P-05-784 Prescription drug dependence and withdrawal - recognition and support – Correspondence from the Petitioner to the Committee, 27.11.17

When talking about prescribed drug dependence (PDD) in this submission I am describing patients who take medication exactly as prescribed by their clinician. There has been no "misuse". When they chose to stop, they find that they are unable to as they develop, within a very short time frame (generally within a week), symptoms which are worse than those for which they were originally prescribed the medication. These symptoms are withdrawal due to physical dependence. This differs from psychological dependence where the patient will not come off the drug for fear of not being able to cope without it. It also differs from addiction where more of the drug is required for a desired effect.

My name is Stevie Lewis and in 1996, at the age of 41, I was prescribed an SSRI (Selective Serotonin Re-uptake Inhibitor) antidepressant for intermittent insomnia and PMT. In 2002, after several attempts at stopping and failing, I discovered that I had become physically dependent on the drug. For years I kept trying to come off the drug and each time the withdrawal symptoms got worse and worse. In 2009 I developed a movement disorder which has its roots in long term use of an SSRI antidepressant. Eventually I stopped in 2013 and have been through a long and crippling withdrawal.

When I embarked upon this journey of petitioning the Welsh Government, I imagined that the first problem that would face me would be convincing the Committee that PDD exists, and as a result the first page of my submission would be listing statistics and research proving the extent to which people become dependent on antidepressants, benzodiazepines, Z drugs (hypnotics), and opioids. However, it seems clear from the letter from Rebecca Evans AM to the Committee that PDD is a given.

So why is this petition necessary? Because of four fundamental problems. Firstly, no-one wants to admit that antidepressants are as problematic or worse than the other drugs I listed above. If that's the case, what is there left for a doctor to help a patient in emotional distress? Secondly, just as with the recent mesh scandal, doctors do not believe patients when they say they think they are dependent and have withdrawal symptoms, leading them

to diagnose Medically Unexplained Symptoms, many of which are identical to withdrawal symptoms. Thirdly, if withdrawal is recognised, the main option for help for patients in Wales is the Drug Misuse Services, which are totally inappropriate for a patient with PDD. And fourthly, there is no formal consistent drug tapering advice available for anyone to access. Therefore, the aspects of the subject I want to draw your attention to for further investigation and recommendation to the Welsh Government are as follows:

TO APPROPRIATELY RECOGNISE PRESCRIBED DRUG DEPENDENCE BY:

1. Recognising that antidepressants cause dependence to a level equal or greater than the benzodiazepines, anxiolytics, hypnotics and opioids. Following that, their addition by the All Medicines Strategy Group to the list of drugs that are targeted for reduction, as benzodiazepines currently are, together with new prescribing guidelines.
2. Recognising the need for proper identification by Welsh NHS employees of the symptoms of prescription drug withdrawal. Without the clear recognition and acceptance of PDD, GPs and A&E departments erroneously diagnose Medically Unexplained Symptoms and refer patients on needlessly to Consultants, Specialists and Psychiatrists.

TO EFFECTIVELY SUPPORT PATIENTS WITH PDD BY:

1. Giving all of Wales access to an NHS funded Prescribed Medication Support Service to match that currently provided across part of North Wales. A service specifically targeted for patients with PDD is required because the promoted alternative is the Substance Misuse Services which treat PDD the same as street drug and alcohol withdrawal. A short withdrawal for patients with PDD is dangerous and potentially life-threatening.
2. Providing approved on-line access to effective tapering plans for each drug.

APPROPRIATELY RECOGNISE PRESCRIBED DRUG DEPENDENCE

1. ANTIDEPRESSANTS

The problems with benzodiazepines and sleeping pills (anxiolytics and hypnotics) have been known for 30 years and I am encouraged to see that the All Medicines Strategy Group has a specific outcome to "encourage a reduction in the inappropriate prescribing of hypnotics and anxiolytics" which is monitored annually in the National Prescribing Indicators. Equally encouraging is the documentation in support of this outcome, namely the "Hypnotics and Anxiolytics Practice Guide" and the detailed 69 page "Educational Pack: Material to Support Appropriate Prescribing of Hypnotics and Anxiolytics in Wales". Rebecca Evans' submission states*: "In addition, a specific Welsh Health Circular providing advice for prescribers on the risk of the misuse of pregabalin and gabapentin was disseminated throughout Wales in July 2016"* which is also a positive move.

