



**Alzheimer's Disease
International**

The global voice on dementia

Strategic Plan 2019-2022ⁱ

Introduction

Alzheimer's Disease International (ADI) is the federation of national Alzheimer and dementia associations around the world. ADI has grown from four members in 1984 to become a global federation of over 90 national Alzheimer and dementia associations, in official relations with the World Health Organization (WHO). Representing people and nations on all continents, ADI is the global voice on dementia. We work in collaboration with many organisations who share our goals and can help to advance our cause, including Dementia Alliance International (DAI), a global organisation of, by and for people with dementia.

We believe that the key to improving the outcomes around dementia lies in a combination of global solutions, and local knowledge. We work with national Alzheimer and dementia associations to raise awareness, to offer care and support for people living with dementia and their care partnersⁱⁱ, and to advocate. We work globally to focus attention on dementia as a health and research priority and campaign for better policy from governments, the WHO and other multilateral bodies.

Dementia knows no social, economic, ethnic or geographic boundaries. Although each person will experience dementia in their own way, most of those affected will eventually be unable to care for themselves, will lose their memories and will need help with all aspects of daily life. There is no cure for dementia yet. It is one of the major non-communicable diseases (NCDs) worldwide, the largest cause of disability among older people, and has a huge economic impact on families and on society.

Our philosophy is to lead by example and bring the best initiatives and ideas especially to those with limited means. We aim to improve the quality of the lives of people with dementia and their families throughout the world now, while we advocate for a cure or disease modifying treatment.

Our vision

Our vision is risk reduction, timely diagnosis, care and inclusion today, and cure tomorrow.

Our mission

Our mission is to strengthen and support Alzheimer and dementia associations, to raise awareness and lower stigma about dementia worldwide, to make dementia a global health priority, to support and empower people living with dementia and their care partners, and to increase investment and innovation in dementia research.

ⁱ This document expresses our high-level strategic objectives and outlines the ways we will seek to achieve them. It covers the period from July 2019 to June 2022. The work that we will do and specific targets that we want to achieve will be defined in detail our annual business plans which are prepared separately and continuously reviewed. Copies of the current annual business plan may be requested from ADI.

ⁱⁱ Where we talk about 'care partners' this includes family carers/caregivers as well as other informal carers and supporters. 'Care partners' is a term suggested by people with dementia, reflecting a more equal relationship.

Our values

Our core values are:

- Respect: Treating all people affected by dementia with respect and ensuring their rights are protected
- Integrity: Transparency in our relationships with each other and our external stakeholders
- Inclusiveness: Reaching out and enabling all stakeholders to be represented and heard equally without prejudice or discrimination while celebrating and leveraging our diversity
- Accountability: Being transparent and accountable, as well as fiscally responsible and effectively governed, with a commitment to excellence in all our work
- Cooperation: Developing mutually beneficial working partnerships and relationships

Our work

ADI is a federation that works by:

- Leading by example and focusing on solutions
- Empowering its member associations
- Developing global campaigns
- Sharing the best ideas, initiatives and practices
- Facilitating good working relationships at all levels
- Encouraging partnerships and coalitions
- Being courageous and determined

The world in which we operate

The statistics of dementia

- In 2019, over 50 million people have dementia worldwide, and this number will increase to over 150 million by 2050⁽¹⁾. There is a new case of dementia every 3 seconds⁽²⁾. People over 55 years of age fear dementia more than any other disease⁽³⁾.
- Already nearly 60% of people with dementia live in low and middle income countries (LMICs). By 2050 this proportion will rise to an estimated 68%, as the increases in the numbers of people living with dementia will be much steeper in LMICs than in high income countries⁽²⁾.
- The annual global cost of dementia is estimated to have been US\$ 1 trillionⁱⁱⁱ in 2018 and to rise to US\$ 2 trillion by 2030⁽²⁾.
- Stigma and lack of awareness are a major issue everywhere. Globally, as many as 75% of people with dementia have not been diagnosed⁽⁴⁾.
- There have been 12 studies on cancer for every 1 on cognitive disorders⁽⁵⁾.

The unanimous approval of the WHO *Global action plan on the public health response to dementia 2017-2025*^{iv} has committed all governments to take action on dementia. ADI supports all seven areas of the plan (the adoption of national plans, risk reduction, diagnosis, care, awareness, data and research) and the targets set to be achieved.

