

# **The Voice** **for people** **living with** **Dementia**



# DEMENTIA IN SA: A SITUATIONAL ANALYSIS

BY ROXANNE JACOBS, MARGUERITE SCHNEIDER AND MARTIN KNAPP

- THE STRIDE PROJECT (SCIENCE, TECHNOLOGY, RESEARCH, AND INNOVATION FOR DEVELOPMENT), funded by the global challenges research fund (gcrf) aimed to contribute to improving dementia care, management and support for people living with dementia and their families (see <https://stride-dementia.org/>).
- Absence of regional and national data in SA, the global burden of disease (GBD) forecasts a 181% increase in dementia prevalence between 2019 (241 937) and 2050 (680 045) for SOUTH AFRICA ([NICHOLS, 2022](#)).



# ***STRIDE* TOPICS FOR REVIEW: THEORY OF CHANGE**

- (1) OVERALL COUNTRY CONTEXT (POPULATION, DEMOGRAPHY);
- (2) HEALTH SYSTEM;
- (3) LTC SYSTEM;
- (4) POLICY CONTEXT.....
- (5) DEMENTIA AWARENESS AND STIGMA;
- (6) EPIDEMIOLOGY AND INFORMATION SYSTEMS FOR DEMENTIA;
- (7) THE DEMENTIA CARE SYSTEM;
- (8) UNPAID CARE AND OTHER INFORMAL CARE;
- (9) SOCIAL PROTECTION; AND
- (10) DEMENTIA RESEARCH (**SEE COMAS-HERRERA, 2021**).

# STRIDE – FINDINGS : HEALTH SYSTEM



This Photo by Unknown Author is licensed under CC BY-NC-ND

- South Africa's health system is divided into two: the public and private sectors. The public sector offers free healthcare to 84% of the population ([Mahlathi & Dlamini, 2015](#)) who cannot afford private medical insurance and the out-of-pocket payments.
- Access to private medical care is contingent on having medical insurance, which few South Africans can afford (16%) ([StatsSA, 2019](#)).
- There are no dementia-specific services at the primary healthcare level, with fewer than ten geriatricians and five geriatric psychiatrists ([Kalula & Petros, 2011](#)) to serve the entire country of over 5.5 million older persons ([StatsSA, 2021](#)).

# ***STRIDE – FINDINGS : LONG-TERM CARE***

- The public sector has a general shortage of available pharmaceutical supplies ([South African Government, 2017](#)).
- Cultural beliefs play an important role in understanding dementia, where symptoms are often viewed with suspicion and fear, and where stigma sends families into hiding and avoiding help-seeking ([Mkhonto & Hanssen, 2018](#); [Mukadam & Livingston, 2012](#)).
- Access to LTC services is largely limited to those who can afford out-of-pocket payments as medical insurance companies do not support LTC and residential care services.



# LONG-TERM CARE (LTC) AND SUPPORT PROVISIONS

- Dementia care in South Africa is largely family-centred;
- Residential facility...
- Specialised dementia LTC services...
- Community-based services ...







# LONG-TERM CARE (LTC) AND SUPPORT PROVISIONS

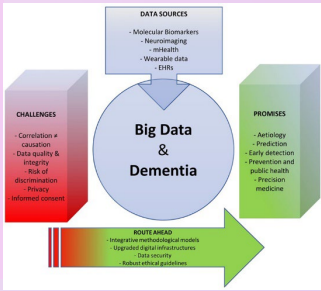
- The needs of older persons are simply not a priority for the country, both on national and provincial level..."**dementia-blind**"
- “We are too prone to think that you nurse people who have dementia...you don't nurse them, you care for them... *All caring for someone with dementia takes is common sense, compassion, a sense of humor and a bit of an innovative aspect in their approach. LOVE/FEELINGS* is what remains.
- Only the wealthy can afford trained nurses;
- Dementia care in SA is over-Medicalised and over-Legalised...

# ***STRIDE – FINDINGS: LONG-TERM CARE***

- Available LTC services (including home care, residential care facilities, respite care) are skewed towards the private sector with many being unregistered with the Department of Social Development as required ([Mahomedy, 2017](#)).
- Community-based services for people living with dementia are limited and based within the NGO-sector, with two dementia-specific NGOs in South Africa nl. Dementia SA and ADASA.
- A small study in Cape Town showed that 79% of persons living with dementia were cared for at home either by a spouse or an adult child ([Kalula, 2010](#)).

