

# Seeking the *Tzelem*: Making Sense of Dementia<sup>1</sup>

BY DAYLE A. FRIEDMAN

**T**he specter of dementia is terribly frightening. We dread the humiliating prospect of losing continence, the agitation of no longer knowing where or who we are, the vulnerability of being at the mercy of strangers caring for us. This is terrain no one wants to enter.

Undoubtedly, anyone who has encountered dementia in a family or at work has witnessed scenes of great tenderness as well as heartrending pathos. I have been confronting the mysterious world of dementia for more than 25 years in my work with elders. What follows is an exploration of the meaning of dementia and an effort to put it in a theological context. My hope is that this reflection will shed light on the work of spiritual accompaniment with individuals with dementia. Since the challenge of dementia is not abstract, but a lived reality, I begin this exploration by describing a few of the elders whose journeys inform my reflections.<sup>2</sup>

## Profiles

Mr. Shapiro, a retired pharmacist, was always impeccably dressed in a suit and tie when he lived at the nurs-

ing home. He often stopped me to ask if I ever got headaches, and if I'd like to know how to get rid of them. I replied that I did, on occasion, get headaches, and would appreciate learning a technique to cope with them. Mr. Shapiro showed me that by rubbing my forehead with thumb and finger, I could reduce the pain of the headache. Though he did not remember our encounters when next we met, I understood that he was a helper and a healer, and he was striving to continue to be authentically himself.

I met Mrs. Schwartz as I came onto her nursing home floor to conduct Shabbat services. Obviously distraught, she was near tears. She asked me to help her. "I must find my way home. I'm very late, and my mother is waiting for me. She'll be so worried."

I could count on meeting Mrs. Applebaum whenever I approached the nurses' station on her floor. She was always pacing frantically back and forth, stopping every passerby to ask the time. I watched as she got a variety of answers from the staff and visitors, some more patient than others. After perhaps the tenth such exchange, Mrs. Applebaum shouted out in exasperation, "This day is never going to end!"

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Rabbi Dayle A. Friedman is the founding director of Hiddur: The Center for Aging and Judaism of the Reconstructionist Rabbinical College.

Mrs. Goldberg was an East-European-born woman with quite advanced dementia. She could no longer speak, but she could sing, and sing she did, all day and all night. She had an amazing ability to take up any melody you started, in any genre — Broadway, folk, liturgical, klezmer. She didn't sing the words, only "la-la" — but with great gusto. Teenage volunteers in the nursing home adored being with Mrs. Goldberg. They lovingly called her "the la-la lady" and competed to sit next to her in the synagogue.

Mrs. Stein was always brought to Shabbat services in her nursing home unit. She would sit slumped over in her geri-chair through the entire service; it was not clear if she was asleep or awake. When we sang the *Shema*, Mrs. Stein would invariably open her eyes and murmur the words.

Encountering dementia is demanding, often surprising and sometimes even exalting. Confront it we must, for it is all around us as our community continues to age. In this quest to make sense of dementia, I want to explore what dementia means to the person, to those around her, and, with supreme *hutzpa*, to God. I will then suggest how these observations can guide the work of spiritual accompaniment with individuals with dementia.

## Defining Dementia

Dementia currently affects about four million Americans. Given the dramatic graying of the American population, this number is expected to rise to 14 million by 2050. According

to current estimates, about 10 percent of those over 65 and 50 percent of those over 85 have dementia. Based on the 2000 National Jewish Population Survey's estimate of 956,000 Jewish elders in the United States, there are at least 95,000 American Jewish elders with dementia today.<sup>3</sup>

Dementia is often equated with Alzheimer's disease. In reality, it is broader than Alzheimer's disease. Dementia refers to a number of related disorders that feature ". . . significant, progressive losses in mental ability, usually but not always in the elderly. Symptoms of dementia include impairment in judgment, thinking, memory and learning as well as possible changes in personality, mood and behavior."<sup>4</sup> Dementia can last for years, and is sometimes broken down into early, middle and late stages. The early stage is characterized by loss of short-term memory and mild confusion; the middle stage includes more dramatic confusion and loss of memory and judgment, and also often includes incontinence; the late stage involves nearly total deterioration of physical functioning, including, eventually, the ability to eat, to speak and to move about unaided.

## The Challenge of Dementia: A Phenomenological Description

What is it like to live with dementia? Is it solely a journey of suffering? Can we even know? Any characterization I offer must be with humility, since I have not been there; I have only witnessed this experience from the outside.

