

***Deva Nation, Building a Compassionate Community for End of Life Care  
A Community Approach to Palliative Care***

**Deva** = ‘Shining One, Angel’ / **Nation** = ‘Community’

**Deva Nation** = A People United in Light and Love

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***“A Compassionate Community recognizes that all natural cycles of sickness and health, birth and death, and love and loss occur every day. It acknowledges that care for one another during life’s most testing moments is not solely a task for health and social services but is everyone’s responsibility.”***

**Phase I:** Complete. (January 2017 – July 2017)

The assessment of interviews has determined the feasibility of the project.

We can now move forward with Phase II.

With gratitude for funding from the **Mankato Area Foundation**, Deva Nation presents the results of a six-month interview process in the Greater Mankato Area. The interviews were targeted to people in the community who have experiences with aging, loss, caregiving, dying, death, and bereavement. In review of over 75 local interviews, there is evidence that documents a need for more end of life education and resources. There is a desire for social action that can build capacity for the community and the systems involved to provide greater comfort and support for those in need. Conversations also demonstrated a real sense of leadership, creativity, compassion, understanding and wisdom within our community around end of life issues.

*The stories and thoughts below have not been recorded; the words are all taken from my notes and in some cases have been paraphrased to summarize or interpret the main ideas that people have shared.*



**Phase II:** (November 2017 – April 2018) Deva Nation is convening key community leaders and members for a series of focus groups to further assess current community challenges and assets. Best practices and policies designed and delivered by the community will go forward as part of the *Greater Mankato Community Charter for Compassionate End of Life Care*.

**Phase III:** (May 2018 – May 2019) Phase III will focus on the implementation of the Community Charter. We will develop a community-wide service directory, hire a community developer/network navigator, create community education opportunities and continue the public conversation and awareness building activities.

## *Community Voices*

*Quotes from Greater Mankato Area Citizens*

How do we show our humanity in a more compassionate way?

### DEATH

To have a direct experience with dying is profound and rare.  
Being present at end of life is beyond intimate, it is pure humanity.  
Stories about death re-embrace what life is about.



We as a community need to take hold; to take charge.  
The goal in the community is to have the capacity to make our own changes.  
When people in Mankato believe, then it happens.



There was a traditional way of caring for our elders within the community that worked. We can learn from our ethnic community and communities of color, learn to draw information about the new way of being in palliative care; a way that is not medical.



My goal is to die in a moment of fullness.



## *Summary of the Interviews*

Death became my teacher only when I surrendered to it and discovered the hard-won gift of grace on the other side. I faced the fear of death head on for 14 years, and then pushed through it when my son died. I can say now that what was dark and cold was the fear. For me, his death was pure love. Death has since become my guide and informs my living. The interviews I was privileged to receive have validated that for many, like me, encountering death can bring more meaning to life and more authentic presence to our service for others. Facing our mortality, in other words, can awaken more compassion for humanity.

When I asked people if they would tell me their experiences, they responded with much enthusiasm – as if the sharing of their story unleashed an opportunity to expand upon its meaning. I was surprised at how these conversations grew the value for what was positive in the remembering and inspired creativity about how to make a difference, if the situation was less than positive.

- During a critical transition of a husband to end of life care, the family was lost in a gap of service over the holidays causing serious stress and suffering. This experience inspired his wife to help make sure it doesn't happen to anyone else. Her commitment to organize volunteer caregiver support to help during the holidays is meaning-making for her and uplifting.
- A young caregiver employee experiences the three-day wake policy in the nursing home as a profound and rare opportunity to begin to come to terms with life and death. Today he is writing his PhD dissertation on individuals and groups who are working towards social change around end of life, including the exploration of the death doula movement.
- After a heart attack, this woman also found meaning, "I've learned, after facing death, that tomorrow could be taken away; I may not get another chance so I do for others whenever I can. I don't have as many inhibitions now."

Today there is a real disconnect around death and dying. But our community members tell me that death has something to teach us. The interview stories have demonstrated that to fix this 'death disconnect' in society is to 'connect' us to life in a way that embraces responsibility, builds community and enriches our humanity.

The interviews have shown that it is time for our elders to be given back their seat of wisdom at our community table. It is also time for us to embrace our ethnic cultures and communities of color as models and teachers in community living, especially around aging and end of life. We have more to learn about how to ensure the needed and desired end of life services for our LGBT community. We will also give voice to and care for the homeless and imprisoned in Greater Mankato.

Several interviewees mentioned the importance of sustainability. As a health promotion movement, the goal is for the positive impacts of community initiatives to continue to go forward after the withdrawal of Deva Nation. The professional input of our health & social services will remain to fill in education and/or service gaps as needed.

There are people who are suffering alone and there are people who are offering to help. I learned from the interviews that one of the barriers that keeps us disconnected is that “we have to have permission to give and to receive now.” People said they would’ve accepted help earlier but didn’t want to be a burden. Or, “People don’t know how to help, they don’t understand what makes them uncomfortable.” People say they are most afraid of what they do not understand.

Many are asking for palliative care in the community. They want help from the moment of diagnosis – guidance, counseling, and social support. Caregivers need emotional and practical support as well as respite. To meet these demands, there lives in our community an extensive knowledge base of life-learned wisdom and skills around dying, death, loss and care waiting to be tapped. With the support of those who have experience and the guidance of our skilled health and social service professionals, we can give people what they are asking for. We can expand our excellent hospital-based program of professional palliative care into new community-engaged, non-medical palliative care services.

Community engagement for end of life care involves collaboration. Ideas sprang up from the interviews. Human resource managers in local businesses could meet to share and develop best practices; art organizations and museums could mobilize the community around death and dying through opportunities of expression – with both gallery and performance events. The Greater Mankato Diversity Council, VINE, Minnesota State University Mankato, Chesley Center on Aging, South Central College, ACT on Alzheimer’s, Greater Mankato Growth, Twin Rivers Art Council, St. Peter Center for the Arts, are all excited about this movement and ready to pitch in. Professionals at Mankato Clinic and Mayo, City and County Officials, and Senior Living Residency Administrators are also willing to participate in building a Compassionate Community for End of Life Care. These collaborative efforts will build end of life education and awareness within our community. As one physician notes, “If people understand hospice and palliative care it could result in earlier enrollment – as these services most often have to be asked for. This would be a game changer.”

Many people believe that experiential learning for children with elders is central to building sustainable social change. “Children are searching, open and present – willing and hungry for attention; elders are wise and patient, filled with knowledge and willing to share. Put children and elders together and you have an opportunity to change the fabric of the community.”

“We are in the process of a real cultural change, and it will take the professionals as well as people throughout the entire community to effect a shift away from our fear and denial of death, toward meaningful and holistic engagement with end of life experiences.”

We have all the ingredients in Greater Mankato to create a national model that allows and encourages public engagement in a new kind of palliative care. **“There are enough people and institutions in our community who are willing to work beyond walls; people who don’t stay bound by constraints and are willing to tackle big issues.”** Changing our cultural fear of death is a big issue. Fear is what stands in the way of more compassionate care. Greater Mankato is saying yes to the challenge. Citizens are saying yes to building a Compassionate Community for End of Life Care.

