Eat Yourself to Health
Nutritional Medicine
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The fight for recognition and appropriate medical care for C.F.S/M.E. And some underlying causes from my clinical and personal perspective.

Musings on the campaigner- Jennifer Brea at a time of Covid-19: Her fight for recognition and appropriate medical care for M.E. patients and the tragic suffering of millions.

Last week Jennifer Brea, fierce campaigner and amazing advocate for those afflicted with M.E. worldwide (around 15-30 million people) has stepped down as Director for M.E. ACTION (an organisation, and global advocacy network she co-founded) in order to prioritise her own well-being. This is because after her full recovery from M.E after major surgery (followed by rehabilitation) for craniocervical instability, atlantoaxial instability, and tethered cord syndrome, her health has since taken a recent set back, having subsequently been sick with COVID 19 for 6 months.

Last week's press release:

https://www.meaction.net/.../important-news-from.../...

Jennifer Brea's story

For those of you who have not heard of Jennifer, she co-founded M.E. Action, in order to build a global movement to fight for recognition, education and research so that people with

M.E. (myalgic encephalomyelitis, also known as Chronic fatigue syndrome or CFS) would have support and access to compassionate and effective care.

She, herself, was struck down some years ago with M.E. whilst she was a PhD student at Harvard after a viral illness. Jennifer saw a multitude of health professionals who were unable to give her a diagnosis. Eventually a psychiatrist diagnosed her with a 'conversion therapy', maintaining it was all in her mind. In shock, but assuming he must be right, she forced herself to walk all the way home from the appointment. That journey home left her so sick, that she become largely bedridden and wheelchair bound for some years thereafter, at times unable to even tolerate the rustling of the sheets in her room.

Despite her poor health at the time, Jennifer went on to give a powerful TED talk in 2017 from her wheelchair - which if you haven't seen already, I urge you to watch. It has been viewed nearly 2 million times and translated into more than 25 languages.

She articulately expressed how M.E. has been under-researched and underfunded and its sufferers derided, along with some other chronic complex conditions that largely affect women. Jennifer noted how it has been viewed as purely psychological (a form of hysteria), as was once the case with diseases like multiple sclerosis and other auto-immune conditions (which are known to affect more women than men), until science since proved they were very real indeed.

She then went on to make the Sundance award-winning, Emmy-nominated feature documentary, Unrest (available on Netflix), further shining light on the thousands of bedridden M.E. sufferers. These actions came at a huge personal cost and sacrifice to her own well-being. And although Brea plans to stay involved with ME Action (she will remain on the board), she announced she would be stepping back as the director of the organisation to prioritise her own health.

Jennifer Brea is a truly amazing woman and should be applauded for the recognition she brought and will continue to bring to fellow sufferers. I hope she makes a complete recovery and am glad she is putting her health first and taking time to process the immense trauma she has experienced.

2020/2021: the epidemic of CVID-19 leaving millions around the world with Long-Covid

I do sincerely hope that given the immense impact long Covid is now sadly having on individuals' quality of life around the world – many left with devastating health consequences, there will be at last increased awareness, compassion and of course research into these post-infectious illnesses.

There needs to be a public rejection of the cruel notion that these extremely unpleasant conditions are a made-up entity. I abhor the once mainstream view in the UK that these post-infectious illnesses were some kind of 'yuppie-flu'. We should look back on horror at how people hugely burdened with these life-changing conditions, had to fight for recognition, treatment and benefits and were stigmatised and belittled in society, including by and to this day some medical doctors.

My own small brush with post-viral fatigue

Bear in mind this was a very, small insight into how it might feel for sufferers and even so, it was a very scary experience.

I will never forget the level of profound exhaustion I had. This was sometime in 2007, after an intense year in which I had gotten married, finished my dissertation on premenstrual syndrome, and then bought our first house which we were renovating (yes very much Type A personality, in those days).

