

BCHPCA FORUM | 2014

FRIDAY MORNING SESSION MAY 9, 2014 11:00-12:00

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

Personal Conversations in Counseling

MODERATOR: GRETCHEN HARTLEY, BCHPCA Regional Director – Vancouver Island [Incoming]; Executive Director, Cowichan Valley Hospice Society

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

GRETCHEN HARTLEY: So welcome everyone. The conversation we're going to have in this room is a counselling conversation. And we want to record your wonderful comments on the part of the panel and participants. So I'm going to be passing this mic around. There's a little microphone on the table that will record all of us in the front row but this is available for people at the back. So I'm Gretchen Hartley. I work at Cowichan Valley Hospice and I've just joined the BCHPCA provincial board of directors. So I'm looking forward to that work. Thank you all for coming today. I'm going to introduce our speakers. I need my glasses.

COMMENTOR: Gretchen, is the microphone working?

GRETCHEN HARTLEY: It's not a microphone. It's for recording; it doesn't amplify, so ...

COMMENTORS: [laughter] It looks like a microphone. A talking stick. But it quacks like a recorder.

So Dr. Wolfgang Linden is the President of the Canadian Psychological Association and he teaches at UBC in Psychology. Dr. Sandra Wong is a Director of the BC Psychological Association, a member of the Disaster Psychological Network, BC

INVITED EXPERTS

- DR. WOLFGANG LINDEN, President, Canadian Psychological Association; Professor, UBC Psychology
- DR. SANDRA WONG, Director, BC Psychological Association; Member, Disaster Psychosocial Network, BC Provincial Disaster Stress & Trauma Responses Services
- JANET COUGHLAN, Chair, Health Practice Enhancement Committee, BC Association of Social Workers; Tri-Cities Hospice Palliative Care Program, Fraser Health
- CHELSEA COOLEGGE, Director, Professional Practice, BC College of Social Workers
- GABY EIREW, Founder and Director, Record Me Now

Provincial Disaster Stress and Trauma Response Services. Janet Coughlan. And I forgot how to pronounce your name. Coughlan, thank you, who was the first person here and I should have done that, is the Chair of the Health Practice Enhancement Committee of the BC Association of Social Workers and also recently retired from the Tri-Cities Hospice Palliative Care Program for Fraser Health. Can you hear me at the back? No. Okay. That's a good tip to us all. Chelsea Cooledge is right here with us. The Director of Professional Practice for the BC College of Social Workers. Andy Gaby Eirew is the Founder/Director of recordmenow.org which appears from my quick Internet search, a really interesting app to help people record important information about themselves for posterity. If there is a question, you can speak to that.

So we're going to proceed by putting some big questions out there and inviting our folks up at this table to start. And there will be an opportunity for us all to ask questions and make comments as we go along. And I just also want to say to everybody in the room that personal experience as we all know is very rich in these conversations and invite you folks to include your own personal experience. So the first thing we're putting out as a question is really inviting you to share your perspectives on the current nature of public conversations on death, dying and planning for care and past opening up conversation. So yeah. Anyone that would like to start? Start at one side and work around? Janet, would you like to?

JANET COUGHLAN: The current situation I feel in some ways that I'm not that well equipped to talk about it because I focus on a particular area and I'm not always aware of what's going on in the wider sphere. I think a lot of progress has been made in the last ten years or so. We are talking more about hospice, death and dying. There's a lot of room for improvement obviously. I think the strides that have been made in advance care planning are quite impressive. I'm just a plug for social workers who have been involved in that. But I think the information on government websites, the focus on looking at advance directives, at people's wishes about the end of life, that's all progressed a long way. As I say we still have a long way to go. But in my own limited sphere, I think some of the educational programs that are going on are very helpful too and perhaps we can talk more about that later on.

CHELSEA COOLEDGE: Similar experience. I came from health care before being with the College [of Social Workers] and in that setting, the advance care planning, it's prevalent. The discussions happen. I think from my perspective I'm concerned that we're missing a larger group, vulnerable groups, lower socio-economic status and minority groups. And a whole variety. How do we engage with them? I don't have the answers but how do we engage more and ensure that those discussions are happening outside of a hospital environment? So I think, yes, what's happening is good and that's great. It's one small piece of it though. Yeah, so I'll leave it at that for now.

GABY EIREW: Yeah, I'm saying similar. We've come a very long way from the 1950s, '60s and '70s. When I was looking at some surveys, and looking at 700 American physicians, they came up that most physicians considered it inhumane and damaging to the patient to disclose their bad news. So I think we're doing really, really well. I think that we have now got talks here on Death Cafes, we've got online forums, we've got websites like Final Fling. They're missing the idea of the word "death" in it but they're getting people out there talking. Bucket List Festival, RecordMeNow, Metastatic Support. We've got death doulas coming back into society which is fantastic, all into the sort of birth stuff. But it's great. We're getting people into the community talking about dying, being there.