## *Categorized Interview Responses*

### **AFTER DEATH CARE**

- In the nursing home where I worked as a young man in Boulder, there was a policy to have a three-day wake for the person who died. Even though I didn't know the person intimately, it gave me and others the needed time to come to terms with death. There was a glaring hole where the person was just gone, routines changed. Just to stop in the 'parlor' room and say a few things out loud to the person who had died was healing. I was lucky to have the chance to explore my emotions. To have a direct experience with dying is profound and rare. I later had eight college roommates – none of whom had had an experience or even a conversation about death and dying.
- I'm upset about the way funeral homes are handling cremations, not talking about cremation and other options that would be, I feel, better for healing, and better financially.
- There is a decline of faith, therefore we provide meaning through rituals and celebration of life.
- One of our beloved employees wanted to work even after his life-threatening diagnosis. We respected his wishes and rallied around him as he created his legacy at the school, teaching others the 'mapping process' he'd developed to do continuous improvement projects. When he died, the school held a memorial moment of silence with his family. We still talk about him in our school convocations.
- Employees are invited to participate in the bedside memorial for residents who have died. A quilt is draped around the body and for dignity the body is taken out the front door. Once/month there is a service honoring those who have passed with stories and memories shared. Our facility is unique in prioritizing this.

### **AGING**

- People need education around aging. Many younger people are "afraid of people who are older".
- Society convenes regularly around youth and students, but not around age.
- I'm upset that the Mankato funding community doesn't support the aging like they do children, museums, music and the arts.
- Building awareness and providing education is vital so that our elders are offered the respect they so completely deserve.
- There is no respect for old people. Out at a restaurant with my 91-year old mom – people stare, and not a nice stare. A retailer tried to get mom to open up a credit card account when she purchased gloves. She's 91. We need community education for retailers also.
- Find a way to give purpose to elders who don't leave the home, create ways for elders still serve the community in ways that honor who they are.
- Young elders need the services of Deva Nation.

- One area of challenge is mail. Due to my Mom writing checks for any donation that was received, the mail was forwarded to my address although they were remaining in their apartment. The challenge is that forwarding is only good for 18 months. There really was no other options when speaking with a Post Office supervisor. We did connect with the post office recently and they stated they would extend....but it is not consistent.

### **ALZHEIMER'S**

- Seventy percent of people with Alzheimer's are living at home.
- The Alzheimer's epidemic is the greatest under recognized public health crisis. All sectors of the community need to create the change to evolve.
- Dementia friendly community elder abuse and ageism are still huge factors in our society. We need education to get the conversations out of the hospital and into the community.
- Dad felt so good that he stopped taking any of his meds for two weeks. An impactful mistake that caused a loss of memory that cannot be gained back. It was determined that he could not go home. During the 10 days living at the nursing home, he packed up his personal items 4-5 times. Finally, he was packed up and walking to the front door to leave when the Director stopped him from walking out. We were called and told he would have to leave right away. We were shock and surprise for him to be "kicked out" of the nursing home and went to an assisted living residence that did have 24-hour care. Then we were informed by that Director that "no" dad could not move in because he was labeled a "wanderer". He is personable and the only issue with his behavior was attempting to leave to go home -- to go home to a place where he felt comfortable. Now what??
- Being home is the priority and especially important when dementia is a factor when the individual is aware enough to know they are not at home. Familiar surroundings being important as with dementia a life of routine is the norm and critical to someone with memory issues.
- It is simply so sad to see and experience this journey for the traditionalist generation. They have given so much in building this country, there must be a better way for the end of their life journey.
- A companion could help optimize transitions.
- Dad couldn't understand mom's Alzheimer's, he was out of his wheel house. He got booklets from the nurse but the not knowing unnerved him. He needed more strategies to cope. "What should I do?" There has to be more education.
- Different neighbors or friends could schedule daily "checks" to see that meds were taken.
- More education on Alzheimer's including spouses.
- We need Alzheimer's education in long-term care. Also there is very little training in the medical field about Alzheimer's. This makes it very difficult for our loved ones with Alzheimer's to interface with clinic appointments or hospital visits.

### **ARTS & STORY TELLING**

- As an artist, I would love to be involved with Deva Nation, to help mobilize the community around death and dying. I have experience building community by bringing people together through opportunities of expression – with both gallery and performance events. There are many organizations that work with the transformative power of arts and creativity to support a healthy aging process and the issues that matter most as we age.
- I want to really emphasize the importance of telling the story as a means to engage community action.
- I believe that it is ALL about the story – how we create environments for caregivers and those they care for to share experiences. How many ways can we tell the story? Art, writing, forums, personal visits -- people really need to be heard; the most important work a volunteer can do may be simply to bring her open-heart presence and listen to the story.
- Sharing stories and art (about death, dying and loss) can create a gentle challenge to prompt changes.
- How do we harness the wisdom of end of life experiences? How do we create a space for story in community and in health systems?
- Elders teaching children a skill like crocheting and then using the time to share stories.
- Storytelling is an intimate dialog of life experiences. Stories about death re-embrace what life is about. Story is connection.
- Engaging death and dying with art & community initiatives, maybe hosted by the Children's Museum.

### **BEREAVEMENT**

- People should not be afraid of saying your deceased loved one's name.
- People don't realize that when you lose a spouse, your labor doubles. VINE offers "demystifying home repairs" class for just this situation.
- After my mom died, I didn't realize how emotionally involved I had been. It's one thing to physically care for someone, but another to realize how empty my life is emotionally without her.
- As a widow I was depressed, I couldn't fix it, needed to learn to adjust.
- We could deal with death in a more proactive and beautiful way if our pain was not at the forefront. Death is such a taboo topic. Sometimes our pain is greater than the experience of celebrating the life of the one who has died.
- Rituals help us celebrate the next journey, giving us a space to talk with others. Still communicating after loved one dies is comforting.

### **BUSINESS**

- Employers and institutions can help families by developing rules, policies, and compassion for responding to the crisis of students and employees.



- Businesses could provide helpful resources. I suggest talking with SMAHRA (a human resource organization) regarding best practices for involving businesses.
- I believe in a framework that prepares the student with personal, workplace and technical skills as well as compassion. It is important for students and employees to learn a sense of compassion – everybody has a role. Commitment to community and responsible citizenry is important when going forth as a student into the business community.
- Human resource departments could provide a packet of helpful resources for employees who suffer loss or crisis. There could be a city-wide best practice sharing.
- Find businesses that have community rooms that are used for public gatherings and use these rooms for conversations/activities around death & dying.

### **COLLABORATION**

- Mankato ACT on Alzheimer's has many common areas of interest with Deva Nation and would like to collaborate. Funding has been cut at the state level for this group as there was no one at this legislative session in 2017 to lobby for them.
- Two community artists met and talked about how important ritual and celebration about the next journey is and how art can be a part of the healing. Both are excited to collaborate with Deva Nation creating these opportunities.
- VINE is open to explore ongoing opportunities to collaborate with Deva Nation.
- Greater Mankato Diversity Council is very enthusiastic about collaboration – seeing many opportunities for the communities of color and different ethnic cultures as a lead in this movement.
- Our goal (Mayo Health System) is population health. Investing in partnerships is part of the strategy of the triple aim.

