

<b>Contents</b>	page
1. Introduction and summary	1
2. About the research	2
3. What people told us about coping with coming off	3
4. Actions and recommendations	12

# Acknowledgements

All the people who carried out this research have experience of coming off, or of attempting to come off, psychiatric drugs.

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Our work was supported throughout by the advisory group: Peter Campbell, Catherine Clarke, Katherine Darton, Diane Denton, Charanjit Dosanjh, Portia Omo-bare, Kerry Sproston and Phil Thomas.

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Finally, thanks from Jim, Jan and Veronica to Alison Cobb, who managed the project and liaised with us on behalf of Mind.

## Drug groups mentioned in this report:

- SSRI antidepressants (Serotonin Specific Re-uptake Inhibitors). A similar drug, Efexor (venlafaxine) has been included in this group.
- Neuroleptics, also known as antipsychotics.
- Mood stabilisers.
- Minor tranquillisers, which includes benzodiazepines.

When specific drug names are used, the drug group is also given. Trade names for drugs are given with an initial capital letter. For example, Seroxat is a trade name for the SSRI, paroxetine.

## Caution

If you are stopping taking medication, it is advisable to reduce the dose gradually, as it is difficult to predict who will have problems withdrawing. It is worth getting as much information and support as you can, and involving your doctor wherever possible.

# 1. Introduction and summary

## Introduction

Mind's research into people's experiences of adverse effects of taking psychiatric drugs\* highlighted the lack of information and support for people wanting to stop taking medication.

The research for *Coping with coming off* set out to find out what happens when people do try to come off psychiatric drugs: the effects of withdrawal and what helps people to succeed.

## Summary

### Why stop?

The most common reasons given for wanting to come off drugs were disliking the adverse effects of taking them and not wanting to be on them long-term.

### Doctors and patients

The research highlighted significant difficulties between doctors and their patients:

- Doctors were unable to predict who could come off their psychiatric drugs successfully. People who came off their drugs against their doctor's advice were as likely to succeed as those whose doctors agreed they should come off.
- People on mood stabilisers or neuroleptics were particularly likely to come off against their doctor's advice or without telling their doctor. About two thirds of people on mood stabilisers and neuroleptics tried coming off against the advice of their doctor or without telling them.
- Where doctors were involved, they were the least likely to be found helpful of any group of people. About half the people who sought or received help from a doctor found them helpful. In contrast, around nine out of ten people who sought help or support from a counsellor or psychotherapist found them helpful, with other service users being found similarly helpful.

### Difficulties

Of the people we interviewed, over half experienced difficulties in coming off their drugs. The most common difficulties were anxiety,

difficulty sleeping and depression. Those coming off SSRIs were more likely to have difficulty coming off than people on mood stabilisers or neuroleptics.

### Success

The biggest factor in influencing success in coming off was length of time on the drug. Four out of five people who had been on the drug less than six months succeeded, compared with under half who had been on it more than five years.

### Benefits

When people who succeeded in coming off their medication were asked about the benefits, they most often said: better mental ability, feeling more alive, having taken back power and control, no longer experiencing the adverse effects, and feeling good about managing without the drugs.

### Recommendations

- All people who prescribe psychiatric drugs to have training in how to support people who take them.
- More funding for services to support people through coming off psychiatric drugs.
- Learning from best practice in mental health and substance misuse organisations.
- Commissioning of user-led projects offering independent information, advice and mutual support for people on psychiatric drugs.
- Dialogue between all interest groups concerned with taking or prescribing neuroleptics and mood stabilisers.
- Further research into people's experiences of trying to come off neuroleptics and mood stabilisers.

This research has highlighted themes that are familiar in many debates about mental health services. They include:

- service users wanting to be listened to and treated with respect
- alternatives to psychiatric drugs
- access to information
- value of peer support
- lack of credibility when you have a diagnosis
- control and coercion
- conflicting views about mental health and distress.

\*Cobb, A, Darton, K and Juttla, K (2001) *Mind's yellow card for reporting drug side effects: a report of users' experiences* (Mind)

## 2. About the research

The research was carried out in two stages:

1. Short interviews with 204 people using a questionnaire. This was intended, primarily, to obtain quantitative information.
2. In depth interviews with 46 people using a topic guide. This was intended, primarily, to produce qualitative information.

### The short interviews

Our intention was to recruit at least 200 people. We were looking for a diverse group in terms of age, where they lived, ethnicity and gender. We also wanted to include a good spread of experience of taking and trying to come off psychiatric drugs among the people we interviewed.