What is missing and is essential for the Welsh government to put in place is the same national policy and approach towards the prescribing of antidepressants, particularly SSRIs and SNRIs. Prescribers in Wales only have NICE guidelines to read or ignore. 64 million prescriptions for antidepressants were written UK-wide in 2016 and the 2017 figure will be much higher. Research has shown that more than half of people taking SSRI antidepressants will have physical and psychological withdrawal symptoms on reducing and stopping the drug.[1] The Royal College of Psychiatrists in their own survey found that 63% reported withdrawal effects (with some antidepressants as high as 82%).[2]

Please see the attached letter from Dr David Healy, Professor in Psychiatry, Bangor, in support of my assertion that the reduction of antidepressant prescribing should be Welsh Government policy. Dr Healy has been the expert medical witness in a number of trials in the US about the harms done to individuals by antidepressant medication, particularly the SSRIs. He has always been on the winning side. He states: *"There is a pressing need to understand antidepressant dependence - how to avoid it and how best to manage it. This is a more serious problem than benzodiazepine dependence".*

2. IDENTIFICATION OF PDD AND WITHDRAWAL

Anecdotally amongst the community of suffers of PDD, is the problem of not being believed by your doctor. It follows then that you are less likely to be believed and supported by family and friends. There is a feeling and evidence, from the lived experience of patients, that rather than educate NHS employees about the serious effects that occur when starting, changing or stopping drugs which cause dependence, particularly antidepressants, NHS staff are being educated to look for and diagnose Medically Unexplained Symptoms (MUS) or Bodily Distress Syndrome (BDS). This is despite the fact that the patient in question is taking a drug that causes dependence. This fact is ignored or overlooked.

The Welsh NHS website covers MUS here.[3] The Royal College of Psychiatry describes MUS here [4]. As you can see, MUS is considered to be more prevalent amongst women and people who have anxiety or depression. Dr Healy's letter indicates that antidepressants have been targeted at women. A woman taking an SSRI presenting with withdrawal symptoms is very likely to be diagnosed with MUS.

A quote from BMC Medical Practice, February 2017 provides the most comprehensive list of my withdrawal symptoms that I have seen in one place: *"Recent studies on BDS [Bodily Distress Syndrome] suggest that central sensitisation not only results in multiple symptoms; it may also prompt several specific symptom patterns described by arousal and/or exhaustion symptoms. These symptoms cluster in four groups:*

1) cardiopulmonary/autonomic arousal symptoms (palpitations/heart pounding, precordial discomfort, breathlessness without exertion, hyperventilation, hot or cold sweats, dry mouth),

2) gastrointestinal arousal symptoms (abdominal pains, frequent loose bowel movements, feeling bloated/full of gas/distended, regurgitations, diarrhoea, nausea, burning sensation in chest or epigastrium),

3) musculoskeletal tension symptoms (pains in arms or legs, muscular aches or pains, pains in the joints, feelings of paresis or localized weakness,

backache, pain moving from one place to another, unpleasant numbness or tingling sensations), and

4) general symptoms (concentration difficulties, impairment of memory, excessive fatigue, headache, dizziness).” [5]

Here is a link to Signs and Symptoms of withdrawal from antidepressants – Fava et al March 2015. [6]

The patient/doctor relationship is hugely damaged by the refusal to believe a patient’s own assessment of the effects of their medication. It is upsetting and inhuman, and potentially leads to further drug interventions, generally of a psychiatric nature.

EFFECTIVELY SUPPORT PATIENTS WITH PDD

1. PRESCRIBED MEDICATION COUNSELLING AND SUPPORT SERVICE

Ms Evan’s submission refers at length to how the Welsh Government supports those with dependency on prescription medicines. *“We invest almost £50m in the substance misuse agenda annually, with £22.6m provided to the seven Area Planning Boards (APBs) which are responsible for commissioning all local substance misuse services in order to support those who are dependent on a range of drugs, including prescription only medicines and over the counter medicines.”*

One of the many distressing situations for someone who discovers they are dependent on prescription drugs is being pointed towards a Substance Misuse Service. It shows a callous lack of understanding of the issues experienced by those physically dependent on antidepressants. Having read the Guidance booklet “Working Together To Reduce Harm: Revised Guidance for Substance Misuse Area Planning Boards 2017”, which is littered with the words “drug misuse” and “alcohol misuse”, I can confirm that there is nothing written in these 34 pages that anyone with prescribed drug dependence would recognise as being of any relevance, help or support to them. For them, there has been no “misuse”.

