

BCHPCA FORUM | 2014

FRIDAY AFTERNOON SESSION MAY 9, 2014 1:30-2:15

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

FEATURED SPEAKER

Planning for Your Life

DR. TREVOR JANZ, Family and Emergency Physician; Regional Medical Director, Kootenay-Boundary and East Kootenay, Interior Health, Nelson BC

Trevor Janz is an emergency physician living in Nelson BC. He serves as Regional Medical Director for Residential Care in Kootenay Boundary and the East Kootenays. He is house physician and medical director for Mountain Lake Seniors Community and Jubilee Manor in Nelson, and serves on the Interior Health Clinical Ethics Committee. Trevor is an active advocate for improving quality of life for frail seniors, advance care planning and good end-of-life care. He also speaks from personal experience. In 1983, while a medical student, Trevor and Patricia Van Tighem were severely injured in Waterton Lakes National Park by a grizzly bear. The story of this experience was told by Patricia in the best-selling book, "The Bear's Embrace".

TREVOR JANZ: Welcome everybody. It's always such a treat for me to be in a room full of heart people. When I feel the energy of this heart people. If you're in this room you're a heart person. I am a heart person and you are a heart person. I'm willing to bet dollars to donuts that you're in this room because of someone that you love. As soon as you love somebody, you know deep in your heart of hearts that sooner or later you're going to have to say goodbye. It's impossible to love somebody without sooner or later being separated from that person. I'm willing to bet that you're here in this room and doing what you're doing in your life because of saying goodbye to somebody.

My somebody was my mother. Like Renu [Bakshi, morning keynote speaker] this morning I lost her much too soon. My mother knit sweaters. I wear my mother every time I talk. [Placing hand on his sweater] This is my mother. This is one of my mother's sweaters. She's with me now. You're here, you're doing this work because of someone that you had to say goodbye to. That might have been beautiful. That might have been a train wreck. It might have been a total disaster. But that's why you're here.

Lorraine [Gerard, BCHPCA Executive Director] and Meg [Milner, BCHPCA President] gave me a nuts and bolts conversation to have with you guys around advance care planning and I'm absolutely going to deliver that. BuT the place I'd really like to take you to, if we have time afterwards, is that heart space and why we're doing what we're doing here. I'm going to start out with the nuts and bolts of advance care planning and then I'm going to hopefully take you to that place of the gifts that death can bring.

When I speak to physicians I speak to lots physicians about different stuff in long-term care. I have three hats: I'm an emerg doc - that's my day job - I do a lot of long-term care, and I'm now a medical director for long-term care helping improve care for seniors in Interior Health. When you speak to doctors, you have to give them your credentials before they'll even listen to you. You have no credibility at all until you've told them why you're an expert in the subject and then they'll actually listen to what you're saying.

My credentials for today are that I'm an emerg doc - that's my day job - I do a lot of long-term care. I'm a house physician - I have been a house physician in a couple of facilities, the only facilities in Nelson [BC] for about twenty-five years. And my 130 residents that I care for, we probably do forty to sixty deaths a year. My real qualifications for the last part of the talk are that

I'm a person who's received a number of gifts from death. Death and I have a long history with each other and losing my mother was a piece of that.

My first wife and I met a bear when I was twenty-three. Things didn't go well. We were badly injured, had a whole pile of surgeries. The first gift that I received from death happened on that day and it was really quick and it was really easy. We were hiking, mother bear, two cubs feeding on a carcass by the trail. We didn't know she was there. Walked right into her, knocked me down, chewing on me, left me for dead. Knocked my wife out of a tree – I heard her scream – chewed on her. I thought it was all over. I tried to get up, [the bear] came back, she chewed on me again for a while.

It was in that moment – the first time I was totally blurred out, I had no idea what was going on – the second time, I knew exactly what was going on. As I was in the bear's mouth – bears attack mouth to mouth, they neutralize each other's jaws – so she was chewing on me. As I heard my jaw break and the teeth around my bones, I realized that I was going to die. At age twenty-three, I was going to die of an accidental death, a violent death. And in an instant, my reaction – Ross [Waddell, BCHPCA advisor] was talking this morning about how people who have had a near-death experience are no longer afraid of death – that captures this perfectly. I would endorse that 100%. There was absolutely no pain. None. From start to two days later, there was no pain. There was no fear. I was so excited.

I read about spirituality in my teens and early twenties and I was so curious about this spiritual world. There I was in the bear's mouth realizing I'm going to die today and boom ... I'm going to find out right today, I don't have to wait seventy years to see heaven. I'm going to find out right here within the next two minutes what heaven looks like. I was so excited for that. There was nothing but eagerness. That gift of complete freedom from fear of death, knowing that life is wonderful, life is great, and when we're done, it's going to be even better. It's going to be even sweeter. I've lived with that absolute conviction since that time. And that's the first gift I received from death.

