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Wendy Burn: Medical community must ensure that those needing support to come off antidepressants can get it

In 2018, while I was still President of the Royal College of Psychiatrists (RCPsych), I co-signed a letter to The Times which stated that "in the vast majority of patients, any unpleasant symptoms experienced on discontinuing antidepressants have resolved within two weeks of stopping treatment."

To my astonishment the letter sparked a furore. A group of psychologists, psychiatrists and patients complained publicly. They were unhappy as they had found stopping antidepressants led to symptoms in patients that were often misinterpreted as a relapse of depression, which in turn led to taking medication for longer periods of time.

Formal complaints were made to RCPsych and to the General Medical Council. I was widely and upsettingly trolled on social media, as were several of my colleagues.

In my many years of clinical practice, stopping antidepressants had not been a problem that my patients had reported to me. Possibly because I have always slowly tapered any medication that my patients were on.

While our letter had been in line with the NICE guidance on antidepressant discontinuation which states "symptoms are usually mild and self-limiting over about one week" we had not included the further guidance from NICE that stated symptoms "can be severe, particularly if the drug is stopped abruptly."

As the President of the College I felt it was my responsibility to find out more from patients who were experiencing these symptoms and consider how they could be supported

Over the next year, I met patient groups who reported harm from using antidepressants. They describe themselves as the "prescribed harm community."

I visited a charity in Bristol which supports people coming off psychiatric medication, working with their doctors. I attended an event run by a group called "Drop the Disorder" who challenge the culture of medical psychiatric diagnoses.

Many people attending this event told me they had been damaged by antidepressants, particularly by their experiences of coming off them.

I talked to "Altostrata" in San Francisco who founded the Surviving Antidepressants website in 2011, this supports people who are having problems stopping psychiatric medication and has a huge collection of case histories. She describes experiencing acute withdrawal symptoms, followed by Post-Acute-Withdrawal Syndrome (PAWS) with ongoing symptoms.

It became clear that I had underestimated the number of people experiencing difficulties in stopping antidepressants and that the problem was widely under-recognised across healthcare.

I spoke to people who reported feeling abandoned with little or no support for symptoms after stopping their antidepressants. Meanwhile, I feared that heated and often polarised arguments were deterring people with mental illness from speaking about their experiences and seeking support.

The College's position in 2018 had not been right.

We worked together with patients, GPs, psychiatrists, stakeholders, campaigners, NICE and PHE to produce a statement on antidepressants and depression which changed our position and gave clear recognition to the difficulties that can arise for some people when coming off antidepressants.

With this position statement we put patients at the centre of our work, listening to critics with an open mind and using this to inform our practice—a significant step in the right direction.

The following extract from the position statement marks this vital change to our approach: "Whilst the withdrawal symptoms which arise on and after stopping antidepressants are often mild and self-limiting, there can be substantial variation in people's experience, with symptoms lasting much longer and being more severe for some patients. Ongoing monitoring is also needed to distinguish the features of antidepressant withdrawal from emerging symptoms which may indicate a relapse of depression."

We also recommended that better support is provided to people who are stopping antidepressants.

Following this update, NICE changed its guidance to reflect the importance and range of withdrawal symptoms. NICE also advise people on antidepressant medication to talk to their practitioner before stopping and to get their support with managing withdrawal symptoms.

This week RCPsych is launching a Patient Information Resource on withdrawing from antidepressants. The resource offers advice to patients on carefully managing the process for stopping antidepressants.

It's been written by a pharmacist and a psychiatrist with their own personal, as well as professional, experience of withdrawal symptoms, along with input from multiple stakeholders.

The online patient resource, available free on the RCPscych website, has been endorsed by the Royal College of General Practitioners and the Royal Pharmaceutical Society.

I'm hoping that the whole medical community will get behind this work to ensure that those needing support to come off antidepressants can get it. Most of all, I hope the resource proves helpful to people on antidepressants, and that no one experiencing mental illness is shamed or intimidated from seeking help.

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Competing interests: None declared.



Stopping antidepressants

This information is for anyone who wants to know more about stopping antidepressants.

It describes:

- symptoms that you may get when stopping an antidepressant
- some ways to reduce or avoid these symptoms.

Disclaimer

This resource provides information, not advice.

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If you have questions about any medical matter, you should consult your doctor or other professional healthcare provider without delay.

If you think you are experiencing any medical condition, you should seek immediate medical attention from a doctor or other professional healthcare provider.

