

Keynote Speech
Carers NSW Conference

10.30 am – 10.50 am 11 June 2009
Duration – 20 minutes

Good morning everyone. It is my pleasure to be here to join you to open the Carers NSW Conference.

We are here today because we all recognize the demands of caring for someone with a disability, chronic disease or mental illness or other special need. We all know that caring is an extraordinary physical and mental challenge and that the demands of caring often go unrecognized and unsupported. We can, I think, also recognize it as a unique gift. It is at the heart of our human nature.

Because of my current role, I will spend some time exploring the challenges of caring some someone living with dementia. I am sure that the challenges experienced in this group reflect and replicate the challenges faced by many who have the responsibility of caring for others.

The Australian population is ageing fast and includes growing numbers of people with dementia. Those numbers are predicted to triple from 230,000 in 2008 to over 730,000 by 2050. One in four Australians over 80 will develop dementia. These alarming statistics show the growing momentum of this disease in Australia.

You may not be aware that deaths from dementia have more than doubled in a decade and it is already the fourth leading cause of death in the country behind heart disease, stroke and lung cancer. Ten years ago it was 7th. In twenty years it will be number one. You may not also be aware that dementia will be the leading cause of disability burden by 2016.

These numbers are so extraordinary in their impact and the physical and emotional demands of caring for a person with dementia are so profound dementia is becoming the emerging social and health challenge of the 21st century. It's the climate change issue of social policy. It is that big and far reaching.

And the case for carers in this area is an alarming one. An Alzheimer's Australia/Access Economics Report released earlier this month warned there be a chronic shortage of over 150,000 paid and unpaid carers by 2029.

Whether you are caring for a loved one with dementia or working as carer in a community or a residential care setting it is clear that unless things change there will not be enough carers to go around.

And we are simply not prepared. Not really ready. Without urgent action we will be overwhelmed and the results for individuals and their carers will be dark and dramatic. Just imagine someone living in remote NSW alone, with dementia with no care.

We need an acceptance of the extent of the problem by policy makers. But a continued commitment of resources and focused spending is the only way to ensure we can meet the future challenge.

The Access Economics Report recommends focusing funding on services that support carers to care for loved ones in the community for as long as possible and also recommends innovative financing mechanisms for aged care to sustain the system into the future.

But something needs to be done - and done now. Right now our health and aged care systems are not able to cope with the dementia tidal wave that is

about to hit us. Hard decisions will need to be made and we need to get more focused on where and how we spend money.

A short term, 'nibble around the edges' approaches won't work for a problem as big as this. What we need is a long term vision for the future of health, aged care and dementia services in Australia.

But statistics only tell part of the story. We need to recognize the unique challenges of caring for a person with dementia, and we need to give these carers the attention they deserve.

While we recognize all carers share many challenges, caring for a person with dementia can be particularly challenging due to the characteristics of the condition. It is a blind alley to suggest one type of care is more difficult than another. How do you compare - lifetime disabled child with - mentally ill? But dementia caring will become more common.

Carers speak of the relentlessness of the experience and the ongoing feelings of grief and loss as the disease progresses. Let me tell you about the heartbreaking journeys of Darrell Bailey and Ray Johnson.

In 2001 Darrell's wife was officially diagnosed with Alzheimer's disease, however, according to Darrell, her symptoms started to appear long before her official diagnosis around 1994 but the Bailey's GP would not agree there was anything different about her changed behavior.

Darrell's world was turned upside down.

He describes having to think for two people instead of one. He describes how he has had to deal with wills, powers of attorney, guardianship and signatories to financial accounts and advance care directives.

He describes coping with 'busybodies' inquiring about his wife's strange behavior, being shunned by relatives and friends and having to withdraw from groups that they have belonged to for years.

During the years following his wife's diagnosis Darrell says there have been just three offers to stay with his wife while he took a break for a few hours, and that they no longer travel. He describes how their world slowly became smaller and smaller.

Darrell talks about how his wife is quickly confused and disorientated. She forgets the date and time. She misjudges the time of day and cannot read an analogue or digital clock face. She has had side effects from medications, including fatigue, leg cramps, hallucinations and weakness, just to name a few. She cannot handle a cordless telephone. Now Darrell does all the driving and worries that if he has an accident at home his wife would be unable to call for help.

