



The MEmo



Waterloo Wellington Myalgic Encephalomyelitis Association

July 2021

Dr. Paul Cheney was a pioneer in the ME/CFS community

Dr. Cheney passed away on June 10, 2021 after a long period of declining health.

Paul R. Cheney, MD, PhD, was a physician of Internal Medicine who was at the center of the chronic fatigue syndrome outbreak of the disease in Incline Village, Nevada at Lake Tahoe with Dr. Daniel Peterson in 1984 to 1987.

He worked exclusively with ME/CFS patients since then and also tried very hard to get the CDC on board with the seriousness of ME/CFS.

Later, he moved to North Carolina and shared a medical practice from 1992 to 1995 with Dr. Charles Lapp. He resided and practiced medicine in Asheville, North Carolina.

Dr. Cheney was a founding Director of the American Association of CFS, now called the International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis. He was a provider of Ampligen for a clinical trial while in North Carolina.

In 2010 at the Invest in ME International ME Conference, regarding Graded exercise therapy, Dr Paul Cheney said: "The whole idea that you can take a disease like this and exercise your way to health is foolishness. It is insane."

- Paul Cheney,
Invest in ME International ME Conference, 2010

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Sufferers of M.E. or any other illness should
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But accepting it doesn't mean
it's defining you



These are the things I've learned.

It's more important to feel okay,
than to say you're okay



It's important to let yourself
rest when you need it.

JEN

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ME/CFS is a serious, chronic, complex systemic disease

by Anthony L. Komaroff, 20 July 2021

<https://www.mdpi.com/2227-9032/9/7/919/htm>

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is an illness defined predominantly by symptoms. Routine laboratory test results often are normal, raising the question of whether there are any underlying objective abnormalities. In the past 20 years, however, new research technologies have uncovered a series of biological abnormalities in people with ME/CFS. Unfortunately, many physicians remain unaware of this, and some tell patients that “there is nothing wrong” with them. This skepticism delegitimizes, and thereby multiplies, the patients’ suffering.

The symptoms caused by any illness should be suffering enough. Yet, with some illnesses, the suffering often is multiplied by skepticism about the illness. That is the case with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

In an article in *Healthcare*, Whitney Dafoe—who has been diagnosed with ME/CFS—describes his experience with an extremely severe form of the illness. He describes the physical and mental crashes and the extreme sensitivity to any kind of sensory input. He also describes the isolation, the loss, the complete and sudden disruption in the life of a young adult, a life that was on the runway and cleared for takeoff.

Why have some physicians and biomedical scientists been skeptical about the “legitimacy” of ME/CFS? Primarily, it is because the illness has been defined largely by symptoms. Since it is difficult for symptoms to be confirmed objectively, physicians have sought objective laboratory evidence of underlying biological abnormalities—abnormalities that an individual cannot simply imagine,

abnormalities that could explain the symptoms. Initially, that proved hard.

When interest in this condition was renewed in the mid-1980s, there was little such evidence: the “standard” laboratory tests ordered by physicians—typically, tests of red and white blood cells, a battery of about 20 chemistry tests, and a urinalysis—produced normal results. That posed a problem for the physicians. Their patients were suffering, and it was their job to make a diagnosis and prescribe a treatment, but the standard test results were normal: the physicians did not have a diagnosis.

At this point, the physicians had several options. First, they could have entertained some new hypotheses about what was causing the symptoms, and ordered new types of tests. Second, they could have said: “I just can’t figure out what’s making you sick, and don’t know how to help you.” Third, although they could not determine the diagnosis, they could have prescribed a treatment that might improve the symptoms even if they were not really sure what had caused the symptoms. That happens every day in the practice of medicine. For example, there is no diagnostic test for migraine headaches, yet doctors make that diagnosis every day based just on a combination of symptoms, and do not dispute the validity of the illness because there is no diagnostic test.

Unfortunately, the normal results of “standard” laboratory tests led some physicians to choose a fourth option: to conclude that there were no underlying biological abnormalities causing the symptoms. Even though the physicians knew that the “standard” tests they had ordered represented only a tiny fraction of all of the tests available to them, the normal results of that tiny fraction were enough for them to render a judgment. It was a harsh judgment: “There is nothing wrong with you.”

