

Coming off Medication

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The following article is one of many resources available to people attending *Thinking about Medication* ventures. It is an updated version of an article that first appeared in *OpenMind*, 123, 2003.

Some people's recovery from breakdown and mental health problems can be helped by psychiatric medication. But for others it can be a hindrance. Even people who find medication helpful at some point usually give consideration to coming off their drugs, especially when they have come through the worst of a crisis. Mental health professionals have often been reluctant (or have lacked the expertise) to assist people in this process, and have frequently engaged in strategies to persuade people to carry on taking their drugs (this is sometimes called *compliance therapy*). The benefits of drugs have historically often been over sold, with the risks, especially of long-term use, going unmentioned (Moncrieff, 2009). In our view this is ethically and legally wrong. In the United States many people have successfully sued mental health professionals and authorities for not warning them of the (sometimes irreversible) adverse effects of psychiatric drugs and associated problems in coming off medication, and people in the U.K. have started to follow suit. There are virtually no designated specialist services to help people come off prescription drugs at a time when we are being swamped with messages of there being a 'pill for every ill'.

Campbell, Cobb and Darton (1998) found that 63% of people who had tried to stop taking their psychiatric medication had experienced problems. Similar figures were found in MIND's survey *Coping with Coming Off* (Read, 2009). People can experience withdrawal or rebound effects, the most common of which include: flu-like symptoms; nausea; sweating; chills; shakes; noise in the ears; dizziness; muscle weakness; spasms; headaches; appetite change; diarrhoea; night sweats; strange and painful sensations (such as electric shock-type feelings and 'weird' sensations in the head). Some withdrawal

effects mirror psychiatric symptoms e.g. mania; hallucinations; agoraphobia; depression; voice hearing; nightmares; panic; extreme tension; insomnia; fatigue; impulsivity; suicidal thoughts; tearfulness; and heightened emotional reactions. These effects can occur within hours, days or weeks of stopping or reducing medication, and may last for hours, weeks, months, or occasionally be permanent (Breggin and Cohen, 1999). It is impossible to predict in advance who might suffer these effects, what the severity of these reactions might be, and who might have no adverse reactions to coming off their medication. However, the longer someone has been taking a drug the more likely the person is to suffer withdrawal reactions, as the body (having adjusted to the daily intake of that drug) reacts to its absence (Moncrieff, 2008).

Other problems with coming off medication include the resurfacing of the original problems and the loss of the benefits of the medication. Although some mental health professionals might call this 'relapse resulting from an untreated illness', people describe benefits from medication even when they do not conceptualise their problems as medical in origin. Psychiatrist David Healy has said that the main effects of psychiatric drugs are the creation of a sense of indifference and a general emotional dampening effect (Healy, 2005). The losing of this, especially if a person is living in a psychologically and socially toxic environment, can be very difficult. People also fear becoming as distressed or disturbed as they were at the height of a previous crisis. Mental health professionals, family and friends can escalate that fear, as they can be worried about how a person might be (and the knock on effects on their relationship with that person) if they are not 'on' their medication. Prediction of breakdown and threat of compulsion are widely reported by people when they try to have conversations about coming off their medication. Until recently there has been little information on withdrawal reactions and how to go through the withdrawal process. In our experience, many people who have abruptly stopped their medication have probably suffered significant withdrawal reactions which have been interpreted as relapse, with the person then being put back on medication, and with increased fear on all sides of the person ever trying to come off medication again.

Our top tips for coming off psychiatric medication

These are based on the first author's experiences of helping people to come off their medication and the second author's experience of successfully coming off medication.

1. Think through the pros and cons of coming off *and* the pros and cons of staying on your drugs. One of the best ways to do this is to brainstorm four lists (see Fig. 12). Do this individually then talk through the list with someone you trust. Only put down things that you feel are important to you (not what you 'ought' to put down) and write things in your own language – in the way the thoughts come to you. Once the lists are complete you may become aware of the mixed feelings you have about being on drugs, but also be in a position to make a judgement about whether overall you want to stay on or come off your drugs. Where does the balance lie? Do the advantages of coming off medication outweigh the disadvantages? The lists may also identify areas you can start to tackle before starting the withdrawal process.
2. Get as much support as you can e.g. from family, friends, your doctor, other professionals. Talk over your reasons for coming off your medication with people who are prepared to listen and support you. But be realistic – you may not get the support of all these people. Many people have successfully come off their psychiatric medication against the advice of mental health professionals (see Crepaz-Keay, 1999). It has been suggested that a sceptical and disillusioned attitude to psychiatry can be helpful regarding the withdrawal process (Lehmann, 2001). But if possible, find a doctor or pharmacist who has successfully helped people come off their medication and will help you in doing this. Workers from substance misuse organisations often have experience of helping people come off a wide variety of illicit and prescription drugs, have sometimes come off drugs themselves, and may be able to offer help, advice or set up a support group specifically for this purpose.
3. Talk to people who have gone through the process of coming off their medication. Learn what you can from their experience, although your experience will be unique. If possible, join or set up a 'coming off medication' group. From a group you might get knowledge and expertise, support and encouragement, positive competitiveness and a reality check that you are not 'going mad'.

