

Forward-ME Response to the draft GRIP statement on the implementation of the new NICE guideline for ME/CFS: NG206.

Submitted: 23 March 2022

Authors

This document responds to a draft implementation plan for the new guideline on ME/CFS: diagnosis and management: NG206. We respond as a group of organisations supporting people with ME/CFS under the 'Forward-ME' umbrella.

Background:

The new guideline represents a significant change in approach to the management of ME/CFS. It recognises severe failings in past approaches and support for people with the condition, saying: *People with ME/CFS may have experienced prejudice and disbelief and could feel stigmatised by people (including family, friends, health and social care professionals, and teachers) who do not understand their illness.*

To be effective, any plan to implement the new guideline must be robust and broad to drive change across not only the healthcare sector, but also care and support services. We must recognise the size of the challenge, and the leadership required at all levels of health and social care to overcome it.

While we recognise the aspirations of the draft, we are concerned that the document in its current form leaves too much leeway for health and social care leaders to disregard the scale of change required.

Given the significant pressures on all health and social care systems, effective implementation is threatened by institutional inertia. Driving the necessary changes will require active, clear and vocal leadership, targeted not only at health professionals, but also others involved in the care of people with ME/CFS such as social care teams, teachers, and family members.

The change from CCGs to ICSs is causing uncertainty regarding responsibility for implementing change. There needs to be clarity regarding which organisations are responsible.

While we recognise that some changes will need time to become standard practice, others (notably the ending of 'graded exercise therapy') must be implemented immediately. Staff in specialist clinics who adhere to the outdated model of ME/CFS must be retrained before continuing to practise. The medical Royal Colleges must update their training materials and disseminate them urgently.

A recurring challenge in considering the implementation of guideline NG206 is ensuring that services are suitable for the full breadth of ME/CFS severities. We recommend those who are working to implement these guidelines consider the range of presentations, from mild to very severe, as one-size-fits all services are may not be appropriate.

The following document reviews each of the areas considered, making general observations, and suggestions for change.

Comments regarding the whole text or areas omitted from the text:

Training:

Acknowledgment of the need for access to health and social care professionals “with expertise in ME/CFS” is welcome, however such expertise is currently poorly available in many regions. Without widespread access to training which reflects the new guideline, this need will not be met. Healthcare providers must recognise the need for increased training of new ME/CFS specialists. This need is increased due to the increase in ME/CFS patient numbers following Covid-19.

There is both a lack of training and lack of personnel to provide equitable treatment to people with ME/CFS across the NHS compared to other diseases. This shortage sustains the systemic injustice that people with ME/CFS have faced for many years.

Raising awareness of new recommendations on therapies:

While recommendations for some therapies may initially appear to have been maintained, providers should be aware that the nature of those therapies are not the same. For example, although Cognitive Behavioural Therapy (CBT) is still recommended in NG206, this is not the same as the CBT provided previously. The past model proposed CBT as curative alongside Graded Exercise Therapy, while the CBT recommended in the new guideline is purely supportive. NHS trusts and staff must be aware of the differences in approach and train staff accordingly.

Reablement:

In developing clinical pathways, healthcare practitioners should be mindful that the NG206 guideline should take precedence for people with ME/CFS. We are particularly concerned about ‘reablement’ as outlined in NG74. Practitioners should be aware that such approaches have caused harm and death to people with ME/CFS. We highlight relevant consultation responses on pages 53-55 written during the development of NG74: <https://www.nice.org.uk/guidance/ng74/documents/intermediate-care-including-reablement-scope-consultation-comments-table2>

ME/CFS Spectrum of severity: from mild to very severe:

We are concerned that the implementation statement does not recognise the variety and complexity of engagement required from healthcare practitioners in supporting people with ME, particularly those with severe and very severe ME/CFS. For example some people with severe and very severe ME/CFS may need interventions such as tube feeding which may be beyond the ability of dieticians. Such cases are highly complex as clinicians able to facilitate tube feeding may not be knowledgeable of the complexities of severe ME, and zealous intervention can cause harm. These cases need careful and considerate cross-functional care including people with expertise in severe ME/CFS.

Creation of Clinical Pathways from primary care:

The statement does not address changes which need to occur in primary care. Primary care have a significant role in suspecting ME/CFS, ruling out alternative diagnoses, and providing initial guidance on management.

Primary care physicians may also need to support people with ME/CFS experiencing fluctuating symptoms, providing new support as necessary, or referring on to specialist support where needed.

Creating New Clinics:

Paragraphs 1.4.3 and 1.4.4 of the guideline require children, young people and adults newly diagnosed with ME/CFS to be referred to a ME/CFS specialist to confirm the diagnosis and develop a care and support plan. This means that clinics will be required for all geographic areas, and may need to be created. We are concerned that this is not clear in the draft implementation statement.

