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**Submission by the Australian Psychological Society to the
House of Representatives Standing Committee on Health
and Ageing Inquiry into**

Dementia: Early Diagnosis and Intervention

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Inquiry into Dementia: Early Diagnosis and Intervention

Dementia Epidemic Requires a Shift in Health Services

It has been estimated that the prevalence of dementia will increase 3-4 fold from approximately 257,000 in 2010 to 981,000 by 2050, leading to a very significant shortfall in the availability of residential aged care places (Access Economic, 2011). In the face of this it has been demonstrated that early diagnosis and intervention is able to reduce the need for residential care placement and to keep people with dementia living in the community for longer.

The Australian Psychological Society (APS) contends that aged care services need to be accessible – consumers must have the opportunity to obtain care where they need it and when they need it, regardless of their physical location or abilities to attend such services. In addition, services need to be equitable, consumer centred and flexible. This will ensure a seamless transition between early assessment of cognitive decline, clear diagnosis, evidence based interventions, education and advanced care planning. Equitable health care for people with dementia will assist with keeping them at home and engaged with their communities for longer, delaying the entry into residential care. Delayed entry to residential care has been estimated to save the government approximately \$100 000 per person per annum (Weimar & Sager, 2009).

One of the major and critical responses to the dementia epidemic is early and accurate diagnosis of the functional abilities of people. This requires an equal consideration between the disease model and the psychosocial contributions to assessment and intervention. At present, the emphasis is on the former. As a consequence, medication is often the first line of treatment, despite evidence demonstrating the effectiveness and cost efficiency of psychosocial interventions.

Any recommendations from this Inquiry and subsequent policy responses therefore, must extend beyond a medical disease model and adopts a comprehensive biopsychosocial view of the functioning and capacities of people with dementia.

Focus on Early Diagnosis

Early diagnosis is key to improved quality of life and independence

As per **Item 1 of the Terms of Reference, early diagnosis and intervention are essential means by which to improve quality of life and maintain independence for people with dementia.** Without a clear and accurate diagnosis, early interventions, appropriate medications, sound prognosis, future planning and well-informed carers are not possible. The standard process of achieving diagnosis falls somewhere between the family GP at one end and the specialist physician, geriatrician or neurologist at the other end – often a combination of both. Much of the decision making relies on medical clinical judgment informed by patient presentation/history and neuro-clinical tests like CT, MRI and SPECT scan. Despite best intentions, and because dementia has multiple types and forms, the diagnosis is too often inaccurate and can result in inappropriate medication and management which can lead to increased distress to the patient and the family.

One of the essential components of the diagnostic and the intervention options are evidence-based, non-medical psychological processes often overlooked and under-utilised by medical practitioners. The diagnostic contributions of clinical neuropsychologists enhances the investigative process by applying sensitive and active measures of cognitive and brain state that are powerful diagnostic tools. In addition, these tests of brain function provide an accurate characterisation of current functioning that provides a solid foundation for prognosis and informed planning and interventions. Then further, psychological interventions for behaviour management, mood disorders and enhancing carer effectiveness throughout the dementia disease progress add significantly to quality of life and can noticeably reduce the reliance on drugs and avoid the complications of polypharmacy.

Therefore any recommendations from this Inquiry must broaden the discussion regarding early diagnosis and intervention to include the evidence-based non-medical methods as they are currently underutilised, highly sensitive and much less invasive. Research evidence suggests the combination of clinical and neuropsychological assessment should be essential components of establishing correct and accurate diagnosis (Schmand, Eikelenboom & van Gool, 2011). Furthermore, cognitive assessment can differentiate between cognitive decline due to normal ageing or mood disorders compared with decline due to dementia related issues.

