

BIO-ETHICS STUDY GUIDE # 13

SPIRITUAL CHALLENGES OF LIVING WITH CHRONIC ILLNESS

Union for Reform Judaism
Department of Jewish Family Concerns: Committee on Bio-ethics

Winter 2004-2005

ACKNOWLEDGEMENTS

This study guide resulted from a conversation between Rabbi Richard Address, Director of Jewish Family Concerns and Rabbi Lawrence "Jake" Jackofsky, regional director for the Union for Reform Judaism's Southwest Council. Jewish Family Concerns is grateful for Jake's idea and his continuous support in developing this study guide. In addition, thanks to Jewish Family Concerns Bio-ethics committee, its immediate past chair Dr. Harvey Gordon, and its current chair Dr. Mort Prager, for all their work and commitment to Jewish Family Concerns. We also thank Dara Frimmer, a student at the Hebrew Union College-Jewish Institute of Religion in New York for her assistance at the beginning of this project and Gila Silverman of *Shleimut* for her input to the study guide. Finally, a special acknowledgement to Rabbi Lisa Izes for coordinating this project. We thank Lisa for all of her work and dedication to the mission of the Union's Department of Jewish Family Concerns.

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An Introduction to the Guide

According to the Centers for Disease Control:

Today, chronic diseases – such as cardiovascular disease (primarily heart disease and stroke), cancer, and diabetes – are among the most prevalent, costly and preventable of all health problems. Seven of every 10 Americans who die each year, or more than 1.7 million people, die of a chronic disease. The prolonged course of illness and disability from such chronic diseases as diabetes and arthritis result in extended pain and suffering and decreased quality of life for millions of Americans. Chronic, disabling conditions cause major limitations in activity for more than one of every 10 Americans, or 25 million people. (“Chronic Disease Overview,” www.cdc.gov)

Given these numbers, it is clear that many members of Reform congregations are living with chronic health conditions. Within the Movement, we are searching to find ways to provide spiritual and emotional support to these members of our communities, and do what we can to support efforts to prevent those illnesses that can be prevented. As we work to create Caring Communities, we need to address the needs of those affected by ill health.

Chronic conditions affect many of our congregants and their families and friends beyond their problems with physical health. These illnesses can affect all aspects of people’s lives- relationships, work, home, emotional and spiritual lives- for many years. Rather than being a short-lived time of crisis, a chronic health condition brings with it a lifetime of coping and adjusting, a perpetually evolving and changing sense of self, and a life lived differently from what might have been expected. Chronic illness may affect people’s participation in Jewish life and their ability to fulfill *mitzvot*, and might diminish their feeling of being welcomed and at home within the Jewish community. At each stage of the process of living with an illness, resources are needed for support, solace, encouragement, and acceptance. Judaism and the Jewish community can provide some of these tools needed to live with a chronic health condition.

- Adapted from Gila Silverman, MPH
Founding Director of the Shleimut Institute

As congregations committed to nurturing and sustaining our members, it is crucial that we examine these issues so that we may do our best to reach those in need in an appropriate manner. Knowing that those who live with chronic illness and their loved ones cope in many different ways, we must be ready to reach people quite literally 'where they live.'

This guide is intended to help educate congregations and individuals. It might help serve as the basis of a community program, or perhaps be used as a study piece for personal reflection. It is intended to be a resource that will open up conversation, lead to new programming ventures, show those people suffering that they are not alone, and perhaps provide some new meaning and insight into one of life's difficult realities.

Bio-Ethics Guide #13 includes a number of deeply personal and moving stories, some programmatic ideas, a sample healing service, texts for study, several valuable articles and some noteworthy resources for those that are ill and their caregivers.

The *Zohar* teaches: If a physician cannot give a patient medicine for the body, he should somehow find and give medicine for the patient's soul. Each of us has the power to help and to heal, sometimes in body and hopefully in spirit. We hope that this resource guide will be a beneficial aid in whichever capacity you turn to it.

As always, the Union for Reform Judaism Department of Jewish Family Concerns can provide you with further assistance as needed. Please contact us at jfc@urj.org or at 212-650-4294 if we can be of help.

L'shalom,

Rabbi Lisa Izes
Assistant Director, Jewish Family Concerns

BH

Rabbi Judith Z. Abrams, Ph.D.

Good Health. Unfortunately, unless one lives a mindful life, one is usually unaware of the gift one has in wellness. This is why the sages suggested that we begin our day with thanks for hearing, cognition, sight, the ability to stand and walk, etc. (B. Berachot 60b). “Met needs don’t motivate,” they say. To demonstrate this idea, try the following exercise. I assume that as you read these words you are breathing normally. Indeed, I imagine you weren’t even thinking about breathing until I mentioned it. Try this experiment: take the biggest, deepest breath you can and hold it. Now try to take another breath. This is what a person with respiratory insufficiency from, say, congestive heart failure feels. I hope this exercise helps you see how much we all take for granted. You’d probably like to say a blessing for your next comfortable breath, now mindful of how wonderful it is.

Persons living with chronic illness are acutely aware of our physical states. We spend a great deal of time in doctors’ offices and a great deal of money on prescriptions and treatments. We have to give our physical state much more of our attention than we used to do.

We have good cultural definitions for the roles of “sick” and “well.” When one is sick, one is to devote all one’s energies to getting well and one is excused from personal and professional responsibilities. When one is well, one is expected to participate in all of life’s activities fully. But what do we do with those who are betwixt and between? What do we do with people who cannot predict how they will be able to perform on any given day? People with diabetes, scleroderma, MS, back problems, thoracic outlet syndrome (my main problem), fibromyalgia, etc., are not just diseased persons. We’re people who are struggling with less than optimal conditions the best we can, for the most part. There are malingerers, true. But the overwhelming majority of persons with disabilities try to live and work to their fullest potential each and every day. Accepting that that “fullest potential” is not what it once was is the hard part. To use the words of the late Rabbi

Edwin Friedman, both sick and well persons need to be non-anxious in the presence of anxiety. In her wonderful book, *The Rejected Body*, Susan Wendell explores the social constructs that contribute to peoples' disabilities. I strongly recommend this book to anyone who is touched by issues of chronic illness and/or disability.

We, who live with chronic illness are used to being told that we're making it up or, to put it more politely, that our condition is psychosomatic. Why? Because often, our conditions do not fit into the cookie-cutter, cook book kind of medicine practiced in this country today. In their anxiety, physicians will often refer a "problem" patient (i.e., one who cannot be diagnosed in five minutes) to someone else or may prescribe so many medications that the patient's intellect is blunted and s/he becomes quiescent. That sounds angry, I know. As a person living with a chronic illness, I am generally not entitled to be angry. I am, after all, diminished in many important ways. Therefore, I should take what is given to me, however diminished, with gratitude. That's the underlying psychology/theology at work. Low self-esteem and the belief that I am being punished by God (and I truly believe that, just as I believe in a God who rewards, as well) add to the misery.

Now, you want to hear the really bad news? I live in Houston, which has one of the largest and most up-to-date medical centers in the world. In addition, my husband is not only a physician but a Full Professor at the Baylor College of Medicine. And on top of *that*, we still have insurance that allows us to see whatever doctor we wish, whenever we wish to do so. You'd think a person with all this *yichus* (pull) would get first-rate treatment, and in many cases I do. I have several excellent, even saintly, physicians and physical therapists whose compassion has been a blessing and a boon. But I still met incompetent and even sadistic physicians and I still wait in doctors' offices for four or five hours past my scheduled appointment time. As a patient, my time is not valued. In the hospital, as soon as they put that band around your wrist you are a piece of meat to be processed. Your *yichus* disappears because you are no longer really a person.

Just as the Baby Boomers created the counter-culture of the 1960's and the Yuppie culture of the 1980's, so they will demand a reexamination of disabilities as they come to experience them more and more frequently. This experience of chronic illness and disability will be caused, ironically, by advances in medicine. Cancer, heart disease and even AIDS have become chronic diseases rather than life-threatening conditions. The Baby Boomers will want to fight these conditions in every possible way. They will demand and fund medical research. They will try denial (e.g., plastic surgery). They may opt for acceptance and proclaim the positive value of chronic illness as something that spiritually enhances their lives. They may also demand the serious study of disabilities. I predict that Disabilities Studies programs will spring up in universities around the country. Just as 50 years ago the idea of Women's Studies in a university would have seemed ridiculous, I predict that 50 years from now we will look benighted for not having had Disabilities Studies at institutions of higher learning.

Up until now, I have addressed the medical, social and intellectual aspects of chronic illness and disabilities. But what about the spiritual aspects of such a condition? I believe that the way in which one handles one's own chronic illness depends on how one has prepared for it. I would say that loneliness is one of the biggest challenges any human being faces and all the more so for a person with a chronic illness. So how can loneliness, more caustic to the soul than almost any other emotion, be ameliorated? I use two techniques: study and cherished memory. You see, I have studied a great deal of rabbinic literature...so much, in fact, that a goodly company of sages are on the "hard drive" of my mind. No matter how isolated I am, I always have them with me. They help me and strengthen me. I also have memories that help me hold fast. I remember my classmate, Rabbi Charisse Kranes, as she was on the day of our ordination in Cincinnati in 1985. On that day, she probably already had the ovarian cancer that would all too soon end her physical life. But for me, she is not dead. She is still alive...singing and inspiring me and celebrating outside I.M.Wise Temple in the spring sunshine. I know that Rabbi Lynne Landsberg was in a catastrophic car accident...but in me she lives on as I saw her when she visited HUC-JIR in Cincinnati in the early 1980s. She was on the board of the CCAR, an assistant rabbi at a prestigious congregation and was turned out in

the most fashionable outfit imaginable. She was the picture of confidence, authority and womanhood all at the same time. She exists in my mind this way. I wonder if I have left memories of my healthy self in some peoples' souls or minds. That would be a great comfort indeed.

For my own part, I honestly wish I had no chronic illness or disability. And yet, I think I am beginning to understand why God has put these things in my life. As usual, in God's infinitely elegant way, God set up the chess game long before I could understand its plan. By writing this essay, I hope I fulfill part of God's mission for me and achieve some redemption of my own suffering by giving it meaning.

A TIME OF CHANGE -- LIFE WITH EARLY PARKINSONS DISEASE
BY FILLIS W. STOBER

Noticing Tremors

Years before I told anyone I began noticing tremors. When, approximately 7 years ago, I agreed to take the Temple Board position of first vice president, and to be Temple president in two years. I kept to myself my reason for accepting.. I had been noticing tremors in my hand every now and then. the neurologist I was seeing for migraine headaches didn't seem concerned, but in the back of my mind, I felt something was wrong. So, when I had the chance to be Temple president, I thought I'd better do this now, while I'm still healthy enough, even though I was already busy with my law practice and family obligations.

When I first noticed the tremors, I had Parkinsons disease on my mind, because my father had recently died from complications of Parkinsons disease after a long struggle. I thought I was imagining the tremors. After all, I was only in my 40's, and my father had not been diagnosed with Parkinsons until he was 69. I was tired of doctors from my quest to find a real diagnosis for my migraines which were brought on by light sensitivity, and I didn't appear to be dying, so I let it go. Besides, the tremors were sporatic. Maybe my hand had tremored when I picked up the coffee pot just because it was so heavy. Or maybe I had been carrying something heavy when I couldn't hold the coffee cup steady.

Finally, my neurologist noted the tremors, but after an MRI told me he didn't know what was causing them. He also said he had no idea why I had pains in my legs, particularly when I walked uphill. Because I was overweight, he hinted that I was just out of shape. I supposed I was. I was ashamed because I needed practice just to walk around the office, and my husband always complained about how slowly I walked. I started exercising to tapes in the morning, just to get limbered up enough to be able to walk during the day. In addition to the difficulty walking, I was also having the strange experience of speaking at meetings and having people act as if they hadn't even heard me.

There were instances when other people noticed the tremors. At a meeting with a client, the client handed me a cup of coffee, and my hand shook uncontrollably. A similar instance occurred at a breakfast room in a motel. I mentioned the tremors to a friend, who said she was sure it was nothing. I decided that I must have carpal tunnel syndrome. I felt pretty good, although I found late meetings at the Temple increasingly exhausting. In fact, as soon as my term as president ended, I stopped going to the board meetings. I couldn't understand how other people had energy for those meetings.

