

Enough is Enough.

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If your GP surgery, hospital, health authority or health board is short of cash or running a large budget deficit then if you arrive for a diagnostic assessment and your doctor is "CFS/ME" friendly and hasn't got the money to chase any possible rare "expensive-to-identify" condition that may or may not pop into his or her head at random; it is far cheaper and quicker to take the shorter route and diagnose and possibly misdiagnose "CFS/ME".

Over the last couple of days, I have been in an exchange of e-mail with Professor Simon Wessely.

Professor Wessely has asked me not to repost his e-mail so I have agreed not to.

I wrote to him to ask him about the status of "CFS/ME" and blood donation and I got a swift reply within 30 minutes or so of sending my e-mail to him.

Professor Wessely said that regarding blood donation, he had not known about the situation regarding "CFS/ME" and the issue of refusing donations from patients.

He did say that this situation was probably one of those precautionary measures due to a long since dismissed link to a possible retro-viral infection.

In reply I took the opportunity of raising the subject of misdiagnosis and "CFS/ME".

I pointed out that the artificial construction of "CFS/ME" has allowed doctors from GP's to consultants to give a diagnosis of "CFS/ME" prematurely when the doctors concerned run out of diagnostic options due to their lack of knowledge.

In the process of doing this, patients end up misdiagnosed because they don't get referred upwards to more senior specialists, they don't get specialist blood tests or other specialist tests focussed on diagnosing rare diseases that the vast majority of doctors do not see.

Patients don't get access to procedures like CT and MRI scans and in fact if an NHS department has a problem with departmental budgets or overspending then it is far easier to hand down a diagnosis of "CFS/ME" than it is to spend money chasing a possible diagnosis of a rare disease.

I cited my own experience especially over the last 4 years.

I had to endure 7 referrals over 4 years and the faulty opinions of 9 specialists before I actually found a senior specialist in immunology and pathology who gave me the correct information.

And even then that specialist decided to make a couple of things up in the medical report sent to my GP that has taken me an additional 6 months to have corrected and I now have written proof of those corrections.

My point to Professor Wessely was that patients are now more than ever more at risk of being medically misdiagnosed if they are given the label of “CFS/ME”.

If nine specialists could not correctly identify the diagnostic criteria for a relatively rare medical condition; a condition they claimed to have a specific specialist interest in then what hope does a patient have being correctly diagnosed with “CFS/ME” by a GP or by a self proclaimed “specialist” at a “CFS/ME” clinic?

I then took this a stage further.

I described the fact that patients who were “handed down” the label of “CFS/ME” have died because of being given that label.

Such patients have found out – on one occasion as they were dying that they had been medically misdiagnosed.

Harry Metsmaker was the first person I know who died because he had been almost certainly misdiagnosed.

Harry was a member of MEActionUK in its early days and he was an excellent contributor. Harry was keen and he always had something useful to add to our discussions.

After an unusual silence from Harry, a message appeared on the group under his e-mail address. This time though it was a message from one of his daughters telling us that Harry had died of heart failure and that he had died suddenly.

After some time and when Laura Jones was still a member of MEActionUK, Laura told us of a relatively young patient with a diagnosis of CFS/ME who lived in South Wales who had also died because he actually had a serious heart condition that went un-noticed, undiagnosed and untreated.

This happened almost certainly because he was given the label of “CFS/ME”. Any symptoms he was suffering from were quite probably wrongly ascribed to “CFS/ME”.

I told Professor Wessely that as far as I was concerned and from my own bitter experience; being given the label of “CFS/ME” by two specialists in Rheumatology who simply ran out of ideas prematurely, was the direct cause of finding myself being progressively confined to my bed for 8 years of my life.

Since the creation of “CFS/ME” It has become very easy to spend less money on patients who turn up in clinics with “complicated” histories.

Such patients might well require lots of money being spent on them in terms of diagnostic procedures. However, by simply linking the symptom of fatigue on physical exertion and joint pain and other things like headaches and common things like fever responses with something “post viral” or stress related and then giving that patient the diagnosis of “CFS/ME” – well that process is relatively cheap and superficially benign.

