

# Global action on dementia

The World Health Organisation's (WHO's) global plan of action on dementia, released at the World Health Assembly in Geneva in May, has been described as the start of a new era for people living with dementia. Currently only 29 governments out of the 194 WHO Member States have a plan or policies specifically addressing the impact of dementia in their country. The *Global Plan of Action on the Public Health Response to Dementia 2017-2025* commits its members, including Australia, to take practical steps by 2025 to encourage progress in dementia awareness, risk reduction, diagnosis, care and treatment, support for care partners and research. Alzheimer's Disease International Chair **Glenn Rees** explains how the plan came to be and what happens next

On 29 May the World Health Assembly adopted a global plan of action on dementia. The level of support for this plan and its urgency can be measured in part by the fact that it took only 12 months for it to move from a request from the WHO Executive Council for a plan to be developed, to its adoption.

The WHO organised a Ministerial meeting on dementia in March 2015 that attracted 20 government ministers and representatives of 80 countries. This led directly to the decision by the WHO Executive Council in June 2016 to request a global plan of action on dementia. By September 2016 WHO's Mental Health Division, led by Dr Shekhar Saxena, had developed a draft plan for consideration by Member States, with a revised draft presented to the Executive in early 2017. It was only this urgency that made the adoption of the plan possible in May.

The plan is one of the most businesslike and transparent documents at the international level in respect of any chronic disease.

While the past year has seen urgent international action, it is built on 10 years of advocacy for a global dementia plan by Alzheimer's Disease International (ADI) the international federation of Alzheimer's associations around the world, and people with dementia and family carers.

The past 12 months has seen a sea change in global action, with ADI and other key

stakeholders, including Dementia Alliance International (DAI), Alzheimer Europe and Global Alzheimer's and Dementia Action Alliance (GADAA), submitting a joint formal response to the draft plan in October 2016. Importantly, a small group of Member States ensured support for the plan through the WHO Executive and finally, for the approval of the plan by the World Health Assembly.

So, what is the plan? What has been the role of WHO and ADI? Why has the plan been adopted now and what happens next?

## The Global Plan

The plan is comprehensive and action based. The WHO cannot compel governments to act, but it is nonetheless a powerful agent for change. The plan identifies seven priority areas for action, with targets set for

each (see table below). It commits the Ministry of Health, Social Care or other department in each country to periodically report to the WHO on the progress of each area of the plan between 2017 and 2025.

It also provides the necessary framework for more countries to introduce their own plans on dementia. For each of the action areas the plan includes proposed actions for Member States, the WHO Secretariat and

## The global plan on dementia: actions and targets

### Action 1 Dementia as Public Health Policy

Target 75% of countries will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies, by 2025.

### Action 2 Dementia Awareness and Friendliness

Target 100% of countries will have at least one functioning public-awareness campaign on dementia to foster a dementia-inclusive society by 2025. 50% of countries will have at least one dementia-friendly initiative to foster a dementia-inclusive society by 2025.

### Action 3 Dementia Risk Reduction

Target The relevant global targets defined in the Global Action Plan for prevention and control of non-communicable diseases (NCDs) 2013-2020 and any future revisions are achieved for risk reduction and reported. [The risk factors for dementia are the same as other NCDs such as cardiovascular diseases, cancers, chronic respiratory diseases and diabetes. The following measures can reduce the risk of cognitive decline and dementia: increase physical activity, prevent and reduce obesity, promote balanced and healthy diets, stop smoking and harmful use of alcohol, promote social engagement, cognitive stimulating activities and learning, and prevent and manage diabetes and hypertension – especially in mid-life – and depression.]

### Action 4 Diagnosis, Treatment, and Care

Target In at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025.

### Action 5 Support for Dementia Carers

Target 75% of countries provide support and training programs for carers and families of people with dementia.

### Action 6 Information Systems for Dementia

Target 50% routinely collect a core set of dementia indicators through their national health and social information systems every two years by 2025.

### Action 7 Dementia Research and Innovation

Target The output of global research on dementia doubles between 2017 and 2025.

international, regional and national partners (eg World Bank, the Organisation for Economic Co-operation and Development (OECD), ADI and Alzheimer's organisations) and detailed indicators for measuring progress towards defined targets.

### Next steps

The WHO is taking action, or plans to do so, to address each of the seven action areas. For example:

- On Action 5 work is underway to develop and deliver Support For Carers ([www.who.int/mental\\_health/neurology/dementia/iSupport\\_flyer.pdf](http://www.who.int/mental_health/neurology/dementia/iSupport_flyer.pdf)), a comprehensive e-health tool to enhance self-help, skills and support for caregivers of people living with dementia, including those in low and middle-income countries.
- On Action 6, the WHO and a group of Member States is currently developing a Global

Dementia Observatory (GDO), a web-based data and knowledge exchange platform to collect and disseminate key dementia information from WHO Member States ([www.who.int/mental\\_health/neurology/dementia/GDO/en/](http://www.who.int/mental_health/neurology/dementia/GDO/en/)). The first stage of the project – to create a framework for data collection – is expected to be completed by the end of 2017. The GDO will collate and disseminate dementia data from Member States to support service planning and policies and health and social care systems. The information will include global and regional dementia reports and country-specific information sheets summarising a country's capacity to support people with dementia. The GDO will also track the implementation and progress of the global action plan.

The following projects are

also in the early stages of development: an analysis of dementia plans; a dementia-friendly toolkit; dementia risk reduction guidelines; clinical guidelines for non-specialised health workers; and setting an agenda for dementia research.

ADI, for its part, has much work to do. This includes supporting Alzheimer's associations in advocating to their governments to prepare and progress dementia plans; implementation of the global plan, including the specific projects WHO is undertaking, and updating figures on dementia prevalence and incidence and the social and economic impact of dementia.

### Conclusion

Australia can be proud of taking the lead with national action on dementia in 2004, in 2012 and again in 2014 (see box p9). However, the policy weakness in Australia has been a lack of urgency in the reform and

prioritisation of community care – to recognise that while dementia is a core part of mainstream aged care, additional funding is needed for dementia-specific respite care and residential care units and for new approaches to end-of-life care for people with dementia.

I also do not believe Australia or other countries can have confidence in access to dementia care and support until there is a commitment to timely diagnosis (and monitoring of the rate of diagnosis) and a guarantee of post-diagnostic support. Only then can people with dementia and their families plan their lives, care and rehabilitation needs with confidence.

The significance of the global plan of action on dementia is that it shows we know what to do. What has been lacking at the national level in many countries is the resources or commitment to tackle dementia. The OECD has observed that there is a consistency in the policies embedded in dementia strategies but “ensuring that these policies are consistently implemented remains a challenge and there is too much uncertainty around which policy approaches are the most effective” (OECD 2015 p56).

The plan combines what we know about dementia policies with a welcome determination to monitor and evaluate. My hope is that Australia will continue to lead the way. ■

**The Global Plan of Action on the Public Health Response to Dementia 2017-2025 is available to read in full at: [http://apps.who.int/gb/ebwha/pdf\\_files/EB140/B140\\_28-en.pdf?ua=1](http://apps.who.int/gb/ebwha/pdf_files/EB140/B140_28-en.pdf?ua=1).**

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## ADI and the WHO

Alzheimer's Disease International (ADI) was formed in 1984 by the US, Canada, UK and Australia. Its mission is to strengthen and support Alzheimer associations, to raise awareness about dementia worldwide, to make dementia a global health priority, to empower people with dementia and their care partners, and to increase investment in dementia research.

ADI has 90 member associations and is growing. It was invited to enter an Official Working Relationship with the World Health Organisation (WHO) in 1996. Since that time the relationship has been of key importance.

ADI's priority is to provide an evidence base for action. Its *World Alzheimer's Reports* (available at [www.alz.co.uk/research/world-report](http://www.alz.co.uk/research/world-report)) published each year in September during World Alzheimer's Month have ensured that policy makers know that there are 50 million people with dementia around the world today, with the prospect of a threefold increase by 2050, and that the cost both to health services and families is already about \$A1.3 trillion.

ADI members, for their part, have sought a commitment from their respective national governments to dementia plans that provide the basis for long-term action for tackling dementia. ADI has trained national Alzheimer association representatives in advocating for national plans and policies since 2006, using the global data and sharing experiences. To support this work ADI

published *Improving Dementia Care Worldwide* (2013), a review of existing national dementia plans from around the world, with recommendations for governments on what a best practice plan should include and how it should be developed and implemented (Pot & Petrea 2013). More recently it has published a *Bibliography of References to National Plans* (ADI 2016).\*

The WHO has been active in placing dementia on the global agenda. The regional WHO organisations are an important platform for ADI members to inform regional meetings about dementia and feed this through to the international level. The WHO partnered with ADI to publish *Dementia: A Public Health Priority* (WHO/ADI 2012), an authoritative overview of dementia worldwide. In addition to valuable best practices and practical case studies from around the world, it contains a comprehensive collection of information, including much data from low- and middle-income countries.

The report highlighted WHO's commitment to making dementia a global health priority by calling on national governments to address the increasing challenges dementia poses on a global, national, regional and local level.

\*Footnote: For discussion of dementia plans and examples of national plans see [www.alz.co.uk/dementia-plans/national-plans](http://www.alz.co.uk/dementia-plans/national-plans).

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■ Glenn Rees is the Chair of Alzheimer's Disease International and lives in Canberra. This article reflects his personal views.

## Accelerating pace of change

The global dementia plan is the result of an accelerating pace of change since 2000 in finally dismissing the centuries old thinking that dementia is an inevitable part of ageing.

Many factors are responsible for this shift, including evidence of the scale of the social and economic impact of dementia, the creation of the first Alzheimer's medications, evidence for dementia risk reduction, social action through dementia-friendly communities ([www.alz.co.uk/dementia-friendly-communities](http://www.alz.co.uk/dementia-friendly-communities)), the first steps to protect the human rights of people with dementia under the Convention on the Rights of Persons with Disabilities (CRPD) ([www.alz.co.uk/sites/default/files/pdfs/access-crpd-dementia.pdf](http://www.alz.co.uk/sites/default/files/pdfs/access-crpd-dementia.pdf)) and adoption of the first dementia plans in France and Australia. (There are 29 countries with national dementia plans.)

Importantly, dementia got a human face through the self-advocacy of people with dementia and action by Alzheimer's organisations, led by Alzheimer's Scotland, to become more inclusive of people with the condition.

Most recently, the work of the Dementia Alliance International (DAI) and Alzheimer's Disease International (ADI) have acted to protect the human rights of people with dementia through the CRPD. It

says a lot about the dehumanising attitudes to people with dementia that it is only now that the rights of those with dementia are being protected within a Convention that was adopted by the UN in December 2006.

The accelerating pace of change this century at the international and national level is well illustrated by the Australian experience. The seminal work of Professors Scott Henderson and Tony Jorm, *The Problem of Dementia In Australia*, published in 1986, provided the basis for policy and political action. Reports such as *Human Rights and Mental Illness* (Human Rights and Equal Opportunity Commission 1993) made recommendations for the care and support of people with dementia that resonate today in terms of the need for dementia-specific care and the protection of the human rights of people with dementia.

Yet it was not until 2004, with the initiative of the Howard Government to make dementia a health priority with \$330 million allocated over five years, that decisive action was taken. Further action followed in the 2012 Living Longer, Living Better package to tackle dementia with additional funding, and in 2014 with an extra \$200 million for dementia research.

Glenn Rees

### AA renews calls for funded dementia strategy

A fully-funded National Dementia Strategy for Australia would go a long way toward contributing to the targets set out in the WHO's global dementia plan, says Alzheimer's Australia CEO Maree McCabe.

Following the release of the WHO plan, Alzheimer's Australia renewed its calls for a funded National Dementia Strategy, saying it should include:

- Increased awareness to reduce stigma and social isolation associated with dementia.
- Risk reduction strategies which look to partner with other health promotion campaigns sharing common risk factors.
- Timely diagnosis to connect people with dementia to the support and services they need sooner.
- A coordinated approach to post-diagnosis care and support.
- Initiatives to improve the quality of care for people with dementia.
- End-of-life care to support the choices of people with end-stage dementia.
- Investment in dementia research and support for consumer involvement in dementia research.

"A plan which achieves these outcomes would go a long way toward contributing to the global targets set out in the Global Plan of Action and ensure that people living with dementia are treated with respect and dignity," Ms McCabe said.

She said a National Dementia Strategy would build on and enhance the National Framework for Action on Dementia 2015-2019, which Australia has already adopted.

## BETTER PRACTICE 2017 RETHINKING AGED CARE DISCOVER CONNECT CREATE

You are invited to register for this year's two day Better Practice conference in Sydney on 17 – 18 August 2017. The theme of this year's conference **Re-thinking Aged Care – Discover, Connect, Create** is about exploring opportunities and challenging ourselves to consider what is needed to deliver on consumer expectations of quality of care and services in aged care. Hear from inspirational keynote speakers including our international keynote Dr Allen Power and the Australian thought leaders and advocates Kate Swaffer and Kate Fulton.

Join us at the end of day one of Better Practice Sydney (17 August) for the announcement of the Better Practice Awards. We are also excited to announce this year's National Innovation and Excellence in Aged Care Awards. To celebrate these great initiatives, a reception event will be held following the announcement of the Better Practice Awards.

Alzheimer's Australia NSW invites you to a highly interactive masterclass on **Transforming your model of dementia practice and culture of care** facilitated by Dr Al Power, geriatrician and Clinical Associate Professor of Medicine at the University of Rochester, New York. This masterclass is taking place on Wednesday, 16 August.

For further information and to register online, visit: [www.aacqa.gov.au](http://www.aacqa.gov.au).

