

TIPS

DEALING WITH ALS

When you are diagnosed with ALS, it may feel like your life falls apart. The following tips can help you and your family to deal with the news.

- **Take time to grieve**

It's probably difficult to grasp that you have a fatal illness which will decrease your mobility and independence. After the diagnosis you and your family will most likely go through a period of grief and sorrow.

- **Remain hopeful**

Your treatment team will help you remain focused on a healthy way of living and the things you can do. Some people with ALS live longer than the three or five years that is usually given as prognosis. Some patients even live another ten years or longer. Remaining positive can benefit your quality of living.

- **Look beyond the physical changes**

A lot of people who suffer from ALS lead, despite the physical limitations, a rich, satisfying life. Try to see ALS as a part of your life, not as what identifies you.

- **Join a patient organization**

It can be nice to share your worries with other ALS patients. Family members and friends who are involved in your care can also benefit from contact with others who also care for someone with ALS. You can find patient organizations nearby through your doctor or the ALS organization.

- **Make decisions now concerning future medical care**

By making plans for the future you remain in charge of decisions that concern your life and care.

With help from your doctor, hospice nurse or social worker you can decide whether you want to have certain life prolonging treatments executed. Make sure to apply for the LEIFcard:

<http://leifkaart.nu/leifkaart/>

You can also decide where you'd like to spend your remaining days. You can consider several options regarding hospice care. Making plans for the future can help you and your surroundings to let go of worries and fears that a lot of people have.

Get in touch with us if you have suggestions or ideas or if you feel the need to talk about this subject.

Translation: Sara De Roy