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**Title: The long and winding road of discontinuing long-term use of antidepressants: learning from my experience.**

**Accessible Summary**

What is known on the subject?

* More people experience withdrawal symptoms when weaning off antidepressants than previously thought; particularly after taking them for a long time.

What this paper adds to existing knowledge.

* I explore my own experience of weaning off antidepressants; detailing conflicting advice I have received from healthcare professionals, and the mental and physical withdrawal symptoms I experienced.
* I relate my experiences to a growing body of research, which have important implications for improving care.

What are the implications for mental health nursing?

* Healthcare professionals should make patients aware of potential withdrawal symptoms they may experience before they wean off antidepressants; regularly review their progress; consider helping them access psychological support whilst weaning off; and engage in open and collaborative conversations with patients throughout.
* Clinical guidance needs to be updated to provide appropriate evidence-based information/advice/recommendations for how best to support patients when coming off of antidepressants.

**Introduction**

I am amongst the 16% of the English adult population who take antidepressants (Royal College of Psychiatrists: RCPsych, 2019), and amongst the 36% of antidepressant users who have been taking them for at least five years (Read et al., 2018). I am in the midst of tapering my dose of the antidepressant Sertraline and reflect on my experience of withdrawal in this paper. People’s experiences of antidepressant withdrawal symptoms has become a ‘hot topic’ over the past year due to increasing evidence indicating that these effects are more severe than healthcare professionals and clinical guidelines acknowledge. Clinical guidelines have controversially stated that withdrawal symptoms are mild and resolve after one week; with the proviso that they can be severe only if the drug is stopped abruptly (e.g. American Psychiatric Association, 2010; National Institute for Health and Care Excellence: NICE, 2009a). However, a recent systematic review (Davies & Read, 2019) concluded that 46% of those who experience withdrawal effects describe them as severe, and the majority experience withdrawal effects for more than two weeks. The RCPsych (2019) recently released a position statement which argued that there should be greater recognition of the potential for severe and long-lasting antidepressant withdrawal symptoms in guidelines; and that NICE should develop clear evidence-based recommendations to help guide gradual withdrawal. They also advocated for high quality research on the incidence, severity and duration of withdrawal symptoms, and how best to manage them.

In this paper I describe my own experiences since I was first diagnosed with depression at the age of 12, through to the present day whilst I am in the process of weaning off antidepressants at the age of 31 (having taken antidepressants for two separate extended periods during this time). Interspersed within the narrative of my own experience, I refer to relevant research and clinical guidelines. My interactions with healthcare professionals during my journey from first prescription, to monitoring, and tapering my dose has been primarily with general practitioners (GPs); however I believe this paper is of relevance to all healthcare professionals working with patients who take antidepressants.

**My first experience of antidepressants**

My first instance of depression occurred aged 12 following my grandfather’s death and the decline of my physical health due to a primary immune deficiency and chronic fatigue. I began taking Fluoxetine at the age of 12 and also saw a family psychiatrist at this time. Due to my mental and physical health taking a decline at such a young age, the management of my health was primarily governed by my parents and healthcare providers during this period. Despite no longer experiencing symptoms of clinical depression after 18 months from starting the medication, I continued to take Fluoxetine until I went to university. There had never been a conversation (within my recollection) about when I may come off of this medication. Perhaps this was because Fluoxetine had been so effective in helping me recover from my depression, return to ‘normal’ life, and facilitate more effective management of my physical health. My parents recollect being told that my depression was due to a chemical imbalance in my brain which could only be resolved by antidepressants; and therefore assumed my need for them would be continuous. I did not question this until I went to university and registered with the university GP practice.