I had gotten flu for the first time in my life. It lasted 2 weeks and although unpleasant, it was the 6 very long weeks after that were traumatic. After the initial viral symptoms had subsided (the usual high temperature, aches and pains etc), I experienced debilitating fatigue to the point I could hardly get off the sofa or even walk around the block for that duration. For someone so active and driven, after a few weeks I started to experience huge anxiety that I wasn't going to recover. It took some months to feel more like myself and it was a tough journey. There are amazing GPs out there and I have one at the moment, but back then I was told it was hypochondria (and just to do some daily jogging), which I found deeply distressing. It's very hard to heal and recover when you aren't being given appropriate support, care and consideration.

The intense chronic pain that I experienced was explained as being 'all in my mind'. Please note that I have been to many lectures on chronic pain since, and just because standard blood work (if the pain is of a nociceptive type, as opposed to an inflammatory type like from rheumatoid arthritis for example) come back as negative, this does not mean 'it is made up'. Neuroimaging is now showing us that there are structural changes to the brain in chronic pain sufferers such as those with fibromyalgia and so on.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5289824/

I feel blessed that with my nutritional knowledge and lots of self-care, rest and appropriate supplementation, I did recover. However not everyone is so lucky. There are millions bedridden around the world with M.E. and other post-infectious conditions. And they are often forgotten about by society. Imagine the genuine trauma of no longer being unable to carry out simple daily activities and then at the same time being seen as 'a fraud' and having to justify to your friends and family that you have a genuine illness. I truly believe it's a travesty.

N.I.C.E releases new guidelines

Gradual changes are afoot with N.I.C.E (National Institute for Health and Care Excellence) soon releasing its new guidelines to stop the recommendation of (fixed) graded exercise as the treatment for M.E/Chronic fatigue syndrome in the UK. A practice, which sufferers have long dismissed and M.E. Action have campaigned against because it has made many patients much worse, suffering rebound post-exertional malaise and significantly as it places the emphasis on them not trying hard enough to get better.
N.I.C.E said 'Chronic fatigue syndrome is a complex, multi-system chronic medicinal condition where there is no one size fits all approach to managing symptoms, stressing the need for tailored, individualised approach.' They also state that cognitive behavioural therapy (C.B.T) should no longer be recognised as a treatment/cure, but as a supportive therapy.

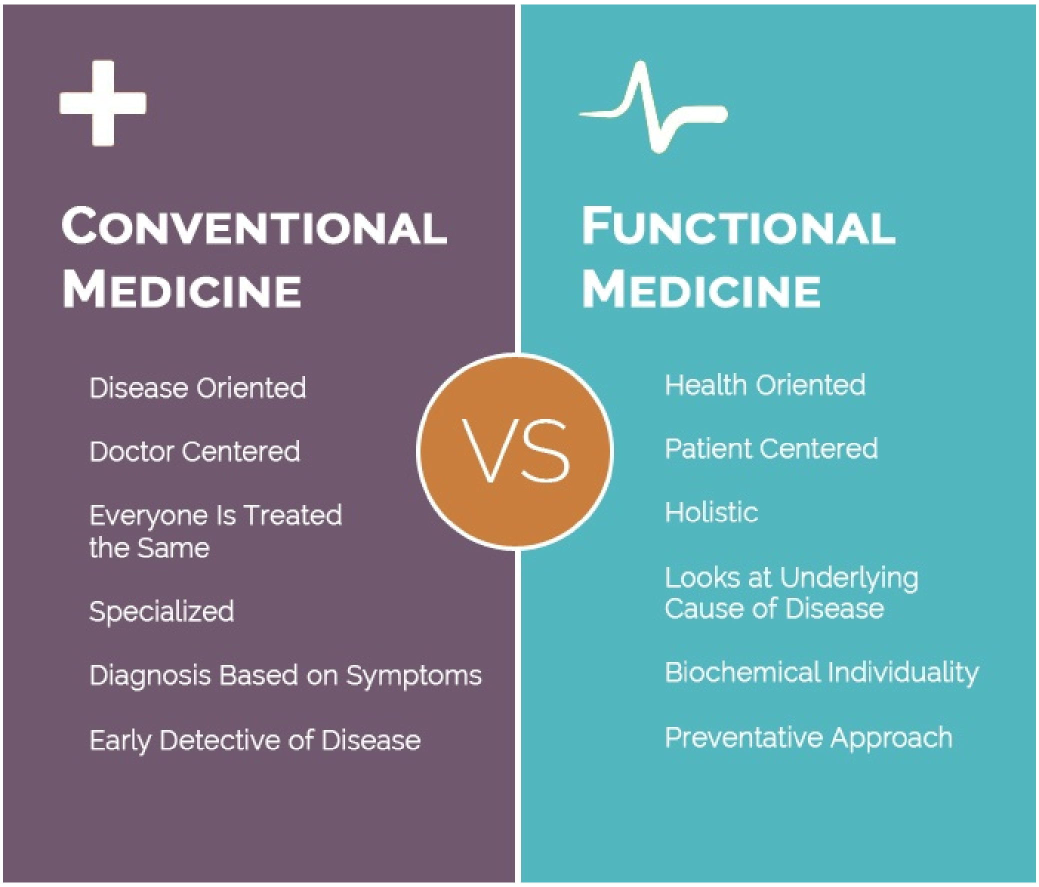
https://www.nice.org.uk/news/article/nice-draft-guidance-addresses-the-continuing-debate-about-the-best-approach-to-the-diagnosis-and-management-of-me-cfs

