

What you may not know about **antipsychotics**

A guide for people taking antipsychotic
drugs and their supporters



National Mental Health
Consumer & Carer Forum



Disclaimer

This guide provides information about antipsychotic drugs, how they work, the evidence base supporting their use, the risks they carry, and alternative responses to psychosis in order to promote informed decision making. It is not intended as medical or professional advice. We encourage you to use this guide not as the definitive resource but as a starting point to embark on your own research and learning.

Further information can be sourced via the Critical Literature Review of the Direct, Adverse Effects of Neuroleptics: Essential Information for Mental Health Consumers, Carers, Families, Supporters and Clinicians nmhccf.org.au.



Table of contents

What causes psychosis?	1
Do antipsychotics cure psychosis?	2
How effective are antipsychotics?	3
The long term use of antipsychotics	5
Can antipsychotics cause harm?	7
Experiences of people taking antipsychotics	9
Tardive Dyskinesia	11
Thinking about coming off antipsychotics?	13
Alternative Approaches	15
Things to ask your doctor about antipsychotics	16

What causes psychosis?

The causes of psychosis are complex and not fully known. As a result of this, there are many theories. The most common is the dopamine hypothesis; which argues that too much dopamine may create psychosis. The dopamine hypothesis came about in a 'cart before the horse' situation where neuroleptics (later named antipsychotics) were found to reduce distress and the symptoms of psychosis, and because neuroleptics blocked dopamine it was then reasoned that psychosis was a disease caused by excessive dopamine.

Despite the lack of evidence about what causes psychosis, antipsychotics continue to be the main treatment. It is likely that many factors contribute to the development of psychosis, and there are other ways of understanding the experience of psychosis beyond the biological brain disease model, including trauma, cultural, spiritual and psychological frameworks of understanding.

The causes of psychosis are not fully known. There are many ways of understanding the experience of psychosis beyond chemical imbalances, genetic predispositions, and brain abnormalities.

Did you know?

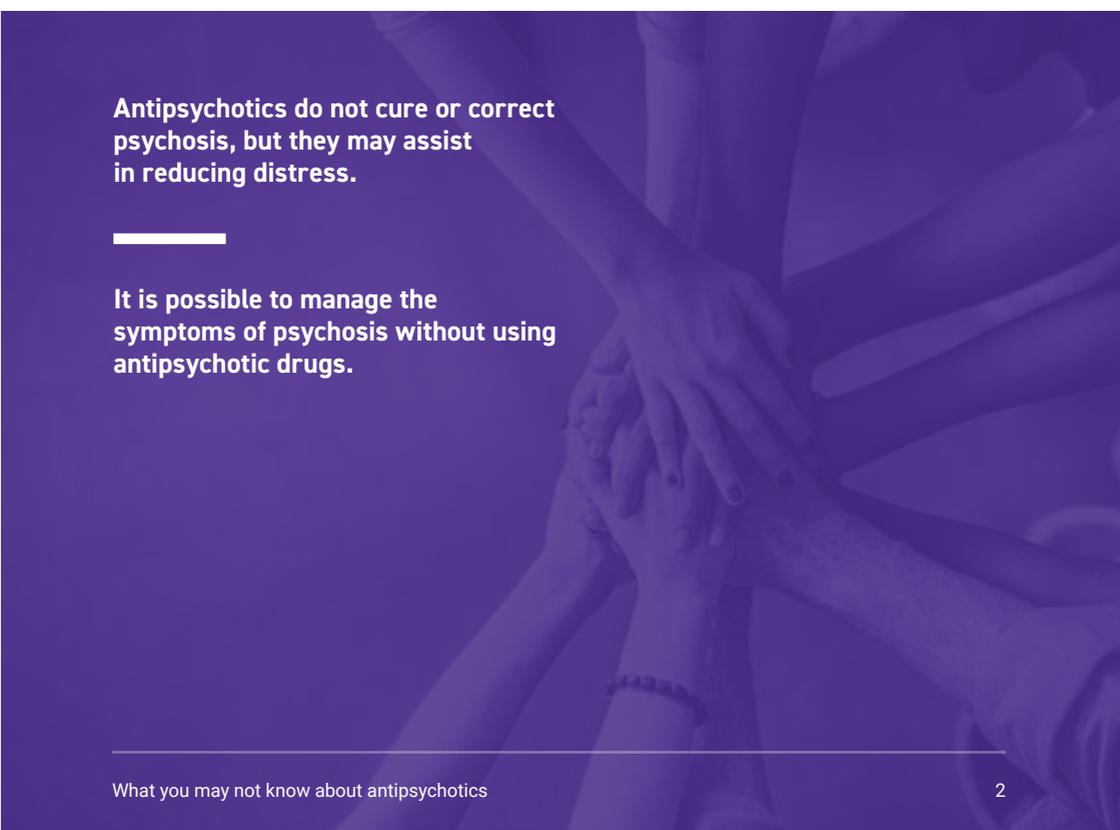
Antipsychotics were originally known as neuroleptics (from Greek meaning 'to seize, take' the nerve). The early use of neuroleptics drugs did not claim to cure or correct psychosis; rather they were observed to create disinterest, disconnection and disengagement. The tranquilising effects of these drugs assisted staff in managing, containing and responding to distress and psychotic symptoms.

