

# Caregiving

*... when a loved one has ALS*



## **COPING WITH ALS**

People living with ALS are continually faced with change and finding ways to cope with it. Patients, their families and caregivers alike 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 patients and families continually find effective ways to cope with the symptoms of the disease.

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 patient 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.

## 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, patients 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 (ALSA) has a network of chapters and support groups across the United States.

**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 ALSA chapter, or call the National Respite Locator Service at 1-800-773-5433, [www.respitelocator.org](http://www.respitelocator.org).

### **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.

*(Reprinted with permission from the American Association of Retired Persons (AARP))*



### **The ALS Association**

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*Phone* (818) 880-9007

*Fax* (818) 880-9006

*E-mail* [alsinfo@alsa-national.org](mailto:alsinfo@alsa-national.org)

*Web site* [www.alsa.org](http://www.alsa.org)

### **National Family Caregivers Association**

10400 Connecticut Avenue, Suite 500  
Kensington, MD 20895-3944

*Phone* (301) 942-6430

(800) 896-3650

*Fax* (301) 942-2302

*E-mail:* [info@nfcacares.org](mailto:info@nfcacares.org)

*Web site:* [www.nfcacares.org](http://www.nfcacares.org)

### **National Alliance for Caregiving**

4720 Montgomery Lane, Suite 642  
Bethesda, MD 20814

*Phone* (301) 718-8444

*Fax* (301) 652-7711

*E-mail* [info@caregiving.org](mailto:info@caregiving.org)

*Web site* [www.caregiving.org](http://www.caregiving.org)

### **Family Caregiver Alliance**

690 Market Street, Suite 600  
San Francisco, CA 94104

*Phone* (415) 434-3388

(800) 445-8106 (*in California*)

*Fax* (415) 434-3508

*E-mail:* [Info@caregiver.org](mailto:Info@caregiver.org)

*Web site:* [www.caregiver.org](http://www.caregiver.org)

### *Other Web Sites*

*(web addresses correct as of July 2002)*

#### **CareGuide**

*Web site:* [www.careguide.com/](http://www.careguide.com/)

#### **Empowering Caregivers**

*Web site:* [www.care-givers.com](http://www.care-givers.com)

#### **ElderCare Online**

*Web site:* [www.ec-online.net](http://www.ec-online.net)

#### **Today's Caregiver On-line**

*Web site:* [www.caregiver.com](http://www.caregiver.com)



## SUGGESTED READING

### Living with ALS

A series of six manuals provided to ALS patients and caregivers without charge by The ALS Association. First published by The ALS Association in 1997; revised 2002.


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*

### Caregiving: The Spiritual Journey of Love, Loss and Renewal

By Beth Witrogen McLeod  
Wiley & Sons Publishing  
Published 1999

### 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](http://www.simonsays.com)  
\$14.00, paper back/ ISBN 0-684-822367



The ALS Association is the only national not-for-profit voluntary health organization dedicated solely to combatting ALS. The mission of The ALS Association is to find a cure for and improve living with ALS.

Information & Referral Service: 800/782-4747

For information about The ALS Association's other programs, please visit ALSA's web site: [www.alsa.org](http://www.alsa.org)



**The Amyotrophic Lateral Sclerosis Association**

*National Office*

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Calabasas Hills, CA 91301-5104

818/880-9007

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