

Young Onset Dementia – the difficult diagnosis and the stressful life for the whole family

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Norway

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Young Onset Dementia - the difficult diagnosis and the stressful life for the whole family

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The project/programme is most relevant to:

Alzheimer's disease & other dementias

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Research Abstract

This is a 2 years observational study of young onset dementia patients (< 65 years, YOD) and their families to gain knowledge of the diagnostic assessment, the course of dementia, the patients/families needs and quality of life. It is in accordance with the goal of the Norwegian Dementia plan 2015. Alzheimer's disease (AD) and Frontotemporal dementia (FTD) patients and their carers will be studied. Power analyses show that 75 patients/carers in each group are needed. For comparison 100 older AD patients will be added. 1. Patients will be recruited from seven memory clinics. FTD patients will be included from memory clinics in Sweden, Denmark and Island. Patients will be examined at baseline, 12 and 24 month. At patient level function in activities of daily living, depression, quality of life, coping, cognition and neuropsychiatric symptoms will be measured. At carer level carers' stress, depression, coping and QoL will be measured. At societal level use of health resources, and costs of care will be examined. 2. The diagnostic assessment, time from first symptom to diagnosis and the barriers and facilitators of diagnostic work-up will be examined. To explore barriers and facilitators focus group interviews with 7-10 family doctors and 7-10 psychiatrist will be conducted. 3. The validity of diagnostic biomarkers; spinal fluid proteins and MRI will be examined. 4. To achieve information of patients' and carers' needs and service delivery we will collect information by: a questionnaire to carers at baseline, 12 and 24 months and interviews with 10-15 patients and 20-25 carers within six months after the diagnostic assessment. The interview guide and the questionnaire, will be made after input from focus group interviews with 5-7 patients, 5-7 carers, and 'Demensforbundet'. 5. In Oslo and Hamar we will develop a program on how to follow-up patients and carers over time in a co-operation between the memory clinics and the primary care service provi

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