Alzheimer's Policy & Impact Playbook

A Strategic Framework and Tactical Guide for Driving Awareness, Funding, and Access in the Alzheimer's Advocacy and Policy Community

NOVEMBER 2025

Global Coalition on Aging

Introduction

Alzheimer's disease, the most common form of dementia, is one of the most urgent and complex public health challenges of our time—affecting over 60 million people globally and projected to reach 135 million by 2050.[1] It is the sixth leading cause of death worldwide, a primary driver of disability and dependency in older adults, and a growing threat to global health systems, economies, and families.[2,3] While this burden is immense, the global response remains fragmented, underfunded, and too often reactive.

Other global health challenges, like cancer, HIV/AIDS, cardiovascular disease, and diabetes, have benefited from coordinated advocacy, political prioritization, and strategic investment, Alzheimer's disease has yet to match the same level of strategic investments and funding. For decades, it has been hampered by stigma and

a widespread perception that "nothing can be done." The result is a care ecosytem that favors late-stage interventions over proactive prevention within a policy landscape that has not kept pace with scientific progress, even though early diagnosis and timely action remain the most effective opportunities to improve patient outcomes.

Today, however, the field is at an inflection point and advocates face a significant moment of opportunity to build on their achievements. Scientific breakthroughs in blood-based biomarkers, digital cognitive assessments, and early-stage treatments offer the potential to transform Alzheimer's trajectory. Public awareness is rising. Political interest is increasing. Cross-sector partnerships are emerging. But opportunity does not guarantee impact. Without coordinated advocacy and sustained systems change, we risk squandering this momentum.

STATISTIC

Key Facts in Alzheimer's Research, Advocacy, and Policy

60M+

60M+ people currently living with dementia

$1.3T

$1.3 trillion+ annual global economic cost

135M

135M projected global cases by 2050

2050

6th

6th leading cause of death globally

TIMELINE

Key Moments in Alzheimer's Research, Advocacy, and Policy

1906 — **Dr. Alois Alzheimer** describes Alzheimer's as a distinct disease

1974 — **U.S. Congress** establishes the **National Institute on Aging (NIA)**

1980 — **Alzheimer's Association** is founded to accelerate research and support

1984 — **Alzheimer's Disease International (ADI)** founded

1987 — First clinical trial for Alzheimer's launched

1994 — Launch of **World Alzheimer's Day**

2010 — Launch of **World Alzheimer's Month**

2011 — **The National Alzheimer's Project Act (NAPA)** establishes a national plan for Alzheimer's in the U.S.

2013 — **G8 Dementia Summit:** The first G8 dementia summit was held

2015 — **FINGER Trial** shows the efficacy of lifestyle intervention on Alzheimer's prevention

2017 — WHO **Global Dementia Action Plan** officially adopted

2020 — UN Declares 2021–2030 as the **Decade of Healthy Aging**

2023 — **Traditional/full FDA approval** granted for **lecanemab**

2024 — **Donanemab** approved by FDA

2025 — **First FDA cleared blood test** to support a diagnosis of Alzheimer's

What This Playbook Is

This Playbook is built on the collective experience of Alzheimer's disease experts, advocates, policymakers, healthcare professionals and leaders from other disease areas—capturing what has worked, what hasn't, and why. By learning from the successes and challenges in fields like HIV/AIDS, cancer, cardiovascular disease, diabetes, and others, we can apply proven strategies to accelerate progress in Alzheimer's disease advocacy and policy.

The Playbook is built to support advocacy at every level and synthesizes findings from expert convenings, policy research, cross-disease lessons, and lived experience to:

1.	Define the core barriers holding back Alzheimer's disease progress across awareness, funding, early detection and diagnosis, and access to treatment and innovation
2.	Prepare and offer clear, actionable recommendations for a range of stakeholders—from local advocacy groups to national policymakers to global institutions
3.	Provide a unified narrative and shared language for the field to use in public messaging, policy discussions, and resource mobilization
4.	Elevate equity, community voice, and sustainability as essential to Alzheimer's disease advocacy strategy

Whether you are building public awareness, advancing regulatory access, or campaigning for national Alzheimer's disease investment, this Playbook is designed to help connect the dots between strategy, messaging, and action to create a clear roadmap for change.

This Playbook was developed in partnership with Eli Lilly & Co.

Who this is for:

- **Alzheimer's Advocates**
- **National and Local Policy Makers**
- **Regulators and Policy Decision Makers**
- **Community Leaders**

The content is organized around three strategic priorities—each reflecting where momentum is most urgently needed:

SECTION I
Enhancing Awareness, Prevention, Detection, and Diagnosis

SECTION II
Securing Funding for Impact

SECTION III
Strengthening Regulatory Pathways for Evidence, Innovation, and Access

Each section includes:

- **Advocacy Actions** to guide policy and advocacy efforts
- **Case Studies and Quotes** that demonstrate innovation, best practices, and lessons from other disease areas

The final section includes Calls to Action for advocates and policy makers—summarizing key steps needed to accelerate Alzheimer's disease progress globally.

The Current Landscape

Despite growing momentum, Alzheimer's remains constrained by structural, cultural, and policy gaps that slow progress in awareness, prevention, early detection and diagnosis, and access to innovation.

Public understanding is growing, but misconceptions remain.

Public awareness is increasing, fueled by advocacy, scientific breakthroughs, and greater media attention. Still, for many, Alzheimer's disease is viewed as an inevitable part of aging—not a condition that can also affect people in midlife, or one that can be detected early, accurately diagnosed, actively managed, and even slowed in its progression.[4]

Stigma still keeps people from seeking help.

Stigma and fatalism are beginning to give way to hope and agency—yet too many individuals and families still delay seeking help due to fear, shame, or misinformation.

