



Key differences between the 2007 and 2021 NICE guideline for M.E./CFS

The National Institute for Health and Care Excellence (NICE) published its 2021 guideline for M.E. on 29 October 2021. You can find it at www.nice.org.uk/guidance/ng206

We have reviewed the 2021 NICE guideline for M.E./CFS and list some of the key differences below, under three section headings:

- Suspecting and diagnosing M.E. – below
- Pacing and energy management – page 5
- Graded exercise therapy and cognitive behaviour therapy – page 8

For each section, we quote relevant sections of the 2007 and 2021 guidelines, along with the explanation from the NICE Guideline Committee about why these changes were made, with the page reference.

Action for M.E.'s Information and Support Service are here if you have questions. We are also working on a template letter you can use to inform your GP or other health professionals about the new guideline – this will be free to download from our website ASAP.

Email us at questions@actionforme.org.uk or call us on 0117 927 9551.

Suspecting and diagnosing M.E.

| 2007 guideline | 2021 guideline |
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| <p>1.2.1.2 Healthcare professionals should consider the possibility of CFS/ME if a person has fatigue with all of the following features:</p> <ul style="list-style-type: none"> • new or had a specific onset (that is, it is not lifelong) • persistent and/or recurrent • unexplained by other conditions • has resulted in a substantial reduction in activity level • characterised by post-exertional malaise | <p>1.2.2 Suspect ME/CFS if:</p> <ul style="list-style-type: none"> • the person has had all of the persistent symptoms in box 2 for a minimum of 6 weeks in adults and 4 weeks in children and young people and • the person's ability to engage in occupational, educational, social or personal activities is significantly reduced from pre-illness levels and • symptoms are not explained by another condition. <p><i>Box 2 Symptoms for suspecting ME/CFS</i> All of these symptoms should be present:</p> <ul style="list-style-type: none"> • 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. |

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| <p>and/or fatigue (typically delayed, for example by at least 24 hours, with slow recovery over several days)</p> <p>AND one or more of the following symptoms:</p> <ul style="list-style-type: none"> • difficulty with sleeping, such as insomnia, hypersomnia, unrefreshing sleep, a disturbed sleep-wake cycle • muscle and/or joint pain that is multi-site and without evidence of inflammation • headaches • painful lymph nodes without pathological enlargement • sore throat • cognitive dysfunction, such as difficulty thinking, inability to concentrate, impairment of short-term memory, and difficulties with word-finding, • planning/organising thoughts and information processing • physical or mental exertion makes symptoms worse • general malaise or 'flu-like' symptoms • dizziness and/or nausea | <ul style="list-style-type: none"> • Post-exertional malaise after activity in which the worsening of symptoms: <ul style="list-style-type: none"> ○ 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. ○ Unrefreshing sleep or sleep disturbance (or both), which may include: <ul style="list-style-type: none"> ○ feeling exhausted, feeling flu-like and stiff on waking ○ broken or shallow sleep, altered sleep pattern or hypersomnia. • 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. <p>[...]</p> <p>1.2.4</p> <p>Be aware that the following symptoms may also be associated with, but are not exclusive to, ME/CFS:</p> <ul style="list-style-type: none"> • 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, sound, touch, taste and smell • pain, including pain on touch, myalgia, headaches, eye pain, abdominal pain or joint pain without acute redness, swelling or effusion. <p>[...]</p> |
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| <ul style="list-style-type: none"> palpitations in the absence of identified cardiac pathology <p>[...]</p> <p>1.3.1.1 A diagnosis should be made after other possible diagnoses have been excluded and the symptoms have persisted for:</p> <ul style="list-style-type: none"> 4 months in an adult 3 months in a child or young person; the diagnosis should be made or confirmed by a paediatrician. | <p>1.3.1</p> <p>When ME/CFS is suspected, give people personalised advice about managing their symptoms. Also advise them:</p> <ul style="list-style-type: none"> not to use more energy than they perceive they have – they should manage their daily activity and not ‘push through’ their symptoms to rest and convalesce as needed (this might mean making changes to their daily routine, including work, school and other activities) to maintain a healthy balanced diet, with adequate fluid intake. <p>1.3.2</p> <p>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 before that if they develop new or worsened symptoms, and ensure that they know who to contact for advice</p> <p>[...]</p> <p>1.4.1 Diagnose ME/CFS in a child, young person or adult who has the symptoms in recommendation 1.2.2 that have persisted for 3 months and are not explained by another condition.</p> |
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(From page 52 of the new guideline) Why the committee made these changes relating to suspecting M.E.

