

Request under Freedom of Information Act 2000

Thank you for your request for information which we received on 14 September 2018.

I am pleased to confirm the following.

Name of organisation: Milton Keynes University Hospital Foundation Trust

Motor Neurone Disease (MND) Services

1. What is your NHS organisation's catchment population?

261,750 (2015) estimate from Milton Keynes Council)

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)?

5. How many newly diagnosed patients with MND were referred to the organisation in each of the last three years?

- a. 2017 – 11
- b. 2016 – 9
- c. 2015 – 8

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

Domiciliary Physiotherapy, Milton Keynes University Hospital (MKUH): 7

Dietetic MKUH, 14

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

No

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

- Acute admissions: MKUH
- Neuro Out-patient setting: MKUH
- Domiciliary Physiotherapy, Domiciliary Dietetics: MKUH, provided in patient's homes
- Speech and Language Therapy, Neuro Rehab Services (OT, Physio, psychology MDT), Clinical Nurse Specialist Neuro Conditions: CNWL- out-patient clinics and patient's home
- Hospice services: Willen Hospice, hospice at home and on hospice site.

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

No- they usually attend the MND care centre in Oxford.

10. If yes,

- a. Where are the MND specialist clinics in your organisation held?
- b. How often are the MND specialist clinics in your organisation held?
- c. How often are patients routinely reviewed in the MND specialist clinics?

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

Neurological Conditions Clinical Specialist Nurse, CNWL.

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?

No Specific Lead at MK Hospital but there is a Neurological Conditions Clinical Specialist Nurse in Community Services (Central North West London – CNWL) Foundation Trust that would support MND patients along with other neurological disorders. This role is not a specific MND lead post.

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

Not specifically but within Milton Keynes, professionals from MKUH, CNWL and Willen Hospice work together as an MDT but there is not one commissioned MDT service for MND.

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

The Neurological conditions clinical nurse specialist attends and facilitates an MDT meeting with representation from Domiciliary Physiotherapy (MKUH), domiciliary dieticians (MKUH), community speech and language therapy (CNWL), community occupational therapy (MK council), CNS Willen Hospice, Willen Hospice Well-being centre, District nursing (CNWL) , neuro-rehabilitation unit (CNWL)

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

1.00 WTE Band 7 Community Dietician for all neurological patients, not just MND – approx. 33% of clinical time spent on MND

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

No

17. If yes,

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

b. What grade are they?

N/A

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

Band 7 clinical team leader

19. 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	Information not available		9		
2016	Information not available		8		
2015	Information not available		Approx. 3 (not sure this is accurate)		

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	Information not available		Information not available		
2016	Information not available		Information not available		

2015	Information not available		Information not available		
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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?

Information not available

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

Service provided by MK University Hospital Nutrition and Dietetic Service, MKCCG are charged for each appointment undertaken

21. 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)

N/A

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

Service provided by MK University Hospital Nutrition and Dietetic Service, MKCCG are charged for each appointment undertaken.

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If you need any further assistance, please do not hesitate to contact us at the address above.

Yours sincerely,
 Freedom Of Information Co-ordinator
 For and on behalf of Milton Keynes Hospital NHS Foundation Trust

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