PETITION 1235 – PRESCRIPTION DRUG DEPENDENCE AND WITHDRAWAL – RECOGNITION AND SUPPORT BY STEVIE LEWIS APRIL 2018

Fourth submission in response to comments from professional bodies, Health Boards and patient's written evidence

TO APPROPRIATELY RECOGNISE PRESCRIBED DRUG DEPENDENCE

I see that the subject of prescription drug dependence (PDD) is not on the horizon for the Health, Social Care and Sport Committee. I am very grateful for the opportunity for this to be discussed further by the Petitions Committee.

From the professional body responses, all responders are in favour of the idea that we need to do more to better support dependent patients and to tackle rising antidepressant prescribing. The BMA Wales fully supports the BMA's actions in PDD, providing a helpline and dedicated support services. The Welsh Royal Pharmaceutical Society is supportive of the petition and agrees that individuals in Wales who become addicted to prescription medicines must be provided with timely and appropriate support. Of all the responders, these two bodies have the greatest knowledge and expertise on the subject of prescription medication, and I would maintain that their opinions on the problems of dependence and withdrawal carry more weight than those of the Chief Executives of the Health Boards.

Of the seven University Health Boards:
Two have dedicated services of some kind (Betsi Cadwalader and Powys).
Three dispute that dependence is related to antidepressants (Abertawe, Aneurin Bevan UHB and Cardiff and Vale).
One leaves it up to GPs and Community Mental Health Teams to manage (Cwm Taf).
One puts substance misuse together with Prescribed Drug Dependence (Hywel Dda).
In short, there is a highly variable response to these issues and Welsh patients will receive markedly different help according to which Health Board they are covered by. If they are covered by Abertawe, Aneurin Bevan UHB or Cardiff and Vale, they will likely get no support for antidepressant dependence and withdrawal whatsoever.

However, in general the Health Boards acknowledge that more needs to be done:
"….the funding that Area Planning Boards receive from Welsh Government commissions a local substance misuse service to treat and support people with alcohol or illicit drug addiction but does not extend to providing a service for prescribed drug dependence and any updates or guidance on reviewing a national treatment framework would be appreciated." **Carol Shillabeer Powys THB**
"At one end of the scale - It is fundamental that a patient considering a licensed medication, known for its dependence / discontinuation capacity, should get clear unambiguous information about the risk about the capacity for that medication to cause dependence or discontinuation syndrome. At the other end of the same scale, managed withdrawal or substitution for those for whom dependence has brought significant morbidity must be available." **Neil Jones Community Addiction Unit Cardiff and Vale UHB**
"We are constantly reviewing and improving our services for patients and would be interested in any recommendations or areas of good practice which this petition may produce." **Alison Cwm Taff UHB**

The Health Boards all show their commitment to reducing drugs which cause dependence in line with the targets set by the All Medicines Strategy Group. These drugs of dependence do not currently include antidepressants. As outlined in my previous submissions, I urge the Petitions Committee to recommend that antidepressants, particularly the SSRIs and SNRIs, are added to that target list. One of the reasons that they are not currently on that list, or that there is resistance to their being added, is demonstrated in several of the letters. The writers helpfully clarify for the committee prevailing expert views on definitions of addiction and dependence:

"*A key consideration within this petition is that it is important to distinguish between true dependence as with opiate analgesics and the issue of discontinuation syndrome from antidepressants…"* **Judith Paget Aneurin Bevan UHB**
"Tolerance and withdrawal are important factors in drug dependence, but are not unique to it, and understanding this is important in understanding the concept of discontinuation syndrome, seen with some antidepressants (where the other symptoms which comprise the dependence syndrome are missing). Caution maybe needed in stopping antidepressants, but the drug group is not associated with drug dependence." **Neil Jones Community Addiction Unit Cardiff and Vale UHB**

"Antidepressants do not cause dependence and are generally not considered to be addictive" **Tracy Myhill Abertawe UHB**

Please, for one moment would you put yourself in the shoes of someone experiencing antidepressant withdrawal? Your physical symptoms are likely to include (note I am not including psychological symptoms here): dizziness or vertigo, electric shock sensations in head, flu-like symptoms, problems with movement, sensory disturbances, stomach cramps, strange dreams, tinnitus, difficulty sleeping[1]

Someone experiencing benzodiazepine withdrawal will have physical symptoms which include: dizziness, stomach cramps, blurred vision, difficulty sleeping, face and neck pain, headaches, nausea/vomiting, nightmares, tinnitus, tingling in the hands and feet[2]. How different are these from yours?

