

Canary in a Coal Mine--M.E. FAQ

by Jennifer Brea, jen@canaryinacoalminefilm.com

Canary in a Coal Mine is a documentary film about Myalgic Encephalomyelitis ("Chronic Fatigue Syndrome"), one of the world's most misunderstood diseases.

It is a story about a medical system that is ill-equipped to treat an illness that challenges its every assumption, the danger of ignorance, and the power of a name. It's the history of a community of millions that to most of the world is invisible.

What is M.E.?

Myalgic Encephalomyelitis is one name for a devastating neurological disease that has gone by many names since the 1930s: atypical polio, Icelandic Disease, Royal Free Hospital Disease, and most recently, Chronic Fatigue Syndrome.

Many researchers believe it is triggered by a virus, but that there is unlikely to be a single viral culprit. Environmental toxins seem to play a role, but not necessarily in all individuals or outbreaks. It occurs in both clusters and sporadic form, like polio did or multiple sclerosis does. Some of its hallmark symptoms are profound cognitive, neurological, and neurosensory impairment, tachycardia that prevents many from maintaining an upright or sitting position, and a perverse response to ordinary exertion.

What causes M.E.? If there are outbreaks, that implies that it's either an infectious disease or an environmental disease.

Possibly both. First, the infectious component. There are many anecdotes that suggest a temporal and spatial commonality: five teachers in a lunchroom, or eight kids who go out sledding trip, come back, and are never the same. When you see that you think: contagion.

No one really knows what the virus is. I can tell you that from the researchers I've been talking to, it seems that it's possible the trigger could be one of several viruses within a family of viruses. It might be triggered by an enterovirus or a herpesvirus, of which there are several. The tricky part is, you look at someone with ME, and they often have high concentration of a number of viruses which can cause some very nasty neurological effects. These are common viruses that most people will all have once they reach a certain age, but our immune systems can't suppress them. The question then becomes, did these viruses cause this illness? Or are they opportunistic infections arising as a result of an acquired immunodeficiency?

Some say that you need not just the presence of a virus, but an individual who is susceptible. There may be genetic factors: there are several people who contacted me

where multiple family members are sick. There is certainly a huge gender dimension: 70-80% are women. There may also be an environmental factor. We know that environmental toxins can alter immune systems and make certain individuals more vulnerable to infection.

It's really complicated, in part because patients often go years before they're diagnosed. Doctors and scientists are in essence trying to reconstruct the Big Bang: no one was there for it, causation is really hard to tease out, and so all you really have are your theories.

This idea of the importance of individual factors is not so strange when we look at some other infectious diseases. Prior to the vaccine, many people who became infected with the poliomyelitis virus were asymptomatic, others became ill and recovered with no lasting damage, while others were severely paralyzed for life. Diseases are always multifactorial, so saying ME is "complex" is true but a nonstarter.

What's the difference between chronic fatigue syndrome and ME?

Chronic fatigue syndrome was a name created by a CDC committee in 1988 in response to a series of outbreaks, most notably the Incline Village, Nevada, outbreak of 1984. It was really unfortunate, not just because the name sucks, but because one, there was already an internationally recognized name for the disease – myalgic encephalomyelitis – and two, the definition they came up with said nothing about some of the most severe neurological and autonomic dysfunction many of us experience. So some of our most devastating symptoms are said to be impossible because they are not in the definition.

The horrid name and the exclusion of those symptoms means that many people diagnosed with CFS probably don't have ME. A lot of people want to lump chronic fatigue syndrome, fibromyalgia and so on into one group. I think we need to study people who are patently self-similar in terms of their histories and symptoms and stop saying "It's all very murky" when the murkiness is man-made.

That said, I do, at the end of the day, think that strict diagnostic criteria are useful for clinical trials but harmful for treatment. Our bodies don't obey medicine's boundaries, and I don't think many diseases do either. For example, I've learned through my own research that what is probably happening to me right now, physiologically, has a lot in common with certain features of multiple sclerosis, HIV, diabetes and certain genetic mitochondrial diseases, in addition to the other neuro-immune diseases that are often lumped together with this disease. Now, who would ever think all these literatures should be speaking to each other? But they should be.

