

Author(s): Nan Barbas, Laura Rice-Oeschger, Cassie Starbuck

License: Unless otherwise noted, this material is made available under the terms of the **Creative Commons Attribution–Non-commercial–Share Alike 3.0 License**: <http://creativecommons.org/licenses/by-nc-sa/3.0/>

We have reviewed this material in accordance with U.S. Copyright Law and have tried to maximize your ability to use, share, and adapt it. The citation key on the following slide provides information about how you may share and adapt this material.

Copyright holders of content included in this material should contact open.michigan@umich.edu with any questions, corrections, or clarification regarding the use of content.

For more information about how to cite these materials visit <http://open.umich.edu/education/about/terms-of-use>.

Any medical information in this material is intended to inform and educate and is not a tool for self-diagnosis or a replacement for medical evaluation, advice, diagnosis or treatment by a healthcare professional. Please speak to your physician if you have questions about your medical condition.

Viewer discretion is advised: Some medical content is graphic and may not be suitable for all viewers.



Perspectives of those who live with memory loss



Ken Saulter was born and raised in Cleveland, Ohio. He received his PhD in Economics from the University of California, Santa Barbara in 1976. He spent his professional career working largely with government and nonprofit research organizations. In his spare time, Ken ran 14 marathons. He is married to Diane Saulter and together they raised two, now married, sons.

GOOD FORTUNE

Ken Saulter

I've had a lot of good fortune in my life. I was able to survive an abusive father, get through high school and college on my own, have a satisfying career, have a terrific family with my wife and two sons, and mostly excellent health over 60 years.

When I think about my professional good fortune four events stand out, and, in particular four phone calls that offered opportunities that shaped my career and literally transformed my life.

The first was from my boss in Cleveland asking if I would be interested in leaving a Johnson & Johnson sales territory in Flint, Michigan, for a territory in Sacramento covering all of Northern California.

The second call was from the University of California, Santa Barbara, when the Chairman of the Economics Department asked if I would commit to entering the UCSB Graduate PhD Economics program with a three-year teacher's assistant stipend.

The third call was from my dissertation advisor. Would I be interested in spending a year in Washington, DC on a Ford Foundation Energy Policy Project working as a staff economist?

And lastly, there was the call from a State Department official asking if I would be interested in accepting a senior staff position with the United Nations Geneva office of the Economic Commission for Europe.

These four opportunities cover the period 1963 to 1976, a little over 10 years, and influenced the rest of my professional life and fulfilled a life-long dream to live abroad.

My professional life came to an end when I was given what many people would consider the worst possible news. But what might have been the end of my good fortune, has turned out to be a new set of learning opportunities.

The bad news was not delivered over the phone. It was delivered in person and ineptly by a doctor, a neurologist, in his office. The doctor told us -- in a rather cold way, sitting across a long office room, and talking over his right shoulder -- that I had Alzheimer's disease and he was sorry to be the one to tell me. My wife, Diane, asked some questions and received discouraging answers. In particular the doctor said that support groups are usually not helpful. We walked out of the neurologist's office without information, without direction, and without hope.

This was unacceptable. It felt like having a verdict of terminal cancer in the 1950s.

We began researching the Ann Arbor area for medical information and family support. And found an abundance of resources via the University of Michigan and the local chapter of the Alzheimer's Association.

Within the next months we had joined the "Coffeehouse" support group at the U-M for individuals with Mild Cognitive Impairment (MCI), joined a research project investigating long-term memory decline, donated my brain to science, AND joined a group in the neighborhood to do a white water rafting adventure down the Grand Canyon Colorado River.

As soon as I could, I began meeting with the Coffeehouse group and became aware of the available medical and care-giving resources and how large the Alzheimer's community was. We definitely were not alone! The fears that I had about my life narrowing and fading away soon were dispelled, at least for now.

We soon realized that telling me I had Alzheimer's was premature, and that living with Mild Cognitive Impairment can be a time full of opportunity and personal growth.

As a member of the Coffeehouse group I've had opportunities to learn about the brain from leading researchers in the field. I've learned both about brain diseases and ways to keep the brain as healthy as possible. I've had opportunities to contribute feedback to health care professionals from the point of view of seniors with cognitive issues and opportunities to speak at conferences for health care professionals.

Coffeehouse is a unique opportunity to learn about the neurology field and how it responds to our questions and concerns. Experts who attended our meetings tried to answer our questions and were, in effect, validating our roles as patient advocates, not solely medical health-care patients.

The participants in the MCI group develop close and caring relationships, and as a senior member of the group I've had a lot of satisfaction learning for myself and helping others to learn.

Life is still stimulating because of the kinds of opportunities that appear from day to day and week to week. My wife amazes me with her determination to help me find activities and connections that actually add to my life rather than detract from it in spite of my physical and cognitive limitations. (Two years after that premature Alzheimer's disease diagnosis I was diagnosed with Parkinson's.)

In addition to my Coffeehouse experiences, I've enjoyed the support and encouragement that comes from members of an Osher Lifelong Learning Institute memoir writing group. Over the last three years I've written about my life and listened to the writing of others that has helped me express myself and feel satisfaction that I'm not just a marginal member of my community. Participating in the writing group is difficult at times, but nevertheless it's an opportunity to express myself as long as I can.

My early experiences in my teen years in particular had to do with sports; sports were a valuable learning tool. Now, in my late years, writing, particularly writing and listening to fellow members' writing, has been the principal means to learning of my inner life.