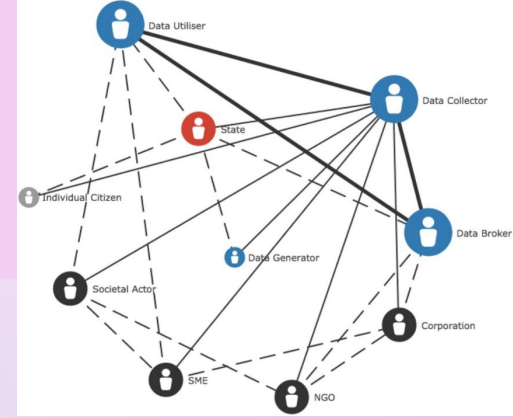


# STRIDE – FINDINGS: POLICY CONTEXT



- South Africa currently has NO NATIONAL DEMENTIA POLICY OR HEALTH PLAN. The Department of Social Development (DSD) is the custodians of the *Older Person's Act* (no.13 of 2006) that **broadly** promotes the rights, protection and care provision for older persons and ageing in general.
- The Older Person's Act recognises the State's responsibility for developing home-based care and providing information, education and counselling services, and includes care for alzheimer's disease and other dementias

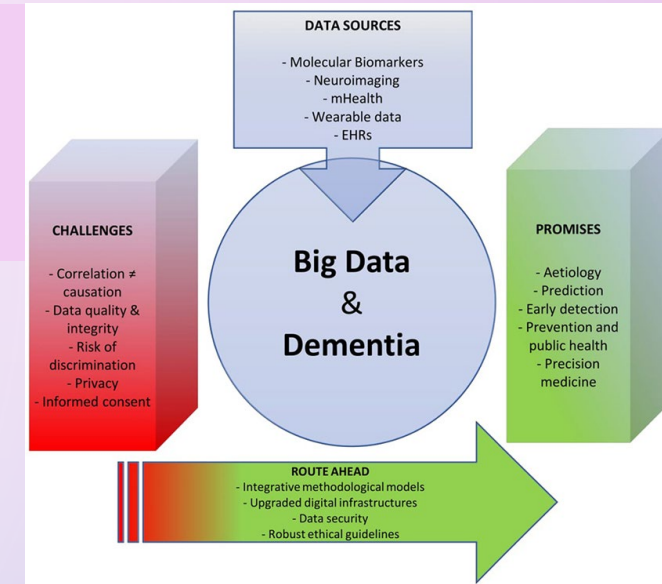
# STRIDE – FINDINGS:POLICY CONTEXT



- Current policies support services for older persons ... *'active ageing'* philosophy that promotes the full participation of older persons in their societies, their own decision-making and keeping them in their families and communities for as long as possible ([Jordan, 2009](#)).
- The shadow side of this philosophy is that the absence of adequate community-based support services for dementia locates care primarily within the family, where women/men often adopt care roles without support, resulting in excessive burden ([LLOYD-SHERLOCK, 2019](#)).

# STRIDE – FINDINGS:POLICY CONTEXT

- Despite these plans for redress of widespread inequality in South Africa, implementation of the NHI has been slow, (1) unclear funding modalities and (2) lack of implementation of plans and sustainability.
- In 2013, the National government adopted the Mental Health Policy Framework and Strategic Plan (MHPF) (2013–2020) that promotes an integrated care model for mental health in South Africa, supporting the decentralisation of primary care to home- and community-based services ([DOH, 2013](#)).
- However, like the NHI, these policies are largely '**dementia-invisible**' with no provisions articulated for dementia care and support services for persons living with dementia and their families. South Africa faces many challenges with policy implementation and corruption across a wide range of sectors.



# **STRIDE – FINDINGS: POLICY CONTEXT**

- An evaluation of the health system costs of mental health services and programmes in South Africa showed that :
  - (i) Despite the National Policy Agenda promoting the decentralisation of services, 86% of mental health service costs remain directed at inpatient services, with the majority of this spending occurring within specialised Psychiatric hospitals,
  - (ii) Significant disparities exist between provinces on resource allocations, and
  - (iii) There is limited evidence of community-based reforms being initiated ([Docrat, Besada and Lund, 2019](#)).

Managing  
Alzheimer's  
and  
Dementia  
Behaviors

COMMON SENSE CAREGIVING  
GARY JOSEPH LEBLANC



# ***STRIDE* – FINDINGS: DEMENTIA AWARENESS AND STIGMA**

- **Nurses and medical practitioners:**
  - **no or very little training in geriatrics / dementia or**
  - **limited experience with the elderly ... management of dementia thus an issue especially when younger people are concerned.**
- **Many believe nothing can be done about it anyway, so don't refer;**
- **Not all cases are picked up, so no relevant data available;**

# LACK OF REFERRAL SERVICES

- “...Family members who have the knowledge, they will say something like ... ‘I live in the Eastern Cape, do you know anyone in this area who can see my mother or my father...who can give a proper assessment? We think she has dementia.’ So that is a well-informed family, but then they don't have a service to go to” (CLINICIAN, PUBLIC HEALTH SECTOR).



