Medication and Mental Illness

A Carer’s Perspective

**Mental Health Carers ARAFMI NSW Inc. (ARAFMI NSW)** is the peak body for mental health carers in NSW. It provides support, education and advocacy for the carers, family and friends of those experiencing mental illness across NSW.

ARAFMI NSW regularly consults with carers across NSW to gain information on their opinions and experiences with the mental health system. ARAFMI NSW also operates a Help Line that provides advice and referrals for carers. Feedback from carers are used to influence changes in policy, legislation and service provision, with the aim of making a positive difference to the mental health system for carers.

**Consultation with Carers on Medication Issues**

In response to the Medication and Mental Illness Issues Paper we consulted mental health carers through various means, such as social media and paper and online surveys. We specifically ran a ‘Topic Tuesday’ in our online forum for carers, (operated in partnership with Sane Australia), where a conversation was initiated with a few prompts from the issues paper (and advice that the issues raised would be included in a discussion paper); and a link to an electronic survey that was formulated with eight open ended questions was also provided.

Both these answers and the conversations in the Forum were de-identified and analysed by a Policy Analyst. Consideration was also given to points raised in our everyday contact with carers. We aim to present a brief overview of carers’ concerns and experiences using some of the suggested prompts.

**Overview**

It is clear that carers have had diverse experiences in the treatment of their loved ones with medication. We were pleased to hear some positive stories from carers about medication being used to support recovery in a meaningful way. Unfortunately, it was also clear that barriers remain to the access of appropriate, timely, and effective treatment including the use of medication.

- **the role that medication has played in your loved one’s recovery**

  Carers recognise the importance of medication but lament the lack of other available services. One carer simply stated

  ‘*We need psychosocial support AS WELL AS medication for our loved ones, they work in tandem.*’
This carer found that including psychosocial supports as part of treatment enabled a dose reduction of medication, and thus a reduction in side effects for the consumer.

Such experiences reflect findings that psychological therapies, such as Cognitive Behavioural Therapy, can improve compliance with medication.¹

**Recommendation:**

*Make such therapies available to all mental health consumers who require hospitalisation whether voluntary or involuntary. This could be achieved by providing more clinical psychologists in hospitals.*

- **the financial cost of medication**

  Many consumers are on several medications as well as attending regular doctor/psychologist/psychiatrist appointments. Even with a health care card the costs can be prohibitive—some carers have to contribute or pay for these treatments as their loved one’s income is not sufficient. Carers also have concerns about the cost of medication causing problems with compliance.

  Although many carers have heard of ‘safety nets’ or carer’s payments, some are unaware of what actual benefits are available and how to access and claim them, e.g. the Medicare Safety Net and the Pharmaceutical Benefit Scheme Safety Net.

  A number of prescribed medications are only available with a private prescription as they are not listed on the Pharmaceutical Benefits Scheme, making some effective treatments unavailable to consumers. Examples included Zyban, Brintellix, and Valdoxan for depression, and lamotrigine for bipolar disorder. Carers are often unable to afford these medications, and this has particular impact on those caring for consumers with treatment resistant illnesses.

  One carer stated:

  > *She is prescribed two [Valdoxan] tablets per day but is unable to afford the cost and is consequently only taking one per day! Her only income is the Disability Pension. My husband and I are both on the Aged Pension (we are 80 years old) and are unable to be of much financial aid to her.*

  Although recognising cost benefit analyses are necessary, the profit driven applications process for PBS listing ensures that medication directed towards a small population or that is off-patent is unlikely to ever be listed. There is a growing body of research into the biological factors involved in mental illness, and medications have been developed that act on serotonergic, noradrenergic, dopaminergic, cholinergic, melatonergic, and glutamatergic pathways.² Despite this ‘no new antidepressant has been listed on the PBS in more than five years, with six PBS submissions rejected in the last four years.’³

  It is unreasonable to expect a pharmaceutical company to apply for a PBS listing when a medication is no longer under patent protection, or to fund a study into the use of a medication in a small population of consumers that can never be profitable.
The inadequate provision of mental health care and treatment is wasteful. Mental health care is focused on crisis management as it has insufficient funds for early intervention and treatment. Where medications are available that are beneficial to the consumer, reduce the need for hospitalisation or intensive treatment, it is a false economy to fail to provide them.

