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The Hon Mr Steve Georganas MP
Chair
House of Representatives Standing Committee on Health and Ageing
Parliament of Australia
Canberra
Via email: haa.reps@aph.gov.au

Submission No. 060
(Dementia)
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Dear Mr Georganas

**Submission to House of Representatives' Standing Committee on Health and Ageing
Inquiry into Early Diagnosis and Intervention in Dementia**

Please accept the following submission to the Standing Committee's Inquiry into Early Diagnosis and Intervention in Dementia. This submission will inform the Standing Committee of two initiatives involving the Australian Institute for Primary Care & Ageing (AIPCA), with the aim of demonstrating how further research and investment in this area will bring about improvements in the early diagnosis and intervention in dementia.

The two initiatives are:

- *Improving GP awareness of dementia*: development, delivery and evaluation of education content on the topic of diagnosing dementia for general practitioners (GPs)
- *Development of new information resources*: background to the development of a new information package about cognitive management and psychological support strategies.

1. GP awareness of dementia

1.1. The Australian Centre for Evidence Based Aged Care (ACEBAC), a constituent unit of AIPCA, hosts the Victoria and Tasmania Dementia Training Study Centre (DTSC). DTSC is funded by the Australian Government's Dementia Initiative and aims to provide dementia education to health professionals and to promote the translation of research evidence into practice. At present, DTSC is conducting several activities relating to the provision of dementia education to GPs, including a project focussed on the development, delivery and evaluation of an education program for GPs on the topic of diagnosing dementia. The aims of this GP education program are to:

- a. Develop education content relating to diagnosing dementia
- b. Develop an education resource for GPs on the topic of diagnosing dementia
- c. Deliver the education content in-surgery supported by educational resource and toolkit
- d. Evaluate the effectiveness of the delivery model
- e. Distribute the education resource nationally
- f. Inform strategies to deliver effective education to GPs nationally.

- 1.2. This project is being conducted in collaboration with the Wicking Dementia Education and Research Centre (University of Tasmania) and the South Australia and Northern Territory DTSCs. The project arose in response to the continuing problem of dementia under-diagnosis by GPs, with many elderly people with dementia never receiving a formal diagnosis. Reasons for low diagnosis rates have been examined in Australia, the United Kingdom and parts of Europe.¹ In brief, dementia takes time and observation to diagnose because it is a complex and variable condition; there are also problems associated with the available screening instruments and shortages in specialist expertise. Reluctance among GPs to identify possible dementia and to follow this up with a formal diagnosis also reflects knowledge- and time-related factors. These include a reported lack of confidence among GPs in diagnosing early dementia, a concurrent lack of the time required to observe patients in order to make a firm diagnosis and, a feeling among many GPs that the early diagnosis or any diagnosis of dementia is not important, due to the incurable nature of most dementia.²
- 1.3. The education program will be offered to approximately 200 GPs, with 24 sessions offered in the north and northwest regions of Tasmania, and a further 18 sessions offered in southern Tasmania. Key issues addressed in the education program and resource include:
- a. Types of dementia
 - b. The five domains of dementia
 - c. Why making a diagnosis of dementia is important
 - d. How to diagnose dementia
 - e. Differential diagnosis of dementia
 - f. Best practice referrals to a memory clinic or specialist
 - g. Services available to support people with dementia and their carers.
- 1.4. The project is being conducted in three separate phases. Phase 1 involves development of the education program and a supporting resource in collaboration with the University of Tasmania, the Royal Hobart Hospital and the Divisions of General Practice in Tasmania. The education resource will consist of an education package and a toolkit. Phase 1 will also see the commencement of the process of recruiting GPs and collection of pre-intervention data.
- 1.5. Phase 2 involves face-to-face delivery of the education program, as supported by the education resource, in individual GP practices in the evening. Phase 3 will involve evaluation of the effectiveness of the content, resource and delivery method. The objectives of the evaluation are to:
- a. Assess any changes in GPs knowledge of/attitude towards dementia diagnosis
 - b. Measure any changes in the number of clients per practice diagnosed with dementia

¹ Hansen EC, Hughes C, Routley G and Robinson AL (2008) General Practitioners' experiences and understandings of diagnosing dementia: Factors impacting on early diagnosis. *Social Science and Medicine* 67:1776-1783; Iliffe S, Manthorpe J and Eden A (2003) Sooner or later? Issues in the early diagnosis of dementia in general practice: a qualitative study. *Family Practice* 20:376-381.

² Bamford C, Lamont S, Eccles M, Robinson L, May C and Bond J (2004) Disclosing a diagnosis of dementia: a systematic review. *International Journal of Geriatric Psychiatry* 19:151-169; Carpenter B and Dave J (2004) Disclosing a dementia diagnosis: A review of opinion and practice, and a proposed research agenda. *Gerontologist* 44:149-158.

c. Identify levels of GP satisfaction with the training program.

