

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

## 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](http://mytube.mymnd.co.uk)'.

If patient wishes to proceed or discuss further

If patient does not wish to proceed at this stage

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

**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)
- ✓ Notifv 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