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Submission to

THE HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON HEALTH AND AGEING

An Inquiry into dementia early diagnosis and intervention

Date: 20th July 2012

Context

We write as Speech Pathologists, who have 20 – 30 + years of clinical experience each, working with people with dementia, their families and service providers. Two of the three authors have also worked within the Cognitive Dementia and Memory Service (CDAMS) within Victoria, and it is from this perspective that this submission is made. This submission, whilst based on our clinical experience, current research and best practice guidelines, is made by us as individuals, NOT as representatives of the organisations where we are currently employed.

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INTRODUCTION

We welcome the opportunity to comment on each of the Terms of Reference of this inquiry, particularly as they relate to the communication and swallowing difficulties of people with dementia. We particularly acknowledge and seek to expand upon submissions made by

1. Cognitive Dementia and Memory Services Victoria (no. 39)
2. Speech Pathology Australia (no. 74)
3. Dr. Carmel Lum (no. 93)
4. Margaret Pozzebon

The gradual, or sometimes sudden, deterioration in communication is a significant presentation in many types of dementia. People even in the early stages of dementia will frequently experience communication difficulties such as:

- Word finding difficulties and / or reduced vocabulary
- Speech that is 'empty', lacking in coherence or repetitive
- Losing track of topic, difficulties managing topic shifts in conversation
- Problems with reasoning
- Difficulties processing / understanding longer information or conversation within noisier or group situations (See Moorhouse, 2010 for a further review of this area)

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Communication skills are vital for active social engagement and meaningful community participation and have been well linked to measures of quality of life. People with dementia and associated communication difficulties often experience social isolation and reduced participation. They also have greater difficulties performing daily functions impacting on independent living (e.g. recording of appointment times, writing of a cheque or a shopping list to help them remember) and have fewer opportunities to meaningfully participate in discussions around planning for their future. Additionally, communication difficulties of the person with dementia have been found to trigger some behaviours of concern (Bourgeois 2002, Burgio et al 2001) which in turn affect caregiver burden (Savundranayagam *et al., 20*05). Behaviours of concern are then often a catalyst for individuals with dementia having to leave their family home or for them requiring a higher level of care

Speech Pathologists are specialists in the area of assessment, differential diagnosis and management of people with progressive communication disorders, such as those occurring in dementia (Speech Pathology Australia Inquiry submission – refer to submission for full outlines of role and specialisation). Additionally, Speech Pathologists are experts in the assessment, treatment and research of swallowing disorders associated with dementia.

Despite this, the majority of people with dementia never see a Speech Pathologist. Many of those that do, frequently are referred only in later stages of disease for advice regarding their swallowing.

This submission seeks to highlight the need for specialist multidisciplinary Allied Health dementia care teams <u>which include Speech Pathologists</u> to be an integral part of all diagnostic and intervention services for people with dementia wherever they live. The rationale for this need will be discussed using the Inquiry's terms of reference.

TERMS OF REFERENCE 1 & 2

1. *IMPROVE QUALITY OF LIFE AND ASSIST PEOPLE WITH DEMENTIA TO REMAIN INDEPENDENT FOR AS LONG AS POSSIBLE;*
2. *INCREASE OPPORTUNITIES FOR CONTINUED SOCIAL ENGAGEMENT AND COMMUNITY PARTICIPATION FOR PEOPLE WITH DEMENTIA;*

Early diagnosis

In Victoria, CDAMS clinics have been successfully established since 1997 to provide early diagnosis, advice, referral and education to people experiencing cognitive / memory loss and their significant others. These clinics seek to offer specialist multidisciplinary team input. (CDAMS Victoria submission to inquiry. No.39)

Speech Pathologists are currently employed in only a handful of CDAMS in Victoria. Where Speech Pathologists are available to CDAMS clinics, much of their work revolves around detailed differential diagnosis of those potentially having a language dominant dementia, such as distinguishing between variants of fronto-temporal dementia, or Primary Progressive

Aphasia (PPA). Please see separate submission from Margaret Pozzebon for details of the highly specialist and vitally important nature of this work.

As Speech Pathologists have not been consistently part of CDAMS teams, access to Speech Pathology assessment and management at this time is inconsistent and inequitable.

There are a number of reasons why this has occurred, including resource limitations within CDAMS at a time of ever-growing waiting lists. However, we also concur with Dr Carmel Lum (inquiry submission no. 93) that a 'biomedical' model is often adopted, focussing heavily on "a diagnostic assessment to determine suitability for prescription of an anti-cholinesterase inhibitor" and treatment being "pharmacological and the determinants of health and illness are viewed as primarily physical". Links from CDAMS to services such as Speech Pathology services which provide a psychosocial management approach are typically not currently well developed, meaning there is no follow up of issues such as communication for the person with dementia in the community.

