PETITION 12235 – PRESCRIPTION DRUG DEPENDENCE AND WITHDRAWAL – RECOGNITION AND SUPPORT BY STEVIE LEWIS JANUARY 2018

Second submission in response to the letter from the Cabinet Secretary for Health and Social Services dated 04 January 2018

TO EFFECTIVELY SUPPORT PATIENTS WITH PRESCRIBED DRUG DEPENDENCE

I am going to address the points in reverse order, and focus first on addressing the subject of appropriate help for those who have already been harmed by prescribed drug dependence (PDD). Mr Gething has not answered your question. You may have noticed that his letter is broadly a rehash of what the previous Minister, Rebecca Evans said. I don't see what more I can do in addition to my previous submission other than stand on the rooftops with a megaphone and shout: "We have not misused. You are neither recognising what has happened to us nor supporting our recovery."

In support of my frustration I would urge you to scan through the document to which Mr Gething refers (Substance Misuse and Delivery Plan 2016-18)[1] and see where you think policy statements are made regarding plans to help those whose health has been damaged from taking prescription drug medication in line with their doctor's advice. It is a document about misuse.

To repeat myself from my last submission, I recognise that it suits the Welsh Assembly government to chunk this issue up into an overall heading of "Substance Misuse", but I will say again that it is damaging and inhuman to do so and hides a truth that I believe people need to be aware of. The word "stigmatising" is bandied liberally around the subject of mental health but I am inclined to use that word here. Forcing patients who have been harmed by drugs that they took under their doctor's advice under the umbrella of "substance misuse" is stigmatising and branding them inaccurately and unjustly, and will continue to result in patients not getting the help they need. It is only right and proper that PDD is openly acknowledged, appropriately resourced and supported, and there is already a team in place in North Wales that can provide a template of care. That template of care differs from the service provided for street drug misuse or POM/OTC misuse. I am requesting the setting up of a separate arm to achieve that aim Wales-wide, funded from the "almost £50 million annually" available as stated by Ms Evans in November 2017.

TO APPROPRIATELY RECOGNISE PRESCRIPTION DRUG DEPENDENCE

I am pleased to read that the Cabinet Secretary for H&SS will ask his officials to investigate the scope and need for further guidance over and above that already in existence for antidepressants.

This may mean that the Committee considers their work to be done in the case of this aspect of my petition. I would like to take the opportunity to urge you to continue to press Mr Gething to agree to treat antidepressants, especially SSRIs and SNRIs, with the same caution as is currently applied to hypnotics and anxiolytics. It is extremely likely that members of the Committee will know someone in their family or amongst their friends who takes an antidepressant. It is their health and care we are talking about here too.

To quote from Johann Hari's book: The Lost Connections: Uncovering the Real Causes of Depression – and the Unexpected Solutions Bloomsbury (2018)[2]

"To me, this seems like the most crucial piece of evidence about antidepressants of all: most people on these drugs, after an initial kick, remain depressed or fully depressed again. Only one in three of the people who stayed on the pills had a lasting, proper recovery from their depression. (And even that exaggerates the effect— since we don't know how many of those people would have recovered naturally without the pills.)"

From The Emperors New Drugs: Exploding the Antidepressant Myth by Irving Kirsch Random House (2009)[3]

"Formerly depressed patients are far more likely to relapse and become depressed again after treatment with antidepressants than they are after psychotherapy. As a result, psychotherapy is significantly more effective than medication when measured some time after treatment has ended, and the more time that has passed since the end of treatment, the larger the difference between drugs and psychotherapy. This long-term advantage of psychotherapy over medication is independent of the severity of the depression. Psychotherapy outperforms antidepressants for severely depressed patients as much as it does for those who are mildly or moderately depressed."

Mr Gething states a reduction in prescribing of antidepressants is a simplistic approach. I would maintain that actually it is extremely difficult and divisive, which is why there are so many of us campaigning to bring this issue to the attention of our various governments. If it were simple, I wouldn't have had to raise a petition and be using this democratic means of getting my voice heard on behalf of the people who have been harmed by antidepressants. Here are some of the reasons why the treatment of people for depression with antidepressants, particularly SSRIs and SNRIs, is a difficult subject to address and why there will inevitably be resistance to the request for a targeted reduction in prescribing.

Firstly, because politicians are being advised by members of the medical profession who consistently sell the benefits of these drugs and downplay the risks. They lend their ears

to professors with medical degrees and strings of letters after their names who are compelling in their insistence of the drugs' safety and efficacy, and that withdrawal (or "discontinuation", the euphemism of choice) is short term. The evidence they turn to is provided by the pharmaceutical companies who hide clinical trials showing harm and provide ghost-written articles, provided by their marketing departments, to medical journals promoting their benefits. This system is described at length by Dr David Healy is his book Pharmageddon[4]. This is the system in place that regularly and persistently drowns out the voices of people who have found themselves physically dependent on antidepressants and unable to withdraw, or find themselves in the hell of withdrawal. I fear that any expert brought in to speak to you in support of the safety and efficacy of these drugs will undoubtedly convince you, and yet again we will be ignored. We fervently hope that via our petitions, this one and the sister petition raised in Scotland, which I will come on to later, you will take us seriously and help us bring about the change that we feel is needed.

