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One sister's gift was memories to last the years

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By Andrea Brown Herald Writer

As kids, Sue and Sylvia Johnson had a storybook sisterhood.

They played with dolls and put on shows. They'd get to giggling over silly stuff and couldn't stop.

Sue was the big sister, 15 months older: the choreographer, the instigator, the go-to girl.

She made everything fun. She sang loud and off-key. It was part of her charm.

“Sue was creative and I was practical,” Sylvia said. “She was Carol Burnett and I was Mary Tyler Moore.”

Sylvia didn't mind being in the shadows of her sparkplug sister. It was where she belonged.

But life has its own plans.

Sue got severe rheumatic fever in her early teens.

“She was in the hospital recovering, and I just thought she was going to die,” Sylvia said. “She had to be in bed all summer when I’m outside playing.”

Sue started having seizures. She was labeled “different.”

“I’d always have the guilty feeling I didn’t want to be around her. I was embarrassed,” Sylvia said. “She’d kind of freak out. She didn’t have a lot of friends and didn’t go to a lot of school activities. It got to be that she was the introvert. I became the popular one.”

Sylvia went to the university. Sue went to business school. She had problems, but she got by.

Then their dad was killed in 1966 when he tried to stop a robbery at a grocery store in their Minnesota hometown. And their younger brother disappeared, never to return.

Sue’s condition spiraled over the years.

Sylvia got married. Sue was committed to state hospitals.

“I think she tried suicide maybe 10 or 12 times. She had scars all over,” Sylvia said.

“Sue was unpredictable. She could fly off the handle or she could be as sweet as could be. I’d kind of be the mediator. My mom had to deal with her mood swings and craziness and make sure she had her medications.”

Sylvia moved to Washington state in 1982, raised four children and worked as an insurance adjustor.

Sue got married and divorced, wrote poetry and short stories, and painted.

“Her writings were often of a sad topic but contained humor, making one laugh and cry simultaneously,” Sylvia said.

Sue embraced with that wit a devastating diagnosis of amyotrophic lateral sclerosis, also known as Lou Gehrig’s disease, in the 1990s. The disease of the nerve cells causes degenerative muscle weakness. There is no cure.

“She said once she had this terminal disease she didn’t have to try to kill herself anymore,” Sylvia said. “It’s sad, but it’s funny. Do you laugh or do you cry?”

By then, Sue had moved to Washington, where other family members had migrated. She was determined to handle each debilitating phase of ALS, adapting from cane, to walker, to wheelchair.

“There were times of total frustration and times when she would just put on her widest grin as if all were OK in the world,” Sylvia said.

It’s that grin that Sylvia remembers often, and particularly around Christmas when she reads slips of paper written by her sister. Sue left to her mother and each of her siblings a jar with 52 slips of paper, each with a different memory of childhood.

Like the sister who couldn't sing but did anyway.

"It would be so embarrassing at church, especially at Christmas," Sylvia said.

"She loved Christmas carols. She'd just sing her heart out. We'd try to make her sing very quietly, but at the very end she was in her wheelchair at church, singing these Christmas carols loud and off-key and people were turning around ... and I just looked at them and smiled: It is what it is. You know, so what. So what if she's off key. Just let her sing."

Sue died in 2002.

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Sylvia Hustad's gift from her sister

What Sylvia Hustad, 66, of Edmonds wrote

"My sister (Sue) was in the last stages of ALS, and her only income came from welfare. However, she managed to give her two brothers, my mother, and me a gift that cost her nothing, but to us was priceless. We each received a jar that had 52 slips of paper in it that contained a childhood memory she had of that person. She instructed us we could only read one of the papers per week, thus our gift would last a year. Some of the memories were quite funny, some profound and tender. My jar comes out every Christmas and it is still the most cherished gift I have ever received."

Samples of slips in the jar written by Sue for Sylvia:

"I remember we had to sit on the floor by the bathroom when we played the card game 'Spit' because you made me giggle so hard I would have to pee."

“I remember you went to kindergarten class with me, but mom made you stop because the teacher said the other kids were bringing their sisters and brothers.”

“I remember we read all the Nancy Drew books and how we hated her because she was so perfect.”

“I remember you cried on a hot July day when I was sick and I begged you to put extra blankets on me because I was so chilled.”

“I remember we had to wear our Mousketeer ears when we watched the ‘Mickey Mouse Club’ at 5 p.m. every day.”

“I remember when Alice explained to you and me about sex. She said it’s the same way dogs do it by getting on top of each other. I think we both had a hard time understanding it that way.”

“I remember when you heard Santa Claus on the roof. I wanted to tell you there were only squirrels. It was the first Christmas I knew there was no Santa Claus, but Mom made me promise not to tell you.”