For these physicians, it was an efficient solution: it transformed what had been their problem—the lack of a diagnosis they were

expected to make—into their patient’s problem. When the patients were told, implicitly or explicitly, that their symptoms were imaginary, it multiplied the suffering.

And then these skeptical physicians also conveyed their judgments, implicitly or explicitly, to the patients’ families, friends and employers. The doctors’ judgment led these people—the people who were most important in the patients’ lives—to wonder whether the patients’ suffering was legitimate. That further multiplied the suffering.

There was always an obvious alternative conclusion to the judgment that “there is nothing wrong with you”: the standard laboratory tests might simply have been measuring the wrong things. Yet that alternative conclusion was ignored.

Since the resurgence of interest in ME/CFS 35 years ago, whole new technologies have become available that allow physicians and biomedical scientists to study human biology in ways that previously were not possible, e.g., noninvasive techniques for imaging the anatomy and physiology of the brain; polymerase chain reaction diagnostics; rapid nucleic acid sequencing; techniques for measuring gene expression; the ability to measure simultaneously thousands of molecules in a single sample (the “omics” revolution); metagenomic studies of the microbiome, and recognition of the impact of the microbiome on human health. In fact, these and other technologies have revealed things that the standard laboratory tests cannot—abnormalities that previously were invisible to doctors.

In 2015 the U.S. National Academy of Medicine (NAM) reviewed a literature of over 9000 publications on ME/CFS, and concluded that it was a “serious, chronic, complex systemic disease”. The NAM estimated that in the U.S., alone, 836,000 to 2.5 million people suffer from ME/CFS, making it somewhat more common than multiple sclerosis.

A large literature now describes multiple underlying biological abnormalities in people with ME/CFS. Some of the evidence comes from tests that have been available for decades but are not part of the “standard” laboratory test battery, and some evidence comes from the new technologies mentioned above. Unfortunately, many physicians are unaware of the new discoveries about ME/CFS.

The abnormalities all converge on and can affect the brain, and fall into five categories.

First, there are anatomic, physiologic and electrical abnormalities in the brain.

Second, various elements of the immune system are chronically activated and in some people those elements are exhausted—perhaps secondary to years of chronic activation. This includes chronic activation of the brain’s innate immune system—neuroinflammation. It also includes evidence of autoimmunity, including autoantibodies directed at targets in the central and autonomic nervous system.

Third, there also is evidence of impaired energy metabolism: the person with ME/CFS feels he or she lacks “energy” because his or her cells have a reduced ability to generate energy molecules (adenosine triphosphate, or ATP). Along with the abnormalities in energy metabolism, there is associated oxidative stress, or redox imbalance.

Fourth, the autonomic nervous system is dysregulated, one consequence of which appears to be impaired blood flow to the brain.

Fifth, there are characteristic abnormalities of the gut microbiome, with increased numbers of pro-inflammatory bacterial species and decreased numbers of butyrate-producing anti-inflammatory species.

What remains unclear are the mechanistic details as to how the abnormalities in each of these five categories affect each other,

and whether one of them is the initial and primary abnormality. In this next decade, the growing community of global investigators who are studying ME/CFS should place a high priority on refining our understanding of each of these categories of abnormality, and an even higher priority on understanding how they are connected. This is essential for developing good diagnostic tests, and effective treatments.

Whitney Dafoe ends the description of his suffering by emphasizing the silver lining around the cloud that he has lived with for nearly 20 years. He says he has learned a great deal about what is important in life, and that “ME/CFS is the greatest teacher I’ve ever had.”

I would like to think that ME/CFS will also prove to be a great teacher to the growing community of physicians and biomedical investigators involved in caring for and studying the illness. In particular, I speculate that the connections between the various abnormalities involving the central and autonomic nervous system, immune system, energy metabolism, redox imbalance, and the human microbiome that have been noted in ME/CFS will prove to be central also to the pathophysiology of many other diseases.

In particular, the COVID-19 pandemic appears to be producing millions of new cases of an ME/CFS-like condition, and NIH has allocated more than \$1 billion to study this and other post-COVID chronic illnesses. Hopefully, this investment will produce more answers.

