



# THE NICE CLINICAL GUIDELINE FOR ME/CFS 2021

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**The National Institute for Health and Care Excellence (NICE) has published the draft of the new clinical guideline for ME/CFS. The ME Association as a stakeholder in the guideline review process submitted its formal response to the draft at the end of December 2020.**

The new guideline will provide an essential framework to NHS and social care services that explains how people with ME/CFS should be treated when they need support from healthcare services. Indications are that the new guideline has the potential to be a significant improvement on the current version.

The ME Association is cautiously optimistic that when the new guideline is finally published on 18 August 2021, it will herald a new beginning for relations between people with the condition and healthcare professionals who work in NHS primary and secondary care, and in social care services.

Following the stakeholder consultation at the end of 2020, the guideline committee received a significant number of comments and suggestions aiming to improve the draft guideline. Because of this additional workload, NICE decided in March to push back the final publication date from April to August 2021.

This free leaflet aims to highlight the main points from the new draft guideline.

#### More information:

■ NICE Press Statement & Media Coverage of New Draft Guideline on ME/CFS, 10th November 2020: <https://tinyurl.com/y3ko2zq7>

■ BMJ: NICE backtracks on graded exercise therapy and CBT in draft revision to CFS guidance, 12th November 2020: <https://tinyurl.com/yxsg4s2c>

#### KEY MESSAGES FROM THE DRAFT NICE CLINICAL GUIDELINE ON ME/CFS

■ Read the full draft clinical guideline on ME/CFS, 10th November 2020: <https://tinyurl.com/vy1sb4zh>

#### Extracts:

### PRINCIPLES OF CARE FOR PEOPLE WITH ME/CFS

#### RECOMMENDATIONS

##### 1.1.1 Be aware that ME/CFS:

■ is a complex, chronic medical condition affecting multiple body systems and its pathophysiology is unclear

■ can have a significant impact on people's (and their families and carers') quality of life, including their activities of daily living, family life, social life, emotional wellbeing, work, and education

■ affects each person differently and varies widely in severity – in its most severe form it can lead to substantial incapacity (see recommendations 1.1.8 and 1.1.9)

■ is a fluctuating condition in which symptoms can change unpredictably in nature and severity over days, weeks or longer – ranging from being able to carry out most daily activities to severe debilitation.

##### 1.1.2 Recognise that people with ME/CFS may have experienced

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#### prejudice and disbelief and feel stigmatised by people who do not understand their illness. Take into account:

■ how this could affect the person with ME/CFS

■ that they may have lost trust in health and social services and be hesitant about involving them.

##### 1.1.3 Health and social care professionals should:

■ acknowledge to the person the reality of living with ME/CFS and how symptoms could affect them

■ take time to build supportive, trusting, and empathetic relationships

■ use a person-centred approach to assess people's needs

■ involve family members and carers (as appropriate) in

discussions and care planning if the person with ME/CFS chooses to include them.

#### 1.1.4 Recognise that people with ME/CFS need:

- early and accurate diagnosis so they get appropriate care for their symptoms

- regular monitoring and review, particularly when their symptoms are worsening or changing (see the section on managing flares and relapse).

#### 1.1.5 Explain to people with ME/CFS and their family or carers that they have the right to decline or withdraw from any part of their management plan and it will not affect other aspects of their care. They can begin or return to an intervention if they feel able to resume.

#### 1.1.8 Be aware that people with severe or very severe ME/CFS may experience some of the following symptoms that significantly affect their emotional wellbeing, communication, mobility, and ability to interact with others and care for themselves:

- severe and constant pain, which can have muscular, arthralgic or neuropathic features

- hypersensitivity to light, noise, touch, movement, temperature extremes and smells

- extreme weakness, with severely reduced movement

- reduced ability or inability to speak or swallow



- cognitive difficulties, causing a limited ability to communicate and take in written or verbal communication

- sleep disturbance such as unrefreshing sleep, hypersomnia, altered sleep pattern

- gastrointestinal difficulties such as nausea, incontinence, constipation, and bloating

- neurological symptoms such as double vision and other visual disorders, dizziness

- postural orthostatic tachycardia syndrome (POTS) and postural hypotension.

