

A Privilege by Jim Ruck

“Alzheimer’s.” This dreadful, early 2010 diagnosis as the cause of Gail’s growing mental lapses was devastating. Gail had retired about two years earlier. I had just retired from a demanding job that required much travel. I had already wanted to become involved with Gail locally in projects that we valued. The diagnosis confronted us with a choice: do we move into the disease, or run from it, or fight it.

Gail and I met in 1987, finding in each other the spark and the values that we had each long been looking for. Faith, community and service were values that motivate both of us all our lives and in our teaching careers. We found soul-mates in each other and a common trust in God’s provident care. How could I choose other than to embrace Gail along with the Alzheimer’s? The disease was a death sentence for her and for “us.” We agreed to participate in UPMC’s Memory Clinic, hoping to forestall the inevitable and to help future victims of the disease. Our decision though was to move into the disease, to make the most of our life together, one day at a time, walking consciously into the unknown. It was a decision made once but reaffirmed countless times ever since.

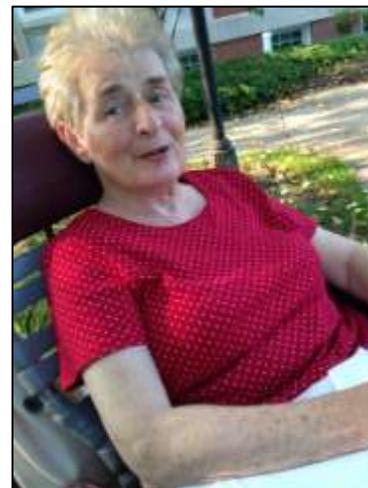
We intensified our volunteer commitments, Gail in working with Pittsburgh’s Hispanic community, as a Hospice volunteer, and in many parish activities, me at Jubilee Kitchen and as a volunteer chaplain at the county jail. We traveled a bit until that became too overwhelming for her. As the disease progressed, I accompanied Gail to her efforts and brought her along to mine. We had lots of good friends that we hosted at home. We maintained an active life walking, getting out to movies and parks, doing the volunteer work, collaborating in household tasks. As friends near and far learned about Gail’s condition, they held us in their concern and prayers. We continue to ride on their energy. Being able to laugh at lots of things every day was to me a sign of the blessing of it all. As a German with an interior temperament, I can’t force myself to laugh “naturally.” That laughs came was a sign of grace, and still is.

Until the summer of 2014, I was not yet doing intensive care-giving. Then things changed. One by one, each of Gail’s involvements became too problematic to continue. Hallucinations and agitation intensified. The strain of being present to Gail, supervising all her activities and doing the practical work of running the house, coordinating doctor visits, overseeing medications, etc., etc. was intense. A friend suggested daycare – needed for Gail (to learn to cope for part of the day without me, to give her a social outlet, etc.) and for me (to give time for neglected chores and some personal down time). Daycare was a life-saver, especially last winter. Hard as it was, coping one day at a time, out of control but confident that God would get us through, kept stress low and allowed laughs to continue.

I knew Alzheimer’s was irreparable. I had some knowledge already because my Mother had its early stages of forgetfulness before dying of other causes. Later, Gail’s Mom lived with us for her last two years and had some dementia. I did not want to learn much more about the dreadful decline. I didn’t want to undermine the present with worries about the future. Making the best of each day, one day at a time, was my priority.

From January, 2015, Gail’s decline accelerated. Caring for her at home, I realized that we were on thin ice, one setback away from disaster. We figured out how to cope with incontinence, her loss of interests, her decline in speech, my needing to feed Gail, and her incessant agitation. But the ice cracked in May. As a bad chest infection and UTI set in, Gail had a major seizure. This landed her in the hospital and from there, being unable to walk, to the Willows.

I was told, “You can’t be both caretaker and husband.” This bothered me: how can I NOT be both caretaker and husband? Our relationship had evolved into one that included much caretaking. But I needed help and lacked any local family support. So the Willows it is, now on the Fourth Floor’s dementia unit. I go every day, usually feed Gail lunch and/or supper, and stay until she is asleep. I want to do everything I can to reassure her, to ease any fear, and to keep her “sparkle” alive. Gail is a loving, social person. She brightens the lives of staff and residents and even visitors with “I love you. You are so special.” For 28 years I have been blessed by her smile and love. It is a delight to see her light up the lives of others, especially on the walks we have been able to take through the first floor.



