



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Office of the Chief Clinical Officer
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Oifig an Príohoifigeach Cliniciúil
Ospidéal Dr. Steevens|Baile Átha Cliath 8|D08
W2A8

Deputy Eamon Scanlon, TD

Dáil Éireann,
Leinster House,
Kildare Street,
Dublin 2

Date: 23rd July 2019

PQ 30206/19 - To ask the Minister for Health the number of children diagnosed with ME in the voluntary sector children's hospital group, other voluntary hospitals and in the HSE acute sector in 2018 and to date in 2019; the criteria used to identify each level of severity that is mild, moderate, severe and profound; the data for same; the diagnostic criteria (details supplied) each paediatric department uses to diagnose ME; and if he will make a statement on the matter.

Dear Deputy Scanlon,

The Health Service Executive has been requested to reply directly to you in the context of the above Parliamentary Question, which you submitted to the Minister for Health for response. I have consulted the Health Pricing Office and the National Clinical Programme for Neurology on this the matter and the following outlines the position.

Response:

Myalgic encephalomyelitis (M.E.) is included within diagnosis code G93.3 Post viral fatigue syndrome. As it is included within this code, figures are not available for myalgic encephalomyelitis only. This code does not breakdown any further so it is not possible to identify levels of severity.

The total number of discharges (rather than number of people) with a diagnosis of G93.3 Post viral fatigue syndrome in 2018 was 19. As the numbers are so small, it is not possible to break this down by hospital. Numbers for 2019 will not be available until the year closes i.e. in 2020.

To date there is no known specific medical diagnostic test to determine or confirm a correct diagnosis of M.E. Assessment and interventions need to be tailored to the individual and can involve multiple speciality areas depending on the individual's specific needs.

The Irish ME trust support the use of the Canadian Consensus Guideline for the diagnosis and treatment of M.E. The diagnosis of M.E. in this document outlines several criteria that 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;
- Autonomic manifestations (e.g. lightheaded-ness, nausea)
- Neuroendocrine manifestations (sweating etc.)



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- Immune manifestations (tender lymph nodes, sore throats etc.)
- The illness persists for at least six months

These are assessments/tests which can be carried out in primary care setting by the General Practitioner. Specialised tests may be required when considering differential diagnoses. Treatment for M.E. is initiated based on the individual's symptoms. In general, these treatments are delivered within the context of primary care, with referrals into secondary care for specialist interventions, specific to the individual in the areas of;

- Neurology
- Rheumatology
- Pain Specialists
- Endocrinology
- Immunology
- Cardiology etc.

These services are generally accessed through Out-patient clinics at secondary care level by the relevant specialty. As with all assessments and treatments, whether they are provided in a primary care or secondary care setting, we aim to provide comprehensive, evidenced-based care for all our patients.

I trust this answers your question to your satisfaction.

Yours sincerely,

Sharon Dwyer,
General Manager, Office of the CCO