

PE1651/TTTTTT

Fiona French submission of 4 February 2018

Since submitting my previous written statement (PE1651/NNNN) I have with great reluctance attended the Substance Misuse Service. I felt very uncomfortable having only ever taken drugs as prescribed. The consultant psychiatrist gave a full and unequivocal **verbal** statement that my current disastrous state of health is entirely the result of 40 years of prescribed Nitrazepam and a far too rapid taper (3 months). He said I should have tapered over **one to two years**. My GP stated in writing that he had planned to taper me off over a matter of weeks, this is contrary to NICE Guidelines. This level of ignorance is wholly unacceptable. The psychiatrist said he would stand by his opinion should I wish to take legal action. He also advised nothing could be done by way of treatment.

He confirmed long-term consumption of benzodiazepines causes dementia-like symptoms, of which I have many. At no point **over the past 40 years** did any doctor ever inform me this would be the most likely outcome. My future looks very bleak indeed. This was the 9th doctor I had consulted in Scotland (4 GPs, psychiatrist, two neurologists (private and NHS) and a neurophysiologist. I am utterly appalled that it has taken four years to achieve an accurate and honest assessment of my dreadful state of health. It has cost me over £1,000 in the process in private consultations, tests and MRI scan. All utterly fruitless because of medical denial and downright dishonesty. I have also of course consulted Dr Terry Lynch, GP in Ireland who knew exactly what was wrong with me at first consultation. Time has been taken up with the GP practice complaints procedures as well as NHS complaints processes. And all because the medical profession wanted to conceal the truth about what had really happened to me. Most patients would of course have given up.

In despair, I recently contacted Dignitas in Switzerland. Other affected patients have also contacted them. I was appalled when they sent me an information pack for the "mentally ill". They informed me that "protracted benzodiazepine withdrawal syndrome", a term I had in fact not mentioned, is a psychiatric diagnosis. So it seems that anything associated with drugs of dependence carries a psychiatric diagnosis. This is unlikely to be made explicit to the patient. Side effects, withdrawal symptoms are regularly mistaken for "mental illness". There is no escape from psychiatry's clutches it would seem.

Response to Petitions Meeting of 18 January 2018 - Members of the online prescribed harmed community listened with great interest to the discussion. We are very grateful to the Committee members for their careful preparation and probing questions. There was considerable dismay when listening to many of the responses given by Dr John Mitchell, Government Adviser and Maureen Watt, Minister for Mental Health. It was felt that neither demonstrated any real understanding of the issues surrounding iatrogenic harm and brain injury and did not express any particular concern about the many serious issues raised in this petition. This left those watching with a poor impression of our Scottish Government.

The language used by the Minister was similar to that used by GPs and consultants in their letters to each other when patients have run into serious trouble with drugs of dependence. For example, the Minister said "... the petitioner feels that it has

happened”, the implication being that it may be untrue. GPs write “the patient believes this, the patient believes that” with the implication being the patient's symptoms or the cause of those symptoms may exist only in the mind of the patient. This causes so much pain and distress. Their purpose is of course to deflect attention away from their own failings. This sort of language is totally unacceptable.

Dr Mitchell suggested that the patient-reported life-changing effects were rare but was unable to cite any research evidence to this effect. He said it would be too difficult to determine. I agree it would be extremely difficult. GPs and consultants more often than not fail to record the fact that drug consumption and/or withdrawal has been the cause of the life-changing event. In my case only “chronic fatigue syndrome” and “neurological functional symptoms” would be found to date. So far, the nature and extent of my disabilities are not recorded and symptoms that are recorded are trivialised.

I can no longer read, it is a great struggle. I can stand for very short periods, walk for short distances with a walking frame and require a wheelchair in a supermarket. My brain does not properly compute my surroundings. I have difficulty processing speech. My fingers are partly numb. My long-term memory is very poor. I have huge difficulty doing small household tasks. I trust that my most recent consultation will result in a written record of these disabilities. I have twice been refused an assessment for dementia but what was not said was that I have benzodiazepine-related dementia-like symptoms. Dr Mitchell suggested that support would be available to patients like myself. I can assure the Committee that I have been offered nothing apart from a few sessions of physiotherapy. This is completely inadequate given the state I have been left in and is totally unforgivable. Hydrotherapy did not materialise. I refused any sort of psychological therapy as it is entirely irrelevant. My GPs have refused to discuss the cause of my disastrous state of health. My own attempts to rehabilitate myself caused further catastrophic effects as I forced myself to walk putting more pressure on my brain.

