



Memories of my Father

by Jeannette Busse

My father James Busse was diagnosed with Alzheimer's disease in February 2017 at the age of 88 years. I was able to secure long term care for him at the Oregon Veterans Home in Lebanon where he resided in the memory care facility for the remainder of his life. He passed away at the age of 91, on December 9, 2020, surrounded by family.

The objective of this article is to share key lessons I learned while overseeing the care of my father for 3+ years during his battle with Alzheimer's disease.

1) **Maintain Continued Connection with the Church**

My parents, Jim and Helen Busse were married for over 51 years and resided in Lebanon, Oregon where I was born and raised. Our family were longtime members of the St. Edward parish and my parents were actively involved in supporting the parish where my mother taught CCD and provided administrative support. My father served as an usher, volunteered at St. Vincent de Paul, and was an active member of the Knights of Columbus. My mother passed away in 2003 when my father was 74 years old.

My father's Catholic faith was a strong stable thread woven throughout the fabric of his life. During his long-term care at the Veterans Home, our family continued to take him to Saturday or Sunday Mass at St. Edward Church while he was mobile and we could still transport him safely. Even though his memory declined significantly, he could still sing the songs and recite prayers and responses during the Mass. In addition, Deacon Richard Triska would visit him weekly to read to him the Holy Scriptures and provide Holy Communion. My father was always able to recite The Lord's Prayer during these visits even when he could no longer hold a conversation. When I informed the Deacon of my father's declining health and that he was entering into hospice care, he arranged for Fr. Peter O'Brien to administer the Anointing of the Sick. On the final day of his life, as I arrived at the Veteran's Home and was informed of his dire situation, I started to call Fr. Peter for last rites. A nurse came out and surprised me by letting me know that Fr. Peter was already in my father's room waiting for me. A medic who worked at the Veterans Home and is a local parishioner recognized my father from when we took him to Mass and called for Fr. Peter. It was incredible to see my father being served by the

parish community at the most vulnerable time of his life. Our family will be forever grateful for their support.

2) Frequent Family Visits are extremely important

So many times I heard from various healthcare staff that many families would stop visiting their family member afflicted with Alzheimer's because the visit wouldn't be remembered anyway, so why visit, etc? In my father's case, frequent family visits made an incredible difference in his health and wellbeing. Holding his hand, reading stories, looking at picture books and family photo albums, helping him with exercises, eating a meal together, taking him for a drive, or spending time outdoors for fresh air, and just being there was so good for him and for me, too. There was so much that was going on with him that was out of my control, yet my time and attention were under my control. Even when it came to the point where he couldn't remember my name, the frequent interaction kept his mind active, and his doctor encouraged my family to continue to be active in his life at the Veterans Home. The staff at the Veterans Home welcomed family participation and became an extended family to me.

3) Partner with the Healthcare Staff and work as a team

I worked closely with my father's doctor and the care staff by participating in all of his medical appointments. They helped me in so many ways to navigate the complex healthcare system. When my father fell and broke his hip, the ER doctor wanted to know if the family wanted to have his hip repaired?!! He was expected to survive the surgery, so wouldn't it be inhumane not to have him rehabilitated? The hospitalist gave him 6 months to live and recommended putting him into hospice immediately after leaving the hospital. His cardiologist told me that he had months, if not only weeks, to live. I was also told that there was a high probability that he would walk again. It was confusing and frustrating to be given all kinds of timelines on the duration of his life. A wise nurse told me, "My patients never fail to remind me that they are on their own timeline."

When my father returned to the Veterans Home after his surgery, I scheduled a meeting with his doctor and the Residential Care Manager (RCM) to walk through all the options for his post-surgery care. We came up with a plan to put my father into physical therapy and start palliative care to combat his congestive heart failure (CHF). Having a good working relationship with the healthcare staff was crucial to developing a plan that fit my father's needs. My father was able to walk again after a few weeks of physical therapy, and palliative care kept his CHF at bay. He lived an additional 18 months. I had to learn to be a strong advocate for my father by asking lots of questions, and I kept asking until I understood all the options to make a good decision. I took good notes during the discussions and wrote down questions when they would arise for follow up.

4) Hospice does not mean giving up hope

As my father's heart became weaker, and his CHF was more acute and less responsive to medications, I again met with his doctor and the RCM to discuss next steps. Hospice was determined to be the best solution for his continued care because heart surgery was no longer a good option because of his frailty. The Veterans Home already had a

good working relationship with a particular hospice provider, so I met with them a couple of times to understand their program before deciding to begin hospice care for my father. What I learned is that hospice care does not mean you're giving up hope for your loved one; you are providing them with an extra level of care that not only helps your loved one, but also assists the healthcare staff and has benefits for family members. Hospice does not extend life or hasten death. The goal of hospice is for comfort and quality of life instead of aggressive treatment. Hospice also provides support for family members with counseling, bereavement care and spiritual support. My father was able to remain in his room at the Veterans Home (the place he called home) for the remainder of his life. What you do not get with hospice is physical therapy or other rehabilitation services or 911 calls to transport to emergency room. The hospice provider for my father had a 12-bed hospital available to handle severe pain management if required.

There is so much more to information to relay about my father's battle with this horrible disease. If there was one song that could summarize my emotional journey with my father's battle with Alzheimer's, it would be "Blank Stares" by Jay Allen. The song still brings tears to my eyes.

<https://m.youtube.com/watch?v=PxEOWhspwEA&feature=youtu.be>

For more info on the Oregon Veterans Home in Lebanon that provides residential long term-care and short-term rehabilitation/physical therapy services for veterans and their spouse, check out the following link:

<https://www.oregon.gov/ODVA/Vets-Homes/Lebanon/Pages/default.aspx>

As a last note, before my father stopped talking, my sister Cynthia bought recordable books available from Amazon to have his voice recorded. She gave them to family members as gifts. Even to this day, months after he has gone, I can hear his voice telling me how much he loves me, from the book, "All The Ways I Love You," by Theresa Trinder.

I love you quicker than a minute. I love you longer than an hour.
I love you like the honeybee loves buzzing round a flower.
I love you stronger than the wind. I love you softer than a cloud.
I love when you are quiet, and I love when you are loud.
I love you closer than your shadow. I love you farther than the sun.
I love you, too, when raindrops fall one by one by one.
I love you round and round the world. I love you through and through.
And when it seems impossible to love you more . . . I do.