

The Sunday Times Magazine

MAY 5 2013

DOUBLE TROUBLE

lie Burchill and Camilla Long
t the beach (and the bars)

A BRUSH WITH BAGHDAD

The underground artists
behind Iraq's renaissance

YOU EVIL BASTARDS...

WE'RE goING to CUT YOUR balls of

STay out of THIS ...

time is running for OUT you ALL.

PRAY TO GOD for FORgive ness

SCIENTISTS UNDER SIEGE

Doctors are facing death threats simply for suggesting
ME, the chronic fatigue illness, is all in the mind



UNDER FIRE
Sir Simon Wessely
had a panic button
installed in his office

this **man** **FaC**ED

Death **THRE**ats

and a **B**use

HIS **CR**iME ?

HE su**G**ESTeD

m.e. is a

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Leading scientists such as Sir Simon Wessely, left, are facing a sustained terror campaign — just for researching the causes of ME. Death threats and abusive emails are commonplace, and some scientists are now under police protection. By **Michael Hanlon**

PORTRAIT BY **RICHARD POHLE**



SOMEONE should PUT you On A TRead MILL UNTIL the exercise cures YOUR Sadistic or is it DELUSIONAL STATE of MIND

Professor Sir Simon Wessely lives on the front line of science. He does not deal with dangerous nuclear materials; nor does he risk his life meddling with lethal microbes. Yet this affable, chatty psychiatrist, who works at the Maudsley hospital in south London and was knighted for his work earlier this year, receives regular security briefings, has his mail checked and x-rayed by security staff and has had panic buttons installed in his office and home. He has been subjected to abuse and death threats, and one person rang him up and threatened to castrate him. He has done a lot of work for the military, helping to treat traumatised war veterans, but they are not the problem. Nor does he engage in animal experimentation. No, Professor Wessely's misfortune is to have entered the bewildering world of myalgic

encephalomyelitis, or ME — initials that strike fear into the hearts of doctors.

The story of ME activism is probably not one you will have heard much about, even though it is just as controversial as vivisection. Because not only do doctors who work in the field get a lot of grief, so does any journalist who covers the story. I was told by more than one colleague that I was mad to even think about writing about it. The story of ME is in fact the story of a war, a bizarre medical conflict that is about 30 years old and which shows little sign of abating. If you take the "wrong" side in this war, the one backed by the vast majority of scientists and doctors, you will receive abuse and harassment — or worse. Doctors have been accused, falsely, of child abuse. Death threats, veiled and overt, are common.

You don't even need to take sides. You can try to be scrupulously fair, but even so, a

word out of line, a slight deviation from what one side of the war sees as the gospel truth, will bring the furies down upon you.

On one side in the ME war are the doctors and scientists (most of them, anyway), and the bulk of the sufferers and their carers. These people believe that ME, which affects about 600,000 people in Britain, is a real and deeply mysterious disease that is often associated with psychological problems. The primary symptom of the disease is fatigue, which can leave sufferers bedridden and unable to work or study for months, or even years. Most doctors who treat ME — also known as chronic fatigue syndrome (CFS) — believe that certain treatments, notably cognitive behavioural therapy and exercise therapies, provide the best hope for many sufferers to get better. Earlier this year, a ground-breaking paper was published in

Psychiatrist

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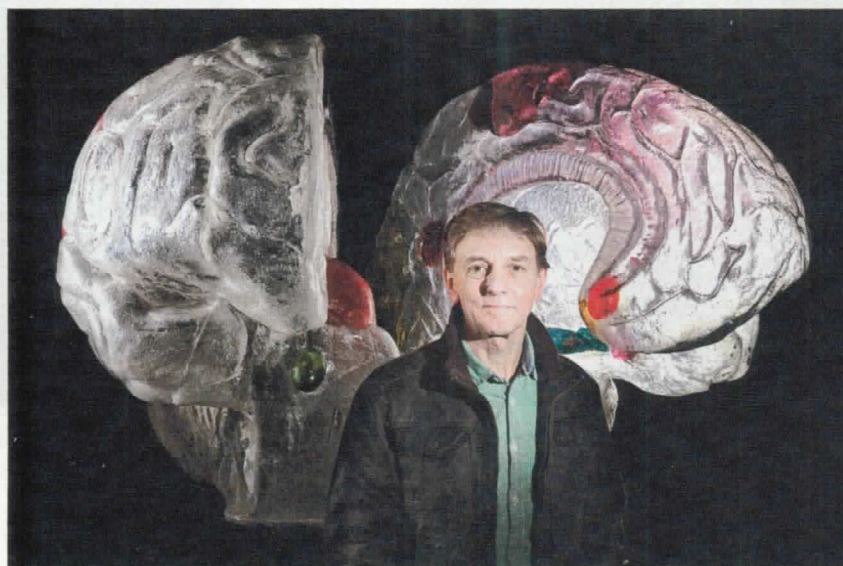
The scientists, led by Dr Judy Mikovits of the Whittemore Peterson Institute for Neuro-Immune Disease in Nevada, were