After I registered at my university GP practice, I booked an appointment to ask for my Fluoxetine and prophylactic antibiotics to be put on repeat prescription. However, the GP was reluctant to give me a repeat prescription for Fluoxetine. He asked why I was still taking it as I had not been experiencing clinical levels of depression for some time. I did not have an answer, as it was not something I had been asked or considered before. He suggested I think about coming off of them, but did not provide any specific guidance on how to do this. This corresponds with the experience of 25% of recent survey respondents who reported being given no advice on how to withdraw from their antidepressants (All-Party Parliamentary Group for Prescribed Drug Dependence: APPGPDD, 2018). I was taken aback by the suggestion, but took it as a clear message that I shouldn’t be taking antidepressants any longer. At this time I also befriended another student who had previously experienced mental health difficulties and had taken Fluoxetine, then come off of them. She advised me on how I could do the same and I set about reducing my dose by taking my tablets every other day for several weeks and then stopping taking them. On reflection I realise that I could have been putting myself in a vulnerable position: I was living in a new place away from my family, seeing a GP who wasn’t familiar with my history, and without the guidance or monitoring of a healthcare professional. Thankfully however, the withdrawal effects I experienced (increased crying and tiredness) were short-lived.

**Staying off of antidepressants**

After stopping taking Fluoxetine I remained reasonably mentally well for four years, managing to obtain a first-class degree, thoroughly enjoy my time at university, and was awarded a PhD studentship. My physical health was also relatively stable, as I was experiencing a low number of infections and my fatigue was more manageable. I did have one set-back during my undergraduate degree when I experienced a relationship breakdown during one of the summer breaks. I began experiencing anxiety and following a panic attack I went to see my GP in my home town. The GP (who was new to the practice) said that he wanted me to take Fluoxetine again. I remember feeling disappointed with this response as I had hoped for another option to support me through this difficult time. I expressed this to the GP and his response was that due to my history he would advise I take the antidepressants. Although I was disappointed with this, I am now aware that NICE guidelines (2009b) advise healthcare professionals to strongly consider antidepressants for patients reporting mental health difficulties who also have a long-term physical health condition, particularly for those who have a past history of depression and whose depression can complicate the care of their physical health. However, on this occasion I went against the doctor’s advice and did not start taking Fluoxetine again. Looking back I think this was because I did not feel that my mental health had declined as much as when I was first prescribed Fluoxetine, and I hoped that this was temporary. Fortunately, on this occasion the anxiety passed fairly quickly.

**Going back on antidepressants**

My mental health began to deteriorate during my PhD. Completing a PhD is an incredibly stressful time, so it is perhaps unsurprising that my health suffered during this time. Throughout my journey, my mental health has been interlinked with my physical health: a decline in my physical health impacts negatively on my mental health, and vice versa. During my PhD I was experiencing a high number of infections and my fatigue increased dramatically. My immunology consultant put me on weekly subcutaneous infusions of immunoglobulins which caused flu-like symptoms, and I was told I would need to have this treatment for the rest of my life. This was a hugely difficult thing for me to process and accept. Added to the stress of the PhD, another relationship breakdown and dealing with loneliness, I began to experience symptoms of both anxiety and depression. I reluctantly went to the university GP practice about this and they referred me to the university counselling service and prescribed Fluoxetine again. This time around, I took it. Unfortunately, reintroducing it to my system made me very physically sick. I have a strong recollection of violently vomiting in the shower when I was staying at a friend’s house, two days after I started taking them. Due to these extreme side effects, the GP advised I stop taking Fluoxetine and try Sertraline instead. I began taking 50mg daily and fortunately the side effects I experienced in the first few weeks were less severe. My mental health improved as the Sertraline took effect and I went on to complete my PhD and begin to accept the nature of my physical health and associated lifelong treatment regime.

**Increasing the dose**

After completing my PhD, I moved back home to live with my parents and started my first post-doctoral research post, working full-time for the first time. I remember struggling with crippling fatigue in those first few weeks, to the point that I would have to nap in my car at the end of the day before I was able to drive home. On some days my parents would have to drive to collect me. I went to my GP about this and to my surprise he suggested doubling my dose of Sertraline. I was unsure how this would impact on my fatigue, but I was desperate for a solution so I gave it a try. To my surprise my fatigue became more manageable within a few days and I stayed on this dose for four years.

