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ALZHEIMER'S FAMILIES-
EMOTIONAL AND SPIRITUAL TOOLS FOR COPING

D.Min. Project

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Chapter I: STATEMENT OF THE ISSUE

A. Background

Receiving a medical diagnosis of a serious life threatening disease can be overwhelming both for the patient and the patient's family. Due to medical advances, diagnoses of diseases that were once fatal, such as cancer and heart disease, may not be as devastating as they once were. Many forms of these diseases can now be treated, cured, or managed, extending life often for many years. By comparison, a diagnosis of Alzheimer's disease is different because there is no cure.

The Alzheimer's Association (2014) states: "None of the treatments available today for Alzheimer's disease slows or stops the malfunction and death of neurons in the brain that cause Alzheimer's symptoms and eventually make the disease fatal" (p. 14). There are some medications that may temporarily slow the progress, but the cognitive decline still continues. After many years, family members are left with someone who resembles their loved one, but who no longer acts and responds as their loved one did in the past.

There is another dimension that is different from other diseases when dealing with a loved one with Alzheimer's disease. In the middle and later stages, the person with Alzheimer's disease can no longer share their thinking with you about the disease nor easily express their needs and desires as they cognitively decline. Neurologist Ronald Andiman (2012), explains that the Alzheimer's experience is different than other serious and terminal diseases: "When people struggle with other life-threatening illnesses…the intellect and the personality are intact enough to allow patients to cope, understand, and at times, make peace with their plight" (p. 102). He explains that such people can show appreciation and gratitude for what their loved ones do for them as their physical health declines. With someone who has Alzheimer's disease, "they have few cognitive or spiritual resources to contribute to their own care and often can't acknowledge the love and caring provided for them" (p. 102).

According to the 2014 Alzheimer's Association Women and Alzheimer's Poll, when people over the age of 60 were asked which condition they were most afraid of getting, 35% said Alzheimer's disease compared with 23% who said cancer (Alzheimer's Association, 2014, p. 55). An estimated 5.2 million Americans had Alzheimer's disease in 2014. One in nine people over the age of 65 have the disease (Alzheimer's Association, 2014, p. 16). Since Alzheimer's disease increases with age, as people live longer and the "Baby Boomer" generation begins to reach age 65, the incidence of Alzheimer's disease will grow dramatically. By 2025 the number of people age 65 and older with Alzheimer's disease is estimated to reach 7.1 million (Hebert, et al as cited in Alzheimer's Association, 2014, p. 21).

Alzheimer's disease is a slow, progressive, and debilitating disease that affects functioning on many levels. There is no definitive test to confirm the disease. It is usually diagnosed based on symptoms after ruling out other causes. The early symptoms are so subtle that it is often not officially diagnosed until years after the early symptoms begin. People age 65 and older survive an average of 4-8 years after a diagnosis of Alzheimer's disease, yet some live as long as 20 years with the disease (Alzheimer's Association, 2014, p. 28).

Three general stages of the disease have been identified (Alzheimer's Association, 2014, p. 6, 31; Alzheimer's Association Webpage - Stages of Alzheimer's; Gleich, 2003, p.83-84).

Mild Alzheimer’s disease, often called the early-stage, presents with the following symptoms:

- Difficulty coming up with the right word
- Trouble remembering names when introduced to new people
- Difficulty remembering recent conversations or events
- Saying the same thing over and over again
- Losing interest in things they once enjoyed
- Having greater difficulty performing tasks in social or work settings
- Forgetting material that one has just read
- Losing or misplacing a valuable object
- Increasing trouble with planning or organizing
- Apathy and depression

Moderate Alzheimer’s disease, often called the middle-stage, is typically the longest stage and can last for many years. (Alzheimer’s Association Webpage - Stages of Alzheimer’s; Gleich, 2003, p.83-84). The same symptoms from the first stage become more apparent. Additional symptoms include:

- Forgetfulness of events or one’s own personal history
- Belief that things are real when they are not
- Feeling moody or withdrawn, especially in social or mentally challenging situations
- Ahowing anxiety or depression
- Inability to process what they hear
- Being unable to recall their own address or telephone number

- Confusion about where they are or what day it is
- The need for help choosing proper clothing for the season or occasion
- Trouble controlling bladder and bowels in some people
- Changes in sleep patterns, such as sleeping during the day and becoming restless at night
- Increased risk of wandering and becoming lost, even in once familiar places
- Personality and behavior changes, including suspiciousness and delusions or compulsive, repetitive behavior like hand-wringing or tissue shredding
- Arguing more than usual

With severe Alzheimer's disease, often called the late-stage, the individual loses the ability to respond to their environment, carry on conversations, and eventually to control movements (Alzheimer's Association Webpage-Stages of Alzheimer's; Gleich, 2003, p.83-84). Communication becomes increasingly difficult. They may be able to say a few words but cannot put those words together to form sentences that make sense. Later symptoms may also include:

- Aggressive behavior
- Increased agitation and anxiety
- Loss of awareness of recent experiences and surroundings
- No longer recognizing family members
- May hallucinate, suffer from delusions and paranoia
- Needing full-time, around the clock assistance with daily personal care
- Changes in physical abilities such as walking, sitting, and eventually swallowing
- Becoming vulnerable to infections, especially pneumonia

Each symptom by itself can be daunting. A combination of many of these symptoms can be overwhelming.

B. Statement of Pastoral Need

Family members of a person who develops Alzheimer's disease face unique challenges and stresses as they adjust to the slow but sure cognitive decline of their loved one. This includes: the process of truly accepting the diagnosis; reminding yourself that even though you recognize the person physically, you cannot expect him or her to respond the way they did in the past; loss of the relationship as it had been; and dealing with changes in behavior which affects social and family structure. For caretakers who have to deal with this on a day-to-day basis, there is the added burden of taking on the responsibilities the person with Alzheimer's used to have, as well as being responsible for their physical care. All of this may bring feelings of frustration, guilt, isolation, anger, emotional and physical exhaustion, and caregiver fatigue, which can lead to extreme stress and burnout.

There can also be a crisis of faith. For those who believe that good people are rewarded and bad people are punished, this can feel like a punishment, leaving a family member to wonder, "What did I do wrong," or "What did my loved one do wrong to deserve this?" For others, they may need additional spiritual resources to get by.

In addition, one questions the purpose of life, particularly the life of a loved one with Alzheimer's disease or dementia, if one has lost the memory of past events and no longer recognizes loved ones or friends. In his book, *God is a Verb*, Rabbi Cooper explains that our most precious gift is awareness. “What would a relationship be if our minds did not function? What would our excellent physical health be worth if we could not appreciate the finer things in life? What would anything be worth if we could not be fully aware of it’s presence (Cooper, D. 1997, p. 33)?” While this was said in the context of a mystical understanding of the world, it can cause one to question if there is any meaning of life left for his or her loved one. Such questions may arise in discussions with one’s clergy. Awareness of the disease can help facilitate such discussions.

For my D.Min. project I will be working with families who have a loved one with Alzheimer’s disease, both primary caretakers as well as other close family members. I will run an eight-week focus group helping family members talk about the difficulties they face and gain support from each other as they share their experiences. Together we will explore emotional and spiritual coping tools, discussing what is or has been helpful in the past, as well as offering suggestions and ideas to try that might be helpful in the future.

Being in a small town, some people may not feel comfortable sharing their feelings and emotions with others in a group who they may also see in other venues. For those who prefer a private setting rather than a group, I will also offer individual counseling. In addition there may be opportunities to meet on a one-time basis with groups who have an interest in Alzheimer’s disease offering a psychoeducational approach.

C. Relevance to Ministry in a Wider Context

We think of Alzheimer’s as a relatively new disease, at least one that is becoming more and more prevalent today. Yet perhaps one of our Patriarchs had the early stages of Alzheimer’s disease or dementia. We read in Genesis 27, “When Isaac was old and his eyes were too dim to see, he called his older son Esau.” Isaac asked Esau to go out to the fields and hunt some food so that he could give Esau his “innermost blessing.” Because of what God had told Isaac’s wife Rebekah when she was pregnant with Esau and his twin brother Jacob, she wanted their other son Jacob to get the blessing. Rebekah came up with a scheme to trick her husband into believing he was giving the blessing to Esau even though he would really be giving it to Jacob. Since Esau had hairy arms, she told Jacob to cover his arms with animal fur to deceive their father.

This story is the source of many interpretations. What is not discussed though is, “How did Rebekah know that Isaac would be so easily fooled?” Wouldn’t any ordinary person, even if he were blind, be able to tell the difference between a human hairy arm, and an arm covered with an animal skin? Did Rebekah know that Isaac’s cognitive abilities were declining? Perhaps the words, “his eyes were too dim too see” can be a metaphor for his ability to think. We often say, “I see,” when we mean, “I understand.” Even Jacob questions Rebekah’s plan, but she is certain that it will work. Spouses are often quicker to notice and accept the cognitive decline in Alzheimer’s or dementia than children are.

Jacob does as his mother says and brings his father cooked food pretending that he is Esau. Isaac seems very confused. “Come closer that I may feel you, my son — whether you are really my son Esau or not.” So Jacob drew close to his father Isaac, who felt him and wondered. “The voice is the voice of Jacob, yet the hands are the hands of Esau.” (Gen. 27:21-22) Commentators wonder whether Isaac really knew what was going on and went along with the plan, or he was really deceived by Jacob and Rebekah. Perhaps there is a third explanation. Maybe Isaac had Alzheimer’s disease or dementia and was easily confused, not being able to recognize one son from the other.

If this is true, it doesn't mean that Rebekah's actions were done out of malice. One of the symptoms of Alzheimer's disease is being unable to make reasoned decisions. Maybe Rebekah knew that Isaac was not capable of making the right decision. From her perspective, God told her that Jacob should be the one to carry on the lineage of the family. Isaac and Rebekah must have had this discussion in the past. Perhaps she feared that he would not remember. She was trying to find a way to carryout what they had agreed upon without embarrassing her husband. We can only imagine what other issues Rebekah might have had to deal with if her husband's cognitive abilities were declining.

In addition to the challenges for the person who has Alzheimer's disease, there are the challenges for the caregiver. While some people with the disease, especially in the late stages, are cared for in facilities such as long-term care, nursing homes, or special Alzheimer's units, more than 15 million Americans provide unpaid care (Alzheimer's Association, 2014, p. 30). Most caregivers are family members - usually a spouse, or an adult child. That close personal connection adds additional emotional stress to the physical burdens of caregiving. According to the Alzheimer's Association, 59% of family caregivers rated the emotional stress of caregiving as high or very high (Alzheimer's Association, 2014, p. 34). In addition to the emotional burden, the physical health of caregivers is also affected. 74% of caregivers reported that they were "somewhat concerned" to "very concerned" about maintaining their own health since becoming a caregiver. Seven percent said that the greatest difficulty of caregiving is that it creates or aggravates their own health problems (Alzheimer's Association, 2014, p. 37).

Alzheimer's family members, spouses and adult children, some of whom are caregivers, are members of our congregations. Yet we don't often know what they are going through. Caregivers often try to, or may be forced to hide their feelings. A diagnosis of Alzheimer's disease can also be accompanied by a sense of embarrassment, isolation, and stigmatization. "Alzheimer's disease undermines two of the characteristics most valued in American society: cognitive ability and self-sufficiency" (Walker, et. Al, 1994, p. 26). Family members feel stigmatized because of the diagnosis their loved one has which, in society's eyes, makes that person inferior. "Caregivers may respond to the stigma by redefining the person as less valuable, less human, and less desired" (Saylor as cited in Walker, et al. 1994, p. 27). In addition, caregivers often avoid going out in public because of the embarrassment they feel being with someone who cannot function according to social norms.

As caregivers start to face reality they search for ways to deal with the declining abilities of their loved one. They can feel disorganized and confused. Their life has been changed and they need to take on new tasks that their loved one used to do. They search for answers and yearn to have the person back that they remember. As the loved one with Alzheimer's disease declines in cognitive abilities and personality changes set in, caregivers and other family members can experience feelings of anxiety, panic and fear. It is also not unusual for caregivers to have a sense of regret and guilt – regret for things they may have said to the person with Alzheimer's or imagined in their minds, and guilt for feeling anger and frustration at the situation they were forced into. Sadness and depression also sink in as they reflect on lost opportunities, the stresses of caring for someone with Alzheimer's, the isolation, the uncertainly of what the future will bring, and worrying about when anticipated changes will occur.

Clergy can play an important role here. Because of the embarrassment, stigma, and guilt, Alzheimer's family members often keep the challenges to themselves. They suffer in silence feeling that no one really understands what they are going through. On the surface their loved one seems normal to everyone else. Those with the disease are able at times, to gather the strength needed to appear "normal" when with other people for short periods of time. Therefore many friends and relatives may not even realize that the person has Alzheimer's disease. Clergy can make a big difference by being the ones to make the first move to reach out to Alzheimer's family members in the congregation. One shouldn't assume they are doing fine. Just an acknowledgement that you know and care can go a long way to bringing comfort to family members.

It is also important to realize that even if a loved one with Alzheimer's disease is put in a nursing home, the need for support for family members does not end. Contact from clergy may be just as important as the family members struggle with intense guilt for having made the decision, even though in reality, they had no choice. In addition family members may feel like a failure for no longer being able to care for their loved one, either physically and/or emotionally. Clergy can play an empathetic role here also.

Adult children have some of the same issues as a spouse might, but also have to deal with seeing their parent, who had always been the caregiver, suddenly become the one needing care. A parent that could always be depended on, now is dependant. Mace and Rabins explain this as a change in roles, which is different from a change in responsibilities. "By 'role,' we mean a person's place in his family. Roles are established over many years and are not always easy to define… Learning a new responsibility can be difficult but changes in roles are often more difficult to accept or adjust to" (2001, p. 195). Adult children may struggle even more silently, especially if they are not the primary caregiver. They feel so helpless, knowing there really is very little they can do for their parent.

An awareness of all the issues involved with Alzheimer's families can give clergy the knowledge they need to reach out to those who are suffering in silence. Clergy can also educate the congregation about the challenges that Alzheimer's families face so if a caregiver decides to bring their loved one to worship services, the congregants present will understand and be empathetic to the behavior of the person with Alzheimer's disease and the needs of the caregiver.

Personal Connection

It is not only the caregivers that are deeply affected by having a loved one with Alzheimer's disease. Other family members also feel the emotional anguish of watching not only their loved ones decline, but if a family member is the caregiver, seeing the toll it takes on the caregiver as well. I know this all too well. My father passed away after having had Alzheimer's disease for over 10 years. My mother was his primary caregiver.

There are certain moments that stick out in my mind as I reflect on those ten years. The first was when I went with my mother to take my father to a neurologist. We all knew that my father's memory was not as good as it had been but it wasn't until the neurologist said the word "Alzheimer's" that the reality sunk in. We had been through cancer with my mother, and my father had a heart attack in his early forties followed by heart-by-pass surgery in his early sixties. This was different. My mother was cured of her cancer. Despite my father's heart disease, it was treated and managed for over 40 years. With a diagnosis of

Alzheimer’s disease, there was no hope. I knew that there was no real treatment for the disease and that he would continually decline cognitively. I dreaded the day that he would no longer remember who I was.

My father had great difficulty with short-term memory early on. He would ask the same question over and over and over again, unable to retain the answer. For example, we would make plans to go to a restaurant for lunch and he would ask, “Where are we going for lunch?” We would tell him and 5 minutes later he would ask, “Where are we going for lunch?” This conversation could go on for a half hour. At the time, he was able to carry on what felt like normal conversations most of the time, so it was easy to forget that he had Alzheimer’s disease. I remember getting so angry with him for “not listening.” It took many years to adjust to this new normal and remember that I couldn’t expect him to think like he used to.

The intellectual decline was disheartening as well. I remember vividly a political conversation our family was having about the presidential elections. My father had strong opinions on many things and always loved to share his thoughts. He tried desperately to join in on the conversation but just couldn’t comprehend the basis of the discussion. He became very quiet and withdrawn. Also, my father loved to teach Bible, and taught children as well as adults most of his life. I remember going with him to one of his adult classes and watched as he tried desperately to teach, but could not carry out logical thoughts.

In addition to watching my father deteriorate, I also observed what happened with my mother as she tried to cope with the incredible emotional stresses and physical burdens that came with being a caregiver for a spouse with Alzheimer’s disease. Her physical health declined under the stress of taking care of my father's physical needs, taking over all the jobs he used to do such as the family finances, dealing with the social isolation that comes with having a spouse with Alzheimer's disease, and most of all the emotional turmoil that comes with living with someone who resembles your spouse but now acts like someone you don't know.

My mother also dealt with the stress of behavior changes in which my father became nasty at times, especially in unfamiliar or uncomfortable situations. Since my parents lived in a senior assisted living community where they ate all their meals, we would try to take my mother out to a nice meal when we came to visit. While she truly appreciated the change of scenery, my father's outbursts, especially to waitresses who did not bring exactly what he wanted, and to musicians who were playing too loud, made the experience very uncomfortable for the rest of us. As others were helping my father go out to the car after the meal, I remember going up to the waitresses and apologizing for my father's behavior, explaining that he had Alzheimer's disease. As an adult child of a parent with Alzheimer's, those years were filled with anguish, frustration and intense sadness for me. It was that much more difficult for my mother, his caregiver.

Because of the experiences of my family and the many others I have spoken with that have a loved one with Alzheimer's, I would like to reach out to those who have a family member with Alzheimer's disease for my D.Min. Project. I hope to focus on ways that Alzheimer's families can find emotional and spiritual support as they continue on this journey, finding tools that would be most helpful to them. By helping others to better cope with the challenges of being part of an Alzheimer's family, this can add meaning to the suffering my family experienced.

CHAPTER II. PRINCIPLES THAT GUIDE AND INFORM

A. Clinical Principles

Alzheimer's disease is a family disease. In addition to the person who receives the diagnosis, other family members, especially spouses and adult children, are significantly affected, both caregivers and non-caregivers. Alzheimer's family members report various emotional symptoms and reactions as a result of their interactions with their loved ones. These include feelings of denial, avoidance, burden, stress, anger, self-pity, despair, anxiety, guilt, hopelessness, embarrassment, isolation, frustration, despair, and depression. The magnitude of responsibility and emotional distress can be overwhelming at times. If we can find ways to offer such families new or additional ways of coping, their sense of burden and emotional distress can be reduced, helping them to live a healthier life both physically and psychologically, in the midst of the turmoil.

Gottlieb and Wolfe (2002) talk about how individuals cope: "Coping resources consist of a complex and dynamic set of cognitive, affective, and behavioral responses that are aimed to regulate their emotions, solve or improve the practical problems they face, and maintain the psychological resistance and strength needed to stay productively engaged in caregiving for a prolonged period of time" (as cited in Papastravrou et al., 2011, p. 702). Pearlin et al. (1990) describe stressors for Alzheimer's families as "the problematic conditions and difficult circumstances experienced by caregivers which strain or supersede the individual's capacity to adapt (as cited in Papastravrou et al., 2011, p. 703). For some caregivers there are moments in which they feel they can no longer be the caregiver. Sometimes these moments are temporary. Other times it begins the steps towards placement in a facility. The Papastravrou model identifies three aspects of coping: reducing expectations, making positive comparisons, and searching for a “larger sense” of the situation. (2011, p. 703).

Cooper, et al. (2008) talked about three categories of coping strategies that people have used to deal with caring for a loved one with Alzheimer’s disease. The first is emotion-focused strategies which include: acceptance (learning to live with it), emotional support from others, humor, positive reframing, and religion. The second is problem-focused strategies that include: active coping (doing something about the situation, taking action to make it better), instrumental support (getting advice from others), and planning (coming up with a strategy about what to do).

Dysfunctional coping strategies, the third category of coping strategies, include: behavioral disengagement, denial, self-distraction, self-blame, substance use, and venting (p. 930). Cooper, et al. (2008) found that of all three strategies, the one that decreased anxiety the most, one year later, were the emotion-focused strategies. Problem-focused strategies had little effect on later anxiety. They feel that to best help caregivers, mental health professions should focus on helping family members increase emotion-focused strategies and decrease dysfunctional strategies.

A study done by Papastravrou et al. (2011) included six coping strategies often found in Alzheimer’s family members: positive approaches and reappraisal, problem solving, seeking social support, wishful thinking, avoidance and denial, and confronting coping, such as expressing anger to the person who caused the problem (p. 705). They found a correlation between positive thinking and lessening of a feeling of burden. Positive thinking included thoughts such as, “I try to see the positive side,” or the person felt he or she changed or grew as a person in a good way. Factors that increased the sense of burden included: wishful thinking, imagining being able to change the situation, or hoping the situation would just go away (p. 705). An important finding in their study is that the use of positive strategies of reappraising and problem solving helped to decrease the sense of burden and decrease depression, whereas the strategies of avoidance, denial, and emotional discharge were correlated with high levels of depression (p. 708). Explaining these different coping tools to Alzheimer's family members can help them to achieve better emotional and physical health.

One area that is greatly overlooked in helping Alzheimer's families is the sense of grief and loss that occurs over the many years of the disease. Ruth Hodder (2006), a writer whose mother had Alzheimer's disease, explains what she experienced personally in an article entitled, "A Sorrow Cloaked with Anger." "In the decade since Mom was first diagnosed with Alzheimer's disease, I too have been grieving. I have grieved actively by learning to recognize and acknowledge both Mom's and my numerous losses" (p. 57). There is also the intense sadness in knowing that things will never get better, but only progressively get worse. There is a grief that comes with anticipating the additional losses to come.

With the actual physical death of a loved one who had Alzheimer's disease, some family members may not feel the intense sadness of a mourner. The grief and loss that other mourners experience after the death of a family member has already been going on for many years with Alzheimer's families. In referring to his sense of loss regarding his mother who had Alzheimer's, Rabbi Richard Address (2012) said, "I was speaking to a therapist who had helped guide my journey, and I remarked that it had occurred to me that I had begun the process of mourning my mother's death when she was placed in the nursing home…It was as if my soul had begun the process of mourning, even though no actual death was in the immediate future" (p. 161).

There are various types of losses that occur for an Alzheimer's family member during the span of the time their loved one has the disease. The largest loss, obviously, is slowly losing the person that was once your parent or spouse and all that accompanies such a realization. Within that larger loss are other experiences of loss. These losses can be categorized into the following: (1) Losses stemming from - having the person physically present but cognitively absent; (2) non-finite loss - not knowing when the loss actually began and when it will end; (3) anticipatory grief - expecting things to get worse; (4) and disenfranchised grief - not being acknowledged by others as being in mourning since their loved one is still alive (Vancouver Island Health Authority, 2002, part 2). Chronic sorrow, another source of loss, is explained by Roos to mean "living with the realization of a loss that cannot be removed and that continually requires energy for adaptation" (as cited in Hodder, 2006, p. 59).

As part of the loss of the overall person, there are many smaller but very significant losses that accumulate over time, particularly with spouses. These include moments such as not being able to share with your spouse when you read something interesting, loss of the conversations you used to have with each other, losing personal privacy as the person with Alzheimer's disease is fearful of being left alone and may even follow you into the bathroom, loss of time for one's self, and loss of past social life because you cannot easily take the person with Alzheimer's with you, and when you do friends feel uncomfortable in their presence. While not as dramatic to the outside world, these accumulated loses are very significant to the person experiencing them. Since they are subtle, and fluctuate for a while until they become permanent, it is often hard for the person to name or recognize them.

Not understanding that these losses occur and are ongoing can have emotional consequences. It can lead to a sense of guilt for not feeling sad when their loved one dies, as well as frustration and isolation while they are alive, not realizing the need to reach out for emotional support. Helping a person name and process such losses while their loved one is still alive can be invaluable towards relieving the intense sadness that family members feel while the person is still present physically. That intense sadness is often misdiagnosed and treated as depression rather than as a normal process of grieving.

Depression is one of the most prevalent feelings reported by Alzheimer's family members. When these symptoms are presented to professionals, common solutions include providing information about the disease, information about how to best offer caregiving, advice to seek out support groups, and psychotherapy for depression with medication if necessary. Yet, a mental health diagnosis of depression may not be the best way to help these family members. There is more going on. Sanders and Adams (2005) explain, "The emphasis on caregiver stress and burden largely overshadows grief and loss" (p. 287).

Grief reactions and depression often present with very similar symptoms but there are significant differences. DSM-V (2013) describes depression as a disorder with the following features: "presence of sadness, empty, or irritable mood, accompanied by somatic and cognitive changes that significantly affect the individual's capacity to function" (p. 155). In reality, a caregiver with intense sadness usually functions at a higher level carrying out all the demands of caregiving. Therefore a diagnosis of clinical depression might not be appropriate or helpful since a goal of depression counseling is to increase functioning.

Grief is not listed in DSM-V as a disorder but is mentioned as a note under the section *Major Depressive Disorder* saying, “response to a significant loss may include feelings of intense sadness which may resemble a depressive episode. Such symptoms may be understandable or considered appropriate to the loss” (p. 161). The grief reaction a caregiver has is a normal reaction. It could be more helpful to acknowledge this and focus the counseling on helping to process the losses that the family member is experiencing.

When professionals address the depression and not the grief, it can be even harder for caregivers to deal with the emotions they are experiencing as a caregiver. Raphael, Minkov, & Dobson explain: “The cognitive focus of depression is on the negative interpretation of self and the world, whereas in grief the focus is on the loss experience” (as cited in Sanders, Ott, Kelber, & Noonan, 2008, p. 498). For caregivers, the situation they are experiencing is based on real demands of caregiving for someone with Alzheimer’s disease, not on a negative interpretation of their life’s experience. Addressing their losses can be a more productive approach to helping family members deal with their situation.

Various researchers who have done work with Alzheimer’s families feel that making this distinction between depression and loss is important in understanding how to best work with the family members. Boss argues that the depression commonly noted in caregivers “probably has more to do with the ambiguity of their loss than the heavy workload.”(As cited in Sanders & Adams, 2005, p. 288) Meuser, et al. say: “Grief associated with dementia caregiving may be the primary determinant of all other caregiver affects” (2005, p. 192).

According to Sanders and Adams: “About half of what we measure as “depressive symptoms, may be due to grief-related experiences and those legitimate, perhaps time-limited, reactions to loss suffered and anticipated by virtue the dementia disease process” (2005, p. 293). Corley found that “even if the caregivers reported that they were not experiencing feelings of grief, indications of loss were present in their statements” (As cited in Sanders & Adams, 2005, p. 288).

It is also helpful to understand that the sense of grief and loss is not constant and may vary depending on the relationship of the family member to the person with Alzheimer’s disease or the stage of the disease the person is in. A study done by Meuser & Marwit (2001) found, “The grief process is different for adult-child caregivers than for spouse caregivers” (p. 667). It also varied by the stage the person with Alzheimer’s was in. In the early stages, adult-child caregivers were in denial, not able to accept the changes they were noticing. They avoided discussing the future and minimized their feelings. They often attributed the changes to normal aging. They also expressed the losses as self-focused, including their loss of freedom. Spouse caregivers were better able to accept the changes they were noticing in their spouse. They were “more open, accepting, and realistic about their mate’s present condition and the impending burdens” (p. 667). They were also able to express their feelings of sadness and expressed their losses related to the decline of their partner and the loss of companionship.

During the moderate stage of Alzheimer’s, adult-child caregivers could no longer deny what was happening. The predominant emotions felt were: “anger, frustration, jealous of others who are not experiencing Alzheimer’s disease caregiving, and guilt over newly emerging wishes that the parent would die" (Meuser & Marwit, 2001, p. 667). Grief is highest for this group during this stage.

For spouse caregivers, the second stage brings a gradual increase of the feelings experienced during the first stage. It is accompanied by an increase in empathy and compassion. An explanation for why spouses react differently, is that when parents are healthy, children don't imagine their parents aging poorly. Whereas for spouses, "they prepare for this all of their married life" (Meuser & Marwit, 2001, 667). It is at the third stage that spouse caregivers experience an upsurge in grief and a shift towards anger and frustration. For both groups, when the disease progresses enough that there is a need for nursing home placement, emotions change. At first there is a feeling of relief, but this is followed by "unwanted feelings of self-care and of being uncoupled" (p. 667).

