



**Alzheimer's Disease  
International**

*The global voice on dementia*

# From Plan to Impact VIII

## *Time to deliver*



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## Contents

Foreword.....	4
Executive summary .....	8
Key messages.....	9
Introduction.....	12
Methodology.....	18
<b>CHAPTER 1</b>	
Dementia as a public health priority.....	21
<b>CHAPTER 2</b>	
Dementia awareness and friendliness.....	26
<b>CHAPTER 3</b>	
Dementia risk reduction.....	31
<b>CHAPTER 4</b>	
Diagnosis, treatment, care, and support.....	36
<b>CHAPTER 5</b>	
Support for dementia carers.....	41
<b>CHAPTER 6</b>	
Information systems for dementia.....	47
<b>CHAPTER 7</b>	
Dementia research and innovation.....	52
Report summary.....	58
Appendix A.....	59
Appendix B.....	64



## Foreword



Last year, while attending a three-day dementia conference in Xi'an, China, I was struck by how many of us were gathered there from all over the world, witnessing the development of what could possibly be the most ambitious national dementia plan in the world in terms of scale. One night, a group of us ventured out for dinner and soon realised that not one of us

spoke a single word of Chinese. Had it not been for a kind Singaporean who came to our rescue, we would have been lost – and very hungry! That trip was a real lesson on how vast and diverse the world is, how we can all get lost not matter how savvy we think we are, how kindness can save the day, and how much fun can be had even when we are exhausted, just by opening our minds and enjoying otherness.

We are all different, shaped by our cultures and our lived experiences, but it is our common purpose and common ground that unite us. Alzheimer's Disease International was founded 41 years ago to break barriers, explore and celebrate the differences and the similarities between us all, and to learn from them. This has made us stronger and has enabled us to improve and elevate our support of people living with dementia and their care partners.

The values of diversity and inclusion that have been our guiding lights for years are right now under serious threat. For the first time, I am truly worried that the critical work happening in dementia research, which has been an incredible source of hope, may possibly come to a halt.

We all know that science does not and must not have barriers. ADI has advocated passionately for more science and innovation to occur in lower- and middle-income countries as it relates to dementia – but this nascent and critical area of work is at risk. Countless projects are having to pull the plug on work that could hold the key to future advances in dementia treatment.

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Without the Global action plan, we would lose a precious tool to advocate on behalf of the weakest amongst us.

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Funding cuts to the World Health Organization (WHO) are also seriously bad news for our movement. The WHO remains the only forum where governments come together and discuss with real interest and expertise how to improve the health and living conditions of their populations. The dedicated and meticulous work of our colleagues at the WHO has been instrumental in getting the concept of national dementia plans up and running.

For the past 18 months, ADI has worked energetically to ensure that the WHO's Global action plan on the public health response to dementia 2017-2025 is renewed. In January 2025, 22 governments backed our plea to extend the plan until 2031 – but since then, uncertainty has reigned over whether this will go through. The Global action plan – which has been the focus of the From Plan to Impact report and, more critically, of ADI's work long before it was approved eight years ago – is at risk. This report will be released only a few days before the vote. If it is in your power to do something about it, please help us. We have written and spoken tirelessly to scores of governments, but it won't get done unless enough member states are willing to stand up and shift the tides.

Without the Global action plan, we would lose a precious tool to advocate on behalf of the weakest amongst us. We would lose the leverage to engage with governments productively on the development of their national dementia plans and to help them understand the critical societal implications of neglecting dementia in this era of ever-ageing populations, as dementia is fast becoming one of the leading causes of death in a growing number of countries.<sup>1</sup>

If dementia is no longer deemed a public health priority, awareness raising, risk reduction, diagnostics, treatment, care, and support will all suffer. Every year, I see how one action area of the plan gains more traction than the others. While all progress is great, these issues are all linked and need to be moved forward together, not just one at a time, to succeed and prioritise the wellbeing of the people who are ultimately the true beneficiaries of our work: people living with dementia and their care partners.

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<sup>1</sup> Arthurton, L., Barbarino, P., Anderson, R. et al. Dementia is a neglected noncommunicable disease and leading cause of death. *Nat Rev Neurol* 21, 63–64 (2025). <https://doi.org/10.1038/s41582-024-01051-w>



For example, brain health and life-course dementia risk reduction are incredibly important. Addressing modifiable risk factors could reduce or delay up to 45 percent of dementia cases,<sup>2</sup> as ADI detailed in its World Alzheimer Report on the topic in 2023.<sup>3</sup> But if we only plan for what may happen in 30 years' time and not for what is happening now, we would be neglecting our duty of care.

Another example: if, thanks to new emerging therapies, we increase the diagnostic and treatment capacity of every nation, we would be taking a huge step forward. However, if only a small segment of people living with dementia are eligible for existing disease-modifying treatments – where will the others turn?

In short, we still need far more care provision, which remains inadequate and patchy in much of the world. Care and support are how ADI's member associations across the globe have become such precious and useful resources to families wherever they live. These initiatives would benefit from scaling up and being applied at the local level everywhere.

There is still a long way to go, but, as ever, we all have a role to play to help resolve what I call the jigsaw puzzle of dementia. It is not easy, but together we have incredible strength, resilience, and knowledge.

Yet I still believe that civil society cannot resolve this herculean task on its own. Governments are a critical part of our path to success, and they must be persuaded to come on board.

Some trailblazing governments have shown us that this is possible, a number of which you will find in the pages of this report. Be inspired. Together we will succeed.



**Paola Barbarino**  
Chief Executive Officer  
London, May 2025

<sup>2</sup> Livingston, G. et al., Dementia prevention, intervention, and care : 2024 report of the *Lancet* standing Commission. The *Lancet*, Volume 404, Issue 10452, 572-628.

<sup>3</sup> Long, S., Benoit, C., Weidner, W. 2023. World Alzheimer Report 2023: *Reducing dementia risk: never too early, never too late*. London, England: Alzheimer's Disease International.

## Reflecting on eight years of the Global action plan on dementia: an international perspective

In a landmark decision in 2017, WHO member states unanimously adopted the Global action plan on the Public health response to dementia 2017–2025<sup>1</sup> committing to ambitious national responses to tackle dementia worldwide. As the seventh leading cause of death globally, dementia accounts for 30 percent of disability-adjusted life years among neurological conditions, underscoring its status as a global health priority.<sup>2</sup>

Since the plan's inception, significant strides have been made. Advocacy, scientific advances, and cross-sectoral collaboration have bolstered national and international responses, encouraging the exploration of innovative solutions to address existing gaps.<sup>2</sup>

To monitor the plan's progress globally, the WHO launched the Global Dementia Observatory<sup>3</sup> (GDO) in 2017. The GDO collects country-specific information across three strategic domains: policy, service delivery, and information and research. This data enables countries to perform comprehensive situational analyses to identify gaps and areas for national level strengthening. To support countries in addressing identified gaps, the WHO developed the GDO Knowledge Exchange Platform.<sup>4</sup> The platform aims to facilitate bidirectional knowledge exchange, foster mutual learning, and strengthen countries' and communities' capacity by making quality-checked resources available free of charge.

The first round of GDO data collection (2018–2020) informed the development of the 2021 Global status report on the public health response to dementia<sup>5</sup> and subsequent progress reports to the World Health Assembly.<sup>6,7</sup> Compared to the first round of GDO data collection, significantly more lower- and middle-income countries (LMICs) participated in the second data collection round (2024–2025).<sup>2</sup> Increased participation

of LMICs in data collection efforts makes GDO data more globally representative and highlights growing awareness and recognition of dementia as a public health priority.

Despite these efforts, progress to implement the global action plan has been slow, with implementation challenges often hampered by limited resources and competing priorities. As a result, none of the global targets are on track to be met by the end of 2025. GDO data indicates, however, that countries with dementia plans – either stand-alone or integrated – are more likely to meet other key dementia targets,<sup>2</sup> highlighting the importance of formulating robust national responses to dementia.

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So where do we stand after eight years of concerted action?

**1. Raising awareness:** Globally, significant efforts have been made towards raising dementia awareness and creating dementia-inclusive communities. To this end, the Region of the Americas partnered with Alzheimer's Disease International for month-long dementia-awareness campaigns in 2019<sup>8</sup> and 2024.<sup>9</sup> Furthermore, linking awareness and dementia-inclusive initiatives to the Global Network for Age-Friendly Cities and Communities<sup>10</sup> and the United Nations

<sup>1</sup> World Health Organization. (2017). Global action plan on the public health response to dementia 2017–2025.

<https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025>

<sup>2</sup> World Health Organization. (2025). Executive Board 156/36- Global strategies or action plans that are scheduled to expire within one year: Global action plan on the public health response to dementia 2017–2025. [https://apps.who.int/gb/ebwha/pdf\\_files/EB156/B156\\_36-en.pdf](https://apps.who.int/gb/ebwha/pdf_files/EB156/B156_36-en.pdf)

<sup>3</sup> World Health Organization. (2017). Global Dementia Observatory. <https://www.who.int/data/gho/data/themes/global-dementia-observatory-gdo>

<sup>4</sup> World Health Organization. (2021). Global Dementia Observatory Knowledge Exchange Platform. [www.globaldementia.org](http://www.globaldementia.org)

<sup>5</sup> World Health Organization. (2021). Global status report on the public health response to dementia.

<https://www.who.int/publications/i/item/9789240033245>

<sup>6</sup> World Health Organization. (2020). Seventy Third World Health Assembly. Progress reports A73/32.

[https://apps.who.int/gb/ebwha/pdf\\_files/WHA73/A73\\_32-en.pdf](https://apps.who.int/gb/ebwha/pdf_files/WHA73/A73_32-en.pdf)

<sup>7</sup> World Health Organization. (2023). Seventy Sixth World Health Assembly. Progress reports A76/37.

[https://apps.who.int/gb/ebwha/pdf\\_files/WHA76/A76\\_37-en.pdf](https://apps.who.int/gb/ebwha/pdf_files/WHA76/A76_37-en.pdf)

<sup>8</sup> Pan American Health Organization. (2019). Let's talk about dementia. <https://www.paho.org/lets-talk-about-dementia/>

<sup>9</sup> Pan American Health Organization. (2024). Time to act on dementia. <https://www.paho.org/en/campaigns/time-to-act-on-dementia>

<sup>10</sup> World Health Organization. Global network for age-friendly cities and communities. <https://extranet.who.int/agefriendlyworld/who-network/>

Decade of Healthy Ageing<sup>11</sup> provides great opportunities for scaling.

2. **Promoting risk reduction:** Despite advances in our understanding of dementia risk factors, risk reduction messaging is underutilised. To support risk-reduction efforts, the WHO commenced the process of updating its guidelines on risk reduction for cognitive decline and dementia<sup>12</sup> to reflect the latest evidence, consider population-level interventions, and include new risk factors.
3. **Support for carers:** Community-based services for dementia are more common in urban areas, especially in high-income countries, leaving rural populations underserved.<sup>13</sup> Support for dementia carers also varies, with high-income countries offering more comprehensive services compared to LMICs. To facilitate global access to caregiver support, in 2017 WHO launched iSupport,<sup>14</sup> a training and support programme for carers of people living with dementia. To support implementation efforts, foster mutual learning, and harmonise research efforts, the WHO also established an international iSupport network involving implementation teams from 40 countries.<sup>2</sup> To date, iSupport has been used to support carers in 57 countries.<sup>2</sup>
4. **Improved diagnosis:** Countries' ability to report diagnostic rates for dementia vary widely. With a significant number of LMICs indicating not being able to report dementia diagnostic rates, access to timely dementia diagnosis continues to be restricted globally. To support the development of diagnostic tools that are safe, effective, and accessible to all, the WHO developed preferred product characteristics for blood-based biomarkers used to aid the diagnosis of Alzheimer disease in 2024.<sup>15</sup>
5. **Promoting research:** Research agendas dedicated to dementia are more prevalent in high-income countries, highlighting a disparity in the focus and resources allocated to understanding and addressing dementia globally. To support the prioritisation and coordination of dementia research globally, WHO published a blueprint for dementia research in 2022.<sup>16</sup> The Dementia Research Dialogues initiative was launched in 2024,<sup>17</sup> aiming to facilitate the implementation of the blueprint and support the translation of research into practice and policy.

As the global population ages, it is essential to continue building on the progress made by implementing existing resources and ensuring equitable access to new tools and therapies. All actions outlined in the global action plan for countries and partners are as relevant today as they were in 2017.

To achieve the vision of the Global dementia action plan beyond 2025, countries must prioritise dementia in local and global agendas and commit resources to its implementation. With advances in policy, service delivery, information, and research, the extension of the Global action plan presents a timely opportunity to leverage advances to meet global dementia targets. Furthermore, an extension can also strengthen national dementia responses by aligning goals and leveraging the implementation of relevant global mandates, including the Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031.<sup>18</sup>

Given general global instability, now more than ever we must work collaboratively to ensure that no one is left behind. To this end, in 2025, the WHO published a global evidence review on health and migration focusing on refugees and migrants living with dementia.<sup>19</sup> The global evidence review and existing technical products, alongside the global dementia action plan, can help create inclusive, evidence-informed policies.

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## Now more than ever we must work collaboratively to ensure that no one is left behind.

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The past eight years have emphasised that meaningful and impactful change necessitates multisectoral collaboration. The extension of the global action plan reinforces the importance of working together as a global community to realise the vision of the plan to prevent dementia and ensure that people living with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy, and equality.

**World Health Organization Brain Health Unit**

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<sup>11</sup> Decade of healthy ageing- The platform. <https://www.decadeofhealthyageing.org/>

<sup>12</sup> World Health Organization. (2019). Risk reduction of cognitive decline and dementia: WHO guidelines. <https://www.who.int/publications/i/item/978924155054>

<sup>13</sup> Seeher K, Cataldi R, Dua T, and Kestel D: Inequitable access to dementia diagnosis and care in low-resource settings – a global perspective. *The Clinical Gerontologist, Volume 46*, 2023 – Issue 2, Pages 133–137. <http://dx.doi.org/10.1080/07317115.2022.2054391>.

<sup>14</sup> World Health Organization. iSupport. [www.iSupportfordementia.org](http://www.iSupportfordementia.org)

<sup>15</sup> World Health Organization. (2024). Preferred product characteristics of blood-based biomarker diagnostics for Alzheimer disease. <https://www.who.int/publications/i/item/9789240099067>

<sup>16</sup> World Health Organization. (2022). A blueprint for dementia research. <https://www.who.int/publications/i/item/9789240058248>

<sup>17</sup> World Health Organization. (2024). WHO Dementia Research Dialogues: Where Blueprint Meets Practice. <https://globaldementia.org/en/researchdialogues>

<sup>18</sup> World Health Organization. (2023). Intersectoral global action plan on epilepsy and other neurological disorders. <https://www.who.int/publications/i/item/9789240076624>

<sup>19</sup> Dementia in refugees and migrants: epidemiology, public health implications and global responses. Geneva: World Health Organization; 2024 (Global Evidence Review on Health and Migration (GEHM) series). Licence: CC BY-NC-SA 3.0 IGO.



## Executive summary

In 2017, the World Health Organization's (WHO) 194 member states unanimously adopted the Global action plan on the public health response to dementia,<sup>1</sup> an eight-year strategy aiming to tackle the global health challenge posed by dementia, a condition that affected 55 million people in 2019 and is expected to skyrocket to 139 million people worldwide by 2050.<sup>2</sup> The costs associated with the condition are expected to soar from US\$1.3 trillion per year in 2019 to a projected \$2.8 trillion by 2030.

Since 2018, Alzheimer's Disease International (ADI) has published its yearly From Plan to Impact report taking stock of the progress made by member states and highlighting best practices meeting the targets set by the Global action plan. The seven chapters of the report address the seven action areas of the Global action plan: dementia as a public health priority; awareness and friendliness; risk reduction; diagnosis, treatment, care, and support; support for dementia carers; information systems; and research and innovation.

The year 2025 officially marks the end of the initial eight-year period of the Global action plan, but its existence is no less essential than it was when it first began – to the contrary. To mark this milestone, this edition of From Plan to Impact has taken a slightly different approach. Instead of looking back at the past year alone, the seven chapters of this report consist of two essays each analysing the eight years of the Global action plan: one by a thought leader looking back at the progress, setbacks, and opportunities ahead for that specific action area; and another by a representative from a member state government looking at their own country's work, how the Global action plan has had an effect on their dementia policy efforts, and how their efforts can be emulated by other states.

The timespan of the Global action plan has seen incredible advances in dementia research, whether in mapping out risk factors for the condition, developing disease-modifying treatments, or finding more accessible and cost-effective methods to diagnose people earlier. On the policy front, this year has seen 55 national dementia plans put in place, the most plans ever recorded by ADI for From Plan to Impact.

While these achievements must be celebrated, the world continues to fall far short of its commitments. Stigma remains high globally, impeding access to diagnosis, care, and treatment. Research funding is under threat, endangering the momentum of



many studies and clinical trials that could lead to breakthroughs.

For several years, ADI has been advocating for the plan to be extended, so that its impact can continue to reverberate and reach more people living with dementia and their carers, who desperately need more support. The dementia advocacy community, of which ADI is a representative, sees the Global action plan on dementia as a lodestar that can guide states into enacting dementia policies that are comprehensive, multifaceted, and person-centred.

In May 2025, around the same time as this report is released, WHO member states are due to vote on whether or not to prolong the plan until 2031. The extension has been supported by a number of governments that understand the value of upholding the plan, but at the time of writing, we do not yet know how the vote will turn out.

What is for certain regardless of the outcome is that dementia will continue to strongly impact the lives of millions of people living with dementia, informal carers, health and care practitioners, and societies at large. This reality cannot be ignored or dismissed without bearing heavy costs for all.

<sup>1</sup> Global action plan on the public health response to dementia 2017–2025. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO

<sup>2</sup> <https://www.who.int/news-room/fact-sheets/detail/dementia>

## Key messages



- The number of national dementia plans (NDPs) implemented by WHO member states has risen since 2024 from 39 to 45. This equates to 30.8 percent of the 146 target, and only 23.2 percent of all 194 member states who agreed to implement plans in 2017. As of May 2025, 53 countries or territories (including non-WHO member states) had NDPs.
- Dementia plans across WHO member states include 21 in Europe, nine in the Americas, nine in the Western Pacific, four in the Eastern Mediterranean, two in Southeast Asia, and none in Africa.
- Twenty-one countries and territories are currently developing an NDP or are integrating dementia within a wider health plan, including 19 WHO member states.
- The Global action on the public health response to dementia has been an essential tool to advance dementia policy globally. Its impact at the international, national, and local levels cannot be understated, providing countries with a framework to build comprehensive dementia plans that address the multifaceted challenges inherent to this condition.
- Dementia is already a pressing public health concern and is set to become a full-blown global health crisis in the decades to come. The numbers paint a stark picture but need to be repeated. Dementia is the seventh leading cause of death globally, and the leading cause of death in many countries. According to the WHO, the number of people living with dementia is expected to rise from 55 million in 2019 to 139 million in 2050. The skyrocketing number of cases is predicted to lead to related annual costs rising from US\$1.3 trillion in 2019 to \$2.8 trillion by 2030, five short years from now. These worrying projections can be mitigated, but only through concerted, far-reaching efforts at every level.

## Recommendations

- In this eighth From Plan to Impact report marking the final chapter of the Global action plan's initial eight-year run, **ADI calls on WHO member states to vote to extend the Global action plan on dementia until 2031.** You will read in these pages how governments have not met the goals set by the plan; how stigma persists while diagnosis rates lag behind; how health systems remain unprepared to provide treatment and support to the growing number of people impacted by dementia globally. But you will also read about six new national dementia plans launched this year; how advances in technology are making precision diagnosis and risk reduction a reality; and how new treatments are a reality for some and on the horizon for others. At last, we are seeing real momentum in the dementia community. In these turbulent times, when geopolitical conflicts distract policymakers and the depletion of research funding threatens important advances in science, we must steel our nerves, redouble our efforts, and exert more energy to increase the velocity of innovation and change. The Global action plan is our vehicle for that change and it's time we all got on board.
- If the World Health Assembly passes the extension of the Global action plan on dementia that ADI and fellow advocates have long fought for, this will mark a serious victory for the cause. But the fight will not be over, far from it. An extension of the plan should not be considered as permission for member states to sit back and forget about dementia for another six years until the clock runs out again. This should not be a time for complacency. **This extension should be seen as a precious opportunity to make up for lost time and live up to the commitments of the plan.** The Global action plan was devised as a roadmap to achieve better outcomes for people living with dementia, their caregivers, and societies at large; to let it gather dust on a shelf would be a tragic waste.
- ADI does not discount the possibility that WHO member states, overtaken by other priorities and concerns, may choose not to extend the Global action plan for dementia. Should this scenario come to pass, we must not succumb to defeatism. The lives of millions of people are in the balance, and their struggles will not disappear the day the Global action plan expires. Inertia is not an option – the economic and social costs of neglecting dementia as a serious public health issue are enormous. **Regardless of the outcome of the vote, dementia remains an undeniable public health crisis that must be addressed head on by governments and civil society, working hand in hand to secure better prospects for people living with dementia, today and tomorrow.**



## 7 action areas

**1** Dementia as a public health priority



**2** Dementia awareness and friendliness



**3** Dementia risk reduction



**4** Diagnosis, treatment, care, and support



**5** Support for dementia carers



**6** Information systems for dementia



**7** Dementia research and innovation



## Introduction

In 2018, Alzheimer's Disease International (ADI) created the From Plan to Impact report series to keep track of governments' advances relative to their commitments to the WHO Global action plan on the public health response to dementia.

The report was not only meant to tally progress, but also to showcase examples of good policy, research, and practice, encouraging states to adapt these efforts in their local contexts.

This year's edition, marking the end of the initial eight-year timeframe of the plan, offers a final assessment of the progress, opportunities, and setbacks we have seen during the scope of the Global action plan.

As this report goes to print, member states are scheduled to vote on an extension of the plan during the World Health Assembly in May 2025. ADI has been tirelessly advocating for the plan to be extended to maintain crucial policy momentum to advance research and provide people living with dementia, and formal and informal carers with the best diagnosis, care, treatment, and support possible.

But beyond the obvious importance of the GAP as a policy framework, we need to point out that it is an essential *advocacy tool* at the global, regional, and local levels. It provides a mechanism for ADI and others to push for change at the highest level. It is a tool for regional collaboration and cohesion around a chronic condition affecting the Global South most profoundly. It enables ADI, along with our local members, to go straight to governments and challenge their lack of support for people affected by dementia. If we lose this important policy inroad, we cut off an avenue for change that could have dire consequences for decades. Now is the time to steel our nerve and demand that dementia become a true global priority.

It must be acknowledged that the global circumstances of the past eight years have made it difficult for the Global action plan to reach its full potential. The COVID-19 pandemic, economic downturns, wars, and

the recent decimation of research funding have created a climate of uncertainty in which dementia has fallen by the wayside amid other pressing concerns.

Yet the facts are unambiguous: dementia is currently the seventh leading cause of death in the world, and, in a growing number of countries, it has become the leading cause of death. According to the WHO, the number of people living with dementia is expected to rise from 55 million in 2019 to 139 million in 2050. Six out of ten people living with dementia are believed to be living in lower- and middle-income countries (LMICs) with limited access to diagnosis, treatment, and resources. The rise in dementia cases is predicted to lead to an associated increase in the related annual costs from US\$1.3 trillion in 2019 to \$2.8 trillion by 2030.

We know dementia is not an easy or light issue. It forces us to reckon with the taboo topics of ageing and death. Its nature as a slow degenerative condition makes it hard to grasp the gravity and urgency it represents, leading many to sweep it under the carpet as a problem to deal with "later." But if left inadequately addressed, dementia will become the most pressing, and costly, health crisis of our time.

