



Mater Misericordiae
University Hospital
Sisters of Mercy

Eccles Street, Dublin D07 R2WY, Ireland
Tel: +353 1 8032000

Ospideal Ollscoile

Maier Misericordiae

Siuracha na T r6caire

Sraid Eccles, Baile Atha Cliath D07 R2WY, Eire

Web: www.mater.ie



Not for prescription purposes

5 7 2022

Submission to Medical Subcommittee Oireachtas

Establishment of a Long COVID multidisciplinary Clinic and GP support network in Ireland

The Mater Misericordiae University Hospital is home to the National isolation unit, and we were the first to admit patients with COVID19 in Ireland, with me personally admitting the first adult patient on March 2, 2020. While in the first wave of COVID19 with the original virus, it appeared that lung and heart would be the targets of damage, following the establishment of the Long COVID clinic at the Mater in June of 2020, we became aware that the heart and the lungs repaired themselves, and that COVID also affected the brain, and this is where residual damage persisted, and that some people, even a year after infection, had residual symptoms that were all referably to this brain inflammation.

The UK was one of the first to establish Long Covid clinics in 2021, and their focus was primarily on heart and lung rehabilitation, as the first variants had lead to many patients being in the ICU. However, UK NICE guidelines warned that many of the post COVID symptoms needed to be 'managed' and not further investigated, as most investigations of Long COVID patients did not reveal any abnormalities. It appears that abnormalities were below the level of detection of the tests that were done.

Early into the first COVID19 surge, an HRB grant became available for myself and the Mater to lead a project on long covid, which I did in partnership with Professor Walter Cullen, Professor of Urban Family Practice and UCD School of medicine. And we established our clinic at the mater ID, to provide both a research platform as well as a clinical care centre. We developed a protocol called 'Anticipate' and consented 155 patient to perform quality of life assessments on their journey with Long COVID. To date, the ID clinic has seen over 1000 patients, has over 80 follow up patients monthly, and 25 or more new patients been seen monthly.

As stated, early on it was my clinical observation, and also the observation from review of the medical literature, that the brain was the primary target of long COVID. A review by Shin Jie Yong et al, published in January 2021, highlighted the pathogenesis of Long COVID neurological symptoms. We based our understanding and treatment of patients as early as April 2021 on focusing on the brain and the need for brain rehabilitation, as accumulating information from the medical literature supported that this is where the 'money was'. Dr Yong focused on the posterior part of the brain being involved in long covid, with ongoing tissue damage, possible viral persistence and chronic inflammation, all emanating from the brainstem. The brainstem contains numerous distinct nuclei and subparts that regulate the respiratory, cardiovascular, gastrointestinal, and neurological processes. Indeed brainstem dysfunction has been implicated in other similar disorders, such as chronic pain and migraine, and myalgic encephalomyelitis or chronic fatigue syndrome. UK NICE guidelines for the long term management of COVID19 recommends access to multidisciplinary services, including occupational therapy, physiotherapy and clinical psychology, with a range of specialist skills.

Based on our management of many Long COVID patients at the Mater ID clinic, and accumulating medical evidence in early 2021, we submitted an application through the Ireland East Hospital Group to the HSE, in July 2021, to establish a Long COVID multidisciplinary clinic, which included a range of specialist, but critically including neurology/neuro rehab, and psychology support. We heard nothing further about this submission until March of

'Commitment to Excellence'

Vice Chairman: Mr David Begg CEO: Mr Alan Sharp

Directors: Dr Mary Carmel Burke, Mr Rod Ensor, Mr Tony Garry, Prof Cecily Kelleher, Dr Mary McMenamin,
Prof Padraic MacMathuna, Ms Eilis O'Brien, Mr David O'Kelly, Ms Brid Cosgrove, Ms Suzanne Dempsey

Designated Activity Company, Registered in Ireland No. 351402 Charity No. CHY203 Registered Office: Eccles Street, Dublin



Mater Misericordiae
University Hospital

Sisters of Mercy

Eccles Street, Dublin D07 R2WY, Ireland

Tel: +353 1 8032000

Ospideal Ollscoile

Mater Misericordiae

Siuracha na T rocaire

Sraid Eccles, Baile Atha Cliath D07 R2WY, Eire

Web: www.rnater.ie



Not for prescription purposes

2022, when I was provided a document from the Mater CEO, 'interim guidelines for the management of COVID19 in Ireland Dated September 2021.

During 2021 we completed our questionnaires on patients followed in our ID clinic, and initiated some treatments for Long COVID based on the suspected CNS injury of our patients. At one year, many of our patients, including many staff members from the Mater and other hospitals who were referred to ID for evaluation, as well as from GP referrals from the region, had persistent 'brain fog' cognitive issues, exhaustion, sleep disturbances, psychological issues that they did not have before. Also blood pressure, pulse, thermoregulation problems, which were all due to a 'dys-autonomia', abnormal signalling from the vagus nerve as it courses out of the brain. We initially thought that only cranial nerve 1 and 2 were damaged by COVID (smell and taste) but accumulating experience in my clinic showed many of the cranial nerves involved, including the Vagus nerve, which controls the 'fight or flight' response that many long COVID patients experience.

We have published the results of our work in medical journals, and offered to share our results with the National clinical Lead and with the Minister of health. We had a 'dissemination' event in April 2022 to present all of our published results, as required by the HRB, and invited the Minister to attend. We have written to have an opportunity to present our data, as we see gaps in the current 'Interim Long Covid Plan for Ireland'. We have offered to assist in re-writing the guidelines to reflect the current problems that patients are experiencing.

