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2<sup>nd</sup> July 2019

Deputy Roisin Shortall, TD Dáil Éireann Leinster House Kildare Street Dublin 2

## Re: PQ 25292/19

To ask the Minister for Health if he will instruct the HSE to update its diagnostic and treatment procedures for persons with ME to reflect best international practice; if he will address the lack of specialist support within the health service for those suffering with ME; and if he will make a statement on the matter.

Dear Deputy Shortall,

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 National Clinical Programme for Neurology on your question and have been informed that the following outlines the position.

To date there is no known specific medical diagnostic test to determine or confirm a correct diagnosis of Myalgic Encephalomyelitis (ME) nor is there any specific treatment which works for all sufferers. Assessment and interventions need to be tailored to the individual.

As with all assessments and treatments, whether they are provided in a primary care or secondary care setting, we aim to provide comprehensive, evidence-based, safe, up-to-date care for all our patients. We are very mindful of the impact on adults, children and their families of the diagnosis of many of the serious conditions encountered. We aim to support our patients and their families through the range of available treatments.

The Canadian Consensus Guideline outlines that for consideration of a diagnosis of ME, a person should have a number of symptoms in the following areas;

- Fatigue
- Post-exertional malaise and/or fatigue
- Sleep dysfunction
- Pain
- Neurological/cognitive manifestations (e.g. confusion, impaired concentration, memory difficulties etc.)

- At least one symptom from the following two categories;
  - o Autonomic manifestations (e.g. lightheaded-ness, nausea)
  - Neuroendocrine manifestations (sweating etc.)
  - o Immune manifestations (tender lymph nodes, sore throats etc.)
- The illness persists for at least six months

These symptoms can be assessed in primary care setting by the General Practitioner. Unfortunately, the symptoms associated with this disorder are not specific to this condition and it may be necessary for sufferers to attend a number of specialists to rule out other conditions before a diagnosis is arrived at.

Treatment for ME is initiated based on the individual's symptoms. In general these treatments are delivered within the context of primary care. Some patients may require specialist referral for differential diagnosis or treatment based on their symptoms. This may include referral to neurology, rheumatology, psychology, pain specialists, endocrinology, immunology, cardiology, rehabilitation medicine or occupational therapy. Relevant specialists are generally accessed through out-patient clinics at secondary care level. Currently, the GP is best placed to refer patients as appropriate.

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,

Ingthe Waith

Ms Patricia Gilsenan O'Neill General Manager