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What are antidepressants?

They are medications prescribed for depressive illness, anxiety disorder or obsessive-compulsive disorder (OCD). You can find out more about how they work, why they are prescribed, their effects and side-effects, and alternative treatments in our separate resource on antidepressants.

Usually, you don't need to take antidepressants for more than 6 to 12 months. While they can make you feel better, you can get withdrawal symptoms when you stop taking them. Some people will get no symptoms when reducing or stopping an antidepressant – but many do. These symptoms can be physical and mental, although they are different for everyone – and they can be different for individual antidepressants (see Appendix 1).



This resource aims to help you avoid getting any withdrawal symptoms – or get the fewest possible. Talk this over with your doctor so you can find the best way to stop taking them.

What symptoms might you experience when stopping antidepressants and how severe can they be?

The NICE guidelines suggest that for some, withdrawal symptoms can be mild and go away relatively quickly, without the need for any help. Other people can have more severe symptoms which last much longer (sometimes months or more).

At the moment we cannot predict who will get the more serious withdrawal symptoms.

Symptoms of antidepressant withdrawal

If you do get any of the symptoms listed below, tell your doctor.

You may notice:

- dizziness (this is usually mild, but can be so bad that you can't stand up without help)
- anxiety which comes and goes, sometimes in intense 'surges'
- difficulty in getting to sleep and vivid or frightening dreams
- low mood, feeling unable to be interested in or enjoy things
- a sense of being physically unwell
- rapidly changing moods
- anger, sleeplessness, tiredness, loss of co-ordination and headache
- the feeling of an electric shock in your arms, legs, or head (those are sometimes called 'zaps' and turning your head to the side can make them worse)
- a feeling that things are not real ('derealisation'), or a feeling that you have 'cotton wool in your head'
- difficulty in concentrating
- suicidal thoughts
- queasiness
- a feeling of inner restlessness and inability to stay still (akathisia).

See Appendix 2 for a list of all reported symptoms.



What causes antidepressant withdrawal symptoms?

This is still poorly understood. Brain chemicals called neurotransmitters (such as serotonin and noradrenaline) are involved. They allow nerve cells to communicate with each other by acting on nerve endings. Antidepressants increase levels of these chemicals in the space between nerve cells in the brain. Over time, the brain seems to slowly adjust to these increased levels.

If an antidepressant is stopped quickly, the brain will need time to adjust back again. The sudden lowering of neurotransmitter levels seems to produce withdrawal symptoms, while the brain adjusts to the change. The more gradual the changes, the milder and more tolerable symptoms should be – or, indeed, they may not happen at all.

This is why it is usually best to stop an antidepressant slowly.

Who is affected by antidepressant withdrawal symptoms?

Between a third and half of people who take an antidepressant will experience such symptoms to some extent. We cannot yet predict who will get these symptoms.

The risk seems to be greater if you have taken a high dose for a long time, but it can happen if you have taken an antidepressant for just a month. It can also depend on the type of antidepressant you have been taking. You are more likely to get these symptoms (and for them to be worse) if you stop taking an antidepressant suddenly or if you reduce the dose quickly.

How can I tell if it is withdrawal symptoms, or my depression/anxiety coming back?

Some withdrawal symptoms can feel like the symptoms you had before you started the antidepressant. The low mood and difficulty in sleeping of withdrawal can feel like the symptoms of depression. Dizziness is a common symptom of anxiety. In this case, you should carry on taking your antidepressant at the prescribed dose – and talk with your doctor.

If you do get withdrawal symptoms, you can still stop your antidepressant – but may need to do so more slowly (see section on 'When and how to stop antidepressants')

These are some of the ways you and your doctor can tell whether you are having withdrawal symptoms or whether it is the symptoms of a return of anxiety or depression:

1. Withdrawal symptoms normally start soon after your medication is reduced or stopped. This may be one or two days for some antidepressants – or even after missing a single dose. Usually they take a few days to start, and then get worse. The return of depression or anxiety usually takes longer – typically weeks or months. Some antidepressants, like fluoxetine, take a lot longer to leave the body. So, with these, symptoms can start days or even weeks after



- stopping or reducing your dose. This can make it harder to tell if symptoms are due to withdrawal or the return of your original symptoms of anxiety or depression.
- 2. Some withdrawal symptoms do not happen in anxiety or depression such as 'electric shocks' or 'zaps'. People often say, "I've never felt this before" or "This doesn't feel like my depression." Your doctor should ask whether you are getting these symptoms
- 3. Withdrawal symptoms usually improve quickly (in days or even hours) if you restart your antidepressant. This is much quicker than the weeks that antidepressants will normally take to relieve symptoms of anxiety or depression that have returned.