As we work with Alzheimer's families it can be helpful to know what stage their loved one is in to better understand and address the emotions they are experiencing. Anderson & Sanders (2004) found "the strongest qualitative finding is that those caregivers dealing with the late stage of disease score high on grief and depression measures" (p. 206). Those in the early stage were less likely to say there were grieving. They still had hope that things could get better. When they began to observe changes in communication, loss of activities they could enjoy together, and the person with Alzheimer's becoming more dependent, caregivers began to feel more grief as they worried about future decline (p 206).

Worden (2009, Ch. 2) talks of four different tasks of mourning:

- Accepting the reality of the loss
- Processing the pain of grief

- Adjusting to a world without the deceased
- Finding an enduring connection with the deceased in the midst of embarking on a new life

These tasks can be reframed in terms of having a loved one with Alzheimer's disease. One task is to accept the reality of the disease. As stated before, there is no cure at the present time. This means that once a person has been diagnosed with Alzheimer's disease, there will be a steady decline in cognitive function, even though the timing may vary. I believe it is a major turning point in a family member's experience when they can truly accept the diagnosis and no longer expect their loved one to act as before.

Processing the pain of grief is often difficult because the losses that occur are often vague, slowly changing, and hard to define. Also, the process is often done alone because other family and friends may not appreciate the losses that the family member is going through. Friends and other family members may also feel too uncomfortable in the presence of someone with Alzheimer's disease, not knowing how to react, so they stay away.

Family members do not get the community support for their grieving as one would get at a funeral. Rabbi Rachel Adler (2012) found this to be a source of frustration and anger. She talked about her feelings at her mother's funeral: "At the funeral we are all angry. My mother's beloved points out all the friends and relatives who didn't visit when she was alive. We did our mourning alone with no community to comfort us" (p. 83). One way that clergy or counselors can help a family member process the losses they experience is to help them "internalize aspects related to the person who is being mourned. What aspects of that person helped to create and enrich who that family member is today?" (Pearce, 2010, p. 10).

Another task of mourning is to find a way to adjust to a new world in which the person with Alzheimer's can no longer participate as they had in the past. This might mean family get-togethers where the person with Alzheimer's, while still present, takes on a new and different role, often needing to be cared for more as a child. For a spouse, this might mean going out with friends as a single person, rather than as a married couple. Internally this may mean redefining one's identity. One of the challenges is to start feeling "like a 'self' rather than half of a dyad" (Worden, 2009, p. 46). This entire process may not take place until their spouse dies but part of this mourning task can begin during the illness, as the family member is no longer able to be in the role of spouse as they had been throughout their marriage.

The challenge of finding an enduring connection to the person with Alzheimer's can be daunting. An adult daughter whose mother had Alzheimer's disease reported that she "desperately wanted to connect with her mother and expressed deep sadness and pain with the disconnection" (Pearce, 2010, p. 10). The counselor she was talking to tried to show her ways to interact with her mother. Finally the daughter shouted, "But I do not want to connect with this mother, I want my mother back!" (p. 10). The daughter was distancing herself from her mother to avoid the pain and loss that came with longing for what could no longer be. Her task was to find ways to mourn the losses so she could move forward and accept the "new" mother that she had.

For others, while one is in the midst of being with a loved one with Alzheimer's, the disease is so all encompassing that there often is little time to reflect on and remember whom the person was before the disease. It may take until their actual death to be able to start this process. During the first year after my father's death, it was hard for me to think of anything other than the relief of no longer having to experience the "person" he had become or the intense care he required. Slowly, a year later, I began to be able to think back to a time before he got sick, remembering the father that I knew and loved.

Previous experiences of grief and loss can also affect a person's ability to cope with the new loss of personhood with an Alzheimer's family member. Worden (2002) explains, "In order to understand how someone is going to grieve, you need to know if he or she has had previous losses and how these were grieved" (p. 63). If a family member has prior losses that they have not adequately dealt with, this lack of resolution can complicate the grieving process of the new loss of a spouse or parent with Alzheimer's disease. This is complicated by the fact the person is still present and has not physically died.

Concurrent stresses can also make it harder to deal with a family member who has Alzheimer's. An elderly spouse may have his or her own health issues to deal with, which often get exacerbated by the burden of caring for someone with Alzheimer's disease. Adult children may have their own children who have demands on them in addition to the demands of their parent. Job stresses and marital stresses can add to the challenges they face with their parents. Since the causes of Alzheimer's disease are not truly know yet, adult children may also be dealing with the fear that the disease is inherited wondering, "Is this what I will be like in 25 years?" "Who will take care of me if I get like this?"

Since Alzheimer's disease is a family disease, it not only affects the person who develops the disease, but also all the family members including spouse and children. Friedman (1985) understands the family as a system. When one part of the system changes, the entire family changes. "The most outstanding characteristics of systems thinking are its departure from traditional notions of linear cause and effect" (p. 15). It is helpful to understand this as an equation. A + B + C + D = E. A, B, C, and D are individual family members that make up the family system, E. "Each part of the system is connected to, or can have its own effect upon every other part… The components [of the system] do not function according to their 'nature' but according to their position in the network" (p. 15).

This becomes significant with Alzheimer's families. Even though the family member with Alzheimer's is present, he or she has changed significantly and becomes in effect a new "letter" of the system. Just as when there is a new family member due to marriage or birth, the family needs to adjust to having this "new" member of the family. With Alzheimer's there is the additional complication that the new family member is also a long-standing member of the family that has played a role in the family that he or she can no longer play. If the person with Alzheimer's disease is a parent, the role that the parent played in the family system continues to be part of the relationship even as children become adults. If the family member is a sibling, their place in the family system will also change. Each child in a family takes on a certain role based on their relationships with their parents and with their other siblings. Since some of these roles in the family are subtle and not overtly obvious, there may be a sense of feeling unsettled as each family member adjusts and different family members consciously or unconsciously change to fill the void.

All other family members are affected not only in their relationship to the Alzheimer's family member, but in relation to all other members of the family. Sligar (1987) says, "Even in families which have functioned happily with minimal conflict, the onset of the disease causes old issues to resurface and be exacerbated…The natural rivalry which exists in every family is revitalized as each child attempts to be the best caregiver and deal with their guilt that they are so limited in the face of the disease" (p. 346). Reflecting on her family's experience with a mother who had Alzheimer's disease, Hodder (2009) commented, "I believe my personal experience with Alzheimer's disease would have been much less painful had our family been able to reach decisions based on consensus" (p. 67). Often difficult decisions need to be made by families regarding the person with Alzheimer's disease as well as the elderly spouse's ability to continue to provide care and maintain his or her own health. The challenge is that there is often not only one correct or definitive answer. When family members disagree on the best approach, stress levels can become very intense.

Adult children often play a role in helping a parent with Alzheimer's disease, whether as primary caregiver or caring child offering support. When more than one child is involved, dealing with an aging parent can affect the relationship between the siblings. Sometimes it can bring them closer, and sometimes it can reignite old conflicts. Carter & McGoldrick (2005) explain, "Relationships that have been maintained at a superficial level may break under the strain of caretaking or under the pain of the distance that has grown between them" (p. 158). Siblings are forced to deal with each other in new ways as they try to cope with a parent with Alzheimer's disease. This situation "may either draw siblings together or arouse conflicts over who did more or who felt loved less…If there are unresolved problematic issues in a family, they are likely to surface at this time in conflicts over the final caretaking" (p. 158).

Lewis (n.d.) explains a different way of understanding the unresolved issues from childhood. Adult children often interact as adults the way they did as children without realizing it. "These invisible ghosts haunt you when you least expect them…Ghosts have at least three components: frozen images, crystallized roles, and unhealthy loyalty" (location 64/1917). She explains that you may have frozen images of your siblings from childhood that cause you to react to them the same way as adults, even though both siblings have changed. She also explains that parents tend to label their children, "assigning roles that shape part of their behavior…the comic, the smart one, the troublemaker, the irresponsible one, the loner, etc. (Lewis, n.d. location 64/1917). These roles tend to stay with us into adulthood and affect our interactions with our siblings, even if the role labels are no longer descriptive of whom the siblings has become as adults. Unhealthy loyalties may carry into adulthood as two siblings who were close as children tend to agree with each other more easily as adults than other siblings in the family. These ghost reactions are "especially common when siblings are in the presence of their parents or when they are trying to work together to take care of their aging parents" (Lewis, n.d., location 87/1917).

The family dynamics should be taken into account to best help Alzheimer's family members. If possible, arranging to meet with siblings together, or caregiving spouse and adult child, can be helpful. It can provide a safe place to discuss their concerns as well as explain their different perspectives without them needing to be defensive.

There is one additional loss that is very subtle but very present - the loss of the ability to repair relationships. When a person develops Alzheimer's disease past difficult interpersonal issues with his or her spouse or children, some of which have been suppressed for years, may begin to surface again. As the person with Alzheimer's gets more difficult to manage and communicate with effectively, these old hurts and resentments return. For a spouse it may be the sense of imbalance in sharing responsibilities in the house, which are now solely the responsibility of the caregiver. It may be resentment towards the spouse who had interfered with socializing in the past, who now prevents the caregiver from socializing at all. It may be a spouse who didn't feel appreciated enough, and now, is not appreciated at all, but also has to deal with an even more demanding and critical spouse.

When such issues arise and the family member becomes aware of it, this additional loss begins to surface. One then realizes that he or she can no longer repair the cracks in the relationship because the person with Alzheimer's is not cognitively able to understand the issues and discuss them in a meaningful way. Because of this the family member must find ways to resolve the conflicts independently of the loved one with Alzheimer's.

Conflicts between family members can be dealt with in different ways. For some families, they are able to talk things out and resolve the conflicts in a productive manner. For others, in order to "keep the peace" they remain quiet as anger and resentments simmer beneath the surface. They feel that there is time later on to resolve their issues. It may take a crisis to bring things to the surface again. We often hear stories of family members that had been estranged coming together when one receives a diagnosis of cancer. Knowing that their time is limited, they work on repairing the relationship before it is too late. With

Alzheimer’s disease it is different. By the time one realizes their family member has the disease it is already too late. An adult son caregiver explained it this way. “I had a fear of losing a relationship with my mother that I never really had. And so I wasn’t grieving just the loss of our actual relationship, but I was grieving the loss of a relationship we never had, and now could never, would never happen” (Angelica, 2013, p. 6).

For adult children, each child may react differently. “One child may need to grieve the loss of an exceptionally tender and loving parent while a sibling may need to grieve the loss of hope of ever experiencing an authentic connection” (Pearce, 2010, p.10). Each adult child mourns these losses in their own way. As the roles begin to reverse, and an adult child now needs to care for his or her parent, parental issues of not being there enough as a child can come into play. There may be a subconscious feeling of resentment, as the adult child now needs to be the one to be there for the parent, who wasn’t there for him or her. Address (2012) explains, “There is a part of us that may wish to ‘do the right thing. ’ Yet, because of past family dynamics, that desire may come in conflict with personal history and cause undue stress and strain” (p. 89).

As people with Alzheimer’s lose their social filters and begin to say things that are hurtful, feelings of past, hurtful statements are often relived by their adult children. This doesn’t mean that hurt family members don’t try to fix these past wounds. When they do they find the attempts just add to the frustration and anger because the person with Alzheimer’s disease is not cognizant enough to have such a discussion. Some are able to overcome the resentment. Angelica (2013) reflects on the early relationship, or lack of relationship, she had with her mother when she was a child. “My relationship with my mother was different than the others. Our relationship was fractured in my childhood by her failure to protect me from my father's sexual abuse" (p. 7). She said she was able to care for her mother when she realized that her mother transformed from "an empowered, independent woman, to a confused, vulnerable, dependent, innocent elder" (p. 8). Knowing that her mother needed her, she felt as if she had a "call" from God. She spent time learning about her mother. Angelica found that her mother lost her own mother when she was seventeen, her true love left her to marry someone else, as a result she married someone she didn't love, and she was widowed at the age of fifty-two (p.8). Angelica began to understand that in her own feeling of abandonment, her mother had also lived a life of abandonment, with the final abandonment being her mind. This made her even more likely to care for her mother. "Not on my watch will someone who belongs to me be abandoned during her time of need" (2013, p. 8).

Individual Differences

A support group might be a place where family members can voice such thoughts to better understand their feelings and actions towards their family member with Alzheimer's disease. However, some family and person issues have roots in earlier family dynamics unrelated to the disease.

While people who have a family member with Alzheimer's disease may suffer from similar stresses, the psychological tools that one brings to the situation can either help or hinder the ability to cope with their loved one's condition. Pine talks about four different approaches to understanding how one's childhood development can affect the way a person relates later in life: (1) Drive psychology, (2) ego psychology, (3) objection-relations theory, and (4) self psychology (1990).

Drive Theory

The drive theory addresses urges and wishes (Pine, 1990, p. 13). This explains people's behaviors based on biologically based drives that take the form of psychological wishes (p. 33). This may be relevant for Alzheimer's family members experiencing guilt over negative feelings or thoughts they have towards their loved one. Pine explains that when a wish becomes unacceptable it turns into guilt, which is an "aggressive drive turned on the self" (p. 33). It is not uncommon for family members to feel anger and frustration towards their loved one with Alzheimer's disease. Because the family member appears normal it is easy to forget that he or she is not the same person remembered from past experiences. Their forgetfulness, constant repeating of questions, inability to listen and respond appropriately, and overall changes can evoke negative emotions. Family members may lose their loving feelings toward the person with Alzheimer's disease and/or secretly wish that their loved one just "go away," or die. The drive to behave lovingly towards a spouse or parent causes them to know that such feelings are "wrong" and turns those feelings into guilt. Understanding the origin of the guilt can help family members process that guilt.

Ego Psychology

Since having a family member with Alzheimer's requires ongoing adaptation to new situations, understanding ego psychology can be helpful here. The ego can be understood as the source of adaptation (Palombo, Bendicsen, & Koch, 2009, p. 53). Hartman describes the synthetic function of the ego as being able to synthesize experiences and therefore adapt to reality. There are two ways to do this. The first is through alloplastic change. The individual changes the environment to more easily adapt (Palombo, Bendicsen, & Koch, 2009, p. 55). An Alzheimer's family member may find the need to maintain a stable environment for their loved one, avoiding experiences that they used to enjoy such as socializing, eating out in restaurants, going to movies, etc. Since the person with Alzheimer's often shows behavioral changes when exposed to new situations, it is easier for caregivers to avoid such situations, i.e. avoid environments that are stressful to their loved one, even if such experiences had brought them pleasure in the past.

Autoplastic change occurs when an individual changes aspects of himself to help deal with the reality they are facing (Palombo, Bendicsen, & Koch, 2009, p. 55). With Alzheimer's disease, family members need to change their approach to their loved one. They adapt by realizing the person with Alzheimer's is no longer the same person they used to know. Rather than getting frustrated and angry, it helps to remind oneself that the person's behavior is due to the disease and not a personal attack on the family member.

Anxiety is a component of the emotional toll of having a loved one with Alzheimer's disease. Anna Freud talks about three types of anxieties: instinctual anxiety, superego anxiety, and objective anxiety (Palombo, Bendicsen, & Koch, 2009, p. 55). With instinctual anxiety, the ego works to control reactions to instinctual impulses such as hatred, anger, and rage. These are common feelings that can arise as a family members try to cope with the person they are "stuck" with who is difficult to be with, no longer acting like the loved one they used to know. Since such impulses are not acceptable, the superego takes over to suppress such reactions. Objective anxiety results from outside forces, such as those dealing with someone with Alzheimer's, which can also arouse defenses in the individual.

There are various defense mechanisms that come into play in ego psychology including: altruism, avoidance, denial, and displacement. (Palombo, Bendicsen, & Koch, 2009, p. 72). Altruism is a common defense that is called upon by caregivers. It is the ability to attain satisfaction through service to others. Seeing caregiving as a way of helping your loved one makes the situation easier to accept and deal with. Avoidance is another defense that is common with family members. Those who are not primary caregivers may visit less often. Those who are, may try to find other things to do instead of providing the care their loved one needs. Denial is also a common defense. When symptoms first appear, family members are often quick to say they are just normal aging changes. Adult children remain in denial far longer than a spouse. With displacement, the family member may take out their aggressions toward another person or family member rather than show their true emotions to their loved one with Alzheimer's disease. Being aware of these different defense mechanisms can be helpful to understand how to best cope with the situation.

With ego psychology, "the individual is seen in terms of capacity for adaptation, reality testing, and defense…to deal with the inner world of urges, affects, and fantasies and the outer world of reality demands" (Pine, 1990, p. 34). Problems with ego development in childhood can lead to "affect intolerance, unreliable delay and control over impulses" (p. 34). This can come into play for Alzheimer's family members. A person who was not able to develop the ability to adapt well to changing situations or is unable to face reality may have difficulty controlling their emotions and actions towards the person with Alzheimer's. Even for people who have developed a normal ego, extenuating circumstances can tax the ability to cope. Validating the family member's feelings and helping them understand where their strong reactions come from can help them cope with the current situation.

Object Relations

With object relations, the individual is understood in terms of "an internal drama, derived from early childhood [relationships], that is carried around within as memory and in which the individual [re]enacts one ore more of all of those roles" (Pine, 1990, p. 34-35). There is a tendency to repeat these old family dramas with other relationships in adulthood. As the person with Alzheimer's disease changes behavior and personality, this could stir up memories in the family caregiver of earlier negative experiences of a conflicting relationship with a parent. For example, a person who was not able to develop a sense of positive relating to a parent in childhood could have found that sense of relational connection during the years of their marriage. When the relationship to the newer "object," the spouse, is interrupted by Alzheimer's disease, this behavior may bring back the negative emotions from their childhood. Having a discussion with the Alzheimer's family member about how they have related to their spouse, (and others), in the past can be helpful as they learn how to negotiate a relationship with their "new" spouse.

Self Psychology

Self psychology refers to a psychology of self experience, and involves the relationship of self to other. This includes esteem of self, along with "wholeness or fragmentation, continuity or discontinuity" (Pine, 1990, p. 38). This also includes "the actual historical mirroring and ideal formation functions served by the parent for the child" (pg. 38). Parents or child caregivers who are successful in responding to their infant's physical and emotional needs help to form a child with a good sense of self. Such a parent becomes idealized in the mind of the child further developing a sense of self-esteem and confidence. This sense of self is carried into adulthood.

In talking about self psychology, Cooper & Randall (2012) explain “the state of our self – its level of assuredness, its sense of well being - is subject to fluctuations. (p. 2) This fluctuation can be affected by how responsive we feel people are to us. There are three different ways to experience this (p. 3): (1) When we feel others approving of and applauding us we feel confident inside. (2) When others are reliably available to us we feel calm and fortified. (3) When others convey to us that they are like us and we are like them, we feel that we belong.

A positive feeling of self can be interrupted when a spouse or adult child interacts with their family member with Alzheimer’s disease. No matter how much one tries to attend to the needs of the Alzheimer’s person, it is rarely appreciated. A family member can no longer expect their loved one to be available to them emotionally. A spouse or adult child may no longer feel their loved one belongs to the family, at least in the way they did before the disease took over. While these are not the fault of the person with Alzheimer’s because the disease robs them of the mental capacity to do so, it is still hard for the spouse or adult child to see this objectively. In the midst of all the stress, it is hard to remind oneself that the person is not doing this on purpose or to be mean, but can’t help it. The sense of self can feel attacked.

All of this can lead a family member to withdrawal from the person with Alzheimer’s disease and experience anger, sometimes yelling at their loved one in a way they never did before. In self psychology a common reaction to feeling let down is to respond “by drawing back or by striking out… Our withdrawal and/or rage are often ways of trying to hold our self together" (Cooper & Randall, 2011, p. 4). Such a reaction can create a great sense of guilt, being angry with oneself for reacting in such a way towards someone they love.

Clergy can play an important role here. What can be particularly helpful is to be an empathetic, non-judgmental, and caring listener as the family member describes what it feels like to be unappreciated and not listened to by their loved one with Alzheimer's disease. We can become the one who listens and affirms all that the person is doing for their loved one. We can assure them they are doing the best they can under the circumstances. We can be a reliable source of support. When they no longer feel they are like their family member with Alzheimer's disease who had in the past given them a sense of belonging, we can remind them that they belong to the congregational family who is there to offer them a place of support, comfort, calmness, and stability. Being part of an Alzheimer's support group can also give family members a sense of belonging to the group, identifying with others in the same situation.

Bowlby's attachment theory can also help to understand how a spouse or adult child relates to their loved one with Alzheimer's disease. "There is a tendency in human beings to create strong affectional bonds with others…[It explains] the strong emotional reaction that occurs when those bonds are threatened or broken"(Worden, 2009, p. 13). The first attachment a child has is to his or her mother or caregiver as a baby. "Infants seek shelter and safety from predators in the service of survival for forming a secure bond with their caregivers"(13).

This attachment during childhood paves the path for later attachments in adulthood. Spouses often become the new object of attachment. "According to Hazan and Shaver, the emotional bond that develops between adult romantic partners is partly a function of the same motivational system--the attachment behavioral system--that gives rise to the emotional bond between infants and their caregivers" (as cited in Fraley, 2010).

With a couple in which one has Alzheimer's disease, attachment theory can play out in two directions. As the person with Alzheimer's disease slowly regresses, he or she may attach to their caregiver, no longer as a spouse, but as they had attached to their parents when they were children. In attachment theory, when a child is separated from the caregiver for whom they created an attachment for a significant amount of time, several reactions occur. Protest reflects separation anxiety. Separation…leads to the expression of distress signals" (Polombo, Bendicsen & Koch, 2009, p. 292).

This is seen when a caregiver tries to create some physical distance from the person with Alzheimer's disease. He or she may go into a different room of the house to get a break. It is not unusual for the person with Alzheimer's disease to call out their name, question where they are, and then find them. This can include intrusions into the bathroom. A sense of "losing independence" is common among caregivers. It would be helpful to help family members understand the changing perspective of attachment. A spouse or adult child does not want to think of their loved one as a child who attaches to them as a child would to a parent. This is a difficult idea to accept. If they understand what is occurring in the emotional mind of the person with Alzheimer's disease, they may be less resentment towards offering care and support to their loved one.

A spouse who has transferred parental attachment to their spouse when they form a couple, can despair as the person they attached to develops Alzheimer's disease and is no longer available to provide the emotional support they need. This despair reflects a process of grief and mourning. Detachment is a defense against intolerable psychic pain (p. 295). Spouses of people with Alzheimer's disease can go through similar emotions, feeling as their loved one is slowly slipping away. There is an initial protest or denial as the person can no longer be there for them emotionally and socially. Then a sense of despair, grief and mourning overcomes them. Some spouses eventually start mentally detaching from the person with Alzheimer's because they can no longer bear the pain. One spouse told me that even though they had been happily married for over 50 years, things got so bad that he thought about getting a divorce. The person in his home was no longer his wife and he couldn't bear the burdens of caregiving any longer. Being a supportive and empathetic listener can be helpful to a spouse in this situation. Caregivers understand that you can't change things or fix things but it can be very cathartic for them to have a safe place to express their frustrations and feelings.

If a spouse has developed a secure attachment style through earlier healthy relationships, they have "positive mental models of being valued and of being worthy of support, concern, and affection" (Worden, 2009, p. 67). Such people are better able to handle the loss of a loved one when it occurs. This could also help a person deal with the slow and gradual losses that occur with Alzheimer's disease. Others, who did not have healthy relationships as a child, develop insecure attachment styles.

There are several different types of insecure attachment styles. With anxious/preoccupied attachment, a person is "often super-sensitive to slights and other perceived neglect in the relationship" (Worden, 2009, p. 68). In the early stages of Alzheimer's disease, a spouse or adult child may take the subtle changes in their loved one personally and react strongly to them as a form of rejection. A clergy member or counselor can help a family member process such feelings of rejection, helping them to see that the behaviors of the person with Alzheimer's disease is a symptom of the disease itself, and not a result of the family member intentionally rejecting them.

With anxious/ambivalent attachment, "love and hate coexist on almost equal levels" (Worden, 2009, p. 68). When a person with Alzheimer's is no longer able to relate appropriately to a family member and is no longer present cognitively, the family member may experience intense anger and anxiety. The anger can be understood as "the protest of the child [who is separated from his or her parent] to reestablish the physical proximity of the attachment figure" (p. 69). To counteract this emotional reaction, a person may focus only on the positive aspects of their family member with Alzheimer's almost as a form of denial. "The mourner makes their loved one bigger than life so as not to confront the depths of anger on the other side of their experience" (p. 69). This can become a problem if this idealization blurs the true needs of the person with Alzheimer's disease. Here the clergy member or counselor can help the person balance both negative and positive feelings and emotions.

A person who had an unresponsive parent as a child may develop avoidant/dismissing attachment. "Autonomy and self-reliance are of paramount importance to them" (Worden, 2009, p. 69). They feel they can handle it. Such people may not have much of an emotional reaction to their loved one with Alzheimer's disease. This doesn't mean that the emotions don't exist, but they are likely suppressed. At some point they may need to process these emotions. Being a safe and empathetic ear for the family member to explore what they feeling can be helpful.

Someone with avoidant/fearful attachment may have the hardest time adjusting to the losses that occur with Alzheimer's disease. "When death [or loss] takes away any attachments they have developed, they are very likely to develop high levels of depression" (Worden, 2009, p. 70). Here it would be important to identify when in addition to the grief and loss, the person is experiencing true depression.

One last developmental theory that can be applicable here is Erikson's "Stages of Man." Erikson talks of 8 different stages that an individual goes through (Palombo, Bendicsen, & Koch, 2009, p. 209). Each stage determines how a child develops in different areas:

- Infancy – Basic trust or basic mistrust
- Early Child – Autonomy or shame and doubt
- Play Age – Initiative or guilt
- School Age – Industry or inferiority
- Adolescence – Identity or identity confusion
- Young Adulthood – Intimacy or isolation
- Adulthood – Generativity or stagnation
- Old Age – Integrity or despair

Each stage must be successfully mastered before moving on to the next stage of development. Depending on the age of the spouse when their loved one develops Alzheimer's disease, some of these stages can be affected. Adulthood is the time when generativity or stagnation occur. It is at this stage that people focus on career and family. If a person develops early onset Alzheimer's disease the spouse can be at this stage. So can an adult child who becomes the caretaker for their parent. He or she may be very involved in a career or other meaningful work. Their plans may have to be put on hold or abandoned so the spouse or adult child can take care of their loved one who develops Alzheimer's disease. Creating and producing adds meaning to one's life. Rather than feeling they are stagnating when they become a caregiver, a clergy or counselor can help the family member see this as a new role that has meaning. Generativity does not need to be measured only by physical production or a list of accomplishments. Creating a nurturing and caring environment for a loved one with Alzheimer's disease can be generative in a different way.

Older age is the time to reflect on one's life, wondering if one has lived with integrity. Having to become a caregiver at this stage of life can challenge one's opinion of oneself. A caregiver may feel that this is the final chance to see if they can live with integrity as they try to take care of their spouse. With all the stresses, they wonder if they can live up to the ideal. If negative thoughts start to surface, it can lead to feelings of despair that their caregiving is not good enough. Being a supportive listener and validating the importance of the caregiver's role can be helpful.

For a spouse caregiver, it is hard for one to think that one is successful when there is so much that is out of the individual's control. There is so little a spouse can do to change what is happening to their loved one and to themselves. Perhaps it is more about putting things in perspective. McGoldrick et al. (2001) say, "A common thread in successful aging is the dynamic process as older people come to see themselves not as victims of life forces, defined by their limitations, but rather as resilient, with the capacity and initiative to shape as well as be shaped by events" (pg. 273). Clergy and counselors can help a caregiver spouse see their role, not as a burden that makes them feel helpless and inadequte, but as an opportunity to learn and grow from the experience.

