

Source: Tynwald Court (Parliament Isle of Man)

Date: December 14 2021

URL:

<https://www.tynwald.org.im/business/hansard/20002020/t211214%20RHE.pdf>

Ref:

<https://meassociation.org.uk/2021/12/why-are-we-waiting-isle-of-man-me-cfs-campaigners-cry-out-for-new-post-viral-fatigue-service/>

Interim ME service - Creation and assessment  
-----

The Hon. Member for Douglas South (Mrs Christian) to ask the Minister for Health and Social Care: Whether an interim myalgic encephalomyelitis (ME) and chronic fatigue syndrome service has been created; how the Department will measure the success of this service; and what targets have been established for it?

The President

Okay, we move on to Question 8 and I call upon the Hon. Member for Douglas South, Mrs Christian.

Mrs Christian

Thank you, Mr President.

I would like to ask the Minister for Health and Social Care whether an interim myalgic encephalomyelitis ME and chronic fatigue syndrome service has been created; how will the Department measure the success of this service; and what targets have been established for it? My apologies, I am struggling to speak at the moment.

The President

Understood.

The Minister for Health and Social Care (Mr Hooper)

Thank you very much, Mr President.

Manx Care has provided an ME/chronic fatigue syndrome service for several years. However, we recognise that it does not have sufficient capacity to cope with current demand from the ME population on the Isle

of Man.

Both Manx Care and the Department recognise previous attempts to establish an ME/CFS service on the Island have fallen short of what is required and have committed to work in partnership with local support groups, which includes groups established for long COVID sufferers to design and deliver a fit-for-purpose service for people with ME and long COVID. Manx Care are currently prioritising increasing time available for our two senior clinicians who work within the ME/CFS and long COVID population to dedicate to the development of the new service. This time spent will ensure that the new, expanded service is based on firm foundations of evidence-based clinical pathways and strong governance.

Between January and March 2022, the practitioners working within this service, which more recently includes a consultant clinical psychologist, will be hosting several listening sessions on Island with people who suffer from ME and long COVID to find out exactly what they expect from the service, and this will help inform our design. These sessions will be held both virtually and face to face. These events, alongside liaison with peer experts in the UK NHS, will help deliver a world-class ME/CFS and long COVID service for the Isle of Man.

More practically, the team are currently in the final stages of developing a leaflet for people who have been diagnosed with COVID-19 to provide guidance on self-management techniques to help avoid post-viral fatigue. This will be adapted to have much wider applications beyond COVID-19. This will also be accompanied by a refresh of the referral guidelines for GPs into the existing ME/CFS and long COVID service. In addition, our consultant clinical psychologist is sourcing an online support tool to help those suffering with fatigue.

The Department will ensure that patients diagnosed with post-ME and CFS are assessed and treated in line with NHSE and emerging best practice through the Manx mandate assurance process.

The President

Supplementary, Mrs Christian.

Mrs Christian

Thank you, Mr President.

Just to be clear, we are referring to the healthcare for those with post-viral conditions. Given that we are almost two years into this viral pandemic, does the Minister believe our Island's pandemic response

has been satisfactory in respect of post-viral conditions?

The President

Minister to reply.

The Minister

Thank you very much, Mr President.

I think, as I acknowledged in my original Answer, the answer to that is no. We have not currently got a service with sufficient capacity to cope with the current demands that are being placed on it. That is why there is quite a firm commitment from the Department to make sure that this interim service is established as quickly as possible, that GPs have the right information in order to effectively diagnose and refer individuals into the service at a very early stage, and that also support is available for people as they are progressing through the treatment pathways.

The President

Supplementary, Mr Moorhouse.

Mr Moorhouse

Thank you, Mr President.

A lot of work was done during the last administration to move things forward in this area. A small number of individuals with direct experience of this are very proactive. Has the Minister had the opportunity to meet with these individuals yet? As you previously suggested, they are very keen to move things forward and work with the Department.

Thank you.

The President

Minister to reply.

The Minister

Thank you very much, Mr President.

Yes, Hon. Member, I have actually met with the ME support charity quite recently. In fact, I discussed this very Answer with a member of that organisation only the other day, because I was aware that this was coming up, obviously.

So no, I am very keen to make sure that the service is delivered in partnership with local support groups, just like I said in the original Answer.

-----

(c) 2021 High Court of Tynwald