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## A Good Quality of Death

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Phyllis Shacter

This story has to do with love, courage, advocacy, and choice. This story could be about you because illness, end of life issues, and ultimately death, will come to all of us. It is my hope that this information brings you, your families, and your friends greater peace and mind, and that some of your questions and concerns about end-of-life choices get addressed.

Toward the end of 2011, my beloved husband, Alan, was diagnosed with both Alzheimer's disease and laryngeal cancer. Ultimately, he decided to voluntarily stop eating and drinking (VSED) as a peaceful means to the end of his life. It took Alan nine-and-a-half days to die. He died at the age of 76 on April 19, 2013.

Once Alan had made his decision, he lived in a state of deep, calm, accepting presence. He spoke these actual words to me:

I am comfortable and at ease with everything. I just feel great all the time, even when I'm tired. People notice how happy I look. I think that's important because I'm really at the end of this life. I'm sure it goes on. Before, I was burdened by all the things that I thought I should be doing, and I'm not anymore. I have no fear of dying. I don't know how to share this with other people. It's up to you, Phyllis, to do this.

This is our story and journey.

I had a very loving marriage with my husband for 26 years. Alan was a very special man. I never met anyone who didn't like him. He was a Harvard graduate, a computer scientist, a Neuro-Linguistic Programming practitioner, and a jazz pianist. Most importantly, he was a very gentle man.

Alan and I moved from California to Washington State in the fall of 2004. By 2006 we started going to doctors to find out why Alan wasn't feeling well and why he was so tired. Besides having fatigue, Alan's voice

became increasingly hoarse. He was always clearing his throat. Our local doctor first said he had gastroesophageal reflux disease (GERD). This made no sense to us, and we asked to be referred to a throat specialist in Seattle. After being directed to the Otolaryngology Department at the University of Washington Medical Center, we soon found out that Alan had an HPV viral wart on his right vocal cord, and that it needed to be removed. The first procedure was done surgically in the hospital, with anesthesia so it could be biopsied. We were relieved that they found no cancer.

We were told that the viral wart would continue to grow back and that it would have to be removed every three to four months with a laser in an outpatient clinic. I asked if this could become cancerous, and we were told that this was a rare occurrence.

Although Alan and I were familiar with various forms of complementary, alternative medicine, neither of us pursued an alternative to the laser treatments. Dutifully, we went to Seattle quarterly and had this procedure done. During the three-to-four-month intervals, Alan's voice went from being hoarse to being clear. Then it got hoarse again, and it was time for another procedure.

During this same period of time, Alan felt increasingly tired. We began to go from specialist to specialist between Bellingham and Seattle, seeking an answer to why Alan was so tired. Soon after he ate breakfast, he needed to go back to bed for more rest. He began to sleep more and more. We visited two endocrinologists, a cardiologist, a sleep specialist, a hematologist, several internists, one naturopath, and two homeopaths. No one could explain why Alan was so tired. You can imagine our frustration.

During the period of time when we were meeting with all these doctors, both Alan and I noticed changes in Alan's cognitive abilities. They were subtle. He was more forgetful, not as attentive with his driving, not able to track as much information at the same time. If he was working on the computer and I interrupted him, he would get very upset because he couldn't keep track of what he was doing.

In 2007, we both agreed that he should get examined by a neuropsychologist. The two-and-a-half-hour cognitive profile looked at different parts of his brain, and the neuropsychologist could find nothing wrong. But Alan and I noticed that his cognition continued to decline. He was examined again in 2009. Once again, the neuropsychologist could find nothing wrong.

Alan continued to get worse. I started doing all the driving. I began to handle all of our financial responsibilities. Toward the end of 2011, Alan was finally diagnosed with “dementia of the Alzheimer’s type.” We know that Alzheimer’s can exist for years before it can be detected. Although deep fatigue is not always a major symptom of Alzheimer’s, especially in the early and middle stages, it was a key symptom for Alan. Only six weeks after the Alzheimer’s diagnosis, Alan was also diagnosed with laryngeal cancer. The area where the viral wart had been removed became cancerous.