The Diagnosis

After two years of avoiding my neurologist, I went back for a regular check-up relating to my light sensitivity migraine problem. He announced suddenly, as if he thought we had discussed this previously, that I did have Parkinson's disease, but that since I was doing so well, I should just come back in a year.

I was stunned.! I thought, "he must be wrong". I decided to change neurologists, and went to my primary care physician for a recommendation. She moved my arms in circles, and said that I did have a kind of "catching" in the movements that indicated Parkinson's disease. She sent me to a new neurologist. In preparation for the appointment I got my records from my original neurologist, and found that he had diagnosed me with Parkinsons disease two years earlier, but never told me. I was furious, but I still thought it must be wrong. Still, my original neurologist had said he was sure I had Parkinsons because my hand tremored when I wasn't using it, when I was just walking. I spent time watching my hands in the mirror, I noticed the tremor every time I looked.

When I went to the new neurologist, I was sure he would confirm that it was all a mistake. But he didn't. In fact, he insisted on starting me on some medication. I was reluctant at first, but the results were wonderful. My daughter said that my voice was much stronger, (no one had told me it was weak, but she

had noticed, and I had experienced times when people didn't hear me). My legs no longer hurt when I walked. I was so excited, that I went to numerous state parks with my husband and walked and walked. About that time I also found out that a first cousin of mine on my father's side, who was my age, had also just been diagnosed with Parkinson's disease.

My reaction

Despite these good results of the medicine, I was devastated and frightened, having seen what my father had gone through. I reacted by seeking comfort. It was fall in New England, and I insisted that my husband take me to local fairs, week after week. It was a "comfort" activity from my youth. Somehow, seeing the animals and the crowds relaxed me temporarily. I also read books and internet articles on Parkinson's disease to try to find some comfort and ease the pain.

Initially I reached out to people, but for the first time in my life, it didn't help. I even called the firm sponsored employee health line, but the counselor that was in the town where I lived was actually a substance abuse specialist. I saw him two of the three allotted times. When he tried to compare the issues relating to having a disease to being an alcoholic, I decided not to return. A couple of people told me that I was lucky because at least I knew what was wrong with me, and they might later find out they had some disease such as cancer. This logic was ridiculous, because I could someday have cancer too, and I also had type 2 diabetes and chronic migraines. Besides, I was experiencing difficulties now, this wasn't just about the future.

I told people that I worked with most closely at work. It was a relief not to have to hide my symptoms from everyone. Having done that, I decided that I had better tell the firm management, before they heard it somewhere else. People were sympathetic, but really didn't know much about the disease. I have not told any of my clients, although I am sometimes tempted to when I walk down a flight of steps slowly or have trouble staying awake or hiding my tremor at a meeting.

After the initial sympathy wore off, people stopped asking me how I felt. To the outside observer, my condition seemed stable. In reality, my doctor was gradually increasing the dosages of my medication as my symptoms progressed. At one point, the medication was causing me to fall asleep while driving, and the doctor had to decrease one medication and add another. Since then, my legs have started to ache again. I also have the problem that my arms don't swing. To walk at more than a crawl, I need to consciously swing my arms to propel myself forward. This is rather difficult.

This past year at work was especially busy. For an entire year, the only vacation I took was when I added a few days to a trip to a bar association meeting. In addition, my mother, now suffering from her own chronic and fatal illness, pulmonary fibrosis, required additional time. My family hired a woman to stay with her at her home on a full time basis, but because she was housebound we stepped up our visits and outings with her. My brother, sister and I also took turns staying with her every other weekend when her helper was off. Last April, my mother was placed in a nursing home and is now under hospice care, so I try to visit her almost daily. I struggle to keep up with my hectic schedule while managing my symptoms.

Having Trouble with Slowing Down

Of all of the difficulties, the worst for me is giving up activities due to fatigue. This is hard because I am relatively young (54) and have always thrived on being active. My life was exciting and fun, and I didn't think about it changing.

Like most people, I need to work for economic reasons, so I have put all of my energy into work. The job is demanding, and requires time on nights and weekends. Often, I get so tired that my husband, has to pick me up from work. On long trips, my husband does all of the driving now because of the problems I have had falling asleep at the wheel. I had liked taking a turn to drive. I could play the music I wanted, and feel free and independent. My husband also does most of the grocery shopping now, another activity I had enjoyed.

I've also dropped all of my Temple jobs, except one. The job I still have is finite, and should be finished this fall. I rarely go to services on Friday night, because I am too tired, unless it is our monthly Kabbalat service that starts at 6:00, and I can go straight from work. I very rarely go to Torah study, because I am generally too tired to both attend Torah study and visit my mother, and visiting my mother seems more important. However, I miss Torah study very much, as I found it to be a stress relief. My husband sometimes goes without me on Friday nights, and usually on Saturday. I find myself resenting that, although I know it is wrong, because I want to go with him.

The odd thing is, that when I do go to Temple now, it is almost uncomfortable. I see board members talking and laughing in small groups, and giving up that comradery has been very difficult.

I had been agonizing over whether to push myself and do as much as I can while I can, or to take it a little easier. The answer came on its own. While I was busy agonizing, I just became too tired, and started cutting back just because of fatigue. When I did push myself, due to a very busy work schedule this spring, I got pneumonia and was out of work for a week and I am still coughing after a month. Now I need to think about how much I can push myself.

We have a new baby granddaughter, and she is a joy. I am trying to do as much with her as possible while I can. When I hold her in my right arm, however, I tend to tense it up because it feels weak, and she notices and starts to cry, so I hand her to my husband. He's thrilled to hold her, but I am jealous of his health. Changing her diaper is awkward because of my lack of manual dexterity, but I do so anyway because it will only get harder later.

The fear factor

My first concern is financial. Fortunately, I have disability insurance, if I need it, which will make payments until I'm 65. It would be enough to live on, but not enough to add to my retirement fund. Health insurance is perhaps my biggest concern. At retail prices, my medicine would run about \$1,000 per month, and maybe I'll be on even more expensive medicine by the time I retire. I will not have continuing health insurance (except Medicare) after I retire.

The financial pressure is real, but on the other hand so is the time pressure, I don't have unlimited time to be healthy enough to do a lot of things. We are trying to work out reasonable compromises. For example, I wanted to see the Grand Canyon while I still could walk, so we went out west, but used frequent flyer miles to pay for the air fare. I will err on the side of vacationing over saving, because my vacation options later may be limited anyway.

My other fear is my physical and mental deterioration. Because Parkinsons disease is progressive, I am likely to become increasingly slow, increasingly shakey, and increasingly confused mentally. This is a very frightening prospect. I'm afraid that life will stop being fun because I'll be so debilitated. I'm afraid I'll die younger than I should. This fear has become more real to me since my bout of pneumonia because my father died from pneumonia that he was too weak to fight off. Most of all, I'm afraid I'll be a terrible burden to my family, and that I won't be there for them when they need me. I'm scared everyone will forget me when I am sick all of the time, or that my husband will grow to hate me as the burdens of caregiving increase.

I want to stop fearing the future, and to stop seeing that vision of my father in a wheel chair, stiff and confused and unhappy. I try to push it out of my mind. Usually I'm too immersed in what I am doing now to worry about the future. It may never happen—I could die of something else by then or a cure could be developed. Nevertheless, it is difficult to completely stop worrying about the future.

Looking for a spiritual answer

I want to go spiritually to a place where I can see the degeneration of my abilities as a natural process. All the world degenerates, and then new life starts. I want to accept my limitations without jealousy of others. Every day, I wake up and tell myself that it will be a hard day, but that I can do it. I want to stop finding every day to be hard. Most of all, I want to stop fearing the future.

My husband and I once saw a Chinese movie that focused on death. In the movie, recently deceased people were asked to remember their happiest moment. Heaven would be remaining in that moment for eternity. Incredibly, when my husband and I spoke after the movie, we had both selected our the exact same happiest moment: a beautiful day during a beach vacation when we were young and the kids were little, and we had played in the sand with the children with so much joy and gratitude. When I told my husband about my fears of being immobilized in a nursing home, he said that perhaps I would be able to think of that moment, and find the joy of that Chinese heaven. I cling to that thought when I feel low. I want to be able to accept that vision of my life, that even at its worst I can control my thoughts and my attitude. I want to be in a place spiritually where I can live in that peace.

What I have learned.

I've had to find the inner resources to deal my disease and my fears. I think that spirituality can help, because for me, spirituality brings a sense of being a part of a larger whole, puts my problems into perspective, and reminds me to be grateful for all the things I do have and all that I have already had an opportunity to experience. Community can help too. I did attend one support group meeting, it is a group of younger people (most about my age) who are still working, and as they only meet 4 times a year I have so far only found one meeting when I didn't have a conflict. But it did help to be with other people facing the same problems. My community of friends and relatives helps too. They don't treat me like I'm sick, but they are kind and considerate and keep me from feeling alone.

Through no fault of anyone, the Temple as an organization has no particular mechanism to help someone with a chronic, degenerative illness. I don't need clerical visits, for example, because I am still working and functioning; clerical visits are for people that are bedridden or hospitalized. The Temple Mitzvah committee is great in helping a lonely people by visiting them, and helping non-drivers get to the Temple. I, however, am not a shut-in and I am still driving. Although I find that worship is a path to spirituality for me, and therefore helpful, sometimes going to Temple makes me feel worse about not being a really active member anymore. I find people don't have much to say to me, nor I to them. I feel left out of things, whereas I was so recently in the middle of things.

I don't know what a Temple can do about this, perhaps nothing. I would like to throw out some thoughts on this, however. Our Temple had one set of healing services, which I would have liked to attend, but I had a conflict one of the nights. To attend these services, a Temple member had to commit to attend both services. The service wasn't repeated. I think it might be helpful to have a healing service periodically for anyone who wanted to attend, without having to commit to attend a certain number of times. After all, a person who is fatigued or not feeling well is less likely to be able to commit to being at a certain place at a certain time. Providing some type of ongoing spiritual reading might also be useful (ongoing because someone with a chronic illness may live for a while). An internet program for people who cannot leave home, or audio tapes for people with sight problems and video tapes or DVD's for people with hearing problems, could also be useful. For a large enough Temple, a support group for people with chronic illness might be feasible.

Conclusion

Because I was diagnosed with a chronic, degenerative illness immediately after the expiration of my term as Temple president, and shortly after watching my father suffer for many years with the same disease, and die of complications from the that disease, these three aspects of my life are inextricably and emotionally bound together for me. Thus, my decline in energy coincides with my declining activity with my Temple, and constantly calls me to relive those last painful years of my father's life. I see spirituality as a path to help

me focus on the positive aspects of my life, rather than on limitations and fears. I see the Temple as having a role in this by providing paths toward spirituality and community that are more convenient for people with chronic illnesses, and that address some of the emotional issues that face someone with a chronic and/or degenerative disease.

FROM DARKNESS TO LIGHT: A PERSONAL JOURNEY WITH ILLNESS

The hours leading up to Erev Rosh HaShanah are a most significant time for our people, and I believe provide common experiences and shared memories for all. Jews across the globe leaving the office or school early are found scrambling around in preparation for their holiday dinner, the evening service, or both, and rabbis are generally putting the final touches on that first of the High Holiday sermons and worrying about the logistics and choreography to ensue. As a husband, father and rabbi, both scenarios are quite familiar ones. However, several years ago, a new memory was created for me, one, which seemed to be the most horrendous of nightmares, only no matter how hard I tried to pinch myself or wake up, I could not seem to extricate myself from the hell on earth that I was experiencing.

Only hours before I was to stand before hundreds in my congregation and officiate the Erev Rosh Hashanah service, while my older child, then six, was taking the bus home en route from her first day in first grade where she would be greeted not by her parents, but by her grandparents and her one year old brother, I sat in what I could only compare to Auschwitz. The truth is that this was a premier medical facility, no one was unkind or sadistic, yet to me I felt as though God's presence was missing, at least over my head. While the many who surrounded me were receiving treatments, some rather ghastly for their particular cancers, I felt as though I was completely on my own. Stricken by a rare form of Leukemia, I had been previously led to believe that my only brother, contained a bottle of medicine within his body, namely his bone marrow, which could be injected inside of me, following months of high dose chemo and radiation therapies. Seated within the office of the bone marrow transplanter, after an afternoon of being poked and prodded on a metal slab by countless pokerfaced interns and residents, my then only prayer for survival was completely shattered, as I was told that my oncologist was incorrect, my brother would not be a suitable match. Although I attempted to remain composed, fear and disbelief raced through my blood far more noticeable to me than my cancerous cells.

