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Committee Secretary-Dr Margot Kerley
Standing Committee on Ageing
House of Representatives
Parliament House
Canberra ACT 2600 Australia

Dear Dr Kerley,

I only received the House of Representatives Magazine-Issue 13, September/October 2002 from Kay Elson MP, Federal Member for Forde this morning. I was not previously made aware that the Standing Committee on Ageing was seeking written submissions. I therefore hope you will accept my late submission that includes two papers:

- Attachment 1 - Ageing Population-Decline in Cognitive Function (2 pages -pdf)
- Attachment 2 -- Empowering Caregivers: Confused Minds. Burdened Adult Children. Emotional Turmoil (4 pages -pdf)

I have recently published a book, "Midlife's Challenge: Understanding and Coping with Decline in Thinking and Behaviour", which was written for people in their midlife years who are struggling to assist their ageing parents. On Wednesday 12th June 2002, The Honourable Kevin Andrews, Federal Minister for Ageing, officially launch my book.

it three weeks, I am attending a Cognitive Advisors Symposium to be held at the College of St. Scholastics n Duluth, Minnesota, where I am presenting a paper and assisting with the organisation of this conference.

I would be grateful for the opportunity to address your committee and present my views on cognitive decline including the huge ramifications that can be expected with the growth in an ageing Australian population.

Yours Sincerely,

Delaune Pollard
AccOT
Allen Cognitive Advisor

Date: 10 September 2002

AGEING POPULATION-DECLINE IN COGNITIVE FUNCTION

Background

Age-related changes in cognitive (act of knowing) function are the greatest concern for an ageing population. The cerebral cortex shows a larger weight loss than the brain stem, and some nuclei show age-related losses whereas others appear to remain: stable throughout life (Cohen, 1988). Research indicates working memory is located in the pre-frontal cortex area of the brain. When age-related changes occur, the executive function difficulties of working memory can be observed in an inability to master new tasks and skills in new situations. In other words there is a lack of flexibility and an inability to troubleshoot, react appropriately or quickly, in dangerous or technically difficult situations.

Important information to consider:

- **Cognitive impairment**...increases substantially as people age. The primary degenerative process remains untreatable and survey data reports indicate that the prevalence of gradual loss of memory roughly doubles after the age of 65 years with every 5 years of age reaching a level of at least 16% in persons: 80 years and over (Breteler et al; 1992; Katzman & Kawas, 1994); and there is evidence that it can reach 47% among those 85 years and older (Evans et al, 1989).
- The **provision of aged care services** is based on the assumption that people function at the same cognitive level of ability. One of the most common mistakes made by care providers and caregivers is the assumption that, because a person is quite verbally adept, they are equally able to perform everyday tasks to the same level of effectiveness. This is very rarely the case. Often such individuals can "hoodwink" health professionals into believing that there is nothing amiss with them. It is only with more extensive observation and assessment, that the decline in cognitive functioning reveals itself.
- Another mistake commonly made by caregivers is that they attempt to teach new skills of new ways of doing tasks and activities to people with a cognitive dysfunction. What is poorly understood is that individuals with a significant loss of cognitive function are not capable of 'new learning'. Because of their loss of cognitive function they are only further confused and frustrated by those who continue to attempt to change their established patterns of behaviour and thinking.
- An emerging body of literature is currently investigating the **relationship between cognition, health and illness in older adults**. The major hypothesis is that the cognition in healthy older adults remains relatively intact, whereas cognition in those with chronic disease processes shows precipitous declines (Schaie, 1990; Launer et al. 1995)! Empirical evidence lends support to this premise, particularly with reference to chronic disease processes such as hypertension, cardiovascular disease and diabetes (Siegler & Costa, 1985; Elias, Elias & Elias, 1990; Elias et al., 1993; Schaie, 1990; Sands & Meredith, 1992). The Implication here is that changes in cognitive function (typically, memory) might more usefully be viewed as potentially modifiable manifestations of disease and/or manifestations of changes in physiological functioning (Levy, 1998). Cardiovascular diseases, specifically hypertension and heart disease, are of particular interest to cognitive psychologists because these conditions so frequently tend to be associated with. Lower levels of cognitive performance (Elias, Elias, & Elias, 1990; Elias et al, 1990; Eli" & Marshall, 1987). - There is ample evidence that the more serious cardiovascular conditions (atherosclerosis and cerebrovascular disease) increase the risk and extent of cognitive

