

Helsinki Manifesto

1. Background

By 2025, 9.1 million people will be living with dementia in the European Union. By 2050, this number is estimated to reach 14.3 million.¹ According to the World Health Organization (WHO), it is the third leading cause of mortality in Europe and the seventh globally². Furthermore, according to the WHO, the societal cost of dementia in Europe amounted to EUR 392 billion in 2019³.

With ageing demographics across Europe, it is imperative that governments act and ensure available and affordable health care, provide social and legal protection to uphold the rights of people with dementia and their carers, support quality research to develop new treatments and care interventions and take steps to ensure there are enough skilled professionals to meet the needs of people living with the condition wherever they live across the European Union.

Alzheimer Europe issued two Declarations in the past, in Paris (2006) and in Glasgow (2014), calling for action in key areas across a number of domains, both at a European and national level.

Since then and over the past decade, there have been important developments, including the G8 Dementia Summit Communique in 2013, the WHO's Global Action Plan on the public health response to dementia 2017-2025 (and the Status Report published in 2023), the two EU Joint Actions on Dementia and the development of national dementia strategies across a number of European countries. Most recently, the G7 Nagasaki Health Ministers' Communiqué recognised dementia as a priority issue, identifying the need to accelerate research and development across prevention, risk reduction, early detection, diagnosis, and treatment of dementia. It further encouraged Member States to develop and implement strategies and action plans, adopting integrated approaches on dementia in line with the WHO's Global Action Plan on Dementia. It also addresses the need for action in relation to dementia-inclusive communities, the development of effective and affordable treatments, the need for adequate capacity within systems particularly in relation to diagnosis and treatment, as well as the need to tackle the social and environmental risk factors associated with dementia.

Additionally, we have seen significant strides in the understanding of dementia, the underlying mechanisms behind the diseases which cause dementia and significant progress in research into new treatments. Whilst we are still some way from a cure, there is cause for optimism that new, disease-modifying treatments, are within reach.

Despite this, many challenges remain for people with dementia and carers in their daily lives. These include the lack of access to a timely, personalised and accurate diagnosis of dementia; the availability and affordability of care services; complex and inadequate social protection systems; continued stigma and poor understanding of dementia amongst the public. Many of these issues were exacerbated by the COVID-19 pandemic and underlined the importance of a structured and coordinated approach to

¹ Alzheimer Europe, Dementia in Europe Yearbook 2019: <https://www.alzheimer-europe.org/resources/publications/dementia-europe-yearbook-2019-estimating-prevalence-dementia-europe>

² World Health Organization (WHO), Global Health Estimates 2019: https://cdn.who.int/media/docs/default-source/gho-documents/global-health-estimates/ghe2019_cod_whoregion_2000_20195a48bd71-f222-4b00-90e6-b5078fbfc4db_e01200f2-71ae-47bd-a344-03f4647f8127.xlsx?sfvrsn=4aed7378_7

³ World Health Organization (WHO), Global status report on the public health response to dementia (2019): <https://www.who.int/publications/i/item/9789240033245>

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social activities, care services and healthcare interventions, to ensure a good quality of life, both for people with dementia and their carers.

In addition, there has been a deprioritisation of dementia as a policy issue in recent years, often being included within broader topics of mental health or ageing policies without providing specific responses. This unwelcome development overlooks the distinct nature of dementia as a progressive neurodegenerative condition, the scale and cost of which make it a pressing issue, deserving higher prioritisation and greater investment.

The targets of the WHO's Global Action Plan are not on course to be achieved and the needs of people with dementia and carers are not met. Therefore, there is a need for a renewed push at both a European and national level to reprioritise dementia and invest resources to ensure our societies adequately support people living with dementia and their carers.

This Manifesto, supported by a range of national and European organisations, sets out clear actions which should be taken in the next five years by national governments and EU institutions, and will be the basis for Alzheimer Europe's advocacy activities.

