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When Mom cares for adult daughter, Mother's Day carries new meaning

By Paul Aronsohn

It wasn't supposed to be this way. At age 72, my mother, Margot, should be enjoying her "golden" years. After all, she worked most of her life, raised four kids and survived three divorces. Mom's due a little rest and relaxation.

Conversely, at age 45, my sister Patti should be knee deep in the "busy" years. She should be working long hours, raising children and sharing life with a special someone.

But about 20 years ago, their lives ended up on a different path. In 1989, we learned that Patti had a devastating medical condition — one that still has not been effectively diagnosed.

Watching the progression of Patti's terrible disease has been heartbreaking. First, there was her need for a walking cane. Then the need for crutches. Then the need to leave her job ... the need for a wheelchair ... the need for anti-psychotic medications ... the need for a part-time nurse ... and the need for a feeding tube. And throughout this slow, steady, painful process, we have watched as Patti lost her ability to lead any semblance of a "normal" life.

My mother, however, has done far more than watch. She has been by Patti's side every step of this journey. And it is here — amidst what might appear to be a story of loss and hopelessness — where the beautiful story of Margot and Patti really begins. Granted, Mom's relationship with each of her four children has always been close, nurturing and filled with love. But family trauma is greeted differently by different parents. Some run. Some hide. Some ignore. And some, like our mother, step up to the plate in a big way.

In fact, Margot has become many things to Patti; most notably, her roommate, her caregiver and her best friend. At first, they moved to an apartment in our home state of New Jersey. They then moved to Virginia, near where I attended school. Then, they moved to Florida, where the warm weather is better for Patti's physical condition and for Mom's spiritual one.

Through it all, the two of them have become quite a team. They eat together. They watch *American Idol* together. They root for the Florida Marlins together. They laugh together, cry together, pray together. They even recorded the most heartwarming message on Patti's answering machine together — something made necessary by Patti's decreasing ability to speak.

And through it all, they have remained full of life-affirming spirit — which is contagious to all who meet them. Their smiles make others smile. Their laughs make others laugh. Their sense of optimism makes others believe, too.

But there is also pain. For Margot, there is the pain of seeing her child suffer — and feeling hopelessly unable to do anything meaningful about it. There are the tears she sheds, publicly in front of family and friends, and privately in the quiet loneliness of the night. There is the constant questioning of God, of life, and of a world in which someone so innocent, so precious could be made to suffer so much.

For Patti, there is the pain that comes with knowing she will never likely walk again, never likely feed herself again or never likely marry or have children. There are the tears she sheds — most of them publicly, because her disease makes it impossible for her to close the door or create the personal space that so many of us take for granted. There are the memories of a past life filled with jobs and softball games and boyfriends and dancing. There is the vulnerability, the insecurity and the fear of being at the complete mercy of others. And, of course, there is also the constant longing for an answer to the simple, yet painful question: "Why me?"

Fortunately, Margot and Patti are surrounded by a loving family, led by my brother, Robert, who has devoted so much of his life to alleviating their pain, and my sister Leslie, who lives alongside them and helps whenever possible. They are also surrounded by good friends, led by someone appropriately named Joy, who is at once a nurse practitioner and a living angel.

And fortunately, Margot and Patti are able to rely on some support from a federal government recognizing that many parents must care for their adult children — a phenomenon that is dramatically increasing due to the prevalence of life-span disorders, such as autism.

But let's be clear. At the end of the day, when all of us have gone home and gone about our own business, it's Margot and Patti and no one else. When Patti's hygiene needs attention before bedtime, it's Margot who rolls her daughter back and forth across the sheets and takes the needed steps. When Patti wants a nighttime snack, it's Margot who pours the Ensure shake into the feeding tube or spoon-feeds her some yogurt. And when Patti is watching TV, it's Margot who lays her aging body on the floor beside the bed and keeps her daughter company.

Again, it wasn't supposed to be this way. Margot and Patti were once on very different paths. But it is this way, and that's why I thank God everyday that Margot is willing and able to care for my dear sister, and that is why I believe that every day should be Mother's Day.

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