### **COMMUNITY CARE**

- The southern city of my childhood is where people cared for one another in community. For 17 years Ms. Ethel, my grandma, was cared for by the church and community taking turns. During that time she never had to cook a meal. It got to the point that children would wake up and say, "What can we do for Ms. Ethel today?"
- A natural network of neighborhood support came forth for me in my current health challenge. But mine is an exceptionally connected community. Something we could model for other neighborhoods.
- As part of a three-year caregiving community for a friend with ALS, we shared a community network tool for supporting the patient and family – used throughout the illness and for funeral arrangements. [lotsahelpinghands.com](http://lotsahelpinghands.com) is a very effective care tool for the community for help.
- Do what you can in your role to make lives better. This is what lifts and sustains me.
- After the death of my husband I have learned to support others in very specific ways, not, "How can I help?" but, "I'm bringing over dinner on Tuesday, is pasta okay?"

- People don't know how to help, they don't understand what makes them uncomfortable. But when you are building connections, you have to get out of your comfort zone.
- We have to have permission to give and to receive now.
- The transition of going through depression after my heart attack took the help of professionals. For compassion, no one has to go to professionals. It takes community in general to be kind to each other. We need to bring awareness to the simple things learned from a long time ago. We had it before, now we forget to remember.
- I deliver the life insurance policy benefit to the surviving spouse, giving peace of mind & relief during a difficult time. Long-term Care Insurance is another way to build community; to ensure a community of caregivers are available at the end of life. People don't often get long-term health insurance because they don't want to face their mortality, can't put themselves in that phase of life, don't want to talk about it.
- There is a moratorium on building nursing homes and Medicare spots in assisted living are often filled. The importance of new alternative kinds of care are being recognized. Perhaps with state approval eventually community home care programs could receive government benefits.
- It would be good to engage non-family members in care networks.
- I visit the nursing home regularly and simply say, "Hello. My name is \_\_\_\_\_. Would you like some company today?"
- Life on the farm was real community. Never asked for help, yet help was always, always there. My son grew there and now models this kind of giving because he'd seen it.
- Grandma & Grandpa both died on the farm. They saw everyone around them caring and helping out.
- Where do you go for help (other than hospital/clinic)? Lay people could be trained to be dispatched but there would have to be buy-in from professionals.
- We as a community need to take hold; to take charge.
- A companion would be a key role to be both in hospital and at home. To listen, support cheerlead, advocate, and accompany but never to express personal opinion.
- Newly retired folks often find themselves with lack of purpose. Retired teachers would make excellent caregivers.
- Create a bigger network for family that can provide more help & services at home.

## **COMMUNITY DEVELOPMENT**

- We are in the process of a real cultural change, and it will take the professionals as well as people throughout the entire community to effect a shift away from our fear and denial of death, toward meaningful and holistic engagement with end of life experiences.
- There are many ways that a city can contribute to public health.
- In community development, ACT on Alzheimer's states that the kids sector is the most enthusiastic, the most engaged group.
- Memorial day is a good time to honor people in the community -- a mosaic of hues, those living with death and remembering those who have died.

- I've been talking with a group of close women friends for several years about creating an intentional community where we could live together or next to each other to offer support as we age. I believe that "friends are stepping up" – those who are able.
- The goal in the community is to have the capacity to make our own changes. Our westernized medicine is a hierarchical system with the physician as the gate keeper. Urban enhanced healthy living communities have parks as a function of city planning with a health promotion element. This is very much within the context of what a city does. We want health collaborations without requiring a medical chief, building on the assets of all sectors of the community.
- Be careful when you define "stakeholders" that they are people who are capable of nurturing the mission and not coming from a position of 'power over'. Keep the progress of the project in the hands of community members. Sustainability must be addressed.
- Mankato is tough – if you are an outsider you can't break in. People in Mankato with large families don't know you, don't need to get to know you.
- How do we show our humanity in a more compassionate way?
- Because of globalization, people don't live next to each other.
- People could use a community 'safety net' for times of crisis or transition. Those with social safety nets seem to perform better. I'd say it's really a determinant of health.
- In building a new (end of life) culture we need to create positive, ongoing, intergenerational, interactive opportunities. Five to six years of ongoing push becomes a culture. Interaction breeds community in a really neat way over time.
- Millennials are a culture of inclusivity. It is important to engage them to help with culture change.
- I believe that Mankato is the place that can model for the nation how to come together (around community care at end of life). When people in Mankato believe, then it happens.
- The time is right for this movement of community wellness. The University is initiating a Healthcare Career Department which will include aging and dying. MNSU Continuing Education is going to launch a new online course, "End of Life Care and Nurses Conversations with Families".
- You need time, expertise (charisma) and money for a social movement.
- When building teams, it's important not to have just decision makers but also people who are impacted by decisions made. It's important to have passionate and capable people who can carry the mission forward by nurturing it.
- We can regain the skills and traditions of our ancestors but merge it with the values of today, imbuing the community with inclusivity, the ability to open to all--not just family.
- We need a positive asset-based vision/message. Everybody has a role to play.
- There are enough people and institutions in our community who are willing to work beyond walls; people who don't stay bound by constraints and are willing to tackle big issues.
- The only way that change will work is if it comes from outside the system – for a social movement to build so strong that it can no longer be ignored and then the system decides it had better go along.

## **CULTURAL DIVERSITY**

- I believe that our culturally diverse elders could be a real source of support and become a model for the community, as they naturally provide networks of care around their own. Also this gives ethnic groups the rare opportunity to lead in the larger community.
- Ethnic communities can be leaders in the new community palliative care movement as in many communities of color it is still an honor, proper and a privilege to have mom and dad living at home. In these communities it is customary for the community to take care of itself.
- There are similarities between the racial justice and the end of life cultural change movements. The YWCA process of community building/education could serve as the same model for an awareness building/educational event for Deva Nation.
- In the process of community building, importance of trust is critical. Trust and respect is how to approach and work with diverse cultures.
- There is a richness in dialog. The Dakota Tribe has a circle dialog process we use, honoring their tradition.
- The Hmong community takes care of itself. ‘We make sure that this person translates properly—everything stops for a three-day long funeral.’ This is foreign to what we experience with our two-hour funeral.
- Reaffirm that there was a traditional way of caring for our elders within the community that worked – how can we expand this model into our new non-traditional community networks?
- Ethnic communities – yes, there are disparities. Not many people of color use hospice. When you spend your whole life battling to get care, you become deeply suspicious of a program that threatens to take that care away. Plus there are cultures where life-saving measures are to be used at any cost.

## **DEATH**

- Not including death as part of life is social and individual deprivations. My goal is to die in a moment of fullness.
- I have no feeling about death. I guess I’ve never thought about it (30-year old male).
- Being present at end of life is beyond intimate, it is pure humanity.
- Why do we wait until we’re dying to start living?
- After a difficult life-long mother/daughter relationship, in the end I gained so much respect and love for how mom crossed the finish line. It was a very positive experience of sharing and in the end “GO MOM” cheering. There are magical moments and experiences of unexplained mysteries that are often not acknowledged by the medical system. I had such experiences around my mother’s death and they were transformational.
- As a society, we punish people who are dying.
- We need to acknowledge death in our nursing homes, to be able to say goodbye.
- We spend so much time preparing for birth – why not death?

