



*mal* **Submission No. 074**  
(Dementia)  
Date: 02/05/2012

**SUBMISSION TO**

**THE HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON  
HEALTH AND AGEING**

**An inquiry into dementia early diagnosis and intervention**

**PREPARED BY:**

**SPEECH PATHOLOGY AUSTRALIA**

**MAY 2012**





## **THE TERMS OF REFERENCE**

Under the Terms of Reference, the committee will focus on how early diagnosis and intervention of dementia 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 plan for their futures, including organising their 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.

## **INTRODUCTION**

Speech Pathology Australia (SPA) is the national peak body for speech pathologists in Australia, representing approximately 4,700 members. Speech pathologists are university educated professionals with specific knowledge and expertise in all areas of speech, language, communication and swallowing, including disorders of speech, language, literacy and numeracy, as well as difficulties with eating and drinking. Speech pathologists work with children, adolescents and adults with developmental and acquired communication disabilities and special needs prior to and during their formal education, in the public and private sectors, health, disability, mental health and aged care systems.

Speech pathologists have always had a primary role in the assessment, differential diagnosis and management of people with progressive communication disorders such as those occurring under the umbrella of dementia, in aged care facilities such as residential care, speech pathologists are vital in the assessment of communication and swallowing disorders in the elderly. As such, the profession believes it is well placed to provide meaningful input into the Standing Committee on Health and Ageing's Inquiry into Dementia early diagnosis and intervention.

This input is based on evidence published in the literature, an emerging body of research into communication difficulties associated with people with dementia, the growing numbers of people with dementia-based communication disorders, clinical observation by expertly trained speech pathologists and feedback from family and carers of people with dementia.

SPA is pleased to be able to provide written feedback to this very important inquiry concerning the rights of all individuals with a communication disability associated with dementia. SPA wishes to highlight the fact that there is a significant lack of awareness and understanding of the communication difficulties for some people who have a diagnosis of dementia. This exists at the community level within GP practices where the GP may fail to pick up severe progressive aphasia as the first sign of dementia; at the acute level when people are hospitalised into dementia assessment and care beds; at the rehabilitation level where intervention can improve communication function and also delay deterioration; as well as at a residential care level for staff and carers and at a social level for family and friends.





This lack of awareness and recognition of the severe communication impairment for some people with dementia causes unintended discrimination and inequity for this group. Speech pathologists (as part of the health, mental health, community and aged care workforce) can make a significant contribution across the spectrum for assessment, differential diagnosis, improvement, maintenance and some recovery for clients with a communication impairment. Additionally, speech pathologists offer support, information, assistance and education to carers, families and to other professionals working in this system.

On 27 April 2012, the Standing Council on Health released a Communique about Dementia. The Federal Minister for Health, Ms Tanya Plibersek gave notice to the Council that the Commonwealth will be proposing that dementia be designated as a national priority. Speech Pathology Australia applauds this decision as it will allow a greater focus on the disease and promote collaboration in research, education and service delivery.

### **AUSTRALIA AND OUR AGEING POPULATION**

Australia, like other nations in the OECD, faces the serious challenge of population ageing. The number of Australians aged 65 years and over is expected to comprise one-quarter of the population by 2045 – almost twice current levels (Productivity Commission 2005).

Age is the most important risk factor for dementia, and Australians are ageing along with the rest of the world. Taylor et al (2009) quote Henderson and Jorm (1998) as reporting that in 1998, Australia-wide there were approximately 130,000 people with dementia, a number that was projected to rise to 183,000 by 2006 and 210,000 in 2011. Because the elderly segment of the population (65+) will rise dramatically, people with dementia-associated communication problems is one of the fastest growing clinical populations for speech pathologists.

Dementia is already the single greatest cause of disability for Australians aged 65 years and over. It is acknowledged to be the third leading cause of death among Australians after heart disease and stroke.

The Hon Mr. Georganas, said in launching this inquiry " In 2011, there were an estimated 280,000 Australians with dementia .....1600 new cases identified each week, this number is growing rapidly. With population ageing, the number of Australians with dementia is predicted to reach almost 1 million by 2050....."

The current incidence of all types of dementia in the Australian population is 1 per 100 people (Access Economics 2005). More than 95,000 Australians living with dementia experience a communication disability.

### **OVERSEAS DATA**

It was estimated that in 2005, 420,600 Canadians over the age of 65 had dementia. This represents nearly 1.3% of the entire population of around 32 million of which over 12.5% are 65 years or older. Of all Canadian adults with dementia, approximately 280,000 have Alzheimer's disease, one of the many different types of dementia (CSHA 1994).

A recent incidence study (2000) based on a national prevalence data set shows that there are 60,150 new cases of dementia diagnosed each year in Canada, of which 39,000 are new cases of Alzheimer's disease. These figures are similar to worldwide prevalence and incidence data that shows an exponential rise in the occurrence of dementia in all its forms (Byrne et al 2005).





