A ‘Good’ Death with Dementia: An Autoethnographic Exploration of Voluntary Stopping Eating and Drinking (VSED)

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Voluntary stopping eating and drinking (VSED) has become increasingly recognized as a legal, appropriate, and ethical way to hasten death at the end-of-life. It is one of few options available for people with dementia to hasten their death. My Dad wanted to use VSED after he was diagnosed with dementia; because there is little information about how and when VSED is being used as an end-of-life option for people with dementia, our family was mostly on our own to identify resources to help him realize this choice. The purpose of this thesis is to address this gap using a mix of autoethnography and in-depth interviews with VSED experts in Washington State and the Netherlands, using a narrative format that contextualizes personal experiences into larger social conversations. I explore the question of what is a ‘good’ death and what options an individual with dementia has to hasten his/her death with VSED. My analysis looks at how to prepare for VSED; how to know when to begin; the process itself; the role of the caregiver; and a cross-cultural look for other options. The observations and discussion from this research indicate...
that VSED deserves ethical and legal clarity and that individuals with early-stage dementia need better options to voluntarily hasten their death while they still have the capacity to do so.

Dementia, Voluntary Stopping Eating and Drinking, VSED, End-of-life, Right to Die, Netherlands, bioethics, euthanasia, hastening-death, ‘good’-death
ACRONYMS

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<tr>
<td>APS</td>
<td>Adult Protective Services</td>
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<td>KNMG</td>
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<td>PAD</td>
<td>Physician aid-in-dying</td>
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BACKGROUND

My Dad used to jest that there are two guarantees in life: to be born and to die—and that everything in-between is unpredictable. We live in a death phobic culture where it has become harder to come to terms with death (Sontag, 1978). There are established social, political, economic, and medical structures to manage death and dying—but our understanding of them is peripheral. My Dad wanted a choice in his death, but getting the death that you want takes work and is never a guarantee. In February of 2016, my Dad was diagnosed with Mild Neurological Cognitive Decline consistent with dementia—by the time we got home he couldn't remember the name of the diagnosis. My Dad knew immediately that he did not want to live to end-stage dementia. He had firsthand knowledge of this condition having watched his Mother die from it as a “stranger among strangers” and that her disease “broke his heart”. Dementia, for my Dad, was a horrendous end-of-life and a terrible way to die. Aided by his independent and stubborn spirit he was committed to finding another option— he wanted a ‘good’ death.

What is a ‘Good’ Death

The notion of a ‘good’ death is a complicated concept, as death and dying are embedded with social, cultural, religious, and political meanings (Kellehear, 2007). Over the past century, dying has shifted from being a public activity and natural part of life, to a private and managed process (Kellehear, 2007). Death has become increasingly medicalized, driven by a desire and capacity to treat or cure illness with the hope of delaying death (Gawande, 2014). The social construction of a ‘good’ death has been aided by the hospice movement and perspectives that emphasized the need for social, psychological, and spiritual end-of-life support (Seale, 1998). In 2000, Steinhauser and colleagues elicited views from patients, families and clinicians about the factors
that they all agreed contributed to a ‘good death. The factors elicited complemented earlier research and included pain and symptom management, clear decision making, psychosocial well-being, spiritual well-being, and autonomy (Field, 1997; Emanuel, 1998; Singer, 1999).

Steinhauser and Tulsky (2015), in their recent comprehensive chapter on Defining a ‘Good’ Death in the Oxford Textbook of Palliative Medicine, updated this analysis and summarized empirical investigations about the importance of culture in a ‘good’ death. They ultimately conclude that there is no right way to die and write that “each end-of-life experience is a process to be negotiated and renegotiated in the context of that patient’s and family’s values, preferences, and life course” (p. 81). The language of a ‘good’ death risks imposing a sense of paternalism, implying that one must meet certain criteria in order for one’s death to be ‘good’. Steinhauser and Tulsky (2015) suggest that patients and families define and redefine goals for care at the end of life, recognizing that “the patient is the expert on their life” and thus should set the agenda for how to invest their time, energy, and resources.

A ‘Good’ Death with Dementia

Achieving a ‘good’ death is complicated by a diagnosis such as dementia. The term dementia describes the symptoms consistent with cognitive decline; these symptoms affect memory, reasoning, and behavior. In the United States Alzheimer’s disease is the sixth leading cause of death and there are an estimated 5.5 million older adults living with cognitive decline—the number is projected to be 13.8 million by 2050. In addition, there are over 16 million informal caregivers providing unpaid care for people with dementia (Alzheimer’s Association, 2018). Not always viewed as such, a dementia diagnosis is a terminal diagnosis; life expectancy after diagnosis is between 3-12 years (Beaufort, 2016). Dementia brings with it paradoxes; the
individual looks the same but their behavior and decision-making has changed. Do you listen to the wishes of the person pre-dementia or their present-day requests? Many people with dementia set up Ulysses Contracts: “do what I am saying now, not what I will say then”. These types of instructions are now used in advance directives; the question dementia brings is can a person in one state of mind make a decision for their future self? What if they change their mind?

**Options for a Good Death**

Access to high quality end-of-life care varies greatly based on geography, insurance coverage, finances, and available services (Palliative Care, Report Card). Nonetheless, it is important to map out some of the ways in which individuals access a ‘good’ death at the end-of-life. On one end of the spectrum there is letting a disease take its natural course; for example, with pneumonia or cancer, making the decision to not treat or stop treatment. As the disease progresses a patient may gain access to hospice services—once they have a prognosis of six months or less to live. Hospice services are generally considered complementary to helping patients achieve a ‘good’ death. Either at-home, or at a hospice-house, patients are provided comfort-care measures to maximize quality of life. The other end of the spectrum is a hastened death. This is choosing measures to speed up the processes of death and dying. There are various means to hasten death. For example, in the United States, hastening your death is legally accessible on the state-level. Physician aid-in-dying (PAD) is legal in seven states and the District of Columbia (although California’s statute was overturned on May 25, 2018 by a court ruling and is no longer in effect until further notice) (Death with Dignity Acts, 2018). In these jurisdictions, eligible patients, who meet strict criteria, are allowed access to lethal medications that they are competent to self-administer.
In the Netherlands, aid in dying is primarily done with physicians participating in euthanasia, in which clinicians administer the lethal medications with their patient’s consent. There is also auto-euthanasia, which is when a patient obtains a lethal prescription illegally and hastens their own death. Auto-euthanasia can happen globally, but is common in the Netherlands where an individual wants their death to be completely autonomous (Vink, 2016). Doctor Boudewijn Chabot is the most prominent figure in this debate, his books are consistently mentioned for setting the standard for hastened death, VSED, and auto-euthanasia (Chabot, 2014). Auto-euthanasia is a Dutch term that is used to describe any measures that a person takes themselves to hasten their death; examples are obtaining lethal medications without a physician or VSED. Chabot believes that the death of patients should not be placed in the hands of physicians, he “argues that patients capable of this should do it themselves, and to differentiate between this conscious act and suicide he coined the term auto-euthanasia” (Beaufort 2016). There are no comprehensive statistics on the frequency of auto-euthanasia.

