



**Alzheimer's Disease  
International**

*The global voice on dementia*

# From Plan to Impact VI

*Making every step count*



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## Foreword



In 2017, all 194 Member States of the World Health Organization (WHO) unanimously adopted the Global action plan on the public health response to dementia 2017–2025. It was a pivotal moment, finally making dementia a much-needed global health priority. If everything had gone well, I would have opened this report by happily announcing the final furlough in Alzheimer's

Disease International's (ADI) almost 40-year battle for people living with dementia and their families to have a better life. In the last year, we have had some really positive news, with new National Dementia Plans launched in Armenia and Uruguay, and commitments from 20 further governments to develop plans. These announcements have mainly come as a consequence of ADI's #WhatsYourPlan campaign, of which we are immensely proud. However, this edition of our From Plan to Impact report series frustratingly shows that the key targets of the Global Action Plan are far from being met. The WHO update at this year's 76<sup>th</sup> World Health Assembly will echo these findings.

Strikingly, only around 20% of Member States have developed National Dementia Plans over the last six years. As we say in Italy, mathematics is not an opinion, and the figures show disappointingly slow progress against a target of 75% of nations. Indeed, in some countries like France and England – nations that formerly led the way and have the means to help their citizens – there have been steps backward, not forward. All of this is happening while we are on the cusp of great biomedical and technological advances in treatments and diagnostics, which will see those same citizens clamouring for more support, not less, from their governments.

We at ADI have learnt so much in the last six years, as we have been called upon more and more by governments to help them draft their plans. We have seen dementia tucked away under broader neurological conditions plans, mental health plans, and healthy ageing plans. But, as we have maintained for years, dementia is a complex condition that touches upon all aspects of life. Relatives can struggle to juggle work with their caring duties at home and develop mental health issues themselves, often exacerbated by a loss of income; young adults are often left to care for their grandparents, becoming isolated and missing out on education; and people living with dementia often

struggle to receive a proper diagnosis, and can be left alone, unsupported, and unable to access care. The multifaceted considerations of dementia are difficult to adequately address without specific, targeted policies – and without governments transparently funding diagnosis, treatment, care, support, and research.

However, let me be clear about something. While we strongly believe that a standalone dementia plan is by far the best way to help those who are living with dementia and their families, we are also pragmatic. As we note in the recommendations of this report, *perfect should not be the enemy of good*.

If a government tells us it does not have the resources required to deal with all seven areas of the Global Action Plan, we suggest they start with something simple – for example, conducting a public health campaign on dementia risk reduction, which can easily be pegged to campaigns for other conditions; raising awareness of warning signs of dementia at the primary care level; or even hosting their own clinical trials programmes, something that is increasingly becoming an issue for lower- and middle-income countries. If a government has an established risk reduction strategy under a non-communicable disease framework, then that is a foundation to start to integrate dementia. ADI will always work with governments to find the most implementable solutions – our principle is that you have to start somewhere.

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**We need to galvanise the dementia community, to innovate, to accelerate plan development, to hold governments to account, but to also work with and alongside them.**

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This brings me to the hardest part of this foreword, something I would have preferred not to write but that alas must be said. With progress on the Global Action Plan looking bleak six years on (we would need an unachievable 107 new plans created in the next two years to reach the 75% target), ADI is going to formally propose an extension to the plan in order to give the world's governments until 2029 to reach the targets.

This is a difficult decision to take, because there are a lot of positive things happening globally and we are building great momentum, which you will read about in this wonderful report. This year has seen positive news in dementia policy coming from the most unlikely corners of the world – the aforementioned new plans in Armenia and Uruguay, regional plan innovation in



Pakistan, and commitment from Ukraine to commence development, despite the current invasion. Our #WhatsYourPlan campaign, now in its second year, is going swimmingly, influencing many governments to start working on their plans. There is positive news in data sharing and in technical innovation – the essay in this report about the portable MRI alone will bring cheerfulness to everyone in our field.

However, we still need the important multilateral instrument that is the Global Action Plan in order to officially engage with governments. There is a risk of complacency by extending the plan, but we all need to commit to redouble our efforts should the extension be approved. We need to galvanise the dementia community, to innovate, to accelerate plan development, to hold governments to account, but to also work with and alongside them, to build on existing successful plans and models and to ensure that all nations develop National Dementia Plans. We need to make sure that no one is left behind.

To avoid losing momentum, we need all of you. To wake up in the morning knowing we represent so many voices, so many wonderful people living with dementia in need of better support and care, makes us work that much harder to get to where we need to be. To have all of you supporting, contributing, sustaining, and cheering us on makes such a difference. Thank you for not giving up, thank you for helping every day, thank you for being there and for being strong. We will get there, hopefully sooner rather than later.



**Paola Barbarino**  
Chief Executive Officer  
London, May 2023

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## Executive summary

As the seventh leading cause of death in the world,<sup>1</sup> dementia remains a deeply neglected and underserved health condition globally. Often repeated is the World Health Organization (WHO) statistic predicting that the number of cases of dementia in the world will rise from 55 million in 2019 to 139 million by 2050. If little is done by then, the situation will only get worse for people living with dementia and their families, who already struggle to get timely diagnosis, accurate information, and adapted support.

The WHO Global action plan on the public health response to dementia 2017–2025<sup>2</sup> was created with the aim of improving the lives of people with dementia and their carers, all while decreasing the impact of dementia on communities and countries through a series of seven action areas: dementia as a public health priority; dementia awareness and friendliness; risk reduction; diagnosis, treatment, care, and support; support for dementia carers; information systems for dementia; and research and innovation.

Six years into the plan, however, these targets are far from being reached. Notably, Action area 1, which calls for 75% of the WHO's 194 Member States to have adopted a National Dementia Plan, is faced with inaction from many governments.

There are nonetheless encouraging developments afoot: clinical trials are showing results that are grounds for cautious optimism about the emergence of disease-modifying treatments; information regarding risk reduction, warning signs and symptoms, and how to best care for someone living with dementia is more accessible than ever in a variety of formats; knowledge and technology are being used in innovative and collaborative ways to help raise awareness and increase rates of diagnosis.

In 2023, COVID-19 is no longer monopolising the world's attention, but health systems are still feeling its shockwaves. The pandemic has had a knock-on effect on people seeking access to timely diagnosis and support. Now more than ever, it is imperative for dementia to be treated seriously by governments as a health policy priority. ADI is calling on the WHO to extend the Global Action Plan until 2029, as an acknowledgment that Alzheimer's disease and other forms of dementia need to be taken seriously by states, and to ensure advocates can continue to use this tool



as leverage in their efforts to meet the needs of people living with dementia and those that support them.

More than a year since ADI launched its #WhatsYourPlan campaign, its successes show that where there's a will, there's a way. The campaign, which seeks to propel collaborative efforts between governments and key stakeholders to develop and implement solid National Dementia Plans, is proof that cross-sector dialogue and tools can make a concrete difference in policy. The fight for a better world for people living with dementia is far from over, and we must use every means at our disposal to turn this goal into reality.

<sup>1</sup> <https://www.who.int/news-room/fact-sheets/detail/dementia>

<sup>2</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.

## Key messages



- The number of National Dementia Plans (NDPs) implemented by Member States has remained unchanged since 2022 at 39. This equates to around 26% of the 146 target, and only around a fifth of all 194 Member States agreeing to implement a plan in 2017. As of May 2023, 46 countries or territories (including non-Member States) had NDPs.
- Dementia plans across WHO regions include 20 in Europe, eight in the Americas, two in Southeast Asia, six in the Western Pacific, three in the Eastern Mediterranean, and none in Africa.
- 22 countries are currently developing an NDP or are integrating dementia within a wider health plan.
- 54 new plans are needed annually to reach the WHO target of 146 plans (75% of Member States) by 2025. This is based on data collected from Alzheimer and dementia associations between January and April 2023 and assumes no additional plans are launched this calendar year.
- ADI's #WhatsYourPlan campaign has gained momentum this year, with 52 country associations and stakeholders participating, 154 official letters, 29 meetings with ministries of health, and 20 commitments to develop NDPs.
- ADI estimates that, globally, 75% of people with dementia are undiagnosed and up to 85% are not accessing post-diagnostic care. Health systems need to be strengthened to provide a clear pathway for timely diagnosis and access to ongoing care and support, especially as new disease-modifying drugs enter health systems.
- In the absence of NDPs, or in areas where dementia diagnosis and care pathways are disjointed and unclear, it is the third sector (e.g.: civil society, non-governmental organisations, etc.) that develops innovative projects or services to plug key gaps through public-private partnerships.
- Data collection and harmonisation is becoming increasingly important as global projects seek to understand the life-course factors that impact dementia. We must ensure that data is collected from across the globe, across diverse populations, or we risk using biased data that may undermine scientific understanding or the development of appropriate healthcare approaches.
- Despite a decreasing emphasis on the COVID-19 pandemic globally, ADI continues its extensive efforts to influence plans for the future WHO Pandemic Preparedness and Response Treaty. The disproportionate impact of the pandemic on people living with dementia should never be repeated, and governments must include humanitarian and pandemic response planning in their NDPs, as suggested in the Global Action Plan.

## Recommendations

- **ADI calls for an extension of the Global Action Plan on dementia's deadline until 2029**, to enable Member States to adhere to their 2017 commitments, particularly regarding the development of National Dementia Plans (NDPs).
- **Governments must accelerate efforts to develop NDPs.** ADI urges governments to accelerate the development, funding, and deployment of NDPs to provide best practice care and support for people with dementia.
- Some countries have taken the decision to integrate dementia into other policies, such as healthy ageing, mental health, neurology, or non-communicable diseases (NCD). In these cases, **integrated strategies or plans should always include the targets, indicators and, critically, ringfenced budgets that relate to the seven action areas of the WHO Global Action Plan.**
- While ADI believes NDPs are the best way to ensure dementia is adequately addressed, we recognise that many hurdles can impede governments' ability to produce comprehensive dementia policy. **Perfect should not be the enemy of good;** any efforts to improve the situation of people living with dementia, whether at a local level or focusing on only some of the action areas, should be encouraged to fill the gap until an NDP is implemented.
- **ADI invites governments to collaborate with #WhatsYourPlan.** The ADI campaign offers tailored support to governments – bringing together key stakeholders to work collaboratively towards the creation and implementation of NDPs.
- **Health systems need to be strengthened.** As we stand on the cusp of treatments and diagnostic breakthroughs, even high-income countries are not prepared for confirmatory diagnosis, which will result in people progressing out of treatment options.
- **All nations must recognise the role of informal carers, particularly women, and address the hurdles and costs associated with their role.** With so many people with dementia worldwide relying mainly on the unpaid support provided by family members and friends, ADI urges governments to address equal opportunities for women when developing national plans.
- **Data collection and harmonisation across research is crucial.** ADI encourages the development of data collection protocols that are universally available, with platforms that can safely make data accessible to the scientific community to accelerate better understanding and impact. We also encourage more governments to contribute to the next round of updates for the WHO Global Dementia Observatory (GDO).
- **ADI calls on governments to invest in dementia research and innovation.** Governments should invest a minimum of 1% of the societal cost of dementia into research. This report is peppered with examples of public-private partnerships that have innovated solutions to palliate key dementia care gaps. ADI encourages governments to support these efforts and work in partnership to embed them into policy to ensure sustainability and equitable access.
- **COVID-19 and future pandemic responses remain important.** Although many countries have moved on from the global pandemic, reverberations continue to be felt. Governments must consider dementia and NCD risk factors and build in resilience for future pandemics to ensure equity of access to treatment, care, and support and to avoid disruptions to the diagnostic pathway.



## 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

The World Health Organization (WHO) adopted the Global action plan on the public health response to dementia in May 2017, setting an eight-year framework through which the organisation's 194 Member States could improve the lives of people with dementia, their families, and communities by 2025, with seven defined action areas requiring periodic reporting from governments on their progress.

Dementia is the seventh leading cause of death in the world and, increasingly, the leading cause of death in some countries. As the global population ages, the condition will only become harder to ignore as a social issue. According to WHO data, the number of people living with dementia is expected to rise from an estimated 55 million in 2019 to 139 million in 2050. Of the people currently living with the condition, 60% are believed to be living in lower- and middle-income countries (LMICs), with limited access to treatment and resources. The rise in dementia prevalence is predicted to lead to an associated increase in the annual costs related to the condition, from US\$1.3 trillion in 2019 to \$2.8 trillion by 2030.

The From Plan to Impact report series was established by ADI to survey the progress made by governments in meeting their commitments to the Global Action Plan, which they unanimously adopted. In this report, you will find that ADI has made the distinction between countries and territories that have Alzheimer and

dementia associations affiliated with ADI, and WHO Member States, as not all territories that have national plans for dementia are part of the WHO and bound to the Global Action Plan. The information presented in this report is intended to represent an up-to-date (as of May 2023) and holistic view of progress towards the targets of the WHO Global Action Plan.

Through the report, ADI highlights developments in dementia policy, research, and advocacy over the past year across the world. The report also features accounts depicting the reality of what people living with dementia and their carers are going through, and why the need for better support systems is crucial, at an individual and collective level. The cases shown in this sixth edition of From Plan to Impact seek to serve as examples to inspire and emulate, by showing the variety of ways in which governments, organisations, and individuals can take meaningful steps that make a difference.

With only two years left before the scheduled end of the Global Action Plan, the targets set by the WHO remain far from reach. Rather than preemptively declare defeat, ADI urges on governments to recognise the urgency of the situation, and calls on the WHO to extend the Global Action Plan to 2029. This extension should not be seen as an invitation to slacken the pace, but rather as an opportunity for states to fulfil their commitments and reinvigorate their efforts to prioritise dementia.

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The cases shown in this [report] seek to serve as examples to inspire and emulate, by showing the variety of ways in which governments, organisations, and individuals can take meaningful steps that make a difference.

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## What is a national dementia plan?

In 2017, the World Health Organization (WHO) developed the Global action plan on the public health response to dementia, aiming to improve the lives of those living with dementia and their carers whilst mitigating the impact of dementia on communities and countries.

People living with dementia and their carers require specialised and multisectoral support, which can change as their condition evolves. Identifying and addressing these needs requires action across all levels of society, including at a global, regional, national, and community level.

The Global Action Plan has sought to identify the various strands that constitute effective dementia policy through seven action areas, with Action area 1 encouraging Member States to implement National Dementia Plans or strategies.

The WHO characterises a National Dementia Plan as the following:<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.*

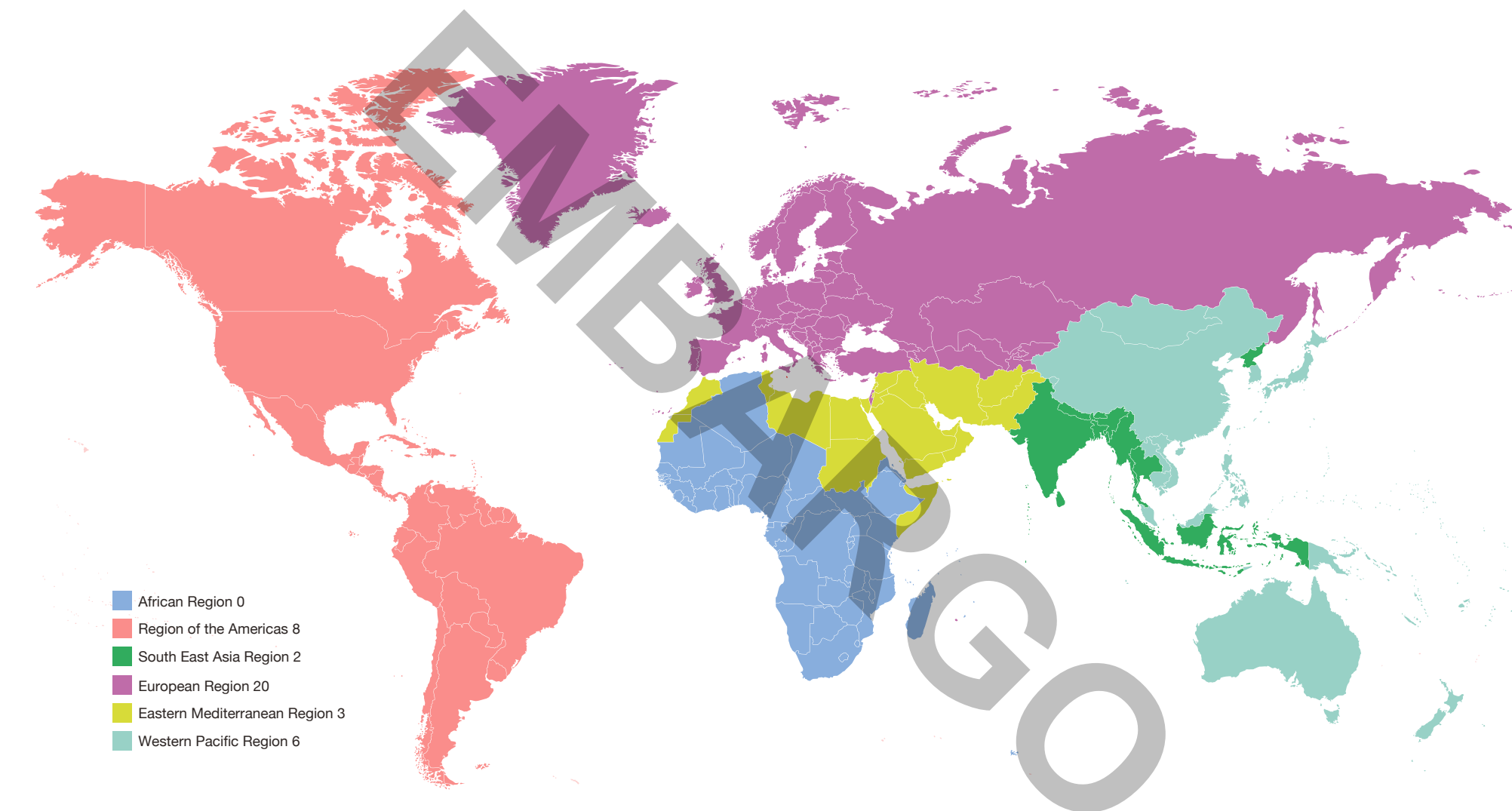


There are typically two broad types of dementia plans: standalone and integrated plans. A standalone National Dementia Plan or strategy typically focusses solely on dementia. An integrated dementia plan embeds dementia into other broader policy on issues such as ageing, non-communicable diseases, or neurodegenerative disorders. Ideally, whether a country chooses to implement a standalone or integrated plan, governments should commit to ring-fenced funding for dementia and address as many of the seven action areas of the Global Action Plan as possible to be effective.

Due to the unparalleled global burden that dementia presents, alongside the complexities associated with care and support for those living with dementia and their carers, ADI believes that stand-alone National Dementia Plans encompassing all seven action areas of the Global Action Plan are the best and most robust way to manage the multifaceted challenges of dementia to healthcare systems, governments and, of course, the people directly impacted by the condition.

