## Submission No. 014

(Dementia)

Date: 23/04/2012

Dementia has both an economic and a social impact on society and is the single biggest health issue facing Australia in the 21<sup>st</sup> century (Deloitte Access Economics 2011). Tasmania has one of the highest incidence rates of dementia in Australia due to its ageing population.

## Improve quality of life and assist people with dementia to remain independent for as long as possible

The Community Dementia Service, which is part of the Northern Area Health Service, has been operating in the Launceston area for the past 15 years. The Community Dementia Service consists of a team of health professionals who offer consultation, assessment, information and the provision of direct care to people with dementia living in the community. In addition, we provide education and support for the families and carers of our clients. The Community Dementia Service also operates a day respite centre for clients with dementia in Launceston and manages 7 Extended Aged Care at Home Dementia (EACHD) packages of care in the Meander Valley area.

The CDS operates from 7.30 am to 9.30 pm seven days a week (including public holidays) and our day centre operates Monday to Friday. Our philosophy of care is based on the principles of personalised care, valuing the worth of every person, maximising autonomy, independence and participation, providing an environment and experiences that are meaningful to our clients and recognising the importance of working in partnership with the client, family and friends.

Our service model is unique in Tasmania in regard to our team structure and case management model. Our service operates from a central office with all clients' case managed by a Registered Nurse. Our team includes Enrolled Nurses and Health Care Assistants; all who have specialised skills and knowledge in dementia care which enables our team to provide care to meet identified client needs. These skills are necessary when providing care to individuals with dementia who often lack insight into their condition. Our approach needs to be balanced between promoting choice and autonomy while providing needed support and services to enable people to be cared for in the community.

On average number the CDS provides care for 50-55 clients in the Launceston area and 7 clients in the Meander Valley area. Some of our clients live alone while others have a live-in carer. We have a strong focus on building partnerships with the client, family and friends to enable the best possible plan of care for our clients. The partnership with family and carers also facilitates the provision of support and education for carers. The education involves the balance between carers caring for themselves, as well as their loved one, and also planning future care for the client. Our aim is to provide support to enable individuals to remain at home, in the community, for as long as possible.

## Early Diagnosis / Helping people with dementia and their carers plan for their futures

Identified barriers to diagnosis in Tasmania include the small number of specialist diagnostic services, limited consultation time and the person's lack of insight into their cognitive impairment. There are recognised benefits of an early diagnosis of dementia including an opportunity to understand and adjust to the diagnosis of dementia, access to treatment options (medication and behavioural therapy and treatment of conditions that may cause dementia); enabling the person with dementia to be actively involved in decision-making and planning (Enduring Power of Attorney and Enduring Guardianship; Advanced Care Directives) and education and support of carers and family members. Research has suggested that involving community nurses in the diagnostic process may improve detection rates by overcoming some of these barriers (Paterson & Pond 2009).

Primary Health North (PHN) is committed to improving the pathways to an early diagnosis of dementia. PHN recently conducted a six month trial of a Dementia Assessment Tool (developed by Dr Jane Tolman, Director of Aged Care Services, Royal Hobart Hospital) to assist General Practitioners (GP's) in the assessment and diagnosis of dementia. The aim of the trial was to evaluate the effectiveness of the assessment document and determine the future use of this assessment tool by PHN.

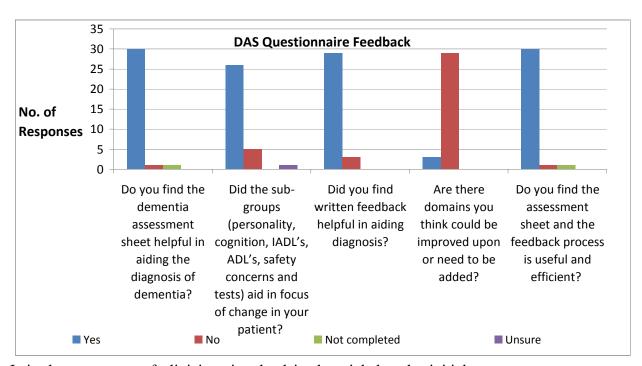
39 referrals were received during the 6 month trial period which was conducted from the 1<sup>st</sup> July 2012 to 31<sup>st</sup> December 2012. Referred clients were assessed in their own home by an experienced PHN clinician. The forming of a therapeutic relationship is intrinsic to a thorough and accurate assessment as individuals being assessed often lack insight into their conditions and carers are emotionally distressed. Clinicians need to adopt a flexible approach that will facilitate the completion of the assessment, be able to provide information and support to both the individual and carers and provide post-diagnosis information and support services.

The completed assessment material was forwarded to the client's GP. This included the completed Dementia Assessment Sheet; additional screening tools such as the Addenbrooke's Cognitive Examination (a cognitive test that assesses five cognitive domains – attention/orientation, memory, verbal fluency, language and visuospatial abilities) and the Geriatric Depression Scale (a validated tool used to identify depression in older people) if this was clinically indicated. A letter outlining information regarding the client's life history, progression of symptoms, collateral information gained from family members, GP's and other service providers and our recommendations was also sent to GP's.

This assessment can also prompt a discussion with GP's regarding an individual's decision making capacity, including those that have legal consequences (medical treatment, making a will, advance care directives and financial decisions). On completion of client assessments areas included in recommendations to GP's, when indicated, included the need for medication reviews, driving assessments, invoking of Enduring Powers of Attorney or appointment of a Power of Attorney, encouraging Advanced care Directives and the need for specialist assessments.