I am grateful for the opportunities I've had to be a mentor to others with MCI as I participate in Coffeehouse. I believe more understanding of these diseases can help alleviate the anxiety we experience as we face the future. We are bringing the "Muhammad Ali and Michael J. Fox learning and caring" to our own community.

BETWEEN US

Ken Saulter

Losing my memory,
Losing my memory to a terminal disease,
Is getting to be a problem.

Like when I'm in a group
And people talk to me and then,
Suddenly, I fall silent,
While my brain, and my heart, skip a beat.

We know it's not a so-called senior moment.
Eyes divert to shoe laces or thereabouts,
Anywhere else but the ceiling.
The moment becomes one of palpable discomfort.

So here I am, a fraction of a man,
A clown without make-up or costume,
Waiting giant seconds to recover.

I'm told I will not remember these bricks of separation
In the wall that is, regrettably, being built between us.

I worry a lot about little things, like forgetting
My locker combination, after 20+ years of use.
--- Or forgetting large things, like the names of my sons,
--- Or maybe someday, the address where I live,
--- Or, luckily, maybe not.

But, against our wills,
The wall keeps getting higher and higher.

Still, I'll keep on living, accepting losses and
Focusing on what I've got -- and you.

Meanwhile I'll keep trying to lower the wall between us,
--- Or slow it down,
--- Or build a gate,
--- Or do something.

Ken Saulter writes: “These ideas were inspired by what I learned at the 2009 Edna Gates Conference. This poem explores the idea of dementia as the wearing of an internal mask worn every day. It also recognizes the important role that caregivers serve by supporting and encouraging personal expression among those who have to deal with the burden of the mask and the struggle to keep one’s identity.”

MY MASK AND I

Ken Saulter

I look out through my mask occasionally,
To see who is there or if I have to speak. Can you see me?

Too bad my voice is so broken, but my mask and I
Know who I am. Can you hear me?

I've lost a lot of memories, but plenty remain.
My mask and I stand stoically as memories shift in and out.
Do you know who I am?

The world is smaller with a heavy mask on, and where is my smile?

Where is the touch of my hand? Will I always feel lonely?
My body and mind grow stiff. My mask and I know why.
Maybe I'll turn to stone someday. Will I learn anything, anymore?

I look out through my mask, occasionally,
To see who is there or if I have to speak.
My voice keeps getting smaller. Can you hear me?

And my body becomes less and less.
Can you touch my hand? Must I take that pill?

And then, suddenly, someone different looks at me
And hears me and smiles at me and I see things in a new way.

And I become more, rather than less.
And my mask melts day after day and
People look at me directly and see me as I am.
And there's no more "through a mask" living.
The table has turned as has the burden of the mask.

... Do you see the bright colors I've chosen for my canvas?

... Isn't my voice strong?

... Yes, and I see that you are listening to me now!



Josephine Moreno was born in Dallas, Texas in 1923. She came to Michigan, to a new way of life awaiting her and her family. As she describes it, "We lived in the country with no electricity, no gas for cooking and heating, and no running water. I met my husband, Daniel, in Mt. Pleasant, Michigan. We were the proud parents of four children. At present, I am a widow and very content living in an assisted living community near Lake Michigan."

HOW I LEARNED TO SPEAK ENGLISH – AN ELEMENTARY SCHOOL MEMORY

Josephine Moreno

I grew up speaking Spanish. It was not until I went to Michigan that I recall hearing English spoken for the first time. Our family always spoke Spanish in our home. This is what I remember.

It was April 1928 when our family left Dallas, Texas, for Michigan. There were five children in our family and I was the youngest, only being four years old. So, the few oldest ones were sad about the move to Michigan. Dallas was a large city. There they had attended school and there were things they were involved with in junior high. I, being the youngest, only knew that school days were ahead for me, and I was too young to think about this.

Things I recall on the trip: There were two buses traveling together with people hoping to find work in Michigan. They were told there was work in Michigan. We did not stop at restaurants. We were given food that the bus company was providing. They served sardines often. And to this day, I don't care for them.

How many days it took to travel, I don't recall. We crossed the Mississippi River on a ferry on a cold afternoon. Somewhere on the road there was an accident on one of the buses, and people were injured. There was a delay on the trip. We finally arrived in Michigan. It was an April spring day. Our family was taken to the William Bradley farm near Prattville, Michigan. It was a small village. We were given a tenant house on the farm to begin our home life in Michigan. This was where I heard the English language in conversation for the first time. Of course I didn't know what they were saying, it was "foreign" to me!

One day Mrs. Bradley came to ask permission if I could come to her house for lunch. Their granddaughter, Roberta, was coming there to visit. So my sister took me there. We were greeted by Mrs. Bradley, and she said, "Josephine can have anything on the table she wishes to eat, but must say it in English." So, then she pointed to each dish a few times saying in English what the food was. And we sat at the table.

The only thing I could remember to say was potato. I said something like this, "Pasa de potato por favor!" That meant, "Pass the potato please!" My first word in English was potato.

Mrs. Bradley gave me anything else I wanted. I was nervous and shaky. My sister went with me. I had never been in an English-speaking house. After the meal, Roberta and I had a nice time becoming acquainted and getting to know one another. I couldn't speak English and she couldn't speak Spanish, but that was not any problem. We had a good time. Kids can get along with no problem.

We lived there until fall. My father asked if we could please move to where there was a school so my sister and brother could attend. They moved us to Waldron, Michigan. We lived there a short while and then they moved us to Metamora, Ohio. That was 1929 and I was old enough to attend first grade.

