

Health and Wellness through Loss

What Do We Mean by Health and Healthy Living?



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Lavinia Weissman

Overview

Shortly after my mother's death, I had dinner with one of my meditation teachers, Rabbi Nehemiah Polen; he suggested that I start writing to answer this question: "What is in the silence of my meditation?"

This article is one of the pieces of writing from my reflection on this question.

What all began for me very early in life. My grandmother died 5 months before I was born. My mother inside of a year had married, lost her mother and moved into her own home with my father and then had my grandfather join them just before I arrived. This woman never had time to see how grief was altering her inside. She had never resolved her childhood grief going through a pogrom in Korwitz, a village outside Warsaw.

The violence and harm inflicted on my mother and her family, similar to an experience of death, stripped them of everything---their wealth, their home, their sense of belonging, their entire way of life (in the dark of one very long night). My mother's family found their spirits shrouded with this darkness all their lives.

In contrast, my father's family born to poverty and starvation in the Ukraine through their challenges and poverty held to their faith and spirit with grace and gratitude for every form of improvement that came to them in life. Death and loss were part of living and this view taught to me by my father became the river of faith that ran through my spirit when all the loss I came to know was as stripping and difficult.

There was one factor that added great complexity. During the time I grew up post World War II , death and the rituals related to death and dying was altered considerably by the way we work, die and tend to our health. My early childhood left me with enough memory that I could see things a bit differently, while I sought to find for myself a level of health and wellness to coincide with significant loss.

My mothers' death was a milestone that marked the end of such significant and constant loss through which I had my own investigation of how to find balance, health and wellness over 25 years of my own personal challenges. The foundation I brought to this experience fed my faith and spirit. Meditation helped me find peace, reconciliation and healing. In the silence of my meditation I grew a view of death in balance with health and wellness with a more ecological perspective.

Here is the story from which this perspective has grown.

The Story

These days I am paying attention to health and wellness---

I am aware that so many simply think that health includes sickness, birth, death and dying, going to the doctor, getting a lab test, procedure or prescription---usually followed by, "Will insurance cover the expense?"

I am acquainted with this reality having been touched by the grief provoked by layoffs, economic downturn, chronic illness, the challenge of living with a life threatening illness and cycles of multiple deaths.

My recent experience pushed me to question how in the United States, we relate to health, living and dying. Americans tend to focus on a desire to find a medical solution for everything. When someone we know is dying, people diminish their experience with mechanical conversation and avoid the emotional terrain accompanied by death.

A few months before my mother died, she called me and announced in a very hopeless agitated way, "I'm up shit creek. My doctor said he has no treatment left to help me. I am going to die." How do you respond to a 92-year-old woman when she is scared, speaks out of anger and lashes out at you? All I could say is, "Mom, I am so sorry. Is there anything I can do for you?"

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I had been the witness to her most recent medical saga. I say saga because the reports and reading between the lines grew out of frenetic and emotionally driven activities focused on exploring options and protecting my mom from the reality that she had begun an end of life cycle and would now begin hospice care.

Mom's kidney lab tests indicated total failure. I am not only a daughter in this situation. I am a former health care administrator and wellness expert. I could not figure out how a doctor, at this time, could recommend kidney dialysis and why this would be a viable option for a 92-year-old woman who lived with a brain lesion and the threat of chronic heart failure. My sister had told me that the doctor and she had decided not to tell my mom about her brain lesion and I knew that my mom had been at the door of chronic heart failure for six years.

Just the fact that my mom had lived these past six years was a miracle. During those years, I had advocated for my mom through a medical error episode that led to a psychotic break and caused her heart failure. During this episode that was a result of mis-medication and an antibiotic interaction with all her other medications, Mom lost the ability to make her own informed decisions. So when I arrived at the emergency room, the medical professionals separated me from Mom, due to my excessive exhaustion caused by 3 days of sleep deprivation and they confronted my mom with her refusal to cooperate with anyone. The medical system stripped her of her rights because she was causing harm to herself and others.

As a result, I was unable to act on my mother's behalf or learn about options for her treatment. In this state of losing her rights, mom was stripped of her dignity, pushed to a child-like state and left to deteriorate. No matter what my issues were with my mom and her history, her situation was simply inhumane.

My mom was placed in a geriatric psych unit and diagnosed with dementia. The chief of service at the hospital was chief of staff to a chain of nursing homes. This doctor pushed to have her transferred to one of the nursing homes for permanent living until death at a cost of \$10K plus per month. I stepped in at the psych unit to guard and advocate for her.

This situation would immediately put my mother into a spending down scenario until all that was left was Medicare to cover her costs till death. She would be mechanically tended to in a high production nursing home not staffed sufficiently to take care of dependent patients, most of whom had no families and friends to visit or care for them. While my relationship with my mother was very difficult, I would not wish this for anyone as a passage to death.