One way to conceive of dementia

is as a *midbar*, a wilderness. For the ancient Israelites, the 40 years of sojourning in the *midbar* after their liberation from slavery were mysterious and difficult. They wandered with few guideposts toward an unknown destination. They could not sustain themselves without divine help. They were vulnerable before people they met along the way, and before the harsh realities of nature. They could not return to Egypt, the place of their memories, and they could not truly imagine what lay ahead.

Perhaps people with dementia experience their lives as a kind of *midbar*. The loss of memory is the hallmark of their condition. This memory loss is distinct from the ever-duller recall with which those of us in midlife or beyond contend. For example: I am constantly misplacing my keys, desperately trying to recall the name of that colleague I always enjoy running into at professional conferences, and searching for the word that is on the tip of my tongue. Annoying though it is, this memory loss is normal, and not symptomatic of dementia; it is what gerontologists call “benign forgetfulness.”

The person with dementia experiences a progressive loss of memory as first short-term and eventually nearly all memory becomes inaccessible. The awareness of this loss is most acute in the early phase of dementia. The sense that one is losing one’s memory can be terrifying. Depression and agitation are often concomitants of early-stage dementia. Losing our memory means losing our connection to ourselves and, eventually, to those who have shared

our lives.

## The Present Moment

When you cannot remember the past and cannot conceive of the future, what you are left with is the present moment. Being present in and aware of the moment at hand can bring joy if the moment is positive and despair if it is not, for in that moment of *midbar* nothing else is imaginable. It can be a sweet and tender privilege simply to sit with a person with dementia, just holding hands, just being there, without distraction or agenda.

The *midbar* in which the Israelites wandered contained places of beauty and moments of amazing power. This is also true for the *midbar* of dementia. While memory and other faculties may fade, many people experience an unabated capacity for joy and love, at least until the final stages of the disease.

Diana Friel McGowin wrote a fascinating memoir of her journey through *dementia*. In it, she passionately asserts her continued engagement with life:

If I am no longer a woman, why do I still feel I’m one? If no longer worth holding, why do I crave it? If no longer sensual, why do I still enjoy the soft texture of satin and silk against my skin? If no longer sensitive, why do moving song lyrics strike a responsive chord in me? My every molecule seems to scream out that I do, indeed, exist, and that existence must be valued by someone!<sup>5</sup>

When short-term memory fails,

the world around one can offer many surprises. Rita Bresnahan observed this about her mother's experience with dementia:

And she [my mother] 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. She lives David Steindl-Rast's words: “Any inch of surprise can lead to miles of gratefulness.”<sup>6</sup>

## Oases of Connection

There are remarkable oases of connection to be found in the *midbar* of dementia. Against the background of so much loss, I have sometimes seen an especially keen appreciation for life's goodness. For example, one daughter described a sublime afternoon spent sitting with her father as they wordlessly watched the autumn leaves falling outside the window of the nursing home. The two of them were completely absorbed in nature's drama. They had no need for words or action.

In the *yotzer* (creation) prayer, we praise the Eternal for “renewing in goodness each day the work of creation.”<sup>7</sup> The person for whom a familiar, beloved person or object can continually seem a surprise is living those words. In this experience of delight, in which each moment seems new, the person with dementia may experience what the rest of us are too

busy to notice: each moment is a gift, and not to be taken for granted.

## Depersonalization

Unfortunately, the person living with dementia often suffers from being treated as a non-person. In his courageous book *Dementia Reconsidered*, Tom Kitwood decries what he calls the depersonalizing tendencies of malignant social psychology. He lists seventeen dehumanizing responses to people with dementia, of which the following seem particularly salient:

Treachery: using deception to distract, manipulate or force the person into compliance;

Disempowerment: depriving the individual of control over his or her life;

Infantilization: treating people with dementia like “wrinkled babies” instead of mature adults with history, dignity and will;<sup>8</sup>

Invalidation: failing to acknowledge the subjective reality of a person's experience or feelings; and

Objectification: treating the person as if he or she were “a lump of dead matter to be pushed, lifted, filled, pumped, or drained, without proper reference to the fact that they are sentient beings.”<sup>9</sup>

These dehumanizing responses are rampant in settings in which elders with dementia receive care. There are extreme examples, such as a staff member telling an elder who asks to be taken to the bathroom that she wears diapers and should just urinate in them. But there are also more insidious forms of dehumanization, such as using terms of endearment in speaking to an elder;

perhaps the retired physician doesn't want to be called "sweetie," nor does the homemaker necessarily want to be told how "cute" she looks. Every time staff members speak about an elder as if they are not present, the elder's dignity is assaulted. Each approach by an escort who begins pushing a wheelchair without addressing the person in it is a diminution of that individual's personhood.

