

## **A Jewish Response to Dementia: Honoring Broken Tablets**

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Reprinted with permission from Rabbi Cary Kozberg. Rabbi Kozberg is the director of rabbinical and pastoral services at Wexner Heritage Village in Columbus, Ohio.

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Joe always puts me in the right mood for preparing for Shabbat: a warm handshake, a friendly smile, and an enthusiastic, “Rabbi, it’s time to talk to the Boss!” It’s true that sometimes when I ask him to recite the blessing over wine he forgets the words, and the answers he offers to questions don’t always fit the questions he was asked. Joe has Alzheimer’s Disease and is a resident in the long-term care facility where I am a chaplain. Though he still has remarkable social skills, he has lost most of his short-term memory, is often incontinent, and needs assistance with everyday activities. But with all of his deficits, he is still one of the most spiritually alive people I know.

His son Steve, however, doesn’t experience him that way. For Steve, Joe is a shadow of the person he used to be. “He’s not really my dad anymore,” he often remarks. Even after two years Steve does not see what his dad can do, but rather what he can no longer do. As Joe’s decline progresses, Steve visits less frequently. When he does visit, it is with the look of palpable sorrow that acknowledges the reality of human brokenness and frailty.

For families and friends of those with dementia, this reality is an unwelcome but all too familiar constant of daily life. Every day they must watch as their once vibrant, energetic, and independent loved ones irreversibly change into people who need continuous supervision and help carrying out the simplest tasks. These changes occur over time—sometimes years, sometimes decades. They affect not only the people with the disease, but also the lives of those who care for them.

How *do* we care for such individuals, who are like the first set of tablets that Moses shattered—“broken” yet still sacred? The challenges that accompany caring for people with dementia can be, and often are, devastating. At the same time, they present opportunities for us as caregivers to experience renewed meaning and purpose in our own lives, and even a new understanding of *kedushah* (holiness). How we respond to these challenges depends not only on how we understand and interpret them, but also on what resources we have available when they arise.

### **What is dementia?**

Dementia is a condition that brings about the impairment and/or loss of mental activity affecting an individual’s understanding, judgment, memory, mood, and behavior. Dementia is not synonymous with “being crazy”, and although the frequency of dementia increases significantly in people over the age of eighty, it is not a direct result of the aging process. Some dementias may be treatable and reversible, but only a neurological examination by a competent physician can determine a definite diagnosis. A person with

an irreversible dementia such as Alzheimer's Disease-the leading cause of dementia in the United States-will eventually become so cognitively impaired as to require constant care and assistance in performing the most basic everyday tasks.

Increasing awareness of dementia illnesses has led to a growing number of excellent resources for caregivers, including more attention to not only addressing the physical and emotional needs of dementia patients and caregivers, but to their spiritual needs as well.

### **Hearing the Voice: Meeting Spiritual Needs**

It is a widely held belief that people suffering from dementia no longer have spiritual needs. After all, if they can no longer think, reason, or reflect, how could spirituality be important to them? Wouldn't efforts to promote their spiritual well-being be a waste of time and resources?

Dementia may steal the mind but it cannot encroach upon the soul. In my work I see how alive and vibrant the soul can remain, even when a person's cognitive capacities are significantly diminished. This is because God addresses each person in the way he or she is able to hear, as Midrash Tanhuma affirms: "The voice of the Eternal is in the strength-that is, fitted to the strength, the ability-of each and every person: men according to their abilities, women according to their abilities, and young according to their abilities, the elderly according to their abilities."

As I've learned from folks like Joe, sometimes the soul can hear the Voice even better, and respond more spontaneously when the mind no longer gets in the way.

### **Honor, Respect, and Foster Community Connection**

For people like Joe, whose religious practice has always been a vital aspect of life, continued participation in familiar rituals and ceremonies, particularly those known from childhood-where common melodies are sung and customary prayers and passages from sacred texts are recited-remain essential for maintaining a life of quality and meaning. Such participation should continue regardless of whether a person lives at home or in a long-term care facility

While spiritual care includes addressing religious needs, it is not limited to them. Even without any religious affiliation or personal forms of piety, we all have spirits and shine when given attention or become dull if neglected. As Rev. Elbert Cole, a pioneer in the field of spiritual care and dementia, suggests, people with dementia have the same needs as all people. They need to:

- Love and be loved, respected and appreciated
- Express compassion and share of themselves
- Feel productive, stimulated, and secure
- Celebrate the joy of living

In other words, people with dementia have a special need to feel connected. Indeed, because of their cognitive decline they often feel overwhelmingly *disconnected*: from their surroundings, from other people, even from themselves. Such disconnection is evident when a person asks, "Where am I?" "When can I go home?" "Is that my wife/husband?" or when a person converses with his or her own image in a mirror as if it

were someone else. For all intents and purposes, people and dementia are strangers-to others, and sometimes even to themselves.

How do we keep our loved ones with dementia connected? We affirm their personhood. We continue to:

- Help them look and feel beautiful or handsome
- Help them engage in activities that make them feel productive, useful, and proud of their accomplishments
- Listen to their stories and concerns, even if we have already heard them a million times before
- Help them celebrate important moments in their lives and in the lives of their loved ones-birthdays and anniversaries, for example
- Keep them rooted in their religious and cultural heritage, helping them to continue to participate in worship services and holiday celebrations
- Help them *feel* that they are still people by continuing to love them

### **Love Your Neighbor as Yourself: It's Not Easy to Do**

Loving and caring for someone with dementia sometimes requires superhuman effort and energy particularly when the person becomes more confused, begins to wander or rummage, is increasingly restless and agitated-particularly in the late afternoon, a phenomenon called *sundowning*-and needs constant supervisions.

