

Good Afternoon Everyone!

My name is Bob Lesh and I am representing the “Consumer” or in this case a CAREGIVER as a member of the California Taskforce on Family Caregiving nominated by the Multiple Sclerosis Society. Before I go any further I would like to say what an honor and wonderful experience it has been to be part of the Taskforce and interface with the other members as well as the academic team from USC. As I look back on my life and all the ups and downs that I know we have all experienced, I certainly would not have pictured myself, a life-long east coaster up to sixteen years ago, speaking about caregiving experiences to members of the California Assembly. How did I get here?

45 years ago my fiancée, Alice (now wife) and I sat across from the Chief of Neurology at Albany Medical Center to review the findings of a complete battery of tests given to Alice. He started out by saying that the good news was that she did not have a brain tumor. However, he was almost certain that she had Multiple Sclerosis. Her symptoms were optic neuritis, numbness in certain parts of her body and tingling in her limbs, all, as we have come to recognize, are classic early symptoms of MS. There were no MRI's at the time to verify his diagnosis, but, as it turns out, his diagnosis was spot on and that attack to her body ended up being her first major exacerbation. He discussed MS with us and basically told us to go out and live our lives as there was no cause or cure (there still isn't). Fearless like most young adults are in their mid-20's we got married a year later and moved to the Syracuse, NY area where we had 2 children and I started my career in medical sales not knowing what effect MS might have in our lives.

Caregiving – regardless of the situation - usually occurs in phases. The nature of the illness/disease/age dictates the involvement and subsequent needs at different points of the care cycle. For the first 15 years of our marriage Alice had a few exacerbations that slowed her down for a while, but she recovered which is also typical in relapsing remitting MS. During this period there were more emotional than physical issues to deal with which were not evident to the outside world. She was able to work part time and participate in normal activities and even started her own catering business which ended when she had an exacerbation that didn't allow her to recover her ability to walk. That is the point that I consider my initial start or **Phase I** as a part time caregiver. At that point we made the necessary changes (widen doorways, install ramps and a chair lift) to make our home accessible which was paid out of pocket. Not daunted by her loss of walking, Alice decided to get a Master's degree in Rehabilitation Counseling at Syracuse University. I was fortunate enough to be able to help her by typing all her papers. Subsequently, she was able to work as a rehab counselor for four years. All the while I was able to work at my job and even take on additional responsibility when I became a Regional Manager for the Northeast in 1985 when the children were 9 and 11. I feel blessed that I had a job where I was appreciated and my family situation was accepted and understood. I can see today how caregivers are really strapped down by their jobs which absolutely causes additional stress to themselves and their families.

How did we get to California?

In February of 1994 our 17-year old son died in a weather related car accident. That absolutely changed our lives and future plans. Our daughter dropped out of college for 2 years and when she returned, she chose to go to the west coast to avoid the bad weather and ended up at USF. After graduation she stayed in San Francisco and got married. I changed jobs in 2001 because I

could no longer do the travel as a manager. However, a territory with my new company became available in the Bay area and I took the opportunity to transfer to the Bay area in July of 2002 to be closer to our daughter and future grandchildren. We immediately became involved with the local MS support group and tried to learn as much about MS as possible. In trying to create accessible living like we had back in NY, we bought a house together with our daughter and son-in-law (pooling income) and made it accessible. Unfortunately, the MS continued to progress, and Alice started losing the use of her primary hand which took us to another level of caregiving where she had to be transferred by a caregiver. This was where **Phase 2** began as life got more complicated and Alice needed more care. Both her physical and emotional condition became more compromised and unfortunately, after 5 years, we could not sustain the family relationship. We were fortunate to find a wonderful part time caregiver (4 hrs./day, 5 days/wk.) who started working for us while we were living in the house and transitioned with us when we moved back to an apartment which enabled me to continue working.

As I mentioned earlier, there is a lot of stress related to family caregiving that causes **collateral damage** to other family members – children, siblings, etc. Both Alice and I have heard about these family situations in support groups, from neighbors and from friends that we have at our adaptive PE classes. **The recommendations we are presenting today are in direct response to addressing these issues.**

Phase 3 or full-time caregiver started about 4 ½ years ago when I retired. Our caregiver that we had for 7 years got a full time job and left and my subsequent 2 part time caregivers got pregnant and could no longer work so I have been doing it all full time for the past 3 years. Additionally, caregiver costs have risen along with the cost of living so I have just built my life around taking care

of Alice, our 2 wonderful dogs, and being “Uber Grandpa” by helping with transport of our grand daughters to and from ballet and school. Fortunately, we have a great climate and can get out most days to recreate with the dogs and our friends at a local park and attend Alice’s classes at De Anza college for adaptive physical education which also allows me to work out and helps keep me in shape for my transfer duties. The challenges are now more of an inconvenience since, in the last 4 years I have had to pass on 2 reunions and a graduation back on the east coast because of being cost prohibitive from a caregiver perspective. For example, it is costing me \$400 just to be here today.

During my participation in The Taskforce I have been able to reflect back at all the time and energy and money spent over the years as well as the emotional roller coaster that I willingly dealt with and accepted as a husband during our 44+ years of marriage and hopefully was able to use this experience to help create our recommendations. As a member of the Caregiver Taskforce I have gotten an even greater appreciation for the caregivers who are thrown into an unexpected caregiving situation without the time or knowledge of how to deal with the Caregiver role. Accordingly, I stand behind **all** the recommendations presented today and am especially interested in moving forward to create policy to increase access to affordable caregiver services and supports, including respite care that allows caregivers to take a break.