

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

Social Conversations

MODERATOR: DONALDA CARSON, BCHPCA President [Incoming] Executive Director, Prince George 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 your program/event in engaging and educating the public about death and dying, and advance care planning
- the potential for your program/event to partner with hospice palliative care organizations to promote public and personal conversations on death, dying and advance care planning
- the potential for your program/event to partner with hospice palliative care organizations to advocate for hospice palliative care in British Columbia

DONALDA CARSON: Well welcome everyone. I think we'll get started with this session. And I'm quite excited to see so many people here. This mic's not amplifying it in the room, it's recording it. So I'll speak louder so all of you can hear me. And now that you're quiet, you will. My name's Donalda Carson. I'm the Executive Director of the Prince George Hospice House and Hospice Society. And I'd like you to know that our President is here today, Mike Hickey. And so I have to be on my best behaviour and I'm really nervous about doing a good job now. So I'll be the moderator. And if you want to make comments, I have to run over and put this mic in front of you because it's all being recorded.

So now my job today is to read what we're doing here. It's about 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. And I'm sure you've all had some experience with that, whether it be successful or unsuccessful. My next job is to introduce the people at the round table. They're called experts today.

INVITED EXPERTS

- BUCKET LIST FESTIVAL: DR. PIPPA HAWLEY, Founder; Team Leader, Pain & Symptom Management/ Palliative Care Program, British Columbia Cancer Agency; Clinical Assistant Professor and Head, Division of Palliative Medicine, Department of Medicine, UBC Medicine; Director, Pallium
- DEATH CAFÉ IN BC: DON MORRIS – Victoria, ROSS WADDELL – Vancouver, ABEGAEL FISHER-LANG and ANN GILLESPIE – North Shore, DONALDA CARSON – Prince George
- DEATH PICNIC: DR. MARYLENE KYRIAZIS, ROSS WADDELL, Canadian Centre for Death Education
- ALL SOULS: PAULA JARDINE, Artist in Residence, City of Vancouver Mountain View Cemetery | Royal Oak Burial Park, Victoria

Dr. Pippa Hawley is here. She's the founder of Bucket List Festival. She's the team leader of Pain and Symptom Management for the Palliative Care Program at the BC Cancer Agency and a Clinical Assistant Professor and Head of the Division of Palliative Medicine, Department of Medicine at UBC.

Death Café has a few members here, a few experts here. Don Morris from Victoria is involved with Death Café. Ross Waddell is here as well from Vancouver. Abegael Fisher-Lang and Ann Gillespie [North Shore]. And myself and I'm eliminating myself as an expert on this topic of Death Café today [Prince George] so that I can operate the mic.

Death Picnic? Oops, sorry. Canadian Centre for Death Education. That's Marylene [Kyriazis] who's a co-board member with me [of the BC Hospice Palliative Care Association] and Ross Waddell.

And Paula Jardine, Artist in Residence, All Soul's, City of Vancouver Mountain View Cemetery [and] Royal Oak Burial Park, Victoria.

So it's exciting to have all these people together and we'll get started now. And I have to advise you that the roundtable session is being recorded and the recording will be transcribed and summarized. And now we will have our experts make some presentations. Comments.

ROSS WADDELL: Comments. Just read the questions.

DONALDA CARSON: The current nature of public conversations on death, dying and planning for care and the paths to opening these conversations. So we'll have twenty minutes to talk on this topic.

ABEGAEL FISHER-LANG: Could you say it again please.

DONALDA CARSON: It's the current nature of public conversations on death, dying and planning for care and the paths to opening these conversations.

PAULA JARDINE: I'm happy to start. As was mentioned, I'm an artist in residence at Mountain View Cemetery and as well at Royal Oak Burial Park. And the position is one that I invented myself because I am pushy and because I felt the need to bring more beauty to the experience for people following a death. And since being introduced to the subject of death I – and it was through my father's death that I was introduced – I've realized that it's a massive subject that permeates all of our lives, and what a gift to know that.

But to answer the topic that we're talking about, by accident then through my work at the cemeteries, I've realized that by creating social situations as we were just discussing, for instance the flower brigade the night before the event – a gathering of people at Royal Oak or on the morning of the event at Mountainview – we make flower garlands to decorate the altars where people from the public will come and place tributes in memorial of people. And those situations, there's casual conversation and an invitation implied because we're doing an event to remember the dead that finally this is a social situation where we can talk openly about death and if you cry, nobody's going to be upset. They're in fact just going to be very supportive.

PIPPA HAWLEY: I just wanted to say I think the biggest problem we have to just answer the question about engaging the public in conversation is the whole idea of death. And my aim with introducing the topic in a more positive light with the

Bucket List Festival was to focus on the positive aspects of living with a life threatening illness. Because there's a lot of possibility for transformation and resolution and really, some amazing things can happen when people know that their life expectancy is more limited than it would be just normally. So that concept of presenting the topic in a positive way rather than with the "d" word in everything, I think was one part that I felt was missing.