My sister and brother were in the eighth and ninth grades. They took me to the lower level to start grade school. I was introduced to Miss Zimmerman, the first grade teacher. They spoke to her in English, which I did not understand. Then they went to their class room and left me with the rest of the first grade class.

She started the day by singing, "Jesus Wants Me for a Sunbeam." When I heard that tune, I recognized the tune. I softly sang the words in Spanish while they sang in English. We also sang at noon, for lunch time, and at the end of the school day before dismissal. I knew something was about to happen whenever we sang.

Then she taught me to raise my finger to go for a drink or to the bathroom. She would use a lot of gesturing to help me. So my days of learning began. After the morning song, it was game time. I would watch all the others as they

played. They played a game that was a skipping game. The boy would come and bow to the girl, and they would skip to the music. I didn't understand the skipping game. I went home and told my mother that a little boy asked me to play a skipping game. My sister overheard me talking to my mother. She said, "The boy who asked you to skip is named Roy, and his sister is in his class." Roy's sister was in my sister's class. She told Roy to, "Be kind to Josephine!"

Miss Zimmerman wanted me to feel comfortable. On the first day, she gave me many flash cards with pictures and words in English on them. Later, I was learning my ABCs and how to read. I listened and followed along as best I could. I took a book home to read. My sister helped me learn to read. I learned my reading lesson by heart. I still know it today. It goes like this,

Alice said, "Come cat, come to dinner."

And the cat said, "No. We will find our dinner."

That came from the Edson Reader, a blue book. Miss Zimmerman was not fooled. She knew it from memory. But the lessons became easier and easier as I learned more and more of the English language. When you are little and eager to learn, it stays with you. Learning numbers and counting came next. Then we learned to write our name in cursive. That was a lot to learn in nine months of first grade. This is especially true for someone who didn't speak English at the beginning of the year. I learned English because the students spoke to me in English. They were helpful in teaching correct pronunciation. I passed the first grade!

Miss Brian was my second grade teacher and we read stories and did arithmetic. I can't say if I spoke English fluently, but I certainly understood it in second grade. I was always interested in learning something new. I was learning more difficult words and how they were pronounced correctly. I learned the pledge of allegiance in second grade.

In third grade I had Mrs. Hackett. She taught more difficult reading lessons. We started using the library to get books. The librarian would help me choose a book. I remember reading about Hansel and Gretel. There was a play put on by the school at the Methodist Church auditorium. They presented the play Hansel and Gretel, and I was one of the children in the play.

The reading books became harder in third grade. We had an orange-colored school book called, "A Journey to Healthland." It was all about cleanliness. It taught us everything about taking care of your body from brushing your teeth to combing your hair. It was my favorite book and I kept it for a long time.

As I recall these memories, others are starting to flood my brain. I remember stories about Billy Goat Gruff, Jack and the Beanstalk, and Little Red Riding Hood. I am really thankful for my first teachers and how they taught me to speak English. Now, if I could only remember what I had for breakfast.



Phil and Pam have been married for 47 years. They met at Swarthmore College, raised three wonderful daughters, and are active with Friends (Quaker) organizations. They are both retired—Phil from Ford, Pam from counseling practice and parenting education in order to spend more time painting. They feel grateful for family, friends, and many blessings.

WANDERING TOGETHER

Pam and Phil Hoffer

My husband and I have decided to share a bit about an unwanted journey, which began in 2008, that we find ourselves on. We hope that sharing our attempts to navigate this unknown territory will be useful, perhaps first to us and our family, but maybe to others as well.

Conversation

(Journal Entries - January, 2011)

Do you remember anything about that first appointment and the first memory testing?

No, I don't. [long silence] I kinda remember not being able to remember a sequence of numbers and I kind of dismiss that as 'why would I want to remember random numbers anyway,' but that is probably just a defense mechanism. But whatever it was, that was frustrating. I still feel real gratitude for you getting me into the doctor and the research studies. I'm sure I'm better off for doing that and getting on a program to exercise more and get the medicine early to maybe ameliorate all this, even if I can't do anything about the genes I inherited.

Can I jump in here to describe that first appointment? It was REALLY an eye opener for me. THANK GOODNESS for the kindness of the doctor. I was right there with you while the mini-cognitive test was administered. If I had not witnessed that little test and ONLY been given the results it would NOT have had anywhere NEAR the useful and important impact that it did. It was "world shifting" for me.

It wasn't the numbers that gave you trouble, honey. You aced all that part. You were given five nouns to remember, told you could rehearse them, which you did, told you would be asked to repeat them a few minutes later. Then the doctor chatted with you a bit and in a few minutes asked you to recall the five nouns. I knew you had paid attention, saw you rehearse them with clear intention to remember them, and then, you could not recall ONE. Nor could you experience remembering them when offered choices – is it a church, a hospital or a school? You thought really hard, and said to each set of choices, "I don't know, but if I had to guess, I would say...." And then you picked the right noun! But you did NOT have the Aha! recognition of the right word. That just blew me away. And two things happened right away: First, it made me totally and scarily aware that a real problem was going on. And second, and really importantly, a few years of anger I had felt toward you for forgetting our conversations and decisions—all that anger just melted and dropped totally away.

We have talked a lot about why we might want to share openly, and I can wax on and on about reasons, but what is your thinking?

Oh! My thinking is because I might get some beneficial helpful hints that might come back to me if I am open and there is no reason not to admit to a deteriorated memory. If I were in junior high or something, it would be a real stigma not having a memory. I know it is not my fault; there is probably a genetic component.

