my chair in the living room for two years. I can't, I opened it once and closed it again. I could have done it five years ago before my diagnosis and said "Oh sure, intellectually I can do all this. I can make these decisions." So for me, anyhow, if I can give anything back, that's where we need to focus: is not when the diagnosis happens but way before.

COMMENTOR 2 [Wendy Wainwright]: You're going to be sorry you gave us the microphone.

MEG MILNER: It's fine actually. I'm just seeing how these questions that I have here are just plain flowing in the conversation so carry on.

COMMENTOR 3: Terri Odeneal with the Comox Valley Hospice Society. I think just maybe adding a little breadth to what's been said by others here, one of the things that we're doing is really not looking at this as a discussion around end of life

issues per se, when you're talking about people that are having chronic disease and cancers and so forth. We're really broadening the base and looking at talking to kids in university about the discussions about their own lives and interestingly enough, young people are often more open about it than in this day of tweets and twitters, and all of that, are often more open about it than some other generations are. So it's almost, we're encouraging intergenerational conversations and things like "You go snowboarding. What about that tree that some people hit?" "You ride a motorcycle. You ... what about your children? What about ..." And it's fascinating to see that happen. So from a public health perspective, I guess I'd like to see it trickle down into the broader audience.

COMMENTOR 4 [Dr. Lyne Filiatrault, Vancouver General Hospital]: I think all I'm hearing is about normalizing death and starting to de-medicalize it. And I think a good model may be to look at is the IHI, the Institute of Health Improvement. Ellen Goodman has done amazing work and she calls it "the kitchen conversation". So there's a big push at ... American and I didn't realize how Thanksgiving is such a big deal. But entire families from all over the States get together. It's the busiest, it's the worst time to travel, I can tell you that. But it's when everybody's together. And then you can have that conversation. And it was interesting because I got married very late. And I was my husband's [inaudible] so I ended up doing all the paper work from purchasing a house, half a house, having all the wills done and having the advance care plan. And my husband was very appalled that I was doing all that. But I said "To me this is important. Now's the time to do it."

And I think if we could just like you have a "well baby" check, whatever, when you hit forty, when you hit fifty, "Hey. Who's your substitute decision maker?" And it could just start with that. So you engage young people. So it may not be what exactly do you want when you're not going to be able to talk but it may be just "Hey. Let's start the conversations. And "Who's going to speak for you when you can't speak? And if you're ready, what are the kind of things you want?" But I think it has to come down to the public and it has to be de-medicalized. Because I can tell you as a physician, I was trained that a good shift is when nobody dies on my shift. And it's very hard to change that mentality, extremely hard. That's a good shift: nobody dies. Well, maybe it's okay if they die. It's natural.

COMMENTOR 5: Thank you for bringing up the U.S. among other things. Because I grew up in a U.S. model. I come from New York. My family is in New York and Seattle and I've experienced hospice on both sides, and it's federally mandated as opposed to provincially mandated here. That makes a huge difference and I think you were speaking to that. So when I came to BC and I started working hospice here, it was a huge learning curve. And then I discovered most of my doctors in the Columbia Valley are from South Africa. They have the international understanding of hospice. And so I think part of the public discourse has to be an education of the doctors of what BC hospice looks like. Because in Canada, hospice looks completely different from elsewhere internationally. And I think that's a big piece of the puzzle: understanding what role we play or want to play here in conjunction with the palliative team versus what their understanding, what my understanding was coming from New York. And so that educational piece is really important to the conversation as well. And I think once that conversation happens, then it's not such a challenge for doctors to make that shift to including hospice in the conversation and certainly in the "My Voice" document. I think that's a big piece of the puzzle.

Another important part, and I really appreciate Charmaine, your bringing up the equity conversation, because I'm in Interior Health. There isn't equity even West Kootenay to East Kootenay in how Interior Health supports or does not support the hospices. And I think there needs to be a provincial standard around that. And that's another part of the conversation that's really important.

PAUL GULLY: I just wanted to build on what you said, because I was thinking of saying it already, is that the health system, the health services are very much geared to success and how we deem success. And success is cure, five years, ten years. And

you're absolutely right, is that if a patient dies, if a patient dies in hospital, then that's not deemed to be a success, not deemed to be. And I think that's a conversation ... now I don't know what happens during medical training at UBC. I don't know. I haven't had experience. But it would be something that would have to be introduced very early and to give the sense to medical students and other health care providers that this is part of the continuum.

