

CONTROLLING ALS SYMPTOMS: HOW TO REMAIN AS COMFORTABLE AND INDEPENDENT AS POSSIBLE

ALS is a terribly laborious disease. Since you become weaker over time, there are many serious life-threatening changes, which should be kept well under control by a medical team. There are also changes that are not life-threatening, but which nevertheless have an impact on your daily life. By controlling these not life-threatening ALS symptoms, you can still improve your life quality in this neurological disease.

Pain and cramps

ALS stops the signals that are sent from the brain to the muscles. Besides muscle weakness, cramps can also occur. In addition, you can be too weak to get yourself in a comfortable position, which can lead to pain.

It is not clear what is best to relieve this discomfort. Studies have shown that custom exercises give great results. Simple stretching exercises and physiotherapy may help to reduce the cramps associated with this disease. Some medications such as Baclofen, Dantrolene and Tizanidine have shown to be able to relieve muscle spasms.

The pain associated with ALS can be treated with the same medications as those who normally prescribed by the doctors, eg. medications such as Ibuprofen or Acetaminophen. When the disease progresses, stronger medications is to be pre-scribed. This should be prescribed with great caution, because of the risk of respiratory disorders, especially for pALS that are already very weakened by their illness.

Discuss, therefore, first of all with your doctor what medication can be prescribed in your case.

Dementia

ALS sometimes appears together with dementia. It is estimated that 15 to 41% of ALS patients have cognitive changes, depending on how these changes are tested. The most common form of dementia, connected with ALS, is frontal lobe dementia with reduced understanding, changed social behaviour and emotional blunting. There is little agreement on how this dementia can best be controlled and it is certainly not an easy treatment. Sometimes dementia can actually be the result of insufficient sleep or depression, and that is why it is very important to ensure that these complaints are being treated. In the other case, this form of dementia is to be governed by a team of doctors, usually a neurologist, a psychiatrist and a social worker or health care professional. As always, planning is very important here.

Mood

With all the negative changes occurring after the diagnosis of ALS, depression and anxiety may be expected. Surprisingly, these mood changes seem to be less common with pALS, than with people suffering from other diseases, such as epilepsy. If this feeling is present, these symptoms are best treated with a combination of advice, therapy, and medications, such as sedatives or antidepressants. But always in consultation with the doctor.

ALS can also bring on other changes that imitate depression and anxiety. For example, what feels like depression can actually be fatigue. That fatigue is probably due to muscle tension, poor sleep or neurological changes for ALS patients with pseudo-bulbar symptoms. These symptoms are better known as Involuntary Emotional Expression Disorder (IEED). This means that your emotions are unstable, and that you start laughing uncontrollably or shouting in inappropriate situations. A combination of Dextromethorphan and Quinidine has been proven to be effective to control this. Discuss this, however, firstly with your doctor.

Sleep

Insomnia can worsen the fatigue, mood and concentration of pALS. With ALS, a reduced capacity to fall or stay asleep probably results from rising breathing difficulties, worrying, depression or pain. The best approach is to try to treat the underlying problem. For example, is the respiratory therapy satisfactory enough for you, as ALS patient who is suffering from insomnia? In any case, possible calming or hypnotic medications should only be used if there is no alternative left, since they often reduce breathing capacity.

Communication

One of the most frustrating aspects of ALS is losing the ability to communicate normally. As the muscles of the face and larynx weaken, one has to search for new ways to communicate. Fortunately, there are different types of communication devices available, such as alphabet boards, automated systems, Morse code, use of the anal sphincter or infra-red eye movements, according to the needs of the person. Working with a speech therapist can ensure that one is able to communicate as long as possible.

Palliative care

Experts in palliative care specialize in keeping the patient comfortable for as long as possible. This is not the

same as palliative care in the hospital. There, palliative care is only reserved for patients in the last six months of life. If the symptoms of ALS worsen strongly, you can work with palliative care specialists to ensure your comfort and your dignity is maintained as best as possible.

The importance of planning ahead

To always remain as comfortable as possible, you should always plan ahead. ALS is a terminal illness, which usually leads to death within five years. Because some ALS patients live longer, it is very important to plan ahead. Plans for your future health care is very important with this disease. Knowing exactly what types of treatments are desirable in case of total paralysis or possible dementia should be considered and discussed. These are very personal decisions, and it is important that your wishes will be respected. A will or power of attorney can ensure that your wishes will be respected.

Support

If you are diagnosed with ALS recently, you are not alone. Others are already gone before you in what you are experiencing, and there are many books and other resources available. Working with a multidisciplinary neurological clinic is probably best for improving your quality of life and optimizing the necessary health care. You'll also need help from friends, family and caregivers, since your illness progresses. Feel free to ask help yourself to all the people supporting you.

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