Do antipsychotics cure psychosis?

No, antipsychotics do not cure psychosis or correct an underlying chemical imbalance. Unlike other drugs in medicine which target a specific disease, antipsychotics have a global effect on the whole body (much like alcohol or marijuana) which may provide some relief from the distress associated with psychosis.

Because antipsychotics do not cure or correct psychosis it has been argued that the term 'antipsychotic' is misleading and should no longer be used. The term neuroleptic may be more accurate as it captures the broad tranquillizing effect these drugs have on the body and does not claim an 'anti'-psychosis action.

There are many other treatments for psychosis that can be used with or instead of antipsychotics that have shown promising results. Research shows that it is possible to recover after an episode of psychosis without the use of antipsychotics¹⁻².



Antipsychotics do not cure or correct psychosis, but they may assist in reducing distress.

It is possible to manage the symptoms of psychosis without using antipsychotic drugs.

How effective are antipsychotics?

Antipsychotics do not 'cure' psychosis, but they may provide some relief from the symptoms of psychosis for some people. Antipsychotics are commonly categorised into two drug classes; the older, first generation antipsychotics (such as Thorazine, Trilafon and Haldol) and the newer, second generation antipsychotics (including Zyprexa, Risperdal and Seroquel). When the newer antipsychotics were introduced in the 1990s they were hailed as miracle drugs and promoted as being more effective with fewer side effects. Research has revealed that the benefits of the newer antipsychotics have been overstated and their risks, including metabolic syndrome and diabetes, have been underestimated³⁻⁴.

Overall, research shows that in the short to medium term, antipsychotics produce modest gains for some people when compared to placebo⁵⁻⁶. This improvement is typically limited to a reduction in positive symptoms, such as hearing voices or hallucinations. The benefits of antipsychotics must be balanced against their disadvantages. Serious and debilitating side effects, such as sedation, movement disorders and cardiovascular disease are associated with these drugs. There is also emerging evidence to suggest that the postponement of treatment with antipsychotics and the tapering and discontinuation of these drugs may be associated with better outcomes⁹.

Did you know?

Approximately 40% of people with first or second episode psychosis recover without the use of antipsychotics¹⁻².

Did you know?

Psychiatric medications have become a multi-billion dollar industry. Drug trials of antipsychotics are often funded by pharmaceutical companies who have a vested interest in their success. Studies with small or negative effects tend not to be published in research journals. This means that it is difficult to accurately determine how effective these drugs are.



I can handle the illness, but I don't know if I can handle this medication.

— Consumer⁷

Want to know more?

