

## JO and JR Wicking Trust

### Improving dementia care through research – knowledge translation in major policy change and care practice

**Glenn:**

Good afternoon everyone, and thank you to the organisers for inviting me here today.

As a modern health NGO, Alzheimer's Australia's **primary objective** is to bring about change in policy and practice that leads to better care and better quality of life for people living with dementia.

Our credibility turns on whether we can achieve systemic change in the health and aged care system.

This is quite a challenge, but we have positioned ourselves to **succeed in three ways.**

First, we are consumer credible. Alzheimer's Australia takes its lead from consumers, as you will hear from my colleague Ron Sinclair shortly, and their priorities become ours.

Second, we have developed significant intellectual capital, working closely with researchers, clinical experts and service providers.

Third, we are service oriented, both as a provider of services through our state and territory organisations, and through our close relationships with service providers in community and residential aged care, and in primary care and acute care.

My own background is policy. I have sought to take a partnership approach with the Department on key issues, in particular through the Minister's Dementia Advisory Group. This has resulted in our not only having a presence in work with the aged care division but also success in other areas- for example with acute care, primary care and research.

Our partnerships with key decision makers in government and in industry, and our access to clinical and research knowledge are what enable us as an advocacy organisation to achieve our ambition to be a driver of change.

These threads come together in knowledge translation.

**Definitions and understandings** of knowledge translation vary. It is a general term that describes the many different processes for transforming new knowledge into every day practice on a sustainable basis and where possible on a national scale.

The approach we adopt varies depending on the issue but there are some common elements. We have adopted two main strategies:

- First, to work at a high level on health and aged care policy with government to achieve systemic change in health and aged care. We do this, for example, in respect of consumer directed care, dementia risk reduction and dementia care in hospitals.
- Second, at the practice level, to draw on priorities set by consumers, our own expertise and our partnerships with researchers and service providers to translate new knowledge into every day practice.

I will draw on two projects to illustrate the potential of our role as an NGO to achieve change using each of these strategies that would not have been possible without the J O and J R Wicking Trust and the ANZ Trustees.

## **Major Policy Change**

**The example of major policy relates to dementia care in hospitals.** In this case the Trust agreed to support a commissioned project by Alzheimer's Australia from the Australian Institute of Health and Welfare on dementia care in hospitals.

The story starts with consumer advocacy. Over the years it became clear that people with dementia are often not identified by hospital staff with the consequence that there are complications in respect of medications, falls, confusion, malnourishment and dehydration.

Powerful as these stories are in demonstrating how dangerous acute care can be for people with dementia, this is not the hard evidence that is needed to persuade governments to take an interest.

We have a long and valued partnership with AIHW and seeking their involvement in a well evidenced report of the care and cost consequences of dementia care in hospitals was a the first step.

We knew that the Institute already had an extensive data set of over 400,000 over night admissions to NSW hospitals for people aged 50 and over during 2006 and 2007. This data was linked to create records for over 250,000 patients, and information was gathered on primary and secondary diagnoses, transfers within and between hospitals, procedures undertaken and the length of stay.

## The work done by AIHW revealed that:

- Dementia was not recorded as a diagnosis for almost half of the hospital stays for people with dementia
- People with dementia experienced much longer hospital stays which in turn was associated with increased complications, delayed recovery, and poorer mental and physical health outcomes.
- These longer stays resulted in higher costs to the hospital system. Specifically, the average cost of care for a person with dementia in a hospital is 50% higher than for a person without dementia admitted for the same reason.
- 35% of the costs of treating people with dementia are directly attributed to the disease.

This report was launched in February this year at a Parliamentary Friends of Dementia. It followed on from an important stakeholder meeting sponsored by the Ministers Dementia Advisory Group in November 2012 that brought together experts, consumers and researchers from across the country to discuss priorities for enhancing the quality of dementia care in hospitals.

The stakeholder report and the AIHW report have provided the basis **for prioritising the use of the \$40 million** provided in *Living Longer. Living Better*. for dementia care in acute care settings. The initiatives include:

- Improving the management of cognitive impairment using the National Safety and Quality Health Service Standards.
- Improving the environment and design of hospitals for people with cognitive impairment.
- Undertaking an audit of dementia training in the acute care sector to determine what resources are available and identifying gaps.
- Promoting a program for change approach to support projects that build on existing systems in hospitals to improve care outcomes for people with dementia that incorporates a cost benefits analysis.
- Assessing the costs and benefits of a cognitive impairment symbol in the acute care sector

Let me say that while Alzheimer's Australia was a driver in much of this work it would not have been possible without the wonderful support of Professor Henry Brodaty, Associate Professor Mark Yates and other clinicians and researchers. In fact the outcomes could have only been achieved through partnership and working together including the willingness of the Department to listen and take on board the outcomes of the AIHW report and the stakeholder meeting.

There are other examples **where Alzheimer's has achieved significant policy change** in this way for example

1. Alzheimer's Australia has worked for over 12 years with researchers in Australia and overseas to draw together an evidence base on consumer directed care, promoted discussion on CDC through a series of national workshops and at conferences, and taken the evidence to Ministerial and departmental Advisory Committees. One of the cornerstones of the new aged care reforms is CDC - the idea that it should be consumers who determine their care needs within the funding available.
2. Alzheimer's Australia has drawn together the evidence base to support a public health dementia risk reduction program since 2006. Last year, the Government funded Alzheimer's Australia to roll out the world's first publicly funded dementia risk reduction program Your Brain Matters.
3. Lastly, we have taken the lead in pulling the evidence in respect of delays in the diagnosis of dementia, promoted a stakeholder workshop through the Minister's Advisory Group on the diagnosis and management of dementia in primary care. We are now working with the Department and others on prioritising the use of the \$16 million in the ***Living Longer. Living Better.*** aged care reform package to improve the timely diagnosis of dementia

### **Improvement in Dementia Care Practice**

The knowledge translation strategies we have used to improve care practice based on the best available evidence is no less sophisticated and demanding.

**Over \$1 billion of taxpayers' money** is spent each year on health and medical research in Australia, and close to \$1 trillion in total around the globe, yet the translation of the outcomes of this work into better health and aged care is often slow.

Research has suggested for instance that:

- On average there is a 17 year gap between the publication of new research and its implementation in health and aged-care practice.
- In Australia, Professor John Braithwaite has shown that 30-40% of healthcare across a range of conditions is inconsistent with best practice guidelines, and in some cases, is actively detrimental to patient outcomes.
- Furthermore, 20-25% of health care is either unnecessary or harmful, according to US research.

Concerns about the translation of existing knowledge into higher quality care can be readily identified in dementia care

Arguably we should be able to do much better in key areas such as

- The timely diagnosis of dementia. Currently, it takes an average of 3.1 years for people with dementia to get a firm diagnosis in Australia, and half of all people with dementia are not diagnosed at all. This is not good enough for early interventions and advanced care planning.
- Appropriate end of life care and advance care planning for people with dementia
- The misuse of anti psychotic medications to treat behavioural symptoms of dementia when there are safe and effective alternatives.

There are many challenges in dementia care and it is beyond one organisation to achieve change.

The interest of **Alzheimer's Australia in playing a part in improving care practice** is driven by:

- A conviction that consumer involvement in setting priorities and involvement in research is critical to improving care outcomes.
- Better resourcing Alzheimer's Australia to position itself in contributing to improved dementia care including through the employment of highly qualified staff.
- Building on and developing our partnerships with the three dementia collaborative research centres and other experts.
- Working more closely with service providers on projects designed to improve the quality of dementia care.

We first took our **proposal for the National Dementia Quality Care Initiative** to the Board of Alzheimer's Australia in May 2007 and to the J O & J R Wicking Trust later that same year. There followed a long period of discussion during which the Trust first supported us to undertake a feasibility study, then to develop and improve the proposal. It was a requirement of the support pledged by the Trust in April 2009 that we secure funding from other sources and this we did from Bupa Care Services by mid-2009.

In parallel with that process we gained support from the three DCRCs for the establishment of a Consumer Dementia Research Network to identify priorities for the new NQDCI and to take decisions on the projects to be supported.

**The result was the establishment** of the National Quality Dementia Care Initiative, launched in 2009 with \$3.3 million funding from the Wicking Trust, Bupa Care Services and the Dementia Collaborative Research Centres, and under the direction of members of the Consumer Dementia Research Network.

I am going to handover now to Dr Ron Sinclair, the Chair of the Consumer Dementia Research Network.

**Dr. Ron Sinclair:**

**The consumer voice** is not heard enough in research, even though the outcomes of new medical practices directly affect us. Consumer informed research is a key part of knowledge translation as it enables researchers and policy makers to learn about the concerns and priorities of consumers.

**The Consumer Dementia Research Network is a group of 27 consumers** who care for people with dementia or have dementia themselves. We come from every state and territory including major cities and regional areas, we range in age from our 30s to our 70s, and we are representative of diverse groups.

The things that unify the group are our personal experience of living with dementia, and our commitment to improving the quality of dementia care through research and knowledge translation.

The role of the CDRN in the context of the National Quality Dementia Care Initiative is to prioritise the issues for action, select projects and then monitor knowledge translation projects that receive funding.

We do this by **prioritising six areas of concern** with dementia care that we experienced as consumers. We then work with researchers and service providers to identify which of these issues have a strong evidence base to supply answers, and could be feasibly addressed with knowledge translation within the scope of our program.

We then oversee an application and assessment process through which we receive input and expert review from stakeholders, then make the final decisions on funding of projects ourselves. Finally, CDRN members maintain memberships on steering and advisory committees to provide oversight and consumers perspectives.

We have selected eight projects to date that have received over \$2 million funding through the program, and which have all been required to undertake projects that are national in scope and sustainable beyond the funding period. The application criteria included:

- Address evidence-practice gaps within priority areas.
- Demonstrate impact on quality of dementia care.
- Have national impact.
- Directly involve consumers.
- Incorporate an evaluation component.
- Involve an Alzheimer's Australia organisation.
- Demonstrate sustainability.

These projects are:

1. A project to improve the standard of architectural, interior and environmental design for people with dementia.
2. Evidence-based Montessori dementia strategies to family carers of people living with dementia in aged care facilities.
3. A project helping community care providers to deliver person-centred care to consumers with dementia;
4. A new interactive resource to improve communication between staff and family members of people with dementia living in aged care
5. An extension to the existing Heart Foundation Walking program that is providing new opportunities for people with dementia and their carers to join social walking groups right around Australia
6. Providing dementia training to over 1,000 GPs and practice nurses right around the country
7. A project helping people with and without dementia to understand advance care planning, and to engage in the process with family members and medical practitioners
8. An evidence-based framework for palliative dementia care being rolled out to aged care facilities around the country.

You can find more information on all of these projects in the flyer that I believe you've received, and on the website: [www.qualitydementiacare.org.au](http://www.qualitydementiacare.org.au). I'm going to focus on two of them.

## Dementia Enabling Environments Project (DEEP).

Imagine you are a person with moderate dementia. You're walking along the corridor, minding your own business, when all of a sudden you come across a small lever you've never seen before that says 'Pull Down'. What would you do?



You might give it a tug right?



Now you feel like a walk in the garden and you're looking for the door. Exit, great!

# EXIT

As a person with dementia, these are completely rational things to do. But for the nursing home, you are likely to have been labelled a 'difficult resident', setting off the



fire alarm like that – perhaps repeatedly – and you could be facing the prospect of locked doors or chemical restraint.

These are simple examples, but they illustrate just some of the challenges we design into our buildings and our environments for people who don't have completely normal cognitive abilities.

The fact is that many houses, nursing homes, public buildings and outdoor environments that people with dementia have to live in and use are designed and built without any thought whatsoever for their abilities and their needs. This is often enough to tip the balance for a person with dementia from being able to get by with some degree of independence, to needing a much higher level of care.

We've known about these issues for a long time, and have evidence-based guidelines that tell us what should be done. But essentially, many of our homes, buildings and outdoor environments, including many brand new nursing homes that are being built today, unintentionally make life more difficult for people who are already struggling to get by.

Which is why we funded this project. Led by Jason Burton from Alzheimer's Australia WA and Richard Fleming from the NSW/ACT Dementia Training Study Centre, it was the first of our projects to start and the first to finish, and it has been successful in translating the evidence into the beginnings of better environmental design.

The outcomes have included a workshop for consumers on home modifications that is being rolled out nationally through AA; dementia design units in curricula for several university architecture courses around the country; a fantastic interactive website that I'll show you some shots of now; and perhaps most importantly, the very first inclusion of dementia in Australian building design standards – similar to the beginnings of accessibility standards for people with disabilities 20 or so years ago.

## **Start2Talk**

The second project about is developing a campaign and resources to encourage people to think about advance care planning. It's led by Dr Chris Shanley from Liverpool Hospital in NSW who is working with a wide range of partners to implement a program that encourages everyone, not just people with dementia, to think and talk about what they'd like to happen if they were in a situation where they couldn't make decisions for themselves.

This campaign is called Start2Talk, and will be officially launched in October this year.

We know about the benefits to advance care planning from our research colleagues, so the challenge is to encourage people to engage. It's drawing on the lessons from campaigns like Donate Life to put a positive frame around a topic that most people prefer to avoid.

Glenn has talked about the importance of partnerships. CDRN talks the same approach.

First we have one of our members working part-time with the new NHMRC Partnership Centre on Cognitive Decline. This is the first time that I know of in this country that consumers have had such an influential position in such a major research program.

Second we have developed strong relationships with dementia researchers around Australia, and in a few cases internationally. Between the 27 of us, we are involved in almost 50 different research and knowledge translation projects. Our members are increasingly being sought out by people working in the sector to sit on steering and advisory committees, to provide input on a range of issues, and to speak about consumer involvement at a wide range of events and conferences.

Lastly, we have become active and influential in our own right as advocates for dementia research. We successfully advocated for a strong focus on consumer involvement in the McKeon Review of Health and Medical Research and we have members representing the consumer voice on government bodies.

None of this would have been possible without the support of the JO & JR Wicking Trust and their faith in the National Quality Dementia Care Initiative back in 2007, and also without the support of Bupa Care Services, the DCRCs, and of Alzheimer's Australia.

**Glenn:**

## **Conclusion**

Thank you Ron.

I hope we've managed to help you understand how Alzheimer's Australia approaches knowledge translation, and how important ongoing relationships with organisations like the ANZ Trustees and the JO & JR Wicking Trust are to us in these endeavours.

I think I can say with confidence that we are succeeding.

Our policy work has laid the basis for dementia becoming a National Health Priority Area and to secure over \$1 billion government investment in new dementia programs and services.

We have opened up our experiences on both CDRN and the National Quality Dementia Care Initiative to the scrutiny of an independent external evaluator who is due to release a final report on the achievements of the CDRN next month, and of the Quality Dementia Care Initiative in mid-2014. The ANZ Trustees encouraged us to engage this evaluator from the outset, and we have been grateful on numerous occasions for their guidance and advice.

I said at the beginning of this session that Alzheimer's Australia's primary objective is to bring about change in the health and aged care system that benefits people with dementia, and that the way we do this – our core business – is knowledge translation.

At low cost per project we have established processes for improving the quality of dementia care at the national level and outputs have begun to flow. It will take longer to show systemic change and improved outcomes.

Thank you.