

The Long Journey: Family Caregiver of the Year Moves Forward

Joyce Gregory shares insights for families coping with Alzheimer's



“God has been with us, and He will walk with us now as we go on this long journey.” Ron Gregory, who was diagnosed with early-onset Alzheimer’s Disease over a decade ago, recalls these words as his wife’s first comment when they were given the diagnosis by his neurologist. Joyce Gregory, his partner in marriage for 48 years and his caregiver for the past 12 years, has demonstrated not only the power of her faith in supporting the couple on this “long journey,” but the strength she has found in herself.

These words were used in the nomination of the most recent West Central Georgia regional winner for the Georgia Caregiver of the Year Award for family caregiving, awarded by the Rosalynn Carter Institute. Joyce Gregory has taken time to reflect on the changes that a diagnosis of a chronic and progressive illness has brought into the lives of her family, and offer advice to others facing this challenge. A soft-spoken woman, Gregory focuses on her husband’s own efforts, the support of her family, friends, and community supports, rather than her own efforts, in helping them cope with the challenges of Alzheimer’s. But just a few moments of conversation with her reveals the role her own tenacity has played. From the time she first learned her husband’s diagnosis, she has been proactive in her approach -- learning more about the disease, seeking out supports for her and her family, advocating on behalf of Alzheimer’s funding and providing support to other caregivers in her community.

The early journey – learning to cope. When asked about how the family coped early on, Gregory describes the process of “downsizing” they undertook. She notes, “Before, Ron did everything. Yard work, around the house, business – everything. The stress was weighing on him.” So they sold their house and moved into an apartment at Magnolia Manor in Americus, only a few blocks from their previous home. And Joyce Gregory began to learn how to take on many of the roles her husband had assumed before. She describes this act of role transitioning as one of the most difficult parts of the early years after his diagnosis.

Another step in learning to cope with the illness and her new role as family caregiver was to immerse herself in the literature about Alzheimer's disease, attend numerous community workshops, and become involved with a nearby Alzheimer's Association group. That commitment to learning continues to this day, as Gregory is currently participating in the REACH family caregiver program sponsored by the Rosalynn Carter Institute and attending monthly Alzheimer's Association meetings. When asked what part of her training experiences benefited her most, she says, "Learning what I can do from day to day -- the hands on caregiving. And what to expect."

Rewards and challenges. Asked to reflect upon the rewards and challenges of caregiving, Gregory immediately focuses on many of the positive experiences that ultimately resulted from their changes in roles and schedules in the family. She notes, "I was able to give more. He had taken care of everything, and now I was able to give back." She also describes how the experience of Alzheimer's has actually given the couple more time together. Now they are not caught up so much in the outside world and can appreciate such simple things as just holding hands and being together. They visit with their grown children and have what she describes as "really sweet times."

When pressed, Gregory acknowledges the challenges of caregiving. One more difficult aspect of undergoing role changes has been the "touchiness" of having to assume new roles, such as managing business affairs previously handled by a spouse. Another concern she points to is the relative isolation that can overtake the family caregiver. She notes that, at first, "I tried to go it alone. I was trying to protect the family." But she soon realized that going it alone was not fair to her family or herself, and she began to educate and involve her family. Gregory notes ruefully that a diagnosis of Alzheimer's disease in the family does tend to create distance with some friends and acquaintances, who feel uncomfortable around the affected individual as well as the spouse. To overcome a growing isolation, she has made a point of reaching out to friends, joining support groups, and relying upon her church family. "Don't try to go it alone," Gregory cautions other caregivers.

Caregiver needs. Asked about resources that would have made the most difference, she describes the difficulty in obtaining real-time assistance when a problem occurs. While training and workshops focus on what to do in the future, Gregory found that she sometimes needed an immediate question answered when it arose. "I probably needed someone to talk to when I ran into a problem." When discussing caregiver support programs that provide ready telephone contact, she feels that programs that offer such ready access for families are the most beneficial. And what are the resources for which she would advocate most with policymaker and legislators? Gregory points to the need for more financial help to families coping with chronic illnesses such as Alzheimer's. She feels also that more guidance is needed for helping families with financial resources.

Advice to others. In offering other advice to caregivers, Gregory stresses that a family caregiver must "learn to be flexible." She notes how roles and relationships with the family member with Alzheimer's may change not only from day to day, but from moment to moment. She also recommends that caregivers find at least one person to be able to reach out to for support, and that caregivers must educate

themselves about the illness. On concrete suggestion offered relates to communication with medical professionals. She found that writing a letter to her husband's neurologist before an office visit allowed her to share important information without worrying about embarrassing her husband or feeling awkward. She feels it is important for family members to figure out how to communicate most effectively with professionals. The fact that the family sought out a neurologist so early in her husband's illness has bought them more years of relative independence. In summary: Reach out to others. Educate yourself. Be flexible. Communicate.

Her husband's nomination letter for her Caregiver of the Year award offers additional insights about effective caregiving: "She never made me feel inadequate or tried to keep me from doing what I could for myself. Now I see how precious that was and continues to be... we both have remained very active in what we can do and [don't] dwell on what we can no longer do." The journey of Ron and Joyce Gregory so far has been an extraordinary one. As he involves himself with his own support group and remains active, she prepares to attend her next workshop, walk in her next Memory Walk for Alzheimer's funding, and answer the next phone call from someone else needing a moment's support.

This article is the first in a statewide series, "The Faces of Caregiving," provided by the Rosalynn Carter Institute as a service to family and professional caregivers throughout Georgia. For further information on caregiver support, please contact: Rosalynn Carter Institute, phone 229-931-1234 or www.rosalynncarter.org.