How I wished to scream:

"Where are you God? Why is this happening to me - the rabbi, the social worker, the one who had spent countless hours counseling patients with cancer, AIDS and a myriad of illnesses within a wide variety of hospital settings and homes? Furthermore, even if I deserved such a fate, a prolonged and deteriorating illness, marked by pain and indignity, did my wife or my children? Why dear God are you doing this me?"

Perhaps this was Divine retribution for some atrocity I had no recollection of committing, or a major character flaw I was not conscious of. Perhaps, as we entered the period of time when all Jews were to either be inscribed in the Book of Life, or not, God had decided that I was deserving of such a punishment, and that the world would be far better off without me. Perhaps I thought, that God believed that another man would make for a better husband for my wife, and a better father for my children. Perhaps God wanted my fate to be sealed while my children were so young, so that the memory of me could be blotted out and replaced by another who would respond to the title, "Daddy," which I had so cherished each time I heard it uttered by these two sweet young voices.

While I had walked into the bone marrow transplanter's office filled with hope and prayer, I left with nothing but despair. I was presented with the one existing option, daily injections of a potent drug, laden with a plethora of devastating side-effects, including constant flu-like symptoms, and major depression which medications seemed unable to alleviate, which might temporarily keep me alive while a search ensued for a bone marrow donor. However, unrelated donor matches placed great risks. Additionally, as a Jew, of purely German background on both my sides of my family, Hitler did an excellent job of making my options rather slim. Furthermore, as I had served as a hospital chaplain, while a rabbinic student, at Memorial Sloane-Kettering Cancer Center in New York City, I was well acquainted with the many perils associated with bone marrow transplantation. As the doctor I sat before commented, "a bone marrow transplant is an extraordinarily dangerous procedure," I dreaded how within several hours how I would stand upon the bima and recite before hundreds the words, "Who shall live and who shall die"?

How bizarre and incredulous all of this was. Only weeks earlier, life seemed as it should be - routinely normal. Carefree and certain of my physical invincibility, I had scheduled a routine physical examination, as I knew that with the fleeting summer and the emergence of the High Holidays, that period which I have always referred to as "tax season" for the rabbi, would be thrust upon me. How smug I felt as I entered the doctor's office dressed in summer apparel akin to my teenage students. When the nurse who escorted me, commented that I looked some ten years younger than my then forty-two years, I chalked it up to my picture perfect health. There was no doubt in my mind that once again I would be told that I was "medically boring" and my physician, a friend and contemporary and I would spend the appointment waxing philosophical about our lives, his patients and my congregants. However, when my white clad friend, opened the door, his smile was not the broad one I had always experienced, and his demeanor was somehow quite out of the ordinary. Suddenly, my bon vivant attitude came to an abrupt and screeching halt, and never has it, nor do I believe will, return to the state that it had foolishly and naively enjoyed for so long.

My physician held a somber face as he grimly informed me of some abnormality on my blood work. Perhaps it was a lab error - a miscalculation on the part of the technician, but what was to unfold in the coming weeks was more dreadful than anything I could have possibly conceived. Within weeks, the mystery was revealed - a diagnosis of Leukemia, and the world as I had previously conceived it, the natural order which I had known, went completely berserk. From feelings of invincibility and eternal youth, I felt as though there was a snake inside of me, a strange chromosome which my body was suddenly and endlessly producing, which was strangling away at my insides. Although I could not yet feel the ravages of the disease, it was as though above my head a sadistic executioner was sharpening the knife of my guillotine awaiting the final blow.

Youthful, strong and playful; so vibrant and vital had I perceived myself to be up until that moment. What had I done to deserve this - why should I have received such a diagnosis?

As I groped in the darkness for answers, feeling plagued with misery and pain beyond describable magnitude, the juxtaposition of the themes of Divine Retribution and absence of God within the world continually raced through my head. Maybe as I had first considered, I was being punished - maybe this was all meant to be. During my countless experiences in which I had counseled those who believed that they were receiving punishment from God I had attempted to reassure them that there was no correlation between deed and illness. Yet deep down inside I held tight to the belief, that if one performed in a righteous fashion, Divine Providence would always prevail. While I was able to reconcile human frailty, I wondered whether I had failed God, or was God just failing me?

My immediate goal and desire was to get through the holidays, while I still had the strength to stand before my congregation as they had known me, even if my familiar level of spirit and smile had taken leave before beginning any formal treatment. I so desperately wished for one last time to stand upon the bima and serve in the capacity which I had worked so hard to achieve. However, at the Yom Kippur family service, when I saw my precious little daughter enter the sanctuary with my wife and our beautiful, new baby son, and as she beamed her familiar smile at me, it was just too much to bear, and I turned to the ark, as if falling before it, with a face full of tears. Inscribed atop the magnificent doors are the words, are the words in Hebrew, "*Da Lifnei Mi Atah Omed* - Know Before Whom You Stand:" more than ever before in my life, did I seek know God and understand the Divine will.

As I turned to others more learned and more seasoned than myself, I called upon a prominent rabbi, a brilliant orator and scholar, who had not only served as my mentor, and encouraged my application to HUC, but some seven years before, was diagnosed with a rare and incurable form of cancer and was handed a rather grim prognosis. Nevertheless, he had beaten all odds, survived and thrived, so I turned to him for THE ANSWER.

What he said, though well intentioned, was far from comforting, as he blurted out, "The Andy you were is dead - you will never be the same Andy again." How cruel his sentiments seemed, for more than anything, I wished to be the person whom I felt I was loosing. Nevertheless, despite how cutting his words seemed to be, they were as I discovered terribly prophetic. My innocence was lost; anyone who has ever experienced cancer is reminded that we are mortal. Yet, at that moment, the wounds were too fresh, my sense of vulnerability too profound, and the true meaning of what my mentor was offering was not ready to penetrate. Neither the medical establishment nor my cherished rabbinic world seemed ostensibly to offer me hope, solace or answers. And while I questioned the existence of God, how I continued more than ever to seek God - searching for the Divine voice, understanding of the Divine will praying for a miracle to be granted.

As the holidays came to an end, and the gates of Yom Kippur were sealed, the walls seemed to be closing in on me on all sides. My then oncologist was demanding that I begin the then established protocol and wait, and pray, for a bone marrow match. However, just as all seemed so dismal, a ray of light seemed to appear. Upon my

MY THOUGHTS ON LIVING WITH A CHRONIC ILLNESS

I have cancer; actually, I have two kinds of cancer. My family has been dealing with this disease for almost three years now and what stands out most is that the clergy and lay members of the synagogue have no idea what they could do to help.

I am extremely up front about my condition and spend many, many hours in various committees and board meetings. So, I know many rabbis. One asked me what he could do for me. Only one. That question would have meant so much. Even if I had answered, "nothing."

Unfortunately, a lot of people living with chronic illnesses often say they need nothing. I believe most are unaware of the options or afraid of seeming weak and unable to care for themselves and family. If the first step to improving the situation is asking the person what can I do, the next step is informing them what can be done.

There are many who could use lunch with the rabbi, an offer to listen extended to the significant other, a congregational Misheberach at Shabbot service or a private prayer from the rabbi. All these things would have helped me and my wife. When I first announced I had kidney cancer, many people asked how I was doing and received an answer of fine. I wanted more but was unwilling to ask.

Not sure exactly what I was looking for, I waited, hoping the rabbis would know how to handle this. Hoping they would know what it is their role should be. I began to realize the system was flawed when no one came to comfort my wife while I lay in the hospital during the InterLuken2. No one was going to help her with the strength she needed to support me and our family. When I first had surgery many people asked how they could help, but when the illness hit the chronic stage no one knew what to do.

If it is this way for me, a member of the same synagogue for 25 years, a past president of a synagogue and a member of several national and regional boards, a true extrovert that everyone knows and knows everyone, what must the chronic sufferers who are on the periphery feel?

I believe that synagogues need to have a Caring Committee. They need to organize a tactful meeting one on one with an ill member of the congregation and have definite questions in order to obtain definite answers. While asking "what do you need?" may obtain "nothing" or "we are fine." Asking would you like to keep this illness private or can we bring in other members of the congregation in order to help your family may obtain a more positive response. A question such as "How is your faith holding up?" may bring forth a discussion of spiritual issues that need airing.

Even if a person should choose to keep his or her disease between the caring committee's outreach person, the rabbi and themselves, there should be support. Help in the first stages that includes visits for hospital stays seems to happen in any congregations it is what happens after the initial acute phase is over and quizzing about aid needed during these more-trying-than-usual times. That is important.

The Caring Committee outreach person, in concert with the rabbi, should ensure that the chronically ill are able to fulfill their spiritual needs. Again, asking specific questions:

Do you need help with synagogue attendance, personal prayer, and are there any accommodations that may help them attend synagogue and/or Shabbot?

Reflection on this issue, has made me realize that I and my family would have profited from this type of outreach. Many of these issues I am only realizing now, which is why I press for the clergy to initiate the meeting and ask these specific questions. There would have been a great benefit in talking to someone, to relieve the stress, to deal with the issues that arise, and to know that my family had a community of support behind them when needed.

When I entered the hospital for the InterLuken2, spending five days in, then ten days out, for a total of three visits, twice for a total of thirty days in the hospital my wife and sons rotated spending the night with me. I do remember one Rabbi stopping in for a visit: a five minute one. But, I know that my family and I could have benefited from visits from a rabbi or a Caring Committee member bringing steady support, coffee, and tissues in case the tears that my wife held in for me came through when someone was willing and able to support her for a few moments.

In February of 2004, I was diagnosed with prostate cancer for which I started radiation and hormone treatments this June. Again, it is clear that the concern is there, but the knowledge and Caring Committee to ease the concerns of my family and me don't exist. Let's change our attitude towards the chronically ill and extend the wonderful communal spirit that comes with Shabbot to include the mitzvot of Birkot Cholim, caring of the sick.

We struggle, often on and off, with our diseases, wishing for prayer, understanding, and, also, for help. I truly believe it is the Jewish community's, the synagogue's (whether through its leadership or a Caring Committee), and the Rabbis' responsibility to extend themselves. We are a community.

B'shalom Chaverim; In peace my friends.

Lawrence M. Schulner

Cancer Think: Life Ain't the Same and Life Is Great
By Ralph Alterowitz

Prostate cancer means *change*. I certainly did not think about major changes in my life before treatment. Even after treatment, I did not think about permanent changes, probably because I did not expect to be around for long. I dwelled on my life coming to an end in about six months. My two priorities were getting my affairs in order and trying to decide which treatment to choose. But I also thought it was kind of stupid to be particular about what treatment to sign up for if I was not going to be around for long afterward. What difference would it make?

Now, nine years later, I am still around, albeit with many changes in my life. Every addition (because it seems that none of the other things have gone away) is a reminder that I have cancer. From the need for periodic lab tests and medical examinations to an altered diet, such as eating low-fat foods and soy, and making sure I am never too far from a bathroom. . . well, you get the picture. Every mouthful and hearing words like disease, is like a Post-it flag that I was treated for prostate cancer, They also remind me that the cancer may come back (as if it was every gone.) Before each test the question arises in the back of my mind: Will I find out that it has recurred?

Having been successfully treated for prostate cancer means that, like people with chronic illnesses, I must deal with my condition and its ramifications forever. I say "successfully" only in the sense that the cancer's progress seems to have been put on hold. So my life is altered by doing what I need to, to keep the disease in check, at the same time living my life to the fullest, and thinking more about what makes life meaningful, all of this against the background, I have cancer! Sometimes, I have the crazy idea that during the operation, as the cancer surgeon removed my prostate, he implanted a cancer memory chip to make sure that I think about cancer every day for the rest of my life. At least he didn't charge me extra.