Does this mean that antidepressants are addictive or can cause dependence?

Stopping an antidepressant can give you unpleasant withdrawal symptoms – which stop if you start taking it again. It can certainly feel as though you are addicted to the antidepressant – but it's not quite the same as being addicted.

You don't get the craving or constantly having to increase the dose that you do with substances like alcohol, nicotine or benzodiazepines. But it can still be hard to stop taking an antidepressant.

When and how to stop antidepressants

How long you take an antidepressant for depends on why you were prescribed them and whether you have had to take them before. Ask your doctor when is best to start to reduce and then stop taking your antidepressant.

You may need to balance:

The benefits that you get from an antidepressant such as relief from your symptoms of anxiety or depression.

Against:

The problems that can occur after using them for a long period. These include increased side-effects, weight gain – and sometimes they just seem to stop working.

When you agree that it is time to stop, your doctor can help you put together a withdrawal plan. This must be flexible. It should allow you to reduce the dose at a rate that you find comfortable – as slowly as you need to avoid distressing withdrawal symptoms. This is also called 'dose tapering'. Dose reductions will usually get smaller as the dose decreases – some people need to get down to a very low dose before stopping.



How slow should the tapering be?

This is different for everyone. If you have been taking an antidepressant for only a few weeks you may be able to reduce, and stop, over a month or so. Even if you have only mild (or no) withdrawal symptoms, it is best to do this over at least four weeks.

If you have been taking antidepressants for many months or years, it's best to taper more slowly (again, at a rate you find comfortable). This will usually be over a period of months or longer. It's also best to reduce the dose slowly if you have had withdrawal symptoms in the past.

Do remember – if you do get withdrawal symptoms it doesn't mean that you can't stop your antidepressant. You will just need to taper more slowly, with smaller reductions in dose, over a longer period of time.

Only occasionally, where an antidepressant causes serious side-effects, should it be stopped suddenly, without tapering. If this does happen, see your doctor urgently.

How should I gradually reduce my dose?

There is some general advice on how to do this below but it's best to work this out with your doctor, so that they can prescribe the appropriate preparation and dose(s) for you. They will be able to work out any special requirements with your pharmacist, so that the prescription is tailored to what you need.

- If you have been taking antidepressants for only a few weeks then start, as a test, by reducing your regular dose by a quarter (25%) or a half (50%). Allow two to four weeks to adjust to the new dose, to see how things go.
- If you don't get any distressing symptoms, try a further reduction of a quarter (25%) or a half (50%) of the current dose. Allow another 2 to 4 weeks and repeat, with further periods of lowering the dose and waiting.
- If uncomfortable symptoms develop with your first dose reduction, or at any further reduction, stop the reduction. Go back to the last dose at which you felt comfortable and wait until you feel ready to try again perhaps using a more gradual taper, reducing by smaller amounts 5% or 10%.
- How you reduce your dose of antidepressant will depend on what dosages are available in tablet and liquid form in the UK. You can switch to a liquid form of your antidepressant or, if the one you are taking is only available in tablets or capsules, you can change to a similar antidepressant that is available as a liquid. Your doctor and pharmacist can advise you on how best to do this. We don't recommend splitting tablets or capsules yourself, or making your own liquid. It can be difficult to measure the right amount, particularly with small doses. Tapering strips (a roll or strip of pouches containing consecutively slightly lower doses to be taken each day) are prescribed in some countries. They are not yet approved in the UK, so your doctor cannot prescribe them on the NHS.
- Don't try missing medication on some days, this will lead to the amount of the drug in your body fluctuating and make withdrawal symptoms more likely.
- Regular monitoring will allow you and your doctor to recognise any problems quickly, particularly if you have to switch from one antidepressant to another.



- If you have:
 - been taking antidepressants at a high dose for many months or longer
 - developed distressing withdrawal symptoms when you have previously tried to reduce or stop antidepressants

It is probably best, right from the start, to use more gradual reductions of a twentieth (5%) or a tenth (10%) of the original dose – and to see your doctor regularly, so that they can keep an eye on how it is going.

