

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 ②

Conversations Using Expressive Arts

MODERATOR: TERRI ODENEAL, BCHPCA Secretary-Treasurer [Outgoing]; BC Director, CHPCA; Executive Director, Comox 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 expressive arts have in engaging and educating the public in conversation about death and dying, and advance care planning
- the potential for expressive arts professionals and organizations to partner with hospice palliative care organizations to promote public and personal conversations on death, dying and advance care planning
- the potential for expressive arts professionals and organizations to partner with hospice palliative care organizations to advocate for hospice palliative care in British Columbia

TERRI ODENEAL: Well first let me say how happy we are to have all of you here today. This is a topic that is near and dear to my heart. I'm Terri Odeneal. I'm the Executive Director of the Comox Valley Hospice Society and I've also been on the BCHPCA Board for a while. So I was asked to moderate this session, which I suspect will come together without a lot of moderation. But we've had several people invited to talk about the topic of conversations using expressive arts. So first, if it's okay with you, let's begin with introductions. And to my left, I have David Lemon who is Founder and Executive and Artistic Director of Health Arts Society Canada. We wouldn't have known he was in the arts from his tie but it's good. We like it. [laughter] That one just registered; it was a little slow.

DAVID LEMON: I didn't even catch it. I was dreaming. We'll try it again.

TERRI ODENEAL: Let's see. To my immediate right we have Nancy McMaster who is the Co-Founder of the Music Therapy Program at Capilano University. She is also a Fellow with the Association for Music and Imagery. And then Paula Jardine who is the Artist in Residence at All Souls, City of Vancouver Mountainview Cemetery and Royal Oak Burial Park in Victoria. And then to her right is an addition that I appointed or anointed this morning is Christy Linder who is now living in Victoria. But she was really one of the birth mothers of what we did in the Comox Valley which was something that I was anointed to speak on

INVITED EXPERTS

- DAVID LEMON, Founder, Executive and Artistic Director, Health Arts Society Canada
- NICKI KAHNAMOUI, Acting Executive Director, Arts Health Network Canada
- NANCY MCMASTER, Co-Founder, Music Therapy Program, Capilano University; Fellow, Association for Music and Imagery
- CHRISTY LINDER and JOYCE KUHN, Comox Valley Hospice Society (HeARTful Expressions)
- PAULA JARDINE, Artist in Residence, All Souls, City of Vancouver Mountain View Cemetery | Royal Oak Burial Park, Victoria

too. But I think Christy will really do it much more justice than I would, along with Joyce Kuhn who is with Comox Valley Hospice Society and who has been involved.

So with that, we'd like to welcome all of you. Oh I'm sorry Nicki – the person I asked, the person I couldn't pronounce her name. Nicki Kahnamoui. Okay – I could get there if I worked on it. She is the Acting Executive Director of the Arts Health Network of Canada. So we have some people who have a lot of talent and experience around using expressive arts and certainly you [the audience] who have an interest and probably a lot of talent and experience also.

So to start this, I guess, we are taping this session and there's a mic here for the table. And they've given us a mic for people who want to talk who aren't at the table. Now we don't need the mic, I don't believe, for purposes of hearing you. It's not intended for that but it is intended so what you have to contribute will be part of the taped session. So I'm going to set this [mic] over by the edge and maybe Nicki I could ask you when we get to the point where people are going to engage with us, to pass that around so we make sure that ...

COMMENTOR 1 [Ross Waddell, BCHPCA Advisor]: And we discovered in the first roundtable that you have a squeaky roundtable, so it helps if someone just keeps their hands on the table ... on the table not above it. [laughter]

PAULA JARDINE: Oh is this the séance session? [laughter]

TERRI ODENEAL: So ... okay, I'm not sure I can keep my hands on the table. To start with, this morning we're talking about opening conversations. And so the purpose of this, us coming together, was talking about opening conversations to engage, inform and educate the public on death and dying and to initiate discussion on future health care for themselves and their loved ones. As part of that obviously, we, BCHPCA had invited people to come together for this to share their perspectives on some questions that were put together. So I think we'll start with those questions and I think some of this will probably flow out of our discussions. And so we'll kind of see where we go and how this works out. But I guess we would like to ask the folks that have been invited to share their personal experience and perspectives on the current nature of public conversations on death, dying and planning for care and the paths to opening these conversations. And again keeping in mind the idea of using expressive arts. So who would like to start for us?

DAVID LEMON: Well I don't mind starting. Well there are two, I think there are two very distinct questions. One is the conversation about death and dying and the other is the use of the expressive arts. And the conversation about death and dying is always a complicated one and difficult socially. But nonetheless, it's actually becoming quite popular. There are more books now about death and dying than there have ever been. It's because the Boomers are beginning to see, feel a chill. [laughter] And I don't think we have to worry too much about that. I think the danger of, small as we are clearly, groups of people in particular projects, trying to embrace some colossal sociological, psychological developmental issue is really not going to take us very far.

But the expressive arts piece is important. But I think I've been doing this health and arts project which is to bring music to people in long term care and actually in palliative care is the only sort of hospice we work in at Vancouver General Hospital. We'd like to do more in hospices. But is that there's been an awful lot of conversation. But actually the answer is not very complicated. You just get performers who are good at that work going into hospices to play for people who are dying. That's it. There's absolutely nothing standing in the way of actually doing it. It's not like brain surgery. So I've been, I think there are a lot more conversations than there are sort of doings.

