

## Supporting you and your patients with ME/CFS

This briefing by Forward-ME (see p 4) sets out key information about the chronic, fluctuating, neurological condition ME, also diagnosed as chronic fatigue syndrome (CFS, or ME/CFS).

In brief:

- People with ME/CFS experience severe, persistent, activity-induced fatigue characterised by post-exertional malaise, their body and brain's inability to recover after expending even small amounts of cognitive or physical energy, leading to a flare-up in symptoms – see below.
- The NICE guideline for ME/CFS currently recommends Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) for mildly and moderately affected patients, but the strength of this evidence is poor. In reality, extensive patient surveys show that CBT and GET frequently have a worsening effect on symptoms – see p 2.
- Instead, a majority of patients use rest, pacing (carefully managing activity and rest to avoid post-exertional malaise) and/or medication for individual symptoms to manage ME/CFS – see p 3.

### About ME/CFS

Myalgic encephalomyelitis (ME), sometimes referred to as chronic fatigue syndrome (CFS), is a chronic, fluctuating, neurological condition that causes symptoms affecting many body systems, most commonly the central nervous system and immune systems.

- ME/CFS affects an estimated 250,000 adults and children in the UK, and around 17 million people worldwide.
- People with ME/CFS experience severe, persistent, **activity-induced** fatigue characterised by post-exertional malaise (PEM), their body's inability to recover after expending even small amounts of cognitive or physical energy, leading to a flare-up in symptoms. PEM may be delayed, up to 48 hours after exertion.
- Other symptoms can include muscle and joint pain, cognitive **dysfunction, orthostatic intolerance and other manifestations of autonomic dysfunction**, noise and light sensitivities and digestive problems.
- People with ME/CFS can vary enormously in their experience of the illness, and how their symptoms fluctuate. An estimated one in four children and adults with ME/CFS experiences severe symptoms.

The consequences of ME/CFS, and the lack of appropriate treatment for patients, are wide-reaching. Many adults are unable to maintain employment or relationships with family and friends, while for children ME/CFS is the most common cause of long term school absence. While recent studies show ME/CFS patients are no more likely to suffer from poor mental health or emotional problems than the general population<sup>1</sup>, adults with ME/CFS are six times more likely to die by suicide<sup>2</sup>. They may also be at an increased risk of earlier cardiovascular and cancer mortality<sup>3</sup>.

The lack of education/training, appropriate guidance or practical experience with patients mean some doctors struggle with early and accurate diagnosis, and with providing appropriate management advice and treatment. Delay in diagnosis or misdiagnosis, along with inappropriate or inadequate management, can be significant risk factors for a more persistent and severe form of the illness.<sup>4</sup>

The Chief Medical Officer's Report into ME/CFS<sup>5</sup>, and the NICE guideline on ME/CFS, set out clear timeline markers for making an early and accurate diagnosis.

<sup>1</sup> Unger et al., 2017; Multi-Site Clinical Assessment OF ME/CFS: Design and Implementation of a Prospective/Retrospective Rolling Cohort Study. *American Journal of Epidemiology*

<sup>2</sup> Chang et al., 2016, Mortality of people with CFS. *Lancet*

<sup>3</sup> McManimen et al., 2016, Mortality in patients with ME/CFS. *Fatigue*

<sup>4</sup> Derek Pheby et al, 2011, Risk Factors for the Development of Severe ME/CFS. *Biology and Medicine*

<sup>5</sup> CFS/ME Working Group, 2002; [www.tinyurl.com/CMOreport2002](http://www.tinyurl.com/CMOreport2002)

Both recommended that adults should have normally had the diagnosis confirmed within four months from onset of symptoms and within three months for children and young people.

Patient evidence collected by UK charities, the ME Association [2016] and Action for ME [2019], indicates that only a small number are receiving a positive diagnosis within 6 months of onset. These results show that a majority have to wait for over 12 months, and one in five wait more than six years.

### Review of the NICE guideline for ME/CFS

The 2007 NICE guideline for ME/CFS is currently under review. The Chair of the Guideline Development Committee has been clear that it is being **significantly revised** following representation from patients, charities, healthcare professionals and researchers, all agreeing that the existing guideline is outdated and does not reflect the most recent research.

