



From awareness to action: addressing the growing burden of Alzheimer's in Brazil

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This policy brief outlines the current state of Alzheimer's care in Brazil. Alzheimer's disease (AD), the most common form of dementia, is a neurodegenerative and progressive chronic condition that weakens cognitive abilities and results in a loss of autonomy and functionality. The information presented in this profile is based on the literature and a series of interviews with experts working in Brazil.



Background indicators

Population	
Population aged 65+ years	12.1% ¹
Life expectancy at birth	72.4 ¹
AD and dementia	
Prevalence of AD	313 per 100,000 ²
Deaths attributed to AD and other dementias	18.9 per 100,000 ³
Disability-adjusted life years (DALYs) attributed to AD and other dementias	761.5 ⁴
Years of life lost (YLLs) attributed to AD and other dementias	435.3 ⁵

Introduction

AD represents an urgent and growing public health concern, representing 60-70% of all dementia cases.⁶ In Brazil, approximately 1.8m Brazilians aged 60 and older are living with some form of dementia—a number that is projected to rise sharply to nearly 2.8m by 2030 and 5.5m by 2050.^{7,8} And alarmingly, more than 80% of dementia cases in those aged 60 and older remain undiagnosed in Brazil.⁹ The rapid increase in AD cases, coupled with significant underdiagnosis, will continue to place enormous pressure on families,

health systems and society. To address the growing burden of AD, policymakers must:

- Target stigma and lack of awareness of AD to help tackle underdiagnosis
- Roll out structured professional training spanning primary and specialist care
- Ensure health system readiness for advanced diagnostics, treatment and management
- Create an implementation plan for the National AD and Dementia Policy
- Offer structured, multimodal support to caregivers

Current snapshot: AD policy, guidelines and programs in Brazil

■ Yes
 ■ Partially
 ■ No

National AD plan*Existence of a national plan for AD*

Brazil's *Política Nacional de Cuidado Integral às Pessoas com Doença de Alzheimer e Outras Demências* (National Policy for the Comprehensive Care of People with Alzheimer's Disease and Other Dementias) went into effect in June 2024.⁸

AD awareness campaigns*Existence of national AD awareness campaigns*

The National Policy for the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (2024) aims to promote awareness among the general population.¹⁰ Current education efforts remain sporadic, such as National Alzheimer's Awareness Day events.⁸ Experts suggest that public awareness continues to be a challenge. Organizations such as the Brazilian Federation of Alzheimer's Associations (Febraz) have stepped in to fill the gap.¹¹

Clinical guidelines*Existence of clinical guidelines for AD that include early detection, diagnosis, treatment, support and end-of-life care*

The Scientific Department of Cognitive Neurology and Aging at the Brazilian Academy of Neurology has produced guidelines for AD diagnosis, the use of biomarkers and treatment.^{12,13,14} The Ministry of Health has also published guidelines on diagnosis and treatment of AD.¹⁵

Patient support and advocacy*Existence of patient support programs and advocacy groups at the national and local levels*

Some non-governmental organizations (NGOs), including Brazilian Alzheimer's Association (ABRAz) and Febraz are key players in providing support for patients and empowering caregivers through training and resource-sharing.^{11,16} Yet, experts say there are few structured programs to provide patient support, respite care or training for caregivers. The National Policy for the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (2024) includes guidelines for improving support for patients that have not yet been implemented.

Healthcare workforce & training*Availability of healthcare professionals and training for AD*

The National Policy for the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (2024) provides guidelines for improved workforce training.¹⁰ However, there is currently limited availability of training programs, and experts suggest the healthcare workforce remains under-prepared.

Research and development*Availability of funding allocated to Alzheimer's research*

Several state and national organizations, including the National Council for Scientific and Technological Development (CNPq) and the São Paulo Research Foundation (FAPESP), provide funding for Alzheimer's research in Brazil.⁸ However, additional investment is needed to bridge the gaps in research and develop research capacity in all states.⁸ The National Policy for the Comprehensive Care of People with Alzheimer's Disease and Other Dementias (2024) does not include funding for research.¹⁰

Thriving in society*Existence of programs that support AD patients' ability to thrive in society, such as age-friendly environments*

While many non-governmental organizations (NGOs) work to provide support for AD patients, there is no evidence of age-friendly environments that enhance accessibility and social participation for individuals with Alzheimer's.

Epidemiological database*Existence of an epidemiological database or publicly available data on the incidence and prevalence of AD*

There is no evidence of an epidemiological database that tracks the incidence and prevalence of AD in Brazil.

