

Section Three:

Making medication work for you... ?

This section provides an introduction to some of the issues associated with psychiatric medications, from the point of view of consumers. While many of us have experienced medications as being life-enhancing, or even life-saving, we think that the role of medication in our lives is an issue that consumers should have more information about and control over.

Some of us have had powerful, mind-altering medications forced upon us, imposed on our lives and bodies against our explicit wishes. This is an incredibly serious issue. The effects of some psych. drugs are horrific.

Even those of us who have a choice about whether we take medications or not often feel disempowered by the lack of information, being discouraged to do our own research, or feeling like we are just expected to consume whatever has been 'prescribed' for us, regardless of what we experience, or understand (or don't understand!)

The intention of this section is to support consumers to be able to make more informed decisions about the role medications play (or don't play) in our lives.



* Introduction to psychiatric medications – a consumer perspective

From the horse's mouth!

*Little boxes on the hillside, Little boxes made of ticky-tacky,
Little boxes, little boxes, Little boxes, all the same.
There's a green one and a pink one, and a blue one and a yellow one
And they're all made out of ticky-tacky
And they all look just the same.*

Little Boxes, a song written by Malvina Reynolds in 1962

There are many ways to find information about medications from a medical perspective. However, here we provide a mental health consumer perspective on psychiatric medications. This is information that you will not necessarily get in the promotional or instructional material produced by drug companies or from benevolent non-consumer organisations.

First, a word on terminology: 'Medical Drugs' or 'Medications'?

Some of us feel strongly that we should use the term 'drug' because of the significant effects these substances have on our lives. Others dislike the association with illicit drugs, and feel more comfortable with the term 'medication.' We use both terms to reflect this diversity.

What is 'compliance' and why do clinicians talk about it so much?

This term basically means we (the consumers) do what we're told, which may include taking medications as we are told to when we are told to. It tends to be seen by clinicians, 'the system', family, friends, and even ourselves sometimes as essential to our wellbeing.

However, 'compliance' is sometimes not so wonderful. For many people it involves a loss of self-determination, which can cause many long-term, iatrogenic problems including what's known as 'institutionalisation'. We become institutionalised as we lose confidence in our own decision-making and put too much faith in clinical interactions with their 'warped' power relationships.

When medication is forced on us:

Some of us prefer not to use language around 'compliance,' especially



because many consumers have no choice. In this situation compliance is seen by many as 'social control'. That is, for some people forced 'treatment' is no longer 'treatment' at all. We have no choice, no self-determination – none of the things that make us fully human. Involuntary 'treatment' or the threat of it is used to coerce many people into staying on medications whether they want to or not.

Can we have a good life without medication?

Each of us will face this question and we will make different decisions. It will depend on your own experiences, attitudes and feelings.



SIDE-EFFECTS?

Why would anyone stop taking psychiatric medications?

Many of us have done it! There is no shame in experimenting with a drug-free life. There are usually complex personal stories behind a decision to come off psychiatric medications. It might work for you or it might not.

One reason for choosing to try coming off drugs is the terrible effects of some medications, including getting really fat (see next section), dreadful muscle spasms, uncontrollable shaking and trembling, farting a lot, dribbling, smelling more than usual, mood problems, and more. These can be debilitating and it's no wonder we don't want them!

Should I feel guilty or stupid because I trust my psychiatrist and want to keep taking medication?

Is it OK to find the medications useful? Of course! We all want and should be allowed to be the decision-makers in our own lives. If your informed decision is that the medications are useful, then that is great. It is the experience of many people that medications have saved their lives and this has to be a good thing!

Some political and ethical issues associated with psychiatric medication

Some consumers believe the behaviour of large pharmaceutical companies to be questionable, especially in developing countries where people may use medical drugs that have proved to be undesirable (or even dangerous) to people in more affluent countries for various reasons. Many also believe that some companies may have too much influence on major policy decisions and research in the mental health field.

Where to find out more about medication

1. **Consumer perspective:** Many consumers recommend a website called Crazy Meds: <http://crazymeds.us/> because it uses easy to understand language.
2. **Medical perspective:** There are many sources of information on medications from a medical perspective including: the instructions that come with medications; pharmaceutical company websites; the website of the Mental Health and Drug Division of the Department of Human Services; SANE Australia's plain English Guide to Medication and Other Treatments; and MIMS (Monthly Index of Medical Specialties), Australia's resource for doctors. This last one is expensive (around \$200) and can be difficult to understand, but is the most comprehensive information source.



* **Fat is a pharmaceutical issue***

Don't blame me for the effects of your drugs

"I'll have a plate of Olanzapine, Clomipramine and Sodium Valpoarte with some fat on the side please."

Merinda Epstein, consumer, cartoonist and 2004 Human Rights Award winner

There are many unwanted effects of taking medical drugs. Sometimes these are compensated for by the helpful effects of the medication. Often they are not.

Here, the focus is on fat. This is not to neglect other horrible effects such as Tardive Dyskinesia, shaking uncontrollably, walking funny, getting depressed, slowing the body down, and many more – some minor and some extremely dangerous.

However, fat is in the news at the moment, the 'Obesity Epidemic' is attracting funding, but few people are talking about the links with psychiatric medications.

Fat can be fought by exercise, but ...