And I think we're actually at the place where we all know exactly what we need to do. People who are dying don't have a different attitude to music than everybody else does. There's a tendency I find in the general discussion around health and arts to be talking about people who are ill or in long-term care or dying as somehow a completely different breed of person from the people that they were before they ever encountered these issues. And we know, and I see people nodding, we know they're not.

And to get, what does it take to get people to go into hospices to play? You've got to find the right people, they've got to be expert at their playing, and they have to have a certain sensibility. But those things are not that hard to come by. People ... they really aren't. We've been now doing this for years. We have a group of artists who are not professional in – clinically professional – but they're very attuned to the kind of work that works in palliative care. And they play in the larger areas and they play in the corridors and they play in the rooms. And it's been wonderful. The people at VGH are very happy with the program. They have their own music therapist as well, which is a different thing. That's much more of a clinical intervention using music, usually in one to one or in very small groups. Ours is a performance project. But we had a wonderful – I suppose I could call it that – but it was sad but quite beautiful – some people who passed, a person passed away listening to Mozart. So this kind of thing happens.

So I think in short we shouldn't worry too much about the huge – but of course that's just my point of view – the whole issue of death and dying, but the expressive arts as far as we think about music a lot because that's the thing that appeals to people and it's the easiest to deliver. People, even in long-term care, enjoy and as you know, the long term care homes have actually become palliative because many people never leave them. And so there is a point where people simply cannot do something.

Our project is to provide, which I suppose is what expressive art is, is to provide something that gives people pleasure and satisfaction and enrichment just the way it does for everybody else. And I constantly use the line that I think this audience is as important to serve as any other. And that sort of a bit of a mantra because we've got in society all kinds of money from private and government sources to pay for symphony orchestras and opera companies and all that, which is great and I've been part of all that. But how hard it is to get this audience at it. And I worry that we spend too much time working on this audience as if it was somehow different, a different kind of person. That because they're suffering from clinical problems and chronic issues, that therefore they are entirely different and that there can be no value to anything unless it actually approaches dealing with their chronic symptoms. And it won't.

We do a concert, we're lucky. We're in homes where we deliver a concert once every five weeks. We're simply not going to say that 45 minutes of Jane Coop playing Chopin is going to add a second to anybody's life. It will give them a sense of joy and satisfaction and pleasure, or they might be asleep. It doesn't really matter. But that's exactly the same as an audience. There are plenty of audiences in concert halls who are asleep too. So I think we've been making a bit too much of a meal of this, "Well what does it do for them?" So that's my little introductory remark.

TERRI ODENEAL: That's lovely actually and has some very interesting ramifications. Would you like to ...

NICKI KAHNAMOUI: Yeah, I want to talk more about the public though. Because I thought the question was more about how to engage the public in the conversation and not just the people at the hospice and palliative settings. And I think I personally, yes, I think we are getting there. I think there is more talk about death and dying. But I think there's not enough.

I just came back from Iran. I was telling Ross [Waddell, BCHPCA Advisor] about it. During the two weeks that I was there, we talked about seven funerals with friends. During the twenty years that I've been here, I don't think I've talked about that many

deaths. When we do talk about death here, it's either the glorified death in the computer games, or it's the de-humanized death in Afghanistan or Syria. So I don't think in North America we talk enough about death. And I don't think when we do talk about death, we connect it to life. And I do think that they are two parts of the same coin. And we do need to, if we connect that conversation about death to life, life becomes more meaningful and death becomes more meaningful. And I think the arts have an immense role to play in that.

A little while ago, I was a little lost about what I was doing with my life. I'm a certified project manager, so I was like "Well, I'm going to treat this as a project." And I was like so, what is the, I did first of all, I did my lifeline and I did it in art – collage way. And I was like, "Okay, so what is the outcome I want?" And I started writing my eulogy and it as the best thing I've ever done in my life, to write my eulogy. Because then I worked backwards. And I worked backwards and I did collages and I did concept maps and colors – different themes in my life have different colours – and based on that I've got a better sense of what I'm doing in my current life. But I've also thought about my death. And I think that the arts have a huge role to play.

PAULA JARDINE: That's a great idea for a workshop.

NICKI KAHNAMOUI: I would love to do, like I would love to do eulogy workshops. And I've had younger mentees who have come to me lost about what they're doing with their careers and I'm, "Write your eulogy".

PAULA JARDINE: "Write your story."

NICKI KAHNAMOUI: And yeah, I think the arts bring out ... the arts don't let you dabble on the surface for that long. After a while, they force you to go deep. And whether it's engagement or it's listening, whether its active or passive, they force you to go deep. And once you do, it's meaningful, it becomes extremely meaningful. And I think there's [an] immense role that artists, art therapists, professional artists, community artists – all of them – and the general public. We artists' role is to help the general public tap into their creativity so they can create and make meaning of their own life and death. And I think we don't do that enough. So, yeah, that's my little bit.

TERRI ODENEAL: I'm going to ask Christy to take a minute to take off on that with the project that happened in the Comox Valley around using a multitude of arts.

CHRISTY LINDER: So yes, actually it's taking what both of you have said. Hospice organizations [in the Vancouver Island Health Region] a couple of years ago were given the opportunity and the task to be involved with advance care planning. So this is kind of straddling this morning's conversation and this afternoon's conversation. And when the Comox Valley Hospice Society was taking a look at how it is that we could be talking to the public around advance care planning and engaging them within that, through our own conversations we realized that the first thing that we needed to do was actually to do our own work.

