Supporting people living with dementia to remain socially connected

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ACKNOWLEDGEMENT OF TRADITIONAL OWNERS

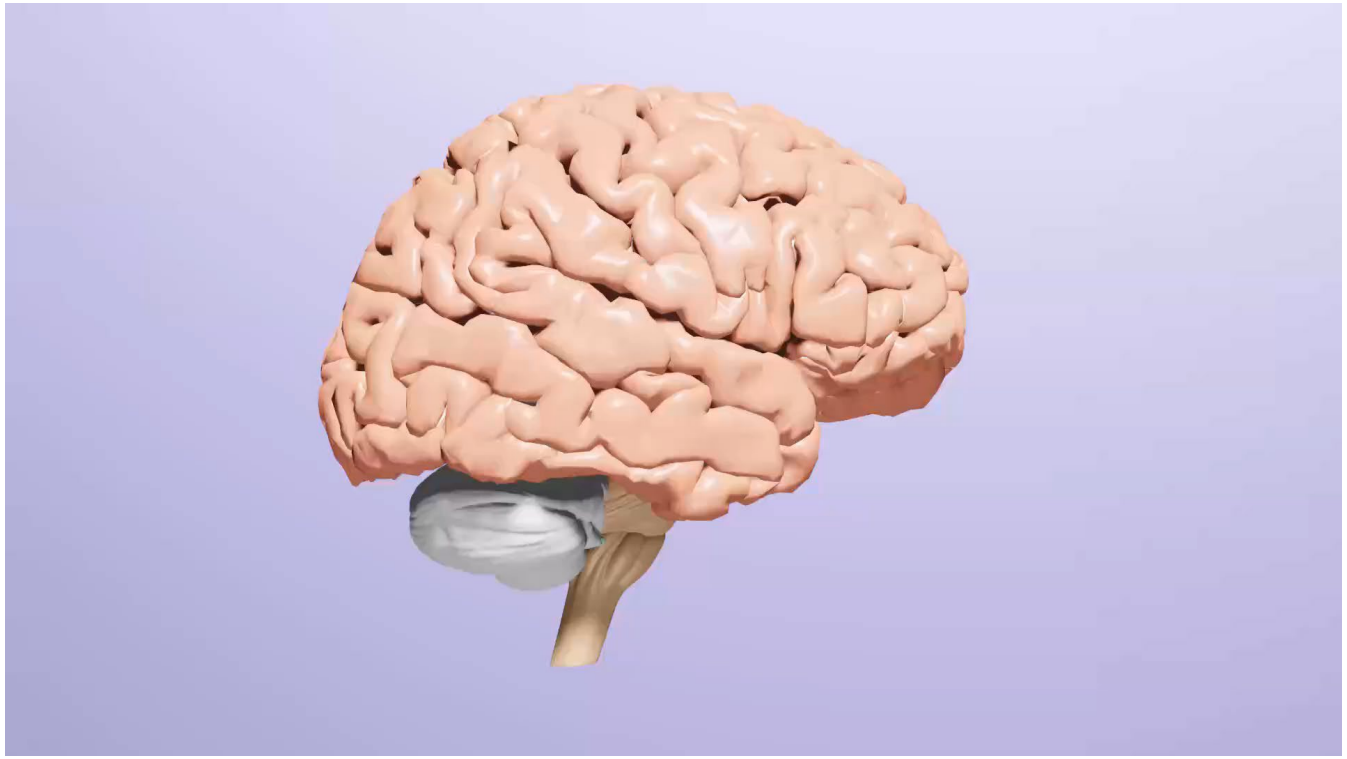
QUT acknowledges the Turrbal and Yugara, as the First Nations owners of the lands where QUT now stands. We pay respect to their Elders, lores, customs and creation spirits. We recognise that these lands have always been places of teaching, research and learning.

QUT acknowledges the important role Aboriginal and Torres Strait Islander people play within the QUT community.

Objectives

- Understand why people living with dementia can become socially isolated.
- Explore practical approaches to supporting people with dementia to remain socially connected.
- Be prepared for the potential of a person with dementia becoming lost.