**Monitoring the dose**

Throughout my time taking Sertraline, I have had repeat prescriptions every six months. Twice a year, I would have a review with a GP in order to get the repeat prescription renewed. Being given repeat prescriptions and being reviewed infrequently has been cited as a reason for 30-50% of cases of long-term use of antidepressants which is not guideline-based. The content and length of each of my medication reviews has varied considerably from GP to GP. Given the nature of general practice in the UK, it is very difficult to see the same GP each time you have an appointment. In my experience, even when I have booked an appointment with a specific GP, I often end up being seen by someone else. The shortest ‘review’ I have had lasted about 20 seconds, during which I sat down, explained the appointment was for a review of my Sertraline, and the GP asked “are you happy with them?” I said “yes” and she said “Ok, come back again in six months”. Occasionally during a review the GP would ask whether I had considered coming off Sertraline, and I would say I was nervous of doing this in case my previous symptoms came back. The response would generally be along the lines of “well if they are working then keep taking them”.

**Beginning to taper the dose**

A turning point in my journey, was when I was seen by a locum, who to my surprise took her time over my medication review. She asked me lots of questions about my history of both my physical and mental health, my levels of social support, and the nature of my work. She gently asked whether I had considered reducing my dose of Sertraline and I asked whether she thought that I should. She said that it was up to me, but if I had been mentally well for some time it is something that I could consider. I had been thinking in the lead up to this review whether I should try to reduce my dose, as I had come to the realisation that I wouldn’t know if I could manage without antidepressants until I tried reducing them. I had read on the website of the UK mental health charity Mind about how best to come off antidepressants, and remember reading advice to reduce by 10% at a time. I asked the GP during my review about this, and she said that she would usually recommend halving a dose of 100mg to 50mg. I expressed my concern about the size of this reduction and asked if I could reduce by a lower amount. As the tablets were only available in 50mg or 100mg, she suggested cutting a 50mg tablet in half and taking that alongside a whole 50mg tablet in order to make my daily dose 75mg. As acknowledged by the RCPysch (2019), gradual tapering of the dose should be recommended by healthcare professionals in order to manage withdrawal, and there is broad consensus that the longer antidepressants have been used; the longer period of time treatment should be tapered. In my case, having taken antidepressants for a long period should have meant a recommendation for slower tapering. However, as acknowledged by the RCPsych, a significant challenge for clinicians is the lack of a defined optimal rate of tapering, and a lack of available guidance/advice in this area.

On the new dose of 75mg, I experienced more severe withdrawal effects than when I had previously weaned off Fluoxetine. This may be due to Fluoxetine having a longer half-life. All my withdrawal symptoms were related to my mental health. I remember feeling like my old symptoms of depression and anxiety were returning which felt demoralising, and made me wonder whether that meant I did need the antidepressants in order to function. With these thoughts going through my head, I ended up having panic attacks during the first few weeks and feeling very teary. As a result, it was difficult for me to cope with work-related stress and other aspects of my life. However, I remembered from my reading online about antidepressant withdrawal that these symptoms were likely to pass after a few weeks, so I persisted. Fortunately, with a supportive partner, parents and work colleagues, I was able to cope with those difficult few weeks. After five or six weeks I remember feeling mentally better, but I was scared to lower the dose again and stayed at 75mg for two-and-a-half years.

Whilst on this dose, I had a review with a GP who I had seen about my mental health a few years previously. He asked me why I was taking 75mg and I explained that I had started to wean myself off, but was then afraid to lower the dose further. He asked “*why* are you trying to wean yourself off your Sertraline?” I remember feeling quite taken aback by the question as I was under the impression that I should be working towards coming off them, given that I had felt fairly mentally well for some time and reducing my dose had been mentioned in a few of my medication reviews with other GPs. I was also in a long-term relationship and coming to an age where I was thinking ahead as to whether I would want to try to start a family in the future, and was aware of some of the risks of taking antidepressants during pregnancy. I expressed these thoughts and concerns to the GP and was met with an impassioned response that I shouldn’t stop taking medication that was keeping me well, as it wasn’t worth the risk of me relapsing. He also expressed that he had seen a number of female patients who had taken Sertraline during pregnancy with no complications. He continued by saying that if my mental health declined during and after pregnancy, the risks to myself and the baby would be greater than the risk of taking the medication. I agreed not to lower the dose further but I left the review feeling confused. I understood his viewpoint and shared some of his concerns, but I still had a niggling thought that I wouldn’t know if I still needed the medication until I tried reducing the dose. I was also cognisant that my mental health had been much the same (once the withdrawal symptoms had passed) after lowering my dose previously, and that other GPs had given me differing advice.