To compound the constant stress of care giving, Darrell faces an overwhelming feeling of loss. "We've lost part of our lives together....I have lost my confidante... we cannot talk over those issues which daily enter our lives because loss of brain cells means her rational thinking and expressions are impaired. I realize my role is to be more understanding, patient, tolerant, forgiving and aware...but it is not the person, it is the disability that is the cause."

And then there is Ray Johnson. Ray was 47 when he died in hospital with dementia after five months waiting for a nursing home bed that never came, because he was "too young to have dementia."

Ray's wife Margaret gave up work as a teacher to care for him in the five years between his diagnosis and death in 2002. It has taken Margaret Johnson years to pick up the pieces of her life after Ray died.

"It is such isolating thing, being a carer of someone with dementia. A person with cancer is able to still make their own decisions and can express their wishes. Once someone's diagnosed with dementia, it's all on the carer's shoulders. Gradually the

carer has to give away their job, their social contacts to become a full time carer and it goes on for years.”

A soon-to-be-released Alzheimer’s Australia NSW research project supports previous studies that have demonstrated the profound impact of grief and loss on the health and well-being of a carer of a person with dementia and demonstrated the huge benefits of support groups for the carers who attend. I suspect this is true of most carers.

But importantly, the unexpected finding, and the one that supports the recognition of the complex and unrelenting nature of caring for someone with dementia, is that the carer’s experience of grief can begin at the time the person with dementia is diagnosed and as the personality of the person they love gradually changes. As one carer said, *“Watching someone you love slowly deteriorate is unbearable.”*

Some carers reported that the grief and loss felt at this time was equal to, or even greater than, the grief felt when the person with dementia dies and that grief can also be amplified by the fact that this type of grief is not recognized by others (or sometimes even by the person themselves) while the person with dementia is still alive.

The unremitting and relentless burden of caring for a person with dementia and the physical and emotional toll it takes on the carer can lead to them becoming demoralized, isolated and psychologically distressed. With numbers of people with dementia set to increase in dramatic numbers across Australia we need to work together to find ways to better support this important group of carers, recognize their unique needs, and put in place dementia-specific support services both for them, and for the people with dementia that they care for.

The Access Economics Report shows that unless there are major policy changes or a significant medical breakthrough, there will simply not be enough people to care and there will not be enough money to pay for services. It is a grim picture indeed, but without a radical re-thinking of how we structure and finance our health and aged care services this is what we will face in the future.

So what do we need?

We need to increase early diagnosis by educating and prompting GP diagnosis and referral, we need to simplify access pathways to services for consumers, and we need to increase the choice and flexibility of services for consumers, such as respite.

We also need to be smarter about how we spend money on services. Lynne Pezzullo, a director of Access Economics, said that providing quality care for those with dementia was the immediate priority in the next two decades and suggests that financing those services will require a “rethinking of financing mechanisms hand in hand with the gradual introduction of saving vehicles over the longer term. “

The National Health and Hospital Reform Commission Inquiry has also recognized the need for radical reform of both the health and aged care systems.

It notes that Australia already spends \$94 billion, or about 9% of GDP on health and aged care services. That is projected to increase to \$246 billion or 12.4% of GDP by 2032/33. These numbers are clearly unsustainable.

Within 30 years the health budget in NSW will consume the entire budget.

That is why innovative caring models will become essential. Our time is coming.

Earlier I mentioned the Gift of Caring

We are better creatures for looking after others. It is part of our special human quality to be compassionate. Our capacity to love is what makes us unique.

And the person being cared for deserves that compassionate care. We all believe every human being has the right to dignified treatment especially those who cannot speak for themselves.

To be involved in caring for such a person is a privilege – a gift.

BUT, it can also be such a burden – draining, exhausting and despairing.

That's why those in need – need us, the professionals, advocates here today.

I am hopeful for the future - paid Maternity Leave – demonstrates things are getting better.

BUT still there are too many stories where carers

- cannot get benefits
- cannot get respite or accommodation

Where the hurdles are too high.

That is why we struggle. All strength to you. You have achieved so much. There is so much skill in this room. We can, I think, be hopeful for the future.