

# Myalgic Encephalomyelitis / Chronic Fatigue Syndrome referral for Adults

## Criteria Based Access

Before consideration of referral for management in secondary care, please review advice on the Remedy website ([www.remedy.bnssg.icb.nhs.uk](http://www.remedy.bnssg.icb.nhs.uk)) or consider use of advice and guidance services where available.

**Early diagnosis and management are advised for best outcomes.** Healthcare professionals should consider seeking advice from an appropriate specialist if there is uncertainty about interpreting signs and symptoms at 3 months and whether further investigations are needed. The NICE Guideline for ME/CFS recommends referring adults directly to an ME/CFS specialist team to confirm their diagnosis and develop a care and support plan.

Referral to ME/CFS providers or services which are not commissioned by the NHS in line with this policy is not routinely funded.

### Section A – Criteria to Access Treatment

Funding Approval for treatment will only be provided by the ICB for patients meeting criteria set out below.

Patients should have fatigue lasting for more than three months, with **ALL** of the following features:

- 1) Debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional, or social exertion, and is not significantly relieved by rest.
- 2) Post-exertional malaise after activity in which the worsening of symptoms:
  - is often delayed in onset by hours or days
  - is disproportionate to the activity
  - has a prolonged recovery time that may last hours, days, weeks or longer
- 3) Unrefreshing sleep or sleep disturbance (or both), which may include:
  - feeling exhausted, feeling flu-like and stiff on waking
  - broken or shallow sleep
  - altered sleep pattern or hypersomnia
- 4) Cognitive difficulties (sometimes described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.
- 5) A physical examination and a blood screen have failed to find any abnormalities (or abnormalities can be explained)

**Other symptoms may be present but are not necessary to make a diagnosis including:**

- a) muscle and/or joint pain that is multi-site and without evidence of inflammation.
- b) headaches
- c) painful lymph nodes without pathological enlargement
- d) sore throat
- e) general malaise or 'flu-like' symptoms including nausea and chills
- f) dizziness and/or nausea
- g) palpitations in the absence of identified cardiac pathology.
- h) intolerance to alcohol, or to certain foods and chemicals
- i) heightened sensory sensitivities, including to light, sound, touch, taste and smell
- j) orthostatic intolerance and autonomic dysfunction, including dizziness, palpitations, fainting, nausea on standing or sitting upright from a reclining position
- k) temperature hypersensitivity resulting in profuse sweating, chills, hot flushes, or feeling very cold
- l) neuromuscular symptoms, including twitching and myoclonic jerks

**Exclusion criteria:**

There is no major psychiatric illness with psychotic or manic features.

The patient is not receiving concurrent rehabilitation from another service.

The patient is not currently undergoing any ongoing medical investigation. Please note that by making this referral it is assumed that all other potential pathologies have been excluded prior to making this referral. This referral cannot be made at the same time as any other pathology referrals.

Domiciliary ME/CFS therapy is not routinely funded, and a specific Exceptional Funding Request will need to be made to agree domiciliary visits.

Inpatient ME/CFS therapy is not routinely commissioned from the local NHS Trusts.

**NOTE**

If the patient in question is clinically exceptional compared to the cohort, then an Exceptional Funding Application may be appropriate. The only time when an EFR application should be submitted is when there is a strong argument for clinical exceptionality to be made. EFR applications will only be considered where evidence of clinical exceptionality is provided within the case history/primary care notes in conjunction with a fully populated EFR application form.

## **BRAN**

For any health- related decision, it is important to consider “**BRAN**” which stands for:

- **B**enefits
- **R**isks
- **A**lternatives
- **D**o **N**othing

## Benefits

- Confirmation of diagnosis which can be helpful for the patient who can then start to adjust to living with the condition and is less likely to be concerned about alternative diagnoses.
- Patient receives guidance regarding evidence-based self-management and rehabilitation.
- Individualised advice for employers can help to keep the patient in employment.
- Specialist advice for educational institutions can help sustainable engagement with education.
- Support with management of sleep problems.
- Identification of comorbidities such as Postural Tachycardia Syndrome (PoTS).
- Energy management strategies can reduce the risk of relapse and establish a baseline of activity to facilitate rehabilitation.
- Longer term review within a specialist Secondary Care ME/CFS Service can reduce pressures on Primary Care
- Access to specialist psychological therapy if the presentation is complicated by secondary depression, anxiety and/or PTSD.

