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Alzheimer's: The Right to Nothing?

An honors thesis presented to the
Department of Business Administration,
University at Albany, State University Of New York
in partial fulfillment of the requirements
for graduation with Honors in Business Administration
and
graduation from The Honors College.

Heather Marie Forster

Research Advisor: Professor Joseph Sheehan

May 2018

Abstract

The purpose of this thesis is to shine light on the inequalities in the types of options Alzheimer's patients are afforded and the different decisions they can or cannot make in comparison to other terminal patients. The main argument of this thesis is to include Alzheimer's patients in current Right-to-Die laws by allowing them to consent to this choice of action before they are diagnosed, or in the early stages while they still have the competence to do so. Another aspect of this thesis is to increase the general public's knowledge about Alzheimer's and other dementias in order to generate support for legislation involving Alzheimer's patients. It is imperative that legislation is passed soon, as Alzheimer's patients have started taking matters into their own hands which can be very dangerous and puts not only them, but their loved ones at risk if something were to go wrong. This argument is not intended to allow a patient suffering from severe dementia to suddenly decide they want assisted suicide, but instead to allow a family member or caregiver who knew the patient's wishes, to honor that wish when the time comes no differently than any other terminally ill patient.

Acknowledgments

At this point I'd like to thank my advisor, Professor Joseph Sheehan for helping me understand the legal terminology, proofreading, and supporting me throughout not only this process, but my entire time here at University at Albany. I'd also like to thank Anita Hanson, Dean Hui-Ching Chang, and Susan Maloney for listening to my original idea and helping me improve the topic piece by piece through their wonderful feedback and insight.

Next, I'd like to thank my family, especially my parents and sister Julie for reading and editing, as well as supporting me throughout the entire process. Thank you, Mom, for always starting every phone call this year with "How's your thesis?" and to my Dad for understanding that my thesis wasn't always the reason I was calling home.

And lastly, I'd like to thank those who helped instill in me a passion for Alzheimer's awareness and equality, my grandmother Ruth Forster and Mr. Gordon Thomas. Without the passion you instilled in me to better understand Alzheimer's this thesis would never have been so interesting to me!

THANK YOU!!

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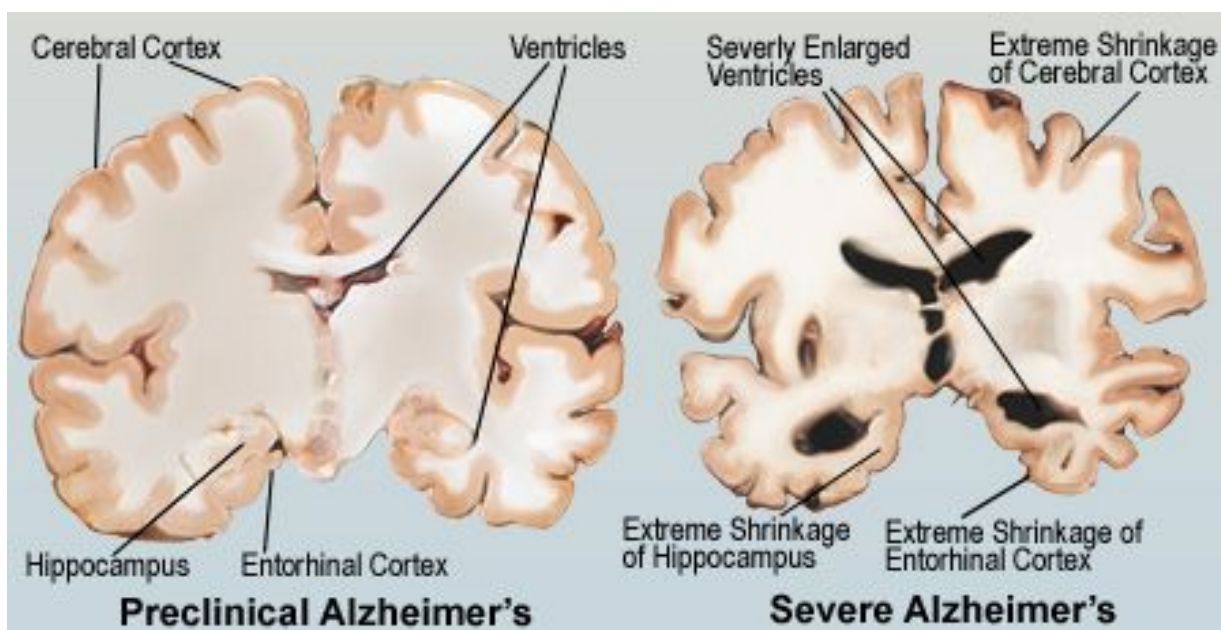
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Introduction:

Alzheimer's disease is a form of dementia that affects a patient's memory, ability to think clearly, and behavior. Symptoms usually develop slowly over years and get progressively worse; eventually becoming severe enough to interfere with daily tasks. There is currently no cure for Alzheimer's and upon diagnosis, the patient will have Alzheimer's until death. This thesis aims to argue the injustice of current legal sanctions excluding Alzheimer's patients from current Right-to-Die Laws, while also drawing light to the Alzheimer's epidemic. This thesis is not intended to support or oppose the right to die, but rather argue the exclusion of Alzheimer's patients in current Right-to-Die laws as a form of inequality, offer up suggestions about how to best include Alzheimer's (and other dementia) patients in these Right-to-Die Laws, and how to best communicate this change to the general public.