And for that matter the “treatments” that result from such a cheap diagnosis are also relatively cheap themselves compared to the possible need for expensive drugs that are often used to treat rare diseases of the immune system as an example.

In reality there are dozens and dozens of relatively rare conditions that share the core symptoms associated with “CFS/ME” yet they have nothing to do with “CFS/ME” and nothing to do with functional psychiatry and I cited Behçet’s disease as one of those conditions.

Professor Wessely then told me that he had never seen a case or made a diagnosis of Behçet’s disease and in my view this demonstrated the point exactly. Professor Wessely did agree with me that the subject of misdiagnosis did occur and he told me that he had seen a few in his time and that he had passed them on to the relevant specialist.

But that reply did not actually address the heart of my point or the heart of this essay.

Functional psychiatrists and anyone giving the diagnosis of “CFS/ME” who claim to know “CFS/ME” back-to-front and inside out should be intimately aware of every condition that mimics what they claim is a functional mental health disorder to ensure to the highest professional degree that they are not giving their patient sitting on the other side of their desk the wrong diagnosis.

The trouble is – the doctors concerned do not bother to make that extensive list or to learn of all the alternatives because all the other specialists in all the other disciplines do that don’t they?

And after all these years eagerly expanding the “CFS/ME” patient base, the people making their careers out of “CFS/ME” have not been at all interested in the real and damaging issue of diagnostic inaccuracy, rare diseases and medical misdiagnoses.

I pointed out to Professor Wessely that in my experience, even specialists including rheumatologists, immunologists, a dermatologist and a neurologist who all claimed to have a specialist interest in Behçet’s disease had made elemental errors of clinical judgement when assessing me.

And this being the case, how exactly was a psychiatrist or a GP able to spot a case of Behçet’s disease if he or she saw one?

And how exactly was a member of a multidisciplinary team at a “Fatigue” clinic able to accurately spot a case of Behçet’s disease if they had no specialist knowledge of such a relatively rare condition.

Behçet's disease is only one rare medical condition from dozens of others and all the others share some of the generalised symptoms as described by "CFS/ME".

I told Professor Wessely that as far as I was concerned, the artificial construction of "CFS/ME" was as far as I was concerned a very dangerous construction as far as the patient was concerned.

And as far as I was concerned, patients severely ill with G93.3 Myalgic Encephalomyelitis were also victims of "CFS/ME" and a probable medical misdiagnosis if "CFS/ME" was deemed to be a functional somatoform disorder.

If patients with the signs and symptoms of G93.3 ME were subjected to CBT and GET as a part of the NICE Guidelines and if patients fail to respond or recover and even deteriorate because of such "treatments" then the possibility of a misdiagnosis should be escalated even further and patients should be taken out of the hands of functional psychiatry and passed on up the NHS to senior specialists in immunology and pathology for ground up reassessment.

It took me 13 years of fighting to get myself seen by such a consultant senior enough to know what they were really looking at and talking about.

It was undoubtedly because of the "CFS/ME" label I was given that caused me to be sent around in circles for 13 years being told that there was little that could be done because of the diagnosis I had been given.

Patients who are given the label of "CFS/ME" should be aware that there is a significant possibility that they could have been medically misdiagnosed by a doctor be that a GP or a specialist who simply had insufficient knowledge to enable them to diagnose a rare or alternative medical conditions.

Professor Wessely described his agreement with me that patients did fall through the net. He told me that he did not think he had ever seen a case of Behçet's disease come through his clinic. He also admitted that a "standard battery of tests" could miss pathology.

However, Professor Wessely seemed unable to comprehend the full implications of what falling through the net means for a patient. When I asked in my e-mail, Professor Wessely didn't address the issue of patients dying because of the "CFS/ME" diagnosis.

It is a fact that some rare pathologies such as Behçet's disease are not even diagnosed with a positive test but instead are diagnosed by the recognition of a pattern of symptoms over time.

