

Covid Recovery Isle of Man
Manx Long Covid Children
(Facebook Support Groups)

Old Timbers, Croit e Quill Road,
Laxey IM4 7JG

Lower Sulby Farmhouse
Abbeylands Estate, Scollag Road
Onchan IM4 5BU

Minister Lawrie Hooper (Open Letter)
Department of Health and Social Care
First Floor, Belgravia House
Circular Road, Douglas
IM1 1AE

15th January 2022

Our Island's Covid Response Blindspot

Dear Minister Hooper

The ongoing viral pandemic has stretched and strained our society in ways we could never have imagined 2 years ago. Our Island's response in testing times has often brought great pride, including the periods when we enjoyed a life without restrictions that was almost unparalleled across the world. Manx politicians have been bestowed honours by the Queen and logistical challenges have been overcome in hospital wards, testing logistics and our vaccine rollout. As an Island we can reflect on how much has been achieved in these 'Covid times'.

On Tuesday 14th December, Claire Christian asked in Tynwald whether "our Island's pandemic response has been satisfactory in respect of post-viral conditions?" You replied "the answer to that is no".

So as an Island we must ask ourselves, why is healthcare provision for post-viral illnesses not a celebrated achievement, alongside other elements of our Covid response? Or perhaps the more pertinent question is, could we have done better? The answer appears to be a definitive yes! Analysing Manx Care shortcomings in respect of this ever-growing group of patients, it seems a lot more could have been done...

The following 5 areas highlight the key inadequacies in patient care:

1. Lack of support for GPs or dedicated treatment and referral pathways
2. Insufficient involvement from those with Long Covid experience in the UK
3. Absence of a public awareness campaign
4. Failure to address historic weaknesses in Post-Viral Healthcare
5. Money talks

1. Lack of support for GPs or dedicated treatment and referral pathways

GPs play a vital role in management of Long Covid cases, both in the early stages of post-Covid recovery and later in the process when formal diagnosis and treatment are required. Good quality early advice can alleviate or avoid the worse symptoms of Long Covid in many cases and accurate diagnosis is imperative for chronic sufferers.

Feedback from our Island's Long Covid sufferers indicates that the quality of advice provided by GPs is hit and miss:

- GPs declining to offer help, claiming that there is nothing they can do
- GPs advice is too vague
- GPs failing to sufficiently warn patients of potential pitfalls when recovering
- A support service team are available to long covid sufferers, but this has not been communicated effectively amongst GPs
- Inadequate expertise to ensure early and accurate diagnosis.
- Insufficient and out of date knowledge of treatment options available

GPs need to be adequately supported with training and with clinical pathways for assessment, diagnosis, treatment and referral. Our communications with Manx Care indicate that so far no training has been provided to GPs regarding Long Covid and it is unclear who will be facilitating the planned training in March 2022 and whether they will have sufficient knowledge of Long Covid. Manx Care's failure, to date, to properly support their GP's is inexcusable.

Training for other medical staff across all Manx Care settings, including hospital staff, is also essential.

The answers you gave in December's Tynwald indicate that no meaningful improvements have been made to the clinical pathways for post-viral healthcare since the onset of the pandemic. Could your Department establish more specific and measurable targets for Manx Care to create greater urgency?

2. Insufficient involvement from those with Long Covid experience in the UK

The needs of Long Covid sufferers often differ from those of ME / CFS sufferers and until greater knowledge of Long Covid is obtained, Manx Care cannot robustly appraise the requirements of a Long Covid service, never mind deliver them.

There is clear value in seeking advice from an established Long Covid pathway in the UK, such as the Post-Covid 19 Rehab Pathway created by NHS Leeds Clinical Commissioning Group, and potential contacts have already been provided to Manx Care. 90 Post-Covid Assessment Services have already been established in the UK. We are concerned that the Long Covid pathways will be inadequate without further input from experienced clinicians.

