

Coalition News

Quarterly Newsletter of the Minnesota Coalition for Death Education and Support
P.O. Box 50651 ♦ Minneapolis, MN 5540 ♦ 763-391-3051 ♦ www.mcdes.org ♦ info@mcdes.org

Vol. 41 No. 4

Since 1977...Education and Support for Those Providing Care to Grieving Persons

December 2019

Mark Your Calendars

Dec 10, 7-9 pm ♦ *Facing Holidays After the Death of a Loved One*. Information at <https://mnthresholdnetwork.wordpress.com>.

Feb 12-13, 2020 ♦ *Grief Support Services Facilitator Training*. This program is designed to teach participants about grief facilitation skills, group process and how to develop and organize a support group. Information at: www.essentiahealth.org/classes-events/ or griefcenter@essentiahealth.org.

April 5-7 ♦ MNPHC Annual Conference: *Honoring Our Past, Building Our Future*. Info at www.mnhpc.org.

April 6 ♦ MNPHC presents a conversation on end-of-life care with BJ Miller and Sunita Puri, hosted by Cathy Wurzer. Info on page 6 and at www.mnhpc.org.

April 24 ♦ MCDES Spring Conference. *Meaning-Centered Grief Therapy*. Info on page 10 and at www.mcdes.org.

April 27 - May 2 ♦ ADEC 2020 Annual Conference in Columbus, OH. Information at www.adec.org/page/2020_Conference.

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MCDES Fall Conference Review *Living with Grief in the Aftermath of Natural and/or Human Caused Tragedy*

Reviewed by Jacklin Steege

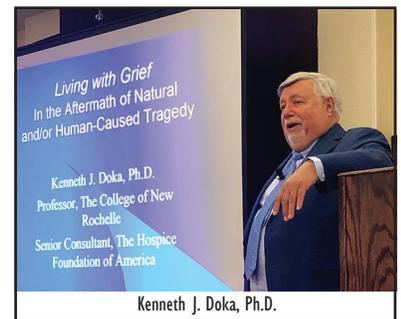
I had the great pleasure of attending the fall 2019 conference “Living with Grief in the Aftermath of Natural and/or Human Caused Tragedy” presented by Kenneth J. Doka, Ph.D. I am currently the Red Cross Disaster Program Manager for Central Minnesota and admittedly probably an atypical participant to these conferences. I did spend several years prior to this career working with a local nonprofit that focused primarily on connecting individuals to area resources, family support services, and childcare respite. In my position now, however, natural and human caused tragedy and disasters are in the forefront of what I do and it’s part of my job to prepare and support a team of volunteers to respond to these events. I was naturally drawn to this conference to continue learning and find a fresh perspective.

My review will be of some key take-aways I found, primarily from a Red Cross response perspective.

Something Dr. Doka said that really stuck out to me was treating what the person presents. I see this as a great reminder and catalyst to deeper thought on how to actually help the person. In our work, it can easily become concerning or frustrating if a person is not reacting to an event the way we think they should. I often get feedback from volunteers, after working with clients, describing how the person/persons reacted and frequently they are laced with how the person wasn’t showing enough emotion or how the person was showing too much emotion. As Dr. Doka stated, we need to deal with the issues as the clients present them. When speaking about sudden loss, he pointed out that initially the feeling is first a loss of safety, followed by the grief. To me, this is just the tip of the iceberg and a huge reminder that, in my line of work, we may have no idea at what point in a person’s experience (or “recovery process” after a tragedy) we are first meeting them.

Other important points from Dr. Doka’s presentation were:

- Styles of Grief
 - Instrumental – typically men, problem-solving coping



Conference Review continued on page 6

From The Editor: On Storytelling

We are all storytellers. We all live in a network of stories. There isn't a stronger connection between people than storytelling. ~ Jimmy Neil Smith, Director of the International Storytelling Center

I love a good story, both as the recipient of a well-told tale and as a sometimes over-eager storyteller. Stories comfort and sustain me. Because of that, and because I am well aware of our impermanence, I recently bought a voice recorder in hopes of preserving some of the stories we tell and re-tell in my own family. Someday, I predict these recordings may well be treasure.

Surely by now our older grandkids can recite verbatim most of the stories they've heard from us. Yet, usually, they are still happy to curl up and listen one more time. I feel a need to preserve that gift.

"Tell us a story, Grandpa!" It's a refrain we hear, especially from the younger ones. Grandpa's tales entertain with silly, personal touches like, "And then Beckett walked right up and pet that old skunk, even though we said, 'Don't do it, Beckett! Don't do it!'" Cue the howls of laughter, even though we know what's coming next and it might be just a little over-exaggerated! But that's half the fun! Stories, in all their forms, make memories.

Coalition News is published quarterly by the Minnesota Coalition for Death Education and Support. Your submissions are encouraged. Editor: Sharon Dardis Layout: Verla Johansson
Deadline for March newsletter: **Feb. 1, 2020.** (covers March, April & May events).
Please send your items to:
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MCDES is a nonprofit 501(c)3 volunteer organization whose purpose is to promote and provide education, opportunities for networking and support to individuals and groups involved with the care of persons confronting death and their families and friends, and those who are bereaved, regardless of the cause of death.