Of course, there is nothing like a cancer memory chip, and yet, cancer is in my everyday language, my daily thoughts, and part of the work I do every day. It can certainly drag one down. Somehow, however, I think it has made my life better.

Much research tells us that when dealing with a difficult medical condition, a positive outlook increases the chances of a positive outcome. (However, research reported in 2004 contradicts this by saying that people who are normally not smiley and upbeat would do

better to be themselves than to engage in a complete emotional makeover. But that is still only one study.)

The Positive Aging newsletter notes, "The meaning we assign to biological events may have significant implications for the course they take. To illustrate, some victims of a heart attack draw meaning from the event...to have a deeper appreciation of life." One study found that "men who were able to find some positive meaning in their heart attacks were less likely to have a subsequent one than those who did not."

Prostate cancer survivors have many reminders that cancer is part of their lives. These cues are in the periodic PSA tests and for some in incontinence pads or sporadic leaks. An everyday prompt for almost every prostate cancer survivor is the bedroom. Erections are elusive, hard to get naturally if they are attainable at all. Medical treatments are available to help with impotence, and many couples are finding that if they work together through the issues involved in impotence—both physical and emotional—they can have a fulfilling sex life after prostate cancer treatment.

We cannot prevent prostate cancer from becoming a life-changing event. At one support group meeting, a man asked me, "Is there anything else after prostate cancer?" Looking for what comes next begins with the option of accepting the life event of prostate cancer as a singular negative outcome or as a potential opportunity. When men choose to accept prostate cancer simply as another life event, then they open themselves up to possibilities that make life meaningful - perhaps more so than before.

Quality living has always been a balancing act. Some people master it better than others. Some men use their prostate cancer diagnosis and treatment as an opportunity to get heavily involved in helping other men and couples struggling with the disease. Others plunge themselves into their work, families, or new careers. For many men, the disease begins a rethinking: Why am I here, and what should I really do with my life?

One man went back to playing tennis and golf despite his incontinence. He even developed an effective device to let him do it. For him, doing what he wanted meant living as he chose. Sure, some things had to change. But it was either accepting change or forgetting part of the life he wanted to have.

Each of us who becomes stricken with prostate cancer must decide for himself how to live after diagnosis and treatment. Fortunately for all of us, men are beginning to learn

from women who have been stricken with breast cancer the power that we have, as individuals and as a community of survivors.

To be sure, life ain't the same after a diagnosis of cancer. But that is not to say that life can't be great.

Ralph Alterowitz an international business consultant and prostate cancer activist, speaks, counsels, and writes on intimacy (www.renewintimacy.org). His and his wife's, Barbara, most recent book is Intimacy with Impotence: The Couple's Guide to Better Sex after Prostate Disease, June 2004, Lifelong Books, Da Capo Press, (available from the Education Center for Prostate Cancer Patients, www.ecpcp.org, 516-942-5000.

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A NEARLY NORMAL LIFE: A JOURNAL OF CHRONIC DISEASE
Jacqueline Sideman Guttman

Fall, 1999

This is how it is:

The public face: On Rosh Hashanah morning, I got up from a chair on the *bema*, walked over to the rabbi's lectern and made a president's speech before an audience of 1000 members of my synagogue. I was, if I may say so, rather elegantly dressed in a blue and black jacket, long black skirt and low-heeled Ferragamo pumps, and nearly every hair was in place. The speech was unusually well received and later, as I made my way out of the building, I was stopped by many people to tell me how moved they had been, even how inspired. It was very gratifying.

The private reality: My husband had to dress me. He helped with my underwear, put on my knee sox (thus the long skirt), zipped the skirt, assisted me with my jacket, fixed my necklace. The shoes, earrings, watch, makeup, contact lenses and hair I managed to handle on my own.

People who know me casually see a tall, fairly well-built woman of a certain age – a leader type – articulate, intelligent, with a reasonably good sense of humor and proportion. Only those who are close know the true me – same qualities, but with an overlay of moderate to severe limitations on my life and myriad accommodations to make it as nearly normal as possible. There are days when it's an effort to walk from my front door to my driveway. On those days, if I can't find a parking space within twenty feet of my destination, I go home. Sometimes I cannot write in the morning. I cannot hold a telephone receiver for more than a minute or two. I am rarely able to cut my own food. I cannot get into or out of the tub or down on or up from the floor unassisted. My computer endurance is often an hour or less.

It is a major, painful, chore to get into a coat or jacket without help. My wardrobe is built around whatever shoes I can wear. Thus, instead of being the short-skirted, high-heeled vamp I'd like to be, I usually wear slacks or ankle-length skirts with high-tops, sneakers and occasionally, flats or, as I call them, "girl shoes." I've cultivated a casual chic look, vaguely and hopefully Katherine Hepburn-ish, and because of my height, it works pretty well.

This is my reality with 28 years of rheumatoid arthritis.

Although people like me may have handicapped placards for our cars, our disabilities are nearly or totally invisible. Unlike people in wheelchairs or those who walk with crutches or canes, our difficulties are unrecognized, and while none of us would prefer to be wheelchair bound – and dread the possibility of that happening at some future time – we all have our own set of issues, at home with our spouses, children, siblings and even parents, in social situations where we may not be able to keep pace with others, and in the workplace, where we are sometimes regarded as being unwilling to pull our weight. The Americans with Disabilities Act does not cover our needs because, after all, looking at those who are worse off physically, who are we to lobby or complain?

I used to be a concert presenter. The hall was in a lovely old mansion, wonderful for chamber music but with logistical difficulties, like a grand staircase and no elevator. After the first of my three major knee surgeries, when I returned to my job I was much improved. My colleagues thought it was great; now I could walk better, go up and down stairs as needed, move chairs, push the piano around. And sometimes I could. But the disease remained of course, as did the difficulties with my hands, aching feet, and general fatigue. Before the place had become sophisticated enough to use a caterer for special events, we used to gather in the kitchen to make canapés, cutting carrots and celery, standing for long periods of time. My ability to do this, especially cutting the damn carrots, was limited and short-lived. After perhaps half an hour, I begged off, looking for some other job I could handle, so as not to appear

lazy. There were days when I could almost keep up, and then I would enthusiastically pitch in. Consequently, some of my peers could not comprehend why, sometimes, I didn't.

If I had to sum up in a word how RA has affected my life, the word would be *thwarted*.

I was a music teacher. I stopped because I felt that to do it right you had to be "on" at all times – and I couldn't. I got a second masters degree and became a concert presenter. After ten years of building a chamber music series and a professional reputation, I gave it up to consult, primarily because I knew a second knee replacement was ahead and I could not in good conscience take a new job until the surgery and rehab were behind me. When I felt ready to reenter the work force, my parents' deteriorating health required increasing attention and I knew full well that I lacked the stamina to be a good daughter, a good executive and a good wife and mother. After 43 years of playing the flute, I gave that up rather than continue to experience the fear that at the next rehearsal or performance, my fingers would give out totally. The most difficult part of that, by the way, was the many well-meaning people who said, "But can't you play for your own pleasure?" to which I replied, "If it were a pleasure, I would not have given it up!"

I'm thwarted in our travels, as is my husband, because of my walking limitations. And yes, I'm thwarted in my sex life, by joints and limbs that lack flexibility. Does this mean we don't travel, or that we don't have sex? Of course not, but always, always, with limitations.

What's the big deal, you might ask. And the truth is, in middle age, few of us can do what we did 20 years ago. The big deal, however, is that these accommodations, adaptations and limitations were an integral part of my life 20 years ago. My children have never known me without them.

Here are some things I love:

- My devoted husband and family and supportive and loving friends.
- Gorgeous, clear weather when the sky looks freshly washed.
- Conducting my synagogue choir.
- Speaking in public.
- Feeling competent.
- Feeling strong
- Feeling sexy.
- Feeling loved.
- A good laugh.
- Chocolate.

Nothing unusual there; no indication of anything out of the ordinary, I don't think. It's my "hate" list that tells a story:

- Old ladies in high heels.
- Struggling to pull up my pants.
- Needing help.
- People who take credit for reaching an advanced age in good health. (No one says, "I was lucky.")
- People who carry on over temporary illnesses or injuries.
- People who tell me what I should or should not eat.
- Ads that promote, "For the relief of minor arthritis pain."
- Childproof containers for arthritis medication.
- Fatigue.

Do I hate the disease itself? I suppose so, but having lived with it for half my life, I'm not sure who I'd be without it. I believe that it has given me a perspective that is denied most people until they are much older than I, and a capacity to enjoy the good moments and (usually) not "sweat the small stuff."

I try not to rush to judgment about people, because I know that you never know anyone's private reality.

Perhaps the most adequate explanation of how I feel is summed up in a statement I once heard in a documentary about living with AIDS. It went something like this: "I've had this disease for so long, and it has become so much a part of my life, that I think that if it suddenly disappeared I'd actually feel a void...but I'd get used to that."

November, 1999

Sometimes I feel like the little engine that could – or couldn't, as the case may be. Like today, I got up early, enjoying the quiet and solitude, and let my husband sleep. I struggled into my robe, proud that I could with one shoulder in need of replacing and two elbows that are shot. I gingerly crept downstairs, grabbed paper and pen, and sat on the couch to write, which is far less difficult than writing at a table or desk. Problem: there were throw pillows around and under me, and I couldn't remove them all. One remains stuck as I write.

Friends

Friends fall into three categories: unaware, over-solicitous and just right.

Unaware – Once, when I was in the depths of a siege of pain, weakness and fatigue that had me convinced that I was dying – and from which I emerged some months later – we had dinner once or twice with close friends who are smart, kind and considerate. Although I am loath to make my health the center of our social life, it was impossible to avoid it altogether. I had begun to limp due to ankle deterioration; I could not lift the bread or butter to pass around; I was unable to serve myself salad or tear or butter my roll. I told them about this book, and that I was embracing RA because it had begun consuming my life. They were quite intrigued and encouraging.

Recently, we had dinner again, during which my possible shoulder replacement came up, largely because the other husband had had rotator cuff surgery some years ago. The next day, I received an e-mail from the wife, my good friend whom I love, saying, "My dear, I had no idea of what you've been going through. I feel terrible. It must be awful" and so on. It was a lovely and concerned note but I was nonplussed. How could they not have noticed sooner? Could their own difficulties with an elderly parent have blinded them totally? Probably – and who could blame them? But still...and these are close friends.

Over-solicitous

Another couple, who after 30 years are more like family, visibly suffer when they watch me. Their response is to practically prostrate themselves in an effort to be helpful. Years ago, when this got out of hand in a restaurant (Are you sure you're comfortable? Do you want to sit here? I'll get up!) I finally let 'em have it, then and there. I told them that to treat me as an invalid was demoralizing, infuriating and unnecessary. For perhaps the fiftieth time I told them – loudly – that I had no qualms about requesting help and that if I assured them once that I was fine, they should drop it. After recovering from their initial mortification, they modified their behavior (somewhat). The problem with such over-solicitousness is that I then must work harder to hide my pains; their suffering on my behalf is almost unbearable. Am I an ingrate? Very well then, I'm an ingrate.

A sub-set of this category is the "Insister" who derives some deep psychological satisfaction from being "helpful." Many years ago, before the days of arthroscopic surgery, I had major knee surgery that necessitated many weeks on crutches and cane. Finally, I had reached the point where I was able to stand and walk with little difficulty, and was exulting in that fact. I was standing at a party, singing around the piano, reveling in my enjoyment and independence, a woman friend offered to bring me a

chair, several times. Each time, I cheerfully declined. When I did decide it was time to sit, I happily found a folding chair, brought it into the room, and sat down. The woman was furious, and actually scolded me for having brought myself a chair when *she* had offered. No response would satisfy her; I had deprived her of the opportunity to be helpful, and she was angry. It was not until I laid out for her my own need to be as strong and independent as most forty-year-olds that she quieted down. Whose need concerned her more? Certainly not mine.

