



Alzheimer's
Australia NSW
Living with dementia

15 July 2005

Dr Michael Keating, AC
Chairman
Independent Pricing and Regulatory Tribunal of New South Wales
PO Box Q290
QVB Post Office NSW 1230

Dear Dr Keating,

Re: Review of Metropolitan Water Agency Prices

Alzheimer's Australia NSW is the peak body in New South Wales advocating for people living with dementia, their carers and families. A not-for-profit organisation founded in 1982, our roles also include providing free support services such as counselling, carer education and information, and working to raise awareness and understanding of the needs of people living with dementia and their families and carers.

On behalf of people living with dementia and their families and carers, we request that you consider the following information* in relation to your draft determination on water pricing.

Background

Access Economics estimates that in 2005, every week 1,000 Australians will be newly diagnosed with dementia (*Dementia Estimates and Projections: Australian States and Territories*, Access Economics, February 2005). In New South Wales alone, there are more than 71,000 people with dementia and this number will continue to increase as our population ages.

Dementia is currently the second largest cause of disability burden after depression, and about half of all people with moderate to severe dementia live in the community in either their own homes or in the home of their carer. There are more than 70 diseases that cause dementia, with Alzheimer's disease the most common, accounting for between 50-70 per cent of all cases.

People with dementia differ in the patterns of problems they have and the speed with which their abilities deteriorate: memory, intellect, rationality, social skills and normal emotional reactions can all be affected.

Alzheimer's Australia NSW

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A person in the early stages of dementia may be slower to grasp complex ideas and take longer with routine jobs, become more forgetful of details of recent events and show poor judgement. With moderate dementia, a person may be confused regarding time and place, be very forgetful of recent events, become lost if away from familiar surroundings and wander. A person with severe dementia needs total care and may lose their ability to understand or to use speech, may be incontinent, need help with eating, and may become permanently immobile. Some abilities remain and the person with dementia still keeps their sense of touch and hearing, and their ability to respond to emotion.

Impact of proposed water pricing

Alzheimer's Australia NSW supports the efforts of Sydney Water to introduce pricing policies that will promote water conservation. However, we are concerned that the draft decision to implement a two-tiered variable usage charge may unfairly penalise people living with dementia, their carers and families.

We note that the Tribunal has examined customer impact and that the draft determination "provides for special measures to be introduced to moderate the impact of the price changes... To moderate the impact of price increases on large low-income families the Tribunal will be requiring Sydney Water to develop a rebate system where each member of a large low-income household will be able to use up to 80kL per annum at the lower tier 1 price".

Alzheimer's Australia NSW submits that Sydney Water should similarly be required to develop a system to moderate the impact of the price changes on households where a person with dementia lives. The rationale for this is that dementia as a condition can lead to higher than average household water consumption.

As referred to earlier, dementia leads to memory loss and confusion: this can mean a person with dementia forgets about water restrictions, forgets to turn off a hose or sprinklers or forgets that the washing has been done, and does it again (and again). A punitive pricing policy will not help the person with dementia to remember but it will place an additional strain on the already stretched resources of the family carer.

Furthermore, incontinence is a common condition for people with dementia. The changes in a person's brain that occur with dementia can interfere with their ability to recognise the need to go to the toilet, be able to wait until it is appropriate to go the toilet, find the toilet or use it properly. Incontinence can be very distressing for the person with dementia and stressful for their carer. Incontinence will necessarily lead to greater water consumption because of the extra washing and cleaning necessary to maintain hygiene.

There are a number of pressures on carers of people with dementia, and for many households, making ends meet is increasingly difficult as they struggle to afford non-PBS listed medications, therapies, respite care, assistive devices, and medical care. Families work hard to give the person with dementia a good quality of life in the security and comfort of their own home.

As a community, we need to support people with dementia, their families and carers. Sydney Water can contribute to supporting people living with dementia by not imposing punitive excess water charges on households of people with dementia, recognising that an additional demand for water can be a direct consequence of the condition of dementia.

Thank you for the opportunity to comment on the draft determination and we look forward to the Tribunal's favourable consideration of the particular needs of people living with dementia.

Yours sincerely

Peter Sawtell
Acting Chief Executive
Alzheimer's Australia NSW