On that note, I was sorry to miss the connections, stories, and memories you all may have made at the fall MCDES conference, especially when I read the evaluation comments. The attendees' reviews were full of statements such as "Ken Doka was a wonderful storyteller," and "Ken effectively used stories to illustrate rituals." To be fair, another comment did say, "He sometimes used too much storytelling," but conversely, another wrote, "The stories throughout the day made it powerful."

Personally, for me, stories make any topic come alive. They open my heart in a way I can't explain. Of course, statistics and research are valuable, necessary teaching tools, and must be included, but a well-told story connects and stays. So, indeed, I missed being there to see all of you, and I am especially sad I missed all those stories!!

Stories this past year, in all genres, seem especially prevalent and rich. Maybe we're searching for meaningful ways to come together. Recent movies, like "Midway" and "Harriet," and even "Judy" dramatized (with some license to embellish) historical facts using memorable cinematography and music. Television's use of documentaries to recount historical topics is certainly storytelling at it's finest! I couldn't get enough of this fall's Ken Burn's series of "The History of Country Music." Frankly, what narratives are better than country music! And then there's all those Ted Talks and podcasts bombarding us these days. I propose we're just plain hungry for stories.

I hope this issue of *Coalition News* might also draw us closer. Thanks, as

always, to those who share time and talent to tell personal stories. I especially love the essays we receive which, in their telling, teach, inspire and offer hope. Thanks to Charlie Greenman for the beautiful tribute and story of his father's death. The lessons Charlie offers are tender and lasting! Thanks to Dorothy Geis scholar, Jacklin Steege, too, for her insightful review of the fall conference. I especially enjoyed the connections she made about the topic of disaster response in relation to her own work at the Red Cross. Thank you, Jacklin!

Don't miss the question posed this issue by Vice Chair, Florence Wright who asks, "What is your 'elevator speech?'" How do you succinctly explain what and why you do what you do? (Submit your stories to sdardis@aol.com. Next deadline is Feb. 1st.) And one last thanks to Kelly Grosklags for sharing stories and lessons she's learned in her work with hospice, oncology, and social work. Once again, well-told stories illustrate and teach. Thank you, Kelly.

Mark your calendars now for the next MCDES conference on Friday, April 24th, 2020. Clinical psychologist Wendy Lichtenthal, who specializes in helping cancer patients and their families, will discuss her experiences and research regarding "Meaning Centered Grief Therapy." Remember to share your organization's upcoming happenings and/or reviews, of death and dying-themed conferences, books,



Sharon Dardis

From the Vice Chair

by Florence Wright, MCDES Vice Chair

Dear Readers,

I'm looking to you for expertise. As a young professional working in palliative care, this issue seems to arise again and again—and I am feeling at a loss. My question to you is this: how do you explain to others what you do for work? What is your “elevator speech?” Do you ever find after sharing that your career involves death, dying, grief, and bereavement, the subject is abruptly changed, or that you are on the receiving end of looks of bewilderment? Do people often tell you what a “special” person you are? Or how “hard” the work “must be?” Do you ever feel like the proverbial “black sheep” when you bring up how fascinating you found the recent Atul Gawande interview? Or how excited you are to attend the next Minnesota Network of Hospice and Palliative Care Annual Conference? I've found that my peers don't seem as excited as I am when I hear about new updates in Medicare regulations, advance care planning, burial options, or changes to hospice eligibility criteria.

One of the problems I've encountered is that the meaning in this work is not something that can be quickly or easily summarized. Sometimes it's even hard to find the words that accurately capture how consequential it can be to sit with a person who is contemplating their mortality, processing a new diagnosis, or reviewing what has been most meaningful to them throughout their life; holding space and presence when countless others have turned away.

It pains me to think that people minimize our work and write it off

as nothing but “depressing, taboo, or morbid.” Sure, it isn't glamorous, and yes, it is challenging. Even impossible and heartbreaking some days. But isn't every job to some extent? What I wish people could understand, and what I wish I could somehow convey, without question, is how much joy there is in this work. How much learning there is to do, and how much opportunity there is to make a difference.

Readers, the obvious is this: our passion related to serving those impacted by death, dying, grief, and bereavement sets us apart in a culture that, by and large, is death-averse. At times it can feel so isolating to do this work. I certainly don't want to die anytime soon, and I imagine many of you, dear readers, don't either. I fully acknowledged that joy is not typically what comes to mind when issues surrounding end-of-life are raised. However, in my work, I see the gifts that illness and death can bring; families coming together, priorities being clarified, communication being opened. I also see people suffering, living with chronic pain, serious illness, experiencing changes to quality of life and enduring loss that conjures questions about whether life is still worth living. For some, death represents hope and freedom from physical and emotional agony.

What I wish I could communicate is the privilege I feel to be doing this work; what a sacred honor it is to enter into the lives of patients and families at such a vulnerable and important time; to see, hear, and feel a person's needs and to do what I can to meet them. I want to share with others what I have learned: that in watching others face their own mortality, I can't help but think about the inevitability of my own death. I have many times consid-

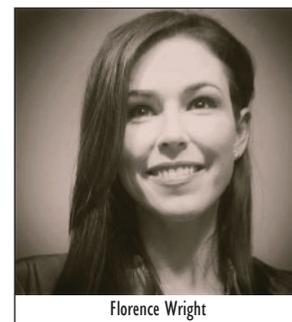
ered where I want to be, who I want to be with, how I want to feel, and what I hope to leave as a lasting legacy.