## DEMENTIA

The syndrome of dementia comprises multiple cognitive deficits including short and long term memory impairment and at least one of the following communication disorders: aphasia, apraxia, agnosia, and/or impaired executive functioning (*Diagnostic and Statistical Manual of Mental Disorders—Fourth Edition*; American Psychiatric Association 1994). The degree of intellectual deterioration is sufficient to interfere with social and occupational functioning which is further affected if communication difficulties are present.

The most common cause of dementia is Alzheimer's disease; other common causes are multiple infarctions, Lewy bodies and Parkinson's disease. The syndrome of dementia is most prevalent in older adults because Alzheimer's disease and other common causes are age-related.

However, there is also a cohort of people who acquire early onset dementia who need to be treated quite differently to older people with dementia. Leading international researchers such as Professor Bradford Dickerson of Massachusetts General Hospital Boston are discussing the need for specialist appropriate services for early dementia related speech and language impairment.

The peak body for dementia in Australia, Alzheimer's Australia has recognised the need to resource the development of knowledge, skilled clinicians and clinical services in this area. There is a huge need for appropriate activity support and respite services for individuals with younger onset dementia. Dementia services for the aged are not appropriate for this group. One on one respite provides assistance for families but does not break down the stigma of allowing younger onset dementia individuals to participate in the community in activities that are typically embraced by their peers (Personal communication from Dr Cathleen Taylor 26 April 2012 to Senior Advisor Professional Issues, Speech Pathology Australia).

**We have observed the difference in the quality of life of two gentlemen with similar progressive language impairments – one man had a family who actively sought ways for him to continue in his role as father and grandfather. They explained his communication problems to his grandchildren, encouraged communication strategies, fostered nonverbal hobbies and ensured that as far as possible he remained engaged and included. The other man's family misunderstood the nature of his impairments believing he suffered from a severe dementia. His lifestyle became restricted, opportunities for communication were limited and his quality of life suffered as a function of social isolation.**

**Editorial**

**Nickels. L & Croot. K. Aphasiology, 2009, 23 (2), 123-124**





## **THE ROLES OF SPEECH PATHOLOGISTS WORKING WITH INDIVIDUALS WITH DEMENTIA BASED COMMUNICATION DISORDERS**

Speech pathologists play a primary role in the screening, assessment, differential diagnosis, treatment and research of cognitive-communication disorders, including those associated with dementia. Given the growth in the number of older adults in Australia, the high incidence and prevalence of dementia in this population, and the negative impact of dementia on cognitive-communication abilities, appropriate assessment and intervention are critical.

In addition to cognitive-communication problems, swallowing disorders are often present in people with dementia. Speech pathologists have a primary role in the screening, assessment, treatment, and research of swallowing disorders associated with dementia.

### **Roles**

The American Speech-Language-Hearing Association in 2005 developed a position statement on the roles of speech pathologists working with individuals with dementia-based communication disorders. The following is taken directly from this position statement.

“Speech pathologists are knowledgeable about normal and abnormal neurological functioning and related aspects of communication. Our educational background and clinical training prepares us to undertake a number of roles related to communication and dementia. These include, but are not limited to, the following:

1. Identification: identifying persons at risk of dementia, taking into account the incidence and prevalence of dementia in different culturally and linguistically diverse populations.
2. Assessment: selecting and administering clinically, culturally and linguistically appropriate approaches to diagnosis and assessment of cognitive-communication disorders of dementia across the course of the underlying disease complex.
3. Intervention: selecting and administering clinically, culturally and linguistically appropriate evidence-based practice techniques for direct intervention with persons with dementia and indirect intervention through their caregivers and environmental modifications.
4. Counselling: providing culturally and linguistically appropriate counselling for individuals with dementia and their significant others and caregivers about the nature of their dementia and its course.
5. Collaboration: collaborating with individuals with dementia and personal and professional caregivers to develop intervention plans for maintaining cognitive-communication and functional abilities at the highest level throughout the underlying disease course.
6. Case Management: serving as a case manager, coordinator or team leader to ensure appropriate and timely delivery of a comprehensive management plan.





7. Education: developing curricula and educating, supervising and mentoring speech pathologists in research, assessment, diagnosis, and treatment of cognitive-communication problems associated with dementia; educating families, caregivers, other professionals and the public regarding the communication needs of individuals with dementia.
8. Advocacy: advocating for services for individuals with dementia; serving as an expert witness.
9. Research: advancing the knowledge base of cognitive-communication problems in the dementias and their treatment through research.”

### **PRIMARY PROGRESSIVE APHASIA**

There is an increasing body of research and awareness that language impairments can be the most prominent initial symptom of people with a number of neurodegenerative disorders, ..... the literature addressing the nature and treatment of the language impairments of individuals with progressive aphasia is growing (Nickels. L., Taylor. C & Croot. K. 2011).

Communication difficulties are among some of the first symptoms of dementia reported by carers. They cite problems such as repeating questions; loss of conversation; word-finding problems; communication difficulties impacting on the functions of daily living and changing the way they previously communicated with their relatives.

