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Context: My qualifications and clinical experience are in the disciplines of Speech Pathology, Clinical Psychology and Clinical Neuropsychology. Since 1978, I have worked in Neuro-rehabilitation, Neurology, Community Mental Health, Sub-acute care with elderly people, Psychiatry and in Memory (Dementia) clinics in Victoria and in the UK. My career also includes a decade in Neuropsychology research and teaching abroad. The breadth of my clinical experience provides me with unique insights on the subject of Dementia and related issues.

I am also a daughter, and I will share with the Committee what I witnessed in my father's 9-year trajectory towards the end stage of his dementia, and how the health care system prepared him and my family as his carers.

I thank the House of Representatives' Standing Committee on Health and Ageing Inquiry into Dementia for the opportunity to provide feedback. In my writing, I am representing myself and will speak to the following Terms of Reference appearing here.

- 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.

My recommendations are:

Recommendation 1 – Promote a greater emphasis on a Psychosocial approach to the assessment and management of early stage dementia

Recommendation 2 – Promote the role of speech pathologists in assessments of dementia, and in providing therapeutic support to the patient and carer.

Recommendation 3 – Promote the role of speech pathologists in assessments of mental capacity for patients diagnosed with Primary Progressive Aphasia and kindred communication disorders.

Recommendation 4: Promote more frequent publications in local newspapers describing dementia and the types of entitlements due to patients and carers. Promote a *balanced* view of dementia in the media.

Recommendation 5: Promote 'palliative care for dementia patients' training among health care staff to support Advance planning more fully.

In the following sections, I will expand on each of these in turn.

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Recommendation 1 – Promote a greater emphasis on a Psychosocial approach in the assessment and management of early stage dementia

As a clinical neuropsychologist, my experience of dementia assessment services in Britain was similar to the work undertaken in the memory clinics in Victoria. However, in Victoria, memory clinics operate largely within the framework of a biomedical model. The *primary* focus of such a model in dementia is to secure a diagnostic assessment of a patient's cognitive impairment for the main purpose of deciding which patients can be offered a prescription for an anti-cholinesterase inhibitor. Often, any form of post-diagnostic therapeutic support, or counselling by the assessment team is unexpected, though a follow-up review with the patient is offered when necessary, to disambiguate a diagnosis. The treatment is pharmacological and the determinants of health and illness are viewed as primarily physical. There is a heavy reliance on giving the patient and carer multiple information leaflets, usually at the time they are also given the news that the patient has a diagnosis of a possible or probable dementia. Naturally, the patient and carer are often in a highly aroused or distressed state at this time, usually causing them to feel over-whelmed, and limited in their capacity to attend to learn new information. There are issues about how this information fits with the patient's and carer's belief systems and models of illness that are rarely addressed. This rather unfortunate situation arises due to the clinic's limitation on time made available for each patient's assessment. Other disadvantages are that the content of leaflets is also often too generic to speak to the 30% of patients who suffer from a non-Alzheimer's dementia, or whose dementia does not result in memory loss as a main symptom. They and their carers do not necessarily relate to issues and strategies described in these leaflets. A great number of these information sheets are also unavailable in languages other than English.

Despite memory clinics having a first-class diagnostic service in Victoria, I often think the value of these assessments are rarely harnessed to their full potential to service the care of the dementia patient. The assessment team's reliance on a one-time information session after the assessment is inadequate to meet the evolving needs to patients and carers. Some will seek support from the Alzheimer's Association as advised but many more people will attempt to normalise their situation first and for some time, before incidentally making their own way in an ad hoc fashion through a myriad of possible community options when the carer can no longer cope. As a professional user of dementia support services and as a carer, my over-whelming feeling is that dementia services are disjointed, making access to it confusing for the user. Not-for-profit organisations like Benetas are thus, forced to create yet another new service, 'Memory Loss and Dementia Service' to help people with dementia by creating 'a tailored plan' through their advisors [3].

