

## Marie Curie Research Grants Scheme

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Development and pilot testing of a web-based decision aid for people with motor neurone disease considering a gastrostomy (DiAMoND).

**Start date:** 10<sup>th</sup> December 2018

**End date:** 9<sup>th</sup> December 2021

**Costs to Marie Curie:** £94,576.70

**Costs to Motor Neurone Disease Association:** £94,576.70

**Total funding awarded:** £189,153.39

### Abstract

#### Background

Dysphagia will affect at least two-thirds of all people with motor neurone disease (MND) during the course of their illness. When dysphagia causes weight loss in patients with MND a gastrostomy is recommended, based on the assumption that there will be a beneficial impact on nutritional outcome and quality of life (QOL). However, there are no randomised controlled trials (RCTs) which explore the efficacy of enteral tube feeding and results from other research is equivocal, weak or lacking with respect to survival, nutritional outcome and QOL respectively. From the patient and carer perspective, there are a number of challenges associated with gastrostomy and several factors which contribute to a delay in undergoing a gastrostomy. One of the conclusions from ProGas, a large longitudinal prospective cohort study which investigated optimum timing and method of gastrostomy for people with MND, was that whilst earlier gastrostomy might improve clinical benefit, some patients may not wish to undergo this. This is reflected in current NICE guidelines.

Whilst there are some excellent educational resources about tube feeding for people living with MND, including 'myTube', an online outcome from ProGas, there are no published patient decision aids (DAs) for this patient group. DAs do more than provide information, they support patients to make their decision explicit and to make an informed choice through improved knowledge and risk perception. They can also provide a framework for discussion with family members and clinicians. By presenting evidence-based information, communicating the risks and benefits associated with each option, checking understanding and clarifying personal values and preferences, a DA can help patients with MND make a decision about whether a gastrostomy is congruent with their values and appropriate for them.

#### Aim

To develop and pilot test a web-based patient DA which adheres to the International Patient Decision Aids Standards (IPDAS) for people with MND deciding whether to have a gastrostomy.

## **Methodology**

Informed by IPDAS guidelines and supported by a stakeholder steering and design group, we will: 1) Systematically review the evidence base and extant resources using standard methods. 2) Conduct semi-structured interviews with MND patients, carers and professionals and carry out thematic analysis to explore personal experiences, information needs, timing and presentation of information. 3) Synthesise the findings from 1) and 2) using a framework analysis approach and then prioritise content for the DA using the MoSCoW process. 3) Produce a prototype web-based DA and seek feedback from study participants (alpha testing). 4) Following review of feedback, produce a second version. 5) Test this version with new patients, carers and clinicians (beta testing) using the “think aloud” method. 6) Review results, produce a third version and carry out further beta testing 7) Review results and produce the final prototype 8) Conduct a feasibility study and process evaluation to explore the acceptability and practicality of the DA for patients, carers and clinicians in the clinical setting and assess potential benefit.

## **Outcomes**

The main outcome will be the patient DA which will also be a useful resource for carers, clinicians, support workers and researchers. Assuming favourable feasibility study results, and with the agreement of the funders, it is anticipated that the DA will be made available at the end of this project, with the caveat that its efficacy has not been confirmed in a randomised control trial. Dissemination will be facilitated by a launch event and policy briefing, and the tool will be presented at education events organised by the MND Association and at the International Symposium on ALS/MND. Online links from the MND

Association and Marie Curie websites and potentially MND/ALS organisations in other countries will also be used for dissemination. Three peer-reviewed publications are planned: a systematic review of the evidence base, a qualitative analysis of the interviews and a paper describing the development and feasibility testing of the DA.

## **Future work**

Further funding will be sought to explore use in patients with changing cognitive ability, and to evaluate the efficacy of the tool in different contexts e.g. clinic, at home. The process used to develop the DA, and the network made with UK researchers and clinicians could facilitate the development of other MND patient DAs.