alzheimer's
QUEENSLAND

Understanding Dementia

Living with dementia 02 – changes we noticed

link

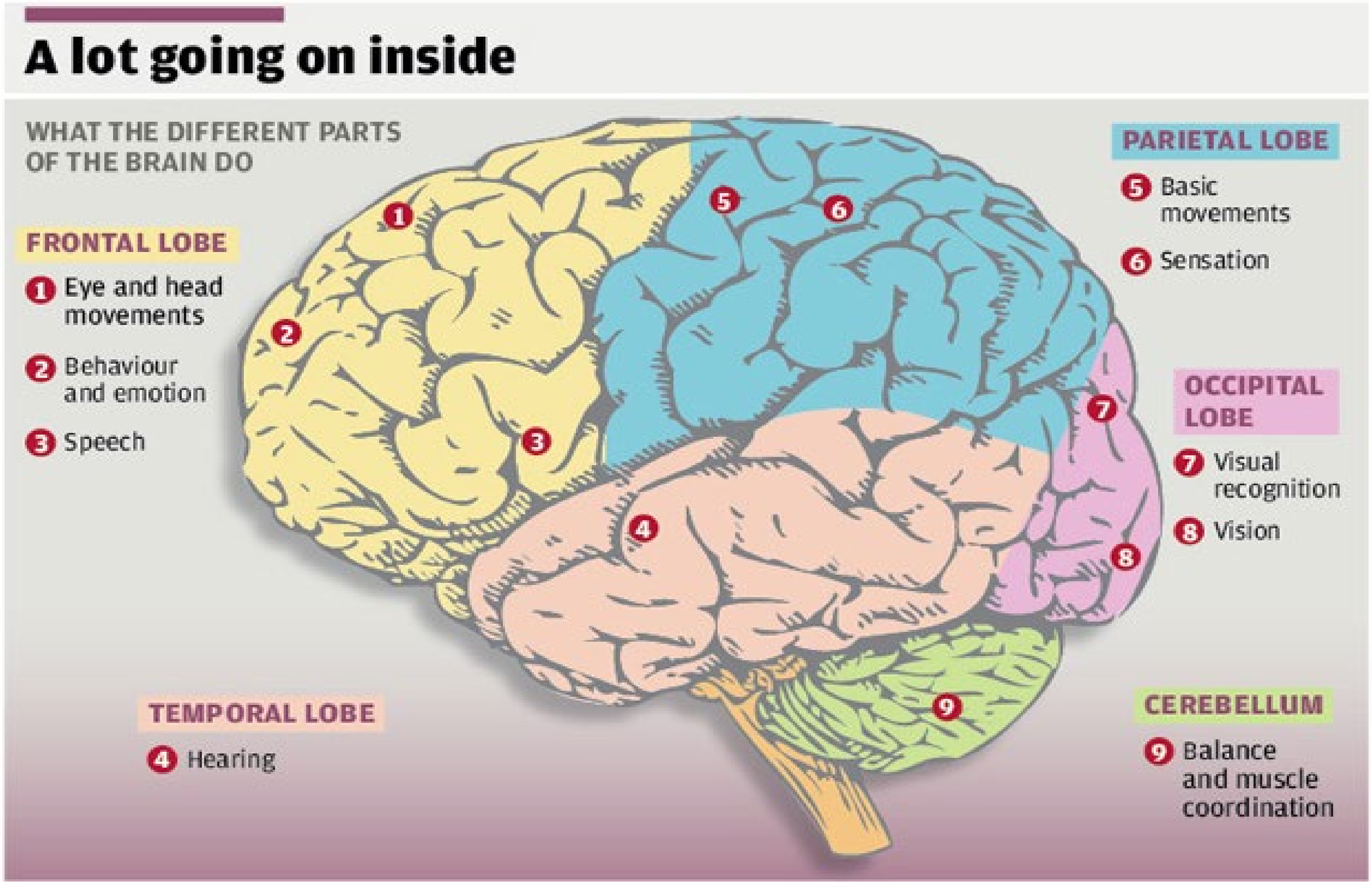
What is dementia?

- Not one single disease
- A collection of symptoms
- Over 100 causes
- Physical disease of the brain
- Progressive and irreversible
- NOT a normal part of ageing

Prevalence in Australia

- Dementia affects almost 1 in 10 people aged 65 years and above in Australia.
- 2017 Dementia Australia statistics indicates that of the people living with dementia, 55% were females and 45% were males.
- In 2018, dementia was the leading cause of death among Australian females, surpassing heart disease.
- The rate of dementia in Aboriginal and/or Torres Strait Islander peoples is up to 5 times higher than non-indigenous Australians.
- The 2021 Dementia Australia Prevalence Data reveals that an estimated 472,000 people in Australia living with all forms of dementia and this figure is projected to increase to 1,076,000 people by 2058.
- Just over 1% people living with dementia are estimated to be under 60 years of age.

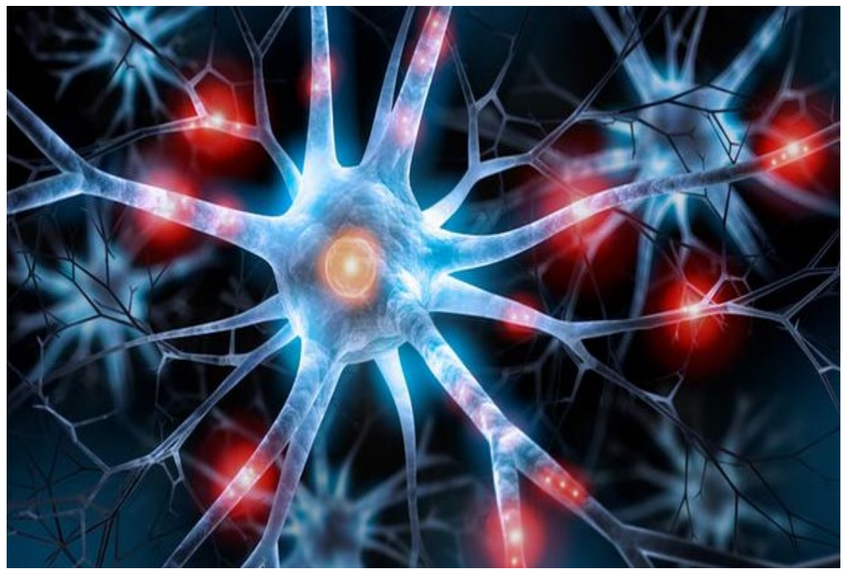
Inside the brain

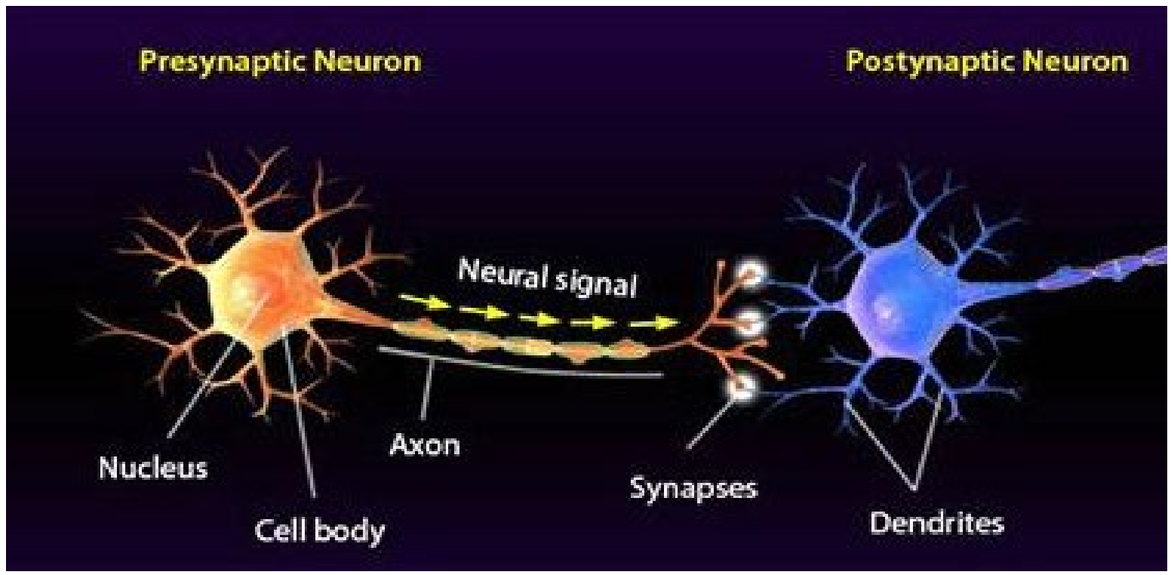


Synapse

In the adult human brain:

- 100 billion brain cells (neurons)
- Forming a million new connections every second we are alive
- One brain cell sends signals to a receiving cell in the form of neurotransmitters
- It is in these changing connections memories are stored, habits learned and personalities shaped.





Risk Factors for dementia

- **Age** – The older the person is, the greater their risk of developing the disease.
- **Gender** – Alzheimer's disease appears to affect more women than men and Lewy body dementia is the opposite
- **Family history** – The risk of developing the disease is greater if a primary relative (parent, grandparent or sibling) developed Alzheimer's disease prior to the age of 65 years.
- **Other health conditions** – cardiovascular disease, diabetes, chronic depression, and other mental health conditions may increase the risk of dementia.
- **Head injury** – A severe head injury or repeated blows to the head may increase the risk of developing dementia, but not necessarily Alzheimer's disease.
- **Down syndrome** – For unknown reasons, people with Down Syndrome are prone to developing Alzheimer's disease in their thirties or forties.

Common causes of dementia

- Alzheimer's disease (50-75%)
- Vascular dementia (20-30%)
- Dementia with Lewy Bodies (5-10%)
- Frontotemporal dementia (up to 5%)
- Younger onset dementia (for aged below 65)

Less common types

- Wernicke – Korsakoff syndrome (excessive consumption of alcohol)

- HIV associated dementia

- People with Down Syndrome are prone to developing Alzheimer’s disease in their 30-40s.

- Posterior Cortical Atrophy (dramatical decline in visual processing)

Alzheimer’s disease

- Characterized by two types of deposits in the brain

  - *Plaques - clumps of beta amyloid protein outside of neurons*
  - *Tangles - bundles of twisted filaments called Tau inside neurons*

- Can be either sporadic or familial.

- Disease prognosis 3-20 years; Averagely 7-10 years

- Changes in brain occurs 10-20 year Before any symptom is experienced

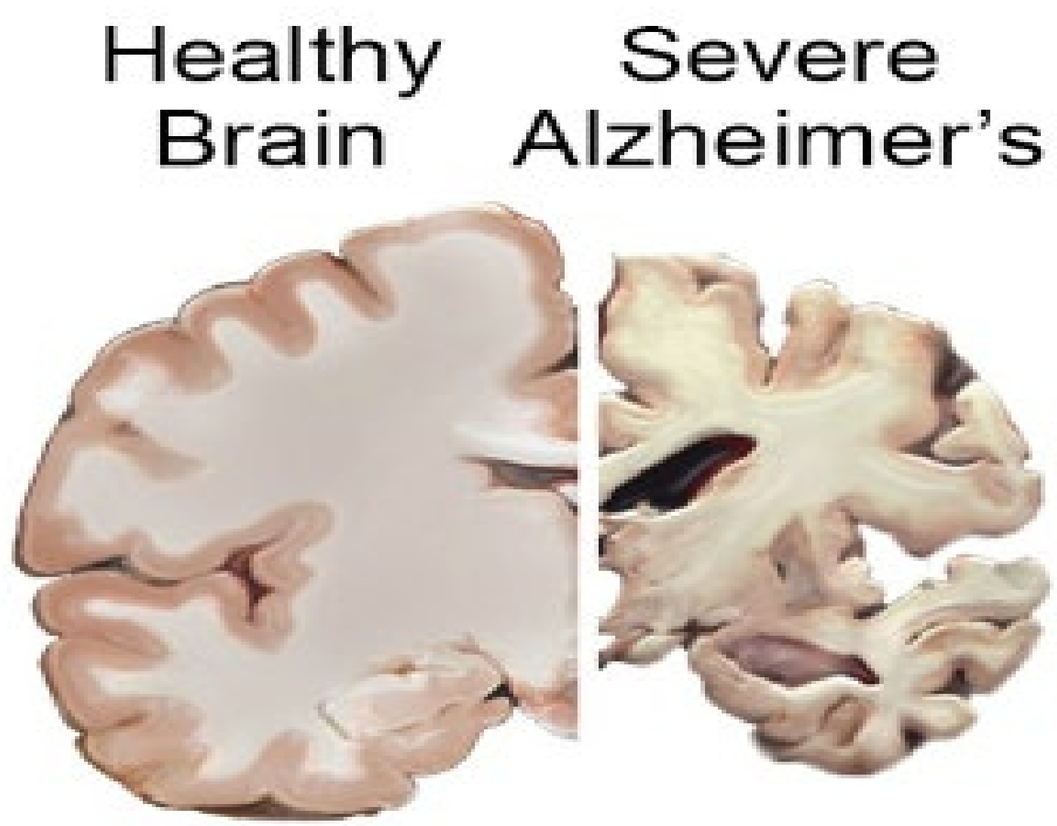


Fig. 1. Normal human brain.

