

All Party Parliamentary Group for Prescribed Drug Dependence



Call for national helpline to support patients affected by Prescribed Drug Dependence (PDD)

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v3.1

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1.0 Key points

- In the UK up to 10m people are taking benzodiazepines, sleeping pills, antidepressants or other psychiatric medications at any given time, and 10m people receive opiate painkiller prescriptions each year.
- Prescription numbers are rising generally, and in particular antidepressant prescribing has increased over 500% since 1992.
- Dependence can result in a variety of harms, including side effects and withdrawal effects. In addition, opiate dependency can result in overdose, which can be fatal.
- Side effects and withdrawal effects can be severe and last for months and sometimes years, leading to disability.
- Specialist support services are required to help and support patients with prescribed drug dependence, as existing drug and alcohol services are inappropriate.
- There is a lot of variability in terms of the response by doctors – including psychiatrists – to the issue of prescribed drug dependence and withdrawal, due to a lack of awareness and relevant training.
- There are no NHS services that provide such specialist support.
- There are however a small number of charities and support groups which provide specialist support services, but cover only a small fraction of the UK, and they report a significant increase in demand over recent years.
- Following the devolution of the NHS, these charities report difficulties obtaining funding, and two have closed down, leaving only one part-time national helpline with inadequate staffing.
- It is therefore proposed that the government should fund a national helpline to provide support and advice to this group of patients, alongside a website which acts as a prescribed drug and withdrawal resource for both doctors and patients.
- The helpline would include a range of services including information on prescribed drug dependence, slow tapering protocols, coping strategies, support for carers and family members as well as liaison with primary care services.
- The helpline would have the following benefits:
 - It would help patients by providing appropriate support during withdrawal, help with symptom management and referrals to in-person local support groups;
 - It would be a relatively low cost yet effective national response to recognised gaps in local provision;
 - It would lead to a reduction in costs from reduced prescribing levels, and from a reduction of GP time taken up by affected patients;
 - It would be evidence of a commitment to meet the urgent needs of a prominent, and increasingly vocal, minority group;
 - It would provide an opportunity to put into practice the commitments made by a succession of health ministers as well as the 2013 Addiction to Medicines Consensus Statement.

2.0 Background

Prescriptions for psychiatric drugs, sleeping pills and opioid painkillers have risen dramatically over recent years. It is estimated that up to 10m people – or 15% of the UK population – are taking benzodiazepines, sleeping pills, antidepressants or other psychiatric medications at any given time.

In addition, around 10m people in the UK are prescribed opiate painkillers annually, on top of millions more who purchase codeine-based over-the-counter products.

Psychiatric drugs, sleeping pills and painkillers are all psychoactive, and can therefore lead to dependence. For many patients, dependence can result in a variety of harms, including side effects and withdrawal effects. In addition, opiate dependency can result in overdose, which is sometimes fatal.

Withdrawal effects vary in terms of their duration and severity. For some patients, they are mild and self-limiting, while for others they can be very severe and last for months and sometimes years, leading to disability. Doctors are often unaware that these long-term symptoms can be caused by medication, which can lead patients to seek support outside of primary care.

There are no NHS services that provide specialist support for individuals suffering from withdrawal from prescribed drugs. There are however a small number of charities and support groups which provide limited help and advice. However, while demand is rising for their services, these organisations have struggled to maintain funding in recent years. Two have closed down in the past 18 months, leaving only one small charity running a limited helpline.

While there is no good data estimating the number of people in need of prescribed drug support services, the charities and support groups report a significant increase in demand over recent years. These patients are often experiencing severe, long-term withdrawal symptoms, and require specialist support both tapering from their medication as well as coping with the sometimes disabling symptoms.

It is therefore proposed that the government should fund a national helpline to provide support and advice to this group of patients, most of whom have become dependent simply because they followed their doctor's advice.

3.0 Existing provision

In June 2012 APPGITA (All-Party Parliamentary Group on Involuntary Tranquiliser Addiction) undertook a survey to determine the level of the provision of NHS services for involuntary tranquiliser addiction. This followed an assertion by the Department of Health that there were services available across most of the country. The Department of Health made this claim following a report published by the National Treatment Agency which states that '94% of those partnerships... reported that there was local service provision in place for those that reported problems in relation to [prescription] medicines.'¹

However there was a major flaw in the NTA report; it only surveyed existing illegal drug and alcohol treatment services rather than considering the need of patients in the wider community. As the report itself states, 'there might well be another population of individuals who wouldn't dream of stepping foot inside a traditional drug treatment service.'² We argue that this accounts for the vast majority of patients with prescribed drug dependence.