The committee took into account both the lack of evidence on diagnostic tests and the evidence that people value realistic advice about ME/CFS (particularly around diagnosis) when making the recommendation to explain how the condition is recognised.

The committee acknowledged there is ongoing discussion in the ME/CFS community about which diagnostic criteria should be used to identify and diagnose ME/CFS. The committee made a recommendation for key symptoms based on the evidence review of the current diagnostic criteria, but no 1 set of criteria was agreed to be better overall. The factors influencing these discussions are the broadness of the inclusion criteria, the definition of some of the symptoms, and the usability of the criteria as a clinical tool. There are concerns that many of the existing criteria do not accurately identify people with or without ME/CFS.

Based on both the evidence and their experience, the committee agreed that the Institute of Medicine’s 2015 criteria had the best balance of inclusion and exclusion of all the reviewed criteria, but it needed to be adapted for optimal use. In particular, the committee felt that

the 6-month delay should be reduced so that management could start earlier, and that fatigue and post-exertional malaise should be defined clearly to make it easier to interpret the revised criteria.

Based on their experience, the committee decided that a diagnosis of ME/CFS should be suspected if people have all 4 key symptoms (debilitating fatigue, post-exertional malaise, unrefreshing sleep or sleep disturbance [or both], and cognitive difficulties) for a minimum of 6 weeks in adults and 4 weeks in children and young people. The committee agreed it would be unusual for an acute illness, including a viral illness, to persist longer than this in someone who has all 4 key symptoms. They emphasised it is the combination and interaction of the symptoms that is critical in distinguishing ME/CFS from other conditions and illness.

Currently, because there are no validated diagnostic criteria for ME/CFS, this leads to confusion about which criteria to use. The committee agreed to make a recommendation for research on diagnostic criteria to inform future guidance.

In addition to the 4 key symptoms, the committee noted that many of the criteria used to define ME/CFS also include other symptoms that are commonly experienced by people with ME/CFS. They agreed that although these symptoms are not crucial to a diagnosis, they are important for understanding ME/CFS and helping to manage symptoms, so they made a recommendation to raise awareness of them.

(From page 55 of the new guideline) Why the committee made these changes relating to diagnosing M.E.

The committee agreed that although a 6-month delay before diagnosis is built into the Institute of Medicine criteria, the criteria could be safely amended by reducing this period to 3 months. The committee saw removing this delay as useful because it might enable earlier management and could potentially improve longer-term outcomes.

Reflecting the common theme across the evidence about a lack of knowledge of ME/CFS and evidence that non-specialists in ME/CFS are not confident about diagnosing and managing ME/CFS, the committee recommended referring people with ME/CFS to an ME/CFS specialist team at 3 months to confirm their diagnosis and develop a care and support plan.

Pacing and energy management

NB. Balancing out activity and rest is sometimes called “energy management,” “activity management” or simply “pacing,” which is the term Action for M.E. – and the people we support – most often use. “Energy management” is a term more often used by health professionals, as it includes more than just pacing, such as planning and prioritising and managing sleep.