Fig. 12. Making the decision to stop or carry on taking medication

<p><i>Good things/advantages in coming off meds</i> <i>e.g.</i> <i>'I won't feel zombied out'</i> <i>'I'll feel more confident if my weight returns to normal'</i> <i>'I can drive'</i> <i>'It will confirm I'm better'</i></p>	<p><i>Bad things/disadvantages in coming off meds</i> <i>e.g.</i> <i>'I might have another breakdown'</i> <i>'I might struggle to get to sleep'</i> <i>'My partner might get uptight/get on at me to take them'</i> <i>'I had a panic attack when I didn't take them for a couple of days'</i></p>
<p><i>Good things/advantages in staying on meds</i> <i>e.g.</i> <i>'I don't risk the withdrawal effects'</i> <i>'I'm quite stable'</i> <i>'There's no risk of people getting worried or getting on at me about deciding to come off'</i></p>	<p><i>Bad things/disadvantages of staying on meds</i> <i>e.g.</i> <i>'side effects – lethargy, weight gain'</i> <i>'sex life is affected, which affects my relationship'</i> <i>'I don't like doing what others think is best for me rather than what I want'</i></p>

4. Read up as much as possible on your drugs, the common withdrawal effects from your drugs, and about how to maximise your chances of doing it successfully. Useful books, including books written by people who have taken medication and which provide many accounts of people's experiences of coming off psychiatric drugs – such as Lehmann (2005) and Read (2009) – are reasonably priced and can be obtained by your local library. Several websites have also recently been set up (e.g. www.comingoff.com) that include advice written as collaborative projects by mental health services users and professionals (e.g. *The Harm Reduction Guide to Coming Off Psychiatric Drugs and Withdrawal* by The Icarus Project).

5. Make sure you have alternatives to medication as ways of coping with things. Have strategies to help with the possible increase in emotional sensations and withdrawal reactions. Sometimes you might need to just 'sit things out', but relaxation techniques and doing physically and psychologically soothing things can help.
6. Try to get in as good physical health as possible before starting to come off your drugs. If possible, start the process at a time of relative stability in your life, and be prepared to put other aspects of your life on hold if you have severe withdrawal reactions.
7. View coming off your medication as a journey (it could be a roller coaster ride!).
8. Plan it well and be prepared to possibly do it more slowly than you would ideally want.
9. Withdraw from one drug at a time if you are on more than one drug. Consider leaving withdrawing from 'side-effects medication' (e.g. procyclidine) and, if you have been on them a long time, minor tranquillizers (e.g. benzodiazepines) until last.
10. The longer you have been on a drug, the longer period you should consider regarding withdrawal. Be prepared to think in terms of months, rather than weeks, if you have been on a drug for over a year. People who have been on psychiatric drugs for many years have often taken over a year to come off.
11. Take a step-by step approach: taper your dosage. Reducing your dosage by 50% is a big step – people do succeed by taking such big steps (or by stopping their drugs altogether in one go), but by doing so you are increasing the risks of having withdrawal reactions to the drugs. Medically trained practitioners more frequently recommend just a 10% reduction each step, with at least a week to ten days between each reduction (longer if you have been taking a drug for more than a year, or if you have severe reactions to reducing your dose). Ask your doctor and pharmacist to supply your drugs in doses that allow you to take incremental steps in your dosage (e.g. a mixture of 2mg, 5mg, 10mg tablets, or if this is not possible consider changing to the same (or a very similar drug) that comes in liquid form). For some drugs (especially the minor tranquillisers) the steps might need to be smaller than others, and the final step might need to be broken down into very small reductions before you finally stop.

12. Try and analyse whether anxiety about recent or future reductions is primarily psychological or physiological, and if the former try and challenge anxiety-inducing thoughts and get reassurance from others.
13. If you have severe reactions to reducing your dose be prepared to raise the dose again temporarily in order to (i) check that your reaction is a withdrawal/rebound effect (ii) reduce the dose by a smaller amount at the next step.
14. Be flexible – be prepared to change and adapt your plans. You might want to take breathers in between steps, or put things temporarily on hold if things become stressful in your life. It might take time to find a plan that suits you. Everybody's reactions to coming off medication are different, and there are no set rules.
15. Remember that thousands of people have come off their medication and lived lives free of psychiatric services.