

THE CASE FOR A NATIONAL PRESCRIBED DRUG HELPLINE

All Party Parliamentary Group for Prescribed Drug Dependence
September 2017



“I am just not willing to do this any longer. Day after day after day, what I have has nothing to do with a life. My thoughts are killing me. I am terrified because I am still on another med. I am terrified that it makes things worse but I am just so bad that I cannot come off. I am cognitively crippled. My brain just doesn't work at all. The mental and physical horror is just killing me. On top, I just lost everything in my life that can be lost....relationship, work, friends, and now my home.

And the only thing I can do is **NOTHING** but trying to accept. I am so sick of accepting. I am so sick of not being able to get my life in order. So sick of having to calm myself everyday all day and try to tell myself that when I come out of this, I will be so much wiser and transformed into a saint. Well, I do not want to be wise and do not want to be a saint, I just want this to **END**. I am completely broken and honestly do not want to fight anymore.”

Anonymous patient, September 2017

THE ISSUE

- Over 1 million patients are taking dependency-forming medications unnecessarily in England, including benzodiazepines, z-drugs, antidepressants and opioids.
- Dependence can result in a variety of harms, including side effects and withdrawal effects. These can be debilitating and last for months and sometimes years, often leading to long-term disability.
- Many doctors respond inappropriately to prescribed drug dependence and withdrawal symptoms, due to a lack of awareness and relevant training.
- Large numbers of patients are suffering alone at home, unable to work, with no NHS support, relying on peer-to-peer support via the Internet.
- Dedicated support services are required to support these patients, as existing drug and alcohol services are inappropriate.
- A small number of underfunded charities provide these services, but they cover only a fraction of the UK, and they report a significant unmet increase in demand over recent years.
- The APPG-PDD is calling for a national helpline to support for this group of patients, alongside a withdrawal resources website for both doctors and patients.

CURRENTLY AVAILABLE DATA

- 15.9 million prescriptions for benzodiazepines & z-drugs were issued in the community in England in 2016¹
- Research published 2017 in the British Journal of General Practice suggests over 250,000 patients are taking benzodiazepines for at least one year (far beyond NICE guidance of two to four weeks)²
 - Of these, around half are estimated to be willing to accept prescribed drug withdrawal services
- 64.7 million prescriptions for antidepressants were issued in the community in England in 2016, an increase of over 200% since 2006³
 - Research published in the BMJ has shown that the rise in antidepressant prescribing is mainly explained by increases in the proportion of patients receiving long-term treatment⁴
 - 63% of patients experience withdrawal symptoms when stopping antidepressants⁵
- Researchers at the University of Roehampton estimate that 770,000 long-term antidepressant users in England are taking them unnecessarily⁶
- 23.9 million prescriptions for opioid analgesics were issued in the community in England in 2016, an increase of 200% since 2006⁷

THE COSTS OF UNNECESSARY PRESCRIBING⁸

- Using an estimate of 250,000 unnecessary long-term benzodiazepine & z-drug users in England, we calculate that their unnecessary use is costing the NHS in England:
 - £15.2m per annum
- Using an estimate of 770,000 unnecessary long-term antidepressant users in England, we calculate that their unnecessary use is costing the NHS in England:
 - £44m per annum
- In addition, we calculate that unnecessary GP consultations for unnecessary antidepressant and benzodiazepine / z-drug prescriptions may be costing the NHS in England:
 - £81m per annum
 - Assumes 4 per year per patient @ £20 per consultation
- Total unnecessary costs of prescribing and consultations estimated to be £140.2m per annum
- These figures do not include other costs to the economy e.g. disability claims and lost tax revenues, nor the costs of opioid prescribing and appointments