Neuropsychological testing of dementia includes the assessment of cognitive capacities using standardised and psychometrically sound measures (e.g., the Wechsler Adult Intelligence Scale, Wechsler Memory Scale). Early assessment and re-testing can expose early decline in sensitive skills like executive functioning of the brain, reductions in short term memory, attentiveness, planning capacity and flexibility of thinking. Neuropsychological measures have been identified as the most significant prognostic indicators for Alzheimer's disease 2 to 10 years before its diagnosis, in non-demented people (Albert et al., 2007; Artero et al. 2002; Elias et al., 2000; Tierney et al. 2005). Also, neuropsychological tests can accurately predict progression within 10 years of diagnosis (Tierney et al., 2010). Hence, neuropsychological testing for dementia is highly accurate, sensitive, non invasive and predictive.

In addition, as the brain is a highly adaptive and compensatory organ, early intervention should be more comprehensive than medications alone. Rehabilitation via targeted and individualised cognitive, behavioural and emotional strategies delivered by qualified psychologists should be included as standard options.

Multi-Modal, Multi-Disciplinary and Non Medicalised Early Diagnosis

Unfortunately, as with most complex health and mental health conditions, diagnosis for dementia has erroneously focused primarily on the biological diagnosis of symptoms. It is the failure of the medical profession to adequately diagnose and treat dementia (Weimer & Sager, 2009) which leads to late diagnosis and inappropriate interventions being utilised. In the USA, it has been reported that 40 and 80 percent of people with dementia remain undiagnosed and untreated in their primary care setting (Boise, Neal, & Kaye, 2004; Magsi & Malloy, 2005; Valcour et al., 2000). As such, failing to diagnose progressive cognitive impairments early, renders potential intervention ineffective (Clare & Woods; 2003, 2008).

Multi-modal and multi-disciplinary delivery of early assessment and diagnosis of dementia is not only best practice and must be endorsed as such but it increases access for the community and disadvantaged populations that would otherwise be unable to access medical services alone. For example, specialised psychologists, capable of diagnosing dementia, can easily provide outreach services to rural and remote regions where expensive medical diagnostic tests (e.g., MRIs) may not be available.

Differential Diagnosis and Treatment

Differential diagnosis is an essential component of early and accurate diagnosis of dementia as the ageing population often experience co-morbid physical, psychological and mood disorders. People with suspected dementia must be assessed by mental health trained psychologists to rule out co-morbid conditions such as depression (Pachana & Helmes, 2010). Depression and dementia present with similar symptoms (e.g., poor concentration, low mood, and irritability) therefore depression must always be eliminated as a differential or diagnosed as a co-morbid disorder since depression in the elderly is treatable (Lebowitz et al., 1997; Reynolds et al., 1999) and sadly often goes undiagnosed.

Although correct diagnosis of psychological disorders is vital, it is not always easy to obtain. Perhaps the main challenge for accurate assessment is that multi-morbidity (when a person has two or more mental and/or physical health conditions) is very common, if not the norm (Hyer et al., 2005). Multiple illnesses, conditions and deterioration in cognitive functioning can make determining or deciding on which symptoms belong to which disorder extremely complicated.

Additionally, competent use of diagnostic and assessment instruments and valid interpretations of the results are crucial to developing treatment plans that respond to a person's needs. For example, one of the most frequently used medical measures of cognition that informs decisions for people with dementia is the Mini-Mental State Examination (MMSE) (www.pbs.gov.au). It is recognised that people not trained in the administration of the MMSE can inadvertently or unwittingly affect the results and scoring of the test; thus increasing the chance of under- or over-estimating the level of cognitive impairment, and in turn affecting treatment decisions. Psychologists and neuropsychologists are highly trained in the accurate delivery and interpretation of psychometric measures of cognitive capacity.

The implications of inaccurate or possibly erroneous diagnosis of a person with dementia are vast and varied including prescription of the wrong medication or, put simplistically, failure to treat. Psychologists and neuropsychologists can make a significant contribution to determining the accurate working diagnosis of brain activity and exclude differential mental health diagnoses to ensure people with dementia are accurately diagnosed.

Benefits of Early and Accurate Diagnosis

Early and accurate diagnosis is the key to improved outcomes for people with dementia and broader community wellbeing as it enables early and appropriate intervention. Early and appropriate includes individualised treatment of individuals

with dementia, offering them the opportunity to improve their quality of life and even rehabilitate their brain function where possible. Additionally, early intervention increases the opportunity for carers to become educated in the expected progression of dementia and to establish, with the aid of health care professionals, advanced care planning.

