SUBMISSION AND RECEIPT OF CLASS OF 2006

COMPLETED RABBINIC THESIS

I, Terry Treseder, hereby submit two (2) copies of my/our
(Please print)
completed thesis in final form, entitled

Mourning the Psychosocial Loss of Progressive Dementia:
Prayer, Ritual and Support for Family Caregivers

2-14-06
Student Signature / Date:

Additional Students, if applicable (please print, sign, and date)

"The author has my permission to submit this thesis in partial fulfillment for requirement for ordination."

Name of Advisor: Rachel Adler

Signature of Advisor: Rachel Adler

RECEIPT BY REGISTRAR

The above named thesis was received by the Registrar's Office

Feb 22, 2006
Date

Carol Loper
Registrar

by

Mourning the Psychosocial Loss of Progressive Dementia
Prayer, Ritual and Support for Family Caregivers

By Terry Treseder

Thesis Submitted in Partial Fulfillment of the Requirements for Ordination

Under the Advisement of
Dr. Rachel Adler

Hebrew Union College - Jewish Institute of Religion
2006

Praised be the God
of imperfection

Your flaws are everywhere

In the elm's unbalanced foliage
and the asymmetric faces of Your creatures.

You form the ripping floods
that tear the forests
and bend tornadoes in a twisted dance.

The lion is blotched with age and mud,
and the Shabbas silverware lies stained
as a reminder.

Praised be Your Torah of scratches and scars.

Praised be Your discolorations,
for they are puzzles and poems
of Your sacred character.

("Yotzer" by Danny Siegel)

Dedication Page

For my friend Elaine, who continues to mourn the dying of her mother.
--Terry

This is dedicated to my parents, Diane and Jack Roseman, who were both robbed of the ability to remember. They will be remembered, honored and loved always. I know they would join me in thanking Terry and encouraging her to devote energy and passion to understanding ways rabbis can provide much needed support to victims of dementia and their caregivers. --Carol

For my wife, Adele, an intelligent woman with a graduate degree who loved to read -- philosophy, the classics, mysteries, biographies, Shakespeare. In 56 years of happy marriage there were many, many wonderful experiences to describe. The beautiful bride. The look of adoration on her face when tending her little ones. The loving look in her eyes when each of her grandchildren were born. The joy of witnessing spectacular winter sunsets. Her gleeful, carefree response when sipping coffee in full sunlight at midnight on a street side cafe in Norway. To witness the deterioration of Adele's beautiful intellect and personality is a cruel, cruel experience for all of us who are near and dear to her and love her deeply! --Mort

To Lorraine Helman Rubin, a devoted teacher who would be comforted to know that the readers of this thesis were learning something about coping with the disease that took her learning from her. --Rachel

My mother, Sylvia Rubin Shleier, was a magnificent woman who lit up countless rooms and hearts with her sparkling eyes and warm loving smile. Her positive outlook on life and her ability to recognize only the good in people endeared her to everyone whose life she touched. This was her legacy to me and to all who knew and loved her.
--Joyce

Dedicated to my Mother, Martha J. Rieser. Throughout her life Martha conducted herself in all situations with great "class". Alzheimer Disease robbed her of many things, but she retained a core dignity that serves as a model for me, every day. Thank you, Terry, for the opportunity to tell our story and contribute to your thesis for the aide and comfort of caregivers and their care recipients.
--Jaye

Mourning the Psychosocial Loss of Progressive Dementia:
Prayer, Ritual and Support for Family Caregivers

Thesis for Rabbinic Ordination
By Terry Treseder

Table of Contents

Mourning the Psychosocial Loss of Progressive Dementia
Prayer, Ritual and Support for Family Caregivers

Thesis for Rabbinic Ordination
By Terry Treseder

Chapter One
"Introduction"

> Human is not whole. Human is full of holes. Human bleeds.
> Human births its worlds in agonies of blood and bellyaches ...
> Human knows that what it weds need not be perfect to be infinitely dear.
> Human holiness results when our fragments are gathered together
> with awe and reverence
> with compassion
> with outstretched hands.
> That is the only way we can be whole, not perfect but *shalem*, complete.[1]

What do we mean by "psychosocial loss"? Essentially we are talking about the loss of a relationship caused by the psychosocial death of a loved one. Kenneth J. Doka defines psychosocial death as "a loss in which the psychological essence, individual personality, or self is perceived as dead, even though the person physically remains alive. In other words, the persona of the individual is so changed that others experience the loss of that person as he or she previously existed."[2] This loss causes anguish. As one grieving spouse put it, "All you have is a shell, mocking what once was."[3]

Conditions which cause psychosocial death include irreversible coma, stroke and dementia. My thesis deals with the latter, the most prevalent cause of psychosocial death.

---

[1] Rachel Adler, "Those Who Turn Away Their Faces: The *Metzora* as Radically Ill", unpublished early draft, November 17, 2005.
[2] Kenneth J. Doka "Mourning Psychosocial Death: Anticipatory Mourning in Alzheimer's, ALS, and Irreversible Coma" in *Clinical Dimensions of Anticipatory Mourning: Theory and Practice in Working with the Dying, their Loved Ones and their Caregivers*, ed. Therese A. Rando (Research Press; Champaign, Illinois) 2000
[3] Anonymous caregiver cited by Doka, "The Role of Ritual in the Treatment of Disenfranchised Grief" in *Disenfranchised Grief: New Directions, Challenges and Strategies for Practice* ed. Kenneth J. Doka (Research Press; Champaign, Illionois) 2002

Progressive dementias include Alzheimer's Disease, Vascular Dementia, Dementia with Lewy Bodies and Frontotemporal Dementia. Dementia can also be the result of brain damage caused by tumors, neurosyphillis, AIDS, Parkinson's, Pick's, Huntington's and Creutzfeldt-Jacob Disease. There are treatable and even reversible conditions which cause dementia-like symptoms, such as reaction to medication, metabolic abnormalities, nutritional deficiencies, depression and infection. If left untreated, however, they can lead to permanent brain damage.[4] For this reason, early signs of dementia ought to be medically investigated immediately. Certainly a rabbi should encourage such an investigation. My primary focus is on the three most common dementias afflicting our elderly, each represented by at least one member of my caregiver focus group:

Alzheimer's Disease (AD) is the fourth leading cause of death among older adults. 10% of Americans over 65 years of age are clinically diagnosed with AD. That percentage goes up to 47% by age 85. 5.5 million people today are afflicted with AD. That figure will triple by 2050 if, as projected, our elderly represent 22.9% of our population.[5] AD is characterized by brain atrophy, neuritic plaques in the cerebral cortex and the accumulation of neurofibrillary tangles. Its etiology is uncertain, but its symptoms include memory loss, confusion, mental deterioration, lethargy, total helplessness, inability to interact with others and finally death. Throughout it's unpredictable but relentless progress, victims respond with varying degrees of paranoia, depression,

---

[4] Nancy L. Mace and Peter V. Rabias, *The 36-Hour Day* (Johns Hopkins University; Baltimore, Maryland) 1991, p.17.

[5] Rosemary Blieszner and Peggy A. Shifflett, "The Effects of Alzheimer's Disease on Close Relationships between Patients and Caregivers" in *Family Relations* v39 Jan 1990; Rebecca J. Ponder and Elizabeth C. Pomeroy "The Grief of Caregivers: How Pervasive is it?" in *Journal of Gerontological Social Work* v27 (1/2) 1996; Rodrigo Kuljis, "Alzheimer Disease" on-line at www.emedicine.com, April 12, 2005 update; and Doka, "Mourning Psychosocial Loss" op.cit.

delirium, and anxiety, though most do not exhibit all of these symptoms.[6] At one time AD was believed to be an inherited disease, a misconception that continues to terrify grown children of AD victims. We now know that familial forms of AD account for less than 7% of all cases, and are largely related to rare early-onset forms of the disease.[7] As rabbis we can relieve a great deal of fear and anxiety by educating our congregants, particularly family caregivers, regarding the random nature of AD.

Vascular Dementia is the second most common form of dementia, caused by the destruction of blood vessels in the brain by strokes of varied intensities, as well as by other conditions such as heart failure that deprive the brain of oxygen. Besides memory loss, symptoms include severe depression, disorientation, early-onset incontinence, delusions, and radical mood and behavior swings. This condition divides itself among a variety of clinical forms ranging in severity and symptomatology, including some which are reversible with early detection and treatment. The onset of vascular dementia is more sudden then AD, and has a more stepped pattern, but often degenerates into a form of AD.

Dementia with Lewy Bodies (DLB) accounts for 10-20% of dementias. Up to 40% of AD victims have concomitant Lewy Bodies. Lewy Bodies are cytoplasmic inclusions in nerve cells which impair critical neuronal circuits.[8] DLB shortens life expectancy, often as a result of swallowing problems that lead to malnutrition. Victims are at risk for falls because of impaired mobility and balance. DLB is commonly misdiagnosed as AD. Because AD medication can actually exacerbate DLB symptoms, it is important to note symptoms peculiar to DLB. These include visual and auditory

---

[6] In fact, members of my focus group whose loved ones were diagnosed with AD surprised me with stories of constant cheerfulness that characterized their loved ones to the end.
[7] Kuljis, "Alzheimer Disease" op.cit.
[8] Howard A. Crystal, "Dementia with Lewy Bodies" online at www.emedicine.com, July 5, 2005 update.

hallucinations, alternate periods of cognitive alertness and disorientation, Parkinson-like motor disfunctions and unexplained or sudden loss of ambulatory functions. As rabbis, we ought to urge further diagnostic tests if a caregiver mentions any of these abnormalities to their loved one's "AD".

Whether psychosocial death occurs with the relentless and unpredictable deterioration of AD, the stepped descent of a vascular dementia or the intermittent peaks and valleys of DLB, the resulting loss is equally devastating to loved ones. And it is no conventional loss. Over the course of research and interaction with surviving caregivers I learned that the ordeal of losing an intimate incrementally over time inflicts scarring emotional trauma that will continue to haunt the caregiver long after their loved one dies. It is a permanent sorrow that will surface periodically for the rest of their lives.

Stress on caregivers is compounded by four demographic trends unique to modernity. First, ever increasing life-spans due to improved nutrition, hygiene and antibiotics translate into an ever increasing population of elderly in need of care. In 1900, the average life-span for Americans was between 40 and 45. The projected average life-span for a child born today is 80 years -- a doubling of human longevity over the course of the last century.[9]

Second, declining birthrates translate into a larger percentage of the population who are elderly, and fewer people to care for them. Currently 12% of Americans in

[9] Figures are based on data from *National Vital Statistics Reports* v53 n6 Nov 10, 2004, prepared by Elizabeth Arias (U.S. Department of Health and Human Services).

general are over 65 years old. 18% of North American Jews are in this age group. As noted earlier, these percentages are estimated to double by 2050.[10]

Third, the marked decline of multigenerational families means that the burden of eldercare is no longer shared by several family members living close at hand. Before the 20th century, the aged were almost universally integrated into the households of their children who were supported and geographically integrated into a larger extended family. Today, less than 4% of all households in America are multigenerational, most of which are of newly immigrant status.[11] This means that the burden of extended periods of caregiving are falling upon the frail shoulders of an elderly spouse, or upon the wage-earning shoulders of a single grown child. Although this situation has naturally led to a rising trend in institutionalizing our elderly, the actual numbers are surprisingly low. Currently one million elderly people are in the care of 19,000 nursing homes across the country. That represents 5% of the elderly. However, 20-30% of all elderly will spend some time in nursing homes, most likely towards the end of life. [12] These figures suggest that a great many of our elderly are at least partially cared for at home through most of their elder years, but that eventually their care becomes overwhelming for their loved ones. On the other hand, these figures also suggest that 70-80% of our elderly are either dying alone in their homes or cared for by a loved one from beginning to end. Mace and Rabias interpret these figures in a positive light: "It is important to know that almost all

---

[10] According to the 1990 National Jewish Population Study cited in Dayle A. Friedman's "Letting Their Faces Shine: Accompanying Aging People and their Families," in *Jewish Pastoral Care: A Practical Handbook from Traditional and Contemporary Sources* (Jewish Lights; Woodstock, Vermont) 2001.

[11] Pre-20th century family profiles are based on Steven Ruggles' "Multigenerational Families in Nineteenth-Century America" in *Continuity and Change* v18(1) May 2003 (Harvard University Press). Ruggles credits the decline of the multigenerational family in the 20th century to "the rise in wage labor and diminishing importance of agricultural and occupational inheritance." Current 1990-2000 trends come from *U.S. Census Bureau News* 2000 (U.S. Department of Commerce; Washington DC).

[12] I obtained these figures from Seniors-Site.com.

families do care for their elderly and sick as long as possible. It is simply not true that most Americans abandon their elderly or "dump" them into nursing homes. Studies have shown that, although many older people do not live with their children, they are closely involved with or cared for by them. Families usually do all they can, often at great personal sacrifice, to care for ill elderly members before seeking help."[13]

Fourth, great strides in curative medicine have created a phenomenon unique to our era -- extended physical life beyond psychosocial death. According to an estimate by the American Hospital Association, 80% of Americans now die a "negotiated" death, meaning that they or their loved ones choose to forgo life-saving treatment.[14] This trend in medical advancement carries three implications for our caregiver. One is the protracted time an individual is likely to endure as a caregiver. It could go on for years or even decades. Another is the increased emotional pressure of making end-of-life decisions for their loved one. Finally, the caregiver burden is painfully augmented by long-term anticipatory mourning over the pre-death loss of a loved one through psychosocial death ... a death we are unprepared as a society to acknowledge, let alone mark with comfort, sustenance, or validating ritual.

The emotional cost of caregiving is exponentially far greater than ever possible in a pre-modern world. As it now stands, we have little to offer these people as clerics of faith communities. Although there is a growing awareness of the need for pastoral counseling, communal support and ritual markers for caregivers mourning psychosocial loss, the field remains remarkably barren. It is practically non-existent in the Jewish

---

[13] *The 36-Hour Day*, op.cit., p181
[14] As cited in *Kent's Guide to the Sociology of Death*, 2005.

world. What little I could find is included among my appendices, most of it created during this past year.

Thesis Project

For my thesis project I am creating ritual markers for family caregivers mourning the psychosocial loss of a loved one through progressive dementia. Prayers and laments from Jewish tradition as well as innovated ritual will be part of a pastoral response that will focus mainly on community support and validation. With the experience gained from this project I hope to continue developing meaningful pastoral and communal response to caregivers in mourning.

Ethic for Developing Ritual

My ethic for developing ritual is based on three assumptions. First, a Jewish ritual is necessarily religious in nature and therefore ought to reflect Jewish morality as circumscribed by our tradition. In defining what that means for me, I am taking my lead from three great talmudic scholars and ethicists of our day: Rabbi Elliott Dorff (Conservative), Rabbi Irving Greenberg (Orthodox) and Rabbi David Ellenson (Reform).

In speaking about contemporary bioethical concerns in general, Dorff asserts that it is not enough to determine what works. It is also critically important to determine our ultimate hopes and fears, what we value in life, and how we conceive of life in the first place.[15] These are the concerns of religion. "It is only when we have these ultimate

[15] Elliot N. Dorff, *Matters of Life and Death: A Jewish Approach to Modern Medical Ethics* (Jewish Publication Society) 2003, p395.

perceptions and convictions in mind that we can sensibly make the specific decisions contemporary medicine calls upon us to make."

Dorff makes a case for framing biomedical decisions within the particularity of a religious tradition.

> Religions create communities committed to their ideologies by putting their specific understanding of reality into stories that can be easily shared, rituals that can help people live out their understanding of life and feel part of a group that shares it, and institutions that make it possible to teach and share the group's common convictions. These features make religion a powerful and popular way to speak about reality and to guide important decisions in life (396).

Judaism, Dorff asserts, arrives at moral decisions through an ongoing, dialectical interaction between ethics and tradition. Jewish law, he emphasizes, is not frozen in normative Judaism. "The classical rabbis made it very clear that the Jewish tradition they were shaping, which we identify today as normative Judaism, is *not* fundamentalist, even with regard to the Torah; it rests rather in the hands of the rabbis of each generation who interpret and apply it according to their own understanding of God's will. It is, then, the way in which the rabbis of each generation understand morality that must govern how Jewish law is shaped to be morally good and, therefore, Godlike (399)." This presupposes a theology in which God is moral. Jewish law, in turn, is fundamentally committed to morality and "to an underlying theology of a moral God who commands it." This same theology should also guide us in our response to the bioethical challenges presented to us by modern circumstances.

Such a dialectical relationship between tradition and moral sensibility is aptly labeled "covenantal" by Rabbi Isaac Greenberg, who argues that "the dialectical interplay between 'power and partnership' that is the mark of the relationship between God and

humanity in the Bible provides the proper model for Jewish medical ethics as well." [16] He asserts that "an ethic of power, an ethic of human beings charged with responsibility and control for their own decisions, as the proper Jewish model to be employed in our time."

In subscribing to this approach, Rabbi David Ellenson explains that "this means that one must search out the tradition for those precedents relevant to the making of an ethical decision."[17] Informed choice -- the motto of Reform approach to tradition -- mandates both a thorough search for underlying principles informing Jewish law and the responsible determination of basic principles of morality. Applying the dialectical approach in making moral bioethical decisions to my project means mastering classical texts touching on issues relevant to caregivers mourning psychosocial loss, determining enduring underlying principles behind these texts, and then dialoging them with my own moral sensibilities in order to construct Jewish boundaries within which to contextualize innovative ritual.

My second assumption in developing Jewish rituals for caregivers is that such rituals ought to address the specific pastoral needs of participants. At best, inappropriate ritual will fail in its purpose. At worse, it will do more harm than good. A ritual constructed out of ignorance is not only meaning-less, but irresponsible. This does not mean I have to be a "technician" as opposed to a "dreamer" in my creative enterprise; only that my "dreams" arise from a fertile field of factive substance sown into a rich soil of potent metaphors. This part of my ethic comes from my own conscience, a sense of responsibility towards those who trust me with their painful vulnerabilities.

---

[16] David H. Ellenson, "How to Draw Guidance from a Heritage: Jewish Approaches to Mortal Choices" in *Contemporary Jewish Ethics and Morality: A Reader,* ed. Elliot N. Dorff and Louis E. Newman (Oxford University Press: Oxford) 1995, p137.
[17] ibid

My third assumption is that a thorough understanding of ritual theory and practice will expand my creative resources and therefore greatly enhance the development of a responsible liturgical response that "feels" traditional to participants. In summary, then, my ethic of ritual development entails a moral interpretation of Jewish tradition, an understanding of the pastoral needs of participants, and a thickening knowledge of ritual theory and practice.

Methodology

My methodology for this project closely follows the dictates of my ethic for developing ritual:

1. Solicit personal narratives, insight and general guidance from a focus group composed of caregiver survivors. This group would act as partners with me during the course of my thesis development, both in grounding my research in their reality and in developing ritual and communal response that meet the needs of caregivers dealing with progressive dementia.

2. Research and interpret Jewish law and tradition in the areas of aging, dementia, caregiving and psychosocial death, and work out ethical and moral boundaries from this research.

3. Research pastoral issues related to family caregivers of victims suffering from progressive dementia, and funnel my findings through my focus group for critique, input and elaboration.

4. Research ritual theory and practice.

5. Apply preliminary pastoral and ritual theories to a live case. While developing my thesis I had the opportunity to act as rabbi for an unaffiliated family dealing with progressive dementia in their 84-year-old father. With Dr. Adler's permission I dovetailed my efforts on their behalf with my thesis project. The experience validated my research and helped me to gain valuable insight into application.

6. Develop working ritual markers, prayers and laments in consultation with Dr. Rachel Adler, my advisor for this thesis, and Rabbi Stephanie Dickstein of the National Center for Jewish Healing.

7. Submit working drafts of ritual markers, prayers and laments to my focus group for critique and improvement.

About my Focus Group

At my request, the director of Jewish Family Services in Salt Lake City, Carol Einhorn, hand-picked participants for my focus group based on criteria we developed together. She acted both as screener and intermediary in order to protect their privacy. Selection was based on the following criteria:

1. They had to be Jewish, preferably a mix of synagogue affiliated and non-affiliated.

2. They had to have at least two years experience as a caregiver for a loved one with progressive dementia.

3. They had to be at least two years distanced from the death of their loved one.

4. They had to be articulate individuals and willing to participate.

I am thrilled by the power, honesty and compassion of these individuals. It has been a great pleasure to be tutored by people who understand suffering and are determined to help others in need of comfort. As I will be referring to them continually, let me introduce them to you now. For their protection, I am only referring to them by their first name:

Carol: Both her parents suffered from Alzheimer's Disease before they died. In the case of her father, she was a long-distance mourner as he lost memories of her. "I think I finally experienced the beginning of grief when I visited him in person -- he was living 2000 miles away. We spent an hour reliving my childhood and at the end of it he asked me how I knew so much about that little girl. And I looked at him ... I thought we were connecting ... that's when it hit me that there was no connection between the little girl who was Carol and the woman who was sitting next to him. That was about six months before he passed away. But that's when I realized ... there was nothing."

Carol served as her mother's caregiver for seven years while her mother lived in a nursing home. Four years into the nursing home phase -- three years before she died -- Carol's mother had completely forgotten Carol. But Carol experienced psychosocial loss over time. "It is incremental. First they don't know your name *one* time, but they know another time. Then they don't know your name and they don't know ... it's just gone. But at the same time they remember sort of a relationship, but then the relationship is gone. So it is incremental. I would say that I experienced grief over and over."

Mort: Mort and his wife, Dell, were in their late 70s when she developed Alzheimer's Disease. As the daughter of an Orthodox rabbi, Jewish tradition was important to Dell. She was an intelligent woman who earned her Master's Degree in English Literature and attended the Jewish Theological Seminary. She met Mort, a

biochemist, in 1944 when they were both active in a Zionist group called Masada. Ironically, Mort's earliest research is now the basis for current break-throughs in pharmaceutical treatments of AD.[18] Mort began to suspect something might be wrong with Dell when she habitually "lost" huge chunks of time wandering in the car whenever she went out shopping. On one occasion they drove separate cars to a dealership to drop one car off for repairs. Even though she was suppose to be right behind Mort, she did not show up at the dealership for two hours. "What happened?" Mort asked. "Nothing," Dell replied, "I got here right behind you." The same exchange took place the following week when they drove back to the dealership to pick up his car and she came back to the house five hours later with both doors on the passenger side caved in. Even though the driver who ran into her car left a note on the dashboard, Del remembered nothing. The incident scared Mort badly. Their grown children did not live nearby, but called and visited frequently. They urged Mort to take Dell in for examination when her conversations with them sounded disoriented and confused. After a diagnosis of AD, Mort cared for his wife for five years before he was physically overwhelmed by caregiving tasks. He placed her in a nursing home a year before she died. As far as he is concerned, he lost his wife two years before she died. "I felt like I lost my wife. Gone. Absolutely gone."

Joyce: Her mother lived on her own during the first stages of her vascular dementia, although Joyce's brother lived nearby and checked on her frequently. She managed to hide her condition for a long time, and in fact, managed to fool a great many people to the end of her life because social etiquette and conversation came naturally to

[18] While deconstructing the chemistry behind German nerve agents, Mort specifically elucidated the mechanism in neuro-transmission, cholinesterase. German nerve agents blocked this mechanism as an anti-cholinsterase. Mort worked on developing a reversible anti-cholinesterase, which is now being investigated as a means of bypassing the plaques blocking neural transmission in the brains of AD victims.

her. Her son eventually placed her in a Jewish nursing facility and acted as her primary caregiver until he died. Joyce then brought her mother to her home to live with her. "I don't think I realized how bad things were, how much she lost, until my brother died and I had to bring her out here to live with me. Interacting with her on a daily basis made me realize much more than I had before how much she had lost in terms of her memory and her ability to care for herself, and in terms of the mother I knew as I grew up ... I would probably say that's when the grieving process started for me, when I realized that she was no longer the mother that I grew up with and the roles had reversed by that time." Joyce remembers that her mother always walked around singing. Her favorite songs were Yiddish songs, particularly "My Yiddisha Mama." When her mother stopped singing, Joyce experienced one of many periods of grief. A tile plaque decorated with blue flowers and hummingbirds from her mother's kitchen reminds her of the mother she lost over time. It reads, "I sing in the kitchen when there is someone to praise my cooking." Joyce cared for her mother at home for a year before placing her in a nursing home -- in a room adjacent to Carol's mother. Joyce continued to care for her mother in the nursing home for another fourteen months. Years earlier she lost a four-year-old son, who died after ten months in a coma following an accident. So she has experienced psychosocial loss both as a mother and as a daughter.

Jaye: A young mother raising small children when she cared for her mother, Jaye cared for both her parents, each suffering from a different form of dementia. Her father's "dementia" was a side effect of heavy pain medication for a broken vertebrae. She lost him psychosocially six months before he died. "In the end, he didn't know who I was. I was ... it could have been anybody. But he often hated me because I was the one at the

hospital and skilled nursing center with him either to get a feeding tube inserted or whatever. He realized I was the decision-maker." Her mother had Alzheimer's Disease, so the mental deterioration was both long-term and incremental. Jaye's mother, too, hid her condition for a long time with her many years of social bearing to prop her up. But disease finally overwhelmed her desperate attempt at mastery. "I remember the day very well when she asked me who I was, and I said 'I'm Jaye', and she said, 'You're too old to be Jaye.' She connected that she had a daughter somewhere ... but the child, not me." Psychosocially, Jaye's mother was completely gone the last year of her life.

Rachel: Her mother hid her DLB dementia well into its progress. She did so by leaving notes to herself around the house reminding her what to do. Her significant other, who lived nearby, suspected something was happening to her, but simply accepted the gradual change in her, taking added tasks upon himself in order to keep her independent. Her two daughters habitually came to visit her every May when she returned from Florida to her Illinois home. But her condition worsened beyond her ability to disguise. One year, Rachel and her sister were appalled by their mother's condition. She wandered around disoriented, did not know what was in her cabinets and displayed alarming lapses in reality. They hired a companion to stay with her during the day. Over the course of the following year, they hired a full-time companion and each sibling took turns visiting their mother for a 3-day weekend every other month. Their mother's significant other checked on her three times a week. Rachel initiated a series of diagnostic tests in order to get a proper diagnosis. Physicians at a regional clinic for dementia were unable to decide between AD or Multi-infarct Dementia (a form of vascular dementia). Rachel and her sister determined much later -- based on their own research and observation of their

mother -- that she actually had DLB (sudden loss of locomotive skills and vivid visual hallucinations), hence the extreme symptoms of DLB she suffered as a result of her AD medication. In spite of an advanced directive against intubation and their mother's refusal to swallow liquid food, Rachel's sister insisted on keeping her mother alive for another five years. Rachel continued to visit her mother, even though the ordeal of watching her mother slowly die a bad death -- a death she perceived as stripped of dignity and humanity -- forced her into depression. When she came to visit, she coped by paying meticulous attention to caregiving tasks. "But it got harder and harder to cope. I would wait until I got home and then cry, usually alone, sometimes with my husband." She began to see a therapist. She describes the ordeal as "an intolerable burden on me." She remembers her first grief experience with her mother's dementia. It occurred one year after she and her sister first suspected dementia, five years before her mother died. By that time her mother believed that her condominium belonged to her full-time caregiver. Her mother suffered anxiety over her prolonged stay in "somebody else's" house. "I want to go home," Rachel's mother cried, "When is my mother going to come get me?" When Rachel tried to comfort her, she retorted, "You are very kind, dear, but I would prefer to be with a member of my family." Rachel did not get the chance to grieve the loss of her mother when it occurred. She had to wait five years before her mother died physically. By that time, the rituals of condolence and mourning were too late to be of much comfort.

This five-person focus group has proven to be my most valuable resource for my thesis project. I am deeply indebted to them for their insight and guidance, given at great cost to them emotionally, and in some cases physically. Following this chapter is a copy of the questions which I sent to members of my focus group in preparation for our first

meeting. Their verbal answers to these questions are on an audio recording of our subsequent meeting.

Focus Group Questions

[These questions are meant to give us a place to start]

A Psychosocial death is one in which the dying person loses memories of you and/or recognition of you. They are unable to interact with you as they once did. Each of you experienced the loss of a loved one months or years before they died physically. Describe the circumstances in which you began to experience grief over the psychosocial loss of your loved one.

How did you cope with the loss?

What kinds of things did you do to express your feelings?

What kind of help did you seek?

What did you need from your rabbi? In retrospect, how could she/he have helped you through your ordeal?

How were other family members responding to your loved one's condition?

Did the situation cause conflict in the family? If so, over what issues?

What kind of support did you get from your social network (including work, synagogue, friendships)?

What kind of ceremony might have helped your grieving process?

Healing circle

Mourning ritual

Ritual marking change in relationship

Ritual of caring (performing symbolic gestures of your new role as nurturer)

Other?

Who would you have chosen to participate in such a ceremony?

Representatives of Jewish tradition (rabbi, cantor, lay leader)

Family members

Support group (people who had experienced the same loss)

Religious community as a whole

Other

Have you ever helped or counseled (formally or informally) someone going through the same loss you experienced? If so, how did that work out for you and them?

Chapter Two

"Boundaries and Context: What Jewish Tradition has to say about Caregiving for the Elderly Suffering from Dementia"

> Rabbi Joshua ben Ilim dreamed that his neighbor in Paradise would be Nanas, the meat-dealer. He visited the meat-dealer to ask what good deeds he was performing to deserve a high place in Paradise. The dealer said, "I know not, but I have an aged father and mother who are helpless; I give them food and drink, and wash and dress them daily." The Rabbi said, "I will be happy to have you as my neighbor in Paradise."[1]

Jewish tradition has little to say about mourning the psychosocial death of a loved one. It does, however, have a great deal to say about the treatment of our elderly, and a few words about the treatment of those specifically suffering from dementia. There are also laws regarding the treatment of those who are physically alive but mentally dead. In addition, the Talmudic story of Rabbi Judah and his caregiver serves not only as a foundation text for *halakha* regarding end-of-life decisions in the presence of suffering but, I would argue, serves as a model for both communal and caregiver response to progressive dementia. In total, there is enough material to determine the enduring principles which ought to inform the ethical boundaries of mourning psychosocial death -- principles which are in harmony with Jewish law and tradition.

Jewish Tradition and its Attitude towards Old Age

In their respective surveys of classical Jewish literature regarding old age, Walter Jacob and Steven Carr Reuben argue that Jewish tradition regards old age as a blessing, and that old age is associated with wisdom and power.[2] But whereas Jacob goes so far as

---

1. Midrash quoted in Seder ha-Dorot cited in *The Talmudic Anthology: Tales and Teachings of the Rabbis* ed. Louis Newman (Behrman House; NJ) 1945 p310
2. "Beyond Methuseleh -- Who is Old?" in *Aging and the Aged in Jewish Law: Essays and Responsa* ed. Walter Jacob and Moshe Zemer (Rodef Shalom Press; Tel Aviv) 1998; and "Old Age: Appearance and

to argue that old age is not necessarily associated with physical or mental debilitation, Reuben points out the sobering side-bars of reality that appear in later biblical writings and throughout rabbinic literature. Although Jacob's cheerful conclusions hold up more or less in the Tanach, they fail to acknowledge the more gloomy ruminations of our rabbinic sages, who definitely viewed old age as a mixed *bracha* -- a cursed blessing.

Old Age in Biblical Texts

The three biblical terms traditionally translated as "old" (as in "elderly") seem to support Jacob's assessment. שיבה "white hair" is identified linguistically with שבע "full/satiated", effectively associating the white hair of old age with a full and plentiful harvest of years:

> They continue to bear fruit in שיבה
> their white-haired-old-age
> full of sap and new vigor (Psalm 92:15)

Abraham dies "at a good שיבה white-haired-old-age, old and שבע full-and-content."[3] The word זקן "beard" is associated with wisdom through a playful reading of זקן as זה קנה "One who acquired", meaning one-who-acquired-wisdom.[4] It is the זקנים, the "elders", both old and wise, who govern Israel in her ancient days.[5] Finally, חכמה "wise woman" is also an "old woman".[6] Citing passages in the Exodus account, as well as Proverbs and Job, Jacob makes the case that old age is biblically associated with wisdom,

---

Reality", *Journal of Psychology and Judaism* v.16 no.3, respectively.

3. Gen. 25:8. See also Gen. 15:15 and 24:1 for additional positive descriptions of Abraham's longevity.
4. B.Kiddushin 32b: אין זקן אלא חכם "*zaken* old age only means *hacham* wisdom"
5. Ex. 3:16,18;4:29;12:21;19:5,6;18:12;19:7; 24:1,9,14; Lev. 4:15;9:1; Num. 11:16,24,25,30;16:31; Deut. 5:20;19:1221:2-4;22:15,16,18;25:7-9;27:1;29:9;31:9,28;32:7. An additional 92 references throughout the remainder of the Tanach attest to the role of the elderly as judges, rulers, witnesses and key participants in ritual observances.
6. Jacob only mentions שיבה, which he translates interpretatively as "full/satiated" (as in שבע), and זקן. But he includes prooftexts from Proverbs in his argument that old age is associated with wisdom. By doing so, he is translating חכמה as "old woman/wise woman".

leadership, vitality and power.[7] He notes that in our foundational narratives, "years are a sign of blessing, and the parade of diminishing age in early Genesis represents a biblical view that humanity has declined." In other words, longevity was a sign of Divine blessing and even superhuman strength. "Moses was one hundred and twenty years old; undimmed were his eyes, unabated his vigor (Deut. 34:7)."

Jacob also points out the notable absence of the elderly as necessary objects of charity in prophetic writings calling for social justice. "How does the Bible deal with the elderly when they become feeble or disabled? Even the feeble aged are not listed as objects of charity. They are not included with the widow, the orphan, and the stranger. These three categories are frequently mentioned and become standard, but the aged are never added to them. Old age is not considered a disability, and the aged are not seen as needy."

My survey of these terms largely supports Jacob. Old men and women are hospitable, powerful, articulate and shrewd.[8] In 1 Samuel, the future absence of a זקן in a household is part of a divine curse, a sign of calamity and destruction (2:31-32), while the promise of a full 100-years lifetime is part of a vision regarding the future messianic age (Isaiah 65:20).

But as Jacob admits, there are a few disquieting references to the downside of old age. To King David's generous offer to provide for him in the royal household, the aged Barzillai replies, "How many years are left to me that I should go up with Your Majesty

7. The "elders" as councilors in Num. 11:16; Job 12:12; 32:6-22; wisdom as an old woman in Prov. 1:20-33; 8:3-30; 9:1-6. Although חכמות is portrayed as a nonspecific female in the text, Jacob probably made an implied connection to the חכמה references in II Samuel and/or to Maimonides' equation between זקן and חכם as noted later in this chapter.
8. Jud. 19:15-23; 2 Sam. 14:2-19; 20:15-22.

to Jerusalem? I am now eighty years old. Can I tell the difference between good and bad? Can your servant taste what he eats and drinks? Can I still listen to the singing of men and women? Why then should your servant continue to be a burden to my lord the king?" (2 Sam. 19:35-36, JPS trans.). Psalm 90:10 declares that the 70 or 80 years of our lives are מעל ואון "suffering and sorrow". The author of Ecclesiastes spells out the nature of this suffering during the "bad days" of old age,[9] "of which you will say, 'I have no pleasure in them'" (12:1-7). Poetic language not withstanding, the physical deterioration of old age is candidly described: weak and trembling arms, bent legs, missing teeth, diminished eyesight, hearing and sensual pleasure; fear of heights, of travel, of death itself. Jacob reads the narrative of King David's old age as a positive example of power in old age. I disagree, as does Reuben. We read the account beginning in the first chapter of 1 Kings as that of a helpless, enfeebled old man treated as though he were already dead by his family and erstwhile "loyal" members of his court. Reuben asserts that the miraculous conception and birth of Isaac to aged parents is an early reference to the physical debilities of old age -- the exception in this case proving the rule that old age is marked by loss of virility and sexual potency (Gen. 18:12; 21:7). He also ascribes Isaac's loss of vision to old age (Gen. 25:8).

Despite these concessions to the infirmatives of old age, however, I agree with Jacob and Reuben that the Tanach as a whole venerates and idealizes the elderly. The references above represent the few instances where disabilities are mentioned, and they do not reflect ancient, canonized ideology. "The disabilities of age are rarely mentioned," Jacob concludes, "and no need to provide special care for the elderly seems felt. The

9. An exegesis of Ecc. 12:1 from B.Shabbat 151b: *Before the days of sorrow come*, meaning "the days of old age"

aged appear to be part of a family that looks after them."

Old Age in Rabbinic Texts

The same cannot be said of rabbinic writings regarding old age. Reuben concludes that "old age is granted to an individual by God as a reward for the proper fulfillment of *mitzvot* and *Mishpatim*" (p139). After my own survey of the material, I feel compelled to side with Ruth Langer that in rabbinic Judaism "age generates physical and mental debilities that create dependency, often accompanied by personality changes that threaten to undermine the familial relationship."[10] These debilities overtake everyone, be they righteous or wicked, scholarly or ignorant. Old age is not seen as a "reward", but as a consequence of our human condition.

How does our tradition define "old age"? Whereas the biblical text remains ambiguous about it, the rabbis gave it a timetable. The Mishna defines an old woman as one who is no longer menstruating[11], whereas a man's life-cycle is described curvilinearly in M.Avot 5.21:

He (Yehuda ben Tema) used to say:

Five years old --	for Bible
Ten years old --	for Mishna
Thirteen years old --	for *mitzvot*
Fifteen years old --	for Talmud
Eighteen years old --	for huppa
Twenty years old --	for pursuit (of a livelihood)
Thirty years old --	for vigor
Forty years old --	for understanding
Fifty years old --	for counsel
Sixty years old --	for זקנה
Seventy years old --	for שיבה
Eighty years old --	for strength
Ninety years old --	for bending over

10. "Honor Your Father and Mother: Caregiving as a Halakhic Responsibility" in *Aging and the Aged in Jewish Law*, op.cit.
11. M.Niddah 1.5; M.Kelim 24.6; 28.9; 29.1

> One hundred years old -- it is as if he had died and passed away and disappeared from the world.

I left זקנה and שיבה untranslated because they appear to be understood differently by compilers of the Mishna and Talmud. The fact that a man is "strong" at age 80 suggests that these terms, leading up to 80, have the positive biblical connotations of "wisdom" and "fullness". The Talmud, on the other hand, utilizes these terms as markers to denote the onset of old age at sixty, both for men and women, interestingly enough.[12] One *halakhic* ruling in the Talmud suggests that the Amoraim regarded the phrase "years of strength" -- applied to a man 80 years old or more -- as a euphemism for extreme old age, someone who, on the contrary, is terribly weak. Such a man may die momentarily, and for that reason a third party cannot deliver a *get* on his behalf on the presumption that he is still alive.[13] This might suggest that 80 is beyond "old" and into the category of "terminally ill".

The Talmud actually assigns a market value to the elderly by gender. A woman under sixty years old is valued at 30 shekels, whereas a man under sixty is valued at 50 shekels. Status changes dramatically after sixty years:

> Why is a female, when she is old, valued only at one third (10 shekels), whereas a man at not even a third (nothing)? Said Hezekiah: People say, "An old man in the house is a burden in the house, an old woman in the house is a treasure in the house." ---B.Arakin 19a

---

12. I quickly noticed a distinct difference between the overall optimism of Midrash Rabbah and Mishna, and the overall pessimism of the Babylonian Talmud. This distinction is reflected in my bibliography of primary texts. A typical midrash declares that Israel cannot survive without her aged, and that they are beloved before God: "Why is Israel compared to a bird? Just as a bird can only fly with its wings, so Israel can only survive with the help of its elders. Great are the elders, for if they are old they are beloved before God, and if they are young, their youth is but of secondary consequence " (Exodus Rabba 5.12; Leviticus Rabba 11.8). This midrash and others like it did not make it into the Talmud.
13. B. Gittin 28a. A *get* is not valid from a dead man. Since a man of extreme old age may die before his agent delivers the *get*, his wife has the right to refuse such a document -- a right she is likely to exercise given the stimatized legal and social status of a divorcee as opposed to a widow.

The brutal reality of talmudic times seems no different from our own: the elderly are less valuable than the young. But it cuts deeper. Given the usual gender comparables in the Talmud, this passage is remarkable. An old woman is more valuable than an old man, because she can still manage a household and transmit skills and remedies to a younger generation.

The fullest treatment of old age in the Talmud, B.Shabbat 152a, could easily be called a rabbinic lament. It is part of a *sugya* that begins in 151b with the Mishna's prohibition against closing the eyes of a dying person, literally a יציאת הנפש, "departing soul-body". To do so is equivalent to murder. The Mishna is clearly referring to someone whose physical death is imminent, so vulnerable that the slightest disturbance would be enough to kill them. The rabbis of the Talmud, however, use the phrase יציאת הנפש to transition from imminent physical death to the slow physical and mental dying of the old. They compare the יציאת הנפש to "a lamp that is going out, and a man comes along and puts his finger on it. Immediately it goes out." Following this *mashal* is an extensive exegetical commentary on the two biblical passages which Walter Jacob identified as the only negative reports regarding old age in Tanach -- Ecclesiastes 12:1-7 and 2 Samuel 19:35-36.

The opening verse of Ecclesiastes appears embedded in 151b:

> *Remember also your Creator in the days of your youth, before the evil days come*
> This refers to the days of old age.

The lament begins in earnest with verse two at the top of 152a:

> *In the day when the keeper of the house shall tremble*
> these are the flanks and the ribs
> *and the strong men shall bow themselves*

the legs
and the grinders cease
the teeth
and those that look out of the windows darkened
the eyes

A series of lived experiences interrupt the exegesis:

The emperor asked R. Joshua b. Hanania,
"Why didn't you attend the Be Abedan (a gathering for the sages of Rome)?"
He replied,
"The mountain is snowy and surrounded by ice.
The dog does not bark.
And the grinders do not grind."

Bialik and Ravnitzky interpretation[14]
My hair and beard are white.
My voice is barely audible.
And my teeth are worn to the gums.

The school of Rav used to say (of old age), "What I did not lose I seek."

Bialik and Ravnitzky interpretation
I walk about bent as though looking for something lost on the ground.

It was taught, R. Yose b. Kisma said,
"Two are better than three"

Soncino interpretation
The two legs in youth are better than the three -- i.e., the additional stick -- of old age.

and, "Woe for the one thing that goes and does not return!"
What is that?

R. Hisda said, "One's youth."

When R. Dimi came, he said,
"Youth is a crown of roses;
Old age is a crown of thorns."

Rabbi asked R. Simeon b. Halafta,

14. Hayim Nahman Bialik and Yehoshua Hana Ravnitzky, eds, *Sefer Ha-Aggadah*, trans. William G. Braude (Schocken Books, NY) 1992.

"Why were we not permitted to receive you on the Festival,
as my ancestors used to receive your ancestors?"
He replied,
"The rocks have grown tall,
the near have become distant,
two have turned into three,
and the peacemaker of the home has ceased."

Bialik and Ravnitzky Interpretation
"I have become old.
Walking up hill has become harder.
My eyes, which once could see far in the distance, barely see close range.
I now walk with the help of a walking stick.
My sexual potency is no more."

We return to the Ecclesiastes exegesis:

And the doors shall be shut in the street
these are the apertures of man
when the sound of the grinding is low
because the stomach fails to digest
and one shall rise up at the voice of a bird
even a bird will awake him from sleep
and all the daughters of the music shall be brought low
even the voices of singers sound like a whisper to him

Now we turn to the 80-year-old Barzillai of II Samuel:

I am this day fourscore years old: can I discern between good and bad?
This shows that the opinions of old men are not dependable.
Can your servant taste what I eat or drink?
This shows that the lips of old men grow slack.
Can I hear any more the voice of singing men and women?
This proves that the ears of old men are heavy.

R. Ishmael contributes a conditional note of optimism:

As for scholars, the older they grow the more wisdom they acquire,
as it is said: *With aged men is wisdom, and in length of days understanding.*[15]
But the ignorant, as they wax older, become more foolish,
as it is said: *He removed the speech of the trusty, and taketh away the understanding of the elders/old men.*[16]

---

15. Job 12:12
16. Ibid. 20.

The sugya completes the Ecclesiastes mantra:

> *Yea, they shall be afraid of that which is high*
> even a small knoll looks to him like the highest of mountains
> *and terrors shall be along the way*
> when he walks on a road his heart is filled with fears
> *and the almond tree shall blossom*
> this refers to a herniated disc
> *and the grasshopper shall be a burden*
> the rump
> *and desire shall fail*
> the passions

It ends with the sad confirmation of lived experience:

> R. Kahana was expounding a portion [of scripture] before Rav.
> When he came to this verse, he [Rav] uttered a long sigh.

To this massive dirge we can add the following observations:

> As soon as a person's teeth fall out his means of a livelihood are reduced, for it is said: *And I also have given you cleanness of teeth in all your cities, and want of bread in all your places* (Amos 4:6). ---Niddah 65a

> *Therefore let every pious man pray unto You when hard times befall* (Psalm 32:6), "hard times" being old age, according to R. Abba. Concerning his old age, a man should pray that his eyes may [continue] to see, his mouth to eat, and his feet to walk. For when a man grows old, all his functions desert him.
> -- Tanhuma, *Mi-Ketz* 10

It appears that social welfare was no more automatic for the elderly of rabbinic times as it is today. In addition to physical frailty, the aged are subject to the indignity of infantilization: "People are accustomed to say: when we were young, we were considered adults in wisdom; now that we are old, we are considered as children."[17] There are times when a great scholar will question the Deuteronomistic theology that old age is a reward for righteous behavior:

> Raba said: [Length of] life, children and sustenance depend not on merit but [rather on] mazzal (luck). For [take] Rabbah and R. Hisda. Both were saintly Rabbis; one master prayed for rain and it came, the other master prayed for rain

17. B.Baba Kamma 92a

> and it came. R. Hisda lived to the age of ninety-two, Rabbah [only] lived to the age of forty. In R. Hisda's house there were held sixty marriage feasts, at Rabbah's house there were sixty bereavements. (B.Moed Katan 28a, Soncino trans.)

From Raba's point of view, old age does not appear to be a reward for the righteous, for the righteous die randomly at various ages just like everyone else.

Other than an occasional one-liner from Midrash Rabbah,[18] old age is not particularly welcome, nor is it necessarily associated with vitality or wisdom. Two other Talmudic passages besides R. Ishmael's statement in B.Shabbat 152b above view vitality and wisdom in old age as predicated upon a lifestyle initiated while young:

> R. Akiba said: If a man studied Torah in his youth, he can also study it in his old age; if he had disciples in his youth, he can also have disciples in his old age. -- B. Yevamot 62b

> R. Nehorai said: I abandon all trades in the world and teach my son only Torah, for every trade in the world stands a man in stead only in his youth, but in his old age he is exposed to hunger. But the Torah is not so: it stands by him in his youth and gives him a future and hope in his old age. --- B.Kiddushin 82b

Again, note the reference to the economic vulnerability and consequent hunger of the aged, who outlast their usefulness in the marketplace. But the infirmities of old age are not confined to the physical body.

> There is an argument in the Mishna over the assumed wisdom of the old:
>
> Elisha ben Abuyah says,
> "He who learns when a child -- what is he like?
> Ink put down on a new parchment.
> He who learns when an old man -- what is he like?
> Ink put down on a parchment full of erasures."[19]
>
> R. Yose ben R. Judah of Kefar Habbabli says,
> "He who learns from children -- what is he like?
> One who eats sour grapes and drinks unsettled wine.

---

18. i.e. Shemot Rabba 5.12: "How welcome is old age! The aged are beloved by God."
19. A palimpsest. As parchment was expensive, it was often recycled by erasing what was previously written on it. Soncino notes, "the rough surface causes spluttering and 'running' of the ink, rendering legibility difficult, if not impossible." Modern interpretations of this argument deconstruct its meaning. A palimpsest can symbolize the multi-layered interpretations made possible by lived experience.

He who learns from old men -- what is he like?
One who eats ripened grapes and drinks vintage wine."

Rabbi says,
"Do not look at the bottle but at what is in it.
You can have a new bottle full of old wine,
and an old bottle which has not got even new wine."[20]

The issue behind this exchange is age discrimination. Elisha assumes that only the young can learn, while Yose assumes that only the old can teach. Rabbi discounts both biases. Individuals are to be judged wise or foolish based on the content of their knowledge, not by the outward signs of maturity. This text reaffirms societal assumptions regarding the wisdom of old age, while challenging those assumptions by opening the possibility of old age without wisdom or even empty of any thought at all.[21] Most rabbinic passages teach that a life of scholarship will eventually make one wise in old age[22], but not all sages believed that a life of scholarship guards against dementia. B.Nedarim 41a gives two examples of great sages who lost their memories through "illness".

You turned his bed in his sickness (Psalm 41:4).
R. Joseph said, "This means that he forgets his Torah (his learning/memory)."
R. Joseph fell ill and forgot his Torah.
But Abaye restored it to him. Hence R. Joseph frequently said,
"I have not heard this law!"
and Abaye would remind him,
"You yourself did teach it to us and did deduce it from this particular baraita."

When Rabbi [Judah] had studied his teaching in thirteen different interpretations, he taught R. Hiyya only seven of them.
Eventually Rabbi fell sick [and forgot his Torah].

Thereupon R. Hiyya restored to him the seven versions which he [Rabbi] taught him, but the other six were lost.

---

20. In other words, the young can be wise, while the old can be empty of thought. Avot 4:20.
21. Even in the Mishna allowance is made for old age when a member of a beit din renders a poor ruling, essentially acknowledging unintentional error due to dementia (M. Horayot 1.4).
22. For a complete list of citations, refer to the bibliography under primary texts.

Note that that dementia is the result of illness, a disease, not of old age. This sugya makes no connection between aging and dementia, only between illness and lost memory. This text also presents a potent metaphor for memory and knowledge -- that of Torah. We can easily extend this metaphor to describe the process of memory loss in the context of Jewish tradition. Just as Torah scrolls wear out over time, some of its letters rubbed out or rendered unreadable, so memories can fade over time and lose coherency. And just as we preserve Torah by faithfully copying it onto a new scroll with fresh ink, so we are enjoined to faithfully record the memories of our loved ones before they fade away completely. The text continues:

> There was this certain reaper who listened to Rabbi and learned [the other six versions] by rote. R. Hiyya went and learned them from the reaper. Then he went and restored them to Rabbi. Whenever Rabbi saw this reaper, he would say to him, "You made me and Hiyya." There are those who say that Rabbi actually said, "You made Hiyya, and Hiyya made me."

Rabbi's statement is remarkable, for traditionally it is the teacher who "makes" or "creates" a student. In the cases of Abaye and Hiyya, the student literally reconstructs the broken memory of his master as a supreme act of honor and respect. Note also that neither Abaye nor Hiyya removes his teacher from his place of honor in the halls of greater learning, but rather stands by and helps the older man to maintain his customary role as master, thereby observing the rabbinic dictum to "observe [the respect due to] an elder who has forgotten his Torah through a misfortune [such as illness]."[23]

We are given another redemptive metaphor for dementia in other parts of the Talmud. Learning and memory are compared to Torah itself, or more specifically, to the stone tablets engraved with the original covenant on Mount Sinai:

---

23. B.Sanhedrin 96a

> Rabbi Joshua ben Levi said:
> Honor and respect the aged and saintly scholar whose physical powers are broken, equally with the young and vigorous one; for the broken Tablets of Stone no less than the whole ones, had a place in the Ark of the Covenant. --B.Berakot 8b
>
> ...*which you broke, and you shall put them in the ark* (Deut. 10:2)
> R. Joseph taught:
> This teaches us that both the tablets and the fragments of the tablets were deposited in the ark. Hence a scholar who has forgotten his Torah through no fault of his must not be treated with disrespect. -- B. Menachot 99a

If we read these texts together, the Ark of the Covenant is the young disciple into which the master's teachings have been deposited. It is the sacred responsibility of the young to remember the lost memories of the old, to hold them in safe-keeping for future generations. The memories of the old become Torah for the young.

Closely linked to this metaphor is that of a burning scroll. The Talmud, in B.Avodah Zarah 18a, relates the story of Rabbi Hanina Ben Teradion who, contrary to Roman law, both studied and taught Torah publicly with a Torah scroll in his lap. The authorities seized him, rolled him up in his own Torah scroll, placed bundles of branches around him and set the bundles on fire. As he died, his disciples cried out to him, "Rabbi! What do you see!" He cried out in return, "The skins [of parchment] are burning! But the letters are soaring on high!" In other words, the body may be destroyed, but the mind-soul is immortal and indestructible.

So what are we to make of old age? Is it holy or profane? Perhaps a good medium position would be Mark Washofsky's argument that even though old age is accompanied by infirmity of body and/or mind, old age in itself is not a disease to be cured, but rather a natural part of the life-cycle. "Old age is an intended and fully natural state of that life, which though it may be associated with infirmity and pain, is not be

treated as a *medical* objective, as an enemy to be liquidated."[24] This train of thought -- contextualizing old age within the natural life cycle of living and dying -- finds support within the Mishna and Talmud.[25] Old age is neither to be idealized nor abhorred. It is simply part of living and dying. On the other hand, there is a sense that we owe the aged a measure of respect and even reverence as semblances of the Divine image, as well as sacred depositories of memory -- regardless of how broken and fragmented that image, or that memory, may be.