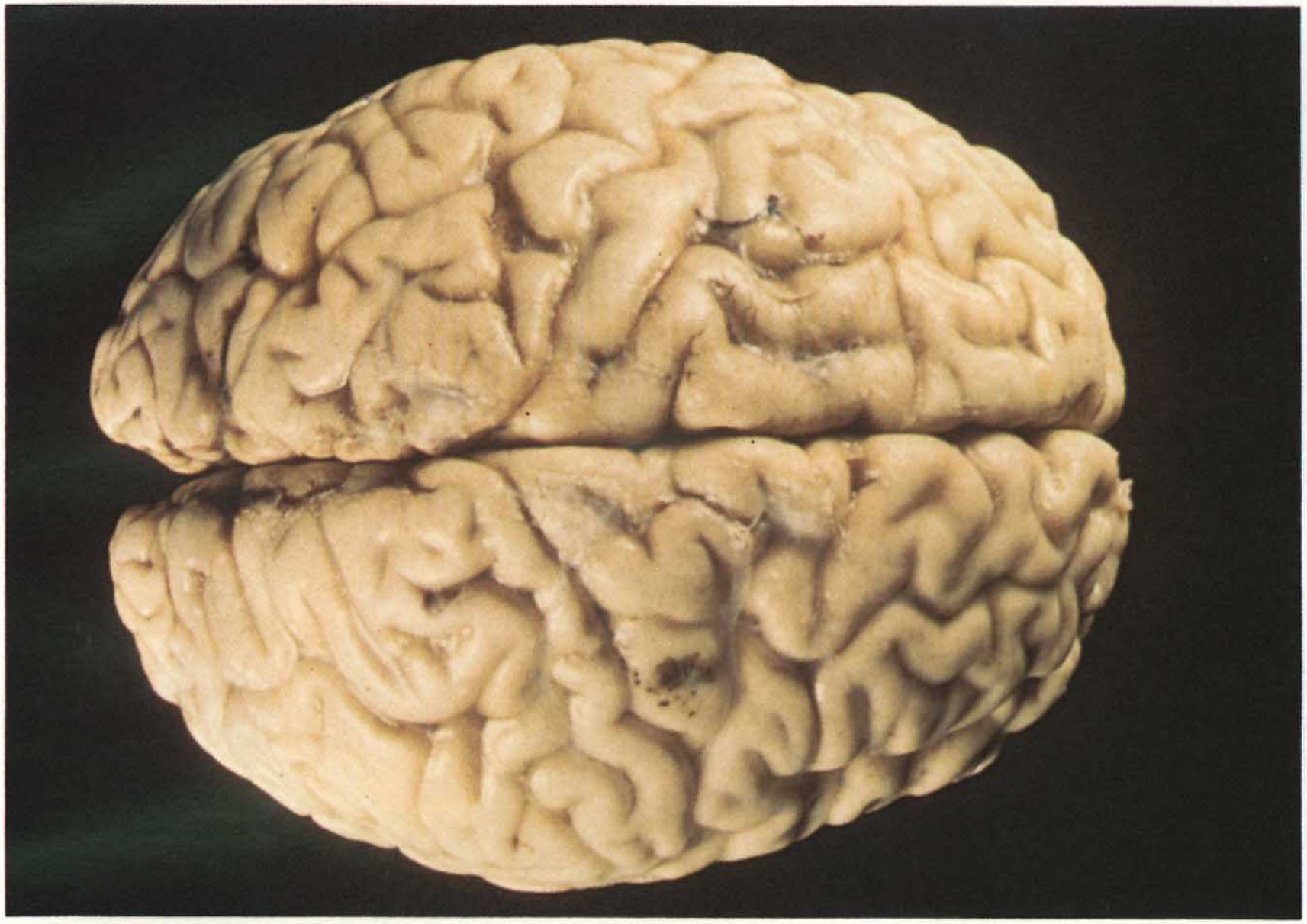


Fig. 2. Brain of patient with Alzheimer's Disease. Note atrophic surface area lost by decrease in gyri, and deeper, wider sulci.

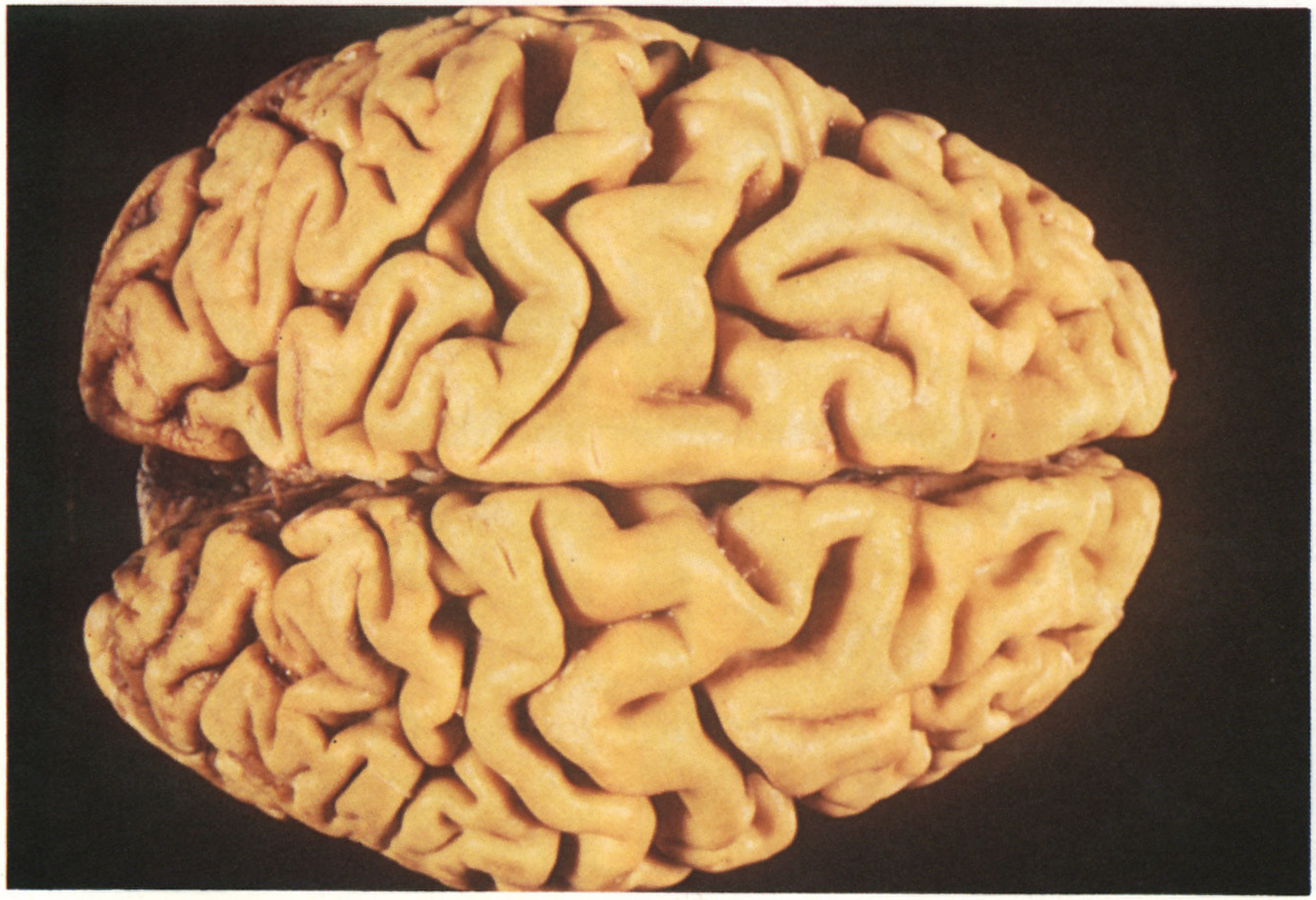


Fig. 3. Normal brain section.

