PE1651/RRRRRRRR
Fiona French submission of 9 May 2018

In my previous submissions to the Public Petitions Committee (PE1651H/NNNN/TTTTTT) I outlined my medical history, withdrawal experiences and resulting iatrogenic harm. It is over five years since I tapered off Nitrazepam and three years for Venlafaxine. I consumed Nitrazepam for nearly 40 years and various antidepressants for about 35 years. I continue to recount my story because it reflects the many ways in which the medical profession seeks to avoid responsibility for iatrogenic harm resulting from drugs of dependence. This results in patients like myself being passed from pillar to post and back again, causing pain and distress and costing the NHS unnecessary expenditure at a time when the public is told that the NHS cannot afford growing demand on its services.

I remain in bed for the most part, I am still unable to stand for more than 10-15 minutes, I rarely get outside and walking is very difficult. To have written acknowledgement that my disabilities are iatrogenic in nature is very important. However, I also wanted it made clear, in writing, that I should not be prescribed benzodiazepines or antidepressants again should I lose capacity to consent to treatment in the future. I know this will be no guarantee of protection but together with an Advanced Directive I hope it might help.
I have had a great deal of time to reflect these past few years, and what strikes me is that I have had an adverse reaction to many medical interventions over the years, starting off with the adverse reaction to Nitrazepam in 1975, epileptic fits from antidepressants in 1979/80 as well as many other, less serious but debilitating adverse effects including an admission to hospital after being prescribed Prozac. After a colonoscopy in 2010, I was in bed for many months, very unwell indeed, and was unable to return to work. Even ten years of IBS was eventually diagnosed by a chiropractor as resulting from my misaligned spine **pressing on nerves** leading to the gut. The connection between all these issues is my central nervous system, but no doctor will have made that connection. I doubt they would be interested. They have always been more interested in my state of mind.

On 2nd February 2018, I consulted with an addictions psychiatrist at the Substance Misuse Service. I state again that this is not an appropriate service for patients who have been prescribed drugs of dependence and I strongly object to the fact that this is the only available expertise available to me regarding benzodiazepines. The consultation went well, as outlined in previous submission. I then waited patiently for a copy of the letter to my GP. I phoned several times and was advised the consultant was busy or out of town or hadn't yet signed the letter. I phoned again after 2.5 months and was advised "There is no letter". I submitted a complaint to NHS Grampian. The consultant was contacted very quickly after I tweeted NHS Grampian and copied in the press. I received a letter on 8th May 2018, over three months after the consultation took place. The consultant also phoned me to apologise for the long delay and for any distress caused. I can only speculate as to the real reasons for the three month delay. Unfortunately, the letter contains factual inaccuracies and I have returned it asking that these be corrected. I was particularly upset to read "Fiona undoubtedly views the majority of her difficulties as related to long term benzodiazepine **MISUSE** …" but appreciate this was most likely a simply mistake by a psychiatrist working in SMS.

The letter makes the following statement which I do not disagree with. "it would be reasonable to assume that the majority of her difficulties are indeed related to protracted (benzodiazepine) withdrawal symptomatology." However, it then says "I could find no evidence of any other major psychiatric illness on interview". I can only assume then that protracted benzodiazepine withdrawal syndrome is classified as a major psychiatric illness

but I have asked for clarification on this. I am aware that drug dependence and withdrawal are listed in the Diagnostic and Statistic Manual and are therefore psychiatric diagnoses. Consequently any issues related to drug dependence falls under the remit of the Minister for Mental Health. The sheer scale of prescribed drug dependence in Scotland is staggering and I see no strategy being developed to tackle it and I question whether extended roles for pharmacists will put even the smallest dent in the problem.

The letter also states "She informed me that she was not looking for any recompense from the NHS about this but was very keen to ensure she was not prescribed benzodiazepines in the future because of the harm she **perceives** they have done to her." So once again it is only my perception that I have been harmed which rather contradicts his earlier statement about withdrawal symptomatology. He did not state that I am now very damaged and could not cope with attempting legal action, the stress would undoubtedly cause me further harm. Nor did he state that it is now 4.5 years since becoming bedridden and I am outside the 3 year time limit for legal action, no doubt the various doctors I have consulted so far intended this to be the case. The letter does, however, state that I should never be prescribed antidepressants or benzodiazepines.