The other point, talking about the conversation, and it made me think that my partner and I went on a long bike trip last summer and we thought okay, we're going to be close to some pretty big trucks and a lot of traffic therefore it's time to redo our wills, which I thought was a great opportunity to talk this over with our children which we just hadn't, well, really got around to in recent years. So it's also encouraging people to use that kind of opportunity then to have a conversation in the family which then normalizes it.

CHARMAINE ENNS: So I think it's interesting when we talk about a public health approach, when we start off about a societal level and we come back down to the health care system. Because we're all aware, I think, that the system needs change, needs improvement. So if we approach the example that death is a failure, well we'll never be able to embrace what we need to do. And nor will we be able to provide the quality of dying as best as possible and suffering that people really not only expect but should expect.

So if we have, we know that most of the people, when people are polled, most people prefer to die at home. But the fact is that most people who die, die in a hospital. So there's a huge disconnect. We also know that home is being redefined. So what's home for one person isn't necessarily home for another. Even if we look at the health care system, what are we doing in our long-term care facilities where we're ... now the paradigm isn't about, again, that malignant process, but we're talking about protracted chronic diseases where people are in the process of ending life. Their life is ending on this planet. But what are we doing to actually provide them with the relief of suffering and the quality that they deserve in that home environment of that long-term care facility, versus, let alone what we're doing in our homes, our private home? What are we doing to support our care, our providers, our carers?

What are we doing to look at – we mentioned equity already – we look at populations who don't get the opportunity to access hospice that exists. Already a small number of people get to access palliative care or hospice. But when you look at who's actually getting to access it, it's a huge equity/inequity debate. It's huge. Rural, remote populations. People who are institutionalized. People who have mental illness. People who are at the young end of the age extreme. People who don't fit the paradigm as we're used to it. That doesn't make sense when we already know we're all going to die. This is a ... if anything affects the public, it's birth and it's death. Right? Both of those things affect all of us. So I think we also have to work at, for us within the health care systems, getting that conversation started. And looking at it as if, we're not about, it's not always about health, it's about wellness. And wellness means well to the end, as good as possible, as much as we can. So it's changing our lexicon a bit and the way we have, the way we look at the life spectrum.

MEG MILNER: Do you know, it's an interesting perspective with the topic of public health in relation to end of life support and care and starting the conversation. Because on a personal level, I had both of my parents die fairly young at home of cancer and in two different provinces. And we had the privilege as a family of being able to have them die at home. Because we were supported by, not at all, health care in the community. Not at all. Nothing to do with public health. It was the acute care teams who then transferred us to hospice support in BC. Hospice societies don't exist in Alberta like they do in BC. It was a friend of mine, a nursing friend, who literally came to help my father with my Mom in Calgary. But there's such a gap.

I'd like to go back to the public health conversation and focusing on that. Because I'm hearing that particularly in BC there's the hospice societies, free-standing, but also the small community hospices providing grief and bereavement support. And saying this is a huge drain of emotional resources for people who are experiencing end of life in our province. And the support is coming from that community groups in BC. And there's a gap it seems to me. There's the wish and the interest. But how can we have public health start to engage the public and how can we have public health start to engage and work with the resources that are here already doing the work. But it would be huge. And I'm hearing also from everyone that upstream, we need to go upstream. So we're talking at schools about end of life choices, advance care plans.

PAUL GULLY: I think public health as we've talked about before should offer this overview of a population in terms of essentially being able to describe what's going on and therefore, who's dying at home, who's not. Even the family circumstances. And both my parents died in England. My father died in a nursing home, my mother died at home. But my sister is a public health nurse. Therefore she knew what services there were. And there was a local hospice as well. But how many, with the way the families are now, they're coming together at Thanksgiving but they're not together for the rest of the time. Who is at home, who is able to provide that support? But also the changing demographics of those who are dying. Long-term survivors of HIV and AIDS, long-term survivors of Hepatitis C for example. The character, the nature of those people who are coming to the end of life is actually changing. So there should be a capacity to have that information available, to collect those data. Now there's a recent BC Health Services strategy document that came out which did talk about the importance of end of life and care. But, that's fine, but we, in order to be able to say, "How do we design a health system to deal with that, cope with that?" we have to have information, we have to have that analysis which I think hopefully, public health should be able to provide. I think it would be interesting to encourage our colleague, the Provincial Health Officer to have a report on death and dying from a public health perspective. That would be an advance wouldn't it?

