

**WRITTEN QUESTION TO THE MINISTER FOR HEALTH AND SOCIAL SERVICES
BY DEPUTY S. PITMAN OF ST. HELIER
ANSWER TO BE TABLED ON MONDAY 15th JULY 2013**

Question

Would the Minister advise how many people have been treated for ME/CFS (Chronic Fatigue Syndrome) by the Health Service in the last 10 years and provide figures for each year 2000 to 2012?

Is there a specialist doctor or consultant that treats these patients?

What public information, if any, is provided by the Health Service to Islanders about the illness and the family support available?

Answer

Chronic Fatigue Syndrome (CFS), also sometimes referred to as ME (Myalgic Encephalomyelitis) is a relatively common condition that causes persistent fatigue and exhaustion. It affects everyday life and it doesn't go away with sleep or rest.

Symptoms can be mild, moderate or severe. Although the condition can, in its most severe form, be seriously debilitating and require lengthy periods of rehabilitation, the vast majority of other cases are dealt with in the community by GPs.

The number of patients who present to the Hospital with severe, disabling CFS/ME is very low.

Hospital data – which is available for the past two years – records no cases of hospital admissions, where Chronic Fatigue Syndrome (CFS) has been the primary condition, while anecdotally, the Consultant Neurologist recalls that around five patients have required hospital admission for CFS in the past seven years.

No outpatient episodes are clinically coded, which is in line with UK practice.

While we have data showing the number of Outpatients and which clinic patients attend, information about the condition for which they are being seen/treated is not routinely recorded within HSSD databases.

The information is retained in the patient notes and GP correspondence only, and HSSD does not have access to GP patient records.

A patient with suspected or diagnosed CFS/ME, referred by their GP to the Hospital, would initially be referred to the Consultant their GP felt would be the most appropriate, given the specific the symptoms a patient is displaying. This may be a pain clinic, orthopaedic, physiotherapy or neurology etc.

However, it is common practice that the patient will, ultimately, also be seen by the Neurology consultant, who has primary responsibility for this field, and fully understands the frustrations and challenges faced by those suffering with CFS.

In the event a patient is diagnosed with severely disabling CFS/ME, the Consultant may refer the patient to Kings College Hospital in London for a more specialist opinion on symptoms and potential treatment pathways.

This, however, happens very infrequently as the number of patients presenting to the Hospital with severe CFS symptoms is extremely low.

A dedicated ME/CFS website – www.nhs.uk/Conditions/Chronic-fatigue-syndrome - provides a wealth of helpful information, guidance and advice on the condition, as well as links to support networks and groups, and can be accessed via a link on our HSSD website www.gov.je/Health

Clinicians, nurses and other HSSD staff will assist patients with accessing this information, directing them to the websites and/or printing off relevant background information, support group contact details etc.