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The Final Act of Love

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After my husband, Mark, was diagnosed with young-onset dementia, it became very important to him to make his advanced care plan and end of life wishes known. Initially, we both reviewed and reconsidered our previous appointments of power of attorney for finances and our health care advocates. Wow! It was so much different this time than when we had previously made these appointments. A diagnosis of dementia changed the decision from a hypothetical need in the distant future to a real need in the near future.

After the legal work was completed, Mark and I met with a counselor to talk about potential future care needs and how we would meet them. We began by discussing care in our home. We also discussed under what circumstances, if any, Mark would consider supports and services outside of our home. While Mark indicated that he hopes to have his care needs met at home, he made it very clear he does not want to be a *burden* and is very concerned about the *quality of life* for his family. Therefore, he is willing to receive care outside of the home when his family determines it is necessary for our wellbeing. Since arriving at this decision, our entire family (children, their spouses, and grandchildren) have visited and are monitoring residential options to determine which setting, if needed, will allow Mark to shine.

Our discussion regarding end of life care was the most difficult for me. Early after Mark's diagnosis, he signed a Do Not Resuscitate Order. It was his belief and mine that a death from another illness or accident resulting in death would be preferable to the end states of dementia. Again, we spoke with our counselor as well as our pastor and physician. We even attended seminars related to end of life and spirituality. Mark's end of life wishes are much different than my wishes for him. Initially, I listened to his thoughts and wishes, but thought to myself (ashamedly) that I would ultimately do what I wanted regarding his care. After all, how would he know? Since Mark's wishes could possibly end his life earlier rather than later, I asked him to speak privately with our counselor, pastor, and physician. I wanted each of them to know that Mark's decision was not a result of any pressure on my part (in fact, it was the opposite). Ultimately, Mark's end of life desires have remained the same and I am proud to report I am the one who has changed. I now recognize that Mark's end life wishes are his own and I have decided I will honor them. As difficult as it will be when the time comes, honoring Mark's wishes will be my final act of love for him.