decline. Not only has it been shown that untreated hypertension is'. Inversely related to cognitive functioning, that is, those with high numerical blood pressure scored lower on 'cognitive tests (Elias et al; 1993). But there is also evidence that medications that prevent subtle brain changes due to hypertension, low blood pressure; and elevated blood sugar have an important impact on the occurrence of cognitive impairment (Loaner et al 1995). It may well be that healthy older adults who. Maintain an active physical and intellectual life will show little or no loss of cognitive abilities unless (or until) confronted with serious disease (Levy, 1998).

- It is not the cognitive, functional or behavioural problems associated with ... that cause caregivers to become severely stressed, depressed, or physically ill; but rather the caregiver's inability to cope with them. (Chui & Smith, 1990; Kemp, 1998; Zarit et al., 1980), An elderly person with a cognitive disability can change from being a likeable, tolerant, competent person to an argumentative, self-centred; disagreeable person, who is no longer able to accept change or let others assist them, "they know best". The 'informal' caregivers (family members) are likely to suffer the most anguish and despair, which in turn can lead to them venting their frustration's on formal care providers who are trying to assist. (See Appendix 1)
- The constant ongoing changes that me rapidly occurring with globalisation and the acceleration in information technology are beyond many peoples' ability to understand, or for them to learn new procedures, which in mm can lead to resentment and anger. As decline in cognitive ability is neurobiologically based and is not reversible, the question should be asked, "How best can we provide for these people, and their carers, thus limiting the stress levels of all concerned?"

Policy to meet the requirements of the Ageing Population

Promote **healthy lifestyle** changes that encourage better health and lessen the likelihood of reliance on medications to maintain elderly health, which in turn will assist in the maintenance of cognitive function.

- Move on from **impairment driven practices** that push elderly people to overcome problems that me biologically hard-wired into their DNA. *If* people are pushed to participate in programs that are beyond their cognitive ability, they become exposed to errors in safety, self-neglect and frustration, and will inevitably respond with. Negative behaviour. What is required are "Just Right Challenges" that match activity demands m the individual's retained cognitive abilities.

- **Empowering `informal' caregivers** with knowledge which develops a greater understanding of cognitive decline and allows them to set realistic expectations for the elderly person they are assisting.
- **Encourage businesses and organisations** that provide a service to the general public, to employ sufficient staff to demonstrate and show elderly customers layouts, procedures and processes. Talking to elderly customers or banding them written information with instructions is not sufficient to enable an elderly person to conceptualise:
- **Establish** the necessity for all-new **homes**, and **renovations** to existing homes, to be built to Adaptable Housing Standard. (AS 4299) principles. This is vitally important for formal caregivers that work in private homes; they must protect themselves and their clients from serious accidents.
- **Greater flexibility** and job sharing in **workplaces** for carers of elderly relatives. It is important that carers who are working are able to continue working, so they are not denied their retirement entitlements.
- **Establish caregiver seminars** and lunchtime talks in the workplace; this time might be the only time available to provide training and assistance to caregivers.

The rapid, continuous change of pace in today's society is creating a greater gulf between those who are able to adjust and those who are locked-into using well-learned skills and habits. As the science of medical knowledge grows, so life expectancy increases and aged people with cognitive disabilities live longer and require increasingly prolonged care.