The phasing out of the net medical expenses tax offset has also had a financial impact for carers.

**Recommendations:**

An independent process that is funded by government looks at cost effective medication solutions for consumers and carers free from considerations of maximising profits for the medication manufacturers, including the subsidisation of some non-PBS listed medicines that are more effective if less profitable.

- **Receiving the right type of medication for your loved one**
  Many carers felt that health professionals should make greater efforts to develop a rapport with their loved one, and to spend more time with consumers to properly assess them and go over symptoms. There was a feeling that too much prescribing was based on a ‘one size fits all’ process, and that a more considered and personalised approach is clinically and ethically required.

Questions as to the suitability of General Practitioners being the initiator and or sole prescriber for their loved one were raised. Are GPs experienced and educated enough in psychopharmacotherapy to perform this role?

Comments made by some carers referred to prescribing practices as treating their loved ones as ‘guinea pigs’. Whilst it is appreciated that some trial and error is required to find the most effective treatment for their loved one, carers also had experienced instances of clinicians unilaterally changing medication, when their loved one was stable, without prior discussion and for no apparent reason.

This sometimes had disastrous consequences. For example, one man who had lived in the community on medication for years was encouraged to stop by a support worker and was next heard from by his family a few weeks later from a prison in another state.

Another barrier to receiving the right type of medication was the difficulty in accessing appropriate services. Carers could often only access a properly monitored initiation of effective medication after reaching crisis point and hospitalisation. Carers also had experiences of “set it and forget it” prescribing- their loved one may have improved somewhat but there may be more effective medications to assist in the consumer’s recovery, as one carer put it:

*Doctors don't care too much for finding out the best medication as long as the consumer is not showing psychosis.*
**Recommendations:**

A second opinion on medication regimes should be routinely sought, either by a psychiatrist or preferably from a pharmacist, who are generally much better at managing medication issues than psychiatrists or other doctors. Only GPs who have received additional training in psychopharmacotherapy should be allowed to prescribe potentially dangerous psychiatric medication, and a review by pharmacists should be made available to their client’s subsequently. Further education for all GPs regarding medication should be provided.

Routine periodic reviews of medication should be incorporated into all mental health treatment plans.

- **Information provided to you about the medication your loved one was prescribed**

  There were varying reports from carers.

  Some of the common problems were carers being unaware of how long it would take medication to work, what to expect when it was working, and what each medication was for. Carers wanted to know about food, drug, and alcohol interactions, what ongoing physical health tests should be performed, and how to help reduce or treat side effects—especially recommended diet/exercise/lifestyle changes so they could better support their loved one with care and explanations.

  Where some carers reported receiving little information and having to research for themselves, others found pharmacists, GPs, and psychiatrists helpful. Some carers felt overloaded with information at the start of treatment or hospitalisation of their loved one and found it difficult to comprehend and take in so much at such a stressful time. Improved discharge planning and education, and provision of information when the situation had calmed down were suggested.

  **Recommendation:**

  Consider implementing the Pharmaceutical Society of Australia’s suggestion to embed pharmacists in Community Health Teams, and make them available to support the consumer, carer, and treating team with up to date advice.  

- **How to improve the treatment of mental illness using medication**

  Practical considerations of medication management were voiced, such as difficulties in timing and dosage of medication.

  There was a call for increased research to determine long term effects of medication, the effects of medication on young people, and to develop new drugs with fewer side effects and greater efficacy.

  A number of carers believed that medication did not work or that the side effects were worse than any positive effect. Other carers were concerned about the demonisation of medication, and felt that some of the vocal opposition to medication was worrying and misinformed.

  **Recommendations:**
Increased subsidisation of dose administration aids, eg. Webster Packs, for those with multiple medications.

Increase pragmatic research. Routinely collect information from community mental health teams, GP clinics, psychiatric hospitals, etc., regarding treatment with medication and match medication against (deidentified) results, adverse events and side effects to build the evidence to improve use of medication as part of the usual business of the Ministry of Health.

---


3 The Pharmaceutical Benefits Scheme, ‘VORTOXETINE, tablets, 5 mg, 10 mg, 15 mg and 20 mg, Brintellix®’ *Public Summary Statement July 2014 PBAC Meeting*, Lundbeck Australia Pty Ltd.