There's still this big, big voodoo that I really want you to help me with. Because if I say to people "Please record something, in case you die." People say "No". And you say "Why not?" and they say "Well if I do it, then I might die." And I say, "Do you have house insurance." "Oh yes." "If you have house insurance is your house going to fall down?" "No unfortunately no, it's not. Now I've paid, it's not going to." So we have this sense if we've protected ourselves, something might happen. Which we don't have in other spheres of our life. And I don't really get that double standard.

We also have this idea ... how many of you think secretly you might win the lottery? I'm one. Am I the only one? Come on, how many people? You're not just giving away the money. Okay. About how many people think [you're] going to die within the next year? Almost none of us, unless you're on the bucket list. And unfortunately, without giving you the statistics, you're a bit wrong on that one. And so I think we have this blinkeredness that we're frightened to talk about it. We're frightened to contemplate it. And it's brilliant that we're all here in the room. Because we want to talk about it and I would say, rather like a relay, take the baton about death and take it out into your community and keep talking about it. Because maybe like me, if I'm talking about it, I'm talking about it with your group and I'm happy. And if I'm talking about it with my friends, I'm still comfortable. But if I meet someone over, and I'm somewhere fun, "nah". I'll tell them I'm a counsellor, I'm an educator. I tend not to bring up death within the first few minutes of the evening. But I think that's partly our job. Please still invite me. [laughter]

SANDRA WONG: So for me, working as a psychologist. So I always see patients who come to me with pain, both physical pain and emotional pain. And some of them may be experiencing some trauma. So they have experience like near death. So we will talk about death. And it's very interesting because most people when we talk about death, there are three approaches. Some try not to talk about it – escape, avoidance. And some will be calm, like "Okay, that's our life destination. We want to live well and we want to die well. Let's face it." And of course some people are just neutral. "Oh, it's too far away. Not tomorrow; not next month." Yeah, so I start the conversations with my patients and always they give me some new insight. And so I learned a lot from my patients, especially those seniors. Now forty five is already senior, now. Forty-five, fifty-five. [laughter] So and actually, I start to, and for me, myself, I also want to prepare myself. I became a psychologist because I wanted to know how to have a meaningful life. And so now I'm approaching aging – we're all aging – so I want to learn how to have healthy aging. And of course healthy aging means you want to, when you die, with no regret.

So the two doctors I really appreciate and they gave me a lot of inspiration. Both of them are called Paul. One is Dr. Paul Wong and he has developed an approach, a counselling approach called "meaning therapy". And so, and he has done a lot of research on how people deal with death, the death attitude and also how come people have the fear of death. So if you want to continue our dialogue, I think of his work. He has a lot of work in this area, then we can continue that. And the other Paul is Dr. Paul Pearce. He started a new program in Carey [Centre for Health Aging Transitions, Carey Institute]. It's called "Healthy Aging Transition." And it really applies to what we're doing today. And so I bring a journal. It's the "BC Psychologist" for the Spring [2014]. It's on aging. And so I and Dr. Paul Pearce have an article on talking about the different factors contributing to healthy aging. So when we have healthy aging, then we will die with no regret. So I know because this time is very limited, so I will give you some of the links and you can try to read about it and then we can talk more about it.

COMMENTOR: Sorry what is the first person's name?

SANDRA WONG: Paul Wong and Dr. Paul Pearce. Actually he wanted to come to the roundtable discussion.

Wolfgang Linden: It's very flattering to be invited to sit as an expert at this table. Let me assure you I'm no expert. What I can bring, and by all means we can talk about this, I have some experience. Mostly I'm a researcher and the research stuff is not very helpful with this topic and it doesn't get us very far. But I've done quite a bit of consultant work with the cardio transplant team and I also work in psycho-oncology so I do get to deal with the topic both sort of at the integration of clinical and research issues. And last not least, and I suspect this is relevant to all of us or at least some of us, I have some very aging parents who are alive and well, thank goodness. I'm going to visit them next week. But they remind me all the time what the

issue is. And some things we talk about, and some things we don't talk about. But they certainly shape and colour how I look at the topic. Because it's highly relevant.

GRETCHEN HARTLEY: Thank you. So to talk, engage a little bit more in the specifics of the group of guests we've gathered today, can you speak to the role of psychologists and counselling professionals in engaging the public in moving past where we, I think Gaby has talked to well of the ... It's funny. You mentioned the insurance analogy. Gaby's talked well about the, I thought the insurance analogy was a good one because even when you're talking about insurance, my brother sells insurance. He says he mentions what he does at a party and people turn away. Even more so when we're talk about death and dying. But can you speak a little bit to the role of your profession in opening up that conversation. And to those of us in the room who are members of these professions of course.

WOLFGANG LINDEN: For the most part, I would have to say we don't get that much proactively involved. Patients don't generally go and see a psychologist to talk about death and dying issues. We deal with individuals who have health problems where that becomes a topic and then we'll try and deal with it and embrace it. But typically, we're trying to get people to get better and don't deal so much with issues of how to live with the limited amount of what you have. It's a stretch for us to get in there.

GRETCHEN HARTLEY: So there's a little bit of some personal taboos that exist as much.

WOLFGANG LINDEN: Yup. You bet.