Diagnostic tools*Availability of tools for diagnosing AD*

Experts indicate that PET-amyloid and MRI scans are available, but access is limited and often determined by geography or health system (ie, public or private).

Key takeaways

Target cultural resistance, stigma and lack of awareness to tackle Brazil's AD underdiagnosis crisis

Less than 20% of dementia cases are diagnosed in Brazil, and early diagnosis is rare.⁹ “There are many barriers to diagnosis—including awareness about dementia,” explains Raphael Machado Castilhos, Coordinator of the Cognitive and Behavioral Neurology Research Center at the Porto Alegre Clinical Hospital. “In many, many families, dementia is thought to be a natural consequence of aging.” Diagnosis and, especially, early diagnosis depend on public awareness of AD—its demographics, early symptoms and risk factors—and a willingness (and knowledge of how) to seek medical advice.¹⁷

AD is subject to significant stigma and lack of awareness in Brazil. “People think that forgetting things at 80 or 90 is normal,” says Claudia Suemoto, Associate Professor of Geriatrics at the University of São Paulo Medical School and Director of the Brazilian Brain Bank. Such misconceptions often lead to delayed consultations, thereby reducing the likelihood of early interventions.⁸

Patients and their families also fear the consequences of a diagnosis—or assume that nothing can be done to manage AD. “Even when dementia is diagnosed, families often ask, ‘Why bother with treatment if there is no cure?’” says Dr Suemoto. While there is currently no cure for AD, there are treatments that can slow disease progression.¹⁷ “We need to raise awareness that there are things that we can do to improve the lives of patients and their families,” Dr Suemoto explains.

Increasing public awareness of AD must also include education about modifiable risk factors. Dr Suemoto points out that over 50% of dementia cases could be prevented by addressing modifiable risk factors such as hypertension and diabetes control, smoking cessation, physical activity and diet—all of which can be better managed in an educated and health literate population.¹⁸ “One of the biggest modifiable risk factors in Brazil is low education,” says Milton Crenitte, Technical Director of the International Longevity Centre Brazil. “Addressing this, starting with better education for children and teenagers, can reduce Alzheimer's cases in the future.”

“In wealthier countries, underdiagnosis is a challenge. But in Brazil, it's a crisis.”

Celene Queiroz Pinheiro de Oliveira,
President, The Brazilian Alzheimer's
Association (ABRAz)



Mychael Lourenço, Assistant Professor of Neuroscience at the Federal University of Rio de Janeiro's Institute of Medical Biochemistry, says that the government and civil society must work together to help raise awareness. "We need better communication strategies to educate the public and healthcare professionals," he says. The key areas that these campaigns ought to focus on are:

- Correcting the misconception that forgetfulness is a natural part of ageing—to encourage patients and their families to seek support when symptoms first appear
- Encouraging individuals and their families to seek treatment by informing people of the available support and treatment options for AD, thereby reducing stigma
- Raising awareness of prevention—to encourage individuals to reduce their risk of developing AD



"We need to educate the public that getting older doesn't mean losing your cognitive abilities."

Celene Queiroz Pinheiro de Oliveira, President, The Brazilian Alzheimer's Association (ABRAz)

In response to these needs, some formalized patient organizations, such as the *Associação de Parentes e Amigos de Pessoas com Alzheimer* (Association of Relatives and Friends of People with Alzheimer's Disease; APAZ) and the *Federação Brasileira das Associações de Alzheimer* (Brazilian Federation of Alzheimer's Associations; Febraz) have created awareness campaigns and worked to ensure that these campaigns reach diverse communities. Still, as Dr Lourenço explains, the government and civil society must work together to increase the reach and impact of awareness efforts.

Policymakers could emulate and expand the success of existing strategies. One example is the Brazilian Strategy for Prevention and Attention to Childhood Obesity (PROTEJA), launched in 2021 by the Ministry of Health to promote healthy eating and physical activity, and prevent and control childhood obesity.¹⁹ As of 2022, 1,350 municipalities had joined PROTEJA, and the program received a UN award for its impact in combating non-communicable diseases (NCDs). Developing a similar strategy for AD could serve to engage a wide range of stakeholders, challenge stigma and misconceptions, and raise awareness about treatments.

