

How I know ME/CFS* is a physical illness

by Una Hearne

Introduction

I am writing this to put a final nail in the coffin of the idea that ME/CFS is a psychosomatic issue; that it is 'all in the mind'. Having both the physical illness ME/CFS (from age 16) and the mental illness Depression (since birth), I am in a position to demonstrate how easy it is to differentiate between physical and mental issues in diagnosis.

Thirty years ago (in my twenties) I went to doctors with my physical symptoms and was dismissed – like millions of people with ME/CFS – since blood tests showed nothing. Back then all doctors in Ireland believed ME/CFS to be psychosomatic so there was no help available. Although things are better now, there are still many doctors and people in general who are stuck in this belief, which creates enormous hardship for patients. Most importantly doctors need to know there is a robust international diagnostic tool available: [International Concensus Primer for Medical Practitioners ME/CFS](#).

After I was diagnosed with clinical Depression in my thirties, inevitably some doctors have told me or implied that all of my ME/CFS symptoms can be put down to Depression. Despite the evidence that antidepressants work very well for me and when I am not depressed (most of the time) I still have all the physical symptoms of ME/CFS.

I dislike being patronised at the best of times, but when I mention ME/CFS and a doctor begins with 'Well, there is a lot of interaction between the mind and body. It's difficult to say if a symptom is Depression or something else'. Well, spare me. So, while I have no desire to go public with details of my personal health, I am doing it in the hope that my experience will help to educate people.

I have always known that ME/CFS is a physical illness and Depression is a mental illness. I experience ME/CFS as physical symptoms and my state of mind has very little influence on those symptoms. I experience Depression in my head, I have no doubts about where the problem is. It is easy to differentiate in diagnosis if you ask the right questions.

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* Myalgic Encephalomyelitis / Chronic Fatigue Syndrome

So, let me ask you, how do you know when you are sick?

You personally I mean? Have you ever caught a cold, been injured or diagnosed with heart disease and thought 'Oh this is all in my mind, I need a psychiatrist'? No, you quite plainly experience physical symptoms. It's not confusing.

Have you ever experienced anxiety or depression or personality problems and thought the issue was physical? 'Oh I must have caught this worry, bad mood or anger, I need an antibiotic or a splint'? Of course not, you experience the problem in your thinking, mood and relationships.

Given the overwhelming number of patients who correctly identify their own illness as mental or physical – shouldn't the patient's own opinion of what it going on in their mind and body be the primary clue – the starting point for diagnosis? Radical thought, I know.

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Before I demonstrate the difference in diagnosis between ME/CFS and Depression, I must just clarify there are two types of Depression for me. What I call 'ordinary depression' is event-related depression which most people will experience at some point in their lives (often called reactive depression). It is triggered by an event or a series of life events such as bereavement, job loss, having a serious illness, financial or relationship problems. The cause is identifiable and the person does not experience depression otherwise.

This is different from 'clinical Depression' (I'm using a capital D for this to differentiate). This is a mental illness where the person experiences episodes of Depression with no event-related cause. I am using these terms as they need to be differentiated for diagnosis, this in no way implies that ordinary depression is any less intense or awful while it lasts.

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The following is a demonstration of how easy it is to distinguish between ME/CFS and Depression in terms of differentiating symptoms.

1 Symptom - Chronic Fatigue

On its own chronic fatigue proves nothing as it is a common symptom in many illnesses. However it is an illuminating symptom if the right questions are asked.

The pertinent question to distinguish between a physical and a mental issue is:

'When you are confined to bed or sofa for long periods of time, too exhausted to move – what are you thinking and feeling?'

ME/CFS - I'm thinking of all the things I want to get up to do and I'm terribly frustrated, I want my energy back. I'm lying there with a head full of ideas and plans and a body that just can't get up and go. I particularly miss being able to do the work I love.

* Note: ME/CFS and Depression manifest differently in each person, I am only speaking for myself from my own experience.

