

# The Pastoral and Spiritual Care for the Deeply Forgetful



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## Abstract

The aim of pastoral and spiritual care or direction for the deeply forgetful is to help them connect with God even in the midst of their challenges and explore other means of communicating with them. This paper examines the theological and moral reasons to provide pastoral and spiritual care to them that are deeply forgetful and have limited or no cognition at all, as a result of dementia, Alzheimer's, certain other medical conditions and the aging process which may have caused a loss of brain function that have affected memory, thinking, behavior and judgment. It tries to answer the question whether there is any need for pastoral and spiritual care to such persons especially when there is no verbal or non-verbal response.

## Introduction

Our cognitively oriented culture finds it easy to forget forgetful persons. The deeply forgetful in the darkest and most vulnerable moments of their lives, need greater love, compassion and commitment from their families, caregivers and society at large. Some believe that persons with dementia need little or no pastoral and spiritual care [1]. Unless this perception changes demented individuals will continue to be dehumanized and undervalued as if they have no soul. 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, and raise the dead, cast out devils" (Matt. 10: 7-8). Therefore, in terms of methodology, we shall be applying the Judeo-Christian concepts of "seeing things as God sees them" (1 Samuel 16:7) for pastoral and spiritual care to be effective.

This paper is telorded towards that process and to the continuance of that 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. 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 [2]. Consequently, a new paradigm of pastoral and spiritual 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 and spiritual care that requires the use of these abilities will not accomplish anything. However we suggest the new paradigm of using past memories, validation therapy, and the use of senses especially touch along with old rituals, hymns and symbols that trigger memory to be used. 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 and spiritual care they can connect with God through whom they can find comfort and peace. God is very visible and present in the midst of this dreadful disease the theological and moral reasons to provide pastoral and spiritual care must be clearly understood in order to value the soul and life of the individual who is being cared for. Therefore, 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 the deeply forgetful and in turn help them connect with God. It will also help families of the deeply forgetful persons, caregivers, peers, pastors and researchers to better understand ways in which to love and care

for these frail humanity. It is only when one's own understanding is awakened that one can hope to have something to share with others.

### The Deasese

Dementia is the gradual deterioration of mental functioning that affects memory, mood, thinking, concentration, and judgment. These changes often affect a person's ability to perform normal daily activities. It is an illness that usually occurs slowly over time, and usually includes a progressive state of deterioration. It includes decline in memory, and at least one of the following cognitive inabilities: ability to generate coherent speech and understand spoken or written language; ability to recognize or identify objects, assuming intact sensory function; ability to execute motor activities, assuming intact motor abilities, sensory function and comprehension of the required task; and ability to think abstractly, make sound judgments and plan and carry out complex tasks. The decline in cognitive abilities must be severe enough to interfere with daily life. It occurs primarily in people who are over the age of 65, or in those with an injury or disease that affects brain function. While dementia is most commonly seen in the elderly, it is not a normal consequence of the aging process [3].

People with dementia find it difficult to do such things as remember what has happened to them, communicate with other people, and undertake different skilled social behavior. Dementia is usually seen as a memory disorder comprising forgetfulness, primarily about recent events; disorientation regarding time, place and person; grasping items of new information; communication with other people; personality changes and behavior disorders. However, it is more accurate to think of it as a wide range of physical, emotional, behavioral and social impairments that progressively undermine their ability to undertake socially accepted activities of everyday life. The earliest signs of dementia are usually memory problems, confusion, and changes in the way a person behaves and communicates. Cognitive symptoms of dementia can include poor problem solving, difficulty learning new skills, and impaired decision making. Behavior changes can include fear, insecurity, anger, and often, depression like symptoms. Dementia is caused by various diseases and conditions that result in damaged brain cells. Brain cells can be destroyed by brain diseases, such as Alzheimer's disease, or strokes (called vascular or multi-infarct dementia), which decrease blood flow to the brain. Alzheimer's disease is the most common cause of dementia.

