PE1651/RRRRRRR
Petitioner submission 13 April 2018

This is a supplementary submission to take into account a number of important contextual developments that have occurred since mid-February 2018 (Petitioner Submission ref: 1651/WWWWWW) – and are further developing.

UK PRESS and ROYAL COLLEGE OF PSYCHIATRISTS

On **22 February 2018 the Royal College of Psychiatrists** (RCPsych) issued confident national press statements about a newly published Lancet report on a study on efficacy of antidepressants – and suggested that many more patients should be prescribed them. (This was also the stated view of Maureen Watt and John Mitchell in their evidence to the Committee for this petition on 18 January.)

A letter by Profs Burn and Baldwin of RCPsych was published in The Times on 24 February, responding to a letter by James Davies et al (1), which said *'the statement that coming off antidepressants has disabling withdrawal effects in many patients "which often last for many years" is incorrect. We know that in the vast majority of patients, any unpleasant symptoms experienced on discontinuing antidepressants have resolved within two weeks of stopping treatment.'* (2). This has caused great distress to people who have submitted evidence for this petition – and the many others who have experienced dependence and withdrawal and have for years been desperately trying to raise the alarm. RCPsych's own research about antidepressant withdrawal, which John Mitchell referred to in his oral evidence to the Petition committee on 18 January, disappeared from RCPsych website on 26 February. This leaflet "Coming off antidepressants" was dated 2014 and reported a survey of 817 people who completed the RCPsych survey and shared their experiences: "512 (63%) people in our survey experienced withdrawal when stopping their antidepressants". (A full copy of this RCPsych leaflet is attached as an annexe to this submission).

GENERAL PRACTITIONERS / PRESCRIBERS

GP Des Spence (Scotland) is publicly supporting our petition and has written in Pulse 'Time to listen to patients about prescription problems' (3). This is also reflected in his submission Ref BBBBBBB where he says: **"All these problems are not the fault of patients. These problems are the responsibility of the medical profession. We are harming patients everyday and everywhere across the country."** Other GPs that we have spoken with quietly say that they agree with Des Spence – though are afraid to speak out. We have suggested in our email to the Committee on 16 Feb 2018 that "Perhaps the Petition team would be able to send a standard letter/email to all Scottish GP Practices notifying them about these two petitions and inviting any written input they might care to provide?". SAMH conducted earlier research (4)

SUICIDE ISSUES

A **public consultation about 'suicide prevention'** is currently being formally conducted in Scotland (5). Marion Brown and Beverley Thorpe have attended recent public consultation events. The relevance of our Petitions PE01651 and PE01627 have been made known to those conducting this consultation.
The following quotes are within the PE 01651 Submissions are highlighted:

KK (B Frederick): Suicides: One particular issue that conveys the urgency and validity of this Petition is **the suicide risk caused not just by the cruel and disabling withdrawal effects but by those affected not being believed by their own doctors and by family members**
Over the years we have lost too many lives to suicide and this type of crisis management that I deal with happens too frequently.
Doctors Affected by Withdrawal: Throughout the time I have been providing support, I have had people of all backgrounds contact me, including doctors in Scotland and elsewhere, who have been blindsided by an unanticipated withdrawal experience that made them unwell and unable to work and that created chaos in their lives. Sadly, despite promising to speak out and advocate on behalf of the community when withdrawal is over, they have chosen to remain silent, in order to not jeopardise their careers.

SSSSSS (D Healy) Vulnerable groups:

- Those suffering PSSD and PGAD: **These conditions and the response of the medical profession leads to suicides, marital breakups and job loss.**
- those individuals who have been disabled by treatment and who were in receipt of Personal Independence Benefits or other payments who have found their payments withdrawn once they get off treatment
- **withdrawal leads to a higher rate of suicidal events that any other period of treatment**. People should probably be told the reason why they should not just stop. And you need to consider what a woman who has just found she is pregnant should do.

In all populations, active treatments increase the rate of suicidal behaviours, along with exposing their takers to the risks of dependence. Once dependent there are risks to their offspring of birth defects in organ systems or abnormalities of behaviour including asexuality and depression.

RESEARCH AND EVIDENCE – WITHDRAWAL AND HARMS

It is becoming clear that there is very little, if any, clear research into the problems of withdrawal - and 'zero' studies of the harms suffered. On **7 April 2018 the New York Times** carried a major article 'Many people taking antidepressants discover they cannot quit' by Benedict Carey (6) and this has generated much discussion such as OnPoint radio (with Benedict Carey about the research he did for the article) (7) and Kelly Brogan's blog (8).

The **April 2018 edition of Psychiatric Times** includes a very important article (front page and continued over several pages) entitled **'Online Communities for Drug Withdrawal: What Can We Learn?'** (9). This is hugely relevant and includes discussion of, and reference to, our online self-help communities such as Surviving Antidepressants and BenzoBuddies - which have played

such a huge role in supporting affected people and, in the process, gathering essential 'evidence'.