The Brain



- Whole brain
- Frontal lobe
- Occipital lobe
- Parietal lobe
- Temporal lobe
- Brain stem

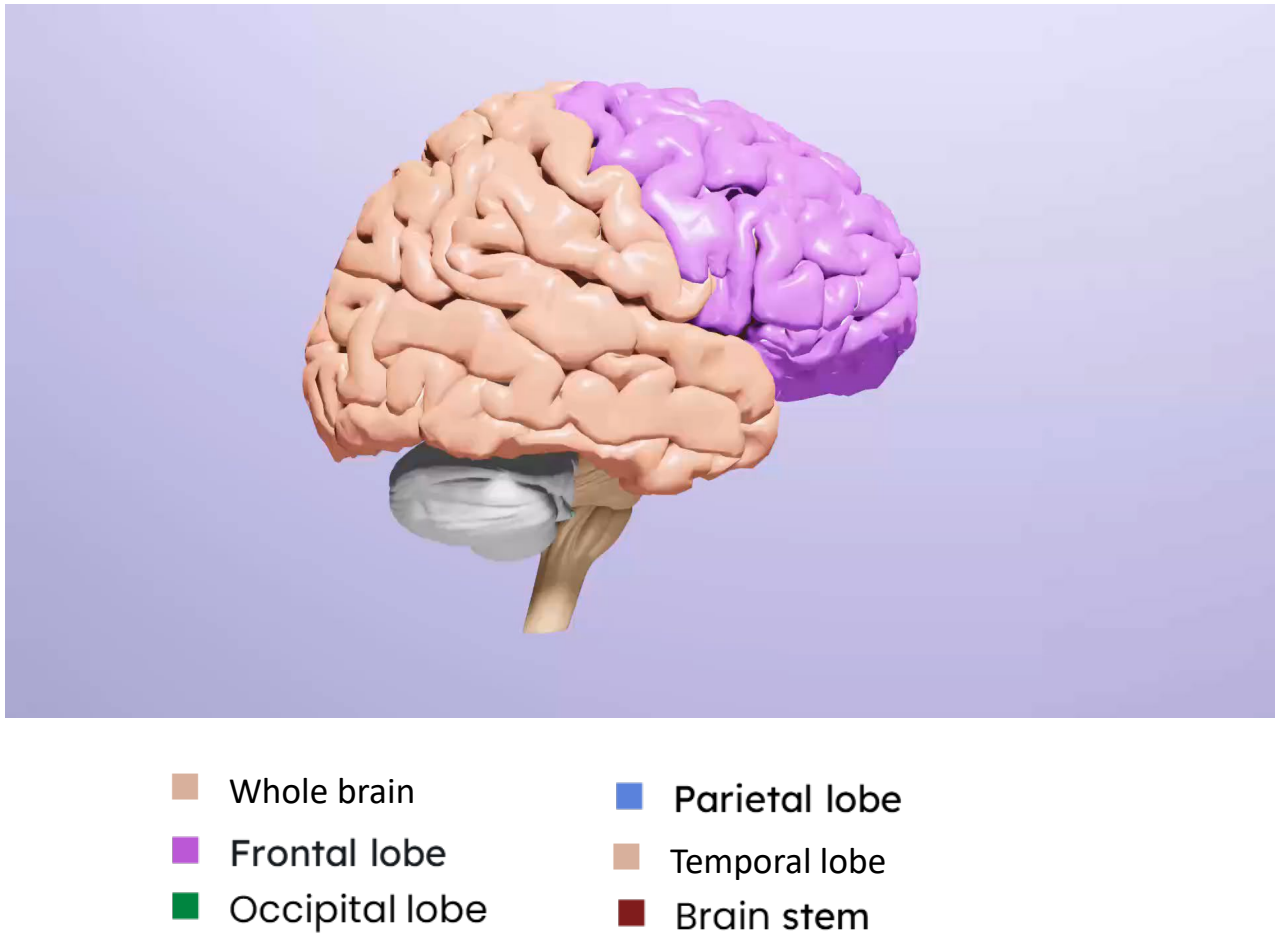
Functional Areas of the Brain

Frontal lobe

This lobe is responsible for higher cognitive functions involving planning, organising and problem solving. Also, ability to start and stop actions and regulating social behaviour.

Damage may cause:

- Changes to personality
- Disinhibited behaviour
- Inability to initiate or to stop activities
- Difficulties with problem-solving



Functional Areas of the Brain

Temporal lobe

This lobe plays a vital function in learning and memory (verbal and visual), perception and recognition.

