

Towards a world without dementia

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I want to thank the National Press Club for giving me this opportunity to talk about things I deeply care about.

The advice I had from Maurice Reilly was not to talk about my life and times in the media because people already know enough about me through *Paper Giants* – the two-part mini series shown on the ABC last year about the creation of *Cleo* magazine and Australia in the 1970s.

But given the current turmoil in the media I hope you won't mind Maurice if I make a few gentle observations. I am too passionate about the importance of independent journalism to resist the temptation...and I have been working in the media since I was 15 and over the years I've seen a lot of changes in our industry.

It seems the new blood sport is to guess what Gina Rinehart might or might not do if she succeeds in getting a seat or two on the board of Fairfax media. However I don't think it is for me or others to attribute motives or views.

What's more important is to stick to the fundamental issues for a valued print and electronic media...such as the integrity of the views being expressed.

It is all too readily assumed that the Australian public are mugs who buy any line that is spun to them whether by politicians or the media. My experience tells me this simply is not true.

It may be inconvenient for governments to deal with a fractious media but whether it is governments in their advertising, or media in pushing particular opinions, the public eventually has the good commonsense to make up its own mind about what is being said.

I find it disturbing that the kneejerk reaction to events in the media should be regulation.

We know from the UK that poor practice in the media behind closed doors eventually leads to the destruction of reputations and public confidence.

There is of course a role for privacy laws and criminal charges that protect against the worst types of behaviours.

But it is remarkably naive to think that those who have the power to influence will not do so in the media they own.

What's important is that the public understands where those views are coming from, that they are informed, supported by evidence and dare I say it, balanced by good journalism of a kind that provides an impartial point of view.

Good journalism is not about lecturing the public on what they should think but rather listening to their concerns and fashioning them into good stories that inform. And it's this connection of journalism with the public and story telling that has always fascinated me.

I count myself fortunate that at different points in my life I have been able to bring together my passion for journalism with being an advocate for causes I strongly believe in.

In 1984 I was asked by the then Minister for Health, Neal Blewett, to chair the National Advisory Committee on AIDS (nacaids) with the objective of increasing awareness about the HIV/aidsAIDS epidemic and changing the behaviour of those at risk.

My role as chairperson came with much controversy. There was a great deal of community fear about the aids virus and it wasn't fashionable back then to be a part of the HIV/AIDS fight.

The early years were tough but what we achieved was incredible.

I was involved in the development of one of the most talked about campaigns in Australian history; the Grim Reaper bowling down people as if they were ten pins at a bowling alley.

When I first saw the grim reaper commercial before it was released to the Australian public, it chilled me to the bone; it impacted on me and everyone that saw it. This style of campaign had never been done before.

It is now a textbook case study in the role that campaigns can play in changing attitudes and behaviours. More importantly, the grim reaper was a public awareness campaign that made people listen, learn and act.

It takes courage on the part of people with dementia to do that and I'd like to pay tribute to them today and thank them. It's not easy to stand up before people, most of whom you don't know and tell your story, to reveal as one woman did... "I feel diminished as a person; I feel diminished as a mother in the eyes of my sons."

Not only were we successful in changing behaviour and dramatically reducing the rate of new HIV infections but the work of the National Advisory Committee led to a change in public attitudes.

Finally HIV/AIDS was something that everyone knew about and we made a conscious decision as a society to fight it together.

Views will always differ about whether dramatic and frightening campaigns such as the grim reaper are too extreme... But I believe there are times when the dramatic use of media is necessary to get positive results.

AIDS was one of the major public health challenges of the 20<sup>th</sup> century; dementia and diabetes are two of the major public health challenges of the 21<sup>st</sup> century – and we know there is a link between the two diseases.

So what is dementia?

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease but rather describes a degenerative neurological syndrome predominantly associated with ageing, which causes profound cognitive and functional disability, and eventually death.

There are many different forms of dementia and each has its own causes.

Alzheimer's disease is the most common dementia accounting for 50-70 per cent of all cases.

The issues we face in confronting dementia are not dissimilar from those of HIV/AIDS and cancer...and include negative attitudes born of centuries of stigma, institutionalisation and ageism.

My concern about the quality of life for people with dementia and their families is the reason why I am committed to my role as president of Alzheimer's Australia. When I accepted the presidency I agreed with our CEO, Glenn Rees, that we had three years to change things.

That's our goal...and failure is not a word in our vocabulary.

I became National President in February 2011. Since then we have launched our Fight Dementia Campaign and combined it with a strong branding and marketing strategy.

Our campaign is designed to raise awareness with politicians and policy makers by telling the stories of people living with dementia. We believe this is the most effective way to overcome the negativity that pervades the politics of dementia and ageing.

The language and intensity of the Fight Dementia Campaign is in a lower key than the Grim Reaper Campaign but it has a force and intent quite different from anything that has been attempted before in advocating for the cause of people with dementia and their carers – be it family or friends.

We want to get the message across that Australia can beat dementia if we confront it the way we have tackled HIV/AIDS, cancer and heart disease.

