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making sense

Making sense of antipsychotics

This booklet is for anyone who wants to know more about antipsychotic medication. It explains what antipsychotics are, how they work, possible side effects and information about withdrawal.

Contents

What are antipsychotics?

Antipsychotics are psychiatric drugs which are available on prescription, and are licensed to treat types of mental health problems whose symptoms include psychotic experiences. These include:

- schizophrenia
- schizoaffective disorder
- some forms of bipolar disorder
- severe depression.

Some antipsychotics may also be used to treat:

- severe anxiety (but only in very low doses)
- physical problems, such as persistent hiccups, problems with balance and nausea (feeling sick)
- agitation and psychotic experiences in dementia (although they're not usually recommended in this case).

Antipsychotics can be prescribed to be taken in various different ways. Most commonly this will be orally in tablet or liquid form, but some of them can also be prescribed as depot injections.

Other terms for antipsychotics

Antipsychotic drugs can also be called neuroleptics. Some people prefer this term because it means 'seizing hold of the nerves', which describes their action more accurately.

You might also hear antipsychotics referred to as major tranquillisers, which is an old-fashioned term for the same drugs.

What should I know before taking antipsychotics?

Informed consent

The law says that you have the right to make an informed decision about which treatment(s) to have. To consent properly, you need to have enough information to understand what the treatment is, what its benefits should be, possible harms it might cause, its chance of success, and available alternative treatments.

Even after you have given your consent you can change your mind at any time. Consent is fundamental to treatment, and treatment given without consent can amount to assault and negligence.

However, if you are in hospital as an involuntary patient under the Mental Health Act (sectioned), you can be treated without your consent. For more information on this, see the Mind page *Consent to medical treatment*.

If you have taken medication before, you may know which drugs work best for you. You might want to write a statement saying which drugs have and haven't helped you in the past, to help make the right choice in the future; especially if you are not able to make your wishes known clearly at the time.

You can do this by:

- making a note on your care plan
- using a crisis card
- making an advance statement (see Mind's legal briefing on *the Mental Capacity Act 2005*).

If you are worried about your diagnosis and treatment, and unsure about the advice you have been given, you could ask either your GP or psychiatrist to refer you for a second opinion.

Patient information leaflets

If you are prescribed medication as an outpatient, it should come with a patient information leaflet (PIL – usually folded up small to fit in the packet); as an inpatient, you may have to ask for it specifically. If you do not receive the PIL, you should ask for it from the person who makes up your prescription.

The PIL contains information such as:

- the trade and generic names of the drug
- the dosage and form it takes, e.g. tablets or liquid
- who should take it
- what conditions the drug is licensed to treat
- cautions about any conditions that mean you should take a reduced dose or not take it at all
- how and when to take it
- possible side effects
- the expiry date
- how to store it safely.

It should also contain a full list of all the ingredients, including the extra contents that hold it together as a tablet or capsule, such as maize starch, gelatin, cellulose, and colourings. This information is important because some people may be allergic to one or other of the ingredients, such as lactose or gluten or a colouring. Gelatin is unacceptable to some people because it is an animal product.

Getting more information from your doctor or pharmacist

The PIL contains only the most important information you need to know about the medicine and if you need to know more, you should ask your doctor or your pharmacist.

Many people would like to have the information about their medicine

before they start taking it. You might like to make a list of questions to ask your doctor, when your prescription is written, such as will the medication make you sleepy, should you take it with meals, or are you likely to have problems coming off it.

You can also talk to your pharmacist, either at your local hospital or your chemist. Pharmacists are drug specialists, and may be more knowledgeable about your drugs than the doctor who prescribes them. They may be more aware of possible side effects, and also possible interactions with other drugs (this is when a drug changes the effect of other drugs you are taking). Many high-street chemists have space set aside where you can talk privately.

There is more information on medicines and their use available from the eMC (Electronic Medicines Compendium) website.

Medicines Use Reviews

If you regularly take more than one prescription medicine, or take medicines for a long-term illness, you can go to your local pharmacist for a Medicines Use Review, in which you can talk about your medicines, what they're all for, and any problems you may have with them. A guide to this scheme is available from the Department of Health.

Drug names

Drugs can have two types of names: their generic name and the trade names given by the drug companies (starting with a capital letter). If a drug is made by more than one company, it can have several trade names, but it always has the same generic name. In Mind's *Antipsychotics A-Z*, drugs are listed using their generic name.

How do they work?

Antipsychotic drugs don't cure psychosis but they are often effective in reducing and controlling many symptoms, including:

- delusions and hallucinations, such as paranoia and hearing voices
- anxiety and serious agitation, for example from feeling threatened
- incoherent speech and muddled thinking
- confusion
- violent or disruptive behaviour
- mania.

Rather than getting rid of these symptoms completely, the drugs may just stop you feeling so bothered by them – so you feel more stable and can get on with leading your life the way you want to.

"They make me feel calm, help me sleep, stop racing thoughts and help blunt hallucinations. Meds don't make life perfect – they just help me cope with the imperfections and struggles I face."

What's the science behind antipsychotics?

There are several possible explanations why antipsychotic drugs can be effective in controlling and reducing psychotic symptoms:

- Blocking the action of dopamine. Researchers believe that some psychotic experiences are caused by your brain producing too much of a chemical called dopamine (dopamine is a neurotransmitter, which means that it passes messages around your brain). Most antipsychotic drugs are known to block some of the dopamine receptors in the brain – this reduces the flow of messages, which may be too frequent in psychotic states.

- Affecting other brain chemicals. Most antipsychotics are known to affect other brain chemicals too, such as the neurotransmitters serotonin and noradrenaline, which are both thought to be involved in regulating mood.

- Parkinsonism. Some academics have suggested that antipsychotics may actually work by causing Parkinsonism (a movement disorder) – not just the physical symptoms, which are well known neuromuscular side effects of these drugs, but also the psychological symptoms, such as not feeling emotions and losing interest in activities.

What different types of antipsychotics are there?

Antipsychotic drugs tend to fall into one of two categories: first generation (older) antipsychotics and second generation (newer) antipsychotics. Both types can potentially work well, but they differ in the kind of side effects they can cause and how severe these may be.

First generation (older) antipsychotics

Key facts:

- mostly developed and first licensed in the 1950s
- sometimes referred to as 'typicals'
- these divide into various chemical groups which all act in a very similar way and can cause very similar side effects, including severe neuromuscular side effects
- however, they're not all the same – for example, some may cause more severe movement disorders than others, or be more likely to make you more drowsy.

Second generation (newer) antipsychotics

Key facts:

- mostly developed and first licensed in the 1990s
- sometimes referred to as 'atypicals'
- in general these cause less severe neuromuscular side effects than first generation antipsychotics
- some also cause fewer sexual side effects compared to first generation antipsychotics
- however, second generation antipsychotics are more likely to cause serious metabolic side effects, including rapid weight gain.

For a full list of all antipsychotic drugs compared by type, form and half-life, see the section 'Comparing antipsychotics' on p.43.

For more details about specific antipsychotics and their side effects, you can also look up each individual drug in Mind's online *A–Z of Antipsychotics*.

"I still take antipsychotic medication today and I don't have a problem with it. I feel so much better than when I was first prescribed an antipsychotic. I know that they work for me and help."

Could antipsychotics help me?

Your doctor's decision to offer you antipsychotic medication is likely to depend on:

- Your exact diagnosis and the symptoms you experience.
  For example:
  – for schizophrenia – all antipsychotics may help control the 'positive' symptoms of schizophrenia (i.e. additions to your thoughts and behaviour, such as seeing or hearing things that other people don't). However, in general only second generation drugs can help with the 'negative' symptoms (i.e. losses in your thoughts and behaviour, such as lacking enthusiasm for life, neglecting your appearance and hygiene, and being unable to concentrate). First generation drugs usually have no effect on the negative symptoms, and some of their side effects may even make them worse. If neither an older nor a newer antipsychotic has controlled your symptoms after trying them for six to eight weeks, your doctor is likely to suggest you try clozapine.
  – for bipolar disorder or severe depression – your doctor is more likely to suggest a second generation antipsychotic.
  – for anxiety – any kind of antipsychotic might work for you, but it would only be prescribed at a very low dose.

