Medication and mental illness

Call for submissions

October 2014
# Table of contents

1. From the Commissioner........................................................................................................... 3
2. Why an issues paper? ............................................................................................................... 4
3. How to provide a submission.................................................................................................. 5
4. How will your submission be used? ....................................................................................... 6
5. Your submission ...................................................................................................................... 7
6. Introduction ............................................................................................................................. 8
7. Issues ..................................................................................................................................... 9
8. Next steps ............................................................................................................................... 12
1. From the Commissioner

The Mental Health Commission of NSW was established under the Mental Health Commission Act 2012. We are an independent statutory agency charged with driving change that benefits people with a lived experience of mental illness and their families and carers.

Medication use is part of the experience of mental illness for many people, particularly those with serious mental illness. The Commission would like to hear people’s experiences to better understand the issues faced. We can then evaluate to what extent the system is responding safely and sensitively to their needs.

I encourage people with a lived experience of mental illness and their families and carers, professionals and the community to assist us in building a knowledge base around this important issue. Your submissions will be used to influence change and work towards improvements for people at those times when life can be difficult and access to safe and effective treatment is needed most.

John Feneley
Commissioner
2. Why an issues paper?

This Issues Paper has been written to allow individuals and organisations an opportunity to provide their experience, opinion and expertise on the key challenges of using medication as a treatment for mental illness. This paper is concerned with those medications that may be prescribed for depression, anxiety, psychosis and to stabilise mood.

One paper cannot seek to capture all issues within this complex area. We expect that comments, feedback and experiences in response to the Issues Paper will extend beyond those listed.

There is academic discussion about the use of medication in the treatment of mental illness. This paper draws on this research, but is written to allow a broader audience to have a voice and to contribute to the discussions that shape decisions about medication and mental health.

We invite consumers, carers, professionals, and concerned members of the community to comment on the use of medication to treat mental illness.

Your submission will play an important role in building the Commission’s knowledge on this issue, assist us to advocate for change, and shape our activities in this area.
3. How to provide a submission

The Commission encourages all interested parties to put forward a submission to the issues raised in this paper, or other issues that are based on their own experiences.

The work of the Commission, and this Issues Paper, are underpinned by our guiding principle:

*We will be guided by the lived experience of people with a mental illness and their families and carers in all that we do.*

Submissions will be received between 1 November 2014 and 30 November 2014.

**Online submission form**

Submissions can be made directly through the Commission’s website at the link below:


**Phone line**

1800 831 133

The phone line will be open Monday – Friday, 9am and 5pm, between 3 and 14 November 2014. Calls to the phone line are free from a fixed land line.

The phone line is operated by the Mental Health Association NSW on behalf of the Mental Health Commission of NSW.

**Post**

Medication and mental illness submission
Mental Health Commission of NSW
Locked Bag 5013
Gladesville NSW 1675

**Email**

Submissions can be emailed for the attention of Carlton Quartly to mhc@mhc.nsw.gov.au

**Contacts**

For further information about the Medication and mental illness Issues Paper, or for assistance in providing a submission, please contact:

The Mental Health Commission of NSW on 02 9859 5200 or 1300 884 563.

Our office hours are 9.00 am to 5.00 pm, Monday to Friday.
4. How will your submission be used?

The Commission regularly supports people to share their experiences of mental health and recovery. We have found that stories help to inform and inspire people with a lived experience of mental illness, carers and services alike. People’s stories also help us know where change is needed and where we should focus our work for reform.

With this in mind, the Commission will use submissions to the *Medication and mental illness* paper to better understand the issues on this important matter and may publicly use excerpts from your submission in our work to reform mental health services. If we do quote from your submission all identifying information will be removed. Additionally if you provide your submission by telephone, notes of the conversation will be made to ensure we accurately capture the issues raised. The Commission may wish to publish your story on our website, enewsletter or social media. Before we publish your story we will contact you via email or phone for your written consent.

**Privacy Statement**

The information collected, including any personal details, will only be used for the purpose for which it was provided. We will not add your email address or name to any mailing list, or disclose the information to anyone else without your permission, except in accordance with the *Privacy and Personal Information Protection Act 1988*.

**Help and Support**

If you or a family member are experiencing distress please contact one of the following numbers:

- Lifeline on 13 11 14
- Suicide Call Back Service on 1300 659 467
- Mental Health Line on 1800 011 511 (24 hour service)

If you would like information about medicines you can talk to a professional on the following number:

**Medicines Line** 1300 633 424, Monday – Friday, 9am to 5pm. Calls triaged by Healthdirect Australia.
5. Your submission

We have prepared this Issues Paper to assist you in preparing your submission. Please do not feel that you must follow all the prompts suggested in the issues paper, or that you must respond to them all.

