

Resisting the rise of psychofascism

We need to be wary of ‘mind-body’ theories that see illness as a psychological choice, says **John Barton**

I have something called Charcot Marie Tooth (CMT). It is named after the three neurologists who identified it in 1886. You lose strength and feeling in your feet and hands, but it usually progresses very slowly. Aside from having terrible balance, I was not really affected by CMT until my mid-40s. As part of my doctorate, I decided to research the experience of progressive disability through the voices of people who have CMT. Nine days before I presented my research proposal to my training institute's approval panel, in September 2013, I was diagnosed with an entirely unrelated and better-known neurological condition - Parkinson's.

Why do I have these conditions? According to the medical model, which presents a mechanistic, technical, clinical view of disease, I got CMT because a genetic mutation, a duplication of a segment of chromosome 17, was passed on to me by my father, who in turn received it from his father. Beyond that, the ancestry of our peculiar family heirloom is unknown. I got Parkinson's because, at some point in my 40s, for reasons unknown, the cells in the *substantia nigra* region of the brain that manufacture the neurotransmitter dopamine started to take early retirement and shut down.

When you get ill, along with your diagnosis, you are given a new identity too. OK, you're a patient now, an ill person. Parkinson's? You are that little old bent-over man, the one in the illustration that's in every textbook and encyclopedia (he seriously needs a makeover - the illustration was first published in 1886). Take your pills, don't make a fuss. Nothing more is expected of you. Shuffle off home and sink into the warm embrace of the sofa

or under the duvet of depression. Keep out of our way. One of my mum's old nursing books states categorically that mental changes from Parkinson's will include 'resentful attitude with emotional lability, depression, lack of concentration, intellectual changes, which may lead to dementia and paranoid delusion. Becomes miserable and over-sensitive'.¹ Such a bleak, oppressive discourse creates and sustains what Foucault calls a 'regime of truth', one that removes any agency, power or hope from the patient while reaffirming the authority and power of the medical system.²

Yes, we get it. We realise that Parkinson's is an unfolding horror show. Physical decline, cognitive decline, and the possibility of dementia and psychosis - these are common occurrences in Parkinson's patients (though by no means a certainty).

Transcending

All medical model approaches are focused only on alleviating and ameliorating deficits. No one ever talks about living a soulful life with them, let alone at times transcending them. People with health conditions can use them to live great lives and do great work. Parkinson's didn't stop Thomas Hobbes from writing *Leviathan*, for example, although it presents a rather grim, feral view of human nature - it was he who described life as 'nasty, brutish and short'. Beethoven did his

best work while fighting deafness; similarly for Monet with blindness. Franklin Delano Roosevelt contracted polio at 39 and lost the use of his legs. He thought his political career was over - instead he became one of America's greatest presidents, steering his nation through the Great Depression and World War II.

At 21, in his final year at Oxford, Stephen Hawking was diagnosed with motor neurone disease, also known as amyotrophic lateral sclerosis or ALS. He was told he had two years to live. But Hawking's was a rare early-onset and slowly progressing form of the disease. He was gradually paralysed over his lifetime. He lost the use of his legs, his body, his voice. But how his mind soared. He became a brilliant physicist, cosmologist and writer. He lived a full, rich life with his disability. 'Don't be disabled in spirit as well,' he said.

I'd just turned 50 when I was diagnosed with Parkinson's. In many ways, this is when I began to live. Ill health is brutal, horrific, desperate at times. But it is not always a tragedy - sometimes it heals.

Psychological choice

The medical model isn't the only choice on the menu. Another view, from the other side of the Cartesian divide, is that illness is a deeply psychological process and therefore something of one's own making.

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This worrying trend, fuelled perhaps by Western flirtations and interpretations of Eastern thought, the 1960s and a spiritual hunger born of a surfeit of materialism, leads the conversation towards a pernicious victim-blaming kind of New Age quackery that can sometimes become dogmatic and extreme. I call this 'psychofascism'.

For some evangelical positive thinkers, angel therapists and other self-appointed psychics, faith healers and meta-physicists, individual power and responsibility are inviolable - they see health and illness as a psychological choice.

One such is Gabor Maté, the widely respected Hungarian-Canadian doctor, writer and public speaker. He declares on his website, drgabormate.com: 'It's my belief that diseases like cancer, ALS, multiple sclerosis and so on, that cause so much suffering for people, all come along to teach something - and that if the lesson is learned, with compassion for oneself, then the "teacher" has done its job

and can then take a hike. That's not a guarantee, but I've seen many examples of people who have taken on their illnesses in this way and either survived or far outlived what medical science would have predicted, or at least greatly improved their own quality of life while alive.'

So show me some of those people who got Parkinson's, learned their lesson and then got better. It has literally never happened.

Writes Susan Sontag in *Illness as Metaphor*: 'Psychological theories of illness are a powerful means of placing the blame on the ill... Nothing is more punitive than to give a disease a meaning - that meaning invariably being a moralistic one.'⁴

The high priestess of psychofascism is Louise Hay, whose book *You Can Heal Your Life* has sold more than 50 million copies. 'I believe we create every so-called illness in our body,' she writes.⁵ If you only have joyous, loving thoughts, you will stay healthy, she says. If you already are ill, fear not - you can

heal yourself. Hay claims to have had cervical cancer in the 1970s - the diagnosis has never been corroborated - and to have cured it exclusively with her thoughts.

