

EDITOR'S CHOICE

Ending the stalemate over CFS/ME

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“Why can’t chronic fatigue syndrome/myalgic encephalitis be like other common chronic conditions where patients, carers, doctors, and researchers work together to pose research questions, gain understanding, and—in the absence of clear explanations and cures—at least find ways to respond to patients’ needs?” So asks *BMJ* deputy editor Trish Groves after attending this year’s Invest in ME conference (doi:10.1136/bmj.d3774). She had accepted the organisers’ invitation with an open mind, heartened by the conference theme: “A case for clinical trials.” But emotions were running high. The PACE trial had just found that cognitive therapy and graded exercise therapy can help, to the fury of patient groups who dispute a psychiatric basis for the condition. Meanwhile serious doubts were growing over a study that had been welcomed by the same groups because it claimed to have found a viral cause. (The editors of *Science* have since published an expression of concern, after the failure of other studies to replicate the finding and evidence that the virus was a laboratory contaminant; *BMJ* 2011;342:d3505). Instead of any clear discussion of how to expand the evidence base for diagnosis and treatment, Groves heard about a disparate collection of small scale laboratory studies. “By the end of the day the case for clinical trials had not been made,” she writes.

Nor is there much hope that it will be, unless we can find a way through the current stalemate. As Groves says, most patients and campaigners believe that only drug treatments based on biological causation will help, and most doctors believe that patients who won’t try graded exercise or cognitive therapy are untreatable. The result is an unproductive standoff in which, as

Nigel Hawkes describes, all progress is being stifled by increasingly aggressive intimidation of researchers (doi:10.1136/bmj.d3780). Online abuse, personal threats, harassment, and referrals to the GMC have made the field a no go area for many. Leading CFS researcher Simon Wessely has moved on to investigating the problems of war veterans. “I now go to Iraq and Afghanistan, where I feel safer,” he says.

A small minority of extremists has hijacked this important debate. But the quiet majority of patients must make sure that their reasonable voices are heard. Ollie Comes has suffered from CFS/ME for 12 years. He gives a clear account of living with “an overwhelming, permanent, and intense malaise.” But he also makes a clear and reasonable request: that the UK consider adopting the narrower Canadian definition for CFS/ME, which distinguishes patients with “delayed, post-exertional malaise and fatigue” from the broad range of people presenting to their doctors with tiredness (doi:10.1136/bmj.d3836).

Despite being heckled by delegates, Trish Groves has offered to attend next year’s Invest in ME conference, to talk about the kinds of research questions and study designs that might attract national research grants and be published in mainstream medical journals. And there is hope that such research may be on its way. As Nigel Hawkes explains, the MRC has set aside £1.5m for research into CFS/ME. To encourage new entrants, the successful proposal must include at least one scientist who doesn’t already work in the field.

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