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Dear Mr Georganas

**Re: Parliamentary Inquiry in to Dementia: early diagnosis and intervention**

Please find attached the submission to the inquiry from Minister Butler's Dementia Advisory Group (MDAG). We present evidence that diagnosis is commonly being made late or not at all, that there are systemic issues why timely diagnosis is not being achieved in primary care and other health settings, and that there are possible solutions to these barriers to timely diagnosis. We also catalogue the benefits of early diagnosis to individuals, to their families, to the health system (including reduced cost of care) and to society generally.

Our submission to this inquiry is in three parts:

- Part A describes the importance of, barriers to and possible solutions to achieving timely diagnosis of dementia in primary care;
- Part B addresses some of the same issues in other health care settings; and
- Part C addresses the specific questions of the inquiry concerning the benefits of early diagnosis.

The response has been authored by Professor Henry Brodaty with assistance from Professor Dimity Pond, Associate Professor Mark Yates, Mr Glenn Rees and Associate Professor Susan Koch and endorsed by members of the Advisory Group. We would also welcome the opportunity of giving evidence in person to the inquiry.

Please contact Associate Professor Susan Koch  
you require further information.

Telephone: if

Yours Sincerely

Associate Professor Susan Koch  
Chair MDAG

Sue Pieters Hawke  
Co Chair MDAG

## House of Representatives Standing Committee on Health and Ageing

### Parliamentary Inquiry in to Dementia: early diagnosis and intervention

**Summary:** we present evidence that diagnosis is commonly being made late or not at all, that there are systemic issues why timely diagnosis is not being achieved in primary care and other health settings, and that there are possible solutions to these barriers to timely diagnosis. We also catalogue the benefits of early diagnosis to individuals, to their families, to the health system (including reduced cost of care) and to society generally.

We divide our submission to this inquiry into three parts: Part A describes the importance of, barriers to and possible solutions to achieving timely diagnosis of dementia in primary care; Part B addresses some of the same issues in other health care settings; and Part C addresses the specific questions of the inquiry concerning the benefits of early diagnosis.

#### **Preamble**

We support both “early diagnosis” and “timely diagnosis” and note that these differ. For example a person with undiagnosed moderately advanced dementia first coming to medical attention on admission to hospital should receive a diagnosis; this would be timely though not early. Early diagnosis refers to reducing the gap from first symptoms to receiving a diagnosis.

This submission does not refer to preclinical diagnosis using cerebrospinal fluids and imaging biomarkers. These biomarkers are relevant in research rather than clinical settings except where genetic issues are involved.

*Targeted screening* followed by more detailed assessment for individuals at high risk of dementia is recommended by many, e.g. people over 75 in general practice, older people admitted to hospital. *Case-finding* is recommended by all, i.e. once concerns or symptoms are voiced, comprehensive assessment is mandatory.

Screening is not the same diagnosis. A positive screen i.e. a score below threshold on a cognitive test merely indicates poor performance which may occur for a variety of reasons. More detailed assessment is required for a diagnosis to be made.

Diagnosis must be followed by management, often including referral to specialist and support services such as Alzheimer’s Australia.

#### **A) How can we improve timely diagnosis in primary care**

- Dementia is a serious, chronic health condition, often with complex physical co-morbidities as well as psychological and behavioural symptoms. Primary care is the first point of contact for people with symptoms of dementia and for their families and is responsible for the bulk of continuing care.
- Issues that constantly arise in the literature and in consultations with consumers and GPs themselves concern prevention, diagnosis, continuing management and care in residential aged care facilities (RACFs).

#### *Prevention*

- Lack of awareness in general community of measures to delay onset of dementia.

- Lack of awareness and lack of promotion of measures to delay onset of dementia by GPs and others working in primary care.

