

rethink



Legacy
publication

side effects

mental health service users' experiences of
the side effects of anti-psychotic medication

Who we are

Rethink, the leading national mental health membership charity, works to help everyone affected by severe mental illness recover a better quality of life. We provide hope and empowerment through effective services and support to all those who need us, and campaign for change through greater awareness and understanding.

Our research findings help us to provide higher quality services, support and treatments for people with mental health problems. By examining the current and future health needs of the whole population we are able to create effective strategies to promote better mental health and prevent mental health problems.

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Foreword

Today, a person with a severe mental illness is far more likely to be living in the mainstream of society than a long-stay hospital. People are more likely than not to have the worst and most disabling symptoms of the illness controlled by medicines and to be able to benefit from a modern range of medical and social treatments delivered in the home and the community. In short, the prospect of recovering a full and meaningful life from the initial devastating diagnosis of a severe mental illness, such as psychosis, is becoming an achievable reality for hundreds of thousands of people.

However, recovery is still a real struggle. It means battling not only against the direct effects of the illness, but overcoming the all-pervasive stigma associated with having a severe mental health problem. It involves finding the strength to be assertive with medical professionals and to demand only the best treatment tailored to individual needs.

Our report, *What happens next?*, looks at one aspect of the struggle faced by hundreds of thousands of people using medicines for severe mental illness – overcoming the side effects.

The 1950s saw the slow introduction of a first generation of medicines that, for the majority of people, proved a powerful weapon in combating the major symptoms of psychosis – hearing disturbing voices and experiencing frightening hallucinations. These medicines, which are still widely in use today, had major drawbacks.

A second generation of medicines – known as “atypicals” because they did not have the “typical” side effect profiles of the older medicines were introduced.

Guidance from the National Institute for Health and Clinical Excellence (NICE) aims to ensure that these second generation medicines are now the norm for people newly diagnosed with a psychosis. But their now widespread use has shown that while they are as effective as the first generation medicines in treating symptoms they have different side effects introducing problems such as significant weight gain, diabetes and sexual dysfunction.

Of course, all medicines for all conditions have side effects. Even over-the-counter headache pills can produce severe side effects in a minority of people. However for many with long-term medical conditions, the side effects of their medicines are carefully explained and monitored, and people are increasingly offered self-management programmes to identify them early and tackle them. In mental health, we are just beginning to put such programmes in place. In many areas of medicine, huge sums of money are invested by government and the pharmaceutical industry in searching for new and more effective medicines. These levels of investment are not found in mental health.

Our report, based on the real-life experiences of people taking these medicines, highlights the need for three points of action – first, a recognition that side-effects are very important, their impacts are significant to individuals; secondly more choice over medicines and appropriate information sharing; thirdly more investment in the search for a third-generation of medicines that are more effective in controlling symptoms and have even fewer and less severe side effects. We draw these conclusions from looking at case studies from our National Advice Service, reviewing information collected in Rethink surveys and examining the experiences of people who took part in several focus groups to specifically address living with the side effects of medications.

Paul Corry

Director of Public Affairs, Rethink

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Case studies

A young woman was admitted to her local psychiatric ward under section 3 of the Mental Health Act. She was six months pregnant and suffering from a severe urinary infection. No treatment was provided for the infection and her request to be transferred to a mother and baby unit was refused by the psychiatrist. Eventually, her gynaecologist agreed to make the referral. The new unit treated both her physical and mental symptoms successfully, but only after weeks of unnecessary suffering.

A young man on heavy depot medication, complained to his GP about palpitations and heart arrhythmia. The GP attributed his symptoms to anxiety associated with schizophrenia and did not feel it was necessary to arrange for an ECG or any other checks on his heart function. Shortly afterwards, the young man was found dead in bed at the hostel where he lived.

A professional woman with a diagnosis of schizophrenia approached her GP for advice about the weight she had gained after changing to a new antipsychotic treatment. She was informed that, at her age, her appearance was of little consequence and that no doubt she would not be looking for a partner.