CHARMAINE ENNS: Have we asked him?

PAUL GULLY: I don't know. We could.

CHARMAINE ENNS: Well let's ask him.

MEG MILNER: I'll make a note to self.

MAYLENE FUNG: This is a huge conversation because we're going from prevention, high-level promotion all the way to the discussion at the end of life. So it's too huge. What piece are we going to chop off and work on for the next little while. I'm hearing there's a huge piece on the public health, health promotion and I'm wanting to move to organizations and support. Because I'm thinking it's not just a health issue.

We go to our banks everyday. Is that something that can be started in a bank conversation because we actually see our banks more than our physicians and our health care system. Or a place where that conversation can happen. That might be an area where the education should go from a public health perspective. Right? Sorry. Educating and promoting in areas where we can ... thinking outside the box, when we're not ... to make it easy, to make it common knowledge, to make it an easy conversation and not a forced one, especially when you're at the end of life.

I know that it is a hard conversation. My sister died last year and that conversation was really hard. She didn't have a will and when she was diagnosed it was like, we had those conversations. That's when the conversations began and we forced a will

at the end within a week. So that was not the right thing, right? So your idea of conversation and all ages is the perfect time to have it, not when you know that you have a disease and when you're ready to go, or ... nobody wants to think about that.

MEG MILNER: What are the thoughts about ... and see I told you I was going to free-wheel it ... what are the thoughts about ... I actually took to my book club advance care plans as the current events topic and passed them out and had a conversation. What are the thoughts about, instead of public health nurses in the future not just doing well baby clinics and immunization clinics, but doing advance care planning? Becoming experts at advance care planning? And going to community events like that and doing a presentation and having ten people who are there ask the questions in that non-family but intimate gathering where you can almost be a bit more objective? And I've done it at the dinner table as well. There you go everybody, around the table, let's complete this. Because it's true ... if you wait until, if I wait until I am, I know that I have a short period to live, then it's very difficult to be objective. And you'll make the best decisions on your own behalf if you're able to do it objectively and with a titch of humour and coming from a place of health and wellness and we talked about that earlier.

COMMENTOR 1 : Can I just make a comment? You mentioned earlier just about limited capacity etcetera and I think sometimes ideas like that, we spin them around and we talk about it and they're great ideas. But they don't happen until we can do all of it. And then we talk to different resources and within the health care system, within [?] and within our own experience and people focus on what we can't do. So when you're in, I've been a caregiver at home for my Mom who passed a number of years ago and then inherited my Grandmother's care after my Mom was gone. And saw her through assisted living to long-term care. And never was there ever a conversation about hospice or support or additional. And I was a sole caregiver through that process. But I found that what I encountered was people saying, "Well we don't do that." There was never a conversation about "Go talk to this person. They might." Or a referral or a conversation that extends to, or an awareness even about community organizations.

I work for hospice now. My grandmother's long-term care facility was less than a hundred yards from the hospice entrance. I had no idea it was there. Never was there a conversation about that. So we talk about ... those conversations are happening and there are great organizations in the community already like ourselves having those conversations. So if we're not at a capacity in one area to do that, then let's put the step in that says, let's start a referral or if there's educating or community education or in-services or professional development that identifies these organizations and has a referral, gives general ... the front line workers the opportunity to refer and not have to say "WE don't do that." So ...

COMMENTOR 3: Terri Odeneal, Comox Valley Hospice Society. Kind of taking off on that, and as I heard people talking about nurses doing this and doctors doing this and professionals doing this, this is something with the new legislation that at least from our approach, can be done person to person. It doesn't require a professional to do it. It's not a will which speaks to dealing with your money and passing on material goods. It's about your values and beliefs. We're using lots of incredibly well-trained volunteers who can recite the fifty some odd pages of that "My Voice" document in all its iterations, and questions beyond that. Who are going out to all kinds of groups, going out to individuals, doing community workshops. And it's fascinating to see the response we're getting, and the uptake we're getting. It doesn't ... I guess my question is, "Does it have to be professionals doing it?" and I think the answer is "No".

