

Freedom of Information Request: FOI 0479

Name of organisation: University Hospitals Birmingham

Motor Neurone Disease (MND) Services

- 1. What is your NHS organisation's catchment population?**
1,200,000
- 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.**
- 4. If yes, what is your NHS organisation's catchment population for MND services (if different to Q1)?**

The MND consultant and CNS service covers the geographical regions noted below:

Birmingham and Solihull

Dudley

Sandwell

Lichfield and Tamworth

Walsall

Wolverhampton

South Staffs (Cannock)

Worcestershire North

Worcestershire South

Herefordshire

South Warwickshire

Patients are also referred from Staffordshire, Oxfordshire and some parts of Leicestershire to see MND consultants.

- 5. How many newly diagnosed patients with MND were referred to the organisation in each of the last three years?**
- a. **2017-2018** - 97
 - b. **2016-2017** - 103
 - c. **2015-2016** - data for the 2016-2016 financial year is not available

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

Approximately 310

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

Yes

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

Patients can access two outpatient clinics with Consultant Neurologists per week, and the Trust also provides an MND MDT clinic once a month. Patients can also access a Respiratory Consultant clinic once a month.

We are also run an outpatient outreach clinic in Marie Curie Hospice Solihull which the UHB MND CNS Band 7 attends. Each patient known to the MND Care Centre is also referred into their local MDT who we work closely with and attend MDT Meetings with – we cover 13 MDTs.

UHB MND Clinical Nurse Specialists offer home visits to each new patient within 2 weeks of diagnosis and ongoing follow-up visits when required and dependent on local support available in the patient's area.

Patients access inpatient services in their own local hospital – normally as an acute admission. UHB is the local acute hospital for a proportion of the MND patients that the service manages.

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

Yes – two clinics per week and a monthly MDT clinic

- 10. If yes,**

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

Outpatient Department, Queen Elizabeth Hospital Birmingham (QEHB)

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

- Two Consultant Neurologist clinics per week with MND CNS in attendance
- One monthly MDT clinic with SALT, Dietician, Physio, OT, Palliative Care Consultant, Respiratory Consultant, Consultant Neurologist, MND CNS and Care Coordinator and Regional Care Development Advisor from the MNDA present.
There is also access to Orthotics in this clinic.

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

- 3-4 monthly with Consultant Neurologists (although dependent on progression rate of patient and patient choice)
- Review in the MND MDT clinic is based on the needs of the patient and at patient request.
- Home visits in between from the MND CNS team can also be requested by patients.
- Patients can also be seen by MND CNS team in any hospital they might be admitted to, if required.

MND Healthcare Team

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

Care Centre Directors are Dr Venkat Srinivasan and Dr Hardev Pall (Consultant Neurologists).

Care Co-ordinator and MND Clinical Nurse Specialist Caroline Davis (RN)

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?

0.05wte for outpatients:

Speech and Language Therapy

Dietician

Physiotherapy

Occupational Therapy

The MND inpatients are seen as part of the neurology inpatient caseload for therapies.

The Care Coordinator and MND Clinical Nurse Specialist (Band 7) is funded:

- 25.5 hours by Motor Neurone Disease Association (non-recurrent funding until Feb 2020)

- 4.5 hours by UHB

The MND Clinical Nurse Specialist Band 6 is funded:

- 22 hours by Motor Neurone Disease Association (non-recurrent funding until Feb 2020)

-3 hours by UHB

- 1.5 WTE Consultant Neurologists have a specialist expertise in MND. MND constitutes 50% of their workload, which is equivalent to approximately 0.75 WTE

- 1 x Respiratory Consultant attends clinic at UHB once per month from University Hospital North Midlands – funded by their Trust

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?

Consultant Neurologist, Clinical Nurse Specialist Band 6, Care Coordinator and MND Clinical Nurse Specialist Band 7, Respiratory Consultant, Dietitian, Occupational Therapist, Physiotherapist, Speech and Language Therapist, Palliative Care Consultant, Orthotist

MND Dietetic Services

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

Dietitian 0.05wte for outpatients

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

17. If yes,

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

Dietitian 0.05wte for outpatients

The MND inpatients are seen as part of the neurology inpatient caseload

b. What grade are they?

Band 6

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

Not applicable

In your organisation:

- 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?**

Year	Hospital inpatient	Hospital outpatient	Domiciliary visit	Community clinic	Other (please state)
2017	16	24	Nil	Nil	
2016	20	24	Nil	Nil	
2015	24	24	Nil	Nil	

- b. How many review contacts for patients with MND were seen by the dietetic service in each of the last three years, and where were they seen?**

Year	Hospital inpatient	Hospital outpatient	Domiciliary visit	Community clinic	Other (please state)
2017	41	48	Nil	Nil	
2016	58	48	Nil	Nil	
2015	148	48	Nil	Nil	

- c. **How many dietetic patients contacts (new and review) were for oral nutrition support, and how many were for artificial nutrition support, in each of the last three years?**

	All healthcare settings		Hospital settings (in-patients and out-patients)		Community settings (clinics and domiciliary visits)	
Year	Oral nutrition support	Artificial nutrition support	Oral nutrition support	Artificial nutrition support	Oral nutrition support	Artificial nutrition support
2017	72 – all out-patients	16 (all IPs are on artificial nutrition)	72 – all out-patients	16 (all IPs are on artificial nutrition)	Not applicable	Not applicable
2016	72 – all out-patients	20	72 – all out-patients	20	Not applicable	Not applicable
2015	72 – all out-patients	24	72 – all out-patients	24	Not applicable	Not applicable

Commissioning of MND Nutrition Services

19. Where does the funding come from for services for patients with MND in your locality?

Funding is determined by the referral source for the patient - GP referrals are funded by the CCG; tertiary referrals and Trust Consultant to Consultant referrals are funded by NHSE.

20. Which organisations and departments are involved in each stage of the commissioning process of nutritional services for patients with MND in your locality:

- 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)**

As above, dependent on the commissioning source, planning and procurement is undertaken via the Commissioning Intentions process. Service delivery and monitoring is undertaken via the Trust Contract Monitoring process.

21. Where does the funding come from for nutritional services for patients with MND (e.g. nutrition and dietetics service) in your locality?

Therapies including nutrition service are predominantly funded by the CCG.

Our patients are covered by several CCGs in their own areas.

