

LIBERTY THEOLOGICAL SEMINARY

MINISTRY OF MEMORIES:
KEYS TO PASTORAL CARE OF NON-COGNITIVE PERSONS

A Thesis Project Submitted to
Liberty Baptist Theological Seminary
in partial fulfillment of the requirements
for the degree

DOCTOR OF MINISTRY

By

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Lynchburg, Virginia

March, 2012

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LIBERTY THEOLOGICAL SEMINARY

THESIS PROJECT APPROVAL SHEET

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*To my earthy father
Capt., John Charles Elliot Corfield, (Retired)
Royal British Army
Who died with Alzheimer's Disease*

*And to all those who
struggle with Alzheimer's, Dementia
and other degenerative, incurable and fatal brain diseases
and to those who love and care for them.*

ABSTRACT

MINISTRY OF MEMORIES: KEYS TO PASTORAL CARE OF NON-COGNITIVE PERSONS

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Liberty Baptist Theological Seminary, 2012

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This work is intended to examine and study the theological and moral reasons to provide pastoral care to persons who have limited or no cognition. Dementia, Alzheimer's, certain other medical conditions and the aging process cause a loss of brain function that affects memory, thinking, behavior and judgment. Most Clergy wrestle with the fact as to whether there is any purpose in ministering to such persons especially when there is no verbal or non-verbal response.

This paper involves surveys, research, collection of historical and biblical data and medical science to evaluate the disease process and explore ways in which to communicate with them and in turn help them connect with God.

This thesis will also help families of non-cognitive persons, caregivers, peers and the writer to better understand ways in which to love and care for these marginalized people.

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CHAPTER ONE

AN OVERVIEW

Introduction

On September 13, 2011 “Religious broadcaster Pat Robertson told his *700 Club* viewers that divorcing a spouse with Alzheimer's are justifiable because the disease is "a kind of death." During the portion of the show where the one-time Republican presidential candidate takes questions from viewers, Robertson was asked what advice a man should give to a friend who began seeing another woman after his wife started suffering from the incurable neurological disorder. "I know it sounds cruel, but if he's going to do something, he should divorce her and start all over again, but make sure she has custodial care and somebody looking after her," Robertson said.”¹

Robertson went on to say the marriage vow “till death do us part” does not bind the able partner because Alzheimer’s is a kind of death that frees him or her to move on with their life. The Merriam Webster Dictionary defines death as the end of life and a permanent cessation of all vital functions. Common sense tells us that death occurs when one’s heart stops beating and breathing ceases.

Many people of faith in this country are shocked and disappointed with Robertson’s comments primarily because he is regarded as a Christian leader and his advice is not compatible with biblical teaching. Along with these many people, this author seeks to be a voice and advocate for non-cognitive people who are very much alive. In the darkest and most vulnerable

1. *CBS News*. “Pat Robertson says Alzheimer's justifies divorce,” <http://www.cbc.ca/news/world/story/2011/09/16/robertson-alzheimers-divorce.html> (accessed November 2, 2011).

moments of their lives, they need greater love, compassion and commitment from their families, caregivers and society at large. Human beings were created by God to have fellowship with him and are yoked to him through their soul and his indwelling spirit despite a sick or deteriorating body. In Jesus' day, the Lepers were considered outcasts and despised by society but Jesus took time to affirm and heal them (Luke 17: 12-19). Their sick bodies did not separate them from God even though it separated them from people. Jesus set an example for us to follow and commanded his disciples to "heal the sick, cleanse the lepers, raise the dead, cast out devils" (Matt. 10: 7-8).

This author not only watched his own father die with Alzheimer's but had the awesome privilege to love and care for Alzheimer's and Dementia patients while serving as Hospice Chaplain for over six years. This gave him firsthand knowledge about the physical, emotional and spiritual struggles of non-cognitive persons, their families and care givers. It is only when one's own understanding is awakened that they can hope to have something to share with others. This paper is dedicated to that process and to the continuance of this conversation. There should never be a time when taking care of a loved one becomes a "burden" nor should there be a time when they are ceased to be cared for because they are irrelevant or not understood.

There is a story about the President of a Bible College that goes like this:

"He was from South Carolina and all this Baptist preacher ever wanted in life was to provide leadership to a Bible College. All his life, he worked for the position and eventually attained it. As he fulfilled his life's dream and vocation, the disease of Alzheimer's struck his wife. Her health degenerated to the point where he could not possibly take care of her and work his full-time job. The preacher came to a decision—to give up his position as president of the Bible College. His peers were incredulous. "What are you doing?" they asked. "Your wife doesn't even know who you are!" The man answered, "She might not know who I am, but I know who she is. She's the woman I made a promise to until death do us part."²

2. Laura Schlessinger, *The Ten Commandments: The Significance of God's Laws in Everyday Life* (New York: HarperCollins, 1998), 234.

The Problem

In light of the fact that many Clergy wrestle with the why and how to provide spiritual services to Dementia patients, this thesis is intended to examine and study the disease process and theological and moral reasons to provide pastoral care to persons who have limited or no cognition within a Christian framework of understanding. It also provides unique ways in which to communicate with them. It is not Pat Robertson alone but society itself who regard mental impairment as a social death in which the person is dying a little at a time with no hope for recovery. VandeCreek says, “Our cognitively oriented culture finds it easy to forget forgetful persons. Some believe that persons with dementia need little or no pastoral care.”³ Unless this perception changes demented individuals will continue to be dehumanized and undervalued as if they have no soul.

Some of the responses to questionnaire sent out by this author to Clergy were disturbing. One individual in particular who works exclusively as a Chaplain to Palliative Care patients when asked why it was important to provide pastoral care services to Alzheimer’s patients said “It is the right thing to do”. The second part of the question was to state theological reasons and scriptural support for pastoral care to which he quoted John 3:16, which have nothing to do with the question or pastoral care. To the question – Have you been able to communicate with non-cognitive persons, the answer was “no.” Unless Clergy are properly trained and have had some courses in Gerontology and CPE, they should never attempt to minister to non-cognitive persons. It is unfaithful to pretend to know how to provide pastoral care. It only brings disrepute to the name of Christ.

The above is just a sampling of the problem to be dealt with and unless the old paradigm

3. Larry VandeCreek, *Spiritual Care for Persons with Dementia* (Binghamton, NY: The Haworth Pastoral Press, 1999), xi.

of providing pastoral care in cognitive and intellectual ways changes it would be impossible to help these non-cognitive persons to connect with God. The Rev. Robert Davis who himself was diagnosed with Alzheimer's disease said, "There is a way to help in these terror filled times, but it is definitely not by reasoning with the patient."⁴

Consequently, a new paradigm of pastoral care to Dementia patients must be devised. It cannot be through preaching, teaching or counsel that requires the intellectual participation of the patient. Those with deteriorated brain function like Alzheimer's disease have diminished verbal, cognitive and intellectual abilities. Any methodology of pastoral care that requires the use of these abilities will not accomplish anything. Later in this paper the new paradigm of using past memories, validation therapy, the use of senses especially touch along with old rituals, hymns and symbols that trigger memory will be discussed. God is very visible and present in the midst of this dreadful disease and the theological reasons to provide such care must be clearly understood in order to value the soul and life of the individual who is being cared for. This aspect is also discussed later in this paper.

Persons with dementia have to deal with the progression of the disease and the numerous challenges that come with it. Some patients have little knowledge or insight into their disability while others acknowledge their everyday struggles with functional and memory loss. Religion and spirituality plays an important and significant role in helping individuals to cope with the disease. While Dementia creates a disconnection from people, with the right pastoral care they can connect with God through whom they can find comfort and peace.

4. Robert Davis, *My Journey into Alzheimer's Disease* (Wheaton, IL: Tyndale House Publishing, 1989), 109.

Research findings support that older persons use spirituality in coping with many stresses in their life, such as disease, illness and mortality.⁵ Furthermore, studies reveal a significant association of spirituality contributes to emotional well-being and self-esteem.⁶ Research shows that pastoral care for non-cognitive persons is neglected woefully. The neglect is more out of a sense of helplessness than an unwillingness to help.⁷ It is also true that cognitive methods used in ministry can hurt rather than help the patient and so new approaches to this ministry is necessary.⁸ This study is more specifically related to Dementia, and especially to those with Alzheimer's disease whose loss of brain function affects their memory, thinking, behavior, and judgment. This thesis proposal was approved and accepted by Liberty University and is intended to help families of non-cognitive persons, caregivers, peers and the writer to better understand ways in which to love and care for these marginalized people.

Limitations of This Study

This study does not address medical treatment and management of Dementia or other brain diseases and is primarily restricted to a new paradigm of pastoral care of these individuals under the Christian belief system and especially to those who live in the United States. While this work can be of some help to others as well, the author's research and work is limited in

5. H.G Koenig, M.E. McCullough & D.B. Larson, *Handbook of Religion and Health*. (New York: Oxford University Press, 2001)

6. P.H. Van Ness & D.B. Larson, "Religion Senescence and Mental Health: The end of life is not the end of hope," *American Journal of Geriatric Psychiatry* 10 (2002):386–397.

K.A. Bickerstaff, C.M. Grasser & B. McCabe, "How elderly nursing home residents transcend losses of later life," *Holistic Nursing Practice* 17 (2003):159–165.

H.B. Bosworth, K.S. Park, D.R. McQuoid, J.C. Hays & D.C. Steffens, "The impact of religious practice and religious coping on geriatric depression," *International Journal of Geriatric Psychiatry* 18 (2003):905–914.

7. Larry VandeCreek, *Spiritual Care for Persons with Dementia: Fundamentals for Pastoral Practice* (Binghamton, NY: The Haworth Pastoral Press, 1999), 60.

8. Ibid., Preface xii

scope as defined above. There are many forms of degenerative, incurable and fatal brain diseases. This work may be of some help to all but is mostly concentrated on Alzheimer's and some types of Dementia. This project does not evaluate or address the various forms of care giving done by Physicians, Nurses, Social Workers, CNA's or members of the family.

Caregiver stress and emotional pain can be substantial and prolonged. These issues are only superficially mentioned to bring perspective to the situation of caring for non-cognitive persons but it does not evaluate or recommend any form of therapy that may or may not be required to effectively cope in such situations. Respite care can help alleviate the intensity of the situation but to prevent patient abuse, caregivers must take care of themselves physically, emotionally and spiritually. Some of the means described to provide pastoral care to the patients can also be helpful to caregivers but it is not conclusive. The issue of safety in caring for non-cognitive persons has not been addressed. It may be necessary to anticipate potential hazards and do everything possible to prevent injury or death including obtaining legal advice to cover liability. It may be necessary to safety proof buildings and facilities that house non-cognitive persons.

Non-cognitive people develop various medical and behavior problems like depression, suicidal thoughts, pressure sores, dehydration, pneumonia, seizures, convulsions, wandering around aimlessly, agitation, anger, irritability, combativeness and even inappropriate sexual behavior or violence. None of these conditions are researched or evaluated. This report does not advocate or recommend any particular plan of care or treatment. Non-cognitive persons are cared for at home, in Nursing Homes, Assisted Living Facilities, Hospice Facilities, State Mental Hospitals and VA Hospitals among others and this author does not evaluate or recommend any

one of these arrangements over the other. Financial and legal issues arising out of caring for non-cognitive persons is not addressed either.

References to the disease evaluation process, causes of dementia, its various forms, and research related to structural changes in the brain, are not conclusive studies. Similarly, drug studies, transplants of brain tissue, abnormal proteins that cause brain damage, effects of neurotransmitters (chemicals in the brain) and others may be occasionally referred to in this paper but are not conclusive in depth studies and must be treated as such. Some Clinical and Research tools and tests are also referenced but are meant for informational purposes only.

There are numerous organizations and resources including books and publications that are helpful in both understanding the disease and ways to cope effectively. Educational opportunities, seminars, online resources, advocacy groups and other support systems are available but not addressed in this project due to its limited focus on providing unique methods of pastoral care to non-cognitive persons. The word “patient” used in this paper refers to a non-cognitive individual with any form of debilitating and degenerating brain disease but more especially one who has Alzheimer’s disease.

Theoretical Basis for the Project

“God’s purpose in creating human beings was to share his love with them, and he asks us to return that love by loving our neighbor”⁹Caring for an individual with the dreaded disease of dementia is an expression of love and a love of neighbor. The biblical story of the “Good Samaritan” is an example of what God expects from his people. It is relatively easy to ignore the pain and suffering of others by walking the other side but there is both a blessing and mandate to

9. Benedict M Ashley, Jean DeBlois, Kevin D. O'Rourke. 5th ed. *Health Care Ethics: A Catholic Theological Analysis* (Washington DC: Georgetown University Press, 2006), 6.

help one another. The irony of the story is that the Levites (Priests) who have a higher calling should have been the ones to help but instead they failed and walked the other side. Using this analogy, this author believes that both the Church and Clergy have neglected ministering to non-cognitive persons. The latter has done it more out of a sense of helplessness than an unwillingness to help. Clergy are not properly trained to minister to non-cognitive persons who are terminally ill. Very few Seminaries offer courses in Thanatology or Gerontology. This affects the level of care that is provided to dementia patients.

There are good theological reasons to provide pastoral care to suffering non-cognitive persons, which is the thesis of this paper. Even when someone walks through the valley of the shadow of death there is no need to fear because God is always with him or her. Suffering is the pathway to glory as modeled by the Golgotha journey. God chose to suffer with humanity in that he came to humanity on a cross and not on a throne. God is all-powerful and has the ability to remove sickness and suffering in a moment of time but that time is not yet. In the here and now, suffering will be a part of human life because of sin but the love of God is so intense towards humans that he is always “present” with them as a participant in their suffering. Consequently, when the “least of these” are ministered to, it amounts to serving God.

Humans were created in the image of God and with a soul. As an image bearer of God, the human life has great value. God refers to men and women as his sons and daughters and heirs to the throne. Of all God’s creation none was made in his image and none was given dominion over the earth except for man because of being fearfully and wonderfully made. Man is honored greatly by God despite the failings and backslidings. God highly esteems the human life and so should all humanity. The human body is not just flesh and blood. It is also soul and spirit. The soul is made to last forever and longs for a continual and unbroken relationship with its creator.

The body will decay and return to dust but this is not the case with the soul. Pastoral care of non-cognitive persons is a caring for their soul with the intent of keeping them connected to God.

Despite a failing memory, pastoral care can help these individuals remember God.

Because of the disease process, Alzheimer's patients may not be able to remember God most of the time. This does not mean they have abandoned God. God has certainly not abandoned them promising never to leave or forsake his children. The deterioration of brain cells causes loss of memory and function but long-term memory is not affected as much. The Judeo-Christian faith is built upon memories of what God had already done for them and so the long-term memory of an Alzheimer patient can recall God's past goodness towards them.

Failing health and the terminal nature of the disease can draw these individuals to God especially in the early and mid stages. When all else fails, God is still there. Sickness and disease is a consequence man's fallen nature, which turns their reliance on God. In the midst of sickness, God can be a source of strength and comfort. Eliphaz the Temanite, Bildad the Shuhite and Zophar the Naamathite attempted to turn away the very sick and afflicted Job from God whereas the opposite was the right counsel. God was angry with them for doing so. Those providing spiritual services must always remember that while the cause of sickness may not be fully understood, Christians can find hope and redemption through suffering.

There are sociological implications to having Alzheimer's disease. Society does not fully understand the disease process and how it affects a human being. The notion that those with dementia are akin to a vegetative state is wrong. Some even consider them semi lunatic. Some of these negative perceptions vary with culture and tradition. In certain cultures, the elderly and sick are revered and respected greatly. In western cultures social isolation and institutionalization of a patient is very common.

Alzheimer patients have a degenerating brain causing mental impairment but they continue to be emotional beings. They are able to experience joy, sadness or even anger. They appreciate companionship, friendship, touch and kind words. The disease process can be delayed with medication and the quality of their life can be enhanced by showing them love and helping them with daily functioning. Removing the negative perception by educating society will go a long way in empathizing with dementia sufferers.

A person with dementia has to face many ethical challenges. Some of these have religious implications but not all. Many of them have to do with life and death. Hastening death and improperly preparing for it are both wrong. Choices about withdrawing treatment that can prolong life or signing off on a DNR (do not resuscitate) order are best made by the patient themselves. Some patients, especially as the disease progresses might require institutionalized care and such choices do have an effect on the quality of life. Both Hospice and Palliative care have holistic approaches of care but the same may not be the case of an Assisted Living or Skilled Nursing Facility. Organ donation is another ethical decision. Holistic care of dementia patients will involve helping these individuals make tough decisions.

Until 1906 Alzheimer's disease was unknown and therefore its name will not be found in historical books or in the Bible. At the same time, the effects of the disease are tied to history because of the ability of an individual to remember the past but not the present. Christians remember Jesus all around the world through the breaking of bread and therefore a nearly intact ability to remember the past is fertile ground to strengthen one's faith in God. All through history, people have suffered from the consequences of sin and every generation has drawn strength from God. While the history and culture of every patient may not be the same,

understanding them and respecting where they come from, is one way of showing respect and sensitivity to their already fractured and bruised lives.

Statement of Methodology

As a method of understanding the problem and arriving at a holistic solution, a variety of related issues will be taken up including a study of the disease process and its effects. Studying the disease will involve collecting all currently available data including symptoms, duration of the disease and its effects on cognition and memory. Each of the seven stages of the disease has specific characteristics that are associated with decline. What these are and how they are treated or cared for is important to know. Interestingly, only the left hemisphere of the brain that is controls behavior and recent memory is destroyed. Many abilities continue to exist with the use of the right half of the brain. Most Alzheimer's patients do not die from the effects of the disease itself but rather from associated diseases and/or complications and each one of those together with its treatment must be known. Some patients develop challenging behaviors like agitation, aggression and depression and these illnesses together with treatment options and availability or use of drugs is important to know in order to provide holistic care. Self identity is altered with Alzheimer's disease resulting in a marked loss of self. While this might not be total, the alteration affects relationships with others and with God. Understanding this dimension of loss is vital to providing spiritual care.

Patients with Alzheimer's face numerous challenges. Loss of memory and cognition impair daily function and as such they may need help dressing, eating and toileting especially in the mid to end stages. Sometimes they forget to chew and swallow their food and need to be reminded to do so. Towards the very end mobility is difficult and incontinence sets in. Being confined to bed complicates matters. Cuts and wounds including bed sores have to be properly

treated. Skin care becomes a priority. Dental hygiene is important too in order to prevent pneumonia. In earlier stages, precaution must be taken to prevent them from wandering away. In institutionalized settings there is potential for elder abuse and careful monitoring of the patient for visible signs may be necessary.

The scientific study of death and dying may need to be grasped and integrated with a Christian understanding of the same subject. One cannot treat something they do not fully understand and the more knowledge one has about the patient, the better they can be cared for. Thanatological studies have relevance to how dementia patients may be perceived. Studying death and dying and its complications will lead to the exploration of the nature, condition and value of the soul. It will also reveal that humans are more than flesh and blood. Nutrition, feeding and management of pain are also important facets of caring for the dying. It would be necessary to meet the physical needs first before providing for the spiritual. Jesus exemplified this method all through his ministry. Geriatrics studies that are associated with healthcare of older people help identify many health issues that are common to that age group. Advances in healthcare and healthcare legislation do have an impact on the Alzheimer's patient. At present Alzheimer's disease is considered custodial care and therefore Medicare and most insurance plans do not cover the cost of room and board. Hospice gets reimbursed a flat fee from Medicare for holistic care and chooses to rent medical equipment and purchase medicines for the patient.

There is continuing research towards finding a cure for Alzheimer's and any knowledge about this development is helpful. The goal is to enhance the quality of life and stay fully informed. Especially when feedback from an Alzheimer's patient may not be fully understood, the more knowledge that can be obtained relative to the disease the better will be the quality of care.

As the disease progresses, some decisions will need to be made either by the patient or by family who is authorized to do so. These decisions may be ethical, moral or spiritual in nature. All of them will be explored together with how it might impact the level and quality of care and spiritual implications if any. Some issues that cause society and the church to dehumanize non-cognitive individuals will be examined. This may not be limited to perceptions about loss of self or social death. Moral issues like the value of a human life and when life ends will be reviewed both from a secular and religious perspective. This is important because how life is valued is related directly to how a dementia patient may be treated. Contributing members of society and especially the higher echelon are considered to be of greater value than a sick and dying individual who is racking up medical bills.

Also considered will be how these non-cognitive individuals are cared for and by whom. The costs associated with the care and the emotional and physical health of the caregiver will be examined. Unless the Caregiver is trained properly, stays healthy and is emotionally and spiritually strong, the quality of life for the patient will likely suffer. Addressing caregiver stress and methods to minister to them are equally important. Some practical solutions like providing relief and a break to the caregiver by sitting with the patient is proven to help. The pros and cons of institutionalization will be discussed including times when this cannot be avoided.

Research indicates that the Church and Clergy have grossly neglected the care of non-cognitive persons as if they had no soul. The reasons for this will be examined as a means of identifying problems and providing solutions towards finding a new paradigm for care. It is already known that most Clergy do not have adequate training and knowledge to provide pastoral care to non-cognitive or dying patients. Also at stake is the negative perception prevalent in society as voiced by Pat Robertson and cited in the Introduction part of this paper. Culture plays

a role in such a perception and some aspects of the western culture will be contrasted with those of the east where Alzheimer's patients are treated more favorably.

Religion offers strength and peace that science or money can never provide. Where the other dimensions of human help ends, the spiritual dimension takes off. Religion provides that glimmer of light when circumstances say there is none; it provides a future when all the evidence points to no future; it provides a purpose and direction, when everything in this world appears meaningless; and it provides comfort when there is no one around to comfort."¹⁰God is able to comfort and heal any brokenness and the theodicy of God found in the scriptures will be explored in relation to sickness and suffering. Personal testimony of individuals and the experiences of this author will be used to develop a new paradigm of pastoral care including unique methods of communicating with individuals who have lost cognition.

As a means of solving the problem raised at the inception of this paper, all published material on the disease such as its effects, treatment, interventions and spiritual care from 1990 to 2011 was reviewed. Additionally, three groups of people completed a qualitative study based on a questionnaire developed by this author and approved by Liberty University. Each group was chosen because of their direct involvement in the care of those who have dementia. The interview group consisted of a Neurologist, several Hospice Medical Directors, a Palliative Care Medical Director and other Doctors in fields of Geriatrics and Elder care. It also included many Chaplains and Caregivers of Alzheimer's patients. Collective responses from these individuals validate the author's hypothesis.

