

# To live with amyotrophic lateral sclerosis (ALS): health-related quality of life, and use and satisfaction with care during the course of the disease

<https://neurodegenerationresearch.eu/survey/to-live-with-amyotrophic-lateral-sclerosis-als-health-related-quality-of-life-and-use-and-satisfaction-with-care-during-the-course-of-the-disease/>

## Principal Investigators

Lotta Widén Holmqvist

## Institution

Karolinska Institutet

## Contact information of lead PI

### Country

Sweden

## Title of project or programme

To live with amyotrophic lateral sclerosis (ALS): health-related quality of life, and use and satisfaction with care during the course of the disease

## Source of funding information

Swedish Research Council

## Total sum awarded (Euro)

€ 228,509

## Start date of award

01-01-2015

## Total duration of award in years

3.0

## The project/programme is most relevant to:

Motor neurone diseases

## Keywords

### Research Abstract

Amyotrophic lateral sclerosis (ALS) is characterized by progressive muscular weakness and wasting, eventually leading to respiratory failure and death on average 2-3 years after diagnosis. There is no cure and clinical management focus on care to alleviate symptoms and to improve survival and health-related quality of life (HRQL). The aims of the project are to describe and explore use and satisfaction with care, factors associated with HRQL in people with ALS and their next of kin during the course of disease, and experiences on mechanical ventilation, in order to facilitate person-centred care. The outcome will also be used for choice of variables in a national ALS quality registry. The project has a longitudinal design with repeated data collections during home visits every 6 months up to 3 years after enrolment. Structured interviews are used for gathering information on socio-demographic and disease-related factors, and questionnaires for information on HRQL, disease severity, cognition, depression, fatigue, coping capacity and burden of care. Qualitative interviews are used for information on experiences of mechanical ventilation. In addition, a questionnaire based on the taxonomy of Ware is used for evaluation of satisfaction with care and healthcare services. Information on use of care and healthcare services is collected through central registers. Descriptive statistics, regression models and content analysis will be used for data presentation and analyses.

### **Lay Summary**

**Further information available at:**

#### **Types:**

Investments > €500k

#### **Member States:**

Sweden

#### **Diseases:**

Motor neurone diseases

#### **Years:**

2016

#### **Database Categories:**

N/A

#### **Database Tags:**

N/A