

“A Woman’s Work is Never Apparently Still Done”

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With the aging of baby boomers comes competition for resources more challenging than prior generations. Some non-profits, which previously could offer a myriad of services, have had their budgets more than 60%. I know, I’ve been there. On 3/30/2007, our lives changed overnight. My husband sustained a traumatic brain injury (TBI) at work and I became his full-time caregiver.

According to the Family Caregiver Alliance, there are around 43.5 million caregivers providing unpaid work to loved ones. Women still shoulder the majority of caregiving duties, and this, often on top of a job, helping to take care of grandchildren, household, and other tasks. The need for support, understanding, and funding for this precious group of women has never been greater.

Like so many, we, at age 66 and 70, have lost over ten years of earning power due to caregiving, placing us in a vulnerable situation as we age in place and cannot work outside the home. While there are programs for very low income families such as IHSS here in California (In-Home Supportive Services), food stamps and the like, our social security income is just above the eligibility lines and don't qualify us for most programs. Therefore, we have to self-pay, or I have to do it myself, with a little help from our friends. We are not alone. There are millions in the same situation as ours.

I’ve learned a lot since that night of 3/30/2007. Both my husband and I have spent considerable time in the early days of my husband’s injury advocating for TBI survivors, participating in brain injury conferences, and interviewing with the media. We were selected for a prestigious grant program whose culmination involved making a presentation to the Family Physicians Association of California in hopes of adding TBI to their continuing education requirements. I was honored at one TBI Conference in Silicon Valley for an award and, as well, was recently named Co-Caregiver of the Year by Del Mar Caregiver Resource Center. Still, despite others doing much of the same thing, many people do not understand what caregivers go through. As one person shared with me, until you are placed in this position, you really can’t imagine what caregiving involves, the time and the expense and the emotional costs.

Given the last ten plus years, I've put together what I would consider my "Wish List" for what I wish I would have known:

*While every caregiving and medical situation is different, caregiving is a large load as your time is really not your own. Also, being responsible for the welfare of someone else can be very time consuming, and exhausting. However, there are some commonalities. One resource which has been helpful to me was to have approached the various nonprofits which assist families like ours. The Brain Injury Association of America (703) 761-0750 has taught us a great deal about TBI and is always there for questions or concerns. The Family Caregiver Alliance, (800) 445-8106 is a treasure trove of information for caregivers. The local nonprofit that has been with me from the beginning, Del Mar Caregivers in Santa Cruz, CA (831) 459-6639 has been there for me time and time again. Despite budget cuts, from providing a listening ear, support groups, caregiver walks, to a paid legal consultation, I don't know what I would have done without them. Most areas have Area on Aging or other senior related resources that can be found online and some also have Independent Living Centers which addresses many of the concerns that people with cognitive problems go through. Of course, not all caregivers are seniors by any means and while choices are more limited, they are out there. Google will be your best friend, as will networking and asking those in the field for specific ideas. I learned that I have had to patchwork a resource network as there is not one agency which can assist with the myriad of needs a family has. I learned how to work the phones, the email, and met a lot of new people who have become very dear to me and who I will be eternally grateful to. I will never be able to repay them but I try.

*Draw up a list of needs which you have and think about who you can ask for help. Even if it's just asking someone to pick up something while they are shopping or sitting with your loved one, walking the dogs or even washing yet another sink full of dishes, every little bit helps. I will never forget neighbors who I didn't know that well showing up one night with a casserole of lasagna. If people ask what they can do for you, ask then what they would like to do from your list. Many people do still want to help but often don't know what to do or say.