- Your past experiences of taking medication, including what's worked for you and what hasn't. For example, if you've tried one kind of antipsychotic and had lots of problems with it, your doctor should offer you a different type instead.

- Your medical circumstances. See our page on *Taking antipsychotics safely* for details of situations where you might need to be particularly cautious about taking antipsychotics, or avoid certain drugs altogether.

- What you want. The choice of which medication you take should

always be made on the basis of a discussion between you and your psychiatrist, taking your preferences into account. You could ask a trusted friend, family member or carer to be included in the discussion if you wish. (For guidance on what you might want to discuss with your doctor, see our pages on *What to know before you take any drug* and *Finding the right drug for you*. For guidance on talking to your doctor, having your say in decisions and making yourself heard, see Mind's pages on *Seeking help for a mental health problem*).

"I'm always trying new medications but none have worked well for me."

How quickly will they work?

This partly depends on how you take them:

- By mouth. If you take them by mouth, in tablet or in syrup form, the sedative effect usually takes a few hours; the liquid form may act more quickly than the tablets.
- Depot injection. Some antipsychotics are available by deep injection into a muscle, known as a 'depot'. This is a slow-release version, which acts slowly and steadily over the course of two to six weeks, depending on the drug. See our page on depot injections for more information.
- Emergency injection. In an emergency you may be given an injection into a muscle. In this case the sedative effect is rapid and reaches a peak within one hour.

Other factors can that also affect how quickly any medication works for you personally include your metabolism, your liver enzymes and how physically active you are.

However you take the drugs, they may calm you down quite quickly but your psychotic symptoms may take days or weeks to suppress.

When could I be given an emergency injection?

An emergency situation would be if you are behaving in a way that is:

- putting yourself at immediate risk
- putting other people at immediate risk.

In a situation like this, doctors may decide that you need something to calm you down as quickly as possible (this is called rapid tranquillisation). They can do this without your consent if you are being detained under the Mental Health Act 1983, often called being 'sectioned'. See Mind's pages on *Sectioning* for information about when it may be legal to section you and what your rights are in this situation.

Emergency medication should ideally be given to you by mouth, but if that's not possible you may need to be given drugs by injection (this would be a fast-acting injectable formulation for emergency use, not a depot injection). The drugs which may be given by emergency injection are: olanzapine, aripiprazole, lorazapam (a minor tranquilliser) or promethazine (an antihistamine). Zuclopenthixol (Clopixol acuphase) and haloperidol may also be used.

Understandably, experiencing rapid tranquillisation like this can be traumatic. Due to this, NICE best practice guidelines state that afterwards you should be given the opportunity to:

- discuss the experience with the health professionals responsible for your care
- write down your own record of what happened, to be kept in your hospital notes.

Remember: if you are not happy with how you've been treated, you can complain. See Mind's pages on *Making a complaint about health and social care.*

Might I need to take other medication as well?

Depending on your diagnosis, the problems you experience, and the kind of side effects your main antipsychotic can cause, your doctor might suggest that a combination of an antipsychotic and another drug might be the best way to manage your symptoms. In this case, they might decide to offer you other kinds of medication as part of your treatment, such as:

- antidepressants, if you are severely depressed
- mood stabilisers, if you have a diagnosis of bipolar disorder or schizoaffective disorder
- sleeping pills and minor tranquilisers, if you are extremely agitated or finding it impossible to sleep
- anti-Parkinson's drugs – these aren't psychiatric medication, but they are sometimes prescribed alongside antipsychotics to help reduce their neuromuscular side effects. See our page on anti-Parkinson's drugs for more information about this kind of medication.

Remember: you should always check with your doctor or pharmacist before taking any drugs together, or closely following one another, in case they could interact with each other badly. See Mind's page on *Taking antipsychotics safely* for more information. For details about a specific drug, you can look it up in our *Antipsychotics A-Z.*

"It's difficult to say [how antipsychotics are working for me] as I was prescribed strong antidepressants and sleeping pills at the same time."

Might I need to take two antipsychotics at once?

Prescribing more than one antipsychotic drug at the same time is called polypharmacy. In most cases doctors should avoid doing this – except in specific short-term situations, such as while you are switching from one drug to another.

However, in some circumstances your doctor may decide to prescribe more than one antipsychotic on a longer-term basis. This may happen if:

- your regular medication doesn't seem to be working well enough
- you and your doctor have found that a careful combination of two drugs is what controls your symptoms best.

You may find that if you are detained in hospital (sectioned) under the Mental Health Act 1983, your doctor is more likely to prescribe you more than one antipsychotic at once, or a higher dose, than someone who is a voluntary patient.

Could taking antipsychotics make me feel worse?

It's important to remember that all drugs can affect different people differently.

Not everybody finds antipsychotics helpful, and they all have the potential to cause unwanted side effects, which affect a lot of people who take them to some extent. Although many people find that the benefits of taking an antipsychotic outweigh any negatives, not everybody does – and your experience will be personal to you. You may need to try a few different drugs before you find the one that suits you best, and work with your doctor to find the right dosage for you.

It's also important to be aware that antipsychotics can be hard to come off, and may cause withdrawal effects if you come off them too quickly. See Mind's page on *Coming off antipsychotics* for more information.

To learn about the possible side effects and withdrawal effects associated with a particular antipsychotic, you can look it up in our *Antipsychotics A-Z*. For ideas on managing your mental health without drugs, see the section 'What if I don't want to take medication?'

What are the safety issues?

This section covers safety considerations regarding:

- what tests do I need before taking an antipsychotic?
- what if I have a medical condition?
- what if I'm an older person?
- could they interact with other drugs?

For safety considerations if you're pregnant or breastfeeding, see the section 'What if I'm pregnant or breastfeeding?' on p.26.

Remember: when thinking about taking any antipsychotic safely, you'll also need to be aware of risks around dosage and side effects. If you have any concerns at all about being prescribed an antipsychotic, make sure you discuss them with your doctor.

Before you take any medication

Before you decide to take any medication, you should make sure you have all the facts you need to feel confident about your decision. For guidance on the basic information you might want to know about any drug before you take it, see Mind's pages on:

- *what you should know before taking any psychiatric drug*
- *receiving the right medication for you*
- *your right to refuse medication.*

What tests do I need before taking an antipsychotic?

Before you start taking an antipsychotic, your doctor should do the following tests to assess your physical health:

- Physical examination (including asking you questions about your health and lifestyle) to record:

– your weight
– your waist size
– your blood pressure and pulse rate
– your diet and level of physical activity
– whether you show any signs of movement disorders.

- Blood tests to measure your:

– blood sugar
– haemoglobin (red blood cells)
– blood fats (cholesterol)
– prolactin level – this is the hormone which stimulates breast tissue development and milk production, so levels are normally low for both men and women, unless you're a women who is pregnant or breastfeeding.

- ECG (heart test), but only if:

– you have high blood pressure or any other symptom that may relate to your heart
– you have a family history of heart problems
– you're going to be admitted to hospital as an in-patient
– an ECG is particularly recommended for the specific drug that your doctor is considering prescribing for you.

Will I need more tests after I start taking it?

After you start taking the medication, your mental health team will need to continue to monitor all the above aspects of your physical health regularly. They will also need to monitor and record:

- whether you're taking the drug in the way you're supposed to
- whether it's actually helping you
- what side effects it's causing – especially any that might be confused with symptoms of psychosis, such as agitation.

