

# 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 2016<sup>1</sup>
- 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)<sup>2</sup>
  - 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 2006<sup>3</sup>
  - 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 treatment<sup>4</sup>
  - 63% of patients experience withdrawal symptoms when stopping antidepressants<sup>5</sup>
- Researchers at the University of Roehampton estimate that 770,000 long-term antidepressant users in England are taking them unnecessarily<sup>6</sup>
- 23.9 million prescriptions for opioid analgesics were issued in the community in England in 2016, an increase of 200% since 2006<sup>7</sup>

## THE COSTS OF UNNECESSARY PRESCRIBING<sup>8</sup>

- 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 2017<sup>9</sup>
- 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?<sup>10</sup>

“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 dependence<sup>1</sup>
- 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 THEIR DOCTORS WHO TURNED US INTO DRUG ADDICTS

**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 normally prescribed by GPs for pain, anxiety, sleeplessness or depression. They also have a muscle relaxant effect, which is why Fiona was given them because her type of epilepsy occurred shortly after she gave birth.

Because benzodiazepines (so-called "benzos") are highly addictive, and for millions of patients should be put on such drugs for only long weeks. Long-term use can also lead to problems with memory and concentration, anxiety and depression as well as withdrawal.

But as the Mail has previously highlighted, thousands of people in the UK are prescribed these pills for months and even years.

**By JOHN NAISH**  
Fiona, 67, 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 putting the pills, for the medication has caused her constant and chronic pain."

My adult life has been dominated by these drugs, she says. "I've had to stop driving, when I've managed to keep behind the wheel, I can't do any more. My mind is so foggy, I can't do any more."

She is hardly a unique experience. Up to a third of those who take benzodiazepines experience bizarre symptoms, according to Glasgow Lecturer, senior professor of clinical psychology at the University of London Institute of Psychiatry.

And yet few other specialists are told their symptoms are "medically unexplained" - or even a sign of mental health problems.

Fiona was on a health training course at university when she was diagnosed with epilepsy at 19 and put on benzodiazepines.

Within two months of starting I was in bed for three months. I suddenly felt desperate and would a way out. "One day, I couldn't explain why my personality had changed so suddenly and dramatically."

I would spend large chunks of the day in bed and developed a fear of being alone.

It was told that my symptoms were that of depression, and I believed it. I kept taking the tablets, thinking they would make me feel better. It didn't help. I had no idea that it could be the drugs that were making me ill.

## 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?

stuck. "I was determined to turn my life around," she says. "After I graduated in 1980, I got a job at Heriots University and then worked in the NHS doing research around mental health and working planning for 39 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 60s, she noticed problems with her memory. As when she developed irritable bowel syndrome, she noticed.

In 2011, a new doctor advised her to enter off medication as it was over four months Fiona gradually stopped her dose before finally stopping altogether.

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

I started to sleep down and becoming more able to function 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 process 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."

As being the MP," says Fiona. In 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 a culture of denial among doctors alongside a litany of broken promises by political leaders.

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

He CP 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 my symptoms

as being the MP," says Fiona. In a leading expert in this field is no doubt her symptoms were caused by the medication.

Even publications from treatment watching the National Institute for Health and Care Excellence (NICE) warn that benzodiazepine withdrawal can cause confusion, toxic psychosis, convulsions or a condition resembling delirium tremens - the latter referring to the symptom seen in alcoholics.

Latest figures show there were 13 million prescriptions for benzodiazepines handed out in 12, 13 in 2013 - with an estimated million-plus prescriptions taken every day, according to evidence published by the BMA in April.

Up to 30 per cent of people who are on a benzodiazepine such as diazepam have trouble sleeping at



Photo: Alan Tan

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*. Frances, though the exact physical cause was not explained.

"The brain starts to wake up, and it over-wakes," he says. "People appear loud and lights appear brighter. They also have a tremor whereby they feel very unsteady and they will walk round the room leaning on to the walls."

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**VICTIMS TOLD IT'S ALL IN THEIR MIND**  
THESE are among the pictures of bizarre disabling problems suffered by Fiona French and countless

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 who works with the BMA on its campaign, explains: "There is a pattern in patients where doctors don't believe that they have withdrawal symptoms, such as panic, fit and psychiatric disorders, such as anxiety and obsessional."

"I've never to regard these victims as "hard-to-treat patients" who escape or defeat their doctors by their behaviour - whose problems are psychological."

"All too often doctors tend to take note of the fact they have been on benzodiazepines for years."

"The medical profession has never studied to take responsibility if they do. They might be sent on a massive scale of psychiatric services."

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

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

## 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
- 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

Blunkett pledged that a Labour government would act to ensure that victims of the drugs, but after Labour was 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, Hadden's campaigning colleague Michael Bevan, a researcher for the All-Party Parliamentary Group on Translocator Addiction, queried such that as a hard-bitten Labour MP Dawn Primorac had asked more than 10 questions pressing for compensation for victims.

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

More hollow words came in 2010, when Health Secretary Alan Dagnall, in 2011, declared: "Translocator addiction is an extreme problem in our country. We must deal with the problem of secure."

Mr Hadden persuaded his local health authority to fund a withdrawal support service for the 1,000 people in GMS stuck on long-term prescriptions.

**MP'S ENDLESS BROKEN PROMISES**  
DOCTORS use the "unexplained" label as a top-out," says Barry Hadden, who has long campaigned for benzodiazepine victims following his own experience of ten years on them.

Hadden, a retired accountant from Oldham, Lancashire, says the symptoms are "unexplained" because the medical profession has never studied to take responsibility if they do. They might be sent on a massive scale of psychiatric services."

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and do the opposite," says Mr Hadden. "Fiona French, a Labour MP and member of the All-Party Parliamentary Group for Drug Policy Reform, adds: "The history of politicians' broken promises for action on these drugs is so bad it threatens to give cynical opportunities to bad politicians. But he is optimistic that change will finally happen."

Now we have a broad base of people supporting the headline, including medical experts, former ministers and members of the House of Lords. I think the pressure will prove persuasive."

In the meantime, patients such as Fiona French have to turn to the internet in order to find support. I joined a group called *Benzo Buddies* and that has been my lifeline for the past three years, she says.

Four years after quitting her pills, Fiona is still troubled by crippling symptoms.

"I've lived a hard life, but I had hoped things would improve in my old days. I look back on my life and there are big things I can't remember. It's not like for me - and maybe doctors didn't know about their effects back in the 1960s - but they do now. Do you are three drugs will be prescribed."

"I'm not a wonderful person. All I want is an acknowledgement that my symptoms have been caused by these drugs."

She takes comfort from the BMA's campaign for a helpline and specialist services for prescription drug dependency.

"This is the first time the medical profession has acknowledged there is a problem with prescribed drugs and that people need help coming out of them," she says.

"You don't expect prescription drugs to do you harm, but I feel I was. I was originally reported by them."

■ **ADDITIONAL REPORTING**  
JO WATERS

## 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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