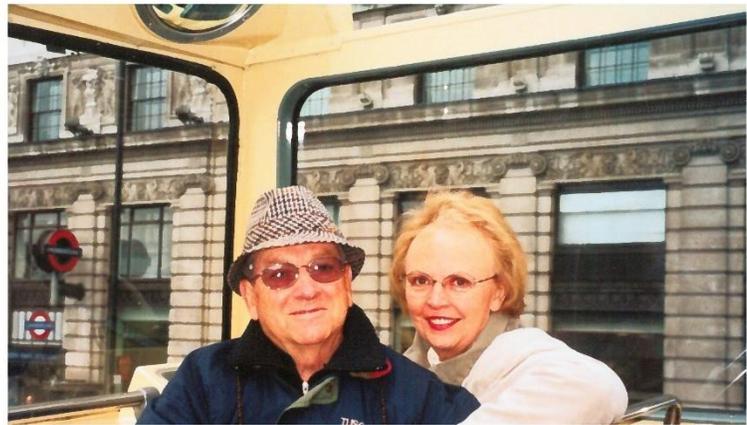


Honor Jones: Family Caregiver and Volunteer

Family caregiving takes many forms. Some caregivers take a parent to doctors' appointments and pick up prescriptions. Others become 24/7 caregivers, proving for all needs of a family member. Caregivers often enter their situation unexpectedly, lacking knowledge of available resources and unsure how to navigate the caregiving role. Everything can seem fine until it is not. Then, the caregiving begins whether you are ready or not.

An example is Honor Jones.

The unexpected happened and her life took an unexpected journey. The following section highlights Honor's experience as a caregiver and later her involvement in the Caregiver Support Initiative.



Max and Honor Jones taking a bus tour of London in 2002, shortly after Max's symptoms began.

Honor Jones became a 24/7 caregiver for her husband, Max, practically overnight. Max began experiencing a loss of strength and mobility of his arms. Sometime before, he had fallen off a ladder and struck his head. Thinking it might be pinched nerve but puzzled by his loss of strength and diminishing muscle, Max and Honor visited several doctors with non-conclusive results. Initially, Max was diagnosed with “man in a barrel syndrome.” Lyme Disease was also considered. Max and Honor finally went to the University of California, San Francisco ALS Center, but Max's condition remained undiagnosed. On one visit, Max felt a heaviness in his chest and walking pneumonia was suspected. Max was admitted to the UCSF Medical Center and diagnosed with pneumonia. He aspirated on a protein drink fed to him. He was immediately transferred to the ICU where he was placed on a ventilator. Continued ventilation required a tracheostomy and a percutaneous (PEG) tube for nutrition.

After a month in the ICU, Max's lungs were clear, but he had been diagnosed with Amyotrophic Lateral Sclerosis (ALS), commonly known as Lou Gehrig's Disease. He was transferred to Tahoe Pacific in Reno, where he stayed for two months. Max's discharge instructions required placement in a subacute ventilator rehabilitation center, except there were none in Northern Nevada! Faced with moving to Las Vegas or California, away from their home, their family, and their social support system, Honor set her mind on finding a way for Max to remain at home. She loved Max. They were nearing their 50th wedding anniversary, Max's 90-year-old father was alive and well, and more grandchildren were on the horizon. Honor would figure out a way to manage his care.

Like many caregivers, Honor did not know where to begin. There were more questions than answers. Honor shared, “There was no information; there was no manual or guidebook. I wasn't familiar with the area's social and community resources. It all hit so fast, I went to the basics. I kept a spiral

IMPACT REPORT 2018

notebook with notes of everything I was told by the doctors, nurses and case workers. But, there really wasn't a definitive roadmap for care for someone in Max's situation. I had to ask questions, investigate and research to figure this all out, which I did. I requested that the staff train me in the hospital. I stayed day and night, watching and learning about all of his required treatment and equipment and how to handle it."

Honor and Max were faced with many decisions after Max's ALS diagnosis. Max decided to retain the trach tube and ventilator since he knew he would eventually be on the ventilator fulltime. Honor suddenly had to tend to all of Max's needs. Honor shared that Max, "had been a very self-sufficient individual and had a strong will to live. As time went on, I would say that it enhanced our relationship although the stress and challenges were at times overwhelming. I remained positive. I had told myself, 'I would not, in any way be negative about this.'" Their lives had a new normal.

