

South Africa

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In South Africa, dementia diagnosis is hindered by limited infrastructure, specialist shortages, and persistent health inequalities. Assessment typically begins in primary healthcare, followed by tests to exclude reversible causes and referral to a specialist for confirmation, often including CT or MRI imaging. However, long waiting times, rural-urban disparities, and misperceptions that dementia is normal ageing delay referral, with diagnosis sometimes taking nearly two years. There is no national screening programme, and tools such as MMSE, IQCODE, AD8, and IADL are commonly used. Advanced diagnostics, including genetic testing and CSF biomarkers, are rarely routine, and high out-of-pocket costs further restrict access.

Highlights

Health system **Non-universal, Mixed funding, (Mixed provision)**

ADI member association(s): **Association for Dementia and Alzheimer's of South Africa NPC (ADASA)**

National dementia plan: **No national Alzheimer's disease or dementia plan in place**

Dementia plan funding: **No plan**

Dementia prevalence rate: **395.7**

Dementia incidence rate: **69.8**

Population: **64874169**

Median age: **29**

Health expenditure (% of GDP): **9**

Diagnosis

In South Africa, dementia diagnosis is hindered by limited infrastructure, specialist shortages, and persistent health inequalities. Assessment typically begins in primary healthcare, followed by tests to exclude reversible causes and referral to a specialist for confirmation, often including CT or MRI imaging. However, long waiting times, rural-urban disparities, and misperceptions that dementia is normal ageing delay referral, with diagnosis sometimes taking nearly two years. There is no national screening programme, and tools such as MMSE, IQCODE, AD8, and IADL are commonly used. Advanced diagnostics, including genetic testing and CSF biomarkers, are rarely routine, and high out-of-pocket costs further restrict access.

Diagnosis pathway

In South Africa, the dementia diagnosis pathway is complex and often inaccessible, constrained by limited infrastructure and unequal access to healthcare. Typically, individuals first consult a primary healthcare provider for medical history review and physical examination, followed by testing to rule out reversible conditions such as depression or vitamin deficiencies. A suspected case is then referred to a neurologist or psychiatrist for specialist evaluation and brain imaging. However, the absence of dementia-specific services, minimal geriatric training, and severe specialist shortages undermine diagnostic capacity. Geographic barriers, transport costs, and persistent misperceptions among healthcare staff further weaken referral systems.

Diagnosing dementia in South Africa is a challenging and cumbersome process for most South Africans, primarily because the country lacks the necessary infrastructure for dementia screening, as well as significant disparities in access to appropriate health care among South Africans. The process of diagnosing dementia in South Africa most commonly consists of three steps .

- (1) If one is experiencing symptoms of dementia, they should consult a primary healthcare provider, who would conduct a review of their medical history and a physical examination.
- (2) Then, several tests for dementia diagnosis would be conducted in order to rule out other, sometimes reversible conditions such as depression, hormonal imbalance, thyroid problems, head injuries, or vitamin deficiencies.
- (3) After a preliminary diagnosis of dementia, a referral is made to a specialist (neurologist or psychiatrist) who will conduct other tests and brain scans to confirm the diagnosis.

In practice, however, diagnosing dementia is a more complex process. There are no dementia-specific services at the primary healthcare level, with fewer than ten geriatricians and five geriatric psychiatrists to serve the entire country of over 5.5 million older people. Many South Africans living in underserved or remote communities face significant barriers to accessing healthcare, including long travel times and high transportation costs to the nearest facility. Diagnostic pathways for dementia are weakened by common misperceptions amongst primary healthcare staff that dementia is a natural part of aging, not requiring referral for further assessment, diagnosis and management of care⁹. Therefore, most people living with dementia in South Africa remain undiagnosed and cared for without professional or other formal support. South Africa has standard treatment guidelines for the pharmacological management of dementia, but the public sector has a general shortage of available

pharmaceutical supplies.

There are many factors influencing access to a dementia diagnosis in South Africa. Variations in the medical training of primary healthcare doctors and nurses were highlighted as a serious gap in the health system, affecting the identification, diagnostic capacity, and management of dementia. For example, training nurses on dementia is not prioritised, with reluctance from both nursing schools and the regulating nursing council to include geriatrics in the curriculum⁹. Even when awareness and understanding of dementia are good, the reality is often that there are no services available to refer patients to, adding to the belief amongst practitioners that nothing can be done to support people living with dementia⁹.

References

- <https://www.adasa.org.za/about-dementia/#diagnosis>
- <https://wiredspace.wits.ac.za/server/api/core/bitstreams/fbfb27fd-de9e-44ef-adaf-c6f68c1e4d9b/content>

Wait times

Status: Long wait time

In South Africa, public healthcare users frequently face long queues and extended waiting lists, particularly for specialist consultations. Rural communities face particular barriers, including limited specialist availability and delays in CT or MRI imaging. Research shows dementia diagnosis may take 22–26 months, largely because early signs are dismissed as age-related changes. Many patients seek specialist care only after functional impairment, with socially vulnerable groups experiencing even longer diagnostic pathways.