What are the symptoms of M.E.?

Some of its hallmark symptoms are profound cognitive, neurological, and neurosensory impairment, tachycardia that prevents many from maintaining an upright or sitting position, and a perverse response to ordinary exertion.

Additional symptoms include: light sensitivity, sound sensitivity, temporary paralysis, numbness or tingling, agraphia, ataxia, aphasia, glucose metabolism dysfunction, and problems with temperature regulation.

For a complete list of symptoms, see: the Canadian Consensus Criteria and the [International Consensus Criteria](#)

How hard is it for a patient to get diagnosed? And once you suspect you have ME, what does one do? Is there a cure?

There are a few doctors who are knowledgeable, and it's really good to find one of those if you can, but you'll probably have to pay out of pocket, so it can be quite expensive. Many tests require a research lab; they're not something most people would have access to. There's a woman we interviewed who was taking an experimental drug that can cause amazing remission in some, but it costs \$40K a year.

There's really no clear treatment. Patients try different things – antivirals, immunomodulators, or Ampligen, which is an experimental drug that works extremely well in a subset of patients. There have been some promising studies with a drug called Rituximab, a non-Hodgkins lymphoma drug, but that is not yet FDA-approved for this condition. There's no magic bullet. You have to try different things until you find what does. So much of the information we are working from is anecdotal. There are definitely people who are able to find some improvement from the off-label use of drugs, or through nutritional and dietary interventions, but many never return to the health they had before.

The most important thing when you get this is complete bedrest. I so wish I had known and been advised to do that, but I was a PhD student in the middle of a hectic semester. And culturally, taking care of our bodies really comes way below a strong work ethic and measurable success in our ranking of priorities. With this disease, you do not exert yourself, you do not exercise, or you will pay. Unfortunately, that is exactly what most doctors will tell you to do – exercise and you will get better – even though that can lead to a permanent worsening of symptoms.

What's the state of research on ME?

There's a body of literature, but very little funding for research. There's more funding for male pattern baldness in America than for ME. The research that has been done clearly shows: 1) we have things wrong with our immune system, 2) there's clear evidence of neurological damage, 3) there is severe mitochondrial dysfunction and 4) there are some very interesting things happening in our microbiomes.

So there are around 20 different ways that you can triangulate this disease with specific tests, if you knew which tests to run, but there's no biomarker. That really confused me at first. What do you mean there's no biomarker? By doing a more sophisticated analysis of EEG data, we can, with a very high rate of accuracy, identify this disease; we can look at things like cytokine markers, or natural killer cell function. We can look at cerebrospinal fluid and mitochondrial function. Some of the abnormalities you'd find are not unique to this disease, but the joint probability of X, Y and Z all falling into a pattern in a single person and that person not having ME is basically zero.

But what we really need, I am told, is a commercially deployable test, a single thing that we can measure that makes it simple and scalable. And I don't know if we're ever going to find that, but even with our current technology, if doctors ordered the right tests and knew the symptoms to look for, I think that they could be diagnosing this now. That's not happening, and doctors don't know about the science. So in the doctor's office, I have "hysteria," and then when I talk to scientists, I have a really mysterious, fascinating disease. And they tell me, here's how your disease is like AIDS. And here's how your disease is like multiple sclerosis.

It's a really tragic thing – there are a lot of people who are severely mistreated because of this. There are people who are getting locked up in psych wards. There are people who are encouraged to exercise and, as a consequence, are permanently harmed. There are parents whose children are taken away from them. There are people who become homeless. It's just really hard for me to fathom the waste of life that this tragedy has created. This happened with multiple sclerosis before we had MRI machines, and we used to put people with epilepsy in psychiatric wards. So this is nothing new. I'm convinced this will happen again with another disease, even when this one is solved, unless our entire approach to medicine changes.