

Long Covid and Myalgic Encephalomyelitis /Chronic Fatigue Syndrome

Margaret Williams 5th November 2022

It is now widely accepted by many medical scientists and clinicians that some people with Long Covid fulfil the diagnostic criteria for ME/CFS and that ME/CFS and Long Covid appear to be the same condition. This information is readily available on the internet.

Myalgic Encephalomyelitis (ME) has been classified in the International Classification of Diseases (ICD) by the WHO as a neurological disease since 1969 (1).

Notwithstanding, for decades an influential group of UK psychiatrists (colloquially known as the “Wessely School” (2) resolutely refused to accept this classification and insisted that ME is the same as chronic fatigue, to which they ascribed the title “Chronic Fatigue Syndrome” (CFS) and which they designated as psychogenic. They published their intention of “eradicating” ME by dropping “ME” from “CFS/ME” when expedient and then reclassifying CFS as a behavioural disorder under syndromes of chronic “fatigue” which are classified in ICD under Mental and Behavioural Disorders at F38.0 (3, 4). These psychiatrists promised that “CFS/ME” could be cured by directive (as opposed to supportive) cognitive behavioural therapy (CBT, this being a form of cognitive re-structuring) and by graded exercise therapy (GET). The close association of these psychiatrists with the permanent health insurance industry and with various UK Departments of State should never be overlooked.

Medical science has at last accepted such a designation to be not only erroneous but actively harmful, as is made clear in the revised NICE Clinical Guideline on ME/CFS (5).

The Facts

In an important current article, Isabella Backman writes that according to Beth Pollack, a research scientist at Massachusetts Institute of Technology (MIT) specialising in chronic diseases including Long Covid and ME/CFS, ME/CFS is a *“neuroimmune, neuroinflammatory illness that affects numerous organ systems throughout the body, involving dysfunction of the vascular, autonomic, neurological, mitochondrial, metabolic, connective tissue, endocrine, and immune systems. In addition to its core symptoms, including severe fatigue that is not relieved after sleep, worsening of symptoms post-physical or mental activity, brain fog, and dizziness, patients may also experience aches and pains, difficulty being upright, digestive issues, night sweats, muscle weakness, flu-like symptoms, shortness of breath, and irregular heartbeat”* (6).

In the same article Backman quotes Akiko Iwasaki, Sterling Professor of Immunology at Yale, who states that as many as one in eight infected people are developing Long Covid, with symptoms indistinguishable from ME/CFS: *“Long Covid has taught the world that these diseases are real, there is a biological basis for them, and we need to study them”*.

Backman continues: *“A hallmark symptom of ME/CFS and now Long Covid is post-exertional malaise (PEM), which entails an oftentimes severe exacerbation of symptoms after cognitive or physical exertion... ‘It can be very harmful to make people with ME/CFS exercise’ says Pollack. ‘They are physiologically exercise-intolerant and have key dysfunctions in cellular*

energy production as well as multi-factorial reductions in cardiovascular and cerebral blood flow’ ”.

Backman is unambiguous: *“According to Pollack... as many as 84% to 97% have at least one other co-morbid condition (and) people with ME/CFS commonly develop a group of illnesses including autonomic dysfunction and POTS, mast cell activation syndrome, connective tissue disorders, small fibre neuropathy, autoimmune conditions, and more, and that these illnesses are often inter-related”.*

She is clear: *“Many illnesses that impact women were overlooked until a biomarker was discovered or an accurate diagnostic test was developed”* and she quotes Pollack: *“Many women with multiple sclerosis weren’t believed until the MRI machine was invented...Fibromyalgia often wasn’t taken seriously, and it turns out that about half of them have small fibre neuropathy – which by the way, is also frequently co-morbid with ME/CFS’ ”.*

Backman notes that Pollack emphasised that for around half of people with Long Covid, their condition meets the diagnostic criteria for ME/CFS.

She further notes that at Yale School of Medicine, Professor Iwasaki (researcher in Immunobiology) and Professor Harlan Krumholz, Professor of Medicine (Cardiology), have several hypotheses for why Long Covid may be causing lingering symptoms, these being first, a level of virus that is triggering inflammation beyond the acute phase; second, the acute infection may trigger autoreactive T and B cells to create an autoimmune response and third, Covid-19 may create a dysbiosis in the gut microbiome and reactivation of latent viral infections. They also consider if SARS-CoV-2 may be causing irreparable tissue damage leading to symptoms such as shortness of breath.

Backman states that in addition to those at MIT and Yale, other researchers are exploring the vascular pathologies of Long Covid and ME/CFS, including clotting, hypercoagulation, and vascular-related autonomic dysfunction, as well as increased interest in mitochondrial function being undertaken at Harvard.

Backman’s article ends by quoting Professor Krumholz: *“Through our combination of deep clinical science and expertise with laboratory science, we can begin to make progress where we’ve been stymied in the past”.*

It is such scientific progress that has nullified 30 years of the Wessely School’s psychiatric dogma that has caused incalculable iatrogenic harm and suffering to people with ME/CFS.