Of the personal lessons that I, as a physician, have learned from ME/CFS, perhaps the most important is that, if patients tell you they are suffering, your default assumption should be to believe them—even if you cannot find an answer with the diagnostic technology you first deploy. Above all, never succumb to the temptation to dismiss the patient’s symptoms because you cannot explain them. That may ease your anxiety, but it only multiplies the patient’s suffering.

Doctors with M.E.

<https://doctorswith.me>

Doctors with M.E. is the global professional association for medical practitioners and scientists in the field, bringing together leading experts, regional associations and the quarter of a million healthcare professionals with ME that already existed pre-pandemic. We are a unique authority on myalgic encephalomyelitis and those Long Covid patients acknowledged by NIH, NIAID and BMA narratives who risk progression to this neuroimmune disease. With professional backgrounds developed in hospitals, surgeries, universities, financial services and think-tanks, our range of expertise is both specific and multidisciplinary.

The first global professional association in the field, we are also the first to be established and led by medics and experts who suffer from ME themselves. We are Doctors with ME and Doctors who stand with ME.

Join the mission and the vision

To improve patient outcomes worldwide by empowering medics, scientists and policymakers with up-to-date practices and scientific rigour, fostering collaboration between professionals, the industries they serve, patients and the public.

To build a future where every surgery, hospital, agency, insurance provider and employer is enabled with accurate information that supports their patients, clients, shareholders and wider stakeholders.



**Excellent videos from the Severe &
Very Severe ME / CFS Project**

<https://www.dialogues-mecfs.co.uk/films/severeme/>

2021 IACFS/ME Virtual Conference

August 19 - 21, 2021

<https://www.iacfsme.org/2021-iacfsme-virtual-conference/>

"Over the years I have cared for loved ones with advanced Alzheimer's, late stage cardiovascular disease and stage 4 cancer. But none of these experiences prepared me for being a carer for a Severe or Very Severe ME patient"

Mary Dimmock - Introduction to "Severe ME" by Greg Crowhurst.

A safe low sensory environment is essential for very severe ME patients. Exposure to stimuli and other physical, cognitive and emotional stressors is likely to increase pain levels, as well as symptoms such as fatigue, brain fog, sleep problems, overall sensitivity levels, and immune symptoms.

"In the States, the Covid-19 Pandemic has brought about the inclusion of Covid-19 patients in an experimental Hospital-at-Home program originally developed for geriatric patients. Daily nursing care, daily physician visits and therapeutics are provided. Therapeutics that cannot be provided at home are performed in very brief hospital visits. This model is appropriate and should be applied to the existing very severely ill ME/CFS patients as well as the long-haul Covid-19 patients whose symptoms are similar to those of severe ME/CFS."

Kenneth J. Friedman, Ph.D.
Guest Editor: Advances In ME/CFS Research and Clinical Care
Guest Editor: ME/CFS - The Severely and Very Severely Affected

Doctors believe in ME

by Dr. Nina Muirhead

<https://www.rcplondon.ac.uk/news/doctors-believe-me>

In 2019, I wrote to the RCP to share [my experience](#) of developing a neurological disease with multisystem symptoms following a virus. This is a disease characterised by symptom exacerbation following exertion, orthostatic hypotension, disturbed sleep, fatigue and cognitive impairment. We are now facing the next post-viral chronic disease challenge, post-acute sequelae SARS-CoV-2 infection (PASC) or 'long COVID'. Averting the next potential 'disaster' is critically dependent on us, as healthcare providers, [believing and providing supportive care](#) to our post-viral patients. Doctors are now being urged to diagnose and systematically [record cases](#) in computerised medical record (CMR) systems. This is especially important, as the [REACT](#) research numbers show that the illness burden is far higher than clinicians are currently recording. Long COVID patients are presenting to us, many with a long list of [multisystem symptoms](#) strikingly similar to the multisystem symptoms of [ME/CFS](#), and we are on the steep learning curve to recognise this disease.