**Voluntary Stopping Eating and Drinking (VSED)**

Another strategy for hastening death is VSED, known as a method of voluntarily refusing or withholding all food and fluid. VSED is an effective, passive, and unique way to achieve a natural death by dehydration in about eight to nineteen days, if the individual successfully abstains from water (Pope, 2014; Wax, 2018). It differs from the loss of thirst and appetite that is part of the natural dying process in that it entails making the conscious choice to refuse food and water with the intention of hastening death. The 1997 Supreme Court decision Vacco v. Quill found that, although there was no constitutional right to assisted suicide, everyone is entitled to refuse “unwanted lifesaving medical treatment” (1997). This decision allows a patient to
withhold or withdraw treatment, including nutrition and hydration. There is little research or clarity about VSED as a method to hasten death, especially for persons with dementia and other cognitive impairments. It is sometimes also referred to as ‘voluntary dehydration’ (Jacobs 2003), or in Dutch “consciously choosing not to eat and drink” (KNMG, 2015). Timothy Quill an expert on VSED says: “it’s for strong-willed, independent people with very supportive families” (Span, 2016). VSED remains widely resisted by both healthcare practitioners and patients, in large part this resistance is due to misunderstanding and uncertainty (Pope, 2016).

While scarce, all the available studies report that VSED is a relatively peaceful and comfortable way to die (Bolt, 2015; Ganzini, 2003). There is a death bed and time for goodbyes; it’s non-invasive and the length of the process allows for a person to change their mind. Ganzini (2003) conducted a study with Oregon hospice nurses who witnessed VSED and rated the quality of these deaths with a median score of 8 on a 9-point scale (with 9 representing a very good death).

The distinction of VSED as a natural death keeps legal authorities away, allows physicians to feel safe in providing support, and it can be important for life insurance claims. Pope (2016) wrote: “while medical aid in dying is characterized as “active” because of the introduction of deadly drugs, VSED is characterized as “passive” because it entails only refusal and withholding.” VSED is not new, but in 2003, reports of hastened death by VSED were rare in the literature (Ganzini, 2003). Over the last decade it has received increased attention in media and research; in October of 2016 the first ever conference on VSED was held in Seattle (Hastening Death, 2016). VSED is a unique form of hastened death because the standards for informed consent and decisional capacity are situationally dependent, allowing VSED to be utilized in patients with early-stages of dementia (Ganzini, 2016).
My Dad’s Lived Experience of Dementia and VSED

The main subject of this work is my Dad, who was a retired 71-year-old male who had worked as a refinery worker. In February of 2016, my Dad was diagnosed with Mild Neurological Cognitive Decline consistent with dementia. At the time of his diagnosis, his body was healthy and active—he had no existing co-conditions. He wanted his ‘good’ death to be reliable and pain-free death. As his cognitive impairment increased, he became more and more distressed about his lack of options for hastening his death. He started searching for other ways to hasten his death when he learned his dementia precluded him from being eligible for Washington State’s Death with Dignity law. He looked into carbon-monoxide, heroin overdose, and helium. He also signed “do not resuscitate” orders and hoped for a heart attack, pneumonia, or stroke to kill him before the dementia got his brain – but, none of those were guaranteed. Above all, my Dad was an honest man and obsessed with not getting anyone in trouble; whatever option he chose, it had to be legal in order to not put me or my Mother at risk of legal consequences.

In October of 2016 our local newspaper published two articles on utilizing VSED in cases of dementia (Relyea, 2016). I won’t forget the excitement in my Dad’s voice when he called saying, “I think I found it, I think I found my way out, it was the front page of the newspaper.” In his joy, he cut out the article and carried it around. That newspaper article was the tipping point, as without it we would have never heard of VSED. It guided us to the resources we needed. VSED became what dominated our conversations and decisions. It was the only legally viable option available for someone with dementia. My Dad was nervous about the process but committed to the end goal. In January 13, 2017 in a letter of intent my Dad wrote:
It has always been important to me to retain a quality of life that allows for my own independence and free will. I am looking at exit strategies because I know that I don’t want to end up in a facility. I would want to do VSED so that my death is my choice. I feel this decision is consistent with my life values.

As we prepared for my Dad’s VSED it was clear there was little research on the process. After his death I found myself left with questions: Was VSED a good death? What other options does a person with dementia have? Was it ethical? Did we start too soon? I imagined my thesis writing to be less personal, but when my Dad chose to do VSED I realized that the story of his death was more powerful than any data I could collect. The purpose of this research is to contextualize my Dad’s VSED experience, comparing our lived understanding with existing literature.

**METHODS**

This project used a combination of qualitative methods, including my autoethnography, that I supplemented with a literature review to inform the design and conduct of in-depth interviews with individuals who had direct experiences with VSED. These three approaches were complementary and allowed me to triangulate data from multiple sources to link the personal and social contexts, which is a key feature of autoethnography. Chang (2016) describes this connection as follows: “Autoethnography is a qualitative research method that uses a researcher’s autobiographical experiences as primary data to analyze and interpret the sociocultural meanings of such experiences.” The intention is that the personal becomes political and that the autoethnographic work contributes to the literature. My role as a researcher and my perspectives given my personal experience are tightly woven into this work and I believe that is
what makes it powerful. I would have not had interview access or the in-depth knowledge of VSED and dementia without my personal experience.

**Data Sources**

**Autoethnography**

This research formally began in February of 2017 when my Dad gave his consent to document his story and have it be the focus of this thesis. When my Dad was diagnosed I started recording a personal journal, taking notes on our meetings, and retaining all the paperwork we filled out. Furthermore, I had photographs and a family-journal where we tracked the progression of his disease. In the following months, I went back through the documentation and treated it as research: categorized and coded it in Atlas TI, established a chronological timeline, and added commentary to events. This story is as authentic and as trustworthy as possible.

**Literature Review**

In my search for answers to my research questions, I began looking at work from the Netherlands, where physician aid-in-dying has included people with dementia. After his death, I made a more comprehensive sweep of the literature. In order to conceptualize our experience, I used peer-reviewed scholarly research and grey literature from organizations. There I found more case-studies (Shacter, 2017; VSED Narratives, 2016) and during my time in the Netherlands I came across specific VSED protocols for physician’s (KNMG, 2015). In the Netherlands, there have been more public cases of individuals hastening their death in early-stage dementia; the impact of this is that legal and ethical precedents for VSED have been established.

