

# Well-being and care burden of close relatives to persons with ALS-FTD

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#### BACKGROUND

It is well documented that many ALS patients will experience changes in their personality which in turn will lead to frontotemporal dementia.

At RCFM, we focus on rehabilitation of the entire family affected by ALS. Relatives to ALS patients with FTD or a behavioral variant of FTD (bvFTD) experience more problems in their everyday lives than regular ALS families, and with that, a heavier care burden that leads to reduced well-being. The burden only increases as the physical function declines.

## AIM AND METHOD

To examine whether RCFM can improve the well-being of close relatives by initiating targeted ALS-FTD rehabilitation including:

- Identification of ALS-FTD problem areas
- Verbalizing everyday problems such as change of roles, care burden and wellbeing
- Informing and teaching about the causes

#### RESULTS

We interviewed 15 ALS couples of which 13 were included in the project.

The population consisted of 9 male and 4 female patients, mean age 66 (range 52 – 76) and 4 male and 9 female relatives, mean age 65 (range 50 – 75).

The pilot study of 13 ALS patients shows that ALS-FTD presents in many ways, and no correlation was found between the different scores. Interviews with relatives and the use of ALS-FTD-Q helped identify problem areas which were not previously mentioned – problems related to shame, sorrow, anger, and frustration. The relatives felt it was a relief to talk about their problems and receive help with the problem areas of ALS-FTD behavior.



and background for behavioral changes

Psychologist sessions, pedagogic support and strategies to handle adverse behavior.

Only ALS-FTD patients with a close relative were included in the study, and all interviews and tests took place at the ALS patients' own home. One consultant tested the ALS patient using the ALS-FRS-R and The Edinburgh Cognitive and Behavioral ALS Screen (ECAS) while another consultant interviewed the relative using the Zarit Burden interview (ZBI) comprising 22 questions, the ALS-FTD-Q screening tool and WHO's index of wellbeing.

We asked the relatives to identify five areas in which they needed information and support. Based on those, we initiated interventions such as information to home nurses and helpers, counselling sessions with a psychologist, information to the family including adult children, assistance from a dementia coordinator, etc.

Rehabilitation aimed specifically at FTD problem areas cannot relieve relatives from the burden, but it can help them make strategies for living and coping with the affected significant other.

Interventions such as home visits to screen for and inform about FTD are time-consuming with an estimated 15 to 60 consultant hours per patient in this pilot study (visits, phone calls, emails) not including transportation.

WHO-5 and a qualitative, unstructured telephone interview with the relatives were used as assessment measures.







### **RECOMMENDATIONS TO THE FIELD**

The relatives recommend that we provide additional information on the combination ALS-FTD and what to expect during the course of the disease. They also request information on where to get help in their local area from people with specialist knowledge about dementia/FTD.

#### **RCFM** recommends

That screening for behavioral changes and FTD is included in the total diagnostic workup and that it is assessed regularly during outpatient evaluations;

That the rehabilitative intervention is designed individually with the patients' and their relatives' resources as its point of departure;

That information and education include sessions with a psychologist and is offered to adult children, helpers and care personnel as well as the patient and his/her spouse.

Finally, we suggest that participation in network groups could have a positive effect on relatives.