It currently recommends Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) for mildly and moderately affected patients, although the strength of this evidence is poor. Forward-ME worked with Oxford Brookes University to conduct a survey of people with ME/CFS to find out how effective these recommended treatments were.<sup>6</sup>

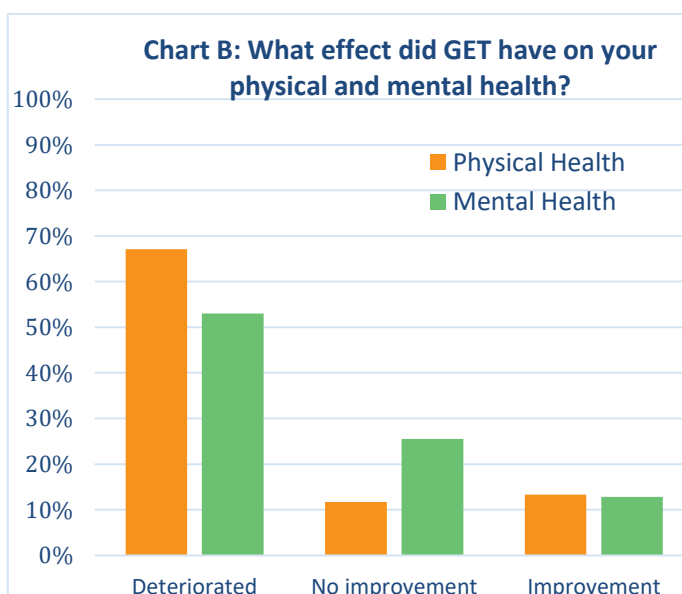
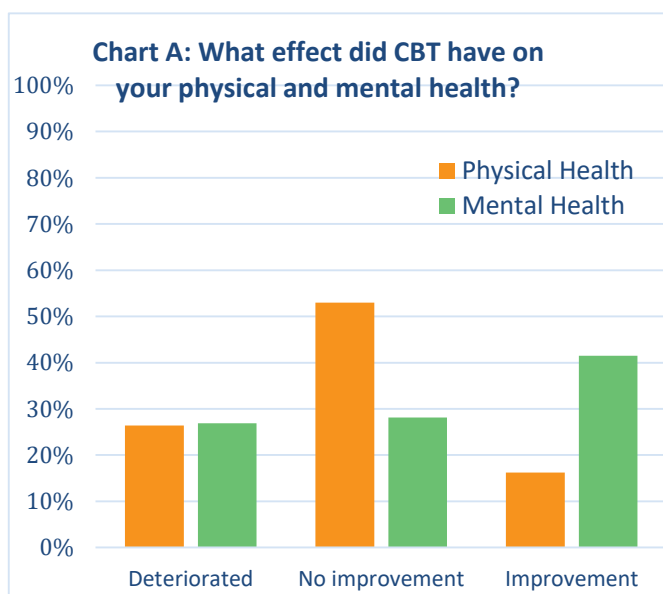
The survey was designed to gather evidence from people who have been offered CBT and/or GET based on the NICE guideline since 2007. Much of the evidence received echoes what we already know from previous surveys and feedback received by charities over a number of years.

Chart A indicates the effect CBT had on the physical and mental health of people with ME/CFS. In addition to this, 47% of people said that their symptoms had worsened because of this treatment.

This survey also found that the number of people who considered their condition as 'severe' increased following the treatment.

Chart B is the results of the GET section of Forward-ME's survey; 81% also said that their symptoms worsened as a result of this treatment.

The results show clearly that CBT and GET are unsuitable treatments or management approaches for ME/CFS. The changes in severity and the worsening of symptoms are clear indications that the therapies being offered are having adverse effects on the health of individuals.