**Informant Interviews**
Participant Recruitment. I networked to find interviews in the Netherlands. I used articles, books, protocols, and end-of-life organizations to find names of individuals and then I reached out via e-mail. I was quickly connected to people who responded to my request for information on VSED, specifically in cases of dementia. In the Netherlands, I spoke to three men: a palliative care expert, a counselor who specializes in end-of-life options, and a retired physician who was an early adopter of assisting patients to hasten their deaths. In Washington State, all three of my informants were women, and recruited from my family’s personal network: two had been involved in my Dad’s VSED process, and the third was referred to me by these women because her husband had also used VSED successfully.

Data Collection and IRB approvals. I conduced face to face interviews with the three participants in the Netherlands in January 2018, and with the three participants in Washington in January and May of 2018. In each in-depth semi-structured interview (see Appendix 1), I explored the participants’ experiences surrounding VSED, specifically the complexities that arise when dementia is involved. The interviews lasted one to two hours and were conducted in private residences. Interview topics included options to hasten death, why people choose VSED, how to know when to begin, and common challenges that arise during the process. In my interviews with the two women involved in my Dad’s VSED, I also asked for their perceptions on our experience and process. All interviews were audio recorded, transcribed, uploaded, and de-identified in Atlas TI. All participants provided written consent and all study procedures were reviewed and approved by the University of Washington Institutional Review Board in November 2017.

RESULTS

Other Ways to Hasten Death: A Cross-Cultural Perspective
There is a misconception that physician aid-in-dying (PAD) is legal in the Netherlands. While it technically remains illegal there, when a physician follows proper procedures of due care and reports the case to a review committee, it is codified as an exception (Hertogh, 2007). Unlike Death with Dignity statutes in the US, Dutch physicians rarely prescribe lethal medications but instead are present at the time of death and often opt for euthanasia by administering intravenous injections. I expected the Netherlands to be an oasis of end-of-life choice for people with dementia, however I discovered that achieving a ‘good’ death with dementia remains complex.

Dutch law allows for euthanasia of a dementia patient who has clearly stated their wish in their advance directive, theoretically allowing for the hastened death of a patient who has forgotten their own end-of-life wishes. However, this very rarely occurs in practice, physicians prefer to rely on a patient’s current situation and present-day autonomy (Hertogh, 2007). Dementia patients who are accessing PAD are typically in the early-stages of the disease (Beaufort, 2017) and even then, physicians are very hesitant. In 2016, only 2.3% (n=141) of the 6,091 cases of euthanasia reported to the review board in the Netherlands were people with dementia (KNMG, 2017).

Each Dutch interviewee deemed dementia not only the worst disease to get, but the most difficult to navigate. They each told me “hard cases” and stories about when the VSED process did not go as planned. They also all emphasized that it was their role “to support and not to judge.” That although it could be difficult, “it’s his or her choice so you have to respect it” (Participant #2).

Soon after my Dad’s dementia diagnosis I had looked into obtaining lethal medications; pentobarbital being the drug of choice. With a little research, I found my way to The Peaceful
Pill Handbook. I could pay seventy-five dollars for online access, but I panicked and worried about its legitimacy. The Peaceful Pill Handbook I would find out later, through interviews in the Netherlands, is a legitimate and important resource for anyone considering auto-euthanasia. It is updated frequently with accurate and pertinent information to obtain a lethal dose of pentobarbital from addresses in either China or Mexico. I was drawn to the work of Dutch author Ton Vink. I had read his article *Self-Euthanasia, The Dutch Experience: In Search for the meaning of a Good Death or Eu Thanatos* months prior. In the article, he told the story of Thomas, an eighty-three-year-old man, “suffering from the onset of dementia” (Vink, 2016, p. 684). Thomas chooses to auto-euthanize, he had the support of his family, counsellor, physician, and pastor. Vink makes the argument that not only physician-euthanasia but also auto-euthanasia fit the standards of a ‘good’ death. He advocates for individual autonomy. Each person should be allowed to make a decision and have that decision respected. The story of Thomas was the death my Dad wanted; I believe my Dad would have preferred auto-euthanasia in the form of lethal medications over VSED.

**Choosing VSED and When to Begin?**

In the Netherlands, there was an understanding that for some people VSED was a “plan B” (Personal Interviews January 2018) that “the patient’s decision to stop eating and drinking may relate to a request for euthanasia that has been turned down” (KNMG, 2015, 4). However, for others it was because VSED produces a natural death which was congruent with their religious beliefs (Participant #2, #5). A person’s decision for VSED was situational, multifactorial, and individualized.
One of the most complicated portions of VSED, or any method to hasten death, in cases of dementia is when to begin? In medical bioethics autonomy reigns supreme (Weiss, 2018). However, the question of if your current competent self can cut off nutrition and hydration for your future demented-self remains unsupported by court decisions (Span, 2016). A person with dementia must begin VSED while they still have competency and autonomous choice, before they slip beyond their ability to make such a decision. If one waits too long the opportunity will be gone (Beaufort, 2016). We heard the phrase: you must start sooner than you think from everyone we came in contact with.

*There is a small group of people, I suppose like your Dad, who says that is a road I do not want to go down [dementia]. I am prepared to give up a certain amount of time of life in order to not get in this situation that I simply do not want to get into. This is very important. We have of course, in the Netherlands, written statements saying when I am unable to recognize my children and I am walking always the wrong direction and whatever then I want to have Euthanasia. That doesn’t work. That is too late. You must realize you must do this in time. Which means actually too soon. (Participant #3)*

There are no rules or protocols about when to start and each individual is different. In every interview, participants noted how dementia seems to stand alone is this special category that people labeled *complex:* participants would shake their heads and say: “difficult.” The tradeoff required finding a middle ground, when the person with dementia begins to approach the threshold of capacity, but not starting too early and losing too many quality days.

Early on in my Dad’s diagnosis we falsely assumed we could utilize Washington State’s “Death with Dignity” legislation which passed in 2008. We live in one of the eight jurisdictions in the United States that allows for physicians to legally prescribe a lethal dose of medications to
patients. The people accessing the legislation in Washington are predominantly white, insured, cancer patients who fear a “loss of autonomy” (Washington State Death with Dignity Act Report, 2017). My Dad fit all those criteria except that he didn’t have cancer. The moment he was diagnosed with cognitive impairment he was simultaneously denied the option of accessing Death with Dignity statutes. Thus, I felt like our family’s VSED journey was less out of choice and more out of a scarcity of other options.