From this much smaller sample of users of illegal drug and alcohol treatment services, only 32,510 patients were identified as having problems with prescribed drugs, and this led some experts to claim that the problem was much smaller than it is. It also led ministers to claim that services were available across the majority of the country when in fact they were not.

As a consequence, APPGITA contacted 149 Primary Care Trusts, asking what services were available in their area to support involuntary tranquiliser addiction. Of the 100 who responded, 83 primary care trusts acknowledged that they had no services, 11 had partial services while only 6 confirmed that they had services.³ It can be reasonably assumed that if there are no services for benzodiazepines – the most recognised category of prescribed drug dependence – then it is very unlikely that there will be services for other prescribed medicines (a conclusion which an informal assessment of services supports).

Currently there are only a handful of charities that provide services in support of individuals seeking to withdraw from prescribed drugs. These are as follows:

<i>Name</i>	<i>Drugs covered</i>	<i>Area served</i>
Addiction Dependency Solutions	Benzodiazepines, illegal drugs and alcohol	Manchester area
Battle Against Tranquilisers	Benzodiazepines	Bristol
Bristol and District Tranquiliser Project	Benzodiazepines, z-drugs and antidepressants	Bristol

¹ NTA report: Addiction to Medicine, 2011, page 16, see <http://www.nta.nhs.uk/uploads/addictiontomedicinesmay2011a.pdf>

² NTA report: Addiction to Medicine, 2011, page 26, see <http://www.nta.nhs.uk/uploads/addictiontomedicinesmay2011a.pdf>

³ Perrot J, 2012, Survey of PCTs Recording Provision of Services for Involuntary Tranquiliser Addiction for APPGITA, see: <http://www.yumpu.com/en/document/view/11700252/survey-of-services-john-perrott-appgita>

Painkiller Addiction Information Network (PAIN)	Opiate painkillers	National
Project Answer	Benzodiazepines, illegal drugs	North Tyne
Prescribed Medication Support Service	Benzodiazepines, antidepressants, other psychiatric drugs	Mold, North Wales
REST (MIND in Camden)	Benzodiazepines	Camden and Islington in London
The Bridge Project	Benzodiazepines, illegal drugs	Bradford

These charities cover a small fraction of the country in terms of the population they serve. Of these, only the Bristol and District Tranquiliser Project offers a part-time national helpline service. The helpline operates from 10am to 3.30pm, Monday to Thursday. Because of high demand and limited resources, callers are often unable to get through on their first or even second attempt.

REST also offers a helpline service but is restricted to its funded geographical area of Camden and Islington.

The devolution of the NHS has led to increased levels of financing uncertainty, and two charities have closed down in the past three years due to a lack of funding. CITAp (the Council for Information on Tranquilisers, Antidepressants and Painkillers) was a small charity based in Liverpool which had been running since the 1980s. It provided a national helpline as well as in person support groups in the Liverpool area. It closed in 2014 after the local authority decided not to provide any further funding. Recovery Road was another small charity based in Cardiff which provided a helpline for people coming off benzodiazepines and antidepressants. Despite overwhelming numbers of calls, it was also unable to secure long-term funding, and closed down in 2013 after only a year of operation.

It should be noted that there are extensive sources of information and support for the harmful effects of misuse of alcohol, tobacco, and illicit substances but very little accessible information and support for the harmful side effects of prescribed medication, and on the difficulties individuals face when withdrawing.

4.0 Evidence of demand

4.1 Benzodiazepines and sleeping pills

There is evidence of demand for support for withdrawal effects for benzodiazepines and z-drugs (sleeping pills). There are roughly 16.5m⁴ prescriptions for these drugs issued annually in England alone, with over 30% of prescriptions containing more than 29 units. This indicates a significant number of people are still being prescribed benzodiazepines for longer than 4 weeks, in contravention of BNF guidelines.⁵

While there has been no systematic review of the prevalence of benzodiazepine prescribing, a poll by Panorama in 2001 of almost 2,000 people revealed that 3% of the adult population had been taking the drugs for more than four months⁶. Given that prescribing levels have remained steady over the past few years, this would have extrapolated to roughly 1.9 million long term users in the UK at the time.

Recent research by academics at the University of Roehampton estimates that the current number of long-term benzodiazepine users in the UK is over 266,000. This estimate was projected from the analysis of data obtained by the Bridge Project (a charity operating in Bradford) for benzodiazepine withdrawal.

There are various online peer support groups supporting people coming off benzodiazepines. The largest in the UK is benzobuddies.org. It has an active membership of about 2,300 with around 50,000 unique visits per month. It is commonly estimated that only 1% of an internet community actively create new content⁷, suggesting that over 200,000 people may be regularly accessing information from benzobuddies.org.

