

Freedom of Information Request

Ref: UHB 17-318

Date 20 June 2017



Thank you for your request for information under the Freedom of Information Act 2000. The Trusts response is as follows:

I am seeking information on the management of CFS.

It appears that the biological basis of ME/CFS is without doubt given the Centre for Disease Controls multi-site study, the Institute of Medicine report, the Agency for Quality and Health Care and the research protocols of the National Institute of Health and statements by its director Francis Collins.

I am seeking information on how the NHS will use these guidelines to implement sound physiologically based rest/activity/exercise programs, now that it is clear that the disease is not a mental health disorder and hence the philosophy underpinning the PACE/Wessley School/mental health belief system is fatally flawed.

Continuous heart rate monitors are now readily available enabling patients to use exercise physiological principles to improve their self management ME/CFS.

Patients are having a 100% success rate and are describing needing to rest much more heavily to start with, and struggling to keep their heart rate within the recommended resting HR range when resting and under their anaerobic threshold when active/exercising.

However, patients are being rewarded by sustainable (albeit slow) increases in capacity and quality of life.

I am seeking information held on the management practices and protocols to be used by the NHS Bristol, given the success of using exercise physiologists/physiological basis/theory that is being implemented at many private clinics and almost "secretly" at a few NHS clinics.

I am only seeking the most recent information from 2016/2017.

The University Hospitals Bristol NHS Foundation Trust does not hold this information. This service is provide by North Bristol NHS Trust. You can make a Freedom of Information request here <https://www.nbt.nhs.uk/about-us/information-governance/freedom-information>.

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Trust Secretary
University Hospitals Bristol NHS Foundation Trust
Trust Headquarters
Marlborough Street
Bristol
BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

To view the Freedom of Information Act in full please click [here](#).

Yours sincerely,

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