

# The Hardest Test: Matriarch guides Tucson family ravaged by early-onset Alzheimer's

Feb 13, 2016

by Stephanie Innes / Tucson.com

Mamta Popat / Arizona Daily Star / Photos



In a life filled with loss, Mary Kay Bush appreciates her many gifts. Here she gets a kiss from daughter Cheryl Minarik Baril during a weekly game of Rummy Cubes at Immanuel Presbyterian Church, 9252 E. 22<sup>nd</sup> St.

"I had wonderful kids and I'm glad I had them. I don't regret anything," she said. "I'd do it again in a heartbeat."

Not that she doesn't feel the pain. Since 1988, she has nursed six of the people she held most dear — her first husband, her second husband, both her parents and two of her three children — as they died. Her husband's side of the family has a genetic mutation that causes early-onset familial Alzheimer's, and the offspring of someone with the mutation has a 50 percent chance of inheriting it. Family members who inherit the mutation are virtually assured to develop the disease.

Caring for a loved one is heart-wrenching and unrelenting work, but Mary Kay has been able to strike what experts say is a crucial balance — caring for others while also taking care of herself. She does it by staying practical and tackling problems as they come.

"I don't look for trouble," she said. "There's no reason to freak out. If you worry, it puts the brakes on what you can do."

Even when it comes to the early-onset familial Alzheimer's that has ravaged her first husband's side of the family, life is what it is.

"You take your chances and suck it up," she said. "I don't have a lot of patience with people who sit and sulk."

A Louisiana-born, Texas-raised mother, grandmother and great-grandmother, Mary Kay is the matriarch of an extended family that looks to her for leadership and strength.

Her spacious, tidy Tucson home is often abuzz with activity — her daughter **Cheryl Minarik Baril** and son-in-law **Mark Baril** spend a lot of time there, and she frequently babysits her three great-grandchildren.

She thinks nothing of having 35 people from Immanuel Presbyterian Church on Tucson's east side over for dinner. Every Tuesday morning she goes to a social at church, and before it starts she is usually in the church kitchen baking sweets and sometimes cooking lunch for the 30 to 40 older church members who gather to socialize and play games like bridge and rummy cubes.

"She would say she's not a leader, but she certainly has the leadership role," said fellow parishioner and best friend **Cheryl Wood**, who has known Mary Kay for more than 30 years.

"If someone is in need, she is always willing to help. There is a woman in a wheelchair and Mary Kay picks her up for choir practice. She knows how important it is for people to be out and to be together," Wood said.

Mary Kay hosted a fall meeting of her Presbyterian Church (U.S.A.) women's circle and organizes prayer chains via email. Many in the group need prayers — among them a woman whose grandson was just diagnosed with cerebral palsy and another whose son has cancer. On a break during the fall meeting, Mary Kay sought out each woman and gave her a hug.

Alzheimer's affects many in her extended group of friends and acquaintances. Mary Kay is considered an expert resource to all of them, someone who knows how to navigate the system and is an aggressive advocate for her loved ones.

Such traits are not in her nature, she insists, but are borne of necessity. When her husband, **Smith "Smitty" Minarik**, first became ill in the late 1970s, he stopped paying the family's bills and taxes. Mary Kay had to quickly learn how to take over.

"I didn't have a clue about finances. I didn't know how to pay property taxes," she said. "I had to learn." She hired an accountant, bought a filing cabinet and started organizing. She learned how to do the jobs that Smitty once did — fix a water pump on the swamp cooler, change a pipe, trim the hedges, mow the lawn. When she needed to hire someone to do work, she made sure it was done correctly and economically.

On at least one occasion she climbed her mesquite tree to show the tree trimmer exactly what she wanted done.

"People think I'm anal about records. I am, but I had to be," she said.

Mary Kay worked as a health clerk at Dunham Elementary School for years — she still has breakfast each week with friends from that time. After Smitty got sick, she turned her attention to operating a strip mall the family had inherited from Smitty's father, selling real estate he'd left them and investing the money.

"The money saved our bacon as far as Smitty was concerned. It put our kids through college — all things we couldn't do on teachers' salaries," she said.

When Smitty started displaying odd behaviors, Mary Kay tried everything she could think of to fix whatever was wrong — laying on of hands, anointing with oil, consulting with medical experts. For a long time she blamed herself because she thought Smitty must be unhappy with their marriage. "I was sitting on a stool crying. Was my lack of faith preventing a miracle? Then you let it go. You eat yourself up if you don't."

### **"ASK MARY KAY"**

An oft-repeated phrase in the Minarik and Baril families is, "Ask Mary Kay."

"Her tenacity is unequivocally her best trait," said her grandson **Kyle Baril**, 29. "She is everything a matriarch should be — demanding in the most loving way possible and completely selfless on a daily basis.

"Everyone trusts her. That's who you go to if you need help."

When her daughter-in-law **Sheryl Stephens Minarik** suspected something was wrong with her husband, Mary Kay's son **Steve Minarik**, the first person she called was her mother-in-law.

