



Tips for Newly-Diagnosed ALS Patients from Will Hubben

Will Hubben was diagnosed with Lou Gehrig's disease in July 1998 and died in May 2004. In November 2000, Will created The ALS Research Digest, an electronic newsletter designed to provide information about the disease to the ALS community. Shortly before he passed away, Will provided ALSA with a number of coping devices he used that helped him immeasurably. In his tips for newly diagnosed ALS patients, Will shared what helped him along the way and some advice that he wished he had followed sooner rather than later.

- 1. Be compassionate to yourself.** If you are like me, your first reaction to being told you may have ALS is shock and fear. We all go through wild emotional swings when we hear such dreadful news. Allow yourself to go through denial, grief, anger, and whatever else you feel without criticizing yourself for it. It's natural and necessary for you to experience powerful emotions. Many feelings will arise again and again as ALS progresses. This will pass, and being gentle with yourself is a big help.
- 2. Reach out to family and friends.** Many people may want to help and not know how. Talking openly to a family member or friend about your situation will help both of you cope. Ask for assistance with preparing meals, running errands, doing household chores, or ask to be taken to the movies. Building a support network will help you and your primary caregiver. Also, this allows family and friends to get involved.
- 3. Learn about ALS. Knowledge is power.** ALS tends to make people feel powerless. Learning all you can about the disease, about supplements and drugs that might slow progression, and about current research, can help empower you. Sharing what you learn will help raise awareness about ALS and the need for more research money.
- 4. Do everything you can for your health.** Improve your diet, quit smoking, take up yoga and/or meditation, practice positive visualization, get plenty of sleep, and work with your doctor to develop your own regimen of helpful vitamins. Every little effort will help you, both physically and mentally.
- 5. Take charge of your treatment.** Pick your health care providers carefully. Remember, they work for you. Talk to your primary care provider and your neurologist about any vitamins and supplements you may want to take. Ask lots of questions. If they don't patiently and respectfully answer (or research) all of your questions, fire them and find someone else. Don't be passive about your treatment options. You are always in charge.





6. Develop a relationship with a major ALS center. Centers and clinics associated with The ALS Association have a lot of experience with ALS. They take a multidisciplinary approach with ALS patients and can be helpful at every stage of the disease. The ALS clinical team is there every step of the way to provide expert medical care to people living with ALS. A list of ALS centers and clinics affiliated with The ALS Association can be found at <http://www.alsa.org/community/centers.cfm>.

7. Do things you have always wanted to do. Take that trip to Europe, spend more time with your family, go skydiving, write a book, or raft the Grand Canyon. Whatever it is, go ahead and do it. In a few months, you may no longer be able to do these activities.

8. Find ways to help others. One of the best ways you can help yourself is to help other people with ALS. Consider raising money for research, joining advocacy efforts, volunteering for clinical trials, attending support groups, and reaching out to others who need emotional support. Giving to others enriches your life as well as theirs.

9. Practice hopeful, positive thinking. Maintaining a positive attitude in the midst of trying circumstances takes practice, but it's worth it. Not only is your moment-to-moment experience improved, but experts agree that a positive attitude can improve your body's resistance to disease. Remaining hopeful helps me to enjoy my life, in each moment. In addition, a lot of promising research is being conducted in many different areas of investigation. Remember, a breakthrough could happen at any time.

10. Stay ahead of the curve. Get a wheelchair when walking difficulties begin, even though you can still walk. Get a feeding tube before you lose weight. Begin using augmentative communication aids before you need them. Get respiratory support by using a BiPAP at night as soon as possible. By taking these and other steps early, you remain in control. No one with this disease regrets doing these things early; many regret waiting too long.

The ALS Association thanks Will Hubben for his contribution to this FYI.

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