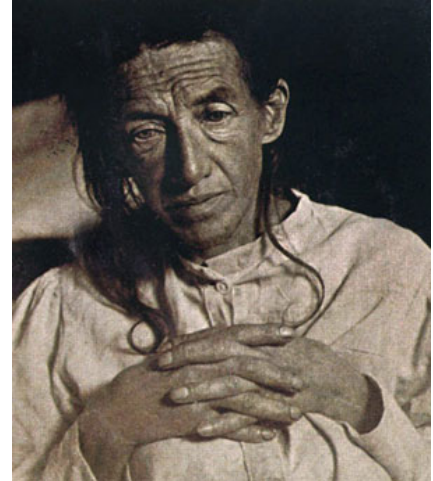
History of Alzheimer's

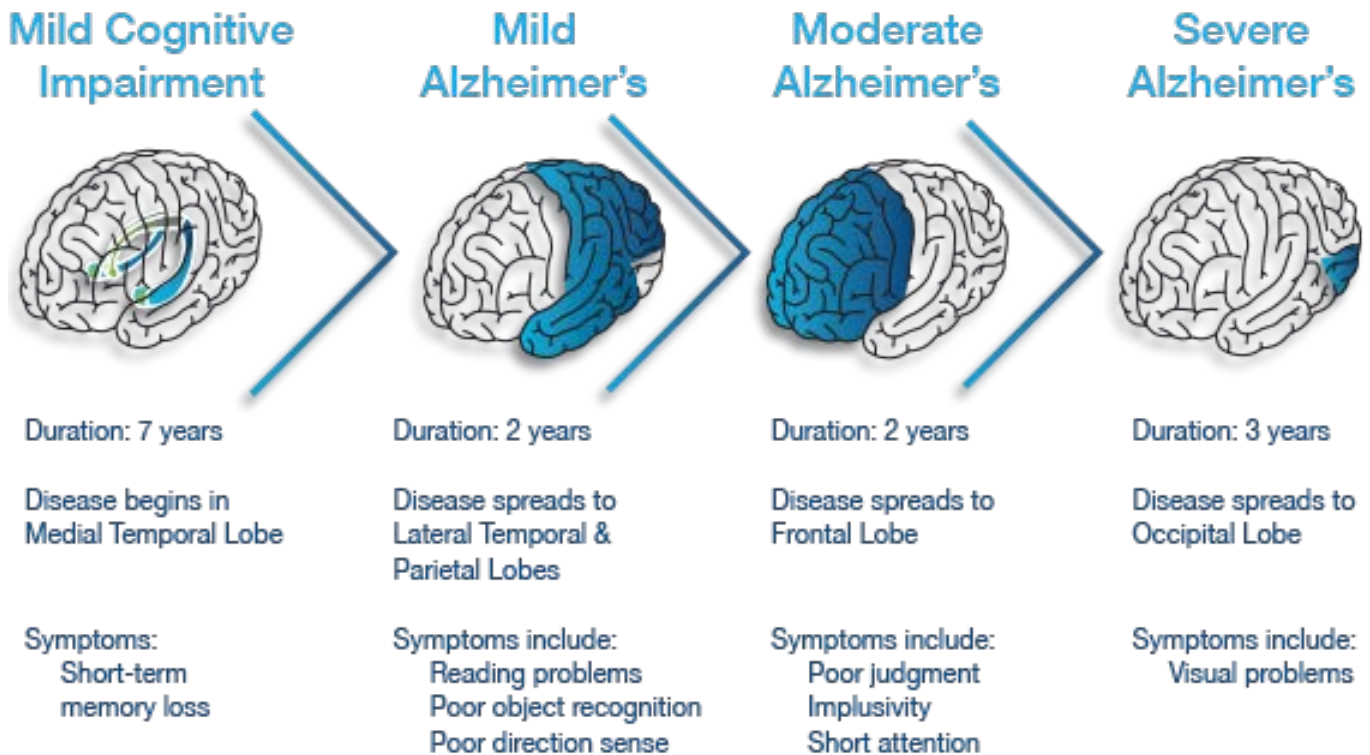
Alzheimer's is currently the sixth leading cause of death in the United States, and may be ranked as high as third, behind heart disease and cancer, for the elderly (65+). Alzheimer's disease has shown a drastic increase with an increase in death of 123% in the past fifteen years and is expected to nearly double in the next fifteen years. Currently 5.7 million Americans suffer from Alzheimer's with nearly 3 million new cases diagnosed each year and these numbers are expected to increase to 14 million American's suffering from Alzheimer's by 2050. Alzheimer's is the most common form of dementia, or the loss of cognitive functions and behavioral abilities that interfere with one's day to day activities. Dementia can range in severity with the simplest stage just slightly affecting a person's functions to the most severe stage, when a person is completely dependent on others to perform basic functions such as remembering to swallow (NIA).

The first case of Alzheimer's was described by Dr. Alois Alzheimer in 1906 when he noticed his patient Auguste D. had a shrinkage in and around the nerve cells in her brain while performing an autopsy on her body. During the last few years of her life she had experienced memory loss, paranoia, and



psychological changes that Dr. Alzheimer's attributed to the shrinkage in and around the nerve cells in her brain describing a "peculiar disease." However, it was not until 1983 that Alzheimer's reached a greater awareness when November was first declared National Alzheimer's Disease Month (Alzheimer's Organization). Since 1983 a lot has transpired in the understanding of how Alzheimer's disease progresses and possible ways to slow the process, but there is still no known way to prevent or cure the disease. Therefore, Alzheimer's disease is chronic, and once diagnosed a patient will suffer with Alzheimer's until the day they die. Currently, Alzheimer's disease is known to have four stages consisting of Stage 1 - mild cognitive impairment, Stage 2- mild Alzheimer's, Stage 3- moderate Alzheimer's, and Stage 4 - severe Alzheimer's. These stages are fully described in the graphic below, although the stage's duration is subject to variation based on each individual patient's progression of Alzheimer's disease.





Understanding my connection to Alzheimer's:

Since I am a graduating senior with a major in Business Administration with Marketing and Management concentrations and an Art minor, I feel that it is best I explain why I've been drawn to this topic and the knowledge I possess in order to allow you, the reader, to have more knowledge of my background and passion for this cause. The reason I chose this topic as my thesis is because of my personal experiences with the disease and those affected by it, as well as my involvement in the causes to help spread awareness and raise money to fund research.

Personal Experience

I first learned about Alzheimer's around 10 years ago when my Grandmother started to lose some aspects of her memory. At first, I did not understand what the problem was, did not old age cause memory problems? While it's true that with old age memory can start to falter, the significance of my grandmother's decline was much more drastic than the "normal" memory loss that comes with old age. Over the years I've seen my grandmother's memory decline and it's been tough to see her try to piece together her life.

The hardest part of this decline was not the fact that my Grandmother no longer remembers all of us, but the look in her eyes when she talks about her brother and asks if he's coming with his wife, my Aunt Bev; only to be reminded he died many years ago. In some cases, family members and friends report their loved ones become an entirely different person after their Alzheimer's progresses, but I am lucky enough to say my grandmother is the same fun-loving grandmother I can remember from my childhood. My grandmother has always been a very organized person and when her memory started to decline she got very emotional about it. Seeing her go through this progression has made me empathize more with Alzheimer's patients, so when I was offered the opportunity to try out for an Alzheimer's All-Star Basketball Classic game in 9th grade, it felt like it was something I needed to do.

Another aspect that draws me to Alzheimer's is the effect it has on loved ones and caregivers. It's very hard to see someone you love decline to a disease that they do not even realize they're suffering from. This change is especially difficult for loved ones turned caregivers.

Simulations

In high school I learned about the Alzheimer's All-Star Basketball Classic, a basketball game that featured the best players on Long Island competing in games, 3-point shooting



contests, and dunk contests all to raise money and awareness for Alzheimer's. At the time, this was just another opportunity for me to play basketball and I already knew a few people suffering from Alzheimer's, so I figured this game represented a good cause and was something I loved to do. In the beginning this event was nothing more than a game to raise money, but as it grew so did my understanding of Alzheimer's and I never could've imagined how much this experience would help shape my life.

This team was not just a basketball team to me, it taught me more about Alzheimer's and how it affects both those suffering with the disease and their loved ones. The fundraiser was started by Gordon Thomas, the son

of John Edward Thomas Sr. a well-known Long Island basketball coach who died due to Alzheimer's (AAB Classic). The first year I was on this team we learned a lot about what Gordon learned from his father's Alzheimer's diagnosis and how it affected the last few years of his life. As the charity game began to grow in popularity over my high school career, Gordon would add new aspects of the program to help us further learn about Alzheimer's disease and what we could do to help. My last year of competition in this event Gordon had a special surprise for me to experience and I never would've guessed how much it would impact my life.

My final year Gordon introduced the Alzheimer's simulation as a part of Awareness Night, where all contestants, sponsors, coaches, and their families got together for a dinner to learn about



Alzheimer's and what the charity game was doing to help the cause. In this simulation I was put into a room and asked to complete five tasks in fifteen minutes. Sounds easy, right? Well, the catch was that you put on a series of devices to simulate the symptoms Alzheimer's patients generally face. These devices consisted of headphones blaring siren noises and hushed voices, goggles that made your vision foggier, shoe and hand inserts to simulate

arthritis, and gloves to reduce your ability to grasp objects. The one thing they could not simulate was the deterioration of my memory and I was a healthy seventeen-year-old, so I thought I'd complete the five tasks no problem. Find the tie, put on the tie, fold five pairs of socks, turn off the stove, and? These were all simple tasks, but what you'll notice is that I only listed four tasks. I listed only four because to this day I still cannot remember the final task I was supposed to complete. What I realized from this simulation was that if a healthy seventeen-year-old cannot complete five simple tasks with only some of the symptoms most Alzheimer's patients face, how on earth could an Alzheimer's patient complete these tasks when they're also dealing with memory problems? This, to me, was the first time I realized that something needed to be done.

