

# Alzheimer Europe calls for dementia to be a priority for European decision-makers



15 January 2024 – The campaign is launched

In advance of the European Parliament elections between 6 and 9 June 2024, Alzheimer Europe launched its European Election Campaign on 15 January, aiming to make dementia a priority issue for decision-makers at a European level.

As part of this campaign, Alzheimer Europe worked with members of the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) to create videos for use on social media, with members of the groups sharing their own experiences of dementia and calling for decision-makers to prioritise dementia.

In its campaign, Alzheimer Europe highlights World Health Organization (WHO) figures which show that dementia is the third leading cause of mortality in Europe and the seventh globally, with a societal cost in Europe estimated to be EUR

Oruen – The CNS Journal editor@oruen.com Copyright © 2015-2024 All rights reserved 392 billion in 2019. Additionally, the organisation points out that by 2025, 9.1 million people will be living with dementia in the European Union, rising to 14.3 million in 2050.

Alzheimer Europe is therefore pushing for the condition to be shown greater attention by European decision-makers and adopted a campaign with three distinct elements aimed at different audiences, demanding that dementia be prioritised as a policy issue:

## The Helsinki Manifesto

Ten years on from the "Glasgow Declaration" (2014), dementia has been deprioritised at a European level and in many European countries. This has taken place despite the growing number of people living with the condition and the continued lack of access to diagnosis, treatment and care, which have been identified as long-standing challenges in countries across Europe.



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In response, at Alzheimer Europe's Annual General Meeting on 16 October 2023 (pictured), in Helsinki, Finland, the organisation's members adopted the "Helsinki Manifesto", which outlines the current position of dementia across Europe and lays the foundation for Alzheimer Europe's campaigning activities over the next five years (2024-2029).

The Helsinki Manifesto is divided into the following policy areas:

- Health
- Research
- Disability and social rights
- Support for informal carers.

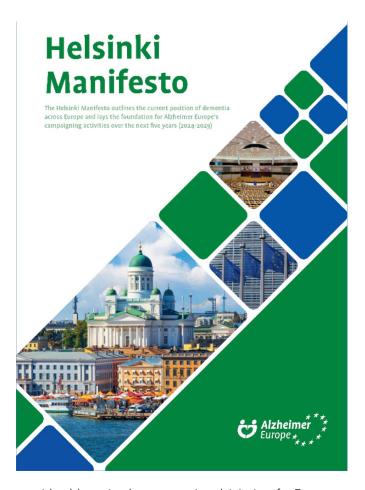
Under each policy area, a brief rationale for action is outlined, followed by a number of specific demands for European and national decisions-makers, including:

- Invest in improvements to support timely diagnosis, including access to imaging, biomarker testing and new treatment options
- An increase in the funding allocated for dementia research which is proportionate to its societal cost, bringing the total funding to at least the level of other non-communicable diseases
- The prioritisation of dementia in future health programmes with dedicated funding for projects and actions in line with other non-communicable diseases (e.g. cancer)
- The development and implementation of a European Dementia Action Plan, to coordinate efforts and programmes across the domains of health, research and social affairs.

European and national organisations with a mutual interest in these policy areas are invited to endorse the Helsinki Manifesto. If your organisation would like to endorse the Helsinki Manifesto, please send an email to <u>info@</u> <u>alzheimer-europe.org</u>

Jean Georges, Executive Director of Alzheimer Europe, said: "With the number of people living with dementia expected to substantially increase in the coming years, as well as the

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considerable societal costs associated, it is time for European decision-makers to prioritise dementia and dedicate the resources needed to address it across the domains of health, research, disability rights and support for informal carers. Our Helsinki Manifesto and associated campaign not only highlight the scale of the challenge presented by dementia but also offer concrete steps for how European decisionmakers can take decisive action in the coming years. We encourage organisations to support the Manifesto, today and help us make dementia a European priority!"

Download the Helsinki Manifesto as a PDF booklet, here: <u>https://www.alzheimer-europe.org/sites/default/</u> files/2024-03/final - <u>helsinki manifesto - digital.pdf</u>

Read a one-page summary of the Helsinki Manifesto, here: <u>https://www.alzheimer-</u> <u>europe.org/sites/default/files/2024-01/</u>

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## <u>final - helsinki manifesto 2023 - 1 page summary.pdf</u>

You can find out more about the Helsinki Manifesto, including which organisations and entities have already endorsed it, here: <u>https://www.alzheimer-europe.org/policy/</u> <u>campaign/alzheimer-europe-election-campaign-2024/</u> <u>helsinki-manifesto</u>

As at mid-July 2024, the Helsinki Manifesto had gathered the support of 74 organisations from across the European region.

## A public Call to Action

In the second strand of the Campaign, Alzheimer Europe has developed a Call to Action, asking for the support of the general public to demand that European decision-makers prioritise dementia and implement the actions of the Helsinki Manifesto. Alzheimer Europe is working with its members to distribute the call throughout its networks, to encourage members of the public to sign the call on its website.

The call has been translated into the different languages of Alzheimer Europe's members, to help the Call be understood more widely and to encourage people to sign up. The text of the call can be seen in the box below:

By 2025, 9.1 million people will be living with dementia in Europe. By 2050, this number is estimated to reach 14.3 million. According to World Health Organization's (WHO) it is the third leading cause of mortality in Europe and the seventh globally. Furthermore, the WHO estimates that the cost of dementia in the European region in 2019 was EUR 392 billion.