Damage may cause:

- Difficulties in understanding speech, recognising faces and objects
- Long and short-term memory loss
- Difficulties learning
- Inappropriate social responses

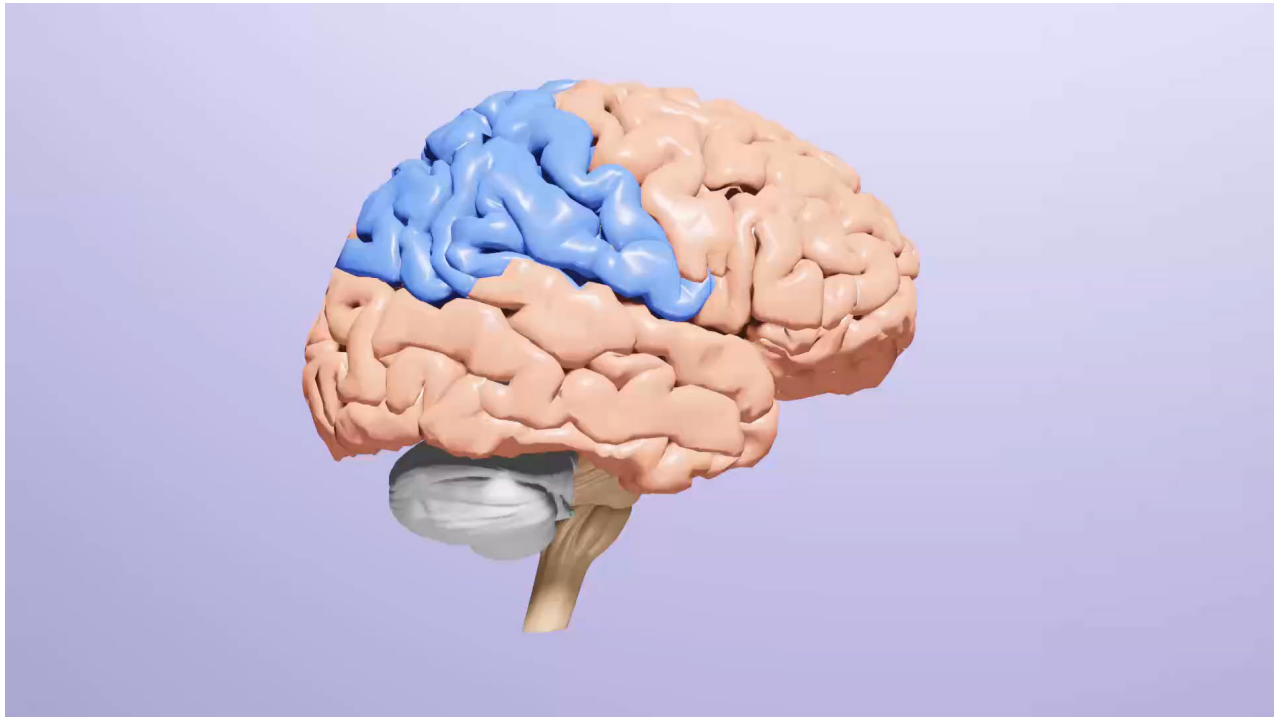
Functional Areas of the Brain

Parietal lobe

Processes information to create an understanding of ourselves and the world around us.
Also, involved in language, body awareness and perception.

Damage may cause:

- Inability to locate and recognise objects
- Disorientation – position and gait
- Difficulties with visuo-spatial skills
- Word-finding skills and language difficulties.



