DCRC
Dementia Centre for Research Collaboration

ONLINE SYMPOSIA 1
Friday 18th June 2021
10am – 12.30pm (AEST)

Dementia Training Australia

Disinhibited Behaviours and Dementia

CHAIRS & EXPERT PANEL

Professor Elizabeth Beattie
DCRC Director, QLD
University of Technology

Dr Nadeeka Dissanayaka
University of Queensland

SPEAKERS & EXPERT PANEL

Theresa Flavin
Dementia Advocate

Marie Alford
Head of Dementia Services
The Dementia Centre

Kate Hawkins
Project Manager
Anglicare

A/Prof Cindy Jones
Researcher
Bond University

Dr Margaret MacAndrew &
Professor Elizabeth Beattie
Queensland University of Technology

Event recording will be available here:
https://tinyurl.com/4kkjbyu5

For more information on DCRC visit www.dementiaresearch.org.au

Australian Government
National Health and Medical Research Council

Changed Behaviours Special Interest Group
ONLINE SYMPOSIUM 1 PROGRAM
DISINHIBITED BEHAVIOURS IN DEMENTIA
Friday 18th June 2021, 10am – 12.30pm AEST

The symposia will be recorded for broad circulation.
Data or information that is not ready for wide circulation will be censored from the recording before distribution.
https://dementiaresearch.org.au/projects/sig-changed-behaviours/

Time	Action and speakers
10:00am – 10:05am (5 minutes)	**Claire Burley** - General housekeeping - Introduce DCRC Changed Behaviours Special Interest Group (SiG) and Dementia Training Australia (DTA), Introduce Co-Chairs
10:05am – 10:10am (5 minutes)	**Professor Elizabeth Beattie,** Director DCRC and DTA (QLD), Queensland University of Technology - Welcome
10:10am – 11:15am	**Session 1: Expert presentations part 1** SESSION CHAIR: Professor Elizabeth Beattie, Director DCRC and DTA (QLD)
10:10am – 10:30am (20-min talk)	Presenter 1 – **Theresa Flavin**, Dementia Advocate (Speaking freely followed by interview style) Talk Title: *Personal experience of disinhibited behaviours and dementia*
10:30am – 10:50am (20-min talk)	Presenter 2 – **Marie Alford**, Head of Dementia Services Affiliation: The Dementia Centre and Dementia Support Australia Talk Title: *Behind the behaviour: What is really going on and what can we do?*
10:50am – 11:10am (20-min talk)	Presenter 3 – **Priyanka Titus (on behalf of Kate Hawkins),** Project Manager, Specialist Dementia Care Program Affiliation: Anglicare Talk Title: *"Nana you can't say that!"*
11:10am – 11:15am (5 minutes)	**5-minute Q&A for presenters 1-3** Moderated by Professor Elizabeth Beattie

Email: c.burley@unsw.edu.au
Address: DCRC, UNSW Sydney, Level 3, AGSM Building, Gate 11, Botany Street, Kensington, NSW 2052, Australia

11:15am – 11:20am (5 minutes)	*Break for 5 minutes*
11:20am – 12:05pm	**Session 2: Expert presentations part 2** SESSION CHAIR: Dr Nadeeka Dissanayaka, University of Queensland
11:20am - 11:40am (20-min talk)	Presenter 4: **A/Prof Cindy Jones**, Associate Professor of Behavioural Sciences Affiliation: Bond University Talk Title: *Disinhibited behaviours: Negative mind to positive response*
11:40am - 12:00pm (20-min talk)	Presenter 5: **Dr Margaret MacAndrew** Affiliation: Queensland University of Technology Talk Title: *Changed awareness of social behaviour*
12:00pm – 12:05pm (5 minutes)	**5-minute Q&A for presenters 4 and 5** Moderated by Dr Nadeeka Dissanayaka
12:05pm – 12:20pm (15 minutes)	**EXPERT PANEL DISCUSSION & AUDIENCE Q&A (all speakers & chairs)** ***'Where do we need to go next with dementia care, research and policy focused on disinhibited behaviours in dementia?'*** Moderated by Professor Elizabeth Beattie, DCRC Director (QUT) / Drs Claire Burley & Nadeeka Dissanayaka
12:20pm – 12:30pm (10 mins)	Dr Claire Burley – Summary and future directions – Close symposium

Email: c.burley@unsw.edu.au
Address: DCRC, UNSW Sydney, Level 3, AGSM Building, Gate 11, Botany Street, Kensington, NSW 2052, Australia

DCRC Changed Behaviours Symposia & Workshop 2021

Behind the behaviour: What is really going on and what can we do?

Marie Alford, Head of Dementia Centre Services

DSA: Who Are We?