Although these are among the typical and expected behavioral changes as dementia runs its course, they will still pose significant demands on you as a caregiver. As your loved one's behavior changes, so will your own feelings and behavior. As your caregivers responsibilities increase, requiring more time and more physical and emotional energy, so will your negative responses. You will probably feel (or have already felt) some or all of the following:

*Fear*-“What's going to happen now?”

*Frustration*-“How can I deal with all of this?”

*Grief*-“He's not really my dad anymore.”

*Anger at your loved one or at the situation*-“Why won't you understand?”

“Why is this happening?”

*Guilt*-“How could I say/do that to my mom?”

*Exhaustion*-“I don't have the strength to go on.”

*Embarrassment*-“Mom was incontinent at the restaurant.”

*Isolation and abandonment*-“Where are my family and friends?” “Where is God?”

All of these feelings may feed an overwhelming sense of despair.

### **Love and Care for Yourself**

It is important to remember that just as the changes in your loved one's behavior are typical and to be expected, your feelings are also typical. They illustrate the gap between your infinite love for the person suffering from dementia and your finite abilities, between what you want for your loved one and why is possible. Sometimes caregivers are so focused on meeting the needs of the person with dementia that they

neglect their own needs. The result is often that many caregivers “burn out”, become ill, and even pre-decease the people from whom they are caring.

For this reason it is imperative that you pay attention to caring for yourself and attend to your own physical, emotional, and spiritual well-being. This is often easier said than done. While caregivers agree that self-care is necessary, they also feel that engaging in self-care means that they are being selfish.

Nothing could be further from the truth. What many people call selfishness is really self-centeredness—that is, caring only about one’s self all or most of the time. Being self-*ish*, on the other hand, is acknowledging that there are times, particularly in the midst of stressful experiences, when the self needs to rest and be nurtured. Looking at it another way, it is simply a matter of physics: whenever physical energy is expended, it has to be replenished.

Thus, a substantial part of self-care is having the wisdom to know limitations: knowing when occasional respite care for you and your loved one is appropriate (in which case adult daycare or a short stay in a long-term care facility may do), and when your loved one needs more than you or anyone else can individually give (in which case permanent residence in a long-term care facility may be necessary). Placement in a long-term care facility is usually a difficult decision for a family, therefore such decisions should be made objectively, with as much information as possible and with the dementia patient’s overall welfare as the primary reason for placement (see Rabbi Dayle Friedman’s *LifeLight*, “When Someone You Love Needs Long-Term Care”).

Knowing the difference between being selfish and self-centered, you can, in good faith and good conscience, care for yourself. You can and should:

- Eat right, exercise regularly, and get enough rest
- Seek out people with whom you can talk: good friends, therapists, or rabbis
- Join an Alzheimer’s or other dementia support group when you can listen and learn from others’ experiences
- Keep enjoying the company of friends and family, and engage in activities that are enriching and edifying to you

You may feel the desire to attend synagogue more regularly, participate in adult education programs and/or in various community organizations. These are all good ways to meet others and resist feeling isolated. In addition, community interaction may also offer excellent opportunities to help educate the congregation and community about the realities of dementia: the crucial need of the individual and his or her caregivers to stay connected to the community, and the community’s religious and moral obligations to make that happen.

### **Why Me? Why Us? Where is God?**

In the midst of what you are facing, you have asked, “Why” Why has this happened to us? Why did God *let* this happen? How is this fair? Is it a punishment or a test? Is this just another example of “life stinks”, or is it somehow an opportunity for bringing more *kedushah* (holiness) and more healing into the world?

These are questions of meaning. As famed psychiatrist Dr. Viktor Frankl taught from eyewitness experience in a concentration camp, suffering is somehow more

bearable when there is meaning to it. When there is no meaning, when there is no understanding of reason or purpose, despair is the result. A significant aspect of spiritual self-care is seriously considering and reflecting upon a number of possible answers to “why?” while also understanding that there may be multiple answers to that question, and that, ultimately, no one else but you will know what the right answers are. Jewish tradition has several millennia worth of teachings on the subject of suffering, and it may be worthwhile to look into them and discuss them with a rabbi or other knowledgeable person.

### **Explore the Power of Prayer**

Today, many of us are more unsure of the efficacy of traditional petitionary prayer than were our forebears. Some of us prefer more contemplative practices such as meditation over traditional prayers that ask God for help. We ask, does prayer really work? There are recent scientific studies that answer affirmatively. But in spite of what science says, the truth about the efficacy of prayer resides in the heart of the one praying, and in allowing one’s heart to be open. As Rabbi Yitz Greenberg taught:

We don’t have to beg or bribe God to give us strength, hope, or patience. We only have to turn to the One, admit that we cannot do this on our own, and understand that bearing up under illness...is one of the most human-and most Godly-things we can ever do.

### **Let Your Heart Take Courage**

When it comes to caring for someone with dementia, a constant and abiding hope is life-saving; its absence can be lethal. It is important to understand what hope is and what it is not. As Dr. Jerome Groopman wrote in *The Anatomy of Hope*, hope is not about maintaining an attitude that “everything will turn out for the best.” It doesn’t arise from being told to “think positively” or from hearing a rosy forecast. Instead:

Hope acknowledges the significant obstacles and deep pitfalls along the path. True hope has no room for delusion...Clear-eyed, hope gives us the courage to confront our circumstances and the capacity to surmount them.

As you and your afflicted loved once face the challenges and obstacles that accompany dementia, it is important to remember that amidst the problems and pitfalls, you can be the vehicle of sacred connection between your loved one and the world, and that you can trust in the ultimate Source of Strength, who is always there for you.