

Dementia: Australia at the crossroads

Australia can be proud of taking a leadership role internationally in 2004 in making dementia a health priority and subsequently in building on that with new dementia initiatives in Living Longer Living Better in 2012 and a \$200 million boost for dementia research in 2014. There are important lessons Australia can now learn from other countries in taking forward policy and action on dementia post the Royal Commission into Aged Care Quality and Safety in respect of planning, dementia risk reduction and introducing greater flexibility and coordination of dementia services.

A great deal has happened internationally since Australia blazed a trail in 2004. Most importantly, in May 2017 the members of the World Health Organization (WHO), including Australia, unanimously adopted the Global Dementia Action Plan (GDAP) 2017-25 (WHO 2017) which identifies seven priority areas for action with specific targets to be achieved. Earlier this year the G20 singled out dementia as one of its global health priorities in its summit declaration on 29 June in the context of promoting healthy and active ageing in the following terms: "We will implement comprehensive set of policies to address dementia, including promoting risk reduction and sustainable provision of long-term care as well as inclusive societies aiming to improve quality of lives of people with dementia and caregivers."

Subsequently the G20 health ministers met in October and in Article 26 of their Declaration committed "to developing and implementing multi-sectoral national action plans, adopting integrated approaches on dementia in line with the Global Action Plan to improve the quality of care and the quality of life of people with dementia, their families and caregivers" (ADI 2019a). Ministers went further in references to policy making, awareness, risk reduction, care, support for carers, data and research and made a strong reference to the Convention on the Rights of Persons with Disabilities (CRPD).

How these important international commitments translate to action at the national level is work in progress. There is a commitment to monitor national action in response to GDAP in 2020, 2023 and



The Australian adaption of the COPE Program is a positive example of support, with structured occupational therapy and nursing intervention for people with dementia and their carers living at home

2025 and Alzheimer's Disease International (ADI) is publishing a report annually, *From Plan to Impact* (ADI 2019b).

It is early days in the life of GDAP but there are lessons for Australia in respect of the plan's seven action areas, both from experience within Australia and overseas, which I outline here.

1. Planning

Dedicated national plans, either stand-alone or integrated with other policies, are critical to taking action on dementia. To be effective these need to be funded, implemented and monitored. Australia has funded and prioritised particular actions including information and awareness activities, training, dementia behaviour advisory services, incentives to meet the extra costs of dementia care, and research.

In this way Australia has done as much if not more than most countries, but has done so without planning and measurement of outcomes. The Australian Government's National Framework for Action on Dementia 2015-19 (Department of Health 2019) has no stated outcomes beyond general statements, for example in regard to rates of diagnosis. It is now overdue for revision.

The 3rd South Korean Plan (South Korea Ministry of Health and Welfare 2015), by comparison, is transparent – with objectives, strategies to achieve them, identified resources and Key Result Indicators (KRIs) and is based on an evaluation of the second plan. There is much detail in the plan but the aspect that impresses me is the commitment to KRIs –

As the Chair of Alzheimer's Disease International for almost five years,



Glenn Rees is well placed to comment on how Australia compares with other countries in terms of dementia care, its response to the World Health Organization's Global Dementia Action Plan 2017-2025 and what lessons we should be learning

both outcome and output and their measurement. For example:

- The decrease in the rate of dementia prevalence by early management of risk factors.
- Measurement of dementia awareness based on a nation-wide survey.
- Numbers of leading schools taking part in overcoming dementia.
- Numbers of dementia friends.
- Establishment of 24-hour visiting respite services, specialisation of services for people with dementia in nursing homes.
- Monitoring of rates of physical abuse.
- National survey on quality of life of caregivers.

The plan is also illustrated with a glimpse of how the expected changes will impact on the stories of individuals with dementia and their carers.

Australia can do better in its next plan – one that should be based on consultation and evidence.

2. Dementia awareness

The ADI *World Alzheimer Report 2019: Attitudes To Dementia*, published in September (ADI 2019c), makes it clear that the issue of stigma goes beyond knowledge to attitudes and behaviours (see p29 for a summary of the report). The experiences reported by people with dementia suggest that there are deeply ingrained cultural and structural factors in all countries that result in discrimination and isolation for people with dementia. Key areas of participation relevant to people with dementia in all cultures and

countries include social relationships and interactions with health care staff. Respondents articulated different ways in which they felt they were treated unfairly because of their dementia in social life, including no longer being invited out, being ostracised, losing contact with people they know, feeling they could no longer contribute and lack of support to make interactions accessible.

