



Impact on NHS workforce and resources

Resource impact

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The updated [NICE guideline on myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management](#) covers every aspect of care for children, young people and adults with ME/CFS, from identification and assessment before and after diagnosis to management, monitoring and review.

It makes detailed recommendations that represent a change to current practice in many areas and will, due to the nature of those changes, take the NHS and social care systems some time to implement. For example, additional infrastructure and training will be needed in both secondary and primary care to ensure that support offered to all people with suspected or diagnosed ME/CFS follows the recommendations in the guideline.

Pre-pandemic, 260,000 people in the UK were estimated to have ME/CFS, of whom 76% were female and up to 25% experienced severe illness ([Counting the Cost, ME Association 2017](#)). With no nationally commissioned service for ME/CFS in either primary or secondary care, it will be for local systems to determine how to structure their services to achieve the aims of the guideline. It is critically important that specialist services for people with ME/CFS are available and commissioned in line with the guideline.

Impact of the guideline on resources

The [resource impact summary report](#) highlights the lack of robust data on current practice. Due to variation across organisations and services, the size of the resource impact from implementing the updated guideline will need to be determined at a local level depending on current local practice.

Recommendations likely to have an impact on practice

The guideline covers diagnosing and managing ME/CFS. The following areas of impact on the system will need to be considered by local commissioners and providers of health, education and social care to comply with the recommendations in the guideline.

Education and awareness

[Sections 1.1, 1.7, 1.8, 1.16](#) and [1.17](#)

Providers and other organisations should update their training for health and social care staff (including those in training) to ensure that up-to-date recommendations and safeguarding implications are disseminated across the health and social care system.

Information for people with ME/CFS, their families and carers

[Sections 1.6, 1.11](#) and [1.12](#)

Providers and other organisations should review and update their information and literature, including online materials, to ensure that these reflect the recommendations in the current guideline.

Availability of experts in secondary care to provide guidance to primary care

[Sections 1.2, 1.4](#) and [1.10](#)

Timely access to experts is not consistent across the system. Commissioners should consider options to support primary care in implementing the recommendations where need is identified.

Referring children and young people with suspected ME/CFS

[Section 1.2](#)

Commissioners and providers should ensure that provision for increased access to early paediatric review for further assessment and investigation for ME/CFS is available where need is identified.

Support for children and young people in education and training

[Sections 1.2](#) and [1.9](#)

- Commissioners and providers should review healthcare system access to school nurses to ensure that the links between primary care, secondary care and educational settings are in place to provide coordinated support, where need is identified.
- Those involved in supporting children in education should be aware that specific reasonable adjustments may be made for children and young people with ME/CFS where need is identified.

Access to ME/CFS specialist teams

[Section 1.4](#)

Commissioners and providers should be aware that investment will be needed to increase the number of specialist clinics and specialists with expertise to formally diagnose ME/CFS and develop a care and support plan where need is identified.

Aids and adaptations

[Section 1.8](#)

Commissioners and providers should note that increased provision of aids and adaptations for people with ME/CFS may be required where need is identified.

Access to social care support

[Sections 1.6](#), [1.8](#) and [1.17](#)

Commissioners and providers should note that increased availability for social care support should be considered for people with ME/CFS where need is identified, for example for people with severe or very severe ME/CFS.

Safeguarding

[Section 1.7](#)

Commissioners and providers should ensure that provision for increased numbers of specialist ME/CFS experts with a specialist knowledge of safeguarding is available where need is identified.

Regular reviews

[Sections 1.7](#) and [1.15](#)

Commissioners should review funding and capacity in primary care, ME/CFS specialist clinics and paediatric clinics to enable the recommended appointments where need is identified.

Equitable access to care and support

[Sections 1.8](#) and [1.17](#)

- To provide flexible services for people with ME/CFS, consideration will need to be given to where and how care is most appropriately provided. Funding and capacity for home visits, online or phone consultations should be considered to enable access in line with the guidance where need is identified.
- Commissioners and providers should take into account that people with severe and very severe ME/CFS may have a greater need for access to care and support, and make appropriate provision where need is identified.

Hospital care

[Sections 1.8](#) and [1.17](#)

Providers should consider the individual needs of a person with ME/CFS in the hospital setting, using system-wide approaches to meet their specific needs in line with the guidance. For some people this may mean provision of a single room or consideration of environmental factors that could affect their symptom burden.

