

**“Live your way, die your way:
An introduction to alternatives in end of life care”**

Presentation by Ellen Newman May 24, 2015

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One of my great joys as a Unitarian has been visiting other Unitarian congregations. I was invited to speak to you about death, because I am very passionate about it, and have decided to make it my purpose to promote death positivity. Many people find that phrase amusing “death positivity”. How can you be positive about death? I am not sure I can answer that question, but I do know that the way we view dying and death in our society doesn’t seem to be very healthy. The way we care for the dying does not give them the dignity, comfort and freedom from suffering they deserve, and the way we care for our dead does not provide us with an opportunity to express our love, to grieve, mourn and honour our dead in a way that is meaningful and unique to us. We are so vulnerable at the time of death, and how we experience that initial phase of grief is critical for us to be able begin to integrate that experience of loss and accept it as part of our lives, so that we can move forward and embrace the fullness of life again.

Kahlil Gibran said:

“You would know the secret of death,

But how shall you find it unless you seek it in the heart of life?

If you would indeed behold the spirit of death, open your heart wide unto the body of life.

For life and death are one, even as the river and sea are one.”

And I would say, if you want to know the secret of life, you need to look upon the face of death.

It is an interesting time to become involved in death care. Things are changing. There is a confluence of factors contributing this and the baby boomers are one of them. They make up the majority of people making decisions for their dying parents, and they themselves are starting to die, so death is on their

minds. At each major life milestone, boomers changed the landscape – when they entered school, when they had babies, and now at the end of life. The result has been a huge shift toward the personalization of death, with a marked increase in Celebrations of Life, as opposed to funerals or memorials. This is a good thing. The move away from the traditional, cookie cutter funeral is something that is discussed quite a bit at the Death Cafés I have hosted and attended. But, in my opinion Celebrations of Life can perpetuate, in a small way, the death denial rampant in our culture – and I’ll speak to that at the end of my talk.

The shift toward personalization is not only because baby boomers need to do things their way, but also because almost a quarter of the population now identifies as non-religious, and a 1/3 identifies as non-Christian. The traditional funeral had a very heavy religious flavour, and wasn’t much about the person who died. The death care industry has had to adapt to this change in a way that sometimes it is not ready for, especially since some of those non-Christian people are from cultures that generally cremate for religious or cultural reasons. Cremation is another trend contributing to the changes in death care – roughly 65% of dispositions in Canada are now cremations as opposed to burial.

We are living longer, but not necessarily better. Long-term chronic health problems that affect our mobility, and our emotional and mental health are becoming the norm. This has fed into the Dying with Dignity movement. As you know, the law prohibiting physician assisted death has been struck down, opening up a vibrant and vocal national conversation about end of life care that has garnered a fair amount of attention. Sadly, the government doesn’t seem to be moving very quickly to enact new legislation, so it is up to us to make our voices heard. Recently, I attended a Dying with Dignity workshop about Advance Care Directives at my home congregation. 30 – 40 seniors were present, and the thing they most wanted to make sure of was that they had access to physician assisted death should disease or dementia make life unbearable for them, or for their loved ones. This level of control and autonomy over our own dying process is extending to what happens to our bodies at death and after as well.

I completed the Contemplative End of Life care course with the Institute of Traditional Medicine in Toronto last summer - which I will refer to it as the CEOLC from now on. I was privileged to learn from

many who are at the forefront of the “alternative death” movement. I came away with so much information, experience and knowledge there is no way that I could ever condense it into a 25 minute talk. I will share some of what I learned of vigil work, legacy work, home funerals, and ways that death can become more person or family centered, even in the funeral home.

Our first instructor was Henry Fersko-Weiss. Henry is a thanadoula - thana meaning “death” and “doula” meaning “servant” - more specifically women’s servant - he borrowed the term from the birth doula movement. He is also the Director of the End of Life Doula program at the Valley Health System in Ridgewood, New Jersey, which is a part of the hospice program offered there. The terms end of life doula and thanadoula are interchangeable

A thanadoula provides informational, emotional, physical and spiritual support, and advocacy to someone who is dying and their family. An End of Life doula also honours the sacred nature of the dying process. During active dying thanadoulas provide information about what is happening physically during the dying process. A thanadoula can explain the choices for how the person approaches their death, they can help to develop a plan for the final days, and provide a continuous, compassionate presence during the dying process. They can serve as link between the professionals involved in the dying person’s care as needed and advocate for their wishes. As a result of the CEOLC, and other organizations online and around the world, there are a number of people practising as thanadoulas in Ontario and the rest of Canada – I have provided some contact information on the hand out.

