Consider gastrostomy if any of the following present

- 5% weight loss from diagnosis
- Bulbar symptoms
- Patient requests a discussion
- Signs of respiratory impairment
- Cognitive change
- Prolonged meal times

Discuss gastrostomy as an option with patient and provide MND Association information ‘Tube Feeding 7B’ and direct to ‘mytube.mymnd.co.uk’.

If patient wishes to proceed or discuss further

- Discuss decision again at future review (if patient wishes)
- Ensure SLT/Dietitian aware of decision
- Offer palliative care referral if not yet known to service
- Consider an ‘Advanced Decision to refuse treatment’ (ADRT) if not already in place

If patient does not wish to proceed at this stage

Refer to nutrition team for discussion and assessment using electronic gastrostomy referral form. Referral accepted from any health care professional who has discussion with patient. Referrer to ensure that the following have taken place:

- Respiratory assessment
- Speech and Language assessment
- Dietetic assessment
- Capacity assessment
- Patient information has been provided as above
- Neurology and Respiratory team aware of referral
- Referral to feeding issues weekly MDT if complex/further discussion required

Periodic review by nutrition team (initially minimum monthly intervals)

When date for gastrostomy arranged, nutrition team to ensure the following:

- Provide RIG or PEG specific leaflet as appropriate
- Discuss care needs with patient. Advise that there may be financial/social/housing implications if additional care required
- Advise that hospital stay may exceed the usual 2-3 days if there are complications or risk of refeeding
- Ensure handover of dietetic care to enteral feed Dietitian
- Ensure referral to company nurse for pre-procedure training
- Admission and bloods to be arranged by Nutrition team. Bed to be requested on Heydon neurology ward (unless patient requires specialist care in an alternative clinical area)
- Notify MND Coordinator re planned admission ext 7221

During/post admission:

- Follow post procedure RIG/PEG care plan. Call Nutrition Nurse team on ext 3159 or Guist ward if concerns
- Patient and carer training prior to discharge
- Issue purple folder to patient to include contact numbers
- Routine follow up by company nurse. For complex trouble shooting call ext 3159 as above

Norfolk Motor Neurone Disease (MND) Care and Research Network
Gastrostomy pathway