Jewish Tradition Regarding Eldercare

Jewish law places responsibility for eldercare primarily on the shoulders of grown children, although the community ideally acts as a safety net under the general mandate to provide *tzedekah* for the poor. Rabbinic discussion regarding eldercare begins with two biblical verses:

> Exodus 20:11
> כבד את אביך ואת אמך למען יארכו ימיך על האדמה אשר יהוה אלהיך נתן לך
> *Honor your father and your mother*
> *that your days will be long upon the land which Adonai your God gave you*
>
> Leviticus 19:3
> איש אמו ואביו תיראו ואת שבתתי תשמרו אני יהוה אלהיכם
> *A man his mother and his father shall revere*
> *and my Shabbatot you shall observe*
> *I am Adonai your God*

The Talmud interprets the words כבד *honor* and ירא *revere* as concrete actions:

> Our rabbis taught:
> What is מורא *reverence* and what is כיבוד *honor*?
> Reverence -- not standing in their place or contradicting their words or "tipping

24. "Is Old Age a Disease? The Elderly, the Medical System and the Literature of Halakha" in *Aging and the Aged in Jewish Law*, op.cit.
25. M. Avot 5:21, B. Nazir 39b, B. Moed Katan 28a, B. Yoma 75b, M.Niddah 1:5, M. Kelim 24:16;28:9;29:1, for example. The one challenge to Washofsky's assertion comes from B. Hullin 24a-b, which rules old age as a disability that disqualifies a man from performing priestly duties.

> the scales" [in favor of a parent's opponent in an argument].
> Honor -- providing food, drink, clothing, covering; helping them in and out. (Kiddushin 31b)

This text recognizes the need for both physical and psychological sustenance when fulfilling our responsibility towards the elderly. It also provides an honorable minimum of fulfilling the mandatory *mitzvah* in the common circumstance when a caregiver feels that what they are doing is not enough. Without such a minimum, no amount of care is ever enough.

Honoring our elderly by caring for their physical needs

According to a 1993 Gallop poll, 85% of Americans consider it the responsibility of adult children to care for their parents.[26] So does Jewish tradition. In fact, the neglect of parents was seen anciently as unnatural, an indication that the child is biologically illegitimate: "He who does not sustain his parents testifies to his own illegitimacy."[27] One midrash ascribes the longevity of early generations in the Genesis narrative as a kind of divine welfare measure to ensure that children lived long enough to care for their long-lived fathers and grandfathers.[28]

Both sons and daughters are responsible for the physical care of their parents, and are to give equal support to their mother and father[29]. As outlined above, we are responsible for providing the essentials of survival -- food, drink, clothing,

---

26. as quoted by Ruth Langer in "Honor Your Father and Mother", op.cit.
27. Eliyahu Rabba 26
28. Tanna de-Be Eliyahu Rabba 16 as cited in *Talmudic Anthology* op.cit. p311. Along these same lines is a midrash from Genesis Rabba in which Abraham requests signs of old age so that people would know when a person is entitled to honor and respect due to old age. Hence, he is the first to experience white hair and wrinkles as a sign of aging (65:9). I believe this text reflects a cultural value already integrated into the fabric of society. It was a social norm to accord respect to the aged.
29. Kiddushin 30b-31a, Mishneh Torah, *Hilchot Mamrim* 6.6. This obligation extends to step-parents, as well (*Mamrim* 6.15).

shelter/warmth -- as well as mobility. Maimonides elaborates the extent to which adult children should accommodate the needs and wishes of their parents. They "should take him out and bring him home and serve him in all the ways one serves a teacher."[30] And how does one serve his teacher? "All the services a servant performs for his master must be performed by a student for his teacher."[31] But there are limits to what a parent can demand of a child. The following talmudic story serves as a basis for both medieval and modern *halakha* allowing a child to transfer physical care of a parent to a third party:

> Rav Assi had an aged mother.
> She said to him, "I want jewelry."
> So he made them for her.
> "I want a husband"
> "I will keep my eyes open for one."
> "I want a husband as good-looking as you."
> Thereupon he left her and went to Palestine.
> (Kiddushin 31b)

Rachel Adler made the observation that this text underscores the dissolution of kinship relationships during progressive dementia. This mother's sexual advances towards her son represent the effect of dementia on personality, behavior and even the parental bond to child.[32]

In his *Mishneh Torah*, Maimonides assumes that Rav Assi's mother is suffering from dementia and ruled the following:

> When a person's father or mother lose control of their mental faculties, [their son] should try to conduct his [relationship] with them according to their mental condition until [God] has mercy upon them. If it is impossible for him to remain with them because they have become very deranged, he should leave them, depart, and charge others with caring for them in an appropriate manner.[33]

---

30. Mishneh Torah, *Hilchot Mamrim 6:3.*
31. Ibid.; *Hilchot Talmud Torah* 5:8.
32. She offered her insight during our review of this text. Dr. Adler is a professor of Jewish Thought at the Hebrew Union College-Jewish Institute of Religion in Los Angeles.
33. *Hilchot Mamrim* 6:10, Touger translation. Yosef Karo incorporated this ruling into the Shulkhan Arukh (*Yoreh Deah* 240.10).

Ruth Langer updates Rabbi Assi's problem to reflect the modern phenomena of declining birth rates, increasing longevity, and advancing medical technology that translates into increased need for caregiving over longer periods of time. "Adult children provide more care and more difficult care to more parents over much longer periods of time than they did in the good old days ... Although having a dependent, elderly parent has become a normative experience, it is one that exceeds the capacities of many families to cope."[34] She, too, refers to Rabbi Assi's action as a precedent. "Jewish tradition does not absolutely require personal care under all circumstances; rather, it legitimatizes third-party care when appropriate personal care is no longer possible or adequate."

Although adult children are required to attend to the physical needs of their parents, they are not required to pay for it. Funding should come from their parents' estate.[35] However, an adult child is expected to spend funds allocated for *tzedeka* on their parents as the need arises. In other words, if IRS law reflected Jewish law, financial support for parents would count as a tax-deductible charitable contribution. This support should not impoverish the resources of the adult child, nor lead to neglect of one's own family.[36]

And what of spouses? What obligation do they have towards one another in old age? According to classical sources, the only obligation an elderly couple has towards one another in a caregiving situation, is financial. Traditionally, a groom pledges to support his wife and to pay for her medical bills as part of their *ketuba* contract.

---

34. Langer cites Elaine M. Brody, "Parent Care as a Normative Family Stress," *The Gerontologist* 25, 1985:23.
35. B.Kiddushin 32a
36. Mishneh Torah, *Hilchot Mamrim* 6:3

In an attempt to apply egalitarian standards to the arrangement, Walter Jacob issues one of the most problematic modern responsum I have yet to encounter:

> Question: A sixty-three-year old man has been diagnosed with Alzheimer's Disease. In nine months he has deteriorated drastically and now needs constant skilled nursing care. His wife, a school teacher, has discovered that her insurance does not cover such expenses, which are more than $2,000 a month. Medicaid will not help until nothing except the house in which they live remains. The wife's lawyer has counseled her to seek a legal divorce, which will shield her resources so that she may have some income when she reaches retirement in a few years. Without such a step she will become dependent upon the charity of her children and the general community. If she takes this step she will, of course, feel that she has abandoned her husband. His condition had degenerated to such an extent that he is unaware of his surroundings and does not fulfill his marital responsibilities.[37]

This case is tragically common in our dysfunctional medical system, which fails to address the escalating problem of progressive dementia among our elderly, and its financial and emotional devastation. Jacob's response, in my opinion, neither acknowledges nor relieves the suffering of this woman. He begins by citing traditional texts that actually offer possible leverage on her behalf. Halakha allows for divorce if:

1. either partner is afflicted with an incurable disease which makes intercourse impossible or dangerous, or

2. the husband is squandering the family assets so that she feels that her maintenance is endangered.[38]

These provisions would seem to allow the wife in this case to legally divorce her husband. However, Jacob says that would be an inappropriate application of the *halakha*, which *implicitly* applies to the young or middle-aged. "These reasons were not intended to deal specifically with the problems of old age which may, naturally, lead to illness,

---

37. *Contemporary American Reform Responsa* (CCAR; NY, NY) 1987 #87
38. Shulkhan Arukh, *Even HaEzer* 117.1; 154.1; 154.3

impotence and unusual expenses." He gives no citation for his conclusion that divorce can only be justified for the young and healthy, and in fact contradicts his exegetical arguments reviewed earlier in this section that rabbinic Judaism assumes health and virility into the "good" old years of later life. Jacob makes a statement that strikes me as astoundingly insensitive: "There is nothing in the question which indicates that they have become estranged from each other." The last statement of the question suggests otherwise. Underlying this statement of degeneration and absence of marital connection is a profound loss of relationship and its accompanying grief. Psychosocial death is, by definition, complete and irreversible estrangement. But even in the event of continued love and loyalty on her part (a likely, but not necessarily accurate assumption), the horror is not that she would consider violating the "sanctity of marriage" through divorce, but that we as a society have forced her in a position where she must choose between her marriage and her own physical well-being.

Jacob goes on to review *halakha* regarding the financial arrangements ensured by the *ketuba*. As part of the *ketuba*, a husband agrees to provide medical care for his wife. According to the Shulkhan Arukh[39], this obligation holds whether the illness is temporary or chronic. But he may set a limit for his wife's medical bills in order to remain solvent. Jacob first posits that under Reform context, the wife is obligated by the same rules as her husband. Fair enough. But then Jacob denies her right to limit the amount of income spent on medical bills. "Whether a spouse possesses this right or not, it is definitely not in keeping with the spirit of marriage and its sanctity." I would point out that grown children -- who, unlike spouses, are biblically mandated to support their parents -- are

39. *Even HaEzer* 69 and 79

not expected to donate more than 10% of their gross income, the amount allocated for *tzedekah*, to the financial support of their parents. Jacob, on the other hand, rules that "the wife is duty bound to care for her husband even though there is no hope of recovery and although it may destroy her resources." A heartless and unsubstantiated verdict if there ever was one. Jacob's responsum fails to carry traditional Jewish ethics into modern context. He fails to acknowledge that,

1. the spouse in question is herself elderly and therefore entitled to support first from her children and second by the community to ensure her independence and well-being.

2. psychosocial loss means the death of a relationship, that she is a widow by meaningful definition and so entitled to the compassion and support enjoined upon us by our prophetic tradition for a widow bereft of her resources.

3. she has the right to limit her financial liabilities for her husband's illness, that right granted to her by Jewish law, not withstanding the "spirit of marriage."

His last statement should have been the focus of his entire responsum. "We should seek alternate ways to help her, both now and in the future." Instead of shaking our fingers at this woman for even considering divorce as a means of saving herself, we should be pounding our chests as a collective and asking ourselves how it came to pass that an old woman should have no other recourse for her survival.

In all fairness to Jacob, he did issue two general responsa that address community responsibility for eldercare. Responsum #26[40] to the question, "Can the community force children to support their parents? Can the community refuse to support them on the basis

---

40. *New American Reform Responsa: Questions and Reform Jewish Answers* (CCAR, NY; 1992).

of the children's obligation?": Citing Rabbi Meier of Fitchburg's responsum that lists the order of *tzedekah*-giving as beginning with close relatives and ending with the total stranger, Jacob concludes, "If the community does not succeed in obtaining such support as the enforcing powers of the modern community are limited, then the community itself is obligated to support the parents."[41] And Responsum #91[42] tackles the common practice of transferring assets to children as a way to protect a parent's financial resources. Communities running nursing homes for Jewish aged see the practice as "subterfuge" and an unfair burden on the community. Jacob's response is gratifyingly sensitive to both the psychological factors in such a scenario, and the need for policy changes that would prevent the confiscation of an elder's entire nest egg into communal coffers:

> We must also be concerned about the psychological implications. The expectations of exhausting one's resources entirely provide a devastating psychological blow to the aged individual. The aged individual, independent and middle class to this point, will now become destitute and helpless. This person sees himself/herself as a ward of the state or completely dependent upon children even for the most minor luxuries. This may well lead to depression and an early death. Furthermore, the children see the institution which will care for the parents as robbing them of the hard-earned savings of their parents in a short period of time. They feel that a disproportionate burden has been placed on their shoulders...

He concludes that, given the extra income from the parent's estate, children have an increased obligation to contribute financially to the care of their parent, but they should not be forced to hand over everything their parents bequeathed to them. Jacob's responsum reflects the heavy emphasis Jewish tradition places on the emotional well-being of our elders.

---

41. In my opinion, this parallels communal responsibility towards educating children at its own expense should parents neglect to do so.
42. *New American Reform Responsa,* op.cit.

Revering our Elderly by Respecting their Psychological Needs

The weight of Jewish law is far more concerned with the emotional well-being of our elders than with their physical needs -- a value statement not yet appreciated in our 21st century love affair with technological efficiency. Reverence begins with a mindset that equates the honor and reverence of one's parents with the honor and fear of God.

> Our Rabbis taught: There are three partners in man -- the Holy One, the father and the mother. When a person honors their father and mother, the Holy One says, "Credit them as though I dwelled among them and they honored me." (Kiddushin 30b)

Maimonides incorporates this teaching into his law code: "The Torah equates [the honor and reverence of one's parents] with the honor and fear of God ... Just as God commands us to honor and fear the Divine name, so, too, God commands us to honor and revere our parents."[43]

Reuben believes that this juxtaposition between human parent and divine parent serves a sociological need. The rabbis recognized the debilitating effect of old age, and so framed the *mitzvah* in strong terms in order to protect the aged from the ravages of the human condition. Chernick and Lander offer the more traditional explanation that the rabbis recognized the impossibility of legislating emotions, and so transformed acts of honor and respect due to the parent into sacred acts of honor and respect for God. Consequently, it is irrelevant whether there is a bond of love or of social obligation based on services received from parents. "Children do not merely repay their parents for services rendered to them in their childhood," Lander explains, "rather they act on the basis of an interpersonal relationship that is a microcosm of their relationship with God."

---

43. *Mamrim* 6:1. See also *Mekilta de-Rabbi Simeon ben Yohai* on Exodus 20.12. In rebuttal to Maimonides, the Radbaz points to Y. Talmud, *Peah 1:1*, which argues that the honor required to show one's parents exceeds that required to show God.

She goes on to explain the transformative possibilities for this kind of framing. "Tradition tries to shift the care giving from an earth-bound burden to a positive statement of a relationship with God, with a God who could not have the debilitations and irritating personality quirks of one's debilitated parent. The onerous care thus becomes not a depressing burden of watching the decline and anticipating the ultimate loss of a parent; it becomes an expression of an enduring positive relationship with the Divine."

As laudable as these explanations are in terms of ethics and modern sociology, they do not embrace the theology that is apparent to me from the texts themselves. Parents are not depicted as "proxies" for God. They are themselves intrinsically god-like in nature by virtue of the fact that they performed an act of creation by creating us. As a generation, they are the parents of our generation and subsequent generations thereafter. When the rabbis see an old person, they don't see an opportunity to express indirect honor and respect for God. They see God in the face of this remarkable person. "He who welcomes an old man is as if he welcomed the Shechina;" "Whenever Rav Joseph heard the sound of his mother's footsteps, he would say, 'I will rise before the Shechina who is coming.'"[44] It's not that we revere the elderly because we revere God, but that we revere the elderly as God made manifest in them. They are not metaphors. They are awesome creators who gave us life. And their current condition does not change that fact.

So far we have been talking about mindset when it comes to "reverence". Jewish tradition goes beyond mindset into action. It translates reverence for the elderly as

---

44. Genesis Rabba 63.6; 113.6 and Kiddushin 31b respectively.

anything that preserves their dignity and self-respect. It means neither standing nor sitting in their accustomed spots, whether it be the head of the table, a designated chair or a particular place in the synagogue. It means maintaining their traditional roles in cherished rituals, and referring to them by their appropriate title and not by their given names. It means treating them with respect in conversation, neither contradicting them in public nor inserting oneself into their decisions[45]. One should not interrupt them in conversation, nor respond to them abruptly or rudely.[46] The elderly are exempt from tasks which are undignified.[47] They get priority during ritual formalities and festive gatherings, while in matters of deliberation and council their opinions are sought even if they are not followed.[48] In addition, "One should never refrain from going to an elder to be blessed"[49]. Other examples of respect in action include opening doors for them, quickly giving them refreshment upon request, and refraining from interrupting their sleep.[50]

Great care must be taken not to expose our elderly to humiliation. "Don't shame the aged, for we shall all be numbered among them" (Ben Sira). Rebuking a parent should be done with circumspection and humility.[51] The rabbis exacted additional fines against guilty parties in a court case if the offence caused shame to an elderly victim:

> Resh Lakish said:
> One who puts an old man to shame must give him a fine proportional to the special shame inflicted because he is an old man.
> A man once insulted Rav Judah b. Hanina [who was old].
> The fact was reported to Resh Lakish, who fined the man a pound weight of gold.
> (Y.Baba Kamma 8)

---

45. *Mamrim* 6.
46. Numbers Rabba 15:17
47. B.Baba Metzia 30a-30b; B.Sanhedrin 18b; B.Berachot 19b
48. B.Berachot 119b-10a; Exodus Rabba 5.12; Leviticus Rabba 11.8
49. Ruth Rabba 6:2
50. B.Kiddushin 31a-31b
51. B.Kiddushin 32a; *Mamrim* 6:11.

Not only is shaming an elderly person punishable by a *beit din*, but by the Holy One as well (B.Menahot 68b).

Tradition acknowledges that humiliation can occur in the way financial arrangements are made for a parent. This is one important reason why eldercare should be financed from the parent's estate when possible. "Now the question 'Who pays?' points to more than the practical details of handling the commandment of 'honor'," Chernick writes, "It points to the the facets of self-worth, control, and decision-making which are the components of independence, the very thing which incapacitated aged lack." Public welfare or reliance on community charity, though sometimes necessary, can be extremely humiliating and ought to be avoided[52]. Maimonides places ultimate financial responsibility on adult children, but only when the parent can no longer meet their own expenses.[53] As Jacob concluded in his responsum, when it is necessary for community resources to be utilized, it must be done in a way that is sensitive to familial relationships and the dignity of our elderly.

Lest we think that shame is not applicable to those who are psychosocially incapable of feeling shame, the Talmud makes it clear that respect extends beyond death in the way we speak of them, and in the way we honor their memory.[54] That being the case, the reason we offer our gestures of respect must go beyond the "feelings" of our elderly into the realm of honoring their personhood and the Divine image they continue to embody.

---

52. B.Kiddushin 32a
53. *Mamrim* 6.3
54. Kiddushin 31b, Mamrim 6;5.

Reverence is to be given even when the parent is demented or medically out of control:

> Aama son of Nethinah was once wearing a gold embroidered silken cloak and sitting among Roman nobles, when his mother came, tore it off from him, struck him on the head, and spat in his face. Yet he did not shame her.
> (Kiddushin 31a)

> Come and Hear!
> How far does the honor of parents [extend]?
> If [your father] takes a purse [of money you would inherit]
> and throws it into the sea in [your] presence
> and [you] refrain from shaming him.
> (Kiddushin 32a)

Dr. Adler pointed out to me that these examples illustrate another dimension of dementia -- that of physical violence, which is typically out of character for the victim's former self. Members of my focus group described episodes of violence as a paintful distortion of the person they once knew. Carol's mother, for example, suddently stabbed a fellow care facility resident in the cheek with her fork. Jaye's mother swung her cane at her daughter for trying to help her dress. Rachel and her sister confronted a situation similar to our second scenario above. They debated whether to take her expensive diamond ring away for safe keeping, fearing she would lose it. They decided that it gave her pleasure and that it belonged to her, not to them. She did, in fact, lose the ring, and no one ever saw it again.

From a legal perspective, the Assi case gives the caregiver an escape when the situation becomes a "stumbling block". According to Maimonides, "Although these commands have been issued, a person is forbidden to lay a heavy yoke on his children and be particular about their honoring him to the point that he presents an obstacle to them."[55] In other words, if an adult child is in danger of losing patience or temper, and

---

55. *Mamrim* 6:8. 6:9 actually penalizes a parent for abusing their privilege of honor and reverence: "A person who strikes an adult son should be placed under a ban of ostracism, for he is transgressing [the

thus treating the offending parent with disrespect, they are urged to place their parent in the care of a third party. Lander updates this directive:

> ...in-home nursing services or some part-time arrangement that relieves the child of full-time care giving is thus fully appropriate under Jewish law when the child's attempts to provide care will result only in a deterioration of the relationships, causing the child to manifest a lack of honor or reverence to the parent. The point at which this occurs will obviously vary from case to case, and each decision must be reached individually.

The rabbis understood the dilemma commonly faced by family caregivers who often must choose between the physical and emotional needs of their loved one. They deal with the issue of prioritization through case scenarios:

> Once a man gave his father several fat chickens.
> The father asked, "My son, can you afford this?"
> And the son interrupted him, saying,
> "Quiet, old man!
> A dog eats quietly, so you eat quietly!"
>
> Another man was grinding meal.
> An official came to enlist a member of the family to perform government work.
> The son said to his father,
> "Do the grinding, my father, and I shall go.
> Thus you will avoid the indignities of public labor."
>
> The Sages said:
> "The first fed his parent well, yet his lot will be Hell.
> The second made his father perform hard labor, yet his lot will be Eden."[56]

This text suggests that what may appear to be honorable treatment of our elderly in one situation, may in fact be shameful in another; what may appear to be shameful treatment in one case, is honorable in another. The outcome is determined by the net psychological

---

charge in Leviticus 19:14]: *Do not place a stumbling block in front of the blind.*"

56. Y.Peah 1.3. This *mashal* also appears in abbreviated form in B.Kiddushin 31a-b. Another priority-setting story occurs in B.Kiddushin 31b. Rav Tarfon brags to his colleagues that he goes so far to honor his mother that he bends down before his mother's bed so that she can step down from and step up to her bed. They scoff, "Well, did she throw your inheritance in the sea right before your eyes without you shaming her for it?" In other words, it is more difficult -- and more important -- to maintain the dignity of a parent than it is to meet their need for mobility. To treat such a parent with reverence is the ultimate test of personal merit.

effect on the parent and the child, as well as on their relationship as a whole. Point in case:

> Rabbi Ishmael's mother came to the rabbis to complain about her son, saying, "Rebuke my son, Ishmael, for he does not show me reverence!"
> The faces of the rabbis grew pale, and they exclaimed,
> "Could it be possible that Rabbi Ishmael does not show reverence for his mother?! What has he done to you?"
> She replied,
> "When he goes to the House of Study, I want to wash his feet and to drink the water I washed them with, and he will not permit it."
> They said [to Rabbi Ishmael],
> "Since that is her wish, revere her by permitting it." (Y. Peah 1.3)

Our tradition recognizes that human personalities vary radically from one to another, and that the types of relationships possible between personalities are virtually endless. What may be sweet to one, is bitter to another, and vice versa. With that reality in mind, the rabbis appended a critical overarching principle to their specific rulings about proffering honor and respect to our elderly: "If a father renounces the honor due to him, it is renounced" (Kiddushin 32a). If we are contemplating a particular action intended to meet our obligation to sustain an elderly person physically or to nurture them psychologically, we must be prepared to suspend such action if they object. Admittedly, this is not always possible, particularly with regards to physical well-being, but it ought to be an important consideration.[57]

Landers applies the rabbinic principle of rendering service that preserves individual dignity to making decisions regarding third-party care. I am reviewing them as an example of this principle in action. Among the considerations she proposes which

---

57. In what seems to me an oppositional reading of the Grindstone scenario above, Freehof permits placing a parent in a nursing facility over their strenuous objection. In this case, the family is overwhelmed by the demands of his physical care. Freehof does make some room for the feelings of the reluctant parent if they are clear-minded, "it is a duty to reason with him until he consents." However, the case is different with dementia, meaning that placement can be made without consultation so long as it is in the best interest of the parent to do so (i.e. supervised medical care).

would specifically apply to people suffering dementia:

1. Issues of physical modesty may destroy a relationship through shame.
2. When removal from a parent's own home is necessary:
    a. Personal space should be re-created for them
    b. They should be surrounded by treasured and familiar possessions.
    c. They should not be required to participate in activities that have never been of value to them. "Those who have filled their lives with intellectual pursuits ought to have an outlet by which to continue them to the extent of their abilities and not be pushed into a day camp roster of crafts, music and games."
    d. Those who had been Jewishly involved ought to be in a setting that encourages and deepens this commitment. Focus group member Carol reiterated the importance of this particular principle for her personally. "If a man wore his tallit during services when he was sound of mind, we ought to place it around his shoulders now that he is dependent on us to remember and respect his previous desires and wishes. This extends to *kashrut* and food preferences they may no longer remember, but would be mortified if they *could* remember."

Lev 19:32 extends respect for the elderly beyond one's parents, which means we have a shared communal responsibility for their psychological well-being: *You shall rise up before a* שיבה *white-haired elderly person, and show deference before a* זקן *elder; you shall venerate your God; I am Adonai.* For the most part, rabbinic literature reads

זקן as "scholar", using this prooftext to justify standing up in the presence of an elderly rabbi.[58] But a discussion in B.Kiddushin refutes this narrow interpretation:

> *You shall rise up before the* שיבה *white-haired* (Lev. 19:32)
> Issi ben Judah said:
> "Any white-haired is meant, even that of the unlearned or of the non-Jew."
> Rabbi Yohanan would rise before an elderly Gentile and say:
> "How many events has he experienced!"
> Abbaye would give his hand to an aged man to make it easier for him to walk.
> Rabba would send his servant to help the elderly, as did his Master, Rav Nahman bar Ya'acov. (33a)

Modern commentators look to this verse as a call for communities to respond to the elderly in ways that preserve their dignity. Stanley Dreyfus points out that Lev. 19:32 is part of the biblical Holiness Code, a melange of ritual and ethical *mitzvot*. "All these *mitzvot* are subsumed under the grand summons to *imitatio Dei*, to the emulation of God's holiness. 'You shall be holy, for I, the Lord your God, am holy.'"[59] Dayle A. Friedman interprets this verse in terms of pastoral care, a role shared by everyone. To "rise before an elder" is to enable them to perform *mitzvot* themselves. We can facilitate this charge by fostering a life of meaning, facilitating a life of celebration, and enabling a life of connection. "The caregiver's task is to create opportunities for older adults to perform adaptive *mitzvot*, doing sacred acts to the fullest extent of their capacities."[60] Danny Siegel augments Friedman's communal obligation to include whatever actions "will rid an elder of possible loneliness and give them happiness." He translates this verse as "You shall rise before an elder and bring out the beauty of their faces", based on an interpretative reading of the root הדר as "beauty, grandeur, awesomeness." He

---

58. Berachot 119b-120a and Kiddushin 32b-3a, for example
59. "Halakha Issues Relating to the Ethics of Aging" in *Aging and The Aged*, op.cit.
60. "Letting their Faces Shine: Accompanying Aging People and their Families" in *Jewish Pastoral Care: A Practical Handbook from Traditional and Contemporary Sources* (Jewish Lights; Woodstock, Vermont) 2001.

proposes that this *mitzvah* requires that we provide "whatever is best suited to the personal needs and desires of the elderly." This means enabling as much as we can their independence, community involvement, companionship and opportunities to pass on a legacy:

> A few ways to do this include giving elders access to computers (and specific networks for elders on the Internet); providing them with cats, dogs, birds, fish, butterflies, plants, and gardens ... providing them with meaningful jobs; adapting automobiles to let them continue to drive despite individual impairments they may have; driving them, if they can no longer drive ... arranging for regular visits with infants and children; installing handrails, ramps, and curb cuts outside synagogues and other Jewish communal buildings; taking photographs with them; reviewing old photographs and writing oral histories with them ...[61]

This may all seem beyond the scope of my thesis, which is supposed to focus on the caregiver, specifically the caregiver of a loved one suffering from progressive dementia. Many items on Siegel's to-do list are simply inapplicable. But his essay is relevant for three reasons. First, whatever we do for one of our elders, we do for their loved ones as well. Any help we give in terms of transportation, visits, involvement and basic eldercare translates into relief for the caregiver, not only from the physical demands of care, but from the emotional stress of psychosocial loss. My focus group repeatedly related how important it was for them to see others care about their loved one, particularly to see their rabbi care about their loved one. A pastoral visit to a loved one is a pastoral visit to their caregiver. To hold the hand of an unresponsive patient is to hold the hand of their grieving child or spouse. Such attention validates their own time and care, while confirming the infinite value of the life they are striving to preserve.[62]

---

61. "The Mitzvah of Bringing out the Beauty in Our Elders' Faces" in *The Heart of Wisdom: Marking the Jewish Journey from Midlife through the Elder Years* ed. Susan Berrin (Jewish Lights, Woodstock, Vermont; 1997).
62. Two members of my focus group told me that their caregiving efforts were not only not appreciated or validated, but actually discouraged and even disparaged. This issue of social stigma and insensitivity will be discussed more fully in Chapter Three.

Second, it challenges us to expand the basic *mitzvah* to "honor" and "revere" our elders into areas we might call "quality of life" issues; to go beyond dutiful care of the body and avoidance of shame into the *kavana* of creating moments of joy and even *kedusha* -- if not for the victim of dementia, than certainly for their caregivers. Finally, his essay brings us back to the Talmudic dictum to greet the aged as if they were the Holy One, to see God in the ruins of a human face. Regardless of where we are in life, our life is intrinsically sacred, because we are created in the image of God. In the case of our elderly, they are creators in their own right. This fundamental tenant in Judaism, that we are created in the image of God, also underlies Jewish law regarding those suspended between life and death -- those physically alive, but psychosocially dead.

Jewish Law Regarding the *Goses*, One who is Dying and Unconscious

In classical Jewish texts, the closest analog to the victim of progressive dementia is the גוסס *goses*. Tractate *Semachot* in the Mishna[63] first addresses legal affairs that may arise while a man -- and it assumes that the *goses* is a man -- is dying. At first glance, it appears to be a list of legal actions that a *goses* may continue to transact. But upon further examination, each item on the list is a personal status or inheritance issue which hinges on whether the man is alive or dead. He does not have to be conscious to resolve the legal issue. He simply has to be definitely alive or dead. *Semahot* essentially rules that in such matters, he is considered fully alive.

> The *goses*:
> Behold, he is considered a living being in all respects.

---

63. Chapter 1. *Semachot* is not located in standard editions of the Mishna, but rather in *B. Masseketot Ketanot* 44a. Although the translation is my own, I will be heavily referencing A. Cohen's translation of this Mishna, *The Minor Tractates of the Talmud: Massektoth Ketannoth* (Soncino Press; London) 1965.

He binds [his brother's wife] to levirate marriage;[64]
he frees [his mother] from levirate marriage;[65]
he [allows his mother] the eating of terumah or disqualifies [her] from [eating] the terumah;[66]
he inherits and he divides inheritance;[67]
[if] a limb is severed [from him], it is considered to be from a living being [and therefore does not transmit ritual impurity];
[his] flesh is considered to be flesh from a living being; [No part of his body transmits ritual impurity];
we sprinkle the blood of his sin-offering and the blood of his guilt-offering [during times of sacrificial ritual in the temple];[68]
until the hour he dies. (*Hilcha* 1)

The few snatches of talmudic legalese available regarding the *goses* confirm that the *goses* is alive with respect to matters of personal status and inheritance.[69] The only concession to his liminal state is in *Arachin 6b*, which forbids calculating a market value for him. As noted earlier, a man under 60 years old was generally worth 50 shekels, while a man over 60 was generally worth nothing. This passage not only suggests that the standard was subject to individualization, but that the value of a *goses* could not be determined -- possibly because the criteria for calculating value were inapplicable.

---

64. Cohen's ff2: Cf. Deut. 25. Should the brother die while he himself is dying, the former's widow is precluded from marrying until she is released by the latter from his obligation to wed her (cf. M.Oholot 1.6)
65. Cohen's ff3: If his father died and left no other children, his mother is free to remarry because the dying man is regarded as living. Even a child who survives one day frees his mother from the levirate. Cf. B.Niddah 43b.
66. Cohen's ff4 & ff5: If his mother is the daughter of a lay-Israelite married to a *kohen*, she may continue to eat *terumah* so long as he remains at the point of death. If she is the daughter of a *kohen* married to a lay-Israelite, she may not eat of the *terumah* belonging to her father which, on the death of her husband, she is permitted to eat when she returns to his home (cf. Lev. 22:12). The reason is that, since her son is regarded as living, it would be contrary to the stipulation in Leviticus *and have no child.*
67. *B.Baba.Batra* 127b makes it clear that a *goses* is physically unable to give gifts or possessions. I am presuming that "dividing inheritance" considers the possibility that a child of the *goses* dies after he becomes moribund, but before he dies. In that case, the deceased child's children are not entitled to an inheritance. It is divided among the remaining siblings. If the *goses* were considered dead, his grandchildren by the deceased child would be entitled to a share of his estate (which the child would have inherited before death).
68. Cohen's ff9: Where a man who brought a sin- or guilt-offering died before it was sacrificed, the animal for the former had to be killed and the latter turned into the fields to graze until it died naturally. But with a dying man ... the ritual connected with his sacrifice was carried out completely.
69. Pesachin 70b; 98a; Yevamot 120b; Nazir 43a; Arachin 18a.

Semahot then lists forbidden actions which essentially treat the *goses* as a corpse:

We may not tie up his cheeks [to prevent his jaws from drooping];
we may not plug up his orifices [assuming he will bloat];
we may not place a heating or cooling device on his navel [assuming he will swell];
until he dies. (*Hilcha* 2)

We then get a list of forbidden actions that could hasten death:

We may not move him;
we may not push him around;
we may not place him on sand or salt;[70]
until he dies. (*Hilcha* 3)

We may not close his eyes.
Anyone who touches or moves [the *goses*]
Behold, he is a spiller of blood!

Rabbi Meir used to say:
He is likened to a sputtering lamp.
Should a man touch it, he immediately puts it out.

Similarly, anyone who closes the eyes of the *goses*,
he is regarded as though he cut short [the dying man's] soul. (*Hilcha* 4)

Semachot then lists specific mourning rituals forbidden over the *goses*:

We may not ritually tear [our garments];
we may not remove our shoes;[71]
we may not recite eulogies;
we may not bring a coffin into the house;
until the hour he dies. (*Hilcha* 5)

We do not summon the people [around him] and recount his deeds.
Rabbi Judah says:
If he היה חכם was a sage, then we may recount his deeds. (*Hilcha* 6)

This last statement suggests that if a *goses* was once a scholar -- or literally, a "wise man"

---

70. Actions intended to preseve a corpse until burial.
71. Eliyahu Touger and Isaac Weisberg translate חולצין as "baring the shoulder" in their translations of related passages in Mishneh Torah and Shulkhan Arukh, respectively. I am going with R. Meir of Rothenberg's literal reading of the word (Cohen's ff17).

-- he is no longer a scholar. He may be physically alive, but his wisdom is gone. It appears that Rabbi Judah is giving permission to eulogize what is already dead -- the dying man's wisdom ... his intelligence if you will.

In his *Mishne Torah*[72], Maimonides defines a *goses* as a moribund individual who appears to be dead, but may only be נתעלף *nit'alef*, a term which means "his senses are lost" (עבדו חושיו).[73] The connotation of *nit'alef* is loss of mental function and/or sensation. An individual in a coma would be considered a *goses*, as would someone mortally wounded and unconscious. This is admittedly not a perfect fit for victims of dementia, but it would be safe to say that since the mental condition of a *goses* is the same or worse than that of an AD victim, for example, we can expect -- *qal ve'homer* -- that prohibitions regarding mourning rituals for a *goses* would likewise apply to the victim of progressive dementia. Maimonides skips the legal affairs section of *Semachot*, possibly because none of them were relevant to lived conditions in post-temple exile. He begins with the underlying principle of the law, and then cuts straight to the treatment of the body, adding traditional rituals of *tahara* -- annointing and washing -- to the list of prohibitions:

> The *goses*:
> Behold, he is considered a living being in all respects.
>
> We may not tie up his cheeks [to prevent his jaws from drooping];
>
> we may not plug up his orifices [assuming he will bloat];
> we may not put a heating or cooling device on his navel [assuming] that he will swell;
> we may not anoint him;
> we may not ritually wash him;
> we may not place him on sand or salt --
> not until the hour he dies.

---

72. *Hilchot Evel* 4.5

73. According to Evan-Shashon's חמלון העברי המרכז.

Maimonides then incorporates the *Semachot* passage referenced above:

> One who touches him (the *goses*)[74] --
> behold, he is a spiller of blood, a murderer.
> To what is this compared?
> To a sputtering lamp.
> Were a man to touch it, he would put it out immediately.
>
> Anyone who closes the eyes [of a *goses*] while he is dying --
> behold, he is a shedder of blood, a murderer.
> Instead, let him wait a little while
> in case he is [not dead, but] *nit'alef* unconscious.

And then he details how we may not mourn the *goses*:

> Similarly,
> > we do not tear our clothes because of him;
> > we do not take off our shoes;
> > we do not recite eulogies;
> > we do not bring a coffin or burial shroud into the house
> > until he dies.

In short, we cannot mourn a loved one as though they are dead if they are still physically alive. We must find other means to frame and express feelings of loss and grief, means which do not abandon the living prematurely to the grave. Interestingly, Maimonides chose to ignore Rabbi Judah's permission to eulogize lost mental powers, probably because Rabbi Judah's ruling represented a minority opinion with which the Rambam disagreed. The existence of this opinion, however, offers possibilities for our generation as we attempt to develop appropriate prayer and ritual for marking the loss of memory and relationship.

> The matter of the *goses* is taken up again in *Shulkhan Arukh*:[75]
>
> The *goses*:
> behold, he is considered living in all respects.

---

74. The Gemara, as you recall, refers to the dying individual as a יוצאת הנפש, a departing soul-body, not a מת. It is clearly referring to someone dying in general. The Rambam is applying it narrowly to one who is physically alive, but unconscious or even psychosocially dead.
75. *Yoreh Deah* 339:1

We may not tie up his cheeks [to prevent his jaws from drooping];
we may not anoint him;
we may not ritually wash him;
we may not plug up his orifices [assuming he will bloat];
we may not remove his pillow from under him;
we may not place him on sand, clay or dirt;
we may not place a dish, spade, flask of water or lump of salt on his
stomach [assuming he will swell].

So far we have a near parallel to the RAMBAM's statement of law, with a slightly different list of actions dealing with corpses. Then we go into forbidden mourning rituals and customs:

We may not send notice [of his death] to surrounding cities;
we may not hire musicians and professional lamenters;
we may not close his eyes
until he dies.

Anyone who closes [the eyes] of the dying is a shedder of blood.
We may not ritually tear [our clothing in mourning];
we may not remove our shoes;
we may not recite eulogies over him;
we may not bring a coffin into the house
until he dies

Nor may anyone recite the *tzidduk haddin* (Mourner's kaddish)
before he dies.

In his commentary to this section of Shulkhan Arukh, Isserles adds important dimensions to the law:

Likewise it is forbidden to cause him to die
so that he may die quickly.
For example, one who has been a *goses* for a long time[76]
and cannot separate [from life] --
it is forbidden to remove his pillow or the mattress underneath him
[just] because some say that the feathers [in the pillow or mattress]
cause this [slow dying].

76. Isserles' assumption that a person may be in a state of *goses* for a very long time contradicts Karo's definition of a *goses* as one who is within three days of dying (*Yoreh Deah* 339:2). Whereas previous sources do not limit the *goses* to three days; and whereas modern halakhists and theologians for the most part reject the three-day limit given modern technological means of extending physical life for considerable periods of time (David Bleich is a notable exception), I am going with Isserles for the purposes of my thesis.

Similarly, we may not move him from his place.
Likewise it is forbidden to place the synagogue keys under his head
so that he can die.

However, if there is something that is preventing death --
[for example if] there is a chopping sound near the house -- a woodchopper -- or
there is salt on his tongue,
and these things are preventing him from dying,
it is permitted to remove the hindrance
for this is a not a [direct] action, but merely removing a hindrance.

We may not cut short a life, but on the other hand, we may not prolong death.

These texts serve as foundational texts for modern medical ethicists struggling with end-of-life issues such as euthanasia and removal of life-support.[77] My use of these texts travels in a somewhat different direction. I am looking for boundaries and limitations within which to innovate mechanisms for mourning psychosocial loss which are consonant with Jewish values. From the laws regarding the treatment of a *goses*, stated first in the minor tractates of Talmud, restated in the Mishne Torah, and again in Shulkhan Arukh, we can derive the following parameters:

1. We are obligated to treat those afflicted with severe dementia as living beings, not corpses. This means we ought to look to their physical comfort and well-being and ensure they are are not abused or neglected in a care facility. To do otherwise is to be a "shedder of blood".

2. We ought to avoid expressing our grief in a manner that implies physical death, i.e. with traditional mourning rites. To do so is to deny the life that continues to reflect the image of God.

---

77. For scholarly summaries of controversial end-of-life debates and the use of these texts by proponents of various points of view, see Elliot N. Dorff's "A Methodology for Jewish Medical Ethics" and Louis Newman's "Woodchoppers and Respirators: The Problem of Interpretation in Contemporary Jewish Ethics" in *Contemporary Jewish Ethics and Morality*, ed. Dorff and Newman (Oxford, 1995); and William Cutter, "Rabbi Judah's Handmaid: Narrative Influence on Life's Important Decisions" in *Death and Euthanasia in Jewish Law*, op.cit.

3. On the other hand, we ought to allow the dying body to die. To artificially prolong death is to deny the natural wearing down of the human body as part of an ongoing creative process, a process that is sacred.[78] In other words, whatever we do for our loved one ought to reflect acceptance and even reverence for their dying.

These parameters force us to remain engaged with an individual who may no longer be the person we knew. The person we knew may be gone forever. This presents a great challenge for those grieving the gradual loss of a relationship. Before addressing this problem, we have one more cluster of texts which offer interpretative possibilities for contextualizing the caregiver within Jewish tradition.

Rabbi Judah and His Caregiver

The central story in this cluster of texts, found in B.Ketubot 104a, is one of three foundational texts which contemporary thinkers cite "for the principle that while death may not be hastened, it is permissible to halt an artificial intervention, if the patient would expire soon and naturally if we left him/her alone."[79] I will be reading it from a different perspective, that of the caregiver and the rabbis who seek to intervene. In order to augment the story into a relevant text for grieving caregivers, I will be prefacing the story with disparate pieces of Talmud, recognizing that reading a particular text within the context of a larger *sugya* is preferable but not always possible when mining our tradition for issues which were not addressed explicitly or directly by our rabbis of

---

78. The boundary between "saving a life" and "prolonging death" is a matter of great debate among Jewish scholars and theologians alike, but beyond the scope of this thesis. Ref. note #70 above.
79. William Cutter, "Rabbi Judah's Handmaid" The other two are the Shulkhan Arukh text translated and discussed above, and the Martyrdom of Rabbi Hanina Ben Teradion (B.Avodah Zarah 18a) briefly referenced earlier in the chapter. Other texts cited by bioethicists include *Book of the Pious* #234, Nissim Geronadi to *Nedarim 40a* and the story of Rabbi Halafta and the woman who wanted to die found in *Yalkut Shemoni.*

blessed memory.

The dying man in this case is Rabbi Judah HaNasi "the Prince", a wealthy fifth generation tanna who redacted the Mishna around 200CE.[80] We know that he was the head of the rabbinic academy in Beit Shearim in Palestine, until he moved to Tzippori where he lived out the remaining years of his life.[81] His intellect and knowledge were legendary, as attested by his titles which include רבינו הקדוש "Our Holy Teacher", בית דין הגדול "The Great Court" and simply רבי "Rabbi".[82]

> From the time of Moses and Rabbi, Torah and greatness were not found together in one place. (Gittin 59a)
>
> All seven attributes that the sages enumerated in the righteous ... were fulfilled in Rabbi and his sons. (Avot 6:9)
>
> Rav said: If the Messiah is among the living, he is like Our Holy Teacher. (Sanhedrin 98b)

According to the sources, he had at least two sons, one of whom succeeded him as head of the Academy, as well as three daughters.[83] He was widowed at least once and married twice.[84]

Rabbi Judah also suffered long-term, chronic pain as well as memory loss due to illness. It is unclear what physical ailment tortured him. A passage from B.Baba Metzia says it was צמירתא -- kidney stones, hemmoroids or some type of inflammation -- and צפרנא -- scurvey, acute diarrehea or some other unidentified disease.[85] Whatever afflictions he endured, they caused him enormous pain whenever he urinated. Talmudic

---

80. Yevamot 64a; Berachot 43a, 57b; Shabbat 52a, 121a
81. Sanhedrin 14a; 32b; Niddah 14a; Ketubot 103b
82. For example, Shabbat 118b and Kiddushin 65b
83. Hullin 98a; Baba Kama 21a, 111a; Baba Metzia 44a, 85a; Horoyiot 13a; Menahot 88a; Nedarim 51a;
84. Ketubot 103b. I will be suggesting in my retelling of his story, that his second wife likely died before he died.
85. These possibilities come from Jastrow, Evan-Shoshan and Soncino note ff5 to Ketubot 104a.

legend claims that every time he went to the privy, people could hear his screams three miles away, even over the cacophonous noise of his great herd of cattle as they stampeded to their feeding troughs (his steward tried in vain to cover his master's cries by throwing grain into the troughs whenever he saw Rabbi Judah heading for the privy). Even sailors at sea could hear his screams of agony.[86]

The well-known story of Rabbi Judah and his "handmaid" is part of a larger *sugya* which actually begins with a different, apparently competing deathbed scene (103a). I would argue that this scene takes place shortly after he began to experience serious health problems, but that he did not actually die until some thirteen or more years later. The contrast between these two scenes is both remarkable and heart-breaking. In the first, Rabbi Judah surrounds himself with his sons, his wife, his students and his colleagues. He settles his affairs in a lucid and intelligent manner -- charging his sons to care for their stepmother, naming his younger son as his successor at the Academy, buying his burial plot in Beit Shearim and even planning his own funeral. The dying man is completely in charge. As his illness progresses, his disciples move him to Tzippori in hopes that a better climate will restore his health. This particular *sugya* does not explicitly mention his memory loss. This comes from another tractate in the Talmud, as mentioned earlier:

> When Rabbi had studied his teaching of thirteen different interpretations, he taught Rabbi Hiyya only seven of them.
> Eventually Rabbi fell sick [and forgot his Torah].
> Thereupon Rabbi Hiyya restored to him the seven versions which he [Rabbi] taught him, but the other six were lost. (B.Nedarim 41a)

I am imagining that his mental deterioration occurred incrementally over time, between

---

86. B.Bava Metzia 85a.

the time R. Judah diagnosed himself as a יצאת הנפש, a departing soul-body, and the last days and hours of his suffering described in our focus text. By the time we get to his second death scene he is living alone with his אמיתיה, traditionally translated as "handmaid". His students and colleagues do not come near him, but instead cluster outside his house. No mention is made of wife or children. I presume that their absence means that his second wife is either dead or living with one of his sons, who are living and working in Beit Shearim.

It is evident that the rabbis regarded the woman caring for Rabbi Judah as no mere housekeeper. Rashi calls her a חכמה based on her vast knowledge of Hebrew, from which she habitually taught the rabbis the meaning of obscure words (B.Meggilah 18a). As a חכמה she is both old and wise. Given that the word אמותיה has as its root אמת, "faithfulness" (as in "faithful attendant"), and given Judah's need for care beyond housekeeping at the opening of this story, we can rightfully describe this woman's role as Rabbi Judah's faithful caregiver. Her loyalty goes beyond kinship obligation, being neither wife nor child. She is an intelligent woman and herself elderly. Her profile, in fact, is not unlike that of many caregivers today.

חזוא יומא דנח נפשיה דרבי,
גזרו רבנן תעניתא ובעו רחמי.
ואמרי: כל מאן דאמר נח נפשיה דרבי,
ידקר בחרב.

On the day when Rabbi's soul-body rested (as he was dying),
the rabbis decreed a fast and prayed for Divine mercy.
And they said: Anyone who says that Rabbi's soul-body rested (is dead),
will be stabbed with a sword.

As modern bio-ethicists and theologians agree, the Talmud assumes that prayer and

fasting are potent healing agents. We can comfortably draw an analogy between prayer in this case and modern medical devises and treatment procedures which can prolong life and ultimately prolong death. Dorff, Cutter, Newman and others typically cast the rabbis in this story as medical professionals -- the doctors who fight death to the very last minute. I suggest two other possible analogies for the role of "rabbi" in this narrative. They could be the family members of a dying person who are not directly involved in the care of their loved one, but stand outside the house and issue demands. Or they could be, well, rabbis -- the learned religious leaders who issue their decrees and *halachot* regarding the dying man's treatment. They, too, stand outside the house. The person standing inside the house is Rabbi Judah's caregiver, who ultimately knows what is best for her charge, even if her legal status vis-a-vis Rabbi Judah might logically deny her any voice at all. At the beginning of his final dying, she raises her voice for longer life.

סליקה אמתיה דרבי לאיגרא.
אמרה: עליונין מבקשין את רבי והתחתונין מבקשין את רבי.
יהי רצון שיכופו התחתונים את העליונים!

Rabbi's caregiver climbed up to the roof.
She said [to God]: Those above are claiming Rabbi, and those below are claiming Rabbi.
Let it be [Your] Will that those below overturn those above!

She pleads for his life. Let human decree overturn the eternal decree of nature! Let it overturn Divine claims on this man she loved! The faithful caregiver responds to Rabbi Judah's condition according to our expectations. When someone is dying, of course we pray for their healing. She is gratified by the rabbis' efforts on Rabbi Judah's behalf. The decree feels just, true and compassionate. As William Cutter wrote regarding this story, "...the Talmudic story seems to rely on the assumption that the reader would pray for the extended life of Rabbi Judah. The story is important because the conclusion is

different from that expectation. Connected to that surprising outcome is the mitigating circumstance which accounts for the change in expectation: *the extreme pain* of Rabbi."[87]

כיון דחזאי כמה זימני דעייל לבית הכסא,
וחלץ תפילין ומנח להו
וקמצטער,
אמרה: יהי רצון שיכופו עליונים את התחתונים!

[But] when she saw how many times he went to the privy,
and [how he kept] taking off and putting on his *tefilin,*
and [how he was continually] doubled up in agony,
she said [to God]: Let it be [Your] Will that those above overturn those below!

Rabbi Judah's frequent trips to the privy suggest acute diarrhea, his "doubling up" stresses extreme agony, his repetitive mechanical actions denote late-stage dementia. In contrast to his earlier self-orchestrated deathbed scene, Rabbi Judah is now utterly mute. He has either lost the capacity to speak intelligently, or he is so utterly consumed by pain that he simply cannot express anything beyond the pain. His caregiver does not merely "see" (ראי) his condition as it is, she "sees" (חזאי) how it's going to be in the future -- what is in store for this man the next day ... and the day after that ... and that day after that, *ad infinitum*. As Cutter observes, "Within this little story itself the maid's experience of Rabbi Judah is not simply reported, but described as having occurred many times. The frequent visits to the privy, and the repeated action of removing his *teflin* and putting them on again are indices -- metonymies of his pain." This story "draws on the idea that witnessing an instance of suffering may lead to a change of mind." The rabbis, here, are acknowledging and, more importantly, giving permission to caregivers to *change their minds* over the course of their vigilance. Cutter explains it from a chaplain's perspective, "The Rabbi Judah story captures a sense of the duration of his illness, which

87. "Rabbi Judah's Handmaid" op.cit.

mirrors very much what happens in the hospital room of dying people. The principle of preserving life often makes a moral sense at the beginning of a long period of suffering, or when discussed in the abstract, and less after sixty days or ninety days, and repeated experience of pain." Just as illness and its moral imperatives evolve over time, so do caregivers and their lived experience. "What is this story about?" Cutter contemplates, "It may be about the power of love to change one's mind or simply about the changing of mind. It may reveal that real emotions come from particularities and details, she saw how he suffered and how often he went to the privy. It may be about the power of human power, and ... the partnership between humans and the divine."

I also think it is about the suffering of a caregiver. I would go beyond Rabbi Judah's pain into her pain. As reiterated by my focus group, to be intimately connected with a dying person while they are dying is to be dying as well. But besides the empathetic pain is the very personal and real loss of companionship she is experiencing. He has no room in his world anymore for anything or anyone outside his suffering. He does not communicate. He does not respond. He no longer recognizes the presence of his long-time faithful caregiver. His mental condition means there is no relationship anymore. *Her* Rabbi Judah is gone forever. She is alone in a house full of suffering. It is a mental anguish outsiders can never fully understand. She not only prays for an end to his suffering, but for an end to her suffering as well.

ולא הוו שתקי רבנן מלמיבעי רחמי.

But the rabbis would not stop pleading [Divine] mercy.