The other gifts came later. They were nowhere near as comfortable. We can talk about those later.

So let's talk about the nuts and bolts. I'm here to talk about advance care planning conversations.

Dying used to be simple. It used to be expected, inevitable. Nothing is certain except death and taxes. A hundred years ago death was a common part of life. It was normal. It was expected. It was standard. It was not negotiable. It was just a given. People didn't want to die in pain. They hoped they wouldn't die alone. They wanted to die a clean death. They didn't want to linger. They didn't want to be a burden. They worried about the hereafter, about the fate of their immortal soul. They didn't want to burn in hell.

Starting about 1930 with the invention of penicillin, modern medicine started to change all that. Everything changed then. The rules have changed a whole bunch and now death is not so inevitable. It can be postponed, it can be negotiated with. You can dodge the bullet. We've got heart transplants and lung transplants and kidney transplants and liver transplants and bone marrow transplants. If it's broken and you should be dead, we can sometimes fix that. [For] many cancers we talk about cure. AIDS is not a terminal illness. AIDS is now a treatable chronic disease. Things have changed a whole bunch and we have far, far more choices than we ever had before. Death is a little more negotiable and a lot more complicated. Our expectations as a culture have changed a whole bunch.

The problem is we're a profoundly death phobic culture. We deny. We avoid. We use euphemisms. We can't say the "d" word. People don't die. They pass over. They cross over. They pass on. They go to a better place. Funeral homes make the whole process invisible. They sanitize it. They slip the body away, they have a little service, boom – done.

This is a very unusual group that I'm speaking to here in that many of you have had a great deal to do with death. But in the general public, most people have never seen a dead person. And even fewer have ever touched a dying person. Almost none of them have ever cared for a dying person and watched them die.

I'm from Nelson. There's a beautiful Doukhobor tradition in the Kootenays [mountain region of BC]. The Doukhobors – Russian, very spiritual, very communally oriented group – would always die at home. When they died, their family – the whole family – would wash and dress their loved one in their best clothes and put them on a table or in a coffin right in the middle of the living room. They were not big houses. Everybody for three days would come and go and sings hymns and songs and tell stories, eat wonderful Russian food – latkes, perogies, borscht. I love Russian food.

Then they'd carry the body – physically carry the body – to the cemetery, walking distance, where they would lower the coffin into the ground. Each person there would put the dirt on the coffin until it was buried in the ground. Everybody in that community from the smallest to the oldest was a piece of that fabric and everybody was connected to that process and they touched and they lived and they felt and they knew in their bones what death was. There was such integration of that.

How far we've come from that now. Think about our popular culture. We keep death at arm's length. We avoid facing it emotionally.

Woody Allen quote: "I'm not afraid if death really, I just don't want to be there when it happens." Yet at the same time our popular media depict violent death and dying and murder all the time, many times a day. If you watch a CSI episode, you've got graphic, photogenic, forensic detail right up close of death. That numbs us to it. It anaesthetizes us. It prevents us from making a connection to that death. It prevents us from engaging our heart in it I guess.

Our children play first-person shooter games. My son, my seventeen year old son, over my vigorous objections is playing these games where the purpose of the game is to kill another human being, in fact as many human beings as you can. You have to get points. You get a number of kills per game and you have to get a certain number of points before you can advance to the next level. It seems like the final goal of this is to become a master killer who can kill more people than anybody else. That killing is anonymous. It's amoral. This is the killing of war. This is the killing of ... it hardens us. It makes us impervious. It closes our hearts to love and compassion.

It's a bit schizophrenic. We're in a popular culture that inundates us with images of death and yet at an emotional level we are closed off from that place. We do not want to go there. Because we avoid talking about it, death has become, often become, an intensely medicalized, hospitalized, intensive care unit kind of experience that may extend our life up a little bit, but oftentimes at severe expense to our quality of life. It often doesn't meet our basic needs as human beings: to be connected, to be known, to be loved, to matter. What could be a deeply meaningful, affirming part of our life often becomes more wounding than healing.

Death is broken in our society. Death hurts far more than it needs to be. Why is this going so badly? Why aren't we talking about this? Why aren't we having conversations with each other? Why aren't we helping our patients and families to make good choices?

My deep sense in this is that patients and families are really just emotionally completely unprepared. They haven't seen this coming. They've tried hard to avoid seeing this coming in some cases and especially about talking about it and at the last minute, faced with choices about treatment, families panic. They can't let go. They grasp at straws because they are nowhere near ready to say goodbye. They've done none of their homework.