Dementia Support Australia

=

DBMAS

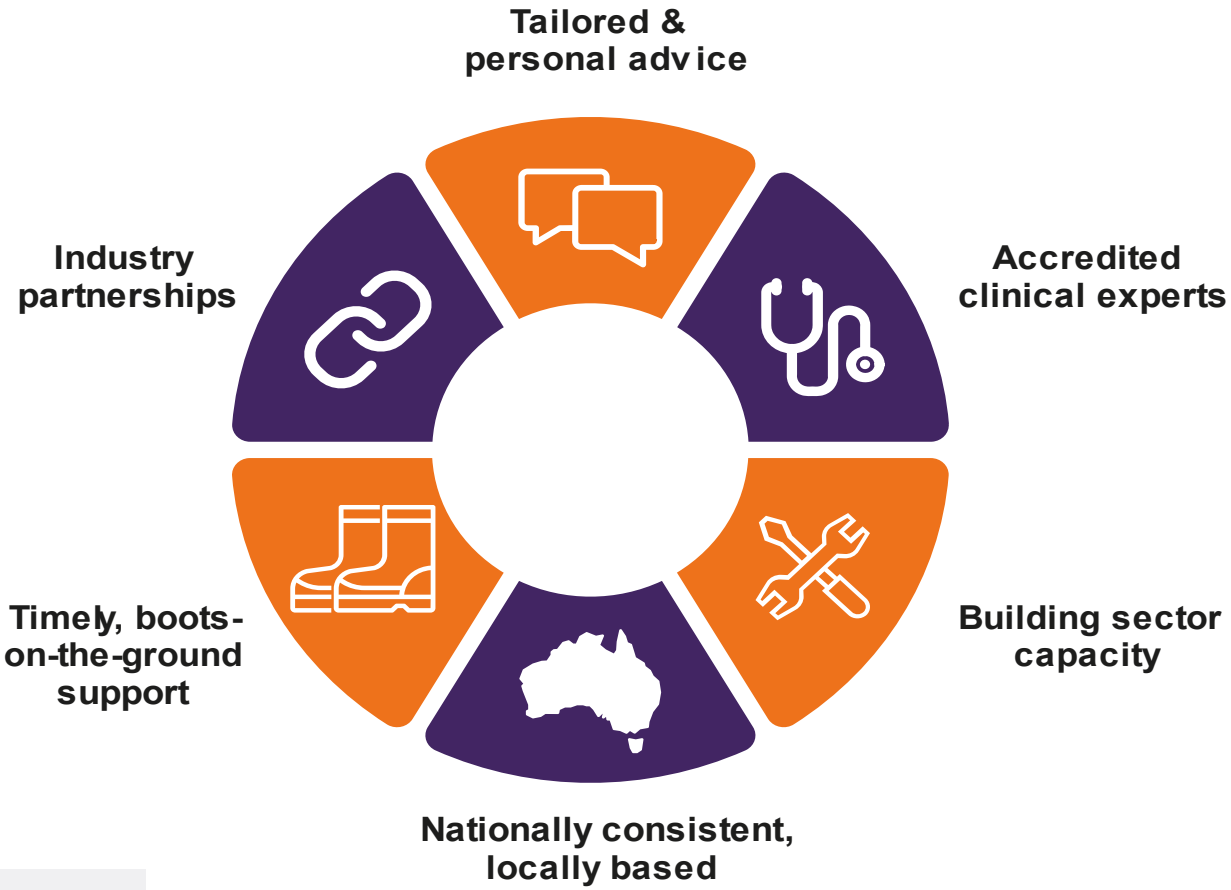
+

SBRT

+

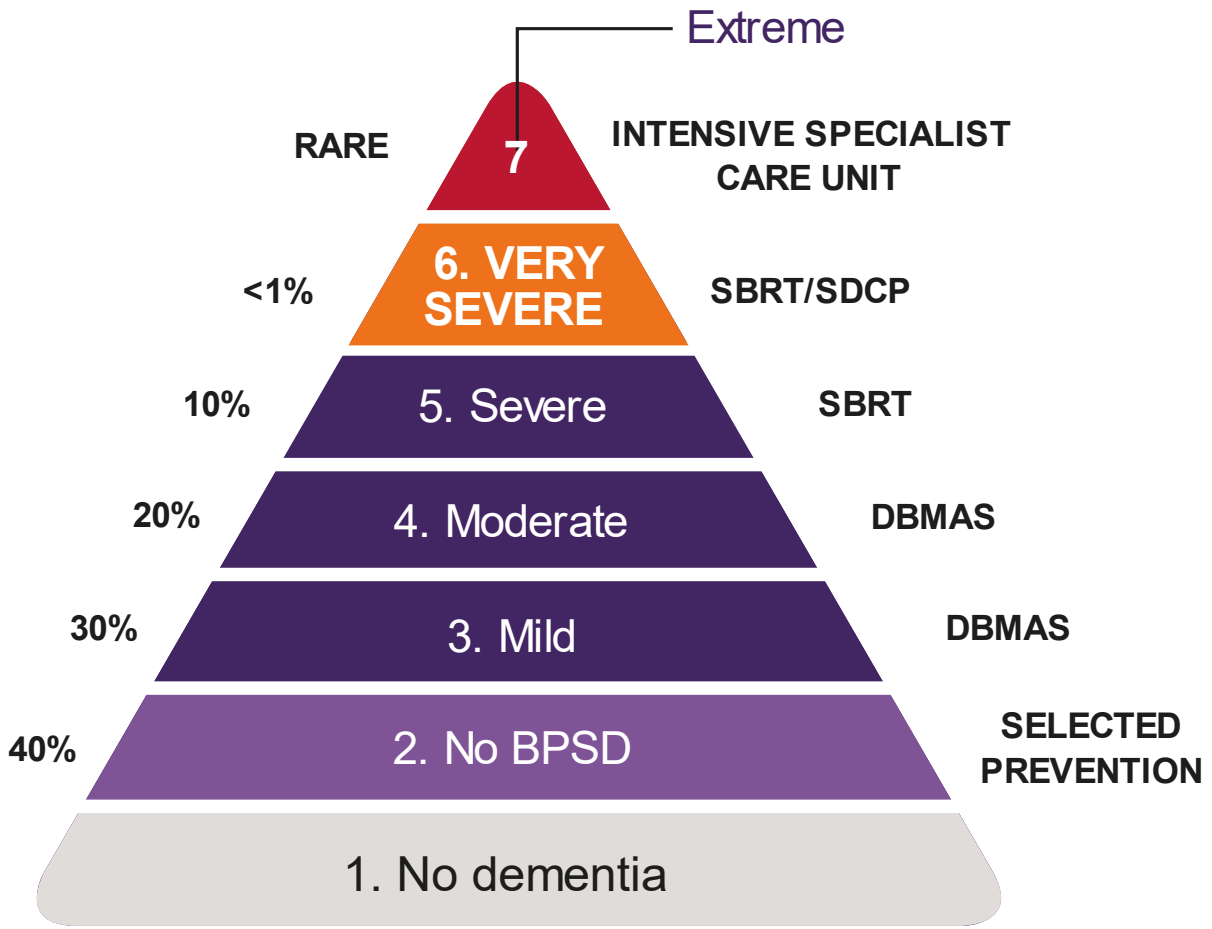
Needs Based Assessment

Eligibilit y for SDCP



Dementia Engagement Modelling Program

DSA: An integrated service



Adapted from: Brodaty, H., Draper, B.M., & Low, L.-F. (2003). Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery. *The Medical Journal of Australia*, 178(5), 231–234.

Dementia Support Australia

A PARTNERSHIP LED BY HammondCare

A Biopsychosocial Model of Care – why this is important

We need to be identifying causes of behaviours, rather than focussing on symptoms.

But…..we are reliant upon a detailed psychosocial history.

Importance of psychotropic medication is de-emphasised

Over/under stimulation

Carer approach

Loneliness

Pain

Delirium

Mood disorders

The model of care is based on identifying causes of behaviours that are contributing factors to referrals

Dementia Support Australia

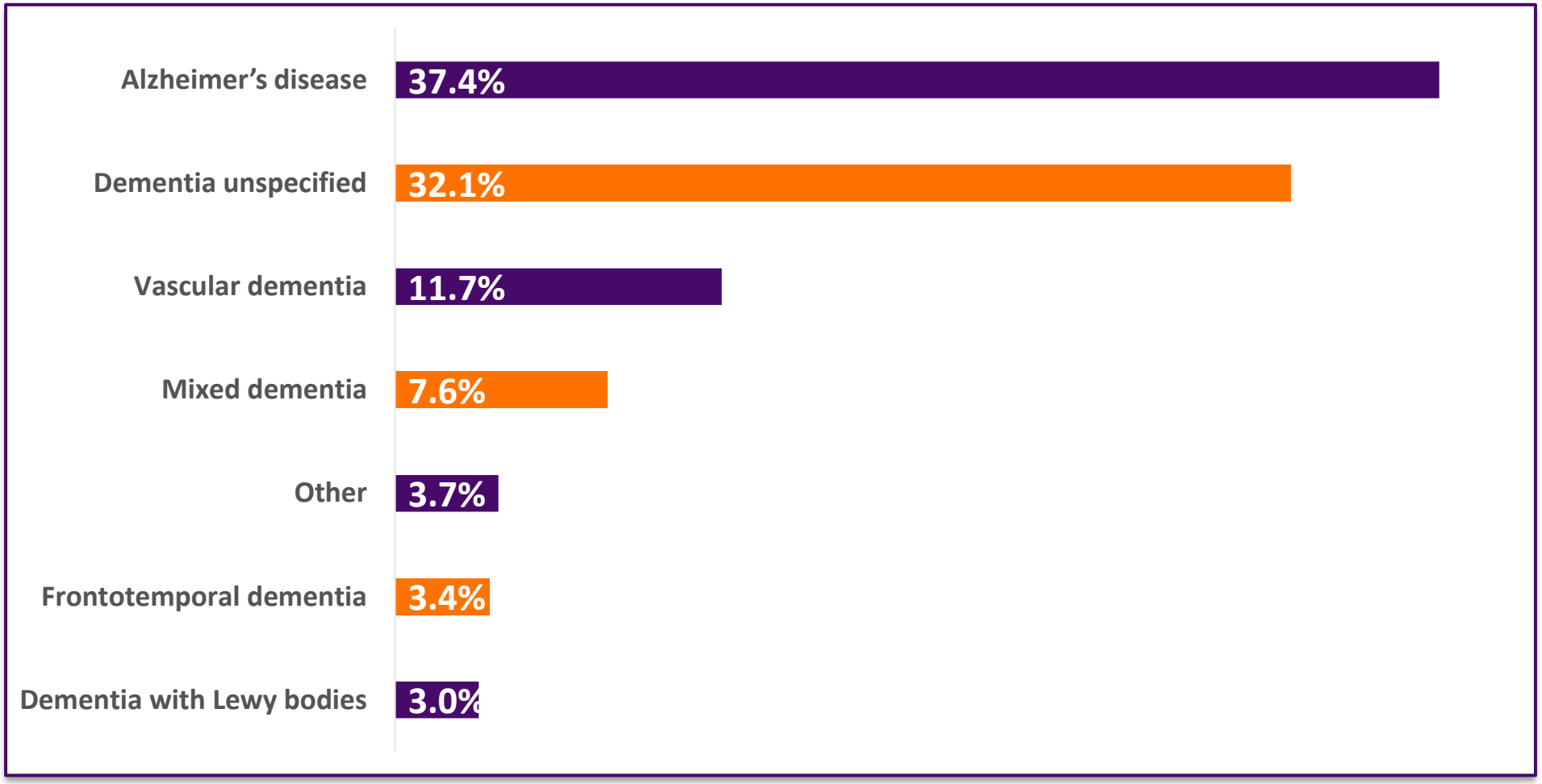
A PARTNERSHIP LED BY HammondCare

Right person, right time

Meaningful and purposeful informal and formal care staff are necessary for DSA to deliver its model of care.

Psychosocial interventions need to be delivered with empathy and understanding, by the right person and at the right time.

Prevalence of dementia in DSA



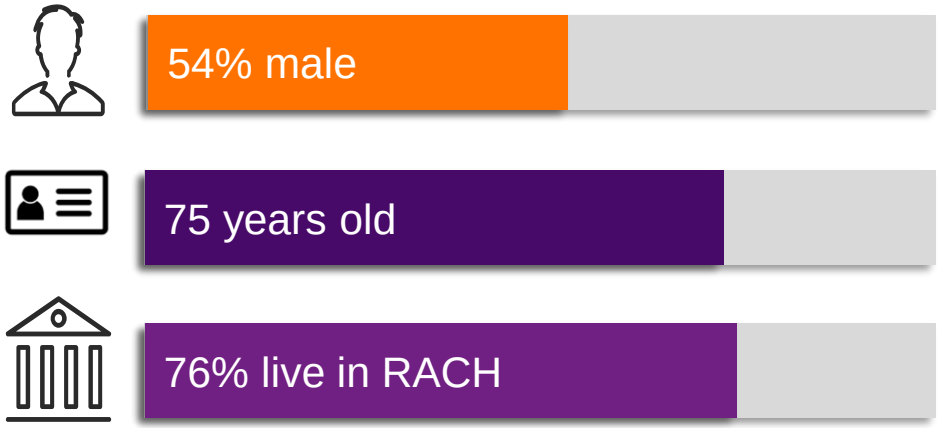
Macfarlane, S. (2021). Evaluating the Clinical Impact of National Dementia Behaviour Support Programs on Neuropsychiatric Outcomes in Australia. *Frontiers in Psychiatry / Frontiers Research Foundation*, *12*, 367.