Her vocal prayer, uttered loudly from the roof of the house, is ignored by the doctors-family-rabbis. They keep the respirator going; the filial arguments; the rabbinic

dictum to "choose life." Beyond this popular reading, I would suggest that the rabbis' response in this story also represents a community that no longer sees the caregiver, that fails to respond to her distress, that abandons her completely. But we are dealing with a חכמה here. She is a wise woman.

שקלה כוזא שדייא מאיגרא
אישתיקו מרחמי
ונח נפשיה דרבי.

She picked up a jar and hurled it from the roof to the ground.
[Startled] they stopped [praying] for [Divine] mercy
and Rabbi's soul rested (he died).

Our caregiver smashes thoughtless complacency and calls attention to the lived reality of suffering in this house. And the community responds. His doctors let go of the "cure" in favor of comfort care. His family steps in to relieve the stress and burden of caregiving. Her religious community acknowledges and strives to meet her stated needs. And their rabbi ...

אמרו ליה רבנן לבר קפרא: זיל עיין.
אזל אשכחיה דנח נפשיה.
קראינ ללבושיה ואהדריה לקרעיה לאחוריה.

[The rabbis] said to [Rabbi] Bar Kapara: Go and see [what happened].
He went and found that [Rabbi's] soul was at rest (dead).
He tore his garment and turned the torn [garment] wrong-side-out.

The community tells their rabbi to make a house visit and see for himself what Rabbi Judah's condition is. I imagine a rabbi acting as a vital bridge to the community during long-term caregiving and as pastoral support until the loved one dies. And he or she is on hand to initiate traditional mourning ritual when the dying in fact dies. This story narrates the role of a family rabbi as the enabler of community support. The rabbi in this story

also frames Rabbi Judah's death in a manner that invites a transformative interpretation:[88]

פתח ואמר:
אראלים ומצוקים אחזו בארון הקדש
נצחו אראלים את המצוקים
ונשבה ארון הקדש!
אמרו ליה: נח נפשיה?
אמר להו: אתון קאמריתו ואנא לא קאמינא.

He opened [his report with a metaphor]:
Angels and mortals grabbed hold of the Holy Ark!
The angels overwhelmed the mortals and the Holy Ark has been captured!
They asked him: Is his soul at rest? (Is Rabbi dead?).
He replied: You are saying it, but I am not saying it.
(i.e., "I am not violating the decree by saying he is dead, but you are guessing correctly.")

The remainder of the sugya describes the elaborate funeral and communal grief response to Rabbi Judah's death. In other words, the rabbis do not stop to condemn Rabbi Judah's caregiver for her actions. Their silence, in fact, implies approval. This would have enormous implications for Jewish response to bio-ethical challenges with regard to eldercare and end-of-life issues. As Cutter reminds us, "...one must not forget that within the rabbinic frame of mind, the stories recorded in the Talmudic material represent actual events which happened within a condition of divine providence. Thus in the rabbinic view, the results represent a sense of the way the world ought to be." This story, in other words, represents an ideal response to this kind of situation. It is for that reason it is cited in legal codes and responsa from that time to today.[89] I agree with

---

88. Of course he also has a very pragmatic reason for speaking metaphorically in this story. The deadly decree issued at the beginning has not yet been annulled, so he must also avoid directly telling anyone that Rabbi is dead, lest he get "stabbed with a sword".

89. To cite four examples:

1. Walter Jacob's Responsum #85 in *Contemporary American Reform Responsa* (CCAR; NY) 1987. A 96-year-old woman refused to sign a medical release to have her foot amputated, a procedure that might correct her condition or may just as likely cause her to die during surgery. The fear of impending amputation caused the woman severe disorientation. Based on the Rabbi Judah story, Jacob concluded, "If an individual is close to death, she should be permitted to die peacefully, and it is not necessary to subject her to needless pain through therapy which can not succeed."

2. Solomon B. Freehof's Responsum #27 in *Reform Responsa* (HUC Press; Cincinnati) 1980. A

Cutter that "...there are principles in this story which may influence decisions about the care of an aging parent who is 'just hanging on'". As pertaining specifically to my thesis project, I derive the following principles from this foundational narrative:

1. Suffering -- both that of caregiver and loved one -- ought to be added to physical maintenance and psychological nurturing as factors which go into decisions regarding a loved one afflicted with progressive dementia. This is a direct application of the already ancient concept of *Kevod habriyot* -- respect and compassion for the suffering of a person created in the image of God.

2. The instincts of the person most intimately involved in the care of a loved one should be respected and heeded. They are the most qualified person to ascertain the needs of their charge, and ultimately to determine when it is time to let the "angels above

---

physician asks if he is duty bound to continue making efforts to keep a patient alive even if the patient is dying and in great pain, or has arrived at the stage of utter helplessness in bodily functions. Citing the Rabbi Judah story Freehof concludes, "When it is manifestly impossible for the patient to recover and he is suffering greatly, it is cruel to use the instrument of prayer to keep him, by force, alive and suffering. Therefore, the conclusion from the spirit of Jewish law is that while you may not do anything to hasten death, you may, under special circumstances of suffering and hopelessness, allow death to come."

3. Moshe Zemer Responsum in "Passive Euthanasia" in *Halakhah Shefuya* (Tel Aviv; Israel) 1993, reproduced in *Death and Euthanasia in Judaism*, op.cit. A man suffering from progressive paralysis of his muscles appealed to the District Court of Tel Aviv for an injunction against his physician and hospital to refrain from connecting him to a lung-heart machine. After citing the Rabbi Judah story, among other sources, he concludes by citing Justice Haim Cohn, "The golden rule of Biblical law, 'Thou shalt love thy neighbor as thyself' was interpreted by the Talmudic Jurists as imposing a duty to choose for one's fellowman the most "beautiful" death possible *mitah yafah* (*Sanedrin 45a, 52a-b*). Both the reasoning behind the talmudic rule and its comprehensive language allow it to be applied more generally to every situation in which man (usually the physician) is faced with a choice between two kinds of death to be caused to his fellowman -- the one agonizing and protracted, the other relatively easy, swift and humane. This most fundamental of all divine commands (B.R. 24:7 in the name of R. Akiba) exhorts one to conduct oneself especially in the face of death, in such a manner as may be dictated by sincere love for the dying person."

4. Solomon B. Freehof Responsum #77 in *Reform Responsa*, op.cit. A terminal patient was dying as a result of a series of strokes (and therefore mentally incapacitated at this point). Two physicians, one of whom was the patient's son, decided -- with the consent of the family -- to hasten the end of withdrawing all medication and fluids given intravenously. Is this procedure permitted under Jewish law? After citing the Rabbi Judah story, Freehof concludes, "If the patient is a hopelessly dying patient, the physician has no duty to keep him alive a little longer. He is entitled to die. If the physician attempts actively to hasten death, that is against the ethics of Jewish law."

overturn mortals below."

4. Duration of illness affects the type of medical and liturgical response appropriate. The caregiver changes as much as their loved one changes over the course of time. Prayers of healing appropriate at the onset of terminal illness or progressive dementia may not be appropriate during end-stage.

3. The role of the community is to be present for both the ill and their loved one, to be sensitive to on-going needs and to render appropriate support.

4. The only way to know what is happening in a home of chronic suffering is to actually go inside the home and "see" for oneself.

5. Cutter's charge to medical professionals ought to be adapted for rabbis as well: So much of our training is focused on Jewish law, Jewish ethics, Jewish tradition, looking for the canonical way to behavior in every situation. But that learning can get in the way of treating a congregant -- be they caregiver or patient -- as a full human being. When core values and their riddles get folded into the human being who carries an illness, the rabbi becomes more human, more tragic, and more a partner with the person served. We fulfill a real partnership with the Creator.

Chapter Three

"The Pastoral Needs of Family Caregivers Mourning Psychosocial Loss"

As I was walking up the stair,
I met a man who was not there.
He was not there again today.
Oh, how I wish he'd go away
--Old English nursery rhyme[1]

He's here, and yet he's not.
Now we see him, now we don't.
Soon we won't.
He's going-going-gone.
--anonymous caregiver

This chapter explores the nature of family caregiver grief over the course of progressive dementia, as well as coping mechanisms and pastoral needs identified by medical and mental health professionals. I am also including valuable input from my focus group.

The Ambiguous Nature of Psychosocial Loss

Pauline Boss, a clinical psychiatrist who has counseled over 4,000 bereaved families, was the first to recognize a category of bereavement which she labeled "ambiguous loss", defined as "a loss situation that remains incomplete, confusing, or uncertain for family members."[2] She articulated two types of ambiguous loss:

1. A person is physically absent, but psychologically present (i.e. a soldier missing in action or a missing child).

---

[1] As quoted in Pauline Boss' *Ambiguous Loss: Learning to Live with Unresolved Grief* (Harvard University Press) 2000, p6
[2] Ibid. p5

2. A person is physically present, but psychologically absent (i.e. a person in a coma or afflicted with dementia, addiction or chronic mental illness).

"Of all the losses experienced in personal relationships," Boss observes, "ambiguous loss is the most devastating because it remains unclear, indeterminate." People hunger for certainty to the point where even sure knowledge of death is more welcome than a continuation of doubt. Not-knowing is stressful and often tormenting. Within the context of progressive dementia, ambiguous loss complicates grief three ways.

First, it forces the bereaved to live with conflicting demands and paradoxes.

- Their loved one is alive, but the person they loved is dead -- gone forever.
- They dread the death of a hopelessly ill loved one, but also hope for an end to the waiting.
- They feel anger towards a loved one for keeping them in limbo, then feel guilty for feeling angry.
- A spouse loses a mate, but they are still formally bound. They don't feel married, but neither are they divorced or widowed.
- A child loses a parent, but the parent is still there as an elderly child needing parental care.[3]
- They have control over the life of their loved one, yet feel powerless to stop physical and/or mental deterioration.
- They feel intensely involved with their loved one, yet barred from the inner life of their loved one.

---

[3] Besides Boss, see also Kenneth J. Doka "Mourning Psychosocial Death: Anticipatory Mourning in Alzheimer's, ALS and Irreversible Coma" in *Clinical Dimensions of Anticipatory Mourning: Theory and Practice in Working with the Dying, their loved Ones and their Caregivers* ed. Therese A. Rando (Champaign, Illinois: Research Press) 2000.

This last point is particularly frustrating for caregivers. Joyce, for example, wondered constantly what her mother might be thinking. "Did she understand death?" Joyce would ruminate, "What was she really feeling? I never got an answer, as hard as I tried." With AD or DLB you can sometimes tell where a loved one might be in their heads, and with whom. Rachel would watch her mother teach phantom students in an invisible classroom of the past. Carol knew that her mother had discovered *her* mother in the halls of her nursing home because she carried on lengthy conversations within the alternate reality of her childhood. Time travel is not necessarily a pleasant dream. Carol told me of one woman who returned to her internment at Auschwitz during World War II. She and her husband had survived seven years in the concentration camp. Her husband, devoted and clever as he was, could not pull her out of her living nightmare into better times. Her nightmare became his nightmare.

The ultimate paradox for the family caregiver: to mourn the loss of a person dramatically changed by the illness while increasing involvement in the person's life. Rebecca J. Walker states the problem succinctly when she says that psychosocial loss "mandates a delicate balance among the mutually conflicting demands of simultaneously holding onto, letting go of, and drawing closer to the dying patient."[4] How does one "disconnect" from a relationship and yet remain connected? not only remain connected but increase one's connection over time? How can one move past frozen grief without shutting out the living person you are duty-bound to nurture? This is the great challenge for caregivers, and it is the greatest challenge facing any rabbi attempting to intervene

[4] "Anticipatory Grief and Alzheimer's Disease: Strategies for Intervention" in *Journal of Gerontological Social Work* v.22(3/4) 1994

with therapeutic ritual and prayer response. How do we help a caregiver grieve their loss without abandoning the person they are mourning?

We have an imperative to make the attempt, because these paradoxes often paralyze a family, rendering them emotionally immobilized because they can't make sense of the situation. Families often cannot problem-solve because they do not yet know the depth or time-frame of the loss.[5] "The tension that results from conflicting emotions, especially when family members' unresolved grief is not acknowledged, becomes so overwhelming that they are frozen in their tracks," Boss observed. "They cannot make decisions, cannot act, and cannot let go (61)." If the uncertainty continues, families will often respond desperately with absolutes, either acting as if the person is completely gone, or denying that anything has changed. Because these absolutes are cognitively dissonant, they inevitably lead to depression, anxiety and interpersonal conflict within the family (7-8). Jaye related the extreme example of her father's reaction to her mother's condition. "Dad could not cope. He was in complete denial. As long as mom was home, he fought to keep her the way she was. He insisted on taking vacations with her and told me to teach her how to put on ribbed girdles for evening wear. Well, there was just no way she was going to be able to dress herself, let alone get into a corset ... Then the week we put her into Garden Terrace (a care facility) he left town for a vacation and came back with a girlfriend who moved in with him and immediately redecorated Mom and Dad's bedroom." Jaye felt intensely angry and scandalized by her father's behavior. "I wanted to kill him."

---

[5] Jaye did not experience immobilization. She believes it is because she was the sole decision-maker. There was only one occasion when she felt frozen in her tracks, and that was when another family member insisted on having an input regarding a particular issue. This suggests that interpersonal dynamics might be an important factor in this phenomenon.

Second, it creates ambivalence towards the loved one afflicted with progressive dementia. Doka compares psychosocial loss to a horror movie, *Invasion of the Body Snatchers*, in which aliens possess the bodies of human beings. They appear to be the same, but their personalities are destroyed. "The bodies of victims are invaded by what seem to be mind snatchers, and, as a result, family and significant others suffer a profound sense of loss. But because the person is still physically alive, grief may not be recognized or considered appropriate."[6] A friend of mine described an occasion when she broke down and screamed at her father, "Where did you take him!? Who are you!? You are not HIM! You are not my dad! ...." After screaming until she was hoarse, she lay her head on his lap and wept. She wept again when she told me the story.

Jaye described the personality changes in her parents as "simply not rational." Their food preferences, tendencies and desires changed daily with no memory of previous preferences. One focus group member recalled a particularly jarring experience when she saw her mother placing her hand on another care resident's thigh in a sexually suggestive manner. "She would never do something like that in public, and I was embarrassed for her. She was a woman of grace and dignity." Another member likewise experienced embarrassment on behalf of a loved one's deteriorating table manners; another when a loved one uttered profanities. Carol remembers the day she came into the care facility and saw her mother eating a sausage and exclaiming how good it was. Carol was mortified for her mother. "My mother would never eat a sausage, or anything else that was unkosher." She strongly feels that food given to a victim of dementia ought to reflect a patient's former dietary preferences and standards "out of respect for the former

---

[6] "Introduction" to *Disenfranchised Grief: New Directions, Challenges and Strategies for Practice* (Champaign, Illinois; Research Press) 2002.

self, even if they don't know enough not to eat it." Joyce experienced pain when her mother forgot that she liked gefilte fish -- a traditional Ashkenazie food that marked her as a Jewish mother. All members of my focus group expressed the paradoxical feeling that somehow their loved one *as they once were* would be horrified by the behavior of their *current self*. They felt an empathetic shame on behalf of their loved one's *former self*. These examples verify the ambiguous nature of a caregiver's grief. The image before them is that of their loved one, but the behavior they witness is that of a complete stranger. These examples also illuminate rabbinic insistence that victims of dementia be treated with all the honor and respect they were accustomed to when they were sound of mind. Something in our minds will not let go of the personality we once knew behind the familiar image before us. Even if they are no longer aware of their behavior and feel no shame regarding it, we feel empathetic shame on their behalf. Carol, now sensitized to this issue, notices when a formerly observant man is brought to synagogue services without a *kippa* or *tallit*. Even though he is unaware of his "demotion", she feels that this is a form of neglect and disrespect.

The anguish felt on behalf of a loved one is particularly acute when the caregiver themselves "desecrate" the divine image of their loved one while caring for their physical needs -- changing diapers being the number one act that inflicts double shame on the caregiver -- first for doing something that feels like disrespect, second for the now-helpless condition of their loved one. And it is not unusual for a person who has lost their mind to yet retain their former instinct for privacy, adding further *tsoris* to the ordeal. One group member remembers when her mother angerly swung her cane at her daughter for reaching down into her pants.

Caregivers are often torn by their ambivalent feelings for their loved one. "There's no conversation, there's nothing," one caregiver confided to Sherry Dupuis, associate director of Alzheimer's Research with the University of Waterloo, "It's just sit there and watch him drooling and it's like, oh my God, this is awful ... As much as you try to get past the whole thing about, you know, that this is your father, it really hurts." Another admitted, "Like have we all been pretending that this woman is even alive? ... Like has it all gone and vanished?"[7] Guilt can come by way of a death wish or a perceived error of omission or commission in care. Ambivalence and guilt seem to go hand-in-hand.

Boss observes that ambivalent feelings are often evident when caregivers mix their tenses when talking about their loved one – sometimes past tense, "was"/"used to"/"would do this", and sometimes present tense, "is"/"now he"/"does this". This is a common indication of confusion about the status of a loved one who is still present but also partly gone (107). Jaye explained how that worked for her. She would start to describe her mother in present tense the way she used to be, and the things she used to like and dislike, then suddenly realize it was no longer true and so would then shift to past tense. This confusion is another reason caregivers often find themselves paralyzed by the situation.

> "People don't know whether to act married or single, to hope or to give up, to hate or to love the missing person, to leave or to stay, to give up or to wait. Family members of patients with Alzheimer's are often both angry and sad: angry at the demands of care giving and sad because they are losing a loved one. To be unable to make a single connection with someone with whom we have had a lifetime of meaningful conversations would give rise to ambivalence in the best of us. But

[7] "Understanding Ambiguous Loss in the Context of Dementia Care: Adult Children's Perspective" in *Journal of Gerontological Social Work* v37(2) 2002.

such mixed feelings can freeze people in place if they block the ability to make decisions for change (72)."

Third, ambiguity compounds the incremental nature of progressive dementia into a seemingly endless ordeal. The end could be a week, a month, a year, a decade away. The ambiguity keeps the caregiver in a slowly descending spiral of uncertainty. The liminal state becomes a twilight zone of despair. One member of my focus group said, "It was *gradual*. I emphasize the word *gradual*. It was like dying piece by piece, never knowing which piece would finish me off." She felt like she was dying, too. The suspense was literally "killing" her. Dupuis picked this up as well. "One of the most painful experiences for family members in dementia care is watching the gradual deterioration and psychological loss of their loved ones."

Involved caregivers will observe what is happening to other residents of a nursing care facility and anticipate the same thing happening to their loved one. They experience great stress knowing what lies ahead, but not knowing when the time will come, or whether they can cope when the time comes. This may account for the paradoxical rise in emotional stress when family caregivers place their loved ones into professional hands. Visits are often viewed as futile and pointless, adding to depression and overall feelings of helplessness.[8] Group members say "amen" to this last point. But they have other reasons why institutionalized care of a loved one is stressful to a caregiver. Carol said that watching the decline of other residents confronted her with the terrifying reality of her own future death. It also saddened her because she would grow fond of other residents in the facility and so grieve over their mental deterioration and eventual death.

---

[8] Ibid.

"I saw so many people coming and going ... I was experiencing everybody else knowing me and then not knowing me. And that was pretty hard. It wasn't a mother, but it was someone you grew fond of, and then they lost total touch with you and then they were dead." These feelings, by the way, are not unlike those commonly experienced by professional caregivers.

Jaye did not like the loss of control over her mother's care. She remembered her mother's former self as someone who took pride in her appearance and grooming. So Jaye would arrange to have her mother's hair done, for example, and a shift worker would then put her mother in the shower. Or she would dress her mother up in nice clothes, only to see her in sweat clothes several hours later. Again, the feeling of utter futility. The sense of shame over invasion of privacy is also multiplied in an institutional environment. Jaye felt mortified for her mother when she saw a 20-year-old man changing her mother's diapers, whereas if a 40- or 50-year-old woman had been performing the task it would not have been so shameful.

Psychosocial death of a loved one can lead to a complicated grief reaction that is necessarily ambiguous in nature simply because the loss one mourns is likewise ambiguous. Boss calls this situation "frozen grief", something that would be pathological melancholia during a normative loss such as the physical death of a loved one, but which is normal during the gradual, ambiguous loss of psychosocial death. "Just as ambiguity complicates loss, it complicates the mourning process. People can't start grieving because the situation is indeterminate (10-11)."

But according to Doka, people do, in fact, go into mourning -- a complex grieving that he calls "Anticipatory Mourning".

Anticipatory Mourning

Dealing with ambiguous loss involves a long, painful grieving process that begins early on during the progress of ambiguous loss, most of it happening while the victim is still alive.[9] It is variously described as the "long good-bye," the "never-ending funeral," or the "ever-dying of the dying." Doka defines "anticipatory mourning" as "the reaction to a perceived impending loss, as well as reactions and responses to losses already experienced within the new reality of the illness."[10] In relation to Alzheimer's Disease, Cynthia Loos and Alan Bowd define it as "...grieving commenced considerably before the death of the person in care, mainly through loss associated with his or her cognitive deterioration."[11]

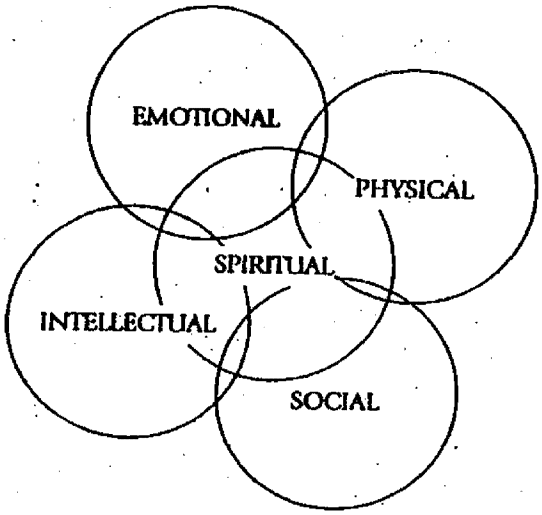
Joyce and Dennis Ashton observed that anticipatory mourning and post-death mourning (clinically referred to as "conventional" or "normative" mourning) share common grief reactions. These are arranged in Figure 1 according to the five dimensions of the human system: emotional, spiritual, intellectual, social and physical.[12] Therese A. Rando made important distinctions between anticipatory mourning and conventional mourning. The two involve different psychological and physical realities. Whereas conventional mourning focuses on the ultimate loss of death, anticipatory mourning focuses on an impending loss as well as other significant losses associated with care giving and incremental psychosocial loss.[13]

---

[9] Ibid.
[10] "Mourning Psychosocial Death"
[11] "Caregivers of Persons with Alzheimer's Disease: Some Neglected Implications of the Experience of Personal Loss and Grief" in *Death Studies* v21 pp501-514 1997.
[12] "Dealing with the Chronic/Terminal Illness or Disability of a Child: Anticipatory Mourning" in Rando's *Clinical Dimensions of Anticipatory Mourning*, op.cit.
[13] "Anticipatory Mourning: A Review and Critique of the Literature" in Rando's *Clinical Dimensions of Anticipatory Mourning*, op.cit.

Five Dimensions of the Human System: Common Grief Reactions

Figure 1



INTELLECTUAL
confusion
disorganization
lack of concentration
intellectualizing
disorientation
absent mindedness
denial

EMOTIONAL
shock
numbness
anger
guilt
relief
depression
irritability
loneliness
yearning
disbelief
sadness
denial
anxiety
confusion
fear

PHYSICAL
changes in appetite
blurred vision
sleep changes
muscle twitches
restlessness
breathlessness
heart palpitations
loss of sexual desire
changes in weight
headaches
bowel changes
crying
exhaustion
dry mouth

SPIRITUAL
impressions
dreams
loss of faith
increase of faith
anger at God
spiritual injury
questioning values
feeling betrayed by God
disappointment in religious clergy and members

SOCIAL
loss of identity
isolation
withdrawal
lack of interaction
energy
loss of ability to function

Rebecca J. Ponder and Elizabeth C. Pomeroy note two other important differences between the two types of mourning. First, the anticipatory mourner does not move through more or less definite stages of grief reaction, but instead experiences all of them simultaneously in a kind of ebb and flow over the course of their loved one's deterioration. Second, while healthy normative mourning is characterized by a gradual decrease in pain, grief reaction in anticipatory mourning typically intensifies over time. "Although the intensity and predominant feelings may wax and wane over the course of providing care, the grief increases with the increasing symptomatology of the patient and does not abate over the long course of providing care."[14] In their study of 100 family caregivers of AD victims they observed three stages of anticipatory mourning:

1. Diagnosis of AD dementia
2. Victim's physical loss of control
3. Loss of relationship (psychosocial death)

Participants experienced various and even contradictory emotions simultaneously. "Both the intensity of grief and the number of grief behaviors increased by the middle stages of grief." In other words, mourning intensified with the onset of psychosocial loss of their loved one.

Another study performed by Gilliland and Fleming substantiated this phenomenon. They found that emotions associated with anticipatory grief are more intense than those associated with conventional grief. Anticipatory mourners experience greater intensities of anger, loss of emotional control and atypical grief responses.[15]

---

[14] "The Grief of Caregivers: How Pervasive is it?" in *Journal of Gerontological Social Work* v27(1/2) 1996.

[15] As cited in Rando's "Anticipatory Mourning: A Review".

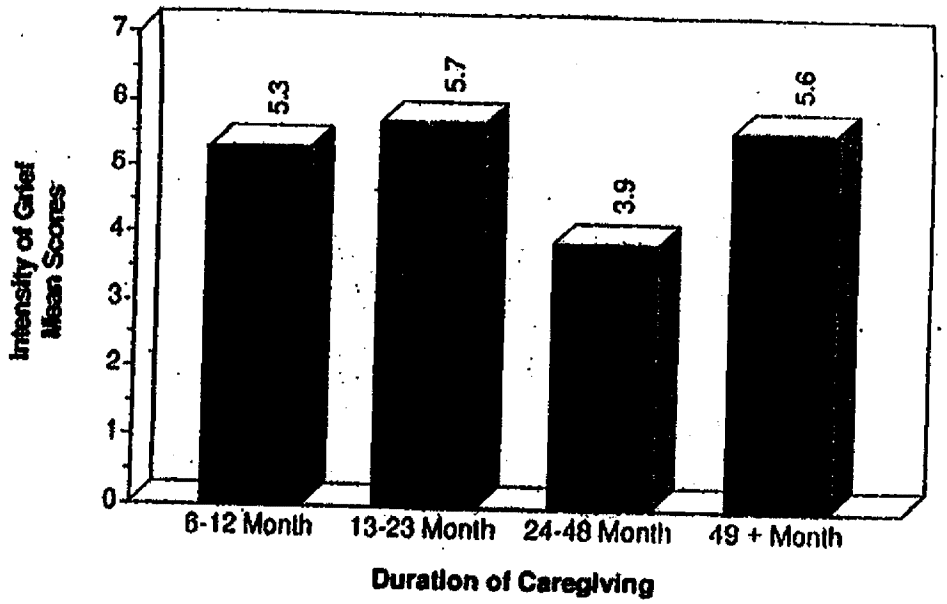
Moreover, the intensity continues beyond the endpoint of death. Subscales measuring despair, somatization, death anxiety, social isolation and denial do not typically change following the death of the loved one.

Ponder and Pomeroy charted correlations between the duration of caregiving and the intensity of post-death grief and discovered a curvilinear relationship (see Figure 2). Six to eighteen months appear to be the "optimal" time for anticipatory mourning in terms of easing post-death grief. This is the window within which anticipatory mourning contributes to and aids the mourner towards emotional healing. On the other hand, they found that a pre-death mourning period of less than six months did not lessen the intensity of post-death grief, while anticipatory mourning periods extending over significant periods of time not only intensifies post-death mourning, but complicates it to the point where a mourner can be permanently haunted by symptoms of Post Traumatic Stress Syndrome. Ponder and Pomeroy did not have a clinically-proven explanation for this phenomenon. They speculate that two factors may be at work here. First, if too much time elapses after the initial diagnosis of terminal illness, the diagnosis ceases to be a reality. The mourner is unprepared psychologically for the final loss. Second, they speculate that the emotional and physical drain of caregiving leaves the mourner unable to cope with post-death grief.

Rando confirms the curvilinear phenomenon of anticipatory mourning and adds her own speculations. She proposes that the ever-increasing involvement of a family member in the care of their loved one inevitably leads to an ever-increasing emotional bond to the dying individual. "That care can make the loss hurt more or leave one with

Figure 2

BAR CHART of Caregiving Mean Scores on Intensity of Grief During Different Lengths



more memories and emotional involvement to disengage from after the loss."[16] In addition, "one's efforts may seem invalidated by the actual death, thus intensifying the grief experience." Also, "a daily routine that centers on the dying person and then is shattered by the death mandates a new pattern of life." Jaye felt that she had lost her "job", her role as a caregiver after years of giving. But she identified two other reasons why the inevitable death of her mother after years of decline was more difficult for her than a conventional death might have been. First, she had lost the ability to do other things with her time. She felt lost in a big time-hole. Second, over the course of her mother's incremental deterioration, she simultaneously experienced incremental loss of support from her social network. By the time her mother died, her support system was almost non-existent, whereas if her mother had died within a short period of time, she would have been comforted by a great deal more people. In other words, at the beginning of her mother's illness, she was part of a supportive community. By the time her mother died, she had no community to mourn with her and comfort her.

Social dissonance stemming from anticipatory mourning can both intensify and complicate post-death mourning. Rando reasons that "a period of anticipation may reduce the amount of public mourning survivors display, putting them in the difficult situation of being expected by others, as well as themselves, to show emotions that already have been worked through. This can cause mourners guilt or shame." These debilitating emotions lead to others, such as psychological conflict, emotional exhaustion, physical debilitation, social isolation and familial discord. Rando sums it all up by saying, "Illness-generated emotional reactions such as anxiety, sorrow, depression, anger and guilt take their toll on

---

[16] Ibid.

anticipatory mourners, as do the stresses inherent in attempting to manage clashing responsibilities, discordant roles and antagonistic tasks." I suspect most, if not all of these speculations are correct. Every member of my focus group continues to grieve their loved one 2-5 years after death, in spite of the formation of new relationships and renewed occupations. Their loved one is painfully ever present in their minds. They express this continuing ache in unique ways. Carol subscribes to the Alzheimer's Association Review and keeps herself up-to-date on the disease. Mort, being the biochemist that he is, combs through medical journals for anything related to AD, particularly research on cholinesterase, the mechanism in neurotransmission which he elucidated as a scientist nearly 60 years ago. Jaye has developed a renewed interest in her previous training as a social worker, and in fact has been the most assertive in feeding me clinical materials that will help me provide constructive counseling to caregivers in the future. Rachel is currently writing a book on pain and suffering, a project that gives her both sorrow and needed release. Joyce accepted chairmanship of our local Jewish Family Services in order to push for advocacy reform. Just recently she attended a funeral in which the rabbi sang "My Yiddishe Mama", the song her mother used to sing in the kitchen before her illness silenced her. It was a moment of renewed grief and mourning. It is clear to me that they were all traumatized and transformed by their long years of service to a single dying human being.

Rando points out the extreme opposite emotional reaction to prolonged anticipatory mourning: the premature detachment or withdrawal from someone who is

not yet dead. There are three areas of social and psychological ramifications of premature decathesis:[17]

1. *They may turn away from the dying one prematurely,* blocking needed emotional support for family caregivers who chose to remain involved with the victim of dementia.
2. *They may not respond "appropriately" at the actual death* and so draw undeserved criticism from others, as well as produce self-criticism, guilt and shame.
3. *They may not feel that a traditional funeral is necessary,* thus depriving family and others experiences afforded by rituals that have historically served critical psychological, social and religious functions.

In spite of the opposing dangers of decathesis and over-fixation, Rando insists that "healthy experiences in anticipatory mourning has a potentially profound and positive influence on post-death bereavement."[18] She and Boss agree that well-facilitated anticipatory mourning allows time to say good-bye and to work out the emotional and psychological implications of personal loss.[19] To understand how anticipatory mourning can be directed into a healthy direction – and how a rabbi can support a family through this process in a manner that is both healing and transformative – we must have some understanding of not only the primary loss of psychosocial relationship, but of multiple secondary losses that complicate anticipatory mourning.

---

[17] "Anticipatory Mourning: What it is and Why We Need to Study it" in *Clinical Dimensions of Anticipatory Mourning*, op.cit.
[18] "Promoting Healthy Anticipatory Mourning in Intimates of the Life-Threatened or Dying Person" in *Clinical Dimensions of Anticipatory Mourning*, op.cit.
[19] In addition to Rando, see Boss' *Ambiguous Loss* p140.

Secondary Losses and Stressors

Caregivers not only suffer the primary loss of a significant relationship, but multiple secondary losses as well. Loos and Bowd define a secondary loss as "any aspect of the caregiver's personal life perceived to have been forfeited because of the demands of the Caregiver role."[20] They see four themes of loss:

1. Loss of social and recreational interaction. Social isolation and cessation of travel and recreational activities are felt keenly by nearly every caregiver in their study, and incidentally by every member of my focus group. From Loos and Bowd's respondents: "I have no social life outside the home at all ... all my recreational activities are gone ... Just to have someone to talk to that would understand ... would be a great help to me"; "Your social life is cut short, friends and family are few ... you feel isolated." Valued friends disappear. "It lasts so long your friends stop calling." "Your social life is cut short, friends and family are few ... you feel isolated."[21]

Doka identifies psychosocial loss as one of several causes of grief which are socially "invisible." He was the first to label this kind of grief as "disenfranchised." "Although the individual grieves, others do not acknowledge that the individual has a right to grieve. The person is not offered the 'rights' or the 'grieving role' that would lay claim to social sympathy and support or given such compensations as time off from work or diminishment of social responsibilities. . . although the person experiences grief, that grief is not openly acknowledged, socially validated, or publicly observed."[22] He

---

[20] Op.cit.
[21] See also William M. Lamers, Jr. "Disenfranchised Grief in Caregivers" in Doka's *Disenfranchised Grief*, op.cit.
[22] "Introduction" to *Disenfranchised Grief*, op.cit.

explains the causality of disenfranchised grief within the context of social norms. Every society has norms that govern not only behavior but also affect and cognition:

"Feeling rules":	What one is supposed to feel in a given situation
"Thinking rules":	How one is supposed to think in a given situation
"Spiritual rules":	What one is supposed to believe

"Every society has norms that frame grieving. These norms include not only expected behaviors but also norms for feeling, thinking and spiritual expression ... They govern what losses one grieves, how one grieves them, who legitimately can grieve the loss, and how and to whom others respond with sympathy and support." Grief over psychosocial loss is simply not covered under our current social norms. Hence the isolation. Doka outlined the ways in which disenfranchised grief exacerbates bereavement:

1. *Intensifies and complicates normative emotional reactions* such as anger, guilt, sadness, depression, loneliness, hopelessness and numbness.
2. *Creates or intensifies ambivalency and crisis,* which in turn complicates grief.
3. *Many factors that facilitate grief are absent,* such as visitation, communal sympathy and ritual.
4. *Preclude social support.* There is no recognized role in which mourners can assert the right to mourn and thus receive support.

Members of my focus group mentioned social stigma as an added source of stress for them. Because Jaye's mother appeared normal and comprehending for a long time into her illness, Jaye's father insisted on keeping her condition a secret. "It was a big betrayal when I told my mother's sister." His fears would seem to be vindicated by the disappearance of their social network when the condition became obvious by her behavior. "One Thanksgiving I was simply too exhausted to fix the big dinner," Jaye recalls, "and no one invited us over for dinner, so we just had soup." Rachel writes, "I

am remembering a family celebration I attended with my mother and her partner when my mother had become demented. For several hours we sat at a table by ourselves and no one approached us. There were present two generations of parents who had turned to my mother for expert professional advice, two generations of children she had played with and talked to and never forgot on their birthdays or Chanukah. But no one sat down to talk to my mother or her caregivers. Lamentations describes prophets and priests bloodstained and blindly wandering the streets: *'Away! Unclean!' People shouted at them/ Away! Away! Touch not!'* (Lam. 4:14). Ours, in contrast, was a silent shunning."

Adler believes that the reason for social stigma lies in the visceral human fear of chaos and death:

> As selves we want to be whole, yet we are destined to fall apart. People whose bodily integrity has been breached, who are maimed or mutilated, remind us of our "disorganized" ultimate destination. People who are liminal or marginal -- who have been pushed to the edges of social boundaries -- also embody this anxiety-provoking place on the edge of the dangerous and the chaotic. This is where "normal society" puts those it stigmatizes as non-normal such as people of color, the poor, and the aged. Add to that a disease and people are greatly tempted to relieve their terrors by casting out or punishing these dangerous Others.[23]

The fear behind social stigma of the elderly suffering from dementia may explain the kind of negative "support" Carol received from her colleagues where she worked. "People kept asking me why I kept going to see my mother. They would say things like, 'I don't understand how you can keep going to see her.' Like they would not keep contact with a parent like that." She found such discouraging exchanges to be depressing. They invalidated her role as a caregiver.

---

[23] "Those Who Turn Away Their Faces", op.cit.

Boss highlights the denial of support rituals that are readily available to conventional mourners. "There is no death certificate, no wake or sitting shiva, no funeral, nothing to bury ... Few if any supportive rituals exist for people experiencing ambiguous loss (7-8)." This leaves the experience unverified and unvalidated by the community around them. The absurdity of ambiguous loss reminds people that life is not always rational and just. "Those who witness it tend to withdraw rather than give neighborly support, as they would do in the case of a death in the family." As a consequence, "highly stressed families experiencing ambiguous losses are too often left on their own to find a way out, because existing rituals and community supports only address clear-cut losses such as death (20-21)." She specifically points to professionals who could make a significant difference, "community, church and medical professionals often inadvertently contribute to the stagnation of grief because they are not accustomed to giving support unless there is a certified loss (30)."

When death finally takes a loved one who has already been psychosocially dead for quite some time, traditional funeral rites can be ineffectual or confusing for everyone. For Rachel, the influx of support and sympathy came far too late. It wasn't there when she truly needed it. Jaye and Joyce, on the other hand, felt they were cheated by the assumptions of well-intentioned comforters who projected relief, rather than grief, onto the mourner. "When someone you love dies at 80, 90, 100, whenever it happens, it happens too soon," Joyce told me. "It doesn't make the death any easier." Lack of sufficient communal sympathy might be the result of mixed signals from the mourner who may, in fact, be experiencing complex grief reactions, as Jaye did when her mother

died. "I felt like I lost traditional support from friends and family. Death is viewed as a relief to the caregiver -- which it is -- but it is still a significant loss."

Joyce, Mort and Rachel offered counter-stories of social support during their years as caregivers. Mort was lucky to have neighbors next door who were medical professionals. They came over often to provide information, advice, referrals and help lifting Adele up after a fall. He also had a gratifying relationship with both his rabbi and Adele's home nursing aide. These relationships were reciprocal in nature. He would take the rabbi out to lunch and assist with synagogue building maintenance issues. He also tutored and mentored the nursing aide's son from drop-out to straight-A student. Joyce's social network remained strong throughout her ordeal. Friends would pick her mother up and take her places. Early on in her dementia, her mother missed a connecting flight in Chicago. A childhood friend in Chicago stayed overnight with Joyce's mother, dressed her in the morning and escorted her onto the plane. "I had an incredible support group of friends." Rachel enjoyed strong, empathetic support from her colleagues. No one, however, could say that they were supported by their religious community.

2. Loss of control over one's life. The Loos and Bowd study found that both spouse and adult child caregivers expressed unresolved anger, frustration and dejection at their loss of control over life events. "I very much resent the fact that I no longer control my life. My self and family come second. I want my normal life again."; "You give up your freedom to come and go as you please"; "I gave up my freedom and privacy for any of my own pursuits. In the end I could hardly leave her sight." Apparently the problem does not go away when the loved one is institutionalized. Caregivers continue to spend

much of the day assisting with care at residential facilities.[24] They are also on call twenty-four/seven in the event of a medical crisis that requires them to make an emergency life-and-death decision. Jaye recalls the time she went to her 30-minute yoga class for respite, only to be pulled out by her son because her mother broke her leg in a fall at the nursing facility. "You think you are going to San Francisco for a vacation, but ... no, a call comes in." Carol remembers her attempt to get away with her husband for their wedding anniversary. It was going to be a single night at a ski lodge. "I had arranged dog care. We were just ready to leave when the phone rings. It's the nursing home." The nursing staff thought her mother was having a heart attack and appeared to be dying (she actually had another six years to live). Carol remembers this particular incident, even though such calls became part of her "normal" routine, because she decided to go ahead with her anniversary plans anyway. She suspended her mother's advanced directive for 24 hours, telling the staff "to do whatever it takes to keep her alive until I get back." Her need for respite overcame her burden of guilt, a burden that spoiled her time with her husband. As part of the personal time-control issue I would add William M. Lamer's loss category of time, energy and frustration spent on endless paperwork related to marshalling financial and caregiving resources for a loved one.[25]

3. Loss of Physical and Mental Well-Being. Caregivers experience disrupted sleep and rest patterns. Besides physical exhaustion they are often unable to find personal time, and so lose a sense of emotional well-being as well.[26] These losses are expressed in terms of restlessness, difficulty concentrating and "short fuses". Although caregivers will sometimes long for their loved one to deteriorate enough so that they can

---

[24] See also Walker, op.cit. and Rando, "Anticipatory Mourning: What it is", op.cit.
[25] Op.cit.
[26] See also Lamers, ibid., and Rando, "Anticipatory Mourning: What it is", op.cit.

be institutionalized, the physical relief afforded by institutionalization is often outweighed by emotional cost, usually in the form of guilt.

4. Loss of Occupation and Financial Resources. Many caregivers are obliged to give up their employment. "For some, work provided a source of social contact and physical and mental activity and had helped offset some of their loneliness." Lamers also points out the financial loss that caregivers experience during the course of progressive dementia.[27] Joyce knows many caregivers who lost their jobs because caregiver responsibilities and numerous crisis calls from a nursing facility impaired their productivity.

Other studies have discovered additional secondary losses. These I will add as an extension to the Loos and Bowd list above.

5. Loss of a Planned Future. Rando observed that caregivers often grieve over hopes, dreams and expectations for a future that involved their loved one. Walker and Boss likewise take note of this loss. Jaye recalled her big loss of a dream, "I was very sad that my children never knew my mother. They never knew a doting grandmother. Instead, they knew a demented grandmother." Her mother's condition also threw her father off track as a functional grandfather.

6. Recurring Losses from the Past. Ponder and Pomeroy discovered that the primary grief over psychosocial loss resurrects old grief. Relationships lost through death, separation, or estrangement are all mourned anew. For a typical spouse caregiver, we are looking at 60-70 years of losses to mourn all over again. The emotional burden is

[27] See also Lamers, op. cit., and Walker, op.cit.

staggering. Walker confirms that current losses are compounded by former losses, and that too many of them will lead to "bereavement overload".[28]

In her dynamic model for anticipatory mourning, Rando includes past, present and future losses as interactive foci. "After receipt of a life-threatening or fatal diagnosis, the experience of mourning is stimulated by losses that have occurred in the past, and those currently occurring, as well by those to come."[29]

7. Loss of Worldview. Boss adds the loss of worldview to the list of stresses faced by many caregivers. "Ambiguous loss makes us feel incompetent. It erodes our sense of mastery and destroys our belief in the world as a fair, orderly, and manageable place (107)." We begin to doubt our own belief system, a system that would normally sustain a person through crisis. Rando calls this the "assumptive world", the mental schema containing everything a person assumes to be true about the world and the self on the basis of previous experience. "It is the person's internal model against which he or she constantly matches incoming sensory data in order to orient the self, recognize what is happening and plan behavior."[30] A religious assumptive world inhabited by an omnipotent and just God, for example, would be challenged by the apparent cruelty of progressive dementia. The loss of God or a relationship with a higher ideal is, I believe, an indication of intense suffering. The problem of theodicy, after all, is nearly always thrashed about in the godwrestle between justice and insensible anguish. Rando includes

---

[28] Op.cit.
[29] "The Six Dimensions of Anticipatory Mourning" in Rando's *Clinical Dimensions of Anticipatory Mourning*, op.cit.
[30] "Anticipatory Mourning," op.cit.

the sense of personal invulnerability as part of a lost worldview. A caregiver involved with the slowly-dying will often face the terror of their own future aging and death.[31]

All of these secondary losses have a compound effect. Walker observed that each time a loss occurs the grief process begins anew, making completion of the process impossible.[32] This happens because the advent of a new loss leaves the previous one unresolved and incomplete. "As each new loss occurs and the patient spirals downward toward the ultimate loss of death, the grieving process is disrupted and individuals recycle over and over again through the various phases of grief."

Multiple secondary losses can be listed among the stressors that complicate anticipatory mourning. In clinical terms, a stressor is a demand placed upon the human being which requires an adaptational change. Rando listed ten stressors brought about by chronic or terminal illnesses:[33]

1. strained relationships
2. modifications in activities and goals
3. increased tasks and time commitments
4. increased financial burden
5. need for housing adaptations
6. social isolation
7. medical concerns
8. differences in school and work experiences
9. grieving
10. normal development tasks of the family and its members must be

[31] Ibid
[32] Op.cit.
[33] "Promoting Healthy Anticipatory Mourning," op.cit.

played out in atypical context.

By far the most critical and potentially damaging stressors are bookend numbers one and ten above, because these permanently impact familial relationships long after the victim is dead. According to Boss, this danger threatens even the most functional family. "Ambiguous loss can cause personal and family problems, not beause of flaws in the psyches of those experiencing the loss, but because of situations beyond their control or outside constraints that block the coping and grieving processes (7)." The ambiguity itself stresses the family. "Few people, professionals or family members, can tolerate for long being in a situation that is out of their control. The stress is too much. As the ambiguity persists, conflicts increase, not just among family members, but also between the family and clinicians (50)."

Boss notes that ambiguous loss disrupts the family in the following ways (20):

A. It diminishes the number of functioning members, requiring someone else to take up the slack.

B. It confuses family dynamics, forcing people to question their family and the role they play in it.

C. It creates a lack of clarity as to what family rules and rituals should be.

D. It freezes people in place so that they cannot move on with their lives.

Symptoms that affect individuals can "radiate in a ripple effect that impacts the whole family, as people are ignored or, worse yet, abandoned. Families can become so preoccupied with the loss that they withdraw from one another. The family becomes a system with nobody in it (11)." All but one member of my focus group experienced

marital stress due to their caregiver responsibilities and emotional turmoil. In one case it led directly to divorce.

Boss observed that individual family members often have differing views of a loved one's absence of presence. This can lead to anger and conflict (49). Dupuis and Walker made similar observations. Psychosocial death occurs for different family members at different times. This leads to different perceptions about the loved one with dementia, particularly with regards to care arrangements. Individual perceptions may change several times as the condition progresses and, in turn, the nature of the ambiguity experienced by family members may shift over time. These varying and shifting perspectives exacerbate tension among family members and may even result in family crisis.[34] Rachel, for example, found herself battling with her sister over life support measures for her mother. In spite of her mother's advanced directive not to intubate her, she was nevertheless force fed with liquids well beyond psychosocial death. The last five years of her mother's life were agonizing for Rachel, who felt that her mother's dignity had been stripped away completely. "They moved her around like a potted plant," she recalled, "half the time in her room, half the time in the living room." I asked her how things were between her and her sister today. "Things are amiable, but there are sore places in me."

The stress of constantly making life and death decisions for a loved one in hospital hallways and ICUs is, oddly enough, missing from the clinical research papers I surveyed for my thesis project. But it is something every member of my focus group reiterated time and again. The pressure was enormous, and the criteria for making decisions rarely clear-cut, even with duly notarized advanced directives. "There are

[34] Op.cit.

always grey areas not covered by an advanced directive," Carol stressed. "Many times I had to decide whether to give my mother antibiotics. I wanted my mother to be comfortable and at peace. But sometimes my mother had violent hallucinations, and I wondered if she was living a good life in her alternate reality." At one time Carol directed the nursing staff not to give her mother antibiotics and prepared herself for her mother's death, only to see her mother recover and continue her slow descent. Carol feels that family members are thrust into the role of medical ethicists without proper preparation, without a process for making end-of-life decisions. "Calls from the care facility over falls, strokes, bladder infections and fevers became routine," Jaye remembers, "and trauma became normal."

Given the tremendous amount of stress and loss experienced by the intimate caregiver – appropriately labeled "pile-up" by clinicians -- it is hardly surprising that they would likewise experience debilitating emotions. The following selected grief reactions from Figure 1 are particularly acute during the process of psychosocial loss and were specifically emphasized by my focus group.

Anger. Caregivers often feel angry at themselves over their inability to perform to their own expectations; angry at their loved one for negatively impacting their life; angry at relatives who don't seem to be doing their share or don't appreciate the situation; angry at medical professionals for perceived inadequacies or lack of sensitivity; angry at society for lack of material support; angry at religious or social community for isolation; angry at God for abandonment.[35] All members of my focus group experienced anger over their powerlessness in a situation that was hopeless. They were used to "fixing" things, but this was something they could not fix.

[35] Doka, "Introduction" and Ponder and Pomeroy, op.cit.

Guilt. Caregivers often feel guilty for feeling angry; guilty over taking respite or initiating other coping strategies to escape the situation; guilty over possible preventions not taken; guilty over impatient responses to their loved one's behavior; guilty over feelings of ambivalence or fears; guilty over institutionalizing their loved one.[36] Focus group members experienced guilt over how much their loved ones lost and would not want to be in their condition; and over their inability to maintain dignity and respectable appearance within a nursing home.

Anxiety. Family caregivers of progressive dementia victims must cope with the added emotional burden of anxiety over their own future as possible victims of AD or other form of dementia, even if they are aware of the latest findings that deny familial inheritance of dementia. They nevertheless experience an intensified awareness of their own mortality and vulnerability. Part of their anxiety focuses on their children and communal network. Will they be abandoned if they slide into the long night of memory loss?

Denial. Gradual losses are often the hardest to acknowledge, as well as painfully intense. As a defense against this pain, denial can take two forms. The caregiver either pretends that nothing has changed, or that their loved one is totally gone from their lives. The victim is ignored as if dead, no longer visited nor touched, as was the case with Jaye's father.

. "While denial can sometimes be healthy when it helps families to maintain their optimism," Boss observed, "it is harmful when it invalidates or renders people powerless."[37] Denial happens when people are unable to accept their new relationship

---

[36] ibid
[37] Boss covers denial from p85-88

with the "absent" family member. "Such people clearly find comfort in absolute thinking, cutting themselves off completely from a loved one who is still living in order to avoid feeling the loss." Such denial "prevents them from making the most of the time they do have with the loved one, or from sustaining partial connections."

Boss sees both a positive and negative side to denial. It can potentially facilitate a hopeful optimism, which is beneficial short-term, providing a temporary respite from the harsh psychological reality of a potential loss. However, there are serious problems with denial:

1. It prevents transformation of relationship so that all those family members still present can move on.
2. It invalidates the presence of the person still there.
3. It blocks creative options for adapting to unclear losses.

Boss concludes that "...denial ultimately causes more rather than less distress for couples and families facing an ambiguous loss. It invalidates and separates them. Each person is alone in his or her private interpretation of who is absent and who is present (50)."

Depression. The cumulative effect of the above mentioned emotions often leads to symptoms of depression, such as confusion, inability to concentrate, and/or physical signs of stress and grief.[38] In a study on the emotional health of 42 spouse caregivers of AD victims, Lore K. Wright, et at, charted the rate and intensity of depression over time as compared to the general population and to stroke victim caregivers (whose onset of dementia was sudden, rather than gradual). As illustrated in Figure 3, AD caregivers experience significantly higher depression scores than either of the other two groups. 46% of caregivers reported significant psychiatric morbidity, while 45% rated their

[38] Doka, "Introduction" and Ponder and Pomeroy, op.cit.

Figure 3

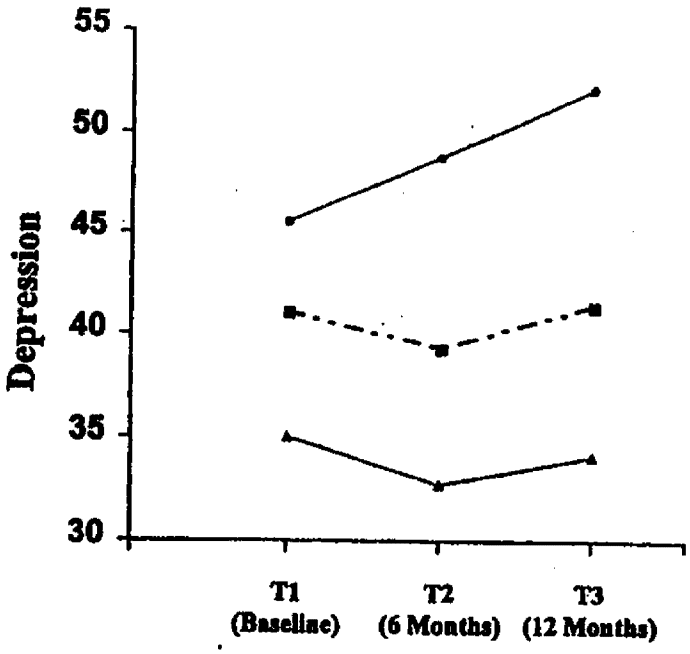


Figure 1 Changes in depression between AD and stroke caregivers. ●, AD caregivers (n = 14); ■, stroke caregivers (n = 7); ▲, controls (n = 11).

physical health as fair or poor.[39] Wright concludes that "AD caregivers' depression warrants attention even in the early phase of the spouse's illness."