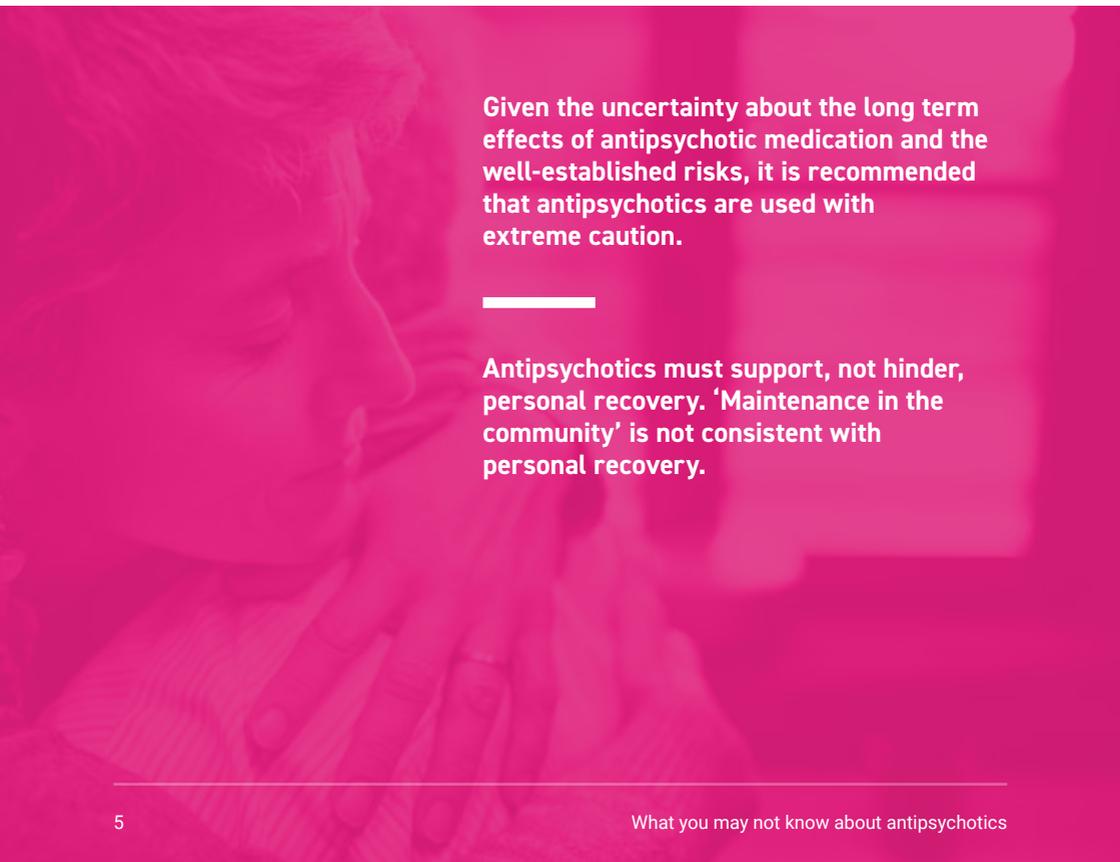
Mad in America is a website that calls for the rethinking of psychiatric care and uses scientific research, as well as the lived experience of those who have been diagnosed with a psychiatric disorder, to encourage change. The website offers a mix of news stories about psychiatric research, original journalism articles, and a forum for an international group of writers including people with lived experience, family members and psychiatrists to discuss and explore issues. Mad in America also offers online courses, including classes on antipsychotics, taught by leading researchers in the field. See madinamerica.com

Read Robert Whitaker's book **Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America** published in 2010 by Crown.

The long term use of antipsychotics

People diagnosed with schizophrenia and psychosis are often kept on antipsychotics indefinitely as it is believed that these drugs prevent relapse after the acute phase.