Dementia Support Australia

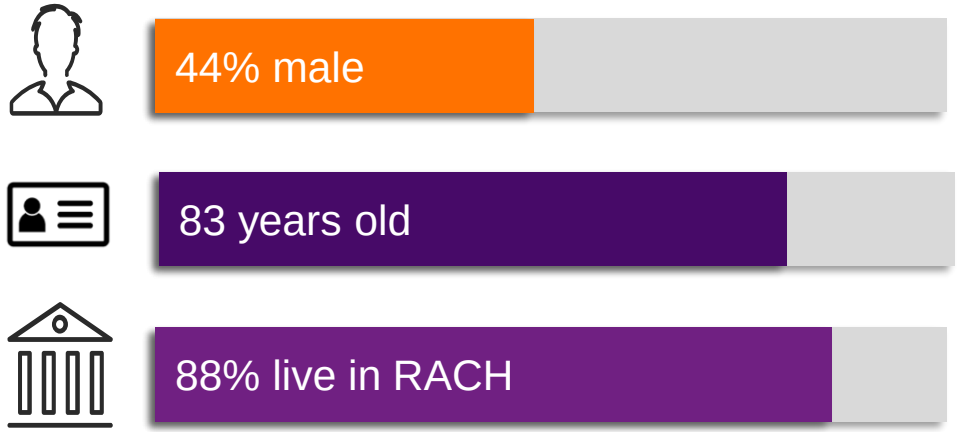
A PARTNERSHIP LED BY HammondCare

Profile of clients supported by DSA

Frontotemporal dementia



Other dementia subtypes

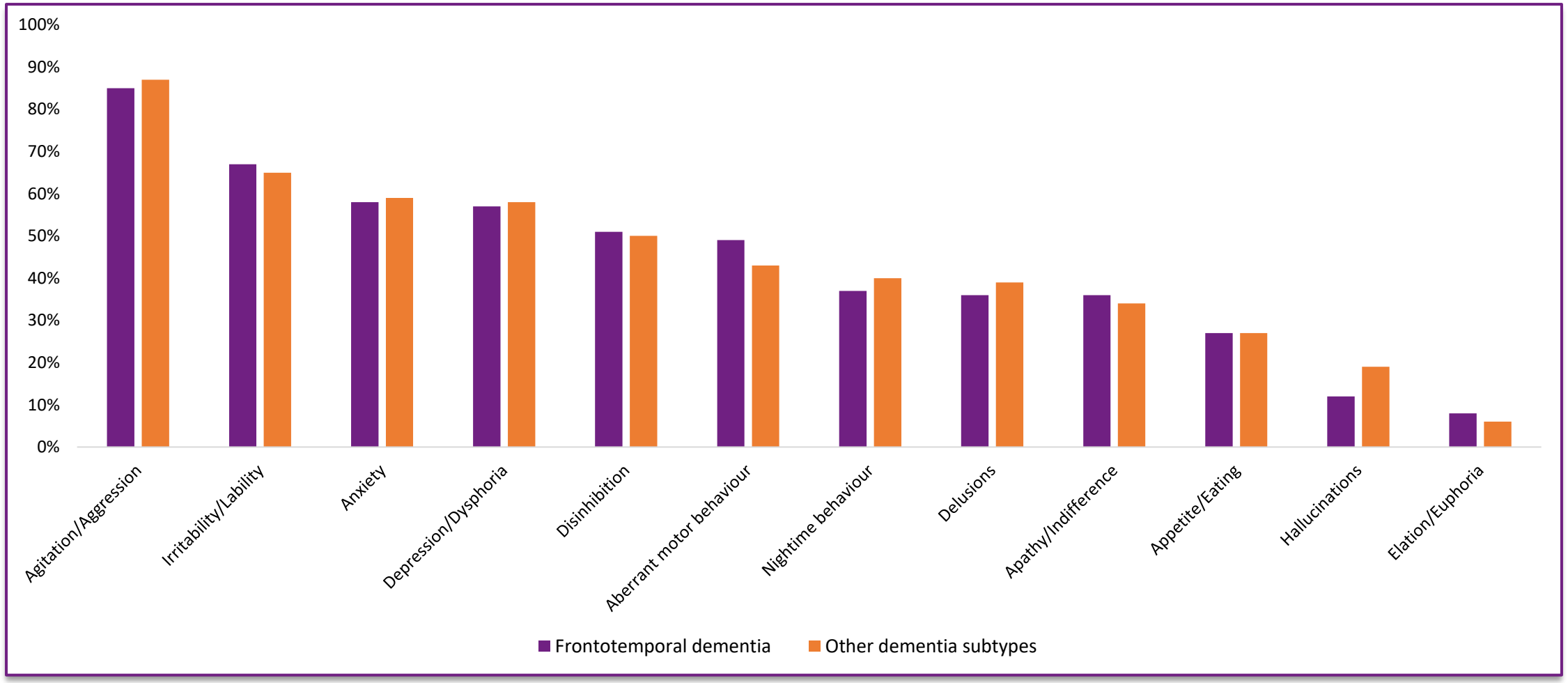


Dementia Support Australia

Funded by the Australian Government
A service led by HammondCare

Data period: last 12 months (June 2020 – May 2021)

Prevalence of behaviour in DSA



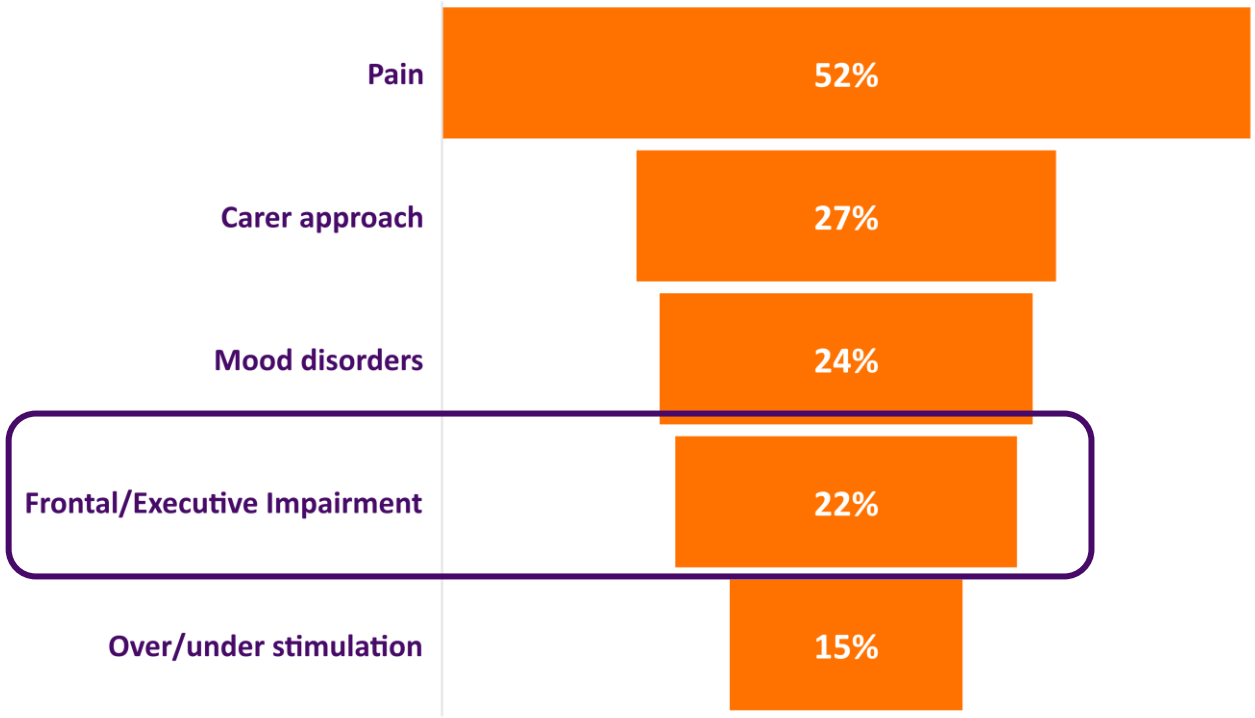
Dementia Support Australia

Data period: last 12 months (June 2020 – May 2021)

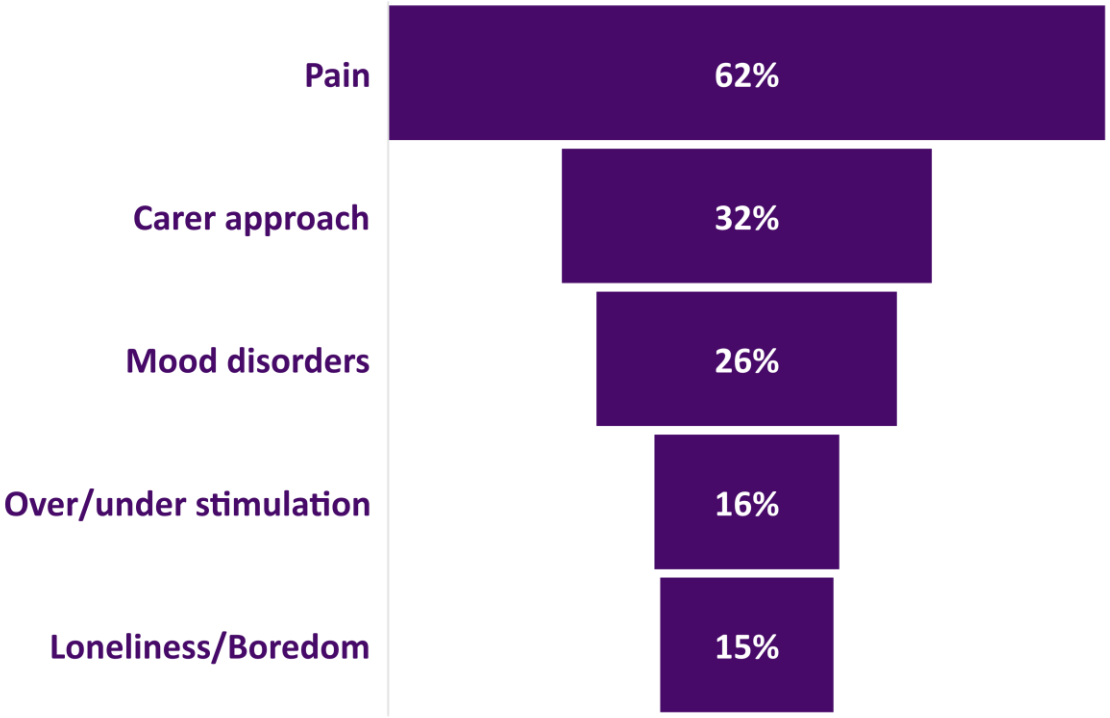
Funded by the Australian Government
A service led by HammondCare

Top 5 causes of behaviour

Frontotemporal dementia



Other dementia subtypes



Dementia Support Australia

Funded by the Australian Government
A service led by HammondCare

Data period: last 12 months (June 2020 – May 2021)

Impact of DSA on behaviour

Dementia subtype	Intake Mean (SD)	Discharge Mean (SD)	Change MCS[a]	Change MPC[a]	Change *d*[a]
NPI severity					
Alzheimer's disease	9.98 (5.89)	3.97 (3.65)	−5.96	−59.71	−1.15
Mixed dementia	9.94 (5.37)	3.44 (3.38)	−6.60	−66.40	−1.39
Frontal lobe dementia	9.99 (5.42)	4.13 (3.39)	−5.94	−59.43	−1.25
Dementia with Lewy bodies	11.85 (6.39)	4.89 (4.79)	−7.09	−59.83	−1.21
Vascular dementia	9.76 (5.71)	3.48 (3.14)	−5.97	−61.17	−1.21
NPI distress					
Alzheimer's disease	13.65 (8.47)	4.58 (4.78)	−8.86	−64.90	−1.21
Mixed dementia	13.76 (7.76)	4.41 (5.22)	−9.41	−68.41	−1.36
Frontal lobe dementia	14.02 (8.31)	5.07 (4.91)	−9.06	−64.65	−1.26
Dementia with Lewy bodies	16.13 (9.23)	6.11 (6.42)	−10.30	−63.85	−1.24
Vascular dementia	13.61 (8.47)	4.04 (4.24)	−9.12	−67.01	−1.26

[a]MCS, MPC and Cohen's d values represent the change from intake to discharge, controlling for age, sex, baseline score and case length.
MCS, mean change score; MPC, mean percent change; d, Cohen's d; M (SD), mean (standard deviation).
Negative signs preceding values represent improvement in scores.