Most South Africans have to deal with queuing systems and long waiting lists when accessing public health services⁹. Despite active redress by the government, the health sector is still characterised by unequal access to services and resources, with an urban bias despite most of the population living in rural areas. Unsurprisingly, significant waits are common, particularly for specialist consultations. Access to diagnostic imaging services, such as computed tomography (CT) or magnetic resonance imaging (MRI) is also subject to considerable delays, particularly in rural and underresourced public facilities . A retrospective study found that diagnosing dementia can take as much as between 22.9 months and 26.2 months, depending on its type, primarily because early symptoms of dementia are more likely to be seen as a consequence of old age . It is only when people become functionally impaired, that they present themselves to specialised facilities, and even then, the process is prolonged for specific groups of patients (e. g. socially vulnerable patients, those from rural areas) due to barriers preventing equitable access to appropriate specialist care.

References

- <https://wiredspace.wits.ac.za/server/api/core/bitstreams/fbfb27fd-de9e-44ef-adaf-c6f68c1e4d9b/content>

Diagnosis cost

Status: Partially covered

In South Africa, medical aids provide limited dementia coverage. Despite its inclusion as a Prescribed Minimum Benefit under the Medical Schemes Act (1998), coverage mainly applies to initial diagnosis, while co-payments,

imaging, and specialist fees create significant financial barriers for most people.

Medical aids typically offer minimal coverage for dementia. While “treatable dementia” is a Prescribed Minimum Benefit under the Medical Schemes Act (1998), schemes generally cover the initial diagnosis and one week of acute psychotic symptom management. Yet, in practice, many South Africans using the public health sector are also expected to contribute to diagnosis costs through co-payments². Costs of imaging tests and specialist visits — all of which are considered necessary for diagnosing the severity of dementia and determining appropriate means of treating it — are out of reach for a majority of the South African population.

References

- <https://www.moneyweb.co.za/financial-advisor-views/counting-the-cost-the-financial-impact-of-dementia/>

Cognitive tests

Status: Available

There is no nationally organised, widespread screening programme for dementia in South Africa. Instead, initial screening typically occurs when an individual or their family raises concerns with a primary healthcare provider, such as a general practitioner (GP). In South Africa, the most commonly used cognitive screening tests are the following:

- (1) The Mini Mental State Examination (MMSE)
- (2) The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), which is more appropriate for people with lower educational attainment.
- (3) Ascertain Dementia 8 (AD8)¹⁴, an eight - item, informant - based screening questionnaire used to detect early cognitive impairments.
- (4) The Instrumental Activities of Daily Living (IADL) scale is often used as a screening tool¹⁴.

Research initiatives are also exploring and validating culturally appropriate screening tools for the diverse South African population.

References

- <https://hsag.co.za/index.php/hsag/article/view/2437>
- <https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.70584?af=R>
- <https://www.wits.ac.za/news/latest-news/research-news/2025/2025-04/pioneering-tests-could-improve-the-assessment-of-dementia-in-ageing-africans.html>
- <https://bergmanross.co.za/ct-scan-vs-mri-whats-the-difference-costs-benefits-and-uses/>

Imaging tests

South Africa possesses 19.6 units of general diagnostic radiology equipment assigned per million people, CT representing 1.7 units¹². South Africa fares better across all imaging modalities in terms of resource availability in the public sector when compared to a low income country. However, significant disparities persist between the private and public health sector, with the former employing 70% of medical specialists. Severe inequalities exist between the provision of specialised radiological equipment and staff in the public and private health sectors in

South Africa as well, with the public sector usage placed under an enormous amount of strain¹². There is an inhomogeneous distribution of CT and MRI resources within different geographic regions in South Africa with an 11-fold disparity between the best and least equipped regions and a 13-fold discrepancy between the public and private sector¹².

In diagnosing dementia, CT and MRI scans are recommended and utilised in South Africa. However, access to these imaging modalities is a significant challenge, particularly in the public sector and rural areas. The high cost of these procedures also contributes to limited accessibility in the resource-constrained public sector. In the private sector, the price of a CT scan ranges between 1500 to 5000 ZAR (85 to 285 USD), while the price of an MRI scan can be between (340 and 1025 USD), making timely access to these services, and, in turn, dementia diagnosis prohibitively expensive for a majority of the population .

References

- <https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.70584?af=R>
- <https://bergmanross.co.za/ct-scan-vs-mri-whats-the-difference-costs-benefits-and-uses/>

Genetic tests

A number of private laboratories offer apolipoprotein E (APOE) genotype investigation. However, genetic tests are generally not part of the diagnostic workup for dementia and dementia-related illnesses, primarily being found in clinical settings .

