

## ADVICE FOR CAREGIVING

The caregiver's part, usually the partner, is very important. He/she is the biggest support after all. But caregiving means offering both physical and emotional support. And this is very exhausting. Especially when there's a household that needs to be run and when there are still children who go to school. On top of that it's also difficult for the caregiver to accept the disease of the partner, because this means the partner will, in a very short period of time, begin to go downhill more and more.

Furthermore there will also be hospital appointments. Here too you, as caregiver, are the most qualified person to stand by your loved one and support them. But a hospital visit does require some preparation.

Each time you go to the hospital, you should bring along a list of your spouse's medicine, with exact doses and other details if necessary. It would also come in handy if you write down a list of all your questions up ahead so you definitely won't forget anything.

Don't hesitate to, aside from the questions you ask, ask for more explanation, seeing as you sometimes need to talk to different specialists, like a neurologist, respiratory therapist, physical therapist, nutritionist and so on. If you don't understand something or are uncertain to execute certain things, ask for more information or suggest a demonstration.

Take something along to take notes so you can reread everything later on, when you have time or have doubts. When you own an iPad, you can record the demonstration. Because at the hospital it might not look so difficult, but when you're home you can start having doubts.

ALS is a progressive disease, so you constantly have to learn new things, seeing as the situation can change a lot in a short period of time. That's why it's necessary to properly keep in touch and communicate well with all therapists.

At the hospital they'll probably also paint a picture as to how the disease will evolve in the future. It might be possible that they'll tell you that, the next time you visit, they'll consider adding a feeding tube or that a voice generator will be necessary. This verdict will in most cases be extremely difficult to hear on a psychological level. And no one wants to be confronted with such things ahead of time. And yet it's good to know what will happen in the future so you can somewhat prepare for it psychologically. If a voice generator would be necessary in the near future, you should gather some information up ahead about how existing communication devices work,

so you know your partner will get what they need when the situation occurs.

It's very important to keep the faith and not lose your courage. Because there will be hard days and milder days. Sometimes you'll want to cry all day but on other days you'll be able to accept everything a bit better and try not to fight it. It's part of the process. Sometimes these 'tear days' will come from very small things. For example opening a photo album. Because living with ALS has you going through a whole range of emotions.

Having enough faith and courage to keep on going starts by taking care of yourself, both physically and mentally. Research shows that people who take care of patients with a chronic disease, sometimes put their own physical and mental health on the line. So don't forget to take care of your own wellbeing and health. If you don't take care of yourself, you run the risk of getting sick as well. We'll begin with physical health. If possible, ask for help with your chores, hire a cleaning lady, take clothes that need to be ironed to an ironing service, ask someone to do the groceries. In any case, try to avoid fatigue. By taking a break in time or organizing fun things, such as taking a walk, meeting friends, sporting a little. Because making time for your own things is extremely important. It's what causes you not to lose courage and to keep up your task as a caregiver.

Concerning mental health and coping with it, it might help you as caregiver to write down all the grief, emotions, fears and thoughts. It's a good idea to keep a diary in which you can put everything together. The benefit of a diary is that after a while you will notice there is progress in your coping process after all.

For those who don't like to write, counseling might be a bigger help. Talk about your deepest feelings with a counselor or psychologist.

It's also important to talk or write about your dreams. Because it's a fact that, as a partner, you'll have to adjust your dreams as well. You'll have to reformulate and adjust your future projects. Because even simple things suddenly become a whole lot more difficult now. These new adjusted dreams will definitely help to accept the new situation.

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