Dementia Support Australia

Funded by the Australian Government
A service led by HammondCare

Macfarlane, S., et al. (2021). Evaluating the Clinical Impact of National Dementia Behaviour Support Programs on Neuropsychiatric Outcomes in Australia. *Frontiers in Psychiatry / Frontiers Research Foundation*, *12*, 367.

Evaluating the Clinical Impact of National Dementia Behaviour Support Programs on Neuropsychiatric Outcomes in Australia

Stephen Macfarlane[1,2†‡], Mustafa Atee[3,4*†‡], Thomas Morris[1‡], Daniel Whiting[1‡], Madeleine Healy[1,5], Marie Alford[1] and Colm Cunningham[1,6‡]

[1]The Dementia Centre, HammondCare, St Leonards, NSW, Australia
[2]Faculty of Medicine, Nursing and Health Sciences, Monash University, Clayton, VIC, Australia
[3]The Dementia Centre, HammondCare, Wembley, WA, Australia
[4]Curtin Medical School, Faculty of Health Sciences, Curtin University, Bentley, WA, Australia
[5]Monash Health, Clayton, VIC, Australia
[6]School of Public Health and Community Medicine, University of New South Wales, Sydney, NSW, Australia

International Journal of Geriatric Psychiatry

EDITORIAL | Open Access

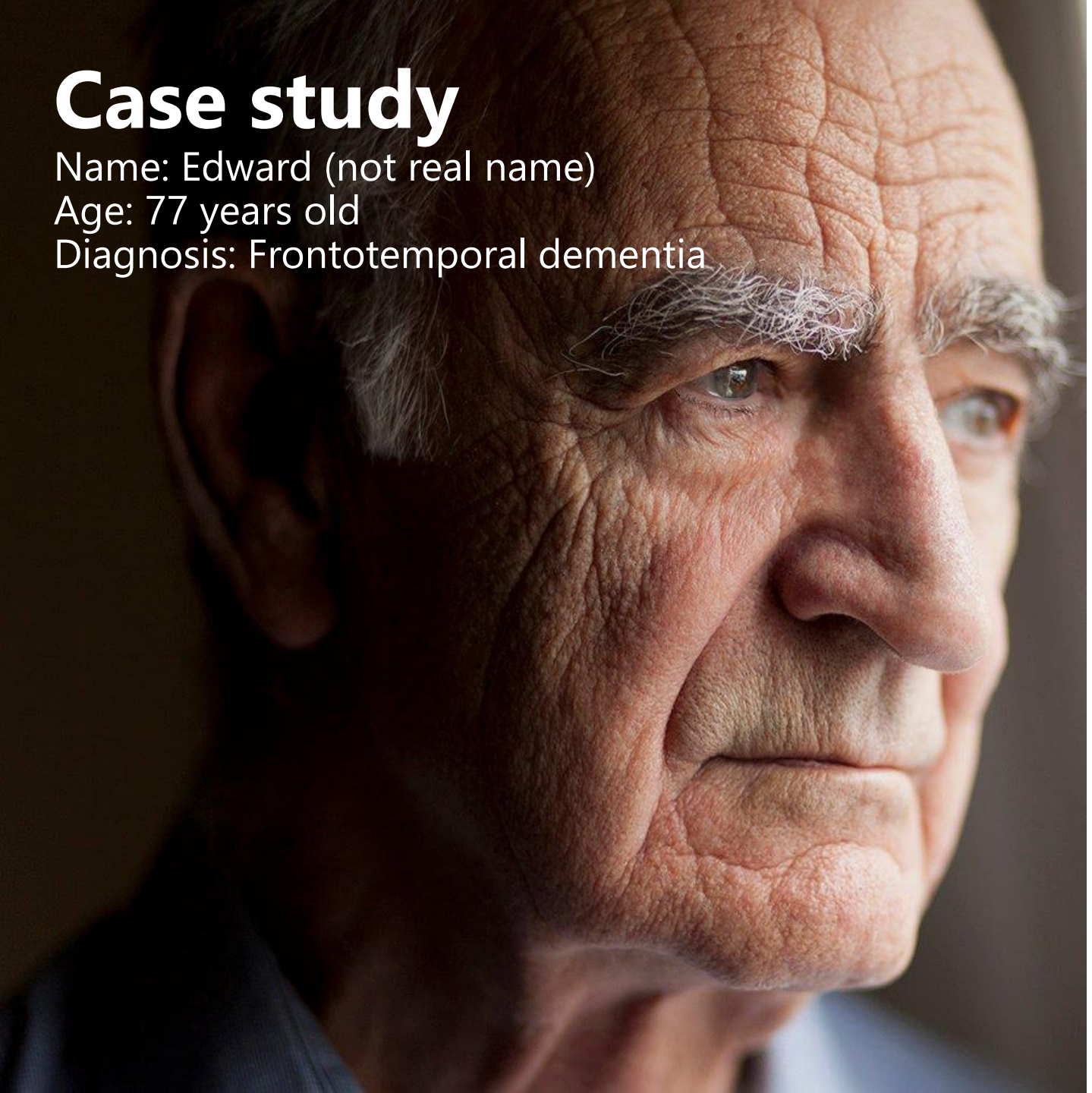
When responsive and reactive meet organic? Treatment implications of language use in the era of #BanBPSD

Stephen Macfarlane, Mustafa Atee, Thomas Morris, Colm Cunningham

First published: 28 March 2021 | https://doi.org/10.1002/gps.5545

Dementia Support Australia

Funded by the Australian Government
A service led by HammondCare



Case study

Name: Edward (not real name)
Age: 77 years old
Diagnosis: Frontotemporal dementia

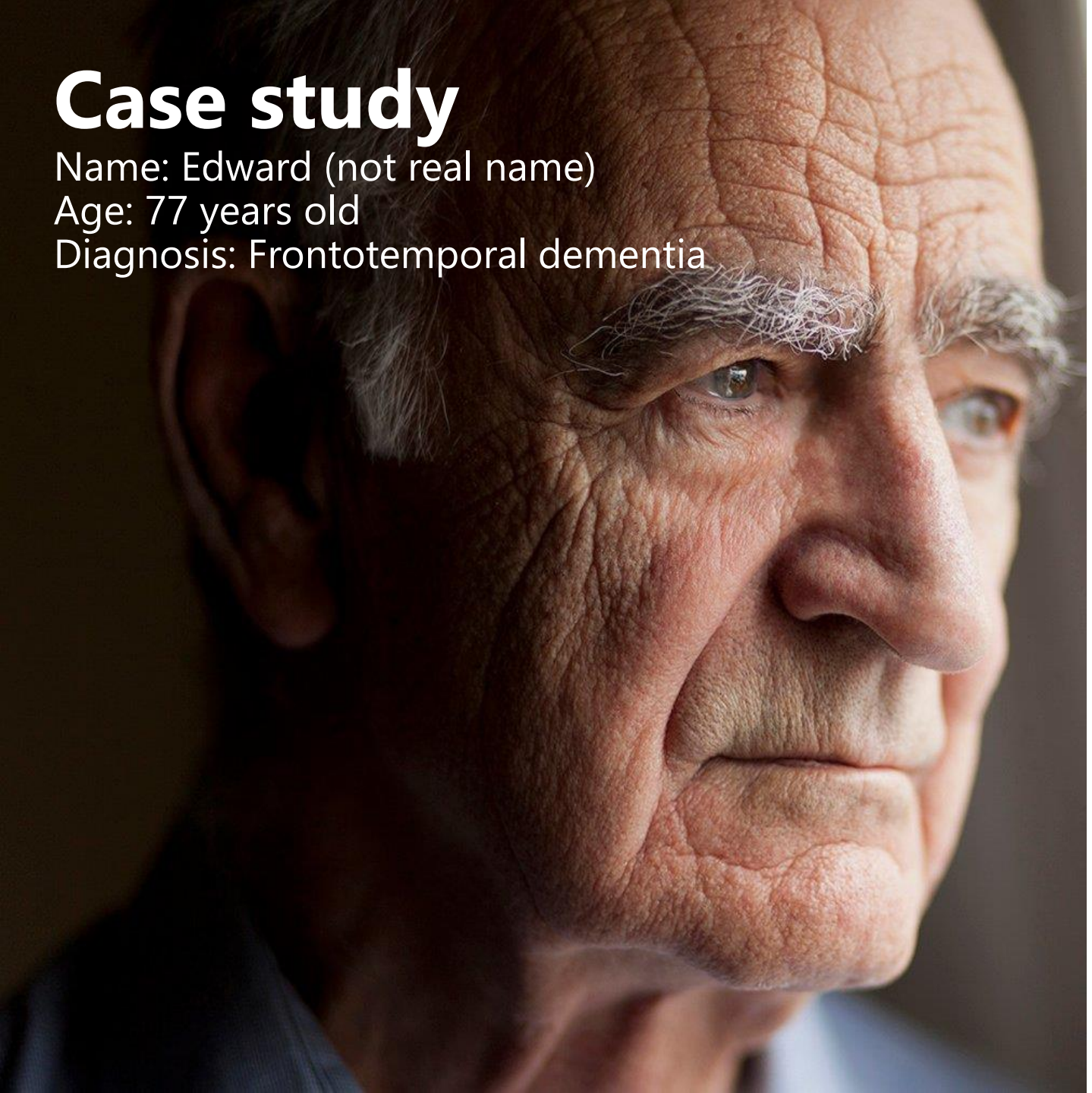
Social history & reason for referral

Edward entered residential care in 2017 when he was no longer able to live independently in his government owned home. He lived alone and had one daughter.

Edward had significant comorbidities including liver failure, osteoarthritis, chronic back pain associated with spinal fracture.

Edward was referred to DSA as he was increasingly:

- making derogatory comments to residents and care staff
- being physically and verbally aggressive to care staff
- making sexualised demands and statements.