The Legal Aspects

Current Right-to-Die Laws

Current Right-to-Die laws are very controversial and are sanctioned by the federal government in the United States, meaning that two patients with the same disease may or may not be able to receive the necessary lethal prescription based on what state they live in or what country they live in. Each of the following states and countries has different qualifications to determine which patients are eligible to receive aid in the dying process. The states and countries that provide the Right-to-Die are:

States

California

Colorado

Hawaii

Montana **(legal by court decision)*

Oregon

Vermont

Washington

Washington D.C. *

Countries

Belgium

Canada

Colombia

England

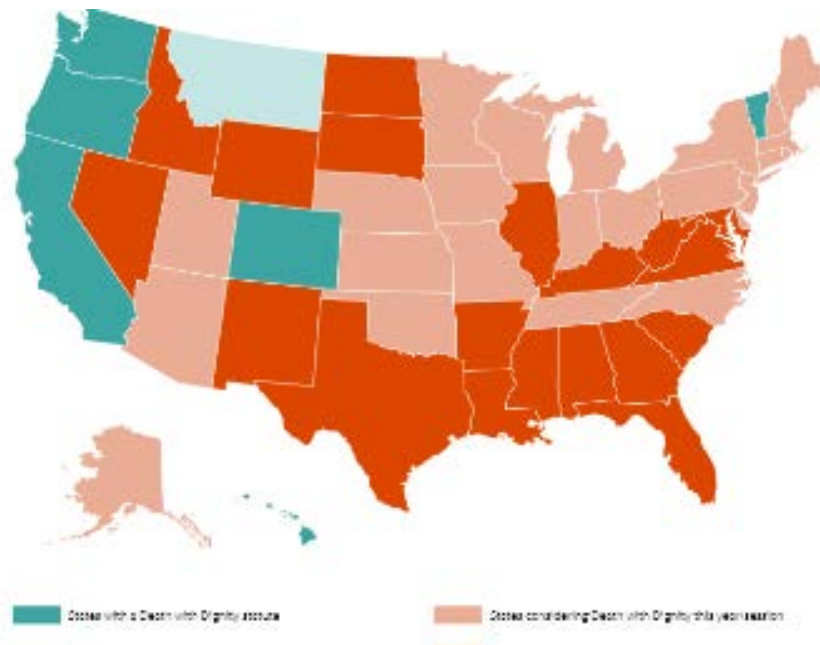
Luxembourg

Switzerland

The Netherlands

Wales

The Right-to-Die laws are still relatively new. Each state/country has their own conditions on who can utilize this right, when they can use it, and how this right can be practiced. Due to these differences, many places require the patient to be a resident of their state/country to qualify for their laws. Other common qualifications are that the patient must be 18 years of age, have a prognosis of 6 months or less, and have made two requests to physicians. The below chart succinctly outlines many of those qualifications.



I. Seven States and DC with Legal Physician-Assisted Suicide

State	Date Passed	How Passed (Yes Vote)	Residency Required?	Minimum Age	# of Months Until Expected Death	# of Requests to Physician
1. California	Sep. 11, 2015	ABX2-15 <i>End of Life Option Act</i>	Yes	18	Six or less	Two oral (at least 15 days apart) and one written
2. Colorado	Nov. 8, 2016	Proposition 106, <i>End of Life Options Act</i> (65%)	Yes	18	Six or less	Two oral (at least 15 days apart) and one written
3. DC	Oct. 5, 2016	B21-0038 <i>Death with Dignity Act of 2016</i> (3-2)	Yes	18	Six or less	Two oral (at least 15 days apart) and one written
4. Hawaii	Apr. 5, 2018	HB 2739, <i>Hawai'i Our Care, Our Choice Act</i>	Yes	18	Six or less	Two oral (at least 20 days apart) and one written
5. Montana	Dec. 31, 2009	Montana Supreme Court in <i>Baxter v. Montana</i> (5-4)	Yes	*	*	*
6. Oregon	Nov. 8, 1994	Ballot Measure 16 (51%)	Yes	18	Six or less	Two oral (at least 15 days apart) and one written
7. Vermont	May 20, 2013	Act 39 (Bill S.77 "End of Life Choices")	Yes	18	Six or less	Two oral (at least 15 days apart) and one written
8. Washington	Nov. 4, 2008	Initiative 1000 (58%)	Yes	18	Six or less	Two oral (at least 15 days apart) and one written

Alzheimer's and other Dementia Patients

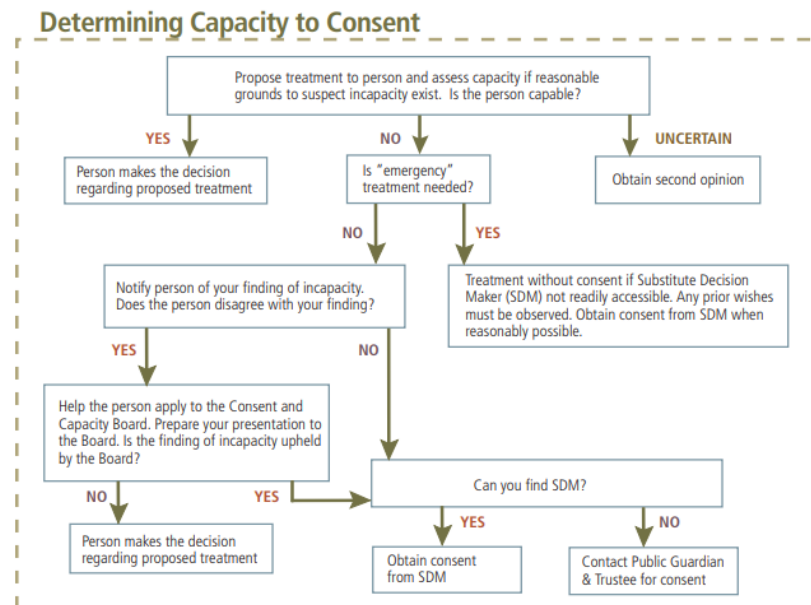
Of the above states with legal physician-assisted suicide, none of them allow patients suffering from Alzheimer's and other dementias to practice the Right-to-Die for various reasons. Of the above countries, only three (Belgium, Luxembourg, and the Netherlands) allow patients with Alzheimer's and other dementias the right to die (The Globe and Mail). These three countries are the only places in the entire world that allow patients with Alzheimer's the right to "death with dignity" as many dementia patients and caretakers refer to it. Despite the fact that only three countries legally allow Alzheimer's patients the Right-to-Die, there are many instances of growing support for dementia patients to be included in the Right-to-Die laws. For example, a recent Canadian Health report showcases that 80% of Canadians believe that Right-to-Die laws should include dementia patients, as long as the guidelines about when a patient can practice this right become more defined to ensure that nothing takes place against the patient's wishes. One method of accomplishing this would be a statutory provision giving patients the ability to "early consent", meaning that dementia patients would have the ability to make their wishes clear before they are diagnosed, or even in the early stages of dementia, an option which will be discussed in further detail later in the *Proposed Solutions* section (Death with Dignity Org , Assited Suicide Org)

