



For better
mental health

Making sense of coming off psychiatric drugs



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Making sense of coming off psychiatric drugs

'It meant I would be swallowing this tablet every single day, forever, and I would never really know my own emotions truly again.'

'I feel more like myself. I feel I'm finally finding myself. Because I started on the medication when I was 17 and I just tried to change myself to fit in with other people... and, now I'm off it, I'm starting to actually be myself.'

'The main problem has been to adjust to the increased range and depth of feelings suddenly available to me after all these years of lithium induced dullness. In learning to cope, I have leaned on newly-coined anger that I allowed myself to be deprived of these feelings for so long.'

'Trust yourself, know your own body, listen and interact with it.'

Many people want to come off their psychiatric medication. This booklet looks at why these medicines are prescribed, the possible effects of coming off them, the best way to withdraw successfully, and how to tell the difference between withdrawal and relapse.

Why are so many people taking these drugs?

Current psychiatric medical opinion encourages doctors to treat problems they have been taught to regard as 'illnesses' with medication. This means that if you have a psychotic episode, your doctor is likely to treat you with antipsychotic drugs (also known as neuroleptics or major tranquillisers) as quickly as possible. If you are diagnosed with schizophrenia or another psychotic condition, you might be prescribed antipsychotics for life; if the diagnosis is manic depression (bipolar disorder) you might be on lithium or other mood stabilisers for the foreseeable future.

You're likely to do slightly better if your problem is anxiety or depression. Doctors won't usually expect you to need medication for very long. No one should be taking a minor tranquilliser such as benzodiazepine, to treat anxiety, for more than four weeks continuously. However, some doctors still think that a person with depression needs ongoing antidepressants, in the same way that a person with diabetes needs insulin. This is a poor comparison. Diabetes is a physical condition with clear causes that are well understood. Insulin is a natural hormone with a very specific role in the body, and shouldn't be considered a drug. Taking it by injection causes few side effects. The same is not true of any psychiatric drug.

Experts are still not sure about the role of psychiatric drugs in controlling moods, emotions and other aspects of the life of the mind. We don't know how they interact with life events and other environmental factors. The most problematic group of psychiatric drugs, the antipsychotics, developed simply because they were seen to work. On the basis that these drugs seemed to have a helpful effect, a key theory about psychosis – the 'dopamine hypothesis of schizophrenia' – was constructed. In other words, the drugs were not developed to meet an error of chemical activity in the brain that was already identified, and there is still argument about whether this theory is correct. (See p. 8 for information about brain chemicals.)

The pharmaceutical industry has always been very active in encouraging doctors to use their products, and society, in general, puts pressure on people to use medication. Much of the media, through ignorance, still circulates the mistaken idea that mental health service users who decide to stop taking their medication are putting society at risk. Doctors in Western Europe and America tend to be cautious about helping patients find other ways of coping with their mental health problems. It's rare to

find doctors who are willing to take a different approach or help people withdraw, who are well enough informed to support them in this. Your doctor may be anxious that if you stop taking your medication, there will be nothing to put in its place and that you will become ill again. (See *What sort of support should I look for?* on p. 21.)

What's the argument against extensive use of these drugs?

People on psychiatric drugs, and their doctors, often don't know nearly enough about the possible side effects, the way the brain responds to these drugs in the long term, and the resulting difficulties people are likely to have when coming off. Some of the side effects are not only unpleasant, but also dangerous; they may worsen the symptoms they are supposed to alleviate and may be permanent in their effect. The longer people are on these drugs, the more likely they are to have side effects or withdrawal problems.

A 2005 Mind report, *Coping with coming off*, found that only 18 per cent of respondents said that their drugs had been mainly helpful, while 21 per cent said they had been mainly harmful. The rest were spread out somewhere in between the two. Most people wanted to come off because of the unpleasant effects, or because they did not want to be on the drugs in the long term.

There is a lot of research quoted by those arguing against the use of antipsychotics.

- It was once thought that the introduction of antipsychotic drugs in the 1950s speeded up people's return to the community. It's now thought that this was really the result of changes in social policy.

- Many studies show that people who are treated with dummy pills do much better, in the long term, than those treated with antipsychotics.
- The drugs are effective in the short term, but long-term use makes people more vulnerable to psychosis. People taking antipsychotics are also more socially dependent.
- The higher the dose, the greater the risk of relapse. Relapse while taking antipsychotics is more severe than when no drugs are used.
- People without medication suffer less from depression, blunted emotions and problems with movement.
- People diagnosed with schizophrenia in poor countries, where they are not treated with long-term antipsychotics, do much better than those in rich nations who are kept on medication.
- The majority of patients do well with no medication.
- People who minimise the use of antipsychotics have good results.

Can I refuse medication?

You have the right, by law, to make an informed decision about which treatment to have, and whether or not to accept the treatment a doctor suggests. To consent properly, you need to have enough information to understand what the treatment is, how it will affect you and what risks it holds. You should learn about its chance of success, and if there are any alternatives to it. Generally, you can only receive treatment that you have specifically agreed to.

