Leeds Regional MND Care Centre: Respiratory Management Pathway

At or within 1 month of diagnosis:

- Full spirometry including FVC in lying & sitting, SNIP, SpO_2, ABG's or TOSCA, PCF, check bulbar function & auscultation.
- Provide information about palliative care services if appropriate & ensure contact numbers are provided for queries/emergencies

3 monthly:

- Spirometry to include FVC in lying & sitting, SNIP, SpO_2, TOSCA, PCF, auscultation & bulbar function.
- NIV should be discussed early to enable patients to consider and then make an informed choice

VC<50% predicted or<1.5l and/or PCF<270l/min;

- Breathstacking and manually assisted cough should be taught and access to cough assist arranged for times of infection. *(VC can be monitored via a cushioned mouthpiece attached to the spirometer if an adequate mouth seal can no longer be achieved).*
- Resuscitation status should also be considered.
- Ensure GP & DN are involved & discuss referral to palliative care

Assess for hyercapnia/symptoms of dyspnoea:

- daytime hypersomnolence
- morning headaches
- increased tCO_2 on TOSCA

Arrange overnight oximetry and a referral made to a respiratory consultant (*if not done already*).

10% drop in FVC or SNIP should highlight a need for more frequent respiratory review and increased monitoring i.e. repeat overnight oximetry

NIV should be considered when the patients' quality of life is affected by: breathlessness, symptoms of increased pCO_2 or abnormal sleep study results

If the patient chooses not to use NIV or NIV is no longer as effective:

- Adequate medication must be offered to alleviate any distress from dyspnoea.
- Liaise with primary care specialist & palliative care services

Usage of >12 hours daily requires an additional ventilator and separate battery to be provided for times of power/equipment failure

If recurrent infections:

- Ensure breathstacking & MAC have been taught.
- Consider a supply of antibiotics at home.
- Refer to respiratory specialist and physiotherapy.
- If thick sticky secretions, consider carbocisteine (mucodyne)

If copious oral secretions: see management of sialorrhea algorithm

Designed and reviewed by Lisa Emmett, Respiratory Physiotherapist