Most people learn about dealing with their own death from other people's funerals. That's how, they sit there and they go through the funeral and they reflect on how they might deal with things themselves. And then they go from the funeral and then they don't deal with it unless they're facilitated by some of the excellent work that goes on after the fact. But my issue is that we're not going to be able to engage people and have the conversations early enough if we wait until the patient's non-verbal and in the last hours of life or has already accepted their inevitable short duration and demise. So I guess that's the one point I want to get across. We've got to get people in early. And I know it's good to raise the 'd' word – it has to be said – but they have to be in the door before you can do the work. So getting them in with something on a more positive aspect is where I was coming from.

DONALDA CARSON: Don?

DON MORRIS: This whole topic, this whole subject and any changes that we're going to make for others, we have to begin by making them for ourselves. So these difficult conversations are best when we connect our heart with our mind with our will to chat it up with those closest to us. And then from there, you get comfortable with it. It's been my process and continues to be my process because it's uncomfortable. However, it's empowering, it's enlivening, it's about life, and it gives us the opportunity to express our values. Thank you.

ABEGAEL FISHER-LANG: May I also add to what Don – my name is Abegael from the North Shore Death Café – that's my other hat is storytelling. To engage in a way which opens the conversation very, very widely. So in our Death Café the tables are open to discuss any topic that anyone wishes. We even have cards on the table that have poems and writings from other people which can start the conversation. So conversation actually starts with, "What is the little death that is happening in your life today? Are you moving? Has someone, something shifted that you unexpected?" So we experience death in small ways all the time to prepare us for the big threshold.

And it's always amazing to me how strangers will come through the door to our Death Café and not know each other at all and be able to sit with a little group of three or four people and open their hearts and minds as Don has said, and have a conversation which is about their deepest, most intimate experiences and fears and curiosities and questions and share that information in such a warm environment. So I feel that this conversation goes before all the conversations which are really about the practical aspects of preparing for the end of life. It's really a human experience.

ANN GILLESPIE: Yeah. I was just thinking it's sort of the airplane syndrome, phenomenon, when you get on a plane with strangers and you leave thinking, "Wow. I just met somebody that I totally connected with at a deep level" because you don't have those kinds of conversations in our everyday lives sometimes. I think all the years of outsourcing in the last hundred years or so – outsourcing death – has separated us from the experience of it. And the collective holding of that experience. And I think Death Café actually does allow us to bring back some of the ... and what you're doing [Paula Jardine] at Mountainview, bring back the collective experience and the shared experience of death. And sort of to try to reclaim – you talked about the values and the stories and those kinds of things around death that we've sort of lost touch with.

And somebody had a lovely phrase which I've co-opted which is reclaiming the ... around "the time of life that is dying". So we think about death as sort of jumping off the cliff and it's not considered part of life whereas I really like that phrase: "the time of life that is dying." So that we're still in life and so that we can look forward to that experience as part of life rather than thinking of it as this separate experience.

I think it's this isolation, the sense of extreme isolation around dying and death that puts the fear in people. And I think that the pathways to discovery are many. So the public events and the Death Cafes and I think the more opportunities people have to learn the words and the language ... it's like we've forgotten the language, I think, and to be articulate around death issues. So I think all these things allow, and there's a lot more happening so there is a groundswell.

DONALDA CARSON: Ross, do you want to make any comments, or Marylene on this first statement?

ROSS WADDELL: I come at it from a number of different perspectives – both Death Café and Death Picnic. And/but I'll talk about my perceptions generally around the issue of conversations around death. I'll tell you my background that got me into it and that was I work with people who have near-death experiences. And for the most part, the people who have those experiences have no fear of death. And I thought scientifically, and as a phenomenon, to have that as the consequence of going through that experience, there must be something being told to us in those experiences. Not everyone has no fear, but most have no fear coming out of the experience.

So I started exploring the issue of fear in death and one of the most renowned writers on this is Ernest Becker who did live in Vancouver and he did die of cancer at quite a young age. And he wrote about the fear of death and how this was at the root of all our fear in life: it was the fear of non-existence essentially.

And so as others have said over time, our ownership of this conversation has been moving into the professional world, into government ... It's like someone else owns our death. And what I'm learning is that we need to take ownership of our own death back. Part of that is being able to talk about it. And you will fear less ... I won't say you won't fear at all ... but you will fear less what you know and you understand. And the only way you're going to know and understand is if you talk about it. And that starts with a personal conversation and a social conversation.

So all of these things that are being represented around the table today, Death Café, Death Picnic, what Paula does, the Bucket List Festival all represent approaches to that. And I'm hoping in the next question that each of you could just describe briefly how you do what you do, like how you do Death Café, how you do the Bucket List Festival, because not everyone will be familiar with exactly what it is you're doing.

DONALDA CARSON: So we'll go on to that next question. Marylene, did you want to speak about this first.

MARYLENE KYRIAZIS: Well, yes and as most of those people said or mentioned, it's not only being able to be involved in those conversations, but even just being able to be in, able to be exposed to situations where you can hear the conversations about death and dying. Even that is a good first step, for those who actually don't want to get involved in talking about it in a safe place where anybody can talk about, anything related to dying.