Informed consent needs to include information about possible withdrawal problems. Few people would want to be on a medication that might have significant and unpleasant withdrawal symptoms, especially if they have had similar problems in the past. Some drug information leaflets (which should come with the medication) include this information when withdrawal

problems are well recognised and documented. But with other drugs, particularly antipsychotics, drug withdrawal is rarely mentioned.

Even after you have given your consent, it doesn't have to be final and you can always change your mind. Your consent to treatment is vital, and treatment given without it can amount to assault and negligence. The Mind report *Coping with coming off* found that a significant number of people said they had been made to take medication against their will on at least one occasion. (To find out more about when treatment can be given without consent, and whether you can do anything about it, see *Mind rights guide 3: consent to medical treatment*.) New mental health legislation is due in the future, which may make it harder for people to refuse treatment.

Why do people have withdrawal problems?

Most psychiatric drugs work on body chemicals called neurotransmitters, which carry messages between nerves, or between nerves and muscles, glands or other organs. They cross the gap (the synapse) between the nerve and its target. There are a lot of different neurotransmitters, and in the brain they interact and influence each other in subtle ways, which we have scarcely begun to understand. The main neurotransmitters, about which we know most, are dopamine, noradrenaline (norepinephrine), serotonin (5-hydroxytryptamine or 5-HT) and acetylcholine. Psychiatric drugs may have various actions:

- antidepressants aim to raise the levels of noradrenaline or serotonin in the brain
- antipsychotics reduce the effects of dopamine
- drugs for dementia aim to increase levels of acetylcholine
- mood stabilisers don't actually target neurotransmitters directly, but affect brain activity by different mechanisms (see p. 20 for more information).

The neurotransmitters work by interacting with receptors. These are minute areas on the nerve or other cells that make the cell respond in the appropriate way. Some psychiatric drugs block these receptors, reducing the effect of a neurotransmitter. Others increase the level of a neurotransmitter, so its effects last longer. Because they all interact, changing the level of one neurotransmitter will change others; so however well a drug is targeted towards a particular receptor, it will have a knock-on effect on the whole system.

One knock-on effect of many psychiatric drugs is to suppress acetylcholine, and this causes some of the side effects people experience. Using a drug can change the number of receptors people have, and this seems to be the cause of many withdrawal problems:

- If a drug increases the levels of neurotransmitters at the synapse, then the number of receptors there reduces. This means the person may not have enough receptors after the drug is withdrawn, making them more likely to relapse. (SSRIs will raise the concentration of serotonin by inhibiting its reuptake.)
- If a drug blocks the receptors, then new receptors are created to make up the shortfall. This makes the person extra sensitive to the neurotransmitter, so that when he or she comes off the drug, this 'supersensitivity' makes them more vulnerable to psychosis and at a high risk of suffering a relapse. (Antipsychotics block dopamine receptors.) Newer 'atypical' antipsychotic drugs are better targeted to particular dopamine receptors, but they still have serious side effects and should be limited to the lowest possible dose for the shortest possible time. A lot of people who have been 'stuck' for years on the older drugs might do better on the newer drugs, or might at least like to try.

Am I addicted?

Addiction means being physically dependent on the drug, with a need to increase the doses to get the same effect, and having a compulsive psychological need to take it. Many people who experience unpleasant symptoms when they withdraw, consider themselves to be 'addicted' to the drug. Many doctors and pharmaceutical companies prefer to call it 'dependence', or even 'withdrawal symptoms' or 'discontinuation symptoms'. The language used, however, doesn't alter the fact that some people have extreme difficulty when coming off psychiatric medication and only achieve it with great determination.

How well will I cope with coming off?

Individuals respond in different ways to psychiatric drugs. Some people can tolerate them very well, with few side effects, and may come off them quickly with no withdrawal effects. Others may have the most severe and unpleasant side effects or horrible withdrawal symptoms, so that they have to come off very slowly and carefully indeed. It's still an open question why there's so much variation, but it's probably due to your personal metabolism, which is at least partly genetic.

Sixty per cent of people who talked to Mind said they had difficulty coming off their drugs. SSRI antidepressants seemed to present the most difficulties, and mood stabilisers the least. Among the most commonly reported difficulties for those coming off were feelings of anxiety, panic attacks, and obsessions, while sleep disturbance was the next most common. (For more information about possible withdrawal symptoms, see p. 17.)

Withdrawal from antipsychotics

People can become 'tolerant' of a drug, meaning they need bigger doses to achieve the same effects. This is a well-known effect of drinking alcohol and taking benzodiazepine drugs, but is scarcely acknowledged in connection with antipsychotics. Someone who has become tolerant may experience withdrawal psychosis (tardive psychosis) – severe withdrawal symptoms, such as disorientation, confusion and hallucinations – if they stop too suddenly. But sometimes people need to stop them immediately because high doses of antipsychotics may cause toxic psychosis, a condition not connected to withdrawal. This has to be carefully managed under medical supervision. (See *What's the best way to come off?* on p. 14., and Mind's booklet, *Making sense of antipsychotics*, details under *Further reading*, on p. 37.)