Once my Dad learned about VSED, we created a list of activation criteria, in the form of markers. Markers are the things that define quality of life and also mark the progression of disease. Establishing markers can be a huge challenge and is dictated by how the individual defines their quality of life. It also requires the support of caregivers to enforce the plan based on the caregivers’ interpretation of the markers, shifting the moral responsibility. Dresser (2017) captures the complexity of markers: “Having activation criteria is morally difficult and places the power back into that of a caregiver.”

My Dad had defined his quality of life “as being able to be fully present with the people and the environment around me” (Death Plan, 2017). While some people have one to two markers we had a more exhaustive list:

- Can no longer drive
- Cannot manage medications alone
- Forgets to eat or bathe
- Struggles to track the conversation
- No longer enjoys being in social settings with friends
- Cannot recall activities from yesterday or from earlier in the day …etc.

Watching for markers was exhausting and required vigilance. Changes couldn’t be ignored because everything was a potential marker. My Dad trusted my Mother and me to tell him when it was time. For me, his biggest marker was when he could no longer do his morning walk alone. This walk was integral to his identity and he told me months earlier that if he
couldn’t go on a walk alone he didn’t want to live. But, dementia is a complicated disease. Dementia patients are known for adjusting to their changed situations. He was content and kept simplifying his life without realizing that markers were flying by. By the time he couldn’t do his walk, he didn’t care that he couldn’t walk alone. I was enforcing a marker for his quality of life that he no longer valued in the same way. At the beginning of June 2017 my Dad entered his “window of opportunity” in where he could begin VSED. However, by the end of June, my Dad didn’t have to rely on my Mother or me to make the call. He himself said that he was ready to begin. A VSED start date was chosen, he would begin July 12, 2017.

**What preparation is necessary for VSED to be successful?**

**Legal issues**

VSED requires enormous amounts of paperwork. Due to its legal ambiguity, it was important that we had as many protective factors as possible; we were creating proof that my Dad was making this decision willingly and on his own.

Filling out each form was consuming work that took multiple rough drafts and long conversations. He filled out a Physician Order for Life-Sustaining Treatment (POLST) form, a bright green form obtained in hospitals and doctor’s offices where my Dad declared his desires for “comfort care only” and “do not resuscitate.” We had copies of his POLST on the fridge, in the glove compartments of cars, and in his wallet. He wrote a letter of intention and we filmed a 1-minute support video of him talking to himself about why he wanted to do VSED—a video he never wanted to see again. We utilized *End of Life Washington’s* Advance Directive and their Advance Directive specific to Dementia and Alzheimer’s. These directives are one of ten different advance directives in Washington and are regarded as some of the most comprehensive.
All of our documents were witnessed and notarized. Prior to his death he also helped write his obituary, fill out his death certificate, and sign his cremation release. We made copies of all the paperwork and organized it in a binder. These binders were given to his Physician, the Death Midwife, and scanned into his hospital records—we even had a “guest copy” in case we got reported and Adult Protective Services (APS) knocked on the door.

An important challenge is that APS considers VSED a form of elder abuse. If someone is an APS mandated reporter (teacher, counselor, et cetera) and they hear of someone who has a start date for VSED, or is actively in the process, they are required to report it to their local APS office. This affected my Dad’s access to mental-health services and kept me from sharing about parts of VSED with my counselor. In our community, a man who was doing VSED was reported to APS, who, after a home visit, deemed the process voluntary and free of any neglect or abuse (Shacter, 2017). My mother lived in fear that APS was going to knock on the door at any moment during the VSED process—luckily, they didn’t.

There is also a legal aspect to preparing for VSED. Our family consulted an attorney who specializes in end-of-life care. We each signed a Release and Assumption of Risks. My Dad’s read “I hereby release all such individuals, including but not limited to, my physician, my caregivers, my wife, and my daughter.” These forms hypothetically freed my Dad’s care team of any responsibility. They provided legal protection, but their merits have never been challenged in a court of law. We signed these documents twice in the lawyer’s presence: the first time being in February 2017 when he clearly had capacity to declare his wishes, then the second time a week before my Dad’s VSED start date, to re-confirm his decisional capacity.

Medical Care Issues
In my interviews, participants all spoke about the need for physician support for VSED, which they said was vital for success. In the United States, you need a physician that is willing to prescribe supportive care medications, be on-call throughout the process, and sign the death certificate. Physicians who work for large religious hospitals or have personal reservations about VSED may be unable or unwilling to support a patient through the process.

My Dad saw his physician regularly but refused to see a memory specialist. He was lucky that his primary care physician was supportive of his VSED decision and respected that it was his choice. We also went outside the medical care system and got help from Death Midwife (also known as a Death Doula) who we identified from the VSED article (Relyea, 2016). The role of a Death Midwife is to provide emotional, spiritual and practical support to families before and after death to maintain the highest possible quality of life (Wahlberg, 2017). We had never heard of a Death Midwife, but she was invaluable in guiding us through the process, step by step. We met with her monthly as a family. She helped us organize all the paperwork we would need, gave us a list of hospital materials and supplies to obtain, she and even organized a support team of hospice volunteers and death doulas that would be with my Dad 24-7 during the VSED process. The support team would join my Dad on his 2nd day of VSED and would be by his side, administering medications to address symptoms, and providing care until his death.

We had been told that finding home healthcare that supports VSED can be difficult, especially in our area which is primarily served by a Catholic health system. Private home-health workers may also have religious values that would not support VSED to hasten death. We were fearful of the stories we heard of caregivers that left patients because they didn’t agree with VSED, or worse, called Adult Protective Services. My Dad valued the relationship with the
Death Midwife immensely, always felt at ease, and never stopped repeating how much “he trusted her.” He, more than anyone, welcomed her as part of the support team.

**Financial Issues**

There was also a large financial cost. VSED is not covered by insurance and required out-of-pocket costs. The accumulated costs of the Death Midwife, lawyer, 24-7 support team, and medical supplies during the VSED process added up to around $13,000 dollars. As a comparative reference that is equal to about two months in a dementia care facility (Nursing Facility Rates and Reports).

**The VSED Process**

Prior to beginning the process, we knew of three other instances of VSED for dementia—all of which had unfolded quietly. When my Dad and I theoretically discussed what VSED would be like, we would ask ourselves the following questions: Would it be painful? Would it last long? Would it be good and comfortable? We weren’t entirely sure how it would go because most of the literature about VSED as a ‘good’ death comes from terminally ill patients who are already close to death. Dementia patients have an illness that is ultimately terminal, but in early-stage dementia, patients can have a healthy body and a demented mind. At the VSED conference held in Seattle, Ganzini (2016) talked specifically about the “hard-cases” of VSED, specifically discussing cases of early-dementia and the impacts of delirium. An example of a hard case is a:

*Patient who decides to pursue VSED before losing autonomy to progressive neurological disease, otherwise only mild to moderate illness burden and suffering, not yet hospice enrolled and develops delirium and thirst during VSED and requests water.*

VSED is complicated with the development of delirium, “in these cases patients forget why they
are not drinking” (13).

