

Memory/Loss/Moments¹
Rev. Myke Johnson
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Allen Avenue Unitarian Universalist Church

Readings

From "Readers Write" in *The Sun Magazine*² Deborah Bayer

At eighty-two my mother received two dolls from my sister-in-law as a present: stuffed, whimsical monsters, flat and pillowlike, in bright colors with Xs or Os for eyes. "Why would she send me these?" Mom asked, laughing. "Does she think I'm in my second childhood?" I was pleased she could see the humor in the gift, but I grew concerned when she repeated herself ten or twelve times: "Does she think I'm in my second childhood?"

Six months later she received the diagnosis: Alzheimer's.

As my mother, once a keen business woman, became less capable in ways of the world, she became more capable in ways of the heart. She was sweet, affectionate, easily delighted—in short, childlike. I got used to buckling her seat belt, telling her when she needed to eat, and guiding her through simple tasks, such as addressing an envelope.

One afternoon at the lakeside she squealed and waved her arms wildly as ducks fought over scraps of bread. Embarrassed, I peeked over my shoulder. Was anyone watching? Then I stopped worrying and looked fully at my mother's unrestrained joy. Suddenly her condition seemed less like a downward spiral and more like coming full circle.

Live Blindly and Upon the Hour³ by Trumbull Stickney

Live blindly and upon the hour. The Lord,
Who was the Future, died full long ago.
Knowledge which is the Past is folly. Go,
Poor child, and be not to thyself abhorred.
Around thine earth sun-winged winds do blow
And planets roll; a meteor draws his sword;
The rainbow breaks his seven-coloured chord
And the long strips of river-silver flow:
Awake! Give thyself to the lovely hours.
Drinking their lips, catch thou the dream in flight
About their fragile hairs' aerial gold.
Thou art divine, thou livest,—as of old
Apollo springing naked to the light,
And all his island shivered into flowers.

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2 *The Sun*, June 2011, p. 33.

3 <http://www.poets.org/viewmedia.php/prmMID/20245>

Sermon

There are about 5 1/2 million people diagnosed with Alzheimer's disease in the United States. One in eight people over 65 have the disease, and Alzheimer's is the fifth leading cause of death for those over 65. Almost 15 million people are providing care to family members or friends with Alzheimer's or other forms of dementia.⁴ What these statistics mean is that it is likely that all of us know someone who is affected by such disease.

What touches my heart and makes this important to me is the experience of individual people I love who are facing this illness. One of them, A2U2 member Jack Berman, has spoken often with us here about his own diagnosis. He wants people to know that early diagnosis is important, because there are treatment options that can help to slow the progress of the disease. Jack loaned me the book he felt was the very best resource. It is called *The Alzheimer's Action Plan*—and is an excellent practical guide for anyone who is facing this disease in their family.⁵

Today, however, I won't be talking about the medical or practical aspects of this disease, and other diseases of dementia. I want to explore the spiritual and human side of these illnesses. What resources do we have in facing these challenges, if we are the one diagnosed? If our loved one has dementia, how can we remain in compassionate relationship to them? And how can we offer support and care to individuals and families in our community?

One of the first things I noticed as I began to write this sermon, was that I felt uncomfortable using the word "dementia." I realized that merely saying the word stirred up inside me the sense of stigma that has become attached to dementia in our society. Alzheimer's is one form of dementia, but there are other diseases which can also cause it. Dementia is the medical term used to describe "symptoms affecting intellectual and social abilities severely enough to interfere with daily functioning." Dementia indicates "problems with at least two brain functions, such as memory loss and impaired judgment or language."⁶

Lynn Jackson and Christine Bryden had been diagnosed with early stage Alzheimer's when they began doing workshops to educate others about the stigma of dementia; they say that the first step in reducing the stigma is to talk about it.⁷ Shame and stigma are fed by silence and secrecy, and can contribute to delay in treatment, social isolation, and greater suffering.

So maybe the most important part of this worship service today is that we are bringing this often hidden issue into our sacred space. We are affirming that dementia is part of our common human condition, and we can talk about it with each other. We are affirming, along with the Alzheimer's Disease International charter, that "a person with dementia continues to be a person of worth and dignity, and deserving the same respect as any other human being."

4 Alzheimer's Association, http://www.alz.org/documents_custom/2011_Facts_Figures_Fact_Sheet.pdf

5 Authors: P. Murali Doraiswamy, M.D., and Lisa Gwyther, MSW, with Tina Adler, published in 2008.

6 <http://www.mayoclinic.com/health/dementia/DS01131>

7 www.dasninternational.org/ADI/Stigma%20Workshop.ppt

That is at the heart of a spiritual response to dementia--to remember the worth and dignity of every person. Our worth and dignity do not go away when we face illness or disability, whether it affects us physically or mentally.