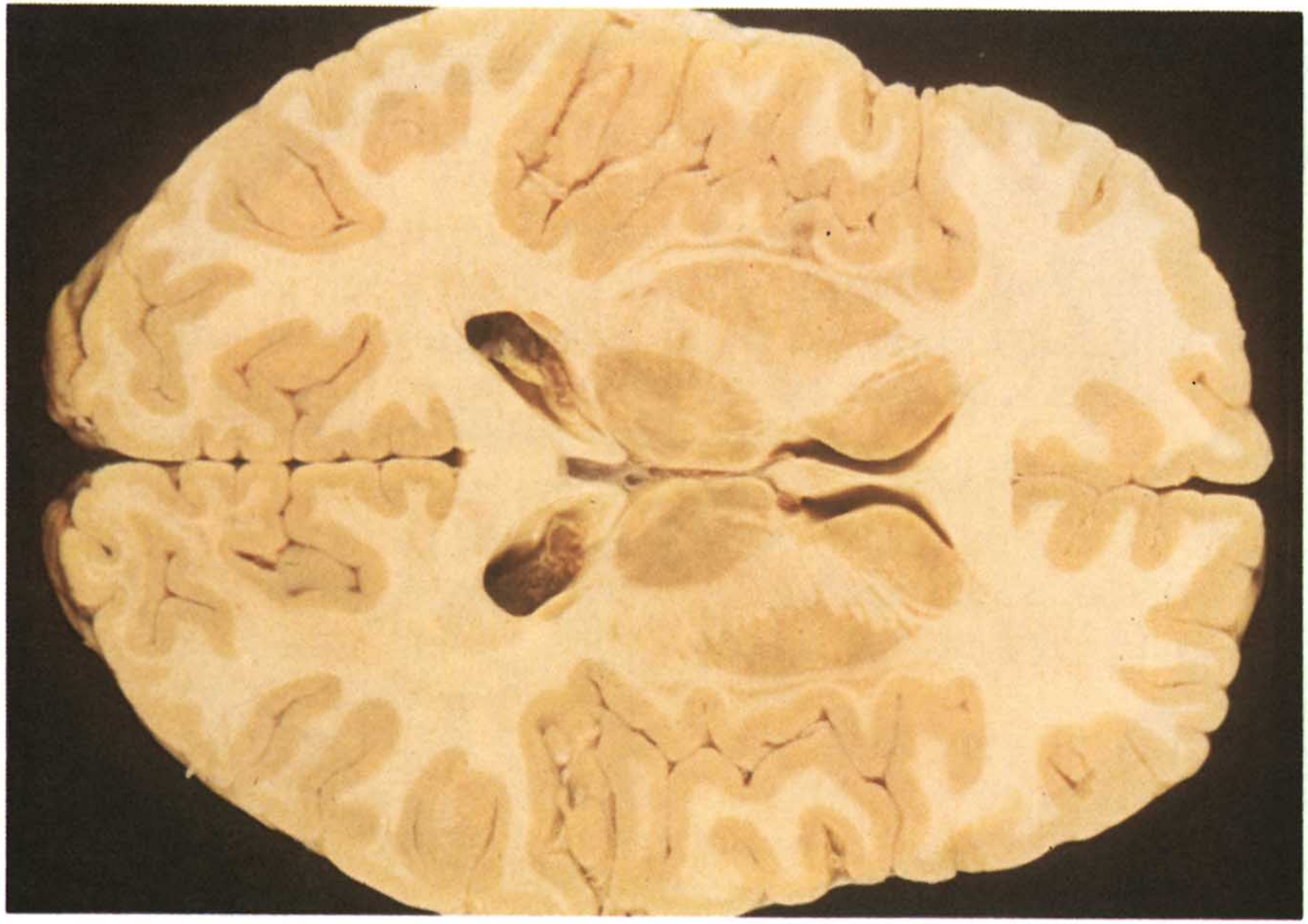
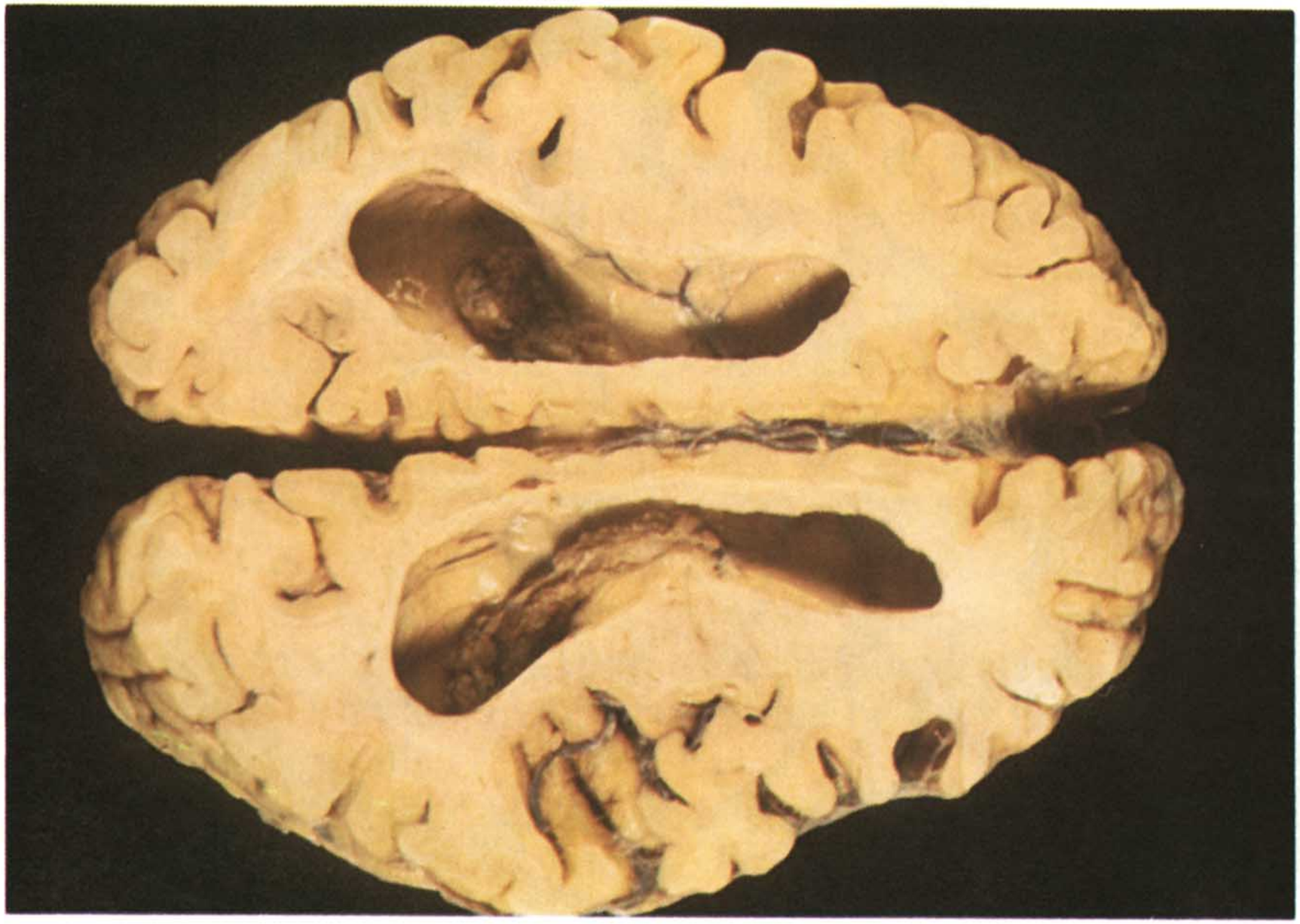


Fig. 4. Brain section of patient with Alzheimer's Disease—enlarged ventricles.



Disease progression

Early stage -

- Persistent and frequent memory difficulties, especially of recent events
- Difficulty in finding the right words for everyday objects; vagueness in everyday conversation
- Misplacing items
- Getting lost in familiar environment; forgetting well-known people
- Taking longer to do routine tasks
- Inability to process questions and instructions
- Deterioration of social skills
- Emotional unpredictability
- Apparent loss of enthusiasm for previously enjoyed activities

Late stage -

- Incontinence
- Difficulty with eating/swallowing
- Severe memory problems
- Significant loss of speech
- Loss of motor skills

Vascular dementia

- Caused by damage to the blood vessel in the brain, signs and symptoms of dementia depends on area of stroke

- Can be caused by a single stroke, or by several strokes occurring over time, disease progression could be difficult to predict

- This damage stops blood supply to the affected brain cells causing them to die and leads to reduced function in this area of the brain.

- A diagnosis of mixed dementia is common when people presents symptoms of both vascular dementia and Alzheimer's disease.

- Two types
  - Multi-infarct vascular dementia
  - Subcortical vascular dementia

Lewy body disease

- Lewy bodies are the abnormal clumps of the protein alpha-synuclein that develop inside nerve cells.