In most cases, the symptoms of dementia occur gradually, over a period of years. Symptoms of dementia caused by injury or stroke occur more abruptly. It affects emotional behavior or personality, language, memory, perception, thinking and judgment (cognitive skills). It usually first appears as forgetfulness. Difficulties often begin with memory, progressing from simple forgetfulness to the inability to remember directions, recent events, and familiar faces and names. Other

symptoms include difficulty with spoken communication, personality changes, problems with abstract thinking, poor personal hygiene, trouble sleeping, and poor judgment and decision making. Dementia is extremely frustrating for the patient, especially in the early stages when he or she is aware of the deficiencies it causes. People with dementia are likely to lash out at those around them, either out of frustration or because their difficulty with understanding makes them misinterpret the actions of others. They become extremely confused and anxious when in unfamiliar surroundings or with any change in routine. They may begin a task, such as cooking, then wander away aimlessly and completely forget what they had been doing. It is also often accompanied by depression and delirium, which is characterized by an inability to pay attention, fluctuating consciousness, hallucinations, paranoia, and delusions. People in advanced stages of dementia lose all control of bodily functions and are completely dependent upon others [3].

### Possible Causes of Dementia

Dementia is often caused by the death of brain cells. Brain cells can be destroyed by brain diseases, such as Alzheimer's disease, or strokes (called vascular or multi-infarct dementia), which decrease blood flow into the brain. Lewy body dementia is another common cause attributed to changes in brain tissue. Other causes may include AIDS, high fever, dehydration, hydrocephalus, systemic lupus erythematosus, Lyme disease, long-term drug or alcohol abuse, vitamin deficiencies/poor nutrition, hypothyroidism or hypocalcaemia, multiple sclerosis, brain tumor, or diseases such as Pick's, Parkinson's, Creutzfeldt-Jakob, or Huntington's. Dementia can also result from a head injury that causes hemorrhaging in the brain or a reaction to a medication. There is currently no known way to prevent dementia associated with Alzheimer's disease. You can decrease your risk of dementia associated with stroke by maintaining a healthy lifestyle, following a heart-healthy diet, and controlling high blood pressure and high cholesterol. Healthy lifestyles, including not smoking and not abusing drugs and alcohol, go a long way in keeping most people in good health. It is important to learn all you can about the disease, seek the help of support groups, and find a responsible caregiver who can give you a break when needed. And above, it is important to know the stages within its development:

- a) **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.
- b) **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.

**c) 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.

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

**e) 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.

**f) 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.

**g) 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 [3].

### Management of THE Disorientation

Once you accept that a demented person is a disoriented person, then you begin to adapt yourself to the new world of disorientation, unless this fact is known and accepted you cannot be of any help to the person suffering from this illness.

Thus one has to learn how to communicate in this "new world" which can be referred to as "Dementia World". When one accepts this dementia world, one learns that opposites can indeed attract. And stick together like glue. Imagine communicating with someone for 50 years or longer. Suddenly the person changed. He or She is no longer the person you always know. If not, then who is he or she? This person you always know starts acting and coping with the world in new and different ways that is strange, bizarre and unsettling. Many of these new behaviors make you angry, they drive you crazy, you feel out of sorts. You just cannot understand it. You continue to try to make sense of what is happening in the way you always have. It does not work. Every day, many times a day, you are at wits end. You do not know what to do. You know that something needs to change and that something is you.

Communicating and accepting Dementia World takes a lot of energy, learning, and patience. In order to begin the process of dealing with communication in a world filled with dementia you first need to make a simple important decision -you want to decrease both your stress as a caregiver, and the stress of the person suffering from dementia. Because what you believe to be true, and what the person living with dementia believes to be true are often diametrically opposed sometimes the exact opposite. Here is the one thing you need to understand. Your view of reality and your loved one's view of reality might be very different. They are different. Ask yourself, what are you doing and how are you reacting when someone living with dementia says something you know to be incorrect or untrue? What are you feeling when this happens? Are you constantly correcting them? If you are constantly correcting a person living with dementia you are heading for the big stomach ache in the sky and anger, stress and angst will always be your routine.

However in order to overcome these emotional outburst you need to start accepting that when a person living with dementia says something they believe to be true it is in fact a reality. It is their reality. In dementia world, reality takes on a different shape. Reality is a reflection of what the person living with dementia thinks and believes. It is this reality that you must focus on, not the way you think things are, or should be. The suggestion here is to develop a frame of reference, a new and different behavior pattern that is one hundred percent diametrically opposed to the way you think and act -the way you thought and acted for your entire life, though this is not easy. It could be one of the hardest things you have ever tried to accomplish. When you accept the Dementia World you start a process of redefining reality, that is, instead of trying to place your loved one back into your reality, you start to interact with him/her based on his/her own view of reality. This new form of life style or communication technique adopted will lead to less stress, anger and angst over time. Less stress build up across a series of situations, leads to less anger and nutty behavior from the person living with dementia. When this new reality is accepted Dementia World becomes a place of peace and understanding. The goal in all communications with

a person living with dementia should be to connect with the person in a positive, constructive and effective way. To establish a positive pattern of communication requires you to develop calm, effective responses that are easily accepted by the person suffering from dementia. By establishing positive patterns of communication and lifestyle over a series of situations you learn how to deal with the new reality that is at the core of what is called Dementia World. The more you practice this, the better you understand it and the sooner it becomes another dimension in your life [3].