Additionally, the holy Bible was used as a means to find theological reasons to provide pastoral care to dementia patients. A high emphasis was placed on the value of the human soul

10. Melvin A. Kimble, Susan H. McFadden et.al. editors, *Aging Spirituality and Religion: A Handbook* (Volume.1), (Minneapolis, MN: Augsburg Fortress Publishers, 1995), 10.

that remains intact despite the debilitating disease. The various passages of scripture including many biblical stories of God's preferential love for the aged and sick will be used to answer the question. God desires that man remembers him from the past and this aspect of the Judeo-Christian faith, which is built upon memories, will be presented. Likewise, there are good moral reasons to love and care for the weakest of society. Caring for someone who cannot care for himself or herself is a wonderful opportunity to love without looking for recompense. Morality and values has an impact on how Alzheimer patients are viewed.

Finally, the issue of communicating with non-cognitive persons will be reviewed. The presented research indicate that traditional methods of pastoral care based upon cognitive abilities cannot be applied since these very abilities are lost in a person that has dementia. Yet communication is possible through unique methods and the myth that non -cognitive persons cannot communicate meaningfully albeit for short periods will be dispelled. Research is provided to support the fact that demented individuals still have a part of brain function that is linked to long-term memories. Therefore, the vantage point to communicate with them will be through stirring up their long term memories through visuals and unique memory triggers. The validation therapy method versus the reality approach will be discussed along with the use of our senses especially "touch" through which communication is made possible.

Literature Review

Society regards mental impairment as a social death in which the person is no more connected to society and is dying a little at a time with no hope for recovery. VandeCreek says, "Our cognitively oriented culture finds it easy to forget forgetful persons. Some believe that

persons with dementia need little or no pastoral care.”¹¹ Unless this perception changes, demented individuals will continue to be dehumanized and undervalued as if they have no soul.

It is necessary to review the existing body of knowledge about the disease, its effects, and spiritual care in order to facilitate a change of perception that is both secular and theological. This will educate the reader, help illuminate the struggles of demented individuals and provide opportunities to effectively care for them as persons of great worth. In order to help elevate these individuals to persons of great worth, this paper will research theological and moral reasons to provide pastoral care to non-cognitive persons and explore ways in which to communicate with them within a Christian framework of understanding.

Accordingly, research on all published material between 1990 and 2011 was done. Findings suggest that demented individuals and especially those in early stages of the disease draw strength, comfort and peace from their relationship with God. Literature has been organized to identify themes and gaps in knowledge.

The Disease: An Understanding of the Topic

According to the Alzheimer’s Association, Alzheimer’s is the most common form of dementia accounting for about 60-80 percent of cases. An estimated 5.3 million people live with Alzheimer’s disease, which is ranked as the 7th leading cause of death (some rank it 6th) in the United States.¹² The primary symptom of the disease is loss of memory due to degeneration of the brain cells. Lensyn believes the gradual loss of brain function impedes communication, hinders relations with others and interferes with a person's ability to conduct daily activities,

11. Larry VandeCreek, *Spiritual Care for Persons with Dementia* (Binghamton, NY: The Haworth Pastoral Press, 1999), xi.

12. Alzheimer’s Association, *Alzheimer’s Disease Facts and figures report*, http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf (accessed November 2, 2011).

resulting in loss of self-autonomy, self-esteem, sense of mastery, and control.¹³ Consequently, these losses could lead to depression, loss of self, and loneliness. Alzheimer's is a devastating disease that robs an individual of self and many look upon it as a social death. This author has seen many such patients in the mid and late stages of dementia at institutionalized settings, sitting in wheel chairs with their head sagging in their laps while drooling and groaning with no one really around to value or affirm their worth.

Spiritual Care: A Representative View of Published Works

There is a growing body of literature that addresses the spiritual care needs of those with dementia. The studies indicate that while dementia creates a disconnection from people, the right pastoral care of these individuals can make a connection for them with God through whom they can find comfort and peace. Everett agrees with this saying, "in the midst of forgetfulness and loss of control, the chaplain represents a God who never forgets us".¹⁴ Koenig et. al found that older persons use spirituality in coping with many stresses in their life, such as disease, illness and mortality.¹⁵ Other studies reveal a significant association of spirituality contributes to emotional well-being and self-esteem.¹⁶ Post and Whitehouse note that it never should be

13. Lensyn J, "Reaching the living echo: A new paradigm for the provision of spiritual care for persons living with Alzheimer's disease," *Alzheimer's Care Quarterly* 5 (2004): 313–323.

14. Deborah Everett, "Forget me not: the spiritual care of people with Alzheimer's disease," *Journal of Health Care Chaplaincy*, 8(1/2), (1999): 86

15. H.G Koenig, M.E. McCullough & D.B. Larson, *Handbook of Religion and Health*. (New York: Oxford University Press, 2001)

16. P.H. Van Ness & D.B. Larson, "Religion Senescence and Mental Health: The end of life is not the end of hope," *American Journal of Geriatric Psychiatry* 10 (2002): 386–397.

K.A. Bickerstaff, C.M. Grasser & B. McCabe, "How elderly nursing home residents transcend losses of later life," *Holistic Nursing Practice* 17 (2003): 159–165.

H.B. Bosworth, K.S. Park, D.R. McQuoid, J.C. Hays & D.C. Steffens, "The impact of religious practice and religious coping on geriatric depression," *International Journal of Geriatric Psychiatry* 18 (2003): 905–914.

assumed that a person with dementia can no longer be reached spiritually.¹⁷ In terms of methodology, Sapp suggests applying Judeo-Christian concepts of “seeing things as God sees them” for pastoral care to be effective.¹⁸ However, material on precise theological reasons for providing pastoral care to these individuals is virtually nonexistent.

Every Chaplain or Clergyman will agree that providing pastoral care to a sick individual through personal visitations or prayers helps comfort and sometimes even heal the person. However, ministering to a non-cognitive person is different because of limitations in verbal communication. Keck feels the problem lies in the fact that pastoral care has not adequately devoted itself to ministry related to Alzheimer’s disease. It presupposes a ministry to cognitive persons who can approach faith intellectually.¹⁹ Ellor is in agreement saying pastoral care in general is geared towards those with cognitive abilities, which are the very abilities that are lost in the person with Alzheimer’s.²⁰

Unless Clergy are trained properly, it would be difficult for them to make a connection with the individual and in turn help them connect with God. Most clergy do not really understand the importance of ministry to persons with dementia. Everett presents new understandings about the relationship between dementia and spirituality and the theological foundations are explored.²¹

17. Post, S.G., and Whitehouse P.J., “Spirituality, religion and Alzheimer’s disease,” *Journal of Health Care Chaplaincy*. 8(1/2). (1999):45-57.

18. Stephen Sapp, “To see things as God sees them: theological reflections on pastoral care to persons with dementia,” *Journal of Health Care Chaplaincy*. 8(1/2), (1999): 25-43.

19. David Keck, *Forgetting Whose We Are* (Nashville: Abingdon Press, 1996), 41.

20. James W. Ellor, Donald K. McKim Editor, *Celebrating the Human Spirit. In God Never Forgets* (Louisville: Westminster John Knox Press, 1997), 3.

21. D. Everett, [General Hospital of Edmonton, Alberta, Canada]. “Forget me not: the spiritual care of people with Alzheimer’s disease,” *Journal of Health Care Chaplaincy* 8, nos. 1-2 (1999): 77-88.

The article ends with a discussion of pastoral strategies that are important in this ministry but falls short of providing theological reasons to provide pastoral care to demented individuals.

Some argue that spirituality in dementia care remains an under researched area of care in which most caregivers lack a basic understanding even of their own spirituality.²² At the same time, a Chaplain's ministry to persons with dementia is vitally important to their clinical well-being. Despite being demented, they can be made to remember God and selected pastoral interventions can help enhance their quality of life.²³ Stolley and others present a psychosocial model called Progressively Lowered Stress Threshold or PLST model of pastoral care.²⁴ Studies involving twenty-three participants indicated that those with early-stage dementia found personal spirituality important in coping with the disease.²⁵

Monney rightfully says the primary focus of research related to spiritual needs of older people, historically and in the present, has been on those whose cognitive abilities are impaired only minimally. He suggests that persons with dementia and a faith background rooted in the Judeo-Christian worldview are often able to respond verbally, physically, and emotionally to various rituals of their faith.²⁶ This is true but the question remains "what are the theological reasons" to provide this spiritual support? It is a well known fact that faith and belief in God

22. D. Doherty, [University of Sheffield, UK]. "Spirituality and dementia," *Spirituality and Health International* 7 (2006): 203–210.

23. S.G. Post, P.J. Whitehouse, [Center for Biomedical Ethics, Department of Religion, Case Western Reserve University, Cleveland, OH]. "Spirituality, Religion, and Alzheimer's disease," *Journal of Health Care Chaplaincy* 8, nos. 1-2 (1999): 45-57.

24. J.M. Stolley, H. Koenig, and K.C. Buckwalter, [Trinity College of Nursing, Moline, IL]. "Pastoral care for the person with dementia," *Journal of Health Care Chaplaincy* 8, nos. 1-2 (1999): 7-23.

25. T. Katsuno, [Tokyo Metropolitan University of Health Sciences]. "Personal spirituality of persons with early-stage dementia: Is it related to perceived quality of life?," *Dementia* 2, no. 3 (October 2003): 315-335.

26. S.F. Mooney, [Regis University, Denver, CO]. "A ministry of memory: Spiritual care for the older adult with dementia," *Care Management Journals* 5, no. 3 (2004):183-187.

helps with coping skills but with diminishing cognitive abilities why should these individuals be made to remember God and then forget him moments later unless there are theological reasons to have them do so? This author seeks to fill this gap of knowledge with the support of research and teachings from the bible.

Bell and Troxel argue that the cognitive losses of individuals with Alzheimer's disease actually make their spiritual needs more apparent. The authors insist that nurturing the spirit of a person with dementia enhances the quality of their life.²⁷ Since the disease is terminal, can it then be argued that connecting with God is really not a means to get better or feel good despite the devastation of the disease but that provision is being made to secure a resting place and return of the soul to its maker?

A qualitative study involving fifteen persons was done to see how people with early stage Alzheimer's cope with loss of self-esteem and social interaction. These participants were not institutionalized, but lived at home, and it was found that prayer, personal faith, and association with their Church family helped them have a positive attitude about their disease.²⁸ This is not hard to agree with especially since the disease is in the early stage in which cognition may only be minimally impaired. Similarly, another study involving twenty-nine patients was conducted in Great Britain which concluded that there was no obvious reduction in their spiritual awareness in early stages of dementia.²⁹ Once again, these studies covered only those who were in the early

27. V. Bell, and D. Troxel, [Lexington/Bluegrass Alzheimer's Association, Lexington, KY]. "Spirituality and the person with dementia – a view from the field," *Alzheimer's Care Quarterly* 2, no. 2 (Spring 2001): 31-45.

28. L. Beuscher, and V.T. Grando, [Vanderbilt University]. "Using spirituality to cope with early-stage Alzheimer's disease," *Western Journal of Nursing Research* 31, no. 5 (August 2009): 583-598.

29. D. Jolley, S.M. Benbow, M. Grizzell, S. Willmott, S. Bawn, and P. Kingston, [Manchester University, et al., UK]. "Spirituality and faith in dementia," *Dementia* 9, no. 3 (August 2010): 311-325.

stages of dementia and the importance of faith but none of the studies asked the question as to what the theological reasons were to provide pastoral care in the first place.

Spiritual Care: A Biblical Perspective

The value of an individual is the soul and in an Alzheimer's patient, the soul remains intact. God's love and care for humanity is linked to how and why he created man. God created man in his own image and likeness (Gen. 1:27). Then God blessed them. Man became a living soul when God breathed into his nostrils the breath of life (Gen. 2:7). A piece of God entered man, which is called the "soul." Caring for that soul is what pastoral care is all about. The body that houses the soul came from dust and to dust it will return but the soul that came from God is yoked to God and yearns to return to Him.

Human beings are more than flesh and blood. A Clergyman may not have the ability to cure Alzheimer's but he can help connect their soul to God. While they still have breath, he can care for their body too, which is made in God's image lest he be in contempt of Matt. 25:43 that says I was hungry, and you gave me no food: I was thirsty, and you gave me no water: I was a stranger, and you never took me in: naked, and you did not cloth me; sick, and in prison, and you did not visit me - as much as you did it to the least of these, you did it to me.

Man cannot live by bread alone but by every word that proceeds from the mouth of God (Matt. 4:4). The human body is the temple of the Holy Spirit (1 Cor. 6:19 and Rom. 8:11). Men may not remember God but he remembers them (Isaiah 49: 14-16). God has a plan for human life that offers hope and a future (Jer. 29:11). The future is eternal life promised to those who believe (Luke 10:20). Even when facing death, "The Lord himself goes before you and will be with you; he will never leave you nor forsake you. Do not be afraid; do not be discouraged" (Deut. 31:8). Jesus' analogy of being the good shepherd who cares for his sheep is a powerful

reminder of God's protective care of his children.

Methods of Communication: Published work

Some people remember God through his creation and nature. Some observed that persons with Alzheimer's reported that spiritual connections to nature brought them a feeling of peace.³⁰ For others, religious symbols were helpful. Matano reported that a clergyman helped make a spiritual connection to God.³¹ The most often reported spiritual coping strategies were prayer and church attendance even though they depended upon others to transport them to church.³² One participant used meditation while walking.³³ It is difficult but not impossible to reach a cognitively impaired person spiritually.³⁴

30. A. Phinney, "Living with dementia from the patient's perspective." *Journal of Gerontological Nursing* 24, (1998):8–15.

Stuckey JC, Post SG, Ollerton S, FallCreek SJ & Whitehouse PJ, "Alzheimer's disease, religion and the ethics of respect for spirituality a community dialogue." *Alzheimer's Care Quarterly* 3, (2001):199–207.

31. Matano T (2000). *Quality of Life of Persons with Alzheimer's disease*. Unpublished PhD diss., University of Illinois at Chicago, Chicago, IL.

32. T. Katsuno, "Personal spirituality of persons with early stage dementia," *Dementia* 2, (2003):315–335.

33. A. Phinney, "Living with dementia from the patient's perspective," *Journal of Gerontological Nursing* 24, (1998):8–15.

34. James W. Ellor. Ed. Donald K. McKim, *Celebrating the Human Spirit. In God Never Forgets* (Louisville: Westminster John Knox Press, 1997), 3.

CHAPTER TWO

ALZHEIMER'S AND NON-COGNITIVE PERSONS

The Disease Process and Available Data

The Merck Manual of Geriatrics defines Alzheimer's as a progressive neuropsychiatric disease mostly found in older adults but not immune to middle aged individuals.¹ Alzheimer's disease is the most common form of Dementia. In the year 1906, Alois Alzheimer who was treating a patient in her fifties found that she had certain symptoms that were usually present among older people. After the woman died, an autopsy was done from which he found microscopic changes called neuritic plaques and neurofibrillary tangles which is characteristic of Alzheimer's disease. The physician's discovery of the disease since bears his name. Given the fact that Alzheimer's disease is a relative new discover, the name cannot be found in the bible or too many history books. The disease is not part of the normal aging process and while there is some medication available to delay the process, there is no cure.

Although the disease is considered neuropsychiatric, most of the symptoms are behavioral until the late stage. The neurofibrillary tangles and plaques referenced above are pieces of brain cells which have broken down. The destruction of brain cells once begun is progressive and irreversible.² The tangles and plaques first appear in the base of the skull called the entorhinal cortex. The brain stem is not affected but the neocortex, which is the upper layer of brain tissue, is affected. The neocortex is an area of the brain that controls intellect and social

1. W.B. Abrams, M.H. Beers and R. Berkow (Editors). *The Merck Manual of Geriatrics* 2nd edn., (Whitehour Station, NJ: Merck and Co. Inc., 1995), 1148.

2. Alzheimer Disease: *A Handbook for Care* (Toronto, The Alzheimer Society of Canada, 1991), 2.

and behavioral choices.³When this area becomes affected, a person will begin to behave out of character.

Brain cells are connected by neurotransmitters, which are chemicals within the brain. When the chemicals (neurotransmitters) decrease, the messages between the cells are interrupted. The brain surface area is reduced by increasing number of plaques and tangles and consequently the dead brain cells, mostly confined to the left hemisphere of the brain, cease to function. It is the area of short-term memory which results in distorted and confusing actions by the individual who has dementia.⁴

Signs of the onset of Alzheimer's disease include forgetfulness, inability to solve basic problems, confusion over time and place, diminished judgment, personality changes, mood swings, loss of short term memory all of which progresses making it dangerous for the individual and challenging for the family. The stress on the family and caregivers is enormous because depending upon the age of the individual the average Alzheimer's patient can live anywhere from three to twenty years from the start of the disease. More than 30% of caregivers are from the "sandwich generation" which means they care for their sick parents while at the same time have to care for children of their own. The financial costs, demands on time, and the loss of one's income to provide full time care increase the stress on marriages and families.⁵There is no cure for Alzheimer's, but the FDA has approved five drugs to delay the progression of the disease in the initial stages. Some initial screening tools include Mini-Mental State Examination (MMSE), Short Portable Mental Status Questionnaire (SPMSQ), Clinical dementia Rating Scale

3. David Snowden. *Aging with Grace: What the Nun Study Teaches Us About Leading Longer, Healthier and More Meaningful Lives* (New York: Bantam Books, 2001), 92.

4. *Alzheimer's Care Guide*. (Reno, NV: Eymann Publishers) March 1997, 1.

5. National Alliance for Caregiving and American Association of Retired Persons. (2009). *Caregiving in the United States*. Retrieved from <http://www.caregiving.org/data/04finalreport.org>. (accessed 11/2/11).

(CDR), and Global Deterioration Scale (GDS). Licensed professionals normally administer these tests.

On August 27, 2001, *Business Week* reported that around 10% of people age 65 and older and 50% of those over 85 develop Alzheimer's. More than 5 million people in the United States currently suffer from this degenerative, incurable and always fatal brain disease. Contrary to Robertson's advice, divorce is uncommon among couples where one partner is suffering from Alzheimer's, according to Beth Kallmyer⁶, Director of Constituent Services for the Alzheimer's Association, which provides resources to sufferers and their families. She also said people could still connect, relate, and have a need for intimacy even when they do not know who you are.

The American Health Assistance Foundation has done some research on Alzheimer's disease and the results are staggering. According to them:⁷

- By 2050, the number of Americans with Alzheimer's could increase to over 15 million.
- One person in the United States is diagnosed with Alzheimer's disease approximately every 69 seconds.
- It is estimated that almost 500,000 new cases of Alzheimer's disease will be diagnosed every year. More than one in three Americans 85 years and older have Alzheimer's disease.
- Alzheimer's disease usually begins after age 60 and risk increases with age. Younger people in their 30s, 40s and 50s may get Alzheimer's disease, but it is rare.
- Approximately 5 percent of all cases of Alzheimer's disease are believed to be familial (hereditary). In familial cases, often called early-onset Alzheimer's disease, symptoms typically appear within the age range of 30 - 60 years.

6. *Everyday Health*, "Is an Alzheimer's Diagnosis Grounds for Divorce," <http://www.everydayhealth.com/alzheimers/0915/is-an-alzheimers-diagnosis-grounds-for-divorce.aspx> (accessed 11/2/11).

7. *American Health Assistance Foundation*. (2011). "The Facts on Alzheimer's Disease," <http://www.ahaf.org/alzheimers/about/understanding/facts.html> (accessed November 4, 2011).

- Alzheimer's disease represents around 70% of all cases of dementia. Making it the most common cause of dementia.
- On average, patients with Alzheimer's disease live for 8 to 10 years after diagnosis, but this fatal disease can last as long as 20 years, or as little as 3 to 4 years if the patient is over 80 years old when diagnosed.
- Currently, the only way to definitively diagnose Alzheimer's disease is to physically examine the brain through autopsy.
- Approximately 70% of Alzheimer's disease patients receive care at home.
- In terms of health care expenses and lost wages of both patients and their caregivers, the cost of Alzheimer's disease nationwide is estimated at \$100 billion per year.
- Nearly half of all nursing home residents have Alzheimer's disease or a related disorder. The average cost of a private room in an Alzheimer special care unit is \$239 per day, which calculates to \$87,362 per year. The care of an Alzheimer's patient, viewed as custodial care, is not covered by Medicare and most health insurance plans.
- In the absence of disease, the human brain often can function well into the 10th decade of life.

10.9 million unpaid caregivers care for an estimated 5.3 million people with Alzheimer's disease which is ranked as the 7th leading cause of death (some rank it 6th) in the United States.⁸ According to the Alzheimer's Association, Alzheimer's is the most common form of dementia while other different forms of the disease include vascular dementia (multi-infarct), mixed dementia, dementia with lewy bodies, Parkinson's disease, frontotemporal dementia, and Creutzfeldt-Jakob disease. Alzheimer's is a progressive disease while vascular dementia can be erratic. Alzheimer's disease is broadly categorized into three stages namely early, mid and late but the Alzheimer's Organization has a list of seven stages based on a system developed by Barry Reisberg, M.D., clinical director of the New York University School of Medicine's

8. Alzheimer's Association, *Alzheimer's Disease Facts and figures report*, http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf (accessed November 2, 2011).

Silberstein Aging and Dementia Research Center. Each of these stages is described briefly below and taken from the Association's website.⁹

Stage 1 – No Impairment

At this stage, the person does not experience any memory problems. An interview with a medical professional does not show any evidence of symptoms of dementia. Function appears normal with no impairment.

Stage – 2 Very Mild Decline

This stage is not easy to identify but some behavior traits include shorter attention span and remembering familiar words or location of everyday objects. The person may feel as if he or she has memory lapses, but no symptoms of dementia can be detected during a medical examination.

Stage – 3 Mild Decline

Forgetfulness in recent events and denial of these including being anxious about the changes are visible signs of the disease. Doctors are able to detect problems with memory and concentration especially in finding the right word to complete a sentence or the name of someone. There is a noticeable difference and difficulty in performing tasks and forgetting material that one has just read including misplacing valuable objects.

Stage – 4 Moderate Cognitive Decline

Some clear-cut symptoms are distinguishable from a medical examination, which includes forgetfulness of recent events, impaired ability to perform challenging mental arithmetic and counting backwards from 100 by 7s. There is forgetfulness about one's own personal history

9. Alzheimer's Association. *Seven Stages of Alzheimer's*, http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp (accessed February 11, 2012).

with behavioral symptoms of being withdrawn or moody especially in social or mentally challenging situations.

Stage 5 – Moderately Severe Cognitive Decline

At this stage, gaps in memory and thinking are noticeable. Individuals begin to need help with day-to-day activities. They may be unable to recall their own address or telephone number. They might be confused as to where they are or what day it is and may require help choosing proper clothing appropriate for the season. However, they may still be able to remember significant details about themselves and family. They would not require assistance with eating or toileting at this stage.

