

The Secretary  
House Standing Committee on Health and Ageing  
House of Representatives,  
PO Box 6021,  
Parliament House,  
Canberra ACT 2600

2 May, 2012

Dear Sir/Madam

I am writing in regard to the Inquiry into Dementia: Early Diagnosis and Intervention.

I am a clinical neuropsychologist currently practicing in Launceston. I began my specialist training as a clinical neuropsychologist in 1990, and have worked in neuroscience, rehabilitation, general medical, psychiatric, and drug and alcohol services since 1992. The majority of my clinical experience comes from working in Clinical Neurosciences at St Vincent's Hospital Melbourne (1995-2010), where more than half of the referrals are to assist neurologists with differential diagnosis of dementia and other conditions where the diagnosis was uncertain. I am currently national chair of the APS College of Clinical Neuropsychologists, and co-author of the APS proposal for neuropsychological services to be funded under Medicare. The APS proposal reviews the literature which demonstrates the value of specialist neuropsychological involvement in the diagnosis and management of dementia (see <http://www.psychology.org.au/Assets/Files/Government-Funded-Clinical-Neuropsychological-Services-Feb2012> ).

Today I am writing in my capacity as a private individual with a strong interest in early diagnosis and intervention for people with dementia. This submission will start by briefly defining dementia and issues in diagnosis of dementia, then addressing the terms of reference of the Inquiry, and will conclude by outlining the contributions neuropsychologists can make to early diagnosis and intervention in dementia. My aim is to demonstrate that obtaining an early, and accurate, diagnosis of dementia is vital before interventions are commenced.

### **Dementia - definition**

Dementia is a term used to refer to an acquired impairment in memory and cognition. Dementia can take many different forms, can arise from a number of conditions, and while memory impairment is the most common feature, some forms of dementia involve changes in behaviour and language rather than memory in the early stages. As a result, there are a number of different diagnostic criteria for dementia. Some are based on clinical features, and some are based on pathology.

The Diagnostic and Statistical Manual - 4th edition (DSM-IV) lists several subtypes of dementia that are due to distinct neuropathological or disease states: these are the dementias due to Alzheimers, Vascular, HIV, Parkinson's, Huntington's, Pick's, and Creutzfeldt-Jakob disease. DSM-IV also lists a number of dementia subtypes that are not necessarily progressive in nature: dementia due to head trauma, general medical

conditions, multiple etiologies, or substance-induced persisting dementia. Confusion can arise where cognitive impairment due to an acquired brain injury is described as dementia: this kind of cognitive impairment usually *improves* over time, in the case of head trauma, and can sometimes be halted or reversed in the case of general medical conditions such as alcoholic Wernicke-Korsakoff syndrome, or in vitamin deficiencies. In contrast, dementia due to Alzheimer's or other neurodegenerative conditions *worsens* over time, and the interventions required for worsening conditions are correspondingly different. In cases of acquired brain injury, there is usually an incident that causes the sudden loss of cognitive function. In dementia, the cognitive changes develop slowly and insidiously over time, and research is showing that the changes in Alzheimer's can develop up to 20 years before clinical diagnosis.

The distinction between dementia due to progressive neurodegenerative disease, which is currently incurable, and cognitive change due to head trauma, mood disorder, or treatable medical conditions, means that accurate differential diagnosis of dementia is vitally important. Dementia should be a diagnosis of exclusion, that is, all treatable causes of cognitive decline should be excluded - through a careful clinical interview and history, review of medications which can cause cognitive side effects, and routine blood and other exams which can identify deficiencies and infections that can result in cognitive change.

Identification of reversible causes of dementia can prevent unnecessary cognitive decline and nursing home placement. As an example, my late father was diagnosed with normal pressure hydrocephalus (NPH) in 2004. He was assessed as needing high-level care before a shunt was inserted to drain the excess fluid from his brain. He made an excellent recovery and lived at home for another 9 years before declining to the extent of needing nursing home placement. While NPH is a rare condition, research shows that treatment with a shunt results in improvements for an average of 5 to 7 years. Without shunting, the person with NPH becomes incontinent, unable to walk, cognitively impaired, and slowly dies. My father went through this sad process over the last 18 months of his life, but we were so grateful that we had him at home, almost normal, enjoying life, but slowly declining, for the 9 years before that.

