Journal of My Mother's Death *a VSED chronicle*

by Marcia Sloane

With supplemental information from Compassion & Choices

What is VSED? For those with a terminal illness, or for those experiencing extreme physical challenges at the end of life, Voluntarily Stopping Eating and Drinking is a way to choose how and when to die. A person must make the decision to VSED for themselves – legally, this decision cannot be made or enforced by others. VSED is possible for those with the mental clarity and inner resolve to make the decision and stick to it.

At the age of 85, my mother, Opal Sloane, moved from her home in Hawai'i to a senior residence facility in California near where I lived. I recall her saying many times that she wasn't interested in "sticking around" if physical problems or mental impairments compromised her quality of life and made her incapable of making a choice about how and when she wanted to die. She was breathtakingly practical, a pragmatist extraordinaire who For over two decades Compassion & Choices has provided support and education to individuals and their families about the option of Voluntarily Stopping Eating and Drinking (VSED). Throughout this story we have included resources to help those who may be thinking about this option or supporting someone who is. For more information on the full range of end-of-life options available, visit: **CompassionAndChoices.org/plan-your-care**

had never considered herself religious or spiritual, though when I was growing up, there were books on Zen Buddhism sprinkled throughout the house, and after she moved to her senior residence in California, she attended meditation groups and classes discussing world religions and death and dying.

For a detailed definition of VSED and a full list of frequently asked questions, visit: CandC.org/vsed

See "Things We Learned" on page 14 to find Marcia's guidance for people considering this option.

In her late 90s, my mother began to have more physical challenges. Carpal tunnel syndrome made it difficult for her to use her hands; she dropped her fork at dinner, "couldn't type, couldn't wipe." Her weight dropped to 85 pounds, her appetite decreased, and she had to sleep and rest for most of the day to have the energy to go to the main dining room or visit friends. She began to get sick more often and lost some control of bodily functions. She stopped driving, started taking advantage of her facility's meal delivery service, and felt she soon wouldn't be able to leave her apartment. Day-today living was getting harder and harder, and at the age of 98 going on 99, feeling she'd had a good full life, she decided it was time to go. Her husband, my father, had died many years prior, and as her only child and closest living relative, I wanted to support her wishes and do all I could to help her die in the way she wanted.

I recall the night she told me and my husband Todd that she was ready to VSED. We were visiting her over the Christmas holidays, and during dinner in the big dining room at her facility, she became quite uncomfortable and said her legs were aching and she needed to stand up and move. We returned to her apartment where she declared in no uncertain terms that she was ready to VSED.

It's a strange moment when the future suddenly becomes the present. My mother and I had many talks over the years during which she shared her process of coming to terms with death. She went through several cycles of feeling life had become a series of déjà vu moments. Yet though she felt "ready to go," she continued to find purpose in living. In her last few years she spearheaded the reorganization of the library at her facility, taught classes to other senior residents on how to use their computers, and never lost her curiosity for other people's lives and work.

After my mother's announcement that she was ready to VSED, she and I set the start date for three months in the future. She wanted the timing to be convenient for my work schedule and for us to have enough time to finalize her affairs and get organized for however long the process would take. She'd recently seen her doctor and he had written her a diagnosis of "failure to thrive." She had asked about VSED and how long the process usually takes, and he estimated two weeks to a month, perhaps less for her.

It is difficult to predict exactly how long a person will take to die once they decide to stop eating and drinking — this depends on the person's physical condition, age, medications taken, illness, height and weight ratio, fluid retention, ability to remain completely free of all fluids, and perhaps a readiness to "let go." For a terminally ill person, the process may take several days to several weeks after intake of food and water stops. Some people experience unconsciousness in as little as two to three days. For those without terminal illness the length of time to death tends to be longer.

Two weeks before my mother's VSED was to begin, the nurse at the senior residence arranged with the local hospice for a representative to meet with my mom. I was present at this meeting and the representative assured us of hospice support through the VSED process, which would include periodic visits You cannot do this alone. You will need 24-hour care during this process, and ongoing hospice care or oversight by your physician. Begin by discussing your end-of-life wishes and concerns with family, caregivers and your primary physician.

