



Coalition News

Quarterly Newsletter of the Minnesota Coalition for Death Education and Support
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Since 1977... Education and Support for Those Providing Care to Grieving Persons

December 2017

Mark Your Calendars

January 21, 2018 ♦ *Caring For Our Own: After Death Care Workshop*. Info at <https://mnthresholdnetwork.wordpress.com/tag/linda-bergh/>.

February 2-16 ♦ *Stay With Me Awhile*, Rochester Civic Theater Company. This play tells the stories of death, grief, and healing. Collected by a Mayo chaplain. Info at <http://www.rochestercivictheatre.org/plays-civic-live/civic-live-events.php>.

February 27 ♦ *35th Annual Minnesota Geriatric Care Conference*, Rochester, MN. Info at <https://nursingconferencesmn.mayo.edu/store/35th-annual-minnesota-geriatric-care-conference>.

March 3 ♦ *Meeting of the Minds Dementia Conference*. Apply for scholarships by Dec 6. Info at www.alz.org/mnnd/in_my_community_13666.asp.

April 8-10 ♦ MNHPC Annual Conference, *Providing Access for All*. Info at <http://www.mnhpc.org/educational-programs/>.

May 4 ♦ MCDES Spring Conference, *Why & How We Get Hooked & What We Can Do About It: The Intersection of Addiction & Grief*. See page 11 and www.mcdes.org.

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MCDES Fall Conference Review

Medical Aid in Dying—Lessons Learned in Oregon and Colorado

Reviewed by Molli Slade

“Ok everybody, what’s for lunch?!” “Lobster and wine!!”

Ben Wolfe led the capacity crowd of 175 in the familiar call and response. We good-naturedly knew we were being hoodwinked. Alas, the very tasty menu for our lunch break at the Doubletree did not include these two luxury items but the content of the MCDES Fall 2017 conference surely did.



Molli Slade

The conference topic was “Medical Aid in Dying (MAiD)—Lessons Learned in Oregon and Colorado”.

The three speakers covered the mind (Pope), body (Grube) and soul (Mooney) of the topic, or in social work speak, the biopsychosocial aspects. I’m not sure if it was intentional or not, but it made for a thorough presentation presented through multiple lenses. I was lucky enough to be one of five attendees awarded a Dorothy Geis scholarship to attend the conference. Thank you to all those who have donated to the fund in order to make it possible for us to attend. I plan to contribute in the future to “pay it forward.” After Edward Holland lit the candle of remembrance and we all took a moment of silence to reflect on those no longer with us, our day began.

Dr. Grube—The Oregon Experience

Board member Florence Wright introduced the keynote speaker, Dr. David Grube, the National Medical Director of Compassion & Choices. He filled our morning with his vast experience and thoughtful reflections on MAiD. In Oregon, the Death with Dignity law has been legal for twenty years.

Dr. Grube shared statistics, personal stories and lessons their community has learned over the past two decades. His main takeaways from this time were threefold;

- ♦ Just having the prescription (on hand) for aid-in-dying medication is a comfort or palliative care. Only 64% of the 1545 prescriptions written between 1998 and 2015 were actually used.
- ♦ People use the law because of fear of loss of dignity, autonomy, anhedonia, and to minimize pain and suffering.
- ♦ The elderly, people with disabilities, and people of color have not been coerced or abused.

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These conclusions show that the law has worked as intended. He outlined how this is not an easy process for a person considering this option. He showed a flow chart of the process in obtaining the medications that would put any “Family Circus” cartoon following Billy’s dotted line to shame. He described some of the the barriers he has encountered in regards to utilizing this option including, family opposition, physicians unwillingness to discuss or inform themselves, pharmacies that won’t fill prescribed medication and institutional barriers (i.e., some cities within states where MAiD is legal, and will not participate).

He shared a marvelous story about a woman he worked with and had the honor to be present in her home when she passed. The woman, a local theater veteran, staged her ending to her specifications and wishes. She made the choice for MAiD after years of suffering with lung disease. He described the intimate gathering of her family, her ability to recite a favorite soliloquy and to lay in her bed with children and grandchildren alongside and draw her final breath. His description brought tears to many eyes as we all imagined the peaceful, dignified perfection for that woman and her family.

He stressed the importance of differentiating between MAiD and suicide. MAiD is an intentional, thoughtful,

engaged process. It allows for heightened communication and engagement with family and providers and allows for a normal grieving process for the survivors. Suicide is often quite the opposite. An impulsive, often violent, decision that leaves the family and loved ones wondering “what if?”

Access to Medical Aid in Dying has increased communication between doctor and patient, reduced hospitalized or institutionalized deaths, increased use of in-home hospice and palliative care resulting in reduced costs (92% of people who choose MAiD are enrolled in hospice and 90% died at home).

Dr. Grube emphasized the importance of a patient’s dignity, comfort and respect. He closed his presentation with this quote from Louis Pasteur, “One does not ask of one who suffers: What is your country and what is your religion? One merely says: You suffer, this is enough for me; you belong to me and I shall help you.”

