

## PE1651/NNNN

Fiona French submission of 3 January 2018

I wish to submit further written evidence following on from my previous submission (PE1651/H) which gave a detailed account of my being prescribed drugs of dependence (a benzodiazepine and various antidepressants) for almost 40 years and enduring a horrendous withdrawal (3.5 years in bed) which has left me cognitively and physically disabled. It is abundantly clear that I have sustained some sort of brain damage due to withdrawal. Yet I have had to endure denial and evasion from most of the doctors I have consulted. I wish to demonstrate the way patients like myself are being (mis-) treated and the immense distress this causes to those of us who have already sustained significant iatrogenic harm. I also have to ask the question “Why?” and I consider some possible reasons.

At the time of writing my previous submission, I had consulted four GPs, a psychiatrist, a private neurologist and a neurophysiologist. None of these doctors acknowledged that my symptoms and disabilities were due to benzodiazepine withdrawal. Both the psychiatrist and private neurologist, the “specialists”, flatly denied it. The GP who advised me to stop taking Nitrazepam after 40 years has now stated in writing (responding to my complaint) that he planned to taper me off over a matter of weeks. This would have been a very dangerous strategy indeed and is against the NICE guidelines on benzodiazepine withdrawal.<sup>1</sup> In fact, I tapered off over three months and the results have been catastrophic. He further states that his experience lies within the Substance Misuse Service and **is therefore not relevant to my case**. Yet, at the same time I am being referred to this service, as advised by NHS neurologist and Medical Director of local health board.

The toxic effects of benzodiazepines have been extensively documented in the medical literature for decades and the effects of withdrawal also, most notably by Prof Heather Ashton.<sup>2</sup> And yet, in 2011, Dr Clare Gerada, then Chair of the Council of the RCGP, stated on national radio that the withdrawal effects had been “overstated”. She was heavily criticised by Prof Ashton, among others.<sup>3</sup> She further described the 30 years taken to reduce benzodiazepine prescribing as a “success”. This is hardly a word the victims of these drugs would use. Benzodiazepines have been one of the biggest prescribing disasters the UK has ever seen. I have gathered together documentary evidence of the many harms caused by benzodiazepines including many harrowing personal testimonies.<sup>4</sup> The campaign for services and for justice, conducted over the past 30 years in England, is already extensively documented at The Resource Site for Involuntary Benzodiazepine Tranquilliser Addiction, Withdrawal and Recovery. Appropriate withdrawal services were never provided and many patients were left to their fate, as we are today.

Given this long history, why should it be so very difficult to obtain an accurate diagnosis of my symptoms? The psychological distress that I have had to endure over the past few years due to systemic denial / avoidance has been horrendous. Either my doctors have no idea the effect their denial and silence would have on me or they were prepared to cause me immense distress in order to obscure the damage done by the drugs and drug withdrawal. I assume it is the latter as they have witnessed my deep distress, they know the reasons for that distress. Even in the midst of this distress my GP was very keen to tell

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<sup>1</sup> <https://cks.nice.org.uk/benzodiazepine-and-z-drug-withdrawal>

<sup>2</sup> <https://www.benzo.org.uk/pws04.htm>

<sup>3</sup> <http://www.bbc.co.uk/programmes/b012wxxw#synopsis>

<sup>4</sup> Action on Prescribed Drug Dependence (Scotland) – Benzodiazepines’ - 21 October 2017

me I might need aggressive treatment for possible metastases (which I do not have). I could not believe a doctor could be so callous or so ignorant of human emotions.

In desperation, I sought the help of a doctor outside the UK/NHS. I consulted privately (by Skype) with Dr Terry Lynch (see Dr Lynch's written submission for credentials). I had a very straightforward consultation with him and he confirmed, without hesitation, that all my symptoms were classic symptoms of benzodiazepine withdrawal. He provided a three-page letter for my GP which I duly passed on by email. The letter has never been acknowledged. My GP has since informed me that he prefers not to communicate by email. I doubt the letter was added to my medical notes as I requested. I have never asked.

I have also consulted with an NHS neurologist. Two days prior to the consultation I was visited by a former GP colleague whom I now regard as a friend. I was in a very distressed state and he was clearly upset to see me that way. I am in no doubt that he contacted the neurologist and asked him to help me out. I very much had the sense that the neurologist had been "primed". The consultation ran fairly smoothly. He acknowledged that my inability to function normally was most likely due to the "shock of withdrawal from Nitrazepam". But his "diagnosis" was once again "neurological functional symptoms", the same "diagnosis" given by the private neurologist. However, he also stated that I had been suffering from "chronic fatigue syndrome" as "diagnosed" by the psychiatrist in 2014. Yet he stated in letter to GP "it seems clear that coming off Nitrazepam .... may have invoked lots of physiological changes and been a trigger for functional symptoms also."