As a professional working in the UK, I found dementia assessment services to generally favour a *Psychosocial approach to dementia* over the traditional biomedical model. This, is largely motived by an understanding that while some symptoms of dementia are caused by brain failure, there are also symptoms that arise from factors other than the actual brain damage an individual may experience.[4] For example, a patient described as displaying 'behaviour problems' may in fact, be someone with an intolerant wife within the context of pre-existing poor marital relations. After a standard medical assessment protocol is observed, practitioners working from a Psychosocial framework reflect *primarily* on how people's behaviour and interactions with people with dementia impact on their symptoms, behaviour and experiences and what can be done to help alleviate these problems.[7] In the UK, much greater use is made of post-diagnostic education and counselling sessions available from a specialist dementia nurse, trained team member or, the assessing clinical neuropsychologist. One or two sessions of person-centred counselling and education were often sufficient. A key goal in Psychosocial interventions is to find ways that will empower the carer to feel confident that s/he will be able to cope with the imminent change in a partner or parent, to help the patient and carer realise that life can continue to be lived meaningfully in spite of a dementia, and to help them overcome any problems that arise as the patient's condition changes. Post-diagnostic counselling is important in minimising the occurrence of carer depression. *When a carer was depressed, UK medical staff made higher use of Clinical Psychology services instead of anti-depressants as a first line of treatment. This had the benefit of not pathologising the carer's response to dementia.* The memory assessment services in the UK, also included out-reach workers who functioned as the first stage of a line of support in helping patients and carers establish links with the Alzheimer's Association and other support networks. The Alzheimer's Association's out-reach officers often worked closely with the assessment team's out-reach workers to provide a tailored plan of on-going support for the carer and patient while the patient was still living at home. This did not exclude the carer forging independent links with other support services. An important outcome of this process was that the patient, the carer and the GP were supported after the diagnostic assessment. They were thus, more inclined to acquire the confidence to keep the patient with dementia at home for longer than would be otherwise possible.

Recommendation 2 – Promote the role of speech pathologists in assessments of dementia, and in providing therapeutic support to the patient and carer.

Primary Progressive Aphasia (PPA) is a focal dementia syndrome with deterioration of speech and language function with relative sparing of cognitive abilities for at least two years of the disease. Impairments affect communication ability in oral expression, comprehension, reading and writing. [1] I note in Victoria that a speech pathologist is rarely a member of the core dementia assessment team and referrals to Speech Pathology for a patient affected with PPA, is far from guaranteed. I understand that this is largely a legacy of how health care services have evolved and a perception among the community that 'little can be done' for the language disorder symptoms of dementia sufferers. This absence of Speech Pathology contribution to dementia care was echoed by Taylor et al (2009) when their survey of adult health settings in NSW revealed that only 20 patients diagnosed with PPA were referred to Speech Pathology during the 12 month period of their study, instead of the statistical prediction for NSW of 13,000 cases affected with PPA or a kindred communication disorder (p.6). Ironically, PPA patients share problems of communication failure similar to those affecting Stroke patients but not the same access to support services after a diagnosis. Similarly, patients with PPA do not share the same ease of access to Speech Pathology services currently provided to other patients diagnosed with progressive conditions such as Parkinson's disease, Motor Neuron disease, etc.

My experience in Victoria and that of my colleagues in Speech Pathology is that the referral pathway to Speech Pathology services from a dementia service is often little used due to admissions policies restricting these patients' access to Speech Pathology (e.g. patients requiring the services of at least two allied health disciplines are prioritised over patients requiring the services of one discipline such as, Speech Pathology), or there is no clear referral route between dementia services and Speech Pathology, and no clear management route for Speech Pathology care of these patients. As a Clinical Neuropsychologist, my attempts to access Speech Pathology to address my patient's communication needs were often frustrated and fruitless.

Taylor et al (2009) describes a US programme for the management of PPA as an example of best practice. This programme recognises that dementia patients with PPA have needs that can be met through an appropriately organised service. They write:

> *The CNADC PPA Program also provides clear recommendations for treatment (Cognitive Neurology and Alzheimer's Disease Centre, 2002). In particular, they suggest that direct treatment of the language impairment (particularly word retrieval disorders) should be used. Indeed, there is increasing evidence that direct impairment based treatment can benefit people with progressive language disorders (e.g., McNeil, Small, Masterson & Fossett, 1995; Schneider, Thompson & Luring, 1996, and all papers in this special issue of Aphasiology). For example, there is evidence that previously "lost" words can be relearned or re-accessed and that treatment can slow the rate of decline for treated items. In addition, the CNADC PPA program (Cognitive Neurology and Alzheimer's Disease Centre, 2002) advises that treatment focusing on the use of augmentative and alternative communication strategies (such as the use of gesture, drawing, and communication books) should be provided even in early stages. Both impairment- and participation-focused treatments are suggested to be important and appropriate, but a key point is that the relative focus of the treatment provided will change as language declines (for a lengthy discussion see Rogers, King, & Alarcon, 2000). The change in a person's communicative ability over time emphasises the need for regular review and reassessment of the person with PPA in order to ensure that the treatment and advice is appropriate to their needs at all stages of disease progression. From the survey results, in 53% of PPA cases the speech pathologist included regular review as part of the management plan. We would suggest that, for a progressive disorder that not only impacts communication, but also may include dysphagia as a later stage symptom, regular review is a necessary*. (p 8)