Alan’s surgeon told him he would die a painful death within six to twelve months unless he had three invasive surgeries. He was also told that there was a 30 percent chance that he would not be able to swallow, speak, or breathe easily following the surgeries. His surgeon, who knew of the Alzheimer’s diagnosis, never mentioned the Alzheimer’s or the possible negative effect of the anesthesia on his brain if he had the surgeries.

We scheduled the first surgery for January 4, 2012. We went to the pre-operation appointment. But while we were waiting for the surgery to occur, we had more conversation and asked ourselves, “Is surgery the only choice?”

Alan looked deep within and made the courageous decision not to have the invasive surgery. He had recently begun to see a naturopathic doctor in the Seattle area. This clinic did not treat cancer. It treated the underlying causes of disease. Alan was given an intensive daily regimen to follow. I became like a drill sergeant, making sure Alan took all his supplements and followed the prescribed diet and protocols. It was more than a full-time job

for me. This was a very challenging time. Because of Alan's cognitive decline, I had to keep reminding him about what he needed to do.

I reached out for help from friends and we set up a Care Calendar. I made requests that were put on a Care Calendar, and people signed up to help ([www.carecalendar.org](http://www.carecalendar.org)). I learned the true meaning of "ask and you shall receive." A lot of caring love came our way.

During this time, Alan also wrote a prayer. I asked about 75 people throughout the world to say this prayer at 7:30 p.m. each night. Alan and I joined this group of people each evening, and we said the prayer with them.

We didn't know if these healing options would cure the cancer, and because Alan did not want to have a painful death from laryngeal cancer, I took the next step as Alan's advocate and contacted End of Life Washington. The people there were very kind and helpful. I learned about the Death with Dignity Law, which exists in Washington State. Alan met with two doctors in our local area and because of his cancer diagnosis, he qualified for the Death with Dignity prescription. The prescription was good for six months. I kept it in our files but did not fill it.

The Death with Dignity Law cannot be used with Alzheimer's and most other neurological diseases. That law states that a person must be in the last six months of life, must be mentally competent, and must be able to self-administer the medication. Alzheimer's patients certainly are not mentally competent when they are in the last six months of life.

In April 2012, after following the naturopathic healing protocol for four months, after having a group of people say a prayer together each evening, and after Alan visualizing the outcome he desired, an amazing thing happened. We returned to the throat surgeon. He said the exact words that Alan had visualized being told: "I can find no cancer and the HPV viral wart is gone too!"

About two months after we learned that Alan was healed from cancer, we celebrated this good news with about 130 people who came to hear the details of this profound healing. Alan and I both spoke and shared the

details of this story. You can find the details on my website, at [www.PhyllisShacter.com](http://www.PhyllisShacter.com).<sup>1</sup> I also detailed this story in my book, "Choosing to Die."<sup>2</sup>

We thought that Alan may get another lease on life and have a few more good years left to enjoy. But the joy we felt when we shared this story with our community of friends only lasted a short time. In about six more weeks, the Alzheimer's became very noticeable, and we could no longer deny it. When this became so obvious, we mostly cried and embraced one another for about one week.

There was a fair amount of Alzheimer's in Alan's biological family and his mother had it for over 10 years. She died a shadow of a person with no physical capacities. Sadly, I was also familiar with Alzheimer's on my side of the family. My father had the disease. I received a phone call from my mother in February 1987, just a couple of days before I had my first date with Alan. She asked me to get to their house as soon as possible. At this point, my mother had been a caregiver for my father for many years through a heart attack, prostate cancer, and now Alzheimer's. Very little was known about Alzheimer's at that time, and there were almost no support systems. My mom was sleeping in a separate bedroom, and she barricaded the door with furniture in case my father tried to come into the room to harm her. He had threatened her life on previous occasions. She called 911 each time. He was always asleep on the couch when the police arrived and had no idea that he threatened my mother. That can be the nature of this cruel disease. Alan and I both knew what could occur if he decided to live into the late stages of Alzheimer's disease.