4.2 Antidepressants

There has been a significant increase in the prescribing of antidepressants over recent years. In 2015 in England alone over 61 million prescriptions were issued for antidepressants, a 6% increase on the previous year and over 500% increase since 1992.⁸ A recent report by the OECD confirms a dramatic increase in the prescribing of antidepressants across the developed world, with estimates that as many as one in ten adults take these drugs regularly.⁹

The Health and Social Care Information Centre published its Health Survey for England in 2013, which showed that 11% of women and 6% of men are taking antidepressants.¹⁰ This would equate to 3.5m women and 1.9m men nationally, making 5.4m in total.

But despite the rising prescription rates and increasing numbers of long-term users, it is uncertain whether long-term use of antidepressants is safe or effective. Antidepressants were approved for

⁴ Health and Social Care Information Centre, <http://www.hscic.gov.uk>

⁵ MHRA Benzodiazepines Learning Module, <http://www.mhra.gov.uk/benzodiazepines-learning-module/index.htm>

⁶ BBC Panorama, The Tranquilliser Trap, 2001 (transcript: http://news.bbc.co.uk/1/hi/english/static/audio_video/programmes/panorama/transcripts/transcript_13_05_01.txt)

⁷ https://en.wikipedia.org/wiki/1%25_rule_%28Internet_culture%29

⁸ HSCIC data, 2015. See <http://content.digital.nhs.uk/catalogue/PUB20200> retrieved 22 Oct 2016

⁹ See <http://www.oecd.org/els/health-systems/Health-at-a-Glance-2013.pdf> retrieved 22 Feb 2014

¹⁰ Health and Social Care Information Centre, <http://www.hscic.gov.uk/catalogue/PUB16076/HSE2013-Ch5-pres-meds.pdf>

public use on the basis of only short-term trials, and there is evidence that long-term use is worsening outcomes for patients.¹¹

In addition, some withdrawal charities and support groups now report that more people are requesting support for antidepressants than for benzodiazepines. Ian Singleton of the Bristol and District Tranquiliser Project says: “Antidepressants seem to cause just as many problems as benzodiazepines... many of the symptoms are the same as benzodiazepine withdrawal... in many cases we have found that the symptoms of antidepressant withdrawal go on for even longer than benzodiazepine withdrawal.”

4.3 *Opiate painkillers*

In the UK, the use of opiate painkillers is widespread. In England, the prescription cost analysis carried out by the Health and Social Care Information Centre indicates that in 2013 over 21 million items were dispensed in the BNF category opioid analgesics, including over 14 million items containing tramadol.¹² In addition, 18 million items containing codeine in combination with paracetamol, ibuprofen or similar drugs were dispensed on prescription. An NTA report highlighted an increase in the community prescribing of opioid analgesics from 228.3 million items in 1991 to 1,384.6 million items in 2009.¹³

Dependence on opioid medications is not documented routinely in UK clinical practice. Attempts to calculate rates of problematic opioid use more widely from the literature have suffered from imprecise and poorly defined terminology. However, the best estimates available from the published literature come from a recent systematic review that included data from 38 clinical studies. Rates of opioid medication misuse ranged from 21% to 29% and rates of addiction averaged between 8% and 12% for patients on chronic opioid therapy.¹⁴

The British Pain Society has recognised the problem and stated: ‘We do not know what the scale of the opioid-related harms is, but all of us see patients in this trap in almost every clinic.’¹⁵

¹¹ El-Mallakh S., 2011, Tardive dysphoria: The role of long term antidepressant use in inducing chronic depression, *Medical Hypotheses* 76 (2011) 769–773

¹² Prescription cost analysis – England 2013 data table, Prescription Cost Analysis England 2013, Health and Social Care Information Centre

¹³ NTA *ibid.*

¹⁴ Vowles KE, McEntee ML, Julnes PS, Frohe T, Ney JP, van der Goes DN. Rates of opioid misuse, abuse, and addiction in chronic pain: a systematic review and data synthesis. *Pain* 2015;156:569-76.

¹⁵ Stannard C. Opioid prescribing in the UK: can we avert a public health disaster? *Br J Pain* 2012; 6: 7–8.