Someone experiencing Heroin (opiate) withdrawal will have physical symptoms which include: difficulty sleeping, tremors, joint and muscle pain, stomach cramps, nausea/vomiting, diarrhoea, involuntary muscle spasm[3]. How different are these from yours?

I am concerned that the academic distinctions and definitions referred to in the Health Boards' submissions are a barrier to the antidepressant class of drugs being recognised at policy level as causing the same distress and potential for harm as those drugs already targeted for reduction. The behaviours around taking the drug may be different but the physical and psychological outcomes for the patient on the absence of the drug are very similar. As a patient taking antidepressants, these views also lead you to not being believed if you think you are in withdrawal and to you not getting the care and support you need. Worse still, you will be kept on the drug because the diagnosis will be that your original symptoms have come back. Only by adding antidepressants to the list of drugs targeted for reduction will all the Health Boards have the appropriate level of incentive to take patients' needs seriously. Only by adding antidepressants to this list together with new up-to-date prescribing guidelines will GPs acknowledge and understand the scale of antidepressant dependence and withdrawal and treat their patients accordingly, rather than continue with the drug or move them on to other specialist departments at a huge cost to the NHS.

In my first submission I claimed that "antidepressants cause dependence to a level equal to or greater than the benzodiazepines, anxiolytics, hypnotics and opioids". My claim at the time was unreferenced. On 07 April the New York Times, a prestigious newspaper, ran an article entitled "Many People Taking Antidepressants Discover They Can't Quit".[4] In a letter in response to that article Dr Kelly Brogan MD wrote:
"*In the first systematized review of SSRI withdrawal, Fava et al.[5] examined 23 studies and 38 case reports leading them to conclude that the euphemistic term "discontinuation syndrome" must be abandoned in lieu of a more accurate depiction of the habit-forming qualities of antidepressants — withdrawal. Yes, just like Xanax, Valium, alcohol, and heroin*."[6]

TO EFFECTIVELY SUPPORT PATIENTS WITH PRESCRIBED DRUG DEPENDENCE

Personal responses - key themes:
Doctors do not inform patients at the start of drug therapy (be they benzodiazepines, antidepressants or opioid analgesics) that there may be difficulty coming off the drugs after a period of time.
The time taken to withdraw from the drugs is vastly longer than that suggested by psychiatrists or GPs. The official guidance is to reduce within weeks; many of the responders had to reduce over years.
Many respondents had to self-support as they did not receive help, advice or support from Psychiatrist's, GPs or Community Mental Health Teams.
Many respondents reported not being believed that their symptoms related to withdrawal. "*The first time that I felt some sort of control over my condition was when we went for the second opinion – and everything that I said was BELIEVED"*. **Shane Cooke**
Patients reporting dependence and withdrawal issues report a wide range of distressing symptoms and often resorted to additional medications to help (either prescribed or over-the-counter) leading to further difficulty and potential harm.
Nearly all reported that they had to become 'experts by experience' because of the lack of knowledge and experience within the medical profession.

One respondent was referred to a Prescribed Medication Dependency Counsellor. *"I can't express how vital these services were to me"* **Anonymous**
Many respondents report life-changing and life-limiting effects even after coming off the drugs.
Many felt marginalised and isolated simply because they wanted to reduce their medication burden.
There is a great deal of unemployment reported, a significant financial consequence both to the individual and to society.
There are cost implications for the health budget, since the management of people struggling to come off their drugs is complex. Many responders report multiple consultations and medical tests/procedures.
One responder reported that Welsh GPs have become dependent on prescription medication but are unwilling to speak out for fear of the impact on their careers.

The written evidence indicates a post-code lottery of help ranging from a customised patient-centred approach, referred to with pride by Betsi Cadwalader, to no acknowledgement of antidepressant withdrawal at all. In my first submission I provided the Committee with a summary of the work and expertise carried out within this Health Board – the Prescribed Medication Support Service - and I continue to urge you to recommend that this approach is delivered Wales-wide.