In her study of seventy AD patients and their families, Boss pinpointed the source of depression to the ambiguous nature of psychosocial loss. The severity of depression did not correlate with the severity of a loved one's dementia. Instead, it correlated with the degree to which family caregivers saw their loved ones as "absent" or "present"; in other words, the degree to which the relationship is perceived to be lost. "Those with loved ones who were 'there but not there' were indeed more distressed than those who had suffered a more ordinary loss (16)."

To complicate things further for those of us seeking to intervene as professional counselors and clerics, every caregiver experiences loss differently. As Loos and Bowd discovered, grief and secondary emotions associated with psychosocial death are "for each caregiver, intensely personal and individual in their effect. Each caregiver experiencing these losses does so in an unparalleled manner." According to Rando, a number of physiological and psychological factors determine the individual course of grief for each caregiver, including physiological and psychological factors, personal characteristics of the mourner, type of illness and manner of death.[40] She observes that sometimes varying factors can actually lead to positive emotions during the course of progressive dementia. Depending on personality and circumstance, caregivers can experience a heightened sense of being alive, of life's preciousness, of routine daily

---

[39] "Emotional and Physical Health of Spouse Caregivers of Persons with Alzheimer's Disease and Stroke" in *Journal of Gerontolotical Social Work* v22(3/4) 1994. Supportive documentation cited in this article include Draper BM, et al, "A Comparison of Caregivers for Elderly Stroke and Dementia Victims" *Journal of the American Geriatrics Society* 40(9), 896-901 1992; Reese DR, et al, "Caregivers of Alzheimer's Disease and Stroke Patients: Immunological and Psychological Considerations" *The Gerontologist* 34(4), 534-540 1994; Prucho RA, et al , "Mental and Physical Health of Caregiving Spouses" *Journal of Gerontology* 45(5) 192-199 1990.

[40] "Six Dimensions of Anticipatory Mourning," op.cit.

events. They may interpret increased emotional involvement with their loved one as a welcome increase in intimacy. They may be carried along by a hope sustained by existential interpretation of suffering.[41]

My focus group added down-to-earth humor as a positive coping mechanism. "Without it, I would have gone stark raving mad," Carol told me. She gave me some examples. "When she took her teeth out and flushed it down the toilet; when she took lipstick and put war paint on her cheeks; when she decided she wanted her room to herself so she moved her bedridden roommate out into the hallway along with all her belongings; when she played practical jokes, something she did all her life." Joyce found emotional respite in the way her mother could fool everybody about her condition through sheer programmed social etiquette and cheerful charm. "She seemed to know all the socially appropriate questions and responses that people would ask her. And she would sit out there in the lobby of the nursing home and greet people as they came in. They would sit down and talk to her and have no idea that she was a resident there. Even her doctor said there were times when she almost fooled him." Both Joyce and Carol emphasize that these were occasional "sparks" of light during the long night of vigilant care and emotional drain. The point is that each case is highly unique, and each caregiver responds differently at various times in their on-going role. Their situation is complicated and so is their response to it.

As overwhelming as the multiple factors above may seem, there are a few bereavement tasks common to all caregivers. It is these tasks that I can specifically address as a rabbi.

---

[41] "Anticipatory Mourning: A Review," op.cit.

Bereavement Tasks

There are a great many models for bereavement in the clinical world. The most helpful for me in terms of overall assessment and intervention strategy is Rando's "Six 'R' Processes of Mourning".[42] My elaborations are in brackets:

1. **Recognize** the loss

    *Acknowledge the loss

    *Understand the loss

    [Secondary losses would also need to be identified and recognized]

2. **React** to the separation [or loss of relationship]

    *Experience the pain

    *Feel, identify, accept, and give some form of expression to all the psychological reactions to the loss

    *Identify and mourn secondary losses

3. **Recollect** and reexperience the [lost relationship]

    *Review and remember realistically

    *Revive and reexperience the feelings

    [Some form of memory retention of loved one before illness]

4. **Relinquish** the old attachments to the [lost relationship] and the old assumptive world

    [Give up unrealistic expectations, hopes, dreams and/or plans for the future with the loved one]

5. **Readjust** to move adaptively into the new world without forgetting the old

    *Revise the assumptive world

    *Develop new relationship with the [loved one]

---

[42] "Six Dimensions of Anticipatory Mourning," op.cit.

*Adopt new ways of being in the world

*Form a new identity

6. **Reinvest** [Form new relationships which are supportive and reciprocal]

Included in another Rando model, "The Six Dimensions of Anticipatory Mourning", are a set of "generic operators" which serve as a useful extended checklist of bereavement tasks:[43]

1. Grief and mourning: Experiencing and expressing the psychological, behavioral, social and physical reactions to the perception of loss.

2. Coping: Actively encountering a stressor in a dyamic attempt to contend with it in one of three functional ways:

a. Problem-focused: managing or altering the situation through problem-solving

b. Emotion-focused: regulating emotional response to the problem through such activities as physical exercise, meditation, having a drink, venting anger, taking respite or seeking emotional support.

c. Appraisal-focused: seeking a pattern of existential meaning in the crisis.

3. Interaction: engagement with another person in which there is mutual or reciprocal action. Restructuring social network.

4. Psychosocial Reorganization: making the psychosocial changes necessary in order to respond to the reality of the situation. This involves cognitive adjustment, role redistribution, and adaptation to the altering status of the loved one and to life in general.

5. Rehearsal and Socialization: Rehearsing the role of bereaved, which means partially living life without the loved one.

6. Planning: Planning in detail for the death of the loved one and for life afterwards

[43] Ibid.

7. Balancing conflicting demands: Consciously dealing with the conflicting demands inherent in anticipatory mourning. These conflicts were addressed earlier in the chapter.
8. Facilitating a "good" death for the loved one: Determining what a "good" death might be from one's own perspective, as well as that of the loved one.
9. Systemic management: Constructively navigating conflicts between family members, between family and medical caregivers, between other social and organizational groups.

If this seems like an overwhelming list of tasks for mourners to complete on their own, the authors of the research papers I reviewed for my thesis would grimly agree. Even under the best of conditions, intervention is not only desirable, but critical for both individuals and family networks navigating their way through the difficult and bitter waters of ambiguous psychosocial loss.

Chapter Four
"A Two-Phase Model for Rabbinic Intervention on Behalf of Caregivers"

We are loved by an unending love.
We are embraced by arms that find us
even when we are hidden from ourselves.
We are touched by fingers that soothe us
even when we are too proud for soothing.
We are counseled by voices that guide us
even when we are too embittered to hear.
We are loved by an unending love.
We are supported by hands that uplift us
even in the midst of a fall.
We are urged on by eyes that meet us
even when we are too weak for meeting.
We are loved by an unending love.
Embraced, touched, soothed, counseled ...
Ours are the arms, the fingers, the voices;
ours are the hands, the eyes, the smiles.
We are loved by an unending love.
---Rabbi Rami Shapiro

The following page outlines my two-phase model for rabbinic intervention, a coherent response to the pastoral needs of those suffering the incremental psychosocial loss of a loved one. The remainder of this chapter is an elaboration of my intervention protocol.

Two Phases: Mort pointed out to me that caregivers initially need immediate practical help, not necessarily sustaining spiritual guidance. They are often overwhelmed by logistical nightmares and transitional upheaval of family structure. Phase One is crisis management, a concerted effort on my part to mobilize resources that will help a caregiver gain mastery of their new reality as quickly as possible. Once order is imposed on this chaos for a period of time, the issues covered in Chapter Three began to take their toll on our caregiver. This is the time to then move into Phase Two, on-going support. Both Mort and Carol, long-time veterans of synagogue life and leadership, offered

valuable advice on how to manage my pastoral duties without neglecting my other responsibilities as a congregational rabbi. I call Mort and Carol my "dynamic duo" (ala "Batman," my favorite childhood adventure series). My two-phase model is a synthesis of clinical intervention strategies and input from my dynamic duo.

Questions to ask myself: These questions are meant to keep me "on track", focused on what I ought to be doing for the caregiver so that I can meet their needs without neglecting other aspects of my rabbinate.

1. What is my role in the life of a family caregiver?
2. What can I delegate or refer to others so that I can fulfill my role?

How I see my role: My answer to the above questions are distilled down to three main roles a rabbi is uniquely qualified to fill:

1. Mobilizer
2. Pastoral counselor
3. Liturgical enabler

Everything in Phase One and Two of my model plugs into one or more of these roles. As the head of a religious community, I am in a position to mobilize communal and peer support for the caregiver. I presumably have on-going relationships with medical, social and mental health professionals as well. And, as I discovered with my experience with the "Levitz" family, I have some moral authority by which to mobilize practical and moral family support for the caregiver, as well as to arbitrate family discord which normally occurs during the course of progressive dementia. I see my role as a pastoral counselor in terms of active listening, reassurance, blessing and mentoring within the context of Jewish tradition. I am not a social worker, psychologist or a marriage

counselor. These roles, I feel, are better met by those professionals trained in these areas. Most relevant to my thesis project, I am a liturgical enabler of emotional and spiritual expression within Jewish tradition, in this case of grief in the face of psychosocial death. The rabbi ideally enables the caregiver to gain peace of mind and strength through prayer, lament and ritual -- both private and communal.

Phase One: Crisis Management

Intervention begins with awareness of need, which may come by way of a call from congregant, family member, social services professional or caregiver.

1. Pastoral Visit

Reflective Listening: Discussing the situation thoroughly with a rabbi is enormously therapeutic in and of itself. Caregivers receive needed validation, recognition, empathy, venting opportunity, communal connection and a mechanism for organizing conflicting grief reactions and stresses into something coherent and understandable. Creating a narrative, which in and of itself imposes order onto chaos, also begins to create a dreamscape from which ritualizing material can be created at a future date and into which a ritual experience can be integrated. This happened naturally with my "Levitz" family. The raw materials welled up from family narratives, while the final ritual gathered everything and everyone up into a transformative experience. As a former journalist, I am naturally inclined to open up the narrative with the standard questions of a news reporter: Who? What? When? and Where?

Who is afflicted?

What happened? What is happening to them? to you? to your family?

When did it start happening?

Where did it start? Where is your loved one now?

Assessment: There are a number of clinical tools available for assessing the needs of caregivers, their afflicted loved ones, and their families. I selected those which are "user-friendly" for rabbis and which seem to be the most effective in achieving my goals for assessment, namely to validate and calm the caregiver, and to determine specific practical needs which can be met through referrals and community resources. Appendix #1 contains four assessment tools for a comprehensive understanding of caregiver needs, family dynamics and the situation in context:

"Pastoral Assessment in the Care of Progressive Dementia" is an instrument I developed based on research represented in Chapter Three, as well as my experience with the "Levitz" family. This can be formally filled out during the visit or completed afterward based on observation and narrative. I prefer the later.

The next three instruments are to be filled out by the caregiver while the rabbi, if logistically possible, visits with the afflicted one. I selected the first two and created the third as primarily validation and mental organizing tools for the caregiver. If they can find themselves in these simple questionnaires, they can be instantly reassured that their experience is "normal", and that there are resources for them in the professional world. These instruments will hopefully prepare them for Phase Two experiences, and so alleviate a great deal of present and future anxieties. These instruments serve the secondary purpose of alerting me as to what kinds of emotional and practical support they need from me. These questionnaires are meant to be reviewed by rabbi and caregiver together:

- "Marwit-Meuser Caregiver Inventory"[1]
- "Five Dimensions of the Human System: Common Grief Reactions", also Figure 1 in Chapter Three[2]
- "Treseder Secondary Loss Inventory" (2005)

Blessing and Reassurance: A caregiver is given reassurance that they are not alone in their time of crisis, and that they have a community that will respond to their stated needs. The visit ends with prayer and/or blessing if the caregiver so desires.

2. Delegation and Referral

Point person among lay members: Mort suggested that a lay member, perhaps someone on the Mitzvah Committee, volunteer to educate themselves on dementia among the elderly, and to act as a resource person for the caregiver. In fact, he thought it would be a good idea to solicit volunteers for each of several types of human crisis, so that as a rabbi I would have a pool of experts and mentors to help me meet the pastoral needs of everyone in my congregation. I think this is a great idea and I plan to implement it. Given what I learned from ritual theory (represented in Chapter Five), such a point person should, if possible, be a surviving caregiver of a demented loved one. This person would contact the new caregiver with information, resources, and a mentor (if not themselves, then another member of the community who is a surviving caregiver). The point person would also organize a network of people in the community who can assist in such things as transportation, meals, and respite. A point brought out in my research in

---

[1] developed by T.M. Meuser and S.J. Marwit (2004). From "Assessing Grief in Family Caregivers" in *Living with Grief: Alzheimer's Disease*, Kenneth Doka (ed.) Hospice Foundation of America: Washington, DC.

[2] developed by Lore Wright, et al, as an adaptation of materials presented by M.A. Ryan (1993).

ritual theory, and warmly confirmed by members of my focus group, is the benefit that surviving caregivers derive from nurturing new caregivers. Joyce, Carol and Jaye told me independently, on their own, that they could imagine themselves leading a support group and acting as a point person for caregivers in the Jewish community. "We are natural caregivers," Jaye told me, "This would be so healing for both of us" (both caregiver and caregiver survivor).

Information is an important solution to the anxieties of ambiguity. But it must be delivered in small doses during the crisis phase of intervention. The information that the point person gives to a caregiver in the midst of chaos should be simple and confined to the current condition of their loved one. Too much information can backfire, as it did for two members of my focus group. When her mother was diagnosed with AD (even though she actually had DLB), Rachel called the local AD association. They terrified her with too much information and advice related to late-stage AD. It further spiraled her anxiety beyond rational processing of the situation. She never called them back. Joyce likewise felt too overwhelmed by the avalanche of caregiver tasks, as well as financial and legal responsibilities, to process reams of clinical materials. "Reading and gathering information can add to the stress," she asserted. "You have no concentration because of your emotional state. And you begin looking for symptoms that may never happen." She shared with me two aphorisms given to her by an oncologist about facts. One recognizes the need for information, the other qualifies the information:

"If I understand, I can cope."

"Those numbers represent other people, not you."

A good book to give out during Phase One -- and recommended by everyone in my focus group -- is *The 36-Hour Day*, by Nancy L. Mace and Peter V. Rabias, a practical handbook for family caregivers of AD written in simple, reassuring language, with user-friendly lists of resources and social services. Most of the guidance can be applied to other types of dementia as well.

Professional resources: Either the rabbi or point person contacts appropriate resources, such as social services, medical and mental health professionals.

3. Family Meeting

The purpose of a family meeting is to share information on their loved one's condition, to distribute caregiver tasks as widely as possible in order to relieve the primary caregiver, to engage in constructive emotional processing, and to prevent or arbitrate familial conflict. The meeting should be highly structured, because families thrown into chaos need structure. A simple agenda worked well for me when I conducted a family meeting for the "Levitz" family. It put them into a problem-solving task mode, a great way to alleviate feelings of powerlessness that can overwhelm a family following a diagnosis of dementia. The agenda does not have to be complicated:

I. Medical update

II. Clarification of needs (based on assessment visit)

III. Delegation of tasks

IV. Family member perspectives

V. Framing within Jewish tradition

My research in clinical intervention strategies and techniques helped me to internalize an appropriate approach to pastoral family counseling.

Lebow articulated the goal of intervention with the family prior to the death is "not to loosen emotional bonds, as is appropriate later (i.e. after the death), on the contrary, it aims at increased involvement balanced with individuation."[3] He identified six adaptational tasks for a family unit when one of its members is afflicted with progressive dementia:

1) Remain involved with their loved one.
2) Remain separate from their loved one.
3) Adapt suitably to role changes.
4) Bear the affects of anticipatory grieving.
5) Come to terms with the reality of the impending loss.
6) Say good-bye to the dying person.

Boss identified open communication and willingness to compromise as key attributes of families who are most successful in dealing with ambiguous loss. "Family members hear one another out and remain respectful of the opinions of their loved ones. *They resolve to attack the problem and not one another* (103)." Individuals in such families seek to overcome the security of known misery by seeking change, reaching out, breaking their isolation, interacting with others in their family and community, talking, disagreeing and compromising. Rando agreed that effective communication is vital to family mastery during times of severe illness and disability, "..communication cannot regularly be left unclear or unresolved without pathological consequences or possible dissolution of family relationships."[4]

Boss' counseling strategy is a preventative one, designed to help families manage their lives and communicate effectively with one another despite the ambiguity of psychosocial loss. She begins with a set of assumptions:

---

[3] Cited in Rando's "Anticipatory Mourning: A Review", op.cit.
[4] "Promoting Healthy Anticipatory Mourning," op.cit.

a. *Stress is simply caused by external change or the threat of change.* Family distress is normal within the abnormal context of ambiguous loss. Families are more open to intervention if the cause of their stress is framed as an external pressure, rather than an internal dysfunction.

b. *People can learn to recover and thrive by learning how to manage the stress.* Persistent distress is not good for any individual or family, but it can be managed.

c. *Information should be shared with families.* Shared knowledge empowers families to take control of their situation even when ambiguity exists.

d. *Ambiguous losses can traumatize.* Symptoms of unresolved grief are similar to Post Traumatic Stress Disorder.

With these assumptions in mind, Boss described her counseling strategy in non-linear form (pp109-117), which can roughly be summarized as follows:

1) *Provide a safe holding environment, a place to sit and talk together.* Family members are encouraged to talk together, sharing information, perceptions and feelings, eventually coming "to a concensus on how to celebrate the part of their loved one that is still present and mourn the part that is lost." Help family members become aware of one another's interpretations of the experience of loss, and to determine if there is some measure of agreement about how they see the situation, recognizing and respecting their different perceptions.

2) *Label the experience as an ambiguous loss.* Provide as much information as possible about the kind of loss they are experiencing in order to minimize denial and enable them to begin making some choices and decisions. Known as the *psycho-educational approach*, it helps to unfreeze the coping process.

3) *Initiate the development of a plan of action.* Problem-solving activity is an effective coping mechanism for families faced with ambiguous loss. Such planning could include identifying possible sources of formal and informal support, medical assistance and various response options to future crises. I would add the planning of ritual markers of loss and continuity.

4) *Encourage ongoing family meetings.* Even if professional help is recruited, these should be called "family meetings", not "counseling sessions", because the family is not dysfunctional, only stressed by external circumstances.

5) *Manage conflict.* According to Boss, conflict is inevitable. It can be managed by reminding family members to attack the situation (or God, if necessary) but not one another, and by encouraging continual intrafamilial communication.

6) *Elicit family narrative and family rituals.* The family is thereby constructing both unity and meaning. I would add that this is where humor can be pulled out for emotional respite. Part of this discussion would be ways in which existing rituals can be modified to accommodate the altered role of the afflicted member.[5] Neimeyer also stressed the need for family rituals, as well as biographical projects shared by family members. These serve to help family members recognize continuity between them and the lost loved one.

7) *Encourage periods of rest or escape.* Whether they take turns caring for their afflicted member, or arrange other care while the whole family takes off, it is important for the mental health of both individuals and the family unit as a whole.

---

[5] Boss insists that any family can learn to change its rituals to accommodate changed circumstance. It may be difficult, "but my work has taught me that everyone, no matter the age, can change if they want to and that they are relieved to learn they can revise cherished family traditions instead of giving them up altogether." p108

8) *Frame the aging and dying of their loved one as part of the natural cycle of life.* As mentioned above under individual counseling, such framing gives meaning to loss. Part of this process is learning to combine spiritual acceptance and mastery.

When family, community and professional support is set in place, and a fairly stable routine established, the caregiver can then decide when they are ready for more sustainable, on-going support from their rabbi and community.

Phase Two: On-Going Support

The goal of pastoral care during this period of time is to sustain the caregiver through a long and difficult period of uncertainty, multiple losses and grief.

1. Mentoring the Caregiver

Because of the nature of her work and religious community, Rachel is surrounded by rabbis. But she did not have a rabbi who was specifically *her* rabbi during her six-year death-watch over her mother. Quoting the poet Samuel Taylor Coleridge, she said, "Water, water everywhere and not a drop to drink." In retrospect, she simply did not know what to ask from a rabbi. So she didn't. Hindsight now tells her what she would have wanted from her rabbi: comfort, truth-telling, and reassurance that she was doing everything she could do. All three of these needs can be met through mapping, emotional processing, respite and facilitating a "good death" for a loved one.

Mapping and journaling: One thing I can do for caregivers is to help them map their progressive loss in incremental steps. This strategy breaks up the fog of ambiguity and imposes a kind of logic sequence to the often unpredictable and seemingly endless

ordeal. Each step represents a definite loss with corresponding adjustments in routine, life style and set of coping strategies. Boss gives an AD example, based on the mapping worked out by one of her clients. "John" drew his simple stairway representing the eight steps of his wife's deterioration, each step also a point of great emotional pain for him:

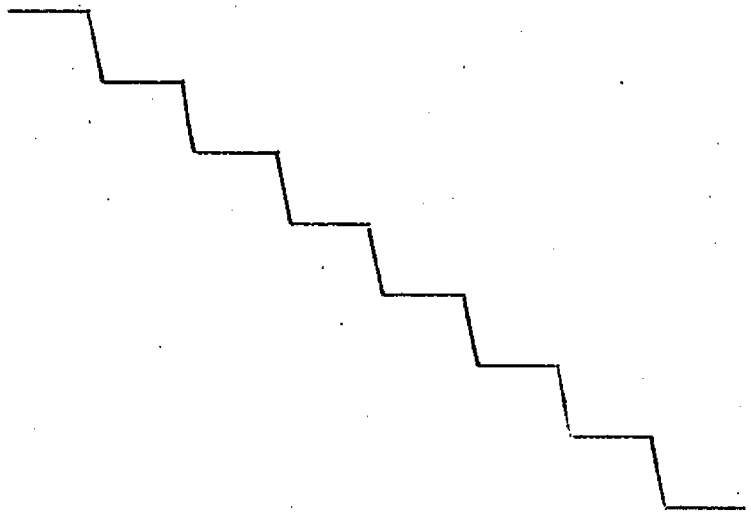
Step One:	She lost her way in her own house
Step Two:	They could no longer take trips
Step Three:	She began wandering at night
Step Four:	She became incontinent
Step Five:	She almost died of pneumonia
Step Six:	She no longer recognized her husband
Step Seven:	They inserted a feeding tube
Step Eight:	She died

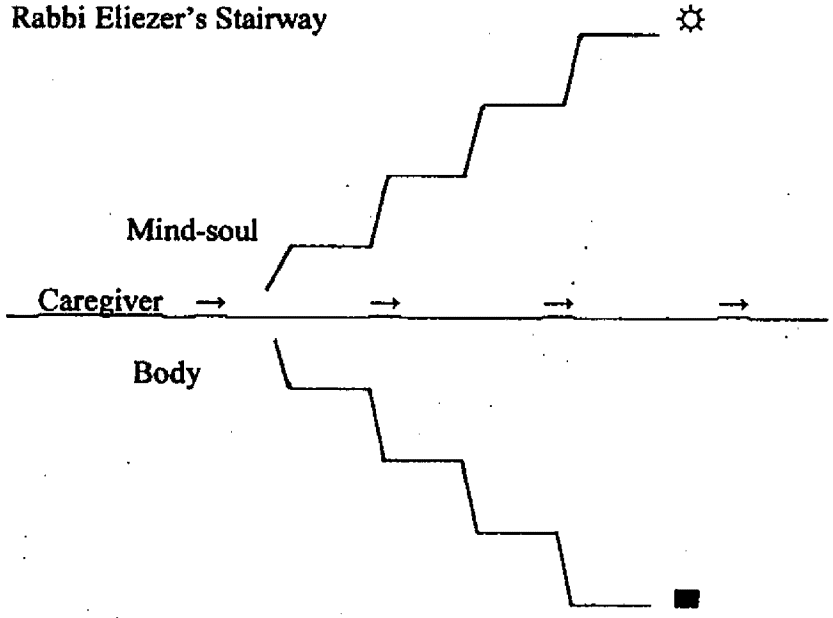
Boss regarded John's mapping strategy as a healthy way to manage ambiguous loss, "...coping with a disease like Alzheimer's need not be devastating. John faced each crisis, made decisions to bring it under control, took respite and recreation during the calmer periods, and continually accepted help from his neighbors and community (79)."

I noticed that John also composed a narrative journey alongside his visual step map. He pulled his experiences together into a "story" that put sense into an otherwise senseless tragedy. I modified John's step map to reflect the rabbinic teaching that when we die we return to that from which we came: the body to dust, the soul to the living God.[6] See Figure 4. With this revised stairway map caregivers can imagine not just the downward decline of their loved one, but a simultaneous upward leave-taking that envisions a lofty place for the essence of the psychosocial personality most grievously mourned. It also helps to transition the anticipatory mourner into conventional mourning with a consistent, continuous metaphor. My focus group members gravitated to one or the other of these stairways, depending on their perception of the truth regarding their

[6] Ecc. 12:7; Perkei de Rabbi Eliezer ch.34 (Trans. Gerald Friedlander)

Figure 4


John's Stairway


Rabbi Eliezer's Stairway
Mind-soul
Caregiver
Body

loved one's deterioration. I recommend presenting both stairways and allowing the caregiver to choose the one which works for them, particularly since the act of making a choice of any kind helps to further empower the caregiver to order their world.

Emotional processing: Boss takes a dialectic approach to emotional processing. She helps her clients to frame their loss, redefine their hope and construct meaning for their experience. Aging and mental deterioration are viewed differently by North American Indian women, she tells her clients. The Anishinabe women, for example, cope with the care of an elder with dementia by combining mastery of the situation with a spiritual acceptance of the illness. "They believed that life is a mystery that they must embrace and give themselves to willingly (17)." Though the example of Anishinabe women may not work with a Jewish caregiver, I *can* frame psychosocial loss within Jewish tradition, drawing from the many textual resources detailed earlier in Chapter Two (see Primary Texts in bibliography), where life stages account for aging, dementia and death as natural processes of creation and life. Elders, in this case, are to be honored even when their Torah of memory fades away. They are entitled to respect. And their caregivers are likewise entitled to respect as *shomerim*, or guardians, of their loved ones.

An article by Rabbi Nancy Flam frames the role of the caregiver in a number of elevating ways. The one which best fits the caregiver of a demented loved one is that of a holy vessel. "Another image that can help us remember our role is to think of ourselves as striving to be *klei kodesh*, vessels for the Divine. We are vessels for God's love and care, servants to the Divine."[7] Elevated framing like this is important, according to Flam, because "one essential element in taking care of ourselves as care providers is to make

---

[7] "Spiritual Nurture for Jewish Pastoral Caregivers" in *Jewish Pastoral Care: A Practical Handbook from Traditional and Contemporary Sources*, ed. Rabbi Dayle A. Friedman (Jewish Lights Publishing; Woodstock, Vermont) 2001

sure that our conceptual understanding of ourselves and our work is a good one. The images we hold of ourselves as care providers influence the way we work, and in so doing, contribute either to our spiritual health or to our depletion and burnout." Although she is speaking to rabbis, this concept applies equally well to Jewish family caregivers.

After framing the situation, Boss helps her client redefine their object of hope. She moves them from denial to reluctant acceptance. Ways of finding hope may include creatively managing the illness, helping others who are experiencing the same pain, preventing others from having the same experience, working for a "good death" without pain for their loved one. "As long as there is optimism and hope," Boss writes, "continuing to work on a relationship with someone who is slowly dying can be a kind of victory (125)."

Boss then encourages her client to construct meaning for their experience. Boss says the clues for doing so come from the family of origin and early social experiences, including religion. "Families are the first place we learn about the rules, roles, and rituals for making sense out of loss." Boss sees rituals and celebrations as sources for clues about a family's tolerance for ambiguity, as well as a likely source for ritual construction. She also looks to storytelling. "Families tell me that old stories filled with rituals, symbols, and metaphors are helpful when they are struggling to make sense of an ambiguous loss (130)". My focus group volunteered their need for stories that connected them with Jewish tradition -- stories, like those presented in Chapter Two, about grown children and spouses dealing with demented loved ones. They wanted these stories to be told at opportune times during support group processing.

Rosemary Blieszner and Robert A. Neimeyer facilitate closure through imaginative communication with a third party, either the loved one lost or with God.[8] Blieszner instructs her clients to finish the statement, "If I could talk to her/him now..." either in writing or verbally with the counselor as proxy. Neimeyer sets up conversations that are either *self with self* using the gestalt two-chair technique; or *self with Transcendent Reality* involving prayerful questioning, personal spiritual journaling, conversations with trusted clerics. These dialectic techniques are all excellent means of processing psychosocial loss.

Nurturing self along with loved one: A caregiver ought to be reminded continually to take respite, beginning with the family meeting in Phase One. Along those same lines they should be encouraged to accept eldercare from family members, friends and community in order to renew themselves so that they can better fulfill their role as a guardian for their loved one. Lam's advice to rabbis apply well to family caregivers as well: "Not only do we need proper rest, but we need to engage in other kinds of activities -- movies, books, socializing and so forth. We must organize our lives to leave room for rest, recreation and exercise ... We need food, exercise, friendship, love, learning, fun, prayer and laughter." She frames the need for spiritual nourishment within the holy vessel metaphor. "It helps to build in regular times for prayer and meditation, for connecting with one's intimate friends, for walks in nature, for spiritual direction, for massage, for exercise. Our personal combination of such habits and commitments keeps the flow of divine abundance, moving through us."

---

[8] Blieszner, "The Effects of Alzheimer's Disease on Close Relationships between Patients and Caregivers," in *Family Relations* v39 Jan. 1990; Neimeyer, "Disenfrachisement as Empathic Failure: Grief Therapy and the Co-Construction of Meaning," in Doka's *Disenfranchised Grief*, op.cit.

Facilitating a "good death" for a loved one: Helping family caregivers facilitate a "good death" for their loved one is not only a moral and ethical imperative, but critical to healthy post-death mourning and long-term spiritual and mental health. Rando says this is an important component of anticipatory mourning:

> If an appropriate death can be enabled by a survivor-to-be for his or her dying loved one, than that same individual's anticipatory mourning will be more positive and in turn, postdeath adaptation will be facilitated. This is the case because those criteria identified to promote an appropriate death for a dying person also nurture healthy anticipatory mourning in survivors-to-be. Correspondingly, individuals engaged in healthy anticipatory mourning are better able to foster appropriate deaths for their loved ones.[9]

Generally speaking, Rando says, a good death is a death one might choose for oneself if a choice were possible. Karen Steinhauser gathered descriptions of the components of a good death from 75 participants in her study, which included terminal patients, recently bereaved families, physicians, nurses, social workers, chaplains and hospice volunteers. She distilled their input into six components of a good death:[10]

1) *Pain and symptom management.* Although 40-70% of Americans experience substantial pain in the last days of their lives, no one wants to feel pain when they die.

2) *Clear decision making.* The dying one feels that they are in control of their own dying.

3) *Preparation for death.* The dying one is ready to die.

4) *Completion.* The dying one views their current experience as part of a broader life course trajectory. They have also made peace with people in their intimate circle and said good-bye.

---

[9] "Six Dimensions of Anticipatory Mourning," op.cit.
[10] "In Search of a Good Death: Observations of Patients, Families, and Providers" in *Annals of Internal Medicine* v.132(10) 2000 pp825-32.

5) *A sense of meaningful contribution to others.* They feel that they have made a difference in other people's lives during the course of their own.

6) *Affirmation of the whole person.* They die with a sense of human dignity and worth.

Although this list reflects a patient's perspective, which may be irrelevant for someone who is already psychosocially dead, it is important that intimates of the dying perceive that these conditions are fulfilled. A "good death" for a loved one means that her dying was painless; that family concensus was clear and united regarding end-of-life decisions; that it was time for their loved one to die; that they had completed unfinished business with their loved one at some point in time; that their loved one would be remembered and honored by others; that their loved one was affirmed as a whole person by medical professionals and clerics. Members of my focus group emphatically agree.

I would add Lamer's condition of presence of intimates at or near the time of dying. As his study affirms, the two things people fear most about death is dying in pain and dying alone.[11] We want to die surrounded by those who love us. Being present in the end goes a long ways towards achieving peace of mind regarding the death of a loved one. In the frequent case when sudden, unexpected death or other unforseen circumstances prevents the primary caregiver from being present at time of death, we can offer this mourner reassurance that they were there when it counted -- during the long months or years of slow, incremental mental and physical dying. Lamers concludes, "The positive impact of observing and participating in the excellent care of a dying person cannot be overemphasized. It assures family and friends that their efforts have been worthwhile, that they have truly assisted the dying person in a meaningful way, and

[11] Op.cit.

that the act of dying has been transformed into a positive experience for all involved. Survivor grief is attenuated because of an awareness that all was done that could or should have been done. Further, involvement in such an experience provides a model for approaching other deaths in the future, including one's own."

2. Periodic pastoral visits with loved one

According to members of my focus group, the most comforting thing a rabbi can do personally is to visit their afflicted loved one. Regardless of mental condition or inability to interact, the visit I am paying to an AD victim is also a pastoral visit with the family caregiver, regardless of whether the caregiver is physically present or not. Caregivers previously involved in synagogue life have the additional need to feel a reciprocal relationship with the rabbi who, in many respects, acts as proxy for their invisible community. So for example, both Carol and Mort enumerated their service to the community as part of their narrative. Each felt that they had earned the care and attention of their rabbi during their time of isolation and grief. Mort was gratified that his rabbi took him out to lunch on occasion before visiting Mort's afflicted wife, taking pride and comfort in the fact that he had a real friendship with the most respected member of the community. Carol, on the other hand, felt deeply betrayed by the lack of involvement of her rabbi during the long years she cared for her mother. The lack of rabbinic support became a disappointing secondary loss for her to bear. Besides the personal devaluation a caregiver feels when their rabbi fails to visit their loved one, they may also feel shame. In Carol's case, the one visit her rabbi made to her mother's nursing home -- a Catholic-run facility -- was embarrassingly short and cold. Though she was not present, the nursing staff -- most of whom were nuns -- expressed surprise by his "walk-through and

made comparisons between him and other (non-Jewish) clerics who visited residents regularly and for longer periods of time. Carol felt shame for her religion, her people, her rabbi and for herself as a Jew.

All focus group members emphatically asserted that visiting the sick is inherently part of being a rabbi.

3. Religious services at the care facility

This is something that can be organized among congregants -- a Shabbat Comes to You. Such on-site services were important to all members of my focus group. Victims of dementia, for the most part, respond positively to religious ceremony. "My mother happily sat through every religious service of every denomination that went through," Jaye remembered. "And if the rabbi could go and say a few prayers and participate, whether it would be every six weeks or whatever, but occasionally go the nursing homes and conduct a brief service, that would be wonderful." Carol joked, "My mother likewise went to any and all services. It was all I could manage to keep the communion wafer out of her hands."

Carol told me about an interactive respite video called "A Kibitz with David," produced by Innovative Caregiver Resources, in which a young family performs a Friday night Shabbat ceremony as though the viewer were present.[12] Her mother responded happily, and Carol feels that it gave her mother peace for that period of time. Joyce told of a time when she played this same video to the entire AD unit. Everyone enjoyed it, including Joyce herself. This confirms ritual theory which documents the peace and

[12] University of Utah; Salt Lake City, UT. 1993. I subsequently bought this video as part of my pastoral tool kit.

respite viewers enjoy when they participate in or even just witness familiar rituals. As mentioned in Chapter Two, including the elderly in community services, celebrations and life-cycle events, regardless of mental functioning, is part of the *mitzvah* to honor the elderly. Both contemporary research and ancient wisdom confirms the value of participation in the ritual life of the community as therapeutic for caregiver and loved one alike.

4. Support Group

My focus group unanimously advocated a Jewish support group held at the synagogue and attended, if not facilitated, by the rabbi. Although all four are veterans of at least one AD or Dementia caregiver support group and two are not religiously affiliated Jews, they all expressed the need for such a group during their ordeal. At least for members of my focus group, the synagogue itself is associated with peace and comfort, while the rabbi is associated with Jewish tradition and community. More importantly, the largely Christian answers to existential anguish and loss frequently discussed in generic support groups are not helpful to Jewish mourners. These caregivers wanted a support group that felt Jewish, that felt like a "home" where they belonged. In my "Levitz" family, the primary caregiver repeatedly expressed the need for "someone like me to talk too." If there had been a support group available for her, I would have placed her in it immediately.

Eileen McKeon Pesek stressed the benefits of a support group for people dealing with loss of any kind: "Support groups can be an especially effective intervention because they provide the opportunity for the griever to make public what he or she feels

must remain private elsewhere. An antidote to disenfranchisement, they can be a safe haven, a place to obtain recognition, understanding and support."[13] She outlined five benefits of support groups:

1) Validation of losses
2) Suggestions for coping
3) Hope from others who are at different points in their grief journey
4) Enhancement of self-esteem through helping others
5) Safe environment to express grief

Pesek points out that a support group is also a cost- and time effective method for providing support and counseling to many people.

My focus group put the need for a support group at the top of their list. Reviewing the pastoral needs of grieving caregivers against Pesek's work, I can understand why this would be the case. Uncertainty and social isolation are the top two stresses in the case of progressive dementia. A support group not only becomes a resource for information and social interaction, it becomes a place for empathetic response, validation, story-telling, emotional expression, and problem-solving. A Jewish support group held in a synagogue and facilitated by a rabbi also opens the possibilities for ritual expression, framing within Jewish history and tradition, and validation from a religious authority representing the larger communal "family."

5. Community validation

Social isolation is the number two stressor for caregivers of victims of progressive dementia, next to uncertainty. Although most clinicians noted the problem, only

---

[13] "The Role of Support Groups in Disenfranchised Grief," in Doka's *Disenfranchised Grief*, op.cit.

Neimeyer[14] had suggestions for communal bridging. He gave two. First, prevent disenfranchisement and empathic failure through community education. In the context of a rabbinate the issue can be addressed in a sermon, panel discussion, adult education course, board meeting and casual conversation. Second, create "communal rituals that affirm shared losses through symbolic action" -- my thesis project. My focus group decided that a Shabbat service dedicated to caregivers, as well as an on-going *mishebeirach* prayer for caregivers would have been enormously comforting to them.

Follow-up

Beyond death we find ourselves on the familiar, well-trodden paths of Jewish tradition and grief counseling, beyond the scope of my thesis. I would only add that the eulogy delivered at the funeral ought to educate attendees about the deceased's previous psychosocial death, as well as some reference to the long grieving period experienced by survivors who are likely feeling relief along with sorrow. The eulogy should honestly reflect a family's state of mourning, which may otherwise be deemed inappropriate by their community. In addition to life review and framing within tradition and history, the eulogy should validate end-of-life decisions and recognition of devoted care.

Ritual Expression as a Component of Pastoral Intervention

As noted throughout this chapter, ritual expression can be utilized in nearly every intervention strategy. Chapter Five is entirely devoted to ritual theory and construction, but it is worth taking a look at what health professionals have to say about ritual and its potential role in facilitating bereavement tasks.

---

[14] Op.cit.

Doka defines ritual as "highly symbolic acts that confer transcendental significance and meaning on certain life events or experiences."[15] His definition "allows the possibility of both collective and individual acts, as long as such acts give meaning to an event or experience ... Rituals allow disenfranchised grievers to name and own their losses ... Rituals provide structure. They offer opportunity to contain and express emotion. Rituals allow a community to come together to witness and interpret an event." Rituals make excellent therapeutic tools, "incorporating many elements of therapy: legitimizing emotional and physical ventilation of grief, allowing a sense of experiencing or doing, channeling emotional catharsis, offering a structure for events fraught with ambivalence (e.g., anniversaries), allowing individuals to reframe events or experiences, and offering support and symbolic mastery." Rituals also transcend time. "They can mark distinct points in the grieving process, allowing grieving people to meet their different needs. Because rituals allow grievers to respond on cognitive, emotional, physical, behavioral and spiritual levels, they are suitable for people with a variety of grieving styles."

Doka delineates four types of bereavement rituals:

1. Rituals of Continuity: these remind survivors that the person is not forgotten.
2. Rituals of Transition: these mark a change or movement since the loss.
3. Rituals of Reconciliation: these complete some degree of unfinished business.
4. Rituals of Affirmation: these affirm the loss and say thank you for the legacies they have received from the deceased or lost person or lessons learned in the experience.

Doka offers five principles for creating ritual for pastoral purposes:

1. Rituals always emerge from the narrative of the mourner's loss.

---

[15] "The Role of Ritual in the Treatment of Disenfranchised Grief," in Doka's *Disenfranchised Grief*, op.cit.

2. Effective rituals tend to have visible elements that also have symbolic significance.

3. Some rituals are private, but others need one or more witnesses to have therapeutic benefit.

4. Therapists (rabbis) can offer ritual as a form of intervention and help mourners plan the ritual.

5. More than one option should always be offered. Offering more than one option empowers the mourner to make choices.

Boss views ritual as a way of navigating ambiguity. It enables us to feel more in charge, even though the ambiguity persists (108). The benefits of funeral rites are equally applicable to grief ritual:

An opportunity to express grief

A way to garner community support

A way to delineate between "before" and "after"

Help for the bereaved in assuming a new role

A context for sharing memories

The two best things about ritual, according to Boss, is its flexibility and its ability to express contradictory truths at the same time. One example from her counseling experience illustrates her point well. One elderly client described how she used ritual to resolve her dilemma of being married-but-not-married. When her husband, who no longer remembered her or knew her, began to press aggressively for sexual relations, she felt uncomfortable. She did not feel comfortable having sexual relations with a man who did not know who she was or that they were married. "She went into the bedroom, took

off her wedding ring, and put it away in her jewelry box. After that, she said, she knew how to manage her husband's behavior. She no longer saw him as her husband but simply as someone she loved and would care for. Just as she had done with their children years ago, she set boundaries, moving him to a separate bedroom and directing his daily routines. The stress level for both patient and caregiver went down. On the day her husband died, two years later, she went to her jewelry box, took out her wedding ring, and placed it back on her finger. 'Now I am really a widow,' she said, 'not just a widow waiting to happen (108)."

When I ran this personal ritual by my focus group, by the way, the reaction was one of horror. None of them could imagine themselves performing such a ritual. In fact, Mort described how he filled his home up with pictures of his wife, and made it a point to display their wedding pictures in the front room where visitors would see these pictures immediately. His private ritual was to repeat his side of their wedding vows to his wife on a regular basis. This encounter impressed upon me the importance of Doka's first principle of creating therapeutic ritual: Rituals must emerge from the narrative of the client's loss. It is a Jungian approach that respects the unique individuality of each mourner, their unique relationship with their loved one and their own dreamscape of associations and unmet needs. That does not mean I cannot assist in the development of private rituals or even construct communal rituals. It does mean that caregivers need to be full partners in creating ritual that will have meaning for them. My strategy for my thesis project, then, is to present a number of possible options, based on ritual theory, pastoral needs and Jewish tradition. My focus group pointed me in the direction I need to go in my creative effort. When I asked them specifically what kind of ritual may have

helped them through their ordeal, they gave me three types of rituals they wanted several years ago.

1. *Personal rituals,* such as a blessing or prayer to accompany repetitive caregiver activities they said felt like rituals for them. Jaye, for example, gave her mother a manicure, or rubbed her mother's hands with lotion when she came to visit. Joyce would apply makeup to her mother's face. Rachel said she would have liked something to do and say before visiting her mother.

2. Opening and closing *rituals for support group* meetings. I am calling these rituals of solidarity.

3. Ritual of recognition within a *worship service dedicated to caregivers.*

If I am going to be a resource for creative ritual formation in partnership with a grieving congregant, I need to have a comprehensive grasp of what constitutes ritual, how it works its "magic" and a wide range of options in terms of ritual elements. To do that I am going back in time to begin my collection of resources, back to visit the earliest ritual theorists we know about, a man by the name of Xunzi in ancient China ....

Chapter Five

"Ritual Theory, Ritual Practice, Ritual Power"

The meaning of ritual is deep indeed!

One who enters it mind-dividing between
hard and white
same and different
will drown there

The meaning of ritual is great indeed!

One who enters it logic-thinking
uncouth and inane theories
of the system-makers
will perish there

The meaning of ritual is lofty indeed!

One who enters it arrogant-minding
looking down on tradition
looking down on other mortals
will meet his downfall there

—Xunzi, (Xun Kuang, third century BCE)
"A Discourse on Rites"

The activity we call "ritual" is difficult to define precisely. Dictionaries often double-back on themselves ("a system of religious or other rites", "of or pertaining to rites") or defeat themselves with boundaries too narrow ("observance of set forms of public worship") or too broad ("prescribed code of behavior regulating social conduct.")[1] The ambiguous nature of ritual invites a broadly ambiguous definition, so that almost any

[1] Random House, unabridged. Note Webster's circular definitions of "ritual" (unabridged edition):

1. a set form or system of rites, religious or otherwise
2. the observance of set forms or rites, as in public worship
3. a book containing rites or ceremonial forms
4. a ritual service or procedure
5. ritual acts or procedures collectively

activity could be interpreted as ritual – everything from table manners, sporting events, mating actions (animal and human), neurotic obsessional behavior and even everyday routines.[2] Each of these types of activities share one or more elements in common with ritual, and each can be consciously ritualized or integrated into ritual, as will be discussed later in this chapter. But we know instinctively, from what theorists call our culturally programmed "ritual sensibility",[3] that these ordinary (or in the case of obsessional neuroses, dysfunctional) behaviors do not constitute ritual *per se*. In his struggle to define "ritual", Ronald L. Grimes takes exception to arbitrary labeling: "Even taking out the garbage is *repetitive* (Tuesday mornings before 8:00AM), *patterned* (from countertop to under the sink, to bins behind the garage, to street curb – always the same order), *Transformative* (of the landscape). Do we really want to define garbage removal as ritual?" Repetition, patterning and transformation are three among several constructive elements of ritual, but they do not comprise the essential nature of ritual.

Scholars of ritual theory do not, as a rule, attempt to define what ritual *is*, but instead explore its attributes, its processes, its construction and its effect on human beings and human institutions. They get at it indirectly, much like the proverbial seven blind men exploring the various parts of an elephant. Each contributes an important insight on a particular aspect of ritual, which cannot give a complete image by itself, but together with other theories of ritual bring us closer to a true understanding of this deep and great and lofty human enterprise.

---

[2] Each of these behaviors, in fact, are explored as "ritualized" or "ritual-like" activities by various contributors to the field of ritual studies. The wide range of behavior described as "ritual" is well represented in *Readings in Ritual Studies*, ed. By Ronald L. Grimes (New Jersey: Prentice-Hall, 1996).

[3] As per Ronald L. Grimes, "Every ritual system cultivates a *ritual sensibility*, a way of being in the world that is at once ideological and sensory." *Deeply into the Bone: Re-Inventing Rites of Passage* (Berkeley: University of California Press, 2000) 344.

Essential Characteristics of Ritual

Ritual is set apart from the ordinary.

The term *ritual*, Grimes writes, "refers to a set of actions intentionally practiced and widely recognized by members of a group. Rites are differentiated, even segregated from ordinary behavior." [4] The prerequisite of *intentionality* -- the intention on the part of participants to engage in activity beyond the routine behavior of everyday life -- eliminates most mislabeled activities from the realm of ritual. Emile Durkheim describes this intentionality as a differentiation between the *sacred* and the *profane*, the passage from one to the other involving a kind of metamorphosis effected through ritual.[5] Within the realm of the sacred, ritual sacralizes space, time, events, people, and objects. Catherine Bell asserts that participants in a ritual traditionally ascribe the distinction between *ordinary* and *extraordinary* to transcendent powers.[6] Ritual metaphorically ushers us into the realm of God -- or gods -- the timeless space of mystery, the deeper subterranean depths of our analogical psyches. "Ordinary acts, when extraordinarily practiced, break open, transforming human conventions and revealing what is most deeply desirable, most cosmically orienting, and most fully human."[7] It is no wonder that Tikopian and Tewa native Americans describe ritual as "spirit work" as opposed to "human work".[8]

---

[4] Ibid; 28.
[5] Emile Durkheim, "Ritual, Magic, and the Sacred" in *Readings*, 188-193. Originally published as "Definition of Religious Phenomenon and of Religion" in *The Elementary Forms of Religious Life: A study in Religious Society* (London: Allen and Unwin, 1915).
[6] Catherine Bell, *Ritual Theory, Ritual Practice* (NY: Oxford University Press, 1992) 74.
[7] Grimes, *Deeply into the Bone*, 346.
[8] Roy A. Rappaport, "Obvious Aspects of Ritual", in *Readings*, 427-440. Originally in *Ecology, Meaning, and Religion* (Berkeley: North Atlantic, 1979)

Ritual is Symbolic Action.

Bell describes ritual as "cultural praxis", or a strategic action that is cultural-specific, emphasizing the primacy of body moving about in specially constructed space.[9] Stanley J. Tambiah sees ritual as a performative drama, "a culturally constructed system of *symbolic communication*"[10] It is a praxis that manipulates symbolic objects, dramatizes through symbolic gestures, speaks through symbolic language, moves through symbolic journeys. Grimes describes ritual as "the enactment of a metaphor".[11] He agrees with Tambiah that ritual is a performance, and even uses drama as a metaphor to further distinguish ritual from everyday "ritual-like" behavior. Daily routines are like *social drama*, "soft and messy", whereas ritual is like *stage drama*, "more sharply focused, fictional presentations of acting." But he distinguishes ritual from theatre entertainment: "To enact any kind of rite is to *per*form," but it is also to "*trans*form."[12] Grimes' distinction pulls ritual into the realm of the extraordinary.

Symbols being what they are – ambiguous and ultimately open to multiple interpretations – the meaning of a particular ritual is necessarily ambiguous. There is some divide among ritual theorists regarding the relationship between belief and ritual. Most agree that ritual is *action* as opposed to conceptual *beliefs*, *doing* as opposed to *believing*. Both Victor Turner and Clifford Geertz view ritual as enacted beliefs, a means

---

[9] Bell, *Ritual Theory*, 98-104.
[10] Stanley J. Tambiah, "A Performative Approach to Ritual" in *Readings*, 495-511. Originally in *Proceedings of the British Academy* (British Academy, 1981)
[11] Grimes, *Deeply into the Bone*, 343.
[12] Ibid; 7.

by which a society's mythology and value system can be directly observed.[13] One has only to learn what particular ritual actions mean to participants in order to decipher underlying beliefs. Bell, on the other hand, sees a dialectical integration of thought and action, although she questions the feasibility of accessing participants' belief system through observation. Observers are also participants, she says, unwittingly creating their own meaning as they interpret what they see.[14] This sentiment stops short of Friz Stahl's dismissal of meaning altogether. From his perspective ritual is all about form and structure. In ordinary action, results count. In ritual action, rules count. It is the very meaninglessness of ritual that makes it psychologically powerful, because it allows full participation without requiring belief of any kind.[15] Grimes does not believe that ritual effectiveness depends on literal belief. It does not even have to resolve moral issues. A ritual, unlike an ethical principle, can thrive on ambiguity.[16]

Ritual is Liminal

Turner coined the phrase that continues to define ritual studies today – *liminality.* According to Turner's model, ritual is a means by which individuals and communities navigate their way through liminal situations, those transitional times when we are "betwixt and between the positions assigned and arrayed by law, custom, convention and ceremonial." [17] Such is the case of our caregiver and their deteriorating loved one. Conventional liminal moments would include change in social status (child to adult,

---

[13] Bell, *Ritual Theory*, 26-27. Turner, in fact, calls ritual the "hermeneutics of culture", and employs this methodology in his anthropological work among the Ndembu. See *The Ritual Process: Structure and Anti-Structure*, (NY: Aldine de Gruyter, 1969) 7.
[14] Bell, *Ritual Theory*, 28-29.
[15] Fritz Staal, "The Meaninglessness of Ritual", in *Readings*, 483-494. Originally in *Numen* 26(1) 1979.
[16] Grimes, *Deeply into the Bone*, 280.
[17] Turner, *Ritual Process*, 95.

single to married, married to divorced, living to dead) or change in season (winter to spring to summer to fall) or change from now-time to the once-upon-a-time of past historico-religious events, or change from one social reality to another (change in structure, law, or power). At times a community will create a liminal state for mega communal or religious purposes (such as the ritual of Yom Kippur). Turner created a threefold model for ritual that both parallels and broadens Arnold van Gennep's scheme for life-cycle rites of passage:

van Gennep:	Separation	→	Transition	→	Incorporation
Turner	Preliminal	→	Liminal	→	Postliminal

In this model, the life of an individual or community is comparable to a house or palace of many rooms separated by doorways. As we pass from one "room" to another, we must go through a *limen*, a doorway which is "neither here nor there".