If you reside in a care facility, discuss your wishes with the nursing director or social worker. You will need their agreement to support you. You will need to make arrangements for 24-hour care once the VSED process has begun. Make sure each care provider understands and is supportive of your plan to stop all oral intake. Whether a family member or a paid caregiver, everyone caring for you must understand and support your plan.

from a hospice nurse, drugs to ensure my mother's comfort, and the handling of the paperwork upon her death in lieu of a visit from paramedics and police. With this assurance, we felt confident and ready to embark on what my mother called a "new adventure."

As it turned out, my mother's VSED journey took seven days. Todd and I rented a cottage within walking distance of my mother's apartment to have a space of our own for resting and recharging. My mother needed care 24 hours a day, so either Todd or I stayed with her, and my mother's close friend Marion, a retired nurse, spelled us for meals and walks. We also hired caregivers for several shifts, and the nurse at the senior residence facility provided invaluable guidance and support. It was definitely a team effort.

I've never kept a journal, but wanted to have a record of this experience for myself and to share with others for whom my mother's journey might be of interest. For most of us, dying is a mysterious business. We are reluctant to think about death, perhaps because we feel we have no control over it and because we live in a society where talking about our own death is largely taboo. But the way I see it, as we approach the end of life, thinking about death offers us an opportunity to allay our fears and empower our lives.

Throughout her life my mother had an unrelenting drive to anticipate all situations that might befall

her and then figure out what she would do in each and every case. My father liked to joke she got her exercise jumping to conclusions. Yet her extreme pragmatism, something I struggled to understand and accept for much of my life, served her very well in planning her death. In retrospect, I deeply appreciate witnessing my mother's preparation, clarity, and fearless resolve. Her VSED journey took some of the mystery out of death, as she showed me a way I might someday choose to die.

I would like to preface this journal of the last week of my mother's life with a dream I had shortly before she decided she was ready to VSED...

My mother is wearing her flowered suit of beigey browns, blues, and deep reds, and a wool brimmed hat. She and I approach an old Victorian hotel built on the side of a hill and enter through a side entrance on an upper level. The floors of the old wooden hotel are saggy with age and carpeted in red. The walls are covered in red velvet. We walk through a combination hallway and parlor appointed with comfy stuffed chairs and end tables, and we are greeted and welcomed by beautiful young women attendants dressed in black and white, some wearing pants, others skirts, some with aprons, some without. At the end of the parlor hall, a door leads out onto a covered porch, and from there cement steps descend to the street below.

As my mother and I walk onto the porch and down the steps, we find ourselves in the midst of large branches and wire. It gets harder and harder to get down the steps, which have become like an overgrown trail with more and more branches and sharp wire to duck under or climb over. It takes all my concentration to keep going, and though I know my mother was right behind me when we started, as the going gets tougher I lose sight of her. When I reach the bottom of the steps, I look back for her and discover she has gone back up the steps into the hotel. The hotel no longer has a front wall and I can see into the parlor hall, where my mother is standing in the center of a semicircle of the beautiful attendants. Everyone is smiling, and my mother is smiling and waving to let me know she's ok.



Picture above and bottom right: Opal Top right: Opal and Marcia





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Journal of My Mother's Death

Day1

A s previously arranged, Mom calls hospice the morning she begins VSED and a hospice representative comes to her apartment to take blood for lab tests. Todd and I arrive in the early afternoon. Mom informs us that for several days prior she has been eating less and less and not missing food. "I am telling myself I don't need food and I don't need this world." The process has begun.

Mom and I sit on the side of her bed and enjoy looking at photos of her relatives, my father's relatives, and me with her and my father.

At the end of the afternoon, hospice calls to inform us that because my mother doesn't have a terminal diagnosis – "failure to thrive" is not considered a terminal condition – and because the results of the morning lab tests don't indicate anything abnormal, hospice would not be reimbursed by Medicare for their services and therefore they cannot assist us. Individuals might not qualify for hospice at the beginning of their end-of-life fast and need to be seen multiple times in order to eventually qualify for the hospice benefit. To learn more about hospice and how to select one that aligns with your wishes visit: **CandC.org/hospice-care**

In retrospect, dealing with this sudden change seems like it should have been a huge shock since we were relying on hospice for critical services. Yet at the time, the shock was mitigated by the strength of my mother's intention. She had begun her VSED journey and we, with her. There was no way she would be deterred.

When she goes to bed this evening, Mom complains of nasal and throat drainage issues and we prop her head up higher with a second pillow.

Day 2

2 am: With assistance, Mom is okay getting out of bed to go to the bathroom. She has phlegm in her nose and throat.

