

Chapter Two

A Brief Review of Time, Space, and the Soul through the Lens of Cognitive Decline

I Wandered as a Lonely Cloud

I wandered lonely as a cloud
That floats on high o'er and hills
When all at once I saw a crowd,
A host, of golden daffodils:
Besides the lake, beneath the trees,
Fluttering and dancing in the breeze.

Continuous as the stars that shine
And twinkle on the Milky Way.
They stretched in never-ending line
Along the margin of a bay:
Ten thousand saw I at a glance,
Tossing their heads in sprightly dance.

The waves beside them danced; but they

**Out-did the sparkling waves in glee:
A poet could not but be gay,
In such a jocund company:
I gazed –and gazed—but little thought
What wealth the show to me had brought:**

**For oft, when on my couch I lie
In vacant or in pensive mood,
They flash upon that inward eye
Which is the bliss of solitude;
And then my heart with pleasure fills,
And dances with the daffodils.**

William Wordsworth (1815)

**(A wonderful poem touching on the power of memory
and the mind's eye.)**

Since Aristotle, we have always believed that time travels in a straight line; indeed identically straight and at the same rate, for all people.

But then came Einstein who told us time was relative, and Dr. Alzheimer, who showed us that when afflicted by the disease that bears his name, that it slows, goes backwards, and sometimes even swirls.

To understand the epidemic of Alzheimer's and other forms of dementia which leads initially to the loss of one's short term memory, and how it should be treated, we need to rethink our ideas about uniform time in the context of the afflicted, and follow the logical implications of time gone awry.

Since Immanuel Kant's 18th century Copernican revolution, where he placed the human mind at the center of the universe, I think it is widely accepted that the human mind imposes itself on the world and that time is fundamental to all we observe and experience. The concept of time and the very existence of time, flows from the mind, our minds.

After all, without the filter of the mind, the world is undifferentiated electromagnetic waves; no color, no causality, no time. Quite simply, the mind is hard wired for time. There is no reality experienced by a sentient being without the rush of time and no time without the mind. This is a powerful statement as to the unique role of the human experience and its contribution to the universe. No getting around it. It would seem that Kant's Copernican revolution is more than metaphor. We are literally the center of all creation, or rather, without the mind, creation is nothing at all. Or in the words of Dick Teresi and Judith Hooper, the brain is a "three pound Universe." And this is true of the mind with, or without dementia.

This insight into the relationship between the connection of time and the mind are endless, and not the least as it relates to our intuition about an afterlife or even the reason people consider suicide, thinking they might survive it spiritually. Perhaps one reason, is because we cannot even imagine time stopping, thus creating the intuitive impression of immortality. Try it. Close your eyes, and try to imagine time stopping. It cannot be done.

Running time is what we are, and try as we might, it is interminable. By the way, this is also true of space, we cannot imagine nothingness. No stopping time, no dismissing space; no wonder Christians and others have such literal conceptions about heaven. Our mental constructs of time and space are elemental to both the universe and how the brain functions, both before and after a diagnosis of Alzheimer's. It seems to me that this fact is often overlooked in the way we treat our loved ones with dementia. We seem to think that just because you're Dad doesn't recognize you that he has ceased to be human, that time and space has ceased to be relevant in his life experience; that he has somehow dropped out of time. This is a terrible mistake and these concepts will be revisited in Chapter Five.

On the other hand, the soul is constant. And this appreciation, must be embraced in the context of a dementia diagnosis and model of care.

We have a consistent awareness of ourselves that is enduring from our childhood to old age. I may not be familiar or certain of the ever changing world around me, but I always know what Stephen Bowman is. The body grows, evolves and fails, but my soul, my mind, my lens, myself, the nous, my essence, atman, or even shadowbox, whatever we call it, forever abides. Perhaps that is why old age and impending death can come as such a shock, or as the German writer, Johann Goethe said, “age takes hold of us by surprise”.