5.0 The harms

Long-term use of psychoactive prescribed drugs is associated with a range of harms both while taking the drug and upon withdrawal. All psychoactive drugs have specific biochemical effects, and over time neurotransmitter systems react to these effects and broader changes begin to occur in the brain and in mental functioning. In his 2001 paper, 'Psychiatric drug-induced Chronic Brain Impairment (CBI): Implications for long-term treatment with Psychiatric Medication', the leading psychiatrist and researcher Dr Peter R. Breggin describes one such effect as 'chronic brain impairment' (CBI). He describes it as being 'associated with generalized brain dysfunction manifesting itself in an overall compromise of mental function'. The symptoms of this syndrome include: cognitive deficits (often first noticed as short-term memory dysfunction and impaired new learning), difficulty with attention and concentration, apathy, indifference (or an overall loss of enjoyment and interest in life activities), affective dysregulation (including emotional lability), loss of empathy, increased irritability and finally a lack of self-awareness about these changes in mental function and behaviour.

5.1 Benzodiazepines

Long-term use of benzodiazepines has various well-understood harms, and has recently been associated with an increased risk of dementia.¹⁶ In 2007, French researchers surveyed 4,425 long-term benzodiazepine users and found 75 percent were 'markedly ill to extremely ill, with significant symptomology, major depressive episodes and generalized anxiety disorder often with severity and disability'.¹⁷ Reports showed long-term benzodiazepine use causes emotional distress, cognitive impairment as well as impaired self-insight.¹⁸ A review of the relevant literature by Australian scientists in 2004 concluded, 'long-term benzodiazepine users were consistently more impaired than controls across all cognitive categories and the higher the intake, dose and period of use (of benzodiazepine), the greater the risk of impairment.'¹⁹

5.2 Antidepressants

There is a growing body of research which suggests that long-term use of antidepressants is leading to worse outcomes for patients. For example, a six-year 1995 NIMH-funded study at the University of Iowa found that depressed people who were medicated were three times more likely to suffer a cessation of their principal social role, and seven times more likely to become incapacitated than those who didn't get treated.²⁰

In addition Ross Baldessarini at the Harvard Medical School, through a meta-analysis conducted in 1997, reported that 50% of patients withdrawn from antidepressants relapse within 14 months. He concluded that the longer the exposure to the drug, the greater the relapse rate.²¹

¹⁶ De Gage, S. Benzodiazepine use and risk of Alzheimer's disease: case-control study *BMJ* 2014; 349 doi: <http://dx.doi.org/10.1136/bmj.g5205> (Published 09 September 2014)

¹⁷ Pelissolo, A., 2007, Anxiety and depressive disorders in 4,425 long-term benzodiazepine users in general practice, *Encephale* 33: 32-38

¹⁸ Golombok, S., 1988, Cognitive impairment in long-term benzodiazepine users, *Psychological Medicine* 18: 365-74

¹⁹ Barker, M., 2004, Long-term effects of benzodiazepine use, *CNS Drugs* 18: 37-48

²⁰ Coryell W, 1995, Characteristics and significance of untreated major depressive disorder, *AJP* 152:1124-29

²¹ Viguera A C, 1998, 'Discontinuing antidepressant treatment in major depression', *Harvard Review of Psychiatry* 5: 293-305.

A Dutch study published in 2000 looked at the outcomes after ten years of 222 people who suffered a first episode of depression. This showed that 76% of those who were not treated with a drug recovered vs 50% who were prescribed medication.²²

Various other papers have considered whether the rising use of antidepressants may be worsening outcomes for patients, concluding that more research is urgently needed.^{23, 24}

5.3 Opiate painkillers

For opioids, the impact of chronic and long-term use can be similarly devastating. Most immediately is the risk of overdose. Mortality trends in the USA show a relentless rise in the number of deaths from OP overdose; in 2010 the figure of 16,500 was more than double the number for 2002 and more than twice the number of deaths from heroin and cocaine combined. While the figures for the UK are not as dramatic, a similar trend can be discerned. For example, in 1996 there was just one death record for Tramadol in England and Wales. By 2011 that figure had risen to 154²⁵ and according to the Office of National Statistics drug-related death figures for England and Wales 2014, the figure for Tramadol is now at 240. In 2013, there were 757 deaths where an opiate painkiller was mentioned on the death certificate, almost as many as for heroin and morphine (765). This had risen by 30% between 2012-2013, again similar to the increase in heroin and morphine-related deaths for the same period. For 2014, the figure for all opiate deaths apart from heroin, morphine and methadone was 760 while the figure for heroin & morphine rose significantly to 952.²⁶ Mortality data from Scotland²⁷ revealed that from a list of selected drugs reported, the numbers of deaths from codeine, dihydrocodeine and related compounds rose from 69 in 2010 to 107 in 2014.