I asserted myself with ethical clinicians outside this facility and advocated that my mom was the victim of mis-medication and being abused. I could demonstrate that up until she began taking antibiotics she had been functioning and balancing her checking account. As a result of my advocacy, Mom was accepted into a state-of -the-art rehab program through my contacts and network. My mother fully recovered and had six more years of life at a quality that had been missing for her since my father became ill in 1986 and she was the primary caregiver for him through 1993, when he died.

In the years post her crisis in March 2000 until her death in December 2005, there were even a few moments when this chronically depressed and anxiety-ridden woman was able to see something good. Her death did not grow out of a catastrophic medical event. Mom died peacefully in her own bedroom at assisted living. I sat with her for her final 3 days.

Two months before this fall, Mom and I had had a phone conversation about what she wanted. Mom knew I would take care of her impeccably if I brought her back to Boston, but she chose to stay with friends and people she knew in Virginia, so that was a gift for me. It was a clear decision from which I could eliminate any feeling of guilt.

While mom was adapting to hospice, my daughter, Katie experienced another loss in early November. Bailey, her nephew, had surgery for a secondary diagnosis, which accompanied his experience with Aleuko Dystrophy. Bailey was six years old. When his lungs began to fill with fluid and it was clear Bailey was not going to live, Katie called me grief stricken. The night Katie called I read to her some of my dad's favorite passages from the Bible- in Psalms and Ecclesiastes.

Bailey passed away the week before Thanksgiving in his mother's arms, with his grandmother, an aunt, his father, baby sister and older brother by his side. In turn, the family and Bailey received loving attention and support by some wonderful people at Duke University Hospital in a hospice program that surpasses what most people will ever know.

I called my daughter at the Robinson/Sauter family gathering place in Maine, where they were healing from Bailey's death over Thanksgiving to tell Katie about Grandma's hospitalization. Generosity at times like these just simply takes over and her step-mom,

Gail said, "We do not want you alone today and you need to be with Katie. Get on a bus and come up here now."

For the first time since Katie and I moved back to the east coast from the Bay Area, we shared a Thanksgiving with all her family. That Thanksgiving I received a gift through the experience I shared with Katie and her father's family. I saw my daughter among people she cared about enjoying the gift of having brothers, sisters, nieces and nephews and others to connect with through grief and love. The whole brood of us by early evening quietly watched TV together, managed a few laughs, and just took comfort from hanging out.

My mom fell out of bed the night before Thanksgiving because of delays surrounding the dialogue between people in her locale about how to obtain a hospital bed and nighttime nursing assistance. I was in Boston, 1100 miles away from her assisted living home in Sun Rise Senior Living, in Arlington, Va.

The following week I flew to Arlington, VA to be with my mom. Katie and her boyfriend picked me up at the airport. Over this 24-hour period, my adult daughter became an angel of support for me that I had never experienced with her before. Katie at the time was the only one to give me accurate and current information about my mom's condition from a medical and emotional viewpoint..

The social service case management routines offered by a Medicare Hospice had been mechanical in both procedure and the way they saw they were offering compassion. The Medicare hospice benefit provided a 6-hour care giving by an on-demand system or caregivers organized like a scheduled triage system.

I arrived at my mom's bedside right after she had returned some time with friends in the social room; the nurses moved her from her wheel chair and she simply fell into a state of sleep, never to wake again.

My daughter helped me find the courage to be with death yet one more time in a way I had never done before. I meditated and served my mom for 3 days contributing with my sister and many others the support that led her to have a peaceful death. This was a remarkable gift of kindness for a woman who, in her early years somewhere about 1923 had experienced the violation of terrorism through a pogrom, in a shtetl called Korwitz, outside Warsaw Poland.

Katie left for home with her boyfriend 2 days before Mom died. She stopped by one last time at about 10 pm. and shouted, "Grandma, it has been wonderful to see you and a lot of fun; I love you and you are the best."

I was outside my mom's door and heard this in the hall. Katie came outside my mom's room to say goodbye to me. I looked at her straight in her face, and put her hands in mine, hugged her and said, "I love the woman you are." She responded by hugging me and said, "Mom I love the women you are."

In the two days that followed, I got to know my mom's caregivers in a different light and on a more personal basis. It was ironic that the caregivers who served my mom at Brighton Gardens Assisted Living facilities were African people who had also been devastated by war, genocide and hunger. These people came to this country to recover and trained in various levels of nursing care. They found healing by caring for strangers who were unlikely to know the experience of being stripped by terror, violence and brutality. I viewed this as an incredible healing for my mother and for me to witness, a healing that Buddhists would describe as practical compassion.

During these four weeks, life took a completely different form. My mother's passage to death was very different from my 1993 experience with my dad. My father died after 7 years of very challenging physical decline involving numerous surgeries, ICU days, and much more. What started with a prostate operation grew into kidney, heart and lung failure. These ailments were on top of a war injury to his spine that was so significant he did not ever have a day without pain since 1946.

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It was ironic that the care givers who served my mom at Bright Gardens Assisted Living facilities were African people who had also been devastated or witnessed--war, genocide and hunger. These people came to this country to recover and trained in various levels of nursing care; in a sense they found healing by caring for strangers that were unlikely to know the experience of being stripped by terror, violence and brutality.