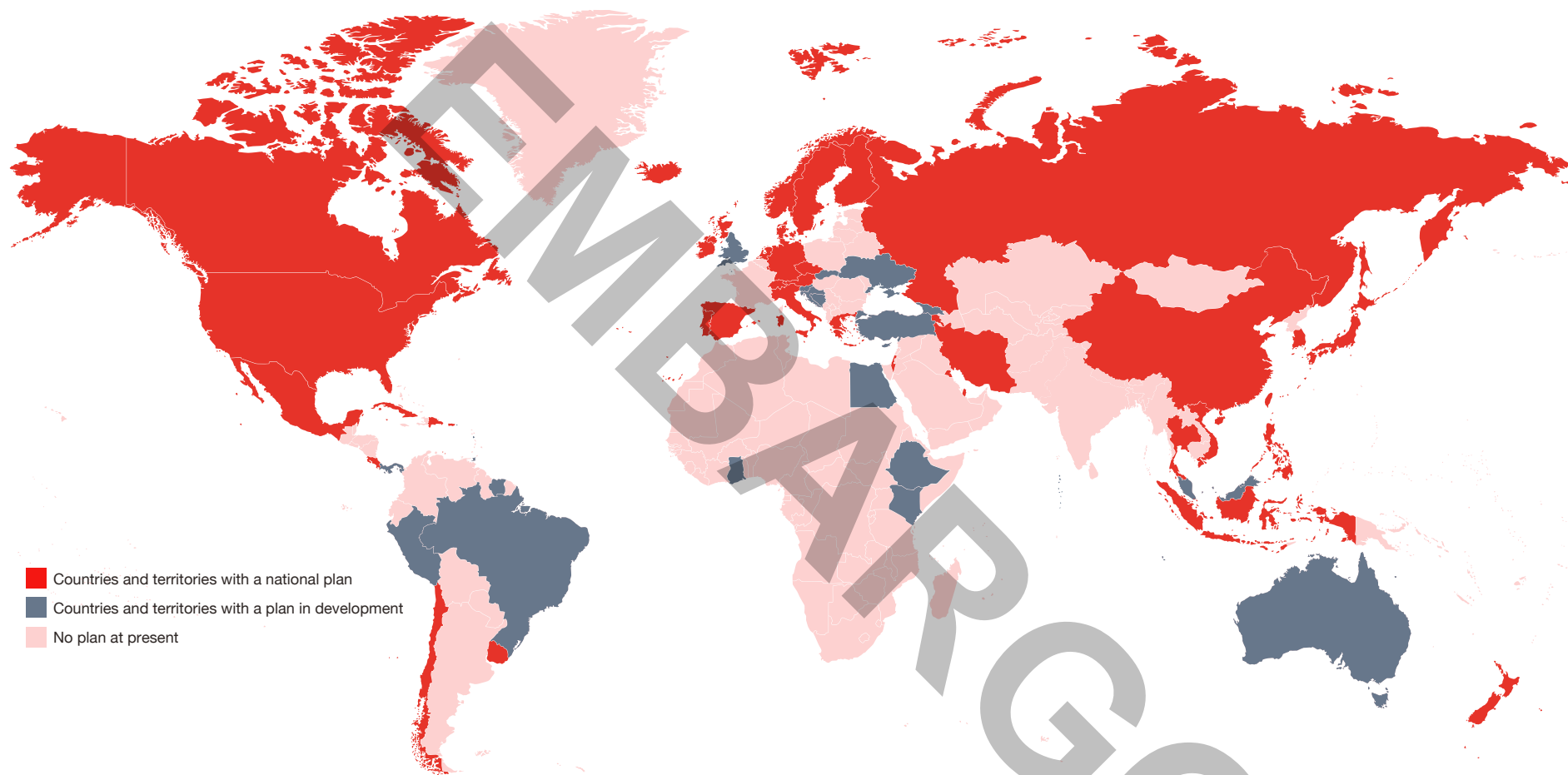
<sup>1</sup> Towards a dementia plan: a WHO guide. Geneva: World Health Organization; 2018. Licence: CC BY-NC-SA 3.0 IGO.

## National Dementia Plans by World Health Organization Region



Based on information received from Alzheimer and dementia associations, April 2023

## Current national dementia plans and plans in development



## Countries and territories with national dementia plan, or with dementia integrated as part of a wider health plan

Armenia	Cuba	Greece	Japan	Netherlands	Russian Federation	Thailand
Austria	Curacao	Iceland	Republic of Korea	New Zealand	Scotland	United States of America
Bonaire	Czech Republic	Indonesia	Kuwait	Northern Ireland	Singapore	Uruguay
Canada	Denmark	Iran	Luxembourg	Norway	Spain	Vietnam
Chile	Dominican Republic	Ireland	Macau	Portugal	Sweden	
China	Finland	Israel	Malta	Puerto Rico	Switzerland	
Costa Rica	Germany	Italy	Mexico	Qatar	TADA Chinese Taipei	

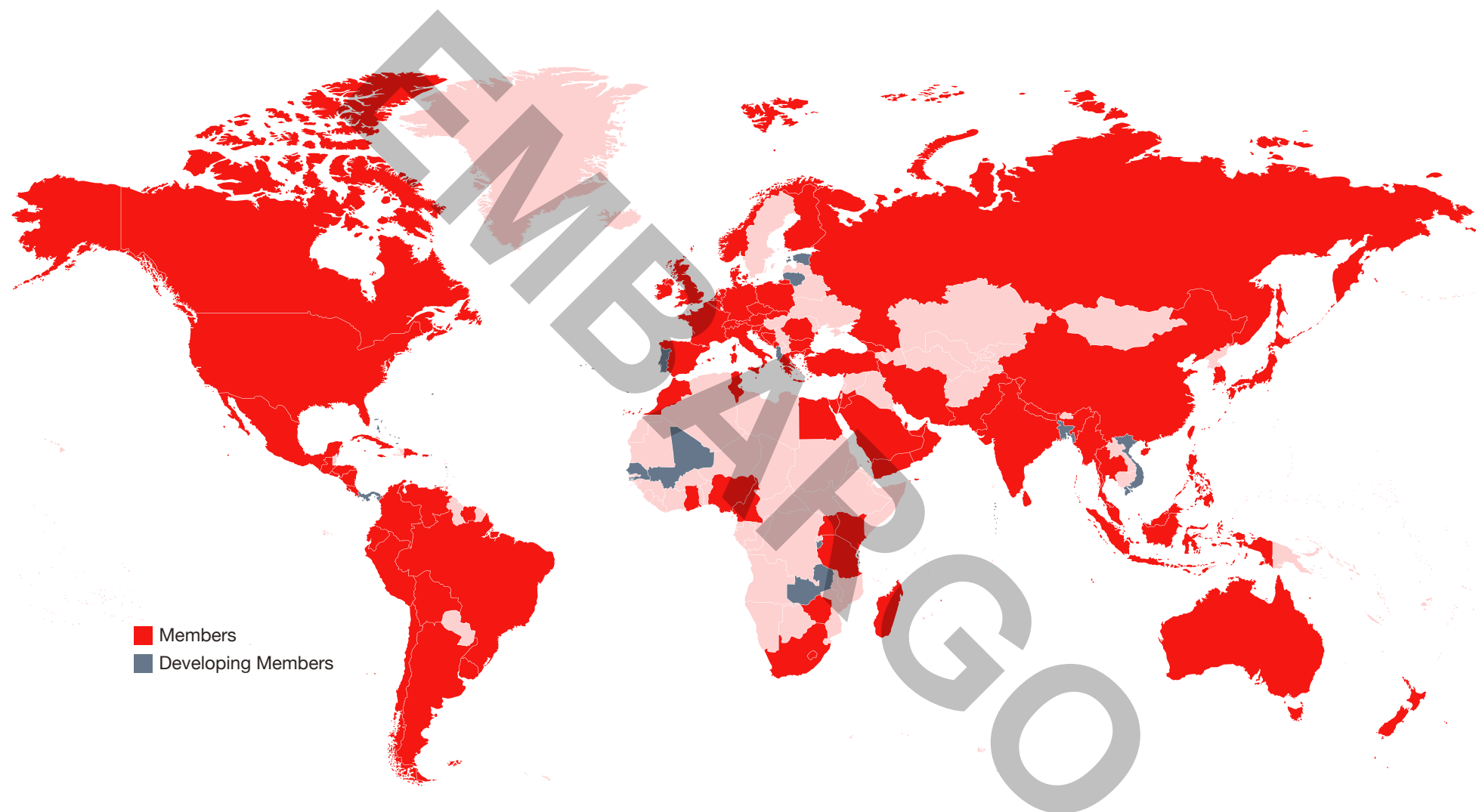
## Countries and territories with a national dementia plan, or dementia integrated as part of a wider health plan, in development

Australia	Cyprus	Georgia	Panama	Ukraine
Bosnia and Herzegovina	Dominica	Ghana	Peru	Wales
Brazil	Egypt	Hong Kong	Slovenia	
British Virgin Islands	England	Kenya	Suriname	
Brunei	Ethiopia	Malaysia	Trinidad and Tobago	
Croatia	Gibraltar	Maldives	Turkey	

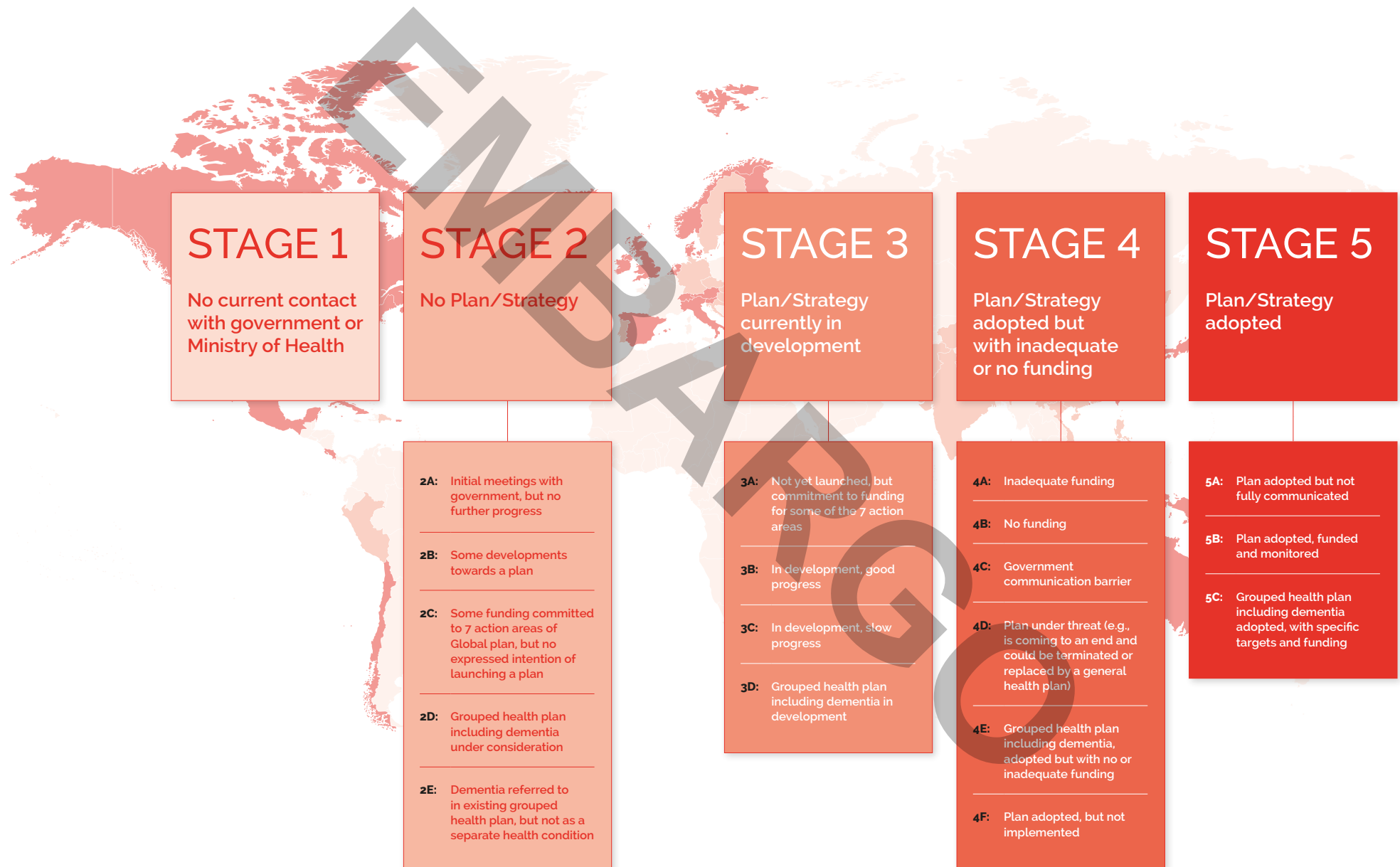
Based on information received from Alzheimer and dementia associations, April 2023



## ADI Members and Developing Members



## 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 and February 2023 to our 105 member associations, 20 developing associations, and five other associations preparing to join ADI's Membership Development Programme. The survey received an 83% response rate, with a total of 108 replies. Each member association is a national Alzheimer or dementia organisation in that country. 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 dementia integrated into another policy area (Action area 1) in their respective countries based on five stages (listed in the graphic on page 15). The survey also asked for examples of policy, advocacy, and practice in relation to the remaining six action areas. 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 based on the WHO action areas. The first section, focussed on Action area 1, is based on evidence obtained from ADI member associations and experts who have been instrumental in the development or implementation of their national plan, or who are advocating for one in their country. The subsequent six sections provide analysis and practical examples relating to Actions areas 2 to 7. Expert commentary and case studies are included throughout, showing the significant global variation in the development and/or application of policies related to dementia through examples of good practice and challenges that have been faced.

# 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.**

**Action area 1 is the cornerstone of the Global action plan on the public health response to dementia; while Action areas 2 to 7 cover the many different angles through which dementia should be addressed, policy is the vehicle that ensures these disparate facets are tackled in a comprehensive way. National Dementia Plans stand as the paragon of government commitment to focusing on dementia in their country in a cohesive way.**

National Dementia Plans are ambitious undertakings: behind the adoption of each National Dementia Plan currently in existence are months – if not years – of forethought, advocacy, and consultations with stakeholders in order to produce an effective roadmap guaranteeing the best possible approach to dementia within the local context. Very often, this process doesn't go as planned. An election or change in government, an economic crisis, a natural disaster, or a global pandemic... as we have seen time and time again, all can upend national priorities and put dementia policy on the backburner. These are obstacles that require dedication and ingenuity to overcome. The efforts required to turn a National Dementia Plan from a simple idea into a document signed by a minister with sufficient funding to enable implementation must be acknowledged.

Luckily, organisations like ADI are there to help. Our #WhatsYourPlan campaign, explored in detail in this chapter, seeks to make the process of creating a National Dementia Plan less daunting for governments by providing support and expertise gleaned from years of policy advocacy worldwide. More than a year since its inception, the campaign has already scored some successes, and encouraged many states to rise to their commitments to the Global Action Plan. ADI's most

recent efforts focused on the Caribbean will hopefully lead to some encouraging updates in next year's issue of From Plan to Impact.

This chapter gives a glimpse into the process of elaborating a National Dementia Plan in vastly different contexts: In Uruguay, where a plan was recently adopted following the structure set out by the Global Action Plan; in Ethiopia, where a push is underway to create what could very well end up being the first National Dementia Plan in Africa; and in Pakistan, where efforts to create a National Dementia Plan have led to the establishment of a regional dementia plan in Punjab.

The Pakistani example is particularly interesting, as it shows that progress can take many forms. While the authors of the plan remain hopeful that the plan will be expanded to the whole country in the future, its implementation at a smaller scale – in the most populous province of Pakistan, no less – is a success in its own right. Victory doesn't happen overnight, and we must celebrate every advance that makes life a little easier for people living with dementia and their families.

Not included among the essays in this chapter, but nonetheless worth celebrating, are the Ukrainian government's efforts over the past year to develop a National Dementia Plan, in large part thanks to the tireless advocacy of ADI member organisation Nezabutni (whose founder, Iryna Shevchenko, wrote a poignant testimony last year about the situation of people living with dementia in Ukraine in times of war<sup>1</sup>). The Ukrainian example is an inspiration for what can be done even in the most difficult of circumstances. If there is a will, there is a way.

<sup>1</sup> Alzheimer's Disease International (2022) *From plan to impact V: WHO Global Action Plan: The time to act is now*. London: Alzheimer's Disease International, pp.22–23

## #WhatsYourPlan

In 2017, Member States of the World Health Organization (WHO) unanimously adopted the seven-year Global action plan on the public health response to dementia. The plan, which covers seven action areas, seeks to improve the lives of people with dementia, their carers, and families, while decreasing the impact of dementia on communities and countries, principally through the adoption of National Dementia Plans. Every year since the adoption of the Global Action Plan, the progress of Member States towards achieving its targets have been tracked through the From Plan to Impact report series. Unfortunately, each year, and thus each iteration of From Plan to Impact, has demonstrated that Member States are falling behind on their commitments and are far from achieving the targets set out in the Global Action Plan.

Recognising the need for urgent action, ADI launched the #WhatsYourPlan campaign in late 2021: a direct-action campaign aiming to galvanise and encourage more governments to develop National Dementia Plans, following on their 2017 commitment.

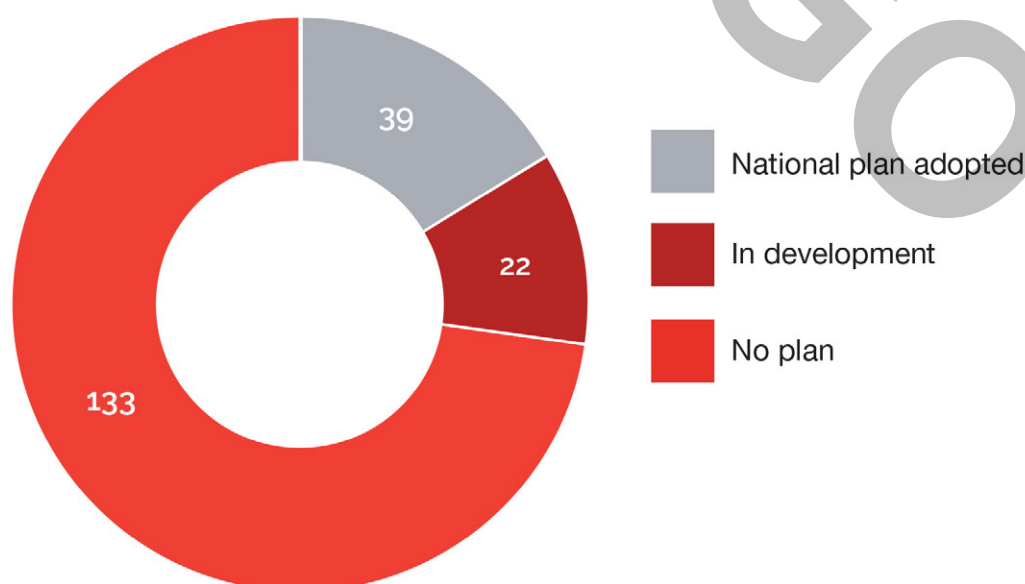
The campaign utilises a simple but effective advocacy methodology. Initially, formal letters are sent to ministries of health, in collaboration with ADI member associations and key stakeholders, to enquire as to the progress of National Dementia Plan development in their respective countries. We were mightily

encouraged by the response and engagement rate, often leading to follow-up ministerial meetings; however, many of these meetings underlined the scale of the challenge, with dementia falling down the list of priorities for many countries, exacerbated by the COVID-19 pandemic.

Where a response is not obtained, subsequent communications are sent. For those countries where the Ministry refuses to engage with ADI, or where the government is not willing to act in accordance with its 2017 commitment, ADI works with its local member associations and key stakeholders to deliver public-facing media and social media awareness campaigns, generating attention around our calls for the development of a National Dementia Plan and galvanising people to directly ask of their governments "#WhatsYourPlan?" The general public, the electorate, when asking this question, carries a lot of power!

At the launch of From Plan to Impact V in May 2022, the #WhatsYourPlan campaign was still in its infancy, with forty associations engaging in its first phase – but it had already had notable successes, with the Brazilian Senate unanimously passing the National Law of Care of People with Alzheimer's and other dementias, a joint letter from ADI and our member, Federação Brasileira das Associações de Alzheimer (FEBRAZ), being read during the debate.

### WHO Member States implementation of national plans





One year on, the campaign has truly gathered pace and impact. This has resulted in over 154 official letters and 51 emails being delivered to ministries of health or relevant departments in relation to the development of a National Dementia Plan. In addition to this, ADI successfully ran a regional awareness raising campaign in the Caribbean in January 2023 (see below), which included 13 ADI member associations. This combined effort has led to over 29 meetings with ministry officials and the commitment to develop 20 National Dementia Plans, over half as many as already in existence.

As #WhatsYourPlan moves into its second year, ADI will ramp up the public-facing aspect of the campaign, seeking to conduct more awareness raising campaigns in ADI member countries. ADI will also seek to build and strengthen the capacity of ADI member associations to bolster their efforts to advocate for National Dementia Plans. In February 2023, ADI successfully ran a #WhatsYourPlan workshop with its European members to develop strategies to advocate

for National Dementia Plans. This objective and theme will also feature in ADI's regional member meetings throughout the year.

