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PRESS RELEASE

NICE ME/CFS guideline outlines steps for better diagnosis and management

NICE has today (29 October 2021) published its updated guideline on the diagnosis and management of myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS).

This follows a successful roundtable discussion convened to address concerns raised by some professional bodies about aspects of the guideline. Following the discussions, NICE is now confident that the guideline can be effectively implemented across the system. Explanatory detail has been added to some sections to further clarify the recommendations.

The guideline covers every aspect of ME/CFS in children, young people and adults from its identification and assessment before and after diagnosis to its management, monitoring and review. It also highlights what support should be offered to people with suspected or diagnosed ME/CFS and their families and carers, and what information, education and support should be available for health and social care professionals.

Paul Chrisp, director of the Centre for Guidelines at NICE, said: “As well as bringing together the best available scientific evidence, we’ve also listened to the real, lived experience and testimony of people with ME/CFS to produce a balanced guideline which has their wellbeing at its heart. NICE hopes that system partners and the ME/CFS community will work together to make sure these important recommendations are implemented.”

Peter Barry, Consultant Clinical Advisor for NICE and chair of the guideline committee, said: “This guideline will provide clear support for people living with ME/CFS, their families and carers, and for clinicians. It recognises that ME/CFS is a complex, chronic medical condition that can have a significant effect on people's quality of life.

“We know that people with ME/CFS have had difficulty in getting their illness acknowledged, and the guideline provides guidance for suspecting and diagnosing the

condition, recognising that there is no specific test for it. The guideline emphasises the importance of a personalised management plan for areas such as energy management - including the importance of rest and staying within the individual's energy limits - the treatment of specific symptoms, and guidance on managing flares and exacerbations.”

The guideline recognises that ME/CFS is a complex, multi-system, chronic medical condition where there is no ‘one size fits all’ approach to managing symptoms.

Enabling people to access care earlier may improve longer term outcomes and help people with ME/CFS and their carers to better understand the condition and how to manage it. The guideline therefore recommends reducing the time from 4 months to 3 months that a person needs to have persistent symptoms before a diagnosis of ME/CFS can be confirmed.

The guideline identifies the symptoms of ME/CFS as debilitating fatigue that is worsened by activity, post-exertional malaise, unrefreshing sleep or sleep disturbance, and cognitive difficulties (“brain fog”). It says that people with all 4 symptoms that have lasted 3 months or more should be directed to a ME/CFS specialist team (in the case of children this should be a paediatric specialist team) experienced and trained in the management of ME/CFS to confirm their diagnosis and develop a holistic personalised management plan in line with this guideline.

It sets out that people with ME/CFS should receive individually tailored support focused on personal agreed goals and a range of approaches should be used depending on the patient's preferences and priorities.

The guideline makes it clear that any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy (GET)¹, should not be offered for the treatment of ME/CFS. Discussions with stakeholders during the guideline pause highlighted that the term ‘GET’ is understood in different ways and the guideline sets out clearly what is meant by the term.

Instead, person centred energy management can be offered as a key component of a personalised management plan. This is a self-management strategy led by the person living with ME/CFS with support from a healthcare professional that can be applied

to any type of activity (cognitive, physical, emotional or social). Reviewed regularly, it is designed to help people understand their energy limits so they can reduce the risk of overexertion worsening their symptoms.

The guideline highlights the importance of ensuring that people remain within their energy limits when undertaking activity of any kind. It recommends that any physical activity or exercise programmes should only be considered for people with ME/CFS in specific circumstances and should begin by establishing the person's physical activity capability at a level that does not worsen their symptoms. It also says a physical activity or exercise programme should only be offered on the basis that it is delivered or overseen by a physiotherapist in an ME/CFS specialist team and is regularly reviewed.

Although cognitive behavioural therapy (CBT) has sometimes been assumed to be a cure for ME/CFS, the guideline recommends it should only be offered to support people who live with ME/CFS to manage their symptoms, improve their functioning and reduce the distress associated with having a chronic illness.

Baroness Finlay, Consultant in Palliative Medicine, Clinical Lead for Palliative Care for Wales, Velindre NHS Trust, and vice-chair of the guideline committee, said:

“ME/CFS is a complex long-term condition that causes disordered energy metabolism and can be profoundly disabling. Those with ME/CFS need to be listened to, understood and supported to adapt their lives. The committee members involved in this guideline have worked particularly hard to ensure care becomes more empathetic and focused on the individual's needs.”

Ends

References

- ¹ Graded exercise therapy is a term used in varying ways by different services supporting people with ME/CFS. In this guideline, graded exercise therapy is defined as first establishing an individual's baseline of achievable exercise or physical activity, then making fixed incremental increases in the time spent being physically active. This definition of graded exercise therapy reflects the descriptions given in the evidence that was reviewed, and it is this approach that the guideline says should not be undertaken. An individualised approach that should be taken for people with ME/CFS who choose to undertake a physical activity or exercise programme is described in recommendations 1.11.10 to 1.11.13.