### *Diagnosis*

- Research and multiple consumer consultation forums have confirmed that GPs do not identify dementia early and do not complete a full assessment as recommended in guidelines<sup>1</sup>.
- Lack of or delay in diagnosis and the subsequent late presentation to services, often in crisis, were among the most commonly reported issues in the consultations for the NSW Dementia Services Framework 2010 - 2015.
- The advantages of a diagnosis are that it can be a relief (paradoxically) and trigger support, medications and planning ahead. On the other hand it is important to respect peoples' preferences not to know and acknowledge possible distress. The clinician's skill is to navigate these issues sensitively.
- Reasons for lack of or delay in diagnosis from GPs' point of view <sup>2</sup> include:
  - Inadequate time
  - Poor remuneration,
  - Nihilistic attitudes
  - Perceived lack of services or treatments for dementia
- Other reasons
  - False negative diagnoses, e.g. GPs reassuring patients that their memory loss is merely old age
  - Also, false positive diagnoses, i.e. misdiagnosing other conditions as dementia.
- Reasons for delay in or lack of diagnosis from patients' and carers' points of view include:
  - Lack of awareness that memory loss and other cognitive symptoms can be early signs of dementia
  - Patient and carer attitudes to dementia e.g. fear, stigma
  - Lack of access to medical assessment (though this less for primary care and more as regards specialist confirmation) especially in rural and remote areas and in certain communities (e.g. Indigenous, CALD)

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<sup>1</sup> For example in a current NHMRC funded study across 5 Australian cities (Newcastle, Sydney, Melbourne, Adelaide and Bendigo), GPs identified as possible, probable or definite dementia only 65/143 (45.5%) of people identified with dementia by the research nurses. Of those identified 58 (89%) had some sort of investigation, 25 (38%) had some sort of cognitive function test and 20% were referred to services

<sup>2</sup>Brodaty H, Howarth, G., Mant, A., Kurrle, S.E. General practice and dementia: A national survey of Australian GPs. *Medical Journal of Australia*, 1994;160:10-14.

<sup>3</sup>[Draper B](#), [Peisah C](#), [Snowdon J](#), [Brodaty H](#). Early dementia diagnosis and the risk of suicide and euthanasia. University of New South Wales, Sydney, Australia. [b.draper@unsw.edu.au](mailto:b.draper@unsw.edu.au)

It is important to note that “there is already evidence that persons with mild cognitive change and early dementia are at risk of suicidal behaviour”<sup>3i</sup> and therefore management strategies must include awareness of this potential

### *Management*

- GPs do not provide the full range of recommended management options to their patients.
- Carers are frequently stressed and depressed. Poor integration with available support and information services results in missed opportunities to organise legal and financial affairs and plan for future care as well as access to emotional support, community services and packages of care.

### *Residential Aged Care Facilities (RACFs)*

- Problems in care of residents in aged care facilities by GPs were frequently raised by families, by RACF providers and by GPs themselves.
- Families noted the difficulty in having GPs make visits to nursing homes, especially when the person with dementia was placed in a facility distant from their home and therefore far from their usual GP thereby requiring consultation with a new GP.
- RACF providers complained that it was often difficult to get GPs to visit residents.
- GPs noted the difficulties and inefficiencies in seeing patients in RACFs, viz. travel time and difficulties finding residents, their files and their nurse.
- GPs report pressure to prescribe psychotropic medications some of which have been found to be potentially harmful.

### **Outcomes sought**

- Better promulgation of preventative strategies by GPs, e.g. management of cardiovascular risk factors for dementia starting at mid life
- More accurate and timely diagnosis
- Early link to information and support
- Attention to carer support needs
- Appropriate management of dementia as a chronic and complex disease
- Better referral pathways and access to dementia experts and medical specialists when diagnosis and management is complex, such as with young patients, atypical symptoms or psychotic or severe behavioural disturbances.
- Better primary care for RACF residents
- Acknowledgement and management of dementia as a terminal illness at time of diagnosis

### **Achieving outcomes**

Outcomes could be achieved through a range of strategies/initiatives to be conducted or funded at different levels of intervention - some suited to a national approach, other specific to state or local levels.

## **Possible strategies**

### **1. Systemic issues**

- a. Adequate remuneration/appropriate funding models for the assessment, diagnosis and ongoing management process
- b. Effective use of MBS items such as health assessments, management plans and team care arrangements.
- c. The capacity for independent remuneration for consulting with carers
- d. Better incentives for the provision of primary care services to residential care
  - i. Consider separate stream of extra training for GPs interested in aged care which once accredited would enable them to receive supplementary payments for nursing home attendance, eligibility to prescribe cholinesterase inhibitors for Alzheimer's disease without the need for specialist referral and possibly a moiety for cognitive testing. (In Netherlands there is a scheme for licensing nursing home specialty doctors).
- e. Integration of GPs, Medicare Locals, Local Health Networks and Aged Care so that GPs and other primary care providers are aware of the services available for dementia in their local area.