Patient and caregiver voices are underrepresented in advocacy.

Although progress has been made, lived experience is still less visible in policymaking and funding debates than in other disease areas. Individuals living with the disease, caregivers and families are not consistently engaged as advocacy messengers, limiting the influence of their stories on policy priorities and resource allocation.

Cognitive health is missing from most prevention strategies.

Health systems are slowly recognizing the importance of cognitive health for overall wellness, but most national non-communicable disease (NCD) strategies, prevention programs, and screening guidelines still overlook cognitive illnesses, such as Alzheimer's disease, or relegate it to specialty care.

Primary care is an untapped front line.

Health systems are not ready for early intervention, and primary care remains a missed opportunity. Clinicians are eager to help but lack the tools, time, training, and reimbursement structures to take proactive steps in detection and referral.

Funding lags far behind the need.

Alzheimer's is one of the fastest-growing and costliest health challenges worldwide, yet it receives only a fraction of the investment dedicated to other major diseases. Global dementia care already costs over $1.3 trillion annually and is projected to double within two decades—yet funding for research, prevention, early detection, and care infrastructure has not kept pace with this trajectory.[5] Without major, sustained investment aligned to the scale of the challenge, efforts in prevention, detection, and treatment will remain fragmented, inequitable, and too slow to match the rising need.

Innovation is outpacing access.

Advances in diagnostics, treatments, and digital tools are promising, but outdated regulatory pathways, slow reimbursement, and inequitable delivery systems delay their impact. The value of new disease-modifying treatments depends on early, biomarker-driven diagnosis—yet too few systems are prepared to deliver this at scale, creating a narrow window of opportunity for patients to benefit. Without coordinated policy change, these breakthroughs will remain out of reach for many who need them most.

SECTION I

Drive Early Action on Awareness, Detection and Diagnosis, and Prevention

STRATEGY

Build a prevention-first, systems-wide advocacy agenda that integrates brain and cognitive health into everyday care, public messaging, and chronic disease strategies—changing how the public, providers, and policymakers think, talk, and act on Alzheimer's.

ADVOCACY ACTIONS

1.	Normalize Alzheimer's as a Public Health Priority
2.	Equip and Incentivize Primary Care
3.	Connect Detection with Meaningful Action
4.	Embed Alzheimer's in Broader Prevention Frameworks

To shift Alzheimer's from a crisis of late-stage care to a model of proactive public health, we must build systems that prioritize awareness, early detection, accurate diagnosis and prevention—together and at scale.

A truly systems-wide approach means embedding brain and cognitive health into everyday care, public messaging, and chronic disease strategies. It requires changing how people think about Alzheimer's disease, how clinicians talk about it, and how policymakers fund and measure progress. This section outlines the four most critical levers to make that shift a reality.

SECTION I

1. Normalize Alzheimer's as a Public Health Priority

Frame Alzheimer's like heart disease or diabetes: something that can be detected and diagnosed early, managed, and in many cases, prevented or delayed.

Lead visible, inclusive Alzheimer's campaigns.

Coordinate local and national advocacy events, media outreach, and public messaging that use culturally relevant, accessible language—and ensure these efforts reach underserved communities and caregivers. Develop simple, shareable messages that are tested with different cultural groups for clarity and impact so advocates can launch campaigns quickly in their own networks.

66

Paola Barbarino
Chief Executive Officer,
Alzheimer's Disease International

"Awareness raising remains one of our greatest needs. Without it, we see frontline practitioners who don't even know that dementia is a disease, and families who delay seeking help because they lack information or pathways to care. We must make Alzheimer's visible—through campaigns, such as the World Alzheimer's Month campaign, that reach every community, use language people understand, and give them the tools to act."

Equip and amplify community advocates.

Build on Dementia Friendly Community efforts by partnering with faith leaders, barbers/hairdressers, educators, and community health workers to share prevention and early detection messages in familiar spaces where people already gather and trust information. Distribute message kits with talking points, social media templates, and visuals so advocates can quickly share consistent, Alzheimer's-focused messages in their own networks. Additional, partner with well-known public figures and cultural influencers to broaden reach and bring Alzheimer's awareness into the mainstream conversation.

66

Victoria Wolodzko Smart
Senior Vice President
of Mission, Susan G. Komen

"When Susan G. Komen was first founded, people were still crossing the street when they saw a breast cancer patient—stigma was everywhere, and creating awareness campaigns was difficult. But now, we've made great strides thanks to a combination of community-driven awareness campaigns through patient advocacy efforts. This worked helped drive policy change, such as passing legislation that created national breast cancer early detection programs."

66

Iryna Vlasenko, DS
Vice President, International Diabetes Federation; Professor, Shupyk National Healthcare University of Ukraine

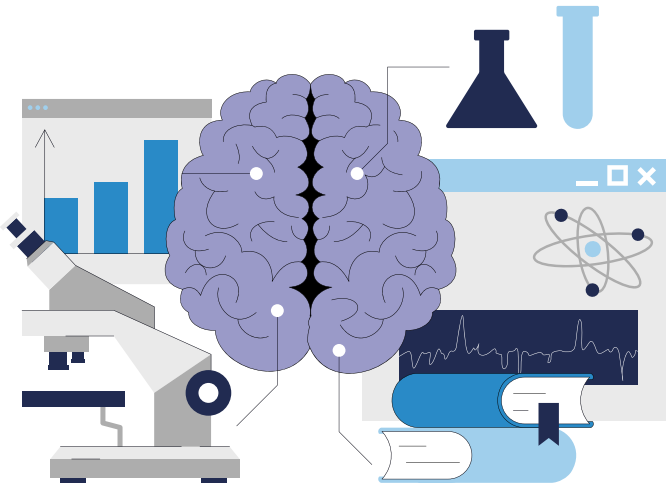
"It is essential to involve all healthcare and social service workers, which will save doctors' time. The multidisciplinary approach has economic benefits. This is especially important in countries with limited financial resources."