Death is coming. I have many experiences of bone-crushing sadness. But I refuse to let death claim our lives before it arrives. Trying to make each day as good as I can is worth the effort. We sit. My mind wanders and I don’t know what is going on in Gail’s head. But I remember a comment from a friend whose wife died of a brain tumor: “I dreamed of us sitting on the porch when we were old.” Gail is far too young to be old. I don’t know how much older she will get. Sitting outside looking at the Presby’s lovely scenery, sitting waiting for her to fall asleep – these are special in a way I can’t describe. Listening to music. Looking at photos. Connecting with some of the other residents, visitors, and staff. Time is empty in a way, rich in a way – punctuated periodically by “I love you,” me to her or still her to me. Special. I don’t know how much Gail benefits from my presence. I think she does. I hope that it dissolves any lingering fear she might have. I know that I benefit from her presence. It is special time, PRIVILEGE.

Nurturing Hope: Coincidence? Make Believe?

My mind struggles to find hope in the midst of the desperation of Alzheimer’s. Waves of realization of the loss that has devastated Gail and our relationship leave me staggering. I try not to avoid the grief or to wallow in it. How to nurture hope? One glimpse came through a chance meeting not long ago.

In August I went to the local shoe repairman. My fairly new walking shoe had a large tear, which started small – from me trying to block Gail pushing back in her wheelchair. As I entered the shop, the repairman was bent over the counter speaking intensely with a customer, who left shortly after I arrived. I asked the repairman is everything was alright. “No, I got to bed after 2 AM because I was at the hospital.”

The man’s son, a doctor from rural Pennsylvania east of Greenburg, had come to town the day before to help his father make final decisions about a tombstone for the man’s wife who had died six months before. When the shoemaker saw his son, he said, “You look terrible. Are you feeling well?” “No!” He tired an Alka-Seltzer, then one of his Dad’s nitro pills. No relief. So the shoemaker insisted that he go immediately to UPMC East’s Emergency Room. As soon as he got there, they flew him to Shadyside where he was operated on for an exploded heart valve and a heart attack, a seven hour procedure.

I learned many of these details when I returned to pick up the shoes. The shoemaker mentioned, “If he hadn’t come into Pittsburgh that day, he would be dead.” Rural Pennsylvania just doesn’t have the medical expertise that would have saved him. From somewhere, out of my mouth came the words, “I think your wife had something to do with this. I think it’s more than coincidence.”

The following week, as I thought of this, I remembered a comment my sister made not long after I met Gail: “I think Mom had something to do with you meeting her.” Mom had died three months earlier, after hoping and hoping that I would “meet someone special.”

Often through Gail’s decline from Alzheimer’s I found myself saying, “Gail is dying. ‘We’ are dying. I don’t know where ‘I’ am in all of this.” Suddenly the realization dawned from somewhere: I am taking care of Gail now. After she passes, she will take care of me.

Wishful thinking? Make believe? Certainly not quid pro quo. But some hint that brought, and still brings, a lot of comfort.

Engaging Gail, filling visit time in satisfying ways

I continue to look for ways to connect with my wife during visits. Since late spring, she has been unable to follow a conversation or say more than a few words at a time. Gail has always been a social person who loves people but who lacks interests in crafts, playing cards, etc. Three activities have been particularly satisfying and fill much of our time during my visits.

1. Walking.

Walks have always been part of our relationship. As Alzheimer’s developed, we took long walks and then shorter ones – whatever Gail could do. This kept her healthy, vented pent up agitation, and used time together productively.

Now that she is largely wheelchair-bound with poor balance, I support her for as far as we can go. We are doing physical therapy hoping that her lean will improve. I also push the wheelchair around PSC and a few blocks across Hulton. She seems to enjoy the walking as well as being pushed! Along the way she connects positively with so many PSC staff and visitors who have been captivated by her sparkle.

