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My wife, Debby, died on November 2, 2020. She was 69 years old. The cause of her death was a relatively uncommon form of dementia known as fronto-temporal dementia (FTD). I can track early signs of her decline as far back as 2015, but in 2017 it became unavoidably obvious that something was seriously wrong. Her speech started to fragment. Her ability to commit ideas to paper and her penmanship began to fall apart (She taught composition throughout her 34 year career.) After an MRI and several days of diagnostic testing a neurologist, said he believed Debby had developed a severe but remediable speech disorder which would diminish in a few months. He recommended intensive speech therapy which was unproductive and frustrating for her. Finally, another physician, a dementia specialist recommended a PET scan which showed definitively the parts of her brain which were essentially dying, how much they had already declined, and led to the FTD diagnosis.

One characteristic of FTD is that its victims become extremely agitated, sometime violently. Three different physicians advised me to place her as soon as possible in a residential care facility which I was able to do in a matter of a few months. Although she had long term care insurance we quickly discovered that the cost of her care was greater than we could afford to pay for that first facility. I had to locate a less expensive facility and found one that was 55 miles from our home. Later, when Debby later fell and broke her hip I knew I could turn to the palliative care team for guidance and support.

Early on the palliative care team was able to work with Debby and me and help us understand what to anticipate. Later, because of Debby's rapid cognitive decline there was little palliative care could do for her. However, they were a tremendous help to me throughout those terribly difficult years. Without the guidance and insight provide by palliative care I don't know that I could have survived the multitude of shocks and obstacles I encountered during her illness. Too often people think of palliative care as a service provided only for patients. However, as my wife's principal care giver I was involved in a stressful sometimes physically painful, personal struggle I never imagined I'd experience. For the help, concern and guidance provided for me, I am forever grateful. Please remember that palliative care serves not only the patient; it sustains survivors too.

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