4:30am: Sometime early in the morning, she calls me to her bed and says, "There's been a change. I felt like I was falling into a black hole where I couldn't talk, and I thought, 'This is it, I'm gone.'"

7:30am: Mom has the dry heaves. They come and go for the next few hours and after each round she says she feels better. Otherwise, she is mostly sleeping and resting comfortably. She likes lying flat on her back.

Mom's comments during the morning:

"We didn't know where it would strike, and it struck in the stomach." "My mouth hasn't been particularly dry. I have saliva." "At some point I'm not going to be able to talk. We're both doing what we want to be doing." "I'm not in good shape, but I'm not in pain."

1:20pm: In the absence of hospice, the nurse at the senior residence facility arranges with my mom's doctor for us to obtain morphine and lorazepam prescriptions.

Mom says, "I keep having dreams. I'm cooking food and then wondering why I'm cooking it. I have to throw it out ... the last time it was rice." She reports having this dream half a dozen times.

Mom stops getting out of bed and we begin changing her diapers, which we will do three or four times a day from now on. She helps us change her by lifting herself up slightly. The skin on her legs is very tender and if we accidentally brush against her legs it is extremely painful for her.

2:30pm: Mom says, "I was worried I would be anxious, but I'm happy, comfortable, calm, not agitated or in pain." She describes what happened to her early this morning. She saw a bright light, had the sensation of falling into a black hole, and then stopped herself from falling. She briefly felt fear and thought, "where am I going ... somewhere beyond where I've ever gone." Then she was no longer afraid and saw a bright circular light like a kaleidoscope, and beyond that a solid light.

8pm: Mom says, "I have never been hungry this whole time."

A person's comfort level depends on many factors, including overall physical condition, age, disease progression, appetite before the fast, as well as emotional concerns. Caregivers or healthcare providers can usually manage any unwanted symptoms. The most frequently reported symptoms include thirst or dry mouth, occasional hunger, and feelings of uncertainty about the approach. Some people have reported that coconut oil (the type used for cooking) can be soothing on the lips, gums and tongue. Use a humidifier in the room. Using ice chips or small sips of water may extend the length of the dying process. Caregivers can also use body lotions to hydrate the hands and skin. Hospice can provide symptom management and can be consulted about additional resources and comfort measures.

It is important to review all medications with a physician before beginning the fast. Your physician may recommend that you avoid medications that may cause dry mouth or thirst. Stopping some medications, such as those for heart disease or diabetes, may secondarily speed up the dying process without increasing discomfort. Medications for pain, agitation, anxiety or other symptoms may be available in forms that don't require drinking fluids, such as sublingual drops, skin creams, skin patches or suppositories. People respond differently to medications, and it is important to inform doctors of any allergies or negative reactions to any medications. It may take healthcare providers some time to find the best medication or combination of medications to meet the individual's needs. Many medications used at the end of life have a sedative property and cause drowsiness, which may lessen possible symptoms of discomfort in the VSED process.

This is the first time I realize this journey might not be easy for me. I see how important it is for me not to get caught in old patterns with my mom. I realize I felt abandoned by hospice. I panicked and now I need to regain my bearings. Hearing an ambulance siren today, I was reminded that what we're dealing with in this apartment is not much different from what the rest of the world is dealing with – the possibility of death. Meanwhile, my mom and I are here together, committed to what we're doing.

Day 3

Mom is back to her old self! After a day of dry heaving, she is no longer uncomfortable and wants chapstick and her first mouth swabbing. She is barking commands and tells me to check the TV to see if Comcast turned off her recording option she had scheduled to kick in two days ago. The kitchen in her apartment is near her bed and Todd and I are concerned about preparing food for ourselves in front of her, but she's involved in her own thoughts and says she is unaware of what's going on in the kitchen.

Elena, our first hired caregiver, comes for two hours in the morning. The first thing Elena asks is, "Did she eat yet today?" We need to make it clear to all caregivers that Mom is choosing not to eat or drink.

When the chaplain from the facility comes to visit, Mom comments, "My first night I felt normal until early in the morning when something started happening, almost a compulsion, wanting to vomit but nothing to vomit. But last night, I was much better. I was expecting to be uncomfortable but I've been fine. I can only say good things about the process. It's almost *too* successful. It is an interesting experience. How so? I can't tell you, but it's different."