We know physical activity can help get rid of unwanted fat. Also, endorphins are found within our body's chemical structure and when they are produced through exercise they are a natural way to produce a feeling of 'contentment' for some or a way of feeling 'a bit better' for others. However, there are some practical realities:

- When we are really fat, most of us are hesitant to be seen exercising publicly;
- It is hard to explain to others the weight gaining effects of most psychiatric medications. Sometimes we haven't even told people about our diagnosis of 'mental illness';
- Exercising often works much better if you can do it in a group but many of us have lost our community to 'mental illness' and so there is no longer a natural community to which we belong;
- Going on 'exercise excursions' with Psychiatric Disability Rehabilitation and Support Services (PDRSS) can be excruciatingly embarrassing

*This is a play on the title of a famous text, *Fat is a Feminist Issue*, written by British psychotherapist Suzie Orbach and first published in 1978. It was updated and re-released in 2008.

for some of us (some have commented that it makes them feel like they are back at school). We are also very vulnerable to being publicly embarrassed, unfortunately even by well-meaning PDRSS staff.

- Gyms are prohibitively expensive for people on Disability Support Pensions (DSPs).

Other activities

Similar situations arise around other activities that might be useful for some overweight consumers. These include getting food from health food shops and eating lots of good quality vegetables, fruit and less junk food.

It is almost always assumed that the problem is with our ignorance so people try to 'train us' to eat better but the issue is often not that we don't know what we should be eating (most of us do know), the problem is often poverty. People with psychiatric disabilities often end up living in poverty.

Many of us are in and out of work because of episodic illness and some of us can't work at all because of what some people call our 'symptoms'. Of course this is not universal. People diagnosed with 'mental illness' can also get on very well in the world but there is also a group whose struggle is mighty.

It's hard not to feel infantilised and patronised during an education session on 'good food choices' given by some young, well dressed occupational therapist who wouldn't know poverty if s/he walked into it. Poverty can mean that we can't even contemplate the joy of buying birthday presents for our family; however, we can still get a little bit of pleasure from a bag of hot chips.

This is about culture and survival – not about being 'good' or 'bad'. Try not to add an extra layer of shame by beating yourself up about what you eat or how you look. Shame, we know, is particularly bad for our mental health.

Whose responsibility?

Sure, we can all take responsibility for the decisions we make in life but it is naïve and unfair to expect distressed and disempowered people to take on this responsibility that belongs largely (pardon the pun) to powerful corporate entities.

Pharmaceutical companies should be putting much more time and energy into making their products less harmful to the already fading personal images of beauty and dignity that accompany the portrayal of 'mental illness.' Self esteem is crucial to where we want to go next on our journey.



* Talking about medication – who’s in control?

Would you like some power with that pill?

Don't ask the doctor, ask the patient.

Yiddish proverb

As discussed earlier, taking medication can be an extremely helpful or profoundly disempowering experience (or, indeed, both).

Whatever our experiences, it can be helpful to feel as if we can take some control over our own interactions with medication, rather than being subjected to the wishes of others.

Here are five ways we can have more power when discussing medication with professionals.

1. Thinking differently about medication:

- **Medication is a tool.** Recovery is hard work and takes more than pills alone. There are many non-drug coping strategies that can be used with or without medication, including love, solitude, art, avoiding alcohol and street drugs, nature, prayer and work. Like any tool, medication should be something that you actively use, rather than passively 'take'.
- **Using medication is not a moral issue** and it is not a sign of weakness to use medications.
- **Learn about your medications.** It is easy to be intimidated by all the jargon that is used. Try to get more informed (use the Consumer Resources outlined on page 101).

2. Thinking differently about yourself:

- **Trust yourself.** You know more about yourself than your psychiatrist will ever know. If you are experiencing unwanted drug effects (such as a feeling of apathy, constipation, loss of sex drive or double vision) trust your perception. Check with the pharmacist or with friends and check books or trusted websites.
- **It's your recovery.** Too often people say that "the drug made me feel better". Don't give the drug all the credit! Even if it was helpful, don't overlook other things you have done to get well and stay well.

- **Your questions are important.** Anyone who has taken psychiatric drugs for some time is likely to have questions – don't be frightened to ask:
 - *Is it worth (still?) taking these medications?*
Have my needs changed over time?
 - *Am I addicted?*
 - *What is the "real me" like now?*
What would I be like if I didn't take these medications?
 - *Are there non-drug methods I can learn to reduce my symptoms instead of using medications?*
 - *Are there any long-term studies on the medication I use?*
Am I at risk? Do I want to take this risk?

3. Thinking differently about psychiatrists and other professionals:

- **Most psychiatrists are too busy for our own good.** Don't assume that your psychiatrist has full knowledge of your treatment history. It's good to keep your own records as well.
- **Psychiatrists are not experts on everything and sometimes psychiatrists are wrong.** It's good to get a second opinion when in doubt, and remember that psychiatrists are trained in *medical* matters. You might supplement medicine with other things that are important to you; for example, spirituality.

4. Being prepared before meeting with your clinician:

- **Set your agenda for the meeting,** rather than simply reacting to what s/he does or doesn't do. Organise your thoughts, concerns and questions, write them down, and bring them with you.
- **Be specific.** The more specific we can be in our communications, the more control we have.

5. Taking charge of the meeting with your clinician:

- **Record what you need to from the meeting.** You can bring a note pad and pen and take notes or tape-record the meeting (with permission, of course). Psychiatrists take notes, so why can't you? Tape-recording can be useful if you have trouble taking everything in during meetings.
- **Announce your agenda at the beginning of the meeting.** If you have prepared, then you know what you want to get out of the meeting.



Communicate this so the meeting addresses these issues.

- **Bring a friend or advocate, if you want to.** Many people bring a friend or support person when they see a dentist or have a physical exam. It makes sense to bring a friend to a meeting with a psychiatrist.

Acknowledgement: Most of this material has been adapted for Australia from an article by Patricia Deegan, *Reclaiming your power during medication appointments with your psychiatrist* (2008). The complete article is available at: www.power2u.org/articles/selfhelp/reclaim.html

