NICE National Institute for Health and Care Excellence

Resource impact summary report

Resource impact
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The guideline covers diagnosing and managing myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (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. It also includes recommendations on assessment and care planning, safeguarding, access to care and management. The guideline updates and replaces NICE guideline CG53 (published August 2007).

The number of people who have ME/CFS is estimated to be around 400 per 100,000 population (ME association, 2020 Health Counting the cost, 2017).

Most of the recommendations in the updated guideline reinforce best practice and do not need any additional resources to implement. However, some of the guideline areas and recommendations may represent a change to current local practice. Where there is a change required to current practice, this may require additional resources to implement, which may be significant at a local level. The need for additional resources may arise in any of the healthcare settings (community, primary and secondary care). Benefits derived from the change in practice may help mitigate any additional costs.

Due to a lack of robust data on current practice and the variation across organisations and services, the size of the resource impact will need to be determined at a local level.

Depending on current local practice, recommendations/areas which may require additional resources and result in additional costs include:

- Suspecting ME/CFS: these recommendations may increase the number of people with suspected ME/CFS who are then referred to a specialist service. This would be specialist adult medical and paediatric services for people with ME/CFS.
- Assessment and care planning by a medical specialist in ME/CFS, and multidisciplinary care: may need additional resources. Experts suggest current provision of specialist teams is very uneven across the country. Therefore, additional staffing may be needed in some areas if there are increases in referrals.
- Access to care: recommendations may need additional staff time or other healthcare resource use (such as equipment for virtual appointments) to implement, for example to offer flexible appointments and home visits for people with severe ME/CFS who are housebound, or bed bound.
- Managing ME/CFS: The guideline no longer recommends the use of programmes that involve fixed incremental increases in physical activity such as graded exercise therapy. However, the guideline recommends a holistic personalised approach, with management strategies based on individual needs and preferences. There are recommendations for energy management programmes involving self-management programmes and physical activity or exercise programmes for people wanting to progress their physical activity or incorporate physical activity or exercise into managing their ME/CFS. These programmes would be undertaken with the support from healthcare professionals in an ME/CFS team. There are also recommendations for cognitive behavioural therapy (CBT), delivered by healthcare professionals with appropriate training and experience in CBT, to help people with ME/CFS to manage their symptoms. The recommendations may result in more referrals to a specialist ME/CFS physiotherapy or occupational therapy service, therefore extra staff time may be needed. A reorganisation of ME/CFS services may be required at a local level to deliver these programmes. Any additional costs or savings should be considered at a local level.
- Reviews: experts suggest some people with ME/CFS, including those with severe and very severe ME/CFS, do not routinely get a clinical review. Therefore, additional capacity/resources may be needed, and which may impact medical capacity at specialist services.
- The management of patients with ME/CFS may result in a resource impact for primary care.
- Training and education in ME/CFS for healthcare and social care professionals is not widespread so additional resources may be needed in this area depending on local current practice.

Implementing the guideline may:

- lead to improved consistency of best practice across the country.
- lead to more people being accurately diagnosed with ME/CFS and fewer people with other conditions being mis-diagnosed. This will mean that people with ME/CFS will not have tests and interventions for conditions they don't have. People with other conditions will have appropriate diagnosis in a more timely manner, allowing them to receive treatment for their conditions at the earliest opportunity.
- improve access to care for people with ME/CFS. This will help people to manage their condition, reducing the risk of the condition deteriorating.
- lead to better health outcomes and care experience.

These benefits may also provide some savings to offset some of the potential costs identified above.

ME/CFS services are commissioned by integrated care systems / clinical commissioning groups and local authorities. Providers are NHS hospital trusts, community providers and GPs.