Mom is lying in bed, seeming quite happy, wondering whether she wants to read. She says she is practicing letting chi rise up through her chakras and exit out the top of her head.

Of the different music CDs I brought to play for Mom, she prefers solo piano music, spacious and slow without a regular pulse. Music seems to be important to her at this time and she has definite thoughts about what she wants to listen to.

2:30pm: More drainage today... Mom says she is "draining in my nose and in my vagina, dribbling all the time in my vagina."

Mom says, "I am not bored. I am content. I thought the process was going to be difficult and unpleasant, but I am more calm and peaceful than I've ever been. I never thought I would attain peace. I thought it just wasn't in me, but now I have."

Attainment of peace aside, Mom continues to bark commands. Her extreme mental sharpness reminds Todd of how he once felt on the third day of a brown rice fast. Despite her barking, the three of us have an inspiring conversation. I am struck by the contrast between my mother's approaching death and the sense I have of limitless time ahead of me. Momentarily suspended outside linear time, I wonder about the purpose of our years of being alive,

Having visions or experiencing disorientation is a common occurrence for those nearing the end of life. For caregivers it's important to continue to comfort and provide caring presence to the dying person and assure them that they are surrounded by people who love and care for them. and I marvel at what each of us goes through on the way to these final moments.

Our mother/daughter dynamic kicks in as I struggle to make the right shaped pad to cushion her tailbone from digging into the bed when she lies on her back, which is most of the time. I'm doing my best to construct a pad out of cotton batting and moleskin but she's angry with me. At the end of the struggle, problem solved, she says, "We're all being creative."

Mom's default patterns can kick in during a crisis. She has never had faith that others can figure things out as well as she can. If ever there were a time for honoring her decisions, it is certainly now, but her lack of faith in others drives me a little crazy.

4pm: Mom has her first "hallucination." She sees "big posters, all black and white, side by side. The first wall has six big posters that have clear pages in front of them. I was thumbing through the clear pages to get back to the black and white." **4:30pm:** Mom says, "A second thing happened – a chill, a movement in the right direction, a change, something new happened, a shift."

Mom says she had the feeling several times today she was sitting up, only to discover she was lying down.

Mom: "I am happy. And I realized I was so into VSED that it never occurred to me that other people would have a problem with my choice, that they would be upset."

As a person becomes less able to move about and is spending more time in bed, a hospital bed can be helpful for relieving pressure on their bodies, giving them more options for positions to lie or sit comfortably and helping caregivers assist with bathing and changing their clothes.

Day 4

Phaedra, our next hired caregiver, comes in the morning for two hours.....Mom enjoys her sponge bath with Phaedra.

When Mom closes her eyes, she sees "rug designs moving and changing into animals," which make her feel a little nauseous.

2pm: We look at more photographs together. Mom says, "I'm enjoying this no end."

She says, "Yesterday I got so much better and I was so alert. Today I'm retreating, giving up, letting go." **3pm:** The hospital bed is delivered and assembled by the two delivery men. The bed takes up most of the living room in Mom's tiny apartment. We've tried to respect my mom's space and leave her furniture, clothes, and papers as they are, but we also needed to get things ready for the hospital bed and clear space for ourselves. We've bagged up some of her clothes, but it feels premature to start carting things out of her apartment.

3:10pm: Mom says, "I can't believe how comfortable I've been except for that night when I was feeling like I was going down the black hole with those dry heaves. But those were no worse than what we've all experienced, and not as bad as the food poisoning I had in China. I've changed my ideas about everything – about how it's going to be."

5pm: Mom is a bit anxious – maybe looking at old photos pulled her back to this world. She has her first dose of morphine, the lowest dose. It seems good for her to try it while she's still so coherent and can communicate how it makes her feel.

6:30pm: Mom awakens and says she feels like warm fluids are washing over her. "Waking up after taking the morphine, I was breathing the way I do when I'm asleep, that deep regular sound when you know a person is asleep, but I was awake." Marion gives Mom a mouth swab "massage" using cold water so her mouth feels better.

Mom says to Marion, "Tell Pat (a good friend) I'm doing great and even better than expected."

Providing oral care on a regular schedule can help ease symptoms of dry mouth; use lip salve, mouthwash, oral sprays and gel like Biotene, soft toothbrushes, glycerin swabs or sponge swab, and rinses with cool water or another beverage of choice (not to be swallowed). Vaseline or non-petroleum based lip balm can be used to keep the lips moist.

