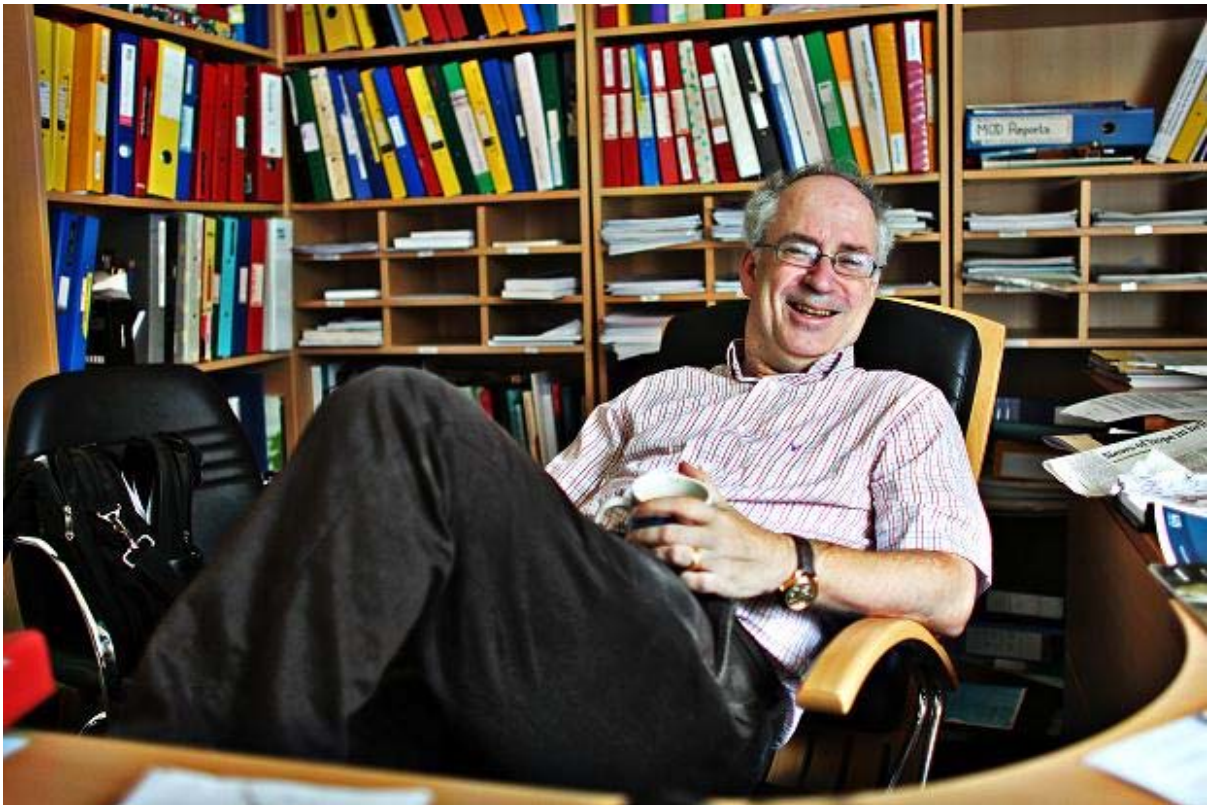


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THE TIMES Medicine

Doctor's hate mail is sent by the people he tried to cure



Simon Wessely relaxes in his office in King's College London
Richard Pohle for The Times

Stefanie Marsh

August 6 2011 12:01AM

In an inconspicuous corner of Camberwell sits the most hated doctor in Britain. Simon Wessely is not vilified by his peers — on the contrary, he is one of the most respected psychiatrists working in Britain today. Nor is he loathed by the thousands of patients he has helped to treat throughout his career — only yesterday he received a letter from a patient who told him: “The research you and your team are doing is crucial to me.”

Curiously, most of the people who hate Professor Wessely have never met him. But over the past two decades they have followed his work from afar, mostly over the internet and what has been written, or — sometimes incorrectly — implied, about him in the papers. He is Britain's foremost authority on ME, or chronic fatigue syndrome (CFS) as it is also known.

