**Motor neurone disease**

First contact with a patient with MND?

Motor neurone disease (MND) is a fatal, rapidly progressing disease that effects the brain and spinal cord. It has no cure.

- **Make sure you find out how they communicate**
- **Never lie them flat even if breathless**
- **Don’t allow them high flow oxygen (unless in their care plan)**

- Consult their care plan
- Avoid A&E wherever possible
  - contact their district nursing team and local care team
  - speak to their local palliative care coordinator or their GP

**People experience MND differently.**
**Please take your time with these patients, and their carers/relatives.**

You may come across a patient with MND. These patients have complex needs. This tool card is to help you understand their condition and to give brief guidance on appropriate treatment for these patients.

**Key points**

People with MND could have a high NEWS score however this could be normal for them. They will have a normal increased respiratory rate and also a lower Sp0₂ that needs to be taken into account. Establish if this has changed.

Do they have an emergency health plan (EHA), an advance care plan (ACP), or an advance decision to refuse treatment (ADRT)?
Airway
- Swallowing issues
- Poor cough reflex
- Saliva blocking airway

Breathing
- High respiratory rate
- SPO₂ 88-92%
- Have they got a Bi-pap machine
- Aetiology of lungs is normal

Circulation
- May be rapid due to the increased breathing rate but could be within normal range

Disability
- 80% of MND patients have communication issues
- Cognitive function is usually normal

Environmental
- Dehydration can be a problem
- They may have a PEG feed – which can get blocked
- They may have a catheter in situ

Consider suction

Place patient on Bi-pap
- BTS guidelines for oxygen use in healthcare and emergency settings (2017)
- 2 litres O₂ with caution to achieve target saturation (JRCALC, 2016)

Tachycardia can be a normal presentation

Take your time with these patients

Have they got a ‘Just in Case kit?’
- The MND Just in Case kit is a box supplied free of charge to a GP for a named patient.
- It is designed to hold medication for the management of symptoms in an emergency: this may include episodes of breathlessness, choking and/or associated anxiety or panic.

For more information about MND see NICE guideline NG42 and visit www.mndassociation.org