

# RETIREMENT & LIFESTYLE EXPO 2016

## DEMENTIA?

# NORMAL AGEING VS. AGEING WITH DEMENTIA

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# WHO WE ARE



- **“Go to”** organisation in SA on all forms of dementia,
- **Strives** to minimize the impact that dementia has on individuals, families and communities by being ....
- **A** leading provider of *awareness, information, education, training, support services* to all those affected by dementia – individuals, families, carers and communities.
- **Advocates** the rights and dignity of those living with dementia.
- All services are supported by ongoing global research.
- **Committed** to upholding the dignity of all persons affected by dementia actively promoting person-centered care models
- **Place** a premium on providing awareness, information and skills for services in under-developed areas.
- **At the forefront** of improving the quality of life of those living with dementia and those who care for them – global alliances & affiliations

**Recently:** Disability Parliament, Min of Social Development Disability Task Team,  
UN Older Persons Working Group  
Epidemiological Research Study  
Speaking Books



# Outline of presentation

Global view of ageing – where is Dementia on the Global health radar?

Ageing vs ageing with dementia

Define dementia & different types of dementia

Changing care needs

Person & family centered care

Positive interventions & multi-disciplinary teams



# 1. Global Ageing

## **First WHO Ministerial Conference on Global Action Against Dementia (Geneva, 16-17 March 2015)**

Affects more than 47 million people worldwide, with more than 75 million people estimated to be living with dementia by 2030. The number is expected to triple by 2050. It is one of the major health challenges for our generation.

**Hidden, misunderstood and underreported, dementia impacts individuals, families and communities and is a growing cause of disability.**

Dementia is not a natural or inevitable consequence of ageing. It is a condition that impairs the cognitive brain functions of memory, language, perception and thought and which interferes significantly with the ability to maintain the activities of daily living.

**Dementia leads to increased long-term care costs for governments, communities, families and individuals, and to productivity loss for economies.**

**POINT 4 & 5 :** Nearly 60% of people with dementia live in low- and middle-income countries, and this proportion is expected to increase rapidly during the next decade, which may contribute to increasing inequalities between countries and populations.



Last two paragraphs .....



## 2. Ageing vs ageing with dementia

### VULNERABILITY

What makes the elderly more vulnerable?

❖ Physical impairments/vulnerabilities

❖ Emotional issues

❖ Cognitive impairments



# Common Aspects of Ageing

**Sensory changes** – hearing loss, vision disorders

**Cardiovascular changes** – high/low blood pressure

**Musculoskeletal changes** – bone density, arthritis, joint problems (hips, knees)

**Neurological changes** – decreased/'slower' reaction time





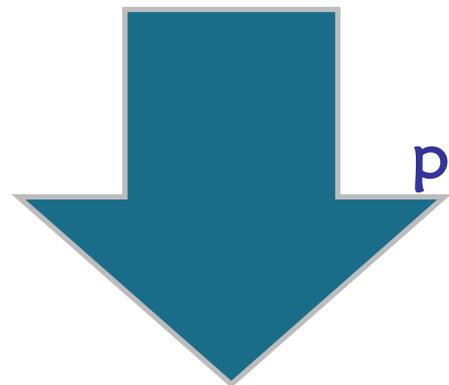
# Physical Vulnerabilities

Normal changes, such as getting thinner in stature, thinner skin, thinning hair and slower reaction times

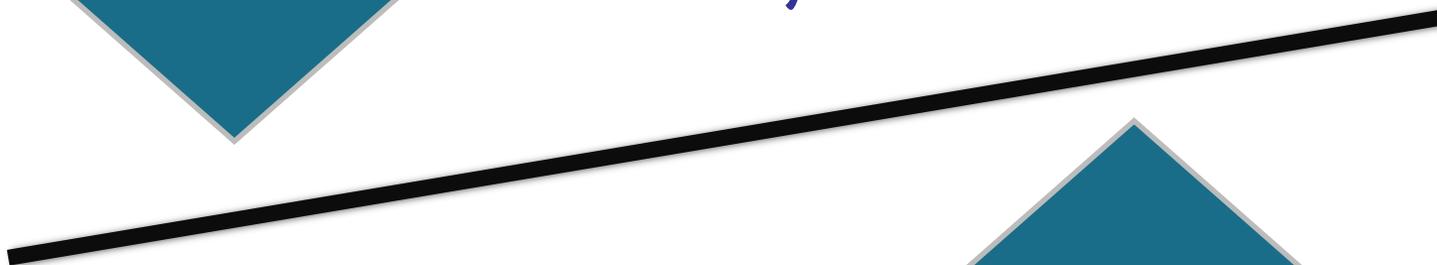
Greater susceptibility to disease and illness

