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Thank you for the opportunity to present to this committee.

I will focus on selected comments on a few areas, rather than attempting a more extensive coverage of these areas, or dementia in total. A dementia plan developed for the central coast, with a broad input, will be supplied to the committee.

I acknowledge your primary focus upon early diagnosis and its implications to improving patient outcome.

In particular, I wish to discuss dementia within specific populations: younger onset, people with disability, and dementia co-morbid with neurological disorders such as Parkinson's disease, Stroke and Multiple sclerosis.

I also will make a brief comment on the structure of general dementia services, and medication safety.

Dementia within specific populations

Younger onset dementia

Diagnostic issues: the diagnosis of dementia in younger people is frequently more difficult compared to older onset patients, and more frequently required at an earlier stage of disease. The accuracy of screening tests designed for an older Alzheimer's disease patient cohort are reduced in younger onset patients. Formal neuro-psychometric assessment therefore plays a far more important role in diagnosis and management.

Poor access to formal neuro-psychometric assessment is a major impediment in diagnosis and management of younger onset patients. Public access to formal neuro-psychometric assessment is very limited outside of major city teaching hospital clinics. Community based private assessment is frequently available, but due to expense, is difficult to use as frequently as is appropriate.

The absence of a Medicare rebate for formal neuro-psychometric assessment is a significant hurdle and needs to be urgently addressed.

Management issues: management begins with a timely and accurate diagnosis.
In the younger onset group the implications of diagnosis are frequently more complex, with work, financial and at times complex family situations (ie child care responsibilities and custody). The cessation of employment, driving, financial and social independence are not mandatory with a diagnosis of early dementing illness. Formal neuro-psychometric assessment has an important role in early patient management.

Early diagnosis must be accompanied by a detailed discussion of the implications of diagnosis. A diagnosis of dementia without appropriate counselling may be more harmful than helpful, with unnecessary early cessation of employment, family, financial and social disruption.

A psychologist, on completion of formal neuro-psychometric assessment and after confirmation of diagnosis is well placed for this discussion. A Medicare rebate for counselling as well as formal neuro-psychometric assessment is important. Access to these rebates by specialists in dementia care would be most appropriate. The access of numerous community rebates only through general practice is problematic, and adds unnecessary delay and opportunities for error or omission.

A Medicare rebate for formal neuro-psychometric assessment and subsequent counselling sessions should be made available via dementia specialist referral.

Younger onset dementia services: The need for specialist younger onset services is covered well by other submissions and is a significant problem, with younger mixed with elderly patients.

Dementia within disability cohorts:

The diagnosis of cognitive decline, with differentiation from other confounding factors or illnesses such as behavioural response to environmental changes, depression etc, is frequently challenging in patients with disability. As a result of the nature of the disability, some cohorts experience higher rates of dementia at an earlier age than non-disabled patients; for example Down's syndrome, where an extra copy of the Amyloid Precursor Protein gene overproduces a key protein in Alzheimer's disease, inducing its early onset.

Appropriate screening tools, availability of trained neuropsychologists, psychiatrists, neurologists, general practitioners, care workers (community and institutional) is urgently needed to cater for this population of patients. This at times is a very highly specialised area requiring management of multiple disease processes, as well as behavioural and environmental issues. A team approach is essential, but facilitating this is a significant challenge.

This issue requires a response at all levels, and is beyond a short summary.

Dementia co-morbid with other Neurological diseases:

Dementia is frequently co-morbid with a variety of neurological diseases. In this setting psychiatric disorders such as anxiety and depression are also frequent.

The symptoms of dementia maybe difficult to differentiate from other features of the disease, and diagnosis and management benefit considerably from formal neuro-psychometric assessment and counselling.

A Medicare rebate for formal neuro-psychometric assessment and subsequent counselling sessions should be made available via specialist referral.

A centralised, Area-based dementia referral process would help facilitate linking patients with dementia services in a distributed community based medical system.

General comments

Embracing the challenges of a distributed community based medical system

Most submissions to this Committee appropriately focus upon a community and community medical/nursing response to the diagnosis and early management of patients with dementia. Whilst there is discussion of specialist dementia clinics, it is unlikely that these will or should be the main focus for the average elderly patient with a suspected diagnosis of dementia.