<sup>6</sup> Forward ME, 2019, [www.forward-me.org.uk](http://www.forward-me.org.uk)

## How this impacts on people with ME/CFS

GET is commonly offered to people with ME/CFS in the UK, despite patient surveys consistently finding that this can cause harm for patients with ME/CFS. These risks are not currently acknowledged in the guideline, undermining the capacity of patients to give informed consent. Patient experience is consistent with evidence that inappropriate exercise is detrimental for people with ME/CFS.<sup>7</sup>

While the guideline states that patients can refuse any treatment, in clinical practice this frequently does not happen. This problem is especially problematic for more vulnerable patients (such as children and the severely affected). Treatments and management should be patient-centered, taking into account the level of severity and stage of the illness, and with potential risks recognised and managed.

Patients are also increasingly labelled under medically unexplained symptoms (MUS), and are routed to inappropriate psychological services that do not recognise the specific characteristics of ME. It is vital that patients receive improved diagnoses of ME and obtain access to clinicians who understand their condition.

## People severely affected by ME/CFS

Currently, there are only limited and inadequate recommendations for severely ill patients. Home visits are often refused, despite domiciliary care being included in the guideline. The NICE guideline states that their care ought to be supervised or supported by a specialist in ME/CFS, but there are very few clinicians providing specialist care and no formal specialist training for doctors. More consideration needs to be given to ensure that this group receives appropriate care.

## Management approaches used by people with ME

Short, regular rest periods throughout the day may help to give time to recuperate. Rest and relaxation are as central to pacing as activity; the amount of rest needed may vary at different stages of the illness.

Pacing is a self-management tool that many people with ME/CFS use to take control of the balance of activity and rest, to prevent a worsening of symptoms. For some, very minimal mental and/or physical activity can cause considerable impact on symptoms, including PEM (see p 1). **The goal of pacing is not to increase activity over time, but to prevent relapse and avoid triggering PEM.** It may be useful to wear a smartwatch to gauge activity levels.

While there is no pharmacological cure for ME/CFS, medication can be prescribed to help with individual symptoms, eg. ease pain, manage orthostatic intolerance and aid sleep. People with ME/CFS often have a limited tolerance to drugs, so starting lower doses than usual may be needed, then slowly increasing if appropriate.

## What can you do to support people with ME/CFS?

- Recognise the reality of their condition and how symptoms affect them.
- Take account of their wishes, age, how severe their ME/CFS is, and any previous experience that is relevant to their current care.
- Encourage shared-decision making and ensure patients have all the information needed to make an informed choice.
- Give them information about ME/CFS, the treatments and care described in this factsheet, and, **if appropriate**, managing work and/or accessing education in a way that meets their needs.
- Give information about local/national self-help and support groups and charities – see p 4 – for patients and their family or carers.

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<sup>7</sup> Twisk, 2017, Dangerous exercise. The detrimental effects of exertion and orthostatic stress in ME/CFS. *Physical Medicine and Rehabilitation Research*

## About Forward-ME

Forward-ME is a collaboration of charities and voluntary organisations (see below) invited by the Countess of Mar to meet from time to time. We aim to promote effective joint working by ME and CFS organisations to maximise impact on behalf of all people with ME and CFS in the UK, and improve recognition, understanding, research, management, support and information for everyone affected by ME and CFS. We are a Board member of the UK CFS/ME Research Collaborative (see below), membership of which is open to anyone with personal/professional experience of ME/CFS; its sixth annual conference takes place in March 2020 in Bristol.

It is essential that people with ME/CFS receive appropriate and timely healthcare. While there are no cures for ME/CFS or treatments that work for everyone, patients can be assisted with management techniques and pharmacological treatments to alleviate their symptoms. The treatment needs of 250,000 adults and children with ME/CFS in the UK must not be ignored while health bodies are updating guidance.

We want to see:

- patients receive a timely diagnosis of ME, not MUS or other broad categories, to ensure that their specific health and care needs are recognised and met
- Clinical Commissioning Groups and Health Boards meet the need in their locality, collect data on prevalence and ensure funding for this patient group is commensurate to the disease burden
- a defined referral pathway, to ensure that all ME/CFS patients consistently receive the same standard of care
- the development of services specifically for people who are severely affected including home visits, consultation by video or phone call, and specialist inpatient services.



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