If you're on a high dose of antipsychotics, you should be given an ECG every one to three months because antipsychotics can sometimes cause heart problems as a side effect. The risk is greater with higher doses. Whatever your dose, if you have unexplained blackouts, you should let your doctor know and they should monitor your heart rhythm regularly.

If you've been on the drug for a year and are getting on well with it, your GP can monitor your physical health instead of your mental health team. Your doctor should review your treatment at least once a year to check whether it's still working well for you – but you can ask them for a review whenever you want one.

What if I have a medical condition?

If you have any of the following conditions, your doctor should use particular caution when prescribing you an antipsychotic. They may also need to monitor you even more regularly to check its effects:

- liver or kidney disease
- cardiovascular (heart and circulation) disease – or a family history of it
- diabetes – or a family history of it
- Parkinson's disease
- epilepsy
- depression
- myasthenia gravis (a rare disease affecting nerves and muscles)
- an enlarged prostate
- glaucoma (a serious eye disease)
- lung disease with breathing problems
- certain blood disorders.

What if I'm an older person?

If you're an older person, your doctor will need to be particularly cautious when prescribing an antipsychotic, and they may need to adjust your dosage. This is because:

- the medication is more likely to cause your blood pressure to drop when you stand up (which can lead to falls) and more likely to cause both high and low body temperature
- as you get older your body becomes less efficient at dealing with drugs generally, so you're likely to need a smaller dose – higher doses will carry greater risks.

Could they interact with other drugs?

Combining other medication with antipsychotic drugs can sometimes cause unpleasant or dangerous interactions. You should always check with your doctor or pharmacist before taking any drugs together, or closely following one another, in case they could interact with each other badly.

This table lists the main interaction risks between antipsychotics and other psychiatric medications. To learn about the interaction risks of a specific drug, you can look it up in Mind's *Antipsychotics A-Z.*

Other psychiatric medications	Interaction risk with antipsychotics
all drugs that have antimuscarinic properties	All antipsychotics can cause antimuscarinic side effects. Combining them with other drugs that also have antimuscarinic properties is likely to make these side effects worse. This particularly applies in the case of: • tricyclic antidepressants • first generation antipsychotics. Anti-Parkinson's drugs are also antimuscarinic. It's possible that an anti-Parkinson's drug could interact with your antipsychotic to make you delirious, which may be confused with your psychotic symptoms.

certain sleeping pills and minor tranquillisers	These can increase the sedative action of all antipsychotics, so they will make you feel even more drowsy. This is particularly true of: • the minor tranquillisers used for anxiety (buspirone, pregabalin and meprobamate • benzodiazepines • the 'z-drugs': zolpidem, zopiclone and zaleplon Parkinson's disease.
carbamazapine (a mood stabiliser)	Taking carbamazepine with antipsychotics has the following risks: • it increases the risk that you might experience unpleasant side effects • it can make your body process the following antipsychotics faster, which makes them less effective: aripiprazole, clozapine, haloperidol, olanzapine, paliperidone, quetiapine, risperidone.
tricyclic antidepressants	Taking a tricyclic antidepressant at the same time as antipsychotic medication increases the risk of causing dangerous disturbances to your heart rhythm. This especially applies to fluphenazine, haloperidol, risperidone and sulpiride.
trazodone (an antidepressant)	First generation antipsychotics can all interact with trazodone. This can increase the risk of: • severe side effects • dangerous disturbances to heart rhythm • experiencing a sudden drop in blood pressure when you stand up.

lithium (a mood stabiliser)	Taking lithium at the same time as an antipsychotic can increase the risk of: • side effects such as muscular disorders (particularly with the first generation antipsychotics) • serious blood disorders (particularly with clozapine) • neuromuscular side effects (with flupentixol, sulpiride, haloperidol and risperidone) • neurotoxicity (a poisonous effect on the nervous system). If your doctor decides to prescribe an antipsychotic alongside lithium, they should start it at a lower dose than usual.

Over-the-counter drugs

You should get advice from the pharmacist or another qualified professional before taking any non-prescription medicine – including complementary or alternative medicines – with your antipsychotic, so they can can tell you about any potential risks.

Alcohol and street drugs

Drinking alcohol can increase the sedative action of all antipsychotics, so it will make you feel even more drowsy. You might want to ask your doctor or pharmacist whether it’s safe to drink with the drug you've been prescribed, and take extra care to know your limits.

It's possible that street drugs may interact with antipsychotics. For

example, if you take amphetamines with chlorpromazine, the effects of one or both can be reduced. See Mind's pages on *The mental health effects of street drugs* for more information. You can also visit the FRANK website (talktofrank.com) for confidential advice on street drugs.

What dosage should I be on?

Finding the best daily dose of antipsychotic for you will depend on lots of factors, such as:

- The specific drug you've been prescribed. Safe dosage rates for different antipsychotics can vary widely – you can look up the recommended range for each drug in our *Antipsychotics A-Z*.
- If you're taking other medication because some drugs can interact with antipsychotics.
- What you find works for you. Drugs work differently for everyone – they can be influenced by all sorts of personal factors such as your age, weight, genes, general health, liver and kidney function, and whether you're able to take the drug as recommended.

You and your doctor should think of a new antipsychotic as a trial, to see whether it helps you and how well it suits you. The aim should be to find a daily dose where the benefits outweigh any side effects, so you can lead the life you want as far as possible.

Key facts about antipsychotic dosage

As a guideline:

- You should always start at a low dose. For many people, low maintenance doses are as effective as higher doses.
- You should try the dose you've been prescribed for four to six weeks to see how it's working.

- Your doctor may then increase it gradually, but only if you both agree it's necessary.
- If you find that your medication isn't working, even after your dose has been increased, then your doctor should consider offering you a different drug rather than continuing to increase the dose of the one you started with.

Be aware:

- The higher your dose, the more likely you are to experience problems with side effects. For example:
  – high doses of first generation antipsychotics in particular are more likely to cause side effects which make it really hard for you to get up in the morning, move your muscles naturally and take part in everyday activities.
  – moderate to high doses of antipsychotics increase the risk of tardive dyskinesia (a serious side effect)

- You have a right to know what dosage you have been prescribed, and why.
- The reasons for any decisions made about your medication – including whether to start, continue, stop or change to another drug – should be clearly recorded by your doctor in your medical notes. This is especially important if your doctor prescribes a dose that's outside the usual recommended range for the drug.

Prn prescribing

Prn prescribing means that you may occasionally be given extra doses of your medication, in addition to your regular daily dose. 'Prn' stands for 'pro re nata', which means 'as the circumstances require' in Latin.

This is most likely to happen if you are an in-patient in hospital, either because:

- the medical staff think you need a bit more medication in some situations, or
- you've asked for a bit more medication in some situations.

If you're given prn doses of medication, this should be very carefully recorded in your notes and monitored by your doctor to make sure that you do not accidentally end up receiving a daily dose that's too high.

Is my daily dose too high?

Generally, antipsychotics aren't licensed for use above the maximum dosages published in the BNF (British National Formulary – the main drug reference book for prescribers). The BNF gives maximum dosages for some antipsychotics but not all of them.

However, there are some circumstances where you may end up with a total daily dose above the recommended maximum. These include:

- If your doctor prescribes you a higher than recommended daily dose. They can choose to do this at their discretion, but it's not common.
- If you are taking more than one antipsychotic at the same time.
- If you are an in-patient receiving prn medication. This is the most likely scenario in which your daily dose may end up higher than the recommended maximum.

You have a right to know how much medication you're taking in total, including prn doses – so if you're not confident in working this out for yourself, your doctor or pharmacist should be able to explain it to you.

Ask them to help you calculate your dose of each drug as a percentage of the BNF recommended maximum for that drug, then add the percentages together to see if the total comes to more than 100%. More than 100% in total would mean your daily dose is exceeding the recommended maximum. Your pharmacist may be able to access a antipsychotic dosage ready reckoner chart published by the Prescribing Observatory for Mental Health UK (POMH-UK) as a guide to help you work out the percentages more easily.