All of these numerous factors play a role in how a family weathers the challenges of Alzheimer's disease. Clergy and mental health counselors can play a role in helping these various family members understand these factors. This knowledge can provide more appropriate and more effective guidance. I believe that regardless of the background of a family member, the most important role of a clergy member or mental health counselor can play is to provide a safe, non-judgmental, empathetic environment in which the family member can talk about their experiences, their emotions, and their sense of their own self through this process.

B. Religious Principles

As a rabbi my theological world-view was challenged when my father developed Alzheimer's disease until I opened my heart to alternative ways of thinking. I remember waiting at the airport for my return flight home after visiting my parents. Being away from my father's constant demands and needs, I had time to reflect on him and his newly named diagnosis. I was suddenly overcome with incredible sadness and distress, and I broke down sobbing. I was so tormented and frightened by the fluctuations in my father's ability to think. At times he was able to carry on a normal conversation and then in an instant it seemed like he had lost his mind and became totally confused and disoriented. In the past I had always turned to God to find comfort and support. As I poured my heart out to God, an idea came to mind. In order to be at peace with my father's diagnosis, I had to change my approach. Rather than thinking my father's mind was gone, I could imagine him just being gone from this earthly world, envisioning that his soul was visiting God for a while.

According to Jewish tradition, when a person dies, his soul returns to God. There is a beautiful morning blessing, *Modeh Ani* that says, "I offer thanks before You, ever-living Sovereign, that you have returned my soul to me in mercy." This blessing was written by the Sages and is based on the belief that while you slept, your soul visited God for a while. When you woke up in the morning, you recited this blessing thanking God for returning your soul to you on earth to live another day. Later rabbis and the teachings of *Kabbalah* understood the soul to have many parts. The *n'shamah* is that part of the soul that contains our emotions and personality. The *ruach* is the animal instinct part of the soul that causes us to seek out physical needs such as food and shelter. The most basic part of the soul, the *nefesh,* is present for all beings that breathe. Applying these ideas to my father when his mind seemed “gone,” I could imagine that his *n’shamah* was visiting God, while his *ruach* and *nefesh* still remained with his body as he continued to be alive (Medwin, 2012, p. 114-122).

There are many different theological possibilities to consider as one attempts to cope with hardship when significantly challenging events occur in one’s life. Some turn to God for strength. Others question how God could do this to them. They may struggle with theological existential questions about what God’s role is, if any, in the process of the disease and suffering in their family. Some may be angry with God asking, “Why me?” or “Why my loved one?” Gillman explains the theological challenge of suffering this way: “If God exists, if His will is sovereign, and if He is just and compassionate, why are pain and suffering so intractable a dimension of human living?” (190, p. 187). When someone suffers, there may be feelings of abandonment, punishment, or indifference attributed to God since the suffering contradicts what they were told about God as one who loves them, cares for them, and was supposed to be there for them.

We often form our understanding of God during childhood. If we have a caring parent who was there for us, even if they were not always physically present at each moment, we can envision God in the same way. Rizutto (1996) explains it this way: “The capacity to represent and fantasize subjective experiences of relations to the object will permit the child to elaborate his representations, the first of these being the maternal object and the child as global representational unit” (p. 185). Winnicott says the face and eyes of the mother are the child’s first mirror. Later on the experience is used in the first representation of God, “whose mirroring function echoes the biblical account of man’s creation in Genesis 1:27, ‘God created man in his own image.’” (p. 186). Rizutto says, “God may draw his characteristics from whichever parent the child has accepted as the more indispensible for his psychic needs" (p. 197). For Alzheiemer's family members, those who had a positive relationship with a parent growing up, are more likely to turn to God for comfort and support during difficult times. Those who had parents who did not meet their emotional needs, may blame God, feeling abandoned once again.

There are many different theological explanations for why people suffer (Medwin, 2013, pp. 175-240). One theological approach to illness is that God is not the cause. Some may see illness and disease as genetically inherited. God may have created the world but as part of that creation biological changes occur due to the laws of nature that were set into motion at creation and have no purposeful intent. Others understand that sometimes disease is the result of pollution of the environment brought on by human beings, or lifestyle choices. When God is removed as the cause of the disease it can open the way to turn to God for comfort, support and strength to deal with the illness. The Talmud teaches, "The *Shechinah*, God's intimate presence, dwells at the bedside of anyone who is ill" (Talmud Nedarim 40a). God's presence can sometimes be felt even more strongly when we, or our loved ones, are stricken with serious illness.

Others do feel that God plays a role in the difficulties in their lives. For them, personal challenges have a specific theological purpose. The most common understanding of God's role in suffering is in the context of reward and punishment. This is a common theme in *Tanakh* (Hebrew Scriptures). We see this very early in the story of Adam and Eve. After they ate from the forbidden Tree of Knowledge of Good and Evil, God said to Eve, "I will make most severe your pangs in childbirth" (Gen. 3:16). Adam was also punished by God. "Because you did as your wife said and ate of the tree about which I commanded you, 'You shall not eat of it,' cursed be the ground because of you. By toil shall you eat of it" (Gen. 3:17). Later on God tells to Abraham, "I will bless those who bless you and curse him that curses you" (Gen. 12:3). The most striking teaching of God as one who rewards and punishes is in Deuteronomy. "See, this day I set before you blessing and curse: blessing, if you obey the commandments of the Eternal your God that I enjoin upon you this day; and curse, if you do not obey the commandments of the Eternal your God, but turn away from the path that I enjoin upon you this day and follow other gods, whom you have not experienced" (Deut. 11:26-28).

The God of the Torah (Pentateuch) can easily be viewed as a punishing God. It is not unusual for a person who follows their religious teachings to ask, "Why? Why is GOD doing this to ME?" Rabbi Harold Kushner (1981) felt that the usual traditional Jewish responses to why people suffer were easy to believe until you or someone you love personally suffered: "I believe in God. But I do not believe the same things about God than I did years ago, when I was growing up or when I was a theological student. I recognize God's limitations. God is limited in what He can do by laws of nature and by the evolution of human nature and human moral freedom" (p. 134). Based on this understanding of God, some Alzheimer's families may see Alzheimer's disease as a physical disease that is the product of nature rather than due to any type of punishment from God.

For others, they are content to know that since they have been a good person and are not worthy of punishment, that eventually they will get their reward, if not now then later, either in this world, or the *Olam HaBa*, the World-to-Come. This concept developed during the Roman period when life for the Jewish people was very cruel under Roman rule. The rabbis encouraged people to continue to follow the *mitzvot,* (commandments and laws), even though they did not feel they were being rewarded. The Talmud teaches, "In this world the wicked are rich and enjoy comfort and rest, while the righteous are poor. But in the *Olam Haba* the Holy One Blessed be God, will open up for the righteous the treasures of *Gan Eden* [Garden of Eden]" (Exodus Rabbah xxxi. 5). The rabbis reassured the people that their goodness would not go unnoticed.

Others may feel that there is a spiritual purpose for their experiences. In Genesis we are told "God put Abraham to the test" (Gen. 22:1). He then asks Abraham to take his son and offer him as a sacrifice on Mt. Moriah. There may be different interpretations of what was being tested but feeling that God is testing you can give one the strength to rise to the occasion. For some, this may inspire them to be able to cope with the challenges of taking care of a loved one with Alzheimer's disease.

The Bible acknowledges that there are times when the reward and punishment system is not applicable. The biblical person Job was "blameless and upright" (Job 1:1). He lost all that he had, suffering without knowing why. When he asked God what he was charged with, he did not get a definitive answer. Instead God replied, "Where were you when I laid the earth's foundations? Speak if you have understanding…Have you ever commanded the day to break, assigned the dawn its place…Have you penetrated to the sources of the sea…Have the gates of death been disclosed to you?...Have you surveyed the expanses of the earth? If you know of these – tell Me" (Job 38:4, 12, 16-18). God explains to Job that there are things that human beings cannot do and cannot know, that are the purview only of God. God shows anger with Job's accusations saying, "Would you impugn My justice? Would you condemn Me that you may be right?" (Job 40:8). Job's reply was, "Indeed, I spoke without understanding, of things beyond which I did not know…Therefore I recant and relent, being but dust and ashes" (Job 42:3,6). Even if like Job, a person doesn't understand why he or she is being tested, one can believe there is a purpose to their suffering even though it is beyond human comprehension.

Whether or not one sees the suffering they are experiencing as coming from God, they can see this as an opportunity to "make lemonade out of lemons." In Judaism, we have an expression that says, "*Gam zu l'tova* – this can also be turned into something positive." Seeing the world this way is also a sign of resilience. People can go through similar difficult events in their lives yet their ability to call on coping skills varies. Some are totally devastated and become "stuck" for a significantly long period of time or for the rest of their lives. Others find a way to move on despite the struggles. While past experiences are important in affecting how one copes in the present, creating meaning out of the challenging experiences can help one bounce back finding the strength to keep going.

Some people have taken tragedies in their lives and found a way to do something meaningful by helping others. They use it as inspiration to do good in the world to counteract their feeling of helplessness because of their situation. Most people are familiar with this practice because of the publicity given to celebrities who have turned their own suffering into something positive. Christopher Reeve and his wife created a foundation to fund research on spinal chord injury after his horse riding accident. Michael J. Fox started the Foundation for Parkinson's Research after he was diagnosed with early onset Parkinson's disease. Both of these foundations have furthered research, finding treatments for their conditions so others may benefit.

Some every-day people become well known because of the work they have done following a personal tragedy. John Walsh became an activist after his son Adam, was kidnapped and murdered. Through his TV show, *America's Most Wanted*, Walsch helped to capture over 1000 criminals. Other people find ways quietly to add purpose to their lives based on their suffering. They support organizations, vote for candidates who support related legislation, and reach out to help others who are in a similar situation. Alzheimer's family members may become active with the Alzheimer's Association volunteering their time or fundraising for Alzheimer's research. Because my father had Alzheimer's disease, and I knew the suffering our family went through, I chose to do my D.Min. project to help other Alzheimer's families.

"Suffering" is a common word used to describe the experience of family members with a loved one with Alzheimer's disease. In the early stages this can also apply to those with the disease who struggle as they begin to realize that their memory loss affects day-to-day living. "Why do people suffer?" is one of the most fundamental questions that all religions try to respond to. Part of the suffering that Alzheimer's family members experience is due to the many losses they experience. Lancaster and Palframan believe that for some, "engagement with the spiritual domain is a fundamental part of grief work" (as cited in Bray, 2013, p. 891). Whether from God or not, many people are able to grow in ways emotionally and spiritually through their suffering that they could not do under more favorable circumstances. "When we are no longer able to change a situation… we are challenged to change ourselves" (Frankl, 2006, p. 112) If we can challenge ourselves to respond in a positive way, we find new ways of healing both spiritually and emotionally. "People forget that often it is an exceptionally difficult external situation which gives man the opportunity to grow spiritually beyond" (Frankl, 2006, p. 72). As much as we prefer not to admit it, it is through such difficult times that we are forced to look inward, to find the strength we never knew we had, so we can move forward.

One way to help Alzheimer's families realize the spiritual growth they have attained is to ask them to reflect on what they have learned during this process about "love, tenderness, vulnerability, suffering, intimacy, communion, courage, strength and survival" (Pearce, 210, p. 10) One adult child caregiver said, "I know I can handle more now – without crumbling – than I ever thought I could" (Angelica, 2013, p. 5). We are inspired to do something of meaning when we are faced with something that it is difficult to make meaning of. Bray explains, "The subtle effects of spiritual emergence are characterized by an acceptance or readiness to integrate transpersonal, religious and spiritual experiences, which result in maturity and expanded consciousness…Spiritual emergencies allow individuals to make changes to values and existential priorities that lead to an expanded worldview." (2013, pp. 894-5). It may be hard to realize these changes as you are going through them. Once the crisis has passed, one can look back and realize that they have become a different and hopefully better person because of what they went through.

In addition to doing something meaningful, Alzheimer's disease also challenges us to infuse meaning into a difficult situation. Such experiences can inspire us to change internally. Dreskin (2012) shares what she has learned. "I continue to learn from [my mom] how to transform what others might see as a severe disability into an opportunity to accept one's shortcomings or lack of experience or knowledge with honesty, grace, and charm" (p. 60). Being with a loved one with Alzheimer's disease also asks of us to view the world from a new perspective. After being extremely frustrated with her mother for continually asking the same question over and over again, Dreskin (2012) said, "I had a realization. My mother actually was not asking me the same question over and over again. She was asking a new question, from her point of view, every time" (p. 60).

With all the difficulties that Alzheimer's families experience, how do they keep going dealing with a loved one who no longer seems to be the same person they loved? One way is to remember that each and every person, regardless of circumstances, is created "in the image of God" (Genesis 1:27). When God created Adam, God breathed into Adam *nishmat chayim*, the breath of life (Genesis 2:7). Keck describes Alzheimer's disease "as a 'theological disease' because of the fierce challenges it poses to our beliefs about what it means to be a human being created by God" (as cited in Kohn, 2012, p. 79). Even as parts of the person seem absent, the person is still alive. The person still has a soul. Rabbi Richard Address (2012) says, "Who can say anything other than there is still a soul in there, locked in some prison of dementia, but still there, somewhere" (p. 159). Remembering that our loved one still has the same soul, even though he or she seems to be a different person, can help the family view the person with Alzheimer's disease more positively.

Rabbi Sheldon Marder (2012) says, "We touch the soul of the person with dementia through acts of empathy and compassion" (p. 83). "While it is hard to remember, it is important to try to treat people who have Alzheimer's with understanding and to relate to them at their level. "If an older adult needs an amputation of a leg, the world knows how to respond. We replace the lost mobility with crutches, an artificial leg, or other alternative ambulatory devices. When a person is losing memory and cognition, we need to do similar things: find ways to use alternatives to memory and rational thinking" (Ellor, 1997, p. 20).

Despite the challenges of being with my father, he always seemed to find a way to make others smile. He would stroll around in his electric wheelchair telling jokes and singing, "*Que sera, sera*, whatever will be, will be." After his funeral we had a memorial service for him at the senior assisted living residence where he and my mother lived. So many people told us how much they loved my father and would really miss him. It was hard for my mother and for us, his children, to remember this side of him because of the ever-present Alzheimer's side of him that we had to deal with. Their words helped us to recognize and appreciate the soul that my father had, despite his Alzheimer's.

How can a family member better relate to a loved one with Alzheimer's disease? One way counselors and clergy can be helpful to the adult child is to help them reflect on what their parent was like before the disease. Have them share stories of their childhood that evoke loving memories of their parent. "When we allow families to introduce us to their loved one through their eyes, they will share thoughts, feelings and memories about who this person with Alzheimer's disease has been in the world. They explore the qualities that the person exhibited throughout their life" (Pearce, 2010, p. 10). For adult children who did not have a good relationship with their parent, "using the world love may be difficult and can certainly be substituted with the words, respect, honor, appreciation, devotion, fondness, admiration, or positive regard" (p. 10). Sharing these stories helps the adult child carry the more positive memories along side the present reality.

Marder (2012) encourages us to find ways to join the patient. "Joining the patient means entering into his world without inhibition and recognize that he is now a different person…We only torment ourselves if we keep comparing our loved one with the way he or she used to be" (p. 85). In her book, "Learning to Speak Alzheimer's," Coste (2003) refers to this as “habilitation,” which involves placing oneself in the world where the person with Alzheimer’s lives, no matter where that world is (p. 34). The goal is to “create and maintain positive emotions” by being on their journey with them, rather than forcing the person with Alzheimer’s to react rationally to our world (p. 18). For example, if the person with Alzheimer’s disease thinks you are her mother rather than her daughter, go along with her. Rather than saying, “No, mom. I am not your mother. I am your daughter,” you can say, “Yes, I am here for you.” If you see this as a call to be cared for, rather than a confusion of facts, you can validate their emotions, which even if not based in reality, is based in their reality.

Angelica (2014) sees this as a type of improv. “The world of improv teaches us to say the next logical thing when someone makes an offer. The next logical thing to say when persons with Alzheimer’s speak from their improvisational reality may not seem true or logical in our world, but it will seem just right in their world” (p. 35). This approach helps to eliminate many of the emotional and behavioral outbursts that occur with those who have Alzheimer’s disease because it avoids the frustration of not being understood by those around them in a world where communication is so difficult.

I remember when I went to visit my father and he asked, “How is your practice doing?” I wasn’t sure what he meant. I had been an optometrist and then became a rabbi. Did he forget that I was a rabbi and still thought I was an optometrist? My sister is a physician. Perhaps he thought I was my sister. At the time I was not aware of the “improv” approach and felt it would be helpful to tell him the truth. In a kind voice I offered, “I am not an optometrist anymore dad. I am a rabbi now. I don’t have a practice.” Perhaps a better response would have been to go along with the world he was in and say, “My practice is doing fine dad. Thanks for asking.”

Another way to join the patient is through touch and emotional connection. Research has shown that positive emotions such as compassion, caring, love, and joy produce smooth and more ordered heart rhythm patterns. Those heart rhythms produce electromagnetic signals that can impact others (Pearce, 2010, p. 10). “This energetic nonverbal communication via heart rhythms produces an immediate and deep understanding and connection between human beings” (p. 10).

I once officiated at the funeral of a woman, Ella, who had spent her life in a home for multiply handicapped adults. She was deaf, blind, and cognitively impaired. For her eulogy I asked one of the aide’s who had taken care of Ella if she was willing to say some words about her. In her remarks, the aide mentioned that Ella could tell which aide had come to help her when the aide stood by her side. She let some touch her and for others she withdrew. Perhaps Ella only allowed those to touch her who emitted positive emotional energy.

The idea that our loved one can sense our moods even without being able to carry on much of a conversation can be helpful to family members. Bringing positive emotions to a visit with a loved one with Alzheimer’s can affect their emotions in a non-verbal but significant way. For those who visit loved one’s in a nursing home, it could be helpful to take a few moments before entering the room to reflect on happy moments or positive feelings, entering the room with “an open, respectful, nonjudgmental positive regard” (p. 10). Trying to focus on the positive wherever possible is important. Ellor says, “If we see the journey as part of life (our life), our goal can become the reflection of God. From this perspective, we can better see the impaired person as one who has strengths and weaknesses, and we can become a fellow traveler through the last days of his or her life" (1997, p. 58).

Cantor Ellen Dreskin (2012) tells a story to help us remember that there is a part of God in each of us. A mother and her daughter were walking home from synagogue. The daughter asked, "Didn't the rabbi say that God was bigger than everyone?" The mother agreed so the daughter said, "Here is what I don't understand. If God is bigger than all of us, and God is inside each of us, then isn't God bound to shine through?" (p. 57). This little girl challenges us to find ways that God shines through our loved ones with Alzheimer's disease even though that divine light may be dim. This is not easy to do. Family members can be overwhelmed with strong emotions of fear, anger, frustration, sadness, and disappointment. It is also a reminder of our common weaknesses. In addition, some family members, especially adult children, fear that they are seeing themselves in twenty or thirty years.

Adult children that must care for their Alzheimer's parent have different reactions. For some there is resentment, which can result from the previous relationship of the parent and child, or from the adult child's panic with the realization that his parent is no longer the care giver, but now the care taker. Likewise, the child is no longer the care receiver, but the care giver. This change of roles can be frightening and disorienting. There is another, more positive way to approach this change. Rabbi Address (2012) discussed a time he took his mother to the doctor. As he went to help his mother get out of the car he realized, "In a flash of insight, you are suddenly aware that this parent has become a frail older adult; that those arms that held you and cared for you now reach out to you for caring, support, and guidance. You experience a revelation, a sense that roles have changed; and you are humbled to realize the responsibility that is now yours. Many of us have had these moments. They are sacred and filled with awe" (p. 85).

Martin Buber talks of connecting with God through relationships with other people. He explains that there are different types of relationships. We have an I-It relationship with most objects. We relate to the object as an "It." An I-Thou relationship is one that describes a meaningful and relationship between two people. "The two parties fully accept one another. One does not 'use' the other and one does not 'judge' the other" (Sonsino & Syme, 2002, p. 89). We can have I-Thou relationships with objects. Buber (1958) gives the example of a tree. "I consider a tree. I can look on it as a picture...I can classify it in a species… The tree remains an object. It can however, also come about, if I have both will and grace, that in considering the tree I become bound up in relation to it" (p. 7). We can also have an I-It relationship with another person. Such a relationship can be one in which one person is providing services for another. An I-It relationship is not necessarily bad. Most people have an I-It relationship, for example, with a cashier in a store, or a server in a restaurant.

The challenge with Alzheimer's disease is to continually hold on to and maintain the I-Thou relationship we originally had with our loved one. This gets harder to do as the person we loved slowly changes and fades from us. In the mid-stage of Alzheimer's there are changes to the person we remember. During the late stage, the person we are with really is "someone else." To Buber, the I-Thou relationship is mutual. Can we find a way to maintain that mutuality amidst the changes that Alzheimer's disease brings? Can we maintain an I-

Thou relationship with our loved one who has Alzheimer's disease, even when we can no longer have a meaningful conversation with them?

Buber (1958) has a third relationship – the I-Eternal Thou. This is the relationship we have with God. "In each Thou we address the Eternal Thou." (p. 101). He tells us that the way to get closer to God is through our relationships with others. If we can see our relating to a loved one with Alzheimer's as a step towards getting closer to God, this can help us better maintain that relationship, even as things change.

How we perceive a situation can strongly affect how we deal with it. Viktor Frankl (2006) was a psychiatrist and a Holocaust survivor who spent three years in different concentration camps. He used his training as a doctor to help those who were ill. Frankl continued to practice as a psychiatrist after the war. Based on his observation of the prisoners in the concentration camps he realized, that all things being equal, those who survived did so because they had a reason to live. He created a type of psychotherapy to help people find meaning from traumatic experiences, which he called Logotherapy.

> The essential transitoriness of human existence is not pessimistic but rather activistic…The pessimist resembles a man who observes with fear and sadness that his wall calendar, from which he daily tears a sheet, grows thinner with each passing day. One the other hand, the person who attacks the problems of life actively is like a man who removes each successive leaf from his calendar and files it neatly and carefully away with its predecessors, after first having jotted down a few diary notes on the back. He can reflect with pride and joy on all the richness set down in these notes, on all the life he has already lived to the fullest (p. 121).

Despite all of the losses with Alzheimer's disease, there are still many wonderful memories that one has had with their loved one. Holding on to those memories and finding positive in the negative is invaluable to maintaining emotional health as an Alzheimer's family member. Frankl (2006) taught that when the future looks bleak it is important to "remember the past; all its joys, and how its light shown even in the present darkness (p. 82).

Chernin (2003) talks about her own experience having a mother with Alzheimer's disease. She noticed one aspect that a period of irritability or anger that is common in Alzheimer's disease, was not present in her mother. Instead her mother has a gentleness that she was never able to show during her life before the disease. She had been a political activist, always fighting for various civil rights causes. "Maybe I thought, Alzheimer's uncovers what is latent, not yet lived; maybe for many people that is their anger. For my mother it was tenderness, the inner core of her fierce indignation about injustice 'to the people'" (p. 4). If someone gets angry as a result of the disease, instead of being resentful, we can try to image what the hurts were in that person's life that they felt a need to suppress the anger.

Another adult child caregiver reflected on the changing relationship she had with her mother who had Alzheimer's disease. "Our relationship was not the same, but in some ways dementia deepened our relationship. I felt closer to mom than I ever had, and my love and respect for her was even greater because of what she was going through" (Angelica, 2013, p. 5).

A caregiver son felt differently, but when asked to reflect back on his experience was able to find the positive. He said he did not exactly experience "joy while caring for his mother, explaining that for him, joy carries a ‘sense of exultation.’ But he was able to recall many moments of pleasure and connection during her illness. ‘I would pray with mom, sing to her, read to her, and tell her what was happening’”(Angelica, 2013, p. 6).

As people with Alzheimer’s disease slowly lose their sense of the world around them, while it is difficult for family members, there is a positive side for the person with Alzheimer’s disease. Their world-view shrinks to include only their immediate surroundings and those few people who are around them the most. Apathy is a common symptom. They no longer care about social pressures or social norms. They no longer feel the usual stresses that the rest of us do. As the later stage develops, some people seem to be content to be in their own world. “A caregiver daughter said,’ It was probably worse for us experiencing mom’s losses than it actually was for her.’ She didn’t seem to know, and she didn’t seem to be suffering like so many terminal ill people do” (Angelica, 2013, p. 4) Cantor Ellen Dreskin (2012) says, “[My mom] is no longer burdened by human drama, disappointments of the past, social obligations, and other people’s preconceived notions of how she ought to behave” (p. 62).

As my father’s condition deteriorated, I wondered how much he really understood about what was happening to him. I got my answer during one visit to my parents. They lived in a senior independent living center. The book, *Broken Fragments,* (Kohn, 2012) that contained a chapter I wrote called *Alzheimer’s and the Soul*, had just been published. My mother asked if I would speak to her Alzheimer’s support group about the book. As we were preparing to go to the meeting my mother asked, “What should we do with dad?” I suggested we take him with us - either he was having a good day and he could comprehend a little of what we would be talking about or his comprehension was not good enough and he would just sit with us enjoying the company. After the meeting I said to my dad, “What did you think of my talk?" His reply was, "I am sure glad I don't have that." He was oblivious, not even aware enough cognitively to know what the disease was doing to him. This lack of awareness can been seen as a blessing. Others, who are given a diagnosis such as cancer that is fatal, can comprehend what that means to them and their family, experiencing the fears and uncertainly that goes along with such a diasease.

Another way of coping is to try to find meaning and purpose in the experience. Frankl (2006) found that it was possible "to practice the art of living even in a concentration camp, although suffering is omnipresent" (p. 44). He believed that "if there is meaning in life at all, then there must be a meaning in suffering. Suffering is an ineradicable part of life" (p. 67). Frankl observed that suffering was all encompassing regardless of whether the suffering was large or small. So it was not the suffering itself, but how one dealt with the suffering, that was important for managing life. It was about finding meaning in the experience and purpose for one's existence. Frankl expressed his thoughts in his book, *Man's Search for Meaning*:

> The meaning of life always changes, but it never ceases to be… We can discover this meaning in life in three different ways: (1) by creating a work or doing a deed; (2) by experiencing something or encountering someone; and (3) by the attitude we take toward unavoidable suffering…The second way of finding a meaning in life is by experiencing something – such as goodness, truth and beauty… or by experiencing another human being in his very uniqueness - by loving him (Frankl, 2006, p. 111).

Such appreciation was expressed by a woman caring for her mother: "I feel like I'm accomplishing something; something I feel strongly about; something I will be proud of, something I feel is very important" (Angelica, 2013, p. 4).

When Frankl was in one of the concentration camps, a friend approached him with a plan to escape. At first Frankl agreed, but after spending that day with his patients he changed his mind. “As soon as I had told him with finality that I had made up my mind to stay with my patients, the unhappy feeling left me…I had gained an inward peace that I had never experienced before” (pp. 58-59). He realized that being with the patients gave him purpose.

Frankl noticed how each patient in the camps handled his or her illness differently. Some became totally apathetic. Others were extremely irritable. Despite their inability to do anything about the physical condition of being a prisoner in a concentration camp, he wondered, “Is there no spiritual freedom in regard to behavior and reaction to any given surroundings?” He concluded, “The experiences of camp life show that man does have a choice of action…Man *can* preserve a vestige of spiritual freedom, of independence of mind, even in terrible conditions of psychic and physical stress…the sort of person the prisoner became was the result of an inner decision, and not the result of camp influences alone” (Frankl, 2006, pp. 65-66).

