

Norfolk MND Care and Research Network

Respiratory Management of Motor Neurone Disease (MND)

At point of diagnosis, Neurologist refers patient to a named Respiratory Consultant within the MND MDT.

The patient should be seen by Respiratory Medicine Consultant within 4 weeks after referral.

Respiratory Team determines suitability for non-invasive ventilation (NIV), mainly based on FVC <50% of predicted. Other elements are also taken into account, such as CO₂ retention, nocturnal desaturation, orthopnoea, and progression of the disease (even if FVC is between 50-60% of predicted). Consider referral to Nutrition Team if NIV is indicated.

If NIV is appropriate and patient consents to a trial

Patient referred to Sleep Specialist Nurses who will set up NIV machine, and offer telephone follow-up and support as required. Information should be provided as per NICE guidelines (2016) 1.14.20

As per NICE guidelines, patient can choose to discontinue NIV at any point.

Offer palliative care referral if not yet known to service
Consider an 'Advance Decision to refuse treatment' (ADRT) if not already in place

If patient is using NIV during the day as well as overnight, provision of an additional NIV machine and/or battery back-up should be considered.

All patients with MND should be seen by a Respiratory Consultant every 4 months (more frequently if indicated) and discussed at the MND MDT.

Referrals can be made to respiratory MND physiotherapist for airway clearance, cough augmentation, breathlessness management and NIV support.

The respiratory team can be contacted for consideration of admission to Hethel Ward for end of life care, if necessary.

If patient does not wish to trial NIV