#### 1.1.9 Recognise that symptoms of severe or very severe ME/CFS may mean that people:

- need a low-stimulus environment, for example a dark quiet room with interaction at a level of their choice (this may be little or no social interaction)

- are housebound or bed-bound and may need support with all activities of daily living

- need careful physical contact when supported with activities of daily living, taking into account possible sensitivity to touch

- need aids such as wheelchairs

- cannot communicate without support and may need someone else they have chosen to be their advocate and communicate for them

- are unable to eat and digest food easily and may need support with hydration and nutrition (see the section on dietary management and strategies)

- have problems accessing information, for example because of difficulty with screens, noise and light sensitivity, headaches affecting their ability to read, or brain fog affecting their concentration.

#### 1.1.10 Personal care and support for people with severe or very severe ME/CFS should be carried out by health and social care practitioners who are:

- known to the person and their family members or carers wherever possible

- aware of the person's needs.

## SUSPECTING ME/CFS

#### 1.2.1 Explain to people presenting with possible symptoms of ME/CFS that there currently is no diagnostic test for ME/CFS, and it is recognised on clinical grounds alone.

#### 1.2.2 If ME/CFS is suspected carry out an assessment, which should include:

- a comprehensive clinical history

- a physical examination

- psychological wellbeing assessment

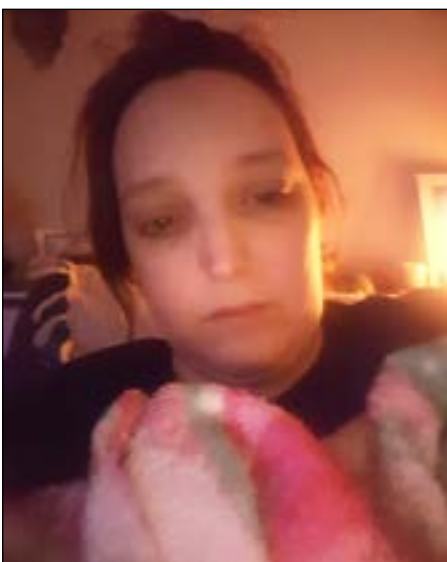
- baseline investigations to exclude other diagnoses.

#### 1.2.3 Suspect ME/CFS if:

- the person has had all of the persistent symptoms (see box 1) for a minimum of 6 weeks in adults and 4 weeks in children and young people

- the person's ability to engage in occupational, educational, social, or personal activities is significantly reduced from pre-illness levels

- symptoms are new and had a specific onset.



**BOX 1 - SYMPTOMS FOR SUSPECTING ME/CFS**

**1. Debilitating fatigability that is not caused by excessive cognitive, physical, emotional, or social exertion and is not significantly relieved by rest and**

**2. Post-exertional symptom exacerbation after activity that:**

- is delayed in onset by hours or days

- is disproportionate to the activity

- has a prolonged recovery time lasting hours, days, weeks or longer and

**3. Unrefreshing sleep, which may include:**

- feeling exhausted, flu-like, and stiff on waking

- broken or shallow sleep, altered sleep pattern or hypersomnia and

**4. Cognitive difficulties (sometimes described as 'brain fog'), including problems finding words, temporary dyslexia or dyscalculia, slurred speech, slowed responsiveness, short-term memory problems, confusion, disorientation, and difficulty concentrating or multitasking.**

**1.2.4 Be aware that the following symptoms may also be associated with, but are not exclusive to, ME/CFS:**

- orthostatic intolerance and autonomic dysfunction, including dizziness, palpitations, fainting, nausea on standing or sitting upright from a reclining position

- temperature hypersensitivity resulting in profuse sweating, chills, hot flushes, or feeling very cold

- neuromuscular symptoms, including twitching and myoclonic jerks

- flu-like symptoms, including sore throat, tender glands, nausea, chills, or muscle aches

- intolerance to alcohol, or to certain foods, and chemicals

- heightened sensory sensitivities, including to light, noise, touch, and smell

- pain, including pain on touch, myalgia, headaches, eye pain, abdominal pain, or joint pain without acute redness, swelling or effusion.

