

**ALZHEIMER'S DISEASE
INTERNATIONAL**

AND

**DEMENTIA ALLIANCE
INTERNATIONAL**



**Alzheimer's Disease
International**

The global voice on dementia



**ACCESS TO CRPD
AND SDGs BY PERSONS
WITH DEMENTIA**

WHO WE ARE



**Alzheimer's Disease
International**

The global voice on dementia

Alzheimer's Disease International (ADI) is the sole international organisation working for people with dementia.



**DEMENTIA
ALLIANCE
INTERNATIONAL**

The global voice of dementia

Dementia Alliance International (DAI) is the global voice of people with dementia.

We work in partnership to enable persons with dementia to have full and equal access to CRPD and other Human Rights Treaties on the same basis as those with other disabilities.

OUR POSITION

Although persons with dementia are indisputably included in CRPD Article 1, they have been excluded from its implementation by Member States. By the same token, CRPD is not reflected in the dementia strategies and plans of 26 Member States and two regions. The exclusion of persons with dementia from the Convention could be considered as an example of systemic if unintentional discrimination.

The greatest single obstacle to the continued participation of persons with dementia in society arises from the stigma and fear of dementia in the general population and under-estimation of their capacity by politicians, professionals, researchers and the community.

As a result of discrimination, persons with dementia are often not diagnosed and/or not told their diagnosis. Even in High Income Countries (HICs), they often do not have access to support services for themselves and their families or to medical treatment. There is also clear evidence in the social media that isolation begins at the point of diagnosis when friends and family members stop visiting.

SOME BASIC FACTS ABOUT DEMENTIA

Dementia comprises a wide range of progressive diseases of which the most common is Alzheimer's Disease. Although age is the greatest risk factor, it is not a normal consequence of ageing and is increasingly being diagnosed in people under 65. Importantly, dementia is not a mental illness and affects not only memory but attention, orientation and other areas of cognitive functioning. The capacity to experience joy, sorrow and grief and to respond to music can remain to the end of life.

Dementia affects 47 million people in all countries; this is likely to double by 2030 and triple by 2050ⁱⁱ. No treatments are currently available to cure or significantly alter the course of dementia, leaving persons with dementia with co-morbidities in a state of progressive disability that can last for 20 or more years. Researchers estimate that dementia is the leading cause of dependency and disability among older persons in both Lower and Middle Income (LMIC) and High Income Countries (HICs)ⁱⁱⁱ.

A recent OECD study concludes that “dementia receives the worst care in the developed world”^{iv}. First person accounts^v and reports from care partners, professionals and Alzheimer Associations world-wide^{vi} all confirm this.

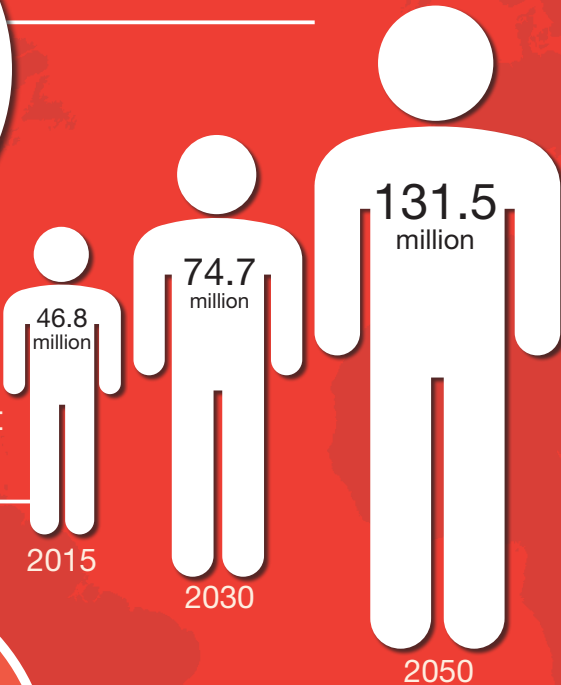
Yet it need not be so. Because people can live for many years before symptoms are severe enough to warrant hands-on care, the first priority expressed by persons with dementia in public opinion surveys^{vii} is *rehabilitation* and support to enable them to remain in their own homes, follow their interests and remain valued members of their communities.

The global impact of dementia



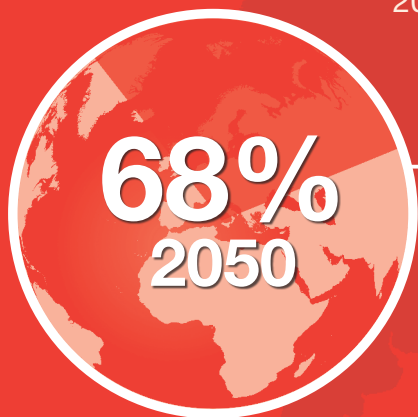
Around the world, there will be 9.9 million new cases of dementia in 2015,

one every 3 seconds



46.8 million people worldwide are living with dementia in 2015.

This number will almost double every 20 years.



Much of the increase will take place in low and middle income countries (LMICs): in 2015, 58% of all people with dementia live in LMICs, rising to 63% in 2030 and 68% in 2050.



