

Motor neurone disease (MND): a guide for patients attending the Respiratory Support and Sleep Centre

Patient information sheet

What to expect on your first visit

- You will be seen by one of our advanced nurse practitioners or a doctor who will take a medical history, focusing on any breathing and/or sleep-related symptoms.
- If you are experiencing problems with throat clearing or coughing, our specialist respiratory physiotherapist may also assess you.
- The assessment will take place in a single room with ensuite bathroom on 3 North West. You can attend with your family and/or carers, though if you need to attend with more than two people then please discuss this ahead of your visit with our co-ordinator (details below).
- Please plan for your day case appointment to take up to three hours.

Tests and investigations

- Blood pressure, heart rate, oxygen level and weight will be checked.
- A chest X-ray will be taken at your first visit.
- A lung function test: this will be undertaken on the ward. It is called a 'respiratory muscle assessment' (RMA). It involves breathing in and out of a mouthpiece at the bedside

to measure the strength of your breathing muscles and lung capacity. The test is not painful and does not involve walking. The RMA test can be repeated at each visit to track any changes.

- A blood gas test will check oxygen and carbon dioxide levels to give an insight into breathing function. The test involves taking a blood sample from an artery in the wrist (ABG) or from the earlobe (CBG).
- An oximetry sleep study may be recommended, sometimes before your appointment and sometimes following it. If so, a small device (like a wristwatch) will be sent for home use. If you have been asked to do a test before your visit, then please bring the device with you to the appointment.

Follow-up appointments

- Follow-up appointments are usually every three months, but the frequency depends on symptoms and test results.
- If, at any point, you are concerned about your breathing or start experiencing morning headaches, drowsiness and difficulties lying down because of breathlessness, please contact us directly and we will arrange to see you promptly.

Author ID: Staff nurse
Department: RSSC
Printed: December 2023
Review date: December 2025
Version: 2
Leaflet number: PI 167



Large print copies and alternative language versions of this leaflet can be made available on request.

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Management of breathing problems

- If breathing muscle function deteriorates, treatment with non-invasive ventilation (NIV) may be offered. NIV involves wearing a mask attached to a small machine (a ventilator), providing extra air into the lungs to support breathing. NIV is only needed if there is an issue with breathing. This is usually identified by the development of symptoms including morning headaches, excessive sleepiness and difficulties lying down because of breathlessness. However, these symptoms are sometimes vague or may have other causes. The tests performed in clinic are also helpful in determining if NIV might be needed.
- NIV is usually initially worn overnight but can also be used during the day. It supports breathing to relieve a number of breathing symptoms and prolong life.
- We will go over this treatment with you during your appointments even if it is not needed. For more information see leaflet PI 60 'Discharge information for NIPPY patients': royalpapworth.nhs.uk/download_file/994/305
- If you opt for NIV, a short admission (one to two nights) will be arranged to set it up. A follow-up appointment will be organised four to six weeks later in our day case clinic to see how you are getting on with the treatment. Ongoing support and adjustment to NIV, if needed, will occur at regular intervals.
- Some patients can develop difficulties with cough, throat clearing, or swallowing difficulties. Additional treatments can help, including medications, suction machines, cough-assist devices or botox injections to the salivary glands. We will discuss these treatment options based on individual need.

Who do we have in the day case team?

- MND link nurses will see you in day case and take your observations.
- MND co-ordinator is available to arrange appointments.
- Consultants who will be available for advice on your visit.
- Advanced nurse practitioners will assess you and set out review or treatment plans for you with the support from the consultant on the day.
- Physiotherapists will be available if needed.
- Speech and language therapists (available on request).
- Dietician (available on request).

Useful contacts

Natasha Everett (MND coordinator): **01223 639452** (Arranges appointments and is a point of contact for patients). Email: natasha.everett1@nhs.net.

RSSC Replacements: **01223 638890** (for replacement masks and NIV machine accessories).

RSSC ward: **01223 638365** (for out of hours support)

MND Connect: **0808 8026262** (MND Association support and advice line).

Please always bring your equipment and your medications with you on the day of your visit such as your NIV machine, overnight oximeter, cough machine etc. Thank you.

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