DONALDA CARSON: Thank you. So the next piece is the current and potential role of your program or event in engaging and educating the public about death and dying and advance care planning. So if we would have the people at the table give their comments about that in regards to their program and the role it has.

PAULA JARDINE: Well I would jump right in. The point of calling myself an artist in residence at a cemetery to me was half of the project. Because it shifted people's thinking of "Oh, art. What does art have to do with death?" And I could go on about that for quite some time. But it was an exploration of what our role as artists in the sacred life of the community is that continues, actually, to drive us as artists. But it's also responding to traditions that I feel were left behind by my ancestors and I've only learned through books – well, started working from the outside in. But it is mostly creating space that you say specifically, "This is a space for you to remember your dead. We're going to create a sanctuary of beauty", is what we call it, "where you can come and it is completely safe for you to have your feelings."

In Victoria at the Royal Oak Burial Park, we do a daytime event on summer solstice or the Saturday closest to summer solstice. We have long pieces of paper that people can write messages on. Two poets wander the area and sit with people. And at the end of their conversation, present a poem to the person based on the words – their own words. We have a woman who collects hankies throughout the year and the poets have beautiful handkerchiefs so if someone is brought to tears, they are gifted with this beautiful hanky. And this all evolved from the many hands that touch these projects. Everybody brings something beautiful to it. And we have music throughout the landscape and the Ensemble Laude sing in the mausoleum, which is sublime. And then we end with the Homegoing Brass Band doing a procession through.

In Vancouver, it's a nighttime event which starts on the Saturday closest to Halloween and then we keep the candles lit throughout the week until the morning of the 2nd of November and that was so that we didn't blow out the candles before the Orthodox tradition of lighting candles. It seemed rude. And it's kind of grown into its own All Souls Week where people know that there will be things going on at the cemetery. They can come and they can have a cup of tea. There are materials for them to make some beautiful tribute. There are people there who they can talk to or not. And the same with ... the special thing about doing it in the dark is that when you feel overcome, you can step back into the privacy of darkness and have your feelings. And there's something really nice about that as well.

DONALDA CARSON: Great. Thank you. Really profound. Would you like to be next?

ABEGAEEL FISHER-LANG: Sure. And I have such respect with what you've done and it's almost like you need to give workshops for every neighbourhood to have this experience. I just think it would be great. In our Death Café, we work, I would, we have an artistic orientation I would say. We are about to do our fourth one next week and we actually have flyers here if anyone is interested in them. Next week's is called "Death Seeds, New Life" so it's the idea of the season and the seeds and the darkness through the winter and then coming into new life. So the question is "How has the death of a beloved brought seeds of life to you? And what seeds of life would you long to live, to leave?" And we will have seeds in pots or something like that which will work in some artistic way.

Before we've done a lot of poetry. The last one we had a short video by Steven Jobs. Ann brought this beautiful ritual. Just a clip for 50 seconds where he was asked, he did a commemorative convocation speech, and he said to the young people, "You're going to be planning your career and your life but the most important thing is how will you live for the next six months." So we saw that and everyone had paper and envelopes and they wrote a letter to themselves dates six months from then, sealed them and we mailed them six months later.

And then we did a Dios de las Muertos [Day of the Dead] with a great table full of sugar skulls and everyone brought pictures and it was like a festival. So I think art really plays a strong role in souling the conversation. So it's not a bleak conversation as has been mentioned here between life and death. It's like, "Yes. Art brings us together, hearing the stories, sharing things,

writing, drawing, listening, having beautiful tables with flowers and cake arranged.” So, yeah. We had, we were just written up today in the Vancouver Courier. So there’s a nice article today in the Vancouver Courier on Death Cafés, on ours in particular. So we have copies of that too.

DONALDA CARSON: Do you have anything to add to that Ann, on Death Café?

ANN GILLESPIE: No, I spoke, that’s well described. I would just say that I think what we find is that people leave feeling really liberated from having the conversations that they have, so. And that sense of shared humanity. I think that comes from those conversations but ...

DONALDA CARSON: Don?

COMMENTOR 1: Is it possible to ask a question?

Donalda Carson: Yeah. We have a question.

COMMENTOR 1: In terms of the Death Café, who is your target? Is it people who have suffered a loss or just anybody, or both?

ANN GILLESPIE: Generally not. We actually don’t recommend that people come if they have just are grieving or experiencing, in the midst of somebody, helping somebody who is dying. Because I think it’s just too emotional.

DONALDA CARSON: It’s the general public that you’re attracting.

ANN GILLESPIE: The general public. And generally we’ve had some young people but generally it’s us.

DONALDA CARSON: A question over here.

COMMENTOR 2 [Lynn Wood, Oceanside Hospice Society]: Yes. I’d like to understand the logistics of it. How do you set it up? What does it look like? Why would people want to come in?

DON MORRIS: The beauty of the Death Café is that it’s a social franchise, and it’s not dependent upon experts of any kind. And so you go the website. Everybody can run one. And I encourage everyone to consider it. Go the website: deathcafe.org and follow the links that then ... download the PDFs that tell you how to do it.