The experience of wandering in the *midbar* of dementia is made harsher by the social context that surrounds it. Just as the Israelites were at the mercy of sometimes hostile others in the wilderness, so those with dementia are vulnerable to attacks on their dignity through dehumanizing treatment. Conversely, the suffering of the person with dementia can be eased by love, respect and tenderness.

### **Family Caregivers: Loving the Stranger**

When our family's beloved Grammy Anne suddenly became extremely impaired, unable to converse sensibly or relate to anything but frightening delusions, my sister Jill continued to visit her almost daily, and cared for her with great devotion. My sister sadly remarked, "This is not Grammy. The person we loved is gone." Encountering dementia in someone we love raises painful questions about what it is that makes us ourselves. This questioning is why David Keck teaches that dementia is a theological disease.<sup>10</sup>

As my family discovered, it is demanding to relate to someone you love

whose personality has been distorted by dementia. Often, the change is negative, as when a distinguished woman whose inhibitions have been diminished by dementia suddenly shouts profanities she would never have dreamed of uttering. Sometimes, the change can be a salutary one, as I learned when I met the family of Esther, the woman who loved to sing. "You must enjoy her so much. She is such a delight," I said. "We do," her daughter said, "especially since she was not always like this. She was tough to live with!" Esther's dementia brought her family a new opportunity to know and appreciate her, in a way that was never before possible.

Loving a person with dementia means facing a long, slow farewell, losing your dear one a little bit at a time. You experience the loss anew every time you see the person you love, and see again how different she is from the way she used to be. This is an ongoing bereavement, but one without routine social or spiritual acknowledgment or support.

### **Reverence and Honor**

The person who loves someone with dementia faces a Herculean task of caring for an ever-diminishing body and mind with *mora* (reverence) and *kavod* (honor).<sup>11</sup> One may need to adjust to radically changed roles as a loved one copes with dementia. The direction of power and dependency may shift. There may be weighty new responsibilities and knotty dilemmas as one balances respect for the person's wishes with concerns for his or her safety and

well-being. Becoming a caregiver for a parent does not mean that you are now your parent's parent, but it is a painful realignment of roles nonetheless.

Bresnahan suggests that acceptance is a key part of the task in caring for a parent with dementia. It is so painful to surrender to our inability to fix the inexorable fading of the one we love. "More than anything," she writes, "I need to accept Mom where she is — and accept my own limitations as well. I once heard another caregiver explain to a fellow elevator-rider, 'There is nothing I can do for him, and I am doing it.'"<sup>12</sup>

One way of articulating the caregiver's spiritual challenge is: "You shall love the stranger."<sup>13</sup> The Torah teaches us in Exodus 23:9 that we must treat the stranger with care, "for you know the soul of the stranger." The stranger before us is the very person you have known and loved for all these years. In the confrontation with dementia, you are asked: can you love this so-familiar and yet totally strange person before you? Can you let go of the expectation that she will behave or appear as she used to, and appreciate her for who she is now? In loving the stranger, can you learn from this person and her journey? The poet Betsy Sholl puts the challenge eloquently:

This old woman...  
isn't my mother,  
is not what I think.  
She's a spiritual master  
trying to teach me  
how to carry my soul lightly  
how to make each step

an important journey,  
every motion and breath  
anywhere  
as though anywhere  
were the center of the earth.<sup>14</sup>

It is a supreme challenge to love the stranger. Certainly, we have a mandate from the Torah to do just that, hard and painful though it be. That this challenge of caring for a loved one with dementia can go on for years, or even decades, makes it even more heroic to overcome impatience, grief and frustration and lovingly do what needs to be done.