NEUROLOGICAL ISSUES

As previously highlighted, there is actually mounting evidence of harm all around us – which is becoming dissipated in the realms of 'medically unexplained' symptoms and 'functional neurological' disorders (FND) – now alarmingly termed 'contemporary' disorders, and likened to 'shell shock'. A recent BMJ article 'Different shell, same shock' (10) includes the statement *"It is increasingly accepted that beliefs about bodily dysfunction can trickle down the hierarchical neural architecture of the brain to produce 'expected' symptoms beyond the conscious control of patients."* It is very disturbing now to see there is an up-coming free public 'Shell Shock Centenary' lecture currently advertised, linking Shell shock, PTSD and FND (11) ***"3 linked public lectures by world experts on Shell Shock and related disorders - including Functional Neurological Disorder (FND), a current and common and cause of severe disability".*** A 2010 article by Charles Whitfield entitled **'Psychiatric Drugs as Agents of Trauma'** (12) offers an explanation including the huge role played by 'medication'. This is clearly evidenced in the accounts submitted for the petition.

In the context of all of the above, the submissions for this petition are very significant indeed and have become a unique collection of voluntarily offered experiential evidence – which surely must be highly respected and valued accordingly.

BMA BOARD OF SCIENCE: PRESCRIBED DRUGS (13)

"Given recent developments, including PHE's planned evidence review, the BMA is hosting a further roundtable meeting for stakeholders, to allow members of the group to update on actions that have been taken since the last meeting and to discuss next steps" (13) BMA representative.
We are invited to participate in a BMA Board of Science Stakeholder meeting on **18 April in London,** where we have been asked to give a brief report about our Scottish Petition.
Draft of our 'report' is appended.

(1) Letter to TIMES 23 February 2018 'Stigma and efficacy of taking antidepressants' by James Davies et al
(2) Letter to TIMES 24 February 2018 'Pills for depression' by Profs Burn and Baldwin
(3) " Time to listen to patients about prescription problems", pulsetoday.co.uk, 7 March 2018
(4) https://www.samh.org.uk/documents/A_SAMH_Survey_of_general_practitioners_in_Scotland.pdf
(5) https://consult.gov.scot/mental-health-unit/suicide-prevention/

(6) “Many People Taking Antidepressants Discover They Cannot Quit”, The New York Times, 7 April 2018
(7) “Antidepressants And The Problem Of Withdrawal”, Wbur, 10 April 2018
(8) “Letter to The New York Times: Many People Taking Antidepressants Discover They Can’t Quit”, kellybroganmd.com, April 2018
(9) http://www.modernmedicine.com/sites/default/files/images/digital/PSY/psy0418_ezine.pdf
(10) https://www.bmj.com/content/359/bmj.j5621
(11) https://www.eventbrite.co.uk/e/shell-shock-centenary-public-lectures-tickets-44591870485?aff=es2 .
(12) http://nhne-pulse.org/wp-content/uploads/2010/12/Psychiatric_Drugs_As_Agents_of_Trauma_JRS508.pdf
(13) https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/prescribed-drugs-dependence-and-withdrawal

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FOR BMA Board of Science meeting Wed 18 April 2018
Report on Scottish and Welsh public petitions:
Prescribed drug dependence and withdrawal

Marion Brown and Beverley Thorpe – for ‘Recovery and Renewal’

Our Scottish Parliament public petition ‘Prescribed drug dependence and withdrawal’, was lodged in May 2017. It refers directly to this BMA board of Science work and is gathering substantial evidence fully published on the Scottish Parliament website (1). This evidence includes patient experiences, as well as government, institutional, professional and individual input. Evidence is being submitted from Scotland and from other countries.

The patient-experience submissions include personal accounts from individual men and women of all ages and backgrounds. Whilst diverse and unstructured, this collected narrative evidence is showing up stark issues: patients’ suffering is variously described in the detail of the individual evidence – devastating effects on health, lives, relationships, employment and families. The thread running through every single patient account (and there are well over 100 now) is that of doctors prescribing powerful drugs which they believe to be ‘safe and effective’ but which have complex and wide-ranging neurological effects which prescribers do not seem to understand. Patient experiences are being disbelieved and discounted.

It is especially alarming to see the number of individual submissions which relate experiences with start dates long after our own (and BMA) attempts to raise concerns. We have written about this for the BMJ (2).

The Scottish petition was first formally considered on 29th June 2017, then on 7th December. On 18th January the petition committee took oral evidence from Scotland’s Minister for Mental Health and Principal Medical Officer. A great deal of further written evidence has now been received and this will be considered by the Petition Committee at the forthcoming meeting next week 26 April.

