

Chapter Five

Spirituality: The Skelton Key for Dementia Care

“Older adults need a vision, not
Only recreation,
Older adults need a dream, not
Only a memory,
God
A Soul,
And a moment,
And the three are always there...”

By Rabbi Abraham Hershel

When I repeatedly asked myself the question as to what should be the purpose of a meaningful model of dementia care, I have said that our guiding principal would be the goal of maintaining the connection of our loved ones with themselves. This will lead them to their loved ones, to their joyful memories, to their spiritual aspirations, and to their life long

ambitions for a meaningful, purposeful life. Is not that the point of life with or without dementia?

Rather than attempting to take them out of themselves with Reality Therapy, behavior modification, or distraction, we should be looking for ways to help them maintain the connection with who they are, who they have been, and ultimately, revivifying their souls. After all, bingo, for example, may have a role, but it is not meaningful as a way to add purpose to who they are and who they have been. Maybe my mom was a cleaning lady or a doctor, was married, or had five children, but bingo only takes her away from who she is and was; takes her away from her determined life. This game leaves her soul unmoored and floating into oblivion in numbers and letters that have little to do with her life's pilgrimage. And maybe this game is just dissonance to an effort to recapture her elusive soul

In this chapter I will take up spirituality in the context of attempting to maintain connection with oneself. In future chapters I will look at other dimensions such as communication, activities, architecture, and families. But spirituality is the tip of the spear. After all, if the life experience of someone living through the dementia lens is dominated by long term memories, what long term memories could be more profound and comforting than our formative religious experience? I keep reminding myself, I was a raging atheist in my 20's, but I was an altar boy when I was ten....

So in regards to spirituality, this then leads to the natural question as to what is the spiritual journey of someone with dementia and how can it be enhanced? And of course the troubling question as to when does that journey end? As I have said, this is the threshold question, in that it addresses the common human dilemma of dementia and how many of us can and should, respond.

This is of course counter intuitive as it relates to how we presently see and treat our loved ones. Currently, the way we manage those afflicted with dementia, is through redirection and seemingly harmless un-truths to manage behaviors. If they try to leave the house to go to “work”, we roll them in front of a TV. Or if they say that their father, who has been dead for forty years, is taking them out to dinner, we typically respond that he has just called again to say he can’t make it and they should plan on staying home tonight. We even have a name for this technique, the “therapeutic lie”, which is utilized constantly. But little thought about the needs of the soul; little thought about honest communication or their needs. I remember when my mother was dying, she couldn’t speak, but she cried when I spoke to her.

This is not to say that there is no practical value to these fibs. Often care givers can be overwhelmed by constant repeated questions, but only that they should be used sparingly. Recently, when visiting a community in Albany, I was asked by a resident no less than fifteen times in twenty

minutes, if I had a light! We will return to this topic in the next chapter.

This question of connecting one to themselves, is a threshold issue when the disease progresses to a certain point, when the “self” starts to become elusive. When the grip on ourselves weakens and we risk becoming incoherent babblers in our expression and thought. We need to consider ways of reinforcing their weakening clutching grasps.

This tipping point becomes critical to our family connections. As mentioned earlier, once we are no longer recognized and we conclude that our loved ones are gone, their soul is gone, and that their spiritual journey ceased. The situation becomes either a crisis, or a rationalization for escape. I often hear, “that is not my mother, that is a husk of her person”, and once this conclusion is reached, the spiral of spiritual and physical death dramatically and prematurely accelerates.

Using the soul as our North Star is completely overlooked in our institutional models of care, and that is a tragedy. After all, the soul is all we actually have in this world. It is the only certain reality, our only ultimate reality that we can actually know. We are not our bodies, or our jobs, or children. We are only our souls and memories collected in our soul’s memory; nothing more or less. Our souls are our touchstones to all of our other realities. So much of how we treat the tragedy of

dementia, turns on our notions of the soul, whether justifying abandonment, or unconditional love.

In this sense, steering for the soul should be the overarching guide for any meaningful model of care for someone with dementia. In this way, by enhancing ones' connection with themselves, we are targeting the ultimate reality therapy; themselves. If what we are afraid of losing of our loved ones to dementia forgetfulness, then we should attempt to connect them to their souls, their humanity, and their ballast in their historic existence.

So for those who struggle with the question as to whether the soul forever abides or prematurely departs through dementia, or whether one's spiritual journey moves forward despite the disease, and how we can maintain a strong connection with our loved ones to themselves, I would like to return to a few ideas touched upon in Chapter Two that bear repeating here as we can more meaningfully appreciate the actual life experience for even someone passing through the advanced stages of the disease:

Number One: We never lose our sense of time and space. Whether we are healthy, or afflicted by dementia, we live in time and space. And though we believe Dad is gone, he is right here living and experiencing time and the world around him. Remember, all sentient beings are hard wired for time and space, and this human characteristic is elemental and ongoing

even as we decline into dementia. My mom may not know my name, but she is still living in, and experiencing this world. The switch of time and space does not go off until we do.

Number Two: Even for those with dementia, we never lose our intuition about those around us. We know who is kind or impatient, indifferent or generous. We are far from husks and we know this from patients with the disease that have recorded their observations such as Gregg O'Brian, who writes "While Alzheimer's can ravage a mind, it cannot erase instinct..." Not only do we live in this world, we continue to interact emotionally with those around us. And perhaps more to the point, our never changing souls that we discussed in Chapter Two, continue to interact emotionally with those around us.