Consequently,

I strive to live my own life more fully and intentionally and focus on appreciating the precious time I have.

Perhaps what separates me from many of the young professionals working in other fields is a certain familiarity with illness, death, and grief that eases some fear of the unknown. I also hold the privilege of being present and open to each person's story. To be death-averse seems to deny people the narrative they deserve, and in effect, diminishes them.

I have found that in the midst of emotionally difficult and medically complex work, it is important to hang on to the cases that bring joy; to share that joy with others; to connect with professionals who understand, and to share my passion for this work. This is just one of the many reasons that I am so grateful for YOU, dear readers, and for MCDES! Thank you for being my community; the people who need no explanation for why I do what I do. Thank you for being the people who truly “get me,” who share the joy that is available in this work for all who choose to find it.



Florence Wright



Holistic Death Resource Kit

Editor's Note: Thanks to Minnesota Threshold Network for giving permission to reprint this article.

Sarah Kerr, PhD, a Canadian death doula and founder of Soul Passages, was the keynote speaker at last month's National Home Funeral Alliance conference. She shared her marvelous Holistic Death Resource Kit with conference attendees and later gave me permission to share it with members of the Minnesota Threshold Network.

Sarah's Holistic Death Resource Kit is a comprehensive overview of the community organizations pioneering this new field, as well as the resources you need to find your own path in it.

This resource guide will be helpful for you if you fall into any of these groups:

- You're healthy now, but want to be prepared to meet death well when it comes.
- You, or someone you care about, has a life-limiting illness or a palliative diagnosis, and you want to learn about the options available.
- You've worked professionally with dying people and their families, and are curious about new ways to offer your services.
- You feel a calling to work with death (which you may not share with many people). You're wondering what that could look like, and how to take the first steps.
- You're not sure what draws you to this topic, or what you want to do with what you learn. Some part

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Lessons on Dying

by Charlie Greenman

My father died this past July at 96. Since my mother's death two years prior, he started giving me (and my siblings) lessons about the process of dying, in real time.

First, when he came to the realization mom was truly gone after 66 years together, he said to my brother: "I'd like to go with her." From that day to the end of his life he never stopped asking about her, looking for her and trying to get to her. "I'm still in Virginia world, she's still in my head." He asked repeatedly if she had died because he was still feeling her presence and that she seemed to be talking to him.

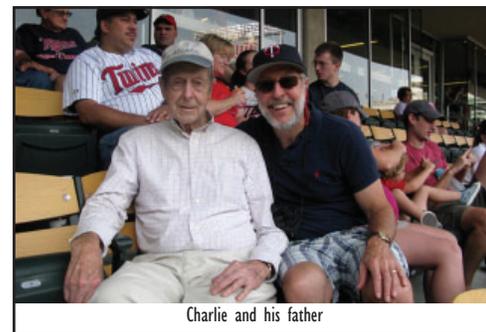
This was the beginning of a continuous reflection that took place in conversations and interactions he had with most of us who visited him. He walked this path very openly, honestly and with his usual curiosity and engagement. He began to say things like "I'm in a quitting mood, not doing anything about it. In the back of my mind I'm thinking I'm not going to be here."

When I first started hearing these statements, it was a little unsettling. I didn't feel at all ready to let go of my dad, in spite of his wish to die. He was teaching me, all of us, that it was important for him to express it freely. He kept on doing it and we learned to validate him doing so.

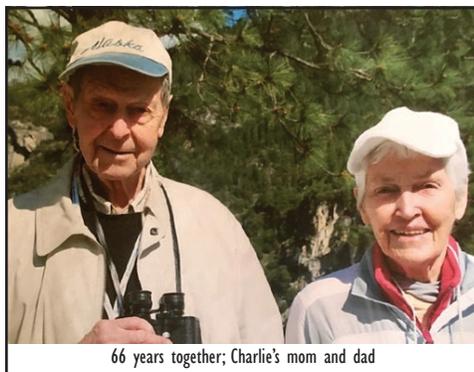
After my mom's death, his dementia grew worse, he was wandering more and having some bad falls. Eventually he couldn't stay by himself in the Assisted Living apartment that he had with mom at Episcopal Homes. We agreed with the staff that he needed to move to Skilled Nursing in The Gardens. This meant earning an ankle bracelet at age 95 and losing much of the physical freedom he'd had before. This did not sit well with a man who was used to going where he pleased, when he pleased.

He started to say things like "This person is very warm to me. It's not enough to keep me alive though." And "I'm not looking forward." Some of these expressions became comical to us after a while because whether he was looking forward to death or not, he still spent several times a day on an elliptical trainer that was available in The Gardens, just as he had when he was more independent. His routines clearly trumped his wishes at some points!

Because of a serious intestinal blockage, he had been in the hospital several times in a short period of time. This happened again after he made the move to The Gardens. He was at Regions Hospital and we were told that only an invasive surgery would possibly correct the block-



Charlie and his father



66 years together; Charlie's mom and dad

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age. We had already spoken extensively with him about his wishes regarding end-of-life measures. We would not put him through a surgery, so he entered hospice. We were told that if the blockage remained, it would be weeks, not months, before dad would die. My sister and I sat with him on his hospital bed to prepare him. He was reflective and said “I lean toward an opportunity to peacefully get out of life. I’ve had a good life. It isn’t good anymore.” He said, “So I’m going to die.” I started to cry. He said “Well if you’re going to cry, I’m not going to die.” My sister and I laughed and assured him it was OK for him to die. We wanted what he wanted.