At a multilateral level, ADI will continue to call for the development of National Dementia Plans at WHO global and regional meetings, exploring the possibility of hosting side events in the Eastern Mediterranean Region (EMRO), European Region (EURO), African Region (AFRO), and the Pan-American Health Organisation region (PAHO). These side events represent an opportunity to further raise the profile of dementia within these respective regions and capitalise on the attendance of Member States and WHO officials to impress upon them the importance of adopting National Dementia Plans.

As a community of advocates, healthcare practitioners, researchers, policymakers, people living with dementia, and carers, we will continue to ask governments throughout 2023 and beyond: #WhatsYourPlan?

## #WhatsYourPlan Caribbean campaign

The #WhatsYourPlan regional public awareness campaign for the Caribbean took place between 16–29 January 2023, with the aim of shedding a light on dementia and the need for National Dementia Plans across 13 countries and territories. This marked the first public awareness campaign to take place as part of the #WhatsYourPlan initiative.

The campaign utilised three direct streams of advocacy. First, by directly writing to ministries of health to inform them of the imminent launch of the campaign and requesting that they expedite progress towards the development of a National Dementia Plan in their country. Second, by engaging the public through social media; and finally, by carrying out a media campaign to raise the profile of #WhatsYourPlan through coverage in news articles, television, and radio.

The two-week campaign had an incredible impact, reaching over 423,200 people on social media

and being addressed in 83 independent pieces of news coverage. The campaign also had a number of significant political successes, with Puerto Rico's Department of Health and the British Virgin Island's Ministry of Health reaching out to our local member associations regarding their National Dementia Plans. Other successes involved a meeting between ADI, our member association Alzheimer's Association of Trinidad and Tobago, and the Trinidadian Ministry of Health's mental health team. Finally, thanks to the campaign, our association operating in St Kitts and Nevis met with country's chief medical officer, who expressed support for the development of a plan. The prime minister later shared similar sentiments when asked about the campaign by a reporter.

ADI will continue to support and advocate for National Dementia Plans in the Caribbean alongside our member associations and will move forwards with new campaigns in other regions.



## Uruguay STAGE 4/5

### National Dementia Plan in Uruguay: The beginning of a path

Uruguay has a long tradition in the scientific approach to dementia. The country founded its Institute of Neurology in 1926, the first in Latin America and the second in the Americas. More recently, the CUDIM (Uruguayan Centre for Molecular Imaging) has been operating since 2010, promoting research excellence in the field of dementia. During the 20<sup>th</sup> century, Uruguay built a welfare state with a broad development of public health and in 2020 became the first country in Latin America to establish a brain health programme under the Ministry of Public Health.

Our country is undergoing dramatic demographic changes, with ageing becoming one of the greatest challenges for public policy, especially in the fields of health, social security, care, and social services. The magnitude of this demographic shift is undoubtedly a major public health policy challenge and deserves, as the WHO has highlighted, systemic and state-level responses. There are an estimated 50,000 people living with dementia in Uruguay, with that number projected to more than double and reach 112,000 by 2050.

This situation has led our government to work on devising a National Dementia Plan in line with the WHO Global Action Plan. In order to establish the basis for our National Dementia Plan, different documents have already been produced in the country, including the National Dementia Guide produced by the Ministry of Public Health in 2015, in coordination with University of the Republic's (UdelaR) Centre on Ageing, containing recommendations for a comprehensive approach to dementia. We have also carried out these efforts alongside civil society organisations such as the Asociación Uruguaya de Alzheimer y Similares (AUDAS), academics, researchers, and different professionals involved in the care of patients with dementia. The present strategy is also aligned with international documents, such as the World Health Organization's Global action plan on the public health response to dementia, the WHO Decade of Healthy Ageing 2020–2030, and ADI's dementia risk reduction strategies.

After a first stage of discussion, a tentative draft of action was elaborated and discussed with ADI

leaders who visited Uruguay in September 2022, validating it. After this visit, the strategic areas were expanded and the final document was signed at the Ministry of Public Health in March 2023, in the presence of various participating organisations.

Uruguay has taken the seven action areas identified by the WHO Global Action Plan as a blueprint upon which to devise its National Dementia Plan.

### Dementia as a public health priority

Uruguay's plan establishes dementia as a public health priority, with the vision of a world in which dementia is preventable, and people with dementia and their carers live well, receiving the care and support they need to fulfil their potential with dignity, respect, autonomy, and equality. We believe that this written document provides a starting point and doctrinal foundation towards these goals, bringing together and coordinating the efforts of ministries, social organisations, academics, researchers, health care providers, and care systems.

### Awareness raising and public communication

Since 2020, campaigns have since taken place on social networks to address stigma against dementia in the country. The Ministry of Public Health has carried out several courses to support carers, with recommendations on patient care, especially during the COVID-19 pandemic, and seeks to continue down that path.

### Dementia risk reduction

The Lancet report on dementia prevention in 2020<sup>1</sup> has been a big source from which Uruguay has sought information in terms of identifying dementia risk factors that can be acted upon. The Pan American Health Organization's (PAHO) HEARTS initiative, already being implemented in Uruguay, focuses on hypertension, a risk factor for dementia. Our strong National Stroke Plan, which includes coverage of certain procedures free of charge

<sup>1</sup> Livingston, G. et al. (2020) Dementia prevention, intervention, and care: 2020 report of the Lancet Commission, *The Lancet*, 396 (10248), 413–446. [https://www.thelancet.com/article/S0140-6736\(20\)30367-6/fulltext](https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext)

through our national health system, also has a direct impact on the risk of vascular dementia.

It is our aim to also be able to adopt a "Brain Health Medical Advice" brief, which could be given by doctors in primary care advising on diet, sleep, physical and mental exercise, socialisation, avoidance of alcohol and tobacco, and cardiovascular risk as part of individual dementia risk reduction. We have also developed a proposal for the inclusion of brain health in school curricula.

## Diagnosis and treatment of dementia

Quality care for people with dementia implies universal access to diagnostic and therapeutic measures and comprehensive healthcare in a system that ensures continuity of care at all stages of their condition. The state must ensure that this care is provided through healthcare providers throughout the country. In Uruguay, specialised clinics are more concentrated in the capital Montevideo, constituting a geographical asymmetry, which needs to be addressed. While there already is universal coverage in Uruguay for anticholinesterase inhibitors and memantine, basic drugs in the treatment of Alzheimer's disease, cost-effective strategies should also be pursued at the primary healthcare level to avoid overprescription of drugs and promote non-pharmacological forms of treatment of certain symptoms.

## Support for carers

The carer is a central target of the dementia strategy, and it is necessary to integrate this cause into the country's mental health services to address the consequences and impact of care. The Ministry of Health and related ministries should continue with public and educational communication actions aimed at family members. Meanwhile, healthcare

training should include strategies to support families and carers – including by increasing the number of virtual trainings for long-term care facilities (known as ELEPEMs in Uruguay).

## Dementia information systems

Uruguay plans to establish areas of academic coordination to obtain information on dementia from electronic medical records, including on the distribution and population characteristics of people living with dementia, in order to improve guidelines for specialised services across the country. We believe that we can improve the dementia figures available to the Ministry of Health through electronic health records, and hope to have the most accurate data on dementia prevalence in Uruguay sometime in 2023.

## Dementia research

CUDIM and different faculties in the biomedical area should continue their research work in the country, as well as approach other regional or international research centres. Uruguay's National Dementia Plan aims to improve accessibility to national and international research funds.

## The future

A commission of experts in Uruguay, in conjunction with ADI and other international organisations, will actively monitor the fulfilment of these objectives. The challenges are many, and the immediate future will probably challenge us even more with new diagnostic and therapeutic advances. In any case, the Uruguayan government is committed to making firm progress in this priority area of public health.

**Dr Ignacio Amorín**, neurologist, co-author of the *Uruguayan National Dementia Plan*



## Pakistan

### The Punjab dementia plan: A region-level milestone

Alzheimer's Pakistan started to advocate for the creation of a National Dementia Plan soon after the Global action plan on the public health response to dementia was adopted during the 70<sup>th</sup> World Health Assembly in May 2017. After the 2018 general elections, our advocacy bore fruit with the new government. In 2019, President of Pakistan Dr Arif Alvi asked Alzheimer's Pakistan to work on drafting the country's first National Dementia Plan.

The pandemic halted our efforts, as the government's attention and resources were diverted towards dealing with COVID-19. In 2021, as the situation improved, Alzheimer's Pakistan was able to present its draft plan to the federal government for adoption and implementation. The Federal Health Ministry observed that the draft plan needed to be approved by all provincial health departments, as the health system in Pakistan is devolved and provinces run their own decentralised healthcare systems. In 2022, the Federal Health Ministry started its consultation process with all four provinces. While Punjab, the most populous province of Pakistan with over 110 million inhabitants, approved the draft plan, the country's other three provinces were delayed in approving the plan, which in turn impeded its official adoption and implementation in Punjab.

Dr Yasmin Rashid, then the Provincial Minister of Punjab for Healthcare and an avid Alzheimer's advocate, asked Alzheimer's Pakistan to concentrate on the province and submit a dementia plan that Punjab could launch on its own, with the expectation that Pakistan's remaining three provinces will follow suit and develop similar provincial dementia plans.

Alzheimer's Pakistan therefore concentrated its efforts on Punjab and reworked its national plan into the Punjab Dementia Plan. The Punjab Dementia Plan was written by Secretary General of Alzheimer's Pakistan Hussain Jafri, with contributions from a number of international and national experts including: Glenn Rees and Paola Barbarino, Alzheimer's Disease International; Caitlin Littleton, Syed Moez Ud Din, and Ajeeba Aslam, Helpage International; Prof. Dr Athar Javed, Pakistan Society of Neurology; Prof. Dr Asghar Zaidi, Government College University Lahore; Prof. Dr Iracema Leroi, Global Brain Health Institute; and Prof. Dr Ali Hashmi, Punjab Institute of Mental Health.



The launch of the Punjab Dementia Plan in October 2022  
(Photo courtesy of Hussain Jafri)

The Punjab Dementia Plan was launched by then-Chief Minister of Punjab Pervaiz Elahi and Dr Yasmin Rashid on October 19, 2022, marking the first big step in the Pakistani government's commitment to supporting and implementing much-needed dementia services in the country.

The provincial government of the Punjab has also announced its intention to develop and fund a detailed operational plan based on the targets and activities listed in the Punjab Dementia Plan. However, there have been some political developments since then, as the legislative assembly of Punjab was dissolved, and new elections were scheduled for late April. The development of the operational plan is therefore on hold until a new government takes over.

The launch of the Punjab Dementia Plan has been a significant milestone in the development of dementia services in the country, marking the first time that the government has recognised dementia as an issue and committed to the development of comprehensive services as outlined in the WHO Global action plan on the public health response to dementia. Punjab is the largest, most advanced, and resource-rich province in the country, and often leads the way in the development of healthcare and other matters. Therefore, we hope the Punjab Dementia Plan will go a long way in the development and implementation of dementia services across the country.

**Hussain Jafri**, Secretary General, Alzheimer's Pakistan



## Ethiopia STAGE 3C

### Developing a proposal for the first African National Dementia Plan

Ethiopia, the second most populous country in Africa, is home to more than 115 million people. Currently, the average life expectancy in Ethiopia is 67.8 years old, but this number is expected to reach 74 years old by 2050 – by which point the prevalence of dementia in Ethiopia is expected to increase by 380–2000%. This astronomical surge is projected to be fuelled by the high prevalence of dementia risk factors in Ethiopia, including increasing ageing population, non-communicable diseases (NCD), infectious diseases (e.g., HIV), and traumatic head injuries.

While all WHO member countries signed onto the 2017 Global Action Plan, committing to developing and implementing national strategies that address dementia, no sub-Saharan African country – Ethiopia included – have so far enacted a National Dementia Plan, whether as a standalone policy or integrated into other equivalent instruments.

In mid-December 2022, a team of fellows and faculties from the Atlantic Fellowship for Equity in Brain Health (AFEBH) programme at the Global Brain Health Institute (GBHI), the University of California San Francisco (UCSF), and faculties from the Department of Neurology, College of Health Sciences, Addis Ababa University (DoN-CHS-AAU) met with H.E. Dr Lia Tadesse, Ethiopia's federal minister of health, and members of her NCD team. The meeting was a huge success, as the minister welcomed the idea of developing a National Dementia Plan, as well as strengthening the existing mental and neurological health strategies in support of dementia care in the country.

As dementia is one of the five leading neurological disorders in Ethiopia, the minister instructed her team to work with local (DoN-CHS-AAU, Alzheimer's Ethiopia) and international (ADI, AFEBH) stakeholders in developing an integrated neurological plan for Ethiopia. Since then, the local team has held several stakeholder meetings to set the direction and frameworks for the development of the national strategy – including a needs assessment, literature review, and proposal development.

National strategies and plans need to focus on prevention through an integrated public health approach focussed on risk reduction [...] as well as raising public awareness about what makes a healthy brain and body.

In the stakeholder meetings, representatives from professional associations (Association of Ethiopian Neurologists), patient organisations (Alzheimer's Ethiopia, Parkinson's Patient Support Organization-Ethiopia, and Care Epilepsy Ethiopia), academic institutions (DoN) and ministry officials took part in conducting literature review, developing proposals, and setting objectives that will address policy gaps. However, lack of commitment and limited engagement from the stakeholders, paucity of locally available data to guide the writeup, and lack of financial support to assist the work are among the challenges we have faced in the process of developing an integrated national neurological strategy, which has taken longer than expected.

The team also published a position paper in *Frontiers in Neurology*, titled "The need for a tailored National Dementia Plan in Ethiopia: A call for action",<sup>1</sup> to further highlight the burden of dementia risk factors in the country. ADI CEO Paola Barbarino meanwhile wrote two letters to H.E. Dr Lia to reiterate that she and her team at ADI, alongside Global Atlantic fellows and Alzheimer's Ethiopia, were ready to support the development of national dementia policy in the country.

In the meantime, our team is partnering with expert health economists to develop a review paper that will assess the economic impact of dementia and how to design a cost-effective dementia prevention strategy in Ethiopia.

<sup>1</sup> Ayele Biniyam A., Ali Seid, Anbessie Mohammed, Zewde Yared Z., Yoseph Selam, Lee Suzee, Valcour Victor, Miller Bruce. 'The need for a tailored National Dementia Plan in Ethiopia: A call for action', *Frontiers in Neurology*, vol.14, 2023. <https://www.frontiersin.org/articles/10.3389/fneur.2023.1126531>



Currently, more than two-thirds of the Ethiopian population is under 30 years old – meaning that national strategies and plans need to focus on prevention through an integrated public health approach focussed on risk reduction, improving physical and mental health, as well as raising public awareness about what makes a healthy brain and body. In addition, introducing simple and accurate diagnostic tools tailored to the language and cultural context of the community will ensure earlier diagnosis at the community setting that will guide timely intervention and proper care. Furthermore, establishing community care centres and rehabilitation services will provide the necessary post-diagnostic support in order to enhance the quality of life of people living with dementia and their families or carers.

Our team is taking the lead in developing the proposal, organising the team, and identifying resources to support the work. We are cautiously optimistic about the realisation of an integrated national dementia policy for Ethiopia, as there is a long road ahead of us full of hurdles and obstacles.

**Yared Z. Zewde**, MD, Global Atlantic fellow, and Assistant Prof. of Neurology, **Biniyam A. Ayele**, MD, Atlantic fellow and Assistant Prof. of Neurology, and **Mohammed N. Anbessie**, Atlantic fellow and consultant Psychiatrist, Department of Neurology, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia

## Key points



Six years after the creation of the Global Action Plan, progress has stalled in the establishment of new National Dementia Plans, with some countries putting an end to their dementia strategies even as others are pushing new ones forward. While we acknowledge the hard work that goes into creating and upholding these plans, people living with dementia worldwide are the ones who pay the price when governments turn a blind eye to their situation. As research witnesses hopeful progress when it comes to disease-modifying treatments, we cannot afford to let governments remain at a standstill. Rather, governments must be encouraged to use National Dementia Plans to strengthen health systems in their countries – to ensure all of their citizens living with dementia can access the treatment, care, and support they need and deserve.

# 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.**

**Awareness is a driver for change – after all, how can we transform that which we do not understand? Even as dementia prevalence is projected to increase dramatically across the world by 2050, we see time and time again that prejudices and misunderstandings are rife when it comes to the societal perceptions of the condition, which in turn affects whether governments feel the urgency to act.**

Lack of awareness also leaves people living with dementia and their carers in the dark about warning signs of the condition, how to face the difficulties that may arise carrying out activities of daily living, and what rights they are entitled to, no matter the stage of dementia they might be in.

Efforts in the field of awareness raising take many shapes. This chapter highlights just a few people and organisations who have found how to make a difference – whether by sharing practical tips in an easily digestible

and entertaining format, like Adria Thompson's popular Be Light Care social media pages, or by conducting workshops on a rights-based approach to dementia, as seen with the Rights Made Real programme in Ireland. The anti-stigma toolkit developed through the STRiDE (Strengthening responses to dementia in developing countries) project, "Don't Forget I'm Human", seeks to humanise people living with dementia based on research in a number of lower- and middle-income countries. Meanwhile, the collaborative efforts between the Alzheimer's Society of Maldives and Alzheimer's Indonesia show the importance of working together for the common good.

World Alzheimer's Month remains a crucial tool for Area 2 of the Global Action Plan. By dedicating 30 days of the year to galvanising attention and support for the cause across the world, ADI and countless dementia advocates hope that these efforts will bear fruit during the rest of the year.

## World Alzheimer's Month 2022: Together we can do so much

In order to address misconceptions, stigma, and discrimination related to dementia, ADI, alongside the WHO, established World Alzheimer's Day in 1994, taking place on 21 September every year since. Eighteen years later, World Alzheimer's Day expanded to World Alzheimer's Month, dedicating the whole month of September to the important task of awareness raising about dementia.

In 2022, World Alzheimer's Month centred on the theme of post-diagnostic support, a follow-up from the 2021 campaign on diagnosis. This focus was inspired by recent developments and potential breakthroughs in both dementia treatment and support. The campaign aimed to encourage everyone to do their part to spread awareness and challenge the stigma that still exists around Alzheimer's disease and dementia, through the tagline: "Together, we can do so much."

Whilst focusing on post-diagnostic support, ADI also highlighted prevalence forecasts from the Institute of Health Metrics and Evaluation (IHME), which suggest that cases of dementia are expected to skyrocket in a number of regions across the world, notably in the Middle East.

In tandem with the theme of World Alzheimer's Month, the World Alzheimer Report 2022, entitled "Life after diagnosis: Navigating treatment, care and support", comprised of some 119 essays from over 215 distinguished authors addressing the issues, challenges, and opportunities at play around the world in the vast field of post-diagnosis support for dementia.

World Alzheimer's Month was a monumental success, achieving a combined social media reach of 35 million across all social media platforms. This traction was mirrored across traditional media, with over 293 pieces of coverage being recorded during the month, 120 of which directly relating to World Alzheimer's Month and World Alzheimer Report activities. In total, ADI recorded over 111 countries participating in the campaign.

In 2023, the World Alzheimer's Month campaign will focus on risk reduction (Action area 3 of the Global Action Plan). Research suggests that up to 40% of dementia cases could be delayed or averted by focusing on just 12 modifiable risk factors. Through its campaign and associated World Alzheimer Report, ADI will seek to raise further awareness of this issue and provide recommendations for how governments and the general public can reduce dementia risk, in the continued absence of a cure for the condition.

### ADI's Digital Intern Scheme: Expanding the reach of World Alzheimer's Month

To build upon the continuing success and reach of World Alzheimer's Month, ADI trialled its first digital intern scheme for the 2022 campaign. Made up of six interns from across the world (Switzerland, Hong Kong SAR, Brazil, Mauritius, India), each intern was tasked with running a 'mini' World Alzheimer's Month.

Four interns (from Brazil, Mauritius, and India) were already associated with the respective ADI member association in their country. These interns used this opportunity to further expand their association's World Alzheimer's Month campaign, including by venturing onto new social media platforms

such as Twitter and Instagram (Mauritius, India). The remaining two interns from Switzerland and Hong Kong SAR helped to leverage ADI's general campaign by creating new visual content and messaging around post-diagnostic support and risk reduction in English, French, and Mandarin through Instagram.

For the 2023 World Alzheimer's Month campaign, ADI will be looking to further tailor and build upon the success of the scheme, with the hope that it will reach more people across the world and make a lasting impact.