Early diagnosis and treatment allows people with a reversible condition to maintain independence and a life with their families. Incorrect diagnosis, especially in younger people, can see people making major life changes in preparation for a cognitive decline that does not eventuate. Instead of treating the underlying cause of the reversible cognitive changes, the person is left in a limbo of not knowing what is wrong, or declining because the reversible cause was not identified and treated early enough.

### **Terms of reference.**

The following is a summary of evidence in relation to each of the terms of reference, prepared by my colleague, Dr Ben Harris, with contributions from members of the College of Clinical Neuropsychologists. We have attempted to provide a

representative, but not exhaustive, account of the evidence for each term of reference.

**1) How early diagnosis of dementia and intervention can improve quality of life and assist people with dementia to remain independent for as long as possible**

- Early diagnosis and intervention are essential means by which to improve quality of life and maintain independence. Neuropsychological research is showing that we can improve quality of life (QoL) and reduce family distress and increase capacity to manage everyday affairs (Kinsella et al, 2009)
- Data from a randomized trial showed that patients with dementia had significant short-term improvement in functional and quality-of-life outcomes after four months of home-based behavioural intervention, (Gitlin et al, 2010). Caregivers in the intervention group continued to experience improvement at 9 months, even though functional improvement did not differ between intervention and control groups at nine months
- Strong evidence exists that supporting and educating caregivers of people with dementia, as well as the early introduction of cholinesterase inhibiting medications, reduces the risk of placement into residential care (Lopez et al., 2005; Mittelman et al., 2006). One major barrier to the implementation of such interventions is the failure of the medical profession to adequately diagnose and treat Alzheimer's disease (AD) (Weimer & Sager, 2009), with studies indicating that between 40 and 80 percent of people with dementia in the USA remain undiagnosed and untreated in their primary care setting (Boise, Neal, & Kaye, 2004; Magsi & Malloy, 2005; Valcour et al., 2000).
- A report by Access Economics (2011) predicted that by 2030 and 2050, with the aging of Australia's population, there would be a very significant shortfall in the available residential care places. Early diagnosis and intervention has been demonstrated to reduce the need for residential care placement and to keep people with dementia living in the community for longer.
- Involvement of psychologists in the assessment of elderly people with suspected cognitive impairment is important to rule out comorbid conditions which can mimic dementia, such as depression (Pachana & Helmes, 2010). This can significantly contribute to an individual's quality of life, as depression in the elderly is amenable to treatment with empirically validated psychosocial approaches, with or without medication as an adjunct to the therapy (Lebowitz et al., 1997; Reynolds et al., 1999).

**2) How early diagnosis of dementia and intervention can increase opportunities for continued social engagement and community participation for people with dementia**

- 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.
- In a Cochrane Review, Clare & Woods (2003, 2008) found that by the time people meet current AD diagnostic criteria, there was no evidence of efficacy of cognitive training, and not enough evidence regarding the efficacy of

cognitive rehabilitation (an individualised goal-setting-based approach). However, when cognitive interventions are applied earlier, preferably when a person does not meet criteria for dementia, there are more promising trends. For example, Olazaran and colleagues (2010) systematically reviewed non-pharmacological therapies and found that the strength of the evidence was enough to make targeted recommendations for carers (i.e. a multicomponent intervention to delay institutionalisation), and also for the person affected (e.g. cognitive training). Other reviews have found promising trends for the efficacy of cognitive interventions for people with mild cognitive impairment (e.g. Jean et al., 2010), whereas similar interventions once people have declined sufficiently to meet the criteria for dementia have shown negative results (e.g. Kurz et al., 2009)

- These studies indicate that failing to diagnose progressive cognitive impairments early in their course renders potential interventions ineffective, and thus, reduces a person's capacity to maintain social and community engagement, affecting their quality of life.

### **3) How early diagnosis of dementia and intervention can help people with dementia and their carers plan for their futures, including organising their financial and legal affairs and preparing for longer-term or more intensive care requirements**

- Previous studies of older people have found that approximately 80 percent 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 the future.
- Early diagnosis of cognitive impairment 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. Attorneys request neuropsychological evaluations in a variety of medico-legal cases, such as whether or not a patient is legally competent to make financial decisions, and since neuropsychological test findings are objective, they are seen as valuable to the legal system (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.
- Education of carers is seen as a primary means by which to improve patient quality of life and resulting in better longer-term outcomes. Multidisciplinary clinicians based in Melbourne recently published a series of information resources for people with MCI and early dementia designed to support and improve cognitive functioning, as well as equipping carers to provide optimal psychological support. They found (Ryburn, Varanelli & Wells, 2011) that three weeks after receiving handouts at the memory clinic, carers who read the new handouts described utilising a much wider variety of cognitive management strategies than those who did not read or receive them.