If you are being prescribed more than the recommended daily maximum, your doctor has a duty to review this every day. But even if your dosage is within the recommended range, if you feel that your daily dose is too high for you then it's important to discuss it with your doctor and ask them to review it.

See 'Can I come off antipsychotics?' on p.51 and 'Alternative to medication' on p.55 for information about other options.

What if I'm pregnant or breastfeeding?

Expecting a baby is an emotional time for anyone, but it can be particularly challenging if you experience a mental health problem like schizophrenia or bipolar disorder which you usually manage with antipsychotic medication.

All antipsychotic drugs carry some risks in pregnancy and breastfeeding. Ultimately, you will need to balance the possible risks to your baby against any potential harmful consequences of not taking your medication (such as potential relapse) and then come to your own decision about what's best for you and your family.

What are the risks?

- Risks to your developing baby in the first trimester. All drugs carry higher risks during the first three months of your pregnancy, when your baby is most vulnerable. However, some antipsychotics carry greater risks than others during this period. For example, prochlorperazine (Stemetil) in particular is associated with malformations in the developing baby if you take it during the first trimester.
- Possible effects on the newborn in third trimester. For example, there's a risk that your newborn may experience a temporary muscle disorder if you take antipsychotics in the third trimester. All risks become higher in the last few weeks of pregnancy, when your baby becomes more vulnerable again.
- When breastfeeding, the drug could be passed to your baby through your breast milk, and it's possible that your baby could experience some side effects from the medication. Drug manufacturers particularly advise against taking second generation antipsychotics if you are breastfeeding. If you want to breastfeed while staying on your medication, ask your doctor to advise you on how serious any risks are with the particular drug you've been prescribed. If the risk is low, you might feel that the advantages of breastfeeding whilst taking your medication outweigh any risks. Advantages to breastfeeding your baby for at least part of the time include: better nutrition for your baby, better immunity for your baby against various illnesses, and more opportunities for the two of you to bond.
- Drugs are not clinically tested in pregnant women, so there's not much evidence around how safe antipsychotics are in pregnancy in general. Newer drugs carry a higher 'unknown' risk than drugs that have been around longer, simply because scientists have had less time to gather evidence about them.

For more information about risks in pregnancy with a specific drug, you can look it up in our *Antipsychotics A-Z*.

What can I do to feel more in control?

- Talk to your doctor as early on as you can. The earlier you start talking to your doctor about your options, the more in control you're likely to feel. This means:
  – for planned pregnancies – as soon as you decide you want to start trying to conceive
  – for unplanned pregnancies – as soon as you think you might be pregnant
- Planning your pregnancy gives you more options for managing risks early on, but it's also a common experience to find out that you've become pregnant without planning it. Whatever your situation, it's important to remember that you have the same right as everyone else to choose whether or not to take medication, and to have your say in decisions about your treatment.
- Seek extra support to help you talk through your options and decide what's right for you.
- If you decide to stay on your medication, ask your doctor how you can reduce risks. For example, you may be able to manage your symptoms effectively on a reduced dose, or consider switching to another antipsychotic which carries fewer risks.
- If you decide to come off your medication, make sure you do it safely. See our pages on coming off medication for more information.
- If you don't plan to become pregnant, use effective contraception.

What extra support can I get?

Coming to a decision you feel comfortable with about what's right for you and your baby can be difficult, and it's understandable to feel conflicted. As well as talking to your doctor or psychiatrist, you might find it helpful to explore these options for extra support:

- Family and friends – if you're able, it can be helpful to talk through your feelings with someone you trust, such as your partner or a

close friend.

- Midwife appointments – you can talk to your midwife about how you're feeling throughout your pregnancy. They can also put you in touch with your local Perinatal Mental Health Team (if there is one in your area) and help make sure you receive plenty of support from your Health Visitor after you give birth.
- Online peer support – websites such as Netmums (netmums.com) and Mumsnet (mumsnet.com) offer a supportive online network for all parents and parents-to-be. Elefriends (elefriends.org.uk) is an online community for people with experience of mental health problems, where you can share your feelings in a supportive environment. It can be helpful to talk to other people who've had similar experiences themselves, who can reassure you that you're not alone. (For guidance on using the internet when you're feeling vulnerable, see Mind's information *How to stay safe online*).
- Specialist websites such as NCT (nct.org.uk), the Breastfeeding Network (breastfeedingnetwork.org.uk) and Action Postpartum Psychosis (app-network.org) can provide general information and support.

You might also find it helpful to read Mind's pages on *How to cope as a parent with a mental health problem*, which includes information on helping yourself, looking after children, and other kinds of support available.

What side effects can they cause?

Every antipsychotic has the potential to cause unwanted side effects. These can vary from drug to drug and from person to person – not everyone will experience side effects, but many people do. This section provides an alphabetic overview of the most serious side effects which can potentially occur with any antipsychotic drug, although some are rare.

For details of the possible side effects of a particular antipsychotic, you can look it up in our *Antipsychotics A–Z*. For further guidance on what to do if you experience a side effect, see Mind's resource *Coping with side effects*.

"With haloperidol my tongue hung out of my mouth and my lips were stretched wide and open. Quietiapine made me feel stoned initially, with huge weight gain."

Antimuscarinic effects

Antimuscarinic effects (sometimes called anticholinergic effects) is the medical term for a group of side effects caused by changes in the level of the messenger chemical acetylcholine. This can have significant effects all over the body, including:

- blurred vision
- constipation (this may become severe enough to be life-threatening if not treated)
- difficulty urinating
- dizziness
- drowsiness
- dry mouth, which can cause tooth decay in the long term
- low blood pressure, especially when getting up from sitting or lying down (taking hot baths increases this risk)
- nausea (feeling sick)
- rapid heartbeat.

These effects are more common with first generation (older) antipsychotics than newer antipsychotics. They can also occur with other types of drugs; for example, they are also particularly associated with tricyclic antidepressants and anti-Parkinson's drugs.

Bed-wetting

This is more likely to occur with second generation (newer) antipsychotics.

Blood disorders

A number of blood disorders are linked to antipsychotics:

- Reduced white blood cells.
- Agranulocytosis, which involves the loss of one type of white blood cell. It means that you are more likely to catch infections and less able to fight them; it's very serious and people have been known to die from it. The risk if agranulocytosis is mainly associated with clozapine. If you are getting sore throats or mouth ulcers, a fever or chills, these may be signs that your immune system is not working as well as it should, and you should see your doctor.
- Blood clotting disorders (venous thromboembolism or VTE). These include deep vein thrombosis (DVT) and pulmonary thrombosis (blood clot in the lung), which can be life-threatening.

Body temperature problems

Antipsychotics can cause you problems with regulating your body temperature. It may become too high or too low, both of which can make you feel unwell.

Emotional effects

Antipsychotics can sometimes make you feel:

- excitable
- agitated
- aggressive
- depressed (although conversely some antipsychotics may have an

antidepressant effect)
- emotionally uneasy and restless
- out of touch with reality
- socially withdrawn and detached from those around you.

They can also cause you to have bizarre dreams or nightmares, which could cause you trouble sleeping.

Eye problems

Antipsychotics may cause various different eye problems, including:

- blurred vision and difficulty reading
- a build up of granular deposits in the cornea and lens (this doesn't usually affect sight)
- degeneration of the retina (the light-sensitive part of the eye) – this can restrict your vision
- glaucoma (a serious eye condition)
- oculogyric crisis – this affects the muscles that control your eye movements, so your eyes may turn suddenly and you can't control where you look.

All antipsychotics also have the potential to cause narrow-angle glaucoma, which is a medical emergency. If you've ever had glaucoma or eye problems you should be particularly cautious about taking antipsychotic drugs, and it may be best to avoid certain drugs altogether – in particular some of the first generation (older) antipsychotics. You can look individual drugs up in our *Antipsychotics A-Z* for more information.