Prior to my Dad’s VSED process I had access to two VSED protocols. One was from the Death Midwife and included paperwork lists, the need for physician support, instructions about how to taper off of food and fluids, and a recommendation for a hydrotherapy colonic prior to his start date. The only published handout I found was from End of Life Washington (Voluntarily Stopping Eating & Drinking, 2017). It included a sample letter to your doctor and frequently asked questions. It’s one page appendix on managing symptoms does not mention that there are hard cases or the possibility of delirium, and lacks any reference to end-of-medications that could be used to manage symptoms.

While in the Netherlands (after my Dad’s death) I was introduced to the KGMG’s protocol that breaks down the dying process into three phases; makes specific and clear reference to the likelihood of developing delirium; and recommends palliative care medications such as haloperidol and fentanyl. The protocols go as far as to not recommend morphine (the drug available to my Dad), as it is processed in the kidneys which are some of the first organs to be affected by dehydration.

Sometimes we make assumptions and conclusions based on incomplete understanding. One Friday in March, we sat at the bar drinking martinis and eating clam chowder and I referenced the literature as some of the only proof I had that VSED was going to go smoothly and provide my Dad with his ‘good’ death. In the case of his VSED, we had fallen complacent to believing the single story—that VSED was going to be an easily obtained ‘good’ death. In a note to himself he wrote about VSED: “you are headed down a, hopefully short, and comfortable road to the next step” (February 2017).
Prior to the start date on July 12th we prepared. My Dad spent those last week’s saying goodbye to friends. My mother and I cleaned the house, setting up the view room to fit a hospital bed. Following the Death Midwife’s list, we obtained the necessary medical equipment and supplies. We prepared water-spritz bottles with fresh mint for when my Dad got thirsty. We couldn’t have any food in the house for over two weeks so we set up a meal-train for me and my Mother and composed e-mails to family, friends, and community, on my Dad’s behalf.

On July 12th my Dad began to taper his caloric intake (see Table 1). Although he required uninterrupted supervision, those days were spent in relative ease. On the morning of July 19th, was the first day of no food or no water, after which time we could no longer offer him anything. His first days of VSED were comfortable. It was almost like a party, full of laughter and movement. At first, he didn’t complain, he wasn’t thirsty, and he never asked for food. Physically speaking my Dad was extremely healthy, he was mobile for seven days, in which we would rotate from front to back porch. We listened to music, I soaked his feet and gave him foot massages, we discussed the sunset, and every morning he would get on the scale, excited by the amount of weight he was losing.

During day four of VSED his agitation and anxiety worsened. We were giving him lorazepam for the anxiety but it wasn’t calming him down. In hindsight, we all (family and care providers) had failed to account for how my father’s love for martini’s twice a day and whiskey would complicate the process. We had not been adequately prepared for his alcohol withdrawals. Everyone says the symptoms of VSED are managed with strong medical support, but we were all in over our heads. His unexpected alcohol withdrawal symptoms meant he needed more medical support and stronger drugs than what we had on hand. He was experiencing delirium and every five to ten minutes he was asking for water. When you asked him how he was doing he would
one interviewee in the Netherlands said, “your Dad was at a greater risk [for delirium] because of his drinking problem; dementia and alcoholics put you at greater risk for delirium” (Participant #2).

Until Day 7 of VSED my Dad was downstairs spending time on the porches. Each day he lost strength and spent more time sleeping. When he lost the ability to swallow pills we switched to liquid lorazepam. Due to low blood pressure and an inability to be on his feet, on Day 9 we put him in Depends—he fought this with unexpected strength. He swung in and out of consciousness, appearing comfortable at times and restless at others. His last words were when he opened his eyes, smiled, looked at my Mother and I, and said “Hi girls” before falling back asleep.

