Losing Everything

A Concise Examination of Alzheimer’s

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Introduction

An Introduction to Alzheimer’s

Alzheimer’s disease is a progressive and fatal disease named after the German physician Alois Alzheimer, who first described it in 1906. Alzheimer's is a disease that destroys brain cells when plaque builds up in the patient’s brain destroying the synapses. This destruction causes problems with memory and thinking and behavioral patterns that are severe enough to affect work, lifelong hobbies and social life. Alzheimer’s is a progressive disease, increasing over time, and is eventually fatal ("What is Alzheimer's"). Each individual is affected differently by Alzheimer’s. The time from diagnosis to death has been seen as being as short as five years to as long as thirty-five years. Because the length of the disease can change so dramatically from patient to patient, it is hard for doctors and psychiatrist to prepare the patient and the family for the road ahead. There are currently medications that can slow the progression of the disease. There are also treatment facilities that are constantly coming up with new breakthroughs in the field. With all of the changes in treating Alzheimer’s, only one thing is certain, the disease is fatal and doctors are years away from any possible cures ("What is Alzheimer's").

Today, Alzheimer’s is the seventh-leading cause of death in the United States ("What is Alzheimer's"). Currently, at least 5.2 million Americans suffer from Alzheimer's, including 200,000 to 250,000 people under age 65. By 2010, projections indicate that there will be 500,000 new cases of the mind-wasting disease each year and nearly one million new cases annually by 2050 (“10 Million Baby Boomers”). Unfortunately, no one is immune to the ravaging effects of Alzheimer’s. Throughout time, this disease has touched actors, musicians, athletes, politicians and thousands of family members in the same way. Marv Owen, Sugar Ray
Robinson, Norman Rockwell, Charlton Heston and Ronald Reagan are just a few of the many recognizable names that have been diagnosed with Alzheimer’s (Kennard).

Throughout his life time, Ronald Reagan and his wife suffered from numerous different health problems including cancer and the Reagans publicized their struggles to bring about public awareness. With this in mind, on November 5, 1994, Ronald Reagan wrote a letter to the American people sharing his diagnosis with Alzheimer’s:

My Fellow Americans,

I have recently been told that I am one of the Americans who will be afflicted with Alzheimer's Disease.

Upon learning this news, Nancy & I had to decide whether as private citizens we would keep this a private matter or whether we would make this news known in a public way.

In the past Nancy suffered from breast cancer and I had my cancer surgeries. We found through our open disclosures we were able to raise public awareness. We were happy that as a result many more people underwent testing. They were treated in early stages and able to return to normal, healthy lives.

So now, we feel it is important to share it with you. In opening our hearts, we hope this might promote greater awareness of this condition. Perhaps it will encourage a clearer understanding of the individuals and families who are affected by it.

At the moment I feel just fine. I intend to live the remainder of the years God gives me on this earth doing the things I have always done. I will continue to
share life's journey with my beloved Nancy and my family. I plan to enjoy the
great outdoors and stay in touch with my friends and supporters.

Unfortunately, as Alzheimer's Disease progresses, the family often bears a heavy
burden. I only wish there was some way I could spare Nancy from this painful
experience. When the time comes I am confident that with your help she will face
it with faith and courage.

In closing let me thank you, the American people for giving me the great honor of
allowing me to serve as your President. When the Lord calls me home, whenever
that may be I will face it with the greatest love for this country of ours and eternal
optimism for its future.

I now begin the journey that will lead me into the sunset of my life. I know that
for America there will always be a bright dawn ahead.

Thank you, my friends. May God always bless you.

Sincerely,

Ronald Reagan (Reagan)

As the brain cells begin to die, the individual’s personality and mental state decay
irreversibly. This degrading condition impacts the person’s family, friends and society at large.
Coping with an Alzheimer’s patient is a challenge for all of the individuals affected by this
disease. This paper will explore how families deal with the ravaging effects of Alzheimer’s and
the current help available for family members and their loved one as they work through the
disease’s effects. This paper will provide a better understanding of the stresses of caring for an
Alzheimer’s patient and the current facilities set up to help the families.
Chapter I
The Stages of Alzheimer's

To understand what an Alzheimer’s patient’s family and friends experience it is important to first understand the stages that the Alzheimer’s patient will go through and the support that they require from their family and friends. There are seven defined stages of Alzheimer’s and because the disease is progressive, the stages become increasingly difficult for the patient. The seven stages of Alzheimer’s are divided into three subcategories from the beginning stages, to the middle stages and ending stages. The three beginning stages of Alzheimer’s are no impairment, very mild cognitive decline; and mild cognitive decline; these stages are usually related to old age and are usually ignored. The middle stages of Alzheimer’s are moderate cognitive decline and severely moderate decline; these stages are often where Alzheimer’s is first diagnosed. The ending stages of Alzheimer’s are comprised of severe cognitive decline and very severe cognitive decline. This is the point where the person fades away and can no longer recognize family and friends ("Stages of Alzheimer's").