"I stayed day and night, watching and learning about all of his required treatment and equipment and how to handle it."

ALS affects motor neurons that control muscle movements, ultimately leading to total paralysis and loss of speech. Mental acuity and sensory faculties remain intact. Max was entirely mentally alert and could feel temperature and pressure. Overtime, his muscles deteriorated, and he became fully paralyzed. Through it all, Honor connected with Max. She danced with Max in his power chair. And, she recalls, "We also kept our cuddle time. Touch is extremely important to a person that can feel. I would take his hand and pet his dog and give her a cookie. I would watch the news with him every night and cuddle, lay next to him, feel him, touch him, talk to him. You have to connect with the person you're caring for physically and mentally."

Honor embraced her challenges as Max's primary caregiver. She hired assistant caregivers to tend to Max and allow her some respite. Honor was always vigilant, waking up in the middle of the night to the faintest noise and would check to make sure Max was alright. She became a "ventilator engineer." She was there 24/7.

Building Empathy

When asked about her most treasured memories as a caregiver, Honor responded there were many but seeing her grandchildren's easy acceptance of Max's condition and watching them navigate Papa's power chair are certainly some. Honor stated she endeared, "watching how the grandchildren accepted Max's disability as normal and how they carried this acceptance to school. Students from a special needs class would leave at the same time. I watched my grandsons accept them with interest and concern regarding their disabilities, when other students sometimes did not. We talked about their disabilities versus Papa's. And I said, 'It's just a disability, that's all it is.'"

IMPACT REPORT 2018

Honor found that caregiving, “is something that we don’t talk about or think about until it happens.” When asked how she survived her caregiving experiences, Honor’s advice to other family caregivers is first to accept the situation. Second, develop coping skills. And, third, keep up with a few vital interests of your own.”

Joining the Caregiver Support Initiative

Honor was the first caregiver to join the Caregiver Support Initiative when it commenced in 2016. At the time, Honor had cared for Max for 10 years. When asked about her first impression of the Caregiver Support Initiative, Honor stated, “I knew there was a tremendous need. I harken back to my spiral notebook where I wrote everything, every person, and every phone number down, over and over, as I learned about contacts, resources, and specific care requirements. When I stayed overnight, I even drew the equipment in my notebook and labeled it all. I had to learn it all and it was a crash course!”

Honor knew other caregivers were facing the same challenges and believed in the Caregiver Support Initiative. Honor explained that when she first got to the meeting she thought: “Yes, we definitely can put this together to help other caregivers on their journey.” Honor has regularly been involved in the Caregiver Support Initiative and observes:

“The Community Foundation brings awareness to the public. As I see it, the Community Foundation is one of the most empathetic, caring, community-minded organizations there is. There are many philanthropic entities, but the Community Foundation stands out through the initiatives it undertakes, such as the Caregiver Support Initiative, resulting in resounding education and public awareness. The Caregiver Support Initiative could not be in better hands. The best of the community’s social services, medical entities, and medical school members and staff joined the Community Foundation to bring the Caregiver Support Initiative to fruition.”

Sharing the Initiative with Max

Because Honor consulted Max on decisions, she naturally told him about her involvement in the Caregiver Support Initiative. Max always took pride in what his family did. “I’d go over something we discussed at one of the meetings and I’d say, ‘Do you think that’s right on?’ And he would tell me through blinks, two blinks were no, one was yes. He communicated that way because he could no longer nod his head or use his eye gauge computer to respond. At the end, he could only blink his eyes.” At first Honor was not sure if Max understood the scope of the initiative. However, when Honor showed him the Washoe Caregivers Guidebook, Max, an engineer, grasped its entirety. “This was right up his alley,” said Honor.

IMPACT REPORT 2018

Max passed away on September 9, 2018. Honor was Max's primary caregiver for 12 years after they were told on discharge that he had three months to live with an ALS diagnosis. Honor credits Max's longevity to his strong will to live, the excellent care and meticulous hygiene she required of herself and others, and of course, the spiral notebook. Although Max and Honor's lives dramatically changed, they maintained their strong relationship, and went on a different and unexpected journey. They were still able to enjoy each other and their family, experiencing many milestones along the way, including their 61st wedding anniversary, birthdays and the arrival of more grandchildren.

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