COMMENTOR 6: Maria Kliavkoff, Hospice Society of the Columbia Valley. So we do meet and greets up and down our valley. We serve fourteen different communities and in the meet and greets we talk about the "My Voice[s]". We train our volunteers to work with "My Voice[s]" so that, at that, when we get the referral they can bring that in and have that conversation. However, we've recently been asked to run workshops for the public on "My Voice[s]" which I think is exactly where we want to be. However the realities of the constraints of our resources and such, is there a way for us to partner with public health who

has said that you want every person to fill in this document? If as you say, we've got the training, our volunteers have the training. If we could start working in partnership to have those conversations. Because the conversations are happening in our communities. The awareness of it is starting to happen. And so we're actually at a next step phase around it. And I'm curious what that might look like. What a partnership might look like.

Meg Milner: So are there any comments on this side of the room?

COMMENTOR 4 [Lyne Filiatrault]: I just wanted to say there's a community in the States called La Crosse. And they've got about 100% buy in. And it's made a huge difference in health care, in end of life care and all. So if you can get it going, I think it makes a big difference.

COMMENTOR 7 [Leslie Rodgers, Fraser Northwest Division of Family Practice]: Yes I too was observing that this side of the room hasn't had the mic yet. So I thought I'd take this opportunity. Leslie Rodgers, I'm a ... these terms won't mean anything but I'll explain ... Shared Care Lead for the Fraser Northwest Division of Family Practice. Our division of family practice is comprised of approximately 210 family practitioners and we're one of thirty-three divisions around the province. And we're funded to do a number of things. The shared care part is what I'm focused on and one of the projects we have underway is, we're developing and trialing something that hasn't been done except probably in La Crosse, which is ... we're developing a community-based strategy. So what can we do from the grass roots up to support advance care planning in the community. So we have brought together community stakeholders, along with acute care and family care practitioners, representatives from the health authority and health care providers like nurses and social workers. And so we've been scratching our heads and pulling out our hair to come up with a strategy.

And we're going to be focusing on three areas over the next two years on what can conceivably be done in our local area and with our acute care catchment area: Royal Columbian and Eagle Ridge Hospitals. The three areas that we've identified are community engagement, and that is very much, we hope, we think, it's going to be working with other partners to get the most that we can to raise the awareness in the local community about advance care planning and assure that people know about, have access to the resources that they need in order to start and advance their conversations. The second part is health care providers working groups. So that's working with physicians and health authorities and nurses, social workers and so on to increase their education and access to supports. So that we understand what is needed so that their parts of the conversation, they're initiating and asking about the conversations. And they have the supports they need to increase their comfort level.

And then the third piece is what we're calling transitions in care. It's a bit of a misnomer. What that means is that we've come to understand that even if the conversations occur and somebody has a piece of the conversation, if the information isn't transferred between the acute care site ... somebody goes to a hospital unconscious and the information isn't there in the hospital. Maybe there's been something on the file notes at the GP office, maybe there's something on the fridge. But we have to have the system in place to assure that those tough conversations that have taken place get communicated, particularly through acute care where likely that's probably the penultimate place where the information about a patient's preferences need to be communicated if he or she can't communicate in that setting. So we realize there's some ... that that's not happening. The communication isn't happening. So looking at the system point of view.

So we're trying to do all this, or at least make some inroads in the next two years, working from the grassroots level. So that's different than coming from the public health policy level. But all these levels need to intersect. And the work needs to be

done at all the levels so we're looking forward to evaluating our successes and blind alleys to be able to share what can be done when you bring together the array of community partners to try to address it from the grassroots level up.

COMMENTOR 8 [Judy Lett, BCHPCA Regional Director – Fraser, Incoming; Fraser Health Authority]: Thank you. My name is Judy Lett. I'm a clinical nurse specialist for hospice palliative care. I work for Fraser Health. And I'd just like to make a comment about some of the things that we've been discussing this morning. I've been working as a specialized nurse in hospice palliative care for the last eight years. Five of those years were in Northern Health and the last three have been in the Lower Mainland. And one thing that's really occurred to me is when I moved into hospice palliative care, I had other colleagues look at me and go "Oh, you're ... Wow. You've really gone to the end now. Jeepers." And so I have noticed that over the years, in my time in palliative care, that there's a real lack of acceptance of the fact that death is a normal process. And we are looking at death as a failure.

