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Inquiry into Dementia: Early Diagnosis and Intervention

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Introduction

It is well recognised that with the continued growth in the ageing population in Australia, and increasing life expectancy, the numbers of people living with dementia, will increase exponentially into the future. This poses significant challenges in terms of meeting the economic, health and social costs associated with dementia into the future.

Dementia in Queensland

In 2011, an estimated 48,000 people were living with the disease in Queensland. By 2025 this is projected to grow to 215,000 people: more than a four fold increase.

While dementia is not a part of normal ageing it is a condition that primarily affects older people with the incidence effectively doubling every five years from the age of 65. In Australia around 1.5% of those aged 65-69 have a diagnosis of dementia; by age 80-84 the incidence increases to 13% (Access Economics, 2009).

The growth in the estimated number of people living with dementia in Queensland is primarily due to the ageing of the population. In 2011, 13% of the population was 65 years and older, by 2056 this is expected to double to 26.1%. This structural shift in the age profile of the population is more significant in the older age groups with the number of persons aged 80 years and older expected to increase from 3.5% of the population in 2011 to 10.6% in 2056.

Queensland is the most de-centralised state in Australia with over half of its population residing outside of the capital city. This de-centralisation creates significant challenges in providing equitable access to diagnostic and support services and early intervention programs. The availability of primary health care including diagnosis, and support services including respite for carers as well as access to specialists is increasingly important to managing dementia in a community setting.

In addition, Queensland also has a high proportion of people from an Aboriginal and Torres Strait Islander background many of whom live in either remote or very remote locations. While there are only a small number of studies that examine the prevalence of dementia in indigenous populations they do suggest significantly higher rates of dementia.

Queensland Health Dementia Initiatives

Queensland Health has developed the *Queensland Health Dementia Framework 2010-2014*, which is consistent with the *National Framework for Action on Dementia.* This framework provides strategic directions for the planning and delivery of services for people with dementia, their carers and families. The *Framework* includes strategies and actions that will deliver improved outcomes for people with dementia in all settings, irrespective of the primary focus of treatment.

Queensland Health has also delivered the following significant achievements in relation to dementia:

- The establishment of the Statewide Dementia Clinical Network. Clinicians now have a lead role in advising and recommending about policy, service planning, and improving the delivery of quality dementia services across Queensland.
- The use of telemedicine, online inpatient assessment and data transfer to take specialist dementia services into rural and remote areas of the state.
- Improved referral to and coordination of dementia services through community hospital interface service models.
- A more highly trained and skilled workforce, particularly within Queensland Health's community health services and its 20 residential aged care facilities.
- An increase in the number of memory clinics.
- Resources for Advance Care planning which are available on line.

Other initiatives which complement Queensland Health's achievements include:

- The *Queensland HACC Dementia Services Development Strategy 2007-2011* which has enhanced dementia specific care and support services for those people with dementia who choose to live in their own home.
- The Dementia Behaviour Management Advisory Service.
- The Queensland Dementia Training Study Centre
- An expansion in services offered by the non-government sector.

Diagnosis

Queensland Health supports accurate and timely diagnosis which leads to evidence based individualised treatment and support services that enhance the quality of life for the client and recognise the needs of their carer.

Making a diagnosis of dementia is somewhat challenging particularly in the early stages of the disease. The majority of cases of dementia begin insidiously with subtle changes to memory and other cognitive functions. This makes it difficult to differentiate between it and other more common reasons for cognitive impairment or decline. This is further complicated as a diagnosis is primarily reliant upon the patient's history and the exclusion of any other underlying pathology.

Even for experienced primary care physicians the process of making a diagnosis is challenging both clinically and pathologically, particularly as there is marked individual variation in symptom manifestation and progression of the disease (Illife and Drennen 2001) nor is there currently any definitive diagnostic tool.

The limitations of the current approaches have led to considerable effort to develop biological markers or a diagnostic test mainly for Alzheimer's Disease. However, these tests have a range of limitations in terms of acceptability (e.g. lumbar puncture for cerebrospinal fluid), inaccuracy (e.g. blood markers), accessibility (e.g. advanced forms of brain imaging) or interpretation and availability (e.g specialist workforce that can interpret the findings and provide clinical advice). Notwithstanding this there are some positive recent reports that a team of scientists at the University of Newcastle have may have identified an accurate, cost effective blood test that predicts the onset of Alzheimer's disease prior to onset of symptoms.

There are however risks with early diagnosis. As identified above, the absence of specific biological markers makes accurate diagnosis in the early stage of dementia complex and problematic. While the proportion of patients incorrectly diagnosed using the most common diagnostic instruments is low, less than 1% (Brodaty *et al*, 2006), this risk is amplified where

a patient is highly educated, does not speak English as their first language and /or has a sensory impairment (Milne, 2010). This supports the use and recognition of a variety of validated tools to support screening and diagnosis including the Mini Mental State Examination (MMSE), the Rowland Universal Dementia Assessment Scale (RUDAS) and the Kimberly Indigenous Cognitive Assessment Screen (KICAscreen).