The time to prioritise dementia as a global community won't be decades down the line, when our societies are older than they are now and future generations and health systems struggle to face the magnitude of the challenge. *The time is now* – by laying the groundwork for a future where dementia is no longer seen as a death sentence rendering people affected by it expendable, but as the worthy focus of a collective duty of care.

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The time to prioritise dementia as a global community won't be decades down the line, when our societies are older than they are now and future generations and health systems struggle to face the magnitude of the challenge. *The time is now.*

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## What is a national dementia plan?

In 2017, the World Health Organization (WHO) adopted the Global action plan on the public health response to dementia, aiming to improve the lives of people with dementia and their carers, whilst mitigating the impact of dementia on communities and countries. Member states voted unanimously to accept and commit to the plan.

People living with dementia and their carers require specialised and multifaceted support throughout the progression of the condition. Identifying and addressing these needs requires action at the global, regional, national, and community levels.

The Global action plan identified seven key action areas that effective dementia policy should address, with Action area 1 encouraging member states to implement national dementia plans (NDPs) or strategies.

The WHO characterises national dementia plans as:<sup>1</sup>

*A dementia plan recognises the value of older people and those with dementia in society. It also asserts the need for policy change aimed at enhancing prevention, treatment and care for people with dementia and their carers through better integration of health and social sectors (i.e., long-term care). A dementia plan is a written document that provides the basis for action to be jointly taken by government and nongovernmental partners.*

*A comprehensive dementia plan identifies a vision for the future and a strategic framework, which highlight a common set of principles and objectives that guide action. It defines and prioritises action areas, identifies coordination responsibilities and mechanisms, and delineates targets to direct resources towards achieving objectives and measuring impact. Together, the main components of a dementia plan act to raise public awareness and create mutual understanding about dementia, address population needs, reduce the burden of dementia, and protect the human rights of people with dementia, their carers, and families.*



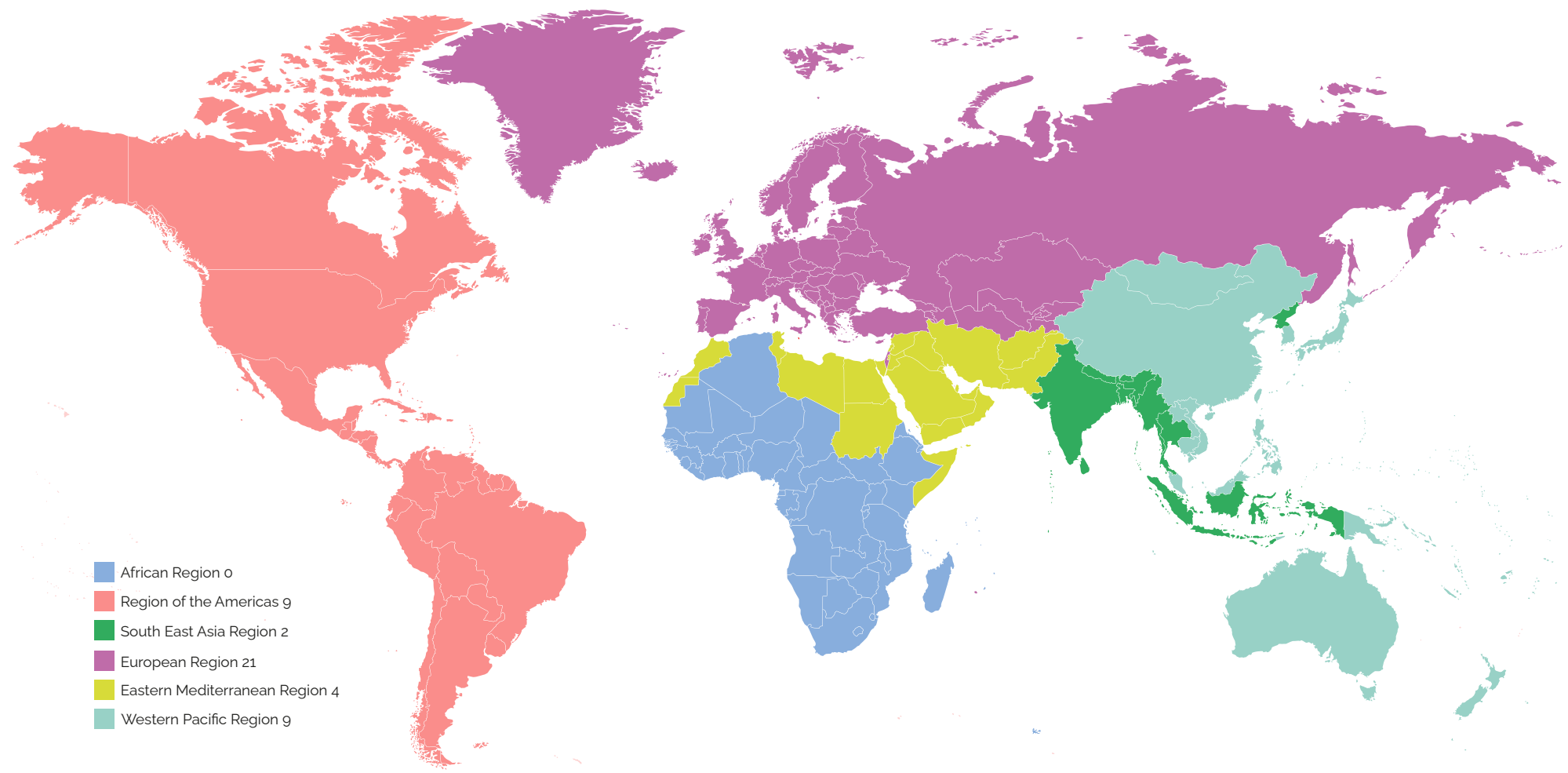
There are two main types of dementia plans: standalone and integrated. Standalone national dementia plans focus exclusively on dementia, while integrated plans incorporate dementia within broader policy frameworks addressing ageing, non-communicable diseases, mental health, or neurodegenerative disorders. Regardless of the approach chosen, governments should dedicate funding exclusively for dementia, as well as address as many of the seven action areas outlined in the Global action plan as possible to ensure effectiveness.

Due to the significance of dementia as a condition projected to affect 139 million people worldwide by 2050 and the complexities associated with care and support, ADI advocates for standalone national dementia plans encompassing all seven action areas of the Global action plan as the most robust way to manage the many challenges dementia poses to healthcare systems, governments and the people directly impacted by the condition. In order to be as effective as possible, these plans should be developed by expert multidisciplinary teams that include individuals with lived experience of dementia and their carers.

<sup>1</sup> Towards a dementia plan: a WHO guide. Geneva: World Health Organization; 2018. Licence: CC BY-NC-SA 3.0 IGO.

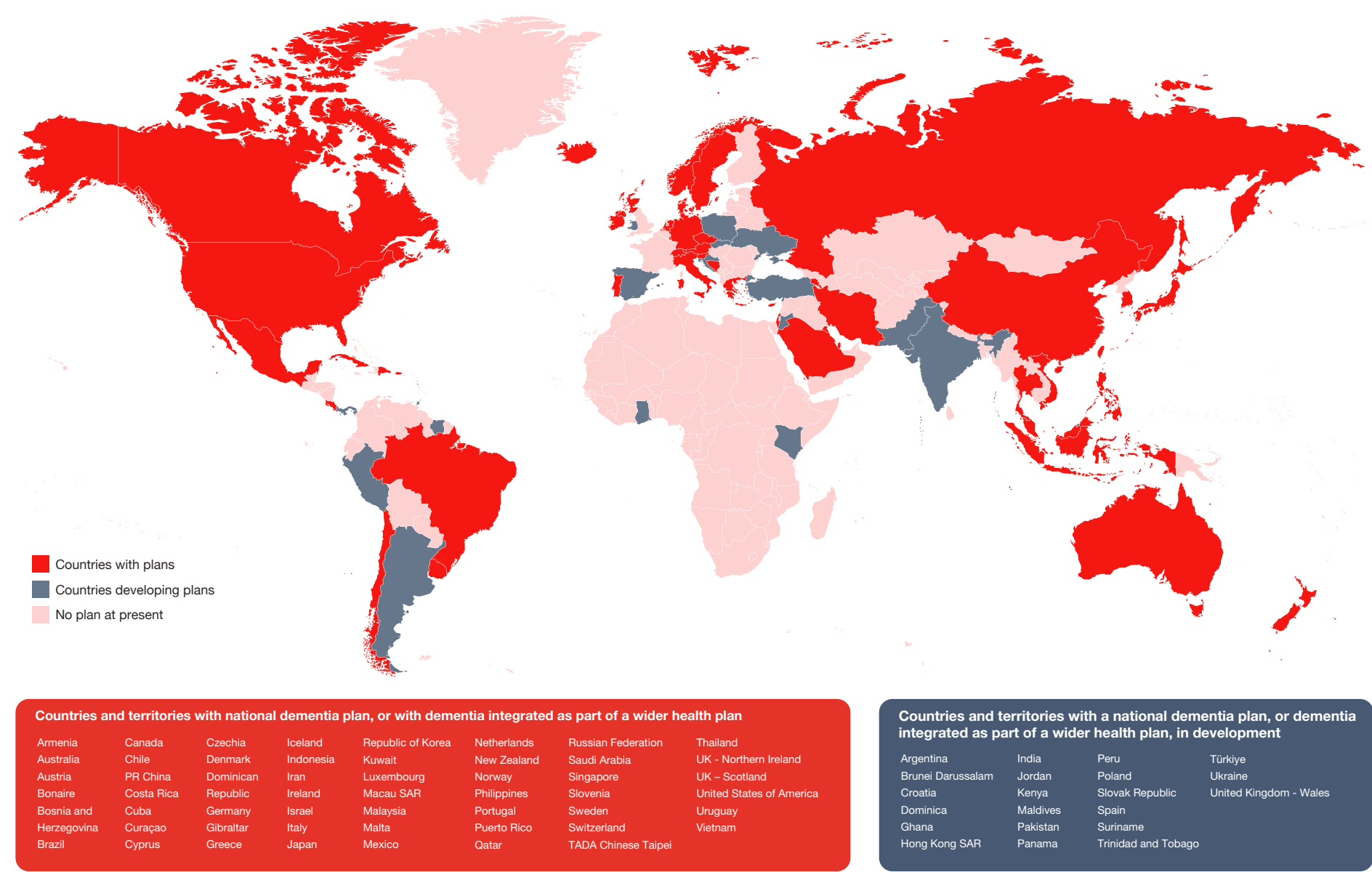


# National Dementia Plans by World Health Organization Region



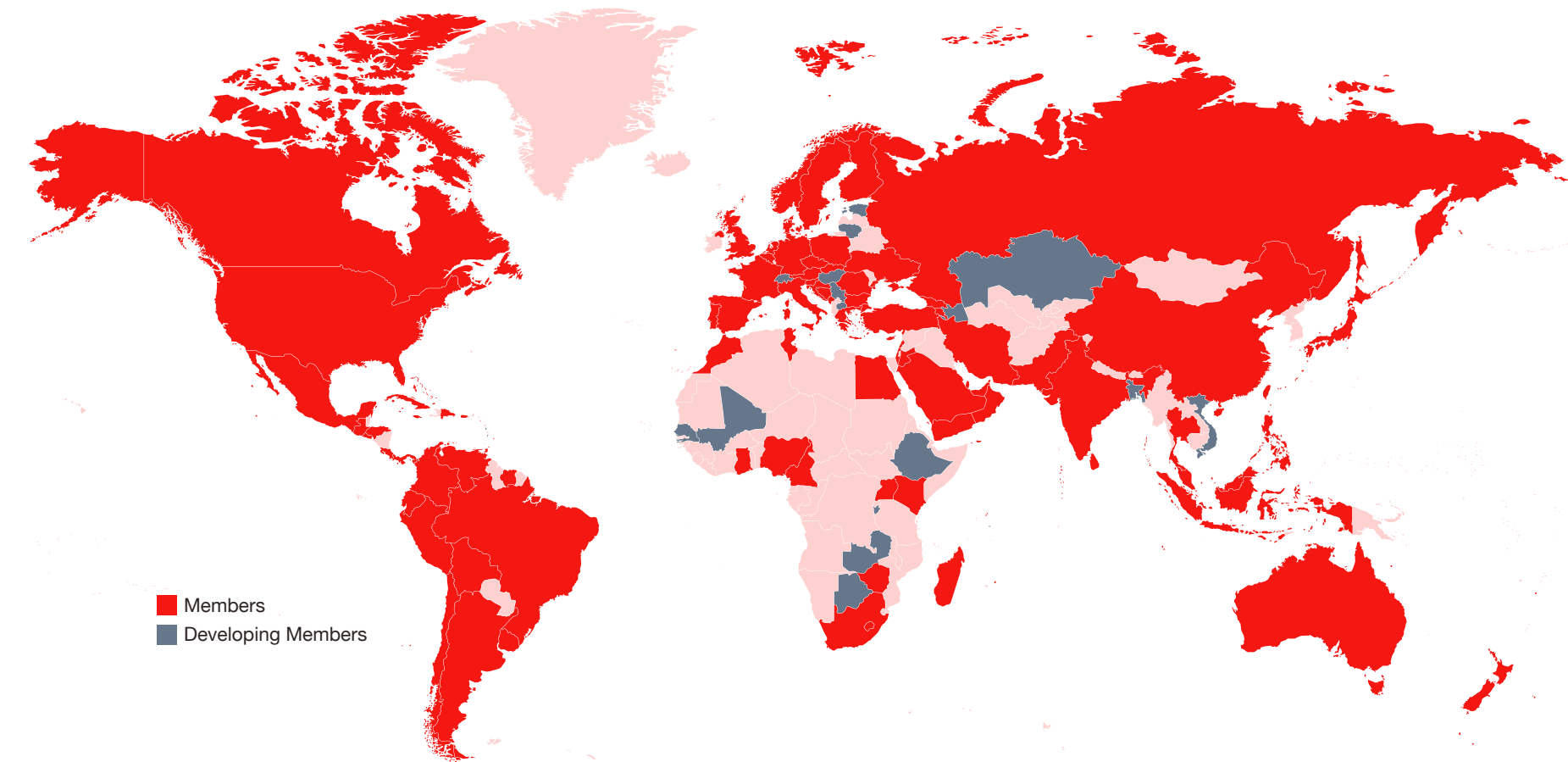
Based on information received from Alzheimer and dementia associations, May 2025

Current national dementia plans and plans in development



Based on information received from Alzheimer and dementia associations, April 2025

ADI Members and Developing Members (as of April 2025)



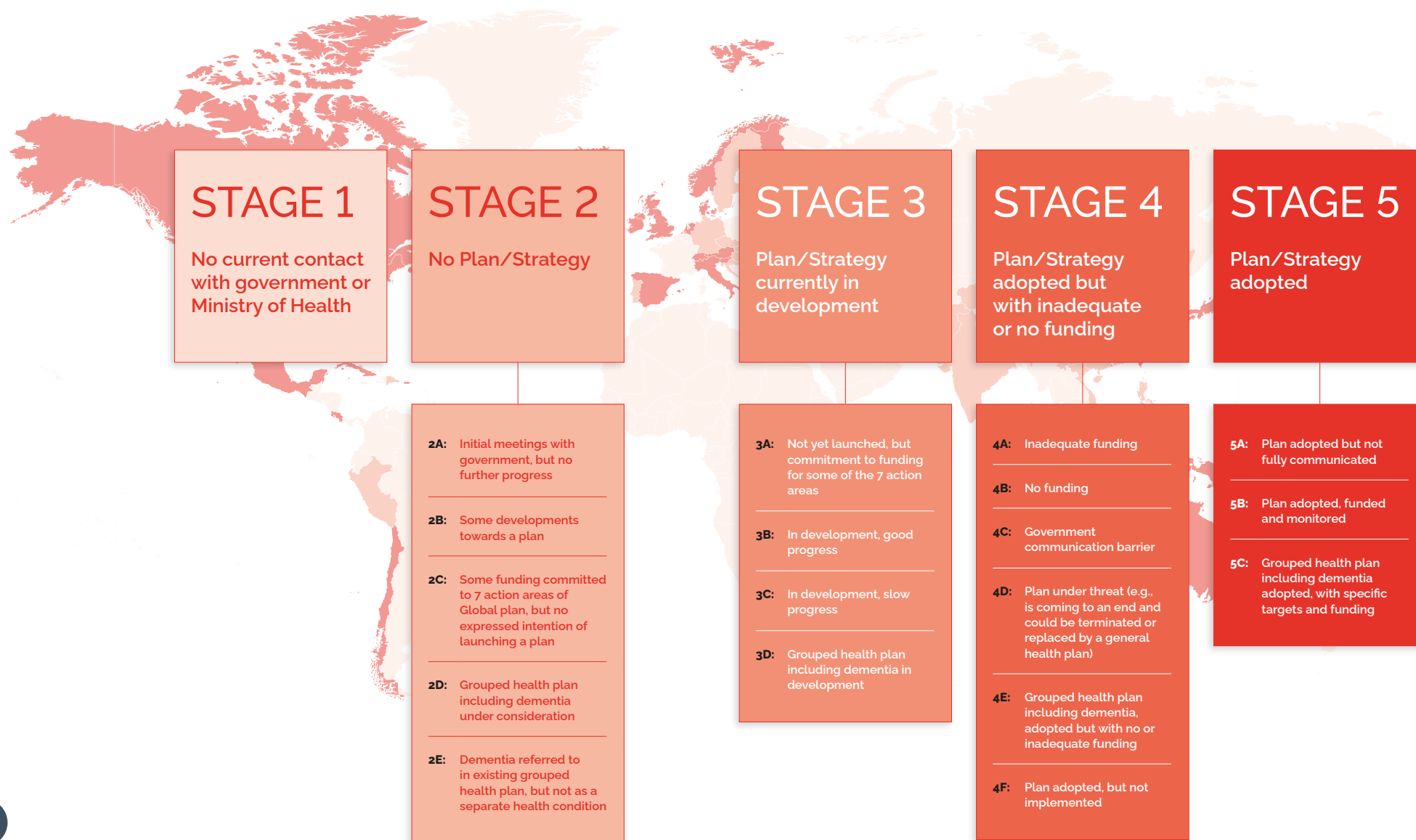
ADI Members

Argentina	Bosnia and Herzegovina	Colombia	Egypt	Guatemala	Jordan	Mexico	Peru	Singapore	TADA Chinese Taipei	Uruguay
Armenia	Brazil	Costa Rica	El Salvador	Honduras	Kenya	Montenegro	Philippines	Sint Maarten	Thailand	Venezuela
Australia	British Virgin Islands	Croatia	England, Wales, NI	Hong Kong SAR	Lebanon	Morocco	Poland	Slovak Republic	Tonga	Yemen
Austria	Brunei Darussalam	Cuba	Finland	India	Lesotho	Netherlands	Portugal	Slovenia	Trinidad and Tobago	Zimbabwe
The Bahamas	Bulgaria	Curaçao	France	Indonesia	Macau SAR	New Zealand	Puerto Rico	South Africa	Tunisia	
Barbados	Cameroon	Cyprus	Georgia	Iran	Madagascar	Nigeria	Qatar	Spain	Türkiye	
Belgium	Canada	Czech Republic	Germany	Israel	Malaysia	Norway	Romania	Sri Lanka	Uganda	
Bermuda	Cayman Islands	Denmark	Ghana	Italy	Maldives	Oman	Russia	St Kitts and Nevis	Ukraine	
Bolivia	Chile	Dominican Republic	Gibraltar	Jamaica	Malta	Pakistan	Saudi Arabia	Suriname	United Arab Emirates	
Bonaire	PR China	Ecuador	Greece	Japan	Mauritius	Panama	Scotland	Sweden	United States	

ADI Developing Members

Aruba	Kazakhstan	Switzerland
Azerbaijan	Lithuania	Vietnam
Bangladesh	Mali	Zambia
Botswana	North Macedonia	
Burundi	Saint Lucia	
Dominica	Saint Vincent & the Grenadines	
Estonia	Senegal	
Ethiopia	Serbia	
Grenada	United Arab Emirates	
Hungary	Seychelles	

## Stages of national dementia plan development



## Methodology

In order to measure states' activity against the WHO Global action plan, ADI distributed a survey in January 2025 to our 105 member associations and 22 developing associations in ADI's Membership Development Programme.

Each member association is a national Alzheimer or dementia organisation in that country or territory. A developing association refers to organisations that are going through ADI's two-year Membership Development Programme and are aiming to demonstrate that they meet the required membership criteria.

The survey asked about the status of a national dementia plan, or if dementia was integrated into another policy area (Action area 1) in each country based on five stages (listed in the graphic on page 17). The survey also asked for policy updates in relation to the remaining six action areas, and whether the associations had observed that the Global action plan had an impact on their country's dementia policy. The survey received an 85 percent response rate, with a total of 108 replies. Where a survey response was not received, ADI conducted desk research in order to estimate a stage.

## Report structure

This report is divided into seven chapters, each one based on an action area of the WHO Global action plan on the public health response to dementia:

1. Dementia as a public health priority
2. Dementia awareness and friendliness
3. Dementia risk reduction
4. Diagnosis, treatment, care, and support
5. Support for dementia carers
6. Information systems for dementia
7. Dementia research and innovation

With the decision about the plan's extension hanging in the balance, ADI has decided to change the structure and focus of our From Plan to Impact report this year. We have distilled each chapter into two key essays: one from a thought leader in the field examining the progress, setbacks, and opportunities that have arisen in that action area during the span of time covered by the Global action plan; and the other by a government representative from a WHO member state talking about how their country has implemented efforts in this action area, and what lessons can be learned by other governments seeking to implement policies in that field.



## The impact of the Global action plan on dementia in advocates' own words

Every year, ADI reaches out to its over 100 member associations, representing Alzheimer's and dementia organisations across the world, for their insights into their countries' progress – or lack thereof – meeting the targets of the Global action plan on dementia.

This year, we asked both our member associations and people with lived experience of dementia on the Global Dementia Expert Panel (GDEP) the following question:

**In your view, has the Global action plan on dementia had an effect on your government's approach to dementia? If so, how?**

Many felt that their governments had not particularly taken the Global action plan into consideration amid broader indifference to dementia – but for countless others, the plan was an invaluable tool for advocacy and inspired tangible change, notably with the elaboration of national dementia plans.

Even among those who did not feel the impact of the Global action plan in their country between 2017 and 2025, hope remained that the extension of the plan could provide a second chance for their governments to finally make good on their commitments.

### Belgium (Stage 2C)



"Not yet in tangible policy actions, but we believe that the extension will be a crucial step to turn ambitions into practice. The seven key areas of the Global action plan can and should give guidance to the priorities of a first national dementia strategy in our country."

### Cuba (Stage 4)



"The Global action plan on dementia was the guide for the elaboration, implementation, and development of the national plan in our country. This strategy, promoted by Sección Cubana de la Enfermedad de Alzheimer (SCUAL) and endorsed by the Ministry of Health, was presented to the highest level of government and recognised as a priority needing attention within the Cuban health system. The Ministry of Public Health monitors its implementation on an annual basis."

### Brazil (Stage 4B)



"Although the Global action plan on dementia may have influenced the development of dementia policy in Brazil, it was largely driven by civil society movements and the efforts of the legislative branch, rather than direct actions from the executive government. While the government has acknowledged the need for action, the executive's response remains limited and insufficiently robust to create the necessary changes in policy and support systems."

### Jordan (Stage 3C)



"The Global action plan on dementia has emphasised the importance of collaboration and communication with other countries to learn from their successes. It has influenced our government's will to update policy and services for seniors to include dementia patients. The plan has also strengthened our advocacy efforts and aligned our goals with global standards."