Supersensitivity (see p. 9) may worsen some of the symptoms that the drugs are supposed to alleviate. It also makes people on antipsychotics more vulnerable to problems with muscles and movements (called dyskinesia), caused by a drug-induced enlargement of the area of the brain that controls them. Tardive dyskinesia is a serious movement disorder, which may have been hidden by the antipsychotic until withdrawal, and which may be permanent in some cases. (Mind's *Tardive dyskinesia* factsheet is available on the Mind website).

Withdrawing from other psychiatric drugs

Other medication is rather different from antipsychotics.

Antidepressants are not generally used for very long. Withdrawal problems are increasingly acknowledged and people are warned to come off them slowly.

The dependency and withdrawal problems with benzodiazepine tranquillisers are well known, so that doctors are strongly advised not to prescribe them for long periods.

Lithium is another long-term treatment with its own set of problems, but with fewer and less severe withdrawal problems than many other drugs. (See p. 20 for more information.)

Having to cope with emotions

Most psychiatric drugs act to suppress your emotions, so when you begin to come off, you may find that your emotions are very strong and hard to deal with. Your doctor may interpret this as a sign that you need the drug, but you could argue that unless you are given the chance to feel your emotions you will never find out how to deal with them. You may find it helpful to talk to a counsellor or therapist (see p. 22).

Your doctor's attitude

One of the problems many people encounter when coming off psychiatric drugs is their doctor's attitude. (See below, *What if my doctor doesn't agree to my withdrawal?*) Doctors can naturally be very concerned about changes in behaviour that follow withdrawal, but may be too likely to see these as signs of a relapse rather than the consequences of withdrawal brought on by sensitivity to the drug, which can look very similar. They may be quick to treat all withdrawal problems with a higher dose of medication. (See *How can I tell the difference between withdrawal problems and relapse?* on p. 17.)

What if my doctor doesn't agree to my withdrawal?

Although it's advisable to consult a doctor before coming off medication, many people don't do so, often because they feel that their doctor won't agree with their decision. Many people who talked to Mind agreed that getting professional help was

important, but they found that, in practice, doctors were not very helpful. Many decided to come off medication against the advice of their doctors, or without involving them in the decision. When coming off, the most helpful people were those who had no role in prescribing their medication, including counsellors, other service users, self-help groups, and complementary therapists.

Doctors seemed to be less concerned than service-users about the side effects of medication, less understanding of their desire to live without drugs, and more likely to doubt their ability to do so successfully. It's been suggested that doctors and other professionals who have taken psychiatric medication themselves are more likely to be sympathetic to people wishing to come off and the difficulty of doing so. However, it seems rare for the doctor to be the one suggesting they come off.

One study¹ revealed how discouraging medical staff were to patients wanting to reduce their medication before coming out of hospital. This negative attitude seemed to harden as patients went on reducing their dose, even when there was no sign of any ill-effects and no deterioration in their condition. Staff would interpret any changes in behaviour, such as getting up late or refusing to attend activities, as a relapse of psychosis, rather than people wanting to take their lives back into their own hands. The study concluded that the attitudes and perceptions of the staff exerted just as much influence on the number of different drugs and the dose they were given as the patient's state of mind.

In Mind's *Coping with coming off* study, people who didn't involve their doctor were just as likely to succeed in coming off as those who did.

1 Thomas A, Katsabouris G and Bouras N, 1997, 'Staff perception on reduction of medication in patients with chronic schizophrenia', *Psychiatric Bulletin*, vol 21, pp. 692-4.

What's the best way to come off?

Although it's possible to stop taking medication all at once, with no ill effects, many people would become very unwell if they did so. It's impossible to tell, in advance, so everyone is advised to withdraw slowly. Experience suggests that the longer you have been taking your medication, the harder you are likely to find coming off, and the longer it will probably take. If you have been taking a drug for six months, you may find it takes another six months to come off it completely. If you have been taking it for 20 years, then you can expect to have to reduce very slowly, perhaps over a period of years, before coming off completely.

Half-lives

It's usually easier to come off a drug with a long half-life than one with a short half-life because withdrawal is more gradual. The half-life of a drug is a way of measuring the length of time it takes for the quantity in the average person's blood to drop by half. How long it will take actually varies from person to person, because some people are 'good' metabolisers and some 'poor' metabolisers. ('Poor' metabolisers also tend to have more problems with side effects.)

The half-lives of some psychiatric drugs are given on p. 26. Pharmaceutical companies also produce a Summary of Product Characteristics (SPC) for each drug. (See *Useful websites*, on p. 36, for information.) Manufacturers list some drugs as having a very wide-ranging half-life. This probably reflects the wide variation between people, the way the drug is metabolised and the influence of other factors (such as diet), or a combination of all three. (This may explain why different people have such different experiences in coming off the same drug.)

Anyone having great difficulty coming off a drug with a short half-life may find it helpful to change to a similar drug with a long half-life. For example, you could switch from paroxetine (Seroxat) to fluoxetine (Prozac). (See *Equivalent doses* on p. 31.)