However the situation gets worse because the NICE Guidelines for "CFS/ME" actively prevents any expensive tests or treatments or the exploration of rare pathologies that Psychiatrists and specialists and GP's may not normally see.

So, once a patient gets shunted into the diagnostic siding having been given a diagnosis of “CFS/ME”, their chances of having a medical misdiagnosis corrected are almost NIL unless they have enough knowledge themselves to fight their way out of the situation they have been placed in.

I know myself that I have been seriously ill now for 13 years.

After my misdiagnosis I became progressively more ill.

Had I developed some other pathology such as Cancer or a heart problem as members of MEActionUK have experienced over the years; there is a significant risk that the symptoms of that new pathology could be missed and instead ascribed by a GP or a specialist to the diagnosis of “CFS/ME”.

If that patient is misdiagnosed in the first place – say with Behçet’s disease and then develops symptoms due to an additional heart condition then it is my view that there could be a dangerous delay or more likely a total failure in treating that secondary condition. Put bluntly, patients could and probably have died from a double misdiagnosis.

In fact, the random attacks of Behçet’s disease can be fatal and heart conditions occur.

Luckily for me I am still here.

For the majority of my illness I was left almost totally untreated and only given low dose antidepressants and pain killers that kept me bed-bound and mostly completely housebound for 8 long years of my life.

We have had members of MEActionUK die over the years because they suddenly found out that they had advanced Cancer or indeed they discovered when they were dying that they had a serious heart condition that had gone undiagnosed and untreated.

I became housebound and bed-bound and after the first 18 months of my illness. I became unable to attend a rehabilitation clinic due to the progressive deterioration of my condition. At that time I was under the care of a rheumatologist who could offer me nothing and didn’t have a clue. Even if he did under the current regime, I’d have been offered CBT, Progressive Pacing Therapy which is just another form of Graded Exercise.

Over the first 9 years I had been told countless times by GP’s and specialists alike that there was little or nothing that could be done for me because I carried the diagnosis of “CFS/ME”.

Due to this dangerous label, doctors would not look further than the end of their desks and they would not consider complex tests or investigations or consider a reassessment.

This form of investigative prevention has now been enshrined in the NICE guidelines and this issue has now made it even more difficult to get out of the nasty loop I found myself trapped in for 13 long years.

Over the years we have been campaigning we have all been fed the mantra that Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) are the best practice forms of treatment that can partially or even fully rehabilitate a person with “CFS/ME”.

As this essay highlights, such treatments are not appropriate or successful for people who are medically misdiagnosed and it is no surprise to me that people who fit the diagnostic criteria, the signs and symptoms of G93.3 Myalgic Encephalomyelitis also do not find themselves rehabilitated or recovered by the application of such “best practice” treatments.

If the WHO classification G93.3 Myalgic Encephalomyelitis is claimed to be a functional psychiatric disorder then it is my view given the available evidence missing from Professor Wessely’s own KCL website that patients who present with the signs and symptoms specific to G93.3 ME are also in a state of medical misdiagnosis.

Such patients should not in my view be seen by psychiatrists or any general specialists and they should not be allowed to be diagnosed with “CFS/ME” by a GP.

Such people should be seen by the best and most knowledgeable immunopathologists and other senior specialists in the country before any diagnosis is made at all to ensure that all of the rare diagnostic options are assessed with as much competence and accuracy as can be achieved.

After all, in the longer term the patients suffer from the slap-dashed process we now endure thanks to the work of functional psychiatrists, the Medical Research Council, The National Institute for Health and Clinical Excellence and some of the ME charities such as Action for ME and the Association of Youth and ME.

It is my view that there are some doctors out there who simply do not care what happens to patients because they have conflicts of interest and all they really care about is increasing the headcount of those who are given a diagnosis of “CFS/ME”.

Over the last four years after it was realised that “CFS/ME” was not an appropriate diagnosis for me anymore, I have found it incredibly difficult to find a doctor with enough knowledge to make any diagnosis at all.