It is quite possible that without his research people struck down by the illness would still be objects of ridicule, regarded as victims of some sort of self-imposed dossier's depression. For it was his research that proved ME was not, as the general public, many doctors and certainly all employers once imagined, "yuppie flu".

He has written more than 600 research papers on the condition. With colleagues at the psychiatric unit at King's College London, he helped to develop a rehabilitation strategy and later set up the first NHS programme designed to treat those who had been left incapacitated by the illness. He discovered that by combining cognitive behavioural therapy and light exercise a third of patients make a full recovery.

Before his work, the standard treatment for ME was rest, with the result that many patients were left incapacitated. Many health professionals agree that he has done more for the sufferers of ME than any other individual, not just in Britain but worldwide.

So it is interesting to learn that the people who loathe him — so much that they often send him threatening letters wishing him dead — are themselves incapacitated with ME. The problem seems to lie in the fact that Professor Wessely is a psychiatrist. As far as the extreme ME lobby is concerned, theirs is a purely a physical disease.

Such was the vitriol and the constant ratcheting up of the threats emanating from the fringes that, ten years ago, Professor Wessely chose to give up his research. "I knew that I was the focus for a lot of the aggression. I didn't think I was helping."

That is somewhat of an understatement. He now works in military health. "I now go to Iraq and Afghanistan, where I feel a lot safer," he has said.

Last week the vitriol of the extremists was laid bare for the first time in the press. "They're not as bad as the animal liberation people," Professor Wessely tells me. "But they're just as fanatical. It's constant stalking, harassment, attempts at intimidation."

Even now the attacks continue. "If I'm giving a scientific conference they will write to people who are sharing a platform with me to tell them how terrible I am. Or they will send e-mail circulars to my university. You can see on their website that they know the most remarkable details of my personal life. They know most of my diary, I don't know how but they do. They use — abuse — the Freedom of Information Act. They make frequent complaints to my principal, to my Dean, to regulatory bodies, to ethics committees, to misconduct committees. I mean it's just a constant litany."

The first sign that he was on the verge of becoming a hate figure among those he had spent so much of his life trying to cure came in the early 1990s.

"I remember finding a bizarre piece on the internet in which I was accused of stealing a computer from one of the patient groups. It became more organised in the mid-1990s. It's a very small number of people. I'm accused of calling patients malingerers, neurotic cripples, of throwing boys into swimming pools, stealing things, of plagiarising, misconduct, falsifying data, being in league with Pharma or the lackeys of insurance agencies, stealing money from the MRC [Medical Research Council], abusing my position when I was on the MRC to ensure that my friends get grants, that everything I do is part of a vast conspiracy to deny the truth — all of which are grossly, professionally defamatory."

If not a little frightening too. “I’ve had people ringing up and say, “We’re gonna get you.” I’ve had death threats. Not many but, you know, you don’t need very many to find them a little bit disturbing.”

Threats and intimidation aren’t things one normally associates with patient lobbying groups. One can hardly imagine contributors to Cancer Research UK threatening to murder leading oncologists. “CFS does live in a very ambiguous territory, somewhere between medicine and psychiatry,” says Professor Wessely. “And that makes sufferers uncomfortable. I think the reason cancer patients clamour for psychological treatments, and they do, is because they are ‘secure’ in their illness identity. So there is no threat to their status or self-esteem. But CFS sufferers are in a different place.”

NHS figures show that a quarter of a million people in the UK have CFS at any one time. And the problem for some is that Professor Wessely is a psychiatrist at all. “I think finally, fundamentally, it is that they cannot stomach the thought that this might be a, quote, ‘psychiatric disorder’. By which they mean — not what I mean — ‘it’s imaginary’, ‘it doesn’t exist’, they are ‘malingerers’.”

There is a debilitating physical disease for which, some insist, there is, as yet, no cure. Certainly, there is no test — a fact that insurance companies in the past have used to their advantage. Even now many insurers won’t cover ME. Should they? “Obviously I’m of the view that we should treat these disorders equally, which is, I think, getting rid of the distinction between neurology and psychiatry.” He said this would partly get rid of the distinction between the “deserving” and “undeserving” ill.