- Three overlapping disorders can be included with Lewy body disease:
  - Dementia with Lewy bodies
  - Parkinson’s disease
  - Parkinson’s disease dementia

- No known cause, no known risk factors identified, no evidence of genetic inheritance, average lifespan 7 years

- People with Lewy body disease are sensitive to antipsychotics medications which can cause rigidity and even death.

Disease progression

Early stage -

- Temporary symptoms – fluctuation between normal and abnormal behaviour, mood and cognition
- Parkinsonism
- Vivid hallucinations/paranoia, acting dream out
- Fixated ideas/thoughts
- Short term memory loss
- Difficulty with language recall
- Sleep disorder/Rapid Eye Movement
- Difficulties judging distances, often resulting in falls

Late stage -

- Incontinence
- Difficulty eating/swallowing
- Significant loss of speech
- Extreme sensitivity to touch
- Severe memory problems
- Severe parkinsonism
- Vacant stare

Frontotemporal dementia

- Also called frontotemporal lobar degeneration (FTLD). First described 100 years ago by Arnold Picks so was previously referred to as Pick's disease.

- Occurs when there is progressive damage to the frontal and/or temporal lobes of the brain. Memory often remains unaffected during early stage.

- Frontal or behavioural variant FTD

- Temporal variant FTD

- FTD can affect anybody. It typically affects people at a younger age than Alzheimer's disease, with symptoms beginning in the 50s or 60s, and sometimes younger.

- Almost a third of people with FTD have a family history of dementia. However, only about 10-15% of cases have familial FTD, in which a gene mutation is passed on that causes the disease.

- Cellular studies of the brain have shown that there are two types of protein which accumulate in brain cells in FTD – tau and TDP-43.

Disease progression

Early stage -

- Fixed mood and behaviour, appearing selfish and unable to adapt to new situations
- Loss of empathy, emotional warmth and emotional responses
- Apathy or lack of motivation, abandoning hobbies or avoiding social contact
- Loss of normal inhibitions, talking to strangers or exhibiting embarrassing behaviour
- Difficulty in reasoning, judgement, organisation and planning
- Distractibility and impulsiveness
- Changes in eating patterns, craving sweet foods, overeating or unusual food preferences
- A decline in self-care and personal hygiene
- Difficulty with language recall

Late stage -

- Difficulty eating/swallowing
- Incontinence
- Severe memory problems
- Significant loss of speech
- Severe parkinsonism
- Extreme sensitivity to touch

Younger onset dementia

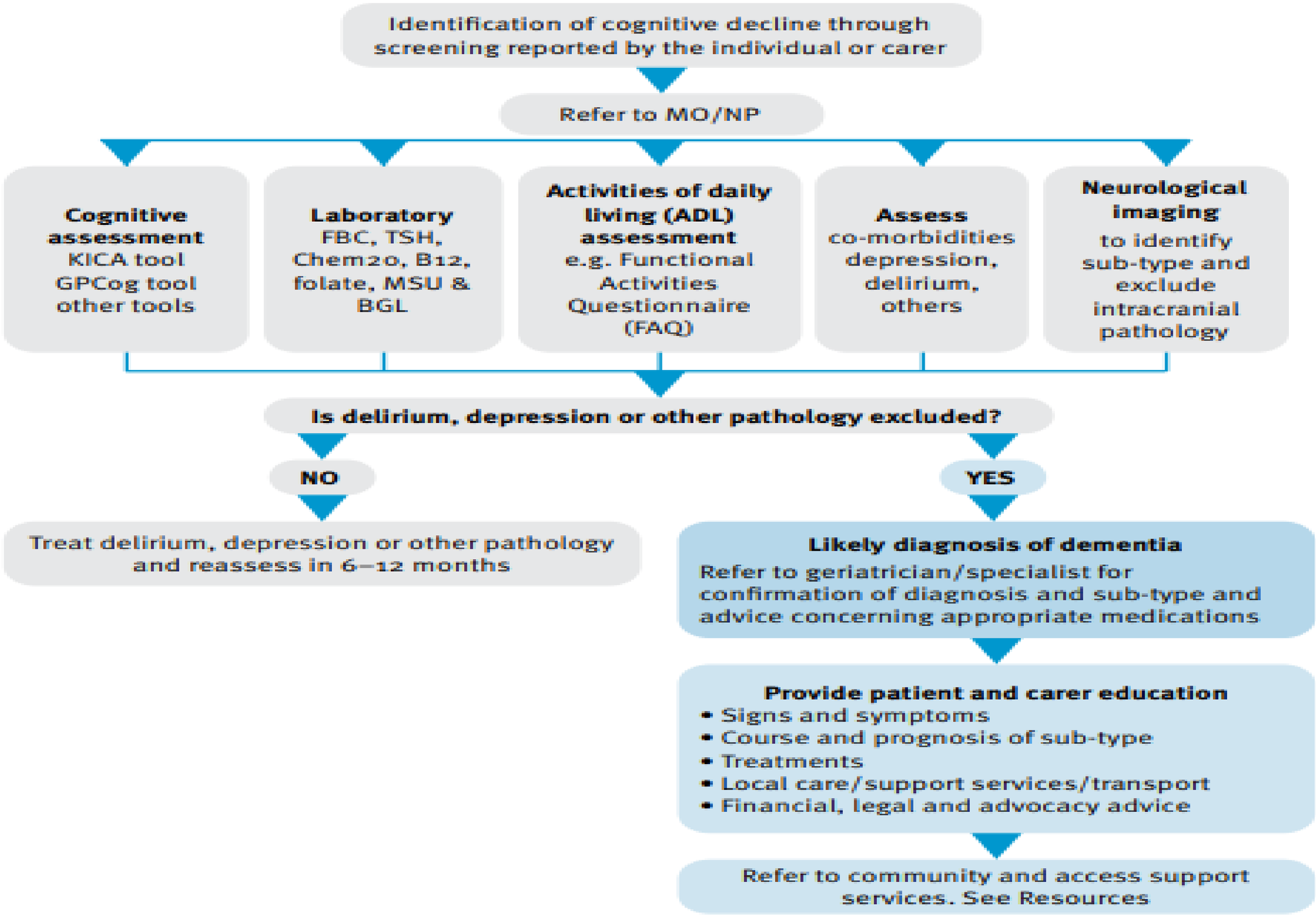
- Used to describe any dementia diagnosed in people under the age of 65
- Maybe caused by any above-mentioned dementia or other neurological condition
- People with frontotemporal dementia may start to show symptoms between age of 45-64
- Tendency of rapid progression
- Dementia Australia dementia prevalence data shows an estimated 28,300 people living with younger onset dementia and this figure is projected to increase to 41,250 by 2058.

Warning signs

The early signs of dementia can be subtle, vague and may not be immediately obvious.

- Memory loss and impairment (hallmark features of most dementia, not typical in Fronto-temporal dementia), short term memory
- Difficulty performing familiar tasks – steps out of order, or skip a step completely
- Confusion about time and place (typical in Alzheimer's disease)
- Problems with words – forgetting names of objects; difficulty understanding complex instructions, numbers and sequencing
- Apathy and withdrawal – loss of interest in people, hobbies, activities and social interactions
- Poor judgment/impulse control – not following road rules, turning off the stove, wearing thin in winter
- Changes in personality/mood – easily angered, more suspicious, increased agitation

Diagnosis process



Benefits of Early Diagnosis

Individual are often already aware there is something wrong and diagnosis may provide some relief.

In Australia, the average time from onset of symptoms to diagnosis is 3.1 years.

