

## Early Dementia

### Terms of Reference

Australia's population is ageing and over the next 20 years the number of people with dementia is predicted to more than double. Early diagnosis and intervention has been shown to improve the quality of life for people with dementia, as well as for family members and carers.

The Committee will inquire into and report on the dementia early diagnosis and intervention practices in Australia, with a particular focus on how early diagnosis and intervention can:

- improve quality of life and assist people with dementia to remain independent for as long as possible;
- increase opportunities for continued social engagement and community participation for people with dementia;
- 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; and
- how best to deliver awareness and communication on dementia and dementia-related services into the community.

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To Members of The Standing Committee on Health and Ageing,

**RE: *Dementia: Early diagnosis and Intervention.***

Preamble:

As a general practitioner interested particularly in the care of the elderly in the community and aged care facilities I have eleven years experience of contributing to the care of patients with all levels of cognitive impairment.

Dementia is not a condition which simply appears and can then be diagnosed. It usually has a gradual onset, with cognitive decline suspected by family and carers early, and then becoming more obvious as time passes. The tendency is usually not to confront a person with this suspicion immediately as all involved are keen to preserve the usual arrangements. Assessment and investigation of the symptoms to exclude other causes of memory loss and confusion is routine medical practice, even though the real purpose

of that investigation may not be overtly presented to the patient and their family.

Wisely, patients tend to be protective of their independence, but this is a barrier to intervention. There is a strong tendency for care providers to take over the lives of the elderly, a process that strips the patient of their independence. Therefore, statements about cognitive decline can be intensely threatening to the patient. Questions immediately arise about the patient's capacity to drive safely, live alone, manage medication, manage food, operate equipment, and maintain their home, for example. Patients' self-interest often leads them to resist admitting that they may not be able to cope. General practitioner's sensitivity to their patients' aspirations can be misinterpreted as inability to recognize the problem of cognitive impairment.

There may also be uncertainty about patients' longevity where there are multiple health problems in existence. When a patient has complex care needs the issue of cognitive impairment colours all the management issues, but those other problems are liable to reduce the range of effective treatments applicable to that individual. An example may be that cognitively impaired patients with significant co-morbidities are less able to participate in social activities and other cognitively stimulating events.

Thirdly, even quite isolated individuals at high risk of poor coping cannot be forced to do anything about their cognitive impairment. It often, possibly it *usually*, requires a breakdown in health to create

conditions in which the person has no choice but to move into a situation where they are cared for better.

Another barrier to early diagnosis and management of dementia is the access to effective treatments. Effective treatments will include:

- a. creating a stable living environment that is familiar
- b. preserving cognitive activity (most aged care facilities do not provide sufficient stimulation to residents)
- c. reducing vascular disease risk factors such as dyslipidaemia and hypertension
- d. taking vitamin E as an anti-oxidant for the lipids in the brain
- e. anti-cholinesterase inhibitors (these are very effective for some patients but access is very difficult as many of our patients are reluctant to repeatedly attend a neurologist due to the inconvenience and the cost)
- f. behavioural treatments to manage depression, delusions, and aggression
- g. supporting families and carers of cognitively impaired patients
- h. treating the most severe complex chronic care needs of many of these patients by a team-based approach led by specialist geriatricians and community dementia nurses

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

Allow easier access to anticholinesterase inhibitors. This will give a specific reason why GP's should make early diagnosis explicit for the patient and their family. At present access to this type of

medication is restricted and involves at least two visits to a specialist. This medication can be very effective in helping some patients function at a dramatically improved level.

Encourage the patients to remain in their own homes as long as possible– this is the key feature of independence in many patients' eyes. Early diagnosis and intervention can allow preparation to facilitate staying at home.

Preserve general health and well-being by facilitating primary care services such as GP, physiotherapy, and group exercise and activity classes. Access for the GP to resources to maintain physical wellbeing of the cognitively impaired patient facilitates the quality of life and independence of the cognitively impaired patient, for example by reducing the medication load which may impact on cognition, and makes it easier for carers to manage the patient at home.