I attended a conference not that long ago for chronic disease management. It was held in the North and there were all the different chronic disease groups. We have done so well in chronic disease management. People are living longer with so many different types of conditions. But guess what? Not one of those chronic disease management groups included palliative care as part of their spectrum of care. Everybody talked about the spectrum of care but there is no recognition that that is a normal part of the process. And so what do we do with our patients when they get there? They fall off the end of the earth. And the number of times I've heard people say, "Well when there's nothing we can do for our patients". And so I'm always blown away by that statement. What do you mean, there's nothing we can do? There's always something that we can do.

And so I think that we really need to ... this is a social thing, this is a cultural thing. We need to take the whole ... there's needs to be a cultural shift of how do we look at life and death in terms of our normal everyday experience. Look at Africa. We need to learn from Africa and India and places where people live and breathe ... living and dying, it's an everyday experience of their life. We have locked away death into hospitals. And even trying to bring that back in the home is a major, major ordeal. We don't have the funding to be able to support that. So how do we create that shift and bring that back into the everyday conversation? Really huge thing.

How do we get our colleagues who are working in acute care services, in chronic disease management to look at this as part of their work? The other thing I have noticed over the years is that when somebody does get a palliative diagnosis, the first thing they do is make a referral to the specialized team. "Oh, can you guys go in and talk to them about death and dying and about advance care planning?" And so, how come this isn't a standard skill among all of our health care providers? And what Kay had said as well. We should not be waiting until people are well into their diseases ... you know how often we hear from people who had chronic, congestive heart failure for fifteen years that ... "Am I dying?" Or COPD where they're very, very end stage.

So this should not be a surprise for patients who are in the chronic disease management group. We should figure out a way of having care that is streamed so that palliative care and regular care needs to be embedded. It needs to be woven together, braided together. So it happens together, not something that you continue in regular care or acute care ... curative based care until you reach that stage. So I think there's a lot to be done. And these conversations should not land in the lap of the specialized care provider. This needs to be something that everybody is comfortable with. And so I think we need to find ways to bring that to the outside community.

PAUL GULLY: It would be, I think it would be great if the patients ... clients, patients, in our situation, were the ones that said, "Okay, what about end of life planning through that?" Because we're actually partly a consumer driven society. So that if your health care provider heard it, rather than sort of felt they had to, they were able to introduce it or hadn't thought of it. And if it came from individuals. So I think that's sort of the public health approach side. If we try and incorporate the conversation into health promotion and so on, then that would help.

But also the other ... looking at it from a community perspective, of course how do you define a community in a large urban environment such as this? Where are the communities? A lot of communities have their approaches. Think of First Nations for example. Is that to enable an appropriate First Nations approach for First Nations individuals, it's the community that would be able to sort of say, "Well that's []" or a faith based group or other cultural groups. And but how ... public health may be able to. I don't know if it would have the resources. I'll put this plug in. Public health has about two percent, if that, of health system resources. So that, it would be nice to have a public health approach if it were to do that. And that would be a, it could be seen as that, then maybe public health could assist in a broader approach across a community, not just the health care providers but beyond that.

CHARMAINE ENNS: So that, I guess that's what I was trying to emphasize before too. Is there's two ... those are two different issues: a public health approach versus the public health workforce. And I think that the way to success is the public health approach. If you ask the public health workforce, you will, we won't make any progress. Because we are, there is no capacity to even do what we're mandated to do under legislation. But if you take a public health approach which is what we try to do as public health physicians. So I'm a medical health officer. I try every day to influence the larger system to see it from that population perspective. Not with the workforce but with the public health approach. In terms of framing the argument, providing the information, making recommendations, providing best evidence. All of those things empower people who are the decision makers or/and at different levels, across different levels, across different sectors and across governments. So I think the public health approach is absolutely what we should do. But if you, but if I would ask you to really think twice about asking the public health workforce because that will be a non-starter.

MAYLENE FONG: Yeah. I would agree with that for sure. Yeah.