I am ready to spend more time making sure that we get a lot of time in with good friends and family, in whatever context, working or walking or playing. And my own feeling is that whatever stigma does attach to Alzheimer's, being open about our situation allows for some of that stigma to be blown out of the water. This early stage we are in has not disturbed our daily lives very much and need not be so terribly frightening. And if we are transparent about it, maybe others can be a little less frightened and get themselves checked out early if they are experiencing significant changes. I am just so grateful to have information early enough that I have been able to take on some major new roles with your help and not wait until that help was not available from you.

At some point, if I really deteriorate, I might say something embarrassing and that might have an effect on our friendships. I just don't know what my physical or social condition is going to be in the future. But if it gets bad, I don't believe I will be seen as contagious. And if I start acting inappropriately, I can cut back on my social interactions.

Well, if there are those that are worried about contagion, we can let those friendships shake out now and make room to deepen ones that hold and even make room for new ones. Sometimes I get “down” and feel like our lives have begun to shrink.

What do you mean? We are still making room for new experiences, like deciding to go more often to Live at the Metropolitan Opera programs when they come to [the movie theater].

True! And that's been delightful.

What Slips Away

(Journal Entry - March 15th, 2011)

Phil is now in his second year on medication and we expect Alzheimer's is the culprit, even though the diagnosis is Mild Cognitive Impairment. The progression is slow-ish. He is still a very warm, witty presence in social situations because he can be in the moment. BUT, it really is changing. And as that has happened, bits of my identity feel as though they are slipping away.

Recently I had a chance to talk with a lovely woman I was introduced to through a friend. This woman's husband had died of Alzheimer's and all throughout their journey, there was another woman with the same experience behind her who had been her mentor. It was such a help to her that she decided after her husband died to do the same mentoring for someone else. When we met, I told her about how quickly I had been coming to tears (I have always been really leaky that way). I was feeling like it was grieving and thought I would get through it. Her really helpful comment was, "Well, you are going to be grieving for a long, long time with many losses ahead and you don't need to wait until that is done. It won't be for a long time. So you don't have to wait."

After that conversation, I went to the pharmacist, asked him what he noted about the various antidepressants, and got information about prices and dosage. Then I talked with my primary care doctor about trying the lowest possible dose of something just to give me a BOWL to carry my feelings in, instead of carrying them in what has felt like a PLATE, with spillage just too easy. Years ago, before my father died, he had asked me to read a message at his memorial service that he wrote to his friends. It was quite beautiful, and as leaky as I am I knew I would choke up and cry and make a mess of it, making my tears what was noticed instead of his words. I asked my doctor for a pill that would allow me to get through this task without breaking down. What she gave me worked like a charm and allowed me to read his lovely message adequately. So I knew about the "Bowl" phenomenon. My wonderful doctor knew what I needed, and within two days I felt the difference. I woke the second day with a slight headache (most unusual) and thought, "Aha, the medicine at work!" And over the last few days, which have contained a number of conversations in which I would have gotten all teary, I simply HAVEN'T.

It is clear that there are unexpected gifts as well as losses in this process. In addition to the personal challenge and reward of growing up further, the process of memory loss in these stages clarifies the importance of finding joy in the present moments. Phil has always been able to find joy easily, and that remains his great talent, undiminished by the process so far, and he remains my teacher in this respect.

Sharing with Our Congregation: Ann Arbor Friends Meeting – April 2011

Dear Friends,

Pam and I have been considering for some time an idea to write a letter together for the newsletter briefly summarizing our current life and medical challenge revolving around my diagnosis of memory loss. We do this in the spirit of openness because we know that important help has already come to us by being open and having shared what is going on with a number of friends. Also because we would want to encourage others to confront any similar difficulties as early as possible. I am lucky to have gotten medical care EARLY, when it is likely to be of most help. We know that our demographic group is likely to encounter problems of memory and cognitive decline, so we definitely don't feel alone.

Our lives have not changed in many respects, but early diagnosis has allowed me to turn over to Pam tasks that I used to do, and I am still able to help her in that transition. We feel a lot of love and support from friends and are happy to share with others anything we learn along the way that might be useful to others. Feel free to talk to us about all this. There is a phrase we have encountered – "The Grace of Diminishment" – that seems to be helpful to keep in mind.

With love and trust,
Phil

SWEETHEART

Pam Hoffer

"Where does all this rain come from?" you ask,
"Is it coming out of the clouds?"
The question is stunning
Your beginner's mind,
Regained innocence,
Preserved curiosity
And your sweet acceptance of not knowing,
Though you are seventy-two and a Harvard grad.

This journey backward, or so it would seem,
Yet stumbles toward enlightenment.
How strange to habitate the present moment
without the monk's lifetime of discipline.

And do I ask such questions or even detect
All that I ignore not knowing, missing out on that beginner mind,
Steering our course by habit and invention.

We rely on each other, going this distance.
I remember a couple I worked with years ago
fragile in their old age and each with Parkinson's
and its festinating gait.
One tended to fall backward, the other forward.
And they could proceed just fine together
When aligned just right.



Reprinted with permission from Club Member, Silver Club Programs, U-M Geriatrics Center
All rights reserved.

The Elderberry Club (Elder, barely) was originally formed in September 2011 as one of the University of Michigan Geriatrics Center's Silver Club Programs. This group of younger women has been meeting weekly to support, educate and share their experiences of living with early onset memory loss. They are a group of vibrant women who are interested in a social gathering for cultural enrichment, expression and creativity.