The next three sections of this paper will examine these stages in depth, and the family reactions to each stage will be uncovered.
The Beginning Stages of Alzheimer’s

According to experts, the first stage demonstrates no impairment. At this point unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview. The first stage is normalcy and there are no visible signs of the plaque that causes Alzheimer’s building up in the brain. The second stage shows a very mild cognitive decline. The beginning of this stage can be related to old age and many ignore it; however, individuals may feel as if they have intermittent memory lapses, especially in forgetting familiar words or names or the location of keys, eyeglasses, phones and other common objects ("Stages of Alzheimer's"). Unfortunately, these problems are not evident during a medical examination or readily apparent to friends, family, or co-workers.

The third stage is known as mild cognitive decline. This is the stage where friends, family or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview; however, most Alzheimer’s cases are not diagnosed this early ("Stages of Alzheimer's"). The third stage of Alzheimer’s is the point where patients can no longer live alone and must move in with family members or to a facility built to help Alzheimer’s patients. “My mother used to live alone in a senior living facility that my dad helped design and plan and she loved it there. She had her freedom but only lived ten minutes from two of my sisters so it was a perfect living situation. However, with more and more memory lapses, my sisters and I had to check in on our mother more and more” (Gould).

The beginning stages of Alzheimer’s are often ignored and attributed to old age. They do not stir up much concern in most families; however, the middle stages are often when family and friends become aware of Alzheimer’s. The middle stages are often the hardest for the patient as
they begin to realize their new mental limitations. The next chapter will explore the middle stages of Alzheimer’s in more depth.
The Middle Stages of Alzheimer’s

By the onset of the fourth stage, the loss of memory is becoming more and more apparent and the patient has reached the middle stage of Alzheimer’s. The fourth stage is known as moderate cognitive decline and a careful medical interview will show several deficiencies in areas such as decreased knowledge of recent occasions or current events, impaired ability to perform challenging mental arithmetic, decreased capacity to perform complex tasks, such as planning dinner for guests, paying bills and balancing the check book. Reduced memory of personal history also becomes apparent and the affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations and around people they are meeting for the first time.

The fifth stage is marked by moderately severe cognitive decline where major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential and living alone frequently often proves impossible. At this stage, individuals may be unable during a medical interview to recall such important details as their current address, telephone numbers and the name of the college or high school from which they graduated. Patients also become confused about where they are or about the date, day of the week or season of the year; they also often need help choosing proper clothing for the season or occasion ("Stages of Alzheimer's"). However, the patient can usually retain considerable knowledge about themselves and know their own name and the names of their spouse or children and they usually require no assistance with eating or using the toilet. This can often be the hardest part for the patient and their family to cope with.

I was watching my mother melt away, and unlike now, she knew what was happening and she knew that she was forgetting things that used to come so easily
to her. It was one of the hardest things for me because not only did I have to try to calm my mother on a daily basis but I was fighting with depression myself. I remember one day when she started crying in the living room, when I went to see what was wrong; she couldn’t remember her favorite television station. I think that was one of the last times I had to help her, after that point she didn’t remember what she was forgetting. It was a time for us both to adjust and learn how to deal with her changing mental faculties. (Gould)

It can be challenging for family members to calm their loved one while controlling their own fear of the future.

The middle stages of Alzheimer’s are difficult because the patient still knows what is going on and they become frighten at their mental deficiencies. The end stages of Alzheimer’s, however, can be the hardest on care givers because their loved one no longer recognizes them as a family member.
The Ending Stages of Alzheimer’s

The ending stages of Alzheimer’s are usually the most difficult for families. This is the first point in the disease where the patient can no longer take care of themselves and frequently cannot even remember their family members. The ending stages of Alzheimer’s are the most challenging to families and counseling becomes necessary because the patient truly becomes lost, families become increasingly frustrated.

