

## THE GOOD NEWS IS YOU'RE WITH ME

Yom Kippur Morning

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"When will I be myself again?" Some Tuesday, perhaps, in the late afternoon, sitting quietly with a cup of tea, and a cookie; or Wednesday, same time or later, you will stir from a nap and see him; you will pick up the phone to call him; you will hear his voice — unexpected advice — and maybe argue. And you will not be frightened, and you will not be sad, and you will not be alone, not alone at all, and your tears will warm you. But not today, and not tomorrow, and not tomorrow's tomorrow, but some day, some Tuesday, late in the afternoon, sitting quietly with a cup of tea, and a cookie; and you will be yourself again."

This poem by Rabbi Lewis John Eron is dedicated to all those in our sanctuary this morning who are living with dementia or who are managing the care of a loved one coping with Alzheimer's or some other form of dementia.

Currently there are 5.7 million people suffering from dementia in our country. The number of Americans with Alzheimer's is expected to triple to 16 million by 2050. It is estimated that 10% of the population over -five and 50% of those over eighty have dementia. Alzheimer's is the third-leading cause of death in the United States. It is the only top ten cause of death with no cure.

It is incumbent upon us as a temple and a caring community to understand what dementia is, to appreciate the difficulties faced by those struggling with Alzheimer's, and to help those caring for a loved one with this illness.

In this regard, I am pleased to announce that the David Raskin Caring Community Fund will sponsor Temple Sinai's first dementia awareness and education program, "Alzheimer's 101," on Wednesday evening, October 24, at 7:30 pm. Please save the date.

What's it like to be an Alzheimer's caregiver? The physical, emotional, and financial toll of caregiving is huge. The caregiver's task is psychologically overwhelming, as they are buffeted by feelings of fear, grief, despair, infuriation, and loss. Dementia can turn their loved ones into people they do not recognize and who no longer recognize them. Caregivers experience the illness talking.

At the same time, the caregivers' literature speaks about moments of special illumination. Moments of beauty and grace and acceptance. Moments when our loved ones' extraordinary lucidity shines through even the deepest fog. The literature describes how parents and their adult children -- after years of estrangement-- become close again.

In an exceptionally touching essay, "That Delicate Membrane, the Heart," author Kim Barnes stood by her father in his hospital bed. "I moved closer, took his hand, curled my fingers into his. 'Stay with us,' I whispered. 'Just a little while longer.' For a moment, I thought he did not recognize me. But then he nodded, tightened his grip. I felt the speed of his pulse beneath my fingers. I closed my eyes and held on."

So much of the caregiver's task is to hold on for dear life. Our task as a caring community is clear and straightforward. Caregivers need care. Our care.

What's it like to live with dementia? In her beautiful essay "Refreshing a Mother's Memory with Love and Stories," novelist Jenny McPhee describes the fear, confusion, and bewilderment that arise when beloved memories are lost:

"... My mother once flourished in a crowd, playing the perfect hostess, making every guest feel as if his or her presence was crucial. Nowadays, any gathering beyond her five daughters flusters her and she often retreats to her bedroom ... [during Thanksgiving, with 35 people sitting around several tables in my mother's dining room] she pulled me aside and said with panic, 'Jenny, who are all these people and what are they doing in my house? I feel so strange to be here with all these people I don't know."

How can we help someone with dementia? In an essay dedicated to her cherished Grandpa Harold who passed away from Lewy Body Dementia, Tori Mandel, the 17 year old niece of temple members Doug and Kim Mandel, teaches that our help begins with empathy.

"I remember when my Grandma first took away his guns and how intense his reaction was. He looked at my Grandma and said 'Judy there is no way in hell you're selling those.' At the time, my family and I didn't recognize the emotional trauma that he was going through. We have never had our memory crumble and lose the ability to do the little things. We have never been stripped clean of our favorite hobbies and our most beloved memories. To us, taking away his guns was the obvious thing to do to prevent any accidents because of his health, but to Grandpa Harold taking away his guns made this a reality. Now I realize he was trying to mask his sadness with toughness."

Here are some other crucial things to know: Dementia sufferers need us to hold <u>their</u> memory in our memory. Rita Bresnahan wrote, "It is not Mom who must remember who I am. Rather, it is I who must remember who my mother is."

Dementia sufferers often feel lonely and isolated. They need us to learn the techniques for communicating and connecting with them, especially the capacity to join them in their world.

Dementia sufferers need to be treated with respect and dignity. As Rabbi Cary Kozberg reminds us every human being, no matter how compromised, is still created *betzelem elohim*, in the image of God.

And perhaps <u>the</u> most important way to be present for those we love and who are suffering from dementia is named by Tori Mandel in her tribute to her beloved Grandpa Harold:

"I knew when the end was approaching and I knew I had to see him before he completely let go. People kept telling me, 'Oh you don't want to see him like this,' 'It's not who your Grandpa really is,' or 'You still have the good memories you shouldn't go visit.'

Hearing those words broke my heart, but I knew that I had to see him because whether or not he looked the same, he was still my Grandpa. Family members questioned why I would want to put myself through that, but I had to dismiss those words and do what I knew was right.

Even if my Grandpa wasn't as strong as he once was and his stature wasn't as broad, I knew deep down that Grandpa was still the same. I didn't care whether or not he was undernourished and pale. I only cared about saying goodbye to the strongest and wisest man I've ever met."

Like Tori, let us learn to look deep down, to see beyond the physical. Our bodies are just the outer shell, the external cover for the core of our being. Nothing can take away the essence of who we really are.

We read in Psalm 71: "Do not send me off at the season of old age; as my powers diminish, do not abandon me!" In her book <u>Family Faith Stories</u>, Author Ann Barr Weems remembers Miss Hester, her childhood babysitter. Ann and her siblings called Miss Hester "Nee Nee." Even after Ann grew up, Nee Nee frequently came to visit and slept over at Ann's house. As the years progressed, Nee Nee aged and became quite forgetful.

One time, in the middle of the night, Nee Nee woke up and said, 'Where am I?' Ann said, 'Nee Nee, it's all right. It's Ann. You're at our house.' Nee Nee had a bewildered look on her face, the look of a lost child. Nee Nee looked at Ann and said, 'Well, I don't know where I am, but the good news is you're with me."

You're with me.

*Gemar chatimah tovah* – May we all be inscribed and sealed in the Book of Life for a good year.