

## **INQUIRY INTO SUBSTITUTE DECISION-MAKING FOR PEOPLE LACKING CAPACITY**

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To: The NSW Legislative Council Standing Committee on Social Issues

**Re: Inquiry into substitute decision making for people lacking capacity**

Thank you for providing Alzheimer's Australia NSW with the opportunity to submit comment to the NSW Legislative Council on Social Issues inquiry into substitute decision-making for people lacking capacity.

**Background**

As the Australian population ages, the number of people affected by dementia is rising. There are currently around 245,000 people with dementia in Australia. By mid-century, more than 1.13 million Australians will have dementia.

Dementia is the leading single cause of disability in older Australians (aged 65 years and older) and is responsible for one year in every six of disability burden for this group. It is also the fastest growing source of major disease burden, overtaking coronary heart disease in its total wellbeing cost by 2023. Dementia will become the third greatest source of health and residential aged care spending within about two decades. These costs alone will be around 1% of GDP. By the 2060s, spending on dementia is set to outstrip that of any other health condition. It is projected to be \$83 billion (in 2006-07) and will represent around 11 % of the entire health and residential aged care sector spending (Access Economics 2009).

Not only are the numbers of people with dementia in the population increasing, but it is less well known that dementia affects younger as well as older Australians. In fact, the number of younger people with dementia (under the age of 65) is increasing according to new prevalence statistics from 10,000 to 15,000 in 2009. People with younger onset dementia are often still employed and have dependent children (Access Economics 2009).

## **Dementia and capacity**

Dementia is highly unique in how it affects and manifests itself in each individual. While there are commonalities in its symptoms and experiences, dementia can affect individuals in very different ways. This needs to be taken into consideration when assessing capacity with regard to dementia. A person's level of capacity will diminish over time but during the early stages of dementia capacity for decision making can fluctuate, so in the case of dementia, the concept of capacity being decision-specific is particularly relevant.

A common problem for people with dementia is that people often assume that once diagnosed, the person no longer has capacity to make decisions at all. It is one of the most disempowering aspects of the disease. Maintaining independence and feeling empowered are paramount for a person with dementia. Suggestions that a person with dementia cannot make decisions for themselves will often be met with resistance, accusation and denial. Understanding the person with dementia's level of capacity can help them maintain their independence for as long as possible.

To balance the need to help support a person with dementia's ability to make their own decisions is the recognition that lack of judgment, lack of insight and memory loss are three common characteristics associated with dementia that place a person with the disease in a more vulnerable position when making decisions, particularly around money and financial planning. In addition, professionals should also be aware that people with fronto-temporal types of dementia, such as younger onset dementia, may often present well and appear to be fully responsible when transacting legal and financial affairs. This can make it difficult for professionals to avert problems.

Given the varying nature of dementia it may be difficult for legal practitioners and other professionals to accurately assess a person's level of capacity at any one point in time. However, while it is important not to assume a person with dementia lacks capacity, it is also important to be aware of the symptoms and signs of dementia and to look out for any changes in behaviors. Diminishing levels of capacity in a person with dementia can often leave a person vulnerable

to extortion and exploitation, particularly if adequate protections are not in place and the person has not planned ahead with regard to substitute decision making.

Below are recommendations regarding substitute decision-making with regard to people lacking capacity, in particular those people with dementia or cognitive impairment.

## **Recommendations**

### **1. Create a single legal definition of capacity to be used in all circumstances and applied across all legislation in NSW**

The current lack of a consistent definition can cause confusion about how capacity is defined and about how to assess someone has capacity. Current definitions in the Guardianship and Protected Estates Acts for example, are based around a person's *incapacity* and limit a person's autonomy to make decisions, rather than maximizing a person's capacity and protecting their right to make decisions for themselves where possible. Alzheimer's Australia NSW supports a human rights based approach to establishing a clear definition of capacity based around maximizing a person's ability to maintain their autonomy and being supported to make their own decisions wherever possible. A decision-specific approach to capacity is more likely to maximize the decision-making capacity of a person whose capacity is in question.

(a) Legislation should reflect the decision-specific nature of capacity to maximize an individual's autonomy.

(b) The appointed guardian should be obliged to assess a person's capacity for each individual decision.

(c) The assessment of a person's capacity with regard to dementia should not just be made at one particular point in time, but should be ongoing and related to each specific decision.

(b) More detailed information and specific guidelines need to be developed in relation to guardianship, capacity and dementia.

### **2. A code of practice should accompany any legislation to provide governing principles behind the definition**

(a) A Code of Practice should accompany legislation with the intention to guide professionals in the application of principles with regard to decisions around such things as accommodation, health and driving.

(b) Professionals should encourage their clients to plan ahead by putting in place an Enduring Power of Attorney and other instruments while they still have capacity, as it can help avert possible conflict later, both for the person with diminished capacity and for those who care for them.

### **3. The need to clarify informal decision-making processes around substitute decision making**

Often older people are pressured into handing over their decision making power to a substitute decision maker well before they have lost their full capacity to do so. In some cases family members may assume that once a diagnosis of dementia has been made, the person no longer has the ability to make decisions for them and decision making powers are swiftly transferred, leaving the person with dementia feeling powerless and frustrated. The current system has no checks and balances in place for situations of informal substitute decision making to address situations of abuse and exploitation.

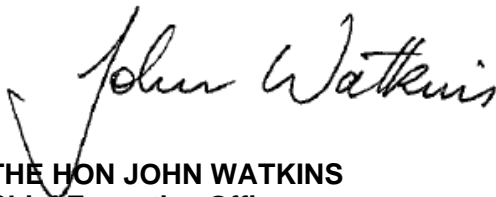
(a) Alzheimer's Australia NSW supports the need to investigate mechanisms that will provide safeguards around informal decisions made on behalf of people whose capacity is limited.

### **4. Recognition of the need for a standardized assessment tool**

Once a clarified single definition has been established then it will enable the development of a more standardized and accurate assessment mechanism for capacity.

Thank you once again for the opportunity to comment on this important issue.

Yours sincerely



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Chief Executive Officer

#### **Bibliography**

**Access Economics (2009) *Keeping dementia front of mind: incidence and prevalence 2009-2050*, Report for Alzheimer's Australia, August**