Alan knew that he was declining quickly. He was sleeping at least 16 hours a day. We began to talk about what choices he had available to him if

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<sup>1</sup> Phyllis Shacter, *How Alan Healed from Cancer*, PHYLLIS SHACTER (Accessed June 8, 2017) <http://www.phyllisshacter.com/the-story/healing-from-cancer/>.

<sup>2</sup> See Phyllis Shacter, *Choosing to Die: A Personal Story* (2017).

he decided he did not want to live into the late stages of Alzheimer's. He had a detailed Health Directive, and he was clear about not being treated for any acute disease in the future, such as pneumonia, the flu, or bladder infection. This could have been a graceful exit for him.

Once we both realized that the Alzheimer's was here to stay and that he would continue to decline, Alan decided he wanted to attend his own funeral. He used to laugh and think it was funny that people had their funerals after they died. He wanted to be present for all that love and attention. Six months before Alan died, we held a beautiful Celebration of Life. Alan was still able to talk fairly well. Both of us enjoyed sharing stories, and people lavished Alan with their love and attention.

Once the Celebration of Life was over, we continued to make our lives public about what we were discussing with regard to Alan's future. We knew that others would be faced with similar challenges in the future.

Alan and I discussed his next steps. I made contact with a volunteer chaplain at End of Life Washington. She asked if I had ever heard of Voluntary Stopping Eating and Drinking and suggested I do some legal research about it.

In my research, I found a paper by Thaddeus Pope and Lindsey Anderson in the *Widener Law Review*. Professor Pope is a health law professor and attorney.<sup>3</sup> This paper explored VSED as a legal option. I shared this information with Alan six months before he died. He could still read at this point and was mentally competent. When he finished reading the paper, he said, "I've read this paper, and I've decided I'm going to VSED." For months, I continued to question him to make certain he was clear about his decision. He finally said, "I've made up my mind. This is what I'm going to do. Please don't ask me anymore."

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<sup>3</sup> See Thaddeus Mason Pope & Lindsey E. Anderson, *Voluntary Stopping Eating and Drinking: A Legal Treatment Option at the End of Life*, 17 *WIDENER L.REV.* 363 (2011) (accessed from [http://papers.ssrn.com/so13/papers.cfm abstract\\_id=1689049](http://papers.ssrn.com/so13/papers.cfm abstract_id=1689049)).

We also learned from Thaddeus Pope that the United States Supreme Court ruled in 1990 that any individual has the right to refuse unwanted lifesaving medical treatment.<sup>4</sup> This includes our right to refuse food and hydration.

It's important to know that many health lawyers, ethicists, and medical doctors believe that a decision to VSED by a mentally competent person is legitimate and deserving of respect.<sup>5</sup> This perspective was prevalent at the first National Conference on Voluntary Stopping Eating and Drinking, held at Seattle University on October 14 and 15, 2016. My presentation at this conference is also available on my website at [www.PhyllisShacter.com](http://www.PhyllisShacter.com).<sup>6</sup>

Only a mentally competent person is capable of the consistency and discipline that is required to successfully VSED. Even the decision of a mentally competent person to VSED, who is not already very close to death, is often misunderstood or misinterpreted by hospice and long-term care providers. This was the case with our local hospice, PeaceHealth, in Whatcom County, Washington. They said they would not provide hospice to my husband until he was in the late stages of a coma. I felt my husband would suffer if this occurred.

Since my husband's death, I have spoken to other hospice medical directors in the Seattle area and they said they would have accepted Alan on the second day of his fast and supported him through the VSED process. In 2015 or 2016, I learned about one hospice in Seattle that did accept two women who chose to VSED at the end of their lives. One woman was in the early to middle stages of Alzheimer's. The hospice accepted her on the second day of her fast. She remained in her daughter's home throughout the VSED experience.

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<sup>4</sup> *Id.* at 377.