Depression - I'm either thinking and feeling nothing at all, my emotions have flat-lined, or I'm overwhelmingly sad and I would much rather be dead. I am mentally and emotionally drained, feel exhausted and have no desire to move.

2 Symptom - Consequences of physical exercise

Two part question here: **'Do you want to do anything active?'** and **'If you do something active, what happens?'**

ME/CFS - I'm desperate to get up, to work, to exercise, to socialise. I am always conscious of how much I am missing out on.

All mental and physical exertion have the same result – Post-Exertional Neuroimmune Exhaustion (PENE). All of my symptoms flare up, I experience a lot of pain and 'crash' – which means I am forced to rest for hours, days or weeks to recover.

The best analogy is having a battery that will only charge to 15 or 20% at best. If I go over my available energy, even for minutes, I crash. Recovery means getting back to this 15-20% level. The only effective management is extreme rest and pacing.

Depression - When I am not in a Depressive episode I love walking especially in natural settings and I find it to be a hugely important preventative measure - as good as antidepressants for me.

In the depths of a Depressive episode I cannot motivate myself to get up and go out. I know from experience that putting pressure on myself to get up is counter-productive and will prolong and probably deepen the Depression. For me, the fastest way through an episode is to mind myself and surf the feelings. Allow them to be and remain aware they are just thoughts and feelings and they will pass. There comes a point in an episode when I know I'm coming out of it and it is sometimes helpful then to get out and walk a little to speed up recovery.

3 Symptom - Physical pain

Again, this is a common symptom in many illnesses. The relevant questions are: **'Do you experience physical pain on a regular or ongoing basis?'** and **'If so, when?'**

ME/CFS - If I go beyond my energy limits mentally, physically or emotionally, even a tiny bit, I will experience physical pain, sometimes localised, sometimes whole body. The more I push it, the greater the pain and the longer it lasts. There is usually a time lapse before the pain sets in. (For some ME/CFS patients, pain is constant, 24/7.)

The only way to minimise it, is to learn my limits and stay well within them. This is not easy as my limits can vary from day to day, randomly. It is impossible to predict and therefore nearly impossible to plan any activities.

Depression I have never experienced physical pain as a result of depression. Mental and emotional pain, yes, but not physical pain.

4 Symptom - Thinking and mood

The questions here are: **'In what ways is your thinking affected?'** and **'In what ways is your mood affected?'**

ME/CFS - Cognitive impairment is very common – usually called 'brain fog'. I've always said 'my brain is out to lunch' to explain when I am having difficulties understanding or communicating. It is one of the numerous symptoms which gets worse the more exhausted I am. I find it debilitating and embarrassing. I experience difficulties retrieving words and my short term memory is appalling. I have developed several coping mechanisms over the years so that most people don't notice. If they do witness it, they are shocked. I find it frustrating and depressing when I don't have access to my brain.

Like many with serious illnesses, I find it depressing (reactive depression) and frustrating when I think about how incapacitated I am, how much life I am missing out on. Ironically I think having clinical Depression has helped me enormously in this compared to other ME/CFS patients, I suffer less and deal with it more quickly when it comes up, because of my experience.

Depression - Clinical Depression is unrelated to life events. I have been hit by episodes when my life is wonderful as often as when it's not so great. My thinking and mood are dramatically different when I am going through a Depression. I'm not myself. When I was a teenager it was a more dangerous state for me as I felt those black thoughts and mood were me, and that I would always feel like that. Happily now, with so much experience and help received, I am now aware when I am in a Depression. Part of me is able to observe the black thoughts and to know that this state will pass, it is not who I am and I will feel differently on the other side. Now, during an episode I just observe the crazy train passing and look forward to the end of it.