## Don't Forget I'm Human: A toolkit to stop dementia stigma

"Don't Forget I'm Human" is a toolkit<sup>1</sup> that aims to tackle the stigma faced by people living with dementia, which people often describe as being as challenging as the condition itself. At the individual level, stigma can undermine a person's life goals, reduce their participation in meaningful life activities, and worsen their quality of life. At the societal level, it can influence policy and reduce funding allocated to care and support.

People living with dementia and their families experience disproportionate stigma and discrimination. Results from the largest ever global survey,<sup>2</sup> led by ADI and the London School of Economics and Political Science (LSE) on dementia-related stigma in 2019, found that 84% of people living with dementia reported experiencing stigma and discrimination in at least one area of their life.

The toolkit, "Don't Forget I'm Human – Stopping dementia stigma", provides a set of practical tools and resources, which can be used in a variety of settings, to help people think about the impact of stigma on people living with dementia and their care partners, and how to actively challenge it.

This toolkit highlights the experiences of people from Brazil, India, Indonesia, Kenya, Jamaica, Mexico, and South Africa and contains anti-stigma strategies and activities that can be adapted widely to other countries to help support people living with dementia, carers, advocacy groups, as well as health professionals. It focuses on first-hand testimonials of people living with dementia and their care partners, describing the consequences and impact stigma has had on their lives. These testimonials, in written and video format, also show tangible ways in which people have overcome stigma, and how they were empowered to live rich and fulfilling lives. We also have practical tips about how to meaningfully include people with lived experience in anti-stigma work, and guidelines about how to use "social contact", the most effective evidence-based anti-stigma strategy to reduce stigma.

In rural Kenya, for example, we worked with people living with dementia, care partners, and the community

to develop an anti-stigma programme. Community health workers were trained to reach out to the community, promote social inclusion, and empower people living with dementia and their carers to confront stigma. A key component of the programme is "social contact", where people living with dementia and their care partners from the community share personal stories of dementia. The programme teaches participants how to encourage behaviour change and become advocates for reducing stigma and discrimination. Within the pilot evaluation, the researchers measured attitudes towards dementia before and one month after the intervention was delivered to the general public. We found a 10% reduction in the belief that "people living with dementia are dangerous more often than not", and a 23% increase in participants agreeing that "people with dementia are a good source of knowledge". This was complemented by qualitative interviews.

The toolkit was a collaborative effort<sup>3</sup> including people living with dementia, carers, advocates, and researchers. It was launched through STRIDE, a project led by the Care Policy and Evaluation Centre (CPEC) at LSE, in partnership with ADI, Dementia Alliance International, and partners in Brazil, India, Indonesia, Jamaica, Kenya, Mexico, and South Africa.

Our aim is for this toolkit to be used as a springboard to stimulate future anti-stigma work and to empower others to share their lived experiences. We hope to continue conversations with groups interested in building on this toolkit from around the world. Although our research and experiences were focused on a diverse group of lower- and middle-income countries, stigma is a global issue that should be addressed in high-income countries as well. Thus, we think it can be relevant for a range of settings.

People can share the toolkit by using the hashtag #DontForgetImHuman.

**Sara Evans-Lacko, Nicha Surawattananon**, Care Policy and Evaluation Centre, London School of Economics and Political Science, United Kingdom

<sup>1</sup> Evans-Lacko S., Farina N., Cleusa Ferri, Ana Carolina Franzon, Carolina Godoy, Hurzuk S., Jacobs R., Mata F., Elaine Mateus, Musyimi C., Levi Muyela, Deborah Oliveira, Ong E., Mariana López Ortega, Surawattananon, N., Weidner W. Don't Forget I'm Human –Stopping Dementia Stigma. The STRIDE Anti-Stigma Toolkit. <https://stridedementia.turtl.co/story/anti-stigma-toolkit/page/1>

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

<sup>3</sup> Evans-Lacko S., Farina N., Cleusa Ferri, Ana Carolina Franzon, Carolina Godoy, Hurzuk S., Jacobs R., Mata F., Elaine Mateus, Musyimi C., Levi Muyela, Deborah Oliveira, Ong E., Mariana López Ortega, Surawattananon, N., Weidner W. Don't Forget I'm Human –Stopping Dementia Stigma. The STRIDE Anti-Stigma Toolkit. STRIDE Toolkit acknowledgments. <https://stridedementia.turtl.co/story/anti-stigma-toolkit/page/12/1>



## USA STAGE 5B

### Lightening the topic of dementia online: One professional's journey

I am a speech language pathologist and over the last nine years, I have provided one-on-one speech therapy to hundreds of ageing adults in long-term care communities, many of whom have dementia. Working with individuals with dementia was never my life-long plan. I didn't know I was going to love it and I didn't have anyone in my life growing up with dementia. But throughout undergraduate and graduate school, one thing I knew about myself was that I loved complex cases. I loved working with people whom others had given up on. I loved hearing that others have "tried everything". I was so enthralled by the idea that I could possibly be the only one willing to really make a difference in someone's life. Truthfully, all my strengths are maximised with my work in dementia care.

After many years of practicing speech therapy and growing in my experience and knowledge of dementia, I moved across the country and set out to do training in long-term care communities. I created social media pages for Be Light Care<sup>1</sup>, originally as proof of my expertise. I imagined that if I introduced myself to executives at a long-term care community, they would be sceptical and unaware of what a speech language pathologist knew about dementia care. I thought I could give them my card or pull out my phone and show them an example of my teaching style. It would be a means to an end.

I never imagined that the videos and content I create would take off like wildfire, reaching hundreds of thousands of people all over the world in its first year. I didn't know how much practical dementia content was needed until followers sent messages stating that they have received more guidance and a better understanding of dementia from my short, easily digestible videos than anything they've been told inside a doctor's office. The ease and accessibility of seeing timely and relevant content on their phone allows isolated carers to realise they are not alone in the struggles they face, but also give them some practical advice for what to do about it. I have always aimed for content that carers can watch and then turn around and use immediately. Now that I've seen the response and read the feedback, I can't ever stop this service of providing accessible, digestible, and practical content.



A still shot from one of Be Light Care's online videos (Courtesy of Adria Thompson)

Even until now, dementia is deeply stigmatised. A diagnosis of dementia may be embarrassing, scary, or isolating. Great medical care for a person with dementia may involve comprehensive and early diagnosis but follow up is often non-existent. Professionals recommend support groups for carers to be amongst others who are also doing their best to care for individuals with dementia. The common advice physicians give is to "get your affairs in order", implying that the end is near. But what do they do when it's not? Dementia is a neurodegenerative disease which means the brain deteriorates over time. Although it constantly is getting worse, it certainly doesn't happen overnight. Individuals with dementia can live many years with their condition.

In the time between the diagnosis and the "end", carers still have to navigate the intricacies of daily life. They still need to get through today, tomorrow, and the next day. They don't know how to help their loved ones shower when they're confused, to eat

<sup>1</sup> [www.instagram.com/belightcare](https://www.instagram.com/belightcare), [www.facebook.com/belightcare](https://www.facebook.com/belightcare), [www.tiktok.com/@belightcare](https://www.tiktok.com/@belightcare).



when they say they aren't hungry, or what to do when they say they want to "go home" when they already are. Even if carers happen to figure out a solution in those moments, dementia is a moving target. The continuous decline means that new symptoms appear on a weekly basis. Carers are not guided through what to expect at each stage.

On the other hand, carers are also not told about the good things to come. Despite the unfortunate existence of the term "dementia sufferer" in society, carers are not told that suffering isn't mandatory, constant, or permanent. They aren't told that they will learn to be more creative, compassionate, and patient. They are not notified of the coming moments of joy and humour. They aren't told that they can do this. No one gives them confidence that they can be a great carer.

I chose the title "Be Light" for my business for the multiple meanings of the word "light". First, I aim to illuminate the topic of dementia. I want to shed "light" on all that is unknown and untold about this disease in a simple and non-intimidating way. Second, I want to light-en the load that so many individuals with dementia and their carers feel. It is a heavy topic and carers often feel like they are carrying a heavy burden. I strive to leave people who interact with my content and myself with a lighter, more hopeful feeling. Finally, I hope that my passion becomes contagious and that I can "light" the spark of other professionals who can come alongside me to serve this population. It is an absolute honour to be a part of so many people's dementia journeys.

**Adria Thompson**, MA CCC-SLP, *Be Light Care Consulting, USA*

## Maldives STAGE 3A

## Indonesia STAGE 5A

### A collaboration for awareness

In April 2021, the Alzheimer's Society of Maldives reached out to ADI in order to become an ADI member association.

As awareness of Alzheimer's and other dementias is minimal in our country, our priority was to create public awareness that might aid in people getting earlier diagnosis. Informational materials were greatly needed, but since we were a new organisation, we had to start from scratch.

However, ADI's Regional Director for the Asia Pacific region DY Suharya made things easier by putting us in touch with Michael Maitimoe and Amalia Fonk-Utomo of Alzheimer's Indonesia in May 2021 so that we could adopt the "10 warning signs of dementia" leaflet they had developed. This was part of ADI's Twinning programme, putting in contact member associations that can learn from one another. Alzheimer's Indonesia's prompt response and immense support was much appreciated.

We translated the leaflet into our native language, Dhivehi, with illustrations customised to fit the Maldivian context. The leaflet was then launched in digitised form on 12 September 2022, by the First Lady of the Maldives Fajna Ahmed at an event titled "Know Dementia – Know Alzheimer's – Importance of early diagnosis". It is with gratitude that we emphasise the support of DY, Michael, and Amalia of Alzheimer's Indonesia for making this project possible and playing an important part in achieving this milestone.



One of the 10 warning signs of dementia, translated into Dhivehi (Courtesy of Alzheimer's Society of Maldives)

We would also like to highlight the continuous support from ADI's Membership Manager and Membership Development Programme Lead Laura Aubert, DY, and the ADI team since the beginning, and we are also thankful to CEO Paola Barbarino for her supportive leadership and open-door policy, also reflected in ADI's culture.

**Mariyam Fiyaza**, co-founder and secretary general, Alzheimer's Society of Maldives, **Michael Dirk Maitimoe**, executive director, Alzheimer's Indonesia



## Ireland STAGE 4A

### A rights-based approach to dementia

The Irish Dementia Working Group (IDWG), founded in 2013, is an advocacy group of people living with dementia supported by The Alzheimer Society of Ireland (ASI). The group is an independent campaigning voice for the lived experience of dementia, with members living in all parts of Ireland.

The IDWG advocates for a rights-based approach for dementia; in the words of Dr Helen Rochford-Brennan, vice chair of IDWG: *"People living with dementia can be denied their human rights from the time of diagnosis. We are not always respected or informed. As we live with the disease, we navigate systems and structures which are not person centred or rights based. As a result, either deliberately or by omission our human rights are denied."*

The group successfully applied for funding from the Irish Human Rights and Equality Commission to empower people living with dementia to understand their human rights and make those rights real and applicable in their lives. They developed a course called 'Rights Made Real' with Professor Suzanne Cahill, in order to move human rights from something intangible that exists on paper, to something that can impact the lives of people with dementia in a positive manner. In 2022, 17 people living with dementia completed that course, delivered by human rights facilitator Eleanor Edmunds. As part of the course, the group spent time considering what they might do in scenarios in which their rights were infringed upon – for example, if they were not given enough facts in a healthcare setting, how they might ask for information and ensure they are treated with dignity and respect.

The course was evaluated by The ASI research team. Following completion of the course,

participants were asked if they had learned about how their human rights could be upheld, with 83% saying "Definitely yes", and 17% saying "Probably yes". There were mixed feelings amongst people with dementia prior to starting the course, anxiety as well as optimism. However, upon concluding, all the participants overwhelmingly noted feeling positive about having completed the training and the knowledge that was given to them, with 92% of respondents saying they felt more empowered after the course.

*"I know how to stand up for my rights,"* one participant said.

People living with dementia are unique learners, and there were challenges retaining information for the duration of the course, which took place over several days. One course participant said: *"Worried I won't remember it in two days. When I go home it will be out of my brain."* There was significant support required to encourage people living with dementia to attend the course, as well as support to plan travel.

Those challenges were overcome successfully, and the outcomes of the course were extremely positive; as well as individual empowerment it re-energised the IDWG – many participants decided to join the group and continue their journey as human rights advocates.

*"My rights are as equal as anyone else's. I'm entitled like everyone else,"* one said.

**Clodagh Whelan**, advocacy manager, The Alzheimer Society of Ireland

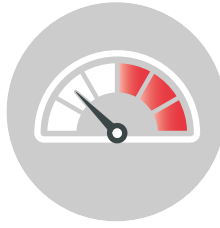
### Key points



Challenging stigma by increasing societal awareness and understanding of dementia is an essential step in improving the situation of people living with dementia. There are as many ways to do so as there are people willing to do this important work – whether national Alzheimer and dementia associations, health and care professionals, researchers, or people living with dementia themselves. In fact, it is crucial for the latter to be included in these efforts; by putting a face and a voice to the condition, we help humanise the issue and remind the public that we are not simply talking about an illness, but about people.

# 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.

**The dementia prevalence forecasts published by the WHO in 2021 and the Institute of Health Metrics and Evaluation in 2022 have sounded the alarm about the projected increase in cases of dementia by 2050 as the global population ages. But these estimates are not unavoidable; the much-discussed 2020 Lancet report on dementia prevention<sup>1</sup> has been an inestimable resource in understanding what factors impact individual and population-level dementia risk. Understanding what can be done by people, communities, and governments to address these risk factors today will go a long way in making the prevalence of dementia more manageable tomorrow.**

One of the most common misconceptions about dementia is that little can be done to avert it – but as stated in the Lancet report, some 40% of dementia cases could be delayed or prevented by tackling 12 modifiable risk factors. Taking these lifestyle and environmental changes seriously could make an incredible difference in the lives of millions of people –

not only people who risk developing dementia, but also their families and carers.

In this chapter, Martin Knapp makes a compelling case for why governments should tackle hearing loss, and how a state-level intervention could have a ripple effect on dementia risk. Many non-communicable diseases impact one another, and well thought out risk reduction efforts can be effective in killing several birds with one stone.

Meanwhile, the Nordic-Japan Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (NJ-FINGERS) project is bringing together experts from two regions of the world with super-ageing societies where dementia is a particularly pressing concern. This international project is a promising example of how multidomain interventions can be developed and refined through international cooperation.

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**Taking these lifestyle and environmental changes seriously could make an incredible difference in the lives of millions of people.**

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<sup>1</sup> Livingston, G. et al. (2020) Dementia prevention, intervention, and care: 2020 report of the Lancet Commission, The Lancet, 396 (10248), 413–446. [https://www.thelancet.com/article/S0140-6736\(20\)30367-6/fulltext](https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext)

## NJ-FINGERS: Japan and Nordic countries collaborate on dementia prevention

Japan and Nordic countries are super-ageing societies – meaning that more than 20% of their population is over 65 years old – and as such, they have an increasing need for dementia prevention. To address this challenge, ADI and five high-profile research institutes and hospitals in Japan, Sweden, Finland, and Norway are collaborating on multidomain preventive interventions within the *Nordic-Japan Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability* (NJ-FINGERS) project, which aims to gain new scientific knowledge in the fields of healthy ageing and precision prevention of dementia.

NJ-FINGERS builds on the pioneering FINGER study of 2015, which demonstrated that multidomain lifestyle interventions, combined with vascular and metabolic risk monitoring, can improve cognition, and help prevent cognitive decline. Several subsequent FINGER-based trials have since been initiated within the World-Wide FINGERS network, which brings together scientific teams from nearly 50 countries. Such collaboration and data pooling from many trials are crucial for the robust analyses needed to develop this research further and identify effective strategies for risk reduction and prevention of Alzheimer's disease and dementia in individuals with specific risk profiles.

As a subgroup to the larger network, the NJ-FINGERS consortium is comparing and analysing regional data and developing tools to accurately identify individuals who can effectively benefit from multidomain interventions, including medical food or putative disease-modifying drugs for Alzheimer's disease. One of the core trials of the project, MET-FINGER, recently started participant recruitment in Europe. MET-FINGER is the first

study that tests FINGER multidomain lifestyle interventions combined with metformin, a drug that aims to counteract Alzheimer's pathology.

In addition, the Nordic and Japanese teams are comparing the feasibility, adherence, and efficacy of the interventions, and investigating relevant biological mechanisms and biomarkers, accounting also for the direct and indirect effects of the COVID-19 pandemic in older at-risk persons. Data from the World-Wide FINGERS-SARS-CoV-2 survey have shown a significant effect on modifiable factors relevant to brain health in older adults. This includes reduced exercise, social isolation, and sleep problems. Another data source is the recently completed Japanese J-MINT study, which includes a series of novel biomarkers in addition to a wide range of lifestyle factors. The main analyses are planned for 2023, but the plan also includes a longer-term follow-up on the effects on dementia development and disability.

As part of the collaboration, a Japanese delegation visited Sweden in late 2022, including visits to Karolinska Institutet and Karolinska University Hospital. In early 2023, the whole consortium met virtually to plan the next steps of the project, which is funded by the Nordic governmental body NordForsk and the Japan Agency for Medical Research and Development (AMED).

**Miia Kivipelto**, MD, PhD, Professor, Karolinska Institutet, Sweden, **Hidenori Arai**, MD, PhD, President, National Center for Geriatrics and Gerontology, Japan, **Dag Aarsland**, MD, PhD, Professor, Stavanger University Hospital, Norway, **Tiia Ngandu**, MD, PhD, Finnish Institute for Health and Welfare, **Francesca Mangialasche**, MD, PhD, Assistant Professor, Karolinska Institutet, Sweden

## The economic case for hearing aids

The sign on the pharmacy counter reads: "You hear with your brain". This reminds customers with hearing loss to wear their hearing aids, and perhaps nudges others to consider consulting an audiologist. Frustrating as it can be when poor hearing makes it difficult to have a conversation, use the telephone, or listen to the radio,

the underlying message is there are also *other* impacts, particularly on how your brain works.

What we now know is that hearing loss is a risk factor for dementia. Indeed, among the twelve modifiable risk factors identified by the Lancet Commission,<sup>1</sup> hearing loss was seen as the most important in terms of relative

<sup>1</sup> Livingston G, Huntley J, Sommerlad A et al. (2020) Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. The Lancet 396(10248):413–446.

contribution to dementia incidence. The worse the hearing loss (if no action is taken), the more advanced the dementia.<sup>2</sup>

## How it may work

Whether eradicating hearing loss would prevent some people from developing dementia depends largely on how they are linked. There will be no preventive effect if their association is simply due to a common cause (e.g., vascular disease). But researchers believe other paths are involved: hearing loss could directly or indirectly (e.g., via social isolation) reduce cognitive stimulation, which could cause atrophy (shrinkage of parts of the brain); or the brain may work so hard to compensate for poor hearing that it has less chance to exercise its higher functions that build 'cognitive reserve' – the brain's capacity to cope with damage.<sup>3</sup>

## Hearing aids

It follows that wearing hearing aids could prevent dementia. The questions are: (1) are they effective; and (2) how to implement? For (1), there is evidence from longitudinal studies that wearing hearing aids reduces the risk of cognitive decline (by up to 19%), although there are uncertainties surrounding other interventions (e.g., cochlear implants).<sup>4</sup> Less is known regarding (2). Delayed diagnosis, stigma, and difficulties in using hearing aids are common barriers. Self-management and better delivery systems (e.g., post-fitting adjustment) may be useful, although evidence quality is low.<sup>5</sup>

## Economics

Providing care and support obviously needs resources: people in the health and care workforce, medications, nursing home beds, and, of course, the considerable time commitments of family and friend carers. These, in turn, need funding. If today's health and care arrangements remain unchanged, the expected growth in the number of people living with dementia will push up costs enormously.<sup>6</sup> Many governments are responding to this by encouraging preventive efforts.

Disabling hearing loss currently affects over 5% of the world's population, which will grow to 10% by 2050.<sup>7</sup> With these large numbers, and given the link to dementia, does it make economic sense to address hearing loss?