Support from your doctor

This is when supportive doctors can be very helpful indeed in changing your prescription to an alternative medication, which allows for slow dose reduction. Doctors can also support someone's request for a supply of antipsychotic to keep in case of a crisis, so the person doesn't have to be on them continuously.

If you feel able to talk to your doctor about your decision to come off, this could enable him or her to learn more about the process, and this may help them to be more confident about your ability to manage your own medication. One interviewee in *Mind's Coping with coming off* study reported that it was her GP who originally suggested that she should come off her drugs, and that her psychiatrist became more open to the idea as she (the 'patient') took more control.

Making small reductions

If you find you have to withdraw very slowly, it can be difficult to make small enough reductions in your dose, especially if your drug comes in capsule form. Sometimes it's possible to break open the capsule and remove some of the content to lower the dose. You should always take care doing this, though, as the contents (for instance, fluoxetine) are sometimes irritating to the skin or the eyes. A pharmacist should be able to tell you if it's safe to do so.

Some drugs are obtainable in liquid form, which can be diluted to make small reductions in dosage. It may be worth asking whether you can change to one of these. You would then need to be very sure what the concentration of the liquid is, and how

much water to add to achieve the dose you wish. You may want to ask a pharmacist to help you with this. Drugs that are available in liquid form are listed on p. 31. (The lowest available doses in solid form are also in the tables on pp. 26-30.)

Allow enough time for your body to readjust to the lower dosage at each stage. You could start by reducing the dose by 10 percent, and see how you feel. If you get withdrawal effects, wait for these to settle before you try the next reduction. Then reduce it by another 10 percent of the original dose. As the dose gets smaller, you may find this rate more difficult to cope with, and reducing by 10 percent of the (reduced) dose may be a better idea. If you started with 400mg of your drug, for example, you could first reduce the dose by 10 percent (40mg), to 360mg. The next 40mg reduction would take you down to 320mg, then 280mg, 240mg, and so on. If you got to 200mg and then found that a further drop of 40mg drop was too difficult, you could reduce by 10 percent of 200mg (20mg), and go down to 180mg, and so on. At each stage, if you find the reduction too difficult to cope with, you can increase the dose slightly (not necessarily back to the previous dose) and stabilise on that before you continue.

Timing

If you take your drug in divided doses several times a day, choose which dose to reduce first, according to which gives you the most troubling side effects. Some people reduce by cutting out doses entirely so, with a drug taken once a day, they would take it every other day. Depending on how short the half-life of the drug is, this may cause fluctuations in blood levels, which may increase withdrawal symptoms. In this case, it may be more manageable to take a reduced dose, daily.

If you are taking more than one drug and you want to withdraw from all of them, withdraw one at a time, and choose which one should come first. If you are taking an antipsychotic and an anti-Parkinson's drug (to control some of the drug's side effects) reduce the antipsychotic before stopping the anti-Parkinson's.

When to slow down

Each reduction may cause increased anxiety and sleep disturbance, which should stop after a couple of weeks. (In the case of antipsychotics, if these symptoms continue for longer than three weeks, then you may be at risk of developing withdrawal psychosis, becoming very agitated and restless, or developing signs of tardive dyskinesia. See p. 11, above, for more information.) You may also feel sick or vomit. These are signs that you are reducing too quickly, and you should put the dose back up to its last level. Your symptoms should then stop. When you feel ready, you can try reducing again, by a smaller amount.

Withdrawal effects

How can I tell the difference between withdrawal problems and relapse?

There are three ways to tell if symptoms are the result of withdrawal, according to one expert, David Healy, who applied it to SSRIs in particular:

- The problems begin immediately after reducing or stopping the drug. (If the original problem has been treated, it should be some time before the symptoms come back, if ever.)
- The symptoms disappear if you go back on the drug, or raise the dose.
- You are experiencing new symptoms as well as some of those that were a feature of your original condition (flu-like symptoms as well as depression, for instance).

These are the kind of withdrawal effects you might encounter:

Minor tranquilisers

Benzodiazepine withdrawal symptoms include: anxiety, depression, panic, agoraphobia, confusion, perceptual disturbances and hallucinations, insomnia, nightmares, suicidal thoughts, memory problems, cold sweats, heart palpitations, breathing problems, high blood pressure, stomach ulcers, nausea, loss of appetite, weight loss, nose bleeds, tremor, muscle spasms, tinnitus, light-headedness, dizziness, detachment, feeling poisoned.

Antidepressants

Withdrawal symptoms for tricyclic antidepressants include: excessive anxiety, restlessness, hyperactivity, insomnia, disturbing dreams and nightmares, flu-like symptoms (headache, sweating, diarrhoea, stomach ache, bowel discomfort, nausea, vomiting, hot and cold flushes, goosebumps), fast or irregular heart beat, low blood pressure, and increased libido. Psychiatric effects include hypomania and mania, apathy, social withdrawal, depressed mood, panic attacks, aggression, delirium and psychoses.