Ritual, according to the ancient Chinese philosopher Xunzi and his modern counterpart Durkheim, mark distinctions within our socio-moral universe -- between different phases of life, for example, or different social roles and hierarchal levels.[18] Between one state and another, we are essentially a non-category in everyday life. By this definition, the *goses* is a prime liminal persona, for he or she is neither living nor dead, living-and-not-living between psychosocial death and physical death. Relationships connected to the *goses* are likewise rendered liminal in nature. The grieving loved one is neither married nor widowed; child nor orphan; parent of a living child nor parent bereaved of a child. These states hold potential danger for individuals and communities alike, for they are natural flash points for confusion and conflict. Turner described

---

[18] Robert R. Campany, "Xunzi and Durkheim as Theorists of Ritual Practice", in *Readings*, 86-103. Originally inn *Discourse and Practice* (Albany: State of New York Press, 1992).

moments of liminal crisis as an oppositional conflict between structure and anti-structure,[19] whereas Bell prefers a circular model in which ambiguity and paradox are in dialectical conflict with order and unity.[20] Liminality generates uncertainty, anxiety, impotence and disorder, which Barbara Myerhoff observes is the very emotive context which invites ritual activity. Grimes views these liminal moments as both a crisis and an opportunity. It is a crisis of self-identity and/or moral confusion, but it is also an opportunity for "momentous metamorphosis", a transformation from one kind of being to another, one mindset to another, one type of community to another.[21] Ritual is a mechanism by which this transformation can take place. It is the very mystical danger of liminal situations that drives human beings into analogical creativity. As Turner observed, "Liminality, marginality, and structural inferiority are conditions in which are frequently generated myths, symbols, rituals, philosophical systems and works of art."[22]

Ritual is Communal

Both models of transition presented by van Gennep and Turner involve public participation. For rites of passage, ritual enacts separation from and incorporation back into a sociocultural matrix of relationships. Gregory Bateson coined the word "schismogenesis" to describe the simultaneous social processes of differentiation and integration effected within this type of ritual.[23] In Turner's anthropological application of his model, community plays an active role in performing and witnessing any ritual. Ritual *drama*, after all, implies ritual *actors* and ritual *observers*. With the exception of

---

[19] Turner, *Ritual Process*, 14-15.
[20] Bell, *Ritual Theory*, 23.
[21] Grimes, *Deeply into the Bone*, 6.
[22] Turner, *Ritual Process*, 128.
[23] Bell, *Ritual Theory*, 102.

Sigmund Freud, scholars almost all agree that "private" rituals remain incomplete and unsatisfying until they are "re-enacted", physically or verbally, within a communal context, such as a support group, family, lecture audience or print media following. Given the plethora of private ritual in Jewish tradition, as well as my focus group's express desire for personal ritual, I would have to disagree with concensus.[24]

Liminality is a crisis for community, as well as individuals directly standing in the doorway. It is a challenge to an ordered, unified moral order. Ritual relieves the anxiety attendant to such a challenge by projecting images of cosmic order on to the place of human experience. "Ritual comes into play during a critical juncture wherein some pair of opposing social or cultural forces come together", Bell observers, during which time ritual becomes a "mechanistically discrete and paradigmatic means of sociocultural integration, appropriation or transformation."[25] Durkheim articulated the socio-cultural nature of ritual practice as a necessary mediator between collective and individual experience. Ritual is a "means by which collective beliefs and ideals are simultaneously *generated, experienced* and *affirmed* by the community."[26]

These four essential characteristics of ritual – its distinction from the ordinary, its performative symbolism, its liminality and its (usually) communal nature – represent a surface understanding of ritual which can act as a useful platform for deeper dives into ritual process and power. The following four approaches to ritual represent cross-disciplinary angles drawing from neurobiology, psychology, anthropology and sociology.

---

[24] Private rituals in Jewish tradition include the morning ritual of washing hands, laying tefillin and draping oneself in a tallit. Some rituals can be public or private, such as placing of stones on a tombstone.
[25] Bell, *Ritual Theory*, 16.
[26] Ibid.;20.

The Underlying Processes of Ritual

The Neurobiology of Ritual

Eugene d'Aquili and Charles Laughlin propose that the source of myth and ritual can be traced neurologically to underlying structuring processes in the human brain. In their article, "The Neurobiology of Myth and Ritual" [27], they speculate that myth-making and ritual originate from the same problem-solving function that account for our adaptability as a species to widely diverse and often hostile environments. They call this function the *cognitive imperative*. The questions *what is this? how does this work?* and *why?* compel us to seek knowledge and understanding about our environment through close observation and higher functions of analytical reasoning, and from this information construct a matrix of meaning and suppositions that allows us to then manipulate our environment.

The price we pay for our adaptability is the *curse of cognition*, a term d'Aquili and Laughlin use to describe the uniquely human anxieties that arise from our awareness of our own mortality in an unpredictable world. The same cognitive abilities that help us understand our world and adapt to it, are the same abilities that cause us to be acutely aware of our vulnerabilities, our potential losses, our own impending death. Our brain works over existential problems along with other types of problems, creatively merging or resolving antinomies, paradoxes and conflicting sensory input. When there isn't sufficient observable information to construct a coherent matrix of meaning, the brain will create analogical connections to complete it. In other words, when we can't get the

---

[27] *Readings*, 132-146. Originally published in *The Spectrum of Ritual: A Biogenetic Structural Analysis* (NY: Columbia University, 1979).

answers through natural observation, we revert to metaphor. Hence the origin of myth and ritual. How does the process work neurologically?

We can begin to understand the process by taking an admittedly reductionist look at the brain as a divided organ, each with an entirely different "worldview". The dominate hemisphere, or "left brain", sees the world in compartmentalized pieces and attempts to connect them into logical relationships. It categorizes commonalities and differences, systems of classes and binary oppositions. It is primarily responsible for our higher cortical functions such as conceptualization, abstract causal thinking and antinomous[28] association (visual, auditory and somaesthetic[29]), which work to make distinctions, categorize phenomenon and basically identify the unresolvable paradoxes or unknowable questions that drive both the cognitive imperative and its accompanying "curse of cognition". To meet the imperative, higher functions collectively known as the "causal operator", or 'g', seek causal links for solving antimonies. It is the casual operator seeking an initial cause to everything, according to d'Aquili and Laughlin, that indirectly generates personified forces like demons, gods and other supernatural entities. The minor hemisphere, or "right brain", on the other hand, "sees" the world as a unified whole. Synthesizing operations, holistic perceptions, harmonies of various kinds (creative and analogical), and an overall sense of well-being are thought to originate in the right brain.

An important mediator between left and right brain functions is the autonomic nervous system, which regulates baseline body function and response to external stimuli. It consists of two mutually inhibitory subsystems: the *ergotropic* (sympathetic), or

---

[28] To think antinomously is to see polar opposites, such as sky/earth, hot/cold, good/bad, left/right, strong/weak, male/female, live/dead

[29] the body's sensing of itself

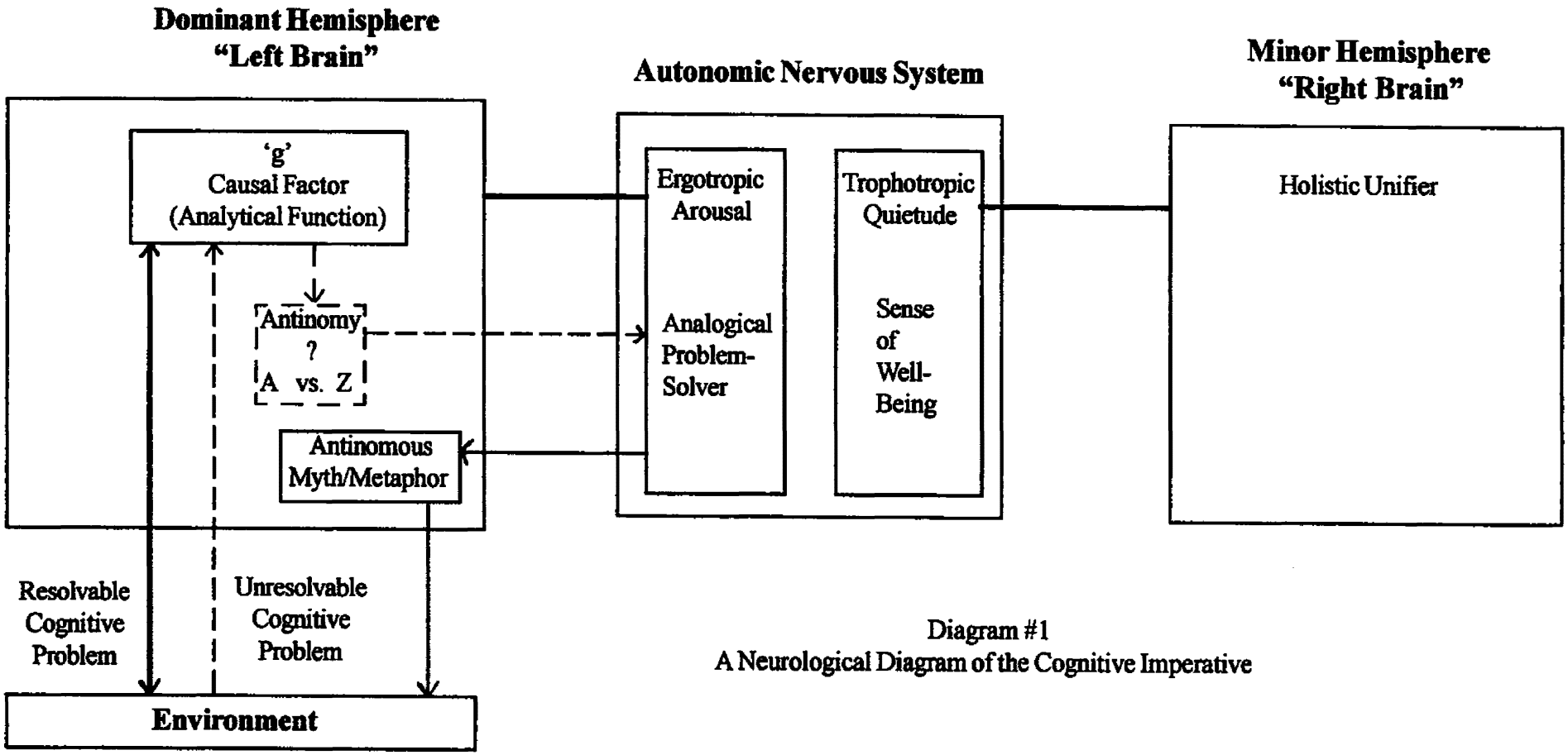


Diagram #1
A Neurological Diagram of the Cognitive Imperative

Bonding with "First Cause" * Bonding with other participants * Intense Emotion/Sense of Unity and Wholeness * Integration of Antinomies into Cosmic Order

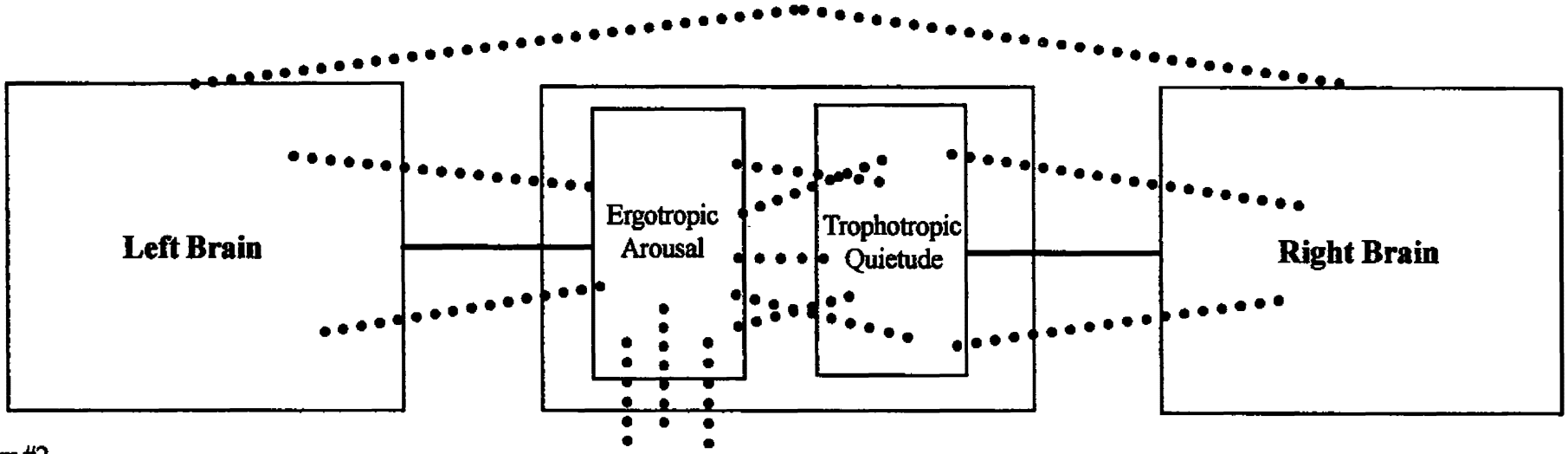


Diagram #2
Hyperarousal State
"Spillover" from Ritual Activity

Repetitive Rhythmic Stimulation/Ritual Practice
(fast/loud music, chanting, dancing, sensory stimulation)

"Oceanic" Unity with Cosmos * Intense Emotion/ Sense of Completeness and Well-being * Dissolution of Antinomies

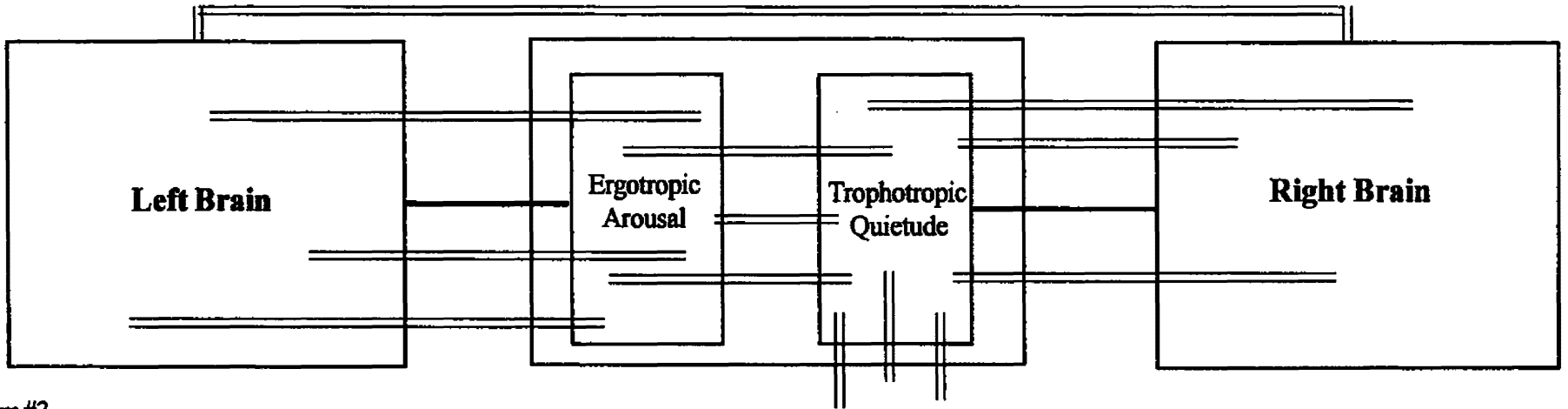


Diagram #3
Hyperquiescent State
"Spillover" from Meditation

Meditative Practice
(Sensory Repression)

arousal system, and the *trophotropic* (parasympathetic), or quiescent system. The *ergotropic system* releases energy in the body in reaction to the environment (this is the source of our fight-or-flight response), and *reaches into our left brain* through amygdala neural connectors. The *trophotropic system conserves energy*, promotes relaxation and sleep, and maintains basic body function and growth. It includes the endocrine glands, parts of the hypothalamus and thalamus, and *reaches into our right brain.* The chart below summarizes the functional divisions within the autonomic nervous system. See Diagram #1 for my conceptual diagram of the Cognitive Imperative as postulated by d'Aquili and Laughlin.

Autonomic Nervous System	
Arousal System Ergotropic (Sympathetic)	Quiescent System Trophotropic (Parasympathetic)
"Left Brain" connection	"Right Brain" connection
Expends Energy	Conserves Energy
Analogical Problem-solving (myth, poetry, music, dance, art)	Holistic Synthesizer (sense of wholeness, well-being)

An ultimate resolution to and peace of mind regarding an unresolvable paradox requires the activation of our trophotropic system and, optimally, a "unification" of the two hemispheres of our brain. This is achieved by what d'Aquili and Laughlin call a "spillover", the hyperstimulation of either the ergotropic or trophotropic nervous system. This can be achieved through ritual or meditation, as illustrated by Diagrams #2 and #3.

Ritual stimulates the ergotropic system with energetic rhythmic patterns – through chanting, music or dance, for example – until energy from the ergotropic "spills over" into the trophotropic system, where antinomies are presented as part of a unified whole and a sense of unity is achieved. "Logical paradox or the awareness of polar opposites as presented in myth appear simultaneously, both as antinomies and as united wholes." In other words, ambiguities "feel" harmonious within the cosmic order. Meditation practices, on the other hand, work from the opposite direction, either suppressing sensory input or stimulating the trophotropic system with slow, measured rhythms. Paradoxes, conflicting axioms and unresolvable unknowns are simply dissolved into a synthesized whole. Regardless of how "spillovers" are achieved, the emotive side-effects of successful synergism between "left brain" and "right brain" functions are four-fold:

- a sense of union with a greater power
- intense pleasure
- awareness that death is not to be feared
- a sense of order and harmony in the universe

D'Aquili and Laughlin judge the efficacy of ritual by how well it relieves existential anxiety. But ritual stimulation has an added emotional effect. Repetitive visual and auditory stimuli can generate a sense of union with other participants in a social group. The rhythmic quality in and of itself produces positive limbic discharges resulting in decreased distancing and increased social cohesion. This may account for the need for communal participation in order for individuals to feel that a ritual is "complete". The "something missing" may be the hyper-stimulating social echo chamber that brings a participant into the universal whole of something greater than themselves.

The ultimate side-effects are the same for meditation and ritual. But they take nearly opposite paths into trophotropic paradise. Whereas meditation is an intensely

individualistic activity requiring a great amount of concentration, discipline and sensory suppression, ritual is accessible to almost anyone. It is easier to stimulate than to repress. And it is easier to do so with other people.

The neurobiological approach to ritual suggests reasons why music, dance, verbal mantras and symbolic objects and gestures serve to enhance the felicitousness of ritual. They both stimulate and are stimulated within the same maelstrom of brain activity, they increase the likelihood of "spillover" into a sense of wholeness. It also suggests why participants don't necessarily have to attach meaning to a ritual for them to benefit from it. Although d'Aquili and Laughlin propose that myth provides a web of meaning with which to interpret ritual, it appears to me as though ritual needs no cognitive interpretation for it be "meaningful" for participants. The mythological construct of a cognitive problem can be long forgotten, but the continued emotive side benefits of the ritual that actuated it virtually guarantees a permanent place in communal tradition.

The Psychology of Ritual

Sigmund Freud observed certain commonalities between obsessional neurotic behavior (apparently senseless repetitive behavior) and ritual ceremonies. Based on his observations, he speculated, "In view of these similarities and analogies one might venture to regard obsessional neurosis as a pathological counterpart of the formation of a religion, and to describe that neurosis as an individual religiosity and religion as a universal obsessional neurosis."[30] Although cross-disciplinary studies into ritual since 1907 have uncovered significant differences between religious and neurotic behavior,

---

[30] Sigmund Freud, "Obsessive Actions and Religious Practices", in *Readings*, 212-217. Originally published in *The Standard Edition of the Complete Psychological Works of Sigmund Freud* (1907).

Freud's theory offers important insights into the psychology behind ritual, insights which have subsequently been explored and expanded by other scholars since his time. His most important contribution to the field is the concept of "displacement", the substitution of a symbolic object for an emotion, abstraction, event or person, which then becomes the focus of a repetitive behavior. Freud postulates that apparently senseless repetitive behavior often have subconscious meanings related to underlying tension or unresolved trauma. So too ritual, like obsessional neurosis, is "a compromise between the warring forces of the mind" expressing unconscious motives and ideas. He draws an implied analogy between psychoanalyst and cleric/anthropologist, "...as a rule the ordinary pious individual, too, performs a ceremonial without concerning himself with its significance, although priests and scientific investigators may be familiar with the symbolic meaning of the ritual. In all believers, however, the motives which impel them to religious practices are unknown to them or are represented in consciousness by others which are advanced in their place."[31] Sixty years later, Claude Levi-Strauss made the connection between "shaman" and psychoanalyst an explicit one, positing that the purpose of ritual "is to bring to a conscious level conflicts and resistances ... permitting their free development and leading to their resolution," an experience initiated by unprovoked intervention of the analyst or "shaman".[32]

Bell reframed Freud's "warring forces of mind" as internal conflict and disequilibrium. One of the functions of ritual is "psychosocial conflict management."[33] The idea of ritual as a mechanism for articulating anxieties over the unknown is familiar

---

[31] ibid p215
[32] L2
[33] B1

to anthropologists like Turner, who sees the purpose of metaphoric units of ritual as three-fold:

- to connect the known to unknown territory
- to reconcile structure and order with anti-structure and chaos
- to transform the mysterious and dangerous into something intelligible[34]

For Turner, antinomy is the stuff of liminality, and it is the task of ritual activity to work through a phenomenon that is both a mystery and absurdity. Geertz models antinomic conflict as one between ethos and worldview, the idealized world and the world actually lived in: "In ritual, *the world as lived* and *the world as imagined,* fused under the agency of a single set of symbolic forms, turns out to be *the same world.*"[35] Ritual reorders and reinterprets circumstances to afford a sense of "fit" between body, community and cosmos, essentially merging the lived-in order with the dreamed-of order. Geertz goes on to describe how ritual alters our sense of time. Ritual time replaces chronological, collective time with experience of flowing duration, paced according to personal significance. An effective ritual, according to Geertz, achieves a sense of continuity with one's past selves. "These pin-points of timelessness are beyond duration and change. In them one experiences the essence of life – or self – as eternally valid; simultaneity has replaced sequence, and continuity is complete." Myerhoff , too, believes that sacred symbols "link participants to their very selves through various stages of the life cycle, transforming individual history into a single phenomenological reality" and that ritual carries a message of order, continuity and predictability, doing so by

---

[34] Turner, *Ritual Process*, 15.
[35] Bell, *Ritual Theory*, 27.

expressing enduring and underlying patterns that link past, present and future, "abrogating history and time."[36] In other words, ritual aids the individual to experience time as an ordered narrative that pulls together and interprets the random chaotic experiences of life and history into a continuing saga in which we play a meaningful role.

Both Geertz and Myerhoff evaluate ritual on its believability. "Through its insistence on precise, authentic and accurate forms," Geertz writes, "rituals suggest that their contents are beyond question, authoritative and axiomatic."[37] His view represents a synthesis of meaning and form. Myerhoff links authenticity with a sense of tradition. "Ritual has the capacity to convince us of the unbelievable and make traditional what is new or unexpected." Ritual succeeds when it grows out of tradition and experience. That does not mean it must remain forever fixed in actual form. In fact, it is the ongoing innovation (renovation?) of tradition, based on situational experiences, which keeps it relevant and re-interpretable.

Jennings proposes that it is the *variation* in ritual which generates self-knowledge about the world and our place in the world. Ritual is a symbolic structure performing noetic functions, a process of metaphoric problem-solving, "generated through the liminal aspect of ritual through bodily action."[38] Ritual is an ontological/cosmogonic praxis, a sensory way of knowing how the world came to be, how it works (or should work?). Important rituals, according to Jennings, repeat the act which founds the world, and does so in a public manner. Jennings posits three "moments" of ritual noetic function: when the participants gain knowledge, when they transmit knowledge and when

---

[36] Barbara Myerhoff, "Death in Due Time: Construction of self and Culture in Ritual Drama", in *Readings*, 324-334. Originally in *Journal of Religion* 62(2) 1982.
[37] Ibid.
[38] Theodore W. Jennings Jr., "On Ritual Knowledge" in *Readings*, 324-334. Originally in *Journal of Religion* 62(2) 1982.

they display knowledge and thereby receive affirmation by outside observers. I am tempted to call Jennings' "ritual knowledge" revelation. We can say that variations in ritual stimulate revelations about the world and about ourselves we didn't "see" before. The weight of tradition and affirmation from others confirms our revelation as an authentic one.

But ritual does more than generate self-knowledge or revelation. It also functions as a mechanism for expressing *and* controlling emotion. The shaman (i.e. cleric), according to Levi-Strauss, gives ritual participants a language with which to express the otherwise inexpressible, making it possible "to undergo in an ordered and intelligible form a real experience that would otherwise be chaotic and inexpressible."[39] Tambiah purposes that ritual distances participants from direct, spontaneous expression of emotion, and thereby safeguards the emotional need for order and meaning. Ritual action simultaneously provides a means of expressing raw emotion while also directing it into the realm of communal acceptance and interpretation. Tambiah also posits that ritual "is precisely a mechanism that periodically converts the obligatory into the desirable."[40] In other words, ritual persuades us that our allotted tasks and roles in society are both natural and worthwhile. Campany concurs that ritual both expresses inner states and shapes emotion. He points out the way funeral rites channel disgust and loathing of the corpse – emotions that are natural but inappropriate – into a performance of reverence.[41] I might add that ritual regulates appropriate emotion even when it is lacking. As a society, we regulate appropriate emotional responses to the birth of a child, sexual attraction, regard for parents, respect for the aged, care for the sick, etc, through ritual. In

---

[39] Levi-Strauss, "Effectiveness of Symbols".
[40] Tambiah, "Performative Approach".
[41] Campany, "Xunzi and Durkheim".

this way inner conflict over how we *should feel* as opposed to how we *actually feel* are mediated through the ambiguity of ritual. The ideal world remains intact, and so is our place in it.

Without ritual to mediate difficult passages in life, the stability of our psychological world is threatened. Grimes asserts that unattended passages equals unfinished business that cause social confusion and are psychologically draining. He calls them "spiritual sinkholes" and "hungry ghosts" that haunt the individual or community in distress indefinitely.[42] Hence the continued "frozen grief" of many surviving caregivers.

The Cultural Meaning of Ritual

Bell defines culture as the primary level of meanings, values and attitudes of a group. She reads ritual as a text rich in cultural meanings which the observer and participant may "decipher" by deconstructing it. In other words, one can derive meaning by interpreting a ritual. This act of interpretation becomes, in turn, a reflection and interpretation of one's own situational concerns and values. The symbolic systems of ritual exist in response to the problems of meaning that arise in real human experiences, such as the problems of good and evil, suffering and death. Besides serving to communicate structural relationships, ritual mediates between cultural ideals and sometimes contradictory social experiences.[43]

According to Rappaport, ritual conveys two types of messages. One is "indexical", the participants' own current physical, psychic or social states. The other is

---

[42] Grimes, *Deeply into the Bone*, 5-6.
[43] Turner, Leach and Geertz. Catherine Bell, *Ritual: Perspectives and Dimensions* (NY: Oxford University Press, 1997), 64-68.

"canonical", messages that are invariant, durable and immutable.[44] He doesn't specify what these messages might be, but based on his reasoning, I would infer that such messages are about the permanence and timelessness of tradition, history, social construct and cosmic universe. Bell emphasizes the dialectic relationship between these two messages, as well as the importance of perceived authority in effectuating these messages:

> ...ritual practices seek to formulate a sense of the interrelated nature of things and to reinforce values that assume coherent interrelations, and they do so by virtue of their symbols, activities, organization, timing and relationships onto other activities ... ritual is used in those situations in which certain values and ideas are more powerfully binding on people if they are deemed to derive from sources of power outside the immediate community.[45]

Bell also stresses the function of ritual as a mediator for both cultural continuity and change. Ritual does this by positing bounded categories and then formally transgressing them. In this way ritual keeps cultural categories responsive to human needs and therefore meaningful. This idea is similar to Pierre Bourdieu's definition of ritual as "strategic practice for transgressing and reshuffling cultural categories to meet the needs of real situations.[46] Marshall Sahlins goes so far as to say that ritual interprets real events through cultural lenses and so creates history: "...ritual creates a meaningful event out of a new and potentially incomprehensible situation, namely, by bringing traditional structures to bear on it."[47] Sherry B Ortner and Jean Comaroff assert that ritual is the mechanism by which "culture molds consciousness in terms of underlying

---

[44] Rappaport, "Obvious Aspects".
[45] Bell, *Perspectives*, 137.
[46] Ibid.; 78.
[47] Ibid.; 77

structures and patterns.[48] All of these theorists see ritual as an activator of cultural meaning.

Cultural meaning is generated through ritual ambiguity, primarily through symbols that can be interpreted in different ways for different situations. Tambiah calls this the "strategic deployment of a metaphor,"[49] emphasizing that ritual does not overtly communicate common understandings of its central symbols. The ancient ritual theorist Xunzi illustrated how this works culturally:

> Only a sage can fully understand ritual. The sage has a clear understanding of it, the gentleman finds comfort in practicing it, the official takes it as something to be preserved, and the common people accept it as custom. To the gentleman it is the way of being human; to the common people it is a matter of serving spirits.[50]

Turner came up with the idea of *condensation*, the simultaneous existence of several meanings for the same symbol, essentially creating a multivocal conveyer of culture both originating in and sustaining the dynamics of social relationships.[51] These theories offer a rebuttal to Staal's thesis that ritual is strictly orthoprax in nature, pure activity without meaning. I agree with Bell and Turner that multiple meanings do not constitute meaninglessness. Quite the contrary, they are rich in meaning. We *could* say that pluralistic interpretations may indicate the loss of original intent. The original meaning may be lost, but participants continue to imbue the ritual with a meaning that works for them and their community. Ambiguity, through condensed metaphor, is a mechanism for "updating" a ritual without discarding its value as a link to the distant past. It gives ritual enough elasticity to contextualize any number of situations over time and therefore

---

[48] Ibid.; 79.
[49] Tambiah, "Performative Approach".
[50] 13.21b; W110 as quoted in Campny, "Xunzi and Durkheim".
[51] Turner, *Ritual Process*, 52.

continually generates cultural meaning. "Structural contradictions, asymmetries, and anomalies are overlaid by layers of myth, ritual and symbol, which stress the axiomatic value of key structural principles with regard to the very situations where these appear to be most inoperative."[52]

Ritual also enacts mythology as a means of generating cultural meaning. What distinguishes myth *per se* from ritualized mythology? We can begin with Durkheim's distinction between myth and religion, myth being a "text", religion comprising a moral community of believers.[53] The difference is that between a sacred story and a group of people who integrate the sacred story as a context for living out their individual and communal lives – what Pierre Bourdieu calls the "habitus", or the real and immediate context of human activity.[54] From there we can look at Rappaport's distinction between myth and ritual. Ritual specifies the relationship of the performer to what he is performing. Myth does not.[55] In other words, ritual brings us physically into the mythic drama as active players.

What is the dynamic behind the synthesis of myth and ritual, particularly in generating cultural meaning? Levi-Strauss describes myth as "a quest for the remembrance of things past."[56] It is a narrative, often centered on a spiritual as well as physical journey. Divine powers and supernatural forces excite the imaginative quest for knowledge of the distant past, of mysteries beyond human understanding that only the very wise and great masters can teach – and only then in riddles. Levi-Strauss purposes that ritual is "psychosocial mythology" in that it coopts the community into mythical

---

[52] Ibid.; 47.
[53] Durkheim, "Ritual, Magic and the Sacred".
[54] Bell, *Perspectives*, 78.
[55] Rappaport, "Obvious Aspects".
[56] Levi-Strauss, "Effectiveness of Symbols".

drama. The mythical drama, however, is not necessarily history transformed. He asserts that ritual regulation of emotion, for example, is effected specifically through mythological enactments. In healing ritual, for example, pain itself is personified, both through psycho physiological mythology – in which there is a metaphorical displacement of physical ailment into mythic drama – and through psychosocial mythology. He continues Freud's comparison of cleric and psychoanalyst, by saying that they both "recover" myth and articulate it, the difference being the origin of their articulated myth. An analyst recovers it from an individual's past, while the "shaman" recovers it from collective tradition. In his model, myth provides the language, while ritual provides the experience. In working with a caregiver to formulate a ritual response to their loss, I am "recovering" myth from both sources -- the individual's past and Jewish tradition.

Myerhoff looks to the particularist, rather than the universal aspects of myth, positing that religious ritual transforms history into myth, pointing to biblical stories, for example, that become mythic in character, and in turn are internalized through ritual. "Stories with no beginning and no end. Time is obliterated and continuity is complete."[57] In other words, ritual mythologizes tribal history into enduring cosmic significance. It is the particular details of the myth for each culture that generate meaning, values and ideology for its particular "habitus".

Mircea Eliade posited the following three components of his pheonomenological approach to myth and ritual;

1. Ritual as a secondary reworking of myth in symbols (per Levi-Strauss)
2. Myth as sacred history (per Myerhoff)
3. Ritual as the reenactments of the deeds of gods in primordial past.

[57] Myerhoff, "Death in Due Time".

Bell summarizes the third component of Eliade's model: "For Eliade, the identification of human acts with the divine models preserved in myth enables people to experience the ontologically real and meaningful, to regenerate cyclical notions of time, and to renew the prosperity and fecundity of the community...Through the ritual enactment of primordial events, according to Eliade, human beings come to consider themselves truly human, sanctify the world, and render meaningful the activities of their lives."[58] Eliade is careful to point out that in traditional societies ritual and myth work in tangent together. Telling the sacred story requires ritual, and intrinsic to the ritual is the reenactment and retelling of the myth itself. In these communities, myth *is* the meaning of ritual. Eliade also views ritual as a sacred drama that legitimizes human acts through an extrahuman model, acts which presuppose an absolute reality that is extrahuman. But he also places a great deal of emphasis on the physical setting for this drama. He points out that the concept of sacred space permeates religious mythology, and that this plays out in ritual, transforming space and time into sacred space and mythical time:

> Through the paradox of rite, every consecrated space coincides with the center of the world, just as the time of any ritual coincides with the mythical time of the "beginning". Through repetition of the cosmogonic act, concrete time, in which the construction takes place, is projected into mythical time ... Thus the reality and enduringness of a construction are assured not only by the transformation of profane space into a transcendent space but also by the transformation of concrete time into mythical time."[59]

Sir James Frazer represents a minority opinion, albeit an important one (as author of *The Golden Bough*). He asserts that myth is a by-product of ritual, not a precurser. In order to understand a myth, one must first determine the ritual that it accompanied.[60]

---

[58] Bell, *Perspectives*, 10-11.
[59] Mircea Eliade, "Ritual and Myth" in *Readings*, 194-21. Originally in *Cosmos and History: The Myth of the Eternal Return* (NY: Harper and Row, 1959).
[60] Bell, *Perspectives*, 5.

Bell prefers a more dynamic, dialectic model for myth and ritual, in which the process of generating cultural meaning involves myth and ritual continuously reinterpreting, and so renewing and updating the other.[61]

Joseph Campbell represents an amalgamated theory of myth and ritual: the psychoanalytical approach of Carl Jung, Eliade's comparative approach mythological studies and Raglan's myth and ritual school of thought. He came up with four functions for synthesizing myth and ritual:[62]

1. Metaphysical or mystical function: to induce a sense of awe and reverence. In other words, to give the sacred drama gravitas and spiritual wonderment.
2. Cosmological function: to provide a coherent image of the cosmos. We might say that this meets the cognitive imperative.
3. Psychological function: to guide the individual's internal development (ala Freud and Levi-Strauss).
4. Sociological: to integrate and maintain individuals within a social community.

And it is to the sociology of ritual we now turn.

The Sociology of Ritual

Whereas the cultural level of ritual deals with the conscious and unconscious ideals and values of a group – what we believe in, how we visualize the sacred – the social level deals with the function of ritual in mediating the lived realities of community

---

[61] Ibid.; chap. 1.
[62] Ibid.; 16.

life. As social dramas, rituals function as an exchange between society and an individual, not between a god and an individual.[63] "We engage in rituals," Edmund Leach asserted, "in order to transmit collective messages to ourselves."[64] Myerhoff extends the sociological aspect by saying that ritual always links fellow participants, but often goes beyond this to connect a group to wider collectivities, even ancestors and those unborn. It connects society to forces of nature and purposes of the deities, reading the forms of macrocosm in the microcosm.[65] Two functionalist models for the sociology of ritual currently dominate ritual studies.

Durkheim's Model of Ritual as Social Control

Durkheim was the first modern theorist to fully articulate ritual as a controlling mechanism for maintaining society. "Symbolic indirection" is the representation of society through ritual objects and gestures created by society. It is through ritual that "collective beliefs and ideals are simultaneously *generated*, *experienced* and *affirmed as real* by the community."[66] Rituals are all about regulating social, political and ecosystemic relations. It is the means by which people sacralize the structure and bonds of community, by which individuals are socialized, and by which opposition is effectively suppressed.

The idea is not new. It goes back to Confucious.

> For Confucious, *li*, or ritual, meant those objective prescriptions of human behavior, whether involving rite, ceremony, manners or general deportment, that bind human beings together in networks of interacting roles within the family as well as in political society. Confucious recognized that ritual could modify behaviour in ways more powerful than regulative rules. *Direct commands, he noted, bring to the subject's mind the possibility of doing the opposite*, and can

[63] Campany, "Xunzi and Durkheim".
[64] Bell, *Perspectives*, 64.
[65] Myerhoff, "Death in Due Time".
[66] Bell, *Ritual Theory*, 20.

> lead to instability. *Rituals, as social action, not verbal expression, have no contraries and can produce harmony of wills and actions without provoking recalcitrance.* [67] (my emphasis)

In other words, you can't argue with a ritual convention.

Bell retells two stories from Chinese history that illustrate the power of ritual in constructing and legitimizing power structures:

> The first story tells how the founder of the Han dynasty (206 BCE.-221 CE) protested when advised that the time had come to consult the books on Confucian ethics and ritual.
>
> "All I possess I have won on horseback," he exclaimed. "Why should I now bother with those musty old texts?"
>
> "Your Majesty may have won it on horseback," retorted his chief counselor, "but can you rule it on horseback?"
>
> In a second story from the T'ang dynasty the perspective shifts and it is not sufficient simply to consult the old books and reenact the ancient rites. Based on his study of the stars and portents, the Grand Astrologer alerted the T'ang emperor to the need to fashion his own distinctive ceremonial. He should at least change the calendar, the colors of court dress, and the names of the government offices so that the people could see the distinct virtue of his rule.[68]

These stories illustrate the need for tradition and ritual *to stay in power*, and the need to innovate tradition and ritual *to assert power*. Bell posits that the ability to address and manipulate ritual symbols of society is the power to define what is real and to shape how people behave. If you control ritual convention, you control social reality – and everyone's place in that reality. Symbols and activities of ritual, according to Geertz, can project idealized images that reflect the actual social situation, on the one hand, yet also act as a template for reshaping or redirecting the social situation on the other. He theorizes that rituals "define power in a two-dimensional way: first, they use symbols

---

[67] Peter A. Winn, "Legal Ritual", in *Readings*, 552-565. Originally in *Law and Critique* 2(2) 1991.
[68] Bell, *Ritual Theory*, 193-194, citing Howard J. Wechsler, *Offerings of Jade and Silk: Ritual and Symbol in the Legitimation of the T'ang Dynasty* (New Haven: Yale University Press, 1985) pp. 5-6 and 6-7

and symbolic action to depict a group of people as a coherent and ordered community based on shared values and goals; second, they demonstrate the legitimacy of these values and goals by establishing their iconicity with the perceived values and order of the cosmos." In other words, they project a social reality that appears incontrovertibly natural. "When expressed in ritual, the *sociocosmic order* is implicitly understood as neither human nor arbitrary in its origins; rather, it is natural and the way things really are or ought to be."[69]

According to Rappaport, the association of ritual "...with ultimate sacred propositions certifies the correctness and naturalness of conventions, the legitimacy of authorities, the truthfulness of testimony and the reliability of commissives." He goes on to say that "...truthfulness, reliability, correctness, naturalness, and legitimacy are vested in conventions and conventional acts by their association with ultimate sacred postulates ... Unquestionableness in turn is closely related to certainty and acceptance, certainty and acceptance to invariance."[70] Rigidly conventionalized ritual leads to legitimazation. Here's how I would chart Rappaport's logic:

Invariance → Certainty → Unquestionableness → Sacredness
↓
Legitimacy of societal conventions, authorities and structures

His conclusion is that "the concept of the sacred itself emerges out of liturgical *invariance* ... They also proclaim an order that transcends time, an ultimate or absolute order of which the temporal order is merely a contingent part." In other words the here-and-now social order is part of the eternal, absolute order of the cosmos, or divine sphere.

---

[69] Bell, *Perspectives*, 66-68; 129; 137.
[70] Rappaport, "Obvious Aspects".

Bloch elaborates the voice of authority through ritual. He points to the formalized language distinctive of ritual as creating a type of religious and sociopolitical authority known as "traditional authority." In traditional authority, the power of an individual or an office is understood to come from sources beyond the control of the community (i.e. God or natural order of universe). The manner of ritual compels comformity. "The obvious codes of formalized and restricted speech used in ritual are the very means by which it does what it does – namely, exercise considerable social control by creating situations that compel acceptance of traditional forms of authority."[71] *Acceptance*, not *belief*, is the key to the social function of ritual. "It is the visible, explicit, public act of acceptance," Rappaport asserts, "and not the invisible, ambiguous private sentiment that is socially and morally binding."[72] He contends that ritual establishes a boundary between private and public processes, thereby insulating public orders from private vagaries (and vice versa).

Although I agree with Rappaport and Bloch regarding their psychosocial analysis of ritual "buy-in", their understanding of ritual as an invariant convention is problematic for me. It does not take into account the second half of the Chinese philosophy of ritual power – its innovation as a means of asserting power – or even the possibility that ritual can be innovated. But they do hint at the source of ritual power – the *perception* that it is rigidly conventionalized and bound up with the unquestionableness of the sacred. It *feels* traditional, rooted in the solid foundation of ancient times.

The ability to intuit authentic ritual tradition is, according to Mary Douglas, related to the amount of symbolic structure and quality of human interconnectedness in a

---

[71] Bell, *Ritual Theory*, 120-122.
[72] Rappaport, "Obvious Aspects".

society. Her version of the Durkheim model takes the form of a Grid/Group analysis[73]. *Grid* is the relative strength of a society's order, classification and symbolic system (formal structure, tradition, ritual). *Group* is the relative strength of communal pressure on an individual to consent to the overwhelming demands of other people. The power of ritual in a society, then, is proportional to the combined strength of established convention and communal interrelationships that pressure conformity. Douglas concludes that societies with weak grid or weak group exert less control, are less ritualized and allow for more individual autonomy. She is suggesting that for ritual to be the controlling power Durkheim proposes, it must be operable in a highly structured, traditional society in which social pressure exceeds individualism.

So far we have a picture of ritual as a tool in the hands of a massive social bureaucracy imprinting its image onto the passive minds of its individual members. Structuralists like E.E. Evans-Pritchard – who analyze the *meaning* of structured relationships of ritual and religious symbols – agree with Durkheim that religions are products of social life, but disagree with his reductionaism. Ritual action may be uniform, but the emotions or interpretations they stimulate vary from one person to the next. They insist that ritual be viewed from the participants' point of view as well, not just that of an impersonal power structure.[74] The multiple interpretations made possible by the ambiguity of ritual – the fact that it does not overtly communicate common understandings of its central symbols – suggests that ritual mediates between cultural ideas and social experiences. A more dynamic model is in order.

---

[73] See her detailed matrix in Bell, *Perspectives*, 45.
[74] Ibid.; 34-35.

Turner's Model of Ritual as Structure versus Anti-Structure

Turner proposes an oppositional relationship between social order (structure) and inversions of that order (anti-structure). Rituals simultaneously affirm the social order and subvert it; legitimize it and modify it. Ritual is a vehicle for unfolding social drama where tensions can be expressed and worked out as part of the dynamic process of a community continually redefining itself. Rituals are "cathartic performances that are responses to situations of anxiety or fear," which "exhibits and exaggerates real conflicts in order to release tensions." It is a mediator between opposing demands of implicit oppositions of concept and behavior. When anomalous events occur, they are "made the ritual occasion for an exhibition of values that relate to the community as a whole, as a homogenous, unstructured unity that transcends its differences and contradictions."[75] Contradictions or challenges to social structure, then, are displayed and mediated in such a way as to reaffirm the fundamental structure, even though changes may have in fact taken place during the process.

Different advocates of this model theorize different conceptual oppositions at work within ritual mediation: ethos vs. worldview[76], social conflict vs. affirmation of social unity[77] or culture vs. nature[78]. The ambiguity of ritual effectively unifies diverse groups, where belief is not expected, but merely acceptance of form. The community is united in practice, even though individuals may differ in understanding. Durkheim views this dynamic as repression of individualism, whereas Turner views it as a form of ritualized struggle for consensus. Max Gluckman introduced the concept of "Rituals of

---

[75] Turner, *Ritual Process*, 92.
[76] Geertz, who basically represents the majority of ritual scholars who follow Turner's model.
[77] Turner and Gluckman
[78] Bateson and Levi-Strauss

Rebellion", in which challenges to the social order are recurrently enacted in order to display its deviancy, and so purge it from lived society.[79] This idea would seem to play into Durkheim's controlling model, except that in the messy social drama of ritual, the "deviancy" can become an accepted norm. The system does not remain static, but is continually under revision and challenge by the social struggles it dramatizes. It effectively performs this task because it both works below the level of discourse (in symbolic acts or language) and accommodates concomitant consent, resistance and negotiation by its intrinsic ambiguity. So ritual enables people to modify their social order at the same that it reinforces basic categories of it. It is this attribute of ritual that makes it a promising tool for removing stigma from the demented elderly and their caregivers, and re-integrating them into our community.

Bell's dialectic approach between ritualized body and ritualized society represents an insider's view within Turner's model. "Essential to ritualization is the circular production of a ritualized body which in turn produces ritualized practices. Ritualization is embedded with the dynamics of the body defined within a symbolically structured environment."[80] The focus of social construction is not so much the overall structure of society, as it is the individual. The body is the medium for internalization and reproduction of social values and for simultaneous constitution of both the self and world of social relations:

Society ↔ Social being

She calls this process "strategic social activity and socialization", which shapes a ritualized individual's understanding of ideology – their worldview, their acceptance of

---

[79] Bell, *Ritual Theory*, 172.
[80] Bell, *Ritual Theory*, 93.

class domination through mystification and the lived and practical consciousness through complicity, struggle, and negotiation. At the same time, ritualization is the *strategic manipulation* of 'context' in the very act of reproducing it. Through ritual, an individual is able to conform society to personal worldview. By rendering power structures socially redemptive, Bell asserts, ritual becomes personally redemptive as well.

Communitas as a Social Dynamic of Ritual

Theorists of both models – be it Durkheim or Turner – agree on one important social dynamic within ritual. Turner labeled it "communitas" – an existential communal experience of potent emotive unity. "Communitas breaks in through the interstices of structure, in liminality; at the edges of structure, in marginality and from beneath structure, in inveriority. It is almost everywhere held to be sacred or 'holy'..."[81] Durkheim observes that effective ritual produces intense emotion, with individuals experiencing something larger than themselves; they experience collective representation as simultaneously transcendent and immanent commonality – God above and the soul within.[82] *Mysterium tremendum*. Communitas, according to Turner, paradoxically emerges where social structure is not. It cannot endure long, for in that tremendous bonding of individuals as one body to a higher "cause", there is no class, structure or organization. Yet when the moment is over, a sense of unity remains. Social ties and structure emerge strengthened and reaffirmed. One could say that communitas answers the cognitive imperative in the most deeply psychologically fulfilling manner, and that is what truly brings people together for ritual experience, and what holds them together in between.

---

[81] Turner, *Ritual Process*, 128.
[82] Bell, *Perspectives*, 25.

Context and Amalgamation

Though deconstruction of the neurobiological, psychological, cultural and social aspects of ritual leads to a deeper understanding and appreciation of the process and power of ritual, their study in isolation can be misleading. Ritual functions on all four levels simultaneously, and in tangent with one another. Bell proposes three interrelated sets of interpenetrations:[83]

1. *Vertical*: hierarchies interacting with egalitarian systems, both paradoxically intrinsic to ritual.
2. *Horizontal*: space-time "here" interacting with space-time "there"; "us" (participants) interacting with "them" (observers)
3. *Concentric*: "local" (in all aspects) interacting with "central"

Along the lines of amalgamation, Lawson and McCauley propose the following complementary approach to meaning and action, form and content, likewise penetrating through all layers of ritual:[84]

Interpretation ↔ Explanation

Culture ↔ Cognition

Semantics ↔ Syntax

Tambiah offers another set of dialectic interpenetrations:[85]

Synchronic ↔ Diachronic

Ontological ↔ Social

Continuous ↔ Changing

---

[83] Bell, *Ritual Theory*, 125.
[84] Bell, *Perspectives*, 71-72.
[85] Bell, *Ritual Theory*, 20.

Traditional ↔ Historical

Ritual mediates all of these forces through all four aspects of its ambiguous nature.

The Human Need for Ritual

Based on the research reflected in the previous section, we can at least define the basic human needs met by ritual. We need ritual because…

… it facilitates our neurologically-driven need for a well-ordered, harmonious universe that incorporates the conflicting categories of our lived existence.

… it meets our cognitive demand for knowledge that is unknowable.

… it relieves our anxieties regarding our own mortality.

… it orders our lives into a meaningful sequence related to something larger than ourselves.

… it allows us to engage in sensory and passionate mythic experience without requirement of literal belief.

… it facilitates human organization and social structure.

… it mediates social conflicts

… it meets our need for unity with other human begins without relinquishing our private autonomy.

… it generates a coherent cultural matrix of world-view, ethos and tradition.

… it mediates our individual and collective identity.

… it aids our navigation through liminal periods in our lives.

… it relieves ambiguous status

The Practical Elements of Ritual Construction

The Problematic Concept of Ritual Innovation

> Underlying all rituals is an ultimate danger, lurking beneath the smallest and largest of them, the more banal and the most ambitious -- the possibility that we will encounter ourselves making up our conceptions of the world, society, our very selves. We may slip into that fatal perspective of recognizing culture as our construct, arbitrary, conventional, invented by mortals.[86]

Rappaport warns against the danger of experimentation. Individual rites are always part of a larger "liturgical order that encodes a basic worldview that is simultaneously cosmic, cultural, physical and biological ... The authority of this liturgical order is a result of the *invariance* of the canonical, no-self-referential encoding, and it gives rise to a particular notion of the sacred as that *quality of unquestionableness*."[87] As a consequence, Rappaport concludes, in this type of system the "less than punctilious performance of a ritual" or any form of liturgical experimentation can undermine the authority of the liturgy and all that rests on it." Because the effectiveness of ritual depends on its *fixity* – in time, place, and procedure – and the certainty of its connection to absolute sources beyond community, the idea of *new* ritual is oxymoronic.

Grimes takes a more positive, though ambivalent attitude towards ritual innovation. He allows the need for it, and in fact his own work encourages it, but he refers to innovation as *ritualizing* – the deliberate act of inventing ceremonies – as opposed to *rite* or *ritual*, terms that seem to require the gravitas of time to prove their place in tradition. "Unlike rites, ritualizing does not typically garner broad social

---

[86] Sally F. Moore and Barbara G. Myerhoff, eds. *Secular Ritual* (Amsterdam, 1977) 22, as quoted in Myerhoff, "Death in Due Time".
[87] Bell, *Perspectives*, 176.

support; it seems to be innovative, dangerously creative, and insufficiently traditional ... Since ritualizing implies the invention of a tradition, it can feel contradictory, because traditions are not supposed to be inventible."[88] Private, non-institutional ritual innovation is a particular problem, as mentioned earlier. "Psychologists have treated private ritual as synonymous with neurosis. Theologians have regarded self-generated rites as lacking in moral character because they minimize social responsibility. And anthropologists have thought of ritual as traditional, collective representation, implying that the notion of individual or invented ritual was a contradiction in terms."[89] These instinctual rejections of private "ritual" may, in fact, be due to the important communal and sociological aspects of authentic ritual explored in the previous section. Having made these statements, however, Grimes concedes that for rites and traditions to live and breathe, they need constant revision. Ritualizing is an important imaginative act.

Myerhoff has her reservations about ritual innovation as well. The invisibility of ritual's origins and its inventors is intrinsic to what ritual is all about. "When we catch ourselves making up rituals, we may see all our most precious, basic understandings, the precepts we live by, as mere desperate wishes and dreams." Ritual innovation carries with it the possibility of failure, because it is easily perceived as a conspicuously artificial affair. Having said this, she asserts the need for ritual innovation. "Ritual is profoundly cultural; it is practiced, maintained by tradition, and deliberately cultivated. Like music and dance, ritual becomes deadening if inspiration, the breath of spontaneity, does not blow through the ritual structure itself."[90]

---

[88] Grimes, *Deeply into the Bone*, 29.
[89] Bell, *Perspectives*, 224.
[90] Myerhoff, "Death in Due Time".