2. Health

Alzheimer Europe wishes to see dementia prioritised within the domain of health and concrete actions taken to improve prevention, diagnosis, care and treatment. Health systems continue to fail people with dementia who are underdiagnosed, with adequate post-diagnostic support only offered in a few countries, whilst many health and social care services continue to be unavailable and/or unaffordable. Many of these issues were exacerbated by the COVID-19 pandemic, with diagnosis rates falling and in-person services affected.

Whilst there has been considerable focus on health at an EU and national level, it has primarily been on the response to the current and future pandemics and Europe's Combating Cancer Plan, without meaningful consideration of future challenges such as the ageing populations in Europe and the growing need for increased support for age-associated conditions such as dementia, frailty etc.

At an EU level, we call on the European Commission and institutions to:

- Recognise the distinct nature of dementia, as well as its scale, cost and societal impact and to provide the necessary political leadership and prioritise dementia as a public health issue
- Dedicate funding for projects and actions related to different aspects of dementia (e.g. prevention, care, treatment etc.) in each year of future health programmes, with equitable funding arrangements, in line with other non-communicable diseases (e.g. cancer)
- Introduce a European Dementia Action Plan, to coordinate efforts and programmes across the domains of health, research and social affairs
- Dedicate funding within the health programme to roll out best practices identified as part of the previous EU Joint Actions on dementia and EU-funded research projects.

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At a national level, we call on national governments to:

- Develop and implement fully-funded national dementia strategies in close collaboration with national Alzheimer's associations and people with lived experience of dementia, in line with the WHO's Global Action Plan on Dementia
- Utilise the resources available under the EU health programme and structural funds to develop dedicated programmes at a national level
- Advocate for dementia to be prioritised in the agenda setting for EU programmes
- Set national targets for the level of diagnosis in the country, with dedicated investments in secondary care services such as memory clinics, and training services for care professionals
- Invest in improvements for the infrastructure to support timely diagnosis, including developments in biomarkers and post-diagnostic services
- Invest in health and social care services, including day care, respite and residential facilities to ensure accessibility and affordability of services
- Develop and implement training programmes for health and social care professionals to ensure a high level of quality care
- Anticipate and support the introduction of new disease modifying treatments for people with Alzheimer's disease, developing the required infrastructure and specialised clinics needed to ensure equitable access.

3. Research

Dementia research has long been underfunded both proportionately to its societal cost but also in comparison to other non-communicable diseases. It is therefore vital to prioritise dementia research in order to:

- Improve our knowledge of the underlying conditions which cause dementia, to support the development of new treatments and, ultimately, a cure
- Facilitate new social and clinical interventions to improve the health and wellbeing of people living with the condition
- Improve data and prevalence data collection to inform the planning and management of services.

In the 10 years since the G8 Declaration on Dementia (2013), there has been some progress in dementia research, with some countries increasing the level of funding for dementia research, including through the EU's research programmes.

It is vital that momentum is not lost. As such, the EU and Member States must redouble their efforts to dementia research by providing the resources needed to ensure that both scientific and practice-based research continue to advance.

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At an EU level, we call on the European Commission and institutions to:

- Include a dedicated “research mission” to dementia in the EU research programme covering basic, clinical and care science
- Increase the funding allocated for dementia research proportionately to its societal cost, bringing the total funding to at least the level of other NCDs
- Increase funding for clinical and care research for health and social care professionals, including around diagnosis, clinical care and therapeutic interventions etc.
- Promote data sharing and ensure continuity, usability and sustainability of collected data and samples once research periods conclude.

At a national level, we call on national governments to:

- Establish long-term and continuous funding dedicated to dementia research
- Improve national data collection programmes for dementia ensuring interoperability of systems and efficient data sharing
- Support the coordination of dementia research within the country by aligning efforts of all relevant institutions
- Provide necessary support for applications for funding from the EU
- Promote academic reward systems that place a greater value on data sharing, transparency and openness by ensuring that data generators are credited when their data are reused.

4. Disability and social rights

People with dementia have a range of protections at a European and international level including within the European Convention on Human Rights, the Universal Declaration of Human Rights, the International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights, the European Charter of Fundamental Rights, the European Pillar of Social Rights and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

These rights are both political and legal in nature and encompass almost every aspect of the day to day lives of people with dementia, their families and carers. Despite this, there is a lack of a common definition of disability across countries, the variation in social protection available, as well as the inconsistent and variable access to health and care services across Europe.