Dad was released back to The Gardens and hospice care. Weeks turned into months. The blockage remitted and he said to someone on the staff: “I feel pretty good. I’m not supposed to be, am I?” So we got used to a new normal, dad in hospice, not dying, and slowly having more dementia with some physical deterioration. Then came more insistent questions from dad about finding someone who could help him to die. “Aren’t there people who can do that?” I explained why that wasn’t possible. He took it in stride although his inquiries continued. My wife once told him that sometimes people go to sleep and don’t wake up. His response was: “Do you think that could happen to me?”

It was then I learned that his behavior was somewhat unusual for the staff at The Gardens. Because of some his honest declarations, they thought he might try to take his own life. So they took his razor blades away, and established other precautions to prevent this. I learned that they were concerned that he was in Spiritual Distress which apparently many residents are, about dying. Once he was assessed as not in Spiritual Distress, he was taken off suicide watch. So my father was also teaching the staff that there is such a thing as wanting to die and talking about it, without having the slightest intent of carrying it out. This helped some of them to not worry and even engage in conversation with him about his hope to die.

One last lesson from him came when he was talking to a Pastor at Episcopal Homes a few months before he died. He recognized that his life was small and that he didn’t have much to contribute. Then he paused and said: “Well, I can be kind.” Kindness, he shared generously for all his days.

So this was my father’s ultimate lesson for all of us. It’s a lesson that MCDES has been teaching for years: that this process of dying, which we are all going to do, doesn’t have to be spiritually distressing and can be beautiful, enlightening, engaging, and loving. I felt so much closer to my dad because he was sharing his adventures in dying so freely. I miss him and his lessons very much. I look forward to putting them to use.

(The day after dad was supposed to be taken off hospice because he didn’t qualify anymore (after 6 months) his blockage returned and he died five days later on July 5.)

Editor’s Note: Charlie Greenman, MP, LP, is a Licensed Psychologist who works at Headway Emotional Health. He has been privileged to work in Community MH centers for much of his career. He has extensive experience working with addiction and its impact on individual’s and families. At Headway, he is a member of the DBT team and works with clients who have suffered trauma, abuse, loss, and PTSD. He appreciates all the lessons he continues to learn from his clients. Charlie can be reached at 763-746-2434 or charlie.greenman@headway.org.

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of you just knows it’s important for you to explore this area.

The holistic death movement is a grassroots project that’s springing up in response to our need for better ways to navigate these important life transitions. The movement parallels important innovations happening within medical and other institutional settings, and it’s guided by a philosophical approach known as death midwifery.

The birth midwifery movement brought birth home and made it a more intimate, family-focused experience. Death midwifery is about doing the same thing, reclaiming death as a meaningful and sacred transition, for the dying person and for those around them. It’s tapping into a deep desire for transformation, and from my perspective, it’s helping bring about a death revolution.

To view Sarah's FREE Holistic Death Resource Kit, go to <https://soulpassages.ca/blog/hdrk/>.

“He walked this path very openly, honestly, and with his usual curiosity and engagement.”

~ Charlie Greenman

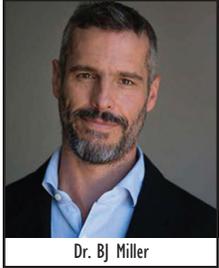
“I am old; I am going to die...I often think about it. I am getting ready...It is time for me to disencumber the world.”

~ Victor Hugo

Mark Your Calendars

April 6, 2020

MNHPC presents an evening with two leading voices in end-of-life care,



Dr. BJ Miller



Dr. Sunita Puri

in a conversation with Cathy Wurzer, host of MPR's *Morning Edition* and TPT's *Almanac* and founder of End in Mind.

Dr. BJ Miller is a hospice and palliative care specialist and leading voice in end-of-life and serious illness care. The author of *A Beginner's Guide to the End: Practical Advice for Living Life and Facing Death*, Dr. Miller seeks to shine a light on healthcare's most ignored yet inevitable subjects: death.

Dr. Sunita Puri is the Medical Director of the Palliative and Supportive Care Service at the Keck Hospital and Norris Cancer Center of the University of Southern California. She is a leading advocate of teaching palliative medicine across all disciplines and of whole person care that keeps patients' values and wishes at the center of their care. Dr. Puri is the author of *That Good Night: Life and Medicine in the Eleventh Hour*.

The evening will include stories and music by Heartwood Healing (www.heartwoodhealing.com).

Visit www.mnhpc.org for more information and tickets.