CASE STUDY

How Breast Cancer Grassroot Advocacy Transformed Public Perception

In the early 1980s, when the Susan G. Komen organization was founded, stigma around breast cancer was pervasive—just as Victoria Smart recalls. People often avoided or even shunned women with the diagnosis, and the topic was seldom mentioned in public. Changing these attitudes required bold, community-driven action.

Breast cancer survivors and their families began organizing highly visible awareness events—from local support meetings to the first Race for the Cure in 1983—to put a human face on the disease. Symbols like the pink ribbon and annual awareness walks rallied millions behind the cause, helping to topple the walls of secrecy and make breast cancer a topic people could openly discuss. Equally important, breast cancer advocacy embraced inclusive, grass-roots tactics to reach underserved groups. For example, Susan G. Komen's Worship in Pink initiative began training volunteers as ambassadors in faith-based communities, so they could share breast health messages in their own congregations. This kind of outreach helped reduce fear of the word "cancer" and connected people with screening resources they hadn't known about. The breast cancer movement shows that sustained, culturally relevant advocacy —led by survivors and community champions— can overcome stigma and drive systemic change, turning a once-silent illness into a widely supported public health cause.



SECTION I

2. Equip and Incentivize Primary Care

Primary care is the front door—but most clinicians lack Alzheimer's disease-specific training, time, or reimbursement models.

Make Alzheimer's core to medical training.

Partner with medical schools, medical societies, nursing programs, and licensing boards to embed Alzheimer's detection and prevention into both early education and continuing professional development—so primary care providers are equipped to act early. Identify and approach key decision-makers to advocate for Alzheimer's content in both pre-service curricula and continuing professional development.

66

Grace Whiting, J.D
Chief Executive Officer
and Lead Strategist,
Whiting Communications

"Even modest investments in early education and training can have a powerful ripple effect—helping young professionals learn from experienced mentors and inspiring them to commit their careers in various disease states."

Ensure Alzheimer's services are reimbursed.

Work with insurers, health ministries, and coding bodies to establish or update billing codes for brief cognitive tests, digital assessments, and Alzheimer's counseling—removing cost barriers for patients and providers. Prepare an evidence brief showing how Alzheimer's services reduce costly hospitalizations and long-term care needs, and cultivate champions inside payer organizations who can push the reimbursement changes from within.

Integrate Alzheimer's care into routine clinical care.

Advocate for cognitive detection and prevention counseling to be standard in existing preventive care frameworks, such as annual wellness visits, blood pressure checks, and diabetes screenings. Build a coalition of medical champions, patient advocates, and caregivers and empower patients with resources, sample questions, and talking points they can use with their own doctors—helping them request screenings and cognitive and memory care services, which builds grassroots demand and reinforces policy advocacy.

66

Jeremiah Mwangi
Director of Policy and Advocacy,
World Heart Federation

"It's crucial to move away from specialists to non-specialists for early detection within the health system at the primary care level. To really make an impact, we should also think across diseases rather than in silos."

STATISTIC **Primary Care Detection and Diagnosis**

50-70%
of people with cognitive impairment symptoms of Alzheimer's are not recognized or misdiagnosed in primary care.[6]

75%
Roughly ¾ of people with dementia worldwide are never formally diagnosed.

90%
In low-and-middle-income countries, studies suggest up to 90% of dementia cases remain undiagnosed, illustrating a significant detection and diagnosis gap.

SECTION I

3. Connect Detection with Meaningful Action

Detection and diagnosis without follow-up undermines trust. Early detection and diagnosis must link to interventions and support—lifestyle programs, treatment options, care navigation, clinical trials, and family planning.

Scott Bertani
Director of Advocacy; Lead HealthHIV; National Coalition for LGBTQ Health

"Detection and diagnosis cannot exist in isolation. For HIV, detection and diagnosis became real when we integrated it across system infrastructure like prenatal care, pharmacies, emergency departments, and community based organizations. We built infrastructure to help community based organizations and care service organizations and community clinics to be able to connect with patients and directly offer support and care."

Build and expand Alzheimer's navigator programs.

Advocate for Alzheimer's-specific navigator roles—modeled after cancer and diabetes care navigators—to guide patients and families from diagnosis through care, support, and community resources. Recruit patient, caregiver, and clinician champions to meet with hospital administrators, health system executives to make the case.

Strengthen community-based referral networks.

Work with medical providers, social services, and community support services to create integrated referral systems that ensure people diagnosed with Alzheimer's disease can quickly access comprehensive support. Create visual, easy-to-navigate materials for patients and caregivers to clarify the care pathway and next steps at the time of diagnosis, helping connect families to the right services quickly.

SECTION I

4. Embed Alzheimer's in Broader Prevention Frameworks

Link Alzheimer's disease to non-communicable diseases (NCD) strategies to unlock additional resources and political capital.

Integrate Alzheimer's into national NCD strategies.

Advocate for Alzheimer's to be embedded in chronic disease and healthy aging plans, with dedicated funding, measurable targets, and accountability reporting. Collaboration between NCD and Alzheimer's advocacy efforts creates powerful synergies, advancing shared goals in prevention, care coordination, and health system resilience. Create and time op-eds, social media pushes, and coalition press statements to coincide with key policy moments so policy makers are directly exposed to consistent, targeted messages at moments when decisions are being shaped. Given that most patients face multiple chronic conditions, speaking with one coordinated voice across NCDs strengthens advocacy and drives collective progress.