Capacity to Consent

Capacity to consent is generally defined as the degree to which a person is able to fully understand the choices and the ramifications of those choices they make. There are many varying definitions of what it means to have the capacity to consent, and each definition is different than those used by other doctors. The ethics guidebook of the UK defines capacity to consent for a competent person as someone who is fully informed with reasonable care and skill and possesses the following skills and knowledge:

- 1) Having the capacity to make a choice about a course of action
- 2) Knowing the risks, benefits, and alternatives
- 3) Understand that consent is voluntary and requires continuing permissions

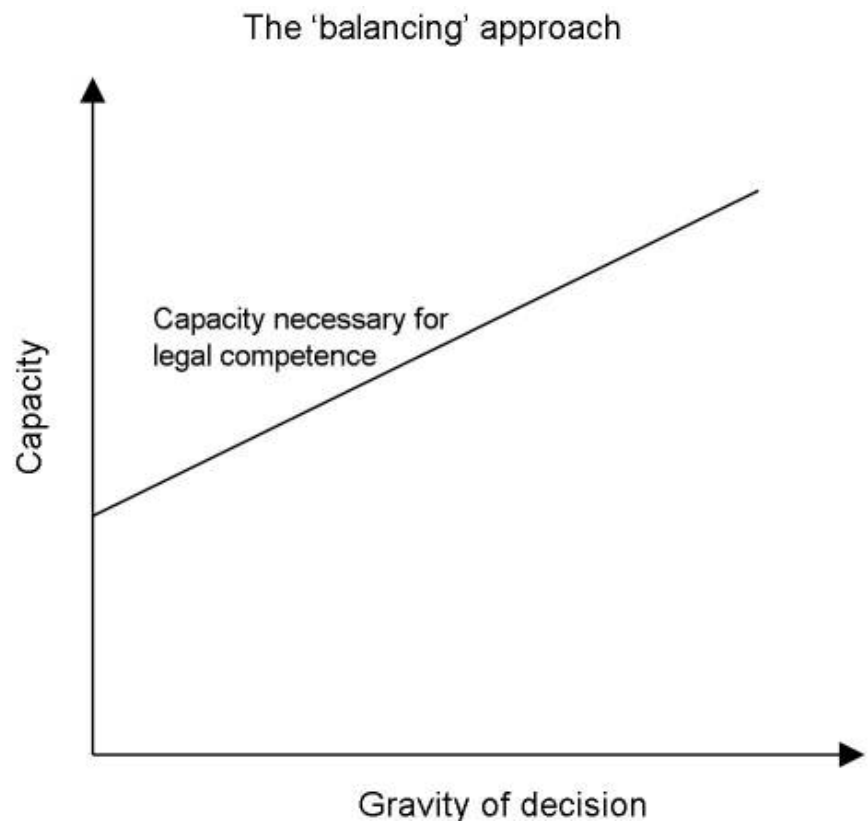
- 4) Understand at any time they can withdraw consent (Ethics Guidebook)



Reprinted with permission from the Mini Task Force of Capacity Issues, The Dementia Network of Ottawa

Another way capacity to consent to treatment is determined is by determining if one is able to understand and appreciate the choices one must make in accordance with the benefits and risks of the decision. In this definition, to understand is defined as the “cognitive ability to remember general information given regarding the proposed treatment” and appreciate means that the person has the ability to weigh information in context to life circumstances. Additionally, the person must be able to reason and make decisions based on their knowledge of the decision’s risks, alternatives, and perceived benefits (CSPO). Similarly, another way medical professionals define capacity to consent is through the person’s ability to decipher the gravity of the situation and the choice they are about to make. As

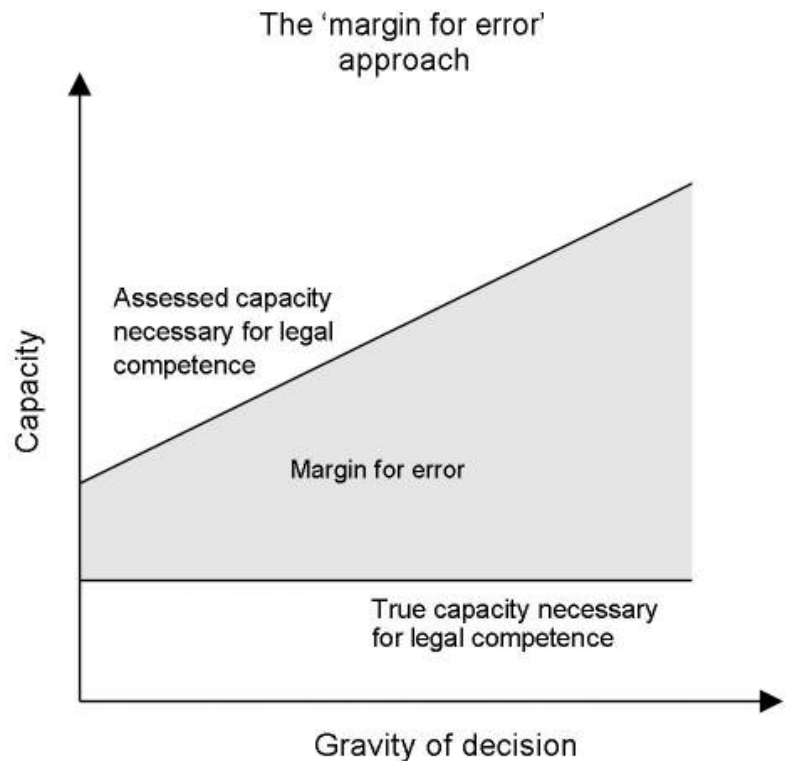
exemplified by the graph (right) the capacity a medical professional assesses for legal competence increases when the gravity of the decisions becomes larger. However, the same study determined that there



is actually no basis for the increase. According to the margin-for-error approach, there is a greater need for medical professionals to be certain that patients possess the true "capacity" when consequences are substantial, which causes the increase.

According to this theory, the true capacity to consent is a

constant, but medical professionals believe it increases with gravity of decisions because they have an increased desire to be certain of the patient's capacity. Therefore, when decisions have more gravity and go against the doctor's recommendations, medical professionals will begin to look into the patient's capacity to consent more, until they can prove the patient possesses the necessary capacity. Next, after determining the patient has the capacity to consent, the doctor should accept the patients' choice (NCBI). Interestingly, in the margin-for-error approach if a patient has the capacity for legal competence in one decision, then they have the capacity for legal competence in every decision, regardless of the decisions gravity. So, because Alzheimer's patients are considered capable to make



legal decisions such as creating their advanced directives and choosing their health care surrogate, they would also be considered to have the capacity to make decisions such as Right-to-Die.

As you can see, there is no one correct answer that defines the capacity to consent because every person is different and also because medical professionals may overestimate or underestimate a patient's capacity based on their own personal opinions and need to be sure the patient has the necessary competence to make grave decisions regarding their health care. Determining capacity to consent is a very subjective measure as no professional can truly measure the capacity of a patient's mind, and therefore medical professionals tend to underestimate the capabilities of patients.

Another reason capacity to consent is hard for doctors to measure is because these decisions can be very tough, or even controversial (which is the case for many Right-to-Die patients). There was a study done by medical writers in which they discovered that when the gravity of the situation was extreme, the doctors tended to allow their personal opinions about the options to outweigh their patient's wishes, regardless of the patient's capacity to consent (NCBI).