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- Intuitive – typically women, emotional coping
- Resonating Trauma
 - People will try and restore the assumptive world – they will predict something bad will happen again and when it doesn't, it starts restoring their sense of safety
- Assisting Responders & Helpers
 - It is not one-size fits all – some people forced to focus on event and debrief may be more harmed by it than helped

Lastly, I wanted to review and share Dr. Doka's piece on violence and tragedy in schools and how it recently was reality to us here in Minnesota. He had many suggestions for reducing violence in schools and creating a school community, including teaching acceptance rather than tolerance. He suggests developing a crisis team in the school and having staff create a false 'all-clear' signal, both excellent ideas. Even had these plans proactively been in place, unfortunately they wouldn't have helped the exception we found ourselves in recently in Minnesota. Red Cross disaster mental health volunteers recently helped support a shooting event on tribal lands that took a lot of learning and listening to be able to support the grief and trauma that the tribal community was feeling after the

event. The large majority of our volunteers had never responded to a tribal event, so they received a 'job induction' before arriving to the scene. The induction focuses on the traditions, rituals, and past traumas of the community they were supporting. In Dr. Doka's presentation, he discussed the role of ritual in public tragedy. If you rephrased the heading and rethought our normal assumption of the word "ritual," his points would be just as applicable. Our volunteers were helping:

- Reaffirm the community,
- Show solidarity,
- Structure public grief, and
- Allow action at a disorganized time.

One of the biggest take-aways from Doka's presentation was the reminder to pose questions as choices. It empowers the individual and helps give them a sense of control, so they can start making choices on their own again. This seems an invaluable tactic which would not only help me get answers to questions I require, but at the same time, help the person with their grief and recovery.

Overall, I was pleased with this entire day, from the presenter to the accommodations. This was my first MCDES conference and I have the Dorothy Geis scholarship to thank. It was a fantastic opportunity for which I am very grateful. I will be sure to recommend future MCDES conferences to others.



Dr. Doka with Scholarship Recipients
Kiki Skyes, Hannah Olson, Vicki Richardson, Sandra Kruse, Jacklin Steege



Dr. Doka with MCDES Board Members
Kay Johnson, Amy Shaleen, Tim Thorpe, Kelli Kinney, Diane Bauer, Chris Lewis, Jan Bergman, Eunie Alsaker, Ed Holland, Allison Chant

The Health Story Collaborative: Healing Story Sessions

by Sharon Dardis

I had a gut reaction when I saw an online announcement for a “Health Story Collaborative (HSC): How to Organize and Facilitate An Event for your Community.” I signed up without really understanding what I might be getting into, but honestly, the invitation had me at the word, “story!”

The presenters and co-founders of “Healing Stories Sessions” (live storytelling events) traveled from Boston. Annie Brewster, an Internal Medicine physician practices at Massachusetts General Hospital, teaches at Harvard Medical School, writes and is an audio producer. She has been featured in Harvard magazine and on cable television programs about health with Jeanne Blake.

Jonathan Adler, PhD is a clinical psychologist and professor of Psychology at Olin College of Engineering in Needham, MA. He is also an Associate Editor of the *Journal of Personality* and teaches at Harvard Medical. His research, which focuses on relationships between identity development in adulthood and mental health, has been covered by NPR, *The New York Times*, *Wall Street Journal*, *Boston Globe*, and many other media outlets. Annie and Jon greeted us with big smiles; they seemed as eager and excited as I was to gather and talk about stories!

I joined a roomful of men and women of all ages. Both patients and practitioners, we settled in with laptops, iPads, notebooks, and pens. The morning was a mix of lecture, discussion, writing, sharing. Annie and Jon gently encouraged stories, saying they were “thrilled” to share their information on

how to facilitate a healing storytelling event in our own communities.

The concept of healing storytelling is both validating and motivating. Our stories matter. But when do medical providers actually have the time to listen or share? As both a patient and (now-retired) nurse myself, I have often experienced the simple human “hunger to engage” that this model represents.

Health Story Collaborative is a fairly simple, yet intriguing concept. The model, started when Annie, not only a physician but also a fairly new patient struggling to deal with the realities of her own diagnosis of multiple sclerosis, started collecting patient’s stories. Her experiences in healthcare convinced her that the current practice of medicine was omitting an essential element of healing; the actual stories of people’s lives. She cited obvious reasons for this omission, one being time constraints, stating that medical teams often, for better or worse, translate the medical “story of you” but may leave out important narratives which there is often, realistically, no time to share.

As a doctor, and as a patient, she yearned to be seen and heard; she wanted to be able to engage with others, to share her story and learn from the stories of others. So, in 2010, with patients’ permission and a voice recorder, she began collecting patient stories. And finally, in 2013, in collaboration with clinical researcher, Jon Adler and entities such as local and even National Public Radio to spread the word, Annie founded and became Executive Director of “Health Story Collaborative.” She and Jon are co-founders and co-presenters of these “Healing Story Sessions.”

In 2012, when Annie met Jon Adler, he was doing research on the health benefits of narrative. The Healing Stories Sessions program was born when they “combined their shared clinical experiences and empirical research with their shared desire to help individuals engage in story sharing for personal empowerment and community building.”

Jon, like Annie, lived with a chronic illness, asthma. As both a clinical psychologist and Professor of Psychology but also as a patient, he wanted to refocus healthcare on people’s individual, unique experiences. His research studies on narrative and health (with a theater background!) connected directly to Annie’s interest in storytelling in medicine. Both Annie and Jon believe that the public sharing of stories is meaningful and therapeutic. They used their combined experience and empirical data to design this program.

The storytelling idea sounded a little like other programs in play today, “The Moth Story Hour,” “StoryCorps,” and “This American Life.” What makes “Healing Stories Sessions” unique, according to Brewster and Adler, is “its foundation in the social science research literature on narrative and its focus on stories as a therapeutic tool.”