JANET COUGHLAN: I guess it's different if you're specifically working in palliative care. And the referrals that I used to get were often from nurses or doctors working with the dying. And specifically for just that kind of counselling and listening and helping with the adjustments they're going through. And I suppose on a one to one basis, that's one thing. I was thinking more before about the public conversations. But I've asked myself the question before, "How comfortable am I talking about it with my own family?" And that's still difficult for me. I've made efforts to do that and to tell them I have written an advance care plan but it's hard. And when my mother was dying, it was hard to talk with her too. She was proactive, thankfully, and made sure that I and my siblings knew what her wishes were and talked a little bit about her fears too. But I suppose because we're so emotionally involved at that level, and yet that's the level we have to start, with our own fears and our own families.

GABY EIREW: I think fear is such a huge one. I'm working with a lady at the moment who has very limited time. And she came to me with her husband because she couldn't talk about dying. And normally in counselling, you ... especially I'm very Rogerian [Carl Rogers] and client centered, I want to go at the pace that the person's comfortable, and this lady knows that the time is ticking and her children are very young and that is a very difficult one, in dying very, very young. I think we've done a huge disservice to ourselves with this whole fight against cancer talk. My husband is a cancer researcher and I find in almost no other area, people really saying "You're a fighter. You're going to be a survivor" which leads us almost inevitably if the person doesn't live, that somehow they've failed. And so I think we sometimes miss out on that beautiful conversation of, "So this is the natural conclusion of your life and what would you like now and how are we going to best spend this time and who do you want to connect with?" and living wakes and all the wonderful rich things that we're all involved in. And so I think this fighting and this failure to where, you "Oh, she's going to beat it" and if she doesn't, well what is she now? I think that's where we're missing the conversation.

COMMENTOR 1 [Lynn Wood, Oceanside Hospice Society]: If you don't mind, I was just curious if we could address at some point how we counteract that negative messaging that counteracts the conversation around death. The Heart and Stroke

Foundation do it too, “Make death wait”. It’s like death is some creepy thing waiting in the wings. So I’d be interested if the group has some ideas around how you counteract that negative messaging with our message.

SANDRA WONG: So what I can share is my experience working with my clients. And usually we’re talking about the fear of death. And so hopefully what we try to achieve is to accept, to acknowledge the reality of death. It’s something unavoidable. So if in the process the client comes to a realization that death is inevitable and they can open themselves to the pain. Because why we don’t want to talk about death, our death or this death, is because there’s a lot of pain. And that’s the way we psychologists work. We try to help them to look inside. What are those strong negative emotions? So sometimes we will come across anger and we know that anger will only lead to control. And also alienation. “I dislike you. I hate you.” And some people, they will talk about their anxiety. The fear of death. And they start to worry. When you’re anxious you worry and then you disengage. And most people, they become depressed, when you’re thinking about death. And depression will result in hopelessness and helplessness. And for the seniors, they become more dependent, because “I lost my mobility. I cannot be productive.” So they become more and more dependent. And some even become delusional because they want to escape. They don’t want to see the reality.

So through the counselling process, we’re helping our, I’m helping my clients and they’re also helping me to see the full picture. And so what is helpful in the process is to see the world to inform, to get more information, to get the resources like from Heart and Stroke [Foundation], from the different organizations to change the world view. Because when you’re in that mentality, you have the tunnel vision. You don’t see a way out. So being informed is very important. And this conference is good because we really gather the resources from the community. And also more important is the relationship matters. I always say that. Relationship matters.

People, they die. Before they die, if they realize that someone cares for them, or they still care for some others, but they know that there are significant others. So that really makes their life more meaningful and also encourage them to do more meaningful activities. Even though they have limited mobility, they still can do something or develop some new interests. Like the Bucket List. So they find new life. So that’s my approach to help people, they are facing aging. I like the word “aging”; I don’t like the word “dying”.

GRETCHEN HARTLEY: So really helping people to engage with whatever, with wherever they are to more fully engage and move forward.

SANDRA WONG: Yes, to more fully engage with life.

GRETCHEN HARTLEY: Because I think it’s true. It’s hard to have a conversation about death or the end of life without talking about life. It’s about life. Our lives.

SANDRA WONG: Yes.

WOLFGANG LINDEN: I’d like to pick up on your point with the [Heart and Stroke] Foundation’s program “Death can wait.” And I’d like to point out that you really have to do a lot of individual tailoring. Because in cardiology, and I work both cardiology and oncology, it’s actually markedly predictable how well you are. You look at cardiac functions, you can take hard diagnostic tests and a cardiologist can tell such and such and you really know how well your ticker works. And I’ve worked in rehab and we had people in there who ran half marathons within less than a year after the heart attack. You have a ton of tools available in cardiology to comfort people and make them actually healthier than they were before.

We don't really have the equivalent in cancer. There is a tremendous amount of uncertainty which you cannot remove. You can't really do a lot. You can do some but not a lot to reduce risk factors. You can push them towards exercise and healthier eating. It is not anywhere near as potent a preventive measure for recurrence as it is in cardiology. So we really need to have programs that are tailored to the disorder that you're dealing with and the person who has the disorder. These two have to be packaged together. And that takes a lot of work. There's no standard program that's going to work for everybody.