## Risks

- The risks associated with contact with a specialist service are low.
- There have been accounts of increased symptoms associated with exercise interventions but these risks can be managed using shared decision-making and supporting the development of self-management skills such as pacing.

## Alternatives

- There are no other evidence-based management options.

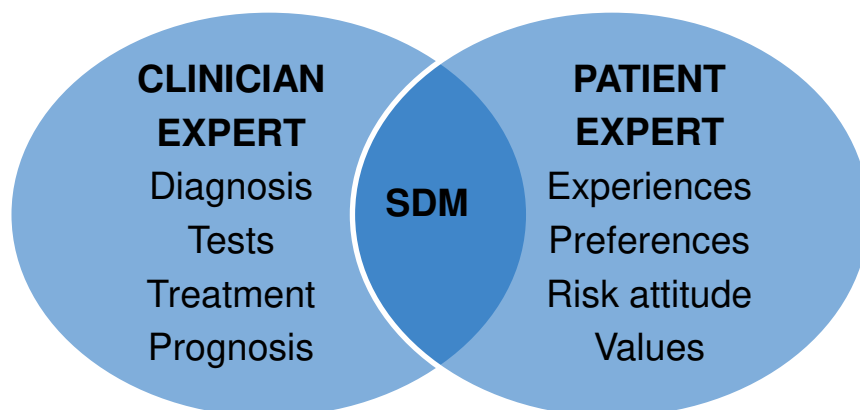
## Do Nothing

- This is an option for patients who are self-managing effectively who are not requesting support with any of these domains: employment, education, sleep management, engagement with daily activities and sustainable physical activity, and mental health.
- Remember, the patient always has the option to do nothing. Doing nothing is an equally reasonable option to doing something. Sometimes “not yet” is a good enough answer until you gather more information.

## Shared Decision Making

If a person fulfils the criteria for ME/CFS treatment, it is important to have a partnership approach between the person and the clinician.

Shared Decision Making (SDM) is the meeting of minds of two types of experts:



It puts people at the centre of decisions about their own treatment and care and respects what is unique about them. It means that people receiving care and clinicians delivering care can understand what is important to the other person.

The person and their clinician may find it helpful to use 'Ask 3 Questions':

1. What are my options? (see sections above)
2. What are the pros and cons of each option for **me**?
3. How do I get support to help me make a decision that is right for **me**?

### ME/CFS – Plain Language Summary

Chronic Fatigue Syndrome (CFS) causes persistent exhaustion that affects everyday life. CFS is also known as Myalgic Encephalomyelitis (ME). Exhaustion caused by CFS/ME doesn't go away with sleep or rest.

ME/CFS can cause long-term illness and disability. Many people (particularly children and young people) improve over time. Most cases of ME/CFS are mild or moderate, but up to one in ten people with ME/CFS have severe symptoms.

**This policy has been developed with the aid of the following references:**

1. [Overview | Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management | Guidance | NICE](#)

2. National Health Service (2021) Health A to Z: Chronic fatigue syndrome (CFS/ME) [online] Myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS) - NHS (www.nhs.uk)

## Connected Policies

N/A

## Due regard

In carrying out their functions, the Bristol North Somerset and South Gloucestershire Clinical Policy Review Group (CPRG) are committed to having due regard to the Public Sector Equality Duty (PSED), and NHSE Evidence-Based Interventions (EBI). This applies to all the activities for which the CCGs are responsible, including policy development and review.

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## Governance

Commissioning policies are assessed for their likely level of impact on BNSSG ICB and the population for which it is responsible. This determines the appropriate level of sign off. The below described the approval route for each score category.

| <b>Policy Category</b> | <b>Approval By</b>   |
|------------------------|--|
| Level 1                | Commissioning Policy Review Group.   |
| Level 2                | Chief Medical Officer, or Chief Nursing Officer, or System Executive Group Chair |
| Level 3                | ICB Board  |

## **OPCS Procedure codes**

Must have any of (primary only): TBC

## **Support**

If you would like further copies of this policy or need it in another format, such as Braille or another language, please contact the Customer Services Team on: **0117 900 2655** or **0800 073 0907** or email them on [BNSSG.customerservice@nhs.net](mailto:BNSSG.customerservice@nhs.net).