### Chazak V'Ematz - Be Strong and of Good Courage: A Yom Kippur Sermon on Alzheimer's Disease

By Rabbi Esther Adler

Mount Zion Temple, 2013/5774

Moses walks into the Jewish nursing home, and is disappointed to find that nobody there seems to recognize him. So he walks up to a little old lady sitting in the common area and says, "Excuse me, do you know who I am?"

"No, dear," the lady says, "But if you ask at the desk, I'm sure they can help you."

My memory isn't as sharp as it used to be. Also, my memory isn't as sharp as it used to be.

Two elderly couples are enjoying friendly conversation when one of the men asks the other, "Fred, how was the memory clinic you went to last month?"

"Outstanding," Fred replies. "They taught us all the latest memory techniques: visualization, association, you name it. It was great."

"Wow! What's the name of the clinic?"

Fred goes blank. He thinks and thinks, but can't remember. Finally, he snaps his fingers and asks, "What do you call that flower with the long stem and thorns?"

"You mean a rose?"

"Yes, that's it!" He turns to his wife.

"Rose, what was the name of that memory clinic?"

If we don't laugh, we might cry. Probably we'll do both. Then we need to talk. We need to speak aloud of something often only discussed in hushed tones. I'm sure you've heard it. "Mom has (whispered:) Alzheimer's." It used to be cancer that we feared speaking of. Then it was AIDS - we're still not over the stigma of that one. Today, it is Alzheimer's disease.

Yom Kippur is a time for naming things. We recite aloud our sins, our hopes and dreams and fears. So today I am going to speak about the unspeakable. I am going to talk about Alzheimer's disease and related dementias. About the devastation of severe memory loss. And, about ways we can respond to lessen the pain and increase the humanity of those who suffer with it and because of it.

Did you know that 50% of all people over age 85 have Alzheimer's disease or related dementias? For people age 65 and up, it is one in eight. And listen to this: every day, another 10,000 Baby Boomers turn 65. We boomers are no longer babies. We are now called the Silver Tsunami. In the next few years, the number of people with Alzheimer's disease and related dementias is going to reach epic proportions. How will we respond? Will we all be going around talking about our loved ones in whispers, or will we prepare ourselves and our community so that our *Kehillah Kedosha* – our holy community - will maintain its holiness?

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<sup>1</sup> http://www.babyboomer-magazine.com/news/165/ARTICLE/1514/2012-02-17.html

This is not a rhetorical question, and there is only one right answer. Because if we don't prepare, we will be in trouble.

I'm proud to say that our community – beginning here at Mount Zion and expanding out to the Twin Cities Jewish community - are already getting to work. We were the first synagogue to have an Alzheimer's Support group which began because a few women who were caring for parents with Alzheimer's reached out to one another. In 2007 they turned to Jewish Family Services for professional support, which led to the formation of the Twin Cities Jewish Community Alzheimer's Disease Task Force, involving representatives from a wide spectrum of Jewish organizations and committed individuals.

About a year ago, our Jewish Community was invited to be a pilot community for ACT on Alzheimer's, a statewide collaboration to prepare local communities for the budgetary, social, and personal impacts of Alzheimer's disease and related Dementias. ACT on Alzheimer's has an impressive list of 150 partners, including health care organizations, advocacy groups, the U, and the State, and more.<sup>2</sup>

So there is great work being done out there. This morning, I will talk about the work that needs to be done *in here*, in our smaller circles of congregation, friends, and family. The work of becoming a more understanding, more aware, more "dementia capable" community. There's no doubt about it: the specter of Alzheimer's is terrifying. It is an inhospitable wilderness no one wants to enter. But we Jews have been in the wilderness before, and I think that experience has something to teach us. <sup>3</sup>

For the ancient Israelites, the 40 years in the wilderness - *BaMidbar* – were mysterious and difficult. They wandered without a roadmap toward an unknown destination. They could not sustain themselves on their own. They were vulnerable to the people they met along the way, and to the harsh forces of nature. They could not return to their past in Egypt,- nor could they imagine what lay ahead.

