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CONTACT: Patricia Klein

Public Relations Specialist
Good Shepherd Hospice, Inc.

www.goodshepherdhospice.org

863-551-3941 (desk)

863-616-2890 (cell)

kleinp@goodshepherdhospice.org

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Caring for the caregiver

Good Shepherd Hospice offers support for those caring for chronically ill loved ones

LAKELAND, FLA. – For 39 years, Tom and Peggy Fife led a happy and normal life together. The couple moved to Lakeland from Ohio in 1979. Tom worked for a local company that packaged medications and pharmacy products. Peggy runs a residential cleaning service. They raised three children and doted on seven grandkids. Tom jogged everyday at lunch time.

That all changed dramatically in May 2007. The previous September Tom sustained a knee injury and underwent surgery, from which he never fully recovered. While at his son's home during Christmas 2006, he tripped and fell, which was unusual. He gradually found it difficult to walk. Tom underwent diagnostic tests that initially ruled out ALS and Multiple Sclerosis. But Tom's symptoms continued to worsen. A second doctor's opinion gave the Lakeland couple a definitive, but life-altering diagnosis – Tom had ALS.

ALS, amyotrophic lateral sclerosis, is also called Lou Gehrig's disease after the New York Yankee's slugger who died of the illness in 1941. The disease progressively destroys nerve cells in the spinal cord and brain, resulting in paralysis. ALS is incurable and fatal.

The couple investigated and tried multiple treatments. Peggy supported her husband but at the same time struggled. She sought to find a program that would help her cope with Tom's disease. She and a friend, whose husband was also diagnosed with ALS, shared their common issues, but they both knew that they needed a venue with more structured support. While reading the newspaper one day, she ran across a calendar listing for a caregivers' support group that Good Shepherd Hospice was forming. Peggy and her friend signed up.

The Good Shepherd Hospice Caregivers' Support Group is a monthly gathering where family members and loved ones of chronically ill patients can meet to share experiences and learn coping skills. The group is free and open to the public, and the group members' loved ones do not need to be enrolled in Good Shepherd Hospice. According to Allyson Moskowitz, Good Shepherd Hospice bereavement manager, the organization saw that offering caregivers' support was a need her department could fill. "As a not-for-profit agency, we want to provide programs that enrich our community," said Moskowitz. "With our expertise in grief counseling, it was a natural extension for us to offer caregivers' support."

Rica Walker, the Good Shepherd Hospice grief counselor who runs the program, says that caregivers can feel as if they are in a lose-lose situation. "Caregivers know that their loved ones are facing tremendous obstacles, and they are at risk of losing someone very close to them," said Walker. "Caregivers – especially those whose loved ones are facing long-term, chronic conditions – are also at risk of losing their identities and their own health by putting the needs of their loved ones before themselves."

Walker said the group offers caregivers education and encouragement on care-giving issues along with a setting to talk freely. "We want the group members to feel comfortable and know that they have to think of themselves," she explained. "We encourage them to eat healthful meals, get enough sleep and carve out a little bit of 'me' time. Caregivers are of no use to their loved ones if they are also sick."

Peggy recalls something Walker told her group at that first meeting: always remember that when they are mad, they aren't mad at their loved ones, but at the illness. Walker instructed the group to share that thought with their loved ones. "It did help me to remember that," said Peggy.

Peggy attended the Good Shepherd Hospice Caregivers' Support Group for about three months. She valued being able to share her feelings in a supportive and confidential environment. "Once I was able to bring up matters, others were able to express themselves knowing you also were experiencing some of the same issues," said Peggy. "We said whatever we wanted, whenever we wanted, because we knew the conversations stayed private."

After his diagnosis, Tom's health continued to deteriorate. In August of 2008, Tom's doctor posed the question, "Do you want hospice or do you want a feeding tube?" Tom chose to enroll in Good Shepherd Hospice, but Peggy proudly says that he continued to "work up to the last 10 days of his life."

The Fifes seamlessly transitioned to hospice care with Good Shepherd Hospice. Peggy was very impressed with the care they received and calls Tom's hospice nurse, Andrea Hart, "an angel." Andrea visited Tom once a week to monitor his condition, arrange for medications, equipment and supplies and to support Peggy. She also prepared Peggy for what to expect as Tom's health declined. "Every time I called, Andrea answered my questions," said Peggy.

But ALS continued to rob Tom of his mobility, and on November 14, the family asked Good Shepherd Hospice for a hospital bed. He died a week later at home.