From the personal responses, a broad overview of the actions deemed necessary to appropriately recognise and support prescribed drug dependence and withdrawal are as follows:

- An acceptance at policy level that antidepressants have the same potential for dependency and harm to some patients as do benzodiazepines, hypnotics, anxiolytics and opioids.

- Education for prescribers – GPs, Psychiatrists, Psychologists, Pharmacists with new guidelines on prescribing, withdrawal and tapering for all drugs of dependence.

- Education for NHS specialists – Neurologists, Cardiologists, Endocrinologists, Gastroenterologists and A&E Staff, all of whom see patients with withdrawal symptoms and fail to recognise them.

- A specialist Prescribed Medication Support Service within each Health Board.

- An on-line portal for both prescribers and the public to access information provided by the NHS and managed by trained NHS staff on prescribed drug dependence. This will tie in with the existing CALL 24/7 Helpline, enabling helpline staff to give clear and concise pointers for help and support to callers irrespective of where they live in Wales.

- Funding should come from the current Substance Misuse funds and the Pharmaceutical Companies whose successful marketing strategies have overplayed the benefits and underplayed the risks, giving them huge profits.

The above actions will enable patients to be prescribed appropriately and, if they have problems, to be BELIEVED. Dr David Healy, one of the experts who has submitted to this petition, in his blog entry of 18th April entitled "The Horrific Effects of Not Being Believed" (about PPD and withdrawal), wrote with reference to his colleagues at the Royal College of Psychiatrists (RCP):
"They can't say this is news. Successive presidents of the British Psychiatric College have been told about this problem for over 20 years since Charles Medawar first wrote to them. They are in great part personally responsible for ongoing injuries from disbelief to thousands, maybe hundreds of thousands of people."[7]

UPDATE ON RELATED CAMPAIGNS OUTSIDE WALES

UK PRESS and ROYAL COLLEGE OF PSYCHIATRISTS

On 22 February 2018 the Royal College of Psychiatrists (RCP) issued confident national press statements about a newly published Lancet report on a study on efficacy of antidepressants – and suggested that many more patients should be prescribed them.

A letter by Profs Burn (RCP President) and Baldwin (Chair of its Psychopharmacology Committee) was published in The Times on 24 February[8], (responding to a letter by James Davies et al[9]), which said '*the statement that coming off antidepressants has disabling withdrawal effects in many patients "which often last for many years" is incorrect. We know that in the vast majority of patients, any unpleasant symptoms experienced on discontinuing antidepressants have resolved within two weeks of stopping treatment."* This has caused great distress to people who have submitted evidence for this and the Scottish petition – and the many others who have experienced dependence and withdrawal and have for years been desperately trying to raise the alarm. We are led to wonder whether the RCP is being wilfully blind to potential antidepressant harm. RCP's own research about antidepressant withdrawal disappeared from RCP's website on 26 February. Their leaflet "Coming Off Antidepressants" was dated 2014 and reported a survey of 817 people who completed the RCP survey and shared their experiences: *"512 (63%) people in our survey experienced withdrawal when stopping their antidepressants"*. (A full copy of this RCP leaflet was previously saved and can be provided.)

This led to a formal complaint of misleading the public on a matter of public safety being lodged with the RCP against Profs Burn and Baldwin by 10 of its own members. The complaint states: *"To mislead the public on this issue has grave consequences. People may be misled by the false statement into thinking that it is easy to withdraw and may therefore try to do so too quickly or without support from the prescriber, other professionals or loved ones."* [10] Alongside the 10 psychiatrists, 10 people with experience of withdrawal lasting more than two weeks also signed the letter. I was one of the signatories.

SCOTTISH PETITION

The next date for this petition to be discussed is 26th April. They now have 150 written submissions from people with lived experience and 20 expert submissions.[11]

PUBLIC HEALTH ENGLAND

Public Health England has announced the scope of the review into PDD, which includes antidepressants.[12]

BMA BOARD OF SCIENCE: PRESCRIBED DRUGS

On 18th April, the BMA hosted a further Board of Science Stakeholder meeting in London for stakeholders, to allow members of the group to update on actions that have been taken since the last meeting and to discuss next steps. Marion Brown, the Scottish petitioner, was invited to give a brief report about Scottish Petition and she reported on my behalf on this Petition.[13]

References:

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