Now I love these Death Cafés because they’re very enlivening and they’re bonding. And it’s a place for people to go to talk about whatever they want to talk about. And I’ve – my wife and I were privileged to put on the first cafés in Canada and I’m privileged to have a deep relationship, a growing relationship with Jon Underwood who is the founder of this. So every now and then we skype, we get together and talk. I share my process and for most of our cafes, we would have pre-thought out topics, maybe a speaker, and so on.

And Jon and his mother who is a psychotherapist, who was advising him from the start, they’re moving the Death Café away from movies, experts, speakers, because we’re the experts, each and everyone one of you. And people come to a Death Café and maybe their mother died four years ago but something’s incomplete. Or maybe their best friend is a doctor who is 65

[years of age] and is considering having cancer surgery with the hope that it will give him a little more life. And he's, the friend is really upset about it.

So I've been slowly falling into Jon's direction, because I know what's coming next. Jon's going to establish a physical Death Café in London over the next few years and it will be a venue for all different creative kinds of performances around death movies and singers and artists and poets and you name it. It's like, serve coffee and tea and like – not a Starbuck's – but a real café.

So I've moved from a lot of bringing in interesting people and having topics. It was going so well that I announced that in two weeks we're going to talk about suicide. And It was wonderful. Everybody ... it touches every one of us. Everybody had a lot to say. But I'm kind of backing away now. However, when there is not enough juice or energy to talk about a particular topic, then it's just fine to present a particular topic for people to talk about. So in this format, Death Café is very democratic and it honours whatever, what each and every person brings in that night for discussion.

DONALDA CARSON: Pippa?

PIPPA HAWLEY: Yeah, so the Bucket List Festivals, this was, the first one we had was in 2011. Originally, it was an idea I had to actually work as a fundraiser for the Ride to Conquer Cancer. And we had one in the Cancer Foundation's spaces at the BC Cancer Research Centre. And it, the feedback I got from it afterwards, wasn't just successful as a fundraiser. It was that the people that attended really found it helpful and useful and they wanted to do more.

So subsequently, we've had a number of other events using the same format and we've had one in Coquitlam, one on the North Shore, one on Vancouver Island. We're going to have one in Chilliwack in September [2014]. I'm hoping that they'll be other places in BC that we can have them going forward. I'm hoping that the hospice societies that have held, organized them will then move to having them again so that it will become a recurring theme.

And I think across the spectrum of people that need to engage in these conversations, I'm trying to get the people that are pre-Death Café. People have already done a lot of work mentally to enter into the concept of the Death Café and it's a fabulous thing to have there in the future. But 90%, probably 95% of people have no way they're going to go into anything like that. And they really need practical, solid information and that's what I'm trying to provide with the Festivals.

DONALDA CARSON: We have a question.

COMMENTOR 3: Is there a website that we can go to to get more information?

PIPPA HAWLEY: There isn't yet, but you can e-mail me. I have applied for the trademark for Bucket List Festivals, not because I want to make any money out of it or anything – far from that. I want to make sure that I have some control because if you do Google "Bucket List Festival", you do come across a number of other things which are not what I would like. And I think there is potential for it to be misused. So I'm hoping ...

COMMENTOR 3: What's your e-mail address?

PIPPA HAWLEY: phawley@bccancer.bc.ca. Once I've got approval for the trademark, which has been about four months since I put the application in, if I do get it then I will register a web domain and then I'll be able to get a website. But I want to get a trademark first.

PAULA JARDINE: What ... might I ask what happens at a Bucket List Festival or is there a chance later?

DONALDA CARSON: Yeah, sorry.

PIPPA HAWLEY: With the help of the local organizers in the community that we're having one, we have a group of speakers who are mostly local who come and give short talks on a variety of different topics through the day. And I try and have an up followed by a down followed by and up followed by a down. So we'll talk about how to travel when you're not well. There's certain things ... it's all very well to say "On my bucket list, I want to walk the Machu Picchu trail." But if you've only got one leg or you're really short of breath and oxygen, you can't do it. Or on the other hand, there are things you can do. Or there may even be ways that you can do the Machu Picchu trail if you work things through correctly, if you know who to ask.

So it's practical stuff like how to get insurance: what happens if you die overseas and you need to have your body repatriated. There are actually insurance coverage, things you can get for that. So it's practical stuff. My mother is in the early stages of dementia. What will happen when I can't take care of her anymore? Well this is how you navigate the health care system. These are, this is the difference between palliative care and hospice and residential care and we go through all of the practical stuff. I do, I usually do the session on living wakes. I've attended a number of living wakes. A lot of patients having living wakes. So I teach people on that.

And Gaby Eirew who is also presenting here at this Forum, she has a marvellous presentation on legacy making with Record Me Now. It's a way you can record your legacy. It's kind of dignity therapy without a dignity therapist which [Dr.] Harvey Chochinov was speaking about just recently. As I was hearing him describe dignity therapy, it's very basically what Gaby does on the website, you can do anywhere, anytime, anywhere in the world as long as you've got a laptop with a camera.

