



RESCUE

Resources & Education for Stroke Caregivers'
Understanding & Empowerment

March/April 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 late-2010, will be: www.rorc.research.va.gov/rescue. Visit the Web site today to subscribe to the **RESCUE Newsletter!**

LONG-DISTANCE CAREGIVING COMES CLOSE TO HOME

By Constance R. Uphold, PhD, ARNP

Web-Based Informational Materials for Caregivers of Veterans Post-Stroke/RESCUE Project Principal Investigator

As a long-distance caregiver myself, the RESCUE project has a special meaning to me. My mother, who is 86 years old, has both cognitive and physical disabilities and lives many states away. During the last two years, she has transitioned from living independently to an assisted living facility and now a nursing home. Each transition has been marked by stress and sadness as I have seen my mother's condition slowly worsen.



The Stroke Caregiving Fact Sheets and RESCUE newsletters connected with our project have increased my understanding of the issues faced by caregivers and have helped me learn to better cope with the changes my mother and my family are experiencing. As a long-distance caregiver, I face different issues than my sister who lives nearby and who must solve problems on a daily basis. The two emotions that have been most difficult for me to overcome are guilt and frustration. I feel guilty that I cannot frequently visit my mother and cannot provide day-to-day care, such as going with her to healthcare visits, laundering her clothes and providing physical care. I feel guilty that my sister, the only local caregiver, is burdened with the bulk of caregiving responsibilities. I want to help and make changes in my mother's care, but I don't want to interfere with the routine caregiving tasks provided by my sister. It can be challenging to maintain the delicate balance between them.

Over the years, I've learned how to better cope. With today's technology, it's easy for me to keep in touch with my mother and sister. I call my mother on the phone each evening and communicate with my mother's health care providers via emails at least weekly. My sister and I plan regular conference calls with the staff in the nursing home to manage and maintain my mother's plan of care. We are currently working with the nursing home to get a Skype connection, which would allow us to stay in even better touch through video chats.

Even though I not in the same city, I can take responsibility for tasks that can be done from a distance. For instance, I am in charge of communicating with the physicians, nurses, social workers, and physical therapists about any healthcare problems that arise. I am the person responsible for arranging services and hiring personnel to help with my mother's care. And, perhaps most importantly, I communicate regularly with my sister who often needs someone to talk to about the daily stressors of caring for an older parent. I try to be supportive and always remember that my sister is the best judge of what my mother needs. My sister, mother, and I have grown together as a family and have gradually met the challenges that inevitably occur as we all get older.



RESCUE FACT SHEET SPOTLIGHT: “LONG-DISTANCE CAREGIVING”

Providing care for a loved one is stressful, even more so when that loved one lives far away. That is why the RESCUE team created a fact sheet about long-distance caregiving. In this fact sheet, caregivers can find out how to get started and what questions to ask when planning their loved one’s care.

Some long-distance caregivers may wonder how they can help from across the miles. Although long-distance caregivers can’t provide daily care, they can help in other ways:

- Arrange services and hire healthcare workers
- Help with finances; pay bills online or through direct deposits or mail service
- Obtain information about insurance benefits
- Learn all you can about their loved one’s medical problems and treatments
- Show their love by telephoning and sending gifts and letters

Also included in the fact sheet is a list of other resources to help identify help in your loved one’s area:

- The Eldercare Locator: <http://www.eldercare.gov>
- Family Care Navigator: <http://caregiver.org>



Next Issue’s Feature: “National Stroke Awareness Month”

MYHEALTHeVET SPOTLIGHT: “CAREGIVER ASSISTANCE”

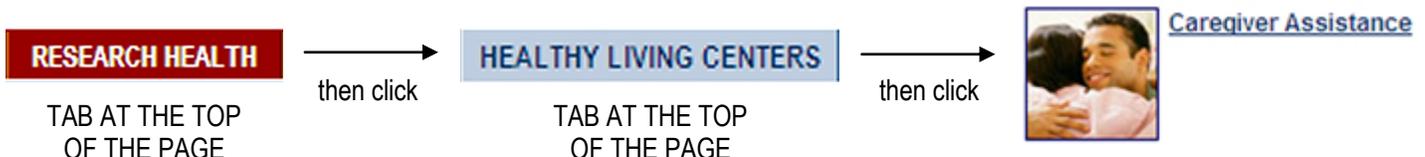


A caregiver is someone who takes responsibility for the care and well-being of another person while playing a role in certain parts of the care required. Caregivers may be a relative, significant other, neighbor, or friend. Whatever the caregiver’s relation may be, it is important that they learn about the condition(s) which may be affecting the person for whom they are caring and help them to make healthy choices so that they will be better able to help.

My HealthVet, the VA Health Care Portal, has created a special area in the **Healthy Living Center** called **Caregiver Assistance**. In this area, visitors will find links to many helpful Web sites that cover topics such as:

- Caregiver resources for specific diseases and conditions and when to get additional help
- How family and friends can provide support
- Benefits of change, how to start healthy living, and special situations
- Understanding and tracking health behavior change progress using various tools available on My HealthVet
- Complementary and alternative approaches

To access the Caregiver Assistance section of MyHealthVet visit <http://www.myhealth.va.gov>, then click on:



JOIN THE RESCUE TEAM IN PROMOTING STROKE AND CAREGIVING AWARENESS

The **RESCUE Project Team** will be sponsoring promotional events during **National Stroke Awareness Month** (May 2010) and **National Family Caregivers Month** (November 2010). These events will take place in the lobby, primary care waiting area, library or canteen of 15 selected VA sites with a high prevalence rate of stroke.

We still need volunteers at the following sites:

- Augusta, GA
- Dallas, TX
- Los Angeles, CA
- Bay Pines, FL
- Houston, TX
- Chicago (Hines), IL
- Indianapolis, IN
- W. Palm Beach, FL
- Seattle, WA

Promotional materials will be distributed to participating sites and will include stroke caregiving fact sheets, an aphasia pocket card, a medication log pocket card, and **RESCUE Web Site** promotional items. If you are located at one of the VA sites above and would like to host an event, please contact Kim Findley at (352) 376-1611 ext. 4951 or email Kimberly.Findley@va.gov.

Finding the Balance between Work and Caregiving



Caregiving in itself is stressful but even more so when the caregiver has to juggle working outside of the home. The American Stroke Association article, "Finding the Balance between Work and Caregiving" provides working caregivers will find tips on how to:

- Prioritize time
- Learn to delegate
- Keep communication channels open
- Utilize employer's resources

To read the ASA article visit:

www.strokeassociation.org/presenter.jhtml?identifier=3030324

Two Great Resources



The Family Caregiver Alliance (FCA) has a handbook for caregivers who are new to the challenges of providing care from afar. The booklet contains information on creating a care team, assessing caregiving needs and finding help in the community. Information included about how to balance work and caregiving. Visit: www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1034

The National Institute on Aging (NIA) created "So Far Away: Twenty Questions for Long-Distance Caregivers" to help address the concerns of long-distance caregiving. Information includes how to know when help is needed and how to decide who in the family does what. Visit:



www.nia.nih.gov/healthinformation/publications/longdistancecaregiving/

- There are likely 54 million caregivers in the United States, and it is estimated that over five million are managing care from a distance.
- The average distance between caregiver and patient is 450 miles.

Facts from StrengthforCaring.com

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.

<http://www.rorc.research.va.gov/rescue>

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