Everything has a context. I believe the context for our struggle with dementia is a society that is focused on individual self-interest. Perhaps we can't even see it, like fish are oblivious to water. But if we contrast our society with some others we might notice how different their values are. Actor and activist Peter Coyote said: "Look at some of the older, more stable cultures around the world: Their organizing principle is not self but community. You don't just do what is good for you.... Any ancient culture would say you don't have the right to do that; you have responsibilities to the old, weak, and infirm, to the widows and orphans.... That is the difference between community-mindedness and self-interest. Our culture is paying the price of self-interest as an organizing principle."⁸

In one account I read, an American couple dealing with the husband's Alzheimer's visited a Tibetan Buddhist teacher to ask for advice. The wife, Olivia, asked the teacher, Tulku Thondup, "How do people regard dementia in Tibet? How do families handle it?" He replied, "Of course, many older people get dementia, but it's not seen as something so unusual, like here. Families usually live in villages or in some community where there are many people in the extended family to help. Someone can wander around and it's okay. If it's a lama or someone who has done a lot of [meditation] practice, they assume they are in high states even if they seem crazy or in strange mind-states."

Olivia goes on to say, "In his culture the dissembling of the mind is looked upon as a natural process, like the dissembling of the body. Both are in the natural order of things. Because community and extended family remain strong forces in society, the elders remain in community. Caregiving is shared by many more family and friends than we have in our nuclear models of living."⁹

Alzheimer's is a painful diagnosis—it is a terminal illness, and like any terminal diagnosis, brings with it the responses of grief, anxiety, anger, denial, and loss. But it is frightening to us in a unique way, because we so often identify our personhood with our mental capacity and our individual independence. If we have Alzheimer's, we will eventually need increasing degrees of care from those around us, and that challenges our sense of value in our self-oriented culture. It challenges the myth that we should all be independent units, charging forward with individual goals and plans. And because our society does not value community, it puts a tremendous burden on the nuclear family to manage on its own.

8 "Against the Grain: Peter Coyote on Buddhism, Capitalism, and the Enduring Legacy of the Sixties," by David Kupfer, *The Sun*, June 2011, p. 11.

9 *Ten Thousand Joys and Ten Thousand Sorrows: A Couple's Journey Through Alzheimer's*, Olivia Ames Hoblitzelle, 2010, p. 25-26.

One lesson that Alzheimer's teaches us is that human beings need each other. There is no shame in our need for each other. Everyone of us will die from some cause or another, and most of us will face a time of illness in which we rely on the care of other people. This is part of the natural order of things—medicine and science may extend our lives by some years, but the dissolution of the body and the mind are a part of what life includes. We don't expect babies to come out of the womb ready to walk and gather food. Yet somehow we expect to end our lives without needing any help.

Because we live in such a self-oriented society, needing help becomes a very difficult spiritual lesson. But, for the same reason, it is also very important for our growth as whole persons. I am not saying that independence is not a good thing. Independence is one kind of life lesson, and dependence is another kind of life lesson. To be whole, we need to balance our attachment to individualism by opening up to the gifts and responsibilities of community. Caring and being cared for can become a spiritual practice for each person that brings us to the essence of love and connection.

So how do we help each other? People in early stage Alzheimer's are more and more taking the lead in letting us know what helps. They have reminded us that they are still themselves. Lynn Walker said, "Even with such a serious diagnosis, we are still capable in many ways. Our minds do not work as fast as they did once, but previously learned skills are still there, and we draw on them to carry on our daily lives. People in the early stage need support and encouragement to continue functioning [normally] for as long as possible. We need support groups. We function better with a support network in place."¹⁰

Norma Selbie said, "There's no two ways about it -- my life is more difficult now than it used to be. Fortunately, with early stage support meetings available, I now have a place where I can come -- to talk and listen, to laugh. And we're not afraid to laugh at ourselves -- and even shed a tear with others who understand my frustrations like nobody else can. These meetings offer a safe haven for people like me. And believe me, they speak health to the very core of my being. While I do live on a slippery slope, be assured that behind the language and memory difficulties, there's still a thoughtful, intelligent person eager to enjoy life for as long as possible."¹¹

A2U2 member Lynne Gibbs, whose father has Alzheimer's, sent me a resource called "Quality of Life Outcomes for People with Alzheimer's Disease and Related Dementia."¹² In this document, "outcomes" are defined as guiding principles for quality of life, expressed from the perspective of a person with dementia. These five principles are deliberately expressed in the first person to give them the power of being stated by a person with dementia. I was moved when I read them, and I want to share the statement with you.

10 Speech by Lynn Jackson, "See Me, Hear Me, Work With Me: Partnering With People With Alzheimer's Disease and Related Dementias" -- Speeches from the 24th National Alzheimer Society Conference, Calgary, AB, April 18-20, 2002, <http://www.alzheimer.ca/english/haveAD/speakingout-02-lynnj1.htm>.