When you think about families in conflict, where you think about families where communication's not gone very well, when I think about the train wrecks that I've been involved in, the deaths that went really, really hard, there's a direct correlation between the degree of unresolved conflict and anger and dysfunction in your family, and how death's going to go. I see some nodding. You guys, when you think about when a family is loving and together, we can do death in a really beautiful way. When family is conflicted and not talking? I mean, Renu's family this morning, beautiful family, very loving, but no communication or communication shut off at a crucial place. Look at the damage that it did, four years later still deeply hurting. Ouch.

So advance care planning is one of our best tools. Advance care planning – the conversation about this, opening up the dialogue – is one of our best tools to relieve that suffering, to empower individuals and families, to allow us more dignity, more personhood, more connectedness, more belonging in our dying.

Advance care planning is a conversation. Pretty simple. It's a conversation about values. It's a conversation about "Would I want medical interventions if I could no longer get up and go out of the house and go for a walk? If I could no longer enjoy my life the way I do now? If I could no longer manage my own bowel and bladder? If I couldn't think clearly for myself? If I couldn't recognize my loved ones and speak to them? At what point would my disability make me reach the point where I wouldn't want to do this anymore? Before that point, yes, it's worth doing, and after that point, no thank you, I think it's time to go."

Advance care planning is a conversation about goals of care. What are we really doing here? Are we treating for cure or are we treating for comfort? Is this about "Let's do everything we can to live as long as possible" or this about "Let's do everything that we can to make this, to help you live as well as possible." Different families, different patients have different answers there. We need to find that sweet spot for that family.

Most people say that the best kind of life and death would be to live right to your dying day with all of your faculties and doing really well and go to bed at night and boom – die in your sleep. I think God and the angels would feel quite cheated. I think we're supposed to get old, we're supposed to lose our abilities, we're supposed to become frail, because that process helps us to let go of all our attachments and wakes us up to why we're really here.

When you think of the average twenty year old, he's got the world by the tail. He's got a car, he's got a girlfriend. What does he know about anything? We have to get old, we have to suffer losses, we have to experience pain, we have to be forced to give up things that we don't really want to give up before we wake up as human beings. That dying process is all about experiencing those losses, feeling that pain and understanding ourselves as human beings at a far deeper level because of those losses. It's a crucial piece.

The sad reality for many older people is that they don't die quietly in their sleep. They get weaker and weaker and sicker and sicker and then they wind up in and out of the hospital and they wind up in hospital all the time with more and more interventions and less and less quality of life and especially less and less dignity and less and less personhood. One of an

older person's worst fears is "I'm just going to be a body in a bed. I'm not going to be me anymore. I've lost my personhood." They're not able to speak for themselves and the family in their grief say "Keep going" and it goes on and on.

When I talk to patients about this, when I have this conversation, the overwhelming response that I get is "When it's my time to go, please let me go. Don't make me linger. If I'm not having any fun, let me go." We can help support patients and families. These advance care planning conversations are about exploring and clarifying values, about empowering people to make choices and to speak up for what they really want, protecting their autonomy, [and] especially easing family distress, healing those rifts, opening those conversations and helping people to connect with each other.

You can imagine that there would be a lot of benefits to this process. In fact, there are plenty. Research shows patients who discuss their wishes for end of life report feeling empowered, having a sustained sense of hope for the future. We avoid these conversations because we don't want to make them afraid of death. In fact, research shows that death anxiety is reduced when people are able to talk about this.

Advance care planning – these conversations – is a highly social process. It's all about relationship. It builds connectedness. When you have highly personal conversations where people talk about their deepest fears and beliefs, guess what happens? They feel more connected. Patients, families, doctors. There's intimacy. There's trust. The relationships are strengthened.

Including the family members in these discussions is the absolute key. When family members are present and they've got a stake in this, when they hear from the horse's mouth, it relieves them of an enormous burden of responsibility. If those family members are later asked to make decisions for their loved one, they can do that with a light heart knowing what their loved one would want, instead of having years of guilt or self-recrimination. We can save years of heartache by having families present in these conversations and as active participants.

To be old, to get old, get sick involves a huge loss of dignity and autonomy. Becoming dependent, incapable, means the loss of personhood. Everything that we do that allows them to be heard and valued and respected and make their own choices lessens by one tiny bit that burden. It eases their pain.

One of my hats is as a Chair of our Kootenay-Boundary Clinical Ethics Committee, the Interior Health Clinical Ethics Committee. I want to speak about ethical principles. Ethically, advance care plans are all about respect for autonomy. Simply put, "My body belongs to me. No decisions about me or my body without my consent. I am the boss of me." An advance care plan is a way of insuring that that right of consent can be carried forward even when you're no longer able to speak for yourself. You can still say what you do or do not want to happen for you.

The ethical principle of beneficence is "Do good, if you can and it's wanted." We are morally obliged to help people if we have that ability. The ethical principle of non-maleficence says "Prevent avoidable harms." If something bad could happen and you could prevent it, you are morally obliged to step in and do so. I see something bad happening so often when it comes to dying and seniors. Advance care planning ensures that unwanted or overly aggressive medical therapies are not carried out if the patient doesn't want them, even if the family tried to insist. As an emerg physician, I see that often. We'll talk about that.