Recent research questions if long term use of antipsychotics is beneficial and suggests it may impede recovery. A study⁸ conducted over a 20 year period found that those individuals continuously prescribed antipsychotics showed more psychotic activity, were hospitalised more frequently, were more anxious and had poorer cognitive functioning than those who were unmedicated. While it is not possible to say that the poor outcomes experienced by the people who continued to take antipsychotics were due solely to the effects of the drugs, it does show that not all people diagnosed with schizophrenia and psychosis need to be maintained on antipsychotic drugs to recover and live positive, connected and productive lives.



Given the uncertainty about the long term effects of antipsychotic medication and the well-established risks, it is recommended that antipsychotics are used with extreme caution.

Antipsychotics must support, not hinder, personal recovery. 'Maintenance in the community' is not consistent with personal recovery.

Did you know?

Studies by the World Health Organisation⁹⁻¹⁰ have shown that people diagnosed with schizophrenia who live in developing nations such as India and Nigeria have better outcomes when compared to those in developed industrialised countries including the US and the UK. It has been proposed that the practice of maintaining people on antipsychotic drugs, which is common in high-income countries, was a key factor that contributed to this difference.

Taking more than one antipsychotic?

The use of two or more antipsychotics is known as polypharmacy.

Currently, there is no convincing evidence to suggest that using multiple antipsychotics is more effective than a single antipsychotic for the treatment of schizophrenia or psychosis¹¹.

Despite research that shows polypharmacy is associated with greater harm and guidelines which warn against this practice, polypharmacy is very common.

Antipsychotic polypharmacy is not supported by the evidence-based medicine literature and is known to increase the risk of severe and disabling side effects, such as tardive dyskinesia (NB refer pg 14).

Other interactions

Little is known about the interactions between antipsychotics and other prescribed or illicit substances. This is concerning because people diagnosed with schizophrenia or psychosis are commonly prescribed multiple antipsychotics and mood stabilisers concurrently and are likely to use a range of other substances such as tobacco, alcohol and caffeine.

Can antipsychotics cause harm?

Antipsychotics are associated with many direct harmful and unwanted effects. Sometimes these effects can be experienced as worse than the problem they were intended to relieve. Common side effects* of antipsychotics include:

Movement symptoms such as trembling, muscle stiffness, slowness of movement, shuffling walk, restlessness in the legs, twisting movements of the body, grimacing, uncontrolled movements of the tongue, lip puckering, and rapid eye blinking.

Metabolic and cardiovascular changes such as increased or decreased appetite, weight gain, diabetes, increased blood glucose and cholesterol levels, changes in blood pressure, and irregular heartbeat.

Hormonal and sexual changes such as excessive growth of hair, acne, painful and swollen breasts, breast enlargement in men, unusual secretion of breast milk, changes in menstrual periods, decreased libido, impaired arousal, and impaired orgasm.

Cognitive changes such as tiredness, drowsiness, feeling sedated, difficulty concentrating, forgetfulness, confusion, dizziness and changes in sleep.

Emotional changes such as feeling anxious, nervous, depressed or agitated.

Other side effects include dry mouth or excessive saliva, blurred vision, constipation, diarrhoea, difficulty urinating, headaches and vomiting.

Neuroleptic Malignant Syndrome is a potentially life-threatening complication of treatment with antipsychotic drugs. Symptoms include fever, severe muscle rigidity, tremor, high blood pressure, postural hypotension, rapid heart rate, confusion, delirium, elevated white blood cell count, and increased levels of an enzyme called 'creatinase'.

People often experience more than one side effect at a time which can have a profound impact on their wellbeing and quality of life. Studies show that people attempt to balance the risks and benefits of antipsychotic drugs which can often leave them feeling as though they are in a no-win situation.

Did you know?

The life expectancy of people diagnosed with schizophrenia is 15 to 20 years shorter than the general population and this mortality gap is widening over time. Physical diseases, such as cardiovascular disease and respiratory disease, make the biggest contribution to the shortened lifespan seen in this population and the role of antipsychotic drugs is gaining attention.

Want to know more?