The wilderness journey began at the shores of the Red Sea. The Israelites stood between an approaching army and the sea, afraid to take those first steps into the water. The first steps into the sea of Dementia are *very* frightening, and we do not like the idea of jumping in. So we rationalize and turn a blind eye to the symptoms, ignoring the early tell-tale behaviors of Alzheimer's disease. "We all lose our keys every now and then," we say. But we don't all put them in the freezer. Denial is not just a river in Egypt. It is a natural coping mechanism in a frightening situation. But it isn't a productive one in this case, because early intervention can make a tremendous difference.

<sup>&</sup>lt;sup>2</sup> http://www.actonalz.org/

<sup>&</sup>lt;sup>3</sup> The metaphor of BaMidbar is introduced by Rabbi Dayle A. Friedman, "Seeking the Tzelem: Making Sense of Dementia" in Jewish Pastoral Care: A Practical Handbook from Traditional and Contemporary Sources. Jewish Lights, 2005

In the beginning stages of Alzheimer's, a person can still participate in decision making about his or her own care. Gerontologist Beverly Engel writes: "It is critically important to plan for the future while one can still express preferences and wishes for future care options." Also, there are now medications which, if taken early on, can slow the progression of the disease. So we need to be courageous and step boldly into to the sea, so that it might open itself for us, and we not drown.

The wilderness contained many perils for the Israelites, yet it also held oases of great beauty, and moments of amazing power. It was in the wilderness that the Israelites met God. In the *Yotzer* prayer in our morning service, we praise God for "renewing in goodness each day the work of creation." This can give us a framework to reconsider the impact of the loss of short-term memory, and more importantly, how we will respond to our loved ones who experience it.

A woman describes her mother's experience with Alzheimer's:

She is constantly surprised — by flowers that have been in her room for days, or by visitors who just step out of the room for a while. "Oh!" she exclaims, smiling broadly at their return, delighted to see them as if they have just come.<sup>5</sup>

Each moment of surprise can lead to one of gratitude. Our job is to be present with her in that moment. It is natural to become annoyed or angry at someone who forgets that you brought her flowers, or that you have been coming EVERY DAY for over a year, and to try to correct her. But in *her* reality, you DID just arrive, probably for the first time.

We have a choice: We can stay in *our reality* and argue: "No, mom, I brought those flowers last week. Mom, I've been here all morning-I just went to the restroom." OR, we can try to be present with her *in hers*: and respond with equal joy, "Yes, it's so good to see you!!" and "The flowers do look lovely in here!"

When trying to reach someone who has dementia, the facts do not matter. Only the connection does. So the next time your 90 year old father tells you he is going to a ball game with his dad tomorrow, tell him "That sounds like fun," instead of pointing out that Grandpa has been dead for decades.

Our ancestors felt lost in the wilderness of Sinai. One of the greatest dangers in the wilds of dementia is loss of one's humanity – that is loss of dignity, being treated as an object or an infant, or simply ignored. The Israelites had divine help in the form of the pillars of cloud and fire that accompanied them.

<sup>5</sup> Walking One Another Home: Moments of Grace and Possibility in the Midst of Alzheimer's, by Rita Bresnahan, Liguori Publications, 2003, page 82

<sup>&</sup>lt;sup>4</sup> Broken Fragments: Jewish Experiences of Alzheimer's Disease, Edited by Douglas J. Kohn, URJ Press, NY, 2012, page 9.

We can accompany our loved ones by being pillars of love, respect, and tenderness. It isn't easy. But, it probably wasn't easy for God either: In the wilderness, Moses and God had to contend with stiff-necked, rebellious, calf-building ex-slaves who didn't want to accept their situation; in the world of Alzheimer's and related dementias, we face frustration, loss, and grief as the people we love become stiff-necked, rebellious strangers. It is hard to love the stranger when the stranger is someone you love.

