End of Life Care on a Human Scale

Ed Lorah, MSW
President, Enso House
Board of Directors
7 June 2017

Twenty-five years ago, as a new hospice social worker, I was waiting in the hallway of a Seattle nursing home for the family of one of my patients to arrive. A door to another patient’s room down the hall suddenly burst open and a young woman emerged very quickly, weeping loudly. On her heels came another, older, woman who physically spun the younger woman around and said, “Stop crying! You’ll get used to this!”

The younger woman was, like me, a new social worker; the older woman a facility nurse. Their patient, an elderly resident of the facility had just died. The social worker had developed a strong bond with her patient and was grieving hard at her death. I was shocked at the nurse’s display of insensitivity, but later realized that her admonishment reflected a core truth: in the “medical-industrial complex,” there is little time to grieve. You have to learn to carry on, and quickly.

A decade later I was a manager in a health care facility caring for people with HIV and AIDS. The facility had thirty-five private rooms, patients were lovingly cared for by an incredibly dedicated staff, and everyone who had gone to nursing school

Guest Story: Walking With My Mom

6 February 2017

It was in March of last year, on a day not particularly different than any other, that we found out my mom had metastatic pancreatic cancer. This news was quite a shock to us as Mums had no outward symptoms of disease except for a small lump which we had thought was a hernia. We educated ourselves about this cancer, along with her options of treatment, and she chose to have only palliative care.

The week of June 12th was a continuous celebration of Mummy’s 95th birthday as immediate family members arrived from different parts of the country. When everyone had gone back to their homes, my mom and I sat down to discuss the choices she would have as her disease progressed. I had visited Enso House years before and the peace I had found there was what I wished for my mom to have. We were greeted with open arms by Ann Cutcher, the resident medical doctor, and Dace, an aide and angel from Latvia. After taking a tour of the facility my mom was free to wander and contemplate her final days on this earth. We sat down to tea and homemade shortbread while Ann engaged my mom in conversation concerning her feelings about life, death, and beyond. My mom felt so completely at ease with Ann that she openly discussed her beliefs and her desire for a peaceful death at home.

November brought a sudden change in Mummy’s health and she declined rapidly. Ann and Ash (another angelic aide!) visited my mom in our home and told her she would be welcome to come stay at Enso House soon. Although her ability to speak was virtually gone, I clearly heard my mom repeat “Enso, Enso” over the next few days. By the end of the month I could no longer care for her at home, and she moved into her treetop nest on the third of December.

Ann, Dace, and Ash had the room ready and suggested I bring pictures, music, and anything personal that my mom could see, touch, or hear.

We offer sincere gratitude to Kim Olsen for generously underwriting these Enso House newsletters.

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Guest Story: Walking With My Mom

I don’t remember her ever being as relaxed and peaceful as she was when she was discussing this most personal experience with these two strangers. There were two rooms in Enso House in which my mom could spend her end days. One room was very open and light, with windows looking out onto a tree lined meadow and pond. The other room was surrounded by trees, which gave the effect of being secure in a nest high up in the branches. This room was darker and more cocoons-like, but in no way felt confining. Ann and Dace had become friends in the short while we spent with them, and on the way home my mom seemed lighter, as if a burden had been lifted from her shoulders. She leaned back, closed her eyes, smiled and told me she loved the “treetop room” and hoped she would be in there when she passed away.

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specifically to be able to work there. In the early days of the AIDS epidemic, when a patient died at our facility, at the request of a patient’s family and friends, their body could remain in the room for a day or two, giving family and staff time to gather, tell stories, and grieve together. Within a few years however, the budget tightened and policies became stricter: the bodies of patients who died at the facility needed to be retrieved by a funeral home as quickly as possible so that the room could be turned around to admit another patient the same day. Today I work for a home health and hospice program in Seattle. In my present role I support clinicians who provide hospice care in people’s homes. Conditions for health care workers are still challenging. The social and economic circumstances for many families are dire: adult children moving back in with aging parents—not by choice but by necessity, poverty, fewer resources for families, untreated mental health and substance abuse concerns, and issues of self-neglect and abuse. On any given day I have several consults with staff to strategize how to provide the services our patients need adequately and safely in their homes. We always have open cases with Adult Protective Services.

Additionally, hospice workers work in far greater isolation than ever before. Cases are assigned via computer and documentation is usually completed at home at the end of the day. Clinicians may go for days with only email contact with colleagues. Clinicians needing support or experiencing burnout receive little institutional support for these issues and, predictably, decreased productivity, increased absenteeism, and conflict within the team are common.

Despite all this, my colleagues do an incredible job. But it is often at the expense of their own self-care, emotional well-being, and sense of belonging to a community.