The total estimated worldwide cost of dementia in 2015 is US\$ 818 billion.

By 2018, dementia will become a trillion dollar disease, rising to

US\$ 2 trillion by 2030

If global dementia care were a country, it would be the

18th largest economy

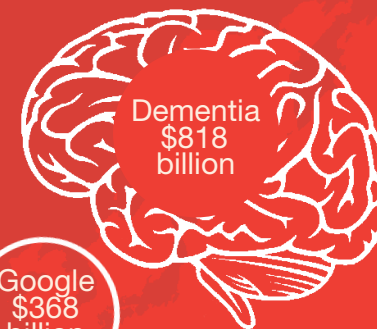
in the world exceeding the market values of companies such as Apple and Google



Apple \$742 billion



Google \$368 billion



Dementia \$818 billion

(source: Forbes 2015 ranking).



This map shows the estimated number of people living with dementia in each world region in 2015.

We must now involve more countries and regions in the global action on dementia.

CRPD GENERAL PRINCIPLES & ARTICLES

The Convention calls for solutions adapted to age, gender and locality that can be addressed through CRPD General Principles and Articles.

The 38 cross-cutting Articles offer key common elements including: capacity, supported decision-making and the protection of the fundamental human rights first set out in the UN Universal Declaration of Human Rights in 1948^{viii}.

Articles 8 and 9 are addressed in an increasing number of Member States by Dementia Friendly Communities (DFCs) and organisations which facilitate access to transport, shops and community amenities. ADI and DAI have made proposals for ways in which DFCs can move to the next step in their development – e.g. by involving people with dementia as equal stakeholders from the outset^{ix}.

Article 30 is reflected in DAI and numerous local and on-line dementia peer support groups, dementia cafes and seminars with world leaders in research and policy development.

Articles 5, 8, 9, 19, 21, 24, 26, 27, 29 and 30 profoundly affect the ability of people in the early to moderate stages of dementia to remain active in the community and continue to pursue their interests.

Articles 14, 16 and 23 promote a good quality of life for people in the late stage of dementia.

Articles 10, 13, 14, 15, 16, and 28 are particularly relevant to persons with disabilities in LMICs where there have been recent examples of torture, and being chained or burned alive following accusations of witchcraft. In HICs there is disturbing evidence of chemical and physical restraint.

Article 28 which promotes an adequate standard of living is also relevant to HICs where current austerity policies are forcing increasing numbers of people to face hunger or be forced to resort to food banks.

RECOMMENDATION

We ask the CRPD Committee to use the full resources of the UN family to promote and facilitate access to CRPD by persons with dementia by monitoring the extent to which persons with dementia are included in the implementation of the Convention by Member States.

For example, by inclusion in Lists of Issues; General Comments; Universal Periodic Reviews; the Annual Conference of States Parties and opportunities presented by the Human Rights Council such as the 2016 Social Forum which will focus on “the promotion and full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities in the context of the tenth anniversary of the adoption of the Convention on the Rights of Persons with Disabilities”.

We also ask that the Committee promote the rights of persons with dementia in the wider context of the 2030 Sustainable Development Goals which were launched by the UN Secretary-General with a commitment to Leave No-one Behind.

ENDNOTES

- i Alzheimers Disease International: www.alz.co.uk; Dementia Alliance International: www.infodai.org
- ii ADI-WHO (2012) *Dementia: A Public Health Challenge*. Geneva: WHO.
- iii ADI (2013) *Global Impact of Dementia: Policy Brief for Heads of Government*. London, 2013, <https://www.alz.co.uk/research/GlobalImpactDementia2013.pdf>
- iv Organisation for Economic Cooperation and Development (2015) *Dementia: the OECD Response*. (http://www.oecd-ilibrary.org/social-issues-migration-health/addressing-dementia_9789264231726-en)
- v Swaffer, K. (2016) *What the Hell Happened to My Brain?* London: Jessica Kingsley Publishers; Taylor, R (2009) *Alzheimer's From the Inside Out*. Baltimore, M d: Health Professions Press; Bryden, C. (2015) *Nothing About Us Without Us*. London: JKP; Whitman, L.(ed.) (2016) *People with Dementia Speak Out*. London: JKP; Rohra, H. (2016) *Dementia Activist: Fighting for Our Rights*. London: JKP.
- vi e.g. Alzheimers Disease International (2012) *World Alzheimer Report: Overcoming the Stigma of Dementia*. <https://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf>
- vii Global Dementia Charter *I Can Live Well with Dementia Statements*. <https://www.alz.co.uk/sites/default/files/pdfs/global-dementia-charter-i-can-live-well-with-dementia.pdf>
- viii UN Universal Declaration of Human Rights (1948) <https://www.humanrights.gov.au/publications/what-universal-declaration-human-rights>
- ix Alzheimer's Disease International (2016) *Dementia friendly communities: Key principles and Dementia friendly communities: Global developments*. <https://www.alz.co.uk/DFC>; Dementia Alliance International (2016) *Dementia Friendly Communities: Perspectives of people with dementia*. World Dementia Report. www.info.dai (in press).

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