When describing the symptoms of withdrawal from SSRI antidepressants, David Healy breaks them down into two groups:

- symptoms 'unlike anything you have had before'
- symptoms that 'may lead you or your physician to think that all you have are features of your original problem'.

The first group include: dizziness (when you turn your head you feel your brain gets left behind); 'electric head' (strange brain sensations which have been likened to goose bumps in the brain); electric shock-like sensations, other strange tingling or painful sensations; nausea, diarrhoea and flatulence; headache; muscle spasms and tremor; agitated and vivid dreams; agitation; hearing or seeing things others can't.

The second group include: mood swings; irritability; confusion; fatigue, malaise and flu-like symptoms; insomnia or drowsiness; sweating; feelings of unreality; disturbed temperature sensations; change in personality.

Many people taking SSRIs, especially paroxetine (Seroxat) and fluoxetine (Prozac), have reported uncharacteristic feelings of violence and suicidal thoughts and actions, and these seem to be particularly associated with changes in dose.

Withdrawal symptoms for Monoamine oxidase inhibitors (MAOIs) are less well known than for other antidepressants, because they are less commonly prescribed. There are conflicting reports on the frequency and severity of withdrawal problems. Reported symptoms include: anxiety, agitation, paranoia, being unusually talkative, headaches, low blood pressure when standing, muscle weakness, shivering and tingling, burning sensations, and mania. Catatonic states have also been reported.

Antipsychotics

Withdrawal psychosis and tardive dyskinesia are two of the most serious problems. (See p. 11, for more information.) There could also be other less severe but still unpleasant effects to contend with: flu-like effects (nausea, vomiting, diarrhoea, headaches, chills, sweating, runny nose); movement problems (involuntary twitches, muscle spasms and tics); psychological effects (insomnia, anxiety, agitation, irritability, and psychosis, including hallucinations, delusions, confusion and disorientation). The psychological effects may be little different from the symptoms of the original problem, and it may be very hard to know for certain which it is.

Neuroleptic malignant syndrome is a very serious condition, which some people have developed on drug withdrawal. It can also

occur as a side effect of the drugs. It can be life-threatening and involves changes in consciousness, abnormal movements and fever. It is important to seek medical treatment immediately.

Mood stabilisers

Mood stabilisers behave differently from other psychiatric drugs.

Lithium does not directly affect neurotransmitters, but slows down the normal electrical traffic of brain cells by replacing the sodium and potassium ions involved. There are no problems, therefore, with increased or reduced receptor numbers. Even so, it's still better to withdraw gradually, because this reduces the risk of depression or mania returning, and allows people to adjust the speed of withdrawal to their own needs. Withdrawal may significantly alter blood flow through the brain, and this could lead to manic states. Slow withdrawal will allow the brain to adjust gradually to changes in blood flow. There is some disagreement among experts about whether the blood flow is returning to normal having been changed by lithium treatment or whether withdrawal leads to an abnormal flow pattern.

Lithium withdrawal may bring common problems such as feeling anxious, irritable, tense, restless and highly emotional or confused. There don't seem to be any physical 'rebound phenomena'.

Carbamazepine is an anticonvulsant that can also be used to stabilise moods. (Much of the information about withdrawal comes from people who have taken it for epilepsy.) Withdrawal symptoms include aching muscles, spasms or twitches, walking unsteadily, sleeping problems, no energy or appetite, headaches, tension, weak memory and loss of concentration. It can also make people feel depressed and irritable, disconnected (depersonalised), paranoid and confused. There are reports of some people having low blood pressure with a fast heartbeat.

Valproate and similar anticonvulsants should be reduced gradually to minimise withdrawal symptoms, 'such as anxiety and restlessness', according to guidelines on withdrawal for people with epilepsy. Other reported withdrawal symptoms of valproate are anxiety, muscle twitching, tremors, weakness, nausea and vomiting. There is also a small risk of having a seizure, even for those who haven't had one before.

What sort of support should I look for?

Loss of self-confidence is very common among people who have been taking drugs for a long time, partly due to the effects of the drugs themselves, and partly due to being in 'the sick role' and dependent on a doctor's prescription. This can make it difficult to make the decision to come off the drugs and to stick with it. The support of friends who have been through the same process and know just how it feels can be immensely valuable.

There are only very few organisations with expertise in coming off medication. (See *Useful organisations*, on p. 34, for more details.) If you are very lucky, you may have a local group near you – for example, in a local Mind association. The majority of people will find that the best source of support and information is the Internet, particularly for SSRI antidepressants, although less so for those coming off antipsychotics or mood stabilisers.

You might also find help available from the local drug dependency team, although not everyone feels comfortable using a service that is primarily aimed at street drug users.

Talking treatments and complementary therapies

Talking treatments (such as counselling, psychotherapy or cognitive behaviour therapy) are increasingly available through the NHS. Some GPs are also qualified to offer homeopathic or herbal medicine, as well as employing counsellors. Some may prescribe exercise for depression, and many have access to various other complementary therapies. However, in some areas you may have to find and pay a qualified practitioner for this kind of help. (See Mind's booklets, on p. 37.). You may also find relaxation classes, meditation, yoga, massage and aromatherapy available locally, especially if you have a Healthy Living Centre or similar organisation in your area. (See *The Mind guide to... series*, on p. 37.)

