

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)

Introduction

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) is a relatively common illness. Data from the UK Biobank suggests that 250,000 patients are affected in NHS England, with women affected 2.4 times more often than men.¹ The Scottish Government Good Practice Statement on ME/CFS in 2010² reported an estimated population prevalence of 0.2-0.4%, affecting any age and ethnic group, but more common in women and people aged 35-55 years. More recently, a systematic review in 2020, to determine the prevalence of ME/CFS in Europe.³ found only 3 studies (2 from UK) estimates ranged from 0.2% to 2.2% prevalence in adults and confirmed an increased risk in women.

ME/CFS is a complex and chronic condition with a variety of symptoms which affect patients differently, and often cause significant disruption to their lives.⁴ Many individuals in healthcare acknowledge that patients have struggled to have their illness recognized and have faced discrimination over the years.

NICE guidelines on ME/CFS have been published in 2007 and 2021.¹ Both guidelines emphasise the importance of early diagnosis, and of avoiding delay in initiating effective symptom management and appropriate therapies. It is often a diagnosis made by the exclusion of other illnesses, resulting in long delays for patients. NICE recommends that the condition should be suspected in patients who have the following symptoms for a minimum of six weeks for adults and four weeks in children and young people. Diagnosis can be confirmed after three months of persistent symptoms:

- debilitating fatigue worsened by activity
- post-exertional malaise
- unrefreshing sleep or sleep disturbance
- cognitive difficulties (often called brain fog)

Patient groups report that affected individuals often miss out on proactive care despite published guidelines promoting early engagement with primary healthcare teams. Despite the lack of evidence regarding the tools required to support the management of ME/CFS, symptom management and self-management strategies appear to be the mainstay of treatment and improving quality of life.¹ This module aims to review the available evidence and encourage clinicians to reflect on how they can make their practice more patient-centred, to improve the lives of patients living with ME/CFS. Research has shown that clinicians who engage with ME/CFS patients and build a therapeutic relationship are particularly valued by them.⁵