Caring for someone with dementia forces us to recognize that there is more to being human than just our brains, that the true essence of our humanity is the *Neshama*— the soul. The part of us that is *B'tzelem Elohim*, in the divine image, stays with us as long as we are alive. While dementia will destroy a person's intellect, it cannot take their soul. The *Neshama* is safe from dementia — but here's a hard question - is it safe from us? Sadly it is we — the well-meaning but exhausted loved ones - who have the power to diminish a soul if we are not very careful.

Theologian Martin Buber distinguishes between two types of interactions: "I-it" and "I-Thou." An "I-Thou" interaction is one in which we communicate soul to soul, without interference from judgments or distractions. The I-Thou interaction is holy, and it is a good model for engaging with a person with dementia. Experts in the field agree that if we want to enter into true relationship with someone with dementia we have to do it on their terms; to enter their world without judgment, and connect soul to soul.

#### Author Rita Bresnahan writes:

It is not Mom who must remember who I am. Rather, it is I who must remember who my mother is. Who she *truly* is. Not merely "an Alzheimer's patient." Nor even merely "my mother." It is up to me to learn to [be] keenly aware of her spirit, honoring her soul-essence, and ...to meet her with love and respect in that sacred place of wholeness..."

Thomas Kitwood, author of the landmark work "Dementia Reconsidered: the Person Comes First" says it loud and clear:

The problem is not that of changing people with dementia, or of 'managing' their behavior; it is that of moving beyond our own anxieties and defenses so that true meeting can occur and life-giving relationships can grow. Only in this way can the personhood of people with dementia be conserved even as their intellection declines.<sup>8</sup>

I know how hard it is to try to engage with someone who can't even recognize you, who won't remember that you even visited. It is easy to fall into the habit of helping with daily cares or visiting without really trying to engage. But the easy way isn't always the best way, and it will be worth the effort to learn to create I-Thou moments whenever possible.

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<sup>&</sup>lt;sup>6</sup> Bresnahan, page 50

<sup>&</sup>lt;sup>7</sup> T.M. Kitwood, Dementia Reconsidered: The Person Comes First, OPEN UNIVERSITY PRESS, United Kingdom, 1997

<sup>&</sup>lt;sup>8</sup> "The Sense of an Ending," by Rebecca Mead, New Yorker Magazine, May 20, 2013. See note 10 for URL.

Many of you know that I love Midrash – the creative interpretation of texts. I think that Midrash can offer us a model for engaging with our loved ones with dementia. Reading a text midrashically means looking beneath the "pshat" or plain meaning of the text to its potential meanings. The sages believed that the real meaning lies in the white spaces between the words.

When people with Alzheimer's communicate with us, we need to learn to read the white spaces, to try to understand beyond the *pshat*. One of the greatest challenges for caregivers is when their loved ones act out in hostile, inappropriate, or strange ways. Tena Alonzo, director of an innovative dementia care program in Arizona has put it very simply: "all behavior is communication." If language was not an option, how would you communicate that you were in pain, or thirsty, bored or annoyed? Just as a blind or deaf person develops other senses in compensation, people who have lost the ability to retrieve the appropriate words have to develop new ways to get their feelings across. If we can try to read what is behind the behavior, we might have better success at connecting.

Alonzo's facility in Arizona has made amazing strides in Alzheimer's care by changing its assumptions, and *responding to patients' needs* instead of *reacting to their behaviors*. "We can't change the way they think, but we can change the way they feel," Alonzo says. Research has shown that pleasant experiences have a positive effect on patients with dementia long after the event itself has been forgotten.

I encourage you read more about Alonzo's innovative approach in New Yorker magazine; I will put a link on the Mount Zion website with this sermon. And remember – the love and joy you give to someone with dementia does make a difference even though it is forgotten.