<sup>5</sup> *Id.* at 376

<sup>6</sup> Phyllis Shacter, First National Conference on Voluntarily Stopping Eating and Drinking (Oct. 14, 2016) (Recording available at <http://www.phyllisshacter.com/the-story/1st-national-conference-vs-ed/>)f

The second woman went into a hospice house in the Seattle area. Her VSED experience was more challenging because each staff person had their own perspectives and beliefs on end-of-life care. It was challenging to set up a consistent standard of care for her. Some people gave her sips of water and orange juice even though this would only prolong her suffering. The hospice finally suggested that the woman move back home with her son so she could continue the VSED process in a more focused way. The hospice continued to support her in her son's home. She died peacefully three days later.

It is essential that there be adequate medical support if someone decides to go through the VSED process. Our personal doctor stepped forward once she heard that hospice would not support Alan through this process. We also had two excellent caregivers, each taking a daily 12-hour shift throughout the VSED process. Our doctor visited Alan three times throughout the nine-and-a-half days. She was on call 24 hours each day. There were many times when we called her in the middle of the night to ask questions and get direction from her.

VSED may occur at home, in an accepting hospice environment, or in a nursing facility. Some people complete Living Wills and state that if they develop dementia and end up in a dementia or nursing facility, and get to the point of no longer being able to feed themselves, then they want their Health Directive agent to request that the patient no longer be fed. These Living Wills are completed when the person is still mentally competent. Unfortunately, the reality is that most nursing facilities will not cooperate and allow VSED due to the fear of legal charges of neglect.

While we were exploring choices, Alan was the one of the first people in Washington State to fill out the Alzheimer Advance Mental Health Directive. It is an excellent document, and you can easily find it on the End of Life Washington website. It is thorough. It protected both Alan's rights and my rights as his wife while he was still alive. There are parts of the advance directive that requires the help of an elder care attorney.

Before Alan made his final decision to VSED, he wanted to explore one more choice. He wanted to visit a good dementia facility and see for himself the realities of such a facility. I thought this was a good idea too. I wanted us to be informed so Alan could make a clear decision. We were fortunate because we had an excellent long-term care insurance policy that would pay for his care in a facility for about four years. I picked the most expensive and reputable facility near us. It cost about \$72,000 per year in 2013. The place we visited was clean and cheerful. There were no locked doors. The staff was pleasant. But the people who lived there had frozen faces. They looked lifeless, and were heavily medicated. Within a few minutes of our tour, we both had to sit down because we were shaking and crying at what we witnessed. As soon as we left, Alan turned to me and said, "I will never live there."

Alan knew he could go on living. But he also knew that his brain and his mental faculties were diminishing quickly. So he made his final decision. He decided he would stop eating and drinking so he didn't have to live into the late stages of Alzheimer's. I told him I would support him through this process, even though this was the most difficult thing I ever had to do. I cried often, alone and with Alan, anticipating the loss of my best friend.

It was completely heartbreaking to know that I was going to lose my husband soon. I wanted us to grow old together. I wasn't going to get to spend the last chapter of my life with him. He knew how difficult this was for me. Except for the times when we cried together and expressed our grief and gratitude to one another, I did not want to burden him with my grief. He had to focus on his decision. He knew that I was on my own journey, and I would have to deal with this in my own way. I was in an almost constant state of anxiety wondering how this would finally resolve.

I didn't know anyone who had done this before. I had no guide or book to read. I received some information from End of Life Washington. I had to investigate most of the pieces myself.

Who would support us? What did I need to do to fulfill Alan's request in a loving and dignified manner? Was this legal? Who would make sure we were supported legally? Who would take care of Alan throughout the process? Who would take care of me? All of these questions were overwhelming.

As the following months went by, Alan became more and more comfortable and at peace with his decision. Over those last months, he said to several friends:

When I didn't know anything about this, as probably very few people do, it sounded horrible. Now that I've investigated it, it doesn't sound horrible and I'm going to do it, VSED. I'm doing it because I have a disease that will rob me of the ability to make this choice. I have Alzheimer's and Phyllis and I went to visit an Alzheimer's facility and I couldn't imagine living there. This helped me make my decision to VSED.