Sarah is a Jewish woman I have been meeting with for the past few months. I visit her in her home because she is physically disabled. She has also struggled with various mental health issues since she was a child. SARAH invited me into her den, which was a comfortable place to talk away from the noises of the house. The walls of the room were lined with bookcases. As I looked closer, I noticed that the shelves were filled with books about the Holocaust. On the walls were posters from various Holocaust movies. I asked her if she has family who had died in the Holocaust. She said that she had a few distant relatives but no one she or her immediate family knew. I questioned her about her obviously intense interest in the Holocaust and she replied, “The Holocaust helps me put things in perspective. I realize that as hard as my life has been, it is easy compared to what happened there."

While nothing can compare to the suffering that occurred during the Holocaust, there are important lessons we can learn about suffering from Frankl's experience. He said, "Everywhere man is confronted with fate, with the chance of achieving something through his own suffering" (2006, p. 68). How an Alzheimer's family member looks at his or her own situation can be helpful in not only accepting what is happening, but finding the positive in the challenge. "One could make a victory of those experiences, turning life into an inner triumph" (Frankl, 2006, p. 72).

It helps to define a purpose that becomes a focus for your experience. Frankl quoted Nietzche saying, "He who has a *why* in which to live for can bear with almost any *how*" (as cited in Frankl, 2006, p. 76). Frankl continues, "It did not really matter what we expected from life, but rather what life expected from us" (p. 77). Caregivers who find purpose in their caregiving can more easily bear the burdens involved with a more positive attitude.

Rabbi Richard Address (2012) suggests, "The 'art' of caregiving places before us unique opportunities to search our own souls, as we, in caring for others, come face to face with the reality of our own mortality" (p. 80). He says we are called to care for our ailing parent. Just as God called out to Abraham and to Moses, "the call of *ayecha* takes on a deeper texture as we hold the hand of the one who held ours and feed the person who fed us" (p. 80). Caring for a loved one with Alzheimer's disease can easily turn into resentment, especially during the later stages of the disease. Helping a family member find meaning in their new relationship with their loved one can turn that resentment into purpose.

Judaism is a religion of hope, teaching always to have hope, especially during difficult times. The Prophet Jeremiah said, “Thus said the Eternal God: Restrain your voice from weeping, Your eyes from shedding tears; For there is a reward for your labor — declares Adonai… there is hope for your future” (Jer. 31:16-17). Throughout our history we have been persecuted by various regimes and governments, yet we never gave up hope that things would get better. The song *Hatikvah,* (The Hope), was adapted by a poem written by Naftali Herz Imber in 1877, during the pogroms of Eastern Europe. It was later adopted as the Jewish national anthem at the First Zionist Congress in 1897 and became the national Anthem of the State of Israel.

Lamm teaches, “Judaism may have made one of its greatest contributions when it actualized a dormant human feature that hides shyly in everyone’s heart – hope. Hope is the sheer will to live on in the face of despair, to picture a better future, to spark a rise to success and an end to suffering. The Jewish people survived pogroms and holocausts, most of all probably, because of this one quality” (Lamm, 1995, p. 1). Hope can be a very difficult word to hold on to with Alzheimer’s families. You can’t hope that the person will recover or be cured. As of this writing, there is no cure for Alzheimer’s disease. There are some medications that may slow the deteriorate somewhat, for a short period, and treat some of the symptoms, but the deterioration is guaranteed to occur and last for many years, slowly getting worse over time. Yet it is so hard to live without hope.

A study done by Duggleby et al. (2009) tried to determine the role of hope in the lives of Alzheimer's families. They asked participants open-ended questions such as: “Tell me about hope. What gives you hope? What kinds of things change (increase or decrease) your hope? What can others do to help you have hope?” The results showed that Alzheimer’s family members need to redefine the word hope in the context of dealing with a loved one with Alzheimer's disease. The main concern was one of "fading hope" or hope that has "worn away." Duggleby explained, "The participants' hope was very much tied to how the person they were caring for was doing that day" (2009, p. 517).

Participants found a need to change their concept of hope from wishing that things will get better to "renewing everyday hope," with a focus on living day by day (Duggleby et al., 2009, p. 517). If they had a particularly bad day with their loved one they would hope that the next day things would be a little easier. One participant said, "I think our hope is to overcome any obstacles that come our way" (p. 517) Their hope was more about themselves hoping they would have an easier time coping than hoping that their loved one would improve, which they knew could not happen. There was also the hope that "things would not get worse" (p. 518). When meeting with a husband whose wife had mid-stage Alzheimer's disease, I asked how he was coping. He replied, "As long as she stays like this, I will be O.K." That was his hope.

In addition to a sense of hope, even if redefined, there were other factors that helped family members to cope and keep going. The first was coming to terms with the situation. This meant "realizing they were doing the best that they could do in caring for a person with dementia" (Duggleby et al., 2009, p. 518) Knowing that they were not alone in their struggles also helped them to accept what was happening. Finding the positive in the situation was also helpful. One participant tried to "bring out the good things that I enjoy in life" (p. 518). Sometimes they needed to connect with others who were more objective to help them find the positives. Others were able to focus on the positive with the help of prayer. Seeing possibilities through setting goals and making choices was an additional helpful approach. One participant said, “I find if you have goals in your life, there is always hope. You, if you have goals, you have hope, otherwise why would you be making these goals?” (p. 519).

Where does this hope come from? Lamm (1995) explains, “If you look under the hood of hope, you will find a remarkable spiritual engine whose major component is faith - a belief in One God…[Hope] accomplished this by making a striking observation that released a flood of spiritual energies. It affirmed that God actually listens to people who petition Him, that He desires their good” (p.2).

People often turn to religion and God to find comfort during difficult times. For some it helps to turn to one’s own religious traditions and prayers. For others, their own personal words of prayer are more powerful. Angelica (2013) talks about an adult son caregiver. As his mother’s disease progressed, and his caregiving responsibilities increased, “he experienced a crisis fraught with stress and spiritual decline…Instead of reverting to reciting the prayers he learned from his parents in childhood, he sat each morning with God, pouring his heart out, asking for help to get through the day” (p. 7). Both familiar and newer religious approaches can be helpful.

How does one find comfort as he or she deals with the challenges of a loved one with Alzheimer’s disease? The Prophet Isaiah cries out, “*Nachamu, nachamu, ami* - Comfort, comfort My people” (Isaiah 40:1) There are many Jewish resources available that could help provide comfort and support. The Psalmists were people who were able to express their emotions through writing beautiful poetry. Psalms contain positive emotions of praise, thanksgiving and joy, but also contain the words of people pouring their hearts out to God in the midst of despair and anguish. “Psalms start with the recognition of just how tenuous life is: we suffer, we experience fear and exaltation; we meet with success and failure; we know contentment and anxiety; we experience betrayal, have enemies, even know the desire for revenge; and we find vindication, comfort, new confidence" (Polish, 2000, p. 13).

It is not always easy to express in words what our hearts are feeling. Some of the following Psalms may be helpful to Alzheimer's families as they try to voice the emotions they are experiencing. The words do not need to be taken literally, but can be understood as a metaphor for what is going on in our lives. For example, we can understand "my enemy" to be Alzheimer's disease. Some of the words of the Psalms have been modified here to be more applicable to the challenges of dealing with Alzheimer's disease. For some, I kept the original words but also put in parentheses words that can be used to better relate to the message of the Psalm. (Note: Adonai is the Hebrew word for God or Lord.) I have suggested seven Psalms, so there is a different one to read for each day of the week. They are also listed with a theme for those who want a Psalm to help address how they are feeling on a particular day.

Psalm 13 – Feeling Alone or Abandoned
How long, Adonai; will You ignore me forever?
How long will You hide Your face from me?
How long will I have cares on my mind, grief in my heart all day?
How long will my enemy (this disease) have the upper hand?
Look at me, answer me, Eternal One!
Restore the luster to my eyes, lest I sleep the sleep of despair;
Lest my enemy (this disease) say, "I have overcome him," my foes exult when I totter.
But I trust in Your faithfulness, my heart will exult in Your deliverance.
I will sing to Adonai, for the Source of Healing has been good to me.

Psalm 23 - Wanting/Feeling Support

The Eternal is my shepherd; I lack nothing.
You help me lie down in green pastures;
You lead me to water in places of repose;
You renew my life; You guide me in right paths as befits Your name.
Though I walk through a valley of deepest darkness, I fear no harm,
for You are with me;
Your rod and Your staff — they comfort me.
You spread a table for me in full view of my enemies (this disease);
You anoint my head with oil; my drink is abundant.
Let goodness and steadfast love pursue me all the days of my life,
and I shall dwell in the house of Adonai forever.

Psalm 25 - Hope

Adonai, I set my hope on You; Eternal One, in You I trust;
May I not be disappointed, may my enemies (the disease) not exult over me.
Guide me in Your true way and teach me, for You are Adonai, my deliverer;
it is You I look to at all times.
Adonai, be mindful of Your compassion and Your faithfulness.
Be not mindful of my youthful sins and transgressions;
in keeping with Your faithfulness consider what is in my favor,
as befits Your goodness, Adonai.
My eyes are ever toward You, for You will loosen my feet from the net.
Turn to me, have mercy on me, for I am afflicted.
My deep distress increases; deliver me from my straits.
Look at my affliction and suffering.
May integrity and uprightness watch over me, for I look to You.
Eternal Source of Healing, redeem Israel (my family) from all its distress.

Psalm 30 – Giving Thanks

I extol You, Adonai, for You have lifted me up, and not let my enemies rejoice over me.
Eternal One, I cried out to You, and You healed me.
ADONAI, You brought me up from Sheol (the dark place),
preserved me from going down into the Pit.
O you faithful of the Holy One, sing to Adonai, and praise the holy name.

One may lie down weeping at nightfall; but at dawn there are shouts of joy.
When I was untroubled, I thought, “I shall never be shaken,”
When You hid Your face, I was terrified.
I called to You, Adonai; to the One I made appeal,
“What is to be gained from my descent into the Pit?
Hear, Adonai, and have mercy on me; Adonai, be my help!”
Turn my mourning into dancing, and gird me with joy,
That my whole being might sing hymns to You endlessly;
Eternal One, I will praise You forever.

Psalm 38 – Feeling Burdened

Adonai, do not punish me in wrath; do not chastise me in fury.
For my iniquities (challenges) have overwhelmed me;
They are like a heavy burden, more than I can bear.
I am all bent and bowed; I walk about in gloom all day long.
I roar because of the turmoil in my mind.
Eternal One, You are aware of all my entreaties; my groaning is not hidden from You.
My mind reels; my strength fails me; my eyes too have lost their luster.
My friends and companions stand back from my affliction; my kinsmen stand far off.
I am like a deaf man, unhearing, like a dumb man who cannot speak up;
I am like one who does not hear, who has no retort on his lips.
But I wait for You, Adonai; You will answer, Source of Healing.
For I am on the verge of collapse; my pain is always with me.
Do not abandon me, Adonai, be not far from me;
Hasten to my aid, Source of Healing.

Psalm 88 – Feeling Down – Hear My Cries

O Adonai of my deliverance, when I cry out in the night before You,
Let my prayer reach You; incline Your ear to my cry.
For my soul is sated with misfortune; I am at the brink of Sheol (this dark place).
I am numbered with those who go down to the Pit;
I feel helpless, and abandoned,
like have put me at the bottom of the Pit, in the darkest places, in the depths.
My companions shun me; I am shut in and do not go out.
My eyes pine away from affliction; I call to You, Adonai, each day;

I stretch out my hands to You.
I cry out to You, Adonai; each morning my prayer greets You.
Do You reject me? Do You hide Your face from me?
I cry out to You, Adonai.

Psalm 121 – Finding Strength
I lift my eyes to the mountains; from where will my help come?
My help comes from the Eternal, maker of heaven and earth.
Adonai will not let your foot give way; your guardian will not slumber;
See, the guardian of Israel neither slumbers nor sleeps!
The Eternal is your guardian, Adonai is your protection at your right hand.
By day the sun will not strike you, nor the moon by night.
I call to you Adonai, guard me from all harm; guard my life.
Guard my going and coming now and forever.

Traditional liturgy can also be a source of comfort. The Jewish tradition requires that ten people be present when you recite the ancient prayers in the *siddur* (prayerbook). There is great wisdom in this teaching. Especially when we are feeling down and want to be alone, joining a prayer community can bring a type of comfort that is different than what we can find being alone. For family members who had been part of a worship community in the past, it would be helpful to encourage them to reconnect with that community or find a new spiritual community in which they feel comfortable.

If the person with Alzheimer's disease is mobile, it could also be beneficial for the family to take him or her with them. The memory loss of people with Alzheimer's disease proceeds backwards from present to past. Someone may have trouble remembering what you just said, but can often remember minute details from their childhood or early adulthood. For those who had been part of a worship community in the past, a worship service may still resonate with them. I remember going to a nursing home with my family, including our then 13 year old son. He had just become a Bar Mitzvah but his great grandmother could not attend the service because she has broken her hip. Since she was in a Jewish nursing home, the rabbi there agreed to let my son read from the Torah during their weekly Saturday morning service. Many residents were wheeled into the sanctuary. Through most of the service they appeared lost, disinterested, or asleep. When the rabbi took out the Torah, all of a sudden the patients eyes lit up with joy as they reached out to touch the Torah and sing along with the Torah service prayers.

One of the challenges for family members who want to take a loved one with Alzheimer's disease to worship services, is the concern about behavior issues during the service. My parents were regular synagogue worshippers during their 60 years of marriage. When my father developed Alzheimer's disease, he found continued comfort and familiarity with the prayers and songs that were recited since these were older memories that still remained. As the disease progressed my father lost all social filters and shouted out inappropriate remarks during services. My mother became so embarrassed that she stopped going to services.

Clergy members can play a role here in educating their congregation about the symptoms of Alzheimer's disease. Most people think Alzheimer's disease is a disease of memory loss. Unless they have personal experience, they don't understand that there are certain behaviors that are also associated with the disease. Without being educated, outbursts like my father had could be considered rude and obnoxious, creating animosity or disdain. While Alzheimer's family members need to be aware if such outbursts are disrupting the other worshippers, more informed congregants could become empathetic and understanding.

For those who are unable to attend worship services, having a prayerbook at home might be a source of comfort for family members. In addition to pouring your heart out, offering your own words to God, traditional prayers can also be helpful. Even though you may be alone, reading those prayers can still connect you to the greater religious community you are part of. Clergy can turn to their religious traditions for sources of appropriate prayers to recommend to their congregants. Here are some specific Jewish prayers that may be useful:

- From Morning Blessings
  - *Modeh Ani:* A prayer offering thanks for being alive
  - *Elohai*: The soul You have given me is pure
  - *Asher Yatzar*: A prayer for health. One can think of this as a prayer for the caregiver so that he or she can maintain their physical health to be able to continue to care for their loved one. It can also be recited for the family member who has Alzheimer's disease, being thankful that at least some physical parts of the person are working as they should.
  - *Nisim B'chol Yom*(daily miracles): In particular - "Blessed are You, Eternal God, who lifts up the fallen," "…who strengthens our steps," "…who gives strength to the weary," "…who made me in the image of God"
- In most services
  - *Mi Chamocha* is the song the Israelites sang as they made it safely across the Red Sea, fleeing from Pharaoh. These words can also be understood as a

metaphor for crossing from a narrow place to a place of greater freedom emotionally and spiritually.

- T'filah
    - Weekday *Shmoneh Esrei*: In particular – "Blessed are You, Eternal God...abounding in forgiveness" (for the times caregivers feel guilty for losing their patience), "…who heals the sick," "…who hearkens to prayer"
    - *Hashkivenu* – A night time prayer asking God to protect us
    - *Modim* (Prayer of thanksgiving) – As a way to try to find small things to be grateful for
    - *Sim Shalom, Shalom Rav*, *Oseh Shalom* – A prayer for peace within the context of inner peace and wholeness
- *Mi Sheberach* (healing prayer)

Felder (2001) has found new ways to look at some of these ancient prayers and blessings from a different perspective. There is a blessing that is recited when one ritually washes one's hands:

Baruch Atah Adonai, Eloheinu Melech Ha-Olam,
asher kid'shanu b'mitzvotav v'tzivanu al netilat yadayim.

Felder sees this as a blessing "to help you focus when you're feeling stressed or distracted" (2001, p.45). He translates the blessing, "Blessed are You, Eternal One, Pulsing Source of all that exists in the world, Who guides us on ways to become holy, and Who inspires us to lift our hands (to raise up our actions and be of service)." He explains that this blessing can help you live your life "with a stronger commitment to following through on what you cherish most and sticking with what you know in your heart is your higher purpose" (pp. 45-46). For Alzheimer's family members this blessing can be a helpful spiritual reminder that the caring they do for their loved one with Alzheimer's disease truly is holy work. Fedder also sees this as a cleansing prayer, not only for your hands but also for your minds. When family members start feeling negative thoughts about their loved one, this can help reframe their thinking.

Birkat HaKohanim, the Priestly benediction, is from the book of Numbers 6:23-27. These words were recited by Aaron and his sons as they blessed the Israelites. It became a blessing that was recited in the ancient Temple in Jerusalem. This blessing is often used today by rabbis to bless wedding couples, individuals for special occasions, and as part of the worship service. Felder translates the prayer (2001, p. 67):

> May the One bless you and safeguard you.
> May the One Illuminate your way and be gracious unto you.
> May the One raise up in your direction to encourage you
> and give you a sense of wholeness and peace.

He suggests this can also be used "to resolve tension and misunderstanding between you and someone else"(p. 67). This is a beautiful way to calm the resentments towards a family member with Alzheimer's disease by reciting this blessing for him or her.

In addition to the fixed regular prayers of Jewish tradition, various people have written new and modern prayers and liturgy, often based on the traditional prayers, using words that are more relevant to specific concerns. In keeping with Reform tradition, sometimes our prayers, with a few changes, can add another dimension to a particular prayer, endowing it with new meaning.

Prayer has always been a means to help me get through difficult times. As I re-read some of the morning blessings, I came upon a prayer that I had recited often, but now took on new meaning after a visit with my father, when I learned to see his Alzheimer's in a new light. Here is the original prayer (CCAR Press, 2007):

Modeh ani l'fanecha, Melech Chai v'kayam,
she-hechezarta bi nishmati.
I offer thanks before You, ever-living Sovereign,
That You have returned my soul to me in mercy.
How great is Your trust."

When this prayer was written by the Rabbinic sages, it was believed that one's soul left the body to be with God during sleep, and then returned to the body as the person awoke in the morning. It was a prayer thanking God for allowing one to reawaken each morning. In light of someone with Alzheimer's, if we take a spiritual approach, seeing the person as a body with a multifaceted soul, this prayer can be seen in a new way, offering a source of comfort to the family members of a person with Alzheimer's. We can envision the soul going to be with God, not just during sleep, but during those times when the person is physically present but cognitively absent (Medwin, 2012, pp. 121-122).

I have rewritten this prayer to be recited by loved ones of a person with Alzheimer's.

(Changes are in capital letters.)

For A Man Who Has Alzheimer's Disease

Modeh/Modah[1] *ani l'fanecha, melech chai v'kayam.*
She-hechezarta BO NISHMATO BA-Z'MAN HAZEH, b'chemla,
Rabah emunatecha.

I offer thanks to You, ever-living Sovereign,
that you have restored HIS *n'shamah* to HIM, AT THIS MOMENT, with mercy.
How great is Your trust.

For A Woman Who Has Alzheimer's Disease

Modeh/Modah ani l'fanecha, melech chai v'kayam.
She-hechezarta BA NISHMATA BA-Z'MAN HAZEH, b'chemla,
Rabah emunatecha.

I offer thanks to You, ever-living Sovereign,
that you have restored HER *n'shamah* to HER, AT THIS MOMENT, with mercy.
How great is Your trust.

Another prayer that may be adapted is the *Mi Sheberach* prayer, which is a prayer of healing. It says, " May the Blessed Holy One be filled with compassion for their health to be restored and their strength to be revived" (CCAR Press, 2007). At every Shabbat service, we offer names of people in need of healing before we recite this prayer. One evening after Shabbat services, a congregant came up to me and said, "Rabbi, I don't know what to do. I want to say a prayer for my sister who has Alzheimer's disease but I know she will never be free of this disease and she will continue to worsen. The *Mi Sheberach* prayer really doesn't apply to her." With my father also in the same situation, I decided to write an additional prayer for healing using the form of this prayer (Medwin, 2012, p. 79).

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[1] *Modeh/Modah* means "I give thanks." If you were a man offering this prayer for a loved one, you would say *Modeh*. A woman offering this prayer would say *Modah*.

Mi Sheberach for Chronic Illness

Eternal God, we ask for mercy and compassion
For those who are burdened with chronic illness.
Give them the strength and courage
To face the daily challenges in their lives.
Compassionate One, give them and their loved ones hope for the future
And at the same time, acceptance of the present.
Help them to find a path towards spiritual wholeness. Be by their side.
Help them to know that You are with them at all times, even in times of doubt.
Source of Healing, comfort them and bring healing to their souls. Amen

Lamentations is a book in *K'tuvim*, the book of Writings in the Hebrew Scriptures. It is a collection of poetic laments, mourning the destruction of the Temple in Jerusalem by Babylonia in 586 BCE. There is a beautiful essay written by Rabbi Rachel Adler (2012), whose mother has Alzheimer's disease, using verses from Lamentations to help describe her mother's condition. Describing one day when she went to visit her mother she says, "My mother can no longer speak, but something is very wrong. My mother is rocking back and forth. She claps her hands. She cries, 'Why, why, why?'…She does not respond to requests to show her where it hurts. It occurs to me that maybe there is no physical locus for her pain, that what I am seeing is the classical expression of lamentation, the hands clapping, the body anguished, the mouth mixing words and cries of pain" (p. 78). The book of Lamentations was written to describe the feelings of the Jews after the destruction of the Temple. Adler sees her mother as a ruined city, abandoned by so many including friends and family.

Alas! Lonely sits the city
Once great with people!
She that was great among nations
Is become like a widow;

The princess among states
Is become a thrall.
Bitterly she weeps in the night,
Her cheek wet with tears.
There is none to comfort her
Of all her friends.
All her allies have betrayed her;
They have become her foes. (Lamentations 1:1-2)

The Hebrew name of the book of Lamentations is *Eicha,* which means "how." Alzheimer's family members who are caught in the day-to day-matters of the disease, may suddenly take a step back and realize how much their loved one has changed. One can't help but ask, "How? How did this happen?" While there are no real answers that will satisfy the questioner, the question still needs to be expressed and heard.

Meditation is another area that can help Alzheimer's family members cope with their emotions and stresses. Meditation not only calms the mind, but also makes physical changes to your body. I remember going to the hospital for an outpatient procedure. I was hooked up to the monitors watching my blood pressure and pulse. I became more and more anxious as I waited for the doctor to come in and my blood pressure and pulse began to rise. I started meditating, using the basic introductory steps listed below. I could actually see my blood pressure and my pulse decreasing on the monitor with each meditative breath I took.

Jewish meditation is a spiritual practice that directs the mind in certain ways to help a person feel calm and whole by connecting to their soul within. The understanding behind the practice is based on *Kabbalistic* teachings. Meditation involves slow focused breathing, which can create a sense of feeling God's presence. When God created Adam, God "blew into him the breath of life" (Gen. 2:7). I believe this is how Adam got his soul from God. As you inhale slowly during meditation, you can imagine that inward breath, the same breath that God breathed into Adam, connecting your soul to God.

The skills are learned and can take time to perfect but this should not prevent someone from beginning the practice. Even short basic meditations can be helpful. I am including three focused meditations based on the book, *Discovering Jewish Meditation* (Gefen, 1999). See Appendix 11 for additional suggested books about meditation and spirituality.

Meditation is best done if the person meditating can close their eyes and listen to the directions rather than have to read them. A group leader can read the directions to the group in a slow, calm voice. If done individually, the person can record the directions for themselves ahead of time. Start by preparing the body and mind. This should be done before beginning each focused meditation listed below. The following guidelines can be used to prepare properly for mediation.

Getting Ready for Meditation

- Sit in a comfortable position.
- Close your eyes.
- Take a slow deep breath in through your nose, filling your lungs, expanding your diaphragm.
- Slowly exhale through your mouth.
- Repeat this a few times, slowly inhaling through your nose, slowly exhaling through your mouth.
- Focus on your breath.
- If your mind wanders, acknowledge that this is normal, then refocus back on your breathing.
- Keep breathing slowly. Now we are going to focus on relaxing the muscles in your body.
- Start at your toes. Relax the muscles in your toes.

- Then slowly move your focus up your body, relaxing the muscles in your calves, then your thighs, then your torso, then shoulders, neck, head, and face.
- Keep the steady slow breathing you began with.

Focused Meditation – Shalom (based on Gefen, 1999, p. 85-87)

Shalom is a magical word. It is translated as hello, goodbye, and peace. But it also has an additional meaning. The root letters of the word – *Shin* ("Sh" sound), *Lamed* ("L" sound), and *Mem* ("M" sound) – also form the Hebrew word *Shalem* and *Sh'lemut*, which means whole or complete. It expresses a type of personal peace. By focusing on the word *Shalom* as part of the meditation, the goal is to bring personal wholeness and healing to the person meditating.

- Begin the slow breathing as mentioned above along with the body scan to relax your muscles.
- Now shift your attention to the word *Shalom*
- Say the word several times to yourself.
- *Shalom, shaaaa…..lommmmm*
- With each breath, feel yourself enveloped in *Shalom.*
- A peace that holds you, that protects you, that gives you strength
- That helps you heal and feel complete and whole
- *Shalom*
- Imagine God spreading over you a *Sukkah*, a shelter, of *Shalom*
- If your mind wanders, bring it back to the word *Shalom*
- Welcome the *Malchei HaShalom,* the messengers of peace
- Feel them embracing you with *Shalom*
- A Divine peace
- A blessing
- *Shalom*

Focused Meditation – Shema (based on Gefen, 1999, p. 100-103)

The *Shema* comes from Deuteronomy 6:4. It is often translated as, "Here O Israel, *Adonai* (Hebrew name for God) Our God, *Adonai* is One." It is seen as a statement of monotheism. A mystical understanding of God would translate the Hebrew *Echad*, not as "one" but as "unity." God is not just one but everything, and we are part of that unity. Reciting the *Shema* as a meditative mantra can use the imagery of being part of God.

In a very quiet hushed voice, say the sounds of the letters in the *Shema*, extending the sounds as long as you can without running out of breath.

- Breathe in slowly and deeply

- Exhale slowly saying: SHHHHH – Quieting the white noise and chaos
- Breathe in slowly and deeply
- Exhale slowly saying MMMMM – hum, like a tuning fork – feel the harmony

Take a few minutes to focus on the breath.

- Inhale deeply through your nose. Let your breath fill you. Allow your chest to expand to its fullest capacity.
- Exhale through your mouth. Hear the sound of air as it exits your mouth. Draw this sound out as long as you can as you deflate your lungs.
- Feel your body releasing tension you are holding. Let your breath carry it away. Relax the muscles in your feet, legs, body, arms, neck, head.
- Watch your breath as it fills your lungs.
- Watch as your body expands to receive it.
- Then notice your chest contract as your breath begins to depart.
- Notice your body release it.
- Keep your mind on your breath.
- To help stop your mind from wandering, add the *Shema*.
- The *Shema* takes the personal and connects it to the community
    - *Shema* – Listen - Inhale deeply (personal, I need to listen)
    - *Yisrael* – All of us - exhale slowly (community)
    - *Adonai* – Inhale deeply (my God)
    - *Eloheinu* – exhale slowly (our God)
    - *Adonai* – Inhale deeply (My God)
    - *Echad* – One – Unity with God - Exhale slowly (unity with all souls)
- The breath flows in. The breath flows out.
- Continue for a few minutes.
- Then sit quietly for a few moments with your eyes still closed.

