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The Royal Australian College of General Practitioners

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Inquiry into dementia early diagnosis and intervention

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Stakeholder details

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1. About RACGP

The Royal Australian College of General Practitioners (RACGP) thanks the House of Representatives Standing Committee on Health and Ageing for the opportunity to contribute to the inquiry into early diagnosis and intervention in dementia.

The RACGP is the specialty medical college for general practice in Australia, responsible for defining the nature of the discipline, setting the standards and curriculum for education and training, maintaining the standards for quality clinical practice, and supporting general practitioners in their pursuit of excellence in patient care and community service.

2. Introduction

General practitioners (GPs) play an important role in recognising, assessing, diagnosing and managing dementia, and maintaining effective and ongoing communication and coordination between the patient, carer and family with primary and specialist providers. As the main primary health care provider, the GP is the first point of contact for patients concerned with possible memory loss. Approximately 83% of the Australian population consult a GP at least once a year and patients with dementia accounted for 0.4% of all GP encounters in 2009-2010 (1). In 2010-2011, 36% of persons aged 45-54 years saw a GP four or more times, this was much higher (72%) in persons aged >75 years (2).

The difficulties of making an early diagnosis, coupled with limited therapeutic options, are major barriers in diagnosing the disease for GPs. There are limited referral options for difficult cases where the diagnosis is unclear and often the patient has to wait for months to access these services. GPs are aware of difficulties in communication and disclosing that a person has dementia will affect both the patient and the family. In addition, dementia is still stigmatised and many people are anxious and distressed on receiving this diagnosis. The RACGP therefore welcomes the Committee's review into some of these issues.

3. Early diagnosis and intervention by GPs

i. Assessment and recognition

Earlier diagnosis allows people with dementia to plan ahead while they still have the capacity to make important decisions about their future care. In addition, they and their families can receive timely practical information, advice and support. Only through receiving a diagnosis can they get access to available drug and non-drug therapies that may improve their cognition and enhance their quality of life. And, they can, if they choose, participate in research for the benefit of future generations. Evidence suggests that:

- Most people with early stage dementia would wish to be told of their diagnosis.

- Improving the likelihood of earlier diagnosis can be enhanced through:
  a) medical practice-based educational programs in primary care
  b) the introduction of accessible diagnostic and early stage dementia care services (for example, memory clinics) and
  c) promoting effective interaction between different components of the health system.
- Early therapeutic interventions can be effective in improving cognitive function, treating depression, improving caregiver mood, and delaying institutionalisation (3).

Dementia is often not recognised early in primary care. There is frequently a delay from onset of symptoms to presentation of these symptoms to the GP, resulting from stigma and lack of recognition by the patient (4). There may also be a delay from the presentation of symptoms to diagnosis, losing valuable opportunity for intervention. It is important that GPs recognise the possibility of dementia when people present with memory loss or other symptoms, and work to identify dementia when it is present. However the task is not simple. Only one in five people who present with memory problems actually has dementia (5). Many people fear they may be getting dementia when they suffer increased duration to recall or lack initial registration due to distraction, stress and depression. GPs should test these people and provide reassurance that their signs do not imply that they will suffer from dementia, especially if a similar outcome has occurred to other family members or friends. GPs can monitor patients over time and can track/detect gradual deterioration in mental functioning. For many patients this is better than relying on a one off assessment. Without early testing and diagnosis these people may face many years of unrelieved fear.

As dementia more commonly occurs in older age groups, multi-morbidities such as hypertension, diabetes, depression and arthritis often exist and complicate diagnosis (6). Testing for dementia in primary care can involve a significant investment in time for the GP, still with an uncertain outcome.

