

## A Tribute to Two Family Caregivers

By Larry Stillwell, Rappahannock County Resource Specialist for Aging Together

Two men I knew died recently within days of each other after long struggles with two different paralyzing and fatal diseases. Thanks to the loving dedication and painstaking hard work of the women who were their life partners, each man was able to live at home throughout his illness. Each died peacefully in his own bed.

Jim Marangoni was well known and well loved in the Rappahannock community. Like my old friend Greg Soltys of Williamsburg, he had a big smile and a big heart, a playful and friendly disposition, and a mischievous sense of humor. And sadly, like Greg he developed an incurable disease that gradually shut down his body and killed him.

Greg had ALS, amyotrophic lateral sclerosis, also known as Lou Gehrig's disease. "If anyone sees Lou Gehrig, tell him he can have his disease back," Greg used to crack sardonically. Jim was diagnosed with corticobasal degeneration (also known as cortical basal ganglionic degeneration), which is even rarer than ALS and equally mysterious and untreatable.

For both men, the disease first weakened their hands and limbs and then eventually forced them into wheelchairs by day and hospital beds by night. By the end, each had to be slipped into a harness and lifted mechanically into or out of bed. Along the way, each man lost the power to feed himself, to chew or swallow easily, and to speak.

During my friendship with Greg and his longtime companion Paula Durham, and the ten months I visited Jim and his wife Carol each week as a Hospice of the Rapidan volunteer, I was privileged to see how these two couples managed the impossible. I am convinced that what kept these men's lives from being truly unbearable was the strength, dedication, and resourcefulness of the women who accepted the demanding full-time jobs of caring for them at home. I take away from my time in the homes of these two couples a deep admiration, a profound awe, for both the character and the accomplishments of family caregivers.

Neither woman could have done it alone, of course. They had invaluable help from professional caregivers, from doctors and therapists, from hospice staff and volunteers, and from clergy, family, and friends. It takes a village, we'd say at Greg and Paula's house, as an incoming acupuncturist and an outgoing physical therapist passed each other on the long wheelchair ramp leading to the front door. In every community, there are legions of these skilled, compassionate people whose daily work is dedicated to supporting those who desperately need their help.

In our community, the Rappahannock Rapidan Community Services Board and Area Agency on Aging can help caregivers of older adults locate resources and supports. Just call Senior Advocate Michael Soule at 825-3100. A new support group for caregivers of all ages has just started here also. We meet two Thursdays each month at The Link in Sperryville. Contact me at 675-2531 for more information about this opportunity to connect with others sharing the same experiences.

Thank goodness Carol and Paula had help. But the bottom line was that it fell to them to learn to manage the myriad demands of caregiving. At the same time, they had to cope with their own fears and emotions caused by the pending loss of their life partner, as well as with their partner's fears and emotions. Either challenge would qualify as a crisis in anyone's life.

Gail Sheehy, famous for *Passages* and other books about life stages, has written a wonderful new book called *Passages in Caregiving: Turning Chaos into Confidence*. In it, she creates an imaginary "want ad" for the role of family caregiver:

"HELP WANTED: Untrained family member or friend to act as advocate, researcher, care manager, and emotional support for a parent or spouse, sibling or friend, who has been diagnosed with a serious illness or chronic disability. Duties: Make medical decisions, negotiate with insurance companies or Medicare; pay bills; legal work; personal care and entertainment in hospital and rehab. Aftercare at home: Substitute for skilled nurse if injections, IV, oxygen, wound care or tube feedings are required. Long-term care: Medication management, showering, toileting, lifting, transporting, etc. Hours: On demand. Salary and benefits: 0."

This is the job Carol and Paula each learned through unexpected on-the-job training, performed day after day for years. As is characteristic of family caregivers, they did their jobs with intelligence, skill, and conscientiousness - even with humor. Most importantly, they did their jobs with love.

Though nearly one-third of American families include an unpaid family caregiver, this quiet kind of heroism usually goes unnoticed. In farmhouses and apartments throughout Rappahannock and across Virginia, people like Carol and Paula are doing the unsung work of family caregiving. They deserve our recognition, our admiration, and our thanks.

*Aging Together is a community partnership taking action now to improve quality of life for the growing population of older adults. Join our local team meeting the 4<sup>th</sup> Thursday of every month at 1:00 at the Rappahannock Library. For more information contact Larry Stillwell at 675-2531 or [lstillwell@agingtogether.org](mailto:lstillwell@agingtogether.org). Visit our website: [www.agingtogether.org](http://www.agingtogether.org).*