Such encounters between healthcare professionals and patients are not uncommon. Bowers et al. (2019) report on findings from a focus group with various healthcare professionals (GPs, GP assistants, nurses, community mental health team workers and psychotherapists) as part of the REviewing long term antiDepressant Use by Careful monitoring in Everyday practice (REDUCE) programme. Healthcare professionals reported fear of destabilising currently well patients by discontinuing antidepressants; which has also previously been evidenced in patients and GPs (e.g. Bosman et al., 2016). Bowers et al. (2019) recommended reassuring healthcare professionals that the risk of relapse may be minimised if discontinuation is accompanied by appropriate psychological support; although there is still a need for further work on providing support for patients who are discontinuing antidepressants, and there are currently significant delays in accessing psychological support through the UK National Health Service (NHS).

**Lowering the dose further**

It was not long after the aforementioned medication review that some problems I had been experiencing with bloating and constipation dramatically worsened. I experienced a faecal impaction with pain so severe I had to go to the Accident and Emergency department (A&E). I made various dietary changes and increased my activity levels as a result, but this issue has (intermittently) persisted to the present day. I raised my struggles with constipation in several appointments with healthcare professionals, and both a GP and my immunology consultant suggested that this could be due to my long-term use of antidepressants. Indeed, research supports the notion that side effects of antidepressants increase with long-term use (Ferguson, 2001), and constipation is reported as a common side effect of Sertraline, something which I was not previously aware of. This then motivated me to try reducing my dose further.

We have now reached three months ago, when I decided to take a lower dose of 50mg. To provide context, I had also recently moved GP practice as I had moved to a new area. I must confess I did not discuss lowering the dose this time with a GP as I was put off after such contrasting viewpoints I had previously faced. I began taking 50mg, expecting my experience to be much the same as previously. I was prepared (as much as I could be) to experience symptoms of anxiety and depression, and had discussed this with my partner, a close friend, and a work colleague in preparation. I timed the lowering of the dose to coincide with a quieter time at work, and without any big life events or changes coming up. However, to my surprise the withdrawal effects I initially experienced were sudden, severe, and not related to my mental health.

The day after taking my lower dose, I woke up feeling fine. I was tired as usual due to my chronic fatigue, but otherwise ok. I drove to work and arrived in the office, but began to feel unusual shortly after arriving. My head felt very strange, tight and fuzzy, and my vision also changed. I can best describe it as my vision couldn’t focus quick enough to keep up with my eye movements. The only time I have experienced something comparable is when I have had a migraine. As the morning progressed I was really struggling to concentrate and was seeing bright lights and squiggly lines in my vision. I was also unable to carry out very simple tasks. Around lunchtime I began to feel nauseous. As the day progressed I found myself becoming off-balance and I remember holding on to the printer in the office to steady myself. This experience remained much the same for the following few days, with the addition of loud ringing and rushing sounds in my ears. This all made it challenging to manage at work, especially in light of my existing day-to-day challenges related to my physical health that I face as a result of my long-term conditions. After a week of these initial symptoms they did reduce in severity, although the tinnitus and bright lights in my vision continued. Ten days after lowering the dose, I also began to cry a lot more than usual. One day, when I was already feeling unwell due to my subcutaneous immunoglobulin infusions; I cried when walking from one side of the room to the other, when making a cup of tea, when making my lunch, whilst showering, whilst walking over the road to the supermarket, and whilst eating dinner. Everything felt so effortful and my body felt emotionally and physically exhausted. Over the next few days I also felt myself becoming more irritable and anxious, and I was not sleeping well: struggling to fall asleep, waking-up regularly, and having nightmares. During this time I also began to experience abdominal pains and my constipation worsened, resulting in another visit to A&E. It is unclear at present whether this flare up was due to lowering the dose of Sertraline; but having ruled out a number of other possibilities it is likely that this might be the case.