Case study

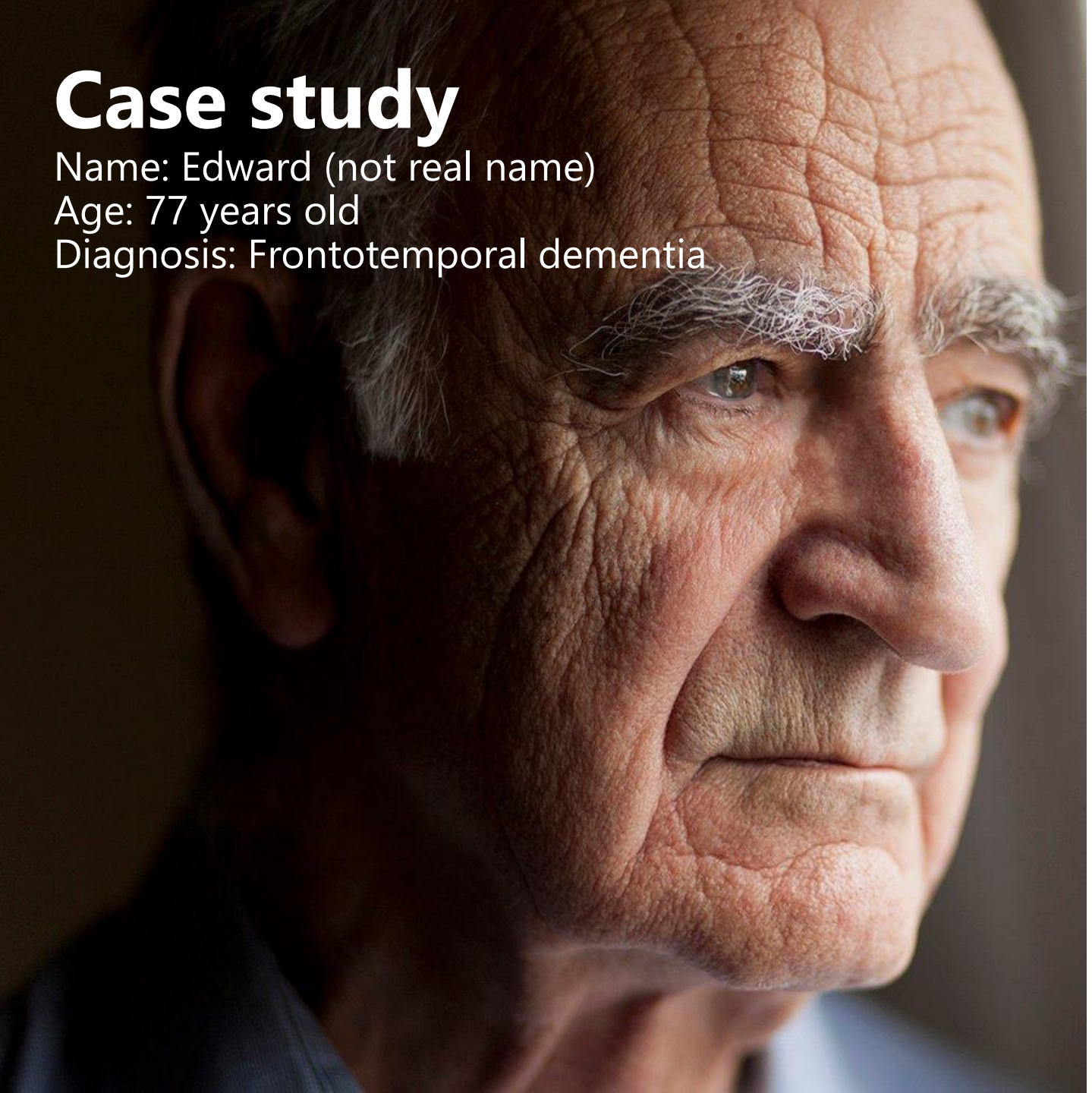
Name: Edward (not real name)
Age: 77 years old
Diagnosis: Frontotemporal dementia

DSA assessment & recommendations

A DSA consultant visited Edward and his carers. Following their assessment and review of Edward's behaviour profile, and social and medical history, the consultant determined that two factors may be contributing to his behaviour:

1. An underlying delirium
2. Pain

Among a number of recommendations including a delirium screen, the DSA consultant completed a formal pain assessment that revealed Edward was in significant pain and that this should be appropriately monitored and managed.



Case study

Name: Edward (not real name)
Age: 77 years old
Diagnosis: Frontotemporal dementia

Client outcomes

Following the provision of the DSA recommendation report, Edward's GP increased his opiate analgesia and staff were monitoring his pain.

Following the implementation of this analgesia, all of Edward's referred behaviours were resolved and staff reported no further difficulties in providing Edward care.

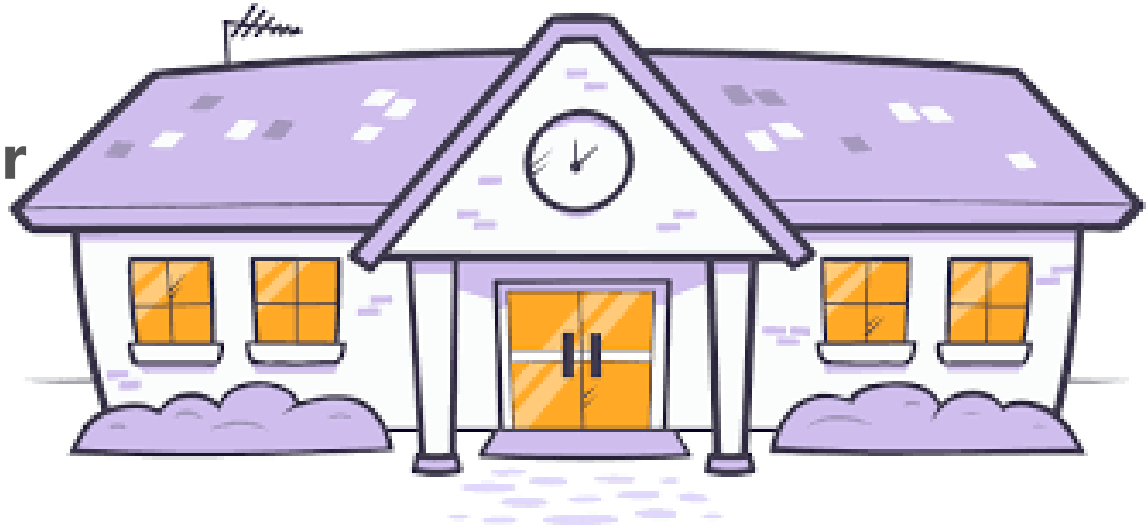
DSA services were successfully then resolved and Edward has not since required the services of DSA.

What if someone doesn't benefit?

Approximately 7% of DSA clients may not benefit from psychosocial interventions?*

Such clients are often re-referred to DSA for further support, but a subset of these will still not benefit from either mainstream or DSA interventions.

These clients may be better supported by Specialist Dementia Care Programs (SDCPs).



Dementia Support Australia

Funded by the Australian Government
A service led by HammondCare

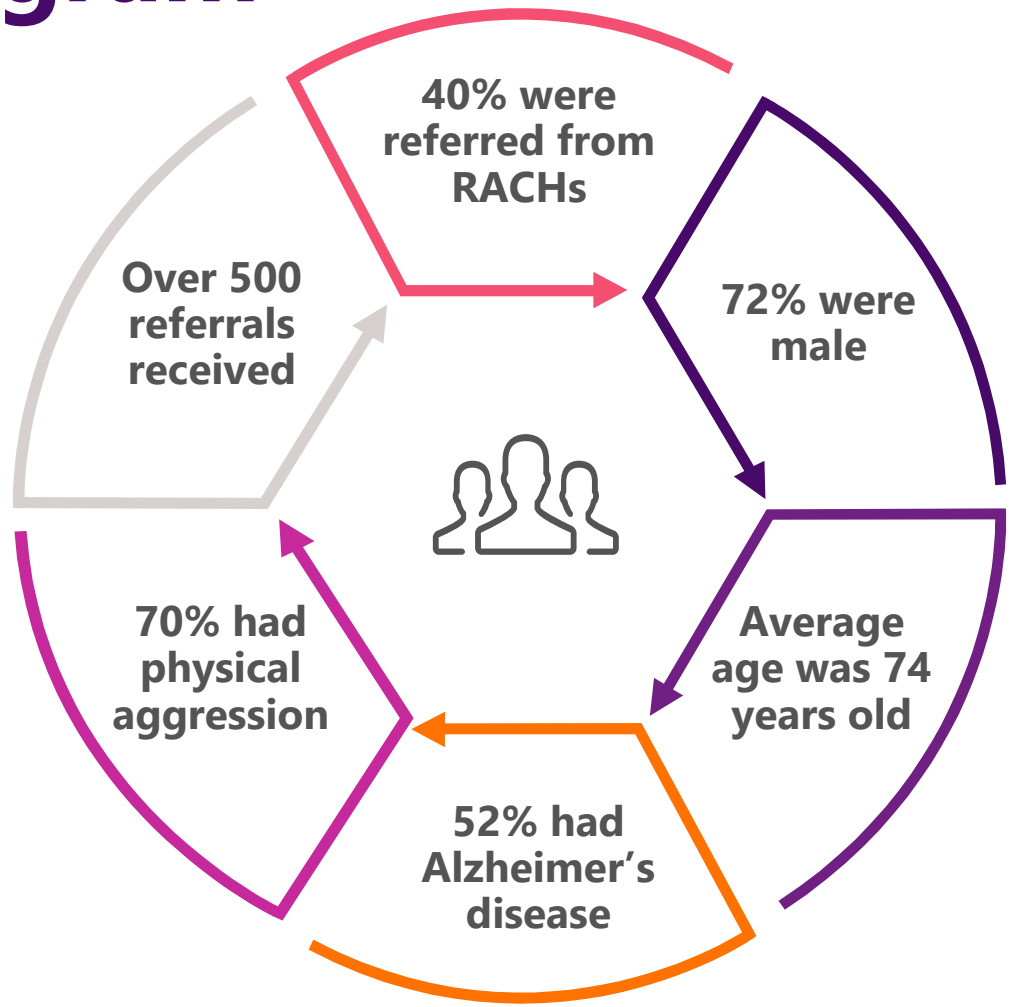
*Macfarlane, S., et al. (2021). Evaluating the Clinical Impact of National Dementia Behaviour Support Programs on Neuropsychiatric Outcomes in Australia. *Frontiers in Psychiatry / Frontiers Research Foundation*, *12*, 367.

Needs Based Assessment program

The Needs Based Assessment (NBA) program provides independent assessments of eligibility into SDCPs.