References

- <https://genesenvironment.biomedcentral.com/articles/10.1186/s41021-025-00332-0>

Biomarker tests

Cerebrospinal fluid (CSF) biomarkers are not universally or readily available in South Africa. Some research initiatives, like the HAALSI - HCAP study, are incorporating biomarker indicators to measure dementia in cognitively impaired participants . However, there is no widespread, routine clinical availability and accessibility of these advanced biomarker tests across the South African healthcare system, particularly in the public sector.

References

- <https://pmc.ncbi.nlm.nih.gov/articles/PMC11987161/>

Treatment & care

Specialised dementia care in South Africa is limited and mostly private, with services such as neurogeriatric and psychogeriatric programs offered by Life Healthcare, Mediclinic, and Netcare. Public hospitals primarily provide diagnostic and acute care, relying on NGOs for ongoing support. High medication costs, scarce geriatric psychiatric consultations, and unaffordable long-term care place the financial and caregiving burden on families. In poorer communities, unregistered facilities have emerged, while most dementia patients are cared for at home by relatives, which reflects severe inequalities in access and formal support.

Specialized facilities and services

Specialised dementia care in South Africa remains limited, with most residential and community-based services concentrated in the private sector. APCC supports hospice and palliative services through 91 member organisations delivering interdisciplinary care. Private providers such as Life Healthcare, Mediclinic, and Netcare deliver specialised neurogeriatric, memory, and psychogeriatric programs. In contrast, public hospitals mainly provide diagnostic and acute care, relying heavily on NGOs, although centres such as Groote Schuur Hospital host specialised memory clinics.

Specialised dementia care facilities, such as dementia villages, nursing homes and community support centres in South Africa are far and few, and mostly privately owned , , . Hence, access to these facilities is mostly reserved for wealthier South Africans.

The Association of Palliative Care centres of South Africa (APCC) is a not-for-profit organisation which works to improve the quality of life for individuals with life-threatening illnesses, including dementia, by supporting various hospice and palliative care services. APCC gathers 91 members providing palliative care services throughout South Africa. Care is provided by interdisciplinary teams, which typically include palliative care trained doctors, nurses, social workers and home-based carers.

When it comes to hospitals specialising in dementia treatment and care, the level of service provided to people living with dementia varies between public and private hospitals. The three largest providers of private hospital care are:

(1) Life Healthcare, which offers specialised neurogeriatric programs at selected acute physical rehabilitation and mental health facilities . These facilities provide specialist services to people typically older than 50 years of age who experience challenges in memory, mood, mental health and activities of daily living. A team approach ensures a thorough assessment so that several clinical tools are correlated to ensure high quality diagnosis and management. Its SGM Clinic, at Life Vincent Pallotti Hospital , is one institution which specialises in comprehensive geriatric and memory services for older people.

(2) Mediclinic is another private hospital care provider which offers specialised neurogeriatric programs at its facilities. One of its most renowned initiatives is known as NEUROCARE, and offers comprehensive, coordinated care by various specialists from a variety of locations . Its head office is located at Stellenbosch Mediclinic, which is considered a leading private healthcare establishment in South Africa.

(3) Netcare is one of the largest private hospital care providers in South Africa, and is known to offer specialised psychogeriatric programs in dedicated wards, focusing on managing psychiatric and behavioral symptoms associated with dementia . Said programs are offered under the umbrella of its Akeso initiative, which, more broadly, deals with providing mental health care.

The public healthcare system faces significant challenges in providing comprehensive dementia treatment and care. Public hospitals do not provide long term residential care for dementia²⁰. Their role is primarily diagnostic and for managing acute crises. Patients are often stabilised, and then sent home with referrals to non-governmental organisations or community support services, upon which South African public health institutions rely heavily. Some public hospitals are known for their specialised services. For instance, the Groote Schuur Hospital (GSH), which is the primary academic hospital associated with the University of Cape Town (UCT) hosts a renowned Memory Clinic , which manages people with memory disorders. Said clinic provides multidisciplinary care for people living with various forms of dementia and other cognitive impairments, offering diagnosis, management, and support services.

References

- <https://livewell.care/about/>
- <https://www.flower.org.za/About-Us/About-Flower-Foundation>
- <https://www.midwaycare.co.za/life-at-midway-care/>
- <https://apcc.org.za/>
- <https://www.lifehealthcare.co.za/news-and-info-hub/mental-health/early-accurate-diagnosis-of-alzheimer-s-is-key-to-providing-best-treatment-outcomes/>
- <https://sgmclinic.co.za/about/>
- <https://neurocare.co.za/>
- <https://www.netcare.co.za/netcare-akeso/our-programmes/geriatrics>

