

Human rights, disability and dementia



The World Health Organisation's Global Dementia Action Plan* adopted in May 2017 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. Dementia Alliance International Chair **Kate Swaffer** explains the significant effort that will be required and why human rights and the recognition of dementia as a disability must be reflected in all regional and national dementia strategies and plans

Dementia Alliance International (DAI) greatly values the WHO's global leadership in meeting the needs of people with dementia. Without this, and the vision and urgency with which it has acted, we might still be talking about the notion of an action plan for dementia. We also value the leadership of Alzheimer's Disease International (ADI), and its commitment to work with the WHO and others, and its strategic partnership with DAI.

ADI has recently released a publication, *National Dementia Action Plans: Examples for Inspiration* (ADI 2017), which highlights some of the great work in developing national dementia plans around the world. Since DAI has worked on human rights for people with dementia, with both the WHO and ADI, there has been significant change in this space globally, and we are now likely to have improved and hopefully faster outcomes.

Taking dementia seriously

While attending the World Health Assembly (WHA) in Geneva for the adoption of the Global Dementia Action Plan, I was very encouraged to note the global dementia community and governments taking dementia so seriously, and I felt hopeful of tangible change. By contrast, when I spoke at the WHO First Ministerial Conference on Dementia in May 2015 I didn't really believe I'd see change in my lifetime. After that event DAI published *The Human Rights Of People Living With Dementia: From Rhetoric To Reality* (DAI 2016). DAI published this paper because, in spite of the rhetoric, little was changing and almost all people being diagnosed with dementia then were being Prescribed Disengagement® (Swaffer 2014-15).

DAI has an abundance of anthropological evidence from within its membership (now representing people

with dementia in 44 countries) that this is still the case. While the diagnosing doctors may tell us there is nothing we or they can do, or that what they may be able to prescribe in the form of a drug may or may not help, their job is mostly to diagnose and monitor our progression. However, they should also be referring us to post-diagnostic services who should provide us with support. Instead, many doctors and service providers continue to promote giving up on life and ignore the possibility of living positively with dementia with proactive disability support, including rehabilitation. For example, in a recent fundraising ride around Australia, Greg Kelly who was diagnosed with dementia aged 59, said in an interview for WIN News Central Queensland (WIN 2017): "The specialist just simply said, go away and get your affairs in order".

Demanding a better deal

While researchers and clinicians are actively moving towards promoting a more timely diagnosis for dementia, it is also becoming clearer that the medical model of care is no longer appropriate for early stage dementia.

There is much work to do, and while people with dementia cannot do it alone, they and their families are now speaking up all around the world demanding a better deal.

The growing group of people with dementia who are self-advocating and/or speaking up publicly, individually and collectively, believe the best way to ensure people with dementia can live with a high quality of life and dignity, without the isolation, stigma and discrimination they currently face, is through a human rights based approach to dementia. Collectively, we are demanding support to live with dementia, not only to die from it. This is a basic human right. And yet, as I wrote in 2015: "There is a systemic and gross

underestimation of the capacity of all people with dementia, even in the later stages of the disease."

Presenting at a side event at the WHA, co-hosted by DAI, ADI, Global Alzheimer's and Dementia Action Alliance (GADAA) and the Swiss Government, I was asked why the Global Dementia Action Plan has been so important to me. In my speech (DAI 2017) I replied, "We need this plan because care is failing, and research for a cure is failing".

Attention to human rights needed

While I'm pleased this plan has been adopted, we believe it is going to take a significant commitment and effort from governments, researchers, the health care sector and civil society. Personally, I wonder if governments understand just what they have committed to.

Following the WHA, one government released its third National Dementia Plan and yet there was no mention of human rights in it. When I queried this with them, I was informed it was due to the word count. Human rights must come before word counts. People with dementia and our families have undisputed rights to better care, which must therefore be reflected in national dementia plans.

I'm regularly asked, "Why are human rights an issue? What's the big deal, and why do you speak up about it so much?" As an invited speaker in 2017 to the Better Practice Conference series around Australia, I was asked specifically to

* The Global Plan of Action on the Public Health Response to Dementia 2017-2025 (Global Dementia Action Plan) was unanimously adopted at the World Health Assembly in Geneva in May 2017. At that time, only 29 governments out of the 194 WHO member states had a plan or policies specifically addressing the impact of dementia in their country.

focus on human rights. I found there to be far less negative pushback from audiences than I'd previously experienced, even though the focus was uncomfortable for some, especially those who are busy building more institutions with 'secure dementia units'.

We know institutional care ensured worse care for orphans and people with disabilities, and moved away from that style of assisted living many years ago. DAI is campaigning globally to phase out institutional care and locked units. I wrote for the *AJDC* on what people with dementia want in residential care (Swaffer 2016), and freedom is one of them. Locking us away, based on us having an illness, is not only a form of segregation, it is a serious breach of human rights as we have a clear right to freedom.

The Australian Government announced significant reforms to home care in the 2015-16 Budget, and the aged care reforms are well under way. Early changes, for example, will mean that a home care package will follow the consumer and we will also be able to change providers.

In addition, all applicable charges will be published on the My Aged Care website. This will translate into the residential care sector as well and, with greater choice and more transparency, consumers will be more inclined to make demands previously not seen before in this sector.

However, the most important message to emerge from the focus groups and interviews that I held in 2015-2016 for my second book (Swaffer & Low 2016), co-authored with Associate Professor Lee-Fay Low, was that: "Listening to consumers is the best place to start, and *it is not just about choice*, it is fast becoming about human rights for people with dementia".

The Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol was adopted on 13 December 2006 at the UN headquarters in New York. To date, 194 countries have ratified the CRPD.

"The CRPD is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorisation of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of

rights must be reinforced (UN 2017)."

Of course the focus on human rights did not begin with the CRPD. The Universal Declaration of Human Rights was adopted by the General Assembly of the UN on 10 December, 1948. This UN Convention was (and still is) meant to protect every single member of civil society in the world – including people diagnosed with any type of a dementia, and who have disabilities caused by the symptoms of their dementia.

Distressingly, but not surprisingly to people with dementia and our families, 67 years later, the Organisation for Economic Co-operation and Development (OECD) report (2015), *Addressing Dementia: The OECD Response* concluded: "Dementia receives the worst care in the developed world".

This is indeed very sobering, but absolutely highlights to me just why we must ensure human rights and the CRPD and other Conventions are reflected in all national dementia plans. This OECD report also confirmed why it was necessary to demand human rights at the WHO conference in 2015; an approach which includes full access to the CRPD and therefore full rehabilitation. For example, Article 26 of the CRPD states that: "States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life." (UNOHCHR 2017).

Principles to ensure real change

In the WHO Global Dementia Action Plan (WHO 2017), human rights, empowerment and accountability are characterised as the 'cross-cutting principles'. These seven principles are, as I understand it, the only part of the plan to be fully accountable, and therefore it is imperative governments and civil society are aware of them. While the seven action steps which form the underlying structural framework of the plan are important, these cross-cutting principles will help to ensure real change:

- 1. Human rights of people with dementia.** Policies, plans, legislation, programs, interventions and actions should be sensitive to the needs, expectations and human rights of people with dementia, consistent with the Convention on the Rights of Persons with Disabilities and other international and regional human rights instruments.
- 2. Empowerment and engagement of**

people with dementia and their carers.

People with dementia, their carers and organisations that represent them should be empowered and involved in advocacy, policy, planning, legislation, service provision, monitoring and research of dementia.

- 3. Evidence-based practice for dementia risk reduction and care.** Based on scientific evidence and/or best practice, it is important to develop strategies and interventions for dementia risk reduction and care that are person-centred, cost-effective, sustainable and affordable, and take public health principles and cultural aspects into account.
- 4. Multisectoral collaboration on the public health response to dementia.** A comprehensive and coordinated response to dementia requires collaboration among all stakeholders to improve prevention, risk reduction, diagnosis, treatment and care. To achieve such collaboration needs engagement at the government level of all relevant public sectors, such as health (including alignment of existing non-communicable diseases, mental health and ageing efforts), social services, education, employment, justice, and housing, as well as partnerships with relevant civil society and private sector entities.
- 5. Universal health and social care coverage for dementia.** Designing and implementing health programs for universal health coverage must include financial risk protection and ensuring equitable access to a broad range of promotive, preventive, diagnostic and care services (including palliative, rehabilitative and social support) for all people with dementia and their carers.
- 6. Equity.** All efforts to implement public health responses to dementia must support gender equity and take a gender-sensitive perspective, keeping in mind all vulnerabilities specific to each national context, consistent with the 2030 Agenda for Sustainable Development, which recognises that people who are vulnerable, including people with disabilities, older people and migrants, must be empowered.
- 7. Appropriate attention to dementia prevention, cure and care.** Steps to realise this focus include using existing knowledge and experience to improve prevention, risk reduction, care and support for people with dementia and their carers and generation of new knowledge towards finding disease-modifying treatments or a cure, effective risk reduction interventions and innovative models of care.