However, early diagnosis could provide following benefits:

- planning finances and nominating power of attorney for when the person can no longer make decisions for themselves
- make choices about the person's future and achieving life goals
- access to drug treatments that may delay or slow down some of the symptoms of dementia
- access to support services to remain living in the community for as long as possible

Delirium Vs Dementia

Characteristics	Delirium	Dementia
Onset	Acute	Insidious
Course	Fluctuating	Stable
Duration	Hours to weeks	Months to years
Attention	Fluctuates	Normal
Perception	Hallucinations	Usually normal
Sleep/wake	Disrupted	Fragmented

Stages of dementia

The course of dementia is characterised in 3 stages

- Mild or early stage dementia where deficits such as self care and memory changes may become evident

- Moderate or middle stage dementia where deficits usually become obvious and the person requires assistance to maintain function

- Severe or late stage dementia characterised by high dependence

Inclusive language to avoid stigmatising

Context	Preferred terms	Do not use
Talking about dementia	Dementia A form of dementia A type of dementia Symptoms of dementia	Dementing illness Demented Senile dementia Going on a journey
Talking about people with dementia	A person/people with dementia A person/people living with dementia A person/people with a diagnosis of dementia	Sufferer or victim Wanderer, aggressor or perpetrators Fading away or empty shell Attention seeker Losing his/her mind Away with the fairies
Impact of caring	Impact of supporting (someone)with dementia Effect of supporting (someone) with dementia	Carer burden Burden of caring
The impacts of dementia	Disabling Challenging Life changing Stressful	Hopeless Unbearable Impossible Tragic Devastating Painful
Behaviours	Changed behaviours Expressions of unmet need BPSD	Challenging behaviours Behaviours of concern Difficult behaviours

Post-diagnosis considerations

- MAC assessment
  - RAS – CHSP
  - ACAT – HCP & residential respite/permanent
  - Functional capacity – ADL's and IADL's

- Build up support network
  - Transport service
  - Domestic assistance
  - Home modification/maintenance
  - Allied health exercise program
  - Personal and social support
  - Centre-based or in-home respite
  - Carer support groups
  - Carer counselling service
  - Dementia helpline

- Pause, reflect, feeling of grief and loss

- Re-evaluate life goals

Home and environmental considerations

- OT assessment on home safety and required modification
- Outdoor – slopes, stairs, uneven or slippery surfaces
- Indoor – stairs, de-clutter, lighting
- Bathroom – rails, over-the-toilet frame, bathtub safety
- Bedroom – night light, floor mat or bed sensor for night-time safety
- Set up home/family communication system – use of diary, calendar or electronic device to keep up to date with plans, arrangements and events
- Home storage – use pictorial labels on cupboards and drawers for easy location of items
- Drive licence – OT assessment on driving safety
- Personal alarm for medical emergency
- GPS tracker for safety when out walking alone
- Pet companionship – physical activity, out of house, social interaction and emotional needs

Medications for dementia treatment

- **Cholinesterase inhibitors**, work by inhibiting the breakdown of a chemical neurotransmitter – acetylcholine

- *Aricept (Donepezil)*
- *Exelon patch (Rivastigmine)*
- *Reminyl (Galantamine)*

- ***Glutamate blocker,*** works by blocking chemical called Glutamate.

- Ebixa (Memantine)

However, they only slow the progression of symptoms and will not halt, reverse or cure the disease.

Other medications to manage secondary symptoms
- Antipsychotics
- Benzodiazepines
- antidepressants

Myths

The course of dementia is predictable

Dementia is a disease of the brain only

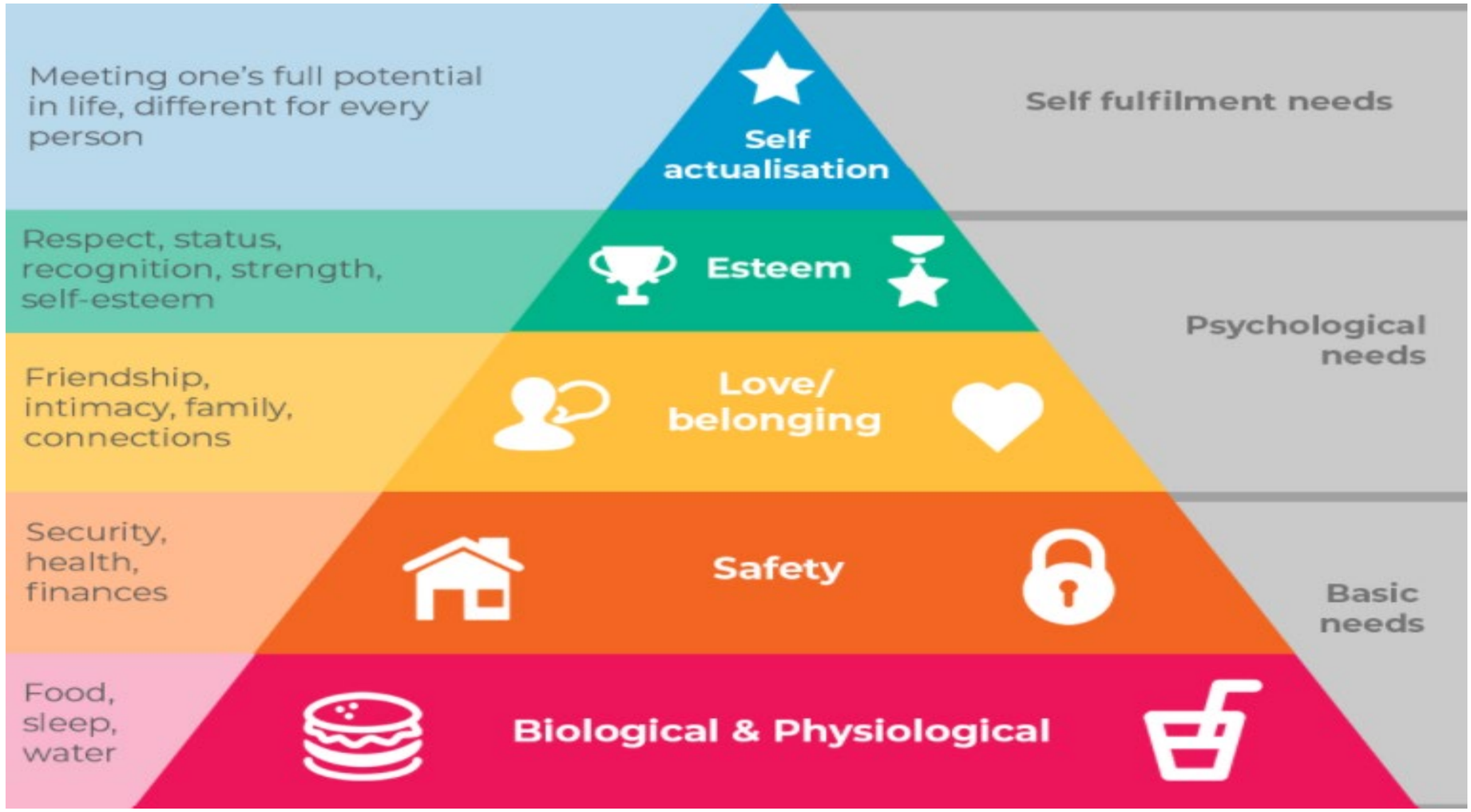
All clients with dementia exhibit challenging behaviour