Day 5

Elena, our first hired caregiver, returns in the morning for four hours.

Marion tells Mom she saw Mom's friends at Sunday brunch today and told them all that Opal was doing well, so they don't have to worry. This makes Mom very happy.

Mom describes a hallucination: "Above me in the ceiling, a water nozzle came down and looked me in the eye from eight feet away. Then it receded."

She says that two or three times yesterday she thought she was "on a bicycle completely covered by water, not in complete control, feet going down, head going up, more vertical." She says, "I dreamed about a top wrap I could wear in bed, a colorful beige top with faded orange wide edging for ties on the sides."

Mom is sleeping much of the time, conversing when awake, and says, "It's easier to let go today. It

requires too much energy to think and stay in control. I feel like I'm beginning to go."

Mom has a pain in her foot and wants her foot to hurt so she can see if the morphine is working. Yesterday, one dose of morphine made her comfortable but didn't quite eradicate the foot pain. I think she wants to test the morphine, maybe for the security of knowing it works. When Todd reassures her that there is plenty of morphine and we are going to give it to her whenever she wants it, she says, "I think you're the only one who really gets it."

She says she wants her death to be as natural as possible and doesn't want the morphine to knock her into unconsciousness. "It's not that I want to live; it's not that I want to die. I want to let my body decide how it's going to carry out my orders." – her orders being no food or water. "I told my body what the rules are. Now I want to let my body carry the rules out." As I leave to do some laundry, Mom says, "I want you to use ammonia in your clothes wash. Just two tablespoons will make everything so nice. I want you to use ammonia in your wash for the rest of your life."

Todd: This experience is at the same time remarkable and mundane, all wrapped in one. Sometimes I am overwhelmed by the pathos, the sorrow, the finality, the grave quality of this process, and other times this feels like some bizarre sit-com with people acting exactly as they always do, as if these are days just like any other days – the emotional dynamics unchanging.

Marcia: I feel worn down. There are no compartments in my brain for filing anything, for keeping track of things, for remembering what I have to do. I feel psychically dislodged. Everything is new.

7:30pm: Todd and I cook dinner at our cottage. Then I return to mom's apartment and play my cello for her. After a few minutes, she is asleep. **9:30pm:** Mom wakes up, I swab her mouth, and change her diaper. In contrast to barking commands this afternoon, tonight Mom is sweet. She tells me I make a good caregiver because I'm so relaxed, which is news to me considering I feel the opposite of relaxed.

Mom is expecting not to be able to speak soon and shows me hand signs she's come up with:

Tracing her mouth with her finger means she needs her mouth swabbed. Making a fist and moving her arm means she needs morphine. The A-okay finger sign means yes. Waving her finger means no.

As she becomes less alert, we plan a routine for swabbing her mouth and administering morphine 6 times a day, every 2-1/2 hours, with or without hand signs.

Day 6

3:09am: Mom says she "wants to be sedated always." She is agitated and feels she needs to have higher dosages so she'll go quicker, feeling that the morphine "helps her move along towards dying."

3:20am: Dose of morphine.

7:35am: I wake from a deep sleep to Mom calling out, "Did you hear that horn?" She wants to know whether she imagined the sound or really heard it. Mom says, "Even though I'm agitated, I'm not uncomfortable or in pain."

11:35am: Mom says she has "no concept of time." She is going into confusion and I find myself wanting to reason with her and raising my voice, then realize reasoning is no longer in the picture. Mom wants a guarantee she will die and die soon. She believes she needs to take morphine in order to die. The last of her rational brain is trying to make sense of what's going on and remain in control. She says, "Today I changed my mind from yesterday. That was Alice (from Alice in Wonderland) running in place. I want Alice to move forward. I want my body to go faster. We're on the cutting edge and I want to move that cutting edge forward."

Yesterday she wanted her body to be able to organically move into death. Today she wants the morphine as a ticket to death.

6:30-8pm: While Todd and I are at supper and Marion is with Mom, the nurse at the senior residence calls Mom's apartment. Mom tells her she

is "spinning, anxious, agitated," and thinks she'd like the morphine more regularly. When Todd and I return, Marion, who has also talked with the nurse, says, "We don't want her to wake up ever again." The nurse has recommended we give Mom lorazepam and morphine every hour as needed so she avoids getting back into an agitated thinking state and can rest, relax, and go with it.