And then there's Stef, my dearest friend since Girl Scout Camp, who can get inside my head, perhaps because she, too, has had on-again-off-again health problems that have now evolved into chronic disease. She offers help or I ask freely. When I decline she does not persist. If I'm irritable, she overlooks it. We talk doctors, herbs, vitamins, art, music, writing, men, crossword puzzles, sons, existing and potential daughters-in-law and potential or existing grandchildren. Our health issues – none of which existed when we were kids or young adults – dominate as necessary and retreat the rest of the time. We can whine without fear of rejection, share our fears, and rejoice in each other's triumphs. We've never lived near each other and have always joked about being neighbors in the nursing home. Last summer, when I was so ill and she was found to have Crohn's disease, the joke began to sound real. She paints, exhibits and is an adjunct professor of both art and mathematics. She, too, has her public face and private reality. We cry for each other, but are grateful we can share our woes.

July, 2003

I wrote the first of the paragraphs above over four years ago, adding other thoughts as they came to me. Now I must write about where things stand today, for the picture is happily and vastly different.

The single most important factor in this virtual miracle is methotrexate, a powerful chemotherapy drug that, two decades ago, was found in low doses to benefit people with RA. I had resisted taking it because of the potential for liver damage, but in 1999, I was desperate for some kind of improvement. I would have tried anything. Not only was I physically ill, I was grieving over the nearly simultaneous deaths of my beloved parents a year earlier, and the physical and emotional issues worked together to drive me down into the abyss. Remarkably, however, just as I was about to start taking a more powerful medication, two things happened: my son and daughter-in-law announced that she was pregnant, and I started to improve. I cannot help but think that the first had an impact on the second, but whatever the cause, the pain level diminished to the bearable and I became reasonably functional once again. I was determined to climb out of that abyss.

In general, I did, although an RA flare will usually leave some damage in its wake. In my case, it was a left shoulder that continued to deteriorate until the cartilage was gone and most arm movement along with it. In addition, I noticed that twice, after wonderful, three-week European vacations, I had lost ground again and had difficulty walking and problems with fatigue. Nevertheless, I managed to do some consultant work and hide most of the problems from my clients. When I needed to make an accommodation, I casually mentioned the disease and the need, and they cooperated.

February, 2002

My rheumatologist and I decided to see if methotrexate would help, even though it is most effective for early onset RA. After 30 years, I was well past early onset, but it was worth a try. I enrolled in an arthritis water exercise class. Each month brought new improvements, which, thank God, continue to this day. I now hurt in one or two places instead of nine. I can hold the telephone to my ear for about 15 minutes; I can work at the computer for hours; walking is rarely a challenge and covering a mile is usually well within my reach; my ankles swell less often; best of all, the lack of pain enabled me to exercise my left arm extensively, and I now can use both hands to style my hair, take dishes out of cabinets, and do all kinds of daily activities that I had thought were permanently lost to me. Recently, I

got in and out of the tub myself, because I had the strength to grab the bars and pull myself up. I can dress myself – even do belt loops – and, joy of joys, help my grandson dress and undress as well.

At 60, I have been getting reacquainted with someone I used to know – me. I'm raring to go, most of the time. Is everything peachy-keen? No. I cannot, and will probably never, play my flute. My capabilities as an arts administrator were never fully realized, and at this age, never will be. Like most of my contemporaries, I lack some of the physical resilience I once had, so bouncing back from flares or fatiguing experiences takes longer than it used to. But our lives are not especially constrained by limitations, which brings me great joy, and my life – which I had begun to feel was nearly over – is more "nearly normal" than it has been in years. For that I am very grateful.

And I can sometimes wear short skirts and medium heels.

August, 2003

I guess it's time to write again.

I have had a pretty wonderful year. Aside from frequent colds – about every 9 weeks from December, 2001 through spring, 2003 – I have been blessed with significant reduction of pain. Each month, it seemed, I was stronger. I could walk a mile or more; I could lift things; I could pass plates across the table; I could cut my own food; I could wear reasonably attractive shoes. I discovered that I'm not lazy by nature, a fact that I'd long since forgotten. Amazing.

I felt ready for anything, or so I thought. The anything did *not* include more health issues.

Over this summer, I developed a cold, which aggravated long-standing vocal nodules to the point that I cannot sing and have a nearly constant sore throat. I must do something about them. Speech therapy? Surgery? NO! I cannot stand more surgery.

In the spring, I'd developed a teeny pimple on my nose that kept bleeding, and in July a biopsy confirmed that it's basal cell cancer. Yesterday, my impression that it must be minute was shattered when I was told that it's at least the size of a dime, and perhaps a nickel. I'll need surgery and a probable skin graft for that. It will be fine, but why me? I was never a sun-bather.

I have been a basket case ever since yesterday. Why? Neither of these is life-threatening. Everyone and her sister, cousin and aunt has basal cell cancer. My mother and grandmother had it, and I didn't even take much notice. But I'm so angry that I'm posthumously and ridiculously hating my parents, just because of their good health. I grew up in an environment where people were rarely sick; my folks had to think about where they kept the Aspirin. They were in their 80's before they had health problems. They misled me into thinking that that's how life would be for me.

I am so very tired. I have no resources left. I cannot bounce up from this. It's just too much. I speak of suicide, although I've always been a life-affirming person. Dr. B___ had it exactly right today. He said that I've had a rough time of it and have devoted a great deal of energy to dealing with the disease, and have no energy left to deal with the relatively small things that crop up. I feel that I'm carrying a ton of sadness on my shoulders. He also told me that methotrexate – my life-saver – encourages tumor growth, so now I have to bear in mind that statistically, breast cancer and lymphoma could lie in my future. I have nothing left.

Yesterday at the dermatologic surgeon's office, I started to weep and told the poor young assistant all my "troubles", apologizing all the while. She was so sweet, and put her arm around me. My husband immediately put his hand on my other shoulder and it was all I could do to keep from slapping it away. I hate being petted. Yuk. Bleacchh.

My shrink and I talked about how angry I am. She correctly observed that, now that I'm older, friends are beginning to have health problems, and when they complain, the reason I get silently annoyed with them is that I've spent 30 years trying to keep my problems mostly to myself. I've worked with pain, played through pain, held up a choir folder when I thought I'd collapse if I had to for another moment, brought up kids through pain, accommodated through pain, weakness and general debilitation. If others have to do that now - at 60 + - frankly, that's too damn bad. They'd just better get used to it. I have.

I'm ready to crawl into a hole and give up. Still, I've been there before, as reading old paragraphs reminds me. I guess I'll deal with it, and come out the other end. But some day, I won't. Either I'll give up, or my body will, and I'll shrivel up and die. But should I feel this way at 60? I'm just so very tired...

October, 2004

A year ago, totally depressed, I decided I had to do something about it. My voice problems turned out to be due to acid reflux - not surprising when you think about all the stuff that's been dumped down my stomach. Along with the usual diet and lifestyle suggestions, voice lessons were recommended to strengthen my vocal cords. Given that I no longer really play an instrument and that I'd always loved singing, I eagerly agreed. I've had only one bout of laryngitis since then, of about 4 weeks' duration, but my singing has really come a long way. I was even the substitute cantor one Shabbat!

The basal cell cancer was removed without a skin graft, and I still have hopes that the scar in the shape of a *lamed* that meanders down my nose will fade even more than it has. I have been working out with a trainer. I am stronger, psychologically, emotionally and physically, as evidenced by two things:

- 1) When my grandson was born 4 years ago, I could not carry him. I could hold him if someone placed him in my arms while I was sitting down but I have never lifted or carried him. Last June, our granddaughter was born, a red-headed little butterball named Nora. We sat in the hospital room and my son Edward handed her to me. When it was feeding time, Ed came to lift her from me. I said "no" - and I stood up and carried that baby to her mother, mentally saying a *shehecheyanu* all the while.
- 2) I went to temple for *Simchat Torah* yesterday and, for the first time in *twenty-two years* I carried a Torah for a *hakafah*. Pure elation.

Baby Nora and a *sefer Torah* - maybe there is a God after all.

LIVING WITH ILLNESS IN THE FAMILY

Janet Abrams, Psy.D.

Changes in health care are putting more demands and responsibility on family caregivers with little attention given to the needs of the family members. Over the course of the past 13 years, as a research scientist and clinician in the Biobehavioral Sciences Division of the Fred Hutchinson Cancer Research Center in Seattle, I have learned both by treating patients and their families and through our randomized clinical trials that at times living with illness is harder on the family system than on the patient. I have also learned how resilient people can be and to never assume that I can predict how a family is going to handle a situation. Every family is unique. People are amazing!

There is an emotional aspect of a person's illness for family members that can be difficult and uncomfortable to discuss and often is left unresolved. It is not uncommon for family members to be concerned about themselves. "Can I catch this?" "If it is genetic then for sure I am going to get it." "Will my daughters get breast cancer just like their mother?" "Will we ever have our normal family back?" "I feel trapped but I'm feeling guilty at the same time." "I just wish he/she would die." "This has gone on forever." "This is just too difficult." Yet feelings and thoughts usually don't just go away. Left unresolved these feelings, which are perfectly normal and even healthy, can cause resentment, anger, bitterness, or depression leading to an even more difficult family circumstance. When family members have a safe environment where it is OK and even encouraged to express themselves, many families grow from the experience of chronic illness and develop an even deeper understanding and appreciation of one another as well as the importance of life.

Some personality styles have an easier time than others in adjusting to living with a person with chronic illness, but almost everyone can learn coping strategies that makes the experience more manageable. They can learn a new 'normal' that works for everyone. In order to do this some people first need to be heard and validated. Others just need to know that what is happening is "normal". It is, however, most important, that the family understands that while cancer has now become a new "family member" it doesn't mean that their own personal needs aren't also important and those needs should be met. So the challenge is to find a way to help the cancer patient but also take care of themselves.

In my 13 years working with cancer patients and their families, I have seen the disease move from an illness in which people had little hope of long-term survival to a chronic illness, thereby changing the demands and dynamics that families live with. I have seen illness therefore become the impetus for people to reevaluate their priorities and perhaps do some things they other wise would not have thought about nor had the strength to do. For some, religious beliefs and spirituality become extremely supportive and comforting. On the other hand, I have also seen religion work to a patient's detriment. This is particularly true when everything is "put in God's hands" with a patient assuming no responsibility or control for his/her treatment decisions and passively waiting to see what happens. Some have said, "This must be God's will. If God wants me to die, then I will die." This is often a sign of depression which when treated can change the course of the patient's outcome.

Several universal themes come up for families living with a member who has a chronic illness. These include loss of control, uncertainty, the unknown, lack of predictability, asking 'why me', looking for an explanation as to what they did to cause this. Often there are no answers, yet part of the human condition is to try to understand and then do something differently

in an attempt to "make sure" it doesn't happen again. This lack of control can be extremely difficult to live with. Some of us delude ourselves into thinking we have more control than we really have. Yet when living with illness the delusion is taken away. It is as if one loses their security blanket which can be very scary.

It is important when working with families in this arena to be aware of the developmental stage of the family members. Adolescent young adults will have different needs than a two year old toddler. Age and life cycle events dictate some of the circumstances families will be adjusting to in addition to living with a chronic illness. The challenge is to maintain a sense of normalcy in the face of illness.

Sometimes family members get into power struggles and need tools to learn more effective ways to manage conflict. This occurs most frequently when people have dichotomous thinking i.e. they "know" what is right and what is wrong. There is always a loser in these situations and someone usually walks away feeling misunderstood. This only adds to an already difficult situation. The challenge is to help people hear the different perspectives without the need to find one solution.

There are many coping strategies that can help family members adjust to living with illness. Helping them to understand that it is normal to have various feelings such as feeling sorry for themselves or that they are getting tired of all that's involved with the care of their sick family member is common. Acknowledging how difficult things have become (listening and validating the experience) and then shifting the focus to areas that are in one's control is a strategy that often empowers people. All of the coping strategies emphasize finding ways to control the parts of their environment that they can, because so much control has been taken away. To help make

living with cancer easier for the patient and his or her family, the following additional strategies have also been useful:

1. Don't make the illness the main member of the family. Often, it becomes the major focus of a family. It's important to remember to make time for other things which have nothing to do with the chronic illness. Find a balance that allows for each family member to have his/her own separate needs fulfilled in addition to making room for chronic illness in the family.

2. Designate one family member as the spokesperson for the family. This person can speak regularly with the medical team and then communicate the information to the rest of the family. This person should also be telling the health care providers the patient's current symptoms. This is important because the medical team will assume things are going well if they are not kept informed of any changes, both mentally and physically.