Central to the efforts that went into the creation of Enso House was the notion that caring for the dying is sacred work, that it must be approached thoughtfully and with respect for all the nuances that end of life care offers. Enso House was not only intended to be a model for excellent care for the dying, but one that supported and encouraged the emotional and spiritual growth of caregivers as well. Instead of simply reflecting the hubris of the “medical-industrial complex,” Enso House has always provided care for patients and their families on a human scale, and at a human pace.

At Enso House staff and volunteers, working together, understand that “being” with a guest and their loved ones is just as important as accomplishing the many “doing” tasks that must be attended to. Silence and presence are invaluable gifts for guests, families, and caregivers.

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mom would enjoy having around her. After she was tucked in we were given privacy to simply be a daughter, instead of a nurse. She opened her eyes, looked around, smiled and said “Thank God!” These were the last words she spoke, as if she could finally relax and let nature take its course. I put my dad’s cologne on her pillowcase, played music that they had danced to in their younger years, and let her sleep.

The women of Enso House, who now included Jo, an RN from Seattle, fed me the best meal I have ever had. There were roasted sweet potatoes with cumin and collard greens from their garden with turkey sausage and quinoa, homemade Latvian rye bread, and salad greens with hummus. This was all topped off with strong black coffee and chocolate chip cookies warm and fresh from the oven. My sister and brother-in-law arrived to sit and reflect with my mom, and they have been astonished and surprised to find that such a place exists. For many of us “in the trenches,” Enso House represents the hope and the possibility that we may continue to find ways to care for each other in a way that “rehumanizes” us; that partners caregivers with the cared for on a human scale, and in a way that supports all of us.

My sister and brother-in-law arrived the next day and were also taken under the collective wing of Ann, Dace, Ash, and Jo. We were fed, comforted, sung to, and even got to join in a birthday celebration. We sat around the fireplace, collected our thoughts, cried and laughed. Even my sister, who has dementia, blossomed under the love and gentle quiet that was shown to us in Enso House. It was an amazing transformation.

We came and went throughout the day, wandered the grounds while friends came to sit and reflect with my mom, and were given the privacy we needed, all the while knowing we were never alone.

My beautiful mom passed on to her new life on December 5th, 2016. She was surrounded with her loved ones and her new family, the women of Enso House, at the moment she moved on. Dace, Ash, and Jo took care of us while Ann made sure all the necessary arrangements were taken care of. We were given the time to grieve in peace, without thought to anything else. I was given the chance to simply be a daughter, instead of a caregiver. That was the greatest gift of all.

I held her hand and said “Well Mummy, you did it — you’re at Enso House.” She opened her eyes, looked around, smiled and said “Where’s God?” These were the last words she spoke, as if she could finally relax and let nature take its course. I put my dad’s cologne on her pillowcase, played music that they had danced to in their younger years, and let her sleep.

The women of Enso House, who now included Jo, an RN from Seattle, fed me the best meal I have ever had. There were roasted sweet potatoes with cumin and collard greens from their garden with turkey sausage and quinoa, homemade Latvian rye bread, and salad greens with hummus. This was all topped off with strong black coffee and chocolate chip cookies warm and fresh from the oven. Not only was the food superb, but the gentle yet strong energy emanating from these women was so comforting that even now as I write this, tears come to my eyes. Later, I went home and slept in my own bed with my own cats, secure in the knowledge that Ann would be spending the night in my mom’s room and that Mums was safe.

The guest’s cat, “Little Brother,” stayed with her at Enso House. Here, Little Brother looks at Mom in a photo from years before.
Looking Toward the Future: Enso House Caregiving Fund

Betsy MacGregor, MD and Charles Terry, JD
Founding Board Members
7 June 2017

Over its decade-and-a-half of providing personalized end-of-life care to people from Whidbey Island and beyond, Enso House has always walked a very thoughtful line with fund-raising, being deeply grateful to our donors and applying the generous gifts we’ve received with great care. It has also sought wherever possible to engage volunteers in carrying much of the ongoing work, such as structural improvements, grounds maintenance, food preparation, fund raising projects, and support for patients and their significant others.

Now, as we find our hair growing grayer, we are looking at the future and feeling an urge to secure Enso House’s caregiving capacity into the coming years.

Our commitment is to provide complete patient care coverage with experienced professionals on site at all times. The challenge is that the flow of patients in and out of Enso House is unpredictable, as is the intensity of care needed by each patient. While much of the care can easily be performed by our medical director and one to two live-in staff, together with our wonderful team of volunteers, we must be able to bolster their vital work in difficult situations by hiring extra skilled help. One strategic way to do this is to establish a fund for the occasional hiring of additional caregivers—i.e., a licensed nurse or doctor—who would work per diem for as long as necessary under supervision by the director and/or other regular staff members in order to assure continuing quality of care. This would allow the primary caregivers to take time for adequate rest and self-care, a vital requirement for providing seamless care to others.

We would be grateful for any additional support you can give as we develop the capacity to continue the kind of care Enso House gives.

