

Living and dying with Amyotrophic Lateral Sclerosis: A Population based Analysis of Palliative Needs, Services and Outcomes in non-malignant terminal illness

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Principal Investigators

Professor Orla Hardiman

Institution

Trinity College Dublin

Contact information of lead PI

Country

Ireland

Title of project or programme

Living and dying with Amyotrophic Lateral Sclerosis: A Population based Analysis of Palliative Needs, Services and Outcomes in non-malignant terminal illness

Source of funding information

Health Research Board

Total sum awarded (Euro)

€ 625,518

Start date of award

07/01/2013

Total duration of award in years

4.0

The project/programme is most relevant to:

Motor Neuron Diseases

Keywords

Research Abstract

Amyotrophic Lateral Sclerosis (ALS) is a progressive neurodegenerative disease. Like the commoner neurodegenerative conditions of Alzheimer Disease, Parkinsons Disease and Frontotemporal dementia, there is no effective treatment. ALS is a good model to study neurodegenerative diseases, as diagnosis is accurate during life, and disease trajectory is rapid. Management of ALS and other neurodegenerations requires a multidimensional palliative approach. Outcome measurements are ideally based on symptom alleviation, quality of life measurements and financial assessments of cost effectiveness. Notwithstanding their complexity, the design of tools to determine and measure outcome is of vital importance. The best way to do this is to map disease progression and service utilization, to determine patients' and carers' experience of current services, and to apply this experience to the design of evidence based changes in practice. This is possible in Ireland, as we have a national Register of ALS, and because over 80% of all cases attend the National ALS Centre in Beaumont Hospital. This project will provide a best practice framework for how to manage the later stages of neurodegenerative disease, including a mechanism that will trigger specialist palliative intervention at the most appropriate time and in accordance with recent Irish health policy. The award will be used to build capacity and cross fertilization of skills in a range of areas including community care delivery and health economics amongst clinicians and academics.

Lay Summary

Further information available at:

Types:

Investments > €500k

Member States:

Ireland

Diseases:

Motor neurone diseases

Years:

2016

Database Categories:

N/A

Database Tags:

N/A