Medications are generally not metabolized as rapidly

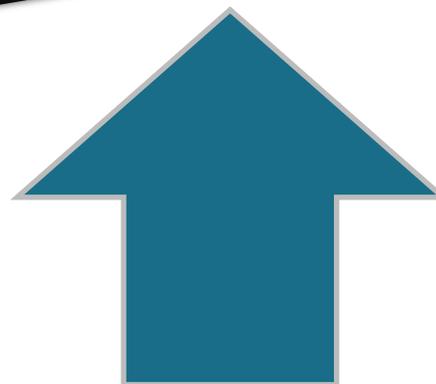
# EFFECTS OF COMMON MEDICATIONS



Treatments for high blood pressure, allergies, and anxiety



Side effects may include confusion, drowsiness, dizziness, and falls



### 3. What is dementia?

Dementia is a term used to describe various different brain disorders that have in common a loss of thinking function.

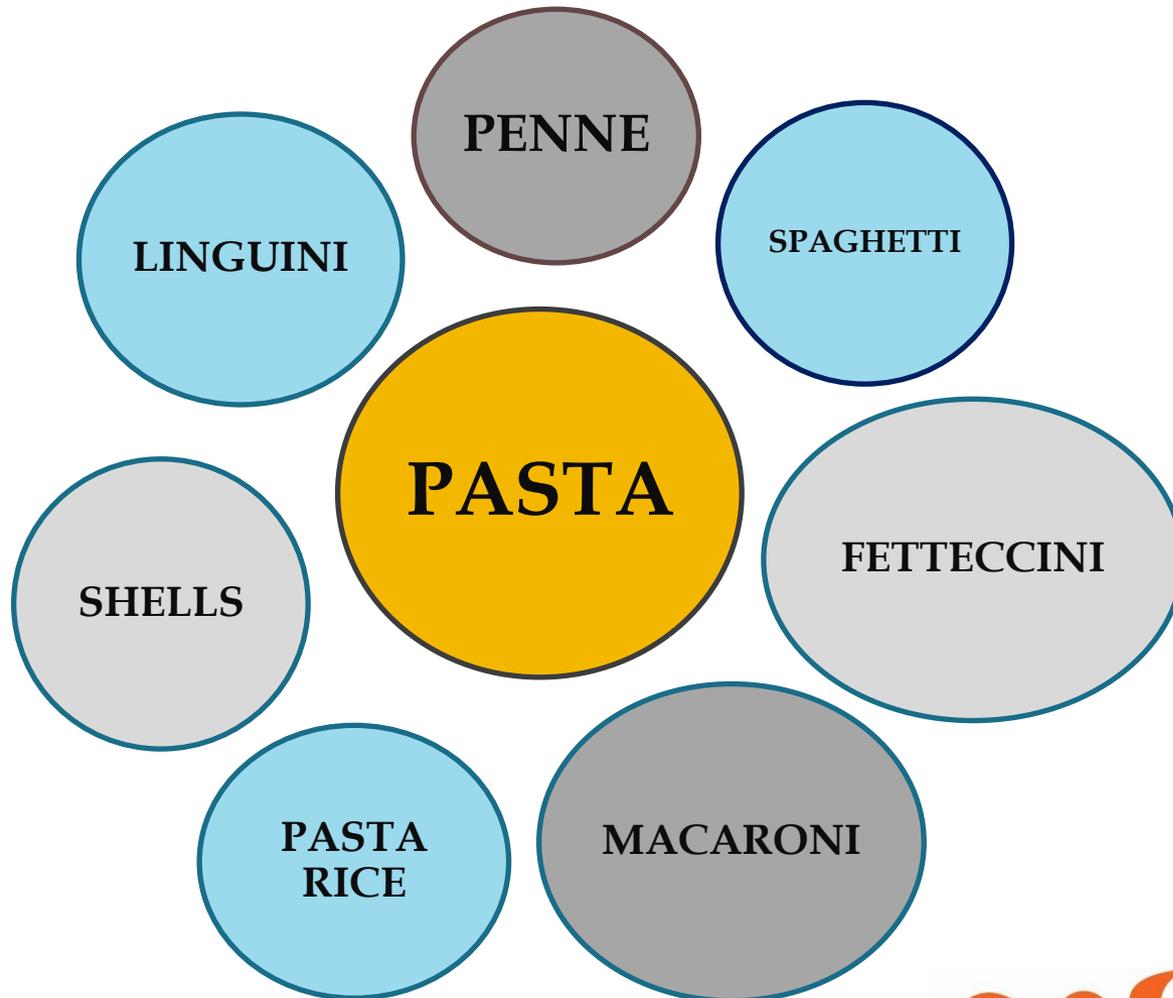
**Dementia is a progressive, degenerative brain syndrome that affects memory, thinking behaviour and emotion.**