The main reason to improve someone's hearing is to improve their quality of life. It is a bonus if it also reduces the future likelihood of dementia. Policymakers need evidence to ensure that available resources are used to best effect – improving quality of life and reducing dementia prevalence in this case. This could include cost-effectiveness evidence that focuses on a primary outcome (e.g., cognitive decline) and cost-benefit analysis that evaluates the monetary values of outcomes plus savings.<sup>8</sup> A modelling study in England concluded that, by supplying and fitting a hearing aid for middle-aged adults with hearing loss who are not using one (about 8% of people with hearing loss), dementia prevalence could reduce by 3.3%. The lifetime saving plus gain in health-related quality of life results in net cost savings of £755 million, making it likely that the intervention would be cost-effective in terms of dementia risk-reduction alone.<sup>9</sup>

## The verdict

Listening to the evidence of hearing aids interventions in preventing dementia should be a no-brainer for policymakers.

**Professor Martin Knapp**, *Care Policy and Evaluation Centre (CPEC), London School of Economics and Political Science, United Kingdom, and Dr Gloria Wong*, *Department of Social Work and Social Administration, The University of Hong Kong, Hong Kong SAR*

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- <sup>3</sup> Griffiths TD, Lad M, Kumar S et al. (2020) How can hearing loss cause dementia? *Neuron* 108(3):401–412.
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- <sup>7</sup> WHO Deafness and hearing loss <https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss>
- <sup>8</sup> Knapp M, Wong G (2020) Economics and mental health: the current scenario. *World Psychiatry* 19(1):3–14
- <sup>9</sup> Mukadam N, Anderson R, Knapp M 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:e13–e20.



## Madagascar STAGE 2A & 2E

### Integrated care for the elderly

In the context of healthy ageing, the WHO encourages member countries to implement integrated interventions that address the health needs of older people, who represent 4% of the population in Madagascar.

Following a request from the FIZOMA (Firaismamben'ny Zokiolona eto Madagasikara), the national federation of elderly people's associations, the Ministry of Health's Non-Communicable Disease Department launched a programme called "Integrated Care for Elderly People" (also known by its French acronym SIPA), in the districts of Antananarivo Avaradrano and Antananarivo Atsimondrano, in June 2022. This programme is part of the broader national strategic plan for the health of the elderly.

Every month, SIPA events take place in a different location for people aged 60 and over. Different healthcare services are given for free, thanks to collaboration with different partners. The types of care services offered include diabetes and high blood pressure awareness and screenings; COVID-19 vaccine; nutrition awareness; ophthalmological consultations; and psychological support.

Madagascar Alzheimer Masoandro Mody, which is a member of FIZOMA, offers its services for free every month during SIPA days, in order to inform the elderly and raise awareness about Alzheimer's disease and related disorders. Warning signs are clearly explained, and if needed, people are referred to specialist doctors.

Risk reduction is also a main issue in the awareness sessions we provide during the SIPA days, as the



A young woman reads about the warning signs and risk factors of dementia during a SIPA day in March 2023 (Courtesy of Muriel Rason-Andriamaro)

aim is to help people focus on healthier habits and reduce their risk of dementia.

From a global perspective, elderly people are increasingly concerned about their health, including their mental health. Many of them are both afraid and curious regarding Alzheimer's disease and wish to learn more about it and receive advice on how to reduce risk. Last year, among a total of 400 people who attended SIPA days, around 150 elderly persons came to the Madagascar Alzheimer association's stand to seek information and advice about Alzheimer's disease.

Madagascar Alzheimer's would like this kind of event to reach more places and people all over the country.

**Muriel Rason-Andriamaro**, vice president, Madagascar Alzheimer Masoandro Mody

### Key points



As written by Martin Knapp, it should be a "no brainer" for Member States and individuals to address dementia risk and do their utmost to prevent more people from developing this condition. Prevention is better than cure, and so long as we are a long way away from finding a remedy, risk reduction should remain high on the agenda.

Many misconceptions remain surrounding dementia risk reduction, which ADI is committed to further addressing in our World Alzheimer Report 2023.



# 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.**

**The broadest of the action areas of the WHO plan, Action area 4 covers the vast and ambitious spectrum from diagnosis to treatment, care, and support for people living with dementia. At stake in this action area is nothing less than the fate of people living with dementia once the first signs of the condition appear: Are they able to access a diagnosis early? What treatments are available to them? Are they supported by their loved ones, their doctors, and other care professionals? Does this support network have access to the right information to care for them in the best way?**

Alireza Atri analyses in a comprehensive manner the breakthroughs we have seen over the past year in therapeutics. Clinical trials for disease-modifying treatments have made headlines, but what does it really mean for people living with dementia? Soeren Mattke's essay goes on to highlight that, as research

progresses, health systems must prepare themselves to meet the expected surge in demand for these new treatments from patients.

For Claire Webster and the rest of the team at the McGill University Research Center for Studies in Aging, who worked hand-in-hand with ADI on the 2021 and 2022 World Alzheimer Reports, dedicated to diagnosis and post-diagnosis support, the medical community has an "ethical imperative" to educate both itself and the broader public on dementia.

On the ground, we are seeing some excellent initiatives, such as the development of an ultra-low-field MRI machine described in this chapter, that could make this kind of diagnostic tool more accessible in lower- and middle-income countries. This kind of innovation can have the sort of far-reaching impact we hope to see more of in the future.

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At stake [...] is nothing less than the fate of people living with dementia once the first signs of the condition appear.

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## A milestone in Alzheimer therapeutics: Confirmation of the amyloid hypothesis brings caveats, opportunities, and challenges

Progress in Alzheimer's disease (AD) therapeutics has not been quick or linear. However, in late 2022, our field finally achieved an important milestone and critical foundational step: confirmation of the amyloid cascade hypothesis, via unequivocal clinical trial evidence from the CLARITY-AD Phase 3 study of lecanemab,<sup>1</sup> to demonstrate that sufficiently lowering amyloid-beta plaques can slow the relentless clinical decline in early AD.<sup>2,3</sup>

Lecanemab is a second-generation amyloid-plaque lowering monoclonal antibody (APL mAb) that mainly binds to soluble amyloid-beta protofibrils. What made the CLARITY-AD evidence so compelling? It was the first time a large (1,795 patients), Phase 3, well designed and well powered study of this class of APL mAb drugs was completed as designed and produced clear results. This is something that had not occurred with an earlier Phase 3 clinical trial programme for aducanumab, a different APL mAb drug, where the studies were stopped too early and produced mixed results. This led to controversy upon aducanumab's accelerated approval by the FDA in June 2021 on the basis of a biomarker effect of plaque-removal being "reasonably likely" to lead to clinical benefits.

The CLARITY-AD results are unequivocal: over the 18-month trial, along with evidence of substantial plaque lowering (approximately 81% of lecanemab-treated participants had plaque levels brought down to amyloid "negative" levels), there were consistent, statistically significant, and robust group-level effects on primary (the Clinical Dementia Rating, CDR, sum-of-boxes) and all secondary clinical endpoints that included validated measures of cognition and daily function. Other prespecified analyses were also convergent in supporting meaningful benefits to patients and families: an approximately 31% lower likelihood, over 18 months, of advancing to the next stage – e.g., of deteriorating from mild cognitive impairment to mild dementia, or from mild to moderate dementia – as well as significant group-level benefits on patient- and carer-reported measures of quality of life and burden. Finally, there were indications that lowering amyloid plaques also

impacted other biomarkers that drive symptoms and clinical progression in AD.

So, is lecanemab a cure? No, far from it. The group-level benefits for the primary and secondary clinical outcomes, while statistically robust, are of moderate magnitude, suggesting point-estimates of between 25–37% for slowing of clinical decline. The expectation of such a "disease-modifying" (versus a "symptomatic") treatment paradigm is not one of "getting better" or "improving" but of, on average, moderately slowing cognitive and functional decline. By doing so, on average and over the 18 months of the trial, a lecanemab-treated patient gained the equivalent of five to six months of "time" relative to those on placebo – thus having a greater likelihood of retaining cognitive and functional abilities for longer, and of delaying (but not altogether stopping) loss of some abilities. Importantly, the disease-modifying treatment paradigm is one of impact on the underlying pathobiology of AD, which would be postulated to produce cumulative benefits with potentially increasing effect sizes in the future to further slow clinical progression. The latter needs to be assessed by long-term studies or follow-up of treated patients, such as with the ALZ-NET patient registry in the United States.

So, what are the caveats? There are many, complex and nuanced. Lecanemab, similarly to the whole class of APL mAbs, comes with substantial safety risks, primarily due to potential side effects termed "Amyloid Related Imaging Abnormalities" (ARIA). ARIA involves a postulated increase in leakiness from amyloid burdened and chronically damaged blood vessels as plaques are removed and can manifest as focal areas of brain swelling or bleeding, while ARIA-E refers to oedemas or effusions. In the context of close surveillance and routine MRI monitoring in clinical trials, these side effects usually involve relatively small areas and most often do not produce symptoms or require additional treatment. With lecanemab treatment, 21.5% of patients experienced ARIA (vs 9.5% with placebo), and 12.6% had ARIA-E, though 78% of ARIAs did not involve symptoms. However, ARIA can

- 1 van Dyck CH, Swanson CJ, Aisen P, Bateman RJ, Chen C, Gee M, Kanekiyo M, Li D, Reyderman L, Cohen S, Froelich L, Katayama S, Sabbagh M, Vellas B, Watson D, Dhadda S, Irizarry M, Kramer LD, Iwatsubo T. *Lecanemab in Early Alzheimer's Disease*. *N Engl J Med*. 2023 Jan 5;388(1):9–21. doi: 10.1056/NEJMoa2212948. Epub 2022 Nov 29. PMID: 36449413
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- 3 Reiman EM. Drug trial for Alzheimer's disease is a game changer. *Nature*. 2023 Mar;615(7950):42–43. doi: 10.1038/d41586-023-00393-7. PMID: 36781970.

be serious, debilitating and, rarely, fatal – mitigation and management are critical. ARIA risk is higher in patients with more microhaemorrhages prior to starting treatment (those with five or more microhaemorrhages were excluded from participation in CLARITY-AD) and in individuals with the APOE-e4 gene variant.

Appropriate use of lecanemab<sup>4</sup> also requires careful selection of patients and safety measures to mitigate risk of potentially serious side effects. These include confirmation of amyloid positivity, correct clinical staging (early AD), baseline MRI criteria, and a patient-centred, shared, and informed decision-making process that clearly delineates realistic expectations and uncertainties regarding benefits, burdens, costs, risks, side-effects, alternatives, and monitoring (including serial brain MRIs). Lecanemab has received FDA-accelerated approval and is due for FDA-traditional approval determination in July 2023. Treatment involves infusions every two weeks, and multiple surveillance MRIs. Notably, access, cost, and coverage issues remain to be determined and are highly contentious.

We are at the beginnings of a new and foundational era in AD therapeutics and care – there are new challenges and great opportunities. In the coming decade, while there will be no magic bullets or cures, there is a rational basis that we can leverage advances to achieve substantial and iteratively better treatments and care. Lecanemab and other APL mAbs currently under development (e.g., donanemab) herald a new paradigm of AD treatment. However, in order to translate these drugs safely and effectively from the highly resourced and controlled environments of clinical trials to the real world of clinical care, we need much greater commitment, coordination, infrastructure, and resources. Clinicians and health systems are not yet ready, and issues related to non-discriminatory access, coverage,

clinical processes, and safety guardrails are evolving. Success will require a robust alliance of stakeholders to collaborate, fund and establish clinical care and real-world research partnerships, infrastructure, and resources – and to feedback learnings from the clinic to design better studies and advance clinical trials.

Greater awareness, choice, autonomy, and access (justice) will lead to improvements in more timely and accurate diagnosis and better care in general. We will need to leverage precision and personalised medicine to use biomarker profiles to narrow populations who may benefit more from APL mAbs, and to lower burden/risks of treatments – to improve on a 25–35% average clinical slowing to potentially 50–80% slowing in some patients. Increasingly, precision medicine in oncology, along with subsuming clinical trials as part of “standard of care”, have accelerated research and substantially improved care and outcomes – e.g., for breast cancer. We should aspire to do the same for AD and related disorders (ADRD).

Combination treatments will also be needed, as amyloid is only partly a driver of cognitive impairment once patients with AD are symptomatic. Finally, armed with new therapeutics, biomarkers (especially blood-based biomarkers), and better understandings, our even greater hopes for impact lie with dementia prevention.

It is a new era in AD/ADRD, and, with thoughtful planning, together we can fulfil its promise for impact for patients and families now, and especially for the coming generations.

**Alireza Atri, MD, PhD, Banner Sun Health Research Institute, Banner Health, Sun City AZ; Center for Brain/Mind Medicine, Department of Neurology, Brigham and Women's Hospital and Harvard Medical School, Boston, MA, USA**

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## We are at the beginnings of a new and foundational era in AD therapeutics and care.

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<sup>4</sup> Cummings J, Apostolova L, Rabinovici GD, Atri A, Aisen P, Greenberg S, Hendrix S, Selkoe D, Weiner M, Petersen RC, Salloway S, For the Alzheimer's Disease and Related Disorders Therapeutics Work Group. Lecanemab: Appropriate Use Recommendations. *J Prev Alzheimers Dis* (2023). <https://doi.org/10.14283/jpad.2023.30>

## Are we ready for the shift from care to cure in Alzheimer's disease?

The recent publication of positive Phase 3 results<sup>1</sup> for the amyloid-targeting drug lecanemab has provided the first unambiguous evidence for the ability of such treatments to alter the trajectory of Alzheimer's disease. While far from a cure, it is the first step into this direction.

As with any paradigm-shifting innovation in medicine, the question arises of how prepared our delivery systems are to provide timely, broad, and equitable access to it. In Alzheimer's disease, this question is particularly pressing because of the combination of high prevalence, a complex diagnostic process, and the need to diagnose and treat in the early symptomatic stages of the disease, ideally in mild cognitive impairment (MCI).

The prevalence of MCI in people aged 65 and older in the US is around 22%<sup>2,3</sup> and similar estimates have been published for other countries. Alzheimer's disease is the underlying aetiology in around half of them.<sup>4</sup> Yet despite the high burden of disease, MCI remains vastly underdiagnosed; according to our recent analysis,<sup>5</sup> only around 7% of the expected cases in the US had been diagnosed in the years 2017–2019. There are numerous

at which treatment will no longer be effective. An important step could be the introduction of population-based screening programmes, and the advent of disease-modifying Alzheimer's treatments might change today's stance of public health agencies of being uncertain<sup>6</sup> of the benefit of such programmes.

Even if MCI is detected in primary care, determination of treatment eligibility and treatment delivery itself is encumbered by several obstacles. Determination of an indication must be done by an Alzheimer's specialist (neurologist, geriatric psychiatrist, or geriatrician), who will confirm early-stage cognitive impairment, rule out other causes, confirm the presence of the Alzheimer's pathology and assess risk-benefit trade-offs. This process involves several office visits, MRI scanning and biomarker testing with a PET scan or analysis of cerebrospinal fluid. Many of these steps, in particular the specialist consultations, are capacity-constrained even in high-income countries. For example, we have predicted<sup>7</sup> that wait times in the US would reach 50 months under current diagnostic technology. While new diagnostic tools, such as blood-based biomarkers<sup>8</sup> and digital cognitive assessments<sup>9</sup> are expected to streamline the evaluation, they are not likely to be widely available by the time the first treatments are approved. Lastly, treatment with amyloid-directed drugs requires regular monitoring for ARIA with MRI scans and typically infusion delivery.<sup>10</sup>

**Solving these problems will require creativity, political will, and funding, and we must act fast and decisively.**

reasons for the low detection rate, reaching from lack of awareness among laypersons and clinicians, discounting of symptoms as normal ageing, and uncertainty of the benefit of detection. As hard to address as such deeply rooted obstacles are, failure to do so means that many will progress to disease stages

Solving these problems will require creativity, political will, and funding, and we must act fast and decisively because every day a patient is not diagnosed and not treated means loss of brain cells and further decline.

**Soeren Mattke, University of Southern California, USA**

- 1 Van Dyck CH, Swanson CJ, Aisen P, et al. Lecanemab in Early Alzheimer's Disease. *New England Journal of Medicine*. 2022;doi:10.1056/nejmoa2212948
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## Advocating for significant dementia education for all

Working with ADI on the 2021<sup>1</sup> and 2022<sup>2</sup> World Alzheimer Reports on the interrelated topics of *"Journey through a diagnosis of dementia"* and *"Life after diagnosis: Navigating treatment, care and support"* provided our team at the McGill University Research Center for Studies in Aging and Dementia Education Programme with the opportunity to gather the most current and reliable information from around the world by leading experts in their respective fields relating to dementia. While there is still no cure for dementia, knowledge is power, and these comprehensive reports hope to be a resource giving people with dementia, their carers, health and long-term care professionals, medical students, and broader communities the tools to better navigate this journey in humane, empowering ways.

A very significant finding common to both reports was the lack of information, education, and training with regards to all aspects of the condition – not only among the public at large, but also among clinicians and other allied healthcare professionals on a global level.

Care pathways for dementia are rarely straightforward or easy to negotiate. Having access to the right educative approaches and information is as crucial for health and long-term care professionals as it is for families affected by dementia. Understanding the evolution of symptoms, pharmacological and non-pharmacological approaches, management of responsive behaviours, safety, impact on activities of daily living, driving, employment, finances, mandates, access to resources and healthcare professionals, end-of-life care... are just a few of the issues that must be addressed upon receiving a diagnosis. As dementia is a progressive, ever-evolving condition that can last many years, persons living with dementia, their carers, and their care team must constantly be adjusting and updating their knowledge and skills in order to provide the best quality of care possible, as well as manage their own needs and expectations.

Issues that became apparent during the elaboration of the 2021 and 2022 World Alzheimer Reports included:

- Clear and ongoing communication by clinicians and health and long-term care professionals is key for persons living with dementia as a best practice to navigate their illness.
- People living with dementia and carers reported receiving inadequate communication from their



### World Alzheimer Report 2022

Life after diagnosis:  
Navigating treatment, care and support



healthcare providers about diagnosis, management and prognosis, lack of management plans, lack of referral to support services, and poor follow-up arrangements. They received neither hope nor practical strategies.

- Learning techniques that incorporate simulation, interactive, blended, and online learning can provide a much more engaging, enriching, and personalised dementia learning experience.
- Lifelong learning skills are an important way in which health and long-term care professionals can better meet evolving societal health needs by developing new competencies, reinforcing, and refreshing previous knowledge and skills, and reflecting on attitudes that may also inhibit quality of care in dementia.

<sup>1</sup> Gauthier S, Rosa-Neto P, Morais JA, & Webster C. 2021. World Alzheimer Report 2021: Journey through the diagnosis of dementia. London, England: Alzheimer's Disease International.

<sup>2</sup> Gauthier S, Webster C, Servaes S, Morais JA, Rosa-Neto P. 2022. World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support. London, England: Alzheimer's Disease International.

Alzheimer's disease and related disorders have no cure yet – and as the population ages and more people are diagnosed, we need to ensure that the public is better educated about the signs and symptoms of dementia. This would prompt individuals to consult healthcare professionals more and gain a better understanding of how to manage their condition. There is a pressing need for governments to develop public awareness campaigns that educate, enact policies that bring about change, create programmes that expand accessibility, and endorse support systems that assist carers.

The world needs to embrace health literacy about dementia. Empowering this concept will ensure the best quality of care, safety, and dignity of the person who is diagnosed.

Medical schools across the globe can play a very important role by thoroughly educating the students of today so that they may be better healthcare

professionals tomorrow. This is not simply relegated to understanding the various diagnostic options, but, most importantly, how to assist an individual and their carer in navigating their post-diagnosis care in a progressively complex medical environment.

Dementia is now one of the leading causes of death, and there exists an ethical imperative in the medical community to properly arm citizens around the world with the necessary knowledge and skills they require, as well as actively engage them in their own healthcare needs. Only in this way can post-diagnosis care become optimal care.

