

Embracing Reality: Spiritual Preparation for Living with Dementia

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“If I get that way, just shoot me.”

“I have taken care of both of my parents through Alzheimer’s. I will *not* let my kids go through that.”

These are just a couple of comments I have heard from people talking about the prospect of living with an illness that causes cognitive loss. Americans are terrified of getting Alzheimer’s or other dementias. A 2017 study found that 38 percent of Americans are more afraid of dementia than anything else, second only to those who fear cancer most.¹ We are scared, and we want to do anything to avoid this fate.

What causes our profound dread of dementia? Most of us have encountered some of the harsh realities of cognitive impairment. We have felt distress when a beloved no longer remembers who we are. We have seen agitation when a family member is disoriented. We have observed dear ones suffering indignities. We have run into inhumane care. Surely, there is much to worry about in contemplating dementia. More than all of this, though, we equate memory with personhood. We believe that without the capacity to remember, we cease to *be*. If we do not remember our friends, relatives, work, what we had to eat or where we went yesterday, who are we? *What* are we?

Our fears have been stoked by personal experience, and by a steady stream of film and media accounts of the tragedy of dementia. People with dementia are depicted as empty vessels, and their

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caregivers as suffering saints. We have a very limited picture of the experience of dementia, the “tragedy narrative.”²

Dementia is far more complex than these simplistic images suggest. In my work as a pastoral caregiver for thousands of people with Alzheimer’s and other dementias, and in my confrontations with dementia in my family, I have seen the sad and scary parts. I have also witnessed delight, growth, healing, and peace. In this essay, I invite us to face the intricate reality of dementia, and I challenge us to personally and spiritually prepare for it, so that we can live with ease and so that we can more compassionately accompany our congregants in this mysterious terrain. I am aware that such preparation is neither normative nor easy, and yet, I suggest that we may well reap unexpected blessings from it.

Costs of Fear

We are unlikely to successfully evade the experience of dementia, a complex of diseases, of which Alzheimer’s is one type. Dementia currently affects about 5 million Americans; this number is expected to rise to 14 million by 2050. According to current estimates, about 10 percent of those over sixty-five and one-third of those over eighty-five live with dementia. One in three people over sixty-five die of dementia.³ Dementia will touch us—if we live long enough, we will likely have it, and even if not, we will no doubt encounter it in our parents, partners, congregants, and friends—and the fear of it colors our perspective on our own aging.

This immense fear has a cost. In our trepidation of the prospect of dementia, we may do everything we can to avoid it. We don’t admit that we could get dementia, so we don’t plan for it. We don’t talk about it with our families and friends. When dementia comes to us or our beloveds, we are drawn to denial. “She’s just a little forgetful.” “He is having a bad day.” “I’m not so bad for my age.” We may, despite our best intentions, gradually distance ourselves from dear ones or community members with dementia, thus increasing their isolation.

Avoiding reality can add to the suffering of the person with dementia and her family members. Because we have not explored, imagined, or planned for dementia, tough decisions become even more wrenching. A middle-of-the-night phone call suddenly prompts stressful choices regarding moves, medical treatment, or

placement in a care setting, all without knowing what the individual might have wanted. How many families have struggled when an elder who, like my Dad, clearly was no longer capable but insisted on continuing to drive? How many people have insisted on staying in their long-time homes, even when they are not able to safely live alone? Denial and resistance can magnify our grief, confusion and agony.

Preparing for Dementia

How can we prepare for living with dementia? Alanna Shaikh, a courageous young woman whose father has early-onset Alzheimer's disease, recorded a TED Talk, "How I'm Preparing to Get Alzheimer's."⁴ Shaikh is reaping guidance for herself from her Dad's journey. She wants to have enjoyable times when she gets Alzheimer's, so she is developing new, hands-on hobbies in which she could still engage if she were cognitively impaired. She is doing physical exercises to enhance her balance, so that she will reduce her risk of falling. And, most intriguingly, she is trying to be a better person. She says admiringly of her Dad, "When you take away everything he ever learned in this world, his naked heart still shines." She has work to do, she says, for "I need a heart so pure that if it's stripped bare by dementia, it will survive."

Jewish Spiritual Preparation: The Wisdom of the Baal Shem Tov

Alanna Shaikh says that the process of approaching Alzheimer's head-on has brought her to "thinking more broadly about how to plan for a future that isn't the future you choose. How can you build a life that you're living right now that prepares you for both the best and worst possible future?" It seems to me that Shaikh's question is a spiritual one, and that we should be able to reach into our Jewish sources to find guidance in this task.

