Cynulliad Cenedlaethol Cymru | Y Gwasanaeth Ymchwil
National Assembly for Wales | Research Service

Chronic Fatigue Department in Wales

Y Pwyllgor Deisebau | 7 Ionawr 2020
Petitions Committee | 7 January 2020

Reference: RS19/11116-2

Petition Number P-05-926

Petition title: To provide a chronic fatigue department in Wales

Text of petition: There is no Chronic Fatigue Department in the whole of Wales! Chronic Fatigue is being overlooked or thought of as depression. I would like to see a Department set up with a view to individuals being assessed properly. General Practitioners say 'there is no cure' or 'you haven't been assessed'. Without a Chronic Fatigue department there can be no research into finding a cure or no means of being assessed.

I have suffered with this for 23years. The onset was after a week of high fever which showed as 104 on the 5th day. Little is known about Chronic Fatigue. I wrote up a Petition recently and collected 65 signatures with a view to setting up a department in Wales; it showed 20 had family members or friends suffering with it. It is so debilitating and such a waste of life. With an inability to think, concentrate or do anything physical without the need to go to bed afterwards. It can take days to overcome any effort however small.

I saw a woman being interviewed on television. She was at a Chronic Fatigue Clinic saying she had received a Myer's Infusion, which consists of Vitamins and Minerals, and felt so well she felt like her old self. It is not available on the NHS. I want to give it a try to see if this is the answer but need to find a private clinic to administer the Myer's Infusion. Last year I had a '5 day window' when I had clarity of thinking and energy. I do not know if this was because of taking a Vitamin B Complex capsule daily for a while. I saw a General Medicine doctor at

Llandough Hospital recently [he sees many individuals with Chronic Fatigue] I told him of this infusion and he is interested in hearing the outcome of the procedure. I will report back to him. In the meantime, will you give your support to this Petition? It is essential to have some hope and the only way to achieve this is to have the right help in the first place. Not live a life unfulfilled. Thank you.

1. Background

Chronic fatigue syndrome (CFS) is a long-term illness with a wide range of symptoms. CFS is also known as myalgic encephalomyelitis (ME).

The main symptoms of CFS/ME are feeling extremely tired and generally unwell. People with CFS/ME may also have other symptoms which are listed on the NHS Direct Wales website. CFS/ME can affect anyone, including children. It is more common in women and tends to develop between the mid-20s and mid-40s age range.

About 13,000 people in Wales are thought to suffer from CFS/ME, and 70 per cent of those are women.

As there is no specific test for CFS/ME, it is diagnosed based on the presenting symptoms and by ruling out other possible conditions. As the symptoms of CFS/ME are similar to those of many common illnesses that usually get better on their own, a diagnosis of CFS/ME may be considered if a person does not get better as quickly as expected. A doctor would be expected to consult a specialist if they are unsure about the diagnosis, or if the patient has severe symptoms.

Treatment for CFS/ME aims to relieve the symptoms and will depend on how CFS/ME is affecting the individual. Treatments include: cognitive behavioural therapy (CBT); a structured exercise programme called graded exercise therapy (GET), and medication to control pain, nausea and sleeping problems.

Most people with CFS get better over time, although some people do not make a full recovery. It's also likely there will be periods when a person's symptoms get better or worse. Children and young people with CFS/ME are more likely to recover fully.

There is guidance from the National Institute for Health and Care Excellence (NICE) for diagnosing and managing CFS/ME. This guidance is currently being rewritten and the new version is expected to be available in October 2020.

News articles

A BBC news article in May 2019 makes reference to a 'humanitarian crisis' for ME sufferers in Wales and that promises of better support from the Welsh Government have failed to materialise. In the article, the chairwoman of the Welsh Association of ME Support said few GPs had enough knowledge of the condition and those left housebound felt "invisible and ignored".

In an ITV news article in June 2019, Dr Charles Shepherd, who is a co-opted member of the committee set up by NICE to review the guidelines, is referred to as saying that provision for ME patients in Wales is particularly poor. Dr Shepherd states:

> "The situation in England is not perfect, but at least we do have a network of hospital-based referral services. In Wales, where there just aren't hospital-based services for people to go to, [the situation] is even worse there.
> I think the response from the Welsh Government has not been satisfactory. There has been a taskforce set up, it has been doing this work for many years, but it really hasn't made the progress it should have done. People in Wales, as far as I can see, are no nearer getting these services."

2. Welsh Government action

In August 2014, a Ministerial task and finish group published its report and recommendations on improving NHS Wales services for patients with ME/CFS and fibromyalgia. Prior to this (2008), the Welsh Government published its service development and commissioning directives for chronic non-malignant pain (this covered conditions such as fibromyalgia and ME/CFS).

In correspondence to the Committee dated 3 December 2019, the Minister for Health and Social Services states that the Welsh Government recognises the impact that CFS/ME has on the lives of individuals and has established a national steering group to consider what further support can be provided and to share good practice. The group consists of representatives from health boards, service user representatives, third sector organisations, volunteer support groups and Welsh Government.

Health boards are responsible for providing services for those living with CFS/ME and the Minister notes that Betsi Cadwaladr University Health Board has a dedicated CFS/ME service. In the majority of other health boards, it is said that CFS/ME services are aligned with pain services, for example, Powys Teaching Health Board runs a pain and fatigue management service. Health boards also have the option to utilise specialist centres for CFS/ME depending on their location. Clinicians in South Wales can for example refer to the Bath Centre for Fatigue Services.

The Minister confirms that clinicians are expected to follow the NICE guidance when caring for people and this does not necessarily require a specialist dedicated service. This treatment should be provided by the healthcare professionals with appropriate skills, wherever they are based.

In May 2019 the Welsh Government published guidance for staff and patients relating to living with persistent pain, which is a common symptom of CFS/ME. Guidance for arthritis and related conditions is also being developed and a consultation will be undertaken in the near future. The Minister notes that the CFS/ME steering group will reflect on both of these guidance documents and consider their relevance for patients within their remit.

In relation to research on CFS/ME the Minister believes it is possible that the existence of a specialist clinic in any disease area could potentially add to the visibility of the condition, and increase capability and experience that would help with the development of collaborative research. However, there are a number of Welsh Government research funding schemes to which researchers with an interest in ME would be eligible to apply.

With regards to Myers infusion, the Minister highlights that the Welsh Government expects the NHS to follow evidence based guidelines. The Welsh Government is not aware of any well-designed trials of high dose intravenous nutrient therapy, nor is there strong evidence to support its effectiveness in the management of chronic pain or associated conditions.