And so as we started that, it was part of a conversation that we had. And that's where we actually took off from. Because we realized that what was most important was not actually having a completed advance care form but to have the conversation. And how is that you just start to engage people in the conversation? One of the things – and Nicki just alluded to that – is that arts don't allow you to stay on the surface. And so the idea was if we engaged people through art to have the conversation, well how is it that we can do that?

The team of people that I work with and that we work [with] together, decided that what we were going to do is actually approach various artists in the community of all different mediums and to really just put it to them “How do you start the conversation around death and dying, around advance care planning? How would you do that? How can you show that artistically in terms of ...” And we put it out there, not only to the artist community but we also then put it out to the general public as well saying “What we’re interested in is your expressions” – and it was called “HeARTful Expressions” – around starting the conversation, knowing that even by just putting it out there, people would be thinking about it. They may actually be having conversations within their own families, as people ... “What is the project that you’re working on?” or “How on earth am I going to be able to ...” So already it was going to start help conversations with friends and colleagues and co-workers and other fellow individuals.

We also indicated that what we wanted to do with, after a period of time, was to then do a display of, or have a venue in which this was actually shown, whether or not it was performing art or it was visual art or those types of things which certainly happened this past spring. So there basically was a whole year. And we titled 2013 as the “Year of the Conversation”. Had lots of opportunities.

We worked with nursing students at one time and they actually has a project that they need to be looking at death and dying as one of their modules. We got them involved I terms of doing “HeARTful Expressions” and then they came back. They all had to come with a finished project of “Starting the Conversation”. And they did. They had wonderful conversations within the class. But it also had them take a look at what was going on within their own lives. And for a couple of people it was timely and they didn’t know it because events happened in their life just afterwards. How serendipitous in terms of what that was.

We had a woman who wrote a play and then actually, that was one of the things that started off, that was put out into the community and a variety of different venues and even went out to other hospice organizations on Vancouver Island, taking a look about having conversation. And it certainly was humorous of course because we had an old lady who was dying and the family members who didn’t want to talk about it. And that’s what the play certainly was all about. We had another woman who did something in claymation, and she did this little video, little short video – a story that she did. We had people who were artists, we had writers and a wide variety of different things that were put out there.

JOYCE KUHN: Singers with special lyrics.

CHRISTY LINDER: Singers with special lyrics. What I’d like to do is just take a moment and pass it on to Joyce because while I was part of getting this going, I have since left the Comox Valley area and am now living in Victoria and was out of the country when they actually had the event itself. So Joyce, maybe you want to talk about what the event itself was.

JOYCE KUHN: Well it was amazing if I do say so myself. And the artistic expressions portion – just the variety of media that we had, and we had it at the Berwick which is a beautiful independent living, but what would you call Berwick?

TERRI ODENEAL: It’s an independent living facility. It’s a cruise ship on land. [laughter]

JOYCE KUHN: But certainly you even have a view of the water. It’s just this beautiful venue with this beautiful view of the harbour and everything. And then we had, of course, the paintings were just magnificent. And we had a little display of art from developmentally challenged people. They had a whole little ...

TERRI ODENEAL: The L’Arche.

JOYCE KUHN: The L'Arche, yeah, that was just so beautiful. And there was even bird houses and intricate woodworking. There was a young woman who danced. She's sixteen years old and she was just phenomenal. There was a Voices Three. It's a singing group. They get together rarely and whenever they do, they just blend so beautifully and it's always well attended. And they wrote a song especially for the occasion and sang it which was just so perfect. One of our members of the committee who is also a retired minister gave a little speech that was just ... The different media were amazing.

Back to the college students, there was everything from ... the perspective from young people was very interesting. They just figure that's for later and that's for old folks. And young people have accidents and it's all that more important that they have had the conversation. And these decisions are more difficult for young people than they are for old people. So there was a young guy who liked to ride motorcycles. He's in his twenties. So he had a broken helmet and a talk that went around that. And there was tap dancers. And there was a mystery game where everybody had a role to play.

You just ... all the different things that came together, the different ways. It was just so creative and phenomenal. And I'm sure it sparked ... I'm getting goosebumps just talking about it. We were so proud of ourselves and it just went so well. And I'm sure there was lots of conversation out of, that stemmed from all of it – certainly in my own family which was very nice. I made my own husband go who of course didn't want to go. And he was amazed and we had some good meaningful conversation after that. So ...

NANCY MCMASTER: Was the event videotaped?

JOYCE KUHN: Just little pieces of it and ...

TERRI ODENEAL: Some of the performances were taped and ...

JOYCE KUHN: And it is on our Facebook page: Comox Valley Hospice Society.

TERRI ODENEAL: Right. It's on our Facebook page. Yeah, and there will be some more pieces on the website. But we should probably move on. And thank you, thank you so much Joyce.

PAULA JARDINE: What was the question again? [laughter] Oh, starting the conversation. Well just a really, I'm not, just in case somebody doesn't know what it is I'm doing. I organize events in two municipal cemeteries. One in Mountainview Cemetery [City of Vancouver Cemetery]. We're coming up to our tenth year. And Royal Oak Burial Park in Victoria. We're coming up to our fifth year. And just by virtue of creating a space in a cemetery, it's implicit in the event that this is a safe place to talk about death. And we always serve tea – tea and cakes – and which is also very traditional.

And while listening to you, I'm reminded that death is the one thing we all have in common and it's pretty multicultural as well. And the, just by creating the space that is obviously to remember the dead – that's what we say we're creating a sanctuary of beauty – people, there's this kind of casual cultural exchange that goes on. Because there you are and you're having tea with somebody and well “When my father died, this is what we did” and blah, blah, blah. And so really important information is in fact being exchanged.

