

Date: Tuesday, 21st February 2023
Our Ref: MB/CM FOI 5566

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Re: Freedom of Information Request FOI 5566

We are writing in response to your request submitted under the Freedom of Information Act, received in this office on 31st January 2023.

Your request was as follows:

I note from your information that you run an optional education session. I wonder if you can advise which clinicians are involved, what topics are covered in this and what evidence you use to support this provision?

I can confirm that the Walton Centre NHS Foundation Trust have not ran a patient focused education session for many years as the number of participants interested dwindled due to increasing resources available online and patients having increased contact with clinicians with specialists skills.

We do run an specialist interest group, prior to COVID this was annually, we ran our first one after COVID in September 2022 virtually. Topics/subjects vary year on year depending on feedback. Previously facilitated equipment workshops, respiratory updates, gastro updates, palliative care well being services, occasionally had patient/carer representatives reflecting on their own experiences. This education session is aimed towards health professionals working across Merseyside/Cheshire/N.Wales who have contact with patients with MND.

What outcome measures you use to monitor condition management/intervention effectiveness. Do you stick with ALS/MND specific ones or use more commonly found, profession specific ones?

The WCFT audit our service every 2 years to NICE guidelines and this is affiliated with the MNDA who collaborate with our service. Regarding specific patient change, often an ALS-FRS could be completed but this only measures functional change, it will not predict prognosis or impact so this is typically reserved for use in research only rather than common practice.

Please see our response above in [blue](#).

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If 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 the Freedom of Information Office at the address above.

Please remember to quote the reference number, FOI 5566 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 Commissioners Office, Wycliff House, Water Lane, Wilmslow, Cheshire, SK9 5AF.

Yours sincerely

Mike Burns

Mr. Mike Burns, Executive Lead for Freedom of Information