The proposed expansion in the use of the validated screening tool (KICAscreen) for cognitive impairment (with full assessment using the KICA-Cog tool) will enable earlier diagnosis of dementia in the rural and remote Indigenous population in Queensland.

While the majority of people would prefer to know if they had dementia, there is some evidence to suggest that a significant minority, prior to diagnosis, would rather no or limited information. In the United States research found that among a sample group of primary care patients with positive screening results, approximately half refused further assessment for fear of losing their drivers licence, employment and health insurance as well as reduced quality of life (Milne, 2010). There are also issues such as anxiety and depression associated with diagnosis. Any increase in diagnosis capacity will need to be accompanied with relevant pre and post diagnostic support.

Given the predicted prevalence of the disease the vast majority of diagnoses will need to be made by general practitioners, and as such their practices are likely to be the first point of contact for information about relevant support services. As such enhanced training and support will need to be provided to the general practice workforce and practices to ensure that they are adequately skilled and supported.

Part of the diagnostic tool kit includes access to neuropsychological assessment. Currently there is no Medical Benefits Schedule item number for this activity with subsidisation limited to Department of Veteran Affairs clientele. There would be a benefit to the community if this was made more available and affordable for relevant cases and linked to telehealth to ensure more equitable access.

Early Intervention and Support Services

While the need for accurate and timely diagnosis is important, there is little benefit unless this is accompanied with appropriate support services for not only the person living with dementia, but also their carer/s and family. These support services include information, advice and support services such the National Dementia Helpline and the Dementia Behaviour Management Advisory Service (DBMAS). Primary health care services are a key link to in raising awareness of the availability of these services given that primary health care services are likely to be the first point of contact for those with a potential diagnosis and their carers.

Anecdotally, the Queensland DBMAS has been effective in assisting with the management of challenging behaviors and supporting carers in a range of settings. Challenging behaviors are a major contributor to families and carers deciding to transition people with dementia to residential aged care. Whilst intended to provide statewide coverage the physical location of the DBMAS service in the south eastern corner of the state has limited the availability and nature of support that can be provided. Expansion of the DBMAS including formal links with clinical support would enhance the assistance provided by this service.

A key benefit of an accurate and timely diagnosis of dementia is that it provides the opportunity for the person with dementia, their carers and families, to understand the disease and its progression. It also provides a timely reminder to ensure that appropriate

future arrangements can be put in place including the preparation of wills, Enduring Power of Attorney arrangements, Advance Health Directives (while the person with dementia still has capacity to make these plans) and future care arrangements.

Also important is access to contemporary information and training about dementia care and treatment options for clinicians and those working in the area. The Queensland Dementia Training Study Centre is important in this regard, in not only disseminating information to clinicians but also raising awareness of issues associated with dementia.

It is also important to enhance research into early interventions to strengthen the evidence base for care and treatment in terms of effectiveness as well as the social impacts of these approaches.

Community Awareness and communication on dementia and dementia-related services into the community

A number of countries have national dementia strategies. Australia, the United Kingdom, France, Netherlands and Norway all have national strategies that include public information strategies to increase awareness of dementia. These strategies also include the objective of providing comprehensive disease and care pathway information to individuals at the time of diagnosis.

A common theme of these national strategies is that broader population awareness is required to promote community awareness and acceptance of the disease. This is important in reducing the stigma that can be associated with a diagnosis of dementia, avoid the sense of social isolation and encourage self/carer management of the condition.

Community awareness of dementia could include messages such as:

- that dementia is not a normal part of ageing
- that a diagnosis does not automatically mean a person no longer has the capacity to make a range of personal decisions;
- previously expressed lifestyle and care preferences should be respected.

Given that the prevalence is likely to increase over a number of years, adopting whole-of-community approach to increasing awareness would be appropriate. In addition to mass media options, whole-of-community approaches could include:

- dementia education in primary and secondary schools
- enrolment and training of citizens in dementia literacy, and
- building networks between people living with dementia and or their carers

Many of the risk factors that are associated with an increased risk of dementia, like tobacco smoking, hypertension and diabetes, are part of existing health promotion and illness prevention campaigns. There is an opportunity to link health promotion messages such as eating a healthy diet, regular exercise, being socially engaged to reducing the risk of developing the condition.

There is also some evidence to suggest that 'what is good for your heart is good for your brain', and that there are a range of risk factors associated with developing dementia (including tobacco smoking, obesity, diabetes and hyperlipidemia at mid-life). There are also some psychosocial factors which appear to protect against the disease (higher education, a socially engaged lifestyle, mentally stimulating activity, regular physical

activity). All of these modifiable factors could be effectively used in educating the broader community about prevention of dementia, while also improving their general health and well being.

Conclusion:

Queensland Health supports timely, accurate diagnosis for people with dementia as an avenue to access appropriate support in the community that maximizes their quality of life. Early diagnosis and access to services enables individuals, their families and carers to access appropriate support services and make arrangements for the longer term, while also potentially allowing primary health care interventions to slow the onset of disease symptoms.

References:

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