Walter Kwan volunteers at the Chinese pavilion in the cemetery and honours his ancestors in his family tradition. And many other Asian people are there saying “Oh wow. You do it like that. We do it like this.” And then other people from other

backgrounds saying “Oh that is so similar to what we do in ...” I don’t know what you do in Iran. But/and also there’s no pan-culture in so many different cultures and it’s important to learn that. But I think just by having an event in a cemetery invites the conversation. And also by calling myself the artist in residence in a cemetery gets people thinking about [inaudible] [laughter].

TERRI ODENEAL: It’s such a great title. That’s wonderful. Thank you so much. And then Nancy?

NANCY MCMASTER: Well my perspective is as a therapist, so as a music therapist. And I thought maybe what would be most useful is to list lots of the activities, approaches that a music therapist would do in addition to providing the beauty, the vitality that you’re talking about. We just bring in very good musicians who are sensitive. So music therapists, you start there – very good musicians who are sensitive – and in addition to that, receptive listening to music which is so rich and can go so many places and can be evocative as well as soothing.

And so for a therapist, you’re open for both. You’re open for needs, you’re open for resources, you’re open for individuality of culture and personality. So maybe four or five things. There is that receptive listening but it might not be a pre-composed piece. I might be on the guitar and just picking a chord for the longest time. It’s like, if it’s not broken, don’t fix it. Okay, we’re here and now I think it’s time for a little colour and come back and that first chord ends up being home. Well often it comes back and says it’s metaphor. Well in a lot of the music is that we will use ...

PAULA JARDINE or NICKI KAHNAMOUI: But it’s following you on that path.

NANCY MCMASTER: Yeah. And that people who are music therapists are trained to do that improv, improvisation. Another would be imaging to music and that’s a guided imagery in music that I use is a particular training of programs of classical music it turns out, but it could be other music. It doesn’t make a difference. Maybe four or five pieces that are chosen. Always there is stability in it. Every piece there is stability. That has to be there. And then on top of that there might be deep grief. It might start here and go down and you make sure that it comes back up. Always this idea of home is already there in what I’m saying. A ground that you come back to that gives you the courage to step out from there to return back home.

One of the angles I was thinking to talk about is what’s the person’s values, and what’s needed? What do they value and what do they believe? At first I put, well what’s true? Yes, well, we die. But actually not everyone believes that. So it’s just a pool [?]. Let me take my assumptions back. Yeah. So truth, belief, values and then needed, what will facilitate that person having experiences in align with those values. Yes, well, again both imagery and music would be both strengths and touching on what is feared. And that might be often emotion. It’s often just emotions of any kind, except for maybe joy. So a balance. All the music we choose is like, well “What’s needed right now?” Comfort, strength, courage, acknowledgement, feeling – even feeling.

So that’s around receiving music, listening to music. Listening to music, again pain tolerance increases. Tolerance of pain increases sometimes – obviously sometimes – with music. And there’s some intense physical pain in palliative care. Thank goodness not always. And belief through pain – dealing with drugs, with good drugs, good medicine. And also emotional pain. So supporting that, the therapist has been trained to be so aware of their own pain, of pain, of what it’s like to feel pain, to be around pain so they’re not aversive to it. And know what it takes to go into that, those areas.

The song lyrics – starting a conversation. I was thinking of Renu [Bakshi, morning keynote speaker], of her mother where nobody talked and I just thought, I wonder if there was a Hindi song that would have been about strength and about faith and

courage at that point, how to start a conversation. Even no conversation, it was in the song. “We don’t have to talk about Mom.” There’s an issue of course. But it’s in there [the song]. And palliative care really often with song choice – give people song choice – and really often, death is mentioned in the second or third verse. And they go “Huh! Well that’s not why I chose that song. I didn’t remember that.” But it’s the songs they chose. And obviously not always, but sometimes.

Song writing. There’s something called a “Legacy Project” with music where “How would you like to be remembered? Is there a gift you’d like to give to your family?” And sometimes, if someone can’t speak, they can point to some songs that you put together, well, maybe these topic areas from what I can gather about this person or just basic values of resources: strength, courage, hope, love, beauty, meaning. There’s a lot of songs that have been written about that. Or yeah, song writing.

Word substitution in a well-known song. For someone that can talk, I’ve seen lots of examples where you just, you go away or even you just read down some of those key words and you go away and you create a song and bring it back. And the person, well the person never had that experience. It’s just like “Oh my gosh, you captured ... this would be really good for my children to know how I feel in my life.” And related to that, if it’s with recorded music or songs, would be life review. So it’s like your eulogy. “Well, what’s my life been? What’s the track of my life been?” And having the songs for that or pieces for that.

And then, this is so often not done in palliative or hospice but relevant when someone has the energy, is improvisation. So you’re feeling this, I don’t know, this love that is overwhelming you for someone that you’ll be leaving. And I would take in some instruments, might take in some instruments and try out each of these instruments and see if there’s one that maybe could be a voice for that feeling. And when people can do that, when they go there, it’s ... It’s the same I think with art, well you’ve got a blank piece of paper and you’ve got all these colours. Which of these colours is the one for that? And so sound can be used like colour. That’s some ideas, so/and there is a music therapist I know in the Palliative Care Unit at VGH, and a brilliant guitar player. And so there’s that whole mixture that includes also that listening.