Henry’s program is part of a home-hospice program. It has been shown that the vast majority of us would like to die at home, surrounded by our loved ones. Hands up – how many here want that? Sadly, that won’t be the reality for most of us, as only 15% of us ever end up that way. Which means most of us will end up in the hospital. So, can this level of support and advocacy be translated to the h setting? Absolutely, especially if, when you go into speak to your doctor about your Advance Care Directive, you talk about some of the more environmental or comforting aspects of the death experience you might like to have in place, as well.

As an exercise, our class was asked to write out our ideal death experience – where would we be, who would be there, what kinds of things might bring us comfort as we die? Something I wasn't aware of is that a person's hearing is the last thing to go. What would you like to hear as you die? Would music be part of your end of life experience? There are now groups of people that will come and sing to the dying. Music therapists are working with palliative care and hospice to provide music at the end of life. Maybe you'd like to hear the voice of a cherished loved one telling you the story of your own life, or reading out notes that people have brought just for that purpose. What about massage, scents, other sounds – like bells, or drums, or the wind in the trees? One woman in our class told us that she would like to die in a cabin in the woods, looking out the window into the forest, and then she said that was too impractical, and it would be too much of a burden for her family. Henry said – well, you aren't going to spend your money on anything else – figure out how to make it happen!

I am hoping that as I shared that bit of our experience, you are thinking about your ideal death. I hope you are thinking about what brings you comfort when you are in great pain, or stressed, or anxious, or confused or scared, as it is very likely those things that comfort you at the time of death. It would be important for you family to know that. As part of your end of life planning, you can include a Vigil Plan.

Like I mentioned, most of us will not die at home, so what kinds of things might make a hospital death more sacred, meaningful and peaceful? When my father died, long before I knew anything like this, I instinctively thought of some ways that we could make the experience better for him and for us. I brought in my most colourful, comfortable blankets, I brought crystals, I brought a statue of Kwan Yin, the Chinese goddess of compassion, I brought his favourite music, I swabbed his mouth with beer and drank some, too, much to the dismay of the nurse. When he finally died, we asked if we could stay with him for a while, and if we could wash him. Which we did, and it was a truly beautiful experience. A thanadoula can help create and facilitate rituals for right after the death, at home or in the hospital. They can also hold space – and this is incredibly important, especially in the hospital, where the environment invites intrusiveness. They can facilitate the acts of closure and connection that we have no idea how to approach, and that can ameliorate a difficult dying, where a person is burdened with emotional distress. Difficult dying can increase negative thoughts and extend duration of grieving.

Thanadoulas can help the dying, and those supporting them with these essential words: I'm sorry, please forgive me, I forgive you, thank you, I love you and Goodbye.

Part of facilitating those kinds of conversations can be helping the dying to create a legacy piece. Legacy work gives a dying person purpose, and can be something of great comfort going forward, as it is a way to bring the dead loved ones presence into the grieving person's on-going life – something that has been shown to be a part of healthy grieving. This could be gathering photographs into a scrapbook, writing the story of the person's life, or recording them telling stories. Henry had an experience with an Italian woman who had died, who was well-known for her love of cooking – preparing meals for her family was central to her life. The thanadoula helped the woman write out her recipes by hand, and then encouraged her to share a family memory that she associated with that recipe, which he then typed. He helped the family put together a booklet with the recipe in her handwriting on one page, and the story she shared on the other, along with pictures and her common sayings, which they then made copies of to present to all the children and grandchildren.

Legacy work is intensely personal, and can centre the dying as it draws their attention away from the physical experience of death toward something more mindful and reflective. Henry and others, like Dr. Sameet Kumar who also taught in the CEOLC course, and wrote a book called *Grieving Mindfully*, believe that bringing a level of mindfulness to the death experience, for both the journeyer and their families, can be deeply healing.

When dying and death were removed from the home, we lost something. Robert Kastenbaum is a well known expert in death and society, and in an article he wrote for *Generations* he spoke about the deep feelings of relief that direct involvement in caring for a dead loved one can provide for a family, and he contrasts that with the feeling of disconnection and confusion that result from being disengaged. This disengagement is what I believe is driving people away from the traditional funeral – even more so than the costs involved. Enter death midwives and the home funeral movement.