- 1.6. To date, the education content has been developed and delivery to GP practices in Tasmania has commenced. A train-the-trainer facilitation package is in development to enable national dissemination of the education program.
- 1.7. We submit to the Inquiry that education program such of this are of vital importance to improving early diagnosis and intervention in dementia. Our development and evaluation of this particular program in Tasmania could serve as the basis for a national approach that will address a substantial barrier to early diagnosis and intervention for people with dementia.

2. Information resources

- 2.1. The Lincoln Centre for Research on Ageing (LCRA), another of AIPCA's constituent units, has developed a new evidence-based resource for people with mild cognitive impairment (MCI) and early-stage dementia (and their carers). Development of this information resource has been conducted by LCAR in collaboration with Southern Health, Monash Ageing Research Centre (MONARC) and Alzheimer's Australia. Funding for the development of this resource was made available by the J.O. & J.R. Wicking Trust.
- 2.2. Our information resource consists of a series of simple, easy-to-read hand-outs covering a range of topics. These hand-outs can be tailored to the individual needs of people with MCI/early-stage dementia and their carers. The range of topics includes:
- a. Focusing attention and avoiding distractions
 - b. Mental techniques
 - c. Using aids
 - d. Managing language problems
 - e. Managing visual processing difficulties
 - f. Getting organised and solving problems
 - g. Adjustment to thinking and memory difficulties
 - h. Supporting someone with memory and thinking difficulties.
- 2.3. In line with the Inquiry's first and second terms of reference, these information resources aim to provide people with new strategies that can assist them to remain independent for as long as possible, and suggestions about how to remain socially engaged.
- 2.4. A sample of these information resources is shown below; the full package is available at <http://www.latrobe.edu.au/aipca/projects/mci>.



Maximising your thinking and memory abilities

Ten key strategies:
to improve your memory and thinking

1) Maintain a positive attitude

The way you feel about yourself can affect how you view life and the extent to which you seize opportunities and keep persisting.

Avoid thinking negative things about yourself, such as “I can’t do that” or “I’m too old”. Instead of thinking about what you can’t do, remember what you can do.

Older people can learn to apply new strategies to cope with memory and thinking difficulties!

2) Stay calm and don’t panic

- 2.5. LCRA has conducted an evaluation of the impact of this information resource. Our evaluation demonstrated 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. However, people with MCI/early-stage dementia may struggle to recall handout contents. Our abstract to the International Neuropsychological Society’s recent meeting, describing our evaluation of the information resource, is included as Attachment I to this submission.
- 2.6. Consistent with the Inquiry’s fourth term of reference—awareness raising in the community—we submit that the Inquiry should consider recommending broader application of these (and similar) information resources as a “minimum standard” of information provision. Service providers are already adopting these resources into practice; despite minimal publicity, the package has already been downloaded approximately 700 times by a range of health professionals across Australia and are currently being utilised by several Cognitive, Dementia and Memory Services (CDAMS) across Melbourne.
- 2.7. In addition, Alzheimer’s Australia are translating these resources into a range of languages other than English and to make available hard copies to the general public. Alzheimer’s Australia and LCRA are attempting to obtain funding for the development of a website to host these information resources and to develop new counselling interventions that incorporate the resource and maximise its utility. Such multi-modal approaches are likely to improve awareness and assist people with MCI/early-stage dementia and their carers.

Summary

We submit that the Inquiry should note the two initiatives described in this submission as examples of approaches designed to improve dementia diagnosis and intervention. The Inquiry should also note that while these (and many other) initiatives succeed as projects, wide-scale rollout and practice change requires additional investment; such investment is not always forthcoming. Funding for “scale-up” of existing (and successful) initiatives should be available from a separate pool, with the stated aim of assisting the move from project to practice.

Yours sincerely

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Attachment I

Ryburn B, Varanelli L, Wells Y (2011) How Helpful are our Handouts? An Evaluation of Information Handouts for Clients with MCI and their Family Members. International Neuropsychological Society Mid-Year Meeting/ASSBI 4th Pacific Rim Conference. *Journal of the International Neuropsychological Society* 17(S2): 46 [Abstract].

Objective: Most health professionals hope to empower clients and their families with the provision of information handouts. However, it is rare that we attempt to evaluate the effectiveness of our handouts. Do the majority of clients or their families take them home and read them? Do clients utilise any of the strategies provided, and to what extent does cognitive impairment affect this? Are some handouts more effective than others? An evaluation of information handouts using telephone interviews with clients and family members is currently underway in a Memory clinic in the south-east of Melbourne.

Participants and Methods: We compared outcomes (including client quality of life and wellbeing) for two groups of forty clients and family members: the intervention group, which received a new information resource, and a comparison group, which received 'service as usual'.

Results: Of the group receiving 'service as usual', the majority reported reading the handouts they received and finding them of use (67% of family members and 100% of clients), but fewer reported referring to the handouts on an ongoing basis (53% of family members and 42% of clients) or were able to describe which strategies they had adopted (20% of family members and 42% of clients).

Conclusions: These initial findings suggest that the handouts provided as part of 'service as usual' may not be a sufficient to educate clients with MCI about the range of cognitive strategies available. This paper will present an overview of the results from the evaluation of the handouts and discuss the broader clinical implications.