PATIENT NEEDS SURVEY

- The University of Roehampton & the Council for Evidence-Based Psychiatry conducted a survey of patients affected by prescribed drug dependence in August 2017⁹
- The survey included 369 responses from UK patients suffering from prescribed drug dependence
- Preliminary findings are as follows:
 - 65% of respondents reported that their doctors gave them little or no information on drug risks and side effects
 - 51% of respondents reported that withdrawal symptoms lasted one year or longer
 - On a scale of 1-10 respondents rated the negative impact of withdrawal on their life to be an average of 8.59
 - 27% of respondents are indefinitely off work due to withdrawal symptoms
 - On average, respondents attended 10 withdrawal-related appointments with their doctor
 - 87% of respondents believe a national 24 hour helpline would be helpful, while 94% believe an accompanying website would be helpful

WHY WOULD A HELPLINE BE USEFUL?¹⁰

“A National Helpline would help because many of us are turned down by our medical professionals who dismiss withdrawal and have no resources to deal with the struggle of withdrawal.”

“Because there is no one to talk too and I personally feel very alone.”

“It would save lives.”

“Because it gets as serious as planning suicide, and its important to have useful strategies to cope.”

“Because we get desperate for information that is not available and having 24 hour access would be a life saver.”

“Many people are too ill to leave their home and cannot reach out any other way.”

“There are crisis points when you’re really hanging on to life by the tiniest thread. It would be good to talk to someone who knows that it is actually the drug wrecking me.”

BMA SUPPORT

- On 24 October 2016 the BMA published its call for a national helpline to support patients affected by prescribed drug dependence¹¹
- It made three recommendations:
 1. The UK government, supported by the devolved nations, should introduce a national, 24 hour helpline for prescribed drug dependence.
 2. Each of the UK governments, relevant health departments and local authorities should establish adequately resourced specialist support services for prescribed drug dependence.
 3. Clear guidance on tapering and withdrawal management should be developed collaboratively with input from professional groups and patients.
- Dr Andrew Green, BMA GP clinical and prescribing policy lead, said: “We believe that establishing a national helpline, similar to the FRANK service, should be a top priority to provide better service to individuals with prescribed drug dependence. This would provide vital, timely support and could be introduced relatively quickly.”

SUPPORT FROM OTHER MEDICAL BODIES

- In April 2017 the APPG-PDD published a Declaration of Support for a national 24 hour helpline and accompanying website. The declaration is signed by numerous medical bodies and charities, including:
 - The BMA
 - The Royal College of Psychiatrists
 - The Royal College of GPs
 - The Royal College of Physicians
 - The Royal Society for Public Health
 - The Medical Schools Council
 - The British Psychological Society

All Party Parliamentary Group for Prescribed Drug Dependence



March 2017

DECLARATION OF SUPPORT

We, the undersigned, support the BMA's recent call for a 24 hour national helpline and accompanying website to support individuals affected by prescribed drug dependence.



SUPPORT FROM THE MEDIA

- The Daily Mail has launched an indefinite campaign in support of the APPG's call for a national 24 hour prescribed drug helpline
- Stories so far include:
 - “Exposed: National disgrace as a quarter of a million patients are turned into drug addicts by their doctors” March 2017
 - “A million patients are taking anti-depressants 'they don't really need' fuelling growing epidemic of addiction to prescription medicines” March 2017
 - “The NHS must help blameless victims” April 2017
 - “Painkillers my GP gave me for a sore neck robbed me of 35 years of my life” April 2017
 - “Betrayed by the doctors who turned us into drug addicts: How a nation of patients became hooked on prescription pills” May 2017
 - “Over-the-counter drug addiction in the UK is set to become more common than heroin and alcohol abuse, alarming new figures from a rehab centre reveal” June 2017
- Prescribed drug dependence and the call for a helpline have also been covered widely in other news media this year, including BBC Radio 5 Live, BBC Victoria Derbyshire, the Today programme, Newsnight, The Guardian, The Telegraph and The Times

GOOD HEALTH — BETRAYED BY THE DRUG ADDICTS WHO TURN THEM INTO

Daily Mail CAMPAIGN

Save the prescription pill victims

FIONA FRENCH'S story makes for shocking reading. For 40 years, the social scientist from Edinburgh was given repeat prescriptions for benzodiazepine drugs to treat her epilepsy. These tranquillisers, which include Valium, are commonly prescribed by GPs for pain, anxiety, depression or depression. They also have a muscle relaxant effect, which is why Fiona was given them because her type of epilepsy caused short, sharp fits.

