

Behavioural Changes in ALS : What Families and Healthcare Professionals Need to Know

<https://neurodegenerationresearch.eu/survey/behavioural-changes-in-als-what-families-and-healthcare-professionals-need-to-know/>

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Ireland

Title of project or programme

Behavioural Changes in ALS : What Families and Healthcare Professionals Need to Know

Source of funding information

Health Research Board

Total sum awarded (Euro)

€ 59,972

Start date of award

14/12/2015

Total duration of award in years

1

Keywords

Research Abstract

Amyotrophic Lateral Sclerosis (ALS) (or Motor Neuron Disease (MND)) is a rapidly progressive neurodegeneration associated with loss of muscle power. Until recently, thinking and behaviour were considered unaffected, but we have shown that up to 50% of people with ALS/MND experience changes in their ability to plan complex tasks, and that family members also frequently notice changes in personality including increased apathy, rigidity, and reduced ability to recognise the needs of others. Although our research shows that changes in behaviour and personality significantly increase the burden of care for families, they are often not reported by families or recognised by health care professionals. Our research also shows that in some

families of people with ALS/MND, and especially those with personality changes, there are higher rates of other psychological and psychiatric conditions such as schizophrenia and bipolar disease, suggesting a genetic predisposition that links some psychiatric conditions with ALS/MND. Understanding this link in affected families is likely to help us to find new and more specific treatments for ALS. The purpose of this proposal is (1) Develop an educational programme for families of those with ALS/MND health care professionals, and inform the public at large about the cognitive, behavioural and personality changes that can occur in ALS/MND; (2) to explain how the possible links between these changes and psychological /psychiatric traits in family members could help us to find new treatments, and (3) to help health care professionals recognize the increased burden associated with thinking and personality changes.

Further information available at:

Types:

Investments < €500k

Member States:

Ireland

Diseases:

N/A

Years:

2016

Database Categories:

N/A

Database Tags:

N/A