ⁱⁱⁱ Trillion being one million million - 1,000,000,000,000.

^{iv} www.who.int/mental_health/neurology/dementia/action_plan_2017_2025

We must remain aware that:

- There is a risk that the ambitious targets of the Global plan may prove too difficult for countries to enact and that national plans may not be adopted and delivered.
- Some governments focus on communicable diseases, deny that dementia is a problem or see tackling dementia as too costly. We need to understand better the national realities to enable and help our members work with their governments and find appropriate solutions.
- Dementia is still perceived as part of normal ageing by many, and dementia care is often not differentiated from elderly care.
- Dementia is a complex illness which requires standalone consideration in national dementia plans and specific mention in other overarching policies such as mental health, NCDs and ageing.
- We need to prioritise support for members in low and middle income countries if they are to address the targets of the Global plan.
- We need to increase activity in areas of the world where we are underrepresented, in particular Africa and Central Asia.
- There is an inadequate investment in dementia research. We call for 1% of the societal cost of the disease to be devoted to research, including care, prevention and risk reduction, the social and economic impact of dementia, basic science, drug development and public health.

What we believe

Dementia is a progressive, chronic disease and there are daily challenges that 50 million people and their care partners experience, but there is hope for the future. ADI believes that:

- Every person with dementia has the right to receive a timely diagnosis, the right to receive care, treatment and support that responds to their needs, and should have the best possible quality of life.
- Negative perceptions of the disease must be reversed, so that everyone accepts people with dementia for their abilities instead of focusing on their deficits, and supports their disabilities.
- Care partners can and must be better supported in dealing with dementia.
- Primary care practitioners, nurses and care workers are key to disseminating knowledge and supporting people with dementia and the care partners and must be well informed about dementia.
- It may be possible to reduce risk of developing dementia at a population level through means including education, smoking cessation, control of diabetes and hypertension, avoiding head injury, moderating alcohol consumption, regular exercise, good diet, social engagement and mental activity, meaning that fewer people at particular ages develop dementia.
- Brain health promotion must be integrated into public health campaigns, with the message that it is never too early or too late in life to make changes.
- Ultimately there will be treatments that will effectively slow or stop the progression of Alzheimer's disease and other dementias, and it is essential that governments and health systems are prepared.
- If governments, global institutions, foundations, companies and individuals unite to take action, we can improve outcomes for people with the dementia and their care partners.

Strategic objectives

Objective 1 – Make dementia a global health priority

ADI will lead global advocacy efforts and support the national advocacy of member associations to make dementia a public health priority.

ADI will:

- Work with the WHO, UN, OECD, World Economic Forum, G7 and G20 (the governmental groups of, respectively, seven and twenty major economies) and other international and inter-regional bodies to develop policies that can be implemented in every country of the world
- Work towards national plans, with sufficient funding, in all member countries
- Contribute towards the monitoring of progress towards the targets of the WHO Global plan, including through the WHO Global Dementia Observatory, and PAHO regional plan
- Advocate for health and care systems to respond better to dementia. This should include;
 - timely diagnosis;
 - post-diagnostic support;
 - access to person-centred dementia services in community care and respite services, residential care, acute care and palliative care;
 - building capacity in care and support for care partners;
 - dementia friendly communities;
 - promotion of risk reduction measures;
 - use of innovation, technology and workforce training
- Seek to achieve greater transparency in care and quality of life outcomes and the best ways to provide support and care
- Monitor the rights of people with dementia within the implementation of the UN Convention for the Rights of People with Disabilities (CRPD)
- Collaborate with Dementia Alliance International, Alzheimer Europe, Alzheimer Iberoamérica, NCD Alliance, and the World Dementia Council, as well as other professional and non-governmental organisations working in dementia or related issues

Objective 2 – Reduce stigma

ADI will seek to reduce stigma by increasing understanding of dementia, researching the issue, recognising cultural differences and acting to protect the rights of people living with dementia.