Despite these distressing symptoms, I was determined to persevere and wait to see whether they would subside after a few weeks. Thankfully they passed after six weeks (except for continuing issues with constipation). At this point I went to see a GP at my new practice about the constipation. I asked whether she thought it could be related to my long-term use of antidepressants and she said that she thought it was very likely and advised me to stop taking them as quickly as possible. I asked what timeframe she recommended and she said that she always advises that when someone is on 50mg of Sertraline they should take one tablet every other day for two weeks, and then completely stop. This differs from guidance from the NHS for patients (<https://www.nhs.uk/common-health-questions/medicines/how-should-antidepressants-be-discontinued/>) and from NICE for healthcare professionals (NICE, 2009b), which state that antidepressants should be slowly reduced over four weeks with some people requiring longer periods. My experience, however, aligns with that of 36% of survey respondents who reported they were advised to reduce their antidepressant dose over a few weeks or less (APPGPDD, 2018). I was quite alarmed by the GP’s recommendation and explained that I had reduced by 25mg previously and had experienced quite extreme withdrawal symptoms which lasted for six weeks. I explained that my physical health already makes it difficult for me to manage, and I wanted to limit withdrawal symptoms as much as possible. The GP seemed surprised at my experience and in response said “well that’s a further sign that you have been on them for too long and you need to get off of them”. I couldn’t help but think back to the very different advice from the GP I had previously seen, who was adamant I should continue to take them. It is very confusing for patients to navigate such conflicting opinions and advice from healthcare professionals. Healthcare professionals themselves have acknowledged that patients experience differing and inconsistent advice/recommendations in relation to discontinuing antidepressants, and attribute this to patients seeing different practitioners each time (Bowers et al., 2019). However, this may be further explained by the lack of clear clinical guidelines related to discontinuing long-term use of antidepressants.

During the aforementioned GP appointment, I explained that I was only comfortable reducing my dose at a slower pace. She was supportive of this, and asked for me to go back to see her once I had stopped taking Sertraline completely to review whether the issues with constipation had changed. I began with a lower dose of 25mg on a Friday, having made sure I kept my weekend free and had booked Monday and Tuesday as annual leave in preparation for any immediate symptoms. However, once again my experience in tapering the dose was different to before. For the first few days I didn’t experience such extreme physical effects. I even cancelled my annual leave on Tuesday and went in to work as I was feeling much better than I was expecting. However, I did begin to experience tinnitus and the bright and squiggly lines in my vision shortly after this. As before I also began to cry more often, and felt that I wanted to shut myself off from other people. I was able to manage at work, but I did work from home where possible and limited my weekend plans. At the point of writing it has been three weeks since I reduced my dose to 25mg and the withdrawal symptoms seem to have subsided quicker than before. Whilst I am writing I have bright lights and squiggly lines in my vision, and I am feeling very tired; but I am not experiencing any mental health-related symptoms. I am feeling hopeful that I will be able to fully come off Sertraline in the near future, which is something I couldn’t previously envisage. My experiences have motivated me to write this paper as I feel there are some opportunities for reflection and learning which could help improve the practice of supporting individuals to discontinue their long-term use of antidepressants.