Approved medication

Generic Name	Trade Name	Used for
Donepezil	Aricept, Aricept ODT, Adlarity, Eranz, Memac, Alzepil, Davia, Donecept, Donep, Donepex, Donesyn, Dopezil, Yasnal, Memorit, Pezale, Redumas, Zolpezil, Namzaric*	Donepezil is indicated for the symptomatic treatment of mild to moderately severe Alzheimer's dementia. Official UK medicine details (MHRA SPC) link
Rivastigmine	Exelon, Exelon Patch, Prometax, Rivastach, Nimvastid	Symptomatic treatment of mild to moderately severe Alzheimer's dementia. Symptomatic treatment of mild to moderately severe dementia in patients with idiopathic Parkinson's disease. Official UK medicine details (MHRA SPC) link

Generic Name	Trade Name	Used for
Galantamine	Razadyne, Razadyne ER, Reminyl, Reminyl XL, Nivalin, Lycoremine, Galsya	Galantamine is indicated for the symptomatic treatment of mild to moderately severe dementia of the Alzheimer type. Official UK medicine details (MHRA SPC) link
Memantine	Namenda, Namenda XR, Ebixa, Memary, Axura, Akatinol, Maruxa, Nemdatine, Namzaric*	Treatment of adult patients with moderate to severe Alzheimer's disease. Official UK medicine details (MHRA SPC) link

*Namzaric = combination of Donepezil and Memantine

** MHRA: Medicines and Healthcare products Regulatory Agency - UK medicines regulator;

SPC: Summary of Product Characteristics - detailed product information

Treatment cost

Most South Africans cannot retire comfortably, so dementia-related expenses typically fall on family members. Medical aid schemes provide limited support, covering only initial diagnosis and brief acute care, while high costs of medications, scarce geriatric psychiatric consultations, and largely private long-term care services make sustained treatment unaffordable. In poorer communities, unregistered and non-compliant care facilities have emerged, leaving many patients without adequate support.

With very few South Africans in a position to retire comfortably, the reality is that when a retiree is diagnosed with dementia, the financial burden often falls to the immediate family of that person, and the economic costs can be difficult to quantify. While “treatable dementia” is a Prescribed Minimum Benefit under the Medical Schemes Act (1998), schemes generally cover the initial diagnosis and one week of acute psychotic symptom management²⁰.

People living with dementia face expenses for medication (1) slowing disease progression, (2) managing anxiety and depression, and (3) controlling behavioural issues like hallucinations and paranoia. In 2010 one study³¹ found that the average out of pocket cost per prescription item for Alzheimer's disease was 596.15 ZAR (34 USD). The average cost per prescription for donepezil was 634.76 ZAR (36 USD), for galantamine 579.58 ZAR (33 USD), for memantine 551.35 ZAR (31.5 USD) and for rivastigmine 825.54 ZAR (47 USD). These costs are relatively high for a majority of South Africans, and are unaffordable to continue treatment for an extended period of time. Unless enrolled in a fully comprehensive medical aid scheme, most plans exclude home nursing, and those that include it are costly with limited benefits. Additionally, consultations with geriatric psychiatrists, scarce in South Africa, can exceed 3000 ZAR (171 USD) per session²⁰.

Specialised dementia long term care services are skewed to the largely unaffordable private sector⁹. In response to the growing need for long term care provision in low income South African communities, there has been a proliferation of unregistered care facilities that do not comply with norms and standards of care for older persons. Ultimately, formal care in South Africa is expensive and unaffordable to most of the population in need of such solutions.

References

- <https://www.midwaycare.co.za/life-at-midway-care/>

Caregiver support

Long-term care for dementia in South Africa is largely inaccessible, with most facilities affordable only to wealthier individuals. Private medical insurance rarely covers extended care, placing the financial and caregiving burden on families. Unregistered, non-compliant facilities have proliferated in poorer communities, while community services are limited and provided primarily by NGOs. Although national data are lacking, a Cape Town study found that the majority of dementia patients are cared for at home by relatives.

Access to long term care facilities is unequal in South Africa, with only a limited portion of South Africans able to afford them. Even most private medical insurance schemes in South Africa do not provide people living with dementia with coverage for long term care, meaning that the financial burden is almost exclusively the responsibility of families. Community services for people living with dementia are limited, and based within the non-governmental organisation (NGO) sector. The South African government relies heavily on the sector to provide psychoeducation, support to people living with dementia and their families, and to link service users to home – based care, counselling groups and legal advice. There are no nationally representative data available in South Africa on caregiving arrangements specific to dementia care, although a small study in Cape Town showed that 79% of people living with dementia were cared for at home either by a spouse or an adult child⁹.

References

- <https://wiredspace.wits.ac.za/server/api/core/bitstreams/fbfb27fd-de9e-44ef-adaf-c6f68c1e4d9b/content>

Policy

Dementia in South Africa remains largely undiagnosed and misunderstood, worsened by socioeconomic inequality, an aging population, and high HIV prevalence. The absence of a national dementia plan exposes patients and caregivers to neglect, stigma, and elder abuse. Existing legislation, including the Older Persons Act, Elder Abuse Protocol, and Mental Health Policy Framework, offers limited dementia-specific guidance. Legal barriers, such as complex curatorship and paternalistic interventions, reduce patient autonomy, while cultural terms like ukuphambana umqondo, ukuhlanya, and amafufunyana reinforce fear and social exclusion. The forthcoming National Health Insurance could improve access, and advocacy groups are lobbying for a dedicated national dementia strategy.