Death midwives, sometimes called home funeral guides, help families care for their dead at home. In Ontario, it is not legal for them to personally perform any body care, or perform any function that could be construed as funeral arrangement or directing a funeral, or charge for their services (but inviting an honourarium is ok). Death midwives can provide information and guidance to a family so that they may do these things themselves.

During the CEOLC course, I was taught about home funerals by Jerrigrace Lyon, a pioneer who has facilitated over 450 home funerals. On Mother's Day, I was thrilled to attend a home funeral practicum where I was able to integrate some of that knowledge, and I learned quite a bit more as well. The practicum was hosted by Alan Grose from the Grand River congregation, and co-facilitated by Kory McGrath, a funeral director come birth midwife who is interested in home funerals, and Don Morris, a gentleman death midwife from BC who was also once funeral director. There are a just a few death midwives in Canada, but the numbers are growing. It is perfectly legal to take care of your own dead loved one in Ontario. You can take possession of the body of your loved one, as long as you are the estate trustee or the legal next of kin. You will need ONE: medical certificate of death from the hospital, or a person's attending physician if it is an expected death in the home; and TWO: a Statement of Death, that a family member can fill out, and then you can register the death yourself, and obtain a burial permit, which is what is legally required to bury a body in a cemetery or take it to a crematorium. Sadly, in Ontario, it is not legal to bury a body anywhere other than a cemetery. A death midwife can help prepare the family for the changes to the body that come with death and instruct the family in how to wash the body – often using those very substances that were used in the dawn of embalming – oil of lavender, and oil of rosemary or eucalyptus, even witch-hazel, all of which have disinfectant properties that can slow decomposition. A death midwife can provide information on the use of dry ice to cool the body which can allow for a viewing or laying in honour. This can be either right in the bed, or on the dining room table, or in a casket – which can be made of cardboard, or constructed by a friend or carpenter or cabinet maker, and decorated and personalized by the family.

Each aspect of this care can become a deeply meaningful ritual or ceremony in itself. The body changes that we have been taught to be afraid of, are explained and rather than seen as repulsive, are accepted as part of the natural process of death. Dry ice slows decomposition quite significantly. A burial or

cremation would be recommended to take place by the third day. Three days seems to be significant. Both Henry Fersko Weiss and Don Morris spoke about 3 days as the time it takes to feel as though the presence or essence of the person is gone from the body, leaving just a shell. A home funeral allows for the family to have many uninterrupted hours alone with their loved one giving those who wish to join the family and support them in their grief a much greater window opportunity to do so. Afterwards, the family can transport the body to the cemetery or to the crematorium themselves.

We are blessed in Brampton, as there are two natural burial grounds within an easy drive – one right in Brampton, and the other in Pickering, and there is a fully green burial ground in Cobourg which is less than 2 hours away. It is perfectly legal to bury a person wrapped only in a shroud in all three of these cemeteries, although in the natural burial grounds they do require there to be a rigid board under the shroud. They do not allow the family to lower the individual into the grave themselves, and use a lowering device, which requires the rigidity.

A shroud is another opportunity for a dying person, or their loved ones, to personalize the death. I am crocheting my own burial shroud. It will take me years to finish it, as it is entirely made up of individual mandalas of very fine cotton. Whatever I manage to get done before I go is what will have to do. But, it can be something as simple as a cotton sheet that the family decorates themselves. You can also order quite stunningly beautiful handmade shrouds online. You can order caskets online, too. I urge you to visit the CINDEA website – CINDEA stands for the Canadian Integrative Network for Death Education Alternatives – where you can find just about anything you'd like to know about home funerals in Canada. Or just google "home funerals". At some point, I hope to prepare an adult education curriculum on the many aspects of death care, including a package of all the documentation and procedures required, but for the time being I urge you to visit that website.

Some in the funeral industry are alarmed by the idea of home funerals, citing health hazards and logistical issues. Quite understandably, they are also concerned for their livelihoods – if everyone took care of their own dead, who would need funeral directors? I don't think it is likely many people will choose to care for their dead at home – just like a large percentage of women don't choose homebirth, even though the option is available to them. But I do think the trend toward increased family

involvement in the care of the dead will grow. This is why it is important for us to start talking to the people in the funeral homes about what we might like.