"Neurological functional symptoms" may seem like a reasonable descriptive label to the layperson but of course it neatly avoids linking my symptoms to benzodiazepine withdrawal. For many years protracted benzodiazepine withdrawal syndrome was an accepted term so what has changed? Patients harmed by drugs of dependence wish more than anything for that harm to be acknowledged, recorded and discussed just as one would expect with other medical conditions. For the harm to be investigated would be even better.

Prof Sir Simon Wessely, Professor of Psychological Medicine, King's College, London is a keen advocate of psychological explanations for "unexplained" physical symptoms including ME/CFS and Gulf War Syndrome, despite considerable bodies of evidence to the contrary.<sup>5</sup> And so it seems that patients suffering iatrogenic harm are being drawn into this psychological net. After all, we are an inconvenience to the medical profession. He is the spouse of Dr Clare Gerada, mentioned above.

Dr Jon Stone, neurologist, Edinburgh is an expert in neurological functional symptoms. <http://www.neurosymptoms.org> At a recent conference, <https://www.fnd2017.org>, Sir Simon Wessely was a speaker on shell-shock. He co-authored a recent article in the BMJ, to which I responded (see e-letters). (*BMJ* 2017;359:j5621) The article states:

"Current models of functional neurological disorders are returning to concepts that were popular before the era dominated by Freudian (psychological trauma) theory. It is increasingly accepted that beliefs about bodily dysfunction can trickle down the hierarchical neural architecture of the brain to produce "expected" symptoms beyond the conscious control of patients."

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<sup>5</sup> 'The incalculable contribution to medical science of Regius Professor Sir Simon Wessely: a thirty year retrospective' Margaret Williams, 28 December 2017.

And so patients who have sustained iatrogenic harm from prescribed drugs are being assigned “diagnostic” labels which have a psychiatric basis. Not that the patients will be informed of this fact, just as they were never informed of the risks of the drugs. The recommendations to GPs and neurologists are to acknowledge patients’ symptoms, do a few cursory tests, and send them home or refer them for some therapy so they can learn to think differently about their symptoms. This is designed to avoid unnecessary healthcare expenditure. My GPs have made it clear they do not wish to talk about the damage I have sustained. As my main concern is the damage done by the drugs, there seems no point now in seeking any further help from them. So I will indeed save the NHS any further expenditure on my behalf. My physical and mental health is clearly of no further concern.

The same approach is being used for patients whose withdrawal symptoms and/or side effects are dubbed “Medically Unexplained Physical Symptoms” or “MUPS”. This term encompasses ME/CFS, IBS, fibromyalgia etc. GPs are being advised to acknowledge patients’ symptoms but to remain “agnostic about aetiology”.<sup>6</sup> This is astonishing. There is ample evidence that ME, for example, is a neurological disorder and the insistence over several decades that it is largely psychological has caused immense distress and harm to many ME patients.<sup>7</sup> It is also deeply worrying that the diagnostic questionnaire for MUPS, the PHQ-15, covers most of the side effects and withdrawal symptoms associated with antidepressants and was developed by psychiatrists in association with the drug company, Pfizer, as was the PHQ-9 for depression. Perhaps the PHQ-15 was designed with drug side effects and withdrawal symptoms in mind. It has indeed been predicted that many patients suffering physical symptoms would indeed be drawn into the psychiatric diagnostic web (*BMJ* 2013;346:f1580).

I asked the NHS neurologist if my various cognitive problems were due to the adverse effects of the drugs. I did not receive a response; this is a common reaction when I ask such questions. I was advised I should seek a referral to the Substance Misuse Service. After four years, I am still seeking a conversation with a doctor about the toxic effects of the drugs I have consumed for almost four decades on medical advice. My request for an out-of-region referral to consult with Prof David Healy was not granted. And so the rather pointless merry-go-round continues and for what purpose? To save money and conceal the facts. Those of us whose lives have been destroyed will not accept this, we are worth more than this, far more.

The Scottish Government states that it takes prescribed drug dependence seriously. I see little substantial evidence of this. Even benzodiazepines continue to be prescribed long-term outside prescribing guidelines<sup>8</sup>. There are no adequate tapering guidelines for antidepressants and they have been on the market for 30 years. NICE guidelines are based on short term studies. And where are the withdrawal support services for patients dependent on prescribed medication? Pharmacists are not in a position to deal with this immense problem. Where is the expertise in Scotland to deal with the neurological damage to patients? Why do patients have to battle for a referral to Prof David Healy in Wales or to consult outside the NHS? Why are there no statistics on the length of time patients have

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<sup>6</sup> “What do guidelines and systematic reviews tell us about the management of medically unexplained symptoms in primary care?” - BJGP Open

<sup>7</sup> “Straight-jacketed by Empty Air - Psychiatry’s long and shameful involvement in Myalgic Encephalomyelitis, Stonebird.

<sup>8</sup> Benzodiazepine and z-hypnotic prescribing for older people in primary care: a cross-sectional population-based study, The National Center for Biotechnology Information.

been consuming drugs of dependence? Why was the policy to reduce antidepressant prescribing abandoned in 2010? And why are we witnessing systemic denial of this entire problem, particularly the iatrogenic harm resulting from consuming these drugs?