| 2007 guideline | 2021 guideline |
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| <p>1.4.2.7 People with CFS/ME have reported pacing to be helpful in self-managing CFS/ME. However, healthcare professionals should advise people with CFS/ME that, at present, there is insufficient research evidence on the benefits or harm of pacing.</p> <p>[...]</p> <p>1.4.6.3 Although there is considerable support from patients (particularly people with severe CFS/ME) for the following strategies, healthcare professionals should be aware that there is no controlled trial evidence of benefit:</p> <ul style="list-style-type: none"> • Encouraging maintenance of activity levels at substantially less than full capacity to reserve energy for the body to heal itself (sometimes known as the envelope theory). • Encouraging complete rest (cognitive, physical and emotional) during a setback/relapse. | <p>1.11.2</p> <ul style="list-style-type: none"> • Discuss with people with ME/CFS the principles of energy management, 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 with support from a healthcare professional in an ME/CFS specialist team • includes all types of activity (cognitive, physical, emotional and social) and takes into account overall level of activity • helps people learn to use the amount of energy they have while reducing their risk of post-exertional malaise or worsening their symptoms by exceeding their limits • recognises that each person has a different and fluctuating energy limit and they are experts in judging 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 maintained or adjusted (upwards after a period of stability or downwards 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. <p>1.11.3 Help people with ME/CFS develop a plan for energy management as part of their care and support plan. Support them to establish realistic expectations and develop goals</p> |

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| | <p>that are meaningful to them. Discuss and record the following in the plan along with anything else that is important to the person:</p> <ul style="list-style-type: none"> • cognitive activity • mobility and other physical activity • ability to undertake activities of daily living • psychological, emotional and social demands, including family and sexual relationships • rest and relaxation (both quality and duration) • sleep quality and duration • effect of environmental factors, including sensory stimulation. <p>1.11.4</p> <p>Work with the person to establish an individual activity pattern within their current energy limits that minimises their symptoms. For example:</p> <ul style="list-style-type: none"> • agree a sustainable level of activity as the first step, which may mean reducing activity • 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. |
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(From page 63 of the new guideline) Why the committee made these changes relating to energy management

The committee discussed how the controversy over graded exercise therapy had resulted in confusion over what support should be available to people with ME/CFS to safely manage their level of activity, including physical activity or exercise. They agreed it was important to provide clarity of information and clear guidance around energy management, physical activity and exercise to people with ME/CFS. The committee also agreed people need clear information about services available to them to support the development of energy management plans.

Based on their experience, the committee agreed that energy management is one of the most important tools that people with ME/CFS have to support them in living with the symptoms of ME/CFS. They agreed that people with ME/CFS should have access to support from an ME/CFS specialist team to develop a plan for energy management.

The committee listed the components of energy management and what an assessment and plan would include, noting that the key component is understanding the principle of using energy in a way to minimise post-exertional malaise. They recommended a detailed assessment that takes into account all areas of current activity and evaluation of rest and

sleep, to establish an individual activity pattern within the person's current energy limit. The committee noted that energy management is not a physical activity or exercise programme, although the principles of energy management do apply to physical activity and exercise programmes.

To avoid potential harms by energy management being wrongly applied to people with ME/CFS without adequate support and expertise, the committee recommended that in specific circumstances, people with ME/CFS should be referred to a physiotherapist or occupational therapist in an ME/CFS specialist team

Graded exercise therapy and cognitive behaviour therapy

| 2007 guideline | 2021 guideline |
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| <p>1.6.2.4 Cognitive behavioural therapy (CBT) and/or graded exercise therapy (GET) should be offered to people with mild or moderate CFS/ME and provided to those who choose these approaches, because currently these are the interventions for which there is the clearest research evidence of benefit.</p> | <p>1.11.10 Only consider a personalised physical activity or exercise programme for people with ME/CFS who:</p> <ul style="list-style-type: none"> • feel ready to progress their physical activity beyond their current activities of daily living or • would like to incorporate physical activity or exercise into managing their ME/CFS. <p>1.11.11 Tell people about the risks and benefits of physical activity and exercise programmes. Explain that some people with ME/CFS have found that they can make their symptoms worse, for some people it makes no difference and others find them helpful.</p> <p>[...]</p> <p>1.11.14 Do not offer people with ME/CFS:</p> <ul style="list-style-type: none"> • any therapy based on physical activity or exercise as a cure for ME/CFS • generalised physical activity or exercise programmes – this includes programmes developed for healthy people or people with other illnesses • any programme that does not follow the approach in recommendation 1.11.13 or that uses fixed incremental increases in physical activity or exercise, for example, graded exercise therapy • physical activity or exercise programmes that are based on deconditioning and exercise avoidance theories as perpetuating ME/CFS <p>[...]</p> <p>1.12.28 Discuss cognitive behavioural therapy (CBT) with adults, children and young people with ME/CFS (and their parents or carers, as appropriate). Explain:</p> <ul style="list-style-type: none"> • its principles, including that it may help them manage their symptoms but it is not curative and • any potential benefits and risks. |