Heart problems

Antipsychotics have the potential to cause:

- increased heart rate

- palpitations
- effects on the heart rhythm, which in extreme cases have been known to cause sudden death. This risk is particularly linked to being on a high dose and taking more than one antipsychotic at the same time.

See our pages on *What are the safety issues?* on p.16 and *What dosage should I be on?* on p.23 for more detail on these risks, and how to manage them.

Liver disorders

Antipsychotics may cause liver disorders and jaundice (yellow skin). You can look individual drugs up in our *Antipsychotics A-Z* for more information.

Metabolic syndrome

Metabolic syndrome is the medical term for a combination of the following symptoms:

- weight gain and obesity
- high blood sugar
- diabetes
- high blood pressure
- high cholesterol.

You don't have to experience all these symptoms to be diagnosed with metabolic syndrome. Experiencing metabolic syndrome then puts you at higher risk of going on to develop:

- diabetes
- stroke
- heart disease.

Metabolic syndrome is thought to make you two to three times more likely to die from cardiovascular disease.

This risk is increased even further if you have an unhealthy lifestyle generally, so it's important to make sure you try to eat a healthy diet and get enough exercise. You'll also need to have regular health checks before and during your treatment (see our page on taking antipsychotics safely for more information).

Neuroleptic malignant syndrome (NMS)

NMS is a serious neurological disorder, meaning it affects your nervous system. It usually develops rapidly over 24–72 hours and may also occur during withdrawal from antipsychotics. The symptoms are:

- sweating or fever, with a high temperature
- tremor, rigidity (feeling stiff and unable to move your muscles) or loss of movement
- difficulty speaking and swallowing
- rapid heartbeat, very rapid breathing and changes in blood pressure
- changes in consciousness, from lethargy and confusion to stupor or coma.

As high temperature and rigidity are usually the first symptoms to appear, NMS could initially be mistaken for an infection. But NMS can be very dangerous if it’s not detected and treated, and can be fatal.

Who's most at risk of NMS?

- It mostly affects people under 40.
- It's twice as common in men as in women.
- The main trigger seems to be a change of dose within the last four to 11 days, although it can occur if you are on a steady, standard dose and have been taking it for many years.

- The risk may be higher with some of the first generation (older) antipsychotics (such as haloperidol) but all antipsychotic drugs can potentially cause NMS.

What's the treatment for NMS?

Treatment may include:

- reducing the fever
- medication to relax your muscles
- medication to counter the chemical imbalance that is thought to cause NMS
- electroconvulsive therapy (ECT) has also been used effectively.

The symptoms may last for days, or even weeks, after coming off the antipsychotic that's causing them. Many people who have had NMS once go on to get it again – so you should only take antipsychotics afterwards if they are essential, and then only at very low doses.

Neuromuscular side effects

Antipsychotics interfere with the brain chemical dopamine, which is important in controlling movement. The drugs may therefore cause movement disorders. These are most common with first generation (older) antipsychotics and less likely with the newer antipsychotics. They include:

- Parkinsonism. These effects resemble Parkinson's disease, which is caused by the loss of dopamine. The symptoms are:
  – your muscles become stiff and weak
  – your face may lose its animation
  – you may find fine movement difficult
  – you may develop a slow tremor (shaking), especially in your hands
  – your fingers may move as if you were rolling a small object between

them
– when walking, you may lean forward, take small steps and find it difficult to start and stop
– your mouth may hang open and you may find that you are dribbling.

- Loss of movement. You may find it difficult to move and your muscles may feel very weak. (Having little energy to move is also a symptom of depression, so if you experience this your doctor may ask if you're feeling depressed).

- Akathisia (restlessness). This is more than just a physical restlessness, it can be emotional as well. You may:
  – feel intensely restless and unable to sit still
  – rock from foot to foot, shuffle your legs, cross or swing your legs repeatedly, or continuously pace up and down
  – feel emotionally tense and uneasy.

- Health care staff might misinterpret these symptoms to mean that you're agitated or very anxious, and suggest you need more medication to calm you down – but if you have akathisia then increasing your dose of antipsychotics won't help. Your doctor may offer to prescribe another medication on top of your antipsychotic to reduce it.

- Muscle spasms. These are acute muscle contractions that you cannot control. They may be painful and can have some serious impacts on your life. For example:
  – If the problem affects the muscles of your larynx (voicebox) you may develop problems with your voice and find it difficult to speak normally (called dysphonia). This can make you feel self-conscious, and may make it hard for people to understand you.
  – If the muscles that control your eye movements are affected it can makes your eyes turn suddenly, so that you can’t control where you look (called an oculogyric crisis). This can feel very unpleasant, and be

disconcerting for people around you. It may also be dangerous – for example, if it happens while you are crossing the road or pouring boiling water from a kettle.

Muscle spasms are seen to particularly affect young men (although 'young' is not clearly defined in the evidence sources).

All these symptoms reduce while you are asleep, so your doctor may suggest that you could avoid the worst of them (as well as feeling less sleepy during the day) if you take your medication as a single daily dose in the evening.

If you're very bothered by neuromuscular side effects, your doctor may also offer to prescribe you anti-Parkinson's drugs to reduce the symptoms.

I experienced twitching, stumbling and slurred speech.

Sedation (sleepiness)

Sleepiness is a common side effect with antipsychotics but some, such as chlorpromazine and olanzapine, are more sedating than others. Sedation can happen throughout the day as well as at night, so if you experience this you might find it very hard to get up in the morning, or to motivate yourself to be active during the day.

Antipsychotics knock me out and make it very hard to function normally.

Sexual and hormonal problems

Many antipsychotics can cause an increase in your prolactin level (prolactin is a sex hormone that causes the breasts to produce milk, so your levels should normally be low – unless you're a woman who is pregnant or breast-feeding). If you have abnormally high prolactin levels,

it's very common to experience some of the following sexual side effects:

- Women:
  – vaginal dryness
  – unwanted hair
  – acne
  – loss of menstrual cycle – but this is unpredictable and your periods may return if your prolactin levels drop back down, so you are still at risk of becoming pregnant if you have unprotected sex.

- Men:
  – priapism (prolonged erection) – this requires urgent medical attention, so if you experience this side effect you should see your GP or go to A&E
  – spontaneous ejaculation.

- Both men and women:
  – breast development and the production of breast milk
  – reduced sexual desire, difficulty becoming aroused and difficulty achieving orgasm
  – osteoporosis, which means your bones become weaker and are more likely to break.

Some of the second generation (newer) antipsychotics have less effect on prolactin and produce fewer of these problems.

"Amisulpride has made my breasts grow and lactate. After having blood tests, it turns out that my prolactin levels have sky-rocketed, which is why I experienced those side effects. I am also now at risk of osteoporosis in the future."

Skin problems

Antipsychotics can cause various skin problems, such as:

- Allergic rashes. These usually occur within the first two months of starting treatment and disappear when the drug is stopped. If you get a rash, you should go to the doctor straight away to have it checked.
- Increased sensitivity to sunlight, especially at high doses. So if you're taking antipsychotics you may need to take extra care to protect yourself from the sun.
- A blue-grey discoloration in some skin types.

Suicidal feelings or behaviour

You may have felt suicidal before as part of your mental health problem but these feelings may be more likely to occur, or become more intrusive, shortly after starting antipsychotic medication. If you feel suicidal shortly after starting medication, be aware that this may be a side effect of the medication rather than your own true feelings.

Remember: if you feel in immediate crisis you can contact the Samaritans on 116 123 (freephone) or go to your local hospital's A&E department and ask for help.

For more information about suicidal feelings, including information about what kind of support is available, see our pages on how to cope with suicidal feelings and crisis services.

Tardive dyskinesia (TD)

Tardive dyskinesia (TD) is a medical term that describes the involuntary sudden, jerky or slow twisting movements of the face and/or body, caused as an unwanted side effect of medication (mainly antipsychotic drugs).

