

Date 08/07/2025
Your Ref
Our Ref 10169

Enquiries to Richard Mutch
Extension 35687
Direct Line 0131 465 5687
loth.freedomofinformation@nhs.scot
richard.mutch@nhs.scot

Dear

FREEDOM OF INFORMATION – ME SERVICES

I write in response to your request for information in relation to ME Services.

Question:

1. What ME-specific services were offered by the health board in 2023, 2024 and 2025 to date?

Answer:

It is not possible to delineate ME-specific services, from the ME/CFS/PVFS Service.

Under the Freedom of Information Act NHS Lothian is not required to create new records to enable it to respond to your enquiry. This information is not collated or held in aggregate form and it would be necessary to review all case files and finance ledgers in relation to ME Services over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

However, the NHS Lothian ME/CFS service operates on a Pan-Lothian basis and was established in 2012 and continues to support the management and rehabilitation of patients from across Lothian. Since 2023 to date, the multidisciplinary service has been staffed by Specialist Physiotherapist, Specialist Occupational Therapists, and Applied Psychologists.

Current staffing levels consist of: 0.5wte Specialist Physiotherapist, 1.0 Specialist Occupational Therapists, and 1.0 Applied Psychologists.

ME CFS Services

The ME CFS service provides an individualised multi-disciplinary approach, supporting individuals in optimising the management of their ME/CFS, improve functioning, support mental health and emotional wellbeing, and enhance quality of life. This includes providing patients with self-management tools in relation to the physical, cognitive, and emotional impact of this long-term condition.

Headquarters
Mainpoint
102 West Port
Edinburgh EH3 9DN

Chair Professor John Connaghan CBE
Chief Executive Professor Caroline Hiscox
*Lothian NHS Board is the common
name of Lothian Health Board*

This can involve activity management strategies to help stabilise energy levels, including establishing baseline levels of activity which a person can manage without escalating their symptoms. This does not include Graded Exercise Therapy which is *not* recommended for those with ME/CFS (NICE 2021).

Psychologists may support individuals in addressing barriers to effective change through psychotherapeutic strategies with people with ME/CFS, where appropriate, whilst ensuring that service users with ME/CFS are involved throughout in decisions relating to their physical, emotional and social care needs.

They also may explore the loss or change in role and identity which can be experienced.

Physiotherapists with a specialist knowledge of ME/CFS support patients with energy management; establish an individual activity pattern within their current energy limits which minimises their symptoms; advise on the management of flare-ups and relapses and address difficulties related to reduced physical activity or mobility. Where appropriate they will also advise on the introduction gentle movement which may include gentle exercises or stretches to maintain or improve functioning and manage pain when this is a goal of the person with ME/CFS.

Occupational Therapists provide support to patients with energy management, activities of daily living, and provide advice on home and workplace adaptations. This is of particular benefit to those patients who experience more severe levels of fatigue.

Service Delivery:

Individuals have the option to attend in person (at the Astley Ainslie Hospital), online via the Near Me platform, or by telephone.

The ME CFS service also offers an online group intervention.

The ME/CFS service will accept referrals of patients who are aged 16 years and over. Children with ME/CFS service will be seen within the paediatric services.

Question:

2. What services were offered in the board area in each of those years, relating to fibromyalgia, chronic fatigue syndrome and similar illnesses?

Answer:

Please see response to Q1A above.

Patients with fibromyalgia can also be referred to the ME CFS service, where fatigue is the primary difficulty. (Where pain is the primary difficulty, patients with fibromyalgia can be referred to the pain management service).

As above, staffing levels within the ME/CFS service over this time period consists of: 0.5wte Specialist Physiotherapist, 1.0 Specialist Occupational Therapists, and 1.0 Applied Psychologists.

Patients referred to the Chronic Pain Service with fibromyalgia are triaged and may be offered an appointment with a Pain Consultant or Nurse Specialist, followed by appropriate ongoing care. Additionally, patients may be triaged or subsequently referred to the Pain Management Programme — a psychology and physiotherapy-led service based at the Astley Ainslie Hospital.

Question:

3. How much has been spent on the provision of ME specific services by the health board in 2023, 2024 and 2025 to date?

Answer:

It is not possible to delineate costs for ME specific services.

Under the Freedom of Information Act NHS Lothian is not required to create new records to enable it to respond to your enquiry. This information is not collated or held in aggregate form and it would be necessary to review all case files and finance ledgers in relation to ME Services over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

Question:

4. How much was spent by the health board in 2024 and 2025 to date in the board area relating to fibromyalgia, chronic fatigue syndrome and similar illnesses?

Answer:

This question covers a wide variety of health specialities e.g. neurology, rheumatology, Primary Care, Specialist Pain Medicine and Nursing, Pain Management, ME/CFS, Rehab Medicine etc. We are therefore unable to answer this question.

Under the Freedom of Information Act NHS Lothian is not required to create new records to enable it to respond to your enquiry. This information is not collated or held in aggregate form and it would be necessary to review all case files and finance ledgers in relation to ME Services over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

The Pain Service and Pain Management Service manages a wide range of chronic pain conditions, including fibromyalgia. It is not possible to isolate specific costs to the management of fibromyalgia alone.

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <https://org.nhsllothian.scot/FOI/Pages/default.aspx>

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive