

The Good, the Bad and the Brilliant
Lessons from the Journey of Living with Dementia

Resthaven Malvern, Activities Hall, 43 Malvern Street, SA 5061

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I am grateful for the opportunity to speak at this launch.

All of us in this room share a vision of a better quality of life for people with dementia and their families. But for us to reach this goal there is a need for a greater community understanding of dementia and the rights and respect that people with dementia deserve. Supporting people with dementia and their families to tell their stories is perhaps the most effective way of achieving that - and the new publication ***The Good, The Bad and The Brilliant*** does that well.

Many of you will know about the Alzheimer's Australia Fight Dementia Campaign. The Campaign is also built around the stories of people with dementia and family carers.

The end result of nine months of campaigning and sharing the experiences of people with dementia is the announcement of aged care reforms made by the Prime Minister and the Minister for Mental Health and Ageing, Mark Butler on 20th April which proposed a package of measures to tackle dementia in ***Living Longer living Better***.

For the first time in the history of Australian health policy, dementia has been addressed not only in aged care but in national health policy – to promote timely diagnosis, safer hospitals and dementia risk reduction.

At long last subject to the agreement of State Health Ministers, dementia will be recognised as a national health priority, alongside eight other chronic diseases.

The aged care reforms themselves have a focus on dementia and they acknowledge the additional cost of providing quality care for people with dementia through supplementary funding for dementia care in both community and residential settings.

And for the first time too there is funding to better support those with younger onset dementia.

It is too soon to celebrate. The issues and concerns raised in ***The Good, The Bad and Tthe Brilliant*** will not go away overnight. In part this is because implementation of reform takes time but the issues not only need a policy and funding response but changes in community attitudes to dementia and, more generally to ageing.

Respect comes through having the power to make decisions over your own life and having the freedom to make choices. With the help of people with dementia, their families, and their carers, we are able to identify the main elements of what needs to be done.

First, we need to promote a greater awareness of dementia. Market research in Australia and elsewhere suggests there remains limited understanding of the symptoms of dementia beyond memory loss, including but not limited to that:

- it can affect younger people
- it is a terminal disease
- Its symptoms develop decades before diagnosis, or
- that lifestyle may offer some the possibility of risk reduction.

Secondly, we need a rights based approach to dementia. Loss of capacity should not mean loss of rights, dignity or entitlements. People with dementia should be able to maintain their autonomy and self-determination for as long as possible, and to be involved in supported decision making over their health care. The evidence shows that this is often not the case.

Thirdly, we need greatly expanded community care services, including flexible and appropriate respite care. ***Living Longer Living Better***, makes a first step in that direction by providing for an expansion of 80,000 community home care packages by 2021. This expansion is welcome but it only a first step.

Fourthly, we need to empower older people and their carers to be able to decide what services they need and when, where and how they will be delivered. This principle, often referred to as consumer directed care, is to be embodied in the aged care reforms.

Alzheimer's Australia believes in particular that respite care needs to be more flexible including a trial of cashing out respite care funding. This would mean giving the consumer cash to spend instead of receiving a service from a provider.

Lastly, we need to believe as a society that we can beat dementia. One way to do that is by investment in dementia research. By any measure dementia research is grossly underfunded in Australia.

I should like to congratulate the Resthaven Board in leading by example and showing the way to others by supporting the Alzheimer's Australia Dementia Research Foundation.

The five elements I have identified will require a huge cultural and attitudinal shift if the respect and dignity that people with dementia are looking for in the Good, the Bad and the brilliant is to become reality.

People with dementia of all ages and their family carers will need to be more confident and better informed about what the options are in order to make their choices.

Service providers will have to enter a new world of responding to the needs of the individual rather than pressing their particular programs of care.

And as a community, we need to be less risk adverse in letting older people make their choices.

To remind us of the size of the task we have only to reflect on the fact that 25 years after adopting the objective in aged care policy to enable people to live at home longer, less than 25% of aged care funding is spent on community care.

And for those with younger onset dementia choice will not be a reality until there are services which provide age appropriate care. I hope that services with a proud tradition such as Resthaven will take up the challenge to be innovative in providing community and residential care services for that group.

Congratulations again on the production of ***The Good, The Bad and The Brilliant.***