A short form was distributed which people were invited to fill in and return if they were willing to be interviewed. On the form, they gave brief details about themselves and their experience.

The forms were distributed through Mind's networks, through internet groups and personal contacts, and it was also available on Mind's website. Other organisations copied and distributed the forms and also made it available on their websites.

In the end, we received 248 forms. Although we did not have the amount of choice we had hoped for, we still ended up with a reasonably balanced group. We chose it to ensure that about half had succeeded in coming off a drug. We can make no particular claim about how typical the experiences of this group were compared with those of all people who have tried to come off psychiatric drugs.

Most of the short interviews were by telephone, the rest were face to face. They were carried out between November 2003 and August 2004. We created a questionnaire and analysed the data using the survey software, Keypoint.

In each interview, we collected some general information about the person's experience of psychiatric drugs. Then we focused on one episode of trying to come off. This was the most recent, unless the person had a strong preference to talk about another episode.

### In depth interviews

We chose the people to interview again, in depth, to give a balance of backgrounds and experience. After much thought and discussion about the pros and cons of phone interviews and face to face interviews, the majority were conducted over the phone. All were recorded and later transcribed.

The interviews were carried out during the period August to November 2004. They were analysed using the 'Framework' method.

### Comparing different drugs

We wanted to find out if people had different experiences, depending on what drugs they tried to come off. When making these comparisons, we only considered people who tried to come off one drug and were on no other psychiatric drug at the time.

This left us with:

- 64 people on SSRI antidepressants
- 21 people on neuroleptics
- 12 people on mood stabilisers.

There were no other drugs groups with 10 or more people, which we decided was the minimum number that would give us meaningful results. The numbers of people in these three drug groups that we did choose are quite small, and this should be remembered when looking at the results.

Also, it should be noted that there may be differences between drugs within these groups. For example, some SSRI antidepressants may be more difficult to come off than others.

**Tables, including details of the demographic characteristics of those interviewed, are available at [www.mind.org.uk](http://www.mind.org.uk)**

# 3. What people told us about coping with coming off

In this section, we present the results of our research. We start with what people told us about their experience of being on psychiatric drugs and follow their journeys through deciding to try to come off them, the difficulties they encountered, the help they received, whether they succeeded and how they felt about it afterwards.

## Experience of being on psychiatric drugs

To understand why people wanted to come off their drugs, we asked about their experience of being on them. We asked how well or badly, overall, psychiatric drugs had worked for them. There was an even spread of positive and negative responses. Nearly a fifth (18 per cent) had found them mainly helpful, with a similar proportion (21 per cent) saying they were mainly harmful. The rest gave an even spread of answers between these two positions.

These figures show that most of the people we spoke to did not find the drugs they took to be straightforwardly beneficial. This sometimes put them at odds with people, such as mental health workers and family members, who had more faith in the drugs.



## Ambivalence about taking an SSRI antidepressant:

“I wish there could have been two of me; one that took the road without Seroxat and one with Seroxat; because I want to know if it has had a positive influence on my life or been a burden.”

## Mixed experience of taking a minor tranquilliser:

“Diazepam saved my life but I can't get off it.”

## Experiencing lithium (a mood stabiliser) as harmful:

“The shakes were terrible; I couldn't walk properly and couldn't see properly.”

We also asked how much choice people had in taking their drugs. They could give more than one answer, reflecting different experiences on different occasions. Their responses indicated how often they had not experienced real choice.

Nearly one third (30 per cent) had been compelled to take them under the Mental Health Act. Just over half (52 per cent) had been in a situation where they felt that if they did not comply they would be compelled. Seventy per cent had felt pressured to take them, and the same proportion had felt powerless or passive about taking them. Just over half (54 per cent) felt they had experienced free choice on at least one occasion.

These figures show how seldom the people who participated in this survey had actively agreed to take their psychiatric drugs in the first place. This was likely to affect their commitment to stay on them.

## Unimpressed with taking an antidepressant, neuroleptic and mood stabiliser:

“I don't think that the medication I'm on makes a lot of difference.”