The principle of justice or fairness. Here we're talking mostly about distributive justice. Distributive justice says in is a system where we've got a fixed amount of resources and when they're gone, they're gone, we have to try and organize those resources to bring the greatest possible good to the greatest number of people.

Do you remember Ariel Sharon, the Prime Minister of Israel? He died in January. He had a huge stroke, a massive stroke in 2006 and he's been lying in an ICU bed until this January when he finally died.

Are you guys aware of the Hassan Rasouli case before the Supreme Court of Canada. It's just decided. Hassan Rasouli was a sixty-one year old fellow. He had a brain tumour, he was operated on and suffered very severe complications after the surgery. He had meningitis, suffered severe permanent brain damage. His physicians after a year said "This is terrible. He's not benefitting from this. He's never going to recover. Can we turn off the ventilator?" His family said "no".

In a very unusual step, the physicians of Sunnybrook Hospital in Toronto took this to the court and said "We consider this to be assault on Mr. Hassan Rasouli, for us to keep him alive, and we would like the permission – whether the family likes it or not – to turn off the ventilator." The court turned them down. They went to a higher court – turned down. Finally the physicians have gone to the Supreme Court of Canada to decide this and the Supreme Court in its decision said "Well actually you have to go to the Capacity and Consent Board and they will give you the decision."

What I'm getting at here is that it is possible to consume a huge amount of resources for what most of us would consider not a whole bunch of gain. An ICU bed – your typical stay for a patient in an ICU bed, you need that bed quite badly for about three to seven days – it's an expensive tool. You don't have that many of them. There are the physicians' and the nurses' time and the bed itself in the hospital and all those tests and the occupational therapist, physiotherapist, rec[reational] therapist, respiratory therapist. This is a very expensive machine that we're running and for ten years there was a bed there that literally hundreds of other people could not access because somebody was in it who didn't benefit from it in any significant way.

Distributive justice says that we are morally obliged to make sure that in a system where we can't give everybody everything that they want, that we make sure that what we've got is spread out to provide the most benefit possible for the most number of people.

The Baby Boomers are aging. We as a society have to have these conversations because we can't do everything for everybody and we're going to have to decide who would really benefit from this. We can't say to people "No you can't have this." We have to converse, we have to have conversations and say "What's best for your loved one? How can we best manage this with you?" and have those conversations with patients and families.

Let's talk about the obstacles. If this is such a great idea to have these conversations, how come we haven't been doing this for the last twenty years?

What's the first obstacle, the biggest one? That's easy: denial and avoidance. This is a conversation about dying. "Yeah. Let's sign up. There will be a crowd at the door." The next obstacle, amazingly, is, I think, magical thinking. Magical thinking is a developmental stage quite appropriate for five to seven year olds that says "If I don't think about this, it's not going to happen. If I never say this out loud, it probably won't happen."

Another obstacle is that we don't want to upset people. We think if we have this conversation, it's going to upset them. In fact, over and over again we see that families are enormously relieved to have these conversations and patients themselves. But they don't want to start them. They don't know how. That's our job. That's your job, to start these conversations, because families desperately need them and we can help them a whole bunch.

Poor communication is an obstacle. I'm going to be up at this podium for three quarters of an hour. I'm going to apologize eight times for doctors. I might as well just get started. [laughter] In the absence of an open and clear discussion about the end of life, many patients may not even know what their diagnosis is or exactly what their prognosis is or how close or far they are from the finish line. That's a conversation that needs to happen. Families consistently report wanting more information, the opportunity to ask questions.

In fact, after death when we go back and look, one of the key determinants of family satisfaction was the availability and involvement of their doctor, and the ability to have discussion and answer questions. The ability to be involved in the decision-making process is crucial for families. That ability had a profound impact on the degree to which families for years afterwards had a sense of closure and resolution about the death of their loved one. If we do a good job of this, it lasts a long time. When we do a bad job of this, it lasts a long time. Families need to feel informed, involved, consulted. [applause]

It's paradoxical but the more life threatening your illness, the less likely we are to actually say the 'd' word. We don't want them to give up hope. We have to keep a brave face. Renu [Bakshi] with her family this morning, [mother with] stage 4 breast cancer, nobody's mentioned the "d" word? Ow. I feel so embarrassed for us as a care team that we couldn't help that family more.

In fact, having a realistic conversation about a person's illness, especially the more serious it is – giving them a realistic picture of where they are, what their prognosis is, what their choices look like – universally empowers them. They feel more part of the team, they feel more in control, they feel like their voice will be heard, they feel braver and more ready to face the future because they know where they stand. We respect human beings when we acknowledge that they're big and strong enough to know about their own death.