Collaborative advanced care planning

As per **Item 3 of the Terms of Reference, early diagnosis of dementia helps to raise issues, such as the organisation of financial and legal affairs, as well as wishes for long-term care, when a person is more likely to be able to participate in decision making about such topics.** Approximately 80% of people report that they would want to know as soon as possible if they had a diagnosis of Alzheimer's Disease (Dale et al., 2008; Dale et al., 2006). Such information allows people living with dementia, and their surrounding care network, to begin to plan for their futures.

Neuropsychological evaluations are requested in a variety of medico-legal cases, such as whether or not a patient is legally competent to make financial decisions or change a will. Since neuropsychological test findings are objective, they are seen as valuable to the legal system in this respect (Prigatano & Morrone-Strupinsky, 2010). Early diagnosis allows greater opportunity for less restrictive decision making devices, such as Enduring Power of Attorney, to be implemented, reducing the need for guardianship and administration orders. To ensure legal and care planning matters are collaboratively decided when the individual with dementia is still able to engage in decision making ultimately relieves the family of the burden of these decisions later when the illness and available health services or residential care places dictate these outcomes.

Increased opportunities for continued social engagement and community participation are contingent, to a large extent, on early diagnosis and intervention. This is because there is evidence that early diagnosis is vital in the efficacy of planned individual and carer interventions. Early diagnosis thus ultimately leads to keeping people with dementia at home longer, improves their quality of life by keeping them socially engaged in their existing communities and networks and protects the quality of life of the family members and community by enhancing the person affected by dementia's ability to remain an active and functional member of the community for longer.

Early Education of carers

An early diagnosis results in early education of carers of people with dementia. Informed carers are seen as a primary means by which to improve patient quality of life and resulting in better longer-term outcomes. One study in Melbourne found that three weeks after receiving educational handouts about dementia, carers described utilising a much wider variety of cognitive management strategies to manage their family member's needs and equipped carers to provide optimal psychological support (Ryburn, Varanelli & Wells, 2011).

Psychologists can play an important role in educating family members in order to manage a person with known neurological disturbances (e.g., Attix & Welsh-Bohmer, 2006). Strong evidence exists that supporting and educating caregivers of

people with dementia reduces the risk of placement into residential care (Mittelman et al., 2006). Family members can support the rehabilitation of people with dementia and extend their independence and social engagement.

In addition, family psychoeducation is essential in helping family members understand the often distressing cognitive and behavioural changes that accompany dementia. Dementia can cause people to act and behave differently, including increased confusion, disinhibition and agitation. To observe a family member behave in this way can be highly distressing and family members must be educated early to prepare them for these changes.

Supporting carers

Furthermore carer's must also be supported in coping with their own grief and emotional distress associated with caring for a family member with dementia. GPs are a good place to start with educating family members as they are also able to refer carer's to psychologists under the Better Access Medicare Scheme if carer's are experiencing mental health disorders such as depression, anxiety, adjustment or debilitating grief associated with their role as carer.

Psychoeducation and psychological support delivered to family members is essential to the management of people with dementia in their homes and community and can be initiated early by psychologists if GPs are trained to refer for early identification and non-medicalised treatment of cognitive deficits.

Improved Quality of Life

Measurement of quality of life

While the APS applauds the House of Representatives for drawing attention to the important issue of quality of life, it is imperative that quality of life is a definable and measureable outcome. The APS urges policy makers to acknowledge that quality of life measures can be seen as subjective and can be influenced by a number of factors such as the settings in which they are used, respondents' interactions with other health and related services and even demographics of the respondents. Furthermore, these measures are unlikely to be helpful for people with advanced dementia.

Therefore, it would be irresponsible for a single quality of life measure to be used as a benchmark, as no single measure can provide a comprehensive and valid way to quantify quality of life in people with dementia. There are a number of principles that the APS would present to the House of Representatives in guiding the suggestion that improved quality of life must be measurable goal:

- No single measure will reliably measure the various dimensions of well-being, satisfaction or even quality of life;
- The best measures will have been extensively validated and researched, often in specific settings;
- Measures targeting specific population groups or settings are much more accurate than overall "happiness measures" for the general population.