A range of EU legislation and policies also exist in this area, including the Accessibility Act, the EU Disability Parking Card, the Employment Equality Directive, amongst others. However, implementation remains variable and experiences of people with dementia are often significantly worse than aim of the legislation.

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At an EU level, we call on the European Commission and institutions to:

- Implement the horizontal non-discrimination directive
- Strongly encourage countries to ratify The Hague Convention of 13 January 2000 on the International Protection of Adults (HCCH 2000 Protection of Adults Convention)
- Expand the EU parking badge scheme across all countries of Europe, with common eligibility criteria including dementia
- Ensure the European Disability Card is available in all countries across Europe, with common eligibility criteria meeting the needs of people with dementia
- Update the European Semester process so that recommendations are linked to EU funding programmes, proactively encouraging Member States to use these funds to address Country Specific Recommendations.

At a national level, we call on national governments to:

- Develop and implement concepts of dementia-inclusive societies, including in relation to dementia-inclusive design of built environments and housing
- Adopt the UNCRPD's definition of disability and recognise that dementia, as a condition which impairs cognitive function, is a disability
- Ratify the HCCH 2000 Protection of Adults Convention
- Ensure the involvement of people with lived experience of dementia in decisions which affect them, both at a policy/strategic level and in decisions regarding care and treatment
- Reform legislation and practice in relation to decision-making, moving away from models of proxy decision-making towards supported-decision making.

5. Informal carers

The needs of carers of persons with dementia are often overlooked, as is their integral role in supporting and ensuring the wellbeing of the person living with the condition.

For carers of people with dementia, the need to balance employment, family life and caring responsibilities can be both mentally and physically exhausting, as well as socially isolating, if they are unable to maintain the same connections as a result of their caregiving role. Additionally, caregiving can often prove to be financially challenging due to the cost of care services and/or loss of income as a result of stopping or reducing paid employment.

Whilst the EU has taken some measures in recent years, few measures have been directly targeted towards carers, with competence in this area still largely lying with Member States. As such, the experience and level of support for carers of people with dementia continues to vary considerably across Europe.

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At an EU level, we call on the European Commission and institutions to:

- Fully implement the provisions of the European Care Strategy, with a specific focus on measures to support informal caregivers
- Ensure full implementation of the Work-Life Balance Directive and strengthen its key points in relation to carers
- Make available resources within the European Social Fund for projects which provide training, support and resources for carers
- Adjust the social scoreboard and European Semester process to monitor the support provided for informal carers and make recommendations on actions for countries to improve the wellbeing of informal carers

At a national level, we call on national governments to:

- Provide greater resources for training for informal carers, particularly where they are supporting a person with a complex health conditions such as dementia
- Improve the level of support provided to carers of people with dementia by social protection systems through improved welfare payments and services, such as respite care
- Adjust social protection systems so that carers of people with dementia have their needs assessed and met, independently of the needs of the person being cared for
- Ensure the involvement of carers of people with dementia in decisions which affect them, both at a policy/strategic level and in decisions regarding care and treatment
- Adjust eligibility criteria of social protection systems to provide greater flexibility for carers to continue to work (if they so wish), whilst allowing them to still receive support for their caregiving role.

6. Conclusion

This manifesto, adopted at Alzheimer Europe's 2023 Annual General Meeting in Helsinki, Finland, will be a core component of Alzheimer Europe's public affairs work over the course of the next five years (2024-2029), aligning with the next term of office of the European institutions. It contains a comprehensive range of measures and actions across the key areas which have the greatest impact on the lives of people with dementia, their families and carers.

For those calls aimed at EU institutions, Alzheimer Europe will actively promote and push for these policies to be adopted by engaging with members of the European Alzheimer's Alliance (MEPs who have agreed to support our policy aims at an EU level) and the Commission. For the calls at a national level, we will actively work with our national members to provide members with support to engage with decision makers in their countries.