RxISK is an independent drug safety website founded by Dr David Healy, an internationally respected psychiatrist, psychopharmacologist, scientist, and author. This RxISK website includes information and resources about drug side effects, dependence and withdrawal, interactions between drugs, and questions to ask your doctor. The website also collects data on the unintended consequences of prescription medications so that researchers can draw attention to these and improve drug safety. See rxisk.org

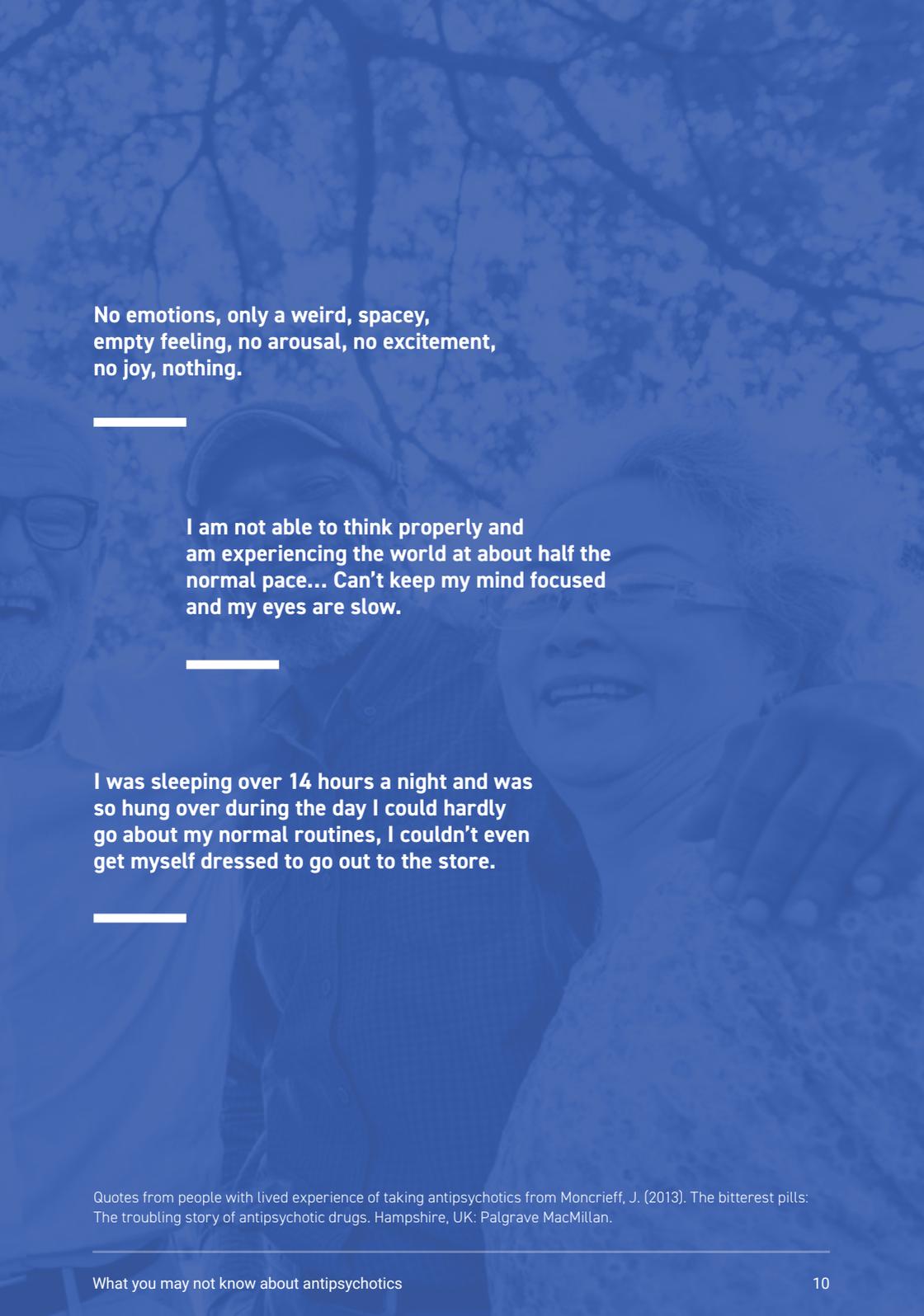
*Please note that this list is not exhaustive. If you or your loved one is concerned about the side effects of antipsychotics please talk to your psychiatrist or doctor. If you are not satisfied with their response you may like to get a second opinion. You may also like to talk to a pharmacist or your peers and explore websites such as RxISK. If you are very unwell, please seek urgent medical attention.