Recognising dementia as a disability

It is clear we need to move from the medical model of care to one that is based on a social and disability pathway of support and care. Post-diagnosis 'care' must be more than just an assessment of our activities of daily living, being advised to get our end-of-life affairs in order, and getting acquainted with care.

As well as being weak on human rights, the medical model is simply too expensive; forget the human cost, governments cannot afford this model of 'care' with its promotion of dependence and learned helplessness.

A key issue in changing this is recognising the symptoms of dementia as disabilities, which also therefore means people with dementia must be afforded the same disability support as any other person with acquired disabilities.

The WHO clearly states that "Dementia is one of the major causes of disability and dependency among older people worldwide," (WHO 2015) yet it is still not being supported that way.

When attending the WHO Mental Health Gap Action Program (mhGAP) Forum in Geneva in 2016, I asked that there be an additional category under the umbrella of mental health, which is where dementia sits at the WHO. Dementia is not a mental health condition, nor is it an intellectual disability or a psychosocial disability. The symptoms caused by dementia are cognitive disabilities, and the WHO has since added a fourth sub-category for dementia: cognitive disabilities.

Now that dementia is being described in UN documents as a cognitive disability, we ask that everyone is reminded, including health ministers worldwide, that people with dementia are fully recognised by the UN as rights bearers under the CRPD treaty.

Hence, it is important to ensure the global dementia community understands the concerns of people with dementia that the Global Dementia Action Plan provides little evidence of using the CRPD Articles to underpin the policy, or the WHO Disability Action Plan, apart from the seven cross-cutting principles.

I also believe by harnessing the CRPD and numerous other Conventions and embedding human rights into dementia plans we will increase independence and reduce the cost to governments and society of dementia.

The WHO *Global Disability Action Plan 2014-2021: Better Health For All People With Disability* (WHO 2015) should now also be applied to people with dementia. This plan's "vision, goal, objectives, guiding principles and approaches" (p3) include:

- A world in which all persons with disabilities and their families live in dignity, with equal rights and opportunities, and are able to achieve their full potential.
- The overall goal is to contribute to achieving optimal health, functioning, well-being and human rights for all persons with disabilities.
- The action plan has the following three objectives:
 - a. to remove barriers and improve access to health services and programs
 - b. to strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community-based rehabilitation, and
 - c. to strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services.

The Sustainable Development Goals (SDGs), adopted by the UN in 2015, are also important to consider when developing national or regional dementia plans. Sustainable Goal number 3: *The right to good health and well-being*, is relevant to the GDAP, as are many of the other SDGs. ADI's Global Charter (ADI 2012), *I Can Live Well with Dementia*, is not possible without good health and well-being. Without disability support for dementia that includes physical and cognitive rehabilitation and a post-diagnostic pathway that ensures independence for as long as possible, well-being will continue to be denied.

Currently, post-dementia diagnosis care does not promote living positively, but instead is a pathway only to dependence and death via aged care, and ensures dependence on families, and then governments.

A new pathway of diagnostic support

Community Based Rehabilitation (CBR) must also be considered when implementing the Global Dementia Action Plan into policy. The aim of CBR is to help people with disabilities by establishing community-based programs for social integration, equalisation of opportunities, and physical therapy rehabilitation for people with any type of disability. This is important in the context of the Global Dementia Action Plan and in the development of national policies.