As such, Alzheimer Europe and its member organisations are asking for your support to call for European Union leaders to make dementia a priority in the forthcoming term 2024-2029, implementing the actions of the Helsinki Manifesto.

Show your support by signing the call!

The Call to Action is available to sign on Alzheimer Europe's website at: <u>https://bit.ly/AECallToAction2024</u>

Or you can access it via this QR code:



As at mid-July 2024, the Call to Action had attracted support from more than 7,400 individuals.

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# Sign the European Dementia Pledge 2024

#DementiaPledge2024

I pledge that, upon my election to the European Parliament, I will:

- 1. Join the European Alzheimer's Alliance
- 2. Support the campaign of Alzheimer Europe and its member organisations to make dementia a European priority, with specific actions in the following four key areas:
  - Ensuring dedicated EU funding for dementia-focused research across all disciplines, commensurate with the societal and economic cost associated with dementia
  - Responding to the scale of dementia as a health challenge by prioritising the condition as part of the next health programme of the EU
  - Acknowledging dementia as a disability, affording people with dementia the rights guaranteed under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
  - Undertaking focused work at an EU level to provide greater support and protections for carers

The third strand of Alzheimer Europe's campaign was its direct appeal to candidates standing in the European Parliament Elections 2024, calling on them to support making dementia a European priority by asking them to sign the Dementia Pledge 2024. Candidates who signed the Dementia Pledge committed to joining the European Alzheimer's Alliance (EAA), upon election, and to prioritising dementia during their work as parliamentarians.

Members of the European Parliament (MEPs) have the opportunity to play a key role in prioritising dementia in a number of ways, including:

- Asking questions of (prospective) Commissioners with responsibility for policy areas such Health, Research and Social Affairs, to ensure dementia is prioritised
- Using their position as members of European Parliament committees or as Rapporteurs in order to improve legislation which will affect people with dementia and their carers
- Raising awareness through their communications activities to colleagues and stakeholders to ensure dementia is understood and addressed at a European level.

The Pledge and signatories can be viewed on Alzheimer Europe's website at:

#### https://bit.ly/DementiaPledge2024

# 19 March 2024 - MEPs attend Alzheimer Europe's reception at the European Parliament in support of the Dementia Pledge 2024 campaign

As part of its Dementia Pledge 2024 and wider EU campaign, Alzheimer Europe invited MEPs to a special reception on 19 March 2024, between 18.00 and 19.30, in the Members' Salon in the European Parliament, at an event hosted by MEPs Milan Brglez (Slovenia), Deirdre Clune (Ireland), Tilly Metz (Luxembourg) and Sirpa Pietikäinen (Finland).

Jean Georges, Executive Director, Alzheimer Europe welcomed around 80 guests to the event, including MEPs, representatives from national members associations, members of the EWGPWD, and Alzheimer Europe Board and staff members. He outlined the priorities of the Helsinki Manifesto, inviting MEPs to sign the Dementia Pledge.

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He also welcomed the three host MEPs in attendance, Milan Brglez, Deirdre Clune and Tilly Metz to address the room, sharing their perspectives on the importance of the campaign and of prioritising dementia both at national and EU level.

During the reception, there was an opportunity for MEPs present to sign a large-scale version of Alzheimer Europe's Dementia Pledge 2024.

Additionally, MEPs had the opportunity to meet representatives of national Alzheimer associations, people living with dementia and carers of people with dementia, to hear first-hand their priorities and how policymakers can help prioritise dementia.



# 9 June 2024 – Dementia Pledge 2024 draws to a close after elections

Following the European Parliament elections between 6 and 9 June, Alzheimer Europe's #DementiaPledge2024 campaign drew to a close. With 304 candidates signed up to the pledge, this arm of the campaign broke the organisation's previous record of 230 candidates who signed up in the run-up to the 2019 European Parliament elections. Alzheimer Europe is hugely grateful to all of the associations who supported this part of the campaign, contacted candidates and played an integral role in making the pledge such a success! Additionally, Alzheimer Europe would like to thank the members of the EWGPWD and the EDCWG for their contributions to the campaign. They were instrumental in helping to send a strong message to parliamentary candidates that dementia needs to be a priority during the coming term.

#### 19 July – Looking ahead: Next steps for the campaign

During the next few weeks, Alzheimer Europe and its national member associations across Europe will write to elected candidates, asking them to follow up on their commitment, as well as asking members to make contact and establish a closer connection between MEPs and national Alzheimer's organisations, working together for a better future for people with dementia and carers in Europe.

Alzheimer Europe will also work during the summer to re-establish the EAA and will announce the new group. Following the Dementia Pledge 2024 campaign and the European Parliament election results, the organisation currently expect upwards of 70 members for this new incarnation of the EAA, which is a multinational and cross-party group that brings together MEPs to support European citizens living with Alzheimer's disease or another form of dementia, as well as their supporters/carers. For a detailed breakdown of the MEPs elected in each country, more information is available on the European Parliament website: <u>https://election-results.eu/</u>

The campaign does not end there, as the organisation continues to seek endorsements from national and European organisations for its Helsinki Manifesto, as well as the support of members of the public for its Call to Action. This campaigning will continue until December 2024 and the policy work emerging from the Helsinki Manifesto will continue for the next five years (2024-2029)

Find out more about the campaign, here: <u>https://www.alzheimer-europe.org/policy/campaign/alzheimer-europe-election-campaign-2024together</u> MEPs to support European citizens living with Alzheimer's disease or another form of dementia, as well as their supporters/carers. For a

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