COMMENTOR 1 [Lynn Wood, Oceanside Hospice Society]: I think my comment related more to the messaging around it. I understand there's lots of good work there.

WOLFGANG LINDEN: Oh yeah, I totally support you.

COMMENTOR 1 [Lynn Wood]: But the messaging around it reflected on the word "death" as sort of a process and my immediate reaction was, it was like somebody was lurking behind the drapes waiting for you in the commercial. It was very vivid and kind of creepy.

GRETCHEN HARTLEY: As opposed to the natural outcome of living.

COMMENTOR 1 [Lynn Wood]: Yeah, so as opposed to a natural outcome. You know you've done everything you can. But you are going to die. And I guess I'm curious as to how we as a group can address those kinds of negative messages.

CHELSEA COOLEGGE: I'll speak to that a little bit. I think as social workers, counsellors, psychologists, we aren't, people don't come with us when everything is good and hunky dory in their life. They come to us when there's concerns they want to work through. And I think we can start having the death and dying conversations before illness. I think a lot of this messaging focuses on, it's related to illness. We have a responsibility to have those discussions prior to illness. When they come to us to discuss other things, generally it's life process. Part of a life process is dying. So us as counsellors and people engaged in that counselling process can have those discussions well before there's a named disease. And then they're hopefully better prepared to be more accepting of an end point when there is a disease that's named. So I think it's backing up, not just looking at the disease process, and starting that conversation then, but starting it well before.

GRETCHEN HARTLEY: So have you got ideas, Chelsea, about how to start the conversation? About how to open the conversation?

CHELSEA COOLEGGE: There's ... I think it depends on the individual. It depends on what they're coming to you with. Where they're at. I think a good way to start is to explore their experience with death. We all have it. Our grandparents, our pets, loss of relationships. It doesn't have to be death. Just exploring loss is often a good way to start. And then it will naturally evolve from there. You can explore fears or anger. I think all of the emotions associated with death are healthy and normal. As you all know probably more than I do, it's working through ... starting the conversation is I think often about what losses have you had in your life. So that's one way. There's lots of ways but that's just one.

GABY EIREW: I would like to start this at the other end of life, in that for me, I started as an educator of very small children and the hardest jobs I have now is when I'm dealing with children who have lost a parent and didn't even know death existed. And so for me books like "Mayfly Day", this story of a mayfly who has this beautiful day and it's one day long and it's terrific and it's over and that's how things are meant to be, is actually quite helpful. And I would love there to be more death education in

school. The reason why there isn't ... I don't know if you know in the 80s, 90s and still a little bit today, there's some death education in America that is really scary. And a lot of it was around Columbine [High School in Colorado]. And as soon as Columbine happened, people linked that to the death education. And I have to say that the death education from what Barbara Walters reported – this is a lot of reading online – did seem to be quite graphic, quite gratuitous. They got kids in school to go and touch cadavers and it was fairly outrageous.

So when I'm thinking of death education, I'm giggling "That is not what I meant". What I mean is really being able to talk to children about life cycle. We talk about ... my son at the moment, age 7 is looking at the caterpillar and it's upside down and it's eating and soon it's going to be a butterfly. But then we don't talk about the next bit. And I would just like us to touch on the next bit.

And in terms of opening conversations, I think partly it's how you are as a person. If we can be open, and really open to people in how we talk, and by showing that we're available, and that we're not going to talk just on this very light weight thing, and if we can talk about what has meaning to you in your life now. Because everyone's life has some meaning and if it doesn't they probably want to talk about why it doesn't. Or what has value. That normally is a good way into what matters now, what you want to do with your time left. If you want to go outside and sit in the gardens, or if you want to continue with your chemo, or whatever it is. What has value for you; who has value for you? What are your favorite things to do at the moment? And what are you missing that or would like to have, and really build on that.

And it leads me back ... I don't know if you know about SPIKES Training. SPIKES is what, it was developed in 2000 in Australia and it's really about how doctors break bad news to people. And it really is about getting the setting right. Listening to the patient's perspective on what they know about their condition. Inviting questions. Giving appropriate information about what's happening to them and what they might like to know. Because often they've have a short meeting with the doctor. They might like to know more. And you might be able to not answer the question, but help them find the answers. And that might help them build a framework for how they want the rest of their life to be and how they want their death and dying to be.

So I recommend you to look up SPIKES which is really about talking about bad news with people. And it's really how doctors are trained and often they try to do it but they might not have time to do it. It's a great set up of getting a good setting, making it appropriate physically, making it appropriate empathically. And I find that good. But I find the hardest challenge to me as a person: giving the feeling that I'm there and I can hold it, I can take it, I can walk alongside them.

SANDRA WONG: So actually I agree. According to research done by Dr. Paul Wong about how people perceive death, and how people ... there's an instrument to measure our fear of death and our acceptance of death. So yeah, you can Google it online. It's called Death Attitude Profile. So you can check, how's your fear and your acceptance? And there's a direct relationship of meaningfulness in one's life. If you find your life is meaningful, then your ability to accept death is higher. So it's good for you to check it out.