## Why people wanted to come off them

When we asked people to tell us about one episode of trying to come off their drugs, these were the reasons they gave for wanting to stop:

Table one	
Reasons given for wanting to come off drugs	Per cent
I didn't like the adverse effects of the drugs	60
I didn't like the idea of being on them long-term	53
I felt better or things were better in my life and I didn't need them	37
The drugs were not useful	32
I had only expected to be on them for a limited time	19
I was advised to come off them by a doctor	7
Other	1
204 people gave a total of 494 responses to this question	

The most common reason for stopping was not liking the adverse effects of the drugs, given by 60 per cent. Thirty two per cent said the drugs were not useful. Both these responses indicate people not experiencing an overall benefit from their medication.

Over half (53 per cent) said they did not like the idea of being on them long-term. Some were concerned about long-term damage to health. Others did not relish the prospect of their minds always being affected by a drug.

### Stopped taking carbamazepine (a mood stabiliser) because of adverse effects:

"It made me so sedated, I could only deal with minimal family commitments. I was sleeping during the day and I've got a seven year old child, so the two things don't mix very well."



### Came off fluoxetine (an SSRI) because of not wanting to be on it long-term:

"I felt a bit controlled by the drug, in that when I thought something I didn't know if that was me thinking or if it was the drug making me think it."

### Reason for coming off Ativan (a minor tranquilliser).

"Pills have never, ever kept me out of bins."

## Making the decision to try to come off

We asked people how their doctor was involved in the decision to try coming off. The results are in table two. The figures for mood stabilisers and neuroleptics are striking. They show that a quarter actually tried coming off against the advice of their doctor. Another two out of five did not tell their doctor. This means that the majority of people on mood stabilisers and neuroleptics tried coming off without the support of their doctor.

### Stopping taking olanzapine (a neuroleptic) without telling staff:

“There’s this fear of being forced into compliance. I know I’m being a bit covert and underhand but the threat has been offered.”

Table two

How did you make the decision to try to come off your drugs?	Per cent			
	All	SSRIs	Mood stabilisers	Neuroleptics
I decided against the advice of my doctor	12	11	25	24
I decided without telling my doctor	26	16	42	38
I decided and my doctor accepted this	28	39	8	19
It was a joint decision between me and my doctor	13	19	17	10
My doctor decided and I accepted this	9	9	0	5
Other	12	6	8	5
Number of responses in this category	204	64	12	21

People who tried to come off without telling their doctor usually did so because they feared opposition, possibly backed up with coercion or compulsion. But some, whose drugs were prescribed by a GP, simply felt that they didn’t need to talk to their doctor first.

### Coming off Seroxat (an SSRI) without involving the doctor:

“I haven’t told my GP but he pretty much allows me to self-medicate. I know he would have said ‘Yes, that’s fine’.”

### Deciding to come off venlafaxine (an SNRI) against a doctor’s advice:

“My psychiatrist’s attitude was ‘If you don’t want to take them I won’t see you, and you are being very, very silly if you came off them’.”



## How quickly people tried to come off and why

We also asked over what time period people came off their drugs. The results are in table three.

Table three	
Over what period did you try to withdraw from your psychiatric drug(s)?	Per cent
All at once, immediately	30
In less than one month	14
One to six months	32
More than six months	21
Number of responses	204

We were interested in why so many people (nearly a third) came off all at once, when the advice usually given is to do it more slowly. There were many reasons.

Some had been told by a doctor or a friend that it was OK to come off all at once. Others had only been on their drugs for a few days. One person had to stop because his drugs were making him suicidal. Another did it spontaneously one New Year's Eve but then monitored herself for signs of distress.

Some people, who came off more slowly, wanted to obtain their drug in its lowest dose or a liquid form, so they could come off gradually. This was an obvious problem for people who were stopping against the advice of their doctor or without telling them. But when doctors were involved, they were not always helpful. There were several instances of doctors denying that a drug could be obtained in a low dose or liquid form when information to the contrary was freely available in publications such as the British National Formulary. Some people ended up doing their own research and presented their results back to their doctors.\*

### On coming off a mood stabiliser in one go:

**"My daughter came home and said 'Mother, you're not taking these, you're lithium toxic' and she threw them in the bin."**

## Difficulties in coming off

Before launching into descriptions of the vast array of adverse effects experienced by people trying to come off their drugs, it should be noted that 40 per cent did not experience any significant difficulties. This leaves 60 per cent who did. This figure rises to 68 per cent for people trying to come off SSRIs.

