

# THE ROLE OF DEMENTIA FRIENDLY COMMUNITIES IN GETTING PEOPLE WITH DEMENTIA HOME SAFELY

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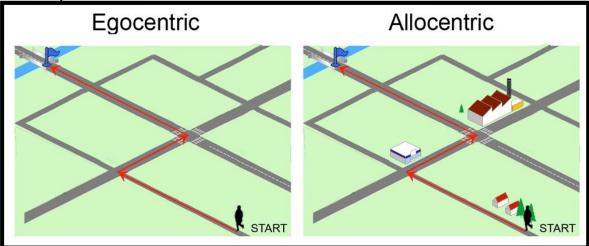


#### **HOW DO WE NAVIGATE?**

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- Allocentric navigation spatial map relying on landmarks
  - Uses the medial temporal lobe of the brain especially the hippocampus
- Egocentric navigation navigation in relation to distance in relation to body position

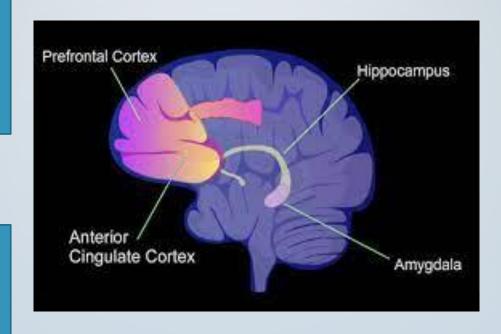
Dependant on parietal cortex



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Prefrontal
Cortex –
Thinking,
planning and
imagination

Basal
Forebrain –
memory and
attention



Hippocampus
/Amygdala –
short term
memory and
spatial memory

## 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 termmemory andspatial memory

Cortex – Thinking, planning and imagination

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

hippocampus Basal forebrain

**Basal Forebrain** – memory and attention

Where was I going?

What was I doing? Rainbow Beach looks lovely.

Image source: https://www.researchgate.net/figure/The-Healthy-Brain-left-and-the-Alzheimers-Brain-right\_fig1\_5261932

### WHO IS AT RISK OF GETTING LOST?

- People with dementia who are able to **mobilise independently** walk, drive, scooter, wheelchair
- > Those with AD more at risk dependant on area of brain impacted
- Males

NEWS > WA NEWS

- ➤ Risk increases as dementia progresses but can occur in early stages no failsafe prevention
- ➤ Has previously experienced a getting lost event lost in their home, at the shops, on the way to the coffee shop.......

Missing WA grandmother, 83, with dementia found after two days lost in bush

Elderly Keilor woman, 81, living with dementia, located after widespread search

Lucy Mae Beers • TNEWS Published: 12/07/2021 • Updated: Monday, 12 July 2021 5:13 PM AEST

Anna Hay and Pip Christmass • TNEWS

Published: 10/09/2021 • Updated: Friday, 10 September 2021 10:04 PM AEST

#### 7 GETTING THE BALANCE RIGHT



Meaningful engagement with community/networks

No Safety Support



Loss of autonomy

### HOW BIG IS THE PROBLEM IN AUSTRALIA?

- 130 people with dementia reported missing in the newspaper in 2011-2015
- Mean age 75 years old
- 74% were men
- 92 cases had outcomes reported

#### (34 cases outcomes not reported)

- 79% were found alive
- 20% were seriously injured
- 21% were deceased

### Updated numbers from SAR Queensland (2020-21):

53 land searchers involved a person with
dementia ~ I/week
89% went missing from home, I I% from a
nursing home
Police search hours = 776 hours; volunteer
searchers = approx. 9,000 hours
Only 3 people were found deceased – 6%
(18% in 2019)

### WHAT IS KNOWN ABOUTGETTING LOST EVENTS

#### Common patterns of getting lost events:

- Found within I-5km of last known location → SAR search protocol
   initiated if aware of risk
  - Often found in dense bush or buildings → Thorough search of immediate area including under obstacles
- Those living at home at greater risk of not being found alive → Be aware
   of the risk and consider strategies
- Delay in starting a search > 6-12 hours increases risk of not being found alive → Raise the alarm after quick search of immediate area

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.



### FACTORS CONTRIBUTING TO THE PROBLEM: LACK OF AWARENESS

 Surveyed health professionals (246), family carers (137) and general public (107)

Question: How long are you required to wait before reporting a missing person to Police?

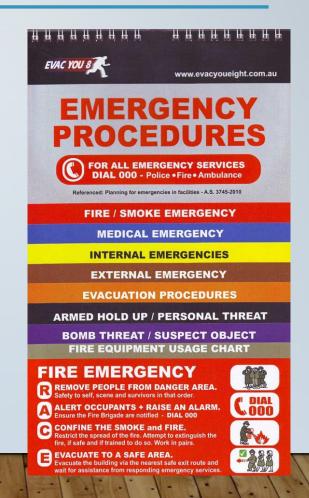
- Over 15% of care partners and 38% of general public would wait 24 hours
- 25% of health professionals did not know.