In the wilderness, the Israelites journeyed and camped in groups, so that none was ever all alone. Isolation is a great peril in the wilderness, and so it is too in the world of Alzheimer's. We need to care for our loved ones who can't remember by literally re-membering them. That is, returning them to membership in the human community, refusing to let them be cast aside. The Psalmist's plea: *Al tashlicheini b'et zikna* – Cast me not off in the time of old age<sup>11</sup> - is an appeal to family and community as much as to God. If we can find the courage and fortitude to stay with them on the journey, if we can recognize that being human is more than intellect, more than memory, we may also learn to value ourselves and others in deeper ways.

It is not only the dementia *patient* that needs to be re-membered into the community, but the caregivers as well. The caregivers *especially*. Caring for a parent or spouse with dementia is exhausting and isolating, and it is up to us to help care for the caregiver. As one husband put it:

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<sup>&</sup>lt;sup>9</sup> Mina Friedler in Kohn, page 92

<sup>&</sup>lt;sup>10</sup> http://www.newyorker.com/reporting/2013/05/20/130520fa fact mead

<sup>11</sup> Psalm 71:9

"Everyone I have spoken to has made the same two suggestions: surround yourself with a support network and look after yourself. Both are easier said than done." 12

Caregivers need to be reminded again and again that they still have friends, that they can still live lives of their own, that they need to take care of themselves and not become secondary casualties of Alzheimer's. We need to step up and offer to help because most people are not going to ask. The Mayo Clinic suggests two principles to follow: first, be specific: "I'm going to the grocery store; what can I pick up for you?" Second, be gently persistent. Caregivers tend to decline the very help they sorely need because they feel they should be able to shoulder it alone. If you are a caregiver, please, allow us to do our job as your caring community, and let us help. I would add a third principle to Mayo's two: Stay in there with them for the long haul. Often we jump in to help at the beginning of the crisis, but Alzheimer's is a very slow killer, and our friends need us even more as time goes on.

Rabbi W. Gunther Plaut served Mount Zion Temple from 1948-1961. In 2004, at the age of 92, Rabbi Plaut returned to this pulpit - which he built – to help us celebrate our sesquicentennial. I'll close today with his words, published in 2003 as his final submission to the Canadian Jewish News, after 30 years of weekly articles. Rabbi Plaut died last year just short of his one hundredth birthday.<sup>13</sup>

One of the fundamental experiences of being human is being subject to physical and mental problems. Rabbis are no exception. I don't hesitate to tell you that last month I celebrated my 91st birthday...Now that I am old, I realize that I once took for granted that the youthful alertness of my own mind would last forever...[But] I have come to feel in this last while that I was strangely debilitated ...The diagnosis was that I now suffer, like many people my age...from Alzheimer's disease. And I want you, my friends and readers, to know this straight from me: I will continue to do my best, but my best is no longer what it once was. So, like everyone else, regardless of age or health, I now face a basic question: how exactly can I do my best in waging a battle against Alzheimer's disease and, of course, for life?

The answer, simple though it may seem, is best expressed by the brief Hebrew expression *Chazak v'ematz* - be strong and of good courage - I will attempt to be as strong as possible and muster up as much courage as possible, knowing that much has been given to me in life, and knowing, as well, that much is in the hands of the Almighty.

And my friends, I would say the same to you in whatever battle you must wage for life and for health: *Chazak v'ematz*, be strong and be of good courage, and may you and I be ranted the privilege of living for as long as our strength and God afford us.<sup>14</sup>

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<sup>12</sup> Kohn, page 160

http://www.holyblossom.org/about-us/rabbis-and-cantor/rabbi-w-gunther-plaut/

<sup>&</sup>lt;sup>14</sup>"Chazak V'Ematz" Canadian Jewish News, December 11, 2003, in Kohn, page 21-22



Alzheimer's Association Minnesota – North Dakota 7900 W 78<sup>th</sup> Street, Suite 100 Minneapolis, MN 55439

24/7 information Helpline 800 272 3900

# memory loss support education

Are you caring for someone affected by memory loss?