The range of adverse effects covered just about every aspect of human functioning. They included:

- emotional problems, such as mood swings, depression and anxiety
- cognitive problems, such as difficulty concentrating and memory loss
- 'psychotic' symptoms, such as hallucinations and paranoia
- physical problems, such as headaches, blurred vision, digestive complaints, shakes and shivers, sweating, difficulties walking and standing, joint and muscle pain, and many more
- sleep disturbance, such as nightmares and sleeplessness.

### Acting on advice from Council for Information on Tranquillisers and Antidepressants (CITA) when coming off Valium (a minor tranquilliser):

**"The psychiatrist told me to cut down by five milligrams every two weeks but I know now that two milligrams every two weeks is more appropriate."**

\*Information on low doses and liquids is in *Making sense of coming off psychiatric drugs*. See inside back page for details.

Anxiety was the most frequently mentioned adverse effect, followed by sleep disturbance. People coming off their drugs were conscious that they may start to experience the symptoms of distress that the drugs had been suppressing. Sometimes, they were also anxious about coming off. The adverse effects of withdrawal could be similar, or even identical to the symptoms of distress. Disentangling these strands of distress, withdrawal and anxiety about coming off could be difficult.

Some people went back on their drugs without being sure what had been happening. One person was convinced she was either depressed or ill, and was about to go back on Prozac (an SSRI) when she found an internet site that listed exactly the symptoms she was experiencing, describing them collectively as a withdrawal syndrome. That gave her the knowledge and strength to carry on, and she was able to come off successfully.

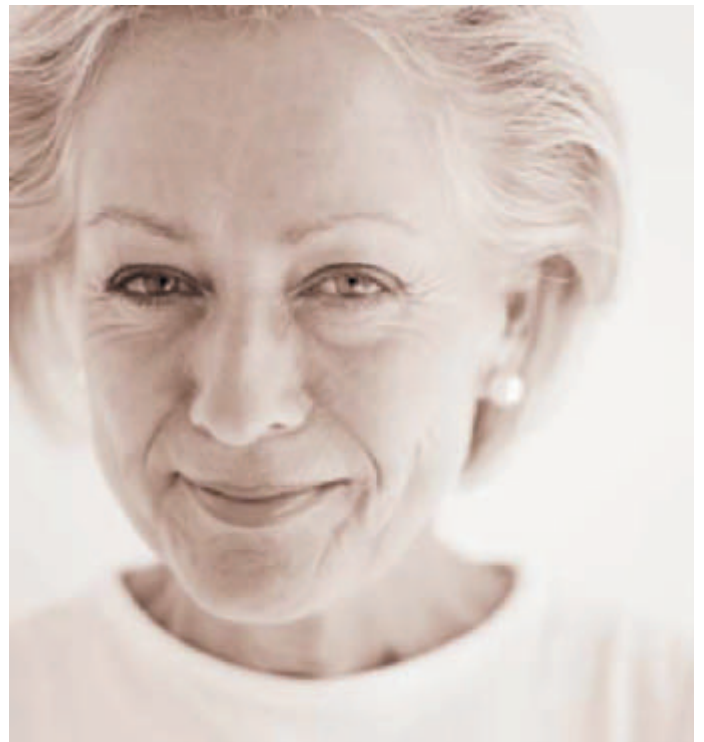
There were people who were clear they were experiencing a withdrawal syndrome, but found it so severe that they gave up trying to come off their drugs or only succeeded after long struggles.

#### Coming off lithium (a mood stabiliser):

“I was mildly euphoric by the time I’d finished but I think that was because I’d got rid of the damned stuff.”

#### While coming off sulpiride (a neuroleptic):

“It’s very strange but almost as if electricity is in my face or head; a very strange feeling as if there’s a lot of static electricity.”



#### Withdrawing from Seroxat (an SSRI):

“I felt as if every time I moved my head there was a bit of brain inside that was sort of being left behind.”



## Seeking and receiving help

We asked people who they had sought or received help from, and how useful they found it. In table four, we have listed the people who provided or offered help in the order that they were rated very helpful.

Table four					
Help received from:	Number of people	Per cent			
		Very helpful	Helpful	Not helpful	Made things worse
Counsellor or psychotherapist	53	53	34	13	0
Support group	52	52	38	8	2
Complementary therapist	39	51	41	8	0
Other service user(s)	81	47	42	7	4
Family member(s)	110	38	35	20	7
Telephone helpline	42	38	28	21	2
Friends (not service users)	100	28	51	16	5
Mental health worker (other than doctor)	76	28	33	33	7
GP	124	13	38	40	10
Psychiatrist	105	12	33	30	24

As doctors prescribe psychiatric drugs, it is reasonable to expect them to be the best source of advice and support about coming off them. This table shows that they were actually less likely to be found helpful than any other group of people from whom help was sought or received. They were also more often thought to have made things worse.