Stage 6 – Severe Cognitive Decline

Memory worsens especially of the short term. Personality changes take place and they could need extensive help with daily activities. Individuals lose awareness of recent experiences and their surroundings. They may remember their name and distinguish familiar faces but have difficulty in remembering names of others. They need help dressing and some assistance with toileting. Bladder and bowel control issues begin to surface. They experience major personality and behavioral changes including suspiciousness and delusions about things. Individuals could wander and get lost.

Stage 7 – Very Severe Cognitive Decline

This is the final stage of the disease in which individuals lose the ability to respond to their environment and carry on a meaningful conversation. They need help eating and using the toilet. They could lose the ability to smile or to sit without support and to hold their head up. Swallowing is impaired and muscles grow rigid. They become incontinent and require 24-hour

assistance and lose the ability to walk. They are prone to infections like pneumonia and are unable to communicate with words.

What are Their Struggles and is there Hope

People with dementia and other mental degenerative disorders often die after having received a poor quality of end-of-life care than what is given to those who are cognitively intact. This writer in the course of being a Hospice Chaplain has walked into several Nursing Homes and long-term care facilities only to see a number of Dementia patients loaded into one room and strapped to a wheel chair with the television turned on as if they were watching something. Many of them have their heads slumped into their laps and lie drooling for hours on end. The new healthcare law (H.R. 3590) contains the Elder Justice Act (EJA), which establishes a Coordinating Council to make recommendations to the Secretary of HHS on the activities of the federal, state, local and private agencies relating to elder abuse, neglect and exploitation.¹⁰ This legislation is very welcome and crucial in protecting the rights of these marginalized individuals.

Scripture tells that all will die but persons with dementia get the short end of the stick because they are unable to verbalize their feelings for better care and understanding of their needs. This disease involves dehumanization and isolation. It is a slow death with loss of self. All aspects of the individual's life are altered including spirituality, relationship with others and relationship with God. Many afflicted with this disease believe that they are no longer worthy in the eyes of God or their loved ones. Dementia is chronic and progressive whose symptoms include short-term memory loss, impairments involving cognition and the ability to reason and

10. The Gerontological Society of America. "Elder Justice," <http://www.geron.org/Resources/older-adults-and-health-care-reform?start=8> (accessed February 12, 2012).

have a sensible conversation apart from impairments in social or daily functioning.¹¹The gradual deterioration of cells in the brain causes the individual to get confused and unable to make sense of the external world along with expression of feelings. Depression can also occur in Alzheimer's patients.¹²

A devout Hispanic Catholic woman in her 30's diagnosed with a rare form of chromosome 14 related to Alzheimer's disease said:

My beliefs help me but I have to keep reminding myself of them. As anyone would, I've wondered why me? I'm a good person, so why is this happening to me? But only God knows. I'm not angry, but I feel helpless because God can't answer my question with a human voice. But I realize he knows what he's doing and he'll take care of me. He'll only give me as much as I can handle. We all have our trials; everybody goes through something that is difficult. I pray often for the strength and for my husband to have the strength to go through this. I have to remember that my husband and I are only human.¹³

It is a difficult task to understand why tragedy and loss come to some people in greater measure than others. Some blame God for punishing them or for allowing them to be the innocent victim. In his book *Partial View*, Cary Henderson notes a significant change in his religious practice. Instead of a spiritual transformation or a nearness to God, he has feelings of anger against God. He wrote in his journal, "I did stop going to church – the biggest reason – well there were two reasons – one of which I am not really enamored of a God who creates something like Alzheimer's and the second is I'm afraid of tripping."¹⁴ People try to make sense of their suffering by wrestling with God; sometimes they affirm his presence but sometimes blame him.

11. David Snowden. *Aging with Grace: What the Nun Study Teaches Us About Leading Longer, Healthier and More Meaningful Lives* (New York: Bantam Books, 2001), 87.

12. *Ibid.*, 47.

13. Snyder, L. *Speaking our Minds – Personal reflections from individuals with Alzheimer's*. (New York: W.H. Freeman, 1999), 146.

14. Henderson, C. *Partial view – An Alzheimer's journal*. (Dallas, TX: Southern Methodist University Press, 1998), 73.

Harold Kushner tries to explain the deep love that God has for his people and the redemption that comes through suffering. In his book *When Bad Things Happen to Good People* Kushner believes that God does not cause pain but rather that God is there as a companion and strength to help endure it. Since Alzheimer's patients can live for up to 20 years from the onset of the disease, the agony and pain is multiplied several fold. Keck refers to Alzheimer's disease as "Deconstruction Incarnate."¹⁵ He also calls it the "Theological Disease."¹⁶

Spirituality or religious practices help individuals cope more effectively with the disease by giving them hope, strength, guidance, something to hold on to, and mostly the hope in an afterlife. An African American man of the Baptist faith says, "God is a foundation that I have. My faith is solid. It's within me and it is me . . . As a child when you're brought up with the scripture and the teaching of the holy word, that puts a foundation under you . . . I try to live by the book. I'm steeped in it now. You couldn't pull me away from it now."¹⁷ Another Protestant man said, "If I were talking to someone who was on the edge of something, I would say to them, "You've got to find something to hold on to." And my faith in God is what I'm holding on to."¹⁸ People of faith know that no amount of suffering or pain is beyond the comfort and healing abilities of God.

It would be irresponsible to assume that the Holy Spirit is incapacitated and unable to work within the souls of those with Alzheimer's disease. The cognitive destruction of the human

15. David Keck. *Forgetting Whose We Are*. (Nashville:Abingdon,1996), 21.

16. *Ibid.*, 18.

17. Snyder, L. *Speaking our Minds – Personal reflections from individuals with Alzheimer's*. (New York: W.H. Freeman,1999), 102.

18. Kielb, R. (2000). *Dealing with early memory loss – A personal perspective*. Rochester: Mayo Foundation for Medical Education and Research, Health Oasis Mayo Clinic, <http://www.mayoclinic.com/invoke.cfm?objectid=2D237C78-919E-4167-AEBFB370C1744A53> (accessed January 29, 2012).

body that results in the inability to care for self and the physical challenges that come from it are devastating both for the patient and their loved ones. The prolonged duration of the disease adds to the suffering besides the financial burden since Medicare does not cover custodial care.

Despite the odds stacked up against Alzheimer's, there is plenty of hope in a loving God and preparations for an afterlife.

Evelyn Underhill quotes Meister Eckhart who wrote a couple of hundred years ago that "God is closer to me than I am to myself."¹⁹ Proverbs 18 and verse 24 speaking of God says he is a friend that sticks closer than a brother. Repeatedly in John 15 Jesus refers to his disciples as his friends. The Comforter was given to us to abide with us forever (John 14:16). God is very near and lives within the human body. When this concept is comprehended and understood by the patient and their families, it provides hope for both the present and the future. Everett says, "in the midst of forgetfulness and loss of control, the chaplain represents a God who never forgets us."²⁰ One of the main purposes of this study is to help these non-cognitive persons to connect with God. In his book *My Journey into Alzheimer's Disease* Pastor Davis writes:

How can I stand to look at this disaster that medical science predicts will most probably overtake me? If I were not a Christian, I do not know how I could stand it. However, since I am a Christian, I can stand it by looking beyond it – looking beyond and considering the glories of heaven where each one of these things will be gone forever to be replaced by perfection, glory and joy.²¹

Although the disease process causes the brain cells to keep dying resulting in loss of short-term memory, amazingly the long term memory is not affected as much. There is hope to communicate with these individuals through their long-term memory which is discussed later in

19. Evelyn Underhill, *Mysticism*, 12th ed. (New York: E.P. Dutton and Co. Ltd., 1911), 101.

20. D. Everett. "Forget me not: the spiritual care of people with Alzheimer's disease." *Journal of Health Care Chaplaincy*, 8(1/2), (1999): 86.

21. Davis, R. *My Journey into Alzheimer's disease: Helpful Insights for Family and Friends*. (Wheaton, IL: Tyndale Publishers, 1989). 42.

this paper. It is important from a spiritual context to have these individuals spend their last days on earth in communion with their creator. Jesus did the same with his father. His last words on earth were “Father, into thy hands I commend my spirit” (Luke 23: 46). As a resurrection people, hope is not in this world but in the one to come. Psalm 49 speaks about building faith in the resurrection and not on worldly power. Riches, power and glory shall wax old because this world is passing away. What will remain is the hope and faith in an everlasting God who will redeem the soul from the grave.

Shortly before his impending death from Alzheimer’s disease, a Baptist wrote a poem “Wings of My Soul” about hope in the eternal provision made for humanity by an everlasting and loving God:

I’m weary and wistful; my living is spent
 My bones ache and rattle, my walking is bent.
 My breathing is painful, my eyes scarcely see.
 My mind’s so demented it barely is me.
 But out in the distance beyond a bright star
 A new home awaits me and it calls from afar.
 And soon I must heed it, my spirit unfold
 And fly through the void on the wings of my soul.²²

Even in the advanced stages of the disease, the hope in an afterlife can be a comforting and sustaining belief.

Are They a Burden and Who Cares For Them?

Care giving to non-cognitive persons is not easy. It involves sacrifice and can be very stressful to spouses and their families. Most non-cognitive persons are incontinent, need to be fed and clothed, but more than that, there is deep frustration with little or no meaningful verbal communication. Reading someone else’s mind all the time can become tiresome and even

22. Green, J.W. Wings of My Soul. *San Diego Chapter, Alzheimer’s Association Newsletter*, 22 (2001): 4.

irritating, but when non-cognitive people are properly understood, there are windows of opportunity to connect with them through their long term memories. This may not ease the emotional pain that comes from watching the degeneration of some one that is respected and loved so very much but intimacy can be made and with the right approach, they can also connect to God.

The American Health Assistance Foundation predicts that every year about half a million people will be diagnosed with Alzheimer's. The magnitude of the disease and ignorance about coping with it is both astounding and alarming. The United States is a Christian country that is both prosperous and blessed whose founding principles in the Declaration of Independence state that all men are created equal, and that they are endowed by their Creator with certain unalienable rights, that among these are life, liberty and the pursuit of happiness.²³ And yet the very government who has a moral duty to uphold and further these ideals (life) is actually impeding them in that Medicare does not cover long term care costs for demented patients.²⁴

About 70% of Alzheimer's disease patients receive care at home.²⁵ Medicare and most health insurance plans view the care of an Alzheimer's patient as custodial care, and so they will not cover the costs. Consequently, family and volunteers have no choice but to provide most of the care. These individuals do not have formal training or the necessary educational background to understand the disease process and provide quality care. They do the best they can but it does

23. US History.Org. "The Declaration of Independence." <http://www.ushistory.org/declaration/document/> (accessed March 14, 2012).

24. Caring.com. "Medicare coverage of Alzheimer's care," http://www.caring.com/medicare_information/medicare-coverage-of-alzheimers-care (accessed November 7, 2011).

25. American Health Assistance Foundation. "The Facts on Alzheimer's Disease," <http://www.ahaf.org/alzheimers/about/understanding/facts.html> (accessed November 7, 2011).

not mean the care provided is the best. Statistics tell us that caregivers are stressed financially, physically and emotionally.

There are nearly 15 million Alzheimer's and dementia caregivers providing 17 billion hours of unpaid care valued at \$202 billion. *Facts and Figures* finds that caregivers not only suffer emotionally but also physically. Because of the toll of caregiving on their own health, Alzheimer's and dementia caregivers had \$7.9 billion in additional health care costs in 2010. More than 60 percent of family caregivers report high levels of stress because of the prolonged duration of caregiving and 33 percent report symptoms of depression.²⁶

Between 5 million patients and 15 million caregivers identified above, there are about 20 million people who are affected by dementia alone. This in turn accounts for 5% of the population, which is very significant. Since there may be little or no verbal communication between the patient and the caregiver, there can be frustration on both sides. However, relative to spiritual care which is the focus of this paper, these challenging issues can easily be resolved through the discovery of unique avenues and windows of opportunity to communicate with demented individuals. Even when other elements of a person's life are restricted with dementia, through creativity, life can still be celebrated.

Sympathizing With the Caregiver But Neglecting the Cared For

Both historic and current research done in the field of nursing and pastoral care of the elderly, center only on those whose cognitive abilities are only minimally impaired. Pastoral care and nursing literature deal with the issue of dementia primarily from behavioral or psychological perspectives and focus extensively on the spiritual needs of the caregiver but only minimally on the spiritual needs of the cared for.²⁷ Similarly, research, development, and the role of religion

26. Alzheimer's Association. "Unpaid caregivers and stress.," http://www.alz.org/alzheimers_disease_facts_and_figures.asp (accessed November 7, 2011).

27. Sharon F Mooney. "A Ministry of Memory: Spiritual Care for the Older Adult with Dementia," *Care Management Journals* 5, no. 3. (Fall 2004): 184.

and spirituality in coping with Alzheimer's focus largely on caregivers and much less to those afflicted with the disease.²⁸

This could be related to lack of a theoretical framework from which to understand what may be happening spiritually to a distinctly confused person and how a person with dementia might still be able to maintain a relationship with God or be ministered to by a God who may be remembered only vaguely, if at all.²⁹ Gwyther has a booklet guide entitled *You are one of us: Successful clergy/church connections to Alzheimer's families* that has specific advice on visiting and ministering to persons with Alzheimer's which is a good resource for those who have difficulty in ministering to those who are cognitively impaired.

It has been the experience of this author from visiting homes of those with dementia that the caregivers would be the ones who steal away most of his time. One of the reasons perhaps is because they have someone to talk to, who is a willing listener. In general, a major part of the conversation is about them self and their struggle in caring for the person lying in the room next door. It is not wrong to minister to them because their needs are legitimate, but there is also a tendency on the part of a chaplain to engage in such a conversation because the caregiver is cognitive and therefore more receptive to the visit. The goal of many chaplains is to "please" the caregiver at the expense of the cared for.

As opposed to caregivers, persons in the advanced stages of Alzheimer's would not be able to communicate their religious beliefs or need for spiritual services, but there is a cry that needs to be heard. It comes from those who are in the early or mid stages. One woman in the early stages of disease said:

28. Lisa Snyder. "Satisfactions and Challenges in Spiritual Faith and Practice for Persons with Dementia," *Dementia*. 2 (2003): 299.

29. Mooney, SF. "A Ministry of Memory: Spiritual care of the older adult with dementia," *Care Management Journal*. Fall 5(3), (2004): 183-187.

I know in my mind God's promise. He will never leave me or forsake me and that nothing can separate me from His love. As my journey into Alzheimer's progresses, my walk with the Lord grows more precious. I am frightened that the day will come when I no longer will be able to think of God's everlasting promises. Then I will have to rely on my dear friends in Christ to keep me close to our Lord and to comfort and reassure me with simple scripture passages and prayer.³⁰

This woman depends upon people like this writer and everyone in the profession of caring for non-cognitive persons not to forget them. They can easily be forgotten and this author has heard the cry. There is a link between cognition and faith. Not being able to remember God's everlasting promises alienates these precious individuals from a relationship with God. This research paper is meant to enlighten caregivers, medical professionals, clergy, and family members that there is hope in a God that does not forget his children and in a new paradigm through which they can connect with God. It is important to get to know the individuals in the early stages of their disease so that there is a clear understanding of their physical, emotional, spiritual and psychological needs.

Others may opine about the personhood of the cared for and what might help them, but when all of them are at different levels of cognitive impairment, the persons themselves are the only ones who truly know their needs. One research study done in Nursing Homes indicates that residents with mild, moderate and advanced stages of dementia were able to describe in their own words what mattered to them spiritually and or religiously, both in the past and in their present circumstances.³¹

While some Alzheimer's patients might feel angry at and abandoned by God, more often spirituality and religion have been found to comfort persons with a dementia diagnosis, giving

30. Lisa Snyder. "Satisfactions and Challenges in Spiritual Faith and Practice for Persons with Dementia," *Dementia*. 2 (2003): 308.

31. Bethel Ann Powers, and Nancy M. Watson. "Spiritual nurturance and support for nursing home residents with dementia," *Dementia*.10 (2011): 75.

strength, providing hope in the possibility of an afterlife, helping with acceptance and relieving fears and anxiety.³² Strong belief and faith in God enables persons with early stage dementia to face difficulties and uncertainty. Similarly, studies done by Stolley, Buckwalter and Koenig that focused on caregivers of persons with dementia report that there is effectiveness of prayer and trust in God's supporting presence.³³ No one said it better than Job. In the midst of experiencing immense pain and suffering and the ungodly counsel of his friends he was still able to say:

Oh that my words were written! Oh, that they were inscribed in a book! That they were engraved on a rock with an iron pen and lead forever! For I know that my Redeemer lives and He shall stand at last on the earth; And after my skin is destroyed, this I know, that in my flesh I shall see God, whom I shall see for myself; and my eyes shall behold, and not another. How my heart yearns within me! (Job 19:23-27 NKJV).

32. Katsuno, T. "Persona spirituality of persons with early stage dementia: Is it related to perceived quality of life?," *Dementia* 2 (2003): 315-335.

Lisa Snyder. "Satisfactions and challenges in spiritual faith and practice for persons with dementia," *Dementia*. 2 (2003): 299-313.

33. Stolley, J.M., Buckwalter, K.C, and Koenig, H.G. "Prayer and religious coping for caregivers of persons with Alzheimer's disease and related disorders." *American Journal of Alzheimer's Disease* 14 (1999): 181-191.

CHAPTER THREE

DEATH AND DYING

Thanatology – Scientific Study of Death and Dying

Caregivers have the responsibility to know as much as possible about the individuals under their care if effective and new methods of spiritual care are to be provided. Studying the meaning of death and dying, and health care of older people in the United States is important since it is relative to how these non-cognitive persons may be perceived. The study of the nature of the disease and its complications will lead to the exploration of the nature of soul and value of life.

It is important to have a medical understanding of the disease and its effects including the functioning of the brain together with a Christian and biblical understanding about the worth of the individual and the need to provide pastoral care. Dying is a complex process. It involves the whole person not just the body. It involves relationships and earthly bonds. The human being is more than a sum of physical parts or flesh and blood; it is also about soul and spirit. Life and death is to some extent a mystery. However, if death is reduced only to a clinical event, life is not honored neither the God who is the author of it.

Humans are relational beings. God created them to be in relationship with each other and with himself. Many people find it comforting to continue talking to their loved one even after they pass into an unconscious state because it maintains the human relationship. These are moments of great healing and sharing of intense and private emotions. It is said that hearing is a sense which may continue even after a patient is unconscious and therefore loved ones should be encouraged to communicate if they so wish.

An individual's human value does not diminish with his or her inability to communicate; he or she is more than flesh and blood and deserve honor and respect. Improving the end of life care especially spiritual care is certainly deeply rooted in Scripture. Unfortunately, "too many Americans die unnecessarily bad deaths – deaths with inadequate palliative support, inadequate compassion and inadequate human presence and witness. Deaths preceded by a dying marked by fear, anxiety, loneliness and isolation."¹ Many also die without the access or provision of spiritual services.

Advocates who work to improve care for dying patients try to determine what is necessary for a good death to take place. Some of the necessary elements for a good death to occur are (1) pain management, (2) adequate preparation for death, (3) strengthening relationships with loved ones, (4) clear communications about important decisions, (5) affirming the worth of the patient, (6) not being alone, and last but not least (7) finding a spiritual or emotional sense of completion.² Some dying patients may choose hospice care. While hospice care is a holistic approach that brings doctors, nurses, social workers, and other professionals as part of the care team, it also involves spiritual services performed by a chaplain. The chaplain's services extend beyond the death of the patient to cover grief-counseling services to family and loved ones.

Some of the most common symptoms in a dying patient are difficulty breathing, pain, and depression.³ The treatment of pain with drugs can become an addiction but in the case of actively

1. Jennings B, Rundes T., D'Onofrio C, et al. "Access to Hospice Care: Expanding Boundaries, Overcoming Barriers," *The Hastings Center Report*, 2003: 33(2): S3-4.

2. Steihauser KE, Clipp EC, McNeilly M., et al. "In Search of a Good Death: Observations of Patients, Families and Providers," *Anal of Internal Medicine* 2000: 132:825-832.
Singer PA, Martin DK, KelnerM. "Quality End of Life Care: Patient's Perspectives," *Journal of the American Medical Association* 281 (1999): 163-168.

3. LaDuke S. "Terminal Dyspnea & Palliative Care," *American Journal of Nursing*. 101(11): 26-31.

dying patients like those with Alzheimer's disease, this is mute. Some dying patients or their families may choose non-drug treatments for pain relief. This includes hypnosis, massage therapy or aromatherapy.⁴ Understanding the process of death and dying and the need to provide medication as and when required is an important component of holistic care. It is necessary to know this even though the focus of this paper is on moral and theological reasons to provide pastoral care to non-cognitive persons. Sometimes Jesus healed by a touch or word and sometimes it involved a poultice of clay (Mark 7:33; John 9:6).

What is interesting about Alzheimer's disease is that although the left hemisphere of the brain cells are damaged and cause memory loss relating to recent events, many emotions continues to exist. This is because behavioral functions like sense of humor, awareness, and response to sensory stimuli and appreciation for music precipitate from the right hemisphere of the brain, which is least affected. Some of these emotions can be fostered to enhance dignity and self worth.⁵

In the late stages of the disease, extra care and precautions are necessary. At this stage, the person is usually unable to walk and bed confinement has complications of its own. The skin can break and pressure sores could begin to form. It is important to change the person's position every two hours to relieve pressure and improve blood circulation. One must be very careful in lifting or moving an individual and there is a specialized way to do it. Bony areas have little flesh to protect them and pillows can be used to reduce the possibility of injury. When a person is confined to a wheelchair or bed, freezing of joints can occur. Moving the individual's arms and legs two or three times a day is helpful.

4. Weiss SC, et al. Understanding the Experience of Pain in Terminally Ill Patients. *Lancet*, 357(96265) (2001):1311-5.

5. Judith McCann-Beranger. *A Caregiver's Guide for Alzheimer Disease and Other Dementias*. (Charlottetown, PEI: 2000), 2.

Food and fluids are necessary to keep the individual healthy. However, a person with late stage Alzheimer's might have difficulty swallowing and if food gets into the airway or lungs, it can develop into pneumonia. It is important not to rush the individual into eating. Smaller snacks throughout the day are preferable than few big meals. When the individual is eating, posture must be upright and must remain so for up to thirty minutes after completion of the meal. When a person has difficulty feeding them self, assistance must be provided. Oftentimes persons with Alzheimer's forget to chew or swallow and would have to be reminded. Eating translates into bowel and bladder movements and at the late stage, most patients are incontinent. Proper diapering and cleaning is necessary to maintain good health and personal hygiene of the individual. It would be wise to limit liquids before bedtime. Adult briefs and bed pads at night can serve as a backup to the daytime toileting schedule.