The sixth stage of Alzheimer’s is referred to as severe cognitive decline. This stage is evident through worsening memory difficulties when significant personality changes emerge and affected individuals need extensive help with routine daily activities. At this stage, individuals may lose most awareness of recent experiences and events as well as of their surroundings, and their personal history. They can normally recall their own name, occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces. They need help getting dressed properly but without supervision, may make such errors as putting pajamas over daytime clothes or shoes on the wrong feet and experience disruption of their normal sleep/waking cycle. They will need help with using the restroom, such as, flushing the toilet, wiping and disposing of tissue properly, marked by increasing episodes of urinary or fecal incontinence. Significant personality changes and behavioral symptoms occur, including suspiciousness and delusions, such as believing that their caregiver is an imposter or that they are being kidnapped and held against their own will; hallucinations, seeing or hearing things that are not really there; or compulsive, repetitive behavior such as hand-wringing or tissue shredding, and the tendency to wander and become lost.

The last and most extreme stage of Alzheimer’s is very severe cognitive decline; this is the final stage of the disease when individuals lose the ability to respond to their environment,
and the ability to speak. The patient will often feel like they are having a conversation but the only thing that can be heard is expressive mumbling. Most patients at this point of the disease are weak and can no longer walk without assistance and even have a hard time sitting in an unsupportive chair such as a dining room chair or wheel chair for extended periods of time. Patients also are unable to feed themselves and usually refuse food given to them beyond a few bites. At this point patients usually die from pneumonia and other infections; however, Alzheimer’s also affects the brain’s ability to control muscle movement and eventually will trigger heart or lung failure; ultimately Alzheimer’s will kill the patients ("Stages of Alzheimer's").

These stages have a profound effect on family members, as each stage brings its own stress and challenges to overcome. Each care taker has their own way of dealing with Alzheimer’s but many of the problems such as frustration, depression, feelings of hopelessness and confusion about the best way of caring for their family member can be seen in family after family.
Chapter II

The Effects of Alzheimer’s on the Family

The effects of Alzheimer’s ravage the body and eventually make daily life impossible for the afflicted; however, the effects on the family can often last long after the passing of the patient. The Alzheimer’s Association believes that taking care of the caregiver is half the battle with Alzheimer’s. Caring for someone who has Alzheimer’s disease can be overwhelming, exhausting and stressful. A family caregiver may feel loss over the dramatic changes in relationships with a loved one with Alzheimer’s, and begin to lose their connection to other family members and friends. Family members often try to hold on to their old relationship with their family member with Alzheimer’s; however, at some point the relationship has to change and that is often a heart breaking moment for families. While taking care of their family member, it is essential that caregivers look after their own physical and mental health (“Coping”).

Taking care of someone with Alzheimer's disease can be an enormous drain on the caregiver and on family resources. For sandwich caregivers, families where a child and adult help to take care of a grandparent, the problem is even more acute. It is clear that care giving is a multigenerational concern. Young adults, and even teens and pre-teens, are being impacted in life-changing ways by their care giving responsibilities. (Preidt)

“Alzheimer’s is a very family oriented disease, it touches many lives. It is a very humiliating type of disease” (Gould). Family members are called upon to support their loved ones while watching the person they once loved fade in to a person that they don’t even recognize and that frequently does not recognize them. Alzheimer’s patients in the last stage of
the disease do not remember their family, and often become disoriented and confused, lashing out at those they once felt comfortable with for no apparent reason. Lois Gould, who took care of her mother in her house for four months, said “Daily life becomes difficult, my mother tried to run away from our home, she packed her suitcase and tried to walk back to New Jersey. It was the worst day, it was the day that I realized it was too much for me and I had to place my mother in an Alzheimer’s facility.” Lois was depressed for months; she went into therapy and started to take anti-depressants after placing her mother in Praxis Alzheimer’s Facility, a highly rated facility only minutes from her house in Nazareth, Pennsylvania. According to the Alzheimer’s Association of Colorado, stress, anger, guilt and grief related to care giving can lead to depression. Caregivers can experience depression at any point in the disease process. This is often brought on by feelings of inadequacy in taking care of parents or grandparents. “Putting her in Praxis was necessary, however the way we were told to do it was a mistake. It was a mistake and if I could start all over I would have done it differently.” Ms. Gould explains, “They told us not to contact her for a few weeks to let her adjust. One day I called to ask a question at the front desk, I could hear my mom screaming in the background that she wanted to go home. I told the nurse that I wanted to speak to her, she responded that it was not my mother and that she was fine and this was for the best.” As she continued her story tears started to creep into her voice, “she was doing it for me, to try to protect me, but I knew it was my mother, I have known her voice since I was a kid. I believe not seeing her made the situation worse for the both of us, but we listened to the experts and did what we were told” (Gould).