The mission statement for HSC, a non-profit, is dedicated to “keeping the patient voice alive in healthcare and harnessing the healing power of stories. HSC strives to make the process of navigating illness less isolating and seeks to empower individuals and families facing health challenges.”

Delivering Difficult News To Patients

by Kelly Grosklags

I am honored to share lessons learned while working with terminally ill patients and their families, and to offer suggestions on helpful ways to communicate with them during a most vulnerable time in life.

We, as health professionals and providers, share a sacred space in helping our patients live their best lives until they die. These may be some of the most important conversation they will have during their disease process and certainly offers an opportunity for us to have an impactful experience with them.

Addressing Difficult Topics

One of the best ways to approach a difficult topic is to ask the patient what they understand about their disease and their diagnosis. Obviously, it can be a smoother discussion if they are well-informed and willing to share details with you. If they do have the most correct information, affirm that for them.

Follow up with “What does this mean for/to you?” Or “What is your sense of what happens next?” Sometimes, people have a good understanding of what is happening, but they also may be disconnected as to what this might actually mean for their immediate future.

Clarifying with Followup

I was working with a gentleman who seemed clear that he had exhausted all of his potential disease-stabilizing treatments. He was aware that his cancer was not curable, yet he didn't seem to understand that the most recent news from his physician suggested it was time to explore hospice.

When I asked him what this meant in terms of “next steps,” he responded that his doctor was very hopeful about a clinical trial drug and that he would likely see a tumor reduction. He was correct in that there was indeed a clinical trial available, however, it had horrible side effects and only a reported 5% chance of any benefit. His physician was clear in his communication with me, as the patient's therapist, that he had strongly advised the patient against the clinical trial. The doctor recommended hospice care. It was important to clarify what the patient had heard from the doctor; was his understanding accurate in relation to the information and recommendations his doctor had provided?

Exploring Options

My patient was correct that his current chemotherapy had exhausted the benefits, yet he seemed not able to hear what this meant for his life expectancy. I was the one who again discussed with him the need to explore hospice as a treatment option. Since his physician had given me permission, it was important to repeat to him what his oncologist had shared. The patient and I had a solid therapeutic relationship. This was essential. When he asked me if I agreed with the doctor's advice, I said I did. After this discussion, the patient began to better trust his health team and eventually moved ahead with hospice as his doctor recommended.

Establishing Trust

Several factors allowed for an easier discussion to take place with my patient about his health realities. In our



Kelly Grosklags

first contacts, I assured him I would always be honest. I established this early on in therapy. There will often be times requiring difficult discussions. Most patients tell me they prefer honesty. If I had not initially established this, it might have become a barrier. It is also helpful to reference these earlier discussions. “Do you remember when we talked about things coming up that might be difficult to accept, yet you said you always wanted me, to the best of my ability, to be honest with you?” This truthful approach builds invaluable trust between therapist and patient.

Difficult Dealings

But what to do with the patient or family who aren't able to acknowledge and/or dodge difficult conversations? Early on in my practice, I realized how important it was for me to have a collaborative relationship with the physician and medical team. This allows an accurate understanding of the patient's condition. Sometimes, they may be doing worse, or maybe better, than they believe.

I once worked with a woman whose breast cancer spread quickly. She was experiencing falls at home and her

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oncologist admitted her to ICU for evaluation. This patient had, in the past, successfully, almost miraculously, overcome many medical crises. Her doctor invited me to attend a family meeting in the ICU.

As the day progressed, the diagnostic test results became increasingly bleak. More malignancies were confirmed. When I entered the patient's room, there were several family members waiting. Their first comment, while laughing, was, "Here she is again, keeping us on our toes. We know her well though and she will pull through again."

Likely Outcomes

The doctor presented the test results and laid out likely outcomes. She explained that the patient had hit a critical juncture in her disease and that she believed "the end" was coming sooner than anyone wanted or expected. Understandably, the family cried, saying they couldn't believe it. Since the patient was on a ventilator, the family requested for more time to allow her to "pull through." The oncologist gently shared her honest opinion, saying in her experience, when patients have this type of progression, their death is imminent.

As the meeting concluded, I observed a collective inability of the family to grasp what had just been said. Had they understood what this all meant? They continued to focus on their loved one's earlier medical scan reports, which only weeks before, had looked much more hopeful.

Regrets and Second Opinions

One clinical approach during difficult times such as this is to ask the family or patient if they would like

a second opinion. As clinicians, we know how grueling the bereavement experience is when regrets are part of the mix. Sometimes, we may be too focused on the immediate moment. We do not think of the long-term implications, of perhaps regretting a medical decision. With this particular situation, I asked permission for a neurology consult and second opinion. Although these important end-of-life discussions are vital and time-sensitive, I never want families to feel rushed. Again, ask them how much they want to know. I encourage them to only allow as much information at a time as they think they can tolerate. This helps in decision-making, whether it is with the patient, their families, or both.

Key Phrases

After the neurologist concurred that the patient's life expectancy was limited, I sat down with the family and gently said, "___ is dying." We know this and I am so sorry. **How** she dies is where love impacts these decisions." This is key so the family realizes that their loved one's body is making the decision...not them. They are honoring the body and following its lead. When this happens, there is a better chance of dying peacefully, which is, of course, what everyone wishes for themselves and their loved ones.