DONALDA CARSON: I did a CD, it must be ten years ago now, speaking to my sons about the values that I taught them and what I wished to see in my older years and those kinds of things. So it's pretty neat. And Pippa has sought out wanting to have a Death, I was going to say a Death Café, a Bucket List event in Prince George in October. So we'll be talking more about that and we're all really excited about it. So Ross?

ROSS WADDELL: I'll talk about both Death Café and Death Picnic. They kind of go together and you'll find out why. Just with Death Café to start, the way it started was actually a Swiss sociologist named Bernard Crettaz, started an event named Café Mortals and it was the first Death Café, in French I guess. And that was round 2005?

DON MORRIS: 2004, in Switzerland

ROSS WADDELL: 2004, okay, in Switzerland. And then it moved to France.

DON MORRIS: Paris.

ROSS WADDELL: Paris. And then to London. And Jon Underwood who sort of leads it out of London and his mother was involved with the Natural Death Society [Centre] which was started about thirty years ago to try to have people take that

ownership back of their own death experience. It [the Natural Death Society] involves a number of different perspectives on death such as home funerals and green burials and things like that. But that was the general focus of it was to have personal ownership of your experience.

And then it [Death Café] arrived not that long ago, when Don started it, that's not that long ago and he was the first one in Canada. And it's kind of exploding all over the world so all the ones that we're doing collectively, there's many, many in cities throughout the world that are occurring. So if you go to the website, that's where you can follow what everybody's doing because they both put their invitations on the web through Jon but they also report on what happened at the events. Each event is kind of different. But the basics are tea, cake and conversation. Not to say that you have to have cake because I know Don does potlucks sometimes.

DON MORRIS: Well we do a lot of things. We like being gracious.

ROSS WADDELL: You do a lot of things. But there's many ways of doing it with a focus on conversation. With Death Café Vancouver, a short story. We found a venue which is in Vancouver which is a sort of trendy corner store, artisanal shop, café – sort of Parisian and Bohemian so we thought it had the right atmosphere – and we approached the owner about hosting it. If you're not used to having somebody come up to you and ask you, "Can we talk about death in your facility?" [laughter] they might question it. But we thought this person probably would be open to it and she wasn't sure.

But she was out with a friend and walking in Chinatown, a different part of Vancouver, and they were walking and they saw this shop and it was getting ready for some new retail business. And some guy went down the street and said to the owner of the shop who happened to be standing outside, looking through the window as the person we contacted went by, "Oh are you opening a Death Café here?" [Audience: "Wow"] Where would that come from? How would he have even known about it? So the woman that we approached said "That was a sign. We needed to have Death Café in our facility."

Ann and Abegael were there. The problem was that it had a very loud compressor, refrigerator. It's not a very big space and a loud compressor. So if you were at the back of the room, you couldn't hear the conversation. So there are logistical issues which we can all share with you if you want to do one of these. So please feel free to contact us if you want to know about any of these things. We'll tell you the good stuff and not all the bad stuff.

We had a real interesting mix. We had half hospice palliative care professionals who were young, really young, because they were friends of my co-host, Joan Trinh Pham, who is a hospice palliative care nurse. The other half were just a whole range of people. Some who were dealing with death, some who were, who had a recent death, some who were facing a death in the near future, a whole range.

But one thing that I do remember is the hospice palliative care people said "We do not have the opportunity to have this kind of conversation in our palliative care teams." They can talk about the clinical aspects – how to approach it from all the perspectives of each of the professionals, because it's all about inter-professional approaches – but the intimate conversations they couldn't have.

And we kept the conversation completely open. We didn't have any topics at all. Things are sort of changing as we do more but we still at the moment are keeping the conversation open. And sometimes it works and sometimes it doesn't and I won't tell why it doesn't work but you can ask me later if you want.

The other thing that I remember coming out of that first Death Café was everyone – a number of people said “It’s like sitting around the campfire.” Well, where do you have the most intimate conversations in Canadian life? Around the campfire, at the cottage, at the beach. These iconic kinds of memories from childhood or from family life where you get into a really, really intimate conversation about things. And at nighttime. And at nighttime. So this is where the idea came for Death Picnic. I talked to Jon Underwood about doing Death Picnic as a Death Café thing, doing it outdoors and he said, “Well, we’d like you to keep the branding Death Café Picnic.” But as it evolved, we decided, Marylene and I decided that wasn’t going to work exactly because this was actually a different event.

When you are with a group of people that you don’t know, and you don’t know what to talk about, what do you talk about?

DONALDA CARSON: The weather.

ROSS WADDELL: The weather or nature. If you’re a true Canadian, you’ll talk about “Oh isn’t it nice outside?”, “It’s raining,” Or “It’s sunny.” Or “Did you see the big tree that fell down across the street?” Or that kind of thing. So I got thinking because what the Canadian Centre for Death Education is about – I’m going to back up a bit here – I do some work with the National Centre for Death Education in Boston and it educates professionals around death and dying issues and I said “How about opening a Canadian version of it” and they said “Great.” But I knew that I couldn’t get up to speed with them right away because they’ve been at it for thirty years.