The Controversy

Arguments for Change

Right-to-Die laws were first passed in Oregon in the year 1994. However, the campaign for the Right-to-Die movement started in 1975, when Derek Humphry helped his wife take her own life during her struggle with breast cancer. Five years later, Humphry founded the Hemlock Society which was the first Right-to-Die organization in the United States. Ten years later (1990) in Portland Oregon Dr. Jack Kevorkian, now commonly referred to as "Dr. Death," was present at the death of a 54-year-old Alzheimer's patient, Janet Adkins. Just four years later, Oregon became the first state to legalize doctor-assisted suicide and then reaffirmed that decision in 1997 and again in 2006. Interestingly enough, the first patient to die through physician assisted suicide was an Alzheimer's patient. However, Oregon and every other state that has adopted Right-to-Die laws rejects Alzheimer's patients through the "capacity to consent" clause of the law (PBS).

Similarly, a Canadian health report labeled dementia as a terminal condition and stated it caused unjust suffering. In that same report, it stated that about 80% of Canadians believed dementia patients should be included in Right-to-Die laws. However, dementia patients have no such rights and the report goes on to state that despite the support from the general population and the definition of dementia as a terminal illness, dementia

patients should not qualify for euthanasia practices (World Alzheimer's Report 2016). However, the same study later claims that;

"Most would agree that people with Dementia should be encouraged and enabled to exercise their autonomy regarding options for future care, consistent with their values and preferences. Early discussions with family carers[sic] that acknowledge the likely loss of decisionmaking[sic] capacity and their increasing role as proxy decision-makers would be likely to assist carers[sic] in assuming this role, and enhance their ability to judge what might be in the person with Dementia's best interests. The empowerment of people with Dementia needs to be stressed, to emphasise[sic] that the palliative care agenda is focused, first and foremost, upon their choices, and their quality of life, rather than cost savings."

World Alzheimer's Report 2016

Therefore, it is hard to distinguish what decisions dementia patients have the capacity to make and what decisions they do not have the capacity to make. As soon as a person is diagnosed with dementia they are considered incapable of making decisions for the Right-to-Die laws, but are encouraged to practice autonomy in decisions about their health care proxy, what happens to their money, where they want to live, and to clarify their wishes to others incase they are no longer able to make their own decisions as the

disease progresses. This is very interesting because on one hand, these patients are considered to be incapable of consenting, but on the other hand, these same patients are encouraged to write down all of their wishes and practice autonomy until they no longer can. This provokes the question: Why are the patients competent enough for one life-altering decision, but not another?

Arguments against

Just as there are arguments for Right-to-Die laws to change, there are arguments against the inclusion of dementia patients in Right-to-Die and Right-to-Die laws in general. Some of these arguments stem from the oaths that doctors and nurses take when they first begin to practice. This argument believes that assisted-suicide as a whole is a violation of medical ethics. The American Nurses Association (ANA) states that a, "nurse must not act deliberately to end a person's life." Similarly, while taking the Hippocratic Oath a doctor states that they will, "give no deadly medicine to anyone if asked, nor suggest any such counsel." However, as I mentioned in the introduction, this thesis does not aim to agree with or disagree with the Right-to-Die, but instead to argue against the exclusion of Alzheimer's patients. Therefore, the arguments against including Alzheimer's and other dementias are more pertinent.

The main argument against the inclusion of dementia patients is that they do not have the competence, or mental capacity, to make decisions due to the side effects of the disease. This argument believes that as time goes on, dementia patients are less capable of making their own decisions and could therefore be taken advantage of and forced into an early death by caregivers or family members. However, the solutions I am suggesting would make it very difficult for this right to be abused, which will be discussed more in depth later on in the section entitled, *Proposed Solutions*.

Why we must act now

Stop Eating and Drinking (SED) & Self-deliverance

Now, more than ever, it is necessary that we act to create a law that includes dementia patients in order to ensure that they are afforded the same rights as every other terminally ill patient. The barriers to this inclusion are evident and it is necessary that the inclusion of dementia patients in these laws do not put dementia patients at risk of being taken advantage of. However, it is quite apparent that those suffering from Alzheimer's, and other dementias, who wish to utilize their right to die have found loopholes when it came "their time."

The most common 'loophole' that Alzheimer's patient use is the process known as SED, or to stop eating and drinking. In this process, patients can deny treatments and refuse to eat or drink. This decision will

typically result in a harmless death within 10-14 days and can be administered by the patient themselves, or with the help of a caregiver. Most patients utilize the SED method because it is the least messy and generally painless because after 5-8 days patients reach a certain level of delirium due to dehydration. Another benefit of the SED method is that it invokes bodily integrity, self-determination, and dignity within the dying process, as opposed to other, more gruesome examples of "self-deliverance." Whether through SED or other methods, it has become increasingly more practiced and acceptable for patients to take matters into their own hands because they are not included in Right-to-Die laws. However, by not involving Alzheimer's patients in these rights, the risk of them suffering greater tragedies is even more prevalent. For example, an Alzheimer's patient who does not want to reach a point where they can no longer remember who they are has several options when it comes to their choice in how they die, few of which are considered to be death with dignity. These 'choices' consist of more gruesome acts (such as cutting, hanging, gunshots, etc....) and less effective acts that could result in the patient surviving and dealing with the after effects of a failed "suicide" attempt.

Stories of Self-deliverance

Throughout my research, I learned a lot about the symptoms of Alzheimer's and the legality behind Right-to-Die laws, but the information that really solidified the need to include Alzheimer's and other dementia patients in Right-to-Die legislation were the journals and memoirs written by Alzheimer's patients and their family members. These stories taught me more about the actual experience one goes through and the feeling of being stuck in a life that is no longer their own, with no way out and some choosing to practice their own self-deliverance. Personally, I could not imagine choosing to end my life so at first, I was hesitant about the Right-to-Die. However, after learning about the injustices done to Alzheimer's and other dementia patients and the pain they can go through, I understood why there was a fight for this right to include dementia patients.

The first story I read was by Norman L. Cantor and was entitled, "My Plan to Avoid the Ravages of Extreme Dementia." I just happened to stumble across it last year when writing a mock grant proposal on Alzheimer's for TPOS 272, or Health and Human Rights. In this article, Norman Cantor discusses why he wants to avoid the extreme stages of dementia, the possible options for his self-deliverance and why each of them is not a good choice, his choice for self-deliverance and why, and when he intends to complete this. The actual story itself was a very hard read

because he is very matter-of-fact when discussing his life and plan for death (My Plan to Avoid the Ravages of Extreme Dementia).

Next, I read a story entitled "The Last Day of Her Life" which was the story about Sandy Bem, her life, her disease, her family, and ultimately her death. Sandy Bem was a Cornell psychology professor who came across her Alzheimer's through a self-diagnostic test while watching an HBO documentary, *The Alzheimer's Project*. Sandy Bem kept a journal of her struggle with Alzheimer's and

as the time goes on her mental descent becomes more apparent. In the beginning stages of her Alzheimer's, Sandy writes about her thoughts and feelings towards Alzheimer's and her imminent mental decline, mentioning "What I



want, is to die on my own timetable and in my own nonviolent way" and that she wanted "to live for as long as I continue to be myself." The most thought-provoking thing that Sandy shared was that it is, "extraordinarily difficult for one's body to die in tandem with the death of one's self (*The Last Day of Her Life*). In terms of the Right-to-Die, this was an argument I found

very compelling because while a patient might not have a 6-month prognosis physically, in 6 months their mind will be nothing like what it was before and eventually the person you see in front of you is an entirely different person than the one you originally knew. This assertion was proven through Sandy's journal because in the beginning stages of Alzheimer's she is intelligent and analytical, but towards the end she does not remember simple things, like how to spell her own daughter's name (NY Times). In the end, Sandy chose to end her life with the help and support of her family. However, if Sandy had not had the help of her ex-husband, it is likely she would've had to end her life a lot earlier than necessary, but because her family knew and respected her wishes they were able to allow her to live longer and then help her remember her old self's wishes when the time came. This story gave me hope that a Right-to-Die law including Alzheimer's and other dementia patients could exist without taking advantage of the patient.