Late stage patients are prone to infection and pneumonia. Good oral health reduces the risk of bacteria in the mouth. The lungs can get affected with bacteria from the mouth, which in turn will result in pneumonia. A soft bristle toothbrush is preferable and brushing teeth at a minimum of once a day is essential. Cuts and scrapes, open wounds or sores are best treated with antibiotic ointment. Obviously, if the injury is of concern professional help must be sought. If the patient exhibits sudden change in behavior, it could be a result of pain. Dry and pale gums, mouth sores, swelling or flushed skin can indicate illness or pain. They may even groan when having pain. Paying attention to non-verbal signs and facial expressions are clues to how they may be feeling.

Alzheimer's patients in the late stages experience the world through their senses. When verbal communication diminishes or completely ceases, "touch" can be a powerful connector. Holding their hands, legs or feet, or gently kissing them can be a powerful way to show love and

add value to their lives. Combing the hair of the patient is another way to reassure them of presence and oneness. If possible, it would help to have them taken outside to feel the breeze, enjoy sunlight and watch nature and things like birds. Pets and young children are very helpful to bring joy to an Alzheimer's patient. Playing music that was appreciated by the individual and sharing old photographs and personal items that trigger memory are some things that can help them feel loved and happy.

Geriatric Studies and Gerontology: Healthcare of Older People

Although Alzheimer's disease is characterized by loss of brain function and consequently memory loss, this is not its complete story. As a result of aging, Alzheimer's patients develop other complications that are concurrent with the disease which directly affect their quality of life. In order to properly care for Alzheimer's patients and provide meaningful spiritual services for them, it is imperative that all caregivers fully understand every facet and struggle of the individual being cared for. These individuals do not choose the disease, rather it comes to them, and the better understood they are, the better they can be cared for. It may be difficult to present the gospel to someone in extreme pain or other health complications without taking care of their physical needs first. Jesus presented the gospel but also took time to have the 5000 or more sit down and have a meal (Matt. 14:14 cf).

The American Geriatrics Society (AGS) is a not-for-profit organization of over 6,000 health professionals devoted to improving the health, independence and quality of life of all older people. Among others, the society has provided leadership and research in the areas of dementia patients and specifically related to healthy aging and the prevention and diagnosis of certain conditions to which they are prone. Geriatric studies have helped healthcare professions and care givers to better understand some psychotic disorders and neuropsychiatric symptoms

found in dementia patients so that quality of life can be enhanced.⁶ Some of the findings of the American Geriatrics Society are enumerated below.

About 20% of Alzheimer's patients have psychotic symptoms that include delusions and hallucinations. Some of these delusions cause them to steal things. Others attempt to misbehave with the opposite sex. There are prescription drugs to help mitigate these issues but medication for behavioral disturbances in dementia is of limited efficacy. Individuals who have behavioral disturbances or neuropsychiatric symptoms (NPS) might need to be placed in a nursing home without which the stress and ability to deal with these issues might be too hard on the caregiver. Psychoactive medication to treat NPS may need to be continued indefinitely.

All antipsychotic agents carry an FDA warning regarding increased mortality in patients but despite these warnings, medications may be needed for treatment of distressing symptoms with significant behavioral disturbances. Similarly, up to 40% of Alzheimer's patients may have depressive symptoms some of which could have preceded the onset of Alzheimer's. Depression occurs more often to those with Alzheimer's disease than with control populations.⁷ Signs of depression include sadness, isolation, loss of interest in activities, anxiety, and, in some cases, the patient might even stop eating. Depression could accelerate decline if left untreated. Not all forms of depression require medication. Some can be treated through recreational programs and activities.

Agitation or aggression is seen in up to 80% of patients with Alzheimer's disease which again is a leading cause of nursing home admission. Certain behaviors are not only harmful to

6. American Geriatrics Society. "Guide to the management of psychotic disorders and neuropsychiatric symptoms of dementia in older adults," http://dementia.americangeriatrics.org/GeriPsych_index.php (accessed January 16, 2012).

7. David Snowden. *Aging with Grace: What the Nun Study Teaches Us About Leading Longer, Healthier and More Meaningful Lives* (New York: Bantam Books, 2001), 47.

others but harmful to the patient too. Apathy is of high prevalence throughout the disease process. In as far as possible, physical restraint in any form should be avoided. Traditional practice of medicine focuses primarily on curing illnesses and healing injuries in which symptom relief is of a secondary focus.⁸ Consequently, many curative treatments for terminal illnesses do not relieve physical, emotional, spiritual or psychological suffering at all.

Pain Management is an important component of healthcare of older people. Some refer to this as “comfort care” that helps enhance quality of life. Symptom relief is managed by drugs, which soothe anxiety and encourage rest. Questions about the importance of treating symptoms, the value of individual autonomy and fears of addiction to narcotics all play a role in how people view pain management.⁹ Physicians are sometimes wary of legal and criminal scrutiny and punishment from prescribing narcotics excessively or to the wrong person.¹⁰ Morphine is particularly good at relieving the two most common symptoms experienced by dying patients, which are pain and shortness of breath.¹¹

Gerontological studies mainly deal with the enhancing the quality of life in older people. In the context of dementia patients, they are housed in a variety of different settings. Some remain at home while others are at residential care, assisted living, or nursing facilities. Because of this diversity, the issues of quality of life and care provided in each one of them could vary greatly. At present, no federal regulatory oversight of assisted living facilities exists. Findings

8. Ruddick W. “Do Doctors Undertreat Pain?” *Bioethics*, 11(3-4) (1997):246-55.

9. Chrystal-Frances E. “Palliative care: A discussion of Management and Ethical Issues (Said Another Way),” *Nursing Forum*, 38(2) (2003): 25-29.

10. Fleming DA. “Relieving Pain: What are today’s ethical and legal risks?” *Missouri Medicine*, 99(10) (2002): 560-565.

11. U.S. Drug Enforcement Administration, <http://www.usdoj.gov/dea/concern/narcotics.html> (accessed December 30, 2011).

from some research done in institutionalized facilities indicate that between 50 to 60% of residents with dementia display behavioral symptoms and low food and fluid intake. 20 to 25% exhibit depression or pain and 14% have high mobility limitations.¹²

Agitation, aggression, depression, apathy, and irritability are significantly associated with a lower quality of life. Agitation or aggression is the strongest predictor of quality of life surpassing the influence of demographic covariates and other neuropsychiatric symptoms. However, findings show that smaller facilities are better able to handle symptoms of agitation that can help to mitigate this quality of life issue.¹³ Nevertheless, the point is that caring for the physical needs of an individual is as important as the spiritual. The bible teaches this principle as an important aspect of holistic care. Clothing the naked, feeding the poor and healing the sick are fundamental teachings of Christology.

In terms of caring for its citizens, the United States Government may be finally waking up and rising to the occasion in as far as helping Alzheimer's patients. Following is an excerpt of a recent news article:

The NIH currently spends \$450 million a year on Alzheimer's research. In his budget proposal to be released next week, President Barack Obama will ask Congress for \$80 million in new money for Alzheimer's research next year. The move is part of the administration's development of the first National Alzheimer's Plan, a congressionally-ordered strategy that will combine research toward better dementia treatments with steps to help overwhelmed families to better cope today. In addition to biomedical research, the administration said it will propose spending \$26 million for other goals of the still-to-be-finalized plan, including caregiver support. "We can't wait to act," Health and Human

12. Sheryl Zimmerman, Philip Sloane et al. Introduction: Dementia Care and Quality of Life in Assisted Living and Nursing Homes. *The Gerontologist*. Vol. 45. Special issue 1. 2005: 7

13. Quincy Samus, Adam Rosenblatt et al. The Association of Neuropsychiatric symptoms and Environment with Quality of Life in Assisted Living Residents with Dementia. *The Gerontologist*. Vol. 45. Special issue 1. 2005: 24

Services Secretary Kathleen Sebelius said in a statement. "Reducing the burden of Alzheimer's disease on patients and their families is an urgent national priority."¹⁴

There may be plenty of hope for those who may be prone to Alzheimer's disease. New research has found clues in the way the disease may spread in the brain. Treatment done on mice is very promising.¹⁵ This discovery could lead to new treatments to stop the spreading of Alzheimer's.

The Loss of Self

In the case of an Alzheimer's patient, the sense of personal identity and memories that shaped an individual is gradually swallowed up in a sea of forgetfulness. This is described as loss of self.¹⁶ Kathleen Fischer said, "Memory enables us to hold fast to our identity and shape it in new ways."¹⁷ Memories remind an individual of their life history and what they have accomplished. Who and what they are is associated to events in their lives. Without memory, there is a loss of self. Memory loss is a loss of self-history and thus a loss of self-identity. Alzheimer's is a mind-altering disease, which impairs intellectual function that comes about with dying brain cells. Some of these declines can be fought by maintaining a person's interests in meaningful ways through physical messages of love, support, compassion, and reassurance.

The declining ability of Alzheimer patients to communicate with others about the present and its relationship to the past has led others to hypothesize an internal loss of self. Cohen and

14. Madhani, Aamer, "Obama to increase Alzheimer's research funding." *USA Today*, February 7, 2012, under "The Oval: Tracking the Obama Presidency," <http://content.usatoday.com/communities/theoval/post/2012/02/obama-alzheimers-research/1> (accessed February 16, 2012).

15. Jasglow, Ryan, "Alzheimer's disease "jumps" across brain cells to spread," *CBS News*, February 2, 2012, under "Health Pop," http://www.cbsnews.com/8301-504763_162-57370328-10391704/alzheimers-disease-jumps-across-brain-cells-to-spread?tag=currentVideoInfo;videoMetaInfo (accessed February 16, 2012).

16. Cohen D and Eisdorfer, C. *The Loss of Self*. (New York: W.W. Norton, 1986).

17. Kathleen Fischer. *Winter Grace* (New York: Paulist Press, 1985), 34.

Eisdorfer suggest that the victim of Alzheimer's disease must eventually come to terms with the complete loss of self.¹⁸ Post refers to dementia as an agonizing deterioration of the self in which the very substratum of the self with respect to identity and coherence is on the path toward radical disintegration.¹⁹ While the loss of self is nonexistent in early stages of the disease, its existence is very pronounced in the late stages as the brain continues to progressively degenerate. Memory loss, absence of verbal communication and non-cognition is seen by some as a kind of death and thus Alzheimer's is also commonly referred to as "the never ending funeral."

The loss of memory is compounded with the inability of Alzheimer's patients to care for them self. Their dependence and need to be fed, bathed, clothed, transported, and diapered also contributes to the loss of self. About 70% of the left hemisphere of the brain that facilitates recent memory gets damaged incapacitating the individual from living in the present.²⁰ All aspects of the individual's life, including spirituality, are altered. A deep sense of loneliness sets in, which could lead into depression. This alteration of self and spirituality affects relationships, and how they perceive the world and God. Clearly, the loss of memory results in loss of self and any related notion of self-fulfillment causing the feeling of an apparent human disintegration.²¹

Kitwood argues that cognitive impairment does not diminish personhood, which is a status that is bestowed upon one human being by others in the context of relationship and social being.²² This contradicts everything that was said in the preceding couple of paragraphs and the

18. Cohen, D., & Eisdorfer, C. *The Loss of Self*. (New York: W.W. Norton & Co., 1986).

19. Post, S.G, To care but never to prolong? *Caring Magazine*. June 1992:42.

20. *Alzheimer's Care Guide* (Reno, NV: Eymann Publishers). March 1997: 1

21. David Keck, *Forgetting Whose We Are* (Nashville: Abingdon Press, 1996), 21.

22. Kitwood, T. *Dementia reconsidered: The person comes first*. (Buckingham: Open University Press. 1997), 8.

personal experience of this author. Cognitive decline does contribute to loss of self without the interference of anyone. Whether the loss of self is total or partial is something that could be debated. Kitwood contends that the more serious threat is the relational impairment that occurs when individuals are deprived of meaningful interaction with others.²³

The absence of first person pronouns in the conversations with dementia patients suggest that self-identities may be compromised. Also, the absence of first person plural forms indicates that they do not seek to have an opportunity to combine their selves with the selves of others.²⁴ Caregivers can help preserve the persona of residents by calling them by name and reconstructing their preferred persona by helping them use first person pronouns and first person plural forms. Unfortunately caregivers do not know this. Many of them loose hope and spouses of dementia patients are often heard saying things like “this is not the man or woman I married” or “he or she just stares at me for hours on end without saying a word.” To compound the problem, speech in the later stages of the disease has been described as senseless and without meaning contributing to the impression of a diminishing self:²⁵ However, not everyone has the same experiences and it is partly due to do the stage of the disease.

But the idea of losing your sense of self as you lose your memory doesn't really fit with much of what I've observed. Even as my father lost his memories, he kept his sense of humor, his sense of rhythm and melody, and his sense of right and wrong. Even as he lost track of his exact relationship with friends and family, he kept his sense of love for all of us. I would argue that he never lost his sense of self. “Loss of self” is baloney,” says Don

23. Kitwood, T. “Toward a theory of dementia care: Ethics and interaction,” *Journal of Clinical Ethics* 9 (1998): 23-24.

24. Jeff A Small, Kathy Geldart, Gloria Gutman and Mary Scott. “The discourse of self in dementia,” *Aging and Society*, 18 (1998): 309

25. Bohling H.R. “Communication with Alzheimer’s patients: An analysis of caregiver listening patters,” *International Journal of Aging and Human Development*. 33(4):1991: 249-267.

Moyer, voicing an opinion shared by many with mild to moderate dementia. “There is always a self, and there is always a bridge to that self.”²⁶

Don Moyer’s experience of his father is unique and the perception of a dementia patient has much to do with how well they are understood. This is where non-verbal communication is important to recognize and practice beside other unique ways to communicate as discussed later in this paper.

The principles of person-centered care toward Alzheimer patients are to recognize them as human and spiritual beings of great value. Despite the extent of their disease, and loss of self, they are still able to communicate their wishes and feelings. Kontos suggests looking beyond what persons say about what they experience to how they use non verbal bodily and expressive behavior (embodied selfhood) in significant ways to remain connected to the world.”²⁷

Ethical and Moral Issues

The two most important aspects of end of life care are respecting life and accepting death. Respecting life would mean that every individual has immense value and there should not be any human involvement to bring about or hasten death. Accepting death means one has to prepare properly for it. Individuals must be provided with the choice of making decisions about their care and treatment (Advance Directives). In the case of Alzheimer’s patients, this would have to be in the early stages. People with Alzheimer’s have the legal right to limit or forgo medical or life-sustaining treatment, including the use of mechanical ventilators, cardiopulmonary resuscitation, antibiotics and artificial nutrition, and hydration. Advance Directives include patients’ wishes

26. Moyer, Don. “The Tangled Neuron: Does Memory Loss Mean Loss of Self?,” *Tangled Neuron*, 2007, under “Info,” http://www.tangledneuron.info/the_tangled_neuron/2007/11/does-memory-loss.html (accessed February 17, 2012).

27. P.C. Kontos. “Embodied selfhood in Alzheimer’s disease: Rethinking person centered care,” *Dementia*, 4 (2005): 553-570.

P.C. Kontos. “The painterly hand: Embodied consciousness and Alzheimer’s disease,” *Journal of Aging Studies* 17 (2003): 151-170.

regarding medical care, organ donation, feeding tubes, and designating a POA to make health care decisions. Treatment decisions should not be made on behalf of a competent patient.

However, it may be important to include close family members in significant decisions unless the patient chooses not to involve them.

While Advanced Directives respect individual choice and autonomy, it also raises ethical concerns, which include the following:²⁸

- Advance directives may improperly influence healthcare providers to limit care leading to under treatment.
- A person frightened of becoming disabled or incapacitated may use advance directives to limit treatment which in reality a person cannot know in advance his or her ability to cope and adapt to living with a disability.
- Advance directives are time consuming for health professionals and may not be useful if a medical treatment decision requires an immediate answer even if a healthcare decision maker has been named.

Advance directives may provide patients with peace of mind to the extent that patients may be comforted knowing that difficult decisions have already been made in the event they become unable to communicate. They may gain peace from knowing that the advance directive may prevent or minimize disagreement among family and loved ones. It can help alleviate guilt on the part of a decision maker who may have a difficult time making hard decisions while being emotionally attached to the individual at the same time.

The need for nutrition and hydration may decline in the last few days of life but is something that should not be denied to patients. If there are risks associated with swallowing, clinically assisted nutrition and hydration (tube feeding) is a realistic solution. Chaplains should exercise discretion and be very careful when administering Holy Communion because a patient can choke on bread and wine. Another question to be addressed is whether it is right to sedate people towards the end of life to combat pain or behavior issues. The philosophy of Palliative

28. Stein J. "The Ethics of Advance Directives: A rehabilitation Perspective," *American Journal of Physical Medicine & Rehabilitation*, 82(2) (2003):152-157.

care is to relieve symptoms of distress and pain with medication and sedatives. The author believes that when a patient is in pain or distress such treatment may be appropriate so long as it is not over medicated. Some Alzheimer's patients do suffer from a lot of pain.

One of the biggest ethical questions is about whether it is right to withdraw or withhold treatment that could prolong life. This might include the option of DNR (Do not resuscitate). This is a personal decision that would need to be made only by the individual or when not able to do so by the one who has been given the authority. From a Christian point of view, this must involve prayer and discernment of the Holy Spirit. Similarly prolonging the life of someone endlessly who would die without life support may not be a right decision unless there is some value or benefit. To the knowledge of this author, there is no scriptural support to prolong life through mechanical ventilation. The United States Supreme Court ruled in 1990 that artificial nutrition and hydration are not different from other life sustaining treatments.²⁹ The Courts also ruled that competent adults may refuse artificial nutrition and hydration treatments and surrogate decision makers may withdraw artificial nutrition and hydration on behalf of an incompetent adult.³⁰

Taking care of someone with Dementia can be extremely hard and emotionally draining. In the vocation of Hospice Chaplain, this author has occasionally come across members of family who cannot wait to welcome death. This is especially true when the sick individual had not been a "good" father or mother or in instances of unresolved conflicts. Sometimes it is because of total physical and emotional exhaustion on the part of the caregiver. Now it is important for the pastor to provide spiritual care for both the patient and the family. The goal

29. *Cruzan v. Director, Missouri Department of Health*, 110 S. Ct. 2841 (1990).

30. *Bouvia v. Superior Court*. 179 Cal. App. 3d 1127, 255 Cal. Rptr. 297 (Ct. App.), review denied (June 5, 1986).

Brophy v. New England Sinai Hospital. 398 Mass. 417, 497 N.E. 2d 626 (1986).

should be to bring about reconciliation and foster an environment of forgiveness and love. One cannot hate brother or sister, or father or mother and claim to love God at the same time (John 2:9 cf).

Therefore, maintaining the dignity of a dying patient is significant and a moral responsibility. Keeping patients clean and the space around them neat and tidy can add to ones sense of dignity. Mouth care and deodorant is important too. Taking time to comb a patient's hair not only helps a patient to feel better but also restores self-worth and dignity. Physical touch and holding the individual's hand may say more than a thousand empty words. This author has been able to express and share the love of Christ far more often through touch than with words. If the patient is in an institutionalized setting it might be a good idea to decorate the room as if it were the individual's own home. Pictures and personal artifacts should be visible and available to the patient. Some patients might need personal items beside them like a rosary or bible. They must be afforded privacy when bathed, dressed or changed after a bowel movement. As much as possible, they should be visited frequently and remembered on important days like their birthday or mother's day, and so on.

Some ethical issues may arise as it gets closer to the end of life. These could involve the choice of Hospice or Palliative Care. Hospice is a holistic and philosophical approach to care that involves doctors, nurses, social workers and chaplains who work as a care team. The goal of hospice is to make the patient as comfortable as possible during the patient's final days on earth. Hospice emphasizes pain control, symptom management, natural death and quality of life to comfort the patient's physical body.³¹ Hospice provides service at home, a nursing home, assisted living facility, hospital or hospice facility. The Hospice team provides medical care, emotional

31. The National Hospice and Palliative Care Organization, www.nhpco.org (accessed February 12, 2011).

and spiritual support, social services, nutrition counseling and grief counseling for both the patient and caregiver.

Palliative care works towards relief of symptoms. It focuses on achieving the best possible quality of life for a patient by emphasizing total and comprehensive care for all a patients needs including pain and symptom management, spiritual, social, psychological and emotional wellbeing.³² Palliative care is very similar to hospice care except that it is not restricted to patients near the end of life. To be on Hospice, one must have a prognosis of six months or less to live and two Medical Doctors have to attest to this fact. Both Hospice and Palliative Care have interdisciplinary teams.

Some ethical issues arise even after death. These may relate to organ donation, conducting an autopsy to determine cause of death for research and education, or for practicing medical procedures by medical students. Respecting the dignity of the deceased versus the value of practicing procedures for medical students is at stake in such decisions. The American Medical Association recommends that because practice with deceased bodies is valuable to students, training should be performed with dignity and permission from the family and in a structured and closely supervised environment.³³

32. World Health Organization, <http://www.who.int/cancer/palliative/en/> (accessed December 30, 2011).

33. Council on Ethical and Judicial Affairs of the American Medical Association. "Performing procedures on the newly deceased," *Academic Medicine*. 2002; 77(12 Pt. 1):1212-1216.

CHAPTER FOUR

HOW DOES THE WORLD PERCEIVE THEM?

History, Tradition and Culture

The history, tradition, and culture of every nation are vastly different. How people relate to each other is conditioned by these factors. In general, the western world, and especially those in the United States, adopts an individualistic outlook in which care about what matters to self is paramount over values or outcomes. “If it feels good, do it” is the motto of many. This kind of idea advances in the postmodern culture. Traditional values no longer form the framework or foundations of one’s thinking. In her book *Smoke on the Mountain*, Joy Davidman talks about how old and sick people are considered to be an encumbrance in the modern home: “Once they were lovingly cared for but now they lead Grandpa gently but firmly to the local asylum, there to tuck him out of sight and out of mind as a case of senile dementia.”¹ Taking care of the elderly especially when they are sick is considered burdensome and an inconvenience to many in western cultures.

This attitude does affect how non-cognitive persons are cared for. The elderly deserve much respect and love but they do not always get it. This author observed a strong reluctance on the part of the African American Community to place their loved ones in institutionalized care. Despite the immense struggles in caring for someone with Alzheimer’s, the preference is to keep him or her at home. They rather see their loved one spend his or her last days in their own home than pass them off to an institution relieving them of the burden. For them it is more a matter of dignity and honor.

1. Joy Davidman. *Smoke on the Mountain* (London: Hodder & Stoughton), 58.

VandeCreek says, “Our cognitively oriented culture finds it easy to forget forgetful persons. Some believe that persons with dementia need little or no pastoral care.”²Our legal system is not sympathetic towards non-cognitive persons either. In the eyes of the law, an individual ceases to be regarded as a full person when a legal definition of incompetence is made. As the disease progresses and in the absence of being able to have a meaningful conversation including the issue of impaired judgment, courts cease to recognize these persons as relevant and so they appoint a legal guardian. Their driving privileges are taken away including their ability to make choices.