## **Professional Caregivers: Transcending Assumptions**

Taking on the job of professionally caring for a person with dementia is provocative. In our society, many of us are hypercognitive, primarily identified with our intellectual sides. We believe we are our brains, so we believe that witnessing the erosion of cognition is witnessing the diminution of personhood. Tom Kitwood suggests that in confronting dementia two primal fears are aroused: fear of frailty/dependency and fear of dying/death.<sup>15</sup>

Many people distance themselves from people with dementia in order to be spared these frightening prospects. In their study of life in an assisted living community, Susan McFadden and her colleagues describe a meeting with a local parish pastor in the elevator. When asked about his visit, he replied, "Well, I have three members here . . . but two are out of it so I just said hello

and left my card.”<sup>16</sup>

The stigma that our society attaches to those with cognitive impairments such as dementia can lead caregivers to form powerfully negative assumptions about the limitations of those for whom they are caring. Christine Bryden, a woman living with dementia, decries what she calls the “toxic lie of dementia,” the assumption that “the mind is absent and the body is an empty shell.”<sup>17</sup> The impact of caregivers’ assumptions can be devastating, as she writes:

This stigma leads to restrictions on our ability to develop our spirituality. It threatens our spiritual identity. It is assumed that the limits due to our failing cognition place us beyond reach of normal spiritual practices, of communion with God and with others. But to what extent are these assumptions due to the limits placed upon us due to the stigma attached to our dementia? . . . The question is, where does this journey begin, and at what stage can you deny me my self-hood and my spirituality?<sup>18</sup>

Even the most dedicated caregivers face frustration as they seek to respect the person with dementia. It is often so hard to know what the person is feeling, experiencing, longing for. The caregiver’s ability to understand the person and his or her wishes is limited. Although each individual’s experience is wholly unique, narratives like those of Bryden and Diana Friel McGowin give caregiv-

ers a window into the experience of dementia. This glimpse of their reality may help those of us on the outside to understand better and more respectfully relate to people with dementia.

## **Dementia in God’s Eyes: Seeing the *Tzelem***

The biblical creation narrative tells us that God created humanity *b’tzelem Elohim*, in God’s own image (Genesis 1:26). Stephen Sapp suggests that the task in approaching a person with dementia is “to see as God sees.”<sup>19</sup> I would suggest that God sees the *tzelem* in the person with dementia, the divine spark within. Rabbi Hershel Matt, *z”l* reflected on his experience in providing pastoral care for people with dementia, and wondered where that *tzelem* could be in those diminished by confusion and incapacity. He suggested that what he was witnessing was “the fading image of God.”<sup>20</sup>

Others would argue that the image of God can never be diminished in a living human being. For example, the Maggid of Mezeritch, an 18th-century Hasidic master, taught that the *tzelem* is an intrinsic element of the human being. The Maggid compared the creation of human beings in God’s image to a father who has a son. Even if the son goes far away, the father always holds the son’s image in his heart and mind. According to the Maggid of Mezeritch, God had an image of humanity in mind before we were even created, and this image is unchanging in past, present and future. We always look the same to God.<sup>21</sup>

Based on this teaching and my own encounters with people with dementia, I would suggest that the *tzelem* is not dependent on cognition or capacity. Amid all of the changes of dementia, the *tzelem* remains, for it is the very essence of our humanity.

## God Sees the Soul

Another way of understanding what God sees in the person with dementia is that God sees the *neshama*, the soul. We are taught that the soul within us is pure, and remains within us until we die.<sup>22</sup> If so, then perhaps the idea that the person with dementia is suffering might be our own projection. How do we know that the person with dementia is not on a higher spiritual *madrega* (level)?

In some spiritual practices, the ideal is “to be present in the present moment.” People with dementia are probably more able to do that than the rest of us. In mystical terms, we speak of the ideal of shedding the *klipot*, the outer shells of superficial, utilitarian identities. Dementia accomplishes this purpose, stripping souls down to their essence. One daughter who flies across the country every few weeks to care for her father, a man with advanced dementia, says it is not a burden but a privilege. “He’s just pure *hesed* (loving-kindness),” she says, “That’s all that’s left.”

According to our tradition, God remembers for us, even when we cannot. In the High Holy Day *zikronot* (remembrance) prayers, we quote the prophet Jeremiah (2:2): “Thus says

the Eternal, I remembered for you the kindness of your youth, the love of your wedding day, how you followed Me into the wilderness.”<sup>23</sup> Even when we are mired in the moment, bereft of all perspective on our lives, God sees more, in boundless compassion. God holds all of who we have been. We may forget, but God does not. God “for eternity remembers all of the forgotten ones . . . and there is no forgetfulness before Your throne of glory.”<sup>24</sup> We are always whole in God’s eyes.