Focused Meditation – Hineini (based on Gefen, 1999, p. 81-85)

The Hebrew word, *hineini,* (hee-**nay**-nee), means “Here I am.” It was recited by Abraham when God called to him at Mt. Moriah. It was spoken by Moses as God called to him from the Burning Bush. This meditation helps us to focus on being “here,” rather than in the past or the future. *Hineini* means being physically present, emotionally ready and spiritually opened to the Divine. It means being open to the possibility of a spiritual connection.

- Inhale deeply through your nose. Let your breath fill you. Allow your chest to expand to its fullest capacity.
- Exhale through your mouth. Hear the sound of air as it exits your mouth. Draw this sound out as long as you can as you deflate your lungs.
- Feel your body releasing tension you are holding. Let your breath carry it away.

- Repeat several times.
- Notice your mind as it begins to quiet down and your body relaxes.
- Move your attention to the word *hineini – Here I am.*
- Focus on *hineini*
- Repeat it silently to yourself.
- *Hineini – here I am.*
- Let the word become filled with your breath. Merge with it so that you experience being fully present.
- *Hineini. Here I am.*
- Not thinking
- Not accomplishing
- Not doing.
- Just being.
- *Hineini – Here I am*
- Full presence
- Readiness to receive
- In body
- In heart
- In mind
- In spirit
- *Hineini – Here I am*
- When your mind wanders, do not judge yourself. Simply notice where you have gone and return to *hineini.*
- If you are distracted by the sounds around you, notice them and return to *hineini.*
- *Hineini – Here I am.*
- To end the meditation, sit quietly for a few minutes.

In addition to the theological questions, I believe that one of the greatest spiritual challenges for Alzheimer's families is that there is no ritual or specific supportive liturgy for such families. In his book, Grief *Counseling and Grief Therapy*, Worden talks about "adjusting to a world without the deceased" as an important part of processing the pain of grief (2009, Chapter 2). This includes external adjustments, internal adjustments, and spiritual adjustments. These adjustments usually occur mostly during the first year of mourning, which includes the funeral, *Shiva* (the seven days following the funeral where the family stays home getting comfort from each other and from others), *Sheloshim* (a less intense period of mourning), and the first year *yartzeit* (anniversary of the date of death). There are prayers and rituals associated with many of these Jewish mourning practices.

When a loved one physically dies, there is the ritual and structure that all religions have created in the form of funeral and mourning customs. Alzheimer's has been described as the "funeral that never ends" (Sligar, 1987). There are many small "deaths" that occur: The death of the person's ability to have normal conversations with you, the death of your social life since people often feel very uncomfortable around someone with Alzheimer's due to cognitive and behavioral changes, and the death of recognition when your loved one no longer knows who you are. Yet, with all of these small but not insignificant deaths, the person is still alive, so you can't have a funeral.

In many ways, the process of mourning the losses of personhood with a family member who has Alzheimer's disease is similar to the process of mourning a physical death, but without the funeral. "The bereaved person searches for meaning in the loss and its attendant life changes in order to make sense of it and to regain some control of his or her life" (Worden, 2009, p. 49). For a family member of a person with Alzheimer's this can be even more challenging in the sense that the person is "gone" but still physically present. This can cause a spiritual crisis "for the individual who is uncertain of what is true and what is good… A person who holds a firm belief that all things are part of God's larger plan may show less distress following the loss of a spouse than a person who does hold this view" (Worden, 2009, p. 73).

Even though there is no formal funeral, many Alzheimer's family members have grieved for such a long time that when the funeral does come, there is little need for mourning. Rabbi

Rachel Adler (2012) shared her thoughts about her mother's funeral. "It feels like mourning someone who has been dead for years" (p. 83). When my father died, I felt no real grief at his funeral because in fact I had been grieving for the ten years he had the disease. I believe our family did follow many of the Jewish mourning rituals, but in reverse order. The year-long period of mourning took place for many years while my father was still alive. The period of *Sheloshim* took place the month before he died because we knew his physical health was failing. *Shiva* took place for us the week before my father died when he was in hospice. We gathered every day and sat by his bedside. When the formal funeral was over I felt more like a mourner after the first year had passed, ready to get back to living.

It is customary to do an unveiling ceremony of the grave marker at the cemetery about a year after a loved one dies. When it came time for my father's unveiling I felt a need to add additional readings beyond the usual unveiling prayers. During my father's illness family members had feelings of anger and guilt as we struggled to deal with the changed person he had become. Because of the disease, some in the family were unable to resolve past issues that had caused conflicts before Alzheimer's set in. I felt that a year after his death enough time had passed to be able to find a way to forgive him, each other, and ourselves, and move on. These readings can be found in Appendix 9.

For people who turn to their religion as a source of comfort, especially after the loss of a loved one, there is no formal ritual for Alzheimer's families to use **during** the extended grieving process with Alzheimer's disease. In Appendix 5, I compiled a collection of readings offering mediations, relevant Psalms, and traditional Jewish prayers and creative prayers that address the emotions and spiritual needs associated with having a loved one with Alzheimer’s disease. Perhaps this can be turned into a booklet to serve as a type of ritual. Each morning, or each evening, one can read a prayer or passage from the booklet, depending on the type of comfort the family member needs at that moment.

Having a loved one with Alzheimer’s disease can be challenging on so many different levels. Understanding both the psychological and spiritual issues involved can be invaluable for a clergy member or mental health counselor working with Alzheimer’s families to better meet the family members’ needs.

CHAPTER III: METHOD OF CARRYING OUT THE PROJECT

A. Approach and Procedure

To carry out my D.Min. project, I plan to form a support group of 6 -10 people who have a family member that has Alzheimer's disease. We will meet for 90 minutes once a week for for eight weeks in May and June. Because I do not know what the numbers will be, initially this will include both caregivers and non-caregivers since there are many emotional issues they both have in common. If I have enough people, and feel the need, I may separate them into two groups. I have been in touch with Jewish Family Service who will be sponsoring the support group. They have arranged for me to hold these meetings at the Jewish Community Center. I wrote an article about my D.Min. project for the local Jewish newspaper which will appear in complete form in early April, and then in abbreviated form two additional times in April, accompanied by an ad for the group. (See Appendices 1 and 2.) In addition I have contacted the local Alzheimer's Association and a nearby counseling center and have given them the information about the support group.

My desired outcome is for participants to feel that they have gained greater understanding of the issues they are dealing with, have learned from and helped others in the group, found a supportive community, have a place to process their grief, and have found new ways of coping that lessen the sense of burden and despair that they were feeling when they first started with the group. The first meeting will involve introducing myself, explanation of the goals and purpose of the group, signing of an agreement contract which deals with issues of respect, confidentiality, and attendance. (See Appendix 3.) The main focus of the first meeting will involve personal introductions in which each participant has the opportunity to share their story and talk about the issues they struggle with the most.

B. Methods for Assessing Outcomes

Meuser & Marwit did a study with Alzheimer's family members. Some of the questions they asked were:

1. Tell us something about yourself- your family, work, and interests.
2. What was your parent/spouse like before he or she became ill with Alzheimer's – work, interests, role in your life?
3. What were your reactions to the early recognition of Alzheimer's – to the early cognitive changes and to the diagnosis?
4. How has your life changed as a result of the caregiving? What have been the major losses? (2001, p. 660.)

These questions may be helpful to form group cohesiveness and start the conversation.

There are several tools available to help quantify how Alzheimer's family members are feeling about the burdens of caregiving and sense of grief and loss. Zarit et al. (1980) has a self-scoring Caregiver Burden Scale in which the participant can quantify the burden they feel from caregiving (as cited in Ankir, et al. 2005). There is also a modified version of this scale as reproduced in American Family Physician (2002). Meuser and Marwit (2005) have created a Caregiver Grief Inventory to help family members identify, name, and classify the various grief experiences they have. This is also a self-scoring inventory that separates responses into: Personal Sacrifice Burden, Heartfelt Sadness and Longing, and Worry and Felt Isolation. (See Appendix 4 for copies of these surveys and inventories.) Based on what I learn about the participants in the first session, I may used modified versions of these questionnaires if I feel it will be useful in helping the participants name the issues they are struggling with. This could then be used at the end of the focus group to assess if their ability to deal with these issues has changed.

In addition, the Vancouver Island Health Authority has created a workbook for dementia caregivers entitled, “Understanding and Managing Loss and Grief (2002). They elaborate on the various dimensions of grief including ambiguous grief, non-finite loss, anticipatory grief, and disenfranchised grief (See Chapter II). This may be helpful if the issues of loss and grief are important factors that arise in the group discussion. I will use the information gathered and issues that surface during the personal stories that are shared at the first meeting to plan the subsequent meetings.

Group Vs. Individual Counseling

Being part of a formal group that has a common interest and need can be more helpful than working individually with the same group leader. Yalom talks about many factors that are involved in the group process that include: instillation of hope, universality, imparting information, altruism, interpersonal learning, group cohesiveness and catharsis (2005, p. 1-2). Just knowing that they are going to be part of a group can give a member hope that there is support available that will help them increasing the chance of a positive outcome (p. 4). Most people feel that they are alone in their suffering. Being part of a group with similar experiences assures that others are also going through this and can be a powerful source of relief (p.7). A support group for Alzheimer’s families can also be an important source of information not only from the leader but from other members in the group as well.

Human beings have an instinctive need to help. According to Schwartz, "You have a certain level of self-awareness, you know a part of you suffers in the same way, so you identify with the sufferer's pain… [There is] an intuitive understanding that the suffering of others affects you because, at some level, the other is you" (Schwartz, 2001, pp. 39-40). In addition, the experience of being important to others is refreshing and boosts self-esteem (Yalom, 2005, p. 13). Particularly in Alzheimer's families, when one feels so helpless, being part of a group is an opportunity to feel that you can be helpful to someone else. While Alzheimer's caregivers are certainly of help to their family members, it is rarely appreciated and noticed by the person they are caring for. In a group they can get that acknowledgement and appreciation not only of what they are doing for their loved one but also that they can help members of the group.

Being part of a group has additional value. "Homogeneous groups provide a powerful sense of commonality, identification, support, and self-validation" (Nichols, p. 3). Yalom says, "It is the affective sharing of one's inner world *and then the acceptance by others* that seem of paramount importance" (2005, p. 56). Because many of the thoughts that Alzheimer's family members have can be perceived as heartless, not caring, indifferent, and lacking love by those who have never been though this experience, the affirmation of a group is particularly important. Being able to express such emotions in a safe place can be very cathartic and validating.

The people who are part of a support group are important for the success of the group. "Those people who tend to do well in group are those who have at least a minimal level of interpersonal skill, motivation for change, some emotional discomfort or anxiety, and an expectation or hope that the group will help" (Nichols, p. 2). There are things for the group leader to be aware of as he or she organizes a group and facilitates the meetings: suitability of an individual for group process, creating a cohesive group through an atmosphere of acceptance, tolerance, sharing and confidentiality, and allowing each member to share and participate according to their comfort level. These factors can create an atmosphere in which sharing becomes more comfortable as time goes on.

Groups are small representations of the larger society. There are certain cultural norms in which some subjects are taboo to talk about. Group participants bring these norms with them to group discussions (Cole, 2009, p. 296). It may be difficult at first, for people to feel comfortable enough to break those norms and begin talking about feelings that could be considered wrong by society. Some common feelings of Alzheimer's family members that may be difficult to talk about openly are: getting angry at their loved one knowing that the person can't help his or her actions; feeling selfish wanting to take some time for oneself; and wishing the loved one would die so that this horrible existence for both the person with Alzheimer's and their family will end.

Yalom explains, "It is the group therapist's task to create a group culture maximally conducive to effective group interaction" (2005, p. 121). Some additional issues that may come up when working with groups are individuals who feel the need to dominate the group, individuals who have unrelated mental health issues that may surface, as well as those who have unresolved issues with the family member with Alzheimer's disease. For those who dominate, the leader can make "group-as-a-whole" comments such as, "He seems to need to do all the talking today… I wonder what we're all avoiding." This can empower the rest of the group to be more proactive (Nichols, p. 5). Other personal issues, if dealt with properly, can be helpful to the group as well as the individual.

In addition, while the group has a common theme, there may be divergent interests that each group member brings to the meetings (Cole, 2009, p. 295). It is therefore important for the group leader to help the participants find common ground. When individual issues arise that may be relevant to one participant but not the others, the group leader will have to decide whether the topic of discussion could also be helpful to the others and should continue or should subtly change the direction of the discussion. Another option is to state that the issue that was raised is important but might be better discussed in an individual setting.

I believe that some of the most important traits for a group leader of a support group for Alzheimer's family members or caregivers are: sensitivity to the caregiver or family member experience, familiarity with the stresses as well as the rewards, and awareness of local and national resources (Salmon, R., & Graziano, R., 2004, p. 129). It is also important for the group leader to be as familiar as possible with the different symptoms of the disease and the effect of those symptoms on family members. Even if a group leader has personal experience with a family member who has Alzheimer's there are many different aspects of the disease. Not everyone who has Alzheimer's or has a loved one with Alzheimer's experiences the same symptoms or reacts the same way to the challenges of the disease.

There are different types of therapy groups. Self-help groups such as Alcoholics Anonymous are self-run and do not have a professional leader. Other groups are run by a mental health professional.

- Interpersonal group psychotherapy (IGP) is based on the understanding that "interpersonal relations are necessary to regulate all aspects of living" (Yalom, 2005). Greatly influenced by Yalom's model of interactional group psychotherapy, “IGP focuses on the here-and-now in the group, an establishment of group cohesion and therapeutic norms, and the interaction between members - with an active approach taken by the group leader and a decreased emphasis on the group-as-a-whole perspective” (Brook, 2003).

- Cognitive Behavioral Therapy groups focus on changing negative and irrational beliefs by replacing such thoughts with positive more constructive interpretations of events. It involves monitoring thoughts and feelings and practicing coping skills to reinterpret one’s outlook (Seligman, n.d.).
- Psychoeducational Group Therapy focuses on providing information about specific topics. Groups are more structured and participants are provided with specific topics to explore and discuss.
- Process-Oriented Group Therapy focuses on the experience of being in a group as an opportunity for healing. The process of expressing thoughts, feelings and experiences in the group can be a vehicle for change (Pollak, n.d.).

Because of the nature of the group, this support group will not be a psychotherapy group. People are not coming because of specific personal psychological issues that they want to deal with. Rather they are coming to find ways to deal with how to cope with a loved one who has Alzheimer’s disease. Since the group has specific needs related to Alzheimer’s disease and may need additional information about Alzheimer’s disease, I imagine the group being mostly process-oriented with a psycho-educational component as needed. As mentioned before, there may be personal psychological issues that surface during the group process. Based on the individual, it will have to be decided if it is best to process such issues with the group, and/or suggest that it be handled in individual therapy.

Some of these issues, especially when dealing with difficult group members, can be addressed in different ways. Community Tool Box suggests an approach called assertive caring. “This sort of caring directly addressed problems within the group without insulting or offending members” (2014, Tips on Handing Difficult Group Members). The steps involved include:

- Show that you understand the member’s position or dilemma
- Set limits
- Suggest an alternative
- Get the members to agree on the alternative

Spiritually, this support group can offer a safe holding place for those who question God as they experience suffering. If they feel comfortable in the group, they can express such thoughts without the fear of being judged. Helping family members wrestle with such theological issues may help them seek out greater meaning in the experiences they are having. This may also help lessen the burdens they feel they are carrying. Prayers and spiritual readings can also be provided as well as other spiritual resources. (See Appendices 5 and 10.)

There are possible problems I anticipate in trying to form a group. Some people do not feel comfortable sharing their feelings with strangers. For others, if they live in a small town they may not want to be part of a group because they know everyone in the group and don’t want to admit that they are not fine. People may want to appear to have everything under control to their acquaintances and members of the community, and sometimes even their friends, even as they are crumbling inside. For such people, private individual counseling may be of more help to them.

CHAPTER IV – WHAT I DID

The goal of this project was to help Alzheimer's family members find new ways of coping, to reduce their sense of burden and emotional distress that results from loving or caring for a family member with Alzheimer's or dementia. New coping mechanisms would enable them to live healthier lives physically, emotionally, and/or spiritually. Because of the nature of the communities I was dealing with, I used several different approaches:

- Support group
- Psycho-educational program
- Individual ongoing counseling
- One time meetings to hear people's "stories"

Support Group

Given the power of group process, I felt the best way to help these family members was to create a focus group. There would be a fixed number of meetings, rather than an ongoing support group, due to of the nature of the D.Min. project. Forming an Alzheimer's support group in small towns was more challenging that I thought. I am connected to two different small towns – the one where my congregation is located and the one where I live. Although I publicized the project in my synagogue I only found one member willing to be part of a support group. (I provided individual counseling for her at the synagogue.) The town in which I live is slightly larger and I was able to create a support group of three people that met for eight weeks.

The make up of the group was quite interesting. Each of the participants had different circumstances and was there for different reasons. Because of this, I had concerns about how helpful the group would be to each other. Despite the differences, the commonality of having a loved one with Alzheimer's disease or dementia gave the group cohesion. They each listened empathically to what the others were saying and offered help and advice where appropriate. They respected each person's situation and were grateful to have each other to share their experiences with, and to learn from. As the group facilitator, I worked to find the balance between allowing the participants enough time to speak about their own situations, giving each person an equal opportunity to speak, and guiding the discussion in a way that would be most helpful.

One woman, Linda, in her 80's, was caring for her husband in his 90's who had dementia. She felt that she was handling things but was interested in what a support group could offer. When asked to tell her "story" she shared that her husband has remained good-natured and still loves to tell jokes. But he repeats things over and over again, hoards things in his night table, doesn't remember where dishes or silverware are in the kitchen, follows her wherever she goes in the house, doesn't like to leave the house, and when he does, wants to go home immediately, even when going to visit family. This is hard for her especially now that the weather is getting better and she wants to go out more. She added, "I am also handicapped. [She walks with a cane.] I don't know if I would be less handicapped if I didn't have the stress."

The second participant, Kate, was a woman whose father had Alzheimer's disease. He had been ill for many years and was in the late stages of the disease. He does not know her name, nor recognize her when she visits. Her mother is her father's caregiver along with round-the-clock aides. Kate feels a sense of burden and anger because of her mother. "I am not angry about the disease. I accept that my father is who he is now and that he is not going to get better. It is what it is. It's my mother that gets me angry. She complains about the aides. I get calls from them saying that she is stopping them from doing their job. She has to be the one to help him. Even though she has the aides for him, she never goes out to take time for herself. I worry about the toll it is taking on her."

The third participant, Terry, was the significant other of a man who was in the process of being tested and diagnosed, but she knew had the signs of Alzheimer's. She had been previously married to an alcoholic and raised two children under that burden and was familiar with support groups having been involved in Al-Anon. She had been together with her significant other for seven years but had started noticing symptoms several years ago. She said this was all new to her and she wanted to learn as much about it as she could. She added, "I need my own time. It is very hard when someone is asking you so many questions. How am I? My blood pressure is way up. I am developing stomach problems. This is eating me up. But I am not going down that path. That is why I came here. I know what groups can do. I have some resentments toward him that he and I can't do all that I want to do because he can't do them." She tries to stay positive. When he gets depressed she tells him, "Let's do what we can do with the time we have. This is what we have. Some people get cancer. This is what we have." At the second meeting, after hearing Linda talk about her many years of marriage, Terry expressed, "I am not that committed and it makes me feel bad. We have only been together for seven years and half of those he has been sick. We are not married. I don't have it in me to stick around like this. So I just take it as it comes."

I had concerns about the benefits or even harm of Terry being in the group with her loved one in such early stages of the disease. I feared that as she heard the stories of the other two participants whose loved ones were in the advanced stages, that she would get frightened and run from the commitment of caregiving for her significant other.

Strong emotions can be present for Alzheimer's families. When asked about the emotions that the members of the group felt in response to their loved one with Alzheimer's/dementia, these were their responses: worry about finances, anger, sadness, overwhelming sadness, scary, fearful, frustrated, guilt, and confusion.

> "Angry because it happened. Angry at my mother. Sad at seeing my mother decline as his caregiver."
>
> "I am not angry, just very sad that it took away our retirement years. It took away our companionship. Would it have been better that he went at 80 with all his faculties? I don't know."
>
> "I don't want to come out of this too wounded."

When asked what they did for stress relief, they mentioned spending time with their dogs, talking to their spouse (for adult children), reading, trying not to isolate, crafts and hobbies. No one in the group was particularly religious so prayer did not come up as an option. I offered the group a handout that I had put together containing relevant psalms and prayers. They felt it might be helpful. (See Appendix 5: Spirituality Handout for Support Group.)

At the final meeting we discussed what people felt the benefits of the group were. (The older woman, Linda, was unable to attend the last several weeks. Her husband's condition had worsened and he was in a rehab/nursing home. She had to spend all day with him to be sure that he ate so could not leave to come to the meeting. He subsequently passed away right after the group ended.)

Terry, despite my concerns at the beginning of the group, seemed to have gained the most benefit. During the first session I asked the participants to fill out the Zarit Caregiver Burden Scale. (See Appendix 4) I also asked Terry and Kate to fill out the same form during the last meeting. Terry showed the following changes: She felt less confused and unsure, less stress, anxiety and fear, less sadness, less frustration and was not in denial as much as she had been before. She also felt she was managing better.

Kate also felt the group was very helpful for her. The results of the second survey showed that she had less sadness, less of a constant sense of responsibility, less worry, and less anger. As she listened to Linda, she could better understand why her mother was so devoted to her father. I had also explained to Kate that from her mother's point of view, the only thing left in the relationship between her parents was her mother's care for her father. If that was taken away from her by the aides there would be nothing left to their relationship at all. Even though her mom knew she needed the aides, it was also important for her to participate in his care. Kate felt that this advice was also helpful. She no longer had the anger toward her mother that she did at the beginning.

Psycho-educational Program

After I completed the support group I wanted to have more experience speaking with other Alzheimer's family members. I showed the movie, "Still Alice," at my synagogue and had a discussion with the participants afterward. ("Still Alice" is a film about a woman who develops Early Onset Alzheimer's Disease [EOAD] and the struggles that she and her family go through.) During the discussion, one of the participants continually tried to usurp the conversation by focusing on all of the hardships she is experiencing in her life, which had nothing to do with Alzheimer's disease. I saw that people in the audience were getting very frustrated by her constant interruption so I said to her in a calm and understanding voice, "I understand that you have had some very difficult experiences in your life. Perhaps this is not the best place to talk about them since we are trying to have a discussion specifically about Alzheimer's disease. Let's talk after the meeting and we can set up a time to speak privately if you would like." This enabled the group discussion to continue on track.

I had asked those who attended the movie about their connection, if any, to someone with Alzheimer's disease and if they might be interested in joining a support group. There was no interest in being part of a group because most of the people who attended were there for general information rather than from personal experience. Since it was an older group, perhaps their interest in the movie was also personal fear regarding their own future.

Showing the movie in that setting was useful in helping people understand more about the symptoms of the disease, as well as learning about the challenges for family members. One of the biggest complaints that Alzheimer's family members have is that friends and family really have no idea what they go through. On the surface the person with Alzheimer's seems normal and so the family members suffer in silence. I believe one of the tasks of clergy is to share information about the disease so members of their congregation can be more understanding, empathetic, and supportive of those in the congregation who are involved with a loved one with Alzheimer's.

Individual Ongoing Counseling

After showing the movie, one person decided to meet with me for private counseling. Her mother has had Alzheimer's for many years and lives in a memory care unit. Her mother is now in the later stages of the disease. Miriam and her sister legally share in the decision making for their mother. Miriam has the additional burden of having been estranged from her parents for many years as well as having an extremely contentious relationship with her sister.

In situations like this I believe the best approach to counseling is self-psychology. A person's perception of self can be greatly damaged due to the various circumstances in his or her life. Miriam's life including estrangement from her parents, a difficult relationship with her sister, and a needy mother who doesn't even know who she is. Empathic listening was very valuable in helping Miriam explore the issues she was dealing with. Creating a caring, non-judgmental, and safe place for Miriam to be able to talk about her family relationships enabled her to process the challenges and begin to understand the dynamics going on between her and her family members. Through our meetings, Miriam was able to start processing the anger and resentments she had with her parents and sister, and talk about her mother's current stage of dementia, in which she can now do very little. These meetings have better enabled her to cope with her mother and sister, and feel more at peace within herself.

Miriam also shared with me her incredible fear of getting the disease. There is a long history of women in her family getting Alzheimer's. Her mother's symptoms started when she was in her sixties. She related that she is only five years away from that age. Miriam asked her doctor if she should be tested but he said that since there was no treatment, nor cure, there was no reason to do so. He told her, "Just live your life and enjoy what you have." After that meeting, Miriam and her husband both retired early, and are enjoying their time together and the opportunity to see their three grown children more often.

One Time Meetings

I was also able to speak to several people who had a loved one with Alzheimer's disease and did not feel they needed any support or counseling but were willing to "share their story" with me. Personally, my experience with Alzheimer's was very difficult. And I know it is difficult for so many other family members. I was curious to find out what the differences were between those who felt a great sense of burden, stress, and suffering, and those who did not. Again, creating a safe, non-judgmental space through empathic listening for people to share their stories enabled them to talk freely about their experiences.

When I was forming the support group, I was surprised that Helen had not responded to join the group. I had known her and her husband for many years and knew that he had advanced Alzheimer's. I sent her an e-mail with a personal invitation to join the group and she responded, "Thank you for your personal note but I was already deciding not to participate in this group because I feel that maybe I'm just too far over the hill and not really suffering or needing any help." After the group was over I approached Helen and asked if she would meet with me privately to "share her story with me" and she willingly agreed.

Helen lives with her husband in their home. He has round-the-clock aides and is in the late stages of the disease. He does not talk and does not recognize anyone, even Helen. As we sat in the dining room and talked, he paced steadily and consistently from the living room, through the dining room, into the kitchen, and back again, non-stop for the entire two hours I was there. This is what he does all day, with an occasional stop on the couch for a nap.

I asked Helen what it was like when she first got the diagnosis. She replied, "I just take what comes. I always loved being the wife of a smart guy. (He was a distinguished professor at a university.) We were a team. He was the brains and I was the happy person. People often talk about a change of personality that comes with Alzheimer's. He was belligerent before the disease. He always carried the woes of the world on his back. With that I took his timber and his negativity. Afterward, he became sweet and darling. When he stopped being negative things got easier for me. No more roller-coaster. Things are emotionally peaceful. I like it this way."

When I asked her how her kids were handling it she replied, "Just the way I am. You live with it and adjust to it." She told me that her adult daughter was living at home and so I asked if I could speak to her also. My conversation with her daughter, Sue, revealed that she was not as accepting of her father's disease as her mother was. She had worked for her father at the institute he had started. She was the first to notice something had changed. It began to be a problem for her at work. People were calling asking why her father had not responded to his e-mails. "At first I thought he was just getting older. But then it got worse. It was so sad for me. I started to have to lie for him. It was horrible."

She shared some of her religious beliefs with me. “I believe in miracles. I pray for him. I really care for him. In my childhood he was a huge part of my life. He was very proud of me. It’s a heart breaker. I think, any day, if God steps in, God could heal him. He is still healthy. His body is strong. He can heal. I have tremendous amount of hope for him sometimes. He is so far gone. The decline is devastating to fathom. So I have my prayer life. I know I connect to his soul. When he looks at me I know that.” I shared with her my idea about his soul spending time with God. She found that comforting and asked for a copy of the article. Sue also shared her fears about getting the disease. “Will I get Alzheimer’s? I always think I am going to keep my marbles. It is too horrifying a thought.”

I also called Helen’s son, Alan, to ask if he would be willing to meet with me. He agreed. This was a unique opportunity for me to speak not only to a spouse, but also their two adult children to see how different people in the same family reacted to having a loved one with Alzheimer’s.

Alan wondered if his father really had dementia rather than Alzheimer’s disease. He said the change came on suddenly, not slowly as Alzheimer’s usually does. (It is not unusual for very intelligent people, for the disease to appear to come on suddenly because their intelligence enables them to hide the symptoms much longer. They are able to come up with tricks to hide the memory loss and other symptoms until they no longer have the capacity to do so.) Alan described his father’s decline as sad. One of his students complained in the professor rating at the end of the semester that he had given the same lecture twice. His father realized that he needed to retire.