Number Three: Because when one loses short term memories, and finds oneself awash in long term memories, many of us, will also find ourselves in a place dominated by religious and spiritual memories. As a new care giver, I was always stunned by the way our residents responded to a rosary, a spiritual chorale, or the reading of the Haggadah. Though a resident has not spoken in months, they will often join in the reading of a prayer in their first language with perfect recollection of the words. This is a common surprise and joy for caregivers who thought they were caring for the living dead.

It should also be emphasized, that these religious memories, are not simply long term memories, they are often profoundly powerful memories that offered reverence,

purpose, and answers to life's most challenging problems. As mentioned above, I am keenly aware that I was a raging atheist in my twenties, but as I have said, I was an altar boy when I was ten. And that altar boy will never leave me, regardless of my age or my secular intellectual journey, and will reign over the atheist as I age. **The primacy of long term spiritual memories is the Third principle of the Peregrine Way.** Of course I fear for the generation that will age without the benefit of the comfort offered by this primordial solace.

It should come as no surprise as David Shenk reminds us, that the temporal lobes of our brains, which can be ravaged by plagues and tangles, “are responsible for primary organization of sensory input, for processing language and for ecstatic feeling of spiritual transcendence”. And he goes on to make the point that a “healthy temporal lobe stimulated by an electrical probe can spontaneously produce powerful religious images...”.

Naomi Feil reminds us that as we approach death we seek resolution with our families and our own personal failings, but we also seek resolution and reconciliation with our spiritual and existential needs and questions. This was clearly expressed by gestalt therapist Erving Polster in an interview when he was 94 when he said, “What is my life about? What does my life mean? What kind of life have I lived? What do I belong to? What am I part of?” This is not merely an intellectual concern, but a deeply emotional one for many of us as we approach “the dark night” of unknown death, and naturally look back. And if our

lives are dominated by long term memories, it is easy to see how early formative spiritual memories can influence that interior dialogue.

I have however been given some meaningful insights into the experience of someone living through dementia's conclusion, and the power of religious ritual, from one of my residents mentioned earlier, Maria. She became for me a splendid and gratifying example of the possibilities of an efficacious and compassionate model of dementia care where the connection to oneself is maintained, through the spiritual lens.

Maria was an Italian woman who spent her career as an executive working for the Internal Revenue Service. When I met her, she was not a happy person, but she unfortunately would constantly repeat the word "apple" while lying motionless in her Geri-chair, never engaging in conversation, unable to feed herself. She would simply stare in silence at the world with a blank expression. This seeming catatonic condition went on for many months. Often, to silence her aggravating chant of "apple", staff would either hide her away, or place a lollipop in her mouth. Her condition was what Naomi Feil would describe as Repetitive Motion.

For some reason I cannot explain, I was drawn to her. Maybe because she was beautiful, perhaps because I sensed a violent struggle going on inside of her. Despite her apparently comatose condition, something was fighting to get out. I

approached slowly and began to talk to her about my day and family. Slowly I began to touch her and after a month of soothing facial caresses, kind words, and especially the repeated recitation of the rosary in our newly built chapel, this religious woman began to open her eyes more, feed herself, and speak. She even became so verbal that I would put her on the phone with my wife, and they would talk about husbands and maybe long lost boyfriends. She seemed to have risen from the dead.

Time went by and all were grateful for Maria's improved condition, but one day after a month of casual conversations and inspired by Naomi Feil, I asked her why she always repeated the word "apple"; was her father a grocer or an owner of an orchard? She said immediately, "No, I was trying to get attention", in her grasping voice.

So to all the world, she was absent, and withdrawn into herself and her worldly obsession with apples, she was in fact in this world, emotionally aware of herself and people around her, and trying to interact. Yes, she said, while the past stilled rolled over her as she sat, but she was not gone and not unaware of time and space, remained emotionally connected to the people around her, and her long term relationship to the ceremonies of the Catholic Church, and her God. It seems that at least in part, the rosary played little bells calling her back to the world and herself.

And no, I never saw Maria receive a visit from her family. They assumed that she was gone a year before her soul actually left us.

As a programmatic matter, for the Peregrine way, we now build a non-denominational chapel in each of our communities, and in the case of our predominantly Jewish facility in Pikesville Maryland, a Shul complete with Torah, prayer shawls, and even a few phylacteries. In each community, we have a spiritual adviser to direct daily spiritual activities that could include services, religiously themed arts and craft projects, Bible study, and the singing of hymns and well recognized choral songs.

If one is stilling living at home, efforts should be made to maintain a connection with one's house of prayer and the community.

It is always curious to me, how much resistance I receive to these religious ideas from my staffs. They are often concerned about alienating agnostics and atheistic residents. But I think they are usually projecting their own values, and not the needs of our elderly residents. I remember when I wanted to build my first chapel in the predominantly Polish Catholic Cheektowaga, New York, I felt like I had a revolt on my hands; they wanted to have a work-out room! So to resolve the crisis, I left it up to our residents and one by one, I asked each their preference. After the vote, it was unanimous; they wanted the chapel. I remember leaving the building that day, and my administrator and star employee, Charlene Brosius, dropped to

her knees, and said she relented and would build our chapel. We both cried. And we let the residents decorate it with religious items from home to make it their own. (We built the work-out room a few months later.)

My staff failed to understand, I was not trying to proselytize or save souls. I was rather bowing to the power and primacy, of my resident's profound long term memories.