Further evidence of the positive benefits of partner training to facilitate communication are also described by Taylor et al here:

> *It is clear from the literature on communication in various types of dementia that training the carers of individuals with dementia has positive benefits. For example, Ripich, Ziol, Fritsch, and Durand (1999) looked at training the partners of individuals with Alzheimer's disease to be better communicators. Their results suggest that communication partners of persons with Alzheimer's disease can be trained to structure questions that result in more successful communication. Benefits of partner training, both in more successful communication and reduction of anxiety and depression are further supported by qualitative studies (Greene & Monahan, 1989; Shulman & Mandel, 1988). Within the aphasia treatment literature there is also a body of evidence that supports the positive benefits of partner training (Boles & Lewis, 2003; Booth & Swabey, 1999; Hopper, Holland & Rewega, 2002; Kagan, 1998; Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001; Lock et al., 2001).* (p. 9)

Recommendation 3 – Promote the role of speech pathologists in assessments of mental capacity for patients diagnosed with Primary Progressive Aphasia and kindred disorders.

As a clinical neuropsychologist in Victoria, I am accustomed to being invited to provide an opinion on a patient's mental capacity. On many occasions, I have observed situations where patients with communication difficulties were deemed by health professionals to possibly lack mental capacity on the basis of questionable evidence. The inarticulate patient allows staff to assume more readily that the patient lacks mental capacity to appoint a Power of Attorney, or lack mental capacity to make or participate in significant decisions affecting their lives (E.g. accommodation choices, ability to continue to drive, to make choices). PPA patients are also more likely to have their right to privacy and confidentiality in the health care system violated, and to feel minimised when communication intended for the patient, is directed to the carer, even when the patient is capable of understanding and communicating his or her wishes, particularly if communication were supported by a skilled speech pathologist.

Currently, health services secure interpreters to support the communication difficulties of CALD patients routinely, and would rarely consider an assessment of mental capacity without the presence of an interpreter. Yet, the same consideration of supporting the communication offered to CALD patients is rarely extended to patients diagnosed with PPA or other pathological communication disabilities in *assessments of mental capacity.*

Given the gravity of the implications of being found to lack mental capacity, I am in favour of advocating a Speech Pathologist be familiar with the patient, and be present in an assessment of mental capacity when a patient with PPA *appears* to lack the ability to comprehend or express him or herself.

Recommendation 4: Promote more frequent feature articles in local newspapers on Dementia and the types of entitlements due to patients and carers. Promote a *balance* view of dementia in the media.

As a clinician, I observe fear as a very common emotion in spouses and family members when first informed of a diagnosis of dementia. It is the 'new cancer' and initial reactions include 'all is lost' and feelings of helplessness. The public's knowledge of dementia is largely informed by the often over-dramatised negative manifestations of dementia in a TV soap drama, or a journalist's investigative account of a failed nursing home, complete with images of ailing elderly residents in the advance stages of dementia. A misattribution of what has caused someone to have dementia is common (e.g. caused by doing nothing at home after retirement). When carer's and patients start out with unjustifiably low expectations of what can be expected from a loved one with a diagnosis of dementia, then they are less inclined to find alternative ways to achieve what they want out of life together and may give up prematurely. A poor quality of life is assured to follow.

I would like to see a rolling public education programme that regularly reports in local newspapers, over-Fifty newsletters and local non-English papers on the subject of dementia. Over 6.1 million people read a local newspaper each week, making this a significant source of education about dementia and preventive measures for a great number of people in Australia.[3] The media need to present a *balanced* perspective of dementia instead of focusing solely on the its negative manifestations. There are many anecdotal reports of people with dementia continuing to perform normal household chores, gardening tasks, cycling, enjoying family gatherings and going on family holidays that are not portrayed in the media. The reports need to form a source of on-going education referring to how families can adapt to living with dementia sufferers (and not just to Alzheimer's dementia). Information needs to be repeated often to increase carers and patients' awareness particularly when it comes to knowing their entitlements and eligibility for concessions. Many people I have met with a family member with dementia are not aware of the Carer's allowance, Companion Card, or Disability Parking permit etc.