A similar public petition, led by Stevie Lewis in Wales and lodged late 2017, is gathering Welsh evidence at the Welsh Assembly (3). The Welsh office of the BMA, the Royal Pharmaceutical Society and all 7 Health Boards have responded positively in support of the petition, with one Health Board reporting its pride at the small Prescribed Medication Support Service that it has been running for 20 years, helping local people with prescription drug dependence. A dozen stories have been sent in as evidence of prescription drug dependence, all of which share the common themes of harm, lack of information and lack of support with dependence and withdrawal. The next Welsh Petition Committee consideration of this is due shortly, on 1st May.

(1) Scottish petition reference PE01651
http://www.parliament.scot/GettingInvolved/Petitions/PE01651
(2) Our recent BMJ piece
https://www.bmj.com/content/360/bmj.k1408/rr-0
(3) Welsh Petition reference P-05-784
http://www.senedd.assembly.wales/mgIssueHistoryHome.aspx?IId=19952&Opt=0

Coming off antidepressants

The aim of this leaflet is to help you decide about when and how to come off antidepressants.

Some people find coming off antidepressants is quite easy. But others may get withdrawal or a return of the depression.

We asked people to tell us what it was like for them to come off antidepressants. This leaflet brings together the views of the 817 people who completed our survey and shared their experiences.

Survey findings

In our survey, the most common drug stopped was Citalopram. This was taken by 235 people. Fluoxetine was next, taken by 173 people, followed by Venlafaxine (109), Sertraline (89), Escitalopram (51), Mirtazapine (38), Paroxetine (29) and Duloxetine (26).
36% stopped their antidepressant suddenly. Males were more likely to do this (m=44%, f=34%). Younger people were also more likely to stop suddenly (59% of 18-24 yr olds compared with just 20% of the over 65s).

512 (63%) people in our survey experienced withdrawal when stopping their antidepressants.

Some drugs were more likely to cause withdrawal than others. In the table below we have split the drugs into 3 groups (high, medium and low withdrawal).

High		Medium		Low	
% with withdrawal		% with withdrawal		% with withdrawal	
Venlafaxine	82%	Sertraline	62%	Fluoxetine	44%
Escitalopram	75%	Citalopram	60%	Mirtazepine	21%
Paroxetine	69%				
Duloxetine	69%				

A further 43 people were on Tricyclic antidepressants. 53% of them had withdrawal. 23 people were on other types of antidepressant, but the individual numbers on these drugs were too small to be able to draw conclusions.

Common withdrawal symptoms

Overall, the most common symptoms were:

- anxiety (70%)
- dizziness (61%)
- vivid dreams (51%)
- electric shocks / head zaps (48%)
- stomach upsets (33%)
- flu like symptoms (32%)
- depression (7%)
- headaches (3%)
- suicidal thoughts (2%)
- insomnia (2%).

Anxiety was the most common symptom for every antidepressant except Duloxetine, for which 'dizziness' was the most common. The least common symptoms across all types were stomach upsets and flu-like symptoms. These patterns were the same for men and women.

Why do people stop?
The people in our survey decided to stop for a number of reasons:

Reason for stopping	Number of people
Felt better	219
Side-effects	213
Didn't help	175
Wanted to try without	45
Pregnant	39
On advice of doctor	21

When to stop?
Deciding when to stop is really important.

If you have had one episode of depression, you are usually advised to stay on antidepressants for 6 months to 1 year after you feel better. If you stop too soon, your depression may come back.

If your problems have been going on for some time, your doctor may advise you to stay on antidepressants much longer.

It is important to be aware of two things if you do stop:
- you may get withdrawal
- the condition for which you were taking your antidepressants may come back.

Seeking advice
We strongly advise that your decision to stop is made with your doctor.

In our survey:
- 372 people got advice from a professional
- 95 from the internet
- 75 from the information leaflet provided with their pills
- 35 from someone who had stopped antidepressants
- 289 did not seek advice.

A quarter of people in our survey were not aware that there could be problems linked with stopping.

What is withdrawal like?
People in our survey reported that the symptoms generally lasted for up to 6 weeks. A small percentage of symptoms lasted longer than this. A quarter of our group reported anxiety lasting more than 12 weeks.

Of the common symptoms reported, the one rated severe by most people was anxiety. The symptoms that were rated moderate by most people were stomach upsets, flu-like symptoms, dizziness, vivid dreams and electric shocks/brain zaps. The less common symptoms were reported as severe: returning depression, headache, suicidal thoughts, insomnia, fatigue and nausea.

I want to stop - how should I go about it?
We would suggest the following:

BEFORE
- **Make an informed decision**
  - discuss the options with your doctor
  - be aware of possible withdrawal or return of depression
- **Make a plan**
  - choose a good time
  - decide the speed of reduction
  - who will you contact if there are problems?

