

**MDT assessment and referral for PEG tube in patients with MND**

<b>Step 1: Patient details</b>	<b>Patient name</b>	Name	<b>Date of birth</b>	DOB.	<b>Contact number</b>	Contact number
	<b>NHS number</b>	NHS no.	<b>Consultant</b>	Consultant	<b>Current location</b>	Inpatient ward no.: Location Outpatient location: Location
	<b>Clinical diagnosis</b>	Diagnosis	<b>Past medical &amp; surgical history:</b>		PMH/PSH	
	<b>Current medication:</b>	Medication	<b>Is the patient on anticoagulant or antiplatelet therapy?</b>		No <input type="checkbox"/> Yes <input type="checkbox"/> (please list): List therapy	

<b>STEP 2: Referral Criteria</b>	<p><b>Does the patient have any of the following Indicators?</b></p> <ul style="list-style-type: none"> <li>• 5 %weight loss from diagnosis</li> <li>• Respiratory impairment</li> <li>• Recurrent chest infections</li> <li>• Physical feeding difficulties or prolonged meal times</li> <li>• Cognitive changes</li> <li>• BMI <math>\leq</math>20</li> <li>• Reduced oral intake</li> <li>• Bulbar symptoms</li> </ul>	Does the patient have assumed mental capacity to make the decision to be referred for gastrostomy insertion?	Have the patient, family and carer been involved in a discussion and given relevant supporting information in a format that is appropriate to them in order to make an informed decision?	Has the patient given informed consent to be referred for consideration of gastrostomy insertion?	Is the patient under the care of the regional specialist respiratory service and had a baseline respiratory assessment or had a respiratory assessment within the last 3 months
	YES <input type="checkbox"/> NO <input type="checkbox"/> Continue to monitor & reassess if any changes	YES <input type="checkbox"/> NO <input type="checkbox"/> Complete Mental Capacity Assessment	YES <input type="checkbox"/> NO <input type="checkbox"/> Ensure discussion & information provided	YES <input type="checkbox"/> NO <input type="checkbox"/> Reassess if patient decision changes in future	YES <input type="checkbox"/> NO <input type="checkbox"/> Baseline assessment required. Complete prior to referral
<p align="center"><b>If 'yes' to all of the above</b> Continue to step 3 and assess patient's level of risk</p>			<p align="center"><b>If 'no' to any of the above</b> Do not refer to PEG MDT until all criteria met or discussion with MND MDT has taken place</p>		

<b>STEP 3: Risk identification level</b>	1. Identify patient's level of risk. Start by assessing the patient against the 'Red' criteria. If any indicators are ticked, this is the risk category for this patient. 2. If no indicators are selected from the 'Red' criteria, assess the patient against the 'Amber' criteria. If any indicators are ticked, this is the risk category for this patient. 3. If they do not meet the 'Red' or 'Amber' criteria, the patients risk category is 'Green'.			
		<b>Red (High risk)</b>	<b>Amber (moderate risk)</b>	<b>Green (low risk)</b>
	<b>Respiratory</b>	<input type="checkbox"/> Recurrent chest infections <input type="checkbox"/> Abdominal paradox <input type="checkbox"/> Reduced chest expansion <input type="checkbox"/> SNIP <40cmH2O or has a poor sniff <input type="checkbox"/> FVC <50% of predicted or has a poor, ineffective cough <input type="checkbox"/> FVC fall > 15% on lying flat <input type="checkbox"/> SpO2 < 94% without known lung disease or <92% with known lung disease	<input type="checkbox"/> Morning headache or orthopnoea <input type="checkbox"/> Breathlessness or increased respiratory rate <input type="checkbox"/> Non-refreshing sleep or daytime sleepiness <input type="checkbox"/> Shallow breathing <input type="checkbox"/> Use of accessory muscles of respiration <input type="checkbox"/> SNIP >40cmH2O or has an adequate sniff <input type="checkbox"/> FVC >50% of predicted or has effective cough <input type="checkbox"/> FVC fall <15% on lying flat <input type="checkbox"/> SpO2 $\geq$ 94% without known lung disease or $\geq$ 92% with known lung disease	<input type="checkbox"/> No respiratory symptoms or fatigue <input type="checkbox"/> Poor speech volume <input type="checkbox"/> Poor appetite
	<b>Ventilation</b>	<input type="checkbox"/> Unable to tolerate or has new non-invasive ventilation or tracheostomy	<input type="checkbox"/> Established on non-invasive ventilation (NIV) without issue	<input type="checkbox"/> Not on ventilation
	<b>Weight</b>	<input type="checkbox"/> >10% weight loss with associated respiratory symptoms	<input type="checkbox"/> >5% weight loss with no associated respiratory symptoms	<input type="checkbox"/> <5% weight loss
	<b>Positioning</b>	<input type="checkbox"/> Unable to lay flat for $\geq$ 20 minutes	<input type="checkbox"/> Can lay flat for $\geq$ 20 minutes or more	<input type="checkbox"/> Can lay flat for $\geq$ 20
<b>Mental state</b>	<input type="checkbox"/> Poor concentration/memory <input type="checkbox"/> Has confusion or hallucinations	<input type="checkbox"/> Disturbed sleep	<input type="checkbox"/> No concerns	