On the morning of July 30th on his 12th day of VSED, I kneeled next to his bed and began coaching him. My Mother joined. We spoke words of encouragement: he was strong, he was safe, he was loved. He sweated, he struggled, and as the clock stuck six-o-clock he exhaled his last breath. The details of his process are described in the Table.
<table>
<thead>
<tr>
<th>Date</th>
<th>&quot;Day&quot; of VSED</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>27-Jun-17</td>
<td>-</td>
<td>Last visit to lawyers to sign final attestations&lt;br&gt; Last visit to Doctor's to get prescriptions written Death Midwife gets HIPPA release to speak directly with doctor</td>
</tr>
<tr>
<td>28-Jun-17</td>
<td>-</td>
<td>Arbitrary start date of VSED decided: July 12, 2017 - based on availability of hydro-colonic appointment</td>
</tr>
<tr>
<td>5-Jul-17</td>
<td>-</td>
<td>E-mail sent to family explaining VSED&lt;br&gt; Prescriptions for liquid lorazepam and morphine filled&lt;br&gt; Ordered hospital bed, walker, beside commode</td>
</tr>
<tr>
<td>9-Jul-17</td>
<td>-</td>
<td>Goodbye with friends</td>
</tr>
<tr>
<td>10-Jul-17</td>
<td>-</td>
<td>Last Dinner out</td>
</tr>
<tr>
<td>11-Jul-17</td>
<td>-</td>
<td>Got a pedicure because didn't want to have &quot;ugly feet&quot; for VSED&lt;br&gt; Last full home-cooked dinner</td>
</tr>
<tr>
<td>12-Jul-17</td>
<td>1/2 Portions</td>
<td>E-mail sent to local community about VSED and support&lt;br&gt; Got haircut and beard trimmed, didn't want to look &quot;shabby&quot; for his death</td>
</tr>
<tr>
<td>13-Jul-17</td>
<td>1/2 Portions</td>
<td>Said goodbye to friends&lt;br&gt; Check-in with Death Midwife</td>
</tr>
<tr>
<td>14-Jul-17</td>
<td>1/4 Portions</td>
<td>Goodbye at his favorite bar&lt;br&gt; Hospital Bed Arrives</td>
</tr>
<tr>
<td>15-Jul-17</td>
<td>1/4 Portions</td>
<td>Last night of real food</td>
</tr>
<tr>
<td>16-Jul-17</td>
<td>Juice Smoothie</td>
<td>Feeling dizzy with diarrhea all day&lt;br&gt; Passes out/seizes 2x</td>
</tr>
<tr>
<td>17-Jul-17</td>
<td>Juice Smoothie</td>
<td>Begins taking lorazepam tablets consistently&lt;br&gt; Final Martini</td>
</tr>
<tr>
<td>18-Jul-17</td>
<td>Water with Lemon</td>
<td>Dizzy during the night&lt;br&gt; Stopped taking all medications&lt;br&gt; Hydro-colonic appointment&lt;br&gt; Check-in with Death Midwife</td>
</tr>
<tr>
<td>19-Jul-17</td>
<td>Day 1</td>
<td>Emotionally difficult on the family&lt;br&gt; Sat on the porches and napping&lt;br&gt; Check-in with Death Midwife</td>
</tr>
<tr>
<td>20-Jul-17</td>
<td>Day 2</td>
<td>First day with daytime support-team&lt;br&gt; Sat on porches &amp; watched the birds&lt;br&gt; Death Midwife is there to facilitate shift-changes</td>
</tr>
<tr>
<td>21-Jul-17</td>
<td>Day 3</td>
<td>Daytime Support-Team continues&lt;br&gt; Sat on porches, talked about his life as a teacher, and watched the yard&lt;br&gt; Check-in with Death Midwife</td>
</tr>
<tr>
<td>22-Jul-17</td>
<td>Day 4</td>
<td>Wanting a lot more &quot;spritz&quot; of mint water, refill of lorazepam tablets and increased dose of lorazepam&lt;br&gt; Before bed he says he feels &quot;quite comfortable&quot;&lt;br&gt; Death Midwife does first overnight shift and first night my Dad spent in the hospital bed</td>
</tr>
<tr>
<td>Date</td>
<td>&quot;Day&quot; of VSED</td>
<td>Notes</td>
</tr>
<tr>
<td>----------</td>
<td>---------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>23-Jul-17</td>
<td>Day 5</td>
<td>Getting &quot;spritz&quot; every ½ hour, seems calmer than yesterday Continued use of lorazepam tablets, got last shower Really hard time watching the sunset, he wanted water and Martini, I thought we were quitting VSED until Death Midwife came and talked to my Dad</td>
</tr>
<tr>
<td>24-Jul-17</td>
<td>Day 6</td>
<td>Still sturdy on feet to use the restroom Spent time on the porches, continued use of Lorazepam tablets First sunset my Dad didn't watch Check-in with Death Midwife</td>
</tr>
<tr>
<td>25-Jul-17</td>
<td>Day 7</td>
<td>Switches from lorazepam tablets to liquid lorazepam No longer sturdy on his feet, last day he is downstairs Meetings with the Death Midwife no longer include my Dad</td>
</tr>
<tr>
<td>26-Jul-17</td>
<td>Day 8</td>
<td>My Dad seems more rested today, I went in and he said, “hey girl” and I said “I am happy to see you resting.” And he said: “me too.” My Dad takes his last trip to the restroom due to low blood pressure Asking for water a lot, used bedside commode</td>
</tr>
<tr>
<td>27-Jul-17</td>
<td>Day 9</td>
<td>Liquid lorazepam and liquid morphine Gets lightheaded when he sits up - switched to Depends When Death Midwife asks my Dad if he knows what she is doing there, and he responds, “saving my ass” Death Midwife calls doctor for stronger medications My Mom says her goodbye</td>
</tr>
<tr>
<td>28-Jul-17</td>
<td>Day 10</td>
<td>5:45am doesn't want to soil his Depends and was fighting, with incredible strength Struggles to swallow morphine or lorazepam - restless 4:30pm Soiled Depends again and had another fight with Death Midwife and support staff 8:30pm first dose of haloperidol I say goodbye to my Dad</td>
</tr>
<tr>
<td>29-Jul-17</td>
<td>Day 11</td>
<td>Combination of haloperidol, morphine, and lorazepam-still restless at times Semi-comatose state Midnight attempt at dying, lots of spiritual activity in the room</td>
</tr>
<tr>
<td>30-Jul-17</td>
<td>Day 12</td>
<td>Little to no medication administered - resting peacefully Starts trying to die at 4:30pm, receiving love and support from family, and dies at 6:00pm Body ceremonial washed, dressed, and placed on dry ice to keep cool We toast to his life and death</td>
</tr>
<tr>
<td>31-Jul-17</td>
<td>Vigil Day 1</td>
<td>Spent time hanging out next to his body Spent time in the house</td>
</tr>
<tr>
<td>1-Aug-17</td>
<td>Vigil Day 2</td>
<td>3 hour open-house I spent a few hours alone in the middle of the night saying goodbye to him again and writing him a letter to be cremated with him</td>
</tr>
<tr>
<td>2-Aug-17</td>
<td>Vigil Day 3</td>
<td>3 hour open-house 6:00pm Removal of his body; family, friends, death midwife, and physician gather to wrap him in his shroud and decorate it with flowers.</td>
</tr>
</tbody>
</table>
Immediately After Death

After the silence, there was movement. A phone call was made to the Death Midwife. We wiped the blue morphine off his beard and chest hair—from when he had spit out the morphine instead of swallowing. We tied a scarf around his head to keep his jaw tight until the rigor mortis set-in. We prepared a warm bowl of water with essential oils. The room was full as we all took turns washing his body down, each person taking a different area. It was therapeutic, calm, and loving.

When he was clean, we dressed him in linen pants, respecting his request to remain shirtless. Then, just as I suspect my Dad would have wanted, we toasted. We passed around whiskey and each one of us took a few minutes to say what we loved about him. For the next three days, a bottle of whiskey would be on his bedside for anyone to have a final drink with the man. I spent those first hours lying next to him. Crying on his shoulder, I felt his body change from living to dead.

Over the next two days we hosted a vigil. We invited people to come and say goodbye. People mingled on the porch and we shared laughs and tears. At night, I would sit next to his bed and talk to him, saying final goodbyes. I never thought I would appreciate keeping his body in the house, in fact the idea had originally terrified me. However, the benefit of seeing his body drained of life was immense.
After three days, all that was left was bone and his cold flesh, kept that way by putting blocks of dry ice under him which were changed with regularity. That evening we gathered and even my Dad’s physician showed up to pay his respects. Along with close friends and the Death Midwife, my Mother and I covered my Dad’s body in flowers and we placed keepsakes with him. Ceremonially we wrapped his body in the shroud, decorating it with fresh flowers. I toasted him for creating such a wonderful and safe home and for showing me unconditional love.
Then we all grabbed a handle of his shroud and carried his body out of the house. With a final goodbye, we placed his body in the car that would take him to be cremated. We would follow his final wish, combining his ashes with those of his two dogs and spreading them in places that were meaningful to our family.