The Substance Misuse Services have a programme which involves withdrawing people over a 3 to 4 week period. For people who are

dependent on antidepressants or benzodiazepines, this approach is extremely dangerous. It is essential that the tapering process is a long, slow, supported one, as it takes months, or even years for those who have taken the drugs for more than a decade, for the serotonin or GABA receptors in the brain to recover and reset. A patient who is withdrawn quickly from her antidepressant is likely to be desperately ill, with a central nervous system that is in crisis, and her life could be in danger. I quote from the correspondence of Barry Haslam, ex Chair of Oldham Tranx[7], a specialist PDD facility in the north of England, to Andy Burnham, Mayor of Greater Manchester in his email dated 22 November 2017: *"I really hope that Greater Manchester can show the rest of the country in how to tackle this very much major hidden public health problem, in order to provide dedicated withdrawal centres and after care facilities that these patients so richly deserve. Substance Misuse and Alcohol Units are NOT the place to withdraw iatrogenic dependent patients who have only taken their drugs as directed by their doctors. It is not just about the stigma but, in providing safe, adequate dedicated withdrawal clinics for those patients brave enough to enter a withdrawal that can take months and even years. SMU Units do not have the necessary expertise."*

There are two noteworthy omissions from Ms Evans' submission which I have discovered during my research and which I hope will lead to some progress in Wales in this particular area. Firstly, Wales has a 24/7 mental health helpline, the NHS funded CALL (Community Advice and Listening Line), which as a matter of routine takes calls from people who suspect they have or do have prescription drug dependency[8] I contacted CALL to establish what they advise in these circumstances. I spoke to [a member of] the Management team. If the caller lives in South Wales, the advice is as follows:

1. To go back to their GP to discuss options (please bear in mind some GPs still do not willingly acknowledge that antidepressants cause dependence and do not have access to tapering plans.)

2. To go to the Drug Misuse Service (most people with antidepressant dependence are shocked and stigmatised by this proposal).

3. To go outside Wales for help, to the Bristol Tranquilliser Project, a free charitable organisation.[9]

If the caller lives in North Wales, the CALL responder breathes a sigh of relief – which brings us neatly on to the second omission from Ms Evan's letter. The advice given by CALL is to go to the Prescribed Medication Support Service & Primary Care Mental Health Counselling Service, based in Mold.[10] This service has been in place for 20 years and covers the Betsi Cadwaladr University Health Board. It is NHS funded and appears to have survived despite rather than because of the Welsh Government. Its absence from any correspondence I have had with the Cabinet Secretary for Health, and from the submission to the Committee is telling.

This service was set up predominantly to help people dependent on benzodiazepines, sleeping pills and over-the-counter medicines as it was clear that a different approach was needed to that taken for street drug misuse. Now they also are helping people dependent on antidepressants, and believe that this need is going to grow because of the ever-increasing prescribing of SSRIs. The existence of this service shows that there is a clear demand in North Wales and therefore there must be the same demand throughout the country. The service is managed by June Lovell and she has given me a document which describes the PDD support service that they provide. I am unable to provide this as a hyperlink so I am including it as an extra page in my submission, to which I hope the Committee will request access.

2. ACCESS TO EFFECTIVE TAPERING PLANS

There needs to be good well-resourced information about safe tapering approved by the NHS and made available online for patients, doctors and public, so that people can have fully informed discussions with their doctors and informed family and social support. The team who run the Prescribed Medication Support Service already has what is needed, and could contribute to the NHS Direct Website, the CALL Website and any other sources accessed by GPs. The Ashton Manual for the tapering of benzodiazepines is another resource well-known in the benzo community but not within the NHS. Also for consideration is the provision of tapering strips, with incrementally

smaller doses of each drug, which can only be sourced at the moment outside the UK.[11] Not all medications can be supplied in liquid form and so patients have to cut their pills in order to taper which is difficult and inaccurate. Some GPs do not want to prescribe the liquid form as it is more expensive. I used liquid Seroxat but struggled to find syringes that had small enough measurements to effectively and safely reduce.

I trust that this document gives the Petitions Committee a feel for the issue of PDD. The petition has in excess of 200 signatures, and many of those are experts in the field of prescribed drug dependence – Clinical Psychologists, Psychiatrists, BACP registered Counsellors and Therapists – people who regularly coach and mentor those who have inadvertently found themselves to be dependent and have nowhere to turn for help from the NHS. Ms Evans has established in her submission that there is plenty of money in the pot for drug and alcohol misuse. This is exemplary, and I am delighted to read that as a society we put so much effort into helping people who misuse drugs, whether sourced off the street or over the counter. Clearly there is no need for extra funding, but I wish and hope to establish a need for some of that money to be used caring for people who did nothing more than follow the advice of their doctors.

As I final point, I have avoided the elephant in the room – the fact that inadequate provision of alternative therapies leads GPs and Psychiatrists to medicate as a first response to a patient in emotional distress, rather than a last, despite antidepressants being no better than placebo for mild to moderate depression. However, Laura Williams' petition number P-05-736 is in the process of raising that awareness with the Committee and progress in Wales will hopefully be made to provide a Mental Health service that is joined up and fit for purpose.

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