Delivering With Compassion

These difficult transitions, discussions and decisions are best handled by allowing adequate time for families and/or patients to process. My wish and reminder for you, as clinicians in your own practice, is for honest, authentic, and loving conversations with your patients. Even the most difficult news is best delivered in as compassionate a manner as possible. I have heard from hundreds of people who

remember most, not **what** the words of the news delivered said but **how** the need was communicated. Doing this with trust, clarity and compassion makes a big difference in future therapeutic outcomes for both patients and families.

Editor's Note: Kelly Grosklags, LICSW, BCD, Fellowship in Grief Counseling is a former hospice social worker with 25 years experience in palliative care, hospice and oncology. In private practice for 15 years, her focus has been cancer patients, many with metastatic cancers and terminal diseases. She also offers grief therapy. Four times a year, Grosklags offers a program called "Conversations with Kelly," in which she seeks, in collaboration with cancer patients, trauma survivors and other medical professions, to help minimize grief and reduce the suffering of others. Kelly's next event, "Say Their Name; A Community Coming Together to Heal" is Thursday, December 5, 2019 at 6:30 p.m. in Minnetonka. For more information: KellyGrosklags@gmail.com.

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or movies, for future issues of *Coalition News*.

So we continue to share stories that sustain us in many ways. Minnesota's own Kate DiCamillo, in *The Tale of Despereaux*, writes, "Stories are light. Light is precious in a world so dark. Begin at the beginning. Tell...a story. Make some light."

And there it is. Tell your stories; unite in the telling and the listening. Thank you for the light you generate in living authentically. Thanks, too, for the good work you continue to do, so well, for so many. Happy holidays and a blessed New Year, filled with meaningful connections, stories, light and hope.

Drawing Clients toward Meaning Making

by Eunie Alsaker

Editor's Note: MCDES Board member, Eunie Alsaker attended an ADEC conference last April which included a one-day training with Wendy Lichtenthal. Eunie's glowing review below offers a glimpse of what we can look forward to at the MCDES spring conference. Eunie says the day helped her, in her own practice, to "listen differently."

Last April I attended the Association of Death Education and Counseling conference in Atlanta. One of the draws of the conference was the opportunity to attend a one-day training on "Meaning-Centered Grief Therapy" with Wendy Lichtenthal. I expected to enjoy the day, but it surpassed all expectations. When a profound loss violates our assumptions about the world and threatens our sense of identity and purpose, meaning can be hard to connect with. Dr. Lichtenthal provides a framework for counseling that draws clients toward both new and past meaning.

After this training, I understood meaning-making therapy in a more comprehensive way. I learned how to pull out and highlight potential meaning. Most importantly, I learned to listen differently. While I don't work with the same population and am unable to use her same session structure, I have found I use information from this training every day in my practice. This approach cuts across all losses and is flexible in its use. It boosted my confidence and made me a better clinician. I am thrilled she is coming to MCDES in April, and I look forward to seeing you there!

MCDES Spring 2020 Conference *Meaning-Centered Grief Therapy (MCGT)* April 24, 2020 Speaker: Wendy Lichtenthal, PhD

The loss of a loved one commonly challenges a griever's sense of purpose, meaning, and identity as well as adaptive meaning-making processes. These challenges sometimes contribute to and are even indicative of prolonged grief reactions. Grief experts have therefore long-argued the value of focusing on "meaning" in therapeutic pursuits. This day-long conference will provide an overview of a manualized therapeutic approach, "Meaning-Centered Grief Therapy (MCGT)," and its core principles. Drawing on research of MCGT with bereaved parents, examples of exercises that may facilitate meaning-making processes and may enhance a sense of meaning will be described, with opportunities for experiential exercises and discussion of applications of MCGT.

Wendy Lichtenthal, PhD is a licensed clinical psychologist specializing in helping patients with cancer and their families. As Director of the Bereavement Clinic in the Counseling Center, she focuses on assisting people who are coping with the loss of a loved one, and specializing in helping those whose grief persists over time. Dr. Lichtenthal also provides psychological counseling to breast cancer patients using a variety of psychotherapeutic approaches, with an emphasis on cognitive-behavioral and existential therapies. In her research and clinical trial work, she strives to develop interventions for people with cancer and their families to better cope with their grief and fears. How do people with advanced cancer and their families find purpose and meaning while contending with advanced disease and loss? Why do some people develop persistent and debilitating symptoms of grief—and what can be done about this? In her work with bereaved parents, she aims to better understand the meaning-making processes, and psychosocial needs, of this unique and profound type of loss. Dr. Lichtenthal is a member of the American Psychological Association, the Society of Behavioral Medicine, and the Association of Death Education and Counseling.

Conference brochures and online registration (www.mcdes.org) will be available by March 1, 2020. As is the case with all MCDES conferences, seating is limited to 175 registrants. CEU's will be available for professionals in Psychology, Marriage and Family Therapy, Social Work, Behavior Health and Therapy, and MN Nurses.