Case studies based on calls made to Rethink's National Advice Service

Rethink surveys

All medications have side effects. We hear everyday through our frontline services from people with mental health problems and carers about the consequences of these side effects; views supported by a number of research surveys carried out to better understand the role of medication, and other treatments and support, in helping people with severe mental illness recovery a better quality of life. What we hear over and over again is that people with severe mental illness want medication that works well but with fewer side effects.

In 2001 Rethink, along with partner organisations Mind and MDF (The Bipolar Association), conducted a survey on service user and carer views on medication and other treatments for mental illness. In total 2,663 replies were received, 2,222 from service users. From this data set several reports were published and evidence was provided to the National Institute for Clinical Excellence (NICE) as it developed guidelines of the treatment of schizophrenia. One of the areas explored in the survey with service users was the side effects of medication. We found that:

- The most disturbing side effects were: sedation and lethargy 22%; weight gain 19%; shaking and tremors 6%; sexual dysfunction 3%.
- Ninety-two per cent of service users reported at least one side effect from a list of seven common effects (muscle shaking/tremor; muscle spasms; sexual dysfunction; loss of energy; effects on eyes; weight gain and inner restlessness).
- 1 in 4 people did not talk to their doctor (psychiatrist) about their medication and 54% of people did not receive any written information about side effects.

In 2003, Rethink carried out another large survey of service user and carer views. Again, questions on medication were included. We received 3005 responses from service users and found that:

- Considering the positive and negative effects of medication, on balance 76% felt medication was helping, 17% were unsure and 7% did not feel the benefits.
- 53% felt always able to talk to the person describing their medication if they had any concerns or problems.
- However, when outlining their main priority for improving mental health services 34% said their first priority was medications with fewer side effects with 58% saying this was one of their top three priority areas.
- Describing the one change that would make the most difference to their quality of life the most frequently noted change was to remove the illness (11%), better personal relationships (10%), increased public understanding (8%) and improved medications (8%).

“Medication – it is vital that the medication available is tailored to the individual – it can be hell being on all different types of medication that doesn’t agree with you – the side effects can be awful.”

“Find jobs for us that we can do with the side effects of our medication catered for.”

“In the future as far as mental health services are concerned I would like to see more compassion from doctors and nurses. I would like to see more research into new medications with less side effects.”

Focus group study

We were recently asked by Bristol-Myers Squibb to run some focus groups to look in particular at how service users manage the sedating effects of anti-psychotic medications. We ran four focus groups in three different geographical locations through Rethink services. The groups were held with service users at different stages of their recovery journey.

The focus groups explored:

- The range of side effects experienced by service users – including in particular the sedating effects.
- The impact of side effects of medication.
- Information and communication received by professionals.

Who participated?

- In total 36 participants took part.
- All participants were currently using anti-psychotic medication to help manage their mental health problem: 61% were taking atypical medications; 19.5% were taking typical medication and 19.5% did not disclose what medication they were taking.
- A range of mental health problems were described including 9 people with schizophrenia, 6 with paranoid schizophrenia, 5 with psychosis, 4 with schizo-affective disorder, 3 bi-polar disorder.
- The focus groups consisted of a mix of participants in terms of gender (20 men, 16 women), ethnicity (72% White British, 3% Asian/Asian British, 19% Black/Black British, 2% other) age (mean 42, range 21-66) and length of illness (mean 7, range 2-46).

What did we find?

