

Executive Corridor
Darlington Memorial Hospital
Hollyhurst Road
Darlington
DL3 6HX
Switchboard Tel: 01325 38 0100
Foundation Trust Office: 01325 74 3625
Corporate Records Office: 01325 74 3700

Request for Information Reference: 08.18.17

Direct line: 01325 743700
Email: cdda-tr.cddftfoi@nhs.net

Email only

6 September 2018

Freedom of Information Act 2000 – Request for Information

Thank you for your request for information received on 9 August 2018 in relation to the County Durham and Darlington NHS Foundation Trust (Trust). We are dealing with your request under the provisions of the Freedom of Information Act 2000.

You requested information regarding Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Specifically you asked for:

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) Data Request.

The information required is for the last five financial years:-

2013-2014
2014-2015
2015-2016
2016-2017
2017-2018

The details I am requesting under the Freedom of Information are as follows:-

- 1. How many patients with a diagnosis of ME/CFS are there in the NHS Trust for your area for each financial year?***

Answer: Previous figures not recorded. Currently we have 486 patients in the service. Period: August 2017 - July 2018, 250 new referrals, 169 new patient contacts & 1,484 review contacts.

2. How long does it take for a patient to reach the stage where an actual diagnosis is made, on average?

Answer: 6 weeks. When the GP has undertaken all blood test & investigations and the patient meets Fukuda Criteria then confirmation is given on initial assessment. Initial assessment times are before 6 weeks from receipt of referral and many times appointments are given within 2 weeks. Diagnosis would only be delayed if the health professional assessing, wanted to ensure other investigations had been completed.

GPs in general refer to us within the first 4 months according to NICE Guideline but may refer after the patient has presented with the symptoms for up to a year.

3. What services are offered to patients to assist to get a diagnosis?

Answer: The services offered to confirm a diagnosis are Occupational Therapy, Physio) and occasionally from a Respiratory Physician and Consultant Immunologist.

4. What is the specific Financial Budget allocated to ME/CFS Patients per year/per patient? (please note it is the financial budget specifically for those patients with ME/CFS, therefore not necessarily a department budget)

During the period statement, we were under contract via our Local CCG for to provide under the community contract a CFS / ME provision. This included to Face with Patient, Patient Proxy, Carer, Parent, Relative and covered Darlington CCG, DDES CCG and North Durham CCG Geographies. The specific value of this contract was on a block contract basis and not specific to variable to levels of activity – therefore it is not possible to provide a per patient figure. Values are also quoted exclusively of commissioning for quality and innovation (CQUIN) incentive funding;

This budget would not include any acute / national tariff driven work which is not

2013-2014	2014-2015	2015-2016	2016-2017	2017-2018
224,223	£220,187	£216,069	£216,199	£216,416

separat
ely
identifia

ble within budgets.

5. What is the specific Financial Budget allocated to Multiple Sclerosis (MS) patients?

Answer: During the period statement, we were under contract via our Local CCG for to provide under the community contract an epilepsy/ MS provision – it is not possible to disaggregate the two and therefore the following figures are inclusive of both. For both this includes - Contacts within the Community Epilepsy / MS Unit including Face to Face and Telephone Contact with Patient, Patient Proxy, Carer, Parent, Relative and covered Darlington CCG, DDES CCG and North Durham CCG Geographies. The specific value of this contract was on a block contract basis and not specific to

variable to levels of activity – therefore it is not possible to provide a per patient figure. Values are also quoted exclusively of CQUIN funding;

2013-2014	2014-2015	2015-2016	2016-2017	2017-2018
£157,736	£154,897	£152,000	£152,092	£152,244

6. How many patients for each year are being treated for MS?

Answer: Please note, these figures are for in-patients only; figures for out-patients will not be recorded and are based on the diagnosis codes from our coding system

Multiple sclerosis (MS)

2013/14: 15
 2014/15: 14
 2015/16: 12
 2016/17: 13
 2017/18: 15

Myalgic Encephalomyelitis (ME) / Chronic Fatigue Syndrome (CFS)

2013/14: 5
 2014/15: 1
 2015/16: 2
 2016/17: 3
 2017/18: 7

7. Which Department receives the funding for ME/CFS Patients? For example: - Neurological etc.

Answer: During the timeframes covered these services were originally managed under the community services remit managed by our Integrated Adults Care Group.

8. How many specialised medical staff does your Trust have that see/treat ME patients? What are their types of qualification and experience?

Answer: Within our CFS/ME team we employ two Extended Scope Practitioners (ESP), a highly specialist physio and a Psychiatrist. These are employed specifically to work with patients with CFS/ME. One ESP is a physiotherapist by background and the other an occupational therapist. Both are qualified to MSc & BSC level and hold additional post graduate courses. The highly specialist physiotherapist has many years' experience of working within the field of pain management (secondment). Both members of staff have worked in the specific field of CFS/ME for over 13 years.

9. Is your Trust aware of the fact that the NICE Guidelines are under a major review, due to pressures of Charity groups and patients who dispute the Pace Trial Results?

Answer: Yes.

10. Is your Trust aware there have been two Westminster Hall debates this year and that there is soon to be a full Parliamentary Debate on how little ME/CFS Patients are being listened too?

Answer: Yes.

11. What are your Trust's plans to make staff more aware of the implications of how people are affected by CFS/ME?

Answer: Specific CFS/ME service with allocated budget. Plan to continue with current service

12. What is your Trust's plan to provide a specialist-based clinics for ME/CFS patients in the near future?

Answer: Current service provided.

13. What is your Trust's plan to help promote local support groups? At present local groups are not being promoted, there are patients left with no support. Local groups can be extremely supportive, to myself and husband.

Answer: Current staff promote voluntary services as accessible to patients across the region.

14. What local funding is being used for research into ME/CFS?

Answer: There are no specific research studies underway for MS within the Trust however an overlap study undertaken does involve CFS for which a grant was received for £995 for Overlap Study and £1,397.94 for 6 Samsung Galaxy Tablets.

In line with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the County Durham and Darlington NHS Foundation Trust website.

If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me on the above telephone number or at the above address.

If you are unhappy with the way your request for information has been handled, you can request a review by writing to:

The Chief Executive
County Durham & Darlington NHS Foundation Trust
Darlington Memorial Hospital
Hollyhurst Road
Darlington
DL3 6HX

If, you remain dissatisfied with the handling of your request or complaint, you have a right to appeal to the Information Commissioner at:

The Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Telephone: 0303 123 1113
Website: www.ico.gov.uk.

There is no charge for making an appeal.

Yours sincerely

Joanna Tyrrell
Freedom of Information Officer