Guest Story: Why I Chose Enso House

by Kim Olsen
20 January 2017

When my father was dying from stage 4 cancer I knew my mother couldn’t properly care for him at home. She was ill from congestive heart failure.

Northwest Hospital had performed radiation and chemotherapy treatments for my father. They had a hospice, but, due to finances they were closing it down. My father was perhaps the luckiest recipient of this closing valuable resource, as he was the last patient admitted to their hospice program. My father was well cared for in his final days.

Many years later, when my husband, Jay Blain, became ill from stage 4 cancer, I knew having a doctor on staff to treat symptoms would make his passing easier. Someone mentioned Enso House to me and said it had made a huge difference in their family member passing peacefully. And it did. Jay Blain was at Enso House for only 3 days before he peacefully fell asleep as the snow was falling on November 26, 2006. Enso House had performed a beautiful Thanksgiving Day celebration with all of Jay’s family just the day before. Jay was able to interact with his family during the dinner, coming to the beautifully-set table in the Enso House dining room, complete with roaring fire.

The amazing Doctor Ann Cutcher called me at 3 am the next morning because she felt it was Jay’s time. Driving through the snow, I was reminded again of the unique character of Enso House, personified by Dr. Cutcher and her board of directors, fellow staff and numerous volunteers. It is an incredibly valuable resource to have here on Whidbey Island.

Enso House volunteers participate in a newsletter mailing party.

While spending their Spring Break at Tahoma Zen Monastery, Whitman College students do some volunteer work at Enso House.

Rotary Westside of South Whidbey work crews help with construction and landscaping projects twice a year.
Sitting Vigil

Cynthia Trenshaw, Enso House volunteer

Sitting vigil with the dying is a being time, not a doing time.

Jeanette
She is quietly undoing everything.
Letting go of everything.
Allowing the contents of her carefully packed luggage to now be disarranged, discarded.
She experiments inside herself by wadding up a neatly folded memory.
By loosening the ties that have secured her to a future.
By unfastening her expectation that this journey would look different than it does.
Can she manage this with skill enough that undoing will not shred her soul in pain?
Can she, without flinching, tug at the adhesive that has fused her self together all these years?

John
He was a trucker and a cook, a heavyweight, her husband.
An unlikely one to keep the vigil gently, to leave to her what inner doing must be done.
Yet hour after hour he sits comfortably at her side, as if they were out for a drive, passing the miles in their well-used camper, passing the time in their well-worn silence,
As if together they were noticing the passing scene, confirming with a glance that the other notices as well, touching sometimes, sharing everything as if by telepathy.

This dying is an inadvertent journey, at the end of which they’ll part. Perhaps forever.
Who really knows?
But now they are together as long as her itinerary will allow.
If she needs something, he brings it. He does not hover anxiously, asking what she wants are (something, anything to do to make him feel a part of it).
He understands the asking would draw her back from her hesitating steps toward the border for which he has, as yet, no passport.
And she must go.
It is time.

So he waits, keeping the vigil and his silence, and comes as close to doing this right as any person can.

Guest Story: Thank You

26 May 2017, email
Hey Ann,
I just wanted to let you know that dad and I are leaving the island today and driving his new (slightly used) Toyota Rav 4 to Wyoming. He’ll be gone somewhere between 2 to 4 weeks I suspect.
Dad is good. A little tired and stressed today from the car shopping and decision making and now the impending travel, but overall I think he is doing well. Jane and I are very happy to have him come stay with us.
Anyhow, I just wanted to say thank you to you and Ash and Shogan and Jo and all of your wonderful volunteers for taking such amazing care of mom and helping her leave us in comfort and love.
I also thank you for putting my dad in a much more resilient place. I can see the age on his body and occasionally on his mind, but the genius is there and I hope with starting doing some walking, playing his cello, getting more good rest, more good food and hopefully more interesting conversation, he will continue to get stronger over the next few weeks.
You guys have done an amazing thing: you have helped my mom die with grace and peace and have helped my dad step back into life. I don’t know how I will ever be able to thank you enough.
Much love, gratitude, and respect,
Karin Berg

Special Thanks

Kim Olsen
Theo Wells
Fraternal Order of Eagles
Trinity Lutheran Church
St Augustine’s in the Woods
Episcopal Church
Rotary Westside of South Whidbey
Rotary Club of South Whidbey
Home Depot Foundation

A New Way to Contribute
Amazon will donate 0.5% of the purchase price of eligible products to Enso House when you shop at AmazonSmile:
http://smile.amazon.com

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Above: Ash and Shogan spend some time repairing the electric hospital bed. Enso House received this wonderful and necessary piece of equipment thanks to a generous gift from Providence Hospital, Everett, WA.
Left: Winter seedlings for the food garden germinate indoors in the cozy Garden Room.