

Forward-ME response to the NICE Guideline for Myalgic encephalomyelitis(encephalopathy)/chronic fatigue syndrome

Forward-ME is a non-charitable collaboration of some 30 representatives from the main ME charities, support groups and medical profession.

N.B. Members of Forward-ME have unanimously agreed that the term 'chronic fatigue syndrome (CFS)' is not an appropriate descriptor for the severity of this disease. Except when referring specifically to the NICE guideline CFS will not be used.

INTRODUCTION

Forward-ME welcome the new NICE Clinical Guideline and hope it will lead to improved healthcare provision and better relations between healthcare professionals and people with ME.

There is still a long way to go before we truly understand what causes and perpetuates this neurological condition, and we encourage researchers and funding bodies to prioritise investigations particularly in those areas highlighted by the guideline's research recommendations.

The key message the guideline carries is that ME is a medical condition that requires a biomedical approach. It is not a biopsychosocial (BPS) condition. We hope that the new guideline will signal a change in some attitudes, just as there has been for diseases such as epilepsy, MS, diabetes, and Parkinson's in the past.

We hope that with this new guideline health and social care professionals, clinical commissioners, charities, and people with ME will all work together to improve healthcare provision and make our incredible NHS accessible to all.

The guideline represents a new chapter in the history of ME. There is no place for those who perpetuated the stigma and misunderstanding that has caused so many people to suffer.

We look forward to working closely with patients, carers, health and social care professionals, commissioners and researchers to implement these recommendations and build a brighter future for people with ME.

We were pleased when NICE agreed to review their 2007 guideline for ME/CFS in September 2018. We appreciate the care with which the Guideline Development Group have managed an extraordinarily complex assignment.

1. We found the following to be particularly helpful:

- They respect patients in a way that is compassionate and just.
- They have understood the needs of the patient community and have recognised most of their needs.
- The special emphasis placed on the needs of children and young people is welcome.
- The recognition that safeguarding is important and that children and young people or those who are severely affected might be in a situation where symptoms are confused with abuse or neglect.
- NICE gives firm directive for informed consent and patient-centred care. It is important that people with ME (and their family members) are completely involved and have a right to refuse care without it affecting future care in any ongoing relationship with healthcare professionals.
- The emphasis placed on early and accurate diagnosis and the recommendation that people with suspected ME begin diagnostic assessment within weeks of symptoms appearing.
- NICE no longer recommend that ME can be treated effectively using cognitive behaviour therapy (CBT) and graded exercise therapy (GET); that exercise needs to be approached with caution, and these therapies are not curative.
- The guideline proposes that people affected by ME take care to conserve energy and employ safe approaches to energy management
- Also, importantly, NICE recognise the need for continued training and education and healthcare professionals.

- We are pleased that specialist teams are commonly led by medically trained clinicians from a variety of specialisms. We agree that all specialist services should be led by medically trained physicians/doctors or consultants. This would help reduce regional health inequalities in medical care for this disease.
- We are pleased to see that the areas for research recommended by NICE, which highlight the inadequacies of current medical knowledge, are key.

2. We have the following concerns:

- There is no acknowledgment that ME is classified by WHO and SNOMED-CT as a neurological disease; the latter mandated within NHS England and being implemented in NHS Wales, NHS Scotland and NHS Northern Ireland. These classifications are important, not only legally to healthcare providers to ensure correct implementation of the protocols, but also to people who have ME because it helps to validate the illness, encourage medical awareness and reduce the stigma that is still experienced.
- The November draft contained clear statements to the effect that 'CBT is not a treatment or cure for ME/CFS' and 'Do not offer CBT as a treatment or cure for ME/CFS'. These statements have been excluded from the current guideline and we feel they should not have been.
- The final guideline states that CBT can be used to help symptom control, though there is no evidence of effectiveness that was considered by the guideline committee. It confirms that CBT does not assume that people have "abnormal illness beliefs", but it appears to leave the door open to accept this as an explanation for symptoms. We feel this is wrong
- The highly respected Oxford Handbook on Psychotherapy Ethics says therapists must clearly distinguish between CBT that helps patients cope with disease and CBT that places responsibility for the illness on the patient. They must recognise that it is legally and ethically unsustainable to provide the latter where it is possible that patients suffer from disease.

- We appreciate that CBT may sometimes be helpful when learning to cope with long-term debilitating illness, but we cannot understand why the ME guideline contains two convoluted pages of advice about CBT when the guideline for multiple sclerosis (CG186), for example, carries a single sentence. It is also too open to misinterpretation that will negate the intention of the guideline.
- Whilst GET is expressly excluded, the introduction of 'exercise programmes' with no explanation of what they could or would involve and no evidence of safety or efficacy in the evidence gathering process leaves open the possibility of further misinterpretation of the guideline or mere rebranding of current practices that will negate the Committee's work. This risk is particularly the case where alternative diagnoses such as functional neurological disorder (FND) are assumed that incorrectly assume diagnostic equivalence. The amended guidelines now risk a very probable contribution to this problem.

3. For the future:

- It is for the funders to prioritise funding for ME research and to ensure that research is of the highest scientific and ethical quality. It is for medical, educational and social welfare practitioners to ensure that people with ME are listened to, that they are treated respectfully and lawfully.
- There is no place for confrontation or division that has existed between the physiological scientific consensus and those who believed that ME is a BPS condition.

We look forward to working closely with all those concerned about ME including patients, carers, medical practitioners, or researchers to build upon the science to create a future where ME is accepted, treated appropriately and people with ME truly cared for.

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