- **Seek support**
  - from friends and family
  - work - will you need some time off?

DURING

- Reduce slowly
- Research suggests:
  - if treatment has lasted less than 8 weeks, stopping over 1-2 weeks should be OK
  - after 6-8 months treatment, taper off over 6-8 weeks
  - if you have been on maintenance treatment, taper more gradually: e.g. reduce the dose by not more than ¼ every 4-6 weeks.
- Stay in touch with your doctor
- Be prepared to stop the reduction or increase your dose again if needed
- Keep a diary of your symptoms and drug doses.

AFTER

- Keep an eye on your mood
- It may take some time before you fully stabilise
- It is important you look after yourself and keep active
- Keep practising Cognitive Behavioural Therapy (CBT)/relaxation techniques if you have been taught these
- Go back to see your doctor is you are worried about how you feel.

Advice from other who have stopped

People who responded to our survey also made the following suggestions (we don't necessarily endorse these suggestions – we leave them to you to consider):

Before deciding to stop

- Be prepared.
- Seek advice first.
- Research, but don't let online stories scare you.
- Listen to doctors and your own body and mind.
- Don't feel societal pressure to come off. If you have a medical condition (diabetes/asthma etc) you shouldn't be made to feel bad for taking medications.
- Stop for the right reason. Not to please others.
- Weigh up pro's of taking drugs against the side-effects from continued use.
- If you don't get on with the GP you've previously seen, ask to see one with an interest in mental health
- It takes time/patience/perseverance.
- Think/write down with someone why you want to stop.

Once you have decided to stop

- Be sure you're ready, avoid stopping during any disruptive periods in your life - the timing needs to be right.
- Talk to someone else who's been there.
- Let others know. Have support around you.
- Understand the possible withdrawal symptoms you might experience.
- Have plans in place to manage your mood. Have something else to focus on.
- Get details of who to contact if you have a problem.
- Advice for family/partners would be useful.
- View it like recovery from an operation. Be good, focussed and approach it in a lifestyle change sort of way.
- If possible plan time off in advance.

During withdrawal:

- Be prepared, sometimes withdrawal can take longer than expected.
- Rest, drink water, eat healthily, and be kind to yourself.
- Take time off work if you need to.

Dose adjustment

- Go slowly – reduce by small amounts.
- Ask if can reduce very slowly at end with liquid instead of pills.
- Keep some tablets in reserve so you can stop extra slowly.
- Increase your dose temporarily to control symptoms if needed.
- Be aware that your symptoms may come back, at any time, if the dose is reduced further .
- Don't be ashamed to go back on antidepressants if needed.
- Don't feel bad if you can't come off at 1st or 2nd attempt.

Setting

- Avoid people/situations that may cause stress whilst coming off.

Activity and monitoring

- Keep a diary to reflect on your thoughts/feelings.
- Exercise.
- Avoid unnecessary responsibilities.
- Ask a friend or someone close to you to monitor your mood in case you go down again – they might notice this before you do.

Symptoms of withdrawal

- Just as side-effects are a sign that medications are getting into your body, withdrawal effects are a sign they are leaving.
- If you get side-effects, don't allow other people minimise their importance.
- It's tough, but persevere, it will get better eventually.
- Side-effects will pass – they are time-limited.
- Be alert to feelings. If your mood gets worse or your anxiety increases, it's not failure, it just might not be the right time to stop.
- Withdrawal symptoms may feel like a return of depression.

After withdrawal

- Expect to feel a little lower or flat for a while afterwards.
- Seek talking therapy to get to the root of the problem/consider talking treatments as an alternative.
- Keeping busy is the key to staving off the depression coming back, as your focus is outside yourself.
- You are not a failure if you can't come off them.
- Recognise why you don't need them and be proud of other ways you've helped yourself.
- Try Cognitive Behavioural Therapy (CBT).
- Do some exercise.

Sources of information suggested by our responders

- http://antidepressantsteps.com/self-help/antidepressants/whenToStop.php
- http://www.mind.org.uk/help/medical_and_alternative_care/making_sense_of_coming_off_psychiatric_drugs
- http://antidepressantsteps.com/_uploads/booklet_full/2.pdf

Final comments

63% of people in our survey said they had experienced withdrawal or a return of depression. This is a higher figure than other research suggests (about 30%). It is possible that the research has underestimated the problem, but it is also possible that people were more likely to respond to our survey if they had problems stopping.

Either way, we hope that you find the advice given in this leaflet useful.

We would also like to reassure readers that despite some people having symptoms of withdrawal when stopping antidepressants, antidepressants are not addictive.

Produced by the Royal College of Psychiatrists' Public Education Editorial Board.
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This leaflet reflects the best available evidence at the time of writing.