Our Support Group is a safe place where people can feel free to share in confidence their ideas, struggles and hopes.

Proven to be an excellent place to find information, education, friendship and support.

Location:

Mount Zion Temple 1300 Summit Ave St. Paul, MN 55105

Open to All!

Date/Time:

Meets the fourth Tuesday of every month at 7:00 p.m.
For more information, contact Chris Rosenthal at 651-690-8920

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the compassion to care, the leadership to conquer

# what you need to know about alzheimer's



Alzheimer's disease is not a part of normal aging; it's a progressive, fatal disease. Alzheimer's is the sixth-leading cause of death in the country and the only cause of death among the top 10 that cannot be prevented, cured or even slowed.

There are currently more than 5.4 million Americans living with Alzheimer's-including as many as 116,000 in Minnesota and North Dakota. By 2050 there could be as many as 16 million with the disease which has the power to bankrupt families, communities and our health care system.

Today, as many as half of people living with the disease never receive a diagnosis. Early diagnosis gives families the chance to start treatment early, when it is most effective, and plan ahead.

what can you do >>

alzheimer's 95 association

Minnesota-North Dakota Chapter

## help and hope

Learn about Alzheimer's disease—its warning signs, who's at risk and what treatments are available.

Connect with the Alzheimer's Association by participating in a support group, getting information about care options or attending one of our educational workshops.

**Advocate** for those affected by Alzheimer's and urge legislators to increase funding for research, care and support.

Volunteer along with hundreds of others who work with us to provide essential services across our communities.

Participate in the Alzheimer's Association Walk to End Alzheimer's®, our annual signature event to raise funds and awareness in communities across Minnesota and North Dakota.

**Donate** to help fund vital research and care programs.



The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's disease<sup>®</sup>.

For information and support, contact the Alzheimer's Association:

> 800.272.3900 alz.org/mnnd

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### Jewish Resources for people with dementia/memory loss and their caregivers

Jewish Family and Children's Service of Minneapolis (JFCS) 13100 Wayzata Blvd, Suite 400

Minnetonka, MN 55305

952.546.0616

Contact: Annette Sandler

Sabes JCC

4330 S. Cedar Lake Road Minneapolis, MN 55416 952.381.3400

Contact: Anita Lewis

Jewish Family Service (JFS) of St. Paul

1633 W. 7th St.

St. Paul, MN 55102 • 651.698.0767

Contact: Chris Rosenthal

St. Paul JCC/Living Well -A Holistic Program for People with Early Memory Loss

1375 St. Paul Ave.

St. Paul, MN 55116 • 651.698.0751

Contact: Barbie Levine

Sholom

East Metro: 750 Kay St. St. Paul, MN 55102 651.328.2000

**Contact**: Director of Social Services

West Metro: 3620 Phillips Parkway

St. Louis Park, MN 55426

952.935.6311

**Contact**: Director of Social Services

**Alzheimer's Association** 

24-hour Helpline: 1.800.272.3900

Senior LinkAge Line

Statewide information and

assistance service • 1.800.333.2433

**Jewish Community Support Groups:** 

Location: Bet Shalom Congregation

Minnetonka, MN

Contact: Rita Kelner • 612.834.0641 Judy Witebsky • 763.546.1658

Location: Temple Israel/JFCS

Minneapolis, MN

Contact: Barbara Rudnick

952.546.0616

Location: Mount Zion Temple

St. Paul, MN

Contact: Chris Rosenthal

651.698.0767

alzheimer's (1) asso

Memory changes that disrupt daily life

Challenges in planning or solving problems

Difficulty completing familiar tasks

Confusion with time or place

Trouble understanding visual images and spatial relationships

New problems with words in speaking or writing

Misplacing things and losing the ability to retrace steps

Decreased or poor judgment

Withdrawal from work or social activities

Changes in mood and personality

alz.org/10signs