I wonder how we can prepare *spiritually* for the prospect of living with dementia. It occurs to me that we might find a framework from the Baal Shem Tov's three-fold approach to contending with unwelcome experiences. He taught:

An individual should cultivate three ways of dealing with adversity: *Hachna'ah*/Yielding, *Havdalah*/Discernment, and *Hamtakah*/

Sweetening . . . If you are able to purify your thinking regarding what is good and pleasant about each of the occurrences that happen to you through Yielding, Discernment and Sweetening . . . you will then be able to hold your footing and you won't be toppled by the husks of evil. You will remain bound in oneness to the Blessed One.⁵

***Hachnaah* (Yielding)**

Hachnaah, the first step in approaching unwelcome experiences, involves facing reality. The Gerer Rebbe teaches in *S'fat Emet* that even in moments of darkness we can connect to the vital divine power hidden within us by “submitting ourselves before truth” (1:246). We can resist the truth of our lives, or we can soften to it. This is not easy or even intuitive—we would certainly prefer to run away from darkness. Many of us are attached to the illusion of control, and we balk at the idea of submitting ourselves to anything.

This business of yielding to unwelcome reality is counterintuitive. It is natural, even reflexive, to deny, to stiffen. When you pull a muscle in your back, your body responds with alarm, attempting to protect the hurt, raw place by hardening around it. You want to make sure that nothing can get to that vulnerable place and injure it further. But a strange thing happens. Instead of feeling better, now you are not only sore but also stiff. You find you have trouble bending, turning, and eventually moving at all. You want to take to your bed; you pray that this will all just pass. Surprisingly, you should do anything *but* this. Stretch, move gently, your doctor tells you, and you will heal. This is yielding. The Baal Shem Tov teaches that *hachnaah* (surrendering to or allowing what is) brings redemption from imprisonment.

Yielding to dementia means including the possibility of having dementia in our pictures of our futures. I have been practicing saying, “When I get dementia . . .” as an invitation to my imagination. My guts rebel as I utter these words, but perhaps it is a tad easier for me than others, because I spent years hanging out in the land of dementia when I was a nursing home chaplain. I got to see people living with dementia as three-dimensional beings. I used to wonder which one I would be—the spirited woman who couldn't speak, but sang constantly; the agitated woman who asked every passerby, “what time is it?”; or the man who believed he worked

there and constantly tried to help his fellow residents. Allowing for the prospect of dementia can empower us to discern our wishes, to make plans, and to collaborate with those who will be charged with our care.

Havdalah: Seeing Both Darkness and Light

If we yield to reality, we discover that what we are facing is not just darkness. The Baal Shem Tov calls us to discern the sparks that are encased in *k'lipot* (shards) as we face brokenness. I imagine this as a spiritual/emotional parallel to the phenomenon of our eyes adjusting to a darkened room; it turns out there is shadow, there are shades of darkness, and, if we try hard, we can make out tiny fragments of light.

Once we know the terrain of our sadness and we can let go of resisting it, we can begin to open ourselves to all of the complex experience. Another way of describing *havdalah* is bringing curiosity to the unwelcome reality. Having arrived in a place we hoped to avoid, we endeavor to take in and fully inhabit the landscape.

Jarem Sawatsky is a professor of peace and conflict studies who is living with, and reflecting on, Huntington's Disease. He watched his mother, uncle, and grandmother live and die with Huntington's, and he himself was diagnosed in his forties. In his moving memoir, *Dancing with Elephants*, Sawatsky writes, "Once you decide to embrace darkness, a different world comes into focus." He dedicates himself to living fully amid reduced capacities and with complete awareness that further decline awaits him. He insists that he is more than his disease. He works to befriend his forgetfulness and frequent falls, rather than to sink into constant anger. He aims "to be thrilled, grateful, wonder-filled and curious about life and living."⁶

Despite the losses and challenges of dementia, activist geriatrician Dr. Bill Thomas suggests that those of us who will live with dementia "have a choice. We can choose tragedy or we can choose joy."⁷

Hamtakah: Wrestling Sweetness

When we have allowed ourselves to dwell in darkness and we have opened our eyes wide to sparks of light within it, the Baal Shem Tov teaches that we are ready to wrest some sweetness out of

a bitter experience. It is interesting that the Baal Shem Tov changes his metaphor from darkness-light to bitterness-sweetness. Ultimately, he hints, what we can hope for is to harvest something of sweetness, something redemptive out of our most anguishing life experiences. Rabbi Burt Jacobson suggests that this sweetness can be seen as dispelling the darkness.

It is vital to note that the Baal Shem Tov is certainly not white-washing the agony of suffering. He himself was orphaned as a young child, his first wife died, and he grew up in an atmosphere of deprivation and violence against Jews. This is not a Pollyannaish denial of suffering's sting. Rather the sage boldly reminds us that even the most wrenching agony may also contain goodness if we are able to be open to it.