And on more than one occasion I have been aware that the doctor I was talking to was in fact trying their damndest to skew the new clinical evidence; trying really hard to maintain the misdiagnosis of CFS/ME even when the medical evidence clearly pointed to the fact that CFS/ME was an unsafe and incorrect diagnosis.

Since the introduction of “CFS/ME” (an artificial diagnosis deemed a heterogeneous label by the 2002 Government Working Party Report into “CFS/ME”) it has become even more of a high-risk lottery for the patient with a rare medical condition.

This artificial “CFS/ME” diagnosis has given the medical profession at every level from your GP to your consultant Rheumatologist or your “Fatigue” Clinic specialist a conduit or a short cut pathway an excuse to hand down a diagnosis of “CFS/ME”

before considering all of the ultimately more costly diagnostic options. The risk of a misdiagnosis is very real and in my view it is a risk far more common than the medical profession would like to admit.

The set of symptoms you have may well look like Simon Wessely's Neurasthenia or Michel Sharpe's Functional Somatoform Disorder but in fact your symptoms could represent a rare medical condition that has never been competently or carefully considered or investigated.

If your GP surgery, hospital, health authority or health board is short of cash or running a large budget deficit then if you arrive for a diagnostic assessment and your doctor is "CFS/ME" friendly and hasn't got the money to chase any possible rare "expensive-to-identify" condition that may or may not pop into his or her head at random; it is far cheaper and quicker to take the shorter route and diagnose and possibly misdiagnose "CFS/ME".

I have been reliably informed that as far as Behçet's disease is concerned, doctors receive about 30 minutes worth of education surrounding this pathology at medical school.

The same goes for other relatively rare conditions.

The majority of doctors after graduation have very little experience of rare medical conditions.

Professor Wessely tried reassure me by stressing that although he was a Psychiatrist he was also a doctor but in the context of this essay that means precious little at all to a patient who might present to any "functional" psychiatrist with a condition such as Behçet's disease for which that doctor has virtually no knowledge or understanding.

And if that psychiatrist or a GP or Rheumatologist or an Immunologist has a special interest in pinning functional symptoms, fatigue, generalised pain and gastrointestinal dysfunction amongst other symptoms, on a diagnosis of "CFS/ME" then that patient could well leave that clinic totally reassured and thankful to that doctor but unaware that they were completely wrongly diagnosed.

Of course those patients might just find out years and years later that they had been misdiagnosed by accident.

If that accident happens under the current system orchestrated by NICE, it might then make those patients realise why session upon session of CBT and Graded Exercise Therapy fail to have any lasting effects.

When those patients are still very ill, disabled and housebound and possibly even bed-bound as happened to me, they may just suddenly realise why they have been so ill and disabled.

I mentioned this previously but I will mention it again; even the specialists I have seen who were not psychiatrists but who claimed to have a special interest in Behçet's

disease have told me things and made claims about diagnostic criteria that I have known were simply and factually untrue.

If I had not challenged what I had known to be untrue, then I would have slid back down the slippery snake on the board game that is “NHS Snakes and Ladders” and I would have ended up back at square one.

The dangerous thing is this - the vast majority of patients out there have little or no medical knowledge at all. Patients usually trust the opinion of the GP or specialist they see and it is on that matter of trust that the doctor patient relationship is built.

As most of you know, I was a diagnostic radiographer and I worked alongside many doctors from nearly every discipline over the space of 8 years. I had total respect and trust for those I worked with at every level.

But having observed and experienced the system now as a patient on the other side of the looking glass; I now have an almost total distrust and disrespect for most of the medical profession surrounding the “CFS/ME” “business”.

I would warn anyone reading this who has been given the label of “CFS/ME” and anyone caring for someone with that artificial heterogeneous label to question the trust they have in the doctors who handed down that diagnosis on you or your loved one.

As I was fighting my way through the system it became apparent to me that patients without the knowledge that I have accrued over the years simply find themselves a victim of a total lottery.