Another current and important article addressing the same issue is equally convincing about the devastation caused by Long Covid and ME/CFS (7). Extracts include the following:

“One felt her heart would explode out of her chest, another lost her ability to speak, and three others experienced unrelenting fatigue that left them confined to a bed, a bath or a wheelchair for much of each day”.

“The youngest is 23, and the oldest is 65... Each has a different set of debilitating symptoms, but all have at least one thing in common -- an immune system sent haywire by the coronavirus...As researchers strive to understand the condition, resemblances to other chronic ailments are coming into focus...(Scientists’) view is clouded by more than 200 symptoms”.

“(Patients) suffer from a combination of exhaustion, rapid heart rate and other bewildering symptoms that suggest the SARS-CoV-2 virus has damaged their nervous systems...Research from the National Institute of Neurological Disorders in Bethesda, Maryland, shows that even mild Covid lung infections can cause blood vessel damage, clotting, and a breakdown of the barrier between the brain and the blood stream. This can allow blood-borne proteins to leak into a patient’s brain, triggering dangerous inflammation, according to a study released by Avindra Nath, the Institute’s director, in July... Michelle Monje Deisseroth, a Professor of Neurology at Stanford University who collaborated with Nath, (says) ‘Without being alarmist, this is a neurological public-health crisis’ ”.

“Researchers say that POTS occurs when Covid damages the autonomic nervous system that controls heart rate, blood pressure, digestion and body temperature...POTS can be a foreboding sign. With time, patients often resemble those with chronic fatigue syndrome, Yale’s Iwasaki says. A study of 41 Long Covid patients published in December found almost half met the diagnostic criteria for chronic fatigue syndrome...also called myalgic encephalomyelitis”.

“Nath, the neurological institute director, sees parallels between the group most commonly afflicted by long Covid and those most likely to develop lupus and other conditions where the immune system attacks healthy issues: typically women around the age of 40. A study of 34 people with POTS found their blood contained immune markers similar to those seen in lupus and rheumatoid arthritis patients, as well as human antibodies directed at the autonomic nervous system. In many autoimmune conditions, ‘the virus is the triggering event, but most of the damage is caused by the immune system’ Nath says. ‘Once it gets hyperactivated, it’s very hard to shut it down, and it just starts attacking the host’ ”.

“In a study released in August, Yale’s Iwasaki attempted to outline the immune abnormalities in long-haul patients. Her most striking findings were related to cortisol, a hormone that helps regulate bodywide functions including blood pressure and inflammation. Cortisol deficiency can cause fatigue, muscle weakness and gastrointestinal upsets -- all common among long-haulers. In Iwasaki’s study, Long Covid patients’ cortisol levels were roughly half those found in people who had never been infected or had fully recovered. ‘It’s one of the strongest physiologic markers that we’ve seen for Long Covid’, says David Putrino, a neuroscientist at the Icahn School of Medicine at Mount Sinai in New York who collaborated on Iwasaki’s study”.

“One of the participants in that trial was Lisa Toran, a neurologist in Wenatchee, Washington, who’s been beset by chronic pain and other symptoms for almost two years. Soon after coming down with Covid in November 2020... her heart raced even when she was lying down...Ten days in, she began to feel better. She took a walk...to a park near their home. Soon after, Toran’s...standing heart rate hit 160 beats a minute. Food virtually stopped moving through her digestive tract -- a condition called gastroparesis -- and she began suffering allergic reactions to foods such as kiwifruit that she’d eaten ‘a million times’”.

“Thao Huynh, an epidemiologist and cardiologist at McGill University Health Centre in Montreal... says scans on more than 100 Long Covid patients showed 30% had signs of active inflammation around their heart and an additional 40% had scar tissue; almost all also had elevated blood markers for Inflammation”.

“Mady Hornig, an associate professor of epidemiology at the Columbia University Mailman School of Public Health in New York, says she's frustrated that physicians aren't talking to colleagues from other specialties to understand the extent of Long Covid's systemic effects”.

“Hornig developed a raft of medical problems, including sticky lung secretions, after getting Covid in April 2020. Chronic nausea and diarrhoea left her bedridden for weeks and required her to be hospitalized for five days almost two years later, when tests showed her entire GI tract was inflamed. She now takes as many as five medications to ease her gastric upsets, nausea, heartburn and inflammation. Tests have repeatedly shown levels of a molecule involved in blood-clot formation are more than double what they should be, indicating ongoing inflammation of her blood vessels”.

“Hornig, who studies chronic fatigue syndrome and related conditions (said) ‘I don't know how you can live like this forever’ ”.

As a direct result of the Wessely School's determination to “eradicate” ME, living like this is what people with ME/CFS have had to do for decades, even though it was officially recognised as a neurological disease by the WHO fifty three years ago.

In addition, they have had to cope not only with no medical help or support but also with ignorant, arrogant and disbelieving doctors who often vilified and mocked them, some of whom made sure that their meagre state benefits were withdrawn and that their rightful applications for permanent health insurance were refused.

If Long Covid is the same disorder as ME, this cutting-edge research into Long Covid will shed more light onto the existing and already substantial body of scientific evidence about ME/CFS, the difference being that all this evidence can no longer be ignored or dismissed by powerful psychiatrists with vested financial interests because so many Long Covid sufferers are doctors themselves and their collective voice will not be silenced.

References

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