

Dear Colleague

## **MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME (ME/CFS): UPDATED CLINICAL GUIDANCE**

As you may be aware, on 29 October 2021 the National Institute for Health and Care Excellence (NICE) published a new [clinical guideline on managing and diagnosing ME/CFS](#).

The NICE guideline provides new recommendations on diagnosing and supporting people with ME/CFS including recommendations on symptom management, specialist and multidisciplinary care, frequency and structure of review, and care for people with severe or very severe ME/CFS. The guidance applies to children, young people and adults, and replaces the previous 2007 NICE guideline.

There is no SIGN guideline for ME/CFS. In the absence of a SIGN guideline, we expect clinicians to refer to other available guidance such as NICE guidelines. Following previous Scottish Government communications to highlight the publication of the draft NICE guidance on ME/CFS, I am now writing to draw your attention to two significant changes in recommended practice in the final published guideline.

### **Graded Exercise Therapy**

The NICE guideline recommends not to offer therapy based on physical activity or exercise as a cure for ME/CFS, or that uses fixed incremental increases in physical activity or exercise. The guideline makes [further recommendations](#) to support clinicians in considering and offering personalised physical activity or exercise programmes to people with ME/CFS, where appropriate.

### **Cognitive Behavioural Therapy (CBT)**

Cognitive Behavioural Therapy (CBT) has sometimes been assumed to be a cure for ME/CFS. The NICE guideline recommends, however, that CBT should only be offered to

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#### **Addresses**

Chief Executives, NHS Boards  
Medical Directors, NHS Boards  
Primary Care Leads, NHS Boards  
Directors of Nursing & Midwifery, NHS Boards  
Chief Officers of Integration Authorities  
Allied Health Professional Leads Network

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support people who live with ME/CFS to manage their symptoms, improve their functioning and reduce the distress associated with having a chronic illness. The guideline makes [further recommendations](#) to support clinicians in discussing and delivering CBT to people with ME/CFS.

### **NICE implementation statement**

On 12 May 2022, NICE published its [implementation statement](#) which sets out the steps needed to put its recent guideline on the diagnosis and management of ME/CFS into practice.

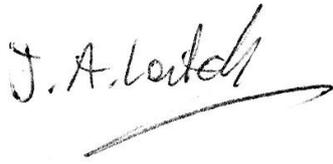
The statement highlights the areas that will have the most need to be considered by NHS Boards, and others working across health, social care and education, to comply with the recommendations in the guideline. These include:

- Updated training for health and social care staff (including those in training) to ensure that up-to-date recommendations and safeguarding implications are disseminated across the health and social care system.
- Investment will be needed to increase the number of specialist clinics and specialists with expertise to formally diagnose ME/CFS and develop a care and support plan where need is identified.
- Ensuring the availability of experts in secondary care to provide guidance to primary care.
- Provision for increased access to early paediatric review for further assessment and investigation for ME/CFS is available where need is identified.
- Funding and capacity in primary care, ME/CFS specialist clinics and paediatric clinics should be reviewed to enable the recommended appointments where need is identified.

### **Scottish Good Practice Statement**

While much of the 2010 [Scottish Good Practice Statement](#) (SGPS) on ME/CFS remains relevant, we note that the NICE guideline will supersede certain sections. We will be updating the SGPS in light of the NICE guideline and will provide a further update later this summer.

Yours sincerely



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