**Conclusion**

Whilst this paper explores the experience of one person (myself), these experiences align with a growing body of research evidence, and could represent important learning opportunities for the improvement of mental healthcare. I feel that my experience regarding the monitoring and tapering of antidepressants; could have been improved through more thorough and sensitive medication reviews. It is important for healthcare professionals to ask patients whether they have considered reducing the dose of their antidepressant, especially for long-term users who have been mentally well for more than six months as evidence suggests that the longer someone has been taking antidepressants, the more likely and more severe withdrawal effects will be. However, this should be asked in a sensitive way and only after exploring the patient’s current mental health needs, what social support they have, and other relevant factors e.g. long-term physical health problems, upcoming stressful life events, and/or the nature of their work/study. Medication reviews should involve an open and sensitive conversation where a decision as to whether to taper antidepressants is reached collaboratively, after the views and concerns of the patient have been listened to. If a patient does not feel able to reduce their dose, it is also important for healthcare professionals to assure them that it is their decision and that there is no pressure for them to do so. However, it may be worthwhile gently suggesting that this is revisited at their next review. For me, I came to the decision to reduce my medication over time and after lots of personal thought and discussion with others. It was a decision that ultimately I needed to come to myself (i.e. not solely the decision of a healthcare professional) in order to motivate me to persist through the withdrawal symptoms. Nevertheless, I acknowledge that the gentle questioning of a GP who took the time to get to know me and my circumstances was helpful in leading me to reduce my dose.

If a patient expresses to a healthcare professional that they would like to wean off their antidepressants, I believe it would be beneficial to warn them about possible withdrawal effects - that can be physical and/or mental health-related - and to review their progress and any withdrawal effects regularly. It would also be beneficial to consider (if feasible) referring them for psychological support (e.g. counselling, cognitive behavioural therapy) and/or engaging in social prescribing (referring to a range of local, non-clinical activities e.g. arts activities, befriending, sports) to support them during their tapering (for a review of social prescribing impacts see Thomson et al., 2015). In my experience, talking therapies have been useful during periods of depression and anxiety; and I feel I would have further benefited from psychological support in preparation for and during the tapering of my dose. Healthcare professionals may also want to suggest that the patient considers putting their own measures in place to prepare for potential withdrawal effects; such as taking time off work, letting family or friends know of support they may need, and/or engaging in self-care activities (e.g. engaging in yoga or meditation). If a patient says to a healthcare professional that they would like to try to reduce their dosage and the healthcare professional has concerns about the possibility of a relapse, I believe it is still important to discuss this in an open and considerate way, ensuring that the views, desires and concerns of the patient are not dismissed. Collaborative and open relationships between healthcare professionals and patients is essential, as being dismissive of patient’s desires may lead to them reducing their medication without guidance and monitoring, as in my experience.

I reiterate and advocate for the RCPsych’s (2019) calls for the development of evidence-based guidance for healthcare professionals on the potential severity and length of withdrawal effects, how best to support patients experiencing withdrawal, optimal rates of tapering, and improved monitoring of patient’s long-term antidepressant use (within which the RCPsych state there could be an important role for specialist nurses). Along with the RCPsych, I also acknowledge the need for increased provision of psychological therapies, community support and social prescribing opportunities in order to ensure there is sufficient availability of support for patients affected by antidepressant withdrawal; and the need for health departments to ensure there is adequate resourcing to reduce high workloads in healthcare settings in order to ensure healthcare professionals have sufficient time/capacity to undertake regular reviews and follow-up.

As an end to this paper, I want to make clear that despite the withdrawal symptoms and side effects I have experienced from antidepressants; I would not change having taken them. Antidepressants have helped me through some difficult and challenging times and I have no doubt that overall my life is better for having taken them. I would not want my experiences to put off someone considering taking antidepressants if they are experiencing mental health symptoms, or to wean themselves off antidepressants before they are ready. Likewise, I would not want to dissuade someone from reducing their antidepressants if they have been mentally well for some time and have support around them, because of the unpleasant withdrawal effects I have described. I do not regret having reduced my dose despite the symptoms I have experienced, and feel hopeful that one day soon I will reach the end of this long and winding road. But I do feel it is something that individuals should be aware of before taking antidepressants and before tapering their dose, in order to be prepared for potential withdrawal effects.

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