Suffolk and North East Essex ICS pathways:

Implementation of these guidelines needs to be standardised nationwide using examples of best practise, and undertaken with end users.

The ME Association is working with Suffolk and North East Essex ICS to develop a new clinical pathway for ME/CFS that incorporates all the recommendations in the new guideline. We recommend that where good practice is being established, this may form a useful exemplar for other trusts who may wish to follow it for their own systems. (Contact: Alexis Johnys: Alexis.Johnys1@suffolk.nhs.uk)

Comments regarding specific paragraphs in the draft document:

Note: all paragraph references refer to guideline NG206.

Education and awareness:

In addition to 1.1.1, 1.1.2, 1.16.1, 1.7.1 to 1.7.5, paragraphs 1.1.3, 1.1.4, 1.1.5, 1.1.6, 1.17.1 and 1.17.2 of the guideline should also be included in this section. These refer to the approach to delivering care, which must be a key feature of any educational programme.

Paragraph 1.8.6 should also be listed here (Give families and carers information on how to access training...).

Paragraph 1.1.2 of the guideline states: *People with ME/CFS may have experienced prejudice and disbelief and could feel stigmatised by people (including family, friends, health and social care professionals, and teachers) who do not understand their illness.*

The paragraph on education advises that “Updated training ... should be *considered* ... across the healthcare system”. Given extensive reports of continued stigmatisation and disbelief by healthcare professionals after the publication of the new guideline, and the attempts to publicly undermine its conclusions by senior members of the healthcare profession (see “Medical leaders sign joint statement in response to NICE guidance on ME/CFS, Royal College of Physicians), there is a clear and significant requirement to implement ambitious educational programmes across the healthcare system. This paragraph should be strengthened to reflect the scale of the gap between past and future approaches.

Given the number of people affected by ME/CFS, we believe education about ME/CFS and raising awareness of its impact should be a requirement.

Given the number of people with ME/CFS who depend on support and care from family members and the community, there is a clear need to provide educational support for the wider public.

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

Given requirements in 1.4.3 and 1.4.4 to refer children, young people and adults with ME/CFS to a specialist team, we believe ME/CFS services will be required in all areas of the country, not just as a support service for primary care.

Support for children and young people in education and training:

In addition to 1.2.7, 1.9.3, 1.9.4, paragraph 1.9.2 of the should also be included in this section.

Those involved in supporting children in education should be aware that specific ‘reasonable adjustments’ exist for children and young people with ME/CFS. Some children with ME/CFS may be too ill to be in school, and those supporting their education need to be aware that this is not school refusal or a welfare and child protection issue.

For children with ME/CFS attempting to return to school, reasonable adjustments should be made to enable access, including reduced timetable if necessary. These are reviewed in paragraph 1.9.2 of the guideline. In these situations it is vital to establish a care and support plan, noting that there should be choice about how limited energy is used, and that this choice is not exclusive to education.

Access to social care support:

In addition to 1.6.7, 1.6.9, 1.6.11, 1.8.5 and 1.8.6 paragraph 1.17.3, 1.17.4 and 1.6.8 should also be included in this section.

Provisions in 1.17.3 and 1.17.4 are vital to people with severe or very severe ME/CFS who require social care. Both represent changes from current practice.

Note that paragraph 1.6.8 advises that social care workers should support access to social support including making a referral for someone if they prefer. Furthermore, children with moderate, severe or very severe ME/CFS may be entitled to support from children's social care as children in need. Social care workers will need to be aware of the particular support available for people with ME/CFS.

Safeguarding:

The guideline recognises that ME/CFS has been misinterpreted as signs of abuse or neglect (1.7.1). The guideline recommends that someone with specialist knowledge of ME/CFS be involved in any cases where such safeguarding suspicions arise. Given past experience, we believe that all those involved in children's safeguarding will need knowledge of ME/CFS, and will require further specialist support if ME/CFS is suspected to avoid compounding the impact of the disease.

There is no expectation that genuine safeguarding issues will arise any more frequently than in the general population. If the recommendations in the guideline on training of staff and access to specialist services are met it should be possible to fulfil this recommendation without further additional expenditure.

Regular reviews:

Paragraph 1.15.3 of the guideline should also be included in this section.

Equitable access to care and support:

Paragraph 1.17.5 and 1.17.6 of the NICE guideline should also be included in this section.

Given the wide range in severity of ME/CFS, services designed for people with mild ME/CFS are rarely suitable for people with severe or very severe ME/CFS. For example, many current ME/CFS clinics ask users to attend weekly sessions lasting over 2 hours each week in a location outside their home. This is impossible for people with severe and very severe ME/CFS. Any implementation plan must ensure that services are flexible and tailored to the limitations of people with severe and very severe ME/CFS and include their carers.