It has to be noted that while a person living with dementia cannot remember, they are still full of feelings and emotions. Therefore, as a caregiver, when you try to correct a person living with dementia you are likely to bring out a negative emotion in him/her. How would you like to be told over and over -you are wrong? How would you like to be corrected over and over? How would you like to be an object of scorn or exasperation over and over? How would you feel? What emotions would you likely express? Would you like the person that is constantly treating you in the way I described above? Would you be nice to him/her? I'll let you decide the answer! Effective communication with someone suffering from dementia requires you to identify the emotion behind the person's words and to learn the ways to address what they are feeling and to validate those feelings. It is likely that when a person living with dementia says something that is opposed to reality as you understand it -that you immediately feel an urge to correct him/her (or worse).

This is a normal feeling and reaction. It is okay. But only to the extent that you understand this (Dementia World) is the way you communicate in the other world. Coming to an understanding that you must develop new and different ways to communicate in the new world "Dementia World", is an essential step towards effective care for the person living with dementia. Although change is never easy, you will need to practice this every day. If you are caring for someone with dementia you will need to go into his/her world -Dementia World. The first steps are to start listening to what he/she says. To accept what they are saying as a "reality". They believe it to be true, why would you not? Understanding that Dementia World's reality is different is a big and important step, a necessary step to communicating effectively with someone that lives with dementia.

However while you are on it, try and remember that they have dementia. You are the caregiver. It is really up to you to change. It is up to you to adjust. The person living with dementia would adjust if they could but he/she cannot. That is just the truth about their condition.

### Use of Nonverbal Communications

It is not easy to learn how persons living with dementia think, feel, and act; and, why they do what they do. When a person living with dementia changes the way he/she communicates with us most of us become confused, disconcerted, upset, frustrated, and then angry. This happens because we continue to communicate

with them in the way we always have over the course of our lives. Sooner or later most of us realize, this is not going to work. Meet harsh words with an equal and opposite nonverbal communication, especially meeting meanness with kindness. Persons living with dementia respond better to hand movements and facial expressions than to speech, this is called "adaptive interaction". "Adaptive Interaction" is based on an approach used by those coping with communicative impairment caused by a stroke, learning disability or severe autism, known as Intensive Interaction. This technique is based on developmental theory that traces how all human beings learn to talk by building on the non-verbal communicative abilities with which they were born. Often being a "guide" is more effective to the deeply forgetful than being a "boss" or a parent. Thus starting with a smile; and then, waiting until you receive a smile in return [3].

Communicating with individuals with advanced dementia in their own terms can have a profound effect on the lives of those living with the illness, according to a specialist in the subject Dr. Maggie Ellis; she says that working with an individual's "non-verbal language" can allow families to connect with loved ones in most powerful new ways. The researcher says the method is a simple but effective means that relatives and professional caregivers can use to retain or create an emotional bond with individuals with advanced dementia. Dr. Ellis developed the method of "reaching out" to individuals in advanced stages of dementia with fellow psychologist Professor Arlene Astell. These researchers found that people with advanced dementia respond more readily to reflections of their own communication behaviors than to speech. Working closely with local nurses, individuals living with advanced dementia and their families, they have witnessed had first-hand the 'transformative' impact of the intervention they call "adaptive interaction". For Ellis "It really is a case of going back to the basics".