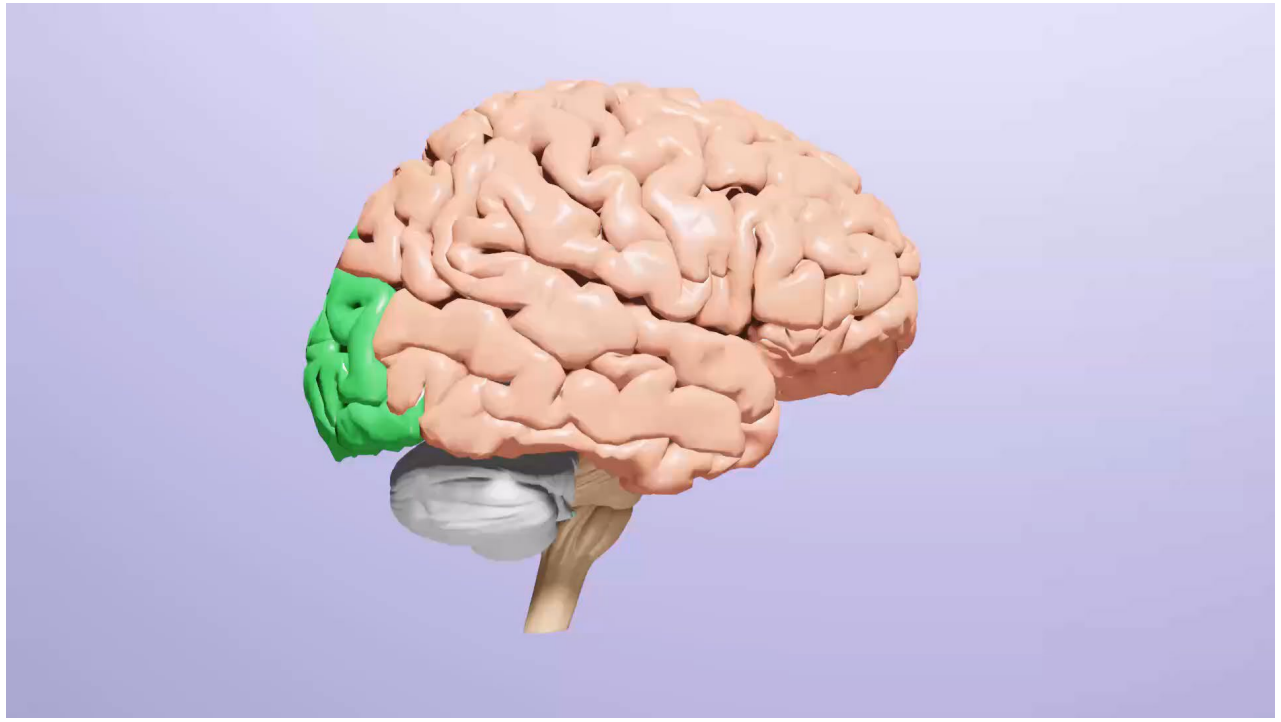
Functional Areas of the Brain

Occipital lobe

This lobe encodes visual information received by the eyes and connects to the temporal and parietal lobes.

Damage may cause:

- Hallucinations
- Blindness
- Inability to see colour or motion



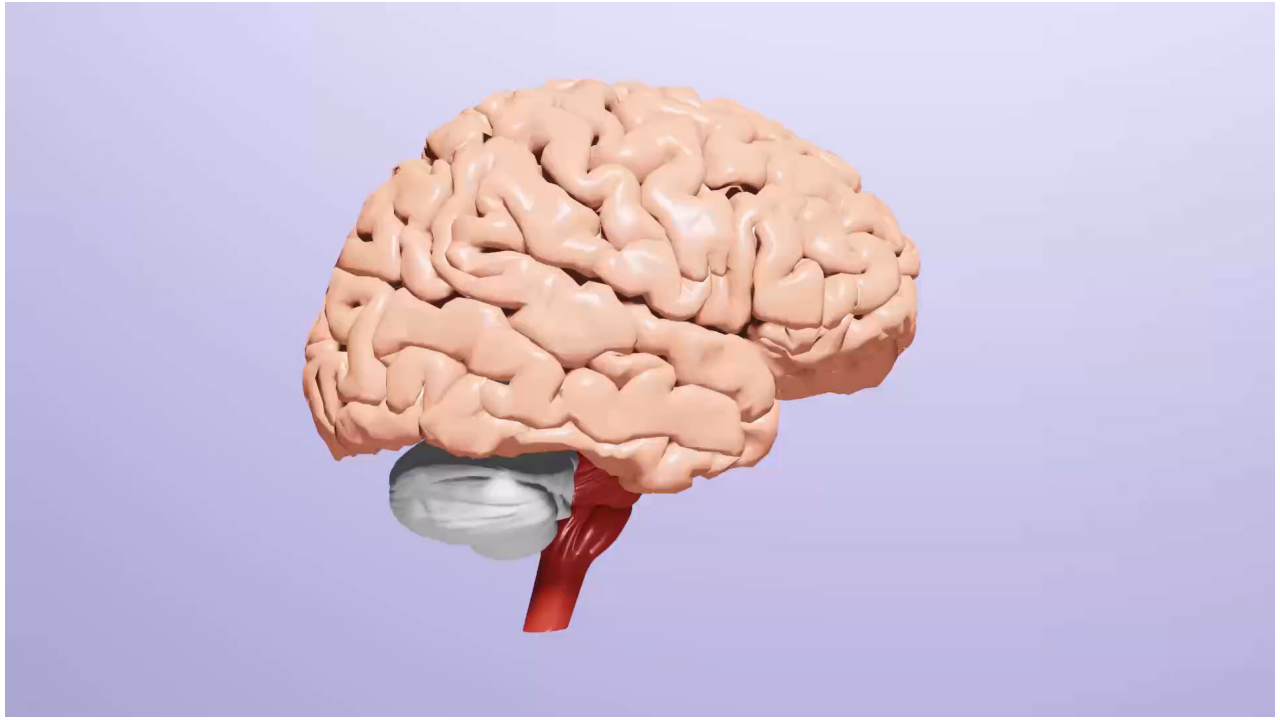
Functional Areas of the Brain

Brain stem

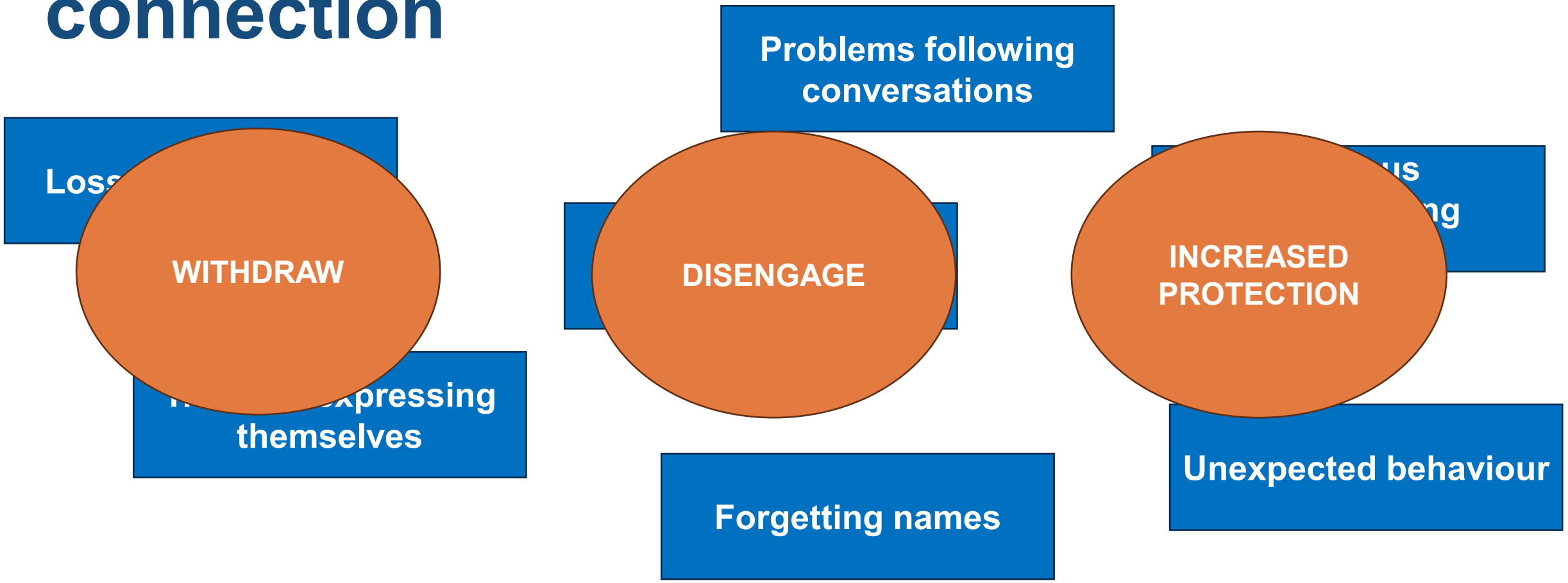
Is located at the base of the skull and includes the midbrain, pons and medulla oblongata. The brainstem is involved in muscle movement, balance and breathing, heart rate and swallowing.