5.4 Withdrawal

Furthermore, withdrawal from these drugs can result in many long-term disabling effects. The severe physical and psychological symptoms can impact negatively on many aspects of a person's life, threatening relationships, careers and financial stability. Withdrawal can also be very long lasting despite the claims of some studies which suggest a recovery period of several weeks to a few months.²⁸ Withdrawal charities report numerous examples of clients taking several years to recover. According to Ian Singleton of the Bristol Tranquilliser Project: 'Most people will have symptoms once they come off these drugs for at least a year... the majority will recover in their second year. But there are some who will take several years.'²⁹

Typical antidepressant withdrawal symptoms include flu-like symptoms, insomnia, nausea, imbalance, sensory disturbances, and hyperarousal. Dizziness, electric shock-like sensations, zaps,

²² Weel-Baumgarten E, 2000, Treatment of depression related to recurrence, *J Clin Pharmacy and Therapeutics*, 25:61-66

²³ Can long-term treatment with antidepressant drugs worsen the course of depression? Fava, G. *Journal of Clinical Psychiatry* 64 (2003):123-33

²⁴ Tardive Dysphoria: The Role of Long-term Antidepressant Use in Inducing Chronic Depression. El-Mallkh, R. *Medical Hypotheses* 76 (2011):769-773.

²⁵ Giraudon, I. et al. (2013) Prescription opioid abuse in the UK. *British Journal of Clinical Pharmacology*, 76 (5), p823-824.

²⁶ Office of National Statistics. Deaths related to drug poisoning England and Wales 2013 (2014) and 2014 (2015)

²⁷ National Records of Scotland (2015). Drug related deaths in Scotland 2014.

²⁸ Haddad, P. and Anderson, I.M., 2007. Recognising and managing antidepressant discontinuation symptoms. *Advances in Psychiatric Treatment*, 13: 447-457 doi: 10.1192/ apt.bp.105.001966.

²⁹ See: How Long Does Withdrawal Last? <http://cepuk.org/withdrawal-advisers/> Retrieved 21 February 2014

diarrhoea, headaches, muscle spasms and tremors, agitation, hallucinations, confusion, malaise, sweating and irritability are also reported.^{30, 31}

Professor Heather Ashton became a leading authority on benzodiazepine withdrawal after managing a large withdrawal clinic in the 1980s. She describes a range of withdrawal symptoms, broken down into physical and psychological categories. Psychological symptoms include insomnia, nightmares, increased anxiety, panic attacks, agoraphobia, perceptual distortions, depersonalisation, derealisation, hallucinations, depression, obsessions, paranoid thoughts, rage, aggression, irritability, poor memory & concentration, intrusive memories. Physical symptoms include headache, pain/stiffness, tingling, numbness, altered sensation, fatigue, influenza-like symptoms, muscle twitches, jerks, tics, 'electric shocks', tremor, dizziness, light-headedness, poor balance, blurred/double vision, sore or dry eyes, tinnitus, hypersensitivity, gastrointestinal symptoms, constipation, pain, distension, difficulty swallowing, appetite/weight change, dry mouth, metallic taste, unusual smell, sweating, palpitations, over-breathing, urinary difficulties/menstrual difficulties, skin rashes and itching.³²

Patient groups report several cases of individuals who have committed suicide as a result of intolerable withdrawal symptoms. In addition, two studies reviewing outcomes of benzodiazepine withdrawal included suicides among relatively small groups of subjects; in both cases withdrawal symptoms were considered as a factor.^{33, 34}

5.5 *Impact of dependence and withdrawal*

As with other serious chronic illnesses, withdrawal can have devastating effects on a person's life beyond the physical and psychological symptoms. Dr. Joanna Moncrieff describes the broader impact of withdrawal: 'If symptoms are troubling and go on for a long time... in some cases people find that they can't get back to work, lose their jobs, they might split up with their family because they continue to be impaired by these symptoms. They will lose their confidence, be depressed as a result of withdrawal and be anxious about the future.'³⁵

The disabling effects of withdrawal also adversely affect family members who, with no understanding of how to manage the complex physical and psychological symptoms, are often overwhelmed and find it difficult to provide adequate and appropriate support.

Psychiatrist Dr. Ronald Gershman writes: 'I have treated ten thousand patients for alcohol and drug problems and have detoxed approximately 1,500 patients for benzodiazepines – the detox for the benzodiazepines is one of the hardest detoxes we do. It can take an extremely long time, about half the length of time they have been addicted – the ongoing relentless withdrawals can be so

³⁰ Warner, C. Bobo, W. Warner, C. Reid, S. Rachal, J., 2006, Antidepressant Discontinuation Syndrome. *American Family Physician*. 8/1/2006, Vol. 74 Issue 3, p449-456.