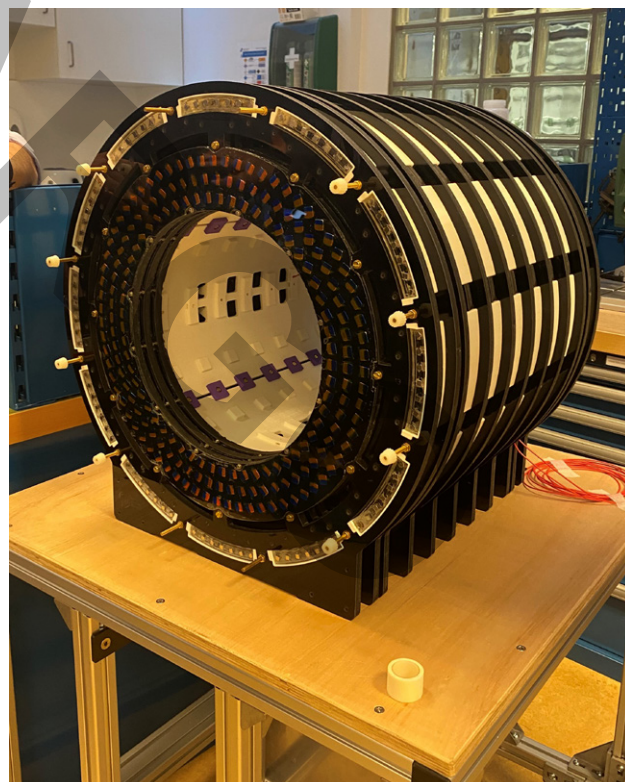
**Claire Webster, Dr Serge Gauthier, Dr José Morais, Dr Pedro Rosa-Neto**, McGill University Research Center for Studies in Aging and Dementia Education Programme Montreal, Canada

## Ultra-low-field MRIs as a pathway to more accessible brain imaging

Imaging of the brain is crucial for diagnosing dementia, as well as studying its neural substrate. Magnetic resonance imaging (MRI) is a key technology that allows insights into the various brain tissues and structures, but access to MRI varies widely across populations.

One of the main barriers is cost, with individuals in lower- and middle-income countries (LMICs) having limited access to brain imaging, with over a hundredfold difference between the average number of MRI units per 1 million population between high-income countries and LMICs. This financial barrier does not just stop at costs of acquiring the machines, but also in periodic maintenance and upgrades, with over a third of MRIs in Africa using hardware and software that is obsolete.<sup>1</sup> Another barrier that is frequent within LMICs, but also occurs in other global regions, is distance to the technology, with most systems being in big cities resulting in little access for rural communities.

The Uncovering Neurodegenerative Insights Through Ethnic Diversity (UNITED)<sup>2</sup> consortium was launched in 2019 to uncover why the brain deteriorates differently across populations. As there is limited accessibility to brain imaging in LMICs, there is subsequently a lack of data to fully investigate this in much of the world's



An in-progress build of the new ultra-low-field MRI at Leiden University Medical Centre (Photo courtesy of UNITED Consortium)

<sup>1</sup> Anazodo UC, Ng JJ, Ehiogu B, Obungoloch J, Fatade A, Mutsaerts HJ, Secca MF, Diop M, Opadele A, Alexander DC, Dada MO. A framework for advancing sustainable magnetic resonance imaging access in Africa. *NMR in Biomedicine*. 2023 Mar;36(3):e4846.

<sup>2</sup> Adams HH, Evans TE, Terzikhan N. The uncovering neurodegenerative insights through ethnic diversity consortium. *The Lancet Neurology*. 2019 Oct 1;18(10):915.



population. Due to this, we partnered with Leiden University Medical Center (LUMC) which recently developed a potential solution to the barrier of MRI accessibility: an ultra-low-field MRI machine. The group in LUMC, headed by Dr Andrew Webb, collaborated with researchers across the globe to develop an affordable and portable MRI system that could be easily set up and run in different situations.

The redesigning of such a machine saw a complete overhaul of the underlying system we see in conventional MRI. Primarily, the magnet consists of thousands of small permanent magnets which produce a much weaker field, and thus less signal. The resulting machine produces an image that is of lower resolution – however these machines can run on less power (even off batteries), with need no external shielding. The software can be operated with minimal training, fewer artefacts are observed due to the weaker field, and it is relatively light (and thus portable). These positives have the potential to overcome some of the accessibility barriers faced.

The innovative machines are relatively new and thus lack data and knowledge of how best to use these devices clinically. Due to this, we are testing the scanner for clinical and research utility with UNITED's partner sites in Paraguay and Bolivia. The scanner is being built locally in South America, in collaboration with LUMC, and data will be acquired alongside clinical care as standard, including paired conventional MRI. With the valuable data that will result from this investigation, state-of-the-art Artificial Intelligence (AI) to improve the quality of the data will be applied.

Importantly, as UNITED is committed to capacity building, local clinicians and researchers will be leading the projects to not only generate knowledge, but also build local expertise.

Together with AI processing capabilities, the ultra-low-field MRIs can have a huge impact on research and clinical care globally. The machines, which are more portable and affordable than conventional MRIs, are not to be seen as 'low-tech' cheaper alternatives, but rather as smart technical solutions to problems faced. This is highlighted due to their multiple positives beyond just the price, such as portability and less impact from contraindications. Implementation of these machines will not only aid us in understanding the neuropathological patterns of dementia across different populations, which in turn will aid clinical care, but also directly aid with more timely diagnosis and more affordable monitoring of such diseases due to higher accessibility of brain imaging in LMICs and beyond.

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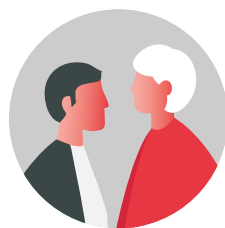
## Key points



Diagnosis, treatment, care, and support are rich fields in which there is plenty of room for positive, engaging initiatives to blossom and have a real-life impact on people living with dementia. Research into treatments has been particularly promising in recent years, even if cautious optimism should remain de rigueur. But until a disease-modifying treatment becomes a reality, healthcare systems worldwide need to be prepared, so such life-changing options are accessible to more than a privileged few.

# 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.**

**On a global scale, support for people living with dementia is overwhelmingly handled by informal carers, such as spouses, adult children, or other close relatives and friends. Women make up 70% of informal carers, providing unpaid care equivalent to an estimated 67 million full-time jobs in 2019.<sup>1</sup>**

Not a single healthcare system on the planet would be equipped to handle the broad scope of tasks [informal] carers take on for free every day.

Informal carers often end up as a mere afterthought in dementia policy, but their role is crucial: not a single healthcare system on the planet would be equipped to handle the broad scope of tasks these carers take on for free every day. To accompany a loved one with dementia and witness the progression of their condition is no easy task, even more so when support networks are not always present to provide needed information, guidance, or simply a listening ear.

The article written by Faye Kwan is a powerful testimony of her own experience as a carer for her grandmother for nearly ten years, highlighting the fact that caring does not need to be a lonesome, isolated journey. In China, Huali Wang reflects on the changing landscape of dementia care in the country, with institutionalised care growing in popularity. She also notes that while many families hire at-home carers, the majority of them are not formally trained to handle the specific needs of a person with dementia.

Mariana López-Ortega looks more closely at the intersection between gender and care in Mexico, pointing out how caring for relatives has a disproportionate impact on women's ability to pursue their studies or careers. This kind of data must be taken into account by governments.

It is not all doom and gloom, however. International initiatives such as the WHO's iSupport are gaining traction thanks to local efforts to translate the manual in the Philippines, making this vital resource more accessible to carers in the country. Every measure that makes life easier for carers – and, by extension, the people they care for – counts.

<sup>1</sup> Global status report on the public health response to dementia. Geneva: World Health Organization; 2021. Licence: CC BY-NC-SA 3.0 IGO.



## Mexico STAGE 4B

### Gender and dementia care: An urgent call to action

Mexico is at an advanced stage of a demographic transition, and it is expected that older people will represent 25% of the population by 2050, reaching 40 million people,<sup>1</sup> up from 12% (15.1 million) in the year 2020.<sup>2</sup> Currently, the role of the state regarding dependency care is non-existent, except for the administration of some residential houses or day centres. While specific legislation and programmes for older adults and/or persons with disabilities are in place, there are no strategies aimed at providing support services to people with functional or cognitive impairment and/or their family carers.<sup>3</sup>

Currently, most older adults in the country are independent and highly functional. However, the pronounced ageing population, especially of those 80 years and older, paired with a rapid increase in the prevalence of chronic diseases and conditions such as dementia, which already represent the highest disease burden in older persons, are expected to dramatically impact health services and the need for health and personal care at home.

As a result of the rapidly ageing population and the absence of publicly funded formal support services, health and personal care is mostly addressed in the private sphere of the home through unpaid family care, with little knowledge and no public support. Within the home, women perform more than 70% of all care work according to diverse sources such as the National Health Sector Accounts, the National Women's Institute, and results from research studies and international organisations. While women are increasingly involved in work outside the home, this has not been accompanied by changes in redistribution of domestic and care tasks with men within the household, increasing gender inequities and posing greater risks to women's own physical and mental health, access to health services, etc. Moreover, the fact that care duties generally pull

women out of the labour force or push them into reduced working hours or informal work (larger flexibility, but no benefits), along with a lack of supporting policies, negatively impacts their lifelong income and access to social security benefits, such as an old age pension.

Dementia care poses great challenges to the future sustainability of the care system in Mexico. In addition to health demands, social inequalities, economic constraints, and the lack of publicly funded programmes, most of the care is left in the hands of families and carers who must cope with the multiple manifestations of dementia related to the progressive deterioration of cognitive functions, all with little or no support,<sup>4</sup> negatively affecting the mental and physical health of both the person living with dementia and the carer. Data from the 10/66 Dementia Research Group study showed that unpaid family care was in addition associated with economic disadvantage, as many of the carers who were employed (35%) had to cut back on their paid work.<sup>5</sup>

### A call to action

It is evident that the creation of a care system that supports unpaid carers is urgently needed. At the macro level, important steps have been taken. First, the National Women's Institute has endorsed and worked closely with UN Women, calling for national strategies that bring together all relevant actors – including the governmental, civil society, academic, and private sectors.<sup>6</sup> In 2020, Congress approved a constitutional reform to recognise the right to care and receive care, and in December 2022, the Senate ratified the Inter-American Convention on the Protection of the Human Rights of Older Persons. Constitutional reform requires that the legislative branch draft and approve legislation to generate the National Care System. Within the Inter-American

<sup>1</sup> United Nations. *World Population Prospects: The 2017 Revision*. New York: United Nations

<sup>2</sup> Instituto Nacional de Estadística y Geografía (INEGI). 2020. Censo de Población y Vivienda. Available at: <https://www.inegi.org.mx/programas/ccpv/2020>

<sup>3</sup> López-Ortega M, Aranco N. Envejecimiento y atención a la dependencia en México [Internet]. InterAmerican Development Bank; 2019. Available from: <https://publications.iadb.org/es/envejecimiento-y-atencion-la-dependencia-en-mexico>

<sup>4</sup> Mejía-Arango, S., López-Ortega, M., Barba-Ramírez, L. (2020). Behavioral and Psychosocial Treatments of Dementia in Mexico. In: Adames, H., Tazeau, Y. (eds) *Caring for Latinxs with Dementia in a Globalized World*. Springer, New York, NY. [https://doi.org/10.1007/978-1-0716-0132-7\\_15](https://doi.org/10.1007/978-1-0716-0132-7_15)

<sup>5</sup> Prince, M., & 10/66 Dementia Research Group (2004). Care arrangements for people with dementia in developing countries. *International journal of geriatric psychiatry*, 19(2), 170–177. <https://doi.org/10.1002/gps.1046>

<sup>6</sup> ONU Mujeres (UN Women). 2015. Trabajo doméstico y de cuidados no remunerado. México: Naciones Unidas.

Convention, the state must guarantee the right to a comprehensive system of care and promote the development of specialised integrated social and healthcare services for older persons with conditions that generate dependency, including chronic degenerative diseases, Alzheimer's disease, and other types of dementia.

These initiatives set the stage for the generation of community-based services that include support to unpaid family carers as an action priority. Other immediate actions can also be taken. To reduce gender inequity, massive awareness campaigns to involve men and redistribute unpaid work should be retaken. In terms of dementia care, increasing

massive public campaigns to increase knowledge and awareness of its associated challenges, and decrease stigma and stereotypes perceiving cognitive impairment and dementia as normal part of ageing. Besides direct support to their care activities, training individuals and families on what to expect as cognitive function deteriorates and how to manage different symptoms will also help to reduce the burden, psychological distress, and negative health impact that they currently bear.

**Mariana López-Ortega**, National Institute of Geriatrics, National Institutes of Health, Mexico



## China STAGE 5B

### Carer support: A vital opportunity for improvement in dementia care

China has a large population, with the weighted prevalence of dementia in people aged 65 years or older between 5–6%. The dependency on carer support increases with the progression of dementia – meanwhile, caring for persons living with dementia has also been shown to impact the carer's quality of life and health.

Currently, "ageing in place" remains the mainstream of aged care. In China, the tradition supports family-based care for older adults. Thus, most people living with dementia are cared for at home. Often, the family employs a home carer to provide 'one-to-one' care for patients with Alzheimer's disease. However, it is likely that the carer will not have formal training in caring for patients with dementia. Many of these carers have a low level of education and literacy and may be isolated in rural communities. Therefore, carer support plays a vital role in China and is a crucial area where memory clinics can improve the standard of care.

Memory clinics have been encouraged to run carer support programmes to empower carers. The first memory café, a dementia carer support group, was established by the Peking University Institute of Mental Health in 2000. Initially, the memory café aimed to provide a platform where psychiatrists could disseminate updated knowledge of dementia to carers, carers could share their experiences and concerns, and mental health professionals could provide psychosocial support



A support group for carers in China (Photo courtesy of Dr Huali Wang)

to alleviate carers' distress. Volunteers and social workers later joined the programme and provided further psychosocial intervention to manage caring difficulties. Nowadays, carer support groups have been set up in many cities, some by memory clinic specialists, some by social workers, and others by non-government organisations. During the COVID-19 pandemic, carer support was sustained via social media and messaging apps, such as WeChat groups.

In recent years, institutionalised care – once considered the last resort for dementia care – has flourished in China. Specific units for dementia care have emerged in caring facilities. In collaboration with Peking University, Alzheimer's Disease Chinese (ADC) has developed a capacity-building programme

for professional dementia carers. We have also developed a smartphone-based neuropsychiatric syndrome management system, which facilitates the identification of target caring difficulties and the application of the DICE (describe-investigate-create-evaluate) algorithm in behaviour management. The WHO iSupport programme has been translated into Chinese, with a study on the effectiveness of WHO iSupport for Chinese carers now ongoing.

As reflected in the documentary "*Mian Dui*"<sup>1</sup> ("面对" in Chinese characters), each minor effort in supporting carers will make significant progress in the long journey of dementia care.

**Dr Huali Wang**, *Dementia Care and Research Center, Peking University Institute of Mental Health, Beijing, China, WHO/Beijing Collaborating Center for Research and Training in Mental Health*

<sup>1</sup> <https://v.qq.com/x/page/c3357qq2l3w.html>



## Malaysia STAGE 3B

### It takes a village: One young family carer's experience

Caring for someone with dementia can be both physically and emotionally demanding – something I learned in my teenage years. What started out as a fall turned into a nearly decade-long journey of helping care for my grandmother. Following a fractured hip bone and lack of mobility, her memory began to deteriorate – but as a young person who had not been previously exposed to Alzheimer's disease, I had assumed that my grandmother's poor memory came naturally with age. Over the years, this was accompanied with hallucinations and rapid mood swings, and as she began to use a wheelchair, I was tasked with dropping by the pharmacy after school to purchase bandages for her pressure sores, along with her medication. One of my most vivid memories during this time was coming home from school one day and being greeted by my grandmother in Bahasa Malaysia, as she no longer recognised me and assumed I was a domestic helper. We used to speak to each other in Hokkien, a Chinese dialect, but in her mind, I was still 4 years old.

It is not easy to watch a loved one slowly slip away, and it can be overwhelming when trying to communicate with someone who is no longer able to understand or remember things the way they used to. Fortunately, my grandmother was the matriarch of a large family, and our family was able to share the responsibility of looking after her, but it did take a village to ensure she was constantly provided with the best care possible.

This October marks ten years since my grandmother passed away at the grand age of 97. Although she lived a long and fulfilling life, this experience has spurred me to pursue stories relating to dementia in my work as a journalist. Raising awareness and reducing stigma associated with the condition should be the top priority when pushing for better healthcare and support services for dementia patients and their carers.

In Malaysia, the government is in the midst of developing a long-overdue national dementia action plan, while a Senior Citizens Bill is also expected to be tabled by 2024. However, the proposed bill could include provisions for legal actions against irresponsible adult children of elderly parents. This would involve salary deductions from children who send their parents to care centres. While several countries do have filial piety laws in place, punitive measures do not serve to improve negative behaviour, and women are often the ones shouldering the burden of unpaid care work. Those who send their elderly parents to care homes are also, more often than not, left with no other choice. Instead, the government should focus its resources on enabling the elderly to live independently, along with more extensive mental health support for carers considering the toll it can take on one's psychological wellbeing. Only then can we move forward in empowering our ageing population.

**Faye Kwan**, *journalist*





## Philippines STAGE 2D

### Translating iSupport in the Philippines

The Philippines is projected to be an ageing society by 2030, with the older population logging in the fastest growth rate compared with other age groups. Dementia prevalence is estimated to be 10.6%,<sup>1</sup> with around four in five cases being Alzheimer's disease/dementia.

In 2018, the Department of Health (DOH) started the Healthy and Productive Aging Program with the development of an action plan, minimally inclusive of diagnosis, treatment, and care of dementia. While a small but significant step in making dementia a public health priority, this programme lacks nationwide implementation and funding. The DOH has dedicated offices to working with the elderly population, as well as offices for mental health and neurological conditions including dementia – however, their current focus is on addressing non-communicable diseases in the elderly and mental health in general. Meanwhile, programmes to address the quality of life of people with dementia and alleviate the mental and physical challenges associated with caregiving are still to be implemented in the continued absence of a National Dementia Plan.

The Filipino family is closely knit, with around 60% of older persons residing and being cared for in multigenerational homes.<sup>2</sup> The COVID-19 pandemic imposed numerous restrictions on activities and movement of vulnerable populations, deemed necessary at the time given the strains on the health care capacity of the country. Despite pandemic restrictions being completely lifted in late 2022, life for people with dementia and their families has not entirely returned to normal. Training and empowering family carers and untrained care professional has thus taken on an unprecedented level of significance.

The Alzheimer's Disease Association of the Philippines (ADAP) felt the need to step up and address this gap by harnessing available self-help

tools such as the WHO iSupport Manual for Dementia.<sup>3</sup> This free downloadable manual contains five modules and lessons with accompanying exercises but was initially inaccessible for many Filipino carers who did not speak English.

ADAP formed a core specialist team and funded the translation of this manual into the Filipino language, before making it available for anyone to download for free on the ADAP website.<sup>4</sup> Knowing the relevance of this project, ADAP successfully obtained official endorsement from ADI, the Philippine College of Geriatric Medicine, the Philippine Society of Geriatrics and Gerontology, the Center for Memory and Cognition of the Philippine General Hospital – University of the Philippines Manila, and the National Institute of Health's Institute of Aging. With constant communication between ADAP, ADI, and the Non-Communicable Disease Division of the DOH, the translation was subsequently endorsed by the DOH for nationwide dissemination.

Taking it a step further, ADAP did ground testing of the iSupport translation, holding free monthly online training sessions for ADAP Support Group members in early 2022. Each chapter of the manual was discussed extensively in every session, with constant guidance from dementia specialists. Working through the modules required frequent assessment for relevance and applicability. The carers' feedback, discussion points, lessons, and issues were documented – and now serve as the basis of the recently launched ADAP project on the Filipino adaptation of the manual.

