



RESCUE

Resources & Education for Stroke Caregivers'
Understanding & Empowerment

January/February 2010

www.rorc.research.va.gov/rescue

This newsletter is a product of a VA research project titled "[Web-based Informational Materials for Caregivers of Veterans Post-Stroke](#)" (Project #SDP 06-327), funded by the VA Health Services Research & Development Quality Enhancement Research Initiative (QUERI). The objective of the project is to develop stroke and caregiver related information and materials to be posted on a VA Web site. Development of the information for the Web site will be based on identified gaps in currently available information and formative evaluation findings. The Web site, to launch in mid-2010, will be: www.rorc.research.va.gov/rescue. Visit the Web site today to subscribe to the **RESCUE Newsletter!**

THE IMPORTANCE OF SOCIAL SUPPORT

Caregiving is a stressful job. Caregivers often feel alone and isolated from the outside world, and many times they neglect their own physical and emotional needs to care for their loved one. This can eventually lead to illness and depression.

To help combat the stresses of caregiving, caregivers should seek out social support. Social support encompasses the various types of help that people can receive from others. This may include physical, psychological and even financial help. A social support network can be made up of family, friends, co-workers and other community members. It can be found in the form of a support group made up of other caregivers or a team of family and friends ready to pitch in. No matter what form, a social support network can be a lifeline to a caregiver. It can provide the caregiver with a sense of belonging and increased self-worth.

The stroke survivor can also benefit from social support. Joining a support group can give them the opportunity to talk with other stroke survivors. It can also give the survivor a chance to get out of the house and make new friends, to share his/her experiences and vent frustrations. Friends and family can also provide support by visiting with the survivor and involving him or her in social activities.

Establishing a social support network early on is important. There are several resources that can help caregivers keep family members and friends informed about the stroke survivor's recovery, as well as help the caregiver identify those who can lend a hand. They include CaringBridge.org and Lotsa Helping Hands (a service of Empowering Caregivers).



CaringBridge.org is a free, personalized website that connects family and friends during a serious health event. CaringBridge makes it easier to share health updates and receive messages of love and support. Visit: www.caringbridge.org (Site also available in Spanish.)



Lotsa Helping Hands is a private, web-based caregiving coordination service that lets family, friends, neighbors and colleagues create a community and assist with the daily tasks that become a challenge when caring for an aging loved one or during long-term caregiving. Visit: www.lotsahelpinghands.com

Each community includes an intuitive group calendar for scheduling tasks such as coverage of transportation to medical appointments, a platform for securely sharing vital medical, financial, and legal information with designated family members, and customizable sections for posting photos, well wishes, blogs, journals, and messages. Now, when someone asks "What can I do to help?" the answer is "Give me your name and email address" – the system takes over and allows people to sign up and start helping.





AMERICAN STROKE ASSOCIATION’S “STROKE CONNECTION” MAGAZINE



“From helping you build a support network or explaining the latest treatments, to raising awareness about rehabilitation options, we’re here for you.”

The American Heart Association (AHA)/American Stroke Association (ASA) publish a bimonthly magazine for stroke survivors, caregivers, family members and healthcare professionals called *Stroke Connection*.

Stroke Connection contains articles about the trials and tribulations faced by stroke survivors and their caregivers, as well as inspiring stories of stroke recovery. The magazine features tips for daily living from healthcare professionals and other stroke survivors and provides in-depth information about common stroke-related conditions such as aphasia, central pain, high blood pressure, depression, and diabetes. *Stroke Connection* keeps readers informed about “how to cope, how to reduce your risk of stroke and how to make the most of each day.”



Some articles from 2009 include:

- *Reclaiming Self-Esteem*: two experts discuss emotional recovery and social reintegration after stroke and the devastating impact stroke may have on the self-esteem of survivors,
- *Finding Help When You Feel Helpless*: using patient advocates to help with issues that come up related to medical care and treatment,
- *A Stroke of Insight*: The story of Jill Bolte Taylor, PhD, a Harvard-trained brain scientist who suffered a rare form of stroke.