Top left: Charles Shepherd, adviser to the ME Association, says too much funding goes into researching

psychological treatments for ME. Below: Professor Colin Blakemore has argued the opposite

I understand that a list is often drawn up in these circumstances — to protect those who might be under threat from potentially

dangerous activists of any hue, not just those who are objecting to scientists undertaking research into ME. Some argue that circulating lists of activists — who in many cases might be mentally ill — has implications for civil liberties. But given the nature and scale of the threat, it is unsurprising that a set of the most worrying names exists — and it is at the disposal of the authorities. After much persuasion, I am shown a list of activists; names that crop up time and again on the ME forums. They are divided into three categories: militant, radical and active. Most ➡ ➡ ➡ ➡



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M.E. patients ?

are prolific posters on the various ME forums and Facebook pages (interestingly, Twitter seems largely immune).

In Britain the number of real extremists probably amounts to about 50-80 people (compared with the 25 or so hard-core animal-rights extremists identified by the authorities), yet they wield influence out of all proportion to their numbers.

The greatest anger — and level of threat — is reserved for apostates. One such was the British virologist Myra McClure, who works at Imperial College London. Professor McClure suspected that ME may be linked to that mouse retrovirus, making her an ME heroine. But in 2010, two years before Science published its retraction, she published a paper in which she showed that the XMRV-ME link probably had no scientific basis.

As a result, she was subjected to a campaign of horrible abuse and threats. One activist wrote relentlessly that he was imagining watching her drown. And a planned visit to America to speak at a conference was cancelled after “credible” death threats were made by American ME militants. I contacted her, through a friend of hers, to request an interview, to be told that she “really wants to put this entire nightmare behind her”.

The most high-profile combatant of the ME war in Britain is Wessely. He is a politically incorrect figure who pulls no punches when describing his tormentors, shaking his head in disbelief at their energetic vitriol. It is perhaps this impiety that has got him into trouble. “It is a religion, they have saints and apostates,” he says. “I was at a party with someone who did not know me and we got talking — it dawned on me it was time to back off.”

Wessely has been accused of just about every transgression going, including patient abuse and even, bizarrely, throwing a child into a swimming pool to check if his paralysis was genuine. One website describes him as “a dangerous madman... an obvious sadist”.

Many online postings compare Wessely to the Nazi death-camp doctor Josef Mengele, perhaps unaware that two of Wessely’s grandparents were murdered, on the same day, in Auschwitz and indeed may have been selected for the gas chambers by Mengele himself. The strangest thing, he says, is the fact that when it comes to his ME patients, he gets no complaints at all. “Yet when I switch on the internet I get all of it, this strange, weird world which does not reflect the real world of south London and my patients.” Wessely lists his

tormentors, who cannot be named for legal reasons. Convictions, for harassment or threatening behaviour, are difficult to obtain. The person who telephoned him to say, “We will come and get you soon”, did not leave a name or address, nor did the man who said he was going to “come and cut your balls off”.

Wessely says the “yuppie flu” tag — a common derogatory nickname for the disease — is a misnomer. CFS is not a disease of well-off malingerers, but, like most illnesses of mind and body, strikes disproportionately at the poor and the disadvantaged.

As for the 2009 XMRV paper, Wessely snorts with derision. He is sceptical of Mikovits, the American lead author of the paper, who was arrested in November 2011 for allegedly stealing material from her former lab and who spent a weekend in jail. She was released without charge.

