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\(^1\)
- 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 2006\(^3\)
  - 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\(^4\)
  - 63% of patients experience withdrawal symptoms when stopping antidepressants\(^5\)
- Researchers at the University of Roehampton estimate that 770,000 long-term antidepressant users in England are taking them unnecessarily\(^6\)
- 23.9 million prescriptions for opioid analgesics were issued in the community in England in 2016, an increase of 200% since 2006\(^7\)
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
The University of Roehampton & the Council for Evidence-Based Psychiatry conducted a survey of patients affected by prescribed drug dependence in August 2017.

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?

“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 it’s 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.”

“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.”

“Many people are too ill to leave their home and cannot reach out any other way.”
On 24 October 2016 the BMA published its call for a national helpline to support patients affected by prescribed drug dependence.

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.”
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
BETRAYED BY THE DOCTORS WHO TURNED US INTO DRUG ADDICTS

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?

By JOHN NAISH

SYMPTOMS WORSE AFTER QUitting

Worried that I was becoming obsessed again, says Fiona, a leading expert in this field. And yet she discovered that doctors were using drugs to treat patients who were suffering from the withdrawal symptoms from drugs such as benzodiazepines.

LACK OF SUPPORT FOR PATIENTS

For too long, there has been a culture of denial among doctors about the symptoms of withdrawal, according to Fiona. She was told by a doctor that she was suffering from a psychiatric disorder. But she later discovered that this was not the case.

WARNINGS GO BACK TO THE SEVENTIES

The risks associated with prolonged use of benzodiazepines have been known since the 1970s, when doctors first started to prescribe these drugs. But the problem persisted and the situation only got worse as new drugs were introduced into the market.

SCANDAL BY NUMBERS

2-4 weeks: the time it typically takes for withdrawal symptoms to start

6-18 months: the time it typically takes for withdrawal symptoms to become severe

700: the percentage of patients who have been prescribed benzodiazepines

MPs' ENDLESS BROKEN PROMISES

VICTIMS TOLD IT'S ALL IN THEIR MIND

These are among the doctors who have been prescribing benzodiazepines to patients who are suffering from withdrawal symptoms. But the patients are not to blame and are not imaginary.
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*
REFERENCES

1. Prescription Cost Analysis 2016, NHS Digital
6. Estimates based on the following research into unnecessary prescribing:
7. Prescription Cost Analysis 2016, NHS Digital