2. Photos

As Gail’s stories and past memories declined, I wrote up as many episodes as I could remember and then put photos to them. For the photos, I used my cell phone to get digital versions of key photos from old albums and boxes. I steadied the iPhone on a chair in a well-lit place to get the digital files. Then I inserted them into the document. The booklet became her “bible” that she took everywhere. I would often read the stories to her and comment on photos. I got the photo idea from when my Mom had Alzheimer’s in the 80s. She had an album of family pictures that kept her oriented.

Then in late spring the words and even photos suddenly lost interest. As Gail declined further, I did simpler albums with fewer pictures on the page. This helped for a while.

Recently I put the photos on my iPad. The iPad gives one large photo at a time, which can be zoomed in, etc. Gail has re-engaged in them, at least sometimes. And it provides something to talk about. Even

looking at the same photos each time I visit gives Gail (who is living almost exclusively in the present) a “new” experience.

Also of possible interest, **Getty Images** is an iPad app that has thousands of photos. PSC has a guest Internet connection to pull them in. Searches yield related photos. Trying it on your loved one’s interests might generate conversation or at least engaging interaction. For example, fishing, children, mountains, lakes, animals, etc.

3. Music

Gail always had some favorite singers and I often put on classical music that I like. As Gail’s agitation progressed and other interests faded, music remained. Watching some videos from WQED fundraisers (Peter, Paul and Mary, John Denver, Celtic Thunder, etc.) kept her attention long after other TV programs no longer held her interest.

I put music onto an iPod that we use regularly at the Willows. Sometimes she will wave her hand or bounce her legs to the beat. Soothing music helps her relax when going to bed. Aides confirm this. I’ve noticed similar interest by some of the residents on the 4th floor of the Willows.

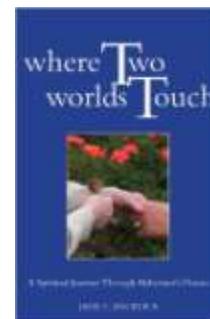
I also have it on my phone which plays into a portable Bluetooth speaker when sitting in her room or taking a wheel-chair walk.

I did one playlist of a dozen or so songs that are easy to sing. Singing or whistling to these engages her.

I share these activities that has worked for us and I welcome any suggestions others might have.

A very helpful resource

Friends called my attention to **Where Two Worlds Touch, A Spiritual Journey through Alzheimer’s Disease** by Jade Angelica. I’ve read it numerous times, repeatedly finding it helpful. Ms. Angelica, who had had a strained relationship with her Mother, moved from New England to Iowa to support her Mother with Alzheimer’s in the nursing home. She used her experiences from a few Improv classes to connect positively with her Mom, even in her delusional world. Angelica offers perspective on the human journey from her ministerial studies to become a Unitarian pastor. She has much advice about the importance of respecting and affirming the Alzheimer’s patient, about living in the present, about connecting with the emotion behind delusional words, about the forgetful patient holding onto and valuing the warm emotional memory of a good visit, about communicating beyond words – heart speech. And most importantly, of finding hope in it all and of continuing the relationship, even reconciling from past hurts. The book is steeped in her personal experiences as well as solid professional sources about the disease and navigating through it in a positive, hope-filled way.



I found Angelica’s insights and suggestions especially helpful around Gail’s hallucinations. She cites research that emphasizes the importance of the feelings behind the hallucinations: fear, inferiority, out of control, overwhelmed, etc. I guessed that the hallucinating mind may do what happens in dreams at night – re-figure events of the day so that the mind can deal with them anew. Angelica suggests

entering the hallucination rather than rationally denying it. And addressing the feelings. When Gail got angry about imaginary people attacking and belittling her, I sometimes screamed at them to let her alone and stop upsetting her. This helped.

At the Willows, I occasionally hear a resident say, "I'm afraid of dying." Angelica urges that this not be met with "You aren't dying! Stop being afraid!" Rather, "Yes, you must be very much afraid, but think of . . .," redirecting the person to something positive: a hope, something good about the day, another interest, etc. Easier said than done, but a path worth trying.