TERRI ODENEAL: This is so inspiring to hear. I’m anxious to hear how this all can interweave and come together.

PAULA JARDINE: Could I just say something? Just about the music in a palliative setting. My experience around death in our culture is there’s still this huge gap between the moment of death and the final disposition. And also in my experience, the music can be a kind of rope that the family – the harpist played my Dad out and then she played at his funeral. And we felt that it connected us.

NANCY MCMASTER: Absolutely. A link.

PAULA JARDINE: Or [at] Dr. Nancy Hall’s funeral we had a procession through the cemetery so all of the different people who had been spelling each other off caring for her were finally together and the music led us. We walked her home.

NANCY MCMASTER: I made a relaxation recording that’s very – it’s called “Simple Fare”, F-a-r-e – so simple food. And I made it for a friend who was about to have a Caesarian and she was all nervous about taking care of her baby. But/so I made it straight from the heart, and really simple pieces. And it’s been used in a lot of palliative places for comfort, relaxation. But the music therapist will often put that on in the hall. So it’s also for grief. It’s just relaxing. And I think because it’s got that heart, it just was made with

PAULA JARDINE: Music creates its own space that carries us. It’s really ...

COMMENTOR 2: Can I ask a question? Sorry. Thank you. Is it on?

TERRI ODENEAL: Yes it's on.

COMMENTOR 2: I'm just curious, because you talk about the arts and incorporating and how important it is to have the players etcetera, can I ask how you, each of you have engaged the artists and the art community in that conversation? Because just saying it's starting the conversation or that it's about death and dying, I imagine there's some context or conversation that needs to happen even to engage someone to come and enter into a hospice or palliative care situation or to be willing to share and be vulnerable in terms of what you're sharing because it's a very personal experience. So I would just be interested to see how that went in terms of having the conversation at the community.

TERRI ODENEAL: And I think now, if it works for everyone, there are a couple more questions that speak to how hospice palliative care organizations can work with the performing artists to come together and promote public and personal conversations on death and dying and also how we can work together to advocate for this. But I think we really need to open it up to the group and have a dialogue because we've thrown some things out and I think it's important for us to hear from all of you.

DAVID LEMON: Well that question is interesting because it seems almost as if it's slightly the other way around. It is the, after all I came with the focus that this is hospice and palliative care and music, and the arts. And artists like everyone else, they're all very busy people, and they have got their own things to do. I don't think artists are the conduit between hospice and palliative care issues and the public. They are able to provide something wonderfully useful to people in long term care and who are dying, just as you have described. And it's actually something that can be quite readily implemented.

So certainly in our work, we find ourselves advocating for the values of music because that's what we largely do although we have some spoken word programs. The values of music played at a particular level for people who are in long term care and essentially palliative situations. And I don't think there's any way in which we can get our artists to then somehow start finding a way to involve the population at large, not in any really substantial, not in a really large scale.

Certainly art is always going to be used as a way of communicating what death is about and they've been doing it. Western art certainly and I'm sure many other cultures. Well they are. All of them, many from First Nations and onward are saturated with the presence of death and helping people to sort of come to terms with it. The Egyptians getting ready for the other life and all the arts that went into that from the, all the things we know about them. So/and music filled, and you alluded to that, music is filled with intimations of mortality. So is poetry, so is literature.

So I kind of, when I see this last question which you've raised, the potential for expressive arts professionals and organizations, so I'm thinking Vancouver Symphony, Vancouver Opera, [Vancouver] Recital Society, PUSH Festival to partner with hospice palliative care organizations to advocate for hospice palliative [care], what ... I'm not sure how they would go about that, how precisely they would do that. Because I think that most people get that hospice, to advocate for it doesn't really need advocating for. People think it's wonderful. I mean everybody wants to end their life at home or in hospice, not in hospital if they can possibly avoid it. So I think that that piece is done. I think the other piece that we've been talking about hasn't been done and I'd like to think there's a way of doing it. Well there is a way of doing it. You pay artists to do the work, either as music therapists or in performance situations.

TERRI ODENEAL: I might add one maybe possibly different perspective on that that I think we experienced when we started the project that we had in the Comox Valley which, and the first piece of that was a play that was written by a local playwright. And I was absolutely amazed when we put this on and it had a lot of humour and it had a lot of very poignant scenes and it was the journey from here to there and it involved family and kind of a stereotypical conflictual family relationships. And we had 140 people in a very crowded theatre there, low [?] theatre performance.

And what I noticed and what I heard from people I knew in the audience who were at that play was that that play put forth for them a different perspective, a perspective where all of a sudden, some people that were very guarded and very unwilling to talk about advance care planning much less death, they came out going “I get it”. Through the laughter, through the, all of that. So it was a venue to touch a certain segment of people to have the conversation and to engage in a way that I don’t think we could have gotten them, I don’t know it would have been possible to get them to another venue so I’m just saying ...

DAVID LEMON: I’m understanding. I just want to clarify then in my own mind. How does that advocate for hospice palliative care?

NANCY MCMASTER: It starts a conversation and that’s what we’re talking about here.

TERRI ODENEAL: It starts conversations.

DAVID LEMON: But how much advocacy does hospice palliative care need?

NANCY MCMASTER: A lot. Some people don’t even know about it.

NICKI KAHNAMOUI: A lot and I’m not even involved in hospice palliative care. I think it needs a lot. I think people are not ready. They just don’t ...

TERRI ODENEAL: It needs a huge amount.

