

ONE LIFE'S END

The Well-Planned Departure of Daphne Fautin

by Robert Buddemeier



Foreword This story is about how my wife (Daphne Fautin) thwarted the unlovely aspects of a terminal diagnosis by preempting with medical aid in dying, and about how she implemented the process. It's written in a continuous care retirement facility – Rogue Valley Manor -- in which death is ever-present, but rarely addressed other than briefly and euphemistically. That is understandable, but not necessarily conducive to either pre-mortem preparation or post-mortem closure.

This account is intended to be about Daphne, but there is no way to avoid presenting the process as I saw it, experienced it, and participated in it. I write it partly as catharsis, partly as reflection, and partly as advice/information/instruction for those interested in a possible approach to something that all of us will do.

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Death – Part 1. Background, attitudes, and approach – When we moved from Kansas to Oregon in 2015, both of us had been strongly conditioned by our observed death experiences. Daphne's father committed suicide; his wife had died, he was on dialysis, and was losing his sight. Her aunt died in a Medicare-accepting nursing home, deaf, blind, and largely immobile. In my case, 3 of my grandparents had died either in pain or after prolonged disability. Together, Daphne and I experienced my sister's 2-year process of death from leukemia, which included a failed bone marrow transplant.

An even larger part of our mutual death experience inventory was my mother's protracted decline and ultimate death from Alzheimer's Disease. Mom had always insisted that she would not go that way, but would kill herself first – she was a member of the Hemlock Society (and took Daphne to a meeting with her). She was also positive and independent, and she kept going until the AD outflanked her and took away her executive function before she realized that she needed to act. In one of those occasional lucid moments that AD patients have, she asked me to kill her. I didn't.

We also had major health problems of our own before we moved – Daphne had heart and spine issues, and I had a neurological condition that produced symptoms similar to Alzheimer's. Before my problem was diagnosed and arrested, I was practicing the procedures of suicide 2 or 3 times a week in hopes of avoiding being ambushed as my mother was.

Given our lack of enchantment with the natural death processes, it's not surprising that one of the factors in our decision to move to Oregon was the Death with Dignity law (although we thought that I would be the first to use it). As soon as we arrived I went to the RVM library and asked for information on DWD. There was none available, so Daphne volunteered to assemble

and keep updated a binder of information on the law and the process. She then followed up by updating and expanding more general information on death, dying, and end of life choices.

The RVM Library compilation on DEATH and preparing for it is contained in a white 3-ring binder on the bottom shelf at the west end of the bookshelves between the reading room and the main library.

In early 2019 Daphne's primary provider spotted white blood cell anomalies in two successive lab tests. Hematology said leukemia. Bone marrow biopsy said a rare, aggressive kind, curable only by bone marrow transplant, if at all. Daphne said "no, thank you." She got two second opinions (no difference) and looked for experimental studies that might enroll her (no luck). Although she had a 3-5 year prognosis at that point, she sought out a DWD attending (prescribing) physician, and made sure that her oncologist would serve as the consulting physician.

Daphne's condition remained stable for much of the next two years, during which she continued to read about death and dying, and to prepare for her own. Part of that preparation was familiarization with End of Life Choices Oregon, represented at RVM by Jan Rowe.

End of Life Choices Oregon (EOLCOR -- <https://eolcoregon.org/>) is a volunteer organization that provides information, advice and support to Oregonians facing end-of-life decisions, including assistance in navigating the DWD process. Jan Rowe (541-857-6131; jurowe96@gmail.com) is the EOLCOR representative on the RVM campus. It's an outstanding organization; use it and support it.

In the Fall of 2020 Daphne's blood cell counts started rising, and she began taking a drug that suppressed cell formation. In spite of blood abnormality, she remained active, and experienced no pain or disability. However, by the end of the year, cell counts had started rising again, and it appeared that the first drug was losing effectiveness.