- I've learned, after facing death, that tomorrow could be taken away, I may not get another chance so I do for others whenever I can. I don't have as many inhibitions now. This is hard to teach, it has to be modeled.
- We haven't considered dying, death and loss in community, as a society. We don't understand loss and the cost to us.
- So the problem? How the lack of understanding our mortality affects life, family and health care decision making. Engaging the community in a deeper understanding of death would lead to more integrative life decisions and achievement of what matters most to them.
- We need to put care at the center of community. There is such a level of societal fear of death. A formaldehyde-soaked body is often the only way we see death and it seems so separate from life.
- In today's society, there is a real disconnect, especially for children, around where food comes from, where the trash goes. There is also a disconnection around death.
- Death is very much a natural part of life, nothing to fear, it just happens to us. After having a heart attack I can come to terms with any kind of trauma. It's a big transition after you've had a heart attack – people around me need to know that I've changed and give me permission for that change. My body is not the same. We need support in the community to learn how to embrace transitions (around life-threatening experiences).
- My hope is to help others walk through their dying process with more knowledge and education.
- Two friends are conversing: The older woman's husband died in April, 2017. She shared that her inner peace and resiliency is due to the fact that they talked about his dying process for four years and shared the journey with each other getting as comfortable as they could with the reality of death. The 38-year old friend confesses that she is terrified of death, "When I think about death I have to turn away seeing only black and void, it terrifies me." When asked what her first experience with death was she said she has never experienced anyone dying.

## EDUCATION

- Framing death as a 'battle' and aging as 'us' versus 'them' – difficult societal issues.
- Police officer notes how important it is for first responders to have training on death and dying. He would often stay with the family giving them a shoulder to lean on when he delivered difficult news. But not all officers do this.
- We need to promote public education around death and dying, to create sustainable support systems with community education.
- There is a need for end of life education in the community. However, let's ask the community what education is needed and desired. There is also a need for education at the health system level.
- Education is the key, especially about advanced directives. This is an insurance policy for when you can no longer make a decision.

- As a physician who sees many dying patients, I see a need for education about alternative treatments.
- To build citizenry in our education systems that embraces responsibility.
- Students who enter my 'Sociology of Death' class emerge so much more mature with rich meaningful experiences. How do we grow a Sociology of Death class in the community when there is not impetus, no 'credit'.
- I was a teacher for 40 years. Things have changed – simple kindness, gestures, simple human respect now have to be taught.
- I think it is futile to educate people about death until they are facing death. We have not had good luck offering classes on caregiver support or about death – nobody comes, probably because caregivers can't get away.
- Language is vital. 'Living toward your death' may be a better way of saying 'dying'.
- Education is the foundation of change. If people understand hospice and palliative care it could result in earlier enrollment – as these services most often have to be asked for. This would be a game changer.
- Education around end of life care – get up stream of the dying process.

#### **HEALTH SYSTEMS**

- The biggest barrier to effective change may be the culture in health systems, which is not geared to hear or respond to feedback from the patient experience. Likewise, the patient often feels that there is a need to please the doctor and may not divulge the truth, saying only what is believed that the doctor wants to hear. If doctors aren't receiving feedback, how will they know the system is broken? How do we bring back the narrative?
- I had to tell the doctor to stop treatment. He had said dad's organs were shutting down yet he was suggesting another major medical intervention.
- The issue for me is how you integrate community and systems without losing integrity of community choice in services. Systems take over.
- People should have more choice. When they are getting treatment they should be told that this treatment could give them three months more to live, but also cause a lot of pain.
- The main issue of health care is the engineering without a moral compass.
- I see people time and time again who talk about how the system failed them. "They told me to take this treatment, this surgery. They sugar coated it, never presented the option of not doing anything." The primary physicians and leaders at Mayo don't know that these conversations exist – they think they are doing a fantastic job. Maybe we can somehow learn from communities, from the people who are doing the right thing – despite the system.
- My mother died in the hospital. Issues that could be improved include the sensitivity of hospital staff around respect for the dying process. After a sudden hospitalization, I returned the next day to find my mother in a dying process with several grand rounds students surrounding her "observing" and talking about her. This was a painful experience for me and I called the primary

physician to dismiss the group. I know the hospital is skilled technically, but this time missing the human element of face-to-face interactions.

- More and more over the last seven years I've seen the nurse's role become just about passing meds.
- Health services need to prepare for companions during weekend and holidays. When patients are in critical transition they and their families can get lost in a gap of service that can cause serious stress and increase suffering. Can there be some kind of caregiver support from the community to fill in the gaps?
- There needs to be help during transition time between hospital & hospice. Someone to coordinate support for families while they are in hospital waiting for hospice – sometimes there is not enough comfort care offered during the critical times of transition or during holidays. Make sure there are no serious gaps in services for families.
- Medical care on call – or teach people to give morphine, like people are taught to give insulin.
- There are enormous resources given through health systems for medical interventions at the end of life and not enough for healthy living and community involvement for wellness including through the end of life. There seems to be a fundamental agreement that this needs to be fixed. How do we fix this?

#### **HOME CARE + CAREGIVER FATIGUE**

- In care teams, caregiver fatigue and stress management is super important. Emotions run high with everyone.
- The greatest need for caregivers is respite – a volunteer who can relieve them of their duties so that they can go to target, or sit by a river – just to get out of the house.
- I wish I would have said yes to help sooner.
- We made our parents big promise to let them stay at home – we need help now to keep that promise of ten years ago. How are we going to make this work?
- We hired a neighbor who likes to chat. A schedule of check-ins was important.
- We needed respite for dad even though he wasn't the one with Alzheimer's.
- How do we traverse Medicare for mom & dad? Even with a booklet it is still overwhelming. What are the resources and how do we access them?
- People don't want to be a burden – volunteers who are *outside* of family circle are helpful.
- It makes me sad when my parents don't want help because they think they are a burden. I want and deserve this opportunity to give back to them.
- The transfer between rehab to the nursing home was suddenly happening. Sunday at 4 pm: "Your mom needs to be discharged by 4:30. Call these nursing homes and decide which ones are your top three choices." We didn't know what questions to ask. And in 30 minutes we couldn't connect with the people we needed to connect with to sort it all out.



## HOSPICE

- My mom just died in hospice; she was tended to by the Mayo Hospice team. A very difficult time getting mom into hospice due to the fact that at 90+ she was not dying but wanted her heart pacemaker turned off, on which her life depended 100%. Mayo hospice helped to provide a rich and meaningful end of life for mom.
- Hospices grew out of a medical model, we missed out involving the community. Compassionate communities takes it back. This is especially important in rural communities.
- If I could have anything as a hospice provider it would be a hospice house; a facility that would engage different modalities of mind, body, spirit for oncology patients and palliative care patients also.
- The two weeks in hospice for my husband were wonderful. There were resourceful people which I have found is not the norm. Given a death scenario, then there was information, respect and excellent technical skills. The palliative care doctor asked good questions, “What worries you about death?” When he replied, “Choking.” She said, “We can take care of that.” This put him at greater ease. And they did take care of things, he had a peaceful death.
- Most helpful is the one-to-one communication. Hospice was loving and kind – no assumptions, reassuring, giving us confidence and walking us through each step. No one talked down to us.
- The continuity of care is important with efforts of keeping seniors in their home. It is so frustrating for us when people who are serving elders--sometimes for years--through our program are no longer a part of service when patient enters hospice. I would like to see fellow professionals work more together as a team. There are many social and health service organizations in town that share the same difficulty with continuity of care for their patients.
- We are constantly getting cancer patients into hospice on the last one or two days of their lives.
- Physical presence - it is one thing to have a virtual idea; if this is really important we will add the physical presence. I hoping for a hospice house that includes space for education, music & the arts – a real community center to surround the end of life care.