³¹ Healy, D. 2012. Data Based Medicine Paper: Dependence and Withdrawal. See <http://davidhealy.org/wp-content/uploads/2012/06/DBM-Paper-Dependence-and-Withdrawal.pdf> Retrieved 21 February 2014

³² Ashton C H., 2002, Benzodiazepines: How They Work and How to Withdraw. Institute of Neuroscience, Newcastle University, Newcastle upon Tyne. See <http://www.benzo.org.uk/manual/index.htm> retrieved 22 February 2014

³³ Ashton H., 1987, Benzodiazepine withdrawal: outcome in 50 patients. *Br J Addict*. 1987; 82: 665-71.

³⁴ Joughin N, Tata P, Collins M, Hooper C, Falkowski J., 1991, In-patient withdrawal from long-term benzodiazepine use. *Br J Addict*. 86(4):449-55.

³⁵ See: Withdrawal Can Be Disabling, <http://cepuk.org/unrecognised-facts/withdrawal-can-be-disabling/>, retrieved 22 February, 2014

incapacitating it can cause total destruction to one's life – marriages break up, businesses are lost, bankruptcy, hospitalization, and of course suicide is probably the most single serious side effect.³⁶

Opiate painkiller dependency (OPD) is a highly distressing medical need that requires early diagnosis and appropriate treatment. OPD can cause serious medical conditions and a person with OPD can experience high levels of anxiety, significant mood swings and may become depressed and withdrawn from family, friends and work colleagues. In some cases, their ability to function well at work and at home is significantly reduced.

The family of a person with OPD may also be significantly affected by their loved one's behaviour. The behavioural changes observed by family members, and the subsequent breakdown in relationships, can be distressing, and made even more so by inadequate levels of awareness and understanding of the patient's needs and condition.

If dependence remains undetected and untreated, patients may progress to a drug addiction, which may then escalate to acquiring opioids through non-legitimate circumstances or by accessing prescriptions from a number of different channels, or to the use of more potent, illicit substances. The use of opioids under such circumstances can be fatal.

5.6 Disability

Side effects and withdrawal effects lead to disability for many people. Withdrawal charities report that many people who suffer severe symptoms become unable to work and often have to resign from their job. This of course has a profound negative impact on patients' lives, as well as causing harm to society through lost productivity and increased health and benefit costs.

A recent report³⁷ which analysed data from the Department of Work and Pensions shows that disability claims for mental disorders in the UK rose from 572,000 claims in 1995 to 1,162,000 claims in 2014. Of the claims in 2014, over 44% were for depressive disorders while 23% were for anxiety and other neurotic disorders. The increase in claims over the past twenty years correlates with a dramatic rise in the prescribing of psychiatric drugs – especially antidepressants where prescription numbers have risen in England by over 500% since 1992³⁸. Some experts contend that the increasing long-term use of psychiatric drugs is contributing directly to the rise in disability claimants.

It should also be noted that the drugs themselves are a significant cost to the NHS. The total cost of psychiatric drugs in England in 2014 was over £567m, while the cost of opiate painkillers in England in 2014 was £305m³⁹. These figures reflect only drugs which were delivered in the community and paid for by the NHS.

³⁶ Gershman, R., quoted in "The Hidden Epidemic"; Colvin, R., 1995, Prescription Drug Abuse, Addicus Books, Inc., 1995, Part I, 53-54.

³⁷ <http://bjpo.rcpsych.org/content/bjporcpsych/2/1/18.full.pdf>

³⁸ HSCIC data, 2013. See: <http://www.hscic.gov.uk/catalogue/PUB13887>

³⁹ <http://www.hscic.gov.uk/article/2021/Website-Search?productid=18058&topics=13210&sort=Most+recent&size=10&page=2#top>

6.0 Helpline services

The helpline service would be targeted at patients who are experiencing side effects or withdrawal effects as a result of dependence upon benzodiazepines, sleeping pills, antidepressants and opioid painkillers. It would also provide information for patients who are considering coming off these drugs.

It will target patients who have usually become dependent on these drugs as a result of taking them as prescribed by their GP or psychiatrist. For this reason, these patients do not identify themselves as 'addicts' and would not consider going to a traditional drug & alcohol treatment centre. In addition, protocols for withdrawing from existing illicit drug and alcohol services are usually unsuitable for patients withdrawing from long-term use of prescription drugs, which require much slower tapers.

Helpline services should be developed in consultation with existing prescribed drug withdrawal support charities who have decades of accumulated experience supporting this patient group.