Damage may cause:

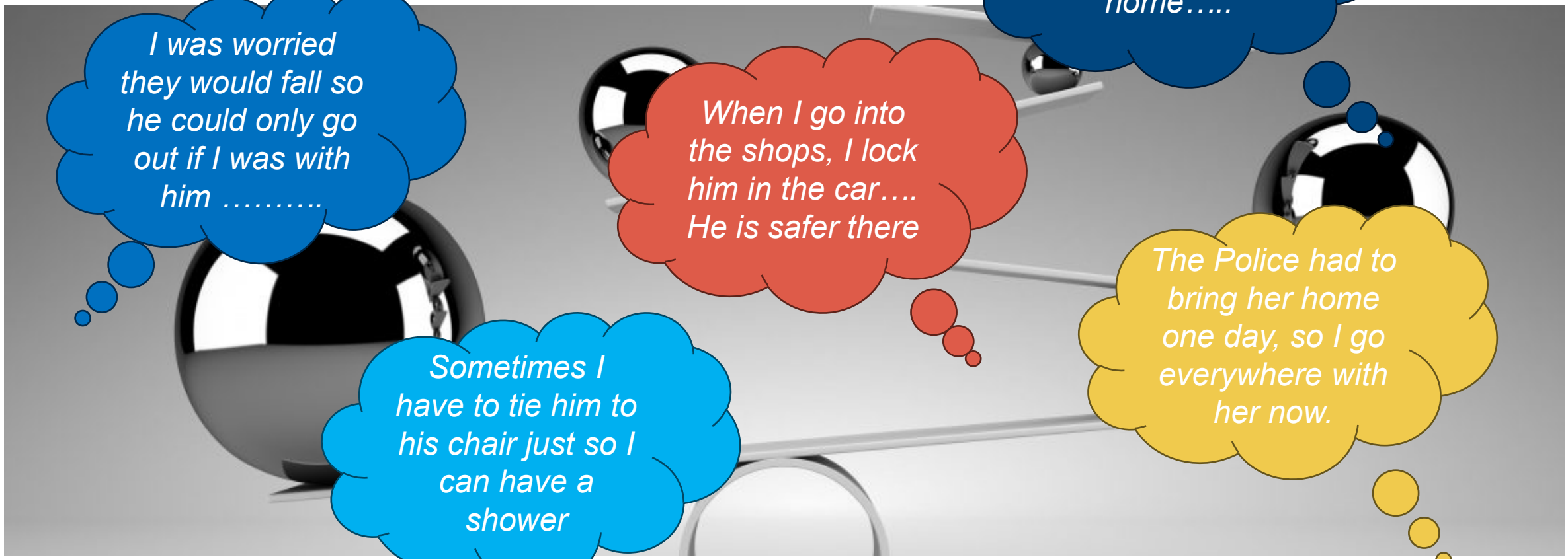
- Problems with short to long memory
- Navigation problems
- Muscle rigidity
- Difficulties with movement/falls
- Difficulties with breathing, swallowing and heart rate.



Impact of brain changes on social connection



Safety vs Autonomy



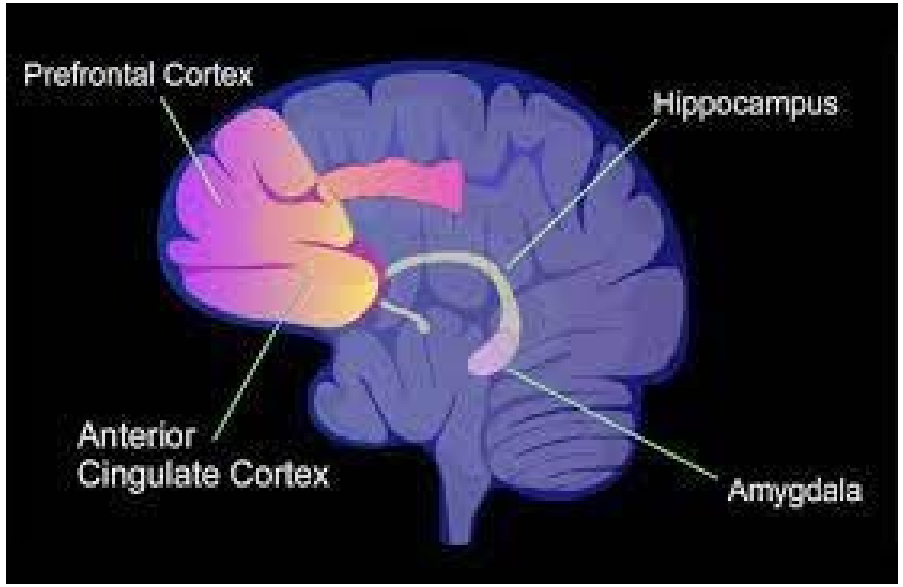
Missing with dementia

- People with dementia getting lost is a global phenomenon – damage to the brain impedes navigation
- 60% of people with dementia will experience getting lost at some point in time (Aud, 2004)
- In Queensland 1 land search per week involves a person living with dementia
- Around 1 in 5 missing persons with dementia will not be found alive (MacAndrew et al, 2018)