All behaviours are related to dementia

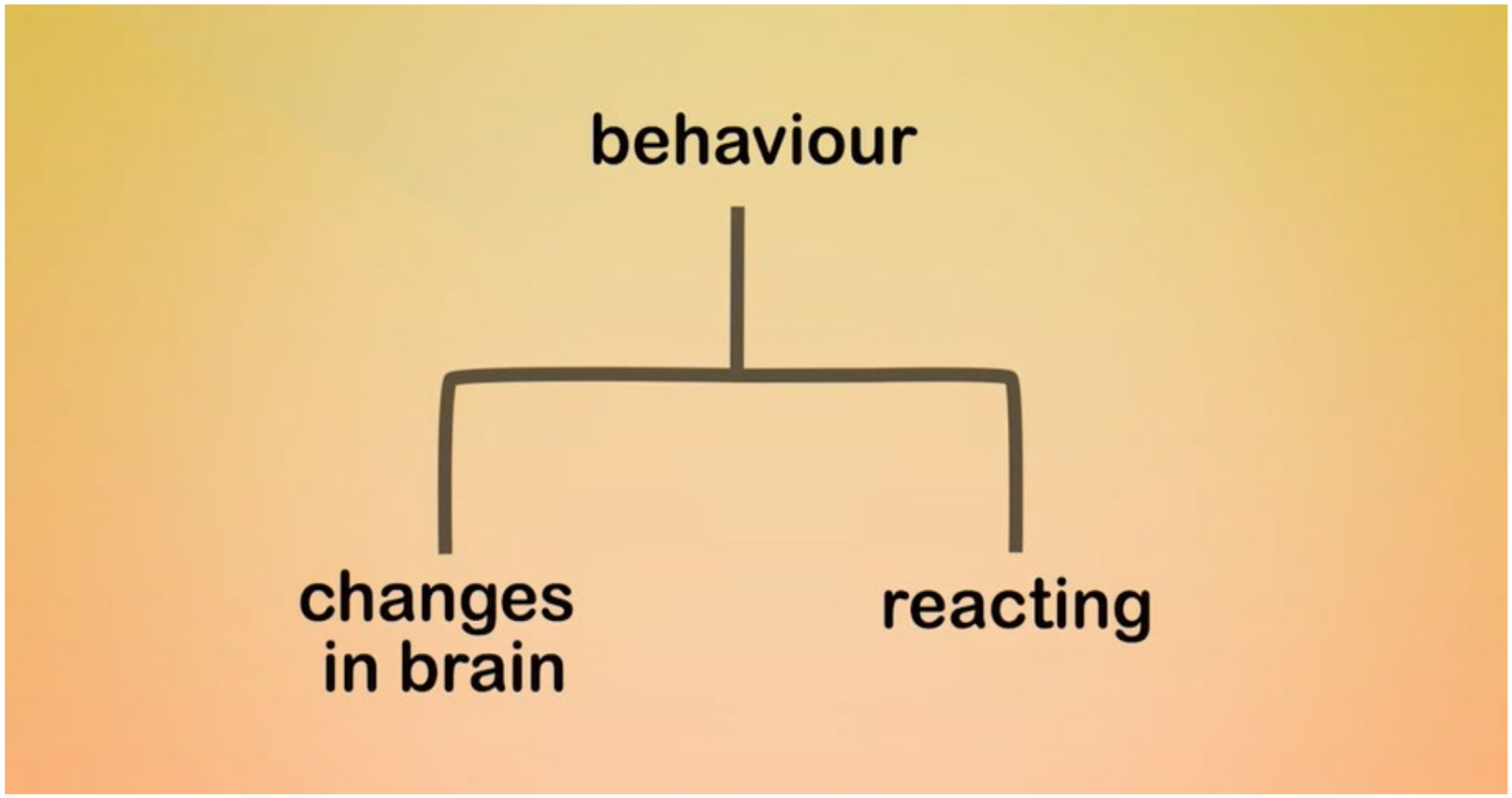
Dementia clients cannot feel pain or process pain differently

Unmet needs model

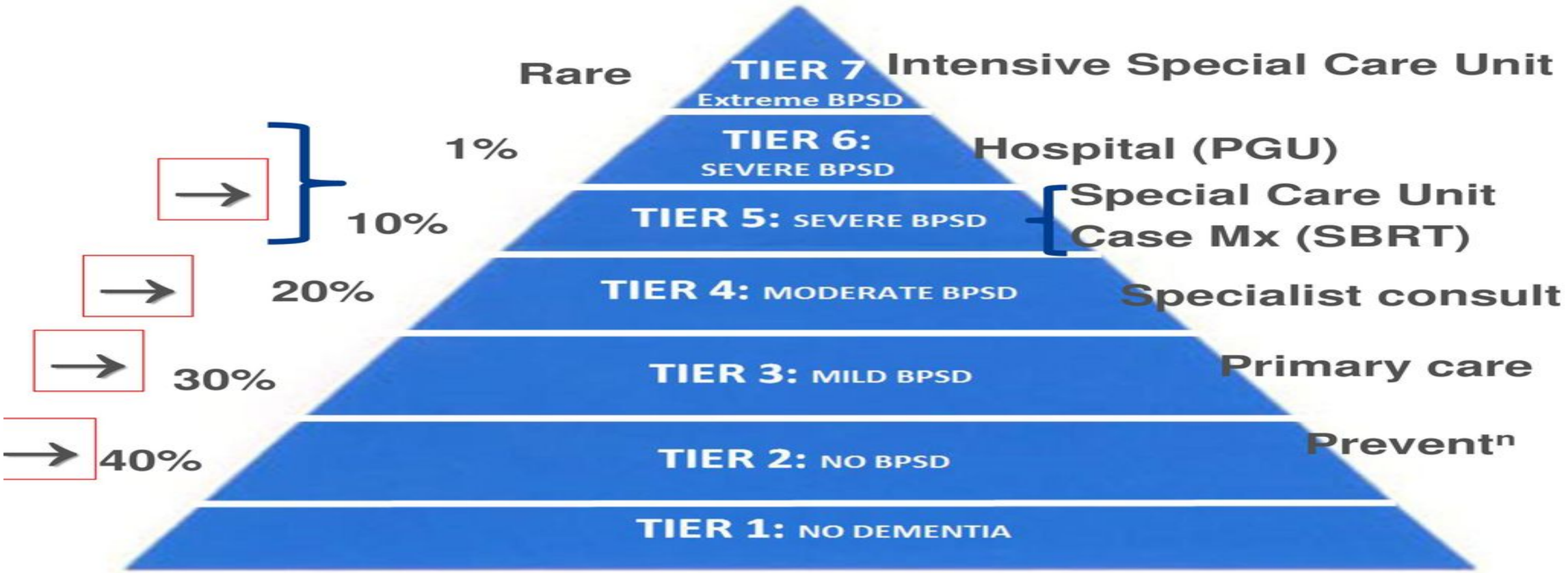
Maslow's hierarchy of needs



Changed behaviours or BPSD



Prevalence of BPSD



Brodaty, Draper & Low (2003) Behavioural and psychological symptoms of dementia: A seven-tiered model of service delivery. MJA; 178: 231–234

Psychosis

Delusions are false ideas or belief.
- Infidelity – betrayal
- Stealing – accusation
- Harming – paranoia

Misidentification
- Not recognise partner or children
- Think own reflection in the mirror is another person
- Think that voices on the TV or radio are from people in the room with them

Hallucinations are false sensations. E.g. people with dementia sees a black cat under his or her bed while others can not.

Both delusions and hallucinations can be very frightening for the person. It is so real to the person, that you will be unable to convince them otherwise.