Another obstacle is uncertainty about the choices. "What do we choose here, this CPR, defibrillation, intubation, ventilation. I don't know – what am I choosing here?" We have to be prepared to explain these things. That's the doctor's job. I'm apologizing again about all these things and what they mean. When I explain this to people, some people say, "Well what the heck? I mean, might as well give it a try. I mean, it can't hurt."

Here we're victims of the Hollywood myth. Every single episode of ER always has at least one cardiac arrest and defibrillation and 75% of the time it works. By the end of this half hour show they're walking out of the hospital doors arm in arm with their loved one murmuring sweet nothings and gazing into each other's eyes. Wasn't that a heartfelt moment?

The truth of this is, and here I'm putting on my "emerg doc" hat. You're older than 65 [years of age] and your heart stops and you're out in the community and you come to my emergency department and I defibrillate you, I have a 25% or 30% chance of getting you back started again. Of those people that get started, only ten out of a hundred will still be alive after a month and only two or three out of a hundred will walk out the door or be wheeled out the door of the hospital in a wheelchair, and most of them will have some degree of anoxic brain damage.

If you're young and you've got a healthy heart and it happens someplace close to a defibrillator, we can do way better than that. But if you're old and your heart is tired and wants to stop, by the time it stops, my chances of getting it started again? Zero. And to do CPR and defibrillation on an 80 year old? That's not the way I would want my mother or anybody else's mother to die. My mother died like that. We'll tell you that story later maybe. I can't think of any 70 plus year old that I've ever actually saved. If you're more than 70. I've heard stories of people defibrillated who go on to have a good outcome but I

personally have never, ever successfully defibrillated and resuscitated somebody who's more than 70 whose heart stopped by itself because it was too tired.

My worst fear – one of my worst fears – as an emerg doc is when a patient comes in the door, they come all the way out from the Slovan Valley, they've been down a long time – at least thirty, forty minutes, that they've been down at least thirty minutes to CPR – and they roll in the door. Their pupils are fixed and dilated, they've got anoxic brain injury. If I'm clear that they've been down long enough, I can just pronounce death. If it's unclear how long they've been down, I'm obliged to give them that chance and I charge up the paddles and put them on. I'm praying that this is not going to work because I know how this movie is going to end. If their heart starts again, this is the story of my father.

72, diabetes, smoker, renal failure, dialysis for a couple of years. Train wreck. Central obesity. That's my Dad. He had been on dialysis for a couple of years, and he would have been ready to go except he had remarried and started a second family and, vasectomy notwithstanding, he ended up fathering another child. He had this teenage daughter and this young wife who really, really loved him and really, really wanted him to stick around for longer.

He was putting up the Christmas lights. He was trying to get the heavy extension ladder off the wall in the garage. Way too heavy, wouldn't ask for help. That's my father. Heart attack right there in the driveway. Dropped. Amazingly, Red Deer Health Services – there in three minutes, started CPR, defibrillated within four – got his heart started again so that he could spend three days in the ICU lying there in the bed while his first family – the five of us kids – and his second family – his lovely wife and his very unprepared daughter – unprepared in the sense that he had only been on dialysis for two years and only had three heart attacks before that and he was only 72. So they were quite unprepared for this, and they had to let go. As soon as we turned off the ventilator, he stopped. His heart stopped right away. He was gone. He had been dead since the moment he hit the driveway. But we just weren't quite ready to do that.

Just because we can do something doesn't mean that it's the right thing to do. Sometimes when I think about medical interventions for people who are dying, I think they're more for the people that we're leaving behind than the dying person.

Sometimes patients fear that a “Do Not Resuscitate” and “no CPR” order and by the way, can I change the words? “DNR, No CPR.” Can we call this from now on, “Allow natural death”? [applause] There's a movement among emerg physicians that's gradually gaining momentum that says, “Let's talk about allowing natural death. Let's not talk about ‘No CPR’. I'm not going to save your life when I easily could just by [blows]. Well no, let's allow natural death.” Patients might think that in allowing a natural death order, means planning for euthanasia, or that if they sign that, the doctors or the family would be stuck with that and if they change their mind they couldn't get out of it and they'd be obliged to die when they didn't want to. We'll talk about changing your mind in a minute.

A big one is, a big obstacle is fear of abandonment. “If I sign this, a DNR means that the doctors will give up on me. There's nothing more we can do. Bye.” Anytime we have these conversations with people, we have to make it absolutely clear that no matter what you choose, “We're always going to do everything that we can to make you as comfortable as we can. I will always be with you. We're going to be with you right to the end.” They need to hear that.