The healthcare professionals at Good Shepherd Hospice know that their support doesn't end when the patient dies. The loved ones of Good Shepherd Hospice patients are eligible for grief counseling for up to a year and longer if necessary. In addition, Good Shepherd Hospice addresses the unique bereavement needs of children and teens who have been impacted by the death of a loved one through the programs offered at the Bethany Center for Grieving Children. Two of Peggy's grandsons, Kristopher and Tyler Kissel, have taken advantage of these services and recently attended the children's weekend grief camp, Camp Brave Heart. Kristopher enjoyed camp so much that he's considering volunteering as a camp counselor when he turns 18.

Peggy Fife credits the Good Shepherd Hospice Caregivers' Support Group with helping her manage some of the challenges of her husband's disease. "I looked forward to going and being able to talk over things that were happening in my life and to hear that others were experiencing the same thing," she remembered.

Now that nearly six months have passed since Tom's death, Peggy Fife can reflect on the many wonderful years she shared with her husband and appreciates the services Good Shepherd Hospice offered her family during a difficult time in their lives. "It is a great program," she said. "I just wish more people knew what it could do for them."

The Good Shepherd Hospice Caregivers' Support Group meets the last Wednesday of each month, from 5:30 to 7 p.m. at the Good Shepherd Hospice Auburndale Community Resource Center, 105 Arneson Avenue in Auburndale. The meetings are free and open to the public. For more information about this and other Good Shepherd Hospice programs, contact Angel Sanders at 863-968-1739.

About Good Shepherd Hospice

Good Shepherd Hospice is a community-based, not-for-profit organization that supports and serves approximately 700 patients each day in Polk, Highlands and Hardee counties as they face the challenges of life-limiting illnesses. Healthcare professionals and trained volunteers embrace the Good Shepherd Hospice mission to make the most of life by relieving the suffering of patients and their families affected by end-of-life issues. The organization has been a part of the community since 1979 and is a 2008 recipient of a Circle of Life Citation of Honor Award. Good Shepherd Hospice is the only local agency offering hospice programs accredited by the Joint Commission, the nation's premier healthcare accrediting body. The United Way of Central Florida partially funds the community programs offered by Good Shepherd Hospice. For more information, please visit the website at www.goodshepherdhospice.org

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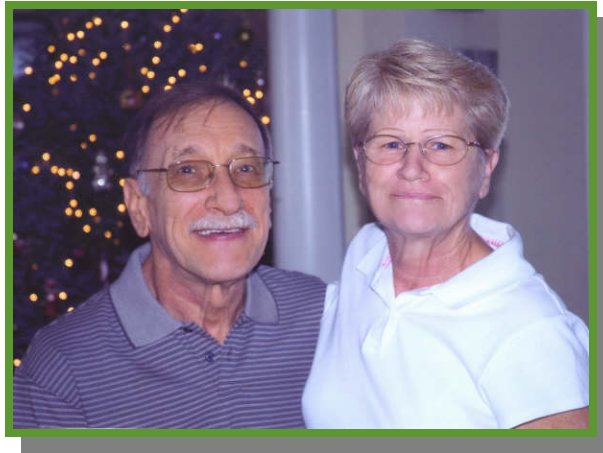


Photo courtesy of Peggy Fife

Tom and Peggy Fife celebrate Christmas 2007.



Photo courtesy of Peggy Fife

Tom Fife, in a photo taken in May 1999, prior to his ALS diagnosis.

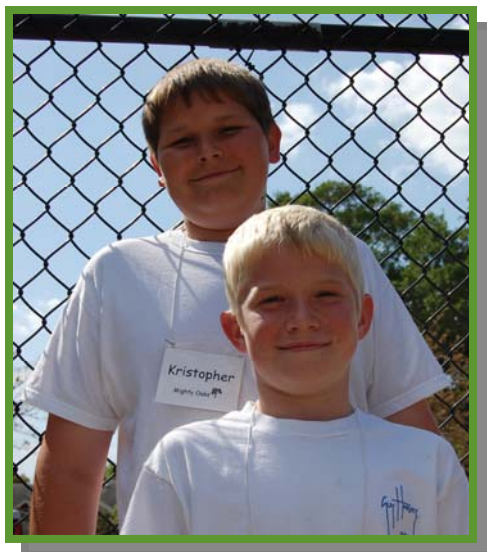


Photo courtesy of Good Shepherd Hospice

Kristopher, 14, (top) and Tyler Kissel, 9, Peggy Fife's grandsons get ready to leave for Camp Brave Heart last March. Camp Brave Heart is a weekend grief camp Good Shepherd Hospice offers for children who have experienced the death of a loved one.