In Ontario, the legislation governing the funeral industry and cemeteries changed recently, and now allows for different levels of service. You can now contract directly with a transfer service – which can transport a body, take care of all paperwork, place your loved one in a casket or container, and wash the body and set the features, and then take the body to the cemetery or crematorium. They just can't arrange a funeral or direct a ceremony or ritual. Funeral homes, by law, must, offer their services a la carte or piecemeal, as opposed to only in packages - so you can go in and pre-arrange a funeral where all they do is the paperwork, and transport the body from the hospital to your home, and from your home to the cemetery. This is a good option if you don't have a vehicle that is suitable for transporting dead people in a dignified fashion – you know, like a mini cooper or something. This option also relieves a grieving family of doing something they might not be in the right mind to cope with - like dealing with the City clerk, or filling in a Statement of Death. You may not know that funeral homes can't charge you to pre-arrange a funeral. Prepaying for a funeral is something different - and is a whole other topic and if you want to know about that you'll have to book another talk!!

Some funeral homes are already rising to the challenge of providing more personal, meaningful death care options for families. A number in Toronto now offer ritual bathing rooms. Originally used by religious groups, more and more secular families are requesting them to care for their own dead. One group of funeral homes has created beautiful cremation witnessing facilities. These rooms can accommodate significant numbers of people and feature comforting and dignified décor. The cremation equipment is state of the art and virtually emission free (the energy they consume is another story making cremation a less than green option– again – invite me back!) The idea of witnessing a cremation may make some of you very uncomfortable. For those families that have requested it, it was a powerfully moving and transformative event. You can witness at any crematorium if you wish, though in most cases the facilities are quite industrial. It can be a profound honour to press the button to start the fire, and an entire service or ritual can be built around this event.

Whether cremation or burial, you can bring your own container – casket or urn – that you buy or make yourself, to the funeral home. You can decorate it whatever way you want.(though crematoriums will have an issue with plastic or glass) You can even decorate caskets you purchase at the funeral home – many allow for panels to be put in the lining of the top so that the personalization can be seen at a viewing – like handprints or hand written notes. Many encourage personalization by leaving coloured markers out for families to draw on the plain pine casket they may have chosen or brought in. Funeral homes are responding to the need to celebrate after the ceremony by allowing families to secure a liquor license for receptions.

What speaks to me about this whole movement is something that I alluded to in the beginning of my talk – we are bringing the dead back into our lives. The Celebration of Life has long been our way. As a Lay Chaplain though, I found the person of honour was not present! We would never celebrate a wedding or a baby dedication without the couple or the baby, why are we celebrating life without the dead? There is great value having the dead present. This is the central purpose of a home funeral, and caring for the dead at home – to see death, to come face to face with the reality of it, can go a long way to helping us deal with our own existential terror and be in a better place to integrate the loss. For those who could just not fathom a home funeral, something as simple as having the urn present at the Celebration, and inviting guests to light a candle and surround the urn in the light, while sharing a memory, can change the Celebration from an event where perhaps it feels that only happy thoughts and cheerful expression are allowed, to something more reflective of the whole complexity of a life, and lived experience. I think it is more fully human to leave space for both joy and sadness, gratitude and disappointment, the good and the bad – for that is life.

Obviously, all of us grieve and come to the experience of loss in our own way – for some, there would be no purpose or meaning in having the deceased part of a ceremony, celebration or ritual, or no purpose in having any type of event at all. I do not intend to make anyone feel as though their custom and/or personal inclination is wrong or harmful. I do feel that we haven't had permission to invite death into our lives, and that death that has been made to seem creepy or frightening or dangerous – mainly due to the funeral profession – and it doesn't have to be that way. Maybe by hearing that there are other options besides an expensive casket, and a bunch of ghoulish funeral directors hanging around in their

black suits, you can now possibly conceive of a way of viewing death that opens you up to life. Just as you would consider your family when preparing a will, or writing your advance care directive or any other practical aspect to prepare for your death, I urge you to make the time to consider making death a more deeply meaningful experience, for yourself, and for those you love and who love you, and will be left behind. Together, we can bring death back into life. As Kastenbaum said, doing so can help us achieve a stronger “inner connection to the value and meaning that guide our lives”.

Thank you.