

From the Chair: Focused on Love

by Kay Johnson, MCDES Chair

“Love is our essential nutrient. Without it, life has little meaning. It’s the best thing we have to give and the most valuable thing we receive.

It’s worthy of all the bullabuloo.”

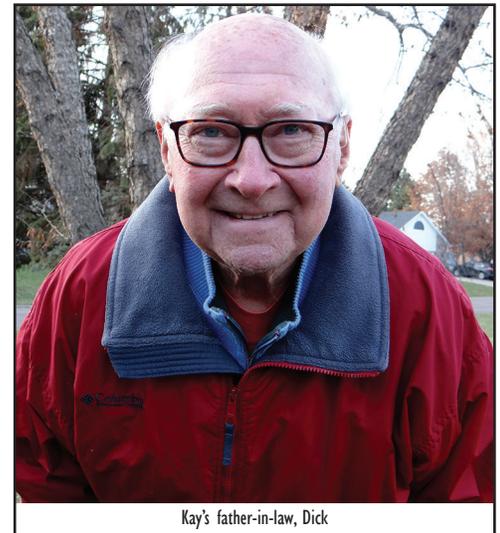
~ Cheryl Strayed

Dick is an 82-year-old man, in good physical health, a kind soul, a fun-loving guy, a mechanical engineer who retired after a successful career, a great provider for his family, a gadget guy, a survivor of child loss (16-year-old son) and a loving family man. I have been so fortunate to call him my father-in-law for the past 31 years. This sweet man was diagnosed with Alzheimer’s approximately 9 years ago and is now a part of the 5.8 million Americans experiencing the gradual deterioration of a lifetime’s worth of wisdom, experience and personal relationships. Overall, I would say that Dick and our family slipped into acceptance of his slow descent into memory loss and confusion. The grief has been present, real and raw throughout the years.

Dick and Ginny just recognized 59 years of marriage and continue to live

together in their own home, despite the increased demanding caregiver challenges. They have one surviving son, daughter-in-law, and three grandchildren. Time together throughout the years as a family of seven included: countless meals together, bleacher time cheering on soccer/football/volleyball/baseball/softball/gymnastics, holiday and special occasion celebrations. We are a small family but one that only knows our time together as one unit.

Due to Dick’s illness, we have gotten used to: not being able to have a conversation or even understand what he means when putting a few words together, monitoring his whereabouts when he decides to stand up and walk away, not being recognized by name, answering his never-ending pointing to the TV and question of “Do you know him/her?,” interpreting what he needs/



Kay's father-in-law, Dick

wants and trying to stay ahead of that, monitoring him in public as he doesn’t seem to have a filter or inhibition controls any longer, and assisting him at restaurants. My husband has lovingly taken on the responsibility of caring for his dad every Saturday at our home along with stopping at their home during the week nights. The expectations of our ability to assist both Dick and Ginny have been unrealistic and yet we continue to be committed to contribute while knowing we are falling short.

My healthcare experience has exposed me to patients at varying stages of dementia, and their families attempting to cope with the endless list of losses. Family members working to maintain their loved one’s dignity, independence and also honor their wishes often related to remaining in their own homes. Family members who become physically and emotionally exhausted meeting all of life’s responsibilities, advocating for their loved one, navigating the healthcare system, attempting to stay afloat with the financial drain of illness, and making the necessary decisions about the type of care needed. I realize all of that and yet, nothing



Kay's family

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prepares you for your own story of a loved one with a chronic disease. So many variables to navigate.

At this point in time, Dick is attending adult daycare during the week and spending Saturday at our home. I have never heard my husband complain about his caregiving duties and giving up one of his precious weekend days. We've had a lot and I would even say, "too much caregiving experience" after having cared for both of my parents as well. We know the road ahead will become even more difficult to travel. The history of Alzheimer's disease has been defined by heartbreak and loss, courage and perseverance. We have found that to be true with our family's story. Alz-

heimer's will not defeat us. We take one moment at a time and we use humor a lot. One of my favorite moments was when Dick was asked who I was and he responded, "the good one." Believe you me, I have gotten a lot of mileage out of that response.

Gratitude is an important part of my life and it is present even during difficult times like this. These caregiving experiences have provided the gift of allowing us to feel that we made a positive difference in how our parents lived and died. Alzheimer's is a thief, stealing everything it can and yet what it cannot take from us, is our love. Dick is not the person that he was, but he is still our person. We are grateful that his personality and sweet demeanor has not changed. The

Johnson family has responded with the purest and deepest form of love imaginable for our beloved dad, father-in-law and grandfather.



Kay, "The Good One," and Dick enjoying "forbidden" sodas.