## Spiritual Caregivers

The role of spiritual caregivers for people with dementia is to emulate God in seeking the *tzelem*. We need to remind ourselves that even when the *tzelem* is not apparent, it is there. In the person who is disoriented, regressed or even unresponsive, somehow the image of God resides.<sup>25</sup> Bryden reminds us of the power of seeking the *tzelem*: “By rejecting the lie of dementia and focusing on my soul rather than on my mind, I can be free of fear of loss of self, and in so doing can also help you to lose your fear that you are losing me.”<sup>26</sup>

*Remember for them:* Spiritual caregivers can also emulate God by remembering for people who cannot remember for themselves. We can connect them to memory. The Talmud contains a poignant narrative about Rav Joseph bar Hiya. Rav Joseph was called “Sinai” because he held all of the laws of the Torah systematically in his head, as if he had heard them directly from God at Sinai.<sup>27</sup> Rav Joseph apparently became ill and suffered major memory loss. The



Talmud recounts a number of cases in which his student, Abaye, gently reminds him of his own teaching. Upon hearing a complex legal discussion, Rav Joseph says, "I have never heard this tradition," and Abaye reminds him, "You yourself have told this tradition to us, and it was in connection with the following that you told us."<sup>28</sup> Abaye connected Rav Joseph not only to his memory, but to his very identity and worth.

In reminding his teacher of his own wisdom, Abaye upheld another of Rav Joseph's teachings:

Rav Joseph teaches that the tablets [of the law] and the broken tablets [that Moses shattered upon discovering the Golden Calf] are both kept in the ark. From here we learn that a scholar who has involuntarily forgotten his learning should not be treated disdainfully.<sup>29</sup>

As we recall their personhood, we remember those with dementia in an additional way. According to Stephen Sapp, by recalling the Latin root of "remember," which comes from the word for "limb," we learn that our role is to return the person to the community: ". . . re-mem-bering those individuals in the sense of bringing them back into the human community, refusing to let them be cast aside and forgotten, which is in effect to dis-member the body."<sup>30</sup> Whenever we respond to an individual as one created in the image of God, we are helping him or her to rejoin the community.

*Respond to the Neshama (the Soul):* In accompanying individuals with dementia, we are challenged to relate to the soul within them. As 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 merely "my mother." It is up to me to [continue to be] . . . keenly aware of her spirit, honoring her soul-essence. Meeting her with caring and love and respect in that sacred place of wholeness which nothing can diminish.<sup>31</sup>

We relate to souls when we let faces shine through the power of ritual. We witness the power of symbol, song and holy times to connect to the part that is whole within the person, as with Sylvia, who found connection through the familiar words, melody and message of the *Shema*. When we use ritual to empower individuals to live in sacred time, there is a chance that, at least in the moment, Rose will feel that the day is more than an endless expanse of waiting that will never end. We are called to adapt our celebration and worship to make them accessible to individuals with dementia, harnessing our creativity to engage people at the time and in the manner that works for them.

## Forging Connection

In accompanying individuals with dementia, we forge a life of connection

for them. In our simple presence, in our caring and fervent commitment to strive to understand the individual, we provide a response to the pastor who said, "There's nothing to do with them because they're out of it." Our response is to be with them in the *midbar*. Diana Friel McGowin eloquently states the urgent need for this accompaniment:

Without someone to walk this labyrinth by my side, without the touch of a fellow traveler who truly understands my need of self-worth, how can I endure the rest of this uncharted journey? I thirst today for understanding, a tender touch and healing laughter.<sup>32</sup>

The work of accompanying elders with dementia requires curiosity. We will do best to follow the advice of Melvin Kimble, who suggests that we practice "hermeneutical phenomenology," inviting the old to be our teachers about aging and meaning.<sup>33</sup> In this learning process, the teaching happens at levels beyond words and surface conversation. We search agitated behavior or speech to unearth the profound concerns the person is trying to communicate. When Shirley tells us she needs to go home to her mother, we may learn worlds about the enduring mother-daughter bond if we inquire into the *derash*, the meaning of this quest. When we acknowledge and validate the emotions reflected in apparently "unreal" content, we can reach and honor the confused elder. As Rita Bresnahan observes, ". . . I am learning that 'the facts' do not matter. Only the relationship does."<sup>34</sup>

We will learn much if we open ourselves to the person with dementia. I learned from Mr. Shapiro, the pharmacist, not only how to relieve a headache, but also how to retain one's essential goodness amid change and brokenness.

