

RESOURCES FOR CAREGIVERS

The ALS Association

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OTHER WEBSITES

(web addresses correct as of May 2010)

CareGuide

Website: www.careguide.com

ElderCare On-line:

Website: www.ec-online.net

Empowering Caregivers

Website: www.care-givers.com
Phone/fax: (212) 807-1204

Today's Caregiver On-line

Website: www.caregiver.com

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.



The Association's Information & Referral Service:
800.782.4747
For information about The ALS Association's other programs, please visit: www.alsa.org

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Caregiving ...when a loved one has ALS



The ALS Association
Guide for Caregivers



COPING WITH ALS

People living with ALS are continually faced with change and finding ways to cope with it. People with ALS, their families and caregivers cite the difficulties posed by the disease's lack of a set pattern of symptoms as well as its lack of a specific manner of progression. ALS onset and progression vary with each person. One spouse/caregiver describes the circumstances as "...so fluid..." As decisions are required and reached, various coping strategies evolve. The progressive nature of ALS requires that people with the disease and families continually find effective ways to cope with the symptoms.

Coming to terms with the need for receiving help from others – the need for a caregiver – is generally something most people are very slow to accept. It is emotionally difficult to receive intimate care from one's spouse, children, or parents. Even the start of personal care by a professional nurse or aide requires time, patience and understanding.

However, the problems associated with caregiving are not limited to the person with ALS. The caregiver, especially the family caregiver – spouse, partner, adult child, parent, brother, sister – needs acknowledgement and support in the process of starting and maintaining the care-providing relationship.

Unlike most formal service providers, family caregivers provide care day and night, over weekends and on demand. Caregiving can include personal care, assistance with mobility in the home, transportation, housework, and grocery shopping, along with looking after other family members' needs. Caregivers are often employed outside the home and may be the primary source of household income which adds even more demands, responsibilities and stress.

CARING FOR THE CAREGIVER

Caregiving is willingly undertaken out of love and devotion to the person with ALS and can be a source of great personal satisfaction. Yet, over time, caregiving exacts an enormous emotional toll, and can adversely affect the caregiver's physical and psychological health, threatening their ability to continue providing care. Concern for the ALS patient often causes the caregiver to overlook her/his own needs – eating properly, getting enough rest, taking time to pursue one's own interests.

Emotional needs are sometimes more difficult to spot and address. Caregivers may experience sadness at the patient's deterioration, guilt for not being perfect, anger at the burden of responsibility, frustration, depression, and dismay at the endless round of daily chores, even uneasiness and disappointment in their perceived change of relationship with their spouse or parent.

As one female caregiver of an afflicted spouse said, "My husband still sees me as his marriage partner, his sexual partner, but sometimes I feel like he's my child, rather than my husband. It's difficult to keep the roles of caregiver and spouse in perspective..."

It is very important that caregivers do not feel alone or abandoned. They must find someone to talk to who is already familiar with ALS and its impact on the patient and family. They need access to a social worker, nurse or psychologist who can help them sort out their feelings and acquaint them with resources in the community. They need a trusted friend – someone who has the right qualities, and the time, to be a sounding board.

THE ALS ASSOCIATION CARE CONNECTION

You don't have to be alone in this journey.

It's easy for people with ALS and their families to become overwhelmed by the wide range of needs they have, from everyday errands to making meals, maintaining their home, getting children to and from school, and so much more. It's hard to know when and how to ask friends and neighbors for help, and how to organize their availability. And for those who want to offer a helping hand, it's difficult to know just what is needed and how you can make a difference.

The Care Connection program is simple: it's a network of volunteers from the community – friends, neighbors, members of community organizations like your church, or other service groups – that provide help for the person with ALS and his or her family, and often give the caregiver a break from their day-to-day responsibilities.

The program provides a plan for organizing help, training and information about what approaches tend to be most effective.

Visit The ALS Association Care Connection website to view the program video at:
www.alsa.org/patient/caregivers/careconnection.cfm

Call your local ALS Association chapter to see if they're featuring the Care Connection program, or call the National Office of The ALS Association for more information.