As a matter of perspective, it is interesting to see how other countries look at an Alzheimer’s patient. A recent article published in the *New York Times* tells of how South Korea has opened a “War on Dementia” and how children are trained and taught to help people with dementia. South Koreans worry that the growing percentage of dementia sufferers could dilute respect for elders and that even the most filial son or daughter will not be filial if they look after a parent for more than three years:

South Korea is training thousands of people, including children, as “dementia supporters,” to recognize symptoms and care for patients. The 11 to 13 year-olds, for instance, were in the government’s “Aging-Friendly Comprehensive Experience Hall” outside Seoul. Besides the aging simulation exercise, they viewed a PowerPoint presentation defining dementia and were trained, in the hall’s Dementia Experience Center, to perform hand massage in nursing homes³.

South Korea is also pushing to make early diagnoses of Alzheimer’s. Hundreds of diagnostic centers have been created and care is heavily subsidized. Numerous nursing homes are being built all over the country to care for the aging population.

2. Larry VandeCreek, *Spiritual Care for Persons With Dementia* (Binghamton, NY: The Haworth Pastoral Press, 1999), xi.

3. Pam Belluck, “Children Ease Alzheimer’s in Land of Aging,” *New York Times*, November 25, 2010.

This author spent most of his early years in India where his father served as an Officer in the British Army. To the best of his knowledge, the culture will never support a hospice or palliative care type of service and there is none present at this time. Unless an elderly individual requires hospitalization, they are kept at home. The whole family provides and cares for the elderly. There are no senior communities or over 55 neighborhoods. The community will ostracize any family who neglects to care for their elderly. In fact, it is not uncommon for neighbors to offer help as well. The elderly are deeply respected and honored, irrespective of whether they are cognitive or not.

Tradition, culture, and society in any part of the world cannot avoid the reality of death but not everyone is able to deal with it. Communicating with one another and expressing oneself is less formal in the eastern part of the world than in the west. We live in a very sensitive and perhaps guarded individualistic society so much so that many people, including clergy, do not know how to start talking about spirituality or spiritual distress. There is a sense of hesitation to broach a personal topic like faith for fear of being disrespectful or upsetting someone. One way to overcome this is to begin to know people, build some trust, and let them know you love them and are on their side. Not every Alzheimer's patient believes in a God. Not everyone believes in a Christian God. Although the United States is considered a "Christian Nation," there are numerous other faith groups in this country. Referring an individual to the Spiritual Leader of their respective faith group is a good gesture and ethical protocol.

Cultural differences can affect communication with the dying. Many cultures do not support the idea of full disclosure when it comes to illness while some want disclosure to family members alone. In Russia, physicians are likely to make full disclosure about a terminal illness

to the patient's family who will then decide what to tell the patient about his or her condition.⁴ The same is the case with Asian Indians. The point is that as caregivers, it is important to show sensitivity to culture. The United States is a land of immigrants and anything done to show respect and appreciation helps build healthy bonds.

Dehumanization and Social Death

With the advance of science and modernity, the meaning and understanding of death has been evolving. Death can be defined on a variety of different levels but most people define death as a physical event in which there is a cessation of all bodily functions including beating of the heart. Some in the medical field will broaden this to include "clinical" or "biological" death. The "social death" phrase evolved and relates to those who die in a social sense consequent to degeneration of the brain or disease, which limits interaction with those around them.

The first available presentation of social death came from Glaser and Strauss. During a discussion of "hopelessly comatose" patients, these authors describe their receipt of "non-person" treatment from hospital personnel when talking freely about things that would matter to the conscious patient. They said, "Socially he is already dead, though his body remains biologically alive."⁵ They also describe some "senile patients" as "socially dead as if they were hopelessly comatose" in the eyes of the families who consign them to institutions and thereafter fail to visit.⁶

Society regards mental impairment as a social death in which the person is no more connected to society and is dying a little at a time with no hope for recovery. A persons' true

4. Becker R. "Teaching Communication With the Dying Across Cultural Boundaries," *British Journal of Nursing*, 8 no. 14 (1999): 938-942.

5. Glaser, B.G. and Strauss, A.L., *Awareness of Dying*. (London: Weidenfeld and Nicholson, 1966), 108.

6. Glaser, B.G. and Strauss, A.L., *Awareness of Dying*. (London: Weidenfeld and Nicholson, 1966), 110.

worth in the eyes of God does not change but fellow human beings and the systems of society diminish their worth and devalue them as being socially dead or insignificant while the truth is they have a soul, are relevant and can still have a relationship with God and fellow human beings. Churches have grossly neglected caring for these individuals. In November 1994, former President, Ronald Reagan wrote a letter to the citizens of America announcing that he had Alzheimer's. The disease which was once passed off as a social death suddenly gained prominence and touched the hearts of all Americans. Reagan was a much loved President and as a consequence of him having the disease, it got some much deserved recognition. But the story is forgotten and dilemmas remain including the diminishing and loss of self. Health problems and the inability to care for oneself without help could lead to an ever shrinking external world which might even mean social isolation.

It is important to debate the idea as to whether Alzheimer's patients can be considered socially dead because how they are perceived would directly correspond to how they are cared for and valued in society. A good place to start would be to ask the question, "What it is that makes an individual into a whole person." What is it that would allow one to say that an individual has a worthwhile life or life of value? The perception of social death may have some correlation to anticipatory grief that precedes the impending death of an Alzheimer's patient. What this means is that the caregiver or family member who is in the position of contributing to the social life of the individual might have given up long before exhausting every available opportunity to communicate.

Labeling someone as socially dead is a serious allegation. In essence, it is the end of an individual's social existence. It might even be considered as a self-fulfilling prophecy that could speed up actual physical death. Social death occurs when a patient is treated as a corpse although

he or she is still clinically and biologically alive. For instance, this is much like allowing someone who was brought into a hospital in a near death state to remain on the stretcher overnight for the fear of unnecessarily having to dirty a bed. Those with Alzheimer's are given a pre-death treatment before the arrival of death, which may never even be close. Social death does not always lead to biological death nor is it a definite concept.

As referenced in the introduction section of this paper, although Pat Robertson referred to Alzheimer's patients as socially dead, 100% of the responses received from surveys sent out to Caregivers show otherwise. When specifically asked if those with Alzheimer's are to be considered socially dead, here below are some of the responses received from caregivers:

“Absolutely not; each time my father saw me I could see a twinkle in his sad blue eyes. He did not know my name but he called me pretty”. Another said, “Not at all – we still can enjoy church; sing and he still goes to Sunday school but does not recall anything except the Lords prayer. To the same question, a Hospice Medical Director writes “No, because they are still relational to the family to which they belong. They interact with loved ones even until death.”

Another Doctor who specializes in geriatrics notes, “In those with advanced dementia though the interaction/conversation may be basic or repetitive, they can still interact and thus are not socially dead.” A palliative care doctor said, “I believe they are far from socially dead. Although they may not be able to verbalize, they do communicate in other ways – why can't people see it?”

Self-perceived social death occurs when an individual accepts the notion that he or she is as good as dead. When a patient is given a terminal diagnosis, it can be a cause to precipitate such thought. Kastenbaum says “Social death must be defined situationally. In particular, it is a situation in which there is absence of those behaviors which we would expect to be directed toward a living person and the presence of behaviors we would expect when dealing with a

deceased or non-existent person.”⁷ Thus, although an individual may be potentially responsive and desperately seeking recognition and interaction, that individual will by this definition be socially dead if others cease to acknowledge his or her continued existence. Consequently, it is paramount to get this right. Non-cognitive persons should never be looked upon as those who cease to have continued existence.

Institutionalization of the Patient

Historically, nursing homes have been the primary setting for the institutional care of older adults. However, during the last decade their prominence in providing care for individuals who do not need medical services has been challenged by the growth of residential care and assisted living facilities.⁸ Estimates indicate that about 30% of residents in residential care or assisted living facilities have moderate or severe dementia as opposed to more than 50% in nursing homes.⁹ Residential care and assisted living facilities are cheaper than a nursing home but may not work for those who require close medical supervision.

As discussed elsewhere in this paper, certain cultures (especially those in the east) are opposed to institutional care. They do not believe the atmosphere or quality of care provided at an institution can match what a family can do for their loved ones. The lack of personalization and emotional involvement in the patient is one of the biggest factors. This author has observed such a feeling among the African American community in the United States. “Many studies have sought to determine the predictors of institutionalization of patients with dementia. Such studies,

7. Kastenbaum R.J. *Death, Society and Human Experience*. (St. Louis: C.V. Mosby co., 1977), 31

8. Sheryl Zimmerman, Philip Sloane et al. “Introduction: Dementia Care and Quality of Life in Assisted Living and Nursing Homes,” *The Gerontologist* 45. Special issue 1 (2005): 5-7

9. Sheryl Zimmerman, Gruber Baldini et al. “Assisted Living and Nursing Homes: Apples and Oranges?,” *The Gerontologist* 43 (2003): 107-117.

performed in developed western societies, have come to various conclusions which may not be supported in an East Asian culture such as that found in Korea.”¹⁰

As discussed elsewhere in this paper, certain cultures do not support institutionalized care although these might be considered a necessity elsewhere. For instance, “Latina dementia caregivers delay institutionalization significantly longer than female Caucasian caregivers. In addition, Latino cultural values and positive views of the care giving role are important factors that may significantly influence their decision to institutionalize loved ones with dementia.”¹¹

Individuals who are in the early to mid stages of the disease have fewer needs. Most of them are able to walk with minimal assistance and do not have to deal with issues of incontinence or inability to feed or cloth themselves. Medical complications are usually far less and with verbal communication they are better understood and more easily cared for. The dynamics change with issues of anger, agitation, or when neuropsychiatric and psychotic symptoms develop. Controlling some of these would require medication or physical restraints such as strapping them down to the bed or wheel chair. These are very challenging to manage within the setting of a private home. Incontinence and troublesome behaviors predict institutionalization in dementia.¹²

Marital status and availability of caregivers with the family do play a role in decisions for or against institutional care. Unmarried individuals having increased functional impairments and

10. Jae-Min Kim, Ill-Seon Shin, Seong-Joo Jeong et al. “Predictors of institutionalization in patients with dementia in Korea,” *International Journal of Geriatric Psychiatry* 17. 2 (February 2002): 101-106.

11. National Center for Biotechnology Information, U.S. National Library of Medicine. “Ethnicity and time to institutionalization of dementia patients: a comparison of Latina and Caucasian female family caregivers,” <http://www.ncbi.nlm.nih.gov/pubmed/15209644> (accessed December 18, 2012).

12. Brian O’Donnell, Heather Barnes, Karen Peterson et. Al. “Incontinence and troublesome behaviors predict institutionalization in dementia,” *Journal of Geriatric Psychiatry and Neurology* 5 no.1 (Jan/March 1992): 45-52

decreased cognitive integrity are more likely to be placed in an institutional setting.¹³ When problems begin to multiply and frequent hospitalizations become necessary family and caregivers are more accepting of institutionalized care. In most cases, death comes from causes other than Alzheimer's. Pneumonia and management of pain is better addressed under close medical supervision. The same would be the case with wounds and pressure sores. Tube feeding if necessary would be difficult to administer or monitor within the setting of a home without the help of professionals.

Caring for the physical need of a dementia patient is as important as the spiritual and psychological. Most of the responses from questionnaire sent out to caregivers indicate in one form or another that they wanted the "best" for their loved ones. Some indicated that they did this in gratitude for what their loved one had already done for them prior to the debilitating disease. In fact, caregivers spend plenty of time and energy to provide the best but are limited with resources and equipment. "The transition to institutional care is particularly difficult for spouses, almost half of whom visit the patient daily and continue to provide help with physical care during their visits. Clinical interventions that better prepare the caregiver for a placement transition and treat their depression and anxiety following placement may be of great benefit to these individuals."¹⁴ While the goal is to enhance the quality of life, this may be difficult to do especially towards the end stages of the disease. A basic need would be a hospital bed but more importantly close medical supervision both of which are available within an institutionalized setting.

13. Mary Severson, Glenn Smith, Eric Tangalos, Ronald Petersen, et al. "Patterns and predictors of institutionalization in community-based dementia patients," *Journal of the American Geriatrics Society* 42(2), (Feb 1994): 181-185.

14. Schulz R, Belle SH, Czaja SJ, McGinnis KA, Stevens A, Zhang S., "Long-term care placement of dementia patients and caregiver health and well-being," *Journal of the American Medical Association* 292, no. 8 (August 2004): 961-967.

Obviously institutional care can be expensive, but it has advantages. For example, most of them have large areas designated for worship with excellent lighting and acoustics. Mass and Holy Communion are usually celebrated in house on the Lord's Day. Restrooms meet ADA specifications and the numerous staff available for housekeeping and personal care takes a big load of the caregiver who at that point would mostly be dealing with the emotional aspect. Pastoral care is more accessible at institutions as well as nursing and social services. Dieticians and Physicians visit regularly to monitor the patients. Volunteers frequently visit institutions providing auxiliary services. Medicines and supplies are always readily available and so are ambulatory services. Most institutions especially skilled nursing facilities have physical therapy equipment and professionals to help. All institutional settings are secure. A patient cannot just wander away.

Changing the Negative Perception

The plight of demented individuals will not get better unless the perception of them changes. They are people of great worth who are made in the image of God. Providing pastoral care to them should be seen as a calling and obedience to God's invitation to love and care for the least of these. Unless the theological reasons are properly understood, neither the Church nor Clergy will change their perception of these persons. Sapp rebukes those who believe soul encounter with God is not possible for those who have Alzheimer's with these words: "the view that God no longer relates to the person with advanced dementia may simply be the imposition of post-Enlightenment psychology onto the person with Alzheimer's disease?"¹⁵ "I will never leave thee nor forsake thee" (Heb. 13:4) is not a conditional promise. Psalm 103 speaks of a God who

15. Stephen Sapp, "Memory: The Community Looks Forward," In *God Never Forgets*, ed. Donald McKim. (Louisville: Westminster John Knox Press, 1997), 38-54.

redeems life from destruction.

Pastoral care is like being a shepherd of sheep in which the shepherd should be willing to leave the ninety nine who are whole and reach out to the one who is lost (Luke 15:4). In bringing this shepherding care analogy to those with Alzheimer's, Ellor identifies a critical starting point: "The first principle of working with a person who has Alzheimer's disease involves a value, rather than a technique. A person who has this disease is still a person. This person should be valued as a person, albeit a person who has memory loss."¹⁶ The value of an individual should not be associated with cognitive ability or good health; rather the value of an individual emanates from the priceless value of their soul. Providing pastoral care for an Alzheimer's patient is a rare privilege used by God to be a conduit of his blessings.

As mentioned previously, South Korea is doing a magnificent job of changing the negative perception of Alzheimer's. They are building new facilities all over the country that are Alzheimer friendly. Many of these facilities will have outdoor recreation areas where patients can interact with nature. Thousands of people including children are being trained to empathize and care for those with Dementia. Care for these individuals is being heavily subsidized and the children are being made to understand that there is a "blessing" in caring for these marginalized people. These great values can be learned and adapted in the United States.

Research on some nursing homes in the United States indicates there is a low prioritization of spiritual care and a lack of staff preparedness in this area. Staff routinely recorded only residents' religious preferences and sometimes, clergy contacts, dates of

16. James W. Ellor, "Celebrating the Human Spirit." In *God Never Forgets*, ed. Donald K. McKim, 55-71. (Louisville: Westminster John Knox Press. 1997), 13

reception of sacraments, or attendance at religious activities. Admission notes about religious history and past practices often were incomplete and only occasionally noted spiritual care goals were documented but lacked information on what these involved or whether the goals were met.¹⁷

This is contrary to the real needs of the patients who coped better with spiritual services. Actually, residents in advanced stages of dementia who were brought to religiously oriented services and events demonstrated a range of behaviors from nodding, smiling and looking about as opposed to blank stares or sleeping.¹⁸

Unfortunately, Clergy and the community of faith in general have difficulty providing spiritual care for non-cognitive persons because they do not understand degenerative brain diseases of the elderly. Like Pat Robertson, some do not consider them as being alive and valuable. The daughter of an Alzheimer's patient presents a subjective view of religion saying:

She might have forgotten God, but God hasn't forgotten about her. I think clergy, doctors, nurses and aides need a special course on spiritual care of people with dementia. I know that deep down inside there, she knows God's presence. There is no medical understanding of that but inside there must be a place for spirituality that does not rely on the brain. It keeps on working and sometimes there's a breakthrough.¹⁹

Research is necessary to study the problem and dispel this perception. This author has engaged in research that sufficiently supports the value of the soul and the ability to communicate with persons who have Alzheimer's despite the dreaded degenerative brain disease.

17. Bethel Ann Powers & Nancy M. Watson, "Spiritual nurturance and support for nursing home residents with dementia," *Dementia* 10(2011): 74.

18. *Ibid.*, 70.

19. Bethel Ann Powers & Nancy M. Watson, "Spiritual nurturance and support for nursing home residents with dementia," *Dementia* 10 (2011): 66.

Research Methodology

Research was done on all published material between 1990 and 2011 findings of which suggest that demented individuals and especially those in early stages of the disease draw strength, comfort and peace from their relationship with God. Additionally, some questionnaires were sent out to key individuals who were directly involved in the care of dementia patients. The purpose was to gain first hand knowledge about the issues confronting dementia patients and how they might be perceived. Answers to these questions are pivotal to developing a new paradigm of pastoral care for non-cognitive persons.

Three distinctive groups of individuals were targeted to respond to survey questions that were reviewed and approved by Liberty University. This was not just a random study and each of these groups was chosen because of their direct involvement in the care of dementia patients. The first group was Medical Doctors who work either in the area of Palliative Care or those who are associated with Nursing Homes, Hospitals, and Hospice who treat and care for dementia patients. Some of them are Medical Directors of hospice providers.

The second group is Chaplains who work for hospitals and hospice providers that minister to the elderly that include dementia patients. Their experiences and pastoral care methodologies used in the spiritual care of non-cognitive persons are valuable in order to develop a new and effective method of pastoral care. The last group is the caregivers themselves. These individuals, though not professionals, struggle with the everyday care of these precious individuals and literally live with the disease and its consequences. Most of them are members of family. The HIPPA laws prevent dissemination of too much medical information but the data collected is adequate to prove this thesis. However, this resulted in a smaller sampling but the

study is still significant.

Based upon the answers that were received, the consensus is that Dementia patients have been perceived negatively incorrectly. All of the responses from caregivers and most responses from clergy indicate that those with the disease are not socially dead. A similar number indicate that communication with them is possible even until death. One doctor who works in the area of geriatric medicine whose patient population is more than 65 years old said, "The patho physiology of dementia (several types) is poorly understood and brain area involvement is not predictable. So even though some patients may have poor recall and language skills, they may understand better than we think."

When the medical doctors were asked if it might be important to provide spiritual services to a non-cognitive Christian one affirmed the need and wrote "they still have some memories and will often try to sing along to "church songs" despite their advanced disease." Another said, "Yes. The power of religion/prayer in healing is underestimated and patients who may not verbalize or respond to family or friends may behave differently when they hear or see a Chaplain at their bed side." Chaplains were less complimentary of the patient's abilities to want or receive pastoral care and had greater hope in what God can do for him or her.

Role of the Church and Clergy

Pat Robertson does not stand alone in ignorance about the disease process and the ways and means in which one can minister and have a relationship to non-cognitive persons.

Unfortunately, only 26% of ATS theological schools in the United States offer courses in

Gerontology.²⁰ Assuming their enrollment levels were the same and that every graduate chose the course (which is the best scenario), it would still mean seven out of ten seminary students are unequipped to handle such cases along with 100% of those who do not attend a theological school. Given the fact that Alzheimer's is the 6th or 7th leading cause of death in the United States, it shows that faith communities have grossly neglected caring for these individuals. This resembles the story of the Levites and Priests that walked right past the man lying in the ditch on the way to Jericho (Luke 10: 30-36). Are those who lose brain function to be considered as dead?

Even those with degenerative brain disease are needy of spiritual care. They can be helped to connect with God but it cannot be accomplished through traditional cognitive ways of pastoral care. A new paradigm involving use of senses, past memories and symbols would have to be incorporated together with an appreciation for the value of their souls. Bell and Troxel²¹ provide an overview of the spiritual needs of persons with dementia. These include the need to be respected and appreciated, to stay connected and show compassion, to give and to share, and to encourage hope. They offer some ways in which to fulfill spiritual needs, such as celebrating their unique religious heritage including music and nourishing one's own spiritual life in the process of caring for another.

Dementia is a progressive disorder of the mind. It is true that consequent to the damaging and deterioration of brain cells, the patient will have difficulty verbally communicating and recognizing people but they still have an unscarred soul. It is unfortunate but the reality is that

20. Princeton Theological Seminary, *Now Is the Time: The Church's Challenge for Older Adult Ministry* (Princeton, NJ: Princeton Theological Seminary, 2007), 9-10

21. Bell, V., & Troxel, D., "Spirituality and the person with dementia – a view from the field," *Alzheimer's Care Quarterly* 2(2) (2001): 31-45.

“Clergy are seldom present with persons who have dementia unless death is imminent.”²²

Demented patients are vulnerable both physically and spiritually. They are very much like little children. Dementia is human development in reverse. Just as adults feed and clothe their children because they are of great worth and are loved, it is appropriate to treat demented human beings in a like manner.

Research tells us that pastoral care for these individuals is neglected woefully. The neglect is more out of a sense of helplessness than an unwillingness to help.²³ Dementia affects the mind and the body but it cannot destroy the soul. Even though the body may require caring for all functions, the soul remains intact. Tragically, society treats non-cognitive persons as if they have no soul. Every soul is valuable and precious in the sight of God. Just as God loves humanity and expects nothing in return, men and women are to love and care for these persons and expect nothing in return. There is a biblical mandate found in the Ten Commandments to “love our neighbor as ourselves” and to “love one another as Christ loves us” (John 13: 34).

Caring for non-cognitive persons teaches to love as Christ loves. Providing pastoral care affirms them to be valued members of faith and society and helps them connect with God. The level of care provided does relate to how they might be perceived. “If persons with dementia are perceived as persons with souls, then mainline churches have been negligent in their ministry to them. If we value these people as children of God, we must treat them as if they were still able to experience a relationship with God. We must believe that God will speak to even severely

22. Princeton Theological Seminary, *Now Is the Time: The Church's Challenge for Older Adult Ministry* (Princeton, NJ: Princeton Theological Seminary, 2007), 11 (foreword).

23. Larry VandeCreek, *Spiritual Care for Persons with Dementia: Fundamentals for Pastoral Practice* (Binghamton, NY: The Haworth Pastoral Press, 1999), 60.

demented persons if He so chooses.”²⁴As conduits of God’s grace, one can play an active role in providing spiritual care by communicating God’s love for them so they can remember God. This is done through unique forms of communication other than exchanging facts or speaking of current events.

