

## 20181003 FOI ref 391-1819 Freedom of information request questions

Name of organisation: UHNM  
Motor Neurone Disease (MND) Services

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1. What is your NHS organisation's catchment population?  
Population of over 900,000.
2. Does your organisation provide healthcare services for people diagnosed with MND?  
Yes.
3. If no, where do patients with MND in your catchment population access healthcare services? If your organisation does not provide healthcare services for people diagnosed with MND, please go to question 15.  
N/A
4. If yes, what is your NHS organisation's catchment population for MND services (if different to Q1)?  
As Q1 currently but with the formation of the North Midlands MND Care and Research Network, this is likely to increase. This will include some areas currently covered by the Birmingham MND Care Centre (based at the Queen Elizabeth Hospital), for example people living in South Staffordshire. No specific numbers are available at this point as to how many more people will be served by the North Midlands Care & Research Network as it develops, but potentially more than double the current / recent numbers. The Respiratory team already cover a very big geographical area including all of the West Midlands.
5. How many newly diagnosed patients with MND were referred to the organisation in each of the last three years?
  - a. 2017  
MND CNS team – new referrals 46.  
Additional 99 referrals to Respiratory Team UHNM for MND patients living outside of area covered by MND CNS team.  
Patients referred to both MND CNS team and Respiratory team only counted once.
  - b. 2016  
MND CNS team – new referrals 32  
Additional 129 referrals to Respiratory Team UHNM for MND patients living outside of area covered by MND CNS team.  
Patients referred to both MND CNS team and Respiratory team only counted once.
  - c. 2015  
MND CNS team – new referrals 33.  
Additional 109 referrals to Respiratory Team UHNM for MND patients living outside of area covered by MND CNS team.  
Patients referred to both MND CNS team and Respiratory team only counted once.

6. What is the total number of patients with MND that are currently receiving healthcare from your organisation?

MND CNS team – current caseload = 80

Respiratory service - additional 289 known to Respiratory team.

Patients under the care of both MND CNS team and Respiratory team only counted once.

7. Is your organisation a specialist care centre for MND?

Yes, as of June 2018 we have this status and receive funding from the Motor Neurone Disease Association. However, we are called a Network rather than a Centre (as in Norfolk, South Wales and other areas).

8. In your organisation, where do patients with MND access services e.g. hospital inpatient services, hospital outpatient services, community clinics, domiciliary visits?

Domiciliary / home visits

Hospital Outpatient clinics

Hospital Inpatient services

9. In your organisation, are patients with MND seen in specialist clinics?

With the creation of the North Midlands MND Care & Research Network, these are in the process of being set up. The plan is for these to be across the Network, (ie Stoke, Stafford, Crewe, South Staffs)

10. If yes,

a. Where are the MND specialist clinics in your organisation held?

Plan – County Hospital (Stafford), Royal Stoke Hospital, considering MDT clinics in Hospices across Network.

b. How often are the MND specialist clinics in your organisation held?

Plan – in different areas, monthly increasing to bi-monthly dependent on patient numbers / need.

c. How often are patients routinely reviewed in the MND specialist clinics?

Expectation is for patients to be seen approximately 3 monthly – potentially more frequently or less frequently dependent on need. With the availability of home visits by MND Clinical Nurse Specialists in-between clinic appointments or as the disease progresses and patients may struggle to attend clinic, again, dependent on patient need.

## MND Healthcare Team

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11. Who leads the MND services in your organisation (job title)?

North Midlands MND Care & Research Network

Co-Directors:

Dr Jonathan Partridge (Consultant Neurologist)

Dr Naveed Mustafa (Consultant in Respiratory Medicine)

Dr Sarah Kelt (Consultant in Palliative Medicine)

Louise Wilsdon (North Midlands MND Care & Research Network Coordinator)

12. In your organisation, which jobs (f.t.e) are specifically funded to provide healthcare for people with MND, e.g. MND clinical lead, MND specialist nurse, MND specialist dietitian?

MND Coordinator (Band 7) – 1 WTE  
MND Clinical Nurse Specialists) – 1.3 WTE

13. Is there a multidisciplinary team (MDT) that provides care to patients with MND in your organisation?

Yes

14. If yes, which professional roles are members of the MDT?

We do have an MDT who provide services for people with MND within UHNM.

MND Clinical Nurse Specialists – MND Specific

MND Network Coordinator – MND Specific

Consultant Neurologists – in & out patients

Respiratory Medicine Consultants – in & out patients

Respiratory (NIV) Clinical Nurse Specialists – in & out patients including home visits

Palliative Medicine Consultants – inpatients (but will be part of MDT clinics being set up)

Therapists who see patients when inpatients include Speech & Language Therapists, Dieticians, Physiotherapists and Occupational Therapists.

We also link with Community services / hospices (non UHNM) who attend MDT meetings to discuss patients across the Network area (regular MND specific MDT meetings are held regularly in Stoke, Stone (Stafford & Stone), Nantwich (Crewe & Nantwich), Lichfield at Samuel Johnson Hospital and also at St Giles Hospice (patients from a wider geographical area discussed at St Giles MDT meeting, due to bigger catchment area).

## MND Dietetic Services

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15. In your organisation how many full time equivalent dietetic posts do you have?

UHNM has 48.3 wte dietetic posts including dietetic assistants

16. Do you have dietetic posts that are specifically funded for MND services ?

No specific funded posts, the inpatients are seen within general dietetic services, usually respiratory for PEG/RIG placement. Outpatients are seen within general services or via primary care services by community dietitians

17. If yes,

a. How many full time equivalent posts do you have?

b. What grade are they?

18. If no, which dietitians see patients with MND? Please list all posts including their job title and grade.

Inpatients Band 7 Stroke/ Respiratory dietitian on NIVU

Band 5 Rotational dietitian, Medicine if admitted to neurology ward

Outpatients Band 6 General Outpatient dietitian

Band 6 Community Dietitian

19. In your organisation, section 12 exemption as detailed in attached letter

a. How many new patients with MND were seen by the dietetic service in each of the last three years, and where were they seen?



2015	section12 exemption	section12 exemption	section12 exemption	section12 exemption	section12 exemption	section12 exemption
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**Commissioning of MND Nutrition Services** **We do not have a commissioned dietetic service for MND**

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20. Where does the funding come from for services for patients with MND in your locality? **We do not have specific funding for MND dietetic services. Patients will be seen by ward dietitians or in general community GP clinics, Community GP clinics are commissioned as a block contract by local CCGs**
21. Which organisations and departments are involved in each stage of the commissioning process of **nutritional services** for patients with MND in your locality: **not applicable**
- a. Strategic planning (assessing needs, reviewing service provisions, deciding priorities)
  - b. Procuring services (designing services, shaping structure of supply, planning capacity and managing demand)
  - c. Delivery of services (which department and where are they located?)
  - d. Monitoring and evaluation (supporting patient choice, managing performance, seeking public and patient views)

Where does the funding come from for **nutritional services** for patients with MND (e.g. nutrition and dietetics service) in your locality? **We do not have specific funding for MND services, patients will be seen from inpatient services by a non-specialist dietitian or within general outpatient services.**

**Patients from South Staffordshire may be seen by dietitians within Midlands Partnership Foundation Trust.**