Proposed Solutions

Pre-consent

Perhaps the biggest argument in opposition to the inclusion of Alzheimer's patients in Right-to-Die laws is that the right would be abused by family members and caregivers. One way to be sure this does not happen is by allowing Alzheimer's patients to express their wishes either before or in the early stages of their Alzheimer's. Just because a patient expresses these

rights, it does not mean they have to follow through on these wishes if their “new self” does not have the same intentions. For example, in the story of Sandy Bem, her family helped her carry out her wishes because that is what the old Sandy wanted. However, her family never made her do anything, but instead informed her of her old wishes and provided her the information to carry out her plan if that was what she still wished to do. This story exemplifies that Alzheimer’s can be included in the Right-to-Die laws without the patient being taken advantage of. Moreover, Alzheimer’s patients are included in Belgium, Luxembourg, and the Netherlands’ Right-to-Die laws through a process of early consent. In most cases, the doctors never actually perform euthanasia on these patients because their “new self” does not know about their previous wishes and does not wish to end their life. By creating an option for Alzheimer’s patients to make their wishes known beforehand, we provide them comfort knowing they will die on their own terms. However, with the changes in their mind also comes a change in their personality and therefore they may no longer have the same wishes. In the case of Sandy Bem, she believed so strongly in dying before dementia reached her fully that she found a way to do that without the help of doctors and so have other Alzheimer’s patients, but these alternative methods can be costly and dangerous. By excluding dementia patients from this right, we are not stopping them from deciding when and how they die, but we are making them suffer and take riskier actions.

As long as a patient makes their wishes known before suffering to the point of becoming a whole new person, I personally see no reason why they are not afforded the same rights as everyone else. An Alzheimer's patient struggling mentally should be treated no different than a sick cancer patient wasting away in a hospital. The main argument against the inclusion of dementia patients in Right-to-Die laws is that they will be taken advantage of. However, is this not true with every terminally ill patient? An old man surviving only by machine is taken off by the order of his wife, but no one suggests that she took advantage of the situation.



My grandfather suffered from terminal cancer at the end of his life and my grandmother knew his wishes. As my grandfather was preparing for a major surgery, he made a deal with my grandmother that she would take him off life support if he did not recover and become self-sufficient after surgery. After undergoing surgery and failing to recover and with my grandmother hesitant, my grandfather used an alphabet board to communicate the message, "What about the deal we made?" His reminder gave my grandmother the courage to have his wishes carried out and he was taken off the machine a day later with the doctor's approval.

Interestingly, my grandmother will never have a choice in her dying process because she has a form of dementia. I am not sure if my grandmother would be a proponent of the Right-to-Die or not, but unlike a cancer patient she does not have the option and that is wrong.

Hardly ever does someone want to watch their loved one die, so the argument that patients would be taken advantage of is hard to believe. In fact, the stories of patients taking their own lives are riddled with familial struggles of children trying to convince their parents that this is not what they truly want. In the story of Sandy Bem, her daughter Emily believed that her father was wrong for supporting Sandy in this decision. However, Sandy stood by her decision and as her decline worsened, Emily began to understand that her mother was gone. Emily did not support her mother's decision at first, but seeing her mother change into a completely different

person made her realize that the mother she had grown up with was already dead. Emily and her family did not force Sandy into completing her wishes, but when the time came they reminded her of what her former self wanted and asked what she wanted to do. Sandy remembered planning out how she would die and decided that she wanted to follow through with her original plan, but at no point was she pressured. This story is a big reason why I believe Alzheimer's patients can be included in Right-to-Die laws without being taken advantage of.

Eliminate 6-month prognosis

One of the proposed solutions I have to improve the regulations behind Right-to-Die legislation is to adjust the time constraint it is based on. Current Right-to-Die laws require a patient to have a prognosis, from at least two doctors of less than six months to live to qualify for the lethal prescription. However, there are many problems associated with this time frame because it requires patients with terminal illnesses to suffer more than they should need to.

Steven Hawking was diagnosed with Lou Gehrig's disease at the age of 21 and was told he would have 2-3 years to live. However, Mr. Hawking ended up living 55 years after that initial diagnosis, 52 years more than doctors believed he had left, and 45 more years than 95% of patients diagnosed with Lou Gehrig's disease. Based on current Right-to-Die laws,

Mr. Hawking would have been allowed to take a lethal dosage at the age of 23 or 24, but he did not believe in the idea of physician assisted suicide, stating it would be "a great mistake (The Guardian)." As time went on, Mr. Hawking began to understand and even promote the use of physician assisted suicide. Mr. Hawking never wanted to go through this himself, but he believed that this would help many people end their unjust suffering stating:

"I think those who have a terminal illness and are in great pain should have the right to choose to end their lives and those that help them should be free from prosecution. We don't let animals suffer, so why humans?"

In accordance with Mr. Hawking's quote above, I looked up laws about when you can put down a pet in different countries. To my surprise, I found very little statutory law regarding euthanasia for pets all over the world, and I found there are many cases where doctors are employed to put down perfectly healthy pets simply because it is more convenient for the owner (The Globe and Mail). I had never thought about the comparisons between putting down an animal and euthanasia for terminally ill patients until I read Mr. Hawking's quote, and I noticed how drastically different they are. I am not arguing that a dog's life has the same value as its owner's life, but I think this is a really good example of why Right-to-Die legislation needs work.

For example, my first dog Abby could not even stand up on her own during the last week of her life. My parents chose to put Abby down because we could all see the pain she was going through simply to move and my parents believed it was more humane to end her suffering. Now, let's pretend that Abby was actually a woman suffering from a terminal illness. The average human lifespan is 79 years, and six months of that time is equivalent to about one month of the 10-13-year lifespan of a dog. Based on current Right-to-Die laws, Abby would not have qualified for euthanasia. She could not move and she could not eat or drink on her own, but she would not qualify for the Right-to-Die because she could have technically survived more than one month (the equivalent time for a dog's lifespan based on six months of a human's average lifespan) if we had put her on a feeding tube.

In terms of Alzheimer's and other dementias, this 6-month prognosis is harder to identify in patients and would likely allow the disease to take its full effect. Most patients of Alzheimer's report differences in their mental deterioration and their bodily deterioration, so many might think they have six months of their "self" left when their body actually has years to live. This concept was best explained by Sandy Bem, a profound mind, as she wrote about the effect Alzheimer's had on her mind, which she felt was an essential part of her being. In these writings Bem stated that when suffering with Alzheimer's it is "extraordinarily difficult for one's body to die in tandem

with the death of one's self" and that she wanted to live only for as long as she continued to be herself.