While neither an exhaustive list, nor specially recommended, the APS is aware of the following measures of quality of life for older adults:

1. World Health Organisation Quality of Life - Older person's version (WHOQOL-OLD; Power et al., 2005) – The WHOQOL-OLD was developed from the WHOQOL-100, tested and validated across cultures, making it suitable for the general older population, including people from culturally and linguistically diverse communities. The WHOQOL-OLD is tailored for people aged over 65 years and is comprised of seven sub-scales (sensory abilities; autonomy; past present and future activities; social participation; death and dying; and intimacy).
2. Older People's Quality of Life (OPQOL; Bowling & Stenner, 2011) developed specifically for people aged at least 65 years. The questionnaire asks people to respond to questions about life overall, health, social relationships and participation, independence, control over life, freedom, home and neighbourhood, psychological and emotional well-being, financial circumstances and religion/culture.
3. Short Form Health Survey-36 (SF-36; Ware & Sherbourne, 1992) – a widely used measure of patient health measuring eight domains (vitality, physical functioning, bodily pain, general health perceptions, physical role functioning, emotional role functioning, social role functioning and mental health). It has however been recommended that when using the SF-36 with older people, that the questionnaire be administered with an interviewer rather than in the context of a mail out.

It is also important to note that there is no overall agreement in the research literature as to what "quality of life" is or should constitute (Bowling et al., 2002). Given this, if different measures have been used, direct comparisons of quality of life will not be valid. So, even if concerns about best-practice tool exist, persisting with the same measure provides meaningful comparisons over time or between groups.

The Government must ensure that dementia policy is driven by evidence-based practice. Practically this would require that all grant applications or program proposals that relate to the diagnosis, treatment, management or education about dementia must utilise a multi-disciplinary approach and include quality of life outcome measures.

As alluded to above, while tools are available to assess and measure quality of life, it remains a subjective measure, depending on the setting and the perception of individuals involved. Despite this, improvements to quality of life can be measured at three levels:

- At an individual level, it can mean the perception one feels secure and certain of their health and service needs in line with their dementia progress. This requires accurate and up to date information, so that individuals and their carers feel in control and have some degree of certainty about their future.
- At a local community level, it means that people with dementia can still have active social engagement with their familiar surrounds. This is both an effective and efficient intervention approach – it is much more economical to

provide care at a local level where people with dementia have existing support networks rather than in an expensive medical or aged care settings.

- At a societal level, it means that people with dementia are seen and accepted as part of the broader community. This is not dissimilar to the way in which people with mental illness and other disabilities have been destigmatised and accepted into the community in the past twenty or so years. People with dementia can make positive contributions to the society, once they have local supportive services in place that are sensitive to their needs.

One illustration of the above is the local community organisations such as senior citizen's clubs. Such organisations are run by dedicated volunteers, often without professional support and backup. One way to strengthen these organisations' effectiveness is to provide education and training by qualified health professionals on dementia, its prognosis and services available. This empowers both local residents and organisations to reach out and discuss issues without having to "see a professional". Providers and service organisations can remain in the background, while the face-to-face work is done by the local community organisations with support from the former on regular basis.

Such an approach will help achieve the stated aims of improvement in quality of life for people with dementia because not only are they being supported by their local communities, they can feel "in control" of their condition. It also means that the local communities are actively promoting "healthy ageing" and "living with dementia" as positive concepts, which, in turn, means that it is more acceptable for people with dementia to seek their services. When such services are provided at a societal level, the community at large both acknowledges and accepts the role of such local organisations as well as people with dementia as an active part of their communities.

It is acknowledged that at some stage, a transition is required so that health care and social service providers will play a more prominent role. By having local organisations doing much of the groundwork as described above, it will create an atmosphere of trust and acceptance between local organisations and service provider organisations, ensuring much smoother transition process and therefore decrease any associated stress. Once again, people with dementia will enjoy improved quality of life and they will be in an active partnership with service providers, as such people have already been "cared for" by their local communities via the providers.