Several international guidelines all recommend that initial assessment of the patient should include:

- comprehensive medical history
- physical examination
- necessary laboratory and imaging tests (7-9)

Full medical history should include interviews with both patient and carer, separately and at the same time to ensure a complete profile is obtained. Routine physical examination and medical history alone is not sufficient to diagnose dementia, so GPs should also perform cognitive tests to screen for cognitive impairment. However, diagnostic tools are limited in their effectiveness and can yield false positives and false negatives that complicate diagnosis. The results of diagnostic tests need to be viewed in the light of the patient's premorbid educational level, English language skills, anxiety or depression levels and general physical wellbeing on the day of screening. GPs should also consider any other underlying multi-morbidities which

may cause a delirium or aggravate cognitive impairment. Depression may present a picture similar to dementia. Many medications (particularly those with anticholinergic properties) may cause cognitive impairment in elderly people and complicate the picture. This all makes screening very complex for GPs and adds to the challenge of delivering a difficult diagnosis, or the possibility, to a patient.

In addition to the challenges of diagnosis, GPs needs to keep abreast of the latest available services, networks, guidelines, therapies and legal aspects in addressing dementia treatment. The RACGP recognises the need for ongoing professional training for GPs to improve knowledge and confidence in early diagnosis and management as well as awareness of available support services (10).

ii. Medication prescribing

Early diagnosis allows the planning for prescribing medications. While there are currently no drugs to prevent dementia or modify the neuropathology of the disease, acetylcholinesterase inhibitors and one NMDA glutamate receptor blocker can improve cognitive function and/or delay or lessen the rate of cognitive and functional decline in patients with mild to moderately severe Alzheimer's disease. However, it should be noted that It is difficult for the GP to get access to medication for Alzheimer's, as under PBS conditions, it requires specialist review. Many medications further impair cognitive function in dementia. Even with early dementia people are at increased risk from medications with an anticholinergic effect, or from benzodiazepines. Early diagnosis and intervention can play a role in reducing the risks associated with these medications, especially falls and early placement. As most patients are elderly the likelihood of existing multi-morbidities is high, further complicating medication prescribing. Timely recognition and diagnosis of dementia will assist in ensuring that patients are not placed at unnecessary risk for adverse medication interactions.

iii. Delirium

Delirium is common even in early dementia, and is considered a medical emergency. In delirium, cognitive and other symptoms present acutely, rather than the slow decline usually associated with dementia. The underlying cause of the delirium should be treated and the possibility of underlying dementia considered. Recognition of dementia early in the course of the disease allows this to be addressed and pre-empts the likelihood of falls and other major incidents occurring. This in turn avoids the need to address major consequences as a result of these incidents. As anaesthetics can also cause delirium in dementia, an early diagnosis and awareness allows for any future preparation to manage the post-operative periods, if required. GPs have a role in informing the surgical and anaesthetic team of the presence of dementia and assisting the family to provide additional care during the post-operative period.

iv. Planning for the future

The GP is well placed to inform the patient and family not only about the condition, diagnosis and prognosis but also about the consideration of legal and financial matters, available support, and care options. Early intervention allows for future planning of more complex areas such as financial planning and future care, to

simpler issues such as driving capacity and daily activity. A diagnosis of dementia does not mean that capacity in any area is automatically lost, but it is a trigger for a capacity assessment. Along with early diagnosis and capacity assessments, Advance Care Planning is an area that GPs are well placed to encourage. The RACGP has produced tools and guidance on Advance Care Planning.

v. The importance of caregivers

As dementia impacts not only people who have the disease but also caregivers and family members, the increasing burden of the disease on both patients and carers need to be recognised. Dementia care is challenging and demanding. The slow progression of the disease means that caregiving can be stressful and tiring. Thus the needs of the primary carer, in particular their psychological state and physical health, should be considered. Multiple demands imposed on caregivers can lead to physical and emotional strain, higher levels of depression and psychological problems, financial implications, as well as risk of social isolation. Interventions include informing and educating carers with coping skills, psychological training, support groups and counselling. Overload of carers can lead to early entry into nursing homes or other care facilities and appropriate interventions have been shown to delay patient entry into nursing homes and lessen admissions into hospitals (11). Carer issues can be reviewed by the GP at the same time as the patient – but financial compensation for the GP under Medicare benefits are not currently available for separate carer interviews. Better GP care decreases the likelihood of admissions into hospitals, reducing burden on the hospital system. It also delays entry into nursing homes resulting in better quality of life for patients who are able to remain in their residence.