Another problem associated with this six-month time frame is that it can be very hard to determine how much time a person has left to live. Requiring two doctors to agree to it could make it very difficult to qualify for the lethal prescription. In fact, prognosticating is one of the most challenging tasks a doctor must face throughout their career, and it is almost impossible for doctors to provide an accurate prognosis unless the patient is clearly days or weeks from dying. Another reason doctors are often off in their prognosis is because they tend to be optimistic about their patient's rate of survival and overestimate their life expectancy. This can occur because doctors are sometimes fearful about being wrong, are sometimes not so well informed, and because they are sometimes concerned about the patient's emotional well-being and would rather give their patient hope of a whole year left rather than telling a patient they only have 6-8 months to live when the doctor does not really know for sure. In one case study, doctors made survival predictions for 468 patients in hospice programs. Of the 468 predictions, 20% were accurate and 63% had been overestimated. Another study showed that doctors predicted a median of 90 days left for patients in hospice care, when in actuality the median was 24 days. As these case studies show, it is very common for doctors to overestimate the time a patient has left by a factor of three to five-fold (NY Times).

These scenarios illustrate what is wrong with the six-month time frame for current Right-to-Die laws. Euthanasia is meant to prevent unjust suffering, but by making patients wait until they have a prognosis of six months we risk patients suffering for months or even years until two doctors deem they have less than six months to live. Also, most important to this argument is that these prognoses are often overestimated by a factor of three to five-fold and could therefore be taking a patient out of consideration for the Right-to-Die choice.

Other areas for change

There are more changes necessary for Alzheimer's and other dementia patients than just changes in the Right-to-Die laws. For example, a person who has Alzheimer's should be on a list that regulates how businesses are able to solicit them. Some dementia patients like to live on their own for as long as they safely can, as was my grandmother's wishes. Sadly, this puts them at risk of being taken advantage of. My dad and his siblings finally decided to move my grandmother out of her home when my grandmother started letting strangers enter her house who claimed to be mold inspectors she had hired before. She paid multiple people to inspect her home for mold in the last month alone. Patients suffering with dementia are already going through enough, and they should not be subject to being taken advantage of.

Alzheimer's and other dementias are also in need of improved treatments and a possible cure for the disease. Currently, there are no medications proven to be affective that slow or stop the damage done to the patient's neurons. As for non-pharmacologic therapies, some show promise but additional research is needed (2016 Alzheimer's disease Facts and Figures).

Marketing

Including Alzheimer's patients in Right-to-Die legislation is a very controversial idea and there are bound to be problems in marketing this change. As a Marketing major I've learned about a lot of ways to reach your audience and I believe I can use that knowledge to help frame the inclusion of Alzheimer's patients in Right-to-Die laws. In order to gain governmental attention for a campaign to include Alzheimer's and other dementia patients, it is imperative that the campaign gain support from voters. One way I believe this can be done is by allowing people to walk in the shoes of an Alzheimer's patient. This can be done through simulations, videogames, social media marketing, and commercials seeking support to start a campaign and lobby for change.

Social Media Posts

While completing my research, I connected most with the stories of Alzheimer's patients and their families. Many of these stories would make for

very interesting blog posts and a social media campaign. A social media campaign could gain a lot of backing by sharing short clips of these emotional stories and allowing the general public to have more access to the pain caused by Alzheimer's. Another possible way to connect with people is through pictures that contain clues and the viewer has to piece together these clues to figure out the life story of an Alzheimer's patient.



Simulations & Video Games

One of the best ways to understand what others are going through is by putting yourself in the same/a similar situation. As I mentioned before, I once went through an Alzheimer's simulation which forever changed the way I view the disease and its effect on those diagnosed. The population of patients with Alzheimer's and other dementias has increased drastically over

the last fifteen years which means that it is likely a majority of the population has some understanding of the disease and its effect on people. However, if not, there are simulations available to allow people to go through what Alzheimer's and other dementia patients go through on a regular basis. These simulations consist of hands-on activities like the one I took in high school, as well as video games and documentaries. Forget-Me-Knot is a new video game created by Alexander Tarvet designed to increase dementia awareness. The game works by placing a character into a room, in which they must discover clues to piece together an understanding of their environment, their past, and their identity (Crisis Prevention Blog). This game is especially useful for medical professionals working with Alzheimer's patients in order to give them a better understanding of how it may feel for the patient to wake up in a strange room.



Conclusion

It does not appear there will be a cure for Alzheimer's disease and other dementias anytime soon. In fact, there is currently no understanding of what complex series of occurrences triggers dementia, or how to treat it. There are some medicines that might reduce various side effects, but they only last for so long. Whether or not you support the Right-to-Die I urge you to support the addition of Alzheimer's and other dementia patients. Over the years, I've learned a lot about Alzheimer's disease and even "experienced" it first hand, so I feel that these patients should be eligible to practice the Right-to-Die because not only do these diseases effect a patient's body, but also their mind and their entire personality. It is said that the person going to get diagnosed for Alzheimer's is not the same one coming out, which is due to the drastic effects the disease has on the patient's personality and the rights patients no longer have because they do not have the "capacity" to consent.

Alzheimer's is growing and is currently the sixth leading cause of death in the United States. Alzheimer's is also predicted to grow by an average of 44% in the United States by 2025, with some states reaching up to a 127% increase (see chart on page 41). With no ability to cure it in the near future likely, it is imperative that we make this process as comfortable as possible and provide patients with the proper resources and framework to make their own decisions regarding their dying process as safe as possible. With the

right legislation, we can give Alzheimer's patient the ability to live their life the way they want to be remembered and allow them to live longer knowing their wishes will be honored, instead of them having to utilize the "death with dignity" process too soon.

Lastly, Alzheimer's is a disease that affects us all in some way or another, and with the rate at which it's growing, it will be more and more likely to affect you personally than ever before. I believe that the death of one's self should be in tandem with the death of one's body, if that is what the patient wishes for. Personally, I don't think I would ever consider using my Right-to-Die, but that doesn't mean there aren't people out there who would. Alzheimer's isn't just one death, it's several little deaths along the way that eventually end in the patient's actual physical death. To put it simply, I believe we should allow Alzheimer's and other dementia patients the ability to minimize the number of deaths they go through in order to maximize the value of the life and legacy they leave behind.

State-by-state growth of Alzheimer’s disease (2000 – 2025)

State	Total 2000	Total 2025	% Increase
Alabama	84,000	110,000	31%
Alaska	3,400	7,700	126%
Arizona	78,000	130,000	67%
Arkansas	56,000	76,000	36%
California	440,000	660,000	50%
Colorado	49,000	110,000	124%
Connecticut	68,000	76,000	12%
Delaware	12,000	16,000	33%
District of Columbia	10,000	10,000	0%
Florida	360,000	590,000	64%
Georgia	110,000	160,000	45%
Hawaii	23,000	34,000	48%
Idaho	19,000	38,000	100%

State	Total 2000	Total 2025	% Increase
New Jersey	150,000	170,000	13%
New Mexico	27,000	43,000	59%
New York	330,000	350,000	6%
North Carolina	130,000	211,000	62%
North Dakota	16,000	20,000	25%
Ohio	200,000	250,000	25%
Oklahoma	62,000	96,000	55%
Oregon	57,000	110,000	93%
Pennsylvania	280,000	280,000	0%
Rhode Island	24,000	24,000	0%
South Carolina	67,000	100,000	49%
South Dakota	17,000	21,000	24%
Tennessee	100,000	140,000	40%

Illinois	210,000	239,000	14%
Indiana	100,000	130,000	30%
Iowa	65,000	77,000	18%
Kansas	50,000	62,000	24%
Kentucky	74,000	97,000	31%
Louisiana	73,000	100,000	37%
Maine	25,000	28,000	12%
Maryland	78,000	100,000	28%
Massachusetts	120,000	140,000	17%
Michigan	170,000	190,000	12%
Minnesota	88,000	110,000	25%
Mississippi	51,000	65,000	27%
Missouri	110,000	130,000	18%
Montana	16,000	29,000	81%
Nebraska	33,000	44,000	33%
Nevada	21,000	42,000	100%
New Hampshire	19,000	26,000	37%

Texas	270,000	470,000	74%
Utah	22,000	50,000	127%
Vermont	10,000	13,000	30%
Virginia	100,000	160,000	60%
Washington	83,000	150,000	81%
West Virginia	40,000	50,000	25%
Wisconsin	100,000	130,000	30%
Wyoming	7,000	15,000	114%

For more information, please visit www.alz.org or call 1.800.272.3900.