Any plan for equitable care and support should recognise the need for home visits for some healthcare services, and the need for staff to prepare for the needs of people with severe and very severe ME/CFS, including avoidance of sensory triggers such as perfumes, bright lights and loud noises.

Such plans should recognise that the people with severe and very severe ME/CFS may experience significant cognitive dysfunction combined with increased pain. The energy needed to receive a visitor may mean that concentration is limited, and holding a conversation can be difficult. Such health visitors will need training to manage such patients, and visits will need to be planned with a carer.

Hospital Care:

We are concerned that the text appears to focus on in-patient care, however out-patient care facilities need to be available for people with ME/CFS who may have significant sensitivities. This should include provision of low-stimulation waiting rooms in hospitals.

Further, some services and treatments such as blood tests and smear tests may be better provided at home.

Suggested change: "A system wide approach to meeting the needs of ME/CFS patients is required, including provision of access to single rooms and areas with low stimulation for both in-patient and out-patient care. Where services can be delivered at home, these may be more appropriate for people with severe and very severe ME/CFS. Where they cannot, consideration must be given to appropriate patient transport arrangements."

Supporting people to work:

Urgent development of new guidelines and education is needed for occupational health workers. The NHS Occupational Health National Guideline from NHS Plus / NHS Health at Work Network is from 2006 and is not in keeping with NG206. It is no longer fit for purpose. (see <https://www.nhshealthatwork.co.uk/chronic-fatigue.asp>)

Education on the impact of ME/CFS may need to extend to social care and benefit services to ensure these are aware of the condition and its impact.

Specialist Support for Energy Management:Decommissioning Services:

The draft statement says: "Commissioners should ensure there is no decommissioning of specialist ME/CFS services now graded exercise therapy and the lightning process are no longer recommended" and "it is critically important that specialist services for people with ME/CFS remain available and are not decommissioned as a result of the recommendations".

We agree that it is important for services to remain available for people with ME/CFS, however if those services do not meet the recommendations of the new guideline, it may be reasonable to close an existing service and re-open an alternative one (decommission and recommission). We would suggest a more flexible wording such as "commissioner should ensure specialist services remain available", which would allow for past clinics to be shut, and new clinics opened.

Note: The Lightning Process was never recommended by NICE.

Specialist dietetic support:

Paragraph 1.17.11 and 1.17.12 of the NICE guideline should also be included in this section.

The draft implementation document notes the potential need for dietitians to support people with ME/CFS, however it fails to consider those with very severe ME/CFS who may require tube feeding either enterally or parenterally. The requirement for support with gastrointestinal problems or inability to swallow goes beyond the scope of a dietician. Specialist gastroenterology support will be needed in these cases (see <https://www.mdpi.com/2227-9032/9/4/459> for examples). This is typically overseen by 'Home Enteral Nutrition Support' (HENS) teams or specialised nurses with additional training.

Cognitive Behavioural Therapy:

Paragraph 1.17.13 of the NICE guideline should also be included in this section.

While the guideline NG206 does maintain a recommendation for Cognitive Behavioural Therapy, this is with the intention of helping the person to manage their symptoms, and is not proposed as curative. CBT approaches provided in the past will not match the approach of the new guideline and practitioners will need retraining.

Research to improve care for people with ME/CFS:

We welcome the recognition of the need for more research. We must recognise that a severe shortage of biomedical research has left us with few therapeutic options for people with ME/CFS. We encourage all healthcare practitioners to advocate for more research spending in this area. We welcome the Coronavirus APPG's call for £100 million / year spending on Long Covid research. We ask for healthcare providers to support this call, and equivalent research for all those experiencing post-infectious disease from other causes.

Education Materials:

Many people report poor knowledge of ME/CFS and other post-infectious conditions among health care professionals. This results in stigmatisation and poor support. The need for updated training is clear, and should be reflected in the implementation statement.

Accordingly the wording should be strengthened to: "Updated training for all health and social care staff (and those in training) is required to ensure up to date recommendations and safeguarding implications are disseminated..."

Education Considerations:

Many healthcare professionals report that they have not learned about ME/CFS and post-infectious diseases during their education. Others report that it has been presented as a functional or psychosomatic disorder.

There is a clear need for improvement in this area, and the statement should be strengthened to reflect this: "A review of medical education with regard to ME/CFS is required to ensure undergraduate and post graduate doctors have an understanding of the diagnosis and management of the condition."

Further notes:

-‘The Lightning Process’: ‘Lightning’ is without an ‘e’

-Prevalence: the guideline cites 250,000, whereas the Implementation document cites 260,000.