Bell is a strong advocate of ritual innovation. She precedes her favorable arguments, however, with a considered response to negative reactions to ritual inventiveness. The dilemma lies in the fact that rituals present themselves as unchanging, time-honored customs of an enduring community. They resist change. "The tendency to think of ritual as essentially unchanging has gone hand in hand with the equally common assumption that effective rituals cannot be invented. Until very recently, most people's commonsense notion of ritual meant that someone could not simply dream up a rite that would work the way traditional ritual has worked."[91]

But change happens all the time. Bell purposes that change is perceived as unchanging because participants in such modified ritual assume that the "variation" is a limited, commonsensical arrangement necessary in a particular situation. It doesn't change the tradition in any fundamental way, it is merely adapted to suit the particular circumstances of an observance. For example, the family patriarch traditionally carves the turkey and breaks bread for Thanksgiving. But when he is crippled by Alzheimer's, the matriarch carves the turkey and breaks bread for Thanksgiving. From the perspective of ritual participants, the fundamental tradition of Thanksgiving is maintained, even though the variation represents a profound symbolic change in communal structure. The change is accepted, along with its cultural message, without objection, because the situation is seen as ... well ... situational.

Bell goes beyond tinkering, however. She aggressively pursues outright ritual invention – constructed intelligently -- as an effective and authentic experience for innovators and participants alike. "Today there is a growing social legitimacy for many types of ritual improvisation as well as the unprecedented visibility of the very dynamics

[91] Bell, *Perspectives*, 223-224.

of ritual invention." Ritual "allows for the formulation and expression of new identities and new ideals impossible to conceive within the rubric of older forms of ritual practice." She offers a number of convincing examples, which can be grouped into two basic types of innovation. The first are situational occasions reflecting current or modern concerns: the women's seder, Arbor Day, mourning rites for felled rain forests, and psychoanalytical rituals for mediating dysfunctional family interactions. I might add candlelight vigils occasioning social protest ("rituals of rebellion"), on-site memorials for terrorist victims, and the Jewish *bat mitzvah* and *bat brit* ceremonies. These rituals all meet a current need not available in our "traditional" matrix of ritual, but they are deemed legitimate by their participants. Bell's most impressive category is that of communal identity. She analyzes in great detail the deliberate construction of ritual as a mechanism for social cohesion and collective identity in such cases as the Freemasons, the former Soviet Union, the international Olympic Games, African-American culture[92] and most especially America itself, with our Pledge of Allegiance ritual (under constant revision), Fourth of July and Thanksgiving Day rituals, and the national anthem with its accompanying ritualized protocol. Though openly constructed by committees, commissioned poets, analysts and "ritual experts", both categories of recently invented ritual are highly effective in generating both "communitas" and social structure.

Bell goes on to propose that a new paradigm of ritual is emerging in the modern Western culture – specifically in Europe and America. It is a paradigm focused on the inward self, rather than the outward collective. "In the newer model, ritual is primarily a medium of expression, a special type of language suited to what it is there to express,

---

[92] particularly the modern ritual invention of Kwanzaa in 1966 by Mauloana Karenga, a professor of black studies.

namely, internal spiritual-emotional resources tied to our true identities but frequently unknown and undeveloped." The new paradigm is apt to define community and society in terms of self rather than the self in terms of the community. Metaphors of wholeness and attainment replace older ones of transcendence and deliverance.[93] This seems to be where my focus group is taking me with our rituals of personal service, solidarity, recognition and expressions of situational grief moments.

This trend carries with it two implications, according to Bell's analysis. First, it encourages creative ritual invention, because it is seen as based on a *universal human instinct*, making the process an absolute of nature. "Ritual practitioners of all kinds in Europe and America now share the sense that their rites participate in something universal ... Belief in ritual as a central dynamic in human affairs – as opposed to belief in a particular Christian liturgical tradition or the historical practice of Jewish law – give ritualists the authority to ritualize creatively and even idiosyncratically. Ritual is approached as a means to create and renew community, transform human identity, and remake our most existential sense of being in the cosmos."[94] This phenomenon may well be a by-product of modernity, along with its relativism and its emphasis on individual over collective, the universal over the particular. This does not mean that a ritual based solely on universal symbols and values is going to work. In fact, without the context of a particular matrix of symbols and tradition it will likely fail (as will be discussed shortly below). It does mean that ritual is now seen as a *universal human enterprise* for mediating inward exploration and a personally redemptive social structure.

---

[93] Ibid.; 241.
[94] Ibid.; 264

Second, the criteria for judging a ritual as effective or ineffective is different. Under the old paradigm, the ritual is effective if it is *performed correctly* (ala Rappaport), the way it has always been performed from time immemorial. Under the new paradigm, there is less weight on authority and tradition and more on efficacy. A ritual is effective if it provokes the desired emotive response. It's not the process that counts, but the results. Was "communitas" achieved? Was the ambiguity resolved? Did participants experience personal transformation? Was there an emotive connection to something "larger than self"? "In the ritual paradigm now becoming dominant in America and Europe," Bell observes, "one expects the rite to work by affecting people's cognitive orientation and emotional sense of well-being." [95] This offers a tremendous challenge to any would-be ritual innovator.

Bell hails this new trend as a fascinating development in the West. I hail it as a fascinating opportunity for a Reform rabbi. Given a Jewish constituency acculturated in Western society – with its trends, universalism and orientation towards personal autonomy – I see great potential in ritual innovation within the movement in order to meet the pressing needs created by modern medical technology. If Bell is correct, acculturated Jews are open to ritualized means of resolving psychosocial dilemmas. As participants in such rituals, they are participating in a legitimate universal enterprise and will judge the authenticity of such rites by emotive response.

Bell's prognosis of modern ritual innovation is optimistic. "Ritual is not primarily a matter of unchanging tradition. On the contrary, some analysts now see ritual as a particularly effective means of mediating tradition and change, that is, as a medium for appropriating some changes while maintaining a sense of cultural continuity ...

---

[95] Ibid.; 241.

Ritualized activities can be taken as traditional within a very short time; they can also be very flexibly appropriated; they may be practiced more or less faithfully despite strong reservations about every aspect of them."[96]

Characteristics of Effective Ritual

Effective ritual is characterized by the following four elements, according to most ritual theorists:

Tradition

The more grounded in tradition a ritual is perceived to be, the greater chance it has of successfully fulfilling its function. "No ritual stands by itself. It is always embedded in a thick context of traditions, changes, tensions, and unquestioned assumptions and practices."[97] Tradition itself is composed of four key attributes which, taken as a whole, provide the "thick context" required for meaningful ritual experience.

First, tradition is associated with a particular group identity. Myerhoff emphasizes this aspect strongly. For her, the effectiveness of ritual "is determined in large measure by a stable, socialized, culturally homogeneous group."[98] Her opinion reflects Douglas' *grid/group* model discussed earlier, in which the relative strength or weakness of ritual experience depends on the relative strength or weakness of ritualized social structure. In fact, everything discussed thus far regarding the cultural meaning and sociology of ritual points to group identity as a critical factor in one's sense of tradition.

Second, tradition appeals to the past. It can even be viewed as a strategic reproduction of the past. Reproduction of the past can be historical (narratives handed

---

[96] Ibid.; 241-252
[97] Ibid.
[98] Myerhoff, "Death in Due Time".

down from previous generations), territorial (linked to sacred places of the past), calendrical (repetition of an annual cycle of events) or precedential (consistent with older cultural precedents).[99]

Third, tradition is composed of a matrix of specific value-laden symbols peculiar to itself, "driven deep into the marrow through repeated practice and performance."[100] Shared images and their associated values provide the ritualized body a cultural "sense of ritual", according to Bell, a sense that embodies specific cultural schemes and strategies conveyed by specific metaphors and symbols.[101]

Finally, tradition contains within it a system for producing authentic ritual "experts" – the shaman, the priest, the rabbi – whose perceived function is to preserve tradition. They are almost universally, if not explicitly, perceived as intermediates between the ordinary and the extraordinary, the profane and the sacred. As such, they are qualified to determine ritual convention. It occurs to me that ritual experts are entrusted with both perpetuation *and* change within tradition. The "situational changes" they initiate are acceptable because they are themselves historically and organizationally "tradition" itself – tradition personified, if you will. Tradition can change itself and yet remain unchanged.

Mystification

Effective ritual transcends the ordinary, as elaborated earlier in the chapter. Bell calls this phenomenon "misrecognition", seeing and not-seeing the symbolic object or gesture for what it is (the profane mysteriously and temporally transformed into the sacred). Turner's "communitas" is part of the mystification of ritual. Mystification is

---

[99] Bell, *Ritual Theory*, 123.
[100] Grimes, *Deeply into the Bone*, 5.
[101] Bell, *Ritual Theory*, 107-108.

characterized by intense, potent emotion. "Joy and woe are woven fine/A clothing for the Soul Divine" (William Blake).

Modeling of the Ideal World or Cosmic Order

Effective ritual frames the situational experience within larger truths or realities. The entire matrix of tradition is represented – its values, ethos, worldview, ideals – within the ritual drama, thereby achieving a sense of consistency, affirmation and internal coherence. It explicitly models the world into the form and image of tradition.

Transformation

Ritual not only communicates something, according to Myerhoff, but is perceived by those participating in it as "doing something". Whether the transformation is a pronouncement of status or an existential transformation of an individual and/or society, as described earlier, it represents a factitive internal or external change – be it a change of heart or a change of personal status.

The Characteristics of Failed Ritual

What are the pitfalls of ritual construction? Grimes compiled a comprehensive list of "infelicitous performances"[102] The first two categories, "misfires" and "abuse", along with their subcategories, were identified by J.L. Austin. Based on his own observations and research, Grimes extended the category of "abuse" and proposed seven others.

---

[102] see Figure #1 in Grimes, "Ritual Criticism and Infelicitous Performances" in *Readings*, 279-293. Originally in *Ritual Criticism: Case Studies in its Practice, Essays in it Theory* (Columbia: University of South Carolina, 1990)

1. Misfires

Nonplays: In this instance, the ritual is deemed illegitimate by ritual authority. It is "not allowed" or simply "does not exist" within tradition. This is perhaps the greatest vulnerability of invented or recently borrowed rites that are seen as completely disconnected from the structures that might legitimate them.

Misapplication: It is a legitimate ritual, but the persons and/or circumstances involved in it are inappropriate. Avoidance of misapplication requires a careful understanding of categories of ritual and their particular function in the tradition. It is important to select the proper *type* of ritual for the occasion. The obvious example I am working with is the prohibition against enacting traditional mourning rituals over a person who is still physically alive. These are simply not allowed.

Flaws: Ritual procedures are carried out "incorrectly" or inconsistently. In other words, they are too vague in form. This is Rappaport's mantra against ritual innovation.

Hitches: The ritual is not complete. Something "important" is left out, or it is interrupted before fulfilling its function. This misfire is most often a performative problem.

2. Abuses

Insincerities: Ritual leaders or participants saying or doing things without the requisite feelings, thoughts or intentions. In Jewish parlance, there is lack of *kavannah*.

Breaches: The ritual ceremony itself is carried out successfully, but subsequently fails because there is no meaningful follow-through to validate the transformative experience. An example that comes to mind is the common lack of follow-through for bnei-mitzvah ceremonies. The rite of passage from childhood to adulthood ultimately

fails, because it is not followed through with adult responsibilities or expectations within the community. The status change is "not real".

Glosses: The ritual proceeds without acknowledging contradictions or major problems. Examples include the pregnant bride at a wedding, the eulogy of a suicide at a funeral, the occurrence of a local or national tragedy just before a "joyous" celebration. Ritual is expected to acknowledge these contradictions in a way that incorporates them into the ritual sociocultural context of tradition. Otherwise it is a denial of reality, and therefore a fantasy.

Flops: Ritual procedure is done properly, but it fails to resonate. It does not generate the proper tone, ethos or atmosphere. This is a performative problem.

3. Ineffectualities

A ritual that fails to bring about the intended observable changes. Grimes is primarily referring to "magic" rituals, which are expected to literally heal the sick, change the weather or effect some other supernatural result.

4. Violation

A ritual is morally wrong or intrinsically demeaning. Here Grimes is making an admittedly ethnocentric value judgment. For him, anything involving the breach of a universal code of morality is an illegitimate ritual. Examples are human sacrifice, criminal activity or unusual emotional or physical cruelty.

5. Contagion

The ritual "spills over its own boundaries." It may be effective, but it is uncontained. This often happens with "rituals of rebellion", which may break into violence and spread out of control. It can also happen in cases of mass euphoria, where

participants lose control of their actions or emotions. As already discussed, one of the functions of ritual is to *control* emotion within prescribed social boundaries.

6. Opacity

The ritual is experienced as meaningless, unrecognizable or uninterpretable. He specifically cites the use of archaic language like Hebrew, which to some extent creates mystery, but will begin to cause confusion if overdone. I would add that a lack of personal connection to the matrix of tradition informing the ritual would add to its opacity.

7. Defeat

One ritual performance invalidates another. Grimes is referring to ritual competition and conquest. His examples are biblical (i.e. Elijah's ritual defeating that of Baal's prophets) and political (the plundering of a conquered ritual system for its symbolic wealth). Closer to home, we can look at the ongoing ritual competition between Passover and Easter, Christmas and Hannukah, in which the mutual pirating of symbols are meant to validate one ritual and supercede another.

8. Omission

A ritual act is not performed, even though the occasion calls for one. A person dies "without proper burial", for example, or a Jewish male goes without circumcision.

9. Misframes

The genre of the ritual act is misunderstood. Observers of a ritual misconstrue its meaning and/or function. An example might be the uninformed observance of Purim, which can easily lead to a gross misinterpretation of its cultural message.

Strategic Elements for Ritual Construction

After conducting my survey of ritual studies I identified the following ten strategic elements for constructing effective ritual:

1. Groundwork: Symbolic action requires a "fact" for which it represents in order for it to be meaningful. The status change represented by ritual transformation should already be in effect. It has only to be formally enacted and recognized. Groundwork includes whatever preparation is necessary to prepare participants for altered status – education, counseling, tasks to be completed, etc.

2. Symbolism: Effective ritual is a coherent, integrated symbolic system weaving individual experience with community, cosmos, and tradition. The following types of symbolism thicken the weave:

a. Iconic symbols of the sacred, of tradition, of community
b. Cross-symbols from other rituals in tradition
c. Condensed symbol (representing several layers of meaning simultaneously)
d. Polarized symbols (clusters of oppositions)
e. Referential symbol (a single symbol alluding to an entire mythical narrative or matrix of meaning).
f. Displacement symbols (objects which represent person, event, value or relationship).
g. Metaphoric actions manipulating symbolic objects

3. Tradition: A ritual gains considerable credibility and legitimacy when it is well

grounded in the cultural matrix of sacred history, customs, values, texts and ideals of tradition. Symbolic exemplars, or "ritual experts" – representatives or even personifications of tradition – should be asked to facilitate the ritual when possible.

4. Community: Communitas requires active communal participation, the involvement of family, friends and community. Individual experience is magnified by a concomitant community "echo chamber" experience. The closer the social ties between participants, the greater the efficacy of the ritual. The participation of what Turner calls "adepts", and what counselors today call "support groups"– people who have suffered the same affliction or experienced the same status change – is particularly powerful for meaningful experience. Grimes asserts that the presence of "survivors" not only generates communitas, but facilitates completion of unfinished rites of closure or mourning for participating "survivors".[103]

5. Sacred space: A sense of the sacred can be achieved by constructing a "sacred space" within which the ritual takes place.

6. Performative Action: Movement and gestures enacted as ritualistic drama. They are characterized by repetitive action, staging, sequential ordering, articulated feelings and evocative presentational style. These are marked by a formal and disciplined manner.

7. Ritual Language: The type of words and the way they are delivered helps to remove the ritual moment from the ordinary here-and-now.

   a. Archaic or poetic language

   b. Restricted conventional and/or performative utterances

   c. Repetition in form and content; construction in pairs of ideas

[103] Grimes, *Deeply into the Bone*, 279.

d. Symbolic speech: metaphor, metonym, paradigm

e. Delivery characterized by emphatic vocal prolongations, controlled modulation, stylized rhythms, tempo or stress patterns, distinctive vowel harmonies

8. Focusing Mechanisms: These are elements that stimulate the ergotropic region of the brain which, among other things, excites communitas: chants, songs, music, dance, incense, mantras, associative foods, etc.

9. Narration of personal history: Personal history is integrated into the larger narrative of communal or sacred history.

10. Follow Through: For a ritual to have lasting meaning for individuals and community alike, it must be followed through with the everyday actions implicitly promised by symbolic action: communal and pastoral support, ideals translated into action, the privileges and responsibilities of new status manifest in behavior.

So far I have explored classical Jewish texts for enduring and underlying principles that should inform my ritual innovations, clinical pastoral research and personal survivor narratives for an intelligent understanding of caregiver needs, and ritual theory for tools and principles with which to construct effective ritual. How does it all come together in the messy reality of lived experience? Just as I completed my research, and before embarking on the creative portion of my thesis project, an opportunity to apply much of my theoretical work to a live situation came my way. I will narrate this case study in Chapter Six before presenting my work-in-progress in Chapter Seven.

Chapter Six

"Bud and Barb: A Case Study in Progressive Dementia"

When I first picture you in my mind, Daddy, I see my favorite photograph. It's a picture that reflects a very handsome young man, tall, lean and lanky. The picture shows you with thick dark hair, a flawless complexion, and wearing a crisp white shirt. In this picture, you are tenderly holding a young girl in your arms. You are smiling and I, the young girl, am embracing you and laughing with great joy. -- Bud's oldest daughter

For fifteen or twenty years
You carried a small poem of mine
In your pocket.

Carried it through all
The scrapes and wars
Until one day it simply
Came apart at the folds

One day it simply fell away
From your hands to your feet
Like the petals of a rose
--- Bud's youngest daughter

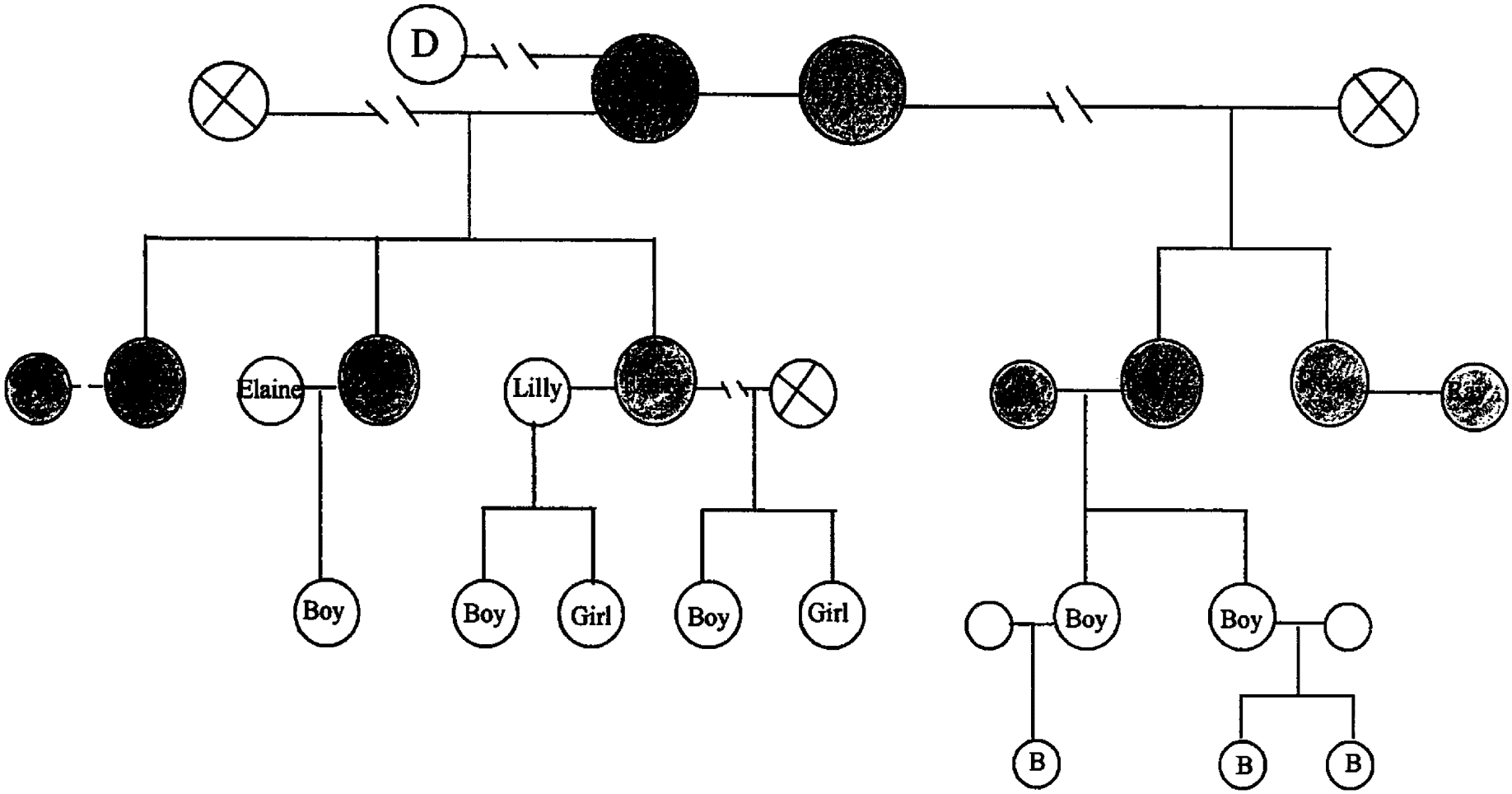
I crossed paths with the "Levitz" family by sheer coincidence. One member of this family insists that it was no coincidence at all. I will call her "Jen" (the names of members of this family have been changed to protect their privacy). Although I hadn't seen Jen for two years, her face popped into my mind the minute I was advised to seek out a well-dressed woman to help me with my wardrobe in preparation for placement interviews. I've watched Jen in action over the years as our chapter Hadassah president, AIPAC president and now the director of a major non-profit organization -- a gracious, attractive, smartly-dressed woman with a big heart and amazing organizational skills. So I gave her a call. After she spent a great deal of time helping me with my wardrobe, I mentioned the topic of my thesis. That's when our relationship changed forever. Could I

help her with her dad? He was losing his memory and his body was getting weaker and more frail by the day. His wife was feeling overwhelmed and seriously considering a nursing home for Bud. Jen seemed uncharacteristically indecisive and even helpless.

My research on ritual theory was complete, but I was just finishing up my clinical research on issues relating to caregivers and their losses, so my intervention protocol was not yet fully formed. My survey of Jewish texts was still in the future, so I had yet to develop my ethical boundaries for innovating therapeutic ritual. My focus group was still an idea, not a reality. I reminded Jen of my inexperience, as well as the underdeveloped stage of my thesis, and I reminded her of the other rabbis in town (there weren't many, as we live in a small town). She rejected each of these rabbis for one reason or another, and since neither she nor her father was affiliated with a synagogue in town, I agreed to meet with her father and stepmother.

Referring to the pictograph on the following page, I will now introduce the main relationships in this family before describing my role and application of newly-learned pastoral techniques to their situation:

Bud and Barb: Bud and Barb were both widowed with grown children when they met and married nearly twenty-five years ago. At the time Jen introduced me to her family, Bud was almost 85 years old, Barb 82. So they enjoyed a long and stable relationship before Bud's illness. Bud was a war hero, an Air Force pilot who flew over a hundred missions during WWII, Korea and Vietnam, a quiet and gracious man even during his illness. He was a strongly identified Jew, but a humanist in his thinking, so he attended High Holy Days and presided over the annual Passover Seder, but enjoyed the religious customs of those close to him, including Barb and her family. Barb was a


D
Elaine
Lilly
Boy
Boy
Girl
Boy
Girl
Boy
Boy
B
B
B

down-to-earth woman of strong character, formerly involved in state politics as the Field Director for Senator Wallace Bennett. She was used to managing all of her affairs and making most of the decisions in their relationship. Though Mormon in upbringing, Barb was likewise a humanist, and so encouraged and enabled Bud's Jewish observance. Passover Seder included everyone on the pictogram around the table. Like Jen, she was uncharacteristically paralyzed by Bud's deterioration.

Jen and Rose: Bud's daughters were extremely devoted to their father, having lost their mother after an extended battle with cancer. They enjoyed a close relationship, even though their personalities were quite different. Rose was an English professor of poetic sensitivity and tenderness, married to an artist, Ray. Jen, as I mentioned earlier, was a managing director with intense task-oriented drive, married to an executive, Jay. Both Ray and Jay are devoted and supportive partners to their wives.

Larry, Eric and Karen: Barb's two sons lived 20 minutes away, while her daughter lived in her home, along with Karen's partner, Kyle. All three children were sweet and amiable people, devoted to Barb and Bud, but passive in nature. Normally this would not have been a problem, because Barb was a consummate matriarch, but in this situation she was unable to marshal the resources of her family to help her. Larry and Eric appeared to have good marriages, though their wives remained invisible to me until our family intake meeting before Bud's funeral. Kyle was a Vietnam veteran, a nurse practitioner like Karen, who obviously loved Bud, but unable to help Barb as much as Jen had hoped because of alcoholism and bouts of depression.

This family is composed of nice people. There are no wicked witches or warlords; no sneaky gollums or criminal drug addicts. But as an extended family, they

are not particularly close. The two families -- Bud's and Barb's -- did not spend time together. As Jen described the situation, "We each had our own space and places in Daddy's heart, and that worked fine for over twenty years." When I briefly came into the picture, Bud and Barb's progeny had little to do with one another except during the annual Passover Seder. There were no feelings of animosity, just independent, separate lives.

Barb actually noticed a change in Bud almost two years before anyone else did. Bud began to feel lost and confused when they went traveling. As much as she loved to go traveling with her husband, Barb soon realized that those days were over. He became more and more anxious about leaving the house, except to do his weekly volunteer work at a nearby hospital. Always meticulous and orderly in his routine -- a reflection of his military training -- his need for invariable routine became extreme. Barb, used to freedom and adventure, began to feel trapped within the walls of her home, with a man who became overly anxious whenever she left and increasingly helpless. Barb determined to shoulder through increasing caregiver tasks herself. But the confinement and burden became too much, even for her. The family finally noticed Bud's deterioration this last Passover. As Lily would later write in her tribute to Bud a month after his death, "This year we've noticed my father-in-law Bud get weaker and more frail. His balance was bad, he had a couple of falls and his memory started to go ... Maybe more than ever before he seemed happy to see us when we got together, and happy to see all the kids." Jen, being who she is, picked up on Barb's despair as well as her father's failing health, and tried to initiate action -- medical testing, a chair lift for the stairs, more caregiving responsibility from Karen and Kyle. But Barb's paralysis became her own.

For some reason, nothing happened. This was a classic case of an ambiguous situation informed by "frozen grief", as described by Boss and numerous other researchers (see Chapter Three). There was nothing wrong with the family. They were simply in a situation that required outside help.

I conducted my initial meeting with Bud and Barb as a journalist – that being my training before entering the rabbinate -- having reviewed Boss and looked over the Marwit-Meuser Caregiver inventory before hand. After interviewing them together, and then Barb by herself, I went home, filled out the inventory and prepared an assessment for the family. The assessment tools in Appendix #1, elaborated at length in Chapter Four, reflect both what worked for me and what I needed but didn't have. Jen set up a family meeting for Bud's side of the family, while Karen set one up for Barb's side of the family. Barb chose not to attend these meetings because she did not want to dominate them. She is a shrewd woman, and had good reasons for not inserting herself in the family conversation about how to help her and Bud, but her absence would later lead to friction between her and Jen.

My goal for these family meetings was to mobilize the family on Barb's behalf, share information so that everyone would have the same perspective on Bud's condition, prepare them for what I thought was going to be a long ordeal (though medical testing was still underway, we thought at that point that he had some form of progressive dementia), and to initiate activity that would relieve Bud's anxieties, collect his memories before they disappeared, honor him in a meaningful way, and begin to prepare them for his eventual death. Since Jen and Jay are both executives, and the leading decision-

makers in this crisis, I felt that they would appreciate an agenda. It would be a familiar structure. The agenda was a simple one:

Bud and Barb Family Meeting

I. Medical update

II. Family member perspectives

III. Clarification of Needs: Bud, Barb, other family members

IV. Frame situation

V. Goals for larger family meeting

VI. Delegated tasks for meeting goals

If you compare this agenda to the one I recommended in my intervention protocol (see Chapter Four), you will note some important differences. Although these meetings went well, they could have gone better. "Family member perspectives" is the opening for sharing feelings and perspectives. That needs to be last on the agenda, so that processing can continue after I leave. According to Jen and Karen, both meetings led to extended family discussion, tears and plans after I left. So information should come first -- the anecdote for ambiguity -- then task items such as needs assessment, goals and delegation. From there we can go into framing the situation within Jewish tradition and on to emotional processing. The agenda turned out to be a great pastoral tool. First, it imposed structure on an unbearably chaotic and uncertain situation. That, in and of itself, had a calming and mobilizing effect. And second, it led to a highly productive family meeting which only took an hour in one case, thirty minutes in the other. Since Jen envisioned a third meeting with both sides of the family, I added Item V above, though it proved

unnecessary. We successfully mobilized the family without it. The following is the Needs Assessment handout I passed out to family members along with the agenda:

Needs Assessment

Bud: Anxiety over physical condition, loss of abilities, loss of control, loss of dignity and meaning in life. Unresolved grief, particularly from WWII days. Wants routine, peace.

He needs:

1. Information on medical condition. A plan for dealing with it.
2. Routine. A predictable daily schedule he can count on. Control.
3. Meaningful Activity. Opportunity to contribute to others.
4. Tell his Life Story. See his life as a narrative that is part of something bigger than he is -- part of a mythic narrative, natural order of things, larger destiny.
5. Legacy. Something that says he made a difference.
6. Grieve for unresolved losses.
7. Closure with family members
   - Thank you
   - I love you
   - I'm sorry
   - Good-bye

Barb: Frustration over confinement, loss of independence, loss of social contacts, loss of political involvement, loss of religious activity. Her feelings are typical of spouses in caregiver roles. She is also beginning to sense a gradual loss of the man she married.

She needs:

1. Information on Bud's medical condition, including a projection of what to expect in the future and a plan for dealing with it.
2. Time away from Bud. Blocks of time she can depend on.
3. Nursing assistance with Bud. Right now he needs help with his catheter. As time goes on, his nursing needs will increase. These should not fall on Barb for two reasons. First, trying to perform these tasks would endanger her own health. Second, doing so would degrade their relationship and accelerate her loss.
4. Emotional support
   a. Support group or clutch of friends who have or are experiencing the same thing with a spouse.
   b. Family support and understanding as she negotiates between her loyalty to Bud and her need for an alternate source of personal interaction and social companionship. Family should be a safe environment where she can vent

her feelings and opinions -- whatever they may be or however they are expressed.

The Family: Progressive dementia of any kind will often stimulate contention among family members. This is normal and does not mean the family is inherently dysfunctional, just under stress by an external situation. Contention in this kind of situation occurs for two reasons:

1. The strain of uncertainty typically leads to conflict. Also, complex emotions over multiple losses can explode, or leave little room for patience and understanding.
2. Different family members move through different phases of loss at different times and with different perspectives. These can be seen as incongruent or inappropriate and lead to angry responses.

How to manage it: Regular family meetings for updates, "venting", and necessary readjustments. Whoever is facilitating these meetings should emphasize the imperative to accept and validate whatever is expressed. If the situation goes on for a long period of time, you may consider a family counselor to facilitate your meetings to insure that relationships do not deteriorate and suffer permanent damage.

This last paragraph ought to be appended to any needs assessment for a family meeting. I am certain it prevented a great deal of *tsoris* over the course of their difficult trial. In fact, the only major relationship problem that threatened family unity occurred between Barb, who was not indoctrinated at these meetings, and Jen. Without determined peace-making efforts on Jen's part, supported by her husband and sister, and the reluctant reciprocity on Barb's part, in concession to the *kippa* on my head, both women would have lost a long and mutually-supportive friendship that predated any marriage ties. It would have been a bitter loss along with the primary loss of husband and father -- just when they needed each other the most. The conflict, by the way, was centered on monetary issues, which I am convinced was not the real source of Barb's lashing anger. It had everything to do with mounting grief and her inability to stop the impending loss of her man. Since I have observed this phenomenon many times in my

personal and professional life -- money as a flash point between the elderly and younger family members. I believe there ought to be resources available for monetary management outside the family network. This would be something investigated by the point person assigned to a family (see Chapter Four under Phase One Crisis Management).

Returning to the family meeting, we worked our way systematically through the agenda and Needs Assessment handout. For Bud, I recommended two things: involvement in a daily minyan -- to give Barb respite, expose him to the calming ergotropic effects of Hebrew prayer (see the section on the neurobiology of ritual in Chapter Five, summarized by Diagram #2), and to give him a means of rendering service to others by making himself part of a traditional minyan needed for a mourner to say Kaddish (something which requires neither physical nor mental strength); and a Birthday Seder as a venue for honoring him and collecting memories. No one was excited about the minyan idea, so we dropped it. But the family moved ahead on the Birthday Seder idea. His 85th birthday was just two and half months away, which made the timing perfect. I briefly summarized two articles on Jewish tradition and aging, giving each member a copy of these articles to read and discuss in greater detail with each other.[1] I also gave them a copy of Boss's book. From the types of conversations I had over the following weeks, I could tell that some family members read the material, including Barb, and others did not. If the situation had gone on as long as I had anticipated, I think they would have all gotten around to reading it sooner or later.

---

[1] "Do Not Cast Us Away in Our Old Age" by Eliezer Diamond, and "The Mitzvah of Bringing Out the Beauty in our Elders' Faces" by Danny Siegel, both in *The Heart of Wisdom: Making the Jewish Journey from Midlife through the Elder Years* ed. Susan Berrin (Jewish Lights; Woodstock, VT) 1997.

Jen took on the responsibility of planning the logistics of the Seder, while Rose and I collaborated on the Haggadah. Her main task was to write a personal history of her Dad and include as many of his remaining memories as possible. My first script was decidedly too long and complicated, given his weakened state. I simplified it considerably so that it could be conducted either around the table or around his bed, and so that he would be the center of the service without having to perform or even speak if he was unable to do so. The pages of Bud's Haggadah are in Appendix #2. As simple as it is, it reflects everything I learned in my research on ritual theory. First, the concept of a Seder came out of family narrative and primary memory of Bud as the leader of their annual family Passover Seder (this is particularly true of his grandchildren). Bud's own brightest memories when I talked with him were of his days as a pilot, and of his family, particularly of Barb. So the picture I envisioned for the front cover was to be of Bud as a younger man in his pilot uniform. The inside cover was to be a family collage, past and present. The reason these pictures do not appear in the haggadah presented in the appendix will shortly be apparent. The haggadah begins with a short responsive that is meant to transport the family into a sacred dream world of memory and peoplehood. The Podwall illustration is meant to define that peoplehood as an inclusive Jewish one. A short narrative by the leader parallels Bud's life with that of Moses. It was an easy parallel to make, not only because of his heroic participation in an epic period of our nation's history, but because he, like Moses, was a Levite. This is followed by familiar Hebrew blessings from the traditional haggadah. Instead of Bud pouring water over his hands in the traditional preparation of a Seder leader, I have family members pouring water over his hands, drawing from the Talmudic tradition of students pouring water over

the hands of their teachers as a sign of deep respect. Not only would it have carried through with his yearly hand washing -- vivid in everyone's mind -- it would have foreshadowed the symbol of hand-washing that would hopefully be engraved on his gravestone (a tradition for anyone who is a Levite). Each family member was to then give Bud a chocolate (his favorite treat), give a one- or two-minute tribute and then light a candle (functioning both as a birthday and Passover candle). "The Telling" was to be excerpts from Rose's biography of Bud. The haggadah ends with a family prayer over Bud, followed by cake and dinner.

It never happened.

Medical tests were necessarily spaced one by one, with time in between for him to recuperate -- a source of great anxiety for the family. We finally got a diagnosis: dysfunctional metabolism in his thyroid, a cause of dementia that can be reversed. Barb was briefly optimistic for a full recovery, but Jen and I knew something else must be terribly wrong. Each time I came to see him he was considerably weaker, until he was completely bedridden. He was not in pain, but he was worried about himself as a burden and about his diminishing cognitive abilities. On one visit, while I sat next to his bed, I suddenly understood why his two strongest memories were of Barb and his WWII days as a fighter pilot. Barb was ever present before his eyes (and he was anxious when she wasn't), while the sound of airplanes streaking across the skies could be heard quite clearly from his window all day long. He always wanted a healing blessing from me, but my probing for memories added to his stress. Trying to remember only reminded him of his condition. I have learned from that to let silence be the lead tool in my effort to comfort anyone suffering symptoms of dementia.

The family came through spectacularly. Barb got instant relief from her burden as caregiver, as well as plenty of respite time, including a weekend vacation while Jen and Jay cared for Bud. Barb's sons came over several times a week, while Karen and Kyle took on more responsibility. Rose spent a great deal of time on the bed with her father, gently remembering for him. On the two occasions I saw them together, it was clear to me that he derived a great deal of joy from her company. Jay unobtrusively straightened out their paperwork, thereby relieving stress from Barb and Jen alike. And Jen spent many hours by the side of her father. The grandchildren began making visits on a regular basis, much to their delight as well as Bud's. As anticipated (thanks to Boss), after Barb was relieved of a great deal of her caregiver burden, her grief over losing Bud rose to the surface. And as much as everyone tried to alleviate her emotional turmoil, it was nevertheless painful beyond endurance, particularly as former losses through death, divorce and estrangement came back to multiply her grief.

We had some cause for optimism when the treatment for Bud's thyroid problem began to take effect. He began to have periods of clear and rational thinking. Then a week before I had to return to Los Angeles to finish my last year in rabbinical school, and three weeks before his birthday, Bud was diagnosed with late-stage Hodgkin's Lymphoma. I offered to call Carol Einhorn (the director who pulled together my focus group) at Jewish Social Services to enlist support and resources. Jen did so herself. Jen and Rose went with their parents to hear the medical options, which were chemotherapy or nothing. Chemotherapy would have given Bud a 30% chance of living another year or two, but it would mean a harsh and toxic treatment that would put him through a great deal of pain. Bud's mind was thankfully lucid at that moment. He listened, told the

doctor that he had presented things very clearly, and then, being the hero he was, pulled himself up and declared that he did not want to have any treatment. His mind was made up. To their credit, the family stood behind his decision, even though it was particularly difficult for Barb and Rose to accept. With Carol's help, Jen took it upon herself to make arrangements for a hospice, a painful task as her father wanted to stay in his own room. But it was the best arrangement for all of them. His end-stage condition required a full nursing staff and a medical team experienced in comfort care. The family went through hell watching Bud die, particularly when he stopped eating and drinking. It became a ten day death watch, with family members rotating shifts to be with him. It could not have been easy to be there for him. But they were. Jen told me, "We never had to make a schedule for staying with Bud at the hospice. Someone was always there." He died without pain, his family near at hand, the way most of us want to go, but will not.

From that point on, I followed through with my training at the college for funeral intake. According to Jen, the successful mingling and unification of Bud's two families during this critical and painful period was a direct result of my intervention. Lily's recent tribute to her father-in-law reflects this newly-found cohesiveness, as well as the impressions she -- as a Mormon in-law normally standing outside the inner circle -- had during this family drama, and the role I played in it. Here are a few excerpts, with my name changes in italics:

> I wasn't close to *Bud* -- he was so quiet -- I hardly knew him. I wanted to know him better, but he didn't talk about himself, so I didn't know him as well as I would have liked.
>
> We were at *Bud* and *Barb's* house to visit them ... and I had my scrapbook to show them. *Bud* was too weak to get up, so we sat with him and *Barb* up in their bedroom. *Larry* had to help *Bud* sit up -- he was too weak to do it himself. *Barb* got up on the bed with *Bud* and held his hand while they looked at the scrapbook

together. He seemed to enjoy seeing us and looking at the scrapbook. I kissed and hugged him, feeling bad that he was so sick and weak and touched that he seemed so happy that we had come to visit.

We visited him at the care center and found him sleepy, and wanting to turn over, but too weak to move himself, so *Larry* helped him get comfortable. I said "Hi" to him and kissed him ... *Jen* was crying and saying that she and her sister *Rose* and *Barb* were so sad and lonely that *Bud* was leaving them and they had spent some time talking and crying together. When *Jen* was telling us this, I started crying and we all had a hug and talked about when we could come over to be with *Bud.*

A couple of days later, *Larry, and our two sons* and I visited him again. It was Wednesday night and the nurse was there putting some music on the CD player for him. She said he'd slipped into a coma and was not responsive. He had an oxygen monitor on his finger which showed oxygen in the 70's, which isn't enough for normal brain function. *Larry* rubbed his head, and I held his hand, thinking it might be the last time.

...we went to *Barb's* house for the family planning meeting *(the funeral intake)* ... We were greeted by the Rabbi -- a 30's sort of serious young woman with her hair pulled back in a spiky pony tail. I didn't know who she was at first, but soon realized she was the Rabbi ... She explained different parts of the funeral and how each one was carried out, what it meant ... "Now I need to hear your stories about *Bud,*" she said, looking around the room. *(Lily recorded all the stories, as well as the laughing and crying that took place during intake).*

The Rabbi was taking notes through all of this, and her face was perfectly calm and patient. I studied her -- she was giving up her Sunday afternoon to be our spiritual advisor, and to bring some comfort and to represent her religion. She seemed completely suited to her calling. I was so grateful to hear all the stories and learn about *Bud* because he was so quiet. He never talked about himself and was happy to just sit and listen to others. I thought it was wonderful that the Rabbi came over with her outline, and got us talking, and created a wonderful experience of closeness. Someone said, "*Bud* would have liked it that we're together" ... The Rabbi commented on what a loving and supportive family we were, and then she finished up talking about the rest of the Jewish funeral.

We buried Bud on his birthday, the day we originally planned to honor him. Instead of leading a birthday tribute, I delivered a graveside eulogy. Jen read the tribute she had written for her part in the Seder. Karen read Rose's tribute -- two beautiful poems, while various family members sang songs and held each other. The memories we

collected over the previous weeks, Rose's biography of her father, as well as our intake meeting for the funeral the night before, all came together in a fitting ritual of good-bye for a war hero. It was a transformative experience for all of us. Bud would have been proud of his family that day.

Evaluation

My experience with the Levitz family was brief, but it was enough to solidify my personal protocol for intervention with a family frozen by the terrible plight of a loved one suffering from dementia. It wasn't a perfect fit, of course. But I learned a great deal from this life-changing experience that I will carry with me into my rabbinate:

1. Life is unpredictable. What I thought was progressive dementia turned out to be cancer.

2. But when things veer sharply into another direction, every tool can be brought to bear, if we are flexible enough to dance with the circumstances we are given.

3. A planned ritual does not have to be enacted to be effective. Preparation for ritual is the real stuff of ritual.

4. I can't fix most things. But I can enable good people to find meaning in even the most tragic and heartbreaking situation.

5. The power of a rabbi is imaginary. If I were to point to the real movers in this life drama, it would have to be Bud and Barb, Jen and Jay, Rose and Ray, Larry and Lily, Eric and Elaine, Karen and Kyle. What they see in me is a reflection of who they are -- their goodness and courage and love.

6. I am a grieving caregiver. To care for a caregiver and their loved one is to be wounded forever.

As my mentor, Dr. Adler, would say, "Life is messy. Life is chaotic." We, as rabbis, have the *hutzpa* to wrestle with the messiness of life and try to impose order on to it. We do so because we cannot stand idly by and watch others suffer from the terror of life's random cruelties. I am grateful that Jen crossed my life when she did. Walking with her and her family, even for just a fraction of time, reminded me why I want to be a rabbi, and the kind of rabbi I want to be. So maybe Jen isn't wrong. Maybe it wasn't coincidence. But I like to think the coincidence was "arranged" by Someone who loves Bud, a Levite who kept his hands and heart good and clean all his life, a hero to the end.

Chapter Seven

"Innovated Ritual and Blessing for the Caregiver Mourning Psychosocial Loss: The Beginning of a Process"

> Rituals lead men around circles of seasons
> along the straight paths
> that depart from birth and arrive at death
> through the alterations of war and peace
> or along the dream tracks
> that cross Australian deserts[1]

Before creating ritual and liturgical pieces for this project, I laid out the following goals:

1. Provide ritual continuity that both echoes familiar Jewish customs and foreshadows future mourning rites, thus contextualizing caregiving and mourning within Jewish tradition and community life, and facilitating both pre- and post-death grieving process.

2. Assist the caregiver in coping with ambiguous loss by acknowledging the life in their loved one, while mourning lost memories and relationships.

3. Offer means of private and public expression of emotions which evoke *kedusha*.

4. Validate and normalize caregiver grief within a supportive community.

My initial creative work focused on the areas specifically requested by members of my focus group, as well as journaling and support group techniques used by grief counselors:

---

1. Roy A. Rappaport, "Obvious Aspects of Ritual", *Ecology, Meaning and Religion* (North Atlantic: Berkeley, CA) 1979. Reprinted in *Readings in Ritual Studies.*

A Caregiver *siddur*
- *Avodat Hesed* blessings (to sanctify service for a loved one)
- Progress Log (to order the chaos and relieve ambiguity)
- Prayers and Meditations (for emotional outlet and respite)
- Dreams and Memories (to journal the experience into a narrative)

A Jewish Support Group
- Opening ritual
- Closing ritual
- A ritual expression of grief when a member experiences a major psychosocial loss of their loved one

A Shabbat service dedicated to caregivers
- A *misheiberach* prayer (to be introduced and carried on weekly)
- A sermon (to educate congregants and initiate support network)

I subjected my initial work to the scrutiny of my focus group, each member working through it on their own, and then the entire group hacking and brainstorming together. The main theme of their work was *simplification.* Many of my elaborate ritual elements were streamlined so that they are now easy to use, easy to understand, and easily integrated into existing tradition. We are all pleased with the final result.

Before presenting what I have created, the work of Rabbi David J. Zucker and his collaborator, Linda Loewenstein, deserves comment and inclusion. Their ritual for mourning psychosocial loss, included in Appendix 3, was written and released this past summer, just as I was researching ritual theory and clinical studies. I studied it with Dr. Adler, as well as with my focus group. We found a number of elements we liked, as well as some we did not.

The Zucker/Loewenstein Ritual for Coping with Dementia

We liked the model of collaboration between rabbi and grieving caregiver. Unlike the members of my focus group, who are years removed from the death of their

loved one, Loewenstein is still caring for her AD-afflicted mother. So we know for a fact that this ritual works for at least one caregiver. With the help of her rabbi, she created a ritual and than enacted it. For that reason alone, it deserves to be an option presented to a caregiver in need of personal, sacred expression of grief. We liked their extensive use of traditional texts and prayer formulas. They, too, chose metaphors and ritual actions/objects which echo those already existing in our tradition, as well as foreshadowing future mourning rituals. Focus group members particularly liked the meditation on Page 5, and the prayer about memory on Page 6.

We found three problematic elements to their ritual. Having read my Chapter Two carefully, members of my group felt uncomfortable with the word "Eulogy" on Page 5 for the "Living Eulogy". But they liked the idea of sharing memories of their loved one, to recall how their loved one was before their affliction. The problem is easily solved by changing the title to something like "Living Memory". A more serious problem is the "Silent Confession" on Page 7. I cannot imagine myself encouraging a caregiver to perform *vidui*. For me, it is a damaging exercise. A cruel one. For a person already burdened with guilt ("I can never do enough"), I would replace this section with statements of affirmation. Finally, the ritual of candle cutting was difficult for my group members to understand. Even after I explained its origin in the Havdalah ceremony, it seemed too complicated and meaningless. This was a problem, by the way, with many of my initial innovations. At least with my particular group of caregivers, simplicity and peace of mind seem to go together.

A Caregiver Siddur

My *Caregiver's Siddur,* in Appendix 4, is composed of elements from both Jewish tradition and clinical grief counseling, a tool for both private and public processing of caregiver losses and experiences.

Avodat Hesed/Service of Lovingkindness: The *Avodat Hesed* ritual is meant to transform visits and acts of service into sacred moments. It begins with the traditional hand washing for visiting the sick. This handwashing also foreshadows the traditional handwashing for a house of mourning. The English dedication of one's hands for service is my innovation. The dedication varies according to the relationship the caregiver has with their loved one, each variation reflecting the rationale for honoring this individual according to classical Jewish texts. Normally one does not say a prayer when washing hands after a sick visit. My group members wanted something that would help them step out of the world of their loved one's dementia and back into the world of other responsibilities and relationships with peace of mind and a clear conscience. Hence the parting prayer:

> May the service of my hands be acceptable to God,
> and may the Holy One grant me peace.

I imagine this prayer on a laminated card tucked into the inside pocket of the *siddur*, as well as printed on the front page.

The Caregiver's Log: This section of the *siddur* helps the caregiver map the decline of their loved one as an incremental journey with a beginning and an end. See Chapter Four for a full discussion of the benefits of such mapping in relieving the anxiety of ambiguity. The caregiver would mark major points of radical change in a loved one's

physical or mental state, or incidents of extreme grief, by putting a date on a "step" and then decribing the change or incident on the journal pages in the log. Maps can be extended with more step pages. These markers would be occasions for expressing grief in a support group through prayer and "Living Eulogy" ritual (see Support Group section below).

My group was divided as to which mapping scheme worked for them -- the straight declining stairway, or the dividing stairway representing the rabbinic view of dying as a separation of mind and body -- each destined for its origin of existence. Because making choices is therapeutic for a caregiver who may otherwise feel powerless, I am including both schemes in the log, with the idea that a rabbi would discuss these two options with a caregiver and encourage an honest choice. Truth-telling about what they perceive is happening to their loved one is essential to a feeling of wholeness.

Book of Dreams and Memories: This section is a journal, in which the caregiver records memories of their loved one, as well as dreams and hopes which will never be realized. This section serves to preserve fading memories, as well as a place to read from during support group sessions.

Prayers and Meditations: This section is mean to be a spiritual respite for the caregiver. It is divided between "Ancient Prayers and Torah" -- selections straight from Jewish liturgy, Torah and rabbinic passages -- and "Modern Prayers and Poetry". Included in the first division are creative Psalmic mosaics composed by Dr. Rachel Adler and myself. I created a number of mosaics, but my focus group rejected all but one as too depressing. They wanted pieces that were uplifting and affirming, not laments or dirges.

They made an exception for expressions of grief from the perspective of their loved ones, who would not otherwise have a voice for their condition. Hence, overwhelming enthusiasm for my Psalm/Lamentations mosaic, "A Prayer on Behalf of My Loved One Who Suffers from Dementia".

The second division, "Modern Prayers and Poetry", includes a poem I wrote comparing dementia to a worn Torah scroll, as well as a prayer written by a focus group member and a poem written by a member of Bud's family. Writing such pieces is a healing exercise, as attested by both of these women.[2]

Support Group Rituals

Part of my intervention protocol (see Chapter Four), is the formation of a Jewish caregiver support group, a pastoral response strongly advocated by my focus group. I developed bookend rituals to set it apart from secular groups of a similar nature, and a simple ceremony for marking a major psychosocial loss. These can be found in Appendix 5.

Opening ritual: Following a technique used by Anne Brener in grief therapy sessions, I have support group members pinning ribbons on their clothing as an outward sign of their inward state. These ribbons echo modern cultural use of ribbons for identity purposes. They also foreshadow the wearing and tearing of black ribbons during a funeral. The facilitator can then call on caregivers to share their experiences according to

2. A publication put out by the National Center for Jewish Healing ("When the Body Hurts the Soul Still Longs to Sing") is an entire collection of prayers, poems and meditations written by the sick and afflicted, a model for helping mourners heal themselves by comforting others with their writing.

the color of ribbons they are wearing, saving the *nachemta*, or "good" experience (represented by blue and yellow ribbons) for last.

Caregivers also light a t-light representing their loved one and place it in on a table in the center of the circle. This light -- representing the living human soul and Divine source from which it came -- echo the candle lighting ceremonies of Shabbat, Havdalah, Hannukah and holiday openings, as well as the menorah and *ner tamid*. They foreshadow the yahrzeit candle and the lights on memorial plaques. The light metaphor is carried through with a large candle representing Jewish tradition, which the facilitator holds up while leading a responsive. Caregivers around the circle then recite their Hebrew name genealogically and the name of the loved one represented by their t-light. This is a standard ritual for opening Rosh Hodesh gatherings. It also echoes the genealogy lists in Torah, thereby reinforcing the Torah as a metaphor for memory. During this naming ceremony, caregivers label themseles as *shomer* or *shomeret*, "guardian protector" of their loved one -- both their physical selves and their fading Torah. It also foreshadows the recital of the deceased's name during El Ma-lei Rachaman chanted during funeral services.