3. Roles (who cooks, cleans, pays bills, laundry etc.) change over time. Every few weeks review who is responsible for the various jobs and tasks within the family. Talking with each other is important! To accomplish this, here are some suggestions:

a. Set aside 30 to 60 minutes each week to discuss what is working well for the family as well as problem areas. It is a time to provide support as well as problem solve.

b. Discuss one issue at a time.

c. Silence: Don't assume everyone agrees with you when there is silence. Ask, "What are your thoughts and feelings about this?"

d. Listen without interrupting and without trying to solve something. Repeat what you heard. (Example: "You're frustrated because the house is a mess and no one seems to be doing their part.") Ask what might help.

4. Humor goes a long way. Find at least one thing a day to laugh at. Examples include renting a comedy video, read cartoons, or read a joke book.

Living with chronic illness is challenging for the patient and the patient's entire family. However, by understanding the challenges, there are many ways to make a difficult circumstance more manageable and at times even a positive experience. By helping people to understand how to adjust their lifestyles in a way that accounts for all of the family member's needs, the stress and demands of a chronic illness can be a workable problem.

The Healing Power of Religious Community

By Rabbi Lynne F. Landsberg

Women of Reform Judaism Biennial

November 5, 2003

Minneapolis, Minnesota

Good Evening. Thank you, Connie Kreshtool.

Thank you, Women of Reform Judaism.

I must warn you that my speech therapist always tells me that I have to speak slowly to be understood. As a person from New Jersey, she knows quite well how pointless that is to say to a New Yorker. Please do let me know if I have to slow down.

As many of you may know, I was in a devastating car accident almost five years ago. My son Jesse, who had just celebrated his 8th birthday, was in the car with me. Jesse's favorite song at the time was a popular tune called "I Believe I Can Fly." At home he would stand with a spoon in his hand like a microphone and croon: "I believe I can fly. I believe I can touch the sky." I loved to watch him so bright and healthy—standing on the precipice of promise.

Thank God, Jesse was not seriously injured. I, however, was left with a traumatic brain injury that has affected me physically and cognitively ever since.

I was in a coma for six weeks and in the hospital for four months. I consider that stage of my injury the crisis period. During the early stages of the crisis period doctors held a dire prognosis for me. They were unsure whether I'd live. Once I passed the crucial seventy-two hour mark still alive, they didn't know if I'd ever wake up. The

doctors prepared my husband, Dennis, by saying that if I awoke, I would not recognize him or our son, Jesse.

I did slowly awake. My "wake-up" was not a classic Hollywood wake-up. It took well over a month, for me to go from being able to move my fingers on command, to mumbling a word or two.

After four months, I came home, in a wheelchair, with 24 hour nursing, unable to care for myself. Five years of intensive rehabilitation have enabled me to come this far.

I thank God for my rehabilitation. I thank God for my resilience. And I thank God for my religion.

Joseph Campbell, the commentator on ritual and religion, drew the connection between religion and resilience. He said that all religious traditions "...call men and women to a deeper awareness of the very act of living itself [as] they guide us through trials and traumas from birth to death." Here, I need to thank Drs. Sybil and Steven Wolin whose writing led me to Campbell and to the connection I make between Judaism and resilience.

Judaism is, at its core, a religion of resilience. All of Jewish literature, all of Jewish history, and all of Jewish liturgy, *move* us through moments of tribulation to moments of celebration. The ancient story central to our people's identity, the Passover story, is about a people who regain themselves after a long experience of adversity. The entire book of *Exodus* is our journey *mi g'nut l'shevach*, our people's passage from slavery and degradation to freedom and glory.

When my family and I celebrated Passover 1999 in the dining hall of the National Rehabilitation Hospital, the concept of resilience was brought home to me in a very personal way.

Judaism presupposes that we can master adversity and it gives us the prescription for action that guides us on our way.

All of Jewish learning enjoins us to turn the experience of slavery inside out, by commanding us to pursue justice. We can and must recognize the suffering of others and actively support and further their resilience. Looking back on my accident I now know that I was the beneficiary of this ethic.

I have identified three ways that the Jewish community supported and furthered my resilience through the crisis period immediately following my accident. Note well, Women of Reform Judaism, there are three important ways you especially can do this for others.

One way is through directed prayer. Another is by visits -- not stop-ins but physically and emotionally being there. And the third is by providing practical support.

I'll start with prayer. Throughout my coma and my whole hospital stay, many prayers were offered on my behalf. Although I was not cognizant at the time, prayers were said I am told in synagogues across the country and in Israel.

Prayers were also said at my bedside by Rabbis, Cantors and lay people. They often sang Debbie Friedman's contemporary musical version of the *Mi Shebeirach*. Before Debbie Friedman, usually Rabbis read the *Mi Shebeirach* in Reform services. As a matter of fact, I have personally thanked Debbie Friedman for teaching the *Mi Shebeirach* to the entire Reform Movement just in time for my accident.

Especially important to me was the prayer and the presence of my family. My husband, Dennis, was on the phone with my 80- year old dad when he got a call on the call-waiting line saying that Jesse and I were in an accident. Within two hours my Dad was in the air on his way from West Palm to National Airport. He moved into our house and sat in my hospital room every day for the next four months.

At our synagogue, Temple Micah, Rabbi Danny Zemel held a public healing service for me. Though the service was about me—it helped my family a great deal by giving them a way to handle their feelings of fear and helplessness.

Not long after the accident, a Rabbi I barely knew, went online asking clergy to pick one of the one hundred fifty psalms to say daily on my behalf. Throughout Jewish history, psalms, recited fervently on someone's behalf, have been thought to be effective directed prayer. All one hundred fifty psalms were selected. People said them daily with family or congregants—and I know many of you were among them. Thank you for your prayers. When I came home from the hospital, almost everyone sent me copies of the daily psalms they had recited along with beautiful and moving notes.

The *Mi Shebeirach* and other prayers made me feel that the arms of the Jewish community were wrapped around me, holding me tightly yet lovingly, keeping me in this world.

Now let's talk about visiting—being there, physically and emotionally being there. This is the second way the Jewish community helped me through my crisis period.

Jews are obligated to visit the sick—that's the mitzvah of *Bikkur Cholim*. The people who visited me were much more than drop-bys. They sat with me, held my hand and told me stories. If I was responsive—though I couldn't yet talk—they included me in

their conversations and laughter. One friend walked into my then coma room, bent over my bed and commanded, "Lynne, wake up! You're missing the "Last Call" sale at Neimans!"

Because of my traumatic brain injury, I do not remember everyone who visited me. One visitor I do remember was Ellen Rosenberg. We both acknowledged that I would be unable to speak at the WRJ Orlando Biennial. She said, "We'll get you back as soon as you are ready." I am ready and I am here!

Among other WRJ women who visited me, I can't help but remember the visit of Roseanne Selfon and her daughter, Lisa. The last time I had seen them together was when I was visiting Lisa in the hospital after she had been struck by lightning. Now I was the patient in the same hospital complex. I think one of us must have said, "We have to stop meeting like this."

Rabbi David Saperstein was the one visitor my family saw most often. I am told that he and the RAC staff not only took charge of the flow of visitors, but even set-up a list serve keeping everyone current with my condition.

The visit that touched me most and continues to touch me to this day was that of Rabbi Alexander Schindler. He sat in my room talking to me, comforting me and making me feel human. "*Zechar l'tzadik Livracha*" "May the memory of the righteous be for a blessing."

Some of the board members of the Mid Atlantic Council, of which I was Regional Director, brought me a challah on a Friday afternoon. I think they helped me say the Motzi. At any rate, that was the first time since my accident that I had said anything in Hebrew.

This incident made me later realize that during my entire crisis period, I was on the receiving end of a core Jewish value -- one that I had become a rabbi to teach -- compassionate and involved *Bikkur Cholim*.

The many people who fulfilled the mitzvah of *Bikkur Cholim* had a powerful effect on me. Whereas prayer kept me here, each visit diminished my feelings of isolation and connected me momentarily to the world.

In addition to visiting, *Judaism* also commands people to lend their time and talents to others in times of need. Fulfilling the Mitzvah of *Bikkur Cholim* is wonderful, but you also have to stick around. Sticking around means providing practical support. Practical support is the third way the Jewish Community pulled my family and me through the crisis period and helped me into the formative post hospital period.

As Jews, we all know the importance of community. As a person in need of help, I learned the importance of a Jewish community able and willing to respond quickly and offer practical support. Friends, colleagues and neighbors coordinated with each other in a very serendipitous way to take care of us.

One phone call led to another, and a whole network formed.

Once I was out of the Emergency Room but still in a coma, the Temple Micah "caring committee" went into action. Their purpose, as per the lessons of the U A H C Department of Family Concerns, is to transform the whole synagogue into a caring congregation by inspiring members to reach out to those who are isolated and in need.

While I was in the hospital, the committee had members of the congregation provide delicious cooked Shabbat dinners for my three guys at home: Dad, Dennis and Jesse. Every Friday, the dinner would arrive with Shabbat essentials: a challah, candles, and

wine for Kiddush. Even after I came home, the meals kept coming and coming until I could stand and, with the help of my nurse and Dennis, prepare Shabbat dinner.

Being able to prepare Shabbat dinner (even with a tremendous amount of help) was for me a crucial step forward. But it was just the first of many sobering realizations that I would never be able to do the things I used to do in the same way I had done them before.

People who suffer traumatic brain injury have to reconnect the brain to the body. In order to do this, they have to re-learn everything all over again. I had to re-learn how to walk, re-learn how to talk, re-learn how to concentrate and read, re-learn how to take care of myself.

Four mothers of Jesse's early friends from Gan Hayered, a synagogue nursery school, *asked* if they could help me re-learn how to cook. I said, "Re-learn? How about teach me how to cook!" My culinary teachers came every Sunday morning after dropping their kids off at Religious school. With the start of Sunday School this year, the women called to ask when they could begin their 4th year of cooking lessons. They have taught me how to make fabulous family food and they proved to me that home cooking can be better than delivered Chinese. These women were among a large group of people who provided meals, rides, errands, invitations for Jesse and shopping for our family.

As prayer kept me here, and visits connected me to the world, practical support helped put my life back in working order so I could begin thinking about being productive again.

Becoming productive has been a lengthy process that began months after my hospital stay and continues to this day.

Since the accident, I no longer wake up in the morning, worrying about my "to do list." I am actually happy to wake up at 6:30 and just be up. I am happy to be able to wake up my son who is not so happy to be getting up at 6:30. I look at the morning sky; I look at Jesse; I look at my husband, Dennis; I look at the dog; I look at the two cats; I even look at the trash men collecting garbage and I thank God for sustaining my life.

As I progress, I am continually impressed that the Jewish community is still helping me in this post crisis period. As I have embarked on a new phase of healing, the three forms of help I have gotten from the Jewish community have entered a new phase of their own: prayer, visits and practical support have morphed. Nevertheless, in their morphed form, they continue to play the same important role in my life. They actively support and further my resilience.

Prayer has helped and always will. Talking to God is great but talking to me also helps. Now that I'm alert and can interact, I find that the Jewish community's voice of prayer has become a voice of encouragement. Every step of my recovery has been backed by a cacophony of cheerleaders, some of whom I had not known previously. Many of my oldest friends and colleagues have returned to my life to encourage me to "keep on keeping on."

The greatest way to rekindle old friendships is to be on the synagogue *Mi Shebeirach* list. My first roommate in college went to her sister's synagogue one Shabbat. She heard my name on the *Mi Shebeirach* list and called me from California. Although I hadn't heard from her in about twenty years, she called me continually after that and joined the Temple Micah congregants and others who applauded each little bit of progress I made.

As I reflect on my experience, I have thought about the relationship between prayer and encouragement. Offering prayer is heartfelt but it is anonymous. On the other hand, encouragement involves direct interaction. Direct interaction may seem intrusive, especially when the person you are encouraging is only an acquaintance. Take it from one who knows, IT IS NOT INTRUSIVE! Encouragement, like prayer, is a healing tool. In fact, I regard encouragement as a morphed form of prayer.

Now let's talk about how *Bikkur Cholim* morphed. While I was in the hospital, those who fulfilled the mitzvah of *Bikkur Cholim* brought the world to me. Once I got home, my visitors brought me to the world.