#### **4) How best to deliver awareness and communication on dementia and dementia-related services into the community**

- Neuropsychologists play an important role in educating family members in order to manage a person with known neurological disturbances (e.g., Attix & Welsh-Bohmer, 2006).
- There is a great need to educate the community, including general practitioners, about dementia. There seems to be a perception that because dementia is common in the elderly, that it is a normal process. This is wrong: just because dementia is common, it is not normal. There is also the perception that nothing can be done about dementia. This is also false. There is overwhelming evidence that cognitive decline can be due to treatable medical and psychiatric conditions. Assuming that memory loss is normal and untreatable in the elderly means that many are deprived the investigations that would identify a treatable cause of dementia.
- The NHS in Britain has recently announced that all over 75's will be screened for dementia. A longitudinal study in Wisconsin, USA, has shown that routine screening combined with offering further evaluation led to a two- to threefold increase in diagnoses of brain impairments in older veterans, none of whom showed signs of memory loss (Riley McCarten et al, 2012). Of the 8000 participants aged 70 and older who agreed to undergo a brief screening during a routine visit to a VA primary care clinic, 26% failed the screening. Of the 28% of these who agreed to further evaluation, 93% were found to have cognitive impairment, including 75% with dementia. Veterans accepted screening well, and providers found the program useful.
- Rather than using expensive computerised cognitive screening measures developed and marketed in some sectors of the health industry, it is recommended that an affordable Australian screening program with further evaluation be based on evidence-based programs with demonstrated utility. Clinical neuropsychologists would be invaluable experts to advise on the sensitivity, specificity, and utility of such screening programmes, given our training as scientist-practitioners, including 4 years of undergraduate training in psychology, statistics, and research design and evaluation, and postgraduate training in psychology, assessment, and diagnosis at an advanced level.

#### **The role of neuropsychologists in early diagnosis of dementia.**

Neurologists, psychiatrists, geriatricians, rehabilitation physicians and other specialist physicians value neuropsychological involvement in cases where there is not clear evidence of brain impairment. This is because neuropsychological assessment is unique in its ability to obtain objective measures of complex cognitive and behaviours, and is useful for distinguishing between early dementia and normal ageing (American Academy of Neurology, 1996).

Neuropsychologists use tools that are psychometrically sound, that is, the tests we use are well-normed, standardized, validated, and have known reliability and test-retest stability. The results of a neuropsychological assessment are combined with an understanding of the patient's unique history, education, occupation, and

personal variables to assist with determining the presence or absence of brain impairment. The result of a neuropsychological assessment is more than a collection of test results – the results are integrated in order to describe the current level of functioning, compared with other people of the same age, and with estimates of prior highest levels of functioning. This makes neuropsychological assessment a unique and highly specialised endeavour, which can give objective evidence of impairment on a single assessment, or provide a baseline for future comparison in cases where a progressive neurodegenerative condition is suspected, as in early dementia.

Brain scans like CT and MRI can show if there is shrinkage or vascular damage in people with possible dementia, but shrinkage and vascular change is common with normal ageing, and may not be accompanied by the clinical signs of dementia. Radiologists use clinical judgement to decide if shrinkage is greater than expected by age. Neuropsychologists use statistically-derived formulae to determine if change on assessment is different from expected by age, education, and estimated premorbid abilities. Functional scans like SPECT (Single Positron Emission Tomography) and PET (Positron Emission Tomography) can show areas of reduced metabolic activity in the brain, but these scans are interpreted using clinical judgement rather than actuarial formulae, and a recent study showed a 35% false positive rate when PET scans were used to diagnose dementia alone. The cases who were incorrectly diagnosed with dementia in this study had vitamin deficiencies or other reversible conditions that can masquerade as dementia, proving that a careful clinical examination, including formal cognitive testing, and exclusion of reversible causes of dementia is needed for diagnosis of dementia.