Ritual for Mourning Psychosocial Loss: The 4-step ritual in Appendix 5 represents a drastic simplification of a much more elaborate 8-step ritual which I originally created. But I agree with my focus members, that this final draft does everything it needs to do in a short period of time, time being an important consideration in a one or two hour support group. This ritual is intended to help the grieving caregiver mourn their loss, as well as symbolically pass the lost memory or personality on to others

so that it can be redeemed. The readings and recitation of memory foreshadow the funeral eulogy. The objects passed around represent the memory and personality that the community helps the caregiver to redeem. The communal comfort rendered verbally at the end is a precurser to the traditional recitation given during Shabbat services following a funeral.

Closing Ritual: This ritual closely resembles that of many healing services.[3] My focus group, interestingly enough, streamlined my innovation so that we ended up with something commonly done throughout the larger Jewish community. I added a Yom Kippur custom in some communities to drape tallitot across the shoulders of congregants standing in a circle, thereby creating a *mishkan*. Not only does this create sacred space, but connects caregivers with each other and with their ancient ancestors. They are enveloped not only with their immediate community, but with the larger community of Israel -- past and present. The song "Oseh Shalom" infuses the experience with the important element of music. As this song nearly always leads to swaying motions, it also encourages the rhythmic body motions that create feelings of well-being. The final blessing -- the oldest blessing in our tradition by at least 3,000 years -- not only authenticates the closing ritual, but the entire support group session.

3. All but the tallit mishkan, for example, can be found in a closing ceremony for a bereavement session in "A Leader's Guide to Services and Prayers of Healing" put out by the National Center for Jewish Healing.

Shabbat Service Dedicated to Caregivers

My major innnovation for community acknowledgement of caregivers and their dying loved ones is the *misheberach* for those dying in mind and body. All focus group members agreed they wanted such a *misheberach* prayer, a prayer that would be introduced at the dedicated service and then carried on weekly thereafter along with the traditional *misheberach* for healing.

A Misheiberach for those dying in mind or body: The traditional *misheberach* prayer pleads for complete healing of body and soul. As one group member put it, "It's like praying that an amputated arm be restored. It's a prayer that cannot be answered, and only fills me with despair." Another said, "It didn't feel right. She couldn't be healed, and besides, it didn't seem right to keep saying her name every week for years. It didn't feel right." They needed a prayer that was honest, and one they could comfortably say indefinitely. I found one *misheberach*, written by Marcia Falk, intended for those in need of general support:

כְּמוֹ שֶׁנִּתְבָּרְכוּ אֲמוֹתֵינוּ וַאֲבוֹתֵינוּ,
כֵּן יִתְבָּרְכוּ _____.
יְהִי רָצוֹן שֶׁיֵּחָלְשׁוּ הַכְּאֵבִים
וְיָפוּגוּ הַיִּסּוּרִים,
יִשְׁלַם הַלֵּב וְתֵרָגַע הַנָּפֶשׁ.
יְהִי רָצוֹן שֶׁיִּשְׁתּוּ
כְּמֵי הַמַּעְיָן
עֲדֵי-עַד מְפֻכָּד.

As those who came before us were blessed
in the presence of the communities that sustained them,
so we offer our blessings

for those among us needing support.

_____,
may your spirit be calmed
and your pain be eased.
may you receive comfort
from those who care for you,
and may you drink from the waters
of the ever-giving well.

This prayer is problematic for our purposes in that it names the caregiver, rather than the afflicted, which my group members found to be embarassing. The Hebrew is also an unfamiliar formula for blessing, making it uncomfortable to articulate for most rabbis and their congregants. Here is my alternative:

מִי שֶׁבֵּרַךְ אֲבוֹתֵינוּ וְאִמּוֹתֵינוּ
אַבְרָהָם יִצְחָק וְיַעֲקֹב
שָׂרָה רִבְקָה רָחֵל וְלֵאָה
הוּא יְבָרֵךְ אֶת הַחֲבוּרִים. _____.
הָרַחֲמָן, הִמָּלֵא רַחֲמִים עֲלֵיהֶם. יְהִי שָׁלוֹם עֲלֵיהֶם.
הָרַחֲמָן, תַּשְׁרֵי שְׁכִינָתְךָ עַל כָּל שׁוֹמְרֵיהֶם.
בָּרֵךְ-נָא אוֹתָם בְּאוֹמֶץ-לֵב. וְחַזֵּק אֶת יְדֵיהֶם.
וְנֹאמַר אָמֵן.

May the One who blessed our ancestors,
Abraham, Isaac and Jacob
Sarah, Rebecca, Rachel and Leah
bless those who are fading from life, _____.
Compassionate One, be filled with compassion for them.
Let them be granted peace.
Compassionate One, let your Presence rest upon all who watch over them.
Bless them with courage and strengthen their hands.
And let us say, Amen.

This is a prayer that follows the traditional formula closely enough that it could easily be said immediately after the healing prayer during the Torah service. It can also follow the same ritual pattern -- the rabbi scanning the room with hand or eyes, people standing as the hand or eye sweeps by them, those standing reciting the name of the afflicted. My group said that this prayer would bring them comfort, and that it was one they would feel comfortable standing and naming their loved one every week. It is also a prayer that I can take with me into homes and hospitals where such a prayer may be needed.

Sermon and ending ceremony: My sermon flows into the ending ceremony, so they are presented as a single unit in Appendix 6. Since this service would be advertised as dedicated to caregivers in general, my sermon necessarily includes all caregivers of the elderly, the terminally ill and the demented. During the sermon I emphasize progressive dementia, because I am specifically introducing support programs for caregivers of those suffering from dementia. These programs are presented as models for similar programs for future needs in the community. The goals of my sermon are to educate congregants about the needs of caregivers and their loved ones, motivate them to join the three-level support network introduced by lay organizers during my sermon (all part of my intervention protocol described in Chapter Four), introduce the *misheberach* prayer for the dying, and symbolically enfold attending caregivers into the larger community with the same closing ceremony we designed for our support group.

Conclusion

The end products of my thesis project represent the beginning of a process, a process that will inform my rabbinate as I seek an appropriate response to the pastoral needs of my congregants. I am now confident that I can address problems for which I have no personal experience and for which there is little, if any, guidance in Jewish tradition. The process is simple:

1. Search for ethical boundaries and inspiration within classical Jewish texts
2 Learn about the particular need from specialists, through research or interview.
3. Collaborate with congregants who have personal experience with the need.
4. Develop a pastoral and liturgical response to the need based on steps 1-3, as well as ritual theory and personal creativity and instinct.

As painful as this process has been for me and for those involved in my project, I believe it was well worth the time, effort and emotional *tsoris*. It is a beginning. Not a perfect beginning, but a solid one.

May the Holy One accept the service of my heart.

ken y'hi ratzon

Bibliography

Primary Texts

Biblical Attitudes Regarding Old Age

Overt Positive Statements Equating Old Age with Wisdom, Vitality, and Authority

Judges 19:15-23
I Samuel 2:31-32
II Samuel 14:2-19; 20:15-22
I Kings 1:6
Isaiah 65:20
Ezekiel 7:26
Psalm 92:15
Psalm 119:100
Proverbs 20:29; 16:31
Proverbs 1:20-33; 8:3-36; 9:1-6
Job 12:12[1]; 32:4-9
Job 32:6-22

Implicit Positive Statements Presenting Old Age as a Divine Reward

Genesis 15:15; 22:7; 25:8
Genesis 24:1
Deuteronomy 6:2; 22:7; 25:15
Judges 8:32
I Chronicles 29:28
Ecclesiastes 8:13
Isaiah 65:20

Old Age as a Time of Physical Deterioration, Sorrow, Vulnerability and Disrespect

Genesis 18:12; 21:2-7; 27:1
II Samuel 19:33-36
I Kings 1:1
Psalm 71:9; 18; 90:10[2]; 92:15
Ecclesiastes 12:1-7

Old Age as a time of Mental Deterioration

Job 12:20
Ecclesiastes 4:13

Neutral Statements Regarding Old Age

Genesis 44:29
Deuteronomy 28:49-50
Isaiah 3:5
Ezra 10:8

Regarding Treatment of the Elderly in General and of Parents in Particular

Exodus 20:12; 21:15
Leviticus 19:3
Deuteronomy 27:16
Proverbs 23:22
Lamentations 5:12

---

[1] Reuben puts this reference in a negative category, reading it as an incredulous question. I am going with Jacob in ascribing a positive attitude towards old age as associated with wisdom. Jacob reads it as a statement. But even read as a question, it can be interpreted as a challenge to a presumed status quo.

[2] Reuben places this reference in his positive category. However, as noted in my thesis, I read this verse as equating old age with hardship and sorrow.

Rabbinic Attitudes Regarding Old Age and Treatment of the Elderly

Major Text on Old Age: B. Shabbat 151b-152a

Statements Associating Old Age with Wisdom and Experience

Genesis Rabba 59:3
Exodus Rabba 3:5
Vayyikra Rabba 25
Deuteronomy Rabba 6
M. Avot 4:20
M. Kinnim 3:6
Y. Shabbat 1.3
B. Haggiah 14a
B. Sanhedrin 17a
B. Baba Batra 119a-120a; 142b-143a
B. Megillah 31b
B. Berachot 28a; 39a
Ben Sira 25:6

Overt Positive Statements Regarding Old Age

Genesis Rabba 59:6; 69:6
Shemot Rabba 5:12
B. Yevamot 62b
Exodus Rabba 5.12
B. Baba Batra 119b-120a; 142b-143a
B. Sukka 53
B. Kiddushin 82b
Leviticus Rabba 11.8

Implicit Positive Statements Representing Old Age as a Divine Reward

Genesis Rabba 58:9; 59:6; 62:2
Exodus Rabba 15; 16
Ecclesiastes Rabba 2:26
M. Avot 6:8
B. Kiddushin 72b
B. Ta'anit 20b
B. Berachot 8a; 8b
B. Baba Batra 121b
Yalkut Shimoni, Isaiah 52:6

Old Age as a Time of Physical Deterioration, Hardship, Vulnerability

Genesis Rabba 47:4; 48:17; 61:13
Vayyikra Rabba 18:1
Ruth Rabba 6:4
Ecclesiastes Rabba 1:3; 12:1-5
M. Avot 5:21
M. Gittin 3.3
Y. Beitza 1
B. Hullin 24a-b
B. Shabbat 52a
B. Avoda Zara 17b
B. Baba Kamma 92b
B. Eruvin 56a
B. Nazir 59a
B. Sanhedrin 76b
B. Ketuba 111b
B. Gittin 28a
B. Baba Kamma 117a
B. Baba Metzia 87a
B. Arakin 19a
B. Niddah 65a
B. Kiddushin 82b
Yalkut Shimoni, Beha'alotha 73b
Tanhuma, *Miketz* 10

Neutral References to Old Age as Part of Natural Life Cycle

M. Avot 5:21
M. Niddah 1.5
B. Nazir 39b
M. Kelim 24.16; 28.9; 29.1
B. Moed Katan 28a
B. Yoma 75b

Old Age Associated with Mental Deterioration

Deuteronomy Rabba 8:6
Song of Songs Rabba 1:10
M. Avot 4:20
Y. Peah 7
Y. Moed Katan 3
B. Shabbat 89b
B. Menachot 99a
B. Sanhedrin 96a
B. Berachot 8b
B. Nedarim 41a
Midrash Ma'seh Torah
Tanhuma, *Ha'yah Sarah*
Yalkut Shimoni, Mishlay 116
M. Horayot 1:4

Major Texts Related to Eldercare

B.Kiddushin 31b-32b; Mishne Torah, *Hilchot Mamrim*, chapter 6

Honoring the Physical Needs of the Elderly

B.Berachot 19b
B.Baba Metzia 30a-30b
B.Sanhedrin 18b
Eliyahu Rabba 26
Tanna de-Be Eliyahu Rabba 16

Respecting the Psychological Needs of the Elderly

Genesis Rabba 63.6; 65.9; 113.6
Exodus Rabba 5.12
Leviticus Rabba 11.8
Numbers Rabba 15.17
Ruth Rabba 6.2
M.Peah 1.1
Y.Bikkurim 3.3
Y.Peah 1.1,3
Y.Moed Katan 3
Y.Baba Kamma 8
B.Berachot 119a-120a
B.Bekorot 30b
B.Baba Metzia 30b; 60b
B. Baba Bara 10b
Mekilta de-Rabbi Simeon on Exodus 20:12
Ben Sira

Reverence for the Elderly Suffering from Dementia

B.Berachot 8b
B.Nedarim 41a
B.Sanhedrin 96a

Treatment of the Dying who are Comatose

M.Semachot (Found in B.Masseketot Ketanot 44a)
Rambam, Mishneh Torah *Hilchot Evel* 4.5
Yosef Karo, Shulchan Arukh, *Yoreh Deah* 339:2

The Caregiver and the Slowly Dying Victim of Dementia

B.Ketubot 104a (plus fragments from other tractates).
"Rabbi Judah and his Caregiver"

Secondary Sources

Adler, Rachel
"Those Who Turn Away Their Faces: The Metzora as Radically Ill"
Unpublished draft
Nov. 17, 2005

Alagiakrishnan, Kannayiram
"Vascular Dementia"
www.emedicine.com
June 29, 2005 update

Ashton, Joyce and Dennis
"Dealing with the Chronic/Terminal Illness or Disability of a Child: Anticipatory Mourning" in *Clinical Dimensions of Anticipatory Mourning* ed. Therese A. Rando (Research Press; Champaign, IL) 2000

Bell, Catherine
Ritual: Perspectives and Dimensions
(Oxford University Press; NY, NY) 1997

Ritual Theory, Ritual Practice
(Oxford University Press; NY, NY) 1992

Blieszner, Rosemary and Peggy A. Shiffleft
"The Effects of Alzheimer's Disease on Close Relationships between Patients and Caregivers" *Family Relations* v39 Jan 1990

Boss, Pauline
Ambiguous Loss: Learning to Live with Unresolved Grief
(Harvard University Press; Cambridge, MA) 2000

Brener, Anne
"Taking the Time You Need to Mourn Your Loss", *Life Lights Series*
(Jewish Lights; Woodstock, VT) 2000

Campany, Robert F.
"Zunzi and Durkheim as Theorists of Ritual Practice"
Discourse and Practice ed. Frank Reynolds and David Tracy
(State University of New York Press; Albany, NY) 1992
as reprinted in *Readings into Ritual Studies*, ed. Ronald L. Grimes
(Prentice-Hall; Upper Saddle River, NJ) 1996

Chernick, Michael
"Who Pays? The Talmudic Approach to Filial Responsibility"
The Journal of Aging and Judaism 1(2) Sp/Sum 1987

Cohen A., trans.
The Minor Tractates of the Talmud: Massektoth Ketannoth
(Soncino Press; London) 1965

Crystal, Howard A.
"Dementia with Lewy Bodies"
www.emedicine.com
July 5, 2005 update

Cutter, William
"Rabbi Judah's Handmaid: Narrative Influence on Life's Important Decisions"
Death and Euthanasia in Jewish Law, ed. Walter Jacob and Moshe Zemer
(Rodef Shalom Press; Tel Aviv, Israel) 1995

D'Aquili, Eugene G. and Charles D. Laughlin Jr.
"The Neurobiology of Myth and Ritual"
The Spectrum of Ritual: A Biogenetic Structural Analysis
as reprinted in *Readings in Ritual Studies*, ed. Ronald L. Grimes
[Upper Saddle River, NJ: Prentice-Hall, 1996]

Diamond, Eliezer
"Do Not Cast Us Away in Our Old Age: Adult Children and Their Aging Parents" in *The Heart of Wisdom* ed. Susan Berrin

Doka, Kenneth J.
Disenfranchised Grief: New Directions, Challenges, and Strategies for Practice
Editor (Research Press; Champaign, Ill) 2002
"Introduction"
"The Role of Ritual in the Treatment of Disenfranchised Grief"
"Psychological Loss and Grief" with Rita A. Aber

"Mourning Psychosocial Death: Anticipatory Mourning in Alzheimer's, ALS, and Irreversible Coma" *Clinical Dimensions* ed. Rando 2000

Dorff, Elliot N.
Matters of Life and Death: A Jewish Approach to Modern Medical Ethics
(Jewish Publication Society; Philadelphia) 2003

"A Methodology for Jewish Medical Ethics"
Contemporary Jewish Ethics and Morality ed. Dorff and Louis E. Newman
(Oxford University; Oxford) 1995

Dupuis, Sherry L.
"Understanding Ambiguous Loss in the Context of Dementia Care: Adult Children's Perspectives" *Journal of Gerontological Social Work* v37(2) 2002

Durkheim, Emile
"Definition of Religious Phenomena and of Religion"
The Elementary Forms of Religious Life: A Study in Religious Sociology
Trans. Joseph Ward Swain (Allen & Unwin; London)
as reprinted in *Readings in Ritual Studies*, ed. Ronald L. Grimes

Dreyfus, A. Stanley
"Halakhah Issues Relating to the Ethics of Aging"
Aging and the Aged in Jewish Law: Essays and Responsa
(Rodef Shalom Press; Tel Aviv) 1998

Eilberg, Amy
"Walking in the Valley of the Shadow:
Caring for the Dying and Their Loved Ones"
Jewish Pastoral Care: A Practical Handbook from Traditional and Contemporary Sources ed. Dayle A. Friedman
(Jewish Lights; Woodstock, VT) 2001

Eliade, Mircea
"Ritual and Myth"
Cosmos and History: The Myth of the Eternal Return
Trans. Willard R. Trask [NY: Harper and Row]
as reprinted in *Readings in Ritual Studies*, ed. Ronald L. Grimes

Ellenson, David H.
"How to Draw Guidance from a Heritage: Jewish Approaches to Mortal Choices"
Contemporary Jewish Ethics and Morality ed. Dorff and Louis E. Newman
(Oxford University; Oxford) 1995

Falk, Marcia
The Book of Blessings: New Jewish Prayers for Daily Life, the Sabbath, and the New Moon Festival (Harper San Francisco; San Francisco, CA) 1996

Flam, Nancy
"Spiritual Nurture for Jewish Caregivers" in *Jewish Pastoral Care: A Practical Handbook for Tradition and Contemporary Sources* ed. Dayle A. Friedman

Freehof, Solomon B.
New Reform Responsa (HUC Press; Cincinnati, OH) 1980

Reform Responsa (HUC Press; Cincinnati, OH) 1960

Freud, Sigmund
"Obsessive Actions and Religious Practices" [1907]
The Standard Edition of the Complete Psychological Works of Sigmund Freud
as reprinted in *Readings in Ritual Studies*, ed. Ronald L. Grimes

Friedman, Dayle A.
"Letting Their Faces Shine: Accompanying Aging People and their Families"
Jewish Pastoral Care: A Practical Handbook from Traditional and Contemporary Sources ed. Dayle A. Friedman
(Jewish Lights; Woodstock, VT) 2001

Grimes, Ronald L.
Deeply into the Bones: Re-inventing Rites of Passage
(University of California Press; Berkeley, CA) 2000

"Ritual Criticism and Infelicitous Performances"
Ritual Criticism: Case Studies in its Practice, Essays on its Theory
(University of South Carolina Press; Columbia, SC) 1990
as reprinted in *Readings into Ritual Studies*, ed. Ronald L. Grimes

Jacob, Walter
"Beyond Methuseleh -- Who is Old?"
Aging and the Aged in Jewish Law: Essays and Responsa
(Rodef Shalom; Tel Aviv, Israel) 1998

New American Reform Responsa: Questions and Reform Jewish Answers
(CCAR; NY, NY) 1992

Contemporary American Reform Responsa
(CCAR; NY, NY) 1987

American Reform Responsa
(CCAR; NY, NY) 1983

Jacob, Walter and Moshe Zemer, eds.
Death and Euthanasia in Judaism
(Rodef Shalom Press; Tel Aviv, Israel) 1995

Aging and the Aged in Jewish Law: Essays and Responsa
(Rodef Shalom; Tel Aviv, Israel) 1998

Jennings Jr., Theodore W.
"On Ritual Knowledge" *Journal of Religion* 62(2)
(University of Chicago; Chicago, IL) 1982
as reprinted in *Readings in Ritual Studies*, ed. Ronald L. Grimes

Kuljis, Rodrigo
"Alzheimer Disease"
www.emedicine.com April 12, 2005 update

Levi-Strauss, Claude
"The Effectiveness of Symbols"
Structural Anthropology, trans. Claire Jacobson and Brooke Grundfest Schoepf
(Anchor; Garden City, NY)
as reprinted in *Readings into Ritual Studies*, ed. Ronald L. Grimes

Levy, Richard N., ed./trans.
On Wings of Awe: A Machzor for Rosh Hashanah and Yom Kippur
(B'nai B'rith Hillel; Washington, DC) 1985

Loos, Cynthia and Alan Bowd
"Caregivers of Persons with Alzheimer's Disease: Some neglected implications of the Experience of Personal Loss and Grief" *Death Studies* v21 pp501-514 1997

Lamers, William M. Jr.
"Disenfranchised Grief in Caregivers" *Disenfranchised Grief* ed. Doka 2002
"Grief in Dying Persons" *Clinical Dimensions* ed. Rando 2000

Mace, Nancy L. and Peter V. Rabias
The 36-Hour Day: A Family Guide to Caring for Persons of Alzheimer's Disease, Related Dementia, Illnesses, and Memory Loss in Later Life
(Johns Hopkins University Press; Baltimore, Maryland) 1991

Myerhoff, Barbara G.
"Death in Due Time: Construction of Self and Culture in Ritual Drama"
Rite, Drama, Festival, Spectacle: Rehearsals Toward a Theory of Cultural Performance ed. John J. MacAloon
(Institute for the Study of Human Issues; Philadelphia)
as reprinted in *Readings in Ritual Studies*, ed. Ronald L. Grimes

Neimeyer, Robert A. and John R. Jordan
"Disenfranchisement as Empathic Failure: Grief Therapy and the Co-Construction of Meaning" *Disenfranchised Grief* ed. Doka 2002

Okon, Tomasz R.
"Spiritual, Religious, and Existential Aspects of Palliative Care"
Journal of Palliative Medicine v8 no2 2005-10-05

Ponder, Rebecca J. and Elizabeth C. Pomeroy
"The Grief of Caregivers: How Pervasive is it?"
Journal of Gerontological Social Work v27 (1/2) 1996

Pesek, Eileen McKeon
"The Role of Support Groups in Disenfranchised Grief"
in *Disenfranchised Grief* ed. Doka 2002

Newman, Louis E.
"Woodchoppers and Respirators:
The Problem of Interpretation in Contemporary Jewish Ethics"
in *Contemporary Jewish Ethics and Morality* ed. Dorff and Louis E. Newman

Rando, Therese A., ed.
Clinical Dimensions of Anticipatory Mourning: Theory and Practice in Working with the Dying, their Loved Ones and their Caregivers
(Research Press; Champaign, Ill) 2000
"Anticipatory Mourning: What is it and Why we Need to Study it"
"Anticipatory Mourning: A Review and Critique of the Literature"
"The Six Dimensions of Anticipatory Mourning"
"Promoting Healthy Anticipatory Mourning in Intimates of the Life-Threatened or Dying Person"

Rappaport, Roy A.
"Obvious Aspects of Ritual"
Ecology, Meaning and Religion
(North Atlantic; Berkeley, CA) 1979
as reprinted in *Readings in Ritual Studies*, ed. Ronald L. Grimes

Reuben, Steven Carr
"Old Age: Appearance and Reality"
Journal of Psychology and Judaism v.16 no.3 1993

Staal, Frits
"The Meaninglessness of Ritual" *Numen* 26(1) (E.J. Brill, Leiden)
as reprinted in *Readings into Ritual Studies*, ed. Ronald L. Grimes

Steinhauser, Karen E., et.al
"In Search of a Good Death: Observations of Patients, Families, and Providers"
Annals of Internal Medicine v132(10) pp825-32 2000

Tambiah, Stanley J.
"A Performative Approach to Ritual" *Proceedings of the British Academy*
(British Academy; London)
as reprinted in *Readings in Ritual Studies*, ed. Ronald L. Grimes

Turner, Victor
The Ritual Process: Structure and anti-Structure
(Aldine de Gruyter; NY, NY) 1969

"Symbols in Ndembu Ritual"
The Forest of Symbols: Aspects of Ndembu Ritual
(Cornell University Press; NY, NY] 1967
as reprinted in *Readings in Ritual Studies*, ed. Ronald L. Grimes

Van Gennep, Arnold
"Territorial Passage and the Classification of Rites"
The Rites of Passage, ed. Monika B. Vizedom and Gabrielle Caffee
[Chicago: University of Chicago Press, 1909/1960]
as reprinted in *Readings into Ritual Studies*, ed. Ronald L. Grimes
[Upper Saddle River, NJ: Prentice-Hall, 1996]

Walker, Rebecca J., et.al
"Anticipatory Grief and Alzheimer's Disease: Strategies for Intervention"
Journal of Gerontological Social Work v22(3/4) 1994

Washofsky, Mark
"Is Old Age a Disease? The Elderly, the Medical System
and the Literature of Halaka"
Aging and the Aged in Jewish Law: Essays and Responsa
(Rodef Shalom; Tel Aviv) 1998

Wright, Lore K., et.al
"Emotional and Physical Health of Spouse Caregivers of Persons with
Alzheimer's Disease and Stroke"
Journal of Advanced Nursing v30(3) pp552-563 1999

Kol Haneshama: Prayerbook for the Days of Awe
(The Reconstructionaist Press; Elkins Park, Pennsylvania) 1999

National Center for Jewish Healing (NY, NY)
"A Circle of Prayer"
"When the Body Hurts, the Soul Still Longs to Sing"
"A Leader's Guide to Services and Prayers for Healing"

Appendix 1

Assessment Tools for Pastoral Caregiver Visit

Pastoral Assessment in the Case of Progressive Dementia

_____
Date of Visit

Name of Afflicted _____ Age _____

Illness _____ Duration to date _____ Stage _____

Primary Caregiver _____ Age _____

Relationship to Afflicted _____

Extent of Involvement in Care of Afflicted One:

- ☐ Full time at home
- ☐ At home with nursing assistance
- ☐ Nursing home
- ☐ Hospice

ASSESSEMENT OF AFFLICTED ONE

Observations of afflicted one during visit:

Mobility:
- ☐ Walks independently
- ☐ Walks with cane
- ☐ Walks with walker
- ☐ Self-propelled wheelchair
- ☐ Assisted wheelchair
- ☐ Bed-ridden

Pain:

None			Severe

Independence:

Feeds self	Assisted	Spoon-fed	Feeding tube

Dresses self		Assisted	Dressed by another

Urinates independently	Assisted	Bed-pan	Incontinent

Mental Condition:

Full memory			No memory

Fully Conversant	Confused		Non-Responsive

Caregiver perceptions of afflicted one:

Physical symptoms and well-being:

Mental and Emotional State:

Afflicted one's stated needs and emotions:

ASSESSMENT OF INTIMATE CAREGIVER

1. Instruct caregiver to fill out the Marwit-Meuser Cargiver Grief Inventory and the Treseder Secondary Loss Inventory, and to highlight applicable emotions listed in the Common Grief Reactions table.

2. Ask the caregiver to give an oral history of the illness, and to elaborate on items which stand out in the assessment inventories

3. Based on your interview with the caregiver, assess extent of primary loss:

   Does caregiver perceive a personality change in loved one?

   If so, how is caregiver responding to the change?

   Where is the caregiver in terms of denial?

   ☐ Pretends nothing has changed, or drastically minimalizes condition.

   ☐ Treats afflicted one as though dead. Ignores presence altogether.

   ☐ Not in denial.

   Extent to which caregiver is experiencing anxiety over uncertainty:

None	Confusion	Indecisive	Paralyzed

   Extent to which caregiver feels emotionally bonded to their loved one:

Very Strong	Strong	Confused over roles	Weak	No bond

4. Where is the caregiver in terms of the Six R's of Mourning?

5. What bereavement tasks are in progress?

6. What are the stated needs of the caregiver in terms of support?

   From Family:

   From Rabbi:

   From Jewish community:

   From social network:

   From medical establishment:

ASSESSMENT OF FAMILY SYSTEM

Family Pictogram:

1. What are the current points of tension in this family?
2. What is the extent of each member's involvement with the afflicted one?
   - Their quality of relationship with the afflicted one?
   - Their perception of the current situation?
   - Their grief reactions, both to primary and secondary losses?

Treseder Secondary Loss Inventory
Intimate Caregiver

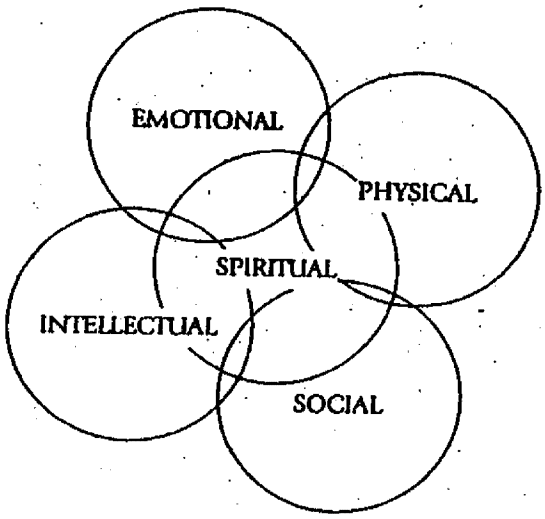
From the following list of secondary losses typically experienced by intimate caregivers, please check those which you are currently experiencing:

- ☐ Family support
  - ☐ Immediate
  - ☐ Extended
- ☐ Friends
- ☐ Social/Cultural activities
- ☐ Recreational activities
- ☐ Travel
- ☐ Future plans with loved one
- ☐ Community support/interaction
- ☐ Personal time
- ☐ Personal future plans
- ☐ Financial resources
- ☐ Career/Job
- ☐ Physical Health
- ☐ Emotional well-being
- ☐ Intellectual stimulation
- ☐ Religious involvement
- ☐ Freedom

From the following list of stresses typically experienced by intimate caregivers, please check those which you are currently experiencing:

- ☐ Strained relationships
  - ☐ with afflicted loved one
  - ☐ with other family members
  - ☐ with friends/associates
  - ☐ with members of community
  - ☐ with medical professionals
- ☐ Social isolation
- ☐ Affects of illness on family dynamics
- ☐ Modifications in daily routine and activities
- ☐ Increased tasks and time commitment as caregiver
- ☐ Medical concerns not directly related to illness
  - ☐ for family member
  - ☐ for self
- ☐ Other
- ☐ Housing adaptations
- ☐ Increased financial burden
- ☐ Bureaucratic "red tape"

Five Dimensions of the Human System: Common Grief Reactions



INTELLECTUAL
confusion
disorganization
lack of concentration
intellectualizing
disorientation
absent mindedness
denial

EMOTIONAL
shock
numbness
anger
guilt
relief
depression
irritability
loneliness
yearning
disbelief
sadness
denial
anxiety
confusion
fear

PHYSICAL
changes in appetite
blurred vision
sleep changes
muscle twitches
restlessness
breathlessness
heart palpitations
loss of sexual desire
changes in weight
headaches
bowel changes
crying
exhaustion
dry mouth

SPIRITUAL
impressions
dreams
loss of faith
increase of faith
anger at God
spiritual injury
questioning values
feeling betrayed by God
disappointment in religious clergy and members

SOCIAL
loss of identity
isolation
withdrawal
lack of interaction
energy
loss of ability to function

MARWIT-MEUSER CAREGIVER GRIEF INVENTORY (SHORT FORM)

1 = Strongly Disagree // 2 = Disagree
3 = Somewhat Agree // 4 = Agree // 5 = Strongly Agree

1	I've had to give up a great deal to be a caregiver.	1	2	3	4	5	A
2	I feel I am losing my freedom.	1	2	3	4	5	A
3	I have nobody to communicate with.	1	2	3	4	5	C
4	I have this empty, sick feeling knowing that my loved one is "gone".	1	2	3	4	5	B
5	I spend a lot of time worrying about the bad things to come.	1	2	3	4	5	C
6	Dementia is like a double loss...I've lost the closeness with my loved one and connectedness with my family.	1	2	3	4	5	C
7	My friends simply don't understand what I'm going through.	1	2	3	4	5	C
8	I long for what was, what we had and shared in the past.	1	2	3	4	5	B
9	I could deal with other serious disabilities better than with this.	1	2	3	4	5	B
10	I will be tied up with this for who knows how long.	1	2	3	4	5	A
11	It hurts to put her/him to bed at night and realize that she/he is "gone"	1	2	3	4	5	B
12	I feel very sad about what this disease has done.	1	2	3	4	5	B
13	I lay awake most nights worrying about what's happening and how I'll manage tomorrow.	1	2	3	4	5	C
14	The people closest to me do not understand what I'm going through.	1	2	3	4	5	C
15	I've lost other people close to me, but the losses I'm experiencing now are much more troubling.	1	2	3	4	5	B
16	Independence is what I've lost...I don't have the freedom to go and do what I want.	1	2	3	4	5	A
17	I wish I had an hour or two to myself each day to pursue personal interests.	1	2	3	4	5	A
18	I'm stuck in this caregiving world and there's nothing I can do about it.	1	2	3	4	5	A

MM-CGI Short Form: Meuser, T.M., Marwit, S.J., & Sanders, S. (2004). Assessing Grief in Family Caregivers. In Living with Grief: Alzheimer's Disease. Kenneth Doka (Ed.). Hospice Foundation of America: Washington, DC., 169-195.

Original 50-Item MM-CGI: Marwit, S.J., & Meuser, T.M. (2002). Development and Initial Validation of an Inventory to Assess Grief in Caregivers of Persons with Alzheimer's Disease. The Gerontologist, 42(6), 751-765.

For more information, contact Tom Meuser, Ph.D., at meusert@abraxas.wustl.edu.

Appendix 2

A Birthday Haggadah

A Birthday Haggadah

[Pix Bud in Uniform]

Bud Levitz
Celebrating 85 Years

The Seder

Leader:	Each of us is a Torah A Book of Memories
All:	*A Book of Dreams*
Leader:	We are filled with the memories and dreams of those who went before us
All:	*We pass on our memories and dreams to those who come after us*
Leader:	And so our people remember
All:	*We never forget*
Leader:	Our people dream on
All:	*We always hope*

[Pix Family Collage]

Leader:

Bud, your story is that of Moses
Like Moses, Bud, you are a warrior
As a prince of Egypt,
Moses fought to secure his country
As an American fighter pilot,
you defended our country
from the greatest threat
the world has ever known.
As a son of Israel,
Moses responded to the cries of his people.
As an enlightened Jew, Bud,
you have always responded
to the pain and suffering of others
You are the Moses of this family, Bud.
That is why we are celebrating your birthday
as a seder this year and years to come

[All Raise cup of wine/grape juice]

בָּרוּךְ אַתָּה יְיָ אֱלֹהֵינוּ מֶלֶךְ הָעוֹלָם
שֶׁהֶחֱיָנוּ וְקִיְּמָנוּ וְהִגִּיעָנוּ לַזְּמַן הַזֶּה

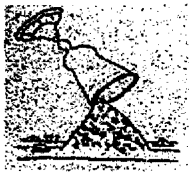
Barukh atah Adonai, Eloheinu melek haOlam,
she-he-khei-yanu ve-ki-ye-manu laz-man ha-ze

Blessed are You, Source of All Life,
who gave us life and sustained us
and allowed us to reach this joyous season

Barukh atah Adonai, Eloheinu melek haOlam,
borei pri ha-ga-fen

Blessed are You, Source of All Life,
who creates the fruit of the vine

[All Drink cup of wine]



Pouring Water

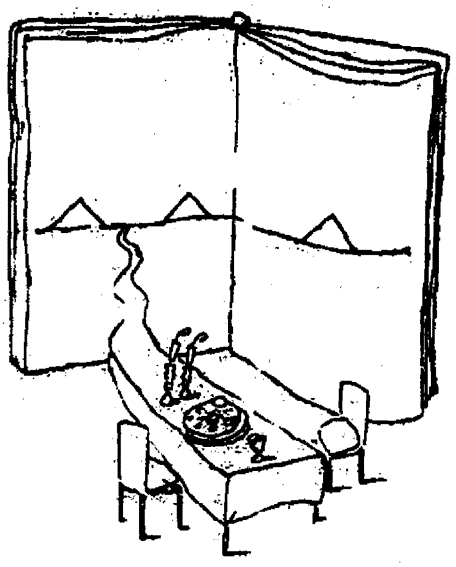
Leader:

Disciples of the wise among us are called
"Those who pour"
meaning those who pour water
over the hands of their teacher.
It is a gesture of deep respect and honor.
Bud, we honor you this day with the rite
of pouring, for you are our teacher.

[Each family member pours water over Bud's hands]
[The last to pour water, dries his hands]

Prayer Circle

[Rabbi leads Family Prayer over Bud]

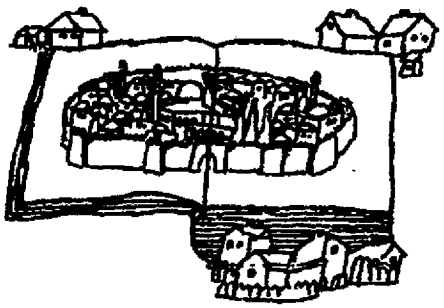


Birthday Cake and Meal

Tribute

Leader: Each of us is a scroll with memories of you
inscribed upon it. They taste sweet like manna.
They are pillars of light that show us the way.

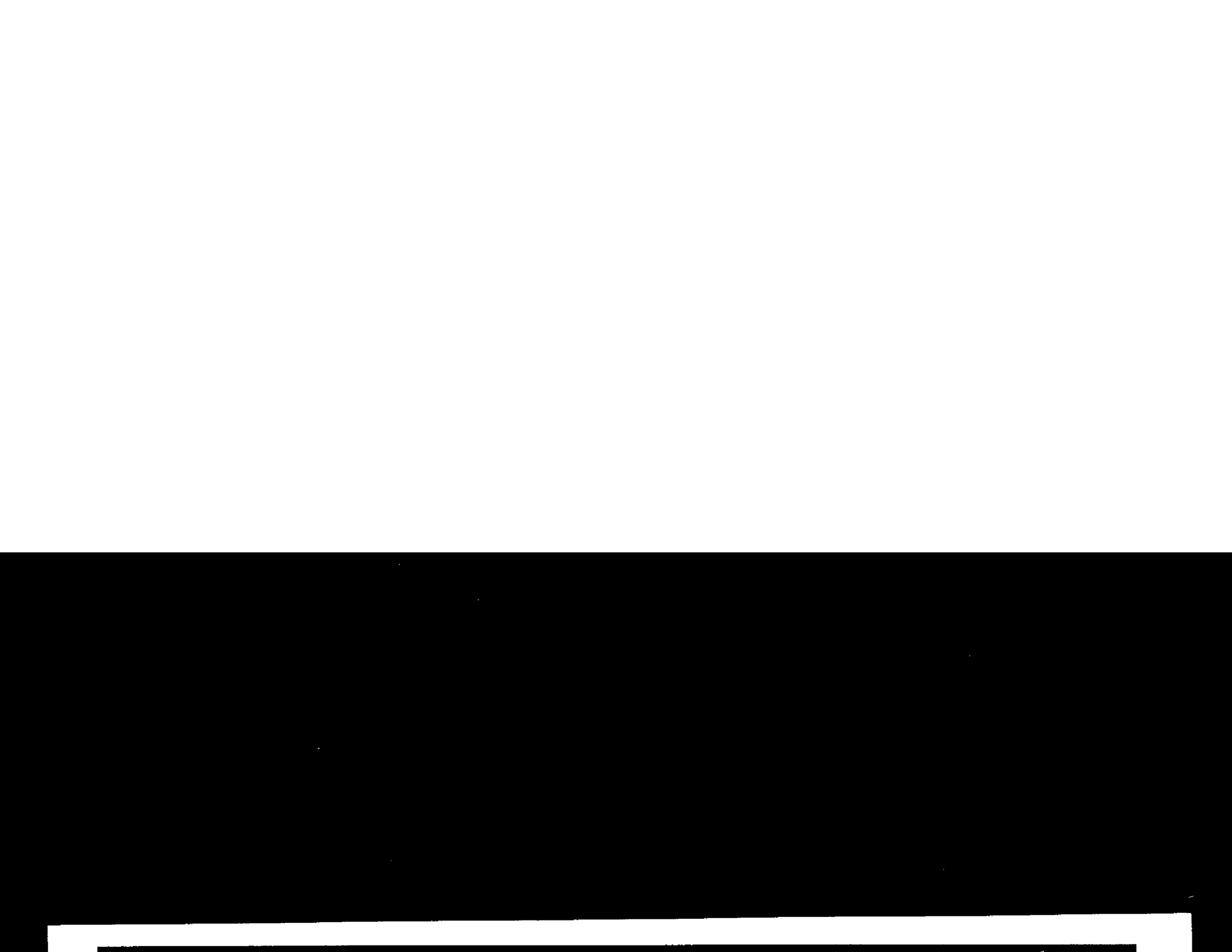
**[Each family member gives Bud a chocolate,
reads his or her tribute, then lights a candle]**



The Telling

Leader: Like scribes of ancient times, we hold your memories
We tell them to one another and to our children
until they become our memories, too.

**[Rose presents picture biography.
Read excerpts from it according to Bud's strength]**



Appendix 3

"Lamenting Our Losses: Rituals for Coping with Dementia"
By Linda Loewenstein and David J. Zucker

REV 13 DJZ/LL

LAMENTING OUR LOSSES: RITUALS FOR COPING WITH DEMENTIA

By Linda Loewenstein and David J. Zucker

(7-22-05 2,400 words)

Learning about the death of someone is always shocking, although it may or may not be surprising. Death is just so ... final. It is indisputably the end of that particular relationship. Nevertheless, in its finality, there is something certain, something definable. And we, as a society, have determined the rituals that surround death. The laws of each state define burial practices, and each religious tradition brings further refinement to our mourning practices. There are boundaries, accepted norms of behavior, even pre-printed notes that thank our friends for their heartfelt condolences.

All of these defined expectations provide a framework as people struggle through feelings of loss and despair. The defined rituals buttress the mourners as they continue to live in the lonely fog that follows the death of a loved one.

But, there are those of us who have a relative lost in the ravages of dementia. The person we knew and loved is gone, yet a shadow of that person exists. How can we mourn the loss while simultaneously respecting the living being that contains the remnants of the person we loved?

Caring for a loved one with dementia is a daunting prospect. Without rituals, without the overt acknowledgement that a monumental change has occurred, we struggle in a spiritual wilderness. Relatives and friends do not have any kind of ritualized way to acknowledge their *ongoing* sense of diminishment and grief at the fact that they no longer have that person in their lives in any kind of meaningful or communicable way.

Rituals remind us, and everyone around us, that the world has shifted, that significant change has happened. Some Jewish rituals reflect changes in time or space—e.g. the ritual welcoming Shabbat on Friday night, the ritual blessing you say when you move into a new home, the joyous "*Shehehiyanu*," a blessing said when reaching a significant milestone in life. The ritualization is the acknowledgement, both internal and external.

Authors Loewenstein and Zucker are Jewish professionals in the Metro-Denver area, and they collaborated on the ritual described below. Loewenstein's perspective is that of a family member, as she describes, "My mother is suffering from Alzheimer's disease. It's a brutal process and I have felt spiritually adrift. I find myself talking about her as if she were dead, yet she's not dead. This new damaged being is not my mother, even though there are flashes of my mother. This version of my mother seems like a badly handicapped twin sister—not really

my mother at all. For the past couple years, I have needed some way to identify and acknowledge this shift in my universe. I have yearned for a comforting ritual to help me walk this long and difficult path."

Author Zucker is a rabbi and full-time chaplain at Shalom Park, a senior continuum of care center in Denver, Colorado. In that latter capacity, he created the Resident's Family Support Group, designed to meet the ongoing needs of families around issues of loss, frustration, anger, helplessness and grief. "In counseling with families," explains Rabbi Zucker, "I began to understand that there are common threads in their stories. Children, spouses, significant others, and siblings need time and a safe place to vent, to lament and to share a commonality of mutual sorrow."

The ritual described below is a result of their combined work and reflects both their personal and professional experience. These rituals have wider application. The person who is "lost" could be severely ill and unable to communicate, with no reasonable prognosis of a return to health. For the purposes of this article, however, dementia is used as a generic term for the condition of the person with whose "loss" is so difficult to bear.

LAMENTING OUR LOSSES: RITUALS FOR COPING WITH DEMENTIA

These rituals are designed for the person who feels the sense of loss. They may be performed alone or you may choose to include others—family or close friends who are aware of your losses. Although it might be possible to include the loved one whose diminishment you're lamenting, it may be easier initially to experience the ritual without that added layer. Obviously, this is an intimate, personal experience, and any modifications or changes you choose to make are encouraged. Please feel free to rework or rewrite anything in your own words, so that the details fit your particular situation.

The frequency of the ritual is also an individual matter. You may find that this helps on a weekly basis, or it might be monthly or quarterly. You may be completely arbitrary in terms of its frequency: a stand alone, once-only event, or it might be a ritual you repeat with long spaces of time in between.

The five stages

1. Preparation
2. Candle Ceremony
3. Living Eulogy
4. Prayers and Pleas
5. Conclusion/Closure

1. Preparation

Items:

Two large candles (Shabbat candles are fine), a knife, matches
Candleholders

In a safe and comforting space, you will first cut one of the candles. Take the candle and cut it unevenly, approximately 2/3 and 1/3. You will then have three candles—one full length and two others of differing shorter lengths. Literally cutting the candles is symbolic. In the physical act of cutting, you acknowledge that there has been a break, a significant rupture with the past. By cutting the thread/wick within the candle, you affirm that what had been the thread of connection has irretrievably and irreparably been severed. Perhaps your loved one no longer recognizes you, or the person is no longer able to interact with their environment, or no longer able to maintain a friendship from the past. In addition, the act of cutting echoes, but does not literally replicate, the Jewish ritual of *Keriyah* (lit. "cutting/rending," the tradition of placing a cut in one's garment as a sign of mourning, based on biblical verses in Genesis 37:34 and

Job 1:20) . Mourners who are in one of the following relationships perform the ritual of *Keriyah* – for one's father, mother, sister, brother, wife, husband, son, or daughter.

Recite these words just before you cut the candle:
Ba-rukh atta Ado-nai, Elo-hey-nu mekor hayim, al d'var k'ritut.

Praised are You, Eternal our God, source of life, concerning the matter of "cutting."

The three candles represent three different periods of time—the past, the present and the future. The longest candle symbolizes the past –the part of memory that is the largest, the time period that is most likely to remain accessible to a person experiencing dementia. It is the most solid and least likely to completely disappear. The present—the middle-sized candle—is less full and more tenuous. The smallest candle represents the future—a short period of time, either real time or the time left for meaningful interaction.

2. Candle Ceremony "Acknowledging the Diminishing Light"

Place the three candles in candleholders and light them. You can choose to say one of the following blessings. These blessings, which focus on light and life/living, are reminiscent of the Saturday night *Havdalah* ritual that marks the division (*havdalah*) between Shabbat (Sabbath) and the normal weekdays. This entire "Lamenting our Losses" ceremony/ritual highlights the division between the life that was and the life that is now.

Recite one of the following prayers, the one that best expresses how you feel about the stages of your loved one's journey.

> *Ba-rukh atta Ado-nai, Elo-hey-nu mekor hayim, borey or, u-mav-dil beyn heh-hayim, v' heh-hai.*
>
> Praised are You, Eternal our God, source of life, who creates Light, and distinguishes between Living and Life
>
> (or)

Ba-rukh atta Ado-nai, Elo-hey-nu mekor hayim, borey or, u-mav-dil beyn heh-hai, v' heh-hayim.

Praised are You, Eternal our God, who creates Light, and distinguishes between Life and Living

(or)

Ba-rukh atta Ado-nai, Elo-hey-nu mekor hayim, borey or, u-mav-dil beyn hayim, l'hayim.

Praised are You, Eternal our God, source of life, who creates Light, and distinguishes between Living and Living.

Meditation
At this time, as I light these candles, I seek the inner strength and courage to help me to light the way to work through the pain of the sense of loss and abandonment that I feel within. I grieve the relationships that were so important to me in past days, and I seek enlightenment and insight so that I will achieve healing within myself and be of comfort to the one I love.

(At the close of this ritual, you will blow out the candles. You can use them again. In time, the smallest candle will burn out and the other candles will be shortened. If/when this ritual is repeated, use a new large candle.)

3. Living Eulogy

The Living Eulogy, similar to a eulogy delivered at a funeral, is an acknowledgment and tribute to the person who was/is so important in your life. A funeral eulogy can serve as an instrument of closure. In the case of this Living Eulogy, closure in the sense of a "final closure" is not possible; the person is still living, although he/she is not accessible (or not fully accessible) because of the dementia. The Living Eulogy is something that you, yourself write. It may be a paragraph, a page, or several pages long. It may be just a memory of a single event. It recalls parts of the life of the person who is there, but curiously, not there. Instead of or in addition to something written, you may also choose to find a favorite photograph of your loved one, a photograph that reminds you of the person's wholeness.

Some of the people who might be present at this ceremony may want to add their own words, either extemporaneously, or through words prepared beforehand.

We suggest that you save the words of the Living Eulogy after the ceremony. At a later date, it might be the basis for another Living Eulogy that you write for the next time(s) you perform this ritual. And when, eventually, the person dies, these Living Eulogies can form part of the funeral eulogy.

4. Prayers and Pleas

This next section, Prayers and Pleas, are longer expressions of the grief and ongoing grieving/loss that you are experiencing. We have offered several examples or suggestions. You might choose to use these models or create your own prayers and pleas.

A prayer about memory

Ba-rukh atta Ado-nai, Elo-hey-nu me-lekh ha-olam, a-sher m'kadesh et amo al y'dei zikhronot.

Praised are You, Eternal our God, ruler of the world, who makes people holy through memory.

(or)

Source of goodness and blessing, strength and holiness, may this be a sacred moment devoted to memory.

Embracing their truth

Help me understand that there is a difference between what is "true" (for my loved one) and what are the actual facts. May I learn to embrace and affirm their truth, irrespective of actual/demonstrable facts.

Allow me to hear words that pain me, words that shame me, without armoring myself with defensive weapons. Help me to understand that fear has tampered with reality.

A prayer for person I have lost

I will be with you in your difficult journey ahead, sometimes physically with you, sometimes spiritually. I will be there, even when you feel, think or say that I am not.

Self-care

Let me not look for signposts where there are none, interpret meaning when there is none, hope when there is no chance. Allow me to accept, to be, instead of to do.

As we journey through this vast desert, help me to create an emotional oasis, a place where I can rest and renew.

How Can I Know?

How do I know where you are when I cannot read the signposts?
How do I find you in the dense forest that shelters you?
How can I reach you when my arms are not long enough?
How can I know if you are at peace?

Is your silence from paralyzing fear or a response to God's comforting embrace?
Do you see flashes of reds and orange or is your world gray?
Do you understand any of my words, find any comfort in the cadence of my voice?
How can I know if you are at peace?

I must believe, believe in a God of mercy, and believe in God's grace.

A Silent Confession

I have failed to understand that the physical items surrounding you, the accumulation and debris of ordinary life, provide you comfort as your mental cupboard becomes increasingly bare.

I have failed fully to comprehend that your continually asked question is new to you each time it is voiced.

I have failed to understand that as much as I hate your life, you hate it even more.

I have run from your presence, gladly distancing myself while asking others to endure the unendurable. Remind me to honor those whose patience is greater than mine.

I have repeatedly attempted to use logic and reason while knowing that the more effective tools are affirmation and diversion. Help me to

remember that your seemingly ordinary language masks your confusion and that words are not always an appropriate tool.

I have maintained a pace that suits me, forgetting that the speeding train of life must slow at dementia's crossroads.

I have cursed the medications that you take that prolong my agony of watching you deteriorate. Please help me treasure those disappearing remnants of your being that still speak of your wholeness.

I have used the private tragedy of your current existence as conversational currency. Please allow others to understand that my pain is often soothed by the balm of social support.

Please help me to provide moments of joy and happiness amid your fear and loneliness.

5 Conclusion/Closure

At this point, the ritual is over and, before blowing out the candles, you may choose to conclude in any way that feels appropriate.

In Jewish tradition, the prophet Elijah never died, but was taken into heaven on a fiery chariot. He continues to live, and is understood to be ever present, ready to help in moments of danger or distress. Elijah also is credited with revealing hidden truths. He is a celestial connection, and is featured in the closing words of the prophet Malachi, where Malachi speaks of Elijah "reconciling parents with children and children with their parents" (Malachi 3:24 Hebrew; alternatively Malachi 4:5). Coincidentally, at the close of the *Havdalah* ceremony, which marks divisions in time, it is traditional to sing of Elijah. Consequently, one way you may choose to conclude this ritual is to sing softly the words of that hymn:

Eli-ya-hu ha na-vi, Eli-ya-hu ha-Tish-bi, Eli-ya-hu, Eli-ya-hu, Eli-ya-hu ha-Gi-la-di.