Bolster early diagnosis through structured professional training spanning primary and specialist care

Given the importance of early detection, primary care professionals are often the first line of defense against AD. However, primary care doctors (PCPs) lack awareness of dementia.²⁰ "There's an outdated belief among some clinicians that cognitive function naturally declines with age," says Sonia Brucki, a Neurologist at the University of São Paulo's Clinical Hospital. Lack of clinician knowledge can lead to delayed referrals and diagnoses, thereby impacting the effectiveness of treatment. Furthermore, training and resource limitations restrict the ability of PCPs to function as an adequate first port of call for potential AD and dementia patients.



“Recognizing cognitive complaints early can allow for **earlier intervention, which benefits both patients and families.”**

Dr Raphael Machado Castilhos, Coordinator, Cognitive and Behavioral Neurology Research Center, Hospital de Clínicas de Porto Alegre

“Primary care doctors are not trained to diagnose dementia, and they don’t have time to screen for it in short consultations,” says Dr Suemoto. While diagnostic criteria and protocols for AD have been introduced to provide primary care practitioners with some support and guidance in initial evaluations, knowledge gaps remain.^{13,12}

Furthermore, shortages of both neurologists trained in dementia management, and healthcare professionals trained in memory and cognition result in delays in treatment.²¹ Celene Queiroz Pinheiro de Oliveira, President of the Brazilian Alzheimer’s Association (ABRAz), says that structured training to enable GPs and specialists to diagnose dementia early is a key priority. “When we organize educational events, the demand is overwhelming—professionals want to learn, but the system is failing to provide structured training.”

In the United States (US), Project ECHO (Extension for Community Healthcare Outcomes), a six-month, bi-weekly, telemonitoring-based dementia care training program from the Alzheimer’s Association, trains healthcare providers on how to provide accurate and timely diagnosis and quality dementia care in the primary care setting.²² The US Alzheimer’s Association found that 95% of survey respondents agreed that the program improves the quality of care, and 94% said that they had changed the way they cared for patients with dementia as a result of participating in the program.²² Policymakers in Brazil should seek to bridge care gaps by developing similar programs—potentially supported by, or in partnership with, organizations such as the Brazilian Alzheimer’s Association.

Futureproof the health system to embrace advanced methods for early AD diagnosis and treatment

Major advances have been made in AD diagnosis and treatment in recent years. Biomarker testing (via PET scans and cerebrospinal fluid analysis) and even blood tests can provide a clear picture of a person’s AD or dementia status.²³ These blood tests have shown an accuracy of 90%, which can negate the need for PET scans and cerebrospinal fluid extraction.²³ Meanwhile, revolutionary monoclonal antibody treatments, disease-modifying therapies that slow clinical decline in AD, are also becoming available.²⁴ Put simply, it is now possible to diagnose AD far earlier and to treat it more effectively.

Yet, limitations to Brazil’s health infrastructure—which already delay diagnosis and referral—threaten to make widespread adoption of these vital new tools difficult or impossible to achieve. Where it is available, AD diagnosis in Brazil is still generally reliant on “clinical interviews, cognitive assessments and MRI scans,” says Dr Lourenço. The availability of PET-amyloid scans is low and geographically-limited because the chemical containing the “tracer” molecule used in the scans is only produced in the south of Brazil and cannot be shipped to all regions owing to its limited half-life. Dr Lourenço adds that even in private hospitals, plasma biomarker samples are often sent abroad because of a lack of local processing facilities, which adds to the cost and increases the time-to-diagnosis.



**“Limited access to imaging and blood tests slows down the treatment process—
it’s a bottleneck in patient care.”**

Sonia Brucki, Neurologist, Clinical Hospital, University of São Paulo

Norberto Anizio Ferreira Frota, a neurologist specializing in dementia care and Scientific Director at ABRAz, says patients relying on access to MRIs via Brazil’s public health system, the *Sistema Único de Saúde*, can wait years, whereas people with private medical insurance can get a scan in weeks. Long waiting times in the public system add to delays in diagnosis and access to holistic treatments. And the disparity between the public and private contributes to inequities in access to AD diagnosis and treatment in Brazil.

“Even when a patient in the public system is diagnosed, their access to proper treatment is often delayed due to bureaucracy,” says Dr Frota. To ensure access to cutting-edge, integrated care, the government must build a funded and structured care pathway. “The cost of these treatments is a major concern—without a public funding plan, access will be limited to the wealthy,” elaborates Dr Frota. “New therapies must be integrated into a well-structured public health framework to ensure equitable access.”

