



1st July, 2024

Deputy Alan Dillon, TD
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

RE: PQ 26047/24

To ask the Minister for Health if he plans to provide further supports and services for patients with chronic fatigue syndrome and fibromyalgia; if the HSE plans to recognise these illnesses as physical illnesses; and if he will make a statement on the matter

Dear Deputy Dillon,

The Health Service Executive has been requested to reply directly to you in relation to the above parliamentary question, which you submitted to the Minister for Health for response. I have consulted with the HSE's National Clinical Advisor and Group Lead for Children and Young People (NCAGL CYP) and the National Clinical Programme for Rheumatology on your question and have been informed that the following outlines the position.

Myalgic encephalomyelitis, also called **chronic fatigue syndrome** or ME/CFS, is a complex, chronic condition affecting multiple body systems. The cause is still uncertain and there is no clear understanding of the pathophysiology nor is there an agreed diagnostic test. The most common symptom is extreme tiredness and it can affect children, young people and adults. ME/CFS affects people differently and is a fluctuating condition in which a person's symptoms can change unpredictably in nature and severity over a day, week or longer. Scientific studies have demonstrated that even mild exercise can provoke ME/CFS symptoms.

To date there is no known specific medical diagnostic test to determine or confirm a diagnosis of ME/CFS. There is no specific treatment for ME/CFS which works for all those affected. Assessment and interventions are tailored to the individual needs. Children and young people usually present to their GP and many are referred onward to a General Paediatrician. General Paediatricians diagnose and help the patients manage the illnesses using primary care supports (occupational therapy, physiotherapy and psychology). If a child or young person requires additional review, they are referred to Paediatricians in CHI with a special interest in chronic conditions like ME and CFS. The CHI Paediatrician will see the child/young person and will discharge the child/young person back to the local Paediatrician with a supportive plan.

Medical support for adults with ME/CFS can be more challenging and can lead to care being provided by a number of specialists at the same time. Other than the GP, there is no general physician who will offer support across multiple systems as is found in paediatrics. Nor is there a specialty multidisciplinary team (MDT) clinic for adult patients living with ME/CFS. Adults with ME/CFS may be referred to a range of specialists (including immunology, rheumatology, cardiology, pain specialists, neurology, and infectious disease) to out-rule other underlying conditions and to confirm ME/CFS diagnosis.

Treatment involves education, exercise therapy and the use of medication. Such treatment can be mainly delivered in primary care. Secondary care specialist consultation is sometimes sought to confirm diagnosis, exclude other conditions or to access services (investigations, physiotherapy, psychology, pain management) when these services are not accessible at primary care. There is currently no national guidance for standardisation of diagnosis or treatment for ME/CFS at primary or secondary care level in Ireland although work is underway to develop this.



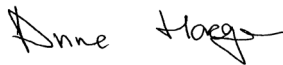
Fibromyalgia is a common disorder characterised by widespread pain in the soft tissues (muscles, tendons, etc.) around the joints and is commonly associated with symptoms including fatigue, brain fog, poor sleep and mood disorders. The cause is not fully understood and there are no abnormalities found on blood tests or imaging studies to confirm a diagnosis. The diagnosis is based on clinical examination.

There is currently no cure for fibromyalgia. The current general systematic plan for fibromyalgia sufferers is to provide treatment to ease symptoms. This treatment comprises a combination of exercise or other movement therapies (e.g., physiotherapy), education, psychological support and medication.

The diagnosis and treatment of fibromyalgia can be delivered in primary care. Patients may sometimes be referred to secondary care for confirmation of diagnosis by a Specialist Consultant Rheumatologist. Patients may also be referred to secondary care to access services such as physiotherapy, psychology or pain management programmes when these services are not readily available at primary care level.

I trust this information is of assistance to you, but should you have any further queries please do not hesitate to contact me.

Yours sincerely



Anne Horgan
General Manager