Intervention

Speech Pathologists are uniquely placed to provide individually tailored intervention for the person with dementia given our expertise in assessment of underlying cognitive- linguistic deficits and strengths. This can include the following approaches:

1. Direct intervention / therapy for cognitive-linguistic deficits are particularly warranted in PPA where language deficits are usually the initial manifestation. (Please see separate submission from Margaret Pozzebon and Moorhouse (2010) for more detailed discussion)
2. Strategies / supports to maximise independent communicative functioning utilising identified residual cognitive strengths

   This may include for example providing a written script to someone having difficulty answering the phone / calling a service due to verbal difficulties, utilising their preserved reading abilities. Speech Pathologists are able to offer many individual strategies to promote continued independence. However, early referral of the person with dementia is required to learn strategy use whilst new learning is still effective. Strategy use can then be carried through and be more supportive to someone as they progress into moderate / later stages of disease progression. However, within existing service networks, such referrals are generally not made in the early stages of dementia.

3. Carer Education and support regarding communication is critical in the management of caregiver burden. In addition, it is efficacious because these caregivers can usually learn new information efficiently and over a relatively short space of time.

There are ubiquitous advice pamphlets regarding optimal communication in dementia. Such pamphlets in isolation from other interventions may affect a change in knowledge base (Newell, 1996), but have not been associated with actual substantial behavioural change in carers (Burgio et al 2002, Bourgeios et al 2004).

A comprehensive education / staff management approach developed to support residential care staff has been shown to be effective in maintaining staff behaviour change in supporting communication (Bourgeios et al 2004).The recent RECAPS and MESSAGE program for caregivers developed and evaluated by a multidisciplinary researchers including speech

pathologists at the University of Qld (Smith et al., 2011) goes some way toward bridging the divide between knowledge and action. It provides a DVD based training program which can be used with groups or individuals. An evaluation of its efficacy amongst a group of caregivers, revealed significant increase in knowledge about support strategies and some increases in overall carer satisfaction (Broughton et al., 2011). It did not, however, examine the key area of actual behavioural change. Speech Pathologists have a significant role to play in extending this type of wide reaching training program to facilitate real change in caregiver interactions. Conversational Partner Training (CPT) is a very helpful framework in this regard.

In recent years, CPT has assisted the communication partners of those with aphasia (an acquired language disorder occurring most commonly after stroke) to optimise interactions (e.g. Kagan et al., 2001) and more recently those with cognitive communication disabilities following Traumatic Brain Injury (TBI) (e.g. Togher, Power, McDonald, Tate and Riedtdjik, 2012). Evidence for the effectiveness of CPT in people with aphasia is very promising (e.g. Turner and Whitworth 2006).

People in the earlier stages of dementia frequently have a similar range of communicative difficulties to those experienced by people with aphasia and traumatic brain injury. Despite these strong parallels, CPT needs to be tailored to the specific needs of individuals with dementia and their conversation partners. CPT programs also allow for conversation partners to actually practice strategies in front of the Speech Pathologist and to obtain feedback and additional help in honing these strategies to meet individual needs so that they are workable and are actually used rather than being put away in a drawer. This type of contact between Speech Pathologists, caregivers and those with dementia does not need to be lengthy, but it does need to occur face to face as part of a multidisciplinary team response to behaviours of concern.

4. Augmentative and Alternative Communication (AAC)

Speech Pathologists are specialists in the use of AAC supports and strategies. For people with dementia, these additional communication tools provide support for the input and output of communication (verbal and written) given cognitive-linguistic constraints, and are particularly vital for those with language dominant dementias such as the variants of Primary Progressive Aphasia (PPA). AAC can take many forms including simple picture boards or books to electronic devices (and more recently iPad apps) of varying complexity which allow the individual to communicate at a range of levels (dependent on residual cognitive linguistic capacity) from basic needs and choices right through to complex thoughts and feelings. Cognitive linguistic strengths and weaknesses of individuals with PPA and other more common forms of dementia manifest themselves in a myriad of different ways. Where AAC is required, specialist skills of Speech Pathologists are necessary to tailor AAC to best meet the needs of particular individuals and their communication partners.

In those with PPA, communication aids compensate for progressive language loss in the context of other more preserved cognitive skills. Work should start early while the person can still learn to use AAC and should include key communication partners in training (Fried-Oken,2008).

There is body of research citing benefits of AAC for many people with dementia. This includes use of

- Communication books / notebooks
- Communication wallets
- Personalised memory supports such as calendars , diaries, cue cards, timetables
- Community request cards
- Personal Communication Dictionaries
- Life Story Books / My Life

For example, use of communication wallets by people with dementia has been shown to assist them to self prompt personal information facts during conversation (Bourgeois 1992), help to reduce the frequency of repetitive questioning of partners by referral to personal information (Bourgeois et al 1997), increase quantity and quality of communication between nursing aides and people with dementia (Bourgeios et al 2001), and reduce challenging behaviours during care routines (Allen-Burge et al 2001).

AAC supports and strategies work best when introduced early in the disease process, when learning of new strategies is still possible. These compensatory strategies can then be adjusted and modified to suit as disease progression alters skills, but the person is already used to the strategy. Therefore people with dementia benefit from early referral to Speech Pathologists to ensure optimal communication is maintained for as long as possible.

Some AAC supports are utilised by the carer to assist with comprehension of their message (e.g. communication books), maintain social interaction (e.g. Life Story Books) or ensure consistent understanding of the communicative intent of the person's actions and behaviours (e.g. Personal Communication Dictionaries, PCDs).