Some question the competence of requisite skills to address spiritual assessment and delivery of spiritual care.²⁵Traditional cognitive methods of pastoral care do not work with non-cognitive individuals. Sapp²⁶ discusses the effective use of Judeo-Christian concepts of “seeing things as God sees them” through which he provides a model for applying this concept to providing pastoral care to demented individuals. Gwyther²⁷ provides clergy with specific advice on visiting and ministering to persons with Alzheimer’s. Post and Whitehouse²⁸ say that it should never be assumed that a person with dementia can no longer be reached spiritually.

24. Jane M.Thibault & Richard L. Morgan, *No Act of Love is ever Wasted: The Spirituality of Caring for Persons with Dementia* (Nashville, TN: Upper Room Books, 2009), 48.

25. McSherry W & Ross, L., “Dilemmas of spiritual assessment: Considerations for nursing practice,” *Journal of Advanced Nursing* 38, no. 5 (2002): 479-488.

26. Sapp, S. (1999), “To see things as God sees them’: theological reflections on pastoral care to persons with dementia,” *Journal of Health Care Chaplaincy* 8(1/2), 25–43.

27. Gwyther, L.P., *You are one of us: successful clergy/church connections to Alzheimer’s families*. Duke Family Support Program, 1995.

28. Post, S.G., & Whitehouse, P.J., “Spirituality, religion, and Alzheimer’s disease,” *Journal of Health Care Chaplaincy*, 8, no. 1/2 (1999): 45–57.

CHAPTER FIVE

REASONS TO PROVIDE PASTORAL CARE

When Does Life End?

In the past, it was relatively easy to define when life ends but with modern methods of treatment including CPR and use of life support machines, the definition is more complex. One popular argument is that death occurs when the heart and lungs or the entire brain has ceased to function. This is the view taken by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in its report on Defining Death published in July 1981.¹ With demented patients, their brain degenerates but they do not lose it entirely which is reason why this author advocates that there is hope and a real need to provide spiritual care besides caring for moral reasons.

Not long ago there was the case of Terri Schiavo that drew national attention. Schiavo suffered brain injury and was considered to be in a vegetative state. After eight years, her husband petitioned the courts to remove her feeding tube. Schiavo's parents objected which led to a court battle that lasted another seven years. The Senate, Congress and even the President of the United States got involved. Eventually, the Supreme Court ruled in favor of the husband having the tube removed citing his wife did not have the ability to communicate or interact purposefully.

Christian Right groups (including the late Dr. Jerry Falwell) strongly supported keeping Schiavo alive. Some Dementia patients also have feeding tubes and as the disease progresses,

1. "Guidelines for the determination of death: report of the medical consultants on the diagnosis of death to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research," *Journal of the American Medical Association* 246(19), (1981): 2184-2186.

opportunities for communication sharply diminish. So in that sense, Schiavo's case is not very different. There are strong moral, ethical and spiritual reasons to value life and love and care for individuals despite brain damage. Their body may be damaged and their intellect or memory may be diminished or lost, but their soul, which is their identity with God, is alive and longs for communion with its creator.

Pastoral care to persons like these helps them connect with God. Society and the legal system are quick to disregard, devalue and even suggest terminating life because of the "burden" the sick individual may be to others around them. This project is about affirming the life of individuals "who do not have the ability to communicate or interact purposefully" by helping change the way people perceive them. It is particularly about the theological and moral reasons to provide pastoral care to them and the opportunities we have to connect their unscarred souls to a comforting and loving God:

Dying is a complex process because it entails the whole of us, especially our relationships, not just our bodies. Even if we are semi-conscious or apparently unconscious there are still dimensions of our reality which can be active and present though not visible. The best science and the best religious faith come to these mysteries of life and death with a necessary humility. We know enough to know that we know so little and understand only a fragment of the immensity of any life.²

According to Jewish tradition, to be alive means to be in relationship with God and to be out of a relationship with God means death. The precise time of death is considered to be the moment at which a person ceases to remember and praise God, whether or not he or she has biological functioning.³ So, from this perspective it is important for their loved ones to stay connected with God to be considered to be alive. Persons with Alzheimer's or other degenerative

2. The Catholic Bishops' Conference of England & Wales - Dept. for Christian Responsibility & Citizenship, *A Practical Guide to the Spiritual Care of the Dying Person* (London: Great Britain, 2010), Introduction.

3. H.W. Wolff, *Anthropology of the Old Testament* (Philadelphia: Fortress Press, 1975).

brain diseases may not remember God all the time (neither do able people) but there are sure and certain ways in which to help them remember and connect with God.

Unfortunately, persons with dementia or similar neurological disorders are not welcome in places of worship. Erwin says, “Dementia patients are too often kept out of church because of erratic, disruptive behaviors. Yet within their long-term memories is a sweet connection with God as seen in the calming effect of old hymns, prayers and scripture readings.”⁴ Before assuming that somebody is dead or irrelevant, it is important for people to understand that the disease affects the body of the individual but does not damage the soul. There are ways and means to support the spirit life of these vulnerable people.

The Value of a Life

To appreciate the value of a life one has to know when life begins or when does life begin to matter morally. A *Google* search on the value of life done today (December 2011) came up with 1,830,000,000 pages in 0.19 seconds. This speaks about the importance of life and obviously, the human life is supreme over all living things and more valuable than the life of an animal or plant. Healthcare is one of the most prominent ways in which to express the value of life. Taking good care of one’s own health and protecting the health of others is an expression on the value of life.

Society may not have the ability or resources to save every human life but if they decide on “selecting” whom they should save or care for, it may cast a shadow on how a human life is valued. Some things that come into play here is abortion and euthanasia. A good question to ask is “why does a human life have value?” This can be answered from a religious, moral, or ethical perspective, but the bottom line is that other than procreation, humans are incapable of creating life despite the advances in medical science. It is possible to bake a cake using some ingredients

4. Kathie T. Erwin, *Lifeline to Care with Dignity* (St. Petersburg, CL: Caremor, 1997).

or make an airplane with steel, rubber, and glass that will fly, but humans have no such recipe to create a human life. Thus, the value of life lies in the nature of humanity in that all humans are created in the image of God. Flesh and blood came alive when God breathed into the nostrils of man and placed a soul within him. The value of a non-cognitive person is great in the sight of God and there are good spiritual reasons to keep them in communion with their creator. God's love for humanity is so immense that he gave his only begotten son to die for us on the cross that whosoever believes on him might be saved (John 3:16).

Is a male versus a female life more valuable, or is it valuable based upon the family into which the child is born, or is it valuable if the color of skin or race is of a particular kind? Is it less valuable if someone has special needs? Is it worth saving the life of a child versus saving the life of a sick elderly individual who racks up hefty medical bills? The United States Government valued the life of Osama Bin Laden at fifty million dollars (dead or alive) but paid only around two million dollars to the families of every person who died at the World Trade Center. It paid only two hundred dollars for some Afghans who were killed in combat activities by mistake. Our secular government values lives differently for a variety of reasons but God values every life just the same because of the value he places on our soul. God is not a respecter of persons (Acts 10:38) and causes the rain to fall on the just and the unjust (Matt. 5:45). He formed every human being from their mother's womb (Isaiah 44:24, Jer. 1:5). How significant then is the life of a person with Alzheimer's? Very significant actually and even from a moral perspective, they were once contributing and valuable members of society and should never be considered as anything less so long as they have life and breath.

It is known from medical science and research of Alzheimer's disease that the brain cells keep dying causing loss of short-term memory, but amazingly, the long-term memory is not

affected as much. This project is also aimed at finding ways in which to communicate with these individuals through their long-term memory. It is important from a spiritual context to have them spend their last days on earth in communion with their creator. Jesus did the same with his father. His last words on earth were: “Father, into thy hands I commend my spirit” (Luke 23: 46).

As a resurrection people, hope is not in this world but in the one to come. Psalm 49 speaks about building faith in the resurrection and not on worldly power. Riches, power and glory shall wax old because this world is passing away. What will remain is the hope and faith in an everlasting God who will redeem the soul from the grave. As a secondary benefit, this research will also help families of non-cognitive persons, caregivers, and peers to understand better ways to love and care for these marginalized people.

Most Christians understand that human beings are created out of the boundless love of God because He created them in his own image (Gen. 1:27). Their value and dignity rests with God who is their source and sustainer of life. The social or economic status of an individual can change from time to time, but their value in God’s sight never changes. As created beings and image bearers of God, men and women have an obligation to nurture, respect, and promote the integrity of life. Humans have no authority to neglect, harm, or destroy life. The human body is the temple of God and his Spirit dwells within that temple (1 Cor. 3:16). His indwelling is of a permanent nature because he promises, “I will never leave nor forsake you” (Deut. 31:6, 8; Josh. 1:5 & Heb. 13:5). Therefore, the caring for a fellow sick man or woman amounts to respecting and caring for the God that is in that person.

There was a time when King David was fearful of old age and its incapacitation and thus he said to God, “Cast me not off in the time of old age; forsake me not when my strength fails” (Ps. 71:9). Again in verse 18 of the same Psalm, David said, “Now also when I am old and gray

headed, O God, forsake me not; until I have shewed thy strength unto this generation, and thy power to everyone that is to come.”Both young and old men are to praise the name of the Lord (Ps.148: 12,13). It is important to look beyond the person with the disease to the person within. Persons possess more than memory and intellect; they also have emotion, relationship, imagination, will, and aesthetic awareness.⁵

Theological Reasons and Scriptural Support for Pastoral Care

The New Paradigm

The new model of pastoral care has a different focus. It is based upon the value the creator places on the human soul in which the pastor assumes the role of a fellow pilgrim.⁶ According to Augustine a “man is not merely a body or merely a soul, but a being constituted by body and soul together. This is indeed true, for the soul is not the whole man; it is the better part of man and the body is not the whole man; it is the lower part of him. It is the conjunction of the two parts that is entitled to the name of ‘man’ and yet those parts taken separately are not deprived of that appellation even when we speak of them by themselves.”⁷ Thomas Aquinas has similar beliefs on the soul reiterating that the human body without a soul is more accurately called a “corpse.” Resurrection entails that the selfsame person rises again and “this is effected by the selfsame soul being united to the selfsame body.”⁸

5. Post S.G., and Whitehouse, P.J., “Spirituality, religion and Alzheimer’s disease,” *Journal of Health Care Chaplaincy* 8 (1999): 45

6. James W. Ellor, “Celebrating the Human Spirit.” In *God Never Forgets*. ed. Donald K. Mc Kim, 1-20, (Louisville: Westminster John Knox Press, 1997), 2

⁷ Augustine, *Concerning the City of God against the Pagans*, trans. Henry Bettenson (London: Penguin Books, 1972), 13.24, 541.

⁸ Thomas Aquinas, *Summa Theologica*, trans. Fathers of the English Dominican Province (New York: Benzinger Brothers, Inc., 1948) Suppli. Q. 79, a. 2.

The body of an Alzheimer patient might be decaying and the mind cognitively impaired, but the soul remains unscarred requiring care of the soul. The new model of pastoral care will also reflect the understanding that about 70% of communication that takes place is non-verbal.⁹ Unique non-verbal methods that are sensorial and tied to past memory will be used as memory triggers. Prayers, Bible passages, hymns, and liturgies learned in childhood together with non-cognitive methods using music, faith symbols, and pictures will be used.¹⁰ The person who provides spiritual care to an Alzheimer's patient needs "to be creative and extend his or her repertoire of helping techniques beyond those based on rational conversation and the ability to remember."¹¹ When communication is established through reviving past memories, the gospel can be presented and a connection made with God.

Research supporting the need for Spiritual Care

Unlike Robertson's advice, the scriptures have a warning about the responsibility of a caregiver to the weakest of society. The responsibility of caring cannot be delegated to others. Living in an individualistic society that teaches to care for self before reaching out to someone else has no place in scripture. Rather, the consequences of pursuing one's own happiness and not caring for the marginalized are found in the gospel of Matthew (25: 41-46):

Then shall he say also unto them on the left hand, Depart from me, ye cursed, into everlasting fire, prepared for the devil and his angels: For I was an hungred, and ye gave me no meat: I was thirsty, and ye gave me no drink: I was a stranger, and ye took me not in: naked, and ye clothed me not: sick, and in prison, and ye visited me not. Then shall they also answer him, saying, Lord, when saw we thee an hungred, or athirst, or a stranger, or naked, or sick, or in prison, and did not minister unto thee? Then shall he answer them, saying, Verily I say unto you, Inasmuch as ye did it not to one of the least

9. Deborah Everett, *Forget Me Not* (Edmonton: Inkwell Press, 1996), 98

10. Marty Richards, "Meeting the Spiritual Needs of the Cognitively Impaired," *Generations* (Fall, 1990): 63.

11. Stephen Sapp, "To See Things As God Sees Them: Theological Reflections on Pastoral Care to Persons with Dementia." In *Spiritual Care for Persons with Dementia*. ed. Larry VandeCreek. 25-43, (Binghamton, NY: The Haworth Pastoral Press, 1999), 29.

of these, ye did it not to me. And these shall go away into everlasting punishment: but the righteous into life eternal.

While no study was found that addressed theological or moral reasons to provide pastoral care, some spiritual appraisals were done in which patients linked the cause of their disease to an act of God. One participant each in studies done by Bahro¹² and Stuckey.¹³ blamed themselves for not living according to God's teachings. Both described God as being judgmental. Some participants in studies done by Katsuno¹⁴ and Matano¹⁵ doubted God's existence and felt that God was testing them.

Some studies showed that God is loving and helpful and that the disease was an opportunity to rely on God.¹⁶ Problem-solving styles in this literature saw God as a provider and protector.¹⁷ Katsuno sees a surrender style of coping as a decision to hand over control of a problem to God, trusting that he will guide and protect.¹⁸ Hope in the afterlife was another form of affirming God's involvement in their terminal disease.¹⁹

Norberg argues that in the advanced stages of any dementing disease people need bodily,

12. M. Bahro, E. Silber & T. Sunderland, "How do patients with Alzheimer's disease cope with their illness? – A clinical experience report," *Journal of American Geriatric Society* 43, (1995): 41–46.

13. J.C. Stuckey, S.G. Post, S. Ollerton, S.J. FallCreek & P.J. Whitehouse, "Alzheimer's disease, religion and the ethics of respect for spirituality a community dialogue," *Alzheimer's Care Quarterly* 3, (2002):199–207.

14. T. Katsuno, "Personal spirituality of persons with early stage dementia," *Dementia* 2 (2003): 315–335.

15. T. Matano, *Quality of Life of Persons with Alzheimer's disease*, (Unpublished PhD diss., University of Illinois at Chicago, Chicago, IL. 2000)

16. L. Snyder, "Satisfactions and challenges in spiritual faith and practice for persons with dementia," *Dementia* 2 (2003): 299–313.

17. Ibid.

18. T. Katsuno, "Personal spirituality of persons with early stage dementia," *Dementia* 2 (2003): 315–335.

19. L. Snyder, "Satisfactions and challenges in spiritual faith and practice for persons with dementia," *Dementia* 2 (2003): 299–313.

psychological, and spiritual consolation.²⁰ However, he offered no theological or moral reasons to provide pastoral care to those who may only remember God vaguely if at all. In contrast, Carlson and Hellen get close to providing a theological reason. They consider all persons with dementia unique and deserving of respect, honor and care because they have inherent value.²¹

Theological Reasons for Pastoral Care

The inherent value of a human being flows from the fact that they were created in the image of God (Gen. 1:27). There are numerous scholarly interpretations about what it means to be created in the image of God. For example, Karl Barth argued that relationship is the divine image.²² For Thomas Aquinas it was the human ability to think and reason and use language and art far surpassing the abilities of animals.²³ Bromiley links the meaning to our ability to make moral decisions but goes on to say that “In Himself Christ already sums up all that humanity is to be . . . He is a perfect representation of God to man” and that the metaphor of image is paralleled by the metaphor of sonship, in that Christ is the Son in its fullest sense.²⁴ In speaking of the uniqueness of human creation in God’s image Philip Hughes says "Man, whatever his affinities with the animal realm, is radically distinguished from all other earthly creatures by the fact that

20. A. Norberg, [Department of Nursing, Umea University, Sweden]. “Consoling care for people with Alzheimer’s disease or another dementia in the advanced stage,” *Alzheimer’s Care Quarterly* 2, no. 2 (Spring 2001): 46-52.

21. D. Carlson, C.R. Hellen, “Undo the box--celebrate the gift: spirituality and activity.” *Alzheimer’s Care Quarterly* 1, no. 2 (Spring 2000): 56-66.

²² G.W. Bromiley, "Image of God," in G.W. Bromiley, editor, *International Standard Bible Encyclopedia*, vol. 2. (Grand Rapids, MI: Eerdmans, 1988), 804.

²³ Thomas Aquinas, "Man to the Image of God," in Millard Erickson, editor, *Readings in Christian Theology, Volume 2: Man's Need and God's Gift* (Grand Rapids, MI: Baker, 1976), 37-43.

²⁴ G.W. Bromiley, "Image of God," in G.W. Bromiley, editor, *International Standard Bible Encyclopedia*, vol. 2. (Grand Rapids, MI: Eerdmans, 1988), 804.

he alone has been created in the divine image and is intended by constitution to be a godly creature."²⁵

Therefore, as image bearers of God it can be deduced that humans are always connected to Him (Rom. 8:15-16), which is the reason why they need to be nourished by His word and presence. Man shall not live by bread alone, but by every word that proceedeth out of the mouth of God (Matt. 4:4). Rabbi Cary Kozberg says the worth of the human soul comes from God's choice of humans and "Jewish tradition teaches that a genuine understanding and appreciation of human existence ultimately must be grounded not in notions of usefulness and cognitive ability but rather in the belief that human life is unconditionally holy. It is holy because it is God-given."²⁶

Additional theological reasons to provide pastoral care are found in several passages of Scripture. When all else fails, men and women are to search for God and he will be found (Jer. 29:13). People may not remember God but he remembers them (Isaiah 49: 14-16). God has a plan for every human life that offers hope and a future (Jer. 29:11). People cannot remove themselves from the presence of God because he is everywhere and desirous of leading and protecting them (Ps. 139: 7-14; Ps. 23). The human body is the temple of the Holy Spirit (1 Cor. 6:19 and Rom. 8:11). Humans are called to share in eternal life (1 Tim. 2:4).

Jesus is the resurrection and the life (John 11:25). In the end, man goes to his eternal home (Eccl. 12:5; John 17:21). Eternal life is promised to those who believe (Luke 10:20; Job 19:25-26; John 3:16; 5:24; 11:23-24; 17: 1-3; 1 Cor. 15: 12-57; 1 John 5:11-13). God is intricately involved and present in the midst of human suffering (John 5:2-18; John 11:33-35;

²⁵ Philip Edgcumbe Hughes, *The True Image: The Origin and Destiny of Man in Christ*. (Grand Rapids, MI: Eerdmans, 1989), 7.

²⁶ Cary D Kozberg, "The Whole World is Full of His Glory," *The Journal of Pastoral Care* 48, no.1 (1994): 89

Isaiah 63:9; Luke 15: 11-32; John 16:33; John 14:27). Even when facing death, “The Lord himself goes before you and will be with you; he will never leave you nor forsake you. Do not be afraid; do not be discouraged” (Deut. 31:8). Believers are considered to be the sons and daughters of God who instinctively cry out “Abba Father” when in distress. God mandates the care of the sick and suffering (Matt. 25: 32-45). Every manner of sickness including brain disease and eventually death is a consequence of sin. Christians must fight sin in all of its forms throughout their lives.

The world is energized by wealth and status but not God. Conversely, God is energized only by his word and promises and our lives should be filled with them. In fact, the bible says the cares of this world, and the deceitfulness of riches, choke the word (Matt. 13:22). Alzheimer’s patients are unattractive to the world but they easily get the attention of God. In a sense, their sickness sets them apart from worldly pleasures and pursuits leaving them open and available to the word. At this vulnerable stage in their life worldly riches cannot sustain them. What they need is faith and hope in God. Faith cannot come without the word. Faith comes by hearing, and hearing by the word of God (Romans 10:17). Therefore, it is absolutely necessary to feed the Alzheimer soul with the word. For without the word there will be no faith and without faith, there can be no hope. The word is food for the soul and while the flesh gets weaker in preparation to leave this world, the soul gets well fed in preparation to meet the Lord.

The hymn writer Sabine Baring-Gould correctly said that “Christian soldiers are marching unto war, with the cross of Jesus, going on before.” Therefore, there should never be a time when a Christian is permitted to let their guard down. In times of deepest need or sickness, it is the word of God that strengthens a Christian. It did so for Jesus in the temptation. Thus despite brain disease, the strong must feed the weak soul with spiritual food (the word) and there

are unique ways to do so. The single most powerful weapon a Christian has against sin, sickness and depravity is the word of God. It is more powerful than a two edged sword (Heb. 4:12).

As members of God's family, a fellow Christian has an obligation to love and care for one another which include the sick and dying (Matt.10:8). There are also moral obligations to care for the sick and weakest of society. For instance Parents love and care for their babies despite them being incontinent and non-cognitive. Similarly, dementia patients who are also incontinent and non-cognitive deserve and need the same kind of love and affection. Like babies they have to be fed, changed and hugged. Humans look to babies as a joy but regard sick and old people as a burden. As opposed to this human response, God says, "And even to your old age I am he; and even to hoar hairs will I carry you: I have made, and I will bear; even I will carry, and will deliver you " (Isaiah 46:4). God is a restorer of life and a nourisher of old age (Ruth 4:15).

The Bible teaches that God created man and woman in his own image. He highly esteemed them in that He gave them dominion over every living thing and placed them in the same garden where He walked back and forth during the day. By this, it can be deduced that "God's purpose in creating human beings was to share his love with them, and he asks us to return that love by loving our neighbor"²⁷ God desired to have a perfect relationship with humans but unfortunately, Eve was deceived which brought about the fall and alienation from God that included death. Since that time, a battle has been raging between God and Satan for the human soul. People are promised a restored fellowship and eternal life with God when they repent of their sins and accept Jesus as their Savior. Therefore, it is imperative that humans cleave to God.

27. Benedict M Ashley, Jean DeBlois, Kevin D. O'Rourke 5th ed., *Health Care Ethics: A Catholic Theological Analysis* (Washington DC: Georgetown University Press, 2006), 6.

One of the purposes of providing pastoral care to demented individuals is to keep them in a restored relationship with God.