1. Large numbers of side effects are experienced

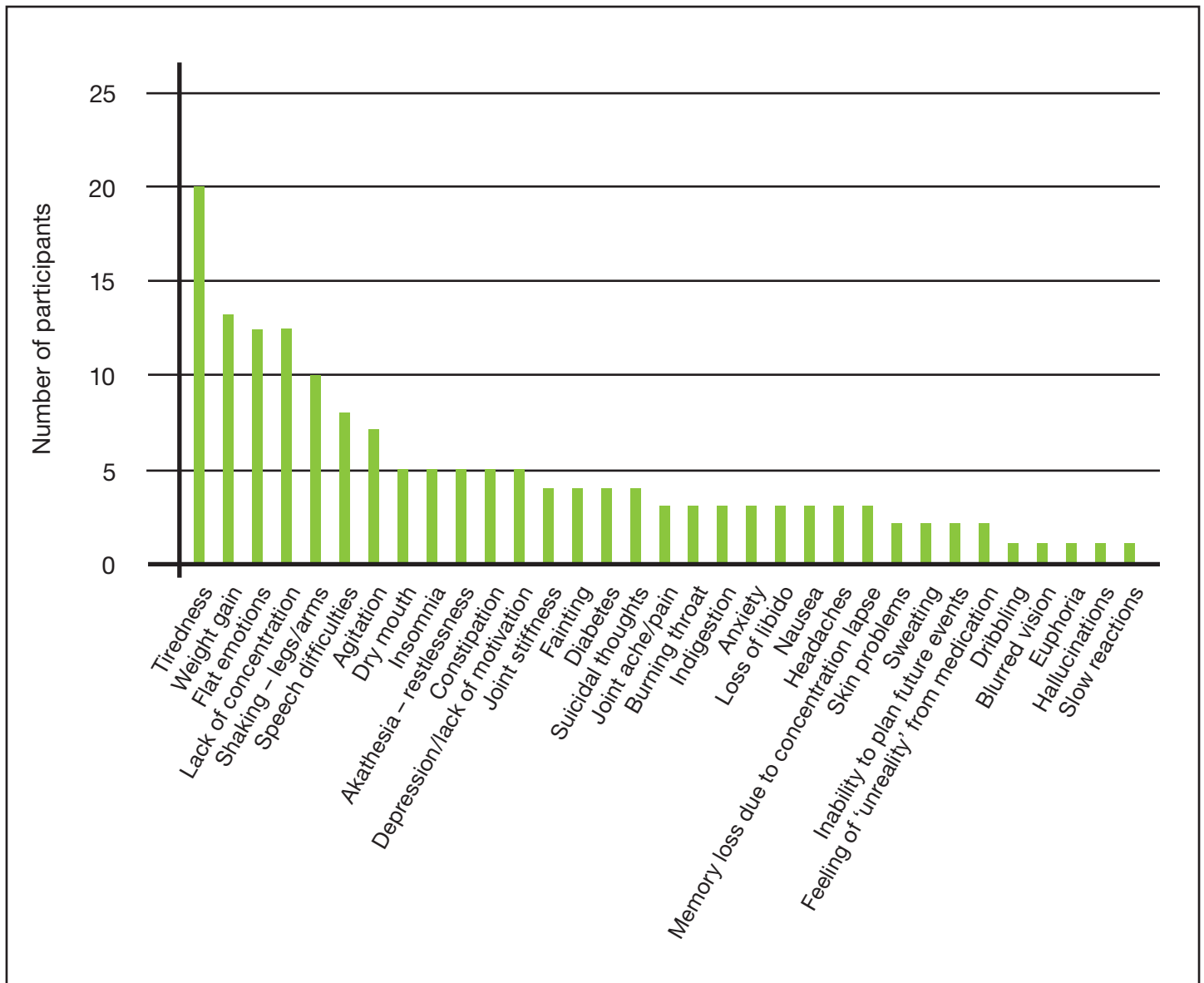
Figure one shows the range of side effects described by our small sample. In total 33 different side effects were described. For some side effects such as lack of concentration participants may have found it difficult to differentiate between the effects of their mental health problem and the side effects of their medication. However, for others such as weight gain the direct impact on quality of life from medication is clearer. The message that we heard from participants though is that taking medication for a mental health problems does lead to a number of painful, disturbing and difficult to manage 'side effect' consequences. The wide profile of side effects reported are summarised into four key clusters:

- sedating effects
- physical effects
- movement effects
- mood effects.