The helpline service will provide patients with a combination of support and guidance, to include:

- Drug information, including common side effects, appropriate dosages and typical duration of treatment;
- Advice on withdrawal, including tapering protocols, duration of taper and optimal tapering methods;
- Information on withdrawal symptoms especially reassurance regarding symptoms and suggestions for coping strategies;
- Rights and advocacy information;
- Details of local specialist in-person support services, where available;
- Recommendations for non-drug alternatives to help patients cope with the underlying issues after withdrawal;
- Information and advice for carers and family members;
- Where appropriate, liaison with the patient's GP to ensure co-ordination of treatment.

In addition to the helpline, we propose that a website should be set up which will act as a prescribed drug and withdrawal resource. It will include information, including tapering protocols, for patients, doctors and other medical practitioners.

7.0 Expected outcomes

7.1 Benefits for patients

By providing appropriate support and advice, the helpline will:

- Improve patients' knowledge and understanding regarding prescribed drug dependence, thereby enabling them to make informed decisions about treatment and care;
- Support patients who decide to come off with appropriate protocols for tapering;
- Enable individuals to manage the symptoms caused by withdrawal effects and side effects;
- Raise awareness with both GPs and their patients about the options available in managing the consequences of long term prescribed drug use;
- Improve patients' psychological wellbeing and reduce social isolation through facilitating access to in-person support groups;
- Greatly improve the quality of life for patients who are able to come off their prescribed drug.

Many patients are unaware of all of the negative effects and only realise the degree of harm caused with hindsight. As Professor Ashton notes: 'Many users have remarked that it was not until they came off their drugs that they realised they had been operating below par for all the years they had been taking them. It was as though a net curtain or veil had been lifted from their eyes: slowly, sometimes suddenly, colours became brighter, grass greener, mind clearer, fears vanished, mood lifted, and physical vigour returned.'⁴⁰

7.2 Benefits for the Department of Health

The helpline will also have the following benefits for the Department of Health:

- It would be relatively low cost yet effective national response to recognised gaps in the local provision of prescribed drug dependence support services.
- It would be evidence of commitment to the 2013 Addiction to Medicines Consensus Statement.
- It would be evidence of a commitment to meet the urgent needs of a prominent, and increasingly vocal, minority group.
- It would result in a reduction in costs from reduced prescribing levels and a reduction of GP time taken up by affected patients.
- It would be an opportunity to gather data from the helpline to determine the scale of the issue and to identify gaps in current local service provision.

Lastly, a helpline would provide an opportunity to put into practice the commitments made by a succession of health 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.'

⁴⁰ Ashton C H., 2002, Benzodiazepines: How They Work and How to Withdraw. Chapter 2, Institute of Neuroscience, Newcastle University, Newcastle upon Tyne. See <http://www.benzo.org.uk/manual/index.htm> retrieved 22 February 2014

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

8.0 Why not primary care?

Withdrawal charities report a variety of approaches by GPs to treating and withdrawing patients from these drugs. Some are experienced and are aware of side effects and withdrawal effects, and understand for example the importance of slow tapers.

Others deny that the drugs can cause these problems, or insist on rapid tapers which can cause great harm to patients. Often, due to a lack of training and awareness in this area, doctors will misdiagnose withdrawal or side effects as a new illness, which can lead to the unnecessary addition of new drugs. This can result in the potentially harmful use of multiple drugs, known as polypharmacy.

It is clear that there is a lot of variability in terms of the response by doctors – including psychiatrists – to the issue of prescribed drug dependence and withdrawal. A national helpline and website would therefore help to bring about consistency in terms of the support provided in primary care.

8.1 Risk of misdiagnosis

The duration of withdrawal symptoms can lead to confusion for many doctors and patients, increasing the likelihood of misdiagnosis and the addition of unnecessary medication. In addition, the extreme nature of the symptoms can lead to alternative medical explanations as well as unnecessary tests and treatments. For example, Dr. Peter Haddad describes two patients who withdrew from antidepressants and were misdiagnosed as having suffered a stroke; the symptoms were so severe that neither could walk unaided.⁴¹

In another paper, Haddad describes five ways in which antidepressant discontinuation symptoms can lead to misdiagnosis and unnecessary treatment. This includes misdiagnosis as a recurrence of an underlying psychiatric illness: 'Discontinuation symptoms that follow recovery from a depressive illness and termination of antidepressant treatment may be misdiagnosed as a recurrence of depression, i.e. a further depressive episode. This may lead to unnecessary reinstatement of the antidepressant and a more negative prognosis, with significant social implications.'⁴²