### Brunei Darussalam (Stage 3D)



"Despite lack of a national dementia plan, the WHO Global action plan on dementia and the GDO progress indicators have been helpful in advocating for national initiatives for dementia within the Ministry of Health, as these are seen as targets for WHO member states to achieve."

## Kenya (Stage 3C)



"The global action plan has guided Kenya's efforts to draft a national dementia action plan that aligns with the WHO's objectives. The global framework has provided Alzheimer's and Dementia Organization Kenya (ADOK) and other stakeholders with a structured roadmap to advocate for better policies, services, and awareness.

The Global action plan on dementia has positively influenced policy development, advocacy, and awareness in Kenya, but its full potential remains unrealised due to resource constraints and competing health priorities. Continued focus on implementation is necessary to achieve meaningful impact for individuals and families affected by dementia."

## Thailand (Stage 5B)



"In 2017, we were invited to join a Ministry of Public Health (MoPH) session in which both academics and the ministry staff brainstormed on how to create dementia services in Thailand linked the Global action plan's seven action areas. After the pandemic, it felt that everyone in the MoPH turned their attention to COVID-19 instead of dementia."

## Ukraine (Stage 3B)



"The Global action plan has significantly supported our advocacy efforts. Mentioning Ukraine's obligation to develop a national dementia plan as a WHO member state immediately captured attention, serving as a powerful endorsement of our initiatives. It reinforced that our advocacy was not just an independent NGO effort, but a reminder of our country's commitment."

## Malaysia (Stage 5A)



"The extension of the Global action plan is crucial for countries in the initial stages of development. Without it, dementia is likely to be deprioritised, leaving countries without future strategies to push their global action plans."

## Yemen (Stage 2A)



"The Global action plan is in English, it first has to be in Arabic to be understood here. A presentation should be arranged to orient Yemeni health authorities and facilitate positive outcomes. Our association cannot do that without the support of a bigger influence like the WHO."

## Qatar (Stage 4E)



"The Global action plan enabled Qatar to have its first national dementia plan in 2018, becoming the first Arab nation to have a national dementia plan.

The first version of our plan was formatted within the principles of WHO's global dementia framework, and the second version took on the specific requirements highlighted by the WHO's newly revised Global Dementia Observatory Platform."

## Zimbabwe (Stage 2A)



"There is certainly more awareness in the country and many more people are coming forward for help and information from all parts of the country. We are making a difference, but it is not enough to help the hundreds and possibly thousands of people who are living with dementia and the effects it has on families and society as a whole."

# Chapter 1

## Dementia as a public health priority



**WHO target: 75% of countries (146 of 194) will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025.**

Since the very inception of the Global action plan, Action area 1 became, fundamentally, the *raison d'être* of the whole endeavour. Embracing the belief that dementia – a condition that affected 55 million people in 2020, a number that is projected to rise to at least 139 million by 2050 – represents a public health emergency that deserves to be taken seriously is the baseline to implementing meaningful policy changes at the local, national, and international levels.

And yet, the target of 146 WHO member states developing or implementing national policies, strategies, or frameworks for dementia was never reached – far from it. The year 2025 marks the highest number of national dementia plans in place since the beginning of the Global action plan; yet with only 45 member states currently having a national dementia policy in place, we are far from the initial goal set by the plan.

In his essay, ADI Deputy CEO and Head of Policy and Communications Chris Lynch looks back at the first eight years of the Global action plan, which align with his time in the organisation. "Time, from a policy perspective, can feel glacially slow," he reflects. "For someone living with dementia, their friends, and families, time is the most precious commodity."

This crucial discrepancy between the urgency of addressing dementia at the individual level and the time necessary for governments to examine the issue, draw up policies, and implement them can lead to understandable frustration. When national dementia plans lapse without follow-up – due to a host of reasons such as a change in government, economic or political crises, or the impact of the COVID-19 pandemic – untold numbers of people living with dementia, their loved ones, and health and care professionals are affected.

Thankfully, some states understand the profound importance of addressing dementia. Yoshimasa Tosaka, counsellor for general policy planning for Japan's Ministry of Health, Labour, and Welfare, recounts in his essay how his country has prioritised dementia through a multifaceted approach that actively includes the voices of people living with dementia in the development of policy.

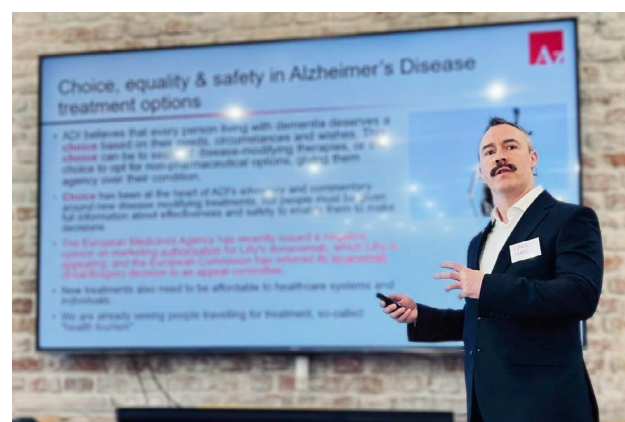
Holding the record for the world's oldest population, Japan should serve as an example for our increasingly ageing societies. Dementia is set to become the leading cause of death in many countries in years to come. Only through proactive, thorough, and inclusive planning can the multifaceted consequences of this condition be addressed sensitively and effectively for the benefit of all.

## Making dementia a public health priority: the long road ahead

The eight-year duration of the World Health Organization's (WHO) Global action plan on the public health response to dementia (GAP)<sup>1</sup> has mirrored my own time at Alzheimer's Disease International (ADI) as deputy CEO and director of policy and communications. Starting my role in 2017 as the global plan was launched, my primary policy objective was – and remains – dementia plan implementation. Eight years later, I find myself questioning my own impact on the goals of the action plan, especially in light of the fact that three members of my family have been diagnosed with Alzheimer's disease. Simultaneously, I ponder why so few governments have made good on their 2017 commitment to make dementia a priority and develop strategic national responses.

Time, from a policy perspective, can feel glacially slow. For someone living with dementia, their friends, and families, time is the most precious commodity; every minute counts. Identifying dementia as a global health priority and making it the first action area of the global action plan infers an appreciation, not just of the scale of the challenge, but of the urgency of responding to what is undoubtedly one of the greatest health and care crises of our time. The primary goal of the global plan is to improve the lives of people with dementia, their carers, and families, while decreasing the impact dementia has on them as well as on communities and countries. An eight-year time period was identified to do this, but despite some key progress, this initial timeframe is ending with none of the targets of the global plan being met.

Looking at how governments have responded to the injunctions of the action plan brings into stark relief the different ways in which we value time. The action plan target is 146 national plans, the equivalent of 75 percent of the member states that unanimously adopted the global plan.<sup>1</sup> Is it acceptable that only 45 member states are currently compliant with Action area 1 of the global plan? It is a fluid picture, with some new plans being launched, others lapsing, and some being integrated into other health strategies. Yet, in an ideal world, 100 percent of countries would develop fully funded, standalone national plans, undoubtedly the best tool governments have available to tackle the multifaceted and complex challenge of dementia. But these past eight years have taught us that conditions are never ideal.



Chris Lynch speaks at the AD/PD conference in Vienna, Austria in April 2025.

Undoubtedly, there have been some major barriers to implementation, including the COVID-19 pandemic and multiple ongoing financial and humanitarian crises. At a policy level, ever-changing governments and ministers of health reaffirm the importance of retaining institutional memory and commitments beyond the terms of governments or influential individuals. But by any measure, the fact that, eight years on, we stand at only 30.8 percent of the 146 national plan target is unacceptable to the more than 55 million people living with dementia today and the forecasted 139 million by 2050.<sup>2</sup>

The development of national dementia plans (NDP) has progressed slowly. Dementia is anticipated to become the third leading cause of death in 166 countries and territories by 2040 and is already the leading cause in a growing number of countries.<sup>3</sup> Figure 1 illustrates the gap that must be bridged and why an extension to the global plan is essential. The global plan is a robust tool, its thorough development by WHO, ADI, and key international stakeholders has given us a vital instrument to work with. Governments unanimously committed to it and to developing their own strategic responses in the form of national plans that should prioritise dementia, measuring the current and future impact and deploying appropriate resources and funding. This is sadly lacking at present.

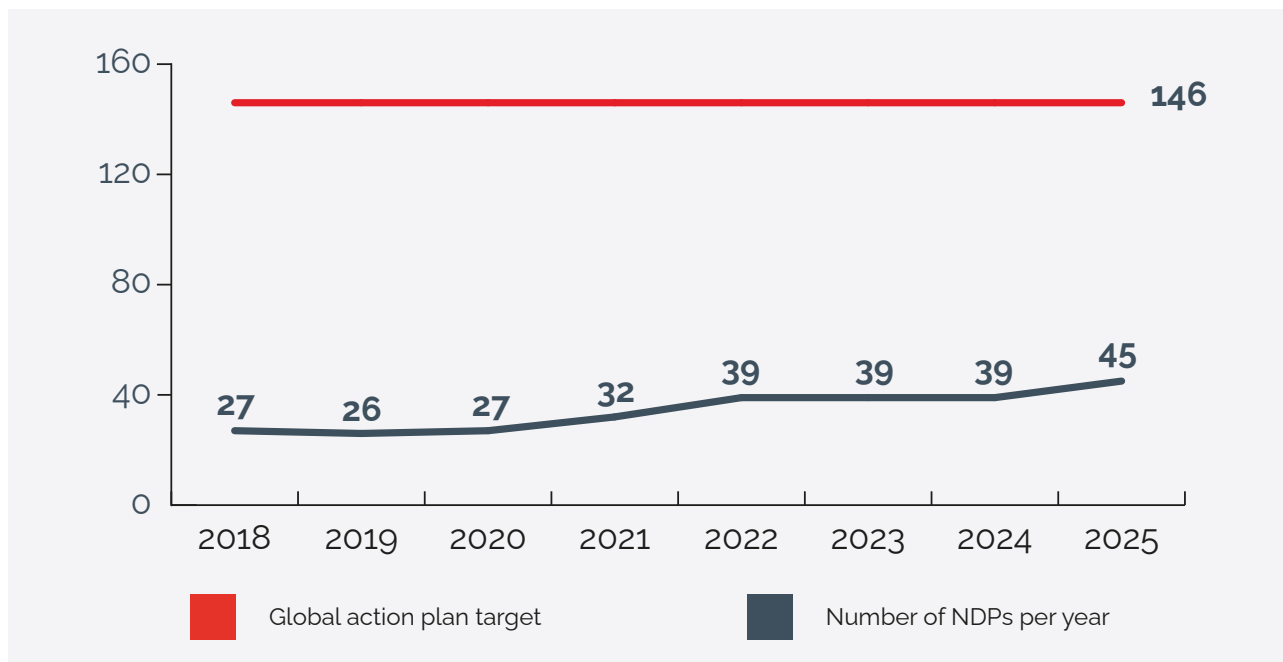
With the drive for an extension to the global plan, time is once again of the essence. People living with dementia cannot afford any further delays and governments must seize this opportunity.

<sup>1</sup> Global action plan on the public health response to dementia 2017–2025. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO

<sup>2</sup> Global status report on the public health response to dementia. Geneva: World Health Organization; 2021. Licence: CC BY-NC-SA 3.0 IGO

<sup>3</sup> Arthurton, L., Barbarino, P., Anderson, R. et al. Dementia is a neglected noncommunicable disease and leading cause of death. *Nat Rev Neurol* 21, 63–64 (2025). <https://doi.org/10.1038/s41582-024-01051-w>

Figure 1: National dementia plans (by year)



The picture, however, is not all pessimistic. There are currently 19 plans under development in member states. We have also seen important progress during the time period, none more so than the recent introduction of the first disease-modifying treatments for Alzheimer's; the emergence of blood-based biomarkers, which could revolutionise the diagnosis pathway; and expanding research data that reveals that up to 45 percent of cases could be delayed or even prevented.<sup>4</sup> All of which reaffirm why robust national plans are required to capitalise on innovation and progress.

Initial governmental leadership on the international stage from countries including France and the United Kingdom ensured a global focus on dementia, but we need consistent champions and multilateral leaders to both maintain dementia as a priority and galvanise much-needed funding. Other governments have intermittently championed the cause on the global stage, including Australia, Canada, Italy, Japan, and the Netherlands; and the US has shown outstanding leadership in funding research. A number of G7 and G20 presidencies have elevated dementia, including the Okayama Declaration under Japan's G20 leadership in 2019 and successive G7 commitments under the presidencies of Japan in 2023 and Italy in 2024.

From Plan to Impact, ADI's annual progress report on the GAP, has continued to shine a light on dementia globally. The report has revealed the glacially slow pace of national plan development between 2017 and 2025, but has also showcased many examples of best practice around the world across the GAP's seven action areas, including diagnosis, treatment, care, research, and risk reduction. Of note during this period, national plans have been launched in countries of all sizes, from Brazil and China to Qatar and Singapore (a full list of current national dementia plans and their status can be found in this report).

Frustratingly, former leaders on the global stage, including France and United Kingdom, have let their dedicated plans lapse or have integrated them into group health plans, which can lack transparency on budgets and targets. Meanwhile, a number of countries have continued to build on and improve their plans, launching multiple editions, fine-tuning and improving them. Notable plans include Japan, the Netherlands, and the Republic of Korea, with Australia recently committing to a new 10-year plan and Chile, an important voice on dementia in the Pan-American Health Organization region, conducting a full review of its plan prior to relaunching in 2025. In the Middle East, where forecast prevalence figures are as high as 2,000 percent by 2050,<sup>5</sup> regional momentum needs to build

<sup>4</sup> Livingston, Gill et al. Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission. The Lancet, Volume 404, Issue 10452, 572–628

<sup>5</sup> Nichols, Emma et al. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. The Lancet Public Health, Volume 7, Issue 2, e105 – e125



around the plans that have already launched in Qatar, Iran, Kuwait, and Saudi Arabia.. Dispiritingly, there are still no national plans in sub-Saharan Africa, despite extensive advocacy from ADI member associations and support at the WHO regional level.

The WHO's own progress report, the Global Status Report on the public health response to dementia based on data in the Global Dementia Observatory,<sup>2</sup> alongside ADI's findings and commentary, raised the alarm that none of the targets of the global plan would be met by the 2025 target date. A 'Defeating Dementia' summit in The Hague in 2023 offered a platform to amplify our growing call for an extension of the global plan. Eighteen months of advocacy by ADI resulted in over 20 governments supporting a resolution recommending an extension at the WHO's Executive Board meeting in February 2025.

The WHO's global action plan clearly identifies the challenge:

*"Given the range of the population affected directly or indirectly by dementia and the complexity of this*

*condition, dementia requires a whole-of-government, broad, multistakeholder, public health approach. Such an approach will lead to a comprehensive response from the health and social care system (both public and private) and other government sectors, and will engage people with dementia and their carers and other relevant stakeholders and partners."*

What appears to be missing today is a sense of urgency. In 2024, ADI ran a global awareness campaign titled "Time to act on dementia." This was developed in response to our global survey of over 40,000 people on attitudes to dementia, which showed that continued low awareness levels and stigma, including among health and care practitioners, are still major barriers to progress.<sup>6</sup>

Time was at the heart of this campaign, and time must be the key value driver behind immediate government and stakeholder response going forward to ensure that the global plan is not only retained and extended, but also delivered.

**Chris Lynch**, deputy CEO and director of policy and communications, Alzheimer's Disease International

## Devising dementia-inclusive national policies in Japan

Japan has enacted significant developments in dementia policies in recent years. As the country with the oldest population in the world, Japan needs to prepare for an increase in dementia prevalence. In 2022, the number of elderly people with dementia in Japan was approximately 4.43 million, and the number of elderly people with mild cognitive impairment was about 5.59 million – meaning that around one in 3.6 elderly people is either living with dementia or at risk of developing the condition.

In response to this situation, the Japanese enacted the Dementia basic law in 2023, and based on this law, we developed the National dementia basic plan in 2024.

Japan's dementia policy has two pillars: the first is to create dementia-friendly communities, and the second is to promote innovation. Japan's long-term care insurance system was introduced in 2000. Since then, community-based integrated care systems have made significant progress. We have developed community general support centres, medical centres for dementia, and dementia supporters in every municipality to create a society in which people diagnosed with dementia can continue to live as themselves in a good environment as long as possible.

Meanwhile, clinical research on dementia treatment has been conducted for many years in Japan. Innovative therapies that target the root causes of Alzheimer's disease were approved in 2023 in Japan, thanks to contributions from Japanese pharmaceutical companies. We are also following up on patients treated with lecanemab to confirm its safety and efficacy and are working on the development of blood biomarkers to improve early detection and early intervention. Given this situation, it can be said that we are entering a new era in the treatment of dementia. Considering the rapid advancements in technology, the significance of early detection and intervention for dementia is greater than ever.

However, these anti-amyloid beta antibodies are not effective for all types of dementia and are only suitable for patients in the early stages of Alzheimer's disease. As a result, the target group for the treatment is limited, and it cannot be used by people with other types of dementia. Additionally, while such treatments can slow the progression of dementia, unfortunately, they cannot cure the condition at this time. This makes post-diagnosis support for people with dementia and their families more important than ever.

<sup>6</sup> Alzheimer's Disease International. 2024. World Alzheimer Report 2024: Global changes in attitudes to dementia. London, England: Alzheimer's Disease International.



Japan hosted the G7 summit in 2023, bringing together health ministers and prioritising dementia.

## Involving people living with dementia in policy

Under these circumstances, the enactment of the Dementia basic law and the formulation of the National dementia basic plan in Japan are significant achievements.

The Dementia basic law was created with the voices of people with dementia, with the aim of creating an inclusive society. The concept of the national basic plan based on this basic law is involvement of people with dementia, echoing the Convention of the Right of Persons with Disabilities: "Nothing about us, without us."

The National basic plan organises the fundamental measures for dementia into 12 areas, including: promoting public understanding of people with dementia; promoting barrier-free lives for people with dementia; ensuring opportunities for involvement in society for people with dementia; supporting decision-making and protecting the rights and interests of people with dementia; and developing systems for providing health and medical services and welfare services.

Furthermore, the plan specifies key performance indicators to advance these measures through

"processes," "outputs," and "outcomes" in four areas: 1) public understanding; 2) respect for the will of people with dementia; 3) communities where people with dementia can live as themselves in a good environment as long as possible; and 4) promotion of innovation and technology.

This plan particularly emphasises the process rather than just numerical outputs, by evaluating through encounters and dialogues with people with dementia and their participation in policymaking.

All local governments are required to formulate their respective plans to promote policies on dementia, while involving people living with dementia and their families in this process. It is expected that through this approach, the dementia policy of each municipality will be continuously promoted.

Japan believes that its efforts are highly compatible with the WHO's Global action plan. It is essential for us to share our knowledge and insights on dementia policies and innovations with countries around the world, so that we can mutually enhance our approaches and outcomes. I hope that our country's efforts will contribute to the endeavours of our global partners.

**Yoshimasa Tosaka**, *counsellor for general policy planning, Ministry of Health, Labour, and Welfare, Japan*

## Key points



**Without the cornerstone of making dementia a public health priority, the Global action plan loses its meaning and becomes inconsequential. The plan's extension to 2031 is a crucial opportunity for WHO member states to recommit to carry this pledge forward beyond 2025.**

# Chapter 2

## Dementia awareness and friendliness



**WHO target: 100% of countries will have at least one functioning public awareness campaign on dementia to foster a dementia-inclusive society by 2025; 50% of countries will have at least one dementia-friendly initiative to foster a dementia-inclusive society by 2025.**

Despite eight years of awareness-raising and advocacy, stigma remains a significant barrier across all the action areas of the Global action plan. In 2024, ADI followed up on its 2019 global survey on attitudes to dementia, to see what had changed in the span of five years during which the Global action plan was in effect. The results, examined in detail in the World Alzheimer Report 2024,<sup>1</sup> highlight the complex and persistent nature of stigma and dementia worldwide. Concerningly, 80 percent of the general public still believes that dementia is a normal part of ageing, whilst 65 percent of health and care professionals think the same.

Undeniable progress has been made in raising awareness of dementia, although that progress is unevenly distributed. A growing number of countries have increased efforts to not only raise the profile of dementia but also to improve its perception amongst the public and healthcare professionals. Far too often, dementia remains a condition that is feared and reviled. Breaking down these misconceptions is key to making societies less hostile towards people living with dementia and their carers – while being mindful of avoiding the trap of “benevolent othering.”

“Dementia friendliness” is a concept that has gained significant traction over the past decade – but we are

now witnessing a shift towards dementia *inclusion*, actively involving people living with dementia in the process of developing policies and programmes. As ADI board member and longstanding advocate Emily Ong writes in her essay for this chapter, “this transfer and reorientation of power to people with lived experience is essential for meaningful engagement and dismantling the structural thinking of ‘I will solve this problem for you’ to ‘We will solve it together, and in the process, we will grow.’”

Mexico is one of the countries that has invested in dementia awareness through its national dementia plan. The National Institute of Geriatrics details in its essay how the country has adapted the Dementia Friends initiative to the local cultural context and actively participated in international surveys (such as ADI's) to better apprehend the state of dementia awareness in the country.

What the institute makes clear is the importance of government involvement. “One of the main lessons learned has been the importance of political will to increase awareness and reduce stigma towards dementia,” the essay reads. “Awareness-raising should not only target the general population, but also public servants and health professionals.”

<sup>1</sup> Alzheimer's Disease International. 2024. World Alzheimer Report 2024: Global changes in attitudes to dementia. London, England: Alzheimer's Disease International.

## Dementia awareness: what has changed and what have we learned?

It has been eight years since the WHO launched the Global action plan on the public health response to dementia 2017 – 2025. The plan's vision is **"a world in which dementia is prevented and people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality."**

The plan is grounded in seven cross-cutting principles and human rights of people with dementia, including the principles of equity, empowerment, and engagement of people with dementia and their informal carers. The goal is to improve the lives of people with dementia, their informal carers and families, while decreasing the impact of dementia on them as well as on communities and countries.

The World Alzheimer Report 2024 on global changes in attitudes to dementia showed that stigma remains a harsh reality for people with lived experience of dementia, including informal carers and their families.<sup>2</sup> Violation of the human rights of people with dementia<sup>3</sup> is another hard truth that has barely changed. Globally, people with lived experience of dementia continue to be excluded from having a say and participating in policies, programmes, and services that impact their lives.<sup>4</sup>

Disappointing as the lack of political leadership on dementia is, failing to make the condition a public health priority and stagnating on the targets of the action plan amid pervasive stigma, there is still a silver lining of hope experienced by people living with dementia and informal carers in certain parts of the world.

So, what has changed over the eight years as far as dementia awareness and dementia-inclusive society are concerned and what have we learned?

### Going beyond awareness

The WHO global target for dementia awareness aimed for 100 percent of countries to have at least one functioning public awareness campaign on dementia to foster a dementia-inclusive society by 2025, and for 50 percent of countries to have at least one

dementia-friendly initiative to foster a dementia-inclusive society by the same year.

Based on Global Dementia Observatory (GDO) data, 36 countries stated that their dementia plans included actions or objectives to address dementia awareness, stigma reduction and encouragement of dementia-friendly communities; 87 percent ran a dementia awareness campaign and 96 percent implemented dementia-friendly initiatives.<sup>3</sup>

While the high implementation rate is encouraging, being aware of the signs and symptoms of dementia and promoting dementia friendliness do not automatically result in a change of perception towards people living with dementia, nor address felt stigma. More often than not, well-intentioned awareness campaigns and dementia-friendly initiatives aim to tackle enacted stigma but may also unintentionally promote benevolent othering,<sup>5</sup> which can exacerbate negative self-appraisals and fear of being treated negatively.<sup>6</sup>

How can we then ensure more effective dementia awareness campaigns and dementia-friendly initiatives?