REFERENCES

- "#AABClassic." *Alzheimer's All-Star Basketball Classic*,
www.aabclassic.org/about.html.
- "2017 ALZHEIMER'S DISEASE FACTS AND FIGURES." *Alz.org*,
www.alz.org/documents_custom/2017-facts-and-figures.pdf.
- Assisted Suicide Laws Around the World - Assisted Suicide*,
www.assistedsuicide.org/suicide_laws.html.
- "A Dignified Death for Dementia Patients: Who Makes That Call?" *The Globe and Mail*, 25 Mar. 2017, www.theglobeandmail.com/opinion/a-dignified-death-for-dementia-patients-who-makes-that-call/article28760956/.
- "Alzheimer's & Brain Research Milestones | Research Center." *Alzheimer's Association*,
www.alz.org/research/science/major_milestones_in_alzheimers.asp.
- "Alzheimer's Disease Fact Sheet." *National Institute on Aging*, U.S. Department of Health and Human Services,
www.nia.nih.gov/health/alzheimers-disease-fact-sheet.
- "Alzheimer's Disease Growth: U.S. Will See Average 44 Percent Increase in Alzheimer's Disease by 2025 ." *Alz.org*, 2004,
www.alz.org/alzwa/documents/alzwa_resource_ad_fs_ad_state_growth_stats.pdf.
- Boseley, Sarah. "Professor Stephen Hawking Backs Right to Die for the Terminally Ill." *The Guardian*, Guardian News and Media, 17 Sept. 2013, www.theguardian.com/science/2013/sep/17/stephen-hawking-right-to-die.
- Brody, Jane E. "Terminal Illness - Predicting Life Expectancy." *The New York Times*, The New York Times, 6 Mar. 2007,
www.nytimes.com/2007/03/06/health/06mbrody.html.
- Buchanan, Alec. "Mental Capacity, Legal Competence and Consent to Treatment." *Journal of the Royal Society of Medicine*, The Royal Society of Medicine, Sept. 2004,
www.ncbi.nlm.nih.gov/pmc/articles/PMC1079581/.

- "Building Ethics into the Research Design." *Defining and Assessing Competence to Consent*, www.ethicsguidebook.ac.uk/Defining-and-assessing-competence-to-consent-92.
- Cantor, Norman L. "My Plan to Avoid the Ravages of Extreme Dementia." *Bill of Health*, 16 Apr. 2015, blogs.harvard.edu/billofhealth/2015/04/16/my-plan-to-avoid-the-ravages-of-extreme-dementia/.
- DailyCaring. "VIDEO: Experience Alzheimer's for Yourself." *DailyCaring*, 16 Jan. 2016, dailycaring.com/video-experience-alzheimers-for-yourself/.
- "Determining Capacity to Consent." *CPSO*, www.cpso.on.ca/uploadedFiles/policies/policies/policyitems/capacity_consent_july07dialogue.pdf.
- Free, Robert A. "Alzheimer's Patients Deserve Death with Dignity." *The Seattle Times*, The Seattle Times Company, 17 Nov. 2017, www.seattletimes.com/opinion/alzheimers-patients-deserve-death-with-dignity/.
- Harbarger, Molly. "Legislator's Promise to a Dying Friend: Death with Dignity Amendment to Help ALS, Alzheimer's Patients Fails." *OregonLive.com*, 30 Apr. 2015, www.oregonlive.com/politics/index.ssf/2015/04/legislators_promise_to_a_dying.html.
- "Healthy Pets Sometimes Euthanized for Owners' Convenience: Veterinary Groups." *The Globe and Mail*, 22 May 2017, www.theglobeandmail.com/news/national/healthy-pets-sometimes-euthanized-for-owners-convenience-veterinary-groups/article35078438/.
- Henig, Robin Marantz. "The Last Day of Her Life." *The New York Times*, The New York Times, 14 May 2015, www.nytimes.com/2015/05/17/magazine/the-last-day-of-her-life.html.
- Prince, Martin. "World Alzheimer Report 2016." *Alz.co.uk*, 2016, www.alz.co.uk/research/WorldAlzheimerReport2016.pdf.

- Schmid, John. "Alzheimer's Disease - A Brief History and Description." *Best Alzheimer's Products*, 16 May 2016, www.best-alzheimers-products.com/alzheimers-disease.html.
- Sitemap. "5 Influential Alzheimer's Researchers." *Best Value Schools*, 28 Oct. 2017, www.bestvalueschools.com/lists/5-influential-alzheimers-researchers/.
- Smith, Wesley J. "Euthanasia for Alzheimer's Patients? | Wesley J. Smith." *First Things*, Institute on Religion and Public Life, 28 Sept. 2017, www.firstthings.com/web-exclusives/2017/09/euthanasia-for-alzheimers-patients.
- "State-by-State Guide to Physician-Assisted Suicide - Euthanasia - ProCon.org." *Should Euthanasia or Physician-Assisted Suicide Be Legal?*, euthanasia.procon.org/view.resource.php?resourceID=000132.
- "Take Action - States with Assisted Dying Laws." *Death With Dignity*, www.deathwithdignity.org/take-action/.
- "The Evolution of America's Right-to-Die Movement." *PBS*, Public Broadcasting Service, www.pbs.org/wgbh/frontline/article/the-evolution-of-americas-right-to-die-movement/.
- Thomsen, Michael. "Ether One: The Video Game That Tries to Simulate Dementia." *The New Yorker*, The New Yorker, 20 June 2017, www.newyorker.com/business/currency/ether-one-video-game-tries-simulate-dementia?irgwc=1.
- Vittone, Terry. "Can You Win at a Video Game That Simulates Alzheimer's/Dementia?" *Crisis Prevention Institute (CPI)*, Crisis Prevention Institute, 21 Aug. 2017, www.crisisprevention.com/Blog/May-2015/Can-You-Win-at-a-Video-Game-That-Simulates-Alzheim.
- Wessel, Lindzi, and Tracy Seipel. "California's Right-to-Die Law: Should It Exclude Alzheimer's Patients?" *The Mercury News*, The Mercury News, 20 Nov. 2016, www.mercurynews.com/2016/11/18/californias-right-to-die-law-should-it-exclude-alzheimers-patients/.

Woods, Allan. "Quebec Considers Assisted Death for Dementia Patients." *Thestar.com*, 24 Mar. 2017, www.thestar.com/news/canada/2017/03/24/quebec-considers-assisted-death-for-dementia-patients.html.