Recommended strategies:

- Do not automatically assume they are hallucinating, investigate any suspicion the person with dementia may have which is causing them distress
- If they are happy in their reality, leave the situation alone.
- If they are distressed, acknowledge their feelings and let them know you are there to help
- Distract or divert to meaningful engagement
- Learn the person's common hiding places
- If the delusions and hallucinations persist, notify primary GP for a review

Disinhibited behaviours

Common presentations:

- Socially offensive use of language, curse words, swearing
- Inappropriately flirt with someone or make sexual comments
- Exposure or fondling
- Inappropriate urinating or faecal smearing

Possible causes:

- Changes in the brain where common and normal day to day words are lost
- Damage in frontal lobe where understanding of social rules and filter of actions are lost
- Confuse the identify of people
- Physical discomfort
- Disorientation, forgetting and the loss of skills
- Agnosia

Recommended strategies:

- Don’t over-react, brush it off
- Gently remind them their behaviour is inappropriate
- Try to divert and distract them
- Give them something to fidget with
- If in public lead them to somewhere more private

Aggression

Examples:
- Verbally threatening to hit/punch others
- Physical action of hitting out

Possible causes:
- Frustration due to restricted mobility or access
- Anger as the person can not get what he or she wants
- Fear as the person feels threatened or unsafe

Recommended strategies:
- Stop the task, take a step back and provide personal space.
- Ensure the safety of the person, yourself and others nearby, remove others if possible
- Avoid you and other staff cornering the person who shows aggression
- If in a confined space, ensure you have the exit point behind you
- Best not to attempt any form of physical contact such as restraining, leading them away or approaching from behind.
- Leave the person alone until they have recovered and re-approach.
- Look at the person in the eyes and speak slowly and softly. Use validation technique e.g. "I am sorry to see you so upset." Encourage them to talk. "Would you like to talk about it?"
- Offer the person to sit down and have some food and drinks
- Approaching the person slowly and in full view may help. Explain what is going to happen in short, clear statements such as "I'm going to help you take your coat off". This may avoid the feeling of being attacked and becoming aggressive as a self-defense response
- Check whether the aggressive behaviour is about getting what the person wants. If so, trying to anticipate needs may help.
- Activity and exercise may help prevent some outbursts.

Resistive behaviour

Common presentations:

- Uncooperative with activities of daily living such as dressing change, showering, toileting, hair/nail/oral care
- Refuse to attend GP/allied health appointment
- Deny that they have a problem with incontinence
- Not eating or inability to follow instructions

Possible causes:

- Embarrassment or insecurity about inability to remember what to do
- Frustration about loss of control over their body and life in general
- A dislike of the task that must be completed
- Pain or discomfort
- Apraxia

Recommended strategies:

- Approach the person in an upbeat way
- Change the way we prompt
- Maintain their privacy and talk to them to reduce embarrassment
- Invite the person to do things with you or seek help from the person
- Give clear and concise instruction
- Provide positive encouragement and feedback
- Promote independence and self care wherever possible
- Keep to a routine that is preferred by the person
- If further resistance occurs, leave and try again later or ask someone else to try for you.

Sun-downing
NB remember the unmet need model

Common presentations:

- More confused and restless late afternoon or early evening
- Packing and unpacking
- Exit seeking
- Become demanding and suspicious
- Attention span and concentration become more limited

Possible cause:

- Feeling tired
- Related to lack of sensory stimulation after dark
- Attempt to restore sense of familiarity or security by “going home” or “finding mother/children”

Recommended strategies:

- Establish a routine for the person
- Increase the person's exposure to natural day light
- Encourage a short nap up to 40 mins during the day
- As evening draws, darken and reduce noise
- Encourage the person to help with general tasks
- Music may be soothing
- For some a warm bath or shower may help
- Avoid restricting measures

Hoarding

People with dementia may often appear driven to search for something that they believe is missing, and to hoard things for safekeeping.

Possible causes:

- Isolation/boredom
- Memories of the past
- Loss
- Fear of robbery

Recommended strategies:

- Learn the person's usual hiding places and check there first for missing items
- Provide a drawer full of odds and ends for the person to sort out as this can satisfy the need to be busy
- Make sure the person can find their way about, as an inability to recognize the environment may be adding to the problem of hoarding

Depression

- More than 50% people living with dementia has depression
- Depression resembles symptoms of dementia, but is a treatable condition

- Main signs and symptoms include:
  - Unusually withdrawn and emotional
  - No appetite or energy
  - Losing interest in things they usually enjoy
  - Talking about self harm or suicide

Look through the behaviour

The person with dementia might be indirectly attempting to say…

“Please acknowledge me as a whole person and not only for my deficiencies and changed behaviour; for I am not in control of them. I cannot bear to constantly be reminded that I need help… that I am told when to go to the toilet; when to go to bed; when to eat and especially that I can’t go home.”

“Being treated like this has become my entire existence now, and it is absolutely soul destroying. I want to smile once more, laugh again and make light of it all. Please acknowledge me for all my beautiful human qualities, of which I still have plenty. The more you do this, the more these qualities will shine through and show the real me.”

Personal health

- Pain
- Discomfort – tight clothing, dress to the weather
- Feeling tired
- Sensory impairment
- UTI
- Dehydration
- Toileting needs
- Medication changes

Using a problem-solving approach

- What was happening right before the behaviour occurred?
- Who was involved?
- Who was affected by the behaviour?
- What was done about it? And did it work?

- When looking for triggers, five factors to consider:
  - Health
  - History
  - Environment
  - Task
  - Communication

History

- know who they are as a person
- the life they have led and prefer
- To know what is meaningful and of value to them, for an enhanced quality of life.

- Short term memory is affected before long term memory
- Confuse their present with their past
- Not recognizing current home or family members
- Mistaken a staff member with a family member
- Believe they live in a different time of their lives

Environment

- Loud noise
- Clutter
- Over-stimulated activity
- Poor lighting - shadows
- Mirrors
- Items that do not contrast in colour

Task

- Complex tasks can be overwhelming – step by step
- Encourage involvement
- Demonstrating, don’t force, and avoid correcting
- Simplify tasks or have tasks modified to match the person’s strength and abilities
- Refer to whiteboard/communication board for plans and appointments
- Staff visiting – introduce yourself, where you from, why you are here; read the person’s care plan before-hand and know what you need to do to support the person with dementia; and avoid asking them confusing questions

Communication

- Consider environmental noise
- Slow down verbal communication
- Break tasks down into small steps
- Instructions should be delivered clearly and concisely.
- Positive body language is important, gestures should match what is being said.
- Visual cues may help a person with dementia to identify what they need or want.
- Maintain privacy during personal care.
- Encourage independence and self-care wherever possible.
- Talk to the person throughout the task.
- Give no more than two choices at a time.

General communication strategies

- Identify triggers to negative behavioural exacerbations
- Any inappropriate behaviour should be recognised as a symptom of dementia and may be difficult not to take personally
- Communicate quietly and calmly
- Smile, look at the person in their eyes, get down to their level, and speak slowly
- Allow the person time to respond and encourage them to tell you more
- Actively listen to what is being said and acknowledge the person's emotions
- Avoid conflict by listening to the person's perspective whenever possible
- Getting to know the person, their life story, likes and dislikes, personal strength
- Encourage engagement and enablement by focusing on the person's strength and goals
- Find out the memories the person have successfully retained and talk about these with them
- Avoid treating the person with dementia like children
- Use distraction only after empathetically listening and addressing concerns
- Effective communication –Early stage – reality orientation; Moderate to advanced stage – validation technique; reminiscence; Join them in their world
- Music therapy has been successful with behavioural changes through all stages of dementia

What annoys them most about living with dementia?

[Link]

Summary

- Communication – 55% body language, 38% tone and 7% words

- Early stage – reality orientation

- Moderate-advanced stage
  - validation e.g. doll or soft pet therapy
  - Reminisce
  - Join them in their world

- Music

- Touch

- A solution works for one, may not work for others

- Same strategy may not work all the time

- Team discussion, problem solving and trial new

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