- Long-acting antidepressants, like fluoxetine, can take weeks to leave your body (most take just days). So, any withdrawal symptoms may develop several days, or even weeks, after reducing the dose. It is best to wait at least four weeks to see if withdrawal symptoms start.
- No matter how low the dose you get to, you can still get withdrawal symptoms when you stop completely. If this happens you may need to re-start the medication at a low dose for a while before completely stopping it. This may be a dose of lmg or less.
- If you start to get suicidal ideas when reducing and stopping an antidepressant, this could be a withdrawal symptom or the return of depression. You should go back to the last dose at which you felt well and see your doctor as soon as possible. Make sure you know how to get help quickly if you need it.

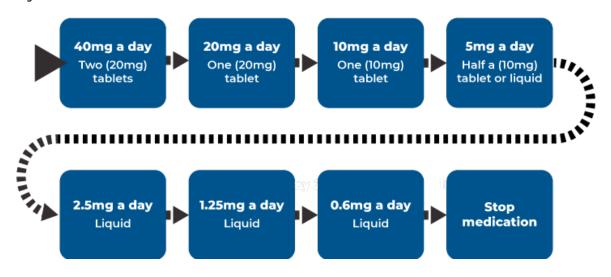
Examples of tapering plans

It's best to agree your tapering plan with your doctor and pharmacist. Below you will find example plans for tapering at different speeds. In your plan, you may not want or need to follow every step, but some people will find that they need to. You may want to make even smaller reductions (such as reducing by a quarter of the dose, not half, or even as small as 1/10th or 1/20th of the last dose at each step). The time between dose reductions should be as long as withdrawal symptoms take to disappear.

You may need to use both tablet and liquid (as in the paroxetine example). If so, this will need to be very carefully managed so that there are no mistakes with the dose.

Citalopram 12-24 weeks = a 3 - 6 months taper

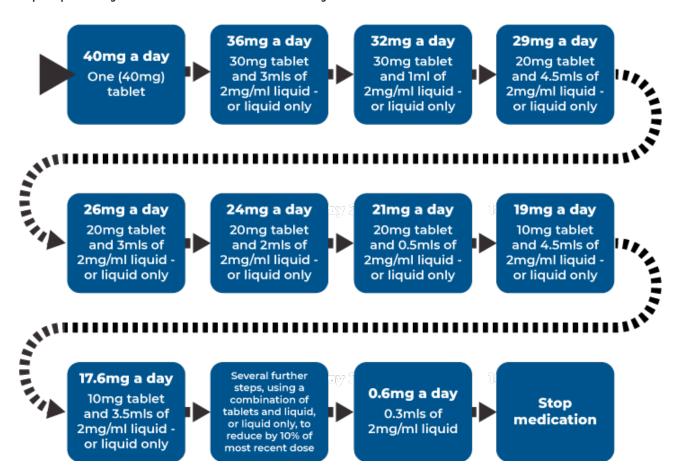
Reduction of dose by 50%, every 2-4 weeks. Some people may need to reduce more slowly.





Paroxetine 20-40 weeks or more = a taper of 5-10 months or longer

Reduction by 10% of the last dose, every 2-4 weeks using tablets and liquid. Some people may need to reduce more slowly.



Appendix 1: Risk of withdrawal symptoms with individual antidepressant

Highest Risk	Moderate Risk	Low Risk	Lowest Risk
Amitriptyline	Citalopram	Bupropion	Agomelatine
Clomipramine	Escitalopram	Fluoxetine	
Paroxetine	Fluvoxamine		
Venlafaxine	Imipramine		
Duloxetine	Lofepramine		
	Nortriptyline		
	Mirtazapine		
	Reboxetine		
	Sertraline		
	Trazodone		
	Vortioxetine		



Appendix 2: Potential types of withdrawal symptoms

Physical symptoms	Sleep symptoms	Emotional symptoms
Nausea	Insomnia	Anxiety
Headache	Increased dreaming	Depression
Dizziness	Vivid dreams	Panic
Abdominal cramps	Nightmares	Agitation
Diarrhoea		(Irritability)
Fatigue		Mood changes
Flu-like symptoms		
Electric shock sensations ('zaps')		
Loss of appetite		
Visual disturbances (double vision; visual trailing)		
Palpitations		
Missed beats		
Sweating		
Flushing		
Tremor		
Tinnitus		
A feeling of inner restlessness and inability to stay still (akathisia)		

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