Experiences of people taking antipsychotics

I've never been able to eat as much as I did when I was on Zyprexa. I gained 40 lbs [18 kg] in no time and my mind was in a constant fog of lethargy and indifference. I didn't care about anything. I just wanted to sit around and eat.

I lost my ability to feel emotions, I lost my libido, I lost my drives, I lost my ability to get an erection.

Although I felt very well, I felt as if I had absolutely nothing to talk about. I kept wondering about whatever [it] was that had been so interesting during most of my life that I had suddenly lost... But I was very much in contact with reality and for that I was thankful.



No emotions, only a weird, spacey, empty feeling, no arousal, no excitement, no joy, nothing.

I am not able to think properly and am experiencing the world at about half the normal pace... Can't keep my mind focused and my eyes are slow.

I was sleeping over 14 hours a night and was so hung over during the day I could hardly go about my normal routines, I couldn't even get myself dressed to go out to the store.

Quotes from people with lived experience of taking antipsychotics from Moncrieff, J. (2013). *The bitterest pills: The troubling story of antipsychotic drugs*. Hampshire, UK: Palgrave MacMillan.

Tardive Dyskinesia

Tardive dyskinesia (TD) is a serious neurological disorder caused by antipsychotic drugs that impacts both muscle control and thinking and cognition. Rates of TD are extremely high and increase with each year of exposure to antipsychotics. TD can develop after only a few doses and it typically affects the muscles of the face, but it can produce an array of spasms and movements in any part of the body. Hallmark symptoms of TD include grimacing, tongue protrusion, lip puckering, and rapid blinking. It can also effect breathing, swallowing and speech and manifest in tremors, stiffness, pacing and shuffling. Signs of the related brain injury include impairments of attention, concentration, memory and dementia.

Antipsychotic drugs not only cause TD, but they mask the symptoms of the disorder. This means that the person becomes worse and worse before the TD symptoms eventually break through. Unless TD is identified at an early stage and the offending drug stopped immediately, it is likely to become permanent.

“ **The widespread use of neuroleptics [antipsychotics] has unleashed an epidemic of neurological disease on the world. Even if TD were the only irreversible disability produced by these drugs, this would be among the worst medically induced disasters in history**

— Psychiatrist and medical-legal expert,
Dr Peter Breggin¹²

It is often claimed that the newer, second generation antipsychotics do not cause TD, but this is not true.

Did you know?

There have been many medical malpractice verdicts against doctors and hospitals concerning TD.

Want to know more?

The Tardive Dyskinesia Resources Centre developed by Dr Peter Breggin, provides information on this drug-induced disorder, as well as a list of medications that cause it, illustrative videos and scientific articles. See breggin.com/antipsychotic-drugs-and-tardive-dyskinesia-resources-center

Side effects?

It has been argued that the term 'side effects' is misleading and should not be used. Sedation and movement disorders (like tardive dyskinesia), are a key part of the drugs action, and have a direct and profound impact on the lives of people who take antipsychotics and their loved ones who support them. By referring to these impacts as 'side effects' it implies that these effects sit to the side of people's lives and are not as important as the therapeutic effects of the drug. The term 'direct effects' may be more appropriate.

Thinking about coming off antipsychotics?