Supporting people to work

[Section 1.9](#)

Commissioners and providers of health and social care services should consider how appropriate and timely access to occupational health services for people with ME/CFS can be achieved.

Specialist support for fatigue management

[Sections 1.11](#), [1.12](#) and [1.17](#)

- Commissioners should ensure that specialist ME/CFS services are available to those who need them in line with the guidance.
- Access to physiotherapists and occupational therapists with expertise in ME/CFS is not consistent across the system. Commissioners and providers should assess local need and service provision to ensure that people get the support they need.

Specialist dietetic support

[Sections 1.12](#) and [1.17](#)

Access to dietitians with a special interest in ME/CFS should be reviewed. Commissioners and providers should assess local need and service provision to ensure that people get the support they need.

Cognitive behavioural therapy

[Section 1.12](#)

Commissioners and providers should ensure that people with ME/CFS, who agree to use CBT to support them in managing their symptoms, have access to appropriately trained and supervised healthcare professionals.

Research to improve care for people with ME/CFS

The guideline committee identified [3 key recommendations for research](#) on diagnostic tests, a core set of health outcome measures to be used for trials of treatments and managing symptoms of ME/CFS, and the effectiveness of the consensus-based diagnostic criteria.

They also made [other recommendations for research](#) on the clinical and cost effectiveness of strategies for self-monitoring techniques in guiding energy management, sleep management and diet.

Education

Education considerations

Updated training for all health and social care staff (including those in training) is needed to ensure up-to-date recommendations and safeguarding implications are disseminated and understood.

Education resources

Education resources on ME/CFS are currently undergoing rapid change and users should expect to see further changes in line with the guidance.

Providers should ensure that existing education resources are updated to reflect the recommendations in the current guideline.

When accessing educational resources in ME/CFS, users should ensure that these have been updated and reflect the current guideline.

Examples of good practice from the perspective of people with ME/CFS

Primary care

“My GP was honest with me, which I really appreciated. She acknowledged that she did not understand what was going on in my body, but she accepted what I was reporting. She did her best to help me where she could, with medication for pain, referrals for investigations and written reports when necessary.”

“My GP was wonderful. I did not know what was happening to me, but she took time to reassure me, and clearly believed what I was saying. She suggested some blood tests to try to identify a cause. I remember the nurse taking the first of several bloods saying “You are poorly, aren’t you?”. The idea that this might all be in my head was never raised... I was able to get the fit notes I needed, and was referred to the ME/CFS service... 4 years later I am a lot better than I was. Early intervention and use of pacing means I have more capability than I could have, and that is thanks to a supportive GP.”

Treatment close to home

“My neuro-physiotherapist came to the house to treat me. She was very sympathetic to my ME – never pushed me. If I could only manage passive exercises, that was what she did. We had to go over the same ground over and over again, as I had frequent relapses due to my noise sensitivity. With this gentle, steady approach, we were able to make progress in the long term – walking with a frame.”

“The consultant did domiciliary visits when I was bedbound. He attended meetings and supported us when a safeguarding alert was raised by social services. He is always knowledgeable about ME research. He was also an excellent advocate for keeping my neuro-physiotherapist in place when the NHS no longer wanted to fund it, and was helpful in ensuring my continuing healthcare funding.”

Secondary care

“I would just like to say a massive thank you to my therapist and the clinic for helping me and changing my life. If it wasn’t for the clinic, I do not think I would have got any of my GCSEs, or be in college now, and that means so much. My life has changed. I still have ME, but I know how to deal with it better than I did and feel like I have a future.”

“Our paediatrician restored some of this family’s trust in doctors by being supportive and understanding, whilst acknowledging that that was all he could do. In fact, he did much more by writing to our GP and the school when necessary.”

“My consultant has been kind and supportive whilst giving practical advice and providing letters for benefit claims. To be believed and sympathised with is so important when little else is available.”

The Guideline Resource and Implementation Panel

The Guideline Resource and Implementation Panel reviews NICE guidelines that have a substantial impact on NHS resources. By ‘substantial’, we mean that:

- implementing a single guideline recommendation in England costs or saves more than £1 million per year, or
- implementing the whole guideline in England costs or saves more than £5 million per year.

Panel members are from NICE, NHS England, NHS Improvement, Health Education England, NHS Clinical Commissioners and when appropriate public health advice and Skills for Care.

The panel does not comment on or influence the guideline recommendations outside NICE’s usual consultation processes and timelines.