And also I think talking about death, why people don't want to talk about death because they are thinking that our body decayed. It is an extension – no more. I no longer exist. But in some people they have maybe spiritual or religious belief. They understand that death is not the ... really the end line. There's maybe afterlife or/and that helps them to motivate ... Death, if you go to YouTube, there's a YouTube [video] about a priest talking about his experiencing of aging and how he viewed death. For him, he's seen the physical pain, the death ... actually something motivated him to live a more fully life by paying more attention to his own spiritual life. So it really depends how we view it.

GRETCHEN HARTLEY: So I have the feeling that there's a lot of expertise in the room here ...

WOLFGANG LINDEN: If I could just add one point to flesh this out. I'm very much in agreement with what I've just heard. And that is it's a hell of a lot less scary of a topic if you build it into life in the first place. And one way of doing this is through an approach I've built into my theoretical orientation as a clinician. It's called acceptance and commitment therapy. And one of the questions you'll often ask at the beginning is not if, but "When you die, how do you want people to talk about you in your eulogy?" And have people spell it out. And if need be, I'll send them how and say "Write it out. Think about it. Talk to people, come back the next week to tell me what it is." Then say, "Are you actually doing things today and tomorrow that will allow people to do this when you die? Are you on the right path?" And I think if you are consistent, if you have a clear view of where you're going and what you want to do, then reaching the "endpoint" if you want to call it that, is no way near as scary because you know you haven't missed life and you can let other people know you're doing the very things that are important to you. And then they won't be so sore that you're gone. So start this super dooper early. You don't need to have a deadly disease first.

GRETCHEN HARTLEY: Yeah. And I love the notion of thinking a lot more about how we talk to our children instead of stealthily swapping up the goldfish, putting in one that almost looks like the one that died.

WOLFGANG LINDEN: We had one of those: "Timothy's floating upside down! What does that mean?"

GRETCHEN HARTLEY: The goldfish graveyard in our yard. Do other people have comments they'd like to

COMMENTOR 2 [Don Morris, Death Café Victoria]: Thank you all for being here and Gretchen for doing such a great job. I really feel that for me personally the energy starting to build here. When Dr. Linden, nobody ... I'm totally with you in getting people to think about how they want to be remembered at their funeral. But nobody ... people don't want to talk about death or about funerals. But they do want to talk about their legacy, because I believe that today the greatest fear we have when we're dying is not pain but will we be forgotten, will we be remembered. So if we can get conversations, and they're very live conversations going about "What did I learn in life? What was meaningful? What were my regrets? What can I pass on to my children and grandchildren?"

So now we're drawing on this ancient 2-3,000 year old tradition, coming from Judaic sources, of ethical wills. You talk to your children and friends on your deathbed. But nowadays, you can use your particular service or get people to write about their life and their values and what values they wish to be passed on. So I think the key to these, the conversations about death, because I'll just throw it out there. I might be wrong but I'd say 98% of us don't want to talk about death because we're so mind identified, emotionally identified, okay? But we do want to talk about what we've learned in life and even where we've failed, so we can help our children and grandchildren not make the same mistakes.

GRETCHEN HARTLEY: I'm wondering Gaby if you could speak a little bit about RecordMeNow and the kinds of questions you put in there.

GABY EIREW: Sure. So just to tell you briefly. I spent five years interviewing over a hundred adults now but who were children when they lost one or both parents. And hidden in lots of questions were the questions about what do they wish they knew from or about the parent who died. And children aged two to four hadn't even thought about it, and I felt horrible, often said "No one told me to not hold mommy's hand." So they thought they were supposed to go with mommy. And that was the

shocking one for me. So for example, the child is always told, “Hold mommy’s hand. Hold mommy’s hand.” Mommy dies. No one says “You know, you’re not supposed to still be with mommy.” The child still has “Hold mommy’s hand. Hold mommy’s hand. Mommy’s gone.”

So one of the key things was actually a message from us as parents to our children to say, “You know what? I’m really sorry if I have to die and I’m really sad because I don’t want to die but I’m so glad you get to live on.” Because often the people grew up and they struggled with the guilt of being alive, their parent being dead, not what the parent wished them. Thinking they have to be super good because everyone at the funeral said how fantastic mommy or daddy was.

So giving a rounded sense of yourself is the most wonderful thing we can give our children. That they don’t have to be perfect. They just need to be who they want to be and that it’s okay. And telling them naughty things you did. Telling them how you dealt with anger. Telling them what you whispered to them at nighttime because they can’t remember it and they feel horribly guilty. Even recording yourself just singing a song will bring back so many memories because they’ll remember “Ah, that’s how you moved your eyebrow. Oh, I remember that.” One lady said to me ... this was some years later after she’d seen her dad on a recording, she said, “It wasn’t him answering the key questions. It was when he said ‘Would you turn the bloody thing off.’” [laughter] And that brought it home, that brought back all the memories for her.

