MND Respiratory Pathway

This pathway is interactive: if you're viewing online, click find out more to view further details. These links will only work if you are connected to the internet. Find more information on respiratory evaluation and management at: www.mndassociation.org/respiratory

Signs and symptoms
Signs and symptoms of respiratory impairment include (but are not limited to):
• early morning headaches
• daytime sleepiness
• orthopnoea
• repeat chest infections
• disturbed sleep.

Gastrostomy
Referral to gastroenterology for discussion of gastrostomy (PEG/RIG/PIG). Timing and method of gastrostomy is dependent on weight loss and respiratory function. Find out more

Secretion management
Consider early referral to respiratory physiotherapist.
• secretion management
• cough augmentation eg manual cough assistance, Mechanical insufflator:exsufflator (MI-E) and lung volume recruitment (LVR) bag
• provision of portable suction. Find out more

Respiratory function testing
Repeat tests every 3-6 months (as appropriate). The multidisciplinary team should continually monitor signs and symptoms of respiratory impairment. Find out more

In the presence of dementia, consider the patients’ ability to give consent and level of understanding. Find out more

MND Just in Case Kit
Ordered by the GP from the MND Association. To be filled with medications to ease symptoms of breathlessness, choking and related anxiety/panic and kept in the home of the person with MND. Find out more

Advance care planning
Sensitive discussions of options, including withdrawal of NIV, ADRT, end of life care. Find out more

Respiratory assessment
Soon after diagnosis and appropriate to the person’s needs, refer for baseline respiratory function tests.
• SpO₂
• FVC/VC
• SNIP
• PCF
Find out more

Assisted ventilation
Offer discussions about possible use of assisted ventilation at:
• diagnosis
• during testing
• when respiratory function changes.

Non-invasive ventilation (NIV)
If NIV appropriate, refer for NIV trial. Discuss benefits, limitations and likely progression of NIV use. It is important to prepare a comprehensive care plan and provide 24hr emergency support and maintenance.

Tracheostomy
Tracheostomy is considered for some patients following discussion with the specialist MDT. Discussions will include increased care needs and impact on family and carers. Occasionally it is used in an unplanned emergency situation. Find out more

Palliation of symptoms
Referral to specialist palliative care services (if not already in contact). Medications include
• antimuscarinics to reduce saliva and lung secretions
• anxiolytics to reduce anxiety/terminal restlessness
• mucolytics to aid with thick, and difficult to mobilise, secretions.
• opioid analgesics to reduce pain, cough reflex, dyspnoea and the feeling of effortful breathing, fear and anxiety. Find out more

Oxygen
Oxygen should be used with caution in those with MND. Find out more

This pathway is interactive: if you're viewing online, click find out more to view further details. These links will only work if you are connected to the internet. Find more information on respiratory evaluation and management at: www.mndassociation.org/respiratory

Thank you to Dr Naveed Mustfa, Consultant Respiratory Physician, University Hospital of North Staffordshire, Ema Swingwood, Respiratory Pathway Lead/Physiotherapist, University Hospitals Bristol NHS Foundation Trust Rebecca Hall, Respiratory Physiotherapist, University Hospitals Bristol NHS Foundation Trust and Alison Armstrong, Nurse Consultant, North-East Assisted Ventilation Service, Newcastle upon Tyne Hospitals NHS Foundation Trust