At first people find it strange or awkward to communicate with an adult using non-verbal communication such as hand movements or facial expressions. It requires time and effort, but the important thing is that it really does work [3]. Ellis writes further that she witnessed some really profound reactions to this type of communication. For some families, it is the only way they have left to engage in meaningful interactions and retain a close connection with their loved ones. They often describe the discovery that they are able to stay in contact as "an amazing feeling". For professional caregivers, the approach provides them with the means of connecting with individuals they care for in a way that may have been previously impossible [3]. Although many of the things the persons living with dementia do and say, often seem odd and annoying. There is no doubt that the deeply forgetful often see things differently in Dementia World. The questions we have to ask are: Why are such behaviors so disconcerting and unsettling to us? Why do we let behaviors that we should have come to expect bother us? Over time we should learn that we are going to hear and see these behaviors over and over. Would it not be easier if we looked at the world from the

viewpoint of the person living with dementia and accept them as normal?

They are, of course, normal in a world filled with dementia. It might be useful to ask yourself, "Why am I allowing the little things to bother me and above all to annoy me. However, once you begin to accept and understand that these new and unexpected behaviors were normal for a person living with dementia you will be able to make it to the new world -Dementia World.

### 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. Naomi Feil introduced the concept of "validation therapy" [4] 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.

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 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 that 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. 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 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 [11].

### Communicating Through the Liturgy and Liturgical Formulae

Liturgy comes from a Greek word "leitourgia" which referred to any public service or function exercised by the people as a whole. It equally means an established formula for public worship, a proscribed ritual which many religious bodies use in their services and in their ceremonial rites. The people who do the work of liturgy are the people of God. Liturgy is worship, but not all worship is liturgy. While worship can be a private act, liturgy is always a communal activity. A working definition of liturgy that I find helpful is 'the official, public worship of the Church'. Liturgy is always an action, something we do; it is not simply a text in a book. Liturgy is a public action, a ritual action, and a symbolic action. We participate in the action of the liturgy

by responding, singing, listening and joining in the gestures. The tangible words and actions made by the Church in liturgy signify the mysterious Word of God who acts in our midst; in fact, the liturgy actually makes present God's action in the world since it is Christ who acts in the worship of the Church, Christ's body.

It is in the proclamation of the word that God speaks to us; it is in the breaking of the bread that we recognize Christ. This description emphasizes that the liturgy is not only communal and public but is the official worship of the Church made present in the gathered assembly. In this act of the Church, Christ acts to save us.

Not everyone can express the depth of this reality in words, but everyone can take part in the singing, the prayers, the scriptures and the sacramental gestures and know that by their participation they touch the mysterious presence and grace of God. In the sacred liturgy the Church celebrates the mysteries of Christ by means of liturgical formulae of signs, symbols, gestures, movements, material elements and words. In this instance we focus on those liturgical formulae that could help the deeply forgetful get connected to God and to the immediate environment [12].

**a) Music, Old Hymns and Rituals:** The creative nature of music serves to facilitate interpersonal contact, communication, self-expression and growth. It can help connect the past to the present. Music is also an integral part of worship [3]. 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 [13]. 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 [3]. 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 [14].

**b) Symbols and Past Events That Trigger Memory:** A religious symbol conveys its message even if it no longer understood consciously in every part. For a symbol speaks to the whole human being and not only to the intelligence. 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 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 [3]. Support from individuals and a personal relationship to God helped patients with coping. 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 [15]. Some reported that nature helped them connect to God. Matano reported that a clergyman helped make a spiritual connection to God [16]. The most often reported spiritual coping strategies were prayer and church attendance even though they depended upon others to transport them to church. One participant used meditation while walking [15]. It is difficult but not impossible to reach a cognitively impaired person spiritually. 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. 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 [3]. 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. 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 more effectively in the end stages when verbal communication is reduced to a word or two [3].

### c) **Theological Reasons for Pastoral and Spiritual Care:**

The theological reasons for the pastoral and spiritual care for the deeply forgetful are rooted in the dignity and right of the human person. This is because where life is involved; the service of charity must be profoundly consistent. It cannot tolerate bias and discrimination, for human life is sacred and inviolable at every stage and in every situation; it is an indivisible good. We need then to show care for all life and for the life of everyone." [17] Therefore, a person's true worth does not diminish as a result of certain health challenges, it becomes an assault for a system of society to diminish and devalue the humanity of others as socially dead or insignificant based on the condition of life. Certain human rights are so fundamental that they can never be gainsaid without belittling the dignity of the human persons. In this regard the International Pact of 1966 (art. 412) presents certain rights that can never be put aside, e.g., every person's inherent right to life, recognition of the dignity of the physical person and the fundamental equality of persons, freedom of conscience and religion [18].