ELDERBERRY CLUB

Kathi Tobey, Elaine Reed, Members of the Elderberry Club

We are women,
gathered in kindness,
living well and
living with memory loss.

We are creative,
supportive, connected
caring, sharing, exploring,
fun-loving, courageous and

Full of Hope....

EVERMORE

Kathi Tobey, Elaine Reed, Members of the Elderberry Club

Evermore...
Learning and Loving
Determined
Endeavoring to excel
Respecting ourselves

Beautiful women inside and out
Abiding hope
Resilient
Ever thankful
Living out our dreams
Young in life!



Reprinted with permission from Club Member, Silver Club Programs, U-M Geriatrics Center
All rights reserved.

The Wisdom Keepers is one of several groups within the University of Michigan Geriatrics Center's Silver Club Programs. Wisdom Keepers is a talented group of multi-aged men & women who are living well with memory loss. They meet weekly for lively reminiscence and friendship, and they are interested in topical discussions, creative projects, outings and social enrichment.

WISDOM KEEPER

Kathi Tobey, Elaine Reed, Members of the Wisdom Keepers Group

Wisdom we impart to others:
Learn from and enjoy each other
Make the most of your time
Decide what really matters to you
Keep in touch with your friends

Who we are:
We are good listeners and interested in learning new things
We're happy people and love to laugh
The young people in our families are our pride and joy
We are open to new ideas and are willing to share
We enjoy life!



Gretchen L. Smith has worked in creative writing and photography for both profit and non-profit organizations over her 40-year career. More than 14 years of that time were spent in non-profit health care. She has a bachelor's degree from Ball State University, is a Distinguished Toastmaster and a graduate of the National Speakers' Association-Michigan Pro-Track Program. To keep her mind active, she has started her own public speaking and writing business – Outside the Lines Communications, LLC.

TICK, TOCK

Gretchen Smith

Tick, tick, tick, tick...blank computer screen: I know the word I want to use. I can see it, but my hands won't let me tap the keys to put it on paper. I stare at the screen fiercely, willing my brain to cough up that word. A half-hour passes. Use a word that's acceptable, close to what I want to say, and maybe the real word will come to me.

I was given a diagnosis with early stage Alzheimer's in December 2008. Nice Christmas present! The doctor asked me several questions after I told him about my trouble with word capture. He gave me some prescriptions and sent me to see a neuropsychologist.

Since that day, I've had three neuropsychological exams and blood work showing I carry the protein that codes for the Apo4 gene associated with Alzheimer's disease. In a pre-screen for a clinical trial I was informed I do not have early-stage Alzheimer's, but Mild Cognitive Impairment.

Most people think it's great I have just Mild Cognitive Impairment. I get a lot of, "Oh, it's part of the aging process. I forget things all the time." I've been asked: "How do you know it's Mild Cognitive Impairment and not just aging?"

My answer is two-fold: First, there was a sentinel moment when I realized that some insidious synapse had derailed my ability to recall descriptive words. Second, Elizabeth Kubler-Ross beautifully outlines the five stages of loss or grief. I am still in Big Denial, Anger and Bargaining after five years.

Let me take you inside the world of someone with Mild Cognitive Impairment whose clock is ticking.

As I began to put my thoughts down, I started with a long narrative history. I became very frustrated because this took me six hours – something that ordinarily I would have written in a half hour. And when I looked at it, my first thought was, "This is crap and says nothing about my inner world."

Every day I struggle with taking the steps needed to jump-start my professional speaking and writing business I've been working on for two years. I know I have to learn social media, but it's like a foreign language to me. I know I need to do this to get myself known. But change is hard, especially when you're afraid you're going to fail.

I make lists everyday – sometimes multiple lists – just to keep myself on task. Everything I must do goes in my calendar and on my phone. I just have to figure out how to set up alerts on my phone. Technology should be easy – it's a big mobile mountain I'm still climbing. I have to re-read everything I write multiple times because I will often put down a very different word than the one I meant – and spell-check will not catch that. I'm not typing a hundred words a minute. I know what I want to say, but my mind keeps putting in words different than what I think I've written.

I used to be able to multi-task and keep 10 projects in mind – what had been done and what yet needed to be done. Now I have file folders for every project. And every scrap of information or communications gets printed out and put in the folder. I can no longer rely on finding the right information in my email or even in my computer file folders. I forget where I put things.

I've lost a cell phone and several presents because I can't recall where I stashed them. Every cord to anything is labeled. I've finally set up a list of passwords because I can't remember which password I've used for which account.

My mind wanders during the day, and it requires every ounce of energy to pull my mind back to a task and keep going. I used to be able to get up early in the morning and go until late at night. Now, it's a struggle to be up before 7 a.m. and stay awake beyond 10 p.m.

I used to be able to rip off addresses and phone numbers without thinking. If it's not in my contact book, you won't be hearing from me. I am a voracious reader, and yet I'm unlikely to be able to tell you the plot of a book I've just read. I had to give up on "Life of Pi" because I was lost on page 10. I've read all the classics and never had any trouble following those plot lines, so fiction is dubious for me. If the plot is too complicated, I just get lost.

I've always valued that my word is a pledge. Now, I'm faced with having to choose just how much volunteer energy I can give. It's easy with Mild Cognitive Impairment to bury yourself in volunteer tasks, and abandon what's most important. For me, it's starting a business that encourages individuals to stretch their intention span and to pay things forward. I don't know how many days, months or years I have before I will lose the cognitive abilities I still have. So, I'm pulling back from volunteering because I don't have the time to let myself dawdle in tasks that require constant contact and follow-up.

