Gastrostomy Placement in People with Motor Neurone Disease - Full Clinical Guideline - DERBY

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1. Introduction

Motor neurone disease (MND) is a characterised by progressive muscle wasting and weakness due to loss of upper and lower motor neurones. This leads to difficulty with speech, swallowing, breathing, mobility and activities of daily living. MND is a terminal disease, with death usually attributed to respiratory failure. Median survival is 3 years, with 10% surviving over 8 years (Simon, Huynh et al. 2015). The management of MND is focused on symptom control and maintenance of quality of life. Weight loss is associated with more rapid disease progression and shorter survival (Marin, Desport et al. 2011, Shimizu, Nagaoka et al. 2012, Marin, Arcuti et al. 2016). Enteral nutrition support, including gastrostomy, is associated with variably improved survival (Spataro, Ficano et al. 2011, Wills, Hubbard et al. 2014). Although gastrostomy feeding only prevented further weight loss in approximately half of patients in a prospective study(2015). Discussions regarding gastrostomy insertion should be instituted early in the disease **before** significant dysphagia and weight loss occurs. 33% of people are likely to die within 100 days of gastrostomy placement if >10% of their diagnostic weight is lost (2015). In people who have not lost significant weight, median survival is still only 12 months.

2. Aim and Purpose

The aim of this document is to guide the safe placement of gastrostomy tubes in this high risk group of patients.

3. Definitions, Keywords

MND – motor neurone disease

PEG – percutaneous endoscopic gastrostomy

RIG – radiologically guided insertion of gastrostomy

EPU – elective procedures unit

NIV – non-invasive ventilation

4. Guidelines

Insertion of gastrostomy should be discussed early in the disease course with an information sheet given and signposting to MND association website and http://mytube.mymnd.org.uk/. At diagnosis and at multidisciplinary team assessments, or if there are any concerns, the person's weight, diet, nutritional intake, fluid intake, hydration, oral health, feeding, drinking and swallowing should be assessed (NICE 2016). Early referral should be made to dietetics.

The benefits of early placement of a gastrostomy and the possible risks of a late gastrostomy should be explained to the patients, including for example low critical body mass, respiratory complications, risk of dehydration, higher risk of mortality and procedural complications and with an adverse risk benefit leading to the gastrostomy not being placed as there is too great a risk of harm. Indications for gastrostomy include: prolonged or effortful meal times, 5% weight loss at diagnosis, recurrent chest infections and difficulty maintaining hydration. It should be noted that a gastrostomy will not prevent aspiration of upper airway and mouth secretions or prevent aspiration pneumonia. A gastrostomy maintains nutritional status, it rarely in this situation improves nutritional status. By the maintenance of a good nutritional status, the ability to overcome infections successfully is improved.

Once the person has agreed to discuss the placement of a gastrostomy tube a risk assessment should be made. The neurology team should refer to nutrition nurses for an out-patient assessment, via nutrition nurse outpatient referral on Lorenzo. Due to the potential respiratory compromise from endoscopic insertion, RIG is the default technique of insertion of gastrostomy in MND patients. The patient will then be categorised into risk groups.

Low risk: no symptoms of breathlessness, can lie fully flat for 20 minutes with no problems. RIG can be requested as a routine slot by nutrition nurses. These patients will be admitted to the neurology ward 409 for their procedure and observation overnight after insertion.

If patients have symptoms of breathlessness or difficulties lying flat recent (within 3 months) spirometry including lying and sitting vital capacity measurements should be available. Results should be discussed with a respiratory consultant with a specialist interest in NIV to determine whether the patient should be seen in NIV clinic prior to procedure or ok to go ahead without NIV on neurology ward.

High risk: Patients already on domiciliary NIV will need admission to a respiratory ward pre and post procedure and NIV availability via a nasal mask during and post procedure.

5.References (including any links to NICE Guidance etc.)

nice.org.uk/guidance/ng42

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6. Documentation Controls

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