11 <http://www.alzheimer.ca/english/haveAD/speakingout-lyons01-normal.htm>

12 <http://www.dhs.wisconsin.gov/aging/dementia/Dementia%20Outcomes%20Care%20Plan%20Tool.pdf>

It reads as if the very best outcome is already present:

“As a person with dementia,
I have the best possible physical well-being
I have meaningful relationships
I experience hope because my future is valued and supported
I am accepted and understood as an individual
I am involved in life”

What I notice immediately is that these principles are ones that all human beings want and need—physical well-being, meaningful relationships, hope, support, acceptance, involvement in life. But there are also particular practices that can enhance these outcomes for people dealing with dementia. At the center of these practices is the goal to foster meaningful relationships with persons who have dementia.

Years ago, working in my first job as an aide in a nursing home, I was taught to correct people with dementia—to remind them of facts and dates to better orient them to reality. Now, that approach has been discredited. It has been shown that a more helpful way to stay in meaningful relationship to people with dementia is to validate their own experience of the moment. As people who care, we can enter their experience of reality in a compassionate and positive way. What is most important is to be connected, and to be affirming. We can focus on creating moments of joy. Even when memory is failing, there is still humor, personality, tenderness, curiosity, spirituality.

Connection can happen even when language is difficult, through our body language and inner openness. Many people who lose the capacity for verbal language can still read and respond to non-verbal language. Recent research suggests that even people with severe dementia who cannot remember that someone has come to visit them, may still carry forward a feeling of well-being and contentment after a positive visit.¹³

Here at A2U2, a few of our pastoral visitors are spending time visiting with people with Alzheimer's. It has been rewarding for both visitors and those who are visited. It has also been a ministry for caregivers—during the visits, family members can take a break to do errands or take some time for self-care. If you would like to request someone to visit in your family, let me know, and we will try to match you up. We need more such visitors, so if you are curious about that, please be in touch.

A particular spiritual lesson evoked by memory loss is the challenge and blessing of living in the present moment. For anyone who has practiced meditation, this is a familiar goal of practice. Buddhist meditation invites us to pay attention to this moment of being. People living with Alzheimer's are entering a passage in which the past and the future begin to be less reliable. But each moment can still hold joy, beauty, connection, and life.

¹³ Research by Justin Feinstein and collaborators, referenced in an article sent to me by Dan Chase.

Cush Anthony wrote to me, "There is a hidden treasure in this illness, that I have been able to find and appreciate. Karen has always been good at living in the moment, but that quality has been increased greatly as her condition has changed. And that deepening of the ability to live in the present has allowed me an opportunity to learn from her how to better savor what is around us at any given time, to see the beauty and appreciate what we are given at that very moment."

In the tradition of Buddhism, Alzheimer's is seen as another opportunity for spiritual practice, both for the person living with the disease, and the caregivers. Olivia Ames Hoblitzelle chronicled the years following her husband Hob's diagnosis. They were both long-time teachers of Buddhist meditation, and their many years of practice gave them tools with which to stay in the moment, remaining open to fully experience moments of loss, and moments of joy. Her book is called *Ten Thousand Joys and Ten Thousand Sorrows*.

Olivia and Hob kept returning to an inner equanimity, in the midst of the ups and downs of a progressive disease. They stayed in communication with each other, and with a circle of support, through the years until Hob's death. It wasn't always easy, but their love deepened and grew through the process. And Hob, who had always been a teacher, remained a teacher—his life became his teaching to his meditation students.

Gilda Radner said: "Life is about not knowing, having to change, taking the moment and making the best of it without knowing what's going to happen next." It is never too late, or too early, to begin such a practice of embracing the present moment.

The spiritual teacher, Ram Dass, author of the book *Be Here Now*, suffered a stroke at age 66 which affected his ability to speak. In a later book about embracing the aging process, called *Still Here*, he tells a story about the ongoing work of attending the present moment.

"I was on board the Taj Express train bound for Agra, with a stop at Mathura where I would get off. Traveling by train in India is full of rich lessons. The trains go slowly, express or not, and we moved at a prehistoric pace, the countryside creeping by, palm tree by palm tree, until I wanted to open the window and scream. But then something began to shift. Rather than resist the slowness and count the minutes, I told myself a little story. 'This trip is going to go on forever,' I said inwardly. 'This present moment will never end. I've been on this train my entire life, and will never, ever get off. Now what?'

"Meditating on this story, I began to surrender into the rhythms and speed of the train, looking out the window at the passing images without the anger of moments before."¹⁴

We are all on the train. We call it life. Eventually, the trip will end in our deaths. Let us remember to cherish each moment, and cherish each person. We need each other. Let us fill each moment with tenderness and care.

14 A Teaching Story from *Still Here: Embracing Aging, Changing, and Dying* by Ram Dass
<http://www.spiritualityandpractice.com/books/excerpts.php?id=13523>