At first they would come, pick me up and take me out to lunch. Since I could no longer work nor drive, I was thankful to have my visitors move me from my kitchen to the outside world.

Over lunch MAC and UAHC people would talk *tachlis*, catching me up on the Reform Jewish world.

When I could walk but was still unsteady, Rabbi David Saperstein asked—no he told me—that he would pick up my nurse and me and drive us to Baltimore to attend the annual Jewish Council for Public Affairs Conference. There I became aware of the goings on of the entire Jewish world, re-learning how we face current events and issues.

Because of experiences like these, I came to see *Bikkur Cholim* as my passport into the world outside my kitchen.

The third area, practical support, at first ordered my world so that I could think about becoming productive again. Like prayer and *Bikkur Cholim*, practical support morphed. It became opportunities to actually become productive.

The first and most important of these opportunities came from, who else—Rabbi David Saperstein. On our way to the conference in Baltimore, David made me gasp when he told me that he wanted me back at the Religious Action Center as soon as I was ready.

It was a whole year before I was physically and cognitively able to respond to his offer. I told David that I would agree to come back to the RAC only if I could volunteer. Actually, I felt that I should be paying the RAC because I considered the opportunity to be “work therapy.”

With my Traumatic Brain Injury, I was and still am easily distracted and confused. So, those of you familiar with the hubbub of the Religious Action Center know that the RAC is not such an easy place for the Brain Injured to have “work therapy.” But I thrive on it.

I began “working” two hours each Monday and Thursday morning. I am still, to this day, at the RAC. I’ve increased my hours to about eight a week and they’ve given me a title: I am now Senior Advisor to the Commission on Social Action.

Another chance to grow came from the Washington Jewish Community Council which gave me its Rabbi Recognition Award for my work in Social Action. They asked me to prepare a response for the award ceremony. That gave me the opportunity to speak publicly for the first time since my accident.

The former Lynne Landsberg used to jot down notes for a talk in the cab on the way over to the presentation. Post-accident it took me months to write and weeks to practice. I was flattered when I heard that David Saperstein, who was in the audience, whispered to a speech writer sitting next to him, “Good job!” Whereupon the speechwriter said to Rabbi Saperstein, “I had nothing to do with it. That’s all Lynne.”]

I was also given the opportunity to grow in the public policy arena. Allan Bergman, the husband of Jan Bergman, the assistant director of the Mid Atlantic Council had recently become, amazingly enough, the Executive Director of the Brain Injury Association! Three years after my accident, Allan invited me to give an inspirational talk on lobbying at the Brain Injury Association's Policy Conference in DC. This opportunity was made for me. I used to speak in synagogues across the country to encourage Jews to lobby for social justice causes. This was the first time since the accident that I was asked to energize people to lobby and now it was to urge Congress to finance brain injury research.

This WRJ biennial offers me the latest opportunity to build my skills. Thank you for inviting me to speak this evening. After Shelley and I have finished speaking, there will be a question and answer period. I have never, since my accident, spoken publicly off the cuff so, please be patient.

The fact that the new Lynne Landsberg cannot speak publicly with the ease of the old, is just one of a long list of deficiencies caused by my brain injury. As I've studied the *Mi Shebeirach*, I have come to understand that my deficiencies fall into two categories which are paralleled in the Hebrew. The *Mi Shebeirach* is a prayer for a speedy recovery but it is specifically for two different kinds of healing.

Vayishlach la m'heira r'fua shleima r'fua hanefesh u'r'fua haguf

“Grant her a speedy and complete recovery.” *Rifaut ha nefesh*, a healing of the “*nepesh*”—commonly translated as “soul.” And *rifaut ha goof*, “healing of the body.”

The healing of the body has come for me even more quickly than doctors had forecast. I am glad to report I have gone from a wheelchair and diapers to dress shoes

and Armani suits. My *rifuat ha nefesh* has been much slower. I consider *goof* as the outer self and *nephesh* as my thinking, feeling inner self—the all-encompassing “soul.” We know what it means to heal the body, but what does it mean to heal the soul?

The healing of the *nephesh* requires one to accept certain harsh realities. My continued healing is dependent on my emotional ability to mourn the old Lynne Landsberg and to embrace the slowly developing skills of the new Lynne Landsberg.

I'm making progress. I have mourned the old size 12 and embraced the new size 6. I call that the coma diet. Seriously, I have learned to no longer measure my successes by comparing them to my former achievements. I now am thrilled every time I can do something new. Who ever thought that loading the dishwasher was going to be so exciting?

This morning, I got out of bed, took a shower in my handicapped accessible bathroom and got dressed with only minor difficulties because I had laid out my outfit the night before. It's been a pleasant yet routine day at this, the 12th Biennial I have attended. But for me it has been extraordinary. I am grateful for every minute of it.

It's not a matter of what I've lost but what I've gained. I have gained not only an appreciation of what is, but the phenomenal and monumental understanding of how much good is in each and every day and each and every person.

Before my injury, I belonged to one minority that was cohesive, strong and articulate – the American Jewish community. Now I belong to a second minority that is often powerless and unheard – persons with disabilities.

We Jews need to make sure the severe discrimination suffered by all Americans with disabilities--- who number millions of people--is made public. We need to make sure that the able-bodied understand that things they may say or do, without thinking --can be ego or life or hope shattering-- to people with disabilities.

When I stopped attending our family synagogue, Temple Micah, because of my accident, I was a nationally known rabbinic speaker. I returned four months later a disabled congregant in a wheelchair.

I felt warmly received, not only by the greeting and affection of members of the congregation, but also by the handicapped parking space, the handicapped accessible entrance, the elevator, and the wide aisles of the sanctuary where my husband could pick a row anywhere and have me sit right next to him.

It behooves us to see that our own disabled are counted in our minyans, by making sure that they can get into our buildings with their various needs met, to pray with us, to learn with us, to meet with us, and to teach us.

The Talmud teaches us that a synagogue should be built with windows in the sanctuary. (Berachot 34b) I believe this is so we can see who is outside and unable to join us. Please, go back to your synagogues and ask yourselves and your leadership if you are doing all you can.

Let us take a hard look and see who is not in our midst. Who is not reading our bulletins or even our prayer books due to the size of the print? Who cannot hear our sermons or choir without special equipment? Who is not participating in a family *Simcha* because they cannot get up to the bimah? Who is not attending our religious

schools because of a physical or learning disability? We would never consciously do it, but are we unconsciously putting a stumbling block before the blind?

My family and I are continuing on the long, tedious, and unknowable road of recovery. Throughout this ordeal, the prayers, visits and practical support of the Jewish community have brought my family and me a long way. When I think of Jesse singing, "I Believe I Can Fly," I know that my future resilience will be on the wings of those prayers, visits and practical support.

Cain Yehe Ratzon.

END

Study Texts on Chronic Illness

Rabbi Alexandri said: "If a person uses broken vessels, it is considered an embarrassment. But God seeks out broken vessels for God's use, as it says: 'God is the healer of shattered hearts.' (Ps.147:3)

Lev. Rabbah 7:2

Whenever the Holy One calls to mind God's children deep in travail among the nations of the world, God- if one dare say this- lets fall two tears into the Great Sea. Their splash is heard from world's end to world's end, and that is the cause of earthquakes.

Berachot 59a

Heal us O God, and we shall be healed.

Daily Amidah

Physical health is a prerequisite for spiritual health, but a healthy body does not in itself produce a healthy spirit.

Hilkhot Deah 4:1 (Maimonides)

It is the spirit that sustains the body. And even if there is sickness in the body, the spirit has great enough strength to support the illness, giving them strength to bear [the illness] and renew their courage. But if the spirit is broken [referring to spiritual sickness] who will lift it up? For then the sickness will affect the body too as it is written, 'A depressed spirit dries the bones' (Proverbs 17:22).

the Malbim (Rabbi Meir Leibush ben Yechiel Michal)

Rabbi Joshua ben Levi said: "When a person is on a journey and has no company, let him occupy himself with study of Torah, for the Bible says, 'They are to be companions of grace.' (Prov. 1:9) When a man feels pain in his head, let him occupy himself with words of Torah... When he feels pain in his entire body, let him occupy himself with Torah, since another verse speaks of it as 'healing for his whole body.' (Prov.4:22)"

Eruvin 54a

Ravin said in the name of Rav: "From where do we know that the Holy One sustains the sick? As it says, 'God will support him upon his bed of illness.'" (Ps. 41:4) Ravin also said in the name of Rav: "From where do we know that the Divine Presence rests above the invalid's bed? From the verse, 'God will support him upon his bed of illness.'"

Nedarim 40a

Why does God give light to the sufferer
And life to the bitter in spirit;
To those who wait for death but it does not come,
Who search for it more than for treasure,
Who rejoice to exultation,
And are glad to reach the grave;
To the man who has lost his way,
Whom God has hedged about? (Job 3:20-23)

My groaning serves as my bread;
My roaring pours forth as water.
For what I feared has overtaken me;
What I dreaded has come upon me.
I had no repose, no quiet, no rest,
And trouble came. (Job 3:24-26)

We cannot escape suffering, but we may find God in spite of it, and even within it.

All who are sick at heart and cry in bitterness,
Let not your soul complain in grief.
Enter the garden of my songs, and find balm
For your sorrow, and sing there with open mouth.
Honey compared with them is bitter to the taste,
And before their scent, flowing myrrh is rank.
Through them the deaf hear, the stutterers speak,
The blind see, and the halting run.
The troubled and grief-stricken rejoice in them,
So do the sick at heart, who cry in bitterness.

(Moses ibn Ezra)

In suffering we seek the comfort of God's sympathy. But part of the comfort is to know that, in spite of the suffering, right is right and wrong is wrong; there is still work for us to do, and therefore life has meaning.

A Prayer When One Is Undergoing a Long and Draining Treatment

I'm tired, God. My doctors say that this treatment will help me, but it is sapping me of my strength. I'm sick of feeling sick, God. Sometimes I want to give up. But most of the time I just want to get better.

I love being outdoors and breathing fresh air. I love the sun and the rain. I love the sky at night. I love my family and friends.

I love life, God. I love it more now than ever before. Please, God, let me keep it. Help me to bear the stench of medicines and hospitals. Give me the stamina to stare down this disease and conquer it.

Fill me with strength, God, and I will fight for my life. Fill me with health, God, that I may live. Amen.

Naomi Levy

Two esteemed scholars, Rabbi Ishmael and Rabbi Akiba, were once walking in Jerusalem. A sick person came to them and asked for a remedy. A man nearby, who overheard the conversation, challenged the Rabbis. "God has sent sickness, and yet you are teaching this man how to be cured! Are you not working against God's will?" The Rabbis answered his question with a question. "What kind of work do you do?" they asked.

"I am a wine grower," the man replied.

"God created wild vines and you cut off the fruit?" the Rabbis asked him.

"But that is the only way to produce more grapes!" the man answered back.

"That is how it is with a sick person," the Rabbi explained. "One must take care of the body to enjoy life. The drugs we recommend are like the fertilizer which you use to strengthen the soil if it becomes weak."

Midrash Temurah, chapter 2

Adonai, You are aware of all my entreaties; my groaning is not hidden from You
My mind reels, my strength fails me, my eyes too have lost their luster.
My friends and companions stand back from my affliction, my kinsmen stand far off.

Psalm 38:10-12

Teach us to number our days so that we may acquire a heart of wisdom.
Let Your servants understand Your ways, and Your children see Your glory.
Let the beauty of our Eternal God be with us, and may our work have lasting value.
O let the work of our hands be enduring!

Psalm 90:12, 16-17

(The following three pieces are from Siddur Lev Chadash, Union of Liberal and Progressive Synagogues, London):

Let me do my work each day;
And if the darkened hours
of despair overcome me, may I
not forget the strength
that comforted me in the
desolation of other times. May I
still remember the bright
hours that found me walking
over the silent hills of my
childhood, or dreaming on the
margin of the quiet river,
when light glowed within me,
and I promised my early God
to have courage amid the
tempests of the changing years.

Max Ehrman

A Service of Healing
Compiled by Rabbi Lisa Izes

Yai dida dai...