For doctors, there are significant internal obstacles around this as you might have guessed. There are several factors at work. Our entire medical culture is about survival as success. It's about preserving life. It's about “I saved him.” In that paradigm, death means failure. Often we as physicians take that as personal failure. “I couldn't save him.” For some physicians, I think we're actually fighting off our own death. That's what we're running from in some cases.

Another thing for sure is that we are very afraid of the patient's emotional needs. The truth is that we're barely holding our own emotional needs in a lot of cases. We're on the edge of not coping with our emotional needs, so to hear about the patient's emotional needs might be too much for many of us. Doctors are people. Many of us, most of us, have unresolved grief issues of our own. So we just don't want to go there. We're avoiding this just as much as you are.

Advance care planning is a conversation. It's about goals, it's about values. We've talked about the benefits. We've talked about the obstacles. Advance care planning is also a document. A piece of paper. You can call it an advance care directive, a living will, a "My Voice", a DNR, no CPR, allow natural death, Medical Orders for Scope of Treatment [MOST]. Those of you from Fraser [Health Region] will have heard that. Alberta – it's a better no CPR order that allows you to express your wishes around end-of-life care, appoint a temporary substitute decision maker. That kind of stuff.

We just passed the Health Care Consent Act last September. We used to have these but they weren't law, and a temporary substitute decision maker at the last minute could overrule them. They are now law, as of last September. If I've got a DNR, it doesn't matter what the family is telling me to do. There at a moment of crisis in the emergency room, if I know it's there, I can say, "Your loved one did not want this, and they are my patient and I listen to what they tell me to do, not you."

Lorraine [Gerard, BCHPCA Executive Director] and Meg [Milner, BCHPCA President] wanted to make it clear that advance care planning is for everyone. It's great for old people. We'll talk about old people some more, but this is for everybody. I'll tell you a story.

Busy Saturday afternoon in the emergency department. The provincial hockey finals were being held in Nelson and all the star hockey teams from across the province were here, were in Nelson, the city. An ambulance rolled in coming up from the Rec[reation] Centre. Full Code 3, lights, sirens. Woman convulsing in a coma on the stretcher. What the hell happened?

The story was her son had been playing in one of the playoff games and had been hit from behind by somebody. She was screaming at the top of her lungs at the referee, calling for a penalty because her son had been hit. She dropped to the ground. Sudden loss of consciousness. She woke up. She had the worst headache of her life. She was nauseated, and her neck was stiff. People are nodding [the audience]. They know the diagnosis. This is a catastrophic inter-cerebral hemorrhage. This is a sub-arachnoid hemorrhage.

Two or three of us in this room have aneurysms in the blood vessels in the base of our brain. As the blood vessels are forming throughout our body, there are spots where the muscle's got a little gap in it and the lining isn't strong enough. If our blood pressure is up, the lining starts to bulge outwards and makes a little pea-shaped aneurysm in the blood vessels. It happens in lots of places but those blood vessels right at the base of your brain and right in tiger country.

The breathing centres, the whole brain stem sits right on top of them, and if in a moment of blood pressure surge – you're making love to your wife or you're lifting your end of the piano or you're screaming at the referee – and your blood pressure peaks? Pop. That can rupture. If it ruptures slowly you develop a terrible headache and we get you to a hospital and we get you to a neurosurgeon and they put a clip on it, and you're saved. If it happens quickly, like in this woman, she's going to start to dip into a coma and the prognosis is terrible when you bleed suddenly like that.

I'm looking at this woman and I know – I haven't even got a CT scan yet – but I'm pretty sure I know what the trouble is and it's not looking good. The husband is a deer in the headlights. He is completely unprepared for this. He has no idea. "No we've

never had a conversation. No I have no idea what her express ...” He could barely talk. No, he had no idea. So we got the ambulance going and tried to stabilize her. Twenty minutes later came back to him. He said, “We did have a conversation. It was about twenty years ago. Our neighbour had been in a car accident and was in the ICU in a coma. We heard about it from his wife. And as we came back to the house, she said to me ‘I would never want to live like that. If that ever happened to me, just let me go.’”

He had taken a while to remember it but by the time he got to Kelowna to the neurosurgeon – husband went in the ambulance. By the time they got to Kelowna – she was doing badly – he was able to look that neurosurgeon in the eye and say, “Just let her go. I know that’s what she would have wanted.” And she died.

It’s never too soon to start talking about advance care planning.

Advance care planning is really crucial for people who already have a significant disease. If you’ve got congestive heart failure or COPD – that’s lung failure – or you’re on dialysis – that’s kidney failure – if you’ve got dementia – that’s brain failure – if you’ve got diabetes and are going to get complications, now is the time to talk to your physician. Now is the time to talk to your family about what you want.

There are a bunch of questions: “How might my condition progress?”; “What does the future look like for me?”; “How will my disease affect my memory, or my ability to express myself?”; “What would it look like if it became life threatening?”; “What would I want in terms of life support or life prolonging therapy?”; “Who do I want to talk for me? Who do I want to make these decisions for me?”