The soul simply does not grow old. But time shows us, that we do. I appreciate that using the word soul, I am complicating matters for some due to the religious connotations of that term and the sometimes modern philosophical dismissal of the concept. But regardless of the lack of a scientific basis for the concept, it is how we all live. What Avicenna, the 11th century Muslim philosopher, said in his “floating man” thought experiment is true for all of us; each of us can imagine ourselves floating free of all sensation but we are still aware of ourselves. We all know this and live with this intuition. This is why when someone dies, we say someone is gone, or passed away, though the body remains before us. We are talking about their soul, their essence.

But I repeat, the issue of the intransience of the soul is not offered up as a theological matter regarding an afterlife, but one of common practical experience. This notion is incisively taken up by Simon de Beauvoir in her tour de force “The

Coming of Age”, in which she relates the written record of some of our greatest Western writers and intellectuals as they reflect on their own life experience of the aging process. For her, this is taken up in the context of their being surprised by their physical decline which often leads to an unpreparedness for death. This in turn, then leads to an existential crisis. It seems that death was fundamental to the human experience from Gilgamesh to Heidegger, but not so much to people like you and me, preoccupied as we are, by youth.

She observes that we often “set up a fixed, unchanging essence, against the deterioration of age and tirelessly {we} tell stories of this being that {we} were, this being that lives on inside {us}”. And goes on to say, “ All { our} lives whether {we} are thirty, or whether {we} are fifty, {we} have still continued to be that child though at the same time {we are} that child no more.”

Beauvoir quotes many as to the strange experience contrasting the aging body to the lack of changes to the soul, but I will quote only two here: Andre Gide tells us near the end of his life that his “heart has remained so young that I have the continued feeling of playing the part, the part of a seventy-year old, that I certainly am...”. And the writer Francois Mauriac recorded at eighty, he was “neither lessened nor fallen nor made richer- but the same...”

This truth came home to me recently while speaking to a charming 82 year old Greek woman with moderate dementia,

when she told me over the phone that her body was old, but her mind was full of youth. I could see her smile.

This rings certainly true in my life. I can easily imagine that one day I will stare at my blue veined shaking hands and hear my mother laugh, listening to the Beatles in my head, and with images of making love to my wife wafting by. Memories yes, but they feel more like barnacles attached to my never changing soul.

We have more than memories, we have memories of our unmistakable constant soul living through those memories. Not only did I have a first communion, but I remember experiencing my soul's presence in that dark church, looking at the cross and feeling that cross the same way I feel today looking at that same cross. Everything at mass has aged, except my soul.

Memories apprehended through the lens of my ever present and constant self. My present is my past, and my past is present....

Standing in a hotly lit hallway driveway sundrenched day on my way home from my first communion from our Lady of Solace dressed in a white gown and gold cape walking toward the shimmering Tudor of my youth three presents are to be mine red and white bicycle fixed with training wheels satin mannequin doll as big as me and a gorilla shaped magnet strong enough to pull a car so the TV tell

us blue brown woody station wagon stopped toe head
brother in lederhosen and bow tie a running haystack
smiling. Plate's crash, hospital lights jar.

This does not change for those experiencing dementia.
Short term memory may become a mystery, but they live in
their long term memories accumulated in their souls, and never
lose their intuition about themselves, and those around them.
The soul abides, and yes, even though my Dad doesn't
recognize me, he is still there living in, and experiencing time
and space Again, we seem to overlook this fact in the way we
offer care. When Dad seems to be gone, we are, more often
than not, gone too.

So we have a challenge to our models of care for those
with dementia. Time runs straight and fast for all of us, yet the
soul stands fast above time. Rocks in a river bed. In that
sense, we are in conflict with the inevitability and inexorability
of time...unless of course, we are stricken by dementia. Then,
time becomes more of like a melody or a floating cloud. How
should we respond as caregivers?

To be sure, time continues to roll over those afflicted in
space, but it no longer has the same predictable sequence in
their space. Sometimes it seems to run straight over some

distant memories that are replayed and repeated in our dementia soaked minds.