8:15pm: Mom has transitioned from being intermittently awake to being asleep all the time. Facing the fact that she won't be waking up again is difficult for me. Todd and I change her diaper and it's much harder because she is no longer awake to help us. I am afraid of hurting her, and my fear is exacerbated by her making moaning sounds and moving her arms though sedated.

The evening of day 6, eyes closed and sedated, Mom traces her lips to indicate she wants her mouth swabbed ... her final request.

Marion showed me how to administer the morphine and lorazepam, even when mom isn't awake, by shooting the little plunger in on the side of her mouth. My confirmation of success is hearing additional moisture in her breathing, a little phlegm sound in her throat that gradually dissipates as the morphine is absorbed into her body.

11pm: Mom is coughing phlegm and I am concerned she will choke on it. I swab her mouth and sop up the extra moisture with tissues and she returns to deep breathing. Mom has mostly been on As death nears, breathing becomes more shallow and irregular. Moaning or "rattling" breathing may occur, but is not believed to be an indication of pain or distress. The body may change temperature and there can be discoloration in the face (flushed red, or pale with bluish or yellowish tones), as well as purple or bluish mottling in the hands or feet.

her back this week, breathing audibly and deeply without phlegm. I feel fortunate that breathing has not been a problem for her.

Day six has been tough, but the goal is to let her go in peace and for us to be in service to the process of her smooth departure. How we, the living, feel about her departure is not the point.

One of the last things Todd remembers Mom saying is, "It is helpful to think of this as a program. There are steps, you follow the program, and you achieve the desired results." Her idea of a "program" was a way to turn the process into something controllable. When she started to feel agitated and uncomfortable, she likened her situation to Alice running in place and not getting anywhere. In order to get somewhere, she wanted to speed things up, with the goal of using up all the morphine. She described this program as "her doctor's plan. He devised a very good program. He said most people who are healthy when they do something like this take about two weeks, but because you only weigh 85 pounds, I think you might only take one week."

Day 7

7:30am: Mom's last breath.

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Opal Shimmons Sloane (1918 – 2017)

"I have lived a long and happy life and feel I have come to the end of it. I'm like the 'one-hoss shay' that 'went to pieces all at once,' and do not want to keep living on and on, gradually becoming more and more incapacitated. I'm thinking of my passing as a new adventure, wondering what will happen."

> Have you heard of the wonderful one-hoss shay, That was built in such a logical way It ran a hundred years to a day, And then, of a sudden, it — ah, but stay, I'll tell you what happened without delay.....You see, of course, if you're not a dunce, How it went to pieces all at once, All at once, and nothing first, Just as bubbles do when they burst. End of the wonderful one-hoss shay.

excerpt from One-Hoss Shay by Oliver Wendell Holmes

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Opal's Obituary

Opal Shimmons Sloane was born in 1918 in Michigan. An only child, she lived on a farm until she was seven, and thereafter grew up in Flint and in several small towns near Flint. She earned a BS in Education and a teaching certificate in business subjects from the University of Michigan. When she decided being a school teacher was not for her, she switched to business.

While in college she met George Sloane, a chemical engineer. They were married in 1943 and had forty-seven wonderful years together. They lived in Michigan, California (where daughter Marcia was born), and Hawai'i. George died in 1990, and after fifty years in Hawai'i, Opal returned to California in 2002.

Known for her wry wit and business acumen, Opal loved gardening, theatre, ballet, opera, traveling, eating out, leading discussion meetings, and using her computer. She was a lifelong student with an insatiable curiosity, always taking courses in a wide variety of fields. She constantly aspired to improve herself and made New Year's resolutions every December. Before she married, she was a private secretary, office manager, and business teacher. While married, she had many part-time jobs in diverse fields. She enjoyed having to think on her feet, and a favorite job was as a professional shopper for a fast food chain. She loved doing income tax and did so professionally for several seasons.

She also did a great deal of volunteer work for PTAs and Girl Scouts, at a low-income alternative high school where she taught shorthand and typing to adults, on a citizens' committee working on a community project, and in other associations. She was a member of several organizations—often an officer including two investment clubs, Kahala University Extension Club, Kindergarten and Children's Aid Society of Hawai'i, Women's Club of America, Planned Parenthood, League of Women Voters, and American Association of University Women.

Opal is survived by her daughter Marcia Sloane and son-in-law Todd Walton.