COMMENTOR 9: [Stacey Joyce, Northern Health] I don't have much of a voice. I'm quite sick. I'm Stacey Joyce. I'm from Northern Health. And so my background actually was public health. I worked in home and community care and palliative care when I worked in Surrey. And when I moved back up to Northern Health, I actually worked in public health. And I worked in public health education and around social marketing. So when I started in palliative care in Northern Health, it was a natural connection for me to think about a public health approach. I'm thinking ... this is just when I started, right ... why aren't we taking a public health approach? So I'm really excited to see that conversation happening here today.

And at the health authority level, I've been working ... because obviously I have connections with public health in our health authority, I'm starting to have those conversations with our public health leadership and starting to make some inroads. But there was a lot of resistance at first around "We don't want to talk about palliative care. We're all about the happy stuff, new babies and ..." right? But I'm definitely trying to make the argument like you said around the benefits of taking that approach to end of life care.

Also in Northern Health we're working, starting to work more with our chronic disease. Making some inroads with them too, trying to partner and work together. So you mentioned that Judy. And also, like Leslie had said, we are trying to work at that system level around education for both the care providers as well as the public to change the attitudes and beliefs around

end of life care. And also the comfort level, so that when the health care providers are talking to patients, they're ready to receive the information to. So those two have to go hand in hand together. And I'm going to lose my voice ... [laughter].

MEG MILNER: I was just going to say, what I heard so far from this last bit was, forget the public health workforce; look at it from a public health perspective. And also to have it driven by the public asking for that service and have a need there that needs to be met. The one piece of that that I see as a challenge is exactly what Renu [Bakshi, speaker] was showing this morning. It was very difficult and it is very difficult for us to remove our emotions and be able to speak objectively and ask for something we need. Because we'll pull up our tents and go home as opposed to facing, standing naked on a cliff. And so that is a conundrum. But it has to be heard. And it's wonderful for us to take those risks now and to start to move forward in that. Is there anything else that we can have that would be levers to move forward the conversation starting? Are there any other thoughts about that? From the public health perspective. That was what my question was going to be about.

CHARMAINE ENNS: So as we've been talking lately, I keep having this vision in my mind. I keep flashing back. For the last few years I've been working in Uganda. And I'm heading back actually next week. And you can't drive 100 meters without one of the dukkahs being, the caskets propped up against the fence, right, with the little window in it. Because that's just, that buying that casket is just as important potentially as buying your bag of sugar for the day versus buying your cell phone sim card or whatever. So it's just so out there and it's just so regular.

But I keep thinking about what have we, why in our society, in our, I call it the overdeveloped countries, why are we so overdeveloped that we have lost where we have all come from in terms of our diversity and our ethnicity. Those conversations or awareness. Because we all come from somewhere from families and upbringings where that wasn't so distant for us. So what's happened that it's made it so hard for us? So and I think it's probably multifactorial and probably everybody around this room could add something to a list to make a fuller list. But I think we have to also think about those things in terms of, at a societal level too. Now that's not easy to solve.

But for example, when our dear friend died and a neighbour made his casket, it was the most beautiful theatre box casket. We called it the box; we didn't call it a casket. And it was propped up in the garage and we all went through as families to look at our dear friend John lying in his box, his cedar box. And with our kids and with our friends. And together, we viewed him as his body, knowing he was gone but his body was there.

So that freedom to be able to do that in society, I think we've lost a lot of that freedom. How do we get that freedom back? To be able to embrace the people we love as they're dying and once they've died, and to be able to do that in a way with grace and dignity. So I think that's also another level we need to approach. It's not just the health care system but it's a societal context as well. And we need to push for it. I think we need to ask for it. I've already decided I want my husband to build my box. "You can build my box. Don't ... we're Mennonites. Don't spend money on a casket, for Pete's sake. Build me a box out of the wood in the garage. We can do it." So anyways, just a thought.

MAYLENE FUNG: I think we value life too much because ...

CHARMAINE ENNS: And that's good. We value life.

MAYLENE FUNG: It's good. But we should also value death. And we don't do that. And I think there's such a social stigma about dying. We don't celebrate when people die anymore. We don't celebrate their life; we mourn the loss. So it's again the negative, right?

COMMENTOR 4 [Lyne Filiatrault]: You know they have those yellow bracelets: “Live Strong” Why don’t we start one today, make one that says “Good Death”. And I think that’s what we need to do is. We’re afraid of growing old. And we all get facelifts and all sorts of botox and stuff, right? And we don’t want to grow old, we don’t want to die. Well what about a good death and having that on a bracelet?