### Legal empowerment to tackle structural stigma

In some places like Japan, Chinese Taipei, or Canada, people with dementia and informal carers feel that things are improving, with their voices influencing decisionmakers at the policy level and others.

Since its inception in 2014, the Japan Dementia Working Group has spoken at the national legislature, central, and local governments, and is involved in the discussion of the Basic Plan on Dementia to promote an inclusive society. Independent bodies like the Health and Global Policy Institute and Alzheimer Association Japan have been instrumental in the legal empowerment process, in which people with dementia and informal carers are able to exercise their rights and take part in the decisions that affect their lives.

<sup>2</sup> Alzheimer's Disease International. World-Alzheimer-Report-2024 [Internet]. 2024 [cited 2025 Feb 6]. Available from: <https://www.alzint.org/u/World-Alzheimer-Report-2024.pdf>

<sup>3</sup> Cohen-Mansfield J. The Rights of Persons With Dementia and Their Meanings. J Am Med Dir Assoc. 2021 Jul 1;22(7):1381–5.

<sup>4</sup> Seeher K. Global status report on the public health response to dementia. [Internet]. Geneva: World Health Organization; 2021. Available from: <https://www.who.int/publications/i/item/9789240033245>

<sup>5</sup> Fletcher JR. Destigmatising dementia: The dangers of felt stigma and benevolent othering. Dementia. 2021 Feb 1;20(2):417–26.

<sup>6</sup> Boyle MP. Enacted stigma and felt stigma experienced by adults who stutter. J Commun Disord. 2018 May 1;73:50–61.



Likewise, the Dementia Advisory Group in Chinese Taipei is strongly supported by the Taiwan Alzheimer's Disease Association (TADA) in elevating the voice of people with dementia at the policy level. The Taipei city government has invited people living with dementia to join policy meetings for more than five years. In Canada, researchers from the University of British Columbia are shifting from traditional non-participation to involving people with dementia as research partners to co-develop knowledge for change.<sup>7</sup>

This transfer and reorientation of power to people with lived experience is essential for meaningful engagement and dismantling the structural thinking of "I will solve this problem for you" to "**We will solve it together, and in the process, we will grow.**"<sup>8</sup> Having people with dementia involved as co-authors or co-leads is an effective way to address public stigma as well as self-stigma. This authentic approach demonstrates that, when given the opportunity and appropriate support, people with dementia can lead the way and exercise their rights, dispelling the misconception that they are "nothing but a burden to society" and sending a powerful message: "**there's life after a dementia diagnosis.**"

## Recognising people with dementia as instrumental agents of change

It is an evidence-based fact that people with lived experience are instrumental agents of change in tackling stigma and should be strongly supported to lead or co-lead interventions in their communities.<sup>9</sup> However, the pervasiveness of structural stigma has restricted the participation of people with dementia at multiple levels and added to the paternalistic attitudes towards them as people lacking comprehension ability.<sup>10</sup> Globally, there are only a few well-established working groups led by people living with dementia, such as the European Working Group of People with Dementia, Dementia Alliance International, the Scottish Dementia Working Group, and the Japanese Dementia Working Group. In 2024, a new advisory group was established within ADI known as the Global Dementia Expert Panel. These working groups are at the forefront of change initiatives and receive support from coalitions of allies, often non-governmental organisations, local dementia associations, and researchers working on dementia.

The involvement of people with dementia in awareness campaigns and dementia-friendliness initiatives can



ADI's Head of Accreditation Amalia Fonk-Utomo, Emily Ong, and Dementia Singapore CEO Jason Foo

ensure a more equitable and inclusive society – in particular for underrepresented population groups living with dementia such as the LGBTQI+ community, disability community, migrants and refugees, minority groups, and families of children with childhood dementia.

From the evidence presented above, countries need to rethink their anti-stigma agenda and operationalisation. Do they engage people with lived experience of dementia meaningfully in the campaign design and not just as testimonies in their campaigns? Have they worked with LGBTQI+ individuals living with dementia and people diagnosed with both HIV and dementia to investigate the kind of dementia-inclusive society that enhances their self-esteem and self-efficacy and promotes their communication and engagement with others? Are there grassroots justice defenders like the one in Japan to raise awareness of rights, laws, and policies affecting people living with and affected by dementia to support them in engaging with in legal and policy reform?

Addressing dementia stigma and building a dementia-inclusive society requires the inclusion of people with lived experience of dementia at every level and the recognition that lived experience is a form of expertise that provides immeasurable value to initiative outcomes. Legal empowerment that can advance systemic change, and effective change comes from the people impacted by dementia.

**Emily Ong**, board member, Alzheimer's Disease International, co-chair, Global Dementia Expert Panel

<sup>7</sup> Mann J, Hung L. Co-research with people living with dementia for change. Action Res. 2019 Dec 1;17(4):573–90.

<sup>8</sup> What Is Legal Empowerment [Internet]. Grassroots Justice Network. [cited 2025 Feb 22]. Available from: <https://grassrootsjusticenet.org/about-us/gjn-what-is-legal-empowerment/>

<sup>9</sup> Lancet T. Can we end stigma and discrimination in mental health? The Lancet. 2022 Oct 22;400(10361):1381.

<sup>10</sup> Alzheimer Europe. Alzheimer Europe summary on 2020 Report Legal capacity and decision making summary.pdf [Internet]. 2020 [cited 2025 Feb 16]. Available from: <https://www.alzheimer-europe.org/sites/default/files/2021-11/Alzheimer%20Europe%20summary%20on%202020%20Report%20Legal%20capacity%20and%20decision%20making%20summary.pdf>



## Addressing dementia stigma in Mexico

In Mexico, approximately 1.3 million people live with dementia, and it is estimated that the figure will reach 3.5 million by 2050. The prevalence of dementia in people aged 60 and over is 7.9 percent (9.1 percent women, 6.9 percent of men), and is higher in rural (9.4 percent) than in urban areas (7.7 percent). Dementia is the second leading cause of disability and the main cause of death in the 70+ age group.<sup>1</sup> Increasing prevalence and the consequent challenge for the healthcare and care of people with dementia alerted various health institutions to the need to develop strategies for care in Mexico.

In 2012, the Mexican Alzheimer's Federation (FEDMA) and the National Institute of Geriatrics signed a collaboration agreement that led to the publication of an action plan for Alzheimer's and related diseases in 2014. In 2024, as a result of the joint work of researchers, academics, healthcare professionals, and civil society, this document was updated and became a national dementia plan aligned with the recommendations from the World Health Organization and ADI.

The national plan is based on four priority strategies for care: dementia screening at the primary care level, developing long-term care services, boosting research, and reducing stigma. With an evidence-based approach and cross-sectoral partnerships, Mexico is moving forward in the dementia response, in line with the Global action plan on the public health response to dementia 2017–2025, with a particular focus on addressing dementia stigma in the country.

### Raising awareness and removing stigma towards dementia

Taking up ADI's recommendations<sup>2</sup> for stigma reduction, specifically the development of dementia friends programmes, Mexico adopted the global Dementia Friends initiative in 2019<sup>3</sup> that seeks to change people's perceptions and attitudes about dementia. Currently, this programme has raised awareness of dementia among 13,200 Mexicans, 32 percent of whom are health professionals.

The National Institute of Geriatrics collaborates directly with the initiative by providing technical advice on the development of materials and training of promoters of the Dementia Friends initiative, as well as the production of scientific evidence on the performance of the programme in Mexico.<sup>4</sup> FEDMA has also promoted Dementia Friends in the broader Americas region by training community promoters in Puerto Rico, Argentina, and Bolivia.

For their part, civil associations have been carrying out various awareness-raising activities in their localities, sometimes accompanied by local and state social and health institutions. They include memory walks, information sessions, workshops, citizen participation fairs, and interviews with local media.

Since 2012, the National Institute of Geriatrics has implemented working groups to generate discussion and awareness with decision-makers in the health sector and the legislative branch to contribute to the creation of public policies, and these efforts have been reflected in various position papers.

### Lessons learned and recommendations

Mexico has made significant progress in dementia awareness, actively participating in international surveys<sup>2,5</sup> to better understand attitudes towards the condition. This knowledge has been key to designing more targeted and effective interventions.

One of the main lessons learned has been the importance of political will to increase awareness and reduce stigma towards dementia. It is clear that awareness-raising should not only target the general population, but also public servants and health professionals. The results of ADI's 2019 and 2024 surveys of attitudes towards dementia report that Mexico continues to show negative attitudes and prejudices, not only from the general population but also from health professionals. It is therefore necessary for the government to adopt awareness programmes at all levels to ensure timely and effective responses.

<sup>1</sup> García-Peña M del C, López-Ortega M, Torres-Castro S, Roa-Rojas P, Flores Vázquez JF. Plan Nacional de Demencia 2024 [Internet]. Instituto Nacional de Geriatria, editor. Ciudad de México: Instituto Nacional de Geriatria; 2025.

<https://www.gob.mx/inger/documentos/plan-nacional-de-demencia-2024>

<sup>2</sup> Alzheimer's Disease International. World Alzheimer Report 2019: Attitudes to dementia [Internet]. London; 2019.

<https://www.alzint.org/resource/world-alzheimer-report-2019/>

<sup>3</sup> Alzheimer's Society. Dementia Friends. London; 2025. <https://www.alzheimers.org.uk/get-involved/dementia-friends>

<sup>4</sup> World Health Organization. The Global Dementia Observatory, Dementia Friends México [Internet]. 2025.

<https://globaldementia.org/en/dementia-friends-mexico>

<sup>5</sup> Alzheimer's Disease International. 2024. World Alzheimer Report 2024: Global changes in attitudes to dementia. London, England: Alzheimer's Disease International. Available from: <https://www.alzint.org/resource/world-alzheimer-report-2024/>

Partnerships between government institutions and civil society have proven to be a key pillar for such efforts. Civil associations have experience in implementing community-based programmes such as support groups, and their work complements the evidence-based approach of health institutions. To strengthen these strategies, it is crucial to involve people living with dementia and their caregivers in the design of public policies and programmes that respond to their needs and expectations. Furthermore, adapting international initiatives such as Dementia Friends to the Mexican culture and context is essential to maximise their impact. Translating materials and adapting them to

local needs can make these initiatives more accessible and effective.

Mexico is working on the implementation of its national dementia plan, which includes the elimination of stigma. The alliance between civil society and government at all levels is fundamental for progress in the fight against stigma, with the priority being to raise awareness throughout society, including public servants, health professionals, and the general public.

***National Institute of Geriatrics, Mexico***



ADI Regional Director for the Americas Diego Aguilar (centre) at Mexico's National Institute of Geriatrics with Institute Director Carmen García Peña, ADI board member Rosa Farres, and FEDMA Chair Dora Quezada in February 2023.

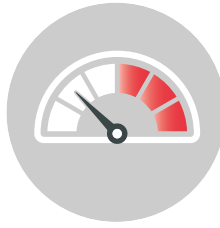
## Key points



**Dementia awareness is not just a matter of individuals taking the initiative to educate themselves and others. Government involvement is essential in order for efforts to be effective, far-reaching, and ensure awareness is not just a passive state, but a call to action. The extension of the Global action plan is key to making more significant strides in tackling at all levels of society.**

# Chapter 3

## Dementia risk reduction



**WHO target:** The relevant global targets defined in the Global action plan for prevention and control of noncommunicable diseases 2013–2020 and any future revisions are achieved for risk reduction and reported.

For far too long, dementia has been seen as an immutable force outside of human control, with the very concept of prevention feeling like a fruitless endeavour. And yet, dementia, as it turns out, is not merely a matter of fate – much more is within our control than we once thought possible.

In parallel to the Global action plan, Professor Gill Livingston has been among the leading lights in the field contributing to the Lancet standing commissions about dementia risk reduction. Research has currently identified 14 modifiable risk factors for dementia, raising the perspective of tackling these factors head on throughout the lifespan.

"Many previously sceptical policymakers, clinicians, and academics now accept that changes in policy and lifestyle can reduce dementia," Livingston writes in this chapter, noting that there remain major gaps in the accessibility and implementation of risk reduction measures across the globe.

On a personal level, behavioural change around risk reduction is far more feasible than ever before. But from a public health perspective, governments still need to intervene to scale up the effectiveness of lifestyle and environmental changes to make a measurable and sustainable impact on dementia incidence. ADI's World

**Dementia, as it turns out, is not merely a matter of fate – much more is within our control than we once thought possible.**

Alzheimer Report 2023 is dedicated to breaking down what dementia risk reduction means and how it can be practically applied.<sup>1</sup>

In Chile, Dr. María Soledad Martínez Gutiérrez and her colleagues in the Ministry of Health's Division of Disease Prevention and Control recount how the state has seen risk reduction as a strategic tactic to tackle dementia head on, in a country where modifiable risk factors constitute 62 percent of the total risk factors for dementia, compared to 40 percent worldwide. The South American country stands as an inspiring example of dedicated engagement with risk reduction, adapting its efforts to its specific needs and context.

With dementia projected to cost the world \$2.8 trillion every year by 2030, risk reduction is a proactive, cost-saving endeavour – but more than that, it is a lifesaving one. So long as a cure remains out of reach and our societies grow older, prevention is the best tool currently in our possession to ensure that dementia does not become a bigger public health crisis than it currently is.

<sup>1</sup> Long, S., Benoist, C., Weidner, W. 2023. World Alzheimer Report 2023: Reducing dementia risk: never too early, never too late. London, England: Alzheimer's Disease International.

## Dementia risk reduction: a significant shift in awareness and implementation

We have been writing in the Lancet standing commissions about dementia risk reduction and prevention for nearly 10 years now.<sup>2,3,4</sup> This period coincides with the World Health Organization's Global action plan on dementia (2017–2025), and also overlaps with the WHO Guidelines on risk reduction of cognitive decline and dementia,<sup>5</sup> which, along with the Lancet commissions, provide evidence-based recommendations on lifestyle behaviours and interventions to delay or prevent cognitive decline and dementia.

Over this period, there has been a shift in acceptance of the idea that many dementias can be prevented. Many previously sceptical policymakers, clinicians, and academics now accept that changes in policy and lifestyle can reduce dementia.

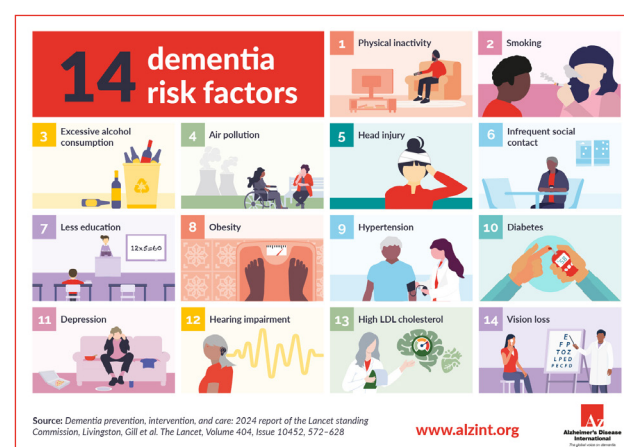
### Growing consciousness of risk

A quick search on the Overton index,<sup>6</sup> which lists the world policy literature, showed 149 separate policy documents – from governments, intergovernmental organisations, and think tanks – that cited the 2017 Lancet commission. Similarly, the 2020 version is cited 152 times in policy documents, and the 2024 commission has already been cited four times.

These numbers show that our commissions have contributed to changes in policy designed to decrease dementia in many countries. Governments have had differing methods for how to do this. One example is legislative change in the United States, where the Center for Disease Control issued the Healthy Brain Initiative Road Map mandating public health to improve brain health nationwide. In order to reach its recommended target to reduce risk factors by 15 percent, the US passed the Building Our Largest Dementia Infrastructure for Alzheimer's Act (BOLD Act) in 2018.

The Nordic Council meanwhile lists holistic public health measures, including free education for all, legalisation and regulation of tobacco and alcohol,

awareness campaigns, public health guidelines and information on healthy food and physical activity, lifestyle counselling, risk factor monitoring, and secondary prevention for high-risk groups. It notes that there is still a lack of awareness in the population, particularly among more vulnerable groups, and that powerful preventative measures such as addressing of hearing loss are often not in place.



In England, all people who receive an NHS health check<sup>7</sup> between the ages of 40 and 74 are supposed to be given information on how to reduce their risk of developing dementia, although this is to date limited to only some of the known risk factors, like hypertension and obesity.

The new Scotland dementia strategy of 2023<sup>8</sup> considers individual rather than public health and includes developing preventative health services, which aim to provide personalised risk reduction plans.

Some countries have policies that target more specific risks. These include the UK tobacco and vape bills to prevent young people smoking; and the Australian concussion guidelines on youth and community sport, lowering the height of legal tackles and preventing people returning to the field after head injury – “if in

<sup>2</sup> Livingston, G., Huntley, J., et al. (2024). Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission. *Lancet*, 404(10452), 572–628. [https://doi.org/10.1016/S0140-6736\(24\)01296-0](https://doi.org/10.1016/S0140-6736(24)01296-0)

<sup>3</sup> Livingston, G., Huntley, J., et al. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*, 396(10248), 413–446. [https://doi.org/10.1016/S0140-6736\(20\)30367-6](https://doi.org/10.1016/S0140-6736(20)30367-6)

<sup>4</sup> Livingston, G., Sommerlad, A., et al. (2017). Dementia prevention, intervention, and care. *Lancet*, 390(10113), 2673–2734. [https://doi.org/10.1016/S0140-6736\(17\)31363-6](https://doi.org/10.1016/S0140-6736(17)31363-6)

<sup>5</sup> Risk reduction of cognitive decline and dementia: WHO guidelines. (2019). In: World Health Organization <https://app.who.int/>

<sup>7</sup> <https://www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk>

<sup>8</sup> <https://www.gov.scot/publications/new-dementia-strategy-scotland-everyones-story/>



doubt, sit them out." Canada has clinical guidance on exposure to noise, and a separate one on provision of hearing aids to prevent dementia.

## Room for growth

Many of these laws, policies, and guidelines come from high-income countries (HICs). This may be because HICs see dementia as having a serious effect on their economy. Many people are looked after by paid carers who are in a short supply, while most care in lower- and middle-income countries (LMIC) is provided by family members. Some policies in HICs specifically target more vulnerable populations, such as people with fewer resources or belonging to minority ethnic groups, who are often exposed to more risk factors that make them vulnerable to developing dementia.

LMICs have traditionally prioritised infectious diseases, and average lifespans have historically been shorter than in HICs, although this fortunately is changing. A majority of people with dementia currently live in LMICs, and this proportion is expected to increase, with around two-thirds of people with dementia living in LMICs by 2050. It is often considered that dementia is a rich-country problem, but these numbers show this is no longer the case. Even in high-income countries, preventative measures, both at the individual and policy levels, have yet to make it to the top of governments' agenda, despite being likely cost-saving for families and for states.<sup>9,10</sup> This can be due of lack of awareness of how dementia affects the individual, their loved ones, and the cost to society, or the belief that dementia risk reduction isn't possible.

There has been considerable progress in recent years, but there is much more to do and many opportunities to do it. Different approaches in various countries – delivered by government, civil society, local councils, and volunteer groups – teach practical ways to implement risk reduction.

## Prevention remains everybody's business.

Prevention remains everybody's business. Leadership from the WHO and governments is crucial, particularly to provide for the most vulnerable. This is the time to redouble efforts worldwide and especially concentrate on the Global South.

The forthcoming extension of the WHO Global action plan on dementia and the WHO non-communicable diseases strategy are opportunities to encourage all countries to take a life-course approach to preventative action. This would lower dementia risk, increase people's quality of life, improve population-level health, and, on the longer term, save governments money.



**Gill Livingston**, professor of psychiatry of older people, Division of psychiatry, Faculty of Brain Sciences, University College London

<sup>9</sup> Mukadam, N., Anderson, R., et al. (2020). Effective interventions for potentially modifiable risk factors for late-onset dementia: a costs and cost-effectiveness modelling study. *Lancet Healthy Longevity*, 1(1), E13-E20. <Go to ISI>://WOS:000659222500008

<sup>10</sup> Mukadam, N., Anderson, R., et al. (2024). Benefits of population-level interventions for dementia risk factors: an economic modelling study for England. *Lancet Healthy Longevity*, 5(9). DOI: 0.1016/S2666-7568(24)00117-X



## Addressing dementia risk and ever-improving policy in Chile

Dementia is a health problem that challenges health and social support systems worldwide and, above all, impacts the lives of people who develop this condition and those who care for them.

In Chile, it is estimated that the prevalence of dementia is 1.06 percent of the general population and 7.0 percent of people over 60 years old, being higher in women (7.7 percent) than in men (5.9 percent) and more prevalent in rural (10.3 percent) than in urban areas (6.3 percent).<sup>11</sup> This data suggests that there are currently an estimated 200,000 people with dementia in our country,<sup>12</sup> and at least as many caregivers.

Meanwhile, Alzheimer's disease has gone from being the sixth leading cause of death in our country in 2011 to the fourth in 2021,<sup>13</sup> according to the Institute of Health Metrics and Evaluation (IHME).

Because of its prevalence in Chile, its economic, social,<sup>14</sup> and welfare impact on the lives of individuals and communities, and its historical relegation as specialty healthcare, it was decided that dementia should be a public health priority. This has resulted in three milestones that demonstrated the need for preventive actions, timely diagnostic processes, and an early and comprehensive approach to dementia:

1. The creation of Chile's national dementia plan in 2017,<sup>15</sup> which is composed of nine objectives aligned with the seven priority areas for public health in the field of dementia defined by the World Health Organization;<sup>16</sup>
2. The incorporation in 2019 of Alzheimer's disease along with other dementias to the Explicit Health Guarantees (GES) regime, which means that, since that year, people with this health problem are guaranteed by law access to proper diagnosis and treatment in a timely manner and with a maximum value to be paid throughout the national territory;
3. The consideration of this health condition as one of the priorities of the mental health agenda of this



ADI's Diego Aguilar with Rodrigo Zárate Soriano and Francisco Cubillos Chaparro, advisors for the Chilean Ministry of Health's Department of Mental Health, at the AAIC conference in Santiago in February 2025.

government. This has meant the implementation of new specialised care centres and the development of a process of evaluation and updating of our plan.

The evaluation process of the national dementia plan has allowed us to visualise gaps, but also important advances in the eight years of its implementation, particularly in the following areas:

- Detection of people with dementia;
- Consolidation of a care network with emphasis on primary care and the creation of specialised mechanisms for more complex cases;
- Training for health workers on diagnostic processes, treatment, and support;
- Regional and national social awareness campaigns to combat stigma about this health condition.

Regarding dementia risk reduction, in Chile, modifiable risk factors for dementia constitute 62 percent of the total risk factors (compared to 40 percent worldwide and 54 percent in South America).<sup>17</sup> As a country, this data

<sup>11</sup> Fuentes P, Albala C. 2014. An update on aging and dementia in Chile. *Dement Neuropsychol*. Oct-Dec;8(4):317-322. Consultado el 20 de Noviembre 2024 desde: <https://doi.org/10.1590/S1980-57642014DN84000003>

<sup>12</sup> Policy Paper Demencias, Universidad de Chile 2019. Vicerrectoría de Investigación y Desarrollo, VID. Disponible en <https://doi.org/10.34720/5amj-bt82>

<sup>13</sup> Instituto de Métricas y Evaluación de la Salud (IHME). Resumen de causas y riesgos de GBD 2021: Enfermedad de Alzheimer. Consultado el 25 de septiembre 2024 desde: <https://vizhub.healthdata.org/gbd-compare/>

<sup>14</sup> Hojman DA, Duarte F, et al. The cost of dementia in an unequal country: The case of Chile. *PLoS One*. 2017 Mar 7;12(3):e0172204. doi: 10.1371/journal.pone.0172204.