It will be important that Dementia Australia builds on the work it has already done to analyse the survey returns from Australia and the available strategies, including supported decision-making, dementia-friendly communities and monitoring the rights of people with dementia under the Convention on the Rights of Persons with Disabilities.

Particularly exciting are the initiatives being taken by the Asia Pacific members of ADI to implement a Youth Engagement Program (YEP). The plan is to launch YEP internationally at the ADI Conference in Singapore in March 2020. This builds on the intergenerational work being done in Japan, South Korea and Indonesia. This involves school education and information programs, young carers sharing their experiences and young people engaging actively in dementia-friendly projects.

3. Dementia risk reduction

New evidence is accumulating rapidly on dementia risk reduction, most recently presented in the *WHO Guidelines on Risk Reduction of Cognitive Decline and Dementia* (WHO 2019). The conclusion is that modifiable risk factors (ie lifestyle and medical conditions) are linked to risk of dementia and other conditions and that by reducing these, 20-30% of dementia cases could be prevented.

The International Research Network on Dementia Prevention (IRNDP) is a multinational network aiming to link researchers globally to foster new research and accelerate knowledge translation that will prevent dementia worldwide. IRNDP has an interactive online hub and works to generate collaborative grant applications, studies, publications and recommendations for policy with input and regional expertise from high-, medium- and low-income countries and key stakeholders including the WHO (Anstey & Peters 2019).

The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) (Rosenberg *et al* 2018) is the first randomised controlled trial showing it is possible to prevent cognitive decline using a multi-domain lifestyle intervention among older individuals. The results have highlighted the value of addressing multiple dementia risk factors

as a strategy to protect brain health and promote overall brain functioning. The FINGER trial is now being replicated internationally including in Australia to achieve harmonisation of methods while allowing for local adaptation.

Other important work is in hand through the Global Brain Health Institute (GBHI) which is dedicated to protecting the world's ageing populations from threats to brain health. GBHI works to reduce the scale and impact of dementia in three ways: by training and connecting the next generation of leaders in brain health through the Atlantic Fellows for Equity in Brain Health program; by collaborating in expanding preventions and interventions; and by sharing knowledge and engaging in advocacy.

To date there has been little action at the national level either in respect of encouraging individuals to reduce their risk or at the population level by governments outside of South Korea (South Korea Ministry of Health and Welfare 2015) and the UK.

4. Diagnosis, treatment, care and support

Perhaps the most ambitious target set in the Global Dementia Action Plan is Action 4, *Dementia diagnosis, treatment, care and support*, namely that *in at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025*. Currently, even in many high-income countries, less than 50% of people with dementia are diagnosed and in most low- and middle-income countries the figure will be very low. Without a diagnosis and post-diagnostic support people with dementia will be denied access to the advice and services they need.

Australia, like many other countries, has given priority to dementia training for doctors in the primary health care system. This is important but not enough if the discrimination in the health systems reported in the *ADI World Alzheimer Report 2019* is to be overcome. Two strategies suggest themselves.

First, to give people with dementia a guarantee of post-diagnostic support. Such an approach, which has been adopted in Scotland (Alzheimer Scotland 2011) would respond to the human rights of a person with dementia and their informal carer to support and empower the person with dementia. Currently in Scotland about 46% of those diagnosed with dementia are offered post-diagnostic support through Alzheimer Scotland and other agencies. It might be of especial assistance to a person with dementia who has no informal carer. This would give Australia's aged care system the human face which My Aged

Care lacks and place an emphasis on a recovery type of approach.

Second, to empower people with dementia and older people generally to be assessed in line with the principles of Australia's National Disability Insurance Scheme (NDIS). The governing principles should be that the person with a disability of any age should be independently assessed, empowered to plan and negotiate the social support they need to decide how their package is managed – whether self-managed or managed by a service provider (Rees 2019)

5. Support for dementia carers

In some other countries there is a greater recognition of the need for flexibility in service delivery to assist the family carer, particularly in the area of respite. Apart from being under-resourced, Australia's care packages approach is rigid, both in respect of matching resources to the needs of individuals and in the supports included.