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In Australia we not need to wait to inform Police

# FACTORS CONTRIBUTING TO THE PROBLEM: RISK IS NOT ASSESSED AND NO MISSING PERSON PLAN

- Risk of getting lost not routinely assessed – care planning is not focused on risk reduction. Hit and miss!!!
- Limited health services have a missing person policy
- Over 50% of health professionals did not know what to do



#### 14 HOW CAN WE DO THIS DIFFERENTLY?

- Strategies to prevent people with dementia getting lost
- Approaches to responding to a missing person report
- Online discussion forums November 2020



6 Police/emergency services



13 professional carers



15 care partners



12 general public

### STRATEGIES FOR KEEPING THE PERSON WITH DEMENTIA SAFE

- Need to raise awareness of the risk
  - Public education campaign
  - Targeted education programs for everyone
- Early and continued assessment of risk factors
  - Implement strategies to reduce risk
- Health services have a policy for monitoring
  - Identification of those at risk of getting lost e.g. ID band, special clothing
  - Respond to alarms
  - Up to date photo and details of the person
- GPS surveillance, alarms, environmental changes, CCTV only as reliable as the technology
- Meaningful engagement
- Notify your community about the risk
- Have Missing person response policy and drills to practice
  - All staff and families to be aware of these



### WHAT DID THE EXPERTS THINK ABOUT THESE RECOMMENDATIONS?

Interviews with 10 people living with dementia in Australia

Need to raise awareness of the risk



Early and continued assessment of risk factors



Health services have a policy for monitoring



GPS surveillance, alarms, environmental changes, CCTV



Meaningful engagement



Notify your community about the risk



Have Missing person response policy and drills to practice



Silver Alert / Purple Alert / Vulnerable persons registry



Police should refer the person for additional support after a getting lost event



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## THE TOP THREE ACTION ITEMS TO IMPROVE SAFETY & AUTONOMY

**PREPARE** 

- Be aware of risk and notify family/community
- Current photo and medical information on hand
- Wear a Medic Alert: diagnosis of dementia + independently mobile



**PREVENT** 

- Identify potential risk factors → respond
- Continued engagement in meaningful activity and community
- Consider technology e.g. GPS tracking, SMART homes, alarm system
- No fail-safe prevention for getting lost



PROMPT RESPONSE

- Have a plan and know what that is Missing persons policy
- Search immediate area → Ring 000
- Tell the operator that person has dementia/memory problems  $\rightarrow$  SAR involvement
- Provide Police details about missing person

### 18 HOW DEMENTIA FRIENDLY/INCLUSIVE COMMUNITIES' HELP

- Members of the community understand what dementia
   is and how it impacts a person reduce stigma
- Dementia inclusive environments Visual cues to aid navigation, toilets visible and easily accessible
- The public becomes more responsive to need: Raise
   public awareness of the risk Should this person be here?
   Can I help you?



Increase understanding and tolerance

Decrease stigma

Promote independence

#### 9 RESPONDING TO THE RISK

- Increase safety measures balance autonomy and safety
  - Family carers need support
  - Potential to use additional services
- Assess walking habits When, where, how much
  - Look at the rhythm of walking and plan care around peak activity times
  - Consider past activity habits has this changed
- Plan care to meet the risk profile

## HELPING SOMEONE WHO MAY BE LOST

The person may take time to process what you are saying

The person may not be able to respond to you

The person may not know they are lost

They might be very frightened

Consider your body language - keep an open and friendly posture – don't be intimidating

Keep your communication simple and allow time to process

Look for a Medic Alert bracelet or phone or label on clothing 21

## WHAT INFORMATION DO POLICE NEED?

- Full and preferred name, DOB, Age, ethnicity, current address
- Previous addresses and employment details
- Places of interest usual walking track, café.....
- Habits and hobbies
- General description & CURRENT PHOTO
- Where they were last seen and what were they wearing
- What do they have with them phone, wallet....
- If they have been lost before where did they go
- Medical issues medications, hearing, vision impairment, dementia/memory issues
- Any other information that may help

Perth | WA New

Safe & Found WA: New database to help locate missing vulnerable people in WA officially launched

Daryna Zadvirna | The West Australian Thu, 12 August 2021 5:24PM | ■ Comment



Let Police know the person has dementia

#### 22 TAKE HOME MESSAGES

- People with dementia are at greater risk of getting lost depends on area of the brain damaged
- Males with AD, who can mobilise independently and have been lost before are most at risk.
- Important to maintain autonomy and connection to community BUT be aware of safety
- No failsafe way of stopping a getting lost event can happen early in the disease process – Prepare, Prevent, PROMPT RESPONSE
- If worried search immediate environment and call Police

### IT IS NEVERTOO EARLY TO REPORT A MISSING PERSON WITH DEMENTIA TO POLICE

131 444 OR 000

#### 23 WHERE TO FIND MORE SUPPORT



National peak body for dementia training: courses, practical resources and training packages that are easy to access and can help make a real difference in your workplace https://dta.com.au/



National peak body for people living with dementia, their families and carers and provides leadership in policy and services. We provide information, education, counselling and support to people living with dementia and families and carers of people with dementia. https://www.dementia.org.au/

Dementia Support Australia Accredited consultants provide advice and recommendations to people who care for someone with dementia whose behaviours are a risk to themselves or others. https://www.dementia.com.au