See Mind's pages on *Tardive dyskinesia* for more information about what it is, what treatments and support are available, and how you can cope with the symptoms.

Tardive psychosis

Tardive psychosis is a medical term that descibes new psychotic symptoms which arise after you have been taking antipsychotics for a while, and which are directly caused by the medication (not your original illness returning).

The word 'tardive' means that it's a delayed effect of the medication.

Why does tardive psychosis happen?

Antipsychotic drugs act by blocking receptors for dopamine (a brain chemical) in your brain. But if you take an antipsychotic for a long time, your brain can respond by creating new receptors to replace the ones that the drug is blocking – and your existing receptors may also become extra sensitive. This can mean that you actually end up more likely to have psychotic symptoms as a result of taking the medication. So over time you may find you need to take a higher dose to maintain the antipsychotic effects.

This risk of tardive psychosis is one reason why you'll need to withdraw from your medication very gradually if you decide to come off it – especially if you have been taking it for a long time. Withdrawing slowly gives your brain time to readjust.

Weight gain

Weight gain is a very common side effect of many antipsychotics, in particular the second generation (newer) drugs. It is linked to:

- increased appetite
- decreased activity
- changes in metabolism (the way your body uses food and converts it to energy or stores it as fat).

If you put on a lot of weight, this can increase your risk of developing diabetes and other physical health problems. It's also understandable to feel frustrated and upset about noticeable changes in your body.

"Awful weight gain, I put on nearly 3st. It made me feel fat and sluggish."

What's a depot injection?

A depot injection is a slow-release, slow-acting form of your medication. It isn't a different drug – it's the same medication as the antipsychotic you're used to taking in tablet or liquid form. But it's administered by injection, and it is given in a carrier liquid that releases it slowly so it lasts a lot longer.

Key facts about depot injections

- You would usually only be offered a depot injection if:
  – you've already been on your medication for a while and you know it's working well for you
  – you expect to keep taking it for a long time.

- Injections are usually given every two, three or four weeks, depending on the drug.
- Your injection will usually be given by a health care professional in a community setting (such as a regular clinic, medical centre or in your own home). You would never be given this kind of drug formulation to manage and administer at home by yourself.
- The injection is made into a large muscle – usually either your buttock, or the largest muscle of your shoulder.
- It's a good idea to alternate between different muscles and sides of your body, to help prevent any injection site problems.

Not all antipsychotics are available as depot injections. For information on

the available forms of specific drugs see our *Antipsychotics A-Z* or look at the section *Comparing antipsychotics* on p.43.

Why might I choose a depot injection?

A depot injection might be a good option for you if:

- you have difficulty swallowing medication
- you have difficulty remembering to take medication regularly
- you prefer not to have to think about taking medication every day.

You may also be given a depot if your doctors agree that you need the drug but feel that you will not take it regularly as prescribed.

Injection site problems

If you regularly have your injection in the same place in your body, you may start to experience problems with that part of your body, such as:

- abscess
- bleeding
- bruising
- irritation
- lumps
- numbness
- pain
- redness
- soreness
- swelling.

If you do have problems with your injection site, make sure you mention this to your doctor, nurse or whoever administers your medication.

As you don't pick up a prescription for a depot injection, you may not be given the Patient Information Leaflet (PIL) which would usually come in the drug packet.

t's always a good idea to read the PIL carefully before taking any medication, so if you aren't given it you should ask for a copy from the person who gives the injection, or your doctor or local pharmacist.

Comparing antipyschotics

This section contains comparison tables, presenting all antipsychotics by:

- names & type of antipsychotic (first or second generation)
- length of half-life
- available form
- dietary information.

Why might I want to compare antipsychotics?

After considering how they can help and issues around taking them safely, you might want to know more about the different antipsychotics available to help you talk to your doctor about what's right for you. For example:

- If you have problems with a particular type of drug, such as first generation (older) antipsychotics, and want to avoid them.
- If you need your medication in a different form – for example, you may have problems with swallowing or find it hard to remember to take your medication correctly every day.
- If you have any dietary restrictions, such as being vegetarian or intolerant to some ingredients.
- If the drug's half-life is important to you – for example, if you are concerned about withdrawal effects and would prefer a drug with a longer half-life. For information about what the half-life means and

why it matters, see our page about medication half-life.

- If you are worried about the impact of particular side effects, such as weight gain. For information about the side effects of a particular antipsychotic, you can look the drug up in our *Antipsychotics A–Z*.

Remember: drugs don't work the same way for everyone, and it's important to find a medication that works for you. See Mind's page on *Receiving the right medication* for more information.

Comparing antipsychotics by type

Generic name	Trade names (UK)	Type of antipsychotic
amisulpride	Solian	2nd generation
aripiprazole	Abilify Maintena	2nd generation depot
asenapine	Sycrest	2nd generation
benperidol	Anquil	1st generation
chlorpromazine	Largactil	
clozapine	Clozaril Denzapine	2nd generation
flupentixol	Depixol, Fluanxol, Flupenthixol	1st generation
flupentixol decanoate	Depixol	1st generation depot
fluphenazine decanoate	Modecate	1st generation depot
haloperidol	Dozic, Haldol, Serenace	1st generation
haloperidol decanoate	Haldol decanoate	1st generation depot
levomepromazine	Nozinan	1st generation
lurasidone	Latuda	2nd generation
olanzapine	Zyprexa	2nd generation
olanzapine pamoate monohydrate	ZypAdhera	2nd generation depot
paliperidone	Invega	2nd generation
paliperidone palmitate	Xeplion	2nd generation depot

pericyazine	Neulactil	1st generation
perphenazine	Fentazin	1st generation
pimozide	Orap	1st generation
pipotiazine palmitate (discontinued in 2015)	Piportil depot	1st generation depot
prochlorperazine	Stemetil	1st generation
promazine	none	1st generation
quetiapine	Atrolak	2nd generation
	Biquelle	
	Ebesque	
	Seroquel	
	Tenprolide	
	Zaluron	
risperidone	Risperdal	2nd generation
risperidone	Risperdal Consta	2nd generation depot
sulpiride	Dolmatil	1st generation
	Sulpor	
trifluoperazine	Stelazine	1st generation
zuclopenthixol	Clopixol Acuphase	1st generation
zuclopentixol decanoate	Clopixol	1st generation depot
zuclopenthixol dihydro-chloride	Clopixol	1st generation

Comparing antipsychotics by half-life

(For information about what the half-life means and why it matters, see Mind's resource *Medication half-life*).

Half-life	Drug name
4–8 hours	prochlorperazine
6–10 hours	benperidol
6–26 hours	clozapine
7–12 hours	quetiapine
about 8 hours	sulpiride
8–20 hours	perphenazine
about 12 hours	amisulpride
about 12 hours	pericyazine
about 20 hours	haloperidol
20–40 hours	chlorpromazine
20–40 hours	lurasidone
about 22 hours	trifluoperazine
about 23 hours	paliperidone
about 24 hours	asenapine
about 24 hours	risperidone
about 24 hours	zuclopenthixol dihydrochloride
about 30 hours	levomepromazine
32–52 hours	olanzapine
about 35 hours	flupentixol
about 55 hours	pimozide
75–146 hours	aripiprazole
4–6 days	risperidone (depot)
6–9 days	fluphenazine decanoate

about 19 days	zuclopenthixol
about 19 days	zuclopentixol decanoate
about 21 days	flupentixol decanoate
about 21 days	haloperidol decanoate
25–49 days	paliperidone palmitate
about 30 days	olanzapine pamoate monohydrate
30–47 days	aripiprazole (depot)
n/a	pipotiazine palmitate
n/a	promazine