3. Absence of a public awareness campaign

Long Covid is a complex illness that affects individuals differently, but one clear and simple message from experts in this field is around a phased return to normal activity, which can be seen in various aspects of society:

- Return to work – *‘If you feel recovered, still display caution as some people with Long Covid have made an initial recovery and relapsed later’* – [Long Covid Work](#)
- Education & children - *‘one thing we do know is that ‘pushing through’ can be harmful and result in worsening of symptoms and the inability to attend any education’* – [Long Covid Kids](#)
- Active people – *‘If anything we’re seeing it more common in the younger patients, the fitter, the very active’* – [BMA’s Lead on Long Covid Taskforce](#)
- General lack of awareness - *“people who have got long covid are people who caught it in the first instance and tried to work through it. They tried to say, ‘it’s only a mild disease, I’ll shrug it off and I’ll get on’ and the result is they’ve been left with much more lasting consequences.”* - [BMA’s Lead on Long Covid Taskforce](#)
- Healthcare – *“Resist ‘pushing through’ fatigue too soon”* – Extract from NHS leaflet regarding Post-Covid Recovery

Why has the Isle of Man Government not produced any public awareness information on this subject in the last 2 years?

4. Failure to address historic weaknesses in Post-Viral Healthcare

Long Covid comes in a variety of forms and ME / CFS symptoms are just one of the many ways sufferers can be impacted. That said, treatment and support for post-viral fatigue inevitably plays a vital role in healthcare during a viral pandemic.

Craig Morris, Vice-President of ME Support Isle of Man suggests that issues with Long Covid healthcare were “sadly predictable”. Craig explains that “those familiar with post viral fatigue felt it was inevitable that the coronavirus pandemic would trigger a new wave of patients with long lasting, debilitating fatigue. The issues experienced by long covid sufferers are the same that have harmed countless local ME sufferers for decades and unfortunately our Island’s health service was ill-equipped to handle these sorts of conditions. Previous Health Ministers and the DHSC had been repeatedly warned about the shortcomings in this area of healthcare, but for years these warnings have not been heeded by the DHSC, causing people with ME and now long Covid to suffer needlessly.”

A brief history of missed opportunities – by ME Support (IOM)

During the winter of 2014 a breakthrough was made and the Health Minister, CEO & Medical Director of DHSC at the time agreed that an 'ME Service' was required. Progress was made with the appointment of a 'steering team' and a GP ME Champion.

In 2016 a sensible plan was forming, but progress stalled and ultimately the project was mothballed. Why support was gradually withdrawn remains a mystery to ME sufferers.

Some hope was offered when funding was agreed for a new ME service by former Health Minister Kate Costain in 2017.

In April 2019 David Ashford said "enough of talking about it, its time to do it" and later promised an ME pilot scheme in 2019 and a full service by April 2020. These did not materialise.

Considering the inevitability of post viral fatigue cases arising from the covid outbreak in March 2020, ME sufferers felt there was clear extra incentive to introduce an ME service to support the inevitable development of 'long covid'/M.E. cases. Regrettably, and not for the first time, the DHSC has not been able to translate patient feedback and expertise into meaningful results.

It has been heart-breaking to hear long covid sufferers explain how little support has been available to them, with the knowledge that so much more could have been achieved before the pandemic even began.

5. Money Talks

Each case of Long Covid has an economic impact - on the individual, the family, the workplace, the economy, and on government revenues, outgoings and workforce. Conversely, preventing and addressing Long Covid will have benefits at all these scales.

On 23rd March 2020, then Treasury Minister Alf Cannan "brought forward £100m of direct support that we need to join this fight across the economy". Within weeks of the pandemic arriving, financial support had been announced for businesses and our economy.

So almost 2 years on, how much funding has Treasury approved to address the threat of Long Covid to our society? Seemingly the only option was to wait until April 2022 and the new financial year: the healthcare requirements of our Island inextricably linked to the budgetary cycle...

Are entrepreneurs and business owners more important than those chronically incapacitated by Covid-19? Could a Long Covid service have been established utilising any of these millions assigned for direct support of our economy? In an area of healthcare where tens of thousands could be transformational, surely Treasury could justify some expenditure sooner.

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Our business community has many vocal voices and many well practised lobbyists and clearly economic support was an important part of the pandemic response, but has the business community drowned out the healthcare needs of Long Covid sufferers that also desperately required attention? Have politicians responded to the group that shouted loudest?

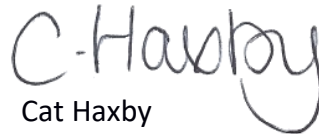
We appreciate that you were appointed to your role relatively recently and we are reflecting on numerous decisions that were made under the previous government, but I hope your department and the new administration can learn any lessons that arise and apply them as we move forward.

Sufferers of post-viral conditions deserve better during a viral pandemic.

Yours faithfully



Alice Quayle
On behalf of
Covid Recovery Isle of Man



Cat Haxby
On behalf of
Manx Long Covid Children