COMMENTOR 8 [Judy Lett]: I just wanted to add on, just sort of going back to the idea that being able to have these conversations is so important. And when we listened to our speaker this morning, hearing her absolute distress at not knowing what her mother wanted and her anger against her father and the crisis that that family experienced and certainly as a health care provider myself over the years, I have seen that same kind of thing. If you go into the emergency department, if people have not had that conversation, that is not the place to start. Because it is in absolute crisis. Everybody’s upset, Everybody’s fighting. Same with ICU. So if we can back those conversations up, way back, somehow. And let’s talk. Let’s get the conversations started so it’s everybody’s job to have the conversations.

And maybe take them into the schools and take them into the universities and take them into the social clubs and that kind of thing. People should be having these conversations everywhere because it’s part of normal living, normal dying. And certainly people who have had those conversations, it’s a completely different picture. They’re composed, they’re relaxed. Everybody has, knows what the plan is and it just goes so much better.

MEG MILNER: We just have a few more minutes.

COMMENTOR 9 [Dr. Mary-Jane O’Leary, UBC Medicine]: I want to make a quick comment. I’m Mary-Jane. I’m a palliative care physician from Ireland and I’ve been working in palliative for the last two years. And it’s a huge cultural shift for me. I work in palliative care for the last five-six years in Ireland where when someone says to you, “I’ve had a good life” i.e. you take that as “I don’t want any more treatment. I know I’m dying.” The conversation ends. Or the other one being, “Just make sure my good suit is pressed.” [laughter] [inaudible 1:10:30] ... assigned, everything’s done. It’s a big cultural shift and I have to say I was a little bit skeptical when I arrived first but I felt we were putting a lot of onus and a lot of pressure on patients and families to make decisions that they maybe necessarily weren’t informed enough to make. And I really feel that particularly when it comes to palliative care and particularly when it comes to families that a lot of pressure is put on them.

I saw last week – I was teaching medical students in UBC – and a [inaudible] wanted a script for what to say to people on [inaudible]. “My daughter is on antibiotics. Should we use antibiotics?” [inaudible] And thought I was trying to educate them around how about just having to go more about a natural conversation. Just general questions. [inaudible] “Your values, your perspectives.” You don’t want to burden them with too information about the nitty-gritty detail of ventilators and breaking your ribs and then we push on your chest. Just sit down and have a normal conversation with “What do you want? What are your hopes?” I think we just have to be very mindful that we don’t overburden them with too much of the finer details.

And certainly volunteers can have these conversations because you’re not getting into the medical technology and all of that. And it’s just about opening conversations. What we want for ourselves and wellness may be very different from what when we’re ill ourselves. So I think it’s just about opening conversation and moving through them.

COMMENTOR 2 [Wendy Wainwright]: I want to make a [inaudible] I’m not going to rant. But something’s just dawned on me. I’m just, I’m slow. But isn’t it interesting that in our culture, we have to have this document for us to even have permission to have the conversation. And it just makes me think that we’re such an individualistic society that we each want to have our

own wishes when we're dying. It's about "me". And yet those other cultures, it's viewed in the culture. We don't all have to have the conversation in the same way because everybody kind of knows how it happens. And it just kind of never has dawned on me in quite the same way as it did now. Isn't that interesting, that ... And I'm all for people having the conversations, don't misunderstand me, but that ethos of the individual and their rights and their priority and just ... I don't even know what else to say about it. But I just find it unusually interesting to think about that perspective. We have the right ...

CHARMAINE ENNS: But we could talk about that for the next hour. Easily.

COMMENTOR 2 [Wendy Wainwright]: Well listen. I know now that you live in Victoria.

CHARMAINE ENNS: Actually I live in Tofino.

COMMENTOR 2 [Wendy Wainwright]: That's close enough. We can access the same telephone service. You're going to hear from me.⁴

CHARMAINE ENNS: Yes.

MEG MILNER: So we've segued into ... I'm sorry we're out of time. We've segued into a thank you very much and you can connect with our content experts, with our experts around the table for the rest of the day. You will be here for the rest of the day? For the morning. And thank you all for participating. Really hugely appreciate all of your information and for participating. And thank you all.

CHARMAINE ENNS: You guys made it easy.