

The eyes have it! Turned down for Exit services, she now works in the program

By Deborah Alecson, FEN Coordinator

Throughout my life, I have had an acute awareness of mortality and our culture's death denial; in particular, that of Western medicine.

There was the mangled birth (then welcomed death) of my first child in 1989, born with irreversible brain damage due to medical malpractice during labor – then the fight my late husband and I had with the hospital to allow her to die.

There was my husband's diagnosis of metastasized pancreatic cancer in 2000 and the insistence of oncologists that he endure brutal and futile chemotherapy until he had the courage to stop and receive hospice care in his final months.

There was my mother's unexpected suicide in 2013 at the age of 86. Finally, by 2017, I developed eye diseases that greatly impacted the quality of my daily existence.

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I had to retire early from teaching undergraduate courses in the field of thanatology. After months of seeing local ophthalmologists who could not figure out what was going on, I found one who diagnosed pre-retinal fibrosis in both eyes. This condition made me see double – the world around me, a complete distortion. Glaucoma in my left eye, diagnosed earlier and caused by a condition called pseudo exfoliation (in both eyes), required an arsenal of eye drops that only increased over time.

I entered a phase of life that required letting go of activities and identities in the world-at-large by redefining who I was as a person, someone not able to do and struggling to be. The eye specialists covered by my insurance were limited with the best outside the network. My son (born 14 months after the death of my daughter) moved out to Colorado the week of my diagnosis to continue his glorious professional ascent. I was alone, and while I was not going blind, I had lost my vision.

I knew about Final Exit Network from my

GLAD SHE WAS REJECTED

work, and in May 2018, I became a member. Soon after, I applied for Exit Guide services. I was certain then – and am certain now – that I would not want to live should I be blind, an assertion I have made to my son and all my friends.

Also, while I threw myself into “vision therapy” to rewire my brain to see straight, I wanted reassurance that should therapy fail and surgery of some kind was not an option, I could end my life peacefully with guidance from FEN.

Seemingly, within hours of reaching out to FEN, I heard from what I have since learned is a “coordinator.” I was impressed by her kindness and lack of judgment.



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She told me to write a personal statement about my condition and why I was applying to the Exit Guide Program, and to get copies of my medical records from the doctors I had been seeing for the eye diseases. I got these documents to her, and soon after, I had a phone interview with someone from the organization, who also was kind and not judgmental.

My application was rejected by the Medical Evaluation Committee (the final step in the process). I was more impressed with this outcome than disappointed. The fact of the matter was, I was able to drive with my left eye covered and a corrective lens for the right – *it was not time to check out.*

Four years later, after four eye surgeries (thanks to becoming eligible for Medicare) and months of pain from uncontrollable eye pressure – then the ultimate, the removal of my left eye last June – I am able *to do* and *be* in the world.

What I am *doing* is being a FEN coordinator for FEN Exit Guide services. It is something I would not have been able to do had my application been accepted!