In the majority of cases the use of presently available screening tools, combined with an adequate history are all that is required for a diagnosis of dementia. In a smaller percentage of patients, referral to specialist services is required. A diagnosis by itself, though, is inadequate, and frequently the main benefit from specialist service referral is to facilitate a dementia management plan, as well as diagnosis.

Considerable variability exists in General Practice, in terms of knowledge base of dementia, and service structure to manage patients with dementia. Many General Practices have a short-duration, high through-put model of medical care. Suggestions have been made to alter Medicare rebates or include other practitioners (Practice nurses or Nurse Practitioners) in diagnosis, as attempts to get around these problems.

It seems unlikely that all GPs will move away from the high through-put model, by simply changing Medicare rebates. More appropriate Medicare rebates, though, would be helpful but only if linked to clear outcomes. Outcomes would include completion of a dementia management plan including referrals to community support services, completion of legal issues (Powers of Attorney and Guardianship, Wills, Driving and Advanced care directives), educations sessions for patient and/or family (or referral to appropriate services), and review of medication safety (as a non-comprehensive example of issues that maybe included in such a care plan). Any practitioner involved in this work should have the same expectation of management with a comprehensive management plan. Simply changing the type of practitioner seems less important than the comprehensiveness of their review.
High through-put models of general practice would still be able to play an important co-ordinating role in dementia diagnosis and care, and models should allow GPs to refer and co-ordinate services, rather than necessarily deliver them personally. Exclusion of some GPs due to work practice would be extremely counterproductive.

Whatever the model developed, all levels of the medical system need to have simple and streamlined access to dementia services, and not simply those with a specialist dementia focus.

The distributed nature of the community medical system also offers great opportunity for multiple points of access to dementia services and diagnosis, from community members, medical (general practice and specialist non dementia practitioners), nursing, pharmacy, and legal profession.

One model to facilitate this would have a central intake, an experienced dementia care worker who would be able to assist with coordinating the care needs of the patient (ie: specialist, medical review, ACAT, dementia support, carer respite, behavioural management services, etc). This person would be an initial contact or focus point and separate to a community based dementia care worker. This is expanded further in the Central Coast Dementia Care Model.

Successful on the Central Coast has been:

1. A multi skilled community based nurse specialist who performs home based dementia assessments. These assessments have a holistic approach with components of an ACAT home assessment, medication safety review, review of legal issues, carer review, screening cognitive assessments and screening mood assessment (Hamilton Anxiety and Depression Scale). This review is then returned to the requesting practitioner (GP or specialist). Links are also made with dementia support services.
2. A Dementia Support Team, with specialist nurses coordinating formal education sessions (ie Living with Memory Loss courses), regular carer support groups, day-centre respite, and home based assessments.
3. Specialist review clinics with a multidisciplinary team, including dementia support nurses. These have included geriatric and neurological specialists.
4. Close links to psychiatric services.
5. A central coordinating and planning group including all members from the various groups involved in dementia care.

Challenges to the service have been the poor funding of services (inadequate for the present area needs); and piecemeal and poorly coordinated government funding of dementia services.

Medication safety

I felt it necessary to include these issues, as they seem to have been overlooked by government, and are important to patients with dementia.

Negligent expansion of generic medications

- **Confusion from proliferation of new trade names**. By simple legislation the government could have expected all generic medication to include the drug name within the trade name of the generic medication (for example John's paracetamol, instead of Paineze). Many groups of medication have seen an explosion of new and unrelated trade names. Patients are now finding it extremely difficult to remember their drug names. This is an extremely unsafe practice and the rush of the Government to save money has been at the expense of patient safety.

- ***All trade names of generic medication must contain the drug name (true generic name).***

- **Multiple generic substitutions.** It has become common-place for retail pharmacies to alter the generic supplied to patients on a monthly basis. New names and at times new tablet size shape and colour all add to increased confusion and chance of medication error. I have admitted two patients in the last 6-8 months due to medication errors related to generic substitution. A legislative break needs to be placed upon retail pharmacies. Even in groups of medication where generic substitution is not safe and not recommended, substitution still continues with little apparent concern or knowledge (for example, generic substitution of anti-epileptics has been associated with increased rates of hospital admission and risk of fractures).

- ***Only a single generic substitution is allowed: with patient and Medical Practitioner permission. Multiple generic substitution only permissible with Medical Practitioner permission.***

Thank you for the opportunity to make this submission.

I would be happy to discuss these issues further.

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