

Muriel and Steve's Amyloidosis Journey

My husband Steve and I were caregivers in the 1990's, and the early 2000's when people more often (with some wonderful exceptions) died with this disease rather than lived with it. Sadly that is still true for many who are diagnosed with deep cardiac involvement, or diagnosed late, after the disease takes its toll on the body.

Our early support meetings in 2004, 2005 and 2006 always included Kleenex at every table to be readily available for many of the attendees who had lost loved ones to amyloidosis. Several of those earlier meetings were part grief groups. (That was when we started the amyloidosis widow(er) group on line and they then put it on Facebook.).

We started the face to face meetings in 2004, as we lost my uncle in September 2003 (Sunday the 28th to be exact.). He lived with us and he requested that we never put him in a home. Unc was an Air Force veteran, never married and very independent until his diagnosis. He was my mother's baby brother, and my husband's best friend. He was more than an uncle as many can understand. He had heart, kidney, liver, and nerve involvement and was crushed when we made him move up to our area near Chicago from his condo in Jacksonville Florida. That was the first, of what I am sure he saw, of many indignities he had to face on his journey. We had to take away his driving privileges when he started to faint from orthostatic hypotension. He required oxygen after a certain time period, and dialysis three times a week about 2 years before he died. He was wheel chair bound from the neuropathy and a fall due to the orthostatic hypotension (a trip to the bathroom in the middle of the night), which was a regular event for him as well. The police investigation was embarrassing (they had to make sure we did not push Unc) and reinforced what we had been taught about proper preparation of all floor areas, as well as vigilance about using walkers and canes in the house.

We all realized that unc could no longer live alone after his second car accident. The first we attributed to his falling asleep at the wheel. It was a year before his diagnosis and he would drive up to us from Florida in spring for the summer, and then drive back in the fall. On a return trip in the mid 1990's he totaled his car and miraculously came through it virtually unscathed. It was only after the amyloidosis diagnosis, that we realized it was orthostatic hypotension (huge blood pressure drops) causing him to faint. The second accident occurred after he moved up to Illinois and living nearby. We never knew exactly what happened, but he was taken to a local hospital and we got him transferred back to Northwestern. That took about a week of red tape and various medical opinions. It was scary and complicated. I had my first bouts of confrontation with doctors at the local hospital. I was not used to being an advocate. I was amazed at my own strength of will. He left the hospital that time a weaker man, less able to take care of himself. It was a sad time for all of us. We knew we were entering a different chapter of this journey.

My husband and I were lucky that we own our own company, and could take turns taking off work, when we were needed to take him to doctors and dialysis appointments. When he was hospitalized at Northwestern (which would be weeks at a time), I would book a room at the hotel across the street so I could be near. The drive was an hour each way and that saved a lot of time. They had a place to lie down in the room on a window seat, but I was not able to sleep that way. You probably ask, "Why did you have to be there so often?" At that time, amyloidosis was not known among many physicians beyond unc's doctor (and even he was a novice). We had to run interference if a group of doctors wandered in on rounds and tried to undo something they thought should be done differently. Also unc got tired of answering all the questions asked at Northwestern (and probably all teaching hospitals) and asked that I be there to respond for him.

We were lucky to have had enough funds to bring in a caregiver Monday through Friday during regular work hours. If I had it to do over again I

would have the caregiver 24/7 so Steve and I could get an occasional break together. I loved my uncle very much, and I am sure that watching him change from a strong independent man to the opposite was as hard on us as it was on him. I found no one could hear me cry in our upstairs, unused bathroom so would go up there to take showers and cry.

My uncle made up a list of quality of life issues that were very important to him. He told me when he could no longer carry them out he wanted to die. One was dining out three times a week. Another was never repeating a meal in a certain amount of days (from the armed services I am sure). He revised the list several times, and his last revision included no more hospital stays. He had his crossword puzzles on the list and food was always a big list item. Over that last year we found the list dwindling. I remember how sad Steve and I were when we saw his daily crosswords no longer being filled out and looking like a child had done them. We were frightened and felt very alone. Our friends and relatives, although kind, just did not understand what we were going through.

When he started having very bad dialysis sessions, we knew that his days or weeks were numbered. The doctors urged hospice, but we were told that hospice (Medicare) did not cover dialysis, so that was not on our list of options. We just could not watch him bloat up and die (we had been told that was what would happen).

On Sunday September 23rd he stayed in bed all day with Steve and I taking turns checking on him. I strongly suspected he had another pleural effusion which would require a visit to the doctor and likely the hospital. The doctor told me if I called him about unc I had to bring him in so he could be treated. I was so torn. I risked going against unc's wishes, and yet I knew I had to do something. I sat in our family room playing out the different scenarios in my mind....hospital, hospice, unc's happiness...never had I been given such a horrible decision to make...when...that night...

We took turns checking up on him since he did not feel well that weekend. He had another difficult dialysis session and his appetite was not too good. When it was Steve's turn to check...about 8pm.he did so and then walked up to where I was sitting on the couch and said, "Muriel, he is gone. "....Unc took the situation out of our handsor God..depends how you look at it, I guess. We were so grateful to them both.

Although it was over for unc it was not so for us. I was sad, depressed and loaded with guilt. I had the shoulda woulda coulda syndrome in spades. Steve kept trying to boost my spirits. Gifts and trips were not working. Yes, time does make it better and time did help...but...Now, 15 years later, it still sneaks up on me, that shoulda woulda coulda guilt thing.

We started the ASG; it grew, and became a passion. We still own our company and I do show up every day, but I can be found updating the website, planning meetings, facilitating some of them, posting EBlasts, moderating our Facebook groups, answering hot line calls and responding to emails. We have wonderful volunteers that help to facilitate the meetings in more than 29 cities, as well as other duties such as liaise with Washington and other organizations.

Many would say, and do, that I should be absolved by now, and I wish I could say that I feel that way. I do feel better, and wallow in the good that we have done, yet those who have walked the walk of caregiver for amyloidosis, understand better than anyone else, that the only thing that will truly erase any negative feelings I have, is not to see anyone, ever again, have to walk the walk of amyloidosis caregiver.