I've always hated meetings, but I finally left a service club because their meetings were running two and one-half hours, decisions were being delayed until more information was gathered. I'm at a point now that any meeting, even a conference call, better be done in an hour, and there better be some action steps as a result. I'm losing the patience I once had for long deliberations. I think of myself as a calm, mindful and meditative person. Now, I encounter this impatient person who is often angry (mostly at myself) and anxious most of the time.

Most people – even those who know me fairly well – think there's nothing wrong with me. They see the high-achieving person they've known. That's because they're not inside my brain. I can be in conversation and if someone interrupts, and the conversation starts again, I'm probably lost because my train of thought has been interrupted.

I can't attend functions where there are more than 20 people around with whom I have to converse. There's just too much remembering who I have been introduced to and what has been said, and yet my goal is to lead workshops and seminars where there are hopefully more than 20 people attending. That's going to require energy, a high attention focus, a notebook, and participants interacting with me. And I will leave feeling drained.

Let me leave you with a few final thoughts. I can't imagine not knowing who I am, or who is with me, or not having something to do. The end result of dementia or Alzheimer's is a body whose organs are functioning, but the mind has left on permanent vacation. I am struggling with myself on this issue. I know what the theological perspective is. I've seen how devastating it is to caregivers to devote precious years to assisting loved ones who don't have a clue about who they are or their daily life. This is frightening to someone whose life has centered around using her mind. Yet there it is....tick, tock, tick, tock.

Leslie Rzeznik is a University of Michigan BA candidate in English, sub-concentration in Creative Writing: Poetry. She was the winner of the Undergraduate Academy of American Poets Award at Michigan for Fall 2012. She suffered a traumatic brain injury six years ago and is working on a poetic series based on her recovery. Some of the poems are featured in this anthology. Ms. Rzeznik's work has previously been published in translation in Lithuania; this is her first publication in English.

STALL

Leslie Rzeznik

She pitches forward

The moment
stalls like a plane at two
thousand feet
that lands safely but breaks
the pilot's neck as it flips
in a rut on the ground

Soon she'll be picking words
from between carpet tufts
that stink with the soles
of two thousand feet

BRAIN KISSES BONE SO HARD IT FORGETS WHAT IT IS

Leslie Rzepnick

What does it mean to mistake
a violet for a jackhammer?

Thought is a heavy vaulted door
that shuts when a dust mote lands
just so then right in the middle of my....

I can't stand to listen to myself but can't stop
talking can't stand to listen to myself.

Others' words read clear and true, but my own
trip and shudder off my tongue, thick and dumb.

My shoulder tics in time with every fractured syllable.

Like an owl casing prey,
each swallow or turn of the head spins
my voice from right to wrong.

The unending hisssssss.

I wish I could unhinge my jaw.

APPROACHING JOY

Leslie Rzeznik

“She's been mute for 10 years,” they said.

Joy's fingertips linger as she walks. They pantomime Bach or Mozart or perhaps even “Muskrat Love.” In those moments when they are perfectly still, I catch an essence of baby kisses or clean-running river water over her outstretched palm, running past the fetal lifemarks of hopes and loves, slipping under the wedding ring (not hers) and evaporating before it hits dimensional reality.

Her spirit protected by neglect and isolation, it's more free than yours or mine, embalmed as ours have been by society's engenderment and cultural morés and spirit-numbing sameness. Joy's eyes bore into your face, staring deep past your molars as you speak, but parking on your pupils during the in-between breaths, as if she'll be able to catch a glimpse of an as-yet-undeveloped photograph if she cannot blink in the split seconds while the aperture flashes.

You wonder if she understands, but find it difficult to be anything but forthcoming under her gaze. She nods and smiles politely in all the right places. Anyone observing the conversation from afar might think she's a particularly engaged companion, that your story is so compelling that she wouldn't think to interrupt. You wonder if she thinks. And if she does, what she thinks.

You get the feeling she knows you. That if she could just talk, she could tell you stories about yourself. Like how you got that scar under your chin that you kept forgetting to ask your mother about before she died. Or that maybe you used to waltz or jitterbug together that summer when you were 17 and developed a sudden but short-lived case of sleepwalking. You dreamt of dancing shadows, but was it Joy?

Joy hasn't spoken, but she laughs. No titters or coy giggles for Joy. Her laugh is befitting of her name. It's deep and swallows anyone within earshot. You're either embarrassed or delighted by her laugh. If you don't laugh with her, sometimes it transmutes into a strange uncontrolled caterwaul, and you're afraid she's going to pee her pants or suffocate herself, and wonder just what you'll do then if you're out in public.

Joy rarely laughs at inappropriate moments. She never laughs at anyone, unless they're already laughing at themselves. Occasionally she turns what could be a decidedly embarrassing moment into an amusing anecdote – just with her laughter. It's sometimes easy to forget she's not quite there with you.

So where is she and how did she get there and will she ever be coming back?

She loves fabric stores. Loves to run those kinetic fingers over linens and wools and printed cottons. She loves the smell of raw silk and screws her face up at polyester. Burlap makes her laugh and flop her hands from the ends of her wrists. She can stand for an hour testing the hand of a silk charmeuse, watching it flow over her fingers like a liquid sand sculpture, again and again. Perhaps she had been a seamstress.