The litmus test is whether our stakeholders support us – and overwhelmingly they do because we are “at last doing something”.

There are some who believe the campaign is overly aggressive and too far removed from the important role of our organisation in supporting those who are living with dementia.

I do understand such concerns and I’m sensitive to them, but our mission has to be to change attitudes and priorities.

What motivated me to take on a campaign that has involved marching on Parliament House here in Canberra last year – my first ever protest march. I enjoyed it actually.

Fellow marcher Sue Pieters-Hawke, Bob and Hazel Hawke's daughter – as you know Hazel has Alzheimer's – knew the protest ropes and was most helpful in coaching me.

"What do we want? More money for dementia. When do we want it? Now!"

And as we marched she shouted "you're not a virgin marcher anymore Ita!"

"But," I shouted back, "I never expected to lose my virginity on the lawns of parliament house, Sue."

Like Sue, my involvement is due to my personal experience. I cared for my father who had vascular dementia, the second most common dementia after Alzheimer's.

It is a period of my life that is burnt forever in my memory. Like me dad was a journalist, editor and author – I followed in his footsteps. His dementia often made him do things that were quite out of character, both amusing and sad.

Dad was aware of what was happening to him as the disease developed and had a level of understanding that he was not quite the person he used to be. He often told me how depressed he felt.

Unfortunately, some of my most enduring memories are how cruel we are as a community to people with dementia and, as a consequence, to their families and those who love them.

Instead of supporting people at a time of great difficulty and challenge, the instinct for many in our community is to turn their back and walk away.

The experience of the person with dementia and their family is made all that much worse by such community attitudes. Instead of helping the person with dementia we're actually making life so much harder for them.

Things haven't changed since dad died. As I've listened to the stories of people with dementia it has become increasingly apparent that we, as a community, and more particularly our health and aged care system are failing them badly in every way. Our society and more particularly our health and care system are failing them badly in every way.

The stories I've heard are backed up by an evidence base that shows that a diagnosis of dementia brings with it social isolation and a sense of shame for the individual.

This has been highlighted again in a report released today outlining the results of a study conducted by the centre for health initiative at the University of Wollongong. The findings suggest that many people hold negative attitudes towards people with dementia.

Of the 616 people who responded to the survey:

- Over half said that people with dementia can't be expected to have a meaningful conversation

- Over a third said people with dementia could be irritating
- One in ten said they would avoid spending time with a person with dementia.

Study respondents also said that if they received a diagnosis of dementia they would feel a sense of shame and humiliation coupled with the fear their diagnosis would mean they'd be discriminated against both in the community and the health sector.

Social avoidance has become the hallmark of the way we treat people with dementia.

We find it hard to relate to someone who is experiencing changes in their personality, their memory and their behaviour. It can be socially awkward when a person with dementia acts in a way that seems inappropriate or strange.

Not surprisingly dementia is the second most feared disease after cancer – among older people it's the most feared disease – but at the same time many people know little about the disease.

Alzheimer's Australia is working hard to dispel the myths that surround dementia.

For instance, a Newspoll survey shows that more than half of all Australians mistakenly attribute the symptoms of dementia as a normal part of ageing. It isn't.

The Newspoll findings, released today by Eli Lilly, also show that:

- More than 50 per cent of Australians think that difficulty performing simple or familiar tasks is a normal consequence of ageing.
- Nearly one in five said that if a family member had memory loss or confusion they would think it was a natural part of ageing.
- 10 per cent of people 19-34 said they had never heard of Alzheimer's disease.

There's no doubt in my mind that our health policy has badly failed people with dementia over the years.

The Department of Health and Ageing has treated dementia as an "ageing" issue rather than as a major chronic disease for many years. This perhaps has helped perpetuate the myth that dementia is just an inevitable consequence of ageing.

But look, enough of the negatives, it's time to be positive.

Our Fight Dementia Campaign is making its mark. A sea change is occurring. I congratulate the prime minister, Julia Gillard and the minister for mental health and ageing, Mark Butler, unreservedly on the commitment they have made to tackle dementia in spite of facing a difficult budget.

The government's *Living Longer, Living Better* package sets the scene for significant reform in aged care and a new determination to tackle dementia, both as a health and aged care issue.

Good policy and additional dollars will be needed to do this effectively and the government's package provides both in key areas across the health and aged care system.

It includes action on early diagnosis, making hospitals safer, dementia risk reduction, additional resources to provide quality dementia care and for the first time support for younger people with dementia.

It is also the first time in the history of Australian health policy that dementia has been recognised as a chronic disease.

Next month the commonwealth government will seek the agreement of state health ministers to make dementia a national health priority area alongside eight other chronic diseases.

I will be deeply disappointed if this doesn't happen.

So will the more than 1.2 million carers of people with dementia in Australia.

The *living longer, living better* package builds on the 2005 dementia initiative of the Howard Government which, at the time, was a world first. If we are to succeed in tackling dementia bipartisan support is essential.

