

Weight management is critical for survival in motor neuron disease

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Researchers from around the UK, led by a team at the University of Sheffield's Institute for Translational Neuroscience (SITraN), have found new evidence to support early nutrition management in motor neuron disease (MND).

The first UK wide study into tube feeding in MND (ProGas) has found that MND <u>patients</u> benefited most from enteral feeding when they had lost less than 10 per cent of their body weight before the intervention.

In contrast, significant <u>weight loss</u> at the onset of enteral feeding was associated with shorter survival.



Based on the results of the study, published in the journal *The Lancet Neurology*, the investigators recommend enteral feeding for MND patients as early as possible at five per cent weight loss from MND diagnosis.

Chief Investigator Dr Chris McDermott, Reader in Neurology at SITraN and Consultant Neurologist at the MND Care and Research Centre at the Sheffield Teaching Hospitals Foundation Trust, said: "These findings will help health care professionals and patients to make informed decisions about the choice of gastrostomy method and timing."

The prospective multi-centre evaluation of gastrostomy in patients with MND (ProGas) included data from 24 centres in the UK.

A total of 330 patients in the study underwent gastrostomy which entails the insertion of a tube in the stomach to facilitate enteral feeding and were followed up for 12 months. The study aimed to provide evidence on the benefits and timing of gastrostomy feeding, as well as the optimum tube insertion method in terms of safety and clinical outcome.

Study author Dr Theocharis Stavroulakis, Research Associate at SITraN, who analysed the UK wide data said: "Although recommended by both the American Academy of Neurologists and European Federation of Neurological Societies, there was little evidence for the optimum method and timing for gastrostomy.

"Decisions in clinical practice are currently largely based on consensus and expert opinion. The aim of our study was to provide evidence for the available treatment options and establish guidelines for best clinical practice to improve care for MND patients."

Enteral feeding is commonly used to support MND patients with severe difficulties in swallowing (dysphagia). The three main methods of



gastrostomy currently used in MND patients are percutaneous endoscopic gastrostomy (PEG), radiologically inserted gastrostomy (RIG), and per-oral image-guided gastrostomy (PIG).

"The findings we present suggest that PEG might be the optimum method of gastrostomy when respiratory function is largely unimpaired, and PIG when respiratory function is significantly compromised," said Dr Stavroulakis.

"Both methods seemed to offer easier post-insertion tube management than RIG. This is crucial in MND where loss of mobility and speech, as well as breathing problems can increase the burden on both patient and carer".

The three gastrostomy methods were found to be as safe as each other with respect to procedural risk, however RIG was found to be associated with higher post-procedural complications associated with balloon-retention gastrostomy tubes and more complex tube management. PEG caused a higher rate of patient distress linked to procedure tolerance.

There were no significant differences across the three methods in terms of survival or weight change. The study showed that delay of gastrostomy might lead to diminishing benefits, especially for patients who at the time of gastrostomy have experienced excessive weight loss from their diagnosis weight. The effect on the quality of life was perceived neutral by the participants, however the burden for the carer increased post-intervention.

The ProGas study was supported jointly by the Motor Neurone Disease Association of England, Wales and Northern Ireland and the Sheffield Institute for Translational Neuroscience at the University of Sheffield.

Director of Research at the UK MND Association Dr Brian Dickie said:



"The results of this research will underpin the development of clinical guidelines to ensure greater consistency across MND clinics and improve the outcomes of gastrostomy for those affected by this devastating disease.

"Building on this evidence," Dr McDermott said: "we now need to better understand the specific nutritional requirements of MND patients, particularly the quantity and quality of nutritional support that patients receive after gastrostomy."

More information: "Gastrostomy in patients with amyotrophic lateral sclerosis (ProGas): a prospective cohort study." DOI: dx.doi.org/10.1016/S1474-4422(15)00104-0

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