Three key criteria are necessary for entry into SDCPs:

1. Behaviour is severe
2. Behaviour is explained by a dementia diagnosis
3. Behaviour has demonstrated intractability to adequate trials of treatment



Data period: Sep 2019 – 15/6/2021

Dementia Support Australia

Funded by the Australian Government
A service led by HammondCare

What to remember?

- This is complex – no simple answers
- Take the time to understand what is happening (behaviour care plans)
- Try to stay calm
- Talk about what's happening with others, learn more their strategies
- Seek help: Dementia Support Australia 24/7 www.dementia.com.au
  Ph:1800 699 799

Dementia Support Australia

Funded by the Australian Government
A service led by HammondCare

Thank you

Disinhibited Behaviours:
Negative Mindset to Positive Response

A/Prof Cindy Jones

Faculty of Health Sciences & Medicine, Bond University

Menzies Health Institute Queensland

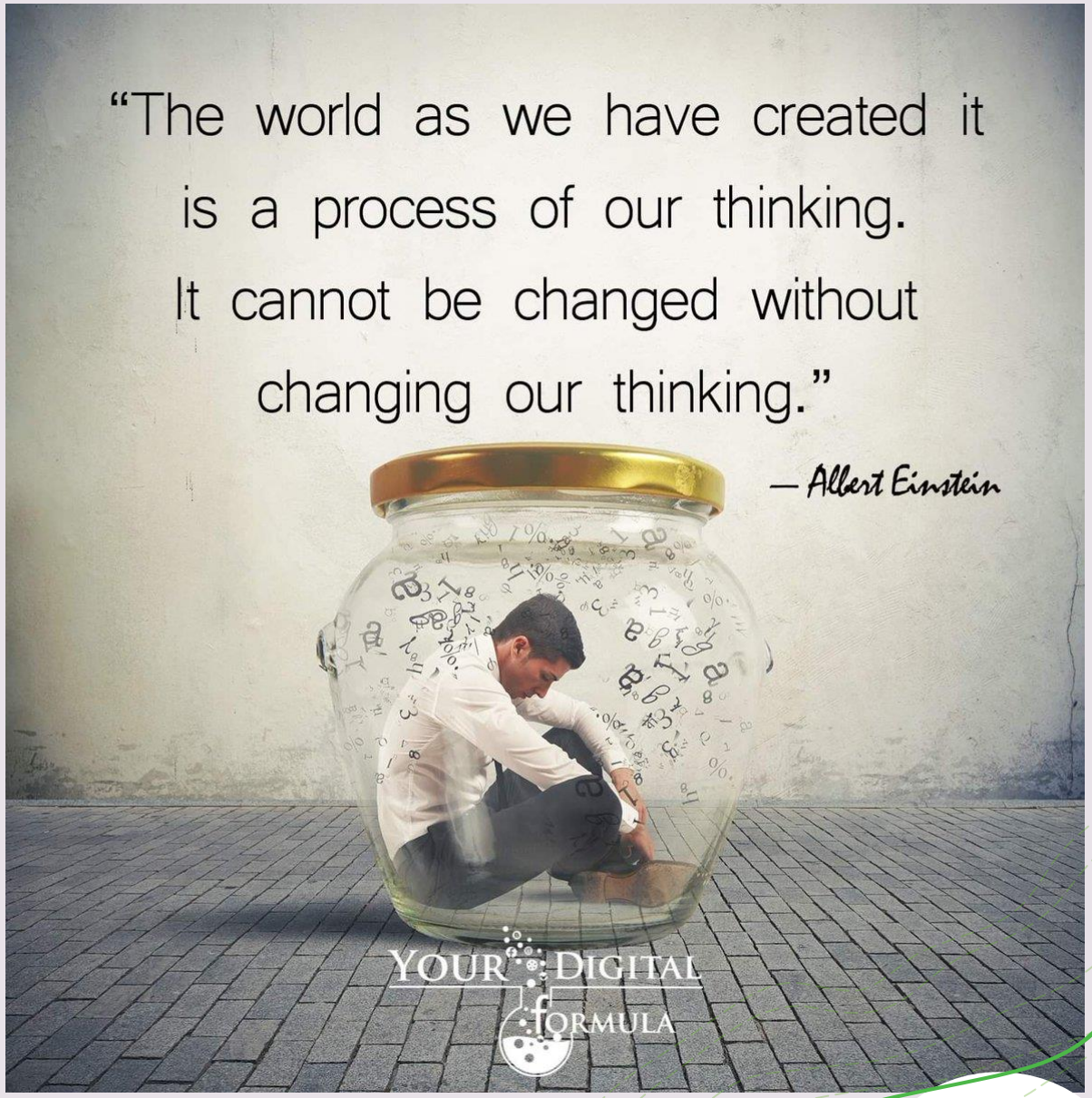
Negative Mindset?

Disinhibited Behaviours

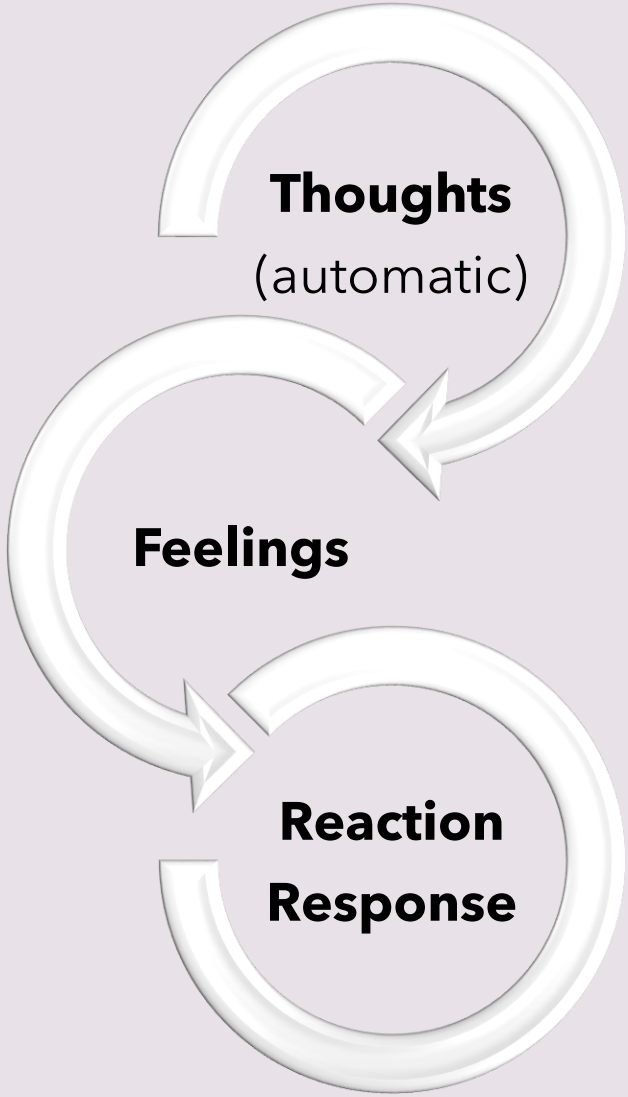
Enormous Stress *(distress, embarrassment, annoyance & frustration)*

Thinking-Feeling Connection

- Does disinhibited behaviour directly lead to emotional response?
  - *"Despite all my care for him, my dad just lashes out and curse at me often and this made me so angry"*
- Is there a missing link?
  - *Thoughts & Beliefs*



Our thoughts influence our feelings...



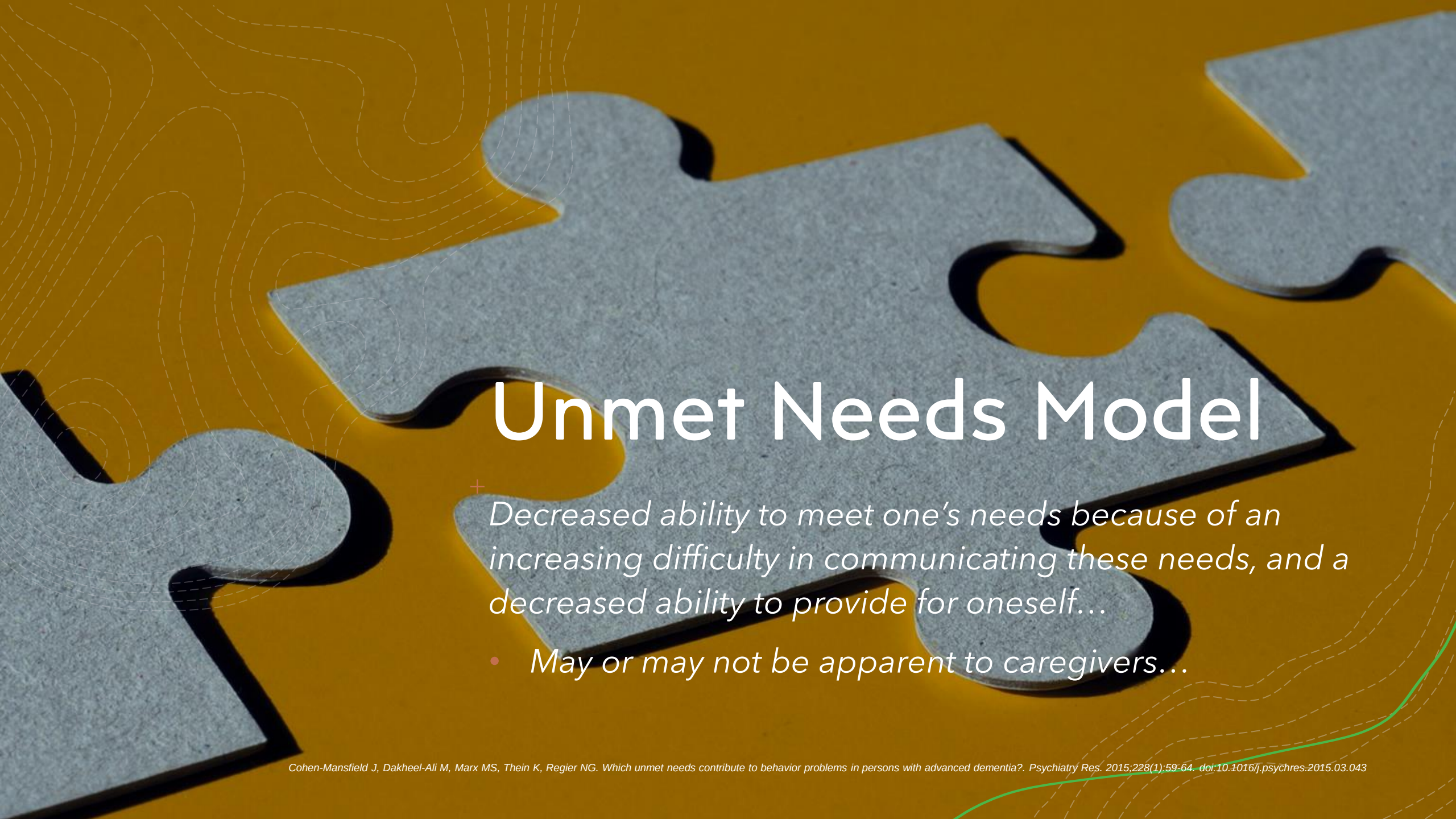
Scenario: You are a carer for your Dad who has dementia and is living with you. A female friend of yours came over for a visit and you just finished having a cuppa and a yarn with her at the veranda. As she is leaving and you are walking her to the front door, both of you saw your Dad talking all his clothes off in the lounge room.