They were rated especially poorly by people on neuroleptics. There were 21 people coming off a neuroleptic who were not on another drug. Eleven of them sought or received help from their GP. Seven said the GP was not helpful or made things worse. Ten sought or received help from a psychiatrist. Eight said the psychiatrist was not helpful or made things worse.

In the in depth interviews, we investigated why so many people found their doctor so unhelpful. We found there were often basic differences of opinion. People said their doctors were:

- more likely to see the drugs as beneficial
- less concerned about the adverse effects
- less likely to understand the desire to live without them
- more likely to doubt their ability to manage without them (especially mood stabilisers and neuroleptics)
- less likely to value alternative strategies and sources of help and support.

Additionally, doctors were often not well informed about the possible effects of withdrawal and the best way to go about it, or chose not to share this information with their patients.

In contrast, people with specialist skills who had no role in prescribing drugs, such as counsellors, were often rated highly, as were 'nonprofessionals', such as other service users and family members. They could be encouraging, supportive and understanding. It was less common to find examples of them giving specific information or expert advice about the actual process of withdrawal, but this was highly valued when offered.

We also asked what other forms of help were useful. The internet was rated highly as a source of information and support, but it was rarely used by people on neuroleptics or mood stabilisers, the people who got least help from their doctors. Books and pamphlets were also helpful in offering information and inspiration about alternatives to psychiatric drugs, but few people had found anything specific about coming off. Activities, such as relaxation methods, meditation, exercise and expressing creativity were highly valued as means of getting through difficult times and providing positive alternatives to medication, as were spiritual and religious beliefs and practice.

**On seeking help from a psychiatrist to come off lithium (a mood stabiliser):**

"I found his attitude extremely depressing. He never gave me any grounds for hope or optimism. He made me feel like I was going to be stuck out of work and on medication, and just about mumbling through for the rest of my life. And I was 41 at the time."

**This woman later came off successfully with support from another psychiatrist.**

**On phoning Battle Against Tranquillisers when thinking about coming off sulpiride (a neuroleptic):**

"I phoned a few times and spoke to someone who really seemed to know what they were talking about, and was able to give me some moral support and talk things through in a logical way."



**On finding a website about withdrawal from Seroxat (an SSRI):**

"I know it's an awful thing to say, that other people are suffering as well, but it's nice to feel you're not alone and not mad or anything."

**On helpful bookshop staff who were knowledgeable about self-help books:**

"Next time I won't go to the doctor, I'll go down to Waterstones."

## Factors that influenced success

Length of time on the drug emerged as the factor that most clearly influenced success in coming off. Four out of five people (81 per cent) who were on their drug for less than six months succeeded in coming off. In contrast, less than half (44 per cent) of people who were on their drug for more than five years succeeded. (Just over half of people who were on their drug for between six months and five years succeeded.)

Our research did not demonstrate that speed in coming off made a difference to success. People who came off slowly were not significantly more likely to succeed than people who did it all at once. But people who came off their drugs all at once were more likely to have been taking them for a short time than people who came off slowly.

When we looked just at people who had been on an SSRI antidepressant for one to five years, we found that they were more likely to succeed in coming off if they took more than a month to do so. The results of our research certainly do not challenge advice that it is best to come off slowly.

But they do demonstrate that there are no firm rules about what works. One person who succeeded in coming off all at once had been on a depot injection for over 11 years.

We knew that many people had tried coming off against their doctor's advice or without telling their doctor. We wanted to know how well they did, compared to people who did involve their doctor. The results are shown in table five.

We can see that whether the doctor was involved made very little difference to success. Just over half (53 per cent) of people who did not involve their doctor succeeded, compared to 44 per cent of people who did. (These figures were obtained by combining the first two categories to give 53 per cent and the next three to give 44 per cent).

These findings challenge some common assumptions. The first assumption is that people should not attempt to come off psychiatric drugs without consulting their doctor. The second assumption is that doctors know better than their patients whether they can safely come off medication.