ADI will:

- Make stigma the focus of the World Alzheimer Report 2019 drawing on existing research and survey work to provide a baseline for future work
- Promote understanding of dementia through World Alzheimer's Month, the international conference and regional meetings
- Publish up to date information about dementia, including dementia policy
- Support and encourage the inclusion of people with dementia and care partners in ADI member associations
- Work with DAI and other organisations on human rights issues and policy

- Support the development of language guidelines and avoidance of stigmatising language
- Promote the development of dementia friendly concepts and encourage members to advocate for their implementation
- Promote person-centred care in its own right and as a way to reduce stigma
- Support the development of tools and programmes to reduce stigma and promote their use by members and others, including intergenerational programmes and education at all ages
- Work together with members to increase use of communication and social media opportunities

Objective 3 – Strengthen membership

ADI will meet the varying needs of Alzheimer and dementia associations and provide programmes that will enable members to best support people affected by dementia and their care partners.

ADI will:

- Actively engage with current and potential member associations to strengthen and support their work
- Work with members to help them evaluate their performance and focus on outcomes
- Regularly survey members to evaluate their needs
- Continue development of regions to better support members
- Continue the Alzheimer University programme, including developing online training for member associations and programmes tailored for specific needs
- Increase the use of webinars to provide information to members and share experiences.
- Facilitate the sharing of best practices between our members and between regions, including through the ADI Twinning Programme
- Support members to provide education and training through evidence-based programmes

Objective 4 – Facilitate research

ADI will facilitate and encourage research and innovation, including in care, prevention, healthcare systems, epidemiology, public health, effective treatments.

ADI will:

- Collect and disseminate information about dementia research and clinical trials, and use evidence to support our work
- Develop evidence-based reports on dementia to facilitate better policy and practice
- Facilitate knowledge transfer between research and practice
- Encourage knowledge exchange and greater understanding about participation in dementia research and clinical trials by facilitating open dialogue between our members, the public, health and social care professionals, people living with dementia and their care partners, and industry, including through Dementia Research Webinars
- Encourage research to benefit low and middle income countries, including facilitating collaboration between research-mature countries and those with restricted capacity

- Actively engage with MSAP (our Medical and Scientific Advisory Panel) and its Executive Committee, to ensure that ADI and member associations benefit from their knowledge and expertise
- Encourage engagement between researchers, Alzheimer and dementia associations, people living with dementia and carers, including through collaboration with the 10/66 Dementia Research Group^v and STRiDE project^{vi}

Objective 5 – Enable ADI to achieve its objectives

ADI will develop funding plans to enable our objectives to be achieved and will use technology and modern communications to execute this Strategic Plan.

ADI will:

- Secure the funding required to support ADI's strategic objectives
 - Generate a minimum of US\$1.5m funding per year
 - Maintain unrestricted income at 75% of total voluntary income
 - Maximise funding opportunities for specific initiatives, such as the Alzheimer University and World Alzheimer's Month, based on the annual business plan
- Develop a strategy for securing increased conference income and ensure that ADI's sponsorship targets are achieved
- Continue to develop ADI's prospect pipeline and put in place a system for monitoring the development of new relationships. New business approaches should ensure:
 - The diversification of ADI's supporter base to include different industry sectors, Trust/Foundation supporters and major donors, and increase the geographical spread of our donors.
 - Income growth for ADI, aiming for at least 10% per annum
- Continue to develop and nurture our staff
- Develop IT and communication systems to communicate and collaborate effectively internally and with our partners

References

1. World Health Organization. Dementia: Key Facts. [Online] 2017. www.who.int/news-room/fact-sheets/detail/dementia.
2. Prince M, Wimo A, Guerchet M, Ali G-C, Wu Y-T, Prina A.M. *World Alzheimer Report 2015 - The Global Impact of dementia: an analysis of prevalence, incidence, costs and trends*. London : Alzheimer's Disease International, 2015.
3. YouGov Polling for Alzheimer's Research UK. 2013.
4. Prince M, Bryce R, Ferri CP. *World Alzheimer Report 2011: The benefits of early diagnosis and intervention*. London : Alzheimer's Disease International, 2011.
5. Patterson, C. *World Alzheimer Report 2018. The state of the art of dementia research: New frontiers*. London : Alzheimer's Disease International, 2018.

^v The 10/66 Dementia Research Group is a collective of researchers carrying out population-based research into dementia, non-communicable diseases and ageing in low and middle income countries www.alz.co.uk/1066

^{vi} STRiDE (Strengthening responses to dementia in developing countries) aims to build research capacity and provide evidence on dementia care in seven low and middle income countries www.stride-dementia.org