When asked what it was like for him, Alan replied, “in many ways we are blessed. My parents had long term care insurance so there is no financial burden on my mother. My dad was a brilliant and compassionate person but he was not pleasant. He could be very difficult. He would get angry at the dinner table and no one knew who set him off or why.” He also added, “It’s a slow death. You are in an ongoing state of mourning. There are things that I am angry about my father, there were things I was proud of him for. I no longer have the opportunity to find closure. If I felt frustrated or proud, had misgivings, wanted clarification, or wanted to give my side of the story – he is already dead in that respect. You question what it means to be alive if you have no memory what so ever. Then who are you? Are you like a houseplant? My father is aware. He sometimes notices things at the dinner table and makes a facial expression. I wonder if he does know but can’t communicate it.” Like so many others with a loved one with Alzheimer’s, Alan and Sue were forced to search within themselves to find answers about the meaning of life and human existence.

I asked Alan about his mother. He replied, “I wonder what my mom gets out of the marriage. She smiles at him and kisses him. But there must also be great loneliness. Yet my mom remains upbeat all the time. In a way he has become the perfect husband. In many ways he is happier than he has ever been. He used to be unhappy. He seemed angry and pent up and worried. He was fraught with anxiety. Now he is on a continual path toward serenity.”

I then asked Alan how it affected him personally. He said, “I start to think about my own forgetfulness. Am I going to get it too? His sisters didn’t get it. Why my dad? Where is the science? Will you and I benefit in time?”

I met with several other individuals who had a family member with Alzheimer's on a one-time basis. Some of them I knew had a family member with the disease. Others willingly approached me to "help me" with my project.

One such man was Sam. He told me he was at peace with his father's disease and did not feel he was suffering or burdened. His father is living alone in an independent living center with round-the-clock aides. Sam visits his father weekly. He has two sisters but they live further away and are content to let Sam take care of their father's needs. He feels that their father's disease has brought him and his sisters closer.

Shortly after Sam's father was diagnosed with Alzheimer's his mother was diagnosed with cancer. "My mom was devastated with my dad's diagnosis." Knowing what was coming with her husband, she opted not to have any cancer treatment and died shortly afterward.

Sam's father was distant when he was a child and there was very little relationship between them. Sam is enjoying the relationship he has with his father now. "My father never showed any emotion but when he sees me now, a real light comes into his eyes. I have a very sweet relationship with my father now. I have great admiration for my father, how he struggles to get dressed and continue to live despite the disease. I have been able to help my father function to the best he can and that make me feel fulfilled." Like all of the other adult children of a parent with Alzheimer's disease, he wonders if it is genetic. Sam is not afraid of getting cancer as much as he is of getting Alzheimer's.

Another woman who volunteered to "help me" with my project was Barb. Her mother had died from Alzheimer's a few years ago. She said she was in denial for several years, making up excuses for the confusing things her mother would do. She and her sister were close as they managed their mom's needs. That was helpful. She had also been in therapy in the past for family issues with her mother and sister and that helped her to better deal with the situation later on. Her mom was very difficult before she had Alzheimer's. With the disease, her mom never got mean. She became quiet and sweeter. That also made it easier.

Eventually Barb's mom was placed in a memory unit. She could not have conversations but still recognized her daughter until the end. Barb told me about her mom's burial which was at a memorial park. "The wind was blowing. I had my arm around my sister. It was spiritual and amazing. Grief and relief. Grief, not for the mother that was sick, but for the woman she was. I felt the loss of not going to visit her any more. Relief that this was finally finished."

I wanted to learn whether these single "tell me your story" interactions had any purpose or meaning for the people I spoke with. I also wondered if the conversation might have stirred up negative feelings that had been suppressed. I sent out a follow up e-mail a few days after our conversations. (See Appendix 6.) Some of the people who had not felt burdened or stressed by their Alzheimer's family member responded that the conversation was neither hurtful nor helpful. Even though Barb had volunteered to help me with my project she felt that the conversation we had was very beneficial to her. She wanted someone to be able to talk to about her mom's disease and she felt much better after our conversation. "My mother had Alzheimer's and passed away three years ago. Lately I have been remembering what she was like before she got ill. So I volunteered to speak about my mother and was able to talk about how funny she was, how she was an expert knitter, and a great cook, and a loving mother. Speaking with someone who did not know her was refreshing. I was also able to talk about the difficult times with someone who was a very good listener and was empathetic…Had I been able to have someone like that during my mother's illness, I am certain that it would have helped me when I was dealing with a mother who was disappearing right before my eyes."

Finally, I learned two things from my conversation with Esther, another adult child, that I hadn't heard from anyone else. (Her mother died from Alzheimer's about a year ago.) The first was in regards to her rabbi. When I asked her what would have been helpful she said, "I love my rabbi and my temple. I am very involved there and go to services every Friday and Saturday. It would have been nice if just every once in a while the rabbi asked how she was doing. I don't need him to visit her. She doesn't know who he is. I have a friend at temple whose uncle had surgery and was put on the *Mi Sheberach* list. (Prayer for healing.) I heard the rabbi ask her how her uncle was doing. But he never asked me."

This is an important lesson for clergy. Many times people are afraid to ask about someone who has Alzheimer's disease because they know the answer will be, "He or she is getting worse." Even for someone who has cancer, there is the possibility that they will improve with treatment. Family members of loved ones with Alzheimer's do their suffering in silence. It is important to reach out to them. Instead of asking, "How is your mother? " it could be reworded as "How are things with your mother?" or perhaps more importantly, "How are you doing?"

In addition Esther told me about a closed Facebook support group called, "Memory People." Here is a description of the group from their Facebook page.

> Memory People™ is an Alzheimer's/dementia and memory impairment Support and Awareness group. We are patients, caregivers, advocates, family members and professionals sharing our journeys with each other, seeking comfort and understanding, and receiving support and helpful information.

> We don't talk about miracle cures or false hopes here. We share about the reality of dementia and memory impairment, and through support and education we find the ability to take another step each day in this journey.
>
> We welcome anyone, even if you're not directly touched by dementia or a memory impairment. You will find knowledge and awareness here.
>
> Memory People was founded by Rick Phelps who was diagnosed with Early Onset Alzheimer's Disease (EOAD) in June of 2010 at the age of 57. Rick created MP to be a safe, comfortable place to bring real-time support to those touched by these diseases and any memory impairment.

Anyone can join as long as you follow the rules of anonymity of the group. People need to know that what they post will not show up in other places so they can be honest and openly share what is on their mind. It is important to know that they won't be judged, and that there are others that have the same thoughts and feelings. The founder, Rick Phelps, also has a blog at a separate URL that is public. (http://phelps2645.blogspot.com). Personally, this Facebook group has helped me better understand my father's Alzheimer's as well as currently handle Alzheimer's related issues with my mother-in-law. I wish I had known about the group when my father was still alive.

Professionally, the group has given me insights and led me down an additional path that I had not planned on exploring initially, but found very helpful in my counseling. I gained a better understanding of what is going on in the mind of a person with Alzheimer's disease. The members of the group are not only family members and caregivers of those who have Alzheimer's or dementia but also individuals themselves who are in the early stages of the disease.

While my father was alive, I blissfully believed that he was not aware of what was happening to him. Earlier in this paper I told the story of how I brought him to an

Alzheimer’s support group that I was talking at. After the talk was over, he replied, “I am sure glad I don’t have that.” From the blog I learned that my father may have had more awareness than I thought. Being able to hear first hand what it feels like to have Alzheimer’s disease, and what is helpful or not helpful to the person with Alzheimer’s, has opened my eyes and enabled a better understanding of ways to deal with issues that come up with people with Alzheimer’s.

I am grateful to Rick Phelps for starting this site and believe he is doing a great service in educating the public more about the disease in areas that are rarely discussed by the “experts.” In fact, he sometimes contradicts what the experts say. You often read that people with Alzheimer’s disease should use their brains as much as possible, equating it to physical exercise to maintain your muscle strength. Rick Phelps disagrees. “The time for brain exercises has long been past when they are diagnosed with dementia. Dementia remember, is a disease of the brain. By having your loved one do brain exercises you are in fact making them do things they simply no longer can do” (Phelps, May 13, 2014). This adds to the person’s frustration and may cause a negative reaction. Phelps concludes, “[S]ome patients love to do puzzles, or brain teasers. But the fact is, you should never make or encourage your loved one to do these things” (May 13, 2014).

It wasn’t until I mentioned the Memory People Facebook page to my mother and explained what it was that she said, “You know, I do remember that your father once asked, ‘What is happening to me?’ Hearing that at one point my father did express his fears about what was happening to him, I began to feel very guilty that I didn’t focus enough on him, and instead focused more on my mother, when visiting my parents. I am using that guilt to help others find ways to make the lives of their loved ones a little better. I now recommend this group to anyone I talk to regarding Alzheimer’s or dementia.

I also gave a talk on two separate occasions at the same seniors’ residential center. The first was open to residents. I was invited back to give an additional talk for both residents and staff. At the first meeting I had not known about “Memory People.” There was a woman in the audience who told me she was diagnosed as being in the early stages of Alzheimer’s. I had spent so much time learning about how to help family members that I didn’t really know what to say to her, other than to listen empathically and know that others in the group were hearing her thoughts.

The second time I met with the group was after I had been introduced to Rick Phelps writings. The same woman was there. She expressed how difficult it is for her because people assume she is normal and don’t understand why she acts the way she does at times. She said the staff get frustrated with her and don’t understand her. I invited her to share her thoughts more publicly with the community. I encouraged her, if she still was able to write, to write a short article in their newsletter. And if that would be hard for her, to ask someone to help her write the article. (I live out of town and was not be able to stay around to help.) She felt encouraged and excited to do this. I would never have given her such a suggestion without the understanding I gained from the “Memory People” Facebook page.

CHAPTER V – UNDERSTANDING THE RESULTS OF THE PROJECT

> (Note: In this section I am making the assumption that readers of this project may be clergy, mental health counselors and/or family members of loved ones with Alzheimer's disease or dementia. Therefore at times I will be speaking directly to clergy or mental health counselors, and at other times, directly to the family members. I belong to all three categories.)

I started this project with the goal of helping those who have a family member with Alzheimer's find ways to decrease the burden and suffering that comes with experiencing their love one decline as they exhibit the various symptoms of the disease. My initial plan was to help people by forming a focus group, which is a limited time support group. Surprisingly I could only find one person interested at my synagogue. There is no local Alzheimer's Association in the community where my synagogue is located but I did get the name of an organization that runs a county wide general caregiver's group. Even that group only had three people and would shortly be ending because two of members of the group had recently lost their loved one. It seems that support groups are not popular in that community. I then turned to the community where I live and was able to create a small group through Jewish Family Service.

There may be many reasons why people who have a loved one with Alzheimer's would not join a support group. In small towns, such as where my synagogue is located, and to some extent the town where I live, everyone knows everyone else's business. This is particularly true within their religious communities. People don't want to appear vulnerable and in need. They want to create a strong front of showing they can handle things. If they came to a support group chances are they would know some of the people in the group. Even if the group has pledged confidentiality, they would also probably run into the same people in other locations and organizations, which might make them feel self-conscious.

I was told that if I wanted people to come forward and talk with me about their family member with Alzheimer's, I would have more success if I changed my approach to say I was looking for people to help **me** with my D.Min. project, rather than to help **them** with their problems. I realized how true this was, as instead I asked people to "tell me their story." As their stories unfolded there were opportunities for pastoral and clinical counseling that were willingly accepted even though they originally came "to help me."

In his blog, Rick Phelps, a man with EOAD, talked about the people he meets when he travels around and lectures about the disease. **"**I found in doing these speaking engagements that most, not all, but most people just want to vent. They want to tell us what they are going through in hopes that they find out they are not the only ones living this nightmare" (Phelps, Sept 2, 2015).

Another factor in affecting the ability to participate in a support group is when the caregiver has not yet arranged for aides or other help and may not be able to leave their loved one alone. One woman brought her husband to the first meeting, with my encouragement, because that was the only way she could participate. He sat on a couch on the side of the room, and after about an hour insisted that they go home. For the next meeting she was able to arrange for someone to watch him at home. The woman only came to a few meetings because her husband had gotten sick and was in a rehab facility. She did not want to leave him to attend meetings because she wanted to make sure he ate his meals, which he was refusing to do.

In addition to the support group, I met with individuals. Through meeting with different people in various situations I found that there seem to be certain common factors that affect how family members react to a loved one having Alzheimer's disease or dementia. The degree of stress and burden varies from very little to overwhelming. Here are the factors that seem to be important in determining the affect on a family member:

- **The Age of Onset** – For those whose loved one has EOAD, defined as having symptoms that begin before the age of 65, (and can start as early as the 40's or 50's), the burden seems greater. Most people assume that decreases in various abilities, both physical and intellectual, are part of aging. While it may be challenging to handle someone who develops Alzheimer's disease in their 70's or 80's, it doesn't usually come as a surprise that some illness or disability would eventually occur. In fact, most people who develop Alzheimer's disease have the symptoms for years before they are officially diagnosed because family members just assume what they notice are normal aging changes. When "aging" symptoms such as memory loss begin at an earlier age when it is not expected, the shock of the diagnosis is much greater and harder to accept.
- **Personality Change –** many people report personality changes that occur in the mid to late stages of Alzheimer's that make it more difficult for family members. It is not unusual for someone with Alzheimer's to become paranoid, angry, stubborn, act out, lose their social filters and say embarrassing things, and/or have delusions or hallucinations. For some of the people I talked with, their loved ones' personality change was different. They went from being difficult and irritable before the disease,

to being kind, sweet, and pleasant once the disease developed. For these family members, they were “enjoying” this nicer version of their loved one.

I have a theory as to why this change in personality happens. One of the symptoms of Alzheimer’s is apathy, which cause people to lose interest in, or awareness of, the greater world. They are only able to focus on the immediate surroundings. All the stresses and worries about what is going on in the world, the community, the family, and their own self-consciousness, slowly disappear as the person with Alzheimer’s is no longer aware of, or loses his or her concern for such matters. In addition all those events from childhood such as growing up in a dysfunctional family, lack of parental love or attention, not feeling safe, trauma, abuse, etc., which influences how people behave as adults either become forgotten amidst the memory loss, or lose their impact and significance on the person due to processing difficulties in the brain. These various factors can cause a person who was angry at the world or those around them, to now be at peace because they are now apathetic to those stressors that caused the difficult behavior before the disease set in.

For those whose personalities worsen with Alzheimer’s, perhaps during their lives they suppressed true feelings of anger or resentment as a way of coping and appearing pleasant. Once the ability to suppress such feelings is not in their control because of the changes in the brain, that anger shows through. The best example I can give you is my father. His parents were deaf. It was not genetic, rather they lost their hearing from a meningitis epidemic in the early 1900’s before there were antibiotics. My dad was an only child so he had to deal with this alone. Based on different reactions he had to deaf people, I believe as a child he was resentful and embarrassed by his parents' disability. His friends would see his parents signing and not understand what they were doing. He would always have to be his parents' ears and go with them to various places to translate for them. He was "different" because of them. I believe he suppressed these feelings, and as an adult he worked hard to be pleasant and easy to get along with. When the Alzheimer's struck, that anger he kept in from childhood came through.

- **Who the Care Giver Is –** While it is difficult for any caregiver, those who are spouses often have a greater acceptance of caring for their spouse. One spouse told me, "We have been married for over 50 years. Of course I would care for him." Generally, married couples know that if you are lucky enough to live to old age, one will get sick and will need the other to care for him or her. Adult children who are caregivers can be more resentful of having the responsibility. They often give up their jobs and their social life to care for their parent. They feel that they are losing out on an important part of their life. Some adult children are torn as they try to care for children living at home and their needy parent at the same time. It is also psychologically hard as the roles are reversed when the child needs to care for the parent, rather than the parent caring for the child. If there are siblings, there may also be resentment from the caregiver sibling feeling that the others are not helping and have no idea what the caregiver is going through.
- **Relationship to Person With Alzheimer's –** With the people I met with, those who seemed most negatively affected were daughters of mothers with Alzheimer's. They missed the mother/daughter bond that had existed before the disease. If the father was still alive, there was also resentment toward the father for not taking better

care of their mother. The spouse knows long before others that a loved one has Alzheimer's disease because he or she lives with it daily. Adult children often don't find out until the disease has progressed far enough for the symptoms to be very noticeable. If the daughter lived further away and didn't see her parents that often, She was often upset at the appearance of her mother who had always taken extra care to look clean and groomed, and well dressed. One woman shared with me, "My mother had long stubbles coming out of her chin when I saw her. She had always plucked those hairs. How could my father let her get like that? And her toenails were so long she could only wear slippers. How could he not have noticed that?" Sons, especially those who had previously difficult relationships with their fathers, seemed to enjoy their visits with their fathers who were now more mellow and agreeable.

I also noticed that adult children were in denial for a longer time than the spouse. It is hard for a child to accept the mental decline of their parent. Part of that may also be the fear of inheritance. Without exception, every adult child mentioned his or her fear of getting the disease. Personally, every time I have trouble thinking of a word, I immediately fear that this may be the beginning of Alzheimer's. There is some proof that EOAD may be inherited, but with onset in the older years, there is uncertainly in the scientific community whether there is a genetic factor. Regardless of the facts, the fear is real. If there was a strong family history, the fear was palpable.

Some adult children denied that their parent had Alzheimer's and preferred to call it dementia. The symptoms are very similar and for the lay community, the words are pretty much interchangeable. (Alzheimer's is the most common form of dementia.) I was trying to understand the need to deny the term Alzheimer's. Dementia is often thought of as something that comes with old age. People see it as the modern term for senility. Somehow that doesn't seem as threatening. There may also be a need to have a known cause, such as in vascular dementia, allowing the adult child to feel there is something that can be done to prevent them from getting the disease if they could keep up their health. One man told me that every time he feels too tired to get on the treadmill, he thinks of his father with Alzheimer's disease and that motivates him to exercise.

While adult children are aware of the recommendations that may stave off Alzheimer's disease, such as exercise, healthy eating, losing weight, and using your brain, they are also skeptical because many of their parents lived lives that reflected those recommendations. One son whose father was a brilliant professor said, "If using your brain keeps off Alzheimer's then my father shouldn't have gotten it."

- **For Spouses, Is the Person with Alzheimer's At Home or in a Facility? -** The burden of caring for a loved one at home is intense if a spouse is doing the care by themselves. Some families had been able to afford long term care insurance and so were able to have home health aides as needed. For them, the burden was lessened. While it was still hard for such spouses to watch the decline of their spouse, they were relieved of the physical aspects of caregiving and had someone to talk to who knew first hand what was going on.

  One of the hardest decisions a family has to make is to put a loved one in a nursing home or memory care unit. While the physical caregiving burden was gone, the guilt was usually tremendous. Phelps says to take yourself out of the equation as you make such a decision.

> In the end, if you take yourself out of the equation, and do what is right for your loved one you will always win, and you will save yourself a lot of heartache in the long run.
>
> > "Momma never wanted to be in a nursing home"....well,
> > "Momma never wanted to not be able to go the bathroom alone either" or
> > "Momma never knew she would forget her kids and grandkids names".
>
> There are a whole list of things Momma would never want. You have to go with what is best for her. Not what is best for you, or what she may have wanted...Do what is right. Not what is popular. You will never go wrong by doing this. Never... (Phelps May 12, 2014).

- **For Adult Children, Is the Spouse Still Alive and is she/he the Caregiver**? - Adult children who have one parent caring for the other parent, don't only deal with the deterioration of the parent with Alzheimer's but also see the toll it takes on the other parent. It is common for the physical health of the caregiver to decline along with the mental decline of their spouse. One woman I spoke to said, "I accept that my dad has Alzheimer's and there is nothing that can be done but it is so hard to watch my mother give up so much and never take a break. I worry about her health."
- **Do The Adult Children Get Along**? - Many decisions need to be made for a parent that has Alzheimer's. If the children get along and can work together, they support each other, which lessens the burden. For adult children that cannot get along, this adds to the burden as each has a different opinion. This makes consensus hard to come by. One of the siblings may dominate the others needing to be in control,

taking away opportunities of participation from their siblings who may be very interested in helping. These conflicts, which often start in early childhood, may become dormant as each child moves on to live their own lives, only to be reactivated with the stress of having a parent with Alzheimer's.

- **Approach and Attitude** – Some caregivers see their task as a calling. They are more able to find meaning in the difficult work they are doing. One woman from the group, was a caregiver for her significant other. Since she was not married to him, she did not have the same legal and long-term connection that most spouses have. Terry, mentioned in chapter IV, was unsure at first if she could maintain such a commitment but later on she felt she could by looking at the situation differently. She realized that by caring for her significant other, she was making up for the care she was unable to give her father when he was sick. There was a purpose to her caregiving beyond the relationship she had with her significant other. Those who have resentment toward having to be the caregiver, or resentment towards other family members who do not help, have a much harder time.
- **Previous Emotional Issues –** One of the women I met with had been through counseling years before regarding issues she had with her mother and sister. She was able to resolve many of the issues. She felt that this was helpful as she took on the new challenges of having a mother with Alzheimer's. Her sister had also gone for counseling in the past. Because of the sisters' ability to deal with problems they had before dealing with Alzheimer's, they grew closer as they shared the caring and decision making for their mother.

Another woman I spoke with had not had counseling and had several psychological issues going back to her teenage years regarding her sister and her father. Favoritism, jealousies, and resentments plagued the family. For a while she was estranged from her parents feeling they didn't show any love or interest in her own children. When her father suddenly died and she had to come and be with her mother she learned of the living conditions in her parents' home. (It seemed as if her father also had dementia but her mother's was more advanced making him the caretaker by default.) Her sister was not interested in getting involved, so Miriam had to take on the entire task of finding an assisted living facility for her mother. Then her sister criticized her for the place she found.

Having all of the pre-existing family issues that were never resolved greatly added to the stress that she was feeling. In fact, she felt totally overwhelmed at times. Miriam and I had several counseling sessions together. This enabled her to start understanding some of these issues and that made caring for her mother and accepting her condition a little easier. She could benefit from additional counseling to help deal with her sister but is not pursuing it at the moment.

A past history of depression can be exacerbated by having a loved one with Alzheimer's disease or dementia. When counseling, it is important to differentiate between true depression and sadness due to the ongoing losses that are occurring. One woman I met with was a spouse caregiver whose husband had passed away six months earlier. She told me she had sought out counseling during the last years of her husband's life because the burden she felt was starting to affect her health. She was treated for depression with talk therapy and anti-depressants. When I asked if

> it was helpful, she said, “Not really.” We further discussed the idea of her intense sadness coming from the continued losses due to the disease. She replied, “The therapist never talked about the idea of losses with me. I wish I had know this back that. I think that would have been more helpful.”

The most unexpected, yet most useful information that helped me counsel family members was when I learned of the Facebook group, “Memory People.” Having focused my attention on the family members who did not have Alzheimer’s disease my thoughts about lessening the stress and burden were similar to general counseling advice given to lessening stress, which included talk therapy, relaxation techniques, including prayer and meditation, and getting support both emotionally and physically (if the person was the caregiver). I really did not focus on the person with Alzheimer’s because the information available says there is no cure and it is questionable whether medication helps the symptoms of memory. That was also a topic that should be left to the medical doctors to decide.

“Memory People”, with over 12,000 members, is similar to a support group. Since people felt safe to share **exactly** what they were feeling, I learned a great deal professionally about what so many people go through. It was also a help to me personally as I gained insights into my father’s illness and received advice about my mother-in-law who now is in the mid-stages of Alzheimer’s. While I cannot quote what people said on “Memory People” because it is a closed and confidential group, the founder does have a blog and has given permission to use what he writes since his goal is to make as many people as possible aware of Alzheimer’s disease and its symptoms. Here are some of the things he wrote that gave me greater insights into what a person with Alzheimer’s disease experiences:

It’s the Disease - It is difficult to deal with all the changes that occur in a loved one with Alzheimer’s disease. The hardest times are when they do things that are embarrassing, when they follow you everywhere you go and you don’t get a break, or when they do or say hurtful things. It is easy to become resentful of the person with Alzheimer’s. Even with the most patient family member, anger at their loved one is not unusual. One of the important aspects of counseling became explaining or reminding family members of the symptoms of the disease. Most people assume that Alzheimer’s means memory loss but there is so much more to the disease. It is the other symptoms of behavioral change and inability to process information that are the harder symptoms to deal with. It is so easy to take these actions personally even if you know in theory that it is the disease causing the person to react that way. Phelps explains, “We just want answers... ‘Why does my love one act the way they do? Why do they constantly do absurd things, say hurtful, hateful things?’ ‘Can someone explain this to me? I just don't understand.’ I can sum this up for you in three words. IT’S THE DISEASE. It's always the disease. I know that isn't the answer anyone wants to hear, but it is the answer to this and all other things patients do” (July 2013).

We Don’t Mean To - “I think the one thing people, caregivers, and family members should realize is that ‘we don't mean to.’ When your loved one does the things they do, they don't mean to. When they say things that offend you, hurt you, mentally or physically, they don't mean to” (Phelps, August 21, 2015). Many family members carry deep hurt for many years because of things their loved one with Alzheimer’s said or did. In one instance, a family member invited her parents for the Thanksgiving week-end. She planned and made arrangements for them to come, even cancelling some other plans later in the week-end to be able to spend time with her parents. After a day, her father, who was in the early stages of Alzheimer's disease but appeared normal, said, "I need to go home. Please take me home now." The daughter was very angry with him and took it personally, not realizing that he felt uncomfortable being anywhere but at home. There was also too much commotion going on for him there which made it harder for him to focus and interact with others, causing him a great deal of stress and unrest. Explaining the more intricate and nuanced symptoms of Alzheimer's can help family members in similar situations better understand the reason for their loved ones' actions.

Do Not Blame the Patient For His or Her Behavior – "Why does your loved one do the things they do? Are they doing these things to irritate you? To get attention? None of these answers are correct. I can tell you this from a patient's perspective. For a patient to do things that intentionally upsets their families they would have to be calculating. With dementia, calculating does not compute" (Phelps, August 7, 2015). Here Phelps is talking about the inability to process thoughts the way you and I can. A person without Alzheimer's disease can purposefully, or in a passive-aggressive way, do and say things to hurt another because of something they did to that person. The normal assumption is that we take what people say or do to us at surface value. It is very easy to become angry and upset from the actions of a loved one with Alzheimer's disease. Phelp's insights can help a family member see the actions from a different perspective.

Dementia and Feelings – "We have feelings. And they are real. More real than they were before our diagnosis. We sometimes have a difficult time explaining them. But it is your job as a caregiver to read between the lines. Simply because your loved one can no longer communicate with you, they still have feelings. Their feelings of anxiety, depression, and fear are only worse with the disease "(Phelps, July 8, 2015). In the mid-stages of the disease, a person with Alzheimer's will often say, "I can't explain it." Even though they can speak, their brain can't come up with the words to express what they are feeling. Certainly when they are in the aphasic stage, it is even harder to know what they are thinking. Sometimes the acting out of a person who has Alzheimer's could be a way of expressing their feelings of frustration not being able to properly verbalize their wishes or needs.

A woman shared with me that she used to visit her mom in the nursing home. Her mother was not able to do anything other than lie in bed. One day, while sitting next to her mother she said to her husband, "I don't know why I bother coming. She doesn't even know I am here. Maybe I won't come anymore." Suddenly she saw tears flowing down her mother's cheeks. She knew then that her mother did appreciate her visits. As hard as it is, it is our job to do our best to try to interpret and understand what our loved one is feelings, even when they can no longer communicate effectively.

