



**Alzheimer's Disease
International**

The global voice on dementia

Strategic Plan 2016-2019

Introduction

Alzheimer's Disease International (ADI) is the federation of national Alzheimer associations around the world. ADI has grown from four members in 1984 to become a global federation of over 80 national Alzheimer associations, in official relations with the World Health Organisation (WHO) and United Nations (UN). Representing people and nations on all continents, ADI is the only global organisation for dementia and the global voice on dementia. ADI is also in collaboration with Dementia Alliance International (DAI), a global organisation of people with dementia.

We believe that the key to improving the outcomes for dementia lies in a combination of global recognition and solutions, and local knowledge. We work with national Alzheimer associations to raise awareness, to offer care and support for people with dementia and their care partners¹, and to advocate. We work globally to focus attention on dementia as a health and research priority and campaign for policy change from governments and the WHO.

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

Our vision

Our vision is prevention, care and inclusion today, and cure tomorrow.

Our mission

Our 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.

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

¹ Where we talk about 'care partners' this includes family carers/caregivers and other informal carers. 'Care partners' is a term agreed by people with dementia, reflecting a more equal relationship.

- Inclusion: Reaching out and enabling all stakeholders to be represented and heard
- Diversity and equality: Celebrating cultural diversity and communicating in multiple languages, without prejudice or discrimination
- Accountability: Being transparent and accountable, as well as fiscally responsible and effectively governed, with a commitment to excellence in all our work
- Cooperative working relationships: Developing mutually beneficial partnerships and relationships.

How we work

ADI is a federation that primarily works by empowering its member associations, taking into consideration their geographical and cultural diversity. Each of our members is a non-profit Alzheimer association supporting people with dementia and their care partners. We can only achieve our objectives if we work closely together with our members, other non-governmental organisations such as HelpAge International and international bodies like WHO, World Dementia Council and the Organisation for Economic Co-operation and Development (OECD). Partnership and coalition building are key parts of the work we do.

The world in which we operate

Despite being the principal organisation combatting the global impact of dementia, external forces influence our organisation over which we have limited or no control. The global landscape in which we operate is challenging. However, we are determined to work together with our partners and members to overcome obstacles and find global solutions to improve the quality of life for people with dementia and their families throughout the world.

External forces that impact on our organisation include the following:

- Dementia is indiscriminate and there is no effective disease-modifying treatment.
- Without a disease-modifying treatment or effective prevention, a rapidly aging global population will result in the number of people with dementia almost doubling every 20 years. In 2015, 48 million people have dementia, and this number will increase to over 130 million by 2050. There are many more millions of care partners who carry the burden of the disease. There is a new case of dementia every 3 seconds. People over 55 years of age fear dementia more than any other disease.
- Already 58% of people with dementia live in low and middle income countries. By 2050 this proportion will rise to 68%, as the increases in the numbers of people living with dementia will be much steeper in low and middle income countries than in high income countries.
- The annual global cost of dementia in 2015 is estimated at US\$818 billion and the cost will continue to increase to over \$1 trillion by 2018 and will severely impact on health budgets.
- More and more countries are developing strategies or plans with measures to improve care and support for people with dementia and their care partners and increase research funding. Despite recent progress, the majority of the countries have still not taken action and the level of public funding is very low compared to other disease areas such as cancer and HIV/AIDS.

- Stigma, myths and lack of knowledge are preventing timely diagnosis and early intervention which leads to poor life outcomes for people with dementia and their care partners and increased spending downstream as a higher number of people require costlier interventions.

What we believe

Dementia is a devastating disease, but despite the daily challenges that 48 million people and their care partners experience, 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.
- 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, and good diet, 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.
- People with dementia must be recognised under the UN Convention on the Rights of Persons with Disabilities.
- 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 – Making 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 WHO, UN, OECD, G7, G20 (the governmental groups of, respectively, seven and twenty major economies) and other international 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
- Advocate for health and care systems to respond better to dementia. This should include;
 - dementia friendly communities;

- timely diagnosis;
 - post-diagnostic support;
 - support and education for care partners;
 - access to person-centred dementia services in community care and respite services, residential care and acute care;
 - promotion of risk reduction measures;
 - use of 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.
 - Seek to include 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, NCD Alliance (an international group representing the main non communicable diseases), and the World Dementia Council, as well as other professional and non-governmental organisations

Objective 2 – Reducing stigma

ADI will seek to achieve this by raising awareness about Alzheimer’s disease and other dementias.

ADI will:

- Promote and support World Alzheimer’s Month and World Alzheimer’s Day
- Organise the ADI annual conference and regional meetings
- Work with and support Dementia Alliance International and support the inclusion of people with dementia in ADI member associations with priority for low and middle income countries
- Promote the development of Dementia Friendly Communities and provide information to members on programmes that are dementia friendly
- Publish reliable information about dementia, including dementia policy, on the ADI website
- Work together with members to increase use of communication opportunities, including with social media

Objective 3 – Strengthening membership

ADI will meet the needs of emerging and established 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 including in respect of special groups
- Continue to survey members to evaluate their needs
- Further explore development of regions to better support members

- Continue the Alzheimer University programme and develop online training for member associations
- Facilitate and encourage the sharing of best practices between our members and between regions, including continuing the ADI Twinning Programme
- Develop Train the Trainer programme to implement with our members
- Implement education programmes including iSupport (an interactive web-based caregiver support tool, designed particularly for those in low and middle income countries) together with WHO and our members

Objective 4 – Facilitating research

ADI will facilitate and encourage research into care and prevention, epidemiology, and finding effective treatments.

ADI will:

- Encourage participation in clinical trials by collecting and disseminating information about them
- Renew membership of MSAP (our Medical and Scientific Advisory Panel) with clearer roles and structure
- Develop evidence-based reports on dementia to facilitate better policy and practice
- Facilitate knowledge transfer between research and practice

Objective 5 – Enablers

ADI will generate sufficient income and use technology and modern communications to execute the Strategic Plan.

ADI will:

- Raise the funds needed to achieve our objectives
- Develop IT and communication systems to better communicate with and inform stakeholders

Annual work plan

These objectives and the outcomes to be achieved will be defined in detail in an annual work plan that will be approved by the Board. Critical will be outcomes in respect of action by global bodies on dementia, the number and quality of national dementia plans, inclusiveness in respect of people with dementia in Alzheimer associations and investment in research. The Board will set a budget to accompany each work plan.