Rabbi Burt Jacobson says that when we have done *Havdalah*, "The energy we have heretofore placed into identification with our adversity and with our suffering can now be released and transformed into joy. This sweetening may not always affect the physical conditions of adversity that impinge upon our lives. We may still find ourselves in a painful situation. But our act of *Havdalah* has brought about an inward change, and we are now able to cope with the external difficulties out of an inner sense of resolution, freedom, and joy."⁸

Perhaps *hamtakah* hints at the possibility that we can be transformed by our unwelcome experience, in this case, by living with dementia. When my late father entered a nursing home with dementia, I prayed that something would happen to his soul. I didn't exactly know what I meant. Dad had many accomplishments, but he was also a complicated person, with much pain in and around him. I could not have imagined what he would be like as a nursing home resident, but I would not have been surprised had he been demanding, impatient, and unhappy. Nothing could have been farther from the truth. Over the four years Dad spent in the nursing home, he was content, loving, and grateful. It was as if his personality burned away, and what was left was pure soul. Dad's sojourn with dementia afforded him a radically different way of being, and it gave me the opportunity to connect with him in a deep and healing way.

Not everyone who lives with dementia has such a profound or positive transformation, but I have witnessed many shifts in souls and relationships on the path. Nader Shabahangi, who

works with people with dementia at AgeSong, a Zen-inspired eldercare organization, teaches about people with forgetfulness, “For those who can truly lay aside their aversion or discomfort and learn to accept what is, the gifts of the soul await; equanimity, intimacy with the dream-world and its magical ways, slowing down to the speed of soul essence.”⁹ My hope is that opening to dementia can defang our fears as we age, enable us to live more fully, and make us more compassionate and more resilient as we accompany family members, friends, and congregants on the journey of dementia.

Practice: Embracing Reality

The Baal Shem Tov’s three-fold approach to unwelcome experience can be a guide for us in approaching the prospect of dementia. Although dementia might be far off, or perhaps not even part of our personal future, practicing embracing reality in the way the sage prescribed can help us to be present to all of what life brings us. We can gently invite ourselves to face that which we are avoiding, thus opening ourselves to choices and goodness, and putting down the burden of resistance and hardening ourselves. This practice of reflection can be a starting place.

I invite you to try this practice when you have at least twenty minutes. Sit comfortably. Breathe naturally and allow your body to relax as much as possible. Take some time to reflect on at least one of the following realms of your life:

- Intimate relationships: partner, parents, children, siblings
- Work
- Home
- Physical health
- Spiritual life

Ask yourself if there is something you are avoiding acknowledging or are resisting. If you become aware of something, notice the resistance. What does it feel like in your body? Is there an image or metaphor that describes it? Allow the resistance to “talk to you”: What would be the worst thing that might happen if you faced the truth? What would be the best? Can you invite yourself to open a bit?

See if there is a hope that you have about this reality. If you wish, you can express that hope as a prayer, on the order of the following:

Makor HaChayim/Source of Life [or whatever name for the Divine suits you] who has sustained my ancestors and me, help me to face _____. Give me strength and courage; guide me on this path whose direction I cannot yet see. Open me to all that is before me; help me to be whole.

Notes

1. Alzheimer's Survey," Metlife Foundation, <https://www.metlife.com/content/dam/microsites/about/corporate-profile/alzheimers-2011.pdf>.
2. See Anne Basting's masterful work on developing deeper and more complex narratives of dementia, *Forget Memory: Creating Better Lives for People with Dementia*. (Baltimore: Johns Hopkins University Press, 2009).
3. Alzheimer's Association, "2019 Alzheimer's Disease Facts and Figures."
4. Alanna Shaikh, "How I'm Preparing to Get Alzheimer's," <https://fellowblog.ted.com/how-do-you-prepare-for-dementia-dc87f72be9ec>.
5. Baal Shem Tov, as translated in Burt Jacobson, *This Precious Moment: The Wisdom of the Ba'al Shem Tov* (Piedmont, CA: Kehilla Community Synagogue, 2016), 52–53.
6. Jarem Sawatsky. *Dancing with Elephants: Mindfulness Training for Those Living with Dementia, Chronic Illness or an Aging Brain (How to Die Smiling Book 1)* (Red Canoe Press, 2017).
7. William Thomas, "A Hundred Miles in Their Shoes," <https://www.edenalt.org/retrospective-bill-thomas-takes-tragedy-narrative/>.
8. Jacobson, *This Precious Moment*, 56.
9. Nader Shabahangi. *Deeper into the Soul: Beyond Dementia and Alzheimer's Toward Forgetfulness Care* (San Francisco: Elder's Academy Press, 2008).