Now it doesn’t follow that everyone has good relationships. There can be ups and downs in every relationship. But just giving your ethical wishes, passing on the wisdom you want to, telling the person “It’s okay. They tried their best. So there will be good days, there will be bad days.” Telling them, to my children, telling them you also farted in class is really exciting and novel. They thought every adult is perfect. Telling the things that you struggled with. Often they won’t see their parents’ romance afterwards. Maybe they will see their parents grieve you. And they won’t see them partner. So telling them about early romances. Telling them about things you got right and wrong. All different things down to recipes.

So we put these questions – it’s completely free – we put it on the app. It’s used in thirty-two countries now; up to 14,000 people a day are clicking it. So it is being used. And please use it in whatever way you want. I don’t mind. And as you say, if you want to write it, if you want to draw – whatever you want to do to leave something emotional to kids. Because another thing otherwise we’re saying is, kind of “Here’s the money, here’s the house, here are the keys.” So I think passing on your emotion and your content is fantastic. That’s RecordMeNow.

COMMENTOR 3 [Gail Madriga, Lillooet Hospice Society]: I just wanted to Hi. I’m Gail Madriga from Lillooett and I just ... I’ve worked in geriatrics for some years as I’m positive a lot of you have. And of course in geriatrics, we have a lot of people that are dying. One of the things I’ve noticed in the nursing practices: a lot of nurses are afraid to ask their patients, “Are you afraid of dying?” And I think that’s really, really important that we feel comfortable in that role. That it’s okay. We are caregivers. And that that’s a way to open the conversation. I’ve done it with a few of my patients. And it’s like a light has gone on. It’s like “Oh, it’s okay to talk about it.” And it is just a simple thing but it’s just so, so very important.

COMMENTOR 4: I’m with the Cranbrook Kimberley Hospice Society, which is a relatively small [hospice] and we’re in a relatively small city. So we don’t have a facility and we don’t ... we provide home visit, one on one connection with a trained volunteer. So in listening to you, it’s really nice to see all this high-priced, high-powered help in one place at one time. But realistically, that’s not going to happen with 99.998 percent of our clients. Because first of all, there aren’t that many psychologists and the ones that there are are very busy with people with current problems. So there’s just ... it’s not likely that our clients are going to see people with your training.

So what, in terms of a volunteer who gets about thirty-five hours of training plus whatever else we can do for them on an ongoing basis, what is realistic for us to expect in terms of their approach? What we try to do is to train them so that they are empathetic and that they are prepared to listen and that they are prepared to walk on the journey wherever that client goes. But we are not counsellors. We are not equipped to deal with complex things, issues. So where do we draw the line in that? How would you suggest that we look at doing that? Or should we bother? Should we just be there as best we can and hope for the best?

GRETCHEN HARTLEY: Are there other volunteers or people involved with those relationships that could speak to that?

COMMENTOR 5 [Frankie Hester, Paul Sugar Palliative Support Foundation]: I guess, my name is Frankie and I'm from the North Shore. I work through Lion's Gate [Hospital] as a volunteer, and through Family Services [of the North Shore]. What I wanted to say just in defense of that is recently I had a conversation with a gentleman that was in hospice and everyone thought he was quite confused. And I like to do the breakfast shifts. And this gentleman was having some difficulty with managing his meal. So I just sat there because we're not allowed to feed anymore. And he, after a short while, he woke up and he said to me, "You're a volunteer." I said, "Yes". He said, "I want to know. What's it going to be like when I die?" And I said, "I haven't had that personal experience. But the reading I've done and what I've heard is that it's not unpleasant. It can be very pleasant. And it's not so frightening." And I said, "Sometimes people tend to sort of cross over a line and come back." And he said, "That's right." And I said, "Sometimes people come that they're familiar with from the past" And he said, "Yes. Mommy." And then he just closed his eyes and said "Thank you." So it was ... he just needed somebody just at that moment to be able to listen to his fear and maybe have some explanation of maybe what might be happening."

GRETCHEN HARTLEY: Yeah. I've heard that story from other places where sometimes it's the person that cleans the room that's just there quietly and able to have a little conversation every day and ... that's really valuable.

COMMENTOR 5 [Frankie Hester]: I was available. So I think as a volunteer it was a gift for me and it was a gift for him. Because it was so wonderful to be able to share that moment with him. It made my day.

COMMENTOR 6 [Mike Hickey, Prince George Hospice Society]: My name is Mike Hickey. I'm visiting from Prince George. I did the session just before this one here that talked about the social conversation piece. And there were two kernels of wisdom I took away from that. And Don [Morris] was one of the panellists there and that's how I managed to get them from. And the piece for me was start the conversation. And have it with your wife, have it with your family. Take the taboo out of there.

And the other piece was making sure we change the culture. Because Janet talked about it as well and said "I've had the conversations with my family, and they're not so easy." When I look around the room, I'm thinking the people who are here, you made it to where you are today mainly because you're a good planner in life. How many people in this room have planned their advance health care directive? I haven't. So we've got three out of thirty-five. So if I was buying lottery tickets tonight, that wouldn't be very good odds. But I think the big thing is taking the taboo out and starting the conversations really early.

