

## **Presentation to Parliamentarians, Tynwald, May 2021**

### **Main points made by the four speakers on the ME Support (Isle of Man) video**

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#### **KEY POINTS FROM THE PRESENTATION**

##### **Dr Charles Shepherd, Medical Adviser to the Association:**

The key point that I'm always trying to get across to my medical colleagues is to try and get in early with management when people have got a post viral fatigue in the hope that you can get them better from that very early stage and then not progress on to full-blown ME/CFS.

There is certainly good evidence from physicians and patients that, if you manage people very early on in this illness, they don't go back to work, they don't go into the cycle of doing too much then crashing, if you can get the activity management correct in the very, very early stages then you can mitigate against a lot of long-term ill-health.

That means going back to good old-fashioned medicine. It's having a period of convalescence and rest when you're in the very early weeks and months following a viral infection. And that's the point we're trying to get across to the Long Covid community as well. Many of these people are often fit, very fit, young adults who are feeling a little bit better. They're going back to work, back to what they might be doing sport-wise and they're crashing again.

You are in a rather unique situation. You're in a small population base. You don't have the easy facility to refer people outside the island for further investigations and your Covid levels as I understand it have been very low. Probably the number of people with Long Covid is relatively small.

I think you may well have a case for actually combining a service if there is the willingness from the Government to set up some sort of service that is going to help people with Long Covid and ME/CFS.

The overlap between those two conditions is far closer than the overlap between ME/CFS and any other condition that we can think of.

##### **Juan Corlett, Vice-President of ME Support (Isle of Man):**

It's not the tiredness that we all know from lack of sleep. You can't catch up with the illness by sleeping in the day. All you can do is ruin your sleep pattern and make yourself worse.

The day is all about endurance. It is just horrible absolutely awful. I was incapacitated, I was unable to talk for large periods, unable to take with a friend for more than five minutes without getting tired.

Work was a distant dream. I couldn't feed myself at times. I couldn't cook for myself. I couldn't even shovel food with a fork into my mouth and it was just horrendous. Life was taken away from me completely.

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I remember lying on the sofa and just watching the clock on the wall, waiting for the next 20 minutes to expire.

The GP clearly didn't have enough expertise herself to give me the practical day-to-day guidance I needed, I think she would have accepted that there is no help available. You're horribly ill. Your life is crumbling around you. You're going to have to sort it out on your own.

#### **Craig Morris, Vice-President of ME Support (Isle of Man):**

Eleven years after my horrendous experience with our medical system, I am still hearing from people experiencing the same problems – delayed diagnosis and harmful treatments.

ME patients have been suffering for 40 years with no meaningful solutions. Frustrated by perennial disappointments, a small group of local sufferers joined forces and wrote another proposal for a local ME service, identifying a number of very simple, cost-effective ways to quickly transform the lives of patients. The support from UK specialists was inspiring and humbling and the final proposal would have massively helped those falling through the cracks.

The proposed changes would also be of net benefit to the Treasury. Increasing occupational therapy capacity for example would be transformational and provide support and referral options to GPs.

There was also a wonderful opportunity to utilise UK-based expertise to improve diagnosis, intervene earlier, prevent needless harm and cascade best practice to health professionals.

We need action now. We can't afford to wait another year.

#### **Lesley Pickering, director of the North West Fatigue Clinic in Blackburn, Lancashire**

##### ***What personal qualities are needed in an Occupational Therapist supporting a patient with M.E.?***

They need a good understanding of the condition and knowing the effect it can have on people. They would need a really positive attitude in telling the person that they can get better and be very encouraging but also having a lot of time and patience to listen to that patient and what their story is.

##### ***What can a GP do to support patients with ME/CFS?***

Once a diagnosis has been given, then the GP should recognise that this is a true condition and is able to offer a referral to a specialist service. All chronic conditions require specialist support. M.E. is no exception to that.

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#### ***What should the GP do to support the patient before they see the OT?***

The GP should have obtained the blood tests recommended in the NICE guidelines to eliminate other possible causes for the condition. They should advise patients to be listening to their bodies and try to pace themselves.

#### ***What support plan would your clinic put in place?***

In straightforward cases, if the person engages quickly with the treatment and is able to follow the rehab programme, they would probably need 6-8 hours of treatment sessions, be seen fortnightly and be regularly reviewed. Cost? About £1000.

In more complex cases, perhaps if the patient was finding it less easy to engage and fearful of taking on more activity, more treatment sessions, spread over a longer period of time with some more reviews. Cost of that? About £1,500.

#### ***Advantages of referral to a private fatigue clinic?***

Quicker referral than to a specialist service in the NHS, where there may be a long waiting list.