Alan was clear about his decision, and he was clear that this was a good choice, a good way for him to avoid living into the unimaginable late stages of Alzheimer's disease. A few weeks before he stopped eating and drinking, he was sitting at our breakfast table, and I was standing nearby. I noticed he was crying. I asked him, "Honey, why are you crying? What are you feeling?" He replied, "I'm not afraid of dying. I've lived a good life. But I want everyone to know about VSED." Before I could think of the words coming out of my mouth, I spontaneously replied, "You'll just have to trust that I'll be your vehicle." Now that I have both a website ([www.PhyllisShacter.com](http://www.PhyllisShacter.com)) and a book, *Choosing to Die*, it is possible for everyone to know about VSED!

Determining a marker and setting a date to start the VSED process can be a huge challenge, but it is essential. Alan wanted to live as long as possible, and he didn't want to miss his mark, the time he would no longer be mentally competent.

Alan's main marker had to do with his quality of life. He determined that his marker be that when he could no longer leave the house to go to our local spiritual center, he was done. We were very involved in the loving and supportive community there.

Alan got to the point where it was exhausting for him to engage much with people. He said to me, "I can't go to the center; I'm just too tired." At this point, he was sleeping at least 16 hours a day. He was losing functions. He had other neurological symptoms. Our doctor thought these symptoms were related to Parkinson's Disease. He had little affect in his face. He shuffled when he walked. He was losing his balance. He was losing the ability to put sentences together. He was no longer able to leave the house and enjoy himself. He said it was time to stop eating and drinking. I also thought it was only a couple of months before Alan would lose his mental competency and, therefore, not be able to track himself and follow through with his desire to VSED. I told him this.

After this difficult conversation, Alan said he wanted to speak with his counselor one more time. We arranged to do this together the following morning. When we got off the phone with her, he turned to me and said, "I'm starting in one week." When I asked him how he was feeling later that afternoon, he said, with tears in his eyes, "I'm feeling sad." When I asked him later that evening how he was feeling, he said, "It's a done deal." We never discussed it again.

To hasten this process, Alan ate no more than 500 calories a day for five days. When he awoke on the morning of April 10, 2013, one week after speaking with his counselor, he no longer ate food or drank liquid. He simply went to bed and stopped eating and drinking.

We placed great emphasis on keeping Alan comfortable. He had a hospital bed, proper ventilation in the room, and a humidifier. I removed all visible food in the kitchen and kept the house free from cooking odors.

Alan wanted to spend the first few days mostly alone. He had already said goodbye to his family and friends. Each night, his daughter called on

the phone, and we put the speakerphone to his ear so he could hear her loving words.

Alan knew that he had choice about medication. He told our doctor that he wanted as little medication as possible because he wanted to be as aware as possible throughout his dying process. Fortunately, our doctor stayed one step ahead of him and kept him comfortable. I didn't want him to suffer at all. The amount of medication a person receives is individual and personal and will depend on the patient-doctor relationship and circumstances. Good medical support is essential.

Our doctor made three home visits during the nine-and-a-half days. Each time, she examined Alan, adjusted his medication, and gave instructions for his continued care.

The caregivers and I continued to spray frequent mists of water in Alan's mouth. We massaged his body with lotion. We played the music he had chosen.

Each day, Alan got visibly weaker and more wobbly. It didn't take long before he couldn't get out of bed without assistance. He went from being able to toilet himself to using the commode, then a urinal, and then having a diaper put on him. He was frequently turned in bed when he couldn't do this himself.

His urine went from normal yellow to dark orange and then it became very dark and minimal. He received a laxative suppository so he wouldn't become constipated and uncomfortable.

