

## PE1651/SSSSSSSS

Petitioner submission of 30 November 2020

We are alarmed to see the Oct 2020 BMJ 'Practice Pointer' by Stone et al encouraging GPs to 'recognise and understand' Functional Neurological Disorder (FND)<sup>i</sup>. We have responded to the BMJ<sup>ii</sup> as has Jill Nickens, co-founder of Akathisia Alliance<sup>iv</sup>. GPs are, it seems to us, guided to 'mis-diagnose' vitally important indications of prescribed drug effects (including life-threatening akathisia) and this is leading to yet more avoidable harm, chronic illness, disability and deaths. Notably the following essential questions do not feature in the list suggested by Stone et al<sup>vi</sup>:

- what is the person's medication history – from the very first prescribed medications, and then over the long term?
- when did the 'unexplained'/'functional' symptoms first become apparent, especially in relation to prescribed medications (i.e. the possibility of adverse medication effects &/or withdrawal)?

Our own Patient Voice research<sup>vii</sup>, collating evidence from our Scottish and Welsh petitions, shows that "In this sample [of 158 cases] 25% of patients with antidepressant withdrawal presenting to their GP were diagnosed with MUS [medically unexplained symptoms], a 'functional neurological disorder' [FND] or 'chronic fatigue syndrome.'

Many of the signs and symptoms associated with these disorders, captured in the often used PHQ-15, overlap with the symptoms of antidepressant withdrawal, including insomnia, feeling tired, nausea, indigestion, racing heart, dizziness, headaches and back pain".

The Royal College of Psychiatrists estimate that "About 1 in 4 people who see their GP have such [medically unexplained] symptoms" and "In a neurological outpatient setting, it is 1 in 3 patients or more"..."Another common term is 'functional' - the symptoms are due to a problem in the way the body is functioning, even though the structure of the body is normal."<sup>viii</sup>.

It is now accepted that antidepressants, especially SSRIs and SNRIs, affect the central nervous system are dependence-forming (as are benzodiazepines) and cause side effects, adverse reactions and withdrawal (Public Health England (PHE) 2019)<sup>ix</sup>.

Meanwhile our Scottish Petition PE1651 has been 'deferred' since 7 March 2019, pending Scottish Government Short Life Working Group (SLWG) which was set up to look at the PHE review in the Scottish context. We were invited to contribute 'patient experience' to the SLWG. This proved frustrating as NICE and SIGN guidance are based on 'evidence' mostly funded directly or indirectly by the pharmaceutical industry. Patients have had no route to input experience of taking medicines over the long term. Our petitions have offered an unprecedented insight into what is happening. This seemed challenging 'evidence' for the SLWG, especially about antidepressants. Prescribers are not aware of the adverse effects of the medicines they are being 'guided' to prescribe.

The SLWG recommendations are due for Scottish Government Public Consultation Dec2020 – Jan2021. We urge the Petitions Committee to take such action as may be appropriate.

Our Open Letter of March 3, 2020, published by the Helensburgh Advertiser (5 March 2020) and sent directly to the Departments of Health in Scotland, England, Wales and Northern Ireland, has not been satisfactorily addressed:

We write to express extreme alarm at the way our concerns – expressed over more than a decade to a considerable number of individuals and groups, representing various committees, specialities, institutions and departments in the UK – have been, and are being, apparently quashed in the UK's national suicide prevention strategy.

Current 'expert' advice on suicide prevention, which is now accepted government policy, is that selective serotonin reuptake inhibitors and serotonin and norepinephrine reuptake inhibitors (SSRI and SNRI drugs – commonly known as 'anti-depressants') are prescribed to any patient who indicates they may be feeling suicidal or have suicidal thoughts.

Our concern is that these drugs can themselves cause such suicidal thoughts/impulses - and also a very serious adverse drug reaction called akathisia, the symptoms of which are so unbearable that they can lead people to end their own lives.

This fact is not recognised by governments, the NHS or the public, and is not mentioned in the national Suicide Prevention Strategy, despite our efforts to draw this important issue to the attention of responsible individuals and departments.

Many people are indeed dying avoidable deaths by iatrogenic suicide – when suffering known and/or extreme and unrecognised adverse prescribed drug effects.

Our efforts have been extensive, and most recently resulted in the online publication of a short film compiled by Peter Gordon, retired NHS psychiatrist, with input from several contributors: 'A Timeline of Missed Opportunities'. This has already been widely shared on social media ([holeousia.com/2020/01/15/a-timeline-of-missed-opportunities/](https://holeousia.com/2020/01/15/a-timeline-of-missed-opportunities/)).

Please watch this short film - and also read the replies/comments section (found at the foot of the above blog post), where further correspondence has been added, including a letter dated February 28, 2020 from the UK Department of Health and Social Care.

We are sharing this open letter as we consider this to be a very serious matter indeed – where the lives of countless people are being knowingly and recklessly put at risk by the national suicide prevention strategy and policy. The public – and indeed prescribers - are being cruelly misled.

We ask specifically that the known risks of SSRI/SNRI drugs in particular (and indeed other medications which can cause akathisia) be fully recognised now - and action taken by governments, cascaded to educate all prescribers, healthcare professionals and the public on how to avoid or mitigate these risks.

---

<sup>i</sup> Stone J, Burton C, Carson A. (2020) Recognising and explaining functional neurological disorder. BMJ <https://doi.org/10.1136/bmj.m3745>

<sup>ii</sup> Brown M et al. Patient research group (2020) Functional Neurological Disorder: Patients' experience & research. BMJ [Re: Functional neurological disorder - Patients' experience & research | The BMJ](#)

<sup>iii</sup> Brown M et al Patient research group (2020) Re: FND – Update Nov 2020 BMJ [Re: Functional neurological disorder - Patients' experience & research: Update Nov2020 | The BMJ](#)

<sup>iv</sup> Nickens J. (2020) A functional neurological misdiagnosis, akathisia and suicide. BMJ [A functional neurological misdiagnosis, akathisia, and suicide | The BMJ](#)

<sup>v</sup> Akathisia Alliance for Education and Research. [Akathisia Alliance for Education and Research](#)

<sup>vi</sup> RCGP online resource MUS – Top 10 tips <https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/-/media/C7B311CF8F3C423F93F57C650BA42DE9.ashx>

<sup>vii</sup> Guy A, Brown M, Lewis S, Horowitz M. (2020) The Patient Voice... antidepressant withdrawal . Sage Therapeutic Advances in Psychopharmacology <https://journals.sagepub.com/doi/10.1177/2045125320967183>

<sup>viii</sup> Royal College of Psychiatrists – Medically unexplained symptoms [Medically unexplained symptoms | Royal College of Psychiatrists \(rcpsych.ac.uk\)](#)

<sup>ix</sup> Public Health England. (2019) Dependence & withdrawal associated with prescribed medicines [Dependence and withdrawal associated with some prescribed medicines: an evidence review \(publishing.service.gov.uk\)](#)