In 2019 ME/CFS was in a clinical blind spot. Meanwhile, biomedical researchers and patients were excited by the emerging evidence. In sharing my experience in 2019 I wrote: '[red blood cell deformability is diminished in patients with ME/CFS](#)'; there is confirmation of [widespread brain metabolite abnormalities in ME/CFS](#)'. Similar phenomenon are being reported now; [phenotype and deformability of blood cells altered by COVID-19](#) lasting for months after coronavirus infection, as well as evidence of [brain metabolite changes](#) in patients with long COVID. The hidden impact on quality of life of [ME/CFS](#) and [Long COVID](#), on both patients and their family members, is enormous, and this is something we should be asking our patients about when we see them in hospital, clinic or primary care.

There have been four recent significant developments in ME/CFS.

[Doctors with ME](#) have responded to the overwhelming clinical and public interest and formed an association of clinicians, patients and researchers. Doctors and GPs are already signing up to hear the latest scientific updates and keep abreast of NICE [guideline developments](#).

[DecodeME](#), the largest ever DNA study of ME/CFS, is recruiting more than 20,000 patients for a genome-wide association study. Developed by the CFS/ME research collaborative (CMRC) and supported by Action for ME, Forward ME, UKRI and NIHR, the study aims to help pinpoint the genetic causes of disease and guide drug development. Our patients who have ME/CFS can register now, and saliva samples will start being collected from September 2021.

The ME/CFS [Priority Setting Partnership](#) has been set up to identify our top ten priorities for ME/CFS research, and is led by people with ME/CFS, carers and health professionals.

There has been an exponential increase in biomedical ME/CFS research publications, which have identified that [ME/CFS is associated with underlying abnormalities of the central and autonomic nervous systems, immune dysregulation, disordered energy metabolism, and redox imbalance](#).

What next? We all have a role to play; the long COVID clinicians will not be able to bear the chronic post viral health burden alone. This is a disease that needs to be recognised by all medical professionals. By working together, and with our ME/CFS and long COVID patients, we can be more proactive about making a diagnosis and recording the disease burden and impact on quality of life for patients and their family members. It is only by widespread professional education, information and support, and proactive coding, that the true scale of this hidden health crisis will be revealed. Following this, appropriate funding can be allocated to manage and support patients, new [medications](#) will be explored, and perhaps, one day, we will discover a biomarker. That would make life easier – believe ME!

The debilitating illness of ME

By CFB Esquimalt Lookout Navy News

June 24, 2021

<https://www.lookoutnewspaper.com/debilitating-illness/>

Being so tired he had to sleep half the day was Wade Walters' first inkling something was wrong.

The former Esquimalt SISIP manager says symptoms were slight and not concerning in 2000, but as time progressed so did the debilitating symptoms.

"I was saving all my energy for work and gradually becoming more and more tired," he says. "All I could do in the day was go to work, and then go home and lay down, get up the next day, and repeat."

On top of his inability to feel refreshed after a long sleep, he had headaches, muscle aches, short-term memory loss, sensitivity to bright lights and loud sounds, bladder dysfunction, night sweats, a chronic sore throat, and a sensitivity to certain foods.

It took a barrage of tests and back and forth doctor visits, but he finally was given an answer: Myalgic Encephalomyelitis, known as ME to those who have it, and formerly known as chronic fatigue syndrome.

Stats Canada estimates there are over 580,000 Canadians, including 77,000 British Columbians, diagnosed with ME.

"I used to have a very active life, now I don't even have the energy to take care of myself or my home properly," he says. "This is like a life sentence."

In August 2018, the illness forced him to resign his position and go on long-term disability. There are few treatment options for ME, which affects many body systems including thinking and concentrating, and there is no cure. Walters has been seeking help from his doctor and through the Complex Chronic Disease Clinic of B.C. Prescription pain medication has provided some relief but reducing stress through

meditation and mindfulness training have been more beneficial, especially to help him cope.

As COVID-19 winds through the world population, research is showing many people who contract the virus and have long-term residual effects are also getting ME.

"I know there are people out there in our community who have contracted COVID-19, think they have overcome the symptoms but can't figure out why they are so tired. It's important to get an early diagnosis and not fall into the trap of pushing themselves to their limit."

For Walters, he is hopeful a cure will be found, and that his energy and mental acuity returns to normal. Until then, the 62-year-old will continue to manage the crippling fatigue where every day feels like a flu day.