**The Role of the Caregiver**

In the immediate aftermath of his death I felt a lot of guilt. Five months later in an interview in the Netherlands I would reference my experience by saying:

*They are painful memories but they are part of my experience. It is what motivates me, so future people don’t have to experience it. It’s your death and it’s your choice. If the outcome is the same, you should be supported and you should have your pain managed. It doesn’t have to be like that.*

The emotional labor was one of the biggest portions of work for me. My Dad had never asked me for anything. This request of helping and giving him the death he wanted was daunting. With my Dad, we had established a version of the Ulysses Contract — do what I said before, not what I am telling you now. His requests for water were incongruent with his long-term goals. When we didn’t give him water we were honoring the version of himself before the disease and before the dehydration. It might not stand-up in the court or in the medical community, but it was what he wanted—the few days of suffering were better than years with dementia. He made a choice and I was to help him accomplish it. This obligation took all of me, emotionally, physically and spiritually – but I would have fulfilled any “ask” he made.

When I interviewed a close friend later about this she said, “In Dutch, we would say you were being over-asked. You were being asked to do something that took too much of you.” My
goal was to make this experience as pleasant as possible. I ignored my emotions and charged ahead never slowing down. During my interview with participant #4, she said:

_You locked down your own emotions, took it day by day. You were going 150 mph. There was very little space for you. I could see you struggling to take care of yourself. It was a hard time. I think the whole situation was unrealistically hard. I think you all handled it with such grace. I don’t think it can be done much more gracefully than you all did it. That is because all three of you were in it, he made the choice, and you guys backed him up and made it happen._

As a caregiver, I checked in on my Dad daily and helped structure his day. It was an interaction in which he trusted me to take charge and I left him with his pride. As a family, this brought us together. It was a team effort and something we were all doing. We did the last things on our bucket list, spent time as a family, and prioritized each other. They were two incredibly difficult years that we filled with memories.

Yet amongst all the anguish of implementing his plan, there was also tremendous beauty and gratitude. The ways in which our community cradled us in support through this process was truly incredible. The spirituality that unexpectedly came to the forefront of the experience amazed my Mother and me. Throughout the experience we had opportunities to share love, to say goodbye, to process our experience, and to be surrounded by support.

**DISCUSSION**

I am walking away from this experience believing that we all have a right to a ‘good’ death and that VSED can be that route for many people. However, there is a danger in only telling the stories of VSED for people on hospice, as this creates a great deal of
misunderstanding about the actual process: for example, that VSED receives widespread approval and support in palliative care organizations. Our experience refuted these claims.

While VSED is not formally opposed in many places, its consideration is inconsistent and unclear. We were met with uncertainty and confusion in almost every realm, forcing us to become our own experts in the process and explain VSED to those around us. Those who consider or do VSED deserve a transparent, concise, evidence-based understanding of the process, with effective policies, support, and legal clarity. This means having VSED cases be documented, broadcasted, and discussed. It means changing polices in institutions such as Adult Protective Services, creating a comprehensive VSED protocol for the United States, and integrating VSED into hospice, professional societies, and care facilities.

My Dad’s choice and subsequent death are exemplary of the work that goes into pursuing a ‘good’ death with dementia. It wasn’t just work for my Dad—but also for my Mother and me. He was turning 70 at the time of his diagnosis, and would die before he turned 72. My Dad was best described as kind, open-minded, fair, and a little bit stubborn. Watching his mother die from Alzheimer’s he knew he did not want that for himself or his family. The experience taught me that we need to talk more about death and dying. My hope in telling this story is that it adds complexity to the research and sparks reflection. I also was pursuing answers to my own questions; my Dad’s death wasn’t what we expected, he had gotten the outcome he wanted, but it left me unsettled about the difficult and painful parts we all had to endure.

CONCLUSION

I took our family’s experience as normal, because it was my lived reality. Shopping for fabrics for a death shroud and debating the merits of hosting a vigil made death and dying a part of our daily life. It wasn’t until further reflection and research that I realized that our experience
was far from the norm. When people would ask me later what was the most beautiful part of the process I would answer, “when he died.” With his death came a sense of relief. He had gotten what he wanted.

As a culture and society, we are not having the conversations we need to be having about death and dying. We need to talk about death in physician’s offices, at cocktail parties, with congregations, and in schools. We need to find ways to initiate this conversation and integrate it into everyday life, especially as we are facing a public health crisis with millions of older adults getting dementia and requiring care. The economic, family, and healthcare burdens are mounting (Wimo, 2012). End-of-life decisions for a patient with dementia are multifaceted—but not allowing options for a hastened death pushes people into the shadows.

No death is the same. Even with the best plan things can fall apart quickly, especially at the end of life. No physician, no research, or no medication can guarantee that death and dying come painlessly. I do believe that some deaths and dying’s are better than others—and those better deaths are harder to access with a diagnosis of dementia. My Dad’s VSED succeeded, but not without huge amounts of will. He was exercising the little bit of autonomy he had left. Patients with early-stage dementia deserve better options. Hastened deaths need to be more inclusive of individuals with early-stage dementia. Everyone should have the opportunity to have the death they want, and in that decision, they should not be judged and they should be supported.


Chabot, Boudewijn. (2014). Dignified Dying a Guide, Death at your Bidding. Amsterdam, Netherlands,


Hastening Death by Voluntarily Stopping Eating and Drinking: Clinical, Legal, Ethical, Religious, and Family Perspectives (2016). Conference at Seattle University School of Law, Seattle, WA.


Schwarz, J. (2009). Stopping Eating and Drinking: This is one option for 'decisionally capable' adults who wish to hasten dying. What are the ethical and legal implications for nurses? *The American Journal of Nursing, 109*(9), 52-62.


APPENDIX 1

In-Depth Interview Guide

**Interviewer Instructions:** Copies of the informed consent form should be provided to the participant. Consent will be obtained from all participants. Participants should be provided an opportunity to ask any questions. Verbal agreement to participate should be taped. The following set of questions is a guide. Try to ask all the questions below in the order given, but it is more important to maintain the flow of discussion. Suggested probes have been included.

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### Welcome and Introductions

**Before turning on the recorder, start with the following introductory script:**

*Hi, my name is ____________. Thank you for meeting with me today. As mentioned earlier, I am a researcher and I am trying to learn more about hastening death through Voluntary Stopping Eating and Drinking (VSED), specifically for patients diagnosed with Dementia. I am interested in hearing your opinions, knowledge, and experience. The goal of this project is to contribute to the field of end of life options for patients with dementia and develop a more comprehensive understanding of VSED. We would love to hear your experience and contributions.*

*We are now ready to begin our discussion. During this conversation, I am interested in understanding all of your thoughts, experiences and opinions. I will ask you questions that you are free to answer in any way you wish. There is no right or wrong answer to anything that I ask. Feel free to elaborate on any of your points. If a question is unclear to you, please feel free to ask me to explain it. We are interested in knowing what you think, so please feel free to be frank and share your point of view. It is very important that we hear your opinion. You do not have to answer all the questions. If you want to stop the interview at any time, just tell me and we can stop. The research team may take short sections of what you say and share them with non-study members.*

*I would like to tape record the interview so I don’t miss anything that you say. I will not include your name on any documents. Your answers will be kept confidential.*

*Is it okay if I make an audio recording of our discussion? [Wait for the participant to give verbal consent to taping]*

*I am turning on the recorder now.*

**Before beginning interview questions, please read the following script for the recording:**

*Today is [day of week], [month, day, year] and it is now [time of day]. I am speaking [participant]. Can you confirm for me again, by stating yes or no, that you are willing to participate in the conversation today?*
You are now ready to begin asking the questions outlined below.