On another occasion, Steve, in the early stages of Alzheimer's disease, got sick with a stomach virus during a family vacation to Rocky Point in Mexico. Sheryl packed up the family and drove directly to Mary Kay's east-side home. Once there, she broke down and began to panic about the future. How was she going to do this? At the time, her husband had diarrhea but did not have the faculties to make it to the bathroom in time. She had two young sons to take care of, too, and was overwhelmed.

"It was so stressful," Sheryl recalled. "Mary Kay looked at me and said, 'OK, what are your options?' "Thank goodness for Mary Kay, who not only had to go through it, but support me through it," Sheryl said. "I love her to pieces. I am so lucky."

When Steve died in July, Mary Kay planned his funeral. She was an expert at it by then — she had planned the final services for Steve's sister, both her husbands and both her parents.

## CAREGIVING BALANCE

Mary Kay is the healthiest kind of caregiver, able to make sure everyone is taken care of without neglecting her own needs, said **Kelly Raach**, regional director of the Desert Southwest chapter of the Alzheimer's Association.

Raach met the family six years ago when she worked at Pacifica, the Tucson facility where Mary Kay's middle child, **Beth Minarik**, spent several years before she died in 2014.

"I have never seen Mary Kay panic," Raach said. "I don't know what she does behind closed doors, but she had the type of personality where she says, 'OK, what are we going to do?' She focuses on the solution.

"Since there is no way to stop Alzheimer's, you can continue supporting yourself and provide the best care possible to the person who has Alzheimer's. She's been able to do that."

After Beth was diagnosed it was inconceivable that any of her other children would be affected, too. Ever practical, Mary Kay made plans just in case.

She got long-term-care insurance for Steve and Sheryl before Steve got sick, a move that ultimately covered a significant portion of his expenses when he was living at Pacifica. She tried to help Cheryl and Mark do the same, but Cheryl was denied because of her rheumatoid arthritis.

In filing cabinets in her den, she still has medical records for Beth and Smitty, beginning with diagnosis and continuing through all their medications and doctors visits.

"You cannot stop that woman. To have gone through all the stuff she's gone through and still have a fairly good outlook on life — boy, that speaks to the human spirit," said Dr. **Geoffrey L. Ahern**, a neurologist at Banner-University Medical Center Tucson who has treated all three of Mary Kay's children.

## THE MAN ON THE ROOF

Mary Kay, whose father was a minister, isn't big on memorizing passages of the Bible. But she has a favorite story that's often told in church.

A man is stuck on his rooftop in a flood, praying to God for help. Someone rows up and offers to help, then someone in a motorboat does the same. But the man on the rooftop sends them both away, saying he is waiting for God to save him.

The man drowns. And when he gets to heaven, he asks why God did nothing to save him. "I did," God tells him. "I sent two boats."

That perfectly sums up Mary Kay's philosophy.

"God doesn't promise you not to have rough times," she said. "The only promise is that he's there with you. People around you are God's hands and feet. If you get so involved in self pity, you can't see anything."

After an Immanuel Presbyterian service last fall, she commented that she particularly liked the Rev. **John Tittle's** sermon about the need for good works to make faith viable.

The day before, she'd shown up with her tools at a site where a Habitat for Humanity house was being built, but it turned out they had more labor than they needed. So she brought some fellow parishioners back to the church and they cleaned the grounds for six hours.

Her friend Cheryl Wood's late husband, the Rev. **Fred Wood**, introduced Mary Kay to her second husband, dentist **Austin Bush**. They were married for 13 years before Bush died of a brain tumor in 2003. Mary Kay says she has had two wonderful marriages and is grateful for her husbands. Not everyone gets such gifts, she said.

"Mary Kay has a very deep faith and you never hear her complaining. It is what it is," Cheryl Wood said. "We've laughed a lot together and we have cried a lot." The two are planning a trip to Budapest and Prague in the fall. Smitty's ancestors were from that part of the world, and Mary Kay wants to learn more about it.

That spirit, to keep going through whatever adversity she faces, impacts those around her.

"She is a person people migrate to. She has her finger on everyone in the church and knows their needs. She is a role model," said **Gale Griffin**, an Immanuel Presbyterian parishioner who counts Mary Kay as a friend.

"She's had her heartaches. But my philosophy is like hers — just because these people have died does not mean we should stop living life. We need to continue spreading joy."



Family portrait in 1985: Mary Kay Bush, right, and her late husband Smith Minarik with their three children, Cheryl, left, Steve and Beth. Steve died in July, Beth in 2014.



"Beth died from early Alzheimer's. So did her brother."

Family Photos Courtesy of Mary Kay Bush



Mary Kay, shown helping Ann Bayes get to church, “would say she’s not a leader, but she certainly has the leadership role,” says her best friend. The daughter of a minister, she isn’t big on memorizing Bible passages.



Every Tuesday since the 1980s, Mary Kay Bush has spent time socializing with friends over breakfast. “I don’t have a lot of patience with people who sit and sulk,” she says.



“Mary Kay Bush, whose faith has played an important part in dealing with the loss of her two husbands and two children, shares a laugh with Robin Staples before the start of Sunday service at Immanuel Presbyterian.”