

# Strategic Plan July 2023 - June 2026<sup>i</sup>

## 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 100 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 partners<sup>ii</sup>, 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

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<sup>i</sup> This document expresses our high-level strategic objectives and outlines the ways we will seek to achieve them. It covers the period from July 2023 to June 2026. 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.

<sup>ii</sup> 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.

priority, to support and empower people living with dementia and their care partners, and to increase investment and innovation in dementia research.

Advocating for governments all over the world to deliver the WHO Global Action Plan on Dementia 2017-2025 is a key part of delivering our mission.

## **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
- Being outspoken about the human rights of those living with dementia and their care partners
- Encouraging the creation of a global movement of dementia advocates

## **The world in which we operate**

### *The statistics of dementia*

- In 2019, over 55 million people have dementia worldwide, and this number will increase to over 139 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).
- Dementia is currently the 7<sup>th</sup> leading cause of death among all diseases (1).

- The annual global cost of dementia is estimated to have been US\$ 1.3 trillion<sup>iii</sup> in 2019 and to rise to US\$ 2.8 trillion by 2030 (1) (2).
- In 2019, informal dementia carers spent over 133 billion hours carer for someone living with dementia, this equates to approximately 67 million full time workers (4)
- Stigma and lack of awareness are a major issue everywhere with 62% of health care practitioners still believing that dementia is a normal part of ageing (5).
- Globally, as many as 75% of people with dementia have not been diagnosed (6) (7).
- There have been 12 studies on cancer for every 1 on cognitive disorders (8).

The unanimous approval of the WHO *Global action plan on the public health response to dementia 2017-2025*<sup>iv</sup> 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. ADI has published since 2018 a report annually monitoring the progress of the plan.

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 (4).
- Some governments neglect dementia due to stigma. Some deny that dementia is a problem or see tackling dementia as too costly. Covid 19 has exacerbated this as while people with dementia and carers have been most affected, governments have deprioritised them (9) (10) (11).
- 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 (5), 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, brain 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 55 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 post-diagnosis support, care and treatment that responds to their needs, and should have the best possible quality of life.

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<sup>iii</sup> Trillion being one million million - 1,000,000,000,000.

<sup>iv</sup> [www.who.int/mental\\_health/neurology/dementia/action\\_plan\\_2017\\_2025](http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025)

- 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 improving education, smoking cessation, control of diabetes and hypertension, avoiding head injury, moderating alcohol consumption, regular exercise, good diet, social engagement and mental activity, reducing pollution, and treating hearing loss, 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 to regulate, pay for and make those accessible. This also includes diagnosis preparedness.
- As the pandemic and also disasters, wars and emergencies have shown, governments must address the needs of people living with dementia in these situations.
- Design solutions exist which can improve the lives of people with dementia and these should be used in domestic, institutional and public settings.
- 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, , 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
- Monitor 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
- 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:

- Continue to monitor the baseline created by the World Alzheimer Report 2019 on attitudes to dementia and stigma.
- 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 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
- In view of the global demand in dementia training and shortage of quality practitioners, continue to develop and grow our dementia training accreditation

### **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
- Maintain the high quality of our successful webinars to provide information to members and share experiences with the wider community
- Facilitate the sharing of best practices between our members and between regions
- 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, focusing on translational research that builds capacity of our ADI members to turn research into policy impact
- 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
- 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.
- Continue to create innovative initiatives with MSAP to benefit the wider research community
- Encourage engagement between researchers, Alzheimer and dementia associations, people living with dementia and carers, including through collaborations with groups such as WW-FINGER, the 10/66 Dementia Research Group<sup>v</sup>, the STRiDE Network, and other projects like COGNISANCE<sup>vi</sup>

#### **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\$1.9m funding per year

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<sup>v</sup> 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](http://www.alz.co.uk/1066)

<sup>vi</sup> 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](http://www.stride-dementia.org)

- 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
- Having developed a strategy for securing increased conference income, ensure that ADI's sponsorship targets are consistently achieved and conferences generate a surplus
- 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
- Continue to implement better ways to work thanks to IT and communication systems that enable us to communicate and collaborate effectively internally and with our partners

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