NANCY MCMASTER: We know about it in the hospital system but the public doesn’t. “That’s about death!”

CHRISTY LINDER: They’re afraid of it. There’s a lot of fear around it because it’s about death and so “I support it. I think it’s important but I don’t need it yet. It’s not for me. At a time when I will, I’ll look at it.” And then they turn away.

DAVID LEMON: But that’s okay.

NANCY MCMASTER: But how much service do we need? We don’t have enough services.

TERRI ODENEAL: We don’t have service to serve them.

NANCY MCMASTER: We don’t have enough yet.

DAVID LEMON: Oh you mean we don’t have enough services.

COMMENTOR: That’s why we’re advocating for more.

NANCY MCMASTER: We have a speaker here.

COMMENTOR 1 [Ross Waddell, BCHPCA Advisor]: Well since I wrote the questions and the reason you're around the table is because I found you [laughter], just to let you know the question that David is referring to is the fourth question and not the second one, but it all ties in together. One thing I was going to say was tell us what you do right now, tell us exactly what your organization is doing right now – you've been doing that somewhat but we really want to know what you do in detail, in brief.

And one of the issues with advocacy is, it's not advocating for people to use hospice palliative care services, it's advocating to the government to provide the funding and the resources for the services that people can actually use. Because we have this tsunami – a demographic tsunami that's coming at the health care system – and we have all these fine people in this Forum who provide those services but there are not enough services, there is not enough funding to provide the care for all the people that are going to need it and want it. So when we talk about advocacy, it's advocacy in many forms. It's including some of what you're saying but it's also the advocacy for the services and the kind of care, the quality of care, the access to care if you're in ... So/and one thing that you're all stating is that, and which we hoped that you would say was that expressive arts are a way of entering the conversation that isn't only just talking about it.

DAVID LEMON: But don't you think, and now I get it totally, this is really about the necessary job of persuading government to come up with more money for services. And that's something which I've encountered a lot, not just in terms of our work but seeing all the other work that goes along. But you asked the specific question, what precisely do we do? Is that what you mean?

COMMENTOR 1 [Ross Waddell, BCHPCA Advisor]: I think everyone needs to know that.

DAVID LEMON: I didn't know so maybe I tried but I didn't work so well. But the idea: we give 45 minute concerts with professional artists, professional performers in series as far as we possibly can, in long-term care homes, so that, residential care homes, so that we would probably ten concerts in a year, so that's once every five weeks or so. And we pay the musicians to do that. And we work with the homes to work on the program. We certainly direct the program, that is the actual music that's going to go in there because we know more about that than they do. But nonetheless we're constantly responding to whatever works for the residents because that's who we're serving. Is that okay?

And palliative is somewhat different because it is a different situation. So we have and we do work with the therapist at VGH [Vancouver General Hospital] and have for several years and the program seems to be working as a, as something that will provide something of value there. And we have a group of artists who have been working fairly consistently in that field. And we would in the event of hospice.

Now your question about the funding for these homes, well it's extremely hard for us to get funding even for our little program. In fact I'm pretty much giving up on government. I think what's needed for this is something that is ... whether the artists can do this I don't know. One group of people this government doesn't really listen to is the arts sector. People in the arts sector have no voice in this government. So using the arts as a means of encouraging governments to put money into hospice is ...

TERRI ODENEAL: Joint with the palliative voice, right [laughs]?

DAVID LEMON: Well actually, it's really a shame. The government will occasionally do extraordinary things. They popped up with half a million dollars for that opera "The Stickboy" that's being done because it's about bullying and that's something the government wants to deal with. And they're going to tour it to schools. And that's about a conversation about not bullying. Whether the kids who are bullying are going to get the message through an opera, I don't know. But that's the idea. Maybe they will. Maybe the arts can do that. But I think that from what I've been talking to people about music therapy, that the therapists are under pressure to get funding for their work, just to get the funding to do that work. So if the government isn't listening to the people actually doing the useful work in these situations, will they listen to them if they're advocating for more hospices and palliative care?

NICKI KAHNAMOU: I think advocating for government funding, it's a two tier approach. You approach government for funding and you need to convince the government. But you also need to create demand and you need to convince the public so it would be a platform that they would vote for. And if there's more public on board and there's more public awareness, appreciation, there would be ideally, in an ideal situation, the supply would be there. And I think arts has a role to play in engaging the public, absolutely. I think for government, you need more evidence. That's what government, especially this government, wants to see – dollars right? But I think the arts can engage the general public in more awareness about hospice and palliative care.

NANCY MCMASTER: I think we're talking about collaborative. If I think of the arts, of some initiative of health care, of maybe affected family members and collaborating with the arts, I would do a fundraiser. I have done fundraisers for instance as music. Or end-of-life planning workshops where there's an artist there, to take it deeper, to take it into more awareness of "Now wait a minute. Actually, what do we, what are we going to need, what do we want?"

NICKI KAHNAMOU: I think BC Transplant did a really good job with arts. They increased the donor registry by using the arts – video and imagery.

DAVID LEMON: Do you think that this government is responding? Do you think it could possibly get enough interest, and I'm not sure how that would be done practically speaking, in engaging people in the arts? Because even those people who are thoroughly engaged in the arts – and there are lots of them – are having a very, very hard time in convincing the government about their own practices. Do you think they can really convince the government on other practices?

NICKI KAHNAMOU: Because you're focusing on artists. I'm focusing on the general public. That's the difference.