66

Tarun Dua
Head of Brain Health Unit,
World Health Organization

"What I've seen is that when noncommunicable disease communities—whether cancer, diabetes, or obesity—set aside competing priorities and speak with a single voice, real efficiencies are gained. Dementia, including Alzheimer's disease, must be part of that united effort."

Co-advocate with other disease groups.

Partner with heart, stroke, or diabetes organizations to jointly push for shared prevention frameworks and risk factor reduction initiatives. Draft position statements then use them in coordinated lobby days, media campaigns, and social media pushes.

66

Lilian Mbau, MD
Executive Director, Center for Cardiovascular Prevention and Rehabilitation

"How can we bring together many different stakeholders and do joint advocacy? We can be much more impactful if we bring together other disease areas which have common elements and mobilize join resources and have a collaborative advocacy movement."

CASE STUDY

NCDA's Joint Advocacy

The NCD Alliance (NCDA) is a non-governmental organisation dedicated to supporting a world free from preventable suffering, disability and death caused by noncommunicable diseases (NCDs). Founded in 2009 by a coalition of leading disease-focused organisations—the International Diabetes Federation, the World Heart Federation, the Union for International Cancer Control, and the International Union Against Tuberculosis and Lung Disease—NCDA today brings together a unique network of over 500 members from more than 100 countries, into a respected and impactful global civil society movement.

NCDA's advocacy focuses on cross-cutting issues that unify the NCD community, namely common risk factors including unhealthy diets, alcohol, tobacco, air pollution and physical inactivity, and the system solutions that strengthen person-centred NCD prevention and care for diverse conditions such as cancer, cardiovascular disease, chronic lung disease, diabetes, mental health and neurological conditions, and many more. The inclusion of a specific NCD target in the Sustainable Development Goals highlights the need for joint advocacy, not only across disease groups but also across global development.

NCDA shapes the high-level NCD agenda by coordinating diverse stakeholders in advocacy efforts at the UN, WHO and international financial institutions, while also supporting national and regional civil society to translate global momentum into stronger national policies, legislation, and resource commitments. By bringing together a diverse membership with united aims and messaging, impact is strengthened at all levels. The broad and inclusive approach has also helped raise awareness and knowledge of NCDs among the general population, and NCDs have become a frequent topic spotlighted in mainstream media, amplifying calls for healthcare that meets the needs of all people living with or at risk of NCDs.

Frame Alzheimer's as a workforce and economic issue.

Use data and lived experience to show how prevention preserves productivity, reduces long-term care costs, and strengthens communities. Partner with business associations, chambers of commerce, and labor unions and provide them with plug-and-play advocacy assets so they can publicly endorse Alzheimer's detection and prevention as a core economic priority, helping carry the message beyond the health sector.

66

George Vradenburg
Co-Founder; Founding Chairman of the Board UsAgainstAlzheimer's; Davos Alzheimer's Collaborative

"Soon, fewer workers are going to have to support larger, older and sicker populations, a consequence of aging demography. That will put a premium on lifelong promotion of the brain resilience and brain capital essential to increased productivity, economic competitiveness and social flourishing."

STATISTIC

$14.5T

Cost of Alzheimer's is projected to reach $14.5 trillion from 2020 to 2050 globally from lost economic productivity.[7]

2020 → 2050

SECTION II

Mobilize Investment to Match the Scale of the Challenge

STRATEGY

Make the economic and human case for Alzheimer's investment so strong that it becomes impossible for policy-makers to ignore—combining compelling data with powerful patient, family and caregiver stories.

ADVOCACY ACTIONS

1. Quantify the Cost of Inaction
2. Position Alzheimer's as a System Readiness Issue
3. Promote Blended Funding Models

Despite its rapidly growing prevalence and staggering economic impact, Alzheimer's continues to lag behind other non-communicable diseases in terms of funding, infrastructure, and global policy prioritization. While there has been meaningful progress in recent years, with increased funding and growing attention from both public and private sectors, much more must be done to secure the long-term, sustainable investments required to address Alzheimer's disease on a global scale.

STATISTIC

Alzheimer's and cancer research funding comparison

Cancer **2-3x**

Alzheimer's funding has grown exponentially, particularly in the US. Yet, it is still the least funded chronic disease relative to its prevalence[8] & cancer research gets about 2-3x more funding than dementia research globally.[9]

Alzheimer's

COUNTRY	Annual Dementia R&D Funding			Comparison: Cancer R&D		
	Last ~5 years	Last ~10 years	**% Change**	Last ~5 years	Last ~10 Years	**% Change**
United States	~$3,800M (NIH, FY24)[10]	~$562M (NIH, FY14)[11]	**+576%**	~$8,100M (NIH, FY24)[12]	~$5,400M (NIH, FY14)[13]	**+50%**
United Kingdom	~£100M (gov, FY22)[14] Note: gov committed to £160m/year by 2024	~£60M (gov, FY22)[15]	**+66.7%**	~£251M (total gov, 2021)[16]	~£200M (total gov, 2015)[17]	**+25.5%**
France	~£470M (2014-2019 Neuro-degenerative Diseases Plan)[18]	~£200M (2008-2012 Plan for ADRD research, ~£40M/yr)[19]	**+95.8% total increase in average annual investment**	~£120-130M (public research funding, 20201)[20]	~£90-100M (public research funding, 2010)[21]	**+20-40%**

SECTION II

1. Quantify the Cost of Inaction

Late-stage care is more expensive than early intervention. Policymakers need to see the long-term savings of early detection and prevention.

Produce country-level economic reports.

Partner with health economists to show how early detection and prevention reduce institutional care costs, extend independence, and improve quality of life. Pair launches with media outreach—interviews and press briefings—so the findings reach both policymakers and the public at the same time.