2. People with mental health problems are caught between 'a rock and a hard place'

We heard how people have to juggle managing the side effects of medication against finding medications that help with the active symptoms of mental illness. These are individual decisions with people finding their own ways to take control of decision making, or asking the doctor to advise what is best in their expert opinion. Finding the 'right' medication for you often takes time and a period of 'trial and error' which can be frustrating.

Figure one: Range of side effects reported by participants (N=36)



Sedating effects

- 63% of participants reported that tiredness was the most common sedating effect of their anti-psychotic medication.
- 38% of participants outlined how medication tended to dampen their emotions and the difficulties they experience in concentration.
- 25% reported difficulties in speech as a result of their medication.

“You can’t feel like normal people feel, you can’t feel your emotions properly. Yeah it dampens you and that’s not nice because you can’t feel happy and you can’t feel sad, you’re just like a zombie kind of thing.”

“I think that’s a case where the emotional sensors are cut out of our communication.”

“You slur your speech so you don’t feel comfortable talking to people.”

Physical effects

- 43% of people outlined weight gain as the most common physical side effect.
- 17% people reported having a dry mouth.
- 17% reported having constipation as a result of medication.

“One big problem is that people don’t take into account body weight. A 6 foot man gets the same medication dose as a young slim girl. I have seen young girls come into hospital slim and beautiful and go out with no confidence as they have put on an enormous amount of weight. I have seen this first hand.”

Movement effects

- 33% of people experienced shaking in the arms or legs whilst taking anti-psychotic medication.
- 17% reported akathisia (inner-restlessness).

“My hands keep going, sometimes I don’t notice it but then my hand goes like that and it takes me about one or two seconds to realise my hand is shaking.”

Mood effects

- 23% of people reported that they experienced agitation as a result of their medication.
- 17% reported that they experience depression and a lack of motivation as a side effect from their medication.
- 17% also reported that they had tried to commit suicide as a result of their experiences of the side effects of their medication.

“The side effects of the medication made me think I had gone to hell and that I was dead. I threw myself out of the window in the hospital and went to all the places I knew people had committed suicide in that hospital, I just laid down trying to die. I thought I was dead, that was what this medication did to me.”

3. Medication severely impacts on people’s quality of life

Side effects from medication can have a significant impact on a person’s quality of life and ability to participate fully in society. They can stop people doing the everyday ordinary things that make a difference to how you feel and what you do such as developing new skills, making new friends, looking after yourself and other. For example one young woman spoke about how she had lost the enthusiasm for life as a result she tended to sleep all day. The focus groups found:

- 33% of service users explained how a lack of concentration/ tiredness from their medication impacted upon their ability to do daily activities.
- 25% of participants explained that they had lost the motivation to do things as a result of the side effects of their medication.
- A quarter of service users also talked about the stigma of looking or sounding odd whilst on medication due to speech and movement difficulties.

Challenging stigma and discrimination associated with mental health issues is a major priority for everyone working in mental health. In this context, it is important to consider how to tackle the contribution that medications play in people’s experiences of social exclusion.

“When you lack concentration it stops you from doing things, simple tasks like reading, in the end you just get into depression and then the next moment you end up on anti-depressants because of the effect of the psychotic drugs.”

“What I’ve found is I’ve completely lost the enthusiasm to do things so it’s affecting my everyday life.”

“It affects your relationships as well as how you are with people.”

“I’d go home instead of painting like I do every day, I’d just lay on the settee or on the bed and crash out.”

“The anxiety that was brought on by the medication made me feel suicidal and that every day seemed to be, how can I put it, hard to see through.”

“It’s interesting that some people don’t understand that some of the physical characteristics that people display are actually the side effects of medication, so your leg goes and you look more like a mental case don’t you.”

“You look ill because of the medication so people become fearful of you and start avoiding you.”