In her book, Hay also claims that diabetes comes from 'longing for what might have been. A great need to control. Deep sorrow. No sweetness left'. 'Accidents,' she opines, 'are no accident. Like everything else in our lives, we create them.' Moreover, the 'probable cause' of Parkinson's, according to Hay, and based on no evidence at all, is 'fear and an intense desire to control everything and everyone'. She suggests a 'new thought pattern', presumably as a cure: 'I relax, knowing that I am safe. Life is for me, and I trust the process of life.'

I have of course entertained psychological explanations for my Parkinson's. My first therapist described me as 'metal man'. I pushed myself. Metal man was embraced by the capitalist machine. False selves can achieve much. But there is anxiety in a suit of armour. I felt disconnected. So maybe metal man literally got on my nerves, for a long time, and my nerves got fried, creating some kind of short-circuit in my brain that precipitated Parkinson's. Perhaps it's a uniquely human disease of disconnection. No other animals get it. Children do not get it either. Nobody ever gets better. Men are 50% more likely to get it than women - a ratio that is in line with the statistics on suicide and addiction. One twin study found that people with challenging jobs involving complexity are more likely to get Parkinson's.⁶ There are even pronouncements of a Parkinson's personality, as reported by Luca and colleagues: 'Since 1913, patients with Parkinson's disease have been described as particularly industrious, devoted to hard work, inflexible, punctual, cautious, and moralist. These psychological characteristics have been so constantly reported that the concept of "Parkinsonian personality" emerged'.⁷

Your body perhaps gets tired of being told what to do and harangued and neglected. Parkinson's might be an embodied manifestation of an intrapsychic schism, a lifetime of super ego-ordained fragmentation. Some of history's most fragmented people succumbed to Parkinson's, including Hitler, Franco and Mao - truly a monstrous trio of metal men.

At some point, the brain cells that create dopamine - the neurotransmitter of love -

simply give up. Perhaps they feel they are not needed - love is not wanted here.

But such an explanation strays into the realm of psychofascism. Any healthcare professional - especially a non-disabled one - who makes pronouncements like these when working with a patient is committing an act of violence.

Cancer is the disease whose victims are most commonly subjected to this kind of judgment. They are told they brought it on themselves by being too emotionally repressed; it is then demanded that they think positively and be 'strong' to beat the disease. Ehrenreich eloquently describes her experience of this in *Smile or Die*.⁸ Ten million people around the world died from cancer in 2020. Did they all fail to learn Maté's 'lesson' that had been offered? How many people with cancer have died believing their death was down to personal weakness?

We don't actually know precisely the reasons for the arrival and progression of cancer, or of any other disease. Cancer is common in all mammals, too, with a few exceptions - mole rats, for instance, almost never get it.⁹ Are we to assume they are better at expressing their anger than their fellow rodents? Did they have better attachment experiences in their youth? This is not to deny psychological processes, but sometimes we are 'thrown' into disease and there is no reason. With life comes disease, disability and death. No one is to blame.

Hay, in an interview with *The New York Times*, was asked if she really believes that people are responsible for their own deaths.¹⁰ Did victims of genocide, for example, or people killed in the Holocaust, get what they deserved? 'Yes, I think there's a lot of karmic stuff that goes on, past lives... it can work that way,' Hay said. 'But that's just my opinion.'

Integration

The medical model generally ignores the mind. People resist any discussion of psychological contributions to physical difficulties because they fear being judged

as weak or accused of malingering.

A decade ago, doctors and researchers who even suggested that there might be a psychological aspect of chronic fatigue syndrome, otherwise known as myalgic encephalomyelitis or ME, received death threats and hate mail. Some were physically attacked. So now doctors have an almost complete aversion to exploring anything psychological at all (beyond the usual cursory 'How's your mood?' question).

But those rejecting the medical model too often embrace its antithesis, psychofascism. What is needed is synthesis. I reject the black-and-white thinking of Cartesian dualism. Merleau-Ponty says Descartes was mistaken - living, our sense of the world and who we are, our subjectivity, these are deeply embodied experiences. Of course they are.

Says Merleau-Ponty: 'The body is our general medium for having a world.'¹¹

The mysterious marriage of mind and body does not submit to certainties. In the words of Suzuki and colleagues: 'Our body and mind are not two, and not one... Our body and mind are both two and one.'¹²

Writes Oken: 'Psychological and biological factors are involved in all aspects of human function - healthy and disordered. All disease and health are psychosomatic; there are no "psychosomatic disorders" because there are no "non-psychosomatic disorders".'¹³

I know that my physical symptoms go hand-in-hand with my overall psychological state at any given time. They affect each other. They are intimately intertwined. They are, perhaps, indivisible. Rather than just doling out pills, a health service could offer genuinely holistic, multidisciplinary treatments for chronic conditions, which could become a springboard for a whole new life - perhaps a life of healthy living, growth, community, creativity.

And spiritual, too. Disease can be like life itself: chronic, degenerative, incurable. And transcendent. In life you may find yourself. In death, may you get over yourself. ■

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