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Apart from those described above I also have the following physical symptoms which fit the International Consensus Primer criteria for ME/CFS:

- Sleep dysfunction – a chaotic pattern which is not impacted by good sleep hygiene and habits.
- Orthostatic intolerance – I can only tolerate being upright (including sitting) for an average of four hours a day. I can't stand for more than about 10 minutes without pain which increases rapidly the longer I stand.
- Muscle spasms – in particular a jumpy leg which contributed to sleep problems – but thankfully has responded to drug therapy.
- Muscle weakness – I vary between normal tough girl who can do housework and gardening to being weak as a kitten, can't even manage a shower.
- Sensory overload in certain situations – even talking to more than one person at a time is exhausting.
- Balance issues.

- Extreme pallor when crashed.
- Loss of thermostatic stability.
- Tender lymph nodes, recurrent flu like symptoms.
- General malaise – this sounds vague but what it means for me is I never feel well. I just feel various degrees of ill.

Apart from sleep dysfunction - none of these symptoms appear in Depression.

It's really not that difficult to differentiate between ME/CFS and Depression is it? Not rocket science, just common sense symptom identification.

I am pretty sure these kinds of differentiators can be extrapolated for other chronic physical and mental conditions.

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While we wait for a cure, or at least good management protocols for ME/CFS we, as patients, must revert to the traditional treatment for all illnesses – rest and no stress. This has always given people the best chance of recovery in the absence of a cure –for example, it was standard treatment for TB before antibiotics. The smart thing is to give the body the support it needs to recover as much as possible naturally.

There are some drug treatments which help with symptom relief for many patients which is encouraging. And there is research now which looks promising and gives us real hope. It is also heartening that ME/CFS is becoming properly recognised by the medical profession. However it does take time for this knowledge to filter throughout the health system so that all doctors are up to date. Here in Ireland we have a good deal of catching up to do with countries who are ahead of us in this area.

I don't believe blame will help anyone. We cannot go back and fix the mistakes of the past, indeed they are inevitable, an integral part of progress. But we can absolutely stop the harm still being done today as a result of mistaken beliefs about this illnesses being a mental issue when it is in fact physical. I think it is worth skipping over recriminations and putting all that time and energy into what we actually need. Please see appendix for this.

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If you are a medical professional I hope this has clarified that ME/CFS is a physical illness. If you are a fellow sufferer I hope this gives you support and validation. If you can use this article to change the minds of people around you, please share it freely.

If I can only change one million minds my work will be done.

Thank you for your time and attention. Wishing you health and happiness
Una

Appendix: What we need

What we need immediately – all equally urgent and important:

- **A dedicated clinic** for ME/CFS. With a specialist consultant in ME/CFS and sufficient staff to support the clinic being a centre of excellence, this will:
 - Give doctors somewhere to refer ME/CFS patients. This would solve 90% of the problems patients experience in GP practices and A&E.
 - Educate GPs and A&E doctors on what to look for to refer to this clinic.
 - Provide proper timely diagnosis for patients – this is essential psychologically and for care and benefits.
 - Build a database of symptoms, treatments and efficacy which could contribute significantly to the research needed.
- **Adopt the Care Plan** being developed by the HSE M.E. Working Group. MEAI members of this group ensure they are referencing international best practice to ensure comprehensive guidelines result from the work of the Group to establish what expected best practice should be for those living with M.E. in Ireland.
- **Remove all references to CBT and GET** and all references to ME/CFS being a mental/emotional issue from all medical literature.
- **Proper funding for research** (ME currently gets less than MS in spite of a higher number of patients).
- **Rationalise HSE and Dept of Social Protection categories** in relation to ME/CFS so that we can access the help we need.
- **Put ME/CFS on the medical curriculum.** Send ICP document to all GPs and A&E doctors along with some incentive for them to read it.

Some relevant organisations:

- MEAI <https://meadvocatesireland.blogspot.com/>
- Irish ME/CFS Association <http://irishmecfs.org/>
- The Irish ME Trust <https://www.imet.ie/>
- Hope4ME and Fibromyalgia NI <https://hope4mefibro.org/>
- The ME Action Network – including Millions Missing campaign <https://www.meaction.net/>
- Solve ME/CFS <https://solvecfs.org/>

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