

Learn about M.E.

Informing professional practice on M.E./CFS



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A partnership project funded through the Scottish Government's Neurological Framework to improve knowledge relating to diagnosis and management of M.E./CFS.

Background

Myalgic Encephalomyelitis (M.E.) or Chronic Fatigue Syndrome (CFS) is a long term, fluctuating, neurological condition that causes symptoms affecting many body systems, more commonly the nervous and immune systems. It is estimated that 20,000 people in Scotland are affected. Obtaining a diagnosis can take years.¹ There are no services for people with M.E.: only one nurse in Fife and there is a lack of understanding around diagnosis and management of symptoms.

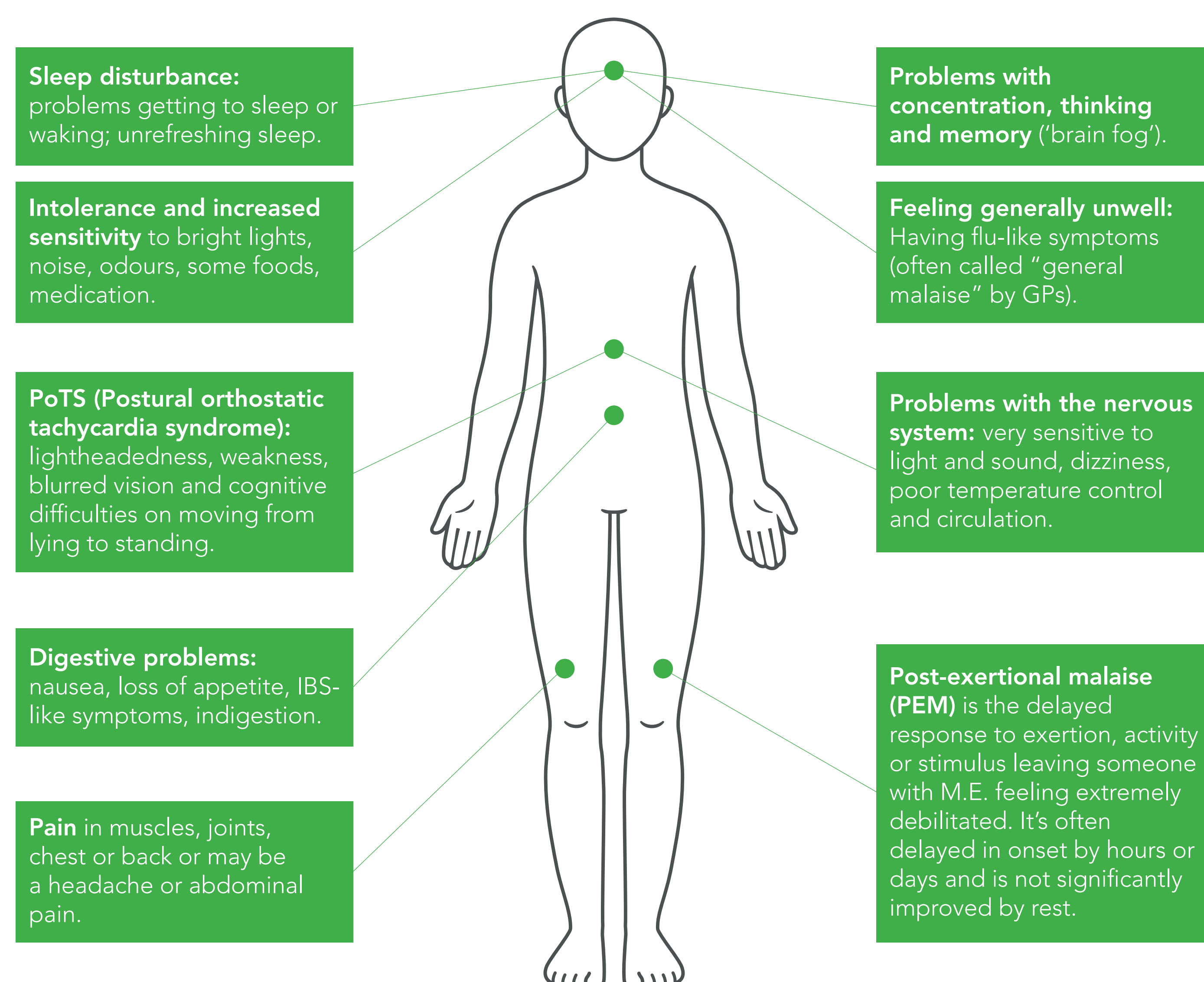
Conclusions and implications

More education is needed on M.E./CFS in primary care. A recent report commissioned by the Scottish Government recommended that GPs need knowledge, confidence and understanding that is appropriate to the condition.²

The lack of specialist services mean that diagnosis, management of symptoms and on-going monitoring will largely remain with primary care. Understanding the need for monitoring and identifying presenting comorbid conditions and support at home for severely and very severely affected people has to be highlighted as a key educational need in primary care.

Symptoms

M.E. is not 'feeling tired.' It is a physical disease and not the result of psychological difficulties. Everyone who experiences M.E. has a different pattern of illness, and symptoms and severity can fluctuate and change over time. Many symptoms are invisible to others as they cannot be easily recognised just by looking at the person. Some symptoms can include:



Summary

A partnership of M.E. charities secured funding to promote a CPD module on M.E./CFS created by medical experts in this field (Dr Nina Muirhead and the UK CFS/M.E. Research Collaborative). It reflects the emerging biomedical evidence, evolving international discussions and the patient perspective of this disease.

The partnership produced a series of podcasts on related topics to complement the training module webinar for social care or social work professionals.

The project aimed to reach 500 healthcare professionals in Scotland. To date, over a 1,000 have accessed and completed the module. As a result of completing the module:

76%

of professionals who completed the module believed they felt more confident in diagnosing M.E./CFS

96%

of professionals completing the module felt that more formal education and training on M.E./CFS was needed



On-going work

The CPD is currently being update to reflect the latest NICE guideline on M.E./CFS³ and further podcasts are planned.

Healthcare professional feedback

This module was concise, informative, and provided evidence-based explanations. It has greatly helped my understanding of diagnosis and management of ME/CFS, and the guidance on Post-exertional malaise and chronic post viral fatigue is likely also to be very applicable to patients with Long Covid.

Dr Shaun Peter Qureshi.

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Social Care professionals feedback

A wide range of organisation fed back after our Social Care webinar that they intended to use the learning for this to inform their support for the people they work with and their staff who live with other health conditions not just M.E.



References

1. Scottish Neurological Alliance. (2022). One in 6 findings from the My Neuro survey in Scotland. Available at URL: <https://www.scottishneurological.org.uk/files/one-in-six-findings-from-my-neuro-survey-in-scotland-final.pdf>
2. Page 29. Blake Stevenson Ltd. 2022. Report on a Scottish stakeholder review of the Myalgic Encephalomyelitis / Chronic Fatigue Syndrome NICE guideline. Scottish Government. Available at URL: <https://www.gov.scot/publications/report-scottish-stakeholder-review-myalgic-encephalomyelitis-chronic-fatigue-syndrome-nice-guideline/pages/3/>
3. National Institute for Health and Care Excellence. 2021. Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management NICE guideline. NICE guideline [NG206]. Available at URL: <https://www.nice.org.uk/guidance/ng206>



Scottish Government's Neurological Framework funding that supports the neurological care and support: framework for action – 2020 to 2025.