You may like to share your experiences on:

- the role that medication has played in your recovery
- problems you have had with taking medication
- the financial costs of medication
- receiving the right type of medication
- information provided to you about the medication you were prescribed.

You may like to share your views and opinions on:

- current challenges in using medication as a treatment for mental illness
- prescribing medication for a mental illness
- how to improve the treatment of mental illness using medication.

Your experiences, views and opinions could be about any of the medicine that may be prescribed for depression, anxiety, psychosis and to stabilise mood. Examples of these medicines can be found on the NPS MedicineWise website here [www.nps.org.au/medicines/brain-and-nervous-system](http://www.nps.org.au/medicines/brain-and-nervous-system).

The Commission has a mandate to reform the mental health system in NSW, and for this reason we are largely concerned with understanding the issues, challenges and opportunities within the state of NSW. The Commission recognises that submissions from elsewhere may highlight important systemic issues. However our reform agenda is first and foremost for the community and people of NSW.
6. Introduction

The views and experiences of medicines as a treatment for mental illness are varied.

Some people who experience mental illness are able to live well without the use of prescription medicines at all. For others medication will be a short-term solution for an immediate mental health crisis, while others will find medication is part of ongoing, or long-term recovery. Some people will combine medication with other supports such as counselling, psychotherapy, or mindfulness, and some will find that medication alone enables an active and productive life.

Irrespective of how and when it is used, medication can have unwanted consequences, including side-effects, and its use should always be thought through very seriously, weighing the potential benefits with the possible negative consequences that might result. People who experience mental illness have a right to have information and explanation on benefits and harms to enable them to choose whether or not to take medication, and to accept or reject medical advice in line with their own preferences.

It is also true that for some people there will be times when their choices are limited. This may happen to someone if they are under an involuntary order in hospital or if they have a Community Treatment Order which requires them to accept medication. Whenever the use of medication is involuntary it must adhere to the principles of care and treatment within the NSW Mental Health Act and it must comply with the requirements of the Act to never be excessive or inappropriate.

For all people – consumers, families and carers, professionals – the choices, information and practices that surround medication and mental health are complex, and sometimes polarising. What everyone can agree on is the importance of the issue and the urgency to get it right.
7. Issues

Cost of health care

People with a mental illness face high costs of health care due to a greater need to seek care, the cost of specialists, and the additional costs of medication. The high cost of medicine can prevent some people from filling prescriptions, so they might split tablets in half, or only take medication every second day to save money. Taking partial doses and delaying starting medication can be harmful to people’s health. It is also important to acknowledge the integral role that carers can play in the lives of people with a mental illness, with many performing the role of purchaser or financer of medication.

Medicines information

Professionals have a duty to provide information so that consumers can use medication correctly and safely. Information assists consumers and carers to make informed choices, and to take a lead or more active role in their recovery. Information about medication needs to be in plain English, it must be factual and current, and it should be comprehensive but not technical. Many consumers and carers speak languages other than English and may have difficulty understanding complex medical information if it is not available in the language they most often speak at home. People also need ready access to their own medication records. These records make it easier to remember important information like past and current medication and the exact brand names and doses.

Communication between professionals

People may have more than one professional writing prescriptions for their medication, for example, a psychiatrist and a GP. People may also move from one care setting to another, for example, from hospital to the community. These situations require clear and timely communication that should be informed by the individual circumstance and preferences of the person and include a full record of medication currently taken as well as medication taken in the past. This information is important because doctors use it to make decisions and identify side effects. When information is incomplete, with strengths, doses or the names of medication missing, people can experience harm to their health.

General practice

General practitioners have an important role in helping and supporting people living with mental illness. Many general practices are busy places where appointments with doctors tend to be short. Some people may choose to see different doctors on each visit. This can mean that GPs may not always have the full picture and can be unaware of what other people are prescribing. All these factors can make it difficult for GPs and consumers to develop the trusting relationship needed to deliver really good mental health care. The result is a primary health care system that can lend itself more easily to the prescription of medication, rather than providing GPs and consumers the time needed to understand the reasons not just the symptoms of mental illness.
Pharmacy

Pharmacists may see people with a mental illness more regularly than any other health professional. This contact means the pharmacist can play an important role in promoting the safe use of medication, detecting and managing side effects, and suggesting other supports. The reality can be that pharmacists, particularly community pharmacists, are disconnected from the prescriber and are viewed as a dispenser of medication, rather than a member of the health care team. The physical settings of pharmacies can also make realising the pharmacists’ potential a challenge. Community pharmacies are often open public spaces with little to no privacy and this can be off putting for people wanting to discuss their mental health.