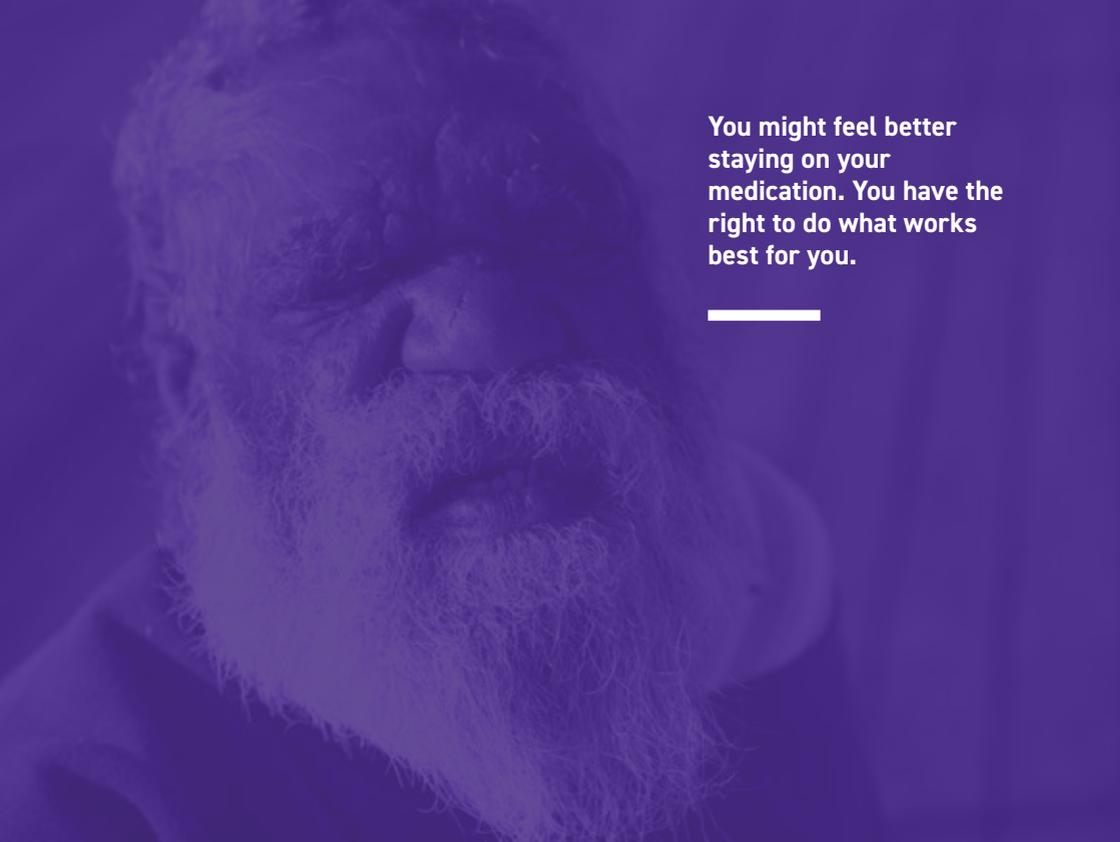
Many people choose to stop taking antipsychotic drugs for a variety of reasons. It may be because they find the drugs unhelpful, the side effects are intolerable, or because they want to recover without drugs. It is not uncommon for people to experience what appears like psychotic symptoms when they discontinue antipsychotic drugs. This is sometimes called rebound psychosis or supersensitivity psychosis. Rather than being the re-emergence of the underlying 'illness', some argue that this is a withdrawal response.

The decision to not take antipsychotic drugs as prescribed or at all is often framed as reflecting a lack of insight and interpreted as evidence of 'mental illness'. People who are 'non-compliant' may risk being hospitalised and treated involuntarily with antipsychotics, and for these reasons they may be reluctant to talk to their doctor and others about discontinuing.

Withdrawal from antipsychotic drugs is dangerous and it is very important and preferable to undertake withdrawal under supervision. If no supervision is available, then careful planning and support is absolutely essential.