What? – Family members often confuse hearing loss with the inability to process what is being heard. "What? I find myself asking 'What' all the time now... I ask what, because then when whatever is said again, it gives me an extra minute or two to figure out just 'what' was 'said'" (Phelps, April 2, 2015). I remember being present when my father had a hearing test performed by an audiologist. We got tired of him asking, "What?" all the time and thought he needed better hearing aids. I watched him raise his hand every time he heard a beep. He heard almost all the beeps and the audiologist said his hearing aids were fine. He looked up shyly and said, “I guess I can hear O.K.” Even knowing this, it is so easy to get frustrated. When I was visiting my mother-in-law she kept saying, “What,” and I said, “You really need to get your hearing checked.” A few moments later I realized that it was probably more her inability to process what I was saying than to hear what I was saying. That is the challenge for family members. Even awareness of the reason behind a loved one’s actions, in the moment it is hard to remain objective.

Dementia Will Never Take My Love In My Heart – “This disease will effect me in ways I cannot even imagine in time. But it will never be able to change my heart. That is where every loved one I have resides. When I am unable to communicate, unable to speak, unable to recognize my loved ones, and to tell them how much I love you, my heart knows"(Phelps, Sept. 23, 2015). Loving relationships involve doing and saying things to show each other that you care about them and love them. With Alzheimer’s or dementia, this becomes one sided. It is hard to believe that there is someone inside who still loves you. Helen knows that even though her husband no longer recognizes her officially by name, and now no longer talks, she still knows he loves her. She can look in his eyes, kiss him, and get a smile from him.

One of the most challenging aspects of the disease is when people in the mid to late stages start acting out, becoming very agitated, screaming, refusing to do what is asked, or are verbally and/or physically abuse. It is important to first find out if there is a cause for the acting out. The person may be frightened of something, there may be too many distractions in the room, they are confused by something you are asking them to do, they sense your frustration or anger, or something is hurting them physically. Reading Phelps’ blog may be helpful in enabling the family member to figure out what might be upsetting their loved one. This is especially important if the loved one is in a nursing home or memory unit. Staff there may not always pay as much attention to your loved one as you do. They are more likely to carry out the job they are told to do, such as give the patient a shower, than to take the time to find a way to do this without upsetting their patient. (One woman with Alzheimer's reported, "The shower frightens me.") If a family member can figure out what is upsetting their loved one, it is always better to remove the source of the agitation if possible, handle the situation in a different way that is less threatening, or remember to be empathetic and compassion as much as possible, and to use behavior modification medications as a last resort.

In addition to all of the various emotional and psychological aspects of having a loved one with Alzheimer's disease or dementia, there is also a spiritual side. The question of "what is the purpose of life" often came up as people struggled with the spiritual issues of having a loved one with Alzheimer's disease. The lack of memory and ability to relate to others begs to ask such spiritual questions as: If a person has no memory, is there still value to the person? Once communication is lost, is the person any different than a beloved pet? What does happen to their soul? Do they really continue to exist even though it is only their physical body that is left?

Reading Phelps' blog helps to realize that the person's soul is still present even if we can't reach it. As we struggle to deal with the decline of a loved one with Alzheimer's disease, in addition to the practical tips it can be very helpful to find ways to maintain an I-Thou relationship, remembering that the person still has a soul, and that soul is their, and our, connection to God. If you can remember that the person's soul is in there somewhere, it can help you find peace in the challenge of maintaining a relationship with a person who has Alzheimer’s disease. As clergy, we can help our congregants find ways of connecting to that soul again.

In summary, there are many factors the come into play when counseling a family member who has a loved one with Alzheimer’s disease or dementia. Here are the important factors to consider:

- What was the emotional and psychological status of the individual before their family member began showing symptoms?
- What was the relationship of the family member to the person with Alzheimer’s disease before the symptoms began?
- What family dynamics are involved with others in the family?
- How knowledgeable is the family member about the disease? (See Appendix 10 for useful websites and Appendix 11 for a list of recommended books.)
- Is the family member aware that the behaviors that are most upsetting are symptoms of the disease and not meant to be personal?
- Do they have a support system, including support groups, other family members, other individuals who also have a loved one with the disease, church or synagogue community, clergy, or friends?
- Who is the primary caregiver? Do they see their job as a calling, or as a responsibility that they resent?
- What are the resources they have to help reduce stress such as exercise, meditation, or prayer?

Carrying out this D.Min. project has had a profound affect on me personally. When my father had Alzheimer's disease our family kept mostly to ourselves. My mom, his primary caregiver, was embarrassed to tell people that he had the disease, and quietly took the barbs directed toward her because my father was "rude" in public at the independent living center where they lived. At times the stress was so overwhelming that she sought out mental health counseling. As the daughter of someone with Alzheimer's who was NOT the primary caregiver, my focus was on my mother and helping **her** to survive. I felt that my grief and suffering was not/should not be as significant as hers.

Most of the Alzheimer's information and articles that are available are directed toward the primary caregiver. Very little is said about other family members. That is why I felt it was important to talk with non-caregiver family members in addition to working with care-givers for this project. Through the research I did and the people I met with, I learned many things that I wish I had known when my father was alive. Perhaps having that information would have made our family struggles easier. I know it would have helped me to better understand the changing dynamics in my family of origin, which was stressful at times. Understanding goes a long way in developing coping skills. Perhaps we all could have found better ways of coping.

I live with a little more guilt knowing I could have acted different toward my father with the understanding of the disease process I now have, and with a little less guilt knowing that under the circumstances, we really did the best we could. While my intent for the D.Min. project was to help other family members of a loved one with Alzheimer's disease, this process has been healing for me. It is my hope and prayer that the results of this D.Min. project will help other individual family members, mental health counselors, or clergy who can help congregants find some peace and acceptance as we all deal with the challenges of having a loved one with Alzheimer’s disease.

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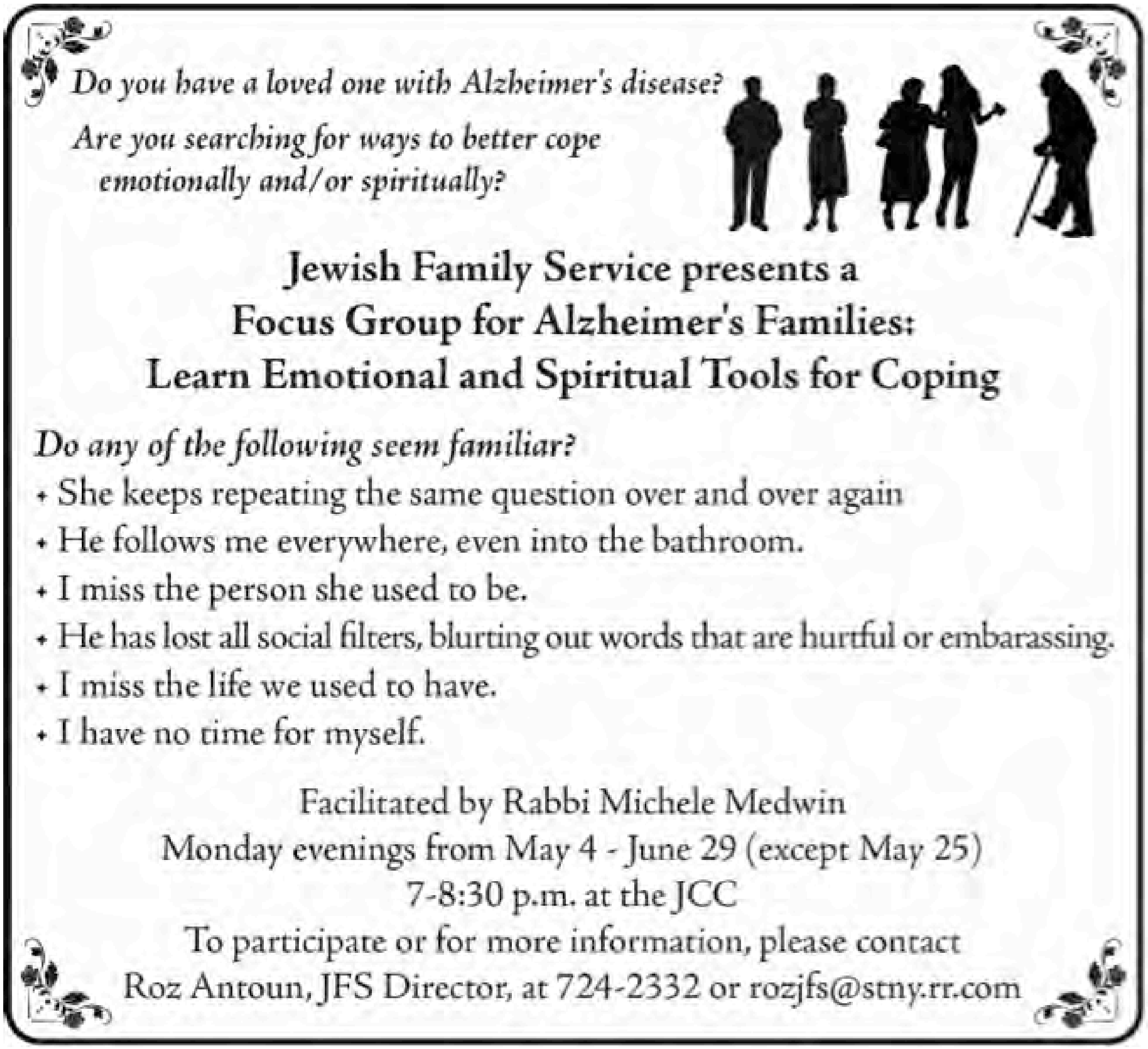
APPENDIX INDEX

Page

Appendix 1. Ad for Group listed in local Jewish newspaper



Do you have a loved one with Alzheimer's disease?

Are you searching for ways to better cope emotionally and/or spiritually?

Jewish Family Service presents a
Focus Group for Alzheimer's Families:
Learn Emotional and Spiritual Tools for Coping

Do any of the following seem familiar?

- She keeps repeating the same question over and over again
- He follows me everywhere, even into the bathroom.
- I miss the person she used to be.
- He has lost all social filters, blurting out words that are hurtful or embarassing.
- I miss the life we used to have.
- I have no time for myself.

Facilitated by Rabbi Michele Medwin
Monday evenings from May 4 - June 29 (except May 25)
7-8:30 p.m. at the JCC
To participate or for more information, please contact
Roz Antoun, JFS Director, at 724-2332 or rozjfs@stny.rr.com

Appendix 2. Article for local Jewish newspaper

JFS to hold “Focus Group for Alzheimer’s Families:
Learn Emotional and Spiritual Tools for Coping”

Jewish Family Service will present a “Focus Group for Alzheimer’s Families: Learn Emotional and Spiritual Tools for Coping” on Monday evenings from May 4-June 29 from 7-8:30 pm, except for Memorial Day, May 25. The group will be facilitated by Rabbi Michele Medwin and held at the Jewish Community Center. The group is open to family and close friends of loved one who either have Alzheimer’s or who have died of the disease. Suggested participants including caregivers, spouses, adult children and siblings. There is no cost to attend. Anyone interested in attending or who wants more information should contact the director of JFS.

An estimated 5.2 million people had Alzheimer’s disease in 2014 and the numbers are growing as the baby-boomers age. Locally, about 44,000 people in central New York have the disease. Medwin knows the cost of Alzheimer’s disease: Her father passed away a year ago after having Alzheimer’s disease for more than 10 years. Her mother was his main caregiver.

“I struggled and became emotionally depleted as I watched my mother deal with the incredible mental and physical strain of caring for her father,” Medwin said in an e-mail interview. “I also had to come to terms with the man who I visited who looked like father, but really wasn’t my father in the same way. I could no longer have the same animated conversations with him about politics, Israel and Torah study. I didn’t know from visit to visit if he would still remember who I was.”

Medwin noted that, in addition to the changes that occur to the person who has Alzheimer’s, family members are also affected. “More than many diseases, Alzheimer’s is a truly family disease in that sense,” she said. “In addition to helping our loved one who has been diagnosed with the disease, family members need to adjust to the slow but continually decreasing cognitive changes, along with personality changes that occur with our loved ones. Since the person doesn’t change physically, family members and close friends experience an ambiguous loss. Our loved ones are at the same time physically present, yet emotionally and cognitively absent.”

According to Medwin, having a loved one with Alzheimer’s disease is like being on an emotional roller coaster that never stops to let you off. “Caregivers and other family members search for ways to cope emotionally with the myriad of feelings they are experiencing," she said. "Some of the emotions expressed are deep sadness, frustration, anger, guilt, loneliness, social isolation and depression. The accumulation and prolonged emotional distress takes its toll."

Medwin recalled, "I remember sitting in the airport waiting to catch a plane home after visiting my parents. We had just returned from the neurologist who had given my father a definitive diagnosis of Alzheimer's disease. I knew that my father's ability to remember was slowly declining, but that word hit me like a ton of bricks. I was emotionally overcome with profound sadness and I began to sob."

As a rabbi who has focused on spirituality and looked for different ways to understand how God works in the world, Medwin searched to try to find a spiritual way to help her deal with her emotions. "According to Jewish tradition, when a person dies his soul returns to God," she noted. "Post-rabbinic Jewish philosophers and Kabbalistic teachings understood the soul of a human being to have three parts. NEFESH is the part of our soul that enters us upon our first breath. This is the soul that comes from God and gives us life; therefore, anything that has life has a NEFESH. RUACH is the animal soul. This can be seen as the part of our soul that provides us with our survival instincts – to eat, to sleep, to seek shelter. All animals possess a RUACH soul. Finally, NESHAMAH is the emotional and intellectual soul – the part of us that makes us 'human' – that learns, creates, has feelings and emotions, and forms relationships with other people."

Medwin used these teachings to see her father's mental absences in a new way. Instead of feeling that her father's mind was "gone," she imagined that the NESHAMA part of his soul was taking a break and visiting with God for a while as the other parts of his soul remained. This idea was the basis for a chapter in the book "Broken Fragments: Jewish Experiences of Alzheimer's Disease through Diagnosis, Adaptation, and Moving On," edited by Douglas Kohn, (URJ Press).

Medwin is currently at student at HUC-JIR studying for a D.Min. degree in clinical pastoral counseling. As part of the requirement for graduation, candidates need to complete a senior project. "In memory of my father, I want to help other Alzheimer's families talk about the struggles and challenges of having a loved one with Alzheimer's disease," she said. "That the subject of my senior project. The goal of the group is to help family members explore ways to cope with their experiences. Through my counseling experience, I can help people talk about coping strategies for the emotional challenges that family members face. As a rabbi, I will provide various spiritual tools for coping."

Medwin will also look at the experiences that occur after a loved one’s death. “There are unique experiences after death that is unlike other losses,” she said. “Because in reality, the losses that one usually experiences after a death has occurred, has been occurring for years before an Alzheimer’s person’s death actually takes place.”

Appendix 3. Agreement for Group

Alzheimer’s Family Focus Group – Emotional and Spiritual Tools for Coping

Facilitated by Rabbi Michele Medwin

AGREEMENT

This focus group is intended to bring together individuals who have a family member with Alzheimier’s disease for the purpose of exploring various stresses related to their situation with the goal of finding emotional and spiritual coping techniques to help ease their perceived burden. It will be of limited duration, consisting of eight weekly meetings of 90 minutes each, during which time participants will learn from their own and others experiences to find ways to better understand and deal with the challenges they face.

The focus group can offer participants a valuable opportunity to experience meaningful and enriching growth. It is the goal of the facilitator that you reap all the benefits that the group will have to offer. In order to assure this, the group will be structured to include the following elements:

RESPECT

A safe environment in which you are able to feel respected and valued. **As a participant you agree to listen with an open heart, be non-judgmental, and respect the opinions, thoughts and space of others.**

CONFIDENTIALITY

A safe environment in which you can feel free to express your thoughts and emotions without concern that what you say will be repeated outside the group. **As a participant you agree to maintain and respect the confidentiality of the statements made by your fellow participants.** (Please note: By law – there are some exceptions to confidentiality such as any statements that involve expressing a sincere intent to harm yourself our others. These must be addressed by the facilitator in private consultation with you and may also include consulting other professionals if necessary.)

ATTENDANCE

Your presence in all group sessions is important. A group dynamic is formed that helps create an environment for growth and change. If you are absent from the group this dynamic affects your experience and that of other participants in the group. **As a participant you agree to make it a priority to attend all meetings, circumstances allowing.** If you are a caretaker, please arrange for someone to cover you for all the sessions scheduled. It is understood that there are situations that may arise in which you will not be able to attend. If that happens, it is important that you contact Rabbi Medwin to let her know. (rabbimedwin@me.com or 607-765-2895.)

The facilitator of this group is Rabbi Michele Medwin who is currently a candidate for the degree of Doctor of Ministry at the Hebrew Union College Interfaith Pastoral Clinical Counseling Program. The organization and facilitation of this focus group, run in cooperation with Jewish Family Service, is a project for her degree program and is under the supervision and support of the College. All sessions will be recorded solely for the use of Rabbi Medwin to evaluate the group process. These recordings will not be shared with anyone else and will be erased after the conclusion of the project.

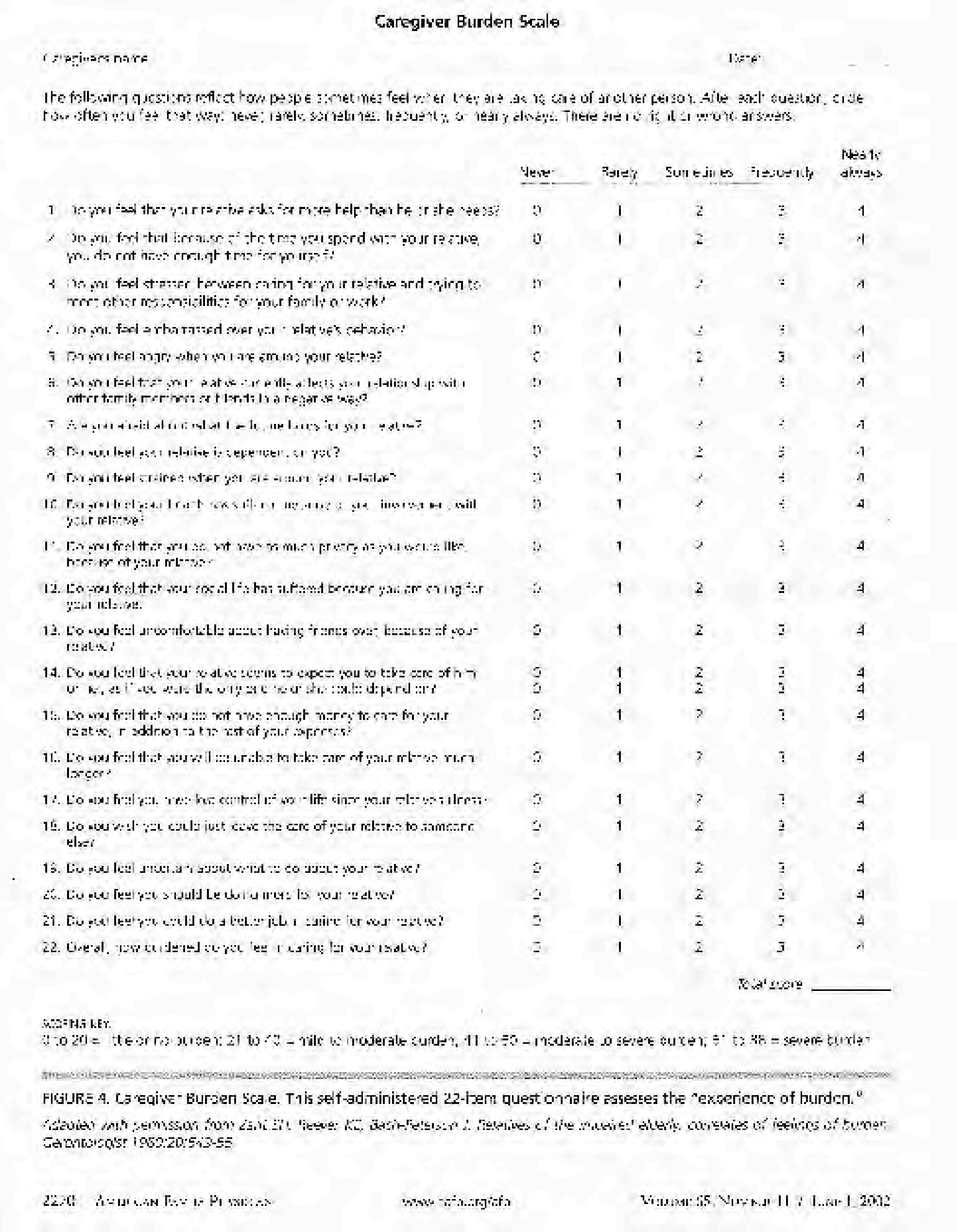
I agree to participate in the Focus Group for Alzheimer's Families in accordance with this agreement.

Print Name ____

Signature ____

Date ______________________________

Appendix 4. Caregiver Burden Scales and MM Caregiver Grief Survey



Caregiver Burden Scale

Caregiver's name: Date:

The following questions reflect how people sometimes feel when they are taking care of another person. After each question, circle how often you feel that way: never, rarely, sometimes, frequently, or nearly always. There are no right or wrong answers.

	Never	Rarely	Sometimes	Frequently	Nearly always
1. Do you feel that your relative asks for more help than he or she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid about what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you do not have as much privacy as you would like, because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over, because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?	0 0	1 1	2 2	3 3	4 4
15. Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Total score ____________

SCORING KEY:
0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden

FIGURE 4. Caregiver Burden Scale. This self-administered 22-item questionnaire assesses the experience of burden.[9]

Adapted with permission from Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 1980;20:649-55.

CAREGIVER BURDEN SCALE

Zarit et al. (1980), *Gerontologist, 20(6), 649-55*

Instructions: Read each statement and rate it on a scale from 0 (never) to 4 (nearly always)

In general, how often do you feel:	Never			Nearly Always	
There is not enough time for yourself	0	1	2	3	4
Overtaxed with responsibilities	0	1	2	3	4
Like you've lost control over your life	0	1	2	3	4
In regard to the relative for whom you are caring, how often do you feel:					
Uncertain about what to do for your relative	0	1	2	3	4
Like you should do more for your relative	0	1	2	3	4
Like you could do a better job of caring	0	1	2	3	4
When you are with the relative for whom you are caring, how often do you feel:					
A sense of strain	0	1	2	3	4
Anger	0	1	2	3	4
Embarrassment	0	1	2	3	4
Uncomfortable about having friends over	0	1	2	3	4
How often do you feel that your relationship with the relative for whom you're caring negatively impacts:					
Your social life	0	1	2	3	4
Other relationships with family and friends	0	1	2	3	4
Your health	0	1	2	3	4
Your privacy	0	1	2	3	4
How often do you:					
Feel you receive excessive help requests	0	1	2	3	4
Feel all the responsibility falls on one caregiver	0	1	2	3	4
Fear the future regarding your relative	0	1	2	3	4
Fear not having enough money to care for your relative	0	1	2	3	4
Fear not being able to continue caring for your relative	0	1	2	3	4
Wish to leave the care of your relative to someone else	0	1	2	3	4
How much does your spouse/loved one depend on you as the caregiver?	0	1	2	3	4

Please rate your overall level of burden in caring for your spouse/relative:

(0) No burden at all (1) Mild Burden (2) Moderate Burden (3) Severe Burden (4) Extreme Burden

Interpretation:

a. No or minimal burden: 0 to 20
b. Mild to moderate burden: 21 to 40
c. Moderate to severe burden: 41-60
d. Severe burden: 61 to 88

MM Caregiver Grief Inventory

Thomas M. Meuser, Ph.D., University of Missouri – St. Louis
Samuel J. Marwit, Ph.D., University of Missouri-St. Louis (Emeritus)

Instructions: This inventory is designed to measure the grief experience of current family caregivers of persons living with progressive dementia (e.g., Alzheimer's disease). Read each statement carefully, then decide how much you agree or disagree with what is said. Circle a number 1 5 to the right using the answer key below (For example 5 = Strongly Agree). It is important that you respond to all items so that the scores are accurate. Scoring rules are listed at the end.

ANSWER KEY

1 = Strongly Disagree // 2 = Disagree // 3 = Somewhat Agree // 4 = Agree // **5 = Strongly Agree**

1	I've had to give up a great deal to be a caregiver.	1	2	3	4	5	A
2	I miss so many of the activities we used to share.	1	2	3	4	5	B
3	I feel I am losing my freedom.	1	2	3	4	5	A
4	My physical health has declined from the stress of being a caregiver.	1	2	3	4	5	A
5	I have nobody to communicate with.	1	2	3	4	5	C
6	I don't know what is happening. I feel confused and unsure.	1	2	3	4	5	C
7	I carry a lot of stress as a caregiver.	1	2	3	4	5	A
8	I receive enough emotional support from others.	1	2	3	4	5	Cr
9	I have this empty, sick feeling knowing that my loved one is "gone".	1	2	3	4	5	B
10	I feel anxious and scared.	1	2	3	4	5	C
11	My personal life has changed a great deal.	1	2	3	4	5	A
12	I spend a lot of time worrying about the bad things to come.	1	2	3	4	5	C
13	Dementia is like a double loss…I've lost the closeness with my loved one and connectedness with my family.	1	2	3	4	5	C
14	I feel terrific sadness	1	2	3	4	5	B
15	This situation is totally unacceptable in my heart.	1	2	3	4	5	B
16	My friends simply don't understand what I'm going through.	1	2	3	4	5	C
17	I feel this constant sense of responsibility and it just never leaves.	1	2	3	4	5	A
18	I long for what was, what we had and shared in the past.	1	2	3	4	5	B
19	I could deal with other serious disabilities better than with this.	1	2	3	4	5	B
20	I can't feel free in this situation.	1	2	3	4	5	A
21	I'm having trouble sleeping.	1	2	3	4	5	A
22	I'm at peace with myself and my situation in life.	1	2	3	4	5	Cr
23	It's a life phase and I know we'll get through it.	1	2	3	4	5	Cr
24	My extended family has no idea what I go through in caring for him/her.	1	2	3	4	5	C
25	I feel so frustrated that I often tune him/her out.	1	2	3	4	5	A
26	I am always worrying.	1	2	3	4	5	C
27	I'm angry at the disease for robbing me of so much.	1	2	3	4	5	B
28	This is requiring more emotional energy and determination than I ever expected.	1	2	3	4	5	A
29	I will be tied up with this for who knows how long.	1	2	3	4	5	A
30	It hurts to put her/him to bed at night and realize that she/he is "gone"	1	2	3	4	5	B
31	I feel very sad about what this disease has done.	1	2	3	4	5	B
32	I feel severe depression.	1	2	3	4	5	C

ANSWER KEY

1 = Strongly Disagree // 2 = Disagree // 3 = Somewhat Agree // 4 = Agree // **5 = Strongly Agree**

33	I lay awake most nights worrying about what's happening and how I'll manage tomorrow.	1	2	3	4	5	C
34	The people closest to me do not understand what I'm going through.	1	2	3	4	5	C
35	His/her death will bring me renewed personal freedom to live my life.	1	2	3	4	5	A
36	I feel powerless.	1	2	3	4	5	B
37	It's frightening because you know doctors can't cure this disease, so things only get worse.	1	2	3	4	5	B
38	I've lost other people close to me, but the losses I'm experiencing now are much more troubling.	1	2	3	4	5	B
39	Independence is what I've lost…I don't have the freedom to go and do what I want.	1	2	3	4	5	A
40	I've had to make some drastic changes in my life as a result of becoming a caregiver.	1	2	3	4	5	A
41	I wish I had an hour or two to myself each day to pursue personal interests.	1	2	3	4	5	A
42	I'm stuck in this caregiving world and there's nothing I can do about it.	1	2	3	4	5	A
43	I can't contain my sadness about all that's happening.	1	2	3	4	5	B
44	What upsets me most is what I've had to give up.	1	2	3	4	5	A
45	I'm managing pretty well overall.	1	2	3	4	5	Cr
46	I think I'm denying the full implications of this for my life.	1	2	3	4	5	C
47	I get excellent support from members of my family.	1	2	3	4	5	Cr
48	I've had a hard time accepting what is happening.	1	2	3	4	5	B
49	The demands on me are growing faster than I ever expected.	1	2	3	4	5	A
50	I wish this was all a dream and I could wake up back in my old life.	1	2	3	4	5	B

FAIR USE OF THE MM-CGI: The inventory was developed and pilot tested on two samples of dementia caregivers: 87 caregivers (45 adult child, 42 spouse) in the development phase and 166 (83 of each type) for pilot testing. Funding support came from the Alzheimer's Association (Grant 1999 PRG 1730). A 3-factor solution materialized (KMO = .896) and these factors are listed below. The authors consider this instrument to be part of the public domain. The authors would appreciate hearing feedback on how the scale is used. Researchers who wish to administer the inventory and/or modify it as part of a formal study are asked to notify the authors of their plans (Tom Meuser, Ph.D., **meusert@umsl.edu** 314-516-5421).