So I thought, how do we do an approach, how do we come into this? And we knew that there was a real need for public conversation at its most basic level, even before people are thinking about death, just the real opening of it. So we were taking all the pieces of information: if you don’t want to talk about it – the one topic that’s a taboo – what do you talk about instead? You talk about weather, you talk about nature. So let’s put it outside. Let’s make it like a campfire. Let’s do it at night time.

So we have the first one planned. It’s going to be in Stanley Park because we needed an iconic location. It’s going to be at Prospect Point on August 25. Why did we pick that date? It’s the last Monday before the long weekend [Canadian Labour Day]: the death of summer, the end of summer – maybe not in Vancouver but in most of Canada. It’s a weekend when people are spending time with their family, on vacation, at the beach, at the cottage, camping. So it’s part of that time when people are closing out with their family and their loved ones for the summer. I did climatic research and found it’s the day that’s least likely to rain across Canada [laughter] – on average in every location.

And what Death Picnic is going to be is a low organized event: people will come, we will have blankets set up on Prospect Point, we will have storytellers. It’s going to be an evening of stories about how things die. Not necessarily people, although it could be people. It could be about pets, it could be about trees, it could be about whales. That was the latest suggestion that was given by a friend because there’s a big news item right now about Newfoundland. It’s got this big dead whale sitting on the beach and no one knows what they’re going to do with it, so ... We want families to come, so we want things that kids would like, so we’re going to talk about how dinosaurs die, we’re going to talk about how stars die.

We’re going to open the conversation at the most fundamental level about death and it doesn’t have to be about my death or your death. It’s just about death and dying. And so we’ll have these stories. We’ll rotate through the evening. You can pick – it will be like this [pointing to Forum program]. It will be the same sort of set up where you can pick what you want to talk about. Forty-five minute storytelling, move onto a different blanket or stay at the blanket you like.

We want this to go across Canada. So we have the one date. Anybody can do it. It's low organized. All you have to do is promote it and we'd like to do that centrally like Death Café. And people bring their own picnics. You don't have to feed anybody. All you have to do is get people who have something really interesting to tell you about what they do, what they study, what they love. And I know there are some people in the room who are storytellers who will be asked to be there.

DONALDA CARSON: Thank you Ross. Marylene, I'll let you start first with the next question if that's okay with you.

DON MORRIS: Could I just add one thing? It will just be ten seconds. To bring the Death Café home to each and every one of us, what is so wonderful is to invite over to your home – not for dinner – at 7:00 for dessert, six people. And have a discussion about the preciousness of life and death. And that's a Death Café right there and that starts it going for you. There's Death Cafes – you know it's kind of a big, sounds like a thing – but some of the most touching ones are in our home with six or eight people. Thank you.

DONALDA CARSON: Okay. We have to move on now to the next question. The potential for your program or event to partner with hospice palliative care organizations to promote public and personal conversations on death, dying and advance care planning. So this is about partnering with hospice programs.

MARYLENE KYRIAZIS: I think I'll get Ross to answer that question.

ROSS WADDELL: I'm of two minds about this: yes and no. So yes, partner with hospice palliative care organizations but not only with hospice palliative care organizations. In order for this to work, and what we're about, what Marylene and I are trying to do with the Canadian Centre for Death Education, we're focused on social change, which we all are. But that's really central to what we're doing, and using social media to do it because we want to hit all age spans. So there's a lot of programming that's attracting people over 50 [years of age]; there's not a huge amount of programming that's attracting people under 50. And that's an area that I've been working on because I actually looked at three Canadian studies that were done of people's understandings about death and younger people are actually much more open to the conversation than older people. But they're not being engaged in it. So somehow, no matter what we do, we have to engage them. Now if you say it through hospice, they may not see the connection unless they have a loved one who's gone through hospice or someone who might need the service, might need the care. But/so both. I just say both is my short answer to that question.

ANN GILLESPIE: Yeah, that's interesting. That makes me suggest that one of the, I think people need to hear about death from so many angles and so many lips and hopefully with some of the same messages, but ...

PIPPA HAWLEY: One will resonate hopefully.

ANN GILLESPIE: One will resonate and they will all support, right? And/so I think there's a real need, like you were talking about, Ross, for collaboration and I think there's other parts of the world that are kind of, I won't say light years, but they're way ahead of where we're at here, like England for instance and Australia and the US even in terms of doing public events, kind of like what you're doing [other roundtable experts], but even broader in terms of all the participants and the different focuses that they have.

So I think, I have this fantasy of having a week, maybe it would tie in with something like that, where there are all different kinds of posters. It could be something like a film festival with speakers – that's sort of the traditional kind of thing – but it still reaches a lot of people and it can start conversations and hit an emotional strain in people through the films. And I know

people who have done these in England. They have an evening where maybe they're talking about options, alternatives like home funerals and dying at home, death doulas and all that kind of thing. So people have an actual chance to touch these things, to let it percolate and try out one of the little cardboard caskets that you can decorate. It's a different kind of visceral experience right?

DONALDA CARSON: So we're interested in how you can collaborate with hospice societies to ...