Arts therapies and spirituality

Joining an art, music, drama or dance group is worth considering. These may be quite informal or may be run by qualified arts therapists, sometimes through mental health organisations, such as local Mind associations, or through a local adult education institute. Local churches, temples, or other religious centres often provide good support, or you could pursue your own form of spiritual practice. (See the *Mind guide to spiritual practice* in *Further reading*, on p. 37.)

What can I do to help myself?

A large number of people have found that major lifestyle changes helped them to come off medication, as long as they were consciously taking control and revising the whole of their lives. One person coming off reported that she was so busy with other things that she forgot to take her medication, and realised that she had come off it almost by chance.

Apart from getting plenty of support, respondents to Mind's *Coping with coming off* survey felt it was advisable for people to know exactly why they were coming off. They stressed the

importance of personal development, of finding new interests, of trying again if they failed the first time and of not replacing medication with street drugs or alcohol. There are a number of strategies that seem to be helpful.

Get to know your triggers for crisis

Many people get to know what situations they find stressful, and either prepare themselves carefully so as to minimise the stress, or avoid them completely. You may find it helps to keep a diary so that you can spot patterns.

Learn how to look after yourself

Don't be afraid to say 'no' if you feel something you've been asked to do will be too much for you. Be prepared to ask your friends or family for help, if that's what you need to keep well. For example, you may find it much easier to keep an appointment if you have someone to go with you. You may find it possible to do something you find stressful if you take a particular token with you (a scarf, a stone, a teddy, or whatever works for you). Don't be afraid to use such things if they help you to get on with your life. (See *How to look after yourself*, under *Further reading*.)

Look at your diet

Try to eat regularly, starting with breakfast. Guard against low blood sugar and try to avoid sugary foods and drinks, which cause big fluctuations in blood sugar. Be aware of foods and drinks that trigger depression in you. Keeping a diary of what you've eaten may reveal responses that you aren't aware of. (See *The Mind guide to food and mood*, under *Further reading*.)

Avoid street drugs

If you have had a bad experience in the past with street drugs, such as cannabis or ecstasy, don't take them, even if all your friends do.

Get enough sleep

Sleep is one of the most important factors in maintaining mental health. If you are coming off medication, and one of the withdrawal effects is sleep disturbance, you may have to be prepared to put up with this for a while and find ways to minimise the ill effects. (See *How to cope with sleep problems*, or *Mind troubleshooters: sleep problems*, under *Further reading*, on p. 37.)

Trust your own perceptions

If you feel that something you are experiencing is a side effect of medication or a withdrawal effect, take your perceptions seriously. Doctors may tell you that 'it's your illness', but you know your body and its responses better than they do. If you are following a programme of slow dose reduction, and you reach a difficult phase, don't be afraid to slow down, or to stop at the dose you are on for longer than you had planned; adapt your plans to fit your experience.

Coming off can sometimes be a big disappointment for people, if it doesn't bring the hoped for improvement. But even if you don't manage to come off completely, you may succeed in reducing your dose, and this could make a significant difference to how you feel. Some people conclude that they are happier taking medication after all. This is also helpful to know. It may be easier to get on with the rest of your life once you have accepted that medication is part of it.

What about friends and relatives?

Family members can be very helpful, but may sometimes overrate the advantages of medication and not appreciate the importance of coming off. They may be much too anxious about you becoming ill again to support your wishes. This seems to be more common with antipsychotics and mood stabilisers than with antidepressants.

Their caution may be understandable if they were involved in distressing decisions to have you assessed and sectioned under the Mental Health Act 1983. They may have been very relieved to see you coming out of hospital more stable on medication. You may need to be very clear about how things have changed for you since then, and what other forms of support you are intending to use when you come off the drugs. They will find it easier to be supportive if you tell them what you are doing and why. Asking them for help with things that you may find difficult during the withdrawal period will give them confidence. Or you could invite them to join in with an activity you've newly undertaken.

People with mental health problems are too often denied the chance to make their own mistakes and take risks. Friends and family can help a lot by respecting what you are doing, allowing you to take responsibility for your own decisions, and being prepared to take some risks with you. Their support may well reduce any risks involved.

Appendices

All information in the following appendices is taken from *British National Formulary 49*, March 2005. (All drugs are referred to by their general names.)

Appendix 1

Minimum available doses and half-lives of psychiatric drugs

Note: Minimum doses are for the drugs in solid form (tablet or capsule) taken orally.