<sup>15</sup> Ministerio de Salud (2017) Plan Nacional de Demencia. Disponible en: <https://diprece.minsal.cl/wp-content/uploads/2024/05/2017-Plan-Nacional-Demencias-1.pdf>

<sup>16</sup> Global action plan on the public health response to dementia 2017–2025. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO. Obtenido desde <https://iris.who.int/bitstream/handle/10665/259615/9789241513487-eng.pdf?sequence=1>

<sup>17</sup> Regina Silva Paradela, Ismael Calandri, et al. 2024. Population attributable fractions for risk factors for dementia in seven Latin American countries: an analysis using cross-sectional survey data, *The Lancet Global Health*, Volume 12, Issue 10, 2024, Pages e1600–e1610. ISSN 2214-109X. [https://doi.org/10.1016/S2214-109X\(24\)00275-4](https://doi.org/10.1016/S2214-109X(24)00275-4)

proves that we have a good opportunity to intervene in a timely manner to address these factors, particularly in those with greater prevalence in our population, such as obesity, hypertension, and physical inactivity.

In this sense, the first objective of our national plan has been to encourage and promote a prevention perspective to dementia by integrating prevention programmes to those that currently exist for other chronic diseases. Thus, addressing dementia risk factors associated with other chronic and metabolic diseases is part of the health objectives proposed in the National Health Strategy 2021–2030.<sup>18</sup> This strategy, which is a navigation chart to address the main health challenges in the country, includes actions on healthy lifestyles (reduction of tobacco and alcohol consumption and increased physical activity, among others) and chronic non-communicable diseases (reduction of cardiovascular and cerebrovascular diseases, diabetes mellitus, and mental health disorders, among others).

Chile has seen a reduction of the smoking population by 23 percent between 2003 and 2016, while at least 32 percent of people with high blood pressure are controlled and have reached normal blood pressure levels. Despite the significant increase in the absolute number of people with obesity and diabetes, according to the Chilean National Health Survey (ENS) 2016–2017 the effective coverage of people with Type 2 diabetes increased from 34 to 55 percent.<sup>19</sup>

The effort to reduce risk factors is transversal across our health system. However, primary care in Chile carries out dementia prevention actions as part of regular health services and reinforcement programmes. Among them, the programme More Self-Reliant Older Adults (MAS-AMA) and various preventive services stand out.

To reduce dementia risk, it is necessary to develop a comprehensive and integrated strategy including initiatives already underway regarding the care of risk factors for non-communicable diseases, for example, making their link to the risk of developing dementia explicit.

In this sense, the actions carried out by the regional ministerial secretariats, which implement the Ministry of Health's policies across the country, are fundamental. They implement workshops and meetings with local stakeholders from different sectors – among them representatives of civil society, patient and/or caregiver organisations, and academics, who can carry out dementia risk reduction work specific to each territory.

Finally, the process of evaluating the progress in the implementation of our national dementia plan has allowed us to visualise progress achieved, persistent gaps, and the need to update our plan by incorporating new actions based on evolving evidence. All this, with the aim of providing a comprehensive and high-quality approach that favourably impacts the lives of people living with dementia, their carers, and communities, but that also addresses dementia risk in society as a whole.

**Dr. María Soledad Martínez Gutiérrez**, head of the Division of Disease Prevention and Control, Ministry of Health, **Psychologist Javiera Erazo Leiva**, head of the Department of Mental Health, Division of Disease Prevention and Control, Ministry of Health, **Psychologist Francisco Cubillos Chaparro**, advisor of the Department of Mental Health, Division of Prevention and Disease Control, Ministry of Health, **Dr. Daniel Jiménez Fernández**, advisor to the Department of Mental Health, Division of Disease Prevention and Control, Ministry of Health, **Psychologist Rodrigo Zárate Soriano**, advisor, Department of Mental Health, Division of Disease Prevention and Control, Ministry of Health, Chile.

## Key points



As Professor Gill Livingston aptly writes, prevention remains everybody's business. The extension of the Global action plan on dementia is an opportunity that should be seized upon by all states to implement life-course approaches to dementia risk reduction, which would reap benefits for individuals and the economy.

<sup>18</sup> MINSAL 2022 Estrategia Nacional de salud para los objetivos sanitarios al 2030. Disponible en:

<https://www.minsal.cl/wp-content/uploads/2022/03/Estrategia-Nacional-de-Salud-2022-MINSAL-V8.pdf>

<sup>19</sup> Ministerio de Salud 2022 Evaluación de final de la década. Estrategia Nacional de Salud para los objetivos sanitarios 2011-2020 disponible en

<https://estrategia.minsal.cl/wp-content/uploads/2022/03/Evaluación-de-Final-de-la-Decada-2011-2020.pdf>

# Chapter 4

## Diagnosis, treatment, care, and support



**WHO target: In at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025.**

Action area 4 is the most expansive of all those identified by the Global action plan for dementia. To lump together diagnosis, treatment, care, and support may be interpreted as an underestimation of the importance of each individual facet – but in fact, it is a reflection of the deep interconnectedness of each of these aspects of the dementia journey.

Recent years have witnessed incredible strides in new diagnostic methods such as blood-based biomarkers, as well as disease-modifying treatments targeting amyloid-related pathologies. This progress should hearten all of us involved in the vast field of dementia and give us hope for the future.

And yet, the present circumstances for people living with dementia are stark. Some 75 percent of people with the condition are believed to be undiagnosed, and 85 percent do not receive post-diagnostic care. Furthermore, those who have received a diagnosis are not guaranteed to have access to the most adequate treatments, whether pharmacological disease-modifying treatments or non-pharmacological therapies. Global inequalities continue to play a significant role in healthcare system preparedness. The COVID-19 pandemic, along with global economic and political instability, threaten efforts to meaningfully address dementia. It should not be a radical statement to affirm that everyone deserves to receive the best treatment possible, regardless of who they are or where they live – and yet this remains far from a reality.

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The current climate might seem grim, but as Professor Linda Clare affirms, "now is not the time to give up." Her essay is an impassioned plea for better treatment, care, and support globally, and for each to be given equal priority. Rehabilitation is an emerging but crucial field in dementia care, which, she argues, should be scaled up. The upcoming World Alzheimer Report in September 2025 will take an in-depth look at this underestimated approach to dementia care.

Conny Helder, the Netherlands' former minister of healthcare, wellbeing and sports, meanwhile looks back at her country's approach to dementia from 2004 until now. As our understanding of diagnosis, treatment, and care has evolved, so has Dutch national dementia policy. While she lauds its ambitious strategy, Helder exhorts her country – and the world – to do more.

"We have to anticipate new developments in diagnostics and treatment, and we need to adapt our current healthcare system in terms of care, cure, and support to the ageing population and the growing numbers of people in the process of developing dementia. There is still room to manoeuvre, but we have to act now," she writes. "We need to keep joining forces worldwide to renew the priority we give to dementia."

## Dementia diagnosis, treatment, care, and support: the need for commitment and ambition

The figures are stark. Only 45 World Health Organization (WHO) member states and eight non-member countries and territories have a dementia plan setting out the policy framework for provision of services and support. In countries such as England and France, there are worrying signs of backward steps. In 2022, only 44 countries had guidelines translating policy into recommendations for practice. The most recent estimates suggest that 75 percent of people with dementia worldwide are undiagnosed. Even more shocking, as many as 85 percent receive no post-diagnostic care. We are still a long way from a "new era" for people with dementia and their care partners. Today, the consequences of growing global political instability and conflict, on top of the longer-term impact of the COVID-19 pandemic, risk diverting attention from efforts to address this major cause of disability among older people worldwide.

Yet now is not the time to give up. Rather, we must stay on the case and redouble our efforts.

The last few years have brought important developments in diagnosis and disease-modifying treatment that will, over time, radically change how we understand and respond to dementia. Clinical symptoms represent the late stage in one of over one hundred neurodegenerative processes. Diagnosis based on biology will determine the underlying pathology and allow for personalised, precision approaches to treatment. This currently requires specialist procedures, but research to identify blood-based biomarkers and develop accessible diagnostic tests is progressing rapidly. Ideally, diagnosis leads directly to treatment, and the first generation of disease-modifying drugs addressing amyloid-related pathology is emerging. This is a source of optimism, despite what are currently modest benefits and considerable risks, but also a source of concern about lack of health system readiness and inequity of access. There will not be a miracle cure or magic bullet, but we can expect gradual enhancement of diagnosis and treatment, so

Yet now is not the time to give up. Rather, we must stay on the case and redouble our efforts.

that eventually we think of dementia as a long-term condition to be managed.

This is key, because none of these developments will remove the need for care and support. On the contrary, they should raise our expectations and ambitions for care provision. We have a moment of opportunity to radically rethink how we understand non-pharmacological treatment, care and support. Just as we have waited a long time for developments in disease modification, so too it has been a long time since the concept of person-centredness prompted a paradigm shift in approaches to care.<sup>1</sup> It is time to revitalise our approach with a coherent framework and clarity of purpose.

Initial evidence on the effects of lecanemab,<sup>2</sup> a new disease-modifying treatment, has been translated as representing a slowing of decline equivalent to five or six months. This prompted a great deal of excitement. In contrast, there was no such excitement when trial evidence showing that cognitive rehabilitation (the rehabilitation of people with cognitive rather than purely physical impairments) for people with dementia reduced decline in functional ability and delayed care home admission by an average of six months<sup>3</sup> was published in 2016. Nevertheless, it has important implications.

Rehabilitation is an established, evidence-based component of healthcare for people with cognitive disabilities resulting from acquired brain injury or stroke, but it is rarely offered to people with dementia, despite evidence that they can benefit.<sup>4</sup> People with dementia can learn and can adjust their behaviour; they may need extra support and more time, but with the right approach, progress can be made.<sup>5</sup> Too often, low expectations mean that people are written off and prevented from regaining functioning where this is potentially achievable. We need to become

<sup>1</sup> Kitwood T. *Dementia Reconsidered: the Person Comes First*. Buckingham: Open University Press; 1997.

<sup>2</sup> van Dyck CH, Swanson CJ, Aisen P, Bateman RJ, Chen C, Gee M, et al. Lecanemab in Early Alzheimer's Disease. *New England Journal of Medicine*. 2023;388(1):9-21. doi:10.1056/NEJMoa2212948.

<sup>3</sup> Amieva H, Robert PH, Grandoulier AS, Meillon C, de Rotrou J, Andrieu S, et al. Group and individual cognitive therapies in Alzheimer's disease: the ETNA3 randomized trial. *International Psychogeriatrics*. 2016;28:707-717. 10.1017/S1041610215001830.

<sup>4</sup> Kudlicka A, Martyr A, Bahar-Fuchs A, Sabates J, Woods B, Clare L. Cognitive rehabilitation for people with mild to moderate dementia. *Cochrane Database of Systematic Reviews*. 2023(6) 10.1002/14651858.CD013388.pub2.

<sup>5</sup> Poulos C, Bayer A, Beaupre L, Clare L, Poulos RG, Wang RH, et al. A comprehensive approach to reablement. *Alzheimer's & Dementia: Translational Research and Clinical Interventions*. 2017;3:450-458. 10.1016/j.trci.2017.06.005.

not only more ambitious but also more focused, more structured, and more personalised in the care domain just as we are in the domain of biomarkers and disease-modifying treatments. Adopting a rehabilitation model offers a route to achieving this. The World Alzheimer Report 2025 will explore in detail how rehabilitation can be implemented to benefit people with dementia and their families.

The ability to function at the best possible level is central to living well with dementia. As ability to manage everyday activities declines, so too do sense of well-being and quality of life.<sup>6</sup> Rehabilitation focuses on optimising functioning relative to a person's capability and health status. This guiding principle offers a conceptual and practical framework for providing health and care services and community-based support.

We already know a great deal about what constitutes good quality care for people with dementia, but even in high-income countries we fail to deliver it. Equitable provision of good quality care must be our ambition. A shared goal should be a focus on directing available resources towards optimising functioning and slowing functional decline through rehabilitation. This personalised, function-focused approach is relevant across all stages of dementia, from enabling people with young-onset dementia to navigate employment challenges through ensuring people with mild-to-moderate dementia remain as independent as possible in everyday activities at home, to promoting autonomy and choice for the growing number of mainly older people with dementia living with complex multimorbidity and frailty. It can be applied in people's homes, community settings, day care centres, residential care homes and hospitals. Rehabilitation may help prevent crises that have costly consequences for individuals and for services, especially when introduced at an early stage.<sup>7</sup> Provision of formal rehabilitation services is a longer-term goal, but we cannot afford to wait. In the meantime, focusing on what the person can do and adopting function-focused strategies to improve independence and confidence can provide crucial benefits. This we can start to do right away.

Rehabilitation works best when the context offers potential for accessible social connections and activities, so that practitioners can signpost people to community activities in line with their preferences. Equipping people to engage and participate can be part of the rehabilitation process. Again, we already know a good deal about addressing these more social needs but often lack the will to invest in the practical solutions required. Greater social resources, such as close relationships and strong social networks, and a more positive social context all contribute strongly to well-being.<sup>8</sup> Feeling lonely or finding oneself isolated can lead to depression and signal decline in well-being.<sup>9</sup> This points to the vital need for communities and societies to include people with dementia in the range of activities that form part of normal life, and to design environments – such as meeting venues – and services – such as public transport – to be accessible. It also points to the value of dementia-specific groups and activities that provide acceptance, enjoyment, and peer support and, for those who wish, an opportunity to engage in advocacy, influence research, or promote public understanding.

Ultimately, the best results will ensue where pharmacological treatments, rehabilitative approaches, and community support can work in synergy. Progress in identifying biomarkers and developing disease-modifying treatments will not eliminate the need for care and support; on the contrary, it should raise expectations. Improved diagnosis and medical treatments will only be meaningful if accompanied by provision of quality dementia care. We need equal commitment and equal ambition across all these research domains to ensure that alongside developments in diagnosis and disease modification we also establish rehabilitation-focused services, enhance community-based provision, and shift societal attitudes to fully include people with dementia.

**Linda Clare** PhD ScD, Professor of Clinical Psychology of Ageing and Dementia, University of Exeter Medical School, UK

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- 6** Martyr A, Nelis SM, Quinn C, Rusted JM, Morris RG, Clare L, et al. The relationship between perceived functional difficulties and the ability to live well with mild-to-moderate dementia: findings from the IDEAL programme. *International Journal of Geriatric Psychiatry*. 2019;34:1251-1261. 10.1002/gps.5128.
- 7** Jeon Y, Simpson J, Fethney J, Krein, L, Shin M, Low L-F, et al. Effectiveness of the Interdisciplinary Home-based Reablement Programme (I-HARP) on improving functional independence of people living with dementia: a multicentre, pragmatic, randomised, open-label, controlled trial *Journal of Neurology, Neurosurgery & Psychiatry* 2025. doi: 10.1136/jnnp-2024-334514
- 8** Clare L, Wu Y-T, Jones IR, Victor CR, Nelis SM, Martyr A, et al. A comprehensive model of factors associated with subjective perceptions of "living well" with dementia: findings from the IDEAL study. *Alzheimer Disease and Associated Disorders*. 2019;33(1):36-41. 10.1097/WAD.0000000000000286.
- 9** Clare L, Gamble LD, Martyr A, Sabatini S, Nelis SM, Quinn C, et al. Longitudinal trajectories of quality of life among people with mild-to-moderate dementia: a latent growth model approach with IDEAL cohort study data. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*. 2022;77(6):1037-1050. 10.1093/geronb/gbac022.



## Addressing dementia diagnosis and care with an eye towards the future in the Netherlands

In the Netherlands, we set out to define the country's first dementia policy in 2004 with the National Dementia Programme 2004–2007, followed by the Dementia Care Chain Programme 2008–2012, and the Dementia Delta Plan 2013–2020. The latter was a huge step forward in a more integral approach including focused research, diagnosis, care, and support. It was followed by the National Dementia Strategy 2021–2030, which aims for people living with dementia to be able to function as valued members of society, receiving appropriate support and care. It also aims to organise sufficient scientific research in order to prevent, treat, and possibly cure the underlying causes of dementia.

While this is already an ambitious strategy, in my opinion it is time to step things up even further. We have to anticipate new developments in diagnostics and treatment, and we need to adapt our current healthcare system in terms of care, cure, and support to the ageing population and the growing numbers of people in the process of developing dementia. There is still room to manoeuvre, but we have to act now.

The number of people with dementia, compared with the growing labour shortages in the Netherlands, is already straining our current healthcare system. It will mean not only immeasurable suffering for patients and their loved ones, but that the burden on our healthcare system and society at large will be too much. Without a policy shift, one in three people of working age will have to work in healthcare by 2040, compared to one in six workers in 2025 – that is not a realistic option.

Furthermore, there are a number of scientific breakthroughs on the horizon that we need to anticipate in a timely manner. The shift from syndrome-based diagnostic tools to diagnosis based on biology, and especially the possibility of more accessible diagnosis through blood-based biomarkers, will change the demand for diagnosis. In addition, once more disease-modifying drugs are approved, it is likely that more people will come forward for a diagnosis and do so at a younger age. This alone will drive the demand for post-diagnosis care and support upwards.

It is time not only to widen the scope of our dementia strategy, taking into account these scientific advancements, but also to redefine dementia pathways as integrated pathways for elderly healthcare.

***We need work on high-quality, person-centred, effective care and support for people with dementia as an integral part of elderly care.***



Conny Helder speaks for World Alzheimer's Month 2024.

This can be done by making better use of support strategies aimed at slowing down the development of dementia and retaining self-reliance. In the Netherlands, we have shown that a targeted, well-structured day-care programme with a combination of social interaction, physical exercise, and (re)learning competences like preparing a meal, can activate people with even late-stage dementia enough to continue to live at home instead of being admitted to a nursing home or being fully reliant on family care. There are huge varieties of course when it comes to how people respond to this kind of daycare, but the overall assessment is positive.

There are different forms of this kind of targeted support in the Netherlands. In my experience, people with dementia benefit hugely from these social innovation approaches by remaining part of broader society and retaining some form of self-reliance. Since this is a different approach than what we are used to in the Netherlands – i.e. admitting people with dementia into the care-home system, which feels more adequate but is in fact often less effective in terms of outcomes – it takes time to implement. The transition needs to be accompanied by tailored research into the effectiveness of care and support. Organising high-quality (medical) care and support for the elderly in their own homes instead of in care- and nursing homes demands a different organisation of our primary medical and home care systems. This too, should be taken into account in the updated strategy.

On a societal level, we need to approach ageing differently so we can lay the groundwork for healthy ageing. Staying active and participating in society can slow down development of undetected dementia, so we should take

this seriously and broaden the scope of interventions to earlier in life instead of waiting for the first symptoms.

***We need to promote and financially support more scientific research.***

As part of the National Dementia Strategy 2021–2030, we launched several research consortia with a total budget of 140 million euros over a 10-year period. These consortia cover fundamental research areas such as the pathogenesis of Alzheimer's disease, lifestyle and risk-reduction strategies, development of diagnostic and prognostic tools, young-onset dementia, and personalised care and support. Each consortium is multidisciplinary in set-up and aimed at scientific breakthroughs with real value for the lives of people with dementia.

We can adjust to the progress that's been made and reevaluate research priorities. Making diagnosis easily accessible through blood-based biomarkers will create new opportunities. Having a diagnosis early on is key to having better outcomes for people living with dementia, for instance, when we can develop prognostic models. More research can also speed up the development of disease-modifying treatments. I'm convinced that once blood-based biomarkers and more disease-modifying drugs are approved, more people will come forward for diagnosis. That will inevitably mean a surge in post-diagnosis care. From a policy perspective, it is important to assess these consequences and adjust the strategy in time, in order to prevent an overburden of the healthcare system with adverse effects.

Of course there are many ethical hurdles to face. We cannot expect early diagnosis of Alzheimer's to be fully in sync with the rhythm of development of effective treatment. But we have to work on developing both and manage the ethics accordingly. Building a real database of prevalence of Alzheimer's will help to understand the early stages, and perhaps the origins, of the disease better and that will enhance treatment possibilities.

***We need to keep joining forces worldwide to renew the priority we give to dementia.***

Learning from the Dutch experience, it is clear that developing a dementia strategy takes time, constant adjusting and international cooperation. With the current progress on developing dementia strategies, it is obvious we should step up in using and adjusting the framework of the WHO Global action plan.

I'm aware that this is ambitious. But to me, it's not just a policy ambition, but a worldwide moral obligation to act now. An obligation to people with dementia and their loved ones, but also an obligation to younger generations and societies at large.

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**It's not just a policy ambition, but a worldwide moral obligation to act now.**

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Dementia is not a normal part of ageing, but a condition that is a huge burden on society and we should do everything we can to address it.

**Conny Helder**, former minister of healthcare, wellbeing and sports, Netherlands

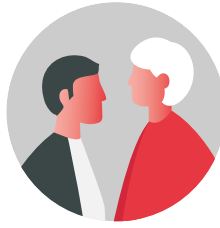
**Key points**



**The rapid evolution of techniques and knowledge in the fields of diagnosis, treatment, care, and support should inspire hope – and action. Pending the extension of the Global action plan on dementia, WHO member states should seize the opportunity to ensure these innovations get applied widely and improve the lives of as many people living with dementia as possible.**

# Chapter 5

## Support for dementia carers



**WHO target: 75% of countries provide support and training programmes for carers and families of people with dementia by 2025.**

We have already cited several times in this report that dementia prevalence will increase to 139 million by 2050. If this is the case, then the number of informal carers – spouses, friends, children, sometimes neighbours – could be double that number. Families, particularly women, provide the bulk of care for people living with dementia.

Governments have fallen well behind the Global action plan on dementia's goal of 75 percent of nations (146 countries) providing support and training to carers. The most recent count from the WHO in 2021 found that only 47 countries did so.<sup>1</sup>

Globally, 70 percent of informal care is provided by women. If we were to tally the amount of unpaid care provided to people living with dementia, it equalled approximately 67 million full-time jobs in 2019 – over five years ago, when we had far fewer cases of dementia worldwide.

The burden of care is great. In ADI's global survey for the World Alzheimer Report 2024 on attitudes to dementia,<sup>2</sup> carers reported higher levels of loneliness than the general population. Carers shared that anticipating discrimination changed their own behaviour and increased their isolation. For example, 43 percent stopped inviting friends over due to concerns about how they might treat their loved one, while 47 percent stopped accepting invitations to visit friends or family. Forty-one percent stayed home – avoiding travel or

taking vacations due to concerns that the person they care for could be treated negatively.

In her essay, Adelina Comas-Herrera describes the unmet needs of unpaid carers, particularly around information about post-diagnostic care options and services, knowledge about the disease trajectory, and information on how to provide care. She explains that sharing knowledge isn't enough – evidence shows that active participation of carers and support is key. She calls for dementia care guidelines that include evidence-based interventions to support carers.

Nicola Vanacore and his team do a deep dive into carer support in Italy, sharing how the country zeroed in on providing specific interventions that led to well-rounded support. First, they developed a series of focus groups and surveys that aimed to better understand the experiences of families providing unpaid care to people living with dementia. Italy then developed guidelines and training for professionals as well as a residential course for information and training of family members.

It's time for governments to look at providing support for informal and unpaid carers as an investment in the future, rather than a burden in the present. The Global action plan provides a starting point – but only if governments use it.

<sup>1</sup> Alzheimer's Disease International. 2024. World Alzheimer Report 2024: Global changes in attitudes to dementia. London, England: Alzheimer's Disease International.