STATISTIC **The Cost of Inaction**

3x

1) The global burden of dementia will nearly triple (growing from 36M in 2021 to 90M in 2050) and will become the third greatest contributor to global health loss* among people aged 70+.[22]

3x

2) In the US, average spending on someone with Alzheimer's is nearly three times higher than spending on other older adults.[23]

$ **$3T** 2030

3) Global estimates of economic burden of Alzheimer's was ~$1.3 trillion in 2019 and is expected to rise to ~$3 trillion through 2030.[24]

*(disability and premature mortality)

66

Sanne Frost Helt
Senior Director for Policy, Program, and Partnerships, World Diabetes Foundation

"At the country level, it's important to engage with policy makers, equipping decision makers with an understanding of the economic impact of inaction—to the individual, community, and society. This drives domestic resource prioritization and allocation."

Highlight workforce productivity losses.

Document the real economic toll of Alzheimer's disease on both individuals living with the disease and their caregivers—focusing on missed work, early retirement, and reduced productivity, highlighting losses in ways that enable policy makers and economic planners to understand the broader societal stakes. Deliver these findings to trade associations, business councils, and industry events where policymakers and economic influencers are present.

Pair economic data with lived experience.

Center the voices of those most affected by the disease by coordinating testimony from people living with Alzheimer's, their caregivers, and employers to humanize financial arguments and make them resonate with decision-makers. Identify and train a speaker roster that equips these individuals with clear, authentic talking points connecting their personal experiences to the broader economic case for early detection and prevention.

66

Johanna Ralston
Chief Executive Officer, World Obesity Federation

"It's often that combination of lived experience plus the very stark numbers that shifts policymakers...when you can show them both the human and the financial stakes together, it's very hard for them to ignore."

SECTION II

2. Position Alzheimer's as a System Readiness Issue

This isn't just about one disease—it's about aging, resilience, and health system sustainability.

Michel Matter, MD
President, Geneva Doctors' Association

"If you want to have an impact, don't just stay in your own field—bring together other disease areas, researchers, hospitals, industry, caregivers. That's when governments listen, because they see costs and solutions across the whole system."

Embed Alzheimer's in broader resilience agendas.

Meet with local and national planners to include Alzheimer's prevention and care in aging-friendly city programs, disaster preparedness plans, and community resilience strategies. Position Alzheimer's as a driver of long-term economic stability by linking early detection, timely intervention, and caregiver support to productivity gains, reduced costs, and stronger social systems. Align these efforts with existing frameworks such as the UN Decade of Healthy Ageing, the WHO Global Action Plan on NCDs, and national strategies on cardiovascular and diabetes health to reinforce shared priorities and maximize policy impact.

Expand care infrastructure through policy change.

Lobby legislators for funding to grow the dementia care workforce, open more facilities, and expand home- and community-based support services. Bring together policymakers, regulators, and advocates to present concrete, localized evidence alongside real patient, family and caregiver stories that illustrate the human impact. Follow the event with targeted outreach to key budget decision-makers, pairing each ask with a clear policy so momentum turns into action.

Reframe Alzheimer's investment as preparedness.

Collect and share real-world case studies showing how investments in Alzheimer's detection, treatment, and care strengthen the health system's ability to respond to other chronic conditions and crises, providing policy makers with clear evidence that investments in Alzheimer's strengthen system-wide preparedness and resilience.

SPOTLIGHT

The "brain economy" is an emerging framework that positions brain health as essential to national prosperity, productivity, and resilience. Just as cardiovascular health has long been linked to workforce and economic outcomes, brain health—including the prevention, detection, and treatment of Alzheimer's—directly shapes labor participation, caregiver productivity, healthcare costs, and social cohesion.

When deployed intentionally, positioning Alzheimer's within the broader brain economy and brain health framework can be advantageous in settings where it adds momentum rather than detracts focus from specific Alzheimer's needs. By adopting this lens, Alzheimer's advocates can engage new stakeholders—finance ministries, development banks, and multilateral forums—that may not otherwise prioritize dementia. Framing investments in early detection, timely intervention, and care as drivers of productivity and cost savings makes Alzheimer's central to broader resilience agendas.

Embedding Alzheimer's in the brain economy conversation also expands the coalition: employers, workforce organizations, and education systems all have a stake in sustaining healthy brains across the life course. While it is important to seize these opportunities, advocates should also ensure that Alzheimer's priorities remain clear and visible within larger coalitions. While this approach will not suit every context, used strategically, the brain economy can elevate dementia alongside other pressing global challenges without losing its distinct place in health and policy discussions.

Lefkos Middleton, MD
Professor of Neurology,
Imperial College London

"We know that there are modifiable risk factors for Alzheimer's and certain diseases, such as diabetes and hypertension and other cardiometabolic disorders, are significant risk factors. If we can better treat these chronic conditions, we can have a reduced risk of Alzheimer's later in life."

Conny Helder
Former Minister of Health,
Welfare and Sport,
The Government
of the Netherlands

"It's important to have the evidence showing what does good care look like. Is it putting people into institutions and nursing homes or can we implement more cost-effective care models. We have better care models, that are not only cheaper, but better and more effective for people, and these need to be showcased."

SECTION II

3. Promote Blended Funding Models

Sustainable progress requires partnerships across sections.

Forge public–private funding partnerships.

Convene roundtables that bring together government agencies, companies, and nonprofits to co-fund early detection programs, navigator roles, and awareness campaigns. Follow up with a joint action plan that outlines each partner's role, timelines, and measurable outcomes, and use press releases or public announcements to create accountability and momentum.

66

Mathieu Morand
Director of Impact Scaling,
City Cancer Challenge

"It is really important to bring together stakeholders at various levels—the institutional level, public and private, and advocacy perspective, in order to build investment cases from the ground up."