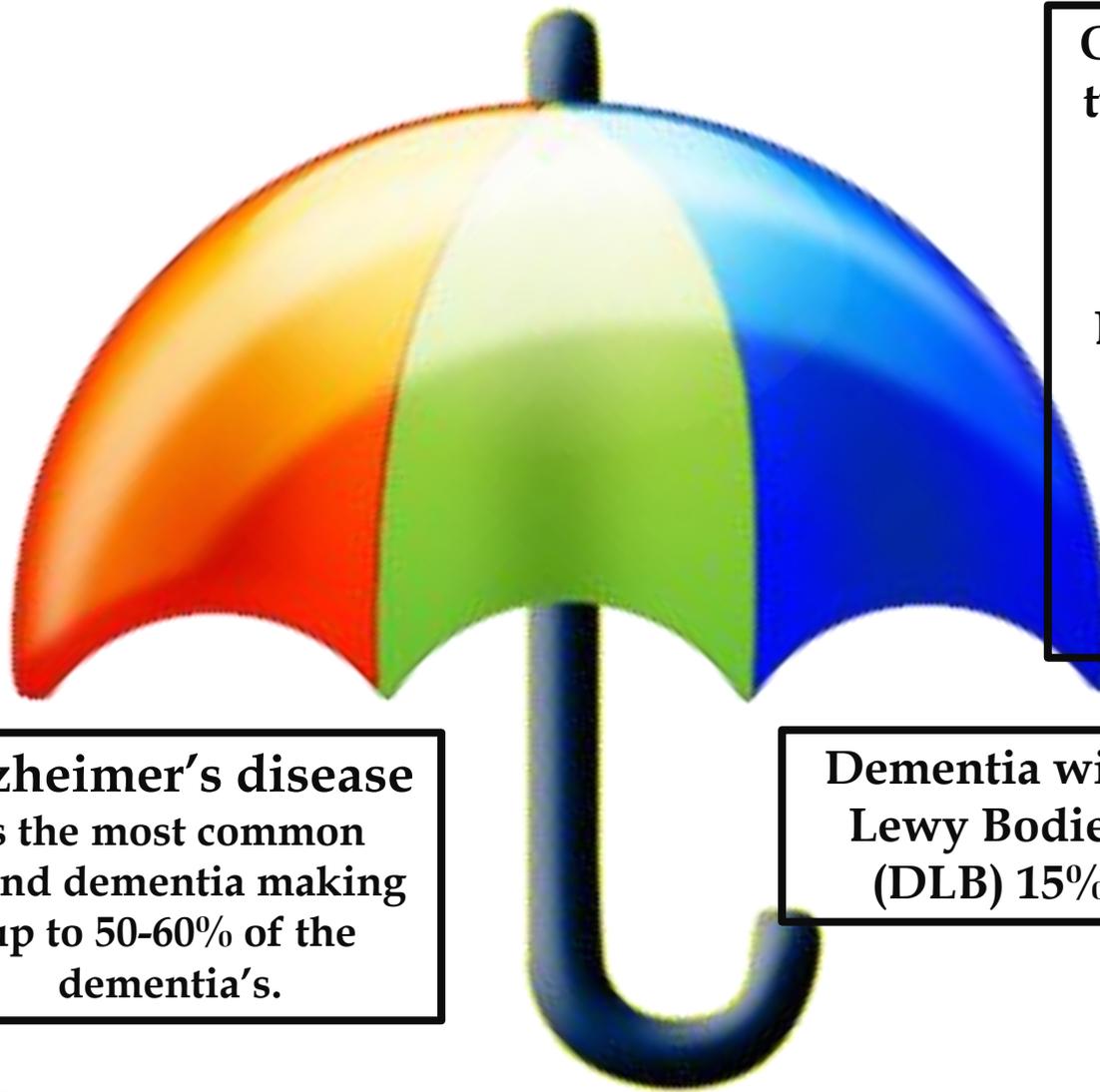
Dementia knows no social, economic, ethnic or geographical boundaries.