National dementia plan

In South Africa, dementia is often undiagnosed and poorly understood, exacerbated by socioeconomic inequality, an aging population, and high HIV prevalence. The lack of a national dementia plan leaves patients and caregivers at risk of neglect, stigmatisation, and elder abuse. Although legislation such as the Act on Older Persons, the Protocol on the Management of Elder Abuse (2010), and the Mental Health Policy Framework (2013–2020) provide general guidance, dementia-specific provisions are limited, which highlights gaps in coordinated care, protection, and community-based support.

Currently, South Africa does not have a national dementia plan or strategy in place. Yet, other pieces of legislation do make reference to dementia as a public health issue, or vaguely set out the responsibilities of the state in managing it.

- The Act on Older Persons (2006) governs the rights, protection and care provision for older persons in general⁹. It recognises the responsibility of the South African state for developing home-based care, providing information, education and counselling services, and includes care for Alzheimer's disease and other dementias. Programs established by the Act are responsible for coordinating these services.
- Considering the lack of a national dementia management framework in South Africa, people living with dementia could find themselves particularly vulnerable to elder abuse. With that in mind, the Protocol on the Management of Elder Abuse (2010) is a pertinent piece of legislation for many people living with dementia, as it outlines the procedure for managing elder abuse, including from families unable to give appropriate support, and from professional caregivers, nurses or competent medical authorities⁹. In cases of suspected abuse, social workers are obliged to investigate it, and arrange for appropriate care or housing for the person.
- More recently, the South African government adopted the Mental Health Policy Framework and Strategic Plan (2013 to 2020) . Said document promotes an integrated care model for mental health in South Africa, supporting the decentralisation of primary care to home and community based services. However, the policy was deemed to be largely “dementia-invisible” with no explicit provisions articulated for dementia care and support services for people living with dementia and their families⁹.

References

- <https://www.safmh.org/wp-content/uploads/2020/09/National-Mental-Health-Policy-Framework-2013-2020.pdf>
- <https://wiredspace.wits.ac.za/server/api/core/bitstreams/fbfb27fd-de9e-44ef-adaf-c6f68c1e4d9b/content>

Upcoming plans

South Africa is moving toward implementing National Health Insurance (NHI) under the 2023 Act, aiming to provide universal healthcare. Its rollout has been delayed due to controversies over funding, potential restrictions on private insurance, and concerns about increased taxation. The NHI Fund is expected to be financed through general taxes, contributions from high earners, and employee payments. If realised, NHI could improve access to dementia screening and care. Meanwhile, organisations like Association for Dementia and Alzheimer's of South Africa are advocating for a national dementia plan.

Currently, South Africa is moving towards the establishment of a National Health Insurance (NHI), whose primary aim is to institute universal healthcare in the country⁹. However, while the National Health Insurance Act (2023) codified the promise of universal healthcare for all South Africans, its implementation has persistently been delayed, amid controversies about funding and its form . Most controversially, the Act intends to prohibit people from taking out private health insurance for treatment covered by the National Health Insurance Fund (NHIF), which is to be established under its provisions. Currently, three main sources of funding for the scheme have been identified, (1) general taxes, (2) unspecified contributions by people earning above a set amount, (3) and monthly contributions made by employees to the fund. However, opposition parties have voiced concerns over its costs, claiming that the taxation burden would significantly increase, with uncertainties about the funding structure persisting.

In spite of these uncertainties, the development of National Health Insurance (NHI) could be a positive development for people living with dementia, as it should facilitate access to early screening services and treatment. Yet, this remains to be seen upon the implementation of the Act. Currently, no concrete plans for the development of a national dementia plan or strategy exist. Nevertheless, organisations like the Association for Dementia and Alzheimer's of South Africa (ADASA) have recently increased their advocacy efforts, and are actively lobbying the Department of Social Development (DSD) , which is the custodian of the Older Persons Act (2006), in favour of a national dementia plan for South Africa.

References

- <https://www.bbc.com/news/articles/c1030v3p1r8o>
- <https://www.adasa.org.za/about-us/#story>

Policy gaps

In South Africa, legal processes for dementia (like curatorship) are costly and paternalistic, often stripping autonomy, while underused tools and broad Mental Health Act classifications leave patients vulnerable. Cultural stigma, fueled by language, beliefs, and misconceptions, drives families to hide patients and avoid care, deepening social exclusion.