The oncologist recommended going to the next phase of drug therapy, which until recently had only been available by infusion. Daphne asked how long she would have if she didn't go on the new therapy. Six months, the oncologist said. He also said that she would be very likely to "stroke out" – to die from a stroke, or a series of them. After reflection, she declined the treatment, asked the oncologist for certification of the 6 month prognosis and re-contacted the prescribing physician. By this time she was experiencing occasional fatigue, but still no pain or significant disability

She also applied for hospice admission – a recommendation made by EOLCOR – and was accepted into the Asante program. Hospice provides medical and personal support to the patient and family with a team of nurses and social workers – and also handles death certification, so you don't have to have an ambulance and a fire engine visit the house. In addition to regular visits and contacts, Daphne was provided with both pain-relief and anti-anxiety medications, and the social worker spent time with both of us going over the post-mortem actions that would be required.

Within two weeks of Daphne's decision, a bottle of the lethal prescription arrived from a compounding pharmacy in the Portland area. According to the statistics, a substantial number of

people who get the prescription die without taking it – apparently, the knowledge that they possess the means of choice and control provides what they need to go through the unaided dying process. Daphne kept it with her when we made a trip to Corvallis for a “beforehand” visit with her brother and sister.

Let’s jump back up a couple of paragraphs to engage with the social and community aspects of dying. From the time of her initial diagnosis, Daphne made no secret of her condition. Both of us tended to be fairly open about such things, so most people who knew us well (and some who didn’t) were aware both that she had a terminal disease and that she planned to use DWD.

As she entered the final phase, she worked to set a date, as well as to continue and complete her preparations. She wanted to be sure to exit early enough to minimize the risk of a stroke that might compromise her ability to act independently, and I think it was also important to her that she leave as she wanted to be remembered. March 12 turned out to be a time when both her brother and her sister could join us, so that became Death-Day, the target of Daphne’s information campaign. Her volunteer activities, book groups, anyone that might expect or depend on Daphne, were notified of D-Day (When invited to an event on March 14, she replied “I can’t; I’ll be dead then.”).

Reactions? A few people (with successful treatment experiences) urged her to reconsider. A few more suggested that she wait until she wasn’t doing as well – but I think the image of that stroke loomed large in her mind. In any event, most people, including those who initially urged some other action, treated her decision with regretful acceptance. As the word spread, community support grew, and with it, the gratitude that we felt for such positive responses. Notes, flowers, letters, food – all so much more meaningful while the recipient is able to appreciate them.

Death – Part 2. The end game -- 2 weeks before D-day. The support team is in place; hospice people, Jan and a second person from EOLCOR, friends in general and specific subsets. Fr Joel is checking in, Rabbi David is organizing a virtual vigil at Havurah Shir Hadash to coincide with Daphne’s departure.

I tend to think of the physical and mental approach to death as a process of deceleration. My grandmother went oh so very slowly from ambulatory to rocking chair to wheelchair to hospital bed to cemetery plot. Daphne never slowed – she walked and recorded distance in her walking log. She read and recorded books in her reading log. She worked hard at resolving issues, making arrangements and notifying people. She attended meetings and participated up to the end. And she took her prescription meds and supplements up to her next-to-the-last day.

As the time approached, Daphne acknowledged feeling some anxiety, and took the medication provided by hospice. It worked, and took the edge off of her tension. In the last 2-3 days she went on a regular regimen of the Lorazepam and remained generally calm and composed.