Tap into non-traditional funding streams.

Identify target sectors with aligned priorities—such as workforce development, caregiving support, housing and aging-in-place, and corporate ESG initiatives—and position Alzheimer's as integral to their missions. Develop and pitch joint initiatives (e.g., workplace brain health programs, caregiver training networks, resilience-focused community hubs) that deliver measurable benefits for both Alzheimer's advocacy and the partner sector.

SECTION III

Accelerate Evidence, Innovation, and Equitable Access

STRATEGY

Ensure that scientific breakthroughs reach people quickly, safely, and equitably—by modernizing evidence standards, expanding advocacy capacity, and building access pathways that serve all communities.

ADVOCACY ACTIONS

1. Redefine Evidence Generation
2. Rebuild Regulatory-Ready Advocacy Capacity
3. Center Equity in Access Pathways

Alzheimer's research has reached a breakthrough era. But innovation doesn't equal access—especially when approval pathways and reimbursement are slow, and policy change lags behind science.

SECTION III

1. Redefine Evidence Generation

New tools—like blood tests and digital cognitive assessments—require validation outside of traditional clinical trials.

Push for real-world evidence in approvals and reimbursement.

Engage regulators and payers to promote the robust use of real-world data—such as patient-reported outcomes and community program results—in approval and reimbursement decisions. Coordinate participation in key consultations and reviews to ensure decision-makers see credible, practical examples of how real-world evidence can validate clinical benefit and inform and support evidence-based access.

Advocate for global alignment on endpoints and measures.

Collaborate with international advocacy networks to push for consistent surrogate endpoints and meaningful measures that speed up access without compromising safety. Convene cross-border virtual roundtables with Alzheimer's advocacy groups, researchers, regulators, and policymakers to identify priority endpoints and develop a shared advocacy position paper. Present this position to international and policy forums like WHO meetings, G7 health summits, and regulatory meetings to build momentum for alignment.

Frame value in population health terms.

Emphasize that the value of emerging Alzheimer's treatments must be assessed not only by individual clinical outcomes but also by their broader impact on population health, system readiness, and economic sustainability. Use pharmacoeconomic and real-world data to illustrate how early detection and timely treatment can improve quality of life, preserve workforce participation, and reduce long-term care costs.[25] Develop media materials and advocacy briefs that connect these population-level benefits to national priorities in health and productivity—helping policymakers see Alzheimer's as a public health investment, not just a medical expense.

Peter J. Pitts
Founder & President, Former Assoc. Commissioner for External Relations Center for Medicine in the Public Interest (CMPI), FDA

"The economics of Alzheimer's can really help in making a strong case. Because when you look at the numbers relative to delaying onset, delaying progression, numbers are enormous. The pharmacoeconomics are a key building block, not just in regulatory approvals but also in getting investment."

STATISTIC

Early Detection

$8T

A study showed estimates that early detection, specifically identifying people with mild cognitive impairment, could yield up to ~$8 trillion in savings in health and long-term care expenditures, or ~$14,000 per person per year in the US.[26]

$14K

1 YEAR

SECTION III

2. Rebuild Regulatory-Ready Advocacy Capacity

Too often, advocates are excluded from regulatory conversations—or invited too late.

Train advocates to engage in regulatory processes.

Host targeted workshops for caregivers, patients, and advocacy leaders that walk through the step-by-step process of participating in regulatory hearings, coverage reviews, and policy consultations. Identify upcoming regulatory timelines and proactively recruit advocates to participate, pairing them with experienced mentors for confidence and impact.

66

Scott Bertani
Director of Advocacy; Lead HealthHIV; National Coalition for LGBTQ Health

"The HIV experience reminds us that real innovation isn't just science, its making access a reality. Patient advocates were utilized to lay out a new model for regulatory flexibility and put in work to help regulators understand the priorities and the risk benefits from a lived experience perspective to ensure that science is meeting the reality."

66

Brittany Avin McKelvey, PhD
Senior Director of Regulatory Policy, LUNGevity Foundation

"It's so important to bring together industry, the FDA or other regulatory bodies, academics, clinicians and patients to tackle access in a pre-competitive manner. And in oncology, we've really seen the role of patient groups to be that convener. We've found partners value these collaborative relationships, that are not product specific, to really move regulatory and policy ideas forward."

Create and distribute engagement toolkits.

Provide communities with plain-language guides, templates, and talking points to participate in Health Technology Assessment (HTA) and reimbursement discussions.

Recognize lived experience as expertise in decision-making.

Campaign for regulatory bodies to include representative patient and caregiver perspectives in benefit–risk assessments and advisory panels. Use targeted media and social campaigns to spotlight examples of how lived experience has improved past regulatory decisions—creating public pressure and making it politically costly for decision-makers to exclude these voices.

CASE STUDY

How Lung Cancer Advocacy Redefined Evidence and Accelerated Access

When breakthrough therapies began transforming lung cancer care in the U.S., individuals with lived experience and advocates stepped up to ensure the regulatory system kept pace. Advocacy organizations led a push to broaden acceptable evidence generation for treatment approvals, beyond the narrow focus on tumor response or survival. They organized patient-focused forums with regulators, bringing U.S. Food and Drug Administration (FDA) officials, researchers, and even global regulators to the table to emphasize that patient-reported outcomes—like symptom relief and quality of life—are critical endpoints. At the same time, advocacy networks trained patients and caregivers to participate in regulatory hearings and comment periods, ensuring the community could engage early and effectively in shaping standards.

