



The ALS Association
National Office

News Release

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The ALS Association Cares for Those Who Care the Most in New Campaign

CALABASAS HILLS, Calif. (October 26, 2009) – The ALS Association is encouraging caregivers to voice their concerns about their own health as well as the people who require their help around the clock during National Family Caregivers Month in November.

The theme of National Family Caregivers Month is “SpeakUp” and when caregivers speak up The ALS Association is there to listen and help make their lives as easy as possible.

“Most caregivers do not have the time to ask for help because they are too busy meeting the needs of others,” said Sharon Matland, vice president of patient services for The Association. “It is our responsibility as an organization to be extra diligent in reaching out to them.”

As part of National Family Caregivers Month, The Association is launching “Show You Care,” a national campaign to recognize some of the thousands of local primary caregivers critical to protecting and enhancing the quality of life for individuals living with ALS (amyotrophic lateral sclerosis). The daily challenges faced by caregivers, whose own health is adversely affected by providing care on a round the clock basis, are detailed in a series of profiles featured on The Association’s Web site at <http://www.alsa.org/patient/nfcm/>.

Peggy Rode takes care of her husband Jeff Rode, who has ALS, also commonly referred to as Lou Gehrig’s Disease. She is active in support group meetings sponsored by The Association’s Evergreen Chapter in Kent, Wash., and has learned how to better cope with each new day as the disease progresses.

“My biggest challenge is dealing with all the changes that my spouse is going through and how these changes affect the both of us,” said Peggy Rode, an avid gardener who considers her yard to be her “little oasis.” “We are dealing with new challenges everyday.”

Phil Thomas, a do-it-yourselfer, made extensive modifications to his home to make life easier for his wife Kay Thomas, who has ALS. They receive help from The Association’s Greater Bay Area

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Chapter in San Francisco, Calif. The Thomases, both retired military veterans, are trying to enjoy life the best they can.

“Just because your loved one has ALS, do not fall victim to it,” said Phil Thomas, who served in the medical corps in Operation Desert Storm and Operation Desert Shield. “Don’t dwell on what you can’t change or the inevitable. Each day is a gift, a chance to be together, to share with friends and family.”

The public also can make a “Show You Care” donation to support The Association and the fight against ALS by clicking

https://secure2.convio.net/alsa/site/Donation2?df_id=14580&14580.donation=form1.

“One of the most important attributes of being an advocate for your loved one is the willingness and the ability to speak up and keep your eye on the ultimate goal, protecting not only the health and safety of your loved ones but for yourself as well,” states the Web site for the National Family Caregivers Association, which organizes National Family Caregivers Month each year.

Providing constant care takes its emotional and physical toll on caregivers. Signs of burnout include anger, anxiety, depression, feeling overwhelmed and guilty, sleeplessness, premature aging and other symptoms. Studies show that 75 percent of all caregivers are going it alone without help from family and friends.

“If Americans need heroes they need not look any further than the caregivers in their own families,” Matland said. “These are among the most courageous people you will ever meet. They continually give of themselves to provide whatever is needed.”

Caregivers also increasingly include the husbands, wives and, in some cases, the children of military veterans with ALS. That is because military veterans are approximately twice as likely to develop ALS as the general public.

“It is cruelly ironic that these caregivers, who shouldered a tremendous family burden while their loved ones served in the military, now find that burden has increased. They are now on the front lines in the war against ALS; however, they are not alone,” said Steve Gibson, vice president of government relations and public affairs for The Association.

The Association is the leading voice for veterans and their caregivers, having successfully advocated for new regulations at the Department of Veterans Affairs that make ALS a service connected disease. These historic regulations, which were implemented in 2008, provide caregivers with the resources they need to fight back against ALS, including monthly disability compensation, health benefits and assistance to help pay for home health care services that are so vital to veterans with ALS and their caregivers.

As Veterans Day approaches on November 11, all Americans are urged to join The Association in showing their support for the nation’s veterans and their caregivers by sending a letter to the editor of their local newspaper using The Association’s Web site at www.alsa.org/policy/veterans.cfm.

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The Association's national network of chapters also is committed to giving caregivers back as much of their lives before ALS as possible including having more time to take care of personal matters, catching up with family and friends and having a chance for rest and relaxation.

One of the ways The Association looks out for the welfare of primary caregivers is by training and providing ongoing support to the friends and families of caregivers on how to use its Care Connection program at

<http://www.alsa.org/patient/caregivers/careconnection.cfm?CFID=4213050&CFTOKEN=a52b55af9573acfc-DD29A502-188B-2E62-801E06C04869D10D>. This program is based on a network of volunteers from the community that provide help for the person with ALS and often gives the caregiver a much needed break from their day-to-day responsibilities. It provides an opportunity for those who want to offer a helping hand but do not know what is needed. The program provides a plan for organizing help, training and information about how to establish an effective team.

The Care Connection uses the Lotsa Helping Hands Web site at <http://alsa.lotsahelpinghands.com/caregiving/home/>, which offers a simple, immediate way for families facing the challenges of long-term care to organize and communicate with other family members, friends and neighbors. It is an easy-to-use, private group calendar, specifically designed for coordinating visits or help with meal delivery, transportation and other tasks necessary for life to run smoothly.

George Shelton and his wife Amelia, who has ALS, are enthusiastic about their participation in The Association's Care Connection. They are helped by The Association's Jim "Catfish" Hunter Chapter in Raleigh, N.C.

"As a caregiver, the biggest challenge that I face is realizing that I can't do everything by myself," said George Shelton, who likes computer games and watching movies. "My best advice to other caregivers: swallow your pride and let family and friends assist you whenever possible. No one person can do all of this alone."

In honor of National Family Caregivers Month, the Patient Services Department of The Association has assembled a set of Web-based presentations at <http://www.alsa.org/patient/article.cfm?id=1513>, which are designed specifically for caregivers who provide attention and care to people living with ALS. During the informative and practical presentations, experts from their respective fields share experiences and offer tips and support.

"There will be a time in this life when each and every one of us will be called on to assume the role of caregiver," Matland said. "The ALS Association is committed to protecting those who embrace this responsibility from the clutches of ALS. Together we can work to stop this devastating disease from claiming more victims and strive to restore a sense of grace and dignity to those who give so much to meet the needs of their loved ones."

ALS causes the progressive death of the motor nerve cells that operate muscles, robbing the brain of its ability to initiate and control movement. Approximately 30,000 Americans have the disease, for which there is no effective treatment or cure, and can expect to survive on average two to five

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years from the time of diagnosis.

The ALS Association is the only non-profit organization fighting Lou Gehrig's Disease on every front. By leading the way in global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers, and fostering government partnerships, The Association builds hope and enhances quality of life while aggressively searching for new treatments and a cure.

For more information about The Association, visit the organization's Web site at www.alsa.org or call (800) 782-4747.

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