Meuser, T.M., & Marwit, S.J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. The Gerontologist, Vol 41(5), 658-670.
Marwit, S.J., & Meuser, T.M. (2002). Development and Initial Validation of an Inventory to Assess Grief in Caregivers of Persons with Alzheimer's Disease. The Gerontologist, 42(6), 751-765.

Self-Scoring Procedure: Add the numbers you circled to derive the following sub-scale and total grief scores. Use the letters to the right of each score to guide you. *C items with "r" afterwards must first be reverse scored (1→5, 2→4, 3→3, 4→2, 5→1) before adding to calculate your scores.*

Personal Sacrifice Burden *(A items)* = ________
(18 items, M = 54.0, SD = 14.1, Alpha = .93, Split-Half = .91)

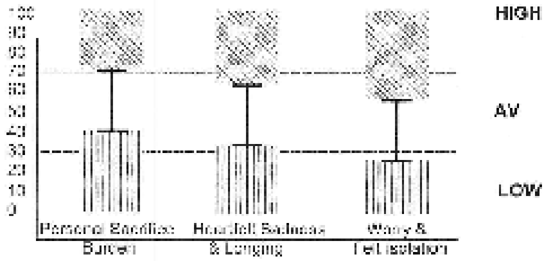
Heartfelt Sadness & Longing *(B items)* = ________
(15 items, M = 48.2, SD = 11.1, Alpha = .90, Split-Half = .90)

Worry & Felt Isolation *(C items)* = ________
(17 items, M = 40.8, SD = 11.8, Alpha = .91, Split-Half = .91)

Total Grief Level (Sum A + B + C) = ________
(50 items, M = 144, SD = 31.6, Alpha = .96, Split-Half = .97)

Plot your scores using the grid to the right. Make an "X" in the shaded section nearest to your numeric score for each sub-scale. This is your grief profile. Discuss this profile with your support group leader or counselor.

MM-CGI Personal Grief Profile



What do these scores mean?

Scores in the top area are higher than average based validation sample statistics (1 SD above the Mean). High scores may indicate a need for formal intervention or support assistance to enhance coping. Low scores in the bottom lined section (1 SD below the Mean) may indicate denial or a downplaying of distress. Low scores may also indicate positive adaptation if the individual is not showing other signs of suppressed grief. Average scores in the center indicate common reactions. These are general guides for discussion and support only – more research is needed on more specific interpretive issues.

Appendix 5. Spirituality Handout for Support Group or Individual Use

Meditation Exercise One - Shema

SHHHHH – Quieting – White noise - chaos
MMMMM – hum, tuning fork - harmony
Take a few minutes to focus on the breath.

- Inhale deeply and slowly through your nose. Let your breath fill you. Allow your chest to expand to its fullest capacity.
- Exhale slowly through your mouth. Hear the sound of air as it exits your mouth. Draw this sound out as long as you can as you deflate your lungs.
- Feel your body releasing tension you are holding. Let your breath carry it away. Relax the muscles in your feet, legs, body, arms, neck, head.
- Watch your breath as it fills your lungs.
- Watch as your body expands to receive it.
- Then notice your chest contract as your breath begins to depart.
- Notice your body release it.
- Keep your mind on your breath.
- To help stop your mind from wandering, add the Shema.
- Personal to community
    - INHALE - *Shema* – Listen (personal, I need to listen)
    - EXHALE - *Yisrael* – All of us (community)
    - INHALE - *Adonai* – (my God)
    - EXHALE - *Eloheinu* – (our God)
    - INHALE – *Adonai* (my God)
    - EXHALE - *Echad* – One – Unity with God - unity with all souls
- Pay attention.
- The breath flows in. The breath flows out.
- Continue for a few minutes.
- Sit quietly for a few moments.

Meditation Exercise Two – Focused Meditatation - Hineini

The Hebrew word, *hineini,* (hee-nay-nee), means "Here I am." It was recited by Abraham when God called to him at Mt. Moriah. It was spoken by Moses as God called to him from the Burning Bush. This meditation helps us to focus on being "here," rather than in the past or the future. *Hineini* means being physically present, emotionally ready and spiritually opened to the Divine. It means being open to the possibility of a spiritual connection.

- Inhale deeply through your nose. Let your breath fill you. Allow your chest to expand to its fullest capacity.
- Exhale through your mouth. Hear the sound of air as it exits your mouth. Draw this sound out as long as you can as you deflate your lungs.
- Feel your body releasing tension you are holding. Let your breath carry it away.

- Repeat several times.
- Notice your mind as it begins to quiet down and your body relaxes.
- Move your attention to the word *hineini – Here I am.*
- _Focus on *hineini*
- Repeat it silently to yourself.
- *Hineini – here I am.*
    - Let the word become filled with your breath. Merge with it so that you experience being fully present.
- *Hineini. Here I am.*
    - Not thinking
    - Not accomplishing
    - Not doing.
    - Just being.
- *Hineini – Here I am*
    - Full presence
    - Readiness to receive
    - In body
    - In heart
    - In mind
    - In spirit
- *Hineini – Here I am*
- When your mind wanders, do not judge yourself. Simply notice where you have gone and return to *hineini.*
- If you are distracted by the sounds around you, notice them and return to *hineini.*
- *Hineini – Here I am.*
- To end the meditation, sit quietly for a few minutes.

PSALMS

Throughout humanity, people have had to deal with difficult and challenging situations. Psalms are a record of people pouring their hearts out to God. Some of the following Psalms have been edited slightly to make the Psalm more personal for an Alzheimer's family member. (Note: Adonai is the Hebrew word for God or Lord. I purposely did not use the name "God" in these Psalms but changed them to a different name for God such as "The Eternal One." Each person has his or her own understanding of God. Sometimes it comes with "baggage" attached. The idea is to free you from specific theology and just feel the cries of the Psalmists.)

Psalm 13 – Feeling Alone or Abandoned

How long, Adonai; will You ignore me forever?
How long will You hide Your face from me?
How long will I have cares on my mind, grief in my heart all day?

How long will my enemy (this disease) have the upper hand?
Look at me, answer me, Eternal One!
Restore the luster to my eyes, lest I sleep the sleep of despair;
Lest my enemy (this disease) say, “I have overcome him,” my foes exult when I totter.
But I trust in Your faithfulness, my heart will exult in Your deliverance.
I will sing to Adonai, for the Source of Healing has been good to me.

Psalm 23 – Wanting/Feeling Support

The Eternal is my shepherd; I lack nothing.
You help me lie down in green pastures;
You leads me to water in places of repose;
You renew my life; You guide me in right paths as befits Your name.
Though I walk through a valley of deepest darkness, I fear no harm,
For You are with me;
Your rod and Your staff — they comfort me.
You spread a table for me in full view of my enemies (this disease);
You anoint my head with oil; my drink is abundant.
Let goodness and steadfast love pursue me all the days of my life,
And I shall dwell in the house of Adonai forever.

Psalm 25 - Hope

Adonai, I set my hope on You; Eternal One, in You I trust;
May I not be disappointed, may my enemies (the disease) not exult over me.
Guide me in Your true way and teach me, for You are Adonai, my deliverer;
It is You I look to at all times.
AdonaiI, be mindful of Your compassion and Your faithfulness.
Be not mindful of my youthful sins and transgressions;
In keeping with Your faithfulness consider what is in my favor,
As befits Your goodness, Adonai.
My eyes are ever toward You, for You will loosen my feet from the net.
Turn to me, have mercy on me, for I am afflicted.
My deep distress increases; deliver me from my straits.
Look at my affliction and suffering.
May integrity and uprightness watch over me, for I look to You.
Eternal Source of Healing, redeem Israel (my family) from all its distress.

Psalm 30 - Giving Thanks

I extol You, Adonai, for You have lifted me up, and not let my enemies rejoice over me.
Eternal One, I cried out to You, and You healed me.
ADONAI, You brought me up from Sheol (the dark place),
Preserved me from going down into the Pit.
O you faithful of the Holy One, sing to Adonai, and praise the holy name.
One may lie down weeping at nightfall; but at dawn there are shouts of joy.

When I was untroubled, I thought, “I shall never be shaken,”
When You hid Your face, I was terrified.
I called to You, Adonai; to the One I made appeal,
“What is to be gained from my descent into the Pit?
Hear, Adonai, and have mercy on me; Adonai, be my help!”
Turne my mourning into dancing, and girded me with joy,
That my whole being might sing hymns to You endlessly;
Eternal One, I will praise You forever.

Psalm 38 – Feeling Burdened

Adonai, do not punish me in wrath; do not chastise me in fury.
For my iniquities (challenges) have overwhelmed me;
They are like a heavy burden, more than I can bear.
I am all bent and bowed; I walk about in gloom all day long.
I roar because of the turmoil in my mind.
Eternal One, You are aware of all my entreaties; my groaning is not hidden from You.
My mind reels; my strength fails me; my eyes too have lost their luster.
My friends and companions stand back from my affliction; my kinsmen stand far off.
I am like a deaf man, unhearing, like a dumb man who cannot speak up;
I am like one who does not hear, who has no retort on his lips.
But I wait for You, Adonai; You will answer, Source of Healing.
For I am on the verge of collapse; my pain is always with me.
Do not abandon me, Adonai, be not far from me;
Hasten to my aid, Source of Healing.

Psalm 88 – Feeling Down – Hear My Cries

O Adonai of my deliverance, when I cry out in the night before You,
Let my prayer reach You; incline Your ear to my cry.
For my soul is sated with misfortune; I am at the brink of Sheol (this dark place).
I am numbered with those who go down to the Pit;
I feel helpless, and abandoned,
Like have put me at the bottom of the Pit, in the darkest places, in the depths.
My companions shun me; I am shut in and do not go out.
My eyes pine away from affliction; I call to You, Adonai, each day;
I stretch out my hands to You.
I cry out to You, Adonai; each morning my prayer greets You.
Do You reject me? Do You hide Your face from me?
I cry out to You, Adonai.

Psalm 121 – Finding Strength

I lift my eyes to the mountains; from where will my help come?
My help comes from the Eternal, maker of heaven and earth.
Adonai will not let your foot give way; your guardian will not slumber;
See, the guardian of Israel neither slumbers nor sleeps!

The Eternal is your guardian, Adonai is your protection at your right hand.
By day the sun will not strike you, nor the moon by night.
I call to you Adonai, guard me from all harm; guard my life.
Guard my going and coming now and forever.

TRADITIONAL PRAYERS

MORNING BLESSINGS

Modeh Ani - The Talmudic rabbis believed that when you slept, your soul visited God. God would return your soul to you when you awoke so you could continue living.

מוֹדֶה/מוֹדָה אֲנִי לְפָנֶיךָ, מֶלֶךְ חַי וְקַיָּם, שֶׁהֶחֱזַרְתָּ בִּי נִשְׁמָתִי בְּחֶמְלָה רַבָּה
אֱמוּנָתֶךָ.

Modeh(Men)/Modah (women) ani l'fanecha melech chai v'kayam,
she-he-che-zarta bi nishmati b'chemla rabah emunatecha.

I offer thanks to You, ever-living God,
that You have given my soul to me in mercy.
How great is Your trust.

Kabballah teaches that there are different parts of the soul. Using this concept, I wrote a modified version of the *Modeh Ani* prayer imagining that when my father seemed distant or not really all "there," that the part of his soul which was his personality, was visiting God. When my father had moments of clarity it was as if God returned that part of my father's soul to him, and to us. Adapted by Rabbi Michele Medwin (Changes are in capital letters.)

FOR A MAN WHO HAS ALZHEIMER'S DISEASE

Modeh/Modah ani l'fanecha, melech chai v'kayam.

She-hechezarta BO NISHMATO BA-Z'MAN HAZEH, b'chemla,

Rabah emunatecha.

I offer thanks to You, ever-living Sovereign, that you have restored HIS *n'shamah* to HIM, AT THIS MOMENT, with mercy. How great is Your trust.

FOR A WOMAN WHO HAS ALZHEIMER'S DISEASE

Modeh/Modah ani l'fanecha, melech chai v'kayam.

She-hechezarta BA NISHMATA BA-Z'MAN HAZEH, b'chemla,

Rabah emunatecha.

I offer thanks to You, ever-living Sovereign, that you have restored HER *n'shamah* to HER, AT THIS MOMENT, with mercy. How great is Your trust.

Elohai Neshama – A Pure Soul

(We give thanks for the wonder and uniqueness of our souls.)

The soul that you have given me, O God, is a pure one. You have created and formed it, breathed it into me, and within me you sustain it. So long as I have breath, therefore I will give thanks to You, Eternal God and God of all ages, Master of all creation, God of every human spirit. Blessed is the Eternal, in whose hands are the souls of all the living and the spirits of all flesh.

Creative Prayer based on Traditional Liturgy

Mi Sheberach for Chronic Illness by Rabbi Michele Brand Medwin

Eternal God, I ask for mercy and compassion
for me and my family, burdened with chronic illness.
Give us the strength and courage
to face the daily challenges in our lives.
Compassionate One, give us hope for the future
and at the same time, acceptance of the present.
Help us to find a path towards spiritual wholeness. Be by our side.
Help us to know that You are with us at all times, even in times of doubt.
Source of Healing, comfort us and bring healing to our souls. Amen

A Caregiver's Prayer

Sustainer of the Universe, help me to care for my loved one,
With hope, courage and sensitivity.
Grant me insight, resourcefulness and the ability to ask for help
And to accept help when it is needed.
May I find the patience to overcome difficult moments
And to find meaning and purpose in the smallest task.
O Eternal God, help me to remember to take care of myself
So that I may have the strength to help others.

Be with me and my loved one, as we journey on this path together.
May the One who makes peace in the Heavens,
Bring peace to me, to my family and loved ones, and to us all.

One Line Verses for Meditation Mantra or Reading Throughout the Day

Be strong and of good courage; have no fear . . . for the Eternal One, your God, is the One who goes with you, never failing you or forsaking you.

Deuteronomy 31:5

Those who hope in God will renew their strength and soar on wings like eagles.

Isaiah 40:31

I see your journey, and I bring healing. I will guide you and bring solace to you. Says the Eternal God: I will heal you! Isaiah 57:18-19

Do not despair because of suffering, for life is suffering. Suffering and also joy. When life brings you suffering, hurt. When life brings you joy, laugh.

Mishnan Avot 1:7

The prayer of a sick person is answered not by having his disease disappear but by his gaining the sense of God's nearness, the assurance that his illness is not a punishment from God and that God has not abandoned him.

Harold Kushner

It may be difficult to believe that we can learn from adversity, yet it is our best teacher. It can open our eyes to things we couldn't see before; It can make us grow in ways we never knew; It can give us the precious gift of compassion; It can teach us a universal truth: Life is not fair; And if we are very thoughtful, it can lead us to God.

Maurice Lamm

When you need a place to turn, turn to God. Even if you never thought to do so, it is easy. Here’s how:

-Talk in your own language, the way you would to a friend.

-Do this when no one else is around to hear.

-Don’t feel guilty for neglecting to do it up to now. God has been waiting to hear from you and is delighted.

-If it is hard at first, keep trying. Practice makes perfect.

-Ask for God’s help - that is what God is there for.

-Tell God everything, God knows it all anyway. Maurice Lam

Appendix 6. One-time meeting follow up survey

Rabbi Michele B. Medwin Candidate for D.Min. in Pastoral and Clinical Counseling

D.Min. Project: Alzheimer's Families - Follow up Survey

Name:

Relation to person who has Alzheimer's/Dementia:

Family relationship: _____Spouse _____Significant other _____Adult child _____Sibling

_____Close Friend _____Other relative

Were you the Caregiver?

_____ Primary Caregiver at home

____ Primary caregiver for loved one in facility/at home with aides

_____ Not the primary caregiver

_____ other ____

1. On a scale of 1-5, what were your thoughts <u>before</u> you had the conversation with Rabbi Medwin about your loved one with Alzheimer's disease/dimentia?

____1 ____2 ____3 ____4 ____5

I was concerned about having to talk about the details.	I was somewhat concerned.	Neutral – or mixed feelings	Wanting to talk about it somewhat.	I wanted someone to be able to talk about it with.

Other thoughts:

2. On a scale of 1-5, how did you feel <u>after</u> you had the conversation with Rabbi Medwin?

____1 ____2 ____3 ____4 ____5

Talking about it made me feel worse.	I felt somewhat worse.	Neutral – or mixed feelings	I felt somewhat better.	I felt much better. It was a relief to be able to talk about what was going on.

Other feelings after the conversation:

3. Do you feel that additional conversations with Rabbi Medwin could be helpful as you try to cope with the challenges of having a loved one with Alzheimer's disease/dementia?

______ I feel like I am handling things OK.

_______ Please contact me. Additional conversations might be helpful.

BEST CONTACT INFORMATION

Phone ________________________________ e-mail ____

Feel free to add any additional thoughts or comments. Your honesty will be helpful as I try to find what is most helpful to families with Alzheimer's disease.

Appendix 7. Excerpts from Rick Phelps' Blogs

(http://phelps2645.blogspot.com)

We Don't Mean To

I think the one thing people, caregivers, and family members should realize is that "we don't mean to." When your loved one does the things they do, they don't mean to. When they say things that offend you, hurt you, mentally or physically, they don't mean to. When I ask my wife over and over "What time is it? What day is it?" I don't mean to. When your loved one is up all hours of the night, and you get maybe two hours sleep, they don't mean to. When you are at the end of your rope, and say and do things as a caregiver, you don't mean to. The thing is,this disease causes the patient and the caregiver to do or say things that they would not normally do or say (Phelps, August 21, 2015).

Do Not Blame the Patient For Their Behavior

Why does your loved one do the things they do? Are they doing these things to irritate you? To get attention? or Just because they can? None of these answers are correct. I can tell you this from a patient's perspective. For a patient to do things that intentionally upsets their families they would have to be calculating. With dementia, calculating does not compute. I cannot say how a caregiver feels about the things their loved ones does, I can only assume at times, even most of the time it is frustrating to say the least. When someone is diagnosed with dementia of any kind, it is a medical fact that they could have had this disease for up to ten years prior to the diagnosis. The changes you see in your loved one have been coming on for a long time. This did not start at the time of the diagnosis (Phelps, August 7, 2015).

Dementia and Feelings

We have feelings. And they are real. More real than they were before our diagnosis. We sometimes have a difficult time explaining them. But it is your job as a caregiver to read between the lines. What are they really saying? Is this difficult? Of course it is. I have said many times caregiving is not rocket science, it's much harder than that. Listen to your loved one. They have feelings. One's feelings don't fade as the memory worsens. Be considerate, be compassionate. It's the right thing to do. Simply because your loved one can no longer communicate with you, they still have feelings. Their feelings of anxiety, depression, and fear are only worse with the disease (Phelps, July 8, 2015).

Struggling, Not Suffering

I'm not suffering, I'm struggling...struggling to hold on to what I have, not dwelling on what I have already lost. With this disease you have a constant worry about what you will lose next. A couple of years ago I woke up and had lost the concept of time. Before that, I had lost the ability to understand anything that I read over two paragraphs. Suffering is not what I call it. Struggling is. Struggling to hold onto what I have. Everyday. There is a reason for everything the patient does, they simply cannot communicate it. They are not suffering, but struggling. There is a difference. But the struggles are so profound that that inside they are indeed suffering. But not from a physical pain, it's a mental pain (Phelps, 2015).

What?

What? I find myself asking "What" all the time now. When someone says what, you figure 9 out of 10 times they didn't hear what you were saying. Well, with dementia, not so much. There is nothing wrong with my hearing. The problem for us patients lies between our ears. I ask what, because then when whatever is said again, it gives me an extra minute or two to figure out just "what" was said. How do I respond, having no idea at times what someone may be talking about. Especially if a couple of things are going on at the time. More than one person talking, music playing, kids around, dogs barking, etc. (Phelps, April 2, 2015).

Dementia Will Never Take My Love In My Heart

Dementia is a disease of the brain. We all know this. But did you ever stop and think where all our loved ones are? They are in our heart. This disease will effect me in ways I cannot even imagine in time. But it will never be able to change my heart. That is where every loved one I have resides. When I am unable to communicate, unable to speak, unable to recognize my loved ones, and to tell them how much I love you, my heart knows. When we tell someone we love them, many times you hear "I love you with all my heart." You won't hear, "I will love you with all my mind."(Phelps, Sept. 23, 2015).

Appendix 8. Ten Absolutes of Communicating with Dementia Patients

1. Never argue, instead agree.
2. Never reason, instead divert.
3. Never shame, instead distract.
4. Never lecture, instead reassure.
5. Never say "remember", instead reminisce.
6. Never say, "I told you", instead repeat/regroup.
7. Never say, "you can't, instead do what they can.
8. Never command/demand, instead ask/model.
9. Never condescend, instead encourage/praise.
10. Never force, instead reinforce.

(Worthington, B., March 13, 2013)

Appendix 9. Readings for an Unveiling

Remember Me

written by Chris Mann, Laura Mann, Rudy Tanzi, Willy Beaman, Dora Kovacs

I need someone to hold, to hold on for me
To what I can't seem to hold on to
The life we used to live, is slipping through my fingertips
Like a thread that's unraveling

I suppose that nothing lasts forever, and everything is lost in its time.

When I can't find the words that I'm trying to speak
When I don't know the face in the mirror I see
When I feel I'm forgotten and lost in this world
Won't you please remember me

There is a Time

Based on Ecclesiastes 3

There is a time for everything, a time for every experience under heaven:
A time for planting and a time for uprooting the planted;
A time for tearing down and a time for building up;
A time for weeping and a time for laughing,
a time for wailing and a time for dancing;
A time for embracing and a time for shunning embraces;
A time for seeking and a time for losing,
a time for keeping and a time for discarding;
A time for silence and a time for speaking.
A time to hate and a time to love.
A time to be born and a time to die.
A time to blame and a time to forgive.

And God said, "I forgive you, as you have asked." Num. 14:20

We Don't Mean To

From the blog of Rick Phelps who has Early Onset Alzheimer's Disease

The one thing I'd like family members to realize is that "we don't mean to."
When your loved one does the things they do, they don't mean to.
When they say things that offend you, hurt you, they don't mean to.
When I say over and over "What time is it? What day is it?"
I don't mean to.
It's the disease.
It's not the person doing what they do.
It's not the person saying what they say.
It is indeed the disease. It's always the disease...

The Gift of Remembering

Eternal God, Master of mercy,
give us the gift of remembering.
May the memories of our loved one be tender and true,
undiminished by time;
let us recall him, and love him, as he was.

When dying is over, a different kind of memory takes over.
Not the memory that is obituary.
Not the memory that records the past indiscriminately.

But an active memory that sifts through the ashes of the past
to retrieve isolated moments
and that gives heart to the future.

That memory is an act that raises up from oblivious
the glories of forgotten years.
Even the memories of failure,
the recollections of frustration and regret are precious.
Broken memories are like the tablets Moses shattered,
placed lovingly in the holy Ark of remembrance.

What is life after death?
Pointers, ensigns, marking places
that raise us up to life and give us a changed heart.
Perhaps a life lived differently, better, wiser, stronger than before.
What is left after death? The life of the survivor.

The Moments Shared

We remember the moments shared,
the times of celebration and the times of difficulty.
We also remember the times of warmth and closeness,
and the times of love and companionship.
We will continue to treasure all that was good in our father and husband’s life,
and we will retain that good in the fabric of our own lives.

In Our Hearts

From the Blog of Rick Phelps

Did you ever stop and think where all our loved ones are?
They are in our heart.
This disease will affect me in ways I cannot even imagine in time.
But it will never be able to change my heart.
That is where every loved one I have resides.
When I am unable to communicate, unable to speak,

Unable to recognize my loved ones,
And to tell them how much I love you, my heart knows.
When we tell someone we love them,
Many times you hear "I love you with all my heart."
You won't hear, "I will love you with all my mind."
Everything we do, it is because of our brain telling us to.
However, we love each other with our hearts.

Appendix 10. Recommended Websites

- Alzheimer's Association - http://www.alz.org
- Alzheimer's Association of Canada – (covers things that Alzheimer's Association does not) http://www.alzheimer.ca/en
- http://www.alzheimers.net - an online community dedicated to education, advocacy and supporting those whose lives have been impacted by Alzheimer's disease and other forms of dementia. Alzheimers.net was created by people touched by Alzheimer's to give caregivers, those with Alzheimer's a place to share our passion for change and a cure for the disease.
- Rick Phelp's Blog – http://phelps2645.blogspot.com, Written by a man who has EOAD. Gives insights into what a loved one with Alzheimer's experiences.
- http://teepasnow.com - Working as a Registered Occupational Therapist for over 30 years her wealth of experience has led her to develop Positive Approach™ to Care techniques and training models that now are used by families and professionals working or living with dementia or other brain changes throughout the world.

Appendix 11. Recommended Books

Resources for Ideas for Caring and Coping

Butler, R. N. (2003). *Learning to speak Alzheimer's: A groundbreaking approach for everyone dealing with the disease*.

Mace, N. L., & Rabins, P. V. (2011). *The 36-hour day: A family guide to caring for people who have Alzheimer disease, related dementias, and memory loss* (5th ed.).

Scott, P. S. (2014). *Surviving Alzheimer's: Practical tips and soul-saving wisdom for caregivers*.

Zeisel, J. (2009). *I'm still here: A breakthrough approach to understanding someone living with Alzheimer's*.

Perspective From the Person with Alzheimer's Disease

Genova, L. (2009). *Still Alice: A novel*.

O'Brien, G., Genova, L., & Shenk, D. (2014). *On Pluto: Inside the mind of Alzheimer's*. Brewster, MA: Codfish Press.

Phelps, R., & LeBlanc, G. J. (2012). *While I still can...: One man's journey through early onset Alzheimer's disease*.

Spiritual Resources

Angelica, J. C. (2014). *Where two worlds touch: A spiritual journey through Alzheimer's disease*. Boston, MA: Skinner House Books.

Gefen, N. F. (1999). *Discovering Jewish meditation: Instruction & guidance for learning an ancient spiritual practice*. Woodstock, VT: Jewish Lights.

Kohn, D. (2012). *Broken fragments: Jewish experiences of Alzheimer's disease through diagnosis, adaptation, and moving on*. New York: URJ Press.

Kushner, H. S. (1981). *When bad things happen to good people*. New York: Schocken Books.

Polish, D. F. (2000). *Bringing the Psalms to life: How to understand and use the Book of Psalms*. Woodstock, VT: Jewish Lights Pub.

Potts, D. C. (Ed.). (2014). *Seasons of caring: meditations for Alzheimer's and dementia caregivers*. Clergy Against Alzheimer's Network.

Roth, J. (2009). *Jewish meditative practices for everyday life*. Woodstock, VT: Jewish Lights Publishing.

Solovy, A. (2013). Alzheimer's, Parkinson's and dementia. In *Jewish prayers of hope and healing* (pp. 130-134).