Some of the signs of antipsychotic withdrawal can look exactly like the symptoms that the drugs were prescribed for in the first place.

Beware that psychiatrists and GP's are generally not trained in discontinuation and may not know how to distinguish withdrawal symptoms from the re-emergence of your original symptoms. It is very important that you educate yourself and have support prior to any attempt to withdraw.



You might feel better staying on your medication. You have the right to do what works best for you.

Want to know more?

The Icarus Project and Freedom Center have created a free, online resource called the **Harm Reduction Guide to Coming off Psychiatric Drugs**. The guide includes information on many different drugs, their risks, benefits, psychiatric drug withdrawal, information for people staying on their medications, a detailed resource section, and much more. It can be found here: willhall.net/comingoffmeds

Read **Psychiatric Drug Withdrawal: A Guide for Prescribers, Therapists, Patients and their Families** by Dr Peter Breggin.

Visit the website **Coming Off Psychiatric Medication** which includes lots of information on planning for the withdrawal process: comingoff.com

Alternative Approaches

Antipsychotics can have a role in personal recovery but as recovery is a unique, individual process, the role of these drugs will be different for each person. There are many other ways to manage distressing experiences and heal beyond psychiatric drugs. These approaches can be used as an alternative to, or in conjunction with, antipsychotic medication. While some people find these helpful, they require research to find out if they are available locally.

Hearing Voices Network are peer support groups for voice hearers where experiences are accepted, welcomed and explored. This approach considers voices and visions to be meaningful experiences which are commonly the result of trauma or distressing experiences.

Psychotherapy and psychological approaches for psychosis may include:

- Trauma recovery
- Gestalt therapy
- Voice dialogue
- Cognitive behavioural therapy
- Relational therapy
- Acceptance and commitment therapy

Medication is just one tool among many that people may choose to use in their recovery.

Open Dialogue

Developed in Finland in the 1980s, the Open Dialogue approach brings together the person experiencing psychosis with their network of friends, family and support people to engage in a therapeutic dialogue. This approach has shown promising outcomes for people, without or with the limited use of antipsychotics.

Want to know more?

Visit the **Beyond Meds** website which includes information about different ways to support wellness and stories of recovery beyondmeds.com

Read **100 Ways to Support Recovery** by Mike Slade: rethink.org/media/704895/100_ways_to_support_recovery_2nd_edition.pdf

Things to ask your doctor about antipsychotics

You have the right to have balanced information about the risks and benefits of antipsychotics. Here are some questions that you might like to ask your doctor during medication meetings:

- How exactly does this medication work?
- How do you think it will help me?
- How long do you think it will be before I feel a benefit from this medication?
- If this medication isn't helping me or causing unwanted effects, would you consider tapering the medication?
- What are the unwanted effects or side effects associated with this medication? (Request a comprehensive list which is clearly explained)
- What should I do if I experience side effects?
- What will you do if I experience side effects?
- How can I manage the side effects of this medication?
- Where and how can I get the best support to manage these?
- Do I need any referrals to other health professionals?
- What other medications or substances should I avoid whilst taking this medication?
- How long do you anticipate I will be taking this medication?
- What is the plan for tapering?
- Could you tell me about your experience supporting people to taper or withdraw from antipsychotic medication?
- Aside from medication, what else can I do to manage my symptoms?
- What other alternative treatments/therapies could I use in conjunction with the medication?
- Who do I contact if I have any questions or concerns about this medication in between appointments?

Want to know more?

The Recovery Orientated Prescribing and Medicines Management Project in the UK developed guidelines based on the views and experiences of people who take psychiatric drugs, their supporters and service providers and offer a number of recommendations to help mental health workers support people to use medication in their recovery. The guidelines can be downloaded for free here: recoverydevon.co.uk/resources

This booklet is based on information from the Critical Literature Review of the Direct, Adverse Effects of Neuroleptics: Essential Information for Mental Health Consumers, Carers, Families, Supporters and Clinicians nmhccf.org.au.

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