### **2. Clinical support**

- a. Clinical guidelines that are simple and easy to use and available in laminated and electronic formats
- b. Care Planning templates/use of Medicare items (simple, easy to use)
- c. Carer "prescription pad"

### **3. Training and education**

Support for continuing professional development of GPs, practice nurses and other primary health professionals in dementia care through providing access to evidence based training and education, (including access by bilingual GPs and Aboriginal Medical Services). *Good clinical governance*: health professionals should be educated, assessed for competency, regularly and randomly monitored and reviewed. Topics should include:

1. Risk factors and prevention
2. Diagnosis
3. Specific population groups
4. Assessment tools
5. Treatment options
6. Non-pharmacological and pharmacological interventions for BPSD
7. Legal issues, driving, advance care planning
8. Ongoing health management
9. Carer support – local support services

10. Advanced dementia, and the particular and very specialised issues relating to end of life care for people with dementia

#### 4. Models of service delivery

- a. More visible, accessible memory services
- b. Greater role for practice nurses, specialist memory practice nurses
- c. Dementia CNCs /Nurse practitioners providing consultation and advice to primary care
  - i. In order to cope with the expected increase in numbers of people with dementia, alternative models of primary care for dementia are proposed. The NSW Dementia Services Framework 2010-2015 recommends a hub and spoke model of practice nurses receiving training in cognitive testing from a community nurse or allied health dementia specialist and performing testing as indicated (in liaison with GP) or as part of 75+ assessment with availability of hub nurse/allied health specialist for consultation. Straightforward diagnoses will be made by the nurse in consultation with the treating GP. More complex cases will be referred to the nurse/allied health dementia specialist for comprehensive assessment and if required, consultation with medical specialists such as geriatricians if diagnosis is unusual or difficult and or psychogeriatricians for psychotic or severe behavioural issues.
- d. Referral pathways for dementia expertise agreed to and promoted. Different models of pathways to diagnosis exist:
  - i. GPs (and primary care nurses) screen, assess those screening positive more comprehensively (including investigations to rule out reversible causes of cognitive impairment), make a diagnosis where this can be clearly made, and refer to secondary specialist services those with complicated presentations, uncertain diagnoses or where special issues exist e.g. those with onset of dementia symptoms at young age.
  - ii. As for (i) but only GPs who have had extra training in aged care make diagnoses; otherwise all patients suspected of having dementia are referred to secondary specialist services.  
*A model exists in mental health whereby GPs who undertake extra training are eligible for supplemental rebates. A similar system could be introduced for aged care so that GPs who undertake such training would be eligible for extra rebates for cognitive testing, for nursing home visits and would be eligible to prescribe anti-Alzheimer's drugs which currently require specialist authorisation. Such a scheme could also relieve the shortage of aged care specialists in rural areas and among CALD and Aboriginal communities.*
  - iii. People with cognitive complaints can access specialist services directly e.g. walk-in self-referral memory disorders or CDAMS clinic.
  - iv. A practice nurse triage system attached to GP group practices or Medicare Locals whereby the nurse would perform cognitive screening on persons at risk or with complaints and liaise with the

treating GP and receive support from a specialist nurse or allied health person i.e the proposed NSW Health hub and spoke model. Practice nurses would require adequate training and support and periodic updates.

- v. In-home evaluation including addressing participant resistance to travelling to Centres for assessment because of distance, problems with transportation and loss of earnings for family members who may have to take time away from paid employment. Home visits may provide more accurate estimations of coping ability in the usual environment.

*Comment:* It is important to recognise that there may not be enough specialist dementia services currently to provide for options (ii) and (iii) generally and certainly not outside major cities. Comparative costs will need to be considered. Consideration should be given to improving access to specialist dementia services in order to encourage GPs to identify possible dementia. Work in Europe has shown that where specialist dementia identification and management services are more easily accessible, GPs are more likely to identify dementia.

A mix of models may be appropriate or streaming/ triaging of cases such as by severity or complexity and setting.