Bim-hey-ra b'ya-mey-nu, Ya-vo a-ley-nu, im ma-shi-ah ben-David, im ma-shi-ah ben David.

Elijah the prophet, Elijah the [person from] Tishbi, Elijah the [person from] Gil'ad. Quickly in our time, come to us, with the Messiah, the son of David.

Appendix 4

Caregiver Siddur

Avodat Hesed עבודת חסד

Barukh attah Adonai	בָּרוּךְ אַתָּה יְיָ
Eloheinu melekh ha-olam	אֱלֹהֵינוּ מֶלֶךְ הָעוֹלָם
asher kid-de-shanu be-mitz-vo-tav	אֲשֶׁר קִדְּשָׁנוּ בְּמִצְוֹתָיו
ve-tzi-vanu al netilat ya-da-yim	וְצִוָּנוּ עַל נְטִילַת יָדָיִם

Blessed are you, Holy One, Source of all life
Who sanctifies us with *mitzvot* and
has directed us to purify our hands

I sanctify my hands for Avodat Hesed, Service of Lovingkindness, for my _____ (*whom I love).

Child: Knowing that in honoring my mother/father, I honor the Holy One, my Creator.

Spouse: Knowing that in honoring my husband/wife, I honor my marriage vows made in covenant before my God.

Other: Knowing that in honoring my _____, I acknowledge that he/she is created in the image of God and so worthy of respect and tender care.

Pour water over each hand three times.

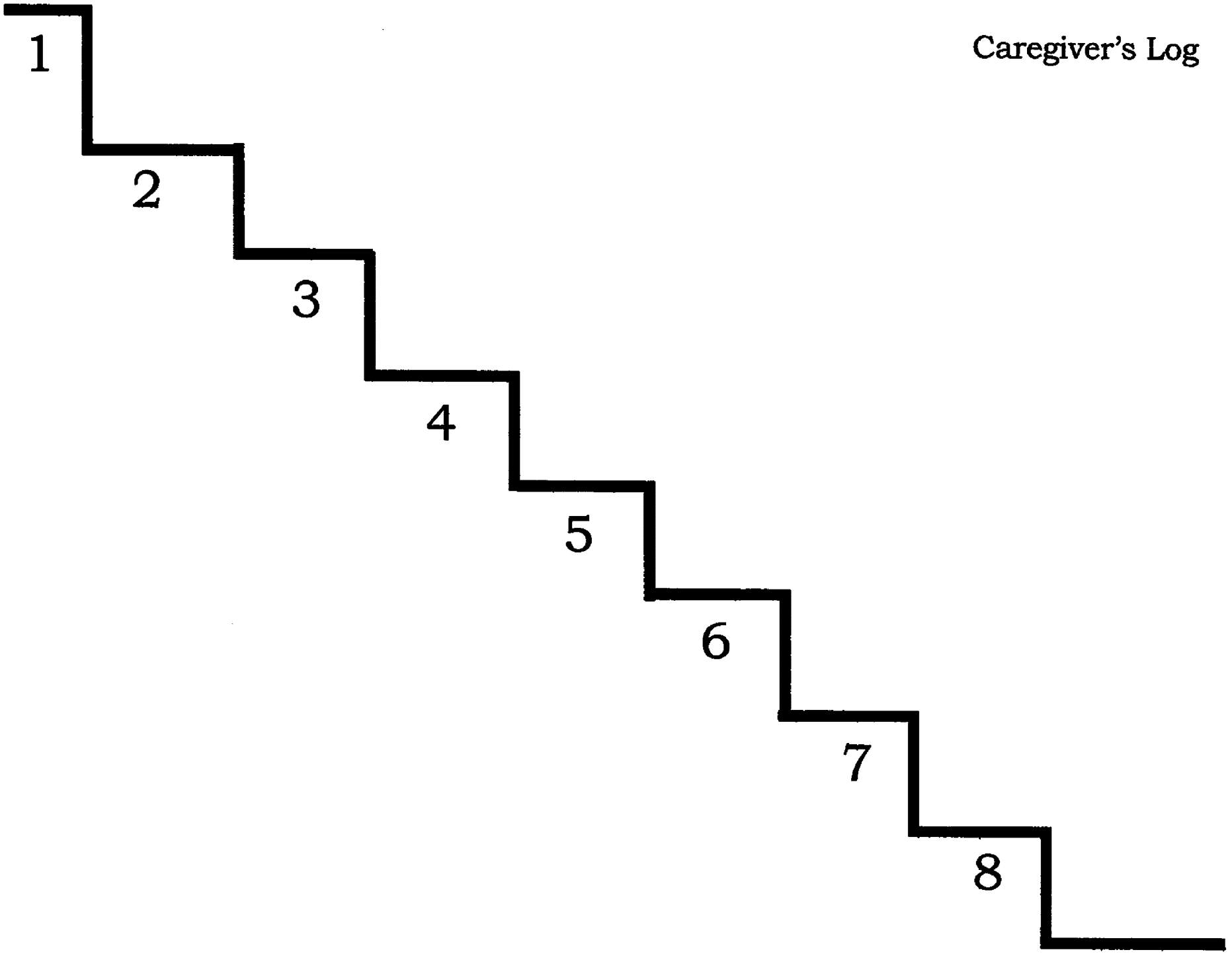
Perform act of service.

Pour water over hands again.

May the service of my hands be acceptable to God,
and may the Holy One grant me peace.

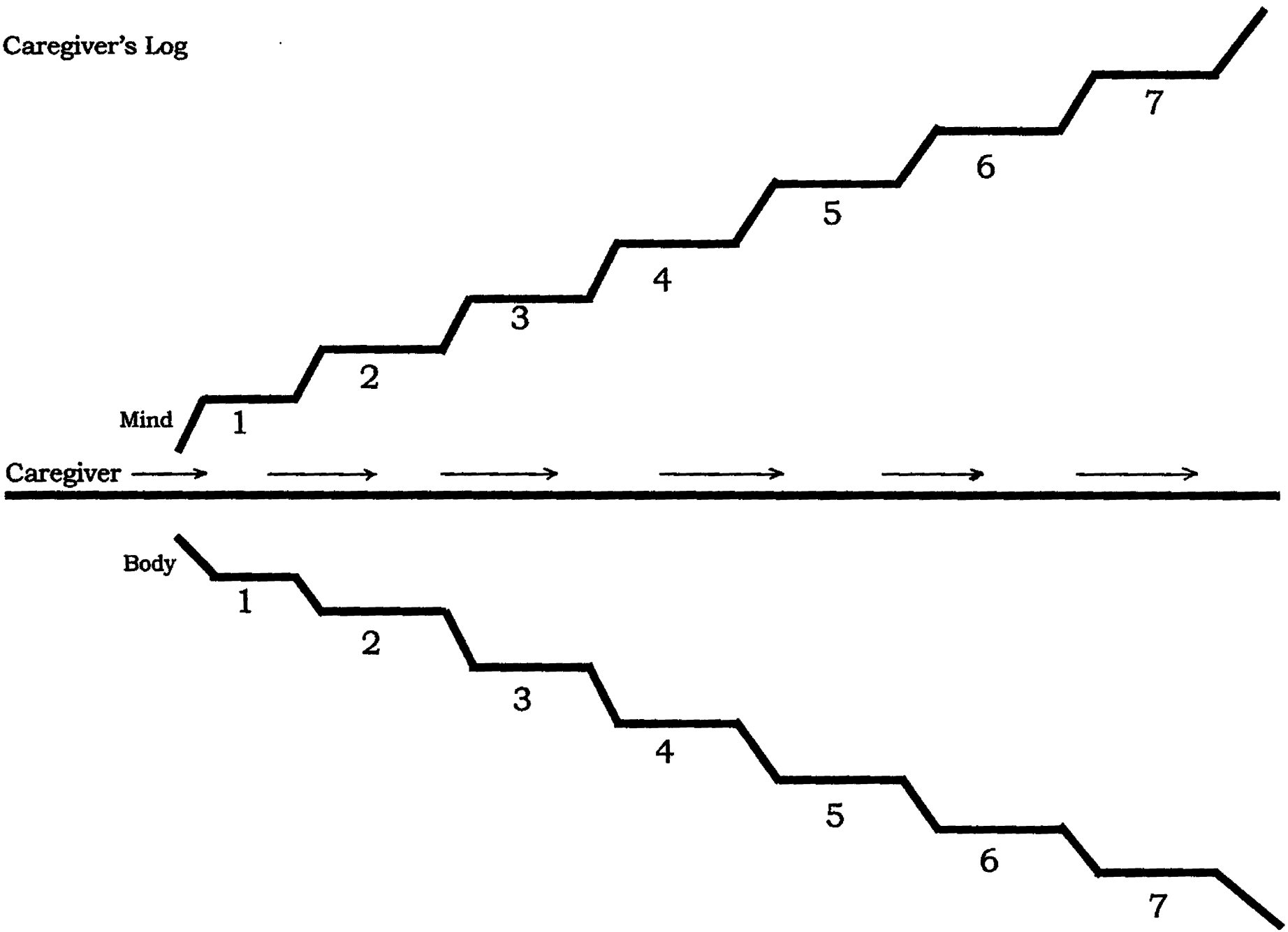
Caregiver's Log

May I learn to take care of myself
May I become a resting place for the Shekina.
May the light of the Divine shine through me and help my loved one
know love, acceptance, joy, peace, beauty and strength



Caregiver's Log

Caregiver's Log



Book of Dreams and Memories

May this be written down for a coming generation,
that people yet to be created may praise Adonai
Psalm 102:19

Prayers and Meditations

I pray a siddur from my heart,
one with torn edges, and all its missing words
I see have long since vanished, flying away
and seeking a resting-place. How
shall I bring a bandage for them
when my heart's siddur with eaten edges
still goes naked?

Amir Gilboa

Ancient Prayers and Torah

Hashkivenu (a bedtime prayer)

הַשְׁכִּיבֵנוּ	Lie us down,
יְיָ אֱלֹהֵינוּ	Adonai our God,
לְשָׁלוֹם	in Peace;
וְהַעֲמִידֵנוּ	and raise us up again,
מַלְכֵּנוּ	our Ruler,
לְחַיִּים	in Life.

וּפְרוֹשׂ עָלֵינוּ סֻכַּת שְׁלוֹמֶךָ	Spread over us Your shelter of peace;
וְתַקְּנֵנוּ בְּעֵצָה טוֹבָה מִלְּפָנֶיךָ	guide us with Your good counsel;
וְהוֹשִׁיעֵנוּ	and save us out of Your mercy,
לְמַעַן שְׁמֶךָ	for Your own Name's sake.

וְהָגֵן בַּעֲדֵנוּ	Shield us;
וְהָסֵר מֵעָלֵינוּ	remove from us
אוֹיֵב דֶּבֶר וְחֶרֶב וְרָעָב וְיָגוֹן	every enemy, plague, sword, famine and sorrow.

וְהָסֵר שָׂטָן	Remove all adversaries, all evil forces
מִלְּפָנֵינוּ וּמֵאַחֲרֵינוּ	from before us and from behind us,
וּבְצֵל כְּנָפֶיךָ תַּסְתִּירֵנוּ	and shelter us in the shadow of Your wings.

כִּי אֵל	For You are
שׁוֹמְרֵנוּ וּמַצִּילֵנוּ אָתָּה	our guarding and saving God,
כִּי אֵל מֶלֶךְ חַנּוּן וְרַחוּם אָתָּה	yes, a gracious and compassionate God and Ruler.

וּשְׁמוֹר צֵאתֵנוּ	Guard our going out
וּבוֹאֵנוּ	Guard our coming in
לְחַיִּים וּלְשָׁלוֹם	Give us life and peace,
מֵעַתָּה וְעַד עוֹלָם	now and always

(Trans. Rabbi Simkha Y. Weintraub, Rabbi Nina Beth Cardin)[1]

---

1. "A Circle of Prayer" pamphlet, The National Center for Jewish Healing (NY, NY)

A Prayer for Protection at Night

בְּשֵׁם יְיָ	In the name of Adonai
אֱלֹהֵי יִשְׂרָאֵל	the God of Israel:
מִימִינִי מִיכָאֵל	May the angel Michael be at my right,
וּמִשְׂמֹאלִי גַּבְרִיאֵל	and the angel Gabriel be at my left;
וּמִלְפָנַי אוּרִיאֵל	and in front of me the angel Uriel,
וּמֵאֲחוֹרַי רְפָאֵל	and behind me the angel Raphael ...
וְעַל רֹאשִׁי שְׁכִינַת אֵל	and above my head the presence of God.

B'shem Adonai Elohei Yisrael:
Mi'mini Mikhael, u'mis-moli Gavriel,
U-mil-fanai Uriel, U'mei-a-ho-rai R'fael,
V'ahl ro-shi Sh'khi-naht El

(Trans. Rabbi Simkha Y. Weintraub, Rabbi Nina Beth Cardin)[2]

From the Sayings of Rabbi Nahman of Bratzlav
All the world before us
is a very narrow bridge,
and the main thing
is not to fear at all.

Isaiah 40:31
Those who hope in God
will renew their strength
and soar on wings like eagles.

Mishna Avot 1:7
Do not despair because of suffering,
for life is suffering.
Suffering and also joy.
When life brings you suffering, hurt.
When life brings you joy, laugh.
Cling to nothing
for all is fleeting.

---

2. Ibid.

A Prayer on Behalf of My Loved One Who Suffers from Dementia
A Psalm/Lamentations Mosaic

Do not cast me off in old age
when my strength fails, do not forsake me. (Ps. 71:8-9)

My mind is stripped of reason;
My senses are numb,
My body and mind fail. (Ps. 73:21-22)

My mind reels;
My strength fails me;
My eyes, too, have lost their luster.
I roar because of the turmoil in my mind. (Ps. 38:11,9)

I am a helpless human being,
abandoned among the dead
like bodies lying in the grave
of whom you are mindful no more.
My friends shun me,
I am abhorrent to them.
I am shut in and do not go out. (Ps. 88:5-9)

Do not abandon me, Adonai;
my God, be not far from me. (Ps. 38:22)

This I do remember,
therefore I have hope.
The kindness of Adonai did not end.
His mercies are not spent.
Therefore I hope in him,
for he does not willfully
bring grief or affliction to mortal beings. (Lam. 3:21-33)

As a father has compassion for his children,
so Adonai has compassion for those who suffer.
He knows how we are formed.
He is mindful that we are dust.
Our days are like those of grass,
blooming like flowers of the field;
a wind passes by and we are no more.
But Adonai's love is steadfast and true. (Ps. 103:13-17)

I lift my eyes to the mountains;
From whence does my help come?
My help comes from Adonai,
Maker of heaven and earth. (Ps. 121:1-2)

(Terry Treseder)

A Psalm Mosaic

How long, Adonai, will you forget me forever?
How long will you hide your face from me?
How long will I have cares on my mind, anguish in my heart all day? (Ps. 13:1-3)

I am a joke to my neighbors,
a horror to my friends.
Those who see me on the street avoid me.
I am put out of mind like the dead;
like an object given up for lost. (Ps. 31:12-13)

I look to Adonai.
I hope,
I wait for God's word,
I look out for God more than nightwatchers for morning,
nightwatchers for morning. (Ps. 130:5-6)

If only I had the wings of a dove,
I would fly away and find rest. (Ps. 55:7)

Even the sparrow finds a home
And the swallow a nest
to settle her young
near your altar, Adonai of the hosts (Ps. 84:4)

Adonai is the healer of broken hearts,
The binder-up of wounds. (Ps. 147:3)

Adonai restores the lonely to their homes,
Sets free the imprisoned safe and sound. (Ps. 68:7)

Like a bird escaped from the fowler's trap;
The trap broke and we escaped. (Ps. 124:7)

Your kindness reaches as high as heaven.
Your faithfulness to the boundless sky. (Ps. 57:11)

For you are my help
And in the shadow of your wings I shout for joy. (Ps. 63:8)

(Dr. Rachel Adler)

Psalm 102

A prayer for a poor man, who wraps himself up,
who, before Adonai, pours out his thoughts, his speech

Adonai, hear my prayer,
let my cry come to You.

Do not hide your face from me;
in the day of my distress,
incline Your ear to me;
on the day that I call,
answer me right away.
For my days are consumed like smoke,
my bones dried up as a hearth
Beaten down like grass, and withered, is my heart,
I forget even to eat my bread.
From the sound of my sighing,
my bones cling to my flesh.
Like a pelican of the wilderness,
I have become --
like an owl of the wastelands.
My days are like a lengthening shadow,
and I, like grass, dry up and wither away.
Adonai has turned to the prayer of the lonely one
(the one truly of the desert)
and has never despised their prayer.
I say, "*Eili! My God!*
Do not remove me in the midst of my days!"
You, whose years extend throughout all generations!
You laid the foundations of the earth,
the heavens are the work of Your hands!
They will perish, but You will endure;
all of them will wear out like a garment;
and as a garment You will change them,
and they will vanish.
But You are the same, the One,
Your years do not end.
Your servant's children
will be securely settled,
and their seed will be established before You.

(Trans. Rabbi Simkha Y. Weintraub)

Zichronot: Remembrances (For Rosh Hashanah and Yom Kippur)

You remember the creation of the universe,
You recollect every creature You formed from of old.
Before You is revealed
Everything that humans cannot see,
Everything that has been buried since the world began.
There is no forgetting before Your throne of Glory,
You remember every single act.

When we become convinced that we do not matter,
That our lives are only wrinkles in the tapestry of the world,

You remember the creation of the universe,
You recollect every creature You formed from of old.
There is no forgetting before Your throne of Glory,
You remember every single act.

When the promise of Your creation seems obscured,
When the thread of goodness merely leads us deeper into the forest,

Before You is revealed
Everything that humans cannot see,
Everything that has been buried since the world began.[3]

Haiyom: Today (For Rosh Hashanah and Yom Kippur)

Today, please strengthen us.	Amen.
Today, please bless us.	Amen.
Today, please lift us.	Amen.
Today, please seek our good.	Amen.
Today, please inscribe us for a good life.	Amen.
Today, please accept our prayers with compassion.	Amen.
Today, please hear our cries.	Amen.
Today, please support us with your power.	Amen.[4]

Lamentations 2:19
Pour out your heart like water
in the presence of the Living God.

---

3. as trans. Richard N. Levy in *On Wings of Awe* (B'nai B'rith Hillel: Washington, DC) 1985
4. Ibid.

Psalm 121

I lift my eyes up to the mountains.
From where does my help come?
My help is from Adonai
Maker of heaven and earth.

From the Sayings of Rabbi Nahman of Bratzlav

All the world before us
is a very narrow bridge,
and the main thing
is not to fear at all.

A Mosaic of Biblical Poetry (From the Machzor for Rosh Hashanah)

You illuminate the lamps of THE ETERNAL,
you, my God, shine brightly on my darkness.
The lamp of THE CREATOR is the breath of human life,
it searches all the recesses within.
For you have saved my soul from death,
truly, my foot from stumbling,
that I might walk about amid God's presence
in the light of life.
Yes, all of these are things that God can do
for someone, even two times, even three,
to bring one's spirit back from lowest depths,
into light, the light of life.[5]

The Priestly Blessing (Numbers 6:24-26)

יְבָרֶכְךָ יְהוָה וְיִשְׁמְרֶךָ	May Adonai bless you and protect you.
יָאֵר יְהוָה פָּנָיו אֵלֶיךָ וִיחֻנֶּךָּ	May the face of Adonai shine upon you and be gracious to you.
יִשָּׂא יְהוָה פָּנָיו אֵלֶיךָ וְיָשֵׂם לְךָ שָׁלוֹם	May the face of Adonai lift up to you and grant you peace.

Yom Kippur Prayer for Peace

May we be remembered and inscribed
in the Book of Life, Blessing, Peace and Sustenance

---

5. in *Kol Haneshama: Prayerbook for the Days of Awe* (The Reconstructionist Press; Elkins Park, Pennsylvania) 1999

A Mosaic of Biblical Poetry (From the Machzor for Rosh Hashanah)

You illuminate the lamps of THE ETERNAL,
you, my God, shine brightly on my darkness.
The lamp of THE CREATOR is the breath of human life,
it searches all the recesses within.
For you have saved my soul from death,
truly, my foot from stumbling,
that I might walk about amid God's presence
in the light of life.
Yes, all of these are things that God can do
for someone, even two times, even three,
to bring one's spirit back from lowest depths,
into light, the light of life.[6]

A religious man is a person who holds God and man in one thought at one time, who suffers harm done to others, whose greatest passion is compassion, whose greatest strength is love and defiance of despair.
(Rabbi Abraham Joshua Heschel)

The heart's intention is the measure of all things.
(Maimonides, *Letter to Hasdai HaLevi,* 12th century)

The Priestly Blessing (Numbers 6:24-26)

יְבָרֶכְךָ יהוה וְיִשְׁמְרֶךָ	May Adonai bless you and protect you.
יָאֵר יהוה פָּנָיו אֵלֶיךָ וִיחֻנֶּךָּ	May the face of Adonai shine upon you and be gracious to you.
יִשָּׂא יהוה פָּנָיו אֵלֶיךָ וְיָשֵׂם לְךָ שָׁלוֹם	May the face of Adonai lift up to you and grant you peace.

Yom Kippur Prayer for Peace

May we be remembered and inscribed
in the Book of Life, Blessing, Peace and Sustenance

---

6. in *Kol Haneshama: Prayerbook for the Days of Awe* (The Reconstructionist Press; Elkins Park, Pennsylvania) 1999

I Am a Torah Scroll

I am a Torah scroll
old and worn out
many of my letters
rubbed off by many readings
There are places where
my parchment is worn with holes
and ragged edges

I am a book of dreams
memories
precious to my people
I may have forgotten some of the dreams
but you can read my face and see them in a skin
wrinkled with remembered laughter
and spotted with forgotten tears

I am a book of prayers
and conversations with God
pleading, praising, wrestling
God has loved my youth away
until my parchment is worn into holes
and ragged edges

Care for me gently
for the name of God is written in me
Memorize the letters of my dreams
before their substance fades away

My gift to you is my life
My Torah is part of your own
Read me often

(Terry Treseder)

Yotser

Praised be the God
of imperfection

Your flaws are everywhere

In the elm's unbalanced foliage
and the asymmetric faces of Your creatures.

You form the ripping floods
that tear the forests
and bend tornadoes in a twisted dance.

The lion is blotched with age and mud,
and the Shabbas silverware lies stained
as a reminder.

Praised be Your Torah of scratches and scars.

Praised be Your discolorations,
for they are puzzles and poems
of Your sacred character.

(Danny Siegel)

A Prayer for a Loved One with Dementia

May you:

Have family and friends that remember you even when you no longer remember them
Continue to be able to express yourself as long as you have something to say
Be able to get pleasure from a warm and familiar touch -- and may touches be plentiful
Have the companionship of a pet that won't care if you repeat yourself
or say strange things
Always have music in your life -- to listen to and to sing
Forget to be judgmental -- of others and yourself
Not be tormented by the knowledge that your mind and memory are fleeting
Be able to laugh and often have things to laugh about
Not be hidden away -- unable to experience Nature and life
Have many visitors
Be treated with the dignity that you deserve
Always feel that you are "at home" -- wherever you are
Be included in special family occasions as long as possible
Have caregivers who know you would like to look your best
Lose or forget any fear of death
Be able to communicate if you are in pain so that help can be given
Not be limited by the carefully constructed walls around yourself
that you built in the past
Have someone remind you to drink and eat even if you are not thirsty or hungry

May your loved ones:

Shower you with smiles and hugs
Continue to expose you to the traditions and songs from your religion and culture
Not give up on you

May the time and place that is your current reality be one that was happy the first time
May the reappearance of long-dead dear ones in your life be a comfort for you
(and may those who care about you not try to convince you that those people
have been dead "for years")
May those whom you have loved not reject you out of fear
May those whom you have loved accept and love you as you are
And may your loved ones protect you from accidentally blowing up or burning down your house.

(Carol Stern Hochstadt, a caregiver survivor)

Things My Father Taught Me

How to fillet a fish
How to read aloud
How to pay bills on time
How to write
How to wear fine clothes
How to skip around the May pole
How to eat corn, drink scotch,

How to love

How to ear a life jacket
How to caress a dog
How to wear a hat, ride a bicycle, drive a car
How to own my life
How to work a job
How to be honest
How to care

How to smoke a cigarette
How to quit
How to keep going

How to bear a hospital
How to wear a ring
How to love

(Joan Levy, a caregiver suvivor)

A Caregiver's Prayer

Adonai Elohai
Holy One, My God
Rachaman
God of Compassion

Have compassion on me, Adonai. My loved one is fading before my eyes. She is losing her memory of me, memories of us together. Some memories (all memories) are gone forever.

I remember ...

Shema Koli, Adonai
Hear my voice, Adonai

Sometimes I feel angry and overwhelmed
Help me rise above my anger
Help me endure the daily challenges
Sometimes I feel that I am not doing enough.
Help me accept what I can do for my loved one
Help me see the goodness and courage of my own soul
Sometimes I feel alone and abandoned.
Help me find friendship and community
Help me seek out relief and support

I need ....

I ask of you, calm my anxieties.
I ask of you, grant me peace.
I ask of you, grant my loved one peace.

Amen

(Terry Treseder)

In Many Houses

In many houses
all at once
I see my mother and father
and they are young
as they walk in.

Why should my
tears come,
to see them laughing?

That they cannot
see me
is of no matter:

I was once their dream:
now
they are mine.

(Diane Cole)

Facing our Feelings

Only by facing our feelings
do we learn and grow.
Pain has a size and a shape,
a beginning and an end.
It takes over only
when not allowed its voice.

(Anne Brener)[7]

As we make our way...

As we make our way through our busy and often lonely days, may our thoughts lead us back to times of smiles and laughter. May our tears and pain be eased by the comfort of our memory. And may God offer us strength and comfort now and always. Amen.

(Rabbi Naomi Levy)[8]

---

7. "Taking the Time You Need to Mourn Your Loss", *Life Lights* series (Jewish Lights; Woodstock, VT) 2000
8. in *The Mitzvah of Healing*

It Takes Two to Remember a Memory

It takes two to remember a memory
It takes two to make it real

Do you remember when we ...
No.
I remember when we ...
I don't.
Do you remember the little girl who ...
Yes, I remember her
but who are you?

The dying memories
They are my memories, too.
And part of her is dying
and part of me is dying.

Don't tell me to remember for both of us.
It's not the same.
Can one hand hold hands?
Can one foot stroll along a shared path?
Can one arm embrace and be embraced?

Let me mourn the dying
the dying memories

You can hold my hand.
Please do.
You can walk with me.
Please do.
You can embrace me.
Please do.

But in so doing
let me eulogize the memory
let me lament the loss

And that will be a memory we share
you and me
because it takes two to remember a memory
it takes two to make it real.

(Terry Treseder)

As the Darkness Lifts ...

As the darkness lifts, don't let that moment pass without experiencing its full force. Take a walk, even if it's only around the block. Breathe deeply. Gaze at the trees, listen to the birds, look up at the sky, take in the beauty. Eat your favorite food. Savor every bite with a renewed appetite for living. Grate a lemon and smell its rind. Hug your family, thank your friends for standing by you when you were in pain. Ask forgiveness from those you alienated. Stand before a mirror and stare into your own eyes. See the hope that shines through. Tell yourself how far you have come and acknowledge the strength you never knew you had. Sit in a quite place and talk to God. Express your full range of emotions. Your anger, frustration, and sadness, as well as your joy, relief and optimism. Give thanks for the power to endure and carry on, for the new day and its promise, for all the blessings you have taken for granted.

Then brace yourself for the struggles that are yet to come.

(Rabbi Naomi Levy)[9]

Courage

Adonai, bless me with courage
Help me gain strength from You
Life has a way of handing us surprises
that take an amazing amount of courage to overcome
Create in me a clear and steady focus
a heart that is filled wit the awareness that
Adonai is with me
on the sunniest day and in the darkest night
I will be whatever life demands of me
Courage is my knowledge of You.

(Anita Moise Rosefield Rosenberg)[10]

The world is new to us ...

The world is new to us
every morning --
that is Adonai's gift
and we should believe
we are reborn each day.

(Baal Shem Tov)

---

9. in *The Mitzvah of Healing* (UAHC Press, NY) 2003
10. ibid.

We are Loved by an Unending Love

We are loved by an unending love.

We are embraced by arms that find us
even when we are hidden from ourselves.
We are touched by fingers that soothe us
even w hen we are too proud for soothing.
We are counseled by voices that guide us
even when we are too embittered to hear.

We are loved by an unending love.

We are supported by hands that uplift us
even in the midst of a fall.
We are urged on by eyes that meet us
even when we are too weak for meeting.

We are loved by an unending love.

embraced, touched, soothed, counseled ...
ours are the arms, the fingers, the voices;
ours are the hands, the eyes, the smiles.

We are loved by an unending love.

(Rami Shapiro)

God, often I think...

God, I often think
You are the only One who listens to me.
That's enough.

(Janet Caro Murphy)[11]

---

11. in *The Mitzvah of Healing*, op.cit.

Meditation before Barchu

Praise Me, says God, and I will know that you love me.
Curse Me, I will know that you love Me.
Praise Me or curse Me, I will know that you love Me.
Sing out My graces, says God.
Raise your fist against Me and revile, says God.
Sing My graces or revile, reviling is also praise, says God.
But if you sit fenced off in your apathy.
Entrenched in "I couldn't care less," says God,
If you look at the stars and yawn, says God,
If you see suffering and don't cry out,
If you don't praise and don't revile,
Then I created you in vain, says God.[12]

God, I need to Know ...

God, I need to know that You are with me; that You hear my cry. I long to feel Your presence not just this day but every day. When I am weak and in pain, I need to know You are beside me. That in itself is often comfort enough. I do not pretend to know Your ways, to know why this world You have crated can be so beautiful, so magnificent, and yet so harsh, so ugly, and so full of hate. The lot You have bestowed upon me is a heavy one. I am angry. I want to know why: why the innocent must suffer, why life is so full of grief. There are times when I want to have nothing to do with You. When to think of You brings nothing but confusion and ambivalence. And there are times, like this time, when I seek to return to You, when I feel the emptiness that comes when I am far from You. Watch over me and my loved ones. Forgive me for all that I have not been. Help me to appreciate all that I have, and to realize all that I have to offer. Help me to find my way back to You, so that I may never be alone. Amen.

(Rabbi Naomi Levy)[13]

A Yom Kippur Meditation

Your joy is your sorrow unmasked.
The selfsame well from which your laughter rises was
oftentimes filled with your tears.
And how else can it be?
The deeper that sorrow carves into your being,
the more joy you can contain.[14]

---

12. in *On Wings of Awe*, op.cit.
13. in *The Mitzvah of Healing* op.cit.
14. Ibid.

Try to Praise the Mutilated World

Try to praise the mutilated world.
Remember June's long days,
and wild strawberries, drops of wine, the dewe.
The nettles that methodically overgrow
the abandoned homesteads of exiles.

You must praise the mutilated world.
You watched the stylish yachts and ships;
one of them had a long trip ahead of it,
while salty oblivion awaited others.
You've seen the refugees heading nowhere,
you've heard the executioners sing joyfully.

You should praise the mutilated world.
Remember the moments when we were together
in a white room and the curtain fluttered.
Return in thought to the concert where music flared.
You gathered acorns in the park in autumn
and leaves eddied over the earth's scars.

Praise the mutilated world
and the gray feather a thrush lost,
and the gentle light that strays and vanishes
and returns.

(Adam Zagajewski)

When Fears Multiply

When fears multiply
And danger threatens;
When sickness comes,
When death confronts us --
It is God's blessing of shalom
That sustains us
And upholds us.

Lightening our burden,
Dispelling our worry,
Restoring our strength,
Renewing our hope --
Reviving us.

(Hershel Matt)
Prelude to the Amidah

Don't let me fall
Like a stone that drops on the hard ground.
And don't let my hands become dry
As the twigs of a tree
When the wind beats down the last leaves.
And when the storm rips dust from the earth
Angry and howling,
Don't let me become the last fly
Trembling terrified on a windowpane.
Don't let me fall.
I have so much prayer,
But as a blade of your grass in a distant, wild field
Loses a seed in the lap of the earth
And dies away,
Sow in me your living breath,
As you sow a seed in the earth.

(Kadya Molodowsky)

Meditation for Zichronot
Judaism does not command us to believe; it commands us to remember.
The commandment of faith in the Torah is *Remember*.
There is a slow and silent stream, a stream not of oblivion but of memory,
from which we must constantly drink before entering the realm of faith ...
The substance of our very being is memory,
our way of living is retaining the remindres, articulating memory.
(Rabbi Abraham Joshua Heschel)

Meditation for Zichronot

Out of the debris of dying stars,
this rain of particles
that waters the waste with brightness;

the sea-wave of atoms hurrying home,
collapse of the giant,
unstable guest who cannot stay;

the sun's heart reddens and expands,
his mighty aspiration is lasting,
as the shell of his substance
one day will be white with frost.

In the radiant field of Orion
great hordes of stars are forming,
just as we see every night
fiery and faithful to the end.

Out of the cold and fleeting dust
that is never and always,
the silence and waste to come --
this arm, this hand,
my voice, your face, this love.

(John Haines)

Eili: My God

My God, my God,
I pray that these things never end ...
the sand and the sea
the rush of many waters
the crash of the heavens
the prayer of the heart

(Hannah Szenes)

If Only I Could Hold Your Face

If only I could hold your face
If only I could wrap up the light in your eyes
and put it away
safekeeping

safekeeping

against mistaken words
against parting
old age

against all human loneliness

We say that love has no beginning and no end
We know such love
flowing out of itself like a river
that meets and parts and meets

It's for that love
our eyes shine

But oh for that time of parting
for that time we are not ever
sufficiently shored against

Take my hands and bless them
as they bless what they long to keep

(Robert Grant Burns)

The Promise of the Day

Look to this day,
For it is life,
The very life of life.
Iin its brief course lie all
The realities and verities of existence,
The bliss of growth,
The splendor of action,
The glory of power --

For yesterday is but a dream,
And tomorrow is only a vision.
But today, well lived,
Makes every yesterday a dream of happiness
And every tomorrow a vision of hope.

Look well, therefore, to this day.

(Sanskrit Proverb)

I pray

I still don't know whom,
I still don't know why I ask.
A prayer lies bound in me
And implores a god,
And implores a name.

I pray
In the field
In the noise of the street,
Together with the wind when, it runs before my lips,
A prayer lies bound in me,
And implores a god,
And implores a name.

(Kadya Molodowsky, trans. Kathryn Hellerstein)

The Rains

The rains have washed the ice away
and all over the woods, the birches

have dropped their scrolls
whose secret maps lead inside

to the tweet, tick, scritch, and gulp,
to the rumble of distant sky

and the muffled roar of sea,
sounds washed in rain like music

you have heard before,
you have not heard before,

the raw material of your life
abounding.

(Marcia Falk)

We Know Her

We see her in the shimmering blades,
their bright green waving on the hill,

and hear her through the cottonwoods, the birches,
flying free through their leafy crowns.

We breathe her as she lifts to the sky
the scents of the newly furrowed field,

and feel her touching our forehead
in our fevered dreams.

Only her taste is saved
for tomorrow --

the dark taste of her emptiness,
remembered honey of mother's milk --

manna of our longing,
wind.

(Marcia Falk)

Slender Ships

Slender ships drowse on swollen green water,
black shadows sleep on the cold heart of water.
All the winds are still.
Clouds shift like ghosts in the speechless night.
The earth, pale and calm, awaits lightning and thunder.
I will be still.

(Anna Margolin, trans. Marcia Falk)

All the Winds

All the winds have grown still
as though someone rocked them softly to sleep
between naked branches of the trees
on a rainy autumn night.

All the sorrows have made their home
at my doorstep, as though -- in all the world --
they had no other harbor
but my eyes, my hands, my smile, my word.

(Rachel Korn, Trans. Marcia Falk)

Last Apple

"I am the last apple
that falls from the tree
and no one picks up."

I kneel to the fragrance
of the last apple
and I pick it up.

In my hands -- the tree,
in my hands -- the leaf,
in my hands -- the blossom,
and in my hands -- the earth
that kisses the apple
that no one picks up.

(Malka Heifetz Tussman, trans. Marcia Falk)

Praise the World

Praise the world --
praise its fullness
and its longing,
its beauty and its grief.

Praise stone and fire,
lilac and river,
and the solitary bird
at the window.

Praise the moment
when the whole
bursts through pain

and the moment
when the whole
bursts forth in joy.

Praise the dying beauty
with all your breath
and, praising, see

the beauty of the world
is your own.

(Marcia Falk)

Recalling our Ancestors, Remembering Our Lives

נִזְכֹּר אֶת מְסֹרֶת הַדּוֹרוֹת	Recalling the generations,
וְנִשְׁזֹר בָּהּ אֶת שְׁרִיגֵי חַיֵּינוּ	we weave our lives into the tradition.

נְבָרֵךְ אֶת עֵין הַחַיִּים	As we bless the source of life
וְכֹה נִתְבָּרֵךְ	so we are blessed

(Marcia Falk)

Sustaining Life, Embracing Death

נְבָרֵךְ אֶת הַמַּעְיָן	Let us bless the well
-- עֲדִי-עַד מְפַכָּה	eternally giving --
מַעְגַּל הַחַיִּים	the circle of life
הַמֵּמִית וּמְחַיָּה	ever-dying, ever-living.

(Marcia Falk)

Leaves

Leaves don't fall. They descend.
Longing for earth, they come winging.
In their time, they'll come again,
For leaves don't fall. They descend.
On the branches, they will be again
Green and fragrant, cradle-swinging,
For leaves don't fall. They descend.
Longing for earth, they come winging.

(Malka Heifetz Tussman, Trans. Marcha Falk)

Hallowing Our Namings

Let us sing the soul in every name
and the name of every soul,
let us sing the soul in every name,
the sacred name of every soul.

(Marcia Falk)

Blessing of Peace

Eternal wellspring of peace --
may we be drenched with the longing for peace
that we may give ourselves over
as the earth to the rain, to the dew,
until peace overflows our lives
as living waters overflow the seas.

(Marcia Falk)

A Caregiver's Prayer

Adonai Elohai
Holy One, My God
Rachaman
God of Compassion

Have compassion on me, Adonai. My loved one is fading before my eyes. She is losing her memory of me, memories of us together. Some memories (all memories) are gone forever.

I remember ...

Shema Koli, Adonai
Hear my voice, Adonai

Sometimes I feel angry and overwhelmed
Help me rise above my anger
Help me endure the daily challenges
Sometimes I feel that I am not doing enough.
Help me accept what I can do for my loved one
Help me see the goodness and courage of my own soul
Sometimes I feel alone and abandoned.
Help me find friendship and community
Help me seek out relief and support

I need ....

I ask of you, calm my anxieties.
I ask of you, grant me peace.
I ask of you, grant my loved one peace.

Amen

(Terry Treseder)

Marcia Falk's Misheiberach for those in need of support:

כְּמוֹ שֶׁנִּתְבָּרְכוּ אִמּוֹתֵינוּ וַאֲבוֹתֵינוּ
כֵּן יִתְבָּרְכוּ _____.
יְהִי רָצוֹן שֶׁיֵּחָלְשׁוּ הַכְּאֵבִים
וְיָפוּגוּ הַיִּסּוּרִים.
יִשְׁלַם הַלֵּב וְתֵרָגַע הַנָּפֶשׁ.

יְהִי רָצוֹן שֶׁיִּשְׁתּוּ
מִמֵּי הַמַּעְיָן
עֲדֵי-עַד כְּפֻבָּת.

As those who came before us were blessed
in the presence of teh communities that sustained them,

so we offer our blessings
for those among us needing support.

_____,
may your spirit be calmed
and your pain be eased.

may you receive comfort
from those who care for you,

and may you drink from the waters
of the ever-giving well.

Appendix 5

Support Group Rituals

Support Group

Set-up

* Circle of chairs, small table in center of circle
* Table by entrance with selection of ribbons, straight pins, t-lights and matches
* Small signs for ribbons:

Black:	"Grief"
Grey:	"Sadness"
Orange:	"Stress"
Red:	"Anger"
Blue:	"Peace"
Yellow:	"Joy/Amusement"

Before the session begins, each caregiver lights a t-light representing their loved one suffering from dementia, and places it on the center table. If a caregiver needs to share an experience or emotion with the group, they choose the appropriate ribbon as a visual indicator of their emotional state. They should ask someone else to pin their ribbon on to their clothing.

(The ribbons – representing internal well-being -- echo modern cultural use of ribbons for identity purposes. They foreshadow the tearing and wearing of black ribbons during a funeral and for a period thereafter. The act of piercing someone else's clothing with their ribbon forces participants to acknowledge and validate one another's current state of mind. The lights – representing the living human soul and the Divine source from which it came – echo the candle lighting ceremonies of Shabbat, Havdalah, Hanukkah and holiday openings, as well as the menorah and ner tamid. They foreshadow the yahrzeit candle and the lights on memorial plaques.)

Opening Ritual

When all are seated, the facilitator introduces the group to any newcomers. Holding up a large lit candle, the facilitator leads the following responsive:

This is the light of our tradition.
By its light
we support one another
we support one another
we reveal our hearts
we reveal our hearts
we explore our challenges
we explore our challenges
we invoke the Sacred, the Divine
we invoke the Sacred, the Divine
Source of all life
Source of all Life

Set the large candle among the t-lights.

Each participant gives their Hebrew name genealogically and the name of the loved one represented by their t-light, i.e.,

"I am _____ bat/ben (daughter/son of)_____
bat/ben (daughter/son of)_____...
I am *shomer/shomeret* for _____ my _____."

The session should begin with participants describing the event or emotion behind their ribbon, if they want to do so. These tellings can be the context for personal narrative, advice and expressions of support.

(The recital of Hebrew genealogy is a standard ritual for opening Rosh Hodesh gatherings. It not only echoes these progressive ceremonies, but also the genealogy lists in Torah, thereby reinforcing Torah as a metaphor for memory. I added the shomer/shomeret line to help participants recognize their dignified role as guardian and protector of their loved one -- both their physical selves and their fading Torah. It foreshadows the recital of the deceased's name during El Ma-lei Rachaman)

Ritual for Mourning Psychosocial Loss

Those who have suffered a major psychosocial loss, as represented by a black ribbon, may perform the following mourning ceremony:

1. Narrate the circumstances of grief (may be read from their *Caregiver's Log*).

2. Verbally remember the memory or personality lost (may be read from their *Book of Dreams and Memories*), passing around mementos or photographs as they do so.

3. Read or sing a poem, song, psalm or lament
   (may be chosen from the *Prayers and Meditations* section of their *Caregiver Siddur*).

4. Facilitator leads following response:
   May the Comforter who gives comfort to the mourner
   May the Comforter who gives comfort to the mourner
   give you comfort in your sorrow.
   give you comfort in your sorrow.
   May the Healer who grants healing to the suffering
   May the Healer who grants healing to the suffering
   grant you healing in your suffering.
   grant you healing in your suffering.

(This ritual is intended to help the grieving caregiver mourn their loss, as well as symbolically pass the lost memory or personality on to others so that it can be redeemed. The readings and recitation of memory foreshadow the funeral eulogy. The objects passed around represent the memory and personality that the community helps the caregiver to redeem. The communal comfort rendered verbally at the end is a precurser to the traditional recitation given during Shabbat services following a funeral.)

Closing Ritual

1. Participants stand and drape *tallitot* around one another's shoulders to form one circular *mishkan*, or tent sanctuary.

2. Recite Rami Shapiro's poem, "We are Loved by an Unending Love" as a responsive.

3. Participants sing "Oseh Shalom"

3. Facilitator ends the session with the Priestly Blessing:

Yi-varekha Adonai ve-yish-me-rekha
Ya-air Adonai panav ei-lei-kha vi-khu-nekha
Yi-sa Adonai panav ei-lei-kha ve-ya-sem le-kha shalom

May the Holy One bless you and protect you.
May the Holy One shine upon you and be gracious to you.
May the Holy One favor you and grant you peace

(The tallit mishkan creates sacred space, and connects participants with their ancient ancestors, thereby enveloping each caregiver not only with their immediate community, but with the larger community of Israel -- past and present. The Song "Oseh Shalom" infuses the experience with the important element of music. As this song nearly always leads to swaying motions, it also encourages the rhythmic body motions that create feelings of well-being. The final blessing -- the oldest blessing in our tradition by at least 3,000 years -- not only authenticates the closing ritual, but the entire support group session.)

Appendix 6

Sermon and Closing Ceremony
For Shabbat Service Dedicated to Caregivers

Shabbat Service Dedicated to Caregivers
Sermon

A certain rabbi, renowned for his scholarship and great deeds of lovingkindness, dreamed that his neighbor in Paradise would be the local butcher, a man hardly seen at all in the community. The next morning, this rabbi visited the butcher.

"I dreamed last night that you are destined for a place of great honor in Paradise," the rabbi informed the butcher. "I am curious to know what good deeds you are performing that the Holy One should love you so."

"I don't know," the butcher said, "but I have an elderly father and mother who are helpless. I give them food and drink, and wash and dress them daily."

The rabbi smiled happily. "It is my honor to be your neighbor in Paradise."

Our tradition has long revered those who care for their elderly parents, as well as other loved ones rendered helpless through disease, injury or the natural wear and tear of time. It is a great mitzvah indeed to lay down our time and personal plans in order to pick up the burden of physical and emotional care of a parent, a partner, a child, without hope of recovery or healing -- and to do so with tenderness and respect. Few of us can understand the cost of such care to those who, for the most part, remain invisible among us.

A friend of mine sat with her father on one occasion to reminisce about old times. Carol shared memories of her childhood, while her father nodded knowingly. Yes, he too remembered these experiences with his little girl. It was a warm, Hallmark moment ... that is, until Carol's father cocked his head and stared at Carol, deeply puzzled. "How is it," he asked, "that you know so much about my Carol?"

"That's when it hit me," Carol told me years later, "that there was no connection between the little girl who was Carol and the woman sitting next to her." It was a moment of intense grief that would stretch itself out over the coming years. Carol experienced many such moments with her mother, as well, over the course of a seven-year decline in a care facility. Both of Carol's parents were stricken with Alzheimer's Disease. Over the long years she cared for parents who no longer knew her she was alone in her long-term grief; alone in arranging physical care; alone in processing reams of paper-work; alone in handling a constant stream of day-and-night emergency phone calls; alone in making life and death decisions in hospital hallways and ICU units. Vacations were impossible. She felt torn between her parents and her husband and children who also needed her. Crisis and exhaustion became her normal routine.

This situation, unfortunately, is becoming all too common. 5.5 million people are afflicted with Alzheimer's alone – 10% of Americans over 65 years old. Other forms of progressive dementia double those figures. Dementia can also be the result of brain damage caused by strokes, tumors, and disease. Though not part of statistics, they are part of human tragedy in our midst. A loved one may be clear-headed but stricken helpless by fate of accident, terminal illness or birth defect. Cancer, Parkinson's, paralysis, AIDS,.... the list goes on and on ... the catalogue of ways and means by which the Divine image is mutilated by flesh and blood. Chances are, at some point in our lives, we will either be stricken by one of the flesh-eating demons of our mortality, or we will be caring for a loved one who is so stricken. Theologian Dr. Rachel Adler, herself a caregiver to her mother, wrote:

Human is not whole. Human is full of holes. Human bleeds.
Human births its worlds in agonies of blood and bellyaches ...
Human knows that what it weds need not be perfect to be infinitely dear.

Our rabbis teach us to sanctify our flaws and imperfections.

[Read, "Praise be the God of Imperfection"]

This is a sorely needed prayer in our technocratic world today. Now I have good news and bad news regarding our response to radical, long-term illnesses.

The good news is that we, as Americans and as Jews, are taking responsibility for our loved ones. Only 5% of our elderly, for example, are institutionalized. Although 20% of our elderly will likely spend some time in care facilities, 80% never do. I suspect the figures are even better for afflicted children and spouses. My personal experience with caregivers suggests that most people in care facilities are there as a last resort -- due to concern for proper medical treatment and the overwhelming physical demands of caregiving. And they continue to receive care and attention from family members. So as individual caregivers we are exceptional at keeping the commandment *kibud av ve-em*, honoring father and mother, as well as responding to the suffering of those near to us.

The bad news is that we are failing as communities across America, and among our own people, to support caregivers during their long and lonely vigil. According to several researchers in the field of caregiver grief, the number one source of stress and pain for family caregivers is isolation -- loss of friends, loss of extended family, loss of religious community. This at a time in human history when medical technology can extend the radical condition of deteriorating mental or physical capacity almost indefinitely; at a time when multi-generational households with their built-in support

systems are unknown; when the life expectancy we enjoy today guarantees a longer, darker vigil for the frail elderly spouse or the lone wage-earning child or parent.

So what can we do? There are a number of things we can do to transform our community into a multi-generational family that can support one another in times of need --- things we can do as alert individuals, and things we can do in coordination. I am going to suggest three things each of us can do as alert individuals, and then introduce a three-level program of support that a number of us in positions of leadership have developed together.

As an alert individual, I can do the following:

First, as an alert individual, I can encourage medical evaluation and early diagnosis. I once counseled a family who thought their father had Alzheimer's Disease. His wife covered up his deteriorating memory and confusion for two years before he took a sudden turn for the worse and it became obvious to the entire family that he was not only losing his memory, but rapidly losing his strength and coordination. The oldest daughter insisted on a complete medical evaluation. A series of tests finally revealed that his mental confusion was caused by a problem in his metabolism, a condition easily reversed with the right medication. But just as his mind cleared up, they discovered late-stage cancer. He died three weeks later. Not only did this man and his family lose two years of lucid time together, but they were unable to diagnose the real killer in time. Covering up memory loss or physical deterioration is sadly common among us. We do so out of misconception and fear. We misunderstand old age, for example, as illness. Memory loss is not part of old age. It is part of a disease that, in many cases, can be treated or even reversed. We fear to face the terror of a dying mind. We must overcome

this fear if we are to prepare a rational response to the condition and its aftermath. Most of all, we fear the social stigma that our society places on the helpless. If we, or someone we know, show signs of serious health or mental deterioration, we ought to press for evaluation and diagnosis.

Second, as an alert individual I can offer relief to a caregiver. A caregiver mainly needs time to themselves, time to rest, exercise, spend time with friends or other family members. One caregiver told me she had a wonderful social network of friends while she cared for her mother. They would take her mother shopping, or to the senior center, or simply be in the house while she took off for an hour or two. Another caregiver had excellent help from her children and grandchildren, who set up a schedule among themselves so that she had two-three hours a day to herself, as well as a weekend off every month. The visits from grandchildren and great-grandchildren, by the way, were mutually delightful.

Third, as an alert individual, I can continue my friendship with a caregiver. Most caregivers experience the pain of losing their friends, not only because sudden responsibilities overwhelm their time to connect, but because their friends feel uncomfortable in the presence of their afflicted loved one. One caregiver told me that her social network vanished so completely that they no longer received invitations for major celebrations, holidays or dinners, because of her mother's "strange" behavior. On one particular Thanksgiving she was too exhausted to put together the feast for her young family, so they had soup instead. There was nowhere else to go.

As alert individuals, then, we can press for medical evaluations, we can offer time-off and we can keep one another within our circle of friendship.

Meaningful support also requires a coordinated effort on our part. With that in mind the Mitzvah Committee, in collaboration with Jewish Family Services, is initiating a three-level support program for caregivers of those afflicted with progressive dementia. It is our hope that when this program is established and flourishing, we can then incorporate similar programs for other specific needs in our community. Each of these levels is under the leadership of a capable and experienced caregiver survivor. I am now going to let each of them introduce themselves and the project they are coordinating:

[Coordinator of the Mentoring Program.

This would be the point person described in my Intervention Protocol]

[Coordinator of the Support Group]

[Coordinator of Covenant Network. This person would coordinate congregants willing to donate respite time to a caregiver, as well as dinner and celebration invitations]

As part of this effort, we are also introducing a *misheberach* for those who cannot be healed mentally or physically, but nevertheless need our prayers for peace. Normally we do a *misheberach* in the presence of a Torah scroll, as we did today, as a reminder that each of us is a scroll made of skin and memories, both vulnerable and sacred. But we will introduce this one now. And in the future, we will pray this prayer together after our traditional prayer for healing. If you are a caregiver for someone who is dying in mind or body -- at home or in a care facility -- please rise.

[Caregivers rise]

At some point in this prayer, I will pause and sweep my hand across the room. When my hand reaches you, please say the name of your loved one.

[Give the Caregiver's *mishebeirach*]

Please remain standing while the rest of us offer words of comfort

May the Holy One give you strength
May the Holy One give you strength
May the Holy One give you comfort
May the Holy One give you comfort
May the Holy One give you peace
May the Holy One give you peace

[Transition to service by requesting mourners to stand to say the Kaddish]

[Instruct remainder of congregants to stand and form a tallit sukkah by sharing one another's tallitot across the shoulders]

[Read Shapiro's poem "We are Loved by an Unending Love" as a responsive]

[Sing "Oseh Shalom"]

[End service with the Priestly Blessing]