ADAP's experience as a non-government organisation working with limited resource in a lower middle-income country like the Philippines shows how close cooperation, constant communication, and partnerships with the national government and allies from international organisations like ADI can achieve

<sup>1</sup> Dominguez, J.C., Fowler, K.C. and De Guzman, M.F.P. (2020), In support of a National Dementia Plan: A follow-up study for dementia incidence and risk profiling in Filipino homes. *Alzheimer's Dement.*, 16: e043294. <https://doi.org/10.1002/alz.043294>

<sup>2</sup> Cruz, C. J. P., and G. T. Cruz (2019), 'Filipino Older Persons', in G. T. Cruz, C. J. P. Cruz, and Y. Saito (eds.), *Ageing and Health in the Philippines*, Jakarta, Indonesia: Economic Research Institute for ASEAN and East Asia, pp. 27–46. <https://www.eria.org/uploads/media/Books/2019-Dec-ERIA-Ageing-And-Health-In-The-Philippines.pdf>

<sup>3</sup> iSupport for dementia. Training and support manual for carers of people with dementia. Geneva: World Health Organization; 2019 <https://www.who.int/publications/i/item/9789241515863>

<sup>4</sup> iSupport Para Sa Dementia. Pagsasanay at gabay para sa mga tagapag-alaga ng taong may dementia (a derivative work of iSupport for dementia. Training and support manual for carers of people with dementia. Geneva: World Health Organization; 2019). Manila: Alzheimer's Disease Association of the Philippines; 2022 <https://www.alzphilippines.org>

accelerated gains in making dementia a public health priority despite minimal funding. This spirit of cooperation is essential to amplify efforts to deliver services that improve the quality of life of people with dementia, their families, and carers, and marks a step in the right direction towards an eventual National Dementia Plan.

**Dr Veeda Michelle M. Anlacan**, president, Alzheimer's Disease Association of the Philippines, and **Dr Jan Aura Laurelle V. Llevado**, division chief, Specialty Care Division of the Disease Prevention and Control Bureau, Department of Health, Philippines

## Key points

As the main allies and advocates for people living with dementia, support for informal carers should be an integral part of any dementia strategy. By and large, women continue to shoulder the vast majority of caring responsibilities, often with minimal support or training. As dementia prevalence is set to increase globally, it is crucial to invest now in providing the resources these carers need, so they can in turn accompany their loved ones without sacrificing their own mental and/or financial wellbeing.

# Chapter 6

## Information systems for dementia



**WHO target: 50% of countries routinely collect a core set of dementia indicators through their national health and social information systems every two years by 2025.**

**When used on a global scale, data can help us spot trends and drive scientific innovation. We live in a world of rapid technological change, much of it data driven. The move to harness these 'big picture' opportunities to push science forward, whilst simultaneously safeguarding the needs of vulnerable individuals who are living with dementia, has gathered greater momentum this year.**

The prospect of a potential disease-modifying drug finally entering the marketplace (see Alireza Atri's essay on page 36) has led governments and other key stakeholders to contemplate how to prepare health systems to ensure equitable and timely access to this new treatment. How can we use technology to learn more about the life course of dementia so that we can not only understand risk, but also spot cases earlier to facilitate access when an individual will benefit more from treatment?

In this chapter, Rhoda Au and Tetsu Maruyama explore these complex issues, discussing how the Alzheimer's Disease Data Initiative (ADDI) seeks to develop data collection protocols as well as interoperable platforms

that can house and/or link together data from studies around the world, and to make aggregated data accessible to the scientific community, no matter where they live or work.

Indeed, the call for a more systematic and robust method of collecting data is the major call to action in this chapter's update on the WHO's Global Dementia Observatory (GDO). The GDO collates data from WHO Member States on 35 important dementia indicators and tracks progress against the seven strategic areas of the Global Action Plan. But there is ample room for progress – with their own data showing that a renewed and coordinated effort by stakeholders across all action areas will be needed in order to achieve the targets set by the Global Action Plan for 2025.

Data can be a powerful tool. If something is not counted, it becomes invisible to researchers and policy makers. If we want to ensure that we drive innovation through data, we have to make sure that information systems are supported as an integral component in telling the story of what is happening, and can happen in future, for people living with dementia and their families.

## Preparing the next round of GDO data collection to help monitor and support countries' public health responses to dementia

The Global Dementia Observatory (GDO) provides the monitoring mechanism for the Global action plan on the public health response to dementia. It collates data from WHO Member States on 35 key dementia indicators to strengthen countries' ability to respond to the needs of people with dementia, their carers, and families. The 35 GDO indicators and sub-indicators build a comprehensive logic model that can track progress across the seven strategic 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 for dementia; and research and innovation), including all recommended dementia actions at national, regional, and global levels. Specifically, a core set of GDO indicators is used to measure individual countries' contributions towards achieving the global targets of the Global Action Plan.

In 2021, the WHO published the Global status report on the public health response to dementia,<sup>1</sup> which highlights progress in relation to achieving global targets of the Global Action Plan. It includes data from 62 countries that participated in the first round of GDO data collection and supplemented by the WHO's Global health estimates,<sup>2</sup> the Global Burden of Disease (GBD) study,<sup>3</sup> as well as case studies and country examples. Data show that renewed, coordinated efforts by all stakeholders across all action areas are needed if we are to achieve the targets set by the Global Action Plan for 2025.

The WHO Brain Health Unit is currently preparing for the next round of the GDO data collection, which is planned to begin in summer 2023. For this next round, the WHO encourages vast participation and collaboration among ministries and civil society for access to data. These data are essential to increase the understanding of countries' responses to dementia and achieving the global targets, as well as to help monitor progress among countries and across regions in comparison to data collected via the previous GDO round. Additionally, this next round of GDO data collection will be conducted alongside the monitoring efforts of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2022–2031) (IGAP), WHA decision 75 (11), which aims to improve access to care and treatment for people living with neurological disorders while preventing neurological disorders and promoting brain health and development across the life course.

Collecting quality and standardised data is of great importance if we are to better prepare and support health and social care systems, and communities to respond to the needs of people living with neurological conditions, including dementia, as well as their family members and carers, across all action areas to reach global targets.

*Brain Health Unit, World Health Organization*

## Making data go further in dementia research

Data are at the heart of scientific discovery and the knowledge that accumulates from its analysis. But our understanding of Alzheimer's disease and related disorders (ADRD) is suffering from lack of data. Not volume of data, not quality of data, but the reach of data.

Data represents an incredibly valuable resource and deserves to be used and re-used as widely as possible. The lack of data from people residing outside of North America, Western Europe, and Australia, (which together

represents only 17.2% of the entire world population) is leading to the analysis and interpretation of biased data, thus undermining scientific understanding. This can lead to treatment solutions and healthcare approaches that are either not feasible or not widely applicable.

Now recognised as a life-course condition, where the seeds of risk are sowed across the entire lifespan, the data from which to study this aspect dementia is woefully lacking. Only 3% of research includes those

<sup>1</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>2</sup> Global Health Estimates 2020: Deaths by Cause, Age, Sex, by Country and by Region, 2000–2019. Geneva, World Health Organization; 2020.

<sup>3</sup> Global Burden of Disease Collaborative Network. Global Burden of Disease Study 2019 (GBD 2019). Seattle, United States of America: Institute for Health Metrics and Evaluation (IHME), 2021.

under the age of 50,<sup>1</sup> so it remains poorly understood to what extent early life experiences contribute to overall risk for ADRD. There is a lack of uniformity of data needed to link age, sex, education, and cultures/ language. Moreover, the use of study protocols that rely on expensive equipment and facilities will exclude potential research participants who could add essential diversity. This is also a potential consequence of study exclusion criteria that eliminate the complexity of factors that are likely to underly multiple aetiological pathways to ADRD. The result risks oversimplifying the more complex reality of these critical scientific problems.

These major research gaps can be relatively easily reversed by taking three critical steps. First is to develop data collection protocols that are accessible anywhere, by anyone. Second is to develop interoperable platforms that can house and/or link together data from studies around the world. Third is to make the aggregated data accessible to the scientific community, wherever they reside.

The Davos Alzheimer's Collaborative (DAC) Global Cohort Development (GCD) programme and the Alzheimer's Disease Data Initiative (ADDI) have joined forces to fill these research gaps. The DAC GCD has developed a data collection protocol with the objective of maximising inclusiveness across low-, middle-, and high-resourced research settings. This protocol centres on using the multiple sensors in every smartphone to collect digital data streams that can be automatically uploaded for cloud-based transfer, while also making use of blood, the collection of which is widely feasible. Both these data sources can be analysed for a broad range of clinically and molecularly related ADRD indices. Both can also be

stored for future analysis of measures that are still to be determined. Coupling these with available health records creates an enriched data resource in which there are a core set of common data elements.

The ability to combine existing data from, for example, longitudinal cohort studies or clinical trials of novel interventions requires extensive interoperability of multiple platforms. In partnership with well-established platforms such as Dementia Platforms UK (DPUK) and the Global Alzheimer's Association Interactive Network (GAAIN), ADDI is committed to enabling users globally to find, select, request and – when given permission by the data contributors – analyse data. ADDI's AD Workbench (ADWB) provides FAIR (Findable, Accessible, Interoperable and Reusable) data search for a large and growing number of human studies, and free workspaces in which those data can be combined and analysed by individual researchers or collaborative groups.

ADDI is striving not only to present data from diverse research participants around the world but is also committed to enabling researchers from any part of the world to bring their unique perspectives and expertise to understanding those data by providing tools, workspaces and support through the AD Connect community to everyone, everywhere.

**Rhoda Au, Ph.D.**, professor of Anatomy & Neurobiology, Neurology, Medicine and Epidemiology, Boston University Chobanian & Avedisian School of Medicine & School of Public Health director, Global Cohort Development, Davos Alzheimer's Collaborative; and **Tetsuyuki Maruyama, Ph.D.**, executive director, Alzheimer's Disease Data Initiative

## Key points

**Far-reaching innovations in dementia treatment and care won't be the result of one single person or team's efforts; they will most likely come out of knowledge exchange – sharing data and information on a large scale, allowing researchers, health and long-term care professionals, advocates, and people living with dementia to compare what works and what doesn't from their perspectives, wherever they are in the world. Area 6 of the Global Action Plan highlights something we all know to be true: that if we want to go far, we must join forces – and keep count as we do it!**

<sup>1</sup> Yu, J. T. et al. (2020). Evidence-based prevention of Alzheimer's disease: systematic review and meta-analysis of 243 observational prospective studies and 153 randomised controlled trials. *Journal of neurology, neurosurgery, and psychiatry*, 91(11), 1201–1209. <https://doi.org/10.1136/jnnp-2019-321913>



# Chapter 7

## Dementia research and innovation



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

**Dementia research accounts for only 0.68% of total health research output globally<sup>1</sup> – a statistic ADI laments. However, a pathway has emerged this year that should encourage governments to develop a collaborative approach to dementia and brain health research, with the emergence of a potential disease-modifying drug, lecanumab (see Alireza Atri's essay page 36), and innovative efforts to recognise cognitive impairment and early detection of dementia.**

Progress on the pharmaceutical front has come alongside a renewed effort to facilitate early detection of cognitive decline. This is partly to ensure that people with Alzheimer's disease can benefit fully from potential treatments, but also so that they, along with their carers, can have access to existing interventions that can provide better health outcomes.

In this chapter, we explore how the WHO's recently launched Dementia Research Blueprint supports the global prioritisation of dementia research and provides a mechanism to facilitate timely and high-quality evidence generation, fast-track innovation, foster effective research implementation, and guide resource mobilisation.

We also highlight two new projects (RetiSpec's AI-based eye test in Canada and Brain Health

Armenia Project's early detection memory screening in collaboration with Armenian EyeCare) that use innovative methods to target early detection of cognitive impairment and to facilitate access to treatment, care, and support – two distinct projects in different parts of the world using ophthalmology as a gateway to dementia screenings. We also feature how virtual reality is helping local communities in New Zealand understand the unique issues faced by individuals with dementia, and how they may benefit by "living in someone else's shoes" and incorporate this understanding into how they provide care.

It is tremendously exciting to think about a potential disease-modifying drug and the impact this could have on the lives of people with early signs of dementia and their families in the future. However, we must always remember that there are people living with dementia who deserve care that provides them with a good quality of life *now*. ADI won't rest until there is equal and affordable access to these disease-modifying drugs across the globe. So, while we rejoice about these advances, we need to be mindful that not everyone, everywhere has access to these treatments. In the absence of access to pharmacological treatment, we must ensure that research into care and support is given equal emphasis as governments strive to meet the research targets of the Global Action Plan.

<sup>1</sup> World Health Organization. (2023). Progress report the Global action plan on the public health response to dementia. World Health Organization. [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).

## A WHO blueprint for dementia research

Accelerating research efforts is crucial to address global health challenges. The COVID-19 pandemic has shown how quickly research can advance when the international community works together. However, it has also highlighted the inequitable access to biomedical advances and research infrastructure within and across countries, as well as the need to shift our approach to research towards global public health interests.

Longstanding inequities, lack of sustainable funding, as well as inefficient coordination and collaboration have contributed to hindering scientific progress.

These research challenges are also seen in the dementia field, where longstanding inequities, lack of sustainable funding, as well as inefficient coordination and collaboration have contributed to hindering scientific progress. While there is still no cure for dementia despite tremendous efforts, most countries are not acting on dementia risk reduction despite the growing evidence in its support. A holistic approach to science is needed that focuses on all aspects of research, including basic and clinical research, and its implementation into practice and policy.

The World Health Organization (WHO) has developed a blueprint for dementia research,<sup>1</sup> the first of its kind for non-infectious diseases. The blueprint aims to support the global prioritisation of dementia research and provides a coordination mechanism to facilitate timely and high-quality evidence generation, fast-track innovation, foster effective research implementation, and guide resource mobilisation.

The blueprint summarises the current state of dementia research across six research themes: 1) epidemiology and economics; 2) disease mechanisms and models;

3) diagnosis; 4) drug development and clinical trials; 5) care and support; and 6) risk reduction. Across these themes, the blueprint highlights gaps, outlines actions, and sets milestones to achieve strategic goals. Addressing gaps highlighted by the blueprint requires an enabling research environment that can be achieved through eight essential drivers of dementia research:

1. Empowerment and engagement of people with lived experience
2. Diversity and equity
3. Funding
4. Access to science, materials,
5. Capacity building for research
6. Technology
7. Knowledge translation and exchange
8. Regulatory environments

All stakeholders play a role in operationalising these interconnected drivers of dementia research and making research an integral part of the public health response to dementia, fully recognising the societal impacts of dementia, with consequences spanning well beyond the health and social care sectors. Working together can help foster greater efficiency, equity, and impact.

National and international research agencies and funding bodies could use the WHO's blueprint for dementia research to inform their research priorities and funding streams. Civil society can support advocacy efforts that align with this blueprint, aiming to create a more equitable, efficient, and collaborative research landscape. Researchers can contribute by working to address identified research gaps highlighted by the blueprint.

Adopting this comprehensive and collaborative approach can contribute positively to the promotion and protection of overall brain health and help deliver positive outcomes for people living with dementia, their carers, and families.

*Brain Health Unit, World Health Organization*

<sup>1</sup> A blueprint for dementia research. Geneva: World Health Organization; 2022. Licence: CC BY-NC-SA 3.0 IGO



## Canada STAGE 5A

### RetiSpec: A promising approach to dementia screening through optometry

In Canada, there is a critical need to increase screening rates for Alzheimer's disease. In Ontario, primary care providers are the gatekeepers and initial point of access to medical care, but Ontario's primary care settings are not equipped to effectively assess cognitive impairment resulting in significant under-diagnosis, delayed diagnosis, and misdiagnosis, which lead to downstream impacts on those with Alzheimer's disease, their care partners, and the healthcare system. Canada is projected to have longer wait times for Alzheimer's treatment than any other G7 country.<sup>1,2</sup> Given Canada's healthcare system challenges, it is imperative to identify pragmatic, affordable, and sustainable approaches to increase screening rates for Alzheimer's.

The Davos Alzheimer's Collaborative (DAC) is leading a global call to action to transform the way healthcare systems worldwide detect, diagnose, and treat Alzheimer's. We received a grant from DAC to support a novel community-based Alzheimer's screening programme.

Through this programme, adults 65 years or older who reported a memory concern could undergo our screening process through one of two entry points: (1) the Alzheimer Society of Toronto for cognitive assessment; or (2) their annual optometry visit, where individuals could receive RetiSpec's AI-based eye test to detect biologic signatures of Alzheimer's. With the participant's informed consent, cognitive assessment results were shared with their primary care provider to maintain continuity of care. The project also facilitated access to a nurse practitioner for those without an available primary care provider.

Additionally, we are evaluating the risks, benefits, facilitators, and barriers to these community-based settings as means of sustainable health system access points for cognitive and RetiSpec assessments. We aim to offer a pragmatic, affordable, and sustainable way to increase rates of Alzheimer's screening in Ontario, Canada.

The study began recruiting in October 2022, and early findings indicate:

#### Community-based settings can support early detection and continuity of care

Community-based settings can play a crucial role in the early detection and management of Alzheimer's disease. Social workers from the Alzheimer Society of Toronto performed cognitive assessments in several neighbourhoods and hosted "pop-up" screening clinics in senior-based locations, improving accessibility for clients and expanding the programme's reach.

To support continuity of care, a nurse practitioner with training in memory disorders was available to meet with participants. Reasons for appointments included: "not having a primary care provider" and "memory concerns not adequately addressed by primary care provider". The initial screening enabled timely investigations by primary care or the nurse practitioner to identify the cause of cognitive symptoms and address management. Overall, these community-based channels can support continuity of care for those with memory concerns.

#### Optometry is a promising venue for Alzheimer's disease screening

Optometrists routinely identify signs of neurological conditions (e.g., papilledema can be a sign of brain tumour<sup>3</sup>) and facilitate specialist referrals. However, since Alzheimer's disease is not routinely discussed in optometry settings, we facilitated an expert-led discussion about Alzheimer's disease to ensure optometry partners gained increased knowledge and confidence to discuss memory concerns with their clients.

Optometry offers a promising venue to increase awareness of brain health and access to screening

<sup>1</sup> Mattke S. Canada's Health System Preparedness for a Future Alzheimer's Treatment. Canadian Neuroscience Innovation Summit. Toronto, ON; 2019.

<sup>2</sup> Mattke S, Hanson M. Expected wait times for access to a disease-modifying Alzheimer's treatment in the United States. *Alzheimer's & Dementia* 2022; 18 (5): 1071–1074.

<sup>3</sup> Rigi M, Almarzouqi SJ, Morgan ML et al. Papilledema: epidemiology, etiology, and clinical management. *Eye and brain* 2015; 7:47

for Alzheimer's disease. Technology such as RetiSpec's, which can leverage existing imaging infrastructure, offers a scalable way to integrate into optometry workflows. Discussing memory concerns in optometry clinics may help to increase reach to those without access to a primary care provider and reduce stigma by normalising brain health discussions – an approach in line with a "dementia-friendly community".<sup>4</sup>

### Next steps

Next, we will expand our optometry footprint to allow comparisons in how Alzheimer's disease screening differs across optometry settings. We are also undertaking clinical proof of concept and validation activities to assess the use of the RetiSpec eye test for other markers of disease, which we aim to offer in the future. Our long-term goal is to offer a single eye test experience that provides multiple outputs that can be used for differential diagnosis of neurodegenerative diseases.

Additionally, we observed demand for service expansion relative to eligibility age, geography, and language offerings. Since 20% of ineligible individuals were between ages 55–64, we will expand our programme to include this group. Future programmes should consider these needs and offer services accordingly.

Finally, we will assess programme sustainability after grant funding concludes. Our approach offers a novel, low barrier means of increasing Alzheimer's screening rates, with findings that will have broad applicability to global settings of varying resource capacities.

**Sharon Cohen, MD, FRCPC**, Behavioural Neurologist and Medical Director, Toronto Memory Program;  
**Jennifer Giordano, MSc**, Manager of Clinical Operations, RetiSpec; **Catherine Bornbaum, PhD, MBA**, Head of Clinical Operations and Partnerships, RetiSpec

<sup>4</sup> Shafii, S.; Crockett, A., Dementia-friendly communities. In Textbook of Dementia Care, Routledge: 2019; pp 45–55.

## Armenia STAGE 4B

### Ocular and cognitive screenings mark positive collaboration across Armenia

In June 2022, Alzheimer's Care Armenia launched the Brain Health Armenia Project (BHAP), funded by the Davos Alzheimer's Collaborative (DAC). BHAP is a country-wide early detection memory screening – a first for the country – and Alzheimer's disease and memory screening training programme for primary care physicians and nurses. BHAP's multidisciplinary team is collaborating with the Armenian EyeCare Project's Mobile Eye Hospital to conduct memory screenings on patients throughout the country. The team also conducts screenings in all six regions of the country in polyclinics and hospitals.

