

# Dance of Loss

Longing for the life shared before a husband's dementia

BY GINNIE HORST BURKHOLDER

It is a May morning as I listen to Anne Murray sing “Could I have this dance for the rest of my life?” I once knew that sentiment for my husband. I miss the vibrant person who invited that feeling, and I miss the dance.

I do my exercises with the sun on my back, sitting in front of an east window. Finished, I stare at the wallpaper. I am back in time when it was hung by my husband, who always said he could do anything. The match is off on this wall. Was this the beginning of this cannibalistic disease or just one of those mistakes anyone can make?

I look at two more walls. One matches perfectly. Another waited years for the papering job to be completed. He had lost interest. Or was it the disease again? I am flooded with memories of life before the onset of this progressive dementia caused by brain abnormalities called Lewy bodies. I marvel at all we managed to enjoy before his diagnosis nine years ago at the age of 51.

People say you have your good memories. It is true. I remember that once he knew my birthday, knew I didn't want sugar on my cereal, knew I needed a backrub, tossed me a wink. But the longing for what was eats at me, and I cannot stay there. The memories are stark reminders of what should have been. Like a bird with nowhere to land, my thoughts avoid the past and the certain deterioration in the future and, instead, alight unwillingly in what we have, the present.

Nelson still remembers my name, but he doesn't remember me. Usually. Last night, he couldn't say my name. He resorted to “Amy's mom.” I hurt for him, provided my name, and said, “I'm here. What do you need?”

I'm calm, compassionate, but inside, like a leaky faucet, sadness drips from a never-ending spigot of loss.

The loss and longing are everywhere. It is there at lunch in an innocent conversation with my sister about water softeners when I ask how much salt they go

through. She doesn't know; her husband takes care of that. The longing for someone to be the live-in handler of such responsibilities explodes like a fire burst inside of me. I cannot escape that I alone am the manager for this household.

Another lunch, and another sister is having her neck rubbed by her husband. She says it feels so good she doesn't want to move. I feel the stiffness in my own neck and shoulders, and know the futile longing for Nelson to be able to do what he once would have done willingly and easily. Lewy body disease has made his motions stiff and wooden.

Reminders are all around me. Couples our age are traveling. “We take turns driving.” It is like the carrot that should have been ours has gone to everyone else.

This morning I say to him, “Eat something and take your pills.”

“You played a trick on me,” he answers. “There is nothing in there.”

I tilt the pills from the container into his hand and assure him there is. I no longer bother to wonder why or how he can do what he does.

His offering of love to me is the morning

kiss goodbye at the beginning of the day as he goes out the door to his adult daycare or the things he made as he comes back home later that afternoon. There is a snowman made from fuzzy little puffballs, a small painted wooden horse, or a card with some painting on it. He brings them proudly and we put them on display.

I long for him to anticipate my need and bring me unexpected love offerings. But the blinds this disease has pulled over his vibrancy are opened for only brief moments. “You are my queen for the day,” he says, as I tuck him in for the night. In those moments, I know his love remains even though the dance is gone, replaced by wooden feet, confusion, this always unpredictable disease, and so much longing for what could have been. **NN**