## Magic Moments

This work requires patience. We struggle to be with the person in silence, to be satisfied when nothing seems to be happening. Sometimes, we learn that a great deal is happening, as did the daughter who discovered anew the wonder of falling leaves as she sat in silence with her father. In accompanying people with dementia, we ambitious caregivers need to measure accomplishment in a different way. Any progress may register in millimeters, not inches. Yet we must be prepared for "magic moments," when a person who seems generally quite confused may suddenly speak or connect with great clarity and profundity. One such magic moment occurred in conversation with Anna.

Anna was a feisty, fun-loving woman who had formed many close friendships with other elders during her years in the nursing home. Only when she passed age 100 and painfully fractured a hip did she begin to be confused. One day, as she sat in her geri-chair, Anna was moaning, saying over and over, "Oy, Mama, oy, Mama." I sat down next to Anna and took her hand. "You're thinking a lot about your mother, aren't you, Anna?" Anna turned to me and said, "It's always Mom in the end."

Anna could not have said what day

of the week it was, nor did she necessarily remember the chaplain sitting next to her. Somehow, though, Anna knew what really counted. She realized that she was near the end of life. She was aware that she longed for the comfort of her mother, and she believed she would soon be joining her.

Ultimately, dementia is a mystery. If we can find the courage to walk alongside those who journey in this *midbar*, we, too, will be transformed. Debbie Everett has identified the “surprising paradox” of ministry with dementia: It leads us, the spiritual caregivers, to live more authentically. Everett writes,

As we open ourselves to embracing [persons with dementia] as wholly worthwhile and valuable persons that need motivated and loving care, they expel us from our intellectual theological boxes. In the process, they introduce us to a God who is also dancing and laughing in the bizarre places where chaos reigns.<sup>35</sup>

As we learn from those we accompany that the human being is more than intellect, more than memory, even more than cognition, we learn that we are, as well. We learn to value ourselves for our very essence.

## A Concluding Blessing

Confronting dementia puts us in touch with the profound fragility of so much that we cling to in this life—memory, identity, relationship. In this awesome and mysterious journey, may

we remain connected to the One whose compassion is boundless, who remembers us, and remembers the Covenant that binds us in eternal love. May we bring that compassionate connection to all of our relationships.

## Resources

- The Foundation for Alzheimer’s and Cultural Memory has developed collective reminiscence work that gives voice to elders with dementia: [www.memorybridge.org](http://www.memorybridge.org).

- “Island on a Hill” is a CD recording of elders from San Francisco’s Jewish Home who became Psalmists and singer-songwriters with the help of Rabbi Sheldon Marder and musician Judith-Kate Friedman: [www.cdbaby.com/cd/judithkate](http://www.cdbaby.com/cd/judithkate)

- Sacred Seasons Celebration Kits, produced and distributed by Hiddur: The Center for Aging and Judaism, enable elders in residential settings to join in Shabbat or holiday celebrations, even when a Jewish spiritual caregiver is unavailable. Comprehensive, easy-to-use kits for Shabbat and holidays include everything a staff member or volunteer without Jewish background needs to facilitate a joyous observance: [www.sacredseasons.org](http://www.sacredseasons.org).

- The TimeSlips Project has collected hundreds of stories, and produced plays and art exhibits based on narratives of individuals with dementia: [www.timeslips.org](http://www.timeslips.org).

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1. This essay is adapted from my chapter by the same name in *Jewish Pastoral Care*:

*A Practical Handbook from Traditional and Contemporary Sources*, Dayle A. Friedman, ed. (Woodstock, VT: Jewish Lights Publishing, second edition, 2005). An early version of this paper was delivered at the National Association of Jewish Chaplains' 2005 conference.

2. Details have been changed to protect the confidentiality of these individuals.

3. Miriam Rieger, *The American Jewish Elderly*, United Jewish Communities Report Series on the National Jewish Population Survey 2000-2001 (New York: United Jewish Communities, September, 2004). Note that this number is likely an underestimate, since the study did not include elders in nursing homes or other institutional settings, which are likely populated with disproportionate numbers of individuals with dementia.

4. Debbie Everett, "Forget Me Not: The Spiritual Care of People with Alzheimer's Disease" in *Spiritual Care for Persons with Dementia: Fundamentals for Pastoral Practice*, Larry VandeCreek, ed. (Haworth Press, 1999), 79.