*When I first became a caregiver, I tried to become perfect as the Doctor said that my husband would be well in a couple of weeks. At the three month mark, that was not true. When I set up my first intake here at the house with Del Mar Caregiver Resource Center (CRC), I had a clean house (last time it was clean I think!), I had baked cookies, and another sink full of dishes was awaiting me. I greeted the case worker, said I needed to finish dishes and started toward the kitchen. The next thing I knew I had my hands in the suds and turned

around and started crying uncontrollably. It was the first time I had talked about my feelings and from then on, I never felt alone again. I have also learned that while we are told to take care of yourselves, it is nearly impossible sometimes. The day that Del Mar CRC came, the case worker was very honest with me and said even if you poke your head outside or look at a budding flower, that's taking care of yourself. Caregiver depression undoubtedly goes along with caregiving. Talk with your Doctor about what you can do. Del Mar Caregiver Resource Center has an excellent website (<https://www.delmarcaregiver.org/>) as do other caregiving nonprofits. Their online resources have been helpful to me, and especially their "Caregiver Bill of Rights." Two examples that have made a difference for me are: 1. It's ok to feel what you are feeling. Go with it. 2. Have one thing that you do that has nothing to do with caregiving, it will nurture you.

*Speak up! When someone asks you where on earth have you been or what are you doing with your life now, tell them. I honestly did not know what caregiving was save for the primly dressed and perfectly groomed older women at the Church of my youth who never said a word and were active in the community. I thought that I was going to have time to learn how to play the guitar and write the Great American novel when my husband first became ill. So when you get the glazed looks that I am sure I gave others before I was in this position, forgive them. Know that they are doing their best and they really don't know what they are doing, or in this case, not doing. Don't take it personally. Know that as with a grief journey, you will change and so could some of your friendships. Don't give up on them, they may come around. Forgive them again. You will meet so many likeminded people who will become part of your world who will provide support, and you, to them. Don't take, learn to give. I can spot a caregiver a mile away now and find that they seem to gravitate toward me. I have learned to be a listening ear and share resources with them, give them my number and let them know that they are never alone through this. Everyone will be different as far as the level they would like to do this. And even I have no interest in going through what I term "Caregiver 101" with them, but I well remember how alone I felt and how I was under the impression that there was nothing that could be done. Nothing could be further from the truth. Don't give up.

*Speaking of which, if you are up to it, and want to do something for the effort, and for future generations, try contacting your state or national representatives and suggest that they consider writing bills to fund middle class and upper lower income families for in-home caregiving assistance. Offer to consult with them and share your experience as they can gain much insight from your hard-won efforts. If you see opportunities to write Letters to the Editors or post on social media when the subject comes up, do it, it really only takes a few minutes and it is important so that others don't have such a struggle in the future.

*Finally, to paraphrase former First Lady Rosalyn Carter, most people living today will be caregivers, will be cared for, or know someone who is a caregiver. Before a crisis comes on, plan ahead. Start forecasting the future and consider the worst case scenario: what do you need to sustain your lifestyle if something happened? Assume you will get little consistent help from others and government entities as many people do mistakenly assume. I can count on my hands how many times I've heard others say that their daughter or their neighbor or the government will take care of them. In terms of the family, yes, they will be helpful but not everyone is cut out for caregiving. Of those who do, once again, they themselves will need help and that usually comes in the form of self-paying. We thought having six months of emergency funds set aside was enough. It was not, especially with a lifelong chronic medical condition like TBI. Set aside every extra penny you can, earmark it for emergencies and start making plans and have a good nest egg for "what if." See an estate planning attorney and get a Will or Trust done, get your Durable Power of Health done and in some states like California, a POLST form. Include instructions on who you would want to take care of you and your loved one if you couldn't. Include your pets in on your plans and let your family and close friends know your wishes.

The "new normal" that we have learned to live was certainly not anything we had ever planned nor wanted. However, you do find out how strong you are through these challenges, you learn how to turn the proverbial lemons into lemonade, and learn to be more empathetic, kinder, and more compassionate. You also learn what is truly important and the necessity of saying the hard "no," to yourself and others. You become a new person, a better person, and better than you could have ever imagined. Most of all, hang in there, you WILL get through this!