The BHAP team screens 400–500 people per month using the Montreal Cognitive Assessment Test (MoCA), as well as a demographic healthcare questionnaire. BHAP also developed the first Memory Café in the capital city of Yerevan for people with memory loss and their carers. A database has been developed for continued work, including assessing the prevalence of cognitive impairment in the country and future research.



Dr. Jane Mahakian with Armenian EyeCare Project Director Nune Yeghiazaryan (Photo courtesy of Dr. Jane Mahakian)

The Brain Health Armenia Project team has visited 39 villages and towns in six different provinces throughout Armenia. To date, the Brain Health Armenia Project has screened over 3,300 people and has conducted Alzheimer's disease trainings with approximately 650 primary care physicians and

nurses. Of the first 1,039 patients screened as part of the project, 451 showed some degree of cognitive impairment. By the end of the project in June 2023, 4,000 people are expected to have been screened, after which we will be able to carry out more comprehensive analysis of the data.

This project is making a significant difference on the ground in Armenia for people with dementia and their families, as well as raising the bar for dementia training of primary care physicians and nurses. By autumn of 2023, we will expand the programme by developing a multidisciplinary in-home cognitive and healthcare programme for people with Alzheimer's

disease and their families, as well as develop Memory Cafés in every region of the country.

Our collaboration with the Armenian EyeCare Project's Mobile Eye Hospital, which aims to provide in-home healthcare services to approximately 500 people per month, will continue as the model of combining ocular and cognitive screenings as a prevention tool, as well as exploring possible biomarkers in a way that may serve as model for other countries.

**Dr Jane Mahakian**, founder, Alzheimer's Care Armenia



## New Zealand STAGE 4B

### Understanding dementia through virtual reality

We know that every three seconds, someone around the world develops dementia – but many of us will never fully understand or appreciate how dementia affects someone living with the condition. That is why the Educational Dementia Immersive Experience (EDIE) is so crucial: it can show us what someone with dementia might experience.

Developed by Dementia Australia, EDIE is the first-ever virtual dementia experience in Aotearoa New Zealand – hosted by highly trained experts from Alzheimers NZ's Dementia Learning Centre over the past year. Co-designed with help from people with dementia, EDIE is a valuable tool that illustrates a scenario someone with dementia might experience.

The Dementia Learning Centre EDIE workshop is a three-hour session available countrywide, suitable for any team of staff providing support to people living with dementia in various care settings. However, carers and whānau (extended family and community) looking after people and loved ones with

dementia can also gain valuable insights from this new perspective too.

The virtual reality experience is one way that we can grow more comfortable in understanding what dementia is like and to start a conversation – by "seeing" dementia and realising that the smallest of changes can make the life of someone with dementia much more comfortable. EDIE can be confronting and shocking for some. But it can change your perspective and open your eyes to the little things you can do to make a difference.

One workshop attendee said: "In health and clinical settings, there is always a need for people to be able to walk in another person's shoes, to better understand their experience or see things from another's perspective."

**Dr Kathy Peri**, director of the Dementia Learning Centre, Alzheimers NZ

### Key points



**Until a cure for dementia has been found, efforts must be maintained – and increased – in the field of research and innovation to improve the lives of people living with dementia. Whether by finding ways for more people to have access to a timely diagnosis so they can benefit from existing treatments at the most impactful stage, or by increasing healthcare professionals' understanding of what dementia actually feels like, there are countless ways in which we can make a difference in risk reduction, diagnosis, care, and inclusion today, until a cure is found tomorrow.**



## Report summary

Six years after the adoption of the WHO Global action plan on the public health response to dementia, it is easy to find reasons to despair. Targets are far from being met, and the number of National Dementia Plans currently implemented is stagnant. If one were to look strictly at these big-picture numbers, one would be forgiven for declaring that the Global Action Plan has failed to galvanise stakeholders into enacting change.

But dementia can't be summed up by numbers; it's about people, millions of individual lives impacted by the condition, having to fight every day for dignity and support. While the scale of the task ahead can at times feel discouraging, it is for them that we must continue pushing onwards, no matter what obstacles lay on our path. The road ahead may be long, but each step counts.

If one looks closely enough, one will find plenty of reasons to hope. Countless individuals – people living with dementia, informal carers, healthcare professionals, researchers, advocates, policymakers – are sparing no effort, each making a difference in their own capacity. It is our hope that the stories in this report will inspire others to roll up their sleeves and contribute in any way they can.

When the Global Action Plan was first introduced, Member States pledged to do their part within the span of eight years. ADI will continue to push for governments to fulfil their commitments within the timeframe of the plan, as time is among the most precious commodities for people living with dementia. But as far as our organisation is concerned, our work won't end in 2025 or 2029, but when every single person living with dementia receives the support they need and deserve. No matter how long it takes.

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## Appendix A

ADI member nations that are WHO Member States, with dementia plans represented by income group, plan stage, and status as of May 1, 2023

Country	WHO region	WHO status	ADI status	Income group	Plan Status	
Argentina	Region of the Americas	WHO	Member	HIC	Stage 2B	Some developments towards a plan, but progress stalled
Armenia	European region	WHO	Member	UMIC	Stage 4A	Inadequate funding
Australia	Western Pacific region	WHO	Member	HIC	Stage 3B	In development, good progress
Austria	European region	WHO	Member	HIC	Stage 5B	Plan adopted, funded and monitored
Azerbaijan	European region	WHO	MDP	UMIC	Stage 2A	Initial meetings with government, but no further progress
Bahamas	Region of the Americas	WHO	MDP	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 including dementia under consideration
Barbados	Region of the Americas	WHO	Member	HIC	Stage 2D	Grouped health plan 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 2D & 2E	Grouped health plan including dementia under consideration & Dementia referred to in existing grouped health plan, but not as a separate health condition
Bosnia and Herzegovina	European region	WHO	Member	UMIC	Stage 3D	Grouped health plan including dementia in development
Botswana	African region	WHO	Potential	UMIC	Stage 2D	Grouped health plan including dementia under consideration
Brazil	Region of the Americas	WHO	Member	UMIC	Stage 3C	In development, slow progress
Brunei	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 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	Nyamiye's answer pending
Cameroon	African region	WHO	Member	LMIC	Stage 2A	Initial meetings with government, but no further progress
Canada	Region of the Americas	WHO	Member	HIC	Stage 5A	Plan adopted, but not fully communicated
Chile	Region of the Americas	WHO	Member	HIC	Stage 4E	Grouped health plan including dementia adopted, but with no or inadequate funding
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

Country	WHO region	WHO status	ADI status	Income group	Plan Status	
Croatia	European region	WHO	Member	HIC	Stage 3D	Grouped health plan including dementia in development
Cuba	Region of the Americas	WHO	Member	LMIC	Stage 5A	Plan adopted but not fully communicated
Cyprus	European region	WHO	Member	HIC	Stage 3C & 3D	In development, slow progress & Grouped health plan including dementia in development
Czech Republic	European region	WHO	Member	HIC	Stage 4A	Inadequate funding
Denmark	European region	WHO	Member	HIC		
Dominica	Region of the Americas	WHO	MDP	UMIC	Stage 3C	In development, slow progress
Dominican Republic	Region of the Americas	WHO	Member	UMIC	Stage 4B & 4F	No funding & Plan adopted but not implemented
Ecuador	Region of the Americas	WHO	Member	UMIC	Stage 2A	Initial meetings with government, but no further progress
Egypt	Eastern Mediterranean region	WHO	Member	LMIC	Stage 3D	Grouped health plan including dementia in development
El Salvador	Region of the Americas	WHO	Member	LMIC	Stage 2B	Some developments towards a plan, but progress stalled
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 3C	"In development, slow progress"
Finland	European region	WHO	Member	HIC	Stage 5C	Grouped health plan including dementia adopted, with specific targets and funding
France	European region	WHO	Member	HIC	Stage 2A	Initial meetings with government, but no further progress
Georgia	European region	WHO	Member	LMIC	Stage 3B	In development, good 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 5A	"Plan adopted but not fully communicated"
Grenada	Region of the Americas	WHO	MDP	UMIC	Stage 1	No current contact with government or Ministry of Health
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 2B	Some developments towards a plan, but progress stalled
India	South-East Asian Region	WHO	Member	LMIC	Stage 2E & 3A	Dementia referred to in existing grouped health plan, but not as a separate health condition & 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
Iran	Eastern Mediterranean region	WHO	Member	UMIC	Stage 4F	Plan adopted, but not implemented
Ireland	European region	WHO	Member	HIC	Stage 4A	Inadequate funding



Country	WHO region	WHO status	ADI status	Income group	Plan Status	
Israel	European region	WHO	Member	HIC	Stage 4F	Plan adopted, but not implemented
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 2D	Grouped health plan including dementia under consideration
Kenya	African region	WHO	Member	LMIC	Stage 3C	In development, slow progress
Korea, Republic of	Western Pacific region	WHO	Member	HIC	Stage 5B	Plan adopted, funded and monitored
Kuwait	Eastern Mediterranean region	WHO	Potential	HIC	Stage 4A, 4D & 4F	Inadequate funding, Plan adopted, but not implemented & Plan under threat
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
Macedonia (North)	European region	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
Madagascar	African region	WHO	Member	LIC	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
Malawi	African region	WHO	Potential	LIC		
Malaysia	Western Pacific region	WHO	Member	UMIC	Stage 3B	In development, good progress
Maldives	South-East Asian Region	WHO	MDP	UMIC	Stage 3A	Not yet launched, but commitment to funding for some of the 7 action areas
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 2A	Initial meetings with government, but no further progress
Mexico	Region of the Americas	WHO	Member	UMIC	Stage 4B	No funding
Montenegro	European region	WHO	Member	UMIC	Stage 1	No current contact with government or Ministry of Health
Morocco	Eastern Mediterranean region	WHO	Member	LMIC	Stage 1	No current contact with government or Ministry of Health
Myanmar	South-East Asian Region	WHO	Member	LMIC		
Nepal	South-East Asian Region	WHO	Member	LIC	Stage 3A	Not yet launched, but commitment to funding for some of the 7 action areas
Netherlands	European region	WHO	Member	HIC	Stage 5B	Plan adopted, funded and monitored

Country	WHO region	WHO status	ADI status	Income group	Plan Status	
New Zealand	Western Pacific region	WHO	Member	HIC	Stage 4B	Plan adopted, but no funding
Nicaragua	Region of the Americas	WHO	Member	LMIC	Stage 1	No current contact with government or Ministry of Health
Nigeria	African region	WHO	Member	LMIC	Stage 3A	Not yet launched, but commitment to funding for some of the 7 action areas
Norway	European region	WHO	Member	HIC	Stage 4A	Inadequate funding
Oman	Eastern Mediterranean region	WHO	Member	HIC	Stage 2A	Initial meetings with government, but no further progress
Pakistan	Eastern Mediterranean region	WHO	Member	LMIC		Regional plan!
Panama	Region of the Americas	WHO	MDP	HIC	Stage 3C	In development, slow progress
Peru	Region of the Americas	WHO	Member	UMIC	Stage 3C	In development, slow progress
Philippines	Western Pacific region	WHO	Member	LMIC	Stage 2D	Grouped health plan including dementia under consideration
Poland	European region	WHO	Member	HIC	Stage 2B	Some developments towards a plan, but progress stalled
Portugal	European region	WHO	MDP	HIC	Stage 4B & 4F	No funding & Plan adopted, but not implemented
Qatar	Eastern Mediterranean region	WHO	Member	HIC	Stage 4A	Inadequate funding
Romania	European region	WHO	Member	UMIC		
Russian Federation	European region	WHO	Member	UMIC		Grouped health plan including dementia, adopted but with no or inadequate funding & Plan adopted, but not implemented
Saint Kitts and Nevis	Region of the Americas	WHO	Member	HIC	Stage 2A	Initial meetings with government, but no further progress
Saint Lucia	Region of the Americas	WHO	Potential	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	Potential	UMIC	Stage 1	No current contact with government or Ministry of Health
Saudi Arabia	Eastern Mediterranean region	WHO	Member	HIC		
Senegal	African region	WHO	MDP	LIC	Stage 2E	Dementia referred to in existing grouped health plan, but not as a separate health condition
Serbia	European region	WHO	Potential	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 2A	Initial meetings with government, but no further progress
Singapore	Western Pacific region	WHO	Member	HIC	Stage 5A	Plan adopted but not fully communicated
Slovak Republic	European region	WHO	Member	HIC		
Slovenia	European region	WHO	Member	HIC	Stage 3A & 3B	Not yet launched, but commitment to funding for some of the 7 action areas & In development, good progress
South Africa	African region	WHO	Member	UMIC	Stage 1	No current contact with government or Ministry of Health

Country	WHO region	WHO status	ADI status	Income group	Plan Status	
Spain	European region	WHO	Member	HIC	Stage 4B	Plan adopted, but no funding
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
Suriname	Region of the Americas	WHO	Member	UMIC	Stage 3C	In development, slow progress
Sweden	European region	WHO	MDP	HIC	Stage 5	Plan adopted and funded
Switzerland	European region	WHO	Member	HIC		
Tanzania	African region	WHO	Member	LMIC		
Thailand	South-East Asian Region	WHO	Member	UMIC	Stage 4E	Grouped health plan including dementia, adopted but with no or inadequate funding
Tonga	Western Pacific region	WHO	Member	UMIC	Stage 2A & 2B	Initial meetings with government, but no further progress & Some development towards a plan, but progress stalled
Trinidad and Tobago	Region of the Americas	WHO	Member	HIC	Stage 3B	In development, good progress
Tunisia	Eastern Mediterranean region	WHO	Member	LMIC	Stage 2B	Some developments towards a plan, but progress stalled
Turkey	European region	WHO	Member	UMIC	Stage 3B	In development, good progress
Uganda	African region	WHO	Member	LIC	Stage 2D	Grouped health plan including dementia under consideration
Ukraine	European region	WHO	MDP	LMIC	Stage 3B	In development, good progress
United Arab Emirates	Eastern Mediterranean region	WHO	Member	HIC	Stage 2A	Initial meetings with government, but no further progress
United Kingdom – England	European region	WHO	Member	HIC	Stage 3D	Grouped health plan including dementia in development
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
Yemen	Eastern Mediterranean region	WHO	Member	LIC	Stage 2B	Some developments towards a plan, but progress stalled
Zambia	African region	WHO	MDP	LMIC	Stage 2A	Initial meetings with government, but no further progress
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 May 1, 2023

Country	ADI member	Plan stage	Plan status
Aruba	Member		
Bermuda	MDP	Stage 2A	Initial meetings with government, but no further progress
Bonaire	Member	Stage 4F	Plan adopted, but not implemented
British Virgin Islands	Member	Stage 3D	Grouped health plan including dementia in development
Cayman Islands	Member	Stage 2A	Initial meetings with government, but no further progress
Curacao	Member	Stage 4F	Plan adopted, but not implemented
Gibraltar	Member	Stage 3B	NDP imminent at the time of print
Hong-Kong	Member	Stage 3C	In development, slow progress
Macau	Member	Stage 5A	Plan adopted but not fully communicated
Northern Ireland	Member	Stage 4B	Inadequate funding
Puerto Rico	Member	Stage 5A	Plan adopted but not fully communicated
Scotland	Member	Stage 4A	Inadequate funding
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
Wales	Member	Stage 3B	In development, good progress

## Appendix C

Non-ADI member nations that are WHO Member States,  
with no dementia plan as of May 1, 2023

Country	WHO region	WHO status	ADI status	Income group
Afghanistan	Eastern Mediterranean region	WHO	Non-member	LIC
Albania	European region	WHO	Non-member	UMIC
Algeria	African region	WHO	Non-member	UMIC
Andorra	European region	WHO	Non-member	HIC
Angola	African region	WHO	Non-member	LMIC
Antigua and Barbuda	Region of the Americas	WHO	Non-member	HIC
Bahrain	Eastern Mediterranean region	WHO	Non-member	HIC
Belarus	European region	WHO	Non-member	UMIC
Belize	Region of the Americas	WHO	Non-member	UMIC
Benin	African region	WHO	Non-member	LIC
Bhutan	South-East Asian Region	WHO	Non-member	LMIC
Burkina Faso	African region	WHO	Non-member	LIC
Cambodia	Western Pacific region	WHO	Non-Member	LMIC
Cape Verde	African region	WHO	Non-member	N/A
Central African Republic	African region	WHO	Non-member	LIC
Chad	African region	WHO	Non-member	LIC
Comoros	African region	WHO	Non-member	LIC
Congo	African region	WHO	Non-member	LMIC
Cook Islands	Western Pacific region	WHO	Non-member	N/A
Côte d'Ivoire	African region	WHO	Non-member	LMIC
Democratic Republic of the Congo	African region	WHO	Non-member	LIC
Democratic Peoples Republic of Korea	South-East Asian Region	WHO	Non-member	LIC
Djibouti	African region	WHO	Non-member	LMIC
Equatorial Guinea	African region	WHO	Non-member	UMIC
Eritrea	African region	WHO	Non-member	LIC
Fiji	Western Pacific region	WHO	Non-member	UMIC
Gabon	African region	WHO	Non-member	UMIC
Gambia	African region	WHO	Non-member	LIC
Guinea	African region	WHO	Non-member	LIC
Guinea-Bissau	African region	WHO	Non-member	LIC
Guyana	Region of the Americas	WHO	Non-member	UMIC
Haiti	Region of the Americas	WHO	Non-member	LIC
Hungary	European region	WHO	Non-member	HIC
Iceland	European region	WHO	Non-member	HIC
Iraq	Eastern Mediterranean region	WHO	Non-member	UMIC
Kazakhstan	European region	WHO	Non-member	UMIC
Kiribati	Western Pacific region	WHO	Non-member	LMIC
Kyrgyzstan	European region	WHO	Non-member	LMIC
Lao People's Democratic Republic	Western Pacific region	WHO	Non-member	LMIC
Latvia	European region	WHO	Non-member	HIC
Liberia	African region	WHO	Non-member	LIC



Country	WHO region	WHO status	ADI status	Income group
Libya	Eastern Mediterranean region	WHO	Non-member	UMIC
Luxembourg	European region	WHO	Non-member	HIC
Marshall Islands	Western Pacific region	WHO	Non-member	UMIC
Mauritania	African region	WHO	Non-member	LMIC
Mongolia	Western Pacific region	WHO	Non-member	LMIC
Micronesia	Western Pacific region	WHO	Non-member	LMIC
Monaco	European region	WHO	Non-member	HIC
Mozambique	African region	WHO	Non-member	LIC
Namibia	African region	WHO	Non-member	UMIC
Nauru	Western Pacific region	WHO	Non-member	UMIC
Niger	African region	WHO	Non-member	LIC
Niue	Western Pacific region	WHO	Non-member	?
Palau	Western Pacific region	WHO	Non-member	HIC
Papua New Guinea	Western Pacific region	WHO	Non-member	LMIC
Paraguay	Region of the Americas	WHO	Non-member	UMIC
Rep. of Moldova	European region	WHO	Non-member	LMIC
Rwanda	African region	WHO	Non-member	LIC
Samoa	Western Pacific region	WHO	Non-member	UMIC
San Marino	European region	WHO	Non-member	HIC
Sao Tome And Principe	African region	WHO	Non-member	LMIC
Sierra Leone	African region	WHO	Non-member	LIC
Solomon Islands	Western Pacific region	WHO	Non-member	LMIC
Somalia	Eastern Mediterranean region	WHO	Non-member	LIC
South Sudan	African region	WHO	Non-member	LMIC
Sudan	Eastern Mediterranean region	WHO	Non-member	LMIC
Swaziland	African region	WHO	Non-member	LMIC
Syrian Arab Republic	Eastern Mediterranean region	WHO	Non-member	LIC
Tajikistan	European region	WHO	Non-member	LIC
Tanzania, United Republic of	African region	WHO	Non-member	LIC
Timor-Leste	South-East Asian Region	WHO	Non-member	LMIC
Togo	African region	WHO	Non-member	LIC
Turkmenistan	European region	WHO	Non-member	UMIC
Tuvalu	Western Pacific region	WHO	Non-member	UMIC
Uzbekistan	European region	WHO	Non-member	LMIC
Vanuatu	Western Pacific region	WHO	Non-member	LMIC

## 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	Low 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 105 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)

EMBARGO

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**Alzheimer's Disease  
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