5. Diana Friel McGowin, *Living in the Labyrinth: A Personal Journey through the Maze of Alzheimer's* (New York: Delacorte Press, 1993), 114.

6. Rita Bresnahan, *Walking One Another Home: Moments of Grace and Possibility in the Midst of Alzheimer's* (Lingouri, Missouri: Lingouri/Triumph), 82.

7. Daily morning service, *Shaharit*, my translation. See, for example, *Daily Prayer Book*, translated by Philip Birnbaum (New York: Hebrew Publishing Company, 1977), 71.

8. I learned this term from the late Maggie Kuhn, founder of the Gray Panthers.

9. Tom Kitwood, *Dementia Reconsidered: The Person Comes First* (Buckingham, England/Philadelphia: Open University Press, 1997). Kitwood developed a list of 17 depersonalizing tendencies of what he calls

"malignant social psychology" in relating to individuals with dementia.

10. David Keck, *Forgetting Whose We Are: Alzheimer's Disease and the Love of God* (Nashville, TN: Abingdon Press, 1996).

11. These are the two basic aspects of obligations toward parents, according to the Babylonia Talmud, tractate *Kiddushin*, 31b.

12. Bresnahan, *op. cit.*, p. 110.

13. See Deuteronomy 10:19 for one of the many examples in Torah of this commandment.

14. Betsy Sholl, in *Mother to Daughter, Daughter to Mother, Mothers on Mothering: A Daybook and Reader*, Tillie Olsen, ed. (Old Westbury, N.Y.: Feminist Press, 1984), 245, cited in Bresnahan, *Walking One Another Back Home*.

15. Kitwood, *Dementia Reconsidered*, 14.

16. Susan McFadden, Mandy Ingraum, Carla Baldauf, "Actions, Feelings, and Values: Foundations of Meaning and Personhood in Dementia," *Viktor Frankl's Contribution to Spirituality and Aging*, (Haworth Press, 2000), 83.

17. Christine Bryden, Elizabeth MacKinlay, "Dementia—A Spiritual Journey Towards the Divine: A Personal View of Dementia," *Journal of Religious Gerontology*, Vol. 13, No. 3/4 (2002), 69-75.

18. *Ibid.*

19. Stephen Sapp, "To See Things as God Sees Them: Theological Reflections on Pastoral Care to Persons with Dementia," in *Spiritual Care for Persons with Dementia: Fundamentals for Pastoral Practice*, Larry VandeCreek, ed. (Binghamton, N.Y., Haworth Press, 1999), 37.

20. Hershel Matt, "Fading Image of God? Theological Reflections of a Nursing Home Chaplain," *Judaism*, Vol. 36, No. 1, (Winter, 1987).

21 Cited in *Itturei Torah*, Aaron Jacob Greenberg, ed. (Tel Aviv: Yavneh, 1985) on *Parashat Bereshit*.

22. See the prayer *Elohai Neshamah* from the daily *Shaharit* service, my translation. “The soul that you have implanted within me is pure. You created it, you formed it, and you are destined to take it from me and to return it to me in the time to come [after death].” For the context, see, for example, *Daily Prayer Book*, translated by Philip Birnbaum. (New York: Hebrew Publishing Company, 1977), 15-16.
23. Translation mine. For the context, see, for example, *The Metsudah Machzor*, Avrohom Davis, translator (Brooklyn, NY: Metsudah Publications, 1985), 317f.
24. Translation mine. For the context, see, for example, *The Metsudah Machzor*, 320.
25. Interestingly, the Babylonia Talmud (*Berakhot* 10a) indicates that the soul “sees and is not seen.”
26. Bryden, “Dementia: A Spiritual Journey.”
27. Babylonian Talmud, *Berakhot* 64a.
28. Babylonia Talmud, *Eruvin* 10a.
29. Babylonian Talmud, *Menahot* 99a. My translation. I’m grateful to Rabbi Beth Naditch for pointing me to the connections between these texts.
30. Sapp, “To See Things as God Sees Them.”
31. Bresnahan, *Walking One Another Back Home*, 50.
32. Friel McGowin, *Living in the Labyrinth*, 14.
33. Melvin Kimble, cited in McFadden, et al., “Actions, Feelings, and Values.”
34. Bresnahan, *Walking One Another Back Home*, 38.
35. Debbie Everett, “Forget Me Not: The Spiritual Care of People with Alzheimer’s Disease” in VandeCreek., et al., *Spiritual Care for Persons with Dementia*, 87.