Negative Thought ☹	*"Oh dear, I can't believe she just saw that. She must think my Dad is weird, an exhibitionist or a sexual deviant! For goodness' sake, I just wish Dad will stop doing that"*
Feeling(s)	Embarrassed and annoyed.
Reaction/Response	Inappropriate sexual behaviour that needs to be stopped.

Scenario: You are a carer for your Dad who has dementia and is living with you. A female friend of yours came over for a visit and you just finished having a cuppa and a yarn with her at the veranda. As she is leaving and you are walking her to the front door, both of you saw your Dad talking all his clothes off in the lounge room.

Positive Thought ☺	*"Hmm, she looks taken back. Is Dad feeling hot or uncomfortable in those clothes? Are they too tight on him or is the material of the clothing irritating him!"*
Feeling(s)	Calm but concerned albeit some embarrassment.
Reaction/Response	Checking out if Dad is feeling hot or if there is an issue with the clothing.


Changing mindset:
Could disinhibited behaviours
reflect an unmet need?

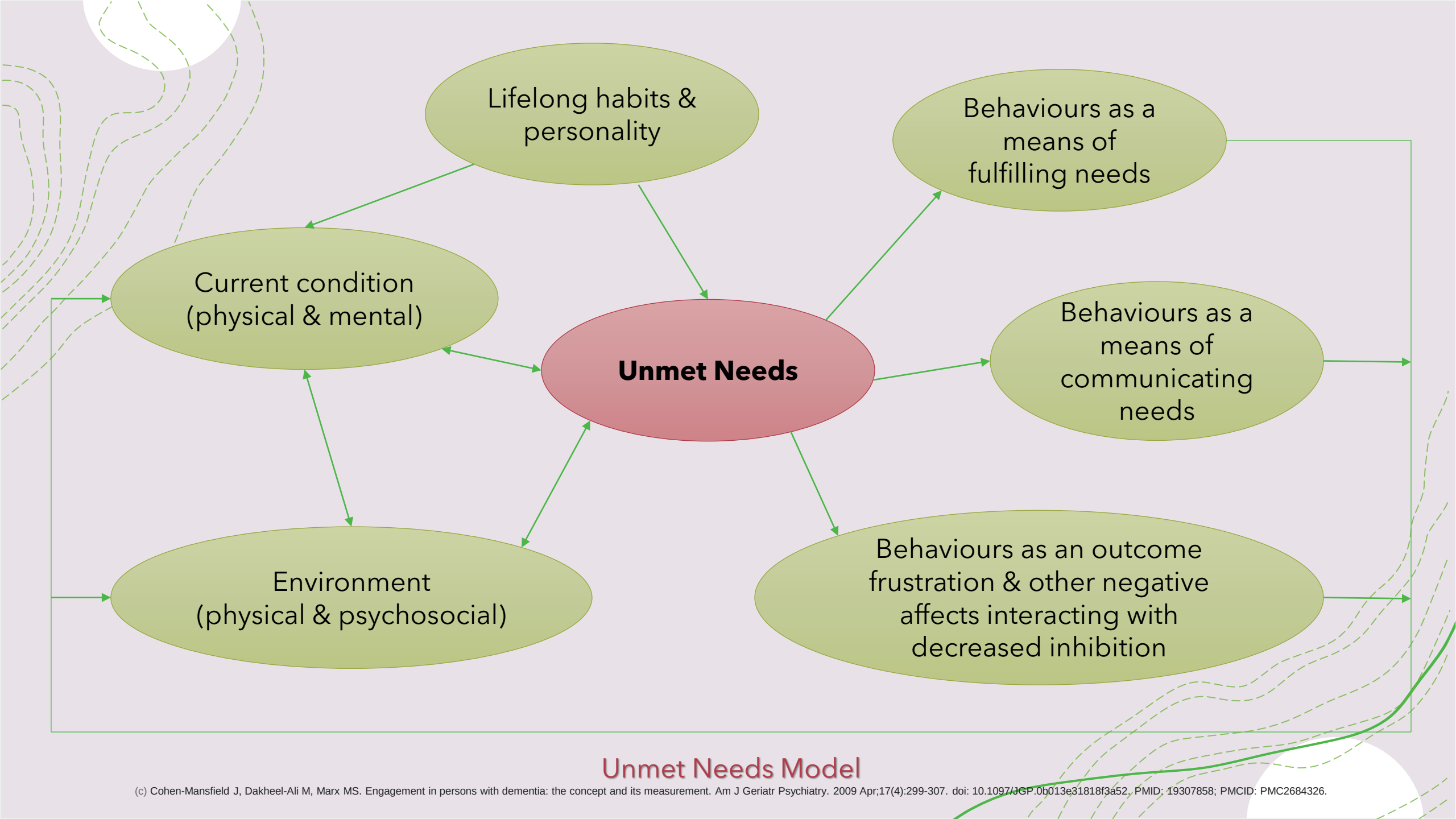


Unmet Needs Model

Decreased ability to meet one's needs because of an increasing difficulty in communicating these needs, and a decreased ability to provide for oneself…

- *May or may not be apparent to caregivers…*

Cohen-Mansfield J, Dakheel-Ali M, Marx MS, Thein K, Regier NG. Which unmet needs contribute to behavior problems in persons with advanced dementia?. Psychiatry Res. 2015;228(1):59-64. doi:10.1016/j.psychres.2015.03.043



Unmet Needs Model

Negative Mindset to Positive Response

Changing thoughts and beliefs (mindset)

Reduce negative feelings

Leading to positive reaction/response

Improved outcome for people living with dementia & caregivers


THANK
YOU

DCRC
Dementia Centre for Research Collaboration

Changed Awareness of Social Behaviour

Dr Margie MacAndrew &
Professor Elizabeth Beattie

Australian Government
National Health and Medical Research Council

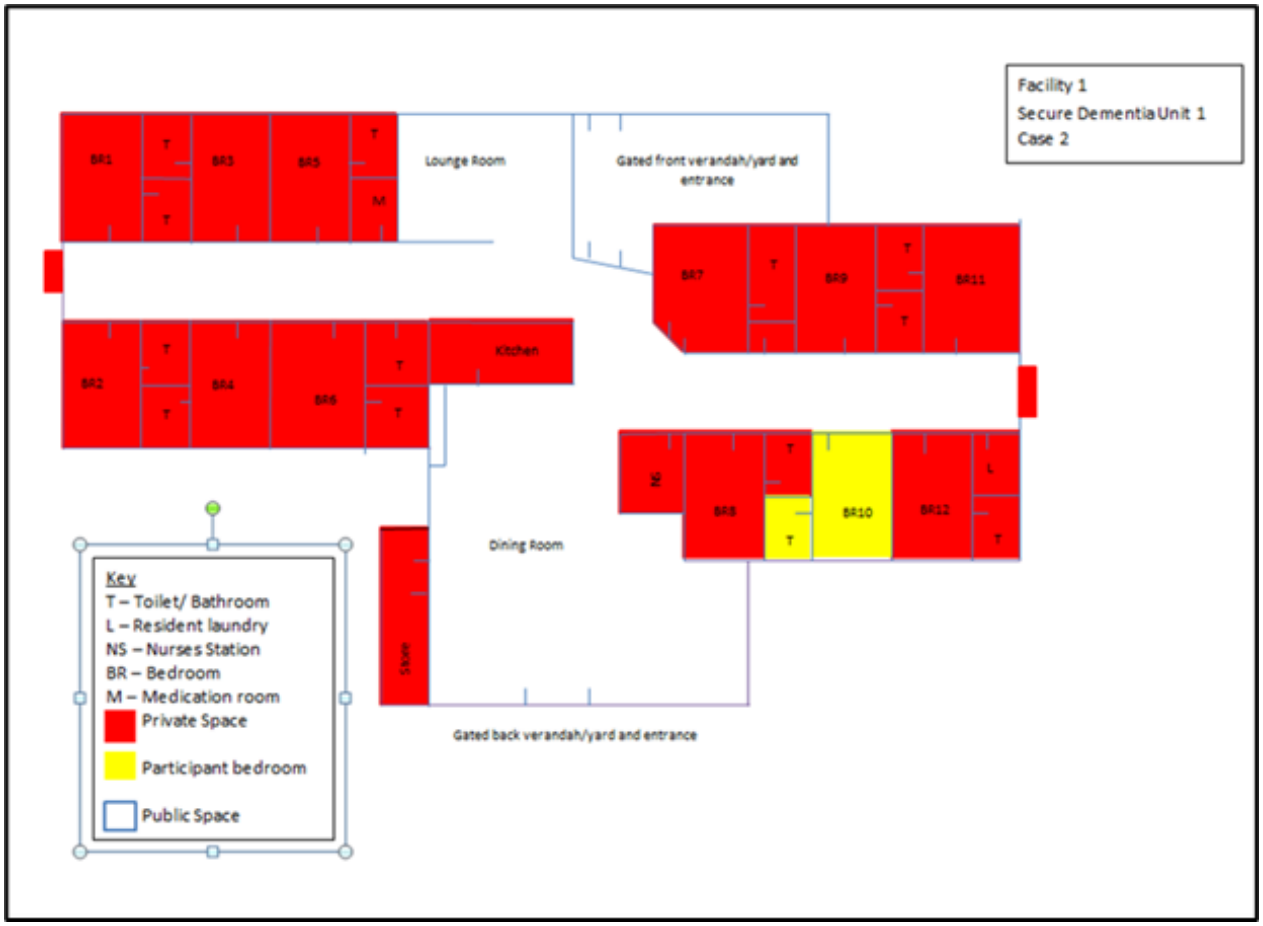
QUT

Overview

- Explore the concept of private space and socially acceptable behaviour in residential aged care (RAC).
- Examine what occurs when established boundaries of private space are crossed in RAC.
- Discuss the outcomes of research focussed on boundary crossing