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Things We Learned

Mouth swabbing

Abstaining from water greatly speeds up the dying process, but to help keep my mom comfortable, we swabbed the inside of her mouth with a small sponge on the end of a stick designed for this purpose. The sponge is moistened and then fully wrung out in order to moisten the tissues inside the lips and mouth without hydrating the body. Swabbing with cold water feels best. day, all which make pre-scheduling breaks important. Having our own space nearby worked well for us. To be on the safe side, we reserved the cottage for a month, though it turned out we needed it less than half that time. We purchased travelers' insurance without knowing that only certain circumstances allow for reimbursement. However, change in the health status of a family member was one of those allowed circumstances.

Hospital Bed

In retrospect, we would have arranged for the hospital bed to arrive a few days earlier. It was higher and wider than my mother's bed with controls allowing her to sit up or raise her legs. She was more comfortable in this bed and we had an easier time reaching her, changing her diapers, and sitting near her on the edge of the bed.

Caregivers

If caregivers are hired from an agency, it helps to know in advance what their skill level is and to have all the supplies they will need ready when they arrive: a wash basin for a sponge bath, gloves, mouth swabs, etc. It's also important for all caregivers to understand that the patient is choosing not to eat or drink.

Todd and I, the primary caregivers, needed time away every day to rest and recharge. How long the VSED process will take is unpredictable, and the person undertaking VSED needs care 24 hours a

Hospice

Several days after my mother died, the hospice nurse phoned to apologize for hospice not providing us with their services. We learned later that different hospices follow Medicare guidelines differently, some relying on reimbursement from Medicare for services rendered, some not. While "failure to thrive" might be a satisfactory diagnosis to engage some hospices, it wasn't satisfactory for the hospice in our area.

In the absence of hospice, we were very fortunate to have the guidance and support of the nurse at my mother's residence. She made contact with my mother's doctor for the needed prescriptions and notified the County after my mother died. That notification resulted in the startling early morning arrival of two uniformed paramedics to check my mom's vitals, confirm her death, and make sure no foul play had been involved. Then a uniformed policeman arrived and took pictures of my mother which he sent via his phone to the coroner. To complete the paperwork, he called my mother's doctor to ask if he would sign off on the death certificate, which the doctor did. Though my mother had discussed VSED with her doctor at her last appointment, because of hospice's assurance of support, we didn't see a need to notify him about her VSED start date. When hospice withdrew, we were fortunate he was there for us.

Acceptance and Forgiveness

Looking back, there are things we wish we had done differently. I regret we didn't up the dosage of morphine earlier on Day 6 when my mother expressed a desire for that. I wish I had played cello for her another time or two. But the VSED week went fast and it took energy on all levels – mental, emotional, physical, and psychic – to keep up with the ever-changing landscape of my mother's journey.

Influenced by Buddhist teachings, I imagined my mother's body remaining in her apartment with us for a few days after she died to give her soul time to peacefully depart. However, the senior residence had rules necessitating the pickup of a body soon after death, and Todd and I had little energy left for more than dressing her in her colorful muumu, and sitting quietly with her until the attendant arrived from the mortuary. Upon his arrival, the attendant wheeled in a trolley onto which he spread a white blanket. He transferred my mother's body to the blanket, wrapped her up, and asked me to let him know when I was ready for him to cover her face. When I indicated he could go ahead, he completed his preparations, expressed his condolences, and wheeled her body out of the apartment. I gazed out the window and caught sight of a flurry of birds as they flew from a tree into the blue sky of a new day.

Prior to her death, I had arranged with my mother's residence to hold a memorial service. My mother was happy knowing there would be an occasion to remember her, but otherwise she had little interest in what might happen after she died. Three weeks following her death, Todd and I picked up her ashes at the mortuary on our way to the memorial. The community room at the senior residence was packed with friends and acquaintances, festive with food, photos, flowers, and a table filled with dozens of my mother's scarves for attendees to take with them and remember her by. It was a beautiful tribute to my mother, a joyful celebration of her life.



Reading through this journal, I am reminded that while the experience was not easy, the strength of my mother's commitment to VSED combined with our complete support for her decision made the process possible. In the end, undertaking this journey didn't feel so different from committing to other goals we set for ourselves in life. With imagination and determination we achieve our dreams, and in doing so experience the joy of expressing who we are. I believe that was what my mother felt throughout those seven days – she was expressing who she was in the way she chose to die.

Please feel free to share this journal with others interested in VSED.