Recommendation 5: Promote 'palliative care for dementia patients' training among health care staff to support Advance planning.

Most of the information about dementia given to families focuses on memory loss and little refers to dementia as a *terminal* disease that causes brain failure, that in turn controls the functions of the heart, metabolism, eating, respiration etc. We know that ultimately, no matter what the diagnosis, patients with advance dementia present with a conglomeration of symptoms that make it difficult to tell which disease the patient had at the outset. Yet, patients and in particular, their families are rarely advised of the common changes resulting from a dementia over time. We know from a prospective study over 18 months of nursing home residents with advanced stage dementia, the main problems affecting these patients are: eating problems (86%), pneumonia (41%), difficulty breathing (46%), pain (39%) and fever (53%) - all caused by brain failure.[5] Patients commonly die from an eating-related disorder related to an underlying dementia and a majority die slowly rather than sudden and unexpectedly. Presently, most patients with dementia die in nursing homes rather than in palliative care.

My father was diagnosed with a Mixed dementia and as a family, we were 'successful' in supporting him to live a meaningful life during his 9-yr journey with his dementia. He was medically well in all respects except for his profound episodic memory loss and a moderate swallowing problem (dysphagia), and he recognised his family till the end. Throughout his dementia, he received regular 6 monthly reviews by a neurologist who always held a more pessimistic view of my father's capabilities than we did. She addressed my mother and not him and saw him in terms of a future in a nursing home without discussing alternative options open to the family. Fortunately, my father's ongoing mobility and functional abilities allowed him to remain home. He led a spontaneous, meaningful and self-regulated home life around a routine set of household chores and exercised at a local gym 3 times a week right into the last year of his life. Despite his dysphagia of 5 years duration, he ate carefully chosen 'normal' meals with the family and enjoyed holidays. Yet, after his death, *we were left with a sense of failure* that was confusing among family who cared for him in his last days. Despite being health care professionals ourselves, we were caught unaware of the nature of the physical and physiological changes that naturally occur when a human can no longer drink or eat (despite wanting to). Without labouring an account of events, our confusion arose because *none of the medical and nursing staff who cared for my father in his last 2 weeks prepared us for the experience of watching my father die from starvation and dehydration.* In the beginning, we failed to recognise when he started to die and we were still willing him to live when he could no longer do so. We walked him to help maintain his mobility and we struggled to feed and hydrate him orally as his capacity to swallow diminished daily through increasing weakness. I commend palliative care-at-home but better support for family-carers is needed (E.g. transfer training, and what to do if the patient is unable to rise from bed one day?) Individually, we stayed with for my father in an acute care hospital and cared for him around the clock for 6 days as he needed continual supervision, then at home for 5 days with palliative home care support, which ended in his transfer to a palliative care unit 3 days before he died. Most disappointingly, the care my father received in this palliative care unit was virtually non-existent apart from serving hotel functions, and providing personal care duties, though still my father managed to develop oral ulceration while in the unit. We thought the staff lacked sensitivity, as did the unit. (E.g. parking a cleaning cart outside my father's room soon after he died, and turning off Internet access immediately after his death without advising the family so we could not inform family overseas). Those final days remain a disturbing memory for us. We feel we failed because we did not protect my father or ourselves from this traumatic experience.

I learnt later that staff in this palliative care unit were more accustomed to caring for oncology patients as they get to know these patients due to repeat admissions to the unit before the patient dies. The circumstances for admission for advanced dementia patients are different in this respect, resulting in staff offering care to someone who is often non-communicative and in my father's case, too weak to even acknowledge their presence.

Our experience was not atypical, as I have heard similar accounts from friends and colleagues (E.g. Family who observed a nurse cross the newly deceased patient's name off the board in the ward, or the nurse who exclaimed, "Good!" in front of the family after she checked the patient's vital pulses to confirm his death.) My associates say they were so 'exhausted' or disappointed by what happened that they rather not to think about it, let alone communicate their experience to the authorities.

I do not think there is enough attention given to health professional training on the subject of dying from dementia currently and how best to prepare and support the patient and the family through this process. Any initiative aimed at extending patient care at home must consider what is euphemistically called 'the end–game' plan and ensure the patient and family are provided with *early* education and advice on the subject of dying from dementia.

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