Delivery of Awareness and Information

Destigmatise and normalise discussing memory loss

Stigma, shame, inaccurate information and erroneous beliefs regarding opportunities for treatment continue to influence the reasons why people choose to discuss their symptoms with their health care professionals or family members. In addition, family members often find themselves protecting their family member by “covering up” their symptoms. For example, a wife who notices that her husband has begun to confuse the functions of appliances in the kitchen may unconsciously or consciously, ensure she is the only one to use those appliances. When family members ask “Has Dad begun to lose his memory?” she reports she too is losing hers as a way of covering her fears and suspicions.

As per ***Item 4 of the Terms of Reference, the general population of all ages needs to be provided with accurate and official information about dementia, delivered by the Government.*** As stated on the previous page, people can be cared for by their communities to understand dementia and destigmatise the issue. In order to support communities to do this, however, an education campaign helping people identify the early signs, symptoms and opportunities for primary care management of dementia are needed. This will enable people to feel comfortable to approach their GP once health care services are required. The older population is, however, not the sole target of information. Younger family members, colleagues and acquaintances are as capable of noticing symptoms of dementia and, furthermore, may be more open to early intervention than the older population.

Campaigns that highlight preparedness for the future, protecting independence and offering long term engagement with the community would assist with destigmatising a very feared condition. A dementia campaign that resembles those of campaigns for retirement, superannuation or financial security are essentially proposing the same ideals; independence, security and long-term quality of life. For example, “Discuss your memory with your GP today. It will keep you thinking clearer, for longer”.

Primary health care providers are an excellent source of information for people of any age, to discuss their own or a family member’s symptoms of dementia. Information campaigns with hard copy information such as posters or flyers could be provided to all primary care providers for their waiting rooms, urging people to discuss their memory issues while presenting for other health issues.

Campaigns that target activities that have a higher presence of older adults such as sporting clubs (e.g., bowls), local community centres/shopping centres or RSLs provide the members of their communities the opportunity to support each other and encourage one another to seek treatment once it is required. Targeting older adults who are currently engaged in their communities is not only a preventative strategy as it will potentially keep them engaged in their communities for longer, it will also target those people who are potentially most able to benefit from early intervention.

Furthermore, consistent with increasing equity of health care to the older population, suburbs with an older age range (e.g., census data) could receive information in their local newspapers. Those who are already isolated in their

homes must also be offered information and as such television or radio may reach those who are “at risk”, if not currently experiencing symptoms of dementia.

Conclusions

The Government’s Terms of reference focus on seeking responses regarding issues of quality of life, independence, social engagement, community participation, planning for futures (care and financial) and delivery of information all towards effective early diagnosis and intervention for dementia sufferers

The APS urge the Government to consider the following:

- Health care for people at risk or experiencing symptoms of dementia must be equitable and reach them where they are when they need it;
- Non-medical assessment and diagnostic processes (such as those by clinical neuropsychologists) are highly sensitive and useful procedures that are currently under-utilised by medical services;
- Non-medical psychological interventions (such as those provided by psychologists and clinical psychologists) for the managements of mood disorders and behaviour problems can make a major contribution to cost-effective and non-invasive treatment of the demented;
- A multi-disciplinary and non-medicalised approach, which includes psychologists, is evidence-based and best-practice;
- managing and treating psychological and mood diagnoses is not emphasised by the Terms of Reference but is essential in delivering appropriate and targeted treatment to people with dementia;
- Early detection facilitates the possibility that advanced care planning could occur while the person with dementia has the ability to participate in the decision making process;
- Carers are a significant key to enhancing the quality of life of people with dementia and actively keeping them at home and engaged with their communities for longer and therefore need appropriate support;
- Quality of life is a measure of the human impact of dementia and must be a key outcome measure in health care policy;
- Communities must be supported to destigmatise symptoms of dementia which ultimately helps transition people from community support to health care services when they are needed;
- All primary health care services are an essential vehicle for an education campaign to encourage people to discuss their dementia symptoms with their health care providers.

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