The Minister reiterated the Government’s position that it takes prescribed drug dependence seriously. The Minister also said that the year on year increases in antidepressant prescribing are associated with better awareness of mental health issues, reduced stigma and better diagnosis and treatment of depression. Whilst we would all welcome reduced stigma around mental health, the Minister did not present any evidence to support her views. A research study in England has demonstrated that anti-stigma campaigns have less impact on public opinion than had been hoped. (Smith M (2013) Anti-stigma campaigns: time to change. BrJPsych, 202 (s55) s49-s50)

Dr James Davies, Roehampton University has conducted research for the APPG-PDD and estimates that 800,000 patients in England have been taking antidepressants for more than two years and do not clinically require them. There is no reason to believe that Scotland is any different but there are no publicly available statistics to refer to as far as I am aware. Of course patients have to withdraw whatever the reason for initial prescribing unless they stay on the drugs for life.

On 24 January, Public Health England announced a year-long review of PDD (Prescribed Drug Dependence) such is their concern. It is therefore astonishing that

there is no such concern in Scotland where more than one million patients are being prescribed benzodiazepines and antidepressants. All should be given the opportunity to taper off these drugs if they so wish and support services should be in place to help them. Dr Mitchell referred to a study “Key Information on the Use of Antidepressants in Scotland”. This examines prescribing data for a million patients and concludes there is no evidence that GPs are prescribing these drugs for no good reason. However, it does not consider how long patients have been kept on the drugs. It is known that the longer patients are on the drugs, the more difficult it can be to withdraw from them.

Dr Mitchell referred to RCPsych website guidance on antidepressant discontinuation. Discontinuation syndrome is the term preferred by the drug companies to give the impression that withdrawal is less problematic than for benzodiazepines. Yet, the experiences of many patients would suggest that antidepressant withdrawal can be every bit as horrendous as benzodiazepine withdrawal. Dr Mitchell accepted uncritically the results of a survey of 817 patients, conducted by RCPsych. Few details were given about how the survey was conducted or how long respondents had been on the drugs. There are thousands of patients online reporting a wide range of problems with withdrawal so surely that is equally relevant evidence. Dr James Davies, Roehampton University has conducted a survey of the online prescribed dependent community. See Council for Evidence Based Psychiatry: 2017 Prescribed Drug Withdrawal Survey.

“The responses we received were as moving and informative as they were upsetting. The true scale of the suffering generated by injudicious prescribing and medication harms was evident on every page.”

Advice given by RCPsych is in line with NICE guidelines on antidepressant tapering which is based on short-term studies. The tapering advice is too fast. A clinical trial in The Netherlands was a failure because the Dutch Guidelines are also too fast. (Eveleigh et al (2017). BJGP Open, 2017-0169) A second clinical trial is to be conducted. Prof Tony Kendrick, Southampton University, is conducting a trial also looking at tapering methods. He believes that between a third and a half of people taking antidepressants could stop with appropriate help. The study is funded for six years, patients desperately need help right now.

Patients require the tools to taper slowly and accurately. It is extremely difficult to cut small tablets into equal pieces or to open up capsules and take out beads or powder. Patients are refused liquid preparations by GPs on grounds of cost or because GPs do not see the need to taper slowly. The tapering strips can only be obtained from The Netherlands via the internet at some considerable cost to the patient. A prescription is required and GPs may not agree to provide one. As things stand at present, setting up a helpline would be very difficult because there is no one with sufficient knowledge of tapering and withdrawal to staff that helpline. Existing NHS helplines and out of hours services are also of little use to patients as evidenced by responses to an online survey conducted by myself for the BMA, as requested by PHE (results available on request). GPs clearly do not have sufficient education and training in this area, as stated in the BMA report of 2016 on PDD. It is astonishing that there are addiction clinics dedicated to the problems of illegal drug addiction but no such facilities for PDD patients, when many more patients are

affected by the latter. It is alarming that after decades on the market, no research has been conducted to date into safe tapering methods for antidepressants. It is a scandal that we are in this situation after the horrendous disaster caused by benzodiazepines from the 1960s onwards, ruining countless lives.

So to conclude I can see absolutely no evidence whatsoever that the Scottish Government takes the issue of PDD seriously. To preside over ever-increasing rates of prescribing whilst failing to take any steps to ensure patients can safely withdraw is to me a complete dereliction of duty. The ignorance of GPs around this subject is one of the main causes of the catastrophic life-changing events that are reported. It certainly was in my case. I can only imagine that is why the evidence of such events is being kept well hidden and therefore can never be quantified.