Legal barriers

In South Africa, dementia care is complicated by legal barriers that create practical and emotional challenges for families and caregivers, who must navigate expensive court processes and provide extensive medical documentation to secure curatorship or administration. Curatorship, the most common route, is often seen as paternalistic, stripping patients of autonomy. Broad classification of dementia under the Mental Health Care Act (2002) reinforces stigma, while early interventions like Special or Inter-Vivos Trusts are underused due to lack of awareness and legal guidance. These gaps leave patients vulnerable and highlight the urgent need for dementia-specific legal reform and support.

A number of legal barriers make caring for people living with dementia unnecessarily difficult. South African law invalidates a standard Power of Attorney once a person living with dementia loses mental capacity, in contrast to most other jurisdictions, which recognise Enduring or Lasting Powers of Attorney. To regain control over the affairs of an individual living with dementia, multiple legal channels can be pursued, but are known to be notoriously complex and costly. South Africans can resort to (1) appointing a curator bonis or ad personum, (2) administratorship, and (3) establishing a Type A (Special) Trust or Inter - Vivos Trust, which are more appropriate for early stage people living with dementia. Yet, the first two legal avenues are those most commonly used, and are known to involve protracted legal battles, as substantial medical evidence, including reports from at least two medical practitioners, one of whom must be a psychiatrist, is required to prove the mental incapacity of individuals. Moreover, the curatorship system is often described as paternalistic, stripping the individual of their autonomy and decision-making rights and placing them under the control of the appointed curator. Also, while the Mental Health Care Act (2002) provides for care and legal interventions like curatorship, its broad categorisation of dementia under “mental illnesses” can reinforce stigma.

References

- <https://edufime.co.za/articles-additional-resources/planning-for-dementia/>
- <https://www.gov.za/documents/mental-health-care-act>

Cultural barriers

In South Africa, dementia stigma is reinforced by cultural beliefs and language, with terms like ukuphambana umqondo, ukuhlanya, and amafufunyana promoting fear and discrimination. Misperceptions about racial prevalence and traditional cures lead families to hide patients, avoid medical care, and perpetuate social exclusion, with no legal protections in place.

Symptoms of dementia are frequently interpreted with suspicion or fear, and these beliefs directly fuel public stigma and discrimination, leading to social exclusion, families hiding individuals, and avoidance of formal healthcare services. The lack of neutral terms for dementia in local languages, with terms like ukuphambana umqondo (twisting of the mind) or ukuhlanya (madness) in isiZulu, and amafufunyana (bewitchment) being used, reinforces negative perceptions. In some communities, there is also a perception that dementia is a disease which only affects white people, or that it can be cured by a strong sangoma (traditional healer), leading to mistrust towards, or avoidance of conventional dementia care.

References

<https://pearl.plymouth.ac.uk/cgi/viewcontent.cgi?article=2095&context=pms-research>

- <https://pmc.ncbi.nlm.nih.gov/articles/PMC10262328/>

Research

Innovative dementia initiatives in South Africa integrate natural therapies, autophagy research, and socio-economic interventions. UCT, Pretoria, and Stellenbosch studies, along with Africa-FINGERS and cash transfer programs, focus on culturally informed, multidisciplinary, and affordable strategies to prevent cognitive decline and improve Alzheimer's care.

Selected academic institutions

[University of the Witwatersrand](#) [University of Cape Town](#) [University of Pretoria](#) [University of the Free State](#)
[Stellenbosch University](#)

Clinical trials and registries

The University of the Witwatersrand is conducting extensive research on the health and aging of adults above the age of 40 in rural South Africa, within the scope of its Health and Aging in Africa – A Longitudinal Study of an INDEPTH Community in South Africa (HAALSI) study . Conducted in cooperation with a number of American institutions, such as Harvard University and the Indiana University in Bloomington, one of its significant components is the HAALSI Dementia Study, which investigates the prevalence, incidence and risk factors of cognitive decline and dementia, including Alzheimer's disease.

While the primary goal of the HIV Prevention Trial Network 068 study³⁹ was to examine the impact of conditional cash transfer interventions on HIV incidence in younger women, the enrolled cohort was also examined as a control group in a study which determined that monthly cash transfers were associated with a slowing of cognitive decline and reduced risk of dementia among older South Africans living in rural areas.

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References

- <https://www.su.ac.za/en>
- <https://www.pnas.org/doi/10.1073/pnas.2321078121>

Selected innovative methods

Innovative dementia research in South Africa spans natural, lifestyle, and socio-economic interventions. Pretoria's Phytomedicine Unit targets plant-based cholinesterase inhibitors, while Stellenbosch investigates spermidine-enhanced autophagy. UCT's Ingqondo study links HIV-driven brain inflammation to amyloid accumulation. The Africa-FINGERS project evaluates culturally tailored multimodal interventions and establishes a continental Alzheimer's biomarker repository. Additionally, Indiana University's cash transfer studies in rural Mpumalanga suggest financial support can slow cognitive decline. Collectively, these initiatives highlight culturally informed, multidisciplinary, and cost-effective strategies to prevent and treat dementia in South Africa.