Areas of the brain needed to navigate

Prefrontal Cortex – Thinking, planning and imagination

Basal Forebrain – memory and attention

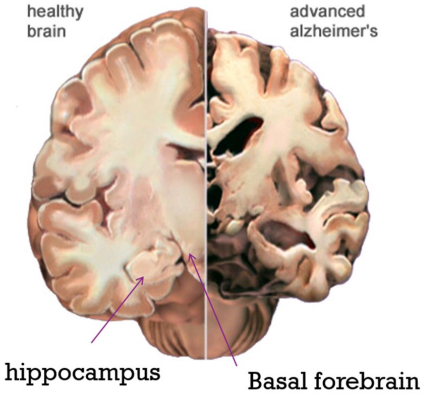


Hippocampus/ Amygdala – short term memory and spatial memory

Image Source: https://www.psypost.org/2017/03/study-gps-navigation-switches-off-parts-brain-otherwise-used-48464

What happens to the brain with Alzheimer's disease (AD)

- Most common cause of dementia – 70% of people with dementia have AD
- More common in older people
- Brain is damaged by plaques and tangles
- Areas of the brain impacted → symptoms experienced



Hippocampus – short term memory and spatial memory

Where was I going?

Cortex – Thinking, planning and imagination

How do I get there? *That doesn't look familiar!!*

Basal Forebrain – memory and attention

What was I doing? *Rainbow Beach looks lovely.*

Where am I?

Factors contributing to the problem

Data sources: Literature reviews, national survey, public consultation, interviews with lived experience experts:

- Lack of awareness of the risk and what to do: Surveyed health professionals (246), family carers (137) and general public (107) - > **50% did not know when to report a missing person.**
- Current assessments do not consider the full scope of wandering characteristics or risk of getting lost
- Health services do not routinely have a Missing Persons Procedure or staff do not know what it is.
- Delays in involving Police in the search for a missing person with dementia reduces the potential of finding them alive.

3Ps to GHS with dementia: Intervention

Prepare

- Raise awareness of risks associated with wandering and getting lost → **Education & Training**

Prevent

- Risk assessment and risk reduction care plan

Prompt Response

- **Missing Persons Procedure** for health care services

Prepare

- Raise awareness of the risk – everyone needs to know
  - Is that person in the right place?
  - Do they look distressed?
  - Are they dressed for the situation/conditions?
  - Are they wearing a hospital ID or gown?

- Don’t be afraid to offer them help.
- Know what to do when you are notified someone is missing

AI-generated image created by Microsoft Copilot. (2025). *Older person walking outside in pyjamas*. Generated on July 25, 2025.

Prevent

- Risk factors for getting lost:
  - Diagnosis of dementia and able to walk independently
  - Male with Alzheimer's disease
  - More severe cognitive impairment BUT can occur early in disease
  - A previous getting lost event without additional safety mechanisms
  - Most go missing from home

