

ME/CFS Services

Health and Adult Services Scrutiny Committee

5th February 2025

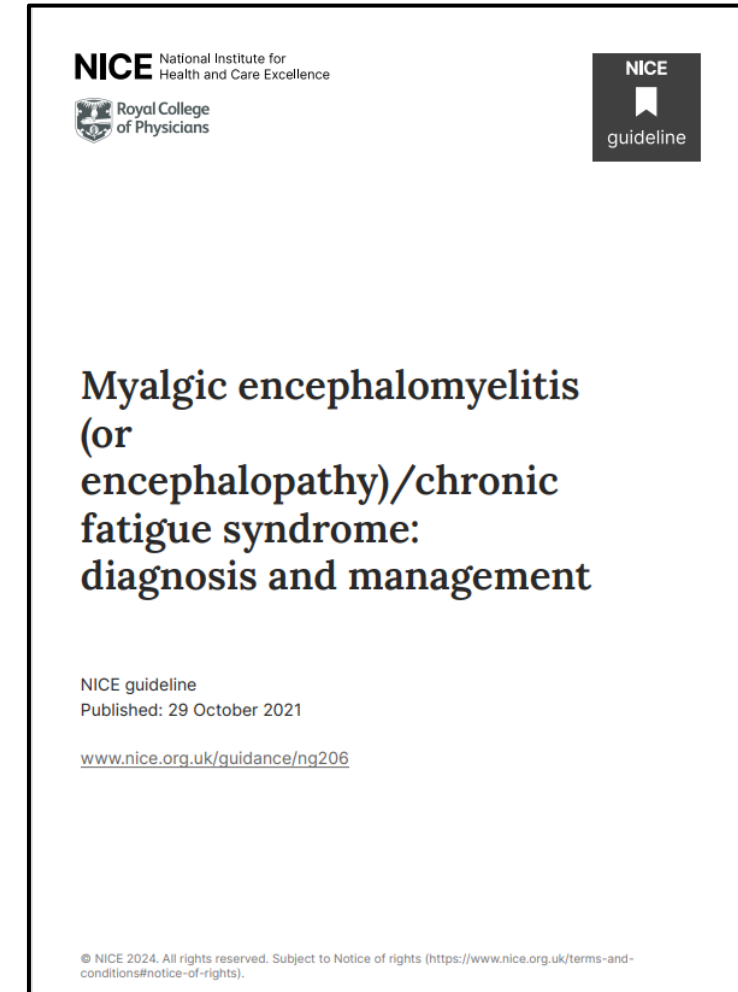
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Scrutiny Committee Query

- *The ME Association estimates that more than 1.25 million people in the UK live with a diagnosis of Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and Long Covid. ME/CFS is a debilitating, long-term neurological condition with varying degrees of severity.*
- *People with ME/CFS experience delayed worsening of symptoms after minor activity. It prevents people from functioning normally, stops or restricts ability to work or go to school, and leads to a lower quality of life.*
- *There are no effective drug treatments available. Treatments focus on improving functional ability and self-management.*
- *ME Action, the international campaign organisation, calls for greater education in hospital systems and medical schools about ME/CFS, and for major hospitals to treat ME.*
- **Lancashire County Council resolves:**
- To encourage greater understanding and improve the health outcomes of those affected by ME/CFS and Long Covid in Lancashire and asks the Health and Adult Services Scrutiny Committee to:
 - (i) Request information from the Lancashire and South Cumbria Integrated Care Board on numbers of people with ME/CFS and Long Covid and the treatment options available across Lancashire.
 - (ii) Investigate what ME/CFS and Long Covid training is given to existing and future staff on the updated NICE guidelines.
 - (iii) Consider how to approach the Secretary of State for Health and NHS England requesting further investment in research and training about ME/CFS and Long Covid.

NICE Guidance

- Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management NICE Guideline (NG206) Published 29th October 2021
- Covers diagnosing and managing ME/CFS in children, young people and adults. It aims to improve awareness and understanding about ME/CFS and when to suspect it, so that people are diagnosed earlier.
- These recommendations build upon previous NICE Guidance (CG53) that was published in August 2007.
- The Guidance was developed pre-COVID-19 pandemic
- ***Training for health and social care professionals:***
- ***1.16 – Training for health and social care professionals***
- ***1.16.1 – Health and social care providers should ensure that all staff delivering care to people with ME/CFS receive training relevant to their role so they can provide care in line with this guidance. Training should include:***
 - ***Helping them to understand what ME/CFS is and its diagnosis and management***
 - ***The experiences of people with ME/CFS***



ME/CFS Services and Long COVID

- ME/CFS has long been recognised as a 'Post-viral Fatigue Syndrome'
- ME/CFS is a complex and chronic medical condition that effects multiple body systems
- Symptoms include flu-like malaise, sleep difficulties, brain fog and a profound fatigue that is unlike normal tiredness. People may also experience chronic pain, headaches, nausea, digestive problems, sensitivity to light, sound and other stimuli
- Symptoms come and go and change or worsen with little warning, causing distress and disrupting people's lives
- **ME/CFS is different for everyone.** It can range from a milder illness to a severely disabling one that leaves some people housebound or bedbound
- Intervention for ME/CFS, Functional Neurological Disorder (FND), Chronic Pain and Long COVID have some similarities but also have different principles. Movement and exercise are recommended in Chronic Pain and some Long COVID patients but can be harmful for people with ME/CFS
- Long COVID is being recognised as a 'Post-viral Fatigue Syndrome' similar to ME/CFS that is triggered by the COVID-19 virus

Severity of ME/CFS

- **Mild ME/CFS** – people with mild ME/CFS care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. They often have reduced hours, take days off and use the weekend to cope with the rest of the week
- **Moderate ME/CFS** – people with moderate ME/CFS have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities.
- **Severe ME/CFS** – people with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They may spend most of their time in bed and are often extremely sensitive to light and sound
- **Very severe ME/CFS** – people with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube fed.

