

Response by Arafmi WA Caring for mental health carers Submissions to Senate Inquiry into the process of listing medicines on the PBS

Arafmi Mental Health Carers and Friends is the pre-eminent mental health carer organisation in Western Australia. We have been providing free a counselling, information and support services to family members and friends of people with a mental illness since 1976.

Arafmi WA have over 500 members in WA and Arafmi is an Australian wide agency supporting mental health carers. The treatment of mental illness is often complex and difficult and can take some time to find the right medication to have a response to the mental illness. For carers, this can mean a long time of stress trying to balance the impact of symptoms and behavioural changes on the consumer, on themselves and to other family members especially children. We feel strongly that any medication that is recommended by the PBAC should be made available to mental health clinicians to offer relief to those affected by the often torturous nature of mental illness.

Comments in response to terms of reference - (a) the deferral of listing medicines on the PBS that have been recommended by the Pharmaceutical Benefits Advisory Committee;

The drug Invega Sustenna (a form of Risperidone used for the treatment of schizophrenia) which has been approved by the PBAC and has been deferred on the PBS.

Arafmi recently heard from a psychiatrist from Graylands who presented his experience treating patients with the drug Invega to Arafmi staff members and carers. He trialed this drug with those patients who had sever forms of schizophrenia who had been in hospital for long periods. This pilot used Invega drug for those not responding to other forms of Risperidone and who lived in remote areas. During his discussions he described how Invega had a 4 week period between treatments, which needed less follow up time for clinicians, reducing their work load in remote areas, allowing for more time with patients but also did not require to be kept in a refrigerator. The 4 week gap also had a 5 day window allowing for an extension of up to 5 days before or after the 4 weeks when the medication could be repeated, resulting in patients staying well for longer. The psychiatrist found that some patients who had not been responding to other forms of risperidone responded to this drug Invega Sustenna. It is vital that any alternative forms of medication that has longer treatment gaps should be offered to consumers especially in remote areas where treatment is often difficult to maintain. Consumers often miss on medication due to the long distances that they need to travel to access treatment, this has financial implications on the consumer and often the family members who may need to travel with them. Having medication in 2 week periods can also mean that during those final days the medication begins to wear off and for some, consumers can begin to have symptoms of un-wellness. Any medication that is recommended by the PBAC should be made available to mental health clinicians. **(I have not used the psychiatrist name as I do not have permission, as I understand that any submissions may be called to give evidence)**

Comments in response to terms of reference (b) any consequences for patients of such deferrals

A 4 week gap would have a huge impact on the consumer and their families, saving them time and money to come to appointments.

For many families living in remote areas this form of medication would be more beneficial with longer periods between treatments, and consumers staying well for longer resulting in less financial, physical and emotional stress for carers and consumers.

Regards

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