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Submission to the House of Representatives Standing Committee on Health and Ageing Inquiry into Dementia: Early Diagnosis and Intervention – 2 May 2012

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Our background perspective:

Denise Chaston is a registered mental health nurse who has extensive experience and expertise in dementia practice. Denise has been a Clinical nurse specialist with prescribing authority in the UK and has conducted research into the needs of people with young onset dementia. Denise has also held academic posts in the UK and New Zealand.

Kylie Wood is currently the manager of the Aged Care Assessment Team and Community Options service in the NWAHS. She is a specialist grade occupational therapist with specific interests in rehabilitation, geriatrics, community development and research.

Whilst both employed within the Tasmanian Department of Health and Human Services (DHHS), we prepare and provide this submission as independent community members with a specific interest and expertise in the inquiry topic, and do not claim to represent the views of DHHS in this matter.

Introduction:

The North West of Tasmania is a rural and remote region which requires a different approach to dementia care than metropolitan areas, with complicating factors such as poor transport, social isolation and lesser health care supply (Innes et al, 2006). Dementia care resources in the area are limited and fragmented, particularly specialist medical input (ad hoc and of variable quality) and impacted by a high turnover of GPs in the area. This results in an inequitable service for those people with dementia living in this area. In Tasmania the majority of people with dementia live outside the capital city catchment (Access economics report, 2009). In the North West region these people are particularly geographically dispersed.

Much dementia support in the area is the result of goodwill of passionate individuals. It is a sad indictment that many health professionals and service providers in the North West state that they themselves would not like to age here with the current level and quality of service/support available. We recommend that a Nationally specified minimum service be available to all regions across Australia using innovative models of care and incorporating technology for remote access.

Whilst funding is an issue for specific dementia service provision, attitude and approaches can be implemented freely for the benefit of people with dementia and their carers. In our opinion, dementia care has been made too simplistic. The quality of training is poor and of variable evidence base. We Recommend a National training approach that is developed by leading experts in the field including people with dementia themselves and carer representation. This needs to have its delivery monitored. We are aware that much training is conducted based on out of date information by a range of qualified and less qualified or experienced trainers. The “TIME for dementia” program is supported by us as a high quality learning resource already widely available. Dementia education in undergraduate health professional training should also be a mandatory competency.

There already exist key notable reports and frameworks that address broadly the issue being investigated. These include the National Framework for action on dementia (2006-2010) which was found to be effective in its evaluation report at the end of 2010 and extended through 2011 before being ceased. In Tasmanian, the “Dementia services Pathway – an essential guide to effective service planning” (KPMG, 2010) and the work of the Aged care and Rehabilitation Clinical Network has repeated similar themes of the importance of early recognition, diagnosis, early intervention and care planning as well as health promotion approaches; additionally the role and opportunity for key allied health and nursing (who are already credited with upskilling GPs in dementia) to contribute more to prevention, awareness, diagnosis and care planning. It becomes a source of continual frustration and disappointment that multiple reports and recommendations are made with little implementation and sustainability; this affects both health care providers and more importantly people with dementia and their care supporters.

Comments on Terms of Reference:
We believe that many aspects of the information we have provided overlap the terms of reference points and ask that you consider our input across all four topic questions. This is the nature of the complex needs of people with dementia and an integrated care approach.

How early diagnosis and intervention can:

- **Improve quality of life and assist people with dementia to remain independent for as long as possible**
    - An early diagnosis of dementia provides an opportunity for a person to recognise their illness and go through an adjustment process like any other person diagnosed with a progressive incurable (but not untreatable) illness. This is also essential for the significant others in the person’s life as they are able to see the illness separate from the person and prepare themselves to continue to adjust their support roles.
    - People with dementia are able to maintain their function and participation in daily activities and the community with the appropriate level of skilled support. People are able to live independently in familiar environments. Early diagnosis and intervention can flag an early assessment, for example by ACAT, to access community based packages such as CACPs to provide support during the early stages of the disease to support independence as long as possible.
    - Consideration especially needs to be given to supporting people with an early diagnosis (or young onset dementia) to remain in their work roles for as long as possible as these people remain able to be productive with adequate sensitivity and support. For example, training a work colleague in dementia to be a buddy (Jubb, Pollard & Chaston, 2003), and also improving employers in dementia awareness and management in the work setting, perhaps similar to the beyond blue approaches to workplace mental health awareness. A focus on HR staff training to identify and manage performance issues that may be associated with young onset dementia. (Jubb et al, 2003). This will be more critical as the incidence of young onset

    dementia may increase with increasingly stressful lifestyles, alcoholism, better disease identification and the increasing specified age of retirement (currently 67 years).