## INTERGENERATIONAL LEARNING

- Intergenerational training is important - bringing together elders with children. It doesn't happen so much as it did in my childhood. When my grandparents got old they moved in with us. I learned so much from Grandpa and treasure what he modeled and taught me. Today many children do not have the experiences of interacting with or learning from elders.
- We could have kids check out elders as they do a library book, and vice versa. Elders and kids participating could have bios available.
- As a 4-year old, she grew up watching her grandma age and die. So she was not at all frightened at the funeral.
- Involve retired teachers in conversation with children, maybe in the scouts or other youth programs.
- Children are searching, open and present – willing and hungry for attention; elders are wise and patient, filled with knowledge and willing to share. Put children and elders together and you



have an opportunity to change the fabric of the community. We need more intergenerational experiences.

- All ages can have a shared learning objective – all project-based education with a guide.
- Schools could have a program where children ‘adopt a nursing home’ or ‘adopt a neighborhood’ and kids have a commitment six times a year to visit as a part of their life learning curriculum.
- In elementary schools it’s important for kids to get back in touch with the cycle of life - let’s bring animals and gardens back into the classroom.
- There are models of child daycare in long term care facilities that have a great impact on the young and the old.
- I work with millennials every day and they are not finding value.
- Joint teaching of children and parents is key – both receive a mastery of skills, there is equanimity.
- We continue to disable each generation; by not acknowledging death we disable our ability to cope with change.
- There is a desire for intense connection in youth, a lot of them don’t know how to do it.
- Intergenerational education especially before teenage years, 9-10 years old is most effective in my experience. At this age, children are grappling with major life questions, silently for the most part. For most kids today the physical world doesn’t seem very lasting to them. Millennials aren’t worried about picking out china patterns – they are searching and hungry for deep connections, value.
- Get children involved/familiar with aging. Bringing generations together for social renewal, reaffirm the community value of elders.
- Develop curriculums for kids on death and dying.
- Develop peer mentoring tools – understand that each generation will have its own response to death and dying and ideas about how to have conversations; the more intergenerational voices that are heard the greater holistic approach will be produced.

## ISOLATION

- I run a program of caring companions where volunteers consistently visit vulnerable citizens weekly or every other week. One of the challenges is that the volunteers are isolated. I’m working to arrange regular meetings where they can network, share experiences and offer support to one another.
- As a caregiver, a loss of independence was isolating (lack of time and need to stay at home) but now friends have come to terms with my caregiving transition and a network of care has evolved for me.
- The sense of belonging and connection is a big factor in people living longer and healthier.
- We need community capacity building. People remain isolated, lack of conversation is a huge barrier to changing attitudes.
- Ms. D. is a 90-year old resident of a senior living residents. She wants to make sure that she is not complaining of her \$9000/month small single bed room. Yet it took three weeks for an ice-

pack to be purchased and delivered by the home to address an injury. Her main concern is that since she has no local family members, there is no one who can shop for her or bring her things she needs or desires. What do you want, Ms. D.? “I’d really like an orange and have been asking. I told them that I would peel it, they don’t need to.” It costs Ms. D. \$90 for a round trip to go to a store to get supplies, to visit someone, or to go to the bank. A companion program could be most beneficial – even a community member visiting once/month to help her feel in control and not so isolated.

- There is deep loneliness and isolation for people who are facing death.
- Mom had so much purpose in life, now doesn’t leave the house, and feels trapped with nothing to do at home.
- Many people are lonely, those who have no children or none nearby. Who can I visit?
- Decrease caregiver isolation; have companions who can advocate and coordinate *for caregiver needs*.
- Healthy living through end of life by giving people “purpose and passion”.

#### **PALLIATIVE CARE**

- We miss the palliative care ‘house calls’ of the past and feel that our community is actually moving backwards in palliative care efforts. Also, people when told options of cancer treatment are often not given the option to do nothing. There needs to be more education, more choice.
- My father is dying. It is vitally important to make the time to be there, yet extremely hard balancing that with my work commitments. My father’s generation is less likely to take advantage of palliative care, feeling like they are fine on their own, not willing to ‘put anyone out’.
- You can’t put the cart before the horse, we need to educate primary care physicians about palliative care so they know what it is – not ask for palliative care and then educate.
- Although community has progressed and understands and engages with hospice, there is a misconception of palliative care. Resources in the community could help bridge the huge education gap. People still don’t know the difference between hospice and palliative care. This is the gap.
- You don’t have to go to a hospital to get care. Care should be impeded in our community, into police work, schools, work places – conversations about what matters most could surround the community, enveloping people in care.
- The thing of it is, it just makes sense (advanced care directives). At the end of the day it’s what we want but we are afraid to talk about it.
- A woman is dying. What matters to her is to attend her son’s wedding. Palliative care (when Mankato had community-based palliative care) arranged for all the details including how she would get her hair done for the wedding. No other care team is thinks about what matters most in this way.
- Palliative care is the inquiry, “What is burdening you now?...okay, let’s have a conversation about that.”

- They (health professionals) couldn't transform the community while also taking care of the patients. There was a high demand for in-patient palliative care services and not enough staff to serve the community (regarding Mayo's former community-based palliative care services in Greater Mankato, which included community education, awareness building workshops and home visits).
- I'm afraid that palliative care is getting eaten up by the medical/industrial complex.
- I think that any opportunity for the community to get involved in palliative care is wonderful. I think there are many layers to palliative care. The professional layer, the highest, the middle layer, which are individuals trained in palliative care, but are not necessarily medical, and then a layer at the bottom that may not have conversation training but are involved through community actions.
- There is a palliative care program that is a companion/friend volunteer program for kids with Cystic Fibrosis in Florida. This model does not have training, rather regular debriefing, very effective.
- I believe that no one should be in pain, and people should know to ask for palliative care if not offered it.
- Our ethnic communities can inform and reframe what palliative care looks like – a new model of traditional, proactive mindsets. The notions and narratives of traditional communities are not in our current definition of palliative care. This is a chance for communities of color to lead the larger community, which is rare. Today the traditional communities have operated in protocols that often do not align with their beliefs.
- There used to be palliative care in the community but not now. People need to understand what it looks like.
- Medical services and community practice – there are so many silos that need to integrate. We need a strategic process to meet the needs of patients in the community.
- We have a strong inpatient palliative care team; now next to build from inpatient to outpatient to community.
- I have a terminal disease – have had it for many years. I fight for palliative care but can't get it. I want counseling. Not the "how did that make you feel" kind of counseling. I want to go deep – I'm dying.
- Palliative should address the human aspects of chronic illness, for everyone who needs it – not just for those who are in the hospital. How to make ourselves vulnerable and strong, to create a good sense of self-esteem? I don't look like I'm dying but I am. Although I enjoy connecting, it can't be about small talk. I fatigue so easily. I want palliative care, I need help doing this.
- What is palliative care? It's the antidote to the industrialization of health care.
- Find a person to coordinate volunteers to be a support person/friend & engage other community palliative care persons.
- There are hospice volunteers – can we have palliative care volunteers in the community?
- We can learn from our ethnic community and communities of color, learn to draw information about the new way of being in palliative care; a way that is not medical.