The first time my wife and I travelled without our daughter – we have one daughter, she's 24 now – but when she was about 12 or 13 years old, we travelled for the first time without her. And I said to my wife, "We need to make sure we have our will." "Oh my God, no. We can't talk about dying. It means we're going to die if we talk about dying." And ever since we've been changing our will. But even when I go home now, I've got to have that conversation again. Because for me, I want that legacy. I want people to know what I want when I die. And it's going to come sooner or later.

In the session this morning we talked about the presentation, I think it came from Steve Jobs, and he said “Plan your next six months. Live for your next six months.” And that’s what we need to do. We need to get out there. Get that living happening. And get the word out there. Because is it, what kind of salesmen can we be if we don’t believe it ourselves. So we’re not facing our own mortality in saying, “Yeah. I better get my planning done.” How can I go to the bedside or into someone’s home and convince them they need to do it. So I think that’s, we just need to be better at selling.

COMMENTOR 7 [Barb Warren, Comox Valley Hospice Society]: Barb Warren from the Comox Valley. I think that your point is really well taken. I think we need to start at home. And recognize where the ripples are. I started, when I started doing the advance care planning work in the Comox Valley, I started with my family. I have three adult children and my husband and I travel together. And so I had to have the conversation with all three of my children because all three of their phone numbers are in my passport. And they all needed to hear the same information.

But the fascinating thing was, once I started the conversation with them, so my two oldest children have children. I found out they didn’t have wills. One of them is in a blended family and there was the whole conversation about “Well, wait a minute. What happens if I die and I’ve got three children from the first marriage that I don’t want them to be split from the two children that ...” So we got in ... so the ripple effect was that both the children who have children now have wills. Their friends now have talked about what would happen for them. So in fact the ripple effect of my conversation with those three children has been that I’ve hit adults in the 35-45 age range that surround my children and I’ve hit 21 year olds who surround my eldest grandchild. So in fact we need to recognize there is a ripple effect if we start. And I think ... I challenge you. You need to start.

COMMENTOR 6 [Mike Hickey]: And that’s what drives the cultural change.

COMMENTOR 7 [Barb Warren]: You bet.

GRETCHEN HARTLEY: And so we’re talking now a little bit about wills. But of course as a lawyer friend of mine says, we’re better at planning for when we’re cold than we are for planning for when we’re still warm, but ...[laughter]

COMMENTOR 8: I’m Geri Arkell and I’m from Campbell River [Hospice Society]. I do advance care planning for our community. What I found is I started out with very decrepit old folks, some with breathing troubles, chronic illness. It didn’t go very well. I think because of the finality of it all. Anyway, so I’d made a decision that I’m now going for the fifty plus people. I’m going to the women’s groups because we all know that women will get this done. And so the women, the 50 plus women will get their 20 year old daughters, they will get their mothers and they will get their grannies. And that’s how we need to do this. And so with this talk too, I try to bring some of my nursing background to say, “It’s not like TV. “

CHELSEA COOLEGE: I’m wondering if we should ... I don’t think any of us addressed ... I’m sorry I don’t know your name but ... I guess my one thought is that’s fantastic training ... empathetic listening, being present. I don’t know if it’s possible but having maybe like a peer mentor group or some kind of group for the volunteers to be able to go back and consult with, say “I’m facing the situation. What can I do to help support this person?” Whether that means referring them on to a social worker or psychologist, or is there something they can do in that moment to help. So is there a possibility to have some type of consultation service for them to go back to and check in with? But I think it’s not an easy answer, especially in small towns I realize it’s a challenge when there’s not the professionals who are there. And the volunteers do a fantastic job and I think that’s sometimes more important is to be there and the empathetic listening.

JANET COUGHLAN: I was going to say much the same thing actually. That I think volunteers ... I would really validate the role of volunteers. You can reach so many more people. The empathetic listening is often the core of what people are seeking. But I do think you need professional back up and if you don't have that, then I would hope there are ways you can search that out somehow. I know in the palliative teams I've worked with, we've been there for the volunteers as well. And the hospice societies had professionals on board. As Chelsea said, that's not always easy in small societies, but, in small towns, but I would hope that there is some way that you can have that link. Because I do think it's important. There are times when maybe you just need reassurance that you're doing the right thing. But you also need to know when there might be a more serious complex problem.

GRETCHEN HARTLEY: So we've got a couple more brief questions – I'm just looking at our time here – which is about the potential for psychology and counselling professional organizations to partner with hospice palliative care organizations to promote both public and personal conversations on death, dying and advance care planning. So asking about your organizations. And I'll put that out to this group and ...

