Care for the Caregiver

Caring for your loved one with ALS is not easy. You feel like you are on a roller coaster with emotions; afraid, happy, sad, guilty, anger, embarrassed and helpless. These feelings are all normal. Just because you have negative feelings does not mean you are not a good caregiver. It means you are real, honest and human. Like they say on a plane, “In the event of an emergency, put the oxygen on yourself first and then help those you are traveling with”.

Get your mask on and let’s get some air:

1. **Breathe.** Take a Walk. Put those shoes on and just go around the block. Eat healthy and plan time away. If you wait until you are ready to scream, it will take you longer to relax.

2. **Get Support.** There are always friends and family who ask what they can do. Have a list ready. Simple errands like dropping off dry cleaning, taking car to the garage or picking up groceries need to be on the list and are easy enough to do. Accepting their offers. It may feel weird at first but you will find that people really like helping.

3. **Share your feelings.** You have got to have someone to talk to. A close friend or family member can be just the shoulder you need. If it is too hard, then seek out an ALS support group. Talking to another caregiver can be just what you need. If you want to be private, then seek out a trained professional.

4. **Choices.** You cannot be everything to everyone. Setting your boundaries is necessary for survival. Be realistic. Practice saying, “Oh I wish I could help, but I can’t right now”. Stop, don’t say another word. You don’t need to explain any further.

Seek out volunteer programs that may be in your area from church organizations or community services. If you live in Boise, Boston, Dallas- Ft Worth, Los Angeles, Orange County, San Francisco Bay area or St. Louis, you can contact the fabulous program called Extra Hands. Extra Hands was started by an ALS patient in St. Louis. Student volunteers they will wash the dishes, walk the dog, read you the newspaper, or any other non-medical task you want. ALS patients have much to teach the Extra Hands student about courage and determination. Their site is [http://www.extrahands.org](http://www.extrahands.org) or contact at (314) 997-2311.