- An 85-year-old woman lives alone. She states that the only way that this can happen is because of her apartment manager and the facilities manager who check on her, along with a weekly visit from healthcare. She walks laboriously with a cane. Over the last three years she has had 23 surgeries and is in severe chronic pain. She is not dying and she is not in the hospital. She doesn't know what palliative care is.

## **RESIDENTIAL CARE**

- Children, like elders, you meet them where they are at. The elders in the community home inspire and sustain – even helping staff through their grief and fear. Our nursing home is a community that lets “me be me”; authenticity is at the core, with everyone having a role. You have to have the confidence to care for others and to be cared for as well, you have to like who you are.
- You have to work through things in learning to receive. Some feel that they are not deserving of care, not understanding that to give is not a burden but an honor.
- At our care facility it's okay to make a mistake, you regroup every day, sometimes often – and you need to have a sense of humor.
- If I could have one thing it would be that when people are sent to our nursing home for transitional care, that we could have a care meeting with professionals and the patient and the family – just to sit down and talk about why they are here. So often people have not been told that they are dying, including the man who came here on his sixth visit to recover from his lungs filling with liquid yet again due to congestive heart failure. No one has had the important conversation with him that he is dying.
- I found that in caring for elders I needed them more than they needed me. I feed off their strength, they are stronger than me. I have faith in them.
- All of us are included, we were a team in a lot of ways.
- People are guarded about not bothering you with their problems.
- More public interface with elders. For example, our nursing home has a public restaurant in its facility. The general public could be made aware of this.

## **RESOURCES**

- Resources for people are needed. For example, a daughter who does not have a checklist for immediate steps, what legalities, where to turn upon the death of her father.
- I needed a checklist when my husband died. I didn't know what to do, did I have to sign papers? What else? It was hard.
- We need resources to augment professional services.
- Finances – it is so hard to sort out event with county support.
- We need to set up programs that can carry the conversation forward.
- Fortunately a friend called when my husband was in hospice. He said he didn't want to be out of place but asked if he could help get papers together. I said yes and we found that my name had

been removed from the checking account. My husband died two days later. With two small children it would've been hard to survive having no access to money until after probate.

- We need resources in the community to help bridge the education gap.
- How do you know what question to ask about the dying process? If I was told I was going to die, I would have a checklist.
- We needed a family process checklist. How do we know that it's time to transition to the next thing when we don't even know the stages of the disease (Alzheimer's)?

#### **UNDERSERVED**

- We do ministry to those in jail as well. Our outreach is to do a 1x/month healing service – hundreds of people come and are divided into groups of depression, recovery, kids, divorce, etc. In this way they find those who have need.
- There is a specific respectful, inclusive language to use when talking to elders of the LGBT community. We need to have educational programs that can help to create LGBT friendly environments in care communities allowing same-sex and/or non-married couples to live together; ensure that partners and/or friends are part of the care support team.
- There is also the plight of those people who are marginalized and facing end of life, like my brother who was working construction, living in a hotel had no insurance and did not have money for pain medications. I would like to see more continuity of care – support in every state from retirement, to being a caregiver, to widowhood, to being cared for, through death.



## *List of Interviewees from the Greater Mankato Area*

*With gratitude for the graciousness of those who were willing to share their stories -- as the one who is facing death, the family, caregiver, first responder, service or health professional -- we are learning more about how people experience aging, loss, dying, caring, death and bereavement in the Greater Mankato Area, what is good and what happens when it is not so good. Thank you.*

Sheila Anderson, Nurse Practitioner Specialist, Family Medicine, Mayo Health System\*  
Holly Anthony, Madison Lake Community Member; End of Life Coach; Digital Marketing Specialist  
Ryan Baldeo, P.A. –C. Palliative Care, Mayo  
Marcia Bahr, Director of Marketing and Communications and President of Foundation, Mankato Clinic  
Mary Bliesmer, RN; Former School of Nursing Chair, MNSU\*\*  
Laura Bowman, Regional Director, Community Relations and Community Development, Mayo  
Laurel Brummund, RN; Bereaved Daughter  
Kathy Brynaert, MN Politician, Former MN House of Representatives; Youth Development Leader  
Sally Burdick, Senior Companion, Lutheran Social Services; Bereaved Wife  
Timothy Bye, Madison Lake Community Member  
Barbara Carson, MNSU Faculty, Sociology and Corrections; Bereaved Wife  
Sharon Chader, LSW; Director of Elder Care Services, Inc.  
Carla Chesley, Mayo Foundation Rep.; Former Ex. Dir. Greater Mankato Early Learning Initiative  
Sheila Daggett, Senior Specialist, Public Affairs, Mayo Clinic Health System  
Pam Determan, Executive Director VINE  
Louise Dickmeyer, Director, Continuing & Professional Education, MNSU  
Diane Dobitz, Board Member Unitarian Universal Fellowship  
Barb Dorn, Executive Director YWCA Mankato  
Donald Ebel, MNSU Director of the Aging Studies program and the Chesley Center on Aging  
Teresa Ebel, Gerontology Research Scholar  
Kathryn 'Jay' Elliot, MNSU Faculty Anthropology of Aging  
Ann Rosenquist Fee, Executive Director St. Peter Center for the Arts  
Tony Filipovitch, MNSU Professor Emeritus Urban and Regional Studies  
Dana Footner, Beautician; Bereaved Daughter and Sister  
Jo Gangestad, Fellowship Minister, Hope Interfaith Center; Retired Early Childhood Special Educator  
Linda Giersdorf, Executive Director Minnesota River Area Agency on Aging  
Janet Goff, Champion Dementia Friends MN; Bereaved Daughter  
Trudie Gustavson, Retired Business Executive  
Julie Hawker, Diversity Coordinator, VINE; Bereaved Sister  
Bukata Hayes, Executive Director, Greater Mankato Diversity Council  
Susan Howard, President Lifelong Learners; Bereaved Wife  
Alice Johnson, North Mankato Community Member  
Kathy Jensen, Executive Assistant, Greater Mankato Diversity Council  
Michelle Kaisersatt, Artist, The Keyhole Studio, Vessels & Lidded Urns; Bereaved Wife  
Barb Kaus, Executive Director, Greater Mankato United Way  
Michelle Keane, Retired Teacher; Bereaved Daughter