Comparing antipsychotics by form available

Form	Antipsychotics available in this form		
tablets	amisulpride	levomepromazine	prochlorperazine
	aripiprazole	lurasidone	promazine
	benperidol	olanzapine	quetiapine
	chlorpromazine	paliperidone	risperidone
	clozapine	pericyazine	sulpiride
	flupentixol	perphenazine	trifluoperazine
	haloperidol	pimozide	zuclopenthixol dihydrochloride
dissolving tablets	aripiprazole	olanzapine	risperidone
	asenapine		
liquid	amisulpride	haloperidol	promazine
	aripiprazole	pericyazine	sulpiride
	chlorpromazine	prochlorperazine	trifluoperazine
injection	aripiprazole	haloperidol decanoate	pipotiazine palmitate
	chlorpromazine	olanzapine	prochlorperazine
	flupentixol decanoate	olanzapine pamoate monohydrate	risperidone
	fluphenazine decanoate	paliperidone palmitate	zuclopenthixol
	haloperidol		zuclopentixol decanoate
suppositories	chlorpromazine		

Comparing antipsychotics by dietary considerations

Dietary consideration	Drugs this applies to
Contains lactose	amisulpride
	aripiprazole
	benperidol
	chlorpromazine
	clozapine
	flupentixol
	haloperidol
	olanzapine
	paliperidone
	pericyazine
	perphenazine
	prochlorperazine
	promazine
	quetiapine
	risperidone
	sulpiride
	zuclopenthixol dihydrochloride
Contains gelatine	asenapine
	risperidone (some tablets)
	trifluoperazine
Contains coconut oil	flupentixol decanoate
	zuclopenthixol

Contains sesame oil	fluphenazine decanoate
	haloperidol decanoate
	pipotiazine palmitate

Can I come off antipsychotics?

Some doctors may suggest that once you're on these drugs, you need to stay on them for some time – or indefinitely. Many people do remain on them for a long time, and you might feel that this is the right choice for you. However, if you have been taking antipsychotics for some time and have been well, you may want to stop and see if you can cope successfully in other ways.

For ideas on how you could manage your symptoms without medication, see the section *Alternatives to antipsychotics* on p.55. For more information on withdrawal, see Mind's resource *Coming off psychiatric drugs*.

"I feel so much better being off – less drugged up and more alive."

If you have been taking antipsychotics for some time (a year or more), it can be quite difficult to come off them. Some people may be able to stop without problems but others can have great difficulty. As a rule:

- You will need to come off slowly and gradually by reducing your daily dose over a perod of weeks or months. On the whole, the longer you have been taking a drug for, the longer it's likely to take you to come off it.
- Avoid stopping suddenly – if you come off too quickly you are much more likely to have a relapse of your psychotic symptoms or to

develop tardive psychosis.
- Get support from people close to you. Ideally this will include support from your GP or your psychiatrist as well as friends, family and peer support from other people who've had similar experiences and can relate to what you're going through.

What if my doctor doesn't want me to come off my medication?

Unfortunately a lot of people find that their doctors are not very supportive of their decision to come off antipsychotics, and don't offer as much help as they would like. But it's important to remember that taking medication is your choice. You have the right to try coming off if you want to – and to change your mind.

For guidance on giving yourself the best chance of coming off safely and successfully, see Mind's pages on *Coming off psychiatric drugs.*

"I took myself off and found I could feel emotions again, which was scary, but worth it."

When's the best time to try coming off?

There's no universal 'best time' to try coming off antipsychotics – everyone's different, and there are all sorts of different factors that might affect your chance of success. But when considering when would be best for you, it might be helpful to think about the following:

- What else is going on in your life right now? If you're under lots of extra stresses from other life problems (such as moving house, financial worries or concerns about your family) how might this affect your ability to cope?
- Would you prefer to feel relaxed and unburdened, so you're able to

pay close attention to how you're feeling day to day, or would you find it easier to be busy so you're distracted by focussing on other things?
- Have you got a support group nearby or other people in your life who can help you if you start to find withdrawal difficult?
- If you've tried to come off your medication before but have not been able to manage it, what factors might have played a part then? Can you avoid or minimise them when you try again?

Remember: whenever you decide to try coming off, it is always important to withdraw slowly and safely. It might take a long time, or you might find that you become comfortable on a lower dose and decide not to come off completely. The main thing is that you find a way to manage your symptoms that works for you.

"I came off them too fast and I wasn't physically or mentally ready for that. [I think] it's really important to make sure you come off them really slowly and under the watchful eye of a professional."

Will my psychotic symptoms come back?

Medication can help to stabilise your symptoms, so it's possible that your psychotic symptoms may return if you stop taking it – but it's not certain. There are many other factors that can influence your chance of becoming ill again besides taking medication. For example:

- while on medication you may have received other forms of treatment such as talking treatments and arts therapies that have helped you discover and practice new ways to cope
- you may have been able to make changes in your life since your last episode that mean you are less likely to become ill again
- if your friends and family are supportive of your decision to try coming off, this can also reduce your risk of relapsing.

Some psychiatrists believe that people with a diagnosis of schizophrenia who remain on antipsychotics for a number of years have fewer relapses than those who are not on antipsychotics. However, not all psychiatrists agree with this – and a lot people with a diagnosis of schizophrenia don't find it to be true for them personally.

Remember: you are much more likely to have a relapse if you try to come off your medication too quickly.

"Trying to come off was exhausting – my mood swings came back with a vengeance. Felt like I'd totally lost it again."

What withdrawal symptoms might I get?

The main withdrawal symptoms associated with antipsychotics are:

abnormal skin sensations	nausea (feeling sick)
aching muscles	neuroleptic malignant syndrome
anxiety	restlessness, agitation and irritability
diarrhoea	runny nose
dizziness and vertigo	shaking
feeling too hot or too cold	insomnia (inability to sleep)
feeling withdrawn socially	sweating
headaches	tardive dyskinesia
loss of appetite	tardive psychosis
mood disturbances	vomiting (being sick)

Unfortunately there's no evidence on how common these withdrawal symptoms are, so there's no way to know how likely you are to get any of them.

For information on withdrawal symptoms of a particular drug, you can look it up in our *Antipsychotics A-Z*.

I was on a very small dose so I found it easy to stop – no side effects. My energy levels are back, but I have noticed I'm not sleeping as much and I'm a bit edgy, so I'm monitoring myself closely using a sleep and mood journal.

Alternatives to antipsychotics

Many psychiatrists believe that severe mental health problems like schizophrenia must be treated with medication, but if you don't want to take antipsychotics, there are alternative treatments you can try. You may find it's possible to manage your symptoms, or to make a full recovery, without medication. This section covers:

- Talking treatments
- Arts therapies
- Ecotherapy
- Complementary therapies
- Peer support groups
- Healthy lifestyle changes.

In conjunction with antipsychotics, I have found that distraction techniques are a great way of dealing with troubling thoughts and voices in my mind. Anything and everything that is a distraction is ever so helpful for me, from painting my nails to baking a cake, from watching a DVD to colouring.

Talking treatments

The National Institute for Health and Care Excellence (NICE) – the organisation that produces best practice guidelines in health care –

recommends that, for most conditions, you should be offered other kinds of treatments in addition to medication, such as a talking treatment. For more information see Mind's resources on:

- Talking treatments
- Cognitive behavioural therapy (CBT)
- Dialectical behaviour therapy (DBT).

For information about which types of talking therapy are recommended for specific conditions, you can look up our information on different diagnoses in our *A-Z of mental health*.

Arts therapies

You might find this kind of treatment a helpful way of dealing with your symptoms – especially if you find it difficult to talk about them. You may be able to express your feelings very effectively through painting, clay work, music or using metaphor in stories or drama therapy.

See Mind's pages on *Arts therapies* for more information.

Ecotherapy

Ecotherapy is the name given to a wide range of treatment programmes which aim to improve your mental and physical wellbeing through doing outdoor activities in nature.

See Mind's pages on *Ecotherapy* for more information.

Complementary and alternative therapy

Some people also find other complementary therapies helpful in managing symptoms, such as aromatherapy, reflexology or ear acupuncture.