Strangely, there is only one sentence in the letter which refers to my consumption of Venlafaxine and it is entirely inaccurate. "She was prescribed Venlafaxine for a period of time but this did not appear to improve her situation and to her thinking it worsened things." The context of this sentence implies that I was prescribed it to help with withdrawal from Nitrazepam which is incorrect. There is no mention of the fact that I have consumed a variety of antidepressants over 35 years, suffered many adverse effects from them, that I tapered off Venlafaxine between August 2014 and June 2015, after tapering Nitrazepam early in 2013. I have requested that these **facts** are recorded in a revised letter. I suspect that these omissions are deliberate.

When I suggested to the consultant that antidepressants were causing many harms to patients and that they were as bad as benzodiazepines, he responded that this was not his area of expertise. So clearly if I wish to discuss the ramifications of long-term antidepressant dependence, withdrawal and iatrogenic harm, I would need to seek yet another referral to another consultant, presumably another psychiatrist, but not an addiction specialist. I find this utterly astonishing. The Scottish Government states that it takes prescribed drug dependence seriously. It certainly does not seem that way to me. Quite the opposite. Do we not have any expertise in Scotland such as that provided by Prof David Healy in Wales, someone who can deal with the combined issues of dependence, withdrawal and iatrogenic harm from both benzodiazepines and antidepressants or is it simply the case that no one is willing to take responsibility for what is happening to patients here in Scotland and the harm that has been sustained?

I believe the issues raised by my ongoing personal account are mirrored by the silence and denial emanating from RCPsych and RCGP. RCPsych has rejected the complaint regarding the letter in The Times and an appeal has been lodged.. (1) I listened with dismay to a recent podcast circulated by the Royal Society of Medicine in which Prof Simon Wessely is interviewed along with his wife, Prof Clare Gerada, on the subject of antidepressants.(2) I was dismayed particularly by Prof Gerada"s statement "… I do talk to people who **claim that their lives have been ruined by antidepressants**. I was astonished that after 26 years as a practising GP she could " … **count on one hand the number who have gone on to have long term problems withdrawing from antidepressants or problems coming off antidepressants."** I was also surprised that she would say **"So, far, far, far more patients have problems coming off**

benzodiazepines …" as she had previously said on national radio that benzodiazepine withdrawal was overstated. (3)(4) And yet again she suggested that every time we focus on withdrawal, patients tell her they are ashamed of taking antidepressants and afraid to admit they are depressed. This is intended to silence the voices of campaigners.

By contrast, I was extremely heartened to hear the words of Dr Dee Mangin, Family Physician and Associate Professor, McMaster University, Ontario, Canada and co-founder of RxISK. Dr Mangin has conducted research into antidepressant drug dependence and withdrawal and spoke recently on CBC radio.(5) She said:

"Patients are the experts in the way medicines affect them. Just because it's not written in the drug data sheet, it doesn't mean that it's not a real experience. When numbers of patients are telling us the same thing, we fail to listen to them at our peril."

"I realized that I didn't have the data I needed to have a conversation with a patient about how long we should carry on (taking antidepressants), when we should stop, how we should stop," she said. "So we have a big chunk of people in the population taking these medications in the long term and really there are no studies in primary care to support that."

"I think that one of the difficulties patients have faced over the years is that reporting these symptoms to friends or family or their doctors and not being believed. To have the symptoms attributed to some sort of psychological illness rather than being heard or acknowledged."

"I think initially the most important research was done by patients who noticed these clusters of symptoms, who noticed the similarity of what they were experiencing and started to talk to each other online."

Approximately 20% of adults is now consuming an antidepressant in Scotland and the UK has one of the highest rates of consumption according to OECD statistics.(6)

The Alberta College of Psychologists in Canada was very happy to deal with my recent complaint about one of its members whose comments in a public online forum concerned me greatly and quickly arranged a tele-conference with me. I was very pleased to have my concerns listened to and addressed appropriately. I am disappointed that I have not been afforded a similar courtesy by those in positions of responsibility in my own country.

(1) Professor John Read: UK Royal College of Psychiatry Dismisses Complaint, Mad in America, 1 May 2018

(2) https://videos.rsm.ac.uk/video/rsm-health-matters-podcast-episode-1---antidepressants-antibiotics-and-the-gender-pay-gap

(3) https://www.bbc.co.uk/programmes/b012wxxw#synopsis

(4) https://www.benzo.org.uk/pws04.htm

(5) http://www.cbc.ca/radio/whitecoat/i-was-sobbing-uncontrollably-patients-say-antidepressants-difficult-to-quit-1.4658787

(6) OECD (2017), "Antidepressant drugs consumption, 2000 and 2015 (or nearest year)", in *Pharmaceutical sector*, OECD Publishing, Paris, http://dx.doi.org/10.1787/health_glance-2017-graph181-en.