On the morning of the third day, I was surprised with a phone call from a local social worker from Adult Protective Services. She said that their agency had received a call about possible elder abuse. She said she would be at our house in 10 minutes to investigate. I'm glad I didn't have more notice about this visit because this visit stunned me.

The social worker walked into our lovely home. I first took her into our living room. This room was across the hall from Alan's bedroom, and he could hear our conversation. We had a glass coffee table in our living room

adorned with memorabilia from Alan's life. Flowers beautified the environment, and we had 24-hour candles burning throughout his VSED process.

I initially spoke with the social worker. Then I took her into Alan's room. We both sat at the end of his hospital bed, and the social worker began to ask him questions about his choice. He was still quite alert and answered her questions clearly, but with few words. Then I left her alone with Alan for a few minutes. I went upstairs and called our elder care attorney and gathered our legal paper together. Then I had the opportunity to educate the social worker about Alan's choice.

I showed her his detailed Health Directive. We used the form from the End of Life Washington website. Their forms are excellent. I also showed the social worker his completed and notarized copy of the Alzheimer's Advance Mental Health Directive, and a copy of the long white paper by Thaddeus Pope and Lindsey Anderson that described VSED as a legal option. The final document I showed her was the two witnessed and notarized Release and Assumption of Risk statements that were separately completed and signed with Alan's and my names. These last documents protected the doctor, caregivers, and myself. Alan took all the responsibility for his decision.

The social worker listened carefully and took many notes.

She wrote a positive report. The case was closed and cannot be reopened. Although I offered to give a class on VSED to the social workers at our local Adult Protection Services office, they have not yet taken me up on my offer.

Weeks later, I received a personal letter from the social worker. These are some of her exact words, "I'm glad to have met you, and I truly appreciate all I learned from you. Your courage, strength, and love were and are unique to behold."

On days three and four, Alan had some increased restlessness and showed some signs of discomfort due to dehydration. He never complained

about hunger. He was given appropriate medication so he would remain comfortable.

By the fourth day, Alan wanted people around him more, and he wanted to be touched gently.

I gave explicit instructions that I be the only person who could talk with Alan if he asked for food or water. On two occasions on the fourth and fifth days, he did ask for water. Each time I said to him:

You said you don't want to eat or drink so you can die because you don't want to live into the late stages of Alzheimer's. I'll give you whatever you want. But if I give you water, it will take you longer to die. Would you like a glass of water, or would it be okay if I spray your mouth with mists of water until you are satisfied?

Both times he said that mists of water were enough. I was, of course, prepared to give him whatever he wanted.

On the sixth day, Alan could only talk metaphorically in gibberish. I began to spend much of my time in the small hospital bed with him. It was comforting for both of us. On this day, he looked at his wrist and imaginary watch and said, "I've got to get the milk. What time is it? The people are at the party."

On day eight, we could hear the rattling in his lungs.

He could no longer communicate with his words and his eyes were closed. I said, "Alan, I am here with you. If you are comfortable, blink your eyes." With his eyes still closed, he was able to move his eyelids and I knew he was okay. On this same day, he mouthed his last words to me: "I love you."

The caregiver awakened me a little after midnight on the morning of the ninth day. Alan's breathing had shifted and was now loud and rapid. I crawled into bed with him and stayed there until about 5:30 a.m. I knew he was close to his death.

Later that morning, the doctor came to our house and examined him. She said that only his brain stem was alive. His heart was still strong and she

predicted that he would live another one to three more days. He was in a coma.

After the doctor left our house, I spontaneously walked into Alan's bedroom, closed the door, and began to talk to him. Then I stopped and sang a sacred chant that we both knew and loved. Then I started talking with him again:

You are so courageous. I'm proud of you. You're going to get your wish and not have to live into the late stages of Alzheimer's. We've partnered in so many ways before, and this is our last partnership. I'm going to be all right. You can let go now. Be free. Let go. I'm going to help midwife you Home.

While I was talking with Alan, his breathing abruptly changed from that loud, rapid breathing, to just a couple of very long, gentle breaths. His last breath was so gentle that I could barely detect it. He left his body.