How fast dementia progresses depends on the individual.



# Simply understanding the term...





Over 100 different types of dementia including

- HIV AIDS
- Neurocognitive Disease (HAND)
- Alcohol related dementia
- Korsakoff's
- Mad Cows Disease (CJD)

**Alzheimer's disease** is the most common found dementia making up to 50-60% of the dementia's.

**Dementia with Lewy Bodies (DLB)** 15%

**Vascular dementia** 20%



Greatest risk factor for developing a dementia is

**AGE**

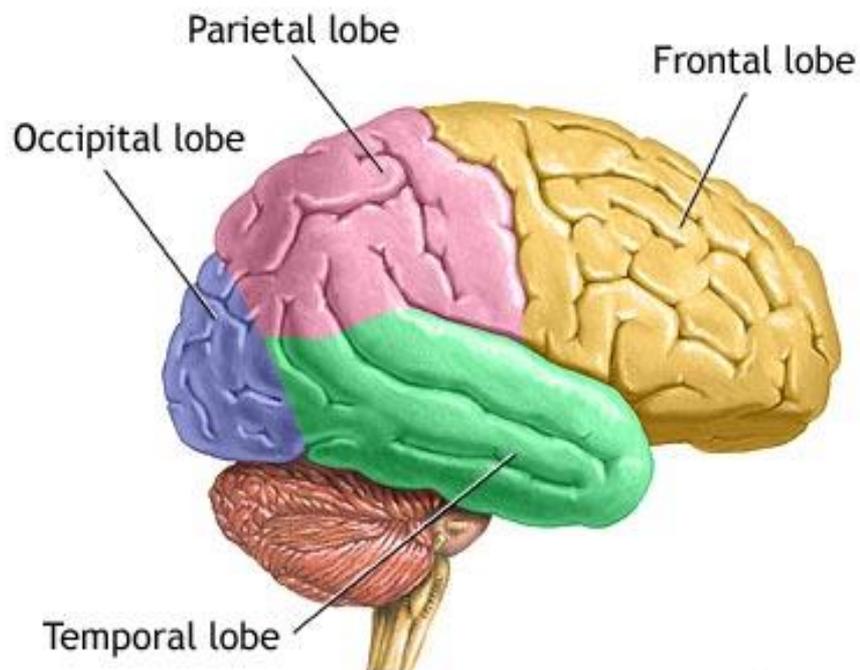


Age (years)	Prevalence
Below 64	1 in 1000
66-79	1 in 20
80-84	1 in 5
85+	1 in 3

**However : MCI & Young Onset Dementia**  
which is onset before age 65 becoming more prevalent  
as a result of more awareness, better screening, more services  
available



# The Brain is the control centre of your body .....



ADAM.

**FRONTAL LOBE** – decision making, write, organise, get things going, decide who does what and when, receive feedback from other centres, judgement, respond appropriately, reasoning  
**PARIETAL LOBE** – language, speech, reading, calculations  
**LIMBIC SYSTEM** – consciousness, sleep, appetite, emotions, learning, memory  
**OCCIPITAL LOBE** – visual information system  
**TEMPORAL LOBE** – filing system and memory



## 4. Changing care needs

Each person with dementia .... manifests the disease differently and it progresses at different rates in different people

One person with dementia .... Is one person with dementia – not a one size fits all

### ASSESSING : ADLs (Activities of Daily Living)

Activities needed for independence in the home or in the community :

Mobility

Dressing

Toileting

Bathing

Feeding oneself

Continence



# ASSESSING : IADLs

(Instrumental Activities of Daily Living)

Activities needed for independence in their own home or in the community :

- Handling finances (Frontal Lobe)
- Use of the telephone (Frontal, parietal, limbic, occipital and temporal)
- Transportation (incl driving) ???
- Medication management ???
- Meal preparation & Shopping ???