I have had a chance to review the Draft Long COVID19 guidelines v4 dated July 2021, which outlines a plan that appear to be taken from the UK plan, and indeed most references are taken from the UK, and some from Italy. By the time that this document was completed and distributed and enacted, the 'goal post' had shifted. It focuses on early post covid 19 follow up with a group of 8 pulmonary specialists, and a cadre of dieticians and podiatrists funded (no mention of psychologists). However, as stated, for those of us managing patients in the hospital, the accumulating evidence at that time was that the lungs were healing, the heart was healing, but the brain was not healing. In addition, when I reviewed this Long COVID document, I was surprised to see the Mater ID was not included as a site for follow up, despite us generating most of the scientific data in Ireland on this subject, and also managing, I suspect, more patients with Long COVID than any other site in Ireland.

I am providing you some of our many published articles on Long COVID emanating from the Mater ID clinic in a separate communication. I would also like highlight the 'Long COVID Briefing Paper' for NPHET, from the office of the CCO Feb 15, 2022. It still focuses on the establishment of post acute clinics, establishment of long covid clinics, and a tertiary referral for neurocognitive clinics for those with complex neurocognitive/neuropsychological symptoms. It provides also a literature review, but fails to include any of the Mater publications which were in the public domain at that time. It also comments that the current plan is an 'interim MoC, it will be an agile process'.

To summarise from our publications, about 1/3 of our long covid still have significant 'neurocognitive defects' at one year (anticipate study)

From our GP supported publications, 15-20% of people with long covid have unexplained anxiety, depression, PTSD, and some are experiencing problem alcohol use to cope with the challenge of Long COVID.

We have just published the first pilot on the use of Low Dose Naltrexone and its utility in Long COVID. It appeared to benefit, within two months, a group of patients who had been unwell for an average of 333 days.

Based on the current gaps in the Irish Long COVID plan, I have met with the neurorehabilitation specialists who attend the Mater and who are part of the plan to staff the New Trauma Centre at the Mater. And we have discussed a plan

'Commitment to Excellence'

Vice Chairman: Mr David Begg CEO: Mr Alan Sharp

Directors: Dr Mary Carmel Burke, Mr Rod Ensor, Mr Tony Garry, Prof Cecily Kelleher, Dr Mary McMenamin, Prof Pdraic MacMathuna, Ms Eilis O'Brien, Mr David O'Kelly, Ms Brid Cosgrove, Ms Suzanne Dempsey

Designated Activity Company, Registered in Ireland No. 351402 Charity No. CHY203 Registered Office: Eccles Street, Dublin 7



Mater Misericordiae
University Hospital
Sisters of Mercy

Eccles Street, Dublin D07 R2WY, Ireland

Tel: +353 | 8032000

Ospideal Ollscoile

Mater Misericordiae
Siuracha na Trícaire

Sraid Eccles, Baile Atha Cliath D07 R2WY, Eire

Web: www.mater.ie



Not for prescription purposes

to deal with the current issues that patients are facing. Some are currently being discharged from the Post covid clinics as nothing is being found wrong with them (no cardiac or pulmonary abnormalities). Some have bounced from one specialist to another with many thousand euros worth of testing (pulmonary function tests, CT chest, CT brain, Holter monitoring), and are being told they have found nothing wrong. I had recent contact from a psychiatric nurse who is one year with long COVID and has overwhelming anxiety, and cannot attend work. She has been referred to a psychiatrist privately, first appointment available February 2023. GPs do not have a clear referral pathway nor guidance on management of long covid, and patients are coming to me having been prescribed a long series of medicines that just control the symptoms, from pain killers, to nerve blockers, to addicting sleeping pills. And the patients are no better.

What we propose at the Mater is a centre for Neurorehabilitation with national network to support GPs, as there are so many patients throughout the country with Long COVID and many of them cannot travel, as they are too ill. This neurorehabilitation centre will focus on 'brain rehabilitation' as patients with Long COVID act very much like patients who have experienced 'closed head injuries'. A group of neuro-rehab specialists, neurologists, ID physicians, psychologists/psychiatrists, and neuro physiotherapists need to be the 'primary' team managing these patients, as the CNS is the problem with our patients with Long COVID. In addition, we propose to engage our colleagues Professor Cullen and team Family Medicine to develop a set of educational materials ,guidelines and protocols so that GPs with a special interest in Long COVID can understand this condition, and appropriately manage these patients.

COVID 19 is ever mutating and changing. Ireland must be 'agile' and adapt the long COVID plan to serve the patients who are currently being let down by the current plan. We have known for 18 months, based on accumulating scientific data that brain damage is the issue with long COVID. We need a new plan and new resources and staffing to support these patients to recover and return to being contributing members of society.

Respectfully submitted

Professor John (Jack) Lambert, Mater, Rotunda, and UCO School of Medicine

'Commitment to Excellence'

Vice Chairman: Mr David Begg CEO: Mr Alan Sharp

Directors: Dr Mary Carmel Burke, Mr Rod Ensor, Mr Tony Garry, Prof Cecily Kelleher, Dr Mary McMenamin,
Prof Padraic MacMathuna, Ms Ellis O'Brien, Mr David O'Kelly, Ms Brid Cosgrove, Ms Suzanne Dempsey

Designated Activity Company, Registered in Ireland No. 351402 Charity No. CHY203 Registered Office: Eccles Street, Dublin