Japan has respite services for those with dementia, including for those with higher level needs, and these can be accessed 24/7. If Australia is to enable more people with dementia to live in the community, managed respite services are needed that ensure carers can plan access to respite for blocks of time and that people with dementia are offered social or other activities that interest them.

There has been significant research into the needs of carers, including physical, relational and emotional. The issue is how to adapt those research protocols to the reality of the services whose resources are stretched. One positive approach is the adaptation of The Care of Older Persons in their Environment (COPE) program to the Australian care environment by researchers at the Universities of Sydney and Flinders. COPE (www.copeprogram.com.au) is a structured occupational therapy and nursing intervention for people with dementia and their carers living at home that is designed to assist in independently managing everyday activities.

6. Information systems for dementia

The target for this action in the Global Dementia Action Plan is that 50% of countries routinely collect a core set of dementia indicators through their national health and information systems every two years by 2025. The Global Dementia Observatory, established by the WHO with members including Australia, is a welcome development to provide a web-based data and knowledge exchange platform to collect and disseminate key dementia information from WHO member

states. The information will include global and regional dementia reports and country-specific information sheets summarising the implementation progress of the plan in 2020, 2023 and 2025.

Australia has not been well positioned to develop a good evidence base for dementia policy and care. However, the Australian Dementia Network (ADNeT) offers the prospect of bringing together Australia's leading researchers to progress dementia prevention, treatment and care through a Clinical Quality Registry (CQR) for newly diagnosed dementia or mild cognitive impairment; through expanding and supporting memory clinics and clinical trial sites; and establishing longitudinal and trial-ready cohorts.

7. Dementia research and innovation

There has been an increase world-wide in investment in dementia research, but as argued in the *World Alzheimer Report 2018: The State Of the Art of Dementia Research* (ADI 2018), it is much below what is needed or relative to other non-communicable diseases, notably cancer. There is a consensus on priorities around research into cause, disease modifying treatments and biomarkers and prevention. But there needs to be a much greater focus on the concerns of people with dementia and their carers about the flexibility and quality of dementia care including integrated health and social care and access to respite care – the cost-effectiveness of

different models. It is unreasonable to expect carers to coordinate without signposts and points of contact and without the certainty of access to planned respite. There is a need to engage change management experts and economists in research in a system change approach

Conclusion

Australia has the opportunity in acting on the Interim Report of the Royal Commission into Aged Care Quality and Safety and reviewing and revising its National Framework for Action on Dementia 2015-19 to build on both domestic and international experience to seriously plan for a future in which dementia will significantly impact the health care system and to improve the quality of dementia care and support for people with dementia and their carers. ■

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Global survey reveals attitudes to dementia

Alzheimer's Disease International (ADI) has released its annual World Alzheimer Report, this year titled *Attitudes To Dementia*. The report presents findings of the world's largest-ever survey on attitudes to dementia – asking people living with dementia, carers, health and care staff, and the general public for their views on stigma related to dementia.

In total, almost 70,000 people across 155 countries responded to the survey – a 28-fold increase compared with ADI's last survey on stigma, conducted in 2012. Some of the key findings include:

- Almost 80% of the general public are concerned about developing dementia at some point and one in four people think that there is nothing we can do to prevent dementia.
- 35% of carers across the world said that they have hidden the diagnosis of dementia of a family member.
- Almost 62% of healthcare providers worldwide think that dementia is part of normal ageing.
- 40% of the general public think doctors and nurses ignore people with dementia.

A large part of the report is made up of contributions from around



the world, including several from Australia: 10 essays by experts (for example, *Thinking More Deeply About Dementia Friendliness* by Dr Linda Barclay, Monash University, and Glenn Rees, ADI); 21 case studies (including for example, *Stigma and Negative Attitudes Towards People With Dementia Still Pervade: The Importance Of Working Together* by Kate Swaffer, Dementia Alliance International) and write-ups of nine programs to reduce stigma (see *Can Design Play A Role In Increasing Awareness And Challenging Stigma Around Dementia?* by Professor Colm Cunningham, HammondCare).

ADI concludes that "...we still have a long way to go to 'normalise' the language, attitudes and behaviours around dementia and integrate people living with the condition fully into society in a supported way."

It makes 10 recommendations, aimed at a variety of stakeholders including, for example, the promotion of dementia friends' programs, increased public advocacy of people living with dementia, and specialised education for healthcare practitioners.

The report is available to download at www.alz.co.uk/research/world-report-2019.

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