When Miriam was sick her brother Moses prayed:
'O God, pray, heal her please! We pray for those who are now ill.
Source of Life, we pray:

Heal them

We pray for those who are affected by illness, anguish, and pain.

Heal them

We pray for those who do the sacred work of caring for others.

Sustain them

Grant courage to those whose bodies, holy proof of Your creative goodness,
are violated by illness and pain.

Encourage them

Grant strength and compassion to families and friends who give their loving care
and support to overcome despair.

Strengthen them

Grant wisdom to those who probe the deepest complexities of Your world as
they labor in the search for treatment and cures.

Inspire them

Grant clarity of vision and strength of purpose to the leaders of our institutions
and our government. May they be moved to act with justice and compassion.

Guide them

Grant insight to us, that we may understand that whenever death comes, we
must accept it- but that before it comes, we must resist it, by prolonging life and
making life worthy as long as it is lived

- adapted from the liturgy of
Congregation Sha'ar Zahav

*Esa einai el heharim mei'ayin yavoh ezri
Ezri mei'im Adonai oseh shamayim va'aretz.*

I lift up my eyes to the mountains. From where will my help come?
My help will come from the Creator, Maker of heaven and earth.

FOR THE BODY

אשר יצר

ברוך אתה יי אלהינו מלך העולם אשר יצר אתהואדם
 בחכמה וברא בו נקבים ונקבים חלולים חלולים. גלוי
 ונדוע לפני כסא כבודך, שאם יפתח אחד מהם או
 יסתם אחד מהם, אי אפשר להתקיים ולעמוד לפניך.
 ברוך אתה יי, רופא כל בשר ומפליא לעשות.

*We praise you, Eternal God, Sovereign of the universe:
 With divine wisdom You have made our bodies, combining veins, arteries, and vital
 organs into a finely balanced network.
 Wondrous Maker and Sustainer of life, were one of them to fail- how well we are aware!-
 we would lack the strength to stand before You.
 Source of our health and strength, we give You thanks and praise.*

FOR THE SOUL

אלהי נשמה

אלהי, נשמה שנתת בי טהורה היא! אתה בראתה, אתה
 יצרתה, אתה נפתתה בי, ואתה משמרה בקרבני. כל זמן
 שהנשמה בקרבי, מודה אני לפניך, יי אלהי ואלהי אבותי
 ואמותי, רבון כל המעשים אדון כל הנשמות.
 ברוך אתה יי, אשר בידו נפש כל חי ורוח כל בשר איש.

*My God, the soul You have given me is pure.
 You created it, You shaped it, You breathed it into me
 and You protect it within me.
 I offer thanks before You, Eternal One,
 my God and the God of my fathers and mothers,
 Guide of all deeds, Sovereign of all souls.
 Blessed are You, Eternal One,
 in whose hands are the souls of all the living
 and the spirits of all flesh.*

May I be at peace.
May my heart remain open.
May I know the beauty of my own true nature.
May I be healed.

*May we find the world in our lifetime,
our completion in the world to come,
and our hopes realized in those who follow us.
May our hearts meditate in understanding,
our mouths speak wisdom,
our tongues sing songs of jubilation.*

We offer our prayers, O Source of strength, to those in need...

Hear our voices; answer our prayers.

To those in pain from the torment of disease...

Ease their pain and give them comfort.

To those whose spirits are in need of renewal...

Lift their hearts and raise their heads.

To those who are lonely, who look for friendship...

Let us reach out with outstretched hands.

To those in silent distress...

Enable us to look within their souls, to sense the signals beckoning our concern.

Even as we seek peace and comfort...

Let us not close ourselves off to those who need us.

We offer our prayers, O Source of strength, to those in need.

Hear our voices; answer our prayers.

For those who visit, care, and comfort:

May you be comforted by your
ability to care and give comfort.

May you derive strength from
your own deeply held faith to be
emotionally present to
suffering and grief.

May your prayers give voice
to the awesome state of our mortality
in the face of the infinite.

And may you find grace to help
others see that rage against loss
carries within it the feisty spark
of its own divine energy.

That our outcry is as
important as our tears.

- Ken Gorfinkle

*Eili, Eili
 shelo yigameir l'olam
 k'chol v'hayam
 rishrush shel hamayim
 b'rak hashamayim
 t'filat ha'adam.*

O God, my God
 I pray that these things never end:
 the sand and the sea,
 the rush of the waters,
 the prayer of the heart.

Meditations for a time of silent reflection...

Healing is not a philosophically abstract concept. It is the constant struggle to keep balance, to juggle with the tensions of life. Healing is the counterbalance to the forces that pull us apart at any given moment in our lives. When we give attention to the need for healing, we become God's witnesses of pain and suffering, and also to the possibilities for joy. The uniquely Jewish paths toward healing- the biblical, the mystical, and the liturgical- offer possibilities for each Jew to heal his or her personal history, relationship with the self and with others, and to create a Jewish identity based on understanding.

The "path toward healing" can be followed through examination and personalized analysis of our classical and traditional heroes and their struggles, through examination of the Jewish mind and its yearning for wholeness and cleaving to God, and by accepting the invitations into the tents in time, in joining the orbit of and to the One.

- Marcelo Bronstein

Like you I
love love, life, the sweet smell
of things, the sky-blue
landscape of January days.

And my blood boils up
and I laugh through eyes
that have known the moist buds of tears.

I believe the world is beautiful
and that poetry, like bread, is for everyone.

And that my veins don't end in me
but in the unanimous blood
of those who struggle for life,
love,
little things,
landscape and bread,
the poetry of everyone.

- Roque Dalton, transl. Jack Hirschman

Hope is not the same as joy that things are going well, or willingness to invest in enterprises that are obviously headed for early success, but, rather an ability to work for something because it is good, not just because it stands a chance to succeed. Hope is definitely not the same thing as optimism. It is not the conviction that something will turn out well, but the certainty that something makes sense, regardless of how it turns out. The deepest and most important form of hope, the only one that can keep us above water and urge us to good works, and the only true source of breathtaking dimension of the human spirit and its efforts, is something we get, as it were, from "elsewhere." It is this hope, above all, which gives us the strength to live...even in conditions that seem as hopeless as ours do, here and now.

- Vaclav Havel

Hineni

Here I am again
Without much to offer by way of moral worth
I've a rich collection of defeats
Maybe that's to your liking?
I don't know, do you?
If I'm to be quite frank
Your likes and dislikes have never been
All that clear to me
Presumably love is something you're in favor of
And I've found it possible to love
But never without a certain anguish
Whether that's the way you intended it
Or that's a problem all my own
I can't say, can you?
I've never wanted to pain others
I've never wanted to pain myself
I guess I can plead good intentions
But I needn't tell you about good intentions
And the road to...
I've often wondered: did you yourself intend
When you got it all going
That to live would be so complicated
To find a way in the world so hazardous?
Did you have any idea at all
That living would involve such confusion
And such heartbreak?
I can't be sure any of this will mean much to you
I can't even be sure that you exist
As more than a figment of my own mysterious psyche
It's a risk to open up to you
Who knows, I may be branding myself a terrible fool
But what's not a risk? What's guaranteed to be foolproof?
So here I am again
Praying for some modest bravery
So that I can go on saying to you?
Here I am again.

- Stanley Chyet

Be with me, God. I feel so lost. I can't seem to escape the dark cloud that is hanging over me today. Help me, God. Give me strength to combat despair and fear. Show me how to put my pain into perspective. Teach me to have faith in the new day that is coming. Thank you, God, for today's blessings, for tomorrow's hope, and for Your abiding love.

Amen.

Teach me always to believe in my power to return to life,
to hope, and to You, God,
no matter what pains I have endured,
no matter how far I have strayed from You.
Give me the strength to resurrect my weary spirit.
Revive me, God, so I can embrace life once more
in joy, in passion, in peace.

Amen.

God who speaks in silence, teach me not to fear silence.
Remind me that running from pain only causes more pain,
that distraction is no cure for suffering.
Give me the courage to embrace the stillness, to encounter the quiet,
that I might learn to hear Your holy voice.

Amen.

When I feel tainted, God, remind me that I am holy.
When I feel weak, teach me that I am strong.
When I am shattered, assure me that I can heal.
When I am weary, renew my spirit.
When I am lost, show me that you are near.

Amen.

- Rabbi Naomi Levy

Mi Shebeirach*Mi shebeirach avoteinu, M'kor habracha l'imoteinu*

May the Source of strength, who blessed the ones before us

Help us find the courage to make our lives a blessing

And let us say: Amen

*Mi shebeirach imoteinu, M'kor habracha l'avoteinu*Bless those in need of healing with *r'fua shleima*

The renewal of body, the renewal of spirit

And let us say: Amen

The Intention

Healing is both an exercise
 and an understanding
 and yet not of the will
 nor of the intention
 It is wisdom
 and a deeper knowledge
 of the daily swing
 of life and death
 in all creation
 There is defeat
 to overcome
 and acceptance of living
 to be established
 and always
 there must be hope
 Not hope of healing
 but the hope which informs
 the coming moment

and gives it reason
 The hope which is
 Each man's breath
 the certainty of love
 and of loving
 Death may live
 in the living
 and healing rise
 in the dying
 for whom the natural end
 is part of the gathering
 and of the harvest
 to be expected
 To know healing
 is to know that
 all life is one

- Margaret Torrie

A person must learn to stand before God.
 A person must learn how to walk before God.
 A person must learn to pick oneself up after one falls.
 What do you do if you feel that you can't pick yourself up?
 Then you keep on walking and dancing until you dance your way to heaven.
 - Rebbe Nachman of Bratslav

Y'vareichacha Adonai v'yishmerecha.
 May God bless you and keep you.

Ya'eir Adonai panav eilecha vichuneka.
 May God's face shine upon you and be gracious unto you.

Yisah Adonai panav elecha vayesem l'cha shalom.
 May God bestow favor upon you and give you peace.

Kein y'hi ratzon

Tefilat HaDerech

May we be blessed as we go on our way.

May we be guided in peace.

May we be blessed with health and joy.

May this be our blessing. Amen

May we be sheltered by the wings of peace.

May we be kept in safety and in love.

May grace and compassion find their way to every soul.

May this be our blessing. Amen

FACING SERIOUS ILLNESS FOUR PERSONAL STORIES

- *Are you, or is someone you care about, facing serious illness?*
- *Have you been caught off balance by the intense emotions created by illness?*
- *Are you looking for strategies to help you cope during this difficult time?*

If so, you won't want to miss this inspiring and practical program.

Hear four Temple Emanuel members—**Judy** , **Ruth** , **Gary** , and **Marty** —describe the way sickness affected their sense of self, their priorities, their relationships, and their faith. **Rabbi David** will be on hand to offer additional insight into the spiritual dimensions of illness.

Leave the program with a packet of helpful take-home material: a bibliography of books about coping with illness, pamphlets on facing a medical crisis, and a collection of prayers that offer hope and comfort.

Come . . . register for this moving, practical program. You'll be glad you did!

RSVP to Gilda at:

Date: Sunday, October 26 **Time:** 10 a.m. to 11:30 a.m. **Location:** Library

Refreshments will be served

Books:

Jewish Paths toward Healing and Wholeness: A Personal Guide to Dealing with Suffering, Kerry Olitzky, Debbie Friedman
Jewish Lights Publishing, Woodstock, 2000

Healing of Soul, Healing of Body: Spiritual Leaders Unfold the Strength & Solace in Psalms, Simkha Weintraub, ed.
Jewish Lights Publishing, Woodstock, VT 1994

Jewish Pastoral Care: A Practical Handbook from Traditional and Contemporary Sources, Dayle Friedman, ed.
Jewish Lights Publishing, Woodstock, VT 2001

Visiting the Sick: The Mitzvah of *Bikur Cholim* – Sharon Selib Epstein
Jason Aronson Inc., NJ 1999

Web Resources for Caregiver Support

www.caregiver.org/caregiver/jsp/home.jsp

www.caregiving.com

www.caregiving.org

www.familycaregivers.org

www.nahc.org (National Association for Home Care and Hospice)

www.ncjh.org (National Center for Jewish Healing)

www.nfcacares.org (National Family Caregivers Association)

www.stoppain.org/caregivers

www.wellspouse.org