Wendy Lichtenthal, PhD

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The objectives are powerful but simple. (1) Help story-sharers find a greater sense of coherence and meaning in illness through the process of crafting a narrative. (2) Give story-tellers a chance to feel seen and heard. (3) Give audience members the chance to bear witness to suffering and resilience. (4) Foster a sense of shared humanity between patients, audience, members, and providers. (5) Rehumanize and strengthen the patient-provider experience. (6) Learn from and be inspired by one another.

During the next four hours, in workshop as participants, we wrote our own stories and then, with the help of Annie and Jon and other partner participants, we fleshed out details and edited.

Writing the first assignment took only five minutes. We wrote “The Story of My Name,” then shared it with a partner, who listened and then repeated what they’d heard. We discussed how the exercise felt. Some said it made them feel vulnerable, or that they were disappointed some details they valued in their own name-story had been omitted by the teller. We discussed the potential benefit of including even more details for a richer personal story. Other comments from group members said it made them feel visible to hear their story repeated and valued. They felt “authentically seen.”

Another longer classroom exercise focused on writing about a “turning point” in our lives. Many wrote about a loss they’d experienced, of health, of a job, of a relationship. Jon explained the “science of our stories.” He said our identities develop by sharing our personal stories and that we play “two roles in this process, one as the main character and one as the narrator.”

Differing narratives can be either beneficial or detrimental to mental health; that it is less the content of the stories having an impact on well-being than the themes people use to tell them.

Some themes Jon mentioned included “agency,” how engaged we feel in impacting the course of our lives and how we respond when things happen, “communion,” as it relates to relationships with others, and “redemption,” as representing both positive and negative moments that give rise to affective sequences (i.e. starting the story with a “bad” but ending with a “good.”) Higher levels of redemption, he told us, are associated with positive mental health. Jon shared that the theme of “contamination” is the inverse of “redemption”...stories that “start good and end bad.” These are often associated with poorer mental health outcomes. Jon reminded us that these themes, as well as many others, relied on studies of groups of people and that “observed effects were individual and complex, unfolding dynamically over time.” He told us that each person is the expert in their own storytelling. Annie and Jon encouraged us to “handle each story with the curiosity and respect it deserves.”

The four hours with Annie and Jon flew by. I left inspired, empowered and convinced of the power of Healing Story Sessions. Patient or practitioner, I would encourage you to explore this idea further. For more information about “harnessing the Healing Power of Stories,” or for more about the Health Story Collaborative, visit www.healthstorycollaborative.org. If you have questions or ideas on how you might wish to help continue HSC’s work in Minnesota, you can also contact Annie directly at abrewster@healthstorycollaborative.org.

Stages and Grief

By Deb Kosmer

Editor’s Note: Poet Deb Kosmer is a bereaved parent of 14 year-old-son, Shawn and 44 year-old step-daughter, Kelly. Deb is also a bereaved sister, daughter, grandparent, aunt, and friend. She is a retired social worker, grief counselor, and bereavement coordinator, who writes and finds comfort in the written word.

There are no stages
 There are feelings
 Lots of them
 Running rampant
 All over the place
 And there is deadness
 Not feeling anything at all
 And there is back and forth
 And simultaneous feelings
 And doubt and fear
 And guilt and shame
 And despair and rage
 And so many questions
 And so few answers
 And well meaning advice
 From those who don’t get it
 Profound sadness
 A lot of things
 But there are no stages
 It is not a disease
 With a predictable
 Pattern or outcome
 It is your heart
 Splattered open
 Bleeding and raw
 Until somehow
 Some way
 You start over
 From where you are
 In your own time
 In your own way
 Grief is a lot of emotions
 Expressed and repressed
 In a multitude of ways
 But there are no stages.

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Coalition News

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Grief Resources

Jewish Grief Education/Support Group:
www.jfcsmpls.org.

Pathways—A Healing Center: www.pathwaysminneapolis.org.

The Grief Project: www.griefproject.org.

North Metro Grief Support Coalition:
763-413-2985.

Allina Support Groups:
www.allinahealth.org. Search for “grief
support.”

Capitol City Grief Coalition: Contact
coordinator Lois Knutson, 651-227-4430.

Downtown Coalition for Grief Support:
www.mplsgriefsupport.com.

MN Network of Hospice & Palliative Care:
<https://www.mnhpc.org/grief-support>.

Children’s Grief Connection:
www.childrensgriefconnection.com.

Compassionate Friends:
<https://www.compassionatefriends.org/>.

Hastings Area Grief Coalition: [https://
account.allinahealth.org/events/59327](https://account.allinahealth.org/events/59327).

Weathering Life’s Losses—Adult Support
Group, and Kids in Grief Support Group.
Thurs., Stillwater, 651-430-4586.

West Suburban Coalition:
www.westsuburbangriefmn.org.

Youth Grief Services, Fairview:
www.fairview.org/youthgrief.

The Young Widowed Support Group:
mraem@parknicollet.com.

Center for Grief, Loss & Transition:
<http://griefloss.org> or 651-641-0177.

South Mpls Coalition for Grief Support:
www.trustinc.org/programs/grief-support

Bloomington-Richfield Grief Coalition:
www.brgriefcoalition.com.

Prince of Peace Grief Support, Burnsville:
<https://popmn.org/mission/support-groups>

Edina Coalition for Grief Support:
www.edinagriefsupport.org.

Grief Support-Essentia Health-St. Mary’s
Medical Center (Duluth):
www.Essentiahealth.org/griefsupportduluth