

**Widow-in-Waiting**  
**Everyone's Story is Unique—Here's mine**  
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**January, 2015**

I was introduced to my husband the week of the Cuban Missile Crisis. One month later we were engaged and six months later we were married. I loved his principles--to work for social good rather than money. I also loved the fact that in 1963 he was a feminist. After we were married, I announced I would stop working to take care of the children. Steve knew how much I was committed to my field and he would not hear of it. He said, "We will figure this out and share responsibilities." He has made my life wonderful. I respect and love this brilliant man. We have had a wonderful life.

The Beginning of the End

Six years ago, I received a call to come to the George Washington hospital emergency room as my husband had fallen down the 188-foot long Dupont Circle subway escalator. It was a miracle that he did not break any bones nor injure anyone else. It took the doctors over 5 hours to stitch him up.

That was the beginning of the gradual six-year decline. First, he used a cane, then a walker, and finally a wheel chair. He had numerous surgeries—pace maker, hip replacement, knee replacement, heart by-pass and other minor surgeries. Then he had a major fever with a high white blood count but was saved by massive doses of antibiotics. Our children came immediately as the doctors did not expect him to survive. A month later he had emergency surgery on an incarcerated hernia. Once again, the children came for his expected death.

After that hospitalization, his doctors suggested no more surgery. We were admitted into Hospice at home.

What It Means to Have One's Life On Hold

Somewhere during this 6 or 7-year stretch, and most especially during the time since Steve had been in hospice, I began to see myself as a widow-in-waiting. My life revolved around his health, his care.

The implications of this are enormous. My life on hold is filled with cancellations, contradictions, conflict, and coping.

Cancellations. I canceled a business trip to South Dakota because, at that time, Steve was actively dying. Then I cancelled my trip to Las Vegas to help my close friend celebrate her big birthday because Steve was having emergency palliative hernia surgery. Then my close, close friend died. I wanted to go to her funeral but stayed home instead.

I discussed these cancellations with my friend Stephanie whose husband is ill. I found I was not alone. Stephanie had just canceled her trip to New York because of her

husband's 5<sup>th</sup> hospitalization this year. And we discussed that we are continually cancel theatre, lunch and dinner dates. Stephanie has almost \$1000 worth of unused Air Tran tickets. We each think things are stabilizing and boom, a fever goes over the top, someone falls, or a more dramatic event occurs.

For many widows-in-waiting, life is suspended. Several years ago, we put our apartment on the market and placed a deposit on an apartment in a retirement community, thinking it would be good for Steve to be in a protected environment with activities on the premise. Two weeks after the realtor began marketing our apartment, we found that Steve was internally bleeding. I panicked, cancelled the apartment in the retirement community and took our apartment off the market—much to the realtor's dismay.

Life is filled with Contradictions. My husband was very frail, he had dementia, and his quality of life had diminished. He knew me and the children and is well aware of his surroundings. He needed round the clock care because he was too heavy for me to care for and he could no longer take care of his daily living.

I was constantly experiencing opposing emotions. I wanted him to live; I wanted him to die; I wanted to be with him all the time, I wanted to be out doing things; I wanted time to stand still, I wanted time to fast forward so I could figure out what I wanted to do with whatever time I have. I needed knee surgery since I was in pain, but I didn't want to have surgery that could make me immobile.

And Conflict is Right Around the Corner. My husband was in Hospice at home, but he was no longer actively dying. Hospice means that he will not undergo further surgery or treatments. His care will be palliative. That sounds clear-cut but can lead to conflicts. First of all, he wanted more surgeries in order to get better. Our son argued that his father's voice should be heard. I loved that our son was fighting for his father even though I was now in the position of opposing both my husband and son. Why not let my husband decide for himself? Unfortunately, the social worker in a rehab center and in Hospice determined that he has dementia and is unable to make wise medical decisions.

An aside: I need to add that so many caregivers report conflicts between at least one other member of the family who sees the situation differently than the main caregiver. It is difficult to stand up to other members of the family—difficult because you feel so vulnerable and unsure about what to do.

At one point, my husband had such pain, but otherwise was not deteriorating. I got permission from Hospice to take him to his urologist and his hernia specialist hoping that they could tell me how to make him more comfortable without surgery. The hernia specialist advised a second palliative surgery. Then came the big decision. I felt so alone. I knew if I opted for surgery, he would have to leave Hospice. I had been so definite about no more surgery, even fighting about it. I made an appointment with his long-term doctor to discuss the dilemma and, to my amazement, he changed course. He felt that palliative surgery to relieve him of pain would be a good idea since he had not died as expected. As long as his doctor felt that way, I went along with it. He had the surgery and was home in a day, in great pain.