Those are really useful conversations.

I thought I’d make this practical for you. How do I approach advance care planning and practice?

In the emergency room – there are elective discussions you guys have out in the community – in my world in emergency, I’ve got a 64 second conversation because I’m a big guy and there’s lots [of patients] so it’s “chop, chop, chop”. I’m happy to have this. Every patient that’s admitted to the hospital we’re now legally obliged to have that conversation in Interior Health anyway, as they come in the door. It’s a good thing because it normalizes the conversation and by the time you’ve been asked this same thing six times, you start to expect it and you get more comfortable with it.

May I borrow you? [selects person from audience] You don’t even have to get out of your chair. You don’t even have to say anything.

[Role playing] “Sandi? What’s your last name? Armitage. Sandi, I’m ... yeah, you’ve got a bad pneumonia and we’re going to need to bring you into the hospital and I think you’re going to need some antibiotics. Is that okay with you? Yeah?”

“Now I have this conversation with everybody but I need to ask you some questions about what your choices might be. And I’m really glad that your husband and your sister are here with you to hear about this because they may be actually required to help speak for you if you’re not able to speak for yourself. So I think it’s really important that they’re here so that they can hear from the horse’s mouth what it is that you would want.”

“Now you’re doing really well with your pneumonia and I think you’re going to do fine. But I need to talk to you about some possibilities just in case things go badly. If you were to ever have a big fat heart attack or a stroke or something like that and your heart stopped and your breathing stopped and you’re dying essentially, there are some people who would want us to do CPR and try and restart their heart again – that’s defibrillation – or put a tube down their throat – that’s intubation – or connect them to a life support machine – a ventilator – to breathe for them to try and keep them, to try and get their life started again. And there are other people who would never want that, say ‘Don’t you ever do that to me. I’d never want to be kept alive on machines.’”

“What would you say Sandi? [Sandi answers] Do it all. There you go.” See the right answer for Sandi is “Do it all.”

There might be a more focused conversation.

Say Sandi had had her first stroke and she’s being admitted. “Sandi, you’ve had a first stroke and what we know about strokes is they sometimes come in clumps. I need to ask you a question about feeding tubes, because different people feel quite differently about it. If you were to have a much more serious stroke, a very devastating stroke where you were completely paralyzed on your right hand side, and you’d completely lost your ability to speak, and you couldn’t walk and you couldn’t talk. For many people that involves losing your ability to eat and to swallow. If you weren’t able to eat or swallow, you’d die unless we fed you. And there are some people who would want us to put a feeding tube in through their nose and down into their stomach to keep them alive. And there are other people who would say, ‘If I can’t walk and I can’t talk, and I can’t eat, and I may not understand what’s going on around me, I don’t think I’d sign up for. No thank you.’”

“How would you feel about that? [Sandi answers] Don’t want that? How is that for you husband and daughter? How would that be for you guys? [Sandi comments] They’d agree.” [laughter]

There. That’s been two minutes. That’s all it takes. And we’re engaged. We understand what the choices are. They’ve heard from the horse’s mouth what this person would or would not want and the reasons for wanting that. Sometimes the conversation goes on longer because there are lots of ins and outs. In dementia care, this conversation often takes quite a bit longer because there’s a whole bunch of education for the family around what’s going on and what the future might look like. But this is the two minute corridor conversation.

I think I’d have this conversation in an emergency with a temporary substitute decision maker. If it was your wife that was rolled in on the stretcher and you were the husband and I’m now asking you “What would your wife want?” that’s a different conversation. When I’m speaking to the temporary substitute decision maker, one of the things that I often need to remind them is “By the way, I’m not asking you what you want. I’m asking you what my patient would want. What they would say. And what they want and what you want may be the same but they might not be. And I’m not asking what you want. I’m asking what he would want if he were able to speak for himself.” That reminder is a crucial one.

I think that’s probably all I’ve got to say about ... Oh, we’re running out of time. I’ve got seven minutes left to talk about the important stuff. The gifts of dying. The gifts that death brings.

Over the last twenty or thirty years, I’ve seen a lot of people die in a lot of different ways and some of them go beautifully, gracefully, quietly. It’s lovely. The family’s all connected, surrounded by love. Very integrated, very healing experience. I’ve seen people die kicking and screaming. Fighting to the last breath. You guys have seen this. I’m sure you’ve seen deaths like that.

When I'm dying, I'd like to do this gracefully. Wouldn't it be nice? When I'm dying, I'd like to be old and wise and kind. I'd like to be enormously pleased with everybody who's around me. I'd like to be very grateful for all that I've been given. Not "It wasn't enough" but "Thank you so much for all I've received." I'd like to be faintly amused and a little bit joking around about it. I'd like to be open and curious. I'd like to be trusting. I'd like to be loving and simple.