On Wednesday (March 10), Daphne had her hair cut (and got another stamp on her frequent-haircut bonus card). Brother Charlie, sister Donna and sister-in-law Susan arrived. Charlie is an RN, MPH health professional, and provided welcome expertise to the rest of us throughout the buildup as well as the event. After a brief period of awkwardness, we settled into a routine of take-out food and pleasurable reminiscing, through the rest of Wednesday and Thursday



March 11, 2021 – left to right, Daphne, Charlie, Donna

Friday, March 12. Daphne gets up early, takes her anti-anxiety pill (and I think for the first time does not take her vitamins), does the usual catwork, and settles down to do the newspaper puzzles. We shower, dress, get set up – towels on the couch; she is worried about losing control even though the experts say it's unlikely. I make her a cup of tea and she goes back to the puzzles until family arrives. Then she takes the advance meds – anti-nausea and sedative. Jan's co-worker arrives, and I ask her whether it's better to mix the lethal powder and the apple juice by shaking or whisking. Whisk, she says. I mix the potion while Charlie prepares to give Daphne mango sorbet to quench the bitter taste of the prescription.

The Rabbi arrives, as does Jan. Reb David knows that none of us are conventionally religious. He reads some poems; we do the last in unison. Then he asks us all to say something to Daphne – of gratitude, love, blessing. It is so very hard. Then he asks her to say the Sh'ma -- the appropriate (Hebrew) last words for a Jew. She does so calmly, and picks up the cup. Jan asks "Daphne, do you know what will happen if you drink that?" "Yes," she answers "I'll die." And she drinks it.

Susan gives her two spoonfuls of sorbet to take away the bitter taste of the medicine. She leans against me and I start massaging her scalp – something she always liked. She asks for another spoonful of sorbet, and then drifts off at about 10:15. I take her glasses off and hand them to the Rabbi. We wait, talk a little, and the Rabbi plays on his phone some of the vigil that is being held at the synagogue. It's on Zoom, so people are participating from all over – my daughter in Australia got up at 4 a.m. to be there. I have yet to watch the video, but people tell me it was beautiful. After a little longer we recline her on the couch, well-padded with pillows.

Her breathing is audible, but she remains completely motionless. Time goes on. It's clear that Daphne is not going to give up quickly, no matter what her intentions were. We excuse the Rabbi and the EOLCOR team – there are enough of us to keep each other company, and Charlie has any medical knowledge that might be needed. I take off Daphne's earrings – little anemones, hand crafted by a fellow marine biologist to look like the one we discovered in Papua New Guinea that she named *Anthopleura buddemeieri* when she published the description. Without any conscious organization, we take turns sitting close to Daphne, at her side or by her head.

The hospice nurse calls just before shift change time, and suggests that since Daphne is taking longer to die than is typical, we might want to put another towel under her. We do that, and the movement seems to trigger some sort of internal reset. Her breathing shifts from slow and shallow to rapid and shallow – and at 5:15 it stops. Charlie checks for the pulse that we know is not there.

We cry, text the Rabbi, and call Jan and the hospice (which notifies the mortuary), and then wait, with the now-silent body on the couch. I take off her wedding ring – it's tight over the knuckle, and Susan applies some liquid soap.

Post-mortem, pre-mortuary. “Do you want to spend some time alone with her?” No. The meaningful time has all been spent. That poor dead thing is not Daphne – life was her definition, and vice versa. I had been afraid that the departure of the body would be wrenching. It isn't. It is a relief to see her remains start the journey through fire and back into water – however after-the-fact, a re-experiencing of energy and motion, ultimately leading to a place where life abounds.

Loss, seasoned with relief. Everybody drained. Light the candle, lift the wine glasses, have a snack, collapse.

Next day, we start through her list of who should have what. Daphne was the family packrat, well-organized and dedicated. In addition to all of the artifacts out in the open, there are about 8 trunks of written material, photos, records, and memorabilia dating back to the 1950s. Much of it had come from overseas to begin with, and had been maintained through many moves. There were many exclamations of recognition and discovery as things that I had always thought of as “Daphne stuff” turned into heirlooms or treasured mementos before my eyes.

On Sunday, two cars-full depart; Charlie will come back with a rented van later to pick up the trunks and a few pieces of furniture. And there will be plenty left to remind me of Daphne.

Note: A website has been set up for people who would like to know more about Daphne, since there is nobody familiar with all of her diverse experiences and accomplishments:

<https://thecomplement.info/daphne>