

## Tapering antidepressants:

why do tens of thousands turn to Facebook groups for support?

I write as an individual severely impacted by withdrawal after tapering an antidepressant (AD) too quickly in 2017. The resulting symptoms triggered the most frightening, gruelling, debilitating, and lonely experience of my life. One of the major problems I encountered was the repeated denial of this issue by GPs and psychiatrists. It left me in a perilous state with an overwhelming feeling of not being able to find the right help or support.

AD withdrawal has a long history in scientific literature, with many papers describing its occurrence and symptomatology. Most recently, Cosci and Chouinard<sup>1</sup> provided a very detailed description of the myriad of symptoms people experience. Symptoms fall into many categories including affective, cognitive, gastrointestinal, neuromuscular, sleep, sexual, and even psychotic and behavioural. This level of complexity can often result in misdiagnosis.<sup>2-3</sup> In addition, without careful management, protracted withdrawal can result in extended periods of suffering over many months and even years, and symptoms that are often untreatable.<sup>4</sup> Recent research concluded that over half of people coming off ADs will suffer withdrawal symptoms, of which one in two cases will be severe.<sup>5</sup> This suggests that AD withdrawal is likely to be something that GPs frequently see in their practice.

In 2020, the Royal College of Psychiatrists released new, comprehensive guidelines on stopping AD medication. It recognises and describes the likelihood that many patients will need to taper off their medication very slowly to avoid withdrawal symptoms. However, when healthcare services fail to recognise these symptoms or misdiagnose them as a recurrence of previous distress, functional neurological (FND), or even medically unexplained (MUS) symptoms,<sup>2-3</sup> many patients seek support elsewhere. Most commonly this support is provided by online withdrawal support communities on dedicated websites<sup>4</sup> and, now increasingly commonly, in private Facebook groups.<sup>6</sup>

My recent publication 'The role of Facebook groups in the management and raising of awareness of antidepressant withdrawal: is social media filling the void left by health services?'<sup>6</sup> describes the composition and growth of Facebook withdrawal support groups. It also discusses the need for these groups in the context of the frequency and prevalence of AD withdrawal.

The article was co-authored by John Read of the University of East London, and Sherry Julo, who manages one of these groups, dedicated to helping people carefully taper off the AD venlafaxine and which has over 6400 members. The article tracks 16 groups and their growth over a period of 13 months, during which membership grew by 28.4%. The groups advocate a slow, careful parabolic taper off the drugs, the theory of which has been carefully described in a 2019 article published in the *Lancet*.<sup>7</sup>

### WHAT DO FACEBOOK ANTIDEPRESSANT WITHDRAWAL GROUP MEMBERS WANT FROM THEIR DOCTOR?

As discussed, there is a huge amount of evidence that patients' withdrawal symptoms are often misdiagnosed when trying to stop taking ADs. They are told that this is evidence they need to stay on the medication for an extended period and even for life. This outcome is commonly reported in the groups studied. In fact, it is much more likely that emerging symptoms are withdrawal and not a re-emergence of previous symptoms of emotional distress.

Research is now underway to extract this evidence and allow members of these groups to express their opinions and share their experiences of how they have successfully tapered off their ADs. In addition, their experiences will contribute to the establishment of dedicated withdrawal support services. In the meantime, I would urge doctors to challenge what they know about relapse when helping patients to stop taking their ADs. There is a need to explore the likelihood that tapering these drugs can

be very difficult for a lot of people. Breaking tablets in half for a few weeks to reduce their dose may not work for them. Tapering may take an extended amount of time and require a considerable amount of support from their GP. Ultimately, the members of these groups want to know their GP will acknowledge, understand, and support them if difficulties occur, and have the knowledge to help them avoid painful and sometimes debilitating withdrawal symptoms.

#### Ed White,

Ed campaigns and conducts research to help better understanding of antidepressant withdrawal, and support others who want to safely taper their antidepressant medication.

Email: [edward\\_white@tiscali.co.uk](mailto:edward_white@tiscali.co.uk)

This article was first posted on *BJGP Life* on 23 March 2021; <https://bjgplife.com/tapering>

DOI: <https://doi.org/10.3399/bjgp21X716309>

### REFERENCES

1. Cosci F, Chouinard G. Acute and persistent withdrawal syndromes following discontinuation of psychotropic medications. *Psychother Psychosoma* 2020; DOI: <https://doi.org/10.1159/000506868>.
2. Guy A, Brown M, Lewis S, Horowitz M. The 'patient voice': patients who experience antidepressant withdrawal symptoms are often dismissed, or misdiagnosed with relapse, or a new medical condition. *Ther Adv Psychopharmacol* 2020; DOI: <https://doi.org/10.1177/2045125320967183>.
3. Brown M, Lewis S. The patient voice: antidepressant withdrawal, medically unexplained symptoms and functional neurological disorders. *Journal of Critical Psychology, Counselling and Psychotherapy* 2021; **20(4)**: 14-20.
4. Hengartner MP, Schulthess L, Sorensen A, Frammer A. Protracted withdrawal syndrome after stopping antidepressants: a descriptive quantitative analysis of consumer narratives from a large internet forum. *Ther Adv Psychopharmacol* 2020; DOI: <https://doi.org/10.1177/2045125320980573>.
5. Davies J, Read J. A systematic review into the incidence, severity and duration of antidepressant withdrawal effects: are guidelines evidence-based? *Addict Behav* 2019; **97**: 111-121.
6. White E, Read J, Julo S. The role of Facebook groups in the management and raising of awareness of antidepressant withdrawal: is social media filling the void left by health services? *Ther Adv Psychopharmacol* 2021; DOI: <https://doi.org/10.1177/2045125320981174>. eCollection 2021.
7. Horowitz MA, Taylor D. Tapering of SSRI treatment to mitigate withdrawal symptoms. *Lancet Psychiatry* 2019; **6**: 538-546.

“... when healthcare services fail to recognise these symptoms [of antidepressant withdrawal] or misdiagnose them ... many patients seek support elsewhere.”