Focus on implementation to ensure that the national dementia policy fulfills its potential

Brazil has made significant strides at the policy level in addressing the growing challenge of AD. The first-ever National Dementia Report (ReNaDe), published in 2023-24, revealed the scale of dementia prevalence, underdiagnosis and the potential for prevention in Brazil.²⁵ This was followed by the *Política Nacional de Cuidado Integral às Pessoas com Doença de Alzheimer e Outras Demências* (National Policy for the Comprehensive Care of People with Alzheimer’s and Other Dementias), which aims to create an integrated framework for dementia and AD care, emphasizing early diagnosis, interdisciplinary treatment and caregiver support.⁸

While these policies are a positive first step, experts say that there is no clear implementation plan. “We don’t have a federal regulation that enforces this policy across all regions—implementation is still missing,” says Dr Lourenço. “Advocacy groups like the Brazilian Federation of Alzheimer’s Patients (Febraz) are pushing for concrete plans, but we are still far from implementation.”

Policymakers could look to Ceará and Rio Grande do Sul, two of the few states in Brazil with a structured dementia care policy. Dr Frota contributed to the development of the Ceará policy, which covers primary, secondary and tertiary care, and includes standardized screening tools, professional training and improved access to medications. “Our model could serve as a reference for a structured approach to dementia care,” he says.

While state plans can serve as a guide, national investment and implementation are key. Policymakers must devise a sustainably-funded plan for implementation that spans the entire research and care continuum. “A proper policy should include research funding, healthcare improvements, better training for doctors, and prevention strategies,” says Dr Lourenço.

Boost caregiver support to increase skills and reduce financial and psychological strain

Most dementia care in Brazil falls on family members, who often leave the workforce without financial support.²⁶ Meanwhile, levels of stress and anxiety can be high among caregivers.²⁶ “Most caregivers in Brazil are unpaid and untrained, which affects both their wellbeing and the quality of care they provide,” says Dr Lourenço. Part of the reason that the burden is so high is the lack of government programs for respite care or home-based support, adds Dr Suemoto.

Experts cite a range of tools needed to create a support system for caregivers. These tools include structured care models that incorporate multidisciplinary teams and community-based interventions, better support systems to reduce burnout, and structured training.^{27,28} “We have no national caregiver training programs,” says Dr Suemoto. “Families are left to figure things out on their own.”

Direct financial support is also an important tool. “We need financial recognition for caregivers—just like we do for maternity leave or disability benefits,” says Dr Queiroz Pinheiro de Oliveira. There are three key requirements: respite care to help ease the burden on caregivers and allow them to work and manage their own wellbeing; formal financial assistance to help cover the direct

and indirect costs (such as lost earnings from having to give up work) resulting from caregiving responsibilities; and training programs to provide caregivers with the know-how they need to deliver effective care while ensuring their own wellbeing.

To reduce the burden on caregivers and improve support, policymakers in Brazil could look to emulate nearby Paraguay, where the *Política Nacional de Cuidados* (National Care Policy), approved in 2022, aims to balance the distribution of care responsibilities for children, the chronically ill, dependent older adults and people with disabilities. Seeking to increase equity in care responsibilities—especially in terms of reducing the disproportionate burden on women—the policy covers the public and private sectors, civil society, families, and communities, generating partnerships and new models for the provision of care services.²⁹

“Families often don’t know where to turn for help. We need more support groups and channels for caregivers to share their challenges.”

Milton Crenitte, Technical Director, International Longevity Centre Brazil



Summary



EDUCATION

Raise awareness of AD and dementia among the public.

How: Work with civil society organizations to increase awareness and knowledge of AD among the public.



TRAINING

Improve knowledge of AD among healthcare professionals.

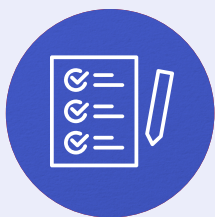
How: Implement structured training programs for primary care physicians, nurses, psychologists and specialists.



INTEGRATION

Counteract public/private, urban/rural and other fragmentation in the health system.

How: Implement a structured, sustainably-funded care pathway to ensure that equitable access to new treatments and diagnostic tools is available across the health system.



IMPLEMENTATION

Prioritise implementation of the National Policy for the Comprehensive Care of People with Alzheimer's Disease and Other Dementias.

How: Develop a plan spanning research, diagnosis and care to ensure that the national policy is fully implemented across the country.



CARER SUPPORT

Enhance support for caregivers.

How: Implement a structured support system for caregivers that incorporates financial recognition, multidisciplinary and community-based assistance, training, and wellbeing assistance.

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