In-Depth Interview Questions

General questions:
- We are here today to talk about VSED—Voluntarily Stopping Eating and Drinking. When an individual chooses to hasten their death by ceasing to drink or eat. What is your experience with VSED?
  - Can you tell me a little about those experiences?
- In your experience or experiences—what type of person or patient is choosing VSED? Are there any similar characteristics?
- Have you seen VSED used in the case of dementia?
  - If yes, under what circumstances?
  - If no, do you think it could be used for people with dementia?
- Have you participated in the VSED process for someone with dementia, either personally or professionally?
  - Please tell me a little of your story of witnessing VSED for someone with dementia?
- What are some of the challenges of VSED for patients of Dementia?
- What are common things that derail VSED for patients with Dementia?

Prior to VSED:
- When was this individual diagnosed with dementia?
  - What experience did the patient have with dementia? (Did they have family members or friends with the disease?)
- How did they hear, begin to consider VSED?
- What were the patients motives for VSED?
- What did you know about VSED before starting this process?
- How did you find out information about VSED?
- Did they have any other end-of-life options aside from VSED?
- Did the individual encounter anyone who opposed the decision of VSED? How was it handled?
- What paperwork was done prior to VSED?
  - Can you be specific?
- Was your family physician involved in the VSED process?
  - Why or why not?
  - What was your experience with the medical field pertaining to VSED?
- Why was your experience seeking legal counsel prior to beginning VSED?
- What role does the family play in the VSED process?
- How do you know the correct time to begin VSED?
- Did you use markers? How did you set those markers? What did you use as markers?

VSED Process:
- Where did VSED occur? Was this location suitable for the process?
Support:
- Did you feel well supported?
- What social support did you have?
- What legal support did you have?
- What medical support did you have?
- Where would of you have wished for more support?

Challenges
- What was the most challenging aspect of the VSED process for you?
- What appeared to be the most challenging for the patient?

- What was the most rewarding part of the process?
- Was the family included in the VSED process?
- Was religion or spiritual included in the VSED process?
- How many days did VSED take?
- What additional resources do you wish you had?
- What would you have done differently? Or wish you would have known ahead of time?
- Is there a certain aspect or part of it that re-plays in your mind?
- How have you incorporated or used this experience moving forward? What impact has it had on you life?

Questions specific to Legal Experts:
- Is VSED legal?
- Is VSED legal for patients with dementia?
- How do you determine competency for a patient with dementia to do VSED?
- At what point is that competency no longer valid?
- Can you speak to your perspective on how advanced directives and patient’s autonomy come into interaction during VSED for patients with dementia?
- If a patient with dementia is asking for water during the VSED process are family or caregiving staff required to provide it?
- What would make VSED illegal for a patient with dementia?
- Can an advanced directive be used for VSED, if the patient with dementia no longer remembers the document or why they wanted to use it?
- When is it too late to do VSED for a person with dementia?

Questions specific to Medical Professionals or End-of-Life Caregivers:
- How did you first learn/hear about VSED?
- Please describe your role or experience in the VSED process?
- Please share the role of families in the VSED process? What affect did VSED have on family members?
- How were the symptoms of dehydration/anxiety/etcetera managed?
- Did the patient(s) experience discomfort
  - If yes, what type of discomfort and what actions were taken
- Articles and people talk about the patient “letting go”, does this mean anything to you? If so, what does it look like, how is it experienced?

Questions specific to Academics:
• What research have you done about VSED?
• Have you looked specifically at VSED for patients with dementia or Alzheimer’s?
  o If yes, what have you found.
  o If no, why not?

Future of VSED
• What would you advise anyone or any families considering VSED in the case of dementia?
• If diagnosed with dementia, and knowing what you know, would you pursue VSED?
  o Why or why not?
• Do you think VSED for patients with dementia is commonly used? Do you think it should be more accessible?
  o If so, what could be done to make it more accessible.
  o If not, why?
• What research, resources, or information needs to be developed to make VSED more accessible?

The Netherlands
• Will you please tell me more about your background and your work?
• Talk to me about dementia and dementia services in this country. What does dementia care look like? Are people going into homes? Staying with families? Are dementia patients able to get physician assisted death? With what stipulations? Are they accessing self-euthanasia. Or doing VSED?
• Will you give me an overview about how physician assisted death, self-euthanasia, and VSED all interact within the Netherlands.
  o The end of life decision
  o Legal ramifications
  o Review Committees (RTE)
• What is the difference between physician assisted suicide and euthanasia
  o Do you also need to have a “terminal illness” or be within close to six months of dying?
• What are the legal ramifications of each?
  o Euthanasia with the ramifications of an advanced directive?
• What does referred to an end-of-life clinic mean? How is that different?
• Why are people choosing VSED? The frequency was reported around 2% of deaths – would you think this has increased or remained the same?
• VSED for dementia?
• Does there need to be more autonomy for the individual in the euthanasia practices?
• How do you know when is the right time for someone with dementia? How do you define quality of life? Do you use markers – of guidelines?
• How would you initiate VSED by Advanced Directive?
• VSED in the Netherlands is not considered suicide. It is an exercise of self-determination. Does this mean it doesn’t have any legal ramifications? It is considered natural?
• Who is providing medical support?
• What paperwork is necessary before beginning?
• Does VSED usually happen after Euthanasia requests have been turned down? Does anyone pursue this as the first option?
• Would VSED work in a care facility for someone with dementia? / VSED for dementia has to occur before nursing care?
• Is a care-provider conscious objection to providing VSED care a common occurrence - one of the biggest hurdles in the US is to find a provider
• What are the most typical problems you see arise?
• In which ways does it go well?
• Have you seen people suffer? What is the most difficult VSED case you have seen?
• What is the typical VSED experience?
• If someone during the middle phase of VSED was constantly asking for water, even if previously stated they didn’t want it, would you have to give it to them?
• What do you advise with alcohol and VSED?
• In what direction should we be headed in?
• Can you put me in contact with a family member of someone who did VSED? I want to get a grounding of the experience. Talk about the logistical day to day parts.
• Is it easier to VSED then get medication?
• How do you get self-euthanasia medication here?
• What legal ramifications would that have for family or individual or physician?

Is there anything else you would like to add? Do you have any questions for me before we end our conversation today?