ME/CFS Services

- According to research on population statistics, 0.2 – 0.4% of the UK population have ME/CFS. Since the COVID-19 pandemic it is anticipated that these figures are much higher.
- **There are significant gaps in service for ME/CFS across LSC ICB**
- On the national e-RS (electronic referral system) the following options are listed:
 - Broadgreen (Liverpool University Hospitals NHS Trust);
 - Harrogate and District NHS Foundation Trust;
 - Royal Hallamshire Hospital (Sheffield Teaching Hospital NHS Trust);
 - The Royal Victoria Infirmary (Newcastle Upon Tyne Hospitals NHS Foundation Trust)
- Wrightington, Wigan and Leigh Teaching Hospitals NHS Foundation Trust (WWL) provide a ME/CFS specialist assessment, treatment, advice and support for adults who have a diagnosis of ME/CFS – *this service is restricted for residents who are registered with a GP in Wigan Borough*
- Liverpool service at Broadgreen is now closed to out of area referrals
- There is no other service for severe presentations across the UK

LSC ICB Services

- There are limited services for ME/CFS patients across LSC ICB with many localities utilising charitable organisations and networks to manage patients.
- Historically (circa. 2016) there were local services in place across each PCT/CCG area, but they were time-limited funded arrangements which have all since ended.
- There is an **online training course about ME/CFS** but it is not mandatory for NHS staff. It is a start, but only useful if you have an understanding and patient experience of ME/CFS and is focussed on diagnosis ([Myalgic Encephalomyelitis | chronic fatigue syndrome | CPD](#))
- There is a reliance on national charities to support patients and their families with ME/CFS. There is a national helpline run by the ME Association (0344 576 5326) and a wealth of supporting materials and links on different websites to provide additional guidance documents and information relating to ME/CFS:
 - [Action for ME](#)
 - [The ME Association - The ME Association](#)
 - [Myalgic encephalomyelitis / chronic fatigue syndrome - Support for neurological conditions | The Brain Charity](#)

Central Lancashire Moving Well service

- Across Central Lancashire ME/CFS services are provided as part of the **Moving Well Service** – this service was commissioned in 2016/17 as an integrated MSK, Pain, Rheumatology, Physiotherapy and ME/CFS service.
- The service is available for people who are registered with a GP practice in Greater Preston, Chorley or South Ribble. Estimates for prevalence within Central Lancashire equate to 1,576 people
- Most patients referred with symptoms of MW/CFS to the Moving Well service are within the moderate/severe categorisation
- The ME/CFS service aims to provide supportive, holistic patient-centred advice to aid acceptance, education and self-management for adults with mild or moderate ME/CFS.
- Myalgic Encephalomyelitis (ME), Post-viral Fatigue Syndrome (PVFS) and Chronic Fatigue Syndrome (CFS) are some of the names used to describe a syndrome, which is probably a similar type of condition and whose main feature is excessive fatigue
- ME/CFS affects people in different ways and no two people experiences the illness in the same way. The main feature is persistent physical and mental fatigue which differs from normal tiredness. It is not adequately relieved by rest and is usually out of proportion to the activity undertaken.
- A diagnosis is made by excluding around 40 other conditions that cause fatigue. Your GP will have arranged a variety of blood tests, liver function tests and routine biochemistry tests prior to attendance at the clinics
- <https://youtu.be/nJFbugw7zQw> - Tilly's Story 'To Recovery and Hope'

Long COVID Services

- The leads for Long COVID services across LSC ICB have detailed that they are still awaiting national guidance and confirmation of funding arrangements from NHS England for 2025/26 – this has been escalated both regionally and nationally. They have provided the following updates:
- What Long COVID clinics are currently open within your Trust?
 - Lancashire and South Cumbria has a number of adult Long COVID service provision in place delivered by the following Providers – Blackpool Teaching Hospitals (BTH); Lancashire and South Cumbria Foundation Trust (LSCFT); East Lancashire Hospitals Trust (ELHT); HRCG Limited; University of Morecambe Bay Hospitals Trust (UHMB)
- Are any of your existing Long COVID clinics intending to close in the near future?
 - NHS England guidance states that dedicated services should continue to be offered to support people suffering on-going effects of COVID-19 infection. Whilst a review a Long COVID services across Lancashire and South Cumbria continues the ICB are awaiting guidance/funding confirmation from NHS England
- Investigate what Long COVID training is given to existing and future staff on the updated NICE guidelines:
 - Long COVID staff within Providers have been providing bespoke in-house training on Long COVID including primary/GP colleagues
 - Vocational Rehabilitation training
 - POTS (Postural Orthostatic Hypertension Syndrome) training
 - Fatigue Management training
 - Compassion focussed psychological support training
 - Health coaching training
 - Behavioural Activation training
 - [BTS Physiology Webinars 2024 - Series 1 | British Thoracic Society | Better lung health for all \(brit-thoracic.org.uk\)](#) for respiratory training.



**Lancashire and
South Cumbria**
Integrated Care Board

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