

## WHAT I HAVE LEARNED

The last time I spoke as a caregiver was in 2012. Dave my (now late) husband was with me and I spoke about caregiving in terms of using the numerous assistive devices we had acquired, which worked, which didn't and where to look to research availability. I also spoke of dealing with his increasing disability and weakness and the uncertainty about what the future held. Now, I know what the future held and how we managed as the years went by. What I have to say grows mostly out of my personal experiences and the shifting "new normal" as each one came along. I will try to address the more universal aspects of this experience of taking care of an IBM patient, or, as I view it, a victim of IBM.

I will share with you the bibliography of books on the subject of caregiving, but my experience was different in one major respect. Most of the literature presumes that the patient is mentally disabled (dementia or Alzheimer's) as well as being physically challenged. I was fortunate. I could tell anyone who asked that I had the "best part" of Dave because literally to his last breath his mind was clear as a bell. Even when the effort of speaking was exhausting, I learned that if I framed my side of the conversation so that he could respond by nodding or shaking his head or pointing, we could have substantive, meaningful conversations. However, when I realized that his physical ability to carry on a long conversation was waning I suggested, and he agreed that we needed to talk about long-term plans and needs on a

deeper level than just a DNR order if that appeared necessary. A very useful tool was a document called “Five Wishes, because it could be used by checking choices or crossing out what was not desired.

Initially, Dave’s diagnosis in 1999 was PM. He was treated primarily with Prednisone with no side effects, and although there was some muscle weakness, most of it was manageable by just learning to move slowly and deliberately. After about 4 years, his doctor eased him onto Methotrexate. By 2004, Dr. Mammen at a Myositis Conference asked him why he was attending a PM lecture when it was obvious to him that now Dave had IBM. From that point, the weakness increased and he needed more and more help with the ADL’s. Since he wanted to keep working, I decided that being a full-time caregiver was more important than running off to the courthouse, so I helped him dress (buttons were a challenge), drove him to work and picked him up. It had become obvious that as his body started to abandon him his self image was more and more tied up in his ability to continue working because his colleagues wanted and needed his skills. He would be physically exhausted, but mentally so upbeat that I vowed never to take that that away from him. I also vowed that I would keep him at home and be responsible for his physical care even if (as it happened) in time he required the most personal care.

At this point, I ran headlong into the truism that I could not ever hope to make the disease move more slowly, or go away altogether. I decided to retire and did not miss going to work; after 36 years, practicing law was no longer “fun” but I found myself becoming angry, not at Dave, but with every loss of muscle strength, I became more and more furious at the disease. Since my health insurance had a fairly generous mental health benefit, I started seeing a counselor/therapist.

Those visits were a safe place where I could be angry with the disease, the unfairness, the frustration and helping me face that, much as my nature is to control things, the only thing I could control was my reactions. IBM did not care what I thought. Also, I found that if I let my anger show to Dave, he would feel he had to apologize for “doing this” to me. I had many close friends who listened, were sympathetic, marveled at “How fine” they thought I was doing, but they were my friends. My therapist could explain and reassure me that my anger and frustration were normal and appropriate and that I was not being selfish or disloyal to have those feelings. Every few weeks, and later, every few days, brought a “new normal” so I continued to go for counseling and it really helped. This was one of the first things I learned; that after 2 or 3 weeks, I needed to see the counselor for a “refill” of belief in what I was doing. It occurred to me that sometimes time changed the most simple acts in the way they were perceived. For example, the first time I fed Dave was when we shared a piece of wedding cake and we were laughing. The first time I realized that he could not move a spoonful of oatmeal or a forkful of green beans to his mouth and it was time for me to start feeding him,, we both cried. Similarly, there is an old Yiddish proverb that says that when a parent feeds a child, they both laugh but when the child has to feed the parent, they both cry, and so it was. (I should point out that I may from time to time make reference to something that has a Judaic overtone. This is what I am familiar with, but from my reading the same thought, philosophy and principles apply throughout Christianity)

As the reality of his inevitably increasing disability sank in, we acknowledged that this was not the life we chose, but that I could not imagine doing anything other than caring for him whatever his needs

became. And it was a changing normal, sometimes within the same day; the hand that could bring a spoonful of cereal to his mouth in the morning was too weak to bring a forkful of green beans to his mouth at dinner.

It had always been hard for me to accept help, when it was offered because that would have meant me admitting that I needed help . Even harder was reaching out to ask for help before it was offered and not to feel embarrassed or somehow diminished by asking, but in due course, I began to realize that I would have to .Working through an agency I was able to find a CNA with whom Dave felt comfortable. We began with her helping Dave dress and eat, and hold the newspaper and turn the pages for him and we gradually arrived at the point where he told me that he was OK with her showering him and cleaning him in the bathroom. This is essential, because a man in this position can feel invaded by strangers giving him the most personal of care. I cried when he told me that he felt this was the beginning of him losing his last shred of dignity, My therapist and our daughters finally made me see that I was not failing him by sometimes turning these duties over to an aide.

I learned patience. I quickly realized that, once he had to admit he could no longer work at the job he loved, even working from home, a positive image was inextricably connected with how useful he felt. When he was able (by now he was in a power chair) to balance a tray on his lap, he would set or clear the table, one dish at a time. Learning to slow down and let him do it was hard for me but he needed it. The same applied to washing himself in the shower. brushing his teeth and the like. He loved gardening, and while he could no longer dig and plant, our wonderful neighbors recognized his interest and knowledge

and he was able to participate. His mind let him be a source of information and advice about landscaping in the community. He longed for independence, so he would insist on going out and about in his chair, carrying a “man-bag” that held car keys he could no longer use, a wallet long after his fingers lost the ability to take out a credit card or a dollar bill, and such. Was it frustrating, even annoying to me to cater to this need for independence? Yes. Would I have ever dreamed of telling him no.? Absolutely not. Fortunately, Dave was able to express his feelings and emotions and once when I expressed annoyance at having to adjust the man bag around his neck, he told me that he knew it was “silly” (his word) but he needed it anyway, so after that it became part of our routine. At this same time, I realized that his desire to make my life easier by saying that whatever was easiest for me was his choice, whether for a meal or which TV program to watch was not making my life easier. I explained it by saying that physically taking care of him was sometimes tiring and left me no energy to try to crawl into his head to see what he really wanted. He accepted that and learned to be clear not only about his needs, but his wants.

His ability to tell his feelings was a blessing. For example, after turning him in bed became beyond my strength, we got a Hoyer Lift, and a PT who came to teach us how to get him into the sling. After 2 tries, it was apparent that the sensation of being in the sling to move him from the bed to the chair was literally throwing him into a panicky state, so we never used it again. There came a time when sleeping in bed was not possible because he could not turn over or do anything to make himself comfortable, so he slept in this recliner in the living room. I slept in the bedroom until one night when he had a nightmare and awoke trembling. I lay down on the couch next to his chair so I could reach out

and touch him. About 2 days later he remarked how comforting it was to have me nearby,, so after that I slept on the couch. I was comfortable and he felt safe. I then realized that even if I was in the house, being in a room alone was scary for him. The more disabled he became, the more things were frightening. I say this, and describe other things I did not to make myself look good, but to heighten your awareness of the numerous little things that are sometimes more important to caregiving than the big, obvious ones liking feeding, dressing, etc.

For a man who is more and more disabled by disease, going out in public presents challenges to his sense of dignity. This has nothing to do with how the personnel he interacts with treat him. There was no problem for a waiter to stand guard outside the Mens' room door so I could help him in the bathroom when there was no family bathroom. It was the reality of it being known that he needed this kind of help that hurt him. Wearing a bib and having me feed him in public became so painful to him that we "ate out" by me bringing in restaurant meals, setting the dining room table with candlelight and matching napkins and placemats, and inviting friends. No matter how I tried to reason with him, he felt it was embarrassing, so we just did not do it, not because I was giving in to him, but by this time living day to day was such a challenge that it did not seem like a good idea to increase his stress.