Mary Kitchenmaster, Mankato Community Member; Bereaved Daughter  
Jo Klein, Care Ministry Director, Hosanna Lutheran Church  
Susan Klesath, RN, Hospice and Palliative Care Manager, Mayo  
Joyce Kolbet, School Sister of Notre Dame; Caring Connection and Community Living Coach, VINE  
Jeff Kotulski, DO, Director, Between the Bridges Healing Center  
Kristi Krengel, Reiki Healer; Bereaved Mother  
Greg Kutcher, MD, Director of Hospice, Mayo  
Karla Larson, Eagle Lake Community Member; Caregiver  
Noelle Lawton, Executive Director, Twin River Council for the Arts  
Jean Lovett, 30-year Kidney Transplant Survivor  
Sandi Lubrant, Community Organizer, ACT on Alzheimer's Mankato; Bereaved Sister  
Nicholas MacMurray, PhD Candidate, End of Life/Social Change  
Christopher McEachron, MNSU Grad Student Experiential Education; Wilderness First Responder  
Byron (Pat) McGregor, MD, Board Member, Mankato Clinic  
Jenn Melby-Kelley, Business Owner; Bereaved Daughter  
Lois Miller, Retired Funeral Director  
Judy Mountain, Financial Services, New York Life Insurance Company  
Peg Mudroch, MNSU Graduate Student, Gerontology; Bereaved Daughter  
Kris Nordgren, Community Member, Bereaved Daughter  
Lynn Nordgren, Retired Teacher, Bereaved Daughter  
Annette Parker, PhD, President, South Central College  
Jennifer Pfeffer, Executive Director, Ecumen Pathstone Living  
Ceceli Polzin, Community and Customer Relations Manager, Mankato Clinic  
Joyce Prahm, Financial Director, MN River Area Agency on Aging; Bereaved Daughter in Law  
Maura Randall-Kutcher, Retired Social Worker; Former Admin. Hospice Bereavement; Cancer Survivor  
Catherine Rasmussen, SCC Leadership and Civic Engagement  
Carol Ries, LSW, Community Living Coach, VINE; Bereaved Wife  
Dori Ronne, Elder in Mankato Residential Living Center  
Jacek Soroka, Director of Spiritual Services, Mayo; Hospice Chaplain  
Sue Spellacy, Activities Coordinator, Ecumen Pathstone Living  
Vance Stuehrenberg, Blue Earth County Commissioner; Retired Police Officer  
Mary Styndl, Community Member; Heart Attack Survivor  
Laura Turk, North Mankato Community Member; Cancer Survivor  
Karen Sandersfeld, North Mankato Community Member  
Kathy Sheran, MN Politician, Former Member MN Senate; Former Assistant Professor of Nursing MNSU  
Pete Steiner, Host Talk of the Town, KTOE Radio  
Mary Wichtendahl, LSW, Caregiver Coach, VINE  
Heidi Wyn, Mankato Business Owner  
Jonathan Zierdt, President and CEO, Greater Mankato Growth, Inc.; Cancer Survivor  
Donna Zimmerman, Retired Lawyer; Caregiver Team Member for a friend who died of ALS



\* Reference to 'Mayo' is the Mankato Clinic Health System Mankato

\*\* Reference to 'MNSU' is Minnesota State University, Mankato



## ***Building a Compassionate Community for End of Life Care*** ***A Community Approach to Palliative Care***

### **Why do we need a new approach to end of life care?**

The majority of populations have expressed a preference to remain at home at end of life, yet most continue to die in hospital settings. With stretched health budgets and an aging population, the increasing demand for the desired care and support will outstrip capacity of provision. The Compassionate Communities movement considers death, dying, and loss to be an important public health issue.

In the United States, a community (or public health) approach to palliative care is difficult because palliative care is viewed as a service delivery system alone; a service most often only seen at the bedside of a dying person. What we're doing here is civic development and in a private system like the United States, it is extremely hard to understand. Palliative care benefits from a community approach by developing a wider context in which palliative care services can make their contributions.

Consider that this public health movement is a health-promoting approach that engages the entire community, professionals and citizens from every sector, coming together in a united compassionate response to provide support to those in need. As such, we will apply the principles of public health – ***prevention, harm reduction, early intervention, and sustainability*** – toward the social, psychological and spiritual needs commonly associated with death, dying, loss, and care. The answers to some of our complex health and care system challenges can be found in the community by nurturing the creativity, passion, and assets that already exist.

### **Global History:**

The World Health Organization (WHO) *Healthy Cities* movement, which has gained an international foothold since its inception in 1986, is the model for Compassionate Communities. Dr. Allan Kellehear, President of Public Health Palliative Care International (PHPCI), founded the model for Compassionate Communities in 1999. Dr. Kellehear expanded the WHO concept of *Healthy Cities* to include and support living well to the very end of life. Today, Compassionate Communities for End of Life Care is a thriving international movement operating in hundreds of cities in over 22 countries. These burgeoning global initiatives are demonstrating the future of end of life care.

### **What Is It?**

A Compassionate Community for End of Life Care expands the responsibility of palliative services from a few highly trained specialists to all members of the community. For most of us, 95% of the experiences in aging, serious illness and bereavement will occur outside our visits with health professionals or hospital stays. ***Aging, loss, and dying are not medical issues with social aspects, but rather social issues with medical aspects.*** The goal of a Compassionate Community is to mobilize citizens to provide practical and emotional support for all of its community members affected by difficult aging, serious illness, caring, dying, loss, death and bereavement.

- It is a new way of thinking about how care is provided to people who are dying.
- It involves communities and professional services working together to understand, build capacity and address issues to improve experiences in end of life care and bereavement.
- It relies on the identification, development and nurturing of caring networks, around the person and their caregiver, shifting the concept of person-centered care to ***network-focused care***.



## What's Next?

### Next Step:

The next step for Deva Nation is to bring more of the public into our community approach to end of life care. In the fall of 2017, we are convening a community sector-specific focus group series. Five focus groups will meet, each group gathering three times.

Developed action plans of sector-specific best practices and policies will go forward as part of the *Greater Mankato **Community Charter** for Compassionate End of Life Care*. The comprehensive report of all focus groups will become a strategic blueprint for the public education and community palliative care services that will help bring about social changes for the improvement of end of life care in our community.

### Evidenced Based Research:

Researchers of the compassionate communities have gathered evidence substantiating that this approach reduces isolation, supports bereavement, and normalizes attitudes toward death and dying. Important research from the UK has also shown that it can reduce the burden on health systems, reduce hospitalizations and ultimately create significant savings for local health services.

A Compassionate Community in Frome (a small community of 30,000 people in eastern Somerset, England) demonstrates from 2013-2106 a 30% reduction in all emergency admissions to hospital admissions resulting in annual savings equivalent to \$3 million USD. Although the benefits are far beyond the financial, we recognize that financial benefits can create a case for supporting this model of care.

### Conclusion:

Deva Nation's goal is create the sustainability of compassionate end of life care by embedding policies and practices into the culture of established organizations and groups. *Greater Mankato Compassionate Community for End of Life Care* is a health promotion initiative model. As such, we adhere to the sustainability principle as stated by Dr. Kellehear, **"Part of the criteria for the success of health promotion is not only that we are able to prevent or reduce harms, and that we can successfully act early to do so, but that such efforts continue to work long after we have stopped supporting them. Health promotion initiatives, if they are worthy of the name, are sustainable."**

It is really important to remember that a community approach to palliative care is not another service. Rather, it is the anchoring of health promoting policies and practices into a new culture of care where individuals are motivated by empathy and kindness to support others through acts of compassion. It is the development of a community where people are supported to be creative, active and resourceful in response to their own and each other's unique and shared needs; a community where there is easily accessible and integrated care and support available for all.



## ***The Compassionate City Charter*** (an example of a city or community charter)

©Allan Kellehear, UK

Compassionate Cities are communities that recognise that all natural cycles of sickness and health, birth and death, and love and loss occur every day within the orbits of its institutions and regular activities. A Compassionate City is a community that recognises that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone's responsibility.