**Table five**

### How the decision was made and how successful it was - all participants

	Number of people in this category	Percentage completely successful
Decided against advice of doctor	24	50
Decided without telling my doctor	54	54
I decided and my doctor accepted	55	40
Joint decision between me and doctor	27	56
My doctor decided and I accepted	17	41
Other	23	52
Total	200	49

**Lessons learned from trying, unsuccessfully, to come off olanzapine (a neuroleptic) all at once:**

**"If I'm going to do it at all, it's going to be piecemeal, in stages, and it has to be done with a consortium of experts and not just a one man show."**

## Learning from experience

People's attempts to come off their drugs resulted in varying degrees of success. Some started but felt unable to continue. They were not always sure if their difficulties were a withdrawal syndrome or distress re-emerging as they came off the drugs. Others came off their medication but went back on again. Some people were making slow progress in coming off and were hopeful of eventually succeeding. Others had succeeded in coming off and staying off their drugs, although some were prepared to go back on them if necessary.

People who didn't succeed in coming off had a variety of explanations. Some were straightforward. For example, some people thought it showed they needed their medication. One man decided he had come off too quickly and without support. Others were less sure, wondering if they had become so used to the drug that they simply couldn't manage without it.

They also had to decide whether to try again and, if so, what to do differently. One woman decided to prioritise other ways of pursuing her recovery, such as using psychotherapy. A man who tried coming off olanzapine (a neuroleptic) was hoping for better services for people wanting to withdraw from psychiatric drugs, based on the lessons learned by people who had succeeded.

Undoubtedly, trying and failing could be painful. One man had been on medication for 45 years and said it was his life's ambition to come off it. He succeeded for a month and had some intense and exhilarating experiences but ended up being sectioned.

There was not always a clear cut division between success and failure. One person had come off her drugs but it did not feel like a success because she was struggling with her feelings. Another had to go back on medication but the new drugs suited her better than the one she had come off.

### On becoming depressed after coming off Ciprolex (an SSRI):

"The experiment was successful to the extent that it emphasised the need for some antidepressant medication."

## Benefits of coming off

Despite a range of experiences, people who succeeded in coming off and staying off their drugs were frequently enthusiastic about the benefits, which encompassed a vast range of feeling and functioning. Most commonly mentioned, by about one third of the people who succeeded, was being able to use their minds better – for example, being more alert, better able to concentrate or improved memory. A similar number mentioned having their lives back, and feeling more alive or human. Around one fifth mentioned one of these benefits: taking back power and control over their lives; no longer experiencing the adverse effects of medication; or knowing they could manage without drugs.

### Benefit of coming off Valium (a minor tranquilliser):

"My beaten up old car goes for its MOT in January every year and, when I was taking the medication, I used to stand there watching every single move the mechanics were making, listening to every little squeak. But after I stopped taking the medication, I just took it round there, went away and came back again – quite a difference."

### On coming off Largactil (a neuroleptic):

"A feeling of great exhilaration, a feeling of getting my power back and being able to do things I couldn't do before."

# 4. Action and recommendations

## Action

The preliminary findings of this research became available in December 2004. They were discussed in a seminar attended by people from many interest groups, who helped to draw up the recommendations. They have also been circulated to relevant professional bodies and presented at Mind's annual conference in March 2005.

Through Mind's action, they have already made an impact.

Evidence that doctors were not good judges of who could successfully come off their medication was sent to the pre-legislative scrutiny committee on the Draft Mental Health Bill. Mind will continue to use this research to support the case against compulsion in the community.

Mind has revised its own standard caution against coming off without medical advice. As doctors were found often to be ineffective in providing information and support, the new advice will emphasise the importance of seeking information and support from a wide variety of sources.

Mind has produced a booklet, *Making sense of coming off psychiatric drugs*, to fill the gap in availability of information. (See inside back cover for details).

Mind will continue to publicise the research, raise awareness through training and conferences, and campaign for better information and support for people wanting to come off psychiatric drugs.

A more detailed account of the *Coping with coming off* research will be published as a book in 2006.

"I found the research fascinating. I am very interested in the cognitive dissonance between the doctors and patients and also the finding that the longer someone is on medication the harder it is to come off. I have never seen patient leaflets address this. There are also big training implications for GPs."

Andre Tylee,  
Professor of Primary Care Mental Health

"We welcome this significant research highlighting the importance of offering patients with psychiatric illness genuine choice and involvement in decisions about medicines."

Joanne Shaw, Director of Medicines Partnership, a Department of Health programme aimed at helping people to get more out of medicines

## Recommendations

How can people who want to or are willing to come off psychiatric drugs be helped to do so in the best way?