The more disabled a man becomes, the harder it is for the couple to find creative ways to enjoy the intimacy they once knew. Touching, hugging (even if he could no longer hug back,) kissing can be accomplished, and it takes away from the feeling that your entire lives are nothing but care taking.

Dave always chose his own clothing when we went shopping in the catalogs. After wearing sport jackets became uncomfortable and well-nigh impossible, he perused the catalogues and we would order sweaters, shoes, slacks, whatever. The reality that he was not going places where he could wear everything he acquired did not matter. Him wanting to buy sweaters and shirts meant that he was still fighting the disease. One of the signs of depression is often that the patient stops caring about his appearance. Choosing his outfit each day became more and more important. Even in what turned into his last day, he rolled into the closet and chose a pair of slacks, a shirt and a sweater. In every instance, as long as he was willing to fight, I would fight alongside him.

## TAKING CARE OF THE CAREGIVER

When you are taking care of a person who can no longer take care of himself, it is very easy to lose yourself in the process, and you should not and cannot allow this to happen. Constantly needed physical care is physically and emotionally exhausting for the caregiver and there are limits to your physical and emotional strength. Rabbinic teaching from Maimonides who was a 13<sup>th</sup> century physician and teacher, physician to the Caliph of Bagdad as well as to the Jews of his time is that if the task of caring for a loved one becomes too difficult you have the right, if not the duty to turn the task over, at least temporarily to someone who is competent and perhaps less emotionally involved than you. It was this teaching that led me away from feeling guilty for hiring a CNA who could take care of his basic needs, even if I was there and just exhausted. It also freed me to go out grocery shopping just to give

myself a change of scenery. My counselor finally led me to the understanding that taking care for myself was an integral part of taking care of Dave because if I came back renewed, there was more of me to give to him..

The Talmud also teaches that the holy presence, or the holy spirit if you prefer hovers over the one who is sick,. That means that as you look at your loved one who is impaired by disease or frail you must remember that he or she is still nevertheless made in the image of the deity and nothing can take away that person's inherent dignity as a human being. This means that the person is not the disease. Just as we are learning that a person is not "autistic" or "epileptic" but is an individual who is afflicted with autism or epilepsy. Your IBM patient is not IBM; he or she has Inclusion Body Myositis, and that might define his or her physical limitations, it does not define the person who cannot hold a spoon or bring a tissue to his nose unassisted.

Please indulge me with one more teaching from the Bible. The legend goes that after Moses smashed the 10 Commandments in fury over the idolatry of the people, he went back up the mountain and received another set.. The broken pieces were preserved and traveled with the Holy Ark. From this, as tired, unhappy frustrated caregivers, we learn that that which was once holy remains holy even in its broken state. Similarly, people who are broken, physically or mentally or both are still holy people created by whatever God you believe in, and if they were once holy, they remain holy, even in their broken state.

Lastly, I want to touch on something that no one might want to. The research into IBM is just tiptoeing into possible breakthroughs for managing the symptoms and a cure may not be possible in your or your



loved one's lifetime. The most valuable gift we as caregivers can give to our patient, and indeed to ourselves is the gift of reassurance that the person you are caring for matters to you, is precious in your eyes and will not be abandoned by you and that your patient, your beloved, the one who matters to you can always feel safe in your faithful care. If it is your spouse or partner, he or she needs reassurance that you did not marry him or her for the ability of any specific part of his body or mind to perform and that the life you may have shared has value because you shared it, even if the body you are sharing it with now is different, damaged, disabled or in no way similar to what each of you was when you first came together.

You must also take for yourself as the caregiver the reassurance that you did the best you could to keep that person physically comfortable, and feeling safe. Anyone who has been in this position can consider himself or herself as much a hero or heroine as if you had battled the enemy known as IBM with implements of war, but battle you did and you should let yourself be reassured. It was not the life you would have chosen, never let yourself be talked out of knowing that you put forth heroic efforts to take care of your patient and yourself.