<b>STEP 4: PEG MDT further information</b>	<b>Confirm risk category:</b>	Red <input type="checkbox"/> Amber <input type="checkbox"/> Green <input type="checkbox"/>			
	<b>Does the patient have any of the following contraindications:</b>	No contraindications <input type="checkbox"/> EOL/limited life expectancy <input type="checkbox"/> Advance decision against gastrostomy <input type="checkbox"/> End stage dementia <input type="checkbox"/> Current chest infection/pneumonia <input type="checkbox"/> Oesophageal constriction or obstruction <input type="checkbox"/> Morbid obesity or thick abdominal wall <input type="checkbox"/> Coagulation abnormalities <input type="checkbox"/> Recent myocardial infarction <input type="checkbox"/> Total or partial gastrectomy/gastric surgery <input type="checkbox"/> Gastro-oesophageal reflux with aspiration <input type="checkbox"/>		Active gastric ulceration/malignancy <input type="checkbox"/> Gastric outlet obstruction <input type="checkbox"/> Large hiatus hernia <input type="checkbox"/> Crohns disease <input type="checkbox"/> Disseminated metastatic disease <input type="checkbox"/> Liver disease <input type="checkbox"/> Anorexia nervosa <input type="checkbox"/> Pregnancy <input type="checkbox"/> Peritonitis <input type="checkbox"/> Peritoneal dialysis <input type="checkbox"/>	
	<b>Has the patient been assessed by a dietitian?</b>	Yes <input type="checkbox"/> date: Date No <input type="checkbox"/> - All patients to be seen by dietitian prior to PEG. Refer to local dietitian dept. for assessment.			
	<b>Has the patient been assessed by a Speech &amp; language therapist (SLT)?</b>	Yes <input type="checkbox"/> date: Date. No <input type="checkbox"/> - All patients to be seen by SLT prior to PEG. Refer to local SLT dept. for assessment			
	<b>What is the patients current:</b>	Date taken: Date Weight (kg): Weight. Height (m): Height BMI: BMI			
	<b>Weight history (E.G. usual weight, weight loss)</b>	Weight history			
	<b>Blood results</b>	HB: result PLT: result PT: result			
	<b>Relevant further comments or information</b>	Further comments or information			
	<b>Referrer details (complete in block capitals)</b>				
	<b>Name:</b>	Name	<b>Designation:</b>	Designation	
<b>Signature:</b>	Signature	<b>Professional registration no.</b>	Registration number	<b>Date:</b> Date	

**If this patient meets the above criteria send this completed document to the PEG MDT and MND MDT:**

**Email:** [stees.pegreferrals@nhs.net](mailto:stees.pegreferrals@nhs.net) and [stees.mnd@nhs.net](mailto:stees.mnd@nhs.net)

**Phone:** 07741616365 or ext 53574

**All patients will be discussed in the weekly PEG MDT, held each Friday morning. Referral needs to be sent to the PEG MDT by Thursday at 12 noon to be discussed at the PEG MDT that week.**

<b>STEP 5: PEG MDT (for completion by PEG MDT only)</b>	<b>Is this patient deemed appropriate to proceed with PEG?</b> Yes <input type="checkbox"/> No <input type="checkbox"/> If no please specify reason: Reason	<b>Confirm risk category based on all available information:</b> Red <input type="checkbox"/> Amber <input type="checkbox"/> Green <input type="checkbox"/>		
	<b>Step 6: PEG MDT to identify the route of PEG insertion appropriate for this patient</b>			
	<b>Red (High risk) <input type="checkbox"/></b>	<b>Amber (moderate risk) <input type="checkbox"/></b>	<b>Green (Low risk) <input type="checkbox"/></b>	
<ul style="list-style-type: none"> <li>• Push gastrostomy to be inserted via trans-nasal endoscopy (TNE) in a seated position with no sedation, on a dedicated consultant list experienced in the care of patients with potential respiratory compromise.</li> <li>• MND Specialist Nurse to be present during the procedure.</li> <li>• If appropriate non-invasive ventilation must be available during &amp; post procedure.</li> <li>• If there is a delay in procedure of more than 2-3 weeks, re-evaluate in MND MDT</li> </ul>	<ul style="list-style-type: none"> <li>• Gastrostomy to go ahead on a dedicated consultant list experienced in the care of patients with potential respiratory compromise.</li> <li>• Pull PEG technique to be used, however consider TNE push PEG technique if use of sedation is contraindicated.</li> <li>• If appropriate, non-invasive ventilation must be available during &amp; post procedure.</li> <li>• If there is a delay of more than 3-4 weeks, re-evaluate in MND MDT</li> </ul>	<ul style="list-style-type: none"> <li>• Gastrostomy may go ahead on a routine list using a pull PEG technique.</li> <li>• Continue to monitor and if there is a delay of more than 6 weeks, re-evaluate in MND MDT</li> </ul>		

<b>PEG MDT</b> <b>Further comments or information</b>	Further comments or information
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**All high and moderate risk patients:**

- To have a guaranteed bed prior to procedure going ahead on ward areas trained in the use of NIV, PEGs and caring for those with a diagnosis of MND. This would usually be neurosciences, gastroenterology or respiratory services
- Any patient who has had a change in respiratory function or is at risk of refeeding syndrome is to be admitted the night before the procedure.