“We all knew the paper was doubtful, those rates are far too high to be credible, and I was pretty confident it couldn’t be replicated. I was surprised to discover she was offering blood tests the same day the paper was released. Four weeks later, she pops up sharing a platform with Andrew Wakefield [the discredited British doctor who purported to show a link between the MMR vaccine and autism].” I am told there is a substantial crossover between ME activism and the anti-MMR brigade.

Another person who has incurred the wrath of ME extremists is the Bristol-based consultant paediatrician Esther Crawley. She runs the largest child ME treatment centre in the world, and was the first to recognise that the disease can strike at primary-school age. Crawley has devoted her life to treating sick children with this debilitating illness.

In 2010, Crawley’s team got a grant to investigate a treatment called the “lightning

process”, a controversial technique based on neurolinguistic programming. Not all doctors are convinced that the lightning process is credible, yet Crawley insists it is worth

investigating. “As children and families are receiving it, we need to know whether it works or not. If it doesn’t work or causes harm, we need to know,” she says.

“When we announced that we had received funding in 2010, the abuse started. It started with emails. And very difficult telephone calls. They all said we should concentrate on XMRV research.

“But the results of the XMRV research were terrible... Mikovits seemed to be implying that children go onto antiretrovirals [powerful drugs used to treat HIV infection, with strong side effects]. I thought this was completely immoral. I gave a talk in the West Country. I pointed out the massive conflict of interest. The talk was doctored and sent out as a DVD. It had me saying all sorts of things I didn’t say.”

Things soon got worse for Crawley — death threats, mostly online. Overwhelmingly busy, she hoped the threats would go away and initially ignored them, but eventually she began to take notice and even considered stopping her work. “I got nasty phone calls, nasty emails. This went on for about a year. I contacted the police. We had advice and training regarding parcels and so on. I am not going to overplay it, but I felt a bit anxious going home. I have children.” She showed me some of the emails. In one she is referred to as an “evil bastard”. Another reads: “To those of you who are responsible for preventing us sick ME sufferers from getting the help we need, wasting £5m on flawed bullshit and trying to discredit the real scientists who are trying to help us, you will all pay.” Is “you will pay” a threat? Crawley thinks it is.

Scientists often find their work attracts controversy, even hatred. Professor Colin Blakemore is an Oxford neuroscientist whose work on live animals has famously led to letter bombs, death threats and a barrage of abuse from anti-vivisection extremists. But even he, probably Britain’s most reviled researcher, was unprepared for the virulence of the ME campaigners. “I didn’t get bombed, it is true, but it was almost as bad,” he says. “This made no sense at all.” When Blakemore was in charge of the Medical Research Council, he made a series of recommendations about the funding of research into ME. After concluding that the bulk of cash would be most profitably spent investigating ➤➤➤

psychological treatments, there was outrage from the "community". "I remember being accosted at Liverpool railway station [by an angry activist]," Blakemore says. "I was completely unprepared."

The ME extremists have, in their own terms, been hugely successful. Only a tiny minority resort to actual threats. More often, scientists who engage in "psychological" research are subjected to a war of attrition. The claims always amount to nothing, yet dealing with them — and with hundreds of Freedom of Information (FoI) inquiries (as, by law, all publicly funded scientists are required to do) can eat up so much time that there is little left for actual research. No one argues that it is wrong for medical research to be open to public scrutiny; indeed, all the researchers I spoke to wanted their findings to be openly disseminated and discussed. But the desire to liberate information has had some unexpected and unwelcome consequences.

"A lot of people have left the field because of this," says an exasperated Professor Peter White, a psychiatrist at Queen Mary, University of London, and one of the world's leading researchers in the treatment of ME. "I spend a quarter of my time dealing with FoI requests, complaints and other harassment, rather than doing more research and treating patients."

In America, where ME extremism is even more virulent, doctors have been hounded out of their jobs. William Reeves, an American virologist and co-discoverer of the link between human papilloma virus and cervical cancer, gave up his CFS-related work at the Centers for Disease Control and Prevention after a torrent of vitriol was unleashed upon him for daring to suggest that the condition was "stress-related". After Professor Reeves died of a heart attack last August, there was celebration on some ME forums. "He's not really dead, it's all in the mind," was the posting on dailystrength.org.