Instead of it taking one to three more days like the doctor had just said, he left his body in fifteen minutes, with me by his side, loving him and talking to him.

And what was I experiencing through all this?

I was vulnerable, grief stricken, anxious, and fearful. I knew that the only way I would ever get over the grief was to go through it and experience it. I had professional support. It took me a long time. As I write this, it is three years and seven months since Alan's passing. I am grateful that joy has come back into my life again and that I have the ability and desire to share our story for the benefit of others.

I partnered with my husband every day of our marriage. We helped one another become the best human beings we could become. Although I went through the normal grieving process of losing my husband, my grief was complicated by the fact that we both had minimal guidance about how to go through the VSED process.

I experienced a lot of judgment because of other people's beliefs. This resulted in my feeling traumatized with acute stress. If not eating and

drinking had been an acceptable and known choice in our culture, I believe I would have experienced much less stress.

I'm sharing this information as a way to move forward this end-of-life choice so that it becomes an accepted and supported choice in our culture.

Beliefs and opinions about death vary widely. What is a belief?

One of Alan's favorite quotes, framed and posted over his desk, is this:

A belief is just a story you tell yourself about what is.

A belief is just a feeling of certainty about what is.

A belief is not the Truth.

Our beliefs are often formed during our childhood. They are based on religious and cultural upbringing. As we age, we have the opportunity to reexamine our beliefs. What beliefs serve us? What beliefs correspond to our real experience? What beliefs limit our life or diminish our experience?

As our friends and family and community became aware of Alan's decisions, we encountered a variety of other people's beliefs. For example, when I was looking for support and contacted our local hospice, I was told they would not help Alan until he was in the end stage of a coma. This information shocked me. From a place of compassion, I believe that all hospices, the religious institutions that support some of our hospices, and Medicare regulations need to address and support VSED.

Alan's potential caregivers had their beliefs. It was a challenge to find the right caregivers. Caregivers endeavor to help people extend their lives with a good quality of death, not shorten their lives with a good quality of life.

Some people in our community asked, "Is Alan committing suicide?"

We didn't focus on how others perceived his choice or how they labeled it. It was not an issue for us. What mattered to us was that Alan be able to have a good death, a conscious death, on his terms.

By not eating and drinking, Alan was saying "Yes" to his life, on his terms, up to his last breath. He made a clear decision, made with the support of loved ones. It gave him the opportunity to plan his death, to take care of

unfinished personal and emotional issues, and to say goodbye to his family and friends.

After this intense event and process was over, and Alan was no longer with us, many people came forward and expressed what a profound effect Alan's choice had on them. People perceived his actions as loving and courageous and a demonstration of his civil rights. They saw dignity in his death, and some felt deep relief knowing this option is available to them in the future if necessary.

Other people in the community shared their beliefs and said Alan was dying prematurely. Yes, it was true that Alan could have lived longer. His decision to VSED could not be timed perfectly. He did give up some quality of life, as well as days being alive, for a good quality of death on his terms. He always remembered that his mother suffered with Alzheimer's for more than ten years, and he was certain he did not want to experience this.

In the end, most of what we say and live by are Beliefs, not the absolute Truth. Beliefs shift and change.

What are your own limiting beliefs about death? How do those beliefs affect the relationship with those you love and those you help?

What you personally think, feel, and do is your own domain. By learning about our story, it is my hope that you have new perspectives and open your mind and heart to the VSED choice.

I miss my husband very much. Yet I'm glad he did not have to live into the late stages of Alzheimer's disease. He said he wanted everyone to know about VSED. I am carrying out his request because I witnessed his peaceful death. I respect his courage. His demonstration broadened my own perspective about my death. He had a good quality of death, and he did this by voluntarily not eating and drinking.

We can support and educate people and give families more end of life choice when facing the horrors of Alzheimer's and other degenerative diseases.

Please be proactive with this information. Share it with your families, your friends, your patients, your clients, and your colleagues. Then let each individual choose.