

Supporting effective management of ME-CFS

Action for M.E. briefing for primary healthcare professionals in Scotland

Myalgia 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's 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.

Symptoms of ME-CFS fluctuate in nature and severity over time, and are provoked by physical or mental exertion. Its key symptom is post-exertional malaise, 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 and myalgia and/or joint pain that can be widespread and migratory. Pain, rather than fatigue, may often be the patient's worst symptom.

Comments from adults living with M.E.

- "I was addicted to my former life and it took me a long time to realise that I had to make a transition to a new life."
- "I gave in to expectations, despite thinking it wasn't the right thing to do, and it was damaging. That's when we need those around us to validate the condition and to encourage us to do only what our bodies are capable of doing at that time."

Key considerations for you and your patient

- The SGPS highlights that it is crucial to "tailor interventions to the needs and circumstances of the individual patient."
- One in four people with ME-CFS are severely affected and will require home visits and their care needs assessed and regularly reviewed.
- Acknowledge the reality of your patient's symptoms and the impact on their life. People with ME-CFS continue to experience disbelief from family, friends and health professionals about how the condition affects them.
- Support effective communication by encouraging patients to record symptoms in a diary, or offer longer appointment slots or a series of appointments including home visits and telephone appointments for the severely affected. See *Managing ME-CFS: a guide for GPs in Scotland* at www.actionforme.org.uk/key-resources
- ME-CFS is a fluctuating condition. Most people will have a time when they have been acutely ill and not able to move or do much.

- Early diagnosis is recommended, at four months for adults and three months in children (confirmed by paediatrician). Even with no firm diagnosis, access to information, support and advice should be provided from the outset. Patients can be referred to the SGPG patient guide and Action for M.E.'s *Newly diagnosed with M.E.* booklet (see www.actionforme.org.uk/key-resources).
- While there is currently no pharmaceutical intervention targeted particularly at ME-CFS, a number of approaches have been found to help some people with the condition. The SGPS offers a care pathway; symptom management advice, signposting and resources are available at www.actionforme.org.uk/primary-care
- Research (Pheby and Saffron, 2009) has found that early management of symptoms such as post-exertional malaise is the most important factor in how the condition progresses. Referrals may need to be made to the designated clinical services, for assistance with the management of sleep problems, bowel-related symptoms, pain and to support people to manage their energy and activities.
- Pharmacological management can also be used to relief some symptoms like migraines and IBS. Any vitamin deficiencies (eg. vitamin D) should be treated. Be mindful that people with ME-CFS are often very sensitive to the effects of medication. Read more at www.actionforme.org.uk/pharmacy
- Pacing can support effective management of energy, activity and rest, avoiding the “boom and bust” cycle common to ME-CFS, working with a Specialist Occupational Therapist. See www.actionforme.org.uk/pacing
- Rest for short periods when a person is neither sleeping nor engaged in physical or mental activity throughout the day can be helpful. Mindfulness or yoga can support rest and regulation of the body and mind.
- Counselling or CBT could be of benefit to some people who are finding it difficult to accept their diagnosis or adjust to living with this long-term condition, which can be exacerbated by thoughts such as: “If I just tried harder, I’d be better.” Graded exercise/activity therapy is reported by some patients to be useful. However, others report that it has caused harm. See www.actionforme.org.uk/evidence-for-GET-CBT
- Treatment approaches should never include an imposed rigid schedule of activity and rest – flexibility is key – or unsupervised or unstructured vigorous exercise, as this is likely to worsen symptoms. Specialist approaches should only be delivered by practitioners with experience of M.E.
- 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

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.

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