Drug	Minimum available dose	Half-life
Tranquillisers (Benzodiazepines)		
alprazolam	250mcg	12 to 15 hours
chlordiazepoxide	5mg	6 to 30 hours
clorazepate	7.5mg	not available
diazepam	2mg	1 to 4 days
flurazepam	15mg	not available
loprazolam	1mg	12 hours
lorazepam	1mg	12 to 16 hours
lormetazepam	500mcg	not available
nitrazepam	5mg	24 hours
oxazepam	10mg	not available
temazepam	10mg	7 to 11 hours
Sleeping pills		
zaleplon	5mg	1 hour
zolpidem	5mg	2.4 hours
zopiclone	3.75mg	3.5 to 6 hours

Drug	Minimum available dose	Half-life
Anxiolytics		
bupirone	5mg	2 to 11 hours
meprobamate	400mg	not available

Antipsychotics (typical)

benperidol	250mcg	not available
chlorpromazine	10mg	20 to 40 hours
flupentixol	3mg	35 hours
fluphenazine	1mg	14.7 hours
haloperidol	500mcg	20 hours
levomepromazine	25mg	30 hours
pericyazine	2.5mg	not available
perphenazine	2mg	not available
pimozide	4mg	55 hours
prochlorperazine	5mg	not available
promazine	25mg	20 to 40 hours
sulpiride	200mg	8 hours
thioridazine	10mg	10 hours
trifluoperazine	1mg	22 hours
zuclopenthixol	2mg	1 day

Drug	Minimum available dose	Half-life
Antipsychotics (atypical)		
amisulpride	50mg	1 day
aripiprazole	10mg	3.5 to 6 days
clozapine	25mg	12 hours
olanzapine	2.5mg	3 days
quetiapine	25mg	7 hours
risperidone	500mcg	24 hours
sertindole	4mg	3 days
zotepine	25mg	14 hours

Antipsychotics (depots)

flupentixol decanoate		not available
fluphenazine decanoate		6 to 9 days
haloperidol decanoate		not available
pipotiazine palmitate		not available
riperidone		not available
zuclopenthixol decanoate		not available

Antimanic drugs

valproate	250mg	14 hours
carbamazepine	100mg	16 to 24 hours
lithium	200mg	24 hours

Drug	Minimum available dose	Half-life
Antidepressants (tricyclics)		
amitriptyline	10mg	9 to 25 hours
amoxapine	50mg	8 to 30 hours
clomipramine	10mg	21 hours
dosulepin	25mg	50 hours
doxepin	10mg	51 hours
imipramine	10mg	19 hours
lofepramine	70mg	5 hours
nortriptyline	10mg	16 to 38 hours
trimipramine	50mg	not available

Antidepressants (MAOIs)

phenelzine	15mg	not available
isocarboxazid	10mg	not available
tranylcypromine	10mg	not available

Antidepressants (reversible MAOI)

moclobemide	150mg	2 to 4 hours
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Drug	Minimum available dose	Half-life
Antidepressants (SSRIs)		
citalopram	10mg	1.5 days
escitalopram	5mg	30 hours
fluoxetine	20mg	4 to 6 days
fluvoxamine	50mg	13 to 15 hours
paroxetine	20mg	24 hours
sertraline	50mg	26 hours

Antidepressants (SNRIs)

duloxetine	30mg	8 to 17 hours
venlafaxine	37.5mg	5 hours

Antidepressants (others)

flupentixol	500mcg	35 hours
mirtazapine	15mg	20 to 40 hours
reboxetine	4mg	13 hours
tryptophan	500mg	not available

Appendix 2

Psychiatric drugs that are available in liquid form

Benzodiazepines: nitrazepam, temazepam, diazepam

Antipsychotics: chlorpromazine, haloperidol, pericyazine, promazine, sulphiride, thioridazine, trifluoperazine, amisulpride, risperidone

Mood stabilisers: lithium citrate, carbamazepine,

Antidepressants: amitriptyline, lofepramine, trazodone, citalopram, fluoxetine, paroxetine, mirtazapine.

Appendix 3

Equivalent doses

SSRIs:

Change to 20mg fluoxetine (Prozac) liquid from:

paroxetine (Seroxat) 20mg

venlafaxine (Efexor) 75mg

citalopram (Cipramil) 20mg

sertraline (Lustral) 50mg

Benzodiazepines:

Change to 5mg of diazepam (Valium) from:

chlordiazepoxide 15mg

loprazolam 0.5-1.0mg

lorazepam 500mcg (0.5mg)

lormetazepam 0.5-1.0mg

nitrazepam 5mg

oxazepam 15mg

temazepam 10mg

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Useful organisations

Mind

Mind is the leading mental health organisation in England and Wales, providing a unique range of services through its local associations, to enable people with experience of mental distress to have a better quality of life. For more information about any mental health issues, including details of your nearest local Mind association, contact the Mind website: www.mind.org.uk or MindinfoLine on 0845 766 0163.