Because of the disease, Alzheimer's patients may not be able to remember God most of the time. This does not mean they have abandoned God. Disease and sicknesses, which are consequences of sin, can either cause people to be angry with God or make them draw closer to him. In sharing the love of God with demented patients, this author believes they can continue to have a relationship with God and draw closer to him albeit he is only sweetly remembered in their past memory. God desires that He is remembered from the past. The Judeo-Christian faith is built upon memories of what God had done for them. For example, in the book of Numbers through observing a ritual and symbolic act, memory is stirred to remember God. In chapter 15, verses 37 to 41, the Lord said to Moses:

Speak to the people of Israel, and bid them to make tassels on the corners of their garments throughout their generations, and to put upon the tassel of each corner a cord of blue; and it shall be to you a tassel to look upon and remember all the commandments of the Lord, to do them, not to follow after your own heart and your own eyes, which you are inclined to go after wantonly. So you shall remember and do all my commandments, and be holy to your God, who brought you out of the land of Egypt, to be your God: I am the Lord your God.

Another example is the Passover ritual in Exodus 13. Moses instructs the Israelites to "remember this day" (v. 3) when they came out of Egypt from bondage by the hand of the Lord. The observance of Passover is meant to serve as a perpetual memorial and remembrance of God's saving acts on behalf of his chosen people.

Similarly, the Lord's Supper is celebrated to remember the Lord's death and coming again in the New Testament. Praising God and thanking him for his mighty blessings of the past are grateful memories to remember. The writer of Psalm 111 says God has "caused his wonderful works to be remembered." Response to memory also means that people are to tell

others about the faithfulness of God. Another form of responding to memory of God is an emotional and spiritual longing for him to act in the present situation in a similar manner as he did in ages past. When God's people responded in obedience to his divine commandments, memories of past events in their individual and collective histories served “to remind” them of times and seasons in which their identities were firmly established in the God of their fathers.

There is a beautiful story about Hezekiah’s death foretold by Isaiah the prophet. Hezekiah could have accepted the news but instead he asks God to remember his past. He said, “Remember now, O Jehovah, I beseech thee, how I have walked before thee in truth and with a perfect heart, and have done that which is good in thy sight. And Hezekiah wept sore” (Isaiah 38:3-4). God then remembered Hezekiah’s past and added fifteen years to his life. God remembers and honors a person’s past good deeds (including those of demented individuals) and in like manner, humans are to remember with gratitude what God has already done for them.

With death so close, the Psalmist pleads with God saying his soul is full of troubles and is counted with them that go down into the grave whom God remembers no more. He is afflicted and asks God for mercy suggesting, “will the dead arise and praise thee” and will your loving kindness be declared in the grave or your wonders be known in the dark or your righteousness in the land of forgetfulness (Ps. 88: 1-12). “For the grave cannot praise thee, death cannot celebrate thee: they that go down into the pit cannot hope for thy truth. The living, the living, he shall praise thee, as I do this day” (Isaiah 38:18-19). These passages of Scripture and others illuminate the fact that there is much hope for the Alzheimer’s patient and that providing pastoral care for them in their vulnerable years is compatible with God’s plan for their latter lives.

God has a watchful eye over people in their twilight years and shows special favor to them. God’s care of the old is best seen in his burial of Moses (Duet. 34: 6). Scripture says not to

despise mothers when they are old (Prov. 23:22). Defying medical science, Abraham and Sarah were blessed with a son in their old age (Gen. 18: 11cf). Elizabeth also had a son in her old age (Luke 1:36). The book of Joel says, “I will pour out my spirit on all flesh . . . and your old men shall dream dreams” (2: 28). Jesus told Peter “when you are old another will gird you and carry you” (John 21:19). The counsel of old men is considered to be good (1 Kings 12:8). Old people have a prophetic voice (Gen. 49:1). God honors old people (Gen. 24:1) and the blessings of an old man are powerful and irrevocable. This is seen in Israel’s blessing of Joseph. His eyes were dim but God’s presence was greatly upon him. The same can be observed when Isaac blesses Jacob and Esau (Gen. 27:1). All of these show that God honors the aged and has a preferential love for them. It is a model for people to follow. Loving the sick and aged is a biblical mandate.

Moral Reasons – An Opportunity to Love

Love is the foundational emotion that a caregiver should possess if they are to care for someone with Alzheimer’s disease. People with this disease live highly emotional lives and respond to the world emotionally. As a result, love is sensed when it is present. Persons with dementia respond to love in any form and the need for love is great.²⁸When working with this population Elliot states “It is of utmost importance to both give and receive love.”²⁹Brennan repeatedly stated his awareness of the overwhelming presence and reality of love and identifies a correspondingly increasing level of empathy he himself feels for others.³⁰ Similarly, Davis realized he needed much love in his life and asked that it be part of an effective pastoral

28. Hazel Elliot, “Religion, Spirituality and Dementia: Pastoring to Sufferers of Alzheimer’s Disease and Other Associated Forms of Dementia,” *Disability and Rehabilitation*. 19, no. 10 (1997): 437.

29. *Ibid.*, 436.

30. Tim Brennan, “Article Fourteen,” http://www.nhisgarden.com/his_eyes/article-fourteen.html (accessed December 29, 2011).

intervention.”³¹

Morality is concerned with what is right and wrong. The word “moral” is synonymous with “good” or “right.” Pushing this further, a moral individual will pursue good and shun what is bad. Loving the unlovable is a moral act. Empathizing with an individual who is terminally ill is an act of love. Loving someone is a deliberate choice than cannot be coerced. It flows from the character of an individual who chooses to do good without looking for a return. Opportunities to “love” are often overlooked. This author has found an immense and unexplainable sense of fulfillment and joy in loving those who have Alzheimer’s.

The moral teaching of the Bible to love one another and one’s neighbor as himself or herself is both therapeutic and comforting. This commandment is more fitting as an expression of human need rather than a requirement from God. Loving someone is a sharing of what God has already done for that individual. 1 Corinthians chapter 13 is all about loving one another. It says that love never fails and is a preferred gift even over spiritual gifts of speaking in tongues, prophecy and so on. Even when compared to the spiritual grace of faith, love is the preferred choice. It would not help anyone even if he or she gave away all of their riches for good causes but lacked the ability to love. Money cannot buy what love can do. Every gift is said to diminish but love is meant to last forever but tragically, it is so sparingly used. Post says:

The moral task is always to enhance the person with dementia. That cues seem to affect memory? What music or activity seems to add to well being? How can capacities still intact be creatively drawn out? How can modalities of touch and voice convey love to the person? Rather than think of people with dementia as out of reach because of forgetfulness or as unworthy because of cognitive disability, the moral task is to bring them into discourse in creative ways.³²

31. Robert Davis, *My Journey Into Alzheimer’s Disease* (Wheaton, IL: Tyndale House, 1989), 111.

32. Stephen Post, “A Moral Case for Nonreductive Physicalism,” In *Whatever Happened to the Soul?*, ed. Warren S. Brown, Nancey Murphy and H. Newton Malony. (Minneapolis: Fortress Press, 1998), 201.

There have been innumerable instances in which this author has visited homes and institutions where patients and family were present and had only a few words to say. Even those words were not necessarily from Scripture or even related to matters of faith. It was the “presence” of another human being that communicated that they were valuable and loved. Everett says, “I have discovered that ministry is only as good as the minister who values presence as the core element of love and care. Christian theology is built on the concept of the incarnation, God with us.”³³ There are good moral reasons to love and care for the weakest of us all. Caring for someone who cannot care for himself or herself is a wonderful opportunity to love without looking for recompense.

Morality is also about showing respect and dignity to one another especially to an aged or sick individual. Model citizens cannot only be “takers” but “givers.” To whom much is given, much is required. Opportunities to give back are a rare privilege that should never be allowed to slip by especially when it involves a human life. The Creator gave his life for men and women which are sufficient evidence of the worth of a human being. The simple act of being with another person intentionally is a powerful statement in itself and does not necessarily have to be accompanied with words.

Sometimes silence accomplishes more than a thousand words because body language and intent do not go unnoticed. Psalm 46:10 says to be still and know that he is God. God’s peace and presence is more easily found in the calm and “stillness” of life than in chaos. However, being “present” with someone is not necessarily a theological idea. A simple act conveys one’s feelings toward another and an exposition of love. Carlson and Hellen consider all persons with

33. Deborah Everett, “Forget Me Not:: The Spiritual Care of People with Alzheimer’s Disease.” In *Spiritual Care of Persons with Dementia: Fundamentals for Pastoral Practice*. ed. Larry VandeCreek. 77-88. Binghamton, NY: The Haworth Pastoral Press, 1999. 84.

dementia unique and deserving of respect, honor, and care because they have inherent value.³⁴

Everyone knows the golden rule which is to do unto others as you would have others do unto you! Most civilized societies are founded on this moral reciprocity. Simple decency and respect for one another is a basic tenet for a happy and rewarding life.

When a loved one is afflicted with Alzheimer's, we must always remember that what we see isn't always what we get! The real mother we knew and love has not died within her body. Mother is still there even though we can't see her. On a spiritual level, which transcends the physical senses, she truly sees and hears you. She is aware of your presence and feels your love. So you honor your mother not only because of who she was but because of who she is.³⁵

Most religions teach good morals and especially the need to respect and honor the elderly. Even in the absence of any religion, it seems to be the right and proper thing to do.

Helping Family Members and Caregivers

The Alzheimer's Association reports that caregivers experience high levels of stress.³⁶ If caregivers are burned out, the patient will suffer greatly. Maintaining the health and well-being of caregivers is essential for proper care of dementia patients. Over 50% of caregivers develop depression. Physical illness, isolation, anxiety, and burnout are common. Unless caregivers are healthy and emotionally and spiritually strong, they would not be able to provide good care for their loved ones. Some might lack training. Intensive education and support of caregivers may delay institutionalization of patients with dementia. Adult day services for patients and respite

34. D. Carlson, C.R. Hellen, "Undo the box--celebrate the gift: spirituality and activity." *Alzheimer's Care Quarterly* 1, no. 2 (Spring 2000): 56-66.

35. Schostak, Zev. Keepers of the Broken Tablets, *National Council for Young Israel*. Viewpoint, (Winter 5767/2006): 68.
http://www.spiritualcarecollaborative.org/docs/workshop_handouts/T1.3%20Schostak%20Part%203.pdf (accessed February 20, 2012).

36. Alzheimers Association. Caregiver Stress,
http://www.alz.org/living_with_alzheimers_caregiver_stress_lwa.asp (accessed December 17, 2012).

services for caregivers may help coping abilities. At the Association's website, a caregiver stress check is available, which is a quiz along with a personal list of resources to help manage stress. This would be a good place to start. It is healthy for a caregiver to ask for help if the necessity arises.

Some of the stresses for caregivers come from changes in relationship with the cared for. With memory and physical decline, the Alzheimer patient's needs constantly change requiring more and more support from the caregiver. A caregiver must know what these entail and receive proper training along with emotional and spiritual support to cope. Anticipatory grief can set in early, escalating an already stressful situation. When caring for an Alzheimer patient becomes challenging or overwhelming due to changes in the condition of patient, it might be appropriate to consider placing the individual in an institutionalized setting.

Rabbi Schostak believes the long-term victims of Alzheimer's and dementia are not the patients but the family members.³⁷ In a research study involving 1229 caregivers conducted in 2007 by Dr. Herbert Randy et al. to explore the relationship between religion and mental health in active and bereaved dementia caregivers, Dr. Randy concluded that religious beliefs and practices, and especially religious attendance, were associated with better mental health for the caregivers.³⁸ Many local chapters of the Alzheimer's Association have monthly or bi-monthly grief counseling meetings. People sharing similar struggles come together to receive

37. Schostak, Zev. Keepers of the Broken Tablets, *National Council for Young Israel*. Viewpoint, (Winter 5767/2006): 69.
http://www.spiritualcarecollaborative.org/docs/workshop_handouts/T1.3%20Schostak%20Part%203.pdf (accessed February 20, 2012).

38. "Religious Beliefs and Practices Are Associated With Better Mental Health in Family Caregivers of Patients With Dementia: Findings From the REACH Study," *The American Journal of Geriatric Psychiatry* 15, no. 4 (April 2007): 292-300.

encouragement and hope together with emotional and spiritual support. Many of them bond well and become good friends. They also become wounded healers.

Responses received from surveys asking caregivers what has been most difficult in caring for their loved one indicate that most of them lacked emotional support. The second factor was the physical aspect of taking care of their loved one although they did not complain about it. Interestingly, only third on the list was the need for spiritual support, which indicates that physical need must be met first before presentation of the spiritual. This is compatible with Jesus' model of ministry. The many practical problems raised in this paper is precisely to meet this very purpose which is to understand what is going on and meet that need before sharing the good news of the gospel.

Caring for Alzheimer patients on a full time basis could cause social isolation for the caregiver. Friends may pull back and restrict contact to occasional phone calls. Caregivers should take the initiative to talk to their friends and family about the disease and how it has affected their life style, and ask for continued friendship and support. Friends may not be comfortable visiting especially when they do not understand the disease process. However, one can expect support and understanding after properly explaining the disease.

No one escapes the effects of this terrible disease. Residents, families and staff alike must cope with extended and unpredictable disease trajectories.³⁹Caregivers and close family members are in no less need of spiritual care than their afflicted loved ones. The Pastor or Chaplain who provides spiritual care may not be able to cure the disease but the same person can facilitate a relationship between the Alzheimer soul and God. The same can be accomplished for

39. Chen, J., Chan, D., Kiely, D.K., Morris, J.N., & Mitchell, S.L., "Terminal trajectories of functional decline in the long term care setting," *Journal of Gerontology* 62a (2007): M531-536.

the caregiver. It is very possible to help both the cared for and caregiver to discover and experience the peace and love of God in the midst of suffering.

As a resource, the Alzheimer's Association has what they call a Caregivers Notebook. It was developed and written with input from caregivers. It covers topics from taking good care of oneself, understanding the basics of the disease, legal and financial planning, and caring for the patient. Each chapter has a place to write notes for future reference. The book costs about \$18 including shipping. They also offer DVD's which offer practical advice and guidance in caring for people with dementia. Their website also offers recommendations and advice for daily care activities that range from communication, eating, bathing, incontinence to depression and late stage care.

Some practical ways to help caregivers would include any or a combination of the following:

- visit on a scheduled basis and listen to their story patiently without interruption. Establish a phone contact system to check on them,
- provide meals and help with household chores or grocery shopping,

Take the patient and or caregiver on outings. Sometimes sit with the patient to relieve the caregiver.

CHAPTER SIX

COMMUNICATING WITH NON-COGNITIVE PERSONS – A MINISTRY OF MEMORIES

The Vantage Point of Past Memories

As the disease progresses, non-cognitive persons may no longer be able to remember God's everlasting promises. Corey maintains that "[n]o matter how profound the degree of dementia and confusion, there is a holy place inside that still recognizes and responds to God."¹ As cognition deteriorates, their thought process becomes more fragmented and forgetful. Therefore, ministry of God to Christians with dementia must be a ministry of memories reminding them repeatedly of how much God loves them, of what Jesus has already done and is still doing for them, and of who their identity is in Christ. By being present with them, reading scripture and praying with and for them, their past memories can be rekindled to remember God and find peace and comfort in his loving presence. The rekindling of past memories is the gateway to a new paradigm of pastoral care to non-cognitive persons.

Rabbi Zev Schostak, a Chaplain who worked with dementia patients, shares his experiences of them, which confirm that past memories can help them remember God:

I believe that behind the mask of dementia, there are occasional glimmers of the person we once knew and loved. He or she is still there and these glimmers are manifestations of the soul. Sometimes, an elderly parent with dementia has a magic moment, where she recognizes her child, smiles and speaks clearly for a few minutes only to revert to a nonsensical state. At a musical program, a resident with advanced Alzheimer's spontaneously taps his feet to the beat of music popular 50 years ago and hums along. At religious services, demented residents respond positively to the prayers of their childhoods, reflecting their joy in being able to participate in an experience which still has meaning in their lives.²

1. Judy Corey, "Edna's Song," *Healing Ministry* 8, no.1 (2001): 18.

2. Schostak, Zev., "Keepers of the Broken Tablets," *National Council for Young Israel*. Viewpoint, (Winter 5767/2006:67). http://www.spiritualcarecollaborative.org/docs/workshop_handouts/T1.3%20Schostak%20Part%203.pdf (accessed February 20, 2012).

The very essence of pastoral care is more about listening than speaking. While many of the stories related by non-cognitive persons to a chaplain or caregiver are historical and may not make sense, listening to them can be an important pastoral intervention. It not only raises the esteem of the patient but also validates who they are. More importantly, it opens the door to conversation that can be steered into moments of deep spiritual value. However, in the very late stages of dementia, people do not speak at all. While this is a handicap, it does not destroy hope or the ability to reach into their soul. Instead of words, the provider of spiritual services will need to use other senses like touch, visuals, symbols, and music.

Everett says, “Though a person’s soul experience may not be evident to my observation, is it any less real? If we think so, we as human beings are a very arrogant lot, for the relationship of a person with God is difficult for anyone to determine or define.”³We have absolutely no evidence other than assumptions that God is unable to commune with non-cognitive individuals. This author has witnessed many a precious demented soul pass on to glory with a smile on its face. How can this be explained other than an encounter with God?

Validation Therapy Versus Reality Approach

Caring for demented people requires commitment and an infusion of God’s love. It is difficult to really care for someone without divine strength. However, the reality-oriented approach is futile in caring for non-cognitive persons. Trying to force one’s reality of time and the present on a demented individual is wrong and counterproductive. Demented persons live in their own time and place, which is not the present, but the past. Communication is provisioned by entering into their world instead of correcting or contradicting what they say or do. Listening empathetically is important.

3. Deborah Everett, *Forget Me Not* (Edmonton: Inkwell Press, 1996), 78.

Naomi Feil introduced the concept of “validation therapy” to communicate with non-cognitive persons. What this means is that the patient’s opinions are validated by acknowledging, respecting, hearing, and regardless of whether or not the listener actually agrees with the content, they are being treated with genuine respect as a legitimate expression of their feelings, rather than being dismissed.⁴ This way, the caregiver goes into the patient’s own reality and works from the vantage point of past memories; thus, pastoral care to non-cognitive persons is considered a ministry of memories.

There are specific interventions and techniques used within the validation approach that incorporate behavioral and psychotherapeutic methods to meet the needs of individuals with different stages of dementia. Studies conducted by Mortan and Bleathmann indicate that there was some increase in levels of interaction using validation therapy.⁵ In another article, Bleathman notes that validation therapy is an exciting and important therapeutic development which can restore self-worth and ease the stress suffered by elderly people with dementia.⁶ In another case study done at a facility in Italy with 50 patients, an author found that Validation Therapy was able to reduce the severity and frequency of behavioral and psychological symptoms in dementia thus improving relationships.⁷

People with dementia do not live in the present; their reality is not ours. The Chaplain or Pastor of those with dementia is called to the task of learning to enter into the time realm of these

4. Naomi Feil and Vick De Klerk-Rubin, *The Validation Breakthrough: Simple Techniques for Communicating with People with 'Alzheimer's-Type Dementia* (Baltimore, MD: Health Professions Press, 2002), 26.

5. Ian Mortan and Christin Bleathman, “The effectiveness of validation therapy in dementia: A pilot study,” *International Journal of Geriatric Psychiatry* 6, no. 5 (1991): 327-330.

6. Christine Bleathman, “Validation therapy with the demented elderly,” *Journal of Advanced Nursing* 13, no.4 (1988): 511-514.

7. L. Tondi, L Ribani, M. Bottazzi, G.Viscomi and V. Vulcano, “Validation therapy (VT) in nursing home: a case control study,” *Archives of Gerontology and Geriatrics* 44 supplement. (2007): 407-411.

people, which is certainly not the present. Their present moment is really their past. Sharing the love of God does not require an individual to be confined to a specific era of time. Heschel says, “All it takes to sanctify time is God, a soul and a moment and the three are always here.”⁸ As a form of practical advice it would be a good idea for a Chaplain to keep conversations simple, speak slowly and clearly, avoid asking questions and try to maintain eye contact.

The question arises about how a dementia patient can be aware of God and find him when he or she no longer recognizes close members of family or friends, or even his or her own name for that matter. Theologically speaking, God cannot be found. He is somewhere in the heavens or even as close as living within the human body, but it is He who makes himself known. He left the heavens to reveal himself to humans through His Son. Likewise, God can barge into any circumstance or time of a person’s life and is not limited by non-cognition. If God was limited in any way, questions relating to how he can be found may have some validity. Everett says, “The one who attempts to bring God to the person with dementia finds God already there, profoundly, in the face and eyes before them.”⁹ Paul reminds us that nothing can separate us from the love of God (Romans 8:39). Cognitive people often assume that cognition is necessary to commune with God but if this be so, how would they explain Lazarus listening to the voice of Jesus and coming forth when he was already dead for three days? (John 11:42-43). Sapp also reminds his readers that “it is God who reaches out to humans – the initiative is his.

8. Abraham Heschel, “The Older Person and the Family in the Perspective of Jewish Tradition” in Lefevre and Lefevre, *Aging and the Human Spirit*, 42, quoted by Eugene C. Bianchi, *Aging as a Spiritual Journey* (New York: Crossroad Publishing, 1993), 164.

9. Deborah Everett, *Forget Me not* (Edmonton: Inkwell Press, 1996), 165.

Therefore does it matter what condition a person may be in if God chooses to come to that person.”¹⁰

Traditional methods of pastoral care based upon cognitive abilities cannot be applied since these very abilities are lost in a person that has dementia. Communication is still possible through unique methods and the myth that they cannot communicate meaningfully albeit for short periods will be dispelled. Hymns, prominent prayers and promises of the bible that were learned earlier in life remain lodged in the long term memory of dementia patients which can be accessed and repeated without much trouble. These serve as coping mechanisms for the patients and research support such an idea. For example:

There have been several studies focusing on the effectiveness of various tools for use in spiritual intervention in mental care. Certain studies (Greasley et al., 2001; McLaughlin, 2004; Mohr, 2006; Nolan & Crawford, 1997; O’Reilly, 2004; Swinton, 2001) show the importance of health care providers’ awareness of their own spiritual needs, as well as knowledge of different religions and their basic symbols and rituals. The use of various spiritual expressions and tools such as prayer, biblical or scriptural reading, meditation, and sacred music seem to be effective in alleviating psychiatric mental suffering (MacNutt, 1977).¹¹

Use of the Senses

When verbal communication is limited, it becomes necessary to explore other avenues that can accomplish the task. Non verbal communication is a powerful method of interacting with dementia patients. Traditionally, the use of the five senses opened communication channels. More recently however, Neuroscientists feel they may be on the verge of identifying “a sixth human sense that intuitively perceives the Divine” a core, basic and fundamental part of the

10. Stephen Sapp, “Memory: The Community Looks Forward.” In *God Never Forgets*. ed. Donald McKim. (Louisville: Westminster John Knox Press, 1997), 94.