The leading researcher and psychiatrist Dr. Joanna Moncrieff believes that psychiatric drugs may, over time, perpetuate the very disorders they were intended to treat. She argues that, 'the problems that occur after discontinuation or reduction of long-term psychiatric drug treatment may be caused by the process of drug withdrawal itself... the recurrent nature of psychiatric conditions may sometimes be iatrogenic.'⁴³

In the UK withdrawal charities frequently encounter patients who have been put on multiple psychiatric medications, often in order to counter withdrawal or other negative effects. As Ian Singleton from the Bristol Tranquilliser Project says: 'It's very common for people in withdrawal to find that doctors ascribe their symptoms to other things, leading to other drugs such as antidepressants and major tranquillisers [antipsychotics] which can be extremely difficult to come

⁴¹ Haddad P M, 2001, Antidepressant discontinuation (withdrawal) symptoms presenting as 'stroke', *J Psychopharmacol* March 2001 vol. 15 no. 2 139-141

⁴² Haddad P., 2007, Recognising and managing antidepressant discontinuation symptoms, *Advances in Psychiatric Treatment*, 13: 447-457 doi: 10.1192/apt.bp.105.001966

⁴³ Moncrieff J., 2006, Why is it so difficult to stop psychiatric drug treatment? It may be nothing to do with the original problem, *Med Hypotheses*, 67(3):517-23.

off. This means that instead of withdrawal taking a year or two, you might be looking at 5 to 10 years for those people to get fully well. It's a total waste of their life.'⁴⁴

We also note the following results from a 2014 survey by the Council for Evidence-based Psychiatry of UK patients affected by prescribed drug issues⁴⁵:

- 60% of patients were told by their doctor that the negative effects were not caused by the drugs, and 23% were given a new diagnosis based on negative drug effects.
- 71% believe they were not given any appropriate support by their doctor while 24% were told that their doctor wanted to prescribe new drugs for their symptoms.

⁴⁴ From filmed interview on <http://cepuk.org/withdrawal-advisers/> Retrieved 13 Feb 2014

⁴⁵ Prescribed Drug Issues Survey, 2014, Council for Evidence-based Psychiatry

9.0 Why a national helpline?

For more than ten years, drug telephone helpline services such as Talk to Frank have played a first line role in the prevention of the harm associated with the use of drugs. Helpline services are both a tool for public health policy and an opportunity to help targeted patient groups.

Drug helplines have the following advantages:

- They are available nationally, and therefore can provide support to people living in areas with insufficient local provision of services.
- They are a cost-effective way of providing information, advice, referral and help.
- They are easily accessible, as close as the nearest telephone.
- They are interactive; callers are actively listened to and heard by someone with an understanding of their situation, helping often isolated individuals realise they are not alone with their problem.
- They are personalised and adaptable to individual needs.
- They are confidential and ensure anonymity.
- They are sources of important data to inform future services and policy, and to identify gaps in service provision.
- They are easy to publicise.
- They can complement and link into other social and treatment services.
- They offer a safe and easy first contact with sources of information and with treatment options.

In addition, a helpline is particularly appropriate for patients suffering from prescribed drug dependence, for the following reasons:

- Current service provision is very variable and limited to small parts of the country. A helpline would instantly enable patients from all over the UK to access timely, appropriate advice.
- There can be lots of stigma and guilt for people who have become dependent on prescription drugs and who would not consider themselves 'drug addicts'. For this reason, many are ashamed to seek help in person but are more likely to use a helpline.
- Patients suffering severe withdrawal are frequently bed-bound and often unable to leave their house. A helpline for these patients can be a lifeline and is sometimes their only connection to the outside world.

10.0 Conclusion

The impact of long-term use and withdrawal from psychoactive prescription drugs can be devastating, leading to a range of harms including disability and death. Studies demonstrate that long-term use often leads to worse outcomes for patients, yet prescription data shows that the rate of prescribing continues to increase, with millions of people in the UK taking prescribed psychoactive drugs long-term.

There are no NHS services which provide the specialist support needed by this cohort of patients. While some GPs are aware of the issue and can provide suitable advice, many are uninformed and as a result misdiagnosis can occur, leading to the unnecessary prescription of additional or substitute drugs.

The APPG for Prescribed Drug Dependence calls upon the Public Health Minister and the Department of Health to fulfil the commitment of successive health ministers by providing an appropriate helpline service for these patients. Such a helpline would ensure that there is timely, consistent, nationwide support for a group of patients who have become dependent – and often disabled – because of treatment received through the NHS. The Public Health Minister and the Department of Health should therefore recognise the urgent need for services in this area, and provide the necessary resources to ensure that there is an effective national solution to this growing national crisis in public health.