  - Risk assessment and quality of life balance requires skilled assessment. One of the biggest barriers to giving people more control over their lives is an overly cautious approach to risk. 'Safety first' approaches are disempowering for people with dementia (Clarke *et al.*, 2009; Nuffield Council on Bioethics, 2009) and this approach can prevent people with dementia from doing things that most people take for granted. Skilled clinicians are required to enable the client directly or support their carers to facilitate self-determination as long as possible, particularly with regards to choices about accommodation and participation in a range of pre-morbid activities and interests.
  - A skilled workforce is critical to screen and diagnose dementia (Page et al, 2007). This includes access to specialist geriatricians/psychogeriatricians, dementia competent GPs, dementia nurse practitioners or clinical specialists, dementia skilled allied health, and day to day care and support staff who receive specialist dementia training and ongoing support.
  - Early diagnosis is also very important for the timely trials of pharmacological and therapy/lifestyle interventions that may slow the progression of the disease and thus sustain a higher level of functioning for as long as possible with potential delay of entry to residential (Clare, 2002; Keady et al, 2007). Medications known as cholinesterase inhibitors have shown that about 50-60% of people who take they demonstrate a slight improvement or a stabilisation of their condition over a 6 months period. (National Institute for Health and Clinical Excellence 2009).
  - In our opinion the uptake of these pharmacological advancements in dementia care may be underutilised due to the lack of overseeing specialists to guide and initiate treatment and the capacity for regular monitoring. Additionally, programs such as Active Cognitive Enhancement (ACE) may be beneficial. In the specific case of alcohol related dementia, cognitive decline may be reversed with supported alcohol withdrawal and sustained abstinence (up to 60% of people demonstrate improvement).

- **Increase opportunities for continued social engagement and community participation for people with dementia**
  - The People Relying On People (PROP) group is an example of a client driven initiative. It was set up in the UK as a constituted group of younger people with dementia for mutual support, to be active political lobbyists, and to provide education to health professionals and the public. This group produced a DVD and such a group model could be replicated in Australia. The PROP group also viewed themselves as Dementia ambassadors who went out to speak about their disease; *this recognised people with dementia as experts in their condition.*
  - Dementia cafes were an initiative from Holland first set up in 1997 in "response to the trauma, drama, and tragedy of dementia" (Miesen et al, 2004). This concept has been successful and adopted internationally as an informal situation for socialisation

    and mutual support and access to information. This is a key example of a program for community capacity building.
    - People with dementia having input into service planning and evaluation (not just for dementia specific services but all services that may have contact with people with dementia); this could be made a requirement for all Aged Care Programmes and HACC services, and guidelines/resources be available to assist this process. The voice of people with dementia is critical to quality service development.
    - Dementia being included in all disability groups e.g . same as being in a wheelchair.
    - Anti-discrimination approaches to improve social attitudes and reduce social stigmatisation and isolation could be incorporated into broader government policies and programs such as social inclusion agendas.
    - Alzheimer's association type cards for people with dementia to communicate their needs and how to engage with them; also cards for carers (attach a sample card).
    - Community development model to engage with community organisations and businesses to accommodate individuals or groups with dementia e.g. groups going out for lunch, retaining autonomy in financial transactions etc.
    - Support for communities to implement social Inclusion principles and practices that consider the needs of people with dementia as much as other physical, cognitive or psychological disabilities. Development of such projects may require short to medium term employment of community development officers, perhaps within the context of local councils, to work with people with dementia and their carers to identify and address barriers and establish sustainable practice.

- **Help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer term or more intensive care requirements**
    - Post diagnosis counselling for people with dementia is beneficial to enable the person to progress with their life and make choices about their future.
    - People who receive an early diagnosis are able to participate more fully in their future care planning with regards to formulating advanced care directives, appointing enduring POA and Guardians and communicating their future care wishes.
    - We also believe that early diagnosis and intervention , preparing a life history for care planning in later stages –tells their personal story when they are no longer able to (this results in better person centred care – seeing the person not the illness).
    - We have found that the exclusion of dementia from the umbrella of older person's mental health (MH) poses challenges for accessing input for differential diagnosis or co-morbidities. In the UK dementia falls within the MH realm of services and so assists with minimising service gaps. Dementia does not always fit best with aged care services. This severely impacts a multi-disciplinary approach to best dementia care.
    - There needs to be a single point of access for people with dementia to prevent duplication (and therefore resource wastage and poor system experiences for clients and carers), which offers a transparent and clear care pathway. The work of Bullock

    and Naidoo (2001) on an integrated care pathway for dementia based on best practice could be used as solid foundational work with updating.