The Phytomedicine Unit within the Department of Pharmacology at the University of Pretoria is at the forefront of research aimed at identifying safer and more efficacious treatments for Alzheimer's disease derived from natural sources. This research programme bridges traditional knowledge with modern pharmacological investigation. A key focus of the Unit is the investigation of plant-derived compounds as cholinesterase inhibitors.

Researchers at Stellenbosch University have conducted groundbreaking work on the natural polyamine spermidine, investigating its potential to combat Alzheimer's disease by enhancing autophagy — the cellular process responsible for clearing damaged components and aggregated proteins. A decline in autophagic efficiency is associated with aging and is implicated in the pathogenesis of neurodegenerative diseases.

The Ingqondo study, led by Assoc. Professor Sam Nightingale, from the University of Cape Town (UCT), is a compelling example of research that capitalises on the demographic diversity of South Africa, as well as its unique health landscape, to investigate fundamental questions about Alzheimer's disease. The study is predicated on the hypothesis that the accumulation of amyloid protein, a key feature of Alzheimer's disease, might be a downstream consequence of chronic inflammation or infection within the brain, which, in turn, is often triggered by HIV.

Building on the success of the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER), the Africa - FINGERS project is a multinational collaboration of dementia experts, aimed at assessing the feasibility and sustainability of multimodal brain health strategies and interventions on the African continent. In addition to designing, implementing, and assessing culturally informed models and protocols for lifestyle interventions in different countries, the consortium is working to establish the first biomarkers repository for Alzheimer's disease and related dementias. South African researchers and institutions, notably from the University of Cape Town (UCT), are involved in this project.

Researchers from Indiana University in Bloomington have determined that monthly cash transfers were associated with a slowing of cognitive decline and reduced risk of dementia among older South Africans living in rural areas. A randomised monthly cash transfer intervention, said study was published in Proceedings of the National Academy of Sciences, a very prestigious journal. Data was drawn from two overlapping cohorts in Mpumalanga Province, (1) HPTN, which included young women and their primary caregivers, and (2) HAALSI, which enrolled older adults from the same households. Cash transfer interventions could serve as cost effective strategies to promote healthier cognitive aging and lower dementia risk in vulnerable low and middle income country populations.

References

- https://www.up.ac.za/institute-for-cellular-and-molecular-medicine/news/post_2125569-alzheimers-disease-old-friends-and-new-promises
- <https://www.sun.ac.za/english/Lists/news/DispForm.aspx?ID=9382>

<https://www.telegraph.co.uk/christmas/2023/12/01/battle-to-defeat-hiv-might-help-unlock-alzheimers/>

- <https://fbhi.se/world-wide-fingers-collaboration-groups/>
- <https://europepmc.org/article/MED/40646178>
- <https://www.nia.nih.gov/news/south-africa-cash-transfer-programme-slowed-cognitive-decline-midlife-and-older-adults>

Support

ADASA and Age in Action provide nationwide dementia support, including 24-hour helplines, virtual support groups, caregiver courses, provincial trainings, and awareness campaigns. The NWU TRACTOR initiative and ADASA's A Moment to Forget radio campaign engage communities, raise awareness, and promote early screening. DementiaSA and ADASA also offer online resources and downloadable materials for caregivers and healthcare providers, while media coverage highlights real-world caregiving challenges, emphasising the need for accessible information, public outreach, and community-based support.

Organizations are listed for informational purposes based on publicly available sources. Inclusion does not necessarily indicate affiliation with or endorsement by Alzheimer's Disease International (ADI).

Selected national associations, patient family associations, NGOs:

[Association for Dementia and Alzheimer's of South Africa NPC \(ADASA\)](#) [DementiaSA](#) [South Africa Depression and Anxiety Group \(SADAG\)](#) [Age in Action](#)

Selected initiatives

ADASA maintains a provincial presence and advocates for a national dementia plan, while Age in Action mobilises 800 NGOs to care for 150,000 older adults. Helplines from ADASA, DementiaSA, and SADAG provide 24-hour guidance. DementiaSA offers virtual support groups and caregiver courses, and ADASA organises provincial trainings, awareness events, and community campaigns. The TRACTOR initiative by NWU engages communities across 2,000 kilometers, symbolising dementia's progression and caregiver resilience.

ADASA maintains a presence in every South African province, employing 29 permanent and contractual staff members, and collaborating with an additional 20 community developers⁴⁶. ADASA recently increased its engagement with government and health institutions, lobbying the Department of Social Development (DSD) for the institution of a national dementia strategy, and greater investment in dementia-related research⁴⁶.

Age in Action, formerly known as the South African Council for the Aged, is an umbrella body representing more than 2.7 million older South Africans. It gathers more than 800 non - governmental organisations, which provide vital services to more 150 thousand older South Africans who have varying needs for support and care. Its mission is directly relevant to people living with dementia⁴⁸, as Age in Action strives to "provide community based health care services for frail, bedridden, vulnerable and needy older persons", as well as to "provide empowerment programmes for vulnerable and needy older persons".

