

Source: Isle of Man today

Date: May 23, 2022

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URL:

<https://www.iomtoday.co.im/news/health/new-service-gives-people-much-needed-hope-547904>

Ref: <https://www.tynwald.org.im//business/opqp/opqp/2022-PP-0070.pdf>

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New service gives people 'much-needed hope'

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A charity that supports people with ME/CFS has said recent updates on the Manx Care integrated service with Long Covid gives its members 'much-needed hope'.

Health Minister Lawrie Hooper told Tynwald on Tuesday that the ME/CFS and Long Covid service would be 'up and running from July of this year'. It cost the government in the region of 400,000 pounds to create the service that is aimed to support clinicians across the care sector in delivering 'informative advice as well as providing those dealing with post-viral symptoms a non-judgemental service'. Mr Hooper described it as a service that 'other services can learn from' and Manx Care has appointed a dedicated service development lead to take forward the project 'at pace'.

This followed listening events organised by Manx Care in February and March where it spoke to members of the public who have been affected by ME/CFS (myalgic encephalomyelitis and chronic fatigue syndrome) and Long Covid. As a result, training will be offered to all healthcare professionals.

ME Support vice president Craig Morris said after the sitting: 'We're feeling optimistic, are pleased with recent progress, and the plans we've seen suggest that the coming months should see Manx Care deliver tangible results. An integrated and specialist service that puts patients of all ages at its heart will transform the experience of those with ME/CFS and Long Covid, and Mr Hooper's emphasis on prompt diagnosis and intervention shows how carefully he has listened to our priorities and concerns. We're grateful for his leap of faith in working so closely with us. Post-viral fatigue is about to be taken a lot more seriously and the government's investment in a specialist service and training health professionals will improve the quality of life for hundreds of people on the Isle of Man. Our service also has the potential to set a gold standard that will be of interest around the UK and further afield.'

Garff MHK Daphne Caine, who posed the original question concerning the project, said she had spoken with constituents who had said they were not receiving the best advice.

Mr Hooper said it was 'concerning' to hear that the help available wasn't currently being well received and urged anyone who has a bad experience to raise it formally through the complaints process. He felt the current service wasn't adequate, which he explained was the 'whole purpose of the project'. 'Every service could benefit from more engagement with service users,' the minister added.

Mrs Caine also asked how Manx Care is increasing public awareness of post-viral recovery techniques which could reduce the risk of exacerbating Long Covid symptoms, to which Mr Hooper replied that two leaflets had been released on the subject. He said that in February 2022, Manx Care developed a Long Covid resource page which details background, symptoms, a summary on self management of symptoms, plus includes internal and external resources. There is also a 27-page leaflet that will shortly be published on how to manage post-viral infection symptoms, which will be printed and put in GP practices.

Mr Hooper added: 'I'm not particularly happy with the speed this has progressed but it is now progressing at pace. 'Of course, it's something I think should have happened much sooner but you can't change the past.'

Russell Fleming, communications manager at ME Association, also said: 'The ME Association has been greatly encouraged by the work being completed on the Isle of Man to establish an ME/CFS and Long Covid specialist service with a medical lead and experienced health professionals. 'We would like to praise the hard work from ME Support and its patient volunteers. Without their unwavering commitment, the ME/CFS and Long Covid specialist service would not be almost ready to receive its first referrals. We'd also like to thank the Manx government and those ME/CFS specialists working for the NHS in the UK who gave their professional time to advise on this project. It has been a privilege to work with them all and we are incredibly heartened at the developments now taking place.'

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