It is imperative that debilitating cognitive disabilities, which have such a profound effect on individuals and their families, as well as the community and the nation, are acknowledged and that Federal Policies are developed to provide for the special needs of people with cognitive disabilities.

Empowering Caregivers: Confused Minds. Burdened Adult Children. Emotional Turmoil

"The way to 'do' is to be"- Tao Te Ching (1030-20713C)

An estimated 25% of families living in developed countries are caring for an adult with a cognitive impairment. This caring role is an unavoidable hidden drain (emotionally, physically and financially) for those who are responsible for assisting others. Contrary to popular belief, only approximately 10% to 20% of family caregivers use formal services available from public and private agencies. Knowing that 80% to 90% of families are using informal caregiving, it is also perceivable that many of those carers may also be functioning at a lower cognitive level/mode. In most cases, allied health professionals are not approached to intervene until a crisis situation occurs. It is then that these cases can become extremely complex and time consuming, taking a considerable amount of expertise to reach a satisfactory outcome. Unfortunately, many health professionals are not skilled sufficiently to provide such in-depth services to clients, informal primary caregivers and family members.

Difficult caring roles bring many challenges; caregivers of adult people with cognitive disabilities share common concerns, heartache and stresses. A carer can be on call 24

hours a day, listening for and trying to anticipate the unexpected. This becomes a 'taxing emotional roller-coaster ride, especially for the adult children who clearly hold passed memories of how their parents lived their lives.

Caring assumes even greater proportions when other health professionals or family members, who misguidedly believe that because the person being assisted is verbally adept, they are equally adept at looking after themselves on a daily basis. Many family carers have a 'knowing' that their loved ones are experiencing difficulties, but in some cases can not convince the medical practitioner: and/or other health service providers of the reality of their concerns and problems. This is distressing; and demeaning, particularly for family members who have their relative's best interest in mind. The caregiver's needs are seldom considered and their input about what is: going on with their loved ones is rarely solicited. Frequently, nobody even bothers to advise them, or demonstrate how best to carry out the tasks they have taken on out of. Love and a sense of responsibility towards the ones they: are caring for -- often it is at a huge cost to them in terms of time, money (not only in outlay but also in lost wages, pension credits and career opportunities), their personal interests and their health.

The range of stresses that caregivers experience is all encompassing. Many midlife carers say they feel more squeezed than stressed, as they struggle to juggle the competing demands of caring for an aged parent with a cognitive disability, being. Centrally important to immediate family members, and managing their own careers. Some of the more important negative effects that: are experienced by working' caregivers can include time lost from work, lower productivity, having to quit a job to 'provide care, lost career opportunities and lower future earnings; all this is when they are desperately trying to provide for the time when they can enjoy retirement.

Empowering caregivers with the necessary knowledge, realistic expectations and coping strategies provide' them with a greater: sense of self-efficacy, and very: importantly lightens their caring burden. Suggesting and arranging a family meeting to discuss difficult medical and legal issues can also be very helpful. It is then that the identification of needs, airing of concerns and delegation of tasks should be addressed in an open, supportive forum involving all available family members. Their family meeting also serves to lift some of the burden of concern from the shoulders of the many, informal carer as well as promoting their wellbeing and health.

In an effort to provide the best possible care for a family member or friend, caregivers often sacrifice their own physical and emotional needs, which can cause stress for vein the most. capable person. The resulting feelings of anger, anxiety, sadness, isolation, exhaustion-and then guilt for having these. feelings-can exact a heavy toll. Concerns about depression arise when the sadness and crying don't go away or when negative feelings and self-talk are unrelenting. Early attention to symptoms of depression through exercise, a healthy diet, the positive support of family and friends, and consultation with a trained health. professionals may help to prevent.. the development of a more serious state of depression in the long term.

In the paper written by Dr Boaz, there are two pertinent statements "You have to give them permission to take care of themselves" and caregivers' health problems are "not a function of caregiving but of self-neglect." Universal feelings of guilt are damaging to the general wellbeing of the carer, who invariably becomes highly stressed and distressed by what they see as their inability to cope with their caring role.

