
The **ALS** counsellor scheme in Denmark

Facts:

Denmark has about 5 million inhabitants.
The incidence of ALS is about 5.
The prevalence of ALS is about 300.

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Background:

Since 1998, the Institute for Neuromuscular Diseases has completed three studies concerning people with ALS.

The first study concluded that treatment and support options exist within the Danish Social and Health System which might benefit people with ALS.

These are, however, only to a limited extent offered to people with ALS.

The second study analysed the current treatment options at the hospitals and evaluated the quality and co-ordination of the treatment.

The study concluded that quality targets could be set up resulting in improved treatment for people with ALS.

Improvement is only possible if interdisciplinary knowledge and experience are centralised and co-ordinated both in the hospital sector and the municipal sectors and, not least between the two sectors themselves.

The third study analysed methods and models for gathering and disseminating information, in order to promote a co-ordinated and continuous approach to the management and care provided by the hospital and the municipal sectors to the ALS patient throughout the course of his disease.

The study concluded that in spite of the increased co-ordination between the hospital and the municipal sectors there is still a huge demand for information about the disease and its consequences.

Furthermore, establishing a local network around and with ALS patients and their relatives is important.

This led on to the fourth project, where the ALS counsellors' appointments have been extended by 3 years and supplemented with a half-time psychologist.

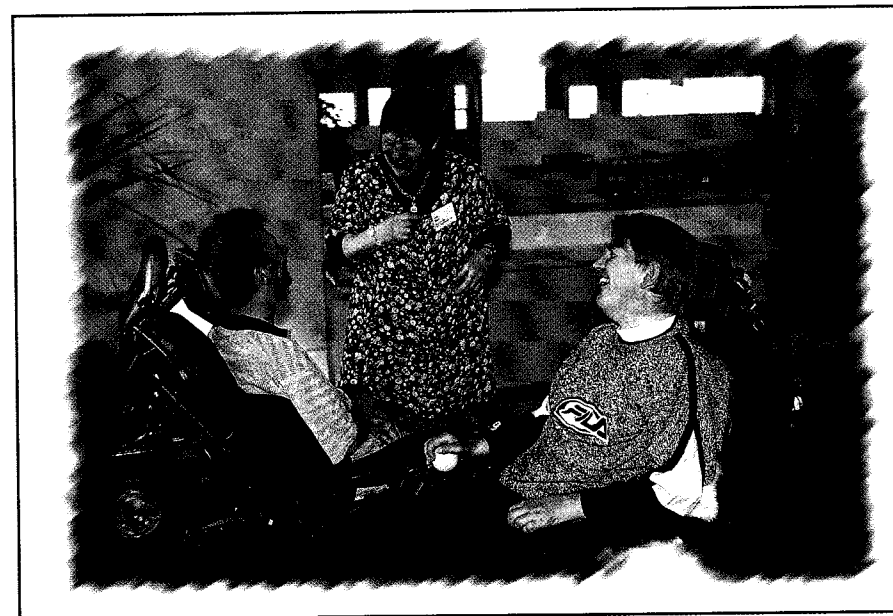


Foto: Niels Juel Berg

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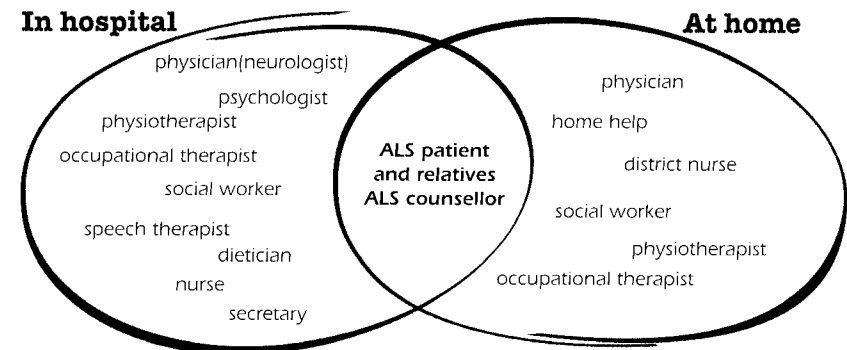
The objective of a counsellor scheme for ALS patients and their relatives is to promote the development of a network around and with the ALS person in order to ensure that the help and support needed are based on a co-ordinated interdisciplinary management from hospital and local area, and that this management is based on knowledge of and experience in the course of the disease and the possibilities for treatment and support.



Methods:

ALS patients are referred to or informed about the scheme by 15 Danish neurological departments with ALS teams. The ALS counsellors' attention is divided between individual- and group based offers. The starting point is an examination of the individual's resources and needs, where both the patient and the relative(s) participate in the decision-making process.

Essential tasks for the counsellors are to create flexibility in order to enable the local network to readjust to an actual problem at any given point in the course of the disease, and to contribute to the awareness of a joint goal, a mutual understanding of agreements, and a sharing of responsibility.



The ALS counsellors' work/working areas:

When giving advice, the counsellors lay weight on the need to cut across professional barriers and sectors to co-ordinate efforts and provide an overall evaluation of the situation.

The ALS counsellor may offer, inter alia, to:

- Prepare and guide the local authority, in collaboration with the hospital service, concerning need for help and support.
- Arrange home visits and participate in interdisciplinary meetings with the ALS patient, the relative(s) and local carers, e.g. home help, visiting nurse, occupational therapist, physiotherapist, social worker and the patient's G.P.
- Draft a report concerning agreements reached during the home visit/interdisciplinary meeting.
- Provide guidance on e.g. personal and practical help, homefitings, choice of technical equipment or help in handling the crises which may result from the disease.
- Participate in hospital check-ups to ensure treatment initiatives are followed up locally.
- Teach and supervise home help and local carers.
- Serve as sparring partners for the hospital ALS team.
- Arrange themedays and courses for ALS patients, their relatives and carers, partly to provide guidance on the disease, its treatment, equipment and so on, partly to provide the families with an opportunity for meeting others in similar situations.



Foto: Claus Haagensen/Chili

Who can use the counsellors?

Anybody with ALS, their relatives and people dealing with ALS professionally may avail themselves of the counsellor scheme. Most of the ALS patients will be referred by the hospital doctor and will then be contacted by an ALS counsellor.

The services of the ALS counsellors are free.

The counsellor scheme has been established in collaboration with the Ministry for Social Affairs as a 3-year project running from 1st May 1999 to 30 th. April 2002.



Foto: Claus Haagensen/Chili