DAVID LEMON: Oh I am talking about the general public. No, no. Do you think that the general public, okay, do you think the general public is actually listening to anything much that artists are saying?

MULTIPLE COMMENTORS: Yes. Absolutely.

NANCY MCMASTER: Theatre, dance, yes.

TERRI ODENEAL: I'd like to hear from some of you about your questions.

COMMENTOR 2: I have a good example, actually. I live in Langley and my kids attend the Langley Fine Arts School which has done, they've done some huge works in engaging the public and the community at large in terms of conversations. So they do an "Arts Matters" series and bring in a variety of artists, acclaimed artists. So Sir Ken Robinson has come in, David Bouchard

came in, Dan Mangan. So really rallying the troops so to speak in a variety of ways. So/but they did it from a number of folds. So they engaged the students first in artistic study on a particular topic area etcetera. I have ideas written here because I'm going to go talk to them about doing some work for us in the Arts Matter piece which stem from this conversation.

But I think it is powerful to see one engaging the youth and giving them a voice, in that bringing in experts they realize that they both have something to learn from each other and then taking it to the broader community. We've seen our community pay more attention. And that's including the Arts Council funding locally. I think it's a, I know it's not as far reaching in terms of provincially or federally, but I think there's some opportunity that allows us to, it's a continued conversation. Its give people something to talk about and to learn in a different way.

And I think arts – the expressive arts in particular – you talked about death being a component. It's always been a component of the arts when you look at, if you look at all those great stories, there is a component of loss in so many of them – in music and in plays and all of those pieces and the ways we express. So it's been interesting to see, even with my children, that our conversations have started and often head into difficult territory, but have started from artistic experiences that they've had, either at school and otherwise. So yeah, I think there's some great opportunity.

COMMENTOR 3 [Ann Gillespie, North Shore Death Café]: I was just going to say that I think, well I don't quite know how this fits in, but I was, when I was looking, considering the whole idea of advance directives, there's a town in the [United] States called LaCrosse, and what are they're, they're Wisconsin. Fifty thousand, fifty-six thousand people. And that is the only, across the States there's probably about 30% of the population who have completed advance directives. It's growing. But in that town they have 96% of people who have done that.

What the government hears from that is that there's a lot of these people who are making choices about not accepting being on life support and that kind of thing. So they're making choices. One assumes at an earlier stage they've had the dialogue, they've had the conversation. Perhaps been triggered by arts, expressive arts involvement. So I think there's sort of a staging of how things kind of, the dominoes and how things fit in, where the arts fit in and where the public picks up once they're educated.

Because I think through the process, people ... I think the whole idea of individual rights and patient rights doesn't usually extend to death. We think about it in so many other ways around disability and other kinds of things. But in the general conversation, we're not talking about our rights as patients in terms of how we die. And I think when people start thinking about those things and realize, "Oh hey. Only 30% of people can actually access hospice or palliative care" – I don't know what the statistics are but people are going to, that's where it's going to come from. It's not directly from the arts but I think the arts has a very specific role in motivating and educating and stimulating that conversation, so people can demand.

COMMENTOR 2: I don't know how they got the 90%. It makes me want to contact this community.

NICKI KAHNAMOU: Can I? I'm taking up too much air time but when we talk about public education, I think it's also important to talk about the use of arts in educating health professionals. I think they're, health professionals are trained on life, on saving life, not on death as much. And the arts have a role to play there, and the medical humanities programs that are popping up across the ... We've got more and more medical humanities programs. Next year, there's going to be a conference in Vancouver that UBC is hosting that's going to have, there's going to be a medical humanities component to it. So I think there is definitely room there also for education of health professionals and the use of arts for educating them.

CHRISTY LINDER: And I think for me, I actually go down to the individual and work up. And so it can start as simply as at the bedside in terms of using art expressively in whatever modality or form that it happens to be that is providing quality of life and care for the individual who is ill and/or their family members. Artists, professional artists, informal lay artists, also live and die and so do their family members. And some of them will come and utilize hospice as well. One of the things that we do know is that when people have good experiences with hospice at such a crucial part in life with somebody they care so much about, they talk about why isn't there more hospice, why isn't there more support for that.

So they become people who can start to advocate for us, those who are coming with an artistic background, an expressive background, a musical background or whatnot can also become advocates, either speaking out vocally or by taking their skills and reinvesting it back into the organization or the larger organization, BC Hospice Palliative Care [Association] for example. So that they become involved at the community level itself, whether or not, and one of the ways that they may do that is becoming a hospice volunteer themselves, starting up or helping to maintain a program, or by offering the opportunity to be able to use their talent as a way for doing some fundraising or some advocacy for the organization.

I know of one particular fellow in the Comox Valley who had been involved with "Voices Three" which is a musical group that does come together. He was playing for a concert that was supporting the hospice society days after his mother died. And he's a well-known fellow in Canada for what it is that he plays. He has been involved with hospice on the periphery for the last six to eight years.

And so there are different ways in which artists themselves can get involved or be involved at individual levels but also how it is that they can use the voice to start doing some advocacy because there are times in which somebody who has a name, so to speak, that is recognized, who may then, having had a good experience with hospice, with their loved ones, or for somebody that's been important to them, to be able then to carry that forward. And those are voices also get heard at different levels.