- e. Specialist health/mental health services for older people – outreach/mobile team to GP practices or Medicare Locals (which would then reach out to practices eg like the National prescribing Service), and to residential care facilities to support primary care practitioners.

## 5. Public awareness

- a. Through Alzheimer's Australia campaigns
  - i. "*Dementia is a word not a sentence*",
  - ii. Not all memory loss is dementia; some causes of memory loss are reversible, see your GP
  - iii. More positive messages that help is available
- b. Through public health campaigns that promote an understanding of normal ageing, normalises planning ahead, and encourages us to put a range of mechanisms in place as we age (wills, Enduring Power of Attorney, enduring guardianship discussions re advance care planning)
- c. Public awareness that dementia is a terminal illness

## 6. Further research into above – translation of research into practice, e.g.

- a. Best ways for GPs to improve their skills in diagnosis and management
- b. Evaluate alternative models of primary care for dementia, e.g. practice nurses, nurse practitioners, community dementia CNCs (as outlined).

## B) Improving timely diagnosis in other health settings

- 1. Diagnosis of cognitive impairment, specifically of dementia and delirium, is often overlooked in when older people are admitted for medical or surgical reasons to

emergency departments or acute hospital wards. Yet dementia is associated with longer length of stay, behavioural complications, higher rates of falls and fractures and more expensive admissions than non-demented patients with same conditions.

2. Management of people with dementia in hospitals can be sub-optimal if health professionals are not aware of the limitations of cognitively impaired patients in even seemingly simple matters such as filling in menus or adhering to treatment regimens.
3. Early diagnosis combined with training of hospital health professionals into how to assist patients with cognitive impairment has the potential to reduce complications of care for their primary reason for admission and decrease length of stay.
4. Improved management in Residential Care facilities to prevent unnecessary hospital admissions

### **C) Benefits of early diagnosis. How can early diagnosis:**

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

- i. By reversing dementia if a reversible cause can be discovered; this is uncommon but does occur and every person with symptoms of dementia must have a comprehensive assessment to rule out this possibility
- ii. By enhancing safety in workplace for those still working – supervision to avoid mistakes or accidents, reallocation of duties to fit with retained capacities – and so remain active for longer
- iii. By monitoring and if necessary assessing driving so as to enhance safety with driving
- iv. By optimising management of other medical conditions e.g. through strategies to remind affected persons to take medication regularly, which can be critical for certain conditions such as diabetes, and so maintain the health of persons with dementia for longer
- v. By alerting the person, and his or her family, friends and doctor to the need to assist the person psychologically and so mitigate or prevent concomitant depression or anxiety
- vi. By helping families and friends to understand changes in people with dementia leading to better relationships and development of strategies to compensate for cognitive deficits
- vii. By receiving advice from health professionals such as occupational therapists and from Alzheimer's Australia (*Living with Memory Loss* course) on strategies to compensate for memory loss.
- viii. As diagnosis is essential before commencing anti-Alzheimer's drug treatment, by enabling such medications to be commenced earlier which may have greater benefit in helping people with dementia stay independent longer.

#### **2. Increase opportunities for continued social engagement and community participation for people with dementia?**

- i. By alerting others to make them more tolerant and supportive e.g. golfing or bowling partner who can keep score for person with poor memory, allowances for bridge partner
- ii. By structuring social engagements so as not to be overwhelming
- iii. Through support groups for people with early dementia which can be virtual (e.g. [www.dasninternational.org](http://www.dasninternational.org)), organised locally or through Alzheimer's Australia
- iv. By building on retained strengths of person with early dementia e.g. activities where recent memory is not essential such as tennis, chess, trivial pursuits (which taps into long-term memory), walks with friends.

**3. 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?**

- i. by enabling planning for future – life decisions, living arrangements, proximity to services and family, timing of events such as an overseas trip
- ii. by alerting the person and the family to the need for financial planning
- iii. by enabling affairs to be arranged in timely manner while person with dementia still has legal mental capacity – enduring power of attorney, enduring guardianship, advance directives – to give the person reassurance that his or her wishes will be respected and carried out.
- iv. Programs are available through Alzheimer's Australia to achieve this – the Living with Memory Loss Program and counselling.