<sup>2</sup> World Health Organization. (2021). Global status report on the public health response to dementia. <https://www.who.int/publications/i/item/9789240033245>

## Support for dementia carers: a work in progress

Action area 5 of the WHO Global action plan on dementia recognises that informal carers, most of whom are family members, shoulder the main share of the costs of dementia through their unpaid care work. Unpaid care represented the equivalent to an estimated 67 million full-time jobs in 2019, with women making up 70 percent of informal carers.<sup>3</sup>

The actions proposed for member states in the WHO plan include providing accessible and evidence-based information, training programmes, respite services, and other resources tailored to the needs of carers to improve knowledge and caregiving skills – such as coping with challenging behaviours. These actions can enable people with dementia to live in their communities for as long as possible while reducing stress and consequent health problems for their carers.

For health and social care professional staff, the action plan encourages training programmes, including identifying and reducing stress and burnout among carers. Additional actions include the development or strengthening of social protection of carers and involving them in the planning of care.

Eight years on, where do things stand?

### Carers' unmet needs

A recent scoping review of the unmet needs of people affected by dementia<sup>4</sup> showed that the most frequently reported unmet needs for unpaid carers related to information about post-diagnostic care options and services, knowledge about the disease trajectory and what to expect, and information on how to provide care. They reported psychological distress mostly linked to social isolation and the demands of caregiving, and distress linked to negative experiences with care services and providers.

The same review found that health and social care professional staff reported a lack of training on care

provision and a lack of knowledge about dementia. Formal caregivers working in residential care settings experienced distress due to lack of alignment between the way they had to work and their values, whereas care workers in domiciliary setting lacked support from peers and reported feeling undervalued and isolated.

A previous review by Bressan et al.<sup>5</sup> similarly found that the key needs of carers of people with dementia are to be supported, receive accessible and personalised information, be trained and educated in providing dementia care and, crucially, have a balance between providing care and meeting their own needs, emphasising the need for social, psychological, and emotional support, as well as access to formal care.

### What works in addressing the needs of carers of people with dementia?

There is a growing body of evidence showing that there are effective interventions to support carers. On the one hand, there is evidence that suggests that multicomponent interventions have an effect on most outcomes for carers, and also reduce the risk of institutionalisation of the person diagnosed with dementia. On the other hand, evidence shows that interventions that only provide knowledge without active participation have very limited effects.<sup>6</sup> This resonates with recent findings about the iSupport self-guided intervention to reduce mental health problems for dementia carers, which has been adapted and implemented in more than 40 countries. iSupport was not found to be effective in a randomised controlled trial in the UK,<sup>7</sup> or in pilot trials in India and Portugal, raising questions about the lack of involvement of human contact in the delivery of the intervention.<sup>8</sup> In contrast, a trial of an iSupport Chinese version that included a carer peer support group and monthly facilitated meetings did find improvements in the mental health of the intervention group.<sup>9</sup>

While most of the research has been conducted in high-income countries, there is a growing body of

<sup>3</sup> Global status report on the public health response to dementia. Geneva: World Health Organization; 2021. Licence: CC BY-NC-SA 3.0 IGO.

<sup>4</sup> Koh, W. Q., Roes, M., et al. (2024). What are the unmet needs in people affected by dementia? A scoping review of reviews. *Aging and Mental Health*. [under review].

<sup>5</sup> Bressan V, Visintini C, Palese A. (2020) What do family caregivers of people with dementia need? A mixed-method systematic review. *Health and Social Care in the Community*. 2020; 28: 1942–1960. <https://doi.org/10.1111/hsc.13048>

<sup>6</sup> Walter E., Pinquart M., How Effective Are Dementia Caregiver Interventions? An Updated Comprehensive Meta-Analysis, *The Gerontologist*, Volume 60, Issue 8, December 2020, Pages e609–e619. <https://doi.org/10.1093/geront/gnz118>

<sup>7</sup> Windle G., Flynn G., et al., (2025) Evaluating the effects of the World Health Organization's online intervention 'iSupport' to reduce depression and distress in dementia carers: a multi-centre six-month randomised controlled trial in the UK. *The Lancet Regional Health – Europe*, Volume 48, 101125. <https://doi.org/10.1016/j.lanepe.2024.101125>

<sup>8</sup> Brijnath, B. and Antoniadou, J. (2025) WHO's iSupport model for dementia care: why the mode and measures matter. *The Lancet Regional Health – Europe*, Volume 48, 101144. <https://doi.org/10.1016/j.lanepe.2024.101144>

<sup>9</sup> Xiao, L., Ullah, S., et al. (2024) The effects of a facilitator-enabled online multicomponent iSupport for dementia programme: a multicentre randomised controlled trial. *International Journal of Nursing Studies*; 159, 104868. <https://doi.org/10.1016/j.ijnurstu.2024.104868>

evidence in middle-income countries. A systematic review of effectiveness of interventions to support carers of people with dementia in lower- and middle-income countries found 48 studies, conducted on 12 countries, none of which were lower-income countries. This review and meta-analysis found that the effects of the interventions were stronger than in similar studies in high-income countries. This may be due to less robust study designs, but a potential explanation could also be that the controls experiencing "usual care" had less support than their counterparts in high-income countries.<sup>10</sup>

## The elephant in the room: the role of formal long-term care

It is important to highlight that research into unpaid carers generally (not just for people with dementia) is increasingly showing that the negative impact of caring is highly dependent on the intensity of care they provide, with studies showing that carers who provide more hours of care per week have lower levels of wellbeing, worse physical and mental health, and are at higher risk of impoverishment.<sup>11,12</sup> In Europe, the evidence suggests that countries where there are more generous provisions of formal long-term care (including home- and community-based care) have fewer unpaid carers providing intensive care, while in contrast, the total number of unpaid carers is higher.<sup>13</sup>

There is also growing evidence that, despite unpaid care being considered "free," it has substantial costs, even to governments. Unpaid carers, particularly those providing more than 10 hours of care per week, pay lower taxes, receive more welfare benefits, and have higher healthcare costs than non-carers or carers who provide fewer hours of care.<sup>14</sup>

## What can be done?

Countries need dementia care guidelines that include evidence-based interventions to support carers. A systematic review of guidelines to support carers of



Adelina Comas-Herrera (centre) speaks at the ADI conference in June 2022 in London, UK.

people living with dementia, all from high-income countries, found nine guidelines covering six themes: assessment, education, skill training, information provision, psychosocial support, and general support policies.<sup>15</sup> A review of the guidelines of 12 European countries only found two of them recommending specific interventions for carers.<sup>16</sup>

It is important to have well-funded and organised health and long-term care systems that can support the implementation of effective (and cost-effective) interventions. In England, it was found that scaling-up a cost-effective intervention to support family carers could potentially save £68 million annually, while improving the quality of life of countless people.<sup>17</sup>

Leaving family carers to provide long hours of care for years does not save our societies money. The extension of the global action plan is an opportunity for governments to implement a framework of support for carers into policy, embedding it into the care system, which over time can reduce the total costs of care and increase access to cost-effective interventions for informal carers around the world.

**Adelina Comas-Herrera**, director, *Global Observatory of Long-Term Care, Care Policy and Evaluation*, London School of Economics and Political Science

- <sup>10</sup> Chen, F., Hu, Z., et al (2025), Effectiveness of Interventions to Support Carers of People With Dementia in Low- and Middle-Income Countries: A Systematic Review and Meta-Analysis. *Int J Geriatr Psychiatry*, 40: e70054. <https://doi.org/10.1002/gps.70054>
- <sup>11</sup> Yanan Zhang, Matthew R Bennett, Insights Into Informal Caregivers' Well-being: A Longitudinal Analysis of Care Intensity, Care Location, and Care Relationship, *The Journals of Gerontology: Series B*, Volume 79, Issue 2, February 2024, gbadi166, <https://doi.org/10.1093/geronb/gbadi166>
- <sup>12</sup> Stöckel J., Bom J. (2022) Revisiting longer-term health effects of informal caregiving: Evidence from the UK. *Journal of Economics of Ageing*, 21 (2022), Article 100343.
- <sup>13</sup> Verbakel E. How to understand informal caregiving patterns in Europe? The role of formal long-term care provisions and family care norms. *Scandinavian Journal of Public Health*. 2017;46(4):436-447. doi:10.1177/1403494817726197
- <sup>14</sup> Cartagena-Farias J, Brimblecombe N. (2023) The Economic Cost of Unpaid Care to the Public Finances: Inequalities in Welfare Benefits, Forgone Earnings-related Tax Revenue, and Health Service Utilisation. *Social Policy and Society*. doi:10.1017/S1474746423000477
- <sup>15</sup> Gao, W., Zhang, T., Wang, H., Wang, S., Liu, Y., & Pang, X. (2022). Supporting caregivers of people with dementia: A systematic review of guidelines. *Health & Social Care in the Community*, 30, e305–e324. <https://doi.org/10.1111/hsc.13513>
- <sup>16</sup> Neal D., Bartels S.L., Chaouni S.B. et al. (2025) Effective for whom? A review of psychological and social intervention recommendations in European dementia care guidelines, through the lenses of social health and intersectionality. *Behavioral Sciences* (accepted 25 March 2025).
- <sup>17</sup> Knapp M, Lorenz-Dant K, Walbaum M, et al. (2024) Scaling-up an evidence-based intervention for family carers of people with dementia: current and future costs and outcomes. *Int J Geriatr Psychiatry*. 2024:e6059. <https://doi.org/10.1002/gps.6059>



## Support for caregivers of people with dementia: the Italian approach

The 2017–2025 WHO Global action plan on the public health response to dementia was the stimulus for Italy to define and implement actions on the specific seven areas of intervention.

Within the activities of the Italian Alzheimer's and Dementia Fund 2021–2023, we can identify five actions that directly or indirectly offered support to caregivers of people with dementia (PLWD).<sup>18,19</sup>

1. Between October 2022 and July 2023, 21 focus group were conducted (one for each Italian region and autonomous province) involving 142 family members/caregivers. The main themes explored were: a) strengths and weaknesses of regional/provincial care pathways for PLWD; b) improvements in care provision; c) the impact of COVID-19 on the care provision for PLWD and their caregiver; d) training needs for caregivers.
2. A cross-sectional national survey was performed between September 2022 and October 2023 on the socioeconomic conditions of family members and caregivers of PLWD through an online or paper-based questionnaire. We developed an ad-hoc, self-administered questionnaire to get a sense of the profile of the family member, presence and profile of a paid carer, profile of the PLWD, phase of diagnostic suspicion, phase of diagnosis, service provision, cost of the disease, impact of COVID-19, the territory context, ethical aspects, and legal figures. A total of 2,369 caregivers completed the survey, the majority of whom resided in Northern Italy (60.1 percent), followed by the South/Islands (22.3 percent) and Centre (17.6 percent). Caregivers were predominantly females (73.4 percent) and care recipients' children (74.1 percent).
3. In March 2023, a specific residential course for family members was organised at the National Institute of Health. The course was part of a larger project with relatives of people with dementia, the aim of which was to collect information on their needs and difficulties when taking charge of a PLWD, and to

offer relatives skills and strategies useful for their own well-being as well as that of their loved ones. The general objective was to promote the most effective approaches for the family member to care for a PLWD during different stages of the condition. The specific objectives were for participants, by the end of the course, to be able to:

- a. know the main clinical and evolutionary aspects of dementia
  - b. know the relational and communicative aspects in the approach with the PLWD
  - c. learn the main methods of managing the condition at various stages
  - d. know the impact of the condition on the psychophysical health of the family member
  - e. learn the methods of prevention and management of the psychophysical health of the family member
  - f. know the legal figures and the network of services in the area
4. Italy's first national guideline on dementia and mild cognitive impairment<sup>20</sup> addressing diagnosis, treatment, and care within the National Healthcare System was published in November 2024. It includes 167 recommendations on pharmacological and non-pharmacological approaches, and emphasises tailored interventions, comprehensive cognitive assessment, staff training, and palliative care. The guideline also underlines the need to involve PLWD in decision-making and supporting caregivers throughout the entire course of the disease. As part of this operation, a 16-page leaflet was drawn up specifically for relatives of PLWD, notably sharing practical recommendations on diagnosis, the role of different healthcare professionals, post-diagnosis, care models, drug treatments for Alzheimer's disease, non-pharmacological interventions, non-cognitive symptoms, and palliative care.<sup>21</sup>

The guidelines for professionals, "Diagnosis and Treatment of Dementia and Mild Cognitive Impairment," were published in January 2024. It is associated with the interactive diagnostic

<sup>18</sup> Ancidoni A, Sciancalepore F, et al. Permanent Table of the National Dementia Plan Study Group; Istituto Superiore di Sanità FONDEM Study Group; Istituto Superiore di Sanità FONDEM StudyGroup. The Italian fund for Alzheimer's and other dementias: strategies and objectives to face the dementia challenge. *Ann Ist Super Sanita*. 2022 Jul-Sep;58(3):192-196. doi: 10.4415/ANN\_22\_03\_08. PMID: 36128968.

<sup>19</sup> Ancidoni A, Lacorte E, et al. Italy's actions on dementia. *Lancet Neurol*. 2023 Feb;22(2):111. doi: 10.1016/S1474-4422(22)00521-X. PMID: 36681442.

<sup>20</sup> Fabrizi E, Ancidoni A, et al. Guideline Working Group. The Italian guideline on diagnosis and treatment of dementia and mild cognitive impairment. *Age Ageing*. 2024 Nov 1;53(11):afae250. doi: 10.1093/ageing/afae250. PMID: 39544104; PMCID: PMC11564805.

<sup>21</sup> The Italian guideline on Diagnosis and treatment of dementia and Mild Cognitive Impairment. When, what, where. Leaflet for people with dementia and MCI and their carers <https://www.iss.it/documents/d/guest/leaflet-for-people-with-dementia-and-mci-and-their-caregivers>

care pathway intended for health professionals, decision-makers, and family members/caregivers.<sup>22</sup>

5. Finally, in the context of the document "Recommendations for governance and clinics in the dementia sector: reflections on some ethical implications,"<sup>23</sup> drafted in 2020, some recommendations on communication of the diagnosis of dementia, assessment of capacity, legal issues and advance treatment provisions in PLWD are relevant, in particular:
  - a. the development of training initiatives on legal protection tools
  - b. uniform application throughout the national territory of Law No. 38 of 15 March 2010 "Provisions to guarantee access to palliative care and pain therapy"
  - c. the definition of models for taking charge of PLWD that make the legal figures of reference and the paths to follow explicit and accessible to family members
  - d. communication methods
  - e. sharing information
  - f. planning of the communication of the diagnosis of dementia
  - g. the assessment of a PLWD's capacity, first and foremost to express informed consent to treatments, carried out by the clinician from the first interview and repeated over time

This document is available on the Italian National Institute of Health Dementia Observatory website and has been distributed to all regions and autonomous provinces. The group that drafted this document is coordinated by the Ministry of Health and includes representatives of all the regions and autonomous provinces, the three national associations of family members, and scientific societies, as well as the National Institute of Health.

The combination of these five previous actions highlights how Italy has implemented activities that start from the analysis of the needs of PLWD and their families (actions 1 and 2) and then focus on reference documents such as the Guideline for diagnosis and

treatment and the one on clinical governance (actions 4 and 5) for the training of healthcare professionals as well as, in the case of the residential course, for information and training of family members (action 3).

As part of the Alzheimer's and Dementia Fund 2024–2026, a national strategy has been developed to train healthcare workers as well as provide information and training for family members, trying to involve 178 local family associations that have recently been surveyed throughout the country.

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**It is urgent to develop and coordinate policies that can address this [funding] problem by supporting families in the best possible way.**

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The greatest difficulties in Italy are due to the great variance in the organisation of services dedicated to dementia between regions, which creates confusion among family members. Furthermore, the lack of funding for the country's national dementia plan makes it difficult to implement many of the policies that are promoted at the national and local levels. In Italy, it is estimated that the cost of dementia is equal to 23 billion euros per year, of which 63 percent is borne by families.<sup>24</sup> It is urgent to develop and coordinate policies that can address this problem by supporting families in the best possible way.

**Nicola Vanacore**, head of the Dementia Observatory of the Istituto Superiore di Sanità, National Centre for Disease Prevention and Health Promotion, National Institute of Health, Rome, Italy, **Antonio Ancidoni**, **Ilaria Bacigalupo**, **Guido Bellomo**, **Flaminia Camilli**, **Francesco Della Gatta**, **Teresa Di Fiandra**, **Annachiara Di Nolfi**, **Elisa Fabrizi**, **Angela Giusti**, **Eleonora Lacorte**, **Nicoletta Locuratolo**, **Flavia Lombardo**, **Patrizia Lorenzini**, **Alice Paggetti**, **Vittorio Palermo**, **Ilaria Palazzesi**, **Serena Passoni**, **Maria Cristina Porrello**, **Emanuela Salvi**, **Paola Scardetta**, **Francesco Sciancalepore**, and **Francesca Zambri**, the Istituto Superiore di Sanità FONDEM Study Group.

<sup>22</sup> The Italian guideline on Diagnosis and treatment of dementia and Mild Cognitive Impairment Care pathway <https://www.iss.it/documents/d/guest/care-pathway>

<sup>23</sup> Raccomandazioni per la governance e la clinica nel settore delle demenze (italiano) [https://www.demenze.it/documenti/schede/raccomandazioni\\_per\\_la\\_governance\\_e\\_la\\_clinica\\_nel\\_settore\\_delle\\_demenze.pdf](https://www.demenze.it/documenti/schede/raccomandazioni_per_la_governance_e_la_clinica_nel_settore_delle_demenze.pdf). Roma 6 agosto 2020.

<sup>24</sup> Francesco Saverio Mennini, Chiara Bini and Paolo Sciattella, Cost of illness and cost-consequences analysis of dementia in Italy. In: National Guideline on Diagnosis and treatment of dementia and Mild Cognitive Impairment. Italian National Institute of Health, July 2024, pg 352-371. <https://www.iss.it/documents/d/guest/the-full-guideline-english-version>

## Key points



It is vital for policies that address dementia to take into account the needs of informal carers and health and care professionals, who represent the foundation of care and support for people living with dementia. Without the essential, unpaid work of informal carers, our societies would collapse. It is far past time that their labour be recognised. The Global action plan extension is a critical opportunity to do right by them.

# Chapter 6

## Information systems for dementia



**WHO target: 75% of countries provide support and training programmes for carers and families of people with dementia by 2025.**

Data can be a powerful tool for both research and advocacy. Before the 10/66 dementia research group began gathering prevalence and incidence data back in 1998, we had little understanding of the global impact of dementia. Those numbers, picked up by the WHO in the early 2000s, helped shape global advocacy efforts and paved the way for the Global action plan on dementia.

When the Global action plan was established in 2017, tangible data for Action area 6 on information systems was sparse. Our first From Plan to Impact reported the WHO's efforts to rectify this through the development of the Global Dementia Observatory (GDO) to monitor progress of the Global action plan by collating data from WHO member states on 35 key dementia indicators. In our first report, there were only 21 countries collecting data; now, there are over 62.

Through the past eight years, information systems and data collection mechanisms have slowly grown and widened in scope. Registries have become more important – not only keeping track of who has been diagnosed but also identifying patterns and characteristics of patients who might benefit from a particular treatment option and following long-term outcomes, ensuring better care. The use of 'big data' to help spot disease trends and pinpoint precision risk reduction possibilities has gained traction. But there is still much more to do.

Niranjan Bose gives some reasons for optimism in his essay, focusing on the growing opportunities of data. Bose explores the impact better data has had on improving diagnosis, how voice analysis on smartphones is opening new opportunities, and how better understanding of real-world data can lead to a future with large, harmonised data sets that can be shared to facilitate progress.

Anne Øksengård, Marit Nåvik, Karin Persson, and Geir Selbæk meanwhile detail how the NorCog registry has transformed patient care and research innovation in Norway. They describe how the patient registry monitors patient reported outcomes and ensures quality of care across the system, improving diagnostics and post-diagnostic care.

Information systems and the data they produce can play a crucial role in the care and management of individuals with dementia. Collecting, analysing, and sharing data through improved and coordinated information systems will not only help drive better understanding and innovation, but it will also improve patient outcomes, streamline care, and enhance the efficiency of healthcare systems.

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Information systems and the data they produce can play a crucial role in the care and management of individuals with dementia.

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## Fostering a stronger information systems future for dementia

Unfortunately, it is hard to characterise the world's performance to date on Action area 6 of the WHO's Global action plan as anything other than disappointing. The goal established in 2017 was for 50 percent of countries to be routinely collecting core sets of dementia indicators through their national health and social information systems every two years by 2025. Suffice to say, we are nowhere close to that goal. However, dig a little deeper and there are reasons for optimism should the action plan get extended.

The essential idea underlying Action area 6 – that policymakers and providers need substantially more information about dementia to make evidence-based decisions – is more valid than ever. In 2017, when the Global Action Plan was launched, it was projected that 132 million people would be affected by dementias by 2050.<sup>1</sup> According to IHME figures, that number is now estimated to rise to 153 million.<sup>2</sup> If the world is going to address this coming crisis, our knowledge about dementias needs to grow as fast as – or even faster than – the burden of disease.

The good news is that the path from the status quo to a real flow of information that fundamentally changes the way we prevent, diagnose, and treat dementia, support caregivers, and research and develop new solutions is significantly clearer than it was eight years ago.

### Growing opportunities for data

First, our ability to diagnose the condition has improved markedly, which is critical when three quarters of dementias (and as many as 90 percent in lower- and middle-income countries) go undiagnosed. The validation of blood-based biomarkers can mark a paradigm shift, with affordable, early, and definitive diagnoses of Alzheimer's disease and related dementias becoming the norm. Some potential technical developments, like being able to diagnose dementia through dried blood spots from a finger prick, promise to dramatically increase access to diagnosis, giving us a much more specific and thorough understanding of our denominator.

Similarly, we are seeing exciting progress on smartphone-based assessments – for example, digital voice analysis or wayfinding tasks – that seem to

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effectively identify mild cognitive impairment. These tests still need to be validated, but artificial intelligence is helping accelerate that process. Knowing who has dementia, especially in lower- and middle-income countries that are underrepresented in our data but overrepresented in new cases, will be a game changer.

The second development that changes the calculus on information systems is the approval of monoclonal antibodies targeting amyloid, the first disease-modifying treatments ever for Alzheimer's disease. Now that it may be possible to actually slow cognitive decline, we need the data to make evidence-based decisions about how, when, where, and to whom to deploy these treatments.

This dovetails with another development: progress toward better understanding real-world data. Although we are not there yet, it is no longer a fantasy to envision a future in which relevant electronic health records are combined into large, harmonised, and anonymised data sets that yield insights currently hidden from researchers because data is locked up in siloes. There are many, many challenges involved in operationalising these platforms, but it is enticing to consider the possibility of understanding the effectiveness and impact of monoclonal antibodies in a nuanced way from data that is already gathered as a matter of course – instead of trying to create a bespoke, parallel system to collect that data for a second time.

### Fostering a culture of data sharing

Finally, there are now successful models of transformation in dementia data ecosystems to follow. The work our partners at the Alzheimer's Disease Data Initiative has been doing is based on the idea that sharing more study data – and empowering researchers

<sup>1</sup> World Health Organization. (2017). Global action plan on the public health response to dementia 2017–2025. World Health Organization. <https://apps.who.int/iris/handle/10665/259615>

<sup>2</sup> Tran, Quang. Alzheimer's Research UK. Worldwide dementia cases to triple by 2050 to over 150 million people. 6 January 2022. <https://www.alzheimersresearchuk.org/news/worldwide-dementia-cases-to-triple-by-2050-to-over-150-million/>



with the tools they need to analyse it – will help unlock discoveries in Alzheimer's research and development. Alongside our partners, who come from across governments, universities, philanthropies, and the private sector, we have formed exciting collaborations and built tools that change the status quo. The lessons learned from this work can be applied to the larger project of building public health information systems for dementias.