Good practice should be based on respect and information:

Respect for service users' rights to:

- make choices, including about how to come off
- receive information and support.

Information for everyone involved about:

- possible adverse effects when coming off
- best ways to come off
- good ways to support someone who is coming off

"There is a desperate need for information for people who want to try coming off medication, and for informed support from mental health professionals and families and friends so that the process can be as safe and effective as possible. This report should be essential reading for anyone who takes or prescribes psychiatric drugs."

David Crepaz-Keay,  
Senior Policy Advisor, patient and public involvement, Mental Health Foundation



The following people can play a significant role in supporting people to come off psychiatric drugs:

**GPs and psychiatrists** need to be trained in service user perspectives on psychiatric drugs. They should be encouraged to see decisions about medication as being about negotiation, with the service user having the final say.

**Nurses and pharmacists** who have new roles in supplementary prescribing should, like doctors, be trained to understand service user perspectives on psychiatric drugs and be well informed about best practice in coming off.

**All other staff** involved in developing and implementing care plans, supporting and monitoring service users, or offering specialist services should be willing to engage with service users about their experience of and views about the psychiatric drugs they take, including whether they want to come off them.

**Voluntary organisations** have played a vital role in uncovering and highlighting problems with psychiatric drugs, including difficulties with withdrawal from minor tranquillisers and SSRI antidepressants. They have also taken the initiative in providing information and support to service users. Much of this work has benefited from being led by people with personal experience of coming off psychiatric drugs - **experts by experience**. Their role should be strengthened through greater funding for helplines, websites and pamphlets.

Mind proposes that **Primary Care Trusts** (England) and **Local Health Boards** (Wales) should commission voluntary organisations to run projects to offer independent advice and mutual support for all people on psychiatric drugs, whether staying on or coming off. These projects should aim to be led by experts by experience.

**Families and friends** may have a significant role in helping service users to think about coming off and supporting them through it. This role needs to be recognised by mental health workers. Family members and friends should be involved to the extent the service user wants.

**Organisations working in the field of substance misuse** have a great deal of experience in providing programmes and services to help

people through difficulties coming off drugs. Mind would welcome dialogue between people working in mental health and substance misuse to see if there are lessons to be learned about supporting people coming off psychiatric drugs.

This research has highlighted conflict between psychiatrists, on the one hand, and people diagnosed as having severe and enduring mental illnesses on the other, over the long term use of psychiatric drugs. Mind would like to see more debate between **all interest groups** on this issue, with the aim of enabling people who want to try coming off long-term medication to have their right to do so respected and to be practically supported even by professionals who may not agree with the decision.

**Researchers** need to pay more attention to withdrawal from psychiatric drugs. We believe *Coping with coming off* to be the first substantial piece of research to look at coming off the range of psychiatric drugs from the service users' perspective. It should certainly not be the last. As a priority, there is a need for more detailed research into people's experiences of trying to come off neuroleptics and mood stabilisers.

### Contact details of organisations mentioned in this report

Council for Information on Tranquillisers and Antidepressants (CITA)  
JDI Centre  
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Battle Against Tranquillisers  
PO Box 658  
Bristol  
BS99 1XP  
Tel: 0117 966 3629  
Web: [www.bataid.org](http://www.bataid.org)

The new information booklet *Making sense of coming off psychiatric drugs* provides information about coming off different psychiatric drugs, with references to other reading and organisations, and is available from Mind Publications, details overleaf.



**For better  
mental health**

*Making sense of coming off psychiatric drugs*  
is available from:

Mind Publications  
15-19 Broadway  
London E15 4BQ  
Tel: 0844 448 4448  
Email: [publications@mind.org.uk](mailto:publications@mind.org.uk)  
Online shop: [www.mind.org.uk/shopping](http://www.mind.org.uk/shopping)

There is also more information available on  
Mind's website [www.mind.org.uk](http://www.mind.org.uk) and from  
**MindinfoLine**, details below.

For more information about any of the issues  
raised in this report, including details of your  
nearest local Mind association and local services,  
contact Mind's helpline, **MindinfoLine** on 0845  
7660163, Monday to Friday 9.15am to 5.15pm.  
Speech impaired or deaf enquirers can contact us  
on the same number (If you are using BT Text  
direct, add the prefix 18001). For interpretation,  
**MindinfoLine** has access to 100 languages via  
Language Line.

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