We are forced to ask – since when does "science" and "evidence" trump people's experience to the point where we are disbelieved and ignored, and what is the Welsh government going to do to help us? This is not a black or white issue. Yes, of course there are people who say they have been helped by antidepressants. Yet surely it is entirely appropriate for us to ask for specific help for those who say they have been hurt by them, and insist on a means to be put in place to reduce the number of people being hurt in the future.

Secondly this subject is difficult and divisive because the rationale for the use of antidepressants is based on shaky evidence and the medical profession does not want to openly acknowledge this. When challenged the medical profession says that antidepressants are prescribed in the growing numbers that they are because the benefits outweigh the risks. Medicines are licenced for use in the UK by the Medicines and Healthcare Products Regulatory Agency (MHRA). The MHRA licences a drug based on the scientifically proven benefits. When pressed by author, researcher and campaigner Bob Fiddaman for a list of the benefits of fluoxetine (Prozac), on November 24th 2016, the MHRA stated in their reply to him: "…….*benefits are considered to be the therapeutic effects of the product to improve the medical conditions for which a product licence has been granted…… In the case of fluoxetine, it raises the level of the neurotransmitter, serotonin, in the brain which can improve symptoms of depression"*[5]

The MHRA has a Yellow Card System where doctors can report adverse effects – the risks associated with each drug. The Yellow Card system has a list of 27 "Disorders" reported for the SSRI fluoxetine (Prozac)[6], including Cardiac, Ear and Labyrinth, Endocrine, Eye, Gastrointestinal, General, Metabolism and Nutritional, Musculoskeletal and Connective Tissue, Nervous system, Psychiatric, Skin, Vascular. The list for paroxetine, marketed as

Seroxat, the drug I took, is similar. Most of the people who experience adverse effects and withdrawal on SSRIs will have one, usually more, of those listed. I had 7 of the list above in withdrawal and still have 3 post withdrawal. These are the risks when taking an antidepressant. The only benefit the MHRA can cite is: "… *it raises the level of the neurotransmitter, serotonin, in the brain which can improve symptoms of depression".*

The Yellow Card system for antidepressants is vastly underused because when a patient reduces or stops their antidepressant, the ensuing symptoms are diagnosed by the GP as being a relapse of their illness rather than a reportable adverse or withdrawal effect. The only way that the medical profession can "know" that antidepressants work is based on some of their patients telling them, in their opinion, they feel better. So why is it, then, when their patients tell them they feel worse, that opinion is not equally ascribed to the drug? Why is the diagnosis relapse not withdrawal?

"We also have to ask do antidepressants worsen outcomes for patients? A 2011 meta-analysis by McMaster University in Canada discovered: "Patients who use antidepressants are much more likely to suffer relapse of major depression than those who use no medication at all." How many of these patients have been misdiagnosed and may in actual fact be suffering not from relapse but withdrawal?[7]

From the 1970's until recently, patients were told that their depression/anxiety is due to a chemical imbalance in the brain which is corrected by the antidepressant. This is the basis on which I was prescribed Seroxat in 1996 for intermittent insomnia and PMT. There is no scientific evidence to date to prove this. Today the explanation from the Royal College of Psychiatrists is that depression/anxiety is due to inflammation in the brain which is corrected by the same drugs. To date there is no scientific evidence to prove this. Should this theory be proved, logic dictates that anti-inflammatory drugs are likely to be the correcting drug of choice, not neuro-toxins which change the way neurotransmitters are used in the brain. Anti-inflammatories have strong scientific evidence to prove their efficacy.

If 64 million prescriptions for diabetics had been written in 2016 based on no sound scientific evidence and with the side and adverse effects listed above, there would be a public outcry.

Finally, this subject is difficult and divisive because GPs have nothing else in their armoury to offer due to the lack of readily available alternative therapies and the last thing they want to admit openly is the only thing they have to offer causes some people harm. Experts Dr David Healy, Dr Terry Lynch and Dr Noel Thomas have written to you directly to express their concerns. I'll leave the last word to Professor John Read:

"Our survey of 1800 antidepressant users, the largest ever, found that one in four were addicted and 55% experienced withdrawal symptoms when trying to stop or reduce. Meanwhile the drug companies and Royal College of Psychiatry insists they are not addictive. This is a repeat of the years if denial that benzodiazepines are addictive. And antidepressants are no more effective than placebo for about 90% of people."[8]

THE SCOTTISH CAMPAIGN

I wish to bring to the attention of the Committee that there is a sister petition to this in Scotland which has been running since May 2017. The harm done to the people of Scotland by PDD is the same as to the people of Wales. In Wales we are in a better position because we already have in place the targeted reduction of anxiolytics (benzos) and hypnotics (Z drugs/sleeping pills). Also we already have a small, geographically limited Prescribed Medication Support Service as described at length in my last submission.
It would be inspiring if the two Petitions Committees were prepared to collaborate on this issue and even more inspiring if the two Governments would collaborate and cooperate in providing the recognition and help we are seeking. The BMA and All Party Parliamentary Committee for PDD are waiting to hear from you!

The Scottish petition differs from the Welsh one in as much as they have already invited and received many submissions from people with lived experience of PDD. Some of their stories are heart-rending. Every word written applies to Wales as to Scotland. It is a problem which is no respecter of borders. These submissions are publicly available here:

http://www.parliament.scot/GettingInvolved/Petitions/PE01651

I hope you will also decide to allow others with lived experience to share their stories so you can learn more about the depth of the problem and the suffering PDD brings. (At the last minute I have received a submission on his ongoing experiences of PDD from James Moore which I would like to include today).

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