11. Tiburtius Koslander, António Barbosa da Silva and Åsa Roxberg, “Existential and Spiritual Needs in Mental Health Care: An Ethical and Holistic Perspective,” *Journal of Holistic Nursing* 27, no. 1 (March 2009): 39-40.

human brain.¹² Brennan, who was also an Alzheimer patient, writes, “God is in my heart. Somehow, he connects to me physically. I think this feeling is called spirituality. I talk to God because I do not remember prayer.”¹³ There is a sixth sense at work which “feels” his presence but research on this sense is still in progress. Accessing and relating to one’s “feelings” is a very important component of pastoral care and so the potential to use the sixth sense to minister to dementia patients is both promising and exciting. O’Conner says, “I saw that the use of traditional religious symbols that people could touch, hear, see, and smell was a key vehicle in helping patients get in touch with Providence.”¹⁴

In the absence of a verbal communication, touch can convey more than words the loving presence and assurance that God is alive and ever present. Even with cognitive persons, communication is not always with words. Jesus communicated with non-verbal methods when he washed his disciples’ feet. Touching is important because it provides therapeutic relief and is a form of communication. When an individual’s capacity to think or speak diminishes, he or she increasingly uses non-verbal signals like body language. At this point, it does not matter if the individual does not know who the care provider is; conversely, the provider knows who the patient is and above all, God knows the patient and has him or her in the palm of his hands.

Human hands are often used by God to be a conduit of his grace. According to Meiburg, “Of all the forms of nonverbal communication, physical touch is the most powerful. It has great

12. Jeremiah Creedon, “God on the Brain.” *Utne Reader Magazine*. March-April 1998, 8-9.

13. Tim Brennan, “Article Nine,” <http://www.nhisgarden.com/his-eyes/article-nine.html> (accessed December 7, 2012).

14. Thomas St. James O’Connor, “Ministry without a Future: a Pastoral Care Approach to Patients with Senile Dementia,” *The Journal of Pastoral Care* 46, no.1 (1992): 12.

usefulness in the nursing home in general and with confused persons in particular.”¹⁵ It is said that infants deprived of touch will occasionally die. Since Alzheimer’s is in one sense human development in reverse, touch can have a life sustaining effect on them. The warmth of touch cannot be substituted with a wise choice of words or a barrage of Scripture. Combing an individual’s hair or applying lotion on the hands can be an immeasurable act of love and a powerful method of communication. “A gentle human touch can be an effective way to reassure the person. A hug will go further than words.”¹⁶

Research shows that almost seventy percent of communication is non-verbal.¹⁷ Therefore, as mental functioning steadily decreases, spiritual wholeness must be addressed on an increasingly non-verbal level, which includes touch, rituals, symbols, and music.¹⁸ Love is sensed when it is present and persons with dementia respond to love in any form.¹⁹ Another form of communication is presence. Sometimes even a few words may be too many. Speech is silver but silence is gold especially if the situation warrants it. “It is an article of faith in pastoral care literature and in the experience of caregivers that presence communicates the love of God.”²⁰ Stokes believes the ministry of presence must be a time spent together that reminds or invokes

15. Albert L. Meiburg, “Pastoral Communication with the Confused,” *Pastoral Psychology* 31, no.4 (1983): 274.

16. Deborah Everett, *Forget Me Not* (Edmonton: Inkwell Press, 1996), 134.

17. *Ibid.*, 98.

18. Marty Richards and Sam Siecol, “The Challenge of Maintaining Spiritual Connectedness for Persons Institutionalized with Dementia,” *Journal of Religious Gerontology* 7, no.3 (1991): 34.

19. Hazel Elliot, “Religion, Spirituality and Dementia: Pastoring to sufferers of Alzheimer’s Disease and other associated forms of dementia,” *Disability and Rehabilitation* 19, no.10 (1997): 437

20. Deborah Everett, *Forget Me Not* (Edmonton: Inkwell Press, 1996), 99.

the presence of the Holy and not merely a conversation that has no depth or specific content.²¹

Music, Old Hymns and Rituals

The creative nature of music serves to facilitate interpersonal contact, communication, self-expression and growth.²² It can help connect the past to the present. Music is also an integral part of worship. Meiburg notes that it is not unusual for persons with brain loss who have almost lost the power to speak to retain the ability to hum or even sing familiar hymns.²³

Mary was in her end stages of dementia. She would always dress impeccably and mostly by herself. Her jewelry would match her clothing and she even did her own makeup. Sometimes the lipstick would be smeared a bit but anyone looking at her would never sense that she was severely cognitively impaired. This author visited her for a couple of months before she eventually died. He never introduced himself as a chaplain or anything like that. These details are never important. He knew from her bio-data that in her early years, she was the organist in her Church.

In order to trigger memory and eventually have a window of opportunity to present God, he would just take out a hymnal and begin singing some old time favorite like “Amazing Grace.” Mary always quickly joined somewhere in the middle of the first verse itself and would sing right through. Mary would then talk all about those wonderful days and this author would roll the conversation into talking about God and then quickly read a very short verse of scripture and say a small prayer. At the end of the prayer, he would usually find that Mary had moved back to a

21. Janet Stokes, “Ministry of Presence and Presence of the Spirit in Pastoral Visitation,” *The Journal of Pastoral Care* 53, no.2: (1999): 191-199.

22. Kevin Kirkland and Howard McIlveen, *Full Circle: Spiritual Therapy for the Elderly*, (Binghamton, NY: The Haworth Press, 1999), 1.

23. Albert L. Meiburg, “Pastoral Communication with the Confused,” *Pastoral Psychology* 31, no.4 (1983): 276.

non-cognitive state but it would not be without connecting to God! These are precious moments and with the right methods, it is not difficult to share the word of God with these precious souls many of whom were faithful followers of Christ.

Listening to music or joining in singing a hymn is not an intellectual or cognitive event. Music can help break down the walls of cognitive failure. The area of the brain, which responds to music, is the last area to be destroyed by a disintegrating brain. “In neurological terms, the musical areas of the brain are usually in the non dominant hemisphere, the side of the brain which does not control language. Appreciating, responding to, and becoming involved in music do not require the areas of the brain that are usually damaged by the process of ADRD.”²⁴ Old hymns and rituals stored in the past memory of the brain can be accessed. Familiar scriptures like the 23rd Psalm, the many promises in the bible and the Lord’s Prayer are etched in past memory. Clayton describes a novel approach to providing a meaningful worship service for Alzheimer’s patients in which greater stress is placed upon familiar scripture, music, prayers and other right-brain functions, rather than on a sermon or homily.²⁵

Symbols and Past Events That Trigger Memory

A religious symbol conveys its message even if it no longer is understood consciously in every part. For a symbol speaks to the whole human being and not only to the intelligence.”²⁶ Symbols like the Bible, a cross, candles, a crucifix or rosary, picture of Jesus, or other visuals like bread and wine, communion cup, and clerical robes recall times past and trigger meaningful

24. C Bowlby, *Therapeutic Activities with Persons Disabled by Alzheimer Disease and Related Disorders*, (Gaithersburg: Aspen Publishers, 1993), 155.

25. Clayton, J., “Let there be life: an approach to worship with Alzheimer’s patients and their families,” *Journal of Pastoral Care*, 45, no.2 (1991): 177-179

26. Mircea Eliade, *The Sacred and the Profane: The Nature of Religion* trans., W.R.Trask. (London: Harcourt Brace and Co., 1959), 129.

conversation and connection with God. The goal of pastoral care should be to help individuals maintain lifelong religious practices, encouraging reminiscence, making connections through the use of traditional religious symbols and music, altering styles of ministerial visitation and worship experiences and sustaining relationships.²⁷

Support from individuals and a personal relationship to God helped patients with coping.²⁸ This means it would greatly help to provide opportunities for patients to have a personal relationship with God. As previously discussed, cognitive methods are mute when caring for demented individuals. This is where symbols, past events and other memory triggers come into play. Three persons with Alzheimer's reported that spiritual connections to nature brought them a feeling of peace.²⁹ Some reported that nature helped them connect to God.³⁰ Matano reported that a clergyman helped make a spiritual connection to God.³¹ The most often reported spiritual coping strategies were prayer and church attendance even though they depended upon others to transport them to church.³² One participant used meditation while

27. Ryan, E.B., Martin, L.S., & Beaman, A. "Communication strategies to promote spiritual wellbeing among people with dementia," *Journal of Pastoral Care & Counseling*, 59 (2005): 43-55.

28. T.J. Gall, C. Charbonneau, N.H. Clarke, K. Grant, A. Joseph & L. Shouldice, "Understanding the nature and role of spirituality in relation to coping and health: a conceptual framework," *Canadian Psychology* 46, (2005): 88-104.

29. A. Phinney, "Living with dementia from the patient's perspective," *Journal of Gerontological Nursing* 24, (1998): 8-15.

J.C. Stuckey, S.G. Post, S. Ollerton, S.J. FallCreek & P.J. Whitehouse, "Alzheimer's disease, religion and the ethics of respect for spirituality a community dialogue," *Alzheimer's Care Quarterly* 3, (2002):199-207.

30. L. Snyder, "Satisfactions and challenges in spiritual faith and practice for persons with dementia," *Dementia* 2, (2003): 299-313.

31. T. Matano, *Quality of Life of Persons with Alzheimer's disease*, PhD diss. University of Illinois at Chicago, Chicago, IL, 2000).

32. T. Katsuno, "Personal spirituality of persons with early stage dementia," *Dementia* 2, (2003): 315-335.

walking.³³ It is difficult but not impossible to reach a cognitively impaired person spiritually.³⁴

Some of these methods have already been discussed above.

The symbolism of Scripture is very important too. Despite brain degeneration, persons with Alzheimer's are often able to recite familiar verses in scripture that links them to God. Prayer is as important. Although prayer requires some degree of cognition, some prayers like the "Lord's Prayer" and can be recalled from past memory. Abramowitz believes that prayer is very helpful even to the most demented and is the ladder, which connects the earthly being with a Heavenly one.³⁵

Memory loss is one of the most challenging impediments in communicating with those who have dementia. A Catholic man with dementia wrote:

I no longer remember prayers I once recited automatically. The prayers frequently are mixed up with each other . . . As for the sacrament of penance or confession it too requires memory. I do not recall when I last went to confession or how many sins I have committed or what in fact sin is especially if it is non-physical. I don't know if I know all manner of right and wrong – it is more of a feeling of what is right and wrong . . . I am less Catholic now. I didn't mean or want it to happen; it just did. However, God is in my heart. Somehow he connects to me physically. I think this feeling is called spirituality. There is a sixth sense at work that feels his presence. I talk to God because I do not remember prayer . . . I don't understand how one could become less religious and possibly more spiritual. Yet this appears to be happening.³⁶

Based upon the use of language, this individual appears to be in the early to mid stages of the disease. He shares his feelings about his faith in God that can help a Chaplain minister to him

33. A. Phinney, "Living with dementia from the patient's perspective," *Journal of Gerontological Nursing* 24, (1998):8–15.

34. James W. Ellor, *Celebrating the Human Spirit. In God Never Forgets*, ed. Donald K. McKim (Louisville: Westminster John Knox Press, 1997), 3.

35. Leah Abramowitz, "Prayer as Therapy Among the Frail Jewish Elderly," *Journal of Gerontological Social Work* 19, ¾ (1993):72.

36. Brennan, T. (1995), "Comforts of faith fade as God becomes a presence.," *St Petersburg Times*, <http://www.alzwell.com/stpt2.html#2> (accessed January 26, 2012).

more effectively in the end stages when verbal communication is reduced to a word or two.

Research Findings

This is a qualitative study based upon structured questions previously approved by Liberty University and specifically targeting three groups of people that are directly involved in the care of non-cognitive persons. These include Medical Doctors, Chaplains and Caregivers who provided written responses. The research also involved a few personal interviews. The individuals selected answered the questions from their own observations and experience, which are reflected in the charts below. There are significant common responses from all three groups in relation to core questions but there were also some variations in responses to some questions from Chaplains who lack adequate training and education in ministering to those who are non-cognitive.

The first set of figures are responses from 13 Medical Doctors who are directly involved in providing medical care for dementia patients either in their homes, a nursing home, hospice or palliative care facility. Since this author contends that communication is possible with non-cognitive persons although they have a degenerative brain, it was necessary to see if the Medical Doctors collaborated with such an idea. All but one Doctor believe that communication is possible although it might not necessarily mean verbal communication. This possibility opens the door to the opportunity of providing pastoral care. The means to deliver the message is secondary to the fact that communication is actually possible based upon the medical opinion of the majority of Doctors who responded to the questionnaire.

Chart 1. Medical Doctors responses and perception of non-cognitive persons

Questions	Number of Respondents	Answered either “yes” or positively	Answered either “no” or negatively	Neutral/ No answer or Don’t know
Is this your primary area of practice?	13	13	0	0
Would you consider them socially dead	13	10	0	2
Is communication possible despite brain damage	13	12	1	0
Have you been able to communicate	13	10	0	3
Communicate through non verbal’s	13	7	0	6
Is it important to provide spiritual care	13	12	0	1
Are families actively involved in caring	13	10	2	1
Does Medicare cover Alzheimer’s	13	4	5	4

92% of responses from Medical Doctors who indicated that communication is possible despite brain damage also believed that it is important to provide spiritual care to non-cognitive persons. 77% indicated that they have been able to communicate with their patients and an equal number consider them not to be socially dead. However, only 54% were able to communicate through non-verbal means while 46% did not specifically mention how they communicated. 76% of the responses found that families are actively involved in caring for their loved ones but there was some ambiguity about what Medicare covers or does not cover for Alzheimer’s patients. When comparing the responses of Chaplains to Medical Doctors, it appeared that the Doctors were more optimistic about the opportunities to communicate and the need for spiritual care than the chaplains.

Chart 2. Responses from 23 Caregivers about their perceptions

Questions	Family	Other	Yes	No	Touch	Words/Acts of love	Past events	Emotional support	Need rest	Incontinence	Feeding	finances
What motivates you to care	22	1										
Do you consider them socially dead				23								
Is communication possible despite brain damage			23									
Are you able to communicate			23									
How do you communicate?					18	20	23					
Is it important to provide spiritual care			21	2								
What are some difficulties in caring								20	18	14	4	13

Almost 96% of Caregivers surveyed are those who care for members of their own family. 100% of them believe their loved one is not socially dead and the same number had no difficulty communicating with them. 78% are able to communicate through “touch,” 87% communicate with words and acts of love while all of them have found it possible to communicate through past events and long term memory. About 87% of Caregivers lack emotional support, 78% needs rest and time to rejuvenate, while around 60% find incontinence and finances to be challenges they have to deal with.

The most optimistic of all three groups are the Caregivers. It was interesting to note that an overwhelming majority of both Medical Doctors and Caregivers believed that non-cognitive

persons are neither socially dead nor are they unable to communicate. Chaplains are not so optimistic. 36% of Chaplains think they are socially dead and only 45% have had success in communicating. About 60% of Chaplains think it might be important to provide pastoral care while 100% of the Caregivers and 92% of the Medical Doctors think pastoral care is important. 82% of the Chaplains were unable to provide theological and moral reasons to care for non-cognitive persons and while all of them thought it important to stay connected to God despite loss of brain function, only 27% were able to articulate why this was necessary.

These results are no surprise and only prove this thesis. Although 91% of the Chaplains considered providing spiritual care to non-cognitive persons to be their primary area of ministry, none of the respondents had any special or theological training to provide care for such persons. Yet, 100% of them expressed confidence in providing pastoral care even though more than one half of them considered dementia patients to be socially dead, and an even greater number had difficulty in communicating. As VandeCreek observed, pastoral care is woefully neglected towards non-cognitive persons, and the neglect is more out of a sense of helplessness than an unwillingness to help.³⁷

Personal interviews revealed that one of the reasons why Chaplains were having difficulty providing pastoral care is because they used cognitive methods to reach their non-cognitive patients. Many of them assume that even though there is little or no verbal response from the patient, they actually understand and comprehend a lot. It is not plausible to believe that a degenerated brain can work so well, and such a presumption has no medical or empirical support. This belief might provide personal

37. Larry VandeCreek, *Spiritual Care for Persons with Dementia: Fundamentals for Pastoral Practice* (Binghamton, NY: The Haworth Pastoral Press, 1999), 60.

satisfaction of a job well done but the reality might be the very opposite. The objective of this thesis is to help such individuals do a better job.

Chart 3. Chaplain's responses and perception of non-cognitive persons

Questions	Number of Respondents	Answered either "yes" or positively	Answered either "no" or negatively	Neutral/ No answer or Don't know
Is this your primary area of ministry?	11	10	0	1
Have you had any theological/special training in this field	11	0	11	0
Are you confident to provide care?	11	11	0	0
Do you consider them socially dead?	11	4	7	0
Have you been able to communicate?	11	5	3	3
Communicate with touch	11	6	2	3
Communicate through prayer	11	11	0	0
Communicate through presence	11	10	0	1
Communicate with religious symbols	11	5	0	6
Is it important to provide pastoral care	11	7	0	4
Are there theological or moral reasons to provide pastoral care	11	11	0	0
What are the theological/moral reasons?	11	2	0	9
Is it important to stay connected to God despite loss of brain function?	11	11	0	0
To the above, why so?	11	3	1	7

Conclusion

The above qualitative study was undertaken as a holistic approach into solving the problem of finding theological reasons to provide pastoral care to non-cognitive persons and unique ways in which to communicate with them. The study also provides an introduction into the life of an Alzheimer's patient as related to the disease process, their struggles of coping with the disease and the hope they have in a loving God who has promised never to fail nor forget them. It also provides an insight into the scientific study of death and dying that leads to the exploration of the nature, condition and value of the soul. Some geriatric studies related to healthcare of older people that has an effect on the quality of life of an Alzheimer's patient were also reviewed.

The issue of tradition and culture and the impact they have on how these people are perceived together with corresponding moral values, the value of a life and how both church and clergy have neglected to minister to them is also addressed. Caregiver stress and ways in which to help them cope better are provided. Research material and responses to questionnaires dispel the notion that Dementia patients are socially dead and unable to communicate as assumed by Pat Robertson.

The value of this investigation rests on the immense worth of the human soul whose value is defined in the many books of Scripture and affirmed by numerous contributors cited in this work. Spirituality and religion are important interventions for persons with Alzheimer's to find peace and comfort. Nature, music, rituals, and religious symbols help trigger past memory in these individuals, which provide opportunities for them to remember and connect with God. This

study is primarily done from a Christian understanding and therefore it cannot be concluded as to whether persons of other faiths or those with no religion at all are able to cope better or worse than a Christian.

The limited empirical knowledge about theological and moral reasons to provide pastoral care to non-cognitive persons compels the need for future research on the subject. Understanding the theological reasons why pastoral care should be provided to non-cognitive persons will help clergy, care Providers, and family members to place a greater worth and dignity on the lives of these persons who despite having a deteriorating body possess a soul that is intact.

APPENDIX A

Reginald Corfield

420 Kinsale Court, Murrells Inlet, SC 29576

Tel: 843 650 6336
Email: rjcorfield@liberty.edu

To:

Dear

I am a member of the clergy serving as a Hospice Chaplain whose patients are mostly cognitively impaired. I am currently completing a Doctor of Ministry Degree from Liberty University in Lynchburg, VA. My mentor is Dr. Charlie Davidson who is also Director of the D. Min program. The title of my thesis is *Ministry of Memories: Keys to Pastoral Care of Non Cognitive Persons*.

My thesis requires research and analysis of all published material currently available on the subject together with responses from those who might be directly involved in the care of such individuals. In terms of the latter, I have prepared a questionnaire for you and would greatly appreciate your response. I am aware of HIPPA laws and do not need real names of persons that you might refer to or any information that might violate those requirements. Please be assured that any and all information you provide is for research purposes only and will be kept strictly confidential.

Thank you for your participation and for assisting me in my educational and research endeavors.

Yours truly

Rev. Reginald Corfield

Encl: As stated

APPENDIX B

QUESTIONNAIRE FOR **CAREGIVERS** WHO CARE FOR NON-COGNITIVE (ALZHEIMER'S) PERSONS

1. Your name and position _____
2. Employer name _____
3. Your address and or contact info _____

4. For how long have you been associated with or provided care to non-cognitive persons? _____
5. What is your motivation to care for them?

6. What has been most difficult for you in terms of caring for them?

7. Would you consider them socially dead because of their loss of brain function? Explain what you think.

8. Do you believe that it is important to provide Spiritual Services to Non-Cognitive persons and if so, why? State any theological or moral reasons to do so.

9. Have you been able to communicate with non-cognitive persons and if so how?

10. In general, do you think the families are actively involved in the care of the demented individual or are they somewhat disconnected. What has been your experience in general?

Signature: _____

Date _____

QUESTIONNAIRE FOR **MEDICAL DOCTORS** WHO PROVIDE SERVICES OR CARE FOR
NON-COGNITIVE (PARTICULARLY DEMENTED PERSONS).

1. Your name and position _____
2. Your level of education/Field of expertise _____
3. Employer name _____
4. Your address and or contact info _____

5. For how long have you been practicing medicine and caring for elderly
persons? _____

6. Would you consider demented individuals socially dead because of their loss of brain
function? What is your professional opinion?

7. Do you think it is possible to communicate with them despite degeneration of brain cells?

8. Have you been able to communicate with non-cognitive persons and if so how?

9. Do you think it might be important to provide spiritual services to a non-cognitive Christian person and if so why?

10. In general, do you think the families are actively involved in the care of the demented individual or are they somewhat disconnected. What has been your experience in general?

11. Does Medicare cover treatment for Alzheimer's patients? If not, do you know why they are excluded and in your opinion, should they be covered?

Signature _____

Date _____

QUESTIONNAIRE FOR **CLERGY/CHAPLAINS** WHO PROVIDE SPIRITUAL SERVICES
TO NON-COGNITIVE OR DEMENTED PERSONS

1. Your name and position _____
2. Your level of education _____
3. Employer name _____
4. Your address and or contact info _____

5. For how long have you been providing Spiritual Services/Pastoral Care to non-cognitive persons? _____
6. In the absence of verbal communication, at times do you feel lost and unsure of what to say or do? Answer Yes or No? _____
7. Have you received any specific training either through courses at Seminary or elsewhere that deal with providing pastoral care to demented or elderly persons? If so, explain.

8. Would you consider demented individuals socially dead because of their loss of brain function? Explain what you think.

9. Have you been able to communicate with non-cognitive persons and if so how?

10. Do you believe that it is important to provide Spiritual Services to non-cognitive persons and if so, why? State any theological or moral reasons to do so.

11. Do you believe there is any scriptural support to provide pastoral care to demented individuals and if so, what are the specific passages of Scripture?

12. What do you think the implications may be (if any) for a Christian patient not to be connected to God? Are there theological or scriptural reasons to stay connected with God despite loss of brain function?

Signature

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