

THE 10 COMMANDMENTS FOR THE TREATMENT OF ALS

To control ALS of a patient in an optimal way a number of principles need to be followed.

1. Turn every **stone upside down**

The diagnosis is a task of specialists and needs to be confirmed independently, given the diagnosis relies on clinical examination only and there is no objective laboratory test for this disease for the time being. The Amyotrophic Lateral Sclerosis (ALS) type of MND is in most of the cases fatal and each patient has the right on the confirmation of the diagnosis by a specialist.

2. Hope springs eternal.

Even if no other diagnosis seems possible, one should not give up the hope of a less serious outcome. The initial diagnosis ALS could later possibly be weakened and other forms of MND are less malignant. Disintegrate not all hope.

3. **ALS is a 'family disease'**

As soon as the diagnosis has been confirmed, the whole family should be involved in the treatment, as a lot of the pressure will also hit them, and not only the patient. Encourage family members to be present during tests, examinations etc...

4. **Be there early to improve the symptoms.**

A lot of symptoms can be mitigated thanks to a range of simple treatments that can slow down the progression of the disease. Not doing this would be a shortcoming and above all unworthy. Do not pile problems that can be treated where the situation is hard enough already. As the disease worsens and the terminal stage is reached, a generous dose of narcotics during the last days will guarantee a certain comfort, while there is no danger for addiction. Start with full courage and make sure you can carry on like that.

5. **You are not abandoned and left alone**

Early participation in experimental treatments confirms in fact that the ALS patient is not abandoned nor alone: researchers of world renown actively search for a solution for this disease.

6. **However simple, nothing is better than home**

In most of the cases home care is the best solution. Brief hospitalizations for special treatments can be appropriate in a later stage of the disease. However, we recommend the family that at least one member of the family would remain present during the night.

7. **A well informed patient is the best judge of his illness**

Notifying every patient as soon as possible of the likely course of the disease, shows respect for his intelligence and integrity. A decision on what a patient can find the best, always has to be respected. The difficult decisions concerning life support and assistance have to be discussed in an early stage, without any prejudice. The patient should take these decisions himself beforehand. Refusal by the patient to take part in research, his/her choice with regard to life support or his/her wish to follow doubtful treatments or alternative medicines such as vitamin cures, acupuncture, meditation, etc.. should not be drawn into the ridiculous; professional care providers should therefore not lose the focus on the patient.

8. **The patient has the last word**

Never forget that the patient ultimately decides; doctors, nurses, physiotherapists and other providers of health care, are there to help the patient and to support his family in order to be able to live with ALS as well as possible.

9. **Watch over the financial and family situation**

Equal attention should be paid to family life and family finances, especially if the ALS patient is the breadwinner or head of the family.

10. **Keep the spirits up with the patient and his family**

Support the morale of the patient and his family, offer them breathers and assistance during this difficult period. This is perhaps the most important commandment in the treatment from people with ALS. As morale disappears, everything will inevitably go from bad to worse, even the quality of the care. On the other hand a good morale can be a compensation for a lot of, seemingly disastrous, problems.

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On the same page there are also some ideas aimed at pALS, written by Morrie Schwartz.

6 Advices for pALS.

1. Develop yourself the ability to accept voluntarily there are things you can no longer do.
2. Think back to your past, but don't try to return to live in your past. Think back to your past with warm feelings.
3. Concentrate attentively on things that are important for you. Stay committed on it.
4. Enjoy as much as possible how and when you can. Joy can be found in the most unexpected places.
5. Keep you strong by thinking positively, through inner peace, self-respect and self-esteem.
6. Look at yourself as part of nature. Don't forget that it is normal to exit your life with your death. Accept your mortality and try to leave your life behind with inner peace.