The Willows, Presbyterian Senior Care

My wife Gail came to The Willows after four traumatic days in the hospital following a major seizure. From the first, I was deeply impressed by how many of the nurses, aides, housekeepers and kitchen staff called Gail by name and soon took the trouble to get to know her personally.

A few weeks ago, the Willows had a day to celebrate successes in all departments of the facility. What I found missing in all of the display boards and charts was what I value most: this deep care for each resident, even those who are quite demanding or annoying.

I would bet that the increases in performance of patients in physical therapy and recovery has more to do with the quality of care than with ratcheted up professional expertise. I have seen staff struggle to meet the unique needs of individual residents, Gail included. Professional excellence and high standards are important, but their impact is heightened by the personalized touch. This spirit of caring and genuine friendliness is why I want Gail to be at the Willows.

A Wishlist for the Willows

I do have a few suggestions especially for the Fourth Floor and other dementia residents. They are not able to function in the individualistic neighborhoods outside or within the Willows.

More attention, I think, is needed to empowering residents and families to look beyond the "tragedy" of the accident or disease or aging that brought them to PSC. As a faith-based facility, more energy is needed to foster hope and a positive spirit in each resident and their families. More functional residents of the Willows are faced with diminishment from aging and/or from an accident or health problem that brought them to PSC. I wish there were more spiritual care available at Presbyterian Senior Care.

Everyone needs purpose in life. Making life "easier" on one level is good. Better is inviting residents and their families to a higher purpose: to embrace the cross of aging and diminishment, to name the blessings of each day (big or small), to pray for others, to reach out to help others, to look after one another as best they can, to be comforted and invited to deeper trust in God beckoning through the adversity, aging, and/or dementia.

Floors at the Willows are called "neighborhoods." In a neighborhood, residents are free to come into common spaces or to stay in their "homes" as they prefer. Dementia residents though can't make this choice. I think everyone would benefit from a more communal understanding of life at the Willows:

rather than have residents opt into recreational or spiritual activities, presume that residents want to participate unless they or their families opt out. Encourage ways of listening to other residents and interact. And encourage staff to engage residents in communication – with one at a time and especially with each other (unless the matter is in fact, privileged and private). Encourage resident interaction where possible, especially residents looking out for one another. Fostering “Community” takes work but yields great rewards.

In a few cases I see efforts to empower families to help their loved ones – by aides and nurses. Often I don’t. Some residents have regular visitors. Developing inviting ways to coach any interested regular visitor in how to stimulate and help their loved ones in other ways would improve the quality of life of both visitor and resident. And it would free staff to attend to those residents who are more in need. A few examples: showing families how to use the multisensory room on the 4th floor for their loved one (or to suggest similar ways to stimulate residents) could improve the quality of the visit and of the resident’s life; encourage families to take loved ones outside for fresh air and beautiful scenery and to avail themselves of other PSC opportunities; offer help, etc. Perhaps offer short coaching sessions periodically to families on ways to deal with dementia behavior and how to fill visit time in other productive ways (mini-support group sessions) with topics collected from visitors on that neighborhood.

Why I go to the Alzheimer’s Support Groups

More publicity is needed on the value of Woodside Common’s monthly Alzheimer’s support group, speaking to the chaplain or social workers, and other activities that address deeper needs.

I attend the support groups because I find the interaction very helpful. Last year while Gail was still at home and her condition was worsening, I got friends to sit with her, allowing me to attend a group close to home. Actually I was the only participant for a few months, allowing me to get personalized help and invaluable information about emergency procedures, planning, and a host of other things I hadn’t thought of. I was also given the Alzheimer’s Association Hotline number which I used twice for advice to unscramble Gail’s agitation and hallucinations, which had become overwhelming.

In later sessions, I connected with people whose loved ones were either further along in the disease or just beginning it. Sometime I got insights and new ideas. Sometimes I offered my own experience. In every case I experienced that I was not alone and came away heartened. Issues were brought up that I had not yet encountered or thought of. Insights made coping easier. And knowing that I could phone the leader if a problem became overwhelming was like going swimming, knowing that there was a life preserver – just in case.