Battle Against Tranquillisers (BAT)

PO Box 658, Bristol BS99 1XP
tel. 0117 966 3629 or 0117 941 2020
web: www.nscgf.org.uk/bat

Council for Information on Tranquillisers and Antidepressants

3–11 Mersey View, Waterloo, Liverpool L22 6QA
helpline: 0151 932 0102

Hearing Voices Network

91 Oldham Street, Manchester M4 1LW
tel. 0161 834 5768, web: www.hearing-voices.org

National Phobics Society

Zion CRC, 339 Stretford Road, Hulme, Manchester M15 4ZY
tel. 0870 770 0456, web: www.phobics-society.org.uk

No Panic

93 Brands Farm Way, Randlay, Telford, Shropshire TF3 2JQ
helpline: 0808 808 0545, web: www.nopanic.org.uk

Psychiatric Medication Helpline

tel. 020 7919 2999

Manic Depression Fellowship (MDF)

Castle Works, 21 St George's Road, London SE1 6ES
tel. 020 7793 2600, web: www.mdf.org.uk

Rethink Severe Mental Illness

28 Castle Street, Kingston-upon-Thames KT1 1SS
Advice line: 020 8974 6814, web: www.rethink.org

Useful websites

www.benzo.org.uk

Benzodiazepine Addiction, Withdrawal & Recovery

www.dipex.org

Dipex (Personal experiences of health and illness)

www.medicines.org.uk

For detailed information on drugs, the half-life patient information leaflets and summaries of product characteristics

[www.mind.org.uk/Information/ Seroxatwithdrawalinformation.htm](http://www.mind.org.uk/Information/Seroxatwithdrawalinformation.htm)

Pages on Seroxat withdrawal, including link to David Healy's advice.

www.seroxatusergroup.org.uk

Seroxat User Group

www.socialaudit.org.uk

Public interest organisation particularly concerned with SSRIs, medicines regulation and the power of the pharmaceutical industry

www.ukppg.org.uk

UK Psychiatric Pharmacy Group

www.thyromind.info

Thyromind

Further reading

- Accepting voices* eds M. Romme, S. Escher, (Mind 1993) £13.99
- Beyond Prozac: healing mental distress without drugs*
Dr T. Lynch (PCCS Books 2004) £13
- Coping with coming off: Mind's research into the experiences of people trying to come off psychiatric drugs*
J. Read (Mind 2005)
- Coming off psychiatric drugs: successful withdrawal from neuroleptics, antidepressants, lithium, carbamazepine and tranquillisers* ed. P. Lehmann (Peter Lehmann Publishing 2004) £14.99
- Drugs used in the treatment of mental health disorders: FAQs* (4th ed) S. Bazire (Academic Publishing Services 2004) £9.95
- The food and mood handbook* A. Geary (Thorsons 2001) £12.99
- Healing minds* J. Wallcraft (Mental Health Foundation 1998) £12
- How to cope with sleep problems* (Mind 2003) £1
- How to look after yourself* (Mind 2004) £1
- Inside out* (Manic Depression Fellowship 1995) £3
- Learn to balance your life*, M. & J. Hinz (DBP 2004) £9.99
- Living with schizophrenia: an holistic approach to understanding, preventing and recovering from negative symptoms* J. Watkins (Hill of Content 1996) £9.99
- Making sense of antidepressants* (Mind 2004) £3.50
- Making sense of antipsychotics (major tranquillisers)* (Mind 2004) £3.50
- Making sense of counselling* (Mind 2004) £3.50
- Making sense of herbal remedies* (Mind 2004) £3.50
- Making sense of homeopathy* (Mind 2004) £3.50
- Making sense of lithium* (Mind 2004) £3.50
- Making sense of psychotherapy and psychoanalysis* (Mind 2004) £3.50
- Making sense of sleeping pills* (Mind 2005) £3.50

- *Making sense of voices: a guide for mental health professionals working with voice-hearers* M. Romme, S. Escher (Mind 2000) £25
- *The Mind guide to food and mood* (Mind 2004) £1
- *The Mind guide to managing stress* (Mind 2005) £1
- *The Mind guide to massage* (Mind 2004) £1
- *The Mind guide to physical activity* (Mind 2004) £1
- *The Mind guide to relaxation* (Mind 2004) £1
- *The Mind guide to spiritual practices* (Mind 2004) £1
- *The Mind guide to yoga* (Mind 2004) £1
- *Mind troubleshooters: sleep problems* (Mind 2005) 50p
- *This is madness too: critical perspectives on mental health services* eds C. Newnes, G. Holmes, C. Dunn (PCCS Books 2001) £14
- *This is madness: a critical look at psychiatry and future of mental health services*, eds C. Newnes, G. Holmes, C. Dunn (PCCS Books 1999) £16
- *Toxic Psychiatry: a psychiatrist speaks out* P. Breggin (Harper Collins 1993) £12.99
- *Understanding addiction and dependency* (Mind 2005) £1
- *Understanding talking treatments* (Mind 2005) £1
- *Your drug may be your problem: how and why to stop taking psychiatric medications* P. Breggin D. Cohen (Perseus 2000) £13.99

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- Our independence gives us the freedom to stand up and speak out on the real issues that affect daily lives.
- We provide information and support, campaign to improve policy and attitudes and, in partnership with independent local Mind associations, develop local services.
- We do all this to make it possible for people who experience mental distress to live full lives, and play their full part in society.

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