For example, take the Global Neurodegeneration Proteomics Consortium (GNPC). Currently, the GNPC brings together 24 cohorts with nearly 40,000 biosample analyses and approximately 300 million unique protein measures.<sup>3</sup> We believe it is the largest neurodegeneration proteomics data set in the world. Based on unified protein measures across these samples, the GNPC also includes a basic set of associated, harmonised clinical data.

The scope and breadth of this data set gives us hope that it may be possible for researchers to identify complex signatures for early and specific diagnosis and prognosis, as well as biomarkers for disease and disease subtypes, and better indicators for predicting patient response to treatment. It may also be possible to develop predictive models that enable effective treatment during prodromal or even preclinical stages of neurodegeneration.

GNPC is an important breakthrough, and it took many months of work with all the data contributors involved to hammer out legal arrangements that fulfilled requirements and respected patients' data across the full range of different legal regimes. This creative legal work – addressing privacy concerns while unlocking data for collaborative research – can help point other data consortia toward solutions and, eventually, toward a true culture of data-sharing.

To promote this culture, we've also been building a digital data environment platform, the AD Workbench, that makes it easier for dementia researchers to find and analyse data collaboratively in secure workspaces. As of March 2025, AD Workbench now hosts more than 100 unique datasets covering 850,000 combined study participants, and it is being used by over 6,000 dementia researchers from over 100 countries to explore new hypotheses and innovations.<sup>4</sup> The workbench is also fully interoperable with eight other key dementia research platforms and counting. By making more data discoverable across a range of digital platforms, the Workbench and its interoperable partners



Niranjan Bose (right), with Paola Barbarino and Mark Roithmayr at the Alzheimer Disease Discovery Foundation's Melvin R. Goodes Prize ceremony in Stockholm, Sweden in September 2024.

are breaking down the silos that have inhibited progress in research and development. With some tweaking, a similar collaborative digital model could be employed to help countries meet their Action area 6 goals.

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**A research culture that has for too long siloed valuable data for a host of reasons is now learning to embrace the tremendous value of collaborative effort and shared data systems.**

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So, while the world has fallen well short of reaching its Action area 6 targets by 2025, there are still reasons for optimism in the years to come. Compared to eight years ago, dementia is significantly easier to diagnose, even in remote regions, at much lower cost and effort than ever before. Dementia researchers now have access to both exponentially more data and digital workspaces with powerful custom tools that will spur collaboration and innovation and get us to insights faster. And a research culture that has for too long siloed valuable data for a host of reasons is now learning to embrace the tremendous value of collaborative effort and shared data systems, within a context that respects patient privacy. Continuing to promote this collaboration – and helping the exciting changes now transforming dementia research take root in dementia monitoring – is the way forward.

**Niranjan Bose**, co-lead, AD-RIDDLE, EPND and managing director, Gates Ventures, interim Executive Director, AD Data Initiative

<sup>3</sup> Global Neurodegeneration Proteomics Consortium. <https://www.neuroproteome.org/>

<sup>4</sup> Alzheimer's Disease Data Initiative. <https://www.alzheimersdata.org/>

# NorCog – an essential tool for dementia research, health services, and policy planning in Norway

The Norwegian Registry of Persons Assessed for Cognitive Symptoms (NorCog)<sup>1</sup> was established in 2008, bringing together data from 27,256 patients (51 percent women, mean age 73.8).<sup>2</sup> The third Norwegian dementia plan (2020–2025)<sup>3</sup> stated the importance of NorCog in improving the quality of services patients receive when assessing for and treating cognitive impairment and dementia in specialist health services in Norway. NorCog contributes to reducing unjustified variations in healthcare services in the country, with indicators evaluating the quality of dementia assessments across Norway are published annually in a national report.

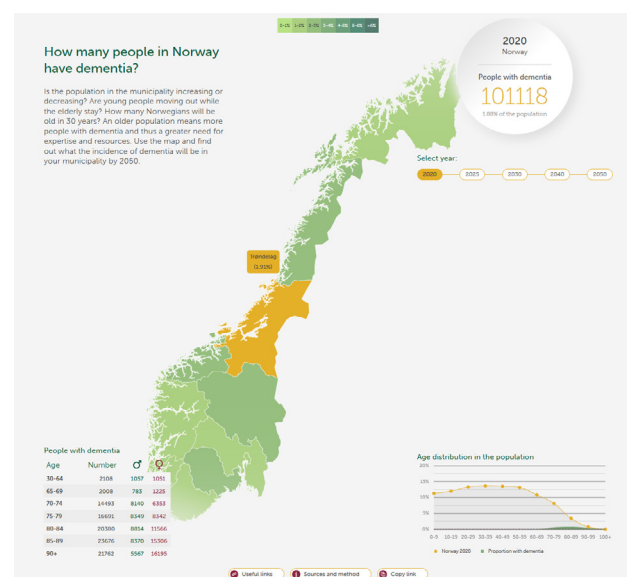
## Improving dementia services nationwide

The Norwegian Health Association, the national patient organisation for persons with dementia and their carers, has been involved in the development of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) recorded by NorCog. The data can be linked to medical records and other national health registries.

The Norwegian Health Association holds, at the time being, the position as the head of the NorCog advisory board. NorCog has approval to collect and keep data for as long as it is necessary to achieve the purpose of the registry. The cost of the daily operation and maintenance of the NorCog in 2025 is estimated to 340,000 euros, which is covered by the southeastern Norway regional health authority and The Norwegian National Centre for Ageing and Health.

Inclusion of new patients to NorCog has recently shifted from a consent-based to reservation-based system<sup>4</sup>. Participation is voluntary following national ethical standards for quality registries. Information about the registry is sent out to the patients in writing prior to work-up at the hospital and is repeated orally at the first visit. If the patients do not actively withdraw from participation in the registry, their data is automatically enrolled. If the patient lacks the capacity to consent, relatives can enrol or withdraw on their behalf.

The NorCog administration reports on a set of quality indicators<sup>5</sup> that the Ministry of Health uses to align the quality of dementia work-up in Norway. The Norwegian



The Demenskart.no website uses NorCog data in order to visualise dementia incidence in Norway.

ministry of health and care services is now looking at how NorCog should be used in all specialist health services, regardless of specialty and professional affiliation. For example, the ministry has set the standard that all patients included in NorCog must complete a PROM form in order to have patient-reported outcomes from all participants. If any hospital has difficulties to meet the standard quality level set by the Ministry of Health, actions will be discussed to mitigate this.

## A tool for research

The data collected by NorCog is also made available for research. As of February 2025, the NorCog research biobank includes biological material – such as EDTA plasma, EDTA whole blood, and whole blood in PAXgene RNA tubes, in addition to cerebrospinal fluid samples from 1,000 patients – from 6,431 subjects.

Collaboration with similar international and Nordic registries is commonplace, especially now that new diagnostics and treatments are evolving. Data from NorCog has been used in many research and quality projects, including on caregiver burden and requirement of available resources. A total of 135 articles have been

<sup>1</sup> Medbøen IT, Persson K, Nåvik M, et al. Cohort profile: the Norwegian Registry of Persons Assessed for Cognitive Symptoms (NorCog) – a national research and quality registry with a biomaterial collection. *BMJ Open* 2022;12: e058810. Doi: 10.1136/bmjopen-2021-058810

<sup>2</sup> <https://www.aldringoghelse.no/forskning-og-utvikling/norkog/information-in-english/>

<sup>3</sup> <https://www.regjeringen.no/en/dokumenter/dementia-plan-2025/id2788070/>

<sup>4</sup> <https://www.aldringoghelse.no/wp-content/uploads/2022/03/norkog-engelsk-pasientinformasjon-2022.pdf>

<sup>5</sup> <https://www.kvalitetsregistre.no/registeroversikt/norsk-register-for-personer-som-utredes-for-kognitive-symptomer/#norkog>

published since the register was established in 2008 using NorCog data.

One example is the recent collaboration between NorCog and the Health Survey in Nord Trøndelag (HUNT)<sup>6</sup> with partial funding from the Norwegian Health Association, to provide dementia prevalence and incidence numbers in Norway and obtain knowledge regarding the dementia diagnostic rate. This has resulted in several publications and the creation of a "dementia map"<sup>7</sup> that can be used to estimate the incidence of dementia in every Norwegian municipality by 2050 – a momentous asset for health services planning in the years to come.

The use of NorCog data by researchers is subject to national ethical and legal regulations, and all research projects must be approved by the national regulatory bodies and the NorCog Steering committee. Applicants from outside Norway are advised to identify a Norwegian collaborator.

NorCog does have some limitations; the data comes from routine clinical practice in geriatric and old-age

psychiatry units and may be of poorer quality than data collected in clinical trials. We are working to mitigate this, thanks to the support of all four Norwegian regional health authorities.

The establishment of the NorCog has been a crucial endeavour to improve dementia diagnostics and post-diagnostic support in Norway. Through ongoing research emerging from the NorCog database, many aspects of dementia in "real life" in Norway are better understood and publicly available – benefits that other states could reap if they emulate NorCog in their own countries.

**Dr Anne Rita Øksengård**, head of research and chair of the academic council, Norwegian Health Association ([anne.rita.oksengard@nasjonalforeningen.no](mailto:anne.rita.oksengard@nasjonalforeningen.no)), **Marit Nævik**, administrative coordinator and specialised nurse, Norwegian National Centre for Ageing and Health, **Dr Karin Persson**, scientific advisor, Norwegian National Centre for Ageing and Health, and **Professor Geir Selbæk**, managing director, Norwegian National Centre for Ageing and Health

## Key points



The Global action plan on dementia has given much-needed impetus to the creation and maintenance of dementia information systems worldwide. More states should recognise the importance of these vital tools to strengthen and improve dementia research and care in their countries and help advance data sharing at the international level.

<sup>6</sup> <https://www.med.uio.no/helsam/english/research/news-and-events/events/disputations/2024/gjora-linda.html>

<sup>7</sup> <https://demenskartet.no/>

# Chapter 7

## Dementia research and innovation



**WHO target: The output of global research on dementia doubles between 2017 and 2025.**

When ADI launched its From Plan to Impact report series eight years ago, the chapter on research and innovation was short. There was little to share; back in 2018, dementia research was heavily underfunded, with a 1:12 ratio of dementia research studies to cancer. There were no disease-moderating therapies (DMTs); risk reduction and brain health initiatives were still in their nascent stages; blood biomarkers (BBMs) and digital cognitive assessments held promise but seemed to be far on the horizon.

A lot has happened since. Although we still have a long way to go, we are clearly at the precipice of progress. Three DMTs have come to market – although one is no longer in use – and the other two are only available in a handful of countries. BBMs and digital cognitive assessments are increasingly available and currently undergoing several implementation studies in real-world settings. Risk reduction multimodal projects such as WW-FINGERS have expanded to 70 countries, providing individuals with tangible methods to improve outcomes and delay cognitive decline. Research is accelerating on potential causes of dementia that go beyond the amyloid/tau hypothesis.

Dr Jeffrey Cummings explores many of these advances in his essay, thoroughly recounting research development across the dementia pathway from risk reduction and early detection to new therapies, equity, and access. MP Joe Robertson drills down into the importance of funding dementia research from a UK perspective, with key recommendations for sustaining dementia as a key policy priority.

The progress of research has been built on solid foundations of scientific work that has been going on for decades, often behind the scenes. The acceleration we are experiencing, the momentum of progress, is the result of two key points. First, there was tremendous investment in funding dementia research between 2018 and 2024. Second, there has been investment by *individuals devoting time* – scientists, clinicians, people with lived experience – years of research, often in labs, unseen and quietly gathering data and results.

Now, in 2025, the dementia research community is experiencing unprecedented cuts to funding as the major funder of Alzheimer's disease and related dementia research (ADRD), the National Institute of Health in the USA, has been forced to freeze access or discontinue funding to many projects, particularly projects with any sort of diversity, equity, and inclusion (DEI) component (in-depth research on how race/sex/gender may impact dementia onset and progression). Even studies looking at hard-to-reach communities, social determinants of health, and diversity inclusion in clinical trials, have been cut. This could set ADRD research back decades.

So, in this eighth From Plan to Impact report, although we hail the progress of dementia research, we must be mindful of the risks posed by cuts to funding. As a scientific community, now is the time to double down on our efforts to ensure that research continues. People living with dementia and their families deserve nothing less.



## Dementia research and innovation: promising momentum

Forward scientific momentum has characterised the growth and accomplishments of Alzheimer's disease (AD) and dementia-related research since the publication of the World Health Organization (WHO) global action plan on dementia in 2017 to 2025. Advances have occurred in basic science understanding of dementia processes; pharmacological interventions for targeting defining aspects of AD; treatments for behavioural symptoms such as agitation; nonpharmacological and lifestyle interventions; the availability of biomarkers (especially blood-based biomarkers); and advances in digital measures and devices.

### A new era of Alzheimer's disease therapies

Some of these advances have become products that have entered the market, and some provide foundational information that will lead to improved care, prevention, and quality of life – yet global accessibility to new products and implementation of science into care are continuing challenges.

### Global accessibility to new products and implementation of science into care are continuing challenges.

Patients with AD and related dementias (ADRD) want therapies to improve their symptoms or slow the progression of loss of daily function. The timeframe from 2017 to 2025 saw the first approval of new treatments for treatment of AD since 2004. Aducanumab (Aduhelm) received accelerated approval by the United States Food and Drug Administration (FDA) in 2021; lecanemab (Leqembi) received accelerated and then standard approval in 2023; and donanemab (Kisunla) obtained standard approval in 2024.<sup>1</sup>

Originally approved in the US, these agents have now been approved and are being used more broadly. Aducanumab has been removed from the market for commercial reasons, while lecanemab and donanemab are experiencing growing use. These drugs represent a new era of disease-targeted therapy for the treatment of AD. They are anti-amyloid monoclonal antibodies that are administered intravenously. These agents slow disease progression and delay clinical decline by 25 to 40 percent. They are approved for use in mild cognitive



Jeffrey Cummings speaks at the ADI end of year forecast in December 2024.

impairment (MCI) and early dementia due to AD. They can produce amyloid-related imaging abnormalities (ARIA) with brain infusion or microhaemorrhage and must be monitored with magnetic resonance imaging (MRI) during the initiation phase. Lecanemab and donanemab are currently being tested in prevention trials of individuals who have evidence of brain amyloid but remain cognitively normal. The goal of these studies is to prevent the emergence of cognitive decline and to maintain normal cognitive function. Improved understanding of the neurobiology of AD, as well as progress in immunotherapies, are the basis for the disease-slowing evidenced by use of these agents.

Next generation anti-amyloid monoclonal antibody strategies are in progress. Induction of treatment with frequent administrations, followed by a maintenance phase with less frequent intravenous infusions, may be appropriate for some agents. Subcutaneous formulations of several monoclonal antibodies are being studied, and antibodies producing more rapid amyloid plaque reduction and exhibiting greater penetration into the brain are in clinical trials. Rapid evolution of monoclonal antibody therapy is anticipated, and active immunotherapy approaches with vaccines are under study.

There is progress in addressing non-amyloid aspects of AD pathophysiology. Advances are being made in disease-targeted therapies (DTTs) for disease processes such as neurofibrillary tangles, brain inflammation, and the improvement in brain circuit function and brain

<sup>1</sup> Perneczky R, Jessen F, et al. Anti-amyloid antibody therapies in Alzheimer's disease. *Brain*. 2023 Mar 1;146(3):842-849. doi: 10.1093/brain/awad005. PMID: 36655336.



connectivity based on synapses.<sup>2</sup> A variety of devices using different types of brain stimulation are being investigated as means of improving cognitive function in those with ADRD. Success in these areas may lead to new treatments or combinations of treatments with approved anti-amyloid agents. Application of artificial intelligence throughout the drug development process (discovery, screening of candidate therapies, animal model testing, participant identification, trial recruitment, etc) is expected to shorten development times and accelerate the emergence of new therapies.

## Building momentum

Neuropsychiatric symptoms are common in ADRD. Agitation, delusions, hallucinations, depression, apathy, irritability, wandering, and pacing are common among patients with AD and erode the quality of life of patients and their care partners. The past eight years have seen progress in addressing these important aspects of ADRD. Brexpiprazole (Rexulti) was approved by the FDA and has now been approved in many other countries for the treatment of agitation associated with dementia of AD. This is the first agent approved for any neuropsychiatric symptom in AD. There are currently ongoing clinical trials assessing the efficacy of agents for treatment of psychosis, agitation, and apathy associated with AD.<sup>2</sup> Reduction of neuropsychiatric symptoms is a key area of research that will have direct and immediate impact on patient and care partner life quality.

## Reduction of neuropsychiatric symptoms is a key area of research that will have direct and immediate impact on patient and care partner life quality.

Patient-Focused Drug Development (PFDD) places greater emphasis on aligning goals of patients and care partners with those of drug developers and clinical trials sponsors. PFDD helps ensure that patients' experiences, values, needs, and priorities are incorporated into drug development and evaluation programmes. Incorporating the patient's voice into trial planning and outcome selection enhances patient-informed quality of life outcomes in ADRD therapeutic development.

Knowledge and implementation of nonpharmacologic and lifestyle interventions are progressing. The

WW-FINGERS study emphasises physical exercise, nutrition, cognitive training, and control of cardiovascular and metabolic risk factors to improve cognitive health and forestall cognitive decline.<sup>3</sup> Lifestyle interventions are globally accessible and produce tangible benefits.

Progress in developing new therapeutics is related in part to the advances in availability of blood tests (blood-based biomarkers) that can accurately diagnose AD, stage the severity, and track therapeutic responses.<sup>4</sup> Specialised brain scans such as amyloid positron emission tomography (PET) and tau PET allow the visualisation and reduction by therapy of key pathologies of AD – amyloid plaques and neurofibrillary tangles, respectively. Blood-based biomarkers, especially phosphorylated tau (p-tau) 217 can be used to screen or diagnose AD and to monitor the response to therapy. New biomarkers are rapidly emerging and will accelerate clinical trials and identification of new therapies for patients with ADRD. Digital measures such as wearable devices that can be monitored remotely are proliferating and likely to be integrated into next generation clinical trials. Translation of the use of blood-based biomarkers and digital measures from clinical trials into clinical care has been initiated, placing new tools in the hands of clinicians.

Innovation is evident in ADRD drug development. Biomarkers are routinely implemented for trial participant selection as well as monitoring of outcomes. Novel trial designs have been introduced into clinical trials such as the randomised discontinuation of drugs for the treatment of neuropsychiatric symptoms to assess the durability of the treatment response. New analyses have made progress such as the conversion of drug-placebo differences on standard outcome measures to "timed saved" analyses that are often more meaningful to clinicians, patients, and care partners. For example, 18 months of treatment with an anti-amyloid monoclonal antibody result in approximately five months of delay to major milestones.<sup>5</sup> Longer periods of treatment may result in greater benefit.

Despite progress in diagnosis and treatment of ADRD, vexing problems remain. At the basic science level, progress is needed in developing biomarkers for brain proteins other than amyloid and tau. Biomarkers for the alpha-synuclein protein that commonly occurs in Parkinson's disease and TDP-43 protein that is characteristic of 50 percent of patients with

<sup>2</sup> Cummings J, Zhou Y, et al. Alzheimer's disease drug development pipeline: 2024. *Alzheimers Dement* (N Y). 2024 Apr 24;10(2):e12465. Dutch. doi: 10.1002/trc2.12465. PMID: 38659717; PMCID: PMC11040692.

<sup>3</sup> Kivipelto M, Mangialasche F, et al. World-Wide FINGERS Network: A global approach to risk reduction and prevention of dementia. *Alzheimers Dement*. 2020 Jul;16(7):1078-1094. doi: 10.1002/alz.12123. Epub 2020 Jul 5. PMID: 32627328; PMCID: PMC9527644.

<sup>4</sup> Jack CR Jr, Andrews JS, et al. Revised criteria for diagnosis and staging of Alzheimer's disease: Alzheimer's Association Workgroup. *Alzheimers Dement*. 2024 Aug;20(8):5143-5169. doi: 10.1002/alz.13859. Epub 2024 Jun 27. PMID: 38934362; PMCID: PMC11350039.

<sup>5</sup> Dickson SP, Wessels AM, et al. 'Time Saved' As a Demonstration of Clinical Meaningfulness and Illustrated Using the Donanemab TRAILBLAZER-ALZ Study Findings. *J Prev Alzheimers Dis*. 2023;10(3):595-599. doi: 10.14283/jpad.2023.50. PMID: 37357301.

frontotemporal dementia and most patients with amyotrophic lateral sclerosis are needed. These proteins also co-occur in some patients with AD, and biomarkers could inform clinicians and scientists regarding possible treatment resistance based on the presence of this co-pathology.

## Equity and access

Advances in treatment of AD such as the anti -amyloid monoclonal antibodies require technologically advanced healthcare delivery systems with capacity to absorb new populations requiring resources such as MRI, infusion centres, diagnostic platforms, and genetic counseling. Such resources are not equitably distributed globally, and access to these advanced medications will not be similar across global populations. Even within high-income countries, distribution of resources in urban and rural areas, as well as between high- and low-income populations, vary substantially and will limit access in low-resource areas.

Development of oral medications would facilitate global treatment advances, and implementation of brain health public awareness campaigns can also reduce global risk for ADRD. Advances in implementation science might lead to frameworks for resource development that can be implemented globally.

Forward momentum in dementia research and innovation is palpable. The approved treatments, while representing important progress, apply to a narrow range of mildly affected individuals, are complicated to use, require substantial safety monitoring, and demand a technologically advanced healthcare delivery system. Drugs that are applicable to patients with a wider range of dementia severity, easier to use, safer, affordable, and more widely accessible are needed. Education strategies, implementation approaches, and growth in regulatory science are all areas where progress can assist in making the remarkable advances of science widely available to improve patients' lives. The current momentum forecasts more progress toward these goals in the next iteration of WHO's action plan on dementia.

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## Forward momentum in dementia research and innovation is palpable.

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**Jeffrey L. Cummings, MD, ScD**, *Chambers-Grundy Center for Transformative Neuroscience, Department of Brain Health, Kirk Kerkorian School of Medicine at UNLV, University of Nevada Las Vegas (UNLV), Las Vegas, Nevada, USA*

## Dementia research in the United Kingdom: an opportunity that cannot be missed

Nearly a million people in the United Kingdom live with dementia, a number that continues to grow. According to Alzheimer's Research UK, If nothing changes, one in two living in the UK will have their lives impacted by dementia, either as a carer, by developing the condition themselves, or both.<sup>1</sup> Dementia has a devastating impact: it is the leading cause of death in the UK, costs the economy £42 billion per year, and is the most feared condition for people over 55. It will soon become the UK's most expensive health condition, overtaking cancer and heart disease.

The good news is that science and research have started to provide tools to address this. There are two treatments approved by global regulators, including in the UK, which slow the progression of Alzheimer's disease in its early stages. There are exciting developments around new ways to improve how we diagnose people with dementia, such as blood tests. This progress builds on the foundations laid by the previous government, but the UK is at a tipping point. Action is needed to ensure patients can benefit from new innovations while accelerating dementia research. The current government, which came to power in July 2024, has an opportunity to capitalise on this, supporting both health and wealth. It's an opportunity that cannot be missed.

In the past decade, the UK saw increases of investment in dementia research to over £100 million per year and the creation of ambitious initiatives such as the Dame Barbara Windsor Dementia Mission (now Goals Programme), which exists to accelerate the development of new treatments, taking inspiration from the UK's COVID-19 vaccine taskforce. Until 2020, a cross-government dementia strategy brought energy and focus to government action.

