



*Making dementia a priority:
changing perceptions, practice and policy.*

Alzheimer Europe Strategic Plan (2021-2025)

Adopted by the Annual General Meeting on 14 June 2021

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1 Introduction

The current document outlining the strategic priorities of Alzheimer Europe is based on the experiences of the organisation's past business and strategic plans-

The document was presented and adopted at the Virtual Annual General Meeting on 14 June 2021 after a survey of the organisation's members regarding Alzheimer Europe's past activities and projects and its future priorities.

The plan builds on the success of the organisation's "Strategic Plan 2016-2020" whilst expanding some of the organisation's key strategic objectives.

2 Our values

Alzheimer Europe and its members fully commit to promoting the rights, dignity and autonomy of people living with dementia. These rights are universal, and guaranteed in the European Convention of Human Rights, the Universal Declaration of Human Rights, the International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights, and the United Nations Convention on the Rights of Persons with Disabilities.

Alzheimer Europe and its member organisations affirm that every person living with dementia has:

- The right to a timely diagnosis;
- The right to access quality post diagnostic support;
- The right to person-centred, coordinated, quality care throughout their life;
- The right to equitable access to treatments and therapeutic interventions;
- The right to be respected as an individual in their community.

3 Our mission

Alzheimer Europe sees its mission as changing perceptions, policy and practice in order to improve the lives of people affected by dementia.

4 Our strategic objectives

Alzheimer Europe will achieve this mission by providing a voice to people with dementia and their carers, making dementia a European priority, changing perceptions and combating stigma, raising awareness of brain health and prevention, strengthening the European dementia movement and supporting dementia research.

4.1 Objective 1: Providing a voice to people with dementia and their carers

By 2025, Alzheimer Europe will have:

- Involved people with dementia and their families and carers in all its activities
- Further developed its European Working Group of People with Dementia (EWGPWD) and set up a European Carers Working Group (ECWP) to advise the organisation on the priorities of people with dementia and their carers
- Developed a business model for these groups for their consultation by commercial companies and academic researchers
- Highlighted the experiences and needs of people with young onset dementia and other types of dementia
- Supported national Alzheimer associations interested in setting up national working groups of people with dementia and their families and carers
- Promoted techniques to meaningfully involve people with dementia and their families and carers in dementia research

- Ensured the full participation, where appropriate, of people with dementia and their carers in the organisation's European research projects
- Developed virtual mechanisms to consult a broader group of people with dementia and their families and carers through online surveys or other means
- Ensured that all working groups set up by the organisation have, where appropriate, representation from people with dementia and their carers
- Fully involved people with dementia and their carers in the organisation of its Annual Conference
- Featured personal testimonies of people with dementia and their carers in its Annual Conference and the organisation's newsletter and magazine
- Continued its membership of and collaboration with the European Patients' Forum

4.2 Objective 2: Making dementia a European priority

By 2025, Alzheimer Europe will have:

- Improved its collaboration with all European institutions: the European Parliament, the European Commission and the Council of Ministers and worked proactively with the Presidencies of the European Union to have dementia recognised as a priority
- Continued to host the European Group of Governmental Experts on Dementia, bringing together national government officials in charge of dementia policies
- Further developed the European Alzheimer's Alliance with Members of the European Parliament from all EU Member States and all political groups
- Updated Members of the European Parliament about its activities and EU and national policy development through the organisation of lunch debates and the publication of the Dementia in Europe magazine
- Organised a week-long exhibition in the European Parliament
- Monitored the development and implementation of national dementia strategies
- Compared dementia policies and presented the results in its Dementia in Europe Yearbook together with identified best practices on topics such as training of healthcare professionals, access to care and treatment, support of national Alzheimer's associations, patient care pathways and funding and organisation of dementia research
- Updated its European Dementia Monitor benchmarking and comparing dementia policies and ranking countries' responses to dementia
- Actively involved its member organisations in policy development and campaigning
- Developed a broader strategic alliance with European organisations of health and social care professionals and researchers including the INTERDEM network, the European Alzheimer's Disease Consortium and the European Academy of Neurology and organised annual European Dementia Summits bringing together key representatives of these organisations to jointly campaign on common policy and research questions
- Used the 2024 European Parliament elections to launch a European Dementia Manifesto in collaboration with its member organisations
- Continued as an accredited organisation of WHO Europe and identified ways of promoting dementia and brain health as priorities at the European level of the World Health Organization

4.3 Objective 3: Changing perceptions and combating stigma

By 2025, Alzheimer Europe will have:

- Continued to promote a rights-based and ethical approach to dementia
- Carried out an analysis of how the principles enshrined in the UN Convention on the Rights of Persons with Disabilities can be applied to persons with dementia