**1.2.5 Do not delay making a provisional diagnosis of ME/CFS. As soon as ME/CFS is suspected, based on the criteria in recommendation 1.2.3, give the person advice about symptom management (see the section on managing ME/CFS).**

**1.2.6 When ME/CFS is suspected, continue with any tests needed to exclude other conditions and explain to people that this does not affect their provisional diagnosis of ME/CFS.**

**1.2.7 Primary healthcare professionals should consider seeking advice from an appropriate specialist if there is uncertainty about interpreting signs and symptoms and whether a referral is needed.**

## REFERRING CHILDREN AND YOUNG PEOPLE WITH SUSPECTED ME/CFS

**1.2.8 When ME/CFS is suspected in a child or young person based on the criteria in recommendation 1.2.3:**

- refer them to a paediatrician for further assessment and investigation for ME/CFS and other conditions

- write to the child or young person's place of education or training to advise about flexible adjustments or adaptations.



## ADVICE FOR PEOPLE WITH SUSPECTED ME/CFS

See section 1.11 for recommendations on managing specific symptoms. This guideline does not cover all the symptoms that can occur in ME/CFS and refers to other NICE guidance in section 1.12.

**1.3.1 When ME/CFS is suspected, give people personalised advice about managing their symptoms. Also advise them:**

- not to use more energy than they perceive they have - they should plan their daily activity to stay within their energy envelope and not push through activity

- to rest as they need to

- to maintain a healthy balanced diet, with adequate fluid intake.

**1.3.2 Explain to people with suspected ME/CFS that their diagnosis can only be confirmed after 3 months of persistent symptoms. Reassure them that they can return for a review if they develop new or worsened symptoms, and ensure they know who to contact for advice.**

## DIAGNOSIS

**1.4.1 Diagnose ME/CFS in a child, young person or adult who has the symptoms in recommendation 1.2.3 that have persisted for 3 months.**

**1.4.2 After a diagnosis, refer adults directly to a specialist team experienced in managing ME/CFS to develop a management plan.**

**1.4.3 If ME/CFS is diagnosed in a child or young person after assessment by a paediatrician (based on the criteria in recommendation in 1.2.3), refer them directly to a paediatric specialist team experienced in ME/CFS to develop a management plan.**

## ASSESSMENT AND CARE PLANNING BY A SPECIALIST ME/CFS TEAM

### 1.5.1 After confirming a diagnosis of ME/CFS, carry out and record a holistic assessment. This should include:

- a full history (including relevant symptoms and history, comorbidities, overall physical and mental health, anything that is known to exacerbate or alleviate symptoms, sleep quality and other causes of physical or emotional stress)
- physical functioning
- the impact of symptoms on psychosocial wellbeing
- current and past experiences of medicines (including tolerance and sensitivities), vitamins and mineral supplements
- dietary assessment (including weight history before and after their diagnosis of ME/CFS, use of restrictive and alternative diets, and access to shopping and cooking).

### 1.5.2 Develop a personalised management plan with the person with ME/CFS (and their family members or carers, as appropriate) informed by the holistic assessment. Based on the person's needs, include in the plan:

- information and support needs (see section 1.6 on information and support)
- support for activities of daily living (see recommendation 1.8.7 on maintaining independence)
- mobility aids and adaptations to increase or



maintain independence (see recommendations 1.8.9 to 1.8.11 on aids and adaptations)

- education, training, or employment support needs (see section 1.9 on supporting people with ME/CFS in work, education and training)
- self-management strategies, including energy management (see recommendations 1.11.2 to 1.11.10 on energy management)
- physical maintenance (see recommendations 1.11.11 to 1.11.14 on physical maintenance)
- symptom management (see recommendations 1.11.27 to 1.11.50 on managing symptoms)
- guidance on managing flares and relapse (see section 1.13 on managing flares and relapses)
- details of the health and social care professionals involved in the person's care, and how to contact them.

### 1.5.3 Recognise that the person with ME/CFS is in charge of the aims of their management plan. The plan should be mutually agreed and based on the person's:

- preferences and needs
- skills and abilities in managing their condition
- hopes, plans and priorities
- symptom severity
- physical and cognitive functioning.

### 1.5.4 Give the person (and their family members or carers, as appropriate) a copy of their management plan and share a copy with their GP.



## PEOPLE WITH SEVERE OR VERY SEVERE ME/CFS

### 1.5.5 Offer home visits to people with severe or very severe ME/CFS to carry out their holistic assessment and develop their management plan.