I may have been able to cope without the support group. But life would have been more pressured, with fewer resources available, and Gail would have been deprived of the insight and advice I received.

How have I been able to stay so calm?

This question by one of Gail's aides, who experiences her decline every day, led to me saying "taking it one day at a time," my German temperament, and patience forged by 30 years of teaching adolescents. But there is something deeper.

From the outset of Alzheimer's diagnosis, I knew I was powerless to defy the illness. I experience this realization daily. I also have had abundant experiences of God's providential care in my life: everything that happens is for a good purpose, God's purpose – recognizable when we see clearly or when we look back later with better perspective. How can God let such horrible things happen to good people – or to anyone? This is mystery. I do know that when Jesus prayed in the Garden of Gethsemane to let this cup pass, his plea went "unanswered." But not my will but yours be done, this Jesus lived, finding the power to accept the Father's will and take one step after another to his death. Crucifixion was the ultimate act of love, revealing conclusively God's boundless love for us – in our brokenness: "Father, forgive them, they do not know what they are doing." Seeing clearly means seeing (often in faith) beyond the apparent loss and pain, trusting that there must be more. That is the power of the crucifix: not just pain and death, but love poured out and privilege – leading through, to fuller life for us all.

I do believe that Alzheimer's is the cross that Gail (and I) have been asked to carry, sharing somehow in Jesus' sufferings. Hard as it is, there are abundant blessings to be had – each day: in making it through the day, in appreciating little blessings, in being able to find much to laugh at, in growing closer as a couple, in having pleasantly surprising connections with friends and strangers, in seeing surprising vitality even in residents on the Willows' fourth floor, and many more.

For me to appreciate the "privilege," two things are necessary. First, live in the present and deal with one day at a time. To idealize the past or worry about the future makes Alzheimer's overwhelming. Trust is key. Life is a journey toward God, at least that is what we were created for. Trust in God; in my own creativity as new challenges arise; in friends and the power of their love, concern and prayers. Trust is pure grace. We can certainly make ourselves worriers, feeding all of the feelings triggered by overwhelming challenges. To purposely refuse to feed these fears, worries, guilt, feelings of inadequacy is a needed step. God gives us the cross but also the help to carry it, as he did Jesus. This I believe and it has so far proven to be true – not always to the head, but to my feet, one step at a time.

The second is a trust that the loss experienced each day is only part of the picture. Dealing with Alzheimer's we are at the edge of mystery: the medical unknowns, the mystery of diminishment, death and whatever is beyond. No one knows what God has ahead for us. Nor did Jesus: "My God, my God, why did you abandon me." Belief that life is beyond death does not ease the pain of approaching it. But do I cultivate hope or wallow in despair – when God has been so good to us in the past?

The Kiss

When Gail dies, I hope that I can be present like the woman I met some time ago doing my Hospice work. I joined Gail volunteering at Forbes Hospice when she was losing the ability to do it alone. When the chaplain learned of our backgrounds, he invited us to become Spiritual Care Volunteers, each week

visiting patients and/or their families in the in-patient unit. Sometimes visits were very short, sometimes just chit chat, and occasionally very profound. Gail was able to continue until the summer of 2014, long after her ability to follow the conversations waned. At appropriate times, she would add: "You are so special. God loves you." The words and still more their wholehearted thrust made her testimony especially compelling and appreciated.

After her decline necessitated daycare and now skilled nursing, I continued our outreach. One afternoon I entered the room of a patient, with his wife and son at the foot of the bed. We connected briefly around living in the same neighborhood. Then the woman stepped to her husband, leaned over, saying "I love you" and kissed him on the forehead. As she did so, she felt his breath on her face, his last breath! An amazing moment sensed immediately by the three of us: so sad, so special, so tender, so precious . . . What a gift!

That's what I want for Gail. I don't know if it will happen. On the nights when I sit with her waiting for her to fall asleep, I often say, "I love you." "God loves you. Jesus loves you . . ." Scripture testifies that love drives out fear. And love alone endures. Love, not just a feeling, but wanting what is best for Gail, wanting to be united with her. I hope Gail can remember how loved she is – now and in the days to come. And how privileged I am to have her love.