These tactics delivered lasting policy change. FDA oncology guidance began embedding patient reported outcomes into trial requirements, and regulators used real-world evidence from lung cancer populations to accelerate approvals, including for therapies targeting rare mutations. Payers followed, expanding coverage for biomarker testing and immunotherapies, while trial eligibility criteria broadened to reflect real-world patients. Together, these advocacy wins modernized regulatory standards and sped access to innovation. The lung cancer experience shows how patient-led advocacy can redefine evidence, institutionalize lived experience in policy, and build the capacity needed to influence regulatory and reimbursement pathways.

SECTION III

3. Center Equity in Access Pathways

If innovation is only available in academic hospitals, it will widen—not close—health equity gaps.

Advocate for scalable, primary care–ready tools.

Work with local primary care clinics and community health centers to identify which screening or monitoring tools they already use—or could easily adopt. Push for adoption of affordable, digital, and easy-to-use diagnostic and monitoring tools that work outside academic centers. Build public demand by sharing patient and provider testimonials through social media, community radio, and local news outlets.

66

Chris Lynch
Deputy Chief Executive Officer & Director of Policy & Communications, Alzheimer's Disease International

"If diagnostics only sit in academic centers, we've already lost. We need to be thinking about what tools can be deployed in a GP's office or a rural clinic, otherwise we'll never close the equity gap."

Increase diversity in research and data.

Mobilize community outreach to enroll underrepresented groups, such as women, racial and ethnic minorities, and rural or low-income populations, in clinical trials and real-world evidence studies, ensuring findings reflect all populations. Partner with trusted local organizations to host clinical trial information sessions in multiple languages, led by both clinicians and community leaders. Recruit and train "trial ambassadors" to share accurate information at community events and through local communication channels, distribute easy-to-share visuals, and spotlight participant stories across newsletters, community media, and policymaker briefings to keep the issue visible.

66

Rosa Giuliani, MD
Consultant Medical Oncologist,
Guy's and St. Thomas'
NHS Foundation Trust

"One of the most important lessons from oncology is that unless you actively design for diversity in trials, it doesn't happen. Equity is not automatic—it requires investment in outreach, in translation, in trust-building with communities."

Design equitable delivery systems.

"Enable policy makers and providers to build Alzheimer's care pathways that reach rural, low-income, and marginalized communities. Use coordinated advocacy days, targeted social media campaigns, and local op-eds to elevate the issue so that equitable access becomes a visible and urgent priority for decision-makers.

CONCLUSION

Turning Advocacy Into Action

Alzheimer's advocacy is entering a new chapter that demands more than awareness campaigns or reactive policies. We now have the science, the tools, and the public readiness to drive bold, system-wide change.

But change won't happen on its own. It requires:

1.	Coordinated action across sectors
2.	Evidence-informed messaging that resonates with decision-makers
3.	Community-driven strategies that prioritize equity
4.	Persistent, loud, and informed advocacy

This Playbook offers a foundation—but it's just the beginning. Every policymaker briefed, every system influenced, and every and every patient and caregiver empowered brings us closer to the vision we all share: a world where Alzheimer's is met not with silence and delay, but with urgency, action, and hope.

Roundtable Participants

Bianca Athanasiou
Senior Strategic Account Director, BBC StoryWorks

Paola Barbarino
Chief Executive Officer, Alzheimer's Disease International

Scott Bertani
Director of Advocacy; Lead HealthHIV; National Coalition for LGBTQ Health

Tarun Dua
Head of Brain Health Unit, World Health Organization

Sebastiaan Engelborghs, PhD
Chair of Neurology; Chair NEUR Research Group Universitair Ziekenhuis Brussel; Vrije Universiteit Brussel

Chloé Garay
Senior Director in International Regulatory Policy, Eli Lilly & Co.

Kate Gillespie, PhD
Assistant Director, Institute for Health Metrics and Evaluation

Rosa Giuliani, MD
Consultant Medical Oncologist, Guy's and St. Thomas' NHS Foundation Trust

Teresa Gmur
Associate Director, Global Corporate Affairs, Alzheimer's Disease, Eli Lilly & Co.

Ishtar Govia, PhD
Founder and Chief Executive Officer, Amagi Health Ltd

Conny Helder
Former Minister of Health, Welfare and Sport, The Government of the Netherlands

Sanne Frost Helt
Senior Director for Policy, Program, and Partnerships, World Diabetes Foundation

Mike Hodin, PhD
Chief Executive Officer, Global Coalition on Aging

Marijke Kremin
Policy and Advocacy Manger, NCD Alliance

Chris Lynch
Deputy Chief Executive Officer & Director of Policy & Communications, Alzheimer's Disease International

Catarina Mastellaro
Head of Strategic Engagement, Mental & Brain Health, WHO Foundation

Michel Matter, MD
President, Geneva Doctors' Association

Lilian Mbau, MD
Executive Director, Center for Cardiovascular Prevention and Rehabilitation

Brittany Avin McKelvey, PhD
Senior Director of Regulatory Policy, LUNGevity Foundation

Lefkos Middleton, MD
Professor of Neurology, Imperial College London

Mathieu Morand
Director of Impact Scaling, City Cancer Challenge

Jeremiah Mwangi
Director of Policy
and Advocacy,
World Heart Federation

Hiroshi Nakamura
Dean, Professor,
Keio Business School

Peter J. Pitts
Founder & President,
Former Assoc. Commissioner
for External Relations Center
for Medicine in the Public
Interest (CMPI), FDA

Johanna Ralston
Chief Executive Officer,
World Obesity Federation

Duane Schulthess
Chief Executive Officer,
Vital Transformation

Susan Wile Schwarz
Head of Health Programs,
Global Coalition on Aging

Katrin Seeher, PhD
Mental Health Specialist,
Department of Health
and Substance Use,
World Health Organization

Victoria Wolodzko Smart
Senior Vice President
of Mission, Susan G. Komen

Iryna Vlasenko, DS
Vice President, International
Diabetes Federation;
Professor, Shupyk National
Healthcare University
of Ukraine