- Campaigned for the recognition of dementia as a disability
- Continued its membership of and collaboration with the European Disability Forum
- Carried out a survey of people living with dementia and their carers on their experiences of stigma, including experienced, anticipated and structural discrimination
- Developed, in collaboration with people affected by dementia, a guide on how to communicate and use non-stigmatising, respectful and inclusive language
- Created, in close collaboration with its member organisations, an annual prize to award an effective campaign in a European country addressing the stigma and perceptions of dementia
- Promoted the continued development of dementia-inclusive initiatives and dementia friends programmes
- Advocated on the importance of inclusiveness of all people in dementia care. research and policies (e.g. minority ethnic groups, LGBTQ+ people, Deaf people)
- Set up a European Dementia Ethics Network with ethicists, people affected by dementia and researchers and academics to prepare positions, when needed, on ethical issues in dementia research and care
- Focused on legal issues and updated its reports on legal capacity and decision making
- Campaigned for the ratification of the Hague Convention for the International Protection of Adults
- Developed its relationship with the Council of Europe and collaborated, in particular, with its Committee on Bioethics
- Contributed to the European Fundamental Rights Platform
- Showcased examples of people living well with dementia at different stages of the disease

4.4 Objective 4: Raising awareness of brain health and prevention

By 2025, Alzheimer Europe will have:

- Supported national associations in providing information for people interested in reducing their risks of developing dementia or in slowing progression by addressing modifiable risk factors through the life course
- Campaigned for the promotion of brain health and dementia prevention as priorities of European and national research programmes
- Included people at risk of developing dementia in its activities and meetings and identified ways of assessing their views and experiences through face-to-face panels and online mechanisms and surveys
- Developed and campaigned on a position on how to disclose risk of developing dementia to people at the asymptomatic and mild cognitive impairment stages of the disease
- Carried out a survey to understand the impact and acceptability of risk disclosure versus a diagnosis of preclinical Alzheimer's disease, as well as public perceptions on the acceptability of preventative measures
- Identified obstacles and barriers to timely diagnosis and promoted clinical pathways ensuring both timely diagnosis of people with mild cognitive impairment and dementia and support of people at risk of developing dementia
- Collaborated with industry partners on promoting health system readiness of European countries for innovative treatments and care approaches
- Monitored the adoption of disease-modifying treatments in national care pathways and campaigned for equal access to innovative treatments in all European countries
- Participated in EU funded research programmes on brain health and prevention

4.5 Objective 5: Strengthening the European dementia movement

By 2025, Alzheimer Europe will have:

- Developed the Alzheimer's Association Academy as a series of online capacity building workshops on issues identified as priorities by national Alzheimer associations
- Updated its report on the European Dementia Movement highlighting the impact of the COVID-19 pandemic on organisations' finances and services
- Identified opportunities for joint awareness raising activities around World Alzheimer's Day and Brain Awareness Week
- Ensured to communicate activities of its national member organisations through its social media activities, monthly e-mail newsletter and website
- Updated its newsletter and overhauled the organisation's website
- Established Alzheimer Europe Conferences as unique networking opportunities exploring hybrid models to combine face-to-face elements with opportunities to connect and learn remotely
- Expanded its membership to all countries of the European Union with a view to reaching all countries belonging to the European region of the World Health Organisation
- Diversified the organisation's funding through a mix of private and public contributions, as well as support from its member organisations
- Carried out a review and updated its statutes and rules and regulations

4.6 Objective 6: Supporting dementia research

By 2025, Alzheimer Europe will have:

- Promoted a holistic approach to dementia research
- Promoted an inclusive approach to dementia research involving people from all social, ethnic and different minority groups as participants and researchers and on funding, ethics and other review boards
- Campaigned for increased funding for dementia research at EU and national level and for greater collaboration between European countries in the field of research
- Developed closer ties with Horizon Europe, the Innovative Health Initiative (IHI) and the Joint Programme Neurodegenerative Disease Research (JPND)
- Updated its report on the prevalence of dementia in Europe
- Provided updates on scientific developments on all aspects of dementia research in its newsletter and on its website
- Updated the working methods and membership of the organisation's Expert Advisory Panel to ensure all types of dementia research are represented and included
- Included experts from all countries represented in Alzheimer Europe in the Expert Advisory Panel and involved them in providing comments on breaking research news and identifying topics and speakers for the organisation's Annual Conferences
- Organised Annual Conferences giving the opportunity to researchers to present scientific findings on all aspects of dementia research
- Enhanced its existing collaboration with the INTERDEM network, the European Alzheimer's Disease Consortium, the European Academy of Neurology and other organisations of researchers in the field of dementia
- Proactively identified funding opportunities for European research projects and collaborated in the development of research proposals
- Represented the views of people with and at risk of developing dementia and their families and carers in European research projects
- Contributed to the discussion of ethical issues raised by EU research projects

- Disseminated information on European projects it is involved in to its member organisations and the general public, via its conferences, newsletters and website
- Continued its involvement with the European Medicines Agency as an active member of the Patients' and Consumers' Working Party
- Developed its Clinical Trials Watch providing easy-to-understand information on all phase II and III clinical trials being conducted in a European country
- Organised information meetings with companies involved in clinical trials to present their research programmes and gather feedback from Alzheimer's associations as well as people with and at risk of developing dementia and their families and cares
- Collaborated with researchers and pharmaceutical companies to understand the experience of participating in clinical trials and research and developed recommendations to improve the recruitment and participation process