



Love and Care for Yourself

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 person for whom they were caring.

For this reason it is imperative that we pay attention to caring for ourselves and attend to our 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. Healthy self-care means acknowledging that there are times, particularly in the midst of stressful experiences, when the self needs to rest and be nurtured. Thus, a substantial part of self-care is having the wisdom to know when occasional respite care for us and our loved one is appropriate. Good self-care can and should include:

- Eating right, exercising regularly, and getting enough rest
- Seeking out people with whom we can talk: good friends, therapists, or rabbis
- Joining an Alzheimer’s or other dementia support group where we can listen and learn from others’ experiences

- Enjoying the company of friends and family, and engaging in enriching activities

Attending synagogue more regularly, participating in adult education programs and/or in various community organizations are good ways to meet others and resist feeling isolated. It may also offer educational opportunities for others about the realities of dementia including the crucial need to stay connected to the community and the community’s religious and moral obligation to make that happen.

Why Me? Why Us? Where Is God?

In the midst of what we are facing, we may ask: “Why?” Why has this happened? 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 *qedushah* (holiness) and more healing into the world?

These are questions of meaning. 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 we 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

For many, belief in the efficacy of traditional petitionary prayer provides comfort. Others prefer contemplation or meditation. Either way, scientific studies point out that prayer does help. Despite what science says, the truth about the efficacy of prayer resides in the heart of the one praying.



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. Hope is not about thinking positively; instead, hope acknowledges the significant obstacles and deep pitfalls along the path, but gives us the courage to confront our circumstances and the capacity to surmount them.

With hope, we can be the sacred connection between our loved one and the world, and we can trust in the ultimate Source of Strength, who is always there for us.

Contact Information

Rabbi Geoffrey Haber, Director
Department of Spiritual Care
ghaber@baycrest.org

3560 Bathurst Street | Toronto, Ontario
M6A 2E1 | 416-785-2500 x3743

www.baycrest.org



Baycrest Health Sciences
is fully affiliated with
the University of Toronto



Honoring Broken Tablets: A Jewish Response to Dementia

Adapted from “A Jewish Response to Dementia: Honoring Broken Tablets” by Rabbi Cary Kozberg and used with permission from Jewish Lights Publishing

Baycrest



How Do We Respond?

For families and friends of those with dementia, the reality of lost physical, cognitive and emotional ability 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. These changes occur over time and 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 are often devastating; yet, they also present opportunities for us as caregivers to experience renewed meaning and purpose in our own lives, and even a new understanding of *qedushah* (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. A person with an irreversible dementia such as Alzheimer's disease will eventually become so cognitively impaired as to require constant care and assistance in performing the most basic everyday tasks.

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? Aren't efforts to promote their spiritual well-being just a waste of time and resources?

Dementia may steal the mind but it cannot encroach upon the soul. A soul can remain alive and vibrant, 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..." Sometimes the soul can hear the Eternal Voice even better, and respond more spontaneously, when the mind no longer gets in the way.

Honor, Respect and Attention

For people whose religious practice was a vital aspect of life, continued participation in familiar rituals and ceremonies 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 that shine when given attention or become dull if neglected. Like all people, those with dementia 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



Feeling Connected

People with dementia need to feel connected because their cognitive decline often makes them feel overwhelmingly *disconnected*: from their surroundings, other people, even 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 with 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 good
- 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

- Help them celebrate important moments in their lives and in the lives of their loved ones such as birthdays and anniversaries
- Keep them rooted and participating in their religious and cultural heritage
- Help them feel that they are still people by continuing to love them

Love Your Neighbor as Yourself: Not So Easy

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 supervision.

As our loved one's behavior changes, so will our own feelings and behavior. As our caregiving responsibilities increase, requiring more time and more physical and emotional energy, so will our negative responses. We 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.