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Request for Information Reference: 01.19.29

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Email only

11 February 2019

Freedom of Information Act 2000 – Request for Information

Thank you for your request for information received on 14 January 2019 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 the CFS/ME clinics. Specifically you requested information as follows:

This is a freedom of information request for your CFS/ME clinic for Durham and Darlington.

(1) Please provide the information that you give ME/CFS patients about the safety and risks of the rehabilitative therapies (e.g. CBT, graded exercise therapy, activity management) provided by your service. If information is only provided verbally, we would be grateful for a brief summary. If you do not give patients such information in any form, please say so.

Answer: No written information is given regarding the safety and risks of CBT, GET or activity management. All treatment interventions are discussed with the patient and this is patient specific so will differ depending on variables such as patients' circumstances, symptom presentation, level of function pre-treatment and their treatment plan.

For GET reassurance is given and that people will feel a difference in their muscles but this is their body responding to the exercise and not necessarily a decline in their symptoms. Also, patients are encouraged to take their pulse rate to help ensure safe practice. Phone calls are made every 2 weeks when undertaking a GET programme and patients can email if they need advice in between clinics.

CBT techniques are used in the CFS clinic and referrals are made to Talking Changes if more intense work is needed. Patients are given handouts on anxiety

management and stress management which can help them to identify what they are anxious about. They can then bring them back to clinic and work through them with the team.

(2) Please provide us with any written guidance that you use to determine whether an ME/CFS patient has been harmed by the rehabilitative therapies (e.g. CBT, graded exercise therapy, activity management) provided by your service. This may include training material that you use to help your staff recognise harms. If you use unwritten criteria to determine whether a patient has been harmed, we would be grateful for a brief summary. If you have no criteria for judging whether a patient has been harmed, please say so. If you used different guidance for the patients in the time period dealt with in Question 3 below, please provide that also.

Answer: Every appointment after initial assessment will begin with a review of any advice/treatment plan given and the goals that were set, and discussion on how this has progressed looking at symptom changes and the patient's feelings regarding their progress since the last appt. This is documented in the patients' medical record and the treatment plan is then adjusted accordingly.

(3) (i) Please provide the number of ME/CFS patients who began rehabilitative therapies (e.g. CBT, graded exercise therapy, activity management) in your clinic in 2016. If data for patients who began in this period is not available, please provide it for the nearest earlier 1-year period, starting on any calendar date.

Answer: There were 116 new CFS patient initial contacts in 2016.

(ii) Please also provide the number of the patients in (i) who dropped out of therapy (a) in total; (b) because their condition worsened or they experienced harm from the therapy; (c) for an unknown reason.

Answer: This data is not collected centrally - it would be documented in individual patient records.

(iii) Please provide the number of patients in (i) who reported to you that they had had an increase in symptoms that had lasted for more than a few days and/or that their symptoms had become severe or distressing.

Answer: This data is not collected - it would be documented in individual patient records.

(iv) Please also provide the number of the patients in (i) whom you recorded as having been harmed by their therapy.

Answer: After initial assessment we work to see patients within 2-4 weeks unless their circumstances make it difficult for them to be seen in this timescale, then after that reviews tend to be every 5 weeks on average. If doing GET however this is followed up every two weeks by telephone. If patients are lost to a follow up it is because they have not attended an appointment and not contacted service within a 2 week time frame. We do not capture data for the number of patients lost to follow up

(v) Please state how long after initial assessment at your clinic patients are followed-up post-treatment and provide the number of patients in (i) who were lost to follow-up.

Answer: This data is not collected - it would be documented in individual patient records.

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