Complementary therapies may also help manage some of the side effects of medication, if you decide to continue with it. See Mind's pages on *Complementary and alternative therapy* for more information.

I enjoy prayer and meditation as well as working at my local Food Bank. I also enjoy doing creative writing.

Peer support groups

Making connections with people who can relate to what you're going through can be really helpful.

- Hearing Voices Network – if you hear voices or have other sorts of hallucinations
- Bipolar UK
- Depression Alliance
- Rethink Mental Illness
- Elefriends.

There may also be peer support or other groups in your area. Call Mind Infoline on 0300 123 3393 or contact your local Mind for information about what is local to you.

Healthy lifestyle changes

- Thinking about what you eat and drink – food and mood are related, so you might be able to manage your symptoms to some extent by making changes in your diet. See Mind's pages on *Food and mood* for more information.
- Exercise – many people find regular exercise helps to lift their mood, boost their energy levels and keep them grounded in reality. See our pages on *Physical activity, sport and mental health* for details
- Get good sleep – sleep quality is very important for your mental health. See our pages on *Coping with sleep problems* for more

information.

What are anti-Parkinson's drugs?

Anti-Parkinsons drugs are intended primarily for treating Parkinson's disease. They are not psychiatric drugs, which means they are not licenced to treat any mental health problems. However they may be prescribed alongside an antipsychotic to reduce neuromuscular side effects which resemble symptoms of Parkinson's disease.

The three anti-Parkinson's drugs which may be prescribed with antipsychotics are:

- orphenadine (Biorphen, Disipal)
- procyclidine (Arpicolin, Kemadrin)
- trihexyphenidyl (formerly called benzhexol).

Anti-Parkinson's drugs are sometimes referred to as 'antimuscarinics' because their main side effects are antimuscarinic. There are no significant differences between these drugs, but you may find that you tolerate one better than another.

When might I be prescribed one of these drugs?

You should only be prescribed an anti-Parkinson's drug if you have actually developed Parkinsonism as a side effect of your antipsychotic and:

- you can't switch to a different antipsychotic
- you can't reduce your dose
- changing the drug or reducing the dose has not helped your Parkinsonism symptoms.

These drugs should never be prescribed to prevent side effects from

occurring if you haven't already experienced any.

What are the risks with these drugs?

- They can cause side effects (see below for details of possible side effects each of these three drugs can cause).
- When coming off them, you may get rebound Parkinson's symptoms if you stop taking them too suddenly – so it's important to reduce your dose gradually. If you are taking one of these drugs with an antipsychotic and you are coming off the antipsychotic, withdrawal guidelines say that it's best to come off the antipsychotic first and then to come off the anti-Parkinson's drug.
- They have a stimulant effect, which means they can occasionally be habit-forming.

You should be particularly cautious about taking these drugs if you have:

- a heart condition
- high blood pressure
- liver disease
- kidney disease.

You should try to avoid these drugs if you:

- have glaucoma (a serious eye condition), or are at risk of it
- are showing signs of tardive dyskinesia
- have myesthenia gravis (a rare, serious muscle disorder)
- are pregnant or breastfeeding – this is because there's very little information on how safe these drugs are, and babies are sensitive to antimuscarinic effects
- have an enlarged prostate.

About orphenadrine

Key facts

- Trade names: Biorphen, Disipal
- Prescribed for: Parkinsonism; movement disorders and other Parkinson's symptoms caused by antipsychotics
- Usual daily dose: 100–300 mg
- Forms available: tablets, liquid
- Half-life: about 14 hours
- tablets contain lactose and gelatin.

Possible side effects

Common	blurred vision	nausea (feeling sick)
(between 1 in 10 and 1 in 100 people)	dizziness	gut disturbances
	dry mouth	
Uncommon	confusion	hallucinations
(between 1 in 100 and 1 in 1,000 people)	constipation	light-headedness
	difficulty sleeping	nervousness
	difficulty urinating	problems with co-ordination
	excitement	sedation
	fast heartbeat	seizures
Rare	memory problems	
(between 1 in 1,000 and 1 in 10,000 people)		

About procyclidine

Key facts

- Trade names: Arpicolin, Kemadrin
- Prescribed for: Parkinsonism, movement disorders and other Parkinson's symptoms caused by antipsychotics
- Usual daily dose: 10–30mg
- Forms available: tablets, liquid
- Half-life: three to four hours
- tablets contain lactose

Possible side effects

Common	blurred vision	difficulty urinating
(between 1 in 10 and 1 in 100 people)	constipation	dry mouth
Uncommon	agitation	nausea (feeling sick)
(between 1 in 100 and 1 in 1,000 people)	anxiety	hallucinations
	confusion	memory problems
	disorientation	nervousness
	difficulty concentrating	rashes
	dizziness	sore gums
		vomiting (being sick)
Rare	psychosis	
(between 1 in 1,000 and 1 in 10,000 people)		

About trihexyphenidyl

Key facts

- Trade names: Agitane, Artane, Benzhexol
- Prescribed for: Parkinsonism, movement disorders and other Parkinson's symptoms caused by antipsychotics
- Usual daily dose: maximum 20mg
- Forms available: tablets, liquid
- Half-life: three to four hours

Possible side effects

Unfortunately, because this drug was first licensed before the current system of recording side effects was widely used, estimates of how likely you are to experience different side effects are not available for trihexyphenidyl. All side effects are listed here in alphabetical order, but you might find them listed in order of how common they are in the patient information leaflet (PIL) – the leaflet that comes in the drug packet.

agitation	dry mouth	memory problems
blurred vision	dry throat	nausea (feeling sick)
confusion	dry skin	nervousness
constipating	excitement	raised pressure in eye
delusions	fast heartbeat	rashes
difficulty sleeping	flushing	restlessness
difficulty swallowing	hallucinations	thirst
difficulty urinating	high temperature	vomiting (being sick)
dizziness		

Useful contacts

Mind
Mind Infoline: 0300 123 3393
(Monday to Friday, 9am to 6pm)
email: info@mind.org.uk
text: 86463
web: mind.org.uk
Details of local Minds, other local services and Mind's Legal Line. Language Line is available for languages other than English.

Bipolar UK
020 7931 6480
bipolaruk.org.uk
Supports people affected by bipolar disorder.

Depression Alliance
depressionalliance.org
Information, support and self-help groups.

Elefriends
elefriends.org.uk
Elefriends is a friendly, supportive online community for people experiencing a mental health problem.

Hearing Voices Network
0114 271 8210
hearing-voices.org
National network and local groups for people who hear voices.

The National Institute for Health and Care Excellence (NICE)
nice.org.uk
For national guidance on evidence-based treatment of many conditions including schizophrenia, bipolar disorder and depression.

Rethink Mental Illness
0300 5000 927
rethink.org
For everyone affected by severe mental illness. Includes information about medication and looking after your physical health.

Further information

Mind offers a range of mental health information on:

- diagnoses
- treatments
- practical help for wellbeing
- mental health legislation
- where to get help

To read or print Mind's information booklets for free, visit mind.org.uk or contact Mind Infoline on 0300 123 3393 or at info@mind.org.uk

To buy copies of Mind's information booklets, visit mind.org.uk/shop or phone 0844 448 4448 or email publications@mind.org.uk

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Providing information costs money. We really value donations, which enable us to get our information to more people who need it.

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If you would like to support our work with a donation, please contact us on:
tel: 0300 999 1946
email: supportercare@mind.org.uk
web: mind.org.uk/donate

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Mind

We're Mind, the mental health charity for England and Wales. We believe no one should have to face a mental health problem alone. We're here for you. Today. Now. We're on your doorstep, on the end of a phone or online. Whether you're stressed, depressed or in crisis. We'll listen, give you advice, support and fight your corner. And we'll push for a better deal and respect for everyone experiencing a mental health problem.

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