By early April 1994, my daughter and I knew were intimately involved in seven deaths. One of these deaths was the murder of a student in my daughter's junior high shot in the head by a disturbed boyfriend in front of her friends who were watching a Sunday football game. This one death reminded me of a year in Boston before we moved to Silicon Valley, when we lived in a community where 125 young adults under 25 were shot or killed and we knew gunfire on our neighborhood street.

That year was very unkind and challenged both of us emotionally and our quality of life. It filled both of us with a fear of uncertainty that is hard to explain. It took me until 1999 to regain some semblance of life that matched who I was and how I worked. I was happy for me, celebrating life again, when we were hit with another phase of transition that ended with numerous deaths during the last six weeks of 2005. These events have led my daughter and me to share in some very difficult learning that we each absorbed in our own way relative to our individual age and experience.

What has influenced my relationship more than anything with my daughter is our shared experience with loss. Katie never knew my childhood experiences when death was less traumatic, less institutionally driven, less mechanical and there was more time for family to connect and to be supportive and to respect the ritual of serving the dying.

After Katie was born with every death we shared, I had to figure out how to get me back to work to put food on the table and pay rent, how to insure Katie got her school work done and how we were to organize social dates, sports and school activities with a demanding work schedule. Katie had to hide her experience because school did not permit grieving. After any death, if there was no money or time to be with family, we had to put our emotions and grief on the shelf and get back to what we had to do.

The supportive and community involved experience I grew up with around sickness, death and dying had changed by the early 80's into an American lifestyle that relied on hiring help, taking your young children to daycare and procuring resources that could care for your elderly parents whether independent or stricken with Alzheimer Disease.

The times had changed and most care formerly given by family members was replaced by day care centers and assisted senior living communities staffed by professional caregivers, if they were affordable.

Peter Arno, Albert Einstein Medical Researcher has measured a niche of unpaid care giving to represent \$306M annually in unpaid wages. According to the **Collaboration for Health and Environment** the cost of disease (chronic illness) for the 100M Americans afflicted with diseases, e.g. Parkinsons, MS, Infertility, birth defects, developmental disabilities, cancer and autism exceeds \$325B per year in the chaotic array of systems of health care delivery and lost productivity.

Yet, having money to buy solutions appears at this time to be the only way to replace what adults and children need during times of loss. Who is available to give the kids hugs and provide emotional support in end of life circumstances when you are most vulnerable and want to rely on community, friends and loved ones? For growing numbers of people whom have no close family and who live in a frame of reference described as a "success economy" that ceased to exist with 9/11; in an economy of lower wages, lost jobs and overseas outsourcing.

The possibility of assuring someone the kindness and compassion of care at end of life has become most challenging since more employers do not offer the flexibility one needs when a loved one dies - time for a funeral and time for connection with all who grieve and can share pain.

In a documentary produced by Peter Jennings shortly before his own death from lung cancer, Jennings' report showed how the science and technology of medicine is paralyzing people from using emotional intelligence to claim more control over our health, quality of life and experience with death.

All of this has left me pondering that in the United States the way we work and engage in life has caused us to forget the simplicity of celebrating and marking lifecycles of birth, growing up, maturity, and death.

We are a country seeking a medical solution for everything and at the same time we have created a "system" that bankrupts people emotionally and financially. We have forgotten the value of celebrating life, marking our transitions with rituals, sharing time with those we

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love. We complain to each other about how hard it is to take time to be thoughtful and quiet with each other, instead of taking the time to create a new legacy of living with emotional intelligence for more health and balance.

If during your years as a wage earner, you are unable to save to have all your needs met when you are retired or unable to work, this dilemma increases in difficulty. So in the case of someone who was a care giver to a life threatened or chronically ill person, your chances for a peaceful death decrease significantly because of lost income.

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Personal Reflection

My mother's death is a major milestone in my life that brings to a close, two decades of my life in which I was sandwiched. While this experience did not consume every day, it was significant portion of time consistently an emotional part of my day for the 20 years. I had to overcome the strain and stress of this experience each day to focus on what I could to get up each day and tend to my own health that was often challenged. Sustaining your own health and economic balance constantly is the ongoing challenge of any person like me sandwiched with child and elder care. This became an interesting experience to learn from given my professional background in health care and organization development.

I have learned through the years that change grows out of a group of fiercely independent people. I learned to create for myself a sense of belonging by imagining a new commons that gathers people who value the merit of sharing a kind of thoughtfulness to be of service to others and in so doing be of service to themselves. Examining and building solutions to this dilemma may be the one area of focus that can lead us to discover how to build a kinder and greater quality health care system in service of health and wellness. I am now certain from my own experience that building a system of healthy communities must include shaping and supporting kinder death experiences for those dying and the people who care for them.

About the Author



Lavinia Weissman

Lavinia Weissman is the founder and CEO of Brilliant Minds, Sweet Hearts LLC. To read more about Lavinia and her practice go to www.laviniaweissman.com. or view her professional profile at www.linkedin.com/in/laviniaweissman.com.