## MANAGING ME/CFS

### 1.11.1 Be aware there is no current treatment or cure (non-pharmacological or 4 pharmacological) for ME/CFS.

Refer to relevant NICE guidance for managing symptoms associated with ME/CFS that are not covered in this section.

## MANAGING ME/CFS

### ENERGY MANAGEMENT

### 1.11.2 Discuss with people with ME/CFS the principles of energy management, its role in supporting them to live with their symptoms, the potential benefits and risks and what they should expect.

#### Explain that it:

- is not curative
- is a self-management strategy led by the person themselves but with support from a healthcare professional
- can be applied to any type of activity
- helps people understand their energy envelope so they can reduce the risk of overexertion worsening their symptoms
- recognises that each person has a different and fluctuating energy limit, and they are the best judge of their own limits
- can include help from a healthcare professional to recognise when they are approaching their limit (children and young people in particular may find it harder to judge their limits and can overreach them)
- uses a flexible, tailored approach so that activity is never automatically increased but is progressed during periods when symptoms are improved and allows for the need



to pull back when symptoms are worse

- is a long-term approach - it can take weeks, months or sometimes even years to reach stabilisation or to increase tolerance or activity

- does not assume that deconditioning is the cause of ME/CFS.

**1.11.4 Based on the person's assessment, establish an individual activity pattern within their current energy envelope that minimises their symptoms. For example:**

- reduce activity as the first step

- plan periods of rest and activity, and incorporate the need for pre-emptive rest

- alternate and vary between different types of activity and break activities into small chunks.

**1.11.5 Agree how often to review the person's energy management plan with them and revise it if needed.**

**1.11.6 Advise people with ME/CFS to reduce their activity if increasing it triggers symptoms, or if they have fluctuations in their daily energy levels.**

**1.11.7 Make self-monitoring of activity as easy as possible by taking advantage of any tools the person already uses, such as an activity tracker, phone heart-rate monitor or diary.**

**1.11.8 Refer people with ME/CFS to a specialist ME/CFS physiotherapy or occupational therapy service if they:**

- have had reduced physical activity or mobility levels for a long time

- are ready to progress their physical activity beyond their current activities of daily living

- would like to incorporate a physical activity programme into the management of their ME/CFS.



### PEOPLE WITH SEVERE OR VERY SEVERE ME/CFS

**1.11.9 Refer people with severe or very severe ME/CFS to a specialist ME/CFS physiotherapy or occupational therapy service for support on developing energy management plans.**

**1.11.10 Be aware when agreeing energy management plans with people with severe or very severe ME/CFS (and their families and carers as appropriate) that changes in activity should be smaller and any increases (if possible) much slower.**

### PHYSICAL ACTIVITY

**1.11.15 Do not advise people with ME/CFS to undertake unstructured exercise that is not part of a supervised programme, such as telling them to go to the gym or exercise more, because this may worsen their symptoms.**

**1.11.16 Do not offer people with ME/CFS:**

- any therapy based on physical activity or exercise as a treatment or cure for ME/CFS

- generalised physical activity or exercise programmes – this includes programmes developed for healthy people or people with other illnesses

- any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy

- structured activity or exercise programmes that are based on deconditioning as the cause of ME/CFS

- therapies derived from osteopathy, life coaching and neurolinguistic programming (for example the Lightning Process).

### OTHER TOPICS COVERED IN THE DRAFT NICE GUIDELINE FOR ME/CFS:

#### Recommendations:

- Information and support (incl. social care)

- Safeguarding

- Access to care

- Supporting people with ME/CFS in work, education, and training

- Multidisciplinary care

- Managing ME/CFS

- Managing coexisting conditions

- Managing flares and relapse

- Review (annual review recommendations)

- Training for health and social care professionals

#### Terms used in the guideline

#### Recommendations for research

#### Rationale and impact

#### Context

#### Finding more information and resources

#### NEXT STEPS

The ME Association as a stakeholder in the guideline review process was invited to submit formal comments on the draft document and this was completed at the end of December 2020.

The guideline committee will now consider all the comments from stakeholders and submit a final set

of recommendations to NICE who will publish the final guideline on 18 August 2021

- **Read the full draft clinical guideline on ME/CFS, 10th November 2020:** <https://tinyurl.com/yylsb4zh>

Read our blog, **NICE announce new publication date for the ME/CFS clinical guideline:** <https://tinyurl.com/cfmsbe6u>

