

Some useful tips for during the initial phase

Because the order in which and the time when the different symptoms occur can differ greatly with each patient, the disease ALS is difficult to divide into 'phases'. An initial phase after the diagnosis and a final phase with complete ADL dependency, can be distinguished.

After the diagnosis

After the diagnosis is clear the ALS patient has a great need for information on one hand, on the other hand this information can be very threatening and frightening to the patient. You have to realize that the ALS patient lives in hope and fear and continually lives in a crisis processing situation, with diverse phases. We'll run through the different phases in both an emotional and rational way. The information can best be given in the shape of an anticipating counseling, where the 'bad news', which means actual problems and the complications in the near future that go with it, and 'good news', which means that which they can (symptomatically) do something about, are always combined.

Tools

Sometimes we're astonished when we see the most clever solutions for problems of ALS patients. A device to talk, a chair which can stand in every position, the possibilities seem endless. In reality the wonderful tools can be disappointing. Each patient has different needs and on top of that the needs change as the disability increases. Furthermore the prices are high and the application requires a lot of time. The quality isn't always as excellent. In this chapter we'll mention a few provisions which each patient will need sooner or later. Different caregivers can share information about this. By the way, in reality the most cases will be talked over with the nurse, therapist or the doctor, to decide in each specific case what the best tool is.

Tips for psychological support:

Accepting ALS doesn't mean giving up on the disease. It has to be the first step to make the best of living with ALS. There's a lot that can be done to help someone with ALS live a productive and enjoyable life. As a family member or friend you'll be capable of offering help in many practical ways. The probably most important contribution is psychological support. Be positive but don't trivialize the situation. On the other hand it's not necessary to stand still at the negative aspects of the disease. Family and friends of people with ALS have to try and find a right balance between hope and reality. This is not an easy task. For some people with ALS and their family the spiritual can be a true source of strength. The ALS Liga as well, which is dedicated to help people with ALS and their family deal with the disease, can be a big support, simply the feeling that someone is always there for you.

Mobility:

Exercises for ALS patients have the goal to retain strength or strengthen muscles that haven't been affected by ALS and retain the suppleness of the affected muscles. It's important to realize that exercising the muscles that have already been weakened by Amyotrophic Lateral Sclerosis will not get stronger. The right exercising program can keep the stiffness of the joints and muscles to a minimum. We won't discuss any specific movement amplitude exercises for the simple reason that each ALS patient needs an exercise program which is adapted to their own individual needs and possibilities. It's important that all exercises are executed up to a certain extent. Exhaustion can only worsen the weakness and can lessen the energy the patient needs for the daily bathroom visit.