I was scared. Would we get back in Hospice? Would they take us back? I remembered worrying about my children getting admitted into the right college, but I never thought I would be trying to pull strings to get us back into Hospice. Luckily, my husband's doctor gave an order for readmission. A nurse came to see if he was qualified. She told me that they had been considering having him leave Hospice since he was not deteriorating. But the new nurse told me right away that he would be eligible. What relief!

How I Coped. At first my coping was dysfunctional. I had two car accidents. The latest was when I was rushing home and drove into the bus station and ripped a city sign right out of its concrete. I had to go to traffic school, pay an enormous fee, and see my insurance premium raised. The good news is that I have not hurt anyone—just my car. This served as a wake-up call: I was not coping well.

I asked Stephanie how she coped. Easy she said. "I've moved from one scotch to two scotches a night." We both realize that our husbands are dying—well, maybe not dying—but moving toward the end of life. How can we possibly laugh! We had to laugh or we'd be sobbing all the time because we loved our husbands.

One night Stephanie woke up and did not hear her husband breathing. Scared, she ran around the bed to hear him better, tripping over his walker and landing on top of him. That woke him up and they ended up laughing.

I have been able to cope with this up-in-the-air time of life because of family and friends. Our adult children, their spouses and children have been a lifesaver to us both. They visit, they call, they care. And friends have been such a source of comfort. They invite me over, or to go out, or visit. In addition, I plan 3-day trips each month. Steve asks, why are you going away. I tell him the truth—caregivers have to get away. He temporarily understands and always says, "Have a wonderful time".

Fortunately, I had a wonderful team of caregivers. I have a friend who runs an agency and she selected perfect people to work with us. They love Steve because he expresses his appreciation for all that they do. He always thanks me for all I do and tells me how much he loves me.

Where does that leave all of us whose lives are on hold?

Transitions waiting to happen include uncertainty, ambiguity, and loss of control. Although my future is uncertain and ambiguous, I spend time thinking about life without my husband. Will I stay in our apartment? Will I downsize? Will I move back to Washington, DC? Am I spending too much time on the future? I was helped by remembering the work of Bernice Neugarten, my mentor and one of the first to study adult development and aging. She found that women engage in what she called "rehearsing for widowhood." I am doing just that. My friend Ruth Lee is also doing that. Her husband had major heart surgery and during that period she fell apart. He is well now but she is voraciously reading everything she can on widowhood. She learned that people survive what they thought would be impossible to survive.

It helps to talk to others in the same boat. Books can also help. I felt as if I were reading my story when I read Gail Sheehy's *Passages in Caregiving: Turning Chaos Into Confidence*. Her identification of "The In-Between Stage" including the complicated emotions and decisions she had to make, resonated with me. It is what I was experiencing.

I rehearsed by comparing notes, discussing what is not discussible with Stephanie, and building humor into my life. It was not an easy transition—there are no end points in sight, yet it is a transition that many men and women face. It's good to share your stories and find others whose lives are on hold.

I looked at my husband one night, struggling to breathe and struggling to stay alive. He wanted to stay alive to help me. I count my blessings—to have had a special husband who worked to make a difference in the world, who fought for workers rights and civil rights, and who always showed his love for me. I wonder if that will comfort me when he is gone.

### The Postscript

Well the inevitable happened. My husband died. At the time of his death, I had emergency back surgery followed six weeks later with a hip replacement. In fact, I was in the rehab center when he died. Fortunately my son and daughter-in-law were with him every minute during his last days, and, of course our daughter had been flying down regularly. Strangely, my being ill was a blessing. Sociologist Gunhild Hagestad described her illness as a period when she was "out-of-time," a period no longer connected to the daily routines of life. Being "out-of-time" provided a protected period to grieve. I moved back into time gradually—first with care at home, lots of physical therapy and determination to walk again.

Five months after his death, we had a memorial in Washington, DC. to celebrate his life. I was no longer a widow-in-waiting, or someone with medical problems. I was becoming the optimistic person I had always been, now carving out a new life strengthened by almost fifty years in a marriage filled with love, romance, excitement. I was, I am, ready to move on."