    - Capacity determinations are difficult to obtain to enact any enduring arrangements in the North West or to support the seeking of Guardianship Board input etc. Guardianship board limitations on receiving health professional reports only from psychologist/doctor is inconsistent with Tasmanian legislation, and inhibits timely decision making – train up nursing allied health etc.
    - Clear national guidelines for the determination of capacity in accordance with best practice evidence should be as robust as the process for initiating mental health orders.
    - *Human rights must be protected and advocated for at every point in the dementia journey. This role should be fulfilled by every person involved in dementia care.*
    - Access to appropriate residential care facilities are problematic for people in North West Tasmania. Recently a 20 bed secure dementia unit was closed at a local facility and reopened as 10 dementia specific extra services (bonded) beds. This now limits accessibility for non-financial clients needing secure unit care to one end of the region – this may necessitate a person moving (and relatives and friends travelling) up to a further 50 km away in an area with very poor public transport options. Already people may have to move 100 plus Km from their original home for secure unit care. Additionally, people whose dementia behaviours are so challenging that local facilities are not able to cope have extremely limited access to specialised support where they are(e.g. through DBMAS)or specialist psychogeriatric evaluation and planning in a safe environment.

- **How best to deliver awareness and communication on dementia and dementia-related services into the community**
    - Focus on health promotion for prevention of dementia where possible for example, exercise, cognitive enhancement (ACE), and general lifestyle factors such as alcohol intake.
    - Awareness programs must also represent the needs of people with young onset dementia.
    - Programmes need to be more accessible by taking awareness campaigns out into the community for example, displays and consult screenings in shopping centres, at regional markets, large events such as shows, age relevant conferences etc.
    - Clear evidence based guidelines about signs and symptoms as a national resource would be useful for example, plain language fact sheets.
    - Innovative media programmes such as the Israeli Alzheimers awareness campaign (http://www.youtube.com/watch?feature=player_embedded&v=7kKAq6lHgeY#!) could be readily adapted in Australia. Communication of messages that prominent public figures may develop dementia and that people with dementia still have a life worth living for example, Pat Summit (US basketballer), Terry Pratchett (author in UK) – this has been demonstrated already with mental health awareness campaigns and public lobbying group campaigns such as http://agewellcampaign.com.au/ . The utilisation of modern social media as well as merchandise as promotion e.g. t shirts, wrist bands etc need to be considered in a broad communication strategy.

- Collaborative partnerships to facilitate a co-ordinated approach to people with dementia are essential between government and NGO/volunteer agencies. Where funded b y government the approach for all services should be consistent. E.g. DBMAS; speaking my language, HACC dementia nurse roles, Local Health organisation (NWAHS)etc.
- There needs to 'bottom up' mechanisms for innovative dementia care ideas/models should be established to pilot and evaluate better ways and disseminate ideas that work broadly.

Recommendations:
In agreeance with the Alzheimer's Disease International and World Health Organisation joint report on *Dementia – a Public Health Priority* (2012) we advocate strongly for the rights of all people with dementia to have:

- Access to skilled health professional support and treatments for early diagnosis and intervention
- To have their cognitive function monitored (for example memory clinics and 'case' management)
- Reduced carer burden through increased carer support services and community engagement
- Support for avoiding premature admission to residential care
- Timely access to information regarding finances, counselling and future care planning
- Access to research initiatives and clinical trials.

Re-implementation of the National Dementia Framework (NFAD)with funding allocation and refinements to address identified shortcomings (DoHA, 2011) in relation to:

- A national communication strategy to promote greater awareness of dementia
- Addressing delays in diagnosis of dementia and optimal management
- Promoting access for all Australians regardless of culture, age and locality
- Better co-ordination of dementia initiatives including research centres, training centres and advisory services.

In addition, greater broad promotion of the NFAD principles is required, with facilitated support and accountability of service providers to enact them. All people with dementia should be treated with respect, dignity, with preservation of autonomy and self-determination, and be included as individuals of worth in our communities. This is applicable at all stages of the dementia journey and is the responsibility of all people who engage with someone with dementia in their care, their home, or their community, as well as to policy makers and service developers. Additionally the needs and rights of their carers and supporters must be considered in planning and decision making.

Established best practice standards and monitoring processes are required for all dementia support services Nationally so that equitable and quality services are delivered wherever people live as well as Nationally consistent evidence based training.

A one page guided diagnostic pathway such as developed in Doncaster, UK is recommended to be adopted and implemented Nationally with follow up evaluation. A common assessment and diagnostic process would facilitate timely and accurate diagnosis, improve communication between multiple providers by using a common language. This is particularly important to avoid known instances of misdiagnosis by generalist health professionals without dementia expertise resulting in inappropriate care, and also for people who due to their deteriorating health move jurisdictions, for example to be closer to family interstate, and subsequently need to engage with a new range of health and support staff.

Whilst supporting best practice dementia diagnosis and early intervention can be delivered primarily in community, there exists a need for options for short stay assessment of people in a monitored environment within their local area. This may not necessarily be in a hospital setting but could perhaps utilise existing facilities such as aged care buildings with access to specialist staff for comprehensive assessment and optimisation of intervention.

Implementing and adapting the range of existing evidence based approaches and programs for early diagnosis and intervention for people with dementia rather than 're-inventing the wheel' to make the improvement in services and practices that are needed now.

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