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

- i. General community approach requires general media awareness campaigns as has been undertaken so successfully by Alzheimer's Australia for many years. Encouragement of inclusion of dementia themes in films, television and print media. Most stories are geared to tragedy of dementia, hardly any to success stories about maintaining quality of life and living well with dementia.
- ii. Awareness is needed to raise the clinical, ethical, and legal dilemmas associated with particular end-of-life issues in the context of dementia. Issues such as terminal dehydration to ensure a peaceful death for people with dementia need to be openly discussed and debated.
- iii. Improved recognition for end-of-life care for people with dementia within the Accreditation Agency
- iv. For specific communities such as those from culturally and linguistically diverse backgrounds, those from Aboriginal and Torres Strait Islander communities, those living in rural and remote areas and people with dementia living alone, concerted efforts and different strategies are required. Such communities often have different beliefs about dementia and about associated behavioural and psychological symptoms; these may have non-medical explanations and may be associated with significant stigma.

- v. Doctors, especially general practitioners, are the health professionals that most people will turn to if worried about their memory. Yet there is robust evidence that dementia, especially when in its earlier stages, is under-recognised by GPs. Training and incentives for GPs (and/or their practice nurses) to reduce the delay in diagnosis are discussed above in this submission.
- vi. Other health professionals such as emergency department health workers and pharmacists need to be aware of dementia and its presentations.
- vii. Other professional groups who come into contact with people with dementia during the course of their work. The more salient ones are listed below:
  - i. Police may come into contact with people with dementia who become lost, are victims of fraud or abuse, have traffic accidents, develop delusions about others stealing valuables or rarely, are perpetrators of violence.
  - ii. Ambulance officers may come into contact with people with dementia when they are unable to deal themselves with medical emergencies or have an acute medical event occurring linked to their dementia such as a stroke, epileptic fit or accidental overdose caused by forgetting
  - iii. Bank employees. People with dementia are prone to financial exploitation and assistance and protection of those vulnerable

### **Recommendations**

1. Undertake awareness and education campaigns for primary care professionals, for primary care professionals and consider linking these to supplementary benefits
2. Undertake awareness and education campaigns for hospital health professionals and other front-line professionals about the importance of recognising cognitive impairment and subsequent actions to take
3. Simultaneously undertake public awareness campaigns, e.g. *"It's not just old age!"* to encourage consumer-led requests for assessments.
4. Provide incentives for GPs to be active in checking for cognitive and functional performance in populations at risks such as outlined above (page 3): adequate remuneration/appropriate funding models for assessment, diagnosis and ongoing management process; effective use of MBS items; independent remuneration for consulting with carers; better incentives for the provision of primary care services to residential care; separate stream of extra training for GPs interested in aged care; and integration of GPs, Medicare Locals, Local Health Networks and Aged Care
5. Promote targeted screening (as first step in assessment) and case finding.
6. Promote use of standardised cognitive screening instruments (as have been evaluated by Commonwealth funded Dementia Outcomes Measurement Suite and now available on line [www.dementia-assessment.com.au](http://www.dementia-assessment.com.au)).
7. Evaluate different models of pathways to diagnosis for effectiveness, efficiency and feasibility (see pages 4 and 5)
8. Improve access to specialist diagnostic and management services from primary care.
9. Set targets to evaluate effectiveness of above measures, e.g. halve time from first symptoms to presentation of symptoms to services, and from presentation to diagnosis of dementia; halve number of people being diagnosed with dementia for first time when they are already needing help with basic activities of daily living;

double the number of patients aged 70 years or older being cognitively assessed within 48 hours of admission to hospital or within 4 hours of admission to emergency department; 50% increase in consumer satisfaction

### **Conclusion**

1. Despite dementia becoming increasingly prevalent, many people with dementia are not receiving a timely diagnosis.
2. Timely diagnosis has many potential benefits for the person with cognitive impairment, for the family, for the health system and for society generally.
3. There are strategies that can be initiated now to improve timely diagnosis and management.
4. Planning should start now and in order to demonstrate effects baseline pre-implementation evaluation should precede introduction of new measures.

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<sup>iii</sup>[Draper B, Peisah C, Snowdon J, Brodaty H](#). Early dementia diagnosis and the risk of suicide and euthanasia. University of New South Wales, Sydney, Australia. [b.draper@unsw.edu.au](mailto:b.draper@unsw.edu.au)