- There is strong evidence that evaluation of dementia requires neuropsychological assessment to be optimally reliable and sensitive. Jacova and colleagues (2007) reviewed the literature and concluded that neuropsychological assessment can detect cognitive deficits several years before the clinical diagnosis of dementia, and that it is vital in the differential diagnosis of common neuropathological causes of dementia, e.g. Alzheimer's disease, frontotemporal dementia, cortical Lewy body disease and vascular dementia. The recently published Diagnostic Criteria and Guidelines for Alzheimer's Disease noted that "despite the existence of multiple studies spanning thousands of participants, the promise of both subjective and objective cognitive measures for assessing risk of progression to AD in individual elders has not yet been fully realized. It is likely that measured change in cognition over time will be more sensitive than any one-time measure" (Sperling et al., 2011). Neuropsychological assessment can provide these serial measurements of cognition over time.
- Neuropsychological assessment should be undertaken as part of a diagnostic evaluation across the lifespan where early diagnosis of cognitive impairment and dementia is needed. For example, the Alzheimer's Disease Neuroimaging Initiative was launched in 2003 to determine whether serial MRI, FDG-PET, other biological markers (e.g. cerebro-spinal fluid CSF biomarkers of  $\beta$ -amyloid), and clinical and neuropsychological assessments can be combined

to measure progression of Mild Cognitive Impairment (MCI) and early AD in a large sample of people aged 55 to 90. It was found (Schmand, Eikelenboom & van Gool, 2011) that a combination of neuropsychological assessment and MRI was the prime method of diagnostic evaluation if AD was suspected, and that CSF and FDG-PET investigations add little to these diagnostic techniques, especially in older adults with MCI or dementia (i.e. those aged 75 years and older), who constitute the vast majority.

- A separate study demonstrated that cognitive markers were consistently significant and generally stronger predictors of development of Alzheimer's disease than biomarkers, and that conversion from mild cognitive impairment to AD a large functional decline rather than a shift in neurobiological characteristics of the disease (Gomar et al, 2011). Understanding of a person's functional capabilities is central to providing individually tailored and responsive approaches to the dementing process.
- Neuropsychological measures of delayed recall have been identified as the most significant prognostic indicators for Alzheimer's disease (AD), 2 to 10 years before its diagnosis, in non-demented participants free of other neurological conditions (Albert et al., 2007; Artero et al. 2002; Elias et al., 2000; Tierney et al. 2005). Also, neuropsychological tests can accurately predict progression secondary to all causes of dementia within 10 years of diagnosis in a large community based sample of non-demented participants (Tierney et al., 2010).

In terms of costs, a neuropsychological assessment, which includes detailed testing, a comprehensive report, and recommendations to assist with any identified cognitive difficulties, would cost \$535 to \$1120 under the APS proposal for neuropsychology to be included under Medicare (see the APS submission at <http://www.psychology.org.au/Assets/Files/Government-Funded-Clinical-Neuropsychological-Services-Feb2012> ). The APS estimated that the cost of this proposal would be \$22 million per year, but that the savings in reduction of inappropriate prescribing, and in delaying nursing home admission, would probably be greater than the costs of the scheme.

There are currently only 411 registered psychologists with endorsement in clinical neuropsychology in Australia, and it would not be necessary, or possible, for every new case of dementia to be referred to a neuropsychologist for assessment. Many people are diagnosed with dementia once their cognitive impairment becomes obvious enough to cause concern to family and caregivers. These people can be diagnosed through a combination of simple cognitive screens that can be administered by a GP, or by a more thorough cognitive examination performed by a geriatrician, psychiatrist, dementia nurse, or occupational therapist. Such a community screening programme was used with great success in the US state of  
Neuropsychological assessment is most valuable for patients with subtle cognitive changes that are not detected on simple screening measures, or for people with high levels of premorbid functioning or complex comorbidities

The APS submission on neuropsychology, which I co-authored, discusses in detail the value of neuropsychological involvement in cases of dementia and associated conditions. The quotations in italics below are selected from that submission.