Hospitals can be dangerous places for people with dementia. With the diagnosis made it might be possible to avoid hospital, or take precautions to keep the patient better oriented. Questions like "is it appropriate to operate on an abdominal aortic aneurysm is a patient with a dementia diagnosis?" as it is a huge operation aimed at avoiding sudden death in the next (X depending on size) years. However the morbidity and time to recover is especially large, and the time the patient is losing is likely to be their last remaining real quality time.

Utilisation of support groups such as Alzheimer's Australia and counselling is generally low among carers. GPs can play a role in encouraging carers to use/obtain more support and as much as possible help carers overcome these barriers. Studies show that carers are more likely to use these services if recommendations are made by the GP (12).

vi. Working with other services

Effective coordination of ongoing health and social care services post-diagnosis is vital for achieving appropriate support and improved quality of life for people with dementia and their caregivers. A wide support network including access to relevant information for managing dementia, community services, services for continuing care and end-of-life palliative care will need to be considered. We hope that Medicare Locals will offer GPs the opportunity to be involved in designing systems of care for people diagnosed with dementia, to provide better overall frontline support and care

involving relevant stakeholders within the local community. Medicare Locals may also help provide integration between different providers and support services and appropriate referral to relevant support agencies/groups. GPs have an important role to play in the coordination across a range of different services to provide a seamless transition from one phase to the next. The role of an extended primary care team (such as practice nurses performing the 75Plus health assessments in the home) could provide extra support services and should be encouraged.

vii. Younger onset dementia

Mental health symptoms that present in people aged in the fifties or younger are often an early sign of dementia. Non-recognition means that many of these people will have prolonged incorrect psychiatric treatment without results. GPs need to be mindful of an early diagnosis of dementia, and that in younger people with psychiatric symptoms frontotemporal dementia should be considered. The possibility of dementia should also be considered by GPs caring for people with a range of chronic diseases, including Multiple Sclerosis, HIV and drug and alcohol abuse.

viii. Preventive activities

While large randomised controlled trials are still being run, there is growing evidence (13) that activities such as exercise and a healthy diet can delay the onset of dementia or slow down progression. Monitoring and management of cardiovascular risk factors (eg. hypertension, obesity, high cholesterol) is also important and may slow down onset or prevent dementia. GPs are well placed to take action in these areas and advise people about the activities that can prevent dementia.

4. Concluding remarks

The difficulties of making an early diagnosis of dementia coupled with limited therapeutic options are major barriers in diagnosing the disease for GPs. There are limited referral options for difficult cases where the diagnosis is unclear and often the patient has to wait for months to access these services. GPs are aware of difficulties in communication and disclosing that a person has dementia will affect both the patient and the family. Dementia is still stigmatised and many people are anxious and distressed on receiving this diagnosis.

While a GP should be able to deliver the news of the diagnosis, therapeutic options are still limited and it is difficult to deliver this news with no good treatment options available. Appropriate guidelines will help GPs in early diagnosis and tailoring care management for both patient and carer. The RACGP's Guidelines for preventive activities in general practice (13) can be used as a guide to assist GPs in recognising symptoms and signs of dementia. It should be noted that these guidelines do not recommend screening for dementia in asymptomatic populations because the evidence does not support it. This resource also has recommendations of protocols and tests to be used for cognitive assessment (13). Other useful resources have been published by the University of New South Wales (with endorsement by the RACGP) (14) and by Alzheimer's Australia (15). Continued professional development and upskilling of GPs in early intervention and diagnosis, ongoing

management as the disease progresses and partnerships with carers, supported by the development of appropriate practice guidelines will be essential in improving care for people with dementia. There is a need for ongoing support and ensuring continued improvement in the quality of life of people afflicted with the disease. It is therefore important that GPs have skills in required tasks and the correct attitudes to both patient and carer.