Dementia not only has an economic impact on the health care system but has a significant impact on the mental and physical health of both clients and their families. Post-diagnostic support was offered by PHN as the importance of providing information to enable individuals to make informed choices about their current and future needs is acknowledged. Follow up support by assessors ranged from a consultancy and short term case liaison role or a referral for case management of clients. Post-diagnostic support also promoted a feeling of independence and maintenance of control over their life for the person who had been recently diagnosed and their family members. This is important to all of us and no less so to an individual who has been diagnosed with dementia.

A Feedback Questionnaire was sent to GP's of clients referred during the trial to obtain their responses and opinions on the content of the assessment format, any identified areas of improvement and whether the dementia assessment sheet was helpful in aiding the diagnosis of dementia. The written feedback from GP's, and the consensus among clinicians involved in the Dementia Assessment Trial, is that there were positive outcomes for clients and their families regarding the assessment and subsequent diagnosis of dementia. Completed General Practitioner Dementia Assessment Feedback Questionnaires were received for 32 out of the 38 clients assessed resulting in an 84.2% return rate. The graph below indicates the positive responses from GP's regarding the assessment process in regard to aiding in the diagnosis of dementia.



It is the consensus of clinicians involved in the trial that the initial assessment to enable a diagnosis of dementia to be made needs to be completed by clinicians with specialised knowledge and skills in dementia care. It is important that clinicians conducting these assessments have an understanding of the principles of interview, history taking and the importance of clinical diagnosis and its implications for the person being tested. The level of training and experience of the involved clinicians, in the area of dementia care, is also important to ensure they have the skills, experience

and understanding to not only conduct the assessment but provide ongoing education and support to enable people to remain at home for as long as possible.

The partnership between PHN and GP's has also been strengthened during the trial period. It is envisaged, if this service continues, there will be an increased number of referrals in the future as more GP's become aware of the benefits of this assessment process. There was no funding provision for the Dementia Assessment Trial with clinicians involved conducting the assessments in addition to their normal role and responsibilities. The average length of time to complete the assessment and additional screening tools, gather collateral information, contact other service providers, family members and GP's and completion of the written report was a minimum of 3 hours. For clients living in rural areas there was also the additional travel time which needs to be taken into account. The provision of post-assessment support was a further commitment of clinician time. If PHN continues to offer this additional service provision the impact on clinician's case loads and capacity will need to be considered.

This assessment tool could improve the capacity of the primary health care system in providing an accurate and timely diagnosis. Assessment is needed not only to confirm a presumption of cognitive change or dementia but to consider differential diagnosis, allow reversal of underlying causal factors, delay the progress of dementia and determine the severity and extent of disability. It will also benefit people with dementia in our region by developing a clear pathway at a local level for referral of people with possible dementia and result in them being able to access appropriate ongoing treatment and support by confirming their diagnosis. It is questionable whether other Primary Health services have the capacity to fulfil this role due to both the specialised knowledge and skills required and the dedicated time required to complete the assessment. The provision of funding for a dedicated Dementia Assessor position would enable further growth and consolidation of this area of service provision. A Dementia Assessor would complement either the Aged Care Assessment Team or the Community Dementia Service.

The lack of access to Geriatricians in the Northern Tasmania area is another evident gap in service provision to dementia clients. Currently, clients are referred to the Launceston General Hospital for specialist consultation by a Geriatrician. Feedback from GP's, other service providers and family members is that obtaining an appointment can be a protracted process due to long waiting lists. This is a concern as timely intervention, in the form of specialist assessment to facilitate diagnosis and determination of treatment options, can have a significant impact on an individual's disease pathway. It would be beneficial to explore the possibility of funding a community based clinic in Launceston for assessment, review and treatment of identified clients. This would enable clients assessed in the community to be referred to a Geriatrician for confirmation of diagnosis and ongoing support.

There are significant savings in the future cost burden of dementia through the provision of an earlier diagnosis by facilitating access to medical treatments and community services (Access Economics 2003). Establishing the availability of a service which supports GP's in the diagnosis, assessment and ongoing management of dementia will provide a strategy for providing care and management for persons diagnosed with dementia clients and their carers. If individuals with dementia are identified in the community there is the potential to decrease the need for crisis

intervention (which may result in acute hospital admissions or earlier admissions to residential care facilities) by supporting individuals with dementia, and their carers, in a planned and effective manner.

Ultimately, aiding GP's in diagnosing dementia will not only improve organisational outcomes but also client outcomes. Individuals have a right to know about their own health and be provided with information that is likely to bring the best health outcomes. The advantages of an earlier diagnosis of dementia include an end to uncertainty for clients and carers, access to treatment options, the ability to plan and undertake care planning, access to practical and emotional support and the opportunity to develop positive coping strategies. A diagnosis of dementia has a life changing impact on individuals and their family members. The clinical effectiveness of this practice intervention is evident and will aid PHN, and ultimately the Northern Area Health Service (NAHS), in the provision of optimal future care for individuals with dementia and their families.

Thankyou for the opportunity to forward a submission regarding dementia early diagnosis and intervention.

Fiona Young Clinical Nurse Consultant Community Dementia Service C/- John L Grove Centre 33-39 Howick St Launceston TAS 7250

## **References**

Paterson N & Pond D (2009), 'Early diagnosis of dementia in primary care in Australia: a qualitative study into the barriers and enablers', Alzheimer's & Dementia July; 5 (4): Suppl: 185.

Access Economics 2003, 'The Dementia Epidemic: Economic Impact and Positive Solutions for Australia', Prepared for Alzheimer's Australia, Canberra.

Deloitte Access Economics 2011, 'Dementia Across Australia: 2011 -2050', Prepared for Alzheimer's Australia.