You don't get there without doing some practice. Some of the practices that I've got, one of them is called "the Death Bed Test". If I'm offered a new job or somebody wants me to do something and I'm not sure, I put myself on my death bed. Okay, if I was on my deathbed and I was actively dying and I looked back at my life and said "Did I, how would I feel about this thing?" Would I be glad that I had invested my life energy and spent months, years of my life doing that? Or not. Would I, if I was doing something and wasn't really sure about it, would I be proud on my deathbed that I had done this? Would I be embarrassed?"

Almost every time I do the Death Bed Test, the answer comes out "I wish I could have done this more gently, more patiently, more kindly." But it just gives me the perspective. I think we don't do this very well because we're unprepared. We haven't done our homework. We're actively avoiding doing our homework.

In Nelson there are yoga studios. There's a yoga practice called Shavasana. How many of you do yoga? Anybody does yoga? Yeah, sure. So there are a few of you who do yoga. In Nelson, there are more yoga studios than coffee shops [laughter] and there are more coffee shops than people, so everybody knows Shavasana. So Shavasana is the corpse pose. You're lying, laid out on the floor as a corpse. After you've done your yoga practice, the instructor will say "Okay. Let's do Shavasana." It's the practice of preparing for death.

You lie down on the floor, sometimes you're covered with a blanket, and you spend ten minutes saying goodbye to everything you've ever known. You say goodbye to everybody that you've loved, one by one if you like. You let go of all your possessions – all the stuff. You let go of the house, the car, the mortgage, the savings plan, the retirement savings. You let go of all the projects: the garden, the kids, the work, all the attachments. You let go of all the stories, all the dramas: "I'm not thin enough"; "I'm not pretty enough"; "I'm not rich enough"; "I don't get lucky often enough" – that's a guy joke, sorry [laughter] – "I'm not respected enough"; "I'm not valued enough"; "My partner doesn't love me or cherish me or tender me the way that I need to be loved". We let go of all those stories.

We have to let go of everything because it's time to go. It's too late to change anything. It's too late to make amends or take back all the stuff that's been said and done. It's time to go. All of this will be gone. And we get to that place and we sit in it.

Then "ding" – the bell goes – and we get up very slowly and we roll our yoga mat and we go back out into the world, and go back out into that world that we just said "goodbye" to. It's not too late to make amends. It's not too late to take back all that's been said and done. We see our life from a very slightly different perspective. Our attachment to all the stuff, our attachment to all those stories that we've been telling ourselves for years is just this much looser than it was before. We're able to value more rightly the people that we love.

Many people who are dying tell me that they really only woke up when they found out that they were going to die. They did more living in the last three or four months of their life than they had the whole time before. It was like they were asleep before and they've only just woken up. The last few months of their life were more painful but also far richer than anything they had had before.

When we stop avoiding and denying our death, we wake up ... to gratitude for what we're given in each moment, the preciousness of our relationships with the people we love. We wake up to the fullness of our life, the gift of the present moment. When we finally feel our frailty, our transitory nature, we also feel our joy, our aliveness, our freedom to create beauty in each moment.

In order for us as hospice palliative care workers to give that gift, we're able to give that only to the degree that we've embraced the gifts that dying has brought us. The people that we said goodbye to, as we feel our way into that, as we really live into that experience of death, we approach the place where we can become a real support for the people that we're with. The support that we bring is our presence.

I'd like to give you an image. I'm going to finish up here - I've run out of time - but, I'd like to offer you a picture.

I would like us to see ourselves as midwives. Birth midwives are guides, helpers in one of life's great transitions. Birth is scary and dangerous and enormously painful and it can go terribly wrong. But the midwife has done all this hundreds of times. She knows this dangerous territory inside out and she is not scared at all. The midwife's job is to ease the tight spots, to steer around the dangerous places, to keep things moving when they try to get stuck, to hold that mother safe. Even in the middle of this scary and dangerous process, to let her relax into the beauty and wonder of what's going on despite all the pain.

You can be - you are - midwives in the dying process. The midwife's job? Ease the tight spots, steer around the dangerous places, keep things moving when they try to get stuck, hold this family safe, let them relax into the beauty and wonder of what's going on despite all the pain.

As midwives in the dying process, the gift that we bring is our presence, our willingness to be right here in the present moment. Our willingness to be here with death, without any denying, without any avoiding. The gift that we bring is our wide open heart, our familiarity with this unknown dangerous territory. Our comfort, our acceptance, our trust in the goodness and the rightness of this process. The gift that we bring is our gentleness, our loving kindness, our humility, our common humanity, our being with each other as human beings.

These are the gifts that death brings. The gifts that you bring in doing this work. This is wonderful work. I thank you for doing it. [applause]