ANN GILLESPIE: Well that's what I was saying, in collaboration with a number of different groups and I think then it would be hospice as one part of that.

PIPPA HAWLEY: I think the opportunity certainly for the Bucket List Festival is with partnership with hospices is key. It's, to me it's a win-win thing for everybody because the hospice societies have usually a large group of very talented and keen volunteers who are able to put together the practical aspects. A lot of people like to do things to help but they're maybe not comfortable with having public conversations. But they're great to go out and organize silent auctions and catering and they feel like they're really helping. So it helps the volunteers. It also engages people with the hospice societies, that they're seen in a very positive light and in a very non-threatening environment. Things like the hospice having the Easter egg hunt. It gets the kids in and it normalizes the whole topic. So I would not be able to do the Bucket List Festivals without the hospices.

DONALDA CARSON: And I did observe that you did it with hospice societies. You didn't go out on your own to do that, which I thought was brilliant.

PIPPA HAWLEY: No. After the first two on my own, I was done. [laughter]

DONALDA CARSON: So there's a few questions and then we have one last question for the experts.

COMMENTOR 5 [Jill Gerke, Vancouver Island Health Authority]: I'm particularly interested, Ross, in the piece you talked about about engaging youth. Because I think as we move into talking about social and cultural change over death and dying, youth are where it's at. So I'm wondering even with the whole panel, about engaging with universities and even with school boards. I know with some of my work in pediatric and adolescent palliative care in Alberta, and through hospices in Alberta, we were engaging with the universities and the school boards to engage in Bucket List conversations with youth and with teens. So I'm just wondering if there's any opportunity there.

DONALDA CARSON: Can you just hold on that? We're going to be finished early so I think there's an opportunity for people in the audience to ask you questions one on one when we're finished as well. Do you want to hold your questions until then?

DON MORRIS: Can I? This is a – of all the four questions, this was the most difficult and complex one. Can hospice partner with the Death Café? This is difficult, okay? I'm an emotional type. If I'm visiting a loved one in a hospice and I see on the bulletin board, "Death Café Tonight", let me tell you: I can't deal with it. Like Ross, yes and no. I believe that we can do it but the Death Café – we have to change the name and we have to change the format. And we want people to sign, we want people to prepare advance care directives. That's got to be the big thing because I've been reading this [the Forum program and questions]. I've been thinking about it. So what we can do is we can create a hybrid. And I'm currently working on that. So it doesn't offend people. You get people in. They have a period of time to talk about what's on their chest at Death Café and then you have the experts and then you have the panel. And it won't be called Death Café. And it can work.

PIPPA HAWLEY: Sounds like a Bucket List Festival.

DONALDA CARSON: So here's your last question and it's the most important one in my mind. The potential for your program or event to partner with hospice palliative care organizations to advocate for hospice palliative care in British Columbia. Anybody?

PIPPA HAWLEY: I can say I think there's a huge amount that, just getting people talking about the topic enables a lot of that advocacy work to go on, especially if you give people concrete information that they can use on a daily basis. Stuff that's really useful to them. I think that really gets them in the door.

ABEGAEL FISHER-LANG: I would agree. Also that there's nothing specific that we do at Death Café. It's an open forum. But people who meet there, because we have had so many palliative care people come to our Death Café, that's the reason we're here today on the panel, so the conversation that starts that people can say "What about this? Have you ever done that? I'd like to see that going?" And it just starts the spark. But we don't have the political mandate.

DON MORRIS: Yeah. Because the Death Café has no ideology, we don't promote anything. The only thing creative I do is I always have musicians because I want to help create a new culture around death that affirms life. So I just love having musicians and it opens the heart. It's a beautiful thing. But getting back to this final question, and the potential of the Death Café to partner with hospice palliative care to advocate for hospice palliative care, no, we're going to – the current way it's set up – we're not going to do that. But we're going to trust in an organic process of offering Death Cafés that people come back and people come back and their values – they get in touch with their values. They talk amongst themselves and then they prepare the documents. But we're going to, it's not going to be out there. Can a hybrid be created for hospitals and hospices? Yeah, and that's what I'm planning so I'm working on it.

DONALDA CARSON: Thank you. You have a question?

COMMENTOR 5: I think that, it's kind of a statement but it's a bit of a question as well because hospice is a scary word to many. And Death Café is equally to me a scary word. And so you blend the two and that's maybe where some of the misconception could be. I have a bereavement coordinator who goes to the Death Cafés and it's quite educational for her. And I think that's where the opportunity would be is in the bereavement side, to offer that. Because there's some people that deal with grief in a whole different level and the Death Café could be a form of them handling their grief. So completely shutting it down to hospices, not necessarily is a really good thing because like I said, my bereavement coordinator has really valued the Death Cafés that she's attended, and it's helped her with helping some of the people that she deals with grieving and education.

DON MORRIS: What did she mean by shutting it down?

COMMENTOR 5: Well I didn't mean, sorry, shutting it down was the wrong word. But I just mean I think there is an opportunity there for hospice societies – not hospices but hospice societies – to work with Death Cafés. And a lot of times, people I find, people are putting hospice and hospice societies as the same. And they're not the same. The societies, we are a whole separate organization that work of course with our local hospices, but its programs and really undervalued.

