

Improving outcomes for people with ME-CFS

Action for M.E. briefing for Occupational Therapists in Scotland

By Fiona Wright, North Bristol NHS Trust

Myalgic Encephalomyelitis (ME) is a serious, chronic, fluctuating, neurological condition that affects an estimated 20,000 adults and children in Scotland.

The Scottish Good Practice Statement (SGPS) says it is characterised by “persistent and fluctuating symptoms of fatigue, pain and loss of endurance to normal activities associated with conspicuous deterioration after exercise.” (www.scot.nhs.uk/scottish-good-practice-statement-on-me-cfs). Within NHS Scotland, a diagnosis of chronic fatigue syndrome (CFS) or ME-CFS is often given.

There are approximately 2,000 newly diagnosed cases of ME-CFS per year in Scotland, and one in four people with M.E. are severely affected, ie. housebound/bedbound and dependent on others for care and support. See www.actionforme.org.uk/severe-me

Comments from adults living with M.E.

- “Anything that felt like regaining a bit of control, a bit of life, has a positive effect. It's mostly about giving myself the best opportunity of getting better, and waiting. There has been slow improvement.”
- “What is helpful will vary at different stages of the illness, In terms of long- term management, it is a bit of everything that helps.”

Symptoms

Symptoms of ME-CFS fluctuate in nature and severity over time, and are provoked by any physical or mental exertion.

A key feature of ME-CFS is post-exertional malaise (sometimes referred to as a ‘crash’), the body and brain’s inability to recover from spending even small amounts of energy, leading to an increase in other symptoms, including:

- persistent or recurrent fatigue
- myalgic and/or joint pain (in the absence of joint swelling or redness)
- sleep disturbance
- flu-like symptoms
- cognitive symptoms (difficulties with memory, concentration, ‘brain fog’)
- digestive and gastro-intestinal symptoms
- postural light headedness or dizziness: an increase in heart rate on standing of 30+ bpm or a standing heart rate of 120+ bpm suggests postural orthostatic tachycardia syndrome (POTS) which should receive specialist attention (*Lewis et al., 2013. Journal of Internal Medicine*)

Key considerations for you and your patients

- Intervention needs to be individualised as symptoms cluster differently for each patient. Setting a baseline (activity that can be managed without making symptoms worse) is an essential first step in all cases.
- Support self-management by asking how long someone can talk for, and offer rests. Brain fog can make sharing and understanding information challenging for patients with ME-CFS, which can be very distressing.
- Be aware of other illnesses: not all symptoms can be explained by ME-CFS.
- Focus on what's important to the individual, give hope and reassurance – with problem solving, adaption, goal setting, small incremental increases if appropriate and set-back management it is possible to feel a lot better.
- A realistic, rehabilitative approach, fostering understanding by using techniques like “teach back” and a commitment to collaboration with the patient avoids the danger of appearing to say: “Get on with it.”
- Let people know that they are not alone: an estimated 250,000 people in the UK have this illness. For information and support, including signposting to local support groups, visit www.actionforme.org.uk, call 0117 927 9551 or email questions@actionforme.org.uk

Types and phases of care and support

It is essential to consider how the condition affects the individual and what's required at this point. Some people may benefit from a graded activity rehabilitative approach, others need an adaptive approach. The British Association for CFS/ME's *Therapy and symptom management in CFS/ME* guide (www.bacme.info) offers a detailed view a rehabilitative approach, in four phases. These phases need not be sequential and can be returned to at any point. There is no set time scale for each phase.

- Engaging: “To engage the patient in a relationship (with the therapist) that facilitates collaborative working to achieve the person's goals with help of therapist's expertise and knowledge base through self-management and making changes.”
- Regulating: “To reduce the variation (boom and crash pattern) through stabilising daily routines, including physiological cycles such as sleep, eating and moving. This provides a sense of control and enables the person to have a foundation for improvement. For some people this may help achieve their goals or for some the goal may be to achieve regulation and stay at this level.”
- Increasing: “To gradually build the level of all areas of activity in daily life, as defined by the person. This may be increases in frequency, intensity, quality and/or duration. This is a consolidating, incremental approach that supports successful integration and can be sustained.” NB. Not all patients may be able to increase activity.
- Sustaining: “To continue improvement towards recovery whilst accommodating the demands of daily life over time.”

DISCLAIMER ME-CFS is a complex condition and this briefing is intended as an introduction only. Guidance on managing co-morbidities, identifying red flags and other matters of clinical judgement are outside its remit.

Action for M.E., 42 Temple Street, Keynsham BS31 1EH. Registered charity in England and Wales no. 1036419
Registered in Scotland no. SC040452. Company limited by guarantee, registered in England no. 2906840