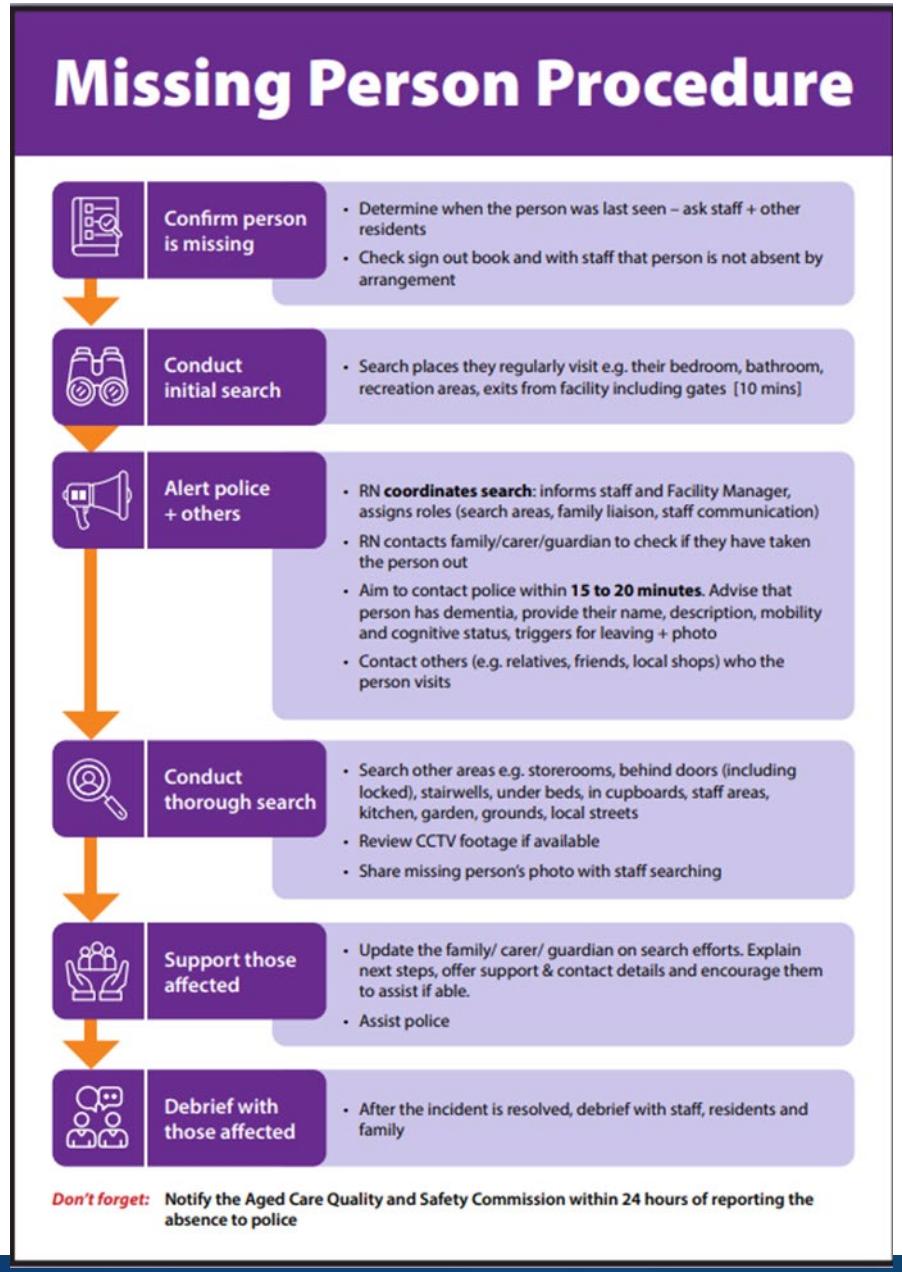
Early and ongoing assessment of risk → person centred care strategies to ↓ risk

Strategies to support safe walking – stay connected

- Aim to support safe walking:
  - Be aware of where they are going and when you expect the person home
  - If possible, ensure they are dressed appropriately
  - May remember to carry a phone
  - Consider GPS tracking – with caution
  - Consider Medic Alert
  - Ensure you share the strategy with the care network
  - Walk with them or join a walking group – consider respite care
  - Grow your social network - Let trusted members of your community know
- There is no fail-safe answer - Be prepared for the worst

Prompt response

- If you are worried about a person's safety – call the Police
- Tell Police they have dementia
- They will need a current photo and as much information about the person as possible:
  - What they were wearing
  - When and where you last saw them
  - Where they usually walk to
  - Places they often talk about
  - Medications, triggers for changed behaviour, preferred communication style



How you can help with a search.

- If it doesn't look right stop and ask – Can I help you?
- Look for a Medic Alert or other ID
- Who do you call – Police or Ambulance?
- If you get a text message from Police – look around your property and neighbourhood – under bushes and buildings
- A smile and a cup of tea go a long way!!!

Take home messages

- As the symptoms of dementia progress, a person's world get smaller.
- It can be challenging to balance safety and autonomy – fewer social connections.
- Mobile people with dementia are at risk of getting lost – safety mechanisms can restrict autonomy.
- Aim to support safe walking but be prepared
- If a person with dementia is missing – do a quick search of the immediate area, then call Police – let them know they have dementia
- Help to create dementia inclusive environments that support the person with dementia to remain connected.

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References

Aud, M. A. (2004). Dangerous wandering: elopements of older adults with dementia from long-term care facilities. *American Journal of Alzheimer's Disease & Other Dementias®*, *19*(6), 361-368.

MacAndrew, M., Schnitker, L., Shepherd, N., & Beattie, E. (2018). People with dementia getting lost in Australia: Dementia-related missing person reports in the media. *Australasian Journal on Ageing*, *37*(3), E97-E103.