Alzheimer’s facilities are different than most specialty medical facilities. Praxis Alzheimer’s Facility in Pennsylvania not only prides itself on the care of patience but also the support groups for the family members. “Alzheimer’s affects everyone in the family, it would
make no sense to treat the patient and leave the family out in the cold, through years of working here I have come to believe that Alzheimer’s is harder on the family than the patient, they need our support. It is almost like an inpatient facility for the patients and an outpatient facility for their families” (Holly). The majority of Alzheimer’s facilities have two segments; the first segment is for people within the middle and beginning end stages of Alzheimer’s. Most people in this section of the facility have exhausted the abilities of their family to take care of them but they do not need extensive medical help. The second segment of the facility is for patients who need extensive medical attention and who are in the last stages of life. Praxis prides its self on the fact that they have the two facilities on the same campus so that family members don’t have to go through the stress of moving their loved one (Information).

There are several options to help families and patients cope with the transition through the different stages of Alzheimer’s. Counseling and Alzheimer’s facilities such as Praxis can help, but there is also several medications that have been shown to slow down the effects of Alzheimer’s and allow families to adjust more smoothly.
Medications

There are currently many different types of medications that can help slowdown the effects of Alzheimer’s and give the family and patient time to deal with the different stages of Alzheimer’s.

"As Alzheimer's disease progresses, declines in cognition, function and behavior worsen. Both adult and non-adult caregivers need to be educated about what to expect and, more importantly, what to do in these cases," Blake said. "Proper diagnosis and treatment are crucial. Symptoms -- loss of function, decline in cognitive ability and difficult behavior -- can be delayed and caregiver burden reduced through medication therapy, which may include combining medications from two FDA-approved Alzheimer's medication classes" (Preidt).

Currently there are several medications on the market that have been seen to slow the effects of Alzheimer’s. Many families place there hope in medications such as donepezil (Aricept), galantamine (Razadyne), rivastigmine (Exelon), and tacrine (Cognex). These medicines are known as cholinesterase inhibitors, and have been approved by the Food and Drug Administration (FDA) specifically for treatment of Alzheimer's disease. Research has suggested that people with moderate to severe Alzheimer's disease who took cholinesterase inhibitors experienced improvement in their clarity of thinking and their ability to complete their daily functions when they also added memantine (Namenda), a new Alzheimer’s drug on the market, to their treatment ("Alzheimer's Disease - Medications"). Although these medications can help slow the progression of Alzheimer’s it is important to remember that the disease will still progress so it is necessary for the patient and family members to know when to start and stop treatments. According to WebMD “The main decision about using medicines to treat failing mental function usually is not whether to try a medicine but when to begin and, later, when to
stop treatment”. Medicine treatment can and should be started as soon as Alzheimer's disease is diagnosed for the best results. However, the person may or may not significantly improve when taking medicines because, like most medications, they do not work for everyone. If the medicines are effective, they should be continued until the side effects begin to outweigh the benefits, the patient no longer responds to the medication, or under the advice of a doctor. This can be a hard decision for caretakers to make, however it is necessary towards the end stages of Alzheimer’s to stop all of the Alzheimer’s medications so as not to prolong the inevitable death ("Alzheimer's Disease - Medications").
Conclusion

It has been well documented that family members are affected by the stresses of taking care of loved ones diagnosed with Alzheimer’s. Many facilities and programs including Praxis and the Alzheimer’s Association currently have programs to help support caregivers and allow them to connect with others going through the same thing. Hospitals around the world are currently searching for cures and are coming closer every year, however medical professionals still feel that any reliable cure is decades away.

Alzheimer’s is a very family oriented disease. Most diseases that families are ready to deal with as their loved ones reach old age are physical and they are ready to assist in what is needed as organs fail and the patient becomes weaker. Alzheimer’s not only takes away a patient’s physical ability to help themselves but it also takes away who that person is, as they become merely a body with no emotions. Any family member who is willing to help an Alzheimer’s patient transition into the last stages of their life, needs to research what they are getting into before they start and needs to make sure that they have their own support system in place.

No matter what family caregivers do, while taking care of a loved one diagnosed with Alzheimer’s, they are going to be affected. Taking care of family members with Alzheimer’s has been shown to cause depression and family tension due to the increased amount of stress. It is important for families to do what they can to love and support their family member, researching treatment options, appropriate facilities and medication. However it is more important for family members to protect themselves by speaking to a psychologist or family about the stress, staying on the lookout for depression, allowing time to themselves and speaking to a psychiatrist about medication if needed.
Works Cited


Holly. Personal interview. 10 Mar 2008.