**FRONTAL LOBE** – decision making, write, organise, get things going, decide who does what and when, receive feedback from other centres, judgement, respond appropriately, reasoning

**PARIETAL LOBE** – language, speech, reading, calculations

**LIMBIC SYSTEM** – consciousness, sleep, appetite, emotions, learning, memory

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# 5. Person centered care

Tom Kitwood defines personhood as : “ A standing or status that is bestowed upon one human being, by other, in the context of relationship and social being. It implies recognition, respect and trust”. (Kitwood, 1997, p8)

**Person-Centered Care (PCC) = V + I + P + S**

**V** = a **Value** base that asserts the value of all human lives regardless of age or cognitive ability

**I** = **Individualised** approach, recognising uniqueness

**P** = understanding the world from the **Perspective** of the service user

**S** = providing a **Social environment** that supports psychological needs



# This means that you should remember that each person with dementia .....

Is a unique individual with their own very different experiences of life

Has their own needs and feelings

Has their own likes and dislikes

Will be affected in different ways by dementia

Reacts to the experience of dementia differently

The experience of dementia will mean different things to different people

And this is also essential to remember when dealing with families.



# Enriched Model of Care :

## Dementia = NI + H + B + P + SP

NI	<i>Neurological impairment</i> that is part of the disease process
H	<i>Health</i> and physical fitness – health status
B	<i>Biography</i> – life history – past lived experiences
P	<i>Personality</i> – how a person is able to cope with a disease process
SP	<i>Social psychology</i> – ensuring that the sense of self is maintained
	<i>Tom Kitwood</i>



## 6. Positive interventions & multi-disciplinary teams



# Evidence of Positive Social & Psychological Support:

General person centred care minimises the escalation of problems into BPSD (Ballard et al, 2009; Cohen-Mansfield et al, 2007 & 2010)

People with dementia have better mood and quality of life if they are cared for by staff that communicate well (CSCI, 2009)

Staff who are trained in person centred care, decrease agitation in high dependency care home residents (Chenoweth et al 2009)

## *BPSD = Behavioural and Psychological Symptoms of Dementia*

“Symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in patients with dementia.” (Finkel & Burns, 1999)

*Delusions, Hallucinations, Agitation, Dysphoria,  
Anxiety, Apathy, Irritability, Euphoria,  
Disinhibition, Aberrant motor behaviour,  
Night-time behaviour disturbances,  
Appetite and eating abnormalities.*



# Latest thinking on INCLUSIVITY & COLLABORATION

The National Quality Forum (UK) recently declared :

*“Person- and family-centered care emphasises the individuality of recipients of healthcare services and their families and caregivers.*

*Person- and family-centered care is an approach to the **PLANNING** and **DELIVERY** of care across settings and time that is centered on **COLLABORATIVE** partnerships among individuals (plwd), their defined family and providers of care. It **supports health and well being** by being **CONSISTENT** with, **RESPECTFUL** of, and **RESPONSIVE** to an individual’s priorities, goals, needs, and values.”*



# CONCLUSIONS & THOUGHTS ....

The starting point for positive intervention and support is :

an understanding of the lived experience of the person with dementia  
AND that of their family (denial, anger, grief, loss ...)  
a recognition of the person's strengths and abilities, needs and life story.

Getting to know the background and life history of a plwd can really help in understanding their perspective and needs – this fosters collaboration and positive integration with families

*'Try to understand how hard it is for us – it's just that you can't see the missing bits that we are having to cope without.'*

*Christine Bryden (2006)*



## We CONTINUE to GROW and STRENGTHEN our PARTNERSHIPS

- o We continue to advocate for better care of people with dementia
  - o Advocate for a social conscience around ageing in South Africa
- o Put pressure on MEDICAL AIDS, Government, trusts and corporates to fund mental health and training of those who care for people with dementia, and awareness for an early diagnosis to ensure better planning
  - o Continue to help families stay in touch.

Thank You!



**DEMENTIA SA salutes the tireless, dedicated efforts of families, carers, nursing staff and communities**

**You add value to those who ...**

**Have a fading Voice that we sometimes cannot hear**

**Have clear and foggy thoughts that almost always scare**

**Have difficulty seeing things as they really are and sometimes forget those they once loved**

**Have difficulty understand things as they were and are now**

**Cannot listen and process so many things at once**

**All you can do – is understand that that is a very scary place, all confusing and muddled .....**

**Hold them in their times of fog; dance and laugh in times of clear mind**

**But above all else, do not judge, ridicule or show impatience, do not argue or correct,**

**Show recognition and respect and soon trust will follow ....**

**Just be present in THEIR shrinking world and share their JOY of just a MOMENT**