There are other rights of a lesser nature but also basically essential. Among these are civil, political, economic, social, and cultural rights concerned with more particular situations. Indeed, in some sense these rights will appear at times as contingent consequences of fundamental rights, as conditions involved in practical application, and also as closely bound to actual circumstances of times and places. Consequently, provided there is no denial of the fundamental rights themselves, these lesser rights may present themselves as less immune, especially in difficult circumstances [18]. The concept of the dignity and right of the human person in a very special way was worked out under the influence of the Judeo-Christian doctrine on man. Today, however, whether through misinterpretation or direct violation, it is too often seriously obstructed and even disfigured in various places especially in the healthcare system. We can find the source of this dignity and right of the human person in the scripture confirmed by reason and experience. "God created man in his own image..." (Genesis 1:27). To truly love another person is therefore, to want his or her true flourishing, and this holds true regardless of one's socio-political and cultural background, and above all to treat others as ends in themselves and not as mere means to an end. In other words, we should treat all human beings as persons who possess the same gift of free will that we ourselves possess, and not as mere object.

Human dignity and right are intrinsic and absolute value of the human person for the mere fact that he or she is a person, and not because of his or her race, religion, achievements, age, health, or any other characteristic. This notion is however not presented univocally today some define it in terms of man's absolute autonomy without any relationship to a transcendent, denying moreover the very existence of

a God who creates and cares. Others, while certainly taking due account of human intrinsic worth and honoring his personal freedoms, in a word his relative autonomy, sees all this as ultimately grounded in the supreme transcendence of God, even if this is presented in differing versions. Finally, others find the source and meaning of man's status, at any rate since the fall above all in man's union with Jesus Christ. Judeo Christian tradition holds a concrete teaching that the human person is a unity of body and soul. Human reason has also reflected on and refined this ancient truth about the unity of the human person. Since a person's body is an intrinsic dimension of him or her, it is not like a vestment that I can choose to wear or not. The human body is not simply a complex organism; it is a human body, the body of a person therefore deserves some honor even in its most frail moments struck by dementia.

d) **Theology and the New Paradigm:** The new model of pastoral and spiritual 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. According to Augustine a "man is not merely a body or merely a soul, but a being constituted by body and soul together [19]. 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. 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 self-same person rises again and "this is affected by the self-same soul being united to the selfsame body [20].

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 and spiritual care will also reflect the understanding that about 70% of communication that takes place is non-verbal. 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. The person who provides pastoral 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. When communication is established through reviving past memories, the gospel can be presented and a connection made with God [3].

The inherent value of a human being therefore, 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. For Thomas Aquinas

it was the human ability to think and reason and use language and art far surpassing the abilities of animals. 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 son ship, in that Christ is the Son in its fullest sense [21]. In speaking of the uniqueness of human creation in God's image Philip Hughes says that man, whatever his affinities with the animal realm, is radically distinguished from all other earthly creatures by the fact that he alone has been created in the divine image and is intended by constitution to be a godly creature [22].

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 proceeded 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." [23]. Additional theological reasons to provide pastoral and spiritual care are found in several passages of the 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; 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 [3]. 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 scripture 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". 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. 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, 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 God, 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 for Pastoral And Spiritual Care

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. When working with this population Elliot states that it is of utmost importance to both give and receive love [24]. Brennan 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 [25]. Similarly, Davis realized he needed much love in his life and asked that it be part of an effective pastoral intervention [26]. 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 [27].

There have been innumerable instances in which Deborah Everett 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 [9]. 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 dementia unique and deserving of respect, honor, and care because they have inherent value [28]. 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. 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.

### Conclusion

A point to always remember in pastoral and spiritual care for the deeply forgetful is that as the disease progresses, the deeply forgetful persons may no longer be able to remember God’s everlasting promises. But no matter how profound the degree of dementia and confusion, there is a holy place inside that still recognizes and responds to God. As cognition deteriorates, their thought process becomes more fragmented and forgetful. Therefore, pastoral and spiritual care to persons 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 and spiritual care to demented 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 [29]. The very essence of pastoral and spiritual care is more about listening than speaking. While many of the stories related by dementia patients 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." [9] We have absolutely no evidence other than assumptions that God is unable to commune with the deeply forgetful individuals. I have witnessed some precious demented soul pass on to glory with a smile on their faces. How can this be explained other than an encounter with God? It is a grace to be a caregiver and a pastor of souls.

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