JANET COUGHLAN: Well, if I could jump in. I did bring an example with me of a program that was done in 2011 as a partnership between Crossroads Hospice and the Tri-Cities Palliative Care Team. So the Executive Director of one and the social worker from another came together. And they actually based the program, which was I think a six-week program, on a book by Dr. John Izzo called "The Five Secrets of Dying" [The Five Secrets You Must Discover Before You Die]. And there was an introduction and they addressed one of those as a focus for the program every week. But it was held at Douglas College and a lot of people were involved in helping to fund and facilitate this. It's just an example. It's an isolated example. There are probably many other programs that have been done in other parts of the province. And I know it possibly didn't reach everyone that it needed to because there was a fee for attending, a small fee. But I think there's a lot of potential in developing more programs. And I would hope that we could do for death and dying, the same kind of thing that we've done with grief over the past few years, which is to bring it out into the public. To make these programs, you see them in the newspaper; "There's a grief support group at ... starting ... "And maybe we can do something similar for death and dying to promote this public conversation.

CHELSEA COOLEGGE: I think we can take lessons from ones ... from public awareness campaigns that have gone well and have created change like, what's that "Not All Bugs Need Drugs"? Whatever it is. There's something like that. And there's lots of commercials about dementia care. And I know those are different examples but what worked with those? And what lessons can we learn from that? And can the professional associations work with hospice and palliative care associations to have some type of public awareness campaign like that? I don't know what that looks like. That's quite vague but let's learn from what works out there.

GABY EIREW: I'm a big fan of Bucket List Festival which I hope you all know about. If you don't have it in your community. I know Pippa Hawley who is here today and who started it is very generous and she just wants to get it out. Bucket List, if you don't know, is a way of people dealing with end of life to come and meet. It's a very positive setting. It's very informative. She gets lots of speakers. And people can meet each other when they are grappling with all different issues. I think we're getting there. But I think we all could help carry it forward.

SANDRA WONG: So actually for the BC Psychological Association, so we would like to provide more opportunities to educate the public and also maybe to train people who have this ability to listen, to [provide] empathy and to support. And also we want to send out a positive message is the time of preparing for dying is something to celebrate. Because we all want to leave a legacy. We want to [leave] something that have some good memories or have some life examples for the next generation.

And so it's good to encourage the awareness and also to have more people engaged. We are the group who can start the conversation and also try to do something together.

GRETCHEN HARTLEY: I love that notion, that time to have those conversations is a time to celebrate how we think about how we want to live our lives.

SANDRA WONG: Yes and also I think talking about, we're always talking about PTSD, Post Trauma Stress Disorder, but now we are more talking about Post Trauma Growth. So, when you're dealing with some crisis, like dealing with death, it's a time for you to grow. You know that the time's limited but you want to grow. And you want to have added value so we can see it from different perspectives.

GRETCHEN HARTLEY: Other ideas about partnering and paying these ideas forward?

COMMENTOR 1 [Lynn Wood, Oceanside Hospice Society]: As a small non-profit operator, we're always challenged with getting money for what we need. And I really can appreciate what you were saying about your experience with using volunteers. We were faced with not having a counsellor available to deal with bereavement and loss. And we got a United Way grant to hire a counsellor with the notion that part of the fee would be donated back to the Society, so that would reduce the professional fee. And I think that there's lots of opportunities out there, especially in small communities, to try and get the fee donated back or half of the fee. Because it's very prohibitive for some small societies to pay. And they, those professionals would gain a tax receipt from the donation back. So you actually have to pay the person the full fee, then they give you half of it back and then they get a tax receipt. So there's a lot of innovative ways that you can get professional expertise and assistance as a non-profit. Just throwing it out there.

COMMENTOR 2 [Don Morris]: I'd like to add something. A friend of mine – a psychiatric nurse – told me about the success of organ donation programs and they have a slogan like “Give the gift of life.” And I think somehow we can, we're intelligent enough to dream up a slogan that's something along the lines of “affirm the preciousness of life, discuss the finite nature of it”, or something. We need to get going on it.

JANET COUGHLAN: Could I just say the program that I was talking about was called “Make Dying Livable”.

GRETCHEN HARTLEY: Final comment?

COMMENTOR 8 [Geri Arkell, Campbell River Hospice Society]: I just wanted to remind people. I don't know how many have accessed the training manual for the BCHPCA and the Canadian training manual for volunteers. But it is just chock full of resources, so just go into it. We get it sometimes and put it on the shelf and take it out as we need it. But it is just a valuable tool that we can use as a resource.

GRETCHEN HARTLEY: Well thank you to everyone. Thank you to our guests and thank you to everyone here for stretching ourselves a little bit about how to open this conversation up in different ways and in different places, particularly through these counselling or supportive relationships. And I think it really is true that it doesn't need to be a professional relationship to be a really, to have a really vibrant conversation. Thank you all.

REFERENCES

- Bucket List Festival

phawley@bccancer.bc.ca

- Death Café
<http://deathcafe.com/>
- RecordMeNow
<http://www.recordmenow.org>
- Centre for Health Aging Transitions, Carey Institute
<http://www.carey-edu.ca/centre-healthy-aging-transitions/>
- Walter F. Bailea et al. (June 12, 2000). SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer. *The Oncologist*. <http://theoncologist.alphamedpress.org/content/5/4/302.full>
- John Izzo (2008). *The Five Secrets You Must Discover Before You Die*. San Francisco CA: Berrett-Koehler Publishers.