**Low risk patients:**

- To have a guaranteed bed prior to procedure going ahead on ward areas trained in the use of PEG and caring for those with a diagnosis of MND. This would usually be neurosciences, gastroenterology or respiratory services

**All patients:**

- To be screened prior to admission following Trust infection prevention and control guidance.
- To remain an inpatient for at least 24 hours post procedure. This may be longer if the patient is at risk of refeeding syndrome and/or social concerns.
- To have the appropriate gastrostomy care pathway followed.
- To be reviewed by dietitian prior to discharge. For SLT review if appropriate.
- To receive PEG nurse review/senior medical review within first 24 hours following procedure. Patient will not be discharged prior to this review.
- To receive PEG training via Nutricia Nurse prior to discharge and receive Nutricia nurse review within 1-2 weeks of discharge from hospital.

**Follow up:**

- If sutures are in-situ, an appointment will be made prior to discharge for removal of these 7 days post procedure.
- All patients to receive dietetic follow up via MND clinic, if able to attend or local dietetic service at home.
- All patients to receive a PEG review appointment in Endoscopy Department, if able to attend, within 3-6 months of discharge from hospital.

**Consider the following if sedating an individual with MND undergoing endoscopic pull gastrostomy:**

- If established on NIV this should be available and ready to use whilst in endoscopy and a nasal mask is recommended. Oxygen should not be used as standard procedure, but should be available throughout.
- Throat spray should not be used as this can potentially increase the risk of aspiration and minimal sedation is normally required with midazolam. Fentanyl should not be required.
- Desaturation may occur in this patient group when lying flat, therefore a trial of lying flat unsedated for 5 minutes whilst monitoring using a saturation probe is recommended.
- If oxygen saturations fall then it may be necessary to sit the patient up slightly and repeat the above step. You may want to consider using patients own NIV if available.
- If saturations are stable you can proceed with sedation. A suggested dose of midazolam is 0.5 - 1mg initially and observing for a further 5 minutes.
- Midazolam's peak onset of action is at 3-6 minutes; therefore it is necessary to wait an appropriate time before assessing whether more is required.
- An acceptable oxygen saturation range for those with MND and known respiratory involvement (or those with NIV) is 88-92%. For those without known respiratory involvement an acceptable oxygen saturation range is 92-94%.
- Depending on level of sedation & O2 saturations you can either proceed with procedure or give further sedation. It is suggested that no more than 0.5mg increments of midazolam is given at a time.
- If a minimally sedated patient is not tolerant of intubation you can try rotating them onto their side for intubation then rotating back onto their back for the gastrostomy insertion.

**Consider the following in an individual with MND undergoing trans-nasal endoscopic push gastrostomy:**

- If established on NIV this should be available and ready to use whilst in endoscopy and a full face mask is recommended. Oxygen should not be used as standard procedure, but should be available throughout.
- Sedation should not be required as this can cause further respiratory compromise.
- Nasal spray should be used to numb the nasopharyngeal tract only.
- The patient should remain upright throughout the procedure and only reclined if tolerable and no desaturation noted.
- If oxygen saturations fall, sit the patient upright and ensure O2 saturations are within range prior to recommencing procedure. You may want to consider using patients own NIV if available.
- An acceptable oxygen saturation range for those with MND and known respiratory involvement (or those with NIV) is 88-92%. For those without known respiratory involvement an acceptable oxygen saturation range is 92-94%.

**References**

1. National Institute for Health and Care Excellence. (2016). Motor Neurone Disease: assessment and management. (NICE Guideline No. 143). <https://www.nice.org.uk/guidance/ng42>
2. British Thoracic Society, (2017). BTS guideline for oxygen use in adults in healthcare and emergency settings. <https://www.brit-thoracic.org.uk/quality-improvement/guidelines/emergency-oxygen/>
3. ProGas Study G (2015) Gastrostomy in patients with amyotrophic lateral sclerosis (ProGas): a prospective cohort study. Lancet Neurol. 14: 702-709.
4. McCulloch A et al. Nasal unsedated seated percutaneous endoscopic gastrostomy (nuPEG): a safe and effective technique for percutaneous endoscopic gastrostomy placement in high- risk candidates. Frontline Gastroenterology 2017; (0)1-5