### **1. Dementia**

*Early and accurate differentiation of the causes of memory problems and various dementia subtypes is especially important where this may affect treatment. For example, in Lewy body dementia, antipsychotic medication is contraindicated to treat hallucinations and donepezil (Aricept) can lead to worsening of symptoms in frontotemporal dementia (Braun et al., 2011). In cases of delirium and depression, diagnosis is crucial for correct treatment and recovery: the underlying cause of delirium must be determined and treated quickly, and depression can sometimes present with dementia-like symptoms in the elderly. Cognitive change due to normal ageing requires no medication.*

*In addition to the clinical and QoL benefits of neuropsychological assessment, a 2009 cost study in the USA showed a savings of \$100,000 per patient when Alzheimer's disease was detected early (Weimar & Sager, 2009). Most neuropsychological tests are of greater utility than cognitive screening measures in the clinical context because of their superior positive predictive value, psychometric properties, standardised development, and availability of demographically-based normative data, (Smith, Ivnik, & Lucas, 2008). Cognitive screening measures used by other professionals have relatively weak sensitivity and specificity, particularly for people with high premorbid baseline intellectual ability, divergent ethnic/linguistic backgrounds, the earliest phases of illness, or with atypical degenerative disease – areas where neuropsychological assessment has unique strengths (Braun et al., 2011, p. 109).*

### **2. Mild Cognitive Impairment (MCI)**

*Unlike normal ageing, MCI is characterised by the presence of abnormal, subtle cognitive deficits that may progress to dementia over time. Braun et al's (2011) review identified nearly 400 peer-reviewed articles related to neuropsychology and MCI. The review showed that early detection and characterisation of MCI is important for informing treatment and prognosis because certain MCI subtypes are more likely to progress to dementia. Neuropsychological assessment is particularly useful for detecting MCI when cognitive deficits are mild and have not affected daily functioning, as such changes are often not evident on clinical interview or neuroimaging. Neuropsychological assessment is sensitive in discriminating between different MCI subtypes, determining different conversion rates to varying types of dementia, and in detecting people with pre-MCI memory complaints who progress to MCI over time. Early detection of MCI informs decisions about medication, providing prognostic data, informing stroke risk, determining functional abilities, and developing compensatory behavioural strategies to improve functional cognitive abilities (see Braun et al., 2011 for review).*

### **6. Parkinson's disease**



*Neuropsychological assessment can help with prognosis and medication by differentiating between syndromes which have symptoms of Parkinsonism, but are not necessarily consistent with Parkinson's disease (e.g. Lewy body dementia, Parkinson's-plus syndromes). Treatment planning in Parkinson's is informed by identification of neuropsychological strengths and weaknesses, and in predicting and measuring post-surgical cognitive outcomes for surgical patients (Braun et al., 2011).*

### **7. Other central nervous system disorders**

*There is a recognised and growing scientific basis for the use of neuropsychological assessment to detect cognitive impairment and guide treatment planning and prognostication in other CNS disorders such as multiple sclerosis (MS), Huntington's disease, hydrocephalus, encephalitis, amyotrophic lateral sclerosis (ALS), brain tumours, and intracranial aneurysms (Braun et al., 2011).*

### **8. Noncentral nervous system medical conditions**

*Neuropsychological assessment is valuable in non-CNS medical disorders because it is sensitive to detecting the presence, nature, and severity of brain dysfunction, and helps guide clinical management and rehabilitation efforts to improve daily functioning, treatment compliance, or work performance (Braun et al., 2011).*

### **Summary and recommendations**

In summary, there is abundant evidence that early diagnosis of dementia is important to differentiate between reversible and irreversible causes of cognitive decline. There is also evidence that early intervention in dementia is more useful than later intervention, and that interventions in dementia can assist with maintaining or improving quality of life for dementia sufferers and their carers, through education and provision of strategies, increased community and social engagement, and through allowing the person with dementia to actively plan for their future while still cognitively able.

This submission has not been able to consider the impact of early -onset dementias, in people under 60, with the accompanying effects on careers and younger families. It has also not addressed the evidence showing that educating families and dementia sufferers about end of life issues in dementia results in improved palliative care at the end of life, fewer burdensome and futile interventions for the dying patient with dementia, and improved understanding of the dying process for the family.

It is hoped that the Committee will have a better understanding of the role that neuropsychologists can play in the assessment and treatment of dementia. Most importantly, it is hoped that this submission has demonstrated the importance of correct and early diagnosis of dementia in order to improve outcomes for individuals, families, and communities.

Please do not hesitate to contact me if I can be of further assistance

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