Kim Mooney The Colorado Experience

Next was certified thanatologist Kim Mooney from Colorado (soul). She is the founder of Practically Dying. According to her website, “Kim lives her life committed to changing our cultural and personal perceptions of death as an insulting tragedy into one of respectful recognition of its rightful and inevitable part in our lives.”

She challenged the audience to think about the terminology and the cultural narratives that we use as a society. “Life is sacred,” “Life is sacrosanct,” “Doctor knows best,” and “we are autonomous and do not need any help from anybody.” It is important that we understand the implications of these phrases for our work and our own self awareness.

She addressed the perceptions of MAiD and what instituting the law in her state of Colorado has looked and felt like. She and Dr. Grube role played a patient seeking information about this option. Dr. Grube took the role of an uninformed and unengaged practitioner and subsequently the role of a patient-centered, choice-affirming provider. The role play was an effective way to see the differences for patient and provider when someone’s wishes and requests are honored and supported. It also stirred the audience to respond with their own experiences and questions of application to their own experiences.

A couple of attendees inquired about end-of-life choices for people diagnosed with dementia. Both Mooney and Grube reaffirmed that these folks are not candidates for MAiD as they are not competent at the time of the decision by the very nature of their disease. This is also true even if their advanced care directives previously

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David Grube, MD



Kim Mooney, BA, CT



Thaddeus Mason Pope, JD, PhD



Role Play with Kim Mooney and David Grube

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specified MAiD as their choice. Discussion followed regarding voluntary stopping eating and drinking (VSED) as an option.

Kim discussed the art of communication and a patient's "middle knowledge;" the cognitive state which occurs with patients with a terminal illness where they actively recognize and realize their mortality. We were reminded that often, as providers, we are given only small clues and windows of opportunity to discuss this topic with patients. She also broached the common concern of someone dying of "being a burden" and that we need to do the work of unpacking this statement with clients and ourselves.

Kim did a wonderful job of describing the psychological impacts on the patient and their families at end-of-life. She reported that Colorado was doing well but that they really were not as prepared as well as they could've been. There has been a learning curve for doctors, providers, hospitals, hospices, nursing homes, pharmacies and most importantly for people seeking more information on MAiD for themselves or loved ones.

After Kim spoke, Ben Wolfe made a quick tribute to Paul Johnson, who has been with MCDES since 1977 and is retiring from the position of treasurer. Paul reported that he will be staying

involved but is looking forward to participating in future conferences as an attendee. Then two gift cards to Red Lobster were randomly drawn so that the winners could enjoy this seafood delicacy.

Thaddeus Mason Pope Ethical & Legal Considerations

Our final speaker was Thaddeus Pope, JD, PhD, a health law professor and bioethicist. He covered MAiD from the social of biopsychosocial perspective (or the "mind" of the mind, body and soul triumvirate) in how this topic is being legislated. He discussed the bills that were simultaneously introduced in the MN House, HF1885, and Senate, SF1572, in 2016 and will be brought up again in 2018 with revisions. Due to the current political climate, it may be a couple years before these bills advance through the hearings and committees, but Pope reflected an overall confidence this would eventually happen.

The MN Senate bill author Senator Chris Eaton was in attendance and was applauded for her efforts on the MAiD behalf. Thaddeus gave a thorough overview of potential paths to legalization along with their benefits and shortcomings as well as the precedents from other states as well as countries that have passed similar legislation. His presentation helped outline what our next steps forward

are in Minnesota. The organization Compassion & Choices, the leading advocate for this legislation, has a strong ground game of education and information. It is well organized to move forward public opinion.

This was an excellent day of learning about Medical Aid in Dying as applied in Oregon and Colorado and how we might clear a path for legalization in Minnesota. The speakers were all top notch, the audience was knowledgeable and appreciative. As a first-time attendee, I felt welcome and comfortable. As a Dorothy Reis scholarship recipient, I felt honored to have been given a chance to share this experience at a time when finances are tight. I am in my final year of my MSW with an emphasis in aging. I work full time in the mental health community services, am interning on a case management team and am raising two daughters, caring for two elderly parents and trying to find time for my supportive spouse. I look forward to the next conference and continuing as an engaged member of this organization. Here's to 40 more years!

Editor's Note: Molli is an MSW candidate at UST/SCU for 2018 and is an Area of Emphasis in Aging scholar. For her clinical research project, she created an arts informed action research project. She developed a "Choose Your Own Adventure" book as a tool for social workers to help address the recurrent themes in research literature about what concerns are most prominent at end-of-life and how to engage clients in this conversation. She is a full-time LSW Care Coordinator, mother of two teen age girls, spouse, health advisor/care taker of two aging parents, clinical intern, community activist and horrible housekeeper. She is very grateful to have as full of a plate as she does.



Conference Scholarship Winners
Mindy Hansen, Peggy Romero, Molli Slade, Stacie Inman, Anne Murphy

Lobster Drawing Winners
Dan Erlandson, Anne Murphy