For our communities to support people with dementia based on the recognition of human rights and dementia as a disability, we need a new pathway of

psychosocial and disability support to live positively and independently with dementia for as long as possible. My vision is timely diagnosis, followed by a support pathway similar to this:

- Focus on assets, not deficits, and quality of life.
- Community-based rehabilitation.
- Acquired brain injury rehabilitation immediately post-diagnosis, which includes exercise and other lifestyle changes in line with other chronic diseases, speech pathology, a neuroplasticity approach, occupational therapy and neurophysiotherapy.
- Disability assessment and support, immediately post-diagnosis.
- Grief and loss counselling, not just information about dying, aged care and 'challenging behaviours'.
- Peer-to-peer support groups for people with dementia, our care partners and families, and for those with younger onset dementia, our older parents and our children.
- Support to maintain our pre-diagnosis lifestyle, if this is our choice.
- Support to continue working if a person with younger onset dementia, again if this is our choice.
- Support to continue usual activities, socialising, sport, recreation, community engagement, volunteering.
- Inclusive and accessible communities – not just dementia-friendly, as too often the awareness-raising initiatives are still based on our deficits.
- Palliative care.

Educated health care staff

Adequately educated health care staff in the dementia sector is the final essential step towards human rights in dementia and providing better outcomes for people with dementia and our families.

We would all be shocked to be admitted to hospital following a diagnosis of cancer, or a stroke or heart attack, only to discover the staff knew very little about those conditions. Yet we still have staff in the acute, aged care and community care settings with minimal knowledge about dementia.

In terms of a business model, this does not make sense. For example, we would only employ IT staff in an IT department or business with the appropriate level of education and experience. With our ageing population who will need some type of community or residential care, and the knowledge that 30% of patients in the acute setting have dementia or cognitive impairment, it is past being a poor business model, it is a basic human rights issue. ➤

My recommendations

My recommendations are that governments and civil society engage with the UN (CRPD), including through policy-making processes, and seek to develop productive relationships with the global network of National Human Rights and Disability Rights Institutions, for example, the International Disability Alliance (www.internationaldisabilityalliance.org) and the International Disability and Development Consortium (www.iddcconsortium.net).

We need the support of all health ministers and their governments to implement the Global Dementia Action Plan so that the 50 million people estimated to be living with dementia today, and the 100 million expected to have it by 2030, will have access to their rights in international law on the same basis as people with other disabilities.

I'd also ask that countries and civil society ensure their dementia policies are based on human rights, and that they work closely with disability organisations in their country or region, as well as ensure that people with dementia are included in the planning and implementation processes of their plans.

The Convention on the Rights of Persons with Disabilities, the WHO Disability Action Plan 2014-2021, Community Based Rehabilitation and the Sustainable Development Goals must be considered in dementia plans and policies.

The Global Dementia Observatory was also launched recently, following the

Global Dementia Action Plan, specifically to track worldwide impact and responses to dementia and will go some way to measuring progress. Whilst it may be recording data from countries, I ask, as someone diagnosed with dementia, what difference will this make to the lives of the 50 million people currently estimated to be living with dementia?

Therefore, I hope countries will have been able not only to measure their implementation of the Global Dementia Action Plan by 2025, but will also have measured whether outcomes for people with dementia and our families have been tangibly improved. ■

You can read DAI's first response to the Global Plan of Action on the Public Health Response to Dementia 2017-2025 at www.dementiaallianceinternational.org/wh-o-adopts-global-action-plan-on-dementia/

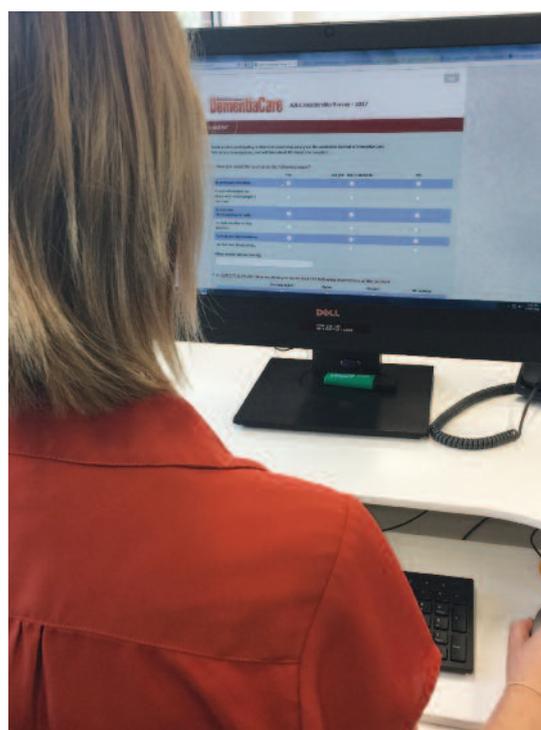
The plan is available to download at:
<http://bit.ly/2CEEAoo>

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