Following advice about medicines

For a variety of reasons, people with a mental illness may either choose not to take their medication, or they may find it difficult to take their medication. Reasons might include weight gain, stigma, or difficulties remembering how and when the medicine should be taken. The side effects of medicines for mental illness can be mild or they can sometimes prevent a person from fulfilling their daily responsibilities, for example, slurred speech and drowsiness can make being an active and attentive parent difficult. People will sometimes make choices between fulfilling responsibilities and taking their medication. Deciding to stop taking medicine, taking it at the wrong times, or not taking it at all could be the right decision, or it could cause health complications, some of which are very serious.

Multiple medications

Many people living with a mental illness take more than one type of medication. A medication regime that involves different types of medicines, to be taken at different times of the day and in varying doses, means that mistakes are more likely. Taking more than one medicine can also increase the chance of a ‘drug-to-drug interaction’ - when one type of medication causes another to be less effective or even potentially harmful. People might be taking a medication for a mental illness, experience side effects, and then be prescribed another to deal with the side effects. Collecting multiple medications can also be difficult, as the scripts are not always due at the same time, and often patients are not allowed to stockpile. This can mean regular trips to the pharmacy.

Drugs and alcohol

Some people live with both mental illness and problems with the use of recreational drugs and alcohol. People turn to drugs and alcohol for a variety of reasons, to help them relax, to deal with stress, or to help them cope with trauma. Living with a mental illness can be much more challenging for people who use drugs and alcohol. They may find sticking to medication regimes difficult, and might miss regular appointments with professionals to review medicines. Drugs and alcohol, when taken with prescription medication, can contribute to side effects, interfere with the intended result, or even heighten the effect of medicines. For example, alcohol can intensify the sedative effects of certain anti-depressants or increase risk of liver problems with some medicines.
Cultural diversity

We are all unique and so is our response and attitudes to medication. However the medicines used to treat mental illness, and their safety trials, have mainly been developed in North America and Europe. Genetic variation, like the way our bodies metabolise or breakdown medicines, can influence the effectiveness of some medicines. Cultural differences, like our beliefs about the use of medication, can influence the way we use medicines. This means that doctors who prescribe medicines need to be aware of a person’s geographic ancestry and culture and consider these when working out the medication and dose most likely to be beneficial and least likely to cause harm, and the medication regimen most suitable for the person.

Access to medication

People in rural and remote areas can find that local pharmacies stock only a limited range of medicines used to treat mental illness. Certain medicines may take several days to arrive and this can lead to delays in starting a course of treatment as well as the increased travel costs of a return visit to the pharmacy. Delays in consumers receiving their medication can also happen if advice given by the GP and pharmacist are different. This could result in another visit to the GP. Some people may feel uncomfortable visiting the pharmacy in a small community because of confidentiality issues. People in all areas of NSW can find that out-of-hours pharmacies are rare or non-existent, which may have consequences for continuity. Stigma and discrimination can also prevent access to medication, where people do not fill prescriptions because of the negative attitudes and stereotyping they can experience.

Older people

Older people living with a mental illness often take medication for a range of age-related health problems at the same time as medication for mental illness. Multiple medications and complicated regimes can result in confusion about what to take and when to take it. The changes to the body naturally associated with ageing can increase the risk of medication causing harm. Medication may have a more prolonged effect on the body than in a younger person, so older people may need lower doses. There is also a growing concern that antipsychotic medications are over-prescribed for older people, and used not just to treat mental illness, but sometimes as a means of behaviour control.

Children and young people

The diagnosis of mental illness in children and young people can be challenging because behaviours like shyness, anxiety, and temper can be developmental stages and part of normal growing up. Guidelines recommend that medication should only be prescribed when psychosocial options like structured parenting programs or cognitive behavioural therapy have first been explored and exhausted. However the number of children being treated with medication for mental illness is rising. These medications have generally not been trialled in children, and the long-term impacts on the developing brain are mostly unknown. The doctors of young people aged 14 and 15 can find it challenging to know when young people are able to make their own choices about medication and when their parent or guardian is best placed to make decisions about their treatment.
8. Next steps

This paper and the call for submissions is a way for the Commission to create an awareness of the issues amongst the consumers, carers, families, the professional community and the public around medication and mental illness, and to encourage an exchange of information and analysis. It aims to provoke discussion about the role that medicines can or should play in supporting people living with a mental illness to be healthy and well.

Your submission will play an important role in building the Commission’s knowledge on this issue and shape our activities in this area.