So again, it comes in at many different levels but we always need to be dealing with the individuals themselves and how it is that they're giving of themselves, whether it's professionally or whether it's personally, whether it's from the heart. And the way to be able to express it. And certainly again, often times what happens is that we may not be able to have the conversation because it's too uncomfortable. We may not be able to have the conversation because we no longer have a voice. We can no longer speak. But the heart can always speak. Just being present with somebody and holding their hand, hearts are talking. And much is being said at that time, just through heart conversations where not a single word is spoken. It's very, very meaningful. And so there are many, many ways for people to do the connection and I think that using art as a different expression, to be able to voice and to have people put voices to what they're thinking, what they're feeling, what they're experiencing, or just being present in that room.

TERRI ODENEAL: I was just going to say I know that lunch is shortly actually getting on us, but please say what you were going to say and then we'll close up.

NANCY MCMASTER: Well just a couple of things and David, I feel like you're the voice of something. I'm not sure what – a skeptic or reason or something. But I seem to have a lot of loose ends to tie up with you. I think not so much with classical musicians, but I think with pop musicians and theatre and dance across all centres and in all cultures, but recently there are artists who have a social conscience, who are social activists, who love to pay forward. We have in England Paul McCartney and a whole bunch of very popular musicians who got involved in fund-raising for music therapy. So that's for music therapy,

not for hospice. But they just raised maybe a million dollars. So that's possible, not only for fund-raising but to be a voice. The arts historically are sometimes a bit of an agitator in society.

DAVID LEMON: Well the issue here is galvanizing the public ...

NANCY MCMASTER: Absolutely. That's what activists do.

DAVID LEMON: ... to get them to put pressure – exactly. But well galvanizing the public so the strength of the public value of the project about which they have become galvanized is so strong that the government will listen to them.

NANCY MCMASTER: Or not government. I think of Cottage [Hospice]

COMMENTOR 1 [Ross Waddell, BCHPCA Advisor]: Government's only one part of it. And I will fully disclose that I worked for government for most of my life as a funder. But it's not just government. That's just one advocacy approach. There's public advocacy for services, for the quality of the services – there's a whole bunch of different perspectives.

MULTIPLE COMMENTS

NANCY MCMASTER: No change is possible or some change is possible. That's ...

PAULA JARDINE: Well apparently the perception is that everything's fine in hospice and you didn't know they needed more resources.

DAVID LEMON: Well I'm not at all surprised they do. I'm not the least bit surprised they do.

TERRI ODENEAL: Comments: Are we done?

COMMENTOR 4 [Meg Milner, BCHPCA President]: I'm sorry. I was just going to quickly say that my day job is in long term care. And while quietly long term care in the background is becoming bigger and bigger for obvious reasons of the number of folks who are becoming elderly and very frail on their way to their end-of-life journey, music therapy, art therapy, expressive arts are a day to day way of life there. And I'm always touched very poignantly by the elder who's not been able to speak for years and we turn on music and immediately she will start to sing the song with the words. And the waking up that happens with music and art is amazing. And it's very alive and well and has become funded through various curious means but all the way across the whole spectrum of long term care which is a quiet growing of the expressive arts in public health in long-term care. So I just wanted to flag that. It's huge and it's happening and it's alive and well.

NANCY MCMASTER: And in palliative care in BC, almost every palliative care has had a music therapist who advocates ... [inaudible].

COMMENTOR 2: I just had a, on another note, I'm in communications and funds development for the hospice society so probably a different approach from anybody. But we have a, it started in supporting our programs within bereavement – more focused on bereavement at this point. We, in our children and youth programs area, we've looked at the community arts funding. So we're waiting for that but through the City and Township within Langley. And we've been able to look at, because funding is often the issue and artists, I'm a believer that when we can access funding that can allow us to pay for artists, that

allows them to give us more time. Because we, I work from the premise we ask everyone for a little bit and don't ask anyone to do all of it. And that makes it easier for everybody. And we are stronger together on a whole variety of levels.

So we have a Moments in Focus project which is a photography project that children and teens are doing to work through their journey through bereavement and expression of their loved one etc. So more symbolic than specific. And then a Narnia Room Project that's in a collaboration with the Kwantlen [Polytechnic University] Arts Program. And they're actually doing fundraising for us because we haven't got word on our funding yet and we don't know if it can happen but they want to do it bad enough. So they said, "Well, we'll use it as an arts and business proposition. Learn how to develop a proposal, go do the fundraising and make the ask, and do the project and installation." So sometimes we've got to decide where we want to go and use that creative process in trying to get there too. So anyway, just wanted to share that.

TERRI ODENEAL: Thank you so much. I know we're running over and I appreciate your time. And I appreciate everyone's participation in such a fulsome discussion. So people will be around and I hope will continue the conversation.

PAULA JARDINE: If anybody is more interested in the projects I'm working on, I've left some bookmarks on the side table with my website. There's some pictures, lots of pictures, and also a little notice about the Royal Oak.

REFERENCES

- Health Arts Society
<http://www.healtharts.org>
- Arts Health Network Canada
<http://artshealthnetwork.ca>
- Music Therapy Program, Capilano University
<http://www.capilanou.ca/music-therapy>
- HeARTful Expressions, Comox Valley Hospice Society
<http://www.comoxhospice.com>
- PaulaJardine.com
- All Souls, City of Vancouver Mountain View Cemetery
<http://nightforallsouls.com>
- Royal Oak Burial Bark, Victoria
<http://www.robpc.ca>
- Creating Space V: New Directions and Critical Perspectives
Arts, Humanities and the Social Sciences
in the Education of Health Professionals
The University of British Columbia
April 24-25, 2015, Vancouver BC
<http://ches.med.ubc.ca/newsevents/csv-en/>