While we can all agree that death threats and abuse are beyond the pale, might the ME activists (like the animal-rights extremists) have at least an intellectual point? It is certainly the case that the medical establishment has not treated ME with the same seriousness as other diseases, such as multiple sclerosis. Sometimes, it has been argued by patient groups, this has resulted in sufferers being denied disability payments. And the hypothesis that ME is, at heart, a viral infection rather than a psychiatric illness is scientifically respectable and certainly worth investigating. Viruses, rather than

lifestyle issues or genetics, are now suspected to be linked to a host of conditions, from schizophrenia to heart disease. There is no *prima facie* reason to believe ME is not the same and, while XMRV is not the cause, another virus could be. Last month, a new initiative, the UK CFS/ME Research Collaborative, was launched to investigate all aspects, including potential causes and treatments, of this enigmatic disease.

According to White: "Many of our patients feel that their doctors have not served them particularly well. They have a real need to legitimise their illness as something beyond their control. There is real anger at not being believed."

Yet mental illness is as "real" as influenza or cancer. Try telling someone with severe paranoid schizophrenia that they are not ill. Are ME extremists not simply denigrating those with acknowledged mental illnesses by pouring scorn on psychiatric diagnoses?

One high-profile ME spokeswoman is the sociology lecturer Angela Kennedy, who insists she does not support the antics of the violent militants. "As an academic myself, I unreservedly condemn any harassment and abuse of researchers. However, raising reasonable objections to something through legitimate means — such as FoI requests or official complaints — is not harassment or abuse." Indeed, she claims, the abuse is often in the other direction: "Hate speech is being waged against people with ME."

Few active ME campaigners are willing to comment on the record. One person who did agree to talk was Laurence Swift, a Kent-based ME sufferer and former veterinarian whose name crops up on many forums. He clearly holds Wessely and his colleagues in contempt, and thinks he has identified the true nature of this disease. "You'll never get rid of ME. It's a retrovirus, it gets into your brain, into your DNA," he says. "I saw a doctor. Hopeless. Gave me antidepressants. Two months. Didn't work. Gave up."

Swift's life has been blighted, he says, by his disease, which he says he caught through having sex with his girlfriend in the early 1990s. He was struck off by the British Veterinary Association after inadvertently killing a cat, and was convicted of indecent assault on a 12-year-old girl in 2004 — both incidents precipitated, he says, by a combination of ME and the heavy drinking he fell into in an effort to self-medicate.

He talks of a "government conspiracy" to cover up an undiagnosed epidemic of "hidden Aids", and describes Wessely as "the ringleader, the nemesis, a villain". What about people who send abusive emails and so forth? "There is no need for that..."

So what on earth is going on? There is, clearly, a (very) small group of people who are using ME as a way of defining themselves and who can cause disruption out of all proportion to their numbers. "It's quite cultish," says Tracey Brown, managing director of Sense about Science. She lists the defining characteristics of the extremist: "Predominantly female, intelligent, in her forties. Brighter than their jobs and education suggest they are." She believes that the activists, as well as comprising genuine sufferers, also attract hangers-on, people seeking a "cause".

Wessely doubts whether most of the real extremists even have ME at all. "The people doing this are anti-treatment. I do not think they have CFS. It makes no sense... If you do not get better you feel resentment at people who do, and resentment at the treatments that helped them. A lot of patients who go to our clinic find the patient groups threatening."

Plenty of experts are doubtful about the "psychiatric" approach, but they shudder at the vitriol poured on people like Wessely. Dr Charles Shepherd, medical adviser to the ME Association, one of the largest and the oldest of the UK patient-support groups, says he is angry that so little money is spent investigating non-psychological causes and treatments for ME, but "unequivocally condemns" those who send threatening emails.

As Fiona Fox says: "The terrible irony is that the very scientists who treat CFS patients, who understand how debilitating this condition can be and who are dedicated to finding effective treatments, have been silenced."

I believe that ME, whatever its true cause, is being used as an anvil by certain disturbed people on which to hammer out their particular beef with the medical profession, and science in general. It takes a lot to go from a profound intellectual disagreement over research funding to producing propaganda videos and making even vague death threats.

I understand why someone would want to attack scientists who experiment on monkeys, even if I do not agree with them. But this is a peculiar phenomenon in its own right, quite separate from the disease, with which it seems to have only a tangential relationship. Perhaps someone should be brave enough to try to research its cause ■