The ongoing government dementia initiative aims to provide a 'better quality of life for people living with dementia, their carers and families' (16). The UK Dementia Health strategy provides funding to train all GPs in dementia diagnosis and care (17). Training of GPs is important to reduce the time from identifying onset of symptoms to diagnosis of dementia. Such training would be assisted by a clearly defined pathway to dementia diagnosis in primary care, with recognition of the limitations of cognitive screening tests. In addition, further training of practice nurses and other primary healthcare professionals in dementia specific skills will be useful in supporting the GP, and provides services to patients in less accessible areas. Medicare benefits targeted to support caregivers and/or family members caring for the patient would further enhance support and care.

The RACGP recognises that people with early stages of dementia are not being diagnosed in primary care and welcomes future Government support for primary care providers to undertake timely dementia diagnosis (18). The initial identification of dementia is an important function of primary care. The challenge for governments is to continually develop and improve early diagnosis, support and coordinate services to cater for both patients with dementia and their caregivers.

5. References

1. Britt H, Miller GC, Charles J, Henderson J, Bayram C, Pan Y, et al. General practice activity in Australia 2009–10. : University of Sydney and AIHW2010 (Accessed May 2012).
2. Australian Bureau of Statistics. Patient Experiences in Australia: Summary of Findings, 2010-11 2011 (Accessed May 2012) Contract No.: 4839.0.
3. Price M, Bryce RF, C. World Alzheimer Report 2011. The benefits of early diagnosis and intervention. 2011 (Accessed May 2012).
4. Speechly CM, Bridges-Webb C, Passmore E. The pathway to dementia diagnosis. Med J Aust. 2008 Nov 3;189(9):487-9.
5. Pond D. The detection and management of dementia in general practice. NHMRC Research Grant, unpublished. 2012.
6. Schubert CC, Boustani M, Callahan CM, Perkins AJ, Carney CP, Fox C, et al. Comorbidity profile of dementia patients in primary care: are they sicker? J Am Geriatr Soc. 2006 Jan;54(1):104-9.
7. Bridges-Webb C, Wolk J, Pond D. Care of Patients with Dementia in General Practice. Guidelines.: NSW Health 2003.
8. National Institute for Health and Clinical Excellence. Dementia - Supporting people with dementia and their carers in health and social care. London: NHS2006.
9. Rabins PV, Blacker D, Rovner BW, Rummans T, Schneider LS, Tariot PN, et al. American Psychiatric Association practice guideline for the treatment of patients

with Alzheimer's disease and other dementias. Second edition. Am J Psychiatry. 2007 Dec;164(12 Suppl):5-56.
10. Pucci E, Angeleri F, Borsetti G, Brizioli E, Cartechini E, Giuliani G, et al. General practitioners facing dementia: are they fully prepared? Neurol Sci. 2004 Feb;24(6):384-9.
11. Brodaty H, Green A, Koschera A. Meta-analysis of psychosocial interventions for caregivers of people with dementia. J Am Geriatr Soc. 2003 May;51(5):657-64.
12. Donath C, Grassel E, Grossfeld-Schmitz M, Menn P, Lauterberg J, Wunder S, et al. Effects of general practitioner training and family support services on the care of home-dwelling dementia patients--results of a controlled cluster-randomized study. BMC Health Serv Res. 2010;10:314.
13. Royal Australasian College of General Practitioners. Guidelines for preventive activities in general practice. RACGP 2009.
14. University of New South Wales as represented by the Dementia Collaborative Research Centre – Assessment and Better Care 2011. 14 Essentials for good dementia care in general practice. 2011.
15. Phillips J, D. P, Shell A. Quality Dementia Care Series: No time like the present: the importance of a timely dementia diagnosis. : Alzheimer's Australia 2010.
16. LAMA Consortium. Dementia Initiative National Evaluation. Overview and Summary of Main Findings. Final Report. Canberra: Department of Health and Ageing 2009.
17. UK Department of Health. Living well with Dementia: A National Dementia Strategy: UK Department of Health2009 3 February 2009. Report No.: 291591a.
18. Commonwealth of Australia. Living Longer. Living Better. 2012 (Accessed April 2012) Contract No.: D0769.