# **LACK OF AWARENESS**

- **There is a need for AWARENESS as well as EDUCATION and TRAINING on dementia for healthcare staff.**
- **Need for general societal awareness...community clinics in all the areas that have staff that are equipped to see the early warning signs, to start doing some psychoeducation around healthy ageing...we're not even out of the starting blocks in many respects of people understanding dementia;**
- **Services are completely inadequate;**

# LIMITED POST-DIAGNOSTIC SUPPORT

- There is no/very little information or support on how to manage dementia beyond pharmacological responses;
- NGO's like Dementia SA and ADASA offer information sessions to families as well as support groups;
- Not everyone can afford these sessions as NGOs have to survive financially with no state funding;
- **Medications that support dementia symptom management are not freely available and come at a considerable cost.**
- For the majority of South Africans that rely on free public health services, dementia largely goes unmanaged:



# MULTI-SECTORAL RESPONSES

- **Need for multi-disciplinary, home-based services**
- **Not just medical ....**
- **Families seek support from the Health system as well as Faith-based or Spiritual communities and Traditional healing...**

# SOCIO-CULTURAL FACTORS: TRADITIONAL HEALING VS. WESTERN MEDICINE

- *“...They [older persons] will start by getting a traditional healer before the western medicine and sometimes things go well, and sometimes things don't go well and when people are too sick, as traditional healers, there are things we can heal and there are things we can't heal. And that's why we have to really understand” (TRADITIONAL HEALER).*
- Traditional healing is family-centred whereas Western medicine is focussed on the individual. The whole family is concerned in the dementia environment therefore the two (together) can bridge the gap in supporting the person with dementia.
- Traditional healers thus also have to be trained in dementia to understand whether its dementia or an ancestral calling.



# **MARINDA BREEDT: 57YRS OLD, DIAGNOSED AT 47YRS WITH ALZHEIMER'S, HAD TO STOP WORKING 3 YRS LATER**

- **No compensation from work**
- **Had to sell her house, pay R20k-R22k for facility fees**
- **Had to appoint a curator for R150 000**
- **Can't afford medical aid anymore**
- **Getting a SASSA disability grant**
- **Kids all still young with very young children so caught in the **sandwich generation**...cannot assist financially**









***EMS KUIPER***

**60 YRS OLD**

**DIAGNOSED AT AGE 49**

**LIVING WITH  
VASCULAR DEMENTIA  
FOR 11YRS**



- **Had to stop working at age 49yrs;**
- **Proactive in planning for her future;**
- **Read a book on caring for a pwd ;**
- **Lived independently in a security estate until she had two more strokes;**
- **Planned for her future financially;**
- **Placed herself in a facility of her choice;**
- **Moved to Assisted living;**





- **Selling her car;**
- **Financial disaster ....Legal system failed her;**
- **Covid and lockdown;**
- **Lack of perception;**
- **Flatlet on first floor .... disaster for Ems;**
- **Ems has lost so much during her journey with dementia, fighting for her independence to this day. Lives to the best of her abilities: crochet, gardening, shopping with organised transport.**



# **SUGGESTIONS TO DEMENTIA CARERS**

- **Do not try to control your loved ones, be patient and give them a chance to make their own decisions/choices;**
- **When accompanying them to the dr, please be quiet and give them a chance to speak to the dr themselves, this also pertains to drs....Speak and look at the person with dementia, not the family member/carer who is accompanying them;**
- **When we are in conversations, please remember that we are slow, give us time to grasp what you have said, time to answer. Therefore do not put words into our mouths as if we are stupid.**
- **Do not speak about us in front of us as if we are not present.**

# **SUGGESTIONS TO DEMENTIA CARERS**

- **We love and appreciate humor .... laugh with me not at me;**
- **Do not be afraid to tell others you have dementia, it can help them to assist you in a shop /understand your behaviour, etc;**
- **Educate yourselves on caring for a person with dementia;**
- **As we lose our abilities due to deterioration of our disease, try to remember that this is still me;**
- **Don't have expectations we cannot meet...don't treat us differently.**

*You are  
not alone..*



**DENISE FREDERICKS**

**0824139956**

**Email: [denise.fredericks3@gmail.com](mailto:denise.fredericks3@gmail.com)**