Dementia research is projected to return £2.91 to the UK economy per £1 invested between 2020–2040, resulting in a £670 million economic impact and supporting the equivalent of 9,309 full-time jobs across the UK.<sup>2</sup> This level of return on investment is projected to increase and will support economic growth. The success of drug trials in dementia, including over 160 global Alzheimer's disease trials, presents a significant opportunity for

if nothing changes, one in two living in the UK will have their lives impacted by dementia, either as a carer, by developing the condition themselves, or both.

patients to access innovative medicines but also opportunities to grow the UK economy.

There are, however, challenges. The UK has seen a reduction in Alzheimer's disease clinical trials in recent years, driven in part by the fallout from COVID-19. Between 2014 and 2023, the UK dropped from second to sixth globally in terms of the number of Alzheimer's disease clinical trials initiated in the calendar year.<sup>3</sup> Amongst the top 10 countries for dementia clinical trials initiated in 2022, the UK has the lowest proportion of phase 3 trial sites,<sup>4</sup> limiting the population's ability to participate in late-stage trials for innovative new dementia drugs. The majority of phase 3 trial sites in the UK for the new disease-modifying treatments for Alzheimer's disease – the first treatments to tackle the underlying mechanisms and slow progress of the disease – are in private centres, making them inaccessible to many.

The government has made some positive steps to address this, building on initiatives already in place that offer tremendous potential benefits by increasing the pace of this work. This includes the work of the Dame Barbara Windsor Dementia Goals Programme, and I am pleased that the government has said it will continue to invest in its work alongside implementing all the recommendations of the lauded review of Commercial Clinical Trials commissioned by Lord O'Shaughnessy in 2023. Yet the UK needs to go further if it is to fully realise the potential.

The National Health Service (NHS) is currently undergoing a period of significant change, with the direction being set out in the upcoming 10-year health plan. The government says it has a focus on improving elective care, setting an 18-week referral to treatment target by the end of this parliamentary term. What the UK also needs is a 10-year plan that looks beyond the

<sup>1</sup> <https://www.alzheimersresearchuk.org/news/how-we-calculated-our-one-in-two-dementia-statistic-and-what-we'll-do-about-it/>

<sup>2</sup> Alzheimer's Research UK. The Economic Value of Dementia Research, 2023.

<https://www.alzheimersresearchuk.org/wp-content/uploads/2023/07/Economic-Value-of-Dementia-Research- July-2023.pdf>

<sup>3</sup> Alzheimer's Research UK. Tipping Point: Our Manifesto for the Future of Dementia, 2024.

<https://www.alzheimersresearchuk.org/wp-content/uploads/2024/05/Tipping-Point-Our-Manifesto-for-The-Future-Of-Dementia.pdf>

<sup>4</sup> Data from clinicaltrials.gov.

immediate pressures on the healthcare system and seeks to address the root causes that are driving ever increasing demand for care, such as dementia. For example, clinical trials are essential to developing new treatments, but does the focus on elective recovery risk incentivising NHS clinicians to deprioritise involvement clinical research?

The government has removed the dementia diagnosis target of 66.7 percent from national guidance, sending a worrying signal that the focus on the condition is diminishing. The word "dementia" does not appear at all in the guidance that is supposed to set out the NHS's priorities.<sup>56</sup> The UK government recently announced that NHS England, the administrative body responsible for overseeing and directing the NHS in England, will be abolished and integrated into the Department of Health and Social Care. The reorganisation will happen over two years, with far-reaching changes that have created uncertainty and risk upheaval of the system.

It is vital that the government continues with both its life sciences and 10-year health plans if dementia research is to be given the priority it deserves. It is imperative that there is a renewed focus on dementia research and diagnosis – not only in the UK, but regionally and globally as well. Investment is key in three areas for

dementia to help both drive economic growth and ensure the NHS is fit for the future:

1. Invest in **dementia research** to help kickstart economic growth across the UK, while also addressing the huge health and social care challenges that dementia poses.
2. Scale up **diagnostic capacity** for dementia to relieve pressure on the health system and wider economy and help ensure that the NHS is fit for the future.
3. Support and accelerate the **adoption of new dementia technologies**, including therapies, diagnostics, and prevention interventions to foster innovation.

Over the last decade, the UK has made hard-won progress when it comes to dementia research, setting it apart as a model for other states to follow. The UK must continue to ensure that dementia research receives the political focus it merits. By adopting these recommendations, the UK can grasp the opportunity to support and inspire global efforts to turn the tide on dementia.

**Joe Robertson MP**, *member of the House of Commons Health and Social Care Committee, UK*

## Key points



The past eight years have seen unprecedented progress in dementia research, giving us hope that treatments will gain in effectiveness and outreach in coming years, and that a cure will one day be on the horizon. These advances are fragile, however; the extension of the Global action plan on dementia is an injunction to us all not to squander the momentum of the past decade.

<sup>5</sup> NHS England. 2025/26 priorities and operational planning guidance, 2025.  
<https://www.england.nhs.uk/long-read/2025-26-priorities-and-operational-planning-guidance/>

## Report summary

Over the past eight years, ADI and fellow advocates have urged WHO member states to fulfil their pledge to implement the Global action plan on dementia in their countries by developing national dementia plans. As the initial timeframe of the plan comes to a close, it's hard to feel optimistic when faced with the undeniable: member states have fallen far short of the targets set by the plan.

Dementia does not discriminate. Yet, how people experience the course of the condition is at the mercy of many factors outside of their control: who they are, where they live, what opportunities for diagnosis, treatment, and care are available to them, and what types of support, if any, are at their disposal.

The world is a different place than it was in 2017 when the Global action plan was created. Uncertainty is rife, and the eruption of simultaneous headline-grabbing crises around the world make it all the more difficult to tackle issues like dementia, which have far-ranging, dire consequences for our societies, but evolve slowly in ways that do not always capture the world's attention.

But there is also enormous fodder for hope. We have seen unprecedented progress in our scientific understanding of the risk factors for dementia; methods have been developed to diagnose the condition more accurately and earlier; emergent disease-modifying drugs are breaking new ground in pharmacological treatment; and person-centred care and inclusion are making a real difference in the lives of many. Many states have been encouraged by the Global action plan to address dementia in their countries, including the insights of people living with dementia in the elaboration of multifaceted policies.

The difficult circumstances we find ourselves in make it even more imperative for us to respond to the urgency of our time. We cannot succumb to despair or defeatism; the lives of millions of people with dementia, their carers, and communities depend on everyone doing their part – whether relatives and loved ones, volunteers in dementia associations, health and care professionals, global advocates, or members of governments at every level.

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## The difficult circumstances we find ourselves in make it even more imperative for us to respond to the urgency of our time.

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While the Global action plan on dementia has not galvanised member states to the degree it had hoped, it has nonetheless been a valuable compass since 2017, showing the way for those dedicated to taking action. Things are starting to change. We have more national dementia plans this year than we have had for the past five years. To lose this momentum would be a tragedy; to let an extension of the plan lead to further complacency would be an outright catastrophe.

Our message has been said time and time again, but it bears repeating: dementia is everyone's business. By showing up for the most vulnerable amongst us, we can create a better world for all of us. That vision, no matter the obstacles, is one worth pursuing.



## Appendix A

ADI member nations that are WHO member states, with dementia plans represented by income group, plan stage, and status as of 30 April 2025

Country	WHO region	WHO status	ADI status	Income group	Plan status	
Argentina	Region of the Americas	WHO	Member	HIC	Stage 3C	In development, slow progress
Armenia	European region	WHO	Member	UMIC	Stage 5B	Plan adopted, funded, and monitored
Australia	Western Pacific region	WHO	Member	HIC	Stage 4 & Stage 4F	Plan/strategy adopted but with inadequate or no funding & Plan adopted, but not implemented
Austria	European region	WHO	Member	HIC	Stage 4A	Inadequate funding
Azerbaijan	European region	WHO	MDP	UMIC	Stage 2B	Some developments towards a plan, but progress stalled
Bahamas	Region of the Americas	WHO	Member	HIC	Stage 2A	Initial meetings with government, but no further progress
Bangladesh	South-East Asian Region	WHO	MDP	LMIC	Stage 2B & 2D	Some developments towards a plan, but progress stalled & Grouped health plan (i.e., dementia is integrated into a broader health plan which could include older persons, non-communicable disease, neurology, mental health etc.) including dementia under consideration
Barbados	Region of the Americas	WHO	Member	HIC	Stage 2D	Grouped health plan (i.e., dementia is integrated into a broader health plan which could include older persons, non-communicable disease, neurology, mental health etc.) including dementia under consideration
Belgium	European region	WHO	Member	HIC	Stage 2C	Some funding committed to 7 action areas of Global plan, but no expressed intention of launching a plan
Bolivia	Region of the Americas	WHO	Member	LMIC	Stage 2B	Some developments towards a plan, but progress stalled
Bosnia and Herzegovina	European region	WHO	Member	UMIC	Stage 4	Plan/strategy adopted but with inadequate or no funding
Botswana	African region	WHO	MDP	UMIC	Stage 2A	Initial meetings with government, but no further progress
Brazil	Region of the Americas	WHO	Member	UMIC	Stage 4B	No funding
Brunei Darussalam	Western Pacific region	WHO	Member	HIC	Stage 3D	Grouped health plan including dementia in development
Bulgaria	European region	WHO	Member	UMIC	Stage 2D & 2E	Grouped health plan (i.e., dementia is integrated into a broader health plan which could include older persons, non-communicable disease, neurology, mental health etc.) including dementia under consideration & Dementia referred to in existing grouped health plan, but not as a separate health condition
Burundi	African region	WHO	MDP	LIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Cameroon	African region	WHO	Member	LMIC	Stage 2B	Some developments towards a plan, but progress stalled
Canada	Region of the Americas	WHO	Member	HIC	Stage 4A	Inadequate funding
Chile	Region of the Americas	WHO	Member	HIC	Stage 5A	Plan adopted but not fully communicated

Country	WHO region	WHO status	ADI status	Income group	Plan status	
China	Western Pacific region	WHO	Member	HIC	Stage 5B	Plan adopted, funded, and monitored
Colombia	Region of the Americas	WHO	Member	UMIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Costa Rica	Region of the Americas	WHO	Member	HIC	Stage 4A	Inadequate funding
Croatia	European region	WHO	Member	HIC	Stage 3D	Grouped health plan including dementia in development
Cuba	Region of the Americas	WHO	Member	LMIC	Stage 4	Plan/strategy adopted but with inadequate or no funding
Cyprus	European region	WHO	Member	HIC	Stage 4B	No funding
Czechia	European region	WHO	Member	HIC	Stage 4A	Inadequate funding
Denmark	European region	WHO	Member	HIC	Stage 5A	Plan adopted but not fully communicated
Dominica	Region of the Americas	WHO	MDP	UMIC	Stage 3C	In development, slow progress
Dominican Republic	Region of the Americas	WHO	Member	UMIC	Stage 4F	Plan adopted, but not implemented
Ecuador	Region of the Americas	WHO	Member	UMIC	Stage 1	No current contact with government or Ministry of Health
Egypt	Eastern Mediterranean region	WHO	Member	LMIC	Stage 2D	Grouped health plan (i.e., dementia is integrated into a broader health plan which could include older persons, non-communicable disease, neurology, mental health etc.) including dementia under consideration
El Salvador	Region of the Americas	WHO	Member	LMIC	Stage 1	No current contact with government or Ministry of Health
Estonia	European region	WHO	MDP	HIC	Stage 2C	Some funding committed to 7 action areas of Global plan, but no expressed intention of launching a plan
Ethiopia	African region	WHO	MDP	LIC	Stage 2B	Some developments towards a plan, but progress stalled
Finland	European region	WHO	Member	HIC	Stage 2C	Some funding committed to 7 action areas of Global plan, but no expressed intention of launching a plan
France	European region	WHO	Member	HIC	Stage 2B	Some developments towards a plan, but progress stalled
Georgia	European region	WHO	Member	LMIC	Stage 2A	Initial meetings with government, but no further progress
Germany	European region	WHO	Member	HIC	Stage 5B	Plan adopted, funded, and monitored
Ghana	African region	WHO	Member	LMIC	Stage 3C	In development, slow progress
Greece	European region	WHO	Member	HIC	Stage 5B & Stage 5C	Plan adopted, funded, and monitored & Grouped health plan including dementia adopted, with specific targets and funding
Grenada	Region of the Americas	WHO	MDP	UMIC	Stage 2A	Initial meetings with government, but no further progress
Guatemala	Region of the Americas	WHO	Member	UMIC	Stage 2A & 2E	Initial meetings with government, but no further progress & Dementia referred to in existing grouped health plan, but not as a separate health condition
Honduras	Region of the Americas	WHO	Member	LMIC	Stage 2A	Initial meetings with government, but no further progress
Hungary	European region	WHO	MDP	HIC	Stage 2B	Some developments towards a plan, but progress stalled
India	South-East Asian Region	WHO	Member	LMIC	Stage 3A	Not yet launched, but commitment to funding for some of the 7 action areas
Indonesia	South-East Asian Region	WHO	Member	LMIC	Stage 5A	Plan adopted but not fully communicated

Country	WHO region	WHO status	ADI status	Income group	Plan status	
Iran	Eastern Mediterranean region	WHO	Member	UMIC	Stage 4F	Plan adopted, but not implemented
Israel	European region	WHO	Member	HIC	Stage 4B	No funding
Italy	European region	WHO	Member	HIC	Stage 4A	Inadequate funding
Jamaica	Region of the Americas	WHO	Member	UMIC	Stage 2A	Initial meetings with government, but no further progress
Japan	Western Pacific region	WHO	Member	HIC	Stage 5B	Plan adopted, funded, and monitored
Jordan	Eastern Mediterranean region	WHO	Member	UMIC	Stage 3C	In development, slow progress
Kazakhstan	European region	WHO	MDP	UMIC	Stage 1	No current contact with government or Ministry of Health
Kenya	African region	WHO	Member	LMIC	Stage 3C	In development, slow progress
Lebanon	Eastern Mediterranean region	WHO	Member	UMIC	Stage 2B	Some developments towards a plan, but progress stalled
Lesotho	African region	WHO	Member	LMIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Lithuania	European region	WHO	MDP	HIC	Stage 2B	Some developments towards a plan, but progress stalled
North Macedonia	European region	WHO	MDP	UMIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Madagascar	African region	WHO	Member	LIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Malaysia	Western Pacific region	WHO	Member	UMIC	Stage 5A	Plan adopted but not fully communicated
Maldives	South-East Asian Region	WHO	Member	UMIC	Stage 3B	In development, good progress
Mali	African region	WHO	MDP	LIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Malta	European region	WHO	Member	HIC	Stage 4A	Inadequate funding
Mauritius	African region	WHO	Member	UMIC	Stage 2B	Some developments towards a plan, but progress stalled
Mexico	Region of the Americas	WHO	Member	UMIC	Stage 4B	No funding
Montenegro	European region	WHO	Member	UMIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Morocco	Eastern Mediterranean region	WHO	Member	LMIC	Stage 1	No current contact with government or Ministry of Health
Netherlands	European region	WHO	Member	HIC	Stage 5B	Plan adopted, funded, and monitored
New Zealand	Western Pacific region	WHO	Member	HIC	Stage 4B	No funding
Nigeria	African region	WHO	Member	LMIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition

Country	WHO region	WHO status	ADI status	Income group	Plan status	
Norway	European region	WHO	Member	HIC	Stage 4A & Stage 5B	Inadequate funding & Plan adopted, funded, and monitored
Oman	Eastern Mediterranean region	WHO	Member	HIC	Stage 1	No current contact with government or Ministry of Health
Pakistan	Eastern Mediterranean region	WHO	Member	LMIC	Stage 3C	In development, slow progress
Panama	Region of the Americas	WHO	Member	HIC	Stage 3B	In development, good progress
Peru	Region of the Americas	WHO	Member	UMIC	Stage 3C	In development, slow progress
Philippines	Western Pacific region	WHO	Member	LMIC	Stage 4E	Grouped health plan including dementia, adopted but with no or inadequate funding
Poland	European region	WHO	Member	HIC	Stage 3B	In development, good progress
Portugal	European region	WHO	Member	HIC	Stage 4F	Plan adopted, but not implemented
Qatar	Eastern Mediterranean region	WHO	Member	HIC	Stage 4E	Grouped health plan including dementia, adopted but with no or inadequate funding
Romania	European region	WHO	Member	UMIC	Stage 2B	Some developments towards a plan, but progress stalled
Russian Federation	European region	WHO	Member	UMIC		
Saint Lucia	Region of the Americas	WHO	MDP	UMIC	Stage 2A & 2E	Initial meetings with government, but no further progress & Dementia referred to in existing grouped health plan, but not as a separate health condition
Saint Vincent and the Grenadines	Region of the Americas	WHO	MDP	UMIC	Stage 2A	Initial meetings with government, but no further progress
Saudi Arabia	Eastern Mediterranean region	WHO	Member	HIC	Stage 4	Plan/strategy adopted but with inadequate or no funding
Senegal	African region	WHO	MDP	LIC	Stage 2A	Initial meetings with government, but no further progress
Serbia	European region	WHO	MDP	UMIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Seychelles	African region	WHO	MDP	LIC	Stage 2D	Grouped health plan (i.e., dementia is integrated into a broader health plan which could include older persons, non-communicable disease, neurology, mental health etc.) including dementia under consideration
Singapore	Western Pacific region	WHO	Member	HIC	Stage 5A	Plan adopted but not fully communicated
Slovak Republic	European region	WHO	Member	HIC	Stage 3	Not yet launched, but commitment to funding for some of the 7 action areas
Slovenia	European region	WHO	Member	HIC	Stage 5B	Plan adopted, funded, and monitored
South Africa	African region	WHO	Member	UMIC	Stage 2B	Some developments towards a plan, but progress stalled
Spain	European region	WHO	Member	HIC	Stage 3C	In development, slow progress
Sri Lanka	South-East Asian Region	WHO	Member	LMIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition

Country	WHO region	WHO status	ADI status	Income group	Plan status	
St Kitts and Nevis	Region of the Americas	WHO	Member	HIC	Stage 2A	Initial meetings with government, but no further progress
Suriname	Region of the Americas	WHO	Member	UMIC	Stage 3C	In development, slow progress
Sweden	European region	WHO	Member	HIC	Stage 5B	Plan adopted, funded, and monitored
Switzerland	European region	WHO	MDP	HIC		
Thailand	South-East Asian Region	WHO	Member	UMIC	Stage 5B	Plan adopted, funded, and monitored
Tonga	Western Pacific region	WHO	Member	UMIC	Stage 2A & 2B	Initial meetings with government, but no further progress & Some developments towards a plan, but progress stalled
Trinidad and Tobago	Region of the Americas	WHO	Member	HIC	Stage 3C	In development, slow progress
Tunisia	Eastern Mediterranean region	WHO	Member	LMIC	Stage 2B	Some developments towards a plan, but progress stalled
Türkiye	European region	WHO	Member	UMIC	Stage 3B	In development, good progress
Uganda	African region	WHO	Member	LIC	Stage 2D	Grouped health plan (i.e., dementia is integrated into a broader health plan which could include older persons, non-communicable disease, neurology, mental health etc.) including dementia under consideration
Ukraine	European region	WHO	Member	LMIC	Stage 3B	In development, good progress
United Arab Emirates	Eastern Mediterranean region	WHO	Member	HIC	Stage 2B	No plan/strategy
United Kingdom – England	European region	WHO	Member	HIC	Stage 2D	Grouped health plan (i.e., dementia is integrated into a broader health plan which could include older persons, non-communicable disease, neurology, mental health etc.) including dementia under consideration
United States of America	Region of the Americas	WHO	Member	HIC	Stage 5B	Plan adopted, funded, and monitored
Uruguay	Region of the Americas	WHO	Member	HIC		
Venezuela	Region of the Americas	WHO	Member	UMIC	Stage 1	No current contact with government or Ministry of Health
Vietnam	Western Pacific region	WHO	MDP	LMIC	Stage 4E	Grouped health plan including dementia, adopted but with no or inadequate funding
Yemen	Eastern Mediterranean region	WHO	Member	LIC	Stage 2A	Initial meetings with government, but no further progress
Zambia	African region	WHO	MDP	LMIC	Stage 1	No current contact with government or Ministry of Health
Zimbabwe	African region	WHO	Member	LIC	Stage 2A	Initial meetings with government, but no further progress



## Appendix B

ADI member nations that are not WHO member states, with dementia plans represented by plan stage and status as of 30 April 2025

Country	ADI member	Plan stage	Plan status
Aruba	MDP	Stage 2	No plan/strategy
Bermuda	Member	Stage 2A & Stage 2B	Initial meetings with government, but no further progress & Some developments towards a plan, but progress stalled
Bonaire	Member	Stage 4F	Plan adopted, but not implemented
British Virgin Islands	Member	Stage 2	No plan/strategy
Cayman Islands	Member	Stage 2A	Initial meetings with government, but no further progress
Curaçao	Member	Stage 4F	Plan adopted, but not implemented
Gibraltar	Member	Stage 5	Plan/strategy adopted and funded
Hong Kong SAR	Member	Stage 3C	In development, slow progress
Macau SAR	Member	Stage 5A	Plan adopted but not fully communicated
Puerto Rico	Member	Stage 4D	Plan under threat (e.g., is coming to an end and could be terminated or replaced by a general health plan)
Sint Maarten	Member	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
TADA Chinese Taipei	Member	Stage 5B	Plan adopted, funded, and monitored
United Kingdom – Northern Ireland	Member	Stage 4B	No funding
United Kingdom – Scotland	Member	Stage 4A	Inadequate funding
United Kingdom – Wales	Member	Stage 3C	In development, slow progress

## Definitions

Membership status	
Member	Full member of ADI. There is one member per country, which is the national Alzheimer's association who have completed ADI's 2-year Membership Development Programme and meet certain criteria
MDP	Member of ADI's 2-year Development Programme
Potential	Due to commence ADI Membership Development Programme
Income classification	
LIC	Lower-Income Country
LMIC	Lower-Middle Income Country
UMIC	Upper-Middle Income Country
HIC	High-income Country

## About ADI

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations throughout the world. Each of our more than 100 members is a non-profit Alzheimer association supporting people with dementia and their families. ADI's 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 carers, and to increase investment in dementia research.

## What we do

- Support the development and activities of our member associations around the world.
- Encourage the creation of new Alzheimer and dementia associations in countries where there is no organisation.
- Bring Alzheimer organisations together to share and learn from each other.
- Raise public and political awareness of dementia.
- Stimulate research into the prevalence and impact of Alzheimer's disease and dementia around the world.
- Represent people with dementia and families on international platforms at the UN and the WHO.



**Alzheimer's Disease  
International**

*The global voice on dementia*

## Key activities

- Raising global awareness through World Alzheimer's Month™ (September every year).
- Providing Alzheimer associations with training in running a non-profit organisation through our Alzheimer University programme.
- Hosting an international conference where staff and volunteers from Alzheimer associations meet each other as well as medical and care professionals, researchers, people with dementia and their carers.
- Disseminating reliable and accurate information through our website and publications.
- Delivering ADI accreditation programme to ensure people living with dementia receive high quality care and support provided by appropriately trained professionals and carers.
- Supporting global advocacy by providing facts and figures about dementia, and monitoring as well as influencing dementia policies.

ADI is based in London and is registered as a non-profit organisation in the USA. ADI was founded in 1984, has been in official relations with the World Health Organization since 1996. ADI is partnered with Dementia Alliance International (DAI), a collaboration of individuals diagnosed with dementia providing a unified voice of strength, advocacy, and support in the fight for individual autonomy for people with dementia.

You can find out more about ADI at [www.alzint.org](http://www.alzint.org)

Alzheimer's Disease International:  
The International Federation of  
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