4. There were mixed experiences regarding choice of medication and access to information

Over and again we hear that people are given no choice and little, if any, information about the medication they are prescribed. The twin foundations of best practice identified by the NICE that all medical practitioners should be following are: (1) where appropriate, to offer people the new “atypical” medications which have been associated with fewer and less severe side effects; and (2) a choice of medications that balance the relief of distressing symptoms with an acceptable range of side effects. However, we found a mixed message over the amount of choice provided and the level of information service users would actually like to receive:

- 45% believed that they did not have any choice in the type of medications they were prescribed, other people did not comment.
- 33% of service users had not been given any information on the side effects of their anti-psychotic medication.

- 30% had tried to speak to their doctor about medication and found that they ‘did not want to hear’.
- In contrast, 12% of service users outlined that they did not want to hear about the side effects of medication as this would cause them further anxiety and apprehension.

“You can suggest that you want to change your medication but at the end of the day it’s their decision.”

“I told the consultant about the side effects and she said oh you have to put up with that.”

“I went to the consultant and I said I don’t want to be on this type of medication any more. He said I don’t see what your problem is, even little children have injections. I said it’s not the injections that are bothering me, the side effects are worse than the illness itself.”

“When you’re angry because of the medications and side effects they say it is your illness.”

It was clear that some people want to have information, and talk openly to their doctor about side effects. On the other hand there are also people who prefer to let their doctor decide which type of anti-psychotic medication is best and they do not want to hear about adverse effects. Some people felt that hearing about the side effects could make them feel more anxious and for some it was a case of ‘doctor knows best’. There was a clear distinction in our sample between people who respected their doctor and those who felt they were ‘fighting the system’ – including powerful psychiatrists who do not listen to their concerns. For this group of service users the message is clear: doctors need to be sensitive to how side effects are described and information sharing is managed taking into account individual needs and preferences.

The Way Forward

“The side effects are worse than the illness itself.”

“I’m very much for more effective drugs that can have less significant side effects.”

The introduction of new anti-psychotics brought along the promise of treating a wider range of clinical symptoms with less disabling side effects, yet Rethink studies show that in 2006 we are still looking for ways to help service users deal with not only the symptoms of their illness, but also the side effects of the medication they are taking.

“First of all I was put on a very old drug and it just made me very, very thirsty, it gave me blurred vision, I couldn’t work properly with it, it gave me the shakes, I was tired the whole time but the newer drugs that I’m on now do actually work for me, but I still do get the lethargy and the tiredness.”

Our research has shown the devastating impacts of the sedating, physical, movement and mood side effects of anti-psychotic medication for people with severe mental illness. Service users want this addressed with better treatments being offered, and we do too.

Recommendations

- Medical professionals need to be alive to the devastating impact side effects can have on a person recovering from severe mental illness and be prepared to discuss openly options for reducing the impact of side effects and alternative medicines. Regular physical health checks for people with severe mental illness must be carried out followed by clear action planning to address any identified problems.
- There is strong evidence that NICE recommendations on making newer “atypical” anti-psychotics more readily available are being implemented for most people. However, many medical professionals are failing to offer the full range of medicines and failing to involve the people taking them in prescribing decisions. NICE recommendations on choice must be followed.
- The pharmaceutical industry has been slow to recognise that the side effects of their products have a major impact on people’s recovery. However, new programmes are now being developed and rolled out to help people recognise and tackle many side effects. The pharmaceutical industry needs to make a public commitment to increase investment in the search for a third generation of medicines that address the urgent need for medicines that are effective at reducing symptoms of severe mental illness without major side effects.
- It is important that service users continue to monitor and speak out about the impact of anti-psychotic medications on their health and well-being, ensuring that new treatments are accessible and responsive to their needs.

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Joining Rethink is easy

If you're affected by mental health problems and would like help, information or advice or if you share our vision of fairer, more enlightened mental health care fit for the 21st Century, we want you to join us.

Our 'Pay What You Can' membership scheme means you don't have to pay to join, but please make a donation if you can to cover costs. Apply online at www.rethink.org or call 0845 456 0455.

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Working together to help everyone
affected by severe mental illness
recover a better quality of life

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