Because benzodiazepines (also known as 'benzos') are highly addictive, and often have side-effects, patients should be put on such drugs for only four weeks. Long-term use can also lead to problems with memory and concentration, anxiety and depression as well as physical dependence and withdrawal symptoms.

But the Daily Mail has previously highlighted thousands of people on benzodiazepines for months and even years. Fiona, 61, was on the drugs for four decades.

"The doctors I see these days seem very puzzled that I was ever not on them at all," she says. "But she's facing the pill, for the medication has caused her constant and chronic pain."

My adult life has been destroyed by these drugs, she says. "To add insult to injury, when Fiona managed to wean herself off the medication (like many others, she had to go it alone), as there is virtually no support for unwanted drug addiction, she suffered terrible long-term withdrawal symptoms that doctors dismissed with an air of indifference."

There is hardly a unique experience. Up to a third of those who quit benzodiazepines experience bizarre symptoms, according to Professor Lader, executive professor of clinical neuropharmacology at the University of London Institute of Psychiatry.

And yet one often hears patients are told their symptoms are "medically unexplained" — or even, a sign of mental health problems. "Fiona was a heady, trusting, trusting person at university when she was diagnosed with epilepsy at 19 and I was her first, and only, friend."

Within two months of starting I made my first suicide attempt. I was suddenly very desperate and would a way out, she says.

"I couldn't explain why my personality had changed so suddenly and drastically. I would spend long hours of the night in bed and develop a fear of being alone."

I was told that my symptoms were those of depression and I believed in it. I kept taking the tablets, thinking they would make me better. It didn't. I came to realise that it could be the drugs that were making me ill."

In 2010, Fiona had to give up her job, which was an administrative job. This caused

By JOHN NAISH

far better despite taking all these pills and it was a struggle just to get through every day," says Fiona.

SYMPTOMS WORSE AFTER QUITTING

"The symptoms were bad enough when she was on the drugs, but even worse if she tried to come off them."

In 1981, Fiona saw a neurologist who said he thought the benzodiazepine pills — she was taking Valium — were making her depression worse and she should be put on other drugs to treat her epilepsy.

But Fiona had to stop taking her own medication after a few weeks as she had become so "anxious, agitated, highly anxious and unable to sleep."

"It was only years later that I made the discovery that benzodiazepines were addictive and what I had experienced was, in fact, drug withdrawal," she says.

Back on the tranquillisers and despite her chronic exhaustion and anxiety, Fiona managed to

WARNINGS GO BACK TO THE SEVENTIES

The risks associated with prolonged use of benzodiazepines have been known about since the Seventies, when withdrawal problems were first revealed in prestigious journals such as *The Lancet*.

"We knew from experiments back in the Sixties that you could have addiction to benzodiazepines on high doses," says Professor Malcolm Lader of the University of London Institute of

Thousands of patients hooked on prescription pills by their GPs — and then told they're imagining their crippling withdrawal symptoms or are even mentally ill. So when WILL the NHS act?

about. "I was determined to turn my life around," she says. "After I graduated in 1980, I got a job at Aberdeen University and then worked in the NHS doing research around mental health and working planning for 30 years."

The work was demanding and all the time Fiona struggled with feelings of depression — despite the medication she was prescribed.

When she reached her 50s, she noticed problems with her memory. At the time she developed irritable bowel syndrome, she retired.