Music makes her seem less otherworldly. Sometimes I'll take her to a nightclub just because she enjoys it so much. She moves and sways like she once had a dancer's body, but mis- or under-use and age have caged her. I can see the men watching her with desire and the women with envy. But never jealousy. She has this gift of being completely engaging from a distance. Strangers are surprised, sometimes offended at first when her lips part only to show her perfect teeth in a perfect smile. Some have the disrespect to ask me pointblank what's wrong with her, as if she were not sitting right next to us.

That's the only time I ever see her agitated, and seems to be one of the few indicators that she not only understands, but can be hurt, by someone's thoughtlessness. I've never seen her cry. She just gets very quiet. Her movement stops. Like a small sleepy child, she rubs her eyes and I know it's time for us to leave.

SHAPES OF MEMORY LOSS

University of Michigan

Back in her room, if it's been a good night, she'll turn on the radio and twirl and dip while she brushes her teeth. She'll let me brush her hair and sometimes French braid it, even though I know it will come undone by the morning. If she's had her feelings hurt, she'll go right to sleep without even changing her clothes. If she were little enough or I were strong enough, I think she'd doze off in the car and let me carry her sleep-grogged form directly to bed, sour breath and all.

Before I leave, I make sure she's tucked in tight, but not too tight, kiss her forehead, and promise her I'll be back same time next week. If the day ever comes when she's able or decides to participate in conversation again, I wonder if I'll miss her silence.



Myriam Torres holds a Masters of Statistics and worked more than 25 years as a research associate at the Institute of Social Research at the University of Michigan, where she received several honors. She recently retired due to developing Alzheimer's. Myriam also served as a lay Christian pastoral worker and founding member of Bethany Association, an ecumenical group of women living single for the Lord. She told her story with a little help from her friends.

WHEN YOUR WORST FEAR BECOMES REALITY

Myriam Torres

My first big clue that something was very wrong came in February 2009. I was on a Christian mission trip to Costa Rica, meeting with a small group of women. Suddenly I couldn't understand a word they were saying. I didn't let on, but I was totally at a loss. All I could do was make a comment every now and then and hope it was all right. I got some puzzled looks, but somehow I made it through the next hour. Afterwards, I reverted to normal.

Things weren't normal, though, when I got back home. I cried all the time without knowing why. In my job as a high-level statistician, I found myself struggling to analyze data and needing to delegate my work to other analysts. "Could be menopause," a friend suggested. I was fifty-six and had already gone through that stage, so it didn't seem likely. "Stress," thought someone else. I took a month off from work, but things only got worse.

A nurse practitioner urged me to see a doctor, and so began two years of medical tests. Early on, after a psychological test revealed "significant" mental impairments, one specialist noted, "probably Alzheimer's disease." If I ever read his comment, I dismissed it right away.

That diagnosis wasn't confirmed until May 2011. By that time, because of my increasing confusion and forgetfulness, I had left the job I loved. And I was wrestling with God in a very serious way.

But I'm Your Bride!

For most of my adult life, I've lived "single for the Lord" as part of an ecumenical group of women who have chosen not to marry in order to dedicate ourselves to a life of prayer and Christian service. And so, though we work at various professions and don't take religious vows, I see myself as a bride of Christ, deeply loved and deeply in love with Jesus.

Every day before work, I used to get up to spend an hour with him. I loved it. I'd praise and worship God singing, reading Scripture, reflecting, and writing down things that struck me. But as I felt myself declining, I became very angry with the Lord. "Is this the way you treat your bride?" I'd ask him. But he was silent.

Deep down, I knew that if I refused to choose "your way, not mine," I was the one who was going to be the loser. Still, for nearly two years I fought and struggled. I denied what was happening, tried to cover up, refused to discuss it. With all my heart I wanted to believe that my problem was sleep deprivation, stress, or even depression – anything but Alzheimer's.

This wrestling went on and on, but at least I kept talking to the Lord. Then one day, during my prayer time, he gave me an unexpected grace. I suddenly realized that I could really trust him with my future. "I accept this," I told Jesus very simply. The peace I felt got me through the final medical consultation, which left no doubt that I have progressive dementia: Alzheimer's disease, according to one last test.

Sherry, a close friend who is also single for the Lord, was with me as I got the bad news.

"Myriam, you're too quiet," she said, when we were back in the car. "What are you thinking?" "I'm okay. I worked it out with God last night. And I told him it's okay, whatever it is."

Sherry couldn't believe what she was hearing. I could hardly believe it myself. It was pure grace, and so freeing to be able to admit what was happening and to talk about it.

Loved and Loving

After a couple of weeks, I felt like the Lord was asking something more: Thank me. Again I wrestled. Accepting my situation had been hard enough. Did I really have to do this too? It was hard, very hard, but again there came the grace to say yes.

Months later, I realized that I was truly grateful for some of the changes I saw in myself. I'm relating to people differently, in a softer, more loving way. "Thank you, Jesus, for this opportunity." And as I prayed, I sensed a call to go deeper – not just to accept and give thanks, but to embrace the journey with trust in God's love and wisdom. This time my response came easily. I embraced it like a gift from heaven.

This may sound strange, but even as I'm losing my abilities, I'm seeing the "gift" side of what's happening. More and more, all I can do is love and be loved. And I feel so much love from so many people! They're praying for me, telling me what I mean to them, thanking me for ways I've helped them.