It is my view that some professionals and their supporters are exploiting the flaws in the NHS and as I have outlined here there are fatal flaws in the NHS that we as patients are dealing with every day.

If you get misdiagnosed and you are unable to check the facts or fight your corner then as the NHS system exists, you stand very little chance of getting your misdiagnosis overturned and getting the correct treatment.

This does not just apply to Behçet’s disease but with other relatively rare diseases that share the core symptoms of “CFS/ME” and may not be identifiable through Professor Wessely’s “standard battery of tests.”

As I have also said before, some pathologies do not even show themselves by positive tests of any kind. Such conditions have to be diagnosed on a pattern of symptoms and a highly detailed background knowledge of that pathology.

In closing, the bottom line from all of the above is that patients suffer as a result of the “CFS/ME” diagnosis and the regime surrounding this diagnosis.

There is a significant risk of being misdiagnosed once or even twice by doctors who simply do not have the knowledge to match your potentially rare medical condition.

Patients can and have died from the “CFS/ME” diagnosis whether they be misdiagnosed, untreated or whether they have a secondary pathology wrongly ascribed to “CFS/ME” such as a serious heart problem or a brain tumour as two examples.

“CFS/ME” is therefore a dangerous diagnosis to give a patient. When this diagnosis gets “handed down” it then becomes a virtual prison sentence to someone who does deteriorate and become housebound and bedbound. Some of those people may well end up having a completely different medical condition anyway that will not respond or resolve using CBT or Graded Exercise or in fact anything a psychiatrist has to offer that patient.

This is why the NICE Guidelines need to be challenged and overturned.

This is why the stranglehold that Functional Psychiatry currently has on patients who initially receive an easy to give diagnosis of “CFS/ME” designed by them, managed by them and claimed to be treated by them, researched and peer reviewed by each other and even cured by their “best practice” “treatments” also needs to be fundamentally reassessed.

The way the diagnosis is give also needs to be reassessed and in my view, psychiatry should be the very last clinical resort for anyone presenting with a potentially rare medical disease.

As many of us are now learning, rare diseases can present with, multiple joint pains, flu like fever, migraines, gastrointestinal dysfunction, fatigue and shortness of breath on exertion, sensitivity to light and sound, heart irregularities and cognitive dysfunction. Circulatory problems can also feature and all of these can and are features of ICD-10 G93.3 Myalgic Encephalomyelitis. Such conditions may well not show up with any present tests.

These symptoms are also key features of ICD-10 M35.2 Behçet’s disease – a condition often diagnosed by a pattern of symptoms without any positive tests. Sitting next to Behçet’s disease at entry M35.3 is Polymyalgia Rheumatica; also sharing many of those symptoms associated with G93.3 Myalgic Encephalomyelitis. There are many others that have nothing to do with any mental health “F” coding.

Conditions such as M35.2 Behçet’s disease have no association with primary care mental health treatment so why by the extensive symptom association and degree of possible severity has G93.3 Myalgic Encephalomyelitis been allowed to have anything to do with mental health classification or primary care?

The World Health Organisation recognised this many years ago but somehow with the advent of two decade’s worth of functional psychobabble and the fix all solution of Cognitive Behavioural Therapy, there has been a desperate attempt to bury anything that could be totally biomedical and absolutely non-mental health in origin.

In light of the above why exactly is the issue of G93.3 Myalgic Encephalomyelitis still open to debate?

Why are patients with potentially rare medical conditions being prevented from being comprehensively investigated because of the existence of the “CFS/ME” diagnosis before mental health issues are considered as a last resort?

Why are these same patients becoming victims of a short-cut slap-dash diagnosis given by doctors who may well have insufficient knowledge and who may also have vested interests in disallowing patients from taking medical opinions from the top specialists in this country?

Enough is Enough.

I hope that the Judicial Review hearing in February can recognise the problems outlined above for the sake of long suffering patients everywhere..

<http://www.meactionuk.org.uk/nicejr.htm>