George Vradenburg
Co-Founder; Founding
Chairman of the Board
UsAgainstAlzheimer's; Davos
Alzheimer's Collaborative

Grace Whiting, J.D
Chief Executive Officer
and Lead Strategist,
Whiting Communications

Endnotes

1. GBD 2023 Disease and Injury and Risk Factor Collaborators. (2025). Burden of 375 diseases and injuries, risk-attributable burden of 88 risk factors, and healthy life expectancy in 204 countries and territories, including 660 subnational locations, 1990–2023: A systematic analysis for the Global Burden of Disease Study 2023. The Lancet, 406(10513), 1873–1922. https://doi.org/10.1016/S0140-6736(25)01637-X

2. GBD 2021 Forecasting Collaborators. (2024). Burden of disease scenarios for 204 countries and territories, 2022–2050: A forecasting analysis for the Global Burden of Disease Study 2021. The Lancet, 403(10440), 2204–2256. https://doi.org/10.1016/S0140-6736(24)00685-8

3. World Health Organization. (2023, December 9). *The top 10 causes of death. World Health Organization.* https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death

4. Frisoni, G. B., Altomare, D., Winblad, B., Cummings, J. L., DeKosky, S. T., Dubois, B., & Scheltens, P. (2025). Alzheimer's disease outlook: Controversies and future directions. The Lancet, 406(10510), 1424–1442. https://doi.org/10.1016/S0140-6736(25)01389-3

5. Alzheimer's Disease International. (2021, September 21). *Over 41 million cases of dementia go undiagnosed across the globe: World Alzheimer report reveals.* https://www.alzint.org/news-events/news/over-41-million-cases-of-dementia-go-undiagnosed-across-the-globe-world-alzheimer-report-reveals

6. Hansson, O., Edelmayer, R. M., Boxer, A. L., Carrillo, M. C., Mielke, M. M., Rabinovici, G. D., Salloway, S., Sperling, R., Zetterberg, H., & Teunissen, C. E. (2022). *The Alzheimer's Association appropriate use recommendations for blood biomarkers in Alzheimer's disease.* Alzheimer's & Dementia, 18(12)

7. Alzheimer's Disease Operational Definitions (ADODs) Collaborative. (2024). *Dementia operational definitions and economic projections. The Lancet Healthy Longevity,* Vol 12(9), e1534-e1543. https://www.sciencedirect.com/science/article/pii/S2214109X2400264X

8. Council for Global Health. (2023, July 19th.). *The cost of inaction. Think Global Health.* https://www.thinkglobalhealth.org/article/cost-inaction

9. Dementia Statistics Hub. (n.d.). *Government investment in dementia research.* https://dementiastatistics.org/statistics/government-investment-in-dementia-research/

10. Alzheimer's Impact Movement. (n.d.). Research. https://alzimpact.org/research

11. Ibid.

12. Ibid.

13. Ibid.

14. Alzheimer Europe. (2020, March 18th). *France calls on international experts to evaluate implementation of its recent neurodegenerative diseases plan.* https://www.alzheimer-europe.org/news/france-calls-international-experts-evaluate-implementation-its-recent-neurodegenerative?language_content_entity=en

15. Ibid.

16. National Institute for Health and Care Research. (2015, September 26). *Initiative in France that included the implementation of the plan. PMC.* https://pubmed.ncbi.nlm.nih.gov/26407550/

17. Ibid.

18. Ministère des Solidarités et de la Santé. (n.d.). *Feuille de route - Stratégie décennale de lutte contre les cancers* [PDF]. https://sante.gouv.fr/IMG/pdf/feuille_de_route_-_strategie_decennale_de_lutte_contre_les_cancers.pdf

19. National Institutes of Health. (2025, June 17). *NIH categorical spending.* https://report.nih.gov/funding/categorical-spending#/

20. UK Parliament. (2024, February 7). CBP-9766 [PDF]. *Research Briefings*. https://researchbriefings.files.parliament.uk/documents/CBP-9766/CBP-9766.pdf

21. Ibid.

22. GBD 2021 Forecasting Collaborators. (2024). Burden of disease scenarios for 204 countries and territories, 2022–2050: A forecasting analysis for the Global Burden of Disease Study 2021. The Lancet, 403(10440), 2204–2256. https://doi.org/10.1016/S0140-6736(24)00685-8

23. Alzheimer's Impact Movement. (2022). *Costs of Alzheimer's disease and other dementias.* https://portal-legacy.alzimpact.org/media/serve/id/62509c7a54845

24. Alzheimer's Disease International. (2018). *World Alzheimer Report 2018: The state of the art of dementia research.* https://www.alzint.org/u/WorldAlzheimerReport2018.pdf

25. Frisoni, G. B., Altomare, D., Winblad, B., Cummings, J. L., DeKosky, S. T., Dubois, B., & Scheltens, P. (2025). Alzheimer's disease outlook: Controversies and future directions. The Lancet, 406(10510), 1424–1442. https://doi.org/10.1016/S0140-6736(25)01389-3

26. AARP. (2024). *Why Alzheimer's cases are increasing.* https://www.aarp.org/health/conditions-treatments/alzheimers-cases-increasing/

Global Coalition on Aging

GCOA represents a cross-section of global business including technology, pharmaceuticals, healthcare, home care, financial, transportation, and consumer sectors. We engage global institutions, policymakers, and the public to drive debate on, create, and promote innovative policies and actions to transform challenges associated with the aging of the global population into opportunities for social engagement, productivity and fiscal sustainability.

For more information, visit
www.globalcoalitiononaging.com

and contact
sschwarz@globalcoalitiononaging.com