James Joyce famously has his great character Leopold Bloom walking across a street in his novel “Ulysses”, but all the while he is thinking about his wife’s impending assignation, the death of his son, and breakfast. He is living, as we all do, entirely in his thoughts. He is walking in Dublin, in time and space, but he recognizes those signposts.

But for someone with dementia, he could be walking across the same street, but does so entirely in the past, and the signposts have faded into the corners of his mind. Time has largely ceased to have relevance to the thought process as it starts to slow, go backwards, and even swirls, as it moves straight over the palette of the soul.

I am reminded by a story told by the writer Laura Wayman from her book “A Loving Approach to Dementia Care”, who related that when coming across one of her dementia patients shuffling by in a hallway, she asks, “Frances, does it feel like you are dreaming”? “Absolutely”, came the answer in sudden clarity, and then, her eyes and face went blank and she continued on her way.

The irregularity of time for the dementia patient is usually overlooked in our treatment models, as we tend to want to force a traditional straight lines in our understanding of our loved one, as we try to save short term memory through

memory saving drugs and rigorous computer games. We seem to hope things can be set right again, if we just pull hard enough on the rails of their minds and at their time patterns. This impulse is understandable: I want to keep my dad near me, the way I know him.

In this way Reality Therapy always has a place in our desperate rational hearts;” Goddamn it Mom, it’s fucking Christmas morning!” But by failing to make accommodations for their different experience of the tempo of time, a distance is established, almost as if a different language might have been adopted

And equally overlooked is the concept of the permanence of the soul (or the self, for those living firmly rooted in Modernity). Emotionally, few of us would ever deny the existence of my Mom’s soul while she is healthy. If asked about whether we hold to the notion that her soul is ever abiding, we would mostly say yes, and we might even add that we would never leave her if she fell into a coma, or became profoundly ill.

But the reality is much different. Frequently when a loved one is afflicted with dementia and the adult child becomes unrecognized, the personal care stops, and the visits end. And God forbid, if the loved one starts to become agitated or angry during a visit, the adult child, consciously or not takes the position that the loved one is dead, the soul is gone. “That’s not my Mom.”

In those Memory Care Communities we operate, we often have only 15% of our residents receive regular visitors and the hard and gratifying work of care and unconditional patience is turned entirely over to strangers.

There seems to be a tragic line that many are often tempted to cross where we equate advanced dementia with a kind of premature death. This is usually a private conclusion manifesting itself in our behaviors and indifference. But one example of an explicit declaration of this thinking was offered by the televangelist Pat Robertson in an interview on “The 700 Club” program. As reported by John Swinton in his book “Dementia: Living in the Memories of God”, a caller asked for advice regarding his friend’s wife who had advanced dementia and “no longer recognized him”. “The caller informed Robertson that his friend’s wife was gone, and that he was “bitter at God”, and has started to see other woman”.

Robertson’s reply shocked many as he expressed thoughts that most of us keep to ourselves.

“ This is a terribly hard thing Mr. Robertson said, clearly struggling to think his way through a wrenching situation. “I hate Alzheimer’s. it is one of the most awful things because here’s the loved one--this is the woman or man that you have loved for 20, 30, 40 years, and suddenly that person is gone”I know it sounds cruel, “he continued, “but if he’s going to do something, he should divorce her and start all over again, but

to make sure she has “custodial” care, somebody looking after her”. When Mr. Robertson’s co-anchor on the program wondered if that was consistent with marriage vows, Mr. Robertson noted the pledge of “till death do us part” but added, “This is a kind of death””.

This kind of thinking reinforces the institutional/warehousing model of care in our country that aspires to only care for the living dead, and is an assault upon compassion and creative empathy.

Both of these oversights regarding time and the soul have tragic consequences for our loved ones with Alzheimer’s. The constancy of time, albeit changed, and respect for the constancy of the soul should be fundamental to our attempts to create a much needed model for care for those afflicted by dementia. Is not joy and meaning still not possible for our loved ones, our future selves?

Put another way, if we want to create comforting and gently stimulating models of care with continued meaning for our loved ones living with dementia, these two polestars of the human experience must be considered.