PCDs are documents compiled by Speech Pathologists in collaboration with carers who know an individual well to document known communicative intent of a person's actions and unique behaviours. This type of information is particularly useful for carers who do not know an individual well and helps prevent escalation of problem behaviours. The specialist skills of Speech Pathologists in structuring these observations are vital in the development of comprehensive care plans for individuals with dementia living in residential care.

TERMS OF REFERENCE 3

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

Speech Pathologists have an important role to play in helping people with dementia better plan for their future.

1. Contributing to the assessment of mental capacity particularly in people with language dominant dementias such as PPA

We have seen many occasions where people unable to speak have been incorrectly assumed to lack mental capacity. Speech Pathologists are specialists in identifying appropriate Augmentative and Alternative Communication strategies that enable a person with severe verbal communication difficulties to communicate their wishes. In the case of

people with variants of PPA, language skills may be diminished early but the person remains capable of understanding. Speech Pathologists must be involved in assessments related to mental capacity of these individuals to support effective communication and thereby enable them to participate in significant decisions about their lives.

2. Helping people with dementia and communication changes use tools to support their participation in decision making, planning re their own lives

Recent research has shown that people with dementia at various stages of the disease can be assisted to more effectively:

- understand spoken messages
- produce more effective on topic communication
- remain engaged and on task for longer

Discussions about wellbeing and wishes for the future can be undertaken using a low technology, inexpensive communication framework known as 'Talking Mats' (Murphy, Gray & Cox 2007, Murphy et al 2010, Oliver et al 2011) 'Talking Mats' were developed by a group of Speech Pathologists at The AAC Unit, University of Stirling, Scotland to help people with a range of communication difficulties express their opinions. They consist of a textured mat on which picture symbols (representing desired activities for example) are placed under a picture based rating scale (eg like, unsure, don't like). Most notably, this simple communication method was shown to particularly be most effective with people with moderate to late stage disease progression. Empowering people with dementia to participate in decision making about things in their daily lives is an important component of person centred care, which is able to be supported by the involvement of Speech Pathologists.

3. Education re swallowing, end of life planning

Dysphagia (swallowing problems) usually occurs in the late stages of dementia. It often leads to aspiration pneumonia which is a major cause of death in this population. Decisions about the complex, ethical and medical issues related to the use of enteral nutrition and hydration at the end of life should be addressed early in the dementia process. This allows people with dementia and their families and carers to understand and participate in this important area of planning for their future care (Cullen, 2011, Modi, Velde &Gessert, 2011 Low, Chan, Hung & Chye. 2003). Speech pathologists have an important role in detecting the early signs of dysphagia and providing information and support in this process.

In some cases, particularly in vascular dementia, dysphagia can occur early. Speech Pathologists provide intervention aimed at maximising swallowing safety, whilst maintaining quality of life throughout all stages of dementia. This could include allowing free fluid in controlled circumstances (Karagiannis, Chivers, Karagiannis, 2011) and focusing on maintaining good oral health (Sarin, Balasubramaniam, Corcoran, Laudenbach, Stoopler, 2008, Adam & Preston, 2006). Behaviours such as distractibility, poor attention, passivity which can present in early dementia impact on mealtimes and hence on nutrition and hydration. The provision of education relating to the detection and management of swallowing and behavioural problems to carers, both professional and family, is another vital area of speech pathology input (Kindell, 2002).

RECOMMENDATIONS

1. That **Speech Pathologists need to be a part of dementia care teams** in the assessment, early intervention and ongoing management of people with dementia in relation to their communication and swallowing.

2. That **additional resources and changes to the existing service system are required** to ensure this occurs *as follows:*

- That **all CDAMs clinics have a Speech Pathologist** employed to provide expert diagnostic assessment advice
- That **specialist multidisciplinary Allied Health dementia care teams are established, with Speech Pathologists included as core team members.** These teams would be able to provide intervention to the person with early stage dementia to maximise their independence and continued community participation, and modify strategies as needed throughout the disease progression. They would provide practical hands on support & education to carers, both family and paid staff. Such input is necessary to ensure people with dementia maintain meaningful participation in their community and delay admission to residential care.
- That these **AH dementia teams may be co-located with existing CDAMS services** (and hence promote links from diagnostic assessment to intervention services), or potentially **be integrated into existing multidisciplinary HACC funded AH teams at local community health /subacute settings**. Such AH intervention services are not currently routinely provided for people with dementia, and additional resources are required to make this happen.
- That **additional resources are required** to ensure equitable access to Speech Pathology services **by all residents of residential care**. Best practice would be to offer seamless integrated person centred care for the duration of a person's life, regardless of their residential location (and therefore government funding department). Therefore, additional funding should be provided to the specialist AH dementia care teams to ensure service provision continues if a person enters residential care.

3. That **undergraduate courses in ALL health related tertiary fields** (e.g. Medicine, Dentistry, Nursing and Allied Health - including and especially Speech Pathology) provide **education regarding normal ageing, the dementia spectrum and a psychosocial approach of management which supports a 'life participation model'**.

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