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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.

Oxygen

Oxygen should be used with caution in those with MND.

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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.

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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**

Respiratory assessment

Soon after diagnosis and appropriate to the person's needs, refer for baseline respiratory function tests.

- SpO₂
- FVC/VC
- SNIP
- PCF

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Breathlessness management

A **physiotherapist** or **occupational therapist** may be able to discuss different approaches to coping with breathlessness. **Find out more**

Advance care planning

Sensitive discussions of options, including withdrawal of NIV, ADRT, end of life care. **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.

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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.

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