https://meassociation.org.uk/2020/07/nice-cautions-against-using-graded-exercise-therapy-for-patients-recovering-from-covid-19/

There are complex and multi-factorial reasons for M.E. otherwise known as Chronic Fatigue Syndrome (plus Postural Tachycardia Syndrome/POTS and fibromyalgia) and now long Covid.

I would never pretend to have all the answers for why some people get post-viral fatigue, chronic fatigue syndrome/M.E. or other post-infectious conditions like POTS and dysautonomia, but what I do know as there is ever increasing research as I have carefully followed the updates of various researchers around the world. However, these findings do not always trickle down into mainstream medicine. Moreover, conventional medications may never have the answer to treating these conditions.

What is important too is these conditions don't come out of nowhere. Even if it's the viral load that is the final nail in the coffin, there has been a preceding period of health imbalances. Most people with post viral fatigue have it because their body was already stretched to capacity preceding the virus.



CONVENTIONAL MEDICINE	FUNCTIONAL MEDICINE
Disease Oriented	Health Oriented
Doctor Centered	Patient Centered
Everyone Is Treated the Same	Holistic
Specialized	Looks at Underlying Cause of Disease
Diagnosis Based on Symptoms	Biochemical Individuality
Early Detective of Disease	Preventative Approach

The form of healthcare I practice is person-centred and seeks to find and then address the underlying causes for ill-health and for that a diagnosis isn't always required for treatment to be effective. Being a nutrition nerd, here are some of the factors at play (this is not an exhaustive list) and please note these are complex conditions with may have overlapping mechanisms, they will never have the completely same aetiology.

Hypothalamic-pituitary-adrenal axis dysregulation, Brain rewiring/maladapted stress response, Trauma, Dysautonomia/autonomic dysfunction, Oxidative stress, Low grade

inflammation, Cytokine storm/immune activation, Dysbiosis, Food intolerances, Cervical cord compression, Auto-immunity and viral-induced auto-immunity, Neuroinflammation and more specifically microglial inflammation,
Brain deviations in mitochondrial energy metabolism (energy deficit at the cellular level), Poor blood flow to certain areas of the brain, Histamine and other neurotransmitter imbalances, Connective tissue disorders, Deconditioning, Methylation issues, Genetics.

These are unlikely to be things a visit to the GP and medication can fix. They are complex conditions but are the sort of puzzle I enjoy getting to the bottom of.

But leaving that aside, what I can say with all my heart is that my own clients who have experienced ME/ chronic fatigue and fibromyalgia, are some of the bravest people I have ever met. Many of whom have also gone on to recover themselves, with my guidance. And I will always have gratitude for the work Jennifer Brea has done and hope there is a more positive future for sufferers of these distressing conditions.

Kirsten Brooks BSc Hon, DN Med is a nutritionist with a degree in nutritional medicine. She has a practice in South London (Eat Yourself to Health) and specialises in treating mental health conditions, burnout, complex chronic conditions such as chronic fatigue syndrome and fibromyalgia, female hormone issues and digestive disorders.

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