Fund medication dispensing aids such as Webster packs. This means mistakes may be reduced in medication dispensing. This does not mean that the capable patient has their independence reduced by imposing Webster Packs where they are not needed– a common problem in my experience.

Avoid systems which rely on scarce resources such as medical specialists for approval– getting a consultation with neurologists and geriatricians can be extremely difficult and expensive. This effectively disenfranchises those patients, delays treatment, and

increases the likelihood of that patient requiring a higher level of care

Increase the number of EPC allied health consultations available to dementia patients– for example one occupational therapy and one dietician assessment each per annum could be allocated so that mobility aids, home safety, and nutritional assessment can be professionally addressed more rigorously.

Encourage, or make it compulsory, that the Comprehensive Medical Assessment that such patients would be eligible for be conducted as a home visit so that the health professional conducting the visit has an opportunity to detect problems and report them.

Provide increased respite care for the patient to enable the patient's carer to undertake their own activities. 2–3 hours isn't really enough, though it is appreciated. Day centres have an important role to play in social, exercise and respite functions. Such centres could be better targeted to early dementia patients to provide sufficiently interesting activities.

Encourage continuation of general practitioners as the hub of patient care in dementia. This requires fortitude to resist the constant calls for increased specialisation of nursing and medical services. The highest level of care possible is the specialised multi-disciplinary team led by a Geriatrician, but this level of care is really appropriate for the challenging cases, and otherwise it is unlikely to be cost-effective. However, what specialisation does, where it goes too far, is fragment the care available and separate the patient from

their GP. I observe that specialised services for other areas of medicine sometimes slip into routine assessment procedures such as a battery of blood tests which is unreflective, recommendations which are impractical to implement in the patient's environment or are already being tried, and superficial or trivial elements of care being actually provided. This has to do with the scale of resources required to make such intensive services really work well.

Consistent and regular consultation with one GP who has the authority to arrange assessment and treatment seems to me to be the most effective approach to cognitive impairment. Sometimes I can see what needs to be done, but it cannot be paid for, and sometimes we need additional help with issues which are difficult to manage. These are issues your Committee can address.

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

This is important as the greatest problem in aged care is boredom. The elderly want to have something useful to do. Of course, in an institution it is not acceptable to allow the elderly to take risks or appear to be exploited as free labour, so they tend to do very little—a recipe for rapid deterioration. Furthermore, the particular constellation of cognitive and physical disease burden, and personality, of these patients means that individually tailored

solutions are required that are expensive to formulate and difficult to sustain.

Obviously patients in their own homes can be very isolated as well. Ironically, a lot of healthy people are unemployed and looking for meaningful activities of their own, which the elderly could benefit from.

Early diagnosis is an opportunity to deliberately involve patients in appropriate activities to slow down disease progression and for them to become engaged and familiar with the social setting, improving the likelihood of maintaining that activity as cognitive function declines.

Increased funding for companionship services is very valuable because many cognitively impaired people are not suitable for a social setting.

Encourage physical activity in these patients in a social setting, as loss of initiative is a key feature of dementia resulting in reduced health– the active over 50's exercise classes and exercise activities in aged care facilities are excellent examples of this.

**How early diagnosis and intervention can 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**

General Practitioners should routinely encourage early planning while the patient has legal capacity.

It is important not to impede effective medical treatment by creating excessively legalistic and bureaucratic systems. Guardianship does not work well for me at the patient level, and should be a last resort. Similarly, creating protected environments for dementia patients in aged care facilities results in loss of independence. The policy of maintaining patients in their own home as long as possible is commendable, because it maximises self-efficacy, preserves a familiar environment, and maximises independence.

**How early diagnosis and intervention can how best to deliver awareness and communication on dementia and dementia-related services into the community.**

Avoid one-stop shops. There cannot be 500 different “one-stop” shops for every disease or social circumstance. There is already a service for this.

The Aged Care Assessment Teams are in a good position to deliver expert contact advice to carers and recommendations to GP’s where the circumstances suit it.

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And

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