Compassionate Cities are communities that publicly encourage, facilitate, support and celebrate care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail, ageing and dementia, death in childhood, grief and bereavement, and the trials and burdens of long term care. Though local government strives to maintain and strengthen quality services for the most fragile and vulnerable in our midst, those persons are not the limits of our experience of fragility and vulnerability. Serious personal crises of illness, dying, death and loss may visit any us, at any time during the normal course of our lives. A compassionate city is a community that squarely recognises and addresses this social fact.

Through the auspices of the Mayor's office or equivalent body, a compassionate city will by public marketing and advertising, by use of the city's network and influences, by dint of collaboration and co-operation, in partnership with social media and its own offices – develop and support the following 12 social changes to the cities key institutions and activities:

Our **schools** will have annually reviewed policies or guidance documents for dying, death, loss and care.

Our **workplaces** will have annually reviewed policies or guidance documents for dying, death, loss and care.

Our **trade unions** will have annually reviewed policies or guidance documents for dying, death, loss and care.

Our **places of worship** will have at least one dedicated group for end of life care support.

Our city's **hospices and nursing homes** will have a community development program involving local area citizens in end of life care activities and programmes.

Our city's **major museums and art galleries** will hold annual exhibitions on the experiences of ageing, dying, death, loss or care.

Our city will host **an annual peacetime memorial parade** representing the major sectors of human loss outside military campaigns – cancer, motor neuron disease, AIDS, child loss, suicide survivors, animal companion loss, widowhood, industrial and vehicle accidents, the loss of emergency workers and all end of life care personnel, etc.

Our city will create an **incentives scheme** to celebrate and highlight the most creative compassionate organisation, event, and individual/s. The scheme will take the form of an annual award administered by a committee drawn from the end of life care sector. A 'Mayors Prize' will recognise individual/s for that year who most exemplify the city's values of compassionate care.

Our city will publicly showcase, in print and in social media, our **local government policies**, services, funding opportunities, partnerships, and public events that address ‘our compassionate concerns’ with living with ageing, life-threatening and life-limiting illness, loss and bereavement, and long term caring. All end of life care-related services within the city limits will be encouraged to distribute this material or these web links including veterinarians and funeral organisations.

Our city will work with local social or print media to encourage an **annual city-wide short story or art competition** that helps raise awareness of ageing, dying, death, loss, or caring.

All our compassionate policies and services, and in the policies and practices of our official compassionate partners and alliances, will demonstrate an understanding of how **diversity** shapes the experience of ageing, dying, death, loss and care – through ethnic, religious, gendered, and sexual identity and through the social experiences of poverty, inequality, and disenfranchisement.

We will seek to encourage and to invite evidence that institutions for the **homeless and the imprisoned** have support plans in place for end of life care and loss and bereavement.

Our city will establish and review these targets and goals in the first two years and thereafter will **add one more sector annually** to our action plans for a compassionate city – e.g. hospitals, further and higher education, charities, community & voluntary organizations, police & emergency services, and so on.

This charter represents a commitment by the city and community to take a view of health and wellbeing which embraces social empathy, reminding its inhabitants and all who would view us from beyond its borders that ‘compassion’ means to embrace mutual sharing. Cities and communities are not merely places to work and access services but equally places to enjoy support in the safety and protection of each other’s company, even to the end of our days.

## Déva's Story



Daniel Déva Ram Dass Pollard was born in Canada on July 20, 1972. By the time he was two months old, he was settled on a farm in Mapleton Minnesota with his friends: Rusty the golden retriever; Gumpa, the sheepdog; nine bantam hens and a rooster. There are many sweet memories about Déva's infant life. I can still see him bouncing along in his red wagon on our morning trips to gather eggs and the garden harvest. On his daddy's shoulders he was taller than the giant sunflowers. Afternoons on the farm were lazy, the hammock often called to us where we would rock in the warm sun with the Cobb River flowing and the summer wind dancing through the treetops.

One fall morning, when Déva was three months old, a scream of an ambulance siren pierced through the dream-like serenity of our lives. In response to my call that Déva was having some breathing difficulties, his grandfather had sent the paramedics. One of them rushed in, lifted Déva from his crib and stared in his eyes. As he ran by me again, I saw that the child he was holding, our son, had turned blue. It was his first seizure. Two years later, after many brain surgeries, radiation and chemotherapy, we were told that Déva had only two weeks to live. Where did we want him to die—at home or in the hospital? We took Déva home and he did die... 12 years later.

Who was Déva? Can you put all the rays of the sun into one child's smile? I think so. Déva was pure light, pure joy. He lived in Mexico, in California, at Lourdes in the south of France—anywhere we, his parents, could track down a new cure or hope for spiritual healing. **He lived, filling each moment of our lives, with unconditional love.**

When Déva was six years old, a best friend entered his life. He called her “sister” and they were glued to each other's sides from day one. Déva was preserved at an age of innocence throughout all of his 14 years. Even in his stature, he remained as small as a four-year old cherub. His sister, Bernadette, grew from the baby he protected to become his big sister, his protector.

At nine years old, Déva weighed only 35 pounds. His waking and sleeping hours were consumed with a constant fight for survival. The seizures left him exhausted and the drugs we gave him, in an attempt to stop the seizures, left him numb. Unable to walk, I carried him. His vocabulary, about 12 words. Malnourished, he entered a five-month hospital stay. There was a difficult surgery, a near-death experience and then, a miracle and a new beginning. The seizures that had plagued his life ended.

Although Déva was tube fed during his last five years and was extremely fragile, it was a glorious time. He was able to attend school and soon became a leader among his peers, as he traveled from class to class on his big wheel and was deservedly nicknamed “motor mouth” because of his endless chattering. He proudly claimed ownership of the Boy Scouts, the Dowling Duster Bowling Team, the Lake Washington Beach Club and the raking of our front yard with his kitty pal, Whiskers.

The hospital and its clinics were a second home to our family. One of the last late-night races to the emergency room led to a ruptured appendix. Over the next eight months in the hospital, we did not recognize that Déva had entered into a dying process. **Spiritual and emotional needs were silenced by our frantic efforts to keep his body alive.** There were, it seemed, endless surgeries trying to save a body that had reached its end. Déva never questioned his fate. He never asked—Why the brain surgeries? Why a gastrostomy? Why an

ileostomy? Why a colostomy? The only question I remember him asking was when I brought him to the intensive care unit for the last time. “Mommy,” he asked, “What is my new nurse’s name?”. I told him that her name was Lori. He responded, “Tell Lori I love her. Tell all my doctors and nurses thank you and I love them.”

When Déva died on an August morning in 1986, it was for us a moment full of grace. His intense and prolonged suffering had ended. After they removed all of the tubes and machines, I held him. Bernadette then took her place in the rocking chair and I laid Déva in his young protector’s arms. It was quiet. A peace whispered through my heart like the gentle wind in the summer treetops.

**Déva came to teach.** His lessons to us were many. Life is pain and great suffering. Life is joy. Life is also marbles in a dump truck, King Castle stories, a Lois Lane sister needing to be rescued, and hospital slumber parties.

Who is Déva? A shining one whose light is ever guiding, ever brilliant. A child, like so many, who comes bearing special gifts that sometimes take all our strength to hold and all our lives to open. And the treasure inside? Perhaps a true healing, a greater understanding of life’s meaning or the longed-for embrace of a natural great peace.

Déva lived much of his life in Mankato, MN—home to his mother, grandparents and great grandparents.

—Mary Ann Boe, Déva’s mom