Breaking down the barrier of self-neglect as well as the statement, "I can manage on my own" can be taxing and hard work for a health professional. This becomes an even greater challenge when it is perceived that the informal caregiver has a cognitive disability. How often has a health professional, or well meaning relative, spent long hours establishing' a workable and functional human and non-human environment only to find on a return visit that the one being cared and/or their partner has asked the helping services not to return. Then find that they had asked someone else to rearrange all that you had so carefully put in place?

Assisting a person with a cognitive disability can be all consuming and uniquely different to other types of care. Not only do the carers spend significantly more hours per week providing care, they also experience employment problems, personal stress, mental and physical health problems, less time to do the filings they enjoy, less time to spend with other family members, and more family conflict than other caregivers. As stressful as the deterioration of a loved one's mental and physical abilities may be for the caregiver, dealing with difficult behaviour is an even bigger contributor to developing symptoms of. depression. Difficult and anomalous behaviours such as wandering, agitation, hoarding and embarrassing conduct makes every day challenging and harder for a carer to get rest or assistance n providing care.

Although male caregivers tend to be more willing than female caregivers to hire outside help for assistance with home care duties, they tend to have fewer friends to confide in or join in positive activities outside the home.

Grief is a natural process, an intense fundamental emotion, a universal experience, which in turn is part of the human experience. It is natural to grieve the death of a loved one who has a cognitive disability before, during and after the actual time of their passing. The process of accepting the unacceptable is what grieving is all about. When someone has a prolonged illness or serious memory impairment, family members may begin grieving the loss of the person's "former self" long before the time of death. This is sometimes referred to as "anticipatory grief." It is virtually impossible for people who are grieving to "move on" before they are ready. Some family caregivers identify more strongly with the person who died and his or her feelings. These people undergo greater emotional turmoil as they experience their loss and hurt. It is also understandable that their responses may be interpreted as "unreasonable." Nonetheless, it is important for them not to judge themselves too harshly when they experience conflicting and overwhelming emotions. It is important to understand that learning to deal with grief is a natural process in learning to live again.

In looking to their own futures, approximately 50% of mid-life caregiver confronted by problems that question:

- Who is going to be there for me?
- What can I do before I age to make my future easier and less complex?
- What steps can I take to prevent myself becoming difficult to handle?
- When I am elderly there will be so many more aged people, have I really thought about and prepared for any challenges in the future?

It is not until people are actually faced with the heartache of seeing a relative decline they consider the real impact and implications associated with the possibility of their own cognitive demise.

STATISTICAL INFORMATION

Age

- The average age of family caregivers caring for someone aged 20+ has been estimated at 43.
- Of those caring for someone aged 50+, the average age of family caregivers is estimated at 46.

Caregiving

- Caregivers use prescription drugs for depression, anxiety and insomnia often as the rest of the population.

Long Distance Caregiving

- The average travel time for these caregivers to reach their relatives is 4 hours. One study found that 19% of caregivers for the elderly lived with the person they were caring for, 46% percent lived 20 minutes or less from the elderly person needing care, and 18% lived over one hour away.

Physical Health

- Schulz, R. and Beach, S. R. (1999) said in their study of elderly spousal caregivers (aged 66-96) that caregivers who experience mental or emotional strain had a 63% higher risk of dying than non-caregivers. 31% of those caring for persons aged 65+ describe their own physical health as "fair to poor".

Mental Health

- Caregivers use prescription drugs for depression, anxiety and insomnia two to three times as often as the rest of the population.

Employment Status

- 25% of all workers provide elder care (65+). Just over half of all caregivers for persons aged 50+ are employed full-time and almost two-thirds are employed either full-or part-time.
- 52 % of working carers want workplace seminars, offering information to build skills.

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