

## ***Submission for the Review of Pharmaceutical Benefits Scheme anti dementia drugs to treat Alzheimer's disease***

Prepared by Vanessa Moroney, Clinical Nurse Consultant, Bendigo CDAMS in consultations with the Cognitive, Dementia and Memory Service Clinic (CDAMS), Bendigo Victoria. This submission does not include input from medical specialist team members.

CDAMS are “specialist multidisciplinary diagnostic, referral and educational services for people experiencing memory loss, or changes to their thinking and for those who care about them” There are 17 CDAMS services across the state. There are 10 Metropolitan services and 7 regional services.

Our role is to provide assessment and early diagnosis of dementia and other related memory problems. Patients have the opportunity to trial medications and to be referred on to appropriate support services from our clinics. Thus our services are central to the dementia support net in our communities.

Our review is as follows:

The Terms of Reference:

**a. Review recent Australian utilisation data on patient initiation and continuation rates to cholinesterase inhibitors and Memantine.**

- CDAMS Bendigo would require statistics on rates of utilisation data which could be accessed by patient records.
- Continuation rates would require a timelier follow up to ascertain data from Services outside CDAMS.
- For Bendigo CDAMS to acquire this data additional funded hours would be necessary and could be requested in terms of a pilot research project.

**b. Review whether the 2 point improvement in Mini Mental State Examination continues to be an adequate surrogate for measuring improvement in patients with dementia treated with these medicines; and are there other more reliable measures of patient relevant outcomes?**

- PBS guidelines allow for improvement in either ADAS Cog or MMSE however this proves restricting in the case whereby symptoms as per these tests remains stable however a functional or social improvement is noted by the person / significant others. CDAMS Bendigo would like to see less focus on test performance alone and to incorporate a more reliable measure as being stabilisation of symptoms rather than improvement and findings to be supported by a social and functional instrument scale. A comparative review of continuation rates in those whom are rated in terms of CIBIS performance could highlight the importance a more observation based testing tool.
- Measures are required for increased happiness, showing an interest in environment, increased insight, recognising family members and friends, being less confused, reduced agitation, increased independence even as mild as eating more or initiating tasks.
- MMSE is required to determine PBS access to AChEI's. It is inappropriate particularly using it on people with learning disabilities, a first language other than English, a lower than average level of education, and indeed a higher than average education and NESB.

**c. Investigate if there is more recent evidence on the safety and efficacy of these medicines that would inform the PBAC about their cost-effectiveness.**

- In order to address the above a review of available literature is required. Again this is a timely task and requires the use of measuring instruments to gauge pre-existing conditions, changes of these conditions, interventions to treat and or manage these conditions, as well as the onset of new conditions thought to be associated with cholinesterase / Memantine therapy. The anecdotal evidence of Bendigo CDAMS team members suggests the overall tolerance of these medications is generally positive but more so improvement / stabilisation of symptoms is commonly reported in other domains such as behaviour, functional, and social activities. Data collected by Bendigo CDAMS at review completed within 6 months of initialising therapy now measures domains of memory, function, and behaviour via a quality tool completed by a significant other. This tool evolved following visit to benchmark assessment and review processes with Ballarat CDAMS.
- Evidence supports reduction in Behavioural and Psychological Symptoms of Dementia in moderate to severe DAT particularly with Memantine and Reminyl.
- Additionally medication assists in the management of co morbidities and the reduction on caregiver burden.

**d. Review the current PBS restriction continuation rule and the likely effect it has on cost effective utilisation of these medicines.**

- The current restriction continuation rule is not reflective of symptom stabilisation but rather attempting for improvement in what is ultimately a degenerative disease. This current rule blocks access for those whom stabilise rather than improve. In turn increasing care needs sooner and minimising overall cost effectiveness on a stretched health care system and band of carers.