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| | <p>1.12.29 Only offer CBT to adults, children and young people with ME/CFS if, after discussing it (see recommendation 1.12.28), they would like to use it to support them in managing their symptoms.</p> <p>1.12.30 For children and young people with ME/CFS who would like to use CBT:</p> <ul style="list-style-type: none"> • involve parents or carers (as appropriate) in the therapy wherever possible • adapt the therapy to the child or young person’s cognitive and emotional stage of development. |
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(From page 65 of the new guideline) Why the committee made this change relating to GET

The committee agreed that clarity of information and clear guidance on energy management in relation to all activity should be available to people with ME/CFS. The committee also agreed that people need clear information about services available to them, and particularly the specific circumstances in which a personalised physical activity or exercise programme could be considered by a person with ME/CFS.

In the committee’s experience, people with ME/CFS have had varying results from physical activity and exercise programmes. The committee agreed it was important to discuss this with people with ME/CFS and to explain to them the possible risks and benefits.

Because of the harms reported by people with ME/CFS in the qualitative evidence, as well as the committee’s experience of the effects when people exceed their energy limits, the committee recommended that people with ME/CFS should not undertake a physical activity or exercise programme unless it is overseen by a physiotherapist who has training and expertise in ME/CFS.

The committee outlined what a personalised physical activity or exercise programme should, and should not, include. In developing recommendations on the content, approach and delivery of physical activity and exercise programmes, the committee considered the benefits and harms associated with graded exercise therapy that had been reported with ME/CFS across the quantitative and qualitative evidence, alongside their own experiences. They recognised that different definitions of the term ‘graded exercise therapy’ are used, and as a result the content and application of graded exercise therapy programmes differ. This has resulted in confusion. Taking into account descriptions of graded exercise therapy in the evidence they reviewed, the committee included a definition in this guideline to clarify what graded exercise therapy is intended to mean in the recommendation.

The committee concluded any programme using fixed incremental increases in physical activity or exercise (for example, graded exercise therapy), or physical activity or exercise programmes that are based on deconditioning and exercise avoidance theories, should not be offered to people with ME/CFS. The committee also wanted to reinforce that there is no therapy based on physical activity or exercise that is effective as a cure for ME/CFS.

For people with ME/CFS who do choose to take part in a physical activity or exercise programme, this should follow the principles set out in this section and the energy management section.

(From page 72 of the new guideline) Why the committee made this change relating to CBT

The quantitative and qualitative evidence was mixed for adults, children and young people, and this reflected the committee's experience. Based on criticisms in the qualitative evidence of cognitive behavioural therapy (CBT) being described as a 'treatment' (cure) for ME/CFS, the committee considered it was important to highlight that CBT is not a cure for ME/CFS and should not be offered as such. Instead, it aims to improve wellbeing and quality of life, and may be useful in supporting people who live with ME/CFS to manage their symptoms and reduce the distress associated with having a chronic illness. It should therefore only be offered in this context, and after people have been fully informed about its principles and aims. The committee agreed if a child or young person would like to use CBT, it was important to adapt the therapy taking into account their cognitive and emotional maturity.

The qualitative evidence showed that people with ME/CFS have found CBT useful when delivered by a therapist who understands ME/CFS, but also that there is the potential for harm when it is inappropriately delivered. To avoid this, the committee made the recommendation about who should deliver CBT and the clinical supervision they should have.

The committee also made recommendations based on their experience to explain the principles of CBT for people with ME/CFS and what people should expect if they decide to consider CBT.