The package holds out the prospect of a health and aged care system which can provide appropriate care to people with dementia and their families.

There is the opportunity to adopt new strategies to achieve timely diagnosis of dementia and avoid the trauma of years spent not knowing what is wrong. In Australia the average time of first recognising symptoms to getting a diagnosis is three years.

We now have a policy initiative to make hospitals safer places for people with dementia. Often people aren't recognised as having dementia – even people who have a clear diagnosis often receive inappropriate care.

Hospital staff are trained in how to provide appropriate care for people with mental health concerns, cancer and heart disease but few are trained to provide appropriate care to people with dementia. I know this first hand from my experience with my father and some of my other older relatives.

It shouldn't be up to the family carer to explain to nursing staff that people with dementia often become confused, agitated and even aggressive when their routine is disturbed as it is when they have to go to hospital.

In respect of aged care reform Australia has had aged care policies for 25 years with the objective of enabling older people to stay longer at home but without the provision of the essential home care services and respite care necessary to make that possible.

Residential care will of course be necessary for many but for too long it has been the first resort rather than the last resort.

Nor have we recognised that to achieve person-centred care, older people and their carers need to have the power of decision – not simply be the recipient of what services care providers may choose to deliver.

The *Living Longer, Living Better* package offers the prospect of expanding home care and enabling older people and their family carers to be genuine partners in decision making about the care they receive.

Alzheimer's Australia will be passionately advocating for an implementation process that's governed by the needs of older people and people with dementia.

Will the Fight Dementia Campaign go on? You bet it will!

The government has yet to address the serious inequity in research funding.

Dementia research in Australia is grossly underfunded in relation to health and care costs, disability burden and prevalence, compared to other chronic diseases.

As part of our Fight Dementia Campaign we sought \$200 million over five years – which would lead to a total investment in research of only one per cent of the cost of dementia.

In 2011-12, the National Health and Medical Research Council investment in dementia research was \$24 million. Over the same period, NH &MRC provided

- \$159.2 million for cancer research;
- \$92.4 million for cardiovascular disease;
- \$71.2 million for research into diabetes;
- \$53.6 million for mental health research; and
- \$14.2 million for asthma research.

This is not a new problem. In the last 10 years NH&MRC investment in dementia research has been one sixth that of cancer.

Even if we put aside the human suffering caused by the disease and just focus on economics, it makes sense to invest in dementia research.

Dementia costs the Australian health system \$6 billion per year and if there is no progress on ways to treat or prevent dementia, within 20 years it will become the third greatest source of health and aged care expenditure.

Investment in health and medical research is a proven approach for mitigating escalating health and aged care costs.

Investment in research through the National Health and Medical Research Council between 2000-2010 is projected to have saved \$966 million in direct/indirect costs to the health care system.

That's why investing in dementia research makes good economic sense.

From the perspective of the person at risk of developing dementia, investment in dementia research is urgent. Research is the only hope for reducing the number of people who have dementia and for developing better ways to provide care and support.

If researchers were to find a way to delay the onset of dementia by five years, the number of people with dementia would be halved with savings of \$67.5 billion by 2040.

Without greater investment in research, key progress in understanding dementia and developing new treatments will be delayed.

The clock is ticking. By 2030 Australia will have 500,000 people with dementia; by 2050 nearly one million Australians will have dementia – that's equivalent to the population of a city three times the size of Canberra.

We can't afford to delay.

There are of course other developments in health policy that we will be watching closely. Just recently the pharmaceutical benefits advisory committee announced that it is reviewing the medications used to treat the symptoms of dementia.

The PBAC says it is concerned that these medications are being prescribed for longer than originally anticipated and costing the government more money than expected.

I was shocked when I heard this news. These medications are already very tightly controlled; many consumers are currently paying more than \$150 a month to access them privately because they don't meet the criteria of improvement in cognitive scores after six months of medications.

These are the *only* medications available to people with dementia and they provide hope for some people with dementia for a limited time.

At the same time, anti-psychotics, which we know do harm to people with dementia, continue to be overprescribed but there is little control or review over their prescription...yet for many clinicians they are the first line of defence for behavioural symptoms.

It's a strange world where some drugs that are valued by people with dementia and their family carers are subject to review but not those drugs that are considered harmful.

It has given me huge satisfaction to use my profile and communications skills in support of important social issues – but I doubt my involvement would have happened the way that it has, had I not been a trained and practised journalist. All the good things, all the varied assignments of my career, have been related to

journalism. I decided when I was 11 that I wanted to become a journalist and I have never regretted that decision.

And although it has been challenging and at times an emotional journey, it has also been rewarding and fun...if you can't have fun it's difficult to be positive and that's critical for anyone serious about changing negative societal attitudes.

Nothing could be more positive than the next stage of Alzheimer's Australia Fight Dementia Campaign; of the need to invest in research and to begin working now towards a world without dementia.

It is an ambitious goal but one worth fighting for and I intend to do exactly that.

Thank you.