A CAREGIVER'S BILL OF RIGHTS

- I have the right to take care of myself. This is not an act of selfishness. It will give me the ability to take better care of my loved one.
- I have the right to seek help from others even though my loved one may object. I recognize the limits of my own endurance and strength.
- I have the right to maintain facets of my own life that do not include the person I care for just as I would if he or she were healthy. I know that I do everything that I reasonably can do for this person and I have the right to do some things for just myself.
- I have the right to get angry, be depressed, and express difficult feelings occasionally.
- I have the right to reject any attempt by my loved one (either consciously or unconsciously) to manipulate me through guilt or anger.
- I have the right to receive considerations, affection, forgiveness, and acceptance for what I do for my loved one as I offer these attributes in return.
- I have the right to take pride in what I am accomplishing and to applaud the courage it has taken to meet the needs of my loved one.
- I have the right to protect my individuality and my right to make a life for myself that will sustain me in times when my loved one no longer needs my full-time help.
- I have the right to expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.

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RESOURCES FOR CAREGIVERS

Support Groups

Getting together with others who are living with ALS, to express one's feelings and exchange ideas can be beneficial to both the patient and caregiver. Many participants say support groups allow them to feel encouraged by others and to "... pat each other on the back..." In many cases, people with ALS and caregivers separate into small groups. "I can share my frustration that way," said one participant. Another caregiver said the separate group for caregivers made her feel like she "...can bond with another caregiver."

The ALS Association has a network of chapters and support groups across the U.S. Please go to www.alsa.org to find one in your area.

Respite Care

Caring for someone with ALS, particularly in the advanced stages of the disease, can be all-consuming. The caregiver needs time away to restore his or her physical and emotional strength.

Depending on the level of care required, respite can be provided by a responsible, caring person who is willing to stay with the patient while the caregiver goes out, or it can be provided by a paid professional health care provider. Family members who do not live in the patient's home or friends may be willing to help occasionally or on a regular basis. One's church or synagogue may have trained volunteers who will come to the home for a few hours. The important thing is to ask for help with the caregiving responsibilities.

There are formal and informal programs that give the caregiver a needed rest by taking over some of the tasks of caregiving. To find out about possible resources available to you, including adult day programs and in-home respite services, contact either The ALS Association's National Office, your local ALS Association chapter, or the National Respite Locator Service (www.respitelocator.org).

SUGGESTED READING & VIEWING

Living with ALS manuals

A series of six manuals provided to people with ALS and caregivers without charge by The ALS Association.

1. *Living with ALS: What's It All About?*
2. *Living with ALS: Coping with Change*
3. *Living with ALS: Managing Your Symptoms and Treatment*
4. *Living with ALS: Functioning When Your Mobility Is Affected*
5. *Living with ALS: Adjusting to Swallowing and Speaking Difficulties*
6. *Living with ALS: Adapting to Breathing Changes*

Living with ALS video series on DVD (includes five sections), provided to people with ALS and caregivers without charge by The ALS Association.

1. *Living with ALS: Mobility, Activities of Daily Living, Home Adaptations*
2. *Living with ALS: Adjusting to Swallowing Difficulties and Maintaining Good Nutrition*
3. *Living with ALS: Communication Solutions and Symptom Management*
4. *Living with ALS: Adapting to Breathing Changes and Use of Noninvasive Ventilation*
5. *Living with ALS: Clinical Care Management Discussion Among ALS Experts*

DVD: You Are Not Alone (Companion to "Your Resource Guide to Living a Fuller Life with ALS")

Brochures provided to people with ALS and caregivers without charge by The ALS Association.

- "Your Resource Guide to Living a Fuller Life with ALS" – for people newly diagnosed with ALS brochure
- "We Are With You Every Step of the Journey" - Certified Center multidisciplinary clinical care brochure

Book: Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill
By Cappy Capossela and Sheila Warnock
Simon & Schuster, 1230 Avenue of the Americas, New York, NY 10020
Published 1995
Order on-line: www.simonsays.com