And God is still using me to speak words that people need to hear. When women I've counseled over the years call and ask my advice, I usually know what to say. I say it more directly, too, because along with Alzheimer's comes a lessening of inhibitions! I noticed this recently, when a woman in my Zumba exercise class said how worried she was that her husband might have dementia. Not only did I tell her how to get medical help, but right there, with other people listening in, I prayed with her. "I feel so much better now," she said afterwards.

Suffering Servants

Don't get me wrong, though. Embracing this journey isn't the same as embracing the disease. I'm doing all I can to stay fit and slow my decline – speech therapy, exercise, social contacts, a good diet. If God chooses to heal me, I'll be ecstatic. And although I've arrived at a basic peace, there are still struggles and tears. I loved being a statistician, being savvy and capable. Now I can't even count. I can't tell time without a lot of effort. If people talk fast, I can't understand what they say. I have a hard time focusing to pray. It's hard to accept help, too, hard to let go.

An experience I had at the airport last year drove home this sense of loss and helplessness. I was traveling with Sherry, but she went through security just ahead of me, so she couldn't help when I got confused at the guards' directions. I couldn't understand where they wanted me to place my luggage. I didn't know which hand they wanted me to raise. "Don't you know one from the other?" one guard jeered.

I stumbled out of the checkpoint crying. I felt so humiliated. "This is what's coming," I was thinking. "This is the way I'm going to be all the time." Explaining it to Sherry later, I could only say I'd had a taste of what it was like for Jesus, when he was stripped of everything and people were mocking him. I take comfort in the fact that I am being conformed to him. I wrote in my journal, "As time goes on and I lose all I have – the ability to communicate, my memory, being able to do my daily functions--I see that all this is making me more like Jesus, the suffering servant."

St. Ignatius Loyola put it more eloquently in words that I now pray from the heart:
Take, O Lord, and receive all my liberty, my memory, my understanding, and my will, all that I have and possess. You have given all these things to me. To you, Lord, I return them. All are yours. Do with them what you will. Give me only your love and your grace, for that is enough for me.

*Reprinted with permission from “The Word Among Us” magazine (January 2013)
All rights reserved.*

IF YOU'RE DEALING WITH MEMORY LOSS

Myriam Torres

Ever since receiving my diagnosis of Alzheimer's disease, I've very actively looked for ways to stay as healthy as possible for as long as possible. I've also become very up front about sharing my findings with anyone who might benefit! Circumstances vary and these may not be for everyone, but here are some of my tips.

Get to a doctor. If you've noticed troubling changes (like the "10 early signs and symptoms" on the Alzheimer's Association website: www.alz.org), but you haven't looked into the cause, go get tested. The sooner you know what you're dealing with, the more time you – and your caregivers – will have to plan and prepare.

Keep moving. Physical exercise helps maintain good blood flow to the brain and has lots of other benefits. I like to go for walks, often with a friend. I've benefited from exercise too. I especially like Qi Gong, a gentle exercise that helps maintain flexibility, balance, and stability and – my number one favorite – Zumba, a Latin dance fitness program. I attend two classes a week and love it!

Eat well. Get those fruits and vegetables, fish, lean meats, and nuts. Enjoy a treat every now and then, but don't overdo it. You'll feel so much better if you have a healthy diet.

Get a pet. Something small that won't be too much work to care for. Mine is a Pomeranian named Zoe. I've never had a dog before, so I'm amazed at what good company she is – fun to play with and alert to anyone at the door. With Zoe around, I never feel alone.

Join a support group. They can be found almost everywhere. Mine is sponsored by the University of Michigan Geriatric Center, and it's been a tremendous help for understanding what is happening to me. There are about 10 men and women in the group, and the social worker who coordinates it is wonderful. We usually share about our daily lives, our questions, struggles, and triumphs. Sometimes we have a speaker – like a pharmacologist who can answer our questions about medications. It's always stimulating and informative. (There are support groups for caregivers, too, by the way.)

Get together with friends. See them as often as you can. Laugh a lot. Have them over, or go out for dinner, a film, a concert (personally, I think music is good for the brain!).

Find a fashion consultant. Maybe it sounds silly, but one of my biggest fears is that I'm going to look ugly. I never know what to put on any more, or what colors go together. When I mentioned this to a good friend one day, she offered to take over. Now she reviews my wardrobe, keeps my closet organized so that I can easily find things that match, and takes me clothes shopping twice a year. She advises me about my hair, too. What a relief!

Ask for help. I've noticed that many people are reluctant to accept help unless they have a way of paying back. But in my background, which is Puerto Rican, we tend to be more direct about expressing our needs. We also expect that family and close friends will help us out even if we can't repay them. I'm not saying that this makes everything easy. Especially in certain areas, I find it very challenging to accept help and relinquish control. But what a blessing to have people who will step in when you need them. So if you have them, ask!

Do crossword and jigsaw puzzles. They're good stimulation. I'm not so good at crosswords any more, but I can still handle a 550-piece jigsaw puzzle and enjoy the challenge.

Prayer helps. Keep talking and listening to God every day. Never neglect him. But find ways of making your prayer time simple and focused. I like going through the daily Mass readings. For a while, I used preloaded mp3 player programs that contain 15 minutes of prayer time for daily use. You could also put on some worship music or an audio recording of the rosary.

Know that God loves you, is with you, and has a plan for your life! It's hard – very hard – but you have to make your peace with God. And trust that he loves you and knows what he's doing with you.

In all this, my biggest help is my love for the Lord and the continuing experience of his love for me. And so, every day, I want to live out one of his more recent words to me: "Be grateful. And use this to help others. Make love your aim." That's my last piece of advice to you, too.