Identifying private space in RAC

Public vs Private spaces



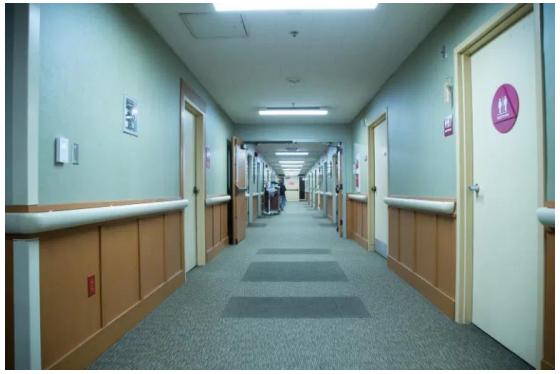
Wandering related boundary transgression (BT)

"…..related behaviour of wandering characterised by locomotion into off-limit, prohibited, or hazardous areas" (p.209)

Moore, H., Algase, D., Powell-Cope, G., Applegarth, S., & Beattie, E. (2009). A framework for manageing wandering and preventing elopement. *American Journal Of Alzheimer's Disease And Other Dementias*, *24*(3), 208-219. doi: 10.1177/1533317509332625

Nursing care staff perceptions of BT

- Very common behaviour
- Occurs frequently across all hours of the day and night
- Staff spend their day redirecting to avoid altercations
- ‘Private space’ ceases to have meaning – no blame assigned
- When the person’ behaviour does not upset others, this is tolerated
- BUT…….



Perceived adverse outcomes – staff and family

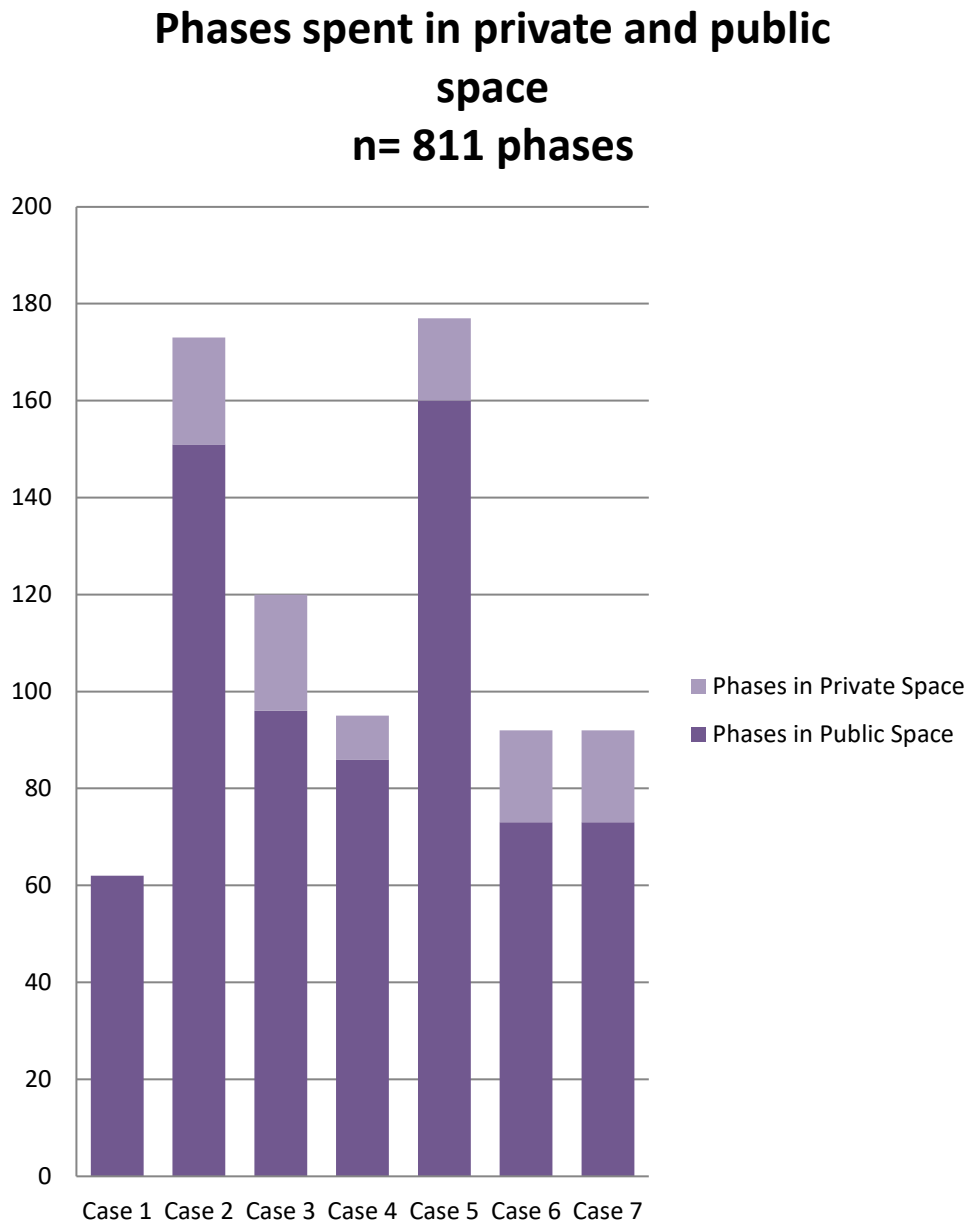
- Transgressing boundaries of private space causes distress for the room owner
- Families are upset by this also – loss of personal belongings
- Belief that BT was related resident-to-resident violence
- Not tolerated when safety is compromised

What does occur during BT?

- Observed 7 residents with severe dementia and history of BT
- Two secure dementia units
- Both units attempted to identify rooms with photos and name plates and memory panels
- 92 observation periods; over 46.5 hours of real time observation
- Duration/frequency of walking/not walking; pattern; location (private/public); duration/frequency BT; what occurred during BT

Characteristics of BT

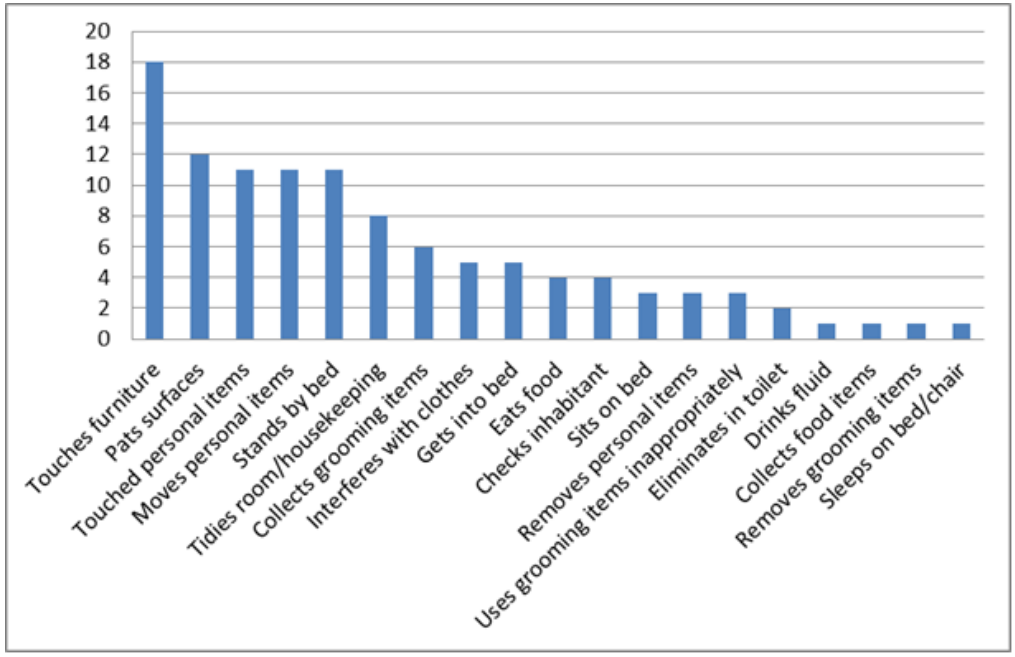
- 14% of the observation time – participants were in private space
- 6 of the 7 participants exhibited BT – 58 BT events observed
- More BT occurred during random pattern (79%)
- Those who walked more and had more random pattern had more BT
- Participants walked alone most of the time
- Bedrooms were the most common private space entered
- Except for 2/58 BT events, the bedroom entered had an open door



Outcomes of BT

- Touching the furniture; patting surfaces; touching personal items; moving personal items; and standing by the bed
- 2/3 BT events – participant did not interact with the physical environment
- Room owner or another resident was present 21% of the time
- Staff were aware of only **4/58** BTs
- Impact on room owner: no response (seemed unaware); distress about possessions being touched; frustration; anxiety
- Impact on family: complaint about having to buy another pair of slippers
- Impact on person exhibiting BT: one participant slapped on hand and attempt to slap another participant; shunned by other residents; spent long periods alone; did not sit with community for meals or activities

'Can you help me? I think there is someone in my room'



'She is in my room again. Just get her out'.

What we learned

- Staff perceptions were not consistent with actual occurrences – less frequent and they were unaware of most BT
- The negative social impact and stigma toward the participants related to them entering bedrooms was surprising – residents have a strong sense of privacy and need for this to be maintained.
- Names on doors and memory boxes were not a deterrent – private space ceased to have meaning
- Closing doors – has other implications but could help some residents
- The family perspective was interesting – the behaviour was accepted to the point where safety was compromised
- Targeting periods of peak activity to engage person in supervised activity may reduce numbers of transgressions