DON MORRIS: Yes. And certainly the societies can put on a Death Café but/and go to deathcafe.org Because once you sign [in], you're a member of this social franchise and you go along with certain understandings. But you don't have to call your gathering a Death Café. Death Conversation Café to help strengthen the spread of the deathcafe.org

DONALDA CARSON: Another question.

COMMENTOR 6: Just in regards to the Death Picnic that you're going to be doing in Stanley Park, for finding the storytellers and doing that promotion because you said it's kind of a low planning event, have you found that it has been easy to find storytellers who are willing to come and participate and what does that really look like from a planning perspective?

ROSS WADDELL: I haven't asked them yet but I know where they are. [laughter] I'm not concerned because when you put a question to someone to share a story about something they love – a person – so we will have people there who work in hospice. We will have people there who work in grief and bereavement. It's not going to be a grief and bereavement session but we will have people who live and work and study and love different aspects that have death. Everything has death in it; everything has loss in it. So when you ask people to talk about something they love for 45 minutes, looking out over the ocean with the mountains in the background and with a bunch of people who really want to hear what they have to say, I am confident that we will have a lot of people wanting to be part of this event, if they're not on holiday.

COMMENTOR 2 [Lynn Wood, Oceanside Hospice Society]: I think what you're talking about is different tools for social engagement. And I think all of those can work very well for hospice. And its hospice's job to show partnerships in the community from what I'm hearing from you. Recently in Oceanside [Hospice Society] on Vancouver Island, we embraced a project which was interactive art which Candy Chang from the States had and it was called the "Before I Die" project. It was very simple to do. We set up some chalkboards and we told the community about it. But what I was surprised to see and also delighted to see was how many children and young families came to write on the chalkboards. We had them at the beach. It was unthreatening and people all engaged in conversations about what they were going to write on the chalkboard. So very simple but it got people together. And I guess what I'm wondering is how I sustain those conversations going forward. Because I saw that spark even in an older community. But we have to keep that spark going.

COMMENTOR 7 [Christy Linder, Comox Valley Hospice Society]: So thank you very much for that spark because I'm going to jump onto that and also connect it here. About four or five years ago, I introduced the idea of "life-centered living" as a stream for hospice organizations which is exactly what each one of, what you're talking about here. I saw that it became important that hospice organizations went out into the community taking the lessons that were learned from those who were dying and their families about living life well. And to take that whole industry which is human growth and development, which is certainly an area of interest that people have had for many, many years now, and finding a way to be able to get them together so that hospice organizations could start to have an earlier conversation with people who ultimately might use their hospice and bereavement services.

And the way to do that, I thought was to develop a stream called "life-centered living" which actually did this kind of thing. It was taking a long look at things like bucket lists, it was taking a look at art, utilizing art, and it was a taking a look at how is it that we grow developmentally and the possibility of hospice organizations working in community partnerships and with collaboration within their communities and with other people in their communities who were doing these kinds of things that were life-growing and life-fulfilling in a partnership. And sometimes hospice would be front and centre and sometimes their participation was one of the by-lines so that people didn't necessarily get caught and scared by those words.

So I'm really excited about what I'm hearing around here because this is just a further growth of something that I was thinking about many years ago. Comox Valley Hospice [Society] did a little of that for a while. But it may be the way to do that collaboration if you start to take a look at finding a program or service title that has that life focus and dying is part of living that allows for that kind of partnership. So that's just one idea to perhaps go forward as a way to do that collaboration.

DONALDA CARSON: Do you want to make a comment?

ABEGAEL FISHER-LANG: Just a short comment. The question over here about the storytelling? I'm a storyteller and I hope you ask me to tell [Death Picnic], I just wanted to say that it's not only the personal stories. They are very empowering and powerful to hear. It's also about the traditional stories. The woman sitting next to you is Mary Gavan who is also a professional storyteller. And she and I just participated in a whole weekend epic storytelling of the Shahnameh, which is a Persian, great Persian stories all weekend. We've done Irish stories and African stories every year for a whole weekend.

But the reason I bring that up is all of world literature have fantastic stories about coming to death and dying and how it's carried and how it's held or not held. And just hearing those stories and hearing poetry really sparks something in us. So I hope that with all the stories that you will have a balance with traditional stories, cultural stories and then personal stories.

ROSS WADDELL: Yeah, and it's a balance of human stories, non-human stories and it's not necessarily storytellers that will be telling the stories. There will be storytellers but there will be people who just love to tell a story about what they love. So to get someone who's an expert in dinosaurs to tell a kid who's five years old about how T. rex left the planet, that can be a very powerful 45 minutes for that child.

ABEGAEL FISHER-LANG: Absolutely. Excellent.

DONALDA CARSON: Okay. I want to thank all of you for coming. There may be an opportunity to ask a question in a few minutes. I want to thank everyone for coming and I want to thank our panel members – called experts – for taking part and sharing their knowledge with us. And we just have a gift from BCHPCA for each of you.

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