

## Safe Patient Selection for PEG in MND - MND gastrostomy pathway development

Emma Wood

### Dysphagia

<https://www.mndassociation.org/professionals/management-of-mnd/management-by-symptoms/dysphagia/>

### Managing dysphagia in MND

<https://www.mndassociation.org/app/uploads/2012/04/information-sheet-p8-dysphagia-in-motor-neurone-disease.pdf>

### Respiratory symptoms in MND

<https://www.mndassociation.org/professionals/management-of-mnd/management-by-symptoms/respiratory-symptoms-in-mnd/>

### Managing respiratory symptoms in MND

<https://www.mndassociation.org/app/uploads/2012/04/information-sheet-p6-evaluation-and-management-of-respiratory-symptoms-in-mnd.pdf>

### Information to share with people with or affected by MND:

- 8A – Support for breathing problems Information sheet  
<https://www.mndassociation.org/app/uploads/2015/07/8A-Support-for-breathing-problems.pdf>
- 8B – Ventilation for motor neurone disease Information sheet  
<https://www.mndassociation.org/app/uploads/2015/07/8B-Ventilation-for-motor-neurone-disease.pdf>
- 8C – Withdrawal of ventilation with MND Information sheet  
<https://www.mndassociation.org/app/uploads/8C-Withdrawal-of-ventilation-with-MND.pdf>
- 8D – Air travel and ventilation for motor neurone disease  
<https://www.mndassociation.org/app/uploads/2019/05/8D-Air-travel-and-ventilation-for-motor-neurone-disease.pdf>
- Eating and Drinking guide  
<https://www.mndassociation.org/support-and-information/living-with-mnd/eating-and-drinking/>

### Nutrition and gastrostomy

<https://www.mndassociation.org/professionals/management-of-mnd/management-by-symptoms/nutrition-and-enteral-feeding/>

### Traffic light approach for respiratory risk to guide decision making

- 2013 MND International Symposium – Oxford MND Care Centre presented traffic light approach to assessing respiratory risk to guide decision making  
<https://www.alsmndalliance.org/wp-content/uploads/2013/11/FINAL-Programe-and-Abstract-Booklet-Electronic.pdf>
- The Grampian Collaborative Pathway 2015/16– traffic light system that risk stratifies MND patients
- Cambridge team adopted nasal unsedated seated PEG technique for patients with respiratory compromise. Published data 2017 <https://fg.bmj.com/content/9/2/105>

### Further resources

- <https://www.rcnevents.tv/>
  - Annual Stephen Hawking Lecture November 2020 – Respiratory Care in MND patients by Dr Ronan Astin – Consultant in Adult Ventilation Medicine UCLH
- <http://mytube.mymnd.org.uk/>
- <https://mybreathing.mymnd.org.uk/>
- <https://www.mndassociation.org/professionals/publications/>

- <https://www.mndassociation.org/support-and-information/information-resources/information-for-people-with-or-affected-by-mnd/>

## References

1. Tomik, B. and R.J. Guilloff, Dysarthria in amyotrophic lateral sclerosis: A review. *Amyotrophic Lateral Sclerosis*, 2010; 11(1-2): 4-15
2. Muscaritoli M, Kushta I, Molino A, Inghilleri M, Sabatelli M, Rossi Fanelli F. Nutritional and metabolic support in patients with amyotrophic lateral sclerosis. *Nutrition* 2012; 28(10): 959–966
3. Radunovic A et al. *Mechanical ventilation for amyotrophic lateral sclerosis/motor neuron disease*. Cochrane Database of Systematic Reviews 2013.
4. ProGas Study G (2015) Gastrostomy in patients with amyotrophic lateral sclerosis (ProGas): a prospective cohort study. *Lancet Neurol.* 14: 702-709.
5. National Institute for health and Clinical Excellence (NICE) (Feb 2016) Motor neurone disease: assessment and management. London. NICE. NG42
6. 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