In 2011, a new doctor advised her to enter off Valium as it was no longer recommended for epilepsy. With no advice or support from her GP on how to do this, over four months Fiona gradually reduced her dose before finally stopping altogether.

While this transition, the immediate withdrawal symptoms, it was not the end of the story.

I started to sleep down and sometimes on the floor over the next few months and was

worried that I was becoming more depressed again," says Fiona, who is divorced.

"I had to stay in bed with the curtains drawn all day as I became sensitive to daylight and couldn't stand the noise of the radio or TV."

"I struggled to even read a book. Every nerve in my body was screaming out. Even wearing underwear was painful — the pressure was like a burning sensation. I felt as if someone was torturing me day and night."

"For the next three months I felt so ill I couldn't even make a phone call. I was totally isolated."

In January 2014, she summoned the strength to take a taxi to see her GP only to be told "it was impossible" that her symptoms could be due to withdrawal from benzodiazepines, but were "all down to depression."

Her GP did agree to refer her to a psychiatrist. "The psychiatrist told me it couldn't possibly be withdrawal effects from the drugs and told me 'to think of any symptoms

as being the MIB'." Says Fiona. But a leading expert in this field is no doubt her symptoms were caused by the medication.

LACK OF SUPPORT FOR PATIENTS

FOR too long, there has been confusion of denial among doctors alongside a litany of broken promises by political leaders.

"The shameful fact is that there are hundreds of thousands of people in this country who, like Fiona, have become innocent hooked on drugs such as benzodiazepines and opioid painkillers prescribed by their doctors, only to find themselves abandoned."

"The next three months I felt so ill I couldn't even make a phone call. I was totally isolated."

It is the shameful way one talk about, which is why the MIB is launching a campaign, led by the British Medical Association (BMA), the Royal College of Psychiatrists and 15 other leading medical organisations and patient groups, for a national 24-hour helpline for those who have become dependent on prescription pills.

Benzodiazepines are one of the most shocking examples of what goes wrong.

Latest figures show there were 11 million prescriptions for benzodiazepines handed out in 12 UK in 2013 — with an estimated million prescriptions taken every year, according to evidence published by the BMA in April.

Up to 30 per cent of people who are on a benzodiazepine such as Valium have trouble coming off

it, according to Professor Lader. In rare cases, withdrawal can even prove fatal. One such death was reported this month in the journal *Annals of Pharmacotherapy*.

At least a third of those with withdrawal problems develop hypersensitivity, according to Professor Lader.

"The brain starts to wake up, and it over-wakes," he says. "Nausea appears and light appears brighter. They also have a tremor whereby they feel very unsteady and they will walk round the room holding on to the walls."

Even guidelines from treatment watching the National Institute for Health and Care Excellence (NICE) warn that benzodiazepine withdrawal can cause "anxiety, panic, psychosis, convulsions or a condition resembling delirium tremens" — the latter referring to the symptoms seen in alcoholism.

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others. And yet, as she discovered, these withdrawal effects are too often labelled by doctors as "medically unexplained" — they are dismissed as "all in the mind."

As Marion Brown, a psychiatrist working with the BMA on its campaign, explains: "There is a pattern in patients where doctors don't believe that their withdrawal symptoms, such as pain, fit and psychiatric disorders such as panic and obsessional, are associated with the drugs."

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SCANDAL BY NUMBERS

2-4 weeks

Maximum time for which benzodiazepines should be prescribed

250,000

Number of Britons prescribed benzodiazepines for more than six months

6-18 months

Time that it typically takes for withdrawal symptoms

from benzodiazepines to clear, according to support groups and some experts

800,000

Number of people taking antidepressants long-term who have been wrongly prescribed

700

The percentage rise in opioid painkiller prescriptions in Britain over the past two decades

Blackwell pledged that a Labour government would act to ensure justice for victims of the drugs. But when Labour won the 1997 General Election, it did not do so.

Labour was not the first political party with empty promises. In 1993, the Conservatives announced that GPs should be given local targets for reducing benzodiazepine prescriptions. Nothing came of it.