Stroke Connection magazine is published six times a year and is available in both a print and electronic format.

[Click here to view a Jan/Feb 2010 issue in electronic format.](#)

For more information about *Stroke Connection* magazine and how to subscribe, visit:

<http://www.strokeassociation.org/presenter.jhtml?identifier=2533>

RESCUE FACT SHEET SPOTLIGHT: “GET HELP FROM FAMILY, FRIENDS & COMMUNITY”

The **RESCUE** project fact sheet titled “*Get Help from Your Family, Friends and Community*” contains information to assist the caregiver in getting the help that they need from others. Caregiving can be a full-time job. Many caregivers also work outside of the home. That is why it is important for caregivers to make a list of what tasks they need help with.



Tasks where assistance would be appreciate can include:

- **Household chores**: cooking, washing and folding clothes, housekeeping, home repair and lawn care
- **Other help**: transportation to medical visits, shopping, information gathering (on available support and services)
- **Social visits**: visiting with the stroke survivor so that the caregiver can take a break

The “*Get Help from Your Family, Friends and Community*” fact sheet also identifies other resources that the caregiver can use to find assistance in their area.

- National Family Caregivers Association (NFCA): http://www.nfcacares.org/connecting_caregivers/
- Faith in Action Volunteers (FCA): <http://www.fianationalnetwork.org/find-fia-program.cfm>
- Family Caregiver Alliance: http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=347



MY HEALTHeVET SPOTLIGHT: “SMOKING AND TOBACCO USE CESSATION”



My HealthVet, the VA Health Care Portal, has created a special area in the **Healthy Living Center** called **Smoking and Tobacco Use Cessation**. This area contains links to helpful information about kicking the tobacco habit, including how to get started. There is also a link to the **Support and Encouragement** page, which features success stories of Veterans who have quit smoking, and stresses that social support from family and friends is very motivating and plays an important role in changing behavior.

To access **Smoking and Tobacco Use Cessation** visit www.myhealth.va.gov,  then click on:

RESEARCH HEALTH

then click

HEALTHY LIVING CENTERS

then click



Smoking + Tobacco Use Cessation

The National Stroke Association (NSA) has a Recovery after Stroke Fact Sheet Series that addresses the many topics that stroke survivors and their caregivers face. The fact sheet, Recovery after Stroke: Social Support talks about the importance of social support in stroke recovery.



The following are reasons why a support group can be beneficial to a stroke survivor:

- Participation in a stroke support group is a good reason to get out of the house and gives the stroke survivor an understanding environment where they can share their story, and their concerns and frustrations.
- It can help the stroke survivor find ways to solve problems related to their stroke and may provide information about products that could help their recovery.
- Participation in the group may encourage the stroke survivor to try new things and to make new friends.

Did You Know?

Caregivers' Unmet Needs

- The most frequently reported unmet needs are finding time for themselves (35%), managing emotional and physical stress (29%), and balancing work and family responsibilities (29%).
- About three in ten caregivers say they need help keeping the person they care for safe (30%) and finding easy activities to do with the person they care for (27%).
- One in five caregivers say they need help talking with doctors and other healthcare professionals (22%) or making end-of-life decisions (20%).

Facts from

Family Caregiving 101

http://www.familycaregiving101.org/not_alone/stats.cfm

Next Issue's Featured Article: "Long-Distance Caregiving"

Links in this Issue



DISCLAIMER OF HYPERLINKS: The appearance of external hyperlinks does not constitute endorsement by the Department of Veterans Affairs or the RESCUE Project of the linked web site, or the information, products or services offered by this site. In addition, this site may have privacy and security policies that are inconsistent with those of the Department of Veterans Affairs. For other than authorized VA activities, the Department does not exercise any editorial control over the information you may find at these locations. All links are provided with the intent of meeting the mission of the Department of Veterans Affairs and the RESCUE Newsletter and forthcoming Web site. Please let us know about existing external links which you believe are inappropriate.



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