There remains an old-fashioned prejudicial view of what “psychiatric” means. “Psychiatric disorders are disorders of the brain but expressed in a way that you can’t see them. I think that schizophrenia is a psychiatric disorder, Alzheimer’s is a psychiatric disorder, OCD [obsessive compulsive disorder] and autism are psychiatric disorders. Why is Alzheimer’s listed as a psychiatric disorder? Well, largely because it is treated by a psychiatrist.”

But what exactly is ME? A collection of symptoms that has much in common with irritable bowel syndrome, fibromyalgia and post-traumatic stress disorder — afflictions that are little understood. Professor Wessely has identified, in some cases, that hormones play a part and that there can be a physical trigger for ME — glandular fever can be a trigger, though flu cannot — but it is to a large extent still a mysterious condition. There was a theory that ME was a retrovirus but it fell apart when tested. Online, ME sufferers conjecture that they have a virus, an immune problem, or poisoning.

Professor Wessely is dedicated, intelligent and well liked. He is also the kind of doctor who has never tried an “alternative” treatment of any kind himself. His attitude towards alternative medicine may sound cold to those afflicted with ME and desperate for help. It is understandable that some take umbrage at what he has said about the condition, especially if they are wedded to the notion that the illness is purely physical.

He directs me to a research paper which found that patients who were labelled with ME did worse than patients who were told they had post-viral fatigue syndrome. In one of his papers he argues: “Ultimately, a pessimistic illness perception can become a self-fulfilling prophecy of non-recovery.

“This group of CFS patients tends to view their symptoms as part of an overwhelming, mysterious, unexplainable disease that struck them out of the blue and from which they most likely will never recover. These illness expectations are often fuelled by the media, support groups . . . and other sufferers.”

He continues: “Like it or not, CFS is not simply an illness, but a cultural phenomenon and metaphor for our times.”

A metaphor that does not apparently translate into non-English speaking countries. “ME is virtually unknown in France, Italy and Spain. Only a small number of doctors will make this diagnosis. So most doctors will not call it this. They will call it neurasthenia, they might call it depression, they might call it stress. Now, that might be that they are blind, or it might be that the patients are too poor to seek healthcare. You see, it’s very difficult to know. But it certainly didn’t strike a chord with them in a way that it does over here. When we gave them descriptions of our typical clinical cases here in Britain, they didn’t recognise them. They said, ‘Nah, we haven’t seen that’.”

Does that mean that there are parts of the world where ME does not exist? “Well it does exist but it’s not labelled. In many countries it’s just not labelled as chronic fatigue syndrome . . . Certainly we know that in Italy we do know only a small number of doctors will make this diagnosis.”

What ME categorically is not, says Professor Wessely, is “what you and I get on a bad day”.

Curriculum vitae

Age 54

Educated King Edward VII School, Sheffield; Trinity Hall, Cambridge; University College, Oxford; the London School of Hygiene and Tropical Medicine, University of London

Career Started training in psychiatry at the Maudsley in 1984, was elected to the Academy of Medical Sciences in 1999, and last year became Vice-Dean for Academic Psychiatry Teaching and Training at the Institute of Psychiatry, King’s College London. There he is Professor of Epidemiological and Liaison Psychiatry and head of the Department of Psychological Medicine. He is also Director of the King’s Centre for Military Health Research, honorary consultant psychiatrist at King’s College Hospital and the Maudsley Hospital, and civilian consultant adviser in psychiatry to the Army

Quickfire

Science Museum or Royal Academy? Science Museum I am afraid, despite having a History of Art degree

Dolly the Sheep or leave it up to nature? Nature sometimes gets it wrong — ask those with genetic diseases — so sometimes it needs some help

Lab coat or leather jacket? Don’t possess either. I do possess a flak jacket, but not for the reasons you might think

Paracetamol or acupuncture? Paracetamol. I have never tried any alternative medicine

In Treatment or Frasier? Happiness was getting on a flight to Sydney and finding they had a channel showing nothing but episodes of *Frasier*

Brian Cox or David Attenborough? Happiness would be getting on the Sydney flight and find I was sitting next to Sir David. My happiness that is, not his

Star Trek or Holby City? *Star Trek*, but only the original cast

Nuclear or solar power? Both

Mental arithmetic or calculator? Calculator

Organic or whatever happens to be on the shelves? Takeaways, because there is usually nothing on the shelves