In 2008, Health's campaigning colleague Michael Bevan, a researcher for the All-Party Parliamentary Group on Translational Medicine, pointed out that as a hardline Labour MP Dawn Primarolo had asked more than 10 questions pressing for compensation for victims.

But according to Mr Bevan, after Primarolo was made Minister for Public Health, her department did not move one inch.

More follow-up came from David Cameron, who, as prime minister in 2011, declared: "Translational medicine is an extreme problem in our country. We must deal with the problem of secure."

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Photo: Alan

MPs' ENDLESS BROKEN PROMISES

DOCTORS use the "unexplained" label as a top-out," says Barry Hadfield, who has long campaigned for benzodiazepine victims following his own experience of ten years on them.

Hadfield, a retired accountant from Oxford, Lancashire, says the symptoms are "unexplained" because the medical profession have never wanted to take responsibility, if they did, they might be sued on a massive scale.

"This is not a medical problem. It is a political problem that needs a political solution."

For decades, politicians have promised much yet failed to deliver. In 1994, Mr Bevan received a personal letter from David Primarolo, then Labour's Shadow Secretary of State for Health, describing benzodiazepine over-prescription as "a national scandal."

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PAST COMMITMENTS FROM MINISTERS

- *'It's an addiction [to prescription drugs], it's not been particularly at the forefront of people's mind, it's not been sexy if you like. I think the time has now come for us to put it up the agenda and I'm more than happy to do that. I think there have been some GPs, who've simply not been following the guidelines from their own professional bodies. They have been over-prescribing these drugs for year after year when they clearly should not be doing that. We can now see with the devolving of power down to local authorities to provide good drug treatment facilities to their communities, hopefully we can redress a great injustice that's been done over many years.'*
- Anna Soubry MP, Public Health Minister, 'World at One', BBC R4, 2013
- *'I'm taking this very seriously. It's an issue that's fallen through the cracks. We want to make sure that training and awareness is raised so that GPs know how to prescribe well and then we need to make sure that we've got the right services in place to give them the help and support they need to get off these drugs and get back and enjoy lives as they should be able to.'*
- Anne Milton MP, Public Health Minister, 'Face the Facts', BBC R4, 2011
- *'The addiction to prescription drugs, such as benzodiazepines, is a very important issue... This review will identify where and how policy should be advanced, so that those addicted to prescription or OTC drugs receive high quality, effective services.'*
- Gillian Merron MP, Public Health Minister, 2009

...BUT ON THE GROUND NOTHING HAS CHANGED FOR PATIENTS

SUMMARY

- The case for a national 24 hour helpline and website for prescribed drug dependence is compelling:
 - It is estimated that over 1 million patients are taking benzodiazepines, z-drugs and antidepressants unnecessarily in England alone
 - The cost of unnecessary prescriptions and GP visits for benzodiazepines, z-drugs and antidepressants is estimated at over £140m per year in England alone
 - A 2017 survey of patients affected by prescribed drug dependence indicates that 87% of respondents would find a helpline 'helpful'
 - 27% of respondents are off work indefinitely due to withdrawal symptoms
 - The call for a helpline is supported by the BMA, the Royal College of Psychiatrists, the Royal College of GPs, the Royal College of Physicians and many other medical bodies
 - The Daily Mail has launched an indefinite campaign demanding a national helpline
 - A helpline would be an effective, low cost response to a growing national public health crisis

“For over 4 years, withdrawal has put my life on hold. It has been hell for me. It caused me to lose all my friends and my social life, I even became estranged to my own family. Early on in withdrawal I tried to commit suicide and I came close a second time. After suffering severely all these years I'm finally starting to see light again, although I'm still tapering other medications.

The hardest part for me was the lack of knowledge/support/belief from professionals. I had to figure it all out by myself.”

Anonymous patient, September 2017

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