

# Patient and Family Resource Guide to ALS

## Section 3 Coping with ALS

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# Coping with ALS

Managing the emotional stress of ALS for patients and caregivers can be an incredibly difficult task for both patients and family members. The unpredictable progression of the patient's physical deterioration contributes to a myriad of feelings that can be very overwhelming.

Depending on the physical challenges, a patient may experience the loss of the ability to:

- Walk, which reduces mobility and the sense of independence
- Use of upper extremities, making dressing, bathing and toileting difficult, which can contribute to a loss of dignity, independence and self-image.
- Speak, resulting in communication and human interaction being more difficult.
- Eat, leading to the loss of independence and opportunities for social interaction.

Trying to identify and name the feelings associated with these issues, such as helplessness, fear, loneliness or anger may help a person to process those feelings. Naming or labeling helps a person with ALS or family member to feel less out of control. It may also help to improve communication between the patient and loved ones.

People with ALS have emotional and physical issues with which to cope. Sometimes when a person cannot move freely, muscles become sore and painful from remaining in the same position. People also have emotional responses to the changes they experience in their lives as a result of physical challenges. For example, some individuals can feel worthless when they can no longer manage responsibilities at home, such as mowing the lawn, taking out the garbage, cooking, or doing the laundry. Others experience intense feelings when they are no longer able to work outside the home or to take care of young children.

The family also has emotional and physical issues to deal with, including helplessness and frustration. Sometimes people with ALS and family members are experiencing different emotions and have different needs. Emotions change from day-to-day; some days they even change from hour to hour. Depression and/or anxiety are very common when trying to cope with ALS. The Les Turner ALS Foundation social workers are available to people with ALS and their family members for counseling in the home and they can help plan strategies to manage the day-to-day challenges brought about by ALS.

It is common to feel overwhelmed when the home environment becomes difficult to navigate. It is important to recognize this, as it is often the cause of frustration, anger and emotional angst. A home assessment by one of our ALS Patient and Family advocates can assist families in maximizing home accessibility and identify when upcoming changes may be needed. The individual's physical changes may also cause a change in roles within the extended family and circle of friends. Those who are used to being "helpers" or "givers" can find it especially difficult to accept the fact that they now need help themselves. This is the time to accept help, and to even ask for what is needed. Often family and friends want to do something, but they

don't know exactly how to help. There are many websites that allow an ALS family to identify their needs and request help. The following are some recommended websites:

- [www.caringbridge.org](http://www.caringbridge.org)
- [www.takethemameal.com](http://www.takethemameal.com)
- [www.mealtrain.com](http://www.mealtrain.com)
- [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)

## Tips for Coping for Persons with ALS

- Break tasks into smaller pieces and do a little bit at a time
- Change your expectations of yourself; understand that you cannot do all that you were doing before AND manage this disease
- Talk to your friends and share the emotional burden
- Ask for help
- Accept help

## Tips for Coping for Caregivers

- Don't ignore your own body, especially if you have medications to take and doctor's appointments to keep
- Arrange to get out of the house on a regular basis, even if just for a 15-minute walk.
- Although you may feel that it is much more important to focus on the person with ALS, you cannot take care of him/her if you become ill
- Talk to your friends and share the emotional burden
- Ask for help
- Accept help

## Resources for Coping:

- **Counseling**  
A Licensed Clinical Social Worker from the Les Turner ALS Foundation can provide counseling for the person with ALS and/or family members, including children in your own home. These visits are scheduled by appointment and are available at *no cost* to the patient and family.
- **General Caregiver information**  
[www.caregiver.org](http://www.caregiver.org) provides information from the Family Caregiver Alliance  
[www.nfcacares.org](http://www.nfcacares.org) provides information from the National Family Caregivers' Association
- **Support groups**  
Support groups are led by Les Turner ALS Foundation professionals. There are in-person monthly meetings in Barrington, Skokie, Wheaton, Chicago as well as virtual

support groups. Please check the Foundation website for current meeting dates ([www.lesturnerals.org](http://www.lesturnerals.org)) or call 847-679-3311.

### **What is a support group?**

A support group is an opportunity for persons with ALS and caregivers to give and receive emotional support and to share information and practical tips. This may include sharing ideas for how to improve function, receiving drug trial information or learning the latest in technological advances. Each group is led by two professional facilitators, which allows participants to divide into two groups: a PALS group and a caregiver group. While they are separated, members of each group have the opportunity to speak freely without worrying about hurting a loved one's feelings. Occasionally a guest speaker attends a meeting. All information and support provided is geared to help cope with the disease in order to maintain as high a quality of life as possible.

### **Why participate in an ALS support group?**

Support groups are a resource to help patients and family members feel a sense of camaraderie with others who are living with ALS. No one can understand the feelings involved better than another patient or caregiver who is also struggling to live with ALS. At support group meetings, some things just do not have to be explained, as they often do in other social situations. The group provides a kind of emotional respite, with understanding and compassion.

### **Can I come to a group if I am afraid to share my feelings?**

Some participants may decide to simply listen, and that is okay. However, most group members soon feel that the support group is a safe place to share feelings. It provides an opportunity to learn how other patients and families cope with similar problems. Most people find that talking with others whose lives have been altered by ALS is helpful.

### **Can I ask questions about practical matters such as drug trials or equipment?**

You can ask about absolutely anything at a support group meeting. The meeting's agenda is to meet the needs of the patients and family members who attend the group.

### **Coping with the Stress of ALS in the Family**

The issue of how children cope when ALS is in the family is extremely complicated for several reasons. The physiological capability of the brain is quite different at various ages. These differences are often referred to as the developmental stage of a child. The developmental stage tells us what we may presume a child has the capability to process and understand. However, within those stages there are always individual variations. Regardless of the child's age or developmental level, the most important thing you can tell her/him is the truth.

When someone in the family has ALS, there is a certain amount of pain from which children cannot be shielded. Therefore, it is most important that children know they can still go to the most trusted grown-ups in their lives to obtain information as they feel ready to ask questions. If children do not ask questions, it is equally as important for those grown-ups to regularly let them know that they are welcome to talk about any concerns at any time. It is a good idea to consult

with one of the Foundation's social workers regarding the extremely important task of supporting the children in the family at various points throughout the disease process.

*Disclaimer: All care has been taken in preparing this document. This information is of a general nature and should be used as a guide only. Always consult your health care team before starting any treatments.*