Primary progressive aphasia (PPA) is a clinical dementia syndrome characterised by the gradual dissolution of language without impairment of other cognitive domains for at least the first two years of illness (Mesulam 2001).

*Quote from a Speech Pathology Doctoral student about her clients with progressive language impairment.*

“Many of them have had a delayed diagnosis which has resulted in incredible anxiety and withdrawal from social interactions and activities of daily living. The communication impairment has impacted on their relationships, independence and social engagement for both the individual and their families.”

A recent study in NSW (Taylor et al. 2009) identified that only a small number of clients with PPA were referred to speech pathologists but that many more people could have been referred. Speech pathologists felt that it was a growing field of practice and that there was a need for more accessible information for clinicians and people with PPA and their carers. In 2001, Mesalam (2001) predicted that PPA may account for 20% of all dementia cases.





## **INTERVENTION BY SPEECH PATHOLOGISTS**

The emerging research suggests very strongly that there is a primary role for speech pathologists in working with individuals who have dementia-based communication disorders.

Speech Pathology Australia strongly recommends that the inquiry takes note of the following recommendations:

1. Referral protocols should include referral to speech pathologists for differential diagnosis of people with dementia-based communication disorders.
2. Assessment needs to identify the current status of the person's language impairment and the impact it has on their communication activities, participation and quality of life.
3. Treatment must track changes over time, monitor improvements, maintenance of abilities or a decline in abilities and adjust the focus of treatment.
4. Speech pathologists are ethically responsible to provide appropriate services that benefit the individual and maximize cognitive-communication functioning at all stages of the disease process.
5. Speech pathologists need to be part of dementia care teams. As part of the multidisciplinary approach to the treatment of people with dementia or early signs of language loss, speech pathologists must be included as part of the primary team involved in the assessment and management plans for this group of people.
6. Education to referrers about the role of language and communication in dementia e.g. general practitioners, neurologists, physicians, geriatricians, community health nurses etc. and referring bodies.
7. Education of individual and carers about the nature of dementia-based communication disorders.
8. The development of appropriate supports and information for people with dementia-based communication disorders as well as support for carers.
9. Regular review and reassessment of the person as the person's communicative ability changes over time.
10. Training carers of people with dementia to become stronger communication partners.
11. Education for individuals and carers about the nature of the disease and the communication disorder, the progression, treatment, support and life planning issues. This will include providing education about the need for strategies that proactively address the consequences of a further decline in communication abilities e.g., how will the client manage future personal, legal, health and financial matters.
12. Regular structured interviews with individuals and their carers to gain an in-depth understanding of the nature of the functional impact of the language impairments.





## **SUMMARY**

Speech Pathology Australia supports the efforts of the inquiry to focus on early diagnosis and intervention for people with dementia. This is crucial in ensuring that people have the best opportunity to engage with appropriate services; maintain their skills and function for as long as possible; live independently in their own homes and actively participate in the community in which they live.

As dementia-based communication disorders are a significant component of a variety of dementias, speech pathologists have an important and active role in increasing community awareness about these difficulties. They have a vital role to play with individuals with dementia and their family and carers.

Speech Pathology Australia believes that speech pathologists can assist people with dementia at many levels to understand the nature of the problem, facilitate communication skills between the individual and the carer, maximise communication opportunities and optimise quality of life. Speech pathologists work integrally with the multidisciplinary team to ensure that best practice intervention is afforded to this group of people.

If you require any further information please do not hesitate to contact Christina Wilson, Senior Advisor Professional Issues on \_\_\_\_\_ or \_\_\_\_\_

Yours sincerely

Christina Wilson  
Senior Advisor Professional Issues.







## References

Access Economics. (2005). Dementia estimates and projections: Australian states and territories. Access Economics Pty Ltd. for Alzheimer's Australia.

American Speech-Language-Hearing Association. (2005). *The Roles of Speech-Language Pathologists Working With Individuals With Dementia-Based Communication Disorders: Position Statement* [Position Statement]. Available from [www.asha.org/policy](http://www.asha.org/policy).

Byrne, K & Orange, J. *Advances in Speech-Language Pathology*, ACQ. December 2005; 7 (4): 187-202

Canadian Study of Health and Ageing Working Group (1994). *Canadian study of health and ageing: Study methods and prevalence of dementia*. Canadian Medical Association Journal, 150, 889-913

Henderson, A. S., & Jorm, A. F. (1998) *Dementia in Australia (Aged and Community Care Service Development and Evaluation Report no 35)*. Canberra: Australian Government Publishing Service.

Mesulam, M. M. (2001) *Primary progressive aphasia*. *Annals of Neurology*, 49, 425-432.

Nickels, L., Taylor, C & Croot, K. (2011) *Clinical assessment of progressive aphasia*. ACQ Vol 13, Number 2.

Productivity Commission (2005) *Australia's Health Workforce, Research Report*, December 2005, Australian Government.

Taylor, C., Kingma, R., Croot, K & Nickels, L. *Editorial*. *Aphasiology*, 2009, 23 (2), 161-174