South Africans have access to two national dementia helplines, which are run by Association for Dementia and Alzheimer's of South Africa (ADASA) and DementiaSA , respectively. Both helplines are available 24 hours a day, and requests made to the helplines are referred to local charters of these organisations, which, in turn, provide specialised guidance to people living with dementia, based upon the region from which they are calling. In addition, the South Africa Depression and Anxiety Group (SADAG) operates over 30 national toll-free mental health helplines⁴⁷, staffed by counselors trained to provide support relevant to family members and caregivers dealing with the emotional and psychological challenges of caring for people living with dementia.

DementiaSA organises weekly virtual support groups, primarily intended for family members of people living with dementia and care partners. Since the COVID-19 pandemic, these support groups have moved to Zoom, and are free of charge. DementiaSA also provides continued, ongoing support to families via a mediated, private WhatsApp group. In addition, the organisation offers a number of one day courses , primarily intended for carers, nurses and community health workers, aiming to educate them about what person-centered care, required when caring for a person living with dementia, entails. While accessing these courses is not free of charge, they are affordable.

The Association for Dementia and Alzheimer's of South Africa (ADASA) periodically organises support groups and trainings , held both virtually and in person, and on a provincial scale. A majority of these activities seem to be centered in the most populous provinces of South Africa, but support staff is readily available in each province. In addition, ADASA specialises in the organisation of community events for people living with dementia and care partners, on one hand, and for a broader audience, on the other hand. These events are meant to raise public awareness about dementia in South Africa. Previously organised events include Run Against Dementia and Dance Against Dementia, concerts, golf days etc. A majority of community events occur in September, in observation of World Alzheimer's Day and Alzheimer's Awareness Month . These campaigns are commonly supported by Alzheimer's Disease International (ADI).

Recently, the Faculty of Health Sciences at North West University (NWU), in cooperation with governmental, community and corporate stakeholders, launched the TRACTOR campaign as a means of raising public awareness about dementia. A sponsored Landini tractor travelled almost 2000 kilometers across South Africa, stopping in towns across the country to host community events, share stories about dementia, and provide support to families of people living with dementia. The image of a tractor, a powerful and familiar presence in many South African communities, was meant to symbolise the slow, steady progression of dementia and the unwavering resilience of carers and families.

References

- <https://www.dementiasa.org/training/>
- <https://www.adasa.org.za/support-training/>
- <https://www.adasa.org.za/events/>
- <https://www.alzint.org/get-involved/world-alzheimers-month/>
- <https://news.nwu.ac.za/trial-run-sparks-momentum-dementia-awareness-matlosana-mall>

Dedicated media outlets

DementiaSA maintains a number of online resources for people living with dementia, their families, carers and the broader population on their YouTube page , ranging from short informational videos to specialised webinars. Many of these resources are shared on their Facebook page or website as well, along with infographics, book recommendations or reviews, and other relevant dementia-related materials. Nevertheless, their online reach seems to be rather limited. On the Media page of their website , an archive of previous promotional campaigns can be found, including advertisements produced for television.

Clockwork Media worked together with ADASA on a public awareness campaign for dementia, with the aim of underscoring impacts of dementia, and the importance of supporting caregivers . The campaign, titled A Moment to Forget, was implemented in partnership with Jacaranda FM and Bok Radio, two widely listened radio stations. It mimicked typical radio spots, but introduced vagueness or incongruity, subtly unsettling listeners. The campaign raised public awareness of ADASA, and generated funding for future educational projects aimed at creating meaningful change. Web traffic to ADASA resources increased by 36% during the campaign, complemented by a 22% rise in social media engagement and a 14% rise in enquiries for early screening. Said success demonstrated the importance of media campaigns in raising awareness about dementia and, by extension, their role in

stimulating early detection of dementia.

The Association for Dementia and Alzheimer's of South Africa (ADASA) also maintains a number of downloadable, printable resources such as flyers, pamphlets and infographics related to dementia. Primarily intended for physicians, community healthcare providers and other dementia management stakeholders, who would, in turn, share these resources with people living with dementia, their families and carers. However, they are a publicly available resource for anyone who would like to learn more about dementia.

Health-e News is an independent health news service, often reporting on issues affecting marginalised communities. It previously covered stories on struggles of families caring for loved ones living with dementia, particularly in areas with limited support services, hence underscoring the real-world impact of the disease and the urgent need for better care.

References

- <https://www.youtube.com/@dementiasa5095/